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## Review

# Clarifying the Concept of Adherence to eHealth Technology: Systematic Review on When Usage Becomes Adherence

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## *Abstract*

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**Background:** In electronic health (eHealth) evaluations, there is increasing attention for studying the actual usage of a technology in relation to the outcomes found, often by studying the adherence to the technology. On the basis of the definition of adherence, we suggest that the following three elements are necessary to determine adherence to eHealth technology: (1) the ability to measure the usage behavior of individuals; (2) an operationalization of intended use; and (3) an empirical, theoretical, or rational justification of the intended use. However, to date, little is known on how to operationalize the intended usage of and the adherence to different types of eHealth technology.

**Objective:** The study aimed to improve eHealth evaluations by gaining insight into when, how, and by whom the concept of adherence has been used in previous eHealth evaluations and finding a concise way to operationalize adherence to and intended use of different eHealth technologies.

**Methods:** A systematic review of eHealth evaluations was conducted to gain insight into how the use of the technology was measured, how adherence to different types of technologies was operationalized, and if and how the intended use of the technology was justified. Differences in variables between the use of the technology and the operationalization of adherence were calculated using a chi-square test of independence.

**Results:** In total, 62 studies were included in this review. In 34 studies, adherence was operationalized as “the more use, the better,” whereas 28 studies described a threshold for intended use of the technology as well. Out of these 28, only 6 reported a justification for the intended use. The proportion of evaluations of mental health technologies reporting a justified operationalization of intended use is lagging behind compared with evaluations of lifestyle and chronic care technologies. The results indicated that a justification of intended use does not require extra measurements to determine adherence to the technology.

**Conclusions:** The results of this review showed that to date, justifications for intended use are often missing in evaluations of adherence. Evidently, it is not always possible to estimate the intended use of a technology. However, such measures do not meet the definition of adherence and should therefore be referred to as the actual usage of the technology. Therefore, it can be concluded that adherence to eHealth technology is an underdeveloped and often improperly used concept in the existing body of literature. When defining the intended use of a technology and selecting valid measures for adherence, the goal or the assumed working mechanisms should be leading. Adherence can then be standardized, which will improve the comparison of adherence rates to different technologies with the same goal and will provide insight into how adherence to different elements contributed to the outcomes.

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### **KEYWORDS**

adherence; eHealth; systematic review

## Introduction

### Adherence and Attrition

One of the main goals of electronic health (eHealth) evaluations is to gain insight into the effects of technology on outcomes such as quality of life, health-related outcomes (eg, glycemic control, weight loss), or psychological outcomes (eg, depressive complaints, anxiety). However, many eHealth evaluations report no or limited positive effects [1-5]. There is strong evidence that this is often related to participants not using technologies in the desired way. For every technology, a proportion of the users will not use the intervention at all, will stop using the technology after a period, or will not use the available elements of the technology as intended [1,6-8].

To gain more insight into this phenomenon, Eysenbach made a plea back in 2005 for reporting the levels of nonusage attrition, or the extent to which individuals stop using the technology [9]. On the other hand, understanding adherence, or how actual usage of the technology may have influenced the outcomes, might be just as important [6]. The term adherence is rooted in the pharmaceutical industry, and according to the World Health Organization's (WHO) definition, it refers to "the extent to which a person's behaviour – taking medication, following a diet, and/or executing lifestyle changes, corresponds with agreed recommendations from a health care provider" [10].

### Adherence to eHealth Technologies

For eHealth technologies, several definitions for adherence can be identified in the existing literature. For example, Christensen et al defined adherence as "the degree to which individuals experience the content of the Internet intervention" [11]. However, the concept of "following the prescribed recommendations" (as implied by the WHO's definition) is missing from this definition. Therefore, Donkin et al referred to adherence as "the degree to which the user followed the program as it was designed" [6]. In accordance with the WHO definition of adherence, this definition contains the concept of intended use, or "the extent to which individuals should experience the content to derive maximum benefit from the intervention, as defined or implied by its creators" [1]. According to these definitions, the intended use is thus the minimum use to establish adherence.

Although adherence is related to other measures such as engagement or nonusage attrition, these terms do not refer to the same or inverse concepts. After all, not using the technology as defined or implied by its creators does not necessarily mean that a participant is not using the technology at all (as implied by the definition of nonusage attrition) [9]. Moreover, definitions of engagement usually incorporate the more subjective attributes of challenge, positive affect, endurability, and aesthetic and sensory appeals [12], whereas adherence is mostly based on measures for usage behavior.

### Determining Adherence

There is now increasing attention for studying the adherence rates and reasons for nonadherence in eHealth evaluations. However, it still can be a challenge to operationalize the intended use for individual eHealth technologies in a certain

context. In the pharmaceutical industry, the intended use (ie, agreed recommendations) is mostly based on the observed or rationalized working mechanisms and the dose-response curves of the medication for a certain condition. As a result, the dosage of one particular medication can vary depending on (the severity of) the condition and the patient's characteristics (eg, age, gender, or weight).

This is in contrast with many prior eHealth studies, which often assume that all users should experience all of the elements of a technology to obtain effects, and in which adherence is thus often operationalized as using everything the technology offers. However, a technology can be designed for multiple target groups and, depending on the individual user goals and the desired outcomes, technology can be used in many different ways in terms of the features that are used, as well as the frequency, time, and place of use [13,14]. Furthermore, the amount of use that is needed to obtain the desired outcomes may vary a lot across different user groups [6]. This implies that users do not always have to experience all of the available elements of a technology or have to use the same elements because usage goals may differ across users as well. Moreover, individuals may also stop using the technology because they have reached their personal goals (early completers or e-attainers) [11,15], and nonusage dropout is thus not always a consequence of losing interest (as stated by Eysenbach) [9].

To summarize, based on the definition of adherence, we suggest that the following three elements are necessary to determine adherence to eHealth technology: (1) the ability to measure the usage behavior of individuals; (2) an operationalization of intended use; and (3) an empirical, theoretical, or rational justification of the intended use. However, to date, little is known about how to operationalize the intended usage of and thus the adherence to different types of eHealth technology. Many systematic reviews gaining insight into adherence to eHealth technology focus on the extent to which individuals use different types of technology and what the reasons for nonadherence are, without a proper operationalization of intended use and adherence [1,6,11,16,17]. These reviews therefore fail to provide insight into how adherence and intended use have been operationalized.

### The Goal of the Review

The goal of this systematic review was to improve evaluations of eHealth technologies by gaining insight into when, by whom, and how the concept of adherence has been used in previous eHealth evaluations, and finding a concise way to operationalize the adherence to and the intended use of different eHealth technologies. We do this by providing insight into how the usage of the technology was measured across previous studies; how adherence to different types of technologies (eg, structured interventions, patients platforms) was operationalized; and if and how the intended use of eHealth technologies has been justified with theory, evidence, or rationale.

## Methods

### Search Strategy

A literature search was conducted using the Scopus, Web of Science, ScienceDirect, and PsycINFO databases. A combination of the constructs “technology,” “intervention,” “adherence,” and “health” was used. To ensure sufficient coverage of each construct, we used different keywords for every construct (see [Multimedia Appendix 1](#)). We excluded other usage-related concepts (eg, nonusage attrition or engagement) because these do not refer to the same concept.

### Eligibility Criteria

All articles that met the following criteria were included in the review: (1) it involved health-related technology (Web-based technologies, apps, wearables, or technologies provided via other devices); (2) the technology was intended to be used more than once by the patient or client; (3) the article described a primary study or a protocol for a primary study that included objective, quantifiable measurements, and an operationalization of adherence to the technology; (4) the study was published in English; and (5) the study was peer-reviewed and published.

Articles were excluded in the following situations: (1) adherence was defined as adhering to offline treatment or as a measure for following a study protocol, (2) the technology studied was only used as a tool for exchanging information without the possibility for further interaction with the system (eg, telemonitoring only, sending or receiving messages like SMS [short message service] interventions, or in chat rooms), and (3) the article was a conference abstract or full text was not available.

### Study Selection

The selection of studies was completed in three steps. First, all titles were screened by two authors (FS and SK) to exclude the

**Textbox 1.** Information extracted from the included articles.

1. *General information* regarding the authors, affiliation, country, year, and journal of publication.
2. *The name of the technology*: when no name was reported, the name was indicated as “N/A.”
3. *The type of technology or the device*: for example, Web-based, mobile phone apps, wearable, or other devices for monitoring.
4. *Type of use (structured, hybrid, or unstructured)*: “Structured use” was assigned to technologies consisting entirely of separate modules or lessons that users had to complete before moving on to the next [6]. “Free use” was assigned to technologies that consisted of different elements that users could then use at their own convenience (eg, a personal health record containing a diary, educational material, and a messaging function; or a wearable connected to a mobile phone app to gain insight into something like activity levels). “Hybrid use” was assigned to technologies with a fixed core, supplemented with other components for free use.
5. *The health care field targeted with the technology*, distinguishing between mental health (eg, targeting depressive symptoms or anxiety), chronic conditions (eg, self-management support for patients with type 1 diabetes mellitus), or lifestyle technologies (eg, losing weight, improving physical activity, or quitting smoking). These categories were assigned depending on the technology’s goal, meaning that an intervention to support patients with chronic conditions maintaining a healthy lifestyle is seen as a lifestyle technology.
6. *The variables that were used to assess adherence*, such as the number of logins, the number of different days that users used the technology, the time spent on the technology, the number of modules or lessons started or completed, and the number of different elements that were accessed or used.
7. *The intended use of the technology*.
8. *Whether the described intended use was justified*, for example, using theory, evidence, or rationale.

**Table 1.** Categorization of adherence operationalizations.

Category	Explanation
Category A	Assigned when adherence was operationalized in terms of “the more usage, the better.” Category A operationalizations do not include an operationalization of intended use, and therefore do not comply with the definition of adherence.
Category B	Assigned when the intended use of a technology was provided without justification (eg, “a user is adherent when logging in at least once a week for three subsequent weeks”).
Category C	Assigned when the intended use of the technology was provided <i>and</i> justified using theory, evidence, or rationale (eg, “we know from previous research that users benefit the most from the technology when finishing module 4, so a user is adherent once module 4 is completed”).

## Results

### Study Selection

A total of 7005 studies were identified via the search. After screening of the titles, abstracts, and full texts, 62 full texts were included in this review. An overview of these articles is presented in [Multimedia Appendix 2](#).

In total, 36 articles were excluded during the full-text screening phase ([Figure 1](#)). Most full texts (n=18) were excluded because they did not include objective, quantifiable measurements, and an operationalization of adherence to the technology (12 primary studies and 6 viewpoint papers). Other reasons for exclusion are presented in [Figure 1](#).

All included articles were published in 2006 or later, and more articles published in recent years were included overall ([Figure 2](#)). The first authors are mostly affiliated in the United States of America (n=15), Australia (n=10), and the Netherlands (n=8) ([Table 2](#)). In total, 24 of the studies were published in the *Journal of Medical Internet Research* or its sister journals.

### Technology Characteristics

[Table 3](#) provides an overview of the technologies that are subjects of the included studies. The technologies described in most of the articles are Web-based (51/62). Furthermore, five are smartphone apps and five are Web-based or smartphone technologies combined with other devices such as wearables. Almost half of the technologies (29/62) were structured technologies, 18 were unstructured technologies, and 15 had a hybrid nature.

Half of all included articles reported adherence to mental health technologies. Most of these technologies targeted depression (n=8) and anxiety disorders (n=5), some of the latter also in combination with depression (n=3). Other mental health technologies targeted postdisaster mental health distress (n=3); cancer-related distress (n=3); general stress management (n=2); eating pathology (n=2); or insomnia, erectile dysfunction, bipolar disorders, mindfulness, and cognitive training (all n=1). Eighteen of these technologies were based on cognitive behavioral therapy. Most of the structured technologies (17/29) and almost all hybrid technologies (12/15) were aimed at improving mental health ( $P<.001$ ).

A total of 25 technologies were aimed at supporting a healthy lifestyle, more specifically smoking cessation (n=7); improving physical activity (n=7); weight loss (n=5); alcohol cessation (n=3); general health promotion (n=2); or healthy eating (n=1). Six technologies were aimed at self-management support for

patients with chronic diseases (diabetes [n=3], inflammatory bowel disease [n=1], hypertension [n=1], or surgical site infections [n=1]). Most of the unstructured technologies were aimed at lifestyle support (13/18).

For all technologies, adherence was mostly operationalized using measures regarding the number of modules or lessons completed and the number of different days, weeks, or months that people used the technology. Adherence to unstructured technologies was mostly operationalized using the number of logins or sessions ( $P=.03$ ), the number of features accessed or used ( $P<.001$ ), and the time spent using the technology ( $P<.001$ ). Adherence to structured technologies was most often operationalized using the number of modules or lessons completed ( $P<.001$ ).

### Operationalization of the Adherence Definition

Out of the 62 included articles, 34 reported adherence only in terms of how often the technology was used (Category A operationalization) [[7,18-50](#)]. In 23 studies, the intended usage was described as well (Category B operationalization) [[51-73](#)], and 5 studies reported the intended usage with a justification for this threshold (Category C operationalization) [[74-78](#)]. The number of publications reporting Category C operationalizations has increased since 2015 ([Figure 2](#)).

[Table 4](#) provides an overview of the characteristics of the studies for adherence category. Although no significant differences were found, we were still able to identify some interesting patterns. Overall, the data show that 20 out of 31 technologies for mental health contain a Category A operationalization, whereas Category C operationalizations are more equally distributed over the three health care fields. Furthermore, 48 out of 56 Category A and Category B operationalizations are for Web-based technologies (whether or not in combination with other devices), whereas a third of the Category C operationalizations are also for smartphone technologies.

Most Category A operationalizations contain a measure for the number of modules that the users accessed or completed (19/34) and the time spent on the technology and number of features accessed and used (both 11/34). Most Category B operationalizations contain the number of days, weeks, or months that people used the technology (11/23), the number of accessed or completed modules (8/23), and the number of logins or sessions (4/23).

Category C definitions are mostly based on the number of accessed or completed modules (3/5 operationalizations). The number of logins and the number of days, weeks, or months

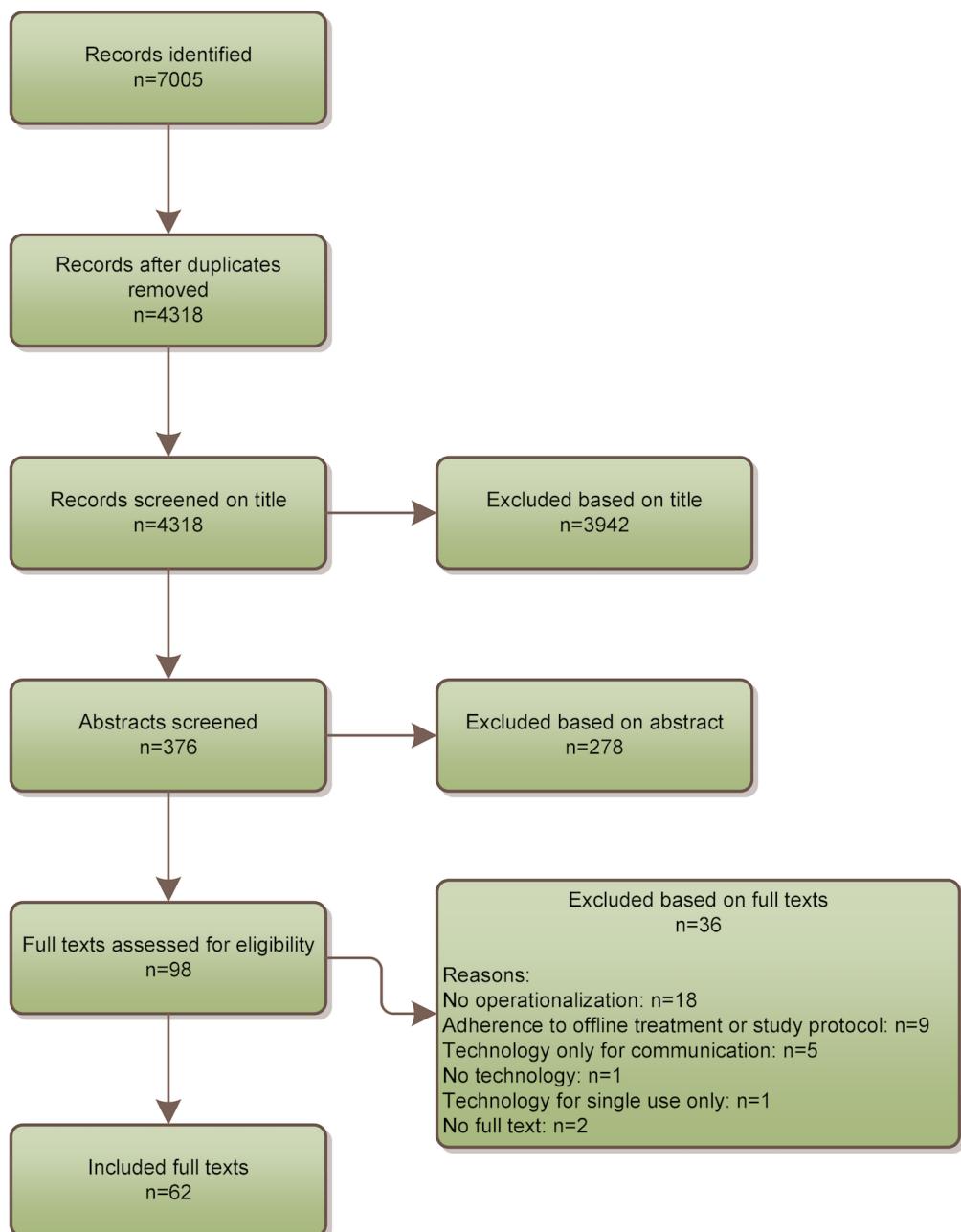
that people used the technology were used in 2 out of 5 operationalizations.

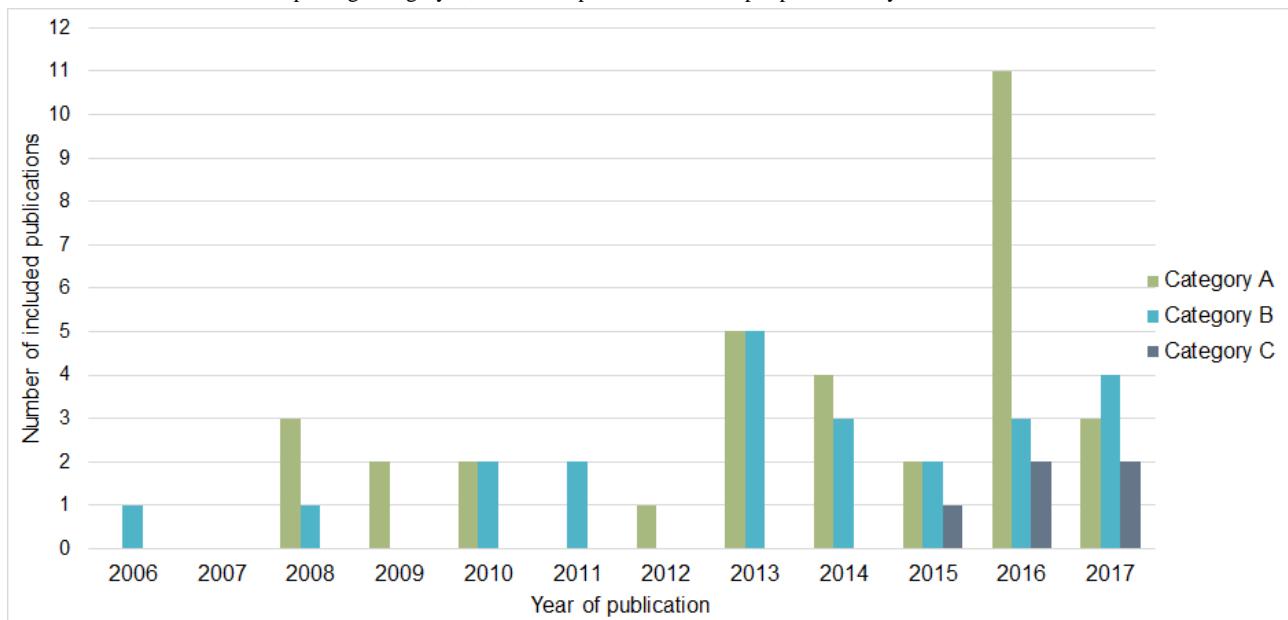
Most operationalizations of adherence are based on a maximum of two different measures, regardless of the category (49/62). Ten out of 13 operationalizations that feature 3 or more measures are categorized as Category A.

The included Category C operationalizations provided justification in various ways. Reinwand et al asked all participants to complete a questionnaire to assess to what extent their lifestyle met the Dutch guidelines for healthy eating, drinking alcohol, physical activity, etc [74]. Recommendations for the use of corresponding elements of the technology were then made based on the outcomes of the assessment and, in turn,

adherence was defined as using the technology in accordance with these recommendations. In the study by Zeng et al, the technology consisted of different elements that were all evaluated as effective in other studies [75]. Users were considered adherent if they used all elements. Beatty et al considered a user to be highly adherent when a therapeutic dose of 66% of the intervention was received [76]. This threshold for a therapeutic dose was obtained from previous studies. In the study by Mertens et al, technology use was represented in relation to medication use, and users were therefore seen as adherent when the technology was used in accordance with the recommendations for medication use [77]. Carolan et al describe a protocol for a study to be conducted to understand the optimum adherence to the technology in relation to the outcomes [78].

**Figure 1.** Flowchart of full text selection.



**Figure 2.** The number of studies reporting Category A, B, and C operationalizations per publication year.**Table 2.** Country of affiliation of the first authors of all included articles.

Country	Number of included articles
United States of America	15
Australia	10
The Netherlands	8
Sweden	5
United Kingdom	5
Canada	3
Germany	3
Switzerland	3
China	2
Norway	2
Austria	1
Denmark	1
Finland	1
Ireland	1
Portugal	1
Spain	1

**Table 3.** Characteristics of structured, unstructured, and hybrid technologies and their operationalizations of adherence.

Characteristics	Structured (n=29)	Unstructured (n=18)	Hybrid (n=15)
	n (%)	n (%)	n (%)
<b>Health care field<sup>a</sup></b>			
Mental health (n=31)	17 (59)	2 (11)	12 (80)
Lifestyle (n=25)	9 (31)	13 (72)	3 (20)
Chronic care (n=6)	3 (10)	3 (17)	0 (0)
<b>Device</b>			
Web-based (n=51)	25 (86)	13 (72)	13 (87)
Smartphone app (n=6)	3 (10)	2 (11)	1 (7)
Web-based or smartphone with wearable (n=2)	0 (0)	1 (6)	1 (7)
Web-based or smartphone with wearable and monitoring device (n=3)	1 (3)	2 (11)	0 (0)
<b>Level of adherence definition</b>			
Category A (n=34)	16 (55)	10 (56)	8 (53)
Category B (n=23)	11 (38)	7 (39)	5 (33)
Category C (n=5)	2 (7)	1 (6)	2 (13)
<b>Number of measures<sup>a</sup></b>			
1 (n=32)	19 (66)	4 (22)	9 (60)
2 (n=17)	8 (28)	7 (39)	2 (13)
3 (n=7)	1 (3)	3 (17)	3 (20)
4 or more (n=6)	1 (3)	4 (22)	1 (7)
<b>Measures of adherence</b>			
Number of logins/number of sessions (n=14) <sup>a</sup>	3 (10)	8 (44)	3 (20)
Number of modules/number of lessons completed (n=30) <sup>a</sup>	17 (59)	2 (11)	11 (73)
Number of features accessed/used (n=16) <sup>a</sup>	5 (17)	9 (50)	2 (13)
Number of exercises completed (n=9)	6 (21)	2 (11)	1 (7)
Number of pages viewed (n=11)	2 (7)	6 (33)	3 (20)
Number of days/weeks/months (n=19) <sup>a</sup>	8 (28)	7 (39)	4 (27)
Time spent (n=14) <sup>a</sup>	2 (7)	9 (50)	3 (20)

<sup>a</sup>*P*<.05.

**Table 4.** Characteristics of Category A, B, and C definitions.

Characteristics	Category A (n=34)	Category B (n=23)	Category C (n=5)
	n (%)	n (%)	n (%)
<b>Health care field</b>			
Mental health (n=31)	20 (59)	9 (39)	2 (40)
Lifestyle (n=25)	13 (38)	10 (44)	2 (40)
Chronic care (n=6)	1 (3)	4 (17)	1 (40)
<b>Device</b>			
Web-based (n=51)	31 (91)	17 (74)	3 (60)
Smartphone app (n=6)	1 (3)	3 (13)	2 (40)
Web-based or smartphone with wearable (n=2)	1 (3)	1 (4)	0 (0)
Web-based or smartphone with wearable and monitoring device (n=3)	1 (3)	2 (9)	0 (0)
<b>Type of use</b>			
Structured (n=29)	16 (47)	11 (48)	2 (40)
Unstructured (n=18)	10 (29)	7 (30)	1 (20)
Hybrid (n=15)	8 (24)	5 (22)	2 (40)
<b>Measures of adherence</b>			
Number of logins/number of sessions (n=14)	8 (24)	4 (17)	2 (40)
Number of modules/number of lessons completed (n=30)	19 (56)	8 (35)	3 (60)
Number of features accessed/used (n=16)	11 (32)	4 (17)	1 (20)
Number of exercises completed (n=9)	6 (18)	3 (13)	0 (0)
Number of pages viewed (n=11)	9 (27)	1 (4)	1 (20)
Number of days/weeks/months (n=19) <sup>a</sup>	6 (18)	11 (48)	2 (40)
Time spent (n=14)	11 (32)	2 (9)	1 (17)
<b>Number of measures</b>			
1 (n=32)	13 (38)	16 (70)	3 (60)
2 (n=17)	11 (32)	5 (22)	1 (20)
3 (n=7)	6 (18)	1 (4)	0 (0)
4 or more (n=6)	4 (12)	1 (4)	1 (20)

<sup>a</sup>*P*<.05.

## Discussion

### Aim of this Review

In this systematic review, we have sought to gain insight into how the concept of adherence has been used in previous eHealth evaluations. In line with the definitions for adherence and intended use maintained by the WHO [10] and Kelders [1], we reviewed not only how usage was measured but also if and how intended use of eHealth technologies was operationalized and justified using theory, evidence, or rationale.

### Principal Findings

We included 62 studies in this review, all published after 2005. The majority of the technologies described in these studies were structured or hybrid Web-based interventions targeting mental health (mostly cognitive behavioral therapy [CBT] interventions) or unstructured technologies for lifestyle support.

We observed a growing number of studies that studied adherence to eHealth technologies since Eysenbach's plea for reporting the levels of nonusage attrition with eHealth technology in 2005 [9]. Although the "prescribed recommendations" or the intended use of a technology form an important element of the definition of adherence [10], and although there is evidence that users do not always have to complete an intervention to experience effects [6,11,13-15], half of all operationalizations are based on the assumption of "the more use, the better" and do not include a threshold for intended use. Sometimes, we do not know (yet) what the intended use of a technology is, or defining the intended use is not necessary to answer the research question(s) of the study. Then, a Category A operationalization suffices for answering the research questions. However, a Category A operationalization only refers to the actual usage of a technology without comparing it with its intended usage. According to the definitions used, they should therefore not be referred to as adherence.

When the intended use for the technology was reported, only a minority of all included studies featured justified Category C operationalizations, making the comparison of adherence across different eHealth technologies more complicated. However, we were still able to observe a small increase in Category C operationalizations since 2015.

Remarkably, the proportion of evaluations of mental health technologies reporting a justified (Category C) operationalization of intended use is lagging behind compared with evaluations of lifestyle and chronic care technologies. This is unexpected because the majority of mental health technologies is based on (principles of) CBT, which is the most studied treatment for depression and has proven effective in many studies [79]. However, a meta-analysis of Van Ballegooijen et al revealed that participants complete approximately 84% of their CBT program in both offline and online treatment. Although a longer treatment duration is associated with better effects [80], this still implies that users do not necessarily need to finish the complete program to experience reduction of their complaints, and that there should be a threshold for intended use. As such, it seems that this knowledge could be used to define and substantiate the intended use of a CBT technology, but in the studies included in this review, this notion has not been put into practice yet.

We were also able to observe some interesting patterns in the composition of measures for adherence and intended use. When the operationalization of adherence consists of a combination of four or more measures, it is most likely a Category A operationalization, whereas most Category C operationalizations consist of one or two measures. This implies that for many Category A operationalizations, a scattershot approach was used when it comes to measuring adherence. In contrast, the results indicated that justifications of intended use are often based on the goal of the technology and/or the assumed working mechanisms, leading to more focused operationalizations that do not require additional measurements to evaluate adherence to the technology. In other words, more measures are not necessarily the key to knowledge if they are not sufficiently specific.

No significant differences could be found between the kinds of measures that are used for all three levels of operationalizations. Category A operationalizations most often contain the number of modules that a user started or completed, the number of features accessed or used, and the time spent online. This seems obvious, as this level of operationalization is mostly used for structured or hybrid mental health interventions consisting of different modules that users have to follow. Category C or justified operationalizations are more often defined by the number of days, weeks, or months that the technology is used by people. This can be explained by way of the finding that Category C operationalizations are used for a large proportion of unstructured and hybrid technologies. As people are able to use the features of these technologies more or less at their own convenience, the development of use over time would probably provide more information regarding adherence than use of the technology's content at fixed points in time only.

## Implications and Recommendations

An important reason for the lack of justifications for the intended use of eHealth technologies might be that there is a lack of knowledge regarding the working mechanisms of technology-based applications [8]. However, the included Category C operationalizations did show that knowledge of the working mechanisms of the technology is not a prerequisite for defining the intended use. After all, the intended use or the “therapeutic dose” can be justified just as well using existing guidelines for healthy living and medication use [74,77] or using previous research regarding other technologies [75,76]. Moreover, the intended use has also been operationalized by linking the (positive) outcomes of individual users to their usage patterns to find the most effective patterns [78].

The fact that we did not find a justification of intended use based on existing models for behavior change was unexpected. For instance, Kaushal and Rhodes found that exercising for at least four times per week for 6 weeks is a minimal requirement for establishing exercise habits [81]. These kind of findings can also be used for determining intended use; for example, a user of a technology to improve physical activity is adherent when using (specific elements of) the technology at least four times a week and 6 weeks in a row.

Another example comes from Kelders et al who found that a group of users dropped out from an intervention for reducing depressive complaints after a lesson that focused on applying newly acquired skills in practice, as doing so can be confrontational [56]. However, following this lesson can also be seen as an important precondition for gaining effects from using the intervention. The intended use of this intervention could thus be operationalized as following the intervention until that critical lesson is completed at the very least. An important aspect of operationalizing the intended use of a technology is therefore to keep the goal of the technology and the desired outcomes in mind. What use is necessary at minimum to reach that goal (eg, to experience certain effects or establish new skills and habits), and how can we translate this into measures for adherence?

Although it has previously been suggested that a combination of a range of different variables for technology usage provides a more meaningful measure of adherence [6], the results of this review show that a limited but deliberate set of only one or two different measures in accordance with the goal of the technology can also be used for operationalizing intended use. At the moment, eHealth evaluations often fail to demonstrate the dose-response relationship (the usage that is minimally needed to experience certain effects) or simply define it as “the more use, the better.” However, the results of this review indicate that Category A and B operationalizations of adherence often do not take the characteristics of the technology (eg, goal, persuasiveness, and user-friendliness) into account. It is thus very possible that dose-response relationships might become more apparent when the measures used to operationalize adherence match the goal of the technology [82,83].

All of the measures for adherence in this review are based on data regarding technology usage. However, the results of a recent literature review of theoretical perspectives on adherence

showed that adherence is a multidimensional concept, influenced by a range of technological, environmental, and individual factors altogether that cannot be evaluated by technology usage alone [8,84]. Therefore, additional measures are needed to determine whether and why users are or have been adherent to technology. For example, a mixed-methods approach that combines usage data with questionnaires, health measurements, and/or interviews could provide important knowledge regarding why people do or do not use the technology, how people learn from using the technology, the minimal use that is needed for users to experience certain effects or to reach certain goals, and how the skills acquired while using the technology are then applied in daily life. These outcomes could then in turn be used for determining the intended use of the technology and translating that concept into concrete measures for evaluating adherence.

In their review, Donkin et al state that it is difficult to compare adherence with different technologies when the measures that are used across the different trials vary [6]. However, this statement is based on Category A operationalizations of adherence where more use is better. When using Category B or (preferably) Category C operationalizations, the actual usage of each individual can be compared with the technology's intended usage. In turn, the percentage of people who adhered to the intervention can be calculated, making adherence a more objective and standardized concept [1]. This approach simplifies the comparison of adherence across technologies with the same goal (eg, improving physical activity) but different technology characteristics (eg, features of the technology, persuasiveness, and user-friendliness) and a different operationalization of intended use. At the same time, this approach also simplifies the comparison of adherence of different users of a specific technology. Ideally, when individuals have different goals for using a technology, they should also have an individual intended usage, which could be used to get more fine-grained, personalized measures of adherence. This will be of added value for both developers and researchers, as this approach will provide better insight into how adherence to the various elements of different technologies contributed to the outcomes that are found, and for whom.

### Limitations

As the goal of this review was to gain insight into how the concept of adherence has been used in previous eHealth

### Conflicts of Interest

None declared.

### Multimedia Appendix 1

Keywords literature search.

[[PDF File \(Adobe PDF File, 323KB - jmir\\_v19i12e402\\_app1.pdf](#) ]

### Multimedia Appendix 2

Included studies and technologies, levels of adherence operationalization, and measures.

[[PDF File \(Adobe PDF File, 75KB - jmir\\_v19i12e402\\_app2.pdf](#) ]

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## Abbreviations

**eHealth:** electronic health  
**SMS:** short message service  
**WHO:** World Health Organization  
**CBT:** cognitive behavioral therapy

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Original Paper

# Mindfulness-Based Cognitive Therapy for Cancer Patients Delivered via Internet: Qualitative Study of Patient and Therapist Barriers and Facilitators

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## Abstract

**Background:** The number of patients living with cancer is growing, and a substantial number of patients suffer from psychological distress. Mindfulness-based interventions (MBIs) seem effective in alleviating psychological distress. Unfortunately, several cancer patients find it difficult, if not impossible, to attend a group-based course. Internet-based MBIs (eMBIs) such as Internet-based mindfulness-based cognitive therapy (eMBCT) may offer solutions. However, it is yet to be studied what facilitators and barriers cancer patients experience during eMBCT.

**Objective:** This study aimed to explore facilitators and barriers of individual asynchronous therapist-assisted eMBCT as experienced by both patients and therapists.

**Methods:** Patients with heterogeneous cancer diagnoses suffering from psychological distress were offered eMBCT. This 9-week intervention mirrored the group-based MBCT protocol and included weekly asynchronous written therapist feedback. Patients were granted access to a website that contained the eMBCT protocol and a secured inbox, and they were asked to practice and fill out diaries on which the therapist provided feedback. In total, 31 patients participated in an individual posttreatment interview on experienced facilitators and barriers during eMBCT. Moreover, eight therapists were interviewed. The data were analyzed with qualitative content analysis to identify barriers and facilitators in eMBCT.

**Results:** Both patients and therapists mentioned four overarching themes as facilitators and barriers: treatment setting (the individual and Internet-based nature of the treatment), treatment format (how the treatment and its guidance were organized and delivered), role of the therapist, and individual patient characteristics.

**Conclusions:** The eMBCT provided flexibility in when, where, and how patients and therapists engage in MBCT. Future studies should assess how different eMBCT designs could further improve barriers that were found.

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**KEYWORDS**

mindfulness; psycho-oncology; cancer survivors; telemedicine; qualitative research

## Introduction

Cancer poses a major psychological challenge for individuals. A meta-analysis of psychiatric disorder in oncological and hematological settings yielded a prevalence of psychiatric disorder of 30% to 40% [1]. In the coming decades, a great increase is expected in the number of people living with cancer [2]. This means that a growing number of cancer patients are in need of effective and accessible psychological treatment.

Mindfulness-based interventions (MBIs) such as mindfulness-based stress reduction (MBSR) [3] and mindfulness-based cognitive therapy (MBCT) [4], the latter more oriented toward those in need of clinical psychological treatment, could be viable intervention options for cancer patients. Mindfulness is defined as follows: “paying attention, on purpose, in the present moment and nonjudgmentally” [5]. Its practice enables participants to recognize habitual, conditioned modes of reacting, and to make a radical shift in how they relate to their thoughts, feelings, and body sensations, as well as to outer circumstances [6], such as when coping with cancer.

Evidence for the effectiveness of MBIs for cancer patients has rapidly expanded. In 2015, an overview including six systematic reviews in heterogeneous cancer patients demonstrated significant small to moderate effects on various psychosocial outcomes in cancer patients [7]. In addition, studies confirmed these effects at longer-term follow-up [8,9]. Moreover, studies demonstrated that the effect of MBIs in breast cancer patients might be mediated by nonreactivity, reduced catastrophizing, and increased self-kindness [10,11]. Notwithstanding the potential of MBIs, several cancer patients encounter practical and psychosocial barriers that hamper access and participation in psychological treatments such as MBIs. These barriers include cancer-related illness, fatigue, limited mobility or disability, limited transportation options, and time constraints [12,13]. Internet-based interventions, such as Internet-based MBIs (eMBIs), may offer solutions to these problems. Mobile MBI apps have already demonstrated their potential [14]. Internet-based interventions are easily accessible, available 24×7, save traveling time, and could be less costly [15]. Evidence of over 100 well-controlled trials suggests that Internet-based treatments can be as effective as group-based psychological treatments for a wide range of psychiatric and somatic conditions [16].

Moreover, a previous review suggests that eMBIs may be helpful in alleviating symptom burden of patients with physical health conditions, particularly when the eMBI is tailored to specific symptoms [17]. A total of 16 studies examining eMBIs for people with chronic physical health conditions were reviewed, of which two specifically targeted cancer patients. A randomized controlled trial (RCT; n=62) investigated the quantitative feasibility of Internet-based MBSR for cancer patients (mindfulness-based cancer recovery [MBCR]) [13]. The Internet-based MBCR (eMBCR) consisted of synchronous videoconferencing sessions. Feasibility targets for recruitment and adherence (5% response rate, 30% eligible, and 85% consented) were achieved, and patients considerably improved

on mood disturbance, stress symptoms, spirituality, and acting with awareness in the Web-based group relative to waitlist controls. Results suggested that eMBCR led to improved energy while also inducing relaxation [18]. In addition, an uncontrolled cohort study (n=257) of severely fatigued cancer patients evaluated an Internet-based mindfulness-based cognitive therapy (eMBCT) [12]. In total, 34.6% (89/257) of the patients showed clinically relevant improvement in fatigue severity and 61.8% (159/257) of the patients adhered to treatment. In sum, evidence for eMBIs in cancer is scarce, but the first results seem promising.

However, how to optimally deliver eMBIs remains unknown [17]. It is unclear whether either synchronous (real time, eg, instant messaging or videoconferencing) or asynchronous (delayed, eg, email or message boards) is to be preferred. Patients are supposed to engage in an experiential inquiry-based learning process together with the therapist in eMBIs [6], but it is unknown whether such an experiential inquiry-based learning process is at all possible in an asynchronous format. In addition, it is unclear whether either facilitated (guided) or self-directed eMBIs are to be preferred. It is argued that the therapists’ capacity to embody qualities and attitudes of mindfulness in the process of teaching is vital for effective delivery of MBIs [6]. Guidance seems to be a beneficial feature of Internet-based interventions in general [19], and exploratory subgroup analyses of a systematic review indicated higher effect sizes of stress and mindfulness skills for guided than unguided eMBIs [15]. However, a previous review also provided some initial support for unguided eMBIs [20]. In short, the question of which eMBI delivery format is preferable in terms of program adherence, mindfulness skills, and outcome improvement needs further investigation [17].

Previously, a qualitative study has provided important perspectives for examining the user experience in an MBI. In a qualitative study of an eMBI for recurrent depression, patients identified aspects such as flexibility and reduced cost, as well as the need for support in time management [21]. Qualitative information on how patients and their therapists experience eMBCT could identify barriers and facilitators, and inform us whether it is possible to design useful, user-friendly, and effective eMBIs for cancer patients and where to improve delivery mode and design if necessary and possible. Therefore, the aim of this study was to gain understanding of the experienced facilitators and barriers of asynchronously delivered eMBCT in a sample of heterogeneous cancer patients and their therapists.

## Methods

### Study Population and Procedure

The patients of this study took part in a 3-armed trial on the (cost-) effectiveness of MBCT for distressed cancer patients (Clinicaltrials.gov no. NCT02138513) [22]. Patients were randomized to either eMBCT, group-based MBCT, or treatment as usual. The RCT is described in more detail in a protocol paper [22]. Patients for this trial were mainly recruited via online media (26.9%, 66/245), patient associations (17.6%, 43/245), and participating mental health care centers (16.7%, 41/245).

In total, 245 cancer patients with any tumor type and any stage of disease scoring 11 or higher on the Hospital Anxiety and Depression Scale were randomized. The local ethics committee approved this study (CMO Arnhem Nijmegen 2013/542).

### Qualitative Assessments: Semistructured Interviews (Patients) and Focus Group (Therapists)

Both patients randomized to eMBCT and their therapists were invited by the researcher to talk about the following questions:

- How did you experience the eMBCT?
- What facilitated and what impeded your participation in eMBCT?
- How did you experience the relationship with the therapist or patient?
- How would you improve the eMBCT?

The abovementioned questions were followed by specific probes. Questions were asked in an open nondirective manner, allowing participants to speak freely about their experiences.

Patients were interviewed via telephone or in person within 3 months after eMBCT treatment completion or dropout. Patients were purposefully sampled to gather an even distribution of completers versus noncompleters and breast cancer versus other tumor types. Patient interviews were conducted by FC and EJ. FC is a PhD student with an MSc degree in behavioral science with no prior experience in qualitative research. He was the trial coordinator for the larger RCT [22], and had conducted baseline and posttreatment research interviews conducting the posttreatment interviews. EJ is a psychologist and mindfulness teacher with an MSc degree in psychology with prior experience with qualitative research.

Therapists were invited for a focus group interview during the last plenary therapist supervision session approximately 3 months after completing the last MBCT. Both the patient interviews and therapist focus group started by explaining confidentiality and the explorative nature of the interview. AS and ML conducted the focus group interviews. AS is a professor of psychiatry in the role of principle investigator of the larger RCT [22], with experience in several qualitative research projects in MBIs. ML is a senior researcher and clinical psychologist in the role of principle investigator of the larger RCT [22], with experience in several qualitative research projects on MBIs.

### Data Analysis

We used conventional qualitative content analysis to analyze the data in which coding categories are derived directly from the text data [23]. We used ATLAS.ti version 7.1 software (Scientific Software Development GmbH, Berlin, Germany). Analysis started as soon as the first interview was conducted and continued with each additional interview. Interviews were transcribed verbatim, and each transcript was coded by 2 independent researchers (FC and EJ) to identify facilitators and barriers. Coding was performed as closely related to the patient's words as possible to minimize subjectivity. After 5 interviews, FC and EJ compared codes with each other, and a common

coding scheme was developed. Remaining transcripts were coded using this common coding scheme and earlier transcripts were recoded. New codes were added when data were encountered that did not fit in the existing coding scheme. After 12 interviews, a larger group of researchers (FC, EJ, MS, ML, and AS) discussed all data within the coding scheme. Some codes were combined during this process, whereas others were split in subcategories. After 31 interviews, no new codes were added and it was concluded that saturation had been reached. All codes referring to the same phenomenon were grouped in a hierarchical structure in subcategories, and subcategories in themes by FC and EJ. The group of researchers (FC, EJ, MS, ML, and AS) subsequently discussed this classification until reaching consensus.

### Intervention and Therapists

The eMBCT was based on the MBCT protocol for recurrent depression published by Segal et al [4]. The content was adapted to cancer patients by particularly tailoring the psychoeducation (eg, managing cancer-related fatigue, pain, fear of cancer recurrence, and effects of cancer on partner communication) and movement exercises to their needs [24].

The eMBCT was mainly text-based and included asynchronous interaction with a therapist similar to the study of Bruggeman-Everts et al [12]. Patients were granted access to a website divided into a workspace containing 9 sessions (8 weeks + 1 full-day silent retreat) and a secured inbox. The therapist initiated the eMBCT by sending a welcome message to the patient. When patients logged-in, they were presented with the overview of all information and assignments due for that week (Figure 1). Each session contained an introductory text, and daily formal (eg, sitting meditation) and informal exercises (eg, awareness of everyday activities) with guided audiotaped files and accompanying diaries. Sessions also contained other home practice such as the pleasant or unpleasant events' diary. The eMBCT was performed individually. To demonstrate the rationale and possible obstacles of each exercise, patients were provided with experiences of other (fictional) patients (Figure 2). Patients were asked to practice and complete the diaries on a daily basis (Figure 3). The therapist provided written feedback on their progress via the secured inbox on a prearranged day of the week (Figure 4). Next week's session only became available after completing the previous session. Patients always had access to their therapist via the inbox. Patients and therapists were notified via their regular email when they received a message via the secured inbox.

We defined adherence as having attended  $\geq 4$  sessions. Therapists without prior eMBCT experience were provided with guidelines and were supervised by more experienced eMBCT therapists. See Table 1 for therapists' characteristics. All therapists fulfilled the advanced criteria of the Association of Mindfulness Based Teachers in the Netherlands and Flanders, which are in concordance with the UK Mindfulness-Based Teacher Trainer Network Good Practice Guidelines for teaching mindfulness-based courses [25].

**Figure 1.** The eMBCT dashboard containing the programme overview.

**Figure 2.** A fellow (fictional) participants' diary entry.

**Figure 3.** Example of an online eMBCT diary form accompanying one of the homework assignments.

**Onprettige gebeurtenissen (dagelijks)**

**Mijn dagboek**

Noteer wat je opviel bij de oefening die je hebt gedaan, zodat we dit kunnen bespreken.

**Day 1 - unpleasant experiences**

<b>What was the unpleasant experience?</b>	<b>Describe the bodily sensations in detail</b>
<p>I was stressed at work today because my boss and I had a disagreement. He thinks I am too slow at work.</p>	<p>Sweaty palms, tense stomach, prickly eyes. I felt my heartbeat</p>
<b>What feelings and emotions did you have during the experience?</b>	<b>What feelings and emotions do you have now, writing this down?</b>
<p>This is so unfair, I work hard. Since my illness I am slower, I can't concentrate as I could before. I can't help getting cancer..</p>	<p>I should have a conversation with him about his expectations of me. I feel frustrated and tired.</p>

Negeer de verplichte velden      [« Vorige pagina](#) of [Volgende pagina »](#)      Pagina: 3 van 9

**Figure 4.** Written therapist feedback via the secured messaging inbox.

**mijnHDI** Begeleiding bij ziekte

**Postbus**

Postvak in (0/2) Verzonden (7) Concepten (0) Contacten Prullenbak (0) Archief (0)

**Nieuw bericht**

Aan: Eltica Client  
Van: Félix Therapeut  
Maandag 17 juli 2017, 16:17

verwijder archief afdrukken

Dear Eltica

This concludes week 4. You are almost halfway! How nice to read that the three minute breathing space has such an effect on you. In what places do you tend to use this exercise? And do you always use the audio file or do you know the three steps by heart? The core is to come to a halt, recognizing what is there at the moment, redirecting your attention to the breath and then to the rest of your body. You could see it as a small break during the day. It could help you to relax, but this is not the goal of this exercise. It is meant to become conscious of certain patterns. It helps some in acknowledging how busy they are, for example.

I read in your unpleasant experiences diary that you were confronted with your own limitations at work and that your boss is not too supportive in this respect. I compliment you for realising that it might be helpful to you to have a conversation with him. Perhaps you can make new arrangements that are better suited to your energy level and needs at work. This could prevent a lot of future frustration!

Good luck with the second part of the training! 😊

**Antwoorden**

Smiley faces: 😊 😐 😂 😊 😊 😊 😊 😊 😊 😊

**Table 1.** Demographical characteristics of Internet-based mindfulness-based cognitive therapy therapists.

Variable (N=8)	Mean (SD)	n (%)
Age, years	55.50 (7.2)	
Gender, female		6 (75)
Years of experience in teaching MBCT <sup>a</sup>	8.75 (2.7)	
Prior experience with eMBCT <sup>b</sup>		4 (50)

<sup>a</sup>MBCT: mindfulness-based cognitive therapy.

<sup>b</sup>eMBCT: Internet-based mindfulness-based cognitive therapy.

## Results

### Sample

Out of the 125 patients randomized to eMBCT, 45 were invited for a posttreatment interview. In total, 12 patients declined and 2 recordings failed. As a result, 31 interviews were used in the qualitative analysis. Interviews lasted from 5 to 25 min. Out of the patients interviewed, 14 had participated in 4 or more sessions of eMBCT, 10 had attended less than 4 sessions of eMBCT, and 7 had not started at all. See [Table 2](#) for patient characteristics.

A total of 11 out of 12 eMBCT therapists were invited for a focus group interview after completion of all eMBCTs. Out of these 12 therapists, 7 therapists agreed to participate and 1 therapist agreed to provide an individual interview with FC for scheduling reasons. Therapists declined either because of having provided too few individual online treatments to share experiences (n=1) or because of scheduling reasons (n=2). The focus group interview lasted for 90 min. The single individual therapist interview lasted for 25 min. The final sample of therapists included both therapists who had experience with online mindfulness before this project (n=4) and therapists who had no prior experience with online mindfulness before this project (n=4). See [Table 2](#) for therapist characteristics.

All patient facilitators ([Textbox 1](#)), patient barriers ([Textbox 2](#)), therapist facilitators ([Textbox 3](#)), and therapist barriers ([Textbox 4](#)) could be divided into the following four themes: treatment setting, treatment format, role of the therapist, and patient characteristics. First, patients' facilitators and barriers are presented per each theme. Then, therapists' facilitators and barriers are presented per each theme.

### Patients

#### **Patient Theme 1: Treatment Setting—Facilitators**

Treatment setting concerned subthemes on the external conditions of the eMBCT: flexibility of timing, the individual nature, and the home practice environment of the training.

#### Time Management

It was considered convenient to be able to manage your own time schedule, which increased treatment receptivity. One patient stated the following:

*Because you can start when you are ready and have the peace of mind for it, you can absorb it much better, because you actually want to at that moment. [Female breast cancer patient (curative), 65 years, completer]*

#### Individual Setting

A patient indicated that the individual setting facilitated a sense of autonomy that helped in taking care of himself:

*I didn't feel like doing the movement exercises. In a group setting I would have had to explain myself, so you are more inclined to go along with the group. But now, being on my own, I carried full responsibility for my own actions. Getting this space felt comfortable, because there were moments at which the therapy really asked a lot of me. At those times I could allow myself to take a time out and decide when I wanted to continue again. [Male prostate cancer patient (palliative), 65 years, completer]*

Furthermore, it was considered to be facilitating not to be confronted with other patients' cancer stories. One patient stated the following:

*This only was about me and I didn't have to spend energy on someone else's story. [Female breast cancer patient (curative), 27 years, completer]*

#### Home Setting

Being able to complete the sessions and exercises in your own home environment and not having to travel was appreciated. One patient stated:

*For me, it was ideal because I knew that the group-based MBCT would take place at [the mental health institute] and it was impossible to reach by public transport. [Female breast cancer patient (curative), 27 years, completer]*

**Table 2.** Demographic and clinical characteristics of Internet-based mindfulness-based cognitive therapy patients.

Variable (N=31)	Mean (SD)	n (%)
Age, years	53.0 (12.3)	
Gender, male		6 (19)
<b>Education level</b>		
Secondary		14 (45)
Vocational or university		17 (55)
Time since diagnosis	3.2 (2.7)	
<b>Cancer diagnosis</b>		
Breast		16 (52)
Other		15 (48)
<b>Cancer treatment intent</b>		
Curative		24 (77)
<b>Active cancer treatment</b>		
Yes		11 (35)
Psychological distress, HADS <sup>a</sup>	16.2 (7.1)	
<b>MBCT<sup>b</sup> adherence</b>		
Completer		14 (45)
<b>Dropouts</b>		
Other priorities		4 (40)
Too difficult		3 (30)
Too intensive		1 (10)
Illness		1 (10)
Missed peers		1 (10)
<b>No start</b>		
Wanted MBCT		3 (43)
Illness		1 (14)
Other priorities		1 (14)
Could not log in		1 (14)
Needed mental health services		1 (14)

<sup>a</sup>HADS: Hospital Anxiety and Depression Scale.<sup>b</sup>MBCT: mindfulness-based cognitive therapy.

**Textbox 1.** Patient facilitators across four themes and subthemes.

## Theme 1: treatment setting

- Time management
  - Program at own time improves receptivity
- Individual setting
  - Sense of autonomy
  - Not having to cope with other patients' stories
- Home setting
  - Not having to travel

## Theme 2: treatment format

- Website
  - Clear and easy to navigate
  - Privacy precautions
- Diaries
  - Rereading own notes
  - Stimulated reflection

## Theme 3: role of the therapist

- Practical guidance
  - Clarifying practical matters
- Mindfulness
  - Deepened understanding
  - Embodiment stimulated practice

## Theme 4: patient characteristics

- Writing fluency
  - Written expression in describing experiences
- Curiosity
  - Curiosity stimulated perseverance

**Textbox 2.** Patient barriers across four themes and subthemes.

## Theme 1: treatment setting

- Time management
  - Responsibility for time management
- Individual setting
  - No learning from peer group
- Home setting
  - Lack of privacy in own home
- Illness barriers
  - Cancer-related reading impairments
- Lack of information
  - Lack of information before start

## Theme 2: treatment format

- Website
  - Complicated
- Diaries
  - Complicated to fill out
  - Obligatory nature was burdensome
  - Describing experiences was confrontational

## Theme 3: role of the therapist

- Asynchronicity
  - No dialogue emerging
- Frequency
  - Wished more frequent feedback

## Theme 4: patient characteristics

- Writing fluency
  - Lack of verbal fluency made diaries difficult

**Patient Theme 1: Treatment Setting—Barriers****Time Management**

Responsibility for your own time management was mentioned as a barrier because it required a lot of self-discipline. One patient stated:

*What I like about it is that I can manage my own time which went very well the first couple of weeks. After a while some chores interrupted me and then at the end of the day I realized: I still have to practice. Sometimes I did not do it anymore and sometimes I did. So you have to be very disciplined to stick to the schedule. [Female cervical cancer patient (curative), 46 years, completer]*

**Individual Setting**

Patients described the lack of a group setting as a drawback of the intervention. They missed the peer support and the ability to learn together in the eMBCT. One patient stated:

*I am a rational being. In a group there are always others who help me to unravel my emotions. This helps me. And I know, when I sit behind my computer my autopilot turns on and the treatment becomes a rational, experimental exercise. [Female breast cancer patient (curative), 54 years, no start]*

## Home Setting

Other patients mentioned that they felt less comfortable having to do exercises at home, not having the privacy they needed. One patient stated:

*I practiced in my home office, but that room is connected to my living room. I found it uncomfortable to practice with my husband around, and even though he would never be eavesdropping, I felt restricted in doing certain exercises. [Female colon cancer patient (curative), 60 years, completer]*

## Illness Barriers

One patient indicated that her cancer type caused her to have trouble reading. As the eMBCT was mainly text-based, this was a problem to her. She stated the following:

*It was mainly physical, I didn't have the energy and my vision is in such a bad state. Even with medication, my vision is bad. And my eyes itch and burn and hurt. [Female bone marrow cancer patient (palliative), 55 years, no start]*

## Lack of Information

Moreover, patients indicated that they would have wished more information on the way the platform and course were organized before the start of the training. One patient stated:

*Expectation management would have helped a lot, I had a very brief instruction. And I have to choose where to put my energy into. What is expected of me, can I handle it, does it fit in my planning? [Female breast cancer patient (curative), 54 years, no start]*

## Patient Theme 2: Treatment Format—Facilitators

The treatment format theme included codes on the facilitators and barriers of the means by which the eMBCT was internally organized and delivered.

### Website

The website was accessible and navigating throughout the website was easy. One patient stated:

*Opening the exercises and the way [the website] guided you through the structure was easy. [Male skin cancer patient (curative), 61 years, completer]*

Moreover, patients valued the privacy precautions and indicated that the website felt safe. One patient stated:

*I thought it was neat that I could see who visited my profile. In my case it was only my therapist according to the system, so I presume that the system is right, but it felt well taken care of. [Female melanoma patient (curative), 33 years, completer]*

### Diaries

The diaries proved to be of value for patients because it enabled them to read back and learn from their own experiences. One patient stated:

*In my own [diaries] I looked back to see what my experiences were yesterday, or how did I handle this*

*last time? [Female melanoma patient (curative), 33 years, completer]*

Patients also indicated that having to write stimulated reflection upon experiences. One patient stated:

*Writing about my feelings was different from when I would have talked about it. It was more reflective, less spontaneous. I noticed that when I mailed I checked it again and again and added a few things. This really was an advantage. It really made me think about what I felt and experienced. Because of the writing itself this really hit me. [Female breast cancer patient (curative), 61 years, dropout]*

## Patient Theme 2: Treatment Format—Barriers

### Website

The website was complicated to some patients. One patient stated:

*The website and its explanation was not really user friendly. There were many steps you had to take before you could do what you actually had to do. [Female breast cancer patient (palliative), 49 years, dropout]*

### Diaries

A patient mentioned that the diaries were complicated to fill out:

*I got the message that some fields still needed to be filled out. In general, I couldn't find where to fill out what in the diaries and it made me quit. [Male prostate cancer patient (palliative), 78 years, dropout]*

Patients thought it was burdensome that the diaries were obligatory. One patient stated:

*It was so much. Filling out the diaries every day [...]. I subscribed for a mindfulness course because I didn't feel well and all of a sudden, you have this huge obligation. [Male palate cancer patient (curative), 30 years, dropout]*

The diaries were also considered quite confronting at times. One patient stated:

*When you had a negative experience, filling out the diary made me revive the negative moment. [Female cervical cancer patient (curative), 50 years, dropout]*

## Patient Theme 3: Role of the Therapist—Facilitators

This theme included codes on the role of the therapist and the way the therapist facilitated or hindered participating in eMBCT.

### Practical Guidance

Patients indicated that the therapist was often able to clarify practical aspects that were unclear. One patient stated:

*I always want to do things right, and I wasn't sure about how I did the meditation exercises in the beginning. Is this the way I am supposed to do this? So after a while I just mailed my therapist asking questions about the how and what of exercises, and*

*I got a prompt reply most of the times. [Female melanoma patient (curative), 33 years, completer]*

### Mindfulness

The ways in which therapists provided feedback enriched patients' understanding of underlying mindfulness values, such as the mild and nonjudgmental attitude. One patient stated:

*(My therapist) was very patient and gave me all the space I needed [...]. She was like this all the time, in everything she did, not forcing, but stimulating me. "Do it for yourself when you do the exercises. If you do them, you could benefit a lot." This made me feel more connected. [Female breast cancer patient (curative), 52 years, completer]*

The embodiment of mindfulness values, such as the nonjudgmental attitude, supported and motivated patients to practice with the right intentions. One patient stated:

*My therapist struck me as very mild. "Don't force yourself, be gentle," that certainly stood out. I don't know how she would have been if I hadn't practiced as much, but she was gentle with me. [Female melanoma patient (curative), 33 years, completer]*

### Patient Theme 3: Role of the Therapist—Barriers

#### Asynchronicity

The asynchronous nature of the feedback proved to be a barrier. According to the patient, the written feedback of therapist did not seem to encourage a dialogue but rather seemed limited to giving responses to questions. One patient stated:

*Suppose I tell you I found the exercise uncomfortable. I then send you a message saying "I found it uncomfortable." Only after 3 days I then get a reply "What was uncomfortable? Can you specify what you mean?" I then specify what I mean in another message. You keep sending messages back and forth over a period of time. If you have a conversation with someone, you have direct interaction. It is a totally different mode of communication. In a business context I think messaging is fine. In this context it was unhelpful. [Female breast cancer patient (curative), 56 years, dropout]*

#### Frequency

As the therapist provided feedback on past weeks' diaries, sometimes questions were left unanswered for a whole week.

Some patients would have liked to have more frequent feedback. One patient stated:

*Just two three times a week a brief moment of contact saying "how are you"? [Female cervical cancer patient (curative), 50 years, dropout]*

### Patient Theme 4: Patient Characteristics—Facilitators

Individual characteristics seemed to influence the fit between patient and eMBCT.

#### Writing Fluency

The ability to express themselves in writing was very helpful for some to give words to their subjective experiences and to ask for clarification to the therapist if it was necessary. One patient stated:

*I am an easy writer, which perhaps set my experience apart from others. I can imagine that if you have a hard time expressing what you do and feel it would be different. [Female breast cancer patient (curative), 61 years, dropout]*

#### Curiosity

Curiosity sparked some to look beyond initial difficulties and to persevere in times of lack of motivation. One patient stated:

*I think I was curious about the coming exercises. Maybe those will be more pleasant to do. This made me continue for a few more weeks. [Female colon cancer patient (curative), 60 years, completer]*

### Patient Theme 4: Patient Characteristics—Barriers

#### Writing Fluency

The heavy reliance on writing skills was a barrier to some patients. One patient stated:

*I liked doing the exercises, but having to write down my experiences on a daily basis [...], to sit down and write it all down, it put me off. For whom am I doing this? [Female breast cancer patient (curative), 51 years, completer]*

#### Therapists

Facilitators and barriers experienced by therapists are depicted in [Textboxes 3](#) and [4](#).

**Textbox 3.** Therapist facilitators across four themes and their subthemes.

## Theme 1: treatment setting

- Timing
  - Flexibility
- Individual setting
  - Tailoring to patient
  - Better suited to some patients

## Theme 2: treatment format

- Asynchronicity
  - More time for reflection
- Schedule
  - Maintaining a schedule prevents dropout
- Writing
  - Stimulated reflection
  - Becomes more goal oriented
- Anonymity
  - Stimulates openness

## Theme 3: role of the therapist

- Feedback
  - Providing group context
  - Provides reassurance
  - Personalizing training

## Theme 4: patient characteristics

- Self-discipline
  - Supporting self-sufficiency

**Textbox 4.** Therapist barriers across four themes and their subthemes.

## Theme 1: treatment setting

- Timing
  - Larger time investment
  - More flexibility warranted
- Individual setting
  - No modeling by peers
  - Elaboration on personal themes

## Theme 2: treatment format

- Asynchronicity
  - No present moment experiences
  - Difficulty to maintain continuity
- Technical issues
  - Technical issues cause delay
- Writing
  - No nonverbal communication
  - Limited in therapeutical repertoire
  - Lack of understanding not readily apparent

## Theme 3: role of the therapist

- Feedback
  - Empty diaries impair feedback
  - More explicit checking and self-disclosure necessary
- Mindfulness
  - Embodying behind computer

## Theme 4: patient characteristics

- Self-efficacy
  - Lack of self-efficacy
- Writing fluency
  - Lack of ability in written expression

***Therapist Theme 1: Treatment Setting—Facilitators*****Timing**

Therapists welcomed the fact in that they were able to choose at what time to provide feedback, which made them adaptive to circumstances. One therapist stated:

*You can provide feedback in between other chores. Sometimes you plan to give feedback from 9 to 10 and then someone enters your office. There goes your planning. I then tell myself [...] “I’ll have time at another moment.” This is an advantage, you can do it in your own time.* [Female MBCT therapist, 60

years, 6 years of experience, prior eMBCT experience]

**Individual Setting**

The individual nature of eMBCT allowed for tailoring to the patients’ specific circumstances and giving feedback on individual real-life examples, which increases the relevance of the feedback. One therapist stated:

*In the group you only have limited amount of time during which you must touch upon the most important themes. Online I have much more choice where to provide feedback on, what it means for a specific*

*patient to react on autopilot, and which personal themes emerge. [Male MBCT therapist, 40 years, 10 years of experience, prior eMBCT experience]*

Another important advantage of the individual nature of eMBCT is that it can be provided to patients who may otherwise be unsuitable for the group. Another therapist stated:

*Some patients can be so disruptive in a group. They don't get the point and only tell their own story. Sometimes you actually wished to provide someone in a group with an individual online training so you can address the individual themes. [Female MBCT therapist, 60 years, 6 years of experience, prior eMBCT experience]*

### **Therapist Theme 1: Treatment Setting—Barriers**

#### **Timing**

Therapists indicated that providing feedback costs a considerable amount of time, which made it difficult for them to stick to a fixed time window. One therapist stated:

*Especially in the beginning, it took me much longer. Because of asking questions, or clarifying issues. Or referring back to earlier diary entries. [Female MBCT therapist, 54 years, 12 years of experience, no prior eMBCT experience]*

Furthermore, therapists indicated that working online required much more flexibility and resulted in fragmentation of the times spent on eMBCT. One therapist stated:

*When a patient indicates that the programme does not work, I start looking for help immediately. Even though I receive this mail outside of my regular time window for feedback. [Female MBCT therapist, 60 years, 6 years of experience, prior eMBCT experience]*

#### **Individual Setting**

Learning from fellow peer experiences in a group setting can be very helpful, and therapists felt limited in bringing in peer experiences themselves. One therapist stated:

*In one-on-one contact, you can bring in experiences from other patients but to really experience them first hand provides another perspective. [Female MBCT therapist, 58 years, 11 years of experience, prior eMBCT experience]*

Moreover, it was often difficult to find the balance between elaboration on personal themes and the eMBCT theme. One therapist stated:

*A tension emerged between someone's personal themes and combining those with this week's mindfulness theme. Sometimes I thought, "this patient is occupied by something entirely different." [Female MBCT therapist, 54 years, 5 years of experience, no prior eMBCT experience]*

### **Therapist Theme 2: Treatment Format—Facilitators**

#### **Asynchronicity**

Therapists and patients interacted asynchronously. This meant that according to the therapists, patients had time for reflection. One therapist stated:

*Because there is some time between practice and feedback some experiences get the time to settle in. Patients can think about it, read it again, check with themselves what they experienced and how they reacted to it. This time in between could perhaps engage patients. [Female MBCT therapist, 60 years, 6 years of experience, prior eMBCT experience]*

Moreover, the asynchronous contact was beneficial to therapists. One therapist stated:

*Sometimes my irritation causes me to cut patients off. Behind the computer I can tell myself "let's put this to a rest for now." [Female MBCT therapist, 54 years, 5 years of experience, no prior eMBCT experience]*

#### **Schedule**

Maintaining a fixed interaction schedule between therapist and patient was very helpful in preventing treatment dropout. One therapist stated:

*When patients are able to put in work on a weekly basis and we stick to this rhythm, a kind of synchronicity emerges and assignments and my feedback to these assignments flow naturally. [Female MBCT therapist, 62 years, 10 years of experience, no prior eMBCT experience]*

#### **Writing**

Writing feedback stimulated contemplation in therapists themselves. One therapist stated:

*By taking a step back I recognized, hey, it annoys me what patients write down. Or I thought by myself, "come on, start practicing." Then I thought, "stop." You can read back your own feedback and then think by yourself "I should not do this." [Female MBCT therapist, 54 years, 5 years of experience, no prior eMBCT experience]*

Due to increasing experience, they got more efficient in their feedback over time. One therapist stated:

*I became a lot more economical in my feedback over time. I tend to scan more for abnormalities or diary entries which I don't recognize, or diary entries of which I think "this could influence dropout." I tend to reply less, but what I say is then more relevant. [Male MBCT therapist, 40 years, 10 years of experience, prior eMBCT experience]*

#### **Anonymity**

The fact that patients were able to write about their experiences rather anonymously was helpful in opening up to experiences, which meant that in general, they shared their experiences in rather great detail. Moreover, it rendered the therapist to use patients' own quotes. One therapist stated:

*Patients think I don't see them and they don't see me. They tend to confide more to a diary. Sometimes they told me "I don't know whether I should write everything down in such an uncensored manner." And I encouraged them to do so. I sometimes used quotes from their own diaries and they asked me "Wow, did I write this down?" They sometimes used impressive words. [Female MBCT therapist, 54 years, 5 years of experience, no prior eMBCT experience]*

### **Therapist Theme 2: Treatment Format—Barriers**

#### **Asynchronicity**

Therapists were unable to comment on present moment experiences. This made it difficult to communicate what mindfulness is about. One therapist stated:

*The experience-driven nature, the contact when a patient says something or shows emotion with which you can work instantly, which everyone immediately feels, that is direct. And it has a lot of impact. This is why things are so slowed down in the online. You have no direct experience to work with. [Female MBCT therapist, 54 years, 11 years of experience, no prior eMBCT experience]*

The asynchronicity made it more difficult to maintain continuity and to prevent dropout from the eMBCT. One therapist stated:

*Whenever a life event took place or I fell ill myself [...] the schedule started to get awry fairly quickly. Patients hand in their diaries too late [...] and you start hopping from miscommunication to miscommunication. In the worst case, the training gets bogged down and the output is zero. [Female MBCT therapist, 62 years, 10 years of experience, no prior eMBCT experience]*

#### **Technical Issues**

Therapists indicated that technical issues also proved to be a barrier to treatment continuity. One therapist stated:

*The technical background might have been a possible reason for dropout. I thought it was difficult myself. The whole logistics of where to find what, how the site was built up, where I had to click. I didn't think it was intuitive. It took me some time. [Female MBCT therapist, 54 years, 11 years of experience, no prior eMBCT experience]*

#### **Writing**

Therapists indicated that a major drawback of the communication in writing is the complete lack of nonverbal communication. One therapist stated:

*I prefer to see someone's nonverbal emotions. And to show that I open up. I had to think about this, how do I do this in writing? Is that even possible? [Female MBCT therapist, 58 years, 11 years of experience, prior eMBCT experience]*

Moreover, they sometimes felt as if their therapeutical repertoire was limited by writing. One therapist stated:

*I noticed that my feedback sometimes, as it was in writing only, did not contain everything I wanted to say. My repertoire is bigger and I was not always able to use all my skills. [Female MBCT therapist, 62 years, 10 years of experience, no prior eMBCT experience]*

Sometimes, because of emphasis on reading and writing, it only became clear at a later stage that the patient did not fully understand everything. One therapist stated:

*Sometimes patients come up with issues that have been taken care of already. Maybe because the training relies so heavily on reading and writing, patients absorb the training differently. [Female MBCT therapist, 49 years, 6 years of experience, no prior eMBCT experience]*

### **Therapist Theme 3: Role of the Therapist—Facilitators**

#### **Feedback**

Therapists indicated that it was facilitating for patients that they were able to provide a group context. One therapist stated:

*You can provide examples from other patients or a funny example from a group situation. [Female MBCT therapist, 60 years, 6 years of experience, prior eMBCT experience]*

In their feedback, they considered it motivating to provide reassurance very explicitly. One therapist stated:

*In the online training I am much more complimentary for doing the exercises despite being so tired, and in the group I am much less inclined to do so. [Female MBCT therapist, 60 years, 6 years of experience, prior eMBCT experience]*

Therapists were also involved in making the training more personal. One therapist stated:

*I make it very clear from the start that "I write this feedback to you. This is not standardized feedback," so the patient knows he or she is dealing with an actual person. Someone actually replied "Good to know that there is a person at the other side." [Female MBCT therapist, 54 years, 5 years of experience, no prior eMBCT experience]*

### **Therapist Theme 3: Role of the Therapist—Barriers**

#### **Feedback**

A lack of diary entries was a turnoff for therapists in providing stimulating feedback. One therapist stated:

*I noticed that it was not very stimulating when patients filled out very little. I think my own feedback will have been much shorter as well, and I much easier reverted to saying "good luck next week." [Male MBCT therapist, 40 years, 10 years of experience, prior eMBCT experience]*

Therapists indicated that they experienced it as a barrier that more explicit disclosure and checking with the patient is necessary. One therapist stated:

*I tell more about myself, “I recognize this when doing the body scan myself,” far more often than I used to do in a group setting, and you have to be very explicit, check and check again how things come across.* [Female MBCT therapist, 58 years, 11 years of experience, prior eMBCT experience]

### Mindfulness

Therapists also stated that it was hard for them to embody mindfulness values behind the computer. One therapist stated:

*When patients start to get doubtful, or skeptical about the training, the power of your presence can be really important. Not in the sense of being able to convince people but with a visible nonverbal way of saying, “everything is OK,” and showing this by being embodied. You can’t do this via the PC.* [Female MBCT therapist, 62 years, 10 years of experience, no prior eMBCT experience]

### Therapist Theme 4: Patient Characteristics—Facilitators

#### Self-Discipline

Therapists indicated that for some patients, the eMBCT was partly a training in self-discipline, which supported patients' self-sufficiency after the training. One therapist stated:

*Some patients train in self-discipline. They have to, which maybe renders them more likely to continue practicing. Yes, dropout is higher, but those who do finish the training are very disciplined in doing so and did it more on their own, without the group context. More self-reliant, which is in line with mindfulness.* [Female MBCT therapist, 54 years, 5 years of experience, no prior eMBCT experience]

### Therapist Theme 4: Patient Characteristics—Barriers

#### Self-Efficacy

In the eMBCT, patients need to be resolute and determined. This was mentioned as a barrier to complete eMBCT. One therapist stated:

*When a patient was not able to login, the webmaster provided a link. The patient then neglected this link. If someone helps you, as a patient you must go for it and say “OK thank you, I will try again, and if it doesn’t work, I will mail you again.”* [Female MBCT therapist, 62 years, 10 years of experience, no prior eMBCT experience]

#### Writing Fluency

Therapists indicated that a lack of writing skills made it difficult to understand patients' messages. One therapist stated:

*Sometimes it was difficult to read past the spelling mistakes and to actually see what someone meant, and not to write down constantly “what do you mean?”* [Female MBCT therapist, 58 years, 11 years of experience, prior eMBCT experience]

## Discussion

### Principal Findings

The aim of this study was to gain qualitative understanding of the facilitators and barriers of eMBCT in a sample of heterogeneous cancer patients. Both eMBCT completers and dropouts participated in posttreatment interviews. Moreover, we conducted a focus group interview with eMBCT therapists. In all, this study adds to the existing quantitative evidence for eMBIs in cancer [7,8] by providing a qualitative perspective. Four overarching themes emerged, which were largely convergent between patients and therapists: treatment setting, treatment format, role of the therapist, and patient characteristics. Patients and therapists are much more flexible in when, where, and how they engage in eMBCT compared with group-based MBCT. However, most eMBCT advantages seemed to come at a price. When patients and therapists mentioned a certain aspect as facilitating (eg, the individual setting: not having to cope with other patients' stories), they also mentioned it as barrier (no peer support).

Patients and therapists reported similar advantages and disadvantages of the timing, the individual nature, the asynchronous nature (for patients, this was detrimental to the relevance of therapist feedback, and for therapists, this was a threat to treatment continuity), the diaries, and the importance of self-discipline. The fact that so many aspects of the eMBCT were mentioned both as facilitator and barrier emphasizes the importance of offering flexibility in eMBIs [21].

There were also differences between patients and therapists. As known from a previous qualitative study on eMBCT [21], bearing the responsibility for time management was a barrier for patients. For therapists, the eMBCT seemed to require a larger time investment compared with group-based MBCT. Moreover, therapists were more concerned with the (vulnerability of) continuity of the training. They also mentioned that missing out on nonverbal information rendered them unable to spot patient withdrawal at an early stage, and to determine the reason for empty diaries. Furthermore, therapists seemed more bothered by communicating mindfulness values in eMBCT than patients. Patients specifically mentioned asynchronicity as barrier to the role of the therapist because the asynchronous communication hindered emergence of a dialogue.

### Clinical Implications

Although studies to date do not suggest that differences between how therapists handle the contact with their clients explain much variance in treatment outcome [16], the necessity of training and support for Internet-based therapists should be acknowledged. New eMBCT therapists should understand the importance of flexible availability and the dynamics of asynchronous interaction to pick up early signs of patient withdrawal.

The current eMBCT was individual, asynchronous, and therapist-assisted. One important adaptation may be to offer a peer support group [26]. The group context in MBIs supports perspective taking and the transition from personal story into investigation of common patterns of distress [6], and may foster

skills relevant to valuing self and feeling close to others, which may help participants feel less isolated [21]. As a stand-alone intervention, formal online peer support group interventions for cancer patients have demonstrated preliminary feasibility and effectiveness [27].

Another consideration may be to employ a synchronous videoconferencing format [13]. This takes away the barriers associated with asynchronous delivery and may facilitate dialogue with the therapist and peer support. A possible caveat may be that videoconferencing does not alleviate the scheduling issues inherent in group eMBIs [13] and that synchronous videoconferencing solutions are technically much more demanding. An alternative to videoconferencing may be to include synchronous written conversations (or “chats”) with therapists or trained volunteers. Chats are becoming increasingly popular as Web-based mental health interventions by themselves and show inconclusive but promising evidence [28].

Eventually, one could employ a blended format, combining the advantages of Web and group-based therapy [29]. Blended eMBIs could have group-based group meetings at the start, midst, and end of the programme. The meeting at the start of the intervention could be used to address practical and technical matters, a midtreatment meeting to address common barriers experienced by patients during practice, and meeting at the end to say goodbye to each other and support patients to take responsibility for the continuation of their mindfulness practice in the future. In between group-based sessions, patients could be offered online sessions. In our view, these practical arrangements could greatly improve the acceptability and effectiveness of eMBCT.

## Research Implications

Previous studies have provided encouraging quantitative evidence, for example, eMBIs in cancer patients [13]. Together with this study, these results provide support for a larger, quantitative trial directly comparing eMBCT with group-based MBCT for cancer patients. Moreover, it would be interesting to directly compare individual eMBCT with individual group-based MBCT. Future trials should test for differences in treatment accessibility, program adherence, and treatment

outcome between eMBCT with and without peer support, with and without synchronous communication modalities, and with and without therapist assistance [17]. This would allow us to further elucidate the predictors and mediators of treatment effect in Internet-based interventions [30] to help us determine which patient to offer group-based versus Internet-based treatment. Moreover, all of the abovementioned design alterations likely impact cost-effectiveness of the interventions, which should be considered [31]. Thus, future studies should preferably assess how different eMBCT delivery formats influence program adherence, mindfulness skills, and treatment outcome, and how different versions of eMBCT delivery formats compare both qualitatively and quantitatively with group-based MBCT.

## Strengths and Limitations

This is the first study to qualitatively explore facilitators and barriers of eMBCT for cancer patients. The relatively large sample size enabled us to reach data saturation and report a broad view of experiences. Moreover, we interviewed both completers and dropouts. Furthermore, we had the opportunity to gather data in the therapists. Nevertheless, our results should be interpreted within the limitations of our findings. We did not perform member checks to ensure validity of the verbatim transcripts. Moreover, the sample of the larger RCT consisted of cancer patients who self-selected themselves for a trial on an MBI. This implies that our findings cannot be extrapolated to cancer patients in general. In addition, some patients or therapists who participated in the training and were invited for focus groups or individual interviews declined participation, which may further limit the generalizability of our findings to all participating patients.

## Conclusions

We aimed to gain understanding of the facilitators and barriers of individual, asynchronous, and therapist-assisted eMBCT for cancer patients. Patients and therapists reported similar advantages and disadvantages of the timing, the individual nature, the asynchronous nature, the diaries, and the importance of self-discipline. Future studies should assess how different eMBCT delivery formats could further improve treatment accessibility, program adherence, and treatment outcome.

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## Conflicts of Interest

None declared.

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## Abbreviations

**eMBCR:** Internet-based mindfulness-based cancer recovery  
**eMBCT:** Internet-based mindfulness-based cognitive therapy  
**eMBI:** Internet-based mindfulness-based intervention  
**MBI:** mindfulness-based intervention  
**MBCT:** mindfulness-based cognitive therapy  
**MBSR:** mindfulness-based stress reduction  
**RCT:** randomized controlled trial

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**Short Paper**

# A 6-Week Web-Based Osteoarthritis Treatment Program: Observational Quasi-Experimental Study

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## Abstract

**Background:** Osteoarthritis (OA) is one of the most common causes of disability, with a burden of disease estimated to increase over time. Joint Academy, a Web-based treatment for individuals with clinically verified knee or hip OA, was developed to increase access to and facilitate implementation of evidence-based nonsurgical OA treatment in accordance with international guidelines.

**Objective:** The primary aim of this study was to evaluate joint pain, physical function, and health-related quality of life (HRQoL) over time of users of the Joint Academy program.

**Methods:** We enrolled 350 patients who were recruited online and completed the initial health journal in the 6-week program. We asked patients to complete an eHealth journal and e-questionnaires, including pain level assessed by a numerical rating scale, as well as a physical function evaluation using the 30-second chair-stand test. In addition, we assessed HRQoL using the 3-level version of the EQ-5D. We also asked participants whether they experienced difficulty walking and were afraid of physical activity due to their OA and their desire for surgery. We collected descriptive data and compared pre- versus postintervention data. As a reference group, we included results retrieved from the Swedish well-structured face-to-face self-supportive OA management program Better Management of Patients With Osteoarthritis (BOA).

**Results:** Of the study cohort (n=350 patients; 239 women, mean age 62 years, mean body mass index 27 kg/m<sup>2</sup>), 71.4% (n=250) completed the program and were included in the study. We used the questionnaires to secure a clinical diagnosis of OA and to establish baseline study values. After 6 weeks of treatment, the change in mean numerical rating scale was larger than the minimal clinical difference (5.4 vs 4.1;  $P<.001$ ), while physical function increased (from 10.88 to 13.14;  $P<.001$ ). The percentage of participants having walking difficulties decreased from 81.7% (196/240) to 62.1% (149/240;  $P<.001$ ), those afraid of being physically active decreased from 22.1% (53/240) to 6.7% (16/240;  $P<.001$ ), and 22.0% (55/250) reported that they had reduced the amount of OA-related medication. After 6 weeks, 24% (13/54) of those desiring surgery at the start of the program were no longer interested. In addition, the comparison between Joint Academy and the BOA program showed similar levels of pain at 3 months, but suggested greater reduction with the use of Joint Academy due to a higher level of pain at baseline.

**Conclusions:** The reported data suggest that participation in Joint Academy is associated with a clinically relevant decrease in pain and an increase in physical function and HRQoL, as well as a decreasing fear of physical activity. This innovative Web-based OA treatment is scalable, is population specific, and can reach a large number of individuals with impaired joints who have Internet access.

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## KEYWORDS

digital treatment; eHealth; telemedicine; osteoarthritis; pain; physical function

## Introduction

Chronic conditions, at accelerating rates globally, are the leading causes of death and disability [1]. Due to an increase in average life expectancy and a higher prevalence of obesity and sports-related joint injuries, the estimated disease burden of one of the most common and costly disabling chronic diseases, osteoarthritis (OA), will markedly increase over time [2]. Thus, health care systems need to prepare for the large increase in demand for OA treatment [3]. According to evidence and international guidelines, the primary treatment of knee and hip OA is nonsurgical and based on exercise, information, and, when necessary, weight loss [4-6]. Despite these evidence-based guidelines, only a minority of all people with OA receive adequate treatment; for instance, more than 50% of patients with OA in Sweden are referred to surgery as a primary option [7].

An alternative to nonsurgical treatment delivered face-to-face to individuals with OA is eHealth. Web-based treatment can increase the accessibility to care, due to its inherent flexibility in comparison with face-to-face treatment. In addition, there are numerous examples of Web-based programs in the literature, reporting beneficial effects on key health-related outcomes [8-11]. To this end, we developed the Web-based OA treatment platform Joint Academy [12] based on national and international guidelines and on a successful Swedish face-to-face concept (Better Management of Patients With Osteoarthritis [BOA] program), in which, to date, more than 90,000 patients have participated [7]. Joint Academy entails a 6-week Web-based program that adheres to evidence-based OA treatment. According to a pilot study, the results of the Joint Academy program on joint pain in individuals with knee or hip OA were promising [12]. Yet the level of physical function and health-related quality of life (HRQoL) after an eHealth intervention are unknown in a larger population. Hence, the primary aim of this study was to evaluate joint pain, physical function, and HRQoL in users of the Joint Academy. The secondary aims were to investigate whether use of the 6-week program is associated with decrease fear of physical activity and desire for surgery, and improve self-reported difficulties walking. We compared pain results with those in the structured face-to-face BOA program.

## Methods

This was an observational and quasi-experimental study. We recruited patients via advertisements and campaigns on the Web to participate in Joint Academy, a 6-week Web-based OA treatment program that provides information, exercises, an online physiotherapist, and education regarding factors of relevance to OA, including lifestyle. The advertisements were placed on search engines and social networks. The program is accessed by using a smartphone, tablet, or computer and encourages user activity by sending email prompts to participants on a regular basis, as described in detail previously

[12]. An orthopedic surgeon and a physiotherapist, using synchronous and asynchronous chat conversations, supervised the clinical progress and were responsible for making a correct patient diagnosis and for identifying eligible patients. The program contained 2 telephone consultations with a physiotherapist that were compulsory, 1 at the start and 1 after 6 weeks. Participants' costs were covered through either a private or a public health plan.

We asked patients to complete an e-questionnaire regarding their overall health and OA symptoms. The e-questionnaire also assessed pain level using the sensitive and reliable numerical rating scale [13], HRQoL using the 3-level EQ-5D (EQ-5D-3L) [14], and physical function measured by the 30-second chair-stand test [15], where participants sit and stand from a chair for 30 seconds, and the number of repetitions is recorded. Participants were also asked whether they experienced difficulty walking and were afraid of physical activity due to their OA (dichotomous replies), as well as whether they desired surgery. All outcomes were self-assessed and chosen according to the International Consortium for Health Outcomes Measurement Standard Set for Hip & Knee Osteoarthritis [16]. To enable a comparison with face-to-face treatment, we matched data from the Joint Academy database on reported joint pain with results at 12 weeks from the BOA initiative, found in the BOA yearly report of 2015 [17].

We defined as completers those participants who reported one of the main outcomes (joint pain, HRQoL, or physical function) at baseline and postintervention in the hip or knee. We excluded outliers of adherence—that is, participants with an activity level in the program below 10%.

Statistical analysis of pre- versus postintervention measurements was by 2-tailed *t* test for pain level, physical function, and HRQoL. For dichotomous and polytomous variables, we used McNemar and Madansky test of marginal homogeneity, respectively. The calculations were performed using the Statsmodels package in Python v3.6.1 (Python Software Foundation) and the coin library in R v3.4.1 (R Foundation).

We collected consent to participate at registration and obtained ethical approval from the Regional Board of Ethics in Lund, Sweden (Dnr 2017/651).

The datasets for this study are available from the corresponding author upon reasonable request.

## Results

The study cohort comprised 350 individuals with a clinical diagnosis of OA in accordance with American College of Rheumatology criteria and international guidelines as judged by a physiotherapist or an orthopedic surgeon after scrutinizing the questionnaires [18]. Table 1 presents patient demographics.

The majority reported "working" as their occupational status, while 4.0% (14/350) were on sick leave. Most participants reported level of physical activity of 90 to 150 (85/350, 24.3%)

and structured exercise of less than 30 minutes per week (97/350, 27.7%).

On the basis of the requirements of available data and level of adherence, we included 71.4% (n=250) of the study cohort in the study. We used the questionnaires within the program to secure a clinical diagnosis of OA and to establish baseline study values. **Table 2** shows the changes in the outcomes studied. Data were missing for pain measurement, HRQoL, and physical

function; however, none exceeded 10% (10/250, 4.0%; 15/250, 6.0%; and 16/250, 6.4%, respectively).

When investigating the distribution of pain improvement over self-reported joint pain at baseline, we observed improvement in patients with both low and high initial pain. However, most of those reporting improvement had more severe pain at baseline (**Figure 1**).

**Table 1.** Patient characteristics at baseline (N=350).

Characteristic	Count
Age (years), mean (SD <sup>a</sup> )	62 (10)
Body mass index (kg/m <sup>2</sup> ), mean (SD)	27 (5)
Female, n (%)	239 (68.3)
<b>Reported pain locations, n (%)</b>	
Knee	201 (57.4)
Hip	145 (41.4)
Other	4 (1.1)
Previous OA <sup>b</sup> treatment, n (%)	61 (17.4)
OA medication use <sup>c</sup> , n (%)	168 (48.0)
<b>Occupational status, n</b>	
Working	176
Retired	149
Other	25
Previous surgery <sup>d</sup> , n (%)	45 (12.9)
Previous diagnosis <sup>e</sup> , n (%)	289 <sup>f</sup> (86.8)

<sup>a</sup>SD: standard deviation.

<sup>b</sup>OA: osteoarthritis.

<sup>c</sup>Patients taking OA-related medication during the last 6 months.

<sup>d</sup>Patients who had joint surgery before entering the program.

<sup>e</sup>Patients with a diagnosis before entering program.

<sup>f</sup>Number of patients reporting outcome, n=333

**Table 2.** Outcome measures at baseline and at follow-up (n=250).

Metric	No. of patients reporting outcome	Baseline	Follow-up (after 6 weeks)	P value
NRS <sup>a</sup> pain score, mean (SD)	240	5.4 (2.2)	4.1 (2.4)	<.001
EQ-5D-3L <sup>b</sup> score, mean (SD)	235	0.65 (0.14)	0.69 (0.15)	.002
Functionality <sup>c</sup> , mean (SD)	234	10.88 (4.50)	13.14 (4.74)	<.001
Difficulty walking <sup>d</sup> , n (%)	240	196 (81.7)	149 (62.1)	<.001
Afraid of activity <sup>d</sup> , n (%)	240	53 (22.1)	16 (6.7)	<.001

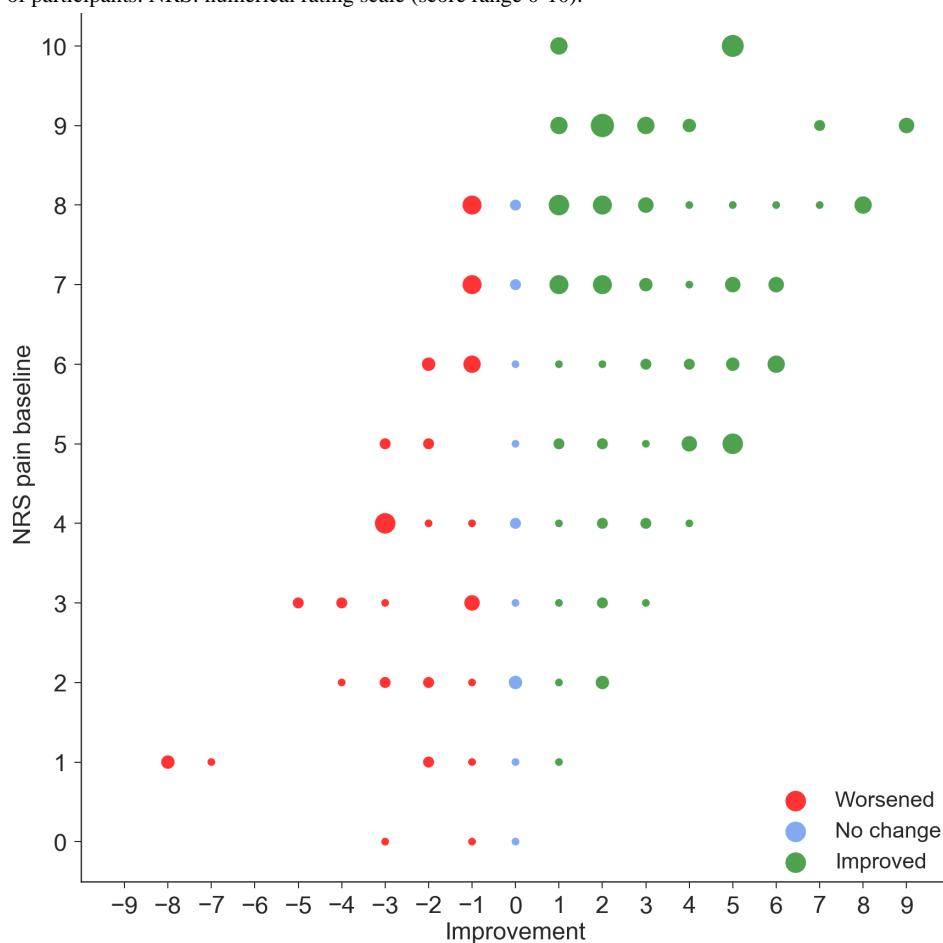
<sup>a</sup>Numerical rating scale, score range 0-10.

<sup>b</sup>3-level EQ-5D.

<sup>c</sup>Physical function measured as the number of repetitions in the 30-second chair-stand test.

<sup>d</sup>Dichotomous response (yes/no).

**Figure 1.** Scatterplot of pain improvement related to baseline joint pain. Plot size is dependent on number of participants at each point; larger plots denote higher number of participants. NRS: numerical rating scale (score range 0-10).



**Table 3.** Patient-rated mean (SD) joint pain with use of Joint Academy and BOA at different time points.

Time points	Joint Academy <sup>a</sup>	BOA <sup>b</sup>
Baseline	5.4 (2.2)	48 (N/A <sup>c</sup> )
3 months	3.5 (2.5)	37 (N/A)

<sup>a</sup>Measured using a numerical rating scale, score range 0-10.

<sup>b</sup>BOA: Better Management of Patients With Osteoarthritis. Pain measured using a visual analog scale, score range 0-100.

<sup>c</sup>N/A: not available.

Investigation of each dimension of EQ-5D-3L separately showed that mobility and pain or discomfort were significantly improved from baseline to follow-up, while changes in self-care, usual activities, and anxiety or depression were not significant. Of participants who completed the 6-week program, 22.0% (55/250) reported that they had reduced the amount of OA-related medication, while 24.1% (13/54) no longer desired surgery (13 of 54 individuals altered their opinion).

The comparison between Joint Academy and the BOA initiative showed similar levels of pain at 3 months but suggested a greater reduction in Joint Academy due to a higher level of pain at baseline (Table 3).

## Discussion

### Principal Findings

The results for the 250 patients included in this study confirm in a larger cohort the previous preliminary findings of decreased pain attributed to participation in Joint Academy [12]. This study also extends knowledge by showing improved physical function for OA patients engaged in Web-based treatment for OA. Patients with OA commonly harbor doubts and fears of using their joints, which may erect a barrier to physical activity [19], a cornerstone treatment of OA. Although we used no validated instruments to assess walking difficulty and fear of movement (kinesiophobia), which may be considered a weakness in the methods, the results suggest that software as medicine may alleviate the patient's concerns regarding being physically active due to pain and OA. Furthermore, despite the

short intervention time in this study, 2 of the dimensions in the EQ-5D-3L scale improved (mobility and pain or discomfort). However, the index did not reach the change that is considered clinically significant (ie, a change of 0.074 [20]). Longer participation with continuous treatment would determine whether EQ-5D-3L scores would continue to improve. This study highlights the potential of a well-structured eHealth program to support patients in managing their symptoms and achieving minimal clinically important changes in chronic musculoskeletal conditions [21]. In addition, the fact that only a minority of all people with OA receive adequate treatment can be readily overcome because Web-based treatments such as Joint Academy are easily scalable.

According to recent systematic reviews analyzing Web-based treatment for musculoskeletal conditions in general and OA in particular, positive effects on physical function and pain were observed [10,11]. Similar to this study, in previous studies the changes in outcomes were, if not superior to, at least comparable with regular face-to-face treatment [7]. The comparison between Joint Academy and BOA on 3-month outcomes (6-week results are not available in BOA) serves as a preliminary report of results, and should be interpreted with caution, since it is based on 2 different sample populations and was not randomized. Such a comparison should ideally be evaluated in a randomized controlled trial, preferably combined with a health-economic analysis. In this respect, the finding that some patients changed their wish for surgery and need for painkillers after the 6-week program is noteworthy. A randomized controlled trial may also answer whether short, but regular, exercises performed daily using a Web-based treatment is more beneficial than outpatient visits twice a week for longer times. As shown here, patients need to spend 5 to 10 minutes every day to achieve significant improvement in only 6 weeks.

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## Conflicts of Interest

Joint Academy is a product of Arthro Therapeutics AB, a Swedish eHealth company. HN is a physiotherapist and part-time consultant at Arthro Therapeutics AB. LED is the cofounder and Chief Medical Officer of Arthro Therapeutics AB (no financial compensation). JD is the cofounder, Chief Executive Officer, and computer scientist of Arthro Therapeutics AB.

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## Abbreviations

**BOA:** Better Management of Patients With Osteoarthritis

**EQ-5D-3L:** 3-level version of the EQ-5D

**HRQoL:** health-related quality of life

**OA:** osteoarthritis

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Original Paper

# Implementation of the Blended Care Self-Management Program for Caregivers of People With Early-Stage Dementia (Partner in Balance): Process Evaluation of a Randomized Controlled Trial

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## Abstract

**Background:** Caring for a family member with dementia puts caregivers at risk of overburdening. Electronic health (eHealth) support for caregivers offers an opportunity for accessible tailored interventions. The blended care self-management program “Partner in Balance” (PiB) for early-stage dementia caregivers was executed in Dutch dementia care organizations. The program combines face-to-face coaching with tailored Web-based modules. Next to an evaluation of program effectiveness, an evaluation of sampling and intervention quality is essential for the generalizability and interpretation of results.

**Objective:** The aim of this study was to describe the process evaluation from the perspective of both family caregivers (participants) and professionals delivering the intervention (coaches) to determine internal and external validity before the effect analysis and aid future implementation.

**Methods:** Implementation, sampling, and intervention quality were evaluated with quantitative and qualitative data from logistical research data, coach questionnaires (n=13), and interviews with coaches (n=10) and participants (n=49). Goal attainment scaling was used to measure treatment-induced change. Analyses were performed with descriptive statistics and deductive content analysis.

**Results:** The participation rate of eligible caregivers was 51.9% (80/154). Recruitment barriers were lack of computer and lack of need for support. Young age and employment were considered recruitment facilitators. All coaches attended training and supervision in blended care self-management. Deviations from the structured protocol were reported on intervention time, structure, and feedback. Coaches described an intensified relationship with the caregiver post intervention. Caregivers appreciated the tailored content and positive feedback. The blended structure increased their openness. The discussion forum was appreciated less. Overall, personal goals were attained after the program (T>50). Implementation barriers included lack of financing, time, and deviating target population.

**Conclusions:** Participants and coaches were satisfied with the intervention, but adapting the content to specific subgroups, for example, younger caregivers, was recommended. Implementation of the program requires more awareness of the benefits of blended care self-management programs and training in tailored self-management skills.

**Trial Registration:** Dutch Trial Register (NTR): NTR4748; <http://www.trialregister.nl> (Archived by WebCite at <http://www.webcitation.org/6vSb2t9Mg>)

**KEYWORDS**

internet; caregivers; technology; therapeutics

## *Introduction*

### **Informal Dementia Caregivers Under Pressure**

Dementia is a syndrome that causes deterioration in cognitive functioning. It affects memory, thinking, orientation, comprehension, learning capacity, language, and judgment, and is often accompanied by deterioration of emotional control, social behavior, or motivation. The impairment is severe enough to interfere with daily life. Dementia is caused by various diseases and injuries that primarily or secondarily affect the brain, such as Alzheimer's disease or stroke [1]. Most people with dementia live at home and are cared for by one or more family members, often referred to as the informal caregivers [2]. Caring for a family member with dementia puts one at risk for depression, anxiety, and other health problems [3]. The benefits of electronic health (eHealth) support for caregivers are increasingly recognized in dementia care practice because it offers an opportunity for accessible tailored interventions. Furthermore, eHealth interventions may fill the expected gap in supply and demand caused by demographic aging and the decreasing working population [2,4].

### **Caregiver Support**

Previous research has found that specifically multicomponent, tailored eHealth interventions are promising for increasing caregiver confidence and self-efficacy and decreasing caregiver stress and depression [5,6]. Furthermore, blending online and face-to-face support may increase caregiver-therapist relations and adherence [7]. Next to intervention delivery, intervention timing might be crucial for efficacy. Early support may help people with dementia and their caregivers adapt to the changes of early dementia and feel more competent in their care skills. However, the current contrast between highly advanced timely diagnostic tools and the lack of available support to match this early diagnosis is troubling [8]. Early interventions can offer support in coping with an insecure future and preparing caregivers for the possibility of further decline and dependency [9] and have been proved to be effective in reducing strain and delaying institutionalization of the person with dementia [10,11]. However, some caregivers may feel stigmatized and refuse help if the information does not fit their personal situation and stage of the disease [12]. Existing programs are mostly aimed at problematic behaviors that occur in the advanced stages of dementia [13-17], or are not specifically adapted to the needs of caregivers during the early stages of dementia [18]. Early-stage interventions may prove to be beneficial if they focus on adaptation to the caregiver role and actively involve caregivers to tailor the intervention to their needs [9,19].

### **Intervention Development, Evaluation, and Implementation**

The Medical Research Council (MRC) framework suggests that intervention developers should put effort into the actual use of effective interventions by considering the implementation during

the first phases of development and evaluation [20]. Following these recommendations, the blended care program "Partner in Balance" (PiB) for early-stage dementia caregivers was developed together with potential users. The program focuses on caregivers' capacity to fulfill their potential and obligations and to help them manage their lives with some degree of independence and to engage in social activities together with the care recipient [21], fitting the new definition of health for chronic conditions [22]. To evaluate the program's effectiveness, a randomized controlled trial (RCT) was performed in the context of daily care practice. Several caregiver eHealth support studies lack methodological rigor [6], and RCTs are considered proper designs for convincing evidence. However, before the effect analysis, evaluation of the sampling quality and intervention quality is essential for the interpretation and generalizability of results and further fine-tuning (or even annulling) of the effect analysis [23]. Furthermore, knowledge of implementation barriers and facilitators in an effect study can aid future adoption and implementation of a new intervention in care practice. Generalization and applicability of findings, for example, the public health significance of interventions (external validity), are particularly of interest for clinicians and policy makers. Implementation can be complicated in the complex and heterogeneous structure and culture of dementia care organizations [24]. Furthermore, the Consolidated Standards of Reporting Trial (CONSORT)-EHEALTH reporting standards for eHealth interventions place additional focus on external validity by assessing the following: (1) the context within participants benefitting from the intervention; (2) the delivery mode, features, and functionality of the intervention; (3) the use of prompts to interact with the intervention; and (4) any cointerventions that may occur. Additionally, a newly developed program can be effective but difficult to implement in care practice if health professionals or policy makers do not accept it. The implementation aspects (ie, costs and intervention description, including frequency, type, and duration of contacts) are important according to the CONSORT-EHEALTH standards. Therefore, process evaluations should focus on internal validity and implementation knowledge to increase credibility [23].

### **Aim of This Study**

Different frameworks for process evaluations have been proposed, but there is no consensus on elements that process evaluations should cover [23]. In this study, we describe first-order (sampling and intervention quality) and second-order (implementation knowledge) process data based on the model of Leontjevas et al [23] to assess the internal and external validity of the PiB trial and its implementation to inform effect analysis. Similar to the Reach Effectiveness Adoption Implementation Maintenance (RE-AIM) model, this model included the recommendations fitting the

CONSORT-EHEALTH standards defining the internal and external validity.

## Methods

### Ethical Approval

The Medical Ethics Committee of the Maastricht University Medical Center+ (MUMC+) approved this study (#12-4-059). The process evaluation was conducted alongside the effectiveness study. Detailed information on the methods are presented in a previous study [25]. A short description is provided below.

### Study Design

A randomized waiting-list controlled trial was conducted in the southern part of the Netherlands. Family caregivers were recruited within memory clinics, mental health care organizations, and caregiver support services. The intervention was delivered and evaluated within these organizations. A waiting-list controlled design was chosen to increase acceptability and adherence to the research protocol in the control group and decrease attrition effects [20]. Data were collected pre- and postintervention and at 3-, 6-, and 12-month follow-up points.

### Intervention

Detailed information about the program components and development is presented in a previous study [21]. In short, the blended care self-management program PiB consists of the following: (1) a face-to-face intake session with a personal coach to familiarize participants with the program, set goals with the goal attainment scaling (GAS) method, and select preferred module themes [26]; (2) tailored online thematic modules, including psychoeducation, behavioral modeling, reflective assignments, change plans, and email feedback from the coach over 8 weeks; and (3) a face-to-face evaluation session with the coach evaluating previously set goals. Furthermore, the participants can interact with other participants via the discussion forum. The participants are free to set their own

**Textbox 1.** Topic list for individual interviews with participants and coaches.

Individual interview participants (n=49)
<ul style="list-style-type: none"> <li>Clarity of content</li> <li>Websites' ease of use</li> <li>Satisfaction with blended care (online and face-to-face)</li> <li>Satisfaction with personal coach and feedback</li> <li>Application and impact on daily life</li> <li>Advantages and disadvantages</li> <li>Recommendations</li> </ul>
Focus group interview coaches (n=10)
<ul style="list-style-type: none"> <li>Feasibility: recruitment, instructions, time investment, and collaboration researchers</li> <li>Value for participating caregivers</li> <li>Barriers and facilitators of program implementation</li> </ul>

personal goals. The module themes are acceptance, balance in activities, communication with family members and environment, coping with stress, focusing on the positive, insecurities and rumination, self-understanding, the changing family member, and social relations and support. The participants choose 4 modules; 2 weeks were allocated for each module. However, the participants were allowed to complete the modules at their own pace in accordance with the self-management approach [27]. The personal page and modules remained accessible for participants after the intervention period. The control group consisted of an 8-week waiting list while receiving usual care (nonfrequent counseling). After the posttest assessment, they were given the opportunity to follow PiB.

### The Personal Coach

The personal coaches were trained, experienced professionals (psychologist or psychiatric nurses) from one of the participating organizations. They attended a 2-hour training session in self-management techniques, goal setting and online help, and regular supervision meetings. Their tasks were familiarizing participants with the online program, supporting them in module choice and goal setting, and giving feedback on the self-reflective assignments through the online messaging portal of the program, which was accessed via email.

### Process Evaluation

First-order (sampling and intervention quality) and second-order process data (implementation knowledge) were collected following a process evaluation framework based on earlier research [23,24].

### *First-Order Process Data: Sampling and Intervention Quality*

The sampling quality was determined by a description of the procedures of recruitment, informed consent (IC), allocation, recruitment barriers and facilitators, and reach. Data were extracted from the research database and 2 focus group interviews with 5 coaches per group (Textbox 1).

**Table 1.** Demographic characteristics of interview participants at T0.

Demographic characteristics (N=49)	Value
Age in years, mean (SD) <sup>a</sup>	69.6 (9.2)
Spouse, mean (%)	48 (98)
Care intensity in years, mean (SD)	1.9 (1.8)
Female, n (%)	35 (71.4)
<b>Education, n (%)</b>	
Primary education	8 (16.3)
High school	17 (34.7)
College	24 (49.0)
<b>Care recipients' stage of dementia, n (%)<sup>b</sup></b>	
Preclinical	31 (63.3)
Mild	16 (32.7)
Moderate	2 (4.0)

<sup>a</sup>SD: standard deviation.

<sup>b</sup>As measured by the Global Deterioration Scale [28].

The information on intervention quality (relevance, feasibility, and performance according to protocol) was gathered from the perspective of both *coaches* and *participants*. Data collection from the perspective of coaches involved the registration of protocol deviations plus the amount and intensity of contact with caregivers on a structured registration form ([Multimedia Appendix 1](#)), an 8-item questionnaire rating the overall usability of PiB and its relevance for caregivers and coaches, with 4 multiple-choice items rated on a 5-point scale (1=completely disagree to 5=completely agree) ([Multimedia Appendix 2](#)) and 4 open-ended items on advantages, disadvantages, recommendations for other organizations or colleagues, and general appreciation of the program. Data from the perspective of the participants were collected postintervention with a semistructured interview ([Textbox 1](#)) with participants in both the intervention and waiting-list group.

**Table 1** shows the demographic characteristics of the caregivers who participated in the interview.

The interviews were audiotaped with the participants' permission. GAS was used to measure treatment-induced change and to compare the relative success of previously set personal goals [26]. GAS is a suitable measure to translate goals into achievement ratings. The scores range from -2 (much less than expected) to +2 (much better than expected), with a score of 0 meaning that the goal was attained. Furthermore, usage of the website (clickstream per intervention component) was tracked. Clickstream data are information trails that users leave behind while visiting the website. As participants clicked anywhere on the webpage, this action was captured in a log file. Clicks represent the number of times a page has been viewed and can be used to track which elements of the website were visited most often [29].

### Second-Order Process Data: Implementation Knowledge

Knowledge on implementation of the program (components delivered and received, barriers and facilitators to

implementation) was investigated with additional items in the questionnaire for the coaches described above (2 open-ended items on barriers and facilitators for program implementation; [Multimedia Appendix 2](#)) and the data obtained from the focus group interviews ([Textbox 1](#)).

### Analysis

Descriptive statistics (SPSS Statistics V22.0, IBM USA, NY, 2013) were used for the quantitative data analysis. The interviews were audiotaped and transcribed verbatim. The deductive content analysis was used for the qualitative data analysis (open-ended questions and transcripts) by authors LB and CS using the qualitative analysis software ATLAS.ti (V1.0.4, GmbH Germany: Berlin, 2014). The first author developed an unconstrained analysis matrix based on the interview themes. Both authors (LB and CS) coded the data for correspondence with or exemplification of the identified categories. Data not fitting the unconstrained matrix served as the basis for additional categories created following the principles of inductive content analysis; conceptual labels were assigned to textual fragments and were organized into categories. Saturation occurred after coding 40 semistructured interviews (eg, no new categories emerged). Existing and newly developed categories were merged into common themes in a consensus meeting (LB and CS). Disagreements were solved through discussion, together with author MV. To determine goal attainment, raw GAS scores were transformed into an individual mean GAS score (T-score). The T-scores included the attainment level and a potential weight assigned to the goals. T-scores of  $\geq 50$  indicate effective goal achievement [26].

## Results

### First-Order Process Data: Sampling Quality

#### Recruitment and Randomization

Caregivers were recruited from memory clinics (MUMC+, Elkerliek Hospital Helmond, Catharina Hospital Eindhoven), ambulatory mental health clinics (Virenze-RIAGG Maastricht, MET ggz Roermond), caregiver support services in the southern regions of the Netherlands, and the Dutch Alzheimer Association. A total of 163 caregivers were invited to participate. See [Figure 1](#) for the study flowchart. If they expressed interest, family caregivers (n=138) received a detailed information letter. Of the information recipients, IC was signed by 58.0% (80/138). Of the 163 recruited caregivers, 154 were eligible for participation. The participation rate of eligible caregivers was 51.9% (80/154). Following the baseline assessment, the participants were randomly allocated to either PiB or the waiting-list control group. The researcher (LMMB) not involved in the assessments performed the allocation. A research assistant blind to the allocation conducted the assessments and recorded the blinding success and reason for the possible unmasking on the case record form. At T1, 68 participants had completed the postintervention or postwaiting list assessment and blinding was intact for 46% (31/68), unsuccessful for 49% (33/68), and for 7% (5/68), a conjecture of allocation was expressed.

#### Barriers and Facilitators for Recruitment

The interviewed coaches (n=10) reported that their caseload comprised several people with dementia living alone without a registered primary caregiver. This was listed as a primary recruitment barrier next to “caregiver does not own a computer” and “caseload only comprises caregivers of people with moderate to severe dementia.” Other barriers included concerns of burden for caregivers, high staff workload, and involvement in other caregiver support approaches. The coaches reported that younger caregiver age and being employed were facilitators for program recruitment because eHealth is best suited to those with a busy schedule and work-related computer literacy.

#### Reach

The caregivers were invited to participate by the clinician who treated their family member (n=122), were informed about the program’s existence by the Dutch Alzheimer Association n=26, or knew caregivers or family members already involved in the program (n=4). Others (n=11) requested information based on editorials in health magazines, local newspapers, and information stands in the southern parts of the Netherlands. The Dutch Alzheimer Association disseminated information about the program via the following: (1) monthly meeting spots for people with dementia and their caregivers, (2) newsletters, and (3) their website and social media platforms, including Facebook and Twitter.

### First-Order Process Data: Intervention Quality

#### Intervention Relevance and Feasibility: Coach Perspective

All coaches (n=13) completed the questionnaire and rated “PiB” as adequately feasible in daily practice (mean 4.5 on a scale of

1 to 5, standard deviation [SD] 0.5) and as fairly easy to integrate into their work-related activities (mean 4.4 [SD 0.5]). The program was rated as a useful addition for family caregivers (mean 4.5 [SD 0.5]) and for the coach as a professional caregiver (mean 4.2 [SD 0.8]). The mean time spent per participant was 6.2 hours (SD 1.5) spread over 8 weeks: intake session, 1.9 hours (SD 0.5); online feedback, 2.5 hours (SD 1.0); and evaluation session, 1.4 hours (SD 0.7). Qualitative analysis of the open-ended questions and the focus group interviews resulted into two themes: advantages for coaches and caregivers, and experienced difficulties and suggestions for improvement. Themes are described below and illustrated with quotations. Each quotation is assigned a code indicating the coach number in the trial.

#### Advantages for Coaches and Caregivers

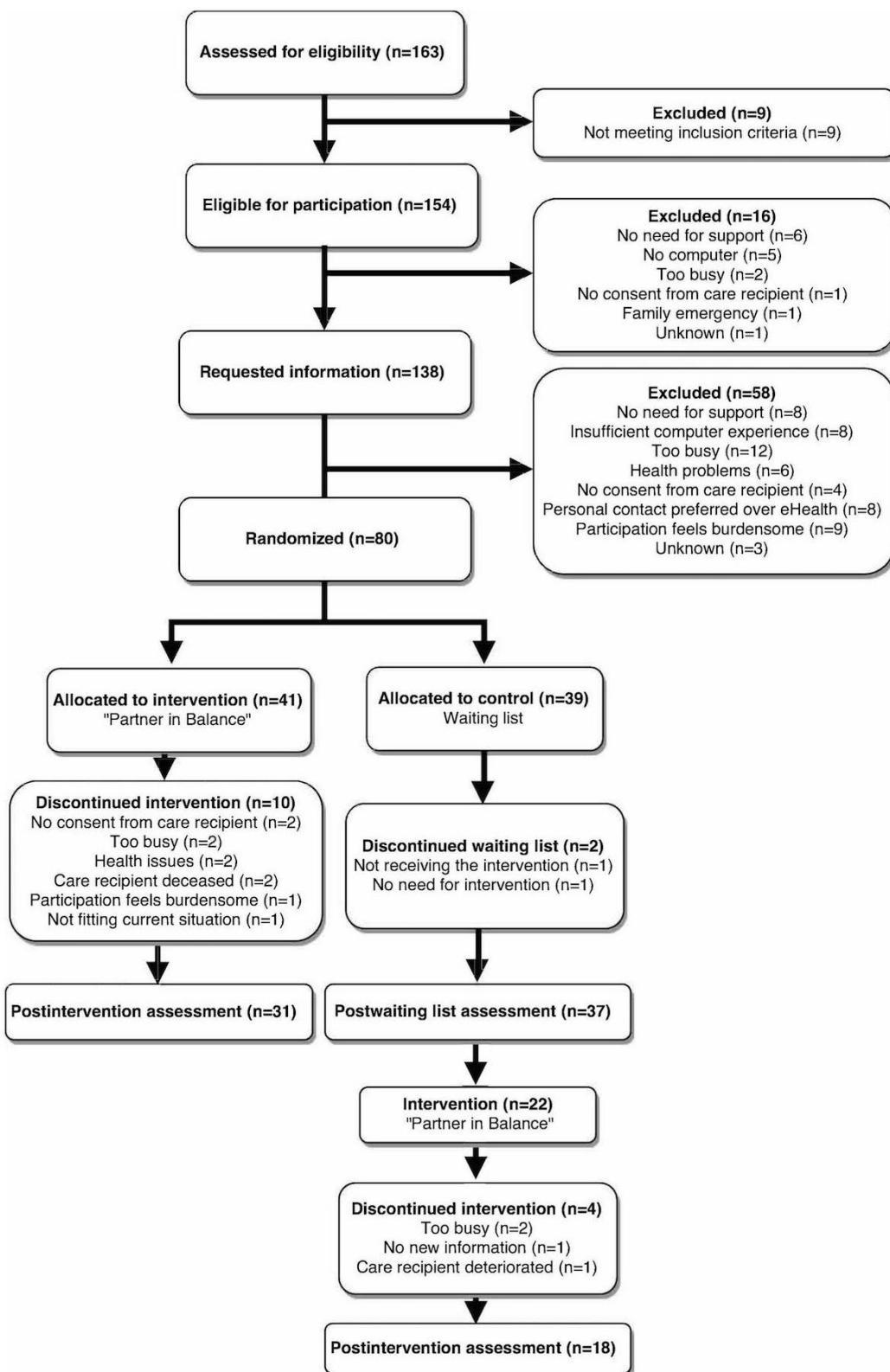
The participants’ detailed input on the assignments enabled coaches to empathize with their situation and focus on their feedback. They reported a more profound relationship with the participant after the intervention. The flexibility to provide feedback whenever and wherever via email was considered positive; it fitted their busy schedule and offered them the time to reflect on their words. Coaches considered the face-to-face intake session crucial for developing a personal connection with the participant. Furthermore, they stressed that the examples offered recognition for participants, and the assignments increased awareness about behaviors and feelings. The program’s focus on quantifiable goals and possible solutions instead of problems was considered valuable for the participants. The availability of the information, assignments, and feedback after the intervention was seen as an advantage over mere face-to-face support. One coach stated:

*By focusing on a particular problem or situation, other issues are raised that normally would not be addressed. It really interrupts the normal routine of both the client and coach. I noticed that it deepens the relationship you have with people. [C1]*

#### Experienced Difficulties and Suggestions for Improvement

Some coaches struggled with their level of direction in the self-management approach because they were accustomed to a proactive role and felt the urge to assist more than instructed for this PiB program. Goal setting during the intake session was considered difficult. However, coaches stressed the importance of goal setting and quantifying possible outcomes of program participation to make them tangible.

Several suggestions for improvement were mentioned. An increase in the user-friendliness of the instant messaging was suggested. Coaches preferred to provide feedback directly in the assignments over providing feedback in a separate message. Furthermore, a possible alarm function for crisis situations and follow-up care options were desired. To avoid confusion in the module structure, making modules available to caregivers one by one was suggested.

**Figure 1.** Study flowchart.

### Intervention Relevance and Feasibility: Participant Perspective

The participants who completed the intervention (n=49) most often selected the available themes *communication with family*

*member and environment* (44×) and *self-understanding* (44×), followed by *the changing family member* (39×), *acceptance* (36×), *coping with stress* (30×), *balance in activities* (24×), *insecurities and rumination* (21×), *focusing on the positive* (20×), and *social relations and support* (20×). Categories that

emerged from the semistructured interviews were divided into the following four themes: program content, program structure, role of the personal coach, and target audience. Each quotation is assigned a code indicating the participant number in the trial.

### **Program Content**

Most participants were satisfied with the content because it suited their current concerns. Specifically, the personalized assignments and challenges were appreciated. It was often mentioned that the content was not innovative but rather a confirmation of the participants' conjectures. Some participants struggled with the primary focus on the caregiver because they felt the care recipient should change. One participant stated:

*I think it is odd that the caregiver has to make changes, and my wife [person with dementia] does not have to learn or change anything. [P25]*

The participants reported increased awareness of their own behavior and its impact on the care recipient. The participants felt that they were challenged to explore their problems, uncover the causes, and actively seek solutions within the possibilities of the current situation. One participant stated:

*You are forced to analyze your problems, but you do not linger in them because you have to look for possible solutions. Do not reach for the stars, but try realistic things. That helped me to put my situation and feelings into perspective. [P28]*

Some participants, however, were frustrated that not every situation has a solution, whereas others experienced a more accepting attitude. Furthermore, the participants appreciated and related to the examples from other caregivers who described their daily encounters with their loved one.

Suggestions for content improvement were also made. The inclusion of links to more disease-specific information was desired. Adding subtitles to the movie clips to watch them on mute was preferred when the care recipient was not aware of the caregiver's participation.

### **Program Structure**

The program structure of blending face-to-face contacts with online modules was experienced positively. The participants mentioned that the face-to-face contact personalized the program and increased their openness during the online assignments. One participant stated the following:

*You need to see who is going to ask you these intimate questions. In my opinion that is a prerequisite for sending such personal information. [P68]*

It was stressed that the module structure facilitated the personal assignments, the examples fostered reflection, and the tips were

used as input. Others reported difficulties fitting their answers into the assignment structure. Some participants mentioned using the website when they had time and often revisited the examples, their own answers, or the feedback. A printed workbook and an autosave option were considered desirable additions.

### **Role of the Personal Coach**

The feedback was considered both supportive and critical at times, allowing participants to reflect on their answers. The participants emphasized that the coach was essential for motivation and questions. Knowing that someone was available to guide allowed them to feel less alone. One participant stated:

*She [coach] made me think about things. You do not expect the feedback to be like the philosopher's stone, but it is nice to get some confirmation and sometimes a critical note; "You are saying this, but how are you going to live up to it?" You are not doing it alone. [P03]*

Participants with a familiar coach reported an intensified relationship after working through the intervention together. Being able to speak freely online and becoming acquainted with the coach on a different level deepened their existing bond. Finally, the participants mentioned that coaches should not participate on the discussion forum because this was a safe zone for caregivers' opinions.

### **Target Audience**

Younger participants felt that the program should be specified to different subgroups. They could not identify with the older population in the examples because they were still employed and dealt with other issues in daily life, such as (young) children living at home. One participant stated the following:

*As a younger and employed person I cannot identify with the older people and their struggles in the movie clips. It makes me feel alone. [P67]*

The discussion forum was not used because caregivers struggled with shame in the early stages, and sharing their story felt like a betrayal to the care recipient. Reading about other people's misery was considered undesirable. Some participants mentioned that the course came too late for them. It was stressed that the program should be made available for all caregivers following a diagnostic disclosure. One participant stated:

*I was exceptionally alert and active in my search for information, but it should be accessible for everyone. Do not wait until people ask for it. I considered it an "integration course" for caregivers. [P54]*

**Table 2.** Number of set goals per domain.

Number of set goals per domain (N=42)	Example of set goal per domain
Communication with care recipient (21)	“I want to stay connected to my spouse.”
Positive activities with care recipient (5)	“I want to find a TV program that is easy to follow so we can enjoy our evening together.”
Social support and contacts (10)	“I want to maintain our social connections”
Time alone and feeling guilty (16)	“I want to go hiking twice a week for 1 hour by myself.”
Tension and anxiety (13)	“I want to be able to talk to my friends about my feelings as a caregiver.”
Role and relationship changes (9)	“I want to accept that it is normal to have an argument about the changes that we are facing.”
Feeling in control by gaining knowledge (8)	“I want to understand the behavioral changes and learn how to adapt to these changes.”
Positive thoughts and rumination (11)	“I want to worry less about the future and enjoy the positive moments we experience together.”

### Goal Attainment

Of the program completers in both groups (n=49), 42 participants set 93 goals in total. Five program completers were not able to set goals because they felt their care recipient should change and 2 completers missed their previously set goals because of coach turnover. Most participants (n=35) achieved  $\geq 1$  goals. Overall, 70 goals were attained (43 attained, 17 higher than expected, and 10 much higher than expected), and 22 goals were not attained (17 lower than expected and 5 much lower than expected). The mean T-score at baseline (set at -2 level) was 25.2 (SD 3.4, range 21.0-30.0). The mean achieved T-score at postintervention was 50.1 (SD 10.08, range 30.0-77.4). The mean set goals per participant were 2.2 (SD 1.1, range 1-4). To create an overview of the goals set by participants, they were categorized in domains. **Table 2** shows the number of goals for each domain, with most goals set on communication with the care recipient, followed by planning time alone without feeling guilty about it, decreasing or preventing tension and anxiety, and obtaining social support.

### Performance According to the Protocol

Intervention performance according to protocol comprised a face-to-face intake session, online modules over 8 weeks, individualized feedback via email for each module, and a face-to-face evaluation session. A total of 10 out of 13 coaches reported performance according to the protocol (77%), and 3 out of 13 reported deviations in intervention time, structure, and feedback (23%). Intervention time was reported to be longer (n=2) or shorter (n=1) than 8 weeks, and the module structure was consumed differently than intended (n=2) or feedback was given by telephone (n=2) or in person (n=1). Reasons to deviate from the protocol included caregiver pace and understanding of the program structure (n=3), illness (n=1), holiday leave (n=1), changes in work load and hours (n=1), personal family emergencies (n=1), and struggling to verbalize feedback in an email (n=1).

Regarding the dose delivered, out of the program completers (n=49), 87.8% (43/49) completed all 4 modules, 6.1% (3/49) completed 3 modules, and 6.1% (3/49) completed 2 modules. The tracked usage data showed 21,946 clicks per module, including exploring the website (2444 clicks), viewing the psychological educational information (3922 clicks), completing the assignments and change plan (8748 clicks), contacting the

personal coach (6489 clicks), and visiting the discussion forum (310 clicks). The total intervention time ranged from 4 to 32 weeks (mean 13.9 [SD 6.8]). Reasons for intervention period variability were holidays, illness, busy schedules, and technical difficulties. Following the intervention period, 77.6% of the program completers (38/49) requested access to the additional modules with (16/49) or without (33/49) the coach at their disposal for questions.

### Second-Order Process Data: Implementation Knowledge

#### Implementation Components

The coaches (n=13) had a professional background as psychologist (n=7) or psychiatric nurse (n=6). During the regular supervision meetings, coaches shared experiences and asked for feedback. Support concerning the website and feedback content was requested outside the supervision meetings via email (n=13) and telephone (n=6) during the trial.

#### Barriers and Facilitators for Implementation

The directors of 22 dementia care organizations in the southeastern part of the Netherlands were asked to participate in the trial. The response rate of the organizations was 73% (16/22). Out of the responders, 63% (10/16) expressed interest in participating in the program. Refusal was based on upcoming reorganization (1/6), the lack of suitable caregivers (4/6), or the high workload of staff members (1/6). Out of the interested organizations, 40% (4/10) organizations choose to implement “PiB” and train staff members (psychologists or psychiatric nurses) to act as personal coaches. Furthermore, 6 organizations (60%) chose to refer caregivers to the coordinating center because of the high staff workload. Categories that emerged regarding implementation barriers and facilitators from the coach questionnaire and focus groups were divided into the following three themes: organizational aspects and financing, time and practical aspects, and the organization’s target population. The themes are described below and are illustrated with quotations, followed by a code indicating the coach number in the trial.

#### Organizational Aspects and Financing

Coaches mentioned that elderly care organizations in the Netherlands often file caregiver support under patient care, which could create problems for the implementation of caregivers

support programs when the person with dementia is not registered. Additionally, financial cutbacks hampered professionals from adopting new support tools. The facilitating aspects included registration of the caregiver independent from the person with dementia, insurance compensation, and integration of online support in already provided caregiver support. One coach stated the following:

*If we cannot register caregiver support, we cannot make time for it. Managers need to be convinced that caregiver support also benefits the person with dementia. [C3]*

### Time and Practical Aspects

It was mentioned that unfamiliarity with the program could create a barrier for future implementation. Training and self-study were considered substantial personal time investments. The coaches suggested training all staff members as coaches and designating the program as regular care to facilitate implementation. One coach stated:

*The program could easily be implemented as regular care if all staff members or a constant group of staff members were trained as coaches. [C4]*

### Organization's Target Population

Professionals mentioned that many health care organizations only treat people with moderate to severe dementia with severe comorbidity, or they expect the family caregivers not to be computer literate because of their advanced age, which hampers implementation of this type of caregiver support.

## Discussion

### Overview

This study described the process of PiB to explore its credibility and generalizability. First-order and second-order process data were evaluated from the perspective of both family caregivers (participants) and professionals delivering the intervention (coaches) to increase the understanding of the mode of delivery [30].

### Sampling and Randomization

The data on sampling quality showed that the participation rate of caregivers was 51.9%. Considering that the average response rate is 27% for caregiver research, our participation rate can be considered substantial [31]. However, these 51.9% only included eligible caregivers who were already familiar with the care parties involved in recruitment. Therefore, they may have been highly motivated and open to support [32]. Recruitment barriers were lack of computers, lack of need for intervention or additional support, etc, which were also reasons for the respondents to decline participation. During the early stages, caregivers may struggle with a fear of stigma and low acceptance [19]. This might explain why some participants struggled with accepting their own crucial role in any desired changes and why participants were not ready to openly discuss their issues in the discussion forum. However, the low use of the discussion forum could also be a consequence of the abundance of currently available online communication tools,

eliminating the need for yet another form of online communication.

Young age and employment were considered recruitment facilitators. This finding is congruent with the findings of previous research stating that lower age correlated to higher eHealth literacy, that is, the skills and knowledge necessary to use online health resources [33,34]. However, seniors' use of the Internet is expected to rise in the near future, increasing the accessibility of eHealth programs, such as PiB [35]. Furthermore, the results show that spouses and children of people with young onset dementia had difficulty identifying with the older caregivers in the examples. Previous research confirmed that younger caregivers struggle with different aspects in daily life compared with older caregivers [36]. It is essential to match program content to the specific needs of the target audience to maximize the benefit of a supportive intervention [6,37,38]. The thematic structure of the program allows for an add-on of specific themes for subgroups, such as caregivers of people with young-onset dementia.

At the postintervention assessment (n=68), the blinding of allocation was intact for only 46% (31/68) of the participants, which can potentially bias the estimation of effectiveness. However, blinding in psychosocial research can be challenging and it is rarely reported if blinding is maintained [39]. This item from the CONSORT may have been developed with studies of pharmacological treatments in mind, but blinding or masking may be unfeasible for certain aspects of psychosocial treatment studies [40]. Other important aspects of psychosocial RCTs need to be considered and reported but are not addressed in the CONSORT statement, for example, adequate reporting of treatment integrity (whether therapists were consistent in providing the specified intervention). Verification of treatment integrity, or fidelity, in outcome studies is essential to ensure that valid comparisons of replicable treatments can be made [41].

### Intervention Quality

The professionals were satisfied with the intervention being manageable considering their busy schedules, giving them time to focus on their feedback. They reported a more profound relationship with the caregiver; the program allowed them to empathize with the caregiver. However, the professionals considered the nondirective attitude toward the participants a challenge in the self-management approach. This issue deserves further exploration because the performance of the self-management health care provider is essential for the participant's performance of self-management tasks and overall intervention effectiveness [42]. It was previously argued that health care providers do not always support self-management education because this is not part of their attitudes, beliefs, or regular care practice [27]. To maximize the effects of self-management programs, increasing the essential clinical competences of health care providers to provide tailored self-management support [43] and raising awareness of the benefits of evidence-based self-management programs for their target population [27] are recommended. For example, this study showed that both participants and coaches mentioned a more profound relationship with one another, which was also

demonstrated in a previous blended-care intervention for depression [44]. Previous research confirmed that the opportunity to reflect on one's feelings anonymously in a private and safe environment is easier than doing so in person, but face-to-face contact increased caregiver openness and coach empathy [7]. The participant compliance with all 4 modules was high (87.8%), which could be explained by the motivational aspect of having a coach [7]. The varying intervention period and dose may influence the effectiveness of the intervention [41]. However, reasons for protocol deviations were diverse and not uncommon for informal caregivers and elderly participants (eg, caregiver pace, time constraints, and illness) [31]. In self-management interventions, the participant is in control and should therefore be allowed to complete the modules at his own pace [27,45]. Furthermore, complex interventions such as PiB are often designed to be implemented with some flexibility to accommodate differences among participants [46].

## Implementation

PiB was evaluated within multiple organizations with coaches from different backgrounds who received training and supervision in self-management and blended care. A relatively high response rate of organizations was found (73%), which could be attributed to the current demand of health care insurance for care organizations to provide eHealth [47]. However, a lack of financing and time could hamper the implementation. To overcome the experienced barriers and implement the program on a larger scale, awareness of the benefits of blended care self-management programs is required in addition to the training of self-management skills for the health care providers. The MRC Framework suggests that implementation should be considered during the first phases of intervention development and evaluation [48]. Involving stakeholders in technological development and evaluation can facilitate implementation in different care settings [49]. As complex interventions are influenced by context, several psychosocial interventions show different results in different settings or countries [40]. Additional information about the process of the implementation is crucial to understanding why an intervention is effective in one setting and not in another [46]. Before implementing the program on a larger (international) scale, barriers and facilitators for implementation should be identified with regard to possible differences based on organizational and cultural contexts. PiB was evaluated within different settings with coaches of different backgrounds delivering the intervention. To evaluate whether the background of the coach has any influence on the intervention outcome, this variable can be considered in the effect analysis. Additionally, the higher rate of dropout in the intervention group showed that this program can be considered burdensome. eHealth interventions in general are not appropriate for caregivers who are not computer literate or have more practical care needs. Several other factors influence the interaction between people with dementia and their caregivers, for example, caregivers' personalities, psychological well-being, and the psychological symptoms of the care recipient. For instance, our results showed that this early-stage intervention came too late to help some caregivers. Caregivers were included based on the stage of the disease of their loved one, but some caregivers had been

struggling with insecurities for years while the stage of the disease was still considered "early." This highlights the need for tailored interventions, not only for the stage of the disease but also for the personal experiences, capacities, and other factors that may contribute to the intervention efficacy. Future research should consider including larger samples to examine the impact of eHealth interventions for subgroups of caregivers to tailor the care offered more efficiently [5]. However, in this study, a relatively high response and participation rate was found, indicating that having the option to choose this type of caregiver support is needed at a minimum. An active role of health care professionals in outlining care and support options early in the dementia process is recommended. Furthermore, sustainability of long-term intervention effects should be evaluated, and a cost-consequence or cost-effectiveness analysis should be conducted to inform decision makers of the value of PiB.

## Methodological Considerations

Several study limitations need to be considered. First, in our study protocol, deviations were measured with the self-report questionnaire for coaches. Previous research measuring protocol deviations with self-report questionnaires and ratings based on audio recordings found large discrepancies between the two measurements, indicating that professionals may not always be aware of their level of treatment fidelity [50]. Second, tracked usage data were measured in clicks. Clicks represent page views, but this clickstream method has a large disadvantage; several people who click on a page do not necessarily read it. Furthermore, 1 in 3 visitors spend less than 15 seconds reading the page, so a measured click does not automatically mean that the attention of the visitor is directed to the information on the page that is being viewed [19]. However, the results showed that the participants spent most of their time on the assignments and change plans and email contact with their coach, which represent the essential elements of a blended-care program [7,44]. Third, GAS was used to rate goal attainment. Goal setting and rating are considered a therapeutic task and were therefore performed by the coaches during the face-to-face sessions. Future research could consider setting and rating goals by an independent research assistant in all treatment arms to consider GAS as an outcome measure. However, GAS is a challenging evaluation method when not all participants set or evaluate goals, goals change during the process, or participants lack insight, communication skills, or the capacity to specify goals, and therefore should be used merely as a complementary scale [51].

## Conclusions

The participants and professionals were satisfied with the intervention, but adapting the content to specific subgroups such as younger caregivers was recommended. Implementation of the program requires more awareness of the benefits of blended care self-management programs and training in tailored self-management skills for the health care provider. Overall, PiB can be considered a valuable addition to the existing caregiver support because it is tailored to the needs of the target audience and deepened the coach-caregiver relationship.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Structured registration form.

[[PDF File \(Adobe PDF File, 19KB - jmir\\_v19i12e423\\_app1.pdf](#) ]

## Multimedia Appendix 2

Coach questionnaire.

[[PDF File \(Adobe PDF File, 21KB - jmir\\_v19i12e423\\_app2.pdf](#) ]

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## Abbreviations

**eHealth:** electronic health  
**GAS:** goal attainment scaling  
**IC:** informed consent  
**PiB:** Partner in Balance  
**MRC:** Medical Research Council  
**MUMC+:** Maastricht University Medical Center  
**RCT:** randomized controlled trial  
**SD:** standard deviation

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Review

# Blended Interventions to Change Behavior in Patients With Chronic Somatic Disorders: Systematic Review

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## Abstract

**Background:** Blended behavior change interventions combine therapeutic guidance with online care. This new way of delivering health care is supposed to stimulate patients with chronic somatic disorders in taking an active role in their disease management. However, knowledge about the effectiveness of blended behavior change interventions and how they should be composed is scattered.

**Objective:** This comprehensive systematic review aimed to provide an overview of characteristics and effectiveness of blended behavior change interventions for patients with chronic somatic disorders.

**Methods:** We searched for randomized controlled trials published from 2000 to April 2017 in PubMed, Embase, CINAHL, and Cochrane Central Register of Controlled Trials. Risk of bias was assessed using the Cochrane Collaboration tool. Study characteristics, intervention characteristics, and outcome data were extracted. Studies were sorted based on their comparison group. A best-evidence synthesis was conducted to summarize the effectiveness.

**Results:** A total of 25 out of the 29 included studies were of high quality. Most studies (n=21; 72%) compared a blended intervention with no intervention. The majority of interventions focused on changing pain behavior (n=17; 59%), and the other interventions focused on lifestyle change (n=12; 41%). In addition, 26 studies (90%) focused on one type of behavior, whereas 3 studies (10%) focused on multiple behaviors. A total of 23 studies (79%) mentioned a theory as basis for the intervention. The therapeutic guidance in most studies (n=18; 62%) was non face-to-face by using email, phone, or videoconferencing, and in the other studies (partly), it was face-to-face (n=11; 38%). In 26 studies (90%), the online care was provided via a website, and in 3 studies (10%) via an app. In 22 studies (76%), the therapeutic guidance and online care were integrated instead of two separate aspects. A total of 26 outcome measures were included in the evidence synthesis comparing blended interventions with no intervention: for the coping strategy catastrophizing, we found strong evidence for a significant effect. In addition, 1 outcome measure was included in the evidence synthesis comparing blended interventions with face-to-face interventions, but no evidence

for a significant effect was found. A total of 6 outcome measures were included in the evidence synthesis comparing blended interventions with online interventions, but no evidence for a significant effect was found.

**Conclusions:** Blended behavior change interventions for patients with chronic somatic disorders show variety in the type of therapeutic guidance, the type of online care, and how these two delivery modes are integrated. The evidence of the effectiveness of blended interventions is inconsistent and nonsignificant for most outcome measures. Future research should focus on which type of blended intervention works for whom.

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## KEYWORDS

telemedicine; chronic disease; behavior

## Introduction

An important challenge of today's health care is the management of patients with chronic somatic disorders. In addition, 1 out of 3 European adults deal with consequences of conditions such as heart failure, diabetes, asthma, or rheumatism [1]. Roughly, 50 million of them have even more than one chronic disorder (ie, multimorbidity) [2]. Patients' behavior can influence the progression of their disorder and their perceived health, particularly when it concerns a lifestyle-related chronic disorder [3]. For those who need support in taking actions related to their lifestyle, a behavior change intervention can be helpful [4]. Examples are an education program for patients with rheumatoid arthritis [5] or an intervention for patients with chronic obstructive pulmonary disease (COPD) focused on physical activity, smoking, disease knowledge, and emotional wellbeing [6].

## Blended Interventions

An upcoming and new delivery mode for behavior change interventions is the use of Internet technologies, such as websites and apps. Although traditional behavior change interventions in primary care are restricted to face-to-face sessions, websites and apps are available at any time and place and can act as an extension of care provided by the professional. Online interventions without therapeutic guidance, however, struggle with disappointing adherence rates [7]. Therefore, it is recommended to combine online interventions with therapeutic guidance. The combination of online care and therapeutic guidance is called blended care, also known as technology supported care [7,8]. Bringing together the personal attention of a professional and the accessibility of an online tool is seen as a highly promising combination, which can stimulate patients to take an active role in their disease management [9]. The potential of integrating online care and technology within regular care for patients with chronic somatic disorders is also described in the recently developed eHealth Enhanced Chronic Care Model. The authors extended the original Chronic Care Model with eHealth tools to promote an informed and activated patient, to create productive interactions with the health care provider, and to increase patients' self-management [10,11].

## Characteristics of Blended Interventions

Present blended interventions have in common that they consist of an online element complemented with therapeutic guidance; however, they show a wide variety in how both elements are delivered and combined. For example, the online part can be

delivered via a website with solely information texts, but supplementary videos, games, and links can be used as well. In addition, the guidance by a therapist can be delivered in various ways, for example, by providing traditional face-to-face sessions, contact by email, or by videoconferencing [12]. One of the challenges in delivering blended care is the integration of online care and therapeutic guidance instead of two separate components [8]. When integrated properly, the website or app is not only supportive to the usual therapeutic guidance but is also a substantial element of the intervention as a whole [13].

Although blended care is seen as promising in terms of effectiveness and improving health care access, the actual usage in daily primary care practice is lagging behind [14]. More knowledge about the characteristics and the effectiveness of blended behavior change interventions may support the usage in daily health care practice. However, to our knowledge, a clear overview of blended behavior change interventions is missing in literature. We conducted a systematic literature review to investigate the characteristics and the effectiveness of blended behavior change interventions for patients with chronic somatic disorders. Chronic somatic disorders are defined as health conditions that are persistent or long-lasting [15]. Mental illnesses were excluded from this review. The first goal was to investigate the varieties of intervention characteristics of behavior change interventions in terms of type of online care, type of therapeutic guidance, the extent of online and therapeutic integration, and the theoretical basis of the intervention [16]. The second aim was to study the effectiveness of blended interventions for behavior change. The following questions were studied:

- Which types of blended behavior change interventions for patients with chronic somatic disorders are available in literature?
- What is the effectiveness in comparison with no intervention, face-to-face behavior change interventions, and online behavior change interventions without therapeutic guidance?

## Methods

### Search Strategy

A comprehensive literature search was conducted using PubMed, Embase, CINAHL, and Cochrane Central Register of Controlled Trials from January 2000 to April 2017. Studies published before 2000 were excluded because of the rapid developments within the field of eHealth. A combination of the

following constructs was used: chronic somatic disorder, eHealth, behavior change intervention, and intervention study. **Multimedia Appendix 1** shows the full range of keywords used for each construct.

Keywords were adapted to control vocabularies for different databases. Additionally, reference lists of included studies and other systematic reviews [13-18] were hand-searched for potentially relevant studies.

### Study Selection and Eligibility Criteria

First step of the study selection consisted of the screening of titles and abstracts of all retrieved studies on eligibility. This was performed by 2 researchers (CK and DB). Subsequently, full texts of all initially relevant studies were independently checked for inclusion by the same researchers. Disagreements about study inclusion were discussed until consensus was reached. Inclusion criteria are provided in **Textbox 1**. Studies on decision support systems or interventions using solely reminder messages as online component were excluded. Interventions in which the online component primarily consisted of health tracking technology or self-monitoring (eg, accelerometer or glucose meter) were also excluded, unless the tracking technology was integrated in a behavior change intervention with information and/or assignments.

### Data Extraction

Data were extracted from studies that met the inclusion criteria. These data comprised study characteristics (type of study, year of publication, type of control group, outcome measures, and timing of outcome assessment), study population (number of participants, age, sex, and type of chronic disorder), intervention characteristics (target behavior, described theoretical basis, duration of intervention, delivery mode and frequency of Internet-based element, delivery mode and frequency of therapeutic guidance, integration of online care, and therapeutic guidance), and type of control intervention. A modified version of the delivery coding schemes of Webb et al [16,17] was used for coding the Internet-based element: (1) assignments, (2) information, (3) enriched information environment (eg, supplementary content and links, videos, and games), (4) automated tailored feedback based on individual progress monitoring (eg, comparison with norms or goals, reinforcing messages, or coping messages), (5) automated follow-up messages (reminders, tips, and encouragement). Coded delivery modes for the therapeutic guidance were as follows: (1) option to request for advice (ask the expert, expert-led discussion board

or chat sessions), (2) face-to-face contact, (3) email contact (scheduled), (4) phone calls, (5) short messaging service, (6) videoconferencing, and (7) discussion forum with peers. For the integration of therapeutic guidance and online care, we distinguished: (a) an integrated blended delivery mode for studies which mentioned that the therapeutic guidance was related to the content of the online care, for example, by discussing assignments or program progress, and (b) a nonintegrated blended delivery mode that was defined when the online care and the therapeutic guidance were described as two separate aspects or nothing was mentioned in the description of the therapeutic guidance about discussing or using a website or an app. Interventions in which the therapist only provided technical support and did not have access to online assignments and progress were also seen as nonintegrated.

Studies were sorted based on their type of control intervention: (1) no intervention, (2) face-to-face behavior change intervention, and (3) online behavior change intervention without therapeutic guidance.

All outcome measures were distilled and grouped into the following five constructs: (1) symptoms and signs, (2) limitations, (3) dealing with the chronic condition (cognitive and behavioral), (4) emotional outcomes, and (5) quality of life. Means and standard deviations for all outcome measurements (pre- and postvalues) were extracted. A *P* value of *<.05* was considered a significant indication for effectiveness.

### Quality Assessment

All articles were independently assessed on methodological quality by 2 researchers (CK and DB). For this assessment, the risk of bias criteria list of the Cochrane collaboration was used [18]. A total of 10 dimensions were assessed, namely, random sequence generation (selection bias), allocation concealment (selection bias), blinding of outcome assessor (detection bias), incomplete outcome data (attrition bias), selective reporting of results (reporting bias), group similarity at baseline (selection bias), cointerventions (performance bias), compliance (performance bias), intention-to-treat analysis, and timing of outcome assessments (detection bias). The criteria of blinding of participants and personnel (performance bias) were not used, as blinding is not possible in the types of intervention investigated in this review. Each study was rated as low risk, high risk, or unclear when there were no data to assess this criterion. Dimensions scored as low risk received 1 point. Dimensions scored as high risk or unclear received 0 points.

**Textbox 1.** Inclusion criteria for this study.

- randomized controlled trial published in the English language
- the patient sample comprised adults ( $\geq 18$  years) with chronic somatic disorders
- the study included an intervention aimed to change one or more of the following behaviors: physical activity, dietary intake, pain coping, and time spent in sedentary activity
- the intervention consisted of a combination of online care provided through a website, app, or automatic email and contains at least two episodes of contact with a health care professional (either face-to-face, personal emails, telephone, or videoconference)
- the blended intervention was compared with waiting list or usual care, a face-to-face intervention, or an online intervention

**Table 1.** Best-evidence synthesis.

Level of evidence	Description
Strong evidence	Consistent findings in multiple ( $\geq 3$ ) high-quality RCTs <sup>a</sup>
Moderate evidence	Consistent findings in at least one high-quality study and at least one low-quality study, or consistent findings in multiple low-quality studies
Inconsistent evidence	Inconsistent findings in multiple studies
Insufficient evidence	Only one or two studies available

<sup>a</sup>RCTs: randomized controlled trials.

Points were counted and summarized as a risk of bias score (range 0-10, where 10 indicates low risk of bias for all 10 dimensions). Studies with a score of  $\geq 6$  were judged as high methodological quality. Interobserver agreement was expressed as the percentage of agreement on bias dimensions between CK and DB.

## Data Analysis

A best-evidence synthesis was conducted to summarize the effectiveness of blended behavior change interventions, using the same method used by Proper et al [19]. For this synthesis, the number of studies, methodological quality, and consistency of findings were all taken into account. A distinction was made for each of the 3 types of control conditions. Outcome measurements that were measured 3 times or more were sorted on level of evidence: strong evidence, moderate evidence, and inconsistent evidence (Table 1). When there were at least three high methodological quality studies, studies with low quality were disregarded from the evidence synthesis. When at least 75% of the studies showed results in the same direction, results were considered consistent. In case of 3-arm studies, all eligible between-group comparisons were included and treated as different studies.

## Results

### Search Results and Study Characteristics

The initial literature search resulted in 8992 articles. After deleting duplicates, 6192 unique articles were screened on title and abstract. A total of 111 selected articles were studied on full text, whereof 29 articles met the inclusion criteria. An overview of the selection procedure is shown in Figure 1.

### Characteristics of Selected Studies

An overview of study characteristics is shown in [Multimedia Appendix 2](#). Sample size ranged from 45 to 463 participants. A total of 17 interventions were targeted on changing pain thinking and pain behavior related to chronic pain [20,21], irritable bowel syndrome [22,23], chronic tinnitus [24], diabetes mellitus [25], multiple sclerosis [26], rheumatoid arthritis [27], fibromyalgia [28], psoriasis [29], and cancer [30]. Furthermore, 12 studies were targeted on changing lifestyle behavior (ie, physical activity, nutrition, and sedentary behavior) for patients with obesity [31,32], diabetes mellitus [33,34], chronic obstructive pulmonary disease [34], multiple sclerosis [35,36], and rheumatoid arthritis [37]. Moreover, 1 study was targeted on asthma self-management skills [38]. Out of all 29 included randomized controlled trials, 21 studies had 2 study arms, 5

studies had 3 study arms, and 3 studies used a 4-arm design. Divided per control group, 21 studies compared the blended intervention with no intervention, 5 studies made a comparison with a face-to-face intervention, and 10 studies compared a blended intervention with an online self-guided intervention. The number of outcome measures per study ranged from 1 to 21.

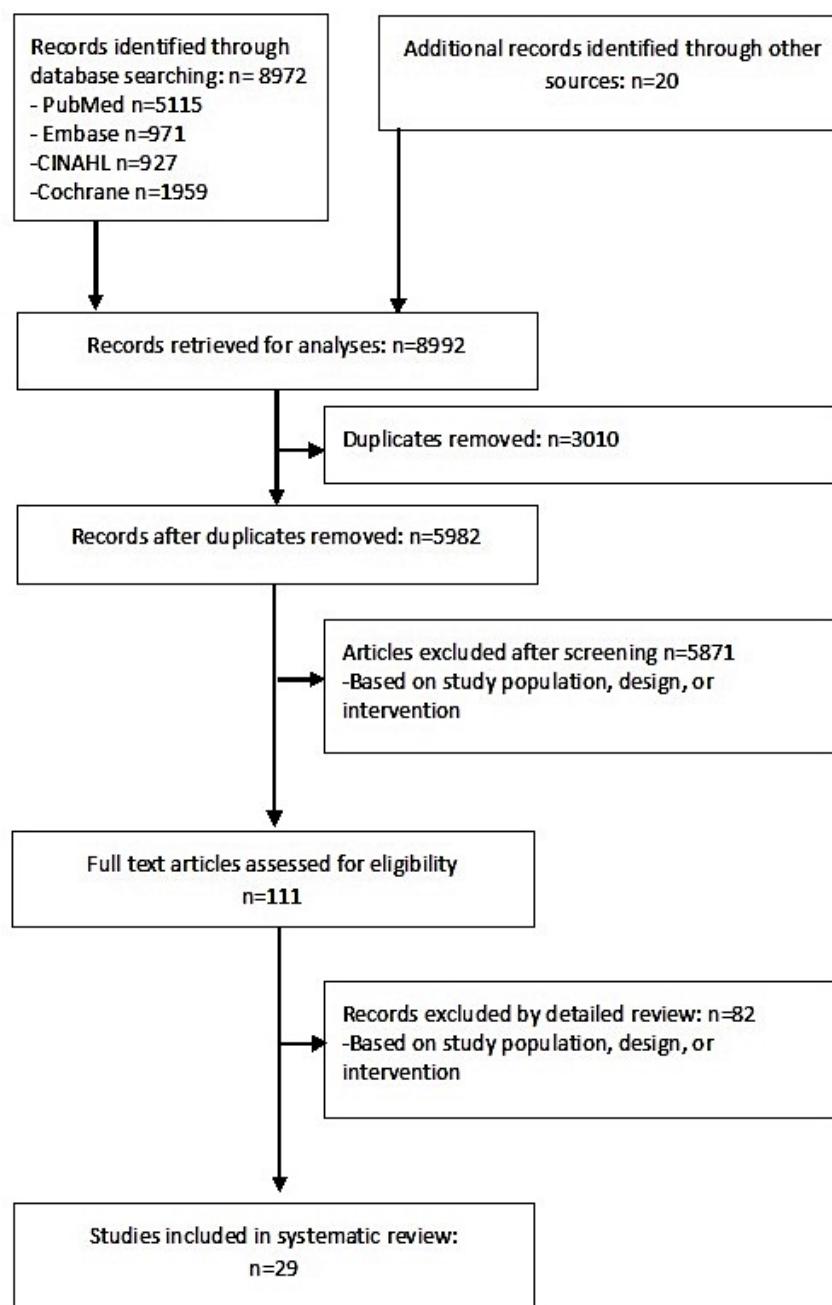
### Methodological Quality

Ten different sources of bias were rated to assess the methodological quality of the studies ([Multimedia Appendix 3](#)). There was 87% agreement between the reviewers. After discussion, consensus was reached and no third reviewer had to be consulted.

In total, 25 studies were rated as high quality [20,21,23-35,37,39,41-49] and 4 studies as low quality [22,36,38,40]. The most frequent sources of bias were not reporting blinding of the outcome assessor (90% of studies) and information about patients' use of cointerventions (93% of studies).

### Characteristics of Blended Behavior Change Interventions

An overview of intervention characteristics is shown in [Multimedia Appendix 2](#). The length of the interventions ranged from 5 weeks to 12 months. Most interventions focused on one target behavior [20-30,32,34-46,48], and 3 interventions were focused on multiple behaviors (ie, nutrition and physical activity) [31,33,47]. A total of 23 studies mentioned a theory as basis for the intervention, most frequently the principles of cognitive behavior therapy [20-22,24,26-30,32,43,44], social cognitive theory [31,36,45], and acceptance and commitment therapy [23,42,48]. In contrast, 6 studies did not mention any theory [34,35,37-39,47]. In 11 studies, the therapeutic guidance was delivered through face-to-face contact [21,30-33,37-39], mostly in combination with email or phone communication [27,29,30,32-34,37-39]. In 18 studies, the therapeutic guidance was non face-to-face [20,22-26,28,34,38,40-48]. In 12 studies, patients had the option to request for advice at a random moment [23-25,27,30,32,34,38,39,45-47]. Frequency of therapeutic guidance varied from weekly contact to bimonthly. A total of 22 studies delivered online care through a website, and the other 3 studies via an app [31,34,47]. Furthermore, 21 interventions were enriched with videos, links, games, automated tailored feedback or automated reminder messages, and in 8 studies, the online care consisted solely of assignments and information [22-24,29,37,39,40,45].

**Figure 1.** Flowchart of selection procedure.

In 7 studies, nothing was mentioned about the use of the website or app during the therapeutic guidance, and therefore, they were classified as nonintegrated [21,24,29-31,37,47]. In all other interventions, the online care and the therapeutic guidance were described to be integrated. For example, in the study of De Boer et al [20], the psychologist emailed personal feedback on homework assignments.

In the study of Buhrman et al [43], the therapist tailored the online care by selecting treatment modules that were in line with the individual needs of the patient.

### Effectiveness of Blended Care Versus no Intervention

Multimedia Appendix 4 demonstrates 21 studies that compared a blended behavior intervention with no intervention. A

complete overview with levels of evidence is given in Table 2. Within the construct of symptoms and signs, strong evidence for a nonsignificant effect was seen for pain reduction [27,28,30,40-44,48], fatigue reduction [27-30], and body weight reduction [32,39]. Within the construct of limitations, inconsistent evidence was found for disability improvement [23,43,44,48]. With regard to the construct dealing with the chronic condition: cognitive measures, strong evidence for a significant effect was found for reducing catastrophizing thoughts [22,28,40-43,48]. Inconsistent evidence was found for improving acceptance of the chronic condition [24,44], reducing fear of movement [28,44], improving pain self-efficacy [28,44], and the coping strategy praying or hoping [40-43].

**Table 2.** Effectiveness of blended behavior change interventions compared with no intervention, face-to-face behavior change intervention, and online behavior change intervention.

Control conditions and constructs	Outcome construct
<b>No intervention</b>	
<b>Symptoms and signs</b>	
Pain	Strong evidence for a nonsignificant effect
Fatigue	Strong evidence for a nonsignificant effect
Body weight	Strong evidence for a nonsignificant effect
<b>Limitations</b>	
Disability	Inconsistent evidence
<b>Dealing with the chronic condition: cognitive measures</b>	
Coping strategy: catastrophizing	Strong evidence for a significant effect
Acceptance	Inconsistent evidence
Coping strategy: praying or hoping	Inconsistent evidence
Fear of movement	Inconsistent evidence
Pain self-efficacy	Inconsistent evidence
Coping strategy: diverting attention	Strong evidence for a nonsignificant effect
Coping strategy: reinterpret pain sensation	Strong evidence for a nonsignificant effect
Coping strategy: coping self-statements	Strong evidence for a nonsignificant effect
Coping strategy: ignore pain sensations	Strong evidence for a nonsignificant effect
Perceived life control	Strong evidence for a nonsignificant effect
Perception of support received from others	Strong evidence for a nonsignificant effect
Perception of received punishing responses	Strong evidence for a nonsignificant effect
Perception of received solicitous responses	Strong evidence for a nonsignificant effect
Perception of received distracting responses	Strong evidence for a nonsignificant effect
<b>Dealing with the chronic condition: behavior measures</b>	
Coping strategy: increase activity level	Strong evidence for a nonsignificant effect
Pain interference with daily activities	Strong evidence for a nonsignificant effect
<b>Emotional outcomes</b>	
Anxiety	Inconsistent evidence
Depression	Inconsistent evidence
Affective distress	Inconsistent evidence
<b>Quality of life</b>	
Generic quality of life	Inconsistent evidence
Health-related quality of life: emotional role impairment	Inconsistent evidence
Health-related quality of life: emotional role impairment	Inconsistent evidence
<b>Face-to-face behavior change intervention</b>	
<b>Limitations</b>	
Physical activity	Inconsistent evidence
<b>Online behavior change intervention</b>	
<b>Symptoms and signs</b>	
Pain	Inconsistent evidence
Body mass index	Inconsistent evidence
Body weight	Strong evidence for a nonsignificant effect

Control conditions and constructs	Outcome construct
<b>Limitations</b>	
Physical activity	Inconsistent evidence
<b>Emotional outcomes</b>	
Anxiety	Strong evidence for a nonsignificant effect
Depression	Inconsistent evidence

Strong evidence for a nonsignificant effect was found for the coping strategies diverting attention, reinterpret pain sensations, coping self-statements and ignorance of pain sensations, perceived life control, perception of support received from others, perception of received punishing responses, perception of received solicitous responses, and perception of received distracting responses [40-43].

Within the construct dealing with the chronic condition: behavioral measures, strong evidence for a nonsignificant effect was found for pain interference with daily activities [28,40-43,48] and strong evidence for a nonsignificant effect was found for the coping strategy increasing activity level [40-43]. Within the construct emotional outcomes, inconsistent evidence was found for reducing anxiety [22,24,26-29,40-44,48], depression [24,26-30,40-44,48], and affective distress [40-43]. Inconsistent evidence was also found for the improvement of generic quality of life [41-43] and emotional and physical health-related quality of life [27-29,34].

### Effectiveness of Blended Care Versus Face-to-Face

**Multimedia Appendix 5** demonstrates 5 studies that compared a blended behavior intervention with a face-to-face behavior change intervention. A complete overview with levels of evidence is given in **Table 2**. Within the construct limitations, inconsistent evidence was found for increasing levels of physical activity [31,34]. All other outcome measures were measured less than 3 times, indicating insufficient evidence.

### Effectiveness of Blended Care Versus Online Care

**Multimedia Appendix 6** shows 10 studies that compared a blended behavior intervention with an online behavior change intervention. A complete overview with levels of evidence is given in **Table 2**. Within the construct symptoms and signs, inconsistent evidence was found for reduction of pain [44,48] and body mass index [31,33]. Strong evidence for a nonsignificant effect was found for body weight reduction [31-33]. Within the construct limitations, strong evidence for a nonsignificant effect was found for improving physical activity levels [31,33,37,45,46]. Within the construct emotional outcomes, strong evidence for a nonsignificant effect was found for reducing anxiety [44,48] and depression [25,44,46,48].

## Discussion

### Principal Findings

This review provides an overview of the intervention characteristics of a new and promising field within health care for patients with chronic somatic disorders. The characteristics of the included blended behavior change interventions showed

a wide heterogeneity. For example, length of interventions ranged from 5 weeks to 12 months. A previous systematic review that studied factors related to online adherence showed that shorter interventions are related to higher usage rates [50]. On the other hand, it is also known that long-term maintenance of behavior change is challenging [51] and that an extension of the intervention with follow-up booster sessions improves the overall effectiveness of face-to-face interventions [52]. The majority of interventions focused on one type of behavior. As many people have multiple unhealthy behaviors linked to risk factors for different chronic diseases, studies should focus on changing multiple behaviors [4]. Such holistic programs have a great potential for targeting complete health profiles and stimulating patients to take an active role in their health management.

The theoretical basis of the intervention content was most frequently based on the principles of cognitive behavior therapy. The aim of the cognitive behavior therapy is to change individuals' unhelpful thoughts, beliefs, and behaviors [53]. In less than half of the studies, the therapeutic guidance was delivered face-to-face, whereas in the other studies, it was delivered completely at distance. Future research is needed to investigate whether face-to-face contact, guidance at distance, or a combination of multiple delivery modes are more or less effective for the overall effectiveness of a blended intervention. The review of Webb et al [16] showed that an "ask the expert" facility is related to higher effectiveness. This additional option was used in 12 out of 29 studies. Furthermore, it is known that the use of an enriched information environment is related to higher effectiveness [16]. Such supplementary content, such as videos and links to informative websites, was used in most interventions. In summary, we can conclude that a wide diversity was seen in the characteristics or ingredients of blended interventions. Given the considerable heterogeneity in the interventions, it was difficult to isolate subtypes of blended interventions for patients with chronic somatic disorders. Future research should focus on which type of blended intervention works for whom, for example, by using subgroup analyses and comparing different types of blended care.

Almost all included studies described that the therapeutic guidance and the online care were integrated with each other. Examples of integration of therapeutic guidance and online care were the provision of therapeutic feedback on online assignments or tailoring of the online intervention by the therapist. This high number of integrated blended interventions surprised us, as in literature, the interconnection of the therapeutic and the Web-based part is described as one of the biggest challenges of blended care [8,54]. When Web-based apps are integrated within health care, online care is often used

as an additional component to usual care, instead of being a substantial element of the intervention as a whole [8]. Although the interventions were described as interconnected, analyses of user experiences are needed to draw conclusions about actual experienced integration.

A wide range of outcome measures were included in our evidence synthesis comparing blended interventions with no interventions or online blended interventions without therapeutic guidance. For some outcome measures, we found inconsistent evidence, and for other outcome measures, we found strong evidence for a nonsignificant effect. The lack of evidence for blended interventions, even when comparing with no intervention, is surprising. Although blended care is described as best of both worlds [8], results of this systematic review do not support this expectation. Before broad-scale implementation of blended behavior change interventions in daily practice, further investigation of how blended interventions should be composed is needed.

A minority of studies compared blended interventions with face-to-face interventions. The evidence synthesis of this comparison showed inconsistent evidence for improvement in physical activity. Particularly, for the comparison of blended behavior change interventions with face-to-face interventions, it would be interesting to investigate cost-effectiveness, long-term effectiveness, and patient satisfaction. The potential added value of blended care above face-to-face care may be found in these outcome measures instead of outcome measures related to symptoms and signs, limitations, behavior, emotions, and quality of life. To illustrate, if face-to-face sessions are substituted by online care, blended interventions may be cheaper than usual care [55]. Another advantage of blended interventions over face-to-face care is the possibility to overcome geographical barriers, as therapeutic guidance in these interventions can be served by a computer or mobile phone.

### Limitations

A methodological limitation of our evidence synthesis is the use of multiple outcome measures and multiple comparisons. This multiplicity may result in an increased risk of false-positive statistically significant indications of the effectiveness of blended behavior change interventions [56]. Moreover, 4 studies were conducted by the same research group [40-43]. These 4 studies investigated interventions targeted on the same behavior and generally used the same measurement instruments. The predominance of these 4 studies within the evidence synthesis may also lead to false-positive statistically significant indications of the effectiveness of blended behavior change interventions.

### Conflicts of Interest

None declared.

### Multimedia Appendix 1

Keywords per construct (PubMed version).

[[PDF File \(Adobe PDF File, 26KB - jmir\\_v19i12e418\\_app1.pdf](#) ]

## Multimedia Appendix 2

Characteristics of studies, participants, and interventions.

[[PDF File \(Adobe PDF File, 97KB - jmir\\_v19i12e418\\_app2.pdf](#) ]

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## Multimedia Appendix 3

Risk of bias assessment.

[[PDF File \(Adobe PDF File, 62KB - jmir\\_v19i12e418\\_app3.pdf](#) ]

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## Multimedia Appendix 4

Outcome measures of studies with no intervention as control condition.

[[PDF File \(Adobe PDF File, 130KB - jmir\\_v19i12e418\\_app4.pdf](#) ]

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## Multimedia Appendix 5

Outcome measures of studies with control conditions online behavior change intervention.

[[PDF File \(Adobe PDF File, 77KB - jmir\\_v19i12e418\\_app5.pdf](#) ]

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## Multimedia Appendix 6

Outcome measures of studies with control conditions face-to-face behavior change intervention.

[[PDF File \(Adobe PDF File, 44KB - jmir\\_v19i12e418\\_app6.pdf](#) ]

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## Abbreviations

**COPD:** chronic obstructive pulmonary disease

**RCT:** randomized controlled trial

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## Review

# End User and Implementer Experiences of mHealth Technologies for Noncommunicable Chronic Disease Management in Young Adults: Systematic Review

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## **Abstract**

**Background:** Chronic noncommunicable diseases (NCDs) such as asthma, diabetes, cancer, and persistent musculoskeletal pain impose an escalating and unsustainable burden on young people, their families, and society. Exploring how mobile health (mHealth) technologies can support management for young people with NCDs is imperative.

**Objective:** The aim of this study was to identify, appraise, and synthesize available qualitative evidence on users' experiences of mHealth technologies for NCD management in young people. We explored the perspectives of both end users (young people) and implementers (health policy makers, clinicians, and researchers).

**Methods:** A systematic review and meta-synthesis of qualitative studies. Eligibility criteria included full reports published in peer-reviewed journals from January 2007 to December 2016, searched across databases including EMBASE, MEDLINE (PubMed), Scopus, and PsycINFO. All qualitative studies that evaluated the use of mHealth technologies to support young people (in the age range of 15–24 years) in managing their chronic NCDs were considered. Two independent reviewers identified eligible reports and conducted critical appraisal (based on the Joanna Briggs Institute Qualitative Assessment and Review Instrument: JBI-QARI). Three reviewers independently, then collaboratively, synthesized and interpreted data through an inductive and iterative process to derive emergent themes across the included data. External validity checking was undertaken by an expert clinical researcher and for relevant content, a health policy expert. Themes were subsequently subjected to a meta-synthesis, with findings compared and contrasted between user groups and policy and practice recommendations derived.

**Results:** Twelve studies met our inclusion criteria. Among studies of end users (N=7), mHealth technologies supported the management of young people with diabetes, cancer, and asthma. Implementer studies (N=5) covered the management of cognitive and communicative disabilities, asthma, chronic self-harm, and attention deficit hyperactivity disorder. Quality ratings were higher for implementer compared with end user studies. Both complementary and unique user themes emerged. Themes derived for end users of mHealth included (1) Experiences of functionality that supported self-management, (2) Acceptance (technical usability and feasibility), (3) Importance of codesign, and (4) Perceptions of benefit (self-efficacy and empowerment). For implementers, derived themes included (1) Characteristics that supported self-management (functional, technical, and behavior change); (2) Implementation challenges (systems level, service delivery level, and clinical level); (3) Adoption considerations

for specific populations (training end users; specific design requirements); and (4) Codesign and tailoring to facilitate uptake and person-centered care.

**Conclusions:** Synthesizing available data revealed both complementary and unique user perspectives on enablers and barriers to designing, developing, and implementing mHealth technologies to support young people's management of their chronic NCDs.

**Trial Registration:** PROSPERO CRD42017056317; [http://www.crd.york.ac.uk/PROSPERO/display\\_record.asp?ID=CRD42017056317](http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42017056317) (Archived by WebCite at <http://www.webcitation.org/6vZ5UkKLp>)

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## KEYWORDS

musculoskeletal pain; health services research; telemedicine; noncommunicable disease; chronic disease; health policy

## Introduction

Young people are digital natives, and the portability and capabilities of digital technologies can act as a lever to connect them to health systems. This capability to connect is especially important for young people with chronic noncommunicable diseases (NCDs) during the critical transition from childhood to young adulthood [1,2].

### Young People's Use of Mobile Technologies to Support Self-Management of Chronic NCDs

We have previously identified how mobile health (mHealth) technologies could support self-management of young people with persistent musculoskeletal pain who are making this transition [2,3] and how to specifically address their self-management needs by improving access to disease information, strategies to manage symptoms, and social support [4]. Self-management is well recognized as a fundamental component of chronic NCD care, denoting the active participation of people in their care with the aim of minimizing the impact of chronic disease on physical health status and functioning and enabling people to cope with the psychological effects of illness [5]. Core self-management skills include problem solving, decision making, resource utilization, forming patient-health professional relationships, taking action, and self-tailoring, all skills that can be feasibly supported by appropriate mHealth technologies as highlighted in findings from a recent systematic review on this issue [1]. Furthermore, the use of mHealth technologies as an enabler to self-management is an intuitive choice for young people, given the high rates of Internet usage globally, with rates nearing 100% for the millennial generation in many of the world's largest economies [6]. Young people are also more likely than older generations to own a mobile phone in virtually every country [6]. Digital technologies can also provide a potential mechanism to help mitigate care disparity [7], reaching across high, middle, and low-income economies [8] to enable the delivery of integrated, holistic information about chronic NCD management [9].

### Evidence-Practice and Policy-Practice Gaps for the Use of Mobile Health Technologies to Support Self-Management of Chronic NCDs

Although the use of mHealth technologies, including mobile apps, to support self-management of NCDs has also grown substantially [10], the evaluation of their quality, safety, and

outcomes indicate that significant evidence-practice and policy-practice gaps remain [1,11,12]. In particular, there is a dearth of high-quality evidence on the use of mHealth technologies to support young people's self-management of their persistent musculoskeletal pain conditions [2,13]. Recent efforts address some of these gaps, providing evidence for how mHealth apps can improve the access of young people with chronic pain to disease information, facilitate symptom management and social support [4], and support their self-management of cancer pain [14,15]. In the context of young people's use of mHealth to support their management of other chronic NCDs (asthma, diabetes, and cancer), findings from a recent systematic review indicate the need for more high-quality studies targeting the development, evaluation, use, and effectiveness of mobile apps [1]. One significant issue common to mHealth interventions is that they fail to be fully embedded into real-world settings and scaled up, with many studies being conducted as pilots or feasibility trials [1,16]. Another key finding from this same review emphasized the critical role of codesign of mobile apps. This means bringing together both end users (here, young people) and implementers (policy makers or health professionals tasked with implementation) to ensure meaningful design and to facilitate strong engagement, adoption, and sustained uptake [17]. Codesign includes consideration of factors such as feasibility, engagement, ease of use, ease of navigation, ease of understanding, satisfaction, acceptability, reliability, functionality, aesthetics, information quality, and subjective quality [1,14,15,18,19].

### Why This Study?

The primary motivation for this systematic review was to inform appropriate mHealth resource design, evaluation, and implementation specifically targeted for young people with chronic NCDs including persistent musculoskeletal pain. The experiences of young people with chronic NCDs diseases were considered more broadly, as the self-management of chronic conditions frequently overlaps and is associated with comorbidities and multi-morbidities [20,21] requiring similar core self-management skills [5]. To optimally inform implementation approaches, a comprehensive understanding of users' experiences and perceptions is essential. Qualitative (including mixed methods) studies are likely to provide the richest insights, and such perspectives and insights are recognized as a critical component of implementation approaches related to interventions and system-wide models of care [22,23]. Additionally, as the implementation of new interventions is recommended to be a partnered process between

end users and implementers, identifying unique and overlapping user perspectives could lead to better shared decision making and care integration [18].

This systematic review therefore had two key aims: (1) to identify users' (end user and implementers) experiences with mHealth technologies to support the self-management of young people with chronic NCDs, and (2) to identify what factors these users (end user and implementers) perceived or experienced as facilitators or barriers to the uptake and implementation of mHealth technologies for young people with chronic NCDs.

## Methods

### Conduct of Systematic Review

This systematic review followed an *a priori* published protocol with detailed methods [13]. Our review is reported in accordance with the Preferred Reporting Items for Systematic Review and Meta-Analysis (PRISMA) statement checklist [24] and Enhancing Transparency in Reporting the Synthesis of Qualitative Research (ENTREQ) checklist [25] (Multimedia Appendices 1 and 2). This systematic review followed an *a priori* published protocol with detailed methods [13] and can be found at: [http://www.crd.york.ac.uk/PROSPERO/display\\_record.asp?ID=CRD42017056317](http://www.crd.york.ac.uk/PROSPERO/display_record.asp?ID=CRD42017056317).

### Eligibility Criteria

#### Types of Participants

This review considered all qualitative studies on young people (in the age range of 15-24 years) with chronic NCDs (end users), which included technologies intended for use by patients [13]. Studies were included where  $\geq 50\%$  of the cohort met the age criteria or where the mean age range (rounded) of participants fell within the 15 to 24 year age range. Additionally, the experiences and perspectives of "Implementers" (defined as including health service delivery providers, administrators, researchers, clinicians, and policy makers) supporting young people with chronic NCDs were included and considered separately.

Chronic NCDs were defined as conditions of long duration and generally slow progression, lasting 3 months or more and included, but were not limited to, musculoskeletal conditions, diabetes, respiratory conditions (such as asthma), cardiovascular diseases, mental health disorders, and cancer [26].

#### Phenomena of Interest

This review considered studies that evaluated the use of mHealth technologies to support young people manage their chronic NCDs [13]. To be included, studies needed to have evaluated users' (implementers and end users) (1) perspectives or experiences (ie, perceptions of feasibility, engagement, ease of use, ease of navigation, ease of understanding, satisfaction, acceptability, reliability, functionality, aesthetics, information quality, and subjective quality) of using mHealth technologies to support the management of chronic NCDs and (2) factors that users (end user and implementers) perceived or experienced as facilitators or barriers to the uptake and/or implementation of mHealth technologies for young people with chronic NCDs [13]. In this review, mHealth included any mobile device or

service, such as mobile phones, short message service (SMS), smartphones, personal digital assistants, and devices that work on wireless technology or Bluetooth-compatible devices [27]. Interventions delivered using a Web-based platform were included only if it was specified that the patient accessed the service via a mobile phone or other mobile device.

### Context

Studies carried out in any setting were considered. The rationale included the portable and accessible nature of mHealth technologies, which enables varied use not just within different care settings by different patients but extending across different contexts by the same patient (ie, continuing to access and utilize the same mobile phone app in the community [locally and remotely] in primary care and tertiary care settings).

### Types of Studies

This review considered primary research studies that used qualitative methods to collect and analyze data, including but not limited to phenomenology, grounded theory, ethnography, critical enquiry, participatory action research, and descriptive qualitative studies. The qualitative components of mixed-methods studies were also included.

### Search Strategy

A three-step search strategy was utilized in this review [13]. An initial limited search of MEDLINE (PubMed) and CINAHL and PsycINFO was to be undertaken, followed by analysis of the text words contained in the title and abstract and the index terms used to describe an article. A second search using all identified keywords and index terms was then undertaken across all databases including EMBASE, MEDLINE (PubMed), Scopus, and PsycINFO. Two independent academic research librarians were consulted to provide feedback on the final search strategy. The search for gray literature included ProQuest Dissertations and Theses, KT, Epistemonikos, as well as health policy and nongovernmental organization literature based on the research team's knowledge. Third, the reference list of all included reports and articles were hand searched for additional studies. Studies published in English were considered for inclusion in this review. The search was carried out in December 2016 by a senior review methodologist (JC). Studies from 2007 were included to align with global access to 147 Wideband Code-Division Multiple Access; the standard found in third generation mobile telecommunications and available globally [28].

Initial keywords used were chronic, long term, persistent, noncommunicable, disease, respiratory, asthma, cystic fibrosis, lung disease, diabetes, cancer, heart disease, cardiovascular disease, pain, muscular disease, joint diseases, musculoskeletal, kidney disease, young, adolescent, adolescence, eHealth, mHealth, mobile application, mobile health app, mobile health application, smartphone application, digital technologies, intervention, qualitative, experience, phenomenology, grounded theory, action research, implementation, implementer, and end user. The full search strategies are included in Multimedia Appendix 3.

## Screening and Selection

### Overview

Search results were collated in a reference database (Endnote X7 version 3.1, Thomson Reuters, New York), duplicates were deleted, and initial screening of titles and abstracts was conducted by one reviewer (JC), followed by the retrieval of full texts. Full texts were then reviewed against the inclusion criteria by two independent reviewers (HS and JC) to confirm eligibility. Disagreements were resolved through discussion.

### Assessment of Methodological Quality

Papers selected for retrieval were assessed by two independent reviewers (JC and HS) for methodological quality before inclusion using the standardized critical appraisal instrument for qualitative research from the Joanna Briggs Institute, JBI-QARI [29]. Studies were not excluded on the basis of quality ratings. Any disagreements were resolved through discussion until consensus was reached.

### Data Extraction

Data were extracted by one reviewer (JC) from papers included in the review using the standardized extraction tool from JBI-QARI [29]. A second reviewer (HS) also completed data extraction for 30% of articles to confirm congruence. The primary focus of data extraction was the identification of specific qualitative findings—reported themes, subthemes, and metaphors—related to the phenomena of interest, which were subsequently synthesized as described below. Additionally, descriptive data, including details about the mHealth apps, study methods, country of development, and age range of participants were extracted.

The credibility of findings was assessed based on how they were supported in the text [29], as follows:

- Unequivocal: findings accompanied by an illustration that is beyond reasonable doubt and therefore not open to challenge.
- Credible: findings accompanied by an illustration lacking clear association with it and therefore open to challenge.
- Unsupported: findings not supported by data.

### Data Synthesis

A meta-synthesis approach was used to organize and interpret pooled data [29]. Initially, three reviewers (JC, AMB, and HS) familiarized themselves with the extracted data and independently developed preliminary categorizations. At a subsequent 3-day workshop, these independently and deductively derived categories were presented, discussed, and iteratively and inductively organized into consensus-based descriptive themes from which we derived new, higher-order themes that extended beyond the findings of primary studies. Findings were linked back to the research questions to ensure relevance and appropriate contextualization. Themes were then subjected to a meta-synthesis to inform declarative statements that could be applied as an evidence-base to our research aims. Four members of the team (AMB, JC, MB, and HS) participated

in the meta-synthesis. Findings based on the experiences of end users and implementers were meta-synthesized separately and compared and contrasted.

On the basis of consensus, a reporting framework was developed to reflect these synthesized findings. The reporting framework was populated with derived themes and supporting evidence from primary study findings. To ensure external validity, one member of the team (JS) with substantial clinical and research expertise in the development and implementation of digital technologies for young people with chronic conditions provided independent feedback over the meta-synthesis process. Where relevant, findings and supporting evidence were adjusted to reflect a consensus decision, and the reporting framework was refined. Finally, a systems and health policy expert (MB) was engaged to assist with final policy and practice recommendations, with a final round of independent review (JS) conducted as outlined previously.

## Results

### Identification and Selection

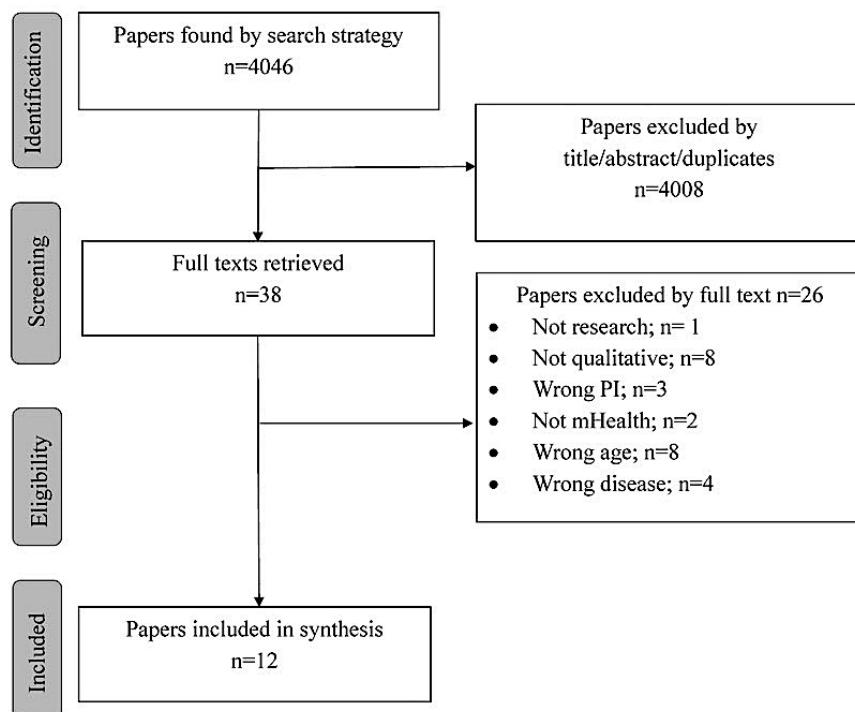
The initial search identified 4046 potential studies from which 1193 studies were excluded as duplicates and 2815 were excluded based on the review on their titles or abstracts (Figure 1).

Overall, 38 studies were identified as potentially meeting the inclusion criteria based on the review of their titles and abstracts. From these, 12 studies were ultimately included [30-41]. Reasons for exclusion included not being a research paper [42], not being qualitative or having a qualitative component [43-50], investigating the wrong phenomena of interest [51-53], not meeting the definition of mHealth [54,55], the population being outside the target age band [19,56-62], and the population being affected by a condition not considered to be a chronic NCD (eg, mHealth promotion interventions with no specific chronic NCD or lifestyle behaviors) [63-66]. Seven studies contributed findings on end users [30,31,33-35,37,39], whereas 5 studies [32,36,38,40,41] reported on implementers.

### Included Study Characteristics

Characteristics of included studies are described in Table 1 (end user studies) and Table 2 (implementer studies). Among end users, mHealth technologies were applied to aid in managing diabetes [30,34,35], cancer (chemotherapy symptom management) [31,37], and asthma [33,39]. Implementers included occupational therapists [32], speech language pathologists [32], nurses [36], physicians [36,40], as well as medical [38,41] and nonmedical [38,41] health care professionals assisting in the management of cognitive and communicative disabilities [32], asthma [36,40], chronic self-harm [38], and attention deficit hyperactivity disorder (ADHD) [41]. Studies on end users were carried out in the United Kingdom [30,37], United States [31,33,39], and Norway [34,35], whereas studies on implementers were conducted in the United Kingdom [38,41], United States [36,40], and Sweden [32].

**Figure 1.** Flow diagram of study identification and selection adapted from preferred reporting items for systematic review and meta-analysis (PRISMA) flowchart. PI=phenomenon of interest; mHealth=mobile health.



**Table 1.** Characteristics of included end user studies.

End user studies	Phenomena of interest	Participants	mHealth <sup>a</sup> technology used	Method or design <sup>b</sup> ; AA <sup>c</sup>	Setting; Geographic location
Ashurst et al 2014 [30]	Use of an app to help prepare for clinical appointments	Young people with type 1 diabetes; aged 16 to 25 years; mean age 20.3 years	Apps developed by young people with diabetes to facilitate agenda setting in clinic consultations, data logging and insulin dose calculation	Open-ended questions (email and web-based); AA: Inductive conventional content analysis; summative content analysis	Community; United Kingdom
Baggott et al 2012 [31]	Perceptions about using mobile oncology symptom tracker (mOST) and any technical difficulties they experienced	Adolescents and young adults with cancer; 13 to 21 years; receiving chemotherapy; mean age 18.2 years	A mobile phone-based electronic symptom diary (mOST)	Interviews and questionnaire; AA: Not specified	Pediatric hospitals; inpatient or clinic settings; United States
Carpenter et al 2016 [33]	How app features promote self-observation, self-judgment and foster positive self-reflection; app features work synchronously to increase adolescents' asthma self-management and improve outcomes	Convenience sample of 20 adolescents with asthma; 12 to 17 years; mean 14.7 years; >50% over 15 years	Two asthma self-management apps (one targeted to adults and one to children)	20 to 30 min telephone interview with verbatim transcription; AA: Framework synthesis based on a framework analysis (self-regulation theory)	Pediatric practice located in an urban area; United States
Froisland and Arsand 2015 [34]	To evaluate the effect of the designed tool with regard to empowerment, self-efficacy, and self-treatment	Adolescents with type 1 diabetes; 13 to 19 years; mean age 16.2 years; >50% over 15 years	Mobile phone-based tool designed to capture and visualize adolescent food intake to affect understanding of calorie counting and help doctor-adolescent communication	Semistructured interview; AA: Deductive approach based on empowerment theory	Pediatric clinic; Norway
Froisland et al 2012 [35]	Adolescent patients' experiences with two different mobile phone apps used for diabetes care	Adolescents with type 1 diabetes; 13 to 19 years; mean 16.2 years	App that contained a visual or picture-based diabetes diary to record physical activity, food eaten that communicated with glucometer and Web-based SMS <sup>d</sup> used to contact providers and receive educational messages	Structured interview (transcribed) with field notes; AA: Inductive qualitative descriptive influenced by phenomenology and hermeneutics	Pediatric clinics; Norway
Gibson et al 2010 [37]	Key benefits of the Advanced Symptom Management System (ASyMS-YG)	Young people; inpatient intravenous chemotherapy; 13 to 18 years; median age 15 years; >50% over 15 years	ASyMS: through which patients can report chemotherapy-related symptoms through mobile	Questionnaires and semistructured interviews; AA: Thematic analysis	Cancer units; United Kingdom
Rhee et al 2014 [39]	Feasibility and user acceptability of mobile phone-based asthma self-management aid for adolescents (mASMAA)	Adolescents with asthma; Adolescent-parent dyads; 13 to 17 years; mean 15.1 years; >50% over 15 years	mASMAA which facilitates symptom monitoring, treatment adherence, and adolescent patient partnership	Focus groups; semistructured questions (recorded and transcribed); AA: Content analysis	Clinical setting (emergency department and primary care clinics in a university medical center); United States

<sup>a</sup>mHealth: mobile health.<sup>b</sup>Qualitative design or study type is specified where explicitly stated within studies, otherwise descriptive detail is provided.<sup>c</sup>AA: analytic approach.<sup>d</sup>SMS: short message service.

**Table 2.** Characteristics of included implementer studies.

Implementer studies	Phenomena of interest	Participants	mHealth <sup>a</sup> technology used	Method or design <sup>b</sup> ; AA <sup>c</sup>	Setting; Geographic location
Buchholz et al 2013 [32]	Professionals' views of satisfaction, participation, and involvement in daily life of adolescents and adults with communicative disabilities who tried texting with picture symbols and speech synthesis through mobile phones	Four occupational therapists and three speech language pathologists who had worked with end users (adolescents and adults with cognitive and communicative disabilities using the intervention)	Texting with picture symbols and speech synthesis in mobile phones	Semistructured interview with independent transcription; AA: Retrospective qualitative analysis theory influenced by directed content analysis	Community setting; Sweden
Geryk et al 2016 [36]	The use of attitudes and preferences for asthma mHealth app features among parents and clinicians	20 caregivers and 6 clinicians involved in the care of adolescents with asthma	Two asthma self-management apps (one targeted at adults and one at children)	Questionnaires and interviews; AA: Thematic analysis	Pediatric practices; United States
Owens and Charles 2016 [38]	Barriers to recruitment and implementation of a texting intervention for adolescents who self-harm	Clinicians and service managers working in child and adolescent mental health services (CAHMS) with adolescents who self-harm	An SMS text messaging (short message service), (TeenTEXT) that delivered, scheduled, or prompted personalized messages	Field notes and focus groups; AA: Inductive thematic analysis	CAHMS; United Kingdom
Schneider et al 2014 [40]	Physicians' views on patient-provider communication with their adolescent asthma patients, mechanisms for relating better with patients, their use of mobile technologies, and willingness to integrate technology in patient care	Residents and attending physicians about mHealth use for adolescents' management of asthma	Mobile technology for patient care (no one specific tool or technology)	Interviews (with recording and transcription); AA: Constant comparative method using a priori codes	One pediatric group in an urban academic medical center; United States
Simons et al 2016 [41]	To explore patients' and health care professionals' views regarding the use of remote monitoring technology (RMT) during medication titration for attention deficit hyperactivity disorder (ADHD)	Health care professionals working with people with ADHD	RMT for people undergoing ADHD medication titration which sent automated text messages (linking to questionnaires)	Exploratory cross-sectional focus group; AA: Thematic analysis and charting were used to search for data patterns within and across participant groups	Four National Health Service mental health providers; United Kingdom

<sup>a</sup>mHealth: mobile health.

<sup>b</sup>Qualitative design or study type is specified where explicitly stated within studies, otherwise descriptive detail is provided.

<sup>c</sup>AA: analytic approach.

## Methodological Quality Assessment

Table 3 shows the findings of the critical appraisal for studies of end users (n=7) and implementers (n=5), respectively. Studies on implementers were scored as higher quality than those on end users.

This was particularly true for question 8 on the representation of participant voices, which were adequately represented for all 5 studies on implementers but only for 4 of the 7 studies on end users. Researchers' cultural or theoretical backgrounds were inconsistently reported (question 6), whereas the impact of the researcher on the research was rarely addressed (question 7).

## Data Analysis and Meta-Synthesis

Results of the meta-synthesis are presented below. Data are presented as a synthesized finding with supporting themes and

component subthemes (for a summary of themes or subthemes, see Table 4). Results are reported separately for end users and implementers. Examples of supporting evidence are provided in Textboxes along with statements about level of credibility. Data were subsequently examined for complementarity, indicating both common and unique user themes, which subsequently informed recommendations for policy and practice. Full supporting data and original findings are presented in [Multimedia Appendices 4](#) and [5](#).

## End Users' Experiences and Perspectives

### Theme 1. Functionality of mHealth Technology

End users perceived the functionality of mHealth technologies as important; specifically, subthemes related to (1) functionality as an important enabler to supporting self-management and (2) person-centered clinical encounters ([Textbox 1](#)).

**Table 3.** Critical appraisal of the methodological quality of included studies.

Users	Question number									
	Q1 <sup>a</sup>	Q2 <sup>b</sup>	Q3 <sup>c</sup>	Q4 <sup>d</sup>	Q5 <sup>e</sup>	Q6 <sup>f</sup>	Q7 <sup>g</sup>	Q8 <sup>h</sup>	Q9 <sup>i</sup>	Q10 <sup>j</sup>
<b>End users</b>										
Ashurst et al 2014 [30]	Y <sup>k</sup>	Y	Y	Y	Y	N <sup>l</sup>	N	N	Y	Y
Baggott et al 2012 [31]	U <sup>m</sup>	U	U	N	U	N	N	N	Y	U
Carpenter et al 2016 [33]	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Froisland and Arsand 2015 [34]	Y	Y	Y	Y	Y	Y	N	N	Y	Y
Froisland et al 2012 [35]	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Gibson et al 2010 [37]	Y	Y	Y	Y	N	Y	N	Y	Y	Y
Rhee et al 2014 [39]	U	Y	Y	Y	Y	U	N	Y	Y	Y
Positive/7	5	6	6	6	5	3	0	4	7	6
<b>Implementers</b>										
Buchholz et al 2013 [32]	Y	Y	Y	Y	Y	N	N	Y	Y	Y
Geryk et al 2016 [36]	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Owens and Charles 2016 [38]	Y	Y	Y	Y	Y	Y	N	Y	Y	Y
Schneider et al 2014 [40]	U	Y	Y	Y	Y	N	N	Y	Y	Y
Simons et al 2016 [41]	Y	Y	Y	Y	Y	Y	Y	Y	Y	Y
Positive/5	4	5	5	5	5	3	1	5	5	5

<sup>a</sup>Q1: Is there congruity between the stated philosophical perspective and the research methodology?<sup>b</sup>Q2: Is there congruity between the research methodology and the research question or objectives?<sup>c</sup>Q3: Is there congruity between the research methodology and the methods used to collect data?<sup>d</sup>Q4: Is there congruity between the research methodology and the representation and analysis of data?<sup>e</sup>Q5: Is there congruity between the research methodology and the interpretation of results?<sup>f</sup>Q6: Is there a statement locating the researcher culturally or theoretically?<sup>g</sup>Q7: Is the influence of the researcher on the research, and vice-versa, addressed?<sup>h</sup>Q8: Are participants, and their voices, adequately represented?<sup>i</sup>Q9: Is the research ethical according to current criteria or for recent studies, and is there evidence of ethical approval by an appropriate body?<sup>j</sup>Q10: Do the conclusions drawn in the research report flow from the analysis, or interpretation, of the data? [29].<sup>k</sup>Y=yes.<sup>l</sup>N=no.<sup>m</sup>U=unclear.

**Table 4.** Summary of themes and subthemes derived for end users and implementers.

User group	Themes	Subthemes
End users	Functionality of mHealth <sup>a</sup> technology	mHealth functionality to support self-management
		mHealth functionality to support young person-centered clinical encounters
	Acceptance of mHealth technologies	Perceptions of technical usability
		Perceptions and experiences around acceptability and feasibility
	The importance of codesign	Intrapersonal factors
		Extra-personal factors
Implementers	Perceptions of benefit	Self-efficacy
		Empowerment
	mHealth characteristics that support young people's management of noncommunicable diseases	Functional aspects of design that support end users' management
		Technical characteristics can help their delivery of clinical care
		mHealth can support positive health behavior change
	Implementation challenges	Micro level factors
		Meso level factors
		Macro level factors
	Adoption of mHealth technologies in a specific young population	The need for training of end users
		The need for design to facilitate uptake and match social context or peer expectations
	Codesign and tailoring	Importance of codesign
		Tailoring to end user needs

<sup>a</sup>mHealth: mobile health.

**Textbox 1.** End user experiences of mobile health (mHealth; theme).

Mobile health (mHealth) functionality to support self-management (subtheme)
<ul style="list-style-type: none"> <li>“I used the symptoms, triggers, and notes, cause—because with the symptoms, it can—it pretty much tells how—like what I’m feeling at that time like throughout the day and the triggers is like if I have a flare up or, uh, an attack or—then it’ll—it’ll help, it’ll show like what—what caused it in the notes because it just—I can just put down everything that happened throughout the whole day.” Carpenter 2016, <i>page 515, column 2</i> (unequivocal)</li> <li>“Like it—it really did help me out, um, and to know about the progress of my-of my asthma...it let me like know more of how my asthma was going during the weeks and—and days.” Carpenter 2016, <i>page 513, column 2</i> (unequivocal)</li> <li>“The triggers, um, I thought it was good because it would help you keep track of like what triggered it before, so you would know to stay away from it or stay indoors if it’s like a certain type of plant blooming or something. And it would help you, uh, remember that for the future years, so you could, um, remember to stay away from it.” Carpenter 2016, <i>Page 514, column 1</i> (unequivocal)</li> <li>“The chart, cause I can like sc-, I can watch it, I can scale my asthma and I can see if it’s worse or if it’s getting better, or if it’s really serious I need to do something about it, it helps me. Um-hum.” Carpenter 2016, <i>page 514, column 1</i> (unequivocal)</li> <li>“And I always remember to take my medicine easier with this app so I think that will help out. Because if I could continue to take my medication on sort of, uh, a consistent flow it makes it easier. And so overtime, I think it will help me control my asthma.” Carpenter 2016, <i>Page 513, column 2</i> (unequivocal)</li> </ul>
mHealth functionality to support person-centered clinical encounters (subtheme)
<ul style="list-style-type: none"> <li>“They’ll [doctors and nurses] be able to know exactly what is happening.” Gibson 2010, <i>page 349, Table 3</i> (unequivocal)</li> <li>“I think that was good...so like if your doctor just wonders how you’re doing when he doesn’t see you, you could, you could send him the chart and he could see how you’ve been doing.” Carpenter 2016, <i>page 515, column 1</i> (unequivocal)</li> <li>“I could give it to my school if there’s a problem with my asthma, they can say, ‘Oh, well she did send us this document saying that she has asthma, so we need to let her take her medicine,’ so that’s a good thing.” Carpenter 2016, <i>Page 515, column 1</i> (unequivocal)</li> </ul>

## mHealth Functionality to Support Self-Management

The functionality of mHealth technologies was perceived as supporting young people's self-management of a range of NCDs including asthma, diabetes, and cancer. Specifically, the functionality offered by mHealth technologies assisted young people in managing their conditions in a number of different ways. This included the following:

- monitoring their health status and symptom triggers via graphical charting [33] and sign or symptom awareness using self-checks [33,37,39]
- improving their comprehension and understanding of their health condition [34]
- providing reminders about medication adherence [33]
- providing ready access to automated tailoring of personal health information related to the management of their condition(s) [33]
- providing relevant information, support, and reassurance about planning for emergencies and safety issues through prompting timely communication with health professionals [35,37,39]

## mHealth Functionality to Support Young Person-Centered Clinical Encounters

The functionality of the mHealth technologies supported a young person-centered clinical encounter by enabling accurate and immediately available clinically relevant personal data at a consultation [30], providing a record of clinical health information to treating practitioners (portability and accuracy of data over a cumulative period of time) [33], and enabling end users to direct the focus of the clinical encounter [37].

**Textbox 2.** Acceptance of mobile health (mHealth) technologies (theme).

<p>Perceptions on technical usability (subtheme)</p> <ul style="list-style-type: none"> <li>“The Diamob app didn't work at the end of the project. The glucometer with Bluetooth worked, but batteries ran out of power quickly.” Froisland 2012 <i>ePub</i> (unequivocal)</li> <li>Overall, reviewers indicated that the apps were worth trialling but a few felt improvements or amendments were needed before regular use. Ashurst 2014 <i>ePub</i> (credible)</li> <li>“But what is cumbersome is that you have to access that Internet browser on the mobile. I would prefer to send normal SMS on the phone...that would make it even easier if you could access it using the usual SMS [on the phone].” Froisland 2012 <i>ePub</i> (unequivocal)</li> <li>“I think it is a lot easier to understand and to have it explained when I can see things.” Froisland 2012 (unequivocal)</li> </ul> <p>Perceptions and experiences around acceptability and feasibility (subtheme)</p> <ul style="list-style-type: none"> <li>“I think most people just don't want to do them [peak flows]. And you don't want to have to—because first, you have to, you know, use it. You have to use it three times and you really start coughing, hacking after you've used it. Most people don't like peak flows. And then in addition to actually having to do the peak flow, you—if you want to see how you're doing really, you have to document it.” Carpenter 2016, page 515, column 1 (unequivocal)</li> <li>Adolescents were able and willing to make adjustment to their routines to accommodate mASMAA and became accustomed to interactions with mASMAA easily (“You get used to it and it becomes routine”; “I feel like it becomes normal, just like...an instinct to do it”) Rhee 2014, <i>page 67, column 2</i> (unequivocal)</li> <li>“It is more about those messages and the information. It has been practical advice, easy to understand, simple facts that are very nice to know. It is better to have it in such small portions instead of reading a lot of information, then everything is poorly read and poorly understood. I liked the way the information was given.” Froisland 2012 <i>ePub</i> (unequivocal)</li> <li>Reviewers' felt the easiest to use apps were self-explanatory and simple to understand. The other apps were also considered easy to use but with some suggestions to improve the user interface. Ashurst 2014 <i>ePub</i> (credible)</li> </ul>
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Whereas some features were reported as not relevant or acceptable (eg, a requirement to record peak flow for asthma management) [33], the use of mHealth technologies was still considered useful and feasible as end users were able to adapt to and accommodate mHealth technology into their routines [39].

### Theme 3. The Importance of Codesign

End users identified the critical importance of codesign of mHealth technologies, which included subthemes based on intra and extra-personal factors considered important to end users [30] (Textbox 3).

#### Intrapersonal Factors

Competing time demands and inadequate knowledge of condition-specific triggers and value judgments (such as a perception of already adequate self-management) [33,34] were cited as factors that needed to be considered in mHealth technology codesign.

#### Extra-Personal Factors

Capacity for tailoring design and making technology more broadly acceptable for end users were important considerations.

**Textbox 3.** The importance of codesign (theme).

Intrapersonal factors (subtheme)
• “I really don’t know what my triggers are, so I really didn’t use it that much.” Carpenter 2016, <i>page 514, column 1</i> (unequivocal)
• “Because, like my asthma is well-controlled, so like a lot of the stuff here I don’t really need, but maybe like other people who have it worse will like probably need it more.” Carpenter 2016, <i>page 515, column 1</i> (unequivocal)
• “[...] one participant noted that she was too busy to use an asthma app.” Carpenter 2016, <i>page 515, column 1</i> (credible)
Extra-personal factors (subtheme)
• [...] much importance was placed on app design (not necessarily development) by diabetic peers because of a mutual understanding of the needs, condition and experiences in order for the apps to offer the most accurate features and details. Ashurst 2014 (credible)
• Most adolescents in the study felt in charge of their own life, however they talked about acceptance as an important factor. Acceptance of own disease and treatment and also acceptance from important others like friends to treatment while in different social settings. Froisland 2015, <i>page 545, Table 1</i> (credible)

**Textbox 4.** Perceptions of benefit (theme).

Self-efficacy (subtheme)
• “[...] adolescents reported increased independence during the trial, as indicated in their improved self-management (e.g., taking medications) without parents’ prompting.” Rhee 2014, <i>page 68, column 2</i> (credible)
• “I felt in control and I liked that you could see if your temperature had improved.” Gibson 2010, <i>page 349, Table 3</i> (unequivocal)
• The direct contact with those they trust was reported as important. To know that they got an answer back, gave a feeling of acceptance and to be paid attention to. Froisland 2015, <i>page 545, Table 1</i> (credible)
Empowerment (subtheme)
• “It has been pretty good to know that if I have an issue, then I can just send a message...Instead of calling Mom or Dad and ask them to call [the physician], and when they have the answer it might be an answer to something I was not wondering about.” Froisland 2012, <i>page 513, column 2</i> (unequivocal)
• “It kind of keeps me to where I can see what I’ve done, instead of it just being in my mom or my doctor knowing how far I’ve come, where—if I’m getting better or worse, if I’m normal for myself or anything, I can kind of keep myself in check.” Carpenter 2016, <i>page 516, column 1</i> (unequivocal)
• Positive response from people who know the disease is important to feel empowered. The SMS application increased the possibility for response directly from their health care professional. Froisland 2015, <i>page 545, Table 1</i> (credible)

## Implementers' Experiences and Perspectives

### Theme 1. mHealth Characteristics That Support Young People's Management of NCDs

Implementers identified multiple components of young people's NCD management that can be supported by mHealth technologies (Textbox 5). Three subthemes emerged: functional aspects of design that support end users' management, technical characteristics that support clinicians' delivery of clinical care for young people, and how mHealth can support positive health behavior change.

#### Functional Aspects of Design That Support End Users' Management

Implementers identified a range of design features that were perceived to support end users' management of their conditions. These included the following:

- tracking side effects and symptoms for clinical management [36,40,41]
- focusing the agenda for clinical appointments [36,40,41]
- reminders for medication adherence and to overcome supply problems [36,41]
- enabling bilateral communication between end users and clinicians [32,36,40]
- overcoming communication deficiencies [32]

**Textbox 5.** Mobile health (mHealth) technology characteristics that support young people's management of noncommunicable diseases (theme).

#### Functional aspects of design that support end users' management (subtheme)

- "This way you can look back over the previous 4 weeks or 3 months and focus on questions such as—"you scored sleep a 2 here, what was happening at the time that made it so unsettled?" It should help parents to be more productive in giving the information we need." Simons 2016, *page 9, column 1* (unequivocal)
- "Participants saw the potential for RMT to provide the ability to easily monitor symptoms, chart them over time, and identify any patterns or unusual behaviors. This would increase people's knowledge, self-awareness, and understanding of and confidence in dealing with their condition." Simons 2016, *page 9, column 1* (credible)
- "The difficulties I come across, [are that] young people are on medication and they tend to run out at the end of the month and their behavior will go sky high, and it will take them a week to get all the medication back into their system. I think it would be really useful if somewhere in the app, say when they're...near the end [they receive a message saying] 'You need to put in a request for repeat prescription.'" [HCP, Site 3] Simons 2016, *page 10, column 1* (unequivocal)
- "... teenagers are busy and communication is limited and I think using technology will improve communication. They'll listen more. I mean, I think they read their texts, you know, and I think reading a short text is much more beneficial and reminder systems on an everyday, I mean, doing something the same way for 2 weeks makes it a habit." Schneider 2016, *page 156* (unequivocal)
- "He has great help from the synthetic speech and he is markedly disturbed when it doesn't really sound like he wants it to." Buchholz 2013, *page 92, column 1* (unequivocal)

#### How technical characteristics of mobile health (mHealth) can help their delivery of clinical care (subtheme)

- Clinicians felt that use of the app could lead to a better medical appointment both in terms of efficiency, patient-centered care, and decision making. Multiple clinicians expressed data security concerns (eg, insecure email) or differed in their preference for information delivery method [...] Geryk 2016 *ePub* (credible)
- Multiple clinicians mentioned that appointment noncompliance is a problem, one stating that "[a]ny extra reminder that families have that they have an appointment I think is helpful." Geryk 2016 *ePub* (unequivocal)

#### How mHealth technology can support positive behavioral change (subtheme)

- "I mean if everything is going well, you could give them sort of positive feedback just like: "Hey, keep up the great work." If not, you could be like: "Are you taking your controller?" Schneider 2016, *page 158* (unequivocal)
- Clinicians generally had positive things to say about the apps as a self-management tool to help parents and adolescents including the following: "hands-on" and provides a "more interactive or fun way to check on their asthma." Geryk 2016 *ePub* (credible)

- habituation of components of self-management (medication management and adherence [40])
- providing alerts for end users and their clinicians about deteriorating health conditions [40]
- remote technology enabling social connectedness and access to health support (motivation, coaching, and providing information to their treating physician) [32,41].

#### Technical Characteristics Can Help Their Delivery of Clinical Care

Implementers identified several technical features that they believed would assist their delivery of clinical care and optimize their engagement with end users, such as communication reminders (use of medicines and low peak flows) and focusing clinical encounters through more efficient preparation [36,40].

#### mHealth Can Support Positive Health Behavior Change

Implementers perceived mHealth technologies to positively influence end users to independently manage their condition and to facilitate positive health behavior change [32,36,40] through independent communication [32], age-related appeal [36], and providing positive feedback to end users (eg, improved asthma tracking, reminders for medication use and refills, peak flow assessment, and communication to health professionals) [40].

### Theme 2. Implementation Challenges

Important challenges to implementation of mHealth technologies were experienced or perceived by implementers as extending across multiple levels of the health care system. This aligned with three subthemes: challenges at the clinical level (micro), challenges at the service delivery level (meso), and challenges at a systems level (macro; [Textbox 6](#)).

#### Micro Level Factors

Factors identified as barriers to implementation at the clinical level included accuracy of health indicator monitoring [36] and a limitation of task-specific capability for specific health conditions [32].

#### Meso Level Factors

At the organizational level, key factors identified as barriers included the internal regulatory environment of organizations [38], resource allocation (remuneration and funding) [40], issues with integration into the current work flow [38,41], organizational climate and readiness for change [38], and interoperability with existing information and technology infrastructures [41].

#### Macro Level Factors

At the systems level, health information security and national or jurisdictional electronic health (eHealth) regulatory frameworks were highlighted as key challenges to implementation of mHealth technologies [36,40].

#### Textbox 6. Implementation challenges (theme).

##### Technical features as barriers to implementation at the clinical (micro) level (subtheme)

- This [technical asthma trigger] feature was more often criticized by parents and clinicians because of its lack of long-term monitoring and feedback capabilities. One clinician expressed the opinions of other participants when stating, “I don’t know what you’d [do] with it. Other than just be aware of it.” Geryk 2016 *ePub* (unequivocal)
- “Basically he seems to think it’s good but he’s frustrated because he thinks...he has very high expectations and to this point he doesn’t feel they have been met” Buchholz 2013, *page 91, column 1* (unequivocal)

##### Organizational level (meso) barriers to implementation (subtheme)

- “The biggest thing is...a time issue, lack of reimbursement...for adding additional duties.” Schneider 2016, *page 157* (unequivocal)
- “We see young people with severe mental health problems, including suicidal ideation, and I’m not sure it’s ideal for this group...Most self-harm is dealt with by family support workers and schools, and they are always looking for additional resources and tools to help with it.” Owens 2016, *page 7, column 1* (unequivocal)
- “The general perception within the team is that using TeenTEXT is too much of an extra burden on top of our existing workload.” Owens 2016, *page 6, column 2* (unequivocal)
- “The organisation doesn’t give clinicians any leeway. We need permission to try anything new and there are so many hoops to jump through before that happens.” Owens 2016 (unequivocal)

##### System level (macro) barriers to implementation (subtheme)

- Clinicians felt that use of the app could lead to a better medical appointment both in terms of efficiency, patient-centered care, and decision making. Multiple clinicians expressed data security concerns (eg, insecure email) or differed in their preference for information delivery method [...] Geryk 2016 *ePub* (credible)
- “Oh, I would love to do it by electronic means. The problem is that then you run into all the HIPAA problems.” Schneider 2016, *page 157* (unequivocal)

### Theme 3. Adoption of mHealth Technologies in a Specific Young Population

Implementers perceived the need for mHealth to be adaptable or tailored for vulnerable populations, referring specifically to young people with cognitive and communicative disability. Two subthemes emerged: (1) the need for training of end users and (2) the need for design to facilitate uptake and match social context or peer expectations ([Textbox 7](#)).

#### The Need for Training of End Users

In a single study, Bucholtz et al [32] identified that specific training of end users is required to facilitate better uptake or adoption of mHealth technologies in this specific population.

#### The Need for Design to Facilitate Uptake and Match Social Context or Peer Expectations

Design to facilitate adoption included a focus on mHealth technology supporting end users “blending in” and a capacity to streamline function with their existing technology (eg, software installed on end users’ own mobile phones). Additional considerations were devices that were physically easy to handle, hardware designed to meet specific end user needs (eg, texting with symbols and speech synthesis), and devices that fit well into end users’ daily routines.

### Theme 4. Codesign and Tailoring

Implementers perceived specific characteristics of mHealth technologies that they considered important to support end users’ management of NCDs. Two subthemes emerged: (1) the importance of codesign and (2) tailoring to end user needs ([Textbox 8](#)).

**Textbox 7.** Adoption of mobile health (mHealth) technologies in a specific young population (theme).

The need for training for end users for some conditions and settings to facilitate adoption (subtheme)

- “It has been easy to handle for him...it has been easy also in terms of making adaptations (for the helper).” Buchholz 2013, *page 91, column 2* (unequivocal)
- “This is an aid that would be of help for a lot of people. I have many colleagues with clients who would need something similar maybe particularly adolescents that are becoming adults.” Buchholz 2013, *page 92, column 2* (unequivocal)
- “Exciting a little more up to date...modern...or she would never have accepted it.” Buchholz 2013, *page 91, column 1* (unequivocal)
- “Yes because if this software was installed in the regular phone I think she would use it more.” Buchholz 2013, *page 91, column 1* (unequivocal)

Need for codesign to facilitate uptake and social currency (subtheme)

- “It’s important to find a situation where you really see the need of being able to text or a person you need to contact where a regular phone call won’t work.” Buchholz 2013, *page 92, column 1* (unequivocal)
- “Yes, it was very abstract I think so when we could show him something more concrete he grasped it better.” Buchholz 2013, *page 91, column 2* (credible)

**Textbox 8.** Codesign and tailoring (theme).

Importance of codesign: implementers identified the importance of working collaboratively with end users to optimize functionality (subtheme)

- “She has great use of them and we have built upon her interests so she can easily reply to a text and she can also send a pre-designed text.” Buchholz 2013, *page 93, column 2* (unequivocal)
- One clinician brought up the benefits of using the feature for “engaging with them [patients]” including jointly inputting information into the plan and/or discussing what patients have previously input to ensure they are getting the correct guidance, especially regarding emergency situations. Geryk 2016 *ePub* (credible)
- “I like the fact that the messages are written by them, so they’re supporting themselves... This fits with what we currently do, which is try and give them a sense of control.” Owens 2016, *page 5, column 1* (unequivocal)

Need for technologies to be tailored to end user’s needs and contexts (subtheme)

- “Yeah it’s like that. He has started to use it more for face to face communication...not just the text-messaging function but more as a communication device.” Buchholz 2013, *page 94, column 1* (unequivocal)
- “I think most of them engage in devices like this for entertainment, right? And so you want to have something that provides them an educational opportunity, um, but also something that they – they won’t get bored with.” Geryk 2016 *ePub* (unequivocal)
- “Don’t forget to pretreat before you go out for soccer practice, or football practice,” specific for that patient’s sport I think would be even more, you know, something that’s specific for that patient.” Schneider 2016, *page 158* (unequivocal)

**Importance of Codesign**

Implementers identified the importance of working collaboratively with end users to optimize functionality requirements as part of the early phase of development of mHealth technologies [32,36,38].

**Tailoring to End User Needs**

Implementers identified the need for the design of mHealth technologies to be adaptable to end users, providing for tailored age-relevant design, content, and functionality [36,40], as well as meeting condition-specific requirements [32].

**Policy and Practice Recommendations and Implications**

On the basis of our evidence meta-synthesis, we derived five key recommendations and described the associated policy and practice implications (Textboxes 9-13). The use of mHealth in management of young people with chronic NCDs can support self-management and drive meaningful change in contemporary health ecosystems. However, identifying and resolving implementation challenges is critical to enabling sustainable scaling-up of mHealth solutions. These recommendations should help to inform appropriate resource design, evaluation, and implementation in a way which all users will find acceptable and which health systems will find sustainable.

**Textbox 9.** Recommendation 1 and implications.

Recommendation: Mobile health (mHealth) technologies should be considered as a potential strategy or solution to enable self-management, to improve clinical encounters, and to encourage positive health behaviors in young people with chronic noncommunicable diseases (NCDs).

Implications:

- mHealth should be considered by consumers and stakeholders involved in the delivery of care as a complement to existing health care options, as a means to enhance care delivery and efficiency and to integrate into care pathways
- To achieve this outcome, it is important to clearly identify end users' needs and also to identify where and when in a young person's care pathway mHealth technologies could meaningfully affect capacity for self-management, improve clinical encounters, and influence positive health behavior
- Policy makers need to respond to the momentum around mHealth by considering current care pathways and support systems and identifying opportunities for integration of mHealth technologies to optimize cocare; to facilitate location-based care; and drive quality, safety, and efficiency in care delivery

**Textbox 10.** Recommendation 2 and implications.

Recommendation: Design of mHealth technologies for young people with chronic NCDs should be a collaborative process involving partnerships with multi-stakeholders (eg, young people, health professionals, digital technology designers, service delivery, and policy makers) to achieve meaningful codesign and to inform appropriate implementation approaches.

Implications:

- A collaboration of relevant stakeholders needs to be engaged from inception and at all stages through planning, developing, testing, implementing and through continuous cycles of improvement (formative evaluation) for mHealth technologies
- Importantly, different stakeholders may be needed at different stages and these stakeholders should be explicitly identified to align with requirements at each stage
- From inception, processes should be informed by contemporary evidence and an appropriate implementation science framework
- The outcome of this collaborative and evidence-informed approach should ensure that mHealth technologies have social currency and are contemporary, relevant and useful to young people

**Textbox 11.** Recommendation 3 and implications.

Recommendation: mHealth technologies for chronic NCD management in young people need to have functional capabilities that allow for tailoring to end users' preferences and person-centered needs.

Implications:

- Implementers need to undertake formative evaluations of mHealth technologies across the development and implementation stages in partnership with young people to ensure that functionality is responsive to their end user needs, including changing developmental and NCD needs
- These formative evaluation outcomes need to direct iterations of mHealth technologies

**Textbox 12.** Recommendation 4 and implications.

Recommendation: Implementation initiatives must consider whole-of-system readiness to adopt mHealth technologies. The use of contemporary mHealth toolkits for planning and scale is advisable [67].

## Implications:

At a health systems (*macro*) level, it is necessary to consider system readiness to support implementation and adherence. This requires identifying gaps and opportunities across the system to support implementation, including

- current policy or strategy platforms
- workforce capacity building initiatives and priorities
- infrastructure and human resourcing
- strategic cross-sector partnerships
- alignment with existing policy, technological, legal, and regulatory frameworks. Compliance with information and communication technology regulatory frameworks is imperative

At the service delivery (*meso*) level it is necessary to consider

- organizational readiness for change (eg, culture, change management leadership, executive support, and technophobia)
- seamless integration of mHealth into existing and planned workflow
- business modeling to capture value, cost effectiveness, and sustainability
- interoperability with existing information and technology systems

At the clinical (*micro*) level, implementers need to jointly assess, in partnership with health providers and end users, the desired functionality, required accuracy of data capture, and security associated with the use of proposed mHealth technologies

**Textbox 13.** Recommendation 5 and implications

Recommendation: Implementers of mHealth technologies must undertake continuous cycles of improvement to maintain technical and functional optimization. The use of contemporary digital health monitoring and evaluation guidance is advisable [68].

## Implications:

- Given the rapidly changing landscape of mHealth technologies, continuous technical updates are needed to address changes (to maintain platform compliance and security)
- Planned review cycles are necessary to allow for iteration and optimization of content and functionality based on analytics data
- A governance framework needs to be developed in advance of implementation, with the aim of addressing project management and guiding these review cycles
- Dedicated resourcing is required to implement such a framework

## Discussion

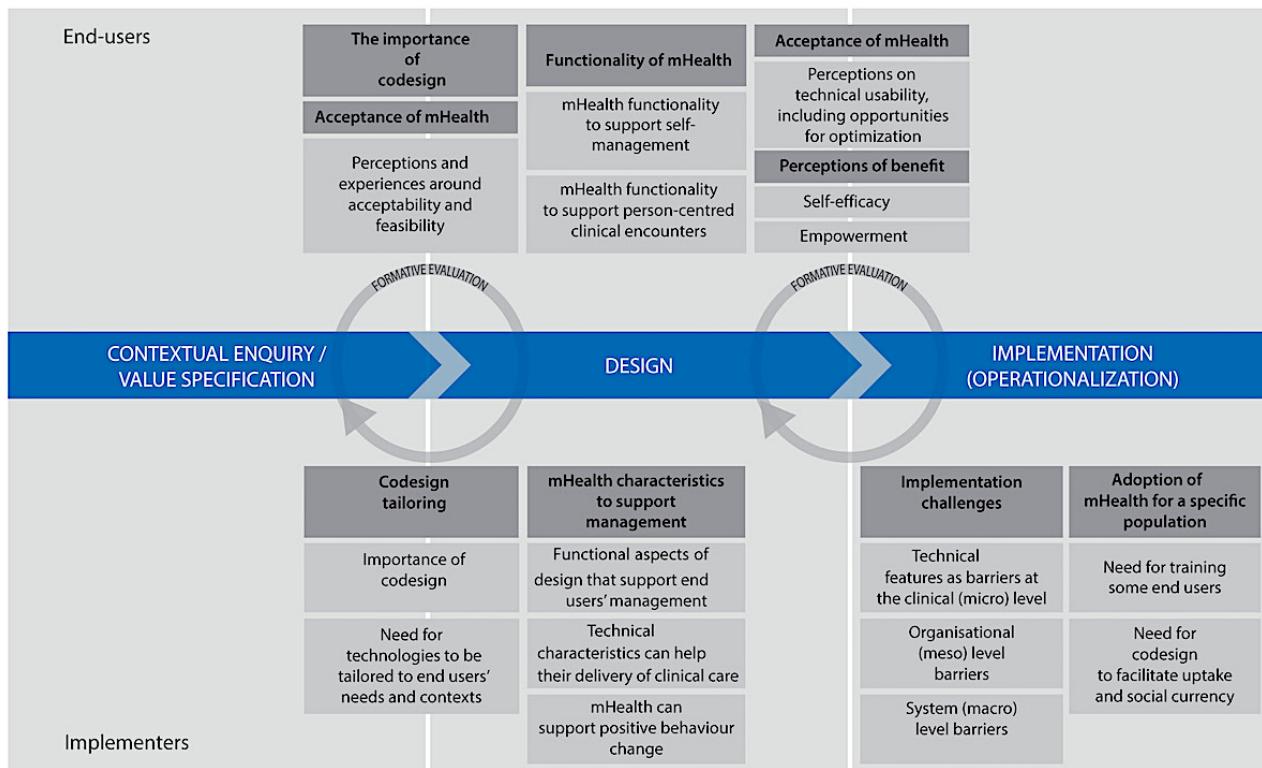
### Principal Findings

This systematic review extends our understanding of users' experiences and perspectives of mHealth for chronic NCDs management in young people and highlights the specific enablers and barriers to implementation. The clear evidence of benefit for the use of mHealth technologies by young people for education, monitoring, and the self-management of their chronic NCDs often fails to sustainably translate into real-world settings, consistent with reports that "... *benefits can only spring from effective implementation that credits interaction with human and organizational factors*" [69]. Our evidence synthesis provides novel insights to inform and guide actionable policy and practice recommendations on "how" we can implement mHealth technologies to better support young people's management of their chronic NCDs. The key findings from this evidence synthesis also show both complementary and unique perspectives on the use of mHealth for chronic NCD

management in young people. Collectively, mHealth technologies were perceived by users as supporting young people's self-management across a range of chronic NCDs including diabetes [30,34,35], cancer (chemotherapy symptom management) [31,37], asthma [33,39,40], cognitive and communicative disabilities [32], chronic self-harm [38], and ADHD [41]. No studies were identified that specifically examined persistent musculoskeletal pain.

Complementary perspectives on the use of mHealth technologies to enable young people's management of NCDs were evident for a number of themes and subthemes. These included codesign of mHealth technologies; functional and technical aspects of mHealth technologies that were person-centered and which aligned with young people's current technology use (habits, routines, and preferences); and which supported the delivery of clinical care and positive behavior change. The benefits of mHealth use were uniquely perceived by end users (young people) as empowering them to more independently manage their chronic health conditions.

**Figure 2.** A representation of the review findings is mapped against relevant elements of the Holistic Framework and applied here as a theoretical underpinning to guide our discussion. Themed categories for end users are represented above the blue line and implementers below. Implementation phases are represented by the central blue line, which indicates a left to right movement showing the continuous and iterative cycles of mobile health (mHealth) development. This includes phases from predevelopment (enquiry or value specification), to design and implementation (operationalization), with formative feedback guiding iterations of mHealth technologies. Note, both complementary and unique user perspectives are evident.



Implementers (specifically clinicians) perceived a great benefit in mHealth affording access to clinical data during consultations and as an enabler to support person-centered clinical encounters. Barriers to the uptake or adoption of mHealth technologies were uniquely identified by implementers as representing “whole of system” (multi-level) factors, including at the clinical level (micro factors), at the organizational level (meso factors), and at the systems level (macro factors). Implementers also identified the need for specific design considerations for mHealth apps for a vulnerable population.

These complementary and unique perspectives highlight both the interdependencies and complexities encountered by different users interacting with a rapidly evolving digital health ecosystem. To interpret our findings and make meaningful recommendations for policy and practice, the use of a design and implementation framework that is plural and pragmatic helps to address such complex interdependencies between human characteristics (users), digital technologies, and health systems. **Figure 2** shows the application of such a framework to our synthesized findings (darker shading indicates themes and lighter shading, subthemes) [69]. This Holistic Framework developed by van Gemert-Pijnen and colleagues [69] has been widely used to guide the design and implementation of eHealth technologies in chronic care management [16]. The framework allows for an inherently fluid, iterative, and cyclical nature of design, implementation, and evaluation of digital technologies. We focused on key domains relevant to our findings (contextual enquiry and value specification, design and implementation [operationalization]) [69]. Given the significant overlap between

contextual enquiry and value specification in our data, these were collapsed into a single domain.

### Complementary Users’ Perspectives on the Importance of Codesign

Codesign emerged for all users as a fundamental design principle and enabler to the uptake of mHealth technologies. The triangulation between user group perspectives is reflected in the mirroring of themes on codesign, as shown in **Figure 2**. These complementary perspectives related to (1) the “contextual enquiry and value specification” domain and (2) the “design” domain. For this reason, codesign is shown in **Figure 2** as overlapping both these domains. A formative evaluation loop guides iterations to mHealth technologies during this developmental phase; a step also identified in the primary studies as an important component of mHealth development. Involving end users and other stakeholder user-groups was perceived as critical to ensuring a clear understanding of (1) what the end user wants and needs to best support their self-management (user-friendly, acceptable, meaningful, and safe) and (2) how mHealth technologies could be optimized to meet person-centered needs and support behavior change. Using participatory models of codesign to jointly develop digital technologies that is meaningful to end users, aligns with current recommendations for development and implementation of digital technologies [16,18,69]. In a recent study published outside of our search dates, user-centered codesign principles were effectively applied to improve usability (easy to use, easy to

understand, efficient to complete, and acceptable) of a real-time mHealth app for adolescents self-managing cancer pain [14].

Clarity was also deemed important by users around identifying who the required stakeholders would be, what specific roles they would undertake, and at what stages they would be needed. These findings are consistent with recommendations from a recent systematic review of mHealth for NCD management indicating a need for explicit identification of relevant stakeholders as a mechanism to help make sense of eHealth systems for users, to specify mHealth purposes and benefits, and to establish their value, including identifying factors promoting or inhibiting engagement and participation [70].

Contextual enquiry allows for identification of factors relevant to guiding mHealth design that is acceptable and feasible for end users; a theme that emerged from users reported in the primary studies in our review and more widely reported by others as a critical design factor [1,70,71]. Contextual factors from our review included value specifications such as the intended use of technology (self-management), the nature of the condition (eg, NCDs, disease status, and level of impairment), the target population (young people), functional requirements (eg, monitoring, medication titration, tracking, decision-support, goal-setting, and cocare), and the care setting (eg, home, school, work, and hospital). Similar factors have been identified in recent systematic reviews of mHealth technology use in NCDs [1,18,27]. Implementers' values were further reflected in their perspectives on the importance of the tailoring capabilities of mHealth to meet end users' specific condition needs. Organizational needs did not emerge in this review as a key codesign value specification, although contemporary guidance on mHealth technology would suggest this is a critical preimplementation factor [67,69].

### Users' Perspectives on the Importance of mHealth Design Characteristics

Emerging evidence supports use of mHealth for self-management to facilitate clinical interactions and to encourage positive health behaviors [16]. To promote use and adherence, mHealth design needs to reflect meaningful functionality for end users [1,4,15,27] and to make sense within the context of their daily lives [16]. Our findings support these recommendations with mHealth functionality identified as a critical design factor by both user groups (Figure 2).

End users' perceived functional characteristics of mHealth technologies as helping their self-management adherence, including self-tracking, condition self-monitoring (condition status and medication), self-observations providing for early warning of condition flare-ups, self-reflection, improving their understanding of their condition, and providing reassurance by facilitating contact with their health professionals. Implementers' perspectives similarly recognized meaningful functionalities could assist adherence by leveraging off young people's habitual use of mHealth technologies. Functionality that extended reach to young people in remote settings, or to those with low accessibility was also perceived by implementers as important; an issue highlighted by us in a study of the gaps and needs of young people with persistent musculoskeletal pain [2] and

consistent with health policy in nations with large care disparity gaps created by geography, such as Australia and Canada.

Functionality characteristics that enabled person-centered care was identified by both user groups as important, including features that focused end users on their condition status and helped them prepare for clinical encounters. From the implementer perspective, technical capabilities were perceived as enablers to supporting their delivery of clinical care. While protecting patient privacy, similar technical capabilities that supported person-centered care by facilitating bilateral communication and which helped the end user focus on the purpose of the clinical encounter were perceived as important. Consistent with these findings, systematic review-level evidence indicates that person-centered care is a key enabler to adoption and adherence of mHealth technologies for self-management [16,18]. This person-centered focus is also central to recommendations from contemporary health policy across all settings and economies [67,68].

Implementers described mHealth technologies as helpful in supporting behavior change for young people with NCDs. For example, through sustained engagement of young people by monitoring of their health condition and by providing positive feedback as reinforcement for behavior change. Here, mHealth technologies may be utilized as a catalytic tool for driving sustainable management of NCDs [67,68]. However, perceptions and actual outcomes around behavioral change do not necessarily align. More effort and focus is required to understand how mHealth technologies can be used to effect meaningful, sustained behavior change [27,72]. This emerging area requires more than pilot or feasibility studies, arguing for more appropriately designed trials, longer term evaluation, and real-world, population-based health monitoring [68,69,73].

### Users' Perspectives on mHealth Technology Implementation Challenges and Solutions

Technical issues associated with real-world use of mHealth technologies impact usability and wider acceptance (end users), scaling-up, and sustainable implementation (implementers; Figure 2). The need to address recognized technical issues and to optimize mHealth technologies in the "readiness" phase of implementation highlights the critical role for rapid, continuous cycles of evaluation (formative and summative evaluation). Linking design refinements to improve end user experience and to help drive adoption and uptake (ie, implementation "success") emerged as important for both user groups in our review. Judging "readiness" and "success" can help mitigate against implementation challenges, and we have derived such a system-level framework that is described comprehensively elsewhere [23].

From the end user perspective, mHealth apps that are readily accessible and downloadable onto young people's current mobile devices is an example of one such "readiness" lever [2,8], especially if apps align with end users' habitual routines [16]. Implementers also highlighted the need for accurate disease monitoring and task-specific capabilities to support young people with unique NCD requirements. These perspectives again emphasize the importance of upstream "readiness" contextual enquiry and value specification as integral to effective

codesign and to supporting successful downstream implementation efforts [23].

Although contemporary health policy reform agendas articulate the need for innovative use of mHealth for NCD management [7,26,74], currently, very limited processes and frameworks exist to guide the development and implementation [17,18,75,76]. This challenge resonates with the findings of our review. Many studies consisted of pilot projects or small-scale implementations with evidence of feasibility and acceptability (as per their study aims), however, without extensive consideration of the implementation frameworks needed for building scale. Even with the application of theoretical frameworks to mHealth technologies to gauge scalability (eg, the use of normalization process theory; person-centered design and participatory methods of intervention development), significant barriers to implementation can still stymie uptake [38]. These same mHealth technology implementation challenges are articulated in reviews of older populations with NCDs [18,72]. In the latter review by Matthew-Maich and colleagues [18], successful implementation of mHealth required addressing factors across the whole of health systems. Our review found similar “whole of system” factors, including at the *micro* level (technical factors); at the *meso* level (organizational, culture, climate, environment, health workforce needs, work flow disruption, technophobia, natural fit for population and health condition, and funding models); and at the *macro* level (regulatory frameworks, governance, and flexibility; **Figure 2**). These multilevel barriers emphasize the critical importance of taking a system-wide approach to supporting implementation (for comprehensive reviews on implementation, see Briggs et al) [77,78]. Such an approach involves the systematic identification of “readiness” for implementation, as well as postimplementation evaluation of “success” [23]. This approach aligns well with the Holistic Framework we have adopted here for the specific embedding of mHealth technologies within complex health ecosystems [16].

## Moving mHealth From Promise Into Policy and Practice

It is hard to see a future without mHealth technologies as a complement to a rapidly evolving health care ecosystem. Digital disruption is here. Rather than focusing on barriers and challenges, perhaps we need to seek opportunities for embedding of mHealth within existing health systems where evidence for effectiveness is already well established (eg, self-management) [16]. Further value may be derived from identifying where in health systems, health services, and clinical populations or interfaces potential synergies can be identified that provide a natural “fit” for implementing and building scale in mHealth use [72]. Here, mHealth can be viewed as a catalytic tool implemented to strengthen health systems [67,79]. In lower and middle-income countries, factors such as a lack of infrastructure, health workforces, resources, and regulatory frameworks have already driven innovative mHealth solutions; for example, using partnerships arrangements and modifications of existing mHealth technologies that can be readily and sustainably implemented [8]. Implementation guidance and enabling strategies to support mHealth initiatives more broadly is

available, for example, in the mHealth assessment and planning for scale toolkit [67].

Beyond implementation, ongoing evaluation and monitoring of mobile and other digital health interventions is deemed critical to inform health policy and practice [80,81]. The World Health Organization provides guidance in this regard from the collective learning of 5 years of engagement with various international lead agencies working to strengthen their digital health deployments, develop robust evaluations, and scale up their activities nationally and regionally [68].

## Strengths and Limitations

The Holistic Framework adopted to underpin the interpretation of our review findings is based on extensive research on the uptake and impact of eHealth technologies and on models for development, implementation, and evaluation [69]. The Framework also provides a level of construct validity to our findings. Whereas consideration was given to alternate implementation frameworks [13] such as the Consolidated Framework for Implementation Research [82], technology acceptance model [83], and normalization process theory [70], none of these frameworks better satisfied the need for both an integrated whole of system approach and one specifically validated for eHealth applications.

The number of studies in this review provided sufficient data to interrogate our review questions and represented both end users and implementers. The yield was not sufficient, however, to enable meaningful sensitivity analyses to be undertaken based on criteria such as study quality, diseases, settings, or credibility of findings. Most studies used mHealth apps to support self-management and comanagement of young people with NCDs. End users included young people in our age range of interest; however, most were focused at the younger end of this range. Generalizability to other cultures and contexts was limited by the small samples and by cultural and socioeconomic specificity. Our results may not be transferable to low and middle-income economies despite almost ubiquitous use of mobile phones. This represents a critical area of research need given the widespread use of mobile technologies in such global settings and the urgent need to address NCDs through health information and health connectivity at scale [84,85]. Implementers were broadly representative of the whole of system; however, health policy makers were not explicitly identified. Although we did not include parents as implementers specifically in our search, for two [36,41] of three possible studies that included parents, their perspectives were captured within pooled implementer data. Explicit parent perspectives may provide important additional insights especially for the younger end of our age range of interest. Data on experiences and perspectives about actual or potential risk and harm associated with use of mHealth technologies were limited, although these are very important factors to consider [86].

Most studies were of short duration, posing challenges for exploring implementation effectiveness and limiting long-term evaluation of outcomes. The quality of studies was variable, and the use of reporting standards for qualitative research (such as the Consolidated Criteria for Reporting Qualitative Research) [87] was inconsistent, possibly suggesting a high risk of bias.

This raises issues of confidence about internal validity and trustworthiness, making the data extraction, interpretation, and the confidence in evidence more complex. The confidence of reported findings could be readily addressed with the use of a reporting system such as Confidence in the Evidence from Reviews of Qualitative Research [88]. Another quality indicator that was insufficiently met for most studies was the positioning of the researcher within the research, arguing again for improved reporting against standards. Some studies also provided secondary data interpretation without explicit quotations to support their interpretation, suggesting potential researcher bias. Study designs that better align with the rapid evolution of mHealth technologies are required as randomized trials are expensive, slow, and do not accommodate the dynamic nature of digital technologies, issues also highlighted by others [15,73].

## Conclusions

Our evidence meta-synthesis revealed both complementary and unique user perspectives on enablers and barriers to designing,

developing, and implementing mHealth technologies to support young people's management of chronic NCDs. mHealth technologies should be considered as a tool to enable self-management, to improve clinical encounters, and to encourage positive health behaviors. Developing mHealth technologies should involve a genuinely collaborative codesign process between end users and implementers, with the capacity to tailor and adapt technologies to meet person-centered needs. This approach will help to ensure meaningful mHealth solutions for young people, while also supporting implementation efforts. Whole-of-system readiness to adopt mHealth technologies must be considered if implementation initiatives are to be successful and sustainable. Continuous cycles of improvement are needed to maintain technical and functional optimization, ensuring that mHealth solutions remain relevant to young people. The use of contemporary frameworks that support digital health monitoring and provide evaluation guidance is advisable.

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## Authors' Contributions

HS, JC, JS, and AMB devised the review. JC and HS screened the papers for inclusion. JC extracted data, and HS confirmed congruence. JC and HS appraised the quality of the papers. JC, HS, and AMB developed categorical themes through an inductive analysis. JC, HS, MB, and AMB reflected on and interpreted the categorical themes to develop new themes and apply a meta-synthesis to inform declarative statements that could be applied as an evidence-base. JS provided external validation of the reporting framework. All the authors (HS, JC, JS, MB, and AMB) provided input to policy and practice recommendations and contributed to drafting, revisions, and final manuscript development.

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Preferred reporting items for systematic reviews and meta-analyses (PRISMA) checklist.

[[PDF File \(Adobe PDF File\), 66KB - jmir\\_v19i12e406\\_app1.pdf](#)]

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## Multimedia Appendix 2

Enhancing transparency in reporting the synthesis of qualitative research (ENTREQ) checklist.

[[PDF File \(Adobe PDF File\), 45KB - jmir\\_v19i12e406\\_app2.pdf](#)]

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## Multimedia Appendix 3

Search strategy.

[[PDF File \(Adobe PDF File\), 54KB - jmir\\_v19i12e406\\_app3.pdf](#)]

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## Multimedia Appendix 4

Themed categories for end users' experiences of mHealth technologies.

[[PDF File \(Adobe PDF File\), 67KB - jmir\\_v19i12e406\\_app4.pdf](#)]

## Multimedia Appendix 5

Themed categories for implementers' experiences of mHealth technologies.

[[PDF File \(Adobe PDF File\), 67KB - jmir\\_v19i12e406\\_app5.pdf](#)]

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## Abbreviations

**ADHD:** attention deficit hyperactivity disorder

**eHealth:** electronic health

**JKI-QARI:** Joanna Briggs Institute, Meta-Analysis of Statistics Assessment and Review Instrument

**mHealth:** mobile health

**NCD:** noncommunicable disease

**SMS:** short message service

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Original Paper

# Estimation of Symptom Severity During Chemotherapy From Passively Sensed Data: Exploratory Study

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## Abstract

**Background:** Physical and psychological symptoms are common during chemotherapy in cancer patients, and real-time monitoring of these symptoms can improve patient outcomes. Sensors embedded in mobile phones and wearable activity trackers could be potentially useful in monitoring symptoms passively, with minimal patient burden.

**Objective:** The aim of this study was to explore whether passively sensed mobile phone and Fitbit data could be used to estimate daily symptom burden during chemotherapy.

**Methods:** A total of 14 patients undergoing chemotherapy for gastrointestinal cancer participated in the 4-week study. Participants carried an Android phone and wore a Fitbit device for the duration of the study and also completed daily severity ratings of 12 common symptoms. Symptom severity ratings were summed to create a total symptom burden score for each day, and ratings were centered on individual patient means and categorized into low, average, and high symptom burden days. Day-level features were extracted from raw mobile phone sensor and Fitbit data and included features reflecting mobility and activity, sleep, phone usage (eg, duration of interaction with phone and apps), and communication (eg, number of incoming and outgoing calls and messages). We used a rotation random forests classifier with cross-validation and resampling with replacement to evaluate population and individual model performance and correlation-based feature subset selection to select nonredundant features with the best predictive ability.

**Results:** Across 295 days of data with both symptom and sensor data, a number of mobile phone and Fitbit features were correlated with patient-reported symptom burden scores. We achieved an accuracy of 88.1% for our population model. The subset of features with the best accuracy included sedentary behavior as the most frequent activity, fewer minutes in light physical activity, less variable and average acceleration of the phone, and longer screen-on time and interactions with apps on the phone. Mobile phone features had better predictive ability than Fitbit features. Accuracy of individual models ranged from 78.1% to 100% (mean 88.4%), and subsets of relevant features varied across participants.

**Conclusions:** Passive sensor data, including mobile phone accelerometer and usage and Fitbit-assessed activity and sleep, were related to daily symptom burden during chemotherapy. These findings highlight opportunities for long-term monitoring of cancer patients during chemotherapy with minimal patient burden as well as real-time adaptive interventions aimed at early management of worsening or severe symptoms.

**KEYWORDS**

patient reported outcome measures; cancer; mobile health

## Introduction

Cancer patients commonly experience a range of both physical and psychological symptoms during treatment. Overall, 60% to 90% of cancer patients endorsed moderate to severe fatigue, 41% to 50% endorsed disturbed sleep, and 38% reported significant distress, with the greatest symptom burden reported by patients undergoing chemotherapy [1,2]. Timely identification and management of these symptoms can preserve patient quality of life, functional status, and other outcomes of great importance to patients and their families. During outpatient treatment, such as chemotherapy, remote real-time monitoring of symptoms can enhance patient-provider communication and prevent potentially life-threatening adverse effects [3,4]. A recent paper reported that electronically monitoring patient-reported symptoms during cancer treatment prolonged patient survival, possibly because earlier clinical management of symptoms permitted patients to tolerate life-prolonging chemotherapy for longer [5].

Mobile devices such as mobile phones are becoming ubiquitous, with 77% of American adults reporting that they own a mobile phone [6]. A growing number of studies have examined the potential value of mobile or Web-based systems for patient reporting of symptoms [7]. Some of these systems include alerts to clinicians if patient-reported symptoms exceed a certain severity threshold [8,9] or tailored self-management support triggered by reported symptoms [10]. Although patient-reported symptom data are valuable, long-term monitoring of patient-reported symptoms (eg, over months or years of chemotherapy) is burdensome, and patients become significantly less compliant at recording daily symptoms over time [11].

Mobile phones are equipped with a suite of sensors that could be used to passively sense behavior associated with fluctuating symptom severity. Such passive detection of symptom severity in real time could permit earlier identification of worsening side effects and improve clinical management of symptoms and patient quality of life. Although this approach has not yet been tested in cancer patients or to detect fluctuations in patient-reported physical symptoms, several recent papers have reported associations between features such as mobile phone usage duration and location and patient-reported measures of depression [12-14] and sleep disturbance [15].

The aim of this study was to determine whether mobile phone and wearable sensor data could be used to estimate daily symptom burden during chemotherapy. We sought to extend previous work in three ways. First, we focused on patients undergoing outpatient chemotherapy treatment, a group that is likely to be older, less comfortable with technology, and more physically ill than samples of undergraduates [14] and young adults [13] in which mobile phone sensors have previously been linked to depressive symptoms. Second, we examined daily burden of psychological (eg, sadness and anxiety) as well as

physical (eg, loss of appetite and pain) symptoms as both are likely to affect quality of life, behavior, and functioning. Finally, we considered embedded mobile phone sensors as well as a commercial activity monitor designed to track daily activity and sleep. We defined behavioral features based on both mobile phone and wearable sensors and used these features to estimate daily patient-reported symptom severity.

## Methods

### Participants

Potential patients were identified for the study by their oncologists. Men and women aged 18 years and above who had been diagnosed with gastrointestinal cancer and were currently receiving chemotherapy were eligible for this 4-week study.

If eligible, participants were provided with an Android mobile phone (Motorola Droid Turbo) with an unlimited data plan for the duration of the study. Two participants already owned an Android phone, and these two participants' own devices were used. The AWARE framework was installed on the phone [16]. AWARE is designed to unobtrusively collect sensor data, including movement and approximate location of the phone, phone and app use, and call and short message service (SMS) events. The AWARE framework was also used to collect symptom ratings up to twice per day in the morning and evening. The AWARE framework stored this information on the device and transmitted deidentified data to a secure server over a secure network connection when the device was connected to Wi-Fi. Participants were asked to keep the phone charged and to carry the phone with them at all times, to give the phone number to their 10 most frequent contacts, and to use the phone for outgoing and incoming communication as much as possible.

Participants were also given a Fitbit Charge HR device to wear for the duration of the data collection, which they were invited to keep after study completion. The Fitbit device collected data including information about activity and sleep.

Participants' medical records were reviewed to extract demographic and clinical information, including age, sex, comorbidities, body mass index (BMI), and details of chemotherapy regimen. After study completion, participants returned the mobile phones to the study team, completed a brief interview about their experience with the study, and received compensation of US \$150. The University of Pittsburgh institutional review board approved all study procedures.

### Patient-Reported Measures

Daily symptom ratings were based on a modified MD Anderson Symptom Inventory [17]. Participants were asked to rate the severity of each symptom "right now" from 0 (not present) to 10 (as bad as you can imagine it could be) using the mobile phone app. Symptoms included pain, fatigue, feeling disconnected from others, trouble concentrating or remembering things, feeling sad or down, feeling anxious or worried, not

enjoying things, feeling irritable, shortness of breath, numbness or tingling, nausea, and poor appetite. Patients were given an opportunity to rate symptoms each morning and evening at times scheduled to be convenient to the patient. For analyses, mean daily severity was computed for each symptom and all 12 symptoms were summed to create a composite reflecting total daily symptom burden (mean 15.90, range 0-117). Total daily symptom burden scores were examined as continuous values for correlation analysis. For classification models, we categorized each day as higher than average symptoms, average symptoms, or lower than average symptoms for that particular patient. To do so, we first calculated the mean of daily summed symptoms for each patient (reflecting each individual's average daily symptom burden) and then subtracted individual means from each of that patient's daily symptom scores and categorized the resulting residual from each day into low (residual of daily mean-individual mean<0), normal (residual=0), and high (residual of daily mean-individual mean>0) symptom burdens. This approach allowed us to predict fluctuations in total symptom burden for each patient over the course of two chemotherapy cycles, adjusting for each individual's typical level of reported symptoms.

### Passive Data Collection and Processing

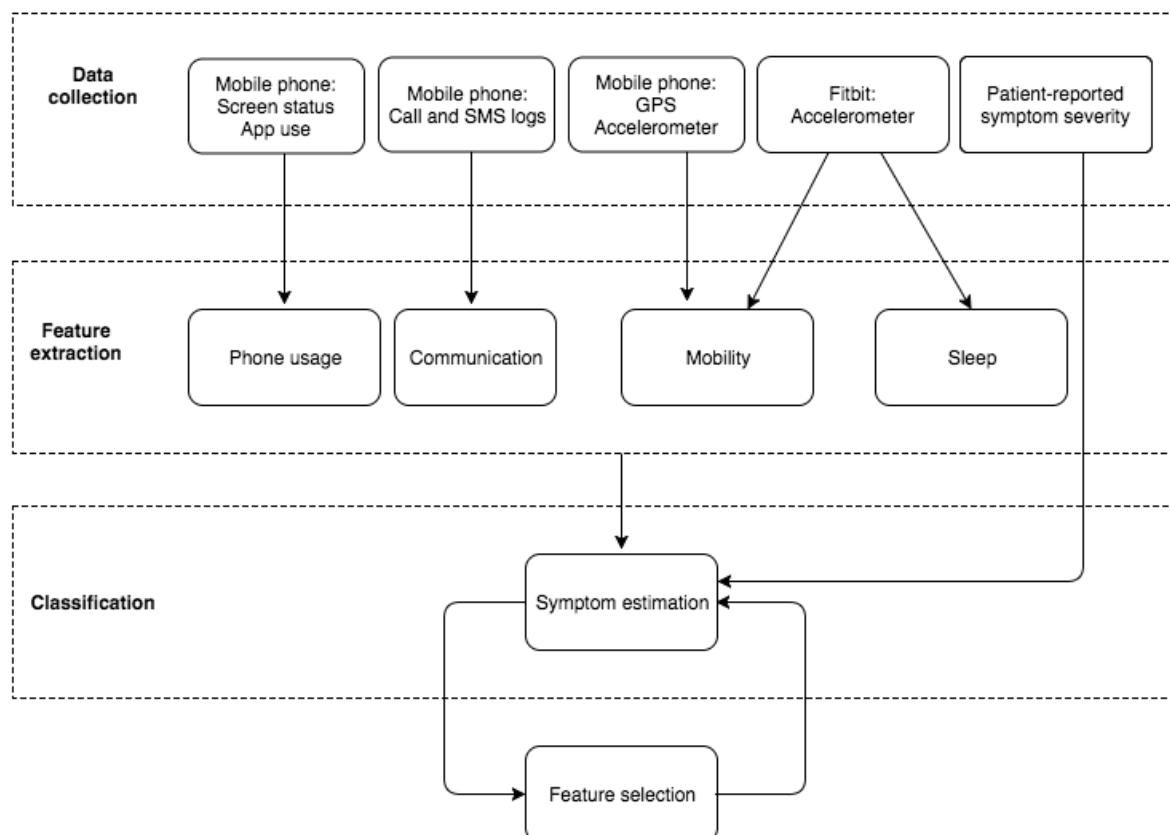
Figure 1 summarizes the methods for passive data collection, processing, and analyses. The data collected from Android phones and Fitbits were preprocessed on the server side to prepare for the feature extraction step, in which a wide variety of statistical features are calculated for the different passive data streams. We downloaded both raw (eg, minute-by-minute step

counts) and aggregated (eg, daily step count) data from the Fitbit cloud as available; raw data were not available for some patients because of technical issues when downloading data.

On the mobile phone side, we collected data from accelerometer (20 Hz), location (every 3 min), activities (every 1 min), event-based device usage (app type, duration of use, and screen lock/unlock time), and communication logs (calls and SMS). For location, AWARE integrates Google fused location application programming interface (API) that collects location data from multiple sources, including global positioning system (GPS) coordinates, Wi-Fi, and network providers. To optimize the battery life, the fused location module records location only if there is substantial movement and change in distance. Although this is beneficial in most situations, it could result in missing location data from participants in case of limited mobility. Physical activity is also acquired using Google activity recognition API that extracts basic activities such as idle/not moving, tilting, on foot, on bicycle, and in vehicle in a battery-efficient way.

Despite careful considerations regarding instrumentation and patient guidance during recruitment, a few challenges affected the data collection and quality. For example, only a few patients accurately entered their weight on the Fitbit dashboard, which affected the aggregated report of burned calories. Technical issues while downloading data from the cloud also caused the majority of heart rate data as well as raw data for some patients to be missing. Therefore, Fitbit data related to heart rate and calories were removed from the analysis, and available Fitbit features varied across participants.

**Figure 1.** Data collection and analyses methods. (GPS: global positioning system).



## Feature Extraction

We computed daily (24 hours from midnight to midnight) behavioral features related to mobility and physical activity, communication, phone usage, and sleep from both mobile phone sensors and Fitbit devices (see [Table 1](#)). The following sections describe the extraction process for each feature category.

### Mobility and Activity Features

Mobility and activity features were extracted from the phone's location and activity data as well as the Fitbit's accelerometer that calculates distance and steps. These features are expected to indicate the severity of symptoms in patients, as both depressive and physical symptoms might limit patients' daily activity and movement. From the GPS coordinates, we extracted the locations patients spend most time at during the day, number of unique locations, location entropy, and travel distance in meters. We used hierarchical DB-SCAN [18], an efficient clustering algorithm, to identify unique and frequent location clusters per day for each patient. These location clusters were then used to identify global locations across days. Global locations are the most significant location clusters among a user's frequent locations. Examples of global frequent locations are one's home or work address.

From activities extracted by the phone's activity recognition module, we calculated number of activities during the day, the most common activity (eg, sedentary), and number of changes in activities. The raw accelerometer data provides fine-grained movements from which we extracted magnitude features including minimum (min), maximum (max), mean, median magnitude, and standard deviation (SD) of magnitude of acceleration of the phone per day.

The Fitbit step count feature is also useful in estimating movement and activity level of patients. In addition to summary features about total daily steps, distance, and floors climbed, we extracted features from minute-level data provided by the

Fitbit API. These additional features included maximum number of steps per minute; number and length of sedentary bouts, that is, continuous chunks of time where 0 steps were taken; as well as number and length of active bouts, that is, continuous chunks of time where at least 1 step was taken as well as the number of steps taken in each bout.

### Sleep Features

Sleep quality and duration is a significant indicator of physical and mental health. Summary sleep features provided by Fitbit include duration of sleep, minutes awake, number of awakenings, and total time in bed.

### Phone Usage Features

Patterns of phone usage have been shown to correlate with self-reported depressive symptoms in young adults [13]. In our study, we hypothesized that change in phone usage is indicative of change in severity of psychological and physical symptoms. AWARE collects the state of screen (on or off) and the app history from the phone. From this data, we extracted the number, type, and duration of apps being used; the number of unique apps; number of changes in apps; the number of times the screen is on or off; and the duration of interaction with the phone as well as duration of battery charges.

### Communication Features

Communication activities reflecting social behavior may be affected by symptom severity [19]. We, therefore, extracted communication features from calls and SMS logs collected on the phone, including the number and duration of incoming and outgoing calls and messages, the number of missed calls, the number of unique correspondents, and the most frequent contact number. As the numbers are hashed to preserve privacy, we can only quantify the frequency of calls by the same number without knowing the contact category the number belongs to, that is, whether the call is from a family member or a hospital.

**Table 1.** Extracted day-level features from each sensor stream.

Category	Source	Features
Mobility and activity	Phone activity recognition	Number of activities, most common activity, and number of activity changes
	Phone accelerometer	Mean, median, maximum, minimum, and SD <sup>a</sup> magnitude
	Phone GPS <sup>b</sup>	Most frequent locations, number of unique locations, time in most frequent location, location entropy, radius of gyration, and travel distance
	Fitbit activity	Total steps, distance, floors climbed, minutes lightly active, minutes fairly active, minutes very active, maximum steps per minute, number and (minimum, maximum, and average) length of sedentary bouts, and number and (minimum, maximum, and average) length of active bouts
Sleep	Fitbit sleep	Minutes asleep, minutes awake, number of awakenings, and minutes in bed
Phone usage	Phone and app usage	Total app use time, apps per minute, number of unique apps used, number of app changes, number of screen unlocks per minute, total duration interaction, and length of battery charge
Communication	Phone communication logs	Number and duration of incoming and outgoing calls and messages, number of missed calls, and number of unique correspondents and most frequent contact

<sup>a</sup>SD: standard deviation.

<sup>b</sup>GPS: global positioning system.

## Data Analyses

We first computed bivariate correlations between each continuous feature and daily symptom severity rating. The purpose of these preliminary analyses was to gain an understanding of the strength and directionality of the relationship between each feature and symptom burden.

## Classification

We defined inference of symptom severity from passive data as a multiclass classification problem where each data point (an aggregated day of data) is assigned a value from the set  $\{-1, 0, \text{ and } 1\}$  equivalent to low, normal, and high symptoms, respectively. We chose a meta-algorithm called rotation forests that uses random forests as the base learner. Random forests are an ensemble of decision tree classifiers with a random feature selection process that is iterated; in each iteration, an independent set of features is selected for the classification. Random forests are robust to errors, outliers, and overfitting. We chose the learning algorithm in an iterative and exploratory manner to test the performance of each learner on a subset of our dataset. The rotation forests with random forests as the base learner performed best on our sample dataset.

To prepare our training set and decrease class imbalance, we used resampling with replacement [20]. This method significantly increases the accuracy of the cross-validated results. We first used stratified cross-validation on the entire dataset including all patients to build a population model of symptom severity estimation. We then repeated the process using data from individual patients to measure the performance of the learning algorithm on estimating each individual patient's symptom severity.

Our focus in this study was to understand the value of passive data alone in inferring the severity of symptoms, that is, we intended to answer the following question: if our (smart) app only has access to passive data tracked from the patient's technology use, how well can it infer the subjective state of the patient as he or she undergoes outpatient cancer treatment?

## Feature Selection

Although all features may add learning weights and contribute to the overall performance of the algorithm, they may also have interdependencies and correlations that make their contribution redundant. In addition, given the technological and psychological challenges associated with data collection in cancer cases, it is important to identify a minimal and robust subsample of data that contributes most to the overall results. For example, if the same level of accuracy can be obtained from only activity-related features from the Fitbit, then the data collection process can be optimized to acquire better quality

data from the Fitbit, thus reducing the burden for both patients and developers.

## Results

### Participant Characteristics

A total of 14 patients were enrolled in the study between February 2016 and July 2016 (mean age 59.7 years, range 40-74, 43% female, BMI mean 27.44). In addition, 42% patients were receiving treatment for esophageal cancer, 21% colorectal, 14% gastric, 14% pancreatic, and 7% biliary cancer.

Participants provided symptom and mobile phone data for 7 to 35 days (mean 21.07 days). Three participants ended data collection early because of disease progression (n=1), stroke (n=1), and treatment schedule (n=1). Not all sensors recorded data for all patients owing to hardware and software issues, so the number of patients across analyses varies because of missing data. In addition, Fitbit data were not available for 5 patients because of data syncing issues. Overall, we collected 295 days of symptom and sensor data.

### Relationship Between Symptom Severity and Passively Sensed Data

Pearson correlation coefficients were computed between daily symptom severity scores and each feature using SPSS version 24 (IBM Corp, Armonk, NY). Table 2 shows all features that were significantly correlated with symptom burden. Greater symptom burden was associated with mobility features (including larger number of different activities detected, less overall and less variable acceleration of the phone, less physical activity, and more and longer sedentary behavior bouts), sleep features (both more sleep and more nocturnal awakenings), phone usage features (fewer apps and unlocks per minute and longer interactions with the phone), and fewer missed calls. Symptom burden was not significantly related to number of activity changes, minimum magnitude of phone accelerometer, location entropy, number of unique locations, radius of gyration, time in most frequent place, travel distance, Fitbit minutes lightly active, minimum sedentary or active bout length, maximum active bout length, minimum steps per active bout, app use duration, number of app changes, number of unique apps, duration of battery charge, number or duration of incoming calls or messages, number or duration of outgoing calls or messages, or number of phone correspondents.

### Estimation of Symptom Severity From Passive Data

#### Population Model Performance

The stratified cross-validation on the population dataset using the rotation random forests with resampling and all extracted features provides 88.1% accuracy.

**Table 2.** Correlations between symptom severity score and features.

Category and features	<i>r</i>	N	<i>P</i> value
<b>Mobility and activity</b>			
Number of activities	.21	206	.002
Maximum magnitude of accelerometer	-.22	220	.001
Mean magnitude of accelerometer	-.28	220	<.001
Median magnitude of accelerometer	-.24	220	<.001
SD of accelerometer	-.25	220	<.001
Fitbit steps	-.20	194	.007
Fitbit distance	-.19	165	.01
Fitbit floors	-.23	165	.003
Fitbit minutes fairly active	-.17	165	.03
Fitbit minutes very active	-.21	165	.006
Fitbit maximum steps per minute	-.57	65	<.001
Fitbit number of sedentary bouts	.52	65	<.001
Fitbit maximum length sedentary bout	.44	65	<.001
Fitbit mean length sedentary bout	.27	65	.03
Fitbit number active bouts	.52	65	<.001
Fitbit mean length active bout	-.29	65	.02
Fitbit maximum steps active bout	-.43	65	<.001
Fitbit mean step active bout	-.47	65	<.001
<b>Sleep</b>			
Fitbit minutes asleep	.33	141	<.001
Fitbit minutes awake	.23	141	.006
Fitbit number of awakenings	.29	141	<.001
Fitbit time in bed	.22	141	.008
<b>Phone usage</b>			
Apps per minute	-.18	269	.003
Duration of interaction with phone	.27	295	<.001
Screen unlocks per minute	-.19	295	.001
<b>Communication</b>			
Number of missed calls	-.22	98	.03

We also examined the value of features in classification by using the correlation-based feature subset selection [21] that computes the predictive ability of each feature along with the degree of redundancy between features. For the population model, the selected features included sedentary behavior as the most common activity during the day, app usage time, median and SD of acceleration, length of phone charge, time in frequent places, duration of phone usage, and the minutes lightly active. We repeated the classification using these 8 selected features only and obtained 87.1% accuracy, only 1% drop in the accuracy compared with using all features.

### Assessing the Value of Device-Specific Features

We were also interested in evaluating the performance of models built with data from each specific device (ie, Fitbit and phone)

to identify a minimal, robust, and least obtrusive set of data channels for data collection. Each analysis is done with all features (ie, all Fitbit or all phone features) first and is repeated with only selected features after feature selection is applied. As shown in Table 3, features extracted from the phone provided better accuracy than Fitbit alone (86.4% accuracy achieved using all phone-related features vs 77.6% accuracy obtained using Fitbit-related features). Interestingly, however, features in the phone activity category provided the highest accuracy of 88.5%, showing the impact of these feature categories in identifying symptom severity. These results are intuitive as mobility and movement are highly associated with symptom severity changes, for example, patients stay longer in bed if they do not feel well. The same level of accuracy is achieved

with features related to phone usage (eg, the duration of phone usage).

**Table 3.** Accuracy of models using only Fitbit or only mobile phone features.

Device and features	Accuracy (%)
<b>Fitbit (all features)</b>	77.6
Number of steps and minutes lightly active	76.9
<b>Phone (all features)</b>	86.4
App use time, SD <sup>a</sup> of accelerometer, length of phone charge, time in frequent places, and duration of phone usage	86.7
<b>Movement (all features)</b>	87.1
Most common activity, minimum acceleration, SD of accelerometer, radius of gyration, and time in frequent places	79.3
<b>Activity (all features)</b>	88.5
Most common activity, SD of accelerometer, and minimum acceleration	78
<b>Location (all features)</b>	63.4
Radius of gyration and time in frequent places	55.6
<b>Phone usage (all features)</b>	88.5
App use time, length of phone charge, and duration of phone usage	85.8
<b>Communication (all features)</b>	62.4
Most frequent contact number	53

<sup>a</sup>SD: standard deviation.

This observation is especially encouraging as phone usage is among the most robust and noise-free data to collect. Overall, findings suggest that future deployments could rely only on passively collected mobile phone sensors (using mobile phones that most patients own and use already) rather than a combination of mobile phone and wearable sensors.

#### Individual Models Performance

Because different mobile phone or Fitbit features may have variable values depending on each patient's pattern of use and because each patient had a different combination of sensor data

features available, we repeated leave-one-day-out cross-validation to measure the performance of the learning algorithm in inferring severity of symptoms using data from each individual patient (see Table 4). The algorithm, on average, achieves 88.4% accuracy with minimum accuracy of 78.1% (patient number 12) and maximum of 100% (patient number 1 and 11). This average increases to 91.1% when classification is repeated with the selected features. The overall accuracy depends on the number of days of data and variations in the symptom severity (the class value).

**Table 4.** Accuracy and selected features for individual models.

Patient	Number of days	Overall accuracy (%)	Accuracy with selected features (%)	Selected features included in the classification
P1	7	85.7	100	Duration of outgoing calls, number of unique phone correspondents, and number of outgoing calls
P2	27	92	96	Changes in activity, app use time, maximum magnitude of accelerometer, and SD <sup>a</sup> of accelerometer
P3	22	92.8	92.8	Maximum magnitude of accelerometer, minimum magnitude of accelerometer, minutes sedentary, and minutes lightly active
P4	15	93.3	86.6	Most common activity, number of app changes, maximum magnitude of accelerometer, and number of awakenings
P5	28	96.1	88.5	App use time, number of app changes, and duration of outgoing calls
P6	14	92.3	100	App use time, most frequent contact phone, number of incoming calls, steps, distance, floors, minutes lightly active, and minutes asleep
P7	16	78.6	85.7	Minutes awake, maximum number of steps, number of sedentary bouts, and average number of steps
P8	16	87.5	87.5	Number of apps per minute, maximum magnitude of acceleration, number of awakenings, and average length of sedentary bouts
P9	26	85	95	Number of activities, app use time, and duration of outgoing calls
P10	35	88.9	88.9	App use time, maximum magnitude of acceleration, mean magnitude of acceleration, number of steps, and minutes lightly active
P11	16	100	100	App use time, number of app changes, and maximum magnitude of acceleration
P12	23	78.1	84.4	Location entropy, number of unique locations, time in most frequent place, travel distance, and number of steps
P13	29	84.4	91.9	Number of activity changes, maximum magnitude of accelerometer, time in most frequent place, duration of interaction with phone, and Fitbit steps
P14	21	82.6	78.3	Time in most frequent locations and average length of sedentary bouts
Average	21	88.4	91.1	-

<sup>a</sup>SD: standard deviation.

## Discussion

### Principal Findings

This study reported on the potential of mobile phone and wearable sensor data to estimate patient-reported symptom severity during chemotherapy. Symptoms such as fatigue and sleep disturbance are experienced by the majority of patients receiving chemotherapy, and other symptoms such as nausea and pain are common and can fluctuate significantly during each chemotherapy cycle. We extracted a variety of day-level features from the mobile phone and Fitbit reflecting activity and mobility, communication, sleep, and phone usage patterns. Many of these features were significantly correlated with daily symptom burden scores. We then trained a classifier that was able to estimate whether patient-reported symptoms on a given day were relatively low, average, or high for that patient with a high degree of accuracy (88%) as well as good precision and recall. Feature selection revealed that the subset of features that produce the best accuracy in symptom estimation were sedentary behavior as the most common activity, fewer minutes lightly active, less overall and less variable phone accelerometer magnitude, and longer time using apps and the phone, and a

population model using only these selected passive features was 87% accurate in classifying high versus average versus low symptom days.

The finding that greater symptom severity was related to greater phone use duration is consistent with studies linking depressive symptoms and mobile phone use [13,22]. The inverse association between symptom severity and activity, whether measured by the mobile phone accelerometer or Fitbit, also echoes findings linking depressive symptoms to reduced mobility assessed using sensors [13]. Previous research using actigraphy during chemotherapy has reported inverse associations between fatigue and activity [23]. To our knowledge, this is the first study to relate mobile phone sensor features to symptom data in cancer patients.

Results of device-specific feature selection indicate that features from mobile phone sensors were more valuable in symptom estimation than Fitbit features. In particular, features related to mobility and activity and phone usage patterns yielded the most accurate models. This suggests that future passive sensing research focused on symptoms could consider relying only on the features derived from the phone accelerometer and GPS as well as information about duration of phone and app usage and

battery charges. Collecting data from these sensors requires no additional devices and tends to produce relatively noise-free data with minimal participant burden.

When data from individual patients were used to create patient-specific individual models using leave-one-day-out cross-validation, the accuracy and selected features varied considerably from 78% to 100% depending on how many days of data each patient had, whether certain features (eg, Fitbit steps) were available for that patient, and how much variability each patient had in the level of symptoms reported over the 4 weeks of the study. Results suggest that passive sensor data may be more useful in detecting symptom burden when symptoms are highly variable and that the relationship between certain sensor features (eg, duration of outgoing calls and duration of app use) and symptom burden will vary based on individual patients' patterns of behavior and technology use.

### Limitations

Results of this study should be considered very preliminary, and a number of limitations warrant mention. First, there were significant missing data because of both the nature of our acutely ill sample and software and hardware issues. The length of study was also limited to 4 weeks (ie, two chemotherapy cycles) to limit participant burden, which resulted in a relatively small dataset. Future research should consider following patients for a longer period of time, such as over several months or an entire course of chemotherapy. Second, most participants used a study mobile phone for data collection, so mobile phone sensor data may not have reflected personal mobile phone use patterns (eg, participants may not have carried the study mobile phone with them at all times or used it to make or receive calls as instructed). Third, we aggregated the severity of each patient-reported symptom to generate an overall symptom burden score for each day. Future research could examine

specific symptoms (eg, fatigue, pain, and cognitive difficulties) to determine whether distinct features estimate different symptoms. Future research could also examine whether passive features can predict symptom fluctuations within a day and whether the previous day or days of passive data can improve prediction of patient-reported symptoms. Finally, we reported the results that were obtained from only one classification method. Our choice was based on the high performance of this method on our sample dataset and the extracted features. However, the results may greatly vary with different data and feature sets.

### Conclusions

Despite these limitations, our findings highlight the feasibility of using ubiquitous mobile phone and wearable sensors to passively detect symptom burden during chemotherapy. Our preliminary findings suggest an approach for passively and accurately detecting severe or worsening symptoms during cancer treatment with minimal burden to patients or providers. Passively sensing fluctuating symptom burden could enable long-term remote monitoring of patients during outpatient cancer treatment and should be considered as a low-burden measurement of patient quality of life to add to clinical trials. Information about passively sensed symptom burden could be integrated into the electronic medical record or shared with the oncology care team. Passive detection of worsening physical and psychological symptoms also enables technology-supported just-in-time adaptive interventions aimed at symptom management. For example, when relatively increased (+1) levels of symptoms are detected, an alert could be automatically sent to the clinical care team or self-management instructions texted to patients. Such personalized real-time intervention could improve quality of life and the ability of patients to withstand life-prolonging cancer treatments.

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### Conflicts of Interest

None declared.

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## Abbreviations

**API:** application programming interface

**BMI:** body mass index

**GPS:** global positioning system

**SMS:** short message service

**SD:** standard deviation

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Original Paper

# Media Consumption and Creation in Attitudes Toward and Knowledge of Inflammatory Bowel Disease: Web-Based Survey

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## Abstract

**Background:** Inflammatory bowel disease (IBD) is a chronic gastrointestinal condition affecting over 5 million people globally and 1.6 million in the United States but currently lacks a precisely determined cause or cure. The range of symptoms IBD patients experience are often debilitating, and the societal stigmas associated with some such symptoms can further degrade their quality of life. Better understanding the nature of this public reproach then is a critical component for improving awareness campaigns and, ultimately, the experiences of IBD patients.

**Objective:** The objective of this study was to explore and assess the public's awareness and knowledge of IBD, as well as what relationship, if any, exists between the social stigma surrounding IBD, knowledge of the disease, and various media usage, including social media.

**Methods:** Utilizing a Web-based opt-in platform, we surveyed a nationally representative sample (n=1200) with demographics mirroring those of the US Census figures across baseline parameters. Using constructed indices based on factor analysis, we were able to build reliable measures of personal characteristics, media behaviors, and perceptions and knowledge of IBD.

**Results:** Among the American public, IBD is the most stigmatized of seven diseases, including genital herpes and human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS). Additionally, IBD knowledge is generally low with 11.08% (133/1200) of the sample indicating no familiarity with the disease and 85.50% (1026/1200) of participants inaccurately answering two-thirds of the IBD index questions with which their knowledge was assessed. Increased knowledge of IBD is associated with lower levels of stigma. However, social media use is currently related to lower levels of IBD knowledge ( $P<.05$ ). Furthermore, findings indicate that participants who most frequently engaged in producing social media content are less knowledgeable about IBD ( $P<.10$ ), highlighting the potential for a dangerous cycle should they be contributing to a Web-based IBD dialogue.

**Conclusions:** Greater efforts must be taken to stymie IBD misinformation across all media, but especially in social media channels, to increase IBD knowledge and reduce stigma surrounding IBD. These findings pave the way for further research qualitatively examining the pervasiveness of specific IBD messages found in today's social media landscape and their impact on enacted stigmas so as to better equip providers and patient advocacy organizations with impactful communication solutions.

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**KEYWORDS**

inflammatory bowel disease; social media; health communication; social stigma

## Introduction

### The Social Stigma Challenge for Inflammatory Bowel Disease Patients

Inflammatory bowel disease (IBD) is a complicated and often debilitating disease with a variety of effects on the quality of life of patients. There are currently 5 million IBD patients worldwide. The symptoms of Crohn's disease (CD) and ulcerative colitis (UC)—both of which are categorized under IBD—are often felt by sufferers to be embarrassing and disabling, and indeed the majority of patients with IBD report perceived stigma [1]. Perceived stigma is defined as the degree to which an individual comprehends a social stereotype to be against them [1]. Other forms of health-related stigma include enacted stigma (actual societal discrimination toward an individual) and internalized stigma (the extent to which the stigmatized individual actually believes in the social stereotype) [2]. Although embarrassment associated with IBD symptoms can, in some cases, lead to isolation, fear of being in public, and ostracization for patients, the stigma experienced by IBD patients has not been studied extensively. Given that, this study examines enacted stigma as it relates to IBD knowledge and different forms of media use on a nationally representative basis.

### Medical Conditions and Media Coverage—An Overview of Inflammatory Bowel Disease

Over the past decade, numerous health care and patient-related organizations have amplified the effort to increase awareness and reduce stigma of this chronic disease. World IBD Day is celebrated each year on May 19 in 36 countries to raise awareness of this disease, and the Crohn's and Colitis Foundation (CCF) supports a range of informational events such as runs/walks, fashion shows, and education days. The CCF also maintains an active media presence on the Web in the form of interactive tutorials, webcasts, and social media to educate patients and clinicians on the recognition, diagnosis, and management of IBD.

At the same time, there is an increased use of social networking sites (SNS) for news and information among the general public. A Pew report found that social media platforms, namely, Facebook but also Twitter, now represent principal media sources for many individuals across age cohorts in the United States [3]. This study, therefore, builds on previous research on technology and health communication [4] by beginning to examine attitudes held by the general American public, how those attitudes relate to IBD knowledge, and specifically looks at different forms of Web-based media use as explanatory factors.

Although previous studies have explored IBD content and users on Twitter [5,6], there are no known studies that have explicitly examined the consumption of social media as well as the creation and sharing of content by users in these Web-based platforms with regard to how they contribute to IBD attitudes and knowledge. Similar studies on other medical conditions, such as antimicrobial resistance, have found that awareness is not only the product of exposure to certain media but is also related to personal experience and discussion [7,8].

We, therefore, incorporate these aspects within a theoretical framework of information exchange and social ties that are commonplace on the Web [9] to build a more well-developed communications perspective on a medical issue that is understudied in general but especially in terms of public attitudes and knowledge in an emerging media environment.

### Communicating IBD in a Public Health Framework and Emerging Media Environment

In the contemporary media environment, access to medical information is abundant and ubiquitous via the Internet and social media, and informational outlets that focus on diseases such as IBD have expanded to new arenas. Through mobile social media interfaces, it is possible for patients, doctors, researchers, friends, family, and even pharmaceutical companies to share information and foster discussion [10].

Within the medical community, the social media phenomenon represents an innovative and potentially transformative frontier in patient communication and the delivery of health information. The ways in which patients utilize social media, including YouTube, Facebook, and Twitter, among other platforms such as blogs and wikis, for assessing medical knowledge as it pertains to their own personal health are poorly understood and therefore of concern to medical and support personnel [5,11]. Some earlier work has suggested that Web-based communication may be especially effective in creating an egalitarian space to discuss and debate issues and to connect to others for the purpose of emotional support [12-14].

Indeed, although investigators such as Garrett [15] have argued that users posting inaccurate content may augment nonfactual information to spread widely and negatively shape attitudes, he nonetheless maintains that the Internet broadly acts as a mechanism to counteract and constrain the intentional efforts of users to propagate misinformation. Specifically, at an individual level, Garrett [15] points to how users may be disincentivized to publicly post information to social media that may not be accurate precisely because they are afraid of being proven wrong or accused of lying by other users who are experts in the area. In medical areas other than IBD, there are a number of cases where the Internet and social media have shown a positive relation to increasing public health awareness such as food recalls and related health risks [16,17]. In these cases, the public's role in spreading news of outbreaks has been essential to the success of such information-driven campaigns.

However, other studies such as the work of Oh and colleagues [18] have found that rumors and misinformation can be exacerbated on social media, even in crisis situations or widespread health risks such as the Ebola or Zika virus. Similarly, findings from Grant and colleagues [19] indicate that interactive media can publicly undermine established medical knowledge by facilitating user-generated content that presents a compelling personal framework not rooted in fact or evidence. At this stage, there is a notable tension in the extant research where findings are not conclusive and may be specific to situation, media, or topic. As one example, a recent study by Groshek and colleagues [8] found that individuals who created and shared Web-based media were increasingly likely to be misinformed about antimicrobial resistance (AMR), as were

more frequent consumers of traditional media, but that those consuming more Web-based information actually had a decreased likelihood of being misinformed about AMR. The only media factor that directly related to an increased likelihood of misusing antibiotics or other AMR-related products was consuming traditional media more frequently.

Considering this background as a whole, as well as taking into account the exploratory nature of this particular work on a disease that has no known cause or cure, and the way it is being introduced and received by the general public, this study thus proposes the following research questions (RQs):

- RQ1: How aware is the general public of IBD and what are the features of the social stigma surrounding IBD?
- RQ2: How knowledgeable is the general public regarding IBD and how does that knowledge vary across social groups?
- RQ3: How do different forms of media consumption and creation relate to the knowledge of IBD?
- RQ4: What relationship exists between the social stigma surrounding IBD, knowledge of the disease, and various media uses?

## Methods

This study included a sample of 1200 opt-in panel respondents through the Web-based survey company, Qualtrics. The demographics of this sample follow those of the US Census figures across baseline parameters. Specifically, 51.00% (612/1200) of respondents were female and the median age was 47 years with a mean of 46.12 (standard deviation, SD=16.70). By age cohorts, 11.75% (141/1200) were aged between 18 and 24 years, 36.25% (435/1200) between 25 and 44 years, 35.00% (420/1200) between 45 and 64 years, and 17.00% (204/1200) were 65 years and older, and in terms of ethnic groups, 74.08% (889/1200) of all respondents were white, 8.92% (107/1200) were African American, 9.25% (111/1200) were Hispanic or Latino, 5.58% (67/1200) were Asian, and a combined 2.17% (26/1200) indicated being either Native American, Pacific Islanders, or of other ethnic background.

Again, in maintaining a relatively close match to the general figures from the census, in terms of household income, there were 26.16% (313/1200) of respondents that earned US \$24,999 or less, 28.67% (345/1200) made between US \$25,000 and \$49,999, 31.83% (382/1200) were in the US \$50,000 to \$99,999 income group, and 13.33% (160/1200) reported earning US \$100,000 or more. Formal education levels showed that there were just 1.50% (18/1200) of respondents who did not graduate from high school or equivalent, 22.25% (267/1200) earned a high school diploma or General Educational Development (GED), there were 26.75% (321/1200) of respondents with some college education completed, 11.25% (135/1200) held a 2-year college degree, 28.08% (337/1200) graduated from a 4-year college, and 10.16% (122/1200) had earned some type of graduate degree such as an MBA, PhD, or JD, which also generally approximated the distributions of all Americans from the last census.

This study also constructed indices based on factor analyses to build reliable measures of concepts. For this block, all items were based on 1 to 10 scales of *very low* to *very high* responses that measured respondents' feelings of social isolation (three items; Cronbach alpha=.881), overall life satisfaction (three items; Cronbach alpha=.770), and general trust in others (two items; Cronbach alpha=.817). There were another two statements that measured fatalism, which is a construct of the belief that individuals lack control to determine their future and that fate dictates one's life (Cronbach alpha=.758). All of these indices were from a series of already validated instruments for each construct [20,21] and assist in developing parameters of control for subsequent analysis.

## Media Consumption and Creation

For this block of variables, respondents answered a series of questions about their media use. All media items measured the frequency of use on an ordinal 1 to 10 scale that had a range from *never* to *all the time*. Television and radio consumption were operationalized by five items that showed a high reliability (Cronbach alpha=.736), and two additional measures were combined about reading local and national newspapers (Cronbach alpha=.650) to round out traditional media consumption. Four additional items regarding the frequency of consuming social media content on the most frequently used channels in the dataset, namely, Facebook, Twitter, and YouTube, and streaming television such as Netflix that loaded strongly and reliably were also included (Cronbach alpha=.776). Finally, for this block, there were another four separate items that measured the frequency respondents reported creating and sharing Web-based media more actively by posting comments, uploading videos, or contributing to discussion threads on social network sites and adding material to wikis (Cronbach alpha=.922).

## IBD Perceptions and Knowledge

The only index constructed for this block was the compilation of 12 true/false items about IBD causes, symptoms, and possible cures, which can be found in [Multimedia Appendix 1](#). These items were developed by a qualified team of subject matter experts, including IBD clinicians and researchers at the Boston University Medical Center and comprised statements that ranged in relative difficulty regarding the depth of knowledge required to answer correctly. For each item, respondents were awarded one point for a correct response and received a score of zero for each incorrect response, which built a theoretical range of IBD knowledge from 0 (no IBD knowledge) to 12 (full IBD knowledge). The executed Checklist for Reporting Results of Internet E-Surveys (CHERRIES) for this index is presented in [Multimedia Appendix 2](#).

In addition, respondents were asked to self-assess their own familiarity with IBD on a scale of 1 (not at all familiar) to 10 (extremely familiar) and if they had been diagnosed with IBD themselves or if they knew anyone with the diagnosis. The final two measures in this block had respondents rank the degree of social stigma attached to IBD relative to seven other medical conditions and then to similarly rank nine symptoms of IBD from least to most embarrassing [22]. These are discussed in greater detail in answering RQ1 in the following section.

## Results

### IBD Perceptions and Knowledge

With respect to the general public's awareness and perceptions of IBD as investigated in RQ1, respondents reported relatively low levels of familiarity with IBD on the whole, with a self-reported average of just 5.54 (SD 2.70) on a scale of 1 (not at all familiar) to 10 (extremely familiar). The mode for this item was 7, with 18.33% (219/1200) of the respondents indicating this familiarity level, which was followed by 4, which was indicated by 15.83% (189/1200) of the respondents, and then 1 (or no familiarity) being reported by 11.08% (133/1200) of the respondents. Similarly, just 9.67% (116/1200) of the respondents in this sample reported personally knowing someone who has been diagnosed with IBD, and only 3.17% (38/1200) indicated having been diagnosed with IBD themselves.

The perception of IBD among the general public was highly negative, with respondents ranking IBD as having the greatest social stigma, on average, among seven health conditions considered here. When ranked on a scale of 1 (least social stigma) to 7 (most social stigma), IBD had the highest mean and was significantly more stigmatized in pairwise *t* tests than all the other conditions except genital herpes. As shown in Figure 1, in descending order from most to least social stigma, IBD (mean 4.34, SD 2.01) was followed by genital herpes (mean 4.22, SD 1.83;  $t_{1,199}=1.37$ ,  $P=.19$ ), alcoholism (mean 4.04, SD 1.76;  $t_{1,199}=3.44$ ,  $P<.001$ ), breast or testicular cancer (mean 3.90, SD 2.04;  $t_{1,199}=6.04$ ,  $P<.001$ ), diabetes (mean 3.87, SD 1.95;  $t_{1,199}=6.47$ ,  $P<.001$ ), obesity (mean 3.85, SD 1.82;  $t_{1,199}=5.55$ ,  $P<.001$ ), and human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) (mean 3.79, SD 2.44;  $t_{1,199}=4.80$ ,  $P<.001$ ).

There were no significant differences in terms of the level of stigma attached to IBD by men (mean 4.40, SD 1.87) or women (mean 4.28, SD 2.13) or across age groups, though social stigma for IBD was lowest among those in the age group of 18 to 24 years (mean 4.26, SD 2.29) and increased with each age cohort to a high among those 65 years and older (mean 4.50, SD 1.83). There were also no statistically significant differences across ethnic groups and income or education levels. Here it seems that respondents were somewhat uniform in their average rankings of IBD in social stigma relative to other conditions posed here.

The most embarrassing sequela of IBD of nine items considered here on a scale of 1 (least embarrassing) to 9 (most embarrassing) was presence of a stoma (mean 5.66, SD 2.81), which was followed by bloody diarrhea (mean 5.14, SD 2.57). Other externally noticeable symptoms such as skin sores (mean 5.10, SD 2.31), excessive weight gain (mean 5.08, SD 2.31), body odor (mean 4.95, SD 2.58), and the immediate and constant

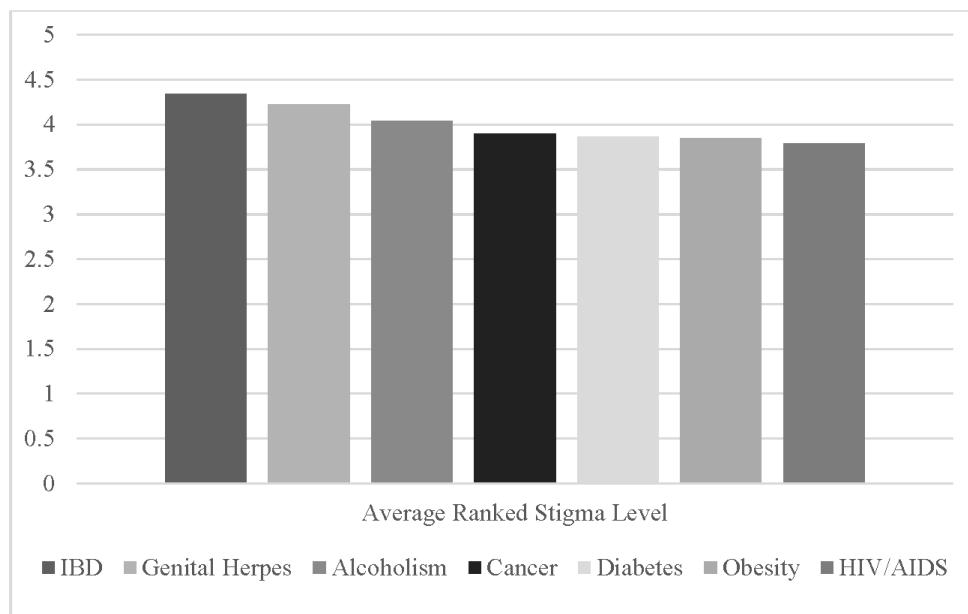
need to find a bathroom because of fecal urgency (mean 4.91, SD 2.44) also generated significant embarrassment. The remaining items of sudden dizzy spells, acne, and gas were within a mean of 4.74 to 4.71 in terms of their average rankings of embarrassment.

These findings suggest that IBD awareness among the general public is relatively low, yet it is highly stigmatized evenly across demographic factors, with both fecal-related and otherwise visible conditions ranking as most embarrassing and likely contributing to the stigma.

Moving forward to RQ2, which was concerned with IBD knowledge—as opposed to awareness—held by the general public, the average number of correct answers in this sample was 6.58 (or 54.8%; SD 1.77) items answered correctly when presented with 12 true/false items about IBD causes, symptoms, and possible cures. The minimum number of correct answers was 2 and the maximum number of correct answers was 11, indicating that not one respondent either answered all 12 items incorrectly or correctly. Altogether, this finding indicates that actual knowledge of IBD is quite low among the general public, with 85.83% (1029/1200) of this representative sample of respondents answering at least two-thirds of these items incorrectly.

As with perceptions of IBD, there was no statistically significant variation in IBD knowledge by gender, with averages of 6.66 (SD 1.82) for females and 6.49 (SD 1.71) for males. There were also no statistically significant differences by age groups, though it may be worth noting that the highest knowledge levels were observed among those 65 years and older (mean 6.69, SD 1.69), followed by those aged between 18 and 24 years (mean 6.69, SD 1.82). Differences in IBD knowledge also were not statistically significant by income levels, though those with the highest income were most knowledgeable (mean 6.70, SD 1.81), with corresponding declines in those averages to a low of 6.41 (SD 1.732) among the lowest income bracket.

Still, there were statistically significant differences across ethnic groups in terms of IBD knowledge, where respondents who indicated being either Native American, Pacific Islander, or of other ethnic background were most knowledgeable (mean 7.00, SD 1.74), on average, followed by white respondents (mean 6.71, SD 1.73), Hispanics or Latinos (mean 6.29, SD 1.86), Asian (mean 6.22, SD 2.04), and then African American respondents (mean 5.92, SD 1.55). Respondents reporting higher levels of formal education also demonstrated higher levels of IBD knowledge, and this was statistically significant. Specifically, those with 2-year, 4-year, or advanced graduate degrees had averages from 6.81 (SD 1.76) to 6.70 (SD 1.88), whereas those with some college education, a high school degree, or education less than finishing high school had means from 6.52 (SD 1.73) to 6.06 (SD 1.16).

**Figure 1.** Average rankings of social stigma by disease (higher values indicate more stigma). N=1200 for all diseases.

### Media Consumption and Creation

Building off of the initial two RQs, RQ3 sought to understand how different forms of media consumption and creation relate to the knowledge of IBD. In this case, media use as it relates to the knowledge of IBD was examined using a hierarchical regression and found several statistically significant factors that helped to explain both increases and decreases in IBD knowledge. Here, in terms of media variables, two factors—creating Web-based content and relying on SNS—were statistically significant and both were negatively related to knowledge. More specifically, this model estimated that as creating Web-based content ( $B=-.06$ , standard error,  $SE=0.03$ ,  $P<.10$ ) and frequency of using social network sites for news and information ( $B=-.07$ ,  $SE=0.03$ ,  $P<.05$ ) increased one unit, there was a related decline in IBD knowledge of .06 and .07 units, respectively.

Other factors that demonstrated a similar negative relationship were being older ( $B=-.13$ ,  $SE=0.07$ ,  $P<.10$ ), more fatalistic ( $B=-.05$ ,  $SE=0.02$ ,  $P<.05$ ), as well as considering IBD as more socially stigmatized ( $B=-.05$ ,  $SE=0.03$ ,  $P<.05$ ). Apart from these items, there were several that related positively to IBD knowledge. These included being white ( $B=.32$ ,  $SE=0.18$ ,  $P<.10$ ), being female ( $B=.20$ ,  $SE=0.11$ ,  $P<.10$ ), being more educated ( $B=.13$ ,  $SE=0.04$ ,  $P\le.001$ ), and self-reporting a greater level of IBD familiarity ( $B=.04$ ,  $SE=0.02$ ,  $P<.10$ ). This full model is summarized in Table 1.

The results of the regression were used to disaggregate the component items of statistically significant media factors. In a bivariate correlation matrix, each variable was separated from the creating Web-based content index and the using social network sites for news and information index. Here, it can be observed that IBD knowledge was most negatively related to uploading videos to platforms such as YouTube ( $r=-.19$ ,  $P<.01$ ) and more frequently contributing to wikis, similar, but not limited to Wikipedia ( $r=-.22$ ,  $P<.01$ ). Apart from those

variables, the individualized measures of relying on different social networks, namely, YouTube ( $r=-.15$ ,  $P<.01$ ), streaming television such as Netflix ( $r=-.12$ ,  $P<.01$ ), and Twitter ( $r=-.12$ ,  $P<.01$ ) were the most negatively related to IBD knowledge.

Furthermore, the media variables themselves show mostly moderate but significant relationships to one another, indicating not only that the constructed indices are valid operationalizations but also that differences in the affordances of media platforms do connect negatively to the development of IBD knowledge among the general public. These results are summarized as a correlation matrix presented in Table 2.

Finally, when examining social stigma surrounding IBD, knowledge of the disease, and various media uses as proposed in RQ4, there were no significant correlations between media use and IBD stigma. The correlation between knowledge and attitudes was very weak ( $r=-.05$ ,  $P<.10$ ). These relationships were explored in greater detail by tracking the stigma assigned to IBD against ordinal rankings of IBD knowledge and each of the media use indices on 4-point scales from *very low* to *very high* that collapsed the variance in the original metrics based on even distributions. Here, none of the media variables again showed any relationship to IBD stigma whatsoever, but IBD knowledge was correlated.

Specifically, as knowledge of IBD increases along this ordinal scale, the stigma attached to it decreases ( $F_{3,112.77}=2.30$ ,  $P<.01$ , equal variances not assumed). Social stigma was highest (mean 4.93,  $SD$  1.72) among respondents showing the least IBD knowledge, and the stigma level dropped at each increasing level of IBD knowledge to an average low of 4.02 ( $SD$  1.77) for those respondents with the most IBD knowledge. Altogether, these findings suggest that the stigma surrounding IBD can best be diminished by increasing IBD knowledge through media campaigns that specifically target social media content and users.

**Table 1.** Regression model of inflammatory bowel disease (IBD) knowledge. N=1195, listwise deletion; overall adjusted  $R^2=.071$ .

Variables	Coefficient (B)	Standard error (SE)	Beta ( $\beta$ )
<b>Step 1 (Demographics)</b>			
Constant	6.066 <sup>a</sup>	.970	
Age in cohorts	-.128 <sup>b</sup>	.071	-.065
Being white	.322 <sup>b</sup>	.182	.080
Being African American	-.357	.235	-.057
Being Asian	-.223	.268	-.029
Being Native American/Pacific Islander/other	.542	.379	.044
Gender (being female)	.200 <sup>b</sup>	.110	.057
Income	.074	.057	.042
Education	.133 <sup>a</sup>	.040	.104
$\Delta R^2$	.040 <sup>a</sup>		
<b>Step 2 (Personal characteristics)</b>			
Isolation	-.005	.024	-.007
Life satisfaction	-.028	.028	-.035
Trust in others	-.023	.028	-.026
Fatalism	-.050 <sup>c</sup>	.023	-.068
$\Delta R^2$	.019 <sup>a</sup>		
<b>Step 3 (Media use)</b>			
Television and radio	-.040	.035	-.046
Newspaper	-.002	.025	-.003
Creating Web-based content	-.057 <sup>b</sup>	.033	-.072
Social network sites	-.065 <sup>c</sup>	.028	-.092
$\Delta R^2$	.020 <sup>a</sup>		
<b>Step 4 (IBD<sup>d</sup> background)</b>			
Personally diagnosed with IBD	-.440	.305	-.044
Know someone diagnosed with IBD	-.112	.186	-.019
Self-reported familiarity with IBD	.036 <sup>b</sup>	.021	.056
Social stigma assigned to IBD	-.051 <sup>c</sup>	.025	-.058
$\Delta R^2$	.007 <sup>c</sup>		

<sup>a</sup> $P<.001$ .<sup>b</sup> $P<.10$ .<sup>c</sup> $P<.05$ .<sup>d</sup>IBD: inflammatory bowel disease.

**Table 2.** Bivariate Pearson correlation matrix for inflammatory bowel disease (IBD) knowledge and stigma in relation to regression-identified media variables. N=1200 for all cases.

Variables	1	2	3	4	5	6	7	8	9	10
1. IBD knowledge <sup>a</sup>	-- <sup>b</sup>	-.05 <sup>c</sup>	-.09 <sup>d</sup>	-.19 <sup>d</sup>	-.07 <sup>e</sup>	-.22 <sup>d</sup>	-.10 <sup>d</sup>	-.12 <sup>d</sup>	-.15 <sup>d</sup>	-.12 <sup>d</sup>
2. IBD stigma	--	-.01	-.01	-.01	-.03	-.01	-.04	-.02	-.01	-.01
3. Post comments		--	.52 <sup>d</sup>	.63 <sup>d</sup>	.42 <sup>d</sup>	.49 <sup>d</sup>	.42 <sup>d</sup>	.41 <sup>d</sup>	.30 <sup>d</sup>	
4. Upload videos			--	.60 <sup>d</sup>	.70 <sup>d</sup>	.36 <sup>d</sup>	.47 <sup>d</sup>	.47 <sup>d</sup>	.43 <sup>d</sup>	
5. Create/share on SNS <sup>f</sup>				--	.44 <sup>d</sup>	.51 <sup>d</sup>	.46 <sup>d</sup>	.40 <sup>d</sup>	.33 <sup>d</sup>	
6. Write to wiki					--	.29 <sup>d</sup>	.45 <sup>d</sup>	.41 <sup>d</sup>	.39 <sup>d</sup>	
7. Facebook news and information						--	.43 <sup>d</sup>	.46 <sup>d</sup>	.42 <sup>d</sup>	
8. Twitter news and information							--	.46 <sup>d</sup>	.41 <sup>d</sup>	
9. YouTube news and information								--	.61 <sup>d</sup>	
10. Netflix/streaming TV news and information									--	

<sup>a</sup>IBD: inflammatory bowel disease.<sup>b</sup>--: perfect correlation with itself of 1.<sup>c</sup> $P < .10$ .<sup>d</sup> $P < .01$ .<sup>e</sup> $P \leq .05$ .<sup>f</sup>SNS: social networking site.

## Discussion

This study sought to examine enacted stigma and public knowledge of IBD, which afflicts over 5 million people worldwide but does not have a long history of prominence on media, public, or policy agendas. As one of the first analyses of its kind on this topic, we carried out a generally representative nationwide survey of the American population to find that the general public is neither very aware nor very knowledgeable of IBD but does harbor high stigma for the disease. Simultaneously, although increased knowledge is inversely related to stigma, those who are most participatory in social media—through creating and consuming content—are found to be less knowledgeable on the topic. By shedding light on the underlying relationships between media participation, knowledge, and stigma, stakeholders will be more informed on the need to combat IBD misinformation and stigma with a multi-channel approach that not only encompasses but also pays particular attention to social media.

### Key Findings for Practitioners, Patients, and Advocacy Organizations

First, the findings identified that IBD awareness is relatively low among the general public in the United States. IBD is also simultaneously the most socially stigmatized medical diagnosis of seven other conditions considered in this study, which include genital herpes, alcoholism, and HIV/AIDS. Interestingly, the high level of IBD stigma was fairly evenly distributed over demographic and media use, and none of these characteristics were related to decreasing or increasing the social stigma attached to the disease. Although an explicit statistical link was not modeled here, it was apparent in survey results that fecal-related and other visible IBD symptoms such as stoma

and skin sores ranked as the most embarrassing manifestations of IBD and presumably contribute to the pronounced social stigma that is attached to the disease across demographic, personal, and media factors.

Second, in addition to a high level of social stigma, IBD also suffers from a relatively low level of knowledge among the general public. When examining knowledge with 12 true/false items (Multimedia Appendix 1), the average number of correct answers was just over half, and a vast majority of all respondents answered at least two-thirds of all items incorrectly. Similar to IBD stigma, knowledge did not vary significantly across many demographic groups or personal characteristics, but it was shown that more educated respondents generally knew more about IBD, as did respondents claiming certain ethnic backgrounds, namely, those who are most typically affected [23].

Other factors were considered jointly and in greater detail in a hierarchical regression model, but it is worth noting here that in one-way analyses of variance (ANOVAs), knowledge of IBD declined significantly across increases in *all* forms of media use, which suggests that there is a systemic lack of accurate IBD information circulating offline and on the Web. In other words, there is not one mediated information channel that is related positively to IBD knowledge. In fact the opposite is true, which indicates that far greater efforts need to be made in raising IBD awareness through multiplatform media campaigns [24].

Each block of the regression model accounted for a statistically significant change in variance explained, but the most interesting findings suggest that increased consumption and creation on SNS are significantly and negatively related to IBD knowledge, even taking into account all other factors introduced to the model. Indeed, much like previous work on antimicrobial

resistance [8], these findings suggest that creating Web-based content, and not just consuming news and information from certain sites or platforms, is part of a somewhat vicious cycle of misinformation [25]. Namely, the most prolific social media creators in this sample were also the respondents with the lowest levels of IBD knowledge. This finding requires us to again consider earlier works concluding that what high-volume producers share with others on social media is likely to affect those who regularly rely on social media for news and information, thereby perpetuating inaccurate beliefs [26-28], which, in this case, would contribute to misinformation about IBD, were it confirmed that they were producing content specific to that topic. Providers, then, must be aware that their patients may be receiving content that constitutes false information.

### Implications for Addressing and Alleviating IBD Stigma

Not unlike earlier studies on public Web-based information [15,29], the confluence of these findings suggests a linkage can be made from social media consumption and creation that relates negatively to IBD knowledge. This in turn is associated with increased IBD stigma, which is otherwise not directly influenced through various information channels. Specifically, and more importantly, increased IBD knowledge was the only factor to demonstrate a positive relationship to decreasing IBD stigma. Reducing this social stigma is, of course, a vital factor in raising acceptance and awareness of IBD in the public at large, and potentially mitigating some of the more serious quality of life issues faced by IBD patients such as work-related and other professional or personal interactions.

### Research Limitations and Opportunities for Further Exploration

One potential limitation that should be mentioned here is that although our sample was drawn from a pool of more than 32 million respondents to build a fully representative and generalizable sample, some limitations arguably remain for Web-based panels in this regard [30]. Even so, it is important to point out that similar stratified Web-based quota samples are regularly being engaged and employed for these sorts of analyses in the field of media research [31]. Another limitation is that the operationalization of social stigma was a nonspecific one, and thus does not explicitly provide details about what aspects of IBD are driving the high levels of stigma associated with the

condition relative to other diseases. Likewise, we do not have knowledge measures on the other conditions that could form the basis of comparative work in future studies.

In addition, further research is warranted to more definitively investigate sources of IBD misinformation, including the qualitative nature of the content produced, as well as its life span and evolution in the emerging media environment, to better understand its effect on other social media consumers' respective IBD knowledge. Such research would not only further clarify these findings but would also add critique to the divergent findings of existing health care communication literature on the role of social media in harming or harmonizing perceptions and knowledge. Most notably, such contribution may also inform stakeholders on specific social media tactics and messages useful in bolstering IBD knowledge and combating related stigmas.

Nonetheless, this study is perhaps the first to examine IBD in a communicative context, and likely one of only a few to map knowledge and public attitudes toward IBD in a broad sense. From the analyses outlined here, with a specific focus on the establishment of uniformly negative knowledge outcomes from all media, but social media consumption and creation in particular, this study advances a better understanding of media affordances [13] that can guide practitioners working in this area to build IBD knowledge and reduce its stigma.

In forging pathways toward that end, media activities promoting IBD causes, symptoms, and treatments should ideally take place across multiple levels, from initiatives facilitated through multinational organizations as well as direct social media interactions between physicians and patients. Perhaps most crucially, social media channels [24,25] must not be ignored because as demonstrated here, they are currently the most significant factors in shaping public knowledge of IBD, which in turn relates directly to stigma associated with the disease.

Considering these results, gastroenterologists and patient advocates must be aware of the impact social media has on negatively shaping public knowledge of IBD. At the moment, social media consumption and creation are both directly related to a lower level of IBD knowledge and thus indirectly related to increased IBD stigma, and this study represents a key platform for stakeholders to intervene positively in reshaping both IBD knowledge and stigma.

### Conflicts of Interest

None declared.

### Multimedia Appendix 1

Index for IBD Knowledge with answers in bold.

[[PDF File \(Adobe PDF File, 243KB - jmir\\_v19i12e403\\_app1.pdf](#) ]

### Multimedia Appendix 2

Checklist for Reporting Results of Internet E-Surveys (CHERRIES).

[[PDF File \(Adobe PDF File, 37KB - jmir\\_v19i12e403\\_app2.pdf](#) ]

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## Abbreviations

**AMR:** antimicrobial resistance  
**ANOVA:** analysis of variance  
**CCF:** Crohn's and Colitis Foundation  
**CD:** Crohn's disease  
**CHERRIES:** Checklist for Reporting Results of Internet E-Surveys  
**IBD:** inflammatory bowel disease  
**RQ:** research questions  
**SD:** standard deviation  
**SE:** standard error  
**SNS:** social networking sites  
**UC:** ulcerative colitis

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Original Paper

# Designing Microblog Direct Messages to Engage Social Media Users With Suicide Ideation: Interview and Survey Study on Weibo

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## Abstract

**Background:** While Web-based interventions can be efficacious, engaging a target population's attention remains challenging. We argue that strategies to draw such a population's attention should be tailored to meet its needs. Increasing user engagement in online suicide intervention development requires feedback from this group to prevent people who have suicide ideation from seeking treatment.

**Objective:** The goal of this study was to solicit feedback on the acceptability of the content of messaging from social media users with suicide ideation. To overcome the common concern of lack of engagement in online interventions and to ensure effective learning from the message, this research employs a customized design of both content and length of the message.

**Methods:** In study 1, 17 participants suffering from suicide ideation were recruited. The first (n=8) group conversed with a professional suicide intervention doctor about its attitudes and suggestions for a direct message intervention. To ensure the reliability and consistency of the result, an identical interview was conducted for the second group (n=9). Based on the collected data, questionnaires about this intervention were formed. Study 2 recruited 4222 microblog users with suicide ideation via the Internet.

**Results:** The results of the group interviews in study 1 yielded little difference regarding the interview results; this difference may relate to the 2 groups' varied perceptions of direct message design. However, most participants reported that they would be most drawn to an intervention where they knew that the account was reliable. Out of 4222 microblog users, we received responses from 725 with completed questionnaires; 78.62% (570/725) participants were not opposed to online suicide intervention and they valued the link for extra suicide intervention information as long as the account appeared to be trustworthy. Their attitudes toward the intervention and the account were similar to those from study 1, and 3 important elements were found pertaining to the direct message: reliability of account name, brevity of the message, and details of the phone numbers of psychological intervention centers and psychological assessment.

**Conclusions:** This paper proposed strategies for engaging target populations in online suicide interventions.

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**KEYWORDS**

microblog direct message; social media; suicide prevention

## Introduction

The number of people with suicide ideation has increased at an alarming rate, and this population suffers both physically and mentally. An estimated 1.53 million people will die from suicide, and even more people will contemplate suicide in the year 2020 on a global scale [1]. Moreover, Asia is the region that has the largest numbers of suicides, and China and India alone occupy 30% of all cases of suicide worldwide, not to mention underreported incidents of suicide. By definition, suicide is a self-initiated act to end one's own life [2], and suicide ideation relates to thoughts that may lead to suicide or nonfatal outcomes. Suicide and suicide ideation are probably complex actions that are associated with the interaction of various factors; it is likely that patients with suicide ideation suffer greatly. According to Gvion and Apté [3], almost 90% of cases of patients with suicide have psychiatric disorders, and those with suicide ideation also experience unbearable mental pain. Not only does the patient suffer, his or her family members and friends are also faced with enormous mental, emotional, and physical stress. In order to alleviate this pain, suicide intervention is vital for this target population.

Substantial research has been conducted for the intervention. Suicide hotlines and intervention centers are the most prevalent ends for suicide prevention. However, De Leo et al [4] suggest that only 20% of patients are willing to seek help and receive treatment. The other 80% are not completely opposed to receiving help but have not proactively asked for help. In other words, this passive help-offering attitude tends to make suicide intervention less available for the population with suicide ideation, who in reality need no less prompt treatment than any other patients.

Machine learning's suicide risk identification on microblogs provides the possibility for proactively finding individuals with suicide ideation. Kessler and Walters [5] find that young people, especially the 24-year-old group, have the highest rate of suicide. Many young people prefer to use the Internet to search for health information, including seeking treatment in early stages of suicide ideation [6]. In China, Sina Weibo is a microblogging platform that enables Chinese media users to disseminate and acquire information and is mainly used by young people. Many users have expressed suicide ideation and have broadcasted suicide attempts on this social media [7-11]. Included on the platform, Direct Message is another vital method of Chinese microblogging. It is similar to Twitter's Direct Message, and users interact with others by sending private messages. Through proactive suicide risk identification, emergent help text via direct message could be provided to those with suicide ideation. Doing so may in turn increase the efficacy of suicide intervention.

The aim of this research was to engage the target group with direct messages by investigating the principles of designing both appropriate format and content of the information from the patients' perspective. Since the target population is often opposed to active help-seeking, it is crucial to rely on the intended users at all levels of the design process. Specifically, we proposed to survey the population with current suicide ideation about acceptable subject lines and intervention descriptions for gaining a better understanding of how to proactively provide the target audience with accurate and effective information.

## Methods

### Overview

Two studies were conducted in this research. The first one examined user preferences and attitudes toward direct messages. Two group interviews were conducted and participant suggestions toward direct messages were solicited. To ensure the reliability and consistency of the results, another group of participants attended an identical group interview. A prototype of the direct messages was then integrated with the comments from the participants of the 2 interviews. In the second study, more patients were invited online to complete surveys about their preferences for direct messages as well as the prototype.

### Study 1

The purpose of this study was to examine user preferences and attitudes toward microblogging direct messages. Individuals were recruited via the Internet and asked to complete the Adult Suicide Ideation Questionnaire (ASIQ-4). The ASIQ-4 is a 4-item, self-reported questionnaire used for screening and measuring the severity of suicide ideation over the previous 12 months [12]. It is a short version of the Chinese ASIQ used in order to increase the efficacy of the screening. The ASIQ-4 uses a 7-point scale indicating the frequency of suicide ideation ranging from 0 (never had this thought) to 6 (almost every day). Participants with a score of more than 1 were eligible to attend a 2-hour group interview to provide feedback on key components of direct messages designed to provide in-time help.

In order to communicate with each participant effectively, 2 identical group interviews were conducted in the sequence of group 1 and group 2. Participants were invited on a first-come-first-serve basis, and each interview lasted 2 hours. A total of 8 participants completed the first interview, and 9 participants attended to the second interview anonymously (see Table 1).

**Table 1.** Demographic information of participants..

Variable	Group 1 (n=8)	Group 2 (n=9)
<b>Gender</b>		
Male	5	4
Female	3	4
Age (years), mean (SD)	23.13 (2.23)	23.22 (2.59)

As a last step, participants received a CNY ￥100 incentive after providing consent. All study procedures were approved by the Group Health Institutional Review Board.

Interviews were led by a doctor from Beijing HuiLongGuan Hospital, the most renowned center in China for suicide intervention. Two groups were presented with a direct message prototype which included general advice on suicide prevention and a link to psychological intervention hotlines. Since microblogging contains many messages to be read, it is important for the direct message to draw the attention of the user by understanding the target population's attitude toward the message. The discussion includes the user preferences and attitudes toward direct message, as well as the advantages and disadvantages of the prototype.

## Study 2

The purpose of study 2 was similar to study 1: namely, to examine variables that contributed to drawing attention to online direct messages for suicide intervention. Unlike study 1, however, participants in study 2 were invited to complete an additional 10-question survey about the design of direct messages after the focused groups' suggestions were integrated.

In total, 4222 Weibo users were invited to voluntarily take part in this study. None of these users had participated in study 1.

To find potential participants, we downloaded 65,352 comments (from March 2016 to September 2016) to the last tweet of a prominent blogger who had committed suicide, and 6 psychology graduate students were recruited to rank the risk level of these comments. The ranking standard consisted of a 4-point rating scale completed by each graduate student. The comment could be ranked as (0) No indication of suicide ideation and practical plan that contains the expression of death wishes or depression, (1) suicide ideation is detected while no detailed plan is made, (2) suicide ideation is detected while emergency intervention is not required (the content includes discussion of the action of death, death kit, death place and time, death will, etc), or (3) high risk of completing suicide, and emergency intervention is needed (detailed suicide plan or possibility of executing the plan within 1 or 2 weeks). After training, the consistency of the 6 psychology graduate student ratings reached a Cronbach coefficient of 0.85. For any user with risk level 3, a direct message was immediately sent out to offer emergency help.

Of 65,352 ratings collected, 8833 were labeled with suicide ideation, including level 1, 2, and 3. After amalgamating the overlapped microblog identifications, 4222 users were invited to complete the ASIQ-4 and the questionnaire about their suicide

ideation anonymously through Psychological Map, the public account of the research group.

## Results

### Study 1

#### User Attitudes Toward Direct Messages

While 63% (5/8) were agreeable to reading all microblog private messages in the first interview, all 9 participants from the second interview (100%) intended to read the messages. All participants in both interviews claimed that they would be more vigilant if the sender were not an acquaintance, and they would like to pay more attention to the category of the account (whether the account is a marketing account) as well as the real purpose of the message. Two (2/8, 25%) appeared to read the private message only if the sender was an acquaintance, and 1 refused to read any messages in the first interview (see Table 2).

#### Online Interaction Through Direct Message

In the first interview, 38% (3/8) took the initiative to interact online using private chat, and in the second interview, 78% (7/9) used private chat for circumstances like greeting strangers.

#### Direct Message Checking Frequency

In the first interview, 75% (6/8) of participants claimed that they checked the private chat as long as they saw microblog notifications, and 13% (1/8) preferred to check messages on a daily basis. The rest (1/8, 13%) chose not to view the chats until the messages automatically popped up.

In the second interview, 44% (4/9) preferred to pay attention to the messages if they saw any notifications in their microblogs, 33% (3/9) chose to view messages on a daily basis, and 11% (1/9) checked messages on a weekly basis. Similarly, 11% (1/9) of respondents preferred not to see the messages unless they appeared on the front page (see Table 3).

#### Direct Message Length

In the first interview, 25% (2/8) believed that they would read the whole chat even if it was of great length. Another 13% (1/8) claimed to read lengthy chats only in the evening when he was the freest. The rest (5/8, 63%), read the messages based on their interest, demand, and the credibility of the sender despite of the length of the chat.

In the second interview, 11% (1/9) had no patience for reading long chats, and the rest (8/9, 89%) had the same attitude of reading the messages based on their interest, demand, and the credibility of the sender (see Table 4).

**Table 2.** User attitudes toward the microblog direct messages.

Variable	Group 1 (n=8)	Group 2 n=9)
Read all microblog private chats	5	9
Vigilant if the sender is not an acquaintance	8	9
Read the message only if the sender is an acquaintance	2	0
Refuse to read any messages	1	0

**Table 3.** Direct message checking frequency.

Frequency	Group 1 (n=8)	Group 2 (n=9)
As long as they see microblog notifications	6	4
Daily basis	1	3
Not to view unless the messages pop up	1	1
Weekly basis	0	1

**Table 4.** Direct message length preferences.

Variable	Group 1 (n=8)	Group 2 (n=9)
Read the whole chat regardless of the length	2	0
Read lengthy chats only in the evening	1	0
Read based on interest, demand, etc	5	8
No patience for long chats	0	1

### Opinions Toward the Direct Message Prototype

Both groups felt the public account name, Psychological Map, was not clear, failed to embody public welfare, and was difficult for them to determine the nature of the account. To solve this problem, naming the account in a warmer way to help the target group feel the social care and support was advised. Another noticeable feedback was the need to highlight the aim of the text to make sure the target population knows that the account is for professional use and intends to support this group under privacy protection. In terms of the text length, shorter length tended to be more suitable for the audience. Both groups also were agreeable to the addition of psychological crisis intervention center phone numbers in the private chat content. A more customized design rather than general advice was expected from the second interview group.

### Study 2

#### Overview

Of 4222 participant surveys, 725 (17.17%) were collected but some of the questions were left blank by certain participants. Before answering the 10-question survey, respondents also provided their background information with regard to suicide ideation and attitude toward suicide online intervention. A total of 88.0% (638/725) were female, and 12.0% (87/725) were male, with an average age of 21.22 (SD 3.69) years. More than two-thirds (493/725, 68.0%) of respondents had university or college degrees, and 93.3% (676/725) were unmarried. While 0.8% (6/725) of participants never had suicide ideation, 99.2% (719/725) had had ideation in the past and 51.2% (371/725) of participants had made suicide attempts; 78.6% (570/725) of the

participants were not opposed to the idea of online suicide intervention. Figure 1 to 10 present the results of study 2.

#### Question 1

Question (Figure 1): Which account name do you prefer to click on and read the details when we send you direct messages for psychological intervention services?

1. Psychological Map
2. Psychological Assistance Community Group
3. Psychological Crisis Intervention Group
4. Life Protector
5. Walking Toward the Sunshine
6. Listening to Your Heart
7. Doesn't matter
8. Other account names (please specify\_\_\_\_\_)
9. Don't want to read any direct messages

When choosing the most preferred account name, there were greater differences in options 6 and 9 compared to the others. While more males (14/87, 16%) chose the name Listening to Your Heart, only 10.5% (67/638) of females preferred this title. In addition, 6.9% (44/638) of the females tended to not read any direct messages but only 1% (1/87) of the males ignored them. These differences may suggest that males tend to be more interested in relatively indirect names than females do.

#### Question 2

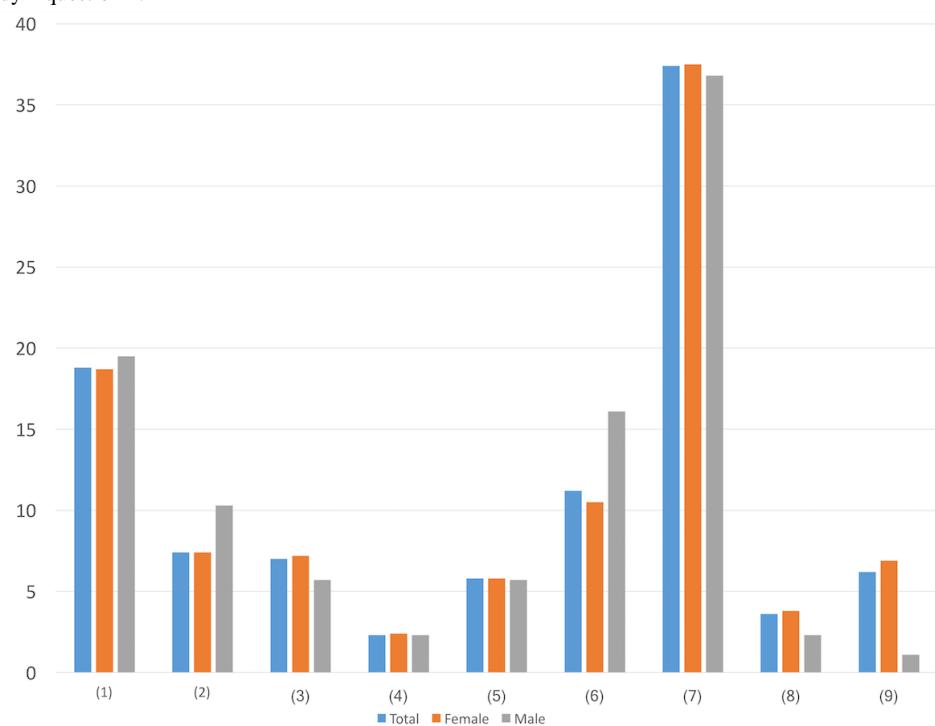
Question (Figure 2): Which self-introduction method is more acceptable for you?

1. We read through your public Weibo posts and found that you were in a bad mood, even considering suicide...

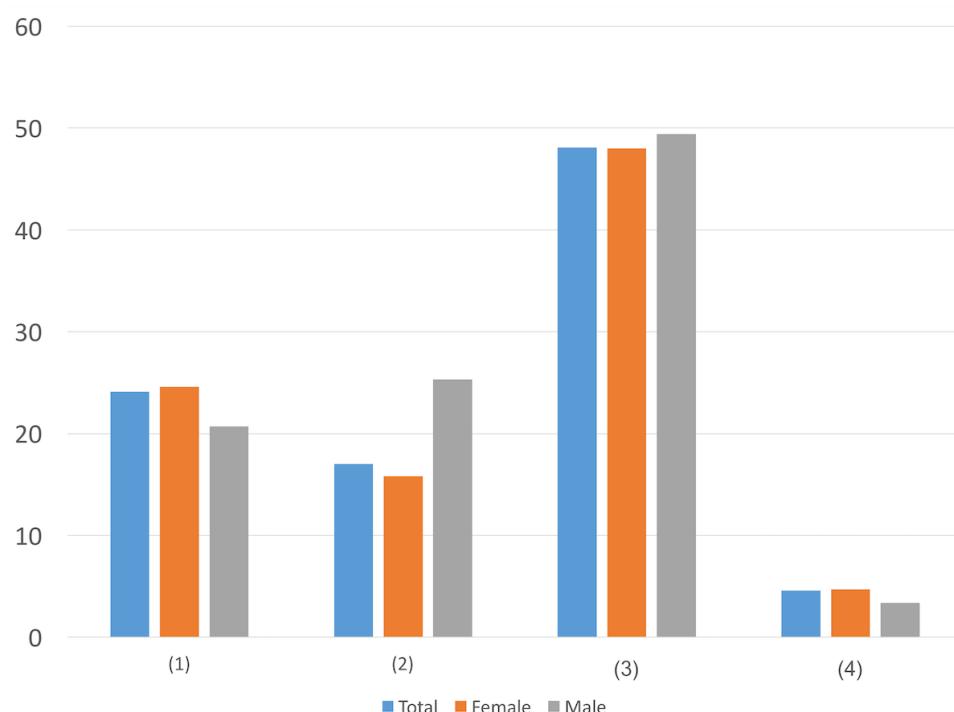
2. Through searching keywords, our online intervention system finds that you are in a bad mood, even considering suicide...
3. Doesn't matter
4. Other ways (please specify \_\_\_\_\_)

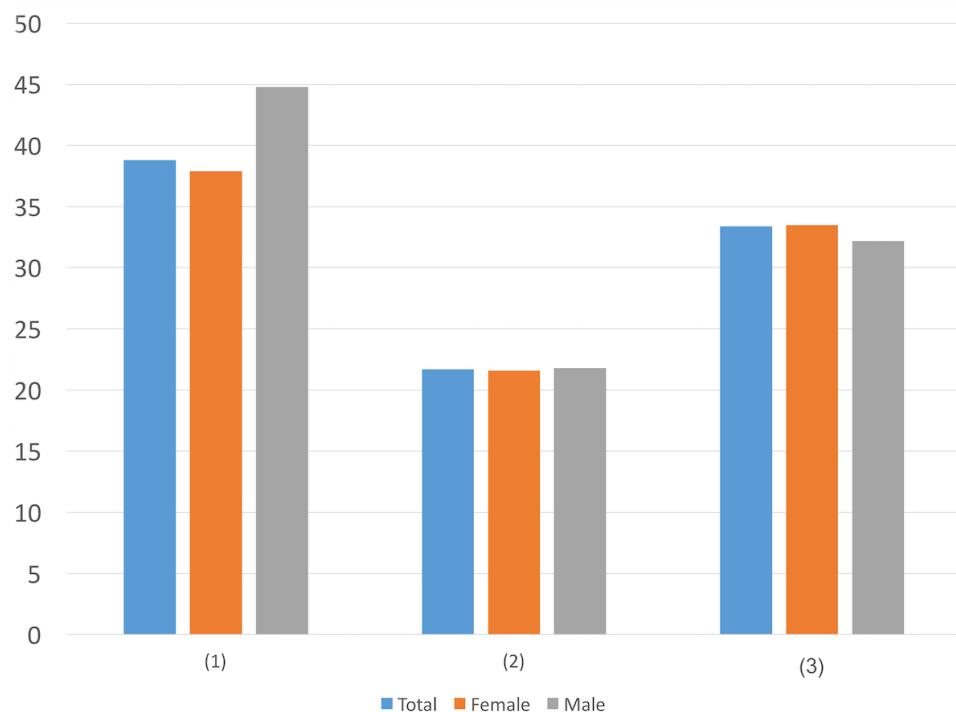
In terms of the self-introduction method, more males (22/87, 25%) prefer the online intervention system finding out their feelings than females (101/638, 15.8%) do. This may indicate that while females value others' help, males tend to not seek help from humans and may feel more comfortable with computer assistance.

**Figure 1.** Results of study 2 question 1.



**Figure 2.** Results of study 2 question 2.



**Figure 3.** Results of study 2 question 3.

### Question 3

Question (Figure 3): When you receive this direct message, do you care about the message's account nature (eg, authority, nonprofit)?

1. Yes
2. No
3. Doesn't matter

With regard to the message's account, more males (39/87, 45%) than females (242/638, 37.9%) were interested in the nature of the account. This may suggest that males tend to be more wary and critical about the source of the information than females do.

### Question 4

Question (Figure 4): At the beginning of this direct message, how do you prefer to be addressed?

1. Greetings
2. Dear Weibo User
3. Dear + your account name
4. Doesn't matter

In this question, more males preferred general phrases like Greetings (28/87, 32%) and Dear Weibo User (4/87, 5%) compared to females. Meanwhile, females (131/638, 20.5%) preferred to be addressed with specific account names. This difference may suggest that males value privacy while females appreciate more help and attention.

### Question 5

Question (Figure 5): Which status do you prefer the direct message account use when reaching out to you?

1. I'm a teacher from... (from a personal perspective)
2. We are... (from a team perspective)
3. Doesn't matter

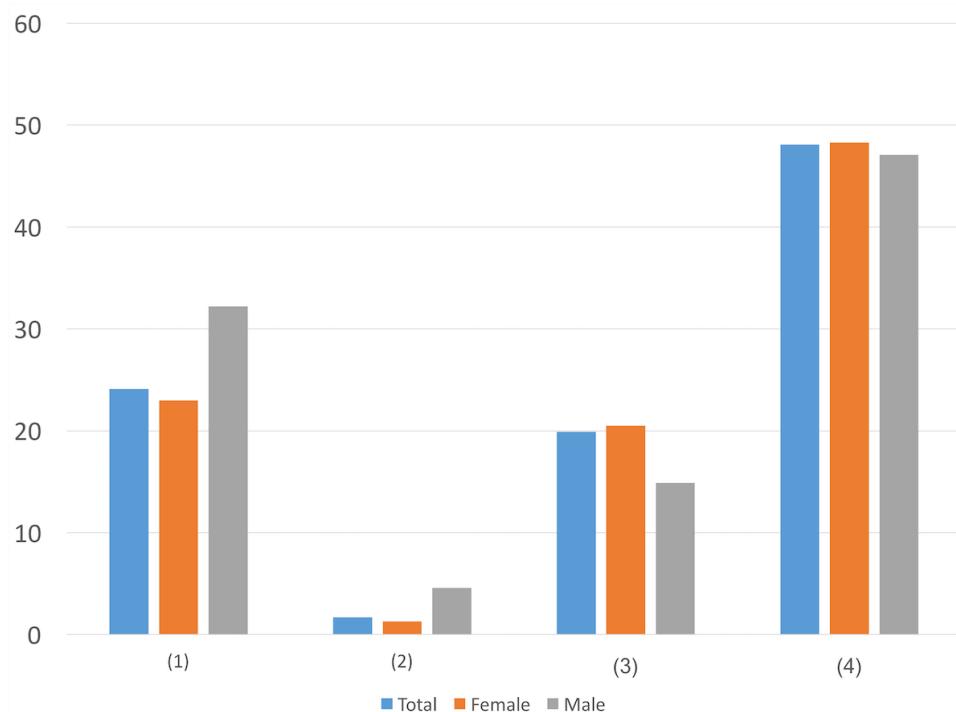
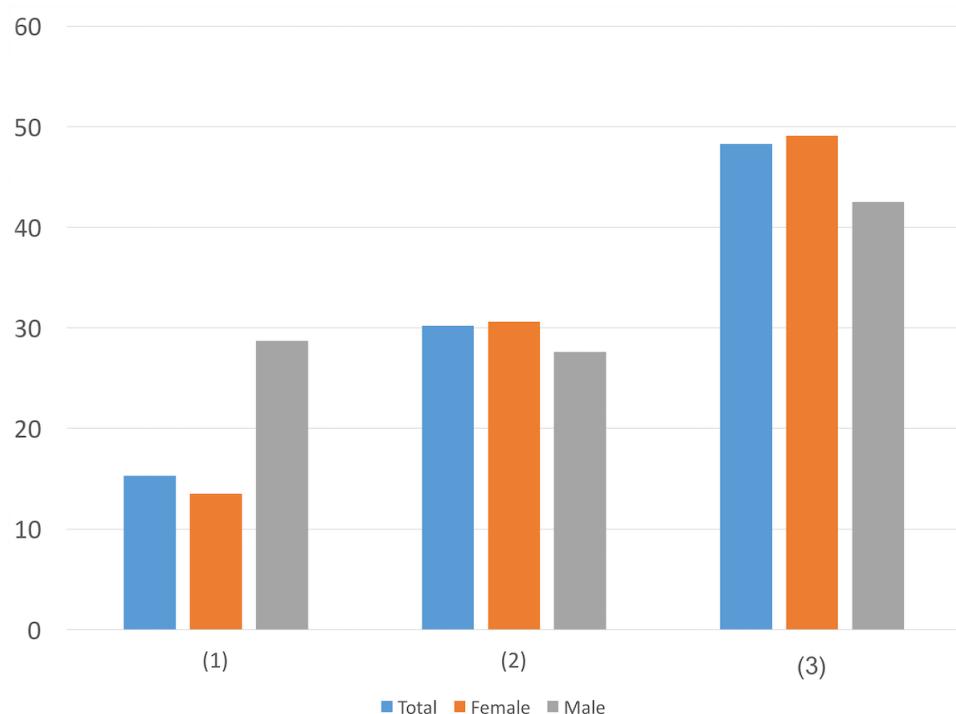
More males (25/87, 29%) prefer to be reached from a personal perspective, and more females (195/638, 30.6%) chose to be messaged by a team. This may indicate that while privacy is the relatively valuable factor for males, warmth and help from others are preferable for females.

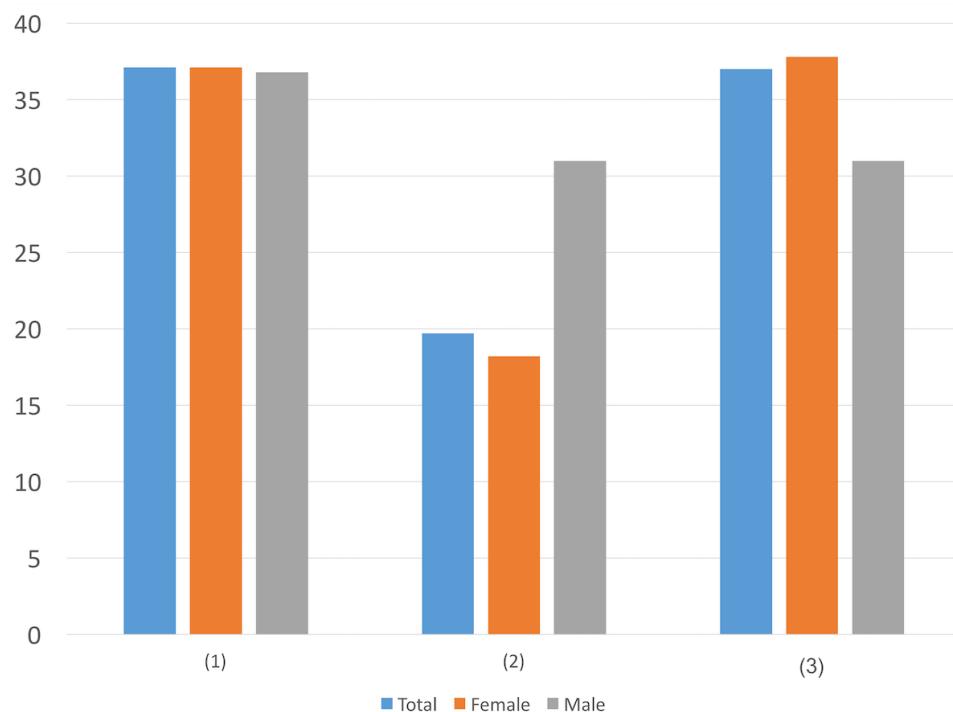
### Question 6

Question (Figure 6): In this direct message, which expression order do you prefer?

1. First state the account's identity and nature, then express concern for you
2. First express concern for you, then state the account's identity and nature
3. Doesn't matter

Most of the population (269/725, 37.1%) preferred to learn the account's identity and nature, then the concern for them. The main difference was in option 2. More males (27/87, 31%) than females (116/638, 18.2%) preferred the message to first express concern for them, then state the identity and nature of the account. This may suggest that the purpose of the message is relatively important for certain males, but the majority value the account's identity and nature the most.

**Figure 4.** Results of study 2 question 4.**Figure 5.** Results of study 2 question 5.

**Figure 6.** Results of study 2 question 6.

### Question 7

Question (Figure 7): If the direct message contains a nonprofit psychological assistance hotline, how do you prefer the number to be presented?

1. If you need anything, you can call this nonprofit psychological assistance hotline: ####
2. This is a nonprofit psychological assistance hotline. Many professional counselors here are ready to listen to your story at any time: ####
3. Doesn't matter

In this question, the main difference was in option 1. More males (15/87, 17%) than females (76/638, 11.9%) preferred the expression “If you need anything, you can call this nonprofit psychological assistance hotline” than “This is a nonprofit psychological assistance hotline. Many professional counselors here are ready to listen to your story at any time.” This result is in aligned with the result in Question 4 as males tend to prioritize their privacy before help and attention from others.

### Question 8

Question (Figure 8): If the direct message contains a link, under what situation would you be the most likely to click on it and read the details?

1. As long as the account is reliable, I will click on it and read the details
2. The letter in this link might be helpful for you

3. Doesn't matter
4. I never click on links

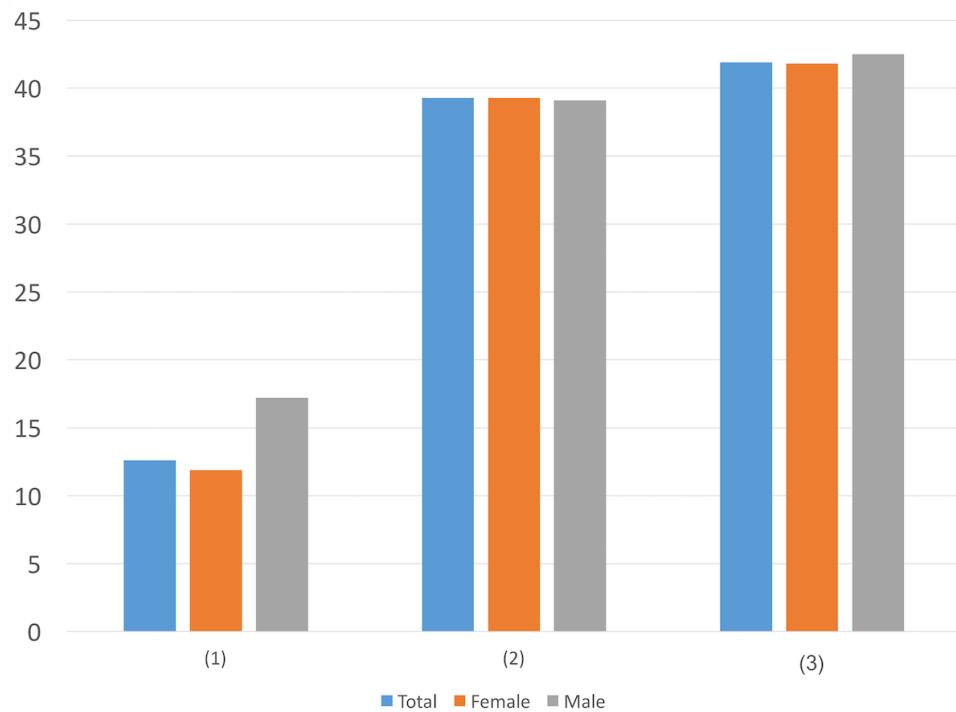
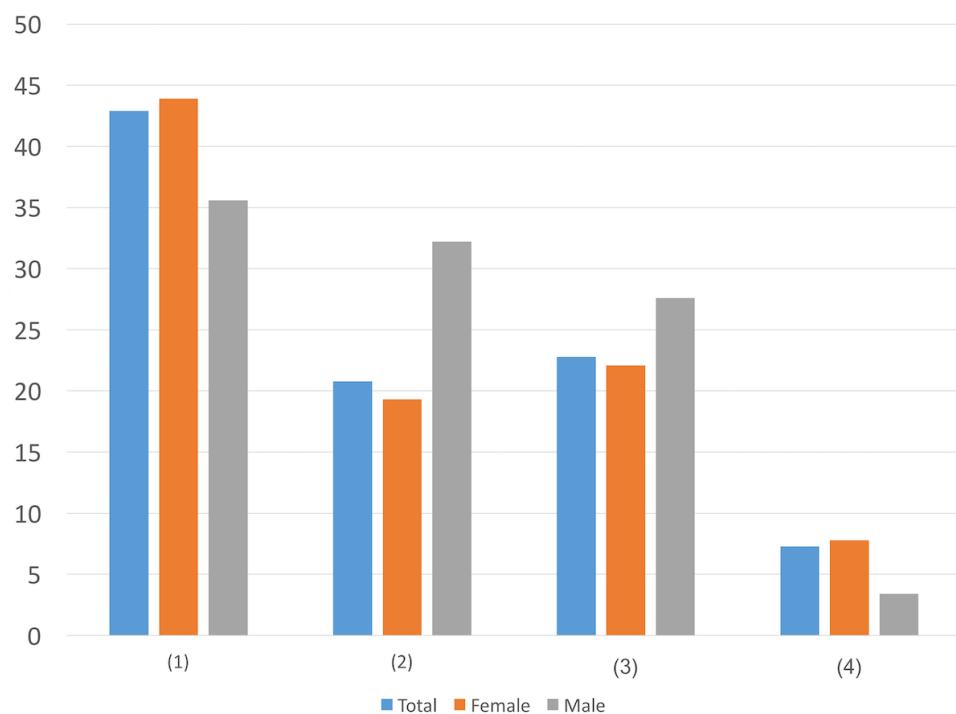
While more females (280/638, 43.9%) prioritized the importance of account reliability, more males (28/87, 32%) believed the content's degree of helpfulness was positively associated with the possibilities of their reading the details of the content. This difference may indicate that women tend to be more willing to seek help as long as the account is reliable, while men may want to ensure the content is valid and helpful before they reach out for advice.

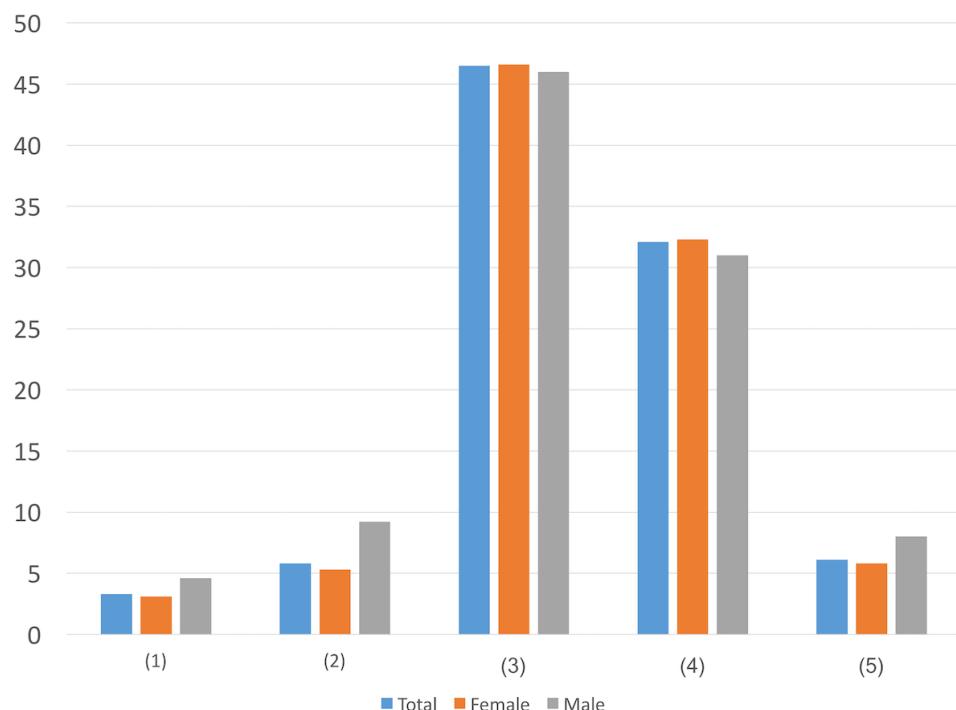
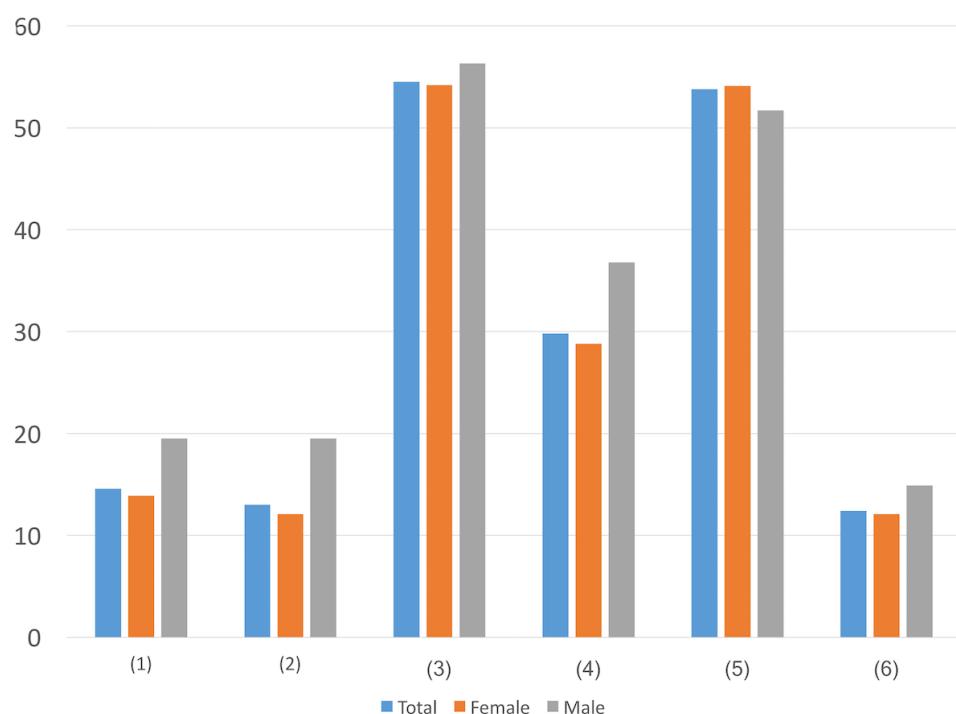
### Question 9

Question (Figure 9): Which caption of the article in the link would draw your attention the most?

1. You only live once, and we try our best to help you get rid of any psychological crisis
2. Dig out the potential to let yourself have a better life
3. Maybe you are in a difficult situation, but there are always solutions for you
4. Doesn't matter
5. Other options (please specify \_\_\_\_\_)

Most people (337/725, 46.5%) chose the caption “Maybe you are in a difficult situation, but there are always solutions for you.” While the participants may have felt neglected in the past due to pressure and discrimination around them, this option may make them feel valued.

**Figure 7.** Results of study 2 question 7.**Figure 8.** Results of study 2 question 8.

**Figure 9.** Results of study 2 question 9.**Figure 10.** Results of study 2 question 10.

### Question 10

Question (Figure 10): What do you hope will be the content of the article? (You can choose more than one answer.)

1. Inspiring words
2. Inspiring stories
3. Specific suggestions for coping with psychological crisis
4. A nonprofit psychological assistance hotline for you to call
5. More content about self-understanding as well as feedback from psychological testing

### 6. Other (please specify\_\_\_\_)

The majority of the respondents with suicide ideation requested the articles to include psychological assessment with feedback (390/725, 53.8%) and practical measures for crisis solving (395/725, 54.5%). The preference may suggest that the target population intends to seek specific advice and self-understanding skills as long as they are willing to click on the link.

## Discussion

### Principal Findings

In study 1, user preferences and attitudes toward direct messages as well as opinions on the prototype were reviewed. The nature of the intervention account received the most attention. The more reliable the account was, the more likely the provided link to extra information was accessed by the audience. In terms of the use of direct messages, they were employed mostly for purposes of comforting friends, greeting strangers, shopping online, etc. Direct messages were usually checked when notifications appeared, and a short text was mostly preferred. It was advised that the account name be changed to a more caring one in order for the audience to feel the support from the society. Another aspect to be changed was the content of the advice. It was suggested that the aim of direct message text to provide professional support and suicide intervention be highlighted. Communication with the patients was also emphasized to be conducted under privacy protection. Instead of a general text for the entire audience, a more customized design based on each individual's situation tended to be preferred. Overall, phone numbers from the psychological intervention centers were preferred to be added to the content of the text.

The goal of study 2 was to survey a large population of microblog users with potential suicide ideation about acceptable engagement messaging for individuals with suicide thoughts. Most participants were not opposed to receive direct messages and showed interest in having psychological assessment with feedback from professionals as well as the practical measures for dealing with a crisis. Consistent with the findings of study 1, study 2 found that the more reliable the account was, the more likely the participants would click on the extra link. This consistency was of much importance because it emphasized the role of the account name's reliability. Indeed, Langford and her colleagues [13] suggest that finding the target population's "usual and trusted information sources and media usage" is crucial. The more comfortable audience members are with the sources, the more likely they will prefer to learn the content of the messages.

In addition, most people (46.5%) chose the statement "Maybe you are in a difficult situation, but there are always solutions for you." While the participants may have felt neglected in the past due to pressure and discrimination around them, this option may make them feel valued. As shown in Langford's study [13], the audience's current perceptions are likely to shape their behavior. In this case, the participants may be shaped by their suicide ideation. If the audience feels the warmth from the society, they may be more likely to click on the link and feel less depressed after seeking help.

The majority of the participants (54.5%) chose specific suggestions for coping with psychological crisis in the article.

Like in the previous statement, if they find that the caption of the article brought them warmth, they may prefer to learn more specific skills to cope with suicide ideation.

In terms of gender differences, males in the groups tended to be more critical about the account name than females, while females preferred to receive attention and help from others. This difference may indicate the various perceptions males and females had toward direct messages; males valued privacy while females appreciated the warmth from the society.

Despite the differences, the reliability of the account was positively associated with both groups' tendency to open the link. It was also important for the text to contain psychological assessment with feedback for each individual. Paying attention to these details was crucial for designing an effective private message for the target population.

### Limitations

There were limitations to this project. The sample size was small, and gender distribution was biased. Future research should apply such messaging questions to a more male population as the male and female groups may have different responses as shown in study 2. Moreover, since the study was conducted on Sina Weibo, there could be a number of significant cross-cultural differences for generalizing the results to other populations (eg, Twitter in the United States). In addition, the interviews were not theory-based due to a lack of prior research for proactive online suicide interventions.

### Conclusion

We consulted with 2 groups of participants with self-reported suicide thoughts to help generate appropriate direct messages for help. Direct message is a vital function in Sina Weibo and may be used to reach any Weibo user with suicide ideation [7-11]. Receiving feedback from our participants was particularly important since we wanted to avoid messaging that would not draw attention and prevent people who had suicide ideation from seeking treatment. The results of the 2 studies showed that the account name's reliability, brevity of the private chat, and details of the phone numbers of the psychological intervention centers as well as psychological assessment were associated with the attractiveness of the private chat. This paper provided 1 model for including target users in the development of direct messages for online suicide interventions.

Future research should include various explorations around messaging (eg, instead of sending out direct messages, a chatbot could be employed to interact with users) to determine how interventions might be delivered based on various message media. Larger samples in a future study could permit us to have a greater understanding of the differences between subgroups of the target population (depending on symptoms, preferences, etc) when delivering the interventions.

## Acknowledgments

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## Conflicts of Interest

None declared.

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## Abbreviations

**ASIQ-4:** Adult Suicide Ideation Questionnaire

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Original Paper

# Using Social Media Data to Understand the Impact of Promotional Information on Laypeople's Discussions: A Case Study of Lynch Syndrome

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## Abstract

**Background:** Social media is being used by various stakeholders among pharmaceutical companies, government agencies, health care organizations, professionals, and news media as a way of engaging audiences to raise disease awareness and ultimately to improve public health. Nevertheless, it is unclear what effects this health information has on laypeople.

**Objective:** This study aimed to provide a detailed examination of how promotional health information related to Lynch syndrome impacts laypeople's discussions on a social media platform (Twitter) in terms of topic awareness and attitudes.

**Methods:** We used topic modeling and sentiment analysis techniques on Lynch syndrome-related tweets to answer the following research questions (RQs): (1) what are the most discussed topics in Lynch syndrome-related tweets?; (2) how promotional Lynch syndrome-related information on Twitter affects laypeople's discussions?; and (3) what impact do the Lynch syndrome awareness activities in the Colon Cancer Awareness Month and Lynch Syndrome Awareness Day have on laypeople's discussions and their attitudes? In particular, we used a set of keywords to collect Lynch syndrome-related tweets from October 26, 2016 to August 11, 2017 (289 days) through the Twitter public search application programming interface (API). We experimented with two different classification methods to categorize tweets into the following three classes: (1) irrelevant, (2) promotional health information, and (3) laypeople's discussions. We applied a topic modeling method to discover the themes in these Lynch syndrome-related tweets and conducted sentiment analysis on each layperson's tweet to gauge the writer's attitude (ie, positive, negative, and neutral) toward Lynch syndrome. The topic modeling and sentiment analysis results were elaborated to answer the three RQs.

**Results:** Of all tweets (N=16,667), 87.38% (14,564/16,667) were related to Lynch syndrome. Of the Lynch syndrome-related tweets, 81.43% (11,860/14,564) were classified as promotional and 18.57% (2704/14,564) were classified as laypeople's discussions. The most discussed themes were *treatment* (n=4080) and *genetic testing* (n=3073). We found that the topic distributions in laypeople's discussions were similar to the distributions in promotional Lynch syndrome-related information. Furthermore, most people had a positive attitude when discussing Lynch syndrome. The proportion of negative tweets was 3.51%. Within each

topic, *treatment* (16.67%) and *genetic testing* (5.60%) had more negative tweets compared with other topics. When comparing monthly trends, laypeople's discussions had a strong correlation with promotional Lynch syndrome-related information on *awareness* ( $r=.98, P<.001$ ), while there were moderate correlations on *screening* ( $r=.602, P=.05$ ), *genetic testing* ( $r=.624, P=.04$ ), *treatment* ( $r=.69, P=.02$ ), and *risk* ( $r=.66, P=.03$ ). We also discovered that the Colon Cancer Awareness Month (March 2017) and the Lynch Syndrome Awareness Day (March 22, 2017) had significant positive impacts on laypeople's discussions and their attitudes.

**Conclusions:** There is evidence that participative social media platforms, namely Twitter, offer unique opportunities to inform cancer communication surveillance and to explore the mechanisms by which these new communication media affect individual health behavior and population health.

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## KEYWORDS

social media; Lynch syndrome; public health surveillance; sentiment analysis

## Introduction

In 2000, President Bill Clinton signed a White House Proclamation that March was to be designated as the Colon Cancer Awareness Month to bring attention to the second leading cause of cancer death in the United States. Lynch syndrome, also known as hereditary nonpolyposis colorectal cancer (HNPCC), is an inherited disorder that increases the risk of colon and rectum cancers, in particular, and many other types of cancer such as the stomach, liver, gallbladder ducts, small intestine, upper urinary tract, brain, and skin [1]. Lynch syndrome is the most common cause of hereditary colorectal cancer, accounting for approximately 2% to 3% of inherited colon cancer cases [2]. March 22 is recognized as the Lynch Syndrome Awareness Day by communities around the world [3].

Social media brought rapid changes to the health communication landscape. In particular, social media platforms have been used to promote healthy behavior [4], improve medical and patient education [5,6], overcome barriers in the delivery of health care [7], and address public health surveillance issues [8,9]. On one side, public health stakeholders, including health organizations, government agencies, pharmaceutical companies, news media, and advocates, use social media to broadly disseminate health information on the Internet. On the other hand, laypeople share their personal health experience, post comments, and express opinions toward specific health issues, medical products, and health care services. However, there have been very few studies on Lynch syndrome and social media. Through a PubMed search, we found only one study, where the authors asked an advocacy organization to disseminate their study information on Facebook to show the feasibility of recruiting participants with Lynch syndrome on a social media platform [10].

Twitter is a free social media platform that enables users to send and read short 140-character posts called "tweets." Twitter analyses have been used in numerous biomedical and public health studies, with a broad range of health topics [11]. For example, Broniatowski et al have successfully used Twitter data for influenza surveillance [12]. Workewych et al hypothesized that Twitter data might be useful for understanding public perceptions and misperceptions of sport-related traumatic brain injuries [13]. Massey et al quantified human papillomavirus (HPV) vaccination communication on Twitter and used

sentiment analysis to examined people's attitudes toward HPV vaccination [14]. Cole-Lewis et al conducted a content analysis to identify key conversation trends about electronic cigarettes (e-cigarettes) by using historical Twitter data [15].

In this paper, we use Lynch syndrome as a case study to find popular Lynch syndrome-related topics discussed on Twitter, examine the correlations between promotional Lynch syndrome-related information (eg, information related to advertising, sales promotion, and public relations) and laypeople's discussions (eg, comments toward health services, opinions to a policy, and self-expression of their feelings), and learn the influence of Lynch syndrome awareness events on laypeople's discussions. Note that we classified the tweets based on information types rather than user types. It is possible that a layperson (eg, Lynch syndrome patient) who was well educated about the disease could also post tweets to promote awareness of and deliver knowledge on Lynch syndrome. Nevertheless, these tweets were categorized into promotional information in our study. Analyzing laypeople's discussions on Twitter will be an extremely helpful tool to glean into laypeople's awareness, perceptions, and attitudes toward Lynch syndrome and colorectal cancer for various stakeholders, including pharmaceutical companies, government agencies, health care organizations and professionals, and news media. For example, health advocacy groups can adjust their health communication strategies from learning the hot topics in laypeople's discussions to optimize the dissemination of promotional health information. Through understanding how awareness events could impact laypeople's perceptions and attitudes, health care organizations have the opportunity to estimate the influence of their promotional health events on laypeople's behavior for future planning.

The central objective of our study was to understand how promotional Lynch syndrome-related health information impact laypeople's discussions on Twitter. This study aims to answer the following research questions (RQ):

RQ1: What are the most discussed topics in Lynch syndrome-related tweets?

RQ2: How promotional Lynch syndrome-related information on Twitter affects laypeople's discussions in terms of topic distributions?

RQ3: Do the Colon Cancer Awareness Month (March) and the Lynch Syndrome Awareness Day (March 22) have any impact on laypeople's discussions on Twitter and their attitudes?

## Methods

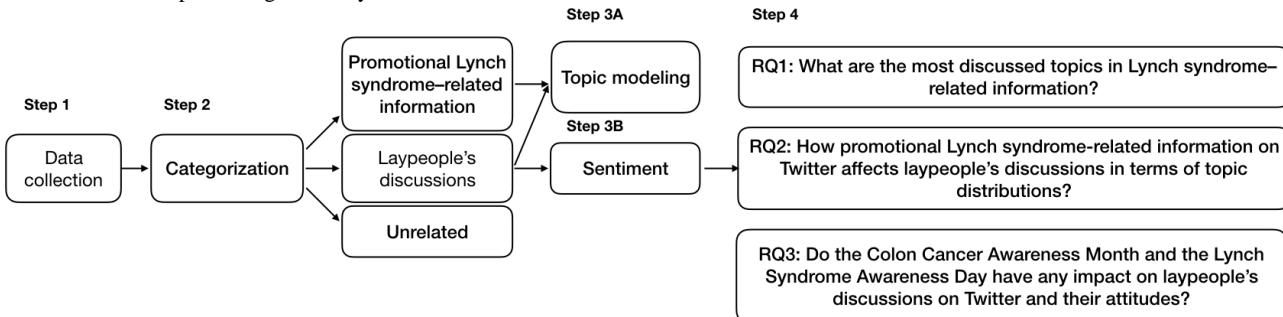
### Data Analysis Overview

Our data analysis comprised the following 4 steps, schematized in Figure 1:

- Step 1 was data collection and preprocessing. We collected public tweets based on a set of keywords related to Lynch syndrome using the Twitter application programming interface (API). We then filtered out non-English tweets and standardized the texts (eg, hashtags and Web links).
- Step 2 was categorization of the tweets. We separated laypeople's discussions from promotional Lynch syndrome-related information. We experimented with two methods to automatically classify the Twitter data—a convolutional neural network (CNN) and a rule-based classifier.
- Step 3 was topic modeling and sentiment analysis:
  - A. Topic modeling: We used the latent Dirichlet allocation (LDA) model to determine the major discussion themes in the collected Twitter dataset for both promotional information and laypeople's discussions.
  - B. Sentiment analysis: We built a CNN to assign each tweet in the laypeople's discussions with a sentiment label, namely, positive, negative, and neutral.
- Step 4 included RQs to examine the relationships between promotional Lynch syndrome-related information and laypeople's discussions through analyzing the results of topic modeling and sentiment analysis. We presented frequency tables for Lynch syndrome-related topics on Twitter, correlations between promotional Lynch syndrome-related information and laypeople's discussions, and trends of topics/sentiments in relation to awareness during the 2017 March Colon Cancer Awareness Month and the March 22 Lynch Syndrome Awareness Day.

Through these analyses, we aimed to answer the three RQs posted above.

**Figure 1.** Twitter data processing and analysis workflow.



### A Convolutional Neural Network Classifier

CNNs have been widely used for sentence classification tasks with state-of-the-art performance [18]. To build a CNN classifier, we first needed an annotated training dataset. We randomly selected 1000 tweets, which were read and labeled by 2 reviewers independently. The annotation task was to categorize each tweet into one of the following three classes: (1) irrelevant to Lynch syndrome (ie, even though a tweet contains Lynch syndrome–related keywords, the tweet may not be relevant to Lynch syndrome, eg, “I don't have time or patience or business entertaining nobody Willie Lynch syndrome”); (2) Lynch syndrome–related promotional information (eg, news, research articles, promotional messages, and advertisements such as “RT @ShewithLynch: #Lynchsyndrome #News: Earlier Screening Could Save Many From Colorectal Cancer, Research Suggests - <https://t.co/DVEb2xaD>”); and (3) laypeople's discussions related to Lynch syndrome (eg, “First #colonoscopy appointment set. I'll have to do this at least once a year for the rest of my life #lynchsyndrome #coloncancerawareness”).

A common strategy for building CNN sentence classifiers is to use word embedding [19] to transform raw texts into vectors of real numbers as features. We used the pretrained word vectors from GloVe, which were trained on 2 billion tweets with 1.2 million vocabularies. For each tweet, a matrix was built by mapping each word in the tweet to its corresponding word embedding vector in d dimensions. As the length of each tweet varies, we padded tweets whose lengths were smaller than the longest tweet with zeros. Thus, all tweets were transformed into word embedding feature matrices with the same dimension. These feature matrices were then fed into the CNNs.

We built two CNNs using the same feature matrices: one that classified the tweets into relevant versus irrelevant, and another one that further classified the relevant tweets into promotion Lynch syndrome–related information versus laypeople's discussions.

### Rule-Based Classification

Through examining a random sample of the collected tweets, we found that 96% of the irrelevant tweets have the keywords “willie” or “willy,” referring to a person named “Willy Lynch.” Thus, we built a simple rule-based classifier that categorized a tweet as irrelevant if it contains any of the two keywords. Furthermore, within the relevant dataset, we observed that 88% of laypeople's discussions did not contain any links. The promotional Lynch syndrome–related tweets were usually mentions of Lynch syndrome–related news, research findings such as new diagnostic or treatment techniques, and health promotion activities. Due to the 140-character length limit of each tweet, users often used hyperlinks in their tweets to refer to the source articles. On the contrary, laypeople's discussions were typically expressions of their own attitudes or opinions without any references to other sources of information. Thus, in the second step, a tweet was classified as promotional Lynch syndrome–related information if the tweet contains any links. Otherwise, the tweet was categorized as a layperson's discussion.

### Step 3A: Topic Modeling

In natural language processing, a topic model is a statistical model that can discover abstract topics in a collection of documents [20]. We used the LDA algorithm in this study to find main topics that are presented in the overall Twitter data, including both promotional Lynch syndrome–related information and laypeople's discussions [21]. LDA is a generative model that represents each document (ie, a tweet in our case) as a mixture of latent topics, and each topic can generate words with certain probabilities. One of the most significant features of topic models is that they do not require any prior annotations or labeling of the documents. Nevertheless, similar to many other unsupervised clustering algorithms, the number of topics is a parameter that needs to be determined a priori. We experimented with three different statistical methods for finding the appropriate number of topics for LDA as follows: (1) Arun2010: Arun et al viewed LDA as a matrix factorization mechanism that can decompose a topic distribution into matrix factors. They then computed the symmetric Kullback-Leibler divergence of salient distributions that are derived from these matrix factors. They observed that the divergence values are higher for the nonoptimal number of topics [22]; (2) Cao2009: Cao et al considered the LDA process similar to the density-based clustering algorithms. Thus, the goal of finding the best number of topics is similar to finding the best number of clusters, where it maximizes the intracluster similarities while minimizing the intercluster similarities [23]; and (3) Deveaud2014: Deveaud et al, similar to the Arun2010 method, used a simple heuristic that estimates the number of latent topics by maximizing the information divergence (ie, Jensen-Shannon divergence) among all pairs of LDA's topics [24]. However, these statistical methods do not always converge, and often, the number of topics discovered does not conform to human judgments. Thus, additional qualitative analysis of the generated topics to determine their quality is still necessary.

Before applying the LDA algorithm, we further preprocessed the Twitter data to lemmatize the words and to remove words that are commonly used but irrelevant to the topics that we aim to discover based on a list of stop words (eg, “it,” “he,” “she,” and “that”). We followed the best practices in training LDA models. As we learned probability distributions of words per topic (and a probability distribution of these topics over the entire collection of documents, ie, tweets) through LDA, each topic can be naturally visualized as word clouds where the sizes of the words are proportional to their probabilities on the topic.

To learn the volume trend of each topic, we also need to know the topic of each tweet. An LDA model can also assign each tweet with topics based on the content of the tweet. As described in the LDA model, each tweet is a mixture of topics, where each topic has a certain probability to appear in the tweet. Thus, all topics have a probability value for each tweet, and topics that are unlikely to appear have a small probability value. In other words, each topic assigned to a tweet has a probability to represent how a tweet will be classified into that specific topic. Thus, we needed to determine a cutoff for the topic probability values so that each tweet was assigned an accurate topic. In cases where the tweet was assigned more than one topics, we chose the topic with the highest probability value.

**Textbox 1.** Three research questions analyzed using the results of topic modeling and sentiment analysis to understand the impact of promotional Lynch syndrome–related information on laypeople’s discussions.

1. What are the thematic topics in Lynch syndrome–related tweets?
  - We qualitatively analyzed the topics discovered from the latent Dirichlet allocation (LDA) model and visualized the latent topics with a set of word clouds.
  - We plotted the volume of tweets for each topic category and ranked the topics by popularity.
  - We examined the descriptive statistics of the overall laypeople’s sentiments as well as their sentiments by topic.
2. How promotional Lynch syndrome–related information on Twitter affects laypeople’s discussions in terms of topic distributions?
  - We calculated the proportion of each topic within their user groups (ie, promotional Lynch syndrome–related information and laypeople’s discussions) and visualized the topic distribution results as word clouds to examine whether promotional Lynch syndrome–related information has a similar topic distribution to laypeople’s discussions.
  - We plotted the monthly trends of the topics for both promotional Lynch syndrome–related information and laypeople’s discussions. We also examined the correlations between these trends using the Pearson correlation efficient.
3. Do Colon Cancer Awareness Month (March) and Lynch Syndrome Awareness Day (March 22) have any impact on laypeople’s discussions on Twitter and their attitudes (ie, positive, negative, and neutral)?
  - We examined how the overall tweet volume changed during these time periods as well as how the tweet volumes of different topics changed.
  - We also plotted the trends of people’s overall sentiments and their sentiments by topic across the entire time period and examined the changes during the event times.

### Step 3B: Sentiment Analysis

Sentiment analysis is a popular natural language processing method frequently used to determine the opinion, attitude, or the emotional state of the writer from a piece of writing. A basic task in sentiment analysis is to classify the polarity (ie, positive, negative, and neutral) of a given text. There are two main sentiment analysis approaches [25] as follows: (1) machine learning–based methods that build classification models from labeled training data and (2) lexicon-based techniques such as Linguistic Inquiry and Word Count [26] that ties word choices to authors’ opinions. Following the machine learning–based approach, we built a CNN model following the same process we used in step 2 for sentiment classification. The training data contained 1092 tweets (ie, we started with 1500 random tweets; after deduplication, 1092 tweets were left for annotation) randomly selected from laypeople’s tweets (ie, as we were only interested in laypeople’s attitudes toward Lynch syndrome) and annotated by two coders (YZ and LJR) into three categories: positive, negative, and neutral. The Cohen kappa is .89, which suggests a strong agreement between the two coders. A third reviewer (JB) was consulted to resolve the disagreements between the two coders.

### Step 4: Research Questions

We answered the three RQs through analyzing the results of topic modeling and sentiment analysis in the following steps (Textbox 1).

## Results

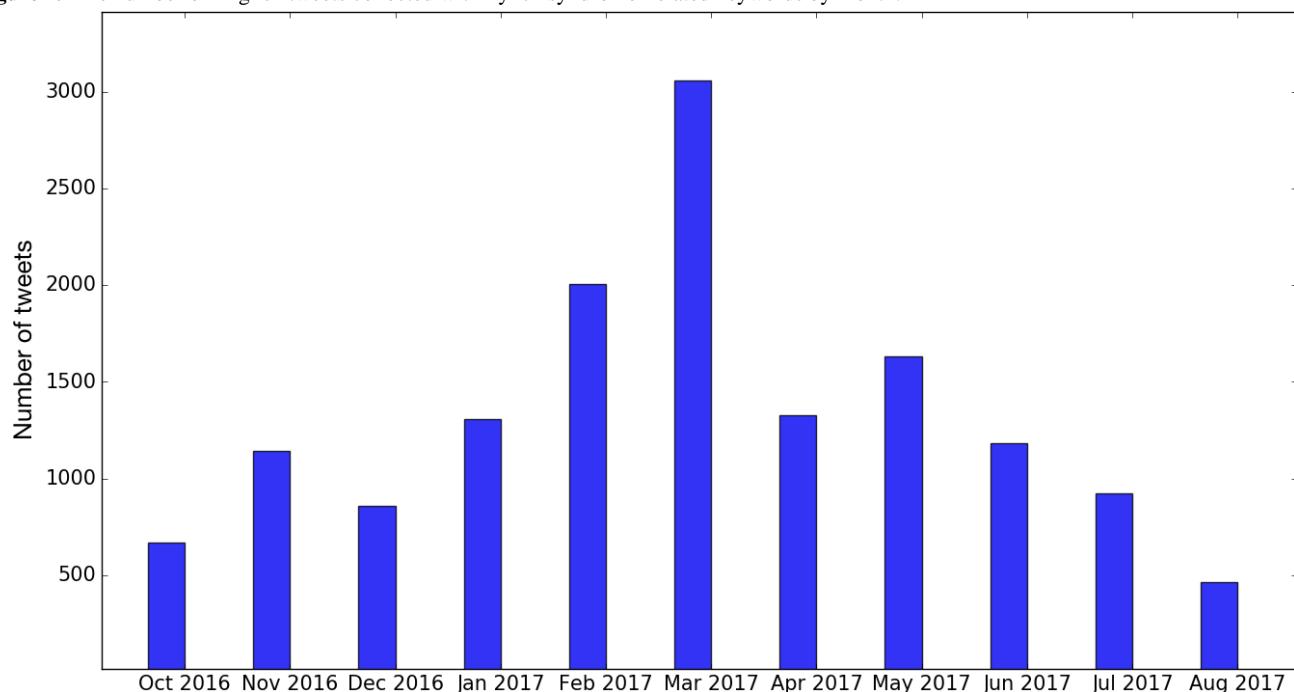
### Step 1: Data Collection and Preprocessing

Using the Twitter API via a Twitter crawler [16], a total of 16,667 tweets were collected from October 26, 2016 to August 11, 2017. After preprocessing and removal of non-English tweets, there were 14,564 tweets left. Figure 2 shows the monthly distribution of the English tweets during that time period.

### Step 2: Categorization of Tweets

The annotation task created a gold standard dataset of 1000 random tweets. There was a moderate agreement between the two coders (ie, Cohen kappa=.72) [27]. A third person reviewed the disagreements and placed those tweets into the appropriate category. We explored two classification methods (ie, a CNN model and a rule-based classifier) and compared their performance. As the dataset is unbalanced (ie, most tweets were relevant as we used very specific keywords to collect these data, and there were more promotional tweets than laypeople’s discussions), we used the weighted precision, recall, and F-measure to measure the classifiers’ performance.

As shown in Table 1, even though the rule-based classifier is simple, it outperformed the complex CNN model in both classification tasks. Thus, we used the rule-based classifier to categorize all tweets. Out of the 14,564 English tweets, 11,860 tweets were classified as relevant. Within the relevant tweets, 2705 tweets belonged to laypeople’s discussions, and 11,077 were promotional Lynch syndrome–related information.

**Figure 2.** The number of English tweets collected with Lynch syndrome–related keywords by month.**Table 1.** A comparison of the two classifiers' performance.

Classification Methods	Relevant versus irrelevant			Promotional versus laypeople		
	Precision	Recall	F-measure	Precision	Recall	F-measure
Convolutional neural network	.651	.807	.720	.514	.717	.599
Rule-based	.938	.935	.936	.877	.870	.873

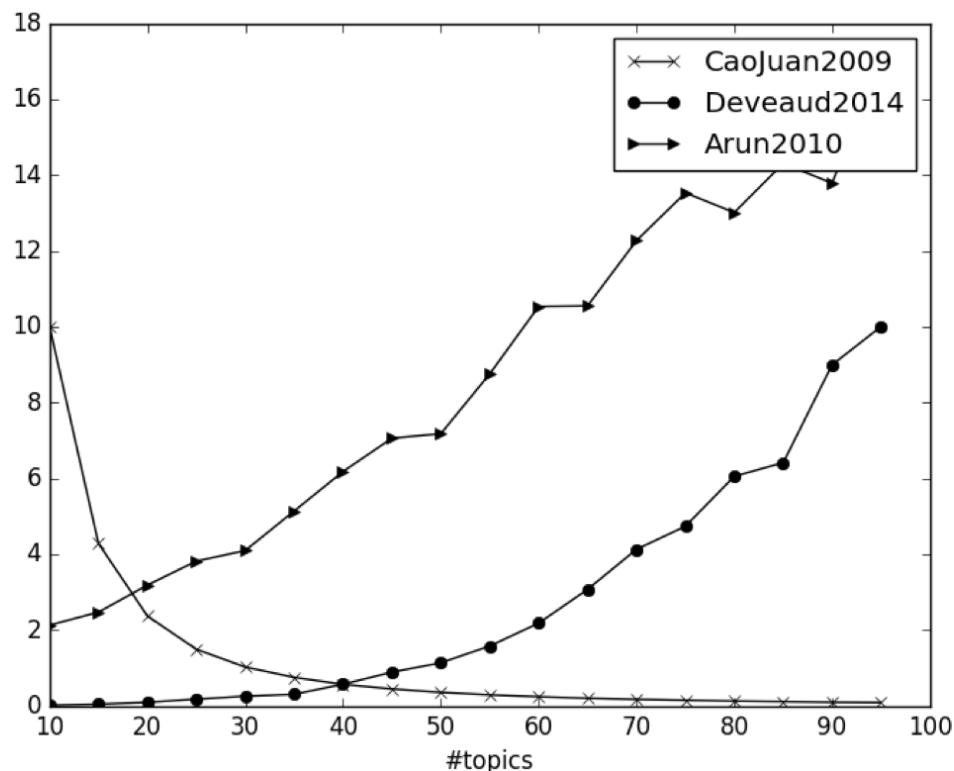
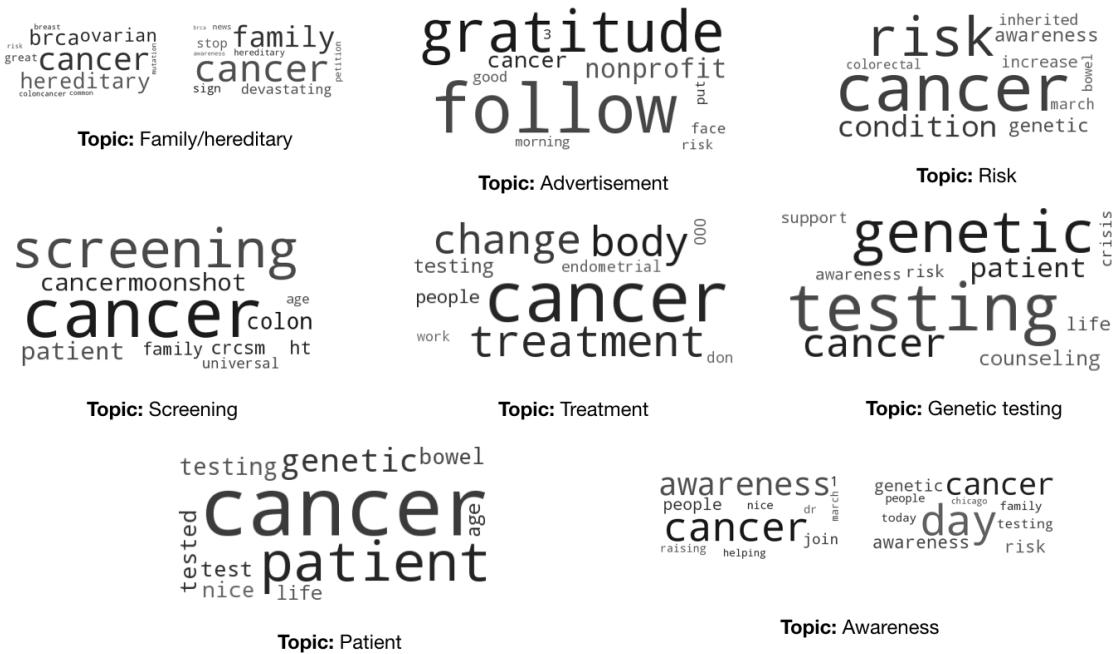
### Step 3A: Topic Modeling

We tried all three statistical methods to find the number of topics in the Lynch syndrome–related tweets (ie, tweets that were classified as relevant). As shown in [Figure 3](#), none of the three methods converged and allowed us to select the appropriate number of topics. Note that we did not show the units of the y-axis in [Figure 3](#) as the three different measures have different units. Nevertheless, the units of the measures were not important as the goal was to find the “elbow” points of the curves, which would indicate the optimal number of topics.

Thus, we experimented with 10, 15, 20, and 30 topics and used word clouds to visualize the results. In each iteration, varying the number of topics ( $K=10, 15, 20$ , and  $30$ ), two coders were presented with the word clouds and a set of example tweets of the topics and were asked to assign each topic a label based on their judgments, independently. Each coder was also asked to identify duplicate topics and topics with poor quality (ie, the keywords in the topic did not represent a cohesive concept). We then chose a  $K$  that generated the least number of duplicate topics and inadequate topics. We determined that the most adequate number of topics was 10 and identified the labels for all topics. In cases where the coders did not agree on the particular label, the conflicts were resolved through discussions

with the entire study team. We also merged the topics that had similar semantics into a single category. For example, “awareness event” typically contains event information to raise Lynch syndrome awareness, whereas the tweets in the “awareness” theme raise Lynch syndrome knowledge. We, thus, combined “awareness event” and “awareness” to “awareness/awareness event.” The final extracted topics and associated word clouds are shown in [Figure 4](#).

After generating the topics, the LDA model was also able to assign a topic probability distribution for each tweet. As shown in [Table 2](#), LDA assigned a probability value to every topic, even when a topic is unlikely to be in the tweet. Thus, we needed to find a cut-off probability value to extract the main topics of each tweet. We first generated a random sample of 50 tweets and iteratively tested different cut-off values. In each iteration, we evaluated the topics above the cut-off probability value assigned to the 50 tweets and manually determined whether the assignments were appropriate. We chose the cut-off value that generated the minimum number of topics for each tweet, and the accuracy was above 80% (ie, more than 80% of the tweets had the correct topic assignments through manual review). As a result, some tweets were assigned multiple topics, whereas others did not have any topics. [Table 3](#) shows an example of tweets in each topic.

**Figure 3.** The three topic modeling quality measures by the number of topics.**Figure 4.** The eight topics learned from Lynch syndrome–related tweets.

**Table 2.** Example of topics and their probabilities assigned to each tweet.

Category	Tweet	Top 3 topics (topic probability)
Promotional	“What is risk of pts w #Lynchsyndrome developing various cancers over time? Population-based study offers answers.”	Risk (.644), genetic testing (.197), treatment (.118)
	“Adapting to body changes during #cancer treatment #LynchSyndrome”	Treatment (.533), patient (.276), family (.139)
Laypeople	“I have Lynch Syndrome with 60-80% chance of dying from colon cancer just like my mother and brother #IAmAPreexistingCondition”	Family and hereditary (.442), screening (.327), patient (.172)
	“My #breastcancer diagnosis caused me to get a #genetics test & found out I have a gene 4 #LynchSyndrome #earlydetection #ColonCancerMonth”	Patient (.716), risk (.128), awareness/awareness event (.119)

**Table 3.** Example tweets by topic.

Topics	Example Tweets
Family and hereditary	“This week, we highlight Lynch Syndrome, Familial Hypercholesterolemia & Hereditary Breast & Ovarian Cancer.” “Aiming to prevent hereditary cancers, researchers focus on #LynchSyndrome #NCICancerCurrentsBlog #Cancer”
Screening	“#Lynchsyndrome #News: Earlier Screening Could Save Many From Colorectal Cancer, Research Suggests” “Universal tumor screening for #Lynchsyndrome: health-care providers’ perspectives.”
Advertisement	“Gratitude to our new followers! Join us #Monday for #GenCSM! #Lynchsyndrome #HereditaryColorectalCancer” “#Lynchsyndrome #GenCSM: Gratitude to all of my new followers! Have a stellar day!! G @ the #Nonprofit:”
Treatment	“Total abdominal colectomy is recommended for treatment of CRC in individuals who are known to have #LynchSyndrome #Hered,” “#Treatment Continues to Advance in #OvarianCancer and Other Gynecologic Malignancies”
Patient	“Patient with newly found #LynchSyndrome says 30+yo children refuse testing due to ‘inconvenience’.” Hope time/education change minds #GCchat,” “1/44 #coloncancer patients have #Lynchsyndrome @HHampel1 @theNCI #Moonshot #hereditarycancer”
Risk	“btw, glioblastoma is very malignant + chemicals like pesticides are risk factors. Genetic disorders like Lynch syndrome is a risk factor.” “Authors state that the cumulative lifetime risk to develop ovarian cancer in their patients with Lynch syndrome: 20% by age 80”
Genetic testing	“mom got back the genetic tests and apparently they pinged the tumor to a genetic mutation so 24% chance of her having lynch syndrome ;;; ugh” “Inherited colon cancer syndromes can be predicted through genetic testing. #GetScreened #LynchSyndrome”
Awareness/awareness event	“Happy #lynchsyndromeawarenessday! #Lynchsyndrome #Genetics” “#coloncancer awareness month - if U were diagnosed w/ CRC, make sure your tumor was screened 4 #Lynch syndrome with IHC or MSI testing”

### Step 3B: Sentiment Analysis

We trained a sentiment CNN classifier with the 1092 annotated tweets. We followed the best practices in machine learning experiments to build the CNN, for example, use 80% of the tweets as the training dataset, and measured the performance of the classifier on the remaining 20% hold-out test set. The performance of the CNN classifier was reasonable (ie, precision: .737, recall: .766, F-measure: .736, and accuracy: .766).

### Step 4: Research Questions

#### *RQ1: What Are the Thematic Topics in Lynch Syndrome-Related Tweets?*

We plotted a histogram of tweet volumes by topic and ranked the topics by volume as shown in Figure 5.

*Treatment, genetic testing, and awareness* were the top three topics in Lynch syndrome-related tweets.

We plotted the sentiment distribution of the overall laypeople’s discussion tweets as well as the sentiment distribution of each topic as shown in Table 4. Overall, most of the tweets were neutral (78.07%), although there were significantly more positive (18.42%) than negative (3.51%) tweets. Across the sentiment distribution of topics, only the *treatment* topic had more negative (16.67%) than positive tweets.

#### *RQ 2: How Promotional Lynch Syndrome-Related Information on Twitter Affects Laypeople’s Discussions in Terms of Topic Distributions?*

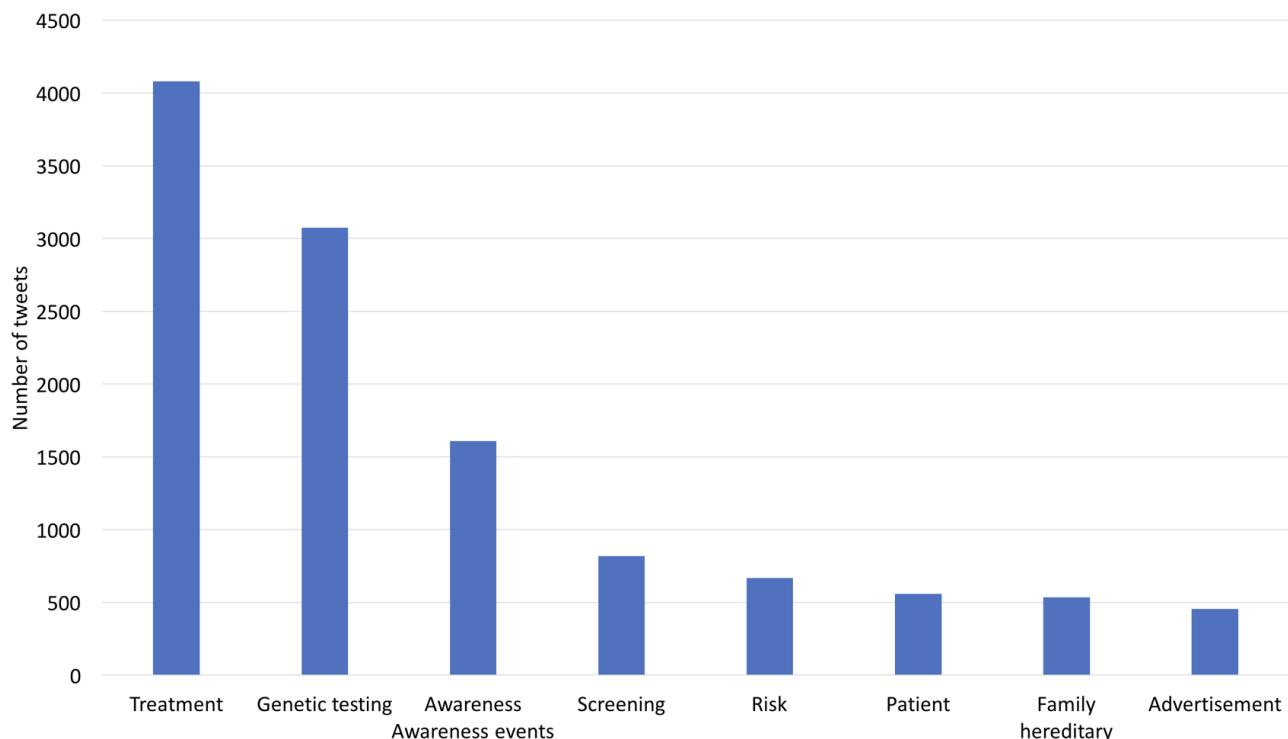
We calculated the proportion of each topic in both promotional Lynch syndrome-related information and laypeople’s discussions and visually compared the results by using word

clouds. As shown in **Figure 6**, the topics and their proportions in the laypeople's discussions were similar to those in the promotional Lynch syndrome–related information

We also calculated the Pearson correlation coefficient [28] between the promotional Lynch syndrome–related information

and laypeople's discussion based on their monthly tweet volumes (as shown in **Figure 7**). As shown in **Table 5**, laypeople's discussions had a strong correlation with promotional Lynch syndrome–related information on the *awareness* topic and moderate correlations on the topics *screening, genetic testing, treatment, and risk*.

**Figure 5.** The number of tweets across different topics learned from the Latent Dirichlet allocation model.



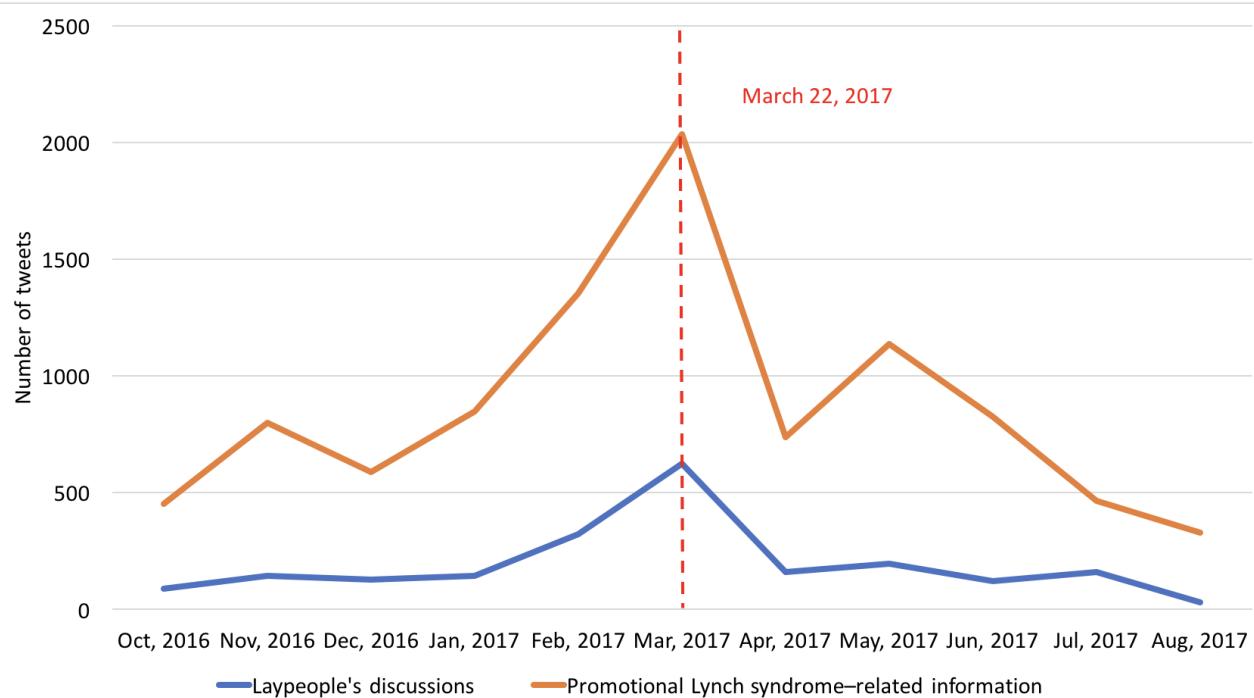
**Table 4.** Laypeople's overall sentiment distribution on Lynch syndrome and their sentiment distributions across topics.

Topic	Positive (%)	Negative (%)	Neutral (%)
Family and hereditary	31 (35.63)	2 (2.30)	54 (62.07)
Screening	11 (8.73)	3 (2.38)	112 (88.89)
Advertisement	36 (41.86)	2 (2.33)	48 (55.81)
Treatment	0 (0.00)	78 (16.67)	390 (83.33)
Patient	97 (49.75)	1 (0.51)	98 (49.75)
Risk	24 (12.00)	0 (0.00)	176 (98.00)
Genetic testing	28 (17.40)	9 (5.59)	124 (77.00)
Awareness and awareness events	60 (20.00)	0 (0.00)	240 (80.00)
Overall	498 (18.42)	95 (3.51)	2111 (78.07)

**Figure 6.** Topic proportions of promotional Lynch syndrome–related information and laypeople's discussions.



**Figure 7.** The number of Lynch syndrome–related tweets by month and by tweet type (ie, promotional Lynch syndrome–related information vs laypeople’s discussions).



**Table 5.** Pearson correlation coefficients between promotional Lynch syndrome–related information and laypeople’s discussions based on their monthly tweet volumes.

Topic	Correlation coefficient	P value
Family/hereditary	.479	.14
Screening	.602	.05
Advertisement	.112	.74
Treatment	.698	.02
Patient	.211	.53
Risk	.659	.03
Genetic testing	.624	.04
Awareness/awareness events	.989	<.001

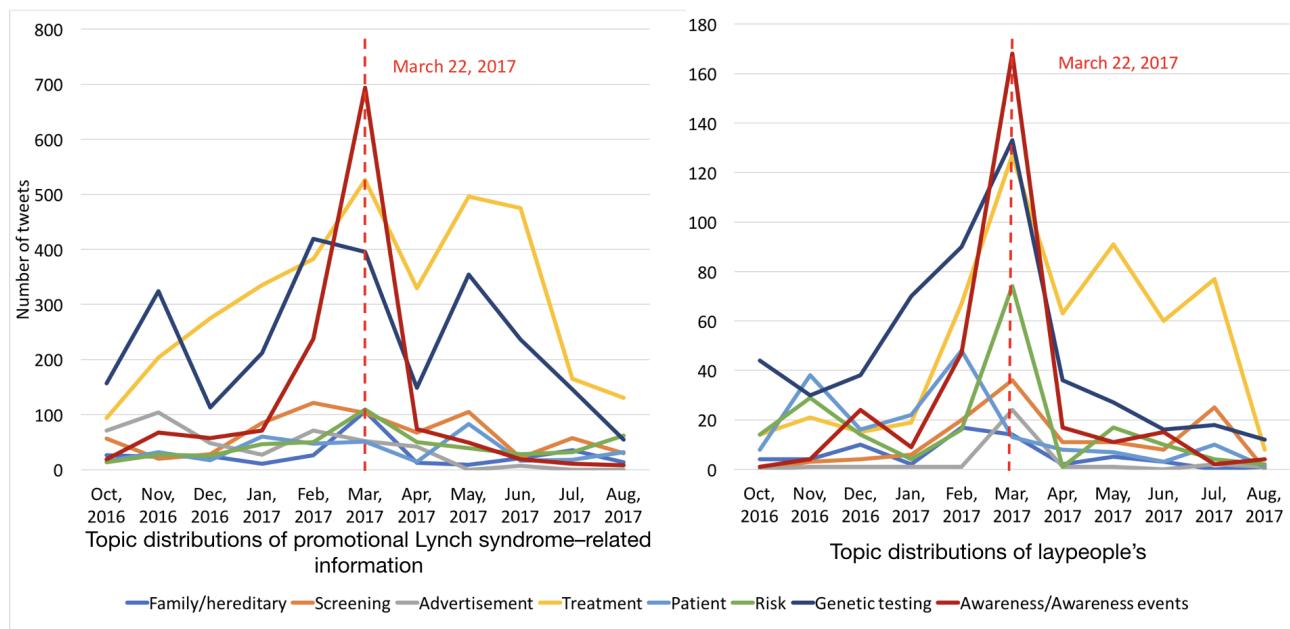
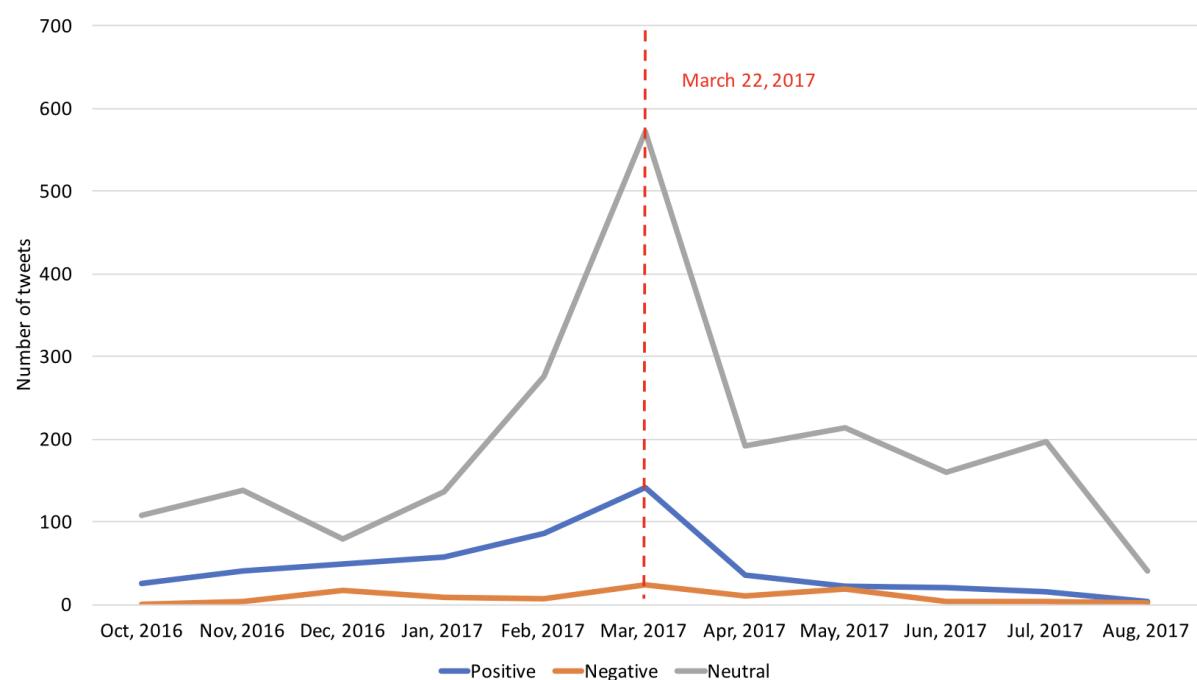
**RQ 3: Do the Colon Cancer Awareness Month (March) and the Lynch Syndrome Awareness Day (March 22) Have Any Impact on Laypeople’s Discussions on Twitter and Their Attitudes (ie, Positive, Negative, and Neutral)?**

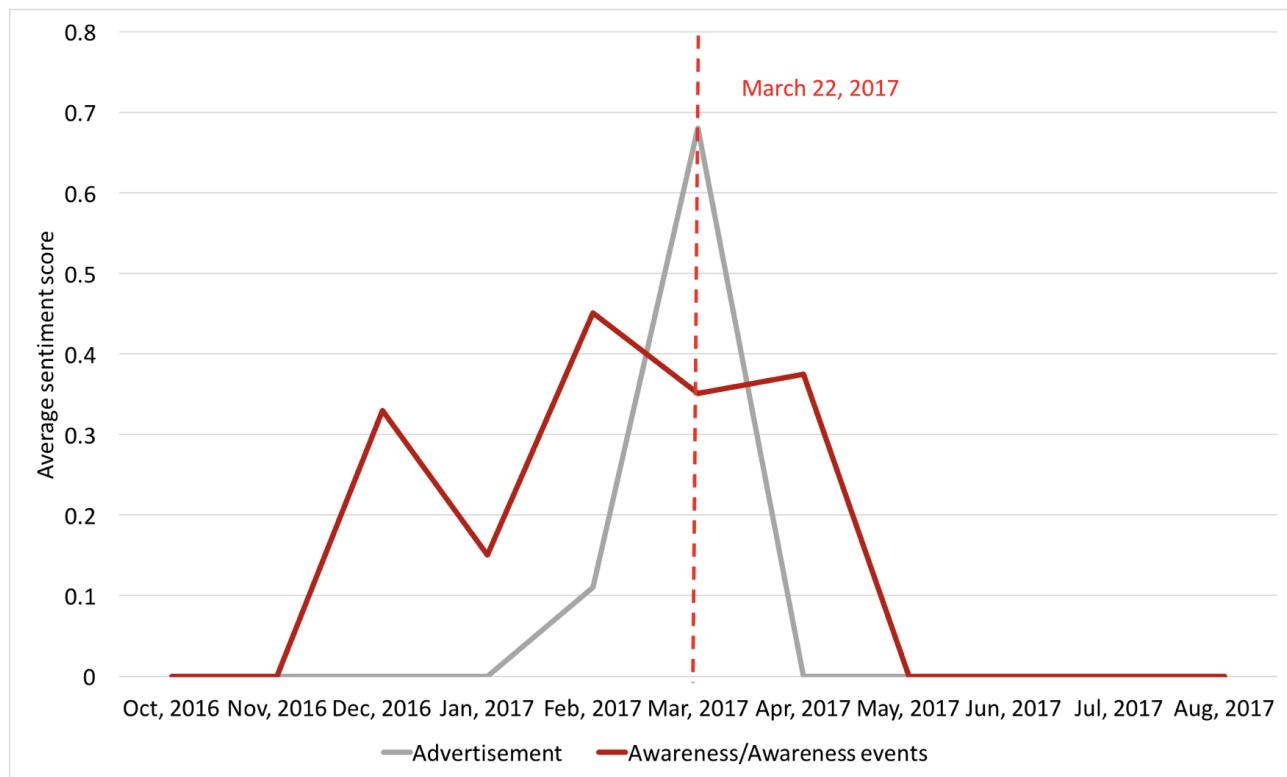
As shown in Figure 7, the overall tweet volume increased dramatically during the March Colon Cancer Awareness Month and peaked around the Lynch Syndrome Awareness Day on March 22, 2017. Furthermore, as shown in Figure 8, the tweet volumes of individual topics followed the same pattern, especially for “awareness/awareness events,” “genetic testing,” and “patient.”

We then plotted the overall tweet volume trends by different sentiment categories in laypeople’s discussions as shown in Figure 9. The volume of negative tweets remained roughly the same across the entire time period. The volume of neutral tweets sharply increased in the month of March, reflecting a significant

tweet volume increase during that month (Figure 2). The volume of positive tweets also increased in March, but it was less aggressive than neutral tweets.

We further analyzed laypeople’s sentiment trends by topic to understand on which topics the laypeople had obvious attitude changes during the awareness events. We constructed an average sentiment score for each month for each topic. For each individual tweet, we assigned it a score of 1 if it was positive, 0 if it was neutral, and -1 if it was negative. We summed up the scores for all tweets in each topic by month and normalized the score by the total number of tweets in that topic category for that month. As shown in Figure 10, the average sentiment scores for “advertisement” and “awareness/awareness events” increased significantly during the March Awareness Month but dropped immediately afterward. There were no clear sentiment trends for other topics.

**Figure 8.** The number of Lynch syndrome–related tweets by month and by topic.**Figure 9.** The number of tweets by month and by laypeople's sentiment.

**Figure 10.** The average sentiment scores for “advertisement” and “awareness/awareness events” topics by month.

## Discussion

### Principal Findings

The goal of our study was to understand how promotional Lynch syndrome–related health information impacts laypeople’s discussions on Twitter. We used topic modeling and sentiment analysis on Lynch syndrome–related tweets to answer the following 3 RQs: (1) what are the most discussed topics in Lynch syndrome–related tweets?; (2) how promotional Lynch syndrome–related information on Twitter affects laypeople’s discussions?; and (3) what impact do the Lynch syndrome awareness activities in the Colon Cancer Awareness Month and Lynch Syndrome Awareness Day have on laypeople’s discussions and their attitudes? We found that “awareness,” “treatment,” and “genetic testing” were the most popular topics in Lynch syndrome–related tweets. Furthermore, laypeople’s attitudes toward “treatment” and “genetic testing” were relatively negative compared with other topics they discussed on social media. It is not surprising that most of the information related to Lynch syndrome on Twitter focused on treatment and genetic testing, and people had more negative attitudes toward these topics because they feared the possibility of having a higher cancer risk or a positive cancer diagnosis and worried about the costs and the quality of the diagnostic methods (eg, “I have had Cancer twice fear of 3x is always on my mind. Not having Medicare is heartbreaking for me” and “cost of genetic testing for lynch syndrome mercedes 300se”).

The topic distributions of promotional Lynch syndrome–related information and laypeople’s discussions were similar. Especially, laypeople’s discussions on “awareness” were highly correlated with the promotional Lynch syndrome–related information on Twitter, whereas their discussions on

“screening,” “genetic testing,” “treatment,” and “risk” were moderately correlated. These results suggest that the promotional information posted by health care organizations and professionals on social media platforms such as Twitter may have a significant impact on laypeople. In part, our results provided the evidence to support the rationale for further developing novel cancer communication strategies in new digital media [29].

Furthermore, health-related awareness events and initiatives such as the March Colon Cancer Awareness Month and the March 22 Lynch Syndrome Awareness Day have great impacts on laypeople’s discussions, perceptions, and attitudes of the health condition. Our analysis of the monthly tweet volume trends revealed that health organizations and professionals made a concerted effort to disseminate promotional Lynch syndrome–related information on Twitter during these awareness events. Furthermore, their efforts had a great impact on raising laypeople’s awareness of the specific health topic, which was evident from the increased tweet volume by laypeople during these awareness events. Moreover, we also observed that laypeople had more positive attitudes during these events as shown in Figure 10. Interestingly, laypeople’s attitudes toward certain topics such as “advertisement” and “awareness/awareness events” became more positive than other topics during these awareness events. The changes in attitudes may be explained by the theory of social influence [30,31]. As laypeople received more positive information about colorectal cancer and Lynch syndrome, they gained a better understanding of the health condition and perceived better health outcomes, which could lead to more positive thinking.

The possibility to positively influence laypeople’s attitudes and their normative beliefs toward Lynch syndrome gives us the

opportunity to design novel participative communication strategies in cancer prevention and control in accordance with behavior change theories. For example, in the theory of planned behavior [32], both attitudes and normative beliefs can shape an individual's behavioral intentions and behaviors. Nevertheless, evident from our results, as shown in *Figures 7-10*, both the volume of the Lynch syndrome-related tweets and the positive sentiments of the laypeople dropped after the awareness events. These results suggest that these awareness events may need to be hosted frequently to have a sustained effect.

Designing an appropriate promotion strategy on social media needs more considerations than traditional media (eg, newspapers, television advertisements, and flyers). Health organizations and professionals need to think about what kind of information social media can deliver, and how the promotional information can achieve their goals (eg, enhancing communication with audience to foster public engagement). Many of the promotional Lynch syndrome-related information in our dataset indeed followed the recommendations for developing health promotion messages on social media [33-35], especially on disseminating critical health information (eg, sharing news, research findings, and the basic knowledge of Lynch syndrome) and engaging the public (eg, Colon Cancer Awareness Month and Lynch Syndrome Awareness Day).

As evidenced in our study, the use of social media is expanding rapidly in health promotions. It is increasingly important to measure the performance of these health promotion strategies. Neiger et al proposed a set of key performance indicators (KPIs) and metrics for evaluating the performance of health promotions in social media [35]. There are four indicators in the KPIs as follows: (1) insight (eg, consumer feedback from social media), (2) exposure (eg, the number of times a promotional information is viewed), (3) reach (eg, the number of people who have viewed the promotional materials and the related content), and (4) engagement (eg, “likes” on the posts, sharing and retweeting the posts, and engaging in the offline events). Our study results can provide more in-depth insights to many of these key indicators. For example, the sentiment analysis results will provide more fine-grained information on users' attitudes toward these health promotion events than simple “likes” on the posts.

Our study focused on analyzing the texts of Lynch syndrome-related tweets, whereas Twitter collects much more information on both the tweets (eg, the links between tweets through retweeting) and their users (eg, user locations, friends, and followers). This information can be leveraged to conduct more in-depth analyses of health-related topics on Twitter. For example, through modeling the retweet networks, we can study how promotional health information spread on Twitter through social network analyses.

## Limitations

First, to automatically categorize tweets and assign each tweet a sentiment, we employed computational classification methods, whose accuracies were not perfect. This imperfection left the possibility of having incorrect results on a micro scale (ie, on individual tweets). Nevertheless, given the large volume of our data, the results on a macro scale should be consistent.

Furthermore, we classified the tweets into promotional Lynch syndrome-related information and laypeople's discussions. However, some of the tweets that we classified as laypeople's discussions might be from health professionals and health advocacy groups. One way to alleviate this issue is to identify these users based on their Twitter user profiles and classify their tweets accordingly. Moreover, the demographics (eg, age, gender, race, and ethnicity) of Twitter users might be confounding variables in our analyses that might need to be controlled. Nevertheless, there was not an easy way to identify Twitter users' demographics, as Twitter does not require its users to provide such information.

Second, topic modeling can only extract abstract topics at a high level. These abstract topics often had more in-depth aspects to explore. For example, “genetic testing” can be further divided into more fine-grained aspects (eg, cost of genetic testing and accuracy of genetic testing). One way to address this issue is to develop a coding book and manually annotate each individual tweet with the fine-grained topics. Nevertheless, such process is labor-intensive and hardly possible with a large volume of Twitter data. One possible solution is to label a small random sample of the tweets and then develop supervised classifiers (similar to the approach we used for sentiment analysis) to label the rest of the data automatically.

Third, Twitter users are not a representative group of the general population. The majority of social media users, in general, tend to be younger; 71% of Twitter users in 2017 are less than 49 years old [36].

## Comparison With Prior Work

A number of studies have used sentiment analysis and topic modeling to analyze social media data on health-related topics. Doing-Harris et al designed a topic classifier and identified common topics on patient comments to understand patient satisfaction toward health services [37]. Lu et al determined the hot topics and measured sentiment expression of different stakeholders to understand their different perspectives [38]. Guillory et al used Twitter data to analyze e-cigarette discussions based on discussion theme and sentiment [39]. Wang et al used keywords matching and topic modeling as well as qualitative methods on social media data to learn actionable information about pollution levels and public responses [40]. Davis et al applied sentiment analysis on Twitter data to learn the public's response to Obamacare [41]. To our knowledge, our study is the first on using Twitter data to understand the correlation between promotional health-related information and laypeople's discussions.

## Conclusions

Our results provided evidence to confirm the positive impacts of awareness initiatives and events that have been widely promoted by health organizations and professionals on social media platforms. Furthermore, a deeper understanding of how these promotional information and events affect individuals' attitudes and their perceived social norm could lead us to better-designed health behavior interventions. A number of future directions can further advance our understanding of the impacts of promotional information on laypeople. For example,

it will provide additional context and information through examining the Twitter users' profiles and the sources of the promotional materials (following the links in the tweets).

Nevertheless, more advanced natural language processing tools and machine learning models need to be developed to process the large amount of Twitter data.

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## Authors' Contributions

JB, YS, RS, and YZ designed the initial study protocol. YG, MP, ZH, and MW provided critical suggestions on the study design. YZ, LJR, and JB annotated the Twitter data. YZ and XD built the classification model for sentiment analysis. YZ and HZ conducted the topic modeling. YZ did the statistical analysis. JB and YZ wrote the manuscript. All authors have provided feedback and edited the manuscript.

## Conflicts of Interest

None declared.

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## Abbreviations

**API:** application programming interface

**CNN:** convolutional neural network

**HNPCC:** hereditary nonpolyposis colorectal cancer

**HPV:** human papillomavirus

**KPI:** key performance indicators

**LDA:** latent Dirichlet allocation

**RQ:** research questions

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Original Paper

# Two-Way Social Media Messaging in Postoperative Cataract Surgical Patients: Prospective Interventional Study

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**Related Article:**

This is a corrected version. See correction statement: <http://www.jmir.org/2018/12/e12120>

## Abstract

**Background:** Social media offers a new way to provide education, reminders, and support for patients with a variety of health conditions. Most of these interventions use one-way, provider-patient communication. Incorporating social media tools to improve postoperative (postop) education and follow-up care has only been used in limited situations.

**Objective:** The aim of this study was to determine the feasibility and efficacy of two-way social media messaging to deliver reminders and educational information about postop care to cataract patients.

**Methods:** A total of 98 patients undergoing their first eye cataract surgery were divided into two groups: a no message group receiving usual pre- and postop care and a message group receiving usual care plus messages in a mobile social media format with standardized content and timing. Each patient in the message group received nine messages about hand and face hygiene, medication and postop visit adherence, and links to patient education videos about postop care. Patients could respond to messages as desired. Main outcome measures included medication adherence, postop visit adherence, clinical outcomes, and patients' subjective assessments of two-way messaging. The number, types, content, and timing of responses by patients to messages were recorded.

**Results:** Medication adherence was better in the message group at postop day 7, with high adherence in 47 patients (96%, 47/49) versus 36 patients (73%, 36/49) in the no message group ( $P=.004$ ), but no statistically significant differences in medication adherence between the groups were noted at preop and postop day 30. Visit adherence was higher at postop day 30 in the message group (100%, 49/49) versus the no message group (88%, 43/49;  $P=.03$ ) but was 100% (49/49) in both groups at postop day 1 and 7. Final visual outcomes were similar between groups. A total of 441 standardized messages were sent to the message group. Out of 270 responses generated, 188 (70%) were simple acknowledgments or "thank you," and 82 (30%) responses were questions that were divided into three general categories: administrative, postop care, and clinical issues. Out of the 82 question responses, 31 (11%) were about administrative issues, 28 (10%) about postop care, and 23 (9%) about clinical symptoms. All the messages

about symptoms were triaged by nurses or ophthalmologists and only required reassurance or information. Patients expressed satisfaction with messaging.

**Conclusions:** Two-way social media messaging to deliver postop information to cataract patients is feasible and improves early medication compliance. Further design improvements can streamline work flow to optimize efficiency and patient satisfaction.

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## KEYWORDS

cataract; social media; postoperative care; medication adherence

## Introduction

### Background and Rationale

Social media platforms on mobile phones have changed the way the world communicates. Medicine as a profession is beginning to embrace these new communication modalities to improve health care delivery. This opportunity is valuable in both high income countries as a means for improving patient engagement and education and in low- and middle-income countries where the limitations of overburdened clinics and staff, transportation barriers, and health literacy issues are challenges to providing health care.

Many mobile health (mHealth) interventions have been studied, including apps to enhance patient education, promote behavior change, and improve medication and visit adherence. Others are directed to improving health care delivery systems through electronic decision support, data sensors, data collection, patient tracking, and electronic health records [1]. There is a growing body of research supporting the use of texting to improve patient follow-up [2-4] and medication adherence in chronic diseases such as HIV, tuberculosis, and hypertension [5-10]. Surgical specialties are starting to utilize mHealth technology to improve postop care. Armstrong et al [11] showed a significant decrease in in-person follow-up visits and higher patient convenience scores after breast reconstructive surgery in patients using a mobile app for follow-up using photos and responses to validated recovery and pain surveys. Semple et al [12] also used photos and validated quality of recovery questionnaires for postop follow-up of breast reconstruction and orthopedic surgical patients demonstrating feasibility and acceptability. In both of these studies, surgeons monitored questionnaires and photos and contacted patients based on this information. Another study in China used a social messaging app (WeChat) for follow-up of head and neck surgical patients in China that was shown to decrease patients lost to follow-up, improve patient satisfaction, save physicians' time, and be more cost-effective compared with usual care [13]. This study allowed for patient-initiated contact through the messaging app for questions.

mHealth interventions to enhance patient adherence have been used in ophthalmology. Some specific examples include medication adherence in glaucoma [14], general outpatient clinic visit adherence [15,16], and postsurgical follow-up for pediatric cataract [17] and trabeculoplasty [18]. Cataract surgery has not yet been impacted by social media and messaging apps. This may be related to the lower use of these platforms in elderly populations with vision problems, but that is starting to change

as patients, even older ones, increasingly use and rely on this technology [19]. In low- and middle-income countries, improving outcomes for cataract surgery requires better patient education, compliance with medications, postop follow-up, and outcome monitoring [20,21]. mHealth technology and use of social media platforms are potential ways to help address these gaps.

### Specific Aim

The specific aim of this research project was to determine the feasibility and efficacy of two-way social media messaging in postop cataract surgery patients. We hypothesize that redesigning patient communication and education regarding cataract surgery postop care using a mobile messaging app is feasible and can positively impact the quality and patient experience of postop cataract surgical care.

## Methods

### Setting

Patients were recruited from the ophthalmology clinic at Srinagarind Hospital, the academic teaching hospital for the Faculty of Medicine at Khon Kaen University and the main tertiary referral center for northeast Thailand. Khon Kaen is the largest city in northeast Thailand with a growing urban population and economy. The surrounding provinces, from which most patients come, are rural, agricultural-based, and less developed. Smartphones are widely available in Khon Kaen and surrounding provinces, with mobile apps being a primary mode of communication. In Thailand, SMS text messaging (short message service, SMS) is relatively expensive and not commonly used; messaging apps such as LINE are the preferred mode of communication.

### Study Design

This is an interventional study with two groups. The control group received standard pre- and postcataract surgical care and education and included watching four educational videos on pre- and postop care in the clinic. The intervention group received standard pre- and postcataract surgical care and education, plus nine messages with standardized content and delivery schedule using the LINE messaging app ([Multimedia Appendix 1](#)). Message content included information about hand and face hygiene, medication instillation and adherence, visit reminders and adherence, medication reminders, and medication tapering schedule. Patients received a link to the same clinic educational videos on YouTube describing the preop and postop eye care and use of drops so they could watch them on demand ([Multimedia Appendices 2-5](#)).

Measurements of medication adherence, visit compliance, and clinical outcomes were obtained at the preop visit, postop day 7, and postop day 30 and compared between the two groups. The other study outcomes focused on the implementation and user experience of the LINE message group and included the number, type, content, and timing of the patient responses to messages. Clinical outcomes were measured, including visual acuity, intraocular pressure, and intraocular inflammation. Patients in the message group also completed a survey regarding subjective assessment of the message content and frequency (Multimedia Appendix 6).

The LINE social media messaging app was selected for this study because it is the most widely used mobile messaging app in the region, is free, has end-to-end encryption for one-to-one chats, automatic deletion from the server after set time, privacy settings to prevent sharing, allows for video links, and the LINE chat history could be downloaded for analysis after the study period.

## Participant Recruitment

Patients recommended to have cataract surgery at the outpatient ophthalmology department at Srinagarind Hospital, Khon Kaen University who met the eligibility criteria were recruited for the study. Recruitment of patients was done in a before and after fashion, recruiting 49 patients for the nonintervention group first, followed by 49 patients in the intervention. This form of patient recruitment was employed to minimize the patient groups from comingling and discussing study-related variables, clinical care, or messages. Patients were eligible for participation in the study if they (1) did not have previous cataract or other eye surgery, (2) had access (directly or through surrogate) to a smartphone and successfully demonstrated facility using the LINE app to send or receive messages and view videos, (3) agreed to follow security settings for LINE study communication, (4) agreed to maintain mobile phone or data service or Wi-Fi service, and (5) agreed to notify the study coordinator if their mobile phone number changed. Patients were excluded if they could not fulfill the above criteria, were younger than 18 years, or were from vulnerable populations including prisoners, those with mental illness, and pregnant women.

Patients in the intervention group could elect to have the messages sent to themselves or a designated surrogate who took responsibility to inform the patient of the messages. Surrogates were direct family members (usually son or daughter) living in the same house. The reasons for using a surrogate typically related to older patients' lack of familiarity with smartphone usage or visual impairment from cataract preventing screen visualization.

## Study Variables

The study variables collected in the nonmessage and message groups included smartphone user (patient or surrogate), medication adherence scores, visit adherence, and clinical outcomes. Additional information collected from the message group included the number of responses by each patient to each message, types of responses to messages, types of questions sent, timing of responses, and patient feedback survey scores.

Medication adherence was measured with an officially validated Thai translation of the 8-item Morisky Medication Adherence Scale (MMAS-8) [22]. Thai translation was performed by Mapi, an independent linguistic institution that provides validated translations of the MMAS-8, and reviewed by linguists at Khon Kaen University. Similar versions have been used in Thailand in studies of medication adherence in diabetes, HIV, and renal disease [23-25]. MMAS-8 is a widely used tool in the United States and other countries to evaluate medication adherence [26]. Patients in the intervention and control groups completed the MMAS-8 at the preop visit to assess their baseline medication adherence behavior and then at POD-7 (postop day 7) and at POD-30 (postop day 30) visits. Patients were given a score of low, medium, or high medication adherence in accordance with the MMAS-8 scoring criteria (low <6, medium 6-8, and high=8).

Visit adherence was measured as the percent of patients attending their scheduled postop appointment. Patients who did not keep their scheduled appointment were considered noncompliant. These patients were contacted and asked to return for their follow-up exam and final data collection. Patients who could not be reached or did not return after being contacted were considered "no show."

Clinical outcomes measured included best corrected (with refraction) visual acuity measured on a Snellen chart at 6 m, intraocular pressure measured with Goldmann tonometry, and intraocular inflammation graded by standardized uveitis nomenclature based on the number of cells per 1 mm<sup>2</sup> high power field [27].

Responses were categorized into two types: (1) simple acknowledgments (eg, thank you) and questions. The type of media used for response was divided into three groups: sticker or emoji, photo, or text. Questions were subdivided into three types: administrative (eg, appointment or scheduling issue); postop care (eg, medication, dressing, and activity issues); and clinical symptoms requiring triage (eg, discomfort or a change in vision).

At the POD-30 visit, patients in the message group completed a 3-question feedback questionnaire evaluating their impressions regarding the frequency of messages, the content of messages, and recommendation for use of messages to other postop cataract patients.

## Statistical Analysis

The demographic characteristics of the patients were summarized as the mean and standard deviation (SD) for continuous variables and as frequency counts with percentages for categorical variables. MMAS-8 scores for low and medium adherence were combined to perform statistical analysis because of low frequency of responses in some categories. The percentage of MMAS-8 low or medium adherence scores was compared with high adherence scores using chi-square or Fishers exact test, depending on response frequency. The association of MMAS-8 score between message and no message groups were presented as odds ratio (OR) and 95% CI and was obtained using multiple logistic regression and generalized estimating equation (GEE). The adjusted OR were obtained in the same

manner with the inclusion of gender, age, and LINE user type into the multivariate model. A  $P$  value of less than .05 was considered significant. All analyses were performed using Stata (StataCorp) version 13.

### Ethical Issues

Approval was obtained from the Khon Kaen University Ethics Committee in Human Research. Informed consent was obtained from all study participants. The research adhered to the tenets of the Declaration of Helsinki. The research was compliant with the Health Insurance Portability and Accountability Act.

## Results

### Demographics

**Table 1** describes the demographics of the study participants. The average age in the message group was 64 versus 68 years in the no message group. Surrogate users of the LINE app was 55% in the message group and 75% in the no message group.

**Table 1.** Demographic data and baseline characteristics of study population.

Study population characteristics	Message, n (%)	No message, n (%)	Overall, n (%)
Number of patients	49 (50)	49 (50)	98 (100)
<b>Gender</b>			
Female	25 (51)	20 (41)	45 (46)
Male	24 (49)	29 (59)	53 (54)
<b>Age groups (years)</b>			
Less than 65	28 (57)	20 (41)	48 (49)
65 and above	21(43)	29 (59)	50 (51)
<b>Line user</b>			
Patient	22 (45)	12 (25)	34 (35)
Surrogate	27 (55)	37 (75)	64 (65)

### Medication Adherence

**Table 2** shows data regarding MMAS-8 medication adherence scores at preop, POD-7, and POD-30 in the message and no message groups. Medication adherence was better in the message group at POD-7 (96% vs 73%,  $P=.004$ ), but no statistically significant differences in medication adherence between the groups were noted at preop and POD-30. There were 4 patients from the no message group who did not keep their POD-30 appointment and did not reschedule, so MMAS-8 survey could not be completed. There were no differences in MMAS-8 scores between patient and surrogate smartphone users at preop, POD-7, or POD-30 visits (**Table 3**). The association of MMAS-8 score by message or no message groups at POD-7 adjusted for baseline score, gender, age, and LINE user type (patient vs surrogate) was significant (adjusted OR=8.6; 95% CI 1.7-43.2;  $P=.009$ ), but the overall association of MMAS-8 score between two groups using GEE become nonsignificant (adjusted OR=2.48; 95% CI 0.86-7.18;  $P=.09$ ; [Multimedia Appendix 7](#)).

**Table 2.** Comparison of the 8-item Morisky Medication Adherence Scale (MMAS-8) score in message and no message groups by visit.

Visit	MMAS-8 <sup>a</sup> score (N=98)				<i>P</i> value <sup>b</sup>
	Low, n (%)	Medium, n (%)	Low and medium, n (%)	High, n (%)	
<b>Preop</b>					
Message	18 (36)	21 (42)	39 (80)	10 (20)	.8 <sup>c</sup>
No message	22 (44)	18 (37)	40 (82)	9 (18)	
<b>POD<sup>d</sup>-7</b>					
Message	1 (2)	1 (2)	2 (4)	47 (96)	.004 <sup>e</sup>
No message	0 (0)	13 (26)	13 (27)	36 (73)	
<b>POD-30</b>					
Message	0 (0)	6 (12)	6 (12)	43 (88)	.74 <sup>e</sup>
No message	0 (0)	4 (9)	4 (9)	41 (91)	

<sup>a</sup>MMAS-8: 8-item Morisky Medication Adherence Scale.<sup>b</sup>*P* value reflects low and medium compared with high.<sup>c</sup>*P* value based on chi-square test.<sup>d</sup>POD: postop day.<sup>e</sup>*P* value based on Fishers exact test.**Table 3.** Comparison of the 8-item Morisky Medication Adherence Scale (MMAS-8) score by a LINE user.

Visit	MMAS-8 <sup>a</sup> score (N=98)				<i>P</i> value <sup>b</sup>
	Low, n (%)	Medium, n (%)	Low and medium, n (%)	High, n (%)	
<b>Preop</b>					
Patient	17 (50)	13 (38)	30 (88)	4 (12)	.19 <sup>c</sup>
Surrogate	23 (36)	26 (41)	49 (77)	15 (23)	
<b>POD<sup>d</sup>-7</b>					
Patient	0 (0)	4 (12)	4 (12)	30 (88)	.57 <sup>c</sup>
Surrogate	1 (2)	10 (16)	11 (17)	53 (83)	
<b>POD-30</b>					
Patient	0 (0)	5 (15)	5 (15)	29 (85)	.34 <sup>f</sup>
Surrogate <sup>e</sup>	0 (0)	5 (8)	5 (8)	55 (92)	

<sup>a</sup>MMAS-8: 8-item Morisky Medication Adherence Scale.<sup>b</sup>*P* value reflects low and medium compared with high.<sup>c</sup>*P* value based on Fishers exact test.<sup>d</sup>POD: postop day.<sup>e</sup>Four patients in surrogate group did not keep POD-30 follow-up, so MMAS-8 score is not available.<sup>f</sup>*P* value based on chi-square test.

## Visit Adherence

Results of visit adherence scores in the message and no message groups at the preop, POD-7, and POD-30 appointments are summarized in [Table 4](#). Visit adherence was lower in the no message group at POD-30: (43/49) vs 100% (49/49) in the message group, *P*=.03, but visit adherence was otherwise 100% in each group at each visit time point.

## Clinical Outcomes

[Table 5](#) shows clinical outcomes at the preop visit, POD-7, and POD-30. Visual acuity was better at POD-7 in the message

group (LogMAR acuity 0.19 vs 0.36, *P*=.02) but was not statistically different between groups at preop or POD-30 visits. After adjusting for age, gender, and LINE user type, the difference in visual acuity at POD-7 remained significant ([Multimedia Appendix 8](#)). Intraocular pressure and intraocular inflammation measurements showed no statistically significant differences between groups at any postop visit.

## Number and Type of Responses to LINE Messages

Each of the 49 patients in the message group received nine standardized messages, resulting in 441 total messages sent. Of the 49 patients, 41 (84%) responded to at least one message and

5 patients responded to every message. Each message elicited a response by approximately 50% of the recipients.

Out of 270 total responses, there were 188 (70%) simple acknowledgments such as “thank you” and 82 (30%) questions. Out of 82 question responses, 31 (38%) were about administrative issues (eg, appointments), 28 (34%) about postop care (eg, medications), and 23 (28%) about a clinical symptom (eg, foreign body sensation). All the questions’ responses about symptoms were triaged by nurses or ophthalmologists and only required patient reassurance or additional information about concerns (Multimedia Appendix 9).

Patients responded to messages using three different media types: stickers or emojis, photos, or typed messages. Out of 270 total responses, 25 (9%) included photographs, usually of a pleasant or happy nonclinical nature. There were 6 (2%, 6/270) patients who sent photos of medication bottles, bandages, or their eye to help explain their question. There were 102 (38%, 102/270) responses using “stickers,” which are colorful, cartoon-like replies similar to emoji’s but larger in size to

communicate a variety of emotions and feelings such as thankfulness, appreciation, or happiness in the LINE app. A total of 143 responses (53%, 143/270) were a typed message.

### Patient Feedback Regarding LINE Message Frequency and Content

Out of 49 patients who received messages, all of them completed the feedback survey; 46 (94%) judged the number of messages to be “just right,” and 3 (6%) wanted more messages. None wanted fewer messages. There were 48 (98%, 48/49) patients who found the message content helpful, with 16 (32%, 16/49) rating it “just right,” 20 (40%, 20/49) “helpful,” and 12 (24%, 12/49) “very helpful.” One of 49 patients (2%) thought the message content was slightly helpful.

There were 39 patients (79%, 39/49) who “recommended” and 7 patients (14%, 7/49) who “strongly recommended” the messages for future cataract surgery patients. There were 3 patients (6%, 3/49) who were “neutral” about recommending the messages to a cataract patient.

**Table 4.** Visit adherence by message and no message groups at preop, POD-7, and POD-30 (Fishers exact test).

Visit adherence	Message, n (%)	No message, n (%)	P value
<b>Preop</b>			
No	0 (0)	0 (0)	
Yes	49 (100)	49 (100)	
<b>POD<sup>a</sup>-7</b>			
No	0 (0)	0 (0)	
Yes	49 (100)	49 (100)	
<b>POD-30</b>			
No	0 (0)	6 <sup>c</sup> (12)	.03 <sup>b</sup>
Yes	49 (100)	43 (88)	

<sup>a</sup>POD: postop day.

<sup>b</sup>Fishers exact test.

<sup>c</sup>Six patients did not keep the scheduled POD-30 appointment; 2 patients later rescheduled.

**Table 5.** Comparison of clinical outcomes between message and no message groups by preop, POD-7, and POD-30 visits.

Clinical	Message (n=49) Mean (SD <sup>a</sup> )	No message (n=49) Mean (SD)	Mean difference	95% CI	P value
<b>Visual acuity (LogMAR)</b>					
Preop	0.90 (0.66)	0.84 (0.55)	0.06	-0.18 to 0.30	.63
POD <sup>b</sup> -7	0.19 (0.25)	0.36 (0.43)	0.17	0.03-0.31	.02
POD-30	0.19 (0.25)	0.36 (0.78)	0.16	-0.07 to 0.40	.16
<b>Intraocular pressure</b>					
Preop	14.65 (3.77)	14.27 (3.79)	0.38	-1.14 to 1.91	.62
POD-7	11.71 (2.61)	12.31 (3.09)	0.59	-0.56 to 1.74	.31
POD-30	13.16 (3.42)	12.22 (3.62)	0.94	-0.50 to 2.38	.2
<b>Intraocular inflammation</b>					
Preop	0 (0)	0 (0)	0	0	
POD-7	0.33 (0.62)	0.38 (0.53)	0.05	-0.19 to 0.28	.68
POD-30	0 (0)	0 (0)	0	0	

<sup>a</sup>SD: standard deviation.<sup>b</sup>POD: postop day.

## Discussion

### Principal Findings

#### Medication and Visit Adherence

Our study showed that two-way social media messaging in postop cataract surgical patients was feasible and favorably received by patients. The medication and visit adherence of the postop patients were both generally high and left relatively little room for improvement in the intervention group, and both message and nonmessage groups showed improvement in medication adherence score from their baseline, suggesting that patients are more compliant because of the recent surgery. However, medication adherence measurements in the message group at POD-7 were significantly higher than the nonmessage group, suggesting that messages helped patients remember or understand the importance of taking their medications earlier in the postop process. This is potentially helpful in patients at risk of developing cystoid macular edema (CME). Visit adherence was higher, reaching 100% in the message groups at POD-30. The emphasis on visit adherence in the messages may have helped achieve this and is clinically important as complications such as CME can still develop at this time. Final clinical outcomes were not different between the message and nonmessage groups, but the visual acuity was higher at POD-7. As we did not detect a difference in inflammation levels between the message and no message groups, we suspect that this is because of an unknown confounder or chance.

#### Communication Modalities

Social media smartphone messaging apps allow for a variety of communication modalities, and our patients used many of them. Written text was used most frequently; stickers were nearly as popular. Stickers are a signature feature of the LINE messaging app and are widely used in Thailand. They are increasingly popular features on similar social media apps

throughout the world. They offer an element of entertainment and sentiment to users. This is an important consideration as lack of patient engagement has been identified as a key barrier in patient adoption of mHealth technologies [28]. The use of photos of the eye, bandages, or medication bottles to help clarify a question was helpful to staff and patients. Ophthalmologists can sometimes benefit from a mobile phone photo of the eye when triaging remotely patients' complaints. A mobile phone camera with proper focus and flash illumination can generate a clinically useful image in postop cataract patients [29].

#### Study Limitations

Our study has several important limitations. We could not confirm if the messages were received as intended though the rapid response suggested that the messages generally were received. Another weakness is that we did not measure phone calls or unscheduled visits to the clinic in the nonmessage group, which would provide valuable information in assessing the impact of our intervention and changes in workload for the clinic staff. Whereas the patient feedback was generally very positive, we did not design the study to determine the optimal frequency and timing of our messages. As our medication adherence measure was a self-reported survey, we acknowledge that it is subject to social desirability bias. This could result in a higher medication adherence score in patients who are concerned about disappointing their surgeon or other members of their care team. We looked for differences in the message and nonmessage groups for medication adherence and visual acuity with regard to age, gender, and LINE user type using a multivariate analysis (GEE) but found no significant differences regarding number, type, or content of messages. However, we were unable to perform this analysis for visit adherence because visit adherence was 100% in all the message groups.

## Comparison With Prior Work

### Medication and Visit Adherence

Our study differs from most other medication and visit adherence studies for chronic disease management in that it looked at an mHealth intervention in cataract surgery postop care, which is a short-term, acute, episodic process. Our results support that reminders in this population can also be helpful in improving compliance. This aligns with findings in other ophthalmic reminder studies [13-17] and postop reminder studies [12,16,17].

### Two-Way Messaging

Two-way messaging has the potential to create voluminous, unwanted responses by patients resulting in increased workload for physicians and staff. Armstrong et al reported that patients using a postop home monitoring app for breast reconstruction surgery sent more emails to clinic staff in the first 30 days [11]. We found clinical symptom questions were similar to those typically seen in routine postop cataract surgery patients and tended to cluster in a small number of patients, similar to the pattern seen in a phone-based system. Many of the questions sent by patients in our study could be easily managed by office and nursing staff, who noted a preference to answering messages on their computer when time permitted rather than receiving phone calls that interrupted workflow throughout the day. Greater convenience and efficiency was also reported when members of an orthopedic care team used a mobile phone messaging app (WhatsApp) for communication [30]. Lyu et al found that using WeChat for clinical follow-up of postop head and neck surgical patients in China is more time-efficient than using telephone follow-up [31]. In the next iteration of the project, we plan to create a simplified “thank you-my eye is doing well” reply to help reduce the number of acknowledgment responses, which would reduce the workload for staff.

### Future Directions

The research supporting the use of mobile phone apps throughout the perioperative period is increasing in the

preoperative, perioperative, and postop periods [32]. Previous research in tele-ophthalmology has demonstrated benefits in screening and remote diagnosis in retinal diseases, glaucoma, pediatric retinopathy, and emergency triage [33]. Our study addresses the opportunity for improving compliance with postop care using social messaging in comparison with some of the other most recent research using mHealth in postop care that focus on self-management tools. These include symptoms surveys, wound photos, and educational information [11,34-36]. Incorporating similar tools in our intervention is an area for further development and research.

To realize the benefits of using social media postop messaging at scale, we see a critical need to develop a robust program to automate messaging for patients at different stages of the postop process and the capacity to adapt these messages for changes in patient management. Other postop studies have incorporated alerts to help automate the monitoring process [11,12], but this does not eliminate the need for managing outliers and adjustments to a patient’s postop care plan. Follow-up with surgeons participating in one postop home monitoring study following questionnaires and photos raised concerns about managing the workload of monitoring patient responses, even without incorporating patient-initiated communications [12].

Another issue requiring further study is to determine the operational impact, including cost and time efficiency of two-way postop messaging. In clinics with a large volume of cataract surgery, this is important information that will ultimately determine uptake of this technology. Low resource settings may not have the option to devote staff to this system unless financial or operational benefits can be demonstrated.

## Conclusions

Using two-way social media messaging for postop care is a promising innovation for not only cataract surgery but other surgical specialties. In addition to improving medication and visit adherence, our impression was that the patients liked the feeling of safety and connection to their care team provided by repeated messaging.

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They would also like to acknowledge that they have obtained written permission from copyright owners for any excerpts from copyrighted works that are included in the study and have credited the sources in the study or the supplemental materials. Use of the MMAS is protected by US copyright laws. Permission for use is required. A license agreement is available from Donald E. Morisky, ScD, ScM, MSPH, Professor, Department of Community Health Sciences, UCLA Fielding School of Public Health.

## Authors' Contributions

TS, KM, and MM developed the research study, collected and analyzed results, and coauthored the manuscript. IA organized the data collection, trained research staff, oversaw initial implementation, and reviewed the manuscript. KT and JT conducted the statistical analysis, produced tables, assisted with the interpretation of results, and reviewed the final manuscript.

## Conflicts of Interest

None declared.

**Multimedia Appendix 1**

Description of pre- and postop cataract surgical care.

[[PDF File \(Adobe PDF File, 27KB - jmir\\_v19i12e413\\_app1.pdf](#) ]

**Multimedia Appendix 2**

Educational video for patients undergoing cataract surgery: before surgery.

[[MP4 File \(MP4 Video\), 104MB - jmir\\_v19i12e413\\_app2.mp4](#) ]

**Multimedia Appendix 3**

Educational video for patients undergoing cataract surgery: day of surgery.

[[MP4 File \(MP4 Video\), 238MB - jmir\\_v19i12e413\\_app3.mp4](#) ]

**Multimedia Appendix 4**

Educational video for patients undergoing cataract surgery: after surgery.

[[MP4 File \(MP4 Video\), 121MB - jmir\\_v19i12e413\\_app4.mp4](#) ]

**Multimedia Appendix 5**

Educational video for patients undergoing cataract surgery: information for family and caregivers.

[[MP4 File \(MP4 Video\), 180MB - jmir\\_v19i12e413\\_app5.mp4](#) ]

**Multimedia Appendix 6**

Patient feedback questionnaire regarding LINE messages.

[[PDF File \(Adobe PDF File, 313KB - jmir\\_v19i12e413\\_app6.pdf](#) ]

**Multimedia Appendix 7**

Association of visual acuity by message or no message groups adjusted for baseline score, gender, age, and LINE user type.

[[PDF File \(Adobe PDF File, 47KB - jmir\\_v19i12e413\\_app7.pdf](#) ]

**Multimedia Appendix 8**

Message response types and media forms.

[[PDF File \(Adobe PDF File, 20KB - jmir\\_v19i12e413\\_app8.pdf](#) ]

**Multimedia Appendix 9**

Message response types and media forms.

[[PDF File \(Adobe PDF File, 20KB - jmir\\_v19i12e413\\_app9.pdf](#) ]

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## Abbreviations

**CME:** cystoid macular edema

**GEE:** generalized estimating equation

**mHealth:** mobile health

**MMAS-8:** 8-item Morisky Medication Adherence Scale

**OR:** odds ratio

**POD:** postop day

**SD:** standard deviation

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Original Paper

# Developing Online Recruitment and Retention Methods for HIV Prevention Research Among Adolescent Males Who Are Interested in Sex with Males: Interviews with Adolescent Males

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## Abstract

**Background:** Adolescent males interested in sex with males (AMSM) are an important audience for HIV prevention interventions, but they are difficult to reach due to their age and social stigma.

**Objective:** We aim to identify efficient methods to recruit and retain AMSM in online research.

**Methods:** Interviews with 14-to-18-year-old AMSM (N=16) were conducted at 2017 Pride events in Boston, MA and Providence, RI.

**Results:** Participants reported that (1) social media platforms are viable recruitment venues; (2) recruitment advertisements should describe the study using colorful/bright pictures, familiar words, and information about compensation; (3) surveys should be <20 minutes in length; (4) modest compensation (eg, email gift card, US \$10 to \$20) was preferred; and (5) communications that remind participants about the length and content of surveys, and compensation, should be sent between study activities to increase retention.

**Conclusions:** Soliciting input from AMSM provides critical guidance regarding recruitment and retention procedures to increase the efficiency of HIV prevention research for this at-risk group.

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**KEYWORDS**

HIV; adolescent males; sexual minority; recruitment; retention; online research; MSM

## Introduction

Adolescent males who are interested in sex with males (AMSM) are at increased risk for HIV in the United States [1]. Elevated HIV rates among AMSM are attributed to early sexual experiences and behavior patterns formed during adolescence [2,3]. Despite evidence of considerable sexual risk-taking [2] and HIV risk among AMSM [1], there is a paucity of HIV research and interventions targeting AMSM [4]. HIV prevention interventions targeting AMSM during adolescence (before or

shortly after their sexual debut) can help them establish healthy sexual behaviors, which will have both short- and long-term benefits [3,5,6].

Social networking websites/phone apps are increasingly used to recruit and retain difficult-to-reach populations in health research [7]. AMSM use the Internet and mobile technology to explore their sexuality and seek resources, so social networking websites/phone apps are particularly important for reaching and providing interventions to AMSM [4]. Community engagement is an important part of the development of social network-based

recruitment/retention strategies for online sexual health and HIV prevention interventions [8], and has been successfully used with adult men who have sex with men (MSM) and youth [9,10]. Although two online HIV intervention studies have successfully recruited and retained samples that include MSM <18 years old [11,12], only one study focused exclusively on AMSM (aged 14-18 years) [13]. We were unable to find any studies that inquired with AMSM themselves about optimal online recruitment and retention methods. The current study sought to fill this gap; specifically, interviews were conducted with 14-to-18-year-old AMSM to understand acceptable ways to recruit and retain them in online HIV prevention research. By having AMSM inform these techniques, researchers will be better prepared to successfully conduct online HIV prevention research and develop online interventions to address HIV disparities among AMSM.

## Methods

A convenience sample of AMSM (N=16) were interviewed during 2017 Boston and Rhode Island Pride events. Potential participants were approached by study staff who briefly described the study and established eligibility. Eligibility criteria included: (1) being 14-to-18 years old; (2) being cis-male; and (3) identifying as gay/bisexual, reporting sexual attraction to male partners, or reporting voluntary sexual contact with a male partner in the past year. Youth provided verbal assent or consent, depending on their age, and completed a capacity to consent assessment. A waiver of guardian permission was obtained.

Forty-four individuals agreed to be screened; of those, 16 (16/44, 36%) were eligible, and of those all (16/16, 100%) agreed to participate. Of the 28 individuals who were ineligible, the most common reasons for ineligibility were not identifying as cis-male (15/28, 54%) and being over 18 years of age (12/28, 43%). Interviews took approximately 20 minutes to complete. Answers were recorded on smartphones using REDCap [14] and data were coded in real-time by the interviewers. The interview was programmed with a list of potential answers for each question, as well as an open-ended response option to capture responses that fell outside the listed options. For open-ended responses, a framework matrix analysis was conducted after data collection was complete [15,16].

Participants were informed as a part of the assent/consent process that the questions they were being asked were part of a larger online sexual health study. Specifically, they were told, “the larger study is designed to determine if an online-delivered sexual health education program might help young men like you stay healthy and avoid sexually transmitted diseases.” For

recruitment, participants were asked which social media websites/phone apps they used, the one they used most frequently, and which ones would be good to advertise on. Respondents were asked about the features that would be important to include in online advertisements and, of those features, which would be the most important to include. For retention, participants were asked about the longest online survey they would be willing to complete, ways to increase retention in a longitudinal online study, preferred forms of compensation, and their preferred compensation amount for a 30-minute online survey. All procedures were approved by The Miriam Hospital Institutional Review Board. Participants received US \$5 for the interview.

## Results

The average age of the sample was 16 years (standard deviation=2). Eight participants (8/16, 50%) identified as a racial/ethnic minority, 11 participants (11/16, 69%) were gay-identified, and 12 participants (12/16, 75%) reported being sexually active with a male partner in the last year.

For recruitment (Table 1), the majority of respondents used Facebook (15/16, 94%), YouTube (14/16, 88%), Instagram (13/16, 81%), and Snapchat (13/16, 81%). The most frequently used websites/phone apps were Facebook (5/16, 31%) and Snapchat (5/16, 31%). The majority of participants said Instagram (12/16, 75%), Snapchat (11/16, 69%), and Facebook (10/16, 63%) would be the best websites/phone apps to advertise on. Participants reported that it was important for online advertisements to include a brief description of the study with short phrases and bullet points (10/16, 63%), colorful and bright pictures (9/16, 56%), information about compensation (9/16, 56%), and familiar/comfortable words (8/16, 50%). Among these options, colorful and bright pictures (4/16, 25%) and a short description (3/16, 19%) were identified as most important.

For retention (Table 2), the majority of respondents (9/16, 56%) would complete a 10-to-20-minute survey. Information about compensation (11/16, 69%), the length of surveys (10/16, 63%), and what kinds of questions would be asked (10/16, 63%) were identified as important information to provide. The majority of respondents said that sending reminders between study activities (15/16, 94%) and providing compensation (12/16, 75%) would increase retention. Participants preferred an email gift card (11/16, 69%) as compensation. More than half of the participants (9/16, 56%) said that US \$10-\$20 is fair compensation for a 30-minute online survey.

**Table 1.** Website use and online recruitment strategies identified by AMSM (N=16).

Website use and recruitment strategies	Total, n (%)
<b>Websites used by AMSM</b>	
Facebook	15 (94)
YouTube	14 (88)
Instagram	13 (81)
Snapchat	13 (81)
Twitter	4 (25)
Tumblr	7 (44)
Pinterest	3 (19)
Google+	1 (6)
<b>Best websites for advertising/recruiting AMSM</b>	
Instagram	12 (75)
Snapchat	11 (69)
Facebook	10 (63)
Twitter	6 (38)
YouTube	5 (31)
Tumblr	5 (31)
Pinterest	1 (6)
Vine	1 (6)
<b>Style and content features for online advertisements</b>	
A brief description with short phrases and bullet points	10 (63)
Colorful and bright pictures	9 (56)
How they will be compensated	9 (56)
Familiar and comfortable words	8 (50)
If parent/guardian permission is required or not	6 (38)
A detailed description of the study	4 (25)
How long the study will take	3 (19)

**Table 2.** Retention strategies identified by AMSM (N=16).

Retention strategies	Total, n (%)
<b>Longest online survey willing to fill out</b>	
5-10 minutes	6 (38)
10-20 minutes	9 (56)
>20 minutes	1 (6)
<b>Information to include in study materials to increase retention</b>	
How participants will be compensated	11 (69)
Length of the survey	10 (63)
Content (ie, what will be asked)	10 (63)
Importance of the questions	5 (31)
Confidentiality assurances	1 (6)
<b>Ways to increase retention in longitudinal online studies</b>	
Send reminders between study activities (eg, phone calls, text messages, or emails)	15 (94)
Provide compensation	12 (75)
Increase compensation value in increments for each activity completed	1 (6)
<b>Preferred forms of compensation</b>	
Email gift card	11 (69)
Check in mail	5 (31)
Cash in mail	2 (13)
<b>Preferred compensation amount for a 30-minute online survey (US \$)</b>	
\$10-\$20	9 (56)
\$20-\$30	7 (44)
\$30+	0 (0)

## Discussion

Facebook advertisements have been the predominant way that online HIV intervention studies have recruited AMSM [11-13]. In addition to Facebook, our results indicate that other social media platforms may also be useful. Specifically, most AMSM in our sample report using multiple social networking websites/phone apps. An assessment of the Facebook advertisements used in the intervention study targeting 14-to-18-year-old AMSM found that having images that are salient to AMSM improved recruitment rates [17]. Similarly, our participants indicated that advertisements including bright and colorful images and words that are familiar to AMSM would be important. Our participants also felt that advertisements should include a brief description of the study with short phrases, bullet points, and information about compensation.

Previous online studies have used varying levels of monetary compensation (US \$10-\$35 per activity) and emailed gift cards to compensate their participants and increase retention [11-13]. Our results corroborate the value of compensation to increase retention, this range of dollar amounts (depending on the length

of the study activity), and the use of emailed gift cards. Although previous studies did not indicate other retention-specific procedures, our participants suggested that sending study reminders between study activities may be an additional way to increase retention. Furthermore, AMSM in our study indicated that informing them about how they will be compensated, the length of the surveys, and what they will be asked could also increase retention. Lastly, participants felt that online assessments should be brief.

A limitation of our study is the small sample size. Nonetheless, these results can inform recruitment and retention procedures in online HIV prevention research targeting AMSM. Additional research testing the suggested recruitment and retention procedures is warranted. Furthermore, as the technological landscape quickly shifts, and because adolescents are early adopters of new technology, it is important to continuously assess the current technologies that youth are using. Ultimately, designing recruitment and retention procedures with the input of the target audience (ie, AMSM) will increase the efficiency, reach, validity, and scientific yield of HIV prevention research. This yield, in turn, can facilitate the development of online HIV prevention interventions for this at-risk group.

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## Conflicts of Interest

None declared.

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## Abbreviations

**AMSM:** adolescent males who are interested in sex with males

**MSM:** men who have sex with men

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Original Paper

# Individual Differences in the Relationship Between Attachment and Nomophobia Among College Students: The Mediating Role of Mindfulness

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## Abstract

**Background:** There is a growing interest in nomophobia, which is defined as the fear of being out of cellular phone contact, or "feelings of discomfort or anxiety experienced by individuals when they are unable to use their mobile phones or utilize the affordances these devices provide". However, only limited research can be found in terms of its determinants at present. Contemporary literature suggests that the relationships among attachment styles, mindfulness, and nomophobia have not been investigated.

**Objective:** This study aims to investigate the mediating effect of mindfulness on the relationship between attachment and nomophobia. In addition, the study also focuses on gender differences in attachment, mindfulness, and nomophobia. A theory-based structural model was tested to understand the essentials of the associations between the constructs.

**Methods:** The Experiences in Close Relationships Scale, Nomophobia Questionnaire, and Mindful Attention Awareness Scale were used to collect data from undergraduate students (N=450; 70.9% women [319/450]; mean age=21.94 years [SD 3.61]). Two measurement models (ie, attachment and mindfulness) and a structural model were specified, estimated, and evaluated.

**Results:** The structural equation model shows that the positive direct effects of avoidant (.13,  $P=.03$ ) and anxious attachment (.48,  $P<.001$ ) on nomophobia were significant. The negative direct effects of avoidant (-.18,  $P=.01$ ) and anxious attachment (-.33,  $P<.001$ ) on mindfulness were also significant. Moreover, mindfulness has a significant negative effect on nomophobia for women only (-.13,  $P=.03$ ). Finally, the Sobel test showed that the indirect effects of avoidant and anxious attachment on nomophobia via mindfulness were significant ( $P<.001$ ). The direct and indirect effects of anxious attachment, avoidant attachment, and mindfulness altogether accounted for 33% of the total variance in nomophobia. Gender comparison results show that there is a significant difference in attachment based on gender ( $F_{2,447}=6.97$ ,  $P=.01$ , Wilk  $\lambda=.97$ , partial  $\eta^2=.03$ ). Women (mean 68.46 [SD 16.96]) scored significantly higher than men (mean 63.59 [SD 15.97]) in anxious attachment ( $F_1=7.93$ ,  $P=.01$ , partial  $\eta^2=.02$ ). Gender differences in mindfulness were not significant ( $F_{4,448}=3.45$ ,  $P=.69$ ). On the other hand, results do show significant gender differences in nomophobia ( $F_{4,445}=2.71$ ,  $P=.03$ , Wilk  $\lambda=.98$ , partial  $\eta^2=.02$ ) where women scored significantly higher than men.

**Conclusions:** In general, individuals who are emotionally more dependent and crave more closeness and attention in the relationship tend to display higher levels of fear or discomfort when they have no access to their mobile phones. However, gender has a differential impact on the relationship between avoidant attachment and nomophobia. This study establishes the impact of mindfulness on nomophobia for women; therefore, future studies should test the effectiveness of mindfulness-based therapy

approaches and confirm whether they are effective and efficient. On the basis of significant gender difference in nomophobia and attachment, we conclude that gender should be taken into account in mindfulness-based treatments dealing with nomophobia.

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## KEYWORDS

reactive attachment disorder; mindfulness; anxiety; phobic disorders; phobia; smartphone

## Introduction

### Nomophobia

Excessive or problematic technology use has been partly explained by attachment theory, which posits that people may cultivate connection to technological devices and may feel uncomfortable upon separation [1]. Among various types of problematic technology use, nomophobia is a relatively novel problem [2,3] or disorder [4], which is defined as the fear of being unable to use one's mobile device [5] or the "the feelings of discomfort or anxiety experienced by individuals when they are unable to use their mobile phones or utilize the affordances these devices provide" [6]. Lin et al [7] categorize nomophobia as a form of situational phobia and suggest its inclusion into the specific phobia in the *Diagnostic and Statistical Manual of Mental Disorders, Fifth Edition* (DSM-V) as a situational phobia [8,9]. Han et al [10] defined nomophobia as a smartphone separation anxiety and argued that when a user perceives the smartphone as an extended self, he or she is more likely to get attached to the device, which in turn would lead to nomophobia by promoting proximity seeking.

Although there is a growing interest in nomophobia, at present, limited research can be found in terms of its determinants. Nonetheless, some of the technology-related situational, dispositional, and environmental antecedents that may share the similar fundamentals with nomophobia are summarized in **Table 1**. This review indicates that there is a common pattern of dispositional (eg, impulsivity, self-control, self-esteem, or introversion), situational (eg, age, gender, marital status, or ethnicity), and environmental (eg, Web-based social support,

amount of time, or stress) antecedents that are associated with technology-related complications.

### Attachment

Attachment styles may be one of the dispositional antecedents of nomophobia, where attachment is defined as "the over-allocation of cognitive and emotional resources towards a particular object, construct, or idea" [21]. Attachment refers to "the mental representations of the self, partner, and relationships called internal working models," which incorporate self-perceptions of one's personal worth of love and care from others and of others' availability and awareness to one's needs [22]. Attachment theory has originally hypothesized the predisposition of humans to form and preserve strong emotional bonds with their caregivers [23]. However, later, the likelihood of emotional bondage beyond humans has been suggested, in the forms of obsessive-compulsive disorder [24], compulsive work [25], or various types of addictions [26-28]. Thus, Van Gordon et al [29] conclude that unhealthy attachments to objects, people, or situations may be developed.

The relationship between attachment styles and substance addictions has been documented in the literature [30,31]. The mechanisms underlying substance addictions may be similar for behavioral complications such as addictions or phobias in terms of technology, Internet, or social media. For example, anonymous and interactive communication in social media can reduce the feeling of social isolation for individuals with an insecure attachment [32]. Recently, Eichenberg et al [30] reported that individuals with a tendency for Internet addiction were categorized as insecurely attached, whereas securely attached individuals showed no tendency for Internet addiction.

**Table 1.** Selected situational, dispositional, and environmental antecedents of technology-related complications.

Study	Domain	Antecedents
Arpacı et al [11]	Internet addiction	Individualism and psychological needs (ie, achievement, affiliation, dominance, and autonomy)
Karacic and Oreskovic [12]	Internet addiction	Age and gender
Lee et al [13]	Smartphone addiction	Self-expressive and utilitarian benefits and locus of control
Kim and Kang [14]	Mobile messenger services addiction	Self-esteem and self-control
Shen et al [15]	Web-based game addiction	Loneliness, achievement, and excitement
Chen et al [16]	Smartphone addiction	Perceived enjoyment, mood regulation, pastime, and conformity
Jeong et al [17]	Digital game addiction	Loneliness, depression, and aggression
Yang et al [18]	Mobile social networking sites addiction	Web-based social interaction ties and Web-based social supports
Bock et al [19]	Mobile phone affinity	Anxious attachment and addiction correlates with depression and impulsivity
Kim et al [20]	Smartphone addiction	Impulsivity

Studies such as these suggest that attachment theory may help us understand the antecedents of technology-relevant behavioral complications such as nomophobia.

Mindfulness is described as “the awareness that emerges through paying non-judgmental attention on purpose, in the present moment, to the unfolding of experience moment by moment” [33]. Mindfulness is found to have positive effects on physical and psychological well-being [34]. In addition, mindfulness has been theorized to have effects on behavioral addictions, depression, mood disorder, and anxiety disorder [34,35]. Consequently, studies have found mindfulness mediation interventions to improve a variety of health conditions [36].

In sum, an evaluation of the contemporary literature suggests that the relationships among attachment styles and problematic technology use have not been fully investigated [37]. An investigation of the effects of various attachment styles (ie, avoidant attachment vs anxious attachment) on nomophobia would be highly original in the literature. Furthermore, studying the potential effects of mindfulness on the association between attachment and nomophobia would be interesting and theoretically warranted. Lastly, because gender roles theory posits that there exist cognitive and emotional differences between men and women, this research aimed to investigate the effects of gender differences on attachment, mindfulness, and nomophobia.

## Theoretical Background and Hypothesis

### Attachment Theory

Bowlby’s [22,38-43] classical research on the infant-mother attachment theory has been extended to different populations [36,37], relationship types [38,39], and nonhuman objects [28,44]. Hazan and Shaver [45] classified attachment styles into three general categories, that is, secure, anxious, and avoidant, which are consistent with the three childhood attachment styles suggested in the original studies with infants.

*Secure attachment* is associated with a positive model of self as well as a positive model of others. Therefore, individuals who score lower on both dimensions are classified as *insecurely attached* [46]. *Avoidant attachment* is associated with a positive model of self and a negative model of others. It can be construed as hypersensitivity to unresponsiveness, rejection, and abandonment. Individuals whose dominant style is avoidant tend to have difficulties with close relationships and intimacy and seek to maintain self-reliance, emotional distance, and control [45]. They distance themselves from others and avoid experiencing negative emotions [47].

*Anxious attachment* is associated with a negative model of self and a positive model of others [45,46]. Anxious attachment is characterized by greater emotional dependence, desire for more commitment and closeness [48], and more intensive attention from partners [47]. Individuals dominant in this attachment style tend to have a fear of rejection, a negative perception of self-worth, worry about being abandoned or unloved, and thereby, seek a higher need for closeness and intimacy [49]. They seem to be obsessive and hypervigilant in the relationship [50]. This study opted to focus on the effects of anxious versus avoidant attachment styles on nomophobia and mindfulness.

Attachment styles have an impact on social interactions and emotional development [51,52], which in turn determine the risk of developing dependence to people, objects, or events [26,53]. Recent studies indicate a significant relationship between attachment styles (ie, avoidant vs anxious) and behavioral addictions [26-28]. In addition, attachment styles are related to the problematic use of technology such as the Internet [54], mobile phones [28], video games [55], and social media [26]. More specifically, anxious attachment was associated with technology-mediated breakups, whereas avoidant attachment predicted the likelihood of technology overuse [56]. Blackwell et al [26] found that both attachment styles predict social media addiction. On the basis of attachment theory and available research findings, we hypothesized that the effects of both anxious attachment (hypothesis 1) and avoidant attachment (hypothesis 2) on nomophobia would be *positively* significant.

### Mindfulness

Mindfulness-based mental health betterment techniques assert that behavioral tendencies that lead to psychological complications can distort individuals’ perceptions of reality and may cause maladjustment [57]. Accordingly, the American Psychiatric Association [58] promotes mindfulness-based therapy approaches, which have been found effective in the treatment of behavioral addictions, depression, mood disorder, and anxiety disorder [35,59].

There is promising evidence for the efficacy of mindfulness-based treatment, suggesting that self-awareness increased through mindfulness practices can target multiple neural, psychological, physiological, and behavioral processes [34,35,60-63]. In the same vein, recent studies argued that mindfulness-based interventions could treat behavioral complications such as Internet addiction [64] and video game addiction [65]. Problematic technology use, such as nomophobia, may also be treated by interventions that gear toward enhancing individuals’ mindfulness levels [66]. Therefore, we hypothesized that higher levels of mindfulness would be associated with lower levels of nomophobia. In other words, there would be a negatively significant effect of mindfulness on nomophobia (hypothesis 3).

There is strong evidence that mindfulness is associated with attachment styles. For example, Pepping et al [67] indicated that avoidant and anxious attachment were significantly associated with lower scores in mindfulness. In another study, mindfulness was negatively linked with anxious attachment [68]. Furthermore, studies have validated the association between mindfulness and attachment styles [69-71]. On the other hand, several studies argued that mindfulness is significantly associated with attachment security [67,72]. Thus, we hypothesized that there would be a significant negative effect of both anxious attachment (hypothesis 4) and avoidant attachment (hypothesis 5) on mindfulness. Finally, based on gender roles theory, we expected significant gender differences between men and women in attachment, mindfulness, and nomophobia.

## Methods

### Participants

A total of 450 students were recruited through convenience sampling method. Of the 450 students, 319 were women (70.9%) and 131 were men (29.1%). Participants' ages ranged from 18 to 40 years (mean age=21.94 [SD 3.61]). In terms of ownership, 99.3% of the participants had a smartphone (447/450), whereas 95.6% (430/450) had mobile Internet. Participants used mobile Internet on an average of 4.58 hours a day (SD 2.92). In terms of college levels, 123 students were freshmen (27.3%); 11 were sophomores (2.4%); 153 were juniors (34.0%); and 163 were seniors (36.3%). Participants came from various study majors such as Psychology (41.3%), Social Science (33%), Health Science (17.1%), and Computer Science (8.6%).

### Measures

#### *The Experiences in Close Relationships (ECR) Scale*

Brennan et al [46] developed the ECR scale, a 36-item, self-report attachment measure, which includes 2 subscales: Avoidance (alpha=.94) and Anxiety (alpha=.91). Sample items from the scale include "I prefer not to show a partner how I feel deep down" (ie, Avoidance) and "worry about being abandoned" (ie, Anxiety). Items are rated on a 7-point Likert scale, ranging from 1 (strongly disagree) to 7 (strongly agree), and higher scores refer to higher levels of avoidance or anxiety. Sümer [73] provided evidence for the reliability and validity of the Turkish version of the ECR scale. Cronbach alpha coefficients for anxiety and avoidance styles were found to be .86 and .90, respectively [73]. In this study, the instrument's internal consistency coefficients for the combined groups, men, and women were found to be acceptable (Table 2).

#### *The Mindful Attention Awareness Scale (MAAS)*

Brown and Ryan [74] developed 15 items rated on a 6-point Likert scale that form a single factor structure to assess the awareness of the present moment and the level of attention. Sample items from the scale include "I could be experiencing

some emotion and not be conscious of it until sometime later" and "I find it difficult to stay focused on what's happening in the present." Özyeşil et al [75] adapted the scale into Turkish and provided validity and reliability properties of the adapted scale. The scale's internal consistency coefficient was found to be .85 in this study (Table 2).

#### *The Nomophobia Questionnaire (NMP-Q)*

The NMP-Q is a 20-item, 5-point Likert type, self-report instrument that assesses the fear of being unable to use mobile devices under 4 subscales (ie, Unable to Access Information, Losing Connectedness, Unable to Communicate, and Giving Up Convenience). Sample items from the questionnaire include the following: "I would be annoyed if I could not look information up on my smartphone when I wanted to do so" (ie, Unable to Access Information), "If I could not use my smartphone, I would be afraid of getting stranded somewhere" (ie, Losing Connectedness), "I would be anxious because I could not keep in touch with my family and/or friends" (ie, Unable to Communicate), or "I would feel awkward because I could not check my notifications for updates from my connections and Web-based networks" (ie, Giving Up Convenience) [5]. Cronbach alpha of the original scale was .92. Yıldırım et al [76] provide the validity and reliability evidence of the Turkish NMP-Q. They found that Cronbach alpha coefficients of the 4 subscales were .90, .74, .94, and .91, respectively. We used the total nomophobia scores in this study, which are computed by summing the 4 subscale scores. The internal consistency coefficients of the questionnaire ranged from .89 to .92 for the combined groups, men, and women in this study (Table 2).

### Procedure

All procedures were performed in accordance with the ethical standards of the institutional board guidelines, and the study was approved by the institutional review board. Before informed consent was obtained, participants were debriefed about the nature and possible consequences of the study. Participation was voluntary and participants received extra course credit for completing the research packet.

**Table 2.** Descriptive statistics, correlation coefficients, convergent validity and discriminant validity, and reliability of the study variables. Statistics reported outside parentheses are for the combined groups, whereas within parentheses are statistics for men and women, respectively.

Variables	Alpha	CR <sup>a</sup>	AVE <sup>b</sup>	Correlations				
					1	2	3	4
1. Anxious	.88 (.87-.89)	.77 (.80-.76)	.52 (.50-.50)	.72 (.71-.71) <sup>c</sup>				
2. Avoidant	.77 (.75-.77)	.84 (.83-.83)	.57 (.55-.55)	.09 (.18-.10)	.75 (.74-.74)			
3. Mindfulness	.85 (.87-.85)	.79 (.70-.78)	.50 (.50-.51)	-.26 (-.24 to -.25)	-.22 (-.42 to -.15)	.71 (.71-.71)		
4. Nomophobia	.91 (.89-.92)	.75 (.81-.77)	.50 (.50-.50)	.54 (.47-.56)	.27 (.23-.28)	-.35 (-.35 to -.35)	.71 (.71-.71)	
Range				1-7	1-7	1-6	1-5	
Mean				4.31 (4.47-4.24)	3.82 (3.55-3.93)	3.77 (3.75-3.78)	3.25 (3.22-3.26)	
SD <sup>d</sup>				1.75 (1.70-1.75)	1.73 (1.63-1.74)	1.33 (1.38-1.31)	1.10 (1.11-1.09)	

<sup>a</sup>CR: composite reliability.

<sup>b</sup>AVE: average variance extracted (for convergent validity).

<sup>c</sup>Discriminant validity coefficients are on the diagonal.

<sup>d</sup>SD: standard deviation.

## Results

### Instrument Reliability and Validity

The normality of the scales suggested minimal skewness (range  $-.34$  to  $.33$ ) and kurtosis (range  $-.50$  to  $2.11$ ). Convergent and discriminant validity of the constructs were investigated by developing a correlation matrix. Hair et al [77] suggest that convergent validity is adequate when average variance extracted (AVE) coefficients exceed or equal  $.50$ . In this study, the square roots of the AVE coefficients (shown in diagonal Table 2) were greater than the interconstruct correlations for all constructs. Thus, discriminant validity was found satisfactory for the constructs studied. Table 2 also illustrates reliability and convergent validity coefficients along with descriptive statistics for the combined groups, women, and men.

### Gender Differences

One-way multivariate analysis of variances investigated statistical differences between men ( $n=131$ ) and women ( $n=319$ ) in attachment, mindfulness, and nomophobia. Results show that there is a significant difference in attachment based on gender ( $F_{2,447}=6.97, P=.01$ , Wilk  $\lambda=.97$ , partial  $\eta^2=.03$ ). Women (mean  $68.46$  [SD  $16.96$ ]) scored significantly higher than men (mean  $63.59$  [SD  $15.97$ ]) in anxious attachment ( $F_1=7.93, P=.01$ , partial  $\eta^2=.017$ ). Gender differences in mindfulness were not statistically significant ( $F_{4,448}=3.45, P=.69$ ). On the other hand, results show significant gender differences in nomophobia

( $F_{4,445}=2.71, P=.03$ , Wilk  $\lambda=.98$ , partial  $\eta^2=.02$ ), where women scored significantly higher than men.

### Confirmatory Factor Analysis

Confirmatory factor analysis (CFA) was used to test whether the proposed measurement models and the structural model were to fit the data. The model fit indices for the measurement models and the structural model are presented in Table 3. Results suggest that the measures used in this study formed adequate measurement models and therefore, provided evidence for the construct validity.

### Hypothesis Testing

To test the research model and hypotheses, structural equation modeling (SEM) was employed with maximum likelihood estimation. The SEM results for the combined groups, men, and women are presented in Table 4. As shown in the table, the positive direct effect of anxious attachment was significant on nomophobia for the combined groups, women, and men; however, the direct effect of avoidant attachment on nomophobia was significant only for the combined groups but not for men or women. Therefore, results shown in Figure 1 supported hypothesis 1 but not hypothesis 2. Moreover, there is a significant negative effect of mindfulness on nomophobia for the combined groups ( $-.13, t_{419}=-2.16, R^2=.15, P=.03$ ) and women ( $-.15, t_{318}=-2.23, R^2=.15, P=.03$ ) but not for men ( $-.13, t_{130}=-1.12, P=.26$ ). Thus, results supported hypothesis 3 for the combined groups and women but not for men.

**Table 3.** Fit indices of the measurement models and the theoretical model. The results of multigroup analysis are shown in parentheses.

Fit indices	Attachment	Nomophobia	Structural model	Acceptable values
Chi-square	83.51 (134.12)	401.75 (574.95)	333.14 (612.78)	
Degrees of freedom	33 (66)	156 (310)	216 (432)	
P value	.001 (.001)	.001 (.001)	.001 (.001)	$.05 \leq P \leq 1.00$ [79]
Chi-square/degrees of freedom	2.53 (2.03)	2.58 (1.86)	1.54 (1.42)	$<3$ [78]
GFI <sup>a</sup>	.97 (.94)	.92 (.89)	.94 (.90)	$\geq .90$ [78,79]
AGFI <sup>b</sup>	.94 (.91)	.89 (.86)	.92 (.87)	$\geq .80$ [78,79]
RMR <sup>c</sup>	.03 (.03)	.06 (.07)	.02 (.03)	$<.05$ [78,79]
RMSEA <sup>d</sup>	.06 (05)	.06 (04)	.04 (03)	$<.08$ [77]
NFI <sup>e</sup>	.94 (.90)	.92 (.89)	.90 (.81)	$\geq .90$ [77]
TLI <sup>f</sup>	.95 (.93)	.93 (.93)	.95 (.92)	$\geq .90$ [78,79]
CFI <sup>g</sup>	.96 (.95)	.95 (.94)	.96 (.94)	$\geq .90$ [78,79]
IFI <sup>h</sup>	.96 (.95)	.95 (.94)	.96 (.94)	$\geq .90$ [78,79]

<sup>a</sup>GFI: Goodness-of-Fit Index.

<sup>b</sup>AGFI: Adjusted Goodness-of-Fit Index.

<sup>c</sup>RMR : root mean square residual.

<sup>d</sup>RMSEA: root mean square error of approximation.

<sup>e</sup>NFI: Normed Fit Index.

<sup>f</sup>TLI: Tucker-Lewis Index.

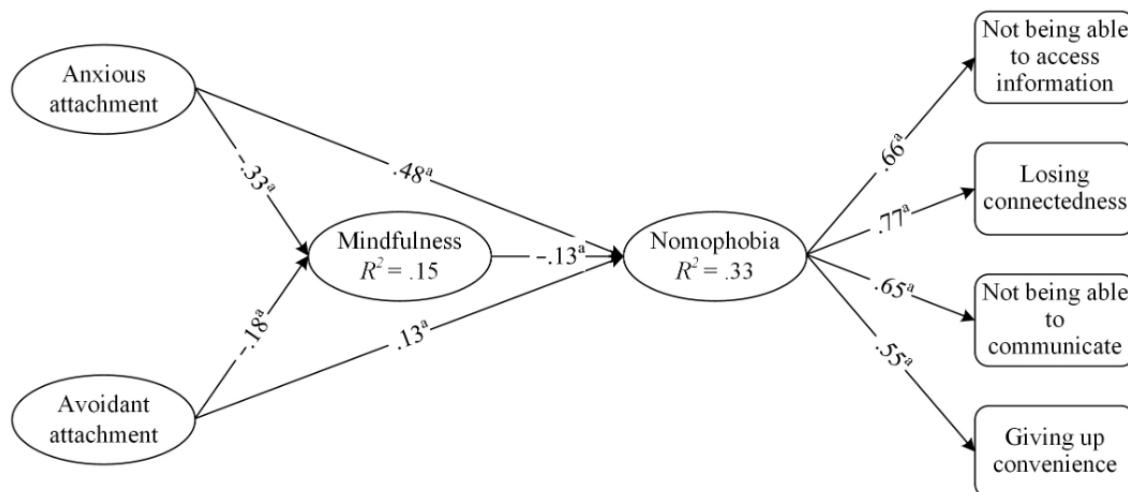
<sup>g</sup>CFI: Comparative Fit Index.

<sup>h</sup>IFI: Incremental Fit Index.

**Table 4.** Structural equation modeling (SEM) and multigroup analysis results. Results are reported for the combined groups (men, women), respectively.

Hypothesis	Estimate	SE <sup>a</sup>	Critical ratio	P value
Anxious → Nomophobia	.48 (.53-.46)	.17 (.42-.18)	6.93 (3.53-5.82)	.001 (.001-.001)
Avoidant → Nomophobia	.13 (.02-.12)	.30 (.37-.29)	2.21 (.18-1.81)	.03 (.86-.07)
Mindfulness → Nomophobia	-.13 (-.13 to -.15)	.35 (.63-.44)	-2.16 (-1.12 to -2.23)	.03 (.26-.03)
Anxious → Mindfulness	-.33 (-.26 to -.31)	.03 (.06-.03)	-4.66 (-2.19 to -3.75)	.001 (.03-.001)
Avoidant → Mindfulness	-.18 (-.33 to -.15)	.06 (.09-.05)	-2.63 (-2.28 to -2.05)	.01 (.02-.04)

<sup>a</sup>SE: standard error.

**Figure 1.** Hypothesis testing results. Manifest variables and their respected error terms underlying the latent variables are omitted to save space. "a" signifies  $P < .001$ .

Furthermore, negative direct effects of both anxious and avoidant attachment on mindfulness were significant for the combined groups, men, and women. Therefore, results supported both hypothesis 4 and hypothesis 5. The direct and indirect effects of anxious attachment, avoidant attachment, and mindfulness altogether accounted for 33% of the total variance in nomophobia. The equations shown in **Table 5** represent the relationships among the constructs.

### Mediation Analysis

A 4-step approach was used to test the mediation effect of mindfulness on the relationship between attachment and nomophobia. First, the direct effects of both anxious ( $SE=.13$ ,  $t=-3.19$ ,  $P<.001$ ) and avoidant ( $SE=.18$ ,  $t=-3.54$ ,  $P<.001$ ) attachment on mindfulness were found significant. Second, both the direct effects of anxious ( $SE=.41$ ,  $t=4.02$ ,  $P<.001$ ) and avoidant ( $SE=.39$ ,  $t=2.11$ ,  $P=.05$ ) attachment on nomophobia

were found significant as well. Third, the direct effect of mindfulness on nomophobia was significant ( $SE=.65$ ,  $t=-3.50$ ,  $P<.001$ ). Finally, the Sobel test showed that the indirect effect of avoidant and anxious attachment on nomophobia via the mediator (ie, mindfulness) was significant ( $P<.001$ ). These results supported full mediation and indicated that attachments have significant effects on nomophobia through mindfulness.

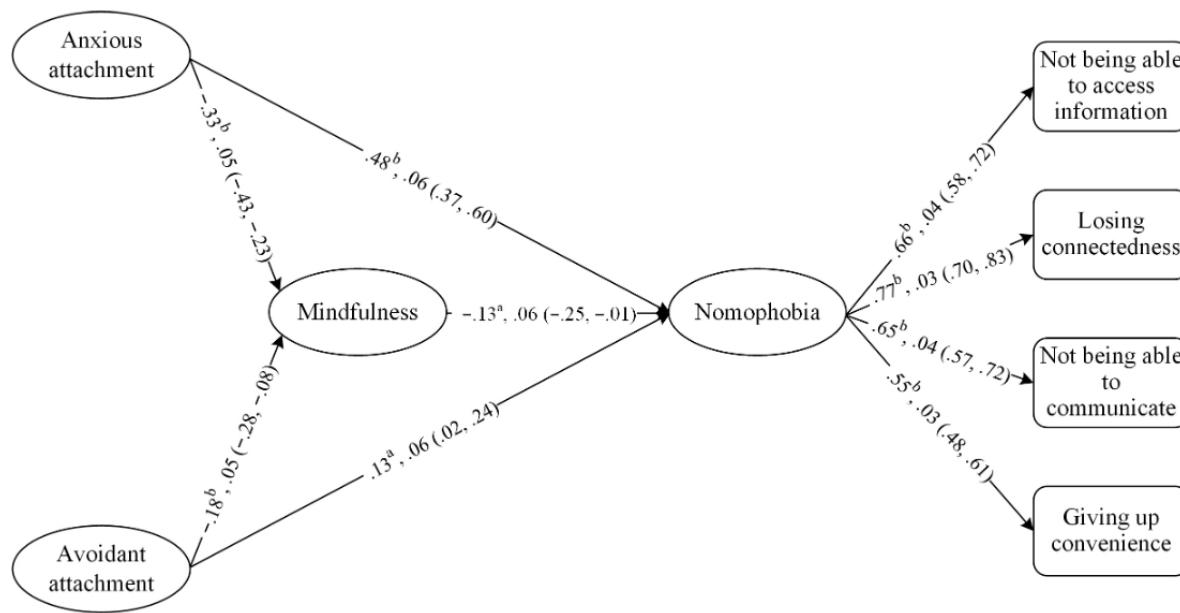
### Randomization Tests

Because we used a nonrandom sample, randomization tests were conducted to support generalizability beyond this study's sample. We employed 5000 bootstrap replicates to test the effects of attachment on nomophobia via mindfulness. Means, standard errors, 95% CIs, significance levels, and the directions of the relations are reported in **Figure 2**, which altogether suggest that similar results closely approximated in the bootstrapped samples.

**Table 5.** Relationships among the constructs. Results are reported for the combined groups (men, women), respectively.

Variable	Equation	Error	$R^2$
Mindfulness	-.18 (-.33 to -.15) x Avoidant -.33 (-.26 to -.31) x Anxious	.13 (.15-.13)	.15 (.24-.12)
Nomophobia	.13 (.02-.12) x Avoidant .48 (.53-.46) x Anxious -.13 (-.13 to -.15) x Mindfulness	3.83 (3.55-3.94)	.33 (.36-.31)

**Figure 2.** Means of 5000 bootstrap replicate coefficients and their standard errors. Within parentheses are 95% CIs. Manifest variables and their respected error terms underlying the latent variables are omitted to save space. "a" signifies  $P=.05$  and "b" signifies  $P<.001$ .



## Discussion

### Principal Findings

One way of explaining why people experience problems in technology use is that of attachment theory. Recent research has found significant associations among different attachment styles and problematic use of the Internet, mobile phones, video games, and social media [26-28]. Therefore, the aim of this study was to further investigate the effects of anxious and avoidant attachment on nomophobia. Additionally, because the concept of mindfulness has been theorized to have plausible effects on psychological complications, we aimed to test whether it would mediate the association between attachment and nomophobia.

In general, we found positive effects of both anxious and avoidant attachment on nomophobia and their negative effects on mindfulness. However, when we analyzed the details of the effects for men and women separately, results revealed interesting patterns. For example, anxious attachment had a significant positive effect on nomophobia for both women and men, even though the link was stronger among men than women. Individuals who are emotionally more dependent and crave for more closeness and attention in the relationship tend to display higher levels of fear or discomfort when they have no access to their mobile phones. Thus, we conclude that anxious attachment is reflected upon a technological object, that is, a smartphone. These findings suggest the likelihood of a strong link between anxious attachment and nomophobia, which should be further scrutinized through experimental studies.

When it comes to avoidant attachment, results are not as straightforward. We found that avoidant attachment shows a significant positive effect on nomophobia on the combined groups ( $N=450$ ); however, the effects reduced to nonsignificance when men ( $n=131$ ) and women ( $n=319$ ) were analyzed

separately. This suggests that gender has a differential impact on the relation between avoidant attachment and nomophobia.

Literature suggest that mindfulness cultivates a better understanding of the nature of existence by mindfully observing the dissolution of affective, cognitive, and sensory processes [29]. In addition, mindfulness is used effectively in various behavioral dependencies such as Internet gaming disorder [35,80]. Lastly, it has been suggested that technology-based addictions may be treated by interventions that gear toward enhancing mindfulness [34,35,61,81]. This study is the first attempt in the literature to investigate the effect of mindfulness on nomophobia. Results indicate a significant direct effect of mindfulness on nomophobia for women but not for men. Women who show higher levels of mindfulness carry lower risk of nomophobia. Similar to our results, Sriwilai and Charoensukmongkol [37] examined the relationship between social media addiction and mindfulness. They found that individuals with higher social media addiction have lower mindfulness scores. These findings indicate that mindfulness-based therapies could be used in the treatment of behavioral addictions for women. Similar suggestions were made by Wahbeh and Oken [36], Garland et al [82], Black [83], Peltz and Black [84], and Garland [85].

Prior studies suggested that men and women show quite different Web-based behavior patterns. For example, Durkee et al [86] indicated that male adolescents prefer to use Web-based games, whereas female adolescents prefer to interact with social networking websites. Our findings broaden the literature by suggesting the possibility of using mindfulness-based treatment techniques with nomophobia for women. There are two general implications of these findings. First, the concept and techniques of mindfulness can be used as a preventive tool to dodge the risk of nomophobia for women. Once risk assessments are completed and under-risk groups are identified, mindfulness exercises may be taught and practiced with under-risk women.

Second, mindfulness-based treatment techniques may be used with clinically diagnosed women to remedy the higher levels of nomophobia. This study establishes the impact of mindfulness on nomophobia at least for women; therefore, future studies should test the effectiveness of mindfulness-based therapy approaches and confirm whether they are effective and efficient.

Findings indicate that there is a significant difference in nomophobia between women and men. Furthermore, there was a significant difference in the attachment styles based on gender. Results indicate that women and men differed in anxious attachment but not in avoidant attachment. These findings imply that women tend to display more anxious attachment than men. Gender differences in attachment can be explained by gender schema theory proposed by Bem [87]. She theorizes that individuals develop cognitive schemas throughout childhood to be able to show gender-appropriate behaviors. Such schemas eventually predispose men and women to form and preserve emotional bonds differently. Previously, Katz and Toner [88] conducted a systematic review to figure out the role of gender differences in the effectiveness of the mindfulness-based treatment for substance use. Their findings suggested that men gravitate less toward the treatments, and thereby, women benefit more from such treatments. These findings imply that gender differences should be considered in mindfulness-based treatments dealing with nomophobia.

### Limitations

There are several limitations of this study. First, using a convenience sampling in recruiting the participants is one of

the limitations of the study. We attempted to overcome this limitation by conducting randomization tests; however, future studies may analyze the hypothesized relationships on longitudinal data or random samples. Second, the study shows an overwhelming use of female subjects as compared with male subjects; the sample size for men is quite limited to test SEM-based analyses, and we suggest that the models established in this study be tested with a larger sample, which is fairly well balanced by gender. Third, neither is the attachment style the only determinant of nomophobia nor is mindfulness the only mediator; however, based on cyber psychology literature, the study focused on these factors. Other dispositional or situational factors (ie, personality characteristics) and mediators (ie, psychological needs) would definitely be worthwhile to explore in future studies. Finally, it would be useful to incorporate qualitative techniques for a detailed investigation of the research problem. Despite these limitations, this study has significant contributions to expand the literature by identifying important relationships among attachment, mindfulness, and nomophobia.

### Conclusions

We found the significant effects of both anxious and avoidant attachment on mindfulness and nomophobia. However, gender has a differential impact on the relation between avoidant attachment and nomophobia. We conclude that gender differences should be considered in mindfulness-based treatments dealing with nomophobia. Mindfulness-based therapies could be used in the treatment of nomophobia, especially for women.

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### Conflicts of Interest

None declared.

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## Abbreviations

**AGFI:** Adjusted Goodness-of-Fit Index

**AVE:** average variance extracted  
**CFA:** confirmatory factor analysis  
**CFI:** Comparative Fit Index  
**CR:** composite reliability  
**ECR:** Experiences in Close Relationships  
**GFI:** Goodness-of-Fit Index  
**IFI:** Incremental Fit Index  
**MAAS:** Mindful Attention Awareness Scale  
**NFI:** Normed Fit Index  
**NMP-Q:** Nomophobia Questionnaire  
**RMR:** root mean square residual  
**RMSEA:** root mean square error of approximation  
**SD:** standard deviation  
**SE:** standard error  
**SEM:** structural equation modeling  
**TLI:** Tucker-Lewis Index

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Original Paper

# Telemedicine in Primary Care for Patients With Chronic Conditions: The ValCrònic Quasi-Experimental Study

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## Abstract

**Background:** The increase of chronic diseases prevalence has created the need to adapt care models and to provide greater home supervision.

**Objective:** The objective of our study was to evaluate the impact of telemonitoring on patients with long-term conditions at high risk for rehospitalization or an emergency department visit, in terms of target disease control (diabetes, hypertension, heart failure, and chronic obstructive pulmonary disease).

**Methods:** We conducted a quasi-experimental study with a before-and-after analysis to assess the effectiveness of the ValCrònic program after 1 year of primary care monitoring. The study included high-risk patients with 1 or more of the following conditions: diabetes, high blood pressure, heart failure, and chronic obstructive pulmonary disease. We assessed risk according to the Community Assessment Risk Screen. Participants used an electronic device (tablet) to self-report relevant health information, which was then automatically entered into their eHealth record for consultation.

**Results:** The total sample size was 521 patients. Compared with the preintervention year, there were significant reductions in weight (82.3 kg before vs 80.1 kg after;  $P=.001$ ) and in the proportion of people with high systolic ( $\geq 140$  mmHg; 190, 36.5% vs 170, 32.6%;  $P=.001$ ) and diastolic ( $\geq 90$  mmHg; 72, 13.8% vs 40, 7.7%;  $P=.01$ ) blood pressures, and hemoglobin A<sub>1c</sub>  $\geq 8\%$  (186, 35.7% vs 104, 20.0%;  $P=.001$ ). There was also a decrease in the proportion of participants who used emergency services in primary care (68, 13.1% vs 33, 6.3%;  $P<.001$ ) and in hospital (98, 18.8% vs 67, 12.8%;  $P<.001$ ). Likewise, fewer participants required hospital admission due to an emergency (105, 20.2% vs 71, 13.6%;  $P<.001$ ) or disease exacerbation (55, 10.5% vs 42, 8.1%;  $P<.001$ ).

**Conclusions:** The ValCrònic telemonitoring program in patients at high risk for rehospitalization or an emergency department visit appears to be useful to improve target disease control and to reduce the use of resources.

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## KEYWORDS

chronic disease; primary health care; telemedicine

## Introduction

Demographic and epidemiological patterns are changing with aging populations and increased prevalence of chronic diseases, causing reduced mobility, along with a need to adapt care models and provide greater home supervision [1,2].

A 2008 review by the Canadian Agency for Drugs and Technologies in Health [3] described the high prevalence of chronic diseases, the great financial and social costs involved, and the attractive prospect of possibly improving patient care through telemedicine. Home telemonitoring and telephone support are the most frequently used ways to perform this kind of monitoring in chronic disease, and there is an important distinction to be made between synchronous (real-time) and asynchronous telemonitoring.

Noncommunicable diseases, particularly cardiovascular diseases, diabetes, cancer, and chronic respiratory diseases, are responsible for more deaths globally than all other causes combined [4]. Many of these conditions, including diabetes, high blood pressure, heart failure, and chronic obstructive pulmonary disease (COPD), can be managed through home telemonitoring programs, which enable health care professionals to monitor patients' progress and to preempt relapses by using information on vital signs and remote symptom questionnaires [5-8].

With regard to comorbid chronic diseases, telemedicine may decrease the use of resources and mortality compared with standard care [9], although there is no evidence that it improves quality of life or satisfaction.

Most studies [5-9] have reported benefits of telemedicine for patients with hypertension, diabetes, heart failure, or COPD with controversial results. It is difficult to pool intervention types and to define what telemonitoring entails. Some authors considered that telephone call monitoring performed by nurses qualifies as home telemonitoring [10], while other authors disagreed [11,12]. A systematic review of home telemonitoring for COPD by Bolton et al found methodological limitations, and those authors recommended improving and expanding studies and considering the costs [13].

In Spain, most projects for monitoring diseases are in hospital settings, and they are associated with a high rate of readmissions. A recent experience with home cardiac rehabilitation after a coronary event [14] showed that a telemonitoring program appears to be useful for improving the risk profile in acute coronary syndrome survivors and can be an effective tool for secondary prevention. A 3-country project on telemedicine for cardiopulmonary rehabilitation in people with COPD [15] found that integrated care services supported by information and communication technologies can improve COPD management. Primary care experiences such as the TELBIL study in the Basque Country in Spain are rare. That program involved participants at very high risk of heart failure and COPD and reported very encouraging results, including reduced hospital

admissions, length of hospital stay, and emergency visits [16]. The PROMETE study showed similar results in patients with severe COPD [17]. Both studies had very few participants. However, their conditions were very serious and generally led to many emergencies and hospital readmissions.

Although previous literature shows that many telemedicine programs have been implemented and evaluated with favorable effects, most of the studies included patients with 1 specific chronic condition, and these study samples are not broadly representative of patients encountered in everyday practice [18]. To assess a telemonitoring program in the real-world population, it is necessary that the study sample include patients encountered in routine clinical practice settings. In addition, high-risk patients are often managed by primary and specialty care, so both hospital and primary care settings should be involved in telemonitoring studies that address such patients.

The aim of this study was to evaluate the impact of telemonitoring on patients with 1 or more long-term conditions at high risk for rehospitalization or an emergency department visit, in terms of target disease control (diabetes, high blood pressure, heart failure, and COPD).

## Methods

### Study Design

This was a before-and-after quasi-experimental intervention study.

### Setting and Study Period

ValCrònic was a 5-year (2011-2016) telemonitoring program in 4 Spanish health centers in the Valencia Region (population 5 million), situated on the Mediterranean coast, within the health departments of Sagunto and Elche: Sagunto health center, Sagunto Port health center II, Elx-El Raval health center, and Santa Pola health center. In December 2013, two additional health centers were incorporated: Elx-Altabix health center and Elx-San Fermin health center. The program was led by primary care services in collaboration with the referral hospital and other institutions in the health sector, with the participation of more than 150 professionals. In the Spanish public health system, primary health centers from the same area have the same referral hospital where patients are admitted. Since the participating health centers belonged to 2 different areas, 2 referral hospitals collaborated in the study in order to collect all hospital admissions and emergency department visits.

Development of the technical procedures and protocols began in April 2011, and participants were recruited from February 2012 to February 2015 for a 1-year telemonitoring intervention. We compared the clinical outcomes before and after the intervention. The program ended in February 2016.

### Study Sample

The study included people at high risk for rehospitalization or an emergency department visit with 1 or more of the following conditions: heart failure, COPD, type 2 diabetes mellitus, and

arterial hypertension. Heart failure and COPD are the most frequent causes of nonscheduled hospital admissions, while diabetes and hypertension consume a large amount of health care resources in the field of primary care due to their high prevalence. Furthermore, we selected these chronic diseases because patients can easily measure their indicators, and which were also sensitive to changes introduced as part of the intervention. We excluded patients who did not sign the informed consent form, did not have a telephone, or had a life expectancy of less than 1 year (based on their physician's opinion).

The Kaiser Permanente model [19] recommends stratifying the risk of patients for hospitalizations or emergency department encounters according to the Community Assessment Risk Screen (CARS) [20]; this screen can identify high-risk patients and has been validated in the Valencia Region by the Polibienestar Research Institute at the University of Valencia [21]. To improve the validity of the scale, we complemented the result obtained (high risk or not) with the clinical judgement of the participant's usual physician.

We used a consecutive, nonprobability sampling method in the primary care setting. In addition, we actively recruited patients who met the inclusion criteria (according to the data in their eHealth records), by means of written invitations to participate in the program.

## Intervention and Measurements

The ValCrònic program is preventive and based on innovative approaches to chronicity such as the chronic care model [22] and the Kaiser Permanente model [19]. The program features continuous telemonitoring of patients with chronic conditions and multiple comorbidities. It is led mainly by primary care but operates in collaboration with hospital services (especially the general medicine service, among others), primary care- and hospital-based emergency services, and the home hospitalization unit.

The intervention consisted of several components: participants measured their own vital signs related to the conditions included in the study and automatically entered them into their eHealth record via a wireless electronic device (tablet) provided to them for the study. In addition, an automated alert system was set up to promptly detect any alterations, which promoted health professionals' proactive involvement. Participants also received health education and awareness interventions tailored to their conditions through informative videos available in the tablet.

On the basis of different possible combinations of the 4 diseases included in the program, we defined 8 individualized care programs and monitored each condition from the patient's home, based on the following indicators: (1) heart failure (blood

pressure, heart rate, symptom questionnaire, and weight gain), (2) COPD (COPD Assessment Test [CAT] questionnaire [22], oxygen saturation), (3) heart failure plus COPD, (4) heart failure plus diabetes (capillary glycemia), (5) diabetes plus COPD, (6) COPD plus arterial hypertension (blood pressure), (7) heart failure plus COPD plus diabetes, and (8) diabetes plus arterial hypertension.

Participants received different tools for self-measurement according to their diseases (Figure 1), along with videos instructing them in how to use them: a set of scales, a blood pressure monitor, a glucometer, and a pulse oximeter. In addition, we used health questionnaires for COPD and heart failure. Participants with COPD also completed the CAT questionnaire [23]. All information was recorded and automatically sent to the health center using the eHealth record functionalities included on the tablet (Figure 2). The frequency of the self-measurements was established individually with each patient, but health information was usually submitted on a weekly basis.

The self-reports were entered in the eHealth records in a similar way to how they would be entered in face-to-face visits to the center. This was possible due to the existence of a unique patient identifier and eHealth record for each patient within the Abucasis health information system (version II; Valencia Health Agency), which was used by the professionals in primary and specialized care in this study. Several months of prior technical work was necessary to ensure compatibility between the data sent from patients' homes and the eHealth records. Changes were also implemented in the clinical records used for hospital admissions in every health department to enable identification of ValCrònic patients in the event they went to an emergency department or were admitted to hospital.

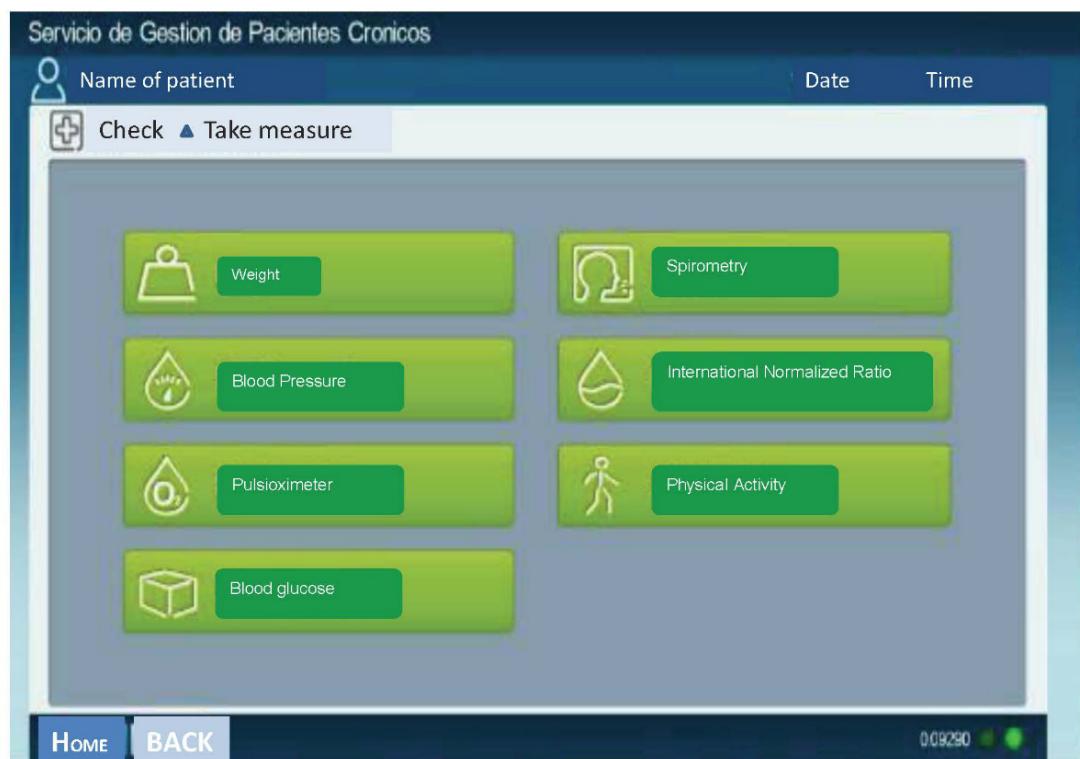
Alerts were programmed into the system to automatically display self-measurement values outside the normal range established for each participant. The primary care nurse who was usually in charge of managing the patient's care was responsible for following up on these alerts by means of the relevant action protocol. Every day, when the nurse opened the eHealth record app, they received information about the patients for whom an alert had been raised in the previous 24 hours or over the weekend. In the event of an emergency, the standard face-to-face procedure was followed.

Upon receipt of the self-measurements in the eHealth center, it was up to the nurse to decide whether to call participants to check the values, ask them to come to the health center, go to their home, or consult a doctor. Before program launch, all the doctors, nurses, and administrative staff at the participating centers received specific training on the study process, the program, and the devices.

**Figure 1.** Telemonitoring program devices, according to a patient's disease: scales, blood pressure monitor, glucometer, and pulse oximeter. COPD: chronic obstructive pulmonary disease.



**Figure 2.** Interface display on the tablet.



In addition, all participants received group training from their primary care nurses or doctors regarding the use of the monitoring devices and software apps. This training included content aimed at improving patient knowledge of self-care. In addition, participants received individualized training in their homes from technical personnel regarding the use of telemedicine devices. Patients received the equipment in their homes and had access to technical assistance via telephone or in-person visits from the company in charge of managing the

operation of the hardware and software (eHealth department of Telefónica España, SA, Madrid, Spain). The communication protocols between monitoring devices, tablets, and eHealth records were developed and implemented jointly by the eHealth center, Abucasis, and Telefónica eHealth technicians.

A senior management committee of 9 people was set up to monitor the activities of the ValCrònic program, composed of representatives from the Regional Health Ministry, including the General Health Care Directorate, the Health Area

Direktorate, the 2 managers of the participating health departments (Sagunto and Elx), the head of Information Technology Systems, and the technical program coordinator; and representatives of Telefónica, who were in charge of the telemedicine devices used. Meetings were held on a quarterly basis. A scientific committee was also set up, composed of the technical program coordinator, representatives of the professionals of the 2 participating health departments, and representatives of Telefónica.

## Outcomes

We recorded the weight and heart rate of patients, the proportion of patients with poor control of systolic ( $\geq 140$  mmHg) or diastolic ( $\geq 90$  mmHg) blood pressure, and the proportion of patients with poor control of hemoglobin A<sub>1c</sub> (HbA<sub>1c</sub>) ( $\geq 8\%$ ).

We also recorded visits to primary care- or hospital-based emergency services due to an exacerbation of the target diseases. Finally, we recorded unscheduled (emergency) hospital admissions. In addition, we calculated indicators of clinical relevance to the ValCrònic program: absolute risk reduction, relative risk reduction, and number needed to treat to prevent a harmful outcome.

## Variables

We collected demographic data (age, sex) from all the participants, as well as the indicators for each condition: weight (kg), heart rate (beats/min), blood pressure (mmHg), capillary glycemia (mg/dL), and HbA<sub>1c</sub> from a venous blood sample (%).

Although other variables were collected during the study period, we did not include them, such as the results of the questionnaires regarding signs and symptoms, in the analyses reported in this paper.

## Data Collection Method

All the information was recorded in the eHealth records either on-site or remotely from the self-measurements made by patients in their homes. We followed and monitored all participants for 1 year to manage their disease.

## Statistical Analysis

### Sample Size

We performed a power calculation to detect a difference of 10% in the proportion of patients who required urgent hospital admissions (unscheduled), estimating 20% in the control group (ie, in the participants before the intervention) and 10% in the intervention group. We determined that we needed a sample size of 174 participants for a power of 80% (20% beta risk) and a confidence level of 95% (5% alpha risk), including possible attrition of 10%.

### Analytical Strategy

We conducted a before-and-after analysis to assess the impact of the intervention on the control of blood pressure and HbA<sub>1c</sub>, as well as on visits to emergency services and hospital admissions. We compared means and proportions of the first

visit (preintervention) with the last visit (postintervention) using the IBM SPSS PC version 21 statistical package (IBM Corporation). To assess intervention effects, we used the *t* test and chi-square statistical test. We calculated indicators of clinical relevance to the ValCrònic program, absolute risk reduction, relative risk reduction, and number needed to treat to prevent a harmful outcome.

## Ethical Aspects

The Committee of Ethics and Clinical Research at the Elx Health Department approved this study. We complied with the procedures and regulations of Law 15/1999 on the Protection of Personal Data of December 13, 1999 (Spanish Data Protection Agency). All participants signed a statement of informed consent and committed to taking care of the equipment loaned to them.

## Results

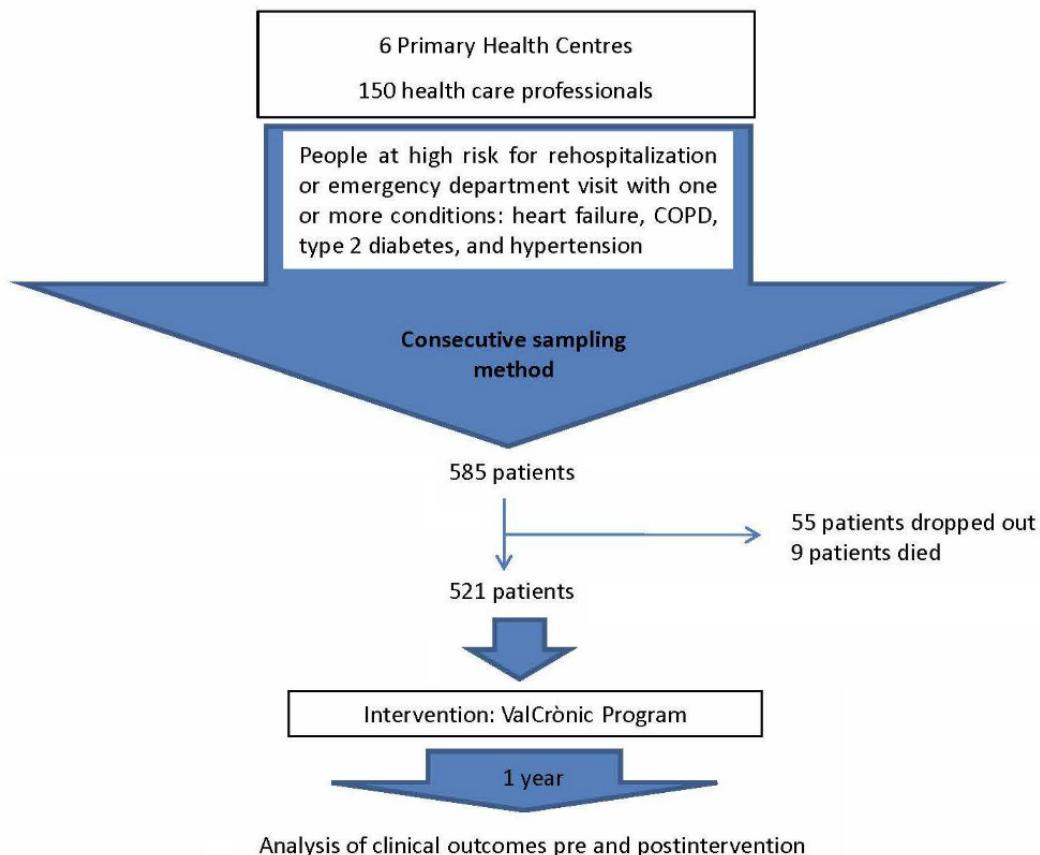
We invited 585 patients to participate, 55 of whom dropped out of the program because they found it difficult to take the measurements alone and had no help. A total of 9 participants died during the intervention. Thus, we included 521 participants in the analysis (Figure 3). Participants' average age was 70.4 years, and over half (n=318, 61.0%) were men. The 70- to 79-year age group was the largest, amounting to 32.3% (n=168) of the total. With regard to hospital admissions, 28.2% (n=147) of the participants were admitted at some point during the year of study. The average number of drug prescriptions was 8.3 per participant. The most prevalent mix of comorbidities was hypertension and diabetes, which involved more than one-third of patients, followed by COPD plus hypertension, and heart failure plus hypertension plus diabetes. These 3 combinations accounted for 61.0% of patients (Table 1).

The ValCrònic program had a significant impact on weight (82.3 kg before vs 80.1 kg after;  $P=.001$ ) and heart rate (74.2 beats/min vs 71.3 beats/min;  $P=.08$ ) in participants in the intervention compared with the preintervention year. Likewise, participation was associated with better control of hypertension: the proportion of people with high systolic ( $\geq 140$  mmHg) and diastolic ( $\geq 90$  mmHg) blood pressures fell by 10% and 44%, respectively. The proportion of people with HbA<sub>1c</sub> of 8% or more also decreased significantly, by 44% (Figure 4).

Figure 4 shows the proportion of participants who went to primary care- or hospital-based emergency services in the year before and the year of the intervention due to disease exacerbation. The ValCrònic program significantly reduced the proportion of people who needed emergency services.

In addition, during the ValCrònic year, the proportion of participants who required hospital admissions, either as a result of an emergency or due to a disease exacerbation, was significantly reduced (Figure 4).

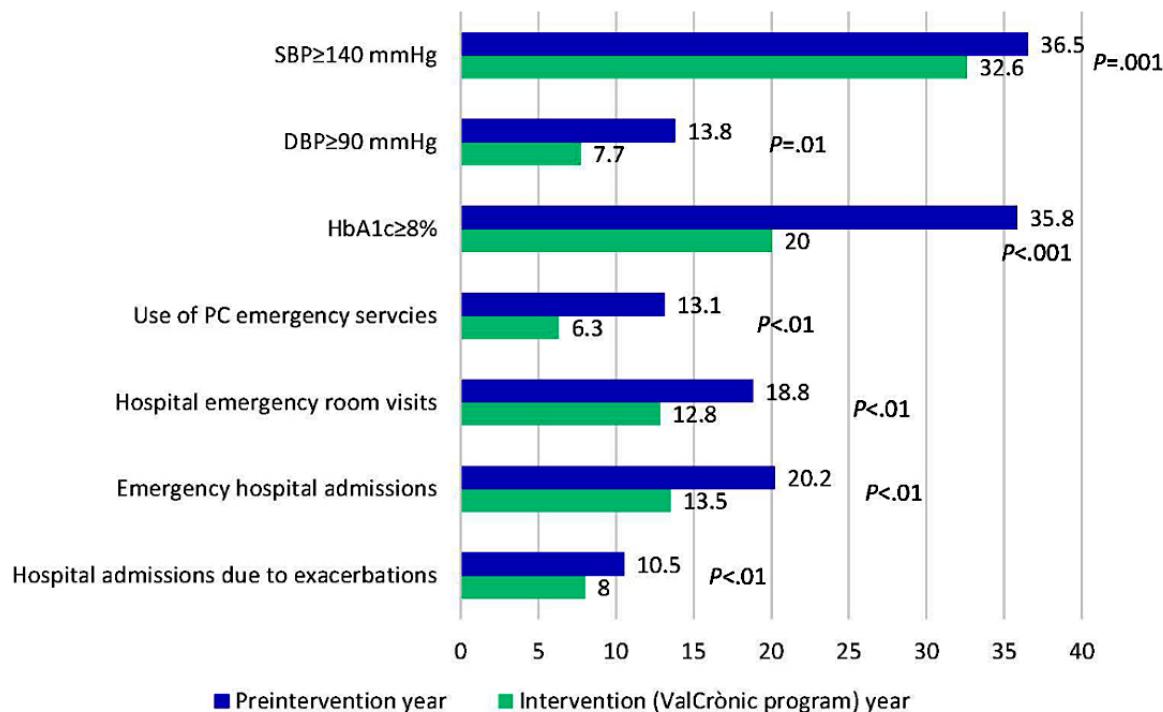
Table 2 shows the indicators that were of clinical relevance to the ValCrònic program.

**Figure 3.** Study flowchart. COPD: chronic obstructive pulmonary disease.**Table 1.** Participant characteristics (n=521).

Characteristics	Data
<b>Sex, n (%)</b>	
Female	203 (38.9)
Male	318 (61.1)
Age (years), mean (SD), 95% CI	70.4 (10.3), 68.9-71.9
<b>Hospital admissions during the year, n (%)</b>	
0	374 (71.7)
≥1	147 (28.3)
No. of drugs prescribed, mean (SD), 95% CI	8.25 (4.0), 7.65-8.85
<b>Disease type<sup>a</sup>, n</b>	
Heart failure	182
COPD <sup>b</sup>	178
Diabetes	333
Arterial hypertension	396
<b>No. of conditions, n</b>	
1	9
2	347
3	141
4	24

<sup>a</sup>Participants could have more than 1 disease.<sup>b</sup>COPD: chronic obstructive pulmonary disease.

**Figure 4.** Comparison between preintervention year and intervention (ValCrònic program) year regarding study outcomes: proportion of patients with poor blood pressure and hemoglobin A<sub>1c</sub> (HbA<sub>1c</sub>) control; and proportion of patients who visited primary care- (PC) or hospital-based emergency services due to an exacerbation or were hospitalized. DBP: diastolic blood pressure; SBP: systolic blood pressure.



**Table 2.** Participants with outcomes of clinical relevance before and during the intervention (n=521).

Outcomes	Time point, n (%)		ARR <sup>a</sup> (95% CI)	RRR <sup>b</sup> (95% CI)	NNT <sup>c</sup> (95% CI)
	Preintervention year	ValCrònic year			
Systolic blood pressure ≥140 mmHg	190 (36.5)	170 (32.6)	3.9 (0-10)	10.7 (0-25)	26 (10-52)
Diastolic blood pressure ≥90 mmHg	72 (13.8)	40 (7.7)	6.1 (2-10)	44.2 (20-62)	16 (9.9-40.3)
Hemoglobin A <sub>1c</sub> ≥8%	186 (35.7)	104 (20.0)	15.8 (10-21)	44.1 (31-55)	6 (4.7-9.6)
Use of primary care emergency services due to exacerbation of ValCrònic conditions	68 (13.1)	33 (6.3)	6.8 (3-10)	51.9 (29-68)	15 (9.5-30.8)
Visit to hospital emergency due to exacerbation of ValCrònic conditions	98 (18.8)	67 (12.8)	6.1 (2-11)	32.2 (9-49)	16 (9.5-62.9)
Emergency hospital admission(s)	105 (20.2)	71 (13.6)	6.7 (2-11)	33.2 (11-49)	15 (8.9-48.1)
Hospital admission(s) due to exacerbation of ValCrònic conditions	55 (10.5)	42 (8.1)	2.5 (0-8)	23.8 (9-37)	40 (20-58)

<sup>a</sup>ARR: absolute risk reduction.

<sup>b</sup>RRR: relative risk reduction.

<sup>c</sup>NNT: number needed to treat to prevent a harmful outcome.

## Discussion

### Principal Findings

Compared with the preintervention year, during the intervention year, people with at least one of 4 chronic diseases (hypertension, diabetes mellitus, COPD, or heart failure) who participated in the ValCrònic program had better weight, heart rate, blood pressure, and glycemic control. In addition, primary care emergency and hospital emergency visits were decreased, despite the participants being a year older and a year further along in their disease evolution.

### Comparison With Prior Work

In participants with diabetes, participation in ValCrònic was associated with improved disease control, reducing the proportion of patients with HbA<sub>1c</sub> ≥8% by 44% in the year of monitoring. Similarly, previous telemonitoring studies in patients with diabetes reported improved control of HbA<sub>1c</sub> and fewer admissions, although with more visits to a doctor (primary care or specialist) [6,9].

The ValCrònic program also reduced the proportion of participants with poorly controlled systolic and diastolic blood

pressures, by 10% and 44%, respectively. A review by Verberk et al [5] found that participants receiving telemedicine experienced a greater reduction in blood pressure than the usual-care control group. As for the use of health care resources, ValCrònic led to a 51.9% reduction in visits to the primary care emergency department and a 32.3% reduction in visits to the hospital emergency department. Emergency admissions fell by 33.2% and admissions due to worsening of the conditions being monitored fell by 23%. The literature contains encouraging examples of studies reporting that telemonitoring resulted in reduced use of sociohealth resources [24] and reduced mortality (by 24%) and readmissions (by 28%) in patients with heart failure, especially for New York Heart Association classes III and IV [25]. Telephone support only reduced mortality due to relapses, but not overall mortality, while heart rate monitoring decreased the risk of hospital admissions due to heart failure by 43% [25]. Visits to emergency services also decreased, but contact with primary care increased, and patient satisfaction and quality of life improved [7,24]. In COPD, most studies have been in people aged over 65 years and with forced expiratory volume in the first second of expiration of 27% to 43% (Global Initiative for Chronic Obstructive Lung Disease class 2-4). Although those authors reported reductions in readmissions and emergency visits, there were no differences in mortality rate, quality of life, or satisfaction [8,26,27].

The Whole Systems Demonstrator, which started in 2008, is the largest telemonitoring experience in Europe, involving 3230 patients in 179 primary care groups. Investigators have found a reduction in mortality and secondary resource consumption in telemonitored patients, but at a higher cost [28]. Giamouzis et al emphasized the need to define the profile of the patient who can benefit from the intervention and for how long [29]. ValCrònic did not enlist additional health care staff to run the program, and we included participants at high risk, often with several comorbidities, as occurs with this type of patient with chronic diseases. Unlike previous studies, this study did not focus exclusively on 1 specific disease, making this program more pragmatic and more generalizable to the realities of clinical practice.

The clinical benefits obtained show that telemonitoring of patients provides an additional benefit to the medical and nonmedical measures used to date, and thus is another option for treating patients with chronic disease. **Table 2** shows that the number needed to treat associated with the program are very favorable compared with the results of other common health interventions. EMPA-REG investigators found that it was necessary to treat 39 patients with empagliflozin to prevent 1 cardiovascular event [30]; in the LEADER study, 66 patients treated with liraglutide were needed to prevent 1 major cardiovascular event [31]; and in the SUSTAIN-6 study, 45 patients treated with semaglutide were needed [32]. To prevent 1 death in the 4S study, 30 patients treated with simvastatin during 5.4 years were needed [33], and when using ramipril, 56 patients treated for 5 years were needed [34]. Thus, ValCrònic is well within the normally accepted parameters for implementation in clinical practice [35].

Regarding the opinion of the participants, a previously published report described high satisfaction among ValCrònic participants

[36]. We also highlight the peace of mind reported by patients and their families, stemming from the knowledge that health professionals were remotely monitoring any changes in glycemia, blood pressure, and oxygen saturation, and that they would follow up if necessary.

## Limitations

The limitations of this study are mainly methodological. We dichotomized participant risk (high risk or not) using the CARS scale and, to improve its validity, we complemented the result obtained with the clinical judgement of the professional who usually treated the patient. There are numerous risk assessment scales, but their validity is usually limited, so we believed it was important that health care professionals assisted in the final selection based on their clinical experience and knowledge of the patient's sociohealth environment.

It is possible that included participants would have been more predisposed to the use of telemedicine. In any case, the high number of participants included suggests that many elderly patients or their family members feel comfortable handling these devices. Elsewhere [36], our group described the degree of satisfaction of patients and their families with the ValCrònic program. We also conducted a survey in patients who opted not to participate, finding no substantial differences in overall satisfaction, although for very different reasons, not only a disinclination to use the health monitoring devices.

As we used a before-and-after study design, we lacked a parallel control group, and the results of this study have to be interpreted with caution. Secular trends or sudden changes might have made it difficult to attribute observed changes to the intervention. However, since it was carried out in two specific health areas, information regarding potential interventions carried out outside the program is available, and there was no interference in this regard. The fact that participants' diseases had evolved for an additional year, and that they were a year older at study end, adds even more value to the good results obtained.

Another factor to take into account is the Hawthorne effect, or the feeling of being observed. In all intervention studies, there is a potential additional beneficial effect due to people knowing that they are participating in a study. However, given the high risk in the included participants, with more than 20% of them having been hospitalized in the previous year, it is difficult to imagine that a benefit like the one described could occur purely as a result of the Hawthorne effect.

Without a clear understanding of the economic implications of telemonitoring interventions, it will be difficult to establish informed national policies regarding reimbursement for these programs. Cost-effectiveness analyses of this program will be published.

## Conclusions

Compared with the preintervention year, during the intervention year, people with at least one of 4 chronic diseases (hypertension, diabetes mellitus, COPD, or heart failure) at high risk for rehospitalization or an emergency department visit and who participated in the ValCrònic telemonitoring program had better weight control, reduced blood pressure and glycemia,

and made fewer visits to primary care- or hospital-based emergency services due to disease exacerbation. In addition, hospitalizations due to an exacerbation of a chronic disease decreased.

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## Conflicts of Interest

JJS is employed by Telefonica España SA.

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## Abbreviations

**CARS:** Community Assessment Risk Screen

**CAT:** COPD Assessment Test

**COPD:** chronic obstructive pulmonary disease

**HbA<sub>1c</sub>:** hemoglobin A<sub>1c</sub>

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Original Paper

# The Effect of Screen-to-Screen Versus Face-to-Face Consultation on Doctor-Patient Communication: An Experimental Study with Simulated Patients

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## Abstract

**Background:** Despite the emergence of Web-based patient-provider contact, it is still unclear how the quality of Web-based doctor-patient interactions differs from face-to-face interactions.

**Objective:** This study aimed to examine (1) the impact of a consultation medium on doctors' and patients' communicative behavior in terms of information exchange, interpersonal relationship building, and shared decision making and (2) the mediating role of doctors' and patients' communicative behavior on satisfaction with both types of consultation medium.

**Methods:** Doctor-patient consultations on pelvic organ prolapse were simulated, both in a face-to-face and in a screen-to-screen (video) setting. Twelve medical interns and 6 simulated patients prepared 4 different written scenarios and were randomized to perform a total of 48 consultations. Effects of the consultations were measured by questionnaires that participants filled out directly after the consultation.

**Results:** With respect to patient-related outcomes, satisfaction, perceived information exchange, interpersonal relationship building, and perceived shared decision making showed no significant differences between face-to-face and screen-to-screen consultations. Patients' attitude toward Web-based communication ( $b=-.249$ ,  $P=.02$ ) and patients' perceived time and attention ( $b=.271$ ,  $P=.03$ ) significantly predicted patients' perceived interpersonal relationship building. Patients' perceived shared decision making was positively related to their satisfaction with the consultation ( $b=.254$ ,  $P=.005$ ). Overall, patients experienced significantly greater shared decision making with a female doctor (mean 4.21, SD 0.49) than with a male doctor (mean 3.66 [SD 0.73];  $b=.401$ ,  $P=.009$ ). Doctor-related outcomes showed no significant differences in satisfaction, perceived information exchange, interpersonal relationship building, and perceived shared decision making between the conditions. There was a positive relationship between perceived information exchange and doctors' satisfaction with the consultation ( $b=.533$ ,  $P<.001$ ). Furthermore, doctors' perceived interpersonal relationship building was positively related to doctors' satisfaction with the consultation ( $b=.331$ ,  $P=.003$ ).

**Conclusions:** In this study, the quality of doctor-patient communication, as indicated by information exchange, interpersonal relationship building, and shared decision making, did not differ significantly between Web-based and face-to-face consultations. Doctors and simulated patients were equally satisfied with both types of consultation medium, and no differences were found in the manner in which participants perceived communicative behavior during these consultations. The findings suggest that worries about a negative impact of Web-based video consultation on the quality of patient-provider consultations seem unwarranted as they offer the same interaction quality and satisfaction level as regular face-to-face consultations.

**KEYWORDS**

teleconsultation; communication quality; patient satisfaction; provider satisfaction; information exchange; interpersonal relationship building; shared decision making

## ***Introduction***

Nowadays, new information and communication technologies have an increasingly prominent role within medical practice [1], and the large majority of studies in this field reveal predominantly positive results of these new technologies, including improved quality and efficiency of health care, enhanced patient participation, access to a wider range of specialists, and time and cost savings [2-5]. Despite the apparent promise, large-scale implementation of Web-based consultations in health care has proven to be difficult, and several studies emphasize the continuing need for research on the impact of these developments on daily medical practice [5-8]. Furthermore, there is only a small amount of evidence indicating that Web-based patient-provider contact results in outcomes comparable or better than face-to-face care [9].

This contradicts the expectation that in the forthcoming years, Web-based consultation will increasingly replace the traditional face-to-face contact in patient-provider interactions [3,10,11]. Although Web-based screen-to-screen contact between patient and health provider (also referred to as video consultation, computer-mediated consultation, or teleconsultation) so far remains relatively uncommon, there is substantial evidence that patients want access to Web-based communication with health care providers adjacent to the regular face-to-face consultations [3,6,7]. Recent studies show that patients hold more positive attitudes concerning Web-based consultations as an acceptable medium for patient-provider communication than health professionals do [6,11-13]. In general, providers seem to be more hesitant, as they are concerned that Web-based consultations are lower in quality than offline consultations and might lead to a depersonalization of health care [3,6,14,15], although recent studies have found that physicians with previous electronic health (eHealth) experience show a more positive attitude to its implementation [7,8].

Further exploration of satisfaction with Web-based consultations is needed from the perspective of both patients and providers [16]. The quality and effectiveness of Web-based consultations may depend on patients' and providers' attitudes regarding Web-based communication. Therefore, this study seeks to investigate the impact of the medium of the consultation (screen-to-screen vs face-to-face provider-patient communication) on patients' and providers' communicative behavior and satisfaction with the consultation. Hence, our first 2 hypotheses read as follows:

H1a: Patients' satisfaction with the consultation is higher in Web-based video consultations than in face-to-face consultations.

H1b: Providers' satisfaction with the consultation is higher in face-to-face consultations than in Web-based video consultations.

Long-standing research of face-to-face consultations has shown that the 3 main pillars of medical communication (information exchange, interpersonal relationship building, and shared decision making) contribute to better patient-provider interactions and more satisfied patients and providers in offline consultations [17-19]. It is still unclear whether Web-based and face-to-face patient-physician interactions differ in quality in terms of information exchange, interpersonal relationship building, and shared decision making, and whether the mediating role of these communicative behaviors on patient and provider satisfaction differs.

Regarding information exchange, studies on computer-mediated communication may explain the impact of audiovisual Web-based consultation on the participants' communicative behavior. Due to the reduction of visual and contextual cues in audiovisual Web-based communication, people tend to ask more questions and share more information in Web-based than in face-to-face settings [20,21]. In addition, we expect that the predictive value of communicative behavior on both patients' and providers' satisfaction with the consultation [18,19] will be generalizable to Web-based consultations. Therefore, our next hypotheses read as follows:

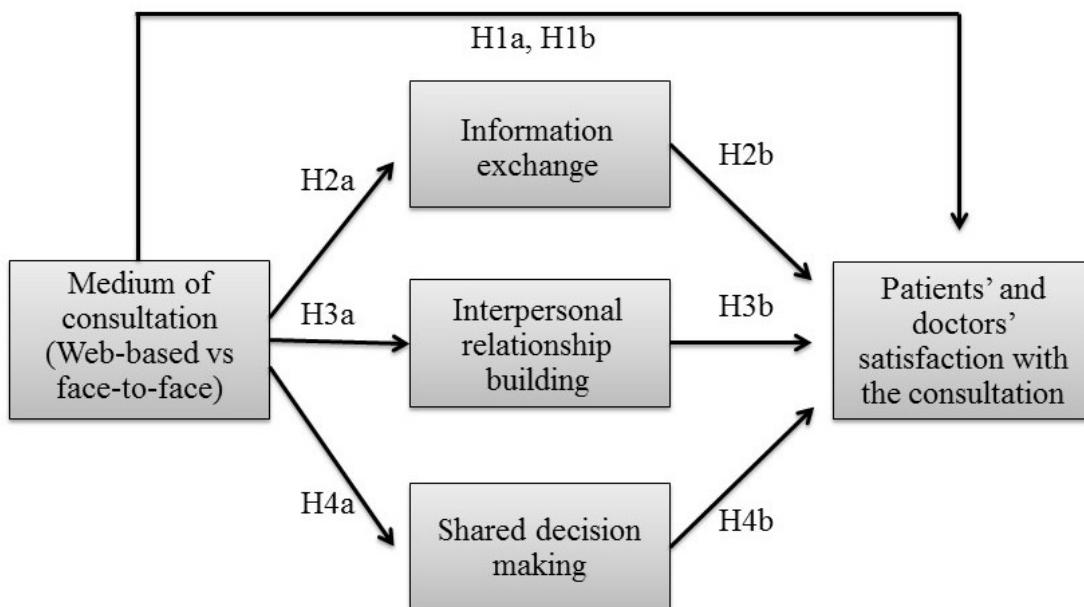
H2a: Web-based video consultations result in more information exchange than face-to-face consultations.

H2b: There will be a positive effect of information exchange on patients' and providers' satisfaction with the consultation.

As for interpersonal relationship building, there is no consensus yet whether Web-based patient-provider consultations are suitable for interpersonal relationship building. Although general studies on computer-mediated communication (CMC) have shown that audiovisual Web-based communication may be equally, or even more, suitable for affective interactions as face-to-face communication [21], empirical studies on patient-provider communication show mixed results [22]. However, in line with earlier research [21], we expect that providers will use more verbal statements of empathy in Web-based consultations to compensate for the lack of nonverbal empathy. Thus, patients' self-disclosure will be likely to rise, leading to more or better interpersonal relationship building. Therefore, our next hypotheses state:

H3a: Web-based video consultations result in more interpersonal relationship building than face-to-face consultations.

H3b: There will be a positive effect of interpersonal relationship building on patients' and providers' satisfaction with the consultation.

**Figure 1.** Overview of the hypotheses.

Over the last two decades, there has been a shift in support away from a paternalistic model of clinical decision making toward an approach wherein the patient takes a more active role, and decisions are reached in partnership between patient and provider [23]. Evidence has been found that the use of new communication and information technologies in health care fosters this paradigm shift toward increased patient participation and autonomy [11,24]. The positive effect of shared decision making on enhancing patients' and providers' satisfaction with the consultation has been well documented in face-to-face patient-provider communication [23,25]. Little evidence exists regarding the outcomes of shared decision making in Web-based consultations. It is expected that this predictive value also holds true for Web-based patient-provider communication, as stated in the following hypotheses:

H4a: Web-based video consultations result in more shared decision making than face-to-face consultations.

H4b: Both in Web-based and face-to-face consultations, there will be a positive effect of shared decision making on patients' and providers' satisfaction with the consultation.

Figure 1 presents an overview of the hypotheses formulated in this study.

## Methods

### Procedure

In our experiment, medical interns and simulated patients performed doctor-patient consultations on pelvic organ prolapse and urinary stress incontinence. These subjects were chosen

because of the high prevalence in women: in Western countries, 20% of women would have undergone surgery for urinary incontinence or pelvic organ prolapse [26].

Twelve interns (fifth and sixth year medical students from the Radboud University Nijmegen in the Netherlands) participated in the experiment. Compared with medical doctors, interns have less experience with either face-to-face or Web-based consultations, which reduces the likelihood that there is an established preference for one or the other. Six certified simulated patients, who were trained to act as actual patients by simulating a set of symptoms [27], participated in the experiment. The use of simulated patients is an often used method, ensuring high experimental control over the conditions [28,29].

Four different scenarios (2 different scenarios with 2 conditions) on pelvic organ prolapse and urinary stress incontinence were written by 2 gynecologists from the Radboud University Medical Center (MG and TN). In the Netherlands, according to the ruling of the Dutch Healthcare Authority NZA [30], it is not allowed to have a first consultation on the Web, so the scenarios served as a second consultation. In the fictional first consultation, the patient had discussed her complaints with the doctor, a physical examination had taken place, and the patient had already been given her diagnosis. In the simulated consultation, the doctor explained the different treatment options, and a decision had to be made about the treatment plan.

Both scenarios for interns and simulated patients consisted of a summary of the first consultation, demographic details of the patient, and information about lifestyle, job, and children. Additional medical information about the diagnosis was added to the interns' scenarios and a description of the concerns of the

patient regarding her illness and the possible treatment, and preferences for certain treatment options were added to the scenarios of the simulated patients.

Each intern received all 4 scenarios. In addition, they received information about the treatment options. Treatment for pelvic organ prolapse can consist of lifestyle change, specialized physiotherapy, fitting of a vaginal pessary or surgery [31]. Two weeks after the interns received all information, a preparatory meeting with all interns was held with MG and SK, to answer any remaining questions. After the meeting, the interns received a questionnaire that they had to fill out directly after every consultation. Reading the questionnaire only after the first consultation could induce specific communicative behavior as described in the questions. With providing the questionnaire beforehand, the possible effect of priming was expected to be the same in all consultations.

Before the experiment, simulated patients received their scenarios and studied them. Later, a preparatory meeting with the simulated patients was held together with MG (gynecologist) and SK. In this meeting, all remaining questions regarding the scenarios and the experiment were answered, and each simulated patient was given the opportunity to practice one of the scenarios. In addition, they also received the questionnaire that they had to fill out directly after the actual experiment.

A total of 48 simulated doctor-patient consultations were held, of which 24 took place in the Web-based setting and the other 24 in the face-to-face setting. There were 6 experimental consultation sessions; 2 simulated patients and 2 interns participated in each session. Interns participated in 1 consultation session, whereas simulated patients participated in 3 consultation sessions. During each session, they each participated in 4 consultations, which were randomly divided over the 2 scenarios and 2 conditions in a manner that each intern and each simulated patient participated in 2 Web-based and 2 face-to-face consultations (see [Multimedia Appendix 1](#)). An intern and a simulated patient could not have a consultation together, right after they participated in a joined consultation. Finally, the study had a counterbalanced repeated measures design in which all scenarios were equally divided over the conditions and in which the order of the scenarios was randomized as well.

Participants in the audiovisual screen-to-screen-condition were led to separate rooms that were equipped with a laptop and a webcam with a built-in microphone, so they could both see and hear each other. The intern and patient interacted through Microsoft Skype. The intern would initiate a video call with the patient through Skype, after which the consultation began. There was no minimum length of the consultation; however, after 15 min, the participants were asked to finalize the consultation. After the consultation, both the intern and simulated patient answered the questionnaire about the consultation.

The face-to-face condition took place in a room that resembled a doctor's office. The patient was led to the doctor's office, after which the consultation began. After the consultation, the patient entered a separate room, so that both participants could fill out the questionnaire about the consultation separately. Care was taken, when switching between consultations, to avoid interns and simulated patients meeting each other right after a

consultation. [Multimedia Appendix 1](#) shows a flowchart of the study design per experimental consultation session.

## Sample

All interns were aged between 22 and 26 years (mean 23.8, SD 1.3). Both male (n=4) and female (n=8) interns participated in the experiment, as gender composition of a group may affect the interaction, such as the amount or type of self-disclosure. Only 1 intern had no prior experience with audiovisual Web-based communication, whereas the other interns reported to use applications for Web-based communication about once every 6 months (4), once every month (2), once every week (4), or more days per week (1), all for personal reasons. None of the interns had used audiovisual Web-based consultation to communicate with a patient.

The simulated patients, all female, were aged between 39 and 57 (mean 47.3, SD 6.3), to match the scenarios used in the experiment. All simulated patients were highly educated; they graduated from either higher vocational education or a university. Half of the simulated patients reported to use software for audiovisual Web-based communication, such as Skype or Facetime, about once every 6 months, whereas the other half of the patients had no prior experience with audiovisual Web-based communication. None of the participants had communicated with a doctor through Web-based consultation before.

## Measures

The operationalization of the mediating variables used in this study was based on the *Patient Participation Scale* (PPS) [32] and the *LEAPS Framework* (Listen, Educate, Assess, Partner and Support) [33] as the 3 main purposes of communication between doctors and patients during a consultation (ie, information exchange, interpersonal relationship building, and shared decision making) are best covered with these 2 scales. In [Multimedia Appendix 2](#), the operationalization is described in more detail.

## Perceived Information Exchange

Five items were used to measure patients' perceived information exchange based on the PPS [32] and the LEAPS Framework [33]. Examples of the items can be found in the detailed version of the operationalization in [Multimedia Appendix 2](#). The response categories for all items ranged from 1 (*completely disagree*) to 5 (*completely agree*). All items formed a one-dimensional scale (explained variance 50%, alpha=.73, mean 3.49 [SD 0.58]).

Doctors' perceived information exchange was measured by 3 items from PPS as in the patients' questionnaire [32], adapted to fit the doctors' perspective. In addition, the following 3 items from the subparts information exchange and *identification of problems and concerns* of the LEAPS Framework [33] were added: "The patient had difficulty remembering instructions," "The patient did not understand my explanations of the medical problem and treatment," and "I could not understand all the patient wanted to tell me." The 6 items (see [Multimedia Appendix 2](#)) formed a one-dimensional scale (explained variance 45%, alpha=.73, mean 4.13 [SD 0.41]).

### Perceived Interpersonal Relationship Building

To measure patients' perceived interpersonal relationship building, 5 items were used, which were derived from the subpart *patients' evaluation of emotional support of the physician* from the Cologne Patient Questionnaire [34,35] and the subpart *interpersonal rapport* of the LEAPS Framework [33]. Examples can be found in the detailed version of the operationalization in [Multimedia Appendix 2](#). Response categories ranged from 1 (*completely disagree*) to 5 (*completely agree*). The items formed a one-dimensional scale (explained variance 50%, alpha=.73, mean 3.80 [SD 0.49]).

To measure doctors' perceived interpersonal relationship building, 5 items were used, which were derived from the Cologne Patient Questionnaire [34,35] and the subpart interpersonal rapport of the LEAPS Framework [33]. Response categories ranged from 1 (*completely disagree*) to 5 (*completely agree*). The items (see [Multimedia Appendix 2](#)) formed a one-dimensional scale (explained variance 47%, alpha=.67, mean 3.84 [SD 0.39]).

### Perceived Shared Decision Making

Patients' shared decision making was measured using 7 items: 3 items of PPS [32] and 4 items of the Cologne Patient Questionnaire [34,35]. Examples of the items can be found in [Multimedia Appendix 2](#). Response categories ranged from 1 (*completely disagree*) to 5 (*completely agree*). The items formed a one-dimensional scale (explained variance 64%, alpha=.89, mean 4.02 [SD 0.63]).

The items measuring patients' shared decision making were adapted to measure doctors' shared decision making by turning the patient's perspective to the doctor's perspective. Example item is as follows: "I sufficiently involved the patient in decisions about the treatment." The 7 items (see the examples in [Multimedia Appendix 2](#)) formed a one-dimensional scale (explained variance 54%, alpha=.83, mean 4.08 [SD 0.49]).

### Satisfaction With the Consultation

Patients' satisfaction with the consultation was measured using the *Patient Satisfaction Questionnaire* (PSQ) [36,37]. Items included were as follows: "How satisfied are you with the way the doctor addressed your needs?" All items were answered on a scale from 1 (*not at all satisfied*) to 5 (*extremely satisfied*). The 6 items formed a one-dimensional scale (explained variance 53%, alpha=.85, mean 4.33 [SD 0.42]).

To measure doctors' satisfaction with the consultation, the items of *PSQ* and the item measuring satisfaction with the treatment decision were adapted to the doctors' situation as suggested by Zandbelt and colleagues [38]. For example, the item "How well did the doctor address your needs?" was modified to "How well did you address the needs of this patient?" The 6 items formed a one-dimensional scale (explained variance 48%, alpha=.76, mean 4.29 [SD 0.39]).

### Covariates

#### Attitude Toward Web-Based Communication

Doctors' and patients' attitude toward Web-based communication was measured with 6 items from Yen and Tu's

Revised *Computer-Mediated Communication Questionnaire* [39]. Items included the following: "CMC messages convey feeling and emotion," "It is easy to express what I want to communicate through CMC," and "My computer skills allow me to be comfortable while participating in CMC." The response categories ranged from 1 (*completely disagree*) to 5 (*completely agree*). In both cases, the 6 items formed a one-dimensional scale. The doctors' scale (explained variance 48%) had an alpha of .76 (mean 3.26, SD 0.52) and the patients' scale (explained variance 44%) had an alpha of .92 (mean 3.17, SD 0.73).

### Perceived Time and Attention

To measure patients' perceived time and attention of the doctor, a total of 4 items were used from the LEAPS Framework [33] and Cologne Patient Questionnaire [34,35]. For example, "The doctor did not spend enough time with me" and "The doctor did not address all the problems I wanted to discuss." The response categories ranged from 1 (*completely disagree*) to 5 (*completely agree*). The items formed a one-dimensional and reliable scale (explained variance 54%, alpha=.70, mean 3.81 [SD 0.58]).

### Statistical Analysis

To test the hypotheses, Preacher and Hayes' procedure [40] to test indirect effects in multiple mediator models was used. Preacher and Hayes' approach is similar to Baron and Kenny's causal steps approach [41] in two respects. First, it also uses regression analyses to investigate how the independent variable (medium of consultation) influences the mediating variables (perceived information exchange, perceived interpersonal relationship building, and perceived shared decision making) and how the mediating variable influences the dependent variable (satisfaction with the consultation). Second, it also tests whether the influence of the independent variables on the dependent variable disappears when the mediating variable is included.

However, Preacher and Hayes' approach extends Baron and Kenny's causal steps approach, as with this procedure, multiple mediators can be tested simultaneously, which allows testing the effects of each single mediator while controlling for the effect of the other mediators, which in turn is particularly useful in this study. Furthermore, covariates can be considered. Finally, the approach of Preacher and Hayes [40] uses bootstrapping to test the significance of the mediating effects. This eliminates the need for multivariate normality, which is unlikely to be achieved in small samples. The analyses and bootstrap estimates that follow are based on 10,000 bootstrap samples. Hence, for each of the possible mediated effects, we tested first, based on the normal theory, whether the various paths that constitute our model were significant. Subsequently, we performed a formal test of the mediated effect based on the bootstrap method.

## Results

### Patient-Related Outcomes

Two separate mediation analyses were conducted, one for the simulated patient-related outcomes and one for doctor-related outcomes. The first analysis was focused on the patients and compared patients' satisfaction with the consultation between

the Web-based video condition and the face-to-face condition (see [Figure 2](#)). The mediators used in the analysis were patients' perceived information exchange, patients' perceived interpersonal relationship building, and patients' perceived shared decision making. The scenario used in the consultation, patients' attitude toward Web-based communication, patients' perceived time and attention, and doctors' gender were entered as covariates.

Hypothesis 1a stated that satisfaction with the consultation would be higher in Web-based video consultations than in face-to-face consultations. The results showed no significant difference in patients' satisfaction between the Web-based condition (mean 4.32, SD 0.41) and the face-to-face condition (mean 4.33 [SD 0.43],  $b=-0.015$ , Standard error [SE]=0.075,  $P=.85$ ), which implies that the medium of consultation does not have an impact on patients' satisfaction with the consultation. This rejects Hypothesis 1a.

Next, the 3 mediators were tested. Hypothesis 2a stated that *Web-based* video consultations result in more information exchange than face-to-face consultations. This hypothesis was rejected as patients' perceived information exchange did not significantly differ between the Web-based condition (mean 3.54, SD 0.40) and the face-to-face condition (mean 3.43 [SD 0.71],  $b=-.137$ , SE=0.162,  $P=.40$ ). An analysis of the covariates showed that the scenario used in the consultation had an influence on patients' perceived information exchange ( $b=.175$ , SE=0.074,  $P=.02$ ), which indicates that some of the scenarios induce better or more information exchange than others.

Hypothesis 2b stated that information exchange would increase patients' satisfaction with the consultation. This hypothesis was confirmed as the results showed a positive relationship between perceived information exchange and patients' satisfaction ( $b=.183$ , SE=0.073,  $P=.02$ ), which implies that more perceived information exchange leads to higher satisfaction with the consultation. Finally, the mediating effect of patients' perceived information exchange was not significant (point estimate=.025, SE=0.034, 95% bias corrected and accelerated (Bca) CI –0.025 to 0.115).

Hypothesis 3a, which stated that Web-based video consultations would result in more interpersonal relationship building than face-to-face consultations, was not supported. Patients' perceived interpersonal relationship building did not significantly differ between the Web-based condition (mean 3.75, SD 0.52) and the face-to-face condition (mean 3.84 [SD 0.48],  $b=-.058$ , SE=0.135,  $P=.67$ ). An analysis of the covariates showed that patients' attitude toward Web-based communication ( $b=-.249$ , SE=0.099,  $P=.02$ ) and patients' perceived time and attention ( $b=.271$ , SE=0.124,  $P=.03$ ) significantly predicted patients' perceived interpersonal relationship building. Hence, the more time or attention patients felt was spent on them, the better they rated the interpersonal relationship with their doctor. Patients' attitude toward Web-based communication was negatively related to patients' perceived interpersonal relationship building, which means that a lower attitude toward Web-based communication leads to more perceived

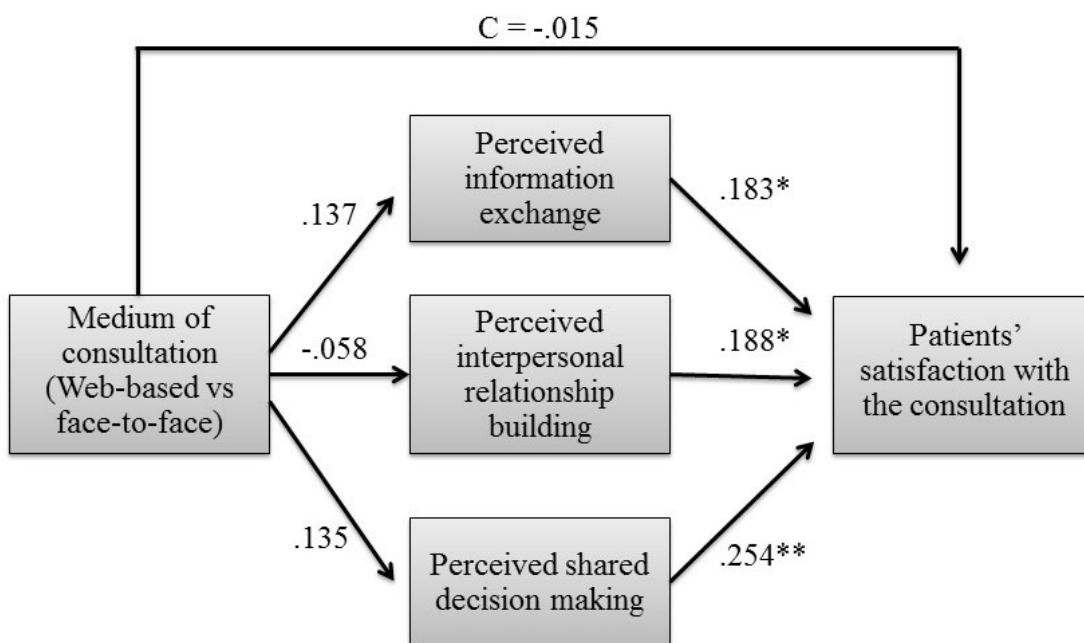
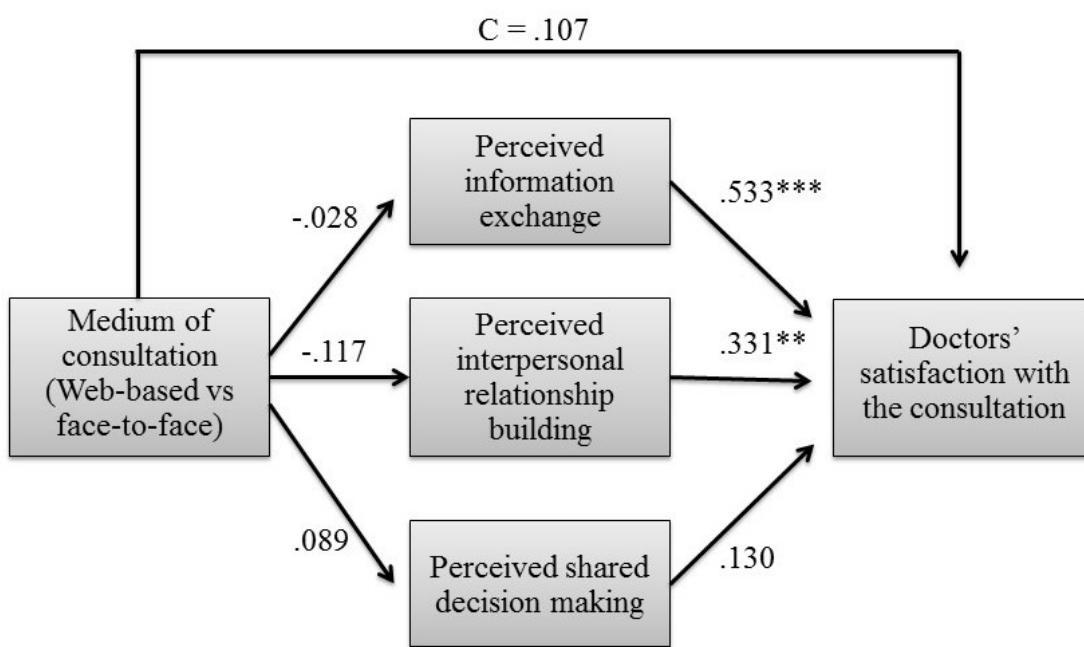
interpersonal relationship building. When splitting the two conditions, the effect of patients' attitude toward Web-based communication remained visible only in the screen-to-screen condition. Hypothesis 3b stated that interpersonal relationship building would increase patients' satisfaction with the consultation. As expected, patients' perceived interpersonal relationship building was positively related to patients' satisfaction ( $b=.183$ , SE=0.088,  $P=.04$ ), which confirms H3b. The mediating effect of patients' perceived interpersonal relationship building was not significant (point estimate=–.011, SE=0.029, 95% Bca CI –0.084 to 0.034).

Hypothesis 4a, which stated that Web-based video consultations would result in more shared decision making than face-to-face consultations, was not supported. Patients' perceived shared decision making did not significantly differ between the Web-based condition (mean 4.01, SD 0.57) and the face-to-face condition (mean 3.99 [SD 0.70]),  $b=.135$ , SE=0.133,  $P=.32$ ). The analysis of the covariates showed that patients experienced significantly more shared decision making with a female doctor (mean 4.21, SD 0.49) than with a male doctor (mean 3.66 [SD 0.73],  $b=.401$ , SE=0.146,  $P=.009$ ). In addition, patients' perceived shared decision making was positively related to patients' perceived time and attention ( $b=.604$ , SE=0.122,  $P<.001$ ). Hypothesis 4b, which stated that shared decision making would increase patients' satisfaction with the consultation, was confirmed. Patients' perceived shared decision making was positively related to their satisfaction with the consultation ( $b=.254$ , SE=0.086,  $P=.005$ ). There was no significant mediating effect of patients' perceived shared decision making (point estimate=.034, SE=0.037, 95% Bca CI –0.024 to 0.121).

Finally, it was tested which covariates were significantly related to patients' satisfaction with the consultations. The analysis showed that patients were significantly more satisfied with the consultation when they had communicated with a female doctor (mean 4.48, SD 0.31) than with a male doctor (mean 4.02 [SD 0.45],  $b=.259$ , SE=0.090,  $P=.007$ ). For the covariates scenario of the consultation, patients' attitude toward Web-based communication, and patients' perceived time and attention, there was no direct effect on patients' satisfaction with the consultation, with all  $P$ s>.15. [Figure 2](#) provides a summary of the patient-related results. Path coefficients represent unstandardized regression weights, where C is the direct effect of the experimental condition on patients' satisfaction with the consultation after inclusion of the mediators.

## Doctor-Related Outcomes

The second analysis compared doctors' satisfaction with the consultation between the Web-based condition and the face-to-face condition (see [Figure 3](#)). The mediators used in the analysis were doctors' perceived information exchange, doctors' perceived interpersonal relationship building, and doctors' perceived shared decision making. Doctors' gender, the scenario used in the consultation, and doctors' attitude toward Web-based communication were entered as covariates.

**Figure 2.** Summary of the patient-related results. N=46; R<sup>2</sup>=.69; \*P<.05; \*\*P<.01.**Figure 3.** Summary of the doctor-related results. N=46; R<sup>2</sup>=.71; \*P<.05; \*\*P<.01, \*\*\*P<.001.

Hypothesis 1b stated that doctors' satisfaction with the consultation would be higher in face-to-face consultations than in Web-based consultations. However, the results showed no significant difference in doctors' satisfaction with the consultation between the Web-based condition (mean 4.31, SD

0.37) and the face-to-face condition (mean 4.27 [SD 0.41],  $b=.107$ ,  $SE=0.066$ ,  $P=.12$ ), when examining the direct effect of the experimental condition on doctors' satisfaction. This indicates that the medium of consultation did not have an impact

on doctors' satisfaction with the consultation. Therefore, Hypothesis 1b is rejected.

Next, the three mediators were tested. Hypothesis 2a, which stated that Web-based consultations result in more information exchange than face-to-face consultations, was rejected. Doctors perceived information exchange did not significantly differ between the screen-to-screen condition (mean 4.12, SD 0.42) and the face-to-face condition (mean 4.15 [SD 0.39],  $b=-.028$ ,  $SE=0.121$ ,  $P=.82$ ). Hypothesis 2b stated that information exchange increases doctors' satisfaction with the consultation. This hypothesis was confirmed as the results showed a positive relationship between perceived information exchange and doctors' satisfaction with the consultation ( $b=.533$ ,  $SE=0.093$ ,  $P<.001$ ), which implies that better perceived information exchange leads to higher satisfaction with the consultation. The mediating effect of doctors' perceived information exchange was not significant (point estimate $=-.015$ ,  $SE=0.065$ , 95% Bca CI  $-0.143$  to  $0.113$ ).

Hypothesis 3a, which stated that Web-based video consultations result in more interpersonal relationship building than face-to-face consultations, was not supported. Doctors' perceived interpersonal relationship building did not significantly differ between the Web-based condition (mean 3.78, SD 0.36) and the face-to-face condition (mean 3.90 [SD 0.42],  $b=-.117$ ,  $SE=0.107$ ,  $P=.28$ ). Hypothesis 3b, which stated that interpersonal relationship building would increase doctors' satisfaction with the consultation, was confirmed. As expected, doctors' perceived interpersonal relationship building was positively related to doctors' satisfaction with the consultation ( $b=.331$ ,  $SE=0.103$ ,  $P=.003$ ). The mediating effect of doctors' perceived interpersonal relationship building was not significant (point estimate $=-.039$ ,  $SE=0.039$ , 95% Bca CI  $-0.079$  to  $0.023$ ).

Hypothesis 4a, which stated that Web-based consultations would result in more shared decision making than face-to-face consultations, was not supported. Doctors' perceived shared decision making did not significantly differ between the screen-to-screen condition (mean 4.04, SD 0.53) and the face-to-face condition (mean 4.13 [SD 0.46],  $b=-.089$ ,  $SE=0.146$ ,  $P=.54$ ). Hypothesis 4b, which stated that shared decision making would increase doctors' satisfaction, was rejected as well. Doctors' perceived shared decision making was not significantly related to their satisfaction with the consultation ( $b=.130$ ,  $SE=0.080$ ,  $P=.11$ ). Therefore, there was no significant mediating effect of doctors' perceived shared decision making (point estimate $=-.012$ ,  $SE=0.024$ , 95% Bca CI  $-0.077$  to  $.024$ ). Finally, the covariates were not related to the mediating variables or doctors' satisfaction with the consultation, with all  $P > .137$ . Figure 3 provides a summary of the doctor-related results. Path coefficients represent unstandardized regression weights, where C is the direct effect of the experimental condition on doctors' satisfaction with the consultation after inclusion of the mediators.

## Post Hoc Analyses

The results of the mediation analyses showed no significant mediation with the medium of consultation (face-to-face vs Web-based). Therefore, post hoc analyses were performed to test whether satisfaction is indeed built on the same three

communication pillars in Web-based consultations as in face-to-face consultations or that, maybe, a certain pillar is more important in one of the modes of communication. We examined whether the medium of consultation might perform as a moderator in the effect of the mediating variables on the dependent variable. First, the medium of consultation was examined as a moderator of the relation between patients' perceived information exchange and patients' satisfaction with the consultation. The medium of consultation explained a significant increase in variance in patients' satisfaction with the consultation ( $\Delta R^2=.08$ ,  $F_{1,44}=4.06$ ,  $P=.05$ ), which implies that the effect of perceived information exchange on satisfaction depends on the medium of consultation. The effect of information exchange on satisfaction was only significant in the Web-based condition ( $b=.533$ ,  $SE=0.207$ ,  $P=.01$ ), but not in the face-to-face condition ( $b=.054$ ,  $SE=0.116$ ,  $P=.65$ ), suggesting that information exchange only predicts satisfaction when patients and doctors communicate online.

Second, it was examined whether the medium of consultation served as a moderator of the relation between patients' perceived interpersonal relationship building and patients' satisfaction with the consultation. The medium of consultation explained a significant increase in variance in patients' satisfaction with the consultation ( $\Delta R^2=.10$ ,  $F_{1,44}=5.65$ ,  $P=.02$ ). Thus, the medium of consultation was a significant moderator of the relationship between patients' perceived interpersonal relationship building and their satisfaction with the consultation. The effect of interpersonal relationship on satisfaction was only significant in the face-to-face condition ( $b=.545$ ,  $SE=0.169$ ,  $P=.002$ ) but not in the Web-based condition ( $b=-.003$ ,  $SE=0.156$ ,  $P=.99$ ), suggesting that interpersonal relationship building only predicts satisfaction when patients communicate face-to-face.

Third, it was examined whether the medium of consultation served as a moderator for the relation between patients' perceived shared decision making and patients' satisfaction with the consultation. The medium of consultation was not a significant moderator between shared decision making and satisfaction ( $\Delta R^2=.00$ ,  $F_{1,44}=.28$ ,  $P=.60$ ). The effect of shared decision making on satisfaction was significant in both the face-to-face condition ( $b=.482$ ,  $SE=0.093$ ,  $P<.001$ ) and the Web-based condition ( $b=.404$ ,  $SE=0.115$ ,  $P=.001$ ), which indicates that shared decision making predicts patients' satisfaction with the consultation in both face-to-face and Web-based consultations.

Finally, the same analyses were performed to examine whether the medium of consultation served as a moderator between doctors' perceived communicative behavior and doctors' satisfaction with the consultations. None of the moderation models were significant, with all  $\Delta R^2<.02$ , all  $F<1.44$ , and all  $P>.235$ . This implies that the effect of doctors' perceived information, doctors' perceived interpersonal relationship building, and doctors' perceived shared decision making on doctors' satisfaction was not dependent on the medium of consultation, and was thus the same for face-to-face consultations and Web-based consultations.

## Discussion

### Effect of the Medium of Consultation on Communicative Behavior

In this study, we examined the difference in doctors' and patients' information exchange, interpersonal relationship building, and shared decision making between Web-based and face-to-face consultations. We found that there were no significant differences between Web-based and face-to-face consultations in any of these three communicative behaviors, which implies that doctors and simulated patients do not perceive communication during a consultation differently when communicating on the Web via video or face-to-face.

The finding that screen-to-screen consultations did not seem to differ from face-to-face consultations regarding the abovementioned outcomes is in line with the *Social Information Processing (SIP) theory* [42]. The *SIP theory* explains that to compensate for the reduction in nonverbal cues in Web-based consultations, doctors and patients may use more verbal cues to create or enhance interpersonal relationships and to exchange the same amount of information as they would face-to-face [42]. Doctors may thus be more likely to show empathy verbally in Web-based video interactions than in face-to-face interactions to compensate for the lack of nonverbal ways of doing so [21,43]. Their findings suggest that nonverbal cues, which are often seen as extremely important in face-to-face interactions [44], may be less important in Web-based interactions, because doctors and patients seem to find other ways to contextualize their messages and to gather and communicate essential information.

Furthermore, it is possible that doctors and simulated patients only *perceive* their communicative behavior the same way in Web-based and face-to-face consultations, whereas their actual communicative behavior differs. Previous research showed that doctors and patients have lower expectations from Web-based consultations than from face-to-face consultations [45]. Therefore, they may be less critical of shortcomings in communicative behavior during screen-to-screen interactions as compared with face-to-face consultations. The reduction of nonverbal cues and the lower level of social presence in Web-based communication may thus change doctors' and patients' expectations of the interaction and in turn their perception. This would imply that in Web-based consultations less cues are needed than in face-to-face consultations to achieve the same effect of perceived information exchange, perceived interpersonal relationship building, and perceived shared decision making.

### Satisfaction With Screen-to-Screen and Face-to-Face Consultations

A further aim of this study was to examine the mediating role of doctors' and patients' information exchange, interpersonal relationship building, and shared decision making on doctors' and patients' satisfaction with face-to-face and Web-based consultations. First, the results showed no difference between Web-based (screen-to-screen) and face-to-face consultations in doctors' and simulated patients' satisfaction with the

consultation. Studies on regular (face-to-face) consultations have shown that communicative behavior is the most important predictor of doctors' and patients' satisfaction with the consultation [44,46]. Therefore, the fact that there was no difference in doctors' and simulated patients' perceived communicative behavior is most likely the explanation for the fact that doctors and simulated patients were as satisfied with the consultation when they communicated face-to-face online.

Second, it was examined whether the three main communicative behaviors of medical interactions had an impact on doctors' and patients' satisfaction. In line with earlier research on offline consultations [44,47,48], this study showed that both doctors' and simulated patients' perceived information exchange and perceived interpersonal relationship building are positively related to their satisfaction with face-to-face and Web-based consultations. This underlines the dual communicative needs of patients [49] as the findings indicate that the fulfillments of patients' instrumental and emotional needs are both predictors of patients' satisfaction with the consultation. In addition, perceived shared decision making was positively related to simulated patients' satisfaction, which underlines earlier studies stating that patients want to play an active role in the decision-making process [50,51]. This in turn enhances their satisfaction with the decision about the treatment [52,53], which predicts general satisfaction with the consultation [54]. However, perceived shared decision making did not predict doctors' satisfaction with the consultation. A possible reason for this could be that simulated patients experience shared decision making differently than doctors. Doctors may perceive shared decision making more as a form of information exchange and they may feel like they still have the final word about the treatment decision [55]. This was also observed in the study by Hamann et al [56], where it was found that if patients insist on their preferences and doubt their doctors' recommendations, physicians consider it as less helpful and even become more annoyed.

The doctors' gender was a significant predictor of simulated patients' satisfaction with the consultation. Simulated patients were more satisfied after having a consultation with a female doctor than with a male doctor. Although the doctors' gender did not predict simulated patients' perceived information exchange and interpersonal relationship building, simulated patients did experience more shared decision making in consultations with female doctors than with male doctors. Therefore, the effect of the doctors' gender on satisfaction with the consultation is probably because of the difference in perceived shared decision making. This is in line with the meta-analysis of Roter et al [33] that suggests that female doctors engage in more patient-centered communication than male doctors. In addition, because of the focus on gynecological health problems in this study, the female patients in this study may have felt more at ease with a female doctor as they may have a better understanding of their problems and as female gynecologists generally adopt a more patient-centered communication style [57].

Finally, the post hoc analyses showed that the medium of consultation serves as a moderator between communicative behavior and simulated patients' satisfaction, which implies

that the effect of communicative behavior on satisfaction depends on the medium of the consultation while the effects of shared decision making on satisfaction were the same for both types of consultation medium; the effects of perceived information exchange and interpersonal relationship building differed. The effect of perceived information exchange on simulated patients' satisfaction with the consultation was only significant in the Web-based consultations, whereas the effect of interpersonal relationship building on simulated patients' satisfaction was only significantly related in the face-to-face consultations. This suggests that simulated patients may expect more information exchange in Web-based consultations and more affective behavior or interpersonal relationship building in face-to-face consultations. The findings of this study suggest that patients especially have lower expectations of affective behavior in Web-based consultations, which is in line with previous studies [45,58]. Patients may see Web-based communication more as a way to share information than to build relationships with their doctor. In addition, the results showed that a less positive attitude toward Web-based communication increased patients' perceived interpersonal relationship building. There may thus be less actual interpersonal relationship building or affective behavior in screen-to-screen consultations compared with face-to-face consultations, but the lower expectations of Web-based communication can make patients less critical about the shortcomings in Web-based consultations.

## Implications

This study has several implications for both theory and practice. The results of this study provide additional support for the importance of the three main communicative functions of medical interactions for doctors' and patients' satisfaction with a consultation. Although several studies have already shown that these behaviors were significantly related to satisfaction in offline consultations [17-19,47,48], this study demonstrates that these three types of communicative behaviors also predict satisfaction with Web-based consultations. Post hoc analyses suggest that information exchange is especially important for satisfaction in Web-based consultations, whereas affective communication is especially important for satisfaction in face-to-face interactions because of the difference in patients' expectations from face-to-face and Web-based video consultations. In the counseling toward therapy for patients with, for example, pelvic organ prolapse, this is an important outcome, suggesting promising future perspectives for Web-based counseling. It has already been shown that computer-based, Web-based counseling across different clinical settings may improve various health outcomes such as improved glucose control and decreased blood pressure [59], management of urinary incontinence [60], and HIV treatment adherence, and risk reduction for people living with HIV and acquired immune deficiency syndrome [61].

Furthermore, important practical implications can be derived from the findings of this study. As discussed in the introduction, the increase in applications for Web-based doctor-patient interactions elicits worries among doctors and patients as they believe that Web-based consultations can dissocialize and dehumanize the original purpose of doctor-patient interactions, which may, in turn, have a negative impact on the interaction

[14,15]. This study shows that these concerns may be unnecessary as there are no differences between screen-to-screen and face-to-face interactions in communicative behavior and satisfaction with the consultation. Other studies have already indicated that Web-based consultations may improve efficiency and reduce the increasing health care costs [62,63]. In addition, previous studies have shown that patients were particularly satisfied with Web-based communication with respect to travel and waiting time, as they could interact with their doctor from their own home at the moment when it is most useful and needed [6,7,16]. Of course, the simulated patients in our study could not profit from those benefits but were still as satisfied with the screen-to-screen as with the face-to-face consultations. These findings underline the potential added value of Web-based video consultations alongside face-to-face consultations as they offer the same interaction quality and satisfaction level as regular face-to-face consultations. Therefore, it is advisable that practitioners and hospitals examine ways to integrate Web-based consultations into their practice. Recent findings showing that physicians with previous experience in using eHealth applications have a more positive attitude toward eHealth implementation and consider that the benefits outweigh its possible difficulties and shortcomings [7,8] are promising in this respect.

## Limitations and Suggestions for Future Research

This study is characterized by a number of strengths and limitations that need to be considered when interpreting the results. First, in this small-scale study, an experimental approach was used in which simulated patients instead of actual patients and interns rather than experienced specialists participated. Although simulated patients ensure high experimental control over the conditions [28,29], they may also be quite similar in characteristics. In this study, all simulated patients were highly educated. Previous research emphasized that less educated patients with low socioeconomic status show low eHealth engagement [64] as they typically have less functional health literacy, which is needed to get information and to understand it, and less critical health literacy, which is needed to critically analyze information and apply it [65]. Therefore, replication with a large and representative sample of nonsimulated patients with different educational levels and different levels of health literacy is needed to confirm our findings.

The participating doctors in this study were young interns who might not yet have a strong preference for a certain type of consultation medium because of their relative lack of experience with medical consultations. Replication with more experienced specialists, who have a long-term experience with regular face-to-face consultations, might yield different results. On the other hand, the absence of a preference for a certain type of consultation medium solely based on experience can also be regarded as a strength of this study as it allows a genuine comparison of consultation medium on the participants' communicative behavior and satisfaction.

Another limitation is the generalizability of the results. This study focused on gynecological health problems because these types of problems often cause embarrassment. The sensitivity of this topic in particular warrants Web-based communication

because of the reduced cues [66]. Furthermore, with gynecology being a leading field in developments of Web-based doctor-patient communication [58,67,68], choosing gynecology was preferable. However, it is necessary to investigate other health care problems as well, as the findings may be different depending on type and phase of the disease. The choice for gynecological health problems also implies that all patients in this study were female. The homogenous group of participants ensured high control over the conditions (and is in that respect a strength of this study); however, it is necessary to investigate whether the same effects count for men as well. To optimally measure shared decision making, this study was set up as a decisional consultation in which the doctor and patient had to make a decision about the treatment. The findings might be different in other types of consultations in which, for example, interpersonal relationship building plays a bigger role. Therefore, replication studies with larger and various patient groups in different phases of their illness will help in determining the generalizability of the results.

Finally, this study focused on doctors' and patients' perceived communicative behavior because behavior is most closely related to satisfaction. However, prior research indicates that self-report measures are at risk for social desirability and reporting bias, and therefore, may be inconsistent with actual behavior measures [69]. In addition, the findings of this study suggest that patients may perceive communicative behavior

differently in Web-based consultations than in face-to-face consultations, possibly because they may have lower expectations from Web-based communication [45]. Therefore, future research should perform a content analysis to compare doctors' and patients' actual communicative behavior during screen-to-screen and face-to-face consultations.

## Conclusions

In conclusion, we found that the quality of doctor-patient communication, as indicated by information exchange, interpersonal relationship building, and shared decision making, did not differ between Web-based and face-to-face consultations. In addition, the results showed that doctors and patients were as satisfied with screen-to-screen consultations as with face-to-face consultations and that there were no differences in the way doctors and patients perceive communicative behavior during these consultations. So far, worries regarding the quality of Web-based medical communication have been a barrier for large-scale implementation of Web-based patient-provider consultations. As this study shows that the interaction quality and satisfaction level are independent of the consultation medium, these results may hopefully offer a step forward in this process. Future studies must be done to demonstrate the efficacy and quality of Web-based medical communication to identify the health outcomes whose benefits appear most promising.

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## Authors' Contributions

MA, KT, TN, and SK wrote the study design. TN and MG constructed the 4 different scenarios on pelvic organ prolapse and urinary stress incontinence. TN, MG, and SK were involved in the inclusion of participants, and MG and SK organized separately preparatory meetings with simulated patients and interns. SK conducted the data collection, and MA and SK analyzed the data. KT, MA, and TN wrote the paper, and all authors agreed with the manuscript's results and conclusions.

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Flowchart of experimental consultation sessions.

[[PDF File \(Adobe PDF File\), 27KB - jmir\\_v19i12e421\\_app1.pdf](#)]

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## Multimedia Appendix 2

Extra explanation of the operationalization of the mediating and dependent variables.

[[PDF File \(Adobe PDF File\), 353KB - jmir\\_v19i12e421\\_app2.pdf](#)]

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## Abbreviations

**CMC:** computer-mediated communication

**eHealth:** electronic health

**LEAPS:** Learn, Educate, Assess, Partner and Support

**PPS:** Patient Participation Scale

**PSQ:** Patient Satisfaction Questionnaire

**SIP:** Social Information Processing

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Original Paper

# Understanding a Nonlinear Causal Relationship Between Rewards and Physicians' Contributions in Online Health Care Communities: Longitudinal Study

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## Abstract

**Background:** The online health care community is not just a place for the public to share physician reviews or medical knowledge, but also a physician-patient communication platform. The medical resources of developing countries are relatively inadequate, and the online health care community is a potential solution to alleviate the phenomenon of long hospital queues and the lack of medical resources in rural areas. However, the success of the online health care community depends on online contributions by physicians.

**Objective:** The aim of this study is to examine the effect of incentive mechanisms on physician's online contribution behavior in the online health community. We addressed the following questions: (1) from which specialty area are physicians more likely to participate in online health care community activities, (2) what are the factors affecting physician online contributions, and (3) do incentive mechanisms, including psychological and material rewards, result in differences of physician online contributions?

**Methods:** We designed a longitudinal study involving a data sample in three waves. All data were collected from the Good Doctor website, which is the largest online health care community in China. We first used descriptive statistics to investigate the physician online contribution behavior in its entirety. Then multiple linear and quadratic regression models were applied to verify the causal relationship between rewards and physician online contribution.

**Results:** Our sample included 40,300 physicians from 3607 different hospitals, 10 different major specialty areas, and 31 different provinces or municipalities. Based on the multiple quadratic regression model, we found that the coefficients of the control variables, past physician online contributions, doctor review rating, clinic title, hospital level, and city level, were .415, .189, -.099, -.106, and -.143, respectively. For the psychological (or material) rewards, the standardized coefficient of the main effect was 0.261 (or 0.688) and the standardized coefficient of the quadratic effect was -0.015 (or -0.049). All estimates were statistically significant ( $P < .001$ ).

**Conclusions:** Physicians with more past physician online contribution, with higher review ratings, coming from lower level clinics, not coming from tertiary hospitals, and not coming from big cities were more willing to participate in online health care community activities. To promote physician online contribution, it is necessary to establish an appropriate incentive mechanism including psychological and material rewards. Finally, our findings suggest two guidelines for designing a useful incentive

mechanism to facilitate physician online contribution. First, material reward is more useful than psychological reward. Second, as indicated by the concave-down-increasing causal relationship between rewards and physician online contribution, although an appropriate reward is effective in encouraging willingness on the part of physicians to contribute to the online health care community, the effect of additional rewards is limited.

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## KEYWORDS

online health care community; physician online contribution; psychological reward; material reward

## Introduction

### Background

With the development of a mature online health care community, more and more people have begun to use online reviews within the online health care community to obtain information about the quality of their physicians [1]. This phenomenon has received the attention of many researchers, and several studies of the online health care community have been conducted focusing on various issues, such as how online physician reviews have been used in different countries [2-7], what the differences between the traditional and online physician reviews are [8], and whether differences in medical specialty areas affect these reviews [5,9]. Nevertheless, in China, even though the online health care community might help consumers look for a good physician, the queues at Chinese hospitals are legendary [10], meaning it is not easy to make an appointment with a physician. The reason is that medical resources are relatively insufficient in the country. Statistically, health spending accounts for only 5.5% of the gross domestic product, and there are approximately 1.8 doctors and 2.4 nurses for every 1000 people [11]. In China, health resources are far less than those in the Organisation for Economic Co-operation and Development countries. More importantly, substantial inequalities remain in the geographical distribution of medical resources; in particular, provinces in western China have the lowest levels of resources [12]. With its potential to mitigate the problems of the long waiting times at hospitals and the low levels of medical resources in rural areas, the online health care community is no longer merely a site for the public to share physician reviews; it has also become a physician-patient communication platform in China.

There have been many companies offering this type of service, among which the Good Doctor website is a typical example [5]. The Good Doctor website (*hao dai fu* means “good doctor” in Chinese) was the earliest online physician review website [13] and has been in operation in China since 2006. In 2016, it began working with the Yinchuan Municipal People’s Government and it has obtained a medical institution license so that it can provide new online medical services in China. According to the Good Doctor website, it included references to 7216 hospitals and more than 480,000 physicians at the end of 2016. Among these, approximately 142,000 physicians included their actual verified identities. They can directly provide medical advice to patients, make appointments for treatment, and share their professional knowledge. Of course, this online health care service cannot replace offline medical interaction entirely, but it can reduce the huge pressure on China’s health care system. The key factor determining the online health care community’s

success is whether the physicians are actively involved in the sites. Therefore, understanding and promoting physician online contribution is a critical issue for the online health care community managers.

### Research Problem

Many studies have investigated online contribution behavior in other kinds of online communities such as Wikipedia [14,15], social Q&A sites [16-18], and open source software communities [19,20]. The importance of member contribution for the sustainable development of online communities has been verified by extensive research [16-18,21]. Establishing an effective incentive mechanism is one of the most common ways to maintain community contribution behavior [22-26]. These related studies can be divided into three categories according to their research methods. In the first, the questionnaire survey is adopted to investigate the knowledge-sharing community [22-23]. This type of study considers both extrinsic and intrinsic incentives and examines their effects on the member’s contribution behavior. The empirical results verify the significant positive effect of intrinsic incentives, but the influence of extrinsic incentives is inconsistent. Second, some studies have discussed the Q&A community [24] and the online learning community [25] by means of an experimental design. They consider only the effect of extrinsic incentive on contribution behavior, and they conclude that the extrinsic incentive has a significant positive effect on users’ online contributions. Third, applying Web technology to collect online community public data is another way to investigate this issue; researchers such as Raban [26] has explored members’ contributions in Google Answers, an online community to help users find expert information possessed by others online. A high-quality answer is scored at a higher rating and, as a way of expressing thanks, some askers might be willing to provide a tip, in the form of a voluntary gratuity payment. Thus, in the work of Raban, ratings and tips were used to measure intangible and tangible incentives, respectively. In addition, the number of answers was regarded as a proxy for a user’s contribution level. The empirical evidence indicates that both intangible and tangible incentives have a significant positive influence on users’ online contribution. Despite the fact that the online health care community has been in existence around the world for over a decade, very little is known about incentive mechanisms that could foster physicians’ willingness to contribute and interact with patients in the online health care community. The online health care community managers can establish incentive mechanisms, such as thank you letters and virtual gifts, which might encourage physician contributions. This study attempts to bridge this gap in our knowledge. We designed a longitudinal

study to examine whether physician online contribution is affected by incentive mechanisms.

## Methods

### Research Model

Figure 1 represents the research model. Five control variables—past physician online contribution, doctor review rating, clinic title, hospital level, and city level—represent the physician's status at a specific time. In other words, these are all stock variables measured at time  $t$ . Psychological (intrinsic) and material (extrinsic) rewards are considered within the incentive mechanism [22,23,26]. Both of these are flow variables measured from time  $t - 1$  to  $t$ . Finally, the physician online contribution is also a flow variable, measured from time  $t$  to  $t + 1$ . Based on this framework, we can verify whether physicians receiving certain rewards changes their online contribution behavior in the next period.

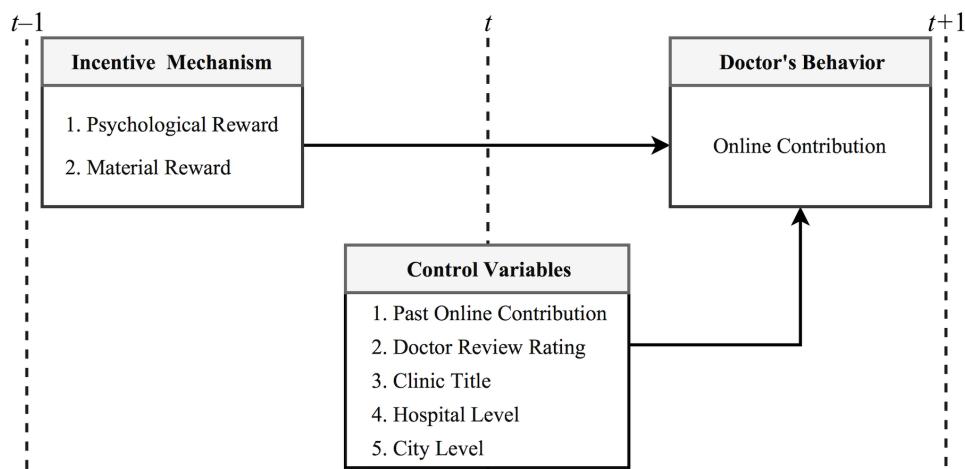
Reinforcing theory, which suggests that stimulus is used to shape behaviors [27], provides a relevant foundation to address the causal relationship between rewards and physician online contribution. From the view of social psychology, people's attitude can be strengthened through intrinsic and extrinsic rewards, whether the effect is a reinforcing or a changing of attitude [28]. In other words, reward is a key factor in behavioral decisions [24,29,30] and can cause repetitive behaviors [27,31]. In this study, our incentive mechanism is comprised of psychological and material rewards. The psychological reward is measured as the number of thank you letters from patients [32]. This reward is regarded as a kind of intrinsic reward, enhancing physicians' self-efficacy and self-worth [22,23,33]. The material reward is measured as the number of received token gifts, which are sold in the online health care community and are used to express gratitude to the physicians. These "virtual gifts" can be converted into a cash equivalent and then deposited into the physician's personal research fund. Thus, they are a kind of extrinsic or economic benefit [22,23]. Further, in light of "the law of diminishing marginal utility" [34], a classic law in economics, we further explore how psychological and material rewards affect the physicians' online contributions. Based on universal human experience, this law states that the

marginal utility derived from each additional unit diminishes compared to that of the previous unit. In our context, when a physician receives more psychological or material rewards, there is a decline in the marginal effect of each additional reward on the physician's online contribution. Mathematically, a function with a positive first derivative and a negative second derivative is termed a concave-down-increasing function. We investigate the existence of this concave-down-increasing relationship between rewards and physician online contribution.

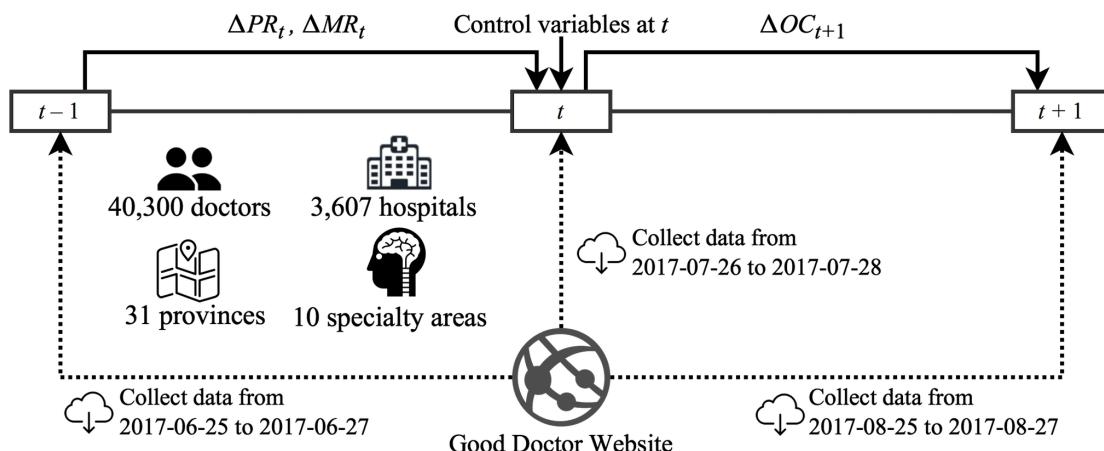
### Data Collection and Processing

By means of Web crawler technology, data for this study were collected from the Good Doctor website on which more than 423,916 physicians' profiles could be found. However, only after a physician applies for a personal webpage is he or she able to provide full online services (eg, online dialog with patients or the sharing of professional articles). Thus, the 142,457 doctors with personal webpages on the site were considered for the purposes of the study to be genuinely involved in the website, and others were not included in our sample. Further, to ensure that the doctor was currently active on the website, the most recent log-in time had to be within 1 month. Thus, we focused on 40,300 doctors who had personal websites and had logged into the Good Doctor website recently. To investigate whether adding psychological and material rewards would cause the physicians' online contribution behavior to change, we designed a longitudinal study involving a data sample in three waves. The data collection process is shown in Figure 2. Specifically, at the start (June 25, 2017), we collected data including the physician's ID and the numbers of received thank you letters and token gifts as proxies for psychological and material rewards. In a follow-up phase 1 month later (July 26, 2017), we collected a second wave of data including the doctor review ratings, clinic title, hospital level, city level, thank you letters, token gifts, and online contribution score. In the last phase (August 25, 2017), we collected each physician's online contribution score again, covering the period of 1 month. It should be noted that due to the specific data collecting period, a seasonal bias may exist in our analysis (eg, many people, including physicians, usually have more vacations in summer).

**Figure 1.** Summary of the proposed model of the effects of psychological and material rewards on physician online contribution. Rewards are measured from time  $t-1$  to  $t$ . Online contribution is measured from time  $t$  to  $t+1$ . Control variables are measured at time  $t$ .



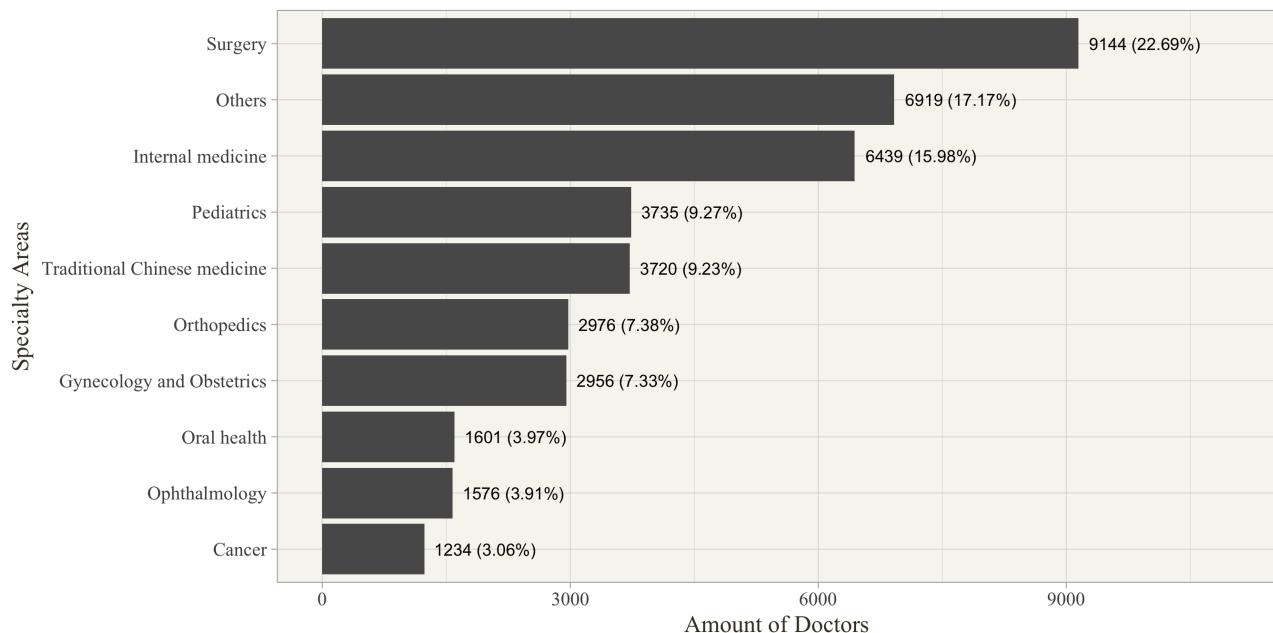
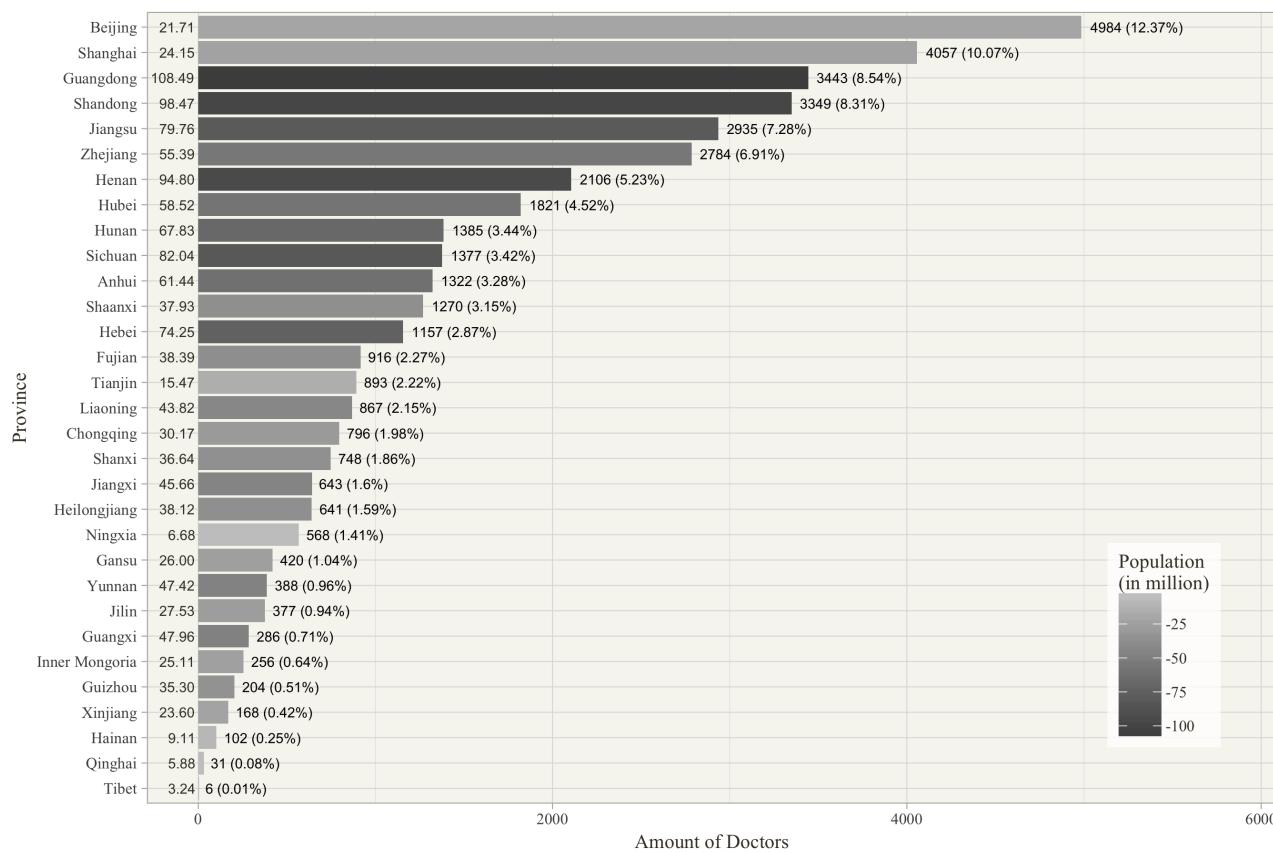
**Figure 2.** Data collection and processing.  $\Delta PR_t$  and  $\Delta MR_t$  represent the increment of psychological reward and material reward from time  $t-1$  to  $t$ , respectively, and  $\Delta OC_{t+1}$  represents the increment of physician online contribution from time  $t$  to  $t+1$ .



## Sample Characteristics

Some of the sample characteristics were worth additional exploration. First, the 40,300 doctors came from 3607 different hospitals, 10 different major specialty areas, and 31 different provinces or municipalities in China. This indicates that our sample was not confined to a specific group. In particular, Figure 3 shows the numbers of physicians in different major specialty areas. Surgery, internal medicine, pediatrics, and traditional Chinese medicine accounted for the largest numbers of physicians, with approximately 23%, 16%, 9%, and 9% of the total number of physicians, respectively. Figure 4 represents the numbers of physicians in 31 provinces or municipalities. In addition, Figure 4 also shows the corresponding populations in 2015, which can be generated from the National Bureau of Statistics of China [35]. In general, the larger population size comes with a larger number of physicians on the Good Doctor website, except for two big cities, Beijing and Shanghai, which are the China's political and economic centers, respectively.

Although the total population of permanent residents in Beijing and Shanghai accounts for only 3.3% of the total in China, approximately 22% of the physicians came from both cities. This might reflect the relative adequacy of medical resources in large cities or partially be due to the promotion strategies of the Good Doctor website. This naturally reflects the relative adequacy of medical resources in large cities. Second, the clinic title is unified nationally corresponding to four levels: resident physician, attending physician, associate chief physician, and chief physician (from junior to senior). These four levels account for 9.1%, 30.5%, 33.3%, and 27.1% of the total doctor population in our sample, respectively. Third, approximately 82% of the physicians come from hospitals in the tertiary category, which is the official certification of the highest quality hospitals. Finally, we also collected the doctors' review ratings, which may be regarded as online word-of-mouth. The mean of these ratings was 3.84 (standard deviation [SD] 0.34) on a scale from 1 to 5, with 5 being the highest score.

**Figure 3.** Number of doctors in 10 major specialty areas (N=40,300).**Figure 4.** Number of doctors in 31 provinces or municipalities (N=40,300).

## Measures

### Online Contribution

Essentially, the existence of online contributions means that members are involved in community-related activities, such as sharing information actively, responding positively to other members' questions, and intuitively interacting with other members [16,21]. In this study, we measured the physicians'

online contribution through the contribution scores listed on the Good Doctor website. There are three principle ways in which the contribution score can change. First, when physicians update their personal information, such as outpatient information and consultation range, in a timely manner, their contribution scores can be increased through the online health care community administrator's audit. Second, physicians are encouraged to post medical articles for patients on the website. After the article

is referenced by the Good Doctor website, the contribution score is updated. Third, if a physician can answer a patient's question online, his or her contribution score will be increased. In this study, increment of physician online contribution was measured as the increment of the contribution score from baseline to follow-up, divided by time interval length in natural logarithmic form. The formula is presented in equation 1 in [Figure 5](#).

The reason for dividing by the number of days between baseline and follow-up in this equation requires explanation. To avoid interfering with the normal operation of the Good Doctor website, our crawler process did not download data very frequently. We spent approximately 3 days collecting all the physicians' data at one time, as shown in [Figure 2](#). Hence, this time is not precisely equal to 30 days for each physician. Dividing by the number of days, which does not need to be an integer, eliminates this slight estimating bias. Specifically, the physician online contribution is regarded as a daily physician online contribution measure. The other two flow variables related to rewards were also obtained by a similar measurement.

### **Psychological Reward**

The number of received thank you letters was used as a proxy for psychological reward. Thank you letters were written by patients to express their thankfulness. The increment of psychological reward is the change in psychological reward measured as the natural logarithm of the increment of thank you letters received from baseline to follow-up divided by the time interval length. The formula is presented in equation 2 in [Figure 5](#).

### **Material Reward**

Patients can express gratitude to physicians by purchasing virtual gifts such as virtual flowers, plaques, and pennants on the Good Doctor website. These gifts are converted to cash equivalents and are deposited into the physician's personal research fund. Thus, the number of token gifts received may be regarded as a proxy for material reward in this study. Specifically, increment in material reward is the change of material reward measured as the natural logarithm of the increment of token gifts received from baseline to follow-up divided by the time interval length. The formula is presented in equation 3 in [Figure 5](#).

**Figure 5.** Equations and variable definitions.

$$\Delta OC_{t+1} = \ln\left(\frac{OC_{t+1} - OC_t}{Day_{t+1}}\right) \quad [1]$$

$$\Delta PR_t = \ln\left(\frac{PR_t - PR_{t-1}}{Day_t}\right) \quad [2]$$

$$\Delta MR_t = \ln\left(\frac{MR_t - MR_{t-1}}{Day_t}\right) \quad [3]$$

$$\Delta OC_{t+1} = \beta_0 + \beta_1 \Delta PR_t + \beta_2 \Delta MR_t + \beta_3 POC_t + \beta_4 DR_t + \beta_5 CT_t + \beta_6 HL_t + \beta_7 CITY_t + \varepsilon_t \quad [4]$$

$$\Delta OC_{t+1} = \beta_0 + \beta_1 \Delta PR_t + \beta_2 \Delta MR_t + \beta_3 POC_t + \beta_4 DR_t + \beta_5 CT_t + \beta_6 HL_t + \beta_7 CITY_t + \beta_8 \Delta PR_t^2 + \beta_9 \Delta MR_t^2 + \varepsilon_t \quad [5]$$

Variables	Definitions
$OC$	Physician online contribution score
$\Delta OC_{t+1}$	Increment of physician online contribution from $t$ to $t+1$
$Day_{t+1}$	Number of days between $t$ and $t+1$
$PR$	Number of psychological rewards (thank you letters)
$\Delta PR_t$	Increment of psychological reward from $t-1$ to $t$
$Day_t$	Number of days from $t-1$ to $t$
$MR$	Number of material rewards (token gifts)
$\Delta MR_t$	Increment of material reward from $t-1$ to $t$
$\beta_0$	Coefficient of the constant term
$\beta_i, i=1, \dots, n$	Coefficients of independent variables
$\Delta PR_t^2$	Square of psychological reward
$\Delta MR_t^2$	Square of material reward
$POC_t$	Past online contribution
$DR_t$	Doctor review rating
$CT_t$	Clinic title
$HL_t$	Hospital level
$CITY_t$	City level

### Control Variables

We employed a number of control variables in this study: past physician online contribution at time  $t$  [15,16]; mean of doctor review ratings at time  $t$  [5,26]; a dummy variable for the clinic title, where chief and associate chief physicians were coded as 1 and others were coded as zero [5]; a dummy variable for hospital level, set to 1 if the physician was from a tertiary hospital and zero otherwise [5]; and a dummy variable for city level, set to 1 if the doctor was from Beijing or Shanghai and zero otherwise [5]. In this study, all control variables were stock variables, which represented the online and offline status of physicians at time  $t$ . The definitions and measurements of all variables are reported in [Table 1](#).

### Statistical Analysis

To examine the research question of whether psychological and material rewards will affect physician online contribution, a

multiple linear regression model was constructed as presented in model 1 in [Figure 5](#).

To investigate the concave-down-increasing relationship between rewards and physician online contribution, we further considered a multiple quadratic regression model as presented in model 2 in [Figure 5](#).

To test the curvilinear impact of the square of the increment of psychological (or material) reward, the increment of psychological (or material) reward was mean-centered to reduce the chances of multicollinearity, and multiplied with the original scores [36]. If  $\beta_8$  ( $\beta_9$ ) were found to be significantly positive or negative, that result would confirm the nonlinear causal relationship between psychological (or material) reward and physician online contribution.

**Table 1.** Variable definitions and measurements

Variable definitions	Measurements
Increment of physician online contribution	Natural logarithm of the increment of the contribution score from time $t$ to $t+1$ divided by time interval length
Increment of psychological reward	Natural logarithm of the increment of thank you letters received from time $t-1$ to $t$ divided by the time interval length
Increment of material reward	Natural logarithm of the increment of token gifts received at time $t-1$ and $t$ divided by the time interval length
Past online contribution	Natural logarithm of the contribution score of the doctor at time $t$
Doctor review rating	Mean of the overall ratings in user reviews of the doctor at time $t$ (on a scale of 1 to 5 with 5 being the highest score)
Clinic title	A dummy variable, coded 1 if the clinic title was chief physician or associate chief physician, 0 otherwise
Hospital level	A dummy variable, coded 1 if the doctor was from the tertiary hospital, 0 otherwise
City level	A dummy variable, coded 1 if the doctor came from Beijing or Shanghai, 0 otherwise

## Results

### Descriptive Statistics

The contribution scores of 40,300 physicians were collected twice, with an interval of approximately 1 month, from July 26, 2017 to August 27, 2017. The increment of all physicians' contribution scores was 10,609,215, meaning the rate of increase was approximately 2.8%. Thus, the mean increment of the contribution score was approximately 263.2 (SD 701.9) per physician. It was of particular interest to investigate the difference across 10 major specialty areas. **Table 2** shows that the contribution scores of the physicians in the specialties of gynecology/obstetrics and pediatrics increased much more than those of others. Specifically, the increments of the contribution scores were mean 413.5 (SD 981.3) and mean 362.2 (SD 822.3) per doctor, respectively. We also observed the increments in the numbers of thank you letters and token gifts in each specialty area. **Table 2** indicates that physicians in the surgery and ophthalmology specialties received more thank you letters (ie,

0.85 and 0.80 letters per physician, respectively). The average increments in numbers of token gifts across specialty areas are represented in **Table 2**. On average, one physician received 1.45 token gifts, but physicians in the pediatrics and gynecology/obstetrics specialties received 1.95 and 1.91 token gifts, respectively.

### Causal Relationship Between Rewards and Physician Online Contribution

**Table 3** presents the regression estimation for model 1 with the 40,300 physician sample. We report the standardized regression coefficients, standard errors,  $t$  values, and  $P$  values for all variables. The coefficient of determination is relatively high ( $R^2=.534$ ); that is, the model is able to explain a substantial amount of variance in the dependent variable. The result demonstrates the significant effect of psychological reward on physician online contribution ( $\beta_1=0.192$ ). We also found a positive and significant relationship between material reward and online contribution ( $\beta_2=0.359$ ).

**Table 2.** Mean increments in contribution scores (July 26-August 27, 2017), number of thank you letters (June 25-July 28, 2017), and number of token gifts (June 25-July 28, 2017) by major specialty area.

Specialty	Increment of contribution score Mean (SD <sup>a</sup> )	Increment of number of thank you letters Mean (SD)	Increment of number of token gifts Mean (SD)
Cancer	207.9 (788.8)	0.6 (26.6)	1.5 (143.1)
Gynecology and obstetrics	413.5 (981.3)	0.6 (32.4)	1.9 (231.9)
Internal medicine	210.2 (592.8)	0.5 (26.2)	1.4 (127.3)
Ophthalmology	269.6 (706.7)	0.8 (33.8)	1.3 (129.1)
Oral health	189.2 (485.1)	0.6 (29.0)	0.8 (86.6)
Orthopedics	170.1 (477.8)	0.7 (30.3)	1.0 (122.5)
Pediatrics	362.2 (822.3)	0.7 (34.0)	2.0 (195.1)
Surgery	212.7 (532.3)	0.9 (37.8)	1.5 (152.8)
Traditional Chinese medicine	235.2 (594.3)	0.6 (24.8)	1.1 (143.3)
Others	342.6 (889.7)	0.7 (32.9)	1.5 (179.2)
Total	263.2 (701.9)	0.7 (32.2)	1.5 (160.2)

<sup>a</sup>SD: standard deviation

**Table 3.** Results for the effect of antecedents on online contribution (N=40,300).

Independent variables <sup>a</sup>	Coefficient <sup>b</sup>	SE <sup>c</sup>	t <sub>40,292</sub>	P
Intercept	1.417	0.011	125.165	<.001
Psychological reward	0.192	0.006	33.112	<.001
Material reward	0.359	0.006	61.827	<.001
<b>Control variables</b>				
Past online contribution	0.450	0.005	89.752	<.001
Doctor review rating	0.246	0.006	41.823	<.001
Clinic title	-0.115	0.010	-11.488	<.001
Hospital level	-0.114	0.012	-9.533	<.001
City level	-0.149	0.011	-13.084	<.001

<sup>a</sup>Model summary:  $R^2=.534$ ,  $F_{7,40,292}=6588$ ,  $P<.001$ .

<sup>b</sup>Standardized regression coefficient.

<sup>c</sup>SE: standard error.

For the control variables, the results show that past physician online contribution ( $\beta_3=0.450$ ) and doctor review rating ( $\beta_4=0.246$ ) had positive associations with an increment in physician online contribution, but clinic title ( $\beta_5=-0.115$ ), hospital level ( $\beta_6=-0.114$ ), and city level ( $\beta_7=-0.149$ ) were negatively associated with an increment in physician online contribution. All the estimates were statistically significantly ( $P<.001$ ).

### Quadratic Effect for Impact of Reward on Physician Online Contribution

**Table 4** reports the regression analysis results for model 2, including the standardized regression coefficients, standard errors, *t* values, and *P* values for all variables. In comparison

to model 1, the coefficient of determination was raised from .534 to .570, meaning the addition of two quadratic variables could improve the original model. All the estimates in **Table 4** are statistically significantly ( $P<.001$ ). The characteristics of the coefficients of control variables were very similar to those in the results of model 1. Turning to the effects of psychological and material rewards, the main effects of both rewards were significantly positive ( $\beta_1=0.261$  and  $\beta_2=0.688$ ). More importantly, the quadratic effects of rewards were significantly negative ( $\beta_8=-0.015$  and  $\beta_9=-0.049$ ). Therefore, the reward did not follow a linear relationship with physician online contribution. In particular, the positive main effect and the negative quadratic effect represent a concave-down-increasing relationship between rewards and physician online contribution.

**Table 4.** Results for the quadratic effect of reward on online contribution (N=40,300).

Independent variables <sup>a</sup>	Coefficient <sup>b</sup>	SE <sup>c</sup>	t <sub>40,290</sub>	P
Intercept	1.417	0.011	134.762	<.001
<b>Main effects</b>				
Psychological reward	0.261	0.008	34.581	<.001
Material reward	0.688	0.009	78.670	<.001
<b>Quadratic effects</b>				
(Psychological reward) <sup>2</sup>	-0.015	0.001	-17.549	<.001
(Material reward) <sup>2</sup>	-0.049	0.001	-49.246	<.001
<b>Control variables</b>				
Past online contribution	0.415	0.005	85.476	<.001
Doctor review rating	0.189	0.006	32.996	<.001
Clinic title	-0.099	0.010	-10.296	<.001
Hospital level	-0.106	0.012	-9.228	<.001
City level	-0.143	0.010	-13.941	<.001

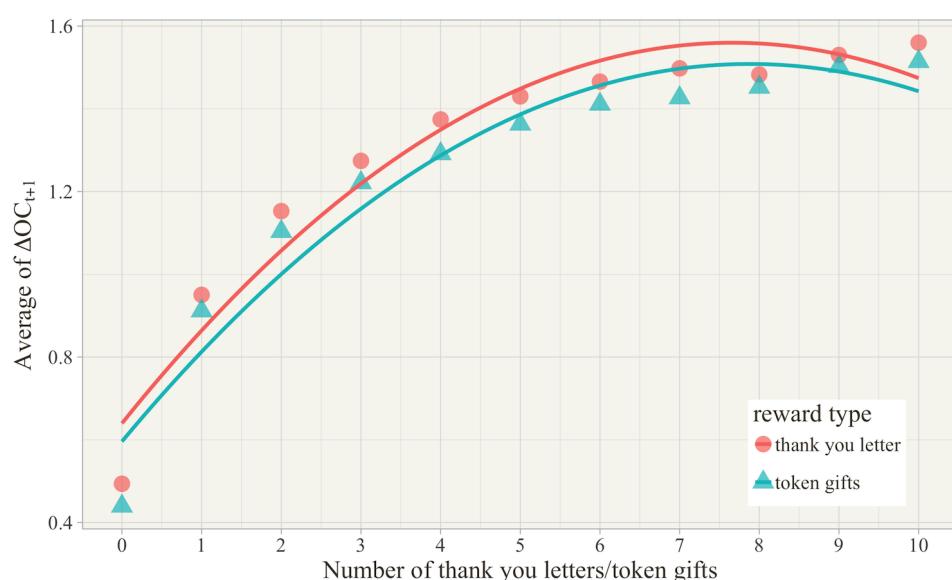
<sup>a</sup>Model summary:  $R^2=.570$ ,  $F_{9,40,290}=5935$ ,  $P<.001$ .

<sup>b</sup>Standardized regression coefficient.

<sup>c</sup>SE: standard error.

To further understand and verify this relationship, all physicians were grouped by the number of thank you letters (or token gifts) received, and the mean value of the increment of physician online contribution was calculated for each group, with the results depicted in [Figure 6](#). In line with the restriction of the data range, physicians receiving more than 10 thank you letters (or token gifts) were excluded in [Figure 6](#), after which 99.3% (or 97.0%) of all physicians were still included. Both figures clearly illustrate that the main effects of rewards are positive and that the marginal contribution decreases with increasing reward levels.

**Figure 6.** Impact of the number of thank you letters/token gifts on online contribution.



**Table 5.** Results for the robustness of the effects of rewards on online contribution for doctors receiving at least one thank you letter or token gift (N=16,029).

Independent variables <sup>a</sup>	Coefficient <sup>b</sup>	SE <sup>c</sup>	t <sub>16,019</sub>	P
Intercept	1.759	0.022	81.474	<.001
<b>Main effects</b>				
Psychological reward	0.143	0.008	17.185	<.001
Material reward	0.480	0.010	48.730	<.001
<b>Quadratic effects</b>				
$(\text{Psychological reward})^2$	-0.005	0.001	-6.097	<.001
$(\text{Material reward})^2$	-0.030	0.001	-27.784	<.001
<b>Control variables</b>				
Past online contribution	0.694	0.011	63.048	<.001
Doctor review rating	0.079	0.009	8.827	<.001
Clinic title	-0.184	0.015	-12.342	<.001
Hospital level	-0.097	0.022	-4.354	<.001
City level	-0.227	0.015	-14.652	<.001

<sup>a</sup>Model summary:  $R^2=.531$ ,  $F_{9,16,019}=2016$ ,  $P<.001$ .

<sup>b</sup>Standardized regression coefficient.

<sup>c</sup>SE: standard error.

**Table 6.** Results for the robustness of the effects of rewards on online contribution in the 10 major specialty areas.

Specialty and effects	Psychological reward		Material reward		<i>R</i> <sup>2</sup>
	Coefficient <sup>a</sup>	<i>P</i>	Coefficient <sup>a</sup>	<i>P</i>	
<b>Surgery</b>					.592
Main	0.265	<.001	0.638	<.001	
Quadratic	-0.022	<.001	-0.048	<.001	
<b>Internal medicine</b>					.558
Main	0.299	<.001	0.778	<.001	
Quadratic	-0.029	<.001	-0.063	<.001	
<b>Pediatrics</b>					.594
Main	0.303	<.001	0.632	<.001	
Quadratic	-0.025	<.001	-0.040	<.001	
<b>Traditional Chinese medicine</b>					.576
Main	0.391	<.001	0.806	<.001	
Quadratic	-0.041	<.001	-0.086	<.001	
<b>Orthopedics</b>					.573
Main	0.281	<.001	0.814	<.001	
Quadratic	-0.019	<.001	-0.083	<.001	
<b>Gynecology-obstetrics</b>					.529
Main	0.545	<.001	0.585	<.001	
Quadratic	-0.084	<.001	-0.026	<.001	
<b>Oral health</b>					.548
Main	0.215	<.001	0.883	<.001	
Quadratic	0.002	0.500	-0.096	<.001	
<b>Ophthalmology</b>					.568
Main	0.355	<.001	0.755	<.001	
Quadratic	-0.028	<.001	-0.081	<.001	
<b>Cancer</b>					.622
Main	0.102	0.045	0.811	<.001	
Quadratic	0.020	<.001	-0.069	<.001	
<b>Others</b>					.599
Main	0.286	<.001	0.730	<.001	
Quadratic	-0.011	<.001	-0.062	<.001	

<sup>a</sup>The standardized regression coefficient related to reward.

More importantly, we further explored the effects of reward on physician online contribution in different specialty areas. Table 6 shows that both the main and quadratic effects of material reward were robust in all specialty areas; these estimates were statistically significant ( $P<.001$ ). For the psychological rewards, the quadratic effects for physicians with oral health and cancer specialties did not have significantly negative coefficients, but the results for other specialties still supported the previous arguments. To sum up, the additional empirical evidence provided here further confirms the robustness of the causal relationship between rewards and physician online contribution.

## Discussion

### Principal Results

The online health care community cannot only reduce medical information asymmetries [37], helping Web users find a good physician or access medical knowledge, but it can also enable patients to communicate directly with physicians online. Thus, the online health care community is a potential solution for the problem of rural-urban health disparities [38], especially in developing countries such as China. Nevertheless, the success of the online health care community depends on whether enough

physicians are actively involved in it. We should first realize that our empirical results cannot be used to explain all the physicians' online and offline contributions to patients, but only their online health care community participation behavior. Our findings showed that, in various specialty areas, the mean levels of physician online contribution were different. Table 2 indicated that the online contribution of physicians in the gynecology/obstetrics and pediatrics specialty areas were much higher than those in other areas. One possible reason is that these physicians have more opportunities to serve patients online or offline. Specifically, pediatrics and obstetrics happen to be a universal event for most people. Most people will not have heart surgery, but a relatively high percentage of couples will decide to have children. In particular, the Chinese people are very concerned about medical issues related to their children, which also creates more opportunities for the physicians to answer patients' questions. This argument is partially supported by the fact that physicians specializing in gynecology/obstetrics and pediatrics have the largest average numbers of reviews in China [5]. Another possible reason is that the physicians in the gynecology/obstetrics and pediatrics specialty areas are considered to be more people-oriented and compassionate compared with other specialties. Both characteristics may lead them to be more willing to take extra time to help more patients. To sum up, our findings can help people understand the current status of physician online contribution in China, but it should be noted that to criticize any physician for making fewer contributions to the online health care community would be very inappropriate.

We further investigated the factors affecting physician online contribution. We first discussed the results related to the control variables, including past online contribution, doctor review rating, clinic title, hospital level, and city level, which were not easy to manipulate or change in a short time. Both past online contribution and doctor review rating could be regarded as measures of the physician's past online behavior. Specifically, a physician with a higher past online contribution implies that he or she is more willing to participate in online health care community activities, and a physician with a higher doctor review rating means that he or she has a better reputation in the online health care community. As shown in Tables 3 and 4, a higher past online contribution and doctor review rating led to more online contribution in the next month. These results were consistent with those of prior literature (ie, people's past contribution was highly correlated with their subsequent contribution) [15,16], and the review rating was a driver for online participation [26]. The other three control variables were related to physicians' offline status. Chief and associate chief physicians, physicians from tertiary hospitals, and physicians from the cities of Beijing or Shanghai were less involved in the online health care community. Because these control variables were hard for the online health care community managers to manipulate, this study was more concerned with the variables related to incentive mechanisms.

Our research design related to the incentive mechanism has two particular merits. First, based on multiperiod samples, we examined whether physicians' receiving different levels of reward in the first month would cause their online contribution

behavior to be different in the next month. The result showed a clear causal relationship between rewards and physician online contribution, not merely a correlation relationship. Second, we considered both psychological and material rewards, which were measured by the numbers of thank you letters and token gifts, respectively. Although the value of the token gift was not high (¥5-¥100), unlike the thank you letters, they could be converted for economic use. Previous research related to online Q&A communities [18] and open source software development communities [39] found that extrinsic motivation (ie, financial rewards) positively inflated participation contribution, but that intrinsic motivation (ie, self-worth or self-efficacy) might have no significant association with participation contribution. However, our findings showed that both psychological and material rewards could increase physician online contribution significantly. Comparing these two types of rewards, Table 3 shows the standardized regression coefficients of increments of material and psychological rewards were 0.359 and 0.192, respectively, meaning that material reward had a larger effect than psychological reward. Moreover, we examined the multiple quadratic regression model in model 2. The positive main effects ( $\beta_1=0.261$ ,  $\beta_2=0.688$ ) and the negative quadratic effects ( $\beta_8=-0.015$ ,  $\beta_9=-0.049$ ) indicated a concave-down-increasing relationship between rewards and physician online contribution. As shown in Tables 5 and 6, all empirical results were robust for the subset of the sample in which physicians received at least one thank you letter or token gift, and were robust for different specialty areas.

Finally, we make two specific recommendations for online health care community managers based on our findings. First, the means of physician online contribution in various specialty areas are quite different; thus, online health care community managers should make an effort to rebalance the online workload of physicians in different specialties. In particular, Table 2 indicated that online contributions of physicians in gynecology/obstetrics and pediatrics specialty areas were much more than those of others, but the number of those physicians was relatively small, as shown in Figure 3. Thus, online health care community managers should attempt to recruit more physicians within the gynecology/obstetrics and pediatrics specialties. Second, our findings verified the importance of incentive mechanisms in the online health care community. Both psychological and material rewards can make individuals more willing to do something. Because the continued effective operation of the online health care community must rely on physicians' participation, a feasible incentive mechanism needs to be developed. We propose two guidelines for managers to refer to: (1) material reward is more useful than psychological reward, even if the received economic benefit is very limited, and (2) to maximize the physician online contribution, online health care community managers should avoid excessive concentration of rewards on a small number of physicians. In other words, the appropriate reward level for each physician is enough, since the marginal online contribution decreases with the reward level.

## Limitations and Future Work

We note some limitations and indicate possible future research issues in this section. First, all data were collected from one single online health care community, the Good Doctor website. Although it is the largest and the first online health care community in China, this means our results may only partially reflect the reality of the physician online contribution behavior. Second, because the increment of the contribution score was calculated from July 26 to August 27, 2017, a seasonal bias may exist. For example, physicians with an internal medicine specialty may be busier in the winter than in the summer. In future studies, more interesting results may be found if we can observe the physicians' online contribution behavior through a cross-season sample. Third, the physician online contribution was measured by the Good Doctor website's contribution score, which was a quantitative indicator and could not reflect the qualitative value of contributions. For example, if a physician answered five patients' questions with careful consideration, he or she would still receive a lower contribution score than another physician who responded to more patients' questions more thoughtlessly. However, to properly measure the quality of contribution is a challenging task.

Two other issues related to physician online contribution can be investigated in future work. First, patients with chronic or acute conditions would come with quite different symptoms and receive different treatment processes [40-42]. In particular, most people with acute illnesses (eg, flu) will soon recover, but chronic health conditions (eg, diabetes) usually cannot be cured, only controlled. The chronic or acute condition might lead to dissimilar physicians' online contribution behavior. Second, and perhaps more importantly, the physician online contribution must meet different types of social support needs including informational [43] and emotional support [44]. The former can be specified into experience-based information, unconventional information, and medical facts [45]. By contrast, emotional support involves a patient's emotions or feelings; for instance, physicians need to listen and talk about patients' concerns in a way that is helpful and reassuring. In terms of mental health, the emotional support may be more important than the

informational support. Therefore, it is also worthwhile to explore the type of social support that the physician online contribution provides for patients.

## Conclusions

To summarize, we investigated a novel online health care community in China, which could be regarded as a physician-patient communication platform. If this online health care community functions well, it could alleviate the hospital queuing problem and the problem of inadequate rural medical resources. However, the most important part of this community is the physicians: only when physicians are willing to actively participate does the online health care community have the chance to succeed. Thus, this paper focuses on the topic of physician online contribution.

This study makes several contributions. First, it is the first study to further our understanding of physician online contribution behavior by analyzing a large amount of real data collected from the most popular online health care community in China. Second, our findings can increase the understanding of physician online contribution behavior. We discovered that the averages of online contribution across 10 major specialty areas were different. Specifically, physicians in gynecology/obstetrics and pediatrics specialties are much more involved with the online health care community than others. In addition, physicians with more past online contributions, with higher review ratings, with lower clinic levels, who are not from the tertiary hospitals, and who are not from big cities expend more effort in the online health care community to share their medical knowledge and to help patients. Finally, we found that when physicians received more thank you letters (psychological rewards) or token gifts (material rewards), they were willing to do more the following month, regardless of their specialty areas. The influence of material reward is greater than that of psychological reward. We further found that to enhance online contribution, extreme rewards are marginally less effective than moderate ones. Therefore, our results provide a guide for online health care community managers to design a useful incentive mechanism to improve physician online contribution.

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## Conflicts of Interest

None declared.

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## Abbreviations

**SD:** standard deviation

**SE:** standard error

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**Original Paper**

# Association Between a Wider Availability of Health Information and Health Care Utilization in Vietnam: Cross-Sectional Study

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## Abstract

**Background:** The rapid and widespread development of mass media sources including the Internet is occurring worldwide. Users are being confronted with a flood of health information through a wide availability of sources. Studies on how the availability of health information has triggered users' interest in utilizing health care services remain limited within the Vietnamese population.

**Objective:** This study examined the associations between the wider availability of sources for health information and health care utilization in Vietnam after adjusting for potential confounding variables.

**Methods:** The data for this study were drawn from a cross-sectional study conducted over a 6-month period in Hue, a city in central Vietnam. The participants were 993 randomly selected adults aged between 18 and 60 years. Information was collected through face-to-face interviews on the types of information sources that were consulted, including traditional media (television), Internet, and health education courses, as well as the impact of such information on health care use (emergency department visits, hospitalizations, doctor visits). Multivariable logistic regression analyses were performed at a 95% confidence level.

**Results:** The prevalence of watching television, using the Internet, and attending health education courses to obtain health information were 50.9% (505/993), 32.9% (327/993), and 8.7% (86/993), respectively. After further adjustments for self-reported health status, the presence of health insurance, and monthly income, respondents who watched television and used the Internet to obtain health information were 1.7 times more likely to visit a doctor (television: adjusted odds ratio [AOR] 1.69, 95% CI 1.30-2.19; Internet: AOR 1.64, 95% CI 1.23-2.19), and also significantly associated with inpatient hospitalization ( $P=.003$ ).

**Conclusions:** The use of widely available mass media sources (eg, television and the Internet) to obtain health information was associated with higher health care utilization. How this interest in health-related information can be used so that it will have a beneficial effect on care-seeking behavior should be a topic of concern to further health promotion in developing countries.

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**KEYWORDS**

health care utilization; health information; mass media; Internet

## Introduction

Searching for health information is becoming more common and people no longer passively trust the advice of specialized physicians. The rapid development of digital media has facilitated an increase in the amount of health information that

the public can easily access. Traditional media sources, such as television, radio, and newspapers, have developed their medical sections to adapt to the public's concern over health issues [1]. In addition, there is a plethora of information available online and searching the Internet for health purposes has become common among the general public in recent years.

Approximately 60% of total Internet users in the US Health Information National Trends Survey reported using the Internet to search for health information [2]. Thus, compared with obtaining health information directly from a doctor, traditional media and Internet, which were generally identified as mass media sources, can provide diverse health information and allow the general population to confirm what they have heard, thereby contributing to improved decisions regarding their health [3,4].

Previous studies have examined the patterns of health care use within the Behavioral Model of Health Care Utilization [5]. The potential effect of seeking health information through mass media on the public's use of health care is a focus of health policy makers. Understanding the relationship between the use of health information sources and health care utilization is necessary because well-informed patients have a better ability to cope with diseases and to make good decisions. A relevant study has suggested that the likelihood that an individual would visit a physician increases by approximately 10% for every 1-hour increment spent searching the Internet for medical information [6]. However, other studies have reported a negative or lack of effect between the use of mass media to obtain medical information and the number of outpatient clinic visits. Based on a survey in Japan, nearly 90% of the respondents thought that their Internet use was not associated with the frequency at which they visited outpatient clinics or made phone calls to their doctors to inquire about health-related issues [7]. Thus, the effect of using mass media sources to obtain health-related information on the actual use of health services remains debatable.

Vietnam is a developing country in Southeast Asia that has successfully placed the growth of information and communication technology industries near the forefront of its economic priorities over the past 15 years. Broadcast media in Vietnam has been undergoing modernization on a daily basis. In parallel, the number of Internet users has rapidly increased from approximately 33 million in 2013 to 44.4 million in 2015 and is presently estimated to reach 65.7 million in 2021 [8-10]. These users are being confronted with a burst of health-related information through a wider availability of sources. Social programs on television and the Internet emphasize not only socioeconomic policy-related news and entertainment, but also health education programs to adapt to the public's increasing interest in seeking health information and using health services. Vietnam's government-run TV stations (national and provincial) always have health education programs at least once per week and sometimes give updates on health news, such as infectious disease epidemics, treatment, etc, in the daily news. However, studies on how the surging availability of information related to medicine affects the decisions of users to utilize health care services remain limited for the Vietnamese population. Thus, the aim of this study was to examine the association between the wider availability of health information sources and health care utilization after controlling for potential confounding variables.

## Methods

### Study Area

The study was conducted in the city of Hue, which is in the central area of Thua Thien-Hue Province in the central region of Vietnam. The city of Hue has 27 administrative quarters, and its population was estimated to be approximately 354,556 in 2015.

### Study Design

We conducted a cross-sectional survey from May to September 2015, using a structured questionnaire that was administered to adults aged between 18 and 60 years.

The participants were selected based on the following criteria:

1. A multistage, stratified cluster random sampling design was used. First, six quarters were randomly selected from among the 27 quarters of the city of Hue (three quarters were selected from urban areas, and three quarters were selected from suburban areas). A total of 30 subgroups were randomly selected from 112 small administrative units of six quarters in the survey (ie, five subgroups per quarter). Second, approximately 18 to 60 adults in each subgroup were systematically selected from a booklet listing the households.
2. The inclusion criteria were age between 18 and 60 years, a history of living in the city of Hue for more than 6 months, the ability to communicate or read, and the ability to meet with the investigators.
3. The exclusion criteria were the presence of mental disorders, cognitive disorders, or an unwillingness to participate.

A total of 1005 participants agreed to participate and the valid response rate was 98.52% (1005/1020). The 12 senior medical students recruited had 1 day of thorough training before visiting selected households. They visited households on weekends and did face-to-face interviews of the individuals. Finally, 993 participants were included in the analysis (12 participants with missing values were excluded).

### Measurement

This survey contained a set of questions about participant's characteristics, the availability of health information sources, health care utilization, and others. The questionnaire was developed from the Health Literacy Survey-Asia-Questionnaire (HLS-Asia-Q), which followed the methodology of the full version of the European HLS Questionnaire (HLS-EU-Q) [11] and has been validated in Asia including Vietnam [12]. This questionnaire included minor questions vetted by public health experts so that it would fit the local context, and then it was pretested for readability and understandability by experienced survey researchers before use in the field.

Demographic and socioeconomic characteristics were identified via the questionnaire, including age (years), sex (male, female), marital status (never married vs married, divorced, or widowed), highest education attainment in the formal education system (junior high school and below, senior high school, or university and above), monthly income in local currency Vietnam dong (1 million VND=US \$44.50; <3 million VND, 3-7 million VND,

or >7 million VND), and the presence of health insurance (yes/no). Health-related characteristics were measured via self-reporting. The participants were asked to rate their overall health status using a five-point Likert scale ranging from 1=very bad to 5=very good. The self-reported health statuses were recorded as “poor,” “moderate,” or “good.”

The availability of health information sources, including mass media sources (watching television, Internet use) and health education courses, was measured via single self-reported items and separate questions (eg, “How frequently do you...?”) with possible responses of “often,” “sometimes,” “rarely,” and “never.” We defined “watching television to obtain health information” as watching medical-related TV series and using the Internet to obtain health information through a computer or mobile phone to search for medical information or update the health news on a Web browser or social networking service. The frequencies were dichotomized as “yes,” including often/sometimes, and “no,” including rarely/never (reference).

Health care utilization was defined as ambulatory visits to health care facilities including emergency department visits, hospitalizations, and doctor visits based on the responses to separate questions such as “How many times have you visited...in the last 12 months?” with possible responses of “0,” “1-2 times,” “3-5 times,” and “6 times or more.” These variables were recorded and classified as either none or  $\geq 1$  time.

## Statistical Analysis

The percentage of participants using mass media sources (television, Internet) and the attendance of health education courses to obtain health information were calculated.

During the descriptive analysis, categorical variables were summarized using proportions and then presented in tables. A bivariate analysis was performed to test for associations between the dependent variable “health care utilization” and other independent variables.

Multivariable logistic regression analysis by the enter method was done to evaluate the independent association between the outcome variables (emergency department visits, hospitalizations, doctor visits) and the availability of health information sources. For each outcome variable of health care utilization, we separately entered the independent variables (eg, watching television, Internet use, and attending health education) after adjustments for the possible influence of the self-reported health status, monthly income, and the presence of health insurance status in the logistic regression model. The Hosmer-Lemeshow goodness-of-fit test with  $P>.05$  was used to assess the goodness-of-fit model. Odds ratios (ORs) assessed the strength of the associations; 95% confidence intervals and a  $P$  value of less than .05 were used for significance testing.

The data were identified and analyzed using SPSS version 23.0.

## Ethical Considerations

This study was approved by the Institutional Review Board of Hue University of Medicine and Pharmacy. The purpose of the

study was explained on the first page of the questionnaire. All the enrolled participants agreed to cooperate with the investigators after the purpose of the research was explained, and responses were regarded as informed consent.

## Results

### Participant Characteristics

The characteristics of the 993 survey participants included in our analysis are summarized in Table 1. The mean age was 39.7 (SD 12.7) years, 57.9% (575/993) were female, most were married (75.3%, 748/993), and 49.2% (504/993) had less than a junior high school education. In terms of wages, 51.4% (843/993) of respondents reported earning less than 3 million VND per month. A “poor” health status was reported by 8.0% (79/993) of the respondents; 84.9% (510/993) of participants had health insurance.

### Frequency of Wider Availability of Health Information Sources

Table 1 also shows the frequency of the availability of health-related information from various sources. Regarding watching medical-related TV programs, 43.4% (431/993) of the participants reported that they sometimes used such viewing for health purposes, and 7.5% (74/993) of them reported that they often used it for health purposes. The frequency of Internet use for obtaining health information was reported as sometimes by 26.2% (260/993) of the respondents and as often by 6.7% (67/993). Only 8.7% (86/993) of participants reported that they sometimes or often attended health education courses to obtain health information.

### Health Care Utilization and a Wider Availability of Information Sources for Health Purposes

In a bivariate analysis, we found that self-reported health status, the presence of health insurance, and monthly income were associated with emergency department visits, hospitalizations, and doctor visits (see Table 2). Self-reported health status was significantly associated with visiting health facilities including emergency department visits ( $P<.001$ ), inpatient hospitalizations ( $P=.02$ ), and doctor visits ( $P=.001$ ). Those having health insurance had higher likelihoods of hospitalization (OR 1.93, 95% CI 1.16-3.20) and doctor visits (OR 3.15, 95% CI 2.16-4.60). Respondents with a monthly income of greater than 7 million VND were 2.4 times more likely to visit a doctor compared to those who had a monthly income of less than 3 million VND (OR 2.44, 95% CI 1.42-4.17).

Table 2 also shows an association between the availability of health information sources and health care visits. Obtaining health information by watching television or by using the Internet were significantly associated with inpatient hospitalization ( $P<.001$  and  $P=.007$ , respectively) and doctor visits ( $P<.001$ ). There was also a significant association between attending health education courses and inpatient hospitalization doctor visits ( $P=.002$  and  $P=.02$ ).

**Table 1.** Participant characteristics by health care utilization (N=993).

Participant characteristics	Total, n (%)	Emergency visit, n (%)	Hospitalization, n (%)	Doctor visit, n (%)
<b>Age (years)</b>				
18-24	171 (17.2)	8 (13.6)	33 (16.3)	86 (16.7)
25-34	195 (19.6)	13 (22.0)	47 (23.2)	101 (19.6)
35-44	221 (22.3)	13 (22.0)	34 (16.7)	98 (19.1)
45-54	243 (24.5)	15 (25.4)	46 (22.6)	134 (26.1)
55-60	163 (16.4)	10 (17.0)	43 (21.2)	95 (18.5)
<b>Gender</b>				
Male	418 (42.1)	22 (37.3)	81 (39.9)	189 (36.8)
Female	575 (57.9)	37 (62.7)	122 (60.1)	325 (63.2)
<b>Legal marital status</b>				
Unmarried	232 (23.4)	16 (27.1)	43 (21.2)	110 (21.4)
Married	748 (75.3)	43 (72.9)	157 (77.3)	401 (78.0)
Separated/divorced/widowed	13 (1.3)	0 (0.0)	3 (1.5)	3 (0.6)
<b>Education</b>				
Below junior high school	489 (49.2)	32 (54.2)	86 (42.4)	220 (42.8)
Senior high school	262 (26.4)	17 (28.8)	56 (27.6)	148 (28.8)
Above senior high school	242 (24.4)	10 (17.0)	61 (30.0)	146 (28.4)
<b>Monthly income (VND)<sup>a</sup></b>				
<3 million	510 (51.4)	37 (62.7)	105 (51.7)	252 (49.0)
3-7 million	412 (41.5)	20 (33.9)	80 (39.4)	212 (41.3)
>7 million	71 (7.1)	2 (3.4)	18 (8.9)	50 (9.7)
<b>Self-reported health status</b>				
Good	298 (30.0)	9 (15.3)	56 (27.6)	142 (27.6)
Moderate	616 (62.0)	37 (62.7)	122 (60.1)	317 (61.7)
Poor	79 (8.0)	13 (22.0)	25 (12.3)	55 (10.7)
<b>Health insurance</b>				
Yes	843 (84.9)	51 (86.4)	184 (90.6)	471 (91.6)
No	150 (15.1)	8 (13.6)	19 (9.4)	43 (8.4)
<b>Watching medical-related TV series</b>				
Often	74(7.5)	4 (6.8)	33 (16.3)	52 (10.1)
Sometimes	431(43.4)	28 (47.5)	93 (45.8)	250 (48.6)
Rarely	295(29.7)	12 (20.3)	49 (24.1)	140 (27.3)
Never	193(19.4)	15 (25.4)	28 (13.8)	72 (14.0)
<b>Getting medical-related information from the Internet</b>				
Often	67 (6.7)	3 (5.1)	24 (11.8)	50 (9.7)
Sometimes	260 (26.2)	15 (25.4)	59 (29.1)	147 (28.6)
Rarely	189 (19.0)	8 (13.6)	33 (16.3)	96 (18.7)
Never	477 (48.1)	33 (55.9)	87 (42.8)	221 (43.0)
<b>Attending health education courses</b>				
Often	9 (0.9)	0 (0.0)	6 (3.0)	11 (2.1)
Sometimes	77 (7.8)	3 (5.1)	23 (11.3)	41 (8.0)
Rarely	115 (11.6)	4 (6.8)	18 (8.9)	52 (10.1)

Participant characteristics	Total, n (%)	Emergency visit, n (%)	Hospitalization, n (%)	Doctor visit, n (%)
Never	792 (79.7)	52 (88.1)	156 (76.8)	410 (79.8)

<sup>a</sup>VND: Vietnamese Dong. 1 million VND=US \$44.50.

**Table 2.** Association between health care utilization and respondents' characteristics plus the availability of health information sources: unadjusted odds ratios.

Participants' characteristics	Emergency visit		Hospitalization		Doctor visit	
	OR (95% CI)	P	OR (95% CI)	P	OR (95% CI)	P
<b>Self-reported health status</b>						
Good	Ref		Ref		Ref	
Moderate	2.05 (0.98-4.31)	.06	1.07 (0.75-1.52)	.72	1.17 (0.88-1.54)	.28
Poor	6.33 (2.60-15.42)	<.001	2.00 (1.15-3.49)	.02	2.52 (1.48-4.28)	.001
<b>Health insurance</b>						
No	Ref		Ref		Ref	
Yes	1.14 (0.53-2.46)	.73	1.93 (1.16-3.20)	.01	3.15 (2.16-4.60)	<.001
<b>Monthly income (VND)<sup>a</sup></b>						
<3 million	Ref		Ref		Ref	
3-7 million	0.65 (0.37-1.14)	.14	0.93 (0.67-1.29)	.66	1.09 (0.84-1.41)	.54
>7 million	0.37 (0.09-1.57)	.18	1.31 (0.74-2.33)	.34	2.44 (1.42-4.18)	.001
<b>Watching medical-related TV series</b>						
No	Ref		Ref		Ref	
Yes	1.16 (0.68-1.96)	.59	1.78 (1.29-2.43)	<.001	1.94 (1.51-2.49)	<.001
<b>Getting medical-related information from the Internet</b>						
No	Ref		Ref		Ref	
Yes	0.89 (0.50-1.57)	.68	1.55 (1.13-2.13)	.007	1.67 (1.28-2.18)	<.001
<b>Attending health education courses</b>						
No	Ref		Ref		Ref	
Yes	0.76 (0.27-2.14)	.60	2.14 (1.33-3.45)	.002	1.73 (1.09-2.74)	.02

<sup>a</sup>VND: Vietnamese Dong. 1 million VND=US \$44.50.

After adjusting for potential confounding variables using multivariable logistic regression for all 993 participants, we found that those obtaining health information by watching television or using the Internet were 1.7 times more likely to have an inpatient hospitalization (television: adjusted OR [AOR] 1.69, 95%CI 1.22-2.34; Internet: AOR 1.62, 95% CI 1.16-2.27)

and visit a doctor (television: AOR 1.69, 95% CI 1.30-2.19; Internet: AOR 1.64, 95% CI 1.23-2.19), and those who attended health education courses were 2.1 times more likely to have inpatient hospitalizations (AOR 2.09, 95% CI 1.29-3.40) (see Table 3).

**Table 3.** Multivariable association between health care utilization and respondents' characteristics plus the availability of health information sources: adjusted odds ratios.

Model	Emergency visit		Hospitalization		Doctor visit	
	AOR <sup>a</sup> (95% CI)	P	AOR (95% CI)	P	AOR (95% CI)	P
<b>Model 1</b>						
<b>Self-reported health status</b>						
Good	Ref		Ref		Ref	
Moderate	2.00 (0.95-4.21)	.07	1.09 (0.76-1.56)	.63	1.27 (0.95-1.69)	.10
Poor	5.75 (2.31-14.28)	<.001	2.08 (1.17-3.70)	.01	3.00 (1.72-5.23)	<.001
<b>Health insurance</b>						
No	Ref		Ref		Ref	
Yes	1.19 (0.54-2.62)	.66	1.70 (1.01-2.86)	.046	2.79 (1.89-4.13)	<.001
<b>Monthly income (VND)<sup>b</sup></b>						
<3 million	Ref		Ref		Ref	
3-7 million	0.77 (0.43-1.38)	.38	0.93 (0.67-1.31)	.69	1.08 (0.82-1.42)	.58
>7 million	0.42 (0.10-1.81)	.24	1.15 (0.63-2.07)	.65	2.13 (1.22-3.74)	.008
<b>Watching medical-related TV series</b>						
No	Ref		Ref		Ref	
Yes	1.24 (0.72-2.13)	.45	1.69 (1.22-2.34)	.002	1.69 (1.30-2.19)	<.001
<b>Model 2</b>						
<b>Self-reported health status</b>						
Good	Ref		Ref		Ref	
Moderate	2.07 (0.98-4.38)	.06	1.18 (0.83-1.69)	.36	1.38 (1.03-1.84)	.03
Poor	6.06 (2.39-15.35)	<.001	2.39 (1.33-4.27)	.003	3.38 (1.93-5.92)	<.001
<b>Health insurance</b>						
No	Ref		Ref		Ref	
Yes	1.24 (0.57-2.70)	.60	1.84 (1.10-3.08)	.02	3.00 (2.04-4.43)	<.001
<b>Monthly income (VND)</b>						
<3 million	Ref		Ref		Ref	
3-7 million	0.77 (0.43-1.38)	.39	0.94 (0.67-1.31)	.70	1.08 (0.83-1.42)	.57
>7 million	0.41 (0.09-1.80)	.24	1.12 (0.61-2.03)	.72	2.09 (1.19-3.67)	.01
<b>Getting medical-related information from the Internet</b>						
No	Ref		Ref		Ref	
Yes	1.21 (0.66-2.20)	.54	1.62 (1.16-2.27)	.005	1.64 (1.23-2.19)	.001
<b>Model 3</b>						
<b>Self-reported health status</b>						
Good	Ref		Ref		Ref	
Moderate	2.01 (0.95-4.24)	.07	1.11 (0.78-1.59)	.01	1.29 (0.97-1.72)	<.001
Poor	5.73 (2.30-14.23)	<.001	2.07 (1.17-3.67)	.56	2.93 (1.69-5.09)	.08
<b>Health insurance</b>						
No	Ref		Ref		Ref	
Yes	1.26 (0.58-2.76)	.56	1.83 (1.09-3.06)	.02	3.04 (2.07-4.48)	<.001
<b>Monthly income (VND)</b>						
<3 million	Ref		Ref		Ref	

Model	Emergency visit		Hospitalization		Doctor visit	
	AOR <sup>a</sup> (95% CI)	P	AOR (95% CI)	P	AOR (95% CI)	P
3-7 million	0.79 (0.44-1.42)	.44	0.92 (0.65-1.29)	.62	1.08 (0.83-1.42)	.56
>7 million	0.44 (0.10-1.90)	.27	1.30 (0.73-2.35)	.38	2.43 (1.40-4.22)	.002
<b>Attending health education courses</b>						
No	Ref		Ref		Ref	
Yes	0.79 (0.28-2.28)	.67	2.09 (1.29-3.40)	.003	1.57 (0.98-2.50)	.06

<sup>a</sup>Adjusted for self-reported health status, presence of health insurance, and monthly income.

<sup>b</sup>VND: Vietnamese Dong. 1 million VND=US \$44.50.

## Discussion

### Principal Finding

This study revealed the effect of a wider availability of mass media sources (television, Internet) for health information on health care utilization. We found that television was still a commonly reported source of health information and that the Internet was rapidly becoming a popular source of health information among Vietnamese adults. After controlling for health status, the presence of health insurance, and monthly income using a multivariable logistic regression analysis, the use of mass media sources for health information was found to be associated with higher health care utilization, especially the odds of doctor visits.

We realized that people continue to prefer traditional media (eg, television) to obtain health information, although an increasing number of people also use the Internet for health purposes [7,13]. Generally, radio is also identified as a traditional medium. However, it was observed that Vietnamese utilization of radio for news was down marginally from 27.6% in 2012/2013 to 24.8% in 2015 and that AM radio was used weekly by 3.8% of Vietnamese and shortwave by 1% [14,15]. This traditional medium is not commonly used to obtain health information. Thus, this study only focused on the impact of television as a traditional medium on health care utilization. The majority of participants in this study used television (50.9%) as a health information source, although the Internet was also used as a source of health information (32.9%); health education courses were also available. Comparing online programs related to health information, which appear to adapt to users' general needs, and traditional health education channels is important. Similar findings regarding the prevalence of users watching medical-related television programs have been observed in Hong Kong and Japan [7,16]. On the other hand, we found that the prevalence of using the Internet for health information in Vietnam was similar or higher than that in other Asian studies in Hong Kong (30.6% in 2009, 38.2% in 2010, and 38.0% in 2012) [16] and Japan (24% in 2007) [7] and lower than that in the United States (58% in 2005, 71% in 2015) [2,17,18], Europe (52% in 2007) [19], and Poland (66.7% in 2012) [20]. Technology advancement in recent times has widely contributed in the improvement of health information dissemination not only through delivery of key health messages, but also enabling interactions among users through the different kinds of mass media.

Since the economic reform of Vietnam (known as *Doi Moi*) in 1986, the country has undergone rapid growth and an improvement in living standards in general, with more equal access to health care services in particular. Health care utilization represents a complex picture in the context of the rapidly developing economic situation and globalization in Vietnam. Self-treatment is still common in Vietnam, accounting for 40% to 60% of all treatments [21,22], although the Ministry of Health has reported overcrowding in hospitals, which have been operating at nearly 150% of their capacity. The size of the health care workforce in Vietnam is relatively small compared with other countries, based on the World Health Organization's standard estimated number of health workers needed to provide adequate primary care coverage, which is at least 2.5 medical staff per 1000 population [23]. The number of physicians per 1000 population in Vietnam was 1.19 in 2013, whereas it was 3.03 in Japan in 2012 and 3.27 in Australia in 2011 [24]. Despite the mobilization of the private sector resources for health services and improvements in the efficiency of health systems in recent years [25], there remains a lack of health care services, insufficient public health education, no control over pharmaceutical promotions, and a lack of efficient drug policies and regulations. Hence, both the underuse of health care services and overcrowding in central hospitals are simultaneously present in Vietnam.

In this context, improving the utilization of health care services among residents depends on not only the availability and quality of services, but also the preferences of users, which are based on their experiences, health status, socioeconomic characteristics, and the availability of health information. The utilization of health care services appears to differ according to the self-reported health status, the presence of health insurance, household economic situation, similar to observations in previous studies conducted in Vietnam and other countries [21,26-28]. In this study, differences in health care utilization, including emergency department visits, hospitalizations, and doctor visits, were observed among self-reported health status subgroups and health insurance users; moreover, the group with higher monthly income of more than 7 million VND had a higher frequency of doctor visits than the poorer groups, but significant differences in the frequency of emergency department and inpatient visits were not observed.

The demand for health care expands from seeking health information to utilizing the health care facilities. We were impressed by the effect of a wider availability of mass media

sources for health information on the frequency of hospitalization and doctor visits even after adjustments for the self-reported health status, the presence of health insurance, and monthly income. The use of mass media sources (eg, television) and the Internet to obtain health information was associated with higher health care utilization among the general public. Obtaining information through these mass media sources to increase health care knowledge, attitudes, and suitable health care use is expected to be important for health care promotion [29,30], particularly for reducing self-treatment in Vietnam, although a gap between the quality and quantity of health services and the demand for health care continues to exist.

Mass media sources could potentially play a role in raising awareness about health care services and in shaping the perceptions of health care and related decision-making [30,31]. Similar findings in previous reports provide strong evidence to support this point. In 2008, Lee et al [1] reported that the increasing use of the Internet was correlated with an increase in outpatient clinic visits after controlling for age and sex in a data analysis. Other authors have also elucidated a significant association between use of health information technology and health services use [29,31,32]. First, we recognized that the availability of health information in mass media sources has triggered the health care interest of the general population [33]. People needed more help from health care professionals with interpreting and understanding the health information they obtained. Medical knowledge obtained from the Internet, in particular, might not be as reliable as information published in academic journals [34] or is less likely to be accredited by medical professors. With a multitude of messages available through a wide variety of mass media sources, inconsistencies can lead to confusion among audiences [35]. As a result, people who use mass media sources might be more likely to visit doctors, especially as outpatients, to clarify and interpret health information. Second, other studies have suggested that people seeking health information through mass media sources are more likely to evaluate themselves as having poor health and may have a greater tendency to seek a doctor's advice regarding their health status [6,31]. Therefore, physicians may need to spend additional time discussing medical topics, interpreting symptoms or health information, and assuring patients.

In addition, based on the multivariable logistic regression analysis, there was also significant association between use of available health information through health education courses

and inpatient hospitalization ( $P=.003$ ). The availability of health information through community health workers is a notable strategy to improve health care utilization. To further support health education in the community, the Ministry of Health through Circular 07 declared that every health worker, regardless of where they work, should receive at least 24 hours of updated professional training [36,37] to improve the quality of health worker and skill to transmit health information to the public. However, there are challenges to focus on this resource to expand the interest in health information compared with more widely available mass media sources.

## Limitations

Although the results of this study extend what is already known and provide new data in the Vietnamese context by controlling for confounding variables, there are several study limitations. First, this cross-sectional study used a structured questionnaire requiring the participants to recall the frequency of use of mass media sources to obtain health information and health care utilization and thus cannot speculate on the order of causality unlike a cohort study design and a recall bias might have affected the results. The assessment would have been more reliable if self-reported information and clinical examinations or health record profiles had been integrated. To ensure the quality of data, we provided the interviewers with rigorous training on interviewing techniques and continually monitored the data quality during the fieldwork process. Second, the data were only collected in one place (city of Hue) and might not be representative of the whole country. Further study involving a nationally representative cohort is needed to provide comprehensive evidence. Finally, factors concerning the quality of health information obtained from mass media sources and used by participants were not examined in this study.

## Conclusions

Notwithstanding the previously mentioned limitations, this study found that a wider availability of mass media sources for health information was associated with higher health care utilization. The diverse nature of health information available through mass media sources might play an important role in the frequency of clinic visits. Despite the gap between demand for health care and the quality of health care services, expansion of interest in health care is likely to be useful for further promotion of health in developing countries.

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## Conflicts of Interest

None declared.

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## Abbreviations

**AOR:** adjusted odds ratio

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Original Paper

# Impact of an Electronic Health Record-Integrated Personal Health Record on Patient Participation in Health Care: Development and Randomized Controlled Trial of MyHealthKeeper

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## Abstract

**Background:** Personal health record (PHR)-based health care management systems can improve patient engagement and data-driven medical diagnosis in a clinical setting.

**Objective:** The purpose of this study was (1) to demonstrate the development of an electronic health record (EHR)-tethered PHR app named MyHealthKeeper, which can retrieve data from a wearable device and deliver these data to a hospital EHR system, and (2) to study the effectiveness of a PHR data-driven clinical intervention with clinical trial results.

**Methods:** To improve the conventional EHR-tethered PHR, we ascertained clinicians' unmet needs regarding PHR functionality and the data frequently used in the field through a cocreation workshop. We incorporated the requirements into the system design and architecture of the MyHealthKeeper PHR module. We constructed the app and validated the effectiveness of the PHR module by conducting a 4-week clinical trial. We used a commercially available activity tracker (Misfit) to collect individual physical activity data, and developed the MyHealthKeeper mobile phone app to record participants' patterns of daily food intake and activity logs. We randomly assigned 80 participants to either the PHR-based intervention group (n=51) or the control group (n=29). All of the study participants completed a paper-based survey, a laboratory test, a physical examination, and an opinion interview. During the 4-week study period, we collected health-related mobile data, and study participants visited the outpatient clinic twice and received PHR-based clinical diagnosis and recommendations.

**Results:** A total of 68 participants (44 in the intervention group and 24 in the control group) completed the study. The PHR intervention group showed significantly higher weight loss than the control group (mean 1.4 kg, 95% CI 0.9-1.9;  $P<.001$ ) at the final week (week 4). In addition, triglyceride levels were significantly lower by the end of the study period (mean 2.59 mmol/L, 95% CI 17.6-75.8;  $P=.002$ ).

**Conclusions:** We developed an innovative EHR-tethered PHR system that allowed clinicians and patients to share lifelog data. This study shows the effectiveness of a patient-managed and clinician-guided health tracker system and its potential to improve patient clinical profiles.

**Trial Registration:** ClinicalTrials.gov NCT03200119; <https://clinicaltrials.gov/ct2/show/NCT03200119> (Archived by WebCite at <http://www.webcitation.org/6v01HaCdd>)

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## KEYWORDS

health records, personal; lifelog data; lifestyle management; clinical intervention; health care service; electronic health records; mobile health; telemedicine; clinical trial

## Introduction

The Precision Medicine Initiative (PMI) is a nationwide project in the United States that aims to build a longitudinal cohort representative of the American population by collecting samples and data from 1 million participants [1,2]. Precision medicine focuses on identifying approaches that will be effective for patients, based on genetic, environmental, and lifestyle factors. In 2016, US \$130 million was allocated to the US National Institutes of Health to build a national, large-scale research participant group (cohort), and US \$70 million was allocated to the US National Cancer Institute to lead efforts in cancer genomics as part of the PMI for Oncology [1,3]. The PMI was launched as part of this initiative, and the All of Us Research Program [4] is a key element of the PMI project. This research program aims to collect the biological, environmental, and behavioral data generated by each participant to gain better insights into individualized care perspectives.

Lifelog patient-generated health data, considered important for PMI implementation, form the next frontier in patient engagement and customized health care [5,6]. As indicated by the name, patient-generated health data require the participation of the patient. Through the availability of numerous devices, and mobile apps compatible with these devices, patients can collect their own health-related lifestyle data, which can be aggregated with their clinical data into their personal health file. This aggregate of lifestyle and clinical data stored in the personal health file is termed lifelog data.

Unfortunately, it is very difficult to accumulate lifestyle data such as daily dietary intake, sleep log, and stress in a longitudinal record. Several studies have been conducted in health care using data from the personal health record (PHR) and its related devices to verify its usability and feasibility [7-12]. Health care apps that are compatible with mobile devices and can collect personal health data serve as tools to improve patient adherence to self-management in a variety of diseases. However, they have limited utility for long-term use, owing to the additional patient burden created by lack of expertise and the absence of professional oversight for evaluation of progress [12-17]. Therefore, a significant need for an intermediate model has been emerging, in which patients and medical staff communicate with each other, ultimately increasing patient adherence for health promotion purposes.

In a previous study [18], we showed that patients with chronic diseases are more likely to use a PHR system that is integrated into a comprehensive electronic health record (EHR). In addition, we showed that patients with a higher number of chronic diseases tend to use PHRs more actively, employing

the self-administered function. Our study was, to our knowledge, the first to determine factors affecting adherence to, and use of, a self-administered function of PHR tethered to a comprehensive EHR, which is an important determinant of active use of a PHR.

This study primarily aimed to determine whether patients would use a PHR app to record lifelog data and to ascertain the ease with which these data could be shared with clinicians during appointments. In addition, we sought to understand whether patients would use the PHR actively and voluntarily, and whether these data could improve clinical profiles. This study therefore aimed to demonstrate (1) the development of an EHR-tethered PHR system that can retrieve data from a wearable device, and (2) the efficacy of such a system paired with a lifelog data-driven intervention modality. In particular, as a further development of our previous studies, we constructed an EHR-tethered PHR module in an EHR-friendly hospital (where a comprehensive EHR system has been operated successfully for over 12 years) and designed a PHR interface based on the lifestyle data requirements of physicians in a clinical setting.

## Methods

### MyHealthKeeper: Improvement on Conventional Electronic Health Record-Tethered Personal Health Records

As the first hospital to attain Healthcare Information and Management Systems Society stage 7 status outside of North America, Seoul National University Bundang Hospital (SNUBH; Seongnam, Republic of Korea) introduced a comprehensive EHR system in all the divisions of the hospital in 2003, launching a related PHR service in 2013 [19]. The hospital has 1340 beds and over 5000 daily outpatients. A task force team was established to conduct a needs analysis and develop the MyHealthKeeper PHR module in this study site. To understand clinicians' unmet needs corresponding to PHR data, and to delineate the most important functionality to be incorporated into a PHR module, we employed a cocreation process.

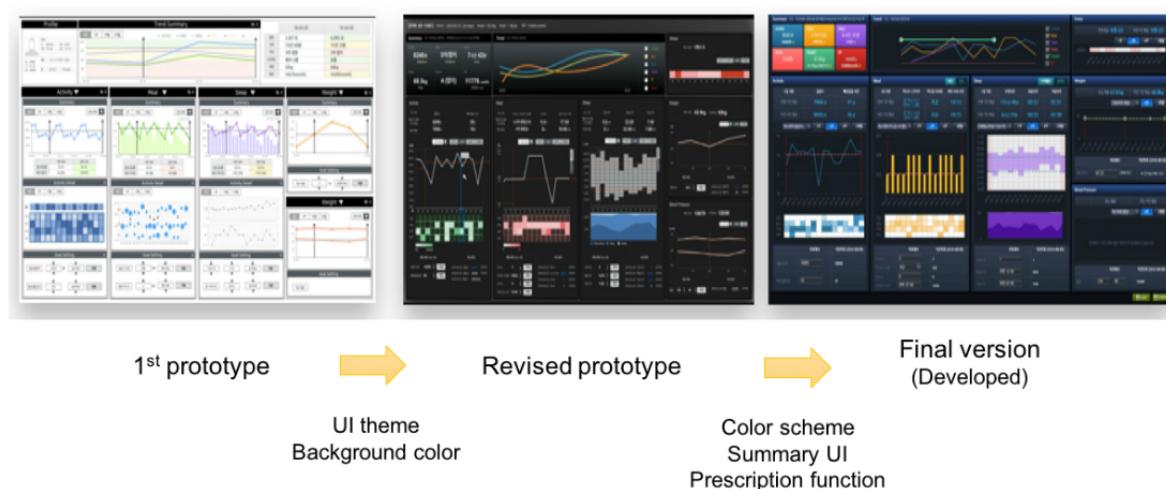
Cocreation is an alternative, collaborative, user experience-based research approach that increases the user's direct involvement [20,21]. In practice, this often takes the form of a collaborative workshop in which business stakeholders, researchers, designers, and end users explore a problem and generate solutions together, considering their different approaches, needs, and points of view. Thus, we conducted a 1-day collaborative workshop for the cocreation process to understand comprehensive PHR data requirements of clinicians, such as practical visualization factors that can reflect patient lifestyle and health behavior. A total of 15 researchers participated in the workshop: 2 clinicians, 4 informatics specialists, 3 developers, and 6 user experience

specialists. **Figure 1** shows the developmental process of our PHR module interface.

Participants were divided into 3 teams to share and analyze opinions regarding the PHR interface and design, organized according to the following questions: (1) What lifestyle-related data categories need to be displayed? (2) What is an effective visualization summary for the clinician? (3) How can we effectively deliver personal feedback in the form of a clinical prescription?

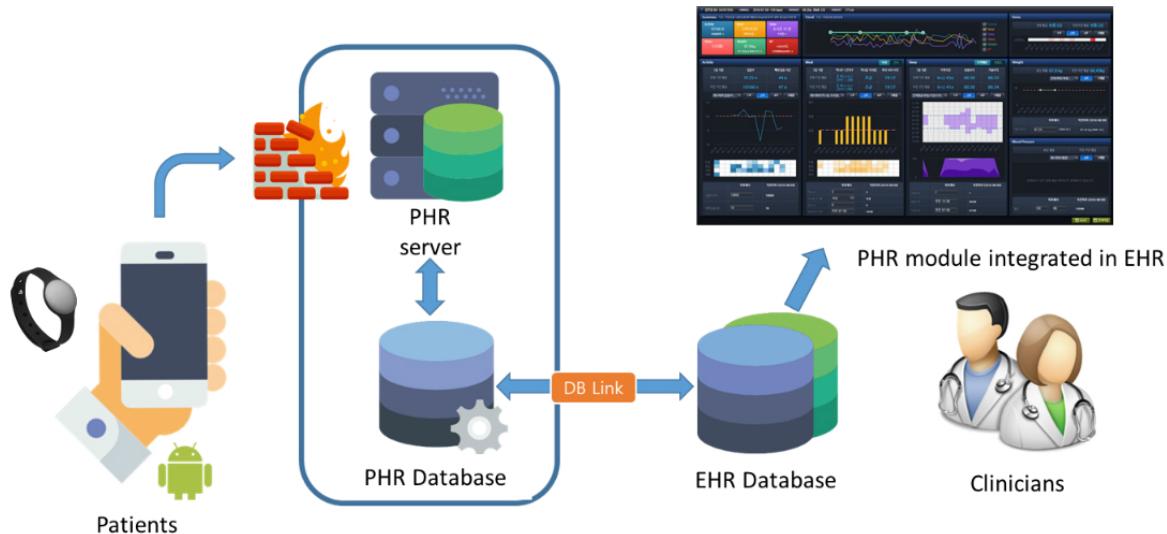
We used the answers to these questions to guide the creation of a final interface design prototype through idea clustering, screen sketching, continuous analysis, and improvement. **Figure 2**

**Figure 1.** Developmental process of the electronic health record-tethered personal health record system. UI: user interface.



**Figure 2.** MyHealthKeeper interface design.



**Figure 3.** Personal health record (PHR) data flow overview. DB: database; EHR: electronic health record.

The MyHealthKeeper interface design showed patient-generated lifestyle data in a graphical format on a clinician's EHR screen. Physical activity was reflected by step count and was visualized as a line graph with the day plotted on the x-axis and the total daily step count value plotted on the y-axis. A heat map was also displayed, with 4 rows depicting data pertaining to the morning, afternoon, evening, and nighttime, and columns pertaining to each day, as in the line graph. We set the default prescription value of daily activity step count to 10,000. We constructed the patient diet records and sleep log plots in the same manner as the activity plots. To visualize the sleep log, we chose a stacked area graph format rather than a heat map, as per clinicians' requirements. Weight and blood pressure change values were plotted as line graphs. Daily stress was summarized as a form of heat map graph. Each lifestyle-related health data plot contained a prescription section for the clinician, which allowed the clinician to specify a healthier daily routine for the patient, considering goals such as preventing weight gain, increasing physical movement, or increasing or decreasing the sleep period.

### MyHealthKeeper: Mobile App

We developed an Android operating system-based mobile phone app designed to collect health-related lifestyle data and tested it in an experimental patient group. The objective of using personal feedback coaching based on a mobile app and a wearable activity tracker is to lose weight for a healthy lifestyle. We designed an app compatible with a commercially available wearable activity device (Misfit Shine; Misfit Wearables Corporation, Burlingame, CA, USA), to collect daily activity data automatically [22].

The MyHealthKeeper app was composed of several logging pages named as follows: daily meal, physical exercise activity, sleep log, stress, blood pressure, and weight value. The main page of this app (Figure 4) showed the total amount of collected

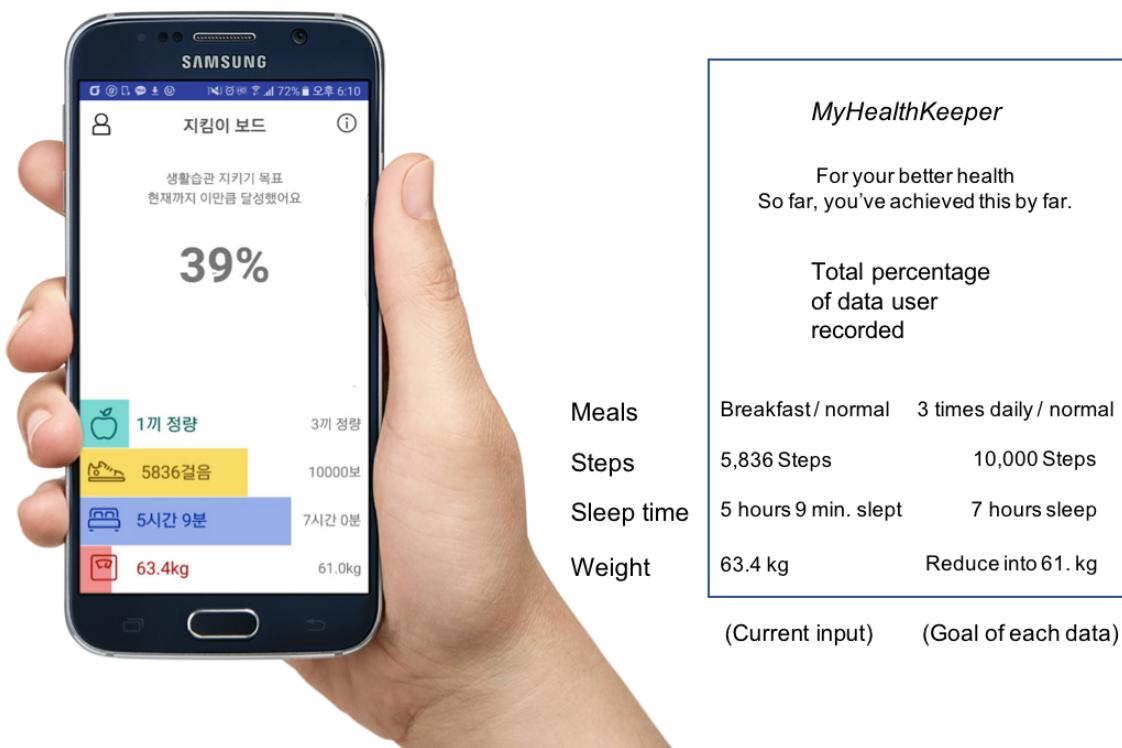
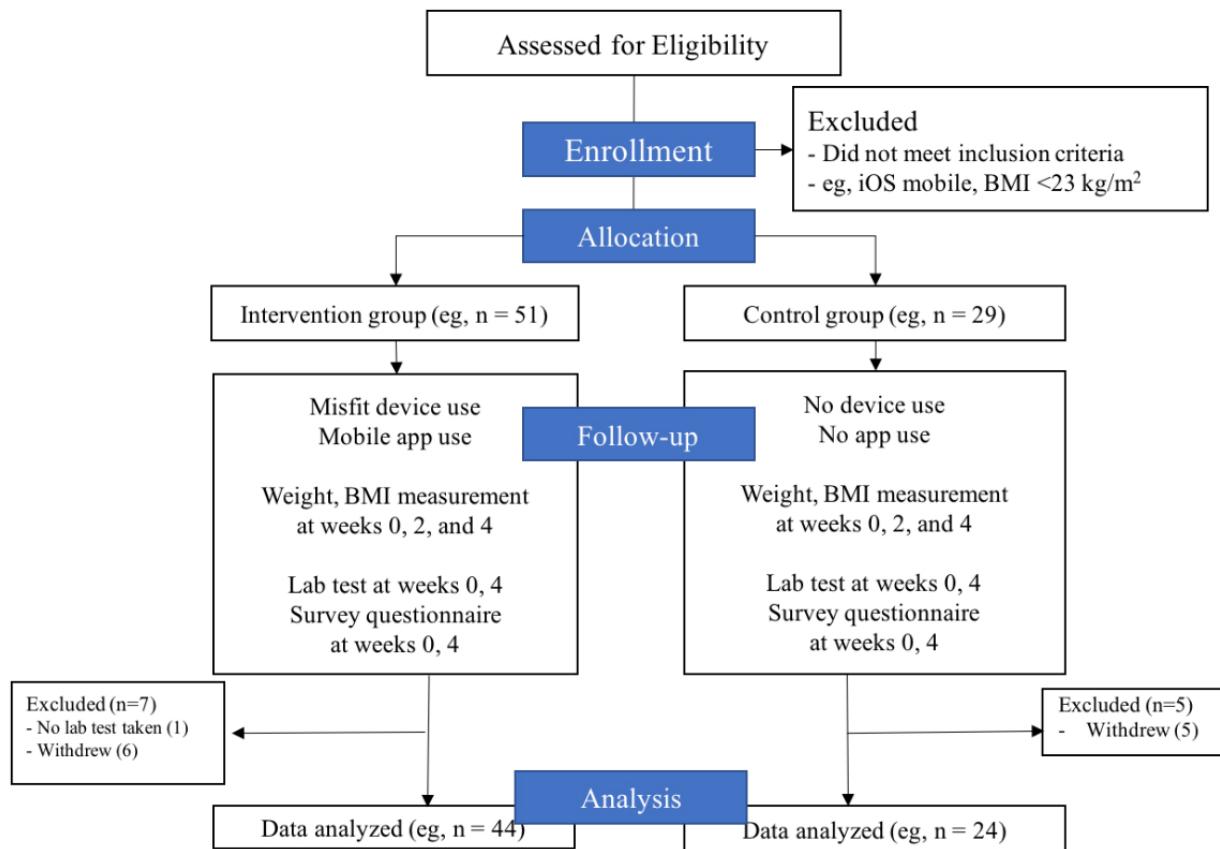
data at the top of the interface (eg, “39%”), current input data at the left side, and the goal of each lifestyle-related status at the right side. At any time, the intervention group participants could check their activity and dietary status with a mobile phone, and access food intake allowances remaining for the day and the amount of moderate- to vigorous-intensity physical activity needed to reach the daily goal. (See [Multimedia Appendix 1](#) for more app pages.)

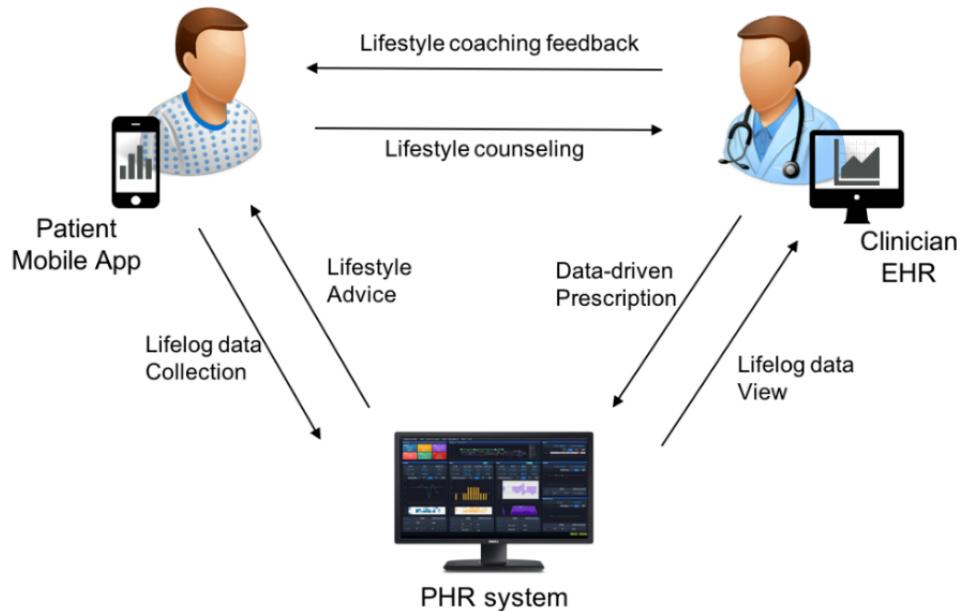
### Clinical Study Design and Participant Recruitment

Our whole study period was 8 months. System planning and the interface design workshop for gathering clinicians' opinions required 2 months. Implementation took 3 months, and after launching the system, the clinical trial was performed for 4 weeks. We conducted a prospective randomized clinical trial in 80 patients who visited the SNUBH outpatient clinic between the months of July and September 2016. We set the following inclusion criteria for enrollment in the trial: (1) patients who provided prior consent to complying with self-management, (2) patients without cardiopulmonary disease, cancer, or other acute diseases, and (3) patients with a body mass index (BMI) of over  $23 \text{ kg/m}^2$ . [Figure 5](#) describes the overall clinical trial study design.

We excluded patients who would not be able to use a mobile app and a wearable device and those who were pregnant. We obtained written informed consent from all participants. All study participants completed a paper-based survey, a laboratory blood test, a physical examination, and an opinion interview.

This study was approved by the SNUBH Institutional Review Board (B-1504-296-302), which was also registered with ClinicalTrials.gov (registration number: NCT03200119), and this study is reported in accordance with the Consolidated Standards of Reporting Trials (CONSORT)-EHEALTH checklist ([Multimedia Appendix 2](#)) [23].

**Figure 4.** MyHealthKeeper mobile app. Left: Korean version interface; right: English-translated description.**Figure 5.** Clinical trial study design.

**Figure 6.** Patient-clinician-system workflow. EHR: electronic health record; PHR: personal health record.

### Personal Health Record-Based Interventions

The main objective of this clinical trial was to analyze the effectiveness of personalized health care management by mobile app use and clinical coaching feedback with an EHR-integrated PHR module. To this end, we randomly assigned enrollees to 2 groups: a PHR-based mobile app and clinical intervention group, and a conventional treatment control group.

The first group (PHR intervention group) received the wearable device, the mobile app software, personal coaching, and the intervention based on the PHR module to encourage a healthy lifestyle. The participants were educated about lifestyle modifications needed to lose weight and were trained in the use of the Android operating system-based mobile phone app (designed to collect lifestyle data); **Figure 6** describes this workflow.

Individualized goals for diet and physical activity were prescribed for each participant by the clinician during a biweekly outpatient visit. The patient lifestyle data were displayed as a summary plot on the EHR interface accessed at the participating hospital and were reviewed by the clinician. Further lifestyle modification was encouraged and prescribed on the basis of the EHR-integrated PHR module. Clinicians made at least one comment for patients whenever they visited the outpatient clinic; therefore, a total of 88 feedback comments (2 visits per patient) or lifestyle health prescriptions were issued on the PHR module.

For example, a 36-year-old male patient visited our outpatient clinic. He was found to be prediabetic in his regular health checkup. He was obese (height 170 cm, weight 74 kg) and had a sedentary lifestyle because he was an office worker. His lipid profile was not good, with a triglyceride level of 13.6 mmol/L, indicating that he usually ate a lot of carbohydrates. At the first visit, his doctor found his daily step counts were below 4000 steps and he ate a lot between meals. Therefore, the doctor made the following written lifestyle health prescription: “Please cut down on every snack between meals and walk more than 10,000

steps every day.” Furthermore, the clinician set a lifestyle goal of a weight loss of at least 500 grams below his current weight by the next clinic visit (2 weeks later). The patient followed the doctor’s recommendations because he noticed that he could share his lifelog data with his doctor via the EHR-tethered PHR app. In fact, he had lost 600 grams by the next visit, and all the lifelog data were naturally integrated into his EHR via the PHR app.

The control group of patients did not receive the lifestyle modification app or the wearable device. They received conventional care pertaining to lifestyle modification for achieving weight loss goals during the 4-week study period.

### Clinical Study Outcome Measure

The primary outcome measure of this clinical trial was weight change. Body weights before and after the PHR-based clinical intervention were recorded and analyzed. We defined BMI as the body mass divided by the square of the body height, expressed in units of  $\text{kg}/\text{m}^2$ , and we analyzed the difference in BMI before and after the study at the end of the study period. We analyzed the secondary outcomes of the study—changes in blood biochemical parameters (cholesterol, triglycerides, high-density lipoprotein cholesterol, and low-density lipoprotein cholesterol)—for each participant. Any decrease in body weight during the study period (4 weeks) was defined as successful weight reduction. It is very important that the measurement be taken using the same method and in the same conditions to ensure uniformity between participants and in the same participant over time. In our study, a skilled nurse helped to measure the patient’s body weight in the hospital health checkup center with the conventional health checkup process (place, dress). Fasting body weight was measured for laboratory checkup.

### Statistical Analysis

Results are presented as mean (SD). We analyzed differences in various parameters between the PHR-based intervention

group and the control group using the chi-square test as appropriate. We used a paired *t* test to examine changes in primary or secondary outcomes in the 2 groups. Statistical analyses were performed using IBM SPSS version 18.0 (IBM Corporation), and  $P < .05$  was considered statistically significant.

## Results

We randomly assigned 80 participants to either the PHR-based intervention group ( $n=51$ ) or the control group ( $n=29$ ). After exclusions and withdrawals (Figure 5), 68 participants completed the study.

### Validation of the Personal Health Record System: Analysis of the Clinical Trial

Among the 68 enrolled patients who completed this study, 44 patients were assigned to the PHR intervention group and the

rest (24 patients) were assigned to the control group receiving conventional care. Table 1 and Table 2 show the demographic and baseline characteristics of study participants.

Our clinical trial study results revealed a significant change in participants' clinical profiles after using the PHR-based clinical intervention as guided by the physician. The PHR intervention group participants who used the MyHealthKeeper mobile app every day and received lifestyle feedback counseling from the clinician showed significantly larger changes in weight, BMI, and triglyceride values than those in the control group (Table 3). The PHR intervention group lost significantly more weight than the control group (mean 1.4 kg, 95% CI 0.9–1.9;  $P < .001$ ; Figure 7). Figure 7 depicts changes in biochemical parameters such as BMI (mean 0.4 kg/m<sup>2</sup>, 95% CI 0.3–0.6;  $P = .000$ ) and triglyceride (mean 2.6 mmol/L, 95% CI 17.6–75.8;  $P = .002$ ) in the 2 groups during the study period.

**Table 1.** Demographic data of study participants ( $n=68$ ).

Characteristics	Intervention group ( $n=44$ )	Control group ( $n=24$ )	<i>P</i> value
Age (years), mean (SD <sup>a</sup> )	37.5 (8.7)	41.3 (11.2)	.30
<b>Sex, n (%)</b>			.68
Male	30 (68)	22 (92)	
Female	14 (32)	2 (8)	
<b>Education level, n (%)</b>			.64
High school degree	6 (14)	4 (17)	
College degree	32 (74)	15 (63)	
Master's or doctorate	5 (11)	5 (21)	
<b>Occupation, n (%)</b>			.13
Professional	10 (23)	7 (30)	
Office worker	15 (33)	10 (42)	
Self-employed	5 (11)	2 (8)	
Manufacturing or services	4 (9)	3 (13)	
Unemployed	10 (23)	1 (4)	
<b>Living status, n (%)</b>			.60
Living with someone	37 (84)	23 (96)	
Living alone	7 (16)	1 (4)	
<b>Marital status, n (%)</b>			.30
Single	11 (25)	2 (8)	
Married	33 (75)	22 (92)	

<sup>a</sup>SD: standard deviation.

**Table 2.** Baseline clinical profiles of study participants.

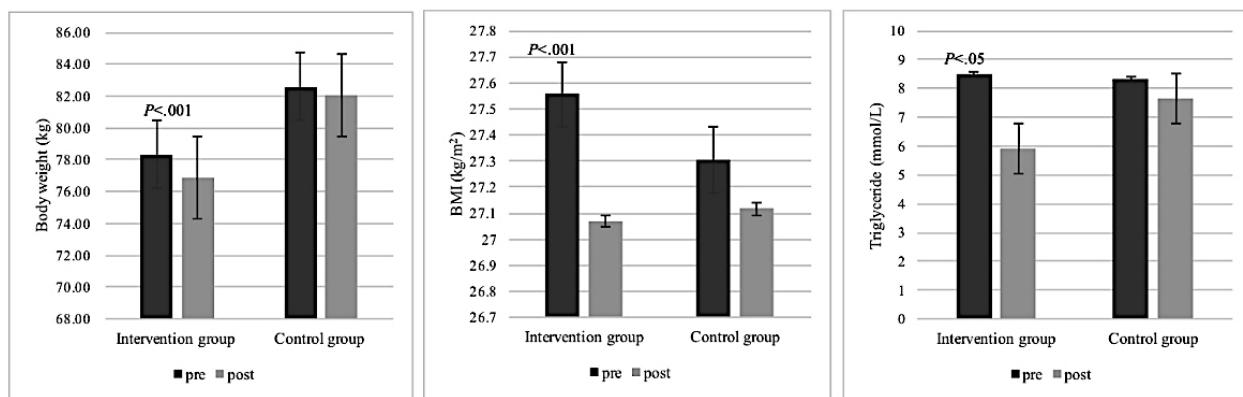
Characteristics	Intervention group (n=44)	Control group (n=24)	<i>P</i> value
	Mean (SD <sup>a</sup> )	Mean (SD)	
Weight (kg)	78.3 (11.8)	82.6 (8.4)	.13
Height (cm)	168.0 (8.7)	174.0 (8.0)	.01
BMI <sup>b</sup> (kg/m <sup>2</sup> )	27.6 (3.0)	27.3 (2.4)	.72
Cholesterol (mmol/L)	10.5 (1.8)	11.2 (1.9)	.12
HDL <sup>c</sup> cholesterol (mmol/L)	2.8 (0.5)	2.8 (0.5)	.84
LDL <sup>d</sup> cholesterol (mmol/L)	6.2 (1.3)	6.8 (1.5)	.07
Triglyceride (mmol/L)	8.5 (6.5)	8.2 (3.8)	.90

<sup>a</sup>SD: standard deviation.<sup>b</sup>BMI: body mass index.<sup>c</sup>HDL: high-density lipoprotein.<sup>d</sup>LDL: low-density lipoprotein.**Table 3.** Clinical profile changes in participants in the intervention (n=44) and control (n=24) groups.

Characteristics	Prestudy value	Poststudy value	<i>P</i> value
	Mean (SD <sup>a</sup> )	Mean (SD)	
<b>Weight (kg)</b>			
Intervention group	78.3 (11.9)	76.9 (11.2)	<.001
Control group	82.5 (8.41)	82.0 (8.3)	<.05
<b>BMI<sup>b</sup> (kg/m<sup>2</sup>)</b>			
Intervention group	27.6 (3.0)	27.1 (2.8)	<.001
Control group	27.2 (2.4)	27.1 (2.4)	.07
<b>Cholesterol (mmol/L)</b>			
Intervention group	10.5 (1.8)	10.4 (1.7)	.61
Control group	11.2 (1.9)	11.3 (2.2)	.79
<b>HDL<sup>c</sup> cholesterol (mmol/L)</b>			
Intervention group	2.8 (0.5)	2.9 (0.5)	.20
Control group	2.8 (0.7)	2.8 (0.5)	.59
<b>LDL<sup>d</sup> cholesterol (mmol/L)</b>			
Intervention group	6.2 (1.3)	6.3 (1.4)	.67
Control group	6.8 (1.5)	6.9 (1.6)	.92
<b>Triglyceride (mmol/L)</b>			
Intervention group	8.5 (6.5)	5.9 (3.0)	<.05
Control group	8.3 (3.8)	7.6 (3.8)	.35

<sup>a</sup>SD: standard deviation.<sup>b</sup>BMI: body mass index.<sup>c</sup>HDL: high-density lipoprotein.<sup>d</sup>LDL: low-density lipoprotein.

**Figure 7.** Changes in weight, body mass index (BMI), and triglycerides in the 2 groups before (pre) and after (post) the intervention. Error bars indicate 95% CI.



## Discussion

In this study, we constructed an EHR-tethered PHR module named MyHealthKeeper and implemented this software in an EHR-friendly hospital, with a 12-year experience in EHR use. Lifelog patient-generated health data, considered important for PMI implementation, require the participation of the patient. We gathered this patient-generated, lifestyle-related health information with a mobile app and an activity tracking device, and transferred the information to the PHR data server to make a summary view based on the practical needs of the clinicians. These requirements were incorporated into the MyHealthKeeper system design. Moreover, to validate the effectiveness of the system, we performed a 4-week clinical trial. The result of the trial showed that PHR use correlated significantly with larger changes in body weight and clinical parameters, signifying a better health status than with conventional treatment.

### Comparison With Prior Work

We aimed to demonstrate the development of an EHR-tethered PHR system that can retrieve data from a wearable device, in conjunction with a lifelog data-driven intervention. A previous study reported that patient-generated health data can improve communication between patients and health care professionals, with a concomitant improvement in patient mental outlook [24]. This study showed that patients actively used the PHR system to improve the doctor-patient relationship. However, PHR systems have pros and cons in the real clinical setting and from continuous development and use. In addition, there was a study to identify factors influencing the willingness of health care consumers to use PHRs in Korea [25]. Only a few studies have been conducted with patients using the self-administered features of EHR-tethered PHR systems, which can enable shared health care and patient-centered practice. A previous study examined the usability of an EHR-integrated PHR system tied in with patient clinical records, which functionally focused on finding an appointment time, reviewing test results, and managing medication dosages [26]. This study was performed as a Web-based patient portal use survey, including video-recorded poststudy interviews for health management purposes, with a patient-centric viewpoint. Taha et al [11] concluded that participants' perceptions of the PHR system were positive, and patients were very receptive to the idea of using PHR systems to help them perform health management tasks. While their

study was highly patient centric, our study focused on both patient and clinician experiences, with a fully integrated PHR module. Furthermore, we studied the impact of PHR-based clinical interventions on clinical profile changes in participants. Mishuris et al [27] also studied PHR and EHR integration usability for clinical workflow design. They performed a qualitative study using two rounds of semistructured interviews with primary care providers, health information software developers, and health care researchers. This study suggested a framework for how to integrate external data into provider workflow in an efficient and effective way. However, the researchers provided only a prototype design, not a complete implementation result.

Recently, several studies have been conducted on lifestyle intervention [8,9,13,14,28,29]. A study protocol for a pragmatic randomized controlled trial for physical activity coaching in patients with chronic obstructive pulmonary disorder, including management of patient-centered daily activity, tracking of cardiovascular disease risk factors, and monitoring of quality of life measures, was published. A different study used EHR data to evaluate a physician-developed lifestyle plan for obese patients in primary care [10,28]. Simple lifestyle changes and dietary interventions were suggested in the plan, which was distributed to obese patients by a family physician as part of routine clinical care. This study reported significant weight loss in older men and a significant reduction in systolic blood pressure in all participants. Although the lifestyle coaching intervention concept was similar to that used in our study, this study did not use a personal lifelog or wearable devices.

### Strengths of the Study

In our previous study [18], we found, to our knowledge, for the first time that patients with chronic diseases tended to use PHR more actively, particularly the self-administered function. According to this previous study, as a first step to move from rudimentary stand-alone PHRs to integrated PHRs and exploratory research, we reported that data gathered from EHR-tethered PHRs may be used to improve PHRs by implementing patient-centric features on the system. Through a cocreation workshop, we obtained detailed requirements from clinicians, to guide our PHR system design. We were thus able to improve on conventional EHRs and incorporate functionality frequently used in a clinical setting. A strong key point of this study is that the clinical trial was conducted to validate the

effectiveness of our PHR system, MyHealthKeeper, during a 4-week period, with a wearable activity tracker to collect individual physical activity data.

### Limitations and Conclusions

Owing to practical constraints, this study could not provide a longitudinal observation of the EHR-tethered PHR system. Because of the short clinical trial period, it was difficult to determine a causal relationship, and the study did not provide information about the precise improvement in the health outcomes of PHR users. However, on the basis of this study protocol, we hope to derive and apply many PHR features of an EHR-tethered PHR system in further studies. Although the clinical trial period was short, a major difference between our study and the others is that we developed an integrated PHR

system into an ordinary EHR system. As a preliminary observation, the primary objective of our study was to demonstrate the development of an EHR-integrated PHR system for clinicians to help patients make lifestyle changes and to determine whether patients followed their doctors' recommendations that are shared via the PHR app. Moreover, the sample number in the clinical trial was small (only a few clinicians were included). Nevertheless, because this study was conducted in a tertiary care general university hospital where an EHR has been in place for 12 years, we hope to implement this system throughout the facility, including a larger number of patients and clinicians in the future. With this integrated PHR system, we also expect to further study longitudinal follow-up and continuous patient engagement.

### Acknowledgments

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### Authors' Contributions

BR analyzed the data and drafted the manuscript as first author. NK contributed to data analysis and helped conduct the clinical trial. EH, SY, KL, HH, and JWK helped conduct the clinical trial and contributed to data discussions. YK and JL contributed the user experience-based PHR interface design development. JWK initiated this study as a principal investigator of this project and SYJ supervised the entire process as corresponding author.

### Conflicts of Interest

None declared.

**Notice of editorial concern:** This randomized study was only retrospectively registered, in violation of ICMJE rules for prospective registration of randomized trials, explained by authors with "technical problems". The editor granted an exception because the risk of bias appears low and the study was considered formative, guiding the development of the application. However, readers are warned to carefully assess the validity of any potential explicit or implicit claims related to primary outcomes or effectiveness, as retrospective registration does not prevent authors from changing their outcome measures retrospectively.

### Multimedia Appendix 1

Detailed mobile app pages per topic.

[[PNG File, 499KB - jmir\\_v19i12e401\\_app1.png](#)]

### Multimedia Appendix 2

CONSORT-EHEALTH checklist (V 1.6.1).

[[PDF File \(Adobe PDF File\), 728KB - jmir\\_v19i12e401\\_app2.pdf](#)]

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## Abbreviations

**BMI:** body mass index

**CONSORT:** Consolidated Standards of Reporting Trials

**EHR:** electronic health record

**PHR:** personal health record

**PMI:** Precision Medicine Initiative

**SNUBH:** Seoul National University Bundang Hospital

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Original Paper

# Text Simplification Using Consumer Health Vocabulary to Generate Patient-Centered Radiology Reporting: Translation and Evaluation

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## Abstract

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**Background:** Radiology reporting is a clinically oriented form of documentation that reflects critical information for patients about their health care processes. Realizing its importance, many medical institutions have started providing radiology reports in patient portals. The gain, however, can be limited because of medical language barriers, which require a way for customizing these reports for patients. The open-access, collaborative consumer health vocabulary (CHV) is a terminology system created for such purposes and can be the basis of lexical simplification processes for clinical notes.

**Objective:** The aim of this study was to examine the comprehensibility and suitability of CHV in simplifying radiology reports for consumers. This was done by characterizing the content coverage and the lexical similarity between the terms in the reports and the CHV-preferred terms.

**Methods:** The overall procedure was divided into the following two main stages: (1) translation and (2) evaluation. The translation process involved using MetaMap to link terms in the reports to CHV concepts. This is followed by replacing the terms with CHV-preferred terms using the concept names and sources table (MRCONSO) in the Unified Medical Language System (UMLS) Metathesaurus. In the second stage, medical terms in the reports and general terms that are used to describe medical phenomena were selected and evaluated by comparing the words in the original reports with the translated ones. The evaluation includes measuring the content coverage, investigating lexical similarity, and finding trends in missing concepts.

**Results:** Of the 792 terms selected from the radiology reports, 695 of them could be mapped directly to CHV concepts, indicating a content coverage of 88.5%. A total of 51 of the concepts (53%, 51/97) that could not be mapped are names of human anatomical structures and regions, followed by 28 anatomical descriptions and pathological variations (29%, 28/97). In addition, 12 radiology techniques and projections represented 12% of the unmapped concepts, whereas the remaining six concepts (6%, 12/97) were physiological descriptions. The rate of lexical similarity between the CHV-preferred terms and the terms in the radiology reports was approximately 72.6%.

**Conclusions:** The CHV covered a high percentage of concepts found in the radiology reports, but unmapped concepts are associated with areas that are commonly found in radiology reporting. CHV terms also showed a high percentage of lexical similarity with terms in the reports, which contain a myriad of medical jargon. This suggests that many CHV terms might not be suitable for lay consumers who would not be facile with radiology-specific vocabulary. Therefore, further patient-centered content changes are needed of the CHV to increase its usefulness and facilitate its integration into consumer-oriented applications.

## KEYWORDS

consumer health information; vocabulary; radiology; electronic health records; natural language processing

## Introduction

### Engaging Patients in Health Care Processes

The modern view of medicine endorses engaging patients in their health care [1]. These efforts have been facilitated by the accelerating adoption of health information technology in the United States [2] after the Health Information Technology for Economic and Clinical Health (HITECH) Act [3]. In 2008, the American Medical Informatics Association's Consumer Health Informatics Working Group identified the need for consumer-oriented tools to improve consumers' understanding of health information [4]. A Web-based patient portal, for example, is an important communication form between the patient and the provider that can increase the transparency of health care processes [5]. A multicentral experimental study conducted in 2012 suggests that a majority of people who accessed their clinical notes through the Web sensed more control over their health care processes and showed an improved adherence in taking medications [6]. Therefore, a number of large health care delivery organizations in the United States have adopted initiatives such as Open Notes, which grant patients a secure access to their medical records through Web portals [7].

### Radiology Reports

Radiology reports are one of the documents that have become unprecedentedly open to patients in multiple medical institutions nationwide [5,8]. However, these reports use clinical and radiology terms that are unfamiliar to the lay public, which creates an opportunity for significant misinterpretation by patients.

In the traditional health care process, radiology reports are where radiologists professionally express their knowledge and expertise to other physicians. The reports serve the purpose of describing diagnostic images to look for abnormalities, leading radiology reports to include a myriad of anatomical structures and pathological concepts. This makes it difficult to interpret such texts for someone without knowledge in the field.

Generally, clinical documentation requires average reading skills higher than those of adults in the United States [9]. Understanding many forms of clinical notes requires formal training in medical terminology. The level of complexity, nonetheless, differs from one type of documentation to another. In comparison with visit summaries, for instance, radiology reports are considered one of the most difficult clinical documentation forms for the lay public to understand [10]. Therefore, providing such clinically oriented reports to patients through Web portals without considering their medical literacy level can be irrelevant and problematic. Reports should continue, nevertheless, to provide the clinical value and accuracy, and adhere to the needed time efficiency of the clinical workflow. Although the heterogeneity in the audience may cause contradictions in the requirements of a radiology report, it is

costly and time-consuming to manually create an additional consumer-friendly version of the report. As a result, an automated maneuver to create a simplified version of the radiology report would be desirable.

### Lexical Simplification

Text simplification is a division of natural language processing (NLP) that can refer to several syntactic, semantic, and lexical methods with the goal of simplifying text [11,12]. Early work in the field of text simplification focused on simplifying Web and newspaper articles for language learners and people with disorders that negatively affect reading abilities [13]. The focus of text simplification is to produce a more readable and understandable text for the reader, without considering if it is shorter or longer. This distinguishes it from text summarization, where the major goal is text shortening. Lexical simplification, for example, is one realm of text simplification that focuses on replacing terms in a context with simpler synonyms [14]. This can be useful when a main reason behind text difficulty is that it includes terms unfamiliar to the readers, which is the case in radiology reports [10].

One important part of lexical simplification is to identify difficult terms and represent those with what are considered simpler terms. Such determination, nevertheless, tends to be subjective and ambiguous, which makes it hard to conduct by a computer. Usually, automated methods used to assign difficulty levels for words include measuring words length, the number of syllables, and usage frequency [15,16]. In different realms of medicine, however, there are ontologies that can predefine medical terms, which might require simplification for the public. For example, RxNorm includes medications' names for every drug in the US market [17], and the Logical Observation Identifiers Names and Codes (LOINC) is a collection of terms used in laboratory observations [18]. Furthermore, to harmonize these efforts, the National Library of Medicine built the Unified Medical Language System (UMLS), integrating similar terms from different ontologies into unified entities, each represented by a concept unique identifier (CUI). These data are constructed in relational tables that form the UMLS Metathesaurus [19]. MRCONSO is one of the tables in the database, and it includes preferred terms and their synonyms linked to CUIs and other identifiers from the original sources of the terms (ie, LOINC).

### The Open-access, Collaborative Consumer Health Vocabulary (CHV)

The UMLS Metathesaurus also includes the open-access, collaborative consumer health vocabulary (CHV) [20] developed by the Biomedical Informatics Department at the University of Utah as an open-source set of biomedical terms that are suitable for laypersons. Research that uses the term *consumer health vocabulary* started in 2003 [21], with the purpose of helping the lay public to understand health information [20]. CHV is a collection of terms found to best represent the medical concepts

for consumers; they are chosen because they are more comprehensible by patients when compared with their synonyms [22].

The CHV has been implemented in the literature as the back end of medical lexical simplification techniques for consumers. This has been, especially, possible because the CHV concepts are linked to the medical concepts in the UMLS. In 2007, Zeng-Treitler et al tested the use of CHV as the basis of a translator prototype that attempted to simplify the content of electronic medical records and biomedical literature [23]. Zeng-Treitler's model changes terms to CHV-preferred terms when available and, if not, provides "explanations" based on the UMLS hierarchical and semantic relations [23]. The correct translations reported in the latter model were considered promising, yet the percentage of incorrect translations was 8.2%. Most of the inaccuracy, as explained, was because of incorrect hierarchical relations in the UMLS such as "tobacco abuse" as "a type of psychiatric problem." The semantic relationships among concepts included in the UMLS Metathesaurus are suboptimal because of the UMLS content being derived from external terminological systems that use a variety of heuristics for conceptual relationships.

Hypothetically, the CHV can help in creating a more consumer-oriented version of radiology reports. Yet, there is a lack of evidence on whether CHV is an appropriate source of lay terms that can simply replace medical terms used in the field of radiology, which has unique contexts and jargon. Any implementation of CHV should take lexical differences into consideration to make sure CHV is a good fit for the required purpose. Text simplification is by nature more sensitive to errors than other NLP techniques. Incorrect translations can make clinical reports more difficult to comprehend and might provide incorrect information to patients, such as defining a "cyst" as "a type of tumor" [23]. Higher comprehension of radiology

concepts would lead to relying on less hierarchical relations, which was shown to introduce more errors.

We believe that automated simplification of radiology reports using lay terms would be beneficial to patients as such simple transformation of medical terms could enhance patients' understanding of the content. The first step in this endeavor is to determine the relevance and comprehension of CHV as a backbone of a lexical simplification tool for radiology reports. The objectives of this study can be conceived by answering the following set of questions:

- What is the content coverage of CHV for concepts included in radiology reports?
- What is the percentage of lexical similarity between CHV-preferred terms and medical terms used in the radiology reports?
- What are the main observations and obstacles in implementing CHV in a lexical simplification tool for radiology reports?

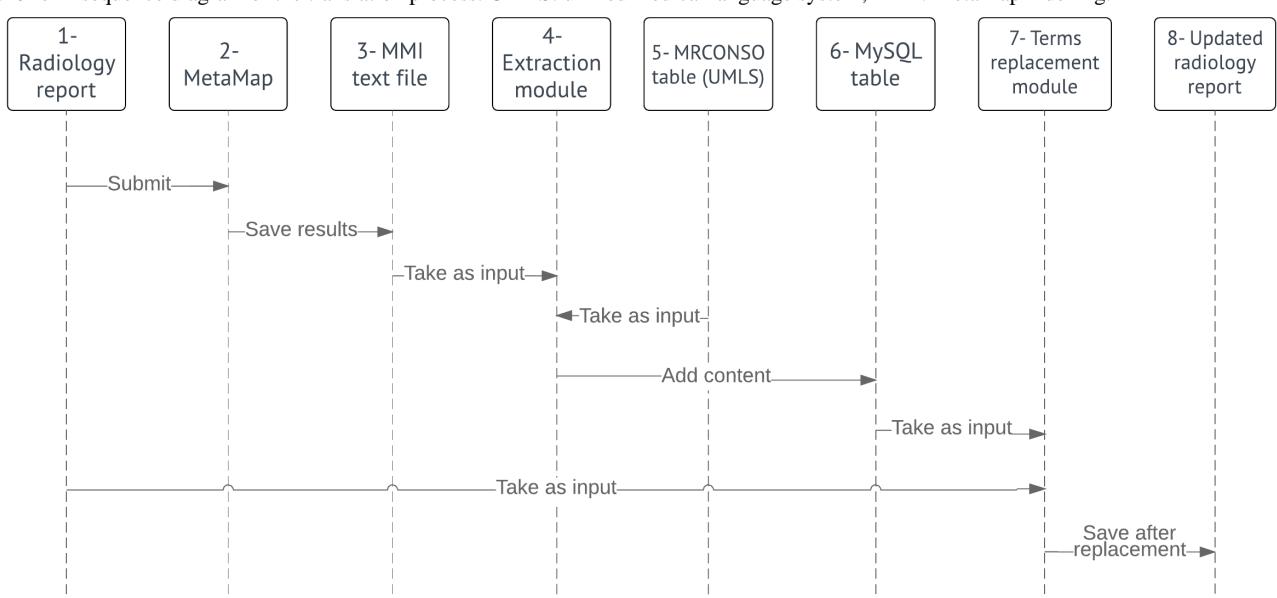
Although content coverage shows the level of comprehension on covering radiology concepts, lexical similarity can indicate how the CHV distinctively describes concepts in a consumer-oriented manner.

## Methods

### Overview

The overall procedure can be divided into the following two main stages: (1) translation and (2) evaluation. The translation process involving the following two components is outlined in **Figure 1**: mapping medical terms to CHV concepts, which corresponds to the objects 1 to 3 in the diagram, and replacing medical terms in the reports with CHV-preferred terms (objects 4-8 in **Figure 1**).

**Figure 1.** A sequence diagram of the translation process. UMLS: unified medical language system; MMI: MetaMap indexing.



## The Translation Process

### **Mapping Terms in Radiology Reports to Their Relevant Concepts in the Consumer Health Vocabulary**

A set of 31 radiology reports were parsed and mapped to the CHV concepts using MetaMap 2016 [24], an NLP tool created by the National Library of Medicine based on the UMLS Metathesaurus. The reports were anonymous Web-published samples from multiple institutions in the United States [25-28]. The sample comprised 10 magnetic resonance imaging (MRI) reports, 6 ultrasound reports, 5 computed tomography reports, 5 nuclear medicine reports, and 5 x-ray reports. The anatomical structures covered in these imaging acquisitions included the abdomen, the chest, the neck, the head, the shoulders, and the ankles. In addition, there were organ-specific acquisitions for the brain, the spine, the kidneys, the liver, and testicles. This was besides two physiology-oriented cases, a Doppler carotid scan and a carotid stress test.

In the mapping process, all the semantic types in the UMLS were included [29], and a low MetaMap evaluation score threshold of 500 out of 1000 was set [30]. Both decisions had been made to ensure that the system is as inclusive as possible in linking report terms to CHV concepts. Restricting semantic types reduces mapping errors caused by linking terms to concepts in irreverent categories (ie, geographical area). It can, nevertheless, affect the comprehension of the tool in detecting some applicable concepts if their semantic types were excluded. Similarly, a low evaluation score threshold would spread the net for the purpose of measuring the content coverage. Although this would increase the risk of mapping words or terms to irrelevant concepts, these incidents were excluded through manual investigation.

### **Replacing Every Mapped Term in the Reports With the Consumer Health Vocabulary-Preferred Term of its Representative Concept**

In the previous process, the output of MetaMap was created in the form of fielded MetaMap indexing (MMI), a pipe-separated structured text document that could be processed with programming scripts. One program using Python programming language [31] was created to extract the CUIs of the detected concepts and the terms that provoked each CUI. This program can detect up to 4 terms for each CUI and load all extracted pieces of data into a MySQL [32] database. In addition, it adds the CHV-preferred terms to a table by matching the detected CUIs in MRCONSO. Another script replaces the list of terms in the table with their CHV-preferred terms counterparts. To facilitate pinpointing during evaluation, the replaced words were marked with square brackets, such as [CHV Preferred Term], to be recognizable for evaluation.

## The Evaluation Process

After completing the term replacement process, we counted medical terms in the reports, such as anatomical structures and abnormalities. Additionally, we included general terms that have been used to describe clinical phenomena and might need clarification, such as “irregular” to describe the margins of a mass. Words, however, that are considered simple English, for instance “patient” or “right side,” were not counted despite being mapped to CHV concepts. When a medical term was not mapped to a CHV concept, it was investigated in the CHV Web portal to eliminate the chances of false negatives in the coverage because of limitations in the mapping process. Similarly, words that had been mapped to incorrect concepts were excluded if they did not have matching concepts in the CHV after a manual investigation. Each term is counted once unless it was written once in full and used again as an abbreviation.

To measure the content coverage of CHV and lexical similarity of terms between the radiology reports and CHV-preferred terms, included terms were classified in two ways. First, to measure the content coverage, terms that are represented by CHV concepts were compared with terms that did not match any CHV concept, following the equation:

$$\text{Content coverage} = (\text{Covered terms} \times 100) / (\text{Total terms})$$

Second, terms mapped to CHV concepts were categorized based on their lexical similarity with the original terms used in radiology reports. Lexical similarity refers to different statistical calculations that are commonly used to measure how close two different languages or two pieces of text are to each other [33]. In this context, it is calculated using the following equation:

$$\text{Lexical similarity} = (\text{Similar terms} \times 100) / (\text{Covered terms})$$

A word is considered lexically similar if its CHV-preferred term is the same word or a variant that is based on the same stem. Additionally, phrases are considered similar if the same words are paraphrased differently (Table 1).

Terms are considered lexically different if their CHV-preferred terms include words derived from distinct stems. This includes preferred terms with added words such as replacing the term “ventricles” with “heart ventricles,” as well as any terms that were totally altered, such as replacing “necrosis” with “tissue death.” The importance of lexical similarity is based on the premise that consumer-oriented terms are supposed to be expressed differently in comparison with clinically oriented reports that are characterized by being difficult for consumers to grasp.

**Table 1.** Examples of lexical similarity classification.

Report term	Preferred term	Lexical similarity
Lateral	Lateral	Similar
Thickening	Thickened	Similar
Abdominal wall	Wall of abdomen	Similar
Ventricle	Heart ventricle	Different
Necrosis	Tissue death	Different

## Results

### Content Coverage

Out of 792 terms extracted from the sample of 31 reports, 695 terms (88.5%) were covered by CHV concepts (Table 2). Coverage per report ranges from 61% to 100% (Figure 2), with an average of 88.5% and a median of 88.9%.

When categorizing the reports based on imaging modalities (Table 3), content coverage ranges approximately between 84% and 94%, with ultrasound being the lowest and nuclear medicine being the highest. For the results of individual reports' analyses please see [Multimedia Appendix 1](#).

### Missing Concepts

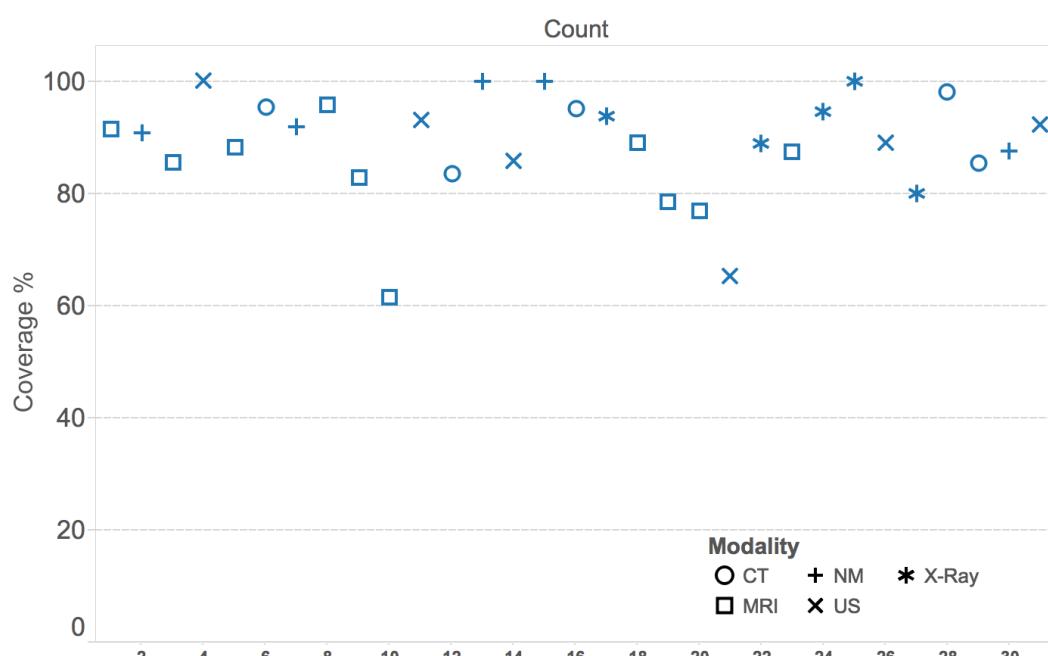
The analysis shows that 97 terms of the 792 terms (12.2%) were not linked to CHV concepts. To illustrate the coverage gaps

found in radiology reports, uncovered terms can be divided into the following four categories:

1. *Human anatomical structures and regions*: 51 terms (53%) are in this category. Examples include "disc space" and "midthoracic."
2. *Anatomical descriptions*: For example, "heterogeneity" and normal and pathologic variations such as "tracheomegaly" represented 28 of the unmapped terms (29%).
3. *Radiology-related techniques and projections*: For example, "post-contrast" and "anteroposterior" accounted for 12 missing terms (12%).
4. *Physiology-related terms*: Six uncovered terms (6%) are considered in this category. Examples are "metabolically active" and "basic" as used in "basic rhythm of atrial fibrillation."

**Table 2.** A summary of terms classification, content coverage, and percentage of similar terms in 31 sample reports.

Category of terms	Similar	Different	Missing	Total covered	Total
Sum	505	190	97	695	792
Percentage (%)	63.8	24	12.2	88.5	100

**Figure 2.** A scatter plot of sample reports percentages of content coverage. CT: computed tomography; MRI: magnetic resonance imaging; NM: nuclear medicine; US: ultrasound.

**Table 3.** Sample reports classified per modality, showing the content coverage and lexical similarity for each set, and the average coverage and similarity for the different modalities.

Modality	Reports' quantity	Similar terms	Different terms	Missing terms	Total terms	Covered terms	Coverage (%)	Similarity (%)
Magnetic resonance imaging	10	229	91	58	378	320	84.66	71.56
Ultrasound	6	52	16	13	81	68	83.95	76.47
Computed tomography	5	90	39	11	140	129	92.14	69.77
Nuclear medicine <sup>a</sup>	5	81	22	7	110	103	93.64	78.64
X-ray <sup>b</sup>	5	53	22	8	83	75	90.36	70.67
Average							88.95	73.42

<sup>a</sup>Includes 1 report of a positron emission tomography-computed tomography procedure.

<sup>b</sup>Includes 1 report of a mammography procedure.

**Table 4.** A summary of terms' classification based on lexical similarity. This classification only includes terms that are covered by the consumer health vocabulary.

Terms	Similar	Different	Total
Sum	505	190	695
Percentage (%)	72.6	27.3	100

In a linguistic manner, there are areas where the CHV fails to cover concepts more than others. Two main areas are compound words and words with affixes such as “extraaxial” and “paracentral.” Another challenge is abbreviations. In many cases, the original terms were present in CHV, but not their acronyms. An example of this is the phrase “left ventricle,” which is present in CHV, but not the abbreviation “LV.” Figure 2 illustrates 2 reports that are noticeably lower in coverage than others, a lumber MRI report being the lowest, followed by a report of a carotid Doppler ultrasound procedure. Although the MRI case mostly contains uncovered anatomical structures, the Doppler ultrasound missed abbreviations to express names of arteries.

## Lexical Similarity

Looking at the terms covered by CHV concepts, the average lexical similarity between the CHV-preferred terms and the terms in the radiology reports was approximately 72.6% (Table 4).

Approximately 27.3% of the covered terms were replaced with terms or phrases that are lexically different from what was written in the reports. In some cases, words were replaced with more familiar descriptions, such as replacing the word “necrosis” with “tissue death” or replacing “cortex” with the phrase “outer layer of an organ.” Other terms were replaced with phrases that include the original terms but with a brief illustration, such as “heart ventricles” in place of “ventricles.” In addition, few terms were replaced with others that can be less familiar. For example, the CHV-preferred term “effusion” replaced the phrase “free fluid,” which was used in the reports.

## Other Observations

### Idiosyncrasies With Semantic Types

When only semantic types of interest were chosen, a concept was found for the word “anterior,” but not the word “posterior.”

As they have an antonymous relationship, one might expect they are in the same semantic category, yet “anterior” is classified in the UMLS as a “functional concept,” whereas “posterior” is a “spatial concept,” a type that was excluded in this experiment. When semantic types were not specified, there were more mappings to irrelevant concepts. For example, the word “no” was mapped to the concept “nitric oxide,” when the semantic types “Biologically Active Substance” or “Pharmacologic Substance” were not excluded. In addition, there were more mappings to words with the wrong sense, word sense disambiguation errors. For example, the word “ultrasound” was mapped to the concept “therapeutic shock waves,” although the meaning of the word in the report refers to “diagnostic ultrasound.”

### Syntactic Errors

In some cases, when replacing terms with others, part of speech of the words is altered, such as when the noun “opacity” replaces the adjective “opaque.” Furthermore, articles, “a” and “an” needed an adjustment after replacing a word that begins with a consonant with another word that starts with a vowel.

### Spelling Errors

The term “homogenous” was written in one report to describe what is usually referred to as “homogeneous.” This has led to mapping the term to a different concept “homozygote,” which is not the meaning in the report. Another case is the term “metastatic,” which is misspelled in one report to be “metastic.” In that case, the term was not mapped to a concept.

### Representation of Consumer Health Vocabulary in the Unified Medical Language System

In the MRCONSO table, it is possible to find 2 CHV terms marked as preferred term with the same UMLS CUI, although only one is expected. As the mapping results from MetaMap are CUI-oriented, there has been an ambiguity in defining the

right CHV-preferred terms in these cases from the MRCONSO table. The situation was different, nonetheless, when searching for a CUI directly in the CHV Web portal. For example, the word “change” has 2 CHV-preferred terms in the MRCONSO table, “change” and “modified,” yet only one preferred term, “change,” was found in the CHV Web portal. This is true for all other concepts in the Web portal, but there has not been a pattern to define that single term in the MRCONSO table.

## Discussion

### Principal Findings

Of the 31 radiology reports examined, the CHV shows an overall high percentage of content coverage (88.5%) for terms found in sample reports. However, unmapped terms were associated with areas that can be uniquely common in radiology reporting. Likewise, there was a high percentage of lexical similarity between the terms used in the reports and the CHV-preferred terms. This has resulted in merely 27.3% of the sample terms to be considered lexically different after replacing them with their CHV counterparts.

### Content Coverage

A substantial amount of the effort that has been invested in the CHV involved broadening content coverage. The findings of this study suggest that the content coverage is perhaps not the highest priority improvement needed at this juncture. Nevertheless, the association between uncovered concepts and terms uniquely used in radiology reporting is notable. This is not surprising as the CHV concepts were created by finding terms that are frequently used in MedlinePlus [22], and many of the missing terms are less frequent and can even be absent in other medical texts. That, nevertheless, does not eradicate the importance of explaining such terms when they appear in patients’ radiology reports.

Another gap in coverage is abbreviations. Acronyms have a high risk of being ambiguous, which makes covering them difficult as their meanings can differ from one field to another. For example, PET and CAT in common terms can refer to types of animals. In contrast, it refers, in radiology, to positron emission tomography and computed axial tomography, respectively. This obstacle, however, can be solved in the implementation. MetaMap, for instance, can circumvent acronyms’ ambiguity by allowing users to predefine them before the mapping process.

### Lexical Similarity

Although a decent percentage of similarity had been expected, the result surpassed our expectations. It shows that about one of every 4 terms of interest is expressed differently in the CHV in comparison with radiology reports. This high level of similarity can be due to many reasons. It is either because some words in the reports are easy to grasp, a simpler explanation does not exist, or they are not explained to the consumer level in the CHV. All these factors are most likely relevant, but this matter requires more research to identify which one is dominant.

The usefulness of the CHV implementation, however, is illustrated when looking at terms that are lexically different.

Explanations, for example, are expected to be easier in many contexts for people without background knowledge in pathology or anatomy. It is worth noting that adding explanations can possibly be problematic depending on the way it is used and the context. We can see that if we replace the term “cortex” with its given definition in the phrase “renal cortex,” without adjusting the sentence. Such a change would affect the readability and the coherence of the text. Another type of replacement that can increase understandability is terms that were modified by adding an extra word (ie, “heart” in “heart fibrillation”). It is, however, important to watch for redundancy, such as when a similar word is adjacent to the replaced term in the original report.

As there is a large percentage of similarity, introducing changes in these terms can lead to little benefit while introducing a risk of avoidable syntactic errors. Therefore, a simplification tool should include a grammatical layer to maintain the parts of speech after terms’ replacements. In fact, such a component is vital for all replaced terms, not only the similar ones. Another straightforward method to reduce syntactic errors is excluding terms from replacement if their CHV-preferred terms are lexically similar. This can be done by stemming the terms and by removing morphological affixes using an NLP algorithm. As a result, a tool would be prohibited from replacing words with others that have the same stem.

### Other Observations

When restricting semantic types, the inclusiveness of CHV concepts was negatively affected, missing potential mappings between terms in the radiology reports and concepts in the CHV. Not specifying them, in contrast, increased mapping errors that were related to the senses of the words. These errors made the text more difficult to read. Moreover, syntactic errors can also affect readability in a negative way. Some of them appeared in the text because of missing a ripple effect of change in the sentence after a one-to-one lexical replacement. Although this might be an inherent characteristic of lexical simplification, applying simple grammatical changes as part of the process would help to mitigate the problem.

Spelling errors are always a possibility in free narrative writing, which makes them an intrinsic challenge in NLP. In this study, misspelling appeared to be affecting lexical simplification more than grammatical errors as MetaMap does not recognize misspelled terms. One way to overcome this dilemma is by using noisy channel algorithms, which are able to predict intended words within a margin of error [34]. Furthermore, any type of premapping spell checking that corrects or excludes misspelled words is helpful.

Overall, the settings of this study were oriented toward its research objectives, mainly finding the content coverage and the lexical similarity. There are, however, possible optimizations to build a result-oriented translator, ranging from available MetaMap options, such as excluding unwanted semantic types and prespecifying acronyms, to postprocessing measures. All these optimizations would be intended mainly to help in simplifying terms without affecting the coherence of the text, which can be the major principle to create a successful lexical simplification process.

The CHV representation in the UMLS, specifically in the MRCNSO table, is an essential part of the translation methodology implemented in this work. It, however, has undermined finding the intended preferred terms for some of the concepts as two preferred terms can exist for one CUI, which does not happen when searching the CHV Web portal for the same CUIs. This may be because when CHV concepts were added to the UMLS, in some cases, two CHV concepts were found to fit one concept in the UMLS. Therefore, a change in the methodology applied in this work can be essential to create a successful lexical simplification tool based on the CHV.

Oh et al discuss a prototype project called “PORTER” that aimed to create patient-oriented reports by first establishing a “lay-language glossary” for MRI knee exams [35]. The CHV can be a good resource to start broadening such a project. Doing so would require a method for extracting preferred terms that can be useful for consumers in the specific matter. It is also possible that focusing the simplification process on the action items of the report would facilitate covering more types of medical imaging procedures while maintaining most of the benefit for the consumers. An actionable representation for patients in radiology can be restricted to the impressions section. Nevertheless, providing the rest of the report is still important for the purpose of transparency.

Generally, research in translation is an ongoing and a promising process. Google, for example, has announced in 2016 a new approach in machine translation for Google Translator using neural networks models for creating a better human-like translation between English and Chinese [36]. This emphasizes the importance of improving the CHV to support the advancements in translations when creating consumer-focused biomedical applications. In that process, automated methods to improve ontologies, known as Ontology Learning, can be advantageous to better encompass CHV [37]. A study investigating the “folksonomy” of terms published by patients in the platform “PatientsLikeMe” elucidates that about half of the terms did not have a match or a synonym in the UMLS [38]. Some of these terms might not have a direct concept that corresponds to them in the UMLS, but there might be a parent concept in the hierarchy where semantically broader concepts can be found. Keselman et al provides a framework of initiating “lay” tagged concepts that can be used for only consumer-based projects and still be linked to the UMLS hierarchy [39]. Doing so will help ontologies to cover more of CHV, which can help to bridge the gap between the two different ways consumers and clinicians describe medical phenomena.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

The full data of the terms' evaluation process.

[[XLSX File \(Microsoft Excel File, 67KB - jmir\\_v19i12e417\\_app1.xlsx](#) ]

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## Abbreviations

**CAT:** computed axial tomography

**CHV:** consumer health vocabulary

**CUI:** concept unique identifier

**HITECH:** Health Information Technology for Economic and Clinical Health

**LOINC:** logical observation identifiers names and codes

**MMI:** MetaMap indexing

**MRCONSO:** concept names and sources table

**MRI:** magnetic resonance imaging

**NLP:** natural language processing

**PET:** positron emission tomography

**UMLS:** unified medical language system

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Original Paper

# Consumer Adoption of Future MyData-Based Preventive eHealth Services: An Acceptance Model and Survey Study

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## Abstract

**Background:** Constantly increasing health care costs have led countries and health care providers to the point where health care systems must be reinvented. Consequently, electronic health (eHealth) has recently received a great deal of attention in social sciences in the domain of Internet studies. However, only a fraction of these studies focuses on the acceptability of eHealth, making consumers' subjective evaluation an understudied field. This study will address this gap by focusing on the acceptance of MyData-based preventive eHealth services from the consumer point of view. We are adopting the term "MyData", which according to a White Paper of the Finnish Ministry of Transport and Communication refers to "1) a new approach, a paradigm shift in personal data management and processing that seeks to transform the current organization centric system to a human centric system, 2) to personal data as a resource that the individual can access and control."

**Objective:** The aim of this study was to investigate what factors influence consumers' intentions to use a MyData-based preventive eHealth service before use.

**Methods:** We applied a new adoption model combining Venkatesh's unified theory of acceptance and use of technology 2 (UTAUT2) in a consumer context and three constructs from health behavior theories, namely threat appraisals, self-efficacy, and perceived barriers. To test the research model, we applied structural equation modeling (SEM) with Mplus software, version 7.4. A Web-based survey was administered. We collected 855 responses.

**Results:** We first applied traditional SEM for the research model, which was not statistically significant. We then tested for possible heterogeneity in the data by running a mixture analysis. We found that heterogeneity was not the cause for the poor performance of the research model. Thus, we moved on to model-generating SEM and ended up with a statistically significant empirical model (root mean square error of approximation [RMSEA] 0.051, Tucker-Lewis index [TLI] 0.906, comparative fit index [CFI] 0.915, and standardized root mean square residual 0.062). According to our empirical model, the statistically significant drivers for behavioral intention were effort expectancy ( $\beta=.191, P<.001$ ), self-efficacy ( $\beta=.449, P<.001$ ), threat appraisals ( $\beta=.416, P<.001$ ), and perceived barriers ( $\beta=-.212, P=.009$ ).

**Conclusions:** Our research highlighted the importance of health-related factors when it comes to eHealth technology adoption in the consumer context. Emphasis should especially be placed on efforts to increase consumers' self-efficacy in eHealth technology use and in supporting healthy behavior.

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## KEYWORDS

health behavior; consumer behavior; eHealth; surveys and questionnaires; personal health record; patient-accessible health record; adoption; UTAUT; PHR

## Introduction

### Overview

Constantly increasing health care costs have led countries and health care providers to the point where health care systems must be reinvented. At the same time, technological development has paved the way for new ways to monitor health and well-being and made it possible for societies to start moving health care toward a more personalized and preventive direction. New digital and mobile technologies point to a future in which consumers will be more involved in the management of their health, generating data that will benefit service providers, helping them to create more targeted, preventive, and personalized solutions [1]. Preventive health care aims at decreasing the likelihood of potential illnesses with protection and early detection [2].

Digital and mobile technologies available for consumers—such as pedometers, heart-rate measurement instruments, and global positioning system-trackers—are empowering consumers to analyze bodily and mental functioning, something that was once the privilege of health professionals [3].

The possibility that consumers would take more responsibility for their own health using preventive services has created a new promise of cheaper, better, and more efficient electronic health (eHealth) tools [4] and health care systems [5]. This has attracted enthusiasm among health providers to move toward data-driven participatory and personalized health care services [1]. Researchers have recently argued that the digitization of information on a massive scale and the digital infrastructures that collect, process, distribute, and utilize this data are allowing radically new combinations of digital and physical components to produce novel eHealth services [6]. However, research has also identified some challenges such as consumers' skills [4] and their fears of privacy [7], as well as societal, ethical, political, and cultural concerns [8-10].

For individuals to take more responsibility for their health, it is essential to find ways to liberate the health-related data that organizations have in their possession about consumers' behavior. It is also important to find incentives for consumers to take active actions with this data. As noted in the study by Kim and Park [11], the effective use of collected health-related data is determined by health consumers' behavioral intention to measure, store, and manage their own data.

The concept of MyData can be defined as a new approach in personal data management and processing that seeks to look at data management from the consumer's perspective, and look at personal data as a resource that the consumer can access and control [12]. Thus, the aim of the MyData approach is to provide consumers with the practical means to access, obtain, and use datasets containing their personal information such as medical records and data derived from various online services and to encourage the organizations holding personal data to give

consumers control over this data [12]. It has also been argued that if consumers had control over their personal data, they would also have better motivation to take care of their health issues [13,14].

To reach their fullest potential and nationwide adoption, it is crucial to understand the consumer perspective on these new health care solutions. A better understanding of health consumers' intentions and behavior would aid the development and implementation of effective and efficient strategies [11]. Thus, it is a matter of consumer acceptance, which determines the final usage behavior, and a broadening of new health services into the daily lives of private households [15]. According to the study by Venkatesh et al [16], consumer acceptance of a technology is determined by intention to use it, which again leads to the actual use of the technology.

Recently, eHealth has received a great deal of attention in social sciences, in the domain of Internet studies. However, only 3% of these studies focus on the acceptability of eHealth to consumers, making consumers' subjective evaluations an understudied domain [17]. This study will address this gap by focusing on the acceptance of preventive eHealth services from the consumer point of view. The objective of this study was to investigate what factors influence the consumer's intention to use MyData-based preventive eHealth services before use.

Technology acceptance is a relatively mature research area and has received plenty of attention in previous research [18]. The most popular theories in the study field have gathered lots of attention, as has the study of eHealth acceptance [19-21]. However, the most popular theories of technology acceptance used in the study of eHealth were originally developed to study technology acceptance in an organizational context, which is why their fit for a consumer preventive eHealth context can be contended [16]. Thus, the research model for this study will be based on the extended version of the original unified theory of acceptance and use of technology (UTAUT) and UTAUT2, developed specifically for the consumer technology acceptance context. Previous research has also shown that it is crucial to apply theories of health behavior to the study of acceptance and use of preventive eHealth services [22-25] because the intention to use preventive eHealth services is similar to the intention to engage in health protective behavior in the sense that both aim to maintain a healthy life [19]. Interactive technologies such as preventive eHealth services that aim for behavioral change and the promotion of healthier lifestyles for individuals will not be successful unless consumers have sufficient motivation to use those systems and take advantage of them [22,26,27].

In this paper, we combine the key factors of UTAUT2 and health behavior theories to our research model and apply the quantitative structural equations modeling (SEM) approach to analyze the relationships between the variables of the framework. Data for the study was collected using a quantitative questionnaire survey. The survey was a part of a large national

research program called Digital Health Revolution (DHR), coordinated by the University of Oulu.

The paper is composed as follows. In section 2 we introduce the previous research and theories that provide the basis for our empirical model. Section 3 presents the methodology and empirical results. Section 4 provides a discussion on the managerial and theoretical implications and the limitations of the study, as well as providing some suggestions for future research.

## Theoretical Background

### Unified Theory of Acceptance and Use of Technology 2

In the study by Venkatesh et al [18], eight theories were compared and tested to form UTAUT. The eight theories were as follows: the theory of reasoned action, the technology acceptance model (TAM), the motivational model, the theory of planned behavior (TPB), combined TAM and TPB, the model of personal computer use, the diffusion of innovations theory, and social cognitive theory (SCT). The main goal for UTAUT was to combine the contributions of the fragmented and mature technology acceptance literature and to form a unified theory to explain the use and acceptance of technology by individuals. UTAUT incorporates the four direct determinants of intention and use behavior that have a significant effect on the use and acceptance of a technology: performance expectancy, effort expectancy, social influence, and facilitating conditions. *Performance expectancy* is defined as the degree to which using a technology will provide benefits to consumers in achieving some goal [16]. Performance expectancy captures the determinants of perceived usefulness, extrinsic motivation, job fit, relative advantages, and outcome expectations from technology acceptance studies [18]. *Effort expectancy* is defined as the degree of ease associated with consumers' use of a technology [16], and it captures the determinants of perceived ease of use, complexity, and ease of use [18]. *Social influence* is determined as the extent to which consumers perceive that important others (eg, family or friends) believe that they should use a technology [16]. *Social influence* captures the determinants of social factors, subjective norms, and image from the technology acceptance literature [18]. *Facilitating conditions* are defined as consumers' perceptions of the external resources and infrastructure that support the use of an information and technology system [16,18]. The definition captures the determinants of perceived behavioral control and compatibility [18]. Facilitating conditions are a direct determinant of behavior in UTAUT and are determined as external conditions that help an individual to perform a behavior. In a consumer context, facilitating conditions can vary between different consumers in relation to application vendors, technology generations, and mobile devices. Thus, consumers who perceive better access to the facilitation conditions will have a higher behavioral intention to use a technology [16].

UTAUT has been successfully adapted and tested in a wide range of contexts such as e-learning [28], mobile services [29,30], mobile banking and mp3 player usage [31], and eHealth [24]. Even though widely used, UTAUT has also been criticized because it was only developed and tested to predict technology acceptance in an organizational context [32]. To close this gap,

Venkatesh et al [16] updated and extended the original UTAUT to study technology acceptance and use in a consumer mobile technology context and proposed UTAUT2. The new model incorporates three new constructs: hedonic motivation, price value, and habit. *Hedonic motivation* is determined as the enjoyment that an individual perceives from using a technology, *price value* refers to the perceived value that exceeds the monetary cost of using the technology, and *habit* is determined as the extent to which an individual will perform a behavior automatically because of learning [16].

### Health Behavior Theories

As noted earlier, the intention to use preventive eHealth services is similar to the intention to engage in health protective behavior. It is therefore crucial to apply theories of health behavior to the study of the acceptance and use of preventive eHealth services. Similar findings have been stated by Riley et al [23], who found evidence for the need for health behavior theories to be applied in the development of user-centric eHealth technologies. Additionally, West et al [25] found a similar need in their study of mobile phone diet apps. Three theories of health protective behavior—namely the health belief model (HBM), protection motivation theory, and SCT—have been successfully adapted in a preventive eHealth context by several researchers [11,19,22,24,33].

### The Health Belief Model

The HBM was developed from social, psychology, and behavioral theories to help understand why individuals do or do not engage in health-related actions. The basic assumption behind the model is that an individual will either choose to engage in a particular health-related action or not based on the desire to avoid an illness and the belief that a particular action will prevent the illness [34].

The original HBM consists of four basic factors that influence an individual's health motivation and intention to take preventive action: the perceived susceptibility (to a negative health condition), the perceived severity (of a possible negative health condition), the perceived benefits (of a particular action preventing the negative health condition), and the perceived barriers (to taking a preventive health action) [34].

Thus, according to the HBM, for an individual to engage in preventive health behavior, she or he must have an incentive to take the action, feel threatened by current behavioral patterns, and believe that the change will lead to valued outcomes at acceptable costs. The HBM was later extended with a self-efficacy factor by combining it with SCT.

Self-efficacy is determined as the extent to which one believes that one is able to perform a behavior that leads to a valued outcome. The HBM was initially developed to predict the intention to engage in simple health behavior such as one-time immunization or screening tests. Thus, changing lifelong habits such as eating, drinking, or exercising is a far more difficult process and requires the confidence that one is able to make the change before an intervention is possible [35]. The HBM has been successfully adapted to technology acceptance theories in eHealth acceptance research. For example, Lin [36] combined TAM, innovativeness theory, and the HBM to study asthma

care mobile services acceptance and found that the combination of these three models significantly improved the predictive value of the mobile health (mHealth) acceptance model.

### Protection Motivation Theory

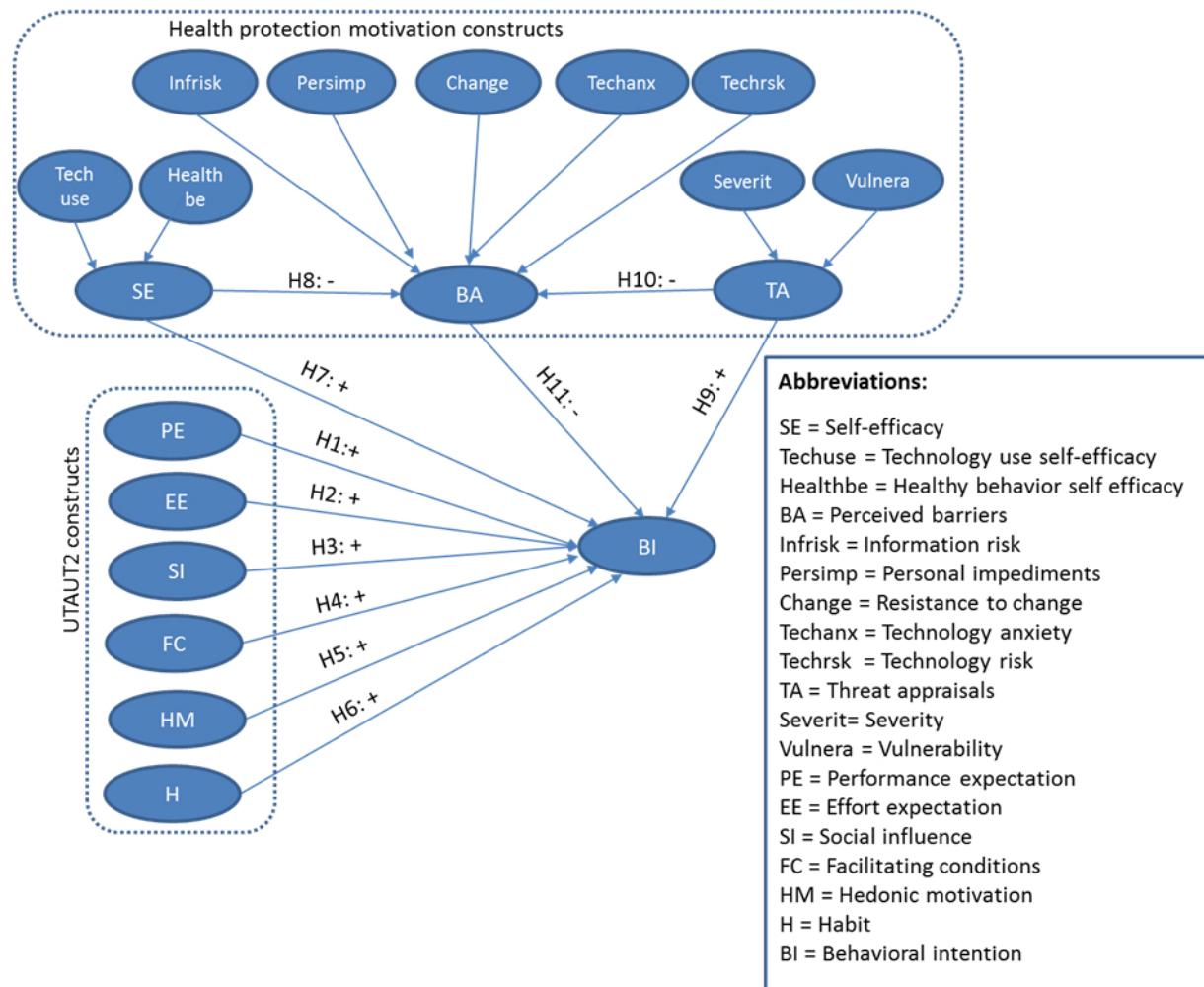
Protection motivation theory is a widely used model for disease prevention and health promotion. Originally developed to explain the effects of fear appeals on health attitudes and behavior, the model is very similar to the HBM. It combines similar factors: severity, vulnerability, response cost, response efficacy, and self-efficacy. According to protection motivation theory, the intention to take preventive health action is formed as a result of two cognitive processes: (1) the individual will evaluate the possible threats (considering severity and vulnerability) of getting an illness and compare them with the intrinsic and extrinsic rewards of a certain negative behavior and (2) the individual will evaluate her or his ability to cope with the threat (response efficacy, self-efficacy, and response cost). As a result of the two processes, the protection motivation will be formulated, which again acts as a force to formulate the intention to take the action [37]. Protection motivation theory has been successfully combined with the technology acceptance theories such as UTAUT in prior research to study mHealth service acceptance [24]. In addition, it has been found to account well for the intention to change one's behavior [38], which is also why it fits so well for the context of preventive eHealth services that promote behavioral change for a healthier lifestyle.

### Social Cognitive Theory

SCT has been successfully adapted to the study of the intention to engage in health protective behavior. According to SCT, six basic determinants influence health-related behavior: knowledge of the risks and benefits of health-related actions, perceived self-efficacy, outcome expectations about the costs and benefits of health-related habits, individual goals, and the perceived sociostructural barriers to and facilitators for an individual making the change and achieve her or his goals. Self-efficacy is the central part of SCT in that it influences behavior both directly and via other determinants. According to Bandura [22], other theories of health behavior predict an individual's health habits well, but SCT is the only theory to provide predictors and principles to guide individuals in behavioral change.

### The Research Model

Due to the objective of this study to investigate MyData-based preventive eHealth service acceptance in a consumer context, UTAUT2 will be adapted as the basis for our research model. As most organizations do not yet provide data for individuals in a format that would be useful and practical from the viewpoint of health data analytics and new health services [39], the use behavior and price value originally presented in UTAUT2 will be excluded from this model. Use behavior will be excluded because the target group of the study cannot experience the use situation of the MyData-based preventive eHealth services. The price value, on the other hand, will be excluded as no service models or price structures for the services in question were yet developed at the time of writing this study.

**Figure 1.** The proposed model for consumer acceptance of future MyData-based electronic health (eHealth) services.

To take account of health behavior factors, the three health behavior theories that are considered complement the UTAUT2 model with three health protection motivation constructs: self-efficacy, threat appraisals, and perceived barriers (see [Figure 1](#)). Although excluded from UTAUT as an insignificant factor for technology acceptance in an organizational context [18], self-efficacy is an important factor in health behavior theories, as it explains how an individual believes in her or his ability to achieve health outcomes [22,34,37]. Previous research has also shown that both technology-related self-efficacy factors [19,24] and healthy behavior-related self-efficacy factors [28] are significant factors in promoting health behavior [40]. Therefore, in our research model, self-efficacy is composed of two elements: technology use and healthy behavior.

Threat appraisals on the other hand play an important role in creating the motivation to take action to avoid a negative health outcome or to improve one's poor health condition [37] while using preventive eHealth services. According to protection motivation theory, threat appraisals include two components: severity (the seriousness of a possible health threat) and an individual's vulnerability (the risk of encountering a health threat). Both components have been found significant in previous research [19,24,36]. Hence, in our research model, we also apply the two-component construct for threat appraisals.

Finally, a wide variety of perceived barriers can have a significant negative influence on behavioral intention to use those systems. In the acceptance of new technologies, consumers have been found to have perceived psychological risks that prevent the adoption of new technologies [25]. There is evidence that consumers generate perceived risks regarding preventive eHealth services, especially before use [33]. Relevant issues that have been considered as barriers to the acceptance of preventive eHealth services are, for example, concerns about information abuse, privacy invasion, personal impediments [19], resistance to change, and technological anxiety [20]. Negative perceptions of the quality of technology-based services can also influence the acceptance of those services [41]. Preventive eHealth services are new innovations that require individuals to gather and store personal and sensitive health data in personal health records [11]. In addition, the adoption of preventive eHealth does not only include adopting a new technology but can also aim for significant changes in an individual's lifestyle [42]. To capture the effect of potential barriers as widely as possible, our research model includes five barrier components considered in previous research: information risk, personal impediments, resistance to change, technological anxiety, and technology risk. A summary table of the studies used as a reference to our research is included in [Multimedia Appendix 1](#).

## Research Hypotheses

### Performance Expectancy

In the context of preventive eHealth services, the use of the technology will provide benefits for an individual in preventing her or him from falling ill [43]. For example, in the future, the analysis and visualization of personal data will allow individuals to understand their health better and to support and enable self-care [39]. Performance expectancy has been found to be the most important direct predictor of behavioral intention in most information technology acceptance [18] and preventive eHealth studies [19,24,44].

Hypothesis 1: Performance expectancy will influence behavioral intention positively.

### Effort Expectancy

Effort expectancy has been found to have a significant effect, especially for the elderly consumers' acceptance of preventive eHealth services [24]. On the other hand, Jung and Loria [45] found that the difficulty associated with the use of preventive eHealth technology is usually related to the user's lack of experience with the use of the Internet in general. Similar findings have been presented by Jung and Berthon [46] about the difficulty of using preventive eHealth services. Effort expectancy has been found to be positively associated with the behavioral intention to use a technology in technology acceptance literature [18].

Hypothesis 2: Effort expectancy will influence behavioral intention positively.

### Social Influence

Social influence can occur as information about the benefits of using preventive eHealth services from a health professional's advice or through media education and also as encouragement from friends or relatives. Social influences can also provide a reminder or trigger for a motivated person to take action. Social influence is determined here as encouragement or reminders from important others or media channels to promote the use of preventive eHealth services [16,36]. Social influence has been found to significantly influence behavioral intention to use a technology [18,19,36].

Hypothesis 3: Social influence will influence behavioral intention positively.

### Facilitating Conditions

The ease of access to the preventive eHealth services is an important factor, especially in the early stages of adoption, before the quality of the information has been determined [46]. The significance of assistance, education, and guidelines has been noted in the study of preventive eHealth services because they help service providers to increase users' comfort and confidence in using the system. In addition, the compatibility of preventive eHealth services with mobile phones and other popular devices that are commonly used by consumers could improve the wider adoption of eHealth services [33].

Facilitating conditions have been found to have a significant positive effect on consumers' behavioral intention to use mobile technologies [16]. Thus, consumers who perceive the future

MyData-based preventive eHealth services as both easily accessible from anywhere at any time and compatible with their devices are more willing to use these services.

Hypothesis 4: Facilitating conditions will influence behavioral intention positively.

### Hedonic Motivation

Hedonic motivation is determined as the fun or pleasure that a consumer derives from using a technology [16]. Other factors from technology acceptance literature that deal with similar emotions (such as enjoyment, joy, or liking) and can be incorporated under the determination of hedonic motivation are the consumer's attitude toward a behavior and intrinsic motivation [18]. Hedonic motivation has been found to strongly impact on behavioral intention to use a technology in a consumer context [16,26].

Hypothesis 5: Hedonic motivation will influence behavioral intention positively.

### Habit

Habit is determined as the extent to which an individual believes performing a behavior (eg, using mobile apps to track exercise) to be automatic as a result of learning during past behavior [47]. According to Venkatesh et al [16], the repeated performance of a behavior in a similar context or environment can produce stored intentions and positive attitudes that are associated with the behavior. Thus, if the person faces a similar context or environment again to that in which the habit was formulated, the stored intentions can be triggered that lead to the same behavior [16].

Hypothesis 6: Habit will influence behavioral intention positively.

### Self-Efficacy

Self-efficacy is defined as one's confidence in one's ability to successfully perform a behavior that leads to a valued outcome. The definition overlaps with the perceived behavioral control factor in the TPB. Self-efficacy is an important factor because it influences an individual's aspirations and goals in general. If one has high self-efficacy, one will set higher goals and will have higher expectations of achieving those goals [22]. Consumers with high self-efficacy will learn faster and be more confident to use preventive eHealth services, which positively influences acceptance of those technologies [24]. As preventive eHealth services are promoting significant changes in consumers' lifestyles that demand individual effort, self-efficacy influences both the acceptance of those goals and success in achieving them. In addition to using preventive eHealth services successfully and achieving these changes in lifestyle, one must have the ability to first, use the technology, and second, one must be able to comply with the healthy behavior.

Thus, a person with high self-efficacy will be likely to believe that using preventive eHealth services will generate better health outcomes compared with a person with low self-efficacy.

Following this, the following can be hypothesized:

Hypothesis 7: Self-efficacy will influence behavioral intention positively.

Another significant aspect of self-efficacy is that it negatively influences cognitive barriers. If one has high efficacy, one will view obstacles as surmountable and will continue on the path to achieving one's goals [22]. An individual is likely to face some obstacles while trying to improve her or his health. According to protection motivation theory, an individual will create the motivation to take part in a preventive health action based on her or his evaluation of the intrinsic and extrinsic rewards of negative behavior (such as unhealthy eating habits or watching TV instead of doing exercise) weighed against the threat of reducing her or his health status. Here, the intrinsic rewards (bodily pleasure) and extrinsic rewards (peer approval) act as barriers to preventive health behavior [37]. Thus, the higher self-efficacy of an individual will negatively influence perceived barriers, as the individual will see those barriers as surmountable with self-control and will also be more involved in achieving her or his goals [22].

Hypothesis 8: Self-efficacy will influence perceived barriers negatively.

### Threat Appraisals

The stronger the threat appraisals are, the stronger the motivation for an individual to take part in healthy behavior [34]. According to Wilkowska and Ziefle [15], consumers with a higher need for health care and higher threat appraisals, such as chronically ill patients, also tend to pay less attention to the risk factors related to eHealth services. Thus, it can be expected that consumers with higher threat appraisals will have a stronger behavioral intention to take part in preventive health behavior and will have a stronger behavioral intention and fewer barriers to using preventive eHealth services. In addition, Kim and Park [11] also found that persons who perceive high health threats will also perceive preventive eHealth services as more useful than healthy people. Following these assumptions, the following can be hypothesized:

Hypothesis 9: Threat appraisals will influence behavioral intention positively.

Hypothesis 10: Threat appraisals will have an influence on the perceived barriers negatively.

### Perceived Barriers

Perceived barriers are defined in the HBM as potential negative aspects that would be expensive, dangerous, unpleasant, inconvenient, or time-consuming when taking a particular health action [34]. Relevant issues related to information risks and technology risks that cause significant barriers to the acceptance of preventive eHealth services are, for example, worrying about information abuse, privacy invasion, the lack of precision of equipment, and excessive charges [19]. The study by Guo et al [20] found that among elderly users, resistance to changing their lifestyle and technology anxiety regarding eHealth technologies both produce significant cognitive barriers to technology acceptance. Other issues that can raise concerns in consumers are, for example, how and for what purpose all the health data gathered from them will be used by the service provider [48].

According to the HBM, barriers have a significant effect on an individual's intention to take health protective actions [34]. Thus, consumers who perceive barriers to health behavior and

the use of preventive eHealth technologies will have less behavioral intention to use MyData-based preventive eHealth services. On the basis of the above, the following can be hypothesized:

Hypothesis 11: Perceived barriers influence behavioral intention negatively.

## Methods

### Measurement

The research model is composed of 16 constructs. The constructs were measured with multiple, reflective items on a 5-point Likert scale. Most of the measurement items were adapted from prior research to preserve content validity. The only exception is the construct *performance expectancy*, in which three additional items were included to reflect the expected performance of the services under the study. However, items were prior evaluated by medical, business, and information systems researchers from the DHR project and statistically tested similarly to all the other items in the other factors. Because at the time of the survey the studied service did not yet exist, we had to measure habit with items reflecting the use of existing eHealth or wellness technologies such as heart rate monitors and mobile phone apps related to exercise or nutrition. This approach is justified by Limayem et al [47], who define habit as the degree to which consumers use technologies automatically because of learning. They further state that habit is conditioned by stable contexts that are characterized by the presence of similar situational cues and goals across more or less regularly occurring situations and that the strength of habit related to multifunctional technologies (such as using different eHealth apps) depends on the degree of frequency and diversity of prior use of these types of technologies. Further justification can be found in the study by Venkatesh et al [16], which found that a repeated performance in a similar context can result in habit formation. Hence, we can assume that because the existing eHealth and wellness services can be regarded quite similar to the developed MyData-based eHealth services (the main differentiator is extent of the utilization of personal data in personalizing the service), the extent of the use of the existing eHealth can be used in operationalizing the habit construct. The original items in the survey instrument were translated into Finnish and reviewed by four experienced researchers from the University of Oulu. A back translation by a professional translator was also performed to ensure item content validity. The items are included in [Multimedia Appendix 2](#).

### Data Collection

Data for the study was collected using a quantitative, Web-based questionnaire survey. The survey was a part of a large national research program, DHR, coordinated by the University of Oulu. The goal of this multidisciplinary research program is to enable the utilization of data about the individual as part of personal, preventive services, which in turn will improve citizens' opportunities for self-management of their well-being. The aim of this study was to investigate what factors influence consumers' intentions to use a MyData-based preventive eHealth service before use. The sample frame was the faculty and the staff of the University of Oulu, a total of 2852 people. The link

to the survey was sent via email. The email included both the link to the Web-based survey in WebPropol survey service and a cover letter explaining the research phenomenon and research context, the purpose of the survey, and the use of the data, as well as encouragement to answer. The email was sent to the sample frame in March 2015, and the link for the survey was open for 1 week. We had a total of 855 respondents out of 2852 (29.98% response rate) who voluntarily chose to answer the survey. The demographic distribution of the respondent group is shown in [Table 1](#).

The gender distribution of the respondent group was female dominated with over two-thirds of the respondents being women. Almost 70% (579/855) of the respondents belonged to the two youngest age groups.

### Empirical Analyses

Empirical analyses were made using SEM with Mplus software, version 7.4. Estimations were made using maximum likelihood based on covariance matrix. First, we ran traditional SEM for the research model. That was not statistically significant, and thus, we tested possible heterogeneity in the data by running mixture analysis.

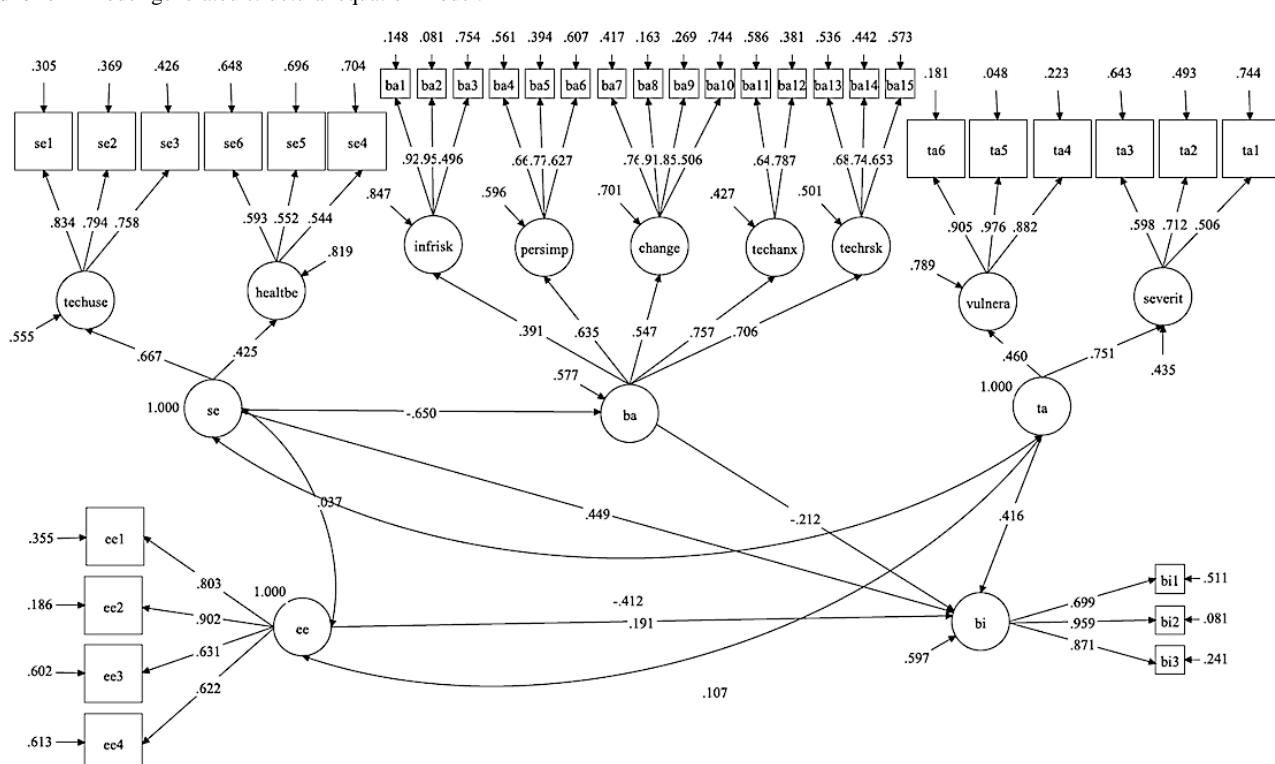
**Table 1.** The demographic distribution of the respondents.

Characteristics	n (%)
<b>Gender</b>	
Male	305 (35.7)
Female	550 (64.3)
Total	855 (100)
<b>Age (years)</b>	
18-25	352 (41.2)
26-35	227 (26.5)
36-45	119 (13.9)
46-55	107 (12.5)
56-65	48 (5.6)
66 and over	2 (0.2)
Total	855 (100)

We found that heterogeneity of the data was not an issue in this case. Thus, we moved on toward model-generating SEM [49]. On the basis of theoretical justifications and fit indices of the generated model (root mean square error of approximation [RMSEA] 0.051—according to Browne and Cudeck [50], a RMSEA value below 0.8 stands for a reasonable error of approximation; Tucker-Lewis index [TLI] 0.906 and comparative fit index [CFI] 0.915—Hu and Bentler [51] argue that a value close to 0.95 for both TLI [nonnormed fit index] and CFI are needed before we can conclude that there is a relatively good fit between the hypothesized model and the observed data; and standardized root mean square residual 0.062), we judge the empirical model to be statistically significant. Average variances extracted (AVEs), squared AVEs, and composite reliabilities (CRs) are presented in [Table 2](#). According to Hair et al [52], all factors excluding the *Healthbe* and CR of *Techanx* are statistically significant. However, according to Steenkamp and van Trijp [53], all factors fulfill a weak and stronger convergent validity because factor loadings are statistically significant and coefficients are substantial.

**Table 2.** Construct reliabilities.

Label	Infrisk <sup>a</sup>	Persimp <sup>b</sup>	Change <sup>c</sup>	Techanx <sup>d</sup>	Techrsk <sup>e</sup>	Severit <sup>f</sup>	Vulnera <sup>g</sup>	Techuse <sup>h</sup>	Healthbe <sup>i</sup>	EE <sup>j</sup>	BI <sup>k</sup>
AVE <sup>l</sup>	0.669	0.590	0.707	0.508	0.592	0.718	0.528	0.655	0.488	0.692	0.684
Squared AVE	0.820	0.768	0.841	0.713	0.769	0.847	0.762	0.809	0.699	0.832	0.827
CR <sup>m</sup>	0.852	0.733	0.853	0.679	0.736	0.944	0.637	0.838	0.582	0.833	0.885

<sup>a</sup>Information risk.<sup>b</sup>Personal impediments.<sup>c</sup>Resistance to change.<sup>d</sup>Technology anxiety.<sup>e</sup>Technology risk.<sup>f</sup>Severity.<sup>g</sup>Vulnerability.<sup>h</sup>Technology use self-efficacy.<sup>i</sup>Healthy behavior self-efficacy.<sup>j</sup>Effort expectancy.<sup>k</sup>Behavioral intention.<sup>l</sup>AVE: average variance extracted.<sup>m</sup>CR: composite reliability.**Figure 2.** A model-generated structural equation model.

**Table 3.** Structural equation model; beta and *P* values.

Predicted construct and predictor constructs	Beta	<i>P</i> value
<b>Behavioral intention</b>		
Effort expectancy	.191	<.001
Self-efficacy	.449	<.001
Threat appraisals	.416	<.001
Perceived barriers	-.212	.009
<b>Perceived barriers</b>		
Self-efficacy	-.650	<.001

## Results

The hypotheses and their judgments based on the SEM results are shown in **Table 4**. Quite surprisingly, most of the hypotheses related to explanatory UTAUT2 constructs were rejected. Only effort expectancy was found to have a statistically significant effect on behavioral intention. The results confirm the health protection motivation constructs of our research model. On the basis of the empirical model, information risk, personal

impediments, resistance to change, technological anxiety, and technological risk are the significant dimensions of barriers. Severity and vulnerability are dimensions of threat appraisals, and finally, technology use and healthy behavior are dimensions of self-efficacy. All three health motivation constructs have a significant effect on behavioral intention. Furthermore, our model also found a correlation between self-efficacy and threat appraisals. In addition, barriers seem to have a negative mediating effect from self-efficacy toward behavioral intention.

**Table 4.** The tested hypotheses.

Hypothesis (H)	Description	Judgment
H1	Performance expectancy will influence behavioral intention positively.	Rejected
H2	Effort expectancy will influence behavioral intention positively.	Accepted
H3	Social influence will influence behavioral intention positively.	Rejected
H4	Facilitating conditions will influence behavioral intention positively.	Rejected
H5	Hedonic motivation will influence behavioral intention positively.	Rejected
H6	Habit will influence behavioral intention positively.	Rejected
H7	Self-efficacy will influence behavioral intention positively.	Accepted
H8	Self-efficacy will influence perceived barriers negatively.	Accepted
H9	Threat appraisals will influence behavioral intention positively.	Accepted
H10	Threat appraisals will influence perceived barriers negatively.	Rejected
H11	Perceived barriers will influence behavioral intention negatively.	Accepted

## Discussion

### Principal Findings

Contrary to prior research applying UTAUT in an eHealth context [54,55], performance expectancy was not found to be a significant factor in explaining behavioral intention. One reason for this result could be that our research was conducted among consumers, whereas the majority of the existing research considers the factors influencing technology use by health care professionals. All in all, most of the hypotheses related to UTAUT2 constructs were rejected. Of the UTAUT2 constructs included in the research model, only effort expectancy seemed to have a significant influence on behavioral intention. It thus seems that the model does not perform well in explaining consumers' intentions to use eHealth services before actual use, which was the case in this study.

Regarding the health protection motivation constructs, the results were the opposite as all three constructs—threat appraisals, self-efficacy, and perceived barriers—were found to have a significant influence on behavioral intention. In addition to the fact that our study focused on the intention to use future services instead of actual service use, there are other possible reasons for the poor performance of UTAUT2 constructs. Due to the focus on preventive eHealth services, the respondent group in our study had a proportion of healthy people who did not have a chronic illness. Our study also had younger participants compared with many other studies [56,57]. Furthermore, whereas many other studies focus on the usage of eHealth services as such [56,58], our study focused on the situations in which a person gave permission to use her or his data in eHealth services.

## Theoretical Implications

Our study contributes to the health information technology literature in two ways. First, we provide a research model that combines the standard UTAUT model with health protection motivation constructs, thus bridging the gap between technology adoption and health behavior theories. Second, our study focuses on increasing understanding of the factors influencing consumers' eHealth technology acceptance instead of focusing on the acceptance of health care professionals.

## Managerial Implications

Our research highlights the importance of the two health protection motivation constructs. Both threat appraisals and self-efficacy were found to be significant determinants of the intention to use future preventive eHealth services. Both technology use self-efficacy and healthy behavior self-efficacy were found to be significant components of the construct. This result suggests that to promote the use of new preventive eHealth services, emphasis must be placed on both technology use and healthy behavior education. Increased awareness of eHealth technology use and healthy behavior will also have a positive effect as it will diminish the effects of perceived barriers, which were found to have a significant negative impact on intention to use a service.

Typically, the importance of effort expectancy has been found in the studies on elderly people's intention to use eHealth services [58]. Our result is thus surprising, as the participants in our study were mainly younger people (under 55 years). The fact that effort expectancy was found as a significant determinant of intention to use the service implies the importance of design issues in new eHealth services adoption. The results by Daim et al [59], indicating that different levels of technology understanding and health literacy can have a significant influence on the user experience of preventive eHealth services, further stresses the importance of design issues. The understanding of the importance of effort expectancy and self-efficacy related to the MyData-based preventive eHealth services has a significant impact on understanding the adoption of the MyData approach and MyData-based eHealth services in general.

## Limitations

There are also some limitations that must be considered when considering the generalizability of our results. The research context of future technologies and services that have not been developed yet to their fullest potential poses some limitations. First, the quantitative survey was based on a hypothetical use situation, and thus, the target group did not experience the actual use of the service. Second, the construct of *habit* had to be measured based on the use experience of existing eHealth apps that are only possibly related to the MyData-based preventive eHealth services of the future. Another limitation for this study is the sampling frame of university staff and faculty. Even though the survey link was sent to people with different educational backgrounds and work descriptions, we must however acknowledge that so called "blue-collar" workers may

be underrepresented. Furthermore, in our study, women are overrepresented because 63.4% (550/855) of the respondents were women and their share of Finnish working age people is 49.65% [60]. This may cause bias because women have been found to be more likely to engage in eHealth activities [61]. Poor performance of UTAUT constructs could also be considered as a limitation. Our approach was not to test the performance of the UTAUT2 model but to find as holistic a model as possible with statistical support, so we included both UTAUT2 and health protection motivation constructs to the research model. This research model, together with the fact that we were studying the intention to use future services, may all play a role in the results. However, based on Model Generating Structural Equation Modeling (MGSEM), we, for example, removed factor *habit*, which is similar in result with Oliveira et al [62]. Furthermore, our results give rise to similar conclusions to previous studies, which highlight the importance of increasing eHealth-related self-efficacy through education and making services easy to use [63,64]. Thus, we can argue that our limitations may not be too limiting because our results are in line with previous studies.

The above limitations lead us to the following suggestions for future research avenues. First, future research should test the acceptance of these preventive MyData-based eHealth services in an actual-use context and investigate how the direct factors perform in that context. Second, future research should also consider a wider coverage of consumers with a nonacademic background to see the relationships between the considered variables in a larger demographic setting. The importance of inclusion of different demographic segments in eHealth research and promotion activities was also stressed in the study by Kontos et al [61].

## Conclusions

Our study contributes to the exploration of the factors influencing the consumers' intention to use MyData-based preventive eHealth services before use. We combine the key factors of UTAUT2 and health behavior theories to our research model and apply the quantitative SEM approach to analyze the relationships between the constructs of the research model. Our results indicate that UTAUT2 constructs perform poorly. Only effort expectancy had a significant effect on the intention to use. Contrary to UTAUT2 constructs, all constructs adapted from health behavior theories—threat appraisals, self-efficacy and perceived barriers—were found to have a significant effect on the intention to use. These results suggest that to promote the adoption of preventive eHealth services among consumers, it is essential to invest in increasing the general awareness of healthy behavior and in the expertise of using eHealth technologies. From societal perspective, this implies increasing investment in health and technology-related education. From service perspective, higher probability of new preventive eHealth service adoption could be achieved, for example, by increasing consumer involvement in the creation of services through collaborative practices.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Summary table of eHealth acceptance studies.

[[PDF File \(Adobe PDF File, 17KB - jmir\\_v19i12e429\\_app1.pdf](#) ]

## Multimedia Appendix 2

Questionnaire items.

[[PDF File \(Adobe PDF File, 196KB - jmir\\_v19i12e429\\_app2.pdf](#) ]

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## Abbreviations

**AVE:** average variance extracted  
**CFI:** comparative fit index  
**CR:** composite reliability  
**DHR:** Digital Health Revolution  
**eHealth:** electronic health  
**HBM:** health belief model  
**mHealth:** mobile health  
**RMSEA:** root mean square error of approximation  
**SCT:** social cognitive theory  
**SEM:** structural equations modeling  
**TAM:** technology acceptance model

**TLI:** Tucker-Lewis index**TPB:** theory of planned behavior**UTAUT:** Unified theory of acceptance and use of technology

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Original Paper

# A Web-Based Training Resource for Therapists to Deliver an Evidence-Based Exercise Program for Rheumatoid Arthritis of the Hand (iSARAH): Design, Development, and Usability Testing

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## Abstract

**Background:** The Strengthening and Stretching for Rheumatoid Arthritis of the Hand (SARAH) is a tailored, progressive exercise program for people having difficulties with wrist and hand function due to rheumatoid arthritis (RA). The program was evaluated in a large-scale clinical trial and was found to improve hand function, was safe to deliver, and was cost-effective. These findings led to the SARAH program being recommended in the UK National Institute for Health and Care Excellence guidelines for the management of adults with RA. To facilitate the uptake of this evidence-based program by clinicians, we proposed a Web-based training program for SARAH (iSARAH) to educate and train physiotherapists and occupational therapists on delivering the SARAH program in their practice. The overall iSARAH implementation project was guided by the 5 phases of the analysis, design, development, implementation, and evaluation (ADDIE) system design model.

**Objective:** The objective of our study was to conduct the first 3 phases of the model in the development of the iSARAH project.

**Methods:** Following publication of the trial, the SARAH program materials were made available to therapists to download from the trial website for use in clinical practice. A total of 35 therapists who downloaded these materials completed an online survey to provide feedback on practice trends in prescribing hand exercises for people with RA, perceived barriers and facilitators to using the SARAH program in clinical practice, and their preferences for the content and Web features of iSARAH. The development and design of iSARAH were further guided by a team of multidisciplinary health professionals (n=17) who took part in a half-day development meeting. We developed the preliminary version of iSARAH and tested it among therapists (n=10) to identify and rectify usability issues and to produce the final version.

**Results:** The major recommendations made by therapists and the multidisciplinary team were having a simple Web design and layout, clear exercise pictures and videos, and compatibility of iSARAH on various browsers and devices. We rectified all usability issues in the preliminary version to develop the final version of iSARAH, which included 4 short modules and additional sections on self-assessment, frequently asked questions, and a resource library.

**Conclusions:** The use of the ADDIE design model and engagement of end users in the development and evaluation phases have rendered iSARAH a convenient, easy-to-use, and effective Web-based learning resource for therapists on how to deliver the SARAH program. There is also huge potential for adapting iSARAH across different cultures and languages, thus opening more opportunities for wider uptake and application of the SARAH program into practice.

**KEYWORDS**

hand function; hand exercises; rheumatoid arthritis; online training; implementation

## *Introduction*

Rheumatoid arthritis (RA) is a chronic inflammatory joint disease that presents with pain, inflammation, stiffness, and reduced muscle strength, joint movements, and joint function [1,2].

Joints of the hands and wrists are very commonly affected in people with RA [2,3], resulting in reduced functional ability of the hands [4-7]. The Strengthening and Stretching for Rheumatoid Arthritis of the Hand (SARAH) program is an individually tailored, progressive exercise program for people with pain and hand function problems due to RA [8,9]. It includes mobility exercises for the hand, wrist, and shoulder and strengthening exercises for the hand and wrist muscles. The exercises are delivered by a therapist with behavioral support strategies for exercise adherence, such as exercise diaries, goal setting, action planning, confidence building, and problem solving, along with routine advice on joint protection, assistive devices, and splints. Between 2009 and 2011, a large, pragmatic, multicenter randomized controlled trial (ISRCTN 89936343) evaluated the SARAH program across 17 National Health Service (NHS) hospitals in the United Kingdom [10]. A total of 490 adults with diagnosed RA, and who had been on a stable drug regimen for at least 3 months, were randomly assigned to receive best practice usual care either alone or in conjunction with the SARAH program. Significant improvements in overall hand function and self-efficacy were seen at 4 and 12 months in participants who received the SARAH program. The program was also found to be safe and cost-effective [10]. Based on this research, the exercise program is now recommended in the UK National Institute for Health and Care Excellence (NICE) guidelines for patients with RA affecting their hands [11].

Due to the success of the program and the NICE recommendations, we are now aiming to disseminate the evidence-based SARAH program to facilitate its use in clinical practice. In the original clinical trial, therapists attended a face-to-face training session (one-half to 1 day in duration) to learn how to deliver the SARAH program. Following the publication of the SARAH clinical trial results, all the patient and therapist materials required to deliver the SARAH program were made available for health care professionals worldwide downloadable from the Oxford Clinical Trials Research Unit (OCTRU) website [12].

However, we recognized the need for a knowledge dissemination tool with the potential to facilitate wider and systematic uptake of the SARAH program by physiotherapists and occupational therapists and its implementation in clinical practice. We, therefore, proposed a free Web-based training program for SARAH, iSARAH [13], to serve this purpose. Web-based training programs use modern telecommunication and information technologies to deliver information and have the capacity to accommodate multimodal learning formats (eg,

written materials, multimedia, animations, feedback, and assessments) [14,15]. They can reach many people at their convenience, can overcome geographical barriers, and are cost-effective in terms of time, effort, and travel [15]. Web-based training has the potential to be an effective method of reaching and training health professionals globally [16-20].

The iSARAH implementation project is based on the analysis, design, development, implementation, and evaluation (ADDIE) model, one of the common instructional system design models used for constructing Web-based programs [21-24].

The analysis stage comprises defining the problem, identifying the target knowledge users, and looking for possible solutions to bridge the knowledge-action gap and user-specific needs for the dissemination tool. In the context of the SARAH program, the knowledge-action gap is the evidence-based SARAH program (current knowledge) and its application in practice (action). The targeted users are the physiotherapists and occupational therapists who routinely treat and prescribe hand exercises to people with RA. We proposed to bridge the knowledge-action gap by educating and training the therapists on the SARAH program with a knowledge dissemination tool (iSARAH).

The design stage consists of finding ways to organize and present the content, identifying modes of delivery, and developing an evaluation plan of the dissemination tool. This stage involves conceptualizing and adapting the SARAH program to fit the Web-based iSARAH.

The development stage involves building iSARAH, evaluating its usability issues, and refining iSARAH to develop the final version.

The implementation stage involves making iSARAH available for NHS therapists.

The evaluation stage will include evaluation of learning outcomes such as knowledge, attitudes, intention to implement and user satisfaction with iSARAH, and evaluation of actual use of the SARAH program by iSARAH-trained therapists in real-world settings.

Here we describe the first 3 phases of the iSARAH implementation project.

## *Methods*

### **Phase 1: iSARAH Needs Analysis**

Specific objectives of this phase were (1) to explore routine exercise prescription practices and outcomes use among therapists who treat people with RA affecting the hands and wrists, (2) to identify barriers and facilitators to implementing the SARAH program, and (3) to collect therapists' opinions and preferences on the design, content, and features of iSARAH.

A convenience sample of physiotherapists and occupational therapists of different countries who downloaded the SARAH program materials from the OCTRU website and gave permission to be contacted by the SARAH team were considered eligible for participation in the SARAH survey. Willingness to provide consent for taking part in the survey was the other inclusion criterion.

We developed a survey questionnaire ([Multimedia Appendix 1](#)) that focused on routine therapist practice patterns in prescribing hand exercises for people with RA, and their experiences of using the SARAH program in clinical practice since they downloaded the SARAH program materials. We also asked therapists about barriers and enablers to using the SARAH program, and their preferences for the content, design, and structure of iSARAH. We sent invitation emails with a weblink containing information about the survey, along with a consent form and some questions relating to the therapists' professional background and experience. Access to the survey was allowed for those therapists who provided online consent. Those who consented were asked to complete the survey within 2 weeks. For nonresponders, a reminder email was sent after 2 weeks, followed by a final reminder a week later.

The survey protocol was reviewed and approved by the medical sciences Inter-Divisional Research Ethics Committee at the University of Oxford, Oxford, UK (reference number R43362/RE001). The SARAH survey was developed using LimeSurvey (LimeSurvey GmbH), an open source survey tool, and was hosted by OCTRU, University of Oxford.

## Phase 2: iSARAH Design

Specific objectives of this phase were (1) to design a paper prototype of iSARAH, and (2) to gain feedback from a multidisciplinary group of health professionals and to agree on the content, delivery methods, frequently asked questions (FAQs), and the navigation, layout, and visual appeal features of iSARAH.

The SARAH research team and information technology experts mapped the SARAH program from the SARAH clinical trial to a 3- to 4-hour Web-based training package for therapists and designed a paper prototype. We proposed a half-day meeting with rheumatology clinicians, researchers, and technology experts based on their convenience and availability to attend the meeting. The purpose of this meeting was to gain collective feedback on the prototype and the survey findings to finalize the design of iSARAH. The paper prototype was presented at a half-day multidisciplinary team meeting (n=17) involving a rheumatologist (n=1), occupational therapists and physiotherapists (n=10; 7 of whom were part of the SARAH trial), SARAH trial researchers (n=4), and information technology experts (n=2).

## Phase 3: iSARAH Development and Usability Testing

Specific objectives of this phase were (1) to develop the iSARAH website, (2) to gain end user feedback on the usability, usefulness, ease of use, and confidence in using iSARAH, and (3) to rectify usability issues and further refine iSARAH prior to its implementation.

This phase involved building iSARAH (preliminary version) and evaluating its usability, usefulness, and ease of use and user confidence [[25,26](#)]. The usability evaluation protocol was reviewed and approved by the medical sciences Inter-Divisional Research Ethics Committee, University of Oxford (reference number R47560/RE001).

NHS hand therapists (physiotherapists and occupational therapists) who were treating people with RA and lived within 2 hours of travel to Oxford were considered eligible for participation in the usability testing. Willingness to provide signed consent was the inclusion criterion. We invited volunteers via the Centre for Rehabilitation Research in Oxford Twitter page and the online community forum of the Chartered Society of Physiotherapy.

Based on the available evidence that 80% of usability issues can be identified by testing with 5 participants and that 95% can be identified with 9 participants [[27,28](#)], we proposed to include 10 therapists who fulfilled the inclusion criteria.

We coordinated individual appointments to attend usability sessions through telephone calls and conducted the sessions at the Botnar Research Centre, University of Oxford. Before evaluation, participants provided signed consent and completed a series of demographic questions. The usability testing procedure was then explained emphasizing that the session was about evaluating iSARAH and not the user. Each session took approximately 90 minutes. The usability testing involved the following procedures.

### Think-Aloud Procedure

The procedure was facilitated by 1 of the members of the SARAH implementation team. Participants were asked to log on to the iSARAH website by registering with test usernames and passwords. They were then asked to navigate through the website, starting from the home page. They were simultaneously encouraged to talk about what they felt, saw, or thought while browsing. The facilitator observed and took notes as participants were asked to verbalize their thoughts. When participants had difficulties in verbalizing, they were encouraged by a “keep talking” signboard and were minimally assisted with prompts (only when required) by the facilitator. All think-aloud sessions were audio recorded.

### Self-Reported Questionnaires

We used the Computer System Usability Questionnaire (CSUQ) [[29](#)] to evaluate user satisfaction, ease of use, information, and interface of the program on a 7-point Likert scale (1=strongly disagree to 7=strongly agree).

We measured iSARAH usefulness on a 5-point Likert scale (1=not at all useful, 2=slightly useful, 3=moderately useful, 4=very useful, and 5=extremely useful).

We measured overall ease of use on a 5-point Likert scale (1=very difficult, 2=somewhat difficult, 3=neither difficult nor easy, 4=somewhat easy, and 5=very easy).

We measured confidence in using iSARAH on a 5-point Likert scale (1=not at all confident, 2=somewhat confident, 3=not sure, 4=confident, and 5=very confident).

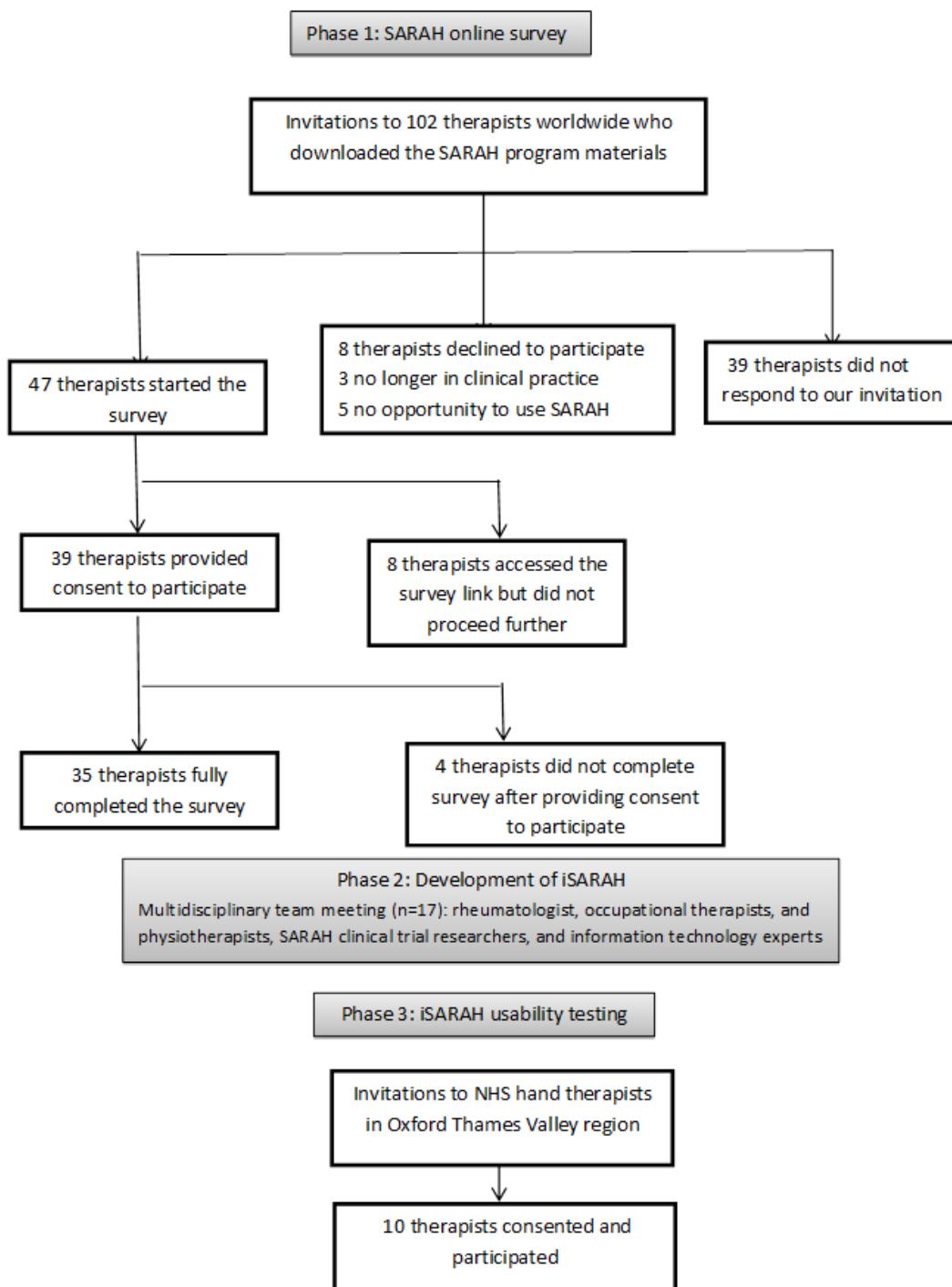
## Interviews

Using a semistructured interview guide, we asked participants about their experiences in navigating iSARAH. Interviews were conducted for approximately 10 to 15 minutes and were audio recorded. We summarized users' comments on iSARAH by listening to the audio files and cross-checking a second time.

## Results

**Figure 1** shows the flow of participants through the 3 phases of iSARAH.

**Figure 1.** Study flow diagram. SARAH: Strengthening and Stretching for Rheumatoid Arthritis of the Hand; iSARAH: Web-based training program for SARAH; NHS: National Health Service.



**Table 1.** Demographic characteristics of therapists participating in phase 1 and phase 3 of the study.

Demographics	Phase 1 (SARAH <sup>a</sup> survey) (n=35)	Phase 3 (iSARAH <sup>b</sup> usability testing) (n=10)
<b>Age groups in years, n (%)</b>		
21-30	4 (11)	0
30-40	5 (14)	2 (20)
40-50	16 (46)	5 (50)
>50	10 (29)	3 (30)
<b>Sex, n (%)</b>		
Male	4 (11)	1 (10)
Female	31 (89)	9 (90)
<b>Profession, n (%)</b>		
Occupational therapists	18 (51)	7 (70)
Physiotherapists	17 (49)	3 (30)
<b>Employment, n (%)</b>		
Full-time	18 (51)	6 (60)
Part-time	17 (49)	4 (40)
<b>Work setting, n (%)</b>		
Public (eg, NHS <sup>c</sup> hospital)	32 (91)	10 (100)
Private practice	1 (3)	0
Other (eg, teaching)	2 (6)	0
<b>Work experience in years</b>		
<5	5 (14)	
5-10	14 (40)	
10-15	3 (9)	
>15	13 (37)	
Median (IQR <sup>d</sup> )	N/A <sup>e</sup>	17 (9.25)
Hours on Internet/day, Median (IQR)	N/A	2 (0.5)

<sup>a</sup>SARAH: Strengthening and Stretching for Rheumatoid Arthritis of the Hand.

<sup>b</sup>iSARAH: Web-based training program for SARAH.

<sup>c</sup>NHS: National Health Service.

<sup>d</sup>IQR: interquartile range.

<sup>e</sup>N/A: not applicable.

**Table 2** describes the key features of the therapists' current clinical practice. Most respondents saw more than 10 patients per month with RA.

Pain, self-reported hand function, joint range of motion, stiffness, grip and pinch strength, and joint deformities were more commonly evaluated as part of their current practice. Performance-based hand function, 28-joint Disease Activity Score, and activities of daily living were the least evaluated outcomes.

The most common type of exercise prescribed by therapists was active range of motion exercises. Strengthening exercises were also frequently used, as were tendon gliding exercises. Nerve gliding, passive, and isometric exercises were much less commonly prescribed.

Self-management strategies, joint protection, and splinting were more commonly prescribed than thermotherapy, therapeutic gloves, work support, advice on activities of daily living, and electrotherapy.

On average, therapists had 4 sessions with their patients (mean 4, SD 3.9). The frequency of review sessions was mostly either once every 15 days, reported by 11 therapists, or every 1 to 2 months, reported by 9 therapists.

Most therapists used exercise sheets and review appointments to encourage adherence with home exercise programs. Exercise diaries, exercise contracts, and telephone reminders were less commonly used.

**Table 2.** Current practices in therapy management of rheumatoid arthritis affecting the hands (n=35).

Survey items	Therapists n (%)
<b>Average number of rheumatoid arthritis patients seen per month</b>	
>15	12 (34)
10-15	11 (31)
5-10	3 (9)
1-5	9 (26)
<b>Hand outcomes evaluated</b>	
Pain	33 (94)
Self-reported hand function	28 (80)
Joint range of motion	26 (74)
Stiffness	26 (74)
Grip and pinch strength	22 (63)
Joint deformities	19 (54)
Performance-based hand function	13 (37)
Disease Activity Score 28 and activities of daily living	4 (11)
<b>Types of hand exercises prescribed</b>	
Active range of motion	34 (97)
Strength	27 (77)
Tendon gliding	20 (57)
Nerve gliding, passive, or isometric	4 (11)
<b>Other treatments</b>	
Self-management and coping strategies	32 (91)
Joint protection advice	30 (86)
Splinting	24 (69)
Thermotherapy	15 (43)
Therapeutic gloves, work support, and advice on activities of daily living	6 (17)
Electrotherapy	2 (6)
<b>Methods to encourage exercise adherence</b>	
Exercise sheets	33 (94)
Review appointments	29 (83)
Exercise diaries	8 (23)
Exercise contracts	2 (6)
Telephone reminders	1 (3)
<b>SARAH<sup>a</sup> program prescribed in practice</b>	
Yes	26 (74)
No	9 (26)

<sup>a</sup>SARAH: Strengthening and Stretching for Rheumatoid Arthritis of the Hand.

About 74% (n=26) of the therapists delivered the SARAH program in their clinical practice, and on average had prescribed the program to 17 (SD 22) of their patients since downloading the materials. More than 50% (17/26) of the therapists who delivered the SARAH program did not find any aspect of SARAH that made it difficult to put into practice. They reported that the SARAH therapist manual, the exercise sheets with

photographs, and the strong evidence base facilitated their use of the SARAH program in their daily practice. Other therapists reported issues with time, funding for exercise equipment, and inability to complete review assessments and exercise contracts.

Therapists who did not use the SARAH program (n=9) reported a lack of appropriate patients to be prescribed the SARAH program, budget, time, and their routine prescription of hand

exercises like the SARAH program as main reasons for nonimplementation. **Table 3** presents barriers and facilitators identified by therapists who completed the survey (n=35).

We asked therapists what they would like to see in a Web-based training program if one were available. **Textbox 1** lists their suggestions.

## Phase 2: iSARAH Design

Following the multidisciplinary team meeting, we identified the specific need to educate and train therapists on the behavioral support strategies and proposed a separate module on this topic. We agreed that a section addressing common questions that might be raised by therapists about the SARAH program in real-world settings should be included in an FAQ section of iSARAH. Attendees provided suggestions for framing these questions. Based on discussions about the iSARAH prototype and SARAH survey findings, the team suggested the following recommendations: (1) to provide weblinks within the text for

additional information on a topic, for example, Splints in RA, (2) to provide a progression status bar to enable users to know where they are in the training, (3) to use consistent names for exercises, (4) to have a separate educational video on joint protection advice, (5) to have a separate module on behavioral support strategies, (6) to have SARAH exercises demonstrated through videos and photographs, (7) to have brief modules, (8) to have a plain layout and use optimal font sizes (14 point), (9) to have an official email support to address technical enquiries, and (10) to ensure iSARAH adapts across different types of Internet browsers and computers at NHS settings and other telecommunication devices.

Specific recommendations were also made regarding the behavioral strategies module: (1) to provide examples of general goals relating to upper limb function to aid therapists with goal setting, and (2) to include model scenarios on filling in the personal exercise guide and Barriers and Facilitators form.

**Table 3.** Barriers and facilitators reported by therapists who completed the SARAH<sup>a</sup> survey (n=35).

Barriers and facilitators	Always a barrier n (%)	Sometimes a barrier n (%)	Neither a barrier nor a facilitator n (%)	Sometimes a facilitator n (%)	Always a facilitator n (%)
Time	7 (20)	16 (46)	11 (31)	1 (3)	0 (0)
Forgetting to use	2 (6)	10 (29)	21 (60)	0 (0)	2 (6)
Belief in its effect on patients	0 (0)	0 (0)	12 (34)	10 (29)	13 (37)
Influence of peers	0 (0)	5 (14)	23 (66)	6 (17)	1 (3)
The need to change practice	0 (0)	5 (14)	14 (40)	8 (23)	8 (23)
Instructions to deliver the program	0 (0)	4 (11)	12 (34)	10 (29)	9 (26)
Current caseload	1 (3)	6 (17)	9 (26)	9 (26)	10 (29)
SARAH exercise equipment	7 (20)	11 (31)	14 (40)	1 (3)	2 (6)
SARAH patient materials	5 (14)	11 (31)	10 (29)	3 (9)	6 (17)

<sup>a</sup>SARAH: Strengthening and Stretching for Rheumatoid Arthritis of the Hand.

**Textbox 1.** Therapists' suggestions for what a Web-based training program should have.

- A simple Web layout and design
- Exercise photographs and videos with clear instructions
- Brief training modules
- A self-assessment section
- Simplified Strengthening and Stretching for Rheumatoid Arthritis of the Hand (SARAH) patient materials
- Instructions on how to complete the personal exercise guide, exercise diary, and Barriers and Facilitators form
- Downloadable SARAH program materials
- Online support for technical queries
- Links for patients to access information or complete outcomes online
- PowerPoint teaching materials
- Compatibility with different browsers, such as Internet Explorer and Google Chrome, and responsiveness in different devices, such as mobiles and tablets

**Textbox 2.** Recommendations to guide the implementation and evaluation phases of the Web-based training for Strengthening and Stretching for Rheumatoid Arthritis of the Hand (iSARAH).

1. Make it clear in iSARAH that the SARAH program is flexible and will be feasible to complete at the user's convenience.
2. Send monthly email reminders to iSARAH-trained therapists.
3. Signpost therapists and their patients to resources needed to deliver the program, which could, ideally, be purchased at a discounted rate (eg, therapeutic putty, resistance bands).
4. Provide multiple hard copies of the SARAH patient materials at no cost to iSARAH-trained therapists for use in clinical practice, if required.
5. Demonstrate high credibility by incorporating information about the SARAH research team and all SARAH peer-reviewed publications.
6. Propose pain and self-reported hand function as the main outcomes for the evaluation phase.

To facilitate effective implementation of the SARAH program by iSARAH-trained therapists in actual practice, we also discussed ways to minimize major implementation barriers reported in the survey (time limitations, forgetting, and difficulties in access to and cost of SARAH exercise equipment and patient materials). Clinicians who had worked on the SARAH clinical trial raised some issues with the original forms used in the trial, and they proposed ways to streamline these forms to make them easier to use.

**Textbox 2** lists suggestions to guide the implementation evaluation phases of the SARAH program.

### Phase 3: iSARAH Development and Usability Testing

#### *Development: Preliminary iSARAH*

iSARAH was built on a Moodle platform (release version 3.1; Moodle Pty Ltd) by the OCTRU information technology team, customized and styled using the Essential Theme add-on. An overview of iSARAH (preliminary version) is provided below.

#### Landing Page

The landing page introduced the iSARAH with a brief statement about the purpose of the website, site contact information, privacy policy, and the modules. Other features included a 2.5-minute preliminary iSARAH promotional video and a prominent widget for logging on to the training.

#### Modules

Module 1 covered clinical aspects of RA, benefits of exercises in RA, UK guidelines in the management of RA, and information about the SARAH clinical trial.

Module 2 covered development and physiological principles of the SARAH program, behavioral support strategies, and instructions on how to deliver the SARAH program.

Module 3 covered the self-assessment.

Module 4 included FAQs to inform the delivery of the SARAH program in different practice settings and patient scenarios.

#### Resource Library

All text materials required to deliver the SARAH program (eg, exercise booklets and videos, exercise diary, RA patient education booklets) and additional reference documents, such as SARAH trial publications, were archived in the resource library.

#### Delivery of Content

A combination of text, photographs, tables, and videos was used to deliver the training. Preliminary videos were produced for iSARAH promotion and instruction purposes of the training.

#### Visual Design and Navigation

A simple Web layout was used consistently across modules to reduce distraction and information overload.

#### *iSARAH Usability Testing*

**Table 1** presents demographics of participants in the usability testing.

#### Think-Aloud Procedure

One of the major usability issues we observed was the difficulty in navigating from the end of one module to the next (eg, from the last page of Module 1 to the first page of Module 2), as there were no direct buttons to take users to the following module. Instead, participants had to click the respective module tabs on the top of the screen to navigate between modules or to proceed to the next module. We also noticed that some additional tabs appearing within the Moodle platform were confusing for the participants.

Hyperlinks to reference documents such as SARAH trial publications and patient materials were reported to be repetitive and distracting. Participants said that photographs showing RA hands and activities of daily living, and other illustrations, did not add to iSARAH but instead occupied screen space and led them to frequently scrolling down to read the whole page. In the self-assessment module, when participants entered an incorrect response to a question, they couldn't find a feature to signpost to the correct response in the respective module. They also reported that information about the SARAH team on the home page was not adequate.

#### Self-Reported Questionnaires

The CSUQ showed that participants overall found iSARAH simple, easy to use, and easy to understand, and they were satisfied in using it (**Table 4**). There was an overall agreement that participants could complete their work quickly and efficiently and recover from any unexpected technical mistakes. There was some uncertainty as to whether the system gave error messages and informed them how to fix problems. Results from Likert scales (**Table 4**) indicated that participants rated iSARAH as useful and easy to use, and that they were confident about using it.

**Table 4.** Questionnaire scores of iSARAH<sup>a</sup> usability testing (n=10).

Questionnaire	Median (IQR <sup>b</sup> )
<b>Computer System Usability Questionnaire items on 1-7 scale <sup>c</sup></b>	
Overall, I am satisfied with how easy it is to use this system	6 (0.75)
It was simple to use this system	6 (0)
I can effectively complete my work quickly using this system	5 (1.0)
I am able to complete my work quickly using this system	5 (0)
I am able to efficiently complete my work using this system	5 (1.0)
I feel comfortable using this system	6 (1.5)
It was easy to learn to use this system	6 (0.75)
I believe I became productive quickly using this system	6 (1.0)
The system gives error messages that clearly tell me how to fix problems	4 (0)
Whenever I make a mistake using this system, I recover easily and quickly	5 (1.0)
The information (such as online help, on-screen messages, and other documentation) provided with this system is clear	6 (1.0)
It is easy to find the information I needed	6 (2.0)
The information provided for the system is easy to understand	6 (1.0)
The information is effective in helping me complete the tasks and scenarios	6 (0.75)
The organization of information on the system screens is clear	5.5 (1.0)
The interface of the system is pleasant	6 (1.0)
I like the using the interface of this system	6 (1.0)
This system has all the functions and capabilities I expect it to have	6 (0.75)
Overall, I am satisfied with this system	6 (0)
<b>Likert scale scores of perceived usefulness, ease of use, and confidence in using iSARAH</b>	
Usefulness (1=not at all useful; 5=extremely useful)	4.0 (1)
Ease of use (1=very difficult; 5=very easy)	4.0 (0)
Confidence in using iSARAH (1=not at all confident; 5=very confident)	4.5 (1)

<sup>a</sup>iSARAH: Web-based training for Strengthening and Stretching for Rheumatoid Arthritis of the Hand.

<sup>b</sup>IQR: interquartile range.

<sup>c</sup>1=strongly disagree, 2=disagree, 3=somewhat disagree, 4=neither, 5=somewhat agree, 6=agree, 7=strongly agree.

## Interviews

In general, users found that iSARAH was a detailed and helpful learning resource for therapists. The most common comments were that participants liked the Web layout, tabs for modules, exercise videos, and the whole content. Some key suggestions provided were to create videos of good sound quality, and to remove excess text and photographs to keep the information relevant and clear.

## Modifications Made to Produce the Final Version of iSARAH

We revised iSARAH to address all major usability issues identified from the think-aloud procedure and interviews (Table 5). We produced good-quality promotional (Multimedia

Appendix 2) and instructional videos using media professionals and removed all irrelevant photographs to allow more screen space. We minimized repetitive links to reference documents and patient materials within modules. We set up clear-cut tabs to navigate between the end of a module and the start of subsequent modules. The SARAH implementation team further reviewed the final version of iSARAH (Multimedia Appendix 3) for content, navigation issues, and grammar.

Prior to official launch on April 3, 2017, we tested and activated the following features: (1) online user registration page, (2) online feedback questionnaire on perceived usefulness, satisfaction, and intention to use the SARAH program in future practice, and (3) download option for the training completion certificate.

**Table 5.** Major usability issues identified and rectifications made.

Usability issues	Solutions implemented in the final iSARAH <sup>a</sup>
Navigation between the last and first pages of consecutive modules was difficult.	Navigation was made easy by adding buttons to take the user from the last page of the previous module to the first page of next module.
Different-colored text was hard to follow.	Only 2 colors were used: black for text and blue for weblinks.
Sections A, B, and C of Module 2 were confusing.	Sections A, B, and C of Module 2 were categorized as separate modules: modules 2, 3, and 4.
Having FAQs <sup>b</sup> and self-assessment labelled as modules was irrelevant.	FAQs and self-assessment were labelled with their same names for more clarity.
Resource library documents were not opening in a separate window, and it was confusing when participants closed the document and wanted to access their last seen page of the training.	Documents were set to easily open up and close in a separate window that will allow users stay on their last seen page of the training.
Too many links within the modules was distracting.	Repetitive links were removed.
Too much scrolling was annoying because of photographs occupying space.	Photographs were removed to allow more space for text and less scrolling.
For the self-assessment, when an incorrect answer was entered, participants were not directed to find correct answers in the respective modules.	The self-assessment section was set to point out incorrect responses. When the user provides an incorrect response, he or she will be directed to the relevant module to learn more on the particular question.
The home page did not cover all essential information about the SARAH <sup>c</sup> program and SARAH team.	More information on the SARAH program, the SARAH team, and the host organization was added. A promo video was produced.
Some Moodle features (eg, tags, buttons) were distracting.	All irrelevant buttons and tags were removed.
The quality of videos could be improved.	Good-quality videos were produced.
A patient could demonstrate exercises in exercise videos.	Exercise videos with a patient volunteer demonstrating the exercises were produced.
There was too much text to read.	The text was reduced, and more bullet points were used.

<sup>a</sup>iSARAH: Web-based training for Strengthening and Stretching for Rheumatoid Arthritis of the Hand.

<sup>b</sup>FAQs: Frequently Asked Questions.

<sup>c</sup>SARAH: Strengthening and Stretching for Rheumatoid Arthritis of the Hand.

## Discussion

The overall purpose of this paper was to present how we developed a Web-based implementation tool (iSARAH) and produced the final version suitable for implementation. The strength of this work is that it followed a recognized model for the construction of Web-based programs [21-24].

### Principal Findings

Engagement with users through the SARAH survey allowed us to identify current practice and learning needs to ensure iSARAH was fit for purpose. From the survey, we established that the exercises included in the SARAH program were commonly used by therapists [6,7,30,31] but the behavioral change techniques were likely to be less familiar [8-10]. It also gave us insight into potential barriers to implementation. Respondents provided information about the features they would like to see in a Web-based training program, and this directly informed the design of the program. Survey findings also directly influenced the selection of outcomes for the evaluation phase of implementation.

Engagement with users continued during the design phase with a face-to-face meeting, as well as carrying out usability testing. Usability testing was essential to producing a user-friendly website that could be deployed for implementation. We believe

this has resulted in a flexible learning experience for users, which is easy to navigate with unlimited access. We included FAQs and self-assessment to ensure that therapists have adequate training and skills to efficiently apply for the SARAH program in actual practice.

The next step is to evaluate the impact of iSARAH training on actual implementation of the SARAH program, including the impact on knowledge and skills of therapists, implementation rates, and patient outcomes. We know from our previous work [32] that training alone may not result in implementation [33]. A Web-based training developed to facilitate the implementation of a cognitive behavior approach for low back pain was shown to be as effective as face-to-face training regarding knowledge and confidence, but actual implementation rates were low and further enhancement of the training was required [33]. We have tried to identify potential barriers to implementation during the development phase of this project so that these are addressed by the Web-based training.

### Limitations

This study has some limitations. First, we neither used observational analysis with video recordings in the think-aloud procedure to observe users' interactions with iSARAH, nor conducted a systematic qualitative analysis of participants' interviews. Second, the CSUQ and Likert scales have not been

tested for reliability and validity in the target population. Hence, the range of scores should be interpreted with caution. Third, the SARAH survey participants were familiar with the SARAH program and hence their responses were prone to the risk of volunteer bias. Additionally, with a low consent rate (39 of 102 participants, 38.2%), the survey findings are at the risk of nonresponse bias from people who did not participate or respond. Fourth, we did not employ iterative cycles of usability testing—that is, consecutive cycles of testing until the point when no further usability issues were identified—but we used the feedback from all participants in a one-off cycle to refine iSARAH.

Evidence-based therapies have been found to be poorly disseminated into routine practice [34]. Some of the barriers often reported by health professionals in practicing evidence are the lack of access to evidence resources [35-37] and nonavailability of the evidence resources in usable formats [38]. In the context of implementing the evidence-based SARAH program, we believe that the easy and free access for health professionals to the SARAH program in a simplified Web-based format has overcome these barriers. We foresee that the training of qualified health professionals directly involved in the rehabilitation of people with RA of the hands would increase their knowledge of the evidence (the SARAH program), and build their skills and confidence to deliver it in practice. The

Web-based training would also be a time-saving learning resource that is also potentially flexible in terms of learning [39] for health professionals from diverse backgrounds of Internet use habits and computer skills. Further, the content of the iSARAH can be adapted [19] for language and cultural differences to assist wider implementation. Thus, it would open opportunities to disseminate the SARAH program among therapists across the world who have limited or no access to the SARAH training.

## Next Steps

In our next steps toward opening more opportunities for wider uptake and application of the SARAH program into clinical practice, there is also a huge potential for adapting iSARAH across different cultures and languages across the world.

## Conclusions

To our knowledge, iSARAH is the first Web-based learning resource for therapists on an evidence-based hand exercise program. A systematic design approach by using the ADDIE model and involving end users has been successful in developing a user-centered iSARAH.

Our ongoing work on the impact evaluation among therapists who completed iSARAH and a service evaluation in people treated by SARAH-trained therapists will provide more insights on the uptake of the SARAH program in actual practice.

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

SARAH therapist survey questionnaire.

[[PDF File \(Adobe PDF File, 105KB - jmir\\_v19i12e411\\_app1.pdf](#) ]

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## Multimedia Appendix 2

iSARAH promotional video.

[[M4V File, 132MB - jmir\\_v19i12e411\\_app2.m4v](#) ]

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## Multimedia Appendix 3

iSARAH website screenshots.

[[PPTX File, 2MB - jmir\\_v19i12e411\\_app3.pptx](#) ]

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## Abbreviations

**ADDIE:** analysis, design, development, implementation, and evaluation

**CSUQ:** Computer System Usability Questionnaire

**FAQs:** frequently asked questions

**iSARAH:** Web-based training for Strengthening and Stretching for Rheumatoid Arthritis of the Hand

**NHS:** National Health Service

**NICE:** National Institute for Health and Care Excellence

**OCTRU:** Oxford Clinical Trials Research Unit

**RA:** rheumatoid arthritis

**SARAH:** Strengthening and Stretching for Rheumatoid Arthritis of the Hand

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Original Paper

# Facebook Groups as a Powerful and Dynamic Tool in Medical Education: Mixed-Method Study

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## Abstract

**Background:** Social networking sites, in particular Facebook, are not only predominant in students' social life but are to varying degrees interwoven with the medical curriculum. Particularly, Facebook groups have been identified for their potential in higher education. However, there is a paucity of data on user types, content, and dynamics of study-related Facebook groups.

**Objective:** The aim of this study was to identify the role of study-related Facebook group use, characterize medical students that use or avoid using Facebook groups (demographics, participation pattern, and motivation), and analyze student posting behavior, covered topics, dynamics, and limitations in Facebook groups with regards to educational usage.

**Methods:** Using a multi-method approach (interviews, focus groups, and qualitative and quantitative analysis of Facebook posts), we analyzed two representative Facebook groups of medical preclinical semesters at Ludwig-Maximilians-University (LMU) Munich. Facebook primary posts and replies over one semester were extracted and evaluated by using thematic content analysis. We developed and applied a coding scheme for studying the frequency and distribution of these posts. Additionally, we interviewed students with various degrees of involvement in the groups, as well as "new minorities," students not registered on Facebook.

**Results:** Facebook groups seem to have evolved as the main tool for medical students at LMU to complement the curriculum and to discuss study-related content. These Facebook groups are self-organizing and quickly adapt to organizational or subject-related challenges posed by the curriculum. A wide range of topics is covered, with a dominance of organization-related posts (58.35% [6916/11,853] of overall posts). By measuring reply rates and comments per category, we were able to identify learning tips and strategies, material sharing, and course content discussions as the most relevant categories. Rates of adequate replies in these categories ranged between 78% (11/14) and 100% (13/13), and the number of comments per post ranged from 8.4 to 13.7 compared with the average overall reply rate of 68.69% (1167/1699) and 3.9 comments per post. User typology revealed social media drivers (>30 posts per semester) as engines of group function, frequent users (11-30 posts), and a majority of average users acting rather as consumers or lurkers (1-10 posts).

**Conclusions:** For the moment, the medical faculty has no active involvement in these groups and therefore no influence on accuracy of information, professionalism, and ethical issues. Nevertheless, faculty could in the future benefit by extracting relevant information, identifying common problems, and understanding semester-related dynamics.

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## KEYWORDS

social media; Facebook; medical education; e-learning; faculty; networking

## Introduction

### Use of Social Networking Sites

Social networking sites (SNSs), led by Facebook with almost two billion monthly active users worldwide in early 2017, transform the way we perceive the world, as well as how we communicate and socialize [1,2]. In the field of medicine, the effect of SNSs can be particularly far-reaching, for example, by changing the doctor-patient relationship [3,4]. Given the fact that a high percentage of university students actively use Facebook and related services, SNSs have also started to change (medical) student and university life [5,6].

Different people use Facebook for different purposes. Kumar et al (2010) described three roles people can take in regards to social media evolution: (1) *passive members (lurkers)*, (2) *inviters*, and (3) *linkers* [7].

According to Stutzman et al (2006), individuals use Facebook for leisure, to learn about each other, or for communication purposes [8]. Mazmans and Usluveli (2010) structural model for Facebook usage describes four main purposes: (1) social relations, (2) work-related, (3) daily activity, and (4) educational usage [9]. Facebook users can exchange information through chat, post information on their personal profiles or profiles of others, look at profiles of peers, share multimedia content, or organize themselves in public, closed, or secret groups.

### Social Networking Sites in Education

These technical features make effective aggregation and modification of knowledge and information possible; they make connectivity and social support easier and therefore, contribute significantly to the creation of new content. For these exact reasons, Lee and McLoughlin (2008) also identified social media as pedagogical tools [10]. Collaboration, communication, material sharing, peer feedback, and social media prowess are considered the main factors important for educational usage of a social media platform [9,11-13].

Some researches compare social media platforms, such as Facebook, to web based educational tools [12]. Others have recognized SNSs as an instrument to teach and educate, focusing on e-learning and interaction with faculty [9,11]. Pilot studies have already utilized Facebook for educational purposes at medical schools, for example, to complement university courses [14,15]. Selwyn (2009) analyzed activities on students' Facebook walls of over 900 undergraduate students to identify different types for educational activity and defined four main categories: (1) recounting and reflecting on university activity, (2) exchange of practical information, (3) exchange of academic information, and (4) displays of supplication or disengagement [9,11].

### The Role of Facebook Groups

However, the educational use of SNSs and its effects are still insufficiently examined. Although Facebook groups have been identified as being useful in faculty-rooted course support, as

well as representing organic (self-organizing) student-based learning environments [16], and although these groups combine many of the aforementioned attributes essential for educational usage, very little is known about which students use these groups, how and for what exact purpose [17]. Some researches argue that certain learning styles are more beneficial for learning through SNSs, but further research is necessary to examine these findings in different settings [18-22].

Facebook groups allow a quick and easy organization of individuals with related interests or characteristics, who can then share posts, pictures, and material on the group's wall [23].

Their technical features have led to some excitement among educators, as they provide a student-centered platform ideally suited for peer-generated content, peer-to-peer communication, and learning and interactive support, combined with social aspects such as peer-mentoring and personal interaction and bonding [24,25].

### Possible Limitations of Social Networking Sites in Education

However, SNS use in education comes with relevant caveats, as some studies hint at problems in structure and (self-) organization, domination of groups and discussions by individuals, feelings of incapability by weaker users, and deviation from educational goals [26,27]. Scripted cooperation to better structure discussions as suggested by computer-supported, cooperative learning-related research did not seem to be very efficient in an SNS context so far.

Measurement of benefits has been elusive, and various pitfalls and dangers of SNS integration into curricula have been reported, for example, privacy issues, online misconduct, and the so-called *digital divide*, excluding individuals who do not have access to SNSs [28-30]. Moreover, one study found Facebook to be a place for reflection on and criticism of study-related content by undergraduate students, joining in with other studies which report students to be wary and opposed to faculty involvement in SNSs [31].

### Aim of This Study

In light of these findings, however, a clear picture on educational usage of Facebook groups has yet to emerge to assess to what extent medical faculties can take educational advantage of these networks. In particular, there is a lack of data on user motivation, user typologies, subjective benefits, and limitations, as well as patterns of posting behavior of students necessary for further analysis and integration into existing (learning) theories [32]. We therefore designed this explorative study to identify the role of study-related Facebook group use; characterize medical students that use or avoid using Facebook groups (demographics, participation pattern, and motivation); analyze covered topics quantitatively and qualitatively; describe dynamics within the groups, as well as posting patterns; and define limitations of Facebook groups with regards to educational usage.

## Methods

### Research Setting

The medical faculty at LMU Munich offers a unique opportunity of further research in the field of educational usage of social media, as the majority of medical students of each preclinical year join year and cohort specific, semester-spanning Facebook groups (ie, named “LMU medical students starting in winter semester 12/13,” used throughout the medical studies of the respective cohort).

We identified two relevant Facebook groups (with participants enrolled in the first and second preclinical year, respectively) by combining the Facebook search function and word-of-mouth advice by enrolled students. The results of the additional interviews and focus groups confirmed that educational usage of Facebook among medical students in the first preclinical years almost exclusively takes place in these groups. Both closed groups used self-identifying names, stating the university (LMU Munich), study subject (medicine), and year of the cohorts’ initial semester (October 2012 or October 2013, respectively).

The groups were initiated by students and required an application for membership, followed by the acceptance through users already in the group. Students formed the first group we studied in their first preclinical semester, 2 or 3 weeks before the first official university event.

### Study Design

A multi-method approach was applied to answer the aforementioned research objectives. For characterization of medical students involved in Facebook groups, we conducted focus groups among Facebook users and structured interviews of specific student groups (*social media drivers* and students not using Facebook here called *new minorities*). For the evaluation of posting behavior and for identification of covered topics, we combined qualitative and quantitative methods to analyze posts in two semester-spanning Facebook groups. Data collection took place after completion of the winter semester in February 2014.

### Group Data Extraction

Groups were double checked by comparing the list of participants with the list of students enrolled in the respective preclinical semester.

All posts and comments of one academic semester (September 2013 to February 2014) were extracted using a custom script leveraging the Facebook Graph API for both groups, which were termed first preclinical year (PCY1) and second preclinical year (PCY2). Raw data contained content, poster identity document, and date for primary posts and replies. Further analysis was implemented in Excel 2010 (Microsoft).

### Qualitative and Quantitative Facebook Data Analysis

Due to expected saturation of data, we applied a thematic and content analysis of 10% of 1246 (PCY1) and 1168 (PCY2) total primary posts in each group over the course of one semester. The 10% analyzed primary posts were randomly chosen from all primary posts throughout the whole semester to avoid

selection bias. Two experienced members of the research team independently defined categories with anchoring examples. Nine main categories were defined in the final general coding scheme.

This scheme was used for coding the remaining 90% of posts and for quantification thereof (see [Figure 1](#)). Our approach provided insight into the absolute and relative (per week over the course of the semester) posting frequencies in the most abundant and relevant categories. If a post complex did not fit into the defined predominant categories, it was assigned to the category “other.” In a second coding step, all categories including the newly identified posts assigned to “other” were reevaluated. This ensured that no relevant topics were overlooked and guaranteed a thorough representation of the groups’ content. Postings were further categorized into “questions” and “statements.” For “questions,” we examined quantitatively the number of received responses and assessed qualitatively the relevance of the answers. Answers were categorized as “sufficient” and “not sufficient.” Questions were put in the category “sufficient” if the reply was constructive and relevant. Further quantitative analysis included the absolute number of posts, primary posts per week, average reply rates, and a classification of members according to their posting behavior (frequency).

Statistical Package for the Social Sciences (SPSS) version 23 (IBM Corp) was used for statistical analysis. Independent samples Mann Whitney *U* tests were used for posting frequency comparisons.

### Focus Groups

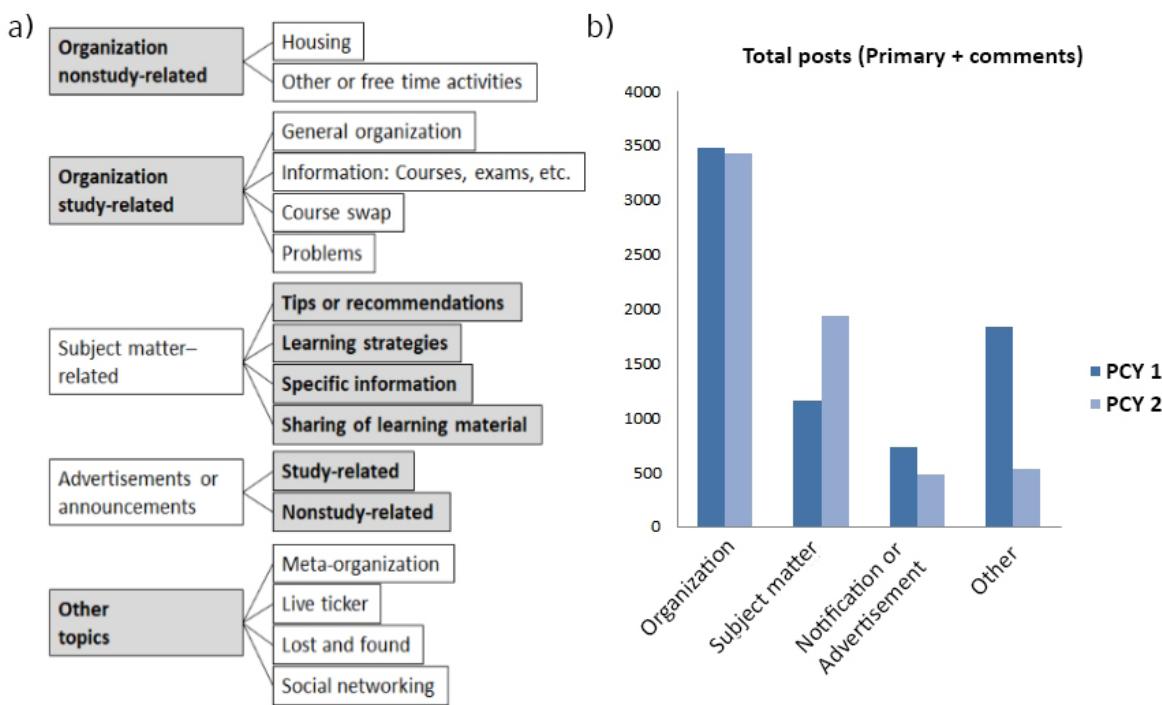
To further assess motivation to join in Facebook groups, participation pattern, posting behavior, and efficiency, we conducted two semistructured focus groups using a precise focus group protocol to ensure consistency over various moderators and sessions ([Multimedia Appendix 1](#)) with medical students from our faculty (n=21). Students from preclinical year 1 and 2 were invited via email. Discussions were based on a protocol using open-ended questions on social media, Facebook and Facebook group usage, and user motivation (20 items).

### Interviews

*Social media drivers* were defined as students with over 30 posts per semester, amounting to only 3.90% (62/1591) of total group members. The motivation and assessment of this subgroup was of particular interest to our research project. Hence, individuals identified by their extensive posting habits in the respective Facebook groups were invited to take part in semistructured interviews (n=4). For each subgroup, a detailed protocol was designed by two experienced authors ([Multimedia Appendix 1](#)).

Moreover, an outside perspective was gained by contacting students of medicine at the LMU Munich not registered on Facebook, so called *new minorities*. These students were identified through word-of-mouth and an email sent to the relevant semesters. Structured interviews focused on reasons for Facebook abstinence, and alternatives for information gathering were conducted (n=6).

**Figure 1.** (a) Qualitative coding scheme for preclinical year 1 (PCY1) and preclinical year 2 (PCY2) groups. Categories and subordinate categories were identified. The shaded boxes indicate categories used for quantitative coding. (b) Number of total posts (primary posts and comments) in PCY1 and PCY2, grouped into the four dominant categories.



All interviews and focus groups were audiorecorded and transcribed. For content analysis regarding the semistructured interviews and focus groups, two independent researchers developed a coding system by abstracting and categorizing the statements of the respective subgroups using MAXQDA (VERBI GmbH). Divergent coding was discussed and resolved.

The LMU ethics committee reviewed the research design and exempted the study from additional ethical approval. Confidentiality and anonymity with regard to electronic data was maintained throughout the study. Any names or potentially identifying information were removed before analyzing the data. The authors had no personal connections to the groups or were not registered members of the groups studied. In addition, authors involved in data analysis only had anonymized data to their disposal. Quotes were all translated from German to English for this manuscript. Pseudonyms were used to maintain confidentiality and anonymity.

## Results

### Demographics

At the time of data extraction, the PCY1 group counted 1213 members, with 71.2% (n=863) of members contributing at least one post per semester, named *active users*. The PCY2 group consisted of a total of 1149 members, with 63.36% (n=728) *active users*. The corresponding student cohorts enrolled in PCY1 and PCY2 at LMU Munich listed a total of 950 PCY1 students (58.9% [560/950] female) and a total of 966 PCY2 students (59.0% [570/966] female).

Approximately 6000 posts were extracted from each group, with about one-fifth of posts representing primary posts (see Table 1).

### User Typologies and Motivation

#### Focus Groups

All focus group participants (n=21, 12 female, and 9 male students) were registered on Facebook and were using semester-spanning groups. Motivation for setting up a Facebook account was mainly socializing and staying in touch with (international) friends and acquaintances. Nevertheless, 2 students registered solely for being able to join the aforementioned student groups. Students agreed that the overwhelming majority of their cohort were members in the respective groups. Medical students in their semesters that were not members of Facebook represented “[...] isolated cases,” as stated by a participant. When asked about relevant subgroups defined by posting behavior, one student stated that “[...] there is always the same 50 people that are very active [...]”.

Students expressed that in semester groups, mainly student-related topics were covered and that organization-related posts were prominent among these. Apart from that, technical- and content-related information was regarded as important. Others recalled that content included scripts, exam questions, lecture slides, advertisements, course swaps, and selling of material such as medical books.

**Table 1.** Group demographics and characteristics. Demographics of the analyzed preclinical year 1 (PCY1) and preclinical year 2 (PCY2) group. Active users were defined as users with at least one post per semester. For user typology, user activity was divided into arbitrary groups, each contributing about one-third of posts. We defined social media drivers as members with >30 posts per semester, frequent posters with 11 to 30 posts, and lurkers with 1 to 10 posts per semester.

Group characteristics	Preclinical year 1	Preclinical year 2
Active users, n (%)	863 (71.15)	728 (63.40)
<b>User type distribution among active users, n (%)</b>		
Social media drivers	28 (3.2)	34 (4.7)
Frequent posters	130 (15.1)	131 (18.0)
Lurkers	705 (81.7)	563 (77.3)
<b>Post contribution (of total posts), n (%)</b>		
Social media drivers	1286 (21.70)	1718 (28.99)
Frequent posters	2270 (38.31)	2300 (38.81)
Lurkers	2370 (39.99)	1909 (32.21)
<b>Total posts</b>		
Primary posts, n (%)	1168 (19.71)	1246 (21.02)
Average comment or primary post	4.1	3.8

Students' perspective on benefits and limitations of study-related Facebook use is detailed in [Table 2](#). Interestingly, participation in Facebook groups was seen as efficient and time-consuming at the same time; efficient because of the ease of access and its usability, enabling group visits while spending leisure time on Facebook (students spent their time on Facebook anyway and could quickly check news and updates in the relevant groups). They felt it was time-consuming because to stay up-to-date, a significant amount of time is necessary to scan through the abundance of posts and comments. Implementation of a similar group on faculty websites was seen as problematic, as students said they would not post as freely and would “[...] feel supervised [...]”.

### Social Media Drivers

In semistructured interviews (n=4), this subgroup reported using Facebook for educational as well as private purposes on a daily basis. When asked about their behavior and motivation for extensive posting in the respective groups, we identified two distinct subtypes:

Some *social media drivers* we interviewed see themselves as service providers, answering questions and providing information as well as resources. Altruism was named as the main reason for this dedication (“[...] it might help someone!”). Further reasons were access to exclusive information (“I am in a rather unique situation since I am not only a student but also work [at this institute] [...]”), as well as the feeling of an obligation to return a favor (“Because in the beginning, I benefited as well.”).

The second subtype comprised students that perform below average and use Facebook groups to get support. Contrary to the first subtype that contributes in sharing information, this subgroup seems to post more questions. For example, one

student stated, “I was very [active], since I repeatedly had questions concerning upcoming exams.” The interviewed students did not express concerns regarding excessive peer pressure, ridicule, or unqualified answers to their numerous questions.

Social media drivers were aware of the imbalance of providing and consuming resources on Facebook and the consecutive varying roles of students in those groups. However, they did not see this nor “steering” the group in certain directions as problematic. From their perspective, the heterogeneity does not interfere with functionality. However, even this preselected group is experiencing limitations when it comes to organizing and administrating posts to maintain a structured way of presenting gathered information. The overall relevance of Facebook for academic outcome was evaluated to be significant (“I do think that access to important information is limited for people not participating in Facebook groups [...]”).

### New Minorities

The interviewed students in that subgroup (n=6) were not members of Facebook at the time of the study, but most used other elements of social media such as Twitter and WhatsApp. They are aware of their minority status regarding (educational) Facebook usage and acknowledged Facebook groups as a highly relevant source for study-related content. One student even stated that “[...] I have to say I can't directly compensate the losses [in study-related info or material]” he suffered by not participating in Facebook groups.

When asked for reasons for their behavior, they mainly expressed concerns also mentioned by Facebook users in focus groups ([Table 2](#)). Prominent reasons were privacy concerns, permanent availability, distraction from studying, and loss of valuable time.

**Table 2.** Qualitative content analysis—students' perspective on benefits and limitations of study-related Facebook groups. Through a qualitative content analysis, benefits and limitations of Facebook groups were extracted from conducted interviews and focus groups.

Categories and subcategories	Anchoring example
<b>Limitations</b>	
<b>Study-related</b>	
Mutual dependence	<i>[...] You can't rely on that. Simultaneously, one always has to look for answers elsewhere [...].</i>
Information overload or disorganization	<i>When I am looking for a certain post—and I know it has to be somewhere, but I don't know when it was posted—[...]. For me, that's annoying.</i>
Factual knowledge	<i>[...] once you take social media and Facebook [...] as your only source for medical education [...] a lot gets lost.</i>
Peer pressure	<i>From my perspective, there is a lot of hysteria going on. Sometimes, not being confronted with that is not a bad thing.</i>
Reliability	<i>Anyone can write something. In the end, you have to find a [reliable] source by your own.</i>
<b>General</b>	
Rudeness	<i>It escalated! People were rude and abusive to individuals that actually committed themselves to the group.</i>
Commercialization	<i>In my eyes, it [marketing] has no place in groups like that.</i>
Permanent availability	<i>[...] the aspect of permanent availability [...] are of high relevance why people say to prefer real social interactions instead of the Internet.</i>
Distraction	<i>I have recognized that my concentration is severely compromised.</i>
Anonymity	<i>It [Facebook group] is too big [...]. There is no feeling of togetherness.</i>
Misleading presentations	<i>Everyone is presenting himself as one wishes to be, and not how one is in reality.</i>
Mismatch with introverted personalities	<i>I am not the type of guy that uses social networks as they are designed.</i>
Limited protection of privacy	<i>I do have some concerns about the privacy policy.</i>
Dependence and irrational involvement	<i>The benefit of not being a user on Facebook is that I [...] don't get lost and waste my time.</i>
<b>Benefits</b>	
<b>Study-related</b>	
Limited control by faculty or dark net	<i>Technically, one would not even be allowed to publish lecture notes online due to copyright reasons.</i>
Collective knowledge	<i>Just think of it. One group has about a thousand members. Given that, there will always be one who knows the answer.</i>
Established platform	<i>The vast majority of students are using Facebook. Thus there is no need to establish a new network.</i>
Free of charge	<i>[...] information on Facebook is free of charge.</i>
Effectiveness	<i>I save time since I get to information more quickly.</i>
Connecting individuals with mutual interests	<i>One can easily organize groups when there are problems [...] since one can directly and quickly contact a lot of people [...].</i>
Exclusive information	<i>I can tell from a friend, who is not using Facebook, that she has disadvantages because some resources can only be found there [Facebook] [...].</i>
<b>General</b>	
Mass media	<i>It is a good thing that everyone is on Facebook.</i>
Intuitive handling	<i>I think it is a cool platform [...] to have an easily exchange with others.</i>
Mobility	<i>[...] and it is a big advantage with smartphones these days.</i>
Innovation	<i>There have been a lot of modifications since I last visited Facebook.</i>
Live blog	<i>All results [of exams] are online instantly, on Facebook.</i>
Online databank	<i>[...] anything that was posted is saved. One can have access to that anytime.</i>
Diversity	<i>That's the advantage of the Internet. One can read a lot of opinions and then decide which one might be the most plausible.</i>
Social network	<i>Social interactions in a society are extremely important. That's why everyone loves this [Facebook].</i>

To access information their peers got through Facebook groups, they utilized alternate ways of communication and contacted different people, for example, writing emails to peers or contacting them in person. They relied on official university platforms and forums, bought printed versions of lecture notes in copy shops, and selectively contacted experts such as peers and faculty members to get support. Two students contacted their fellow students to explicitly gain peer-mediated access to Facebook group content. One student even practiced periodic registration and deregistration on Facebook.

## Discussed Topics

An overview of topics discussed in both groups is presented in **Figure 1** and **Table 3**. Categories were very homogenous in PCY1 and PCY2, as we could not find qualitative differences in posting themes.

## Qualitative Description of Topics

### Organizational Issues

We identified two subcategories of posts concerning organizational themes: study- and nonstudy-related. The part of the groups' posts addressing nonstudy-related organizational issues covered mainly housing in Munich or insurance. In addition, information concerning student jobs and leisure activities were also posted.

The most abundant posts referred to study-related organizational issues. Four subcategories could be identified: (1) general organizational issues (eg, questions concerning course attendance regulations, procedures in case of illness, semester schedule, and directions to classes); (2) Information regarding courses, exams, and clerkships (eg, content-related information, duration, point in time, and prerequisites); (3) problems (difficulty with log-in on university online platforms or overlaps in course schedule); and (4) course swapping.

**Table 3.** Qualitative content analysis—discussed topics. Qualitative content analysis of 10% of posts was used to classify posts. The evolved coding scheme was then applied to the remaining 90% of posts and supplemented to accommodate all posts. Categories, subcategories, and an anchoring example are depicted here.

Categories and subcategories	Anchoring example
<b>Nonstudy-related organization</b>	
Housing	<i>Hi hi! Has anyone a room available from Jan/Feb onwards? Or knows someone? [...]</i>
Jobs or free time activities	<i>Hi everyone! I'm looking for a hands-on medicine related job that can be done in addition to the studies—does anybody know anything in this direction?</i>
<b>Study-related organization</b>	
General organization	<i>Where do (most) lectures and courses take place?</i>
Course or exam or clerkship specific information	<i>Hi, could someone post where the biology course tomorrow at 9 o'clock takes place?</i>
Problems and issues	<i>I cannot login into my account on mecum-online.de. Does anybody experience similar problems?</i>
Course swapping	<i>I need a partner to swap my biochemistry seminar at 12:30-14:00, I need the earlier one. Thanks</i>
<b>Subject matter</b>	
Tips or recommendations	<i>Has anyone studied with the online Thieme learning program for the Biology exam and can tell me if it makes sense?</i>
Learning strategies	<i>Is it true that if you buy the Prometheus [Anatomy] Atlas, you don't need any other book?</i>
Content specific info	<i>Hey people, has anyone discovered the solution for OIN Question 1?</i>
Sharing of material	<i>Hi! Does anyone have the former Biochemistry II exam sheets at hand and could send me the solutions [...]</i>
<b>Notifications or advertisements</b>	
Study related	<i>Come over to our MentoRing Fest! [...]</i>
Nonstudy related	<i>You want a break of all the biochemistry stress and would like to party? Then you should join [Facebook event link]</i>
<b>Other</b>	
Meta-organization	<i>[Facebook group link] for all students that are in Prof. Franks D1 [course] [...]</i>
Live ticker	<i>Is someone right now in the reading hall and can tell me if there is space available? Somehow every [other] place is packed.</i>
Lost and found	<i>Has someone found a white cotton cap with a white pompon at the uni? Maybe in the physiology EEG course room?! Is being heavily missed!</i>
Social networking	<i>I'm also curious. Who of you is also a little bit older and what kind of schooling did you do [before you enrolled in medical school]?</i>

## In Terms of Subject Matter

Most of these posts were related to the curriculum and therefore, also to the subjects being taught at the respective point in time. We further differentiated between tips or recommendations, learning strategies, contextual information, and material sharing.

Students referred to their cohort requesting individual tips, mostly on books and study material. In addition, questions concerning choice of electives were often posted. Others seek advice on learning strategies (which course to visit, when to start preparing for specific exams, and which study material to use). Apart from strategy and tips, content-related information on courses and exams was also shared and requested (questions left unanswered after the end of the lecture and unclear multiple choice questions).

Sharing of learning material and lecture notes could also be found in the Facebook groups we analyzed. This often consisted of exchange of exams or tests of previous years, including sample solutions, scripts, and even books.

## Advertisements and Announcements

As shown in the focus group, advertisements and unsolicited notifications play a (detrimental) role in semester-spanning Facebook groups. We found a number of study-related advertisements that aimed at motivating students to participate in electives or other optional offers and commercial courses. Furthermore, group members looking for volunteers for research projects posted requests and compensation offers.

Nonstudy-related advertisements consisted of leisure activities and events, for example, announcements of parties, sale of concert tickets, and other extracurricular activities including nongovernmental organization call for action.

## Other Topics

In several instances, members of the PCY1 group used this platform to post links to new Facebook groups of a course specific subgroup. In addition, students discussed about their communication through these groups, proposing rules or criticizing inappropriate behavior. This is an example of meta-organization. Another interesting finding was the use of the group as a *live blog*, asking for live updates on space availability in the medical library or progression of a lecture. In that sense, students also exchanged information about questions in oral exams, so that downstream examinees were better prepared. Furthermore, students used the group to assess their peers' level of preparation for upcoming exams to compare it with their own level (this behavior was termed as peer-check).

We also found a use of the group as a *lost and found platform*, with students that found or lost personal items in campus associated buildings and areas posting notifications.

In addition, social networking was present in both groups and covered different aspects. For example, students looked through postings in the group for other students who shared certain characteristics. Some of the features mentioned were above average age, mother- or fatherhood, sports interest, music instrument, or common country or town of origin. In addition,

the group was used to find and contact individuals that students had met in person.

The groups were used to increase economic efficiency. Students could easily identify others with whom they could share expensive medical books or car rides to similar destinations.

Moreover, the groups were used to voice and organize political interests of the cohort. In more than one instance, students mobilized using the groups to defend their interests toward faculty (in that particular semester eg, many posts referred to an ongoing conflict between students and the physics department).

Finally, an amount of posts with humorous content were posted. Students posted study-related images, interesting articles, or videos and jokes often related to extensive studying or clichés and stereotypes of the medical profession.

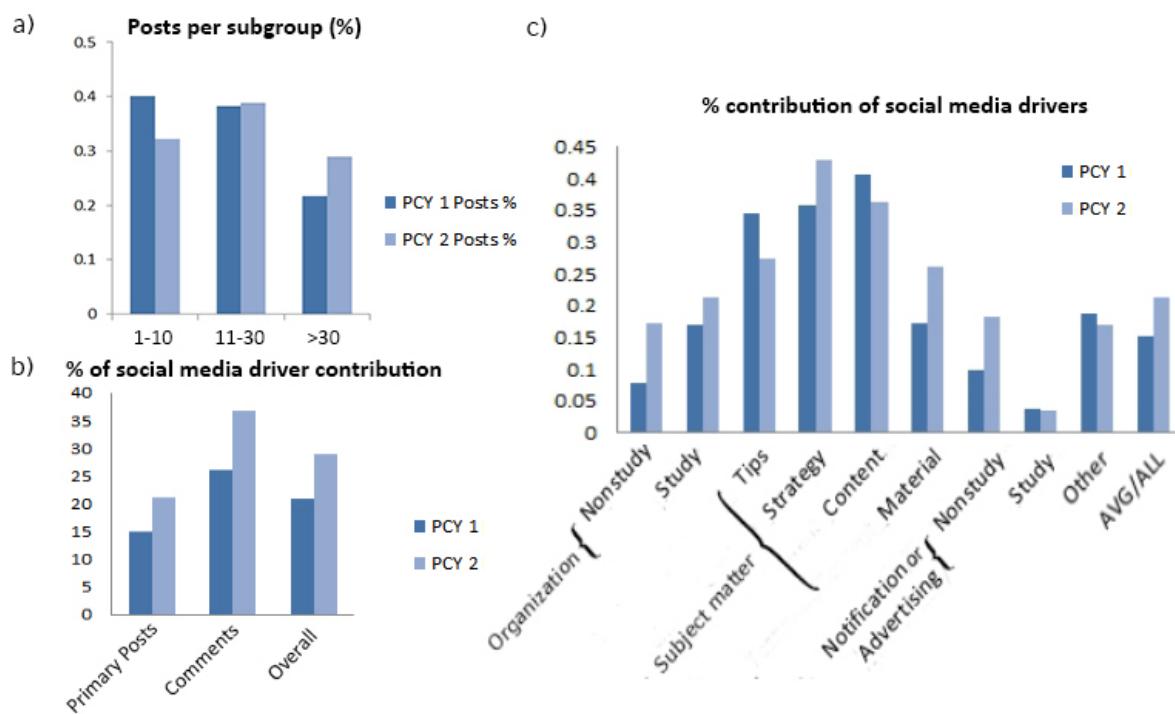
## Quantification of Posting Patterns

Overall posts (primary posts and replies) amounted to 5926 in PCY1 and 5927 in PCY2, showing a sustained posting pattern in the second year (see Table 1). In PCY1 and PCY2, respectively, the large majority of active users contributed 1 to 10 posts, every sixth student contributed 11 to 30 posts, and only a small minority contributed over 30 posts (31-125 posts) through the course of the semester. Interestingly, members with 11 to 30 posts contributed almost the same amount of posts to PCY1 as to PCY2, whereas *social media drivers* (>30 posts) in PCY2 contributed notably more than in PCY1 (21.67%, 1284/5926 in PCY1 vs 29.00% 1719 of 5927 in PCY2 of all posts). Accordingly, students with limited amount of contributions posted less in PCY2 (40.04%, 2373/5926 in PCY1 and 32.17%, 1907/5927 in PCY2; Figure 2).

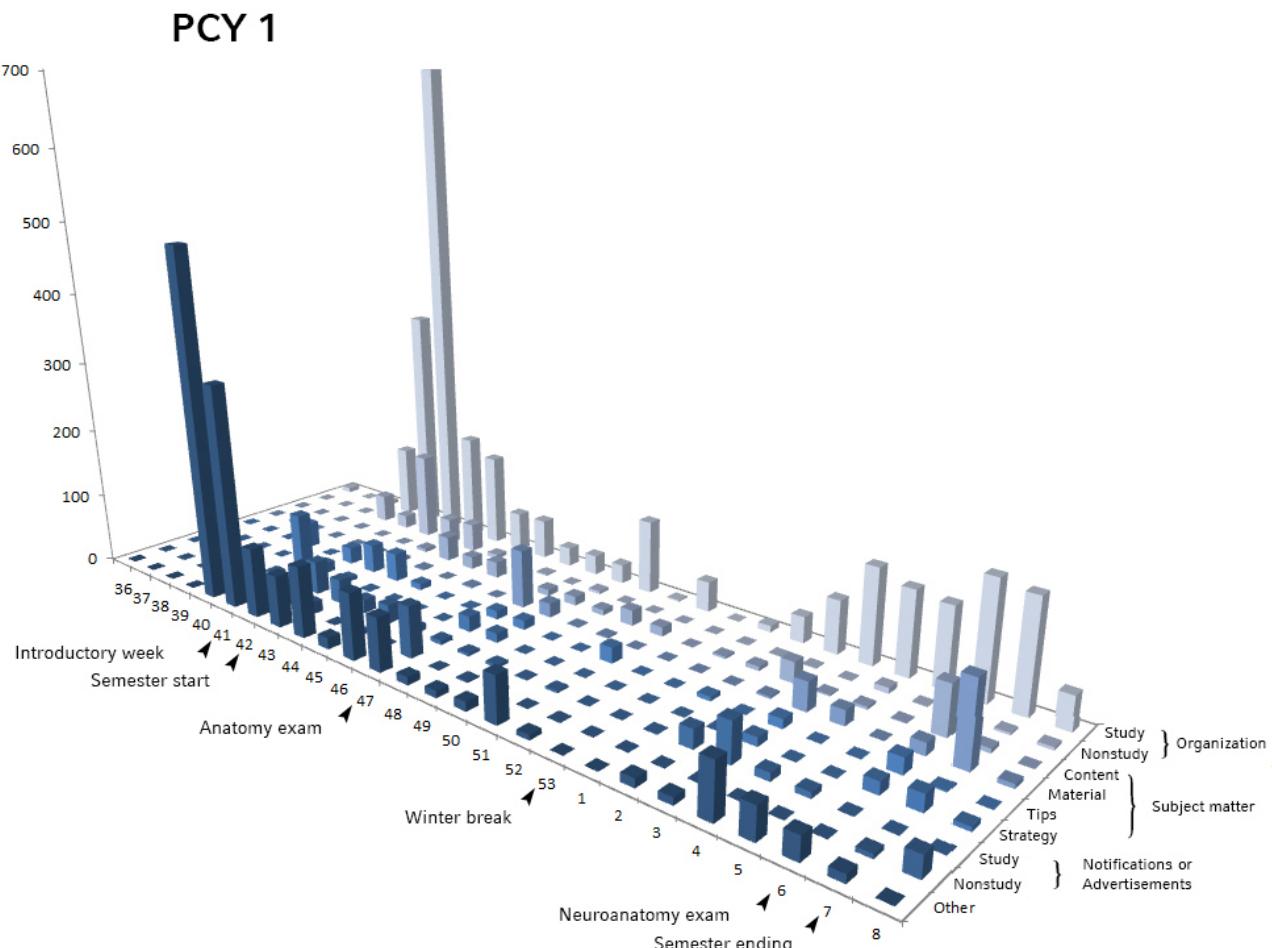
Posts about organizational issues dominated both groups and were equally represented in the first and second year group (58.77%, 3483/5926 in PCY1 and 57.92%, 3433/5927 in PCY2). In contrast, posts on subject matters were almost twice as frequent in the second year group (19.52%, 1157/5926 in PCY1 and 32.73%, 1940/5927 in PCY2) and reflected the second most represented category in that group. On the other hand, students in the first year group posted more about social networking, free-time activities, and sharing of nonstudy-related material (other topics: 31.10%, 1843/5926). Notifications or advertisements were represented relatively similar in both groups (12.50%, 741/5926 in PCY1 and 8.27%, 490/5927 in PCY2; Figure 1).

By correlating the posting frequencies in all nine main categories we defined over time with exams and other major semester milestones, we found a strong correlation between posting behavior and external events (Figures 3 and 4). As seen in Figures 3 and 4, in both groups, most organizational-related posts occurred within weeks of the beginning of the semester. The percentage of posts concerning organizational issues was higher in the first 3 weeks than in other weeks of the semester (PCY1: 245.2 posts vs 74.9 posts,  $P=.05$  and PCY2: 298.0 posts vs 88.4 posts,  $P<.001$ ).

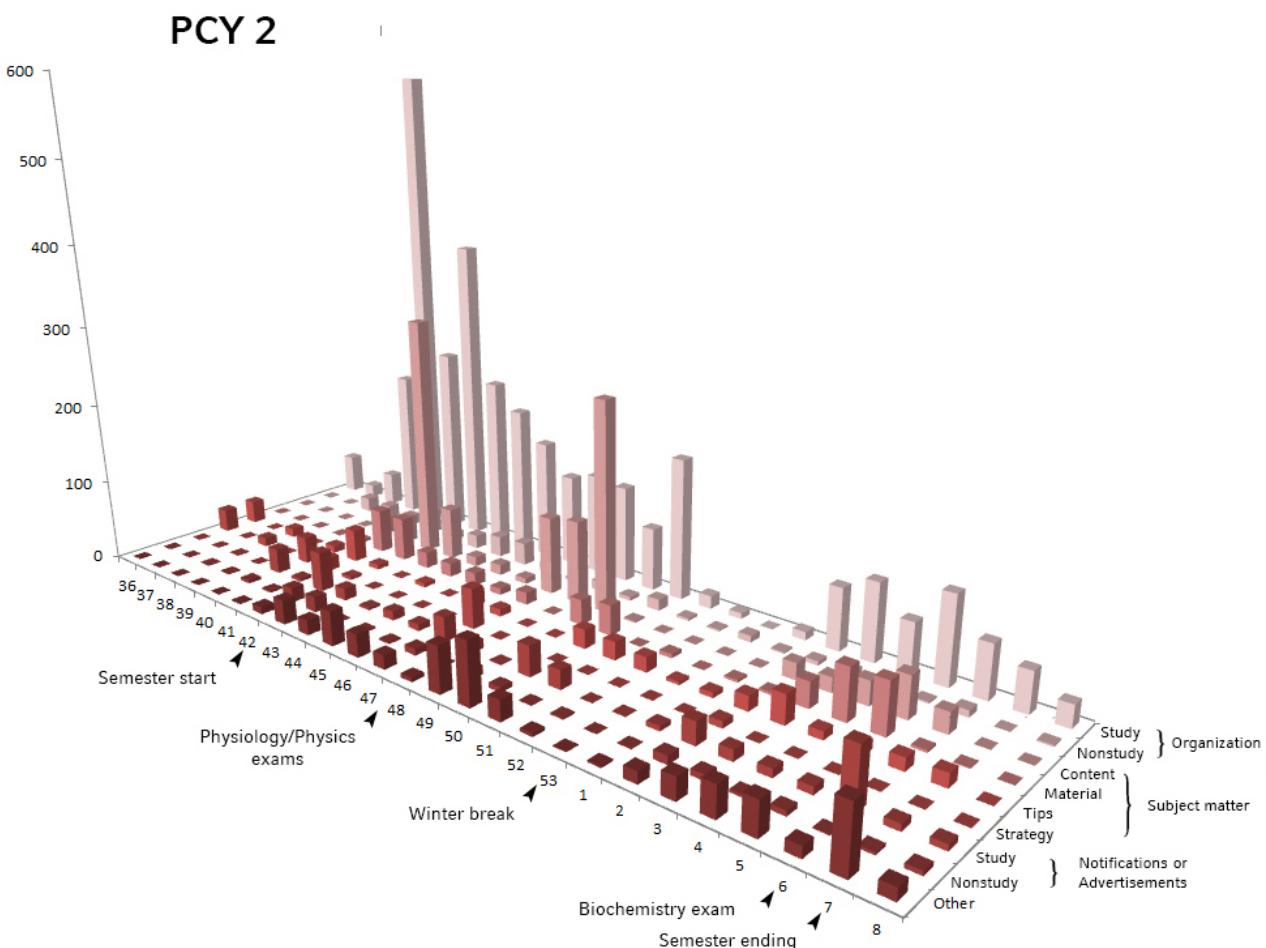
**Figure 2.** (a) Percentage of total posts in preclinical year 1 (PCY1) and preclinical year 2 (PCY2) contributed by subgroups that posted 1 to 10 (lurkers), 11 to 30 (frequent posters), and >30 posts (social media drivers) through the course of one semester. (b) Contribution of social media drivers (>30 posts) to primary posts, comments, and overall posts (primary and comments). (c) Contribution of social media drivers to identified categories.



**Figure 3.** Number preclinical year 1 (PCY1) posts per semester week, divided into identified categories. Time axis (weeks) shows relevant semester events (arrows).



**Figure 4.** Number preclinical year 2 (PCY2) posts per semester week, divided into identified categories. Time axis (weeks) shows relevant semester events (arrows).



Posts concerning subject matter peaked in weeks before the exams. In PCY1, we saw a maximum number of posts on the subject matter during weeks 47 and 7, correlating to the first exams of anatomy and neuroanatomy, respectively. In PCY2, posts on subject matter clustered in week 42, which corresponds to the biology exam, as well as the start of the physics practical course and in weeks 47/48, when PCY2 students took their physics and physiology exam (average 227.8 posts during these weeks vs semester average 34.5 posts,  $P=.001$  on subject matter). To confirm our assumption, we qualitatively looked in to these weeks and verified that these topics are indeed predominant.

In both groups, frequencies in all categories dropped in calendar weeks 52, 53, and 1, which corresponds to the Christmas and New Year semester break (PCY1: semester average 217.6 posts vs semester-break average 23.3 posts,  $P=.002$ ; PCY2: 294.2 posts vs 24.3 posts,  $P=.004$ ).

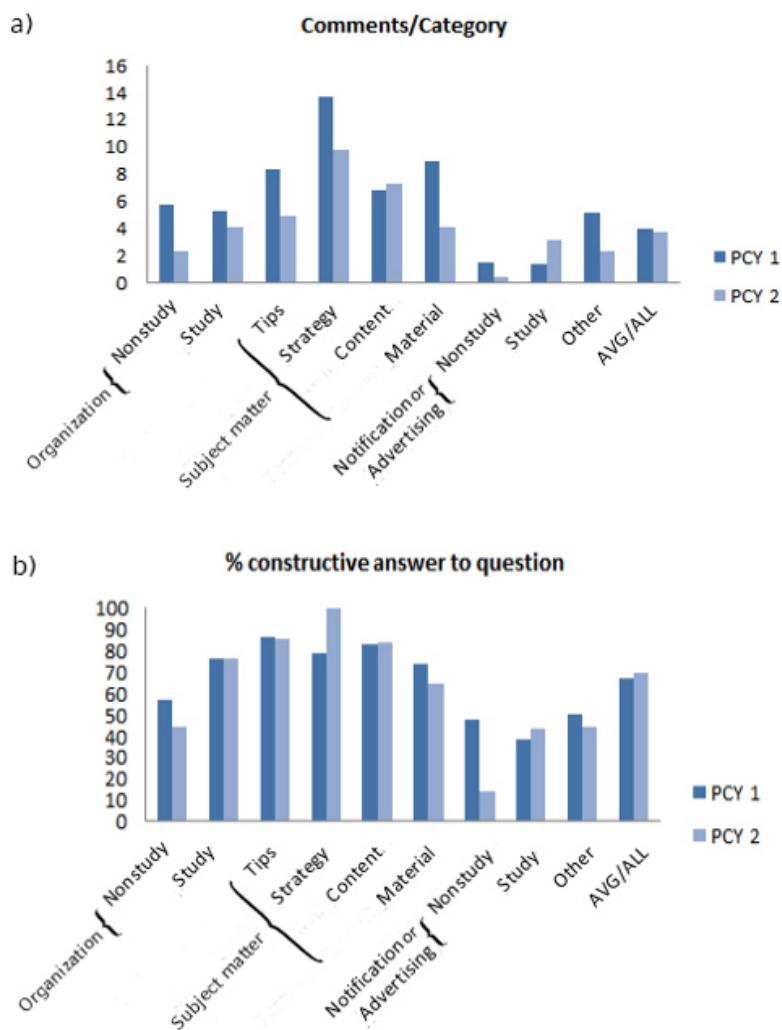
We found that in the first year, 63.13% (738/1169), and in the second year, 77.13% (961/1246) of the total primary posts were questions. Overall, 67.2% (496/738) and 69.8% (671/961), respectively of these questions received satisfactory replies. Questions in the categories “notification” or “other topics” were answered in half or less of cases, whereas questions on subject matter were sufficiently answered in 78% to 100% of cases, depending on subcategory and semester. Study-related organizational questions, which were the bulk of all posts, were

answered in 75.9% (341/449) and 76.2% (428/562) of cases in PCY1 and PCY2 groups (Figure 5).

A similar pattern was apparent when counting average replies per category (Figure 5). The overall average per primary post amounted to 4.1 replies in PCY1 and 3.8 replies in PCY2 and was heterogeneous among the subcategories. In PCY1, posts on subject matter received between 8.4 (tips) and 13.7 (strategy) comments, notifications or advertising 1.5, questions on organizational issues 5.3 to 5.8, and other topics 5.3 comments on average. In PCY2, posts on subject matter received between 4.1 (material) and 9.8 (strategy) comments, notifications or advertising 3.2, questions on organizational issues 2.3 (nonstudy-related) to 5.8 (study-related), and other topics 2.4 comments on average.

In both PCY1 and PCY2, *social media drivers* contributed more replies (22.59%, 1072/4757 and 31.08%, 1455/4681 respectively) than primary posts (15.06%, 176/1169 and 21.19%, 264/1246, respectively) in comparison to their 21.67% (1284/5926) and 29.00% (1719/5927) overall contribution (Figure 2). Analysis of subcategories revealed a similar pattern to the general post and reply average of *social media drivers*, with most involvement in posts on subject matter (strategy: 39%, 11/28; content: 37.3%, 63/169; and tips: 30%, 24/80) and lowest contribution to notification or advertising (7.5%, 35/465; Figure 2).

**Figure 5.** (a) In-detail analysis of comments per primary post, in all identified, coded categories. (b) Replies coded for percentage of constructive answers to questions in different categories.



## Discussion

### Facebook Groups Play an Important Role in Students' Lives

Facebook groups seem to have evolved as the main online social communities for medical students at LMU to complement the curriculum and to discuss study-related content. User typology revealed social media drivers (>30 posts per semester) as engines of group function, frequent users (11-30 posts), and a majority of average users acting rather as consumers or lurkers (1-10 posts). A wide range of topics is covered with a dominance of organization-related posts. By measuring reply rates and comments per category, we were able to highlight learning tips and strategies, material sharing, and course content discussions to be strengths of these groups. These Facebook groups are self-organizing and quickly adapt to organizational or subject-related challenges posed by the curriculum.

In line with a number of studies that show an increase in students' usage of social media for educational purposes [15,16,19,33], our study confirms widespread use of Facebook at a large medical faculty not limited to this purpose. Although there are many ways to use social media (and Facebook in

particular [8]), our results show that students in our faculty mainly use Facebook groups. This is supported by the fact that almost all students in one preclinical year are members of the respective semester-spanning group. The amount of questions and comments posted throughout the whole semester demonstrates continuous usage. Group members stating "without the (Facebook) group I wouldn't survive medical school" or a nonmember commenting "[...] I have to say I can't directly compensate the losses [in study-related info or material]," combined with the fact that some students only register on Facebook to participate in these groups, demonstrate the importance medical students ascribe to these groups. In a similar study performed at the Coalsville School of Social Sciences, students seem to predominantly use the wall function rather than Facebook groups. The difference could be because of the different structure of the curriculum or the time separation between the studies (2006 or 2007 vs 2013 or 2014) [9,11].

Although some of Mason's essential attributes for educational usage of social media, such as communication, material sharing, and peer feedback can also be found in blogs, wall posts, and forums, these elements can be conveniently implemented using Facebook groups [12]. As seen in this study, the high frequency of questions and comments posted and the swiftness of replies

show a considerable flow of information. Aggregation of information is obviously occurring given the amount of shared material, knowledge, and experience present. Finally, as each member of these groups had the means to read posts and react to them (complement, amend, or adjust), modification of informational content was also easily possible. Our work therefore supports Lee's and McLoughlin's assumption that Facebook groups could contribute a lot to creation of new content and could consequently play an important role as pedagogical tools [10].

Next to an educational role deriving from content-related posts, exchange of learning strategies, and feedback, an additional educational value concerning new media literacy skills can be postulated. According to Jenkins, the participation in online social media leads to creation and sharing of information, as well as collaboration with associated individuals. He defined these skills as vital for learning [34]. Students using the described Facebook-Groups presumably get to practice some of the literacy skills such as judgment, multitasking, collective intelligence, navigation, networking, and negotiation. This would be in line with Ahns findings, who examined (using learning analytics) how participatory behaviors correlate with acquisition of new media literacy skills [35]. Due to the lack of individual information (further SNS behavior) concerning group members, learning analytics could not be applied in our case. Further studies should look deeper into that aspect of Facebook-Group use.

#### Four Main Types of Facebook Group Users Are Identified

Virtually all medical students in our faculty seem to be using Facebook groups, if only as passive consumers. It is remarkable that the majority of students in both groups contributed at least one post throughout the semester. The higher number of members in the groups compared with the respective, official student enrollment in each semester could be because of older students joining the group for support and information. For example, the student council encourages older students participating in a first year peer mentoring program to join the respective groups to share information and organize meetings. This might actually add a beneficial vertical axis in information sharing and support.

We identified four main types of students: (1) *new minorities* (students not participating in Facebook groups), (2) *Lurkers* (students joining the groups but hardly participating by posting), (3) *Frequent users* (students contributing above 10 posts throughout the semester), and (4) *Social media drivers* (students with an extensive contribution of more than 30 posts throughout the semester).

Interviews with *social media drivers* revealed a heterogeneous group of students who either posted because of an above average need for help and assistance or to contribute and help other students. These findings are similar to the findings of Kumar et al (2010), albeit in a different context [7].

An imbalance in contribution, as present in this case, could create an environment dominated by few, which dictate topics and discussions. However, we identified three arguments making

a strong case against this assumption: (1) Posting analysis revealed that *social media drivers* are more likely to comment on an existing post than to place a primary post, (2) Topic-wise, the distribution of their comments follows the overall trend, and finally (3) the percentage of constructive answers by *social media drivers* was high. Consistent with this, students we interviewed didn't feel inept or constrained in posting questions and making remarks. Hence, we believe that this particular subgroup makes a positive contribution to the efficacy of the whole group.

Interestingly, although Facebook networks are normally formed based on existing offline social networks or even offline latent ties [36-38], Facebook groups created for educational purposes seem to differ in that aspect. Students formed the first group we studied in their first preclinical semester, 2 or 3 weeks before the first official university event. As a result, participants of the group did not know each other before interacting via the semester-spanning group. It is conceivable that the large amount of communication following formation of the group is attributable to the fact that these groups are the only source of study-related information in the first weeks. One could consecutively hypothesize that after students have made some personal acquaintances and have formed real life peer groups, these alternative sources of information would render the respective Facebook groups less relevant. However, in our study we could not find a reduction in usage between first and second preclinical year (similar amount of questions and comments, similar amount of active users, and similar distribution of postings throughout the semester). Therefore, we infer that offline networks have little effect on the usefulness of educational Facebook groups. Further research and different methodology is necessary to examine the influence of offline networks in the evolution of online educational social media groups.

It needs to be mentioned that the sample size for focus groups (n=21) and interviews (n=10) was small considering the amount of students involved in the group (n=2362), and we can therefore not exclude additional user types to be present. Nevertheless, saturation analysis showed extensive redundancy between the two focus groups.

#### A Wide Range of Topics is Covered, With a Dominance of Organization-Related Posts

Through analyzing all posts in PCY1 and PCY2 over the course of one semester, we were able to qualitatively identify relevant topics, as well as quantitatively assess frequencies and posting patterns. By using a thematic content analysis approach, combining it with a thorough semester-long evaluation, we could reduce biases and get a more holistic impression.

All five themes that emerged in Selwyn's study (2009) through analysis of Facebook wall activity at Coalsville [9,11] could also be identified in the analysis of Facebook group posts at our faculty. This is surprising, as exchange of information in the Selwyn study happened between students that personally knew each other offline, whereas in our study students, at least initially, were not personally acquainted. As Selwyn's study described mere qualitative differences, the predominance of themes could not be compared. Nonetheless, the high

consistency of content despite two different curricula, subjects, and countries suggests that a global framework can be applied for students' educational use of Facebook.

The majority of information exchanged in both groups we examined concerned organizational issues. The almost identical amount of posts in that category found in both years reveals a continuous need for clarification and information. Although faculty websites and brochures provide sufficient information for most of the issues raised, students preferred posting questions in Facebook groups. This is likely because of the immediacy, comprehensibility, as well as the accuracy of replies.

In contrast to the constant amount of posts concerning organizational issues, students in the second year group post a lot more about subject matter. We found that students discuss learning strategies or even explicit learning content. Most likely, this is because of the increasing conceptual and subject specific challenges over the course of preclinical medical studies and the upcoming first state exam after the 2nd preclinical year. Focus groups and interviews revealed the relevance of this aspect. Especially, sharing of learning materials such as scripts or exam questions was named as one of the main reasons for using these groups. Individuals even stated that Facebook was absolutely mandatory for their academic success in medical school. Additionally, the higher rate of overall replies and constructive answers to questions in this category (78% (11/14) to 100% (13/13)) underline the importance as well as strength of Facebook groups in this regard. These results highlight the role of social media in peer education and learning in accordance with findings in the literature [15,21,25,39-42].

In addition to the categories we analyzed, the groups are also used for a broad range of nonstudy-related content. For example, we identified a number of peer-mentoring elements as an interface between education and extracurricular aspects in a preceding study, that is, providing emotional support: "It's absolutely normal to be afraid of the terminology exam and the Latin grammar questions, but it is really easier than you think" [19]. Considering the amount and diversity of issues raised, we conclude that these groups serve as a broad platform for a variety of content.

### Semester-Spanning Facebook Groups Are Highly Dynamic and Show Plasticity

Our in-depth quantitative analysis of posting patterns reveals specific posting patterns over each semester.

The use of Facebook as a *live blog*, for example, concerning currently free seats in the library or questions asked in an oral exam minutes away, exemplifies the dynamics and quick response rates associated with the use of Facebook groups. Not only posts and comments but also posting patterns were highly dynamic. We could show that overall post frequencies and covered topics adapt to current events. As probably most students in each cohort will face comparable challenges and have similar questions at the same time period, this plasticity helps the group to be relevant at any given point in time.

Furthermore, by sharing information so easily, it seems sufficient if only a few members of the group spent time checking primary sources. In effect, this construct contributes

to the efficiency of the whole group, as already described for social media in companies [43].

Tuckman's model of group development consists of four phases: forming, storming, norming, and performing [44]. Essentially, one would expect that newly formed Facebook groups would undergo consolidation over time and therefore, function better at later points in time. In the light of this theoretical framework, the increase in members contributing over 30 posts along with a decrease in students contributing 1 to 10 posts in the second year could be consistent with group evolution. Additionally, the changes in predominant schemes (content- and subject-related posts increased, whereas total posts classified in "other" dropped to roughly one-third, accompanied by a drop in notifications or advertisements) could also hint at a more streamlined discussion and flow of information. Along the same lines, primary posts that include questions increased, as well as the contribution of *social media drivers* to primary posts and replies. We conclude that these groups seem to undergo considerable development over time, which can be explained with phases of group formation according to group theory [44,45].

### Multiple Limitations of the Described Use of Facebook Are Identified

In accordance with previous studies, we identified potential limitations of Facebook groups for educational use. First, privacy issues were prominently expressed by all students we interviewed, especially by the cohort of *new minorities*, and were frequently named as a reason against joining Facebook (and the groups). Students mainly felt their personal data were at risk. Professionalism issues seem to be more relevant in groups formed by students in the clinical parts of their studies, as information could involve patient data [23,46]. This could have not only personal but also legal implications, clearly limiting the use of these groups in contrast to university-hosted, protected platforms, which are already in use at some institutions [14,47].

Furthermore, the identification of even a small percentage of students not enrolled in Facebook for understandable reasons prohibits the option of using these groups as an official platform for the respective semesters.

Moreover, Facebook groups are clearly not designed and programmed for educational purposes. Students complained about technical limitations, which make it hard to organize, share, and find information. For example, similar questions were often posted multiple times. This limits the use of the group as a database. In line with Madge et al (2009), students also described the platform itself as distracting and time-consuming by mixing study-related and private content [48].

Finally, Facebook groups can be easily misused for commercial interests [33,49]. We identified a substantial amount of advertisements in both groups. In a time of personalized advertisements, a homogenous group of students is a very valuable target and could not only lead to distracting advertisement but also hidden product placement, for example, recommendations for certain books or other learning materials.

## Conclusions

We found semester-spanning Facebook groups to be an essential part of the learning environment for most medical students at LMU Munich. A wide range of study-related topics were covered; organizational posts and posts with regard to subject matter seemed predominant. The reach, involvement of students, plasticity, and dynamics make these groups very powerful knowledge bases, as well as platforms for posing questions and starting discussions on a wide range of topics.

Faculty could cover many aspects that are discussed in students' Facebook groups, especially the bulk of organizational questions and posts. However, the dynamics, plasticity, and response time of social media is difficult to match. Nevertheless, faculty could benefit from these groups and use them to their advantage. For example, universities could feed relevant information to the groups, increasing their reach and interacting more closely and directly with their students. Moreover, posting patterns concerning certain topics could be used to identify common problems and understanding semester-related dynamics, reacting more quickly and precisely. Information could be structured

better, and organizational deficits could be easily identified. By reviewing discussed topics, the curriculum could be adapted to challenging teaching and learning content that posed problems to students. The peer teaching aspect could be greatly enhanced by introducing trained senior students providing help and assistance to their younger peers. This could enhance vertical knowledge transfer and information quality at the same time. Moreover, in a less anonymized setting, student with weaker performance could be identified earlier and be supported adequately by mentors and tutors. Curriculum structure, organization, and content are subjects to instantaneous feedback in these groups, allowing for quick adaptations and possibly replacing costly evaluation forms and surveys. Nevertheless, more research is necessary to assess the influence of possible participation of faculty members in these groups, as social media has also been identified as an opportunity to vent study-related frustrations [31].

Additionally, other issues such as the quality of posts, privacy, and knowledge conservation should be addressed before faculties could get more actively involved in Facebook groups [23].

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Interview guidelines.

[[PDF File \(Adobe PDF File, 43KB - jmir\\_v19i12e408\\_app1.pdf](#)]

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## Abbreviations

**LMU:** Ludwig-Maximilians-University

**PCY:** preclinical year

**SNS:** social networking site

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Original Paper

# Evaluating the Dental Caries-Related Information on Brazilian Websites: Qualitative Study

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## Abstract

**Background:** Dental caries is the most common chronic oral disease, affecting 2.4 billion people worldwide who on average have 2.11 decayed, missing, or filled teeth. It impacts the quality of life of patients, socially and economically. However, the comprehension of dental caries may be difficult for most people, as it involves a multifactorial etiology with the interplay between the tooth surface, the dental biofilm, dietary fermentable carbohydrates, and genetic and behavioral factors. Therefore, the production of effective materials addressed to the education and counseling of patients for the prevention of dental caries requires a high level of specialization. In this regard, the dental caries-related contents produced by laypersons and their availability on the Internet may be low-quality information.

**Objective:** The aim of this study was to assess the readability and the quality of dental caries-related information on Brazilian websites.

**Methods:** A total of 75 websites were selected through *Google*, *Bing*, *Yahoo!*, and *Baidu*. The websites were organized in rankings according to their order of appearance in each one of the 4 search engines. Furthermore, 2 independent examiners evaluated the quality of websites using the DISCERN questionnaire and the Journal of American Medical Association (JAMA) benchmark criteria. The readability of the websites was assessed by the Flesch Reading Ease adapted to Brazilian Portuguese (FRE-BP). In addition, the information presented on the websites was categorized as etiology, prevention, and treatment of dental caries. The statistical analysis was performed using Spearman rank correlation coefficient, Mann-Whitney U test, hierarchical clustering analysis by Ward minimum variance method, Kruskal-Wallis test, and post hoc Dunn test.  $P<.05$  was considered significant.

**Results:** The Web contents were considered to be of poor quality by DISCERN (mean 33.48, standard deviation, SD 9.06) and JAMA (mean 1.12, SD 0.97) scores, presenting easy reading levels (FRE-BP: mean 62.93, SD 10.15). The rankings of the websites presented by Google ( $\rho=-.22$ ,  $P=.08$ ), Baidu ( $\rho=-.19$ ,  $P=.53$ ), Yahoo! ( $\rho=.22$ ,  $P=.39$ ), and Bing ( $\rho=-.36$ ,  $P=.23$ ) were not correlated with DISCERN scores. Moreover, the quality of websites with health- and nonhealth-related authors was similar ( $P=.27$  for DISCERN and  $P=.47$  for JAMA); however, the pages with a greater variety of dental caries information showed significantly higher quality scores than those with limited contents ( $P=.009$ ).

**Conclusions:** On the basis of this sample, dental caries-related contents available on Brazilian websites were considered simple, accessible, and of poor quality, independent of their authorship. These findings indicate the need for the development of specific

policies focused on the stimulus for the production and publication of Web health information, encouraging dentists to guide their patients in searching for recommended oral health websites.

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## KEYWORDS

dental caries; internet; consumer health information; health education

## Introduction

The delivery of health care is in a rapid transition from a paternalistic approach to a person-centered model [1,2]. This process aims to improve health outcomes by the construction of a shared decision-making process between health professionals and patients [3,4], characterized by the greater involvement of people in the resolutions and actions concerning their own health [5-10]. The effectiveness of this novel model, however, may be harmed by a considerable number of barriers, such as low education, inadequate access to knowledge, and social and economic deprivation [11].

Dental caries is the most common chronic oral disease worldwide [12], affecting 2.4 billion people [13,14] who on average have 2.11 decayed, missing, or filled teeth [15]. Untreated dental caries impact the quality of life of individuals, socially and economically [16,17], being the first cause of toothache (24.3%) and tooth loss (86%) among Brazilian citizens [18,19]. In addition, dental caries is the fourth most expensive oral condition to be treated [20]; consequently, people are increasingly interested in dental caries-related Web information, particularly about its symptoms and therapies [21]. This disease involves a complex multifactorial etiology, with the interplay between the tooth surface, the dental biofilm, dietary fermentable carbohydrates, and genetic and behavioral factors, which requires a high level of specialization for the production of effective materials addressed to the education and counseling of patients [22-24]. In this regard, the availability of inaccurate contents in open electronic sources may augment the risk of consumption of low-quality dental caries-related information, hampering the person-professional relationship [25,26] and raising the chance of health damages [27]. Even considering habitual Web health consumers and adequate literates, who are more predisposed to identify and reject poor quality information, their decisions are still based on empirical features, such as the order of appearance of links in the search engines, the design factors, and the complexity and the style of information [28,29].

Several studies have already assessed the quality of Web information related to different health conditions [30-39]; however, there is no evidence about the quality of dental Web contents available in Brazil. The aim of this study was to assess the readability and the quality of dental caries-related information retrieved on Brazilian websites.

## Methods

### Study Design

This study analyzed the quality of dental caries-related information available on Brazilian websites. After the development of a specific search strategy, the websites were

retrieved by *Google Search*, *Yahoo!*, *Bing*, and *Baidu*. Duplicates, nonspecific, inaccessible, and/or scientific links were excluded. The websites were evaluated by 2 independent examiners using the DISCERN questionnaire [40], the Journal of American Medical Association (JAMA) benchmark criteria [41], and the Flesch Reading Ease adapted to Brazilian Portuguese (FRE-BP) [42]. Furthermore, the websites were dichotomized by the nature of their authorship (health- or nonhealth-related authors). Finally, the websites' identities were determined by cluster analysis in accordance with the combination of their respective contents (etiology, prevention, and/or treatment of dental caries).

### Search Strategy

The search strategy was designed with regard to the relevance of terms employed by the Internet users. Initially, a general query was performed on *Google Search* to confirm the link of Brazilian Portuguese words to dental caries issues. Additional terms automatically generated by the *Keyword Planner* were included in the analysis. The relevance of each one of 56 terms was subsequently examined in *Google Trends* by observing the monthly variation of their search volume index between the years 2004 and 2015, including all categories of Web queries performed in Brazil (Multimedia Appendix 1). After excluding 53 keywords with irrelevant volume searches, the final search strategy was constructed by the association of three terms (“cárie”+“carie”+“carie dentaria”), which correspond to synonyms and typos of dental caries written in Brazilian Portuguese.

### Selection of Websites

The websites were selected through the 4 search engines with the largest market share: *Google Search*, *Baidu*, *Yahoo!*, and *Bing* [43]. On March 21, 2016, the searches were performed using a computer connected to the Internet, previously set up by clearing the cookies and history of each browser. Advanced queries were filtered by idiom (Portuguese) and country (Brazil). The retrieved links were ordered in rankings, considering the position of their appearance in each search engine tool.

Subsequently, the websites were accessed and registered using the WebCite [44], an online service that archive the information exactly as it was recovered, avoiding changes and updates for further analysis.

Finally, the websites were dichotomized according to the nature of their authorship in health- and nonhealth-related authors. Websites or blogs developed by dental or medical associations, universities, educational institutions, health companies, or health professionals were classified as health-related authors. All other pages were classified as nonhealth-related authors. Furthermore, the information presented on the websites was categorized as

etiology, prevention, and/or treatment of dental caries. The presence or absence of these contents was graphically represented by the software Genesis (version 1.7.7, Graz, Austria), characterizing the identity of each website [45,46].

### The Assessment of Quality of Websites

Two independent examiners (PEAA and MMC) evaluated the quality of websites using the DISCERN questionnaire [40] and the JAMA benchmark criteria [41]. The DISCERN questionnaire is commonly applied to assess the quality of written information on health treatment choices. The instrument is divided into the following 3 sections: (1) reliability of the publication, (2) specific details of the information about treatment choices, and (3) overall quality rating of the document. It consists of 16 questions with 5-level Likert scale, where the score "1" indicates that the criterion was not fulfilled and the score "5" indicates that the criterion was completely satisfied. The total DISCERN score varies between 15 and 80, as the second question must be disregarded when the first question is scored "1." Typically, only the results of the first and second sections of this instrument are used to qualify the health content of documents, as follows: very poor (15-26), poor (27-38), fair (39-50), good (51-62), and excellent (63-75) [47].

The JAMA benchmark consists of a series of 4 qualitative criteria that refer to the description of the authorship (author's name, affiliations, and credentials), attribution (effective references of content), currency (presence of dates of posts and updates of information), and disclosure (the statement of any potential conflicts of interest) of websites. For each fulfilled criterion, 1 point is given, with a total score of 0 to 4.

The websites that were divergently qualified by the examiners were reassessed to the achievement of a consensus score.

### Readability Measures

The FRE-BP [40] was used to assess the readability of the websites based on the following formula:  $\text{FRE-BP}=248.835-(84.6 \times \text{syllables per word})-(1.015 \times \text{words per sentence})$ . These metrics were calculated using the online tool Readable.io (Readable.io, Bolney, England) [48] through

the information of the respective Uniform Resource Locator (URL) of each website. All analyses were performed based on the overall written content downloaded from these links. The reading difficulty of a text is presented according to the following scores: very easy (75-100), easy (50-75), difficult (25-50), and very difficult (0-25).

### Statistical Analysis

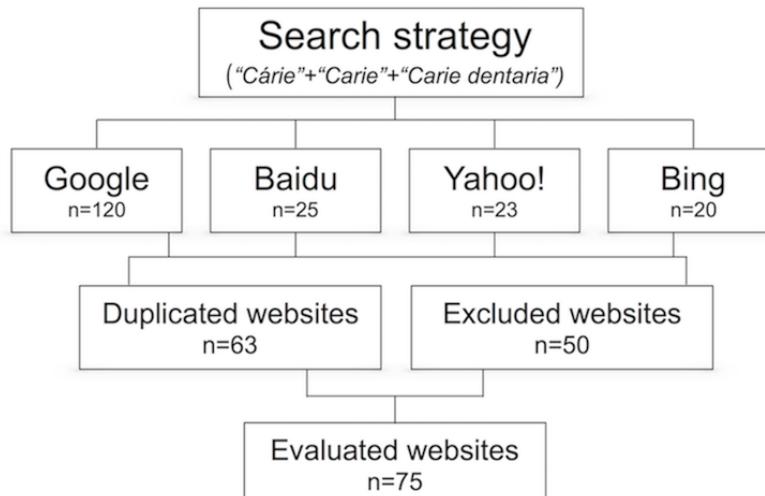
Data were analyzed with the Statistical Package for Social Science (version 21.0; SPSS, Chicago, USA). Although the hypothesis of normal distribution of data was not confirmed by the Kolmogorov-Smirnov test, the statistical analysis was performed by the application of nonparametric tests. The internal consistency of DISCERN was determined by Cronbach alpha. The interrater reliability of DISCERN and JAMA scores provided by the independent examiners was assessed by intraclass correlation coefficient (ICC) for the absolute concordance. The correlations between distinct measures were demonstrated by the Spearman rank correlation coefficients. The significant differences between the dichotomized natures of websites were observed by Mann-Whitney U test. The clusters that emerged from the similarity of websites' identities were determined by the hierarchical clustering analysis using the Ward minimum variance method. Distinct clusters were compared by Kruskal-Wallis test and post hoc Dunn test.  $P$  values of  $<.05$  were considered significant for all analyses.

## Results

### Websites

A total of 188 websites were obtained through the first links sequentially retrieved from *Google Search* (n=120), *Baidu* (n=25), *Yahoo!* (n=23), and *Bing* (n=20). Duplicates (n=63), nonspecific websites (n=21), inaccessible links (n=7), and scientific contents (n=22) were excluded. A total of 75 websites met the inclusion criteria for the analysis, as shown in Figure 1. As duplicates were also excluded sequentially, there was a great predominance of *Google Search* links among those that were effectively evaluated, as follows: *Google Search* (n=66), *Baidu* (n=1), *Yahoo!* (n=7), and *Bing* (n=1).

**Figure 1.** Flowchart depicting the systematic selection of dental caries-related Brazilian websites.



## Reliability of Instruments

The instrument DISCERN displayed an excellent internal consistency (Cronbach alpha=.901), with values of Cronbach alpha varying between .884 and .904 if an item was deleted. A good absolute concordance level was observed between the examiners for the application of the instruments DISCERN questionnaire (ICC=0.73, 95% CI 0.38-0.86) and JAMA benchmark (ICC=0.72, 95% CI 0.56-0.82).

## DISCERN, JAMA, and FRE-BP Scores

The DISCERN and JAMA scores for each website are depicted in the [Multimedia Appendix 2](#). The contents of the websites were classified as of poor quality in accordance with both scores ([Table 1](#)), which were significantly correlated ( $\rho=.58, P<.001$ ) ([Table 2](#)). In addition, the sum of partial DISCERN scores (sections 1 and 2) was strongly correlated with the scores of section 3 ( $\rho=.92, P<.001$ ). A total of 20 websites scored  $\geq 39$ , with a mean overall quality of 3.71. A digital encyclopedia opened to public contributors (“*Wikipedia*”) and a page specialized in dental health information (“*ident*”) showed the two highest DISCERN scores ( $>60$ ). Only 9% (7/75) of the websites presented at least three required information displayed by JAMA benchmark criteria. The minor percentage of pages presented authorship (36%, 27/75), attribution (18.7%, 14/75), currency (17.3%, 13/75), and disclosure (40%, 30/75).

**Table 1.** Descriptive statistics of scores of DISCERN, the Journal of American Medical Association benchmark, and Flesch Reading Ease adapted to Brazilian Portuguese.

Outcomes	S1 <sup>a</sup>	S2 <sup>a</sup>	S3 <sup>a</sup>	DISCERN (S1+S2)	JAMA <sup>b</sup>	FRE-BP <sup>c</sup>
Mean (SD)	18.89 (5.70)	14.59 (5.40)	2.20 (0.85)	33.48 (9.06)	1.12 (0.97)	62.93 (10.15)
Median	18.00	14.00	2.00	33.00	1.00	63.56
Minimum	8.00	7.00	1.00	18.00	0.00	37.98
Maximum	34.00	28.00	4.00	60.00	3.00	88.23

<sup>a</sup>S1, S2, and S3: 3 different sections of DISCERN.

<sup>b</sup>JAMA: the Journal of American Medical Association.

<sup>c</sup>FRE-BP: Flesch Reading Ease adapted to Brazilian Portuguese.

**Table 2.** Cross correlation between the ranking of websites presented in the 4 engines, DISCERN, the Journal of American Medical Association benchmark, and Flesch Reading Ease adapted to Brazilian Portuguese.

Outcomes	Ranking Baidu ( $\rho, P$ )	Ranking Yahoo! ( $\rho, P$ )	Ranking Bing ( $\rho, P$ )	DISCERN (S1+S2 <sup>a</sup> ; $\rho, P$ )	JAMA <sup>b</sup> ( $\rho, P$ )	FRE-BP <sup>c</sup> ( $\rho, P$ )
Ranking Google	.78, .02	.86, <.001	.78, .02	-.22, .08	-.28, .02	.03, .84
Ranking Baidu		.60, .40	.95, <.001	-.19, .53	-.11, .73	.02, .96
Ranking Yahoo!			.77, .07	.22, .39	-.02, .93	-.04, .89
Ranking Bing				-.36, .23	-.19, .54	.03, .92
DISCERN					.58, <.001	-.23, .05
JAMA						.04, .76

<sup>a</sup>S1 + S2 = sum of scores of sections 1 and 2 of DISCERN.

<sup>b</sup>JAMA: the Journal of American Medical Association.

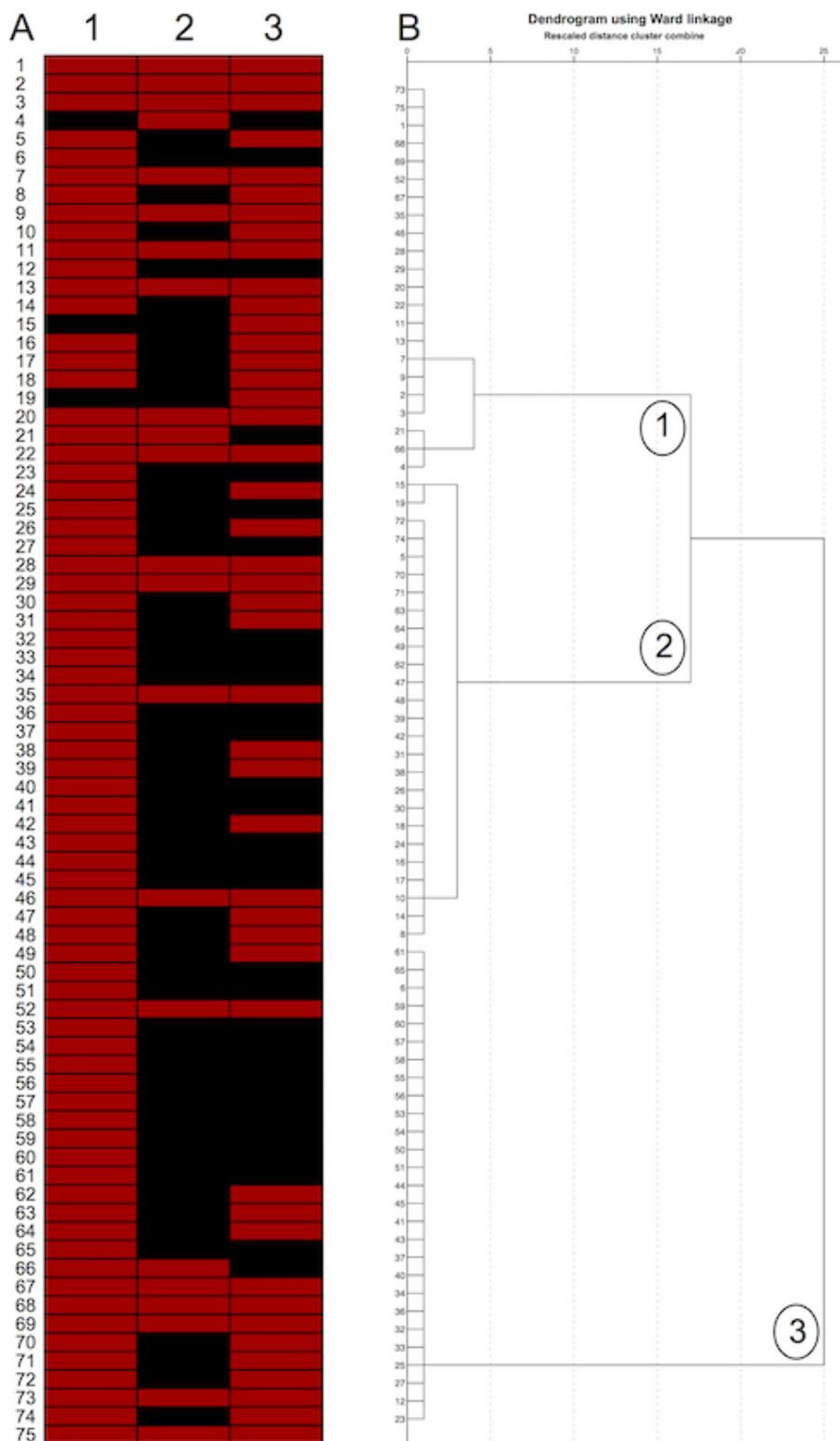
<sup>c</sup>FRE-BP: Flesch Reading Ease adapted to Brazilian Portuguese.

**Table 3.** Descriptive statistics of websites with health- and nonhealth-related authors for DISCERN, the Journal of American Medical Association benchmark, and Flesch Reading Ease adapted to Brazilian Portuguese.

Websites	S1 <sup>a</sup>	S2 <sup>a</sup>	S3 <sup>a</sup>	DISCERN (S1+S2)	JAMA <sup>b</sup>	FRE-BP <sup>c</sup>
<b>Health-related authors (n=38)</b>						
Mean (SD) <sup>d,e</sup>	19.58 (5.76)	14.68 (5.02)	2.34 (0.82)	34.26 (8.85)	1.05 (1.01)	63.26 (10.15)
Median	18.00	14.00	2.00	33.00	1.00	63.87
Minimum	11.00	7.00	1.00	18.00	0.00	37.98
Maximum	34.00	26.00	4.00	58.00	3.00	88.23
<b>Nonhealth-related authors (n=37)</b>						
Mean (SD) <sup>d,e</sup>	18.19 (5.76)	14.49 (5.75)	2.05 (0.88)	32.68 (9.33)	1.19 (0.94)	59.75 (10.34)
Median	18.00	15.00	2.00	33.00	1.00	62.55
Minimum	8.00	7.00	1.00	18.00	0.00	46.24
Maximum	33.00	28.00	4.00	60.00	3.00	72.73

<sup>a</sup>S1, S2, and S3: 3 different sections of DISCERN.<sup>b</sup>JAMA: the Journal of American Medical Association.<sup>c</sup>FRE-BP: Flesch Reading Ease adapted to Brazilian Portuguese.<sup>d,e</sup>Significant statistical differences between the groups (Mann-Whitney *U* test, *P*<.05).

**Figure 2.** Cluster analysis of the websites. (A) The representation of websites' IDs regarding the content of information: etiology (1), treatment (2), and/or prevention (3) of dental caries. Red and black bars mean the presence and absence of the type of information, respectively. (B) Dendrogram depicts three clusters originated from the websites' IDs (hierarchical clustering analysis by Ward's minimum variance method).



**Table 4.** Descriptive statistics of different clusters of websites for DISCERN, the Journal of American Medical Association benchmark, and Flesch Reading Ease adapted to Brazilian Portuguese.

Cluster	S1 <sup>a</sup>	S2 <sup>a</sup>	S3 <sup>a</sup>	DISCERN	JAMA <sup>b</sup>	FRE-BP <sup>c</sup>
<b>1 (n=22)</b>						
Mean (SD) <sup>d,e,f</sup>	19.05 (5.64)	18.05 (6.26)	2.41 (1.01)	39.50 (11.41)	1.05 (1.00)	60.04 (10.87)
Median	18.50	17.50	2.50	38.50	1.00	57.03
Minimum	8.00	9.00	1.00	22.00	0.00	41.23
Maximum	32.00	28.00	4.00	64.00	3.00	78.86
<b>2 (n=26)</b>						
Mean (SD) <sup>d,e,f</sup>	18.85 (4.65)	15.50 (3.78)	2.35 (0.75)	36.69 (8.19)	1.19 (0.85)	65.61 (7.80)
Median	18.00	16.00	2.00	35.00	1.00	66.03
Minimum	12.00	8.00	1.00	22.00	0.00	48.57
Maximum	34.00	24.00	4.00	62.00	3.00	80.28
<b>3 (n=27)</b>						
Mean	18.81 <sup>d</sup>	10.89 <sup>e</sup>	1.89 <sup>d</sup>	31.59 <sup>f</sup>	1.11 <sup>d</sup>	62.69 <sup>d</sup>
SD <sup>g</sup>	6.82	3.33	0.75	8.69	1.09	11.15
Median	16.00	11.00	2.00	29.00	1.00	63.06
Minimum	11.00	7.00	1.00	19.00	0.00	37.98
Maximum	33.00	19.00	3.00	47.00	3.00	88.23

<sup>a</sup>S1, S2, and S3: 3 different sections of DISCERN.<sup>b</sup>JAMA: the Journal of American Medical Association.<sup>c</sup>FRE-BP: Flesch Reading Ease adapted to Brazilian Portuguese.<sup>d,e,f</sup>Significant statistical differences between the groups (Kruskal-Wallis test and post hoc Dunn test,  $P<.05$ ).

## Discussion

### Principal Findings

To the best of our knowledge, this is the first study to assess the quality of dental caries-related information on Brazilian websites. In general, our results showed a predominance of low-quality contents, with a low rate of websites (26.7%) being classified as acceptable to high-quality levels (DISCERN $\geq$ 39). These results are consistent with the results of similar studies [49,50]; Blizniuk et al [49] demonstrated lack of quality of dental caries-related information on English websites (DISCERN=44), whereas Leite and Correia [50] identified only 4 out of 75 Portuguese dental caries-related websites certified with the Health On the Net Foundation (HON) code, a trustworthy certification granted by a nongovernmental institution that evaluates the quality of health information on the Internet [51]. However, we did not consider the HON code in our methods, as only 1 Brazilian website was certified. Surprisingly, the content of this website was qualified as inadequate by both instruments utilized in this study.

We believe that the assessment of the quality of websites was improved by the simultaneous application of distinct criteria, particularly because they were only fairly correlated. Additionally, the outstanding internal consistency and interrater agreement of DISCERN when employed in these analyses are noteworthy. In contrast, the determination of the internal

consistency of the JAMA benchmark is limited because it aims at the elucidation of specific data about technical and editorial production of websites. Although its four elements should be better interpreted individually, we calculated the central tendency measures of the JAMA benchmark to evaluate its relationship with other indicators.

The strict investigation executed by 2 health professionals may be linked to perception biases through the underestimation of the quality of websites; nevertheless, Griffiths and Christensen [52] revealed no significant differences between the scores of DISCERN given by professionals and laypersons. In addition, as cluster-based results were not influenced by the nature of websites' authorship, the better performance of websites that published topics about etiology, prevention, and treatment of dental caries reflects the significant impact of the completeness of contents on the process of qualification of information. This finding is supported by the study of Diviani et al [29], who showed that the amount of information available on a website influences the perception of improved quality of digital contents by Internet users. No significant differences were found when comparing DISCERN scores with JAMA scores of websites of health- and nonhealth-related authors, suggesting that the quality criteria considered in these instruments were not a concern for the most dentists and/or dental companies during the production of electronic contents.

Although the negative correlation between FRE-BP and DISCERN scores was discrete, this trend should be regarded

as an exacerbating factor for the impact of the low quality of information on the Internet users, as it demonstrates that more accessible contents are even worse in quality. This fact raises an important concern with regard to the high percentage of basic literate Brazilian youths (99%) and adults (93%) [53], as the understanding of medical information probably requires more advanced educational abilities [28]. In this context, the shared decision-making process could be deteriorated by the misunderstanding of health information and the development of harmful health beliefs.

### Design considerations

According to the Vital Signs report [54], there are 4 types of individuals with regard to health care situation: (1) those who agree and accept the treatment decision, (2) those who access the Web to confirm the diagnosis given by a professional, (3) those who are involved in the decision-making process, and (4) those who are in complete control of their treatment relying on the information found by themselves. In this context, although health professionals are still considered the most important source of health advice, the easier and more affordable access to the Internet predisposes people to seek health counseling online [29]. Furthermore, 65% of health seekers frequently begin their searches using an engine bar instead of looking for information on specific portals [54]. Consequently, millions of health-related queries are entered in *Google Search* daily [55]; therefore, the methodological approach adopted for the construction of our search strategy probably improved the chances of retrieving the websites in a similar way to that usually performed by netizens.

To evaluate the correlation of the order of appearance of links in the search engines with the quality of their contents, we assessed a quite larger number of websites than the Internet users could be interested in [56]. For instance, Google's PageRank uses more than 200 factors based on Larry Page's algorithms to order the links by their relevance from the query [57]. In this study, the links found on the Google's first page were represented by 5 blogs, 2 dental clinics, and 1 commercial website. Their contents were alarming, for example, with the description of *dental treatments without dentists*. In addition, the order of appearance of the websites was not correlated with DISCERN scores in the 4 different engines, that is, the algorithms created to retrieve the links associated with dental caries seemed to not have any relationship with the quality of available information, which may contribute even more with the deterioration of the health education process.

### Limitations

This study presents some limitations. First, although laypersons could be interested in reading more specialized documents, the

links associated to scientific publications, such as papers and books, were not considered into our analyses. This decision was based on two main reasons: (1) the DISCERN was developed to assess the quality of information presented to health seekers, that is, its application would be inadequate and unproductive to analyze scientific contents; and (2) probably, the great specificity and the technical language of scientific papers lead people to look for documents that explore more general knowledge about the disease. Second, it was not feasible to evaluate other types of website media, such as figures, films, and podcasts, as the DISCERN was specifically developed to assess the quality of written documents. Finally, the unknown audience of the websites prevented the determination of the impact of each source on the diffusion of dental knowledge, although our results were supposedly obtained from the most accessed websites, considering that they were the first dental caries-related links retrieved by search engines.

### Challenges

The development of specific regulations in this field is arduous, requiring an intense debate to avoid the suppression of the rights of freedom of expression and opinion [58]. Likewise, it is almost impossible to control the publication of Web contents, particularly because of the diffusion of personal opinion contained in health blogs. The use of codes and seals for the certification of websites could be a good approach to indicate the useful health information, particularly if the accreditation is based on rigorous criteria and if the Internet users can easily view the certification on the website. Nevertheless, the continuous consumption of misleading knowledge could deteriorate the person-dentist relationship; hence, the professional should be prepared to face this challenge effectively, advising and encouraging their patients to explore information on recommended websites, warning people about the risks of health home practices, and contributing to the production of good quality electronic materials.

### Conclusions

In conclusion, regarding the present sample of Brazilian websites, dental caries-related contents were considered simple, accessible, and of poor quality based on the results of FRE-BP, DISCERN, and JAMA benchmark scores, respectively. This pattern does not seem to rely on the natures of websites' authorship but on the multiplicity of categories of information that they covered. These findings indicate the need for the development of special policies focused on the stimulus for the production and publication of Web health information, encouraging dentists to guide their patients to search for recommended oral health websites.

### Acknowledgments

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### Conflicts of Interest

None declared.

## Multimedia Appendix 1

List of 56 dental caries-related keywords retrieved in Google Search and Keyword Planner (written in Brazilian Portuguese).

[[PDF File \(Adobe PDF File\), 29KB - jmir\\_v19i12e415\\_app1.pdf](#) ]

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## Multimedia Appendix 2

List of websites and respective identities, ranking, DISCERN, and JAMA benchmark scores.

[[PDF File \(Adobe PDF File\), 31KB - jmir\\_v19i12e415\\_app2.pdf](#) ]

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## Abbreviations

**FRE-BP:** Flesch Reading Ease adapted to Brazilian Portuguese

**HON:** Health On the Net Foundation

**ICC:** interclass correlation coefficient

**JAMA:** the Journal of American Medical Association

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Original Paper

# Development and Usability Evaluation of an Art and Narrative-Based Knowledge Translation Tool for Parents With a Child With Pediatric Chronic Pain: Multi-Method Study

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## Abstract

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**Background:** Chronic pain in childhood is increasingly being recognized as a significant clinical problem for children and their families. Previous research has identified that families want information about the causes of their child's chronic pain, treatment options, and effective strategies to help their child cope with the pain. Unfortunately, parents have reported that finding this information can be challenging.

**Objective:** The aim of this study was to actively work together with children attending a pediatric chronic pain clinic and their parents to develop, refine, and evaluate the usability of an art and narrative-based electronic book (e-book) for pediatric chronic pain.

**Methods:** A multiphase, multi-method research design employing patient engagement techniques was used to develop, refine, and evaluate the usability of an art and narrative based e-book for pediatric chronic pain management to facilitate knowledge translation for parents with a child with chronic pain. The multiple phases included the following: (1) qualitative interviews to compile parents' narratives using qualitative interviews; (2) qualitative data analysis; (3) development of an e-book prototype; (4) expert clinician feedback; (5) parent usability evaluation, knowledge change, and confidence in knowledge responses using an electronic survey; (6) e-book refinement; and (7) dissemination of the e-book.

**Results:** A 48-page e-book was developed to characterize the experiences of a family living with a child with chronic pain. The e-book was a composite narrative of the parent interviews and encompassed descriptions of the effects the condition has on each member of the family. This was merged with the best available research evidence on the day-to-day management of pediatric chronic pain. The e-book was vetted for clinical accuracy by expert pediatric pain clinicians. All parents that participated in the usability evaluation (N=14) agreed or strongly agreed the content of the e-book was easy to understand and stated that they would recommend the e-book to other families who have children with chronic pain. Our research identified up to a 21.4% increase in knowledge after using the e-book, and paired *t* tests demonstrated a statistically significant difference in confidence in answering two of the five knowledge questions (chronic pain is a disease involving changes in the nervous system; the use of ibuprofen is usually effective at controlling chronic pain);  $t_{13}=0.165$ ,  $P=.001$  and  $t_{13}=0.336$ ,  $P=.002$ , respectively, after being exposed to the e-book.

**Conclusions:** Our results demonstrate that parents positively rated an e-book developed for parents with a child with chronic pain. Our results also identify that overall, parents' knowledge increased after using the e-book, and confidence in their knowledge about chronic pain and its management increased in two aspects after e-book exposure. These results suggest that art and narrative-based knowledge translation interventions may be useful in transferring complex health information to parents.

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## KEYWORDS

pain; child health; parents; art

## Introduction

Chronic pain (recurrent or persistent pain lasting longer than 3-6 months) in childhood is increasingly being recognized as a significant problem, affecting between 15% to 39% of children and their families [1-4]. Despite the high incidence of chronic pain in children, it is often underrecognized and undertreated by clinicians [5], and there are very few specialized pediatric pain clinics, resulting in complex and lengthy referral processes. Headache is the most common chronic pain complaint expressed by children, followed by abdominal and musculoskeletal pain [6]. Children with chronic pain may experience increased vulnerability to pain, depression, and anxiety, as well as decreased confidence in the ability to function [7]. Parents of children with chronic pain report increased personal levels of depression, anxiety, and distress [8]. The priority of pediatric chronic pain treatment is to return the child to a functional state where they are engaging in daily activities. Three types of interventions comprise pediatric chronic pain treatment: pharmacological, physical, and psychological interventions. Treatment must also address education and support of families' reactions to their child's pain and how they best support their child [9]. Previous research has identified that families want information about the causes of their child's chronic pain and various treatment options, as well as effective strategies to help their child cope with the pain [10]. Specifically, this research surveyed parents (N=14) about expectations before attending the pain clinic and identified that having information about the causes of their child's chronic pain was important or very important to 93% (13/14) of respondents and that having information about medications for pain was important or very important to 72% (10/14); 86% (12/14) of the parents rated reading materials as important. Unfortunately, finding this information has been reported to be challenging for parents [10].

Failure to implement the best available research is pervasive in child health [11], even for common pediatric conditions such as pain, fever, and asthma [12-15]. To date, knowledge translation (KT) efforts have largely focused on ensuring that health care professionals use the latest research to inform their practice; however, emerging evidence suggests that initiatives that target health care consumers (eg, parents) can inform their decision making and shape their treatment expectations [16,17]. KT in child health is unique given the family-centered approach to care and the often essential extent of parental involvement in the care of children. Research has demonstrated that strategies to increase KT to parents by pediatric health care professionals can reduce health care utilization and improve outcomes [18-23].

The power of focusing on KT for both children and parents has yet to be fully realized.

There is an unprecedented demand for consumer-friendly, reliable, evidence-based health information for patients and their families because of the complex nature of health care, the rapid increase in the amount of health research, and the increased accessibility to research offered through the Internet [24,25]. Innovative mediums are superior to traditional standard health sheets for transferring information to consumers [26,27]. Thus, the use of art and narrative-based approaches holds promise for effectively transferring research evidence to patients and families [28]. Previous research in this area illustrates the power of art and narrative-based forms to communicate, engage with, and influence individuals [25,29-34]. To date, limited research has explored using art and narrative forms on digital platforms. The purpose of this research was to actively work together with children attending the pediatric chronic pain clinic in our children's hospital and their parents to develop, refine, and evaluate the usability of an art and narrative-based e-book for pediatric chronic pain.

## Methods

A seven-phase, multi-method design employing patient engagement techniques was used to develop, refine, and evaluate the usability of an art and narrative-based e-book for pediatric chronic pain management to facilitate knowledge translation. Ethics approval was received from our institutional ethics board.

### Compilation of Knowledge User Narratives (Intervention Development)

The project coordinator (trained in qualitative methods and supervised by the principal investigator [PI]) conducted semistructured qualitative interviews with a purposeful sample of family members with a child with chronic pain from the Stollery Children's Hospital (Edmonton, Alberta, Canada). Semistructured interviews ensured the acquisition of rich description and data while simultaneously allowing children and parents the freedom to respond and illustrate their experiences with pediatric chronic pain [35]. Questions focused exclusively on the experience of having a child with chronic pain and moved from general to specific, with interviews later in the data collection period becoming increasingly focused. Themes that were explored in the interviews included the effects of having a child with chronic pain on family life, social life, vacations, and work schedules; feelings regarding the diagnosis; expenses associated with having a child with chronic pain; experiences with the chronic pain clinic and health professionals involved; and parents' hopes or wishes. The interviews were

digitally captured and cleaned before the coordinator coded the interviews.

### Qualitative Data Analysis

Data collection and analysis occurred iteratively [35,36]. As analysis progressed, the interviews became more precise and purposeful [37]. Data collection continued until saturation of major categories [38] was achieved. Analysis occurred in three phases: coding, categorizing, and developing themes. Coding of the interview transcripts was led by the project coordinator and supervised by the PI (SS). Similar codes were then grouped into categories, and larger themes with memos were used to capture the analytic process. NVIVO 11 (QSR International Pty Ltd.) version 11, 2015 was used to facilitate data management during the analytic phase. Trustworthiness of the findings was ensured through iterative data collection and analysis. A summary of the interview themes (effect on the family, emotional experiences with chronic pain, experiences with the chronic pain clinic, families' information needs, and families' hopes and needs) with accompanying data excerpts from the interviews was shared with a creative writer who worked with the research team to develop the narrative for the e-book.

### Developing Prototypes (Intervention Development)

The development of the e-book prototype involved the creation of the composite narrative (compilation of common themes from the interviews), integrating the best available research on pediatric chronic pain management into the composite narratives, development of the artwork, and graphic display of the narrative and artwork. Our team worked with a creative writer, illustrator, graphic designer, and videographer to develop the e-book. We embedded information icons throughout the e-book to provide the best available research evidence on key pediatric chronic pain principles, as well as clear language explanations. Furthermore, additional resources (ie, breathing exercises) were also embedded to help children and families cope with managing chronic pain.

### Expert Clinician Feedback

After the e-book prototype was developed, it was shared with a multidisciplinary team of clinician experts at the pediatric chronic pain clinic that included a physician, psychologist, and nurse practitioner. The pediatric chronic pain service at the Stollery Children's Hospital (Edmonton, Alberta, Canada) provides treatment and care for children 17 years and below who experience chronic, difficult to manage pain. The clinicians reviewed the e-book for knowledge accuracy and are ideally suited for this assessment as they are well abreast of the best available research evidence in this highly specialized field.

### Prototype Usability Evaluation and Knowledge Change

A link to prototypes of the e-book, usability test, and pre and post knowledge tests were emailed (by clinic staff) to all 25 parents with a valid email address in the Stollery chronic pain clinic [39,40] database. Consent was implied if the Web-based survey was completed and submitted. Parents were asked to complete a Web-based survey that assessed their perceptions of the prototype using a 5-point Likert scale and included elements informed by a systematic search of over 180 usability evaluations [41]: (1) usability, (2) aesthetics, (3) language, (4)

level of engagement, (5) ease-of-use, (6) knowledge provided, (7) preference of form over traditional dissemination venues, (8) value-added (please see questions in [Multimedia Appendix 1](#)). Furthermore, parents had the opportunity to provide free text feedback on areas that required revisions or more information. To evaluate parents' knowledge of pain, parents were asked to answer five true or false knowledge questions about pediatric chronic pain and to rate their level of confidence in their responses before viewing the e-book. Evaluation of pain knowledge focused on five main topics: (1) what is chronic pain, (2) what is acute pain, (3) effects of chronic pain on children, (4) how to treat chronic pain, and (5) ibuprofen use and chronic pain. Parents rated their level of confidence in their response to each question using a 5-point Likert scale (very sure to very unsure). After completing the baseline knowledge test, the parents were to read the e-book, and knowledge questions were answered again to assess short-term knowledge changes. Participants were again asked to rate their confidence.

The data was cleaned and managed according to industry standards. Data was entered into Statistical Package for the Social Sciences (SPSS) version 21 (IBM Corp), and descriptive statistics (eg, frequencies), measures of central tendency, as well as paired *t* tests were completed. To uncover potential usability issues, the free text data was analyzed using content analysis, and any suggestions for revision were grouped and examined [42].

### Prototype Refinement

On the basis of the results from the clinician experts and the parent usability evaluation, changes were made to the e-book.

### Dissemination

The finalized e-book was disseminated through the Stollery Children's Hospital via the chronic pain team and the Pain 101 course for parents (a clinic specific course for children and parents who are cared for by the pediatric chronic pain team) through established social media platforms including investigators' Web pages ([www.echo.ualberta.ca](http://www.echo.ualberta.ca)) and TREKK ([www.trekk.ca](http://www.trekk.ca)), a network of health professionals and parents whose goals are to improve emergency care for children. Each of these Web pages is enabled with Google Analytics, thereby allowing investigators to track the visitor behavior attributes such as the number of visits to the e-tools, number of page views, and the average length of time viewing each e-tool [36]. A PDF version of the book was also shared on the local Alberta Health Services website and added to the chronic pain toolkit on the Canadian Association of Paediatric Health Centres Web page. After usability testing was completed on the e-book version, a hard copy of the book was published and distributed to junior high and high schools in and around the Edmonton area, local libraries, families seeking care through the pediatric pain clinic, and the two major children's hospitals in Alberta. An audiobook was generated to serve as an accompaniment for the e-book or hardcopy book.

## Results

### The Product

The creative writer generated a story based on interviews with parents or caregivers of 17 children presenting to the chronic pain clinic. The 48-page book was written in the perspective of a mother and was designed to characterize the experiences of a family living with a child with chronic pain (Figure 1). The e-book encompassed descriptions of the effects the condition plays on each member of the family, including the mother, father, siblings, and the child living with chronic pain. The story highlighted the difficulties and struggles of finding resources to improve the quality of life of a child with chronic pain (Figure 2). To ensure readers understood certain terms, definitions were provided in the index at the end of the e-book. This is further complemented by a series of exercise suggestions that families struggling with chronic pain may use (Figures 3 and 4).

### Usability Testing Results

Evaluation of the chronic pain e-book included assessments of usability and pretest and posttests of pain knowledge, as well as confidence in knowledge responses. Emails were sent to 25 parents from the Stollery chronic pain clinic (all parents with valid email addresses in the clinic database); 22 surveys were started and 14 were fully completed. All 14 surveys submitted were completed by females in the household; 13 of the individuals were mothers, and one was a grandmother. Eleven participants completed or had taken some form of postsecondary education, one completed high school, and one had some high school. Eleven participants indicated that their family or child had been dealing with the chronic pain for 2 or more years, two families' participants indicated that the family had been struggling with the chronic pain for 1 to 2 years, and one participant stated that the family had been struggling with chronic pain for 6 to 12 months. Table 1 describes the demographics of the study population.

Parental reaction to the e-book was generally positive (Figure 5). Usability testing indicated that, in general, parents all agreed or strongly agreed that the e-book was simple to use. Similarly, all parents felt that the book was appealing to look at and that it was interesting to read. In terms of usefulness, again, all parents strongly agreed or agreed that the information provided in the e-book would be useful for families struggling with a child's chronic pain. When asked if parents felt that they had learned more information from the e-book, 1 parent strongly disagreed, 6 parents were undecided, 6 agreed, and 1 parent strongly agreed.

All 14 parents agreed or strongly agreed that the content of the e-book was easy to understand, and similarly, all parents stated that they would recommend the e-book to other families who have children with chronic pain. When asked if parents preferred

the e-book (composite parent narrative with evidence-based information supplemented with illustrations) over standard ways (text only, ie, waiting room pamphlets, discharge instructions, etc.) to receive health information, 2 parents stated that they were undecided, and 12 parents agreed or strongly agreed. Comments on the usability testing survey indicated that parents found that the book paralleled aspects of their own lives. For instance, some comments included:

*This eBook is essentially our lives. It was nice to read a story that we could relate to so easily.*

*I liked the book but I shouldn't have done the survey at work as it made me cry remembering our own situation with our daughter.*

*The book provides an accurate account of what it is like living in a family when a child lives with chronic pain.*

One parent noted that the outcomes to the solutions provided in the e-book may not be similar across all families:

*From my perspective, it showed the Pain Clinic as being the rosy solution to life of chronic pain. It paints the picture that this will be the solution. For some families, it may well be, but for others, it will be a tool to give them knowledge and understanding but it won't be the cure. It was mentioned lightly there is no cure for chronic pain, but families need to understand this going in.*

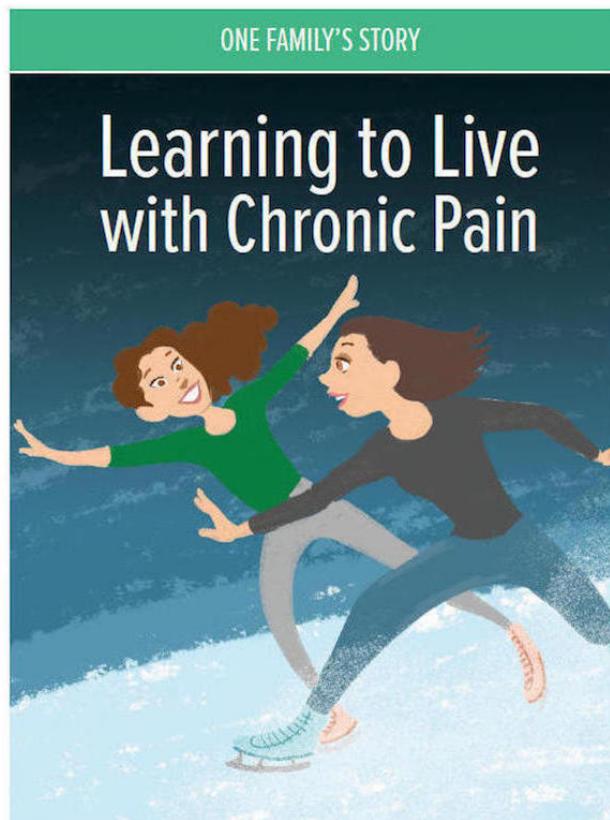
One parent felt the book was a great resource for knowledge dissemination:

*The eBook was great. Hopefully it will aid in getting the word out there to parents who are struggling to help their kids suffering from chronic pain; that there is help.*

### Knowledge Evaluation and Response Confidence

Across the five knowledge topics, we found up to a 21.4% increase in knowledge (range 0-21.4%; Table 2) after being exposed to the e-book. In one of the knowledge topics (topic 4) before reading the e-book, 100% of the participants successfully identified the correct response, and this knowledge was retained post exposure. In three topics, knowledge gains after exposure to the e-book were 7.1% (topic 5), 14.3% (topic 1), and 21.4% (topic 2). In topic 3, there was a knowledge loss of 7.1% after reading the book. We did find a statistically significant difference in confidence of parent answers for two of the five topics (Table 3). Paired *t* tests showed that there was a statistically significant difference in confidence in answering the true or false questions "chronic pain is a disease involving changes in the nervous system" and "the use of ibuprofen is usually effective at controlling chronic pain."

**Figure 1.** Cover of the electronic book (e-book).



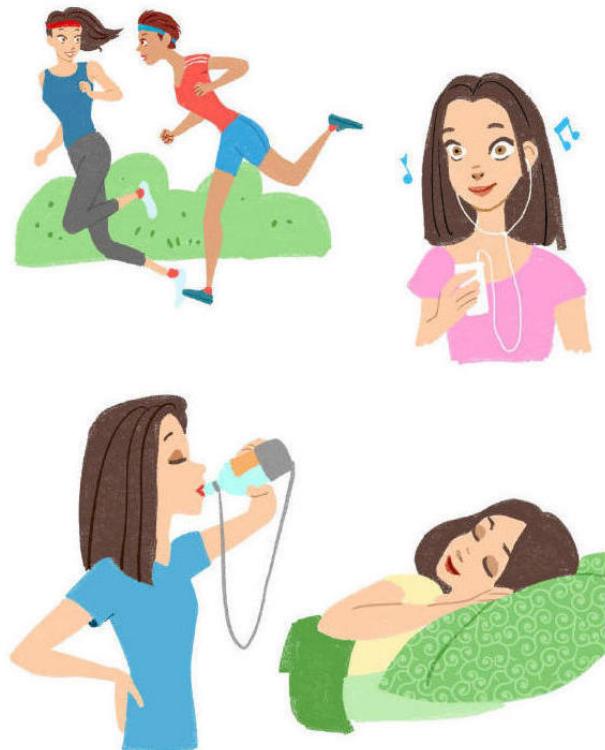
**Figure 2.** Illustration from the electronic book (e-book).



**Figure 3.** Illustration from the electronic book (e-book).

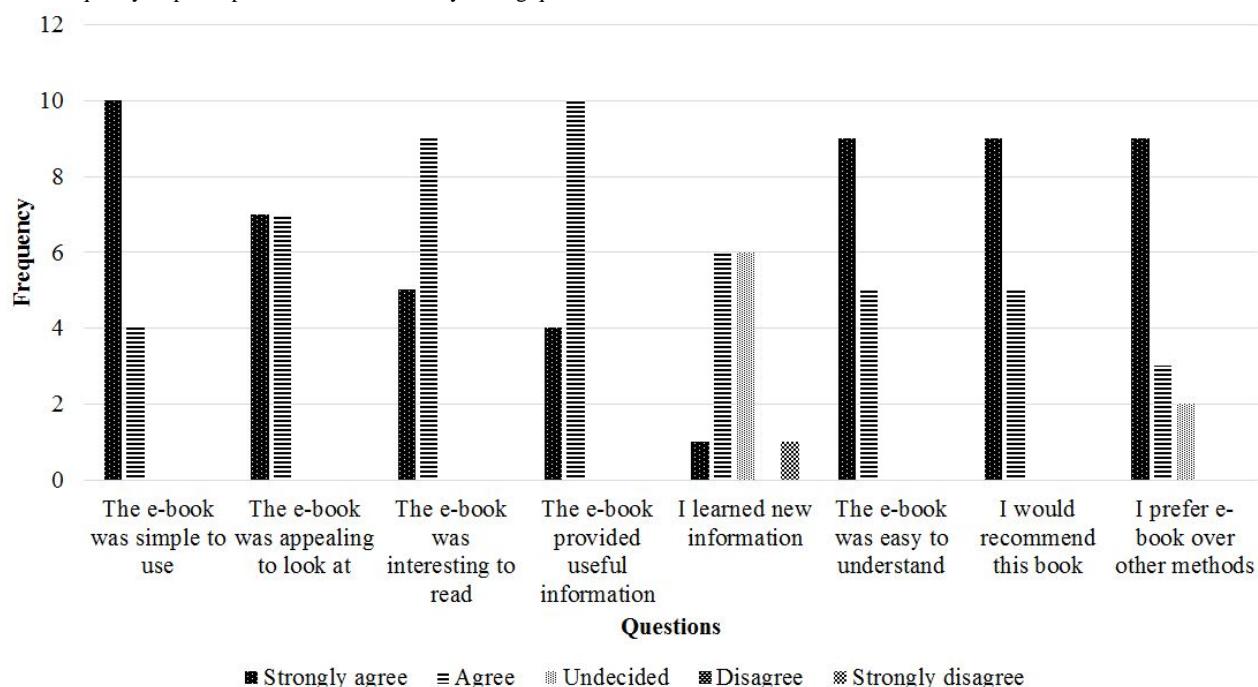


**Figure 4.** Illustration from the electronic book (e-book) depicting four different pain management strategies.



**Table 1.** Survey participant demographic characteristics (N=14).

Variable	n (%)
<b>Sex</b>	
Female	14 (100.0)
Male	0 (0.0)
<b>Age (years)</b>	
31-40	2 (14.3)
41-50	9 (64.3)
≥51	3 (21.4)
<b>Marital status</b>	
Married	11 (78.6)
Single	3 (21.4)
<b>Education</b>	
Some high school	1 (7.1)
High school diploma	1 (7.1)
Some postsecondary	2 (14.3)
Postsecondary certificate or diploma	9 (64.3)
Graduate degree	1 (7.1)
<b>Relationship to child</b>	
Parent	13 (92.9)
Grandparent	1 (7.1)
<b>Age of child (years)</b>	
13	3 (21.4)
16	4 (28.6)
17	5 (35.7)
18	1 (7.1)
Missing	1 (7.1)
<b>Length of pain</b>	
6-12 months	1 (7.1)
1-2 years	2 (14.3)
≥2 years	11 (78.6)
<b>Type of pain (parents select all that apply)</b>	
Headache	8 (57.1)
Abdominal	7 (50.0)
Muscular	6 (42.9)
Arthritis	3 (21.4)
Complex regional pain syndrome	4 (28.6)
Other	5 (35.7)
<b>Electronics used at home (parents selected all that applied)</b>	
Desktop computer	4 (28.6)
Laptop	11 (78.6)
Tablet	12 (85.7)
Mobile phone	13 (92.9)
E-reader	4 (28.6)

**Figure 5.** Frequency of participant answers on usability testing questionnaire.**Table 2.** Changes in knowledge and response confidence before and after exposure to the electronic book (e-book).

Topic or question (correct response)	Scenario		Frequency, n (%)
	Pre	Post	
Chronic pain is a disease involving changes in the nervous system. (true)	T <sup>a</sup>	F <sup>b</sup>	0 (0.0)
	F	T	2 (14.3)
	T	T	12 (85.7)
	F	F	0 (0.0)
Acute pain is a short-term pain caused by disease or injury. (true)	T	F	0 (0.0)
	F	T	3 (21.4)
	T	T	11 (78.6)
	F	F	0 (0.0)
Children with chronic pain often have a difficult time doing regular activities (eg, going to school and hobbies). (true)	T	F	1 (7.1)
	F	T	0 (0.0)
	T	T	13 (92.9)
	F	F	0 (0.0)
Using more than one type of treatment (eg, counseling and medications) at the same time can be more effective at controlling chronic pain than individual treatments. (true)	T	F	0 (0.0)
	F	T	0 (0.0)
	T	T	14 (100.0)
	F	F	0 (0.0)
The use of ibuprofen is usually effective at controlling chronic pain. (false)	T	F	1 (7.1)
	F	T	0 (0.0)
	T	T	0 (0.0)
	F	F	13 (92.9)

<sup>a</sup>T: true.<sup>b</sup>F: false.

**Table 3.** Changes in response confidence before and after exposure to the electronic book (e-book).

Topic or question (correct response)	Pre/Post-test	Confidence					<i>P</i> value
		Very unsure n (%)	A little unsure n (%)	Neither sure or unsure n (%)	A little sure n (%)	Very sure n (%)	
Chronic pain is a disease involving changes in the nervous system. (true)	Pre	2 (14.3)	6 (42.9)	0 (0.0)	3 (21.4)	3 (21.4)	.001 <sup>a</sup>
	Post	0 (0.0)	0 (0.0)	0 (0.0)	3 (21.4)	11 (78.6)	
Acute pain is a short-term pain caused by disease or injury. (true)	Pre	0 (0.0)	1 (7.1)	1 (7.1)	3 (21.4)	9 (64.3)	.17
	Post	0 (0.0)	0 (0.0)	0 (0.0)	3 (21.4)	11 (78.6)	
Children with chronic pain often have a difficult time doing regular activities (eg, going to school and hobbies). (true)	Pre	0 (0.0)	0 (0.0)	0 (0.0)	2 (14.3)	12 (85.7)	.34
	Post	0 (0.0)	0 (0.0)	0 (0.0)	1 (7.1)	13 (92.9)	
Using more than one type of treatment (eg, counseling and medications) at the same time can be more effective at controlling chronic pain than individual treatments. (true)	Pre	0 (0.0)	0 (0.0)	1 (7.1)	1 (7.1)	12 (85.7)	>.99
	Post	0 (0.0)	0 (0.0)	1 (7.1)	1 (7.1)	12 (85.7)	
The use of ibuprofen is usually effective at controlling chronic pain. (false)	Pre	0 (0.0)	2 (14.3)	3 (21.4)	4 (28.6)	5 (35.7)	.002 <sup>a</sup>
	Post	0 (0.0)	0 (0.0)	0 (0.0)	1 (7.1)	13 (92.9)	

<sup>a</sup>Significant at  $P<.05$ .

## Discussion

### Principal Findings

This study evaluated the usability of a novel knowledge translation tool for parents of children with chronic pain. Parental results on the usability on the e-book were very positive, knowledge gains ranged from -7.1% to 21.4% after exposure to the e-book, and we identified that the e-book significantly increased parents' confidence in two areas—(1) understanding that chronic pain is a disease involving the nervous system and (2) in the use of ibuprofen to treat or manage pain. Pain neuroscience education (PNE) is an important aspect of treatment for those who experience chronic pain that has been studied in adults; however, a recent review [43] of PNE for pediatric pain found no published studies that examine how educating parents impacts parental and child function in the context of their child's pain. Our study is the first to examine how PNE, through the use of art and narrative, has significantly increased parental confidence in this area. Although there have been several books published by pediatric pain experts in recent years aimed at educating and helping parents manage their child's chronic pain, none have completed an evaluation on the impact of their book on parental understanding of their child's chronic pain [44-48].

Second, parental data from in our study highlighted the importance of *seeing their experience* in the e-book. This is not a unique phenomenon, and in fact, in some of our earlier research developing books for parents with a child with croup, we noted similar findings. In that study, parents reported that having elements of the narrative (story) mirror their experience validated their emotional reactions to their child's condition and also provided assistance in managing the situation [31,32]. Furthermore, parents in our earlier research reported that employing a narrative with elements that mirrored their

experience normalized the experience, and they felt reassured that other parents had experienced similar emotions. As a result, these parents stressed that this helped them feel less "alone," and sharing similar experiences with other parents was important in decreasing their anxiety.

The notion of validation of experiences, identification, or mirroring of personal experience with the narrative, also called homophily, is fundamental to the success of stories [49] as a knowledge translation medium. Abrahamson [50] has identified that the narrative functions as an intellectual, cognitive, and emotional channel between the story and the reader. The mirroring between the narrative and personal experience facilitates engagement or "awakening" of the reader of the e-book to their previous experience [50] and applicability of information to real-life situations [31]. As a result, this parental validation confirms that the early phases of interviewing multiple parents to understand their experience and then working with a creative team to develop a composite narrative (bringing several parents' experiences together in one story) that incorporates experiences from many parents is fundamental to the success of the e-book as a knowledge translation tool. Kreuter et al [49] further develops the fundamental role of personal identification with the narrative and stresses that stories "work by engaging an audience and modeling behaviors and their consequences." Building on social cognitive theory, Kreuter and colleagues go further to add that the effect of modeling is increased with similarities in the narrative, particularly identification with story characters. In particular, the collection of interviews to obtain rich experiential data maybe particularly poignant when developing knowledge translation tools for chronic conditions such as pediatric chronic pain. Noel and colleagues stressed that the collection of pain narratives from parents with a child with chronic pain was able to capture the multidimensional nature of their experience [51].

Parents in our study identified that they preferred receiving health information in a narrative form rather than the standard information-based format (no story rather exclusive health information). Parents who evaluated the e-book (n=12) agreed or strongly agreed that they preferred the e-book over standard ways of receiving health information. Again, this finding mirrors our previous research [31,32] where parents preferred receiving health information in a story as compared with the standard medical information sheet. There are several potential reasons to explain this preference, including the ability of stories to promote engagement, stories aesthetic appeal, and their novelty. Oatley [52] offers another reason suggesting that human memory is predominantly story-based, and consequently, new information may be more easily integrated if it corresponds with an existing story component in memory. Schrank et al [53] expand on Oatley's notion and outline that indexing of new information in human memory (for future reuse) is increased when links can be made between personal experience and the narrative (e-book). These links facilitate assimilation of new health information with existing memory and increase the potential for integration and use of the new information in future situations [31]. The work of Hinyard and Kreuter reinforce this notion and add that whereas there is only an emerging evidence base on using narrative to transfer health information, it is apparent that narrative information is processed differently than nonnarrative information.

Related research also demonstrates that not only do consumers prefer a narrative format, this narrative format can also spur clinically relevant improvements to patient outcomes. For instance, Houston et al [24] tested the effectiveness of cultural appropriate storytelling to improve blood pressure in 230

African Americans with hypertension. They discovered that the patients with baseline uncontrolled blood pressure that received the narrative-based intervention had substantial and significant improvements in blood pressure at 6 months. Although the evidence base on the use of narrative to influence behavior change and clinical outcomes is emerging, it is apparent that there is potential for this modality, given its obvious applicability with conventional human communication and connections.

## Conclusions

Our research holds promise for future development, application, and effectiveness testing of art and narrative-based knowledge translation interventions for transferring complex health information to parents. Our results demonstrated that parents positively rated an e-book developed for parents with a child with chronic pain and that they preferred this format over standard information-based approaches to transferring health information. Our results identified that parents experienced -7.1% to 21.4% increases in knowledge after exposure to our e-book and identified that parents' confidence in their chronic pain management knowledge increased in two aspects after exposure to our art and narrative-based e-book. These novel findings highlight the potential for digital art and narrative-based knowledge translation tools given their congruence with human communication and learning approaches. Our findings suggest that future research employing digital art and narrative-based tools for knowledge transfer is needed and worthwhile, in particular, assessing these approaches with different types of clinical conditions (ie, acute vs chronic health conditions) and different types of parents (ie, demographics, educational levels, ethnic backgrounds, and learning styles).

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## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Webpage access to the electronic book (e-book).

[[PDF File \(Adobe PDF File, 20KB - jmir\\_v19i12e412\\_app1.pdf](#) ]

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## Abbreviations

- e-book:** electronic book
- KT:** knowledge translation
- PI:** principal investigator
- PNE:** pain neuroscience education

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Original Paper

# The Use of Avatar Counseling for HIV/AIDS Health Education: The Examination of Self-Identity in Avatar Preferences

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## Abstract

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**Background:** The number of adults using the Internet to obtain health information is on the rise. An estimated 66% of the adults reportedly use the Internet to obtain health information related to a specific disease (ie, human immunodeficiency virus and acquired immunodeficiency syndrome, HIV/AIDS). Previous research has demonstrated that health information seekers use the Internet to seek answers to stigma-laden questions from health avatars.

**Objective:** The objective of this study was to identify patterns in the choice of avatar among health information seekers (patients or public health workers) using the Internet to obtain HIV/AIDS information and to describe the demographic characteristics (age, gender, and ethnicity) of health information seekers to determine whether they preferred an avatar that was similar to their own gender and ethnicity.

**Methods:** The Rural South Public Health Training Center (RSPHTC) partnered with the New York State Department of Health to create the HIV/AIDS Avatar project. The avatar project was created to serve as an educational resource for public health workers by providing relevant and accurate information about HIV/AIDS. First, the user was instructed to choose one of the 8 avatars that voiced responses to 100 common questions and answers about HIV/AIDS. Next, the website gave users the option to complete a brief 3-question demographic survey. Finally, the demographic characteristics of each user were compared with the chosen avatar to determine whether they preferred an avatar that was similar to their own gender and ethnicity.

**Results:** The avatar project website was loaded with 800 videos that included the answers to the top 100 questions about HIV/AIDS voiced by 8 avatars. A total of 1119 Web-based health information seekers completed the demographic survey upon accessing the website. Of these, 55.14% (617/1119) users were female. A total of 49.96% (559/1119) users were aged between 30 and 49 years. The ethnicity of the user and the avatar was found to have the strongest connection. All the users choose the female avatar matching their own ethnicity, followed by the male avatar. Additionally, the white female avatar was chosen the most by all users regardless of the age group or gender.

**Conclusions:** Web-based health information seekers using the Internet to access medical research information may feel more comfortable receiving the answers to HIV stigma-laden questions from avatars, rather than receiving information directly from a health care provider. Additionally, providers seeking to utilize avatars to deliver interventions in health care settings may benefit from offering individuals choices in how they receive health information. Having the ability to choose whom you seek information from may lead to an increase in knowledge and awareness and could motivate HIV-positive individuals to seek care.

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**KEYWORDS**

technology; distance education; learning; avatars

## Introduction

Human immunodeficiency virus (HIV) infection is a major global public health problem. Currently, an estimated 1 million people in the United States are living with HIV, and 39 million people are living with the virus worldwide [1]. In the United States, nearly 240 new cases of HIV occur every hour, and an estimated 50,000 people become infected with HIV each year [2]. Despite global actions being taken toward reducing stigma, ignorance, and discrimination, ensuring that individuals have access to the latest and most accurate information about the risks associated with HIV infection is important [3].

Now, more than ever, the Internet has become a primary source for gathering health information among adults. As of 2013, approximately 72% of the adults used the Internet to access Web-based health information. An additional 66% of the adults reportedly used the Internet to access information pertaining to a specific disease (ie, human immunodeficiency virus infection and acquired immunodeficiency syndrome, HIV/AIDS) [4]. Due to the recent growth of Internet-based access to medical and research information, health information seekers (ie, patients or public health workers) are beginning to seek answers to stigma-laden questions from avatars, as opposed to asking a health care provider. In Hinduism, an avatar or *avatara* is a Sanskrit word meaning *descent* and refers to the incarnation (bodily manifestation) of an immortal being [5]. In computing, the definition of an *avatar* varies. Miroslaw Filiciak defines an avatar as the “user’s representative in the virtual universe,” whereas Chris Crawford’s definition defines them as “virtual constructs controlled by human players and function as a means of interacting with other characters.” Moreover, Anya Wood defines avatars as the “computer-generated characters that are used to represent a human” [5-7]. Although avatars can be used to represent oneself, the concept of identity has mostly been related to computing and not health [8-10].

Identity or *sameness* is a driving force in determining who we are as a person. Although several studies have examined identity and avatars in computing [8-10], little research exists on how users select an avatar’s gender and ethnicity when searching for medical information. With the increase in the use of health avatars by users to access medical information, researchers are trying to answer the question regarding the importance of the concept of identity. Specifically, researchers are seeking to examine whether participation and user satisfaction will increase if more resources are used to create avatar choices of all races and genders among other populations who might be using avatars. Specifically to HIV, avatar-based public health trainings

place the control parameters of the HIV epidemic in the hands of each individual by providing tools that are easy to understand and use [11]. The purpose of this exploratory study was to identify patterns in choice of avatar among health information seekers (patients or public health workers) using the Internet to obtain HIV/AIDS information and to describe the demographic characteristics (age, gender, and ethnicity) of health information seekers to determine whether they preferred an avatar that was similar to their own gender and ethnicity.

## Methods

### Overview of the Rural South Public Health Training Center

The Rural South Public Health Training Center (RSPHTC) served medically underserved counties in Florida, particularly in the northern rural regions of the state. The training center provided competency-based training programs for public health workers, enhanced public services, and improved community access to services. Thus, Web-based health information seekers pursuing continuing education credits were able to access a website where the answers to *The Most Common 100 Questions and Answers about HIV/AIDS* were voiced by an avatar.

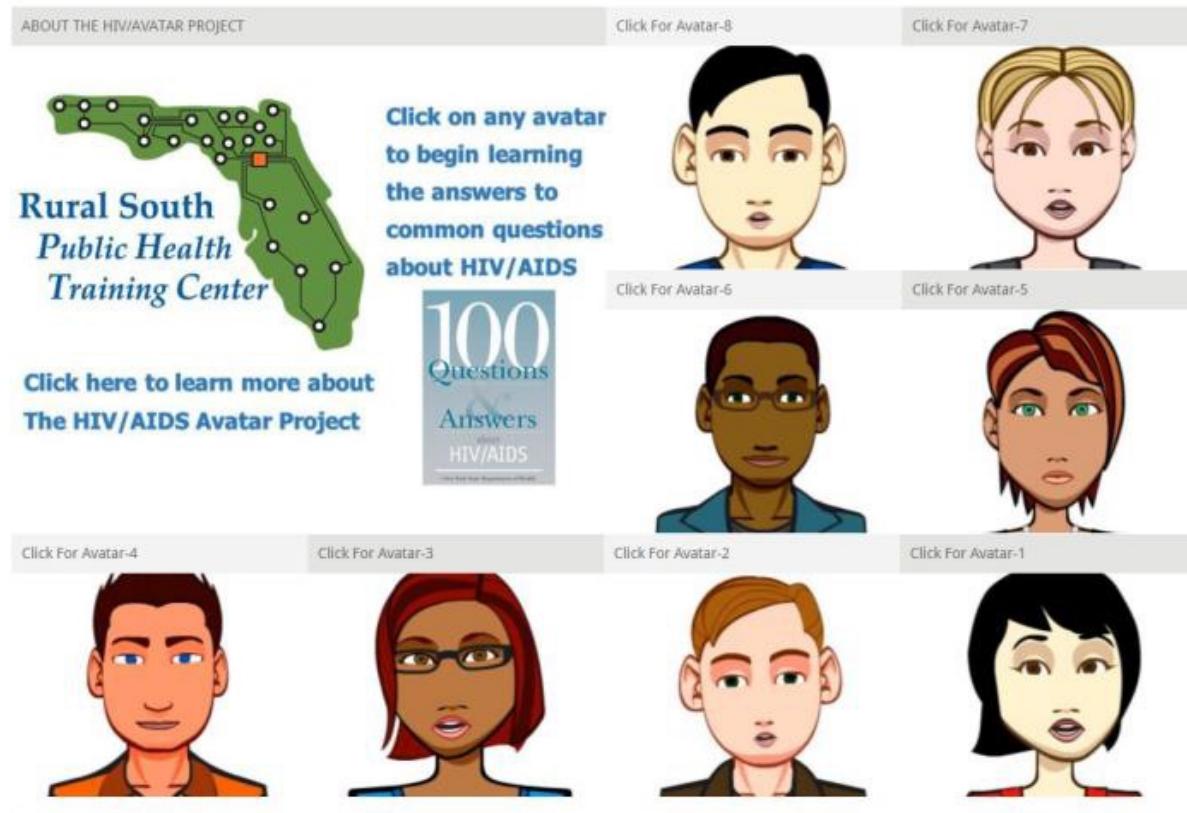
### The HIV/AIDS Avatar Project

#### Avatar and Website Creation

The RSPHTC partnered with the New York State Department of Health to create the HIV/AIDS Avatar project. The avatar project was designed to provide relevant and factual information for patients and to serve as a tool for public health workers. Voki.com, a creative and easy-to-use educational tool, was used to create the avatars. A total of 8 avatars (4 male and 4 female) were created using the simple interface’s default settings (ie, character style, customization, voice, and background) (Figure 1). Character style included selecting classic avatars to represent the top 4 racial/ethnic groups and subgroups in the United States according to the information from the US Census Bureau. The top 4 groups were as follows: white, African American, Hispanic, and Asian American. Next, customization was used to select a theme of neutral colors, casual clothes, etc, of each avatar. Then, using text-to-speech, voices for genders and ethnicities were added to each avatar. The final step involved choosing a background image for each of the avatars and publishing the avatars to the website. Once the avatars were placed on the website, they were randomly moved around so that *proximity* did not alter findings. Furthermore, the avatars were displayed on the same page in a linear display around the logo.

**Figure 1.** This is a screen capture of five of the eight avatars that users could choose to hear responses to the 100 common questions about HIV/AIDS.

### HIV/AIDS AVATAR PROJECT



### Participant Recruitment

The research team employed various recruitment strategies. Participants were recruited through emails, newsletters, and snowball sampling. Information pertaining to the HIV/AIDS Avatar project website was sent via emails and newsletters to

thousands of public health workers across the state of Florida. Information was also forwarded to participants at the University of Florida Health and the Suwannee River Area Health Education Center. The research team also placed advertisements on the RSPHTC website and on YouTube.

**Table 1.** Demographic questionnaire.

Item	Question	Response
Age	What is your age?	18-29 years old 30-49 years old 50-64 years old 65 years and older
Gender	What is your gender?	Male (M) Female (F)
Ethnicity origin (or race)	Please specify your ethnicity.	Black or African American Asian White Latino

### Data Collection

Upon accessing the project website, the user could select one of the 8 avatars to deliver HIV/AIDS information. Next, after selecting an avatar, the user was given the option to complete a demographic questionnaire (see Table 1). If the users chose to not provide the demographic information, they were

redirected to the website where they could access the content directly. The users who chose to complete the questionnaire were asked to report their age, gender, and ethnicity origin (or race). The users' responses were used by the research team for statistical tracking of the chosen avatar in relationship to the demographic information provided by the user. Furthermore, no self-identifiers or Internet Protocol addresses were collected.

All the users were given the option of choosing the information they wanted, with questions grouped by category (ie, basic information and incidence/trends, transmission, testing, risk reduction, and diagnosis and treatment). The project website was also equipped with Google Analytics (Google), which was used to determine the platform the users were using (ie, iPhone operating system and Android), users' accessibility to the website (ie, laptop or cell phone), and the location of the users (ie, region, city, and/or state). This information was not connected to the demographic survey in any way.

### Data Analysis

The research team used the backend analytics, embedded in the HIV/Avatar website, to access the data. Raw counts were used to stratify the users' age, gender, and ethnicity (or race) linked with the avatar chosen by the user to receive information on HIV/AIDS. Next, for each avatar, a corresponding count was associated with the response to the demographic questionnaire variable (ie, age, gender, and ethnicity) that was voluntarily completed by the user before accessing the website's content. The raw counts were analyzed and converted to percentages of those chosen. Over 1000 users responded to the demographic questionnaire. Although this was an initial look at the pattern of choice of avatar in relation to the users' responses to the demographic variables, the data remained focused on these 3 variables singularly. Further data collection and analysis, however, could lead to a larger group of respondents, which would further enhance the data to cross-reference the variables (ie, which avatar a *female* / *18-29* / *Latino* selected).

## Results

The study included 1119 health information seekers who completed the demographic questionnaire. The questionnaire

**Table 2.** Characteristics of Web-based health information seekers (N=1119).

Demographic characteristics	n (%)
<b>Age group (years)</b>	
18-29	325 (29.04)
30-49	559 (49.96)
50-64	209 (18.68)
65 and older	26 (2.32)
<b>Gender</b>	
Men	502 (44.86)
Women	617 (55.14)
<b>Race/ethnicity</b>	
Black or African American	224 (20.02)
Asian	86 (7.68)
White	522 (46.65)
Latino	287 (25.65)

**Table 3.** Demographics of the user and the selected avatar.

User demographics	Avatar demographics							
	Black		Asian		White		Latino	
	Male, n (%)	Female, n (%)	Male, n (%)	Female, n (%)	Male, n (%)	Female, n (%)	Male, n (%)	Female, n (%)
<b>Age group (years)</b>								
18-29	57 (17.5)	52 (16.0)	15 (4.6)	32 (9.8)	37 (11.4)	74 (22.8)	32 (9.8)	26 (8.0)
30-49	66 (11.8)	111 (19.9)	44 (7.9)	46 (8.2)	68 (12.2)	112 (20.0)	34 (6.1)	78 (14.0)
50-64	24 (11.5)	23 (11.0)	17 (8.0)	17 (8.0)	34 (16.3)	52 (24.9)	15 (7.2)	27 (12.9)
65 and older	2 (8)	3 (11.5)	0 (0)	1 (4)	4 (15)	11 (42)	3 (11.5)	2 (8)
<b>Gender</b>								
Male	97 (19.3)	78 (15.5)	18 (3.6)	37 (7.4)	96 (19.1)	108 (21.5)	34 (6.8)	34 (6.8)
Female	52 (8.4)	111 (18.0)	58 (9.4)	59 (9.6)	47 (7.6)	141 (22.9)	50 (8.1)	99 (16.0)
<b>Ethnicity</b>								
Black	65 (29.0)	82 (36.6)	8 (3.6)	5 (2.2)	15 (6.7)	31 (13.8)	4 (1.8)	14 (6.3)
Asian	10 (11.6)	5 (5.8)	12 (14.0)	25 (29.1)	11 (12.8)	10 (11.6)	5 (5.8)	8 (9.3)
White	41 (7.9)	63 (12.1)	31 (5.9)	39 (7.5)	98 (18.8)	176 (33.7)	25 (4.8)	49 (9.4)
Latino	33 (11.4)	39 (13.6)	25 (8.7)	27 (9.4)	19 (6.6)	32 (11.1)	50 (17.4)	62 (21.6)

Among black users who completed the demographic questionnaire, 82 (36.6%) chose the black female avatar, and 65 (29.0%) chose the black male avatar. Twenty-five (29.1%) Asian users chose the Asian female avatar, followed by 12 (14.0%) who chose the Asian male avatar. Moreover, 176 (33.7%) white users chose the white female avatar, whereas 98 (18.8%) chose the white male avatar. Additionally, in Latino users, 62 (21.6%) chose the Latino female avatar, followed by 50 (17.4%) who chose the Latino male avatar.

## Discussion

### Principal Findings

Our exploratory study sought to identify the patterns in the choice of avatar among health information seekers (patients or public health workers) using the Internet to obtain HIV/AIDS information and to describe the demographic characteristics (age, gender, and ethnicity) of health information seekers to determine whether they preferred an avatar that was similar to their own gender and ethnicity. A total of 1119 users completed the voluntary demographic questionnaire. As highlighted in the results, 559 (49.96%) of the users were aged between 30 and 49 years, followed by 325 (29.04%) who were in the age group of 18 to 29 years. Furthermore, 235 (21.00%) of the users were aged 50 years and older, despite many older individuals being sexually active, including those who are living with HIV and may have many of the HIV risk factors as younger individuals [12]. Among gender groups, 115 more female users completed the demographic questionnaire as compared with the male users. Among the male and female users, the white female avatar was chosen the most. Thus, female avatars tend to be highly regarded among many female gamers. Previous research has demonstrated that women who play video games have concerns about the availability and physique of a female avatar [13]; whether or not this holds true for Web-based health information seekers is

unknown. Furthermore, the ethnicity of the user and the ethnicity of the avatar were found to have the strongest connection. The black, Asian, white, and Latino users each chose the male and female avatar representing their own ethnicity. Regardless of the age and gender, majority of users chose the white female avatar, followed by either the white male avatar or the black male or female avatar. Moreover, black participants *exposed to the low-diversity representation of Second Life* were shown to create more white-looking avatars as opposed to black participants *exposed to the high-diversity representation* [14].

This study has significant implication for health care practitioners. Although the use of avatar technology in the medical field is relatively new, health avatars could provide health care practitioners with a new set of tools allowing for better tracking of patients while boosting engagement in care, improving treatment adherence, and decreasing costs [15]. Previous research shows that individuals view avatars just as they view those around them. Thus, if more human-looking avatars are available, users may be willing to open up to them [15]. As denoted by the study findings, creating multiple ethnic avatars may be best, given that the study users were more likely to pick avatars of their own ethnicity. However, if you could only create one avatar for a project, the white female avatar is the most preferred (according to study findings). Among individuals who identify with their chosen avatar, it is hoped that they would be empowered to adopt healthier behavioral choices as a result of the information they receive about the virus through the virtual world [11]. Eventually, using avatars to deliver health information may become the new norm, given that they are readily available, user-friendly, and capable of providing specialty care at the tertiary level [15].

### Limitations

We noted several potential limitations as context for interpreting our findings. Due to the self-reported nature of the questionnaire,

we were unable to determine whether the information reported by the users was accurate. Also, assuming that the users who accessed the project website were either patients or public health care workers may cause some to question the external validity of our findings. Due to the anonymity of the users who completed the demographic questionnaire, we were also unable to determine whether the user was in fact a patient or public health worker. Among the users who accessed the website, we are unable to determine their reasons for seeking the health information. Currently, we cannot determine whether the users were looking for answers to stigma-laden questions because they have been asked these questions before or for self-educating purposes. Although minority individuals with low socioeconomic status (SES) or men who have sex with men have a higher risk of contracting HIV infection, this study did not capture information on these groups. Pursuing this further, the demographic questionnaire asked the users to self-report their age, gender, and ethnicity; however, once the user accessed the website, there was information pertaining to HIV/AIDS that was applicable for everyone. Thus, future research could allow for a better-designed questionnaire that could ask broader questions pertaining to the users' SES, sexual orientation, and marital status. Furthermore, in this exploratory study, we did not account for users who did not identify as either male or female or as both. As completing the demographic questionnaire was optional, we were unable to determine whether users chose not to complete the survey because they did not identify as either

male or female, or they identified as both male and female. Future research should allow the user to write in their gender preference if they do not identify as male or female. Lastly, there was no variation in the age of the 8 avatars that were used in this study. As a result, we were unable to determine whether there was a relationship between the age of the information seeker and the age of the avatar. Future studies seeking to examine patterns of choice in avatars among health information seekers may benefit from creating avatars that vary in gender, ethnicity, and age.

## Conclusions

In summary, HIV/AIDS is a disease that continues to affect millions of individuals around the world. Although several social, economic, and demographic factors increase an individual's risk of contracting HIV, ensuring that individuals have access to the most accurate information is imperative. With an increase in the number of people who are using the Internet to access health information, research demonstrates that many individuals are turning to avatars to seek answers to stigma-laden medical questions. Therefore, health care providers are encouraged to offer multiple avatars, given that people will pick avatars of their own ethnicity. Study findings showed that the white female was the most preferred avatar. Additionally, avatar-based interventions can be used to allow individuals to visualize possible self by providing more *salient and concrete* information about the future, which can motivate individuals to change existing behavior for the sake of future benefits.

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## Conflicts of Interest

None declared.

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## Abbreviations

**AIDS:** acquired immunodeficiency syndrome

**HIV:** human immunodeficiency virus

**RSPHTC:** Rural South Public Health Training Center

**SES:** socioeconomic status

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**Original Paper**

# Getting to the Root of Fine Motor Skill Performance in Dentistry: Brain Activity During Dental Tasks in a Virtual Reality Haptic Simulation

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## Abstract

**Background:** There is little evidence considering the relationship between movement-specific reinvestment (a dimension of personality which refers to the propensity for individuals to consciously monitor and control their movements) and working memory during motor skill performance. Functional near-infrared spectroscopy (fNIRS) measuring oxyhemoglobin demands in the frontal cortex during performance of virtual reality (VR) psychomotor tasks can be used to examine this research gap.

**Objective:** The aim of this study was to determine the potential relationship between the propensity to reinvest and blood flow to the dorsolateral prefrontal cortices of the brain. A secondary aim was to determine the propensity to reinvest and performance during 2 dental tasks carried out using haptic VR simulators.

**Methods:** We used fNIRS to assess oxygen demands in 24 undergraduate dental students during 2 dental tasks (clinical, nonclinical) on a VR haptic simulator. We used the Movement-Specific Reinvestment Scale questionnaire to assess the students' propensity to reinvest.

**Results:** Students with a high propensity for movement-specific reinvestment displayed significantly greater oxyhemoglobin demands in an area associated with working memory during the nonclinical task (Spearman correlation,  $r_s=.49$ ,  $P=.03$ ).

**Conclusions:** This small-scale study suggests that neurophysiological differences are evident between high and low reinvesters during a dental VR task in terms of oxyhemoglobin demands in an area associated with working memory.

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**KEYWORDS**

simulation; fNIRS; functional near-infrared spectroscopy; spectroscopy, near-infrared; virtual reality; psychomotor skills training; dentistry; education, medical

## Introduction

One consequence of working-time directives and curriculum reform in recent years has been a reduction in health care training hours, with claims of up to a 5-fold cut in surgical training hours in some medical specialties [1,2]. In undergraduate dentistry, supervised curriculum hours dedicated to psychomotor skills training have been reduced as a consequence of overcrowding of dental curricula with new material [3]. Inevitably, removal of some of the more hands-on practical components of dental curricula [4] is likely to reduce the amount of psychomotor skills teaching time that undergraduates experience.

As a result, there has been considerable interest among health care professions in identification of individuals who may struggle to acquire the required standard of psychomotor skills by the end of their training [5]. In dentistry, regardless of their progress, all students receive the same number of hours of training. Costly, time-consuming classes are required for individuals who do not achieve the set standards [6]. In response, research has been conducted to establish factors that predict psychomotor skills performance [5,7]. Consistent with other high-risk professions, such as aviation [8], in dentistry personality is increasingly being identified as an important factor in health care psychomotor performance [9].

Surveys of surgeons have identified particular components of personality that are important for general performance [2,5], with conscientiousness having been shown to be a predictor of success across the entire medical undergraduate curriculum [10,11]. Conscientiousness has also been implicated in successful psychomotor performance in dentistry [9,12]. Other aspects of personality thought to play a role are introversion in surgery [11], and warmth, agreeableness, trust, straightforwardness, and compliance in dental technology [9]. The mechanisms underlying the influence of such personality traits are not well understood, however.

One dimension of personality that may have a more direct effect on surgical learning and performance is movement-specific reinvestment, which refers to the propensity for individuals to consciously monitor and control their movements [13,14]. A 10-item questionnaire, the Movement-Specific Reinvestment Scale (MSRS) [15], has been developed and validated to measure this trait. Recent empirical work has shown that the propensity for an individual to consciously monitor and control their movements affects skill acquisition. For example, MSRS scores have been shown to predict the rate of acquisition of a simple laparoscopic skill [16,17].

Studies have shown that greater demands are placed on working memory in movement contexts that induce conscious monitoring and control than in those in which movement control is more automated [18,19]. Working memory is a brain system that is involved in active maintenance, manipulation, and storage of information related to current tasks [20]. Conscious monitoring and control thus depends on working memory [13], so people who score high on the MSRS seem to be more reliant on working memory than those who score low on the MSRS [21,22].

Most research on movement-specific reinvestment has focused on performance outcomes, but little research has examined evidence at a neurological level. One exception is empirical work by Zhu et al [23], who used electroencephalographic measures of corticocortical communication during a golf putting task to demonstrate that people who had a high propensity for reinvestment tended to have greater coactivation between verbal-analytical areas of the brain and motor planning region than did people with a low propensity for reinvestment [24]. The authors concluded that their data presented objective neural evidence that movement-specific reinvestment represents the extent to which an individual is consciously engaged in the process of moving.

In related work, examining neural activity during surgery, Ohuchida et al [25] used functional near-infrared spectroscopy (fNIRS) to demonstrate that trainees with no experience of an endoscopy task had higher oxyhemoglobin demands in the frontal cortex of the brain than expert surgeons. fNIRS is a technique that uses a series of near-infrared light sources and detectors across the surface of the scalp to measure levels of oxygenated and deoxygenated blood in specific regions of the brain. A typical hemodynamic response to functional brain activation involves an increase in oxyhemoglobin and a decrease in deoxyhemoglobin during a task when compared with rest. One study has suggested that oxyhemoglobin responses in the prefrontal regions of the brain are associated with working memory activity [26].

In particular, the dorsolateral prefrontal cortex (DLPFC) is an area of the brain that is heavily involved in executive functions associated with working memory and motor planning [27]. The left DLPFC appears to be involved in observation of new information, preparation for movement, and the creation of new motor patterns, whereas the right DLPFC is implicated in effort-demanding tasks and the supervision and monitoring of movement [28]. What is not yet understood is the relationship between a person's propensity to consciously monitor and control their movements and oxyhemoglobin demands in the DLPFC when performing a dental procedural task. We expected a positive relationship. That is, individuals with a high propensity for movement-specific reinvestment should exhibit greater oxyhemoglobin demands in the DLPFC, reflecting higher levels of working memory engagement in performance.

The aim of this fNIRS study was to investigate whether propensity for movement-specific reinvestment was associated with oxygen demands in the DLPFC during completion of simple and complex dental haptic virtual reality (VR) simulator tasks. By understanding such differences at the neurological level in fine-motor dental tasks, educators can begin to develop training interventions that are better tailored to the needs of individual learners.

## Methods

Ethical approval of the study was granted by the University of Hong Kong ethics research board and written informed consent was gained from all participants prior to taking part.

## Participants

We recruited volunteer fourth-year dental students who had accumulated 6 hours of dedicated curriculum time on haptic VR simulators during the first year of their dental undergraduate degree course, 3 years prior to the start of this study. Between the end of their first year and the start of the study, no additional formal haptic VR simulator sessions were delivered. The students all had real-life caries management experience (beginning midway through their second year), consisting of approximately 3 half days a week of general dentistry by the end of their third year. Records from the haptic hard drive indicated that none of the students had used the haptic VR simulators in their free time in the 3-year period between the haptic VR simulator training in first year and the start of this study.

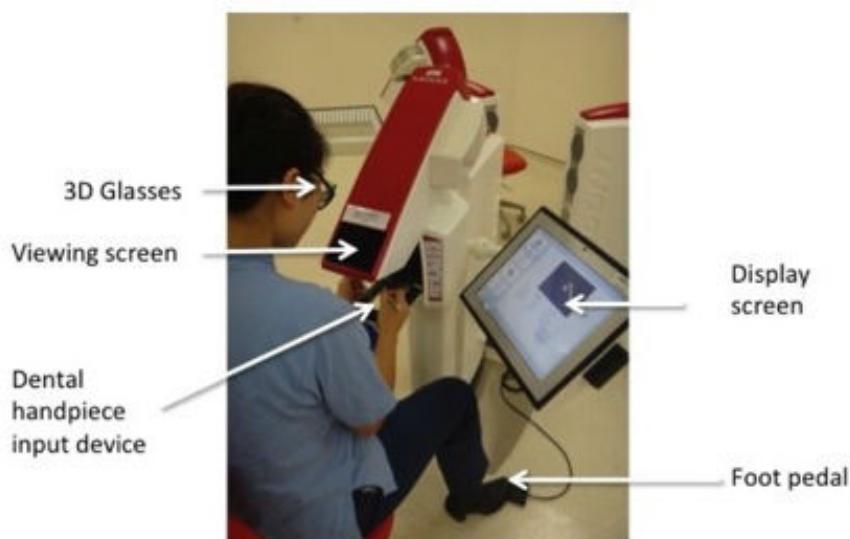
## Dental Haptic Virtual Reality Simulator

The tasks were carried out on the Simodont dental haptic VR simulator (MOOG Inc, Buffalo, NY, USA). With the use of 3-dimensional (3D) glasses, this simulator unit allows visualization of a projected image within a viewing screen, which can be modified using an input device similar to a dental handpiece (drill). Haptic sensory feedback is incorporated into the “handpiece,” providing a more realistic simulation. In addition to the viewing screen, a second screen displays output performance data and a foot control allows the speed of the handpiece to be adjusted, thereby simulating real-life performance (Figure 1).

## Functional Near-Infrared Spectroscopy

We used a multichannel portable fNIRS system, NIRS Sport (NIRx Medical Technologies LLC, Glen Head, NY, USA), to detect the attenuated dual wavelength signals (760 nm and 850 nm) from the left and right DLPFC. We took head measurements to allow accurate placement of the fNIRS cap bilaterally over the prefrontal region. The cap contained 8 source and 8 detector LEDs, allowing blood oxygenation levels to be recorded from 18 channels with a sampling rate of 7.81 Hz (Figure 2).

**Figure 1.** The Simodont haptic dental simulator. 3D: 3-dimensional.



We set the distance between sources and detectors at approximately 3 cm, with the arrangement of the channels compatible with that of the international 10-5 system. Data from the detectors were transferred directly to a laptop computer, with a second laptop computer synchronizing the verbal cues “rest,” “start,” “rest,” and “done” with the marking of recorded data. Video recordings were taken of all participants during the data collection period to allow observations to be made retrospectively. Screen capture software (Snagit, TechSmith Corporation) on the central network computer recorded completion of the tasks at the 3D image level.

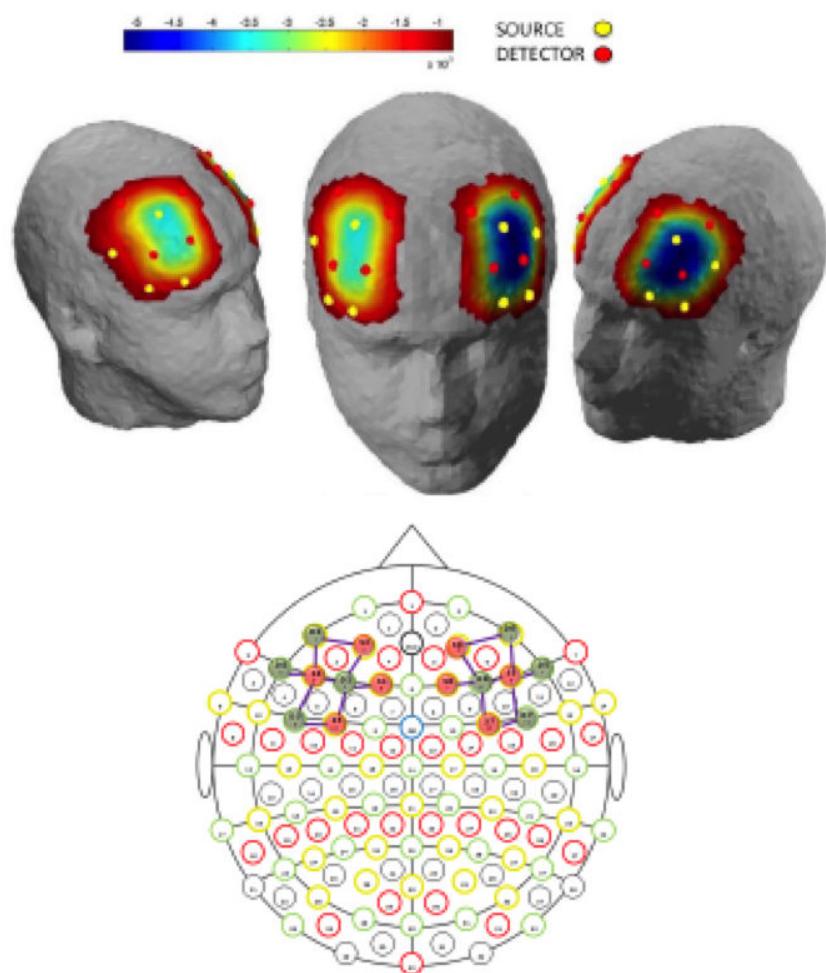
## Procedure

Participants completed 2 tasks (circle, tooth) using the VR simulator, the sequencing of which was counterbalanced. The tasks consisted of (1) removing a target area from a 3D circle shape (Figure 3), and (2) removing a silver amalgam restoration (filling) and adjacent caries (decay) from a simulated 3D tooth (Figure 3).

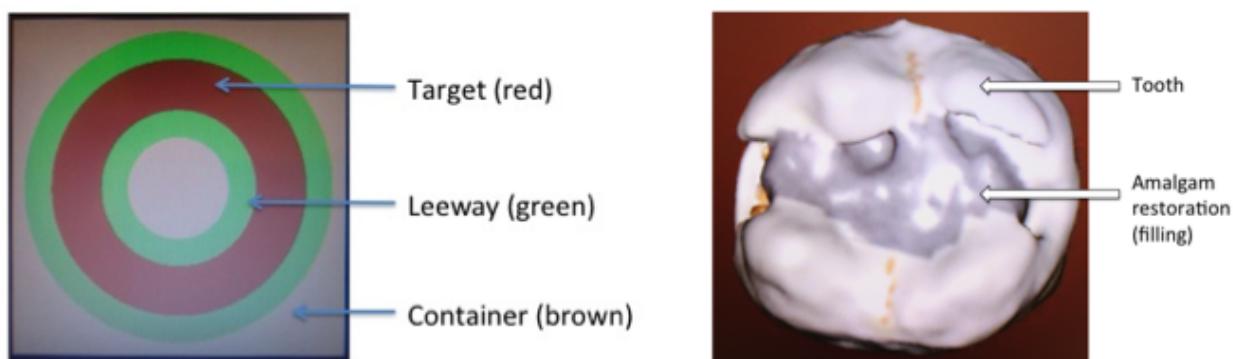
The circle task involved a relatively simple 3D circle shape (Figure 3, left) and had been previously completed by the students as part of their undergraduate haptic psychomotor skills training course. The task required participants to remove as much of the red target band as possible, without damaging the adjacent green leeway areas. Extensive damage to the leeway resulted in damage to the brown container, which was increasingly distant from the target. This task was considered to be simple due to the regularity of the contours and the bold colors clearly defining the regions to be removed and avoided.

The tooth task involved a more complex 3D tooth (Figure 3, right) and had not been completed previously by the students. The task consisted of a simulated tooth containing a 3-surface amalgam restoration (large silver amalgam filling) with adjacent caries (decay). The students were instructed to remove as much of the amalgam and caries as possible without damaging healthy tooth tissue. The task was considered to be more complex due to its similarities to a natural tooth, with irregular and inconsistent features.

**Figure 2.** Locations of sources, detectors, and channels and underlying graphic representation of oxyhemoglobin concentration in the dorsolateral prefrontal cortex during a dental virtual reality task.



**Figure 3.** Circle (left) and tooth (right) tasks using the virtual reality simulator.



Participants were allowed 5 minutes (300 seconds) to carry out each task. They rested for 45 seconds before and after the task to provide a baseline reference for DLPFC activation during the task. During the rest periods, the participants were asked to keep their head as stable as possible to minimize measurement artifacts and to position themselves so that they would be ready to start the task on cue. For each test, the cues (verbal) were produced using voice technology software (NIRStar, NIRx Medical Technologies LLC), with synchronous marking of data

and cues to clearly identify task and rest periods for data analysis. Participants were instructed during the tasks to “complete as much of the task as you can, but as carefully as possible.”

### Performance Measures

For the circle task, the simulator automatically recorded the percentage of target and leeway that was removed, and the extent of any damage to the container as a percentage. The resultant scores were defined as target, leeway, and container scores.

**Table 1.** Movement-Specific Reinvestment Scale items.

Item no.	Question
1.	I remember the times when my movements have failed me.
2.	If I see my reflection in a shop window, I examine my movements.
3.	I reflect about my movements a lot.
4.	I try to think about my movements when I carry them out.
5.	I am self-conscious about the way I look when I am moving.
6.	I sometimes have the feeling that I am watching myself move.
7.	I am aware of the way my body moves when I am carrying out a movement.
8.	I am concerned about my style of moving.
9.	I try to figure out why my actions failed.
10.	I am concerned about what people think of me when I am moving.

The tooth task was scored by 5 qualified dentists (mean experience 15.6 years) who blind rated posttask images of the tooth compared with an ideal preparation. We asked the dentists to independently rank the images in relation to 2 specific components: (1) proficiency in removal of the silver amalgam restoration (filling) and caries, and (2) preservation of sound tooth tissue.

Cronbach alpha of .734 suggested that interrater reliability was within an acceptable range (.7-.95) [29]. We then used the mean score of the raters as the dependent value for the tooth task for each participant (the tooth score).

## Functional Near-Infrared Spectroscopy Data

### Processing and Analysis

We analyzed the fNIRS data using NIRSlab software v2014.05 (NIRx Medical Technologies LLC). The analysis process began with removal of any discontinuities from the data prior to setting a low-pass frequency filter to remove physiological artifacts (0.2 Hz cutoff frequency). We then transformed changes in attenuation at the 760 nm and 850 nm wavelengths into oxygenated and deoxygenated hemoglobin concentration levels, respectively, using the modified Beer-Lambert approach. Overall averaged time-response curves for oxyhemoglobin and deoxyhemoglobin were then plotted for each participant for all 4 tests, allowing a general assessment of data quality. Data from the posttest rest period was more erratic than data from the pretest rest period. Reference to video analysis showed an increase in head movement during the posttest rest period. As a result, we used only the more reliable pretest rest period as a baseline for comparison with the performance test data.

We calculated average levels of oxyhemoglobin and deoxyhemoglobin for the pretest rest and test period of each task. The difference in oxyhemoglobin between rest and test was then calculated to indicate the strength of the hemodynamic response.

### Movement-Specific Reinvestment

We asked all participants to complete the MSRS before they carried out the study tasks. We asked the participants to rate their level of agreement with the 10 statements of the MSRS

(Table 1), by indicating on a 6-point Likert scale from “strongly disagree” to “strongly agree.” Scores can range from 10 to 60.

### Statistical Analysis

Due to the relatively low number of participants (n=19), we conducted nonparametric analyses. We used Wilcoxon signed rank tests to determine whether there was a significant effect of task complexity on oxyhemoglobin responses in the DLPFC during the circle (simple) and tooth (complex) tasks. We also used Wilcoxon signed rank tests to examine whether there were differences in oxyhemoglobin and deoxyhemoglobin responses between the left and the right hemisphere of the DLPFC during the tasks.

We used Spearman rank correlation to determine whether an association was present between MSRS scores and oxyhemoglobin and deoxyhemoglobin responses in the left and right DLPFC during the tasks. We also used Spearman rank correlation to determine whether there was an association between MSRS scores and performance of each task, as well as performance of each task and oxyhemoglobin and deoxyhemoglobin demands. We used Fisher  $r$  to  $z$  transformations to test for interactions between correlation coefficients. The statistical significance threshold was set to  $P<.05$ . All statistical analyses were performed using IBM SPSS Statistics for Windows (version 23; IBM Corporation).

## Results

A total of 24 students (13 female, 11 male; mean age 21.5 years, SD 0.52; all right handed) completed the MSRS. Of the 48 trials carried out, 3 trials had an overall negative oxyhemoglobin difference, indicating either an increased response during the rest period or reduced oxyhemoglobin response during the test. In line with other fNIRS studies [30,31], this overall negative response pattern was seen as inconsistent with a hemodynamic response to functional activation. Consequently, we excluded from the study any participant who performed a test with an overall negative oxyhemoglobin response, resulting in the loss of 3 participants. We excluded an additional 2 participants due to equipment failure, resulting in the data from 19 participants (8 high and 11 low reinvesters) being analyzed for this study.

For the deoxyhemoglobin data, no trends or statistical effects were evident. All further data analysis relates to oxyhemoglobin data.

### Oxyhemoglobin Demands and Task Difficulty

The mean overall change in oxyhemoglobin between rest and task completion was  $1.22 \times 10^{-3}$  mM in the circle task (simple task) and  $1.12 \times 10^{-3}$  mM in the tooth task (complex task). Wilcoxon signed rank test suggested that there was no significant difference in the overall oxyhemoglobin demands between the tasks ( $z=-0.765$ ,  $P=.45$ ).

### Oxyhemoglobin Demands in the Left and Right DLPFC

**Table 2** demonstrates the mean overall change in oxyhemoglobin between rest and task for the circle and tooth tasks in the left and right DLPFC. Results indicate a significant difference in the overall oxyhemoglobin demands between the 2 hemispheres during both tasks, with the left hemisphere having more oxyhemoglobin demands.

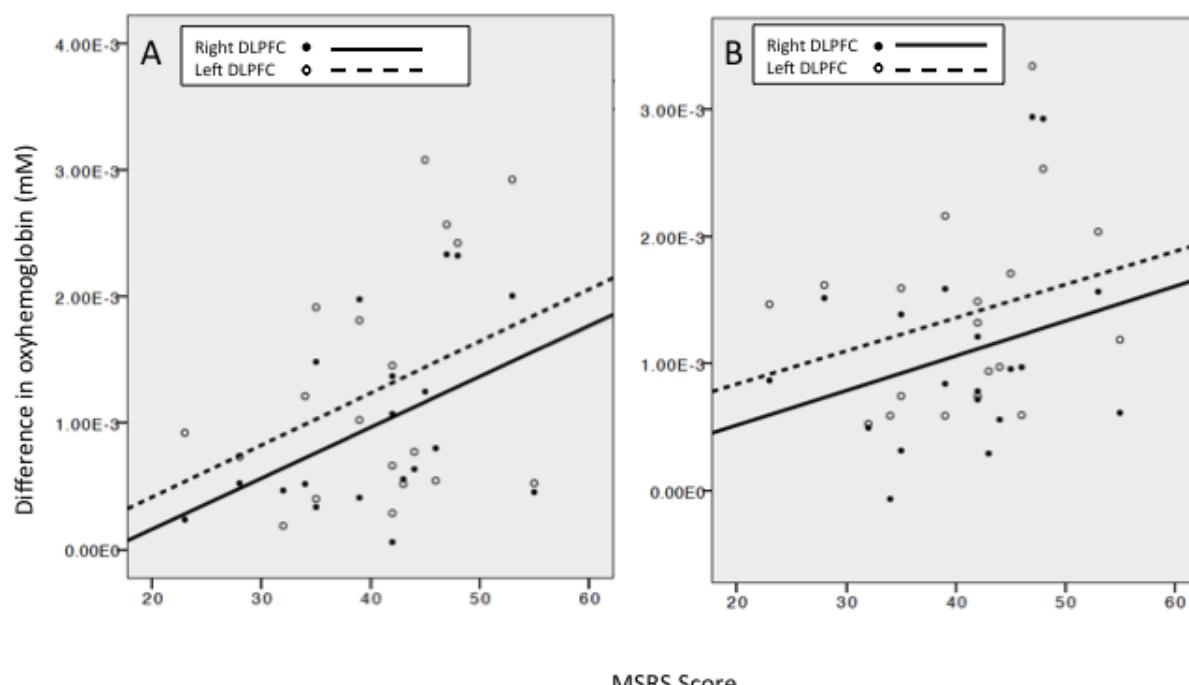
### Oxyhemoglobin Demands and Movement-Specific Reinvestment

Scoring from the MSRS ranges from 0 to 60. The mean score for reinvestment for the participants in this study was 39.7, SD

**Table 2.** Mean overall changes in oxyhemoglobin concentration during the tasks by dorsolateral prefrontal cortex hemisphere.

Task	Oxyhemoglobin (mM) by hemisphere		Wilcoxon signed rank test	
	Left	Right	<i>z</i>	<i>P</i> value
Circle	$1.26 \times 10^{-3}$	$9.8 \times 10^{-4}$	-2.052	.04
Tooth	$1.38 \times 10^{-3}$	$1.08 \times 10^{-3}$	-2.897	.004

**Figure 4.** Relationship between score on the Movement-Specific Reinvestment Scale (MSRS) and oxyhemoglobin demand in the left and right dorsolateral prefrontal cortex (DLPFC) during the (A) circle task and (B) tooth task.



## Performance and Oxyhemoglobin Demands

Spearman signed rank tests indicated that there were no significant associations between oxyhemoglobin demands and performance of the circle task (target:  $r_s=.16$ ,  $P=.94$ ; average leeway:  $r_s=.10$ ,  $P=.61$ ; and average container:  $r_s=.25$ ,  $P=.21$ ) or the tooth task (tooth score:  $r_s=.29$ ,  $P=.19$ ).

## Performance and Movement-Specific Reinvestment

Spearman signed rank tests indicated that there were no significant associations between score on the MSRS and performance of the circle (target, average leeway, and average container removed) or the tooth task (tooth score:  $r_s$  range .060 to .264; target:  $P=.78$ ; average leeway:  $P=.12$ ; average container:  $P=.12$ ).

## Discussion

### Principal Findings

Oxyhemoglobin demands were significantly higher in the left DLPFC during both tasks. Evidence suggests that the left DLPFC has a role in observing new information, preparing for movement, and creating new motor patterns [28]. As both the circle and tooth tasks required movement planning, this may have resulted in significant activation of the left DLPFC.

Interestingly, the hemodynamic response in the DLPFC was not significantly different as a function of task complexity, as has been demonstrated in previous brain imaging studies of the DLPFC [32,33]. The fNIRS literature suggests that there is an increased hemodynamic response in the sensorimotor and visual motion areas as motor task complexity increases [34], and a similar response appears to occur in the motor cortex [35]. However, our data are, to our knowledge, the first to suggest that this may not be the case for the prefrontal cortex.

A higher propensity to consciously control movements, as measured by the MSRS, was associated with increased blood oxyhemoglobin demands in the DLPFC during performance of both tasks, although the association reached significance only in the circle task (see Figure 4, panel A). Nevertheless, neurological differences may exist between high and low reinvesters in the DLPFC during psychomotor dental tasks. This finding is consistent with work by Zhu et al [23], which showed neural differences on electroencephalography between high and low reinvesters during a golf putting task. When the left and right DLPFC were analyzed separately, the association was significant only in the right DLPFC during the circle task. A considerable body of evidence suggests that high reinvesters call upon higher levels of activation of working memory to process and manipulate information during motor tasks [21,22], which is likely to result in increased blood oxyhemoglobin demands [27]. The right DLPFC may be more involved in working memory activities during movement. Fan et al [36] suggested that tasks involving continuous performance and vigilance activate the frontal and parietal regions of the right hemisphere. In music, it has been suggested that the main role of the right DLPFC is to supervise and monitor movement, ensuring that movements match the intended motor pattern [28]. The right DLPFC may well have been increasingly active in

monitoring the previous motor pattern formed for the circle task, accounting for the increase in oxyhemoglobin to the region.

Increased effort is linked to resource demands in the right hemisphere [36-38], with tasks of sustained attention or vigilance, in particular, causing an increase in blood flow to the right prefrontal cortex [37]. The circle task had been used as a test task during the students' previous undergraduate course training. Consequently, students may have had greater expectations of themselves and hence used more effort and attention than in the tooth task. Moreover, the circle task, but not the tooth task, provides an objective score of performance. A monitor linked to the VR haptic simulator shows in real time the percentage of target, leeway, and container that has been removed, which may well have influenced students' expectations.

Factors such as this may explain the findings, as may other factors such as anxiety, which can increase the chances of movement-specific reinvestment [13,16]. Evidence from other domains suggests that a propensity to reinvest is associated with the likelihood of performance breakdown under pressure and reduced ability to multitask [13,39,40]. Such effects appear to transfer to health care professions as demonstrated in a surgical study in which high reinvesters were less able to cope with time pressure demands [17].

Increasingly, health care professionals are becoming aware of the need for individualized training pathways to improve effectiveness. Evidence from this study points to the possibility of using the MSRS to identify reinvestment characteristics in dental students and to modify training appropriately to reduce the possibility of movement-specific reinvestment [13,39]. Implicit motor learning theory [18,39] argues that this can be done simply by ensuring that an individual learns the motor task without acquiring conscious knowledge of how he or she performs the task. The extent to which implicit motor learning is feasible when learning dental procedures is unclear, but it may have a place during the early stages of dental motor skill training. Structured training when learning dental handpiece skills, for example, could initially be replaced by practice protocols designed to reduce errors, which has been shown to cause implicit motor learning [18]. Even if initial skill training has already taken place, and the opportunity for foundational implicit motor learning has been lost, simple changes, such as focusing on external factors, acclimatization, or even "ritualized" behaviors, may go some way to prevent the effects of reinvestment [13].

Our findings suggest that neurological differences between high and low reinvesters do potentially exist in the working memory region during dental tasks, but it is important to remember that the DLPFC is used for many other brain processes and that, as with many brain imaging techniques, it is difficult to localize the exact regions of the brain that are responding. Additionally, our sample size was small, and it was impossible to quantify each participant's exact amount of prior experience with each dental task. Further studies addressing these issues would provide invaluable evidence concerning the neurological and psychological processes underpinning dental procedures performed on a haptic VR simulator.

## Conclusion

Although additional studies are necessary to gain further insight into the neurological processes occurring during movement-specific reinvestment, this small study presents neurological evidence suggesting that a higher propensity for conscious control of movements during dental procedures is associated with greater blood oxyhemoglobin demands in the DLPFC, an area associated with working memory activity. The findings provide further support for the theory of reinvestment [13].

As time for psychomotor skill training in health care becomes even more challenged and an increasingly more complex range of surgical skills is required in dentistry [41,42], it is likely that screening of not only innate technical abilities but also personality traits will increase. Screening will potentially allow the identification of individuals who may struggle to achieve predefined psychomotor skill levels in the allotted curriculum time, allowing individualized training pathways to be put in place earlier in the curriculum for such students. Evidence from reinvestment studies suggests that the MSRS may be a useful additional tool for this process.

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## Conflicts of Interest

None declared.

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## Abbreviations

**DLPFC:** dorsolateral prefrontal cortex

**fNIRS:** functional near-infrared spectroscopy

**MSRS:** Movement-Specific Reinvestment Scale

**3D:** 3-dimensional

**VR:** virtual reality

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Original Paper

# Public Perceptions Regarding Use of Virtual Reality in Health Care: A Social Media Content Analysis Using Facebook

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## Abstract

**Background:** Virtual reality (VR) technology provides an immersive environment that enables users to have modified experiences of reality. VR is increasingly used to manage patients with pain, disability, obesity, neurologic dysfunction, anxiety, and depression. However, public opinion regarding the use of VR in health care has not been explored. Understanding public opinion of VR is critical to ensuring effective implementation of this emerging technology.

**Objective:** This study aimed to examine public opinion about health care VR using social listening, a method that allows for the exploration of unfiltered views of topics discussed on social media and online forums.

**Methods:** In March 2016, NBC News produced a video depicting the use of VR for patient care. The video was repackaged by NowThis, a social media news website, and distributed on Facebook by Upworthy, a news aggregator, yielding 4.3 million views and 2401 comments. We used Microsoft Excel Power Query and ATLAS.ti software (version 7.5, Scientific Software Development) to analyze the comments using content analysis and categorized the comments around first-, second-, and third-order concepts. We determined self-identified gender from the user's Facebook page and performed sentiment analysis of the language to analyze whether the perception of VR differed by gender using a Pearson's chi-square test.

**Results:** Out of the 1614 analyzable comments, 1021 (63.26%) were attributed to female Facebook users, 572 (35.44%) to male users, and 21 (1.30%) to users of unknown gender. There were 1197 comments coded as expressing a positive perception about VR (74.16%), 251 coded as expressing a negative perception and/or concern (15.56%), and 560 coded as neutral (34.70%). Informants identified 20 use cases for VR in health care, including the use of VR for pain and stress reduction; bed-bound individuals; women during labor; and patients undergoing chemotherapy, dialysis, radiation, or imaging procedures. Negative comments expressed concerns about radiation, infection risk, motion sickness, and the ubiquity of and overall dependence on technology. There was a statistically significant association between the language valence of the Facebook post and the gender of the Facebook user; men were more likely to post negative perceptions about the use of VR for health care, whereas women were more likely to post positive perceptions ( $P<.001$ ).

**Conclusions:** Most informants expressed positive perceptions about the use of VR in a wide range of health care settings. However, many expressed concerns that should be acknowledged and addressed as health care VR continues to evolve. Our results provide guidance in determining where further research on the use of VR in patient care is needed, and offer a formal opportunity for public opinion to shape the VR research agenda.

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**KEYWORDS**

social media; virtual reality; qualitative research

## *Introduction*

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### **Virtual Reality in Health Care Settings**

Virtual reality (VR) technology provides an immersive environment that enables users to have modified experiences of reality [1,2]. To date, VR has been used in various health care settings to help treat anxiety disorders, reduce fall risks in older patients, control pain, manage obesity, support physical rehabilitation, and distract patients during wound care [1-9]. By stimulating the visual and proprioceptive senses, VR acts as a distraction to limit the processing of nociceptive stimuli while refocusing the brain on cognitively stimulating, positive, and potentially therapeutic experiences [2]. In a meta-analysis of randomized controlled trials, we found that VR is generally effective and well tolerated by patients across a range of clinical settings, although the existing literature is hampered by small studies of varying quality [10].

Despite increasing awareness about VR and its potential benefits, it remains unclear whether and how best to scale this technology in clinical practice. There are also questions about whether some patients are willing to accept VR in the clinical settings. We previously assessed the acceptability of VR in hospitalized patients [11] and found that most patients find VR to be a positive and pleasant experience that eases anxiety and provides an escape from the confines of a distressful illness experience. Most patients report a willingness to use VR again if given the opportunity. However, we also found that younger patients are more willing to use VR than older patients; that some patients find the technology uncomfortable, intrusive, or confusing to use; and that patients occasionally report that the headsets are difficult to operate, can induce vertigo, or are of unclear benefit. In short, this study suggests that introducing VR into clinical practice requires careful thought, consideration of patient preferences, and an understanding of the risks and benefits of this emerging technology.

The potential health care uses of VR are far-reaching, but acceptability of the technology is an important consideration toward enabling its successful implementation. Addressing concerns about the safety, effectiveness, usability, and accessibility of VR is critical to ensuring that VR interventions and programs are effective. Moreover, it is important to survey public perception not only about concerns surrounding VR but also about use cases in which VR may be most impactful. Patients should have a voice in determining whether, when, and where to implement VR in their own care.

### **Using Social Listening to Examine Opinions of Virtual Reality**

Few studies have examined user perceptions of VR, and of these studies, most focused on narrow applications of VR in clinical settings [12-15]. In this study, we used social listening techniques to examine unsolicited comments posted on Facebook in response to an online video about the use of VR in health care. We selected to study the Facebook posts in

response to the video given that people use the immensely popular social network to share opinions about various topics with their online communities. Facebook is the largest social network with respect to logged-in users; in June 2017, the site had 2 billion monthly active users [16]. In addition, Facebook was the ideal platform to study public opinions about VR, as the video was posted on the site by an online news aggregator (Upworthy) that specializes in posting viral videos. This presented a natural opportunity to study the Facebook posts about VR without explicitly soliciting opinions from users.

The objective of this study was to use social listening methods to examine how individuals perceive health care VR, including understanding general sentiments about the technology, concerns about the use of health care VR, and which settings may be useful future areas for VR research. The results can elucidate facilitators and barriers to the dissemination and implementation of VR in health care. We use quantitative content analysis to characterize online opinions about the use of VR for patient care.

## *Methods*

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### **Study Overview**

In March 2016, NBC News produced a video depicting the use of VR for patient care based on our research at Cedars-Sinai Medical Center and other sites employing VR in clinical practice. The video was edited and repackaged by "NowThis," a digital news company that distributes content to social media sites, and posted on Facebook by Upworthy, yielding 4.3 million views, 36,000 shares, 67,000 "likes," and 2401 spontaneous comments as of December 2016. The video depicts hospitalized patients using VR headsets, features children using VR to ease the experience of cancer treatment, includes brief interview quotes about how VR can be used in health care, and references the emerging role of VR for managing depression, anxiety, and various types of pain [17].

In this study, we expand on our previous research [11] by examining the Facebook posts submitted in response to the video. We employ social listening techniques to capture online public opinion. Social listening offers unique advantages compared with traditional survey methods. One of these advantages is the ability to capture unsolicited discussions among participants without a researcher present, thus overcoming the Hawthorne effect, where individuals may change their behavior when they know they are being studied [18]. Social listening can catalogue opinions from large informant groups and from those who might not otherwise participate in a research study. Furthermore, social listening allows researchers to capture data from a wide demographic and geographic spectrum.

Social listening is an established and efficient way to study online communities [19]. Previous studies have used Facebook to examine the social media activity of clinicians and pharmacists [20,21]; to evaluate Facebook groups focused on

diabetes and explore the information that patients request, the unsolicited information that is provided, and the nature of the virtual communities that congregate on Facebook [22]; and to examine risk perceptions of obesity among social media users [23]. We build on this methodology by using responses to the VR video posted on Facebook as a virtual focus group to characterize public knowledge, attitudes, beliefs, and preferences about the use of VR in health care. We used qualitative methods to develop a list of themes in the data and used this list to apply the codes to the rest of the Facebook posts. We subsequently quantified the results for analysis.

### Gender and Social Media Use

We examined the gender of the informant, given that previous studies have found that men and women express themselves in different ways on social media. Several studies examining interactions and posts on Facebook found that there are notable variations in the use of language on social media by gender [24,25]. Men are more likely to use swear words, whereas women are more likely to use positive, emotion-related words such as “excited” [24,25]. Other studies have found that women are more likely to discuss social relationships (eg, friendships and family), whereas men are more likely to discuss topics such as online gaming, sports, and political topics [25]. Additionally, given that various demographic characteristics, including gender, have been found to be important factors in the adoption and diffusion of technology [26-28], we wanted to explore whether the same holds true for the use of VR. Previous studies have found, for instance, that men value the relative advantage and overall usefulness of technology more highly, whereas women tend to value ease of use [27,28].

### Data Collection and Analysis

We used Microsoft Excel Power Query (2016, Microsoft Corporation) to extract 2401 Facebook comments written in response to the video posted as of 4:20 pm on March 7, 2016. Out of the 2401 comments, we analyzed 67.22% (n=1614) of posts that expressed a measurable sentiment and excluded posts in which users simply tagged friends or included uninterpretable symbols with no other information.

We used the qualitative analysis software ATLAS.ti (Scientific Software Development, Berlin, Germany) to code the Facebook posts [29]. We used ATLAS.ti, given the functionality of the software to support multiple coders and to perform quantitative analyses based on the codes and categories. We used multiple coders (HJP, MEC, and JEF) to enhance the coding process; using multiple coders allowed for the inclusion of multiple perspectives during the code and category development and the ability to discuss coding disagreements among the group. The

first round of inductive coding was used to generate a codebook of themes grounded in the data. We used a consensus process to agree on the final list of codes. The coders then iteratively coded the data several times to categorize each of the Facebook posts into the sentiment categories (positive, negative, and neutral) and major (eg, mental health uses and pain relief) and minor (eg, VR as helpful for anxiety, depression, or stress) themes.

Facebook posts could contain more than one theme if they expressed multiple messages or sentiments within the same post. The unit of analysis was the entire Facebook post. We subsequently used ATLAS.ti to generate code count histograms within major and minor themes. We used the sentiment values and major and minor themes to create a map of attitudes, beliefs, and preferences about the use of VR in health care. We compared perceptions and beliefs by informant gender—a demographic variable accessible through each informant’s Facebook page. If self-identified gender was missing, then we coded that individual’s gender as unknown.

We used the ATLAS.ti code cooccurrence tool to explore patterns among code frequencies regarding gender differences in the categories of Facebook posts, as have been reported in previous research [30]. We used Pearson chi-square tests to examine the association between gender and sentiment valence of Facebook post.

The study was reviewed and approved by the Cedars-Sinai Medical Center’s Institutional Review Board (Pro00044905). No individual subjects were contacted. The only study data used were public posts on Facebook, accessed in full accordance with the Facebook privacy policy.

## Results

### Facebook Comments by Gender, Sentiment, and Theme

Out of the 1614 Facebook comments analyzed, 1021 (63.25%) were attributed to female Facebook users, 572 (35.43%) to male users, and 21 (1.30%) to users of unknown gender (Table 1). Overall, 1197 (74.16%) comments were coded as expressing a positive perception about VR, 251 (15.55%) coded as a negative perception or concern, and 560 (34.70%) coded as neutral. Comments often expressed overlapping themes; thus, the percentage total does not equal 100%. Thematic analysis of the comments yielded 50 unique codes, including 27 positive perception codes, 18 negative perception codes, and 5 neutral codes.

**Table 1.** Sentiment type of Facebook comments by gender.

Gender of Facebook user	Number of codes by language valence		
	Positive	Negative	Neutral
Female	873	100	378
Male	317	148	250
Total codes <sup>a</sup>	1190	248	628

<sup>a</sup>Each comment may include multiple statements; therefore, the number of codes is greater than the number of overall comments.

**Multimedia Appendix 1** depicts the thematic network encompassing positive, negative, and neutral sentiments. The network indicates that opinion about the role of VR in health care is varied; informants reported diverse attitudes, beliefs, preferences, and concerns about the use of the technology. **Multimedia Appendix 2** shows specific examples of Facebook comments left in response to the video.

### Positive Perception Network

**Table 2** lists the 27 codes for positive beliefs, attitudes, and preferences toward VR. Positive perceptions were categorized into the following 2 major groups of first-order concepts: (1) *specific health care uses* and (2) *general uses*. The category *specific health care uses* included the following 5 second-order concepts organized around the use of VR in various settings and conditions: (1) *lack of mobility*, (2) *pain*, (3) *mental health*, (4) *treatment and rehabilitation*, and (5) *drugs*. Secondary concepts under *general uses* included *interest in VR technology* and *desire for personal use and to share with others*.

The second-order concepts of both primary groups encompass additional third-level concepts specifying positive uses and reactions to health care VR. For example, informants identified both acute and chronic pain conditions that may benefit from VR.

Under *specific health care uses*, the most common grouping of Facebook posts pertained to using VR to combat a lack of mobility (n=153), followed by managing pain (n=42), and the use of VR to positively influence mental health or for use in mental health treatment (n=31). Informants expressed opinions about how VR could benefit a variety of populations with a lack of mobility, including patients with long-term hospital stays (n=30), elderly patients who cannot move or travel (n=25), children in the hospital (n=15), cancer patients undergoing chemotherapy or radiation treatment (n=9), patients receiving scans or undergoing other types of imaging (n=8), and wheelchair-bound individuals (n=3). In addition, informants believed that VR could be beneficial for populations facing a lack of mobility, distracting individuals from boredom, and encouraging mental stimulation (n=60), as well as encouraging movement (n=3). Specifically, for mental health, informants noted how VR could be used to manage stress (n=14), anxiety (n=10), and depression (n=7).

General positive responses include the following second-order groups: (1) *interest in VR technology* and (2) *desire for personal use and to share with others*. *Interest in VR technology* had third-order concepts of strong general interest (n=665), positive use of technology (n=80), and remarks expressing that VR was better than television or movies (n=9). The most common third-order concept was *general interest in VR* (n=665), principally comprising nonspecific positive reactions to VR in health care (eg, “cool,” “awesome,” and “I love this!”). Secondary concepts under *desire for personal use and to share*

*with others* include individuals expressing interest in VR for their personal use (n=61) or interest in trying VR (N=49), and wishing that VR had been available in their previous hospital stay (n=39) or that the technology was available or had been available for friends and family members in the hospital (n=31).

Acute pain conditions (quaternary concepts) under the second-level concept *pain* and under the third-level concept *acute pain* identified by informants include VR benefits for patients in labor and delivery (n=15), dentistry (n=13), burns (n=2), and dialysis (n=1) settings.

### Negative Perception Network

**Table 3** lists the 18 codes for negative beliefs, attitudes, and preferences toward VR. Negative perceptions were categorized into the following 2 major groups of first-order concepts: (1) *concerns of VR effects in health care* and (2) *general hesitation/negative reaction*. *Concerns of VR effects in health care* include the following 3 second-order concepts: (1) *paranoia or barriers*, (2) *threats to patient health*, and (3) *negative effects on specific groups*. *General hesitation/negative reaction* includes 2 second-order concepts, including *disinterest* and *more research necessary to support claims*.

The second-order concepts mapped to several third-order concepts specifying the negative reactions and concerns elicited by informants. For example, third-order groups under *paranoia or barriers* revealed user concerns over insurance coverage of VR and costs of use (n=77), VR increasing the societal dependence on technology (n=26), concerns about the information that is transmitted to the user (n=7), VR as a barrier to discharge (n=3), VR creating difficulties in caring for patients (n=2), and concerns about what happens in the room while the patient uses VR (n=2).

The most common codes under *concerns of VR effects in health care* included paranoia or barriers concerning the use of VR (n=153), followed by VR as a threat to patient health (n=31) and negative effects of VR on specific groups (n=16). Informants identified 5 potential threats to patient health with the use of VR in health care, including motion sickness (n=11), vision complications (n=10), infections due to bacteria and other microorganisms because of sharing equipment (n=4), the potential for radiation from the mobile phone to contribute to cancer (n=3), and concerns about patients falling off the bed when using VR (n=3). Informants expressed concerns about pregnant patients and patients in labor (n=16), psychiatric or traumatic brain injury patients (n=3), and those suffering from mental illness (n=3).

Other users wrote about various general hesitations and reactions, including VR as being generally unnecessary (n=42), the ability for drugs and alcohol to achieve the same goal (n=25), the belief that the idea can be improved or advanced (n=17), and the need for more research to support the claims (n=3).

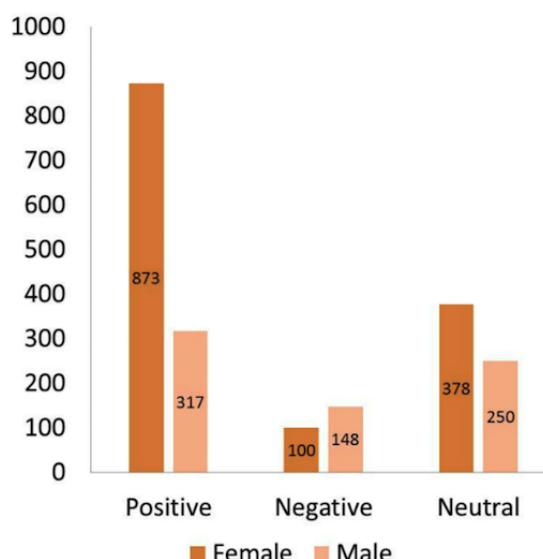
**Table 2.** Distribution of positive beliefs, attitudes, and perceptions toward virtual reality in Facebook comments posted in response to the video.

Positive theme of Facebook comment identified through qualitative analysis	Value (N=1197 <sup>b</sup> ), n (%)
<b>General uses (N=934)</b>	
<b>Interest in VR<sup>a</sup> technology (N=754)</b>	
General interest	665 (55.56)
Positive use of technology	80 (6.68)
Better than TV or movies	9 (0.75)
<b>Desire for personal use and to share with others (N=180)</b>	
General personal use	61 (5.09)
Interest in trying VR	49 (4.09)
Wishes that they had VR in previous hospital stay	39 (3.26)
Wishes that they had VR for friend and family members in hospital	31 (2.59)
<b>Specific health care uses (N=263)</b>	
<b>Lack of mobility (N=153)</b>	
Distract from boredom, encourage mental stimulation	60 (5.01)
Long-term hospital stays	30 (2.51)
Elderly patients who cannot move or travel	25 (2.09)
Children in hospital	15 (1.25)
Cancer patients undergoing chemotherapy or radiation	9 (0.75)
Patients undergoing scans/imaging	8 (0.67)
People who are wheelchair-bound	3 (0.25)
Encourage movement	3 (0.25)
<b>Pain (N=42)</b>	
Labor delivery (acute)	15 (1.25)
Dentistry (acute)	13 (1.09)
Chronic pain (chronic)	11 (0.92)
Burns (acute)	2 (0.17)
Dialysis (acute)	1 (0.08)
<b>Mental health (N=31)</b>	
Stress	14 (1.17)
Anxiety	10 (0.84)
Depression	7 (0.58)
<b>Treatment and rehabilitation (N=19)</b>	
General rehabilitation	13 (1.09)
Adjunct to other therapies	6 (0.50)
<b>Drugs (N=18)</b>	
Adjunct to other drugs	11 (0.92)
Reduces the need for drugs	7 (0.58)

<sup>a</sup>VR: virtual reality.<sup>b</sup>Total does not add up to 100% due to multiple codes per Facebook comment and rounding.

**Table 3.** Distribution of negative beliefs, attitudes, and perceptions toward virtual reality in Facebook comments posted in response to the video.

Negative theme of Facebook comment identified through qualitative analysis	Value (N=251 <sup>a</sup> ), n (%)
<b>Concerns of VR<sup>b</sup> effects in health care (N=164)</b>	
<b>Paranoia or barriers (N=117)</b>	
Insurance coverage and cost	77 (30.7)
Societal dependence on technology	26 (10.7)
Information that is transmitted to user	7 (2.8)
Barrier to discharge	3 (1.2)
Creates difficulties in caring for patient	2 (0.8)
What happens in the room while patient uses VR	2 (0.8)
<b>Threats to patient health (N=31)</b>	
Motion sickness	11 (4.4)
Vision complications	10 (4.0)
Spread of bacteria	4 (1.6)
Radiation/emissions/cancer	3 (1.2)
Falling off bed	3 (1.2)
<b>Negative effects on specific groups (N=16)</b>	
Pregnancy or labor	10 (1.6)
Psychiatric or brain injury	3 (1.2)
Mental illness	3 (1.2)
<b>General hesitation/negative reaction (N=87)</b>	
<b>Disinterest (N=67)</b>	
Generally unnecessary or excessive	42 (16.7)
Drugs and alcohol achieve the same goal	25 (9.7)
<b>More research necessary (N=20)</b>	
Idea can be improved or advanced	17 (6.78)
More research needed to support claims	3 (1.2)

<sup>a</sup>Total does not add up to 100% due to multiple codes per Facebook comment and rounding.<sup>b</sup>VR: virtual reality.**Figure 1.** Distribution of Facebook statements regarding virtual reality technology in health care by gender.

## Neutral Perception Network

There were 5 codes for neutral beliefs, attitudes, and preferences toward VR. Neutral responses were grouped into either *curious/inquiring* responses or *prior exposure/knowledge* responses. *Curious/inquiring* responses were grouped into the following second-order responses: (1) *wants to share information*, (2) *long-term outcomes/future uses of VR*, and (3) *availability outside of the United States*. Responses in the first-order group *prior exposure/knowledge* comprised users who *have already heard about this technology* and users who *compare VR to an existing project or media*. The most common second-order concept was *wants to share information* (n=349). This was followed by the code *compares VR to an existing project or media* (n=140).

## Type of Comments by Gender

Pearson's chi-square test was used to determine if there was an association between language valence (positive, negative, or neutral) and gender. Men were significantly more likely to exhibit negative perceptions about the use of VR in health care than women ( $P<.001$ ; [Figure 1](#)).

## Discussion

### Principal Findings

This case study provides rich data to better understand how the public perceives the use of VR in a health care setting. The results provide innovative, crowdsourced ideas for how to shape VR implementation in health care. For example, the study informants noted that VR could be used in areas such as labor and delivery, dentistry, chemotherapy administration, and in patients undergoing imaging tests. There is preliminary research in some of these areas [31-33], and our findings illustrate that there is public interest in using health care VR for these types of applications. Health care organizations and the VR research community may use the resulting thematic network ([Multimedia Appendix 1](#)) to help determine where further research on the use of VR in patient care is needed.

A 2012 review examining users' perceptions of VR game-based interventions in the rehabilitation setting noted that users were primarily concerned with the technological limitations of VR, the ability of the user to use the VR system independently, the desire to engage in novel physical and cognitive challenges using VR, the ability to connect with other users using VR during rehabilitation, the ability to receive feedback on progress during rehabilitation sessions, and a desire for rich and varied virtual environments [34]. Interestingly, this study found that although the study informants in our study noted that VR could be used for rehabilitation and to encourage movement, their concerns were quite different from individuals who had used VR in the rehabilitation setting. Although study informants in our study focused on cost, potential technology dependence, and safety issues (eg, falling off the bed), users who had used VR in the health care setting noted different types of concerns, including the desire to use VR in a more social manner, the failure of the technology to meet expectations, the ability to use the technology without assistance, and the desire for more realistic virtual worlds. Actual users of VR were less concerned

with overdependence on technology, even those who had used game-based therapies, illustrating that clinicians hoping to use VR may need to address these unfounded fears with new users. This demonstrates that although our findings may be useful in facilitating the dissemination of VR by reducing barriers to use for novice users, more qualitative research is needed to understand how to improve the technology so that it can be used in specific health care settings.

Our findings from this natural experiment indicate that online perceptions of health care VR is generally positive, and most informants believe the technology can benefit various populations in diverse clinical settings. Informants expressed interest in using VR for patients with diminished mobility (eg, those experiencing long-term hospital stays; frail individuals; those receiving chemotherapy, dialysis, radiation, or imaging; and wheelchair-bound individuals) as a drug-free treatment for acute or chronic pain, and for those struggling with mental health conditions such as anxiety and depression. Our findings are in line with those of other studies, which have found that individuals perceive VR as a form of therapy with benefits for the mind and body [35,36]. Previous studies have found VR to be effective in reducing chronic pain [37], aiding in stroke rehabilitation [14,35], improving movement in Parkinson's patients [38-40], treating nicotine addiction [41], reducing anxiety and post-traumatic stress disorder [42], and aiding in the rehabilitation of traumatic brain injury [43].

### Concerns About Virtual Reality and Implications for Use

However, it is important to acknowledge that many informants in this study expressed concerns about using VR for patient care. There are concerns about costs, whether insurance will cover VR as a therapeutic option, and an overarching concern about increasing dependence on technology. The rising cost of health care is a critical issue overall, and previous research has found that individuals are concerned about the gap between those who can afford experimental treatment and those who struggle to get basic medical care [43]. The results from this study illustrate that apprehension about access to and affordability of new technologies is of foremost importance in the public eye. The adoption and dissemination of VR in the health care setting, therefore, will be dependent on how health care systems price this service and whether insurance companies choose to cover the technology and associated VR services. Future studies that examine the cost-effectiveness of adding VR to standard inpatient care will be useful in understanding the added value of VR.

Interestingly, another important barrier to use expressed by informants was the potential of VR to add to the overdependence of technology in society. This finding reveals that individuals feel some trepidation about the current use—and overuse—of technology in society, and that they may not be willing to continue to accept more forms of technology in settings such as health care, despite the potential clinical benefits. Although some individuals may see the use of VR as a way to escape a hospital room, others may be hesitant to use and engage with additional consumer-facing technologies that could prove to be addictive. Researchers should examine whether game-based

VR applications, such as those used in rehabilitation settings, have the potential to be addictive. If users are assured that these applications can be used without fears of overuse, they may be more likely to be open to using the technology.

### Gender Differences in Virtual Reality Use

We found that female users are more likely to comment positively, whereas male users express more concerns about VR for patient care. Our findings are in line with previous research showing that women express positive sentiments more frequently than men in a social media context [25]. We also found that women are more likely to post any opinion about VR, independent of sentiment, which is also consistent with previous research about gender use and social media. Men have been found to be less likely to engage in social media and less likely to use Facebook [44,45]. Women have also been found to express themselves in warmer, more compassionate, and more polite tones than men on social media sites [24].

This study also aligns with other research that finds gender differences in attitudes and adoption of technology [27], including the acceptance and use of technologies such as fitness trackers [46], mobile chat services [47], video games [48], and Internet use overall [49]. Thus, VR, much like other consumer-facing technologies, may be adopted and used by diverse groups in different manners. Researchers studying the diffusion of VR technology should incorporate these gender differences into models of diffusion and should also explore

more in depth how different demographic characteristics influence the use and acceptance of VR.

This study has important limitations. First, the video published by Upworthy portrayed VR in a generally positive light, which could bias Facebook users toward commenting more positively. However, our results indicate that the video still prompted a wide range of far-reaching negative comments, indicating a diversity of sentiment. Second, our sample was limited to people who have a Facebook account and who viewed the video on their feed; similar to other surveys, our sample may not express sentiments that represent the larger population. Compared with the general population, informants in this study may be more interested in new technologies or have social networks that view new technologies in a more favorable light. Third, social listening can only capture comments from users who choose to post. Thus, individuals who prefer to view content but do not post are not represented in our analysis. Another limitation is the relatively narrow scope of the study: we focused on responses to one video posted on Facebook. Future research may expand on this study by exploring public opinion about VR based on various sources. Finally, we were limited in the type of demographic data that we could capture through Facebook.

In conclusion, this social listening analysis of a large social media sample indicates wide acceptance of and interest in using VR for patient care but also reveals concerns that should be acknowledged and addressed as health care VR continues to evolve.

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### Conflicts of Interest

None declared.

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### Multimedia Appendix 1

Thematic network of sentiment in Facebook comments posted in response to virtual reality (VR) video.

[[JPG File, 95KB - jmir\\_v19i12e419\\_app1.jpg](#) ]

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### Multimedia Appendix 2

Examples of Facebook comments about virtual reality (VR) technology in the health care setting.

[[PDF File \(Adobe PDF File\), 87KB - jmir\\_v19i12e419\\_app2.pdf](#) ]

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## Abbreviations

**VR:** virtual reality

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**Original Paper**

# Automatic Classification of Users' Health Information Need Context: Logistic Regression Analysis of Mouse-Click and Eye-Tracker Data

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## Abstract

**Background:** Users searching for health information on the Internet may be searching for their own health issue, searching for someone else's health issue, or browsing with no particular health issue in mind. Previous research has found that these three categories of users focus on different types of health information. However, most health information websites provide static content for all users. If the three types of user health information need contexts can be identified by the Web application, the search results or information offered to the user can be customized to increase its relevance or usefulness to the user.

**Objective:** The aim of this study was to investigate the possibility of identifying the three user health information contexts (searching for self, searching for others, or browsing with no particular health issue in mind) using just hyperlink clicking behavior; using eye-tracking information; and using a combination of eye-tracking, demographic, and urgency information. Predictive models are developed using multinomial logistic regression.

**Methods:** A total of 74 participants (39 females and 35 males) who were mainly staff and students of a university were asked to browse a health discussion forum, Healthboards.com. An eye tracker recorded their examining (eye fixation) and skimming (quick eye movement) behaviors on 2 types of screens: summary result screen displaying a list of post headers, and detailed post screen. The following three types of predictive models were developed using logistic regression analysis: model 1 used only the time spent in scanning the summary result screen and reading the detailed post screen, which can be determined from the user's mouse clicks; model 2 used the examining and skimming durations on each screen, recorded by an eye tracker; and model 3 added user demographic and urgency information to model 2.

**Results:** An analysis of variance (ANOVA) analysis found that users' browsing durations were significantly different for the three health information contexts ( $P < .001$ ). The logistic regression model 3 was able to predict the user's type of health information context with a 10-fold cross validation mean accuracy of 84% (62/74), followed by model 2 at 73% (54/74) and model 1 at 71% (52/78). In addition, correlation analysis found that particular browsing durations were highly correlated with users' age, education level, and the urgency of their information need.

**Conclusions:** A user's type of health information need context (ie, searching for self, for others, or with no health issue in mind) can be identified with reasonable accuracy using just user mouse clicks that can easily be detected by Web applications. Higher accuracy can be obtained using Google Glass or future computing devices with eye tracking function.

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**KEYWORDS**

information-seeking behavior; social media; Internet; consumer health information; medical informatics

## Introduction

### Background

Searching for health information on the Internet is common. A national survey in Scotland found that in 2015, 68.4% (379/554) survey respondents had previously searched for health information on the Internet [1]. Another telephone survey conducted in 2012 in the United States found that 59% (1778/3014) participants used the Internet to find various types of health information, such as symptoms, treatment, dietetic information, and drug information [2]. Web-based health information was mainly used for self-diagnosis, communication with doctors, and for keeping fit. A study in Hong Kong found that users had accessed various types of health information on social media sites (eg, Facebook, Twitter, and discussion forums) to obtain health information [3].

There are various types of health information available on the Internet from general medical terms to users' experience of chronic diseases and drugs [4]. It takes time and effort for Internet users to find health information that is relevant to their situation while filtering out non-relevant information. It has been found that as the time spent in searching for health information increases, user anxiety about the health issue may also increase [5,6]. Health information websites and applications should therefore be designed to provide users with more relevant health information while reducing the users' time spent on filtering out nonrelevant information. Unfortunately, most health information websites provide static health information content to all users, with no attempt to customize or personalize the information to individual needs. Users have to exert substantial effort in skimming and filtering out nonrelevant health information.

Previous studies have found that users seeking health information on the Internet can be categorized into the following three types of user health information need contexts: searching for the users' own health issue, searching for someone else's health issue (ie, for a family member or friend), and browsing with no particular health issue in mind [4,7]. When browsing for own health issue, users tend to make use of case-based relevance judgment to match the information with their own health condition (eg, personal history of disease and personal symptoms). When browsing for other people's health issue, they tend to focus on general information (eg, medical terms, drug names, and drug description). When browsing with no particular health issue in mind, users tend to focus on issues of general interest, current hot topics, and unusual diseases. Users in these three types of health information contexts make use of different criteria in assessing the relevance and usefulness of health information that they encounter on the Internet [4]. Understanding the relations between users' searching or browsing patterns on health information websites and the types of user information need can help website and Web application developers to customize health information for particular categories of users and to increase the likelihood of relevance of the information [8].

This study investigated particular types of user browsing patterns, in particular different types of eye movement durations,

and the associations between them and the three types of user health information context. The eye movements were recorded by a Tobii T60 series eye tracker (Tobii AB, Sweden). As most Internet users access health information websites anonymously, personal profile information is unavailable to the website. Hence, mouse click patterns and, in the future, eye movement data are possible ways of identifying the category of user to achieve some customization of health information. Compared with user browsing patterns such as reading time and mouse clicks [9-14], eye movement data provide more insights on user's relevance decision on whether health information is relevant [4,7].

This study was conducted on a particular health discussion forum, HealthBoards.com. It was chosen as the research platform because it contains various types of health information [4] and has a large number of users and good coverage of health topics.

A typical health discussion forum has a 3-stage user interface interaction structure. Table 1 lists the three types of screens displayed by the system in column 1 and the corresponding user action in column 2. Stage 1 displays the search screen in which the user can either enter a search query or browse a hierarchical menu of health issues to select a category. Stage 2 displays a summary result page of post surrogates (mainly post titles) retrieved for the search query or for the health category selected. Clicking on a post surrogate will display a detailed post screen (Stage 3) with the post content together with comments from other users.

In stage 2 summary result screen, the expected user action is to scan the post surrogates displayed to choose a post to read in detail by clicking on it. In stage 3 detailed post screen, the expected user action is to read the detailed post content. User browsing of a health discussion forum can thus be divided into following the three stages: (1) specifying a search query or browsing the hierarchical menu of health problem categories to select a category, (2) scanning the summary result screen of post surrogates, and (3) reading the detailed post content. Within stage 2 and 3, users can either (a) examine the text closely (indicated by eye fixations) or (b) skim the text to locate the next piece of text to examine (indicated by eye saccades and quick eye movements) [15,16]. This study adopted this framework of user interaction with an information system from previous studies [4,7] to analyze different types of browsing behavior on a health discussion forum.

Bivariate analysis was carried out to identify associations between different eye movement durations and the types of user health information context. Then, multinomial logistic regression analysis was used to develop classifiers to predict the types of health information context from the eye movement durations. The following three types of predictive models were developed: model 1 used only the time spent in scanning the summary result screen and reading the detailed post screen, which can be determined from the user's mouse clicks; model 2 used the examining and skimming durations on each screen, recorded by an eye tracker; and model 3 added user demographic and urgency information to model 2.

**Table 1.** Stages of user browsing and searching in a health discussion forum.

Type of screen displayed by the system	Expected user action
Stage 1. Search screen and hierarchical menu of health problem categories	(1) Enter search query or browse the hierarchy of health problem categories to select a category
Stage 2. Summary result screen displaying a list of post surrogates (mainly post titles) retrieved	(2) Scan the list of post surrogates to select one to click on. This stage can be divided into 2 types of subactions: (a) Examine individual post surrogates closely (indicated by eye fixations) and (b) Skim the list of post surrogates quickly (indicated by quick eye movement and eye saccades)
Stage 3. Detailed post screen displaying detailed post content and user responses to the content	(3) Read the detailed post content and user responses to the content. This stage can again be divided into two types of subactions: (a) Examine and comprehend the content (eye fixations) and (b) Skim the content (quick eye movement)

## Prior Work

This section reviews the following three areas of related research: studies on different types of health information needs during health information seeking, methods of tailoring and personalizing health information by websites and applications, and studies on eye movement patterns in relation to user characteristics.

### Types of Health Information Needs

Information need has been broadly characterized as the perceived need for information that leads to someone using an information retrieval system [17]. It is the motivation for the user to search or browse for information to address a particular issue or purpose [18]. Hence, users' information needs are related to what particular information they want to find. In health information seeking, users want to find different types of health information to address different health information needs. For example, users with coronary syndromes were found to seek information for symptom management as well as for long-term survival [19], whereas users with cancer want to find detailed information of the illness and potential treatments [20]. With the proliferation of social media sites, users are increasingly posting health-related questions on these sites as well as reading other users' posts to address different information needs. Users with diabetes were found to search social media sites for information to manage their condition [21].

In the abovementioned and many other studies of health information needs, the focus was to identify the content of these needs, whereas the context of the information need has not gained much attention [22]. A few studies have acknowledged that users do seek information on behalf of family and friends [2,23]. As early as 2000, a survey in the United States found that about 50% of Web-based health information seekers searched for health information on behalf of someone else [24]. Users have been found to search for health information for family members and loved ones including children [25,26]. In addition, users have been found to find useful health information serendipitously [4,27]. However, there has been no detailed study of health information-seeking behavior on behalf of other people or casual browsing of health information sites. The exception is the recent study by Pian et al [4] who found that users who sought information relevant to other people's health issue focused on different relevance criteria than users seeking information for own health issue. Users seeking health information for their own self focused on detailed symptoms and patient experience, whereas users seeking information for

others focused on basic medical knowledge and basic concepts. On the other hand, users browsing with no particular health issue in mind focused on hot topics and unusual cases. This suggests that websites and Web applications should distinguish between these three types of health information need context and attempt to provide tailored and personalized health information for these categories of users.

### Tailored and Personalized Health Information

Tailored health information has been characterized as specifically designed health information content for specific people based on their unique needs and interests [28]. Tailored health information is related to tailored health communication, aimed at applying specific information and behavior strategies to a particular person to facilitate behavioral change, such as smoking cessation [28]. Tailored health information has been shown to be effective in increasing user's knowledge and understanding of health issues and influencing health behavior change [29]. It is also effective in making health information more relevant to the audience [30]. For instance, tailored Web-based health-related message on breast cancer's association with smoking was shown to increase the awareness of boys and girls on the risk and to stimulate their seeking specific health information rather than general health information [31]. Web-based tailored information on alcohol was shown to be effective in changing unhealthy drinking patterns for adults in the Netherlands [32]. Hence, tailored health information has more impact on users' understanding and knowledge because the information is more relevant to the users' situation and needs [33].

Personalization of websites has been characterized as a process to collect user information during interaction for delivering appropriate services and content. The purposes of personalization include the following: serve user better by predicting user's needs, make the interaction efficient, and provide good experience to encourage repeat visits [34]. The personalization of health information websites can provide more benefits for health information seekers, such as automation and accessibility, extended medical knowledge, user-friendly health-related language (especially for the layman), and patient privacy control [35].

Tailoring of health communication and personalization of health information are related. The former incorporates information strategies and behavioral strategies and often has the ultimate goal of changing health-related behavior by intervention. The latter focuses on providing user-specific information and makes

the interaction between user and health information service more effective. Hence, Rimer and Kreuter [28] stated that "Tailored health communications usually are personalized, but merely being personalized is not sufficient to consider them tailored health communications." The results of this study carry implications for both tailoring of health communication and personalization of health information, as an earlier study has found that users seeking health information for self, for others, or with no specific health issue are interested in different kinds of health information. Thus, detecting the user's health information need context by the website as part of personalization makes it possible for the system to tailor specific types of information that is more likely to be of interest to the user. However, this study does not address the issue of influencing the health information seeker's behaviors.

### ***Eye Movement Patterns in Relation to User Characteristics***

Eye movements are thought to be related to people's cognitive process or cognitive perspective [4,36]. Although eye movements cannot reveal the process or perspective directly, they can serve as a reference for understanding and inferring the related cognitive process [37]. A few studies have been conducted in this area.

Buscher et al conducted studies to investigate the relation between different types of eye movements and user's relevance feedback [16,38]. In this study, the researchers defined reading and skimming as different types of eye movements and use them as indicators of user's relevance feedback. They assigned each type of eye movement a different score and calculated the cumulative scores of both the total examining and skimming found in user's browsing of a particular document. Then, the ratio of reading score to skimming score for a particular document was found to be positively correlated with users' relevance feedback. When the ratio increased, the document was more likely to be thought as relevant.

Pian et al analyzed the health information content focused on by users with the three types of health information need context [4,7]. Content analysis was carried out of what users focused on when browsing a health discussion forum, using users' eye movement data. They divided the browsing process into following two stages: (1) scanning the summary results screen of post surrogates and reading the detailed post content screen (2) and analyzing the types of information that users' eyes fixated on and coding them into different categories of health information. They found that users seeking information for their own health issue focused on case-based health information, including personal disease history, symptoms, and personal feelings. Users seeking information on a health issue of a family member or friend focused on general health information, including basic medical knowledge, terms, and treatments. In contrast, users browsing with no particular health issue in mind focused on issues of general interest, current hot topics, and rare diseases.

Another study investigated the relation between eye movements and users' background knowledge acquisition process [39]. The study developed three types of eye movement measures: Lexical Access Duration Excess (a duration above 113 ms indicates

acquisition of word meaning), perceptual span (the distance that reflects the spacing of fixations and describes the length of text that users take as a unit), and reading speed. They found that these three measures were correlated positively with users' domain knowledge level.

There were still other studies focusing on the relation between users' eye movement pattern and users' cognitive perspectives. A study was conducted to investigate the associations between users' eye movements and their cooking interest [40]. Another study investigated the connection between user's health literacy and their preference of medical illustration [41]. Other studies have investigated user's viewing of Web-based commercial products and potential employees [42,43]. However, these studies did not attempt to develop predictive models. In this study, we sought not only to find the associations between users' eye movement patterns and their types of health information need context but also to develop a logistic regression model to identify whether a user is seeking health information for self, for others, or with no particular health issue in mind.

## **Methods**

### **Study Design and Data Analysis**

This study was divided into two parts. The first part sought to find out the associations between the three types of user health information contexts and browsing durations (eye movement durations), and the second part developed predictive models to identify the user's health information need context from eye movement and other measures.

We have earlier described the 3-stage framework of user interaction with the discussion forum as summarized in [Table 1](#). The focus of the analysis is on stage 2 when the user scans the list of post surrogates in the summary result screen and stage 3 when the user reads the detailed post content. In both the scanning and reading stages, users exhibit the following two types of eye movements: examining (eye fixation, indicating close reading) and skimming (quick eye movements). [Figure 1](#) shows a screenshot of a detailed post content screen with these two kinds of eye movements. The round spots represent examining behavior (eye fixation), and the size of the spot represents the duration of the eye fixation. The lines between two examining spots represent skimming behavior, and its duration is measured by the difference between the timestamp of the user leaving the first examining spot and entering the second examining spot. All the information was stored in the eye-tracking system and was exported to a Microsoft Excel spreadsheet for further analysis.

The user's cumulative examining duration on a particular webpage of the health discussion forum was calculated by adding all the durations of individual examining spots within the page. The cumulative skimming duration was calculated by adding all the skimming durations. Then, a particular user's average examining duration and skimming duration were calculated by averaging all the cumulative examining and skimming durations across the webpages viewed by the user. The average examining duration and average skimming duration for a user were calculated separately for the stage of scanning

the summary result screen and the stage of reading the detailed post content.

To develop the predictive model to identify the particular type of user health information context, we developed 3 models using multinomial logistic regression analysis. Model 1 used the duration of scanning the summary result screen of post surrogates and the duration of reading the detailed post content screen to predict the user's type of health information context. These durations can be recorded from the user's mouse clicks of entering or leaving a particular webpage within the health discussion forum. Hence, it does not require detailed eye

movement data recorded by the eye tracker but only the hyperlink click times that are available to the Web application system. Model 2 used the examining and skimming durations within the two browsing stages in a stepwise multinomial logistic regression to develop a model to predict the user's health information context. Model 3 used the detailed eye movement durations, the user's demographic information, and the urgency level of the health information need to predict the user's health information context. The participants in the study were asked to indicate the urgency of the health information need on a 1 to 7 Likert-like scale, at the beginning of the experiment session. The variables used in the 3 models are listed in [Textbox 1](#).

**Figure 1.** Screenshot of examining and skimming in the detailed post page.



**Textbox 1.** Variable lists for 3 predictive models.

Model 1
<ul style="list-style-type: none"> <li>Duration of scanning stage</li> <li>Duration of reading stage</li> </ul>
Model 2
<ul style="list-style-type: none"> <li>Duration of scanning stage</li> <li>Duration of reading stage</li> <li>Examining duration at scanning stage</li> <li>Skimming duration at scanning stage</li> <li>Examining duration at reading stage</li> <li>Skimming duration at reading stage</li> <li>The ratio of examining to skimming at scanning stage</li> <li>The ratio of examining to skimming at reading stage</li> </ul>
Model 3
<ul style="list-style-type: none"> <li>Duration of scanning stage</li> <li>Duration of reading stage</li> <li>Examining duration within scanning stage</li> <li>Skimming duration within scanning stage</li> <li>Examining duration within reading stage</li> <li>Skimming duration within reading stage</li> <li>The ratio of examining to skimming at scanning stage</li> <li>The ratio of examining to skimming at reading stage</li> <li>Gender</li> <li>Age</li> <li>Education</li> <li>Level of urgency</li> </ul>

This study adapted the following steps used in previous eye-tracking studies [4,7]:

1. Brief the participant on the aim of the study and ask the participant to sign the informed consent form.
2. Ask the participant to describe a particular health information need. If the participant is searching for own health issue or other's health issue, ask for details of the topic. If the participant does not have a particular topic to browse, ask the participant to browse the health discussion forum for fun. Ask the participant for the following demographic information: age, gender, education level, and urgency level of health information need (1 to 7 Likert-like scale).
3. Introduce the eye tracker machine to the participant and complete the eye tracker machine calibration test. This calibration is used to adjust the machine to a particular participant. If the calibration was not successful, the participant was excluded from the study.
4. Ask the participants to browse for relevant information or for fun on the predefined health discussion forum. No time

limit is set for the participant to browse. The participant can browse until the participant is satisfied or wants to stop.

5. Replay the video of the participant's browsing, and ask the participant to comment on why he or she focused on particular texts and why the participant took a longer or shorter time on different pages.

### Study Setting and Sample Size

This study was conducted on a particular health discussion forum, HealthBoards.com. It was selected because it had the highest number of registered users and the highest number of posts. The list of candidate health discussion forums and the basic statistics for HealthBoards.com are given in [Textbox 2](#) and [Textbox 3](#), respectively.

A total of 80 participants signed the informed consent, and 74 participants passed the eye tracker machine calibration test. The demographic profile of the participants is given in [Table 2](#).

### Study Population

The study population can be characterized as laypersons in Singapore who were not health professionals and who did not

have a critical or severe disease. Health professionals and critically ill people were not explicitly excluded from the study. It is just that the participants who volunteered did not include such people. As people with critical or severe diseases and health professionals are expected to exhibit different health information-seeking behaviors [4], the results of this study should not be generalized to them. Separate studies focusing on these two categories of people are needed. For determining critical and severe diseases, we consulted the list of critical illnesses listed on the website of the Life Insurance Association of Singapore, including cancer, AIDS, and coma [44].

**Textbox 2.** List of candidate health discussion forums.

Discussion forums on the patient website

- Health Forum
- HealthBoards.com
- eHealth forum
- netdoctor
- Consumers of Health Forum of Australia
- Mental Health Forum
- PatientsLikeMe
- Health Informatics Forum

**Textbox 3.** Basic statistics for HealthBoards.com.

- Number of registered users: over 1,100,000 registered users as of January 2017; the forum with the second largest number of registered users was PatientsLikeMe with 500,000 registered users
- Number of posts: 879,065 threads and 4,874,692 posts and replies
- Number of subsections on particular health conditions and problems: over 280 subsections
- Number of daily online users: 3000+
- Ranking: Number 1 health forum in Yahoo Health search

**Table 2.** Demographics of research participants (N=74).

Demographics	n (%)
<b>Nationality</b>	
Chinese	32 (43)
Singaporean	34 (46)
Others	8 (11)
<b>Education level</b>	
Undergraduate	22 (30)
Master's degree	32 (43)
PhD	20 (27)
<b>Occupation</b>	
Full-time student	34 (46)
Part-time student	14 (19)
University staff	16 (22)
Working adults	10 (13)
<b>Age in years</b>	
18-20	10 (14)
>20-30	30 (40)
>30-40	25 (34)
>40-50	9 (12)
<b>Gender</b>	
Male	35 (47)
Female	39 (53)
<b>Type of health information context</b>	
Browsing for self	25 (34)
Browsing for others	23 (31)
Browsing with no issue in mind	26 (35)

## Results

### Associations Among Browsing Durations and Demographic Factors

Associations between different browsing durations and different human factors were analyzed by correlation analysis, by analysis of variance (ANOVA), and post hoc analysis. ANOVA analysis was used to analyze differences among more than two categories. It was followed by post hoc analysis to analyze differences between each pair of categories, as three categories of health information context were investigated.

Bivariate correlation analysis was carried out among the following independent variables: the different browsing durations, demographic information, and urgency level. Recall that browsing of the health discussion forum in this study is divided into two stages: *scanning* the summary results screen (displaying post surrogates) and *reading* the detailed post content screen (displaying a post content and comments from users). Each stage is subdivided into *skimming* (quick eye movements) and *examining* (eye fixation). The scanning duration was highly correlated with scanning-skimming duration

(Pearson  $r=.92$ ), indicating that scanning post surrogates is associated with skimming (rather than examining). On the other hand, the reading duration was highly correlated with reading-examining duration ( $r=.89$ ), indicating that reading post content is associated with examining rather than skimming.

Looking at demographic variables, age was found to be positively correlated with reading duration, reading-examining duration, scanning-examining/skimming ratio, and reading-examining/skimming ratio (all significant at  $P<.01$ ) (ie, mainly examining durations). Age was negatively correlated with scanning-skimming duration and reading-skimming duration ( $P<.011$ ) (ie, mainly skimming durations). In summary, older people do more examining, whereas younger people do more skimming.

The urgency level of the information need was positively correlated with reading duration, reading-examining duration, and scanning-examining/skimming ratio ( $P<.016$ ) (ie, mainly examining durations). It was negatively correlated with scanning-skimming ( $P<.01$ ) and reading-skimming ( $P<.05$ ) durations (ie, mainly skimming). Clearly, people with greater

health urgency do more examining, whereas people with lower health urgency do more skimming.

ANOVAs were carried out to find out whether nationality (Singaporean, Chinese, or others), education level (undergraduate, postgraduate, and PhD), and gender were significant factors in explaining differences in the browsing durations.

Nationality was found significant in explaining differences in scanning-examining/skimming ratio ( $F_{73}=7.5$ ,  $P<.001$ ). The ratio was lowest for Chinese nationals, medium for other nationalities, and highest for Singaporean. This means that Chinese nationals do more skimming than examining when scanning post surrogates, compared with other nationalities.

Education level was a significant factor for explaining differences in reading duration ( $F_{73}=4.2$ ,  $P<.05$ ), reading-examining duration ( $F_{73}=5.1$ ,  $P<.01$ ), and reading-examining/skimming ratio ( $F_{73}=6.4$ ,  $P<.01$ ). The three dependent variables have higher values as the education level increases, that is, higher education is associated with longer examining time during the reading of post content.

Gender was not found to be significant.

### Association Between User Health Information Need Context and Browsing Durations

ANOVAs were performed to find out whether the between-group differences (for the three types of health information context) were significant for the different browsing

durations. **Table 3** shows that all the between-group differences were significant ( $P<.001$ ) for all the browsing durations. However, the durations that obtained the highest  $F$  scores were as follows: scanning, scanning-skimming, and scanning-examining.

As the focus of this study was the associations between types of user health information context and different browsing durations, post hoc tests were conducted to identify significant differences between every two groups of participants with different health information contexts. Group 1 refers to the category of seeking health information for self, group 2 refers to the category of seeking for others, and group 3 refers to the category of browsing with no health issue in mind. Post hoc tests determine whether there were significant differences between groups 1 and 2, groups 1 and 3, and groups 2 and 3.

For scanning post surrogate stage, it was found that participants browsing with no particular issue (group 3) had much longer skimming duration than the other two groups of participants ( $P_{1,3}<.001$  and  $P_{2,3}<.001$ ). However, there was no significant difference for skimming duration between participants browsing for self (group 1) and others (group 2) ( $P_{1,2}=.744$ ).

For the examining duration, post hoc tests showed that participants browsing with no particular issue had shorter examining duration than participants browsing for self and with no issue ( $P_{1,3}<.001$  and  $P_{2,3}<.001$ ) and there was no significant difference for this examining duration between participants browsing for self and with others ( $P_{1,2}=.074$ ). The details are given in **Table 4**.

**Table 3.** Results of analysis of variance (ANOVA) test of between-group differences.

Eye movement measures	ANOVA test	
	$F$ (degree of freedom=73)	$P$ value
<b>Scanning post surrogate duration</b>	34.82	<.001
Skimming duration at post surrogate stage	32.06	<.001
Examining duration at post surrogate stage	40.01	<.001
<b>Reading detailed post content duration</b>	24.67	<.001
Skimming duration at detailed post stage	12.18	<.001
Examining duration at detailed post stage	27.19	<.001

**Table 4.** Post hoc test results for different durations.

Eye movement measures	Post hoc test					
	Group 1: Browsing for self (N=25), mean	Group 2: Browsing for others (N=23), mean	Group 3: Browsing with no particular issue (N=26), mean	$P$ value (Groups 1 and 2)	$P$ value (Groups 1 and 3)	$P$ value (Groups 2 and 3)
<b>Scanning post surrogates</b>	20.20	15.50	25.23	<.001	<.001	<.001
Skimming post surrogate	8.38	7.76	14.48	.74	<.001	<.001
Examining post surrogate	11.70	7.74	10.78	<.001	.074	<.001
<b>Reading detailed post content</b>	67.17	52.14	49.39	<.001	<.001	<.001
Skimming post content	19.64	20.40	27.36	.88	<.001	<.001
Examining post content	47.12	31.34	21.68	<.001	<.001	<.001

For the detailed post stage, the post hoc tests showed that the participants browsing for self had longer examining duration, followed by participants browsing for others and with no issue. For the skimming duration, similar results were found as in the post surrogate stage. Participants browsing with no issue had longer skimming duration than the other two groups of participants ( $P_{1,3}<.001$  and  $P_{2,3}<.001$ ), whereas the other two groups of participants did not have significant difference in skimming duration ( $P_{1,2}=.879$ ).

In summary, health information seeking for self is associated with examining (especially in reading the detailed post content). This group of participants obtained the highest reading post content duration and reading-examining duration (significantly higher than that for the other two groups). It obtained medium scanning duration compared with the other two groups. It is similar to searching for others in scanning-skimming duration and similar to no issue in mind for scanning-examining duration.

Health information seeking for others is associated with short scanning duration: it obtained the shortest scanning duration and scanning-examining duration (significantly lower than that for the other two groups), and it obtained medium reading duration and reading-examining duration.

Health information browsing with no specific issue in mind is associated with skimming: it obtained the highest scanning duration, scanning-skimming duration, and reading-skimming duration, and it obtained the lowest reading duration and reading-examining duration.

### Prediction of Particular Type of User Context of Health Information Need

Stepwise multinomial logistic regression was used to develop predictive models (called classifiers) to classify a user into one of the three types of health information context, based on the browsing durations, demographic information, and urgency level. As mentioned earlier, 3 models were developed.

Two versions of model 1 were developed: model 1a made use only of the scanning post surrogates duration and model 1b made use of the scanning post surrogates and reading post content durations. Both durations can be determined by the Web application from mouse clicks on a hyperlink. Model 1a, using just the scanning duration, allows the Web application to classify the user quickly, based on the time spent on the first summary result screen. Model 1a and model 1b are shown in [Tables 5](#) and [6](#) respectively, together with the classification showing their accuracy and confusion matrices.

The classification in [Tables 5](#) and [6](#) indicates that model 1a has an accuracy rate of 75.7% and model 1b has an accuracy of 78.4%. However, these accuracy rates are based on the “training set.” As the sample is too small to divide into a training and a test set, 10-fold cross-validation was used to obtain a more conservative accuracy rate. In 10-fold cross validation, 10% of the participants are randomly selected from the sample to use as a validation set. The remaining 90% are used as a training set to develop a logistic regression model, which is then applied to classify the 10% validation set and calculate the accuracy rate. This is repeated 10 times with different 10% validation sets, and the mean of the 10 accuracy rates obtained are used as a conservative estimate of the accuracy rate of the final model shown in [Tables 5](#) and [6](#). The 10-fold cross-validation mean accuracy rates for model 1a and model 1b (as shown in [Tables 7](#) and [8](#)) were 70.7% and 77.0%, respectively. The reference category is 3 (browsing with no particular issue in mind).

Model 2, as shown in [Tables 9](#) and [10](#), has 3 variables: scanning duration, reading duration, and scanning-skimming duration. This obtained an accuracy of 79.7%, with a 10-fold cross validation mean accuracy of 73.9%.

Model 3, as shown in [Tables 11](#) and [12](#), has 2 additional variables: age and urgency level. This model obtained an accuracy of 89.2%, with a 10-fold cross validation mean accuracy of 83.6%.

**Table 5.** Multinomial logistic regression model 1a with scanning duration only.

Type of information context	B (logistic coefficient)	Standard error	Wald	Degree of freedom	P value	Exp(B)	95% CI for Exp(B)
<b>Browsing for self</b>							
Intercept	5.094	1.603	10.100	1	.001		
Scanning_duration	–	.071	10.324	1	.001	.796	0.693-0.915
<b>Browsing for others</b>							
Intercept	18.636	4.409	17.869	1	<.001		
Scanning_duration	–	.248	16.506	1	<.001	.365	0.225-0.594

**Table 6.** Confusion matrix for Model 1a.

Observed	Predicted as			
	For self	For others	With no issue	Percent correct
Searching for self	21	0	4	84.0
Searching for others	6	17	0	73.9
Searching with no particular issue in mind	2	6	18	69.2
Overall percentage	39.2	31.1	29.7	75.7

**Table 7.** Multinomial logistic regression model 1b with scanning and reading duration.

Type of information context	B (logistic coefficient)	Standard error	Wald	Degree of freedom	P value	Exp(B)	95% CI for Exp(B)
<b>Browsing for self</b>							
Intercept	–	3.869	4.373	1	.04		
Scanning_duration	–	.082	1.338	1	.25	.910	0.775-1.068
Reading_duration	.169	.050	11.578	1	.001	1.184	1.074-1.306
<b>Browsing for others</b>							
Intercept	14.234	4.729	9.061	1	.003		
Scanning_duration	–	.232	9.426	1	.002	.490	0.311-0.773
Reading_duration	–	.044	.177	1	.67	.982	0.900-1.070

**Table 8.** Confusion matrix for Model 1b.

Observed	Predicted as			
	For self	For others	With no issue	Percent correct
Browsing for self	22	0	3	88.0
Browsing for others	3	19	1	82.6
Browsing with no particular issue in mind	3	6	17	65.4
Overall percentage	37.8	33.8	28.4	78.4

**Table 9.** Multinomial logistic regression model 2 with eye tracker information.

Type of information context	B (logistic coefficient)	Standard error	Wald	Degree of freedom	P value	Exp(B)	95% CI for Exp(B)
<b>Browsing</b>							
Intercept	–	5.331	6.561	1	.01		
Scanning_duration	.869	.352	6.108	1	.01	2.385	1.197-4.750
Reading_duration	.134	.052	6.602	1	.01	1.144	1.032-1.267
Scanning-skimming	–	.445	7.905	1	.005	.286	0.119-0.684
<b>Browsing</b>							
Intercept	11.751	4.218	7.763	1	.005		
Scanning_duration	–	.331	4.428	1	.03	.498	0.260-0.953
Reading_duration	–	.046	.070	1	.79	.988	0.903-1.081
Scanning-skimming	.205	.389	.278	1	.60	1.228	0.573-2.631

**Table 10.** Confusion matrix for Model 2.

Observed	Predicted as			
	For self	For others	With no issue	Percent correct
Searching for self	22	0	3	88.0
Searching for others	3	19	1	82.6
Searching with no particular issue in mind	3	6	17	65.4
Overall percentage	37.8	33.8	28.4	78.4

**Table 11.** Multinomial logistic regression model 3 with age and urgency information.

Type of information context	B (logistic coefficient)	Standard error	Wald	Degree of freedom	P value	Exp(B)	95% CI for Exp(B)
<b>Browsing</b>							
Intercept	–	40.208	3.304	1	.07		
Scanning duration	2.594	1.548	2.807	1	.09	13.378	0.644-278.076
Reading duration	.339	.169	4.020	1	.045	1.403	1.008-1.954
Scanning-skimming	–	1.490	3.042	1	.08	.074	0.004-1.379
Urgency health	1.538	.749	4.212	1	.04	4.655	1.072-20.216
Age	.578	.331	3.040	1	.08	1.782	0.931-3.411
<b>Browsing</b>							
Intercept	8.984	5.022	3.201	1	.07		
Scanning duration	–	.404	4.036	1	.045	.444	0.201-0.980
Reading duration	–	.047	.131	1	.72	.983	0.898-1.077
Scanning-skimming	.430	.448	.920	1	.34	1.538	.638-3.703
Urgency health	.529	.343	2.383	1	.12	1.697	.867-3.321
Age	.031	.069	.204	1	.65	1.031	.902-1.180

**Table 12.** Confusion matrix for Model 3.

Observed	Predicted as			
	For self	For others	With no issue	Percent correct
Searching for self	25	0	0	100.0
Searching for others	1	21	1	91.3
Searching with no particular issue in mind	0	6	20	76.9
Overall percentage	35.1	36.5	28.4	89.2

## Discussion

### Principal Findings

In this study, different types of user browsing durations in the summary results screen (listing post surrogates) and detailed post content screen of a health discussion forum were found to be associated with different types of user health information need context.

Users who are seeking information for their own health issue are more likely to closely examine the page content, especially when reading the detailed post content. Their scanning duration (in the summary results screen) is in between the other two groups. It is probably because they know their issue well and

need to focus on health information related to their personal conditions during browsing [4]. Hence, they spend the longest time closely examining the detailed health information to assess whether it is related to them. However, they do not require much time to locate their health topic; hence, their skimming durations are short.

Users who are seeking information for a family member or friend's health issue tend to have a short scanning duration in the summary results screen. They have medium reading durations in the detailed post screen between the other two groups. It is probably because they know something but not much about the health issue of their friend or relative. Hence, they are able to find their topic fairly quickly, reflected in their short skimming durations. They devote more time to examining

basic information on their topic (but not the detailed health content or personal experience information), reflected in their second longest examining durations in the post content screen [4,45].

Browsing with no specific health issue in mind is associated with skimming and the longest scanning duration in the summary results screen. This group had the lowest reading duration in the post content screen. As the users do not have a particular issue in mind, they need to skim over a lot of health information to identify a topic of interest. Hence, they spent the longest time quickly skimming over to locate their interests. In contrast, their examining durations were not long as they do not devote much time to learn and digest detailed content and just read them like reading newspapers or stories [4,7].

In addition, demographic information and urgency of health information need were also found to be significant factors. Older users do more examining (with eye fixations), whereas younger users do more skimming (with quick eye movements). Users with greater health information urgency do more examining, whereas people with lower health information urgency do more skimming. Users with a higher level of formal education were found to spend more time in close reading of post content. People from different countries may exhibit different skimming and examining durations, possibly because of different levels of English reading competency.

As the Internet users have different types of health information need and information context, they naturally focus on different types of health information when browsing a health discussion forum. As the result, their examining and skimming durations differ. In turn, these durations can be used to predict the user's particular type of health information need context. The logistic regression analysis results indicate that the accuracy of prediction can reach 90% when these durations are used together with the user's age and urgency of health information need, as in model 3. In comparison, model 1 using only mouse click information is able to reach an accuracy of 76%.

Use of examining and skimming durations from the eye-tracking system can provide more accurate results. Model 2 that makes use of the eye tracker information, but without personal and demographic information, can reach an accuracy of 80%. This model may be feasible in the near future as mobile phones are already using retina scan, and Google glass is using eye-tracking technologies. An eye-tracking system can record examining and skimming patterns of users scanning and reading text on

the screen, and software programs can be written to analyze these patterns and generate inferences about the user's interests and context, which can be used by the health information platform to tailor health information for the user. These steps can be carried out in the background without disturbing the user's browsing. In addition, the health information platform can request the user to create a log-in account and provide demographic and personal health information that can be used for personalization to improve the user's browsing experience and increase the relevance of health information provided.

As the results indicate that age, education level, and nationality affect the user's browsing duration, future research can investigate these factors in more detail as well as explore more demographic and socioeconomic variables.

## Limitations

This study was conducted at Nanyang Technological University in Singapore, and the research participants were Singapore residents. Users who are not located in the country were not included in this study.

This study focused on a health discussion forum, which has an interface and navigation structure that is similar to that of information retrieval systems and database systems, which typically have a search query screen, summary results screen, and detailed result screen. Information websites, however, have a different interface and navigation structure. The navigation structure and information organization on the screen or webpage will affect how users navigate the site and browse the displayed text.

This study recruited participants with a wide age range and included Singapore citizens as well as local residents with other nationalities (mainly China). Convenience sampling used means that the study did not cover all strata of Singapore society. In particular, residents who did not have university education were not covered. This study did not cover users with critical or severe health problems, whose browsing behaviors are likely to be different from the participants in this study. More focused studies can also be carried out to investigate differences between younger and older people and between local citizens and foreigners (including foreign students).

This study focused on health information browsing on a personal computer (PC) screen. The browsing on mobile devices was not considered. There may be differences between browsing on traditional PC and mobile devices.

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## Conflicts of Interest

None declared.

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## Abbreviations

**ANOVA:** analysis of variance

**DF:** degrees of freedom

**PC:** personal computer

**SE:** standard error

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Original Paper

# eHealth Literacy and Health Behaviors Affecting Modern College Students: A Pilot Study of Issues Identified by the American College Health Association

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## Abstract

**Background:** The eHealth Literacy Scale (eHEALS) has been widely adopted by researchers to understand how eHealth literacy can be put into context. eHealth researchers need to know how to promote positive health behavior changes across college students, given the importance of the Internet to acquire and use health information. The American College Health Association identified a set of key health issues that affect college students today. By understanding how eHEALS might be related to college students' maintenance of their health and their use of online health resources, researchers will be provided with a better understanding of eHealth literacy and its pragmatic implications for health campaigns and future interventions.

**Objective:** The goal of the study was to examine what eHEALS reveals about college student health behaviors identified by the American College Health Association. To understand college student current health maintenance and their intentions to maintain their health and use online resources, the theory of planned behavior was used as the theoretical framework for the study.

**Methods:** Data were collected via a survey of 422 college students that included the eHEALS measure and questions about health issues based on the recommendations of the American College Health Association. These questions asked about college student current health, subsequent use of online health resources, and their intention to maintain their health and make use of such resources in the future.

**Results:** eHEALS was positively and significantly associated with all 8 areas of health issues identified by the American College Health Association for college student current maintenance of health and use of online health resources and for future intention of health maintenance and use of online resources. Key issues that emerged with eHealth literacy were maintaining safe sex practices and seeking out related information, seeking out information on an exercise regime, information on vaccinations, and maintaining a balanced diet.

**Conclusions:** These results suggest several areas that may be targeted for future health campaigns toward college students. In addition, eHEALS was found to be a useful instrument for college students in the United States. Lastly, these results point to a need to deliver targeted information to college students, particularly since eHEALS captures literacy based on positively phrased items.

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## KEYWORDS

eHealth literacy; eHEALS, college student health; online health behaviors

## Introduction

### Background

In recent years, Norman and Skinner [1] developed the eHealth Literacy Scale (eHEALS) to measure eHealth literacy, which refers to “the ability to seek, find, understand, and appraise health information from electronic sources and apply the knowledge gained to addressing or solving a health problem.” eHEALS has been widely adopted by researchers to understand how well eHealth actually works [2,3]. As a result, researchers have found that as eHealth literacy rises, so does the ability to use online health resources effectively [4]. Factors that tend to predict how individuals behave, such as the use of online health resources, include their current use of health resources, past and future intent to use those resources, and self-maintenance of their own health. These factors are ones explained by Ajzen's theory of planned behavior (TPB) [5], which suggests that human action is guided by belief and motivation.

Despite its accolades, eHEALS has only begun to be explored with college students, who are regularly exposed to propaganda and Internet media on health issues and face a number of health issues such as social pressures, maintaining a healthy diet, getting enough sleep, and living with stress from balancing classes, relationships, and work [6]. eHealth literacy can have significant consequences on the quality of health information sought and retained [1,7-10]. Many college students remain uninformed about these issues as well as others identified by the American College Health Association (ACHA) [9-12]. In particular, electronic health literacy remains a vital issue to address among college students, not only so that we can understand their literacy, but so we can create appropriate interventions.

The objective of this study was to address eHEALS and its association with college student health behaviors based on past, current, and future behaviors [5]. In this study, we targeted the 8 areas that the ACHA [12] determined were critical health issues for college students by surveying students at a range of institutions across the United States. eHEALS has already received accolades for its efficacious assessment of eHealth literacy and has been used and adopted across cultures [13] and contexts [7,14-15]. We examined the relationship between eHEALS and intention to engage in healthy practices based on the ACHA's 8 recommended areas. An individual's intent, past behavior, future intent to engage in the use of online health resources, and self-maintenance of one's health are all explained by key determinants of TPB [5]. TPB can indicate how much individuals are willing to care for their health or spend time seeking out online health resources. With eHEALS, a scale that addresses eHealth literacy on a broad level, we can better understand these behaviors.

### Theory of Planned Behavior

TPB was developed by psychologist Icek Ajzen [5,16], and according to TPB, human action is guided by 3 kinds of

considerations: beliefs about the likely outcomes of the behavior and the evaluations of these outcomes, beliefs about the normative expectations of others and motivation to comply with these expectations, and beliefs about the presence of factors that may facilitate or impede performance of the behavior [5,16]. These are respectively known as behavioral intent, subjective norms, and perceived behavioral control. Central to TPB is the intention to perform a given behavior. Intentions are assumed to capture the motivational factors that influence a behavior; they are indications of how hard people are willing to try, of how much of an effort they are planning to exert in order to perform the behavior [5].

TPB has been used in various health contexts to explain an individual's intent to engage in some future behavior, such as diet and fasting [17], obtaining Pap smears [18], mentally adjusting after diagnosis of cancer [19], smoking [20], and other issues. In addition, TPB has been found to be a predictor of future intention to engage in safe sex practices by college students [21], drinking behavior [22], and exercise [23]. TPB has not been examined in the context of electronic health literacy using eHEALS, but the past success of eHEALS [2,3,13,24] and TPB [17-22] research suggest a possible relationship. Health literacy naturally includes recognition of the broader domain of health behaviors—literacy implies an understanding of the context surrounding a particular health care decision. This includes knowledge of others' health behaviors and choices in similar situations—the normative behaviors that guide one's decisions under TPB. In other words, eHealth literacy is partially dependent upon the opportunities and behaviors that others follow throughout their health care, a construct that also guides TPB.

### Electronic Health Literacy

eHealth resources allow patients, providers, consumers, and caregivers to make better health-based decisions [9]. Health literacy is, as defined in the US Department of Health and Human Services' *Healthy People 2010* report, “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” [25]. As Norman and Skinner [1] define it, eHealth literacy is the actual ability to seek, find, and make use of online health information. eHealth literacy goes beyond basic reading ability by understanding and synthesizing online health information to make informed choices and increase overall quality of life [26]. eHealth literacy is multifaceted and requires the skills of basic literacy, basic health literacy, and actual retrieval of information. Our study uses Norman and Skinner's [1] definition since it closely matches the goals of this research.

### eHealth Literacy Scale

eHEALS is widely used today by researchers to measure eHealth literacy [2,13,27,28]. eHEALS is an 8-item measure of eHealth literacy designed to measure an individual's knowledge and ability to find electronic health information and apply that information to health issues. The scale uses a 5-point Likert

scale to rate the statements “I know what health resources are available on the Internet,” “I know how to use the health information I find on the Internet to help me,” “I know how to find helpful resources on the Internet,” “I have the skills I need to evaluate the health resources I find on the Internet,” “I know how to use the Internet to answer questions about my health,” “I know where to find helpful resources on the Internet,” “I can tell high-quality health resources from low-quality health resources on the Internet,” and finally, “I feel confident in using the information from the Internet to make health decisions.” Factor loadings for the original scale ranged from .60-.84 among 8 items.

eHEALS is one of the earliest scale developments to address a need for eHealth literacy for a wide population. Current research has retested eHEALS, although scholars have stated that there is a continued need to do so [7]. eHEALS has been shown to be a reliable and easy-to-use scale. It is based on 6 types of literacy skills: reading, health, information, scientific, computer, and media literacy. In terms of its widespread use, eHEALS has been translated to German [27], Japanese [13], and Dutch [7]. eHEALS tends to be used with specific health issues such as colorectal cancer in Japan [13], where it was found to be positively associated with cancer knowledge. Individuals scoring higher on eHEALS were more likely to undergo cancer screenings [13]. eHEALS also tends to correlate with finding credible Internet sources; for instance, previous exposure to credible online health resources tends to be associated with higher levels of health literacy [28]. More recently, eHEALS scores have been associated with the digital divide among low-income older adults who had a depression diagnosis [2]. Recent scholarship has suggested that as the landscape of the Internet evolves, so do measures of ehealth literacy, including eHEALS; nonetheless, it represents a clear measure of literacy [29].

With growing choices that students can make about their health today—such as getting vaccinated for the human papillomavirus, provided at some universities, or how to balance school and increasing work demands—there is little wonder that many turn to the Internet to seek out information [30,31]. There have yet to be studies published that use eHEALS to better understand college students’ motivation, beliefs, and behaviors associated with online health resources and issues that are most salient to them.

### eHealth Literacy Scale and Broader Health Issues Pertinent to College Students

eHEALS was used to seek out the relationship between the scale and behaviors across a range of health issues identified by the ACHA. Emerging research has explored eHEALS to examine college student beliefs and behaviors relevant to the health issues that tend to affect them the most [32], the potential of eHEALS as a reliable and consistent measure that captures eHealth literacy [1,7], and more broadly, in developing health information technologies [33]. In addition, scholarship has noted an increased need to include theoretical frameworks to assist in developing, tailoring and executing online health research [24,34].

The current executive summary from the ACHA reports that the 8 most common indexes for college student health include drug use, sleep, sexual health, getting vaccinations, proper diet, maintaining friendships, maintaining an exercise regime, and overall general maintenance of health [12]. Regarding the term of general health, there is no additional work on its inclusions/exclusions, and as such, we treated it as a broad index. Delivering information online has become a necessity as most college students report using the Internet to retrieve information about health and well-being. In a 2009 survey by the Pew Research Center’s Internet and American Life Project, 56% of adults reported accessing the Internet, and 80% of Internet users have sought out health information online. Seeking out health information is the third most popular pursuit tracked by the Pew Research Center [35]. Given this, we propose the following hypotheses:

H1: eHEALS will be significantly related to college students’ general health, exercise regime, sleep, getting vaccinations, and maintenance of sexual health, a balanced diet, stable friendships, and a lifestyle free of harmful substances.

Electronic health literacy focuses on individual capacity to use electronic resources appropriately and as such, we would expect individual patterns of health information-seeking to be related to their overall level of electronic health literacy. Therefore,

H2: eHEALS will be significantly related to college students’ current use of Internet health resources in the areas of general health, exercise regime, sleep, getting vaccinations, and maintenance of sexual health, a balanced diet, stable friendships, and a lifestyle free of harmful substances.

Finally, we expect that electronic health literacy will be related to intention to maintain a healthy regime as well as intention to seek out additional Internet resources in these areas. Therefore,

H3: eHEALS will be significantly related to college students’ future intention to maintain a healthy regime in the areas of general health, exercise regime, sleep, getting vaccinations, and maintenance of sexual health, a balanced diet, stable friendships, and a lifestyle free of harmful substances.

H4: eHEALS will be significantly related to college students’ future intention to seek out Internet sources in the areas of general health, exercise regime, sleep, getting vaccinations, and maintenance of sexual health, a balanced diet, stable friendships, and a lifestyle free of harmful substances.

## Methods

### Overview

Following institutional review board approval, this study was conducted among a population of college students at a large midwestern university in the United States. An online survey was developed that included the eHEALS measurement [1] along with a series of planned behavior items to assess college students’ intention to manage their health [5,36]. Recruitment took place via a liberal arts online recruitment system, where

students had the option to take the survey in exchange for a small amount of extra credit in a course of their choice. Students had the option to opt out of the study for an alternative extra credit activity.

Participants took a survey that was created to assess students' use of the Internet to address health concerns or issues. A total of 420 participants participated in the study, ranging in ages from 18 to 35 (mean 20.48, SD 2.14) years, and the majority of participants were undergraduate students (mean 2.76, SD 1.15). Participants reported race/ethnicity of white (330/420, 78.6%), Asian/Pacific Islander (48/420, 11.4%), African American (15/420, 3.8%), Hispanic/Latino (14/420, 3.3%), other (11/420, 2.6%), and 4 missing values.

Participants first answered a series of demographic questions, followed by a question that asked whether or not they have a health condition that requires regular interaction with a physician. Participants were not asked to elaborate on this answer, and no participant chose to elaborate. The majority of participants (380/420, 90.6%) reported not having a major health condition, but 9.4% (39/420) did, with 3 missing values. To understand the level of past behavior, current behavior, and intent to participate in future behaviors, a series of questions were asked relating to each of the major dimensions of health items as identified by the ACHA [12]: general health, exercise, substance abuse, sleep, vaccination, sexual health, diet, mental health, and maintaining friendships. Upon completion of those questions, participants clicked a link to log their answers in the system and were thanked for their time.

## Measures

In the online survey, items provided measures of intent, attitudes, subjective norms, perceived behavioral control, and

eHEALS. To answer the hypotheses, correlations were used as these best answered the questions at hand [36-37].

## Electronic Health Literacy

Electronic health literacy was assessed through the 8-item eHEALS measure through the average of all items measured on a 5-point Likert-scale (mean 3.99, SD .71). The eHEALS items were designed to solicit self-report assessments of knowledge of or comfort in finding, evaluating, or using Internet-based health information resources (eg, "I have the skills I need to evaluate the health resources I find on the Internet" and "I feel confident in using the information from the Internet to make health decisions"). The scale evidenced high internal consistency (Cronbach alpha=.897).

## Behavior

Behavior was measured with a single item for each of the 8 health areas identified from the ACHA, for example: "I have maintained a balanced sleep schedule (approximately 7 to 8 hours per night) so far this semester." The phrasing of the behavior items was taken directly from Ajzen's [36] recommended phrasing for TPB questions. Table 1 shows the descriptive statistics for each area of healthy maintenance.

## Intentions

Following typical recommendations for TPB research [5,16], we measured intentions toward using the Internet for each of the 8 areas identified from the ACHA (See Table 2). The phrasing of the intention items was taken directly from Ajzen's [36] recommended phrasing for TPB questions. Measuring intent allowed us to assess a baseline of mindfulness for using the Internet for each of these identified issues.

**Table 1.** Descriptive statistics for self-reported past behavior for 8 areas of health issues.

Participant self-report of past behavior	Mean (SD <sup>a</sup> )
Overall health	3.98 (0.786)
Exercise regime (at least 2.5 hours per week)	3.33 (1.29)
Maintain lifestyle free of harmful substances	3.32 (1.32)
Sleep (approximately 7 to 8 hours per night)	2.91 (1.20)
Get necessary vaccinations	3.68 (1.16)
Maintain safe sex practices	4.18 (0.917)
Maintain balanced diet	3.48 (1.00)
Maintain positive social relationships	4.41 (0.676)

<sup>a</sup>SD: standard deviation.

**Table 2.** Descriptive statistics for self-reported intention items for the 8 areas of health issues.

Participant self-report of intention to use the Internet	Mean (SD <sup>a</sup> )
Overall health	3.30 (1.01)
Exercise regime (at least 2.5 hours per week)	3.96 (1.17)
Maintain lifestyle free of harmful substances	3.64 (0.109)
Sleep (approximately 7 to 8 hours per night)	3.28 (1.12)
Get necessary vaccinations	3.68 (1.12)
Maintain safe sex practices	3.90 (0.190)
Maintain balanced diet	4.08 (1.13)
Maintain positive social relationships	4.44 (0.234)

<sup>a</sup>SD: standard deviation.

## Results

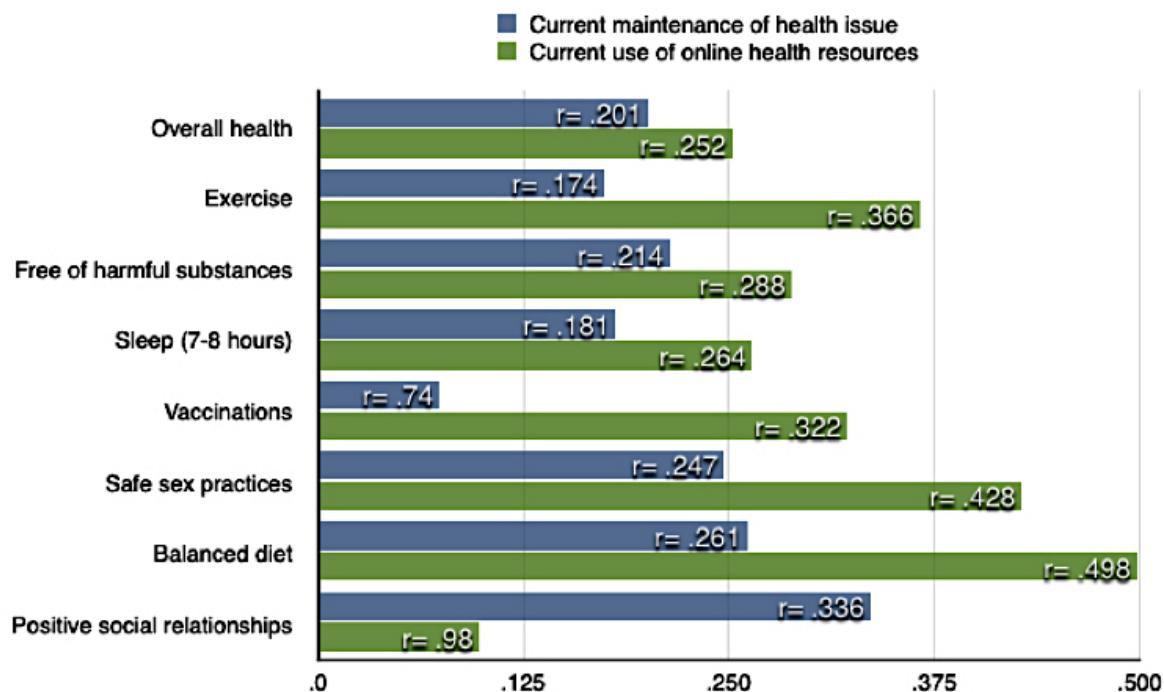
The first hypothesis predicted that electronic health literacy would be significantly correlated with an individual's general health, exercise regime, sleep, getting vaccinations, and maintenance of sexual health, a balanced diet, stable friendships, and a lifestyle free of harmful substances. The results of the survey support this as shown in [Figure 1](#).

Because our researchers come from a communication background in the behavioral sciences, correlation interpretation guidelines were based on the typical guidelines of Cohen [38], who argues that  $r=.100$  corresponds to a small relationship;  $r=.243$  and above is a moderate relationship, and  $r=.371$  and above is a large relationship. Other behavioral scholars, such as Losh [39], have cited  $r=.01$  to  $r=.25$  as a weak relationship,

where  $r=.26$  to  $r=.50$  is moderate, and  $r=.51$  to  $r=.75$  is strong. The  $P<.01$  standard was used for all analyses.

In addressing the first hypothesis, eHEALS was positively and significantly correlated with all 8 areas of health identified by the ACHA. Most notably, self-report of an individual's current maintenance of positive social relationships ( $r=.336$ ,  $P=.001$ ), a balanced diet ( $r=.261$ ,  $P=.001$ ), and practicing safe sex ( $r=.247$ ,  $P=.001$ ) emerged.

The second hypothesis predicted that eHEALS would be significantly related to college student current use of Internet health resources in the areas of general health, exercise regime, sleep, getting vaccinations, and maintenance of sexual health, a balanced diet, stable friendships, and a lifestyle free of harmful substances. Out of the 8 areas of health, 7 were significant at the  $P<.01$  level; the exception was maintaining positive social friendships ( $r=.098$ ,  $P=.05$ ).

**Figure 1.** eHealth Literacy Scale correlated with current maintenance and current use of online health resources.

Current use of online health resources approached a moderate relationship for seeking out information in the following areas: a balanced diet ( $r=.498$ ,  $P=.001$ ), safe sex practices ( $r=.428$ ,  $P=.001$ ), exercise ( $r=.366$ ,  $P=.001$ ), and vaccinations ( $r=.322$ ,  $P=.001$ ). Sleep was significantly and negatively correlated with use of online health resources ( $r=-.264$ ,  $P=.001$ ).

Hypothesis 3 predicted that future intention to maintain health would be related to eHEALS. Maintaining positive social relationships ( $r=.456$ ,  $P<.01$ ), balanced diet ( $r=.358$ ,  $P<.01$ ), and safe sex practices ( $r=.332$ ,  $P<.01$ ) were among the highest correlations addressing this question. Although all other areas emerged as significant and positive correlations, relationships were much smaller.

Finally, the fourth hypothesis predicted that future intention to use online health resources would be significantly related to eHEALS. The strongest relationships were found in this area, with several variables approaching a moderate correlation. Among these, diet ( $r=.486$ ,  $P=.01$ ), the intention to maintain general health ( $r=.451$ ,  $P=.001$ ), exercise ( $r=.380$ ,  $P=.001$ ), intending to maintain safe sex practices ( $r=.378$ ,  $P=.001$ ), maintaining a lifestyle free of harmful substances ( $r=.333$ ,  $P=.001$ ) and getting vaccinations ( $r=.332$ ,  $P=.001$ ) were the strongest relationships. The two weakest relationships included sleep ( $r=.213$ ,  $P=.02$ ) and maintaining positive social relationships ( $r=.187$ ,  $P=.02$ ).

## Discussion

### Principal Findings

In this study, we sought out what eHEALS reveals about college student health behaviors, focusing on health issues recommended by the ACHA. With numerous online options available for information-seeking behaviors, it is important to intimately know the audience and the issues that can inform campaign design and evaluation [40].

We learned that maintaining a balanced diet remains an important issue for college students, particularly as campus food [41-42] options increase in variety and more types of food choices become available to students.

In particular, online health campaigns can be designed for specific college campuses that employ the use of technologies. For example, previous research has evaluated the design, usability, and acceptability of social media resources for chronic health conditions [43] that reinforce the need to use eHEALS as a measure prior to campaign design. Previous campaigns have suggested that some implementation problems lie in understanding the target audience and their actual needs and literacy level [40-42]. We suggest that development of online campaigns geared toward college students should make use of eHEALS as an evaluative measure via pre/post-test; this can be

critical in addressing areas of diet and health, especially if they are tailored to students at various institutions.

Next, it is important for researchers to use theory to help create online interventions for college students that use eHEALS in a theory-based context. For example, TPB allowed us to gain a better sense of student intentions to make use of online resources. Results that were consistent in all findings were maintenance of safe sex practices, diet, and positive social relationships. Internet campaigns have an opportunity to reach student populations, particularly as scholarship in JMIR has noted the need to support the effective use of technology for students [43]. More specifically, as researchers develop tailored Internet campaigns toward specific issues [44], a theory-based intervention can be a useful framework to help gauge attitudes toward health issues and intent to actually engage with a healthy behavior.

### Limitations

This study had several limitations. First, recruitment occurred through a single university. In order for these results to be more generalizable, researchers at different institutions should examine eHEALS among college students; for instance, rurally located universities in medically underserved areas would benefit from similar studies. In addition, tailored interventions for different colleges require different expectations and carefully crafted messages and multimedia design use, especially since Internet-based campaigns may not be the best mechanism for all institutions. Lastly, it is important to note that in this study, participants were recruited through a liberal arts recruitment system. While participants came from a broad range of academic backgrounds, recruitment from different universities entirely would be helpful in better understanding eHealth literacy, critical health issues for college students, and addressing those in the best manner possible.

### Conclusions

This study focused on the relationship between eHealth literacy and health issues that are crucial for many college students. Sexual health emerged as a primary concern, along with diet and maintaining vaccinations. This means that education about safe sex practices are key areas for researchers to target, and the use of online interventions can mitigate possible barriers and unintended effects of traditional face-to-face and mass media campaigns [45]. Developing online interventions, particularly for sensitive issues that relate to sexual health for young adults, will continue to be important in colleges and universities. Knowledge of how eHEALS helps us understand this group is particularly helpful in spurring these efforts. As a result of understanding how eHEALS works with TPB variables, we can begin to see how eHealth literacy is critical to study in an age where we are faced with myriad communication technologies.

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## Conflicts of Interest

None declared.

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## Abbreviations

**ACHA:** American College Health Association

**eHEALS:** eHealth Literacy Scale

**TPB:** theory of planned behavior

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## Review

# Reporting of Telehealth-Delivered Dietary Intervention Trials in Chronic Disease: Systematic Review

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## Abstract

**Background:** Telehealth-delivered dietary interventions are effective for chronic disease management and are an emerging area of clinical practice. However, to apply interventions from the research setting in clinical practice, health professionals need details of each intervention component.

**Objective:** The aim of this study was to evaluate the completeness of intervention reporting in published dietary chronic disease management trials that used telehealth delivery methods.

**Methods:** Eligible randomized controlled trial publications were identified through a systematic review. The completeness of reporting of experimental and comparison interventions was assessed by two independent assessors using the Template for Intervention Description and Replication (TIDieR) checklist that consists of 12 items including intervention rationale, materials used, procedures, providers, delivery mode, location, when and how much intervention delivered, intervention tailoring, intervention modifications, and fidelity. Where reporting was incomplete, further information was sought from additional published material and through email correspondence with trial authors.

**Results:** Within the 37 eligible trials, there were 49 experimental interventions and 37 comparison interventions. One trial reported every TIDieR item for their experimental intervention. No publications reported every item for the comparison intervention. For the experimental interventions, the most commonly reported items were location (96%), mode of delivery (98%), and rationale for the essential intervention elements (96%). Least reported items for experimental interventions were modifications (2%) and intervention material descriptions (39%) and where to access them (20%). Of the 37 authors, 14 responded with further information, and 8 could not be contacted.

**Conclusions:** Many details of the experimental and comparison interventions in telehealth-delivered dietary chronic disease management trials are incompletely reported. This prevents accurate interpretation of trial results and implementation of effective interventions in clinical practice.

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### KEYWORDS

telemedicine; diet; chronic disease; behavior; review

## Introduction

Telehealth is an effective mode for delivering dietary interventions [1,2]. There is a strong relationship between dietary quality and the prevention and management of chronic

diseases [3] including diabetes [4], cardiovascular disease [5], and obesity [6]. Telehealth-delivered dietary interventions have been shown to significantly improve blood pressure, cholesterol, triglycerides, body weight, and waist circumference in people with chronic diseases [2]. There are a multitude of barriers to

face-to-face dietary interventions, including nonattendance to clinics, transport problems, inflexible hours, long wait times, and cost for both the patient and the practitioner [1,2,7]. These barriers can be addressed by adopting telehealth, which has been accepted by participants in dietary behavior change [2,8] and chronic disease management [9-11] studies. Although its use is promising, telehealth is a widely used term, and its emerging use in clinical practice is broad and varied [2,9,10,12-14]. Telehealth methods including mobile health and electronic health, may involve delivery of health care via telephone, SMS text message (short message service, SMS), email, video, website, and other remote devices. These devices can be used for one-on-one consultations, store-and-forward education, behavior change reminders, and remote monitoring and feedback. There remain a number of challenges for introducing telehealth into health care systems, such as inconsistent terminology, evolving telehealth technologies, and limited public and private health funding for implementation into standard care [12]. Developing a strong evidence-base for the use of telehealth will help to better understand how to overcome such challenges.

To implement effective telehealth interventions, practitioners need to know what telehealth is and how it is used. Translating knowledge from trials into clinical practice is crucial for improving health care and chronic disease management. However, this translation is challenged when trials are poorly reported and provide insufficient detail for implementing evidence-based interventions in practice [15-18].

In addition to the complexity of telehealth delivery, dietary behavior change interventions also have many layers of complexity in terms of the number of dietary factors targeted; the need for comprehensive individualized behavior change techniques; interrelated lifestyle behaviors; and the influence of social and environmental circumstances, attitudes, and skill levels [19,20]. Complex nonpharmacological interventions have been recently shown to be poorly reported [21-24]. To our knowledge, no previous studies have examined the reporting of interventions in dietary or telehealth-delivered trials. In addition to the complete reporting of experimental intervention components, it is important that comparison or control interventions are completely described to allow accurate interpretation and evaluation of effect size within and across trials.

This review aimed to evaluate the completeness of intervention reporting of experimental and comparison interventions in published dietary chronic disease management trials that used telehealth delivery methods.

## Methods

### Study Design

This study is a secondary analysis of the articles identified in a systematic review that examined the effectiveness of telehealth-delivered dietary interventions in chronic disease [2].

### Search Strategy

Eligible studies were identified from a systematic review of randomized controlled trials (RCTs) using telehealth methods

to deliver multifactorial dietary interventions in adults with chronic disease, conducted by our team [2]. A literature search was performed across multiple electronic databases (MEDLINE, EMBASE, CINAHL, and PsychINFO) up to November 2015, as detailed previously [25]. A multi-step search approach was taken to retrieve relevant trial publications for this study using forward and backward citation searching; expert correspondence; and searching conference abstracts, theses, dissertations, and clinical trial registries to identify ongoing trials. Two researchers (JK and MW) independently screened the search articles, and disagreements were resolved by discussion.

### Trial Publication Selection

Trial publications were included in this review if they were RCTs, cluster RCTs, or quasi-RCTs conducted in adults (>18 years of age) with at least one diet-related chronic disease. Experimental interventions were required to include two or more dietary components (eg, vegetables and whole grains). Half of the total intervention contact hours or interaction contacts was required to be delivered by telehealth and must have been developed or delivered by a qualified health professional. This study includes all telehealth-delivered dietary interventions, regardless of reporting of dietary outcomes. Studies analyzed in this study met the inclusion criteria as outlined in the systematic review protocol [25]. The original review included 25 studies with diet outcome data; however, this current reanalysis includes an additional 12 studies without diet outcome data, which otherwise met the inclusion criteria for this review. All 37 studies were therefore analyzed for completeness of reporting of the intervention, regardless of the reporting of outcome data.

### Assessment of Trial Reporting

To appraise the completeness of reporting of telehealth-delivered dietary interventions, the Template for Intervention Description and Replication (TIDieR) checklist and guide [18] was used. The 12-item TIDieR checklist is an extension of item 5 of the consolidated standards of reporting trials (CONSORT) 2010 statement [26] and item 11 of the Standard Protocol Items: Recommendations for Interventional Trials checklist [27].

The completeness of reporting of experimental and comparison interventions in each trial was recorded on a data extraction form ([Multimedia Appendix 1](#)) based on the TIDieR checklist [18]. If trials had more than one experimental intervention group, the interventions were assessed separately. Two researchers (MW and JK) independently assessed each trial and discussed differences in the rating of TIDieR items. There was an 88% agreement between the two reviewers before the initial discussion. After reappraisal and further discussion, less than 1% of items appraised were conflicting, which were then resolved with discussion to reach a consensus. If consensus could not be achieved, a third researcher (TH) was available to resolve any conflicts.

### Procedure for Attaining Additional Intervention Information

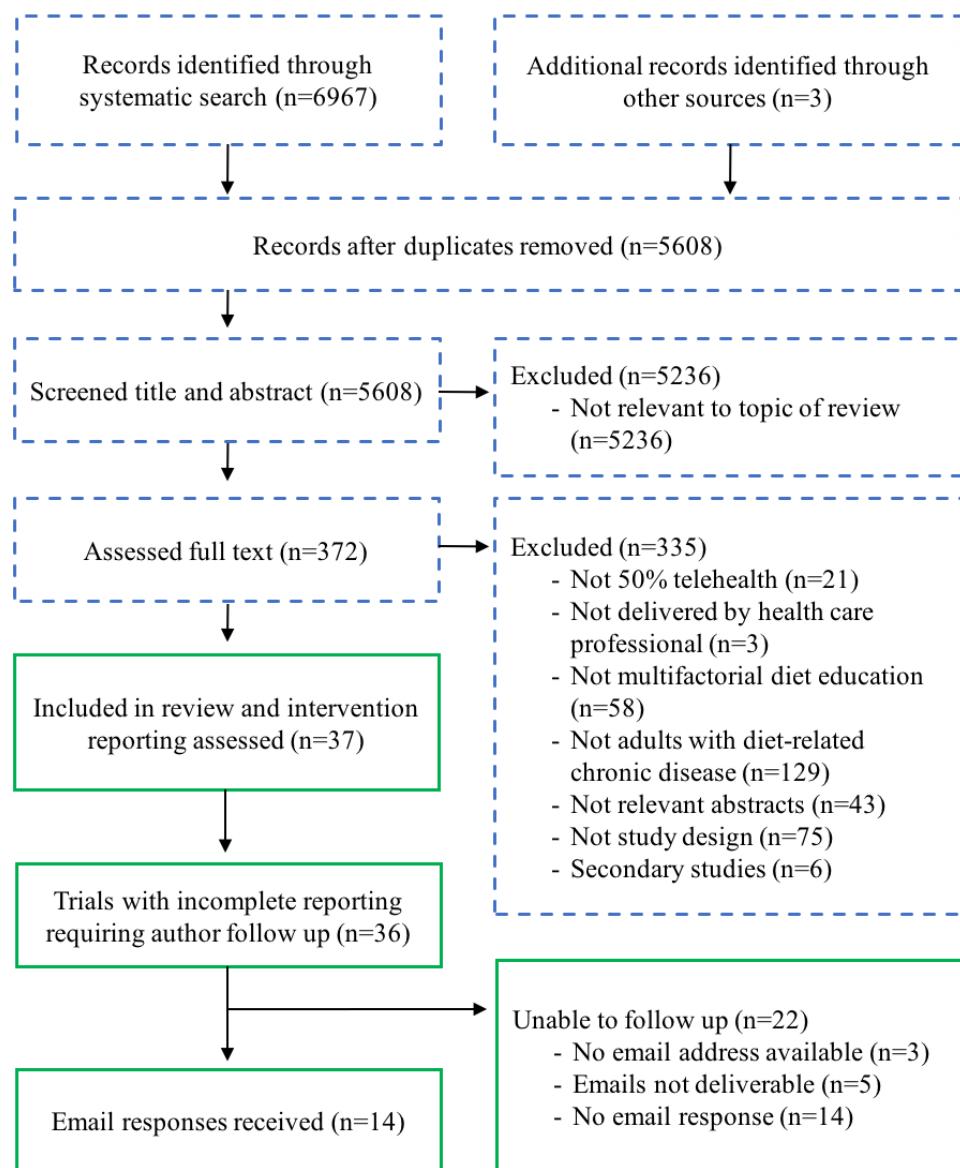
Reference lists, clinical trial registration records, available trial protocols, and trial authors' research profiles were screened to

determine whether additional written information about each trial's intervention was publicly available. Information obtained from these sources was considered, and checklist items were rescored as *complete from additional sources* where relevant. For items remaining incomplete, attempts were made to contact trial authors by emailing them questions specifically related to the incomplete items for the experimental interventions. Where corresponding author email addresses were unavailable, attempts were made to search for alternate email addresses and contact other authors via email. Authors were sent up to three email reminders, each approximately 3 weeks apart. Author responses were used to rescore the TIDieR checklist.

## Data Analysis

Data were analyzed using descriptive statistics (number and percentages) in Excel 2010 (Microsoft).

**Figure 1.** Flow of the trial publication selection and author contact process (blue or dashed boxes represent the steps taken as part of the existing systematic review; green or line boxes were steps taken for this study).

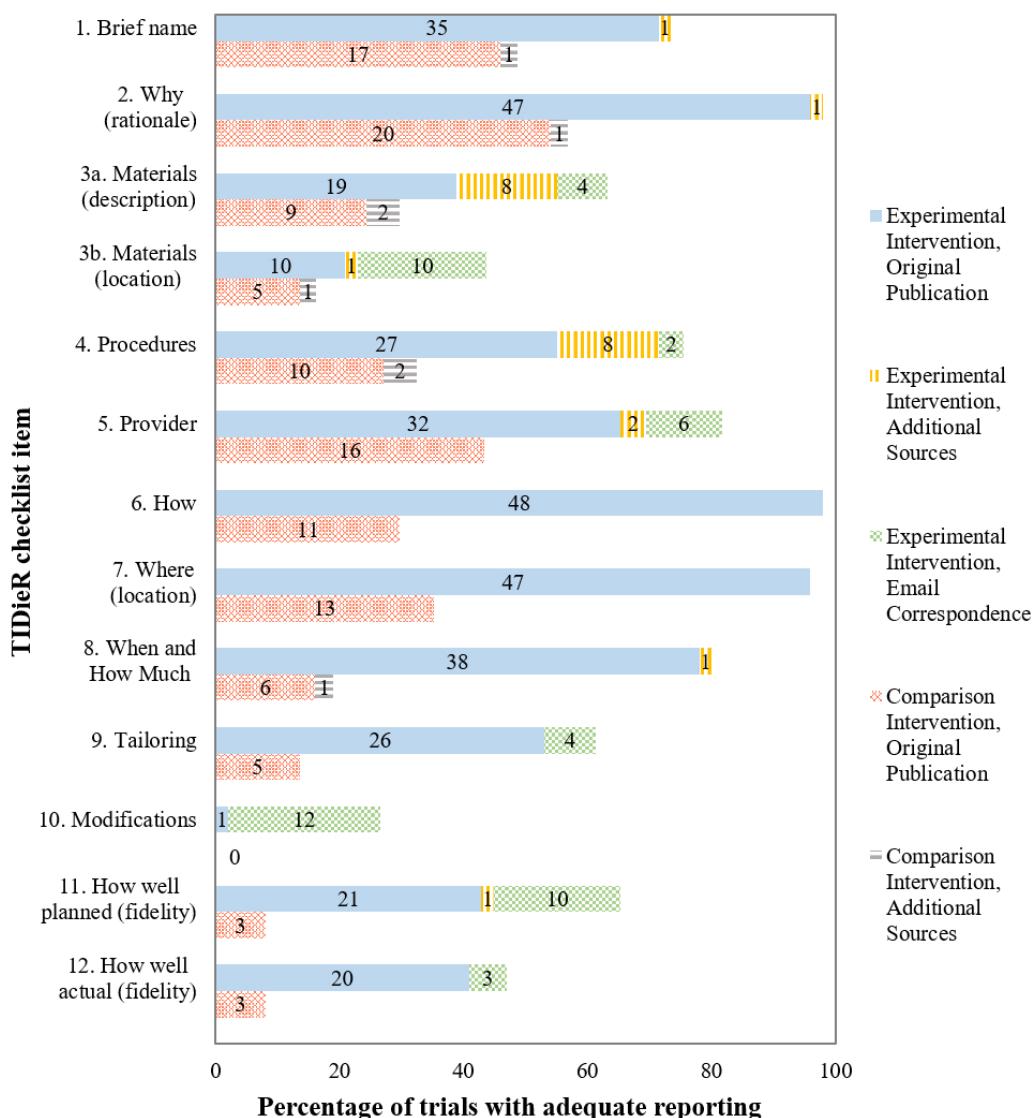


## Results

### Characteristics of Included Trials

A total of 37 trials were included (Figure 1) [2], of which 49 were experimental interventions and 37 were comparison interventions. Of the 37 trials, 29 evaluated one experimental intervention [7,8,14,28-53], 4 trials evaluated two experimental interventions [54-57], and 4 trials evaluated three experimental interventions [58-61]. Trials were published from 1981 and 2016 and conducted in patients with cardiovascular disease or heart failure (n=13) [7,8,29,31,36-40,42,56,57,62], hypertension (n=11) [14,32-34,43,44,54-56,59,60], diabetes (n=10) [14,28,30,35,45-50,56,61], kidney disease (n=3) [51,52,58], and obesity (n=3) [32,53,57]. The majority of trials involved face-to-face interaction between intervention providers and participants before the telehealth component of the intervention.

**Figure 2.** Items with complete reporting across the 12 Template for Intervention Description and Replication (TIDieR) checklist items in 49 experimental and 37 comparison interventions of dietary trials delivered by telehealth. Numbers in bars represent the number of interventions rated as complete.



Most interventions (70%) used the telephone as the telehealth delivery method, others used short message service (SMS), the Internet, video, videoconferencing, and a mix of telehealth methods. Figure 2 shows the percentage and number of experimental and comparison interventions that completely reported each TIDieR checklist item in the original trial publication, in additional sources of published information, and after email correspondence with authors.

### Reporting of Experimental Interventions

Nearly all (98%, 48/49) experimental interventions were incompletely reported in their original publication. Only one publication [8] completely reported every checklist item. Items that were commonly reported included how or the mode of delivery (item 6), rationale (item 2), and location (item 7) of the intervention. Items with the poorest reporting were materials (items 3a-b), modifications to the intervention (item 10), and fidelity (items 11-12). Intervention materials such as training materials, questionnaires, handbooks, leaflets, videoconferencing units, short SMS text messages, or websites were used in all trials. Interventions with incomplete reporting of procedures

(item 4) commonly missed details required for replicating the dietary advice provided to participants.

### Reporting of Comparison Interventions

The majority (78%, 29/37) of comparison interventions were described as “usual care,” whereas others (22%, 8/37) were “control interventions” with less intensive procedures (eg, education sessions without telephone or email follow-up, resources, or extra video education). The most commonly reported items were rationale (item 2), brief name (item 1), and provider (item 5). The least reported items were modifications (item 10), fidelity (items 11-12), materials (items 3a-b), tailoring (item 9), and when and how much of the comparison intervention was provided (item 8). More comparison interventions had intervention details incompletely reported than experimental interventions.

### Searching Additional Sources and Contacting Authors for Intervention Information

Although descriptions of the materials used in the experimental intervention were poorly reported in the original publications

(39%, 19/49), details were provided in additional sources of information (16%, 8/49) and by contacting authors through email (8%, 4/49). The locations of the materials used in the experimental intervention were further reported in email correspondence with authors (20%, 10/49). Searching additional sources of published information was time-consuming and only satisfied an additional 3% and 2% of checklist items for experimental and comparison interventions, respectively. Likewise, attaining information through email required 40 reminder emails to be sent; only 39% (14/36) of authors replied with further information, and author responses were up to 8 weeks after the initial email.

## Discussion

### Principal Findings

This study aimed to evaluate the completeness of reporting of experimental and comparison interventions in dietary chronic disease management trials that used telehealth delivery methods. The key finding was that only one experimental intervention (2%) and no comparison interventions were reported in enough detail to satisfy every TIDieR checklist item. This finding illustrates a major deficit in the reporting of information that is required for health professionals to accurately replicate dietary interventions.

Findings from this study are consistent with other evaluations of the completeness of reporting of nonpharmacological interventions that have found poor reporting across trials of physiotherapy, occupational therapy, smoking cessation, and cardiac and stroke rehabilitation interventions [21-23,62-64]. Reporting of the experimental intervention rationale, mode of delivery, and location or setting was complete in most trials, which is consistent with findings of other studies [21-23]. Although details of intervention providers were not well described in the included publications (65%, 32/49 experimental interventions; 43%, 16/37 comparison interventions), we found a greater proportion of complete reporting compared with previous studies; whereby, details on intervention providers were reported in 59% of original cardiac rehabilitation intervention publications [22] and 38% interventions for upper limb therapies in cerebral palsy [23]. Reporting of the delivery mode, location or setting, and provider details may have been inflated in this study because of the restrictive and predefined inclusion criteria for selecting relevant trials.

Accurate interpretation of intervention effects is limited when the dose and frequency of dietary support or education in each of the experimental and comparison interventions is unknown. The amount (dose) of contact, for example, has been shown to be positively associated with sustained dietary behavior change [1]. Reporting of comparison intervention details, including the dose and frequency of intervention delivery, is necessary for accurate interpretation and evaluation of treatment effect size within and across trials.

Most comparison interventions (78%, 29/37) were briefly described as simply “usual care.” This is of concern because usual care is likely to differ for participants within and between trials because of a multitude of determinants including the health

professional(s) and other personnel involved and the country’s health care system [23]. The completeness of reporting of comparison interventions in randomized trials has been explored previously; whereby, less than 40% of publications completely report the procedures, materials used, mode of delivery, tailoring, modifications, and planned and actual fidelity of comparison interventions [23,64]. Comparison interventions should be reported more completely to allow health professionals to make a clinical judgment on the additional benefit of an experimental intervention.

Trial publications with complete descriptions of physical and informational materials allow readers to use the materials of effective interventions in practice. This study found that descriptions of materials (39%, 19/49 experimental interventions) and where to access materials (21%, 10/49 experimental interventions) were poor, which is similar to previous findings [23,64]. If authors are unable to describe the materials completely in the main publication, they need to specify where further information about or the actual information materials can be found so that all elements of effective telehealth interventions can be used in practice.

Multifactorial dietary behavior change trials, regardless of their mode of delivery, are complex in comparison with trials of simple or single interventions. This is partly because of internal and external influencing factors including social and environmental circumstances, attitudes, and skill levels [19,20]. Tailoring chronic disease management strategies to support individualized dietary and lifestyle behavior change is particularly important. Tailoring of experimental interventions to trial participants was reported in only 53% (26/49) of trial publications. Many interventions were *tailored to each individual*, yet few trials reported the rationale, guides, variables, or constructs used for participant assessment, decision points, or actions for tailoring (eg, questionnaire to determine adherence to diet at a specific time point) [18]. Completely describing tailoring is challenging; however, detailed descriptions help readers to distinguish between intentional tailoring and poor fidelity [65]. As consistent taxonomy for behavior change techniques are further developed [16], reporting of tailoring for behavior change interventions will hopefully become more widespread.

Assessing fidelity in dietary behavior change trials is similarly complex in comparison with simple trials [18,65]. Intervention fidelity encompasses aspects such as the intervention design, delivery and receipt, and how well participants are able to use learned skills outside of formal intervention sessions [66]. Reporting of intervention fidelity is required for readers to accurately interpret reliability and validity, as well as optimize the efficacy of future interventions and clinical practice. Similar to findings in this study, fidelity of complex behavior change has previously found to be poorly reported [67]. For example, 87% (146/168) of behavioral pediatric obesity intervention trials reported less than half of assessed fidelity components.

Although word or page limits in peer-reviewed journals may be one of the restrictions perceived by authors as a barrier to fully describing interventions [68], Web-based supplementary materials and publishing of detailed trial protocols may assist

in overcoming restrictions [19,23]. The incomplete intervention reporting in our sample of studies may have occurred for a number of reasons including lack of awareness by trial authors about what constitutes a complete intervention description and the importance of it; no requirement to adhere to TIDieR checklist by most journals in which telehealth-delivered dietary trials are published; and publication of studies before release of the TIDieR checklist in 2014, although the CONSORT extension for nonpharmacological interventions was published in 2008 and contains some expanded guidance for reporting interventions.

This study is the first to evaluate the completeness of intervention reporting in trials of dietary intervention delivered by telehealth methods. Strengths of this study include the thorough evaluation by two independent reviewers, of intervention reporting including evaluation of additional sources of published information, and email correspondence with authors. Although the TIDieR checklist is extensive, it does not directly specify all variables that may influence the outcome of the intended intervention, such as personal attributes of the person delivering the intervention. The majority of the included trials involved physical activity and lifestyle components, as

well as dietary behavior change components. As the scope of this study was limited to telehealth-delivered dietary interventions, conclusions on the reporting of other telehealth interventions cannot be drawn. This study highlights that trials of complex interventions need to report each component of chronic disease management completely for accurate evaluation and replication of components of the trial, or the trial as a whole.

## Conclusions

Intervention details of dietary trials delivered by telehealth methods are not adequately reported, limiting their replication in research and clinical practice. The least reported items of the experimental intervention were descriptions and locations of the physical and informational materials used. Reporting of comparison intervention details needs to be more complete to allow evaluation of the additional benefit of experimental interventions. Inadequate reporting of trials prevents closure of the translational gap between research trials and clinical practice, thereby limiting the potential for health care professionals to implement effective interventions to assist people with managing their chronic disease. Our findings confirm the pressing need for authors, editors, and reviewers to use the TIDieR checklist to ensure complete reporting of published dietetic trials.

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## Authors' Contributions

MW assessed included studies, conducted the analysis, drafted the manuscript, and had primary responsibility for final content. JK assisted in the conceptualization of the study, conducted the literature search, assessed the studies, and assisted with manuscript preparation and review. DR, TH, and KC participated in the design of the study, provided methodological expertise, and revised the drafted manuscript. All authors read and approved the final manuscript.

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## Conflicts of Interest

TH was on the steering committee that developed the TIDieR checklist and guide. There are no financial conflicts of interest to declare that may have influenced the results of this study.

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## Multimedia Appendix 1

Template for Intervention Description and Replication (TIDieR) checklist and examples of adequate reporting in included trial publications.

[[PDF File \(Adobe PDF File, 62KB - jmir\\_v19i12e410\\_app1.pdf](#) ]

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## Abbreviations

**CONSORT:** consolidated standards of reporting trials

**RCT:** randomized controlled trial

**SMS:** short message service

**TIDieR:** Template for Intervention Description and Replication

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Original Paper

# Estimating the Population Impact of a New Pediatric Influenza Vaccination Program in England Using Social Media Content

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## Abstract

**Background:** The rollout of a new childhood live attenuated influenza vaccine program was launched in England in 2013, which consisted of a national campaign for all 2 and 3 year olds and several pilot locations offering the vaccine to primary school-age children (4-11 years of age) during the influenza season. The 2014/2015 influenza season saw the national program extended to include additional pilot regions, some of which offered the vaccine to secondary school children (11-13 years of age) as well.

**Objective:** We utilized social media content to obtain a complementary assessment of the population impact of the programs that were launched in England during the 2013/2014 and 2014/2015 flu seasons. The overall community-wide impact on transmission in pilot areas was estimated for the different age groups that were targeted for vaccination.

**Methods:** A previously developed statistical framework was applied, which consisted of a nonlinear regression model that was trained to infer influenza-like illness (ILI) rates from Twitter posts originating in pilot (school-age vaccinated) and control (unvaccinated) areas. The control areas were then used to estimate ILI rates in pilot areas, had the intervention not taken place. These predictions were compared with their corresponding Twitter-based ILI estimates.

**Results:** Results suggest a reduction in ILI rates of 14% (1-25%) and 17% (2-30%) across all ages in only the primary school-age vaccine pilot areas during the 2013/2014 and 2014/2015 influenza seasons, respectively. No significant impact was observed in areas where two age cohorts of secondary school children were vaccinated.

**Conclusions:** These findings corroborate independent assessments from traditional surveillance data, thereby supporting the ongoing rollout of the program to primary school-age children and providing evidence of the value of social media content as an additional syndromic surveillance tool.

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**KEYWORDS**

health intervention; influenza; vaccination; social media; Twitter

## Introduction

### Background

In 2012 the Joint Committee on Vaccination and Immunisation recommended the extension of the annual influenza vaccination campaign to include all healthy children aged 2 to 16 years of age in England [1]. This decision was informed by influenza transmission modeling done using an evidence-synthesis approach, showing that vaccination could not only protect the children themselves from infection, but also decrease influenza transmission in the general population. This finding included the indirect protection of at-risk groups, such as people over 65 years of age or those with underlying clinical risk factors [2]. The phased rollout of the live attenuated influenza vaccine (LAIV) program began during the 2013/2014 influenza season. In the first season, the program offered vaccinations to all 2 and 3-year-olds throughout England. A number of geographically distinct pilot regions also offered vaccinations to primary school age children (4-11 years of age) to determine the optimal model of delivery to school-age children. For the 2014/2015 influenza season, the program was extended nationally to offer vaccinations to all 2 to 4-year-olds. Pilot locations were added that offered vaccinations to children either (1) of primary school age (*Primary school*; 4-11 years), (2) the first two years of secondary school age (*Secondary school*, 11-13 years), or (3) both (*Primary and Secondary school*; 4-13 years) to determine optimal models of delivery.

### Motivation

Public Health England (PHE) has been using a variety of surveillance systems to assess the overall population impact of the childhood influenza campaign in children of school-age on influenza epidemiology to validate the direct and indirect effects of vaccinating this age group. The pilot locations for 2014/2015 are of particular interest, as the variation in target groups may offer further insights into the optimal strategies for the national rollout. During the 2014/2015 campaign, most influenza indicators through traditional surveillance systems in both targeted and nontargeted age groups demonstrated a significant reduction in pilot areas that offered the vaccine to primary school age children. However, there was little impact in pilot areas, where only two age cohorts of secondary school age children were vaccinated [3]. These surveillance indicators were based on health systems ranging from General Practitioners' consultation rates to excess mortality.

Whilst such results are important in estimating the intervention's effects on health care services, online user-generated information offers a complementary data source that can provide additional insights into the impact of such campaigns on the wider community, including those persons that do not consult the health care system. Our study also highlights the potential value of user-generated information in the absence of routine evaluation systems. Internet-based surveillance systems are being viewed as novel logistically and economically viable developments that offer great potential as an extension of traditional surveillance systems [4]. Recent research efforts have shown that in combination with *machine learning* techniques, data from social media or search engines can be

used to accurately estimate disease-related indicators such as influenza-like illness (ILI) rates [5-9]. These technologies provide health monitoring systems with additional, publicly available, and potentially more timely sources of data for syndromic surveillance. Furthermore, compared to traditional surveillance systems, user-generated content may offer insights about a wider range of the population, including the bottom part of the disease population pyramid (ie, those that do not seek medical attention) [10].

For the 2013/2014 pilot areas, in order to provide further evidence of the community-wide effects of vaccinating children with influenza vaccine, Lampos et al made use of online user-generated content in combination with statistical natural language processing techniques to estimate ILI rates in the population [9]. By matching nonvaccinated control areas with pilot areas and using flu-related Twitter posts or Bing search queries from these locations, the impact of the campaign within the *Primary school* age pilot areas was estimated, showing a significant decrease (22% to 33% reduction) in influenza transmission in the general population in these pilot areas compared to corresponding control areas [9]. PHE's estimates also showed evidence of a reduction in influenza transmission in targeted and nontargeted age groups in pilot areas compared to nonpilot areas, based on a variety of influenza indicators during a season dominated by circulation of influenza A(H1N1)pdm09 [11].

### Aim

The work in this paper applies the same statistical framework as Lampos et al [9] (with a slightly improved supervised learning approach) on Twitter data for the influenza season of 2014/2015. We aim to assess the impact of influenza vaccine pilot trials in school age children on influenza transmission in those pilot areas. The 2014/2015 season was dominated by circulation of influenza A(h3N2) and influenza B. In addition, we examined the impact of vaccinating different target populations, specifically primary and/or secondary school-age children, on influenza rates in the general population. This analysis provides further insights into the most effective strategies for reducing community-wide influenza transmission. This work also aims to reevaluate the hypothesis that a statistical framework based on online user-generated content can form a valid source for more fine-grained influenza surveillance tasks, such as estimating the impact of a targeted intervention. We repeated the analysis for the 2013/2014 LAIV campaign that was previously studied in Lampos et al [9], but with revised pilot and control areas, for consistency with our study for the 2014/2015 season.

## Methods

### Data Sources

Two data sources were used for the experiments: geo-located Twitter posts related to ILI and official ILI rates provided by the Royal College of General Practitioners (RCGP) [12], the latter defining the *ground truth*. In addition, boundary data and population estimates from the Office for National Statistics (ONS) [13,14] were used to map the vaccine pilot and control areas.

### Twitter Data

The Twitter data consisted of all exactly geo-located Twitter posts in England from August 29, 2011 to August 30, 2015, which comprise approximately 1% of all tweets made by users in England. This number is a rough estimate based on approximately 20% of the United Kingdom population using Twitter, with 33% of active users assumed to be posting 5 tweets per day [15]. Our dataset consists of 350,000 geo-located tweets per day on average. As in Lampos et al [9], the same initial list of 36  $n$ -grams (phrases with  $n$  words) related to ILI was created manually. Then, based on frequent cooccurrence with this list in the Twitter time series data, a set of 217  $n$ -grams was extracted ( $n < 5$ ; see [Multimedia Appendix 1](#)).

The RCGP ILI rates used for model learning were only available on a weekly basis, so frequency rates of this set of  $n$ -grams for a period of 7 days prior to any given day were computed, and formed the explanatory variables. To estimate the impact on the pilot areas,  $n$ -gram frequencies of tweets geo-located in the chosen pilot and control areas during the intervention period were used.

### Official Health Reports

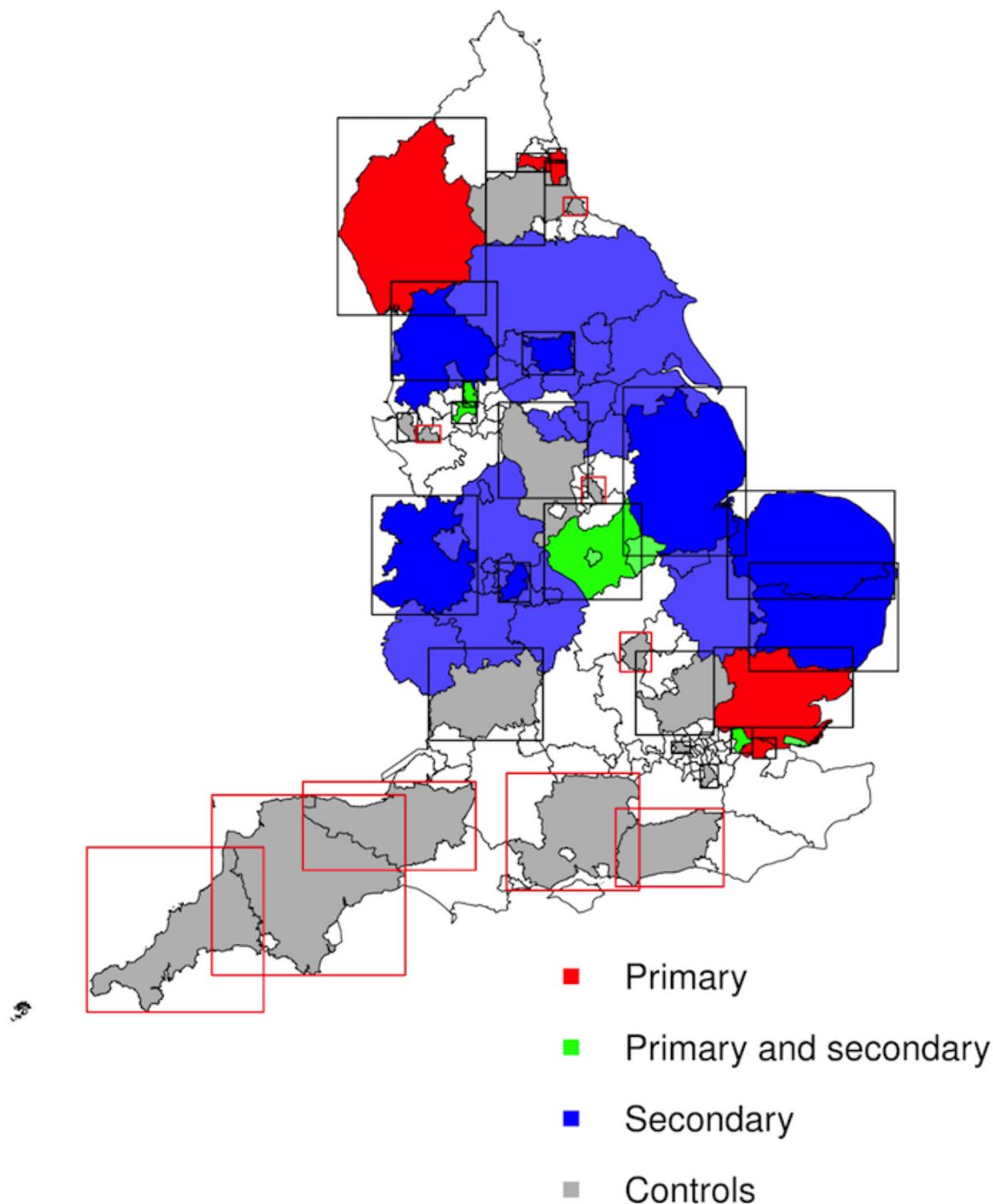
Weekly ILI estimates were provided by the RCGP, a sentinel network of approximately 100 practices in England, which covers a registered population of approximately 1 million persons [12]. These ILI estimates represent the weekly incidence rate of ILI cases/consultations per 100,000 patients registered with eligible practices during that week [12]. The data used cover the period from August 29, 2011 to August 30, 2015 for England.

### Pilot and Control Areas

A total number of 140 local authorities implemented vaccinations as part of the pilot program. To create a suitable list of pilot areas for the impact assessment, these areas were combined on a county level, where possible. This list included a large amount of *Secondary school* pilot areas (37), so only the most populated ones were considered, whilst ensuring an even geographical distribution throughout the country. The geographical distribution and the areas' population sizes were defined using ONS boundary data and population estimates of England, respectively [13,14]. Of the 7 *Primary and Secondary school* pilot areas, 3 were eliminated due to small size or because they were enclosed within another pilot area. Pilot areas involving special schools were ignored, as these included only a small number of schools and were thus unlikely to provide any significant community-wide benefits. This preprocessing resulted in 6 *Primary school*, 4 *Primary and Secondary school*, and 7 *Secondary school* pilot areas.

A list of eligible control locations was chosen according to the following criteria: appropriate distance from pilot areas, a moderate population size, and a plausible geographical spread. These criteria resulted in a list of 16 control areas. Nonoverlapping boundary rectangles represented by their North-East and South-West corners were created around the chosen pilot and control areas. The geographical distribution of the pilot and control areas is shown in [Figure 1](#). [Table 1](#) lists the pilot areas considered for this study. For a full list of control and pilot areas, see [Multimedia Appendix 2](#).

**Figure 1.** Geographical distribution of the pilot and control areas chosen for the study with their corresponding boundary boxes. Control areas with red boxes have a distance of at least 10 km to any pilot area. The “Secondary” and “Primary and Secondary” pilot areas that were excluded from the study are shown without boundary boxes and in a lighter shade of blue and green, respectively. Contains National Statistics and OS data, Crown copyright and database right.



**Table 1.** Pilot areas considered for this study during the 2014/2015 LAIV program with their respective population size [14] and geographical boundary rectangle corner coordinates. Pilot areas that were also used or have partial overlap with the ones used in the 2013/2014 LAIV program are highlighted in italics.

Location	Pilot	Population	North-East corner <sup>a</sup>	South-West corner <sup>b</sup>
Thurrock	Primary school	163,270	51.568, 0.551	51.448, 0.334
<i>Gateshead</i>	<i>Primary school</i>	200,505	54.984, -1.510	54.878, -1.853
South Tyneside	Primary school	148,740	55.011, -1.352	54.928, -1.536
Sunderland	Primary school	276,889	54.944, -1.346	54.799, -1.569
<i>Cumbria</i>	<i>Primary school</i>	497,874	55.189, -2.159	54.040, -3.641
<i>Essex</i>	<i>Primary school</i>	1,431,953	52.093, 1.297	51.632, -0.020
Lancashire	Secondary school	1,184,735	54.240, -2.045	53.667, -3.085
Birmingham	Secondary school	1,101,360	52.609, -1.729	52.381, -2.034
Norfolk	Secondary school	877,710	52.993, 1.745	52.355, 0.154
Leeds	Secondary school	766,399	53.946, -1.290	53.699, -1.800
Suffolk	Secondary school	738,512	52.550, 1.769	51.932, 0.340
Lincolnshire	Secondary school	731,516	53.616, 0.358	52.640, -0.821
Shropshire	Secondary school	310,121	52.998, -2.233	52.306, -3.236
<i>Bury</i>	<i>Primary and Secondary school</i>	187,474	53.667, -2.234	53.512, -2.383
Salford	Primary and Secondary school	242,040	53.542, -2.245	53.416, -2.490
<i>Havering</i>	<i>Primary and Secondary school<sup>c</sup></i>	245,974	51.632, 0.334	51.484, 0.138
<i>Leicestershire</i>	<i>Primary and Secondary school</i>	667,905	52.948, -0.664	52.392, -1.598

<sup>a</sup>Longitude and latitude of the North-East edge of the bounding box

<sup>b</sup>Longitude and latitude of the South-West edge of the bounding box

<sup>c</sup>The secondary school program in Havering included the year 7 cohorts only (11-12 years)

## Statistical Framework

The following sections provide a brief outline of the statistical framework that was implemented. Apart from a slightly improved supervised learning approach, this framework is based on the work by Lampos et al [9], in which it is described and validated in more detail. The method consists of first learning a nonlinear regression model to estimate ILI rates from  $n$ -grams based on user-generated content (tweets in this case). Thereafter, by making use of inferred ILI rates in matched pilot and control regions, a linear modeling approach was applied to assess the potential impact of the intervention in the pilot areas.

### Estimating Disease Rates Using a Gaussian Process

The majority of techniques used to acquire infectious disease estimates from user-generated data involve the use of linear regression models [16-18]. Lampos et al showed that nonlinear methods can improve model performance, especially when working with a smaller feature space consisting of varying  $n$ -gram sizes [8]. The authors proposed the use of Gaussian Processes (GPs) to model ILI rates and successfully applied these to Twitter, Google, and Bing data [8,9]. See below for details of the GP model used in this study.

Let  $\mathbf{X} \in \mathbb{R}^{N \times M}$  be the observation matrix with  $N$  weeks and  $M$  frequency rates of  $n$ -gram features. Then given inputs  $\mathbf{x}, \mathbf{x}' \in \mathbb{R}^M$  (representing rows of  $\mathbf{X}$ ), a GP can be defined as a statistical

distribution for which any finite linear combination of samples is normally distributed and is written as:



Here  $\mu(\mathbf{x})$  and  $k(\mathbf{x}, \mathbf{x}')$  represent the mean and covariance function (or kernel), respectively [19]. By assuming that  $\mu(\mathbf{x}) = 0 \forall i=1, \dots, N$ , the distribution is entirely determined by its covariance function. As our core kernel, the sum of two differently parameterized Matérn functions ( $k_M$ ) [20], with degrees of freedom  $v=3/2$  was found to be the most suitable for estimating ILI rates from Twitter data:



where  $\sigma_m$  represents the overall level of variance and  $l_m$  a characteristic length scale. Assuming that different  $n$ -gram sizes may vary in their usage and are likely to have a more concise semantic interpretation with an increasing  $n$ , we model them with different kernels. The fact that the sum of covariance functions forms a valid covariance function in itself allows for this and we have:



where  $\mathbf{g}_n$  represents the features that belong to each  $n$ -gram category and  $C=3$  is the number of  $n$ -gram categories (3-grams and 4-grams are merged in this particular model). To model noise, we use the sum of a squared exponential:

and a noise function:



( $\delta$  is a Kronecker delta function), as defined in [19].

GP regression involves minimizing the negative log-marginal likelihood function:



where  $\mathbf{y}$  denotes the ILI rates time-series,  $(\mathbf{K})_{ij} = k(\mathbf{x}_i, \mathbf{x}_j)$  and  $\mu = (\mu(\mathbf{x}_1), \dots, \mu(\mathbf{x}_N))$ . Once the model is learnt, newly observed feature frequency rates  $\mathbf{x}_*$  result in new ILI rate estimates  $\mathbf{y}_*$  by computing  $E[\mathbf{y}_* | \mathbf{y}, \Omega, \mathbf{x}_*]$ , the mean of the posterior predictive distribution. The performance of the model was measured using a 10-fold cross validation (random temporal splits) on the training set, using the average Pearson correlation ( $r$ ) and the mean absolute error (MAE).

### Estimating the Impact of the LAIV Program

Once the GP model was trained, the impact of the LAIV campaign in pilot areas could be estimated using the methodology outlined in Lampis et al, Section 3.3 [9], which we briefly describe here as well.

Given a set of pilot and control areas,  $n$ -gram frequencies of Twitter posts geo-located in those areas are extracted for a period before and during the intervention. ILI rate estimates can then be computed for all areas and supersets of areas using a pretrained GP model and we denote these with  $\mathbf{q}_v$  and  $\mathbf{q}_c$  for pilot and control areas, respectively. By looking at these ILI estimates for a number of weeks,  $\tau = \{t_1, \dots, t_N\}$ , prior to the intervention, control and pilot locations with similar influenza activity can be matched based on a strong Pearson correlation,

Assuming a linear relationship in ILI rates between locations with similar influenza activity, a linear regression model can be learnt using  $\mathbf{q}_v$  and  $\mathbf{q}_c$  (ie, the ILI estimates prior to the intervention in the various matched area pairs):



where  $\omega, \beta, \varepsilon_i$  denote the regression's weight and intercept, and independent, zero-centered noise, respectively. Using  $\mathbf{q}_c$ , the ILI estimates in the control areas during the intervention, this linear model can then predict the hypothetical ILI rates in pilot locations during the intervention had the intervention not taken place:



where  $\mathbf{b} \in \mathbb{N}$  with  $(\mathbf{b})_k = \beta \forall k = 1, \dots, N$ .

Comparing these hypothetical ILI rates to the ILI rates estimated by the GP model during the intervention allows the impact of the campaign to be estimated. The following measures were applied:

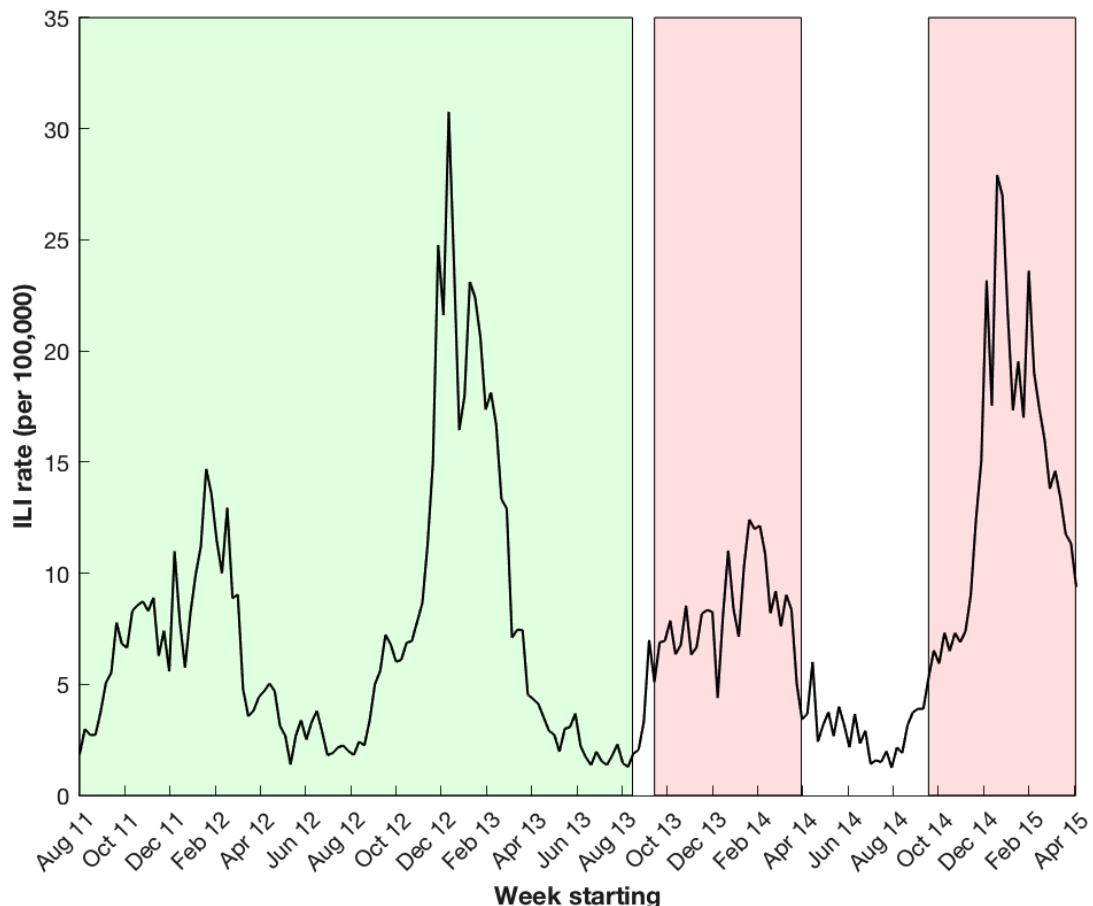


where  $\mathbf{q}$  denotes the mean value of  $\mathbf{q}$ . Thus,  $\delta_v$  and  $\theta_v$  measure the absolute and relative mean impact of the intervention, respectively. Confidence intervals for these measures are produced using bootstrap sampling [21]. This calculation involves sampling with replacement the residuals  $\varepsilon_i$  of the linear regression, adding them to the fitted values, and then running the linear model for these, which produces estimates for  $\beta$  and  $\omega$ . These values are then applied to a sampled (with replacement) set of  $\mathbf{q}_v$  and  $\mathbf{q}_c$ . Repeating this procedure 100,000 times creates sets of estimates for  $\delta_v$  and  $\theta_v$ , from which we can derive confidence intervals using the 0.025 and 0.975 quantiles, provided that their distributions are unimodal and symmetric. Results are considered statistically significant if absolute values are higher than two standard deviations of the bootstrap estimates [9,22].

## Results

We present an assessment of the impact of the childhood LAIV campaign during the 2013/2014 and 2014/2015 influenza seasons based on the previously described methodology. The GP model was trained on RCGP ILI rates in England and Figure 2 shows the RCGP ILI rates used, with the preintervention correlation period and the two impact assessment periods highlighted.

**Figure 2.** Weekly influenza-like illness (ILI) rate (per 100,000) provided by the Royal College of General Practitioners (RCGP) in England with the pre-intervention correlation period highlighted in green and the two impact assessment periods (2013/14 and 2014/15 influenza seasons) highlighted in red.



### Performance of the Supervised Model for Estimating ILI Rates

A GP regression model was trained using weekly Twitter data geo-located in England from August 29, 2011 to August 30, 2015 and the corresponding RCGP ILI rates. Based on a 10-fold cross validation, an average Pearson correlation  $r=0.84$  with a standard deviation of 0.08 and average MAE of 2.42 (weekly ILI rate per 100,000 people) with a standard deviation of 0.52 were measured. This approach is in line with the performance of the GP model used in the previous impact assessment [9].

### Impact Estimates of the LAIV Program

Using the GP model trained on a national level (England), ILI rates for the chosen pilot locations were estimated. This was done for individual pilot locations, the set of all pilot locations, and sets of pilot locations in which the same cohorts were vaccinated (ie, *Primary school, Secondary school*). An exhaustive search of all possible combinations of control areas was performed. These combinations of control locations were matched to the sets of pilot locations during a period prior to the start of the LAIV campaign (August 29, 2011 to September 1, 2013) based on similar influenza activity, as measured by Pearson correlation. The 2013/2014 influenza season is not included in this correlation phase, as this involved the vaccination of 2 and 3-year-olds nationally and a number of

primary school age pilot areas, which could change the linear relationship between certain control and pilot locations. For each pilot area and set of pilot areas, the most highly correlated combination of control areas was used to then estimate the impact of the LAIV campaign for the 2014/2015 influenza season. There is some overlap with the pilot areas of the previous influenza season, so the same analysis was redone for the 2013/2014 season (in this case with a different set of control areas) so results could be compared to previous studies [9,11].

Table 2 and Table 3 show the results for individual pilot locations, and sets of them for the 2014/2015 and 2013/2014 influenza season, respectively. For each area, the tables include the Pearson correlation  $r$ , the mean and 95% confidence intervals of 100,000 bootstrap estimates of the absolute and relative mean impact  $\delta_v$  and  $\theta_v$  during the intervention period, the number of control areas chosen  $n(c)$ , and the size of the population targeted in the pilot  $Pop(v)$  and matched collection of control  $Pop(c)$  areas. The distribution of the bootstrap estimates was assessed graphically and seemed unimodal. Thus, statistically significant results are based on absolute values being higher than two standard deviations of the bootstrap estimates and are highlighted in italics. In addition, a significant preintervention correlation was necessary for reliable impact estimates, which we defined as being a Pearson correlation  $>0.60$ , as was done in the previous study [9].

**Table 2.** Estimates of the impacts of LAIV pilot program during the 2014/2015 influenza season in individual pilot locations and supersets of them. For each area considered, the precampaign Pearson correlation  $r$  with chosen control areas, the mean and 95% confidence intervals of the absolute and relative mean impact  $\delta_v$  and  $\theta_v$  during the intervention period, the number of control areas chosen  $n(c)$ , and the size of the population targeted in the chosen vaccination  $Pop(v)$  and control  $Pop(c)$  areas are presented. Statistically significant results are highlighted in italics.

Pilot area	$r^a$	$\delta_v^b$	$\theta_v^c$	$n(c)^d$	$Pop(v)^e$	$Pop(c)^f$
All vaccinated	0.89	-0.50 (-2.77 to 1.99)	-4.51 (-25.72 to 22.61)	10	9,772,977	5,066,069
<i>All “Primary school”</i>	<i>0.71</i>	<i>-1.15 (-2.19 to -0.15)</i>	<i>-16.97 (-30.09 to -2.42)</i>	8	2,719,231	2,371,367
All “Primary and Secondary school”	0.84	-0.06 (-1.50 to 1.43)	-0.30 (-16.71 to 19.36)	6	1,097,419	2,174,854
All “Primary school” and “Primary and Secondary school”	0.85	-1.35 (-3.37 to 0.66)	-13.01 (-30.54 to 7.31)	9	4,062,624	3,601,377
All “Secondary school”	0.83	0.06 (-1.58 to 1.90)	1.41 (-19.40 to 28.40)	7	5,710,353	4,038,921
Cumbria (“Primary school”)	0.59	0.04 (-0.24 to 0.33)	1.07 (-5.75 to 8.17)	7	497,874	3,999,608
Essex (“Primary school”)	0.68	-0.32 (-1.13 to 0.51)	-5.91 (-20.56 to 10.58)	8	1,431,953	3,199,730
<i>Gateshead (“Primary school”)</i>	<i>0.59</i>	<i>-0.39 (-0.74 to -0.04)</i>	<i>-8.46 (-15.56 to -1.02)</i>	4	200,505	1,551,060
<i>South Tyneside (“Primary school”)</i>	<i>0.34</i>	<i>0.25 (0.03 to 0.52)</i>	<i>6.82 (0.81 to 14.07)</i>	3	<i>148,740</i>	<i>1,697,971</i>
Sunderland (“Primary school”)	0.54	0.12 (-0.05 to 0.32)	3.20 (-1.38 to 8.38)	3	276,889	1,119,136
Thurrock (“Primary school”)	0.32	0.04 (-0.14 to 0.23)	1.01 (-3.56 to 6.24)	3	163,270	753,563
Bury (“Primary and Secondary school”)	0.32	-0.11 (-0.37 to 0.12)	-2.60 (-8.94 to 3.13)	2	187,474	893,813
Leicestershire (“Primary and Secondary school”)	0.81	0.32 (-0.70 to 1.38)	4.97 (-10.01 to 21.22)	6	667,905	2,756,865
Salford (“Primary and Secondary school”)	0.67	0.40 (-0.20 to 1.01)	8.45 (-3.96 to 22.00)	7	242,040	4,183,184
Harvering (“Primary and Secondary school”-year 7)	0.48	-0.03 (-0.35 to 0.31)	-0.55 (-8.23 to 7.79)	4	245,974	1,742,705
Birmingham (“Secondary school”)	0.79	0.53 (-0.27 to 1.34)	10.36 (-4.86 to 27.21)	10	1,101,360	5,435,742
Lancashire (“Secondary school”)	0.65	0.18 (-0.78 to 1.13)	3.45 (-13.41 to 21.40)	8	1,184,735	3,463,060
Leeds (“Secondary school”)	0.63	0.54 (-0.40 to 1.51)	10.81 (-7.41 to 30.98)	7	766,399	2,731,293
Lincolnshire (“Secondary school”)	0.66	-0.29 (-0.78 to 0.19)	-6.09 (-16.20 to 4.25)	6	731,516	1,737,168
Norfolk (“Secondary school”)	0.71	-0.12 (-0.60 to 0.35)	-2.31 (-11.55 to 7.25)	6	877,710	2,784,394
Shropshire (“Secondary school”)	0.35	0.13 (-0.13 to 0.39)	3.30 (-3.18 to 9.71)	6	310,121	2,833,659
Suffolk (“Secondary school”)	0.59	0.10 (-0.34 to 0.53)	2.24 (-7.54 to 12.35)	5	738,512	2,015,339

<sup>a</sup> $r$ : The precampaign Pearson correlation with the chosen aggregation of control areas

<sup>b</sup> $\delta_v$ : The absolute difference in the mean ILI rate during the intervention period

<sup>c</sup> $\theta_v$ : The relative difference in the mean ILI rate during the intervention period

<sup>d</sup> $n(c)$ : The number of aggregated control areas chosen

<sup>e</sup> $Pop(v)$ : The size of the population targeted in the chosen vaccination areas

<sup>f</sup> $Pop(c)$ : The size of the population targeted in the chosen aggregation of control areas

**Table 3.** Estimates of the impacts of the LAIV pilot program during the 2013/2014 influenza season in individual pilot locations and supersets of these locations. For each area considered, the precampaign Pearson correlation  $r$  with chosen control areas, the mean and 95% confidence intervals of the absolute and relative mean impact  $\delta_v$  and  $\theta_v$  during the intervention period, the number of control areas chosen  $n(c)$ , and the size of the population targeted in the chosen vaccination  $Pop(v)$  and control  $Pop(c)$  areas are presented. Statistically significant results are highlighted in italics.

Pilot area	$r^a$	$\delta_v^b$	$\theta_v^c$	$n(c)^d$	$Pop(v)^e$	$Pop(c)^f$
All vaccinated (Primary school)	0.82	-1.03 (-2.00 to -0.10)	-13.77 (-25.01 to -1.45)	9	3,231,685	3,601,377
Leicestershire (Primary school)	0.81	-0.28 (-1.02 to 0.47)	-4.44 (-15.93 to 7.95)	6	667,905	2,756,865
Essex (Primary school)	0.68	0.34 (-0.30 to 1.12)	7.45 (-6.41 to 24.32)	8	1,431,953	3,199,730
Gateshead (Primary school)	0.59	0.38 (-0.06 to 0.85)	9.11 (-1.40 to 20.76)	4	200,505	1,551,060
Cumbria (Primary school)	0.59	0.36 (-0.00 to 0.75)	9.12 (-0.07 to 19.11)	7	497,874	3,999,608
Havering (Primary school)	0.48	0.15 (-0.19 to 0.52)	3.80 (-4.99 to 13.43)	4	245,974	1,742,705
Bury (Primary school)	0.32	-0.09 (-0.34 to 0.14)	-2.40 (-8.44 to 3.64)	2	187,474	893,813

<sup>a</sup> $r$ : The precampaign Pearson correlation with the chosen aggregation of control areas

<sup>b</sup> $\delta_v$ : The absolute difference in the mean ILI rate during the intervention period

<sup>c</sup> $\theta_v$ : The relative difference in the mean ILI rate during the intervention period

<sup>d</sup> $n(c)$ : The number of aggregated control areas chosen

<sup>e</sup> $Pop(v)$ : The size of the population targeted in the chosen vaccination areas

<sup>f</sup> $Pop(c)$ : The size of the population targeted in the chosen aggregation of control areas

For the 2014/2015 influenza season, correlations ranged from 0.32 to 0.89, and pilot areas with larger populations tend to have more control areas, larger populations of control areas, and higher Pearson correlations. The only significant impact was observed in the *Primary school* age pilot areas, for which the results suggest that during the 2014/2015 influenza season the mean ILI rate was reduced by 16.97% (95% CI 2.42-30.09). For the individual locations, Gateshead and South Tyneside did show significant results, but their precampaign correlations were 0.59 and 0.34, respectively; both were less than the predefined threshold of 0.60, which makes their impact estimates possibly less reliable.

The correlations for the 2013/2014 influenza season ranged from 0.32 to 0.82, and whilst none of the individual locations demonstrated significant results, all pilots together estimated a statistically significant impact of a 13.77% (95% CI 1.45-25.01) reduction in the mean ILI rate during that season. Note that for the 2013/2014 season, the primary school-age vaccination was the only program implemented across all pilot areas.

## Discussion

### Principal Results

By using social media content to assess the impact of the childhood influenza pilot program in England in 2013/2014 and 2014/2015, statistically significant results suggest a reduction in the mean ILI rate of approximately 17% (Table 2, row 2, column 4) across all ages in *Primary school* age pilot areas only during the 2014/2015 influenza season and 14% (Table 3, row 1, column 4) in the aggregation of *Primary school* age vaccinated areas during the 2013/2014 influenza season.

### Comparison With Prior Work

Both impact estimates are in line with results from independent studies by PHE that used traditional surveillance systems [3,11]. For the 2014/2015 season, however, the impact results are

generally lower than expected with only a few statistically significant results. For example, it was expected that the *Primary and Secondary school* or the combined set of *Primary school* and *Primary and Secondary school* pilot locations would yield significant impacts, as they included a similar program to that in the *Primary school* pilot areas. Looking at the boundary boxes in more detail (Figure 1) shows that of the 4 *Primary and Secondary school* pilot areas, Leicestershire and Salford both include substantial parts of nonpilot areas, which is likely to have biased their results and underestimated effect sizes. The lack of statistically significant results across all individual locations is possibly due to the sparsity of the Twitter data available. For example, the individual *Primary school* pilot areas did not yield statistically significant impact estimates (with the exception of Gateshead and South Tyneside, which did show significant results, but their preintervention correlations were below the 0.60 threshold), whilst the aggregation of all *Primary school* areas did.

The previous study by Lampos et al implemented a similar approach using Twitter and Bing data to assess the impact of the LAIV pilots during the 2013/2014 influenza season [9]. This study estimated the impact to be approximately 33% for the aggregation of all pilot locations based on Twitter data, which is more than double what was found in this study. The discrepancy between these results is most likely due to two factors. First, the pilot areas used for the 2013/2014 season in the present study are slightly larger than those in the previous one, as some of the reused pilot areas have been expanded. This issue particularly applies to the boundary boxes for Leicestershire and Essex, as the previous study only included parts of these areas. Second, apart from one control area (Liverpool), most of the previous control areas were part of the 2014/2015 pilot program, and thus not reusable. New control areas were therefore selected, which may explain the discrepancy in impact estimates. Nevertheless, given that both studies exhibited a significant impact, the methodology produces

qualitatively consistent results for the same influenza season, even when using a different set of control and pilot areas.

## Conclusions

There is a strong indication that the primary school age vaccination program has the potential to be an effective strategy in reducing influenza transmission in the general population. This notion supports the ongoing rollout of the campaign for primary school children. For a secondary school-only vaccination program offering the vaccine to just two-year cohorts (and not to all children of secondary age), there is no clear evidence of any population-wide effect. Both of these conclusions are in line with findings from previous studies and complement traditional surveillance sources in exhibiting community-wide effects of the LAIV pilot campaign [3,9,11,23].

Most current influenza surveillance schemes rely on established health systems. Although these schemes provide important information on health care-related burden of disease and potential reductions due to vaccine impact, several provide less direct insight into community-wide transmission. User-generated content from social media offers rapid access to a larger range of the population, which has the potential of including a wider community (ie, including those that do not seek medical attention) and thus offers a valuable complementary source for the surveillance and evaluation of public health programs.

## Limitations

There are several potential limitations in this study. Work is still needed to refine the methods used to deal with issues such as noise, model and data biases, and the fact that estimates from user-generated content are not directly based on actual ILI cases. More advanced natural language processing techniques may deliver more accurate results [24]. The choice of control areas requires further refinement; we are seeking an even geographical

distribution as well as an adequate distance from pilot areas to avoid regional biases, and to isolate the potential impact observed in pilot areas, respectively. Furthermore, the methodology is highly dependent on the quantity and type of user-generated data that is available, as this determines the accuracy and interpretation of the ILI rate estimates. The majority of Twitter users, for example, are between the ages of 15-44 years with a higher proportion situated in urban/suburban areas [25]. This factor may skew results towards illness in certain demographic groups. The current framework conducts ILI rate modeling by training on syndromic surveillance data (from RCGP), such that biases that are found there are also passed onto the models. Furthermore, even if these biases can be avoided, there is an issue that no definite ground truth exists to allow for a proper verification.

## Future Work

Future work could aim at moving towards unsupervised models that do not depend on traditional surveillance sources for training purposes. These models could produce their own, independent ILI indicators based solely on user-generated content with the potential of being able to tap into the bottom part of the disease population pyramid [10]. Inference of the demographics of users, such as age [26], socioeconomic status [27,28], or severity of disease [29] could be another focus of forthcoming work. Pebody et al showed that for both influenza seasons the impact of the pilot program was lower as influenza end-points of infection became more severe, which is an insight that the current modeling framework is unable to pick up on [3,11]. With suitable data access in the future, this framework has the potential of assessing the impact of intervention programs whose uptake is variable. The applicability of this framework extends beyond influenza, but across a number of health interventions, thereby allowing for a timely and potentially cost-effective complementary to the collection of traditional surveillance data.

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## Authors' Contributions

VL, IJC, RP, EY-T, and MW conceived the general concept of this research; EY-T provided the Twitter data; VL designed the models; VL and MW performed the experiments; MW and VL wrote the paper; all coauthors reviewed and commented on the manuscript, and approved the final version.

## Multimedia Appendix 1

The list of the 217 *n*-grams used as features in our predictive models for ILI rates.

[[PDF File \(Adobe PDF File, 50KB](#) - ]

## Multimedia Appendix 2

A table of the pilot and control areas chosen with their respective population size, distance to closest pilot areas, and geographical boundary rectangle corner coordinates.

[[PDF File \(Adobe PDF File, 76KB](#) - [jmir\\_v19i12e416\\_app2.pdf](#) ]

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## Abbreviations

**GP:** Gaussian Process

**ILI:** influenza-like illness

**LAIV:** live attenuated influenza vaccine

**MAE:** mean absolute error

**ONS:** Office for National Statistics

**PHE:** Public Health England

**RCGP:** Royal College of General Practitioners

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Original Paper

# Evaluating In-Car Movements in the Design of Mindful Commute Interventions: Exploratory Study

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## Abstract

**Background:** The daily commute could be a right moment to teach drivers to use movement or breath towards improving their mental health. Long commutes, the relevance of transitioning from home to work, and vice versa and the privacy of commuting by car make the commute an ideal scenario and time to perform mindful exercises safely. Whereas driving safety is paramount, mindful exercises might help commuters decrease their daily stress while staying alert. Increasing vehicle automation may present new opportunities but also new challenges.

**Objective:** This study aimed to explore the design space for movement-based mindful interventions for commuters. We used qualitative analysis of simulated driving experiences in combination with simple movements to obtain key design insights.

**Methods:** We performed a semistructured viability assessment in 2 parts. First, a think-aloud technique was used to obtain information about a driving task. Drivers (N=12) were given simple instructions to complete movements (configural or breath-based) while engaged in either simple (highway) or complex (city) simulated urban driving tasks using autonomous and manual driving modes. Then, we performed a matching exercise where participants could experience vibrotactile patterns from the back of the car seat and map them to the prior movements.

**Results:** We report a summary of individual perceptions concerning different movements and vibrotactile patterns. Beside describing situations within a drive when it may be more likely to perform movement-based interventions, we also describe movements that may interfere with driving and those that may complement it well. Furthermore, we identify movements that could be conducive to a more relaxing commute and describe vibrotactile patterns that could guide such movements and exercises. We discuss implications for design such as the influence of driving modality on the adoption of movement, need for personal customization, the influence that social perception has on participants, and the potential role of prior awareness of mindful techniques in the adoption of new movement-based interventions.

**Conclusions:** This exploratory study provides insights into which types of movements could be better suited to design mindful interventions to reduce stress for commuters, when to encourage such movements, and how best to guide them using noninvasive haptic stimuli embedded in the car seat.

**KEYWORDS**

mental health; stress; stress management; mindfulness; in-car experience; interventions; just-in-time interventions; autonomous vehicles; cars; driving; breathing; mindful movement

## ***Introduction***

### **Overview**

Stress affects people worldwide [1,2], yet opportunities to engage people in improving their stress management and coping skills are scarce, in part, because of lack of time and lack of appropriate spaces [3]. Commuting, which in the United States consumes roughly 1 hour per day [4], presents itself as a unique opportunity to deal with stress. Commute offers both a window of time and a dedicated space for the use of stress management interventions. We believe that mindful commute technology can offer a unique opportunity to embrace this problem. Prior research has shown people's preference for short movement-based (somatic) [5-8] and breathing interventions [9-12]. Behavioral interventions should be carefully designed to complement the cognitive and emotional demands of driving. Additionally, a side effect of movement is a potentially higher level of alertness, which could be beneficial for both driving performance and mental health.

Whereas modern seat design may tend toward finding usability solutions, ergonomics can be complemented with somatic or mindful approaches (see Cranz [13] for a thorough introduction). Mindful movement practices have been shown to benefit systemic wellness and mental health (see Clark et al [14] for a review). In this paper, we focus primarily on understanding how people respond to performing basic movements in the context of a typical car seat. We complement our analysis with an assessment of nonintrusive and nonverbal guidance to perform these movements. As a case study, we chose a simple set of interactions implemented on an array of actuators embedded in the back of the car seat. This investigation of basic movements and simple interactions lays the groundwork for future design of in-car mindful movement interventions. Additionally, it addresses the question of how an individual's movement in the car—be it configural or breath-based—might contribute to improving their well-being.

We performed a semistructured viability assessment to gain insights on the use of a car as the scenario for the design of ecologically valid mindful movement interventions. We divided our study in 2 parts: (1) an exploration of the effect of basic movements on people's perceived stress and driving performance and (2) the response to movement cues generated by vibrotactile haptic stimuli embedded in the car seat. In the first part, we explored a series of basic movements aimed at activating different parts of the torso, shoulders, head, and hips. We chose 12 movements that occur in practices that leverage mindful body dynamics, posture, and breathing. Some examples of such therapies are Hatha yoga [7] and yogic breathing [9,15].

Furthermore, alternative therapies, such as Feldenkrais [16] and the Alexander technique [13], leverage similar fundamental building blocks. We define perceived stress as the self-reported level of stress and perceived driving performance as a self-reported account of the difficulty of continuing driving while executing the movements. We correct all self-report metrics for individual differences by subtracting against an individual baseline and normalizing repeated measures.

We present insights drawn from participants driving under highway (simple) and city (complex) scenarios and using manual and autonomous vehicles. The second part of the study focuses on obtaining insights on the conceptual model and emotional response to vibrotactile patterns triggered by a haptic seat. The seat interface is made of a matrix of vibrotactile actuators (see Figure 1). Haptic patterns can be made by coordinating and combining individual actuators. Using the seat interface, we prototyped a range of patterns aimed at eliciting different basic movements. We discuss the adoption and usability issues of in-car haptic-guided movement.

### **Background**

#### ***Stress Management Interventions***

While driving, constant attention on the road is stressful, although it makes us better drivers [17]. As a matter of fact, the Yerkes-Dodson inverted-U relationship between arousal and performance [18] shows that there is an optimal arousal level conducive to higher performance. Too much or too little arousal drives diminishing results. Stress at work can be described as a high arousal level, many times linked to solving challenges or facing threats [19]. With mindfulness training, stress could be reduced by focusing attention on the present.

In a car, we can implement technology that helps balance stress and attention [20]. Multiple sensors and actuators could be placed in proximity to the participant to sense and learn from affect [21] and reduce cognitive load [22]. Beyond traditional psychophysiology sensors [23], the car could also sense affect through voice [24], movement [25], pressure [26], or breathing patterns [27]. Furthermore, effective stress technology interventions [5,28] could be enhanced using multimodal actuation [29] and leverage entertainment systems to increase engagement [20].

It is important to take into consideration the contextual elements that can transform effective interventions in stressors. For example, lack of time, social contexts, or simply lack of concentration can reduce the efficacy of stress interventions [28,30]. New technologies for positive behavior change [31], as well as novel stress management interventions [32], could be repurposed for the car.

**Figure 1.** Vibrotactile prototype with a matrix of vibration motors in a car driving simulator setup.

### Ergonomic and Mindful Movement

Cranz [13] challenges the way we have been using chairs and seats as a passive instrument. She discusses how ergonomic research focuses most of its efforts to adapt our environments to our bodies and tasks. She argues that we should design environments that support our body's natural inclination to move. Several studies have shown the physiological and mental gains obtained by engaging in movement in the office, even if it is just during breaks or intervals [33,34]. Complementary to this compulsory desire to move, Clark et al [14] describe the opportunity to use body movements as a way to engage the mind as well. They elaborate on the importance of understanding how a somatic approach to mindfulness takes advantage of the intrinsic value of the body as a conduit for awareness of the self and the environment. As described by Clark et al [14], the types of movements required to reach such levels of awareness and mindfulness are not necessarily high impact or strenuous. Quite the opposite is true; mindful movement often employs slow engagement of the body in repetitive patterns to allow for awareness of previously ignored but potentially high-impact differences. We propose that the opportunity to engage in mindful movement can be extensive when one is in a car, especially during the commute.

### The Commute as an Ideal Scenario for Mindfulness

Mindful commute technologies could have a 2-fold impact. On 1 hand, mindfulness supports self-regulation and self-compassion [15], and research has shown that even a few minutes a day can reduce social stress impact [35]. On the other hand, brief and regular mindful interventions can improve attention control [33], which in turn could improve driving skills. Furthermore, in-car commuters can take advantage of 3 special characteristics of the commute: quietness, privacy, and relevancy. The car is a quiet and consistent space, which is the preferred setup for mindful practice [34]. The car is a private yet portable space, rolling at 60 miles per hour; no human beings can walk to the door. The time of day when the commute happens is relevant in terms of mental health and stress management. For example, commuters returning home often times carry with them residual stress from constantly facing and solving challenges at work [36]. Alternatively, commuters on the way to work may experience anticipatory stress [36,37] associated with high expectations of productivity. The commute presents not only an opportunistic but an ideal scenario and time to foster mindful behaviors. We propose that engaging in regular and brief mindful movements can benefit people's health, improve their driving skills, and improve their perception of quality of living.

**Table 1.** Morphological box analysis of the design of in-car mindful movement interventions.

	Availability while driving	Relaxation potential	Movement range	Sensing potential	Actuation potential	Score (#highs/#lows)
Neck	High	High	High	Low	Low	1.5
Shoulders	High	High	High	Low	Low	1.5
Back	High	Low	Low	High	High	1.5
Hips	High	Low	Low	High	High	1.5
Lower extremities	Low	High	Low	High	Low	0.67
Upper extremities	Low	High	Low	High	Low	0.67

## System Design

### Body Movements

In this paper, we focus our attention mainly on configural and breath-based movements, which we call breathing exercises in the rest of the paper. For the former, we observe movements that engage key musculoskeletal regions such as the neck, shoulders, back, and hips. For the latter, we draw inspiration from yogic breathing [9,15], which describes posture and breathing exercises aimed at reaching higher levels of awareness. We complement our exploration by observing movements used in 2 alternative techniques: Feldenkrais [16], which aims at mindful comparison of variations on intentional movements, and the Alexander technique [13], which leverages guided visualizations that are conducive to posture improvement [14,36].

To choose the parts of the body to engage in mindful movement, we performed a simple morphological box analysis [38] (see Table 1). We compared key parameters necessary to design mindful movement interventions versus large musculoskeletal groups and performed a simple binary ranking on each parameter (high vs low).

It is easy to recognize that extremities are highly engaged while driving, but other musculoskeletal regions are less engaged. Therefore, extremities are less available to be engaged in movement-based exercises. Hips and back seem to have a lower potential for relaxation. Neck, shoulders, and extremities all get activated when a fight-or-flight stress condition occurs [2]. Neck and shoulders have a higher movement range because of their smaller size and their relative freedom (ie, not touching any car component). This same freedom makes them difficult to sense and actuate on. Body parts in touch with the car could have a sensor or actuator placed in their location. Although hands and feet have direct contact with the car, other parts of the extremities are more difficult to measure, as they do not touch parts of the car. The best musculoskeletal regions are picked based on a simple ratio between positive and negative counts (#highs/#lows). We picked the neck, shoulders, back, and hips.

To systematically explore a variety of movements, we used a functional anatomical bisection of the body in 3 planes—sagittal, frontal, and vertical—and the axes around which body parts rotate—sagittal, transverse, and vertical [39] (see Figure 2). Movements are described based on these planes and axes. Extension and flexion occur in the sagittal plane about the frontal axis. They measure the increment or decrement of an angle between 2 adjacent body parts. Abduction and adduction occur in the frontal plane about the sagittal axis. They measure the movement away from or toward the vertical axis. Rotation movements occur in the traverse plane and include any twisting motion. We complement these movement descriptions with elevation and depression, the movements in a superior or inferior direction.

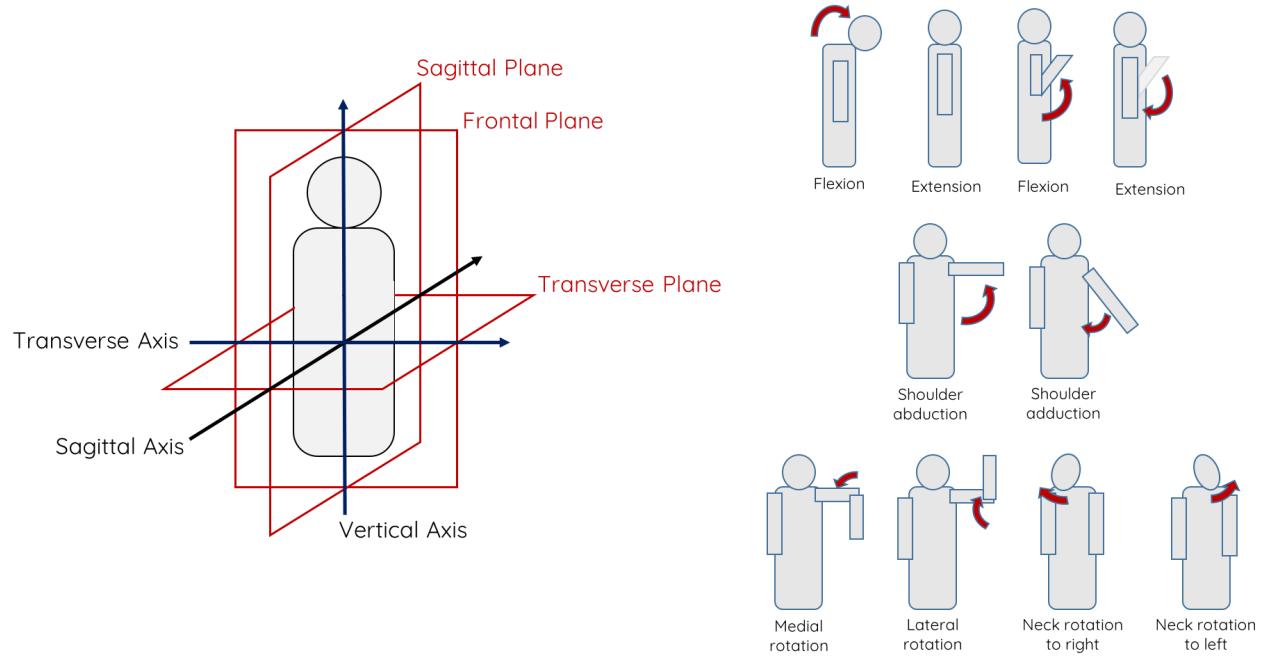
### Simulated Driving

Our experiments were developed in a simulator comprising a large 65-inch curved high-definition screen, the vibrotactile chair, and a computer running the City Car Driving software (Forward Development) [40]. We simulated an average automatic transmission car with wheel, pedals, and gear shift controls. People could adjust the seat position, the seat rest angle, and the pedal position. Direct controls to activate signaling lights and parking brake were provided. Figure 3 shows the contrast between manual and autonomous driving modes. Additionally, we evaluated 2 driving conditions: highway (or simple) and city (or complex). The former occurs on a highway with a moderate load of traffic flowing at the nominal maximum speed. The latter occurs in a city downtown area with multiple cars with moderate aggressiveness and a limited number of pedestrians.

### Vibrotactile Seat

The vibrotactile seat was designed using forty-one 50 dB,  $13000 \pm 3000$  rotations per minute, 2 V to 3.6 V linear resonant actuator vibration motors arranged in a grid covering an area of about  $20 \times 26$  inches (see Figures 1-4). Motors were 3 inches apart horizontally and 4 inches apart vertically (see Figure 4). The grid area was chosen after testing different body shapes. The separation between motors (3-4 inches) was chosen to guarantee clear 2-point discrimination [41,42] in the back.

**Figure 2.** Left: body planes (sagittal, frontal, and transverse) and axes (sagittal, vertical, and transverse). Right: types of movement: extension/flexion, abduction/adduction, and rotation.



**Figure 3.** Left: city driving condition. Right: autonomous condition.



**Figure 4.** Back rest with 41 vibrotactile motor grid arrangement.



**Table 2.** Twelve basic movements. Participants were required to keep eyes on the road only during the manual driving condition.

Movement and body part	Exercise and instruction
<b>Motor movements</b>	
Back and torso	M1—back arch (back flexion/extension): “Arch your back forward and backward.” M2—back twist (back vertical rotation): “Twist your torso with your head up. Grip steering wheel for extra support.” M3—side stretch (lateral back flexion/extension): “Stretch your back side to side.”
Head and neck	M4—head turn (head rotation): “Turn your head as if you were checking your blind spots.” M5—head bend (head flexion/extension): “Imagine a pigeon head nodding.”
Shoulder	M6—shoulder lift (shoulder elevation/depression): “Lift and then let drop your shoulders as if you were shrugging.” M7—shoulder join (shoulder abduction/adduction): “Join your shoulder blades—could be similar (but not identical) to arching back.”
Hip	M8—hip sway (hip elevation/depression): “Sway your hips left and right, similar to a dance move.” M9—deep breathing: “Inhale for 4 seconds, hold for 4 seconds, exhale for 4 seconds, hold for 4 seconds.”
Breathing exercises	M10—dragon’s breath: “Two vigorous short inhales + one long exhale.”
Visualization, breathing, and posture exercises	M11—deep sigh: “Imagine you have completed a complex task and do a deep sigh (Ahhhh...).” M12—loose neck: “Imagine the neck hanging free (such as a bobble head). Move head in all directions so that the back can lengthen and widen.”

## Interactions

### In-Car Movements

We picked basic movements as building blocks for mindful movement interventions. [Table 2](#) lists 12 different movements (M1-M12), which are aggregated in 3 main groups: motor, breathing, and visualization. Motor movements involve the back (M1, M2, and M3), aimed at performing rotations of the head and neck (M4, M5); the shoulders (M6, M7); and the hips (M8) along the 3 axes, transverse, sagittal, and frontal ([Figure 2](#)). Breathing exercises involve deep breathing (M9), which is performed by inhaling through 4 counts, holding the breath for 4 counts, and exhaling for 4 counts, and dragon’s breath (M10), which is performed with 2 high-energy inhales and a vigorous longer exhale. Visualization (M11 and M12) draws inspiration from the Alexander technique [[13](#)], which focuses on body posture. We asked people to imagine the completion of a task

associated with a deep sigh (M11) or to imagine that the neck is detached from the body and to move the head freely (M12). Participants were required to keep eyes on the road only during the manual driving.

### Vibrotactile Patterns

We designed a set of 8 vibrotactile patterns that correspond with the same number of in-car movements (see [Figure 5](#)) and observed whether participants could map these patterns correctly. Additionally, we inquired whether these patterns prompted them to perform any movements. To design these patterns, we used 2 haptic techniques: apparent tactile motion, which recreates the feeling of a continuous swipe when adjacent motors are activated with an overlapping window of a few milliseconds, and phantom touch, which creates the illusion of a tap, a single contact point when adjacent motors are activated in parallel [[29,43](#)].

**Figure 5.** Eight vibrotactile patterns used to study in-car movement elicitation.

Vibrotactile Patterns	Visual Description	Corresponding Movement
<b>Pattern A:</b> Swipe up (Apparent tactile motion), then down on whole back		<b>Back Arch (M1)</b>
<b>Pattern B:</b> Tap (Phantom touch) left shoulder, then right shoulder		<b>Back Twist (M2)</b>
<b>Pattern C:</b> Swipe down (Apparent tactile motion) left side, then right side		<b>Side Stretch (M3)</b>
<b>Pattern D:</b> Swipe left (Apparent tactile motion), then right on upper row (neck area)		<b>Head Turns (M4)</b>
<b>Pattern E:</b> Swipe up (Apparent tactile motion), then down on shoulder blades area		<b>Shoulder Lift (M6)</b>
<b>Pattern F:</b> Swipe left (Apparent tactile motion), then right on lower back		<b>Hip Sway (M8)</b>
<b>Pattern G:</b> Up sequence (x4), Stay at High Row (x4), Down sequence (x4)		<b>Deep Breathing (M9)</b>
<b>Pattern H:</b> Fast Swipe Up (Apparent tactile motion) + Fast Swipe Up + Swipe Down		<b>Dragon's Breath (M10)</b>

## Methods

### Participants

We recruited 12 participants: 6 undergraduate students, 3 graduate students, and 3 staff members. The ages of the 4 women and 8 men ranged from 19 to 37 years, with a mean of 26.4 years. Participants reported being more aware of surroundings while driving (mean 8.21) than while being a passenger (mean 5.36). Most participants (10/12) had limited experience with meditation, and half (6/12) practiced some form of breathing-based stress reduction. Most participants (10/12) had no experience with acupressure stress reduction, but most (8/12) had some experience with haptic stimuli from devices such as mobile phones or smart watches.

### Protocol

We explored reactions to movement using a semistructured assessment protocol divided in 2 parts: first we explored movement execution during the manual and autonomous driving conditions, and then we explored movement elicitation through a vibrotactile stimulus from the car seat. The experiment lasted on average 60 minutes. We used a pre- and a posttest questionnaire to obtain demographics and information on preferences and usability (see [Figure 6](#)).

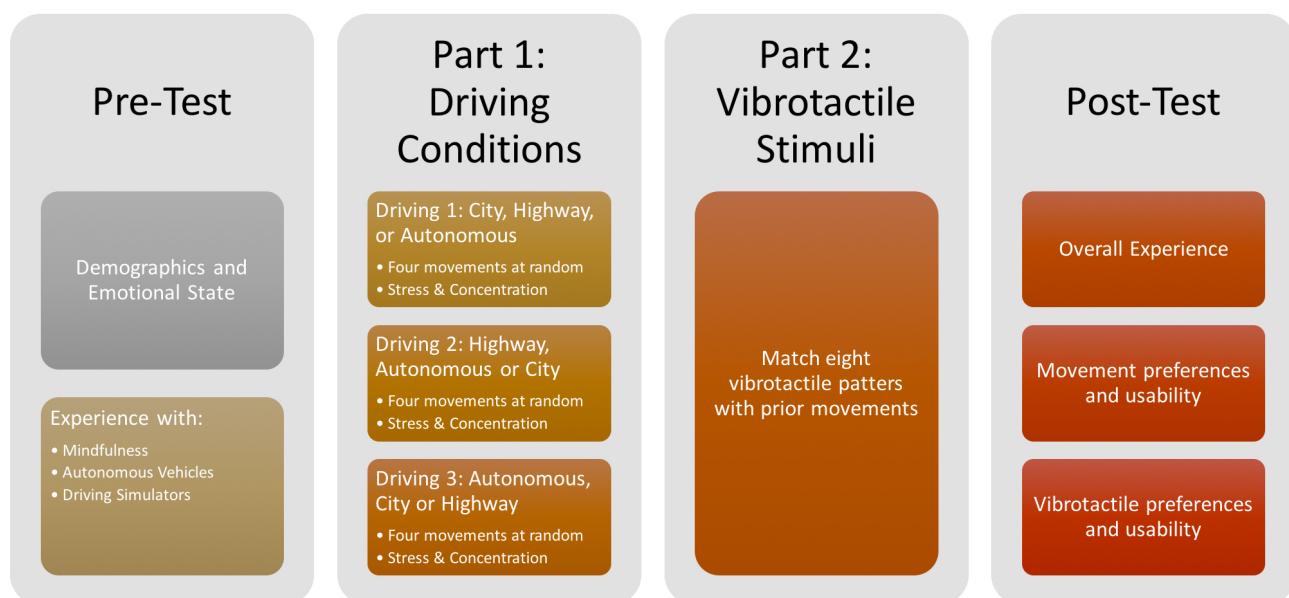
### Pretest

Upon arrival, in the preexperiment phase, participants were asked to complete a survey to obtain demographic information and their previous experience with stress management relaxation techniques, meditation, autonomous driving, simulators, acupressure relaxation, and haptic stimuli.

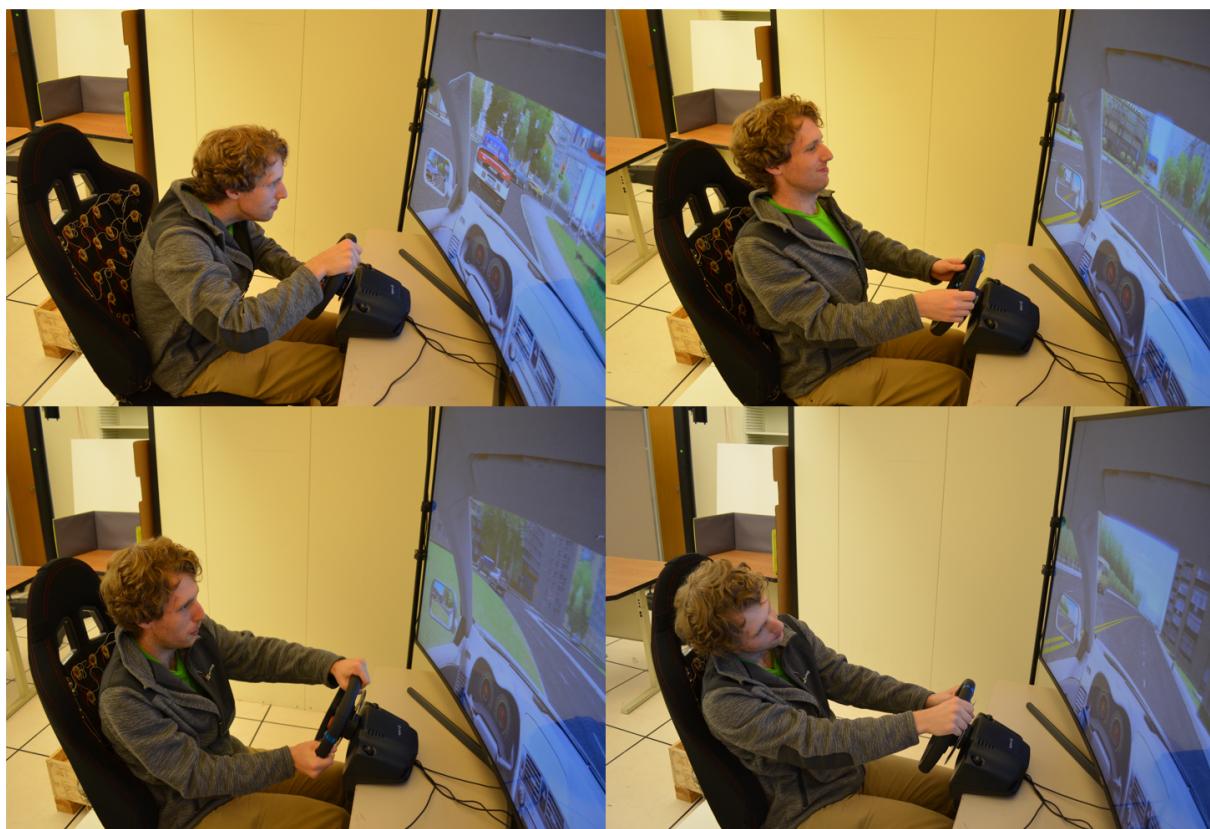
### Part 1: Driving Conditions

The participants were assigned randomly (Latin square) to each of the driving conditions: manual + city (complex driving), manual + highway (simple driving) or autonomous + highway and city. Participants verbally received 4 randomized in-car exercises ([Table 2](#)) per condition. During each round, we used the thinking-aloud technique to motivate people to talk about their stress and overall experience. After each round, participants were asked to report their favorite movements or exercises from the set and their level of stress and concentration. At the end of the study, they reported their top 3 most desired and least desired movements or exercises. [Figure 7](#) showcases a participant driving in a city responding to movement prompts requesting him to perform the following movements: arch his back (M1), join his shoulder blades (M7), perform a sighing visualization exercise (M11), and imagining that his head was not attached to his body (M12). [Figure 8](#) showcases a participant in the autonomous driving condition responding to prompts to twist her back and torso from side to side (M2), move her head forward and backward (M5), lift her shoulders up and down (M6), and breathe deeply (M9).

**Figure 6.** Semistructured assessment protocol consisting of 4 parts: pretest, part 1: movement execution, part 2: movement elicitation, and posttest.



**Figure 7.** Participant driving in a city condition while performing 4 guided movement instructions: arching back, joining shoulder blades, sighing, and imagining that head was not attached to body.



**Figure 8.** Participant in an autonomous vehicle condition while performing 4 guided movement instructions: twisting back, moving head forward and backward, lifting shoulders (shrugging), and deep breathing.



## Part 2: Vibrotactile Stimuli

During the vibrotactile stimuli stage, participants received 8 interactions in randomized order. They responded to the following 2 questions: “Would you agree that this stimulus wants to communicate X interaction?” and “In which driving conditions (city, highway, or autonomous), would you consider using it?”

### Posttest

During the postexperiment phase, participants responded to the following open-ended questions requesting to describe their experience, outline their preferences, express their reactions to performing movements in the car, and express their reaction to vibrotactile stimuli:

- Can you please describe your experience with the interactions?
- What was your experience like with the haptic seat?
- How did interacting with the haptic seat alter your mental state?
- If you could change anything about the haptic seat, what would you change?
- If you could change the autonomous interaction, what would you change?
- Would you consider driving this car in the future?
- Would you consider using a haptic seat in the future?
- Would you use it as a passenger in a regular car?

We analyzed these answers as well as the videos of thinking-aloud statements using a grounded theory approach [44] aimed at discovering key insights that would guide future research of in-car mindful movement interactions.

## Results

### Overview

We observed a preference for movements that are familiar and less awkward, such as breathing. Some people found unusual movements interesting and believed they may use them in the future. Counterintuitively, for some participants, manual driving

on a highway, instead of autonomous driving, seemed to be a condition for earlier adoption of movement-based interventions. It seems that the novelty of a car driving on its own did not allow some people to take full advantage of the movements. Perhaps our simulation of an autonomous car was more aggressive than expected, but, in general, people found themselves monitoring the behavior of the car, in case it made some serious mistake. The city condition seemed to have a cognitive and arousal load that limited the adoption of movement-based interventions.

### Descriptive Statistics

#### Preferred Movements and Exercises

In this section, we describe the most and least preferred movements and exercises (see Figure 9). Two-thirds of the participants (9/12, 67%) reported that they would do any exercise in autonomous mode. Half of the participants (6/12, 50%) preferred the following breathing exercises: deep breathing (M9), dragon’s breath (M10), and the deep sigh (M11). The rest preferred either the shoulder join (M6) or the hip sway (M8).

*[Deep breathing]...Nice. Most natural one. I do that in my meditation. [P5]*

*[Deep breathing]...Not distracting. Helps with boredom. [P1]*

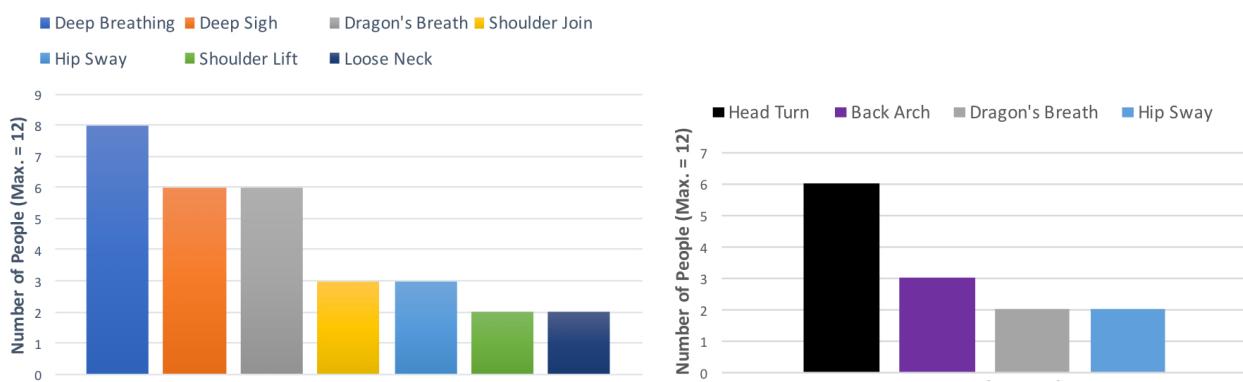
*[Shoulder join]...like this one. It doesn’t distract me from driving. It stretches my body. [P12]*

Participants disliked the head turns (M4) (6/12) because they “couldn’t see the road” (P2). However, one participant found it useful to check the mirrors as well as perform shoulder and torso movements.

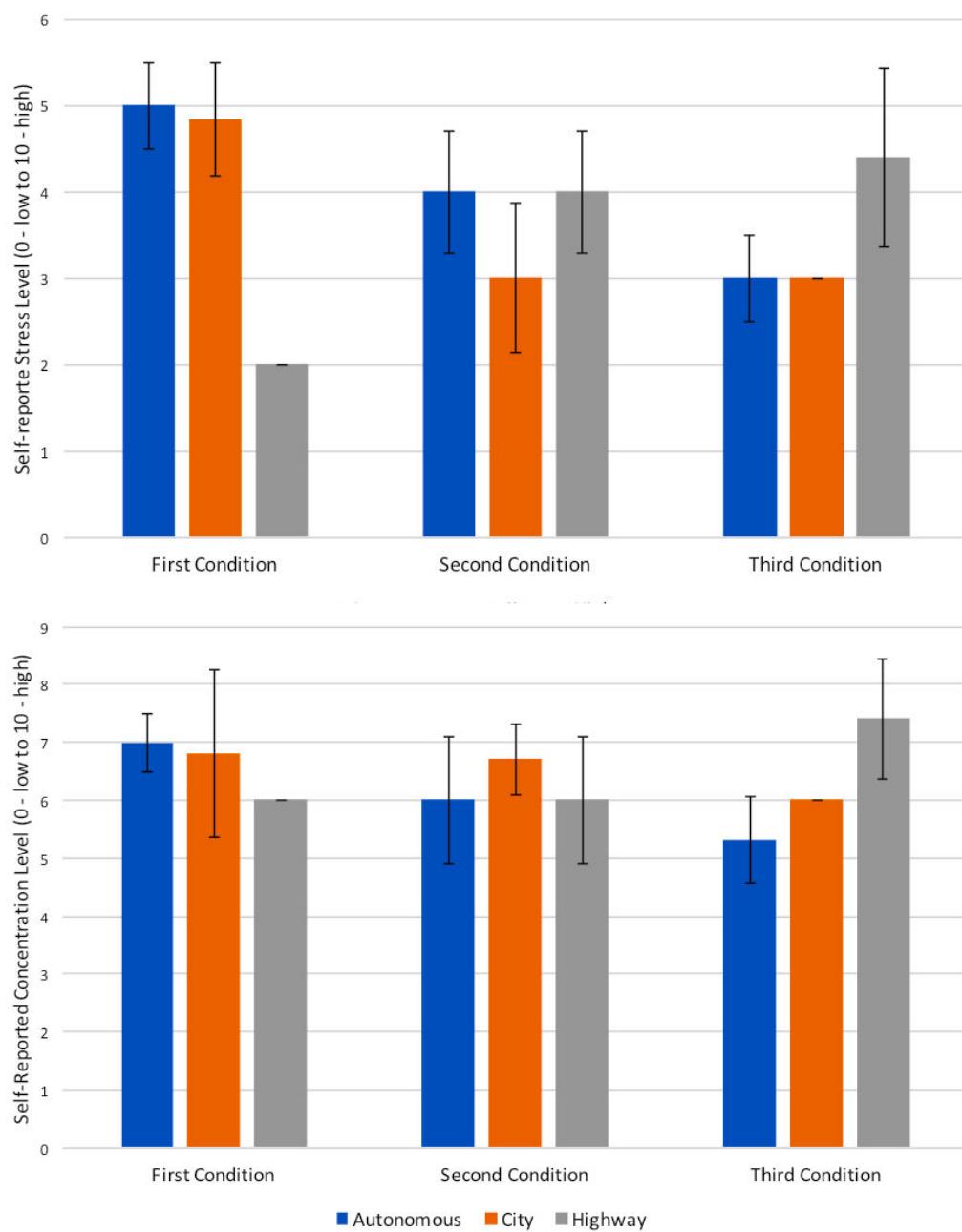
*It was pleasant. Refresh[ing] alert. Drawing me to look at my mirrors. [P3]*

Other participants did not like the back arch (M1) (3/12, 25%). One participant (P4) did not like any of the breathing exercises (M9, M10, and M11), and 1 (P8) found the dragon’s breath (M10) “strange.” Two participants (P9 and P12) disliked the hip sway (M8), as it messed with the use of the pedals.

**Figure 9.** Favorite and disliked exercises.



**Figure 10.** Stress and concentration self-reported metrics for each driving condition, city, highway, and autonomous (city and highway), versus the order in which they were presented in the study. Error bars represent standard error.



### Perceived Stress and Motion Sickness

As expected, participants reported differences in the perceived stress for each of the driving conditions, and the order seemed to influence this perception (see [Figure 10](#)). In the autonomous and city conditions, there was a tendency to have lower stress and lower concentration when these conditions were second or third. This could be because the benefits of not driving are perceived only after people get used to the simulator or the driving exercises. This could indicate a potential interaction effect between complexity and novelty, which should be studied in a controlled experiment. In the highway or simple condition, the tendency is reversed. Here it seems that people were more stressed and had higher concentration when this condition appeared last in the study. Perhaps this tendency can be explained by sheer fatigue. In summary, we believe that novelty

of the simulator, experiment, or driving condition could affect complex or new (autonomous) driving conditions, whereas fatigue could play a role in a simpler or less engaging condition.

People reported the autonomous condition to be more aggressive than expected. Some people described it as if in some cases the car were about to crash or make abrupt lane changes.

*I cannot keep my eyes on the road, I don't trust the car. [P2]*

Despite these differences, on average stress and concentration seemed to be comparable across all conditions (see [Figure 11](#)). These self-reported perception metrics contrast with personal preferences, as described in later subsections. Retrospectively, however, people found the system stressful. Some (4/12, 33%) found the system stressful in both conditions, and some (3/12,

25%) found it only stressful during the manual condition. However, on average people were not affected by the simulator. The total raw score (4.41) was below the average score (7.12) for a virtual reality experience with 157 patients reported by Bouchard et al [45]. Similarly, the nausea average score (1.91) and the oculomotor change (2.5) were both below the similar benchmark metrics [45] for nausea (3.51) and oculomotor change (2.86). People did not complain of motion sickness, although some reported fatigue.

## Participant Comments

### Movements Already Used in Car Situations

Some participants reported using some of the movements already in their daily driving experience. One participant (P12) performed back arching (M1) when fatigued; 3 other participants did different movements to reduce stress. Participant 8 did back twists (M2) and shoulder lifts (M6), participant 3 commonly performed side stretches (M3) and shoulder lifts (M6), and participant 10 did shoulder joins (M5). One participant (P10) practiced meditation and would like to do it in the car, whereas another (P5) practiced deep breathing (M9) but preferred not to do it while driving, as he felt it could be distracting.

### Best Time to Do Movements and Exercises

During manual conditions, the best option to move was during a simple driving condition (highway) in straight paths or while stationary—for example, in a traffic jam or at a stop light.

*I would do the sigh breath on the highway or at red lights because otherwise it consumes my concentration. [P5]*

*I won't stretch my hips while driving. Maybe in auto and at a red light. [P6]*

*It is okay. I don't feel secure doing this [back arch (M1)] while driving. [Distracting?] Yes. [Better when stopping?] Yes, so I am not distracted. [P115]*

In the city condition, drivers slowed down and waited for a straight path to avoid traffic or pedestrians. One participant performing deep breathing (M9) mentioned that it helped him keep his concentration.

*It [deep breathing] is easiest so far. It is calming. I can keep my concentration. [P3]*

Three participants mentioned that a deep sigh (M11) would be interesting if it was cued just after an incident has occurred.

We observed a paradoxical response with respect to the autonomous condition. When asked about their experience with the movements, several participants found the autonomous condition a good time to do exercises. However, half the people (6/12, 50%) described the aggressive nature of the autonomous car as stressful. For instance, although it was not required, a few participants reported feeling stressed trying to keep an eye on the road, precluding them from doing exercises.

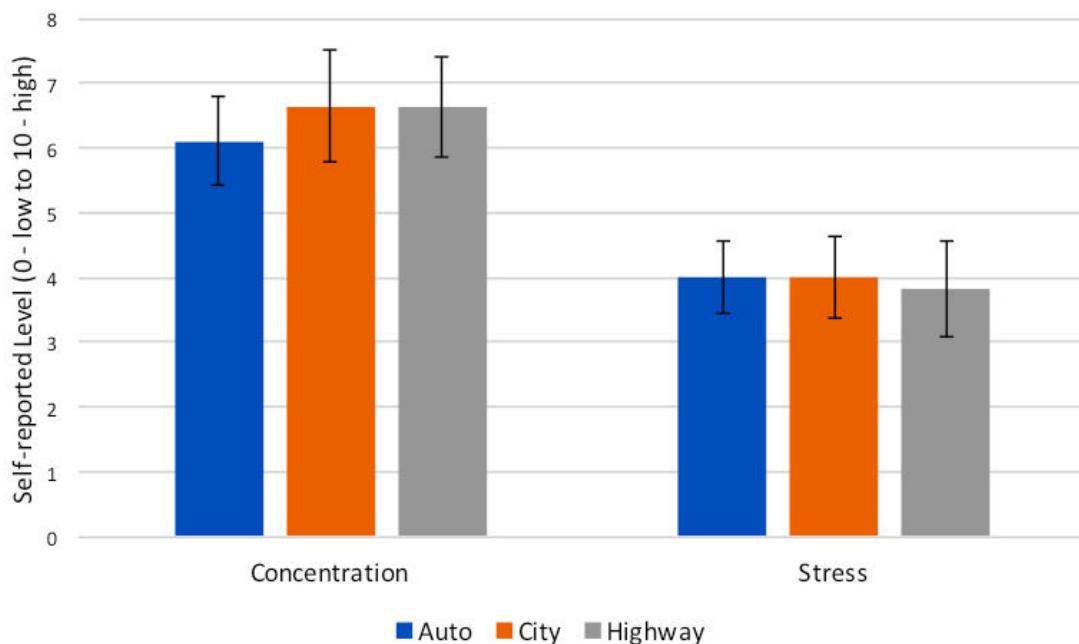
*The autonomous/last drive was the nicest, but most heart-wrenching. Less responsibility over driving feels better. [P1]*

Context could play an important role for some interactions. For example, some people reported feeling self-conscious while doing unconventional movements that felt silly, whereas others noted that adding music to an otherwise unconventional movement could help.

*[Back arch]...Weird, I cannot see. People will think I am in distress. [P9]*

Movements that reestablished symmetry and balance were appreciated.

**Figure 11.** Perceived average concentration and stress. Error bars represent standard error.



*[Deep breathing]...Reminds me to sit upright...I would like to be reminded to sit upright. [P2]*

However, 1 user refused to perform the head (M4) and neck (M12) movements while switching lanes or at a busy intersection.

*[Head bend]...It's a busy intersection and this is a distraction. [P7]*

*[Loose neck]...Impossible to do that and drive. I cannot stay in the lane. Stressful. [P7]*

### **Movements That Interfere with Perceived Driving Performance**

We evaluated how movements affected the participant's perception of driving performance. We focused on movements that seemed to interfere with their regular behaviors while driving, such as steering, visual attention, foot pressure, or other body-related interferences to a comfortable and safe driving experience. Most participants (10/12, 83%) felt that lateral movements would most likely interfere with visual coordination and steering because they made them move their arms and legs from side to side. For example, back twist (M2) led 1 participant (P6) to a complete stop. Side stretch (M3) affected the steering and reduced their field of view.

*[Side stretch]...I cannot drive straight. [P6]*

*I dislike the side stretch...because I couldn't look at the mirrors. [P3]*

Lateral exercises that involved movements affecting the legs, for example, hip swaying (M8), affected the foot pressure on the pedals and steering.

*Everything that moves the lower body affects the pedals. [P9]*

*Strange, it messes with my gas pedal. [P12]*

*Hard to move without releasing pressure on the pedal and moving the steering wheel. [P2]*

Although nonlateral movements were less likely to interfere with steering, 1 participant felt uncomfortable as the back arch (M1) did not allow him to constantly monitor his surroundings:

*Strange to do in a car. You lose your overview of the mirrors. [P4]*

Movements such as bending the head back and forth (M5) or sideways (M6) were reported by some (P6, P11, and P12) as distracting, affecting their use of glasses and in some cases even inducing some motion sickness.

*Cannot see the road, my glasses shift off my eyes. [P12]*

### **Movements That Complement Perceived Driving Performance**

Whereas lateral exercises tended to interfere with driving, forward and backward and vertical motions were reported by most (9/12, 75%) to have less impact on vision and steering.

*Forward [and] backward movements and deep breathing don't affect my control of the wheel. [P2]*

However, some people complained about the size of the seat, which limited movement.

*The seat is tight, I do not feel I am moving right. [P2]*

*It feels good. Strange because the seat is enclosing me when I go back. I do something similar in my car. [P12]*

Some participants (3/12, 25%) felt that lateral exercises were more appropriate when stopped at an intersection because not only was steering less of an issue but the lateral movements helped enhance their awareness of surroundings.

In contrast to motor exercises (M1-M8), deep breathing (M9) was reported by most participants (8/12, 67%) to work well because it did not physically affect steering and thus could be done even while turning. A few (3/12, 25%) found it challenging to keep count of their breaths while driving because it involved mental effort.

*I feel relaxed. Doing the exercises made me remember to breathe slowly. [P2]*

*I needed to put a lot of mental focus for the movements, maybe because I am not used to them. I will probably not do the breathing in a busy road like this though. [P3]*

Dragon's breath (M10) was considered by 2 users (P9 and P10) an energizing exercise that could be used to fight fatigue or boredom.

### **Exercises That Are Relaxing**

Deep breathing was considered by many participants (9/12, 75%) to be relaxing. People also found it relaxing to do head and neck (M4/M5) and shoulder (M6/M7) movements because they loosened spots that were often stiff or sore.

*Rolling shoulders is more soothing than dropping. I do it naturally during my commute, when I feel stiff. [P2]*

Almost half of the people (5/12, 42%) found the backward back arch (M1) ("antslouching") and hip sway (M8) relaxing and particularly useful during long drives. In contrast, the forward back arch (M1) felt unnecessary because it resembled slouching habits.

*I already do this [hip swaying] after a long trip. [P9]*

*[Hip sway]...wants to make me shoot my hips. I appreciate it in the highway condition; it reminds me to move cause I've been sitting for a long time. [P2]*

### **Coherence of Vibrotactile Patterns**

People could match 52% (50/96) of the vibrotactile stimuli to their intended movements either immediately or after 1 guess (see Table 3). Almost 1 in 5 participants (18/96, 19%) explicitly reported that the patterns made sense whereas only 9% (9/96) reported that they didn't make sense. Three movements were guessed correctly by more than half of the participants: back twist (M2) (7/12, 58%), side stretching (M3) (8/12, 67%), and deep breathing (M9) (7/12, 58%) (see Table 3). In general, people found these movements relaxing, good for stretching, or not distracting. In contrast, 2 movements were guess correctly

by less than half of the participants: dragon's breath (M10) (4/12, 33%) and back arch (M1) (5/12, 42%). The others reported being clueless on what the vibration was trying to tell them or felt the pattern was better mapped to an alternative movement. One of them reported that the vibration stimuli should have less intensity (P5).

The reasons why people did not guess correctly were varied (see Table 3, column 3). Some people guessed the intention of the vibrotactile pattern (such as sideways movement) but did not know which part of the body to move; others, despite liking the sensation of the patterns, mapped them incorrectly. Some complained that vibration should simply not be used as a stimulus. One person (P9) could hear the vibration because she was too short, and another (P3) found the vibrations signaling movement of the hips too high. Some found that patterns were similar and that made it impossible to distinguish them, whereas others just could not guess the intention and preferred to use it as a breathing guidance.

### Usability of Vibrotactile Triggers

Almost all participants (10/12, 83%) found the idea of at least 1 vibrotactile pattern appealing for autonomous or highway conditions.

*It depends on the driving mode. I would like to do my stretchy movements in auto. I don't feel like I am risking my personal safety in auto. [P1]*

Most people (11/12, 92%) did not express specific interest in using vibrotactile cues during the city (complex) driving mode. They believed using them might add an unnecessary additional cognitive load. However, some suggested performing deep breathing or shoulder movements while sitting at a red (traffic) light. One participant reported that the vibrotactile signal would

make her more alert and that might be helpful to remind her to check the mirrors.

*[Head sideways pattern]...It was pleasant...[a] refresh[ing] alert. Drawing my attention to look at my mirrors. [P3]*

Most people (8/12, 67%) found deep breathing (M9) either relaxing or pleasurable. Some may have preferred a slower pace.

*[Deep breathing]...Pleasing...I would like a slow vibe up my spine. [P3]*

However, 1 of the 8 suggested instead using air flow (coming from the air conditioning system) to signal when to breathe.

*Vibration is about movement not breathing for me. Use air flow to signify breathing instead of vibrations. [P11]*

The participants who did not like the deep breathing pattern thought that the vibrations were either too strong or that they signaled movement rather than breathing.

*I don't like it. It is vibrating my internal organs. [P2]*

*Vibrations that go up and down signify movement. Breathing vibes should be local. [P12]*

Although all users thought that doing some exercises in the car would be useful, only half (6/12, 50%) reported that they would use a haptic seat in the future in its current state. Only one-third (4/12, 33%) would use it frequently. Others (5/12, 42%) would use it if the following improvements were made: make the seat a different size (P2 and P8), make the vibration stronger (P4) or weaker (P12), improve the vibration patterns (P6), add a massage option (P9), and detect the right moment to use the vibrations (P12).

**Table 3.** Matching vibrotactile patterns and in-car movements.

Vibrotactile pattern	Correct	Reasons for guessing incorrectly
<b>Pattern B: tap left shoulder, then right shoulder.</b> M2—back twist	8/12	“...it is telling me to move sideways but head, shoulder, back [?]” [P11]
<b>Pattern C: swipe down left shoulder, then right shoulder.</b> M3—side stretch	8/12	“Like it. Hip twist.” [P3]
<b>Pattern G: swipe up, hold, swipe down, hold.</b> M9—deep breathing	7/12	“Vibration is about movement not breathing for me.” [P11]
<b>Pattern D: swipe left, then right on neck area.</b> M4—head turn	6/12	“I don't feel it but I can hear it.” [P9]
<b>Pattern E: swipe up and down shoulders.</b> M6—shoulder lift	6/12	“...It is very similar to others in that area.” [P5]
<b>Pattern F: swipe left, then right on lower back area.</b> M8—hip sway	6/12	“For hip twist put it lower...” [P3]
<b>Pattern A: swipe up, then down on whole back.</b> M1—back arch	5/12	“Shoulder shrug? I will just do breathing.” [P9]
<b>Pattern H: swipe up-up-down.</b> M10—dragon's breath	4/12	“Too many pulses for dragon's breath.” [P3]

## Discussion

### Principal Findings

This exploration of in-car movement reveals the potential for interventions that take advantage of movement and breathing techniques. Movement-based interactions should adapt to contextual cues, participant preferences, and road conditions. Specifically, movements that interfere with steering and pedal function, such as lateral flexions and extensions, should be avoided or only used during autonomous driving or when stopped. In contrast, neck or shoulder movements appeared to offer relief. Some even aided the driver by increasing lateral awareness at a stop light or breathing and sighing mindfully after an incident. Deep breathing may be a particularly suitable exercise because of its capacity to relieve stress without physically interfering with steering. Haptic patterns that are well modulated may off-load the cognitive burden of keeping count during deep breathing. On the other hand, some movements may require coaching to be safe during driving. For example, the lateral flexion and extension, although helpful in stretching the back and torso, may not aid driving. Participants should pick their preferred movement and how often it is prompted. New or unusual movements should be introduced gradually.

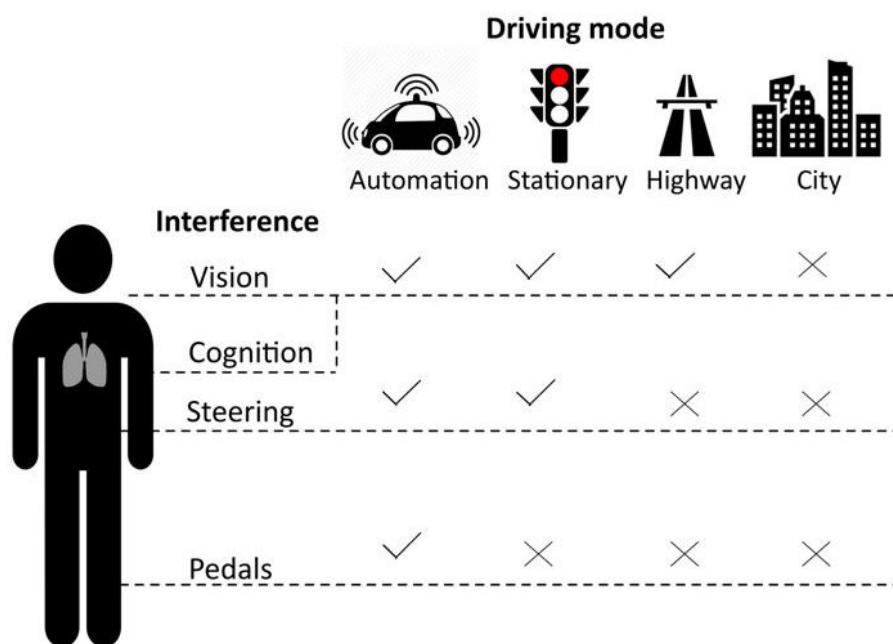
Overall, autonomous driving seems to be an opportunity to adopt more movement-based interventions in the car. However, movements should allow people to see the road, at least until they feel confidence in the automation system.

### Design Considerations

#### *Detecting Driving Modes Is Fundamental for a Safe System*

It is essential to consider the participant's driving mode (autonomous vs manual) and situation (highway vs city) before

**Figure 12.** Interferences caused by movement-based exercises during different driving modes.



### ***Vibrotactile Stimuli Should Be Clear and Customizable***

The intensity, location, and pattern characteristics of the vibrotactile stimuli should be configurable. Haptic signals must be strong enough to be discernible from external vibrations and subtle enough not to distract the participant. Body types must be considered for the layout of the motors. In our study, participants who felt shoulder vibrations too high or too low on their torso were rather confused. Patterns cueing motor movements should be clearly distinguishable from breathing ones. One participant suggested fixing the breathing pattern to 1 body location and having motor movements signal directionality with more ample patterns.

Patterns that guide movements should adapt to baseline conditions. For example, some people indicated a desire for a slower breathing pattern. One option would be to adapt the pace of breathing to the baseline (at rest) breathing rate. The breathing rate could be measured during a stationary condition before the drive. In any case, the pace should be overridable by the user.

Finally, vibrotactile stimuli should not be the only mechanism to stimulate movement. Pressure, air flow, or position could play a role. A multimodal interaction that mixes voice commands, sounds, and lights could perhaps be even more relevant.

### ***Nudging and Feedback Are Necessary for Correct Execution***

Some participants perceived vibrotactile patterns as mere notifications rather than movement guides. Some waited until a vibration pattern was completed to identify and perform the target exercise. To mitigate this, a haptic seat should have a simple nudging system. Scaling the system to better match the range of motion and timing the vibrations to match the duration of a movement will improve how participants follow and execute an instruction.

Feedback, in haptic, visual, or auditory form, may also be necessary for correct execution, especially while the participant is learning to use the system. Sensors such as depth cameras, pressure mats, and breath sensors can be used to evaluate participant movement and provide feedback to the participant and designer.

### ***Practitioners Are More Likely to Accept Mindful Interventions***

Participants who performed meditation or had previous experience with breathing techniques or stretching were more positive about certain movements during the study. Some expressed interest in having a vibration system that would remind them to breathe and stretch more regularly. On the other hand, nonpractitioners questioned the benefits of these movements and instead expressed their desire to use the haptic chair for massage. It is important in future systems to consider both types of participants. Participants who are unaware of the benefit of mindful movements are less likely to adopt a movement-based mindfulness system. A simple introductory set of interventions could be helpful in this case.

### ***Movements Must Comply With the Available Space***

Driver movement is limited by the physical constraints of the car, such as the steering wheel, the car seat shape, the door, and the seat belt. For example, when participants attempted to stretch their torso side to side they felt enclosed in the seat and had to pull their back away from the chair to avoid hitting the seat's edges. Similarly, participants felt physically restrained while performing hip sways and back arches. Motor movements in the car should not require a large space. Participants feel uncomfortable and are less willing to perform a movement if they cannot perform it correctly. Even though the seat belt is not designed to constrain the driver's movement, sudden movements can activate the belt safety functionality, holding the participant back. Movements that require people to press against the seat, such as those practiced in yoga or Feldenkrais, could be beneficial.

### ***Movement Execution Is Influenced by Social Perception***

Participants reported that most movements felt natural to them, and many already stretch their back and shoulders during their commute. However, movements such as the “bobble head” were socially awkward. This may preclude people from doing exercises even while at a red light, because people are more aware of the surrounding drivers. We suggest evaluating the choreographic aesthetics of the movements, adding a complementary stimulus such as music or providing a technical solution such as shading the windows for privacy.

### ***Future Work***

The aim of this paper was to incite and guide researchers and designers studying mindful movements to design and evaluate novel interventions for in-car practice for commuters. We have started engagement with instructors who have responded favorably to our request and with whom we plan to codesign specific in-car interventions for commuters. We aim to validate the efficacy of the interventions in simulator studies and a realistic environment (ie, in a real car). On the basis of the results learned from this study, we plan to focus on the following interventions.

#### ***Guided Movement***

We plan to work with yoga instructors and chiropractors to explore the use of the car seat space and haptic stimulation to design mindful movement interventions for commuters. Initial interactions reveal two types of movement sequences: subtle movement that could be used to deliver immediate results during the highway (simple) driving condition and higher range movement that can be used in the autonomous driving condition. We intend to use a pressure sensor and depth cameras to capture the movement and provide a closed-loop mechanism to enhance the learning process of drivers. Early observations show an opportunity to reduce range of motion constraints by performing movements that require the participant to press against the seat instead of freely moving any joint.

#### ***Guided Breathing***

We are currently using breathing rate sensors to detect the participant's rate and adapt the vibrotactile stimuli to the participant's breathing pace. We plan to explore short and long

sequences that can be used while waiting at a red light, cruising on a highway, or being stationary. We hope to explore the effects of deep and shallow breathing. The former could be used to reduce stress, whereas the latter could be used to recover from fatigue.

## Conclusions

In this paper, we introduce the basis for the design of novel movement-based mindful exercises. Through report and

observation, we establish preliminary design considerations for interactions that leverage mindfulness through movement and breathing techniques. We describe the use of vibrotactile stimuli produced by the car seat to guide and nudge these movements. Implications from our study provide insights into the movements that complement and interfere with driving and the best way to communicate these movements through haptics.

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## Conflicts of Interest

None declared.

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Corrigenda and Addenda

# Correction: Seeing the “Big” Picture: Big Data Methods for Exploring Relationships Between Usage, Language, and Outcome in Internet Intervention Data

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The authors of, “Seeing the ‘Big’ Picture: Big Data Methods for Exploring Relationships Between Usage, Language, and Outcome in Internet Intervention Data” (*J Med Internet Res* 2016;18(8):e241) would like to make changes to the following areas.

1. In the results section of the abstract
  - a. The first sentence of the results subheading in the abstract “On a measure of positive emotion, the average user improved 1.38 points per week (SE 0.01,  $t_{122,455}=113.60$ ,  $P<.001$ , 95% CI 1.36–1.41), about a 11% increase over 8 weeks.” **This should be replaced with:** “On a measure of positive emotion, the average user improved 1.38 points per week (SE 0.01,  $t_{122,455}=113.60$ ,  $P<.001$ , 95% CI 1.36–1.41), about a 27% increase over 8 weeks.”
  - b. The third sentence in the results subheading of the abstract “This estimate predicted that a given user would report positive emotion 1.26 points (or 1.26%) higher after a 2-week period when they used Happify daily than during a week when they didn’t use it at all.” **This should be replaced with:** “This estimate predicted that a given user would report positive emotion 1.26 points higher after a 2-week period when they used Happify daily than during a week when they didn’t use it at all.”
2. In the Study 1 Results section
  - a. The last sentence in the second paragraph in the Study 1 Results section “This suggests an average overall improvement of 11.04 points, or about 11%, over the course of 8 weeks.” **This should be replaced with:** “This suggests an average overall improvement of 11.04 points, or about 27%, over the course of 8 weeks.”
  - b. The second sentence in the fourth paragraph in the Study 1 Results section “This estimate predicted that a given user would report positive emotion that would be 1.26 points (or 1.26%) higher after a 2-week period when they used Happify daily than after a week when they didn’t use it at all.” **This should be replaced with:** “This estimate predicted that a given user would report positive emotion that would be 1.26 points higher after a 2-week period when they used Happify daily than after a week when they didn’t use it at all.”

predicted that a given user would report positive emotion 1.26 points higher after a 2-week period when they used Happify daily than during a week when they didn’t use it at all.”

a 2-week period when they used Happify daily than after a week when they didn't use it at all."

3. In the general Discussion section

- a. The last sentence in the second paragraph in the Study 1 Results section "This suggests an average overall improvement of 11.04 points, or about 11%, over the course of 8 weeks." **This should be replaced with:** "This suggests an average overall improvement of 11.04 points, or about 27%, over the course of 8 weeks."

While the errors do not impact the general findings of the original publication, remediation of these errors will add clarity to the interpretation of the results, as well as accurately represent the magnitude of the results.

The corrected article will appear in the online version of the paper on the JMIR website on December 19, 2017, together with the publication of this correction notice. Because this was made after submission to PubMed Central, the corrected article also has been re-submitted to PubMed Central.

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Corrigenda and Addenda

# Metadata Correction: Brain Activation in Response to Personalized Behavioral and Physiological Feedback From Self-Monitoring Technology: Pilot Study

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The authors of the paper “Brain Activation in Response to Personalized Behavioral and Physiological Feedback From Self-Monitoring Technology: Pilot Study” (JMIR 2017;19(11):e384), made a mistake in the final stage of proofreading. In the affiliations list, affiliation 2 was incorrectly worded as “National Centre for Sport and Exercise Science, Loughborough University, Loughborough, United Kingdom”. Instead, this affiliation should read “National Centre for Sport

and Exercise Medicine, Loughborough University, Loughborough, United Kingdom”.

The corrected article will appear in the online version of the paper on the JMIR website on December 21, 2017, together with the publication of this correction notice. Because this was made after submission to PubMed or Pubmed Central and other full-text repositories, the corrected article also has been re-submitted to those repositories.

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