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# How to Measure Costs and Benefits of eHealth Interventions: An Overview of Methods and Frameworks

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## Abstract

Information on the costs and benefits of eHealth interventions is needed, not only to document value for money and to support decision making in the field, but also to form the basis for developing business models and to facilitate payment systems to support large-scale services. In the absence of solid evidence of its effects, key decision makers may doubt the effectiveness, which, in turn, limits investment in, and the long-term integration of, eHealth services. However, it is not realistic to conduct economic evaluations of all eHealth applications and services in all situations, so we need to be able to generalize from those we do conduct. This implies that we have to select the most appropriate methodology and data collection strategy in order to increase the transferability across evaluations. This paper aims to contribute to the understanding of how to apply economic evaluation methodology in the eHealth field. It provides a brief overview of basic health economics principles and frameworks and discusses some methodological issues and challenges in conducting cost-effectiveness analysis of eHealth interventions. Issues regarding the identification, measurement, and valuation of costs and benefits are outlined. Furthermore, this work describes the established techniques of combining costs and benefits, presents the decision rules for identifying the preferred option, and outlines approaches to data collection strategies. Issues related to transferability and complexity are also discussed.

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## Introduction

Health care costs continue to rise. An important concern for patients, clinicians, and policy makers is whether it is possible to control costs while maintaining the quality of health care services [1]. The use of information and communication technology (ICT) in health care (eHealth) is proposed as a useful tool to increase efficiency, improve access, and improve the quality of care [2,3]. In this paper, eHealth is used as an umbrella term to include telemedicine, telehealth, telecare, telemonitoring, and all other uses of ICT to provide and support the delivery of health care services at a distance [2].

Today, the use of ICT to facilitate care over distance has been investigated in almost all clinical specialties [3]. A wide number

of benefits of eHealth have been reported; it can reduce time to diagnosis, improve equity of access for patients in remote areas, improve quality of life, and improve patient satisfaction [4]. In addition, eHealth has the potential to make health care workers more efficient and produce system benefits and technological spin-offs. For example, remote consultations and monitoring can deal with some of the nonurgent inquiries and thus potentially reduce office visits and other health care encounters, making the health provider more efficient [5,6]. Remote consultations can also replace or help avoid time-consuming face-to-face consultations, and for some patients, burdensome clinic visits [7]. In some situations, the use of eHealth technologies can address an unmet need for patients who might otherwise not have been in contact with their health care provider [6,8].

Another main argument for introducing eHealth services is its cost-saving potential. Some studies have found that monitoring patients at home avoids referrals and hospitalizations [9-11]. Access to relevant patient information and medical expertise to support local decisions can avoid expensive hospital visits [12]. Moreover, avoided referrals and visits have the potential to reduce patient costs associated with seeking medical help.

The cost-saving and efficiency potential of eHealth makes economic evaluation of central importance to the field [12]. Information on its costs and benefits is needed, not only to document value for money and to support decision making, but also to facilitate payment systems to support its uptake and large-scale adoption. In the absence of solid empirical evidence, key decision makers may doubt the effectiveness of eHealth, which, in turn, limits investment and its long-term integration into the mainstream health care system [13]. There is a growing frustration within health care organizations where small-scale research, pilot, or demonstration projects have failed to sustain or increase the level of use after the funding has ended [14]. Funding is often seen as the main constraint to sustaining and increasing the uptake of eHealth services. In order to secure funding, evidence of its positive effects is needed. Another constraint is the lack of health professionals' willingness to use eHealth [15].

Numerous systematic reviews have described the evidence base as inconsistent and have called for more research [4,12,16-19]. A more recent review of reported results is more promising. They found that 23% of the papers concluded that eHealth is effective/cost-effective, and 42% were less confident about the effectiveness/cost-effectiveness. The authors suggested that these initiatives were promising, but claimed that more research is needed [20]. However, a recent large-scale telehealth evaluation—the Whole System Demonstrator project—could not establish cost-effectiveness. This evaluation was designed as a cluster randomized controlled trial with more than 3000 patients. They found no significant improvement in health outcomes, found no reductions in service use assessed over 12 months, and they reported higher costs for the telehealth option compared to usual care [21-23].

Some studies report that eHealth is cost-effective, while others cannot make this conclusion. This inconsistency and a lack of solid comparable evidence on costs and benefits can be one of the reasons for the slow uptake of eHealth interventions. Without such evidence, it is difficult to estimate the economic impact in solid business cases [24]. The decision to implement eHealth systems is generally expensive and will have an impact on different health care providers, patients, and other stakeholders. Business cases can be used to argue and document why the different stakeholders should accept and sustain eHealth. A business case is concerned with the following primary question: What do the stakeholders get out of it? To be able to answer this question, we need demonstrable evidence of costs and benefits. If large-scale eHealth implementation warrants governmental investment, this will also require demonstrable benefits for the patients, providers, and society at large [3].

The lack of economic evidence and solid business cases can further be one of the reasons why the health authorities have been hesitant to develop financial models to support eHealth interventions. Without evidence of cost-effectiveness, incentives in the form of payment systems can be misleading and encourage health managers to invest in inefficient services that cost more and are less effective than the current alternative. On the other hand, without financial models that incorporate and compensate for the resources used to provide and operate eHealth interventions, the use of eHealth services will remain limited.

Should we adopt eHealth services without solid evidence that the benefits justify its costs? It is not realistic to make one general recommendation across different services and settings. The technology, the medical field, the service provided, and local context will decide important cost parameters, such as travel costs, the need for investment in infrastructure and technologies, and the opportunity costs of health professionals, thus making it difficult to compare results across evaluations. Moreover, it is not realistic to conduct economic evaluations of all eHealth applications and services in all situations, so we need to be able to generalize from those we do conduct. This implies that we need to use appropriate techniques and evaluation methods.

This paper aims to contribute to the eHealth research field by providing a brief overview of standard economic evaluation methodology and discussing challenges in conducting cost-effectiveness analyses in eHealth. This overview might be useful in structuring and conducting future economic evaluations of eHealth. This paper outlines basic health economics principles and frameworks and describes methodological issues regarding the identification, measurement, and valuation of costs and benefits. Furthermore, it presents the established techniques of combining costs and benefits, the decision rules for identifying the preferred option, and approaches to collecting the economic data. Issues related to transferability and complexity are also discussed.

## Health Economic Evaluation: Process and Techniques

### Overview

The proper goal of any health care system is to improve the value delivered to the patients [25]. An intervention provides high value if its health benefits justify its costs. Value is measured in terms of the patient benefits achieved per euro/dollar spent. To be able to assess the value, both costs and benefits must be measured at the patient level [25]. Measuring, valuing, and comparing costs and benefits are defined within the economic evaluation framework. Economic evaluation provides information about the costs and benefits of alternative options [26]. Alternative options refer to the different ways in which health care resources can be used to improve health [27]. The alternative option in eHealth evaluations is generally usual care or normal practice. Health care costs represent the value of resources used to produce health, such as equipment, staff, and consumables. Resources outside the health system (nonhealth resources) can also be used, such as the patients' time and the time of their families. Benefits represent all the

nonresource consequences and refer to the value of changes in health outcomes for the patients. These changes can be positive and improve health, or negative and worsen health. Benefits can also include the value of security, information, and access to health services and health information.

## Evaluation Techniques

There are two main alternative techniques for aggregating costs and benefits: cost-benefit analysis (CBA) and cost-effectiveness analysis (CEA). These two techniques differ with regard to how the benefits are valued. CBA values the health outcome and other nonresource benefits in monetary terms. CBA is rarely used in health care evaluations because of the difficulty in assigning a monetary value to health outcomes [27].

In CEA, the benefits are measured as health changes. CEA aims to identify where more benefits can be produced at a lower cost or where lower costs can achieve equal benefits. In CEA, the costs in monetary terms are compared to measures of health outcomes. There are two main types of CEA: standard CEA and cost-utility analysis (CUA). In standard CEA, the costs are compared to a one-dimensional unit of effect. This could be blood glucose levels, wound size, or symptom-free days. CEA is most useful for comparing interventions that address the same health problem. For example, if the objective of using eHealth technologies in diabetes care is to reduce and stabilize blood glucose levels, it seems appropriate for the end point to measure blood glucose levels. On the other hand, it can be difficult to interpret cost-effectiveness in terms of a specific cost per reduction in blood glucose.

In CUA, the outcome is measured as "healthy years" and valued as, for example, quality-adjusted life years (QALYs). QALYs were developed to compare health gains, and they are recognized as the primary metric for measuring health status in economic evaluations [26,28]. QALYs include mortality and morbidity in one single measure [28]. The advantages of using CUA over CEA is that CUA uses one generic measure of health improvement allowing direct comparison on the same scale of different types of health effects. Furthermore, a common unit of measure—money/QALYs gained—allows comparison across different health care programs. One of the criticisms of CUA relevant for eHealth is that the benefits might extend beyond health outcomes and include access, information, waiting time, time saved, and avoidance of burdensome travels.

In both CEA and CUA, the different measures of effectiveness can be compared to the costs in a cost per unit of effect ratio, or a cost-effectiveness ratio (CER). In CEA, this could be a cost per case detected, a cost per reduction in blood glucose levels, or a cost per symptom-free day. CUA allows comparison of interventions across different types of illnesses since all CUAs report results using the same term of costs per QALY gained. Both these analyses address the question of technical efficiency and examine the effects of at least two competing alternatives within a fixed budget. In this situation, the objective is often to establish which alternative maximizes the health outcome for a given cost or minimizes the costs for a given health outcome. Table 1 compares the aggregation of consequences between the different types of analyses.

**Table 1.** Methods for aggregating costs and consequences.

| Type of analysis | Aggregation of consequences |
|---|---|
| Cost-benefit analysis (CBA) | CBA measures the consequences in monetary terms expressed as a net benefit, that is, benefits minus costs. |
| | CBA answers the following question: Is the new eHealth service worthwhile? |
| Cost-effectiveness analysis (CEA) | CEA measures the consequences as health changes, for example, blood glucose levels, wound size, disability days avoided, and life years gained. |
| | CEA establishes which of two or more alternatives is less costly for at least as much benefit, more effective for equal or lower costs, or is more effective and more costly (in a cost per unit of effect). |
| Cost-utility analysis (CUA) | CUA measures the consequences as "healthy years," for example, as quality-adjusted life years (QALYs). |
| | CUA establishes which of two or more alternatives is less costly for at least as much benefit, more effective for equal or lower costs, or is more effective and more costly (in a cost per QALY). |

Cost-minimization analysis (CMA) is a form of economic evaluation comparing the costs of alternative interventions that have equal effects. CMA determines the least costly alternative after the evidence indicates no important differences between the options in health outcome. CMA is generally not viewed to be an appropriate method of analysis in prospective evaluations. It is impossible to establish no difference in the health outcomes of two or more alternative options in advance, and few studies have sufficient power to show equivalence of treatments. Furthermore, the analytical focus in economic evaluations should be on the estimation of the joint density of cost and effect differences, not the outcome difference alone [29]. However, the purpose of eHealth might be to provide consultations or episodes of care. If the objective is to establish the least costly mode of delivering one specific health service, a cost-minimization analysis can be a useful framework [30,31].

Economic analyses that only focus on costs and resource use are defined as partial economic evaluations. Partial economic evaluations, such as cost analysis, can contribute useful evidence to an understanding of the cost side of eHealth interventions, but such evaluations are not well-suited to make any conclusion about cost-effectiveness. Furthermore, avoided hospitalization and travels are not benefits in this context, but costs of the alternative usual care option. If avoided hospitalizations or travels are included as a benefit (eg, in a cost per avoided hospitalization rate), the analyst must ensure that these hospitalization costs are not included as costs of the alternative option as well.

## Decision Rules in Cost-Benefit Analysis and Cost-Effectiveness Analysis

The policy question in CBA is whether one specific health intervention or program is worthwhile. If the monetary benefits exceed the costs, that is, if the results have a positive net benefit (benefit minus cost), the project or intervention is then considered worthwhile. If there are two or more worthwhile projects, the one with the highest net benefit should be chosen [32].

Within the CEA framework, deciding the preferred alternative includes assessing the costs relative to the nonmonetary outcome. A dominant strategy occurs when one alternative is producing at least as many benefits as the alternative option at less cost or is producing more benefits at equal or lower costs. In these situations, the new intervention is cost-effective, and further analysis is not needed. A dominant strategy also occurs if the new intervention costs more and is less effective.

Alternatives can be considered cost-effective even if they generate more benefits and are more costly. In order to assess if these additional benefits are worth the extra cost, a cost per unit of effect ratio, or a CER, is calculated. This ratio must be compared with ratios from an alternative option in an incremental cost-effectiveness ratio (ICER) [28]. In a health system with limited resources, choosing the alternative with the lowest ICER will generate the most value for the money.

In summary, CBA tries to answer whether a particular intervention is worthwhile, that is: Do the benefits exceed the costs? In a CEA or a CUA, the aim is to decide which of two or more alternatives is less costly for the same output or more effective for the same cost. CEA and CUA implicitly assume that one of the options will be undertaken regardless of its net benefit [9].

# Measuring Costs and Benefits of eHealth

## Overview

There is no standard recommendation on the most appropriate measure of costs and benefits for economic evaluations [33,34]. A range of different methods have been used in the literature [34]. The perspective chosen for the economic evaluation will determine what types of costs and benefits to include, for instance, whose costs and benefits are of interest. These are normative issues and must be decided in each specific evaluation. From a societal perspective, resources in all sectors (eg, hospitals, other health care institutions, municipalities, governments, and patients) are included. If the evaluation takes a health provider perspective, only health provider costs are included, and other costs, such as travel and time costs for the patients, are excluded.

## Costing

### Overview

The costs of eHealth interventions can be divided into two broad categories: health care costs and nonhealth care costs. Direct health care costs refer to the physical health resources required to produce a specific eHealth service. Nonhealth care costs are those outside the health care sector, for example, time costs, such as production loss, lost leisure time, travel costs, and costs associated with child care.

### Health Care Costs

Health care costs are calculated in three steps [35]. First, the health resources are identified by estimating the different categories to be included in the analysis. These can be staff, consumables, equipment, installation, readmissions, emergencies, and overhead. Second, these different resource categories are measured using appropriate physical units, for example, type of staff, the amount of time spent on different activities, type of equipment, and number of readmissions and emergencies. Third, the resources are valued using appropriate unit costs. These can be based on hospital staff salaries, marked prices, or price weights based on national tariffs or charges.

The most commonly used method for measuring and valuing health care costs is to use the resource costing method [33]. This method involves collecting health resource use data from patient charts, hospital records, or from case report forms in trials or observational studies and then multiplying service use by price weights. There is no standard method for selecting appropriate resource use and price weights. One way is to break every cost item down into its underlying components, such as laboratory tests, provider time, and drug doses (ie, microcosting). Another more common method is to identify and count health care encounters, different types of service use, or bundles of service use, such as bed days, hospital stays, outpatient consultations, and general practitioner (GP) visits (ie, gross-costing). The decision as to which bundle of resource units to include in the analysis will depend on the ease of data collection and the availability of price weights [33,36]. The resource units used must also be able to identify a true cost difference if it exists. Many evaluations use a combination of the two costing methods [37].

Price weights can be collected from the health institutions involved or previously published studies, or they can be based on national tariffs. The price weights must be relevant for the health decision context. Center-specific price weights can be obtained from the financial departments at the health institutions. National unit costs can be based on diagnosis-related groups (DRGs) or health-resource groups (HRGs), and these are often publicly available in national reference cost schedules. A more detailed description of the different costing strategies can be found elsewhere [33,34,36,38].

Implementing eHealth as part of health service delivery often incurs equipment costs. These costs can be a one-time investment cost or a monthly or yearly leasing cost. A one-time investment cost can be spread over the expected lifetime of the equipment by calculating an equivalent annual cost using a discount factor. For example, assuming a 3-year lifetime of the eHealth equipment and a 3% discount rate, the annual costs are calculated by multiplying the one-time investment costs by 0.915 (discount factor). Discount factors can be found in discount tables available online. This annuitization method is recommended as it incorporates both the depreciation and the opportunity cost of capital [26].

### Nonhealth Care Costs

A societal perspective considers all costs, regardless of who incurs them. Nonhealth care costs are, for example, costs to social services, patients, family, and friends as informal care costs. Costs to employers as loss of production due to absence from work are also nonhealth care costs. These costs can be measured in clinical trials or observational studies. Private costs can include travel costs, out-of-pocket fees, and time costs. Time costs refer to the time patients spend seeking and receiving care and the time family members spend caring for a relative [26]. Time off work is measured as a productivity loss. Production costs are typically valued using gross wage rates. The friction cost method can also be used. Here, the basic idea is that the amount of production loss depends on the time it takes to restore the production level to where it would have been without the worker's absence [39]. The time costs most relevant for eHealth interventions are the patients' healthy time lost due to morbidity, assuming eHealth services improve health outcomes, and the time patients take off work to receive health care. There is no consensus on whether productivity costs should be included in cost-effectiveness analyses. Nor is there any consensus on how time costs should be valued if they are included [36,40].

### Benefit Assessment

Benefits refer to the effects that alternative interventions have on people's health. These nonresource benefits are often measured as health changes and can range from biomedical markers, to event-free time, or to more final health outcomes [38]. Outcome measures included can, for example, be blood pressure and glucose levels, cases of illness avoided, symptom-free days, successful treatments, lives saved, and life years gained. These measurements describe symptom relief and disease progression. However, the outcomes in economic evaluations should include the value patients place on the symptoms and the particular health state. The parallel is with service use on the cost side of the equation, where resource use, such as bed days and outpatient consultations, are not only counted, but also valued by measuring their costs [36]. One outcome measure that puts value on the health outcome is the QALY. The QALY includes quantity and quality of life and incorporates the valuation patients place on each health state. The QALY is the preferred outcome measure for many economists and reimbursement agencies [28,34]. The use of QALYs in telehealth studies has recently been reviewed and can be found in Bergmo [30].

Health outcomes are typically measured in clinical trials using case report forms, patient records, or patient-reported questionnaires at different time points during the trial. To estimate QALYs, the patients complete a generic health-related, quality-of-life (QoL) questionnaire with pre-existing preference weights (values). One of the most commonly used descriptive systems is the EuroQol-5D (EQ-5D) [41]. The EQ-5D is a recognized tool for describing different health states and is recommended in economic evaluation guidelines [26,28,42]. Another system is the Short-Form Health Survey-6D (SF-6D), which can be extracted from the 36-item Short-Form Health Survey (SF-36) and the 12-item Short-Form Health Survey

(SF-12) [43]. These quality weights are then combined with the longevity of the improvement. This involves multiplying the quality weights for the health states developed from the questionnaires with the duration of each health state experienced by the patients. For example, 1 year in full health is one QALY; 4 years in a 0.5 quality state is two QALYs. Details on the measurement and valuation of health outcomes are fully described elsewhere [36,38,44].

Other quality-of-life instruments, such as the SF-36 and the diabetes quality-of-life (DQOL) measure are also clinically relevant and can be used to ensure that the quality of life does not differ between the alternatives under consideration. However, the usefulness of QoL measures in economic evaluations is limited since they do not rank health states according to patients' preferences.

## Data Collection Methods

Data on costs and consequences can broadly be collected in two ways: alongside trials and observational studies, and from the existing literature [26]. New economic data can be collected alongside randomized controlled trials (RCTs), nonrandomized interventions, and observational studies. General issues in economic evaluations are common to all of these methods [26]. The RCT is often used as the gold standard for assessing the effectiveness of health interventions, but it is not always practical in eHealth research settings. Furthermore, strictly controlled trials are not well-suited for economic evaluations. Data collected alongside RCTs will provide reliable information on the particular intervention studied, but not regarding the intervention costs and how well it works for normal caseloads in usual practice. The trial context is usually very different from real-world settings, and conditions that will improve internal validity in randomized controlled trials will undermine the economic evaluation. One way to improve the usefulness of the economic evaluation is to modify the study protocol so it better reflects usual care. A naturalistic or pragmatic study design will increase the generalizability to other patients not included in the trial. A naturalistic study design is considered the gold standard for economic evaluation in health care [45].

Existing data and decision modelling is another approach that will increase the transferability of economic results across patients and settings. The data can come from clinical trials, observational studies, and meta-analyses found in the existing literature. Data can also be found in databases and administrative records. The existing evidence is brought together in a systematic way using decision models. Decision models estimate the expected costs and outcomes of different alternatives using the best available data from the literature. A well-designed model is essentially a tool that can simulate or mimic a clinical trial [46]. Models can simulate different scenarios by making explicit assumptions about the incidence, prognosis, duration, benefits, health-related quality of life, and costs. It allows one to investigate how costs and benefits might change if the values of key parameters in the model change. The purpose of modelling is not to make unconditional claims about the consequences of an intervention, but rather to reveal the relationship between assumptions and outcomes [47].

However, there are a number of valid concerns about using decision modelling [46,48]. The quality and validity of modelling studies are limited by the quality of the data used in the models. Several assumptions about the underlying disease, data, and mathematical relationship between probabilities and outcomes have to be made in modelling. These are all associated with uncertainty. The choice of one parameter over another can bias the model in favor of, or against, one particular strategy. Another challenge is that decision makers are unfamiliar with modelling. The actual calculations are often complicated and not included, and it can be difficult for decision makers to understand and thereby trust the results. To minimize uncertainty and improve transparency, the model inputs should be explicitly shown. Extensive sensitivity analysis will also help minimize uncertainty [46]. The need for, and value of, transparency is widely recognized and is cited in many guidelines [49]. See, for example, the International Society for Pharmacoeconomics and Outcomes Research (ISPOR) guidelines for good practices in decision modelling [47].

## Discussion

### Principal Findings

In this paper, I have provided a brief overview of evaluation frameworks and methodological issues regarding the collection, measurement, and valuation of costs and benefits with particular relevance to the eHealth field. The key issues outlined are as follows: useful frameworks for combining costs and benefits to support decision making, how to measure and value costs, what constitutes a useful benefit measure, how to measure the benefits, the important distinction between measurements and valuation, and approaches to data collection. The use of economic evaluation to assess the economic consequences of eHealth interventions requires adequate use of standard methodology. Transparency in reporting the methodology used is also important to ensure comparability across eHealth evaluations.

There seem to be particular challenges in conducting economic evaluations in the eHealth field. Several authors have pointed out that the heterogeneity of the eHealth field with high diversity in terms of specialties, technology, applications, objectives, context, and with many different stakeholders, can be a major challenge for economic evaluations [31,50]. The costs and effectiveness measures also tend to be multifaceted and involve a wide range of effects on patients, health care providers, and society [50]. To choose one outcome measure for the cost-effectiveness analysis can miss important benefits. It is also recognized that the measurement and valuation of some of the nonhealth consequences in eHealth research poses some difficulties. Typical benefits claimed for eHealth services that are difficult to value include improved access and a feeling of security, the value of information, and the transfer of skills. Furthermore, the QALY measure might be too incentive to capture the main outcome of interest in some of the eHealth studies [51]. When choosing an outcome measure, it is important to consider which method is most likely to be sensitive to the health change for the specific patient group included in the study. Disease-specific measures might be more sensitive to

the health change an eHealth intervention is likely to produce. Disease-specific measures have, for example, been used to calculate QALYs in heart disease and cancer patients [52]. Researchers are working on developing instruments that try to measure broader outcomes within an economic evaluation framework [34,53].

It is important to consider whether the costs and consequences of interventions and their alternatives can be generalized to other settings. For example, using mobile phones to monitor symptoms in diabetes is quite different from providing specialist consultations using video conferencing or using eHealth technologies to enable home dialysis. Generalizing results from one eHealth intervention to another is problematic. The service provided and the local context will decide the most important cost parameters, such as the need for investment in infrastructure and technologies, prices, and the opportunity costs of health care professionals. If the outcome measure used is disease specific and differs from the outcome expected, this will also limit generalizability. The rapid development of this field is also a major challenge for generalizability. It is obvious that the evaluation result of a particular eHealth service is of most value in the setting where the evaluation has been conducted. However, it could be possible to generalize results from one location to another if the differences are minor. Results from an eHealth intervention within the same specialty, using similar technology, with a similar cost structure, and a generic outcome measure (or similar disease-specific measure) can most likely be generalized to a different location with some adaptation. This will require the evaluation to be transparent regarding both the methods and the context [54,55]. For example, the result will be more transparent if the quantities of resources and cost weights (unit costs) are reported separately. Furthermore, how the nonresource consequences have been measured and valued should be specified, and costs and outcomes should be reported both at baseline and at every follow-up interval.

The costing in eHealth studies is generally more straightforward than measuring and valuing health outcomes. However, it can be a challenge to find appropriate cost weights and prices. Rapidly changing technology and prices can make results less useful for decision makers. Some have called for new research strategies to deal with the rapid changes in the eHealth field [56]. The importance of including the costs of supporting the health care providers in using the eHealth interventions should also be mentioned. These can, for example, be costs of training, help desks, and change management. Adequately funding all start-up and troubleshooting costs from the beginning can make the health care clinicians more able and willing to use the new interventions.

Whether to include production loss measured as time off work is also controversial. In practice, patients may already be off work because they are retired or because of their health condition, leaving the actual production loss unchanged. Also, health visits of a shorter duration might not represent production losses at all. Some types of work can be postponed until the person is back or one's colleagues can take over. The relevance of including time costs must be seen in relation to the perspective chosen for the evaluation. From a societal perspective, these costs are relevant, but they are not relevant

if the analyst takes a health provider perspective. The time costs are important in eHealth, and one should find a way to include these costs. One way is to report production loss separately in a sensitivity analysis, leaving it to the decision makers to decide whether to include them. Another way is to report the time (hours or days) lost or gained separately without putting a value on it [26].

Whether to use trial-based data or modelling studies in economic evaluation of eHealth should be seen in relation to the objective, the role of the study, and the viewpoint of those who are expected to use the results [57]. The evidence must be relevant to the decision context. If the objective is to establish the costs and consequences of one particular eHealth service in one specific setting, the most appropriate approach is a trial-based evaluation. If, on the other hand, the decisions require more evidence than can be obtained in one single trial, data from the literature and decision modelling can be used. Whether to use a trial or modelling also depends on the existing evidence base and the quality of these data, as we need high-quality information on specific parameters in different contexts to include in decision models.

eHealth interventions are considered complex interventions by the Medical Research Council [58]. eHealth interventions are often built up from a number of components that may act interdependently, and it may be difficult to assess the many interacting components. It can also be difficult to specify what the intervention is, what is most effective, or how to replicate the intervention beyond the original study [59]. The main challenge in evaluating complex interventions is the high variability in the outcome measures. The problem of specifying the intervention is less of an issue in economic evaluation. Economic evaluations compare the value of what goes in (the resources) with what comes out (the outcomes). If you can specify the inputs and outcomes, it is not necessary to understand how the intervention works [60]. However, most eHealth interventions can be considered complex interventions implemented in complex health care systems. Complex systems pose a bigger challenge for economic evaluations. Complex systems have the tendency to change, be self-organizing, be sensitive to initial conditions, and to behave in a nonlinear fashion [61]. It is important to recognize the differences between complex interventions and complex systems and to choose appropriate evaluation methods to deal with this dual complexity. See Shiell, Hawe, and Gold for more details on economic evaluation of complex systems [60].

## Conclusions and Future Work

eHealth has been around for many years, but basic issues in relation to sustainability and large-scale eHealth systems have not been resolved. The evidence base in relation to access, quality of care, and costs are growing. However, reliable evidence of costs and benefits for decision making is still limited. The lack of evidence on costs and benefits makes it difficult to estimate the economic impact in solid business cases. The different stakeholders need to know the financial consequences of scaling up eHealth services in their local setting. Without economic evidence and solid business cases, health authorities have been hesitant to develop financial models to support eHealth services and systems. Moreover, without payment systems that cover the costs, health providers will be hesitant to invest in and provide eHealth services to their patients. Despite a limited number of large-scale services and sparse evidence that eHealth is cost-effective, interest in eHealth continues to grow. This continuous interest might be explained by the promise of eHealth to solve some of the problems in health care.

What is the best way forward when it comes to sustaining and increasing the uptake of eHealth services? First, we should continue to analyze its effectiveness and cost-effectiveness in rigorous studies. We need to improve the decision information and available data for modelling and business cases. It is not realistic to conduct economic evaluations of all eHealth applications and services in all situations, so we need to be able to generalize from those we do conduct. This implies that we have to select the most appropriate research design, cost and benefit assessment methodology, and data collection strategy in order to increase the transferability of the results. Second, we should continue to look for viable business models that explain how to deliver and sustain eHealth services at reasonable costs. We also need to decide what role eHealth should have in mainstream health care. Without funding models that ensure providers will have reliable revenue to cover the costs, eHealth will continue to be limited to small-scale pilot programs.

## Conflicts of Interest

None declared.

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## Abbreviations

**CBA:** cost-benefit analysis
**CEA:** cost-effectiveness analysis
**CER:** cost-effectiveness ratio
**CMA:** cost-minimization analysis
**CUA:** cost-utility analysis
**DQOL:** diabetes quality of life
**DRG:** diagnosis-related group
**EQ-5D:** EuroQol-5D
**GP:** general practitioner
**HRG:** health-resource group
**ICER:** incremental cost-effectiveness ratio
**ICT:** information and communication technology
**ISPOR:** International Society for Pharmacoeconomics and Outcomes Research
**QALY:** quality-adjusted life year
**QoL:** quality of life
**RCT:** randomized controlled trial
**SF-6D:** Short-Form Health Survey-6D
**SF-12:** 12-item Short-Form Health Survey
**SF-36:** 36-item Short-Form Health Survey

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Original Paper

# Smoking Cessation Intervention on Facebook: Which Content Generates the Best Engagement?

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## *Abstract*

**Background:** Social media offer a great opportunity to deliver smoking cessation treatment to young adults, but previous online and social media interventions targeting health behavior change have struggled with low participant engagement. We examined engagement generated by content based on the Transtheoretical Model of Behavior Change (TTM) in a motivationally tailored smoking cessation intervention on Facebook.

**Objective:** This study aimed to identify which intervention content based on the TTM (Decisional Balance and 10 processes of change) generated the highest engagement among participants in pre-action stages of change (Precontemplation, Contemplation, and Preparation).

**Methods:** Participants (N=79, 20% female, mean age 20.8) were assessed for readiness to quit smoking and assigned to one of 7 secret Facebook groups tailored to their stage of change. Daily postings to the groups based on TTM Decisional Balance and the 10 processes of change were made by research staff over 3 months. Engagement was operationalized as the number of participant comments to each post. TTM content-based predictors of number of comments were analyzed and stratified by baseline stage of change, using negative binomial regression analyses with and without zero inflation.

**Results:** A total of 512 TTM-based posts generated 630 individual comments. In Precontemplation and Contemplation groups, Decisional Balance posts generated above average engagement (*P*=.01 and *P*<.001). In Contemplation groups, posts based on the TTM processes Dramatic Relief and Self-Liberation resulted in below average engagement (*P*=.01 and *P*=.005). In Preparation groups, posts based on Consciousness Raising generated above average engagement (*P*=.009). Participant engagement decreased over time and differed between groups within Precontemplation and Contemplation stages, but was independent of day of the week and time of day the content was posted to the groups. No participant baseline characteristics significantly predicted engagement.

**Conclusions:** Participants not ready to quit in the next 30 days (in Precontemplation or Contemplation) engaged most when prompted to think about the pros and cons of behavior change, while those in the Preparation stage engaged most when posts increased awareness about smoking and smoking cessation. Findings support tailoring intervention content to readiness to quit and suggest intervention components that may be most effective in generating high participant engagement on social media.

**KEYWORDS**

## Introduction

Smoking is the biggest behavioral risk factor for premature morbidity and mortality in the United States, and young adults are the age group with the highest smoking prevalence [1]. Young adults are also an underserved population given that few are reached by currently available evidence-based smoking cessation interventions [2,3]. Novel cessation interventions to reach young adults smokers are clearly needed.

Recent reviews of Internet [4] or social media interventions [5] for health behavior change and a meta-analysis of Web- and computer-based smoking cessation interventions [6] have concluded that these kinds of interventions can have small but significant beneficial effects (eg, effects of Web-based interventions on smoking cessation—relative risk 1.40) [6]. However, low participant engagement with online or social media interventions is a critical obstacle to improving health behavior outcomes [5,7,8]. Research on Internet-based health promotion interventions suggests that peer and counselor support, email/telephone contact, and regular updates to the website improve participant engagement [9]. Further, the results of a Web-based smoking cessation intervention suggested that a prescriptive message tone (vs a motivational tone), a dictated content viewing order (vs navigation autonomy), and email

reminders increased engagement among participants [10]. Compared to other online interventions, social media offer several potential advantages for participant engagement, since they can reach large audiences [11] that are already regular users and familiar with the platform. Further, social media are typically more interactive and require the user to engage more than traditional websites [12] and can promote social connectedness and sharing of experiences [13]. However, little is known about how characteristics of social media interventions are related to participant engagement.

The Transtheoretical Model (TTM) is a well-researched theory of health behavior change [14,15], conceptualizing the process of behavior change into five different stages: Precontemplation (not ready to change in the near future), Contemplation (intending to change within the next 6 months), Preparation (intending to change within the next 30 days), Action (achievement of intended change for less than 6 months), and Maintenance (achievement of intended change for 6 months or more) [15]. Additional dimensions of the TTM include Decisional Balance, or the balance between pros and cons of the problematic behavior and of behavior change [16], and 10 processes of change that aid progression from one stage to the next [17]. See Table 1 for an overview and definition for all TTM content used in the current study.

**Table 1.** Transtheoretical Model (TTM) content (Decisional Balance and 10 processes of change).

| TTM content | Definition |
| --- | --- |
| Decisional Balance | Pros and cons of behavior and behavior change |
| Counter-Conditioning | Substituting healthy alternative behaviors and thoughts for old behaviors |
| Consciousness Raising | Learning new facts, ideas, and tips that support the behavior change |
| Dramatic Relief | Experiencing negative emotions that go along with old behaviors and positive emotions that go along with new behaviors |
| Environmental Reevaluation | Realizing the negative impact of one's behavior and the positive impact of change on others |
| Helping Relationships | Seeking and using social support to make and sustain change |
| Reinforcement Management | Increasing rewards for healthy behavior change and decreasing the rewards for old behaviors |
| Stimulus Control | Removing reminds/cues to engage in old behavior, and using cues to engage in the new healthy behavior |
| Self-Liberation | Making a firm commitment to change |
| Social Liberation | Realizing that social norms are changing to support new behavior |
| Self-Reevaluation | Realizing that the behavior change is an important part of one's identity |

Previous research suggests that processes of change focused on cognitions, affects, and evaluations are more appropriate in earlier stages, while commitment, conditioning, and stimulus control are more appropriate in the more advanced stages [18]. The TTM and its components are frequently used to design Internet-based interventions to promote health behavior change and TTM-based interventions were found to result in significant effects on health-related behaviors including smoking cessation [4,19,20]. With regard to smoking cessation interventions on Facebook, mixed-methods formative work suggested that an intervention tailored to readiness to quit smoking would likely appeal to the widest range of young adult smokers [21]. Yet, there is no evidence as to how social media intervention content

should be tailored to best engage young adult smokers who are in different stages of change.

Engagement in Facebook interventions to change health behavior has previously been operationalized as posting, commenting, or liking of content [22,23], and previous studies also reported that engagement in social media interventions more generally tends to decrease over time [23-25]. In order to develop effective social media interventions for smoking cessation, it is important to know how intervention content should be tailored to produce high participant engagement. However, to our knowledge, no study has examined how intervention content is associated with participant engagement in a smoking cessation intervention delivered through Facebook. Intervention engagement is a meaningful outcome to study,

since results from behavioral smoking cessation counseling studies suggest that abstinence increases with overall contact time (up to 90 minutes) as well as with number of treatment sessions [26]. With regard to digital health interventions, one previous study suggests that higher engagement in a Web-based smoking cessation intervention was positively associated with smoking cessation outcomes [27].

In the context of a feasibility trial of the Tobacco Status Project, a Facebook smoking cessation intervention for young adults, this study aimed to identify which intervention content based on the TTM generated the highest engagement among participants in pre-action stages of change (Precontemplation, Contemplation, Preparation).

## Methods

### Procedure

Recruitment efforts included a paid Facebook ad campaign conducted between June and August 2013 actively targeting young adults 18-25 years old, with details reported previously [28]. When meeting eligibility criteria and consenting to study participation, participants were assigned to private (secret) Facebook groups (invitation only, group and content not visible to anyone but participants) of varying sizes tailored to readiness to quit smoking [14,15]. Upon completion of the baseline assessment, participants were individually randomized to an incentive condition based on the following criteria: (1) those in the "personal" incentive condition were told they would receive

a US $50 gift card if they commented daily on all 90 posts to their secret Facebook group, (2) those in the "altruistic" incentive group were told they would be given a US $50 gift card to the Just Give website to donate to a charitable organization of their choice if they commented on all 90 posts, (3) those in the no incentive condition were not given an incentive to comment. Upon completion of the intervention, data from secret groups were extracted from Facebook through the Facebook application programming interface (API) [29] for analysis.

### Intervention

All participants were invited to a secret Facebook group tailored to their stage of change: Precontemplation (ie, Not Ready to Quit); Contemplation (ie, Thinking About Quitting); or Preparation (ie, Getting Ready to Quit). Research staff made one daily Facebook post for 90 days tailored to their readiness to quit to each group. Posts were adapted from US Clinical Practice Guidelines [26] and Transtheoretical Model skills for smoking cessation [30]. Within each stage of change, TTM content included posts related to Decisional Balance or the 10 processes of change, according to TTM theory. For example, posts focusing on Decisional Balance were used in two of the three groups (Precontemplation and Contemplation) but focused more on eliciting the pros of change in Precontemplation and eliciting both pros and cons of change and reducing cons in the Contemplation groups, according to TTM theory. Table 2 gives an overview of the TTM content used in the different stages of change.

**Table 2.** Descriptive statistics of Transtheoretical Model (TTM) posts.

| TTM content | Total number of posts | Used in stage[a] | Average number of comments | SD | Range |
|---|---|---|---|---|---|
| Decisional Balance | 48 | PC, C | 3.00 | 3.00 | 0-13 |
| Counter-Conditioning | 27 | C, P | 0.74 | 1.77 | 0-9 |
| Consciousness Raising | 137 | PC, C, P | 1.21 | 1.79 | 0-11 |
| Dramatic Relief | 60 | PC, C | 0.68 | 1.30 | 0-6 |
| Environmental Reevaluation | 19 | PC, C | 2.00 | 2.29 | 0-8 |
| Helping Relationships | 18 | C, P | 1.22 | 1.66 | 0-6 |
| Reinforcement Management | 50 | C, P | 0.46 | 0.68 | 0-3 |
| Stimulus Control | 44 | PC, C, P | 0.54 | 0.81 | 0-4 |
| Self-Liberation | 30 | C, P | 0.90 | 1.64 | 0-7 |
| Social Liberation | 57 | PC, C | 1.79 | 2.70 | 0-16 |
| Self-Reevaluation | 22 | PC, C, P | 1.05 | 1.59 | 0-7 |

[a]C: Contemplation; P: Preparation; PC: Precontemplation.

Posts had a mix of imagery, text, and Facebook poll formats. Sample posts can be found in Multimedia Appendix 1. Post order was randomized, but the same order was used for all groups within each stage of change. When posts clearly referenced previous posts (eg, the post of the day before), these were randomized as blocks.

### Participants

Participants were 18-25 years old, English literate, and reported having smoked at least 100 cigarettes in their lifetime, currently smoked at least 3 days per week, and used Facebook at least 4 days per week.

## Measures

### Engagement

Engagement was operationalized as the number of comments a Facebook post received (regardless of the number of individuals commenting). Comments were used as a primary measure of engagement instead of likes or posts because participants were instructed to comment on study posts every day.

### Participant Baseline Characteristics

At baseline, demographic information included age, gender, race/ethnicity, education, and household income. We also assessed average number of days smoking per week (from which we computed percent smoking 7 days per week as "daily") and presence of past year quit attempt (y/n) [31]. Time to first cigarette upon waking (<30 min or >30 min) was used as a measure of dependence [32]. Smoking goal was assessed with one item with seven response options, categorized into three categories: No goal, controlled or reduced smoking, and abstinence [33]. The Tobacco Smoking Stages of Change Questionnaire [15] assessed motivation to quit at baseline, categorizing smokers into one of three pre-action stages of change. Upon completion of the baseline assessment, participants were individually randomized to three incentive conditions: (1) personal incentive, (2) altruistic incentive, and (3) no incentive (see Procedure section).

### Transtheoretical Model Post Content

Posts were classified according the TTM Decisional Balance or one of ten processes of change (see Table 1).

### Post Features

Features of Facebook posts included group membership (one of seven Facebook groups), time of day (1 hour intervals), and day of the week each post was uploaded onto Facebook.

## Statistical Analysis

The relationship between engagement (total number of comments across all groups) and participant baseline characteristics and incentive group were examined using *t* tests. These analyses were based on total engagement throughout the intervention (718 total comments on posts based on TTM as well as other posts). To analyze our main research question of which TTM posts generated the best engagement, only the subset of posts that were based on TTM decisional balance and processes of change were selected (630 comments) and engagement was regressed on TTM post content. Since intervention posts were tailored to readiness to quit, these analyses were conducted separately by baseline readiness to quit smoking (Precontemplation, Contemplation, Preparation). In order to adequately address the over-dispersed outcome variable number of comments, negative binomial regression analyses were used [34], since fit indices suggested a better fit of negative binomial models compared to Poisson models. In the analyses for the Contemplation and Preparation stages, these models were additionally adjusted for excess zeros [35], which improved the model fit compared to negative binomial models without zero-inflation. Zero-inflated models estimate two equations simultaneously, one for the count model and one for the excess zeros. These excess zeros were regressed on the running number of the intervention day the individual post was made to the Facebook group (1-90; compared to posts with at least one comment). The rationale behind this was that as participants progressively disengaged with the Facebook intervention over time, a post made at a later time did not have the same likelihood to elicit engagement, as it had a lower chance to be read in the first place. The predictor TTM post content was dummy coded, and effect/deviation coding was used to estimate the difference in engagement between each individual theory post and the overall/average engagement (the mean of the outcome variable for a given level of the predictor was compared to the mean of the outcome variable for all levels of the predictor variable). The following covariates related to Facebook posts were examined: Group membership (one of seven Facebook groups), time of day (1-hour intervals), and day of the week each post was uploaded onto Facebook. These covariates were analyzed using analyses of variance (ANOVAs), and only significant variables were included in the final regression models. All analyses were conducted using Stata 11.2 [36].

## Results

### Sample Description

Of the 586 respondents who met criteria to participate, 230 signed online consent, and 79 completed a baseline assessment and were assigned to one of seven Facebook groups (number of participants mean 13, SD 5, range 7-22). Participants had a mean age of 21 (SD 2), 20% (16/79) were female, 80% (63/79) non-Hispanic white, and 18% (14/79) non-heterosexual. The median household income was between US $21,000 and $40,000, and 28% (22/79) reported a household income >US $60,000. Well over half (48/79, 61%) reported at least some college education while 56% (44/79) were employed. Of all participants, 75% (59/79) smoked daily and for an average of 3 years (SD 1). Mean age of initiation was 14 (SD 3) with regular smoking by age 16 years (SD 3), on average. The sample averaged 12 cigarettes/day (SD 8), 52% (41/79) smoked within 30 minutes of waking, and 57% (45/79) had made a past year quit attempt. With regard to their smoking goals, 30% (24/79) reported no goal, 60% (47/79) reported a reduction goal, and 10% (8/79) reported an abstinence goal. Of the 79 participants at baseline, 33 participants (42%) were in the Precontemplation stages of change, 36 were in Contemplation (46%), and only a minority of 10 (13%) were in Preparation. Last, 47% (37/79) of participants received no incentive for commenting daily, 28% (22/79) received an altruistic incentive, and 25% (20/79) received a personal incentive. Incentive conditions were equally distributed across stages of change (Precontemplation: 27% altruistic, 24% personal; Contemplation: 28% altruistic, 25% personal; Preparation: 30% altruistic, 30% personal).

The entire sample of 79 participants made a total of 718 individual comments to any intervention content. Of all 79 participants, 48 (60.8%) commented at least once and contributed an average of 15 comments per participant. Further, 42 (53.2%) of participants commented more than once. The 21 users with the most comments (26.6% of the entire sample)

accounted for 593 comments (82.6% of all comments). No participant baseline characteristic significantly predicted intervention engagement (results not shown).

## Intervention Predictors of Engagement With Transtheoretical Model Posts

In order to analyze which TTM content generated the highest engagement, only posts based on TTM theory were selected for analysis. This resulted in the selection of 512 posts, which generated 630 comments. Content was posted between 8 am and 6 pm, and a majority of posts (73%) were made between 1 pm and 3 pm (all Pacific Time). Timing of the post (time of day and weekday) was not significantly associated with engagement.

Time of day reached marginal significance (time of day: $F_{9,502}=1.9$, $P=.05$; weekday: $F_{6,505}=0.7$, $P=.67$). Table 2 displays descriptive statistics according to the TTM-based posts. Of all 512 posts, 268 (52.3%) received at least one comment. The 125 posts with the most comments (24.4% of all posts) received 487 comments (77.3% of all comments). As can be seen in Figure 1, intervention engagement with TTM posts decreased over time in each of the seven Facebook groups (range of correlation coefficients from -.81 to -.55; all $P<.001$) and the number of comments varied by group ($F_{6,505}=29.7$; $P<.001$). Thus, a dummy variable for Facebook group was the only covariate we subsequently included in all further analyses.

**Figure 1.** Engagement with Transtheoretical Model (TTM) posts in each of the 7 groups over time (C: Contemplation; P: Preparation; PC: Precontemplation).
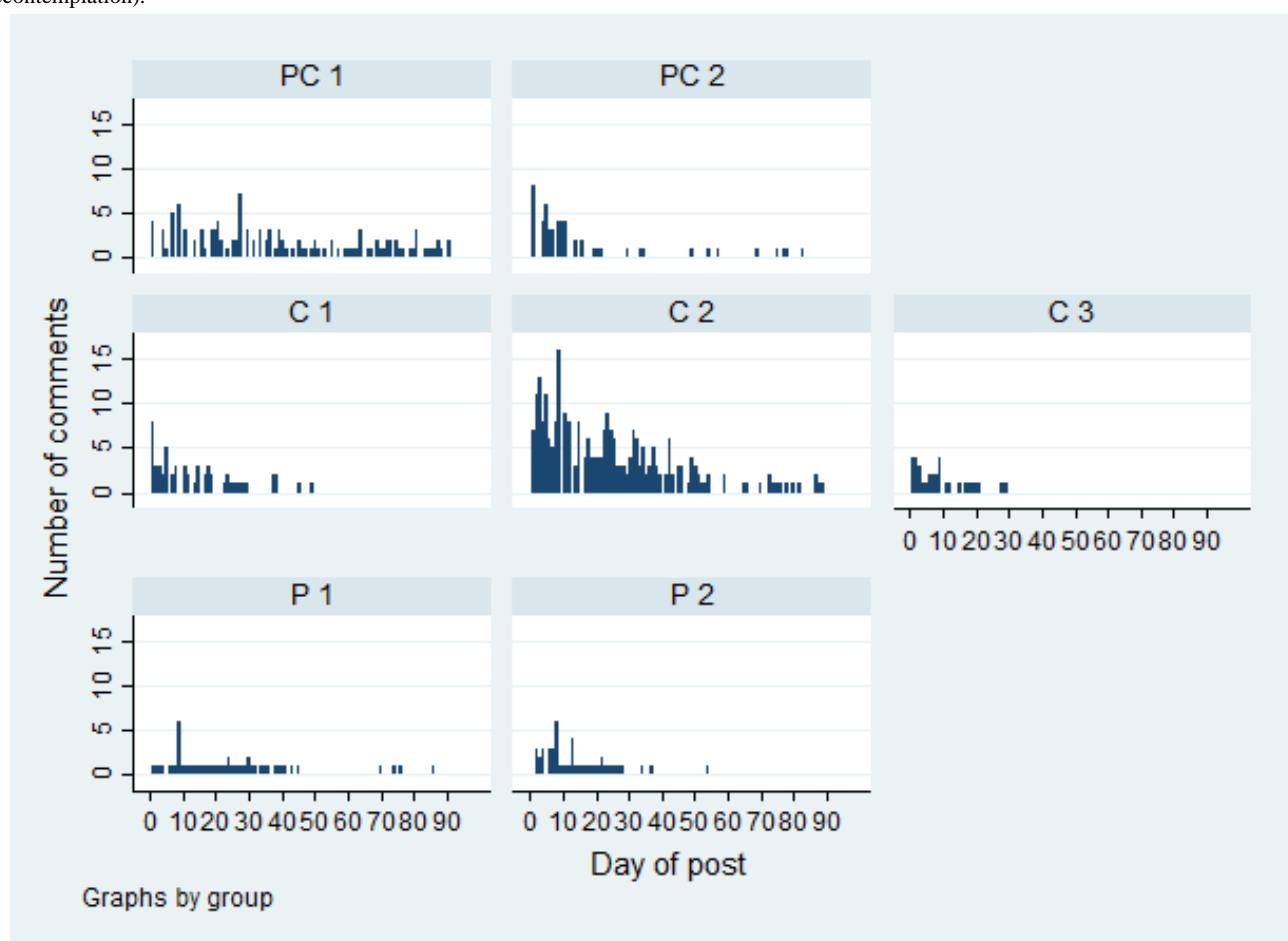


## Intervention Engagement According to Transtheoretical Model Post Content

The results of our negative binomial regression analyses to investigate which post content generated the best engagement are displayed in Table 3. Among participants in Precontemplation, Decisional Balance–based posts generated above average engagement compared to other posts ($P=.01$). Among those in Contemplation, Decisional Balance–based posts were also associated with above average engagement ($P<.001$)

while Dramatic Relief and Self-Liberation posts were associated with below average engagement ($P=.01$ and $P=.005$). Last, among participants in Preparation, Consciousness Raising posts resulted in above average engagement ($P=.009$) and Helping Relationships–based posts were marginally but nonsignificantly associated with above average engagement ($P=.08$). Engagement differed between the two groups in Precontemplation ($P<.001$) and between the three groups in Contemplation ($P<.001$ and $P=.02$). Figure 1 shows engagement with TTM posts in each of the seven groups over time.

**Table 3.** Results of negative binomial regression analyses of Transtheoretical Model (TTM) content predicting intervention engagement, separately conducted for each baseline stage of change (adjusted for excess zeros in Contemplation and Preparation).

|  | b | Standard error | t | P |
|---|---|---|---|---|
| **Precontemplation** | | | | |
| **TTM content** | | | | |
| Consciousness Raising | Omitted[a] | | | |
| Decisional Balance | 0.685 | 0.275 | 2.5 | .01 |
| Dramatic Relief | -0.581 | 0.956 | -0.6 | .54 |
| Environmental Reevaluation | 0.285 | 0.383 | 0.7 | .46 |
| Stimulus Control | -0.204 | 0.704 | -0.3 | .77 |
| Social Liberation | 0.009 | 0.275 | 0.0 | .97 |
| Self-Reevaluation | 0.113 | 0.746 | 0.2 | .88 |
| Group PC2[b]dummy | -0.883 | 0.190 | -4.7 | <.001 |
| **Contemplation** | | | | |
| **TTM content** | | | | |
| Counter-Conditioning | Omitted[a] | | | |
| Consciousness Raising | 0.023 | 0.178 | 0.1 | .90 |
| Decisional Balance | 0.910 | 0.195 | 4.7 | <.001 |
| Dramatic Relief | -0.526 | 0.211 | -2.5 | .01 |
| Environmental Reevaluation | 0.237 | 0.262 | 0.9 | .37 |
| Helping Relationships | 0.127 | 0.477 | 0.3 | .79 |
| Reinforcement Management | -0.374 | 0.558 | -0.7 | .50 |
| Stimulus Control | -0.276 | 0.414 | -0.7 | .51 |
| Self-Liberation | -0.669 | 0.239 | -2.8 | .005 |
| Social Liberation | 0.330 | 0.202 | 1.6 | .10 |
| Self-Reevaluation | -0.385 | 0.285 | -1.4 | .18 |
| Group C2[c]dummy | 1.340 | 0.200 | 6.7 | <.001 |
| Group C3[d]dummy | -0.595 | 0.258 | -2.3 | .02 |
| Inflated zeros - Intervention day | 0.059 | 0.009 | 6.3 | <.001 |
| **Preparation** | | | | |
| **TTM content** | | | | |
| Counter-Conditioning | Omitted[a] | | | |
| Consciousness Raising | 0.628 | 0.239 | 2.6 | .009 |
| Helping Relationships | 0.521 | 0.293 | 1.8 | .08 |
| Reinforcement Management | -0.118 | 0.283 | -0.4 | .68 |
| Stimulus Control | -0.152 | 0.307 | -0.5 | .62 |
| Self-Liberation | -0.569 | 0.868 | -0.7 | .51 |
| Self-Reevaluation | -0.258 | 0.553 | -0.5 | .64 |
| Group P2[e]dummy | 0.031 | 0.213 | 0.1 | .89 |
| Inflated zeros - Intervention day | 0.105 | 0.020 | 5.3 | <.001 |

[a]Dummy for first TTM content (Consciousness Raising for Precontemplation, Counter-Conditioning for Contemplation and Preparation) omitted to estimate each model.

[b]PC2: Precontemplation 2.

[c]C2: Contemplation 2.

[d]C3: Contemplation 3.

[e]P2: Preparation 2.

## Discussion

### Principal Findings

We investigated which intervention content based on the Transtheoretical Model generated the best engagement in a Facebook smoking cessation intervention for young adults tailored to participants' readiness to quit smoking. Different intervention content generated varying levels of engagement according to TTM stage of change.

Participants in Precontemplation and Contemplation showed more than average engagement when posts were based on Decisional Balance. For those in Precontemplation, strategies focused more on increasing the pros of quitting, while posts in Contemplation groups acknowledged cons of quitting while simultaneously focusing on challenging the cons and increasing pros. Decisional Balance strategies are recommended by US Clinical Practice Guidelines for Smoking Cessation [26] and are consistent with motivational interviewing techniques of acknowledging ambivalence and guiding clients to focus on the positive aspects of quitting, effective with young smokers unmotivated to quit [37-39]. Changes in Decisional Balance have been shown to be associated with transitions from Precontemplation to Contemplation or Preparation for smoking [40-42] and other health risk behaviors including exercise [43] in previous studies. As applied to social media, Decisional Balance strategies can harness either a small social network (eg, an intervention group) or one's larger Facebook social network to get help in generating pros and cons of smoking and smoking cessation.

For participants in Contemplation, we found that posts utilizing Dramatic Relief and Self-Liberation generated below-average engagement. Dramatic relief focuses on eliciting negative emotional responses to old behaviors (ie, smoking) and positive emotional responses to newly adopted behaviors (ie, quitting smoking). For Contemplation groups, Dramatic Relief posts were primarily focused on eliciting negative emotions related to smoking through, for example, links to the Legacy Foundation Truth Campaign YouTube videos of current or former tobacco users with severe consequences [44]. Findings suggest that posts focused on associating positive emotions with quitting or posts not linking to third-party websites (ie, YouTube) may have been a more effective strategy in implementing the Dramatic Relief process of change through social media. Self-Liberation posts focused on asking participants to take small steps toward quitting and to share their experience with other group members. It is not possible to know whether lower than average engagement suggests "steps" were not taken or were just not reported in groups. Future posts using Self-Liberation strategies could focus on having participants share strategies in extremely incremental steps or eliciting ideas from participants or group members about which steps they would be willing to take or would suggest for their peers to elicit more sharing in groups.

Posts based on Consciousness Raising resulted in above average engagement among participants in Preparation. The TTM posits that Consciousness Raising takes a less active role than processes such as Counter-Conditioning, Stimulus Control, and Reinforcement Management to help move people from Preparation to Action stages of change. Nevertheless, participants were most engaged with these posts, suggesting that those ready to quit are interested in information about quitting smoking. Posts focused on the health benefits of quitting, for example, may be most engaging in Preparation groups.

Engagement diminished over time in all groups, which is consistent with previous studies on health behavior change interventions using social media [23-25]. However, we also found that engagement was independent of time of day and day of week, suggesting that a Facebook smoking cessation intervention can deliver critical information to participants and has the potential to get them to engage every day. This is especially promising since 70% of Facebook users report daily use [11]. Furthermore, more than 50% of participants in the present intervention actively engaged two times or more, showing that the intervention was interesting enough for them to come back more than once. Compared to online smoking cessation interventions not using social media [10], about the same proportion of participants engaged with the intervention at all (63% vs 61% in our study). However, the participants in our study engaging at least once commented an average of 15 times, which compares favorably to an average of 1.4 visits made to a smoking cessation website [10]. Consistent with previous research [12], these findings suggest that social media can be harnessed to engage participants in smoking cessation and other health behavior change interventions.

We did not find baseline participant characteristics that predicted differences in engagement; however, participants clearly showed varying intensities of engagement. This suggests that we either did not capture important baseline predictors of engagement or that substantial variance in engagement gets introduced at the group level. Indeed, intervention engagement did differ by group. Unfortunately, this feasibility study with seven groups lacked the adequate sample size to investigate group-level factors such as group size, group composition (eg, gender ratio, percentage of daily smokers, or future smoking intentions), or group processes (eg, do a couple of very active participants motivate others to be more active as well?) that may have caused these group level differences. Future studies with larger samples are needed to investigate this topic.

Previous studies of both behavioral smoking cessation counseling [26] and Web-based smoking cessation intervention [27] suggested that higher engagement may lead to better smoking cessation outcomes. Of our 79 participants, 60 (75.9%) completed the follow-up assessment at end of treatment (3-month follow-up). Of these, 7 participants (11.7%) reported 7-day point prevalence abstinence at end of treatment. Participants with self-reported abstinence made an average of 22.4 (SD 21.9) comments, compared to 8.3 (SD 15.1) comments among non-abstinent participants. This difference was borderline statistically significant in a Wilcoxon-Mann-Whitney test ($z=1.9$;

$P$=.05), indicating that engagement was associated with more favorable smoking cessation outcomes in our intervention. When conservatively assuming those not followed-up were still smoking (intent-to-treat or ITT), this difference was statistically significant: abstinent: 22.4 comments (SD 21.9); non-abstinent: 7.8 comments (SD 13.9); $z$=2.0; $P$=.04. However, it should be noted that due to our small participant sample, the achieved test power to detect this effect was only 56% (61% respectively for ITT analysis). A trial adequately powered to investigate this research question more in depth is warranted.

## Limitations

Our findings should be interpreted with several limitations in mind. This study relied on a self-selected convenience sample of young adult smokers using Facebook, and the sample was predominantly male and white. Social networks were formed as part of the intervention rather than derived organically based on the participants' Facebook or other preexisting social network. Strategies are needed to recruit more female and ethnic minority participants through Facebook targeting (eg, placing ads in locations where more ethnic minority smokers reside) and using images to target women and non-white smokers. Further, our intervention was tailored to baseline readiness to quit smoking in accordance with the TTM, and thus participants in each stage of change received different intervention content. This study design feature was accounted for by examining engagement stratified by baseline readiness to change; however, it precluded us from comparing engagement with TTM content between different stages of change. Our analysis of post features was theory-guided and focused on the TTM. We thus did not investigate how other aspects of Facebook posts, such as sentiment (positive/negative) or semantic content were related to participant engagement [45]. This should be examined in future studies. Comments are a conservative measure of engagement; indeed, the absence of commenting does not necessarily mean a person did not see or make some cognitive or behavioral change as a result of an intervention post. These,

however, were impossible to measure in the context of this study conducted entirely on Facebook. In addition, we were not able to take the quality and depth of engagement (eg, comment content, length) into account. However, overall we argue that comments to Facebook posts are likely a more meaningful measure of active intervention engagement [46,47], compared to previous studies that looked at number of website visits or time spent viewing specific websites as measures of engagement (eg, [10,20]). In addition, time of day that the intervention content was posted was not randomized, and the majority of content was posted between 1 pm and 3 pm Pacific Time.

## Conclusions

Social media such as Facebook provide unprecedented opportunities to reach large numbers of young adult smokers with smoking cessation interventions. However, it is crucial to investigate and improve participant engagement in these types of interventions. This study has important implications for interventions with young adult smokers on social media. Results underscore the importance of tailoring intervention content to readiness to quit smoking to maximally engage young adults in social media interventions. Decisional Balance was most engaging to those not ready to quit (Precontemplation, Contemplation stages of change), and Consciousness Raising was most engaging to those in Preparation. Results suggest that in order to increase participant engagement, social media smoking cessation interventions should use posts that increase the pros of quitting for participants in Precontemplation, posts that increase the pros while challenging the cons for participants in Contemplation, and posts that provide information on quitting smoking for participants in Preparation. Although social media are generally integrated into the lives of young adults, strategies are still needed to improve participant engagement in social media smoking cessation intervention over time. Future studies should also examine how engagement with specific intervention content is related to treatment outcomes.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Sample Facebook posts in precontemplation, contemplation, and preparation.

[PDF File (Adobe PDF File), 693KB - jmir_v17i11e244_app1.pdf ]

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## Abbreviations

**C:** contemplation
**ITT:** intention to treat
**P:** preparation
**PC:** precontemplation
**TTM:** Transtheoretical Model

<u>Viewpoint</u>

# Bringing Health and Fitness Data Together for Connected Health Care: Mobile Apps as Enablers of Interoperability

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## Abstract

**Background:** A transformation is underway regarding how we deal with our health. Mobile devices make it possible to have continuous access to personal health information. Wearable devices, such as Fitbit and Apple's smartwatch, can collect data continuously and provide insights into our health and fitness. However, lack of interoperability and the presence of data silos prevent users and health professionals from getting an integrated view of health and fitness data. To provide better health outcomes, a complete picture is needed which combines informal health and fitness data collected by the user together with official health records collected by health professionals. Mobile apps are well positioned to play an important role in the aggregation since they can tap into these official and informal health and data silos.

**Objective:** The objective of this paper is to demonstrate that a mobile app can be used to aggregate health and fitness data and can enable interoperability. It discusses various technical interoperability challenges encountered while integrating data into one place.

**Methods:** For 8 years, we have worked with third-party partners, including wearable device manufacturers, electronic health record providers, and app developers, to connect an Android app to their (wearable) devices, back-end servers, and systems.

**Results:** The result of this research is a health and fitness app called myFitnessCompanion, which enables users to aggregate their data in one place. Over 6000 users use the app worldwide to aggregate their health and fitness data. It demonstrates that mobile apps can be used to enable interoperability. Challenges encountered in the research process included the different wireless protocols and standards used to communicate with wireless devices, the diversity of security and authorization protocols used to be able to exchange data with servers, and lack of standards usage, such as Health Level Seven, for medical information exchange.

**Conclusions:** By limiting the negative effects of health data silos, mobile apps can offer a better holistic view of health and fitness data. Data can then be analyzed to offer better and more personalized advice and care.

## Introduction

Wearable health trackers such as the Jawbone UP [1] and Fitbit [2] have invaded the consumer market and make collection of personal health and fitness data ubiquitous. With the upcoming smartwatches supporting many features of the health trackers, these devices are becoming part of normal life and are integrated into a person's daily routine. Improvements to wearable devices are occurring at a fast pace and newer models integrate improved sensors. For example, the Microsoft Band [3] includes a heart rate monitor, 3-axis accelerometer, gyro, ambient light sensor, skin temperature sensor, ultraviolet sensor, and galvanic skin response. Wearable devices come at a time when chronic

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diseases are on the rise, and at the same time governments are struggling with their health care budgets. Being able to collect biometric data in real time for a prolonged period make wearable devices a great tool to manage, or even prevent, some chronic diseases [4].

Wearable devices and mobile phone health apps can and will change health care by empowering users and educating them to take control of their health. Users are embracing them; according to the Intercontinental Marketing Services (IMS) Institute for Healthcare Informatics [5], as of 2015, there were 165,000 health-related mobile phone apps on Android and iPhone operating systems (iOS) and around 110,000 of these are for health and fitness. The IMS Health Institute [6] forecasts that the sales of wearable technology will grow to almost US $30 billion by 2018. According to Campbell [7], the health monitoring device industry is projected to exceed US $5 billion in 2016, largely due to the focus on patient engagement and prevention. The shift in users' attitudes could lead to fewer doctor visits and the need for fewer tests. It also has the potential to give health professionals better insight into patients' overall health and fitness.

There is an increasing amount of health- and fitness-related information that has been collected and stored in the cloud. However, the data usually reside in silos and in most cases health and fitness data are separated. For example, Fitbit stores all data generated by their trackers on their Fitbit server; the same applies to Jawbone, Withings [8], and iHealth [9]. Newcomers such as Google Fit [10] or Apple HealthKit [11] position themselves as integrators. However, will data stored in Apple HealthKit be available to Google Fit and vice versa? According to Mandl et al [12], these data streams will initially remain confined to their respective platforms and will have very limited ways to integrate with electronic health records (EHRs). To make it even more complicated, what about data stored in EHR systems that are controlled by governments?

Currently, there is no real integration of fitness-related data and health records stored in EHR systems. To provide better health outcomes and better patient engagement, a complete picture is needed which combines informal health and fitness data collected by the user, together with official health records collected by health professionals. By combining these two streams, the data can be analyzed using data analytics and health professional expertise to offer better personalized advice and care. There is good evidence that the integration can improve therapeutic management [13,14].

The objective of this paper is to demonstrate that a mobile app can be used to aggregate health and fitness data and can enable interoperability. It discusses various technical interoperability challenges encountered while integrating health and fitness data into one place. By limiting the negative effects of health data silos, mobile apps can offer a better holistic view of users' health and fitness data and give them more control over their data.

## Methods

Since 2007, we have worked with third-party companies to connect our Android app called myFitnessCompanion [15] to

their sensors, wearable devices, EHR systems, and servers to collect and exchange health and fitness data. Initially, myFitnessCompanion only collected data coming directly from wireless sensors connected to the phone or by manual entry; the data were stored locally on the phone. Based on user feedback and comments, it became evident that our users wanted to control their data and aggregate their health and fitness data from other sources. Users also wanted to have the option to store all their data on one server (eg, Microsoft HealthVault [16]) or only keep it on their mobile device for privacy reasons. Observing this, we decided to develop our app into a health and fitness aggregator app. Today, myFitnessCompanion interacts with a wide range of wireless devices and wearable health trackers, and also aggregates data from third-party apps. It connects with Microsoft HealthVault, Google Fit, Fitbit, Withings, Jawbone, and iHealth servers as well as other EHR systems.

myFitnessCompanion was developed for Android devices and offers personalized exercise tracking and monitoring of biometric data, such as heart rate, respiration, body temperature, weight, food intake, blood pressure, cholesterol, asthma, blood glucose, and many more. It supports 15 different languages and has been commercially available on Google Play since 2011. Prior to the Android app, we developed a similar app using the Microsoft Windows Mobile 6.x platform. At that time, Microsoft did not offer an outlet like Google Play to distribute the app easily and, more disruptively, Microsoft discontinued support for Windows Mobile 6.x devices in 2011, which forced us to choose a new platform. We selected Android over Apple iOS, partially due to our experience with JAVA/C#, but more importantly because of the excellent Bluetooth support in the Android platform compared to iOS at that time.

Our approach was to integrate off-the-shelf, commercially available devices. Simultaneously, we connected myFitnessCompanion with EHR servers, such as Microsoft HealthVault and Google Health (discontinued). These were the first EHR servers available to the general public. A major challenge was to keep up with the different Android operating system (OS) versions coming onto the market at a 3- to 6-month interval, resulting in a continuous process of updating the software to keep up to date with new Android devices and features. Figure 1 shows the ecosystem of myFitnessCompanion.

Devices supporting open standard protocols (Figure 1, box 1) are devices such as the Google Android Wear [17] smartwatches and fitness trackers that allow third-party developers to retrieve the data directly from the device. Fitness trackers such as the Mio LINK [18] or Garmin's Advanced and Adaptive Network Technology (ANT)+ Footpod [19] are open in the sense that they use standard open protocols to transfer health data using Bluetooth or ANT+. These devices are not necessarily connected to myFitnessCompanion and they upload their data directly to a server like Google Fit, which can then be retrieved by myFitnessCompanion. Users can also manually enter health data into Microsoft HealthVault or Google Fit, which is then automatically transferred to myFitnessCompanion.

Devices paired with myFitnessCompanion (Figure 1, box 2) refer to wireless Bluetooth or ANT+ sensors that are paired with

myFitnessCompanion and whose data are directly streamed to the app. These include Bluetooth Smart heart rate monitors and blood pressure monitors. The devices implement an open standard. For example, Bluetooth Smart heart rate monitors from different vendors (eg, Zephyr HxM [20], Polar H7 [21], or Wahoo Blue [22]) all work seamlessly with the app without making adaptations for a specific vendor. Unfortunately, the majority of wireless devices implement a vendor-specific protocol. Sometimes the vendor makes the protocol available, which allows integration with myFitnessCompanion. Examples are A&D [23] blood pressure monitors and weight scales or FORA [24] blood glucose monitors. The disadvantage is that each device-specific software needs to be written to communicate and interpret the data transmitted by these devices.

Closed and proprietary wireless devices (Figure 1, box 4) do not allow third-party developers to communicate directly with the device. Although those devices use standard Bluetooth to communicate with a mobile device, the actual protocol and data format are not public. This makes it near impossible for third-party developers to integrate the device into their mobile app. Fitbit, Jawbone, Withings, and many other vendors follow this strategy and only allow third-party developers to obtain the data via their server through a public application programming

interface (API). This means that these companies obtain all health and fitness data generated by their respective devices. It allows them to analyze and perform data mining, as well as sell the data to interested parties. Users have no choice but to hand over their health, fitness, and other personal data without knowing what is being done with it.

Websites such as MyFitnessPal [25] and FatSecret [26] collect health data by allowing users to input data directly or via their mobile app (Figure 1, box 5). These sites then allow third-party developers to retrieve the data via an open API. Some servers such as Microsoft HealthVault allow two-way communication, whereas others such as Withings do not allow the uploading of data from a third-party app. Some servers only present the collected data in graphical or table format, whereas others analyze the data and provide trend analysis and various insights.

In this paper, we focus mainly on sensor-generated health and fitness data, but it is worth mentioning that 80% of myFitnessCompanion users enter their physiological data manually [27]. We suspect that most users use their existing blood pressure monitor or weight scale devices that are not wirelessly enabled and transfer the readings manually to the app.

**Figure 1.** myFitnessCompanion ecosystem.
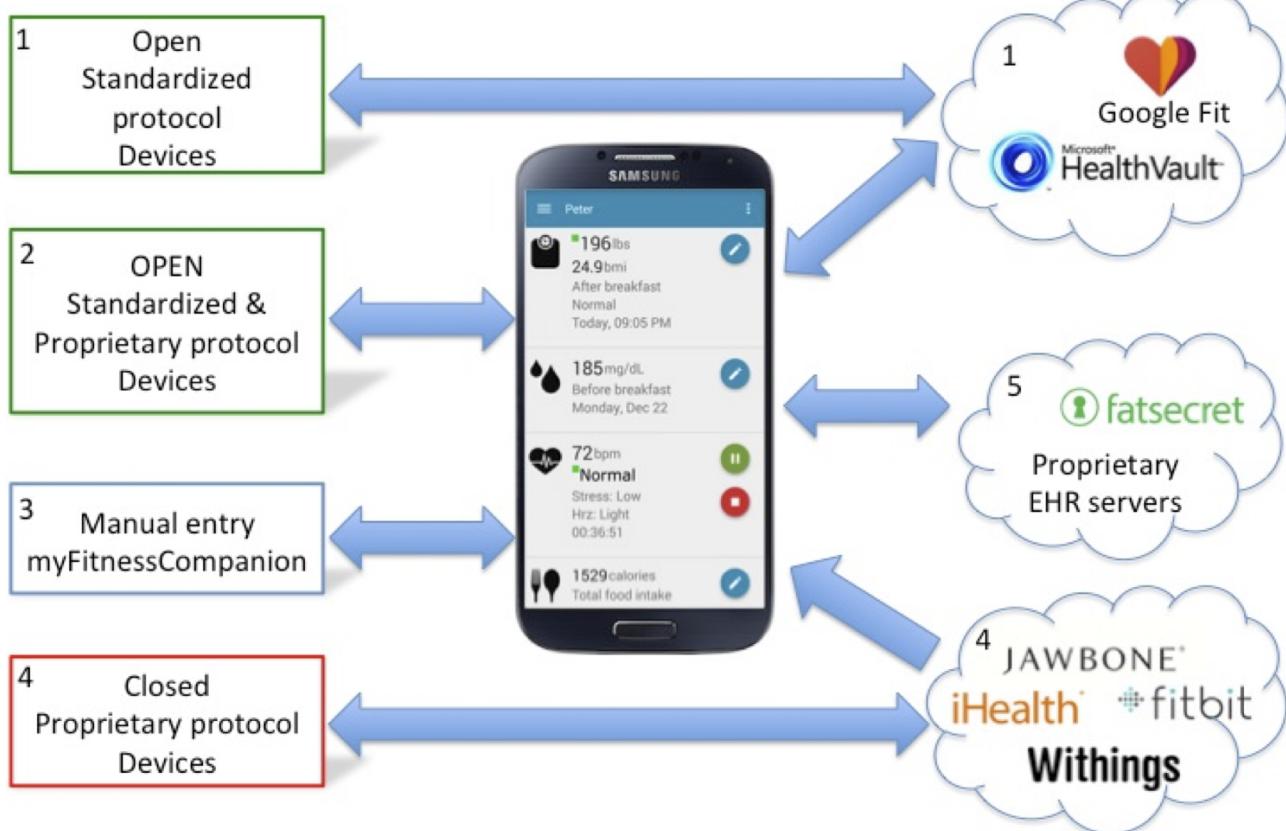


## Results

### Overview

The main result of this paper is a health and fitness app called myFitnessCompanion. The results and discussions in this paper

are based on our experience as an integrator of health data from various sources. The app has over 6000 users. Screenshots of the myFitnessCompanion app are shown in Figure 2 and a video showing the app's functionalities is shown in Multimedia Appendix 1.

**Figure 2.** Screenshots from the myFitnessCompanion app.



## Technical Challenges Integrating Wireless Devices

myFitnessCompanion has integrated a wide variety of wireless sensors ranging from universal serial bus (USB) cable devices to the latest Bluetooth low energy (BLE) devices. We focus on the most commonly used wireless communication protocols.

### *Classic Bluetooth*

Devices that have been on the market for several years mostly use classic Bluetooth. Most mobile phones support classic Bluetooth, whereas only the later and more expensive models support BLE, the latest version. Classic Bluetooth supports different ways to communicate between a device and a mobile phone. We encountered all possible options, which resulted in writing specific software for each device. For example, the A&D weight scale and blood pressure monitor would only activate Bluetooth after a reading is taken. This means that the mobile device has to listen for Bluetooth requests coming from an A&D device and then establish a Bluetooth link. Other devices act as slaves where the mobile phone (master) has to initiate the Bluetooth communication. Yet other devices would alternate between master mode for configuration purposes and then switch to slave mode when data need to be exchanged with the mobile device. In order to integrate a Bluetooth device, we required the protocol specification from the vendor. Dealing with all these different Bluetooth communication modes made the software development complex. Once the Bluetooth communication was solved, the next challenge was to interpret the data received and the data to be sent to the device.

Without exception, all vendors developed their own protocol and data formats to retrieve data from the device or to send commands to the device. Some protocols were straightforward, using plain American Standard Code for Information Interchange (ASCII) text to send or receive data. The Tanita [28] BC590-T scale ASCII protocol is seen in Figure 3. Many vendors, however, implemented complex protocols with numerous commands to control and exchange data. Figure 4 shows the more complex protocol for the OneTouch UltraMini [29]. Without a detailed specification, it is impossible to communicate with these devices.

From our experience, devices using classic Bluetooth to stream data continuously (eg, heart rate) are the most reliable from a connectivity point of view. Devices that only activate Bluetooth after a reading have turned out to be unreliable, especially if a mobile device is not in the area. Often the device would not establish a Bluetooth connection on subsequent readings and the user would be forced to go through the pairing process again.

**Figure 3.** Example of a plain ASCII protocol (Tanita [28] BC590-T scale).

**Figure 4.** Example of a more complex protocol (OneTouch UltraMini [29]).

**Command Message from PC: Read Serial Number**

| STX | Len | Link | CM1 | CM2 | CM3 | CM4 | CM5 | CM6 | CM7 | CM8 | CM9 | CM10 |
|------|------|------|------|------|------|------|------|------|------|------|------|------|
| 0x02 | 0x12 | 0x00 | 0x05 | 0x0B | 0x02 | 0x00 | 0x00 | 0x00 | 0x00 | 0x84 | 0x6A | 0xE8 |

| CM11 | CM12 | ETX | CRC low | CRC high |
|------|------|------|------|------|
| 0x73 | 0x00 | 0x03 | 0x9B | 0xEA |

### Bluetooth Low Energy

The latest health and fitness devices use BLE (aka, Bluetooth Smart or Bluetooth 4.0). Fitbit and Jawbone activity trackers use BLE due to low power consumption while maintaining a similar communication range compared to classic Bluetooth. BLE is characterized by easy pairing with a mobile device and minimal or no user intervention required. Many BLE devices such as heart rate monitors start transmitting automatically when data are available. BLE is rapidly becoming the standard for wearable devices, pushing ANT+ to the background. BLE has built-in features to automatically reconnect to a mobile device if the connection is lost. This eases software development and improves the reliability of device-phone communication. The introduction of BLE, together with standardized protocols for data exchange, makes these devices easy to integrate and use.

However, several vendors such as Fitbit and Withings decided to use proprietary protocols, making it impossible for third-party developers to communicate directly with their devices. We believe that this will change in the near future with other vendors offering similar devices using open protocols. Android Wear and the upcoming Angel [30] wearable device already allow developers to read the data directly from the device. In particular, new releases of Android Wear devices will offer the same (and more) functionality as Fitbit trackers and we believe this will force these vendors to open their devices or lose market share.

### Adaptive Network Technology+

ANT+ is a lesser-known wireless technology. It is characterized by low power consumption and short-range communication. It is mainly used in sports-related devices, such as step counters, fitness equipment, and heart rate monitors. It is similar to BLE, but not many mobile phone makers integrate ANT+ communication into their phones, therefore limiting the popularity of ANT+ devices. ANT+ devices implement a standardized protocol, which makes it easy to integrate these devices.

We believe that over time the market will converge on BLE at the cost of classic Bluetooth and ANT+. BLE is a natural evolution of classic Bluetooth and already the latest mobile phones support BLE and not ANT+. This will force health and fitness device vendors to support BLE if they want to have a slice of the booming health and fitness device market.

### Sensor Data Duplication

myFitnessCompanion can support up to seven active sensors at the same time. It is not common, but customers do use multiple sensors simultaneously. For example, sleep apnea patients use a heart rate monitor and a pulse oxygen sensor concurrently, which results in duplicate heart rate readings varying slightly. Currently, our app records both heart rate readings and tags the source of the readings, which gives the user an indication in case of discrepancies. In future versions, our app will give the user the option to select which sensor should be used for real-time analysis and feedback. With the increase of data sources comes the need to be able to differentiate the sources based on their reliability, quality, and trust levels.

### Sensor Data Reliability

The reliability of the devices varies widely, partially caused by incorrect use by the user. This is a major concern for health professionals when customers present, for example, their blood pressure readings expecting a health professional to make a diagnosis based on self-collected health data. Devices made for the fitness market are not necessarily approved by the Food and Drug Administration (FDA) and, as such, are even less reliable. Currently, myFitnessCompanion cannot identify the quality of a sensor reading; however, it tags the source of the reading. Knowing the source of the data collected is beneficial for a health professional in his/her assessment of the data quality.

## Technical Challenges Integrating Back-End Servers and Electronic Health Records

myFitnessCompanion can upload and download health data from various servers, such as Microsoft HealthVault, Google Fit, Jawbone, Fitbit, and many more. These servers offer an open API where (after authorization) health data can be exchanged. In this discussion, we focus on authorization and use of standards for the exchange of health data.

### Authorization

All servers use some version of open authorization (OAuth). OAuth is an open standard and provides apps like myFitnessCompanion secure delegated access to a server on behalf of the owner. OAuth specifies a process to authorize third-party access to the resources without sharing the user credentials. Once a user has given myFitnessCompanion permission to access health data on their behalf, the app can download and upload data without further user intervention. Figure 5 shows screenshots of the OAuth for Fitbit, Withings, and Google Fit.

Although OAuth is a well-defined standard, the actual implementation varied slightly for the different servers. For example, the FatSecret server supports the OAuth 1.0 specification, but in their actual implementation they used

variable names that differ from the standard. The consequence was that off-the-shelf libraries for OAuth for Android devices could not be used and custom software had to be written to deal with these slight discrepancies.

Microsoft HealthVault uses yet another variant of OAuth and specific libraries needed to be used in order to be able to communicate with the HealthVault server. In addition, some servers implement the OAuth 1.0 version whereas others support OAuth 2.0. All this added up to additional complexity of the software to deal with the various servers. A positive trend is that servers are migrating toward OAuth 2.0, so we can expect in the near future to use one standard for authorization.

**Figure 5.** Screenshots of the OAuth for Fitbit (left), Withings (middle), and Google Fit (right).
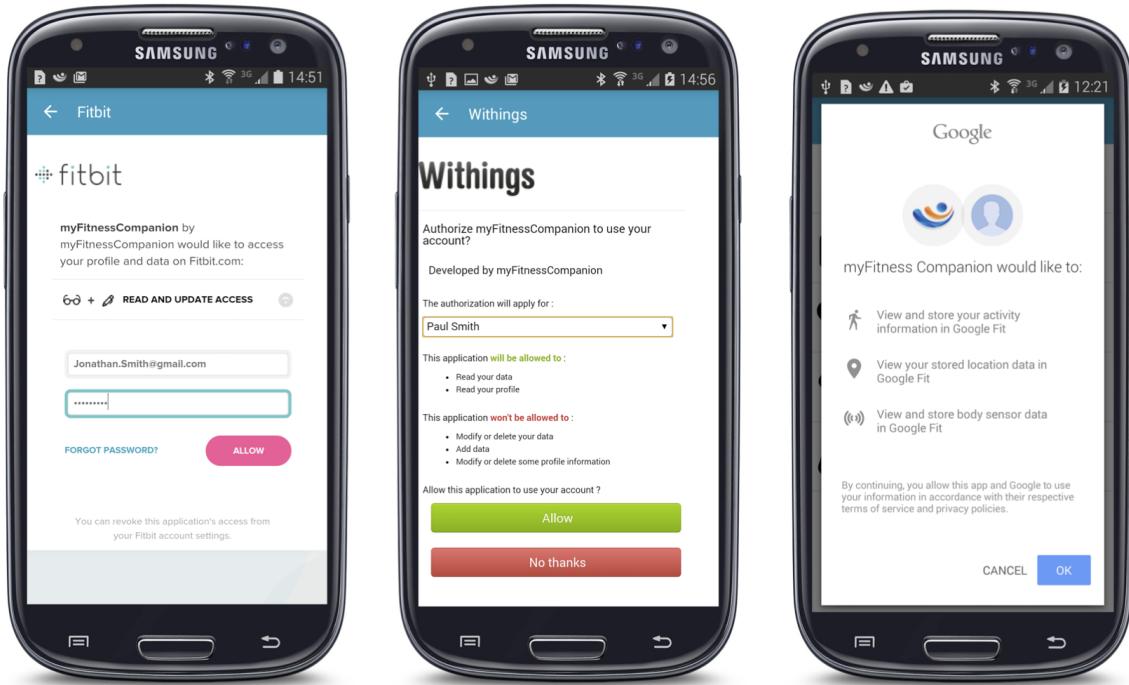


### Health Level Seven Compliance

Once the authorization hurdle had been overcome, the next challenge was to deal with the actual data to be exchanged between myFitnessCompanion and a server. Unfortunately, not a single server used an official standard for health data exchange. Without exception, each server defined its own specific data format. All the efforts made by the Health Level Seven (HL7) standardization group seem to be ignored and not taken into account. The API offered by Microsoft HealthVault is the closest to something that looks like an HL7 specification, but a specific subset has been used with proprietary modifications. The consequence was that each server-specific software had to be written to interpret the data.

### JavaScript Object Notation Versus Extensible Markup Language

On a positive note, most servers offer their data in either Extensible Markup Language (XML) or JavaScript Object Notation (JSON) format, with JSON rapidly becoming the de facto standard. We expect that XML will disappear in the next few years. Fitbit has stopped offering the XML API in 2015 and will only support JSON. Only Microsoft HealthVault solely uses XML and does not offer JSON, which makes it much harder for developers to convert the data into a usable format for further processing. Figure 6 shows example responses using JSON and XML.

**Figure 6.** Example responses using JSON (left) and XML (right).

**JSON Response**

```
{
    "average":{
            "condition":"Prehypertension",
            "diastolic":85,
            "systolic":115
    },
    "bp":[
        {
            "diastolic":80,
            "logId":483697,
            "systolic":120
        },
        {
            "diastolic":90,
            "logId":483699,
            "systolic":110,
            "time":"08:00"
        }
    ]
}
```

**XML Response**

```
<?xml version="1.0" encoding="UTF-8"?>
<result>
  <average>
    <condition>Prehypertension</condition>
    <diastolic>85</diastolic>
    <systolic>115</systolic>
  </average>
  <bp>
    <bpLog>
      <diastolic>80</diastolic>
      <logId>483697</logId>
      <systolic>120</systolic>
    </bpLog>
    <bpLog>
      <diastolic>90</diastolic>
      <logId>483699</logId>
      <systolic>110</systolic>
      <time>08:00</time>
    </bpLog>
  </bp>
</result>
```

### Server Data Duplication

myFitnessCompanion supports a two-way synchronization where data can be uploaded to, and downloaded from, a server. Dealing with one server is fairly straightforward, but issues arise when data need to be synchronized using multiple servers. Should data that originated from, for example, the Fitbit server be duplicated to HealthVault and Jawbone servers, or should the data only be imported to the mobile app and not uploaded to other servers? Because of the API specification of some servers, it is impossible to identify where the data originally came from, so if you upload it to another server it becomes a new reading and imported again into myFitnessCompanion, resulting in duplicates. To avoid this issue, when myFitnessCompanion imports readings from a server, it does not upload these readings to other servers. This means that the app becomes the central point where data from various sources come together.

## Discussion

### Principal Findings

The result of this research is a health and fitness app, myFitnessCompanion, which is able to aggregate data from multiple sources—activity trackers, wireless sensors, and servers—and analyze and present the data in a personalized manner. Over 6000 users use the app worldwide to aggregate their health and fitness data. It demonstrates that mobile apps can be used to enable interoperability. Challenges encountered in the research process included the different wireless protocols

and standards used to communicate with wireless devices, the diversity of security and authorization protocols used to be able to exchange data with servers, and lack of standards usage, such as HL7 for medical information exchange.

In terms of interoperability, we have achieved three levels of interoperability: foundational (the app and EHR can exchange data), structural (the data can be interpreted at the field level of exchange), and semantic (the data can be exchanged and used by both the app and the EHR). If we refer to the six levels of the refined eHealth European Interoperability Framework (eEIF) model [31], we address the technical (ie, apps and IT infrastructure) and semantic aspects. We cover organizational (ie, policy and care process) and legal interoperability aspects for the private clinical EHR systems we interoperate with. For these systems, there are privacy and security measures in place to obtain user trust and acceptance of the complete ecosystem [32].

### Limitations

myFitnessCompanion has been developed for the Android platform. An Apple iOS and Windows Mobile version would be desirable to cover the majority of mobile devices. Currently, the aggregated data reside on a mobile device or are sent to private EHR systems. It would be desirable to have these data stored in government-controlled EHR systems. Unfortunately, tapping into official EHR systems turned out to be complicated. Efforts have been made to connect myFitnessCompanion to Australia's personally controlled EHR (PCEHR) system, but they failed. The PCEHR standards are too complex and difficult to implement. There is no support and no easy-to-use API to

interact with the PCEHR. The new version, called My Health Record, may deal with this issue. Other official EHR systems have security and operational policies that are not coherent with other systems and they do not allow any third-party developer to tap into the system [33]. This makes the integration of the two health data streams complicated and bridging the gap requires time and cooperation from governments to allow third-party developers to tap into their systems on behalf of its users.

Acceptance by health professionals is another hurdle to overcome. From user feedback, we know that users show their collected health data (eg, blood pressure and blood glucose readings) to their health professionals. Some health professionals take this data into account for the diagnosis, but others reject the self-collected data and use their own (often far more limited set of data) for diagnosis. Reasons for rejection include the potential lack of accuracy and the extra time needed to go through the data [34]. There is a need to apply some data mining or filtering techniques to extract the important information from the vast amount of data and save precious time. Once this is in place, we believe that more health professionals will accept self-collected health data, especially if the source of the biometric data is properly tagged and they know where the data came from. It is important that the data are fit for the purpose (eg, fitness trackers to identify the level of activity). A study involving 1406 health care providers in the United States [35] highlights that their acceptance depends on the type of data collected. For example, 60.60% of these health care providers would trust a mobile phone for heart rate information.

Another survey of 1000 American health professionals [36] found that 42% of physicians were comfortable relying on at-home test results to prescribe medication and nearly 66% of physicians would prescribe an app to help patients manage chronic diseases such as diabetes. In addition, 86% of clinicians believe mobile apps will become important for them to manage their patients' health over the next 5 years.

## Comparison With Prior Work

There are a lot of health and fitness apps on the market, and some good state-of-the-art analyses of those apps can be found in various studies [37-39]. An excellent review on the requirements for, and barriers toward, interoperable eHealth technology in primary care can be found in Nijeweme-d'Hollosy et al [40]. Only a few apps address interoperability and are real aggregators of health and fitness data; a research report [41] has identified those apps as the connected mHealth app elite, and positioned myFitnessCompanion in the top five of this group. Google Fit claims to be an aggregator of health data, but its current version is limited to fitness data only. Apple's HealthKit is more promising, storing a wide variety of health and fitness data, but is limited to an Apple ecosystem.

## Conclusions

As stated in the "Introduction" section, a combination of informal health and fitness data and official health data stored in EHR systems is desirable to provide a complete health picture. myFitnessCompanion is able to tap into both the formal and the informal health and fitness data, and aggregate the data in one place. There are a lot of benefits in aggregating the data coming from wearable devices and sensors, especially, for example, for users with chronic disease, as their conditions need long-term monitoring. By combining health data with nonhealth data (eg, location, social media, and habits), one can make interesting correlations and suggest changes to the users' habits and help in dealing with their chronic conditions. Our ultimate objective is to empower users and help them in monitoring their health and fitness in a personalized manner and to improve their quality of life [42]. myFitnessCompanion has the potential to change health care by empowering users and helping them take control of their health.

## Conflicts of Interest

The authors are the owners of myFitnessCompanion Pty Ltd.

## Multimedia Appendix 1

Video showing the functionalities of myFitnessCompanion.

[MP4 File (MP4 Video), 78MB - jmir_v17i11e260_app1.mp4 ]

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## Abbreviations

**ANT:** Advanced and Adaptive Network Technology
**API:** application programming interface
**ASCII:** American Standard Code for Information Interchange
**BLE:** Bluetooth Low Energy
**eEIF:** eHealth European Interoperability Framework
**EHR:** electronic health record
**FDA:** Food and Drug Administration
**HL7:** Health Level Seven
**IMS:** Intercontinental Marketing Services
**iOS:** iPhone operating system
**JSON:** JavaScript Object Notation
**OAuth:** open authorization
**OS:** operating system
**PCEHR:** personally controlled EHR
**USB:** Universal Serial Bus
**XML:** Extensible Markup Language

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Original Paper

# Mobile Phone Apps to Promote Weight Loss and Increase Physical Activity: A Systematic Review and Meta-Analysis

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## Abstract

**Background:** To our knowledge, no meta-analysis to date has assessed the efficacy of mobile phone apps to promote weight loss and increase physical activity.

**Objective:** To perform a systematic review and meta-analysis of studies to compare the efficacy of mobile phone apps compared with other approaches to promote weight loss and increase physical activity.

**Methods:** We conducted a systematic review and meta-analysis of relevant studies identified by a search of PubMed, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), and Scopus from their inception through to August 2015. Two members of the study team (EG-F, GF-M) independently screened studies for inclusion criteria and extracted data. We included all controlled studies that assessed a mobile phone app intervention with weight-related health measures (ie, body weight, body mass index, or waist circumference) or physical activity outcomes. Net change estimates comparing the intervention group with the control group were pooled across studies using random-effects models.

**Results:** We included 12 articles in this systematic review and meta-analysis. Compared with the control group, use of a mobile phone app was associated with significant changes in body weight (kg) and body mass index (kg/m$^2$) of -1.04 kg (95% CI -1.75 to -0.34; I2 = 41%) and -0.43 kg/m$^2$ (95% CI -0.74 to -0.13; I2 = 50%), respectively. Moreover, a nonsignificant difference in physical activity was observed between the two groups (standardized mean difference 0.40, 95% CI -0.07 to 0.87; I2 = 93%). These findings were remarkably robust in the sensitivity analysis. No publication bias was shown.

**Conclusions:** Evidence from this study shows that mobile phone app-based interventions may be useful tools for weight loss.

**KEYWORDS**

mHealth; mobile phone; apps; obesity; physical activity; intervention

## Introduction

Overweight and obesity are a global public health issue and an important feature in discussions about strategies for primary and secondary health care. Developing since the 1960s and now gathering pace rapidly, the issue is contributing, together with population aging, to major increases in the prevalence of high blood pressure and cholesterol levels, type 2 diabetes, and cancers [1]. Mortality rates are increasing with increasing degrees of overweight, as measured by body mass index (BMI) [2].

In 2008, 35% of adults older than 20 years were overweight (BMI ≥ 25 kg/m$^2$) and the worldwide prevalence of obesity (BMI ≥30 kg/m$^2$) had nearly doubled since 1980, from 5% of men and 8% of women to 10% and 14%, respectively [2]. An estimated 205 million men and 297 million women were obese—a total of more than half a billion adults worldwide [3]. For these reasons, identifying effective interventions is an important component in public health efforts to curb obesity, but the most effective strategies for weight loss remain unclear.

With the extensive market penetration of mobile phones, the International Telecommunications Union (ITU) reports that as of 2015, there are more than 7 billion mobile cellular subscriptions worldwide, corresponding to a 97% penetration rate—defined by ITU as mobile cellular telephone subscribers per 100 inhabitants [4]. Advanced-feature mobile phones (those with computer operating systems) have broadened the functions of mobile phones considerably. Mobile phone apps meet a variety of user needs, and are designed and adapted for each type of mobile device; therefore, they are applicable in nearly all social and economic sectors and environments. At present, these apps, apart from their recreational function, are becoming instruments of patient education and support and are also helpful to health care professionals [5]. Nonetheless, the market for health care apps is very fragmented because many of them are very specific or directed at minority diseases or specialties. The world market for medical apps for mobile phones and tablets multiplied seven times over in 2011 alone, reaching a total of US $718 million according to a market analysis by the American firm research2guidance [6]. A recent analysis of app store catalogs identified more than 97,000 mHealth apps, most of them dealing with general health and physical fitness; in general, they facilitate the monitoring of various parameters by individual users and provide general information and support related to those topics [5]. Previous research has suggested that mobile apps may be beneficial in asthma control [7] and diabetes management [8,9].

To our knowledge, no meta-analysis to date has assessed the efficacy of mobile phone apps to promote weight loss and increase physical activity. The objective of this study was to perform a systematic review and meta-analysis of published studies to evaluate the efficacy of interventions that included mobile phone apps compared with other interventions to reduce weight and increase physical activity in populations of children and adults.

## Methods

### Search Strategy

We conducted a systematic literature search of three databases from their inception through August 30, 2015, to identify studies examining the effectiveness of a mobile app intervention compared with a control intervention in achieving anthropometric or physical activity changes: Medline (via PubMed; National Library of Medicine, Bethesda, MD; started in 1966), Scopus (Elsevier; started in 1995), and the Cumulative Index to Nursing and Allied Health Literature (CINAHL; started in 1960). Details on the search strategy are presented in Multimedia Appendix 1. Briefly, our literature search strategy combined synonyms for mobile app (the intervention of interest) with synonyms for the three outcomes: weight, body mass index, and exercise. The search period was all-inclusive up to August 2015. There were no language restrictions. In addition, we manually reviewed reference lists from relevant original research and review articles.

### Study Selection

Two members of the study team (EG-F, GF-M) independently screened studies for inclusion criteria and extracted the data. We included all studies that assessed a mobile app intervention, compared to a control group, with weight-related health measures (ie, body weight, BMI, or waist circumference) or physical activity outcomes. We included studies performed in populations of children and of adults. Exclusion criteria were as follows: (1) no original research (ie, reviews, editorials, or nonresearch letters), (2) case reports and case series, (3) data on body weight, BMI, waist circumference, or physical activity not reported, (4) no control group, (5) participants with any disease except a diagnosis of obesity, (6) mobile telephone intervention based on text messaging, such as short message service (SMS), and (7) intervention used or included personal digital assistants (PDAs). Ethics approval was not required because only published data were analyzed in this review. The study selection process is summarized in Figure 1.

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**Figure 1.** Flowchart for the selection of the articles in this meta-analysis.
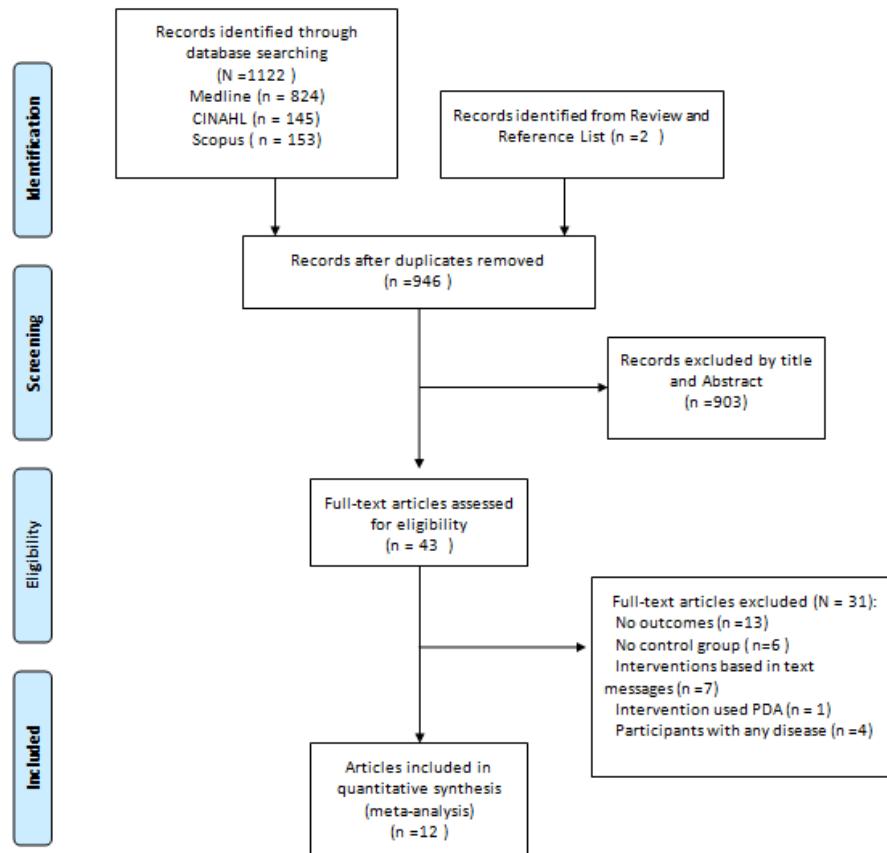


## Data Extraction and Quality Assessment

Two investigators (EG-F, GF-M) independently abstracted articles that met the selection criteria and resolved discrepancies by consensus. A form developed in Microsoft Word was used to extract data from eligible research papers, including author, country of study, age of participants, length of follow-up, sample size, and study outcomes. Study outcomes recorded were mean and standard deviation (SD) body weight, BMI, waist circumference, and/or physical activity. These values were captured as mean changes from baseline to the end of the intervention, with variations reported as SD, standard error (SE), or 95% CI. When there were several publications from the same cohort, the study with the longest follow-up was selected; when the follow-up was equivalent, we selected the study with the largest number of cases, the publication that used internal comparisons, or the most recent study. An intention-to-treat analysis was used wherever possible. The risk of bias was assessed following Cochrane recommendations, considering random sequence generation, allocation concealment, blinding of participants and personnel, blinding of outcome assessment, incomplete outcome data, and selective reporting [10]. Each criterion was categorized as *clearly yes*, *not sure*, or *clearly no*. Criteria for which there were differences between the two evaluators were discussed until a consensus decision was reached.

## Statistical Methods

For each study, the net effect size was calculated as the change in body weight-related and physical activity measures resulting from treatment from baseline to the end of the intervention in the intervention group, minus the change in body weight-related and physical activity measures in the control group during the same time period. The SEs and CIs were converted to SDs for analysis. For studies without SD data, we calculated the variance from CIs or test statistics. If the SD for change between baseline and the end of the intervention was not reported, it was calculated using the following equation [11]:

$$SD^2_{diff} = SD^2_{pre} + SD^2_{post} - 2 \times \rho \times SD_{pre} \times SD_{post}$$

Where $SD_{pre}$ corresponds to the SD at baseline, $SD_{post}$ corresponds to the SD at the end of intervention, and $\rho$ is the correlation coefficient for correlations between measurements taken at baseline and at the end of the intervention.

For body weight and BMI, weighted mean differences (WMDs) were estimated using random-effects models. For physical activity outcomes, standardized mean differences (SMDs) were estimated using random-effects models. Heterogeneity was quantified with the I2 statistic, which describes the proportion of total variation in study estimates as a result of heterogeneity [12]. To further assess the robustness of our findings, we performed several sensitivity analyses by excluding nonrandomized studies, or studies that did not report the intervention in the control group. We also assessed the relative influence of each study on pooled estimates by omitting one study at a time. Finally, we assessed the publication bias by using Egger's test and funnel plots. Statistical analyses were

performed with Review Manager software, version 5.3 (The Nordic Cochrane Centre, The Cochrane Collaboration).

## Results

### Study Selection

The search strategy retrieved 1124 articles from different sources and 12 articles were included in this meta-analysis [13-24] (see Figure 1 and Table 1). One study contributed two articles [14,15]. We used BMI data from the 2011 Turner-McGrievy and Tate study [14], but because that report did not include physical activity measurements, we took the physical activity data from a 2013 publication by Turner-McGrievy et al [15]. Studies were published between 2010 and 2015, and sample sizes ranged from 35 [18] to 361 [22]. There were two nonrandomized controlled trials [13,16], but the rest of the studies were randomized controlled trials. The interventions in many control groups were ones such as traditional interventions or intensive counseling. Only one study did not specify the type of intervention in the control group [13] (see Table 2).

**Table 1.** Characteristics of included clinical trials.

| Author, year | Country | Study design | Population | SS[a] | Men, % | Age in years, mean | Study duration | Outcome |
|---|---|---|---|---|---|---|---|---|
| Lee, 2010 [13] | South Korea | CCS[b] | Voluntary participants from the obese clinic at the fitness center, Seoul | 36 | N/A[c] | 28.5 | 6 weeks | Body weight, BMI[d] |
| Turner-Mc-Grievy, 2011 [14], 2013 [15] | United States | RCT[e] | Overweight and obese men and women | 96 | 24.7 | 44 | 6 months | BMI, physical activity |
| Kirwan, 2012 [16] | Australia | MCCT[f] | General population | 200 | 52 | 40 | 3 months | Physical activity |
| Carter, 2013 [17] | United Kingdom | RCT | Overweight volunteers | 86 | 33 | 41.2 | 6 months | Body weight, BMI |
| Allen, 2013 [18] | United States | RCT | Overweight and obese men and women | 35 | 22.1 | 44.9 | 6 months | Body weight, BMI, waist circumference |
| Brindal, 2013 [19] | Australia | RCT | Adult women with self-reported BMI >25 kg/m$^2$ | 58 | 0 | 42 | 2 months | Body weight |
| Laing, 2014 [20] | United States | RCT | Primary care patients with BMI >25 kg/m$^2$ | 212 | 27 | 43.3 | 6 months | Body weight |
| Glynn, 2014 [21] | Ireland (West) | RCT | Primary care patients | 90 | 36 | 44 | 2 months | Body weight, BMI, step count |
| Smith, 2014 [22] | Australia | RCT | Adolescent boys in low-income communities | 361 | 100 | 12.7 | 20 weeks | BMI, waist circumference |
| Hebden, 2014 [23] | Australia | RCT | Students and staff, Australian University | 41 | 19 | 22.6 | 3 months | Body weight, BMI, MPA[g], VPA[h] |
| Partridge, 2015 [24] | Australia | RCT | Participants at risk of excess weight gain | 250 | 38 | 27.2 | 9 months | Body weight, BMI, MPA, VPA |

[a]SS: sample size.

[b]CCS: case-control study.

[c]N/A: not applicable.

[d]BMI: body mass index.

[e]RCT: randomized controlled trial.

[f]MCCT: matched case-control trial.

[g]MPA: moderate physical activity.

[h]VPA: vigorous physical activity.

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**Table 2.** Characteristics of intervention types and description of apps.

| Author, year | Outcome | Intervention type | Description of app | Control group treatment |
|---|---|---|---|---|
| Lee, 2010 [13] | Body weight, BMI[a] | Mobile phone app + usual care | Smart Diet app: provides a personalized diet profile; promotes knowledge about nutrition using a diet game | Not described |
| Turner-Mc-Grievy, 2011 [14], 2013 [15] | BMI, physical activity | Mobile phone app + podcast + Twitter messages | Diet and physical activity-monitoring app (2010 version of FatSecret's Calorie Counter app) | Podcast only |
| Kirwan, 2012 [16] | Physical activity | Mobile phone app + 10,000 steps program | Self-monitoring and self-reported physical activity levels (iStepLog) | 10,000 steps program |
| Carter, 2013 [17] | Body weight, BMI, physical activity | Mobile phone app | Self-monitoring with managed intervention delivered by (MMM) app | Self-monitoring by using a food diary + a calorie-counting book |
| Allen, 2013 [18] | Body weight, BMI, waist circumference | Mobile phone app + intensive counseling | Lose It! (weight-loss app) | Intensive counseling |
| Brindal, 2013 [19] | Body weight | Mobile phone app + Celebrity Slim program | Support app: My Meals + My Weight + My Task | Celebrity Slim program alone |
| Laing, 2014 [20] | Body weight | Mobile phone app + usual care | MyFitnessPal app | Counseling about activities to lose weight + one-page educational handout on healthy eating |
| Glynn, 2014 [21] | Body weight, BMI, step count | Mobile phone app + usual care | Accupedo-Pro Pedometer app | Physical activity goals and information on the benefits of exercise + Be active physical activity promotion brochure |
| Smith, 2014 [22] | BMI, waist circumference | Mobile phone app + parent newsletters, seminars, sport sessions, lunchtime physical activity-mentoring sessions, teachers attend two 6-h workshops, and one fitness instructor session | Physical activity monitoring, recording of fitness challenge results, tailored motivational messaging, goal setting for physical activity and screen time | Traditional intervention (ie, regularly scheduled school sports and physical education lessons) |
| Hebden, 2014 [23] | Body weight, BMI, MPA[b], VPA[c] | Mobile phone app + SMS[d] text messages + email messages + Internet forums + usual care | Four mobile phone apps per behavior | A 10-page printed booklet |
| Partridge, 2015 [24] | Body weight, BMI, MPA, VPA | Mobile phone app + SMS text messages + email messages + Internet forums + community blog + usual care | Mobile phone apps that provide education and allow self-monitoring | Control participants received a mailed two-page handout, four text messages, and access to a website |

[a]BMI: body mass index.

[b]MPA: moderate physical activity.

[c]VPA: vigorous physical activity.

[d]SMS: short message service.

## Meta-Analysis of Mobile App Intervention and Body Weight

Data from 913 participants were analyzed in nine clinical trials [13,14,17-21,23,24]. Compared with the control group, mobile phone app interventions resulted in significant decreases in body weight, with the pooled estimates of the net change in body weight being -1.04 kg (95% CI -1.75 to -0.34; I2 = 41%) (see Figure 2). In the sensitivity analysis, we excluded the Lee study [13] because it was not a randomized study and did not include any intervention in the control group. The exclusion of this study did not modify the results (WMD -1.04 kg, 95% CI -1.80 to -0.27 kg; I2 = 48%).

The funnel plot showed reasonable symmetry, which suggested no evidence of publication bias in the clinical trials of mobile apps for weight loss (see Multimedia Appendix 2). In the sensitivity analysis, the exclusion of individual studies did not substantially modify estimates; the pooled WMDs ranged from -0.63 to -1.20 kg.

**Figure 2.** Meta-analysis of the net change in body weight (kg) associated with mobile phone app intervention, expressed as the change during the mobile phone app intervention minus the change during the control diet. The area of each square is proportional to the inverse of the variance of the weighted mean difference. Horizontal lines represent 95% CIs. Diamonds represent pooled estimates from inverse variance (IV) weighted random-effects models.

| Author year | Experimental Mean | SD | Total | Control Mean | SD | Total | Weight | Mean Difference IV, Random, 95% CI |
|---|---|---|---|---|---|---|---|---|
| Allen 2013 | -5.4 | 4 | 16 | -2.5 | 4.1 | 18 | 5.5% | -2.90 [-5.63, -0.17] |
| Brindal 2013 | -2.9 | 6.4 | 28 | -2.1 | 1 | 30 | 6.7% | -0.80 [-3.20, 1.60] |
| Carter 2013 | -4.6 | 5.2 | 43 | -2.9 | 5.85 | 43 | 7.0% | -1.70 [-4.04, 0.64] |
| Glynn 2014 | -2.2 | 3.4 | 45 | -1.5 | 4.3 | 45 | 11.8% | -0.70 [-2.30, 0.90] |
| Hebden 2014 | -1.6 | 3 | 26 | -1.4 | 3.18 | 25 | 10.9% | -0.20 [-1.90, 1.50] |
| Laing 2014 | -0.03 | 4.64 | 105 | 0.27 | 4.64 | 107 | 15.5% | -0.30 [-1.55, 0.95] |
| Lee 2010 | -1.9 | 2.3 | 19 | -0.9 | 4.64 | 17 | 6.5% | -1.00 [-3.44, 1.44] |
| Partridge 2015 | -1.9 | 2.84 | 125 | 0.2 | 2.99 | 125 | 22.9% | -2.10 [-2.82, -1.38] |
| Turner-McGriew 2011 | -2.57 | 2.6 | 47 | -2.45 | 4.39 | 49 | 13.4% | -0.12 [-1.56, 1.32] |
| **Total (95% CI)** | | | **454** | | | **459** | **100.0%** | **-1.04 [-1.75, -0.34]** |

Heterogeneity: Tau² = 0.43; Chi² = 13.55, df = 8 (P = 0.09); I² = 41%
Test for overall effect: Z = 2.90 (P = 0.004)
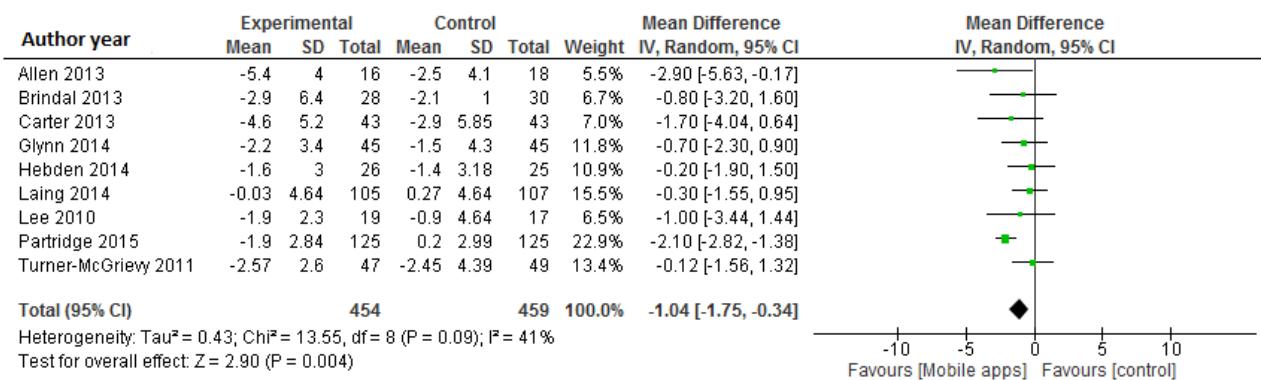
## Meta-Analysis of Mobile App Intervention and Body Mass Index

Data from 1047 participants were analyzed in eight clinical trials [14,17,18,21-24]. Pooled results indicated a significant net difference in BMI between mobile phone app and control intervention groups (WMD -0.43 kg/m$^2$, 95% CI -0.74 to -0.13; I2 = 50%) (see Figure 3). The exclusion of the Lee study [13]

did not modify the results (WMD -0.42 kg/m$^2$, 95% CI -0.76 to -0.07; I2 = 54%).

The funnel plot showed reasonable symmetry, which suggested no evidence of publication bias in the clinical trials of mobile apps for weight loss (see Multimedia Appendix 2). In the sensitivity analysis, the exclusion of individual studies did not substantially modify estimates; the pooled WMDs ranged from -0.36 to -0.59 kg/m$^2$.

**Figure 3.** Meta-analysis of the net change in BMI (kg/m$^2$) associated with mobile phone app intervention, expressed as the change during the mobile app intervention minus the change during the control diet. The area of each square is proportional to the inverse of the variance of the weighted mean difference. Horizontal lines represent 95% CIs. Diamonds represent pooled estimates from inverse variance (IV) weighted random-effects models.

| Author year | Experimental Mean | SD | Total | Control Mean | SD | Total | Weight | Mean Difference IV, Random, 95% CI |
|---|---|---|---|---|---|---|---|---|
| Allen 2013 | -1.8 | 1.3 | 16 | -0.8 | 1.4 | 18 | 8.3% | -1.00 [-1.91, -0.09] |
| Carter 2013 | -1.6 | 4.39 | 43 | -1 | 1.94 | 43 | 3.9% | -0.60 [-2.03, 0.83] |
| Glynn 2014 | -0.8 | 2.1 | 45 | -0.2 | 1.81 | 45 | 9.8% | -0.60 [-1.41, 0.21] |
| Hebden 2014 | -0.6 | 1.37 | 26 | -0.5 | 1.87 | 25 | 8.4% | -0.10 [-1.00, 0.80] |
| Lee 2010 | -0.8 | 0.97 | 19 | -0.2 | 0.92 | 17 | 13.8% | -0.60 [-1.22, 0.02] |
| Partridge 2015 | -0.9 | 1.2 | 125 | -0.3 | 1.26 | 125 | 24.3% | -0.60 [-0.91, -0.29] |
| Smith 2014 | 0.6 | 1.21 | 181 | 0.61 | 1.07 | 180 | 27.0% | -0.01 [-0.25, 0.23] |
| Turner-McGriew 2011 | -0.91 | 4.13 | 85 | -0.26 | 3.86 | 54 | 4.4% | -0.65 [-2.00, 0.70] |
| **Total (95% CI)** | | | **540** | | | **507** | **100.0%** | **-0.43 [-0.74, -0.13]** |

Heterogeneity: Tau² = 0.07; Chi² = 13.86, df = 7 (P = 0.05); I² = 50%
Test for overall effect: Z = 2.80 (P = 0.005)
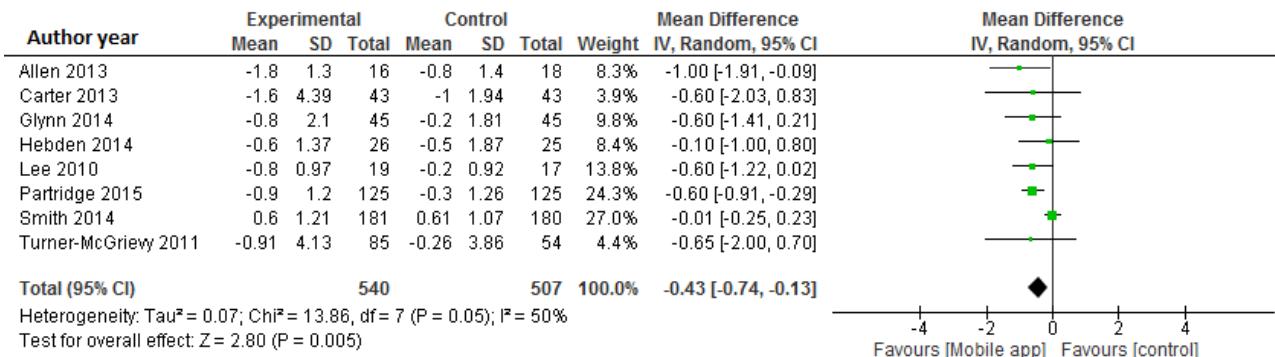
## Meta-Analysis of Mobile App Intervention and Physical Activity

Data from 1243 participants were analyzed in seven clinical trials [14,16,18,20-22,24]. Pooled results indicated a nonsignificant difference in physical activity between mobile app and control intervention groups (SMD 0.40, 95% CI -0.07 to 0.87; I2 = 93%) (see Figure 4). The sensitivity analysis indicated that no single study was the main origin of heterogeneity between studies. Next, we excluded any two

studies in turn and pooled the data of the remaining studies. The heterogeneity was decreased (I2 = 33%) after two studies—Kirwan et al [16] and Smith et al [22]—were excluded (SMD 0.27, 95% CI 0.08-0.47).

The funnel plot showed reasonable symmetry, which suggested no evidence of publication bias in the clinical trials of mobile apps designed to increase physical activity (see Multimedia Appendix 2). In the sensitivity analysis, the exclusion of individual studies did not modify the estimates; the pooled SMDs ranged from 0.17 to 0.51.

**Figure 4.** Meta-analysis of the net change in physical activity associated with mobile phone app intervention, expressed as the change during the mobile app intervention minus the change during the control intervention. The area of each square is proportional to the inverse of the variance of the standardized mean difference. Horizontal lines represent 95% CIs. Diamonds represent pooled estimates from inverse variance (IV) weighted random-effects models.



| Study or Subgroup | Intervention Mean | SD | Total | Control Mean | SD | Total | Weight | Std. Mean Difference IV, Random, 95% CI |
|---|---|---|---|---|---|---|---|---|
| Allen 2013 | -2 | 5.4 | 16 | -1.4 | 7.1 | 18 | 11.9% | -0.09 [-0.77, 0.58] |
| Glynn 2014 | 1,631 | 3,842 | 45 | -386 | 3,281 | 45 | 14.0% | 0.56 [0.14, 0.98] |
| Kirwan 2012 | 159.89 | 1,831.3 | 50 | -4,360.7 | 2,739 | 150 | 14.4% | 1.77 [1.40, 2.13] |
| Laing 2014 | 0.87 | 2.6 | 105 | 0.66 | 2.6 | 107 | 15.0% | 0.08 [-0.19, 0.35] |
| Partridge 2015 | 572.5 | 1,085.8 | 125 | 245.9 | 318.4 | 125 | 15.1% | 0.41 [0.16, 0.66] |
| Smith 2014 | -23 | 129.6 | 181 | -3 | 87 | 180 | 15.3% | -0.18 [-0.39, 0.03] |
| Turner-McGriew 2011 | 67.4 | 252.6 | 47 | 7.9 | 220.6 | 49 | 14.2% | 0.25 [-0.15, 0.65] |
| Total (95% CI) | | | 569 | | | 674 | 100.0% | 0.40 [-0.07, 0.87] |

Heterogeneity: Tau² = 0.36; Chi² = 89.10, df = 6 (P < 0.00001); I² = 93%
Test for overall effect: Z = 1.69 (P = 0.09)

### Risk of Bias in Included Studies

Randomization was considered adequate in most of the studies (see Figure 5). Only one study's participants were blinded as to their allocations [19], and in another study [24] the research staff collecting data on outcomes were blinded to the allocation of participants. For most of the studies we located the original study protocols [15,17,19-24]. Since we found no discrepancies between the outcomes that authors originally intended to measure and those reported in this study, we judged the risk of reporting bias to be low for this domain.

**Figure 5.** Summary of review authors' assessments of risk of bias for each Cochrane item and each included study.
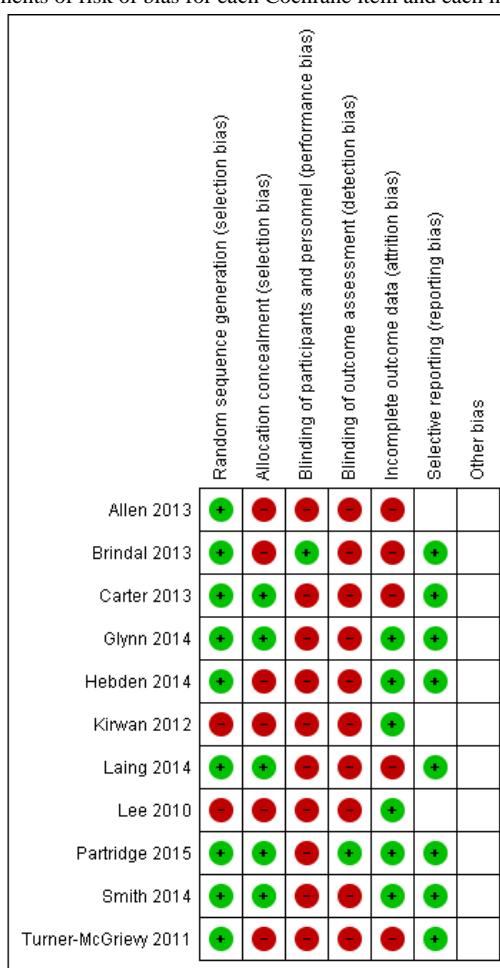


## Discussion

The current meta-analysis suggested that mobile phone app interventions compared with various control interventions significantly reduced body weight by 1.04 kg, reduced BMI by 0.43 kg/m², and nonsignificantly increased physical activity by an SMD of 0.40. Our findings were robust across sensitivity analyses. Although the mean reductions in body weight and BMI were modest, it would not be expected for a single change in weight-loss interventions, such as mobile phone apps, to cause clinically meaningful weight loss compared with other control interventions [25]. Many of the control group treatments were other interventions. This could dilute the analysis, as it is possible that in some of the studies the treatment group showed a significant change, while the control group also

showed a similar significant result. In our sensitivity analyses, the results were not modified when we excluded one study that did not describe if the control group had received any intervention [13].

Some of the most recognizable research in mobile interventions has focused on text-messaging interventions, or SMS. A previous meta-analysis [26] found that mobile phone interventions were associated with significant changes in body weight and BMI compared with the control group (-1.44 kg and -0.24 units, respectively). This meta-analysis included only mobile interventions based on contacts by SMS and multimedia message services (MMS). A previous systematic review found strong evidence from the included RCT that weight loss occurs in the short term because of mobile technology interventions [27]. Another systematic review that included seven articles demonstrated a beneficial impact of text messaging or a mobile app for reducing physical inactivity and/or overweight/obesity [28]. Finally, a recent systematic review found that most apps that are focused on weight loss have inconsistent outcomes [29].

To our knowledge, this study is the first meta-analysis to summarize the evidence to date regarding effects of mobile phone app interventions compared with various control interventions. We excluded from our meta-analysis interventions based only on text messaging and focused solely on mobile phone apps because text-message interventions do not utilize the full potential of mobile phone technologies. Well-designed apps expand the potential for technology-based health interventions to impact populations in ways that previously were not possible and cannot be achieved without the capabilities of mobile phone software. Therefore, the need to regulate this growing market is becoming a concern, with increased advertising claims about effectiveness and researchers emphasizing the need for studies that will contribute scientific evidence about the true impact of these types of apps. The portability of mobile phones enables users to have access 24 hours a day, making possible the long-term management and reinforcement of health behaviors through a variety of communications and apps. Fitness and weight-loss mobile phone apps allow for the tracking of diet, weight, and physical activity; making grocery and restaurant decisions; cooking healthy meals [28]; or gamification of the intervention. Moreover, participants do not need to carry an extra piece of purchased technology, such as a pedometer, to track physical activity.

Several limitations have been noted. Only a small number of available studies assess the effectiveness of mobile phone apps in weight-loss programs, and they included small sample sizes and short follow-up periods. The use of apps for improving physical activity and reducing anthropometric measures is relatively new. More randomized controlled trials with larger sample sizes and longer follow-up periods are needed to determine the effectiveness of mobile apps in improving health outcomes.

A recent study aimed to evaluate diet/nutrition and anthropometric apps based on incorporation of features consistent with theories of behavior change; all apps were found to be very low in theoretical content or use of theory to guide behavior change [28]. The studies included in this meta-analysis also varied in the content and theoretical basis of the intervention. Further investigation into the effective features of the mobile phone apps and the interventions' consistencies with theories of behavior change was not possible; this should be considered an area for future research.

The risk of bias was high in most of the studies and future research should improve on several issues, such as the use of blinding or improving attrition rate. All studies, except for one [19], failed to conceal the blinding of participants and personnel, and only one study [24] blinded the research staff collecting the data on outcomes as to the allocation of participants. Given the nature of the intervention, blinding of participants and personnel is difficult. However, it is important to recognize the possible influence of patient and personnel expectations. Therefore, adoption of blinding techniques, such as the use of sham procedures, blinding participants to the study hypothesis, or using a blinded centralized assessment of primary outcomes, will improve the quality of the evidence [30].

A large attrition rate was noted in some of the studies [17,20] included in this meta-analysis. High attrition rates are common in weight-loss interventions, and the reasons for this are likely complex and varied [31]. Attrition has an obvious impact on the validity of results obtained and can introduce bias; for example, those more motivated to reduce their weight or increase physical activity may remain in the trial. Moreover, several studies found that most participants rarely used the app after the first month of the study [20,23]. As with other weight-loss interventions, the most effective app may be one that can engage people for the longest period. It is known that adherence to self-monitoring of food intake is associated with twice as much weight loss as infrequent monitoring [32]. Without the participant's active engagement, the app is not likely to be used and as a result will not be effective [28]. The most highly ranked engagement strategies identified are (in order of preference) ease of use, design aesthetic, feedback, function, ability to change design to suit own preference, tailored information, and unique mobile phone features [33]. Weight-loss apps may need to be substantially more engaging or less time-consuming to produce weight reduction in the average individual. It would be useful to design strategies to increase "app appeal" before implementing this type of intervention. Gamification of the app, financial incentives, or delivering the app in a setting of group competition could be important adjuncts to increase motivation to use the app and lose weight [20,34].

To our knowledge, this is the first meta-analysis to summarize the effectiveness of mobile apps designed to improve physical activity and reduce anthropometric measures. Our meta-analysis highlighted the need to perform larger, high-quality, randomized controlled clinical trials with longer follow-up. The number of available mobile phone apps is growing steadily, and mobile phones are constantly undergoing updates so the features have changed over time. Incorporating features consistent with theories of behavior change into health-related apps would be useful to improve weight-loss outcomes [35]. We searched several databases in order to avoid publication bias, which is a concern in meta-analyses that only include published studies.

Using funnel plots in our meta-analysis made it possible to exclude publication bias with some confidence.

As the world's understanding of health and how to empower individuals to take better care of their health changes, health professionals must treat this change as progress. However, we must ensure that the patient is using a mobile app with appropriate quality guarantees. This meta-analysis aimed to provide a rigorous, systematic, and quantitative review of the studies that have analyzed the effectiveness of mobile apps and attempted to measure their influence on lifestyle changes. Bombarded by information overload in all arenas, health professionals and managers have a need for the insights provided by a tool like the meta-analysis; this could help them make decisions and decide what direction we should be moving in our efforts to promote weight loss, increase physical activity, and confront the public health crisis presented by overweight and obesity.

In summary, the results from this meta-analysis demonstrated that interventions based on mobile phone apps are associated with more weight loss than other types of interventions. Furthermore, a nonsignificant increase in physical activity was detected. Evidence form this meta-analysis shows that mobile phone app-based intervention may be useful tools for weight loss.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Database search strategies.

[PDF File (Adobe PDF File), 171KB - jmir_v17i11e253_app1.pdf ]

## Multimedia Appendix 2

Funnel plots from the meta-analysis of the association of mobile phone app intervention with (A) body weight change (kg), (B) body mass index (kg/m2), and (C) physical activity. SE, standard error.

[PNG File, 97KB - jmir_v17i11e253_app2.png ]

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## Abbreviations

**BMI:** body mass index
**CCS:** case-control study
**CINAHL:** Cumulative Index to Nursing and Allied Health Literature
**IDIAP:** Institut Universitari d'Investigació en Atenció Primària
**ITU:** International Telecommunications Union
**MCCT:** matched case-control trial
**MMS:** multimedia message service
**MPA:** moderate physical activity
**N/A:** not applicable
**PDA:** personal digital assistant
**RCT:** randomized controlled trial
**SDpost:** SD at the end of the intervention
**SDpre:** SD at baseline
**SMD:** standardized mean difference
**SMS:** short message service
**SS:** sample size
**VPA:** vigorous physical activity
**WMD:** weighted mean difference

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Original Paper

# Mobile Phone and Web 2.0 Technologies for Weight Management: A Systematic Scoping Review

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## Abstract

**Background:** Widespread diffusion of mobile phone and Web 2.0 technologies make them potentially useful tools for promoting health and tackling public health issues, such as the increasing prevalence of overweight and obesity. Research in this domain is growing rapidly but, to date, no review has comprehensively and systematically documented how mobile and Web 2.0 technologies are being deployed and evaluated in relation to weight management.

**Objective:** To provide an up-to-date, comprehensive map of the literature discussing the use of mobile phone and Web 2.0 apps for influencing behaviors related to weight management (ie, diet, physical activity [PA], weight control, etc).

**Methods:** A systematic scoping review of the literature was conducted based on a published protocol (registered at PROSPERO: CRD42014010323). Using a comprehensive search strategy, we searched 16 multidisciplinary electronic databases for original research documents published in English between 2004 and 2014. We used duplicate study selection and data extraction. Using an inductively developed charting tool, selected articles were thematically categorized.

**Results:** We identified 457 articles, mostly published between 2013 and 2014 in 157 different journals and 89 conference proceedings. Articles were categorized around two overarching themes, which described the use of technologies for either (1) promoting behavior change (309/457, 67.6%) or (2) measuring behavior (103/457, 22.5%). The remaining articles were overviews of apps and social media content (33/457, 7.2%) or covered a combination of these three themes (12/457, 2.6%). Within the two main overarching themes, we categorized articles as representing three phases of research development: (1) design and development, (2) feasibility studies, and (3) evaluations. Overall, articles mostly reported on evaluations of technologies for behavior change (211/457, 46.2%).

**Conclusions:** There is an extensive body of research on mobile phone and Web 2.0 technologies for weight management. Research has reported on (1) the development, feasibility, and efficacy of persuasive mobile technologies used in interventions for behavior change (PA and diet) and (2) the design, feasibility, and accuracy of mobile phone apps for behavioral assessment. Further research has focused exclusively on analyses of the content and quality of available apps. Limited evidence exists on the use of social media for behavior change, but a segment of studies deal with content analyses of social media. Future research should analyze mobile phone and Web 2.0 technologies together by combining the evaluation of content and design aspects with usability, feasibility, and efficacy/effectiveness for behavior change, or accuracy/validity for behavior assessment, in order to understand which technological components and features are likely to result in effective interventions.

## Introduction

A recent consensus statement on the prevention and management of noncommunicable diseases stressed the need to focus on behavior change and to develop more user-centered, effective, and efficient preventive programs [1]. Overweight and obesity together are the fifth leading risk factor for global deaths, accounting for around 3.4 million deaths every year [2], making it a global public health priority [3-5]. Technology-based health services, delivered or enhanced through the Internet (ie, eHealth technologies) [6] and, in particular, mobile technologies, offer great potential to increase the reach of public health initiatives and to improve public health [7,8]. For example, behavioral and biomedical "big data" collected through ubiquitous mobile phones and their sensors [9] could be used to predict health trends and illnesses [10], hence optimizing the delivery of health care programs [11].

This potential is enhanced by increasing adoption rates for mobile and Internet technologies. In 2014, there were 6.5 billion mobile subscribers (93% of the entire world population) [12], with mobile phone penetration rates reaching over 70% of the population of many European and North American countries, such as Spain (83%), Canada (78%), the United Kingdom (75%), the United States (73%), and Italy (71%) [13]. Mobile phones allow users to access various Internet services, in particular social media profiles. In Europe, social media are accessed through mobile devices by 26% of the total population (66% of the total active social media population) [14]. Social media apps that "build on the ideological and technological foundations of Web 2.0, and that allow the creation and exchange of User Generated Content" [15] involve very large segments of the population. A recent Pew Research Center's Internet & American Life Project report showed that 81% of online US adults are active social media users, with Facebook being the most popular social networking site, used by 58% of the population [16]. Similarly, in Europe there are 300 million active social media users (about 40% of the entire population), with Northern Europe having the highest rates for Facebook use (56%) [14].

The growth in mobile phone and social media usage supports widespread adoption and diffusion of mobile phone apps. At the end of 2014, there were 1.4 million apps available on Google Play, 1.2 million in the iTunes App Store, and 290,000 in the Amazon app stores [17]. In particular, the use of health and fitness apps has recently shown a rapid and steady growth. In December 2014, compared to the previous year, the time spent on apps in the health and fitness and sport categories increased by 89% and 74%, respectively [18]. Recent surveys show that 19% of mobile phone owners reported downloading an app to track or manage their health [19] which (1) helps set health-related goals (30%), (2) assists with health-related searches (28%), (3) enhances health-related motivation (27%), (4) identifies unhealthy habits (7%), or (5) supports adherence to medications (5%) [20]. The most popular health apps are used for tracking and monitoring physical activity (38%) and diet (31%), and for managing weight (12%) [19].

Following the trends in technology development, the eHealth research literature has increased considerably in the last decade. For example, a PubMed search for eHealth-related terms on June 4, 2015, resulted in 20,176 hits for "eHealth," and 1166 hits for "eHealth interventions." There were also 3148 hits for "eHealth review." This trend is also reflected in the introduction of specific Medical Subject Headings (MeSH) topics, which are used by major electronic databases such as PubMed/Medline, Cochrane Library, and Web of Science. As of July 4, 2015, the MeSH major topic "Cell Phones" (introduced in 2003) produced 4481 hits (373.4 hits/year), whereas "Mobile Applications" (introduced in 2014) produced 357 hits in a year. For Web 2.0 technologies, the coverage is smaller but still indicative of a growing field; the general umbrella MeSH topic "Social Media" (introduced in 2012) produced 1369 hits (456.3 hits/year), whereas the specific term "Social Networking" (introduced in 2012) yielded 732 hits (146.4 hits/year), and "Blogging" (introduced in 2010) yielded only 401 hits (80.2 hits/year).

An increasing number of systematic reviews and meta-analyses on eHealth interventions are available. These evaluate their impact on general health promotion [21], specifically including smoking [22], weight management [23], and diet and physical activity (PA) [24], or they assess effects on health care program delivery [25] and treatments (eg, HIV [26]). Some scoping reviews have described the use of mobile and Web 2.0 technologies specifically for general health behavior change [27-31]. However, most focus on mobile technologies alone [28-31] and do not provide a comprehensive picture of the research involving both Web 2.0 and mobile phone technologies for weight management in particular. The depth and breadth of the potentially relevant literature in this domain prompts exploration of the field in the form of a scoping review [32]. Scoping reviews generally provide an overview or a map of the available literature, hence determining the *scope* of subsequent systematic reviews, which will have narrower or more focused research questions, detailed data extraction, and study quality assessment [33]. Scoping reviews allow researchers to synthesize the literature and to highlight potential gaps and parameters in the available literature.

Therefore, the aim of this scoping review is to provide a systematic, comprehensive, and updated overview of eHealth research into use of mobile phones and Web 2.0 technologies for weight management over the past decade. The general research questions that guided this scoping review were as follows: (1) What is the current state of research discussing the use of mobile phones in combination with Web 2.0 technologies for weight management?, (2) What type of research has investigated these technologies?, and (3) On which methodological and technological aspects has this research focused?

## Methods

### Overview

We conducted a systematic scoping review of the literature describing the role of mobile phone and Web 2.0 technologies for weight management. This review was based on a published protocol (registered at PROSPERO: CRD42014010323) [34]. In accordance with Arksey and O'Malley's proposed framework for scoping reviews [32], we provide a qualitative, descriptive, comprehensive chart/map of the literature on the topic. The chart covers aspects related to design, implementation, and evaluation of mobile and social media technologies employed for promoting and assessing behaviors associated with weight management, in the broader context of obesity prevention initiatives.

### Information Sources

Articles were identified through a comprehensive search in the following 16 electronic databases, covering medicine and behavioral, social, and computer sciences, considering the multidisciplinary nature of the topic: PubMed/Medline, Embase, Global Health, the Cumulative Index to Nursing and Allied Health Literature (CINAHL), PsycINFO, the Cochrane Library (including the Database of Systematic Reviews, the Central Register of Controlled Trials, and the Database of Abstracts of Reviews of Effects), SPORTDiscus, PsycARTICLES, the Psychology & Behavioral Sciences Collection, the Education Resources Information Center (ERIC), Communication and Mass Media Complete, the Association for Computing Machinery (ACM) Digital Library, Institute of Electrical and Electronics Engineers (IEEE) Xplore, the Web of Science Core Collection (including Science Citation Index Expanded, Social Sciences Citation Index, Arts & Humanities Citation Index, Conference Proceedings Citation Index-Science, and Conference Proceedings Citation Index-Social Science & Humanities), and the "grey" literature sources WorldCat Dissertations (via Online Computer Library Center [OCLC] FirstSearch) and OpenGrey. Reference lists of the included studies and reviews were also screened for additional references.

### Search Strategy

Applying the PICOS (participants, interventions, comparators, outcomes, and study design) framework [35], a comprehensive search strategy included keywords and MeSH to describe the population (ie, any population, being obese/overweight, healthy, or interested in weight management), interventions/comparators (ie, mobile phones and social media), and outcomes (ie, weight, body mass index [BMI], diet, and physical activity). We included any study design. The strategy was developed by employing terms and MeSH used in related systematic reviews (eg, on weight management and diet [36], PA [37], mobile phones and mHealth [29,38], and social media [39,40]). Searches were restricted to publications available in English from January 1, 2004 to December 31, 2014 to ensure that relevant modern technologies were included. A sample of the search strategies used across databases and in Medline (Ovid) is provided in the Multimedia Appendix 1. Preliminary searches were conducted in June and July 2014; final searches were conducted in August 2014, and updated on February 27, 2015.

### Eligibility Criteria

We considered any type of primary research article or review describing the use of mobile phones or Web 2.0 technologies (ie, interventions) in relation to weight management and related behaviors (ie, outcomes), including any study design or type, and among any population group. Hence, any article was included that addressed the role of mobile devices and/or Web 2.0 technologies to measure, track, or encourage change in the behaviors that contribute to weight management (ie, PA and/or diet) for the prevention of overweight and obesity. We defined mobile devices as mobile phones, personal digital assistants (PDAs), and handheld and ultraportable computers such as tablets (eg, iPads) [25]. We defined Web 2.0 technologies as "Internet-based applications that allow the creation and exchange of User Generated Content and include social networking sites, collaborative projects, micro-blogging and blogging tools, content communities, virtual worlds" [15].

We excluded the following types of studies: general epidemiological studies on the use of the technologies (eg, effects of radiation from mobile phone use on brains and cells, or their association with cancer; penetration rates of mobile phones in households); studies where mobile phones were simply used as methods for data collection without any further reporting on, or testing of, the assessment methods, and research into mobile and Web 2.0 technologies for clinical management (eg, as decision support tools for health professionals); and studies where mobile phones were used for the self-management of chronic conditions (eg, diabetes, chronic obstructive pulmonary disease [COPD], and heart failure) where weight management was not the primary focus (eg, interventions using mobile phone apps to manage type 2 diabetes in obese patients where the main focus was on blood glucose control). We also excluded articles discussing the use of other technologies alone, such as video game consoles, virtual reality devices, computers, laptops, pagers, land phones, and wearable devices (eg, Fitbit, Nike+, and Jawbone UP), as well as traditional websites with no social media components specified.

### Study Selection, Categorization, and Data Extraction

Articles were selected in a two-step process, which involved two reviewers (MB and LS) who independently screened first the title and abstract, and then the full text of the retrieved articles applying the inclusion/exclusion criteria. One reviewer (MB) completed an initial categorization of the selected articles using an inductively developed "charting" tool (provided in Multimedia Appendix 2), which was improved upon with input from the other authors, and checked for consistency by another reviewer (JS). Data extracted included the following: author's name, year of publication, country of origin, study objectives/purpose (as reported verbatim by the authors), targeted behaviors (eg, PA, diet, or weight loss/management), target population (ie, age group, health status/condition, and gender where explicitly indicated in the paper), type of technology (ie, mobile, Web 2.0, etc, with additional details about the type of mobile and Web 2.0 technology, operating system, and devices tested when reported), and type of study (eg, descriptive, qualitative, mixed methods, randomized controlled trial [RCT], or other quantitative studies). We also

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linked articles that presented data on, or analyzed data from, RCTs to their reported trial registry number (see Multimedia Appendix 3). As this is a scoping review, we did not assess the risk of bias in studies, heterogeneity, or publication bias.

Inter-rater reliability estimates were calculated (see below) and all disagreements were resolved through discussion until consensus was reached in all steps. For selection and data extraction, we evaluated inter-rater reliability using Gwet's first-order agreement coefficient (AC1) statistic [41], a reliable alternative to Cohen's kappa. Gwet's AC1 does not underestimate reliability when the number of instances is small or when there is an asymmetric distribution between agreements and disagreements, as is likely to occur when screening a large number of titles and abstracts [41,42].

## Analyses

A qualitative synthesis of the included studies was undertaken to map the literature as outlined in the research questions. Data were summarized using descriptive frequency tables for the inductively developed categories describing the purpose of the paper, its methodology, and the data reported. The literature was summarized according to the emerging research themes and technology used.

## Results

### Search Results and Study Selection

The search across the 16 electronic databases yielded a total of 6001 records; reference lists and other sources yielded an additional 127 references. After duplicate removal, one reviewer (MB) and a temporary research assistant screened the titles and abstracts of 4540 records, excluding 3872 entries (92% agreement; AC1 .91, 95% CI .89-.92). To ensure consistency in the application of inclusion/exclusion criteria, a third reviewer (JS) screened a randomly selected 5% sample of the references, achieving a 91% agreement with the previous judgments (AC1 .88, 95% CI .83-.94). The remaining 668 references were assessed in full text by the original reviewer (MB) and a second reviewer (LS), and a further 211 were excluded (90% agreement; AC1 .82, 95% CI .79-.85), leaving 457 articles included in this review (Preferred Reporting Items for Systematic Reviews and Meta-Analyses [PRISMA] diagram [43] in Figure 1). As in the first step, a third reviewer (JS) screened a 20% randomly selected sample of full-text articles, achieving 97% agreement and good reliability (AC1 .94, 95% CI .88 - .99). A table with the excluded references and the reasons for exclusion is provided in Multimedia Appendix 4.

**Figure 1.** PRISMA flow diagram.
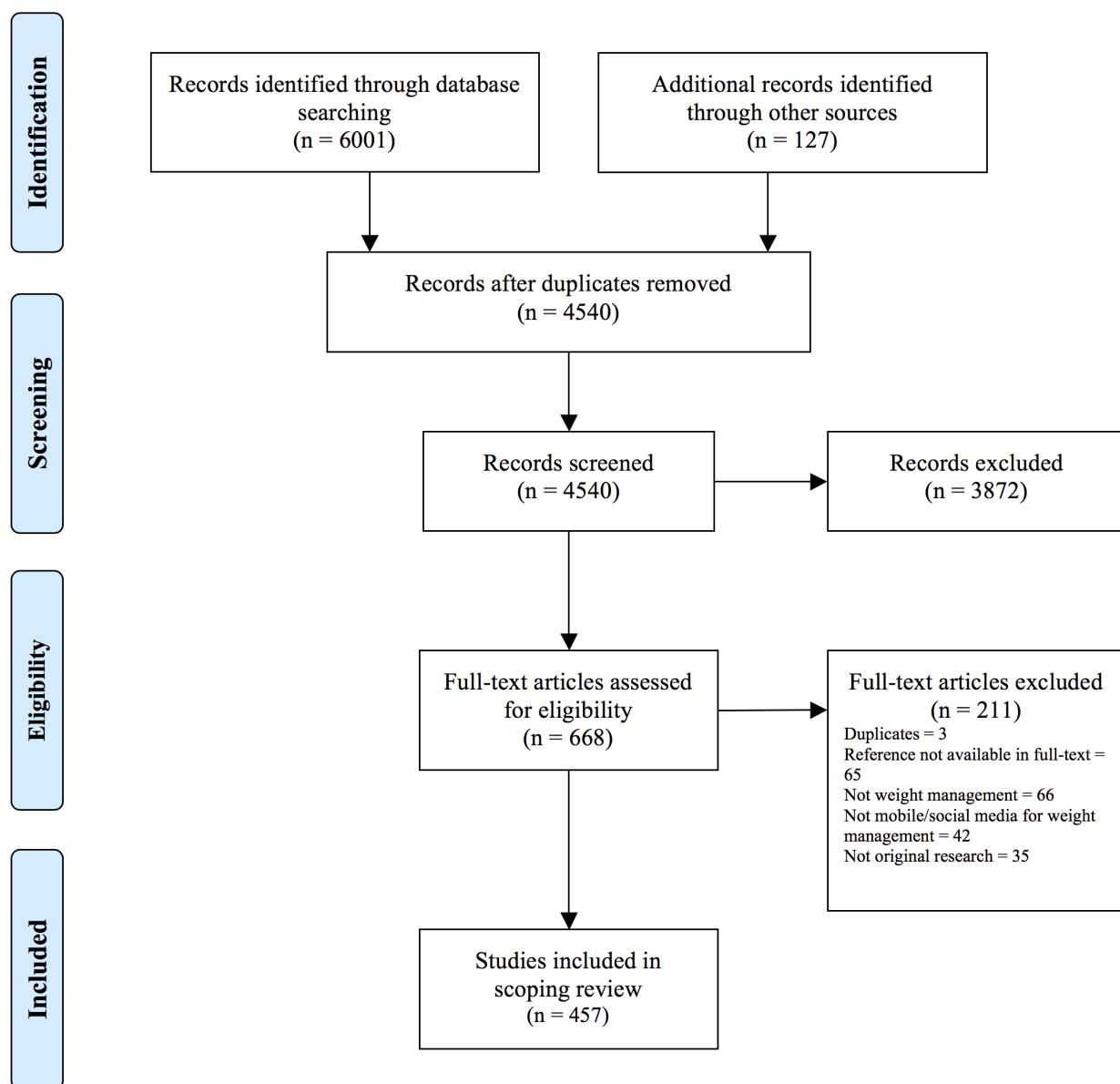


## Article Characteristics

The majority of the 457 included references (364/457, 79.6%) were published as journal articles in 157 different publications, covering a variety of disciplines including medical and health sciences, computing and informatics, education, and psychology. A relatively large number of publications came from high-ranking journals in the fields of medical informatics, health services research, and public health, such as the Journal of Medical Internet Research (36/364, 9.9%), BMC Public Health (21/364, 5.8%), the American Journal of Preventive Medicine (14/364, 3.8%), and the Journal of Telemedicine and Telecare (13/364, 3.6%). The remainder were published as conference proceedings (93/457, 20.4%) presented at 89 different conferences, mostly focusing on pervasive computing and design. More than half of the journal articles were published after 2013 (255/457, 55.8%, range 2004-2014), while the median year for publication in conference proceedings was 2012 (interquartile range [IQR] 3; 63/93, 68% published after 2012, range 2006-2014). Figure 2 shows an overall exponential trend ($R^2$= .94) with the number of journal articles and conference proceedings growing considerably after 2008. Conference proceedings peaked in 2012 and declined progressively as publication in journal articles continued to increase.

Overall, the research was conducted in 39 countries, the majority of which were English-speaking (334/457, 73.1%), including the United States (219/457, 47.9%), Australia (54/457, 11.8%), the United Kingdom (30/457, 6.6%), Canada (17/457, 3.7%), New Zealand (8/457, 1.8%), and Ireland (6/457, 1.3%). Included research was also undertaken in other European countries (75/457, 16.4%), Southeast Asia (35/457, 7.7%), and the Middle East (11/457, 2.4%). Only 2 out of 457 (0.4%) publications originated from Latin and Central America—1 (0.2%) from Brazil and 1 (0.2%) from Mexico—and no articles originated from African countries.

**Figure 2.** Distribution of articles included in scoping review (n=457).
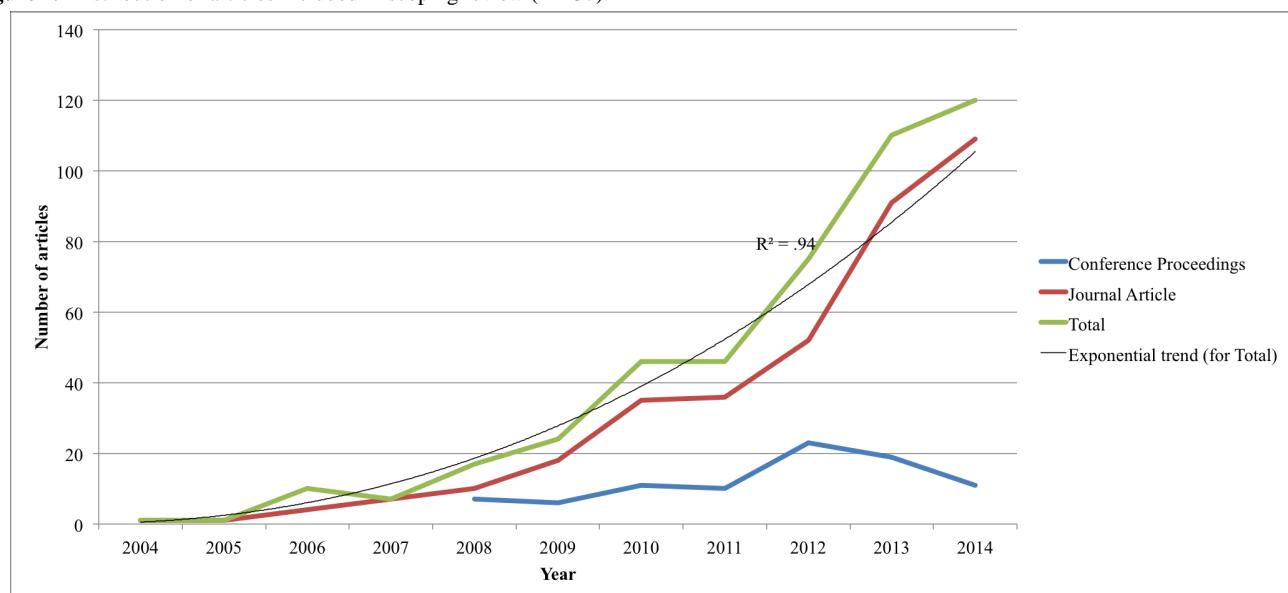


## Categorization of Selected Studies

The first author (MB) developed the charting tool using an initial sample of 40 papers, and the judgements were independently validated by the second author (JS), first using a random sample of 10 papers (80% agreement; AC1 .79, 95% CI .28 - 1.00), then 113 out of 457 (24.7%) included papers, achieving 94% agreement and good reliability (AC1 .94, 95% CI .89 - .98). The second author checked the categorization and data extraction for 239 articles out of 457 (52.3%) for consistency.

## Overarching Research Themes

We categorized primary research and review evidence using three overarching themes. The majority of studies described the role of mobile and Web 2.0 technologies for the first theme, *promoting behavior change* (308/457, 67.4%; 263 primary research articles and 45 reviews), and the second theme, *measuring behavior* (103/457, 22.5%; 96 primary research articles and 7 reviews). The first group included articles that discussed the use of technologies to shape behavior patterns related to managing weight. Technology was construed as a delivery mode for interventions promoting behavior change (eg, through self-monitoring, providing feedback, reminding, and motivating). The second group included articles that specifically focused on the development and evaluation of technologies for assessing physical activity or dietary behaviors, without reporting data on their effects on behavior or weight-related outcomes. These studies focused on data describing the accuracy or validity of apps or systems for physical activity and dietary assessment (eg, activity recognition, energy expenditure estimation, activity classification, food classification and caloric intake estimation, and comparison between self-reported, paper-and-pencil, and objective measures of behavior using the technologies).

A third theme, *overviews of apps and social media content*, encompassed 33 articles out of 457 (7.2%), which presented primary research concerning content analyses of social media and reviews of mobile phone apps and their content. These articles did not focus on the impact of the technologies on behavior or behavioral assessment, but rather on the content characteristics of the media (eg, healthy living blogging communities [44] or Twitter conversations about weight loss [45]). The remaining articles (14/457, 3.1%) included aspects of two or more of the themes. Out of 457 articles, 9 (2.0%) referred to behavior change and behavioral assessment. Of these 9 articles, 6 (67%) were primary research articles describing the development of mobile-based methods for dietary assessment and intervention [46,47], mobile phone apps for exercise monitoring and analysis [48,49], and apps for food intake and calorie balance monitoring [50,51]. Of the 9 articles, 3 (33%) were reviews describing mobile technologies for assessing and promoting PA [52,53] and diet [54]. A further 3 (33%) reviews out of 9 articles included aspects that could be categorized under both the first and third theme: a narrative review and content analysis of a Dutch PA and diet blogging community (Valtaf.nl) [55], a systematic review on mobile phone apps for women's health promotion [56], and a systematic review on mobile phone apps for food intake [57]. Hence, accounting for the overlaps between overarching themes (ie, the articles that covered both aspects are counted twice for each category), there were 468 categorizations in total. The majority of the articles covered *promoting behavior change* (318/468, 67.9%), of which 269 (84.6%) were primary research articles and 49 (15.4%) were reviews: 5 (1.6%) nonsystematic reviews, 5 (1.6%) general scoping reviews, 28 (8.8%) systematic reviews with qualitative syntheses, and 11 (3.5%) meta-analyses. The theme *measuring behavior* included 112 articles out of 468 total categorizations (23.9%), of which 101 (90.2%) were primary research articles and 11 (9.8%) were reviews: 2 (1.8%) nonsystematic reviews and 9 (8.0%) qualitative syntheses. The theme *overviews of social media and mobile phone apps* included 36 articles (36/468, 7.7%).

## Research Themes

Within two of the main overarching themes—*behavior change* and *measuring behavior*—three research themes emerged from the data. These represent the progressive stages in research: (1) *design and development*, (2) *feasibility*, and (3) *evaluations*.

*Design and development* included articles describing systems design [58] or the development of apps and platforms aimed at influencing or assessing behavior without reporting data on their effects, their usability, acceptability, or feasibility. *Feasibility* represented articles describing the results of pilot/feasibility studies focusing on process and procedural outcomes (eg, acceptability, participation, utilization, retention and recruitment, adherence, or compliance), rather than on the effects on behavior or on the accuracy/validity of behavioral assessment. Finally, *evaluations* included studies presenting the effects of technology-based interventions on behavior or weight-related outcomes, or technology-based methods for assessing behavior. Within the evaluations discussing behavior change, we created a distinctive subcategory—*process/outcome evaluations or causal-comparative studies*—which included primary research articles examining sociocognitive or technological factors associated with outcomes in the context of existing interventions, without directly reporting on the effects of the technology on behavior. We created subcategories to account for articles covering a combination of two or three of the research themes described above, which constitute the overlap between the themes. For example, we identified the concept of *usability* as indicating the overlap between *design and development* and *feasibility*, and used it to categorize articles that described the development of a system and measured outcomes such as ease of use, learnability, task efficiency, memorability, satisfaction, and usefulness [59]. The term usability was used with similar connotations in articles from different research fields to describe the elements associated with feasibility and acceptability of technologies in interventions and pilot studies.

Among the total of 366 primary research articles covering the two overarching research themes, *design and development* was discussed in 139 articles (38.0%): 87 (23.8%) covered *promoting behavior change*, 48 (13.1%) covered *measuring behavior*, and 4 (1.1%) covered both overarching themes. *Feasibility* was discussed in 191 primary research articles out of 366 (52.2%): 154 (42.1%) covered *promoting behavior change*, 35 (9.6%) covered *measuring behavior*, and 2 (0.5%) covered both overarching themes. *Evaluation* was reported in 247 primary articles out of 366 (67.5%): 167 (45.6%)—including 20 process evaluation papers—were related to *behavior change*, 75 (20.5%) were related to *measuring behavior*, and 3 (0.8%) covered both overarching themes.

Among the 58 reviews covering the two overarching research themes, 11 (19%) were narrative reviews: 5 (9%) nonsystematic reviews and 5 (9%) systematic scoping reviews on the use of technologies for general health promotion, and 1 (2%) on the use of technologies for dietary assessment [54]. All of these discussed the uses of technologies in general, recognizing their potential for behavior change or behavioral assessment without specifically focusing on design, development, or evaluations. Only 1 review out of 58 (2%) also covered aspects of *feasibility* in conjunction with the evaluation of accuracy and validity of technologies for dietary assessment [60]. No review explicitly reported on the feasibility of technologies for behavior change. The remaining 47 out of 58 reviews (81%) reported data on *evaluation* of technologies for behavior change, 9 (16%) for behavioral assessment, and 2 (3%) for both behavior change and assessment.

A visual summary of the research themes for primary research studies is presented in the Venn diagrams in Figure 3. Table 1 describes the distribution of primary research studies according to research themes and technology type. Articles that appear in more than one research theme are counted twice. The characteristics of the individual articles grouped by research theme and technology type are reported in Multimedia Appendix 3. Examples are provided in the following paragraphs.

**Table 1.** Distribution of primary research articles (n=366) according to research theme and technology used.

| Research themes | Technology | | | Total (n=366), n (%) |
|---|---|---|---|---|
| | Mobile, n (%) | Web 2.0, n (%) | Mobile and Web 2.0, n (%) | |
| **Promoting behavior change** | 192 (52.5) | 31 (8.5) | 41 (11.2) | 264 (72.1) |
| Design | 11 (3.0) | 1 (0.3) | 8 (2.2) | 20 (5.5) |
| Feasibility | 26 (7.1) | 4 (1.1) | 3 (0.8) | 33 (9.0) |
| Evaluations | 54 (14.8) | 6 (1.6) | 9 (2.5) | 69 (18.9) |
| Process evaluations | 7 (1.9) | 8 (2.2) | 5 (1.4) | 20 (5.5) |
| Design and evaluations | 1 (0.3) | 0 (0) | 0 (0) | 1 (0.3) |
| Design and feasibility | 31 (8.5) | 4 (1.1) | 9 (2.5) | 44 (12.0) |
| Feasibility and evaluations | 46 (12.6) | 5 (1.4) | 4 (1.1) | 55 (15.0) |
| Design, feasibility, and evaluations | 16 (4.4) | 3 (0.8) | 3 (0.8) | 22 (6.0) |
| **Measuring behavior** | 94 (25.7) | 0 (0) | 2 (0.5) | 96 (26.2) |
| Design | 10 (2.7) | 0 (0) | 0 (0) | 10 (2.7) |
| Feasibility | 3 (0.8) | 0 (0) | 0 (0) | 3 (0.8) |
| Evaluations | 28 (7.7) | 0 (0) | 0 (0) | 28 (7.7) |
| Design and evaluations | 22 (6.0) | 0 (0) | 1 (0.3) | 23 (6.3) |
| Design and feasibility | 7 (1.9) | 0 (0) | 1 (0.3) | 8 (2.2) |
| Feasibility and evaluations | 17 (4.6) | 0 (0) | 0 (0) | 17 (4.6) |
| Design, feasibility, and evaluations | 7 (1.9) | 0 (0) | 0 (0) | 7 (1.9) |
| **Promoting behavior change and measuring behavior** | 6 (1.6) | 0 (0) | 0 (0) | 6 (1.6) |
| Design | 1 (0.3) | 0 (0) | 0 (0) | 1 (0.3) |
| Evaluations | 2 (0.5) | 0 (0) | 0 (0) | 2 (0.5) |
| Design and feasibility | 1 (0.3) | 0 (0) | 0 (0) | 1 (0.3) |
| Design, feasibility, and evaluations | 2 (0.5) | 0 (0) | 0 (0) | 2 (0.5) |
| Total | 292 (79.8) | 31 (8.5) | 43 (11.7) | 366 (100) |

**Figure 3.** Venn diagrams representing the main research themes for primary research articles (n=366).

## Promoting behaviour change



## Measuring behaviour



The size of the numbers represents the frequency of the articles in the category.

Minimum font size: 36 pt (2 articles)

Maximum font size: 288 pt (71 articles)
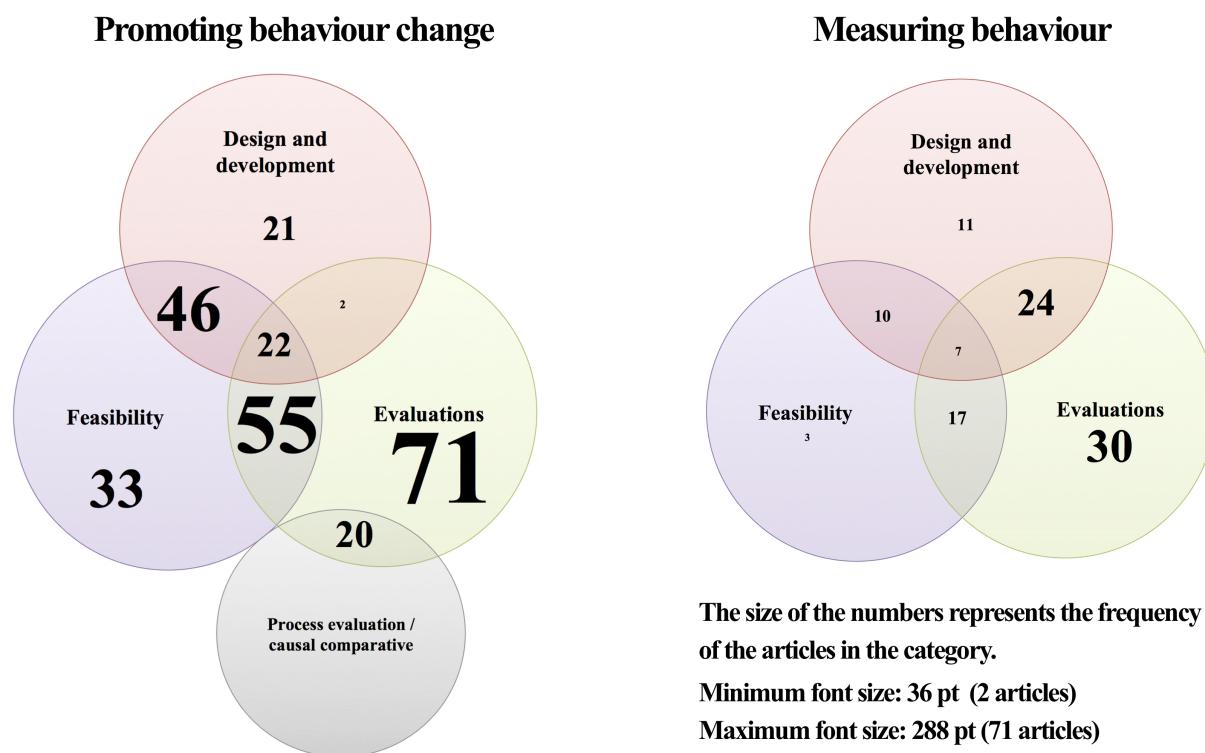
### Research on Technologies for Promoting Behavior Change

The majority of primary research studies dealing with behavior change (138/270, 51.1%) were published in the last 2 years. Most of these focused on mobile technologies (198/270, 73.3%). Research was comprised mostly of *evaluations* (127/198, 64.1%), followed by *feasibility* (121/198, 61.1%), and *design and development* studies (63/198, 31.8%). Examples of studies describing *design and development* and *usability* included testing of research-based apps (eg, UbiFit Garden [61,62] or bActive [63]) or commercial apps (eg, MyFitnessPal [64] or Lose It! [65]) for weight management and PA. Other articles presented details on the design; in addition, they evaluated the effects of technologies on PA behavior using uncontrolled before-and-after experiments (eg, Motivate [66,67] and BeWell [68,69]) or randomized controlled trials (eg, Fit Up [49] or Houston [70]). Several reported on the development and usability of apps for dietary interventions (eg, EatWell [71], Kalico [72], and My Meal Mate [73]). Others focused only on text messaging to support weight loss among a variety of populations and settings (eg, overweight and obese adults [74], female university staff [75], and children [76]). A total of 31 articles (31/270, 11.5%) reported exclusively on the use of Web 2.0 technologies, and mostly focused on *evaluations* (22/31, 71%) and *feasibility* (16/31, 52%). *Design and development* was reported in 8 articles (8/31, 26%). Examples include studies that reported on the development of research-developed social networking communities promoting weight loss (eg, Total Wellbeing Diet (TWD) online program [77] or Social Families (SOFA) project [78,79]), or Facebook-based weight management interventions

among young adult cancer survivors [80] and adult employees with metabolic syndrome [81]. A total of 41 studies out of 270 (15.2%) combined both mobile and Web 2.0 technologies, and almost equally covered all research stages—20 (7.4%) design and development, 19 (7.0%) feasibility, and 21 (7.8%) evaluations. Examples are the ManUp study, which aimed to promote healthy eating and PA among adults using a combination of social media and mobile phone apps [82], the Pounds Off Digitally study [83], and the follow-up, Mobile Pounds Off Digitally study [84].

In terms of reviews on behavior change, 33 studies out of 49 (67%) were published in the last 2 years. A total of 4 out of 5 (80%) general narrative reviews discussed the role of mobile technologies for weight management [85-88], and 4 out of 5 (80%) scoping reviews discussed the use of mobile technologies for general health behavior change, including studies on weight management [27-29,31]. A total of 15 out of 28 (54%) qualitative syntheses on behavior change interventions also specifically focused on mobile technologies. Social media was covered in 1 narrative review on blogs to record PA and diet [55], 1 scoping review on Web 2.0 technologies used among patients and caregivers [30], 1 qualitative synthesis on weight management [40], and 5 meta-analyses on interventions promoting general health behavior change [89], weight management [90], PA promotion [37], or PA and diet [91]. A total of 14 reviews out of 49 (29%) reported on various eHealth technologies, including mobile and Web 2.0, without considering these separately: 1 (2%) nonsystematic review, 12 (25%) qualitative syntheses, and 1 (2%) meta-analysis.

## Research on Technologies for Measuring Behavior

More than half of the primary research studies dealing with behavioral assessment (55/102, 53.9%) were published since 2012. Almost all of these (100/102, 98.0%) focused on mobile technologies employed for dietary or PA assessment. Of the 102 studies, 50 (49.0%) dealt with *design and development*, 34 (33.3%) dealt with *feasibility*, and 70 (68.6%) dealt with *evaluations* of accuracy and validity of mobile technologies employed for dietary or PA assessment. Examples of studies focusing on testing accuracy in PA tracking developed systems using both old (eg, Nokia N97 [92]) and more modern devices (eg, iPhone [93], iPod Touch [94], or Android phones [95,96]). Dietary assessment technologies include those that utilize mobile phone cameras to capture images of food and keep food diaries (eg, DietCam [97]), or native mobile phone apps that allow users to manually input information about the food consumed ([98,99]). A few articles reported on the development and evaluation of the usability of systems that encompassed both PA and dietary assessment (eg, SapoFit [100,101]).

A total of 7 out of the 11 (64%) reviews focusing on technologies for behavior assessment were published since 2013 and all reported on mobile technologies. Of these 11 reviews, 9 (82%) focused on dietary assessment and 2 (18%) focused on PA assessment [52,53]. A total of 2 out of the 11 (18%) reviews were nonsystematic reviews that described various methods for technology-based food assessment, including mobile-based digital photography [102,103]. A total of 4 qualitative syntheses out of 11 (36%) reported on *evaluations* of the accuracy and validity of mobile phone apps for dietary assessment [57,104-106], and 1 (9%) reported on *feasibility* and *evaluations* of these mobile technologies [60].

## Overview of Apps and Social Media Content

The literature on mobile phone apps and Web 2.0 content is recent; almost all studies (19/21, 90%) were published in the last 2 years—7 (33%) studies in 2013 and 12 (57%) studies in 2014—and the earliest study was published in 2011 [107]. In general, most of these reviews focused on mobile phone apps for PA/fitness [108,109], and also analyzed the content of online social networks for PA promotion [110] and dietary and fitness apps [111-114]. Some examined mobile phone apps for dietary control [115-117] or weight loss [107,118]. Only 1 (5%) review and case study out of 21 reported on the use of a website with social media apps for promoting PA [119]. A total of 8 studies out of 21 (38%) investigated whether apps included constructs derived from behavioral theories [117,120] or evidence-based strategies and expert recommendations for behavior change [107,113]. A total of 5 out of 21 (24%) explicitly investigated the presence of behavioral change techniques (BCTs) in apps [108,109]. A total of 7 out of 21 studies (33%) dealt with the evaluation of *usability* principles (eg, heuristic evaluation) in apps [56,116,121] or websites with social media components [110].

Content analyses of Web 2.0 apps were published in the last 7 years, with the oldest study dating back to 2007 [55] and half of the studies (8/15, 53%) published in 2014. Of the 15 overviews of social media, 7 (47%) focused on the analysis of blog content related to weight management. For example, some studies analyzed how members of food blogging communities interact and what information they share [44,122], or how users seek emotional support when dieting [123]. Other research focused on the analysis of how social support is provided in PA-oriented online communities [124] or commercial weight-loss programs such as Weight Watchers [125]. Other studies focused on Twitter as a venue for discussion about childhood obesity [126] and about weight loss among adults [45].

## Discussion

### Principal Findings

There is an extensive body of knowledge on the use of mobile and Web 2.0 technologies for weight management. In this review we included 457 articles published in a wide range of journals and conference proceedings worldwide. The eHealth field is multidisciplinary, encompassing medical informatics, public health, computing and informatics, and health communication. The research originated mainly in the Anglo-Saxon world with a considerable number of studies from Europe, Asia, and the Middle East, showing that eHealth research is conducted on a global scale using English as the *lingua franca* for research dissemination. However, no African studies were identified and only few originated from developing areas of the world (eg, Latin America and Asia Pacific). Considering that in the first quarter of 2015, 334.4 million mobile phones were shipped worldwide (+16% compared to the previous year) [127] and that mobile phone markets have grown considerably in the past 2 years in Latin America, Africa, and Asia Pacific emerging countries [128], we expected more research and anticipate future growth in these regions. The lack of evidence from developing countries may be due to language barriers or a lack of research funds.

Half of the identified articles were published in the last 2 years. This suggests that the body of evidence is expanding rapidly, posing a challenge for reviewers who wish to synthesize this evidence. Increasing numbers of studies means that overall evidence-based conclusions may change rapidly over a short time.

### Research Themes

We categorized research into two main overarching themes: *promoting behavior change* and *measuring behavior*. Emergence of these two main themes suggests that the discipline has largely split into two distinct research streams. The review literature has specialized and focused either on the evaluation of effects on behavior or on the accuracy and validity of instruments assessing PA or dietary behaviors. Only two systematic reviews [52,53] discussed both aspects and reported on mobile technologies for PA behavior change and assessment. This is an important limitation of current research because the effects on behavior cannot be ascertained if the measures are not accurate or valid. Future research could aim to encompass both of these aspects.

We further categorized the articles according to three themes that define the different phases of research development: *design and development*, *feasibility*, and *evaluation*. Through this

classification we gave equal attention and consideration to research that belongs to the area of systems design [129,130], which is often neglected in reviews that focus on the efficacy or effectiveness of interventions. To the best of our knowledge, no other reviews available on the topic have described the evidence from systems design articles. Future studies could seek to integrate the evidence from various disciplines. This scoping review also provides a map of *feasibility* studies testing the use of mobile and Web 2.0 technologies for weight management. A relatively large number of studies reported on the effectiveness of these technologies on behavior and weight-related outcomes. At the same time, a large number of studies reported on the accuracy and validity of mobile technologies for PA and dietary assessment. It was not the aim of this review to provide evidence on the effectiveness of these technologies, but we can conclude that there is a database of reviews and primary studies that report effects needing further synthesis.

## Use of Technology for Behavior Change and Assessment

Research in the domain of behavior change and assessment has focused almost exclusively on mobile devices, suggesting that future health promotion and care is mobile [131,132]. Mobile phones have evolved from just being used for sending and receiving text messages, to more advanced, interactive portable computers linked to the Internet. Information can only be exchanged through the Internet, via wireless networks, or via mobile data packages. Even mobile phone apps designed to promote behavior change use the same architectures and technological infrastructures as Internet programs, so that it is almost impossible to separate the two delivery modes completely.

Many studies described the *design and development* of mobile phone apps for behavior change and behavioral assessment, and many also evaluated them. The majority of such papers reported on evaluations of intervention effectiveness and on the validity and accuracy of technologies for behavior change. Most notably, all research on *measuring behavior* reported on use of mobile apps and mobile-based methods for dietary and PA assessment. A relatively recent subsection of the literature has focused specifically on the evaluation of mobile phone apps. This appears to be an expanding area, now including RCTs and quasi-experimental designs, thereby responding to calls for further studies [27,29].

Relatively little attention has been paid to the application and testing of social media technologies for behavior change or behavioral assessment. Primary research articles dealt exclusively with the role of Web 2.0 technologies for behavior change, but we also found many systematic reviews and meta-analyses on the topic. Compared to the only scoping review on social media for patients and caregivers [30], which included 371 studies, the number of studies we identified was low. This inconsistency can be explained by the different focus of our review (weight management) compared to the more generalized scope of the other review (general health promotion). However, it might also be due to a different definition of social media. In fact, Hamm and colleagues

encompassed studies that used chat rooms and discussion forums, which represent an older type of social media available before the advent of Web 2.0 [133]. Future research should clarify social media definitions, thereby specifying the technologies under investigation. Our review shows that research into social media use for weight management has mostly focused on analyzing the content generated by users rather than on the effects of the use of the media on behavior. *User-generated content* is one of the core, basic features of Web 2.0, which appeared in 1999 [134] but became popular only after the 2004 Web 2.0 Conference [133]. Only a few years later, the first articles were published investigating how users portray themselves on social media, or investigating how they seek emotional and social support or discuss their health (eg, weight loss). These accounts are important to get a better picture on the usage of the medium, but more in-depth analyses of the effects are also required to establish whether and how social media-based interventions work.

## Strengths and Limitations

Unlike other similar scoping reviews, we included a large number of studies, including both review and primary research evidence. Except for Hamm and colleagues' scoping review on social media [30], systematic reviews rarely use other reviews as sources of information for primary research studies. Our approach has generated a systematic, comprehensive, and detailed map of the available evidence on mobile and Web 2.0 technologies used in the domain of weight management. Another strength is the development of a data-driven categorization tool that could be used by other researchers or by journal editors or reviewers wishing to optimize the classification of the literature available in their journals.

A limitation of this study, which is common to systematic reviews in general, is the exclusion of articles not published in English. Unsurprisingly, the majority of articles identified originated in English-speaking countries. Another limitation is related to the inclusion of materials that were available in full text. Even though we searched a broad variety of databases and sources of "grey" literature (ie, conference proceedings, theses, and dissertations), we had to exclude entries that did not have, or were not freely available in, full text. This included meeting abstracts, conference abstracts, and theses and dissertations. During title and abstract screening we identified 32 theses and dissertations that were relevant to the topic, but had to be excluded (in most cases under embargo or not accessible through interlibrary loans) as it was not possible to complete the categorization process. However, we considered these as sources of information about potentially relevant studies. A third limitation is the subjectivity intrinsic to the inductive analytic approach we adopted to categorize the literature, which is common in qualitative research. However, we tried to reduce bias by testing the reliability of the charting tool within our team of reviewers.

## Conclusions

This scoping review provides a descriptive map of the literature on mobile and Web 2.0 technologies for weight management. We described and categorized 457 papers that discussed the design and development, feasibility, and evaluation of these

eHealth technologies for promoting behavior change and also for measuring behavior. Even though the quality of this evidence needs to be evaluated using appropriate analytical strategies, there is an extensive evidence base that assesses the impact of technologies on behavior and weight-related outcomes, in particular by mobile phones and mobile apps. Some research focused exclusively on the analysis of the content of mobile phone apps. Limited evidence exists on social media for behavior change, but a segment of studies focused on the analysis of social media content to understand behaviors related to weight management from a broader, holistic perspective. Future research should analyze mobile phone and Web 2.0 technologies by combining the evaluation of content with design aspects, usability, feasibility, efficacy/effectiveness for behavior change, and accuracy/validity for behavior assessment. This way we could better understand how technologies influence behavior and how they can be more effectively and efficiently used in eHealth interventions.

## Acknowledgments

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Search strategies.

[PDF File (Adobe PDF File), 70KB - jmir_v17i11e259_app1.pdf ]

## Multimedia Appendix 2

Charting tool.

[PDF File (Adobe PDF File), 1MB - jmir_v17i11e259_app2.pdf ]

## Multimedia Appendix 3

Characteristics of included studies.

[PDF File (Adobe PDF File), 672KB - jmir_v17i11e259_app3.pdf ]

## Multimedia Appendix 4

Excluded studies.

[PDF File (Adobe PDF File), 127KB - jmir_v17i11e259_app4.pdf ]

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## Abbreviations

**AC1:** first-order agreement coefficient
**BCT:** behavioral change technique
**BMI:** body mass index

**CINAHL:** Cumulative Index to Nursing and Allied Health Literature
**COPD:** chronic obstructive pulmonary disease
**ERIC:** Education Resources Information Center
**IEEE:** Institute of Electrical and Electronics Engineers
**IQR:** interquartile range
**MeSH:** Medical Subject Headings
**NIHR:** National Institute for Health Research
**OCLC:** Online Computer Library Center
**PA:** physical activity
**PDA:** personal digital assistant
**PenCLAHRC:** Collaboration for Leadership in Applied Health Research and Care of the South West Peninsula
**PICOS:** participants, interventions, comparators, outcomes, and study design
**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses
**RCT:** randomized controlled trial
**SNSF:** Swiss National Science Foundation
**SOFA:** Social Families
**TWD:** Total Wellbeing Diet

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<u>Original Paper</u>

# Social Media and HIV: A Systematic Review of Uses of Social Media in HIV Communication

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## Abstract

**Background:** Social media, including mobile technologies and social networking sites, are being used increasingly as part of human immunodeficiency virus (HIV) prevention and treatment efforts. As an important avenue for communication about HIV, social media use may continue to increase and become more widespread.

**Objective:** The objective of this paper is to present a comprehensive systematic review of the current published literature on the design, users, benefits, and limitations of using social media to communicate about HIV prevention and treatment.

**Methods:** This review paper used a systematic approach to survey all literature published before February 2014 using 7 electronic databases and a manual search. The inclusion criteria were (1) primary focus on communication/interaction about HIV/acquired immunodeficiency syndrome (AIDS), (2) discusses the use of social media to facilitate communication, (3) communication on the social media platform is between individuals or a group of individuals rather than the use of preset, automated responses from a platform, (4) published before February 19, 2014, and (5) all study designs.

**Results:** The search identified 35 original research studies. Thirty studies had low or unclear risk of at least one of the bias items in the methodological quality assessment. Among the 8 social media platform types described, short message service text messaging was most commonly used. Platforms served multiple purposes including disseminating health information, conducting health promotion, sharing experiences, providing social support, and promoting medication adherence. Social media users were diverse in geographic location and race/ethnicity; studies commonly reported users aged 18-40 years and users with lower income. Although most studies did not specify whether use was anonymous, studies reported the importance of anonymity in social media use to communicate about HIV largely due to the stigma associated with HIV. The ability to share and receive information about HIV was the most commonly reported benefit of social media use and the most common challenges were related to technology. Measures of frequency of use, satisfaction, and effects of use varied across studies.

**Conclusions:** Using social media to bridge communication among a diverse range of users, in various geographic and social contexts, may be leveraged through pre-existing platforms and with attention to the roles of anonymity and confidentiality in communication about HIV prevention and treatment. More robust research is needed to determine the effects of social media use on various health and social outcomes related to HIV.

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## Introduction

Social media platforms, including mobile technologies and social networking sites, are being used increasingly as part of human immunodeficiency virus (HIV) prevention and treatment efforts [1-4]. Importantly, social media provides users with the opportunity to generate, share, and receive information through bi- and multidirectional exchanges, which may transcend geographic borders and provide an opportunity for anonymity [5-8]. Although stigma and cultural context may prevent people living with HIV/acquired immunodeficiency syndrome (AIDS) and at-risk populations from accessing in-person HIV prevention and treatment initiatives [9,10], social media can offer a neutral platform for engagement [11]. For example, individuals can seek and share information about specific prevention strategies [4,12], engage in dialog about HIV research [13], and leverage support for issues such as medication adherence and emotional coping for living with HIV [14-17]. Additionally, the increased social support provided by social media has been shown to improve treatment adherence and access to HIV testing and prevention services [18,19], and assist with coping with HIV-related stigma [17]. Social media use among key populations affected by the HIV epidemic, including men who have sex with men (MSM) [20-24], racial and ethnic minorities [25], and adolescents [26,27] is increasing, and studies demonstrate that these groups use social media to form social ties, access health information and emotional support, and build a sense of community with peers [28-32]. The social media activity of these groups can be leveraged to facilitate community engagement [33-35], which has been identified by the Joint United Nations Programme on HIV/AIDS (UNAIDS) as a critical component in HIV control efforts [36].

The widespread use of social media represents an important avenue for communication about HIV [37,38]. Further, as the globalization of HIV and its presence in more geographically distant and underserved communities increases, social media provides an opportunity to extend the reach of HIV prevention and treatment efforts. Currently lacking, however, is a thorough examination of the various users, platforms, and approaches to using social media to communicate about HIV. The objective of this paper is to address this gap by presenting a comprehensive systematic review of the current published literature on the design, users, benefits, and limitations of using social media to communicate about HIV prevention and treatment. This examination can inform critical next steps to ensure appropriate use of social media to reach and engage those most affected by HIV in their local milieu.

## Methods

### Search Strategy

This review paper followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) guidelines [39] and used a systematic approach to retrieve relevant research studies. The review included all study designs and study methods, including qualitative, quantitative, and mixed-methods studies. The literature search was conducted on February 19, 2014, using the following 7 electronic databases: Cochrane Library, Cumulative Index to Nursing and Allied Health Literature, Dissertations, Embase, PsycINFO, PubMeb Central, and Web of Science. The searches were performed using the following defined search terms: (HIV OR "Human immunodeficiency virus" OR hiv infection* OR hiv infections[mesh] OR acquired immunodeficiency syndrome[mesh] OR "acquired immunodeficiency syndrome") AND ("online community" OR "online communities" OR "virtual community" OR "virtual communities" OR Social Media[mesh] OR "social media" OR "Web 2.0″ OR "social medium" OR Social Networking[mesh] OR Social network*) AND (technolog* OR mobile* OR Internet OR online OR Blogging[mesh] OR blog* OR weblog* OR microblog* OR micro-blog* OR Twitter OR tweet* OR "mobile apps" OR "mobile app" OR "mobile applications" OR "mobile application" OR "online forum" OR "online forums" OR "bulletin board" OR "bulletin boards" OR "message board" OR "message boards" OR Skype OR instant messag* OR text messag* OR texting OR text messaging[mesh] OR YouTube OR Flickr OR Facebook OR LinkedIn OR MySpace OR SecondLife OR "Second Life" OR Listserv OR listserve OR "mailing list" OR "mailing lists" OR podcast* OR webcast* OR wiki*). Manual reference searches of identified systematic reviews were also completed.

### Selection Criteria

The retrieved articles were screened for relevance, duplication, and the selection criteria. The inclusion criteria were (1) primary focus on communication/interaction about HIV/AIDS; (2) discusses the use of social media to facilitate communication (social media was defined as platforms allowing for bi- or multidirectional exchange, including blogs, discussion boards, Facebook, etc); (3) communication on the social media platform was between individuals or a group of individuals rather than the use of preset, automated responses from a platform; (4) all literature published before February 19, 2014; and (5) all study designs. The exclusion criteria were (1) the focus on communication/interaction about HIV/AIDS was limited to study implications; (2) not in English; (3) commentary, letters to the editor or opinion pieces, protocols, and feature articles (ie, narrative-style journalistic pieces); (4) primary focus on marketing or advertising; (5) studies in which the social media platform was used for recruitment only; and (6) social media platform was used for data collection purposes only.

We completed title, abstract, and full-text review to identify all studies meeting inclusion and exclusion criteria. Three researchers (MRI, TT, CG) independently screened article titles for inclusion in abstract review. Next, working in pairs, the full research team independently reviewed and evaluated all retrieved abstracts and full texts, and reached consensus on the inclusion for the analysis. The interrater reliability between reviewers was 0.90, indicating strong agreement. Discrepancies were discussed within each dyad until consensus was reached; if no consensus was reached, the article underwent review by the full research team until consensus was reached. Studies excluded during the full-text review stage and their reasons for exclusion are listed in Multimedia Appendix 1.

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## Data Extraction

Data were extracted using a set of 58 defined fields related to the design of the social media platform, social media user characteristics, use of the social media platform, benefits and disadvantages of using the social media platform, and study outcomes. Working in pairs, the research team independently extracted data from each article and then reconciled their responses to ensure consistency.

## Quality Assessment

Two members of the research team (TT, MG) conducted a quality assessment of the 35 included studies using a checklist tool for assessing quality in observational studies [40]. The 6 domains used to assess risk of bias included (1) methods for selecting study participants, (2) methods for measuring exposure and outcome variables, (3) design-specific source of bias, (4) method of control confounding, (5) statistical methods, and (6) other biases (including conflict of interest and disclosure of funding sources). For each study, the quality of each of these 6 items was categorized as low risk (+), high risk (-), or unclear (?) as recommended by the Cochrane Collaboration [41]. We added an additional category of not applicable (N/A).

# Results

In all, 35 selected studies [12-18,42-69] met the inclusion criteria (see PRISMA diagram; Figure 1). Nine studies used qualitative research methods [13,14,16,44,45,50,53,54,61], 11 studies used quantitative research methods [12,15,42,46,48,49,51,52,56,63,66], and 15 studies used mixed methods [17,18,43,47,55,57-60,62,64,65,67-69]. The 35 included studies were summarized by study method, type of social media platform, participants/sample type and sample size, and topic(s) of discussion (see Multimedia Appendix 2). The most commonly described social media platforms to facilitate discussion around HIV were short message service (SMS) text messaging [15,45,47-49,52,55,66,67], discussion boards or forums [13,14,16,43,44,56,64,67,69], and social networking sites (eg, Facebook) [12,46,48,53,59,63,68] (the full list of social media platforms is provided in Table 1). The studies included a range of social media users, including the general public, people living with HIV/AIDS (PLWHA), and/or health professionals. Social media platforms discussed in the studies included a variety of communication features, such as discussion facilitators, directed or guided communication, and chat features. Studies reported various purposes for HIV communication on the social media platform, such as disseminating health information and/or promoting health [12,45,46,48,51,56-59,61-64,67,68], sharing thoughts and experiences [17,42,43,50,53,54,66], providing social support [12,14,16,57,64], and promoting medication adherence [15,47,49,55,65]. Topics of discussion included a range of issues related to HIV prevention (eg, skills and strategies to reduce risk), treatment (eg, medication adverse effects and adherence), coping (eg, disclosure, addressing stigma), and access to resources (eg, HIV services, online resources).

**Table 1.** Social media platforms used in selected studies (N=35).

| Social media tool[a] | Studies |
| --- | --- |
| Blogs (n=4) | Adam et al (2011) [42], Eastham (2011) [50], Kvasny & Igwe (2008) [54], Strand (2011) [17] |
| Discussion forum/board (n=9) | Baelden et al (2012) [43], Brennan et al (1991) [44], Coursaris & Liu (2009) [14], Desouza & Jyoti Dutta (2008) [13], Lou et al (2006) [56], Mo & Coulson (2008) [16], Rothpletz-Puglia et al (2013) [64], Yamauchi 2010 [67], Zhuang & Bresnahan (2012) [69] |
| SMS text messaging (n=9) | Broaddus & Dickson-Gomez (2013) [45], Dean et al (2012) [47], Divecha et al (2012) [48], Dunbar et al (2003) [49], Hightow-Weidman et al (2014) [52], Horvath et al (2013) [15], Lester et al (2010) [55], Wicks et al (2010) [66], Yamauchi (2010) [67] |
| Social networking site (n=7) | Bull et al (2012) [46], Divecha et al (2012) [48], Hildebrand et al (2013) [53], Ko et al (2013) [12], Pedrana et al (2013) [59], Rice et al (2012) [63], Young & Jaganath (2013) [68] |
| Social networking site to private correspondence (n=3) | Feldacker et al (2011) [51], Hightow-Weidman et al (2014) [52], Young & Jaganath (2013) [68] |
| Video (n=3) | Desouza & Jyoti Dutta (2008) [13], Leon et al (2011) [18], Skrajner et al (2009) [65] |
| Chat (n=5) | Leon et al (2011) [18], Moskowitz et al (2009) [57], Pavlescak (2007) [58], Rhodes (2004) [61], Rhodes et al (2010) [62] |
| Conferencing (n=1) | Reid et al (2012) [60] |

[a] Some studies used multiple platforms.

**Figure 1.** PRISMA diagram describing study selection process.
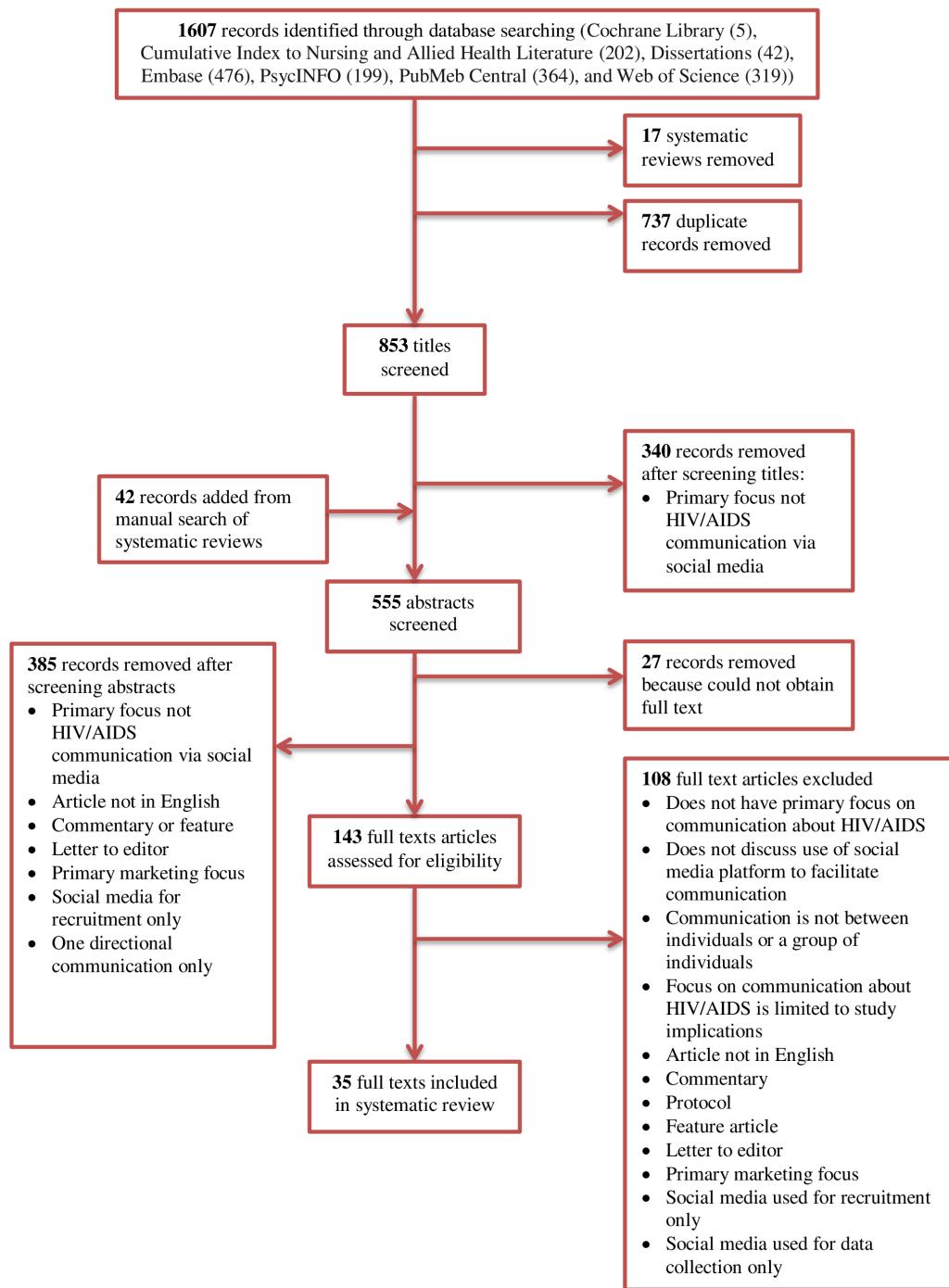


## Quality Assessment

Among the 35 included studies, 5 were at low risk for all 6 methodological quality items (see Multimedia Appendix 3). The remaining 30 studies were at high or unclear risk of at least one of the bias items; none of the studies were at high risk for all bias items.

## Characteristics of Social Media Platform Users

The characteristics of social media users in the selected studies were diverse, representing a range of groups and populations. An assessment of the use of each type of social media platform by user characteristics did not produce a consistent trend. As such, the following results are across all types of social media platforms.

### Geography

A total of 31 studies provided information on the location of social media users and 4 [14,17,45,58] did not provide this information. Seventeen studies described users located in the United States [15,44,46,48-52,54,57,61-65,68] and/or Canada [42,50]. Eight studies described users located in a region other than the United States or Canada [12,18,43,47,55,56,67,69], most commonly South Africa [43,47,67] and China [56,69]. Four studies described a global focus with users located in both the United States or Canada, and other countries [16,59,60,66]. Two studies [13,53] described an unrestricted geographic focus.

### Sexual Orientation and HIV Status

A total of 12 studies reported social media users' sexual orientation, which included heterosexual, homosexual, bisexual, and unsure or questioning [15,18,44,45,52,57,58,61-63,65,68]. All 12 studies included homosexual participants and 2 also included unsure or questioning participants [57,61]. Seventeen studies reported the HIV status of social media users [12,15-18,44,47,49,50,52,55,57,61,62,64-66]. These studies reported a range of study populations, including samples that were HIV-positive only, HIV-positive and HIV-negative, and unknown HIV status. Ten studies were exclusively for HIV-positive users, meaning only users who identified as HIV-positive could access the social media platform [15,18,44,47,49,50,55,64-66]. None of the included studies were exclusively for HIV-negative users.

### Age and Gender

In all, 24 studies reported social media users' age, ranging from adolescents to older adults aged 61 years and older [12,15,18,44-50,52,53,55-59,61-63,65-68]; most of these studies included users aged 18 to 40 years [12,18,44-50,52,53,55,57-59,61-63,65,67,68]. Twenty-six studies reported social media users' gender [12,15-18,42-50,52,55,56,59,61-68]; 7 studies only included males [12,15,16,42,61,62,68] and 2 only included females [47,64]. Of the 17 studies that included both male and female participants, 11 had a majority of male participants [17,18,44,49,50,52,56,59,63,66,67].

### Race

In all, 18 studies reported social media users' race or ethnicity including, but not limited to, black, non-Hispanic white, Latino, and Asian [15,44-46,48-50,52,54,57,61-68]. Among the 17 studies in the United States and Canada reporting race, 5 reported more black social media users than non-Hispanic whites or other racial or ethnic minorities [45,48,52,54,65]. One of the 15 international studies reported users' nationality [67]; the remaining 14 did not report users' race, ethnicity, or nationality.

### Socioeconomic Status

Reporting of social media users' socioeconomic status (SES) varied across studies. Twenty-five studies did not report users' income or employment status; of the remaining 10 studies, 6 studies reported users' income [48,55,56,62,65,68] and 4 studies reported employment status [15,18,47,64]. Studies reporting employment status included users who were unemployed, employed full- or part-time, retired, and/or disabled. Although social media users' income ranged from less than US $10,000 to US $80,000 a year, 5 of 6 studies reporting users' income included low-income users reporting less than US $10,000 a year [48,55,62,65,68]; 1 study was not in the United States, whereas the other 4 were in the United States. Thirteen studies reported users' current education and highest level of education attained, which ranged from high school or less to postcollege [12,15,18,43,44,47,55,56,60,62,64,65,68].

## Design of Social Media Platforms

All studies reported on some aspect of the social media platform, such as whether the platform required disclosure of identity and how users were engaged on the platform.

### Process of Engagement

In all, 6 studies created new social media platforms [15,18,42,43,53,56]; the remaining studies used pre-existing platforms (eg, Facebook, YouTube, or SMS text messaging systems). Twenty-two studies reported that users were already accessing the platform before engagement for study purposes [13,14,16,17,45-48,50-52,54,55,57,58,61-63,66-69] and 10 studies reported that users started using the platform for the purpose of the study [15,18,42-44,49,53,56,64,65]. Social media facilitators included researchers [15,18,43,44,47,49,53,55,56,59,65,68]; nonresearchers, such as community members and program staff [13,14,16,17,42,45,46,48,50,54,58,61,63,66,67,69]; and both researchers and nonresearchers [12,51,52,57,60,64].

### Communication on Social Media Platform

The most common form of communication on social media platforms was described as communication between users [13-16,18,43-48,50,53,54,56,59,64,66-69] followed by communication between users and staff/professionals (eg, clinicians, counselors, health educators, or health professionals) [15,18,44,47,49,51,52,55-62,65,67]. Communication between individuals (ie, one-to-one messaging) was more common between staff and users, and communication between groups of individuals (ie, posting for a group to read and respond to) was more common among users alone.

### In-Person Components

Offline or in-person components that served a complementary or related programmatic purpose to the social media platform were reported in 11 studies [18,42,44,47,51-53,55,63,64,67]. Of these, 8 studies described complementary services being provided in-person, with the most common services being clinical care, counseling, or testing [18,44,47,51,55]. Additionally, a study described how social media users attended in-person workshops to help inform the process of online

engagement [63] and 2 studies had options for individuals to be part of a content-equivalent offline program [53,64].

### *Disclosure of Identity During Platform Use*

Most studies [12-17,42,45,46,48,51,53,54,56,58-64,66-69] did not clarify whether communication was anonymous or if social media users communicated using their real name or any other identifiable information. Two studies [44,50] indicated that users had the option to communicate using their real names. Five studies [18,49,52,55,65] stated that users communicated using their real names or faces on the platform. Two of these studies described videophone [65] or webcams [18] as components of the social media platform, and 3 of the studies [49,52,55] involved clinicians or staff contacting individuals for whom they knew the identity.

### Benefits of Social Media Use

The most common benefits to using social media to communicate about HIV that studies reported were (1) access to information, (2) enhanced ability to communicate, (3) having an anonymous identity, (4) a sense of social and emotional support, (5) establishing a virtual community, and (6) geographical reach. For most studies, benefits were perceived by the target groups/populations. For other studies, the researchers reported on their perceptions of benefits or challenges related to the social media use.

The ability to receive and share information was reported as a benefit in 12 studies. Studies described users appreciating the ease and convenience of accessing information related to HIV care, treatment, and prevention through social media. For example, users in 4 studies [14,15,43,66] reported being able to receive information online from other PLWHA about disease management. Another study [13] explored how social media users interested in HIV research in India were able to share information with other local and global users engaged in the same issues. One study [48] described how teens use their phones to find medical information and share information about HIV and other sexually transmitted infections on social media. Social media users in the remaining 6 studies [12,50,54,56,57,64] reported varied benefits, including access to an alternative, nontraditional source of information about HIV prevention and testing.

There were 9 studies reporting enhanced communication as a benefit. Users stated that social media provided them with an alternative, not in-person, way to communicate about sexual health, HIV testing, and condom use with peers, health professionals, and sexual partners. For example, in one study [44], PLWHA reported a benefit from being able to use social media to communicate with health professionals without leaving their homes. Social media users in 7 studies [12,45,47,59,63,67,68] including adolescents, noted that social media platforms such as SMS text messaging and Facebook allowed them to communicate about topics that they felt uncomfortable discussing in-person, such as condom use and HIV testing. In another study [54], a group of black American bloggers reported that the use of social media, specifically blogging, opened channels for communication about HIV, a topic they believed was underdiscussed within the black community.

Another benefit users reported was the anonymous nature of the social media platforms. Users in 6 studies [14,43,44,47,50,62] mentioned that the anonymity on social media platforms helped to decrease stigma, fear, and discrimination around HIV and allowed participants to tell personal stories about their sexual orientation and HIV status in a manner they would not with friends, family members, or sexual partners offline. The other 2 studies reported that the anonymity of the website allowed adolescent users to seek HIV prevention information [67] and MSM participants to successfully engage in the intervention [61].

Another benefit users reported from engaging in an online community was a sense of social and emotional support [14,16,17,44,47,50,54,67]. More specifically, adolescents, PLWHA, and MSMs reported experiencing a sense of community from engaging with others through social media [12,15,54,63]. Lastly, the ability for health care workers to reach patients and community members to engage with one another, regardless of geographical location, was reported as a benefit of using a social media platform to communicate about HIV [13,18,47,48,50,68].

### Disadvantages of Social Media Use

The most common disadvantages to using social media to communicate about HIV prevention and treatment that studies reported were related to (1) technology barriers, (2) cost, (3) lack of physical interaction, and (4) lack of privacy.

Technological barriers were reported in 12 studies and included users' problems with poor Internet connection [44,49,56,60,61], insufficient access to computers [43,54], lack of technical help [62,67], poor quality of video and audio transmissions [65], low information technology literacy [60], and technical "glitches" [15]. Ten studies reported the cost of social media equipment (ie, personal computers) [18,44,47,65], Internet access [47,55,67], and human resources [52,55,62] as barriers.

Lack of physical interaction was a disadvantage reported in 6 studies [44,50,56,61,66,67] and included limitations in the amount of support health professionals can offer online. Additionally, the absence of verbal or nonverbal cues and the lack of transparency prevented some health professional users from being able to tailor their services and support to specific users. Other recurring disadvantages included lack of privacy and confidentiality [15,47,48,59,61], which prevented participants from sharing personal information out of fear that their information would not be protected. Less frequently cited disadvantages included lack of interest [59-61] and lack of time to communicate with other social media users [43].

### Outcomes of Social Media Use

The most common outcomes of social media use reported were the (1) frequency of social media use, (2) user satisfaction, (3) type of information shared, and (4) effects of social media use.

A total of 19 studies measured frequency of use in a variety of ways. The range of methods used to measure frequency of use included the number of days the social media platform was used

[44]; number of visitors [42,46]; number of videophone calls [65] or video viewings [54,59,63]; number of instant message counseling sessions [57]; and number of conversations [58,62,68], messages [49,52,67], posts [12,15,16], attendance [60], and/or hits on the study website [56].

Eight studies measured users' satisfaction with the platform by assessing acceptability [15,18,49], usefulness [66], quality [60], and access [44] on a scale of high, medium, and low satisfaction. Across these studies, users rated their satisfaction with the various social media platforms as high and reported that they found the platforms simple to use [47,49]. Users also reported the platforms provided access to a diverse group of users and that they would recommend the platform to their friends [55].

Five studies measured the type of information shared on the platforms (eg, access to HIV testing and safer sex strategies) and 4 studies reported that most of the messages contained informational support [13,14,54,63] followed by emotional and social network support [16]. Six studies measured the effects of social media use and found an increase in HIV knowledge [47], HIV-related discussions with online friends [12], number of people seeking HIV testing services [51], and new HIV-positive patients identified [52] along with improved medication adherence among HIV-positive participants [15,49].

## Discussion

Our review yielded 35 studies that used social media to communicate about HIV. Social media has been shown to facilitate discussion and information exchange on a range of health issues [70]. To our knowledge, this is the first review of the current landscape and users of social media to communicate about HIV exclusively. Our findings illustrate the following: (1) the value of using pre-existing social media platforms, (2) the diversity among the characteristics of users, and (3) the importance of the role of anonymity on the platform. Consideration of these findings will help extend the field of social media, specifically when related to communication about HIV prevention and treatment.

Most studies use pre-existing social media platforms (eg, a Facebook page) rather than creating new platforms. There may be a number of benefits to using pre-existing social media platforms to communicate about HIV, which might explain their widespread use. First, developing new social media platforms may be costly or resource intensive; some of these costs may be mitigated by using pre-existing platforms. Second, communicating through pre-existing platforms may decrease barriers associated with end-users learning new social media technology. Lastly, users' familiarity with the platform and connection to other existing users may facilitate more open communication as social media ties increase and users form new virtual communities [71,72]. However, despite the potential ease of using pre-existing platforms, health care professionals in some of the selected studies reported limitations in their ability to form relationships with social media users in comparison to face-to-face interaction. This limitation may have an effect on user satisfaction and use of the platform, which is a matter of concern given the recent increase in digital interactions within health care [73]. Therefore, providing

training and support to both users and facilitators (eg, health care professionals) is critical when implementing social media initiatives to mitigate technological or other usage barriers.

Characteristics of social media platform users communicating about HIV within our selected studies span a wide range of geographic locations, sexual orientations, ages, genders, races, and SES. This is encouraging, given the diverse and global nature of the HIV epidemic, and supports other studies that show the high acceptability and use of social media across diverse groups [25,38,74]. An assessment of the use of varying social media platforms by different types of users did not result in clear patterns; however, several studies in our review describe engagement of traditionally underserved populations, such as low-income individuals, MSM, and PLWHA on a variety of different social media platforms. Given that these populations are often underaccessed with traditional HIV interventions [75-77], these studies show that social media may be a useful engagement strategy [76]. Our findings also suggest that social media can increase access to both social support and information on HIV prevention and treatment. This increase in access is especially significant for PLWHA who may face barriers to accessing care or prevention resources in-person and for other marginalized groups such as rural populations or young MSM [78,79]. As in other studies [80,81], our review finds that most studies reporting age of platform users engage individuals aged 18 to 40 years, suggesting that health promotion messages using social media may have significant reach within this age group. Given the increasing number of adolescents living with and at risk for HIV [82,83], and the increasing numbers of individuals aged 50 years and older affected by HIV [84], there is a need to explore the feasibility of using social media to communicate about HIV prevention and treatment within these age groups. Additionally, future research could investigate other technologies that may be more acceptable or effective at reaching these populations

Social media platforms have varying designs and features, such as options for anonymity, which can be tailored to meet the needs of target populations and increase use and acceptability of the platform [85,86]. Anonymity allows users to control the information they disclose about themselves, which may allow marginalized populations to feel more comfortable communicating about HIV on social media platforms [87,88]. Most studies in this review do not indicate whether or not individuals communicated using their real names. Interestingly, anonymity is cited as a key benefit and lack of privacy is cited as a key barrier to using social media to communicate about HIV. This dichotomy suggests that social media platforms used to communicate about HIV should allow participants to choose if they would like to remain anonymous in order to facilitate engagement. HIV is a highly stigmatized disease [9,89] in which PLWHA make decisions about disclosure of their HIV status [89,90]. These decisions affect subsequent health behaviors, access to social support, and interactions with sexual partners and social networks [91-93]. Social media platforms may provide PLWHA with an opportunity to anonymously rehearse HIV status disclosure, which may facilitate disclosure in real-world settings [94]. An important next step to using social media to communicate about HIV is to identify which designs

best create and facilitate a sense of privacy, confidentiality, and safety.

This review has several limitations. The outcomes of social media communication about HIV prevention and treatment vary greatly. Given the range of outcomes reported, it is difficult to draw any conclusions on how these outcomes relate to the characteristics of users and platforms across studies. This variation represents a significant challenge in surveying the landscape of social media use to communicate about HIV prevention and treatment. Further, the range of literature available on the effectiveness of social media in communication about HIV prevention and treatment is limited. However, this review is a first step to categorizing gaps and trends in the literature in order to identify areas for future research. Despite concerns in the literature about the accuracy of information shared on social media [95-97], this barrier was not reported in our selected studies, and our review was not designed to assess the quality of the information being shared on social media. In addition, the majority of studies selected for this review were at either high or unclear risk of bias for at least one of the bias items. This is a limitation because it is an indicator of the quality of evidence available in the literature and highlights the need for stronger evidence. Lastly, social media use is likely utilized by grassroots and community organizations in HIV communication outside of research contexts; this review did not capture these efforts.

Despite these limitations, our review shows that social media is a promising approach to engage individuals in a dynamic discourse about HIV prevention and treatment, and may allow diverse groups to collaborate on strategies to address the epidemic. Findings from our review are important to design new or leverage pre-existing social media platforms for communication about HIV prevention and treatment, and to illuminate the opportunities for further examination of social media platforms and specific HIV prevention and treatment outcomes.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Studies excluded during full text review.

[PDF File (Adobe PDF File), 97KB - jmir_v17i11e248_app1.pdf ]

## Multimedia Appendix 2

Summary of selected studies (n=35).

[PDF File (Adobe PDF File), 36KB - jmir_v17i11e248_app2.pdf ]

## Multimedia Appendix 3

Quality assessment of selected studies.

[PDF File (Adobe PDF File), 45KB - jmir_v17i11e248_app3.pdf ]

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## Abbreviations

**AIDS:** acquired immunodeficiency syndrome
**HIV:** human immunodeficiency virus
**MSM:** men who have sex with men
**N/A:** not applicable
**PLWHA:** people living with HIV/AIDS
**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses
**SES:** socioeconomic status
**SMS:** short message service
**UNAIDS:** Joint United Nations Programme on HIV/AIDS

Original Paper

# Pro-Anorexia and Anti-Pro-Anorexia Videos on YouTube: Sentiment Analysis of User Responses

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## Abstract

**Background:** Pro-anorexia communities exist online and encourage harmful weight loss and weight control practices, often through emotional content that enforces social ties within these communities. User-generated responses to videos that directly oppose pro-anorexia communities have not yet been researched in depth.

**Objective:** The aim was to study emotional reactions to pro-anorexia and anti-pro-anorexia online content on YouTube using sentiment analysis.

**Methods:** Using the 50 most popular YouTube pro-anorexia and anti-pro-anorexia user channels as a starting point, we gathered data on users, their videos, and their commentators. A total of 395 anorexia videos and 12,161 comments were analyzed using positive and negative sentiments and ratings submitted by the viewers of the videos. The emotional information was automatically extracted with an automatic sentiment detection tool whose reliability was tested with human coders. Ordinary least squares regression models were used to estimate the strength of sentiments. The models controlled for the number of video views and comments, number of months the video had been on YouTube, duration of the video, uploader's activity as a video commentator, and uploader's physical location by country.

**Results:** The 395 videos had more than 6 million views and comments by almost 8000 users. Anti-pro-anorexia video comments expressed more positive sentiments on a scale of 1 to 5 (adjusted prediction [AP] 2.15, 95% CI 2.11-2.19) than did those of pro-anorexia videos (AP 2.02, 95% CI 1.98-2.06). Anti-pro-anorexia videos also received more likes (AP 181.02, 95% CI 155.19-206.85) than pro-anorexia videos (AP 31.22, 95% CI 31.22-37.81). Negative sentiments and video dislikes were equally distributed in responses to both pro-anorexia and anti-pro-anorexia videos.

**Conclusions:** Despite pro-anorexia content being widespread on YouTube, videos promoting help for anorexia and opposing the pro-anorexia community were more popular, gaining more positive feedback and comments than pro-anorexia videos. Thus, the anti-pro-anorexia content provided a user-generated counterforce against pro-anorexia content on YouTube. Professionals working with young people should be aware of the social media dynamics and versatility of user-generated eating disorder content online.

**KEYWORDS**

eating disorders; anorexia; social media; emotions

## Introduction

Over the last decade, the emergence of pro-anorexia (ie, pro-ana) online communities has become a growing public health concern. With the help of information technologies, such communities are easily accessible and interactive, while encouraging harmful weight loss and weight control practices [1-6]. According to a 25-country EU Kids Online survey, 10% of children aged 9 to 16 years had seen eating disorder sites online, with girls being more commonly exposed to such material than boys [7]. Those exposed to such sites display a higher drive for thinness and perfectionism as well as a more negative perception of their appearance [8-10]. In addition, members of pro-anorexia communities report high levels of disordered eating [2,6,11]. Pro-anorexia communities have become a public concern and have aroused critical responses in social media, one example being so-called anti-pro-anorexia (ie, anti pro-ana) communities which oppose pro-anorexia content and provide support for those who are recovering from anorexia [3,12]. This is the first study of pro-anorexia communities that analyzes a large sample of data with sentiment analysis software. It provides a new perspective on the pro-anorexia phenomenon by analyzing emotional reactions to pro-anorexia and anti-pro-anorexia content on YouTube.

The rationale for the use of sentiment analysis here lies in the rapid expansion of social media content. YouTube has more than 1 billion users with 300 hours of video being uploaded every minute [13]. One of the central social media features of YouTube is the opportunity for those watching the videos to either like or dislike the video or to post a textual comment in the comment section below the video. These options are available for all registered users. This interactive feature of YouTube provides insight into audience reactions that can help us to understand how, for example, pro-anorexia videos are reacted to collectively. The social arena provided by YouTube is content driven and, as such, interaction is based on audience participation (eg, through commenting). The bonds formed over shared interests relayed by the videos in question vary in strength, some representing casual interest-based participation and others founded on more fundamental shared interests [14].

Those users commenting on videos concerning a shared interest can be considered part of a self-selected online community whose starting point is the online content itself. Online communities are defined as groups of individuals that interact through an online medium, regardless of the existence of explicit friendship links [15,16]. This concept is often applied to YouTube [17], where the most salient communication mechanism is through video comments. On YouTube, users do not necessarily establish "friendship" links and then subscribe to channels and comment on videos. In this setting, users interact via spontaneous discussion and reactionary expression through video comments rather than with established social peers as is more common on platforms such as Facebook or Twitter. Interaction between users on YouTube is indirect and delayed through textual comments or videos, yet this kind of delayed interaction is able to arouse collective emotions [15]. Furthermore, emotional expressiveness has been found to both motivate user participation and sustain online communities in

the long term [16]. In the context of eating disorders, the audience response becomes important given that peer groups have an influence on disordered eating among adolescents [18,19]. Positive comments to pro-anorexia groups might increase their attractiveness and make anorexia more normalized.

Pro-anorexia communities are found on various social media sites, including Facebook [12], YouTube [20], Twitter, Instagram, Pinterest [21], and Flickr [22]. A new understanding of the scope of their activity requires comparing them to contrasting groups, such as anti-pro-anorexia communities. YouTube users commonly engage in active discussion by expressing either positive or negative sentiments in their messages [23]. User-generated anti-pro-anorexia content may, therefore, contest pro-anorexia content. Notably, responses within the YouTube community might be important for adolescents who tend to seek justification for their actions from peers rather than adults. Simultaneously, young people may also internalize certain values and behavioral norms more effectively from online communities than from various offline sources. These issues suggest that user-generated online content can be a significant source of influence. For example, a recent study found that pro-anorexia YouTube videos were more favored by viewers compared to informative videos describing the health consequences of anorexia [20].

In this study, we examined emotional reactions that pro-anorexia and anti-pro-anorexia videos received on YouTube among registered users. YouTube was selected for this study because it is the most popular social media site characterized by publicly available videos and comments. Both easy access and popularity make YouTube a significant source for information concerning anorexia. The study is built around 3 research questions: (1) what are the general characteristics of the pro-anorexia and anti-pro-anorexia videos and video uploaders, (2) what is the strength of both positive and negative emotional feedback received by these videos, and (3) how do the videos' background information (eg, upload time, video length) associate with the comments posted?

## Methods

### User Profile Selection and Data Collection

The user profile selection was conducted October 15-29, 2014. During that time period, we retrieved YouTube videos using 2 search terms, namely "pro-ana" and "anti pro-ana." Based on Google Trends queries, these were the most popular words used to describe the positive and negative stance toward anorexia. Using additional synonyms would not have changed the search results because of the YouTube search engine's use of query expansion, which involves applying synonyms of search terms to increase recall. We received similar results using "pro-ana," "proana," and "pro-anorexia" and their "anti" counterparts with more than 90% coverage. These search terms were able to cover part of "thinspiration," "thinspo," "anti-thinspiration," and "anti-thinspo" hits as well.

We selected the most popular profiles that included uploaded video material from the past 24 months concerning either the

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pro-anorexia or anti-pro-anorexia stance on anorexia, limiting both profile lists to 25 on the basis of their popularity. The popularity of profiles selected was determined by both video views and channel subscriptions. Notably, the YouTube search engine is also likely to list these channels first due to these criteria. All of the selected profiles were in English as were the included video comments posted during the previous 24 months. In addition, we checked that the profiles were either pro-anorexia or anti-pro-anorexia. The most popular material was created by individuals who often included video blogs concerning their opinion on anorexia. Our data did not include profiles that might be considered official profiles of governmental or nongovernmental organizations.

The second phase of data collection involved the retrieval of information about videos and comments through an automatic crawler using the YouTube Data Application Programming Interface [24]. On November 3-14, 2014, we extracted all of the video comments provided by YouTube as well as any available information of the videos, including title, date, description, and number of views, likes, and dislikes. This approach was similar to that of previous research on YouTube analyses of political campaigns [17] and video popularity [25]. The total video comment material included 1163 videos uploaded by 50 YouTube users. Although all of the users hosted video content concerning anorexia, some included a variety of other types of content. We first excluded 671 videos that did not include anorexia content. In addition, 97 videos were omitted because they did not have any comments. Hence, 395 videos with a total of 12,161 comments were included in the final sample.

User information included the date when the user joined YouTube, their physical location (country), and the number of subscribers to their channel. The gender of profile users was checked separately by viewing profile pages and videos (1=female; 2=male; 3=other). Video information included upload time, duration, number of video views, numbers of video

likes and dislikes, and the total number of video comments and commenter usernames.

Video comments were assessed with the SentiStrength automatic sentiment analysis tool, which uses an algorithm to estimate the sentiment content of texts based on lexical information consisting of a list of sentiment words (approximately 3000) and grammatical categories (eg, negation) [26-28]. SentiStrength is particularly useful when working with big data and short comments, such as those of Twitter or YouTube, because it extracts both negative and positive sentiment strength simultaneously from a given short text, enabling the analysis of texts expressing both positivity and negativity at the same time. Notably, research on linguistics and psychology both show that textual statements can have loadings in both negative and positive scales simultaneously [28,29]. Positive ratings vary from 1 (not positive) to 5 (extremely positive) and negative ratings vary from -1 (not negative) to -5 (extremely negative).

## Reliability Tests

We ran interrater reliability checks throughout the data collection period. Interrater reliability of the YouTube profile users and video contents were assessed by 2 independent raters. Average interrater agreement was 90.68% (Cohen's $\kappa$=.80).

The reliability of the SentiStrength tool was tested in the study. We ran the test with a random sample of 1000 comments with 3 blind reviewers who were given instruction to code the comments on both the positive and negative axis. The raters had, on average, 47.03% (470/1000) full agreement with SentiStrength on the positive scale and 63.70% (637/1000) on the negative scale. In all, 87.20% (872/1000) of their answers showed high similarity (ie, within 1 point of SentiStrength rating) on the positive scale and 88.30% (883/1000) on the negative scale. Mean correlation between raters and SentiStrength was $\rho$=.63 on the positive scale and $\rho$=.69 on the negative scale.

**Table 1.** Interrater reliability figures between SentiStrength and human raters.

| Reliability figures[a] | SentiStrength | Rater 1 | Rater 2 | Rater 3 |
|---|---|---|---|---|
| **Positive scale** | | | | |
| Mean (95% CI) | 2.16 (2.10, 2.22) | 2.11 (2.05, 2.18) | 2.09 (2.03, 2.15) | 2.74 (2.65, 2.82) |
| Full agreement, % | | 53.60 | 55.60 | 31.90 |
| Close agreement, % | | 92.50 | 93.20 | 75.90 |
| Cohen's $\kappa$ | | .349 | .375 | .139 |
| Spearman $\rho$ | | .635 | .647 | .596 |
| **Negative scale** | | | | |
| Mean (95% CI) | −1.93 (−2.00, −1.85) | −1.75 (−1.82, −1.69) | −1.72 (−1.79, −1.66) | −1.94 (−2.01, −1.86) |
| Full agreement, % | | 64.70 | 67.60 | 58.80 |
| Close agreement, % | | 89.70 | 91.00 | 84.10 |
| Cohen's $\kappa$ | | .430 | .470 | .342 |
| Spearman $\rho$ | | .719 | .728 | .630 |

[a] A random sample of 1000 comments were reviewed. Full agreement means that the human rater and SentiStrength had exactly the same rating. Close agreement means that the difference was maximum 1 point on the 5-point scale.

Table 1 shows means and 95% confidence intervals for SentiStrength and raters. It also shows the full agreement, close agreement, Cohen's kappa, and Spearman rho figures for each rater. Based on a 2-sample Mann-Whitney $U$ test, the difference between SentiStrength and raters 1 and 2 was not statistically significant on the positive scale (rater 1: $Z=1.43$, $P=.15$; rater 2: $Z=1.90$, $P=.06$). However, this difference was significant between SentiStrength and rater 3 ($Z=-10.27$, $P<.001$). On the negative scale, there was no statistically significant difference between SentiStrength and rater 3 ($Z=-0.63$, $P=.53$). However, raters 1 and 2 were statistically different on the negative scale (rater 1: $Z=-2.80$, $P=.005$; rater 2: $Z=-3.63$, $P<.001$). Overall, our results indicate that SentiStrength's precision is within human-level accuracy in estimating sentiments from text.

### Measures and Statistical Methods

Our key interest was to analyze responses to both pro-anorexia videos and anti-pro-anorexia videos. First, we provided descriptive statistics on both video types. These included a Mann-Whitney 2-sample $U$ test for the comparison of pro-anorexia and anti-pro-anorexia communities. Our main analyses were based on ordinary least squares (OLS) regression models. We analyzed both positive and negative feedback to the videos by investigating the content of comments and video likes and dislikes. Both negative and positive SentiStrength scales as well as video likes and dislikes were used as dependent variables.

Our regression models controlled for the number of video views, number of comments, number of months the video had been available on YouTube, and video duration. In light of the skewed distribution of these variables, we used logarithmic transformation (natural logarithm) in the analysis. We also controlled for the country of the video uploader (dummy coded, 0=non-English speaking, 1=English speaking) and activity of the uploader as a commentator (0=no; 1=yes). The models predicting positive and negative sentiments were adjusted to account for the clustering of observations on the level of videos.

This procedure had an impact on standard errors. Therefore, we report the adjusted predictions on the regression models (with the other variables in the model set at their means) for both positive and negative sentiments as well as for video likes and dislikes.

## Results

### Video Uploader Statistics

Of 50 uploaders, 46 were female (92%) and the rest represented the category of unknown or "other" gender (eg, transgender). The uploaders came from 13 different countries, almost half from the United States (44%, 22/50); 74% (37/50) were from English-speaking countries. Their user profiles were, on average, 4 years old (mean 52.87 months, SD 28.23, range 9-102) and they had a mean of 2208 subscribers (SD 10,298.54, range 0-70,285). Uploaders were not active in writing comments to other videos. In addition, pro-anorexia profile users and anti-pro-anorexia profile users did not interact in our dataset. There were only 2 comments written by a pro-anorexia uploader to anti-pro-anorexia videos, whereas there were only 4 comments vice versa.

### Video Comment Statistics

Our data included 133 pro-anorexia videos and 262 anti-pro-anorexia videos. As Table 2 shows, these 395 videos had a total of 12,161 comments from 7903 commenters. Only 1.00% (79/7903) of the commenters commented on both pro-anorexia and anti-pro-anorexia videos. Uploaders wrote only 5.80% (705/12,161) of the comments. The videos had more than 6 million total views indicating that this kind of material is widely accessed by YouTube users. Videos had a mean of 15,496 views (SD 37,865.37, range 57-280,253). Table 2 also shows that anti-pro-anorexia videos were more popular based on the number of video views, comments, and commenters. Anti-pro-anorexia videos received more likes than pro-anorexia videos ($Z=-3.21$, $P=.001$) and they also received more positive comments based on SentiStrength analysis ($Z=-3.78$, $P<.001$).

**Table 2.** Descriptive statistics on pro-anorexia and anti-pro-anorexia videos on YouTube.

| Video characteristics | Pro-anorexia | Anti-pro-anorexia |
|---|---|---|
| Videos, n | 133 | 262 |
| Comments, n | 2114 | 10 047 |
| Commenters, n | 1594 | 6309 |
| Comments/video | 15.89 | 38.35 |
| Comment uploaders, n | 115 | 590 |
| Video views (total), n | 1.4 million | 4.8 million |
| Videos views, mean | 10,189 | 18,399 |
| Video active (months), mean (SD) | 34.16 (28.84) | 18.63 (19.90) |
| Video duration (mins), mean (SD) | 251.57 (178.71) | 526.83 (404.09) |
| **Video likes/dislikes** | | |
| Likes, mean (SD) | 33.56 (61.05) | 179.03 (325.58) |
| Dislikes, mean (SD) | 7.35 (18.14) | 7.20 (25.38) |
| **SentiStrength** | | |
| Positive | 2.02 | 2.16 |
| Negative | −1.89 | −1.89 |
| Positive (uploader) | 1.75 | 1.92 |
| Negative (uploader) | −1.61 | −1.75 |

### Differences Between Responses to Pro-Anorexia and Anti-Pro-Anorexia Videos

Our OLS regression models were used to estimate the difference between responses to pro-anorexia and anti-pro-anorexia content after controlling for selected independent variables. The adjusted predictions are presented in Table 3. They show that there was a statistically significant difference between communities on both positive comments and video likes. Anti-pro-anorexia videos were commented on more positively and they also received significantly more video likes. For example, anti-pro-anorexia videos received an adjusted prediction (AP) of 181 (SE 13.81) likes compared to 31 (SE 3.36) likes for pro-anorexia videos. The difference between positive sentiments expressed in the video comments was also statistically significant. The analysis of negative sentiments and video dislikes showed that there were no statistically significant differences between pro-anorexia and anti-pro-anorexia videos.

**Table 3.** Adjusted predictions (APs)[a] of positive and negative sentiments and video likes and dislikes for pro-anorexia and anti-pro-anorexia videos.

| Sentiments and likes | Pro-anorexia, AP (95% CI) | Anti-pro-anorexia, AP (95% CI) |
|---|---|---|
| Positive sentiment (1 to 5) | 2.02 (1.98, 2.06) | 2.15 (2.11, 2.19) |
| Negative sentiment (-1 to -5) | −1.89 (−2.00, −1.77) | −1.89 (−1.94, −1.84) |
| Video likes | 31.22 (24.62, 37.81) | 181.02 (155.19, 206.85) |
| Videos dislikes | 7.30 (5.05, 9.55) | 7.31 (4.44, 10.18) |

[a] APs are based on OLS regression models that controlled for the number of video views and comments, number of months the video had been on YouTube, the duration of the video, uploader's activity as a video commentator and uploader's country information.

**Table 4.** Ordinary least squares (OLS) regression models[a] on positive and negative sentiments and video likes and dislikes for pro-anorexia and anti-pro-anorexia videos.

| Video characteristics | Positive | | Negative | | Likes | | Dislikes | |
|---|---|---|---|---|---|---|---|---|
| | B | P | B | P | B | P | B | P |
| **Pro-anorexia** [b] | | | | | | | | |
| Video views | –0.12 | <.001 | 0.05 | .45 | 17.85 | <.001 | 6.98 | <.001 |
| Number of comments | 0.06 | .087 | –0.20 | <.001 | 11.48 | .005 | 0.56 | .68 |
| Time available online | 0.18 | <.001 | 0.01 | .80 | –14.58 | .002 | –5.91 | <.001 |
| Video duration | 0.07 | .04 | 0.10 | .15 | 5.30 | .26 | –1.33 | .40 |
| Uploader commented video | –0.34 | <.001 | 0.16 | .17 | 2.64 | .85 | 11.68 | .01 |
| Uploader (English-speaking country) | –0.04 | .47 | –0.18 | .15 | 9.33 | .38 | 10.74 | .004 |
| Constant | 1.93 | <.001 | –2.09 | .001 | –109.14 | .002 | –23.69 | .045 |
| **Anti-pro-anorexia** [c] | | | | | | | | |
| Video views | –0.13 | <.001 | 0.05 | .06 | 89.31 | <.001 | 3.42 | .02 |
| Number of comments | 0.08 | .006 | –0.08 | .02 | 66.34 | <.001 | 2.43 | .18 |
| Time available online | –0.07 | .049 | 0.03 | .36 | –55.61 | .003 | –1.35 | .52 |
| Video duration | 0.10 | .005 | 0.12 | .01 | –17.76 | .45 | –3.32 | .20 |
| Uploader commented video | –0.40 | <.001 | 0.11 | .06 | –15.04 | .71 | 1.24 | .78 |
| Uploader (English-speaking country) | 0.00 | .98 | 0.14 | .03 | 64.47 | .08 | 3.21 | .42 |
| Constant | 2.77 | <.001 | –2.89 | <.001 | –475.99 | .01 | –4.17 | .84 |

[a]B refers to the unstandardized regression coefficients. Uploader as commenter and country are included in the model as dummy variables. Logarithmic transformation was used for other independent variables. Range of positive from 1 (not positive) to 5 (extremely positive). Range of negative from –1 (not negative) to –5 (extremely negative).

[b] For pro-anorexia, positive model n=2114, negative model n=2114, likes model n=133, and dislikes model n=133.

[c] For anti-pro-anorexia, positive model n=10,000, negative model n=10,000, likes model n=259, and dislikes model n=259.

Our OLS regression models (Table 4) showed that video background information was significantly associated with the positive axis (positive sentiments and video likes), but less with the negative axis (negative sentiments and video dislikes). These findings are important in understanding the expressed sentiments. Highly accessed pro-anorexia and anti-pro-anorexia videos were more likely to receive less favorable comments (B=–0.12, P<.001 and B=–0.13, P<.001, respectively). Longer videos gained more positive comments. Furthermore, the videos were less likely to receive positive sentiments if their uploader had commented on them. Country did not have any impact on comments. The number of anti-pro-anorexia video comments was associated with positive sentiments. On the negative axis, the number of comments was likely to increase the negativity of the comments for both pro-anorexia and anti-pro-anorexia videos (B=–0.20, P<.001 and B=–0.08, P=.02, respectively).

## Discussion

Our aim was to provide new insights into user reactions regarding pro-anorexia and anti-pro-anorexia content on YouTube using a sentiment analysis approach. We found that anti-pro-anorexia video comments expressed more positive sentiments than those of pro-anorexia videos. They also had more views and a higher number of video likes than pro-anorexia videos. Our analysis based on negative sentiments and video dislikes showed that there were no statistically significant differences between pro-anorexia and anti-pro-anorexia videos. Consistent with earlier findings showing that negativity is the fuel of online conversation [16,30], we also found that the number of video comments was associated with higher comment negativity. However, our analysis showed that major differences exist between responses to pro-anorexia and anti-pro-anorexia videos on the positive axis. Notably, in online commentaries, positive comments may facilitate affiliations between users, whereas negative comments are likely to be more complicated because emotional responses involving sadness and anger might provoke very different responses [16]. This may explain why we found differences on the positive axis, but not on the negative one.

Our results showed that there was little interaction between pro-anorexia and anti-pro-anorexia video commenters, with only 1% of users having commented on both pro-anorexia and anti-pro-anorexia videos. Similarly, a comparison of pro-anorexia and pro-recovery groups on Flickr showed that most of the interaction took place within each group [22]. However, in our study the videos were commented on by almost 8000 people, a number which reflects the popularity of YouTube. Within this context, anti-pro-anorexia uploaders gained higher visibility for their videos and, based on the positive sentiments and video likes, they were more effective in communicating their message. Earlier studies have shown

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that pro-anorexia communities are easily accessible [1,4] and well organized [12], and that their videos receive more likes than purely informative health videos [20]. In our case, anti-pro-anorexia videos were more popular, received more video likes, and, most importantly, they were commented on more positively. We believe that this difference is explained by the fact that in our study, anti-pro-anorexia videos were user generated and also represented recovering anorexics. As such, they provided an effective strategy to contribute to eating disorder recovery online.

Our results also deviate from a recent Facebook study in which a pro-anorexia group was found to be more active and better organized than an anti-pro-anorexia group [12]. The difference between these findings can be potentially explained by the differences between the types of social media examined, namely YouTube and Facebook. YouTube is a publicly available global platform for distributing content. Facebook, on the other hand, tends to provide a more personalized and structured platform that can be managed with greater detail. On Facebook, it is often an individual user that sets up the group and, thus, has more power and means to manage what is said and distributed within the group and how it is structured. This content is also commonly available only to those users who join the group. These are characteristics that can affect both the level of activity and top-down management of the group. On the other hand, YouTube material is available for all the users and it may spread virally to other YouTube users and other social media [31]. For example, the antivaccination movement was able spread information via YouTube and it publicly challenged the mainstream medical point of view [32]. Hence, we have to acknowledge the role and manipulative power associated with social media because it has been found to influence the type of news and information users consume [33].

## Limitations

Our study has its limitations. First, we examined only communities and videos within YouTube; therefore, the results cannot be generalized to other online communities that may function differently depending on varying social media user interfaces. Second, our work is limited to English-language content because it was used as a selection criterion. Thus, results might not apply to videos and comments written in other languages. Third, we limited our analysis to 50 uploaders who were selected based on their popularity. However, despite limiting ourselves to 50 users, the analysis involved a total of 1163 videos, representing a large dataset through limited sources. Fourth, our study focused on 2 contrasting search words that were most commonly used to express either a "pro" or "anti" statement toward anorexia. Despite this limited search criteria, the YouTube search engine optimization guaranteed

coverage of synonyms. Thus, our search results are not compromised by using only 2 search words.

## Implications

Social media has been recognized as a valuable medium for health behavior identification and communication with adolescents and young adults [34]. One specific upside of this is its allowance for engaging so-called hard-to-reach populations [35]. Health and mental professionals working with young people would benefit from understanding social media communities as a whole. Although pro-anorexia content is now available in multiple social media sites [21], some are massively popular, such as YouTube. It is important to increase awareness of social media's relevance among clinicians and educators [21,36]. Because YouTube does not restrict the material shown unless copyrights are broken, different censorship measures cannot be taken. Official routes may not be the most efficient in social media. Our results point out that YouTube users were able to respond to communities such as pro-anorexia and, in fact, those videos opposing pro-anorexia communities were more positively commented on and rated. A recognition of the dynamics of social media is important in understanding what groups or communities at-risk users associate with. This combination of dynamics and group identification would be important knowledge for any clinician treating eating disorders. Furthermore, the existing online material can be used for educational purposes. In addition, it would be possible to develop automatic tools based on thematic search and sentiment analysis to detect the most relevant online discussions on eating disorders in real time. Future studies should continue working with sentiments expressed on online social media platforms preferred by children and adolescents toward improved assessment of the effects of opposing points of view regarding health issues.

## Conclusion

Earlier studies have shown that pro-anorexia communities are active online and encourage unhealthy behavior [1-6]. Our study provides a more dynamic view of social media as we compared the YouTube user responses to both pro-anorexia and anti-pro-anorexia videos. The study showed that the pro-anorexia community has online opponents within the YouTube user community. Many anti-pro-anorexia videos were in fact pro-recovery videos. These videos promote help for anorexics and oppose the pro-anorexia community. These videos were also more popular, gaining more positive feedback and comments than pro-anorexia videos. Therefore, anti-pro-anorexia content appears to be a counterforce on YouTube. This study serves to benefit professionals working with young people by providing them with a deeper understanding of social media activities and the sentiments expressed therein.

## Authors' Contributions

AO conceptualized and designed the study together with DG, AS, PR, and MN. AO ran statistical analyses and wrote the first version of the manuscript. DG provided technical expertise and collected the full video data using an automatic crawler. He wrote parts of the Methods and Results section. AS and MK were involved in data collection. Together with TK, they coded the data, contributed to the research design, and commented on various versions of the manuscript. In addition, they wrote parts of the Introduction and Discussion. MN and PR took part in designing the study. MN wrote parts of Introduction and Discussion. PR took part in the data analysis and reviewed different versions of the manuscript.

## Conflicts of Interest

None declared.

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## Abbreviations

**AP:** adjusted prediction
**OLS:** ordinary least squares

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Original Paper

# Provision of a Medicines Information Service to Consumers on Facebook: An Australian Case Study

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## Abstract

**Background:** Social networking sites (SNSs) have changed the way people communicate. They may also change the way people seek health advice.

**Objective:** This study describes the provision of a medicines information service on Facebook to individual consumers. It aimed to discuss the pros and cons, and inform health and pharmacy stakeholders and researchers about the opportunities and challenges of providing such a service.

**Methods:** We adopted an exploratory approach using a case study method.

**Results:** NPS MedicineWise, an independent, not-for-profit Australian organization, runs a public question-and-answer service on Facebook, dubbed Pharmacist Hour. Consumers following the organization's Facebook page are invited to post medication-related questions often with a suggested health topic. A wide range of questions and comments are posted related to medication usage. The pharmacist answers the queries, providing evidence-based medicines information and using consumer-friendly language, during the specific 1-hour period. The most popular questions in the past 12 months were related to adverse effects, treatment options for conditions, and drug interactions. The service had a mean number of engagements (defined as a like or share of the Pharmacy Hour post) of 38 (SD 19) people and a mean 5 (SD 3) questions per session.

**Conclusions:** The Pharmacist Hour Facebook service addresses the medicines information needs of consumers and indirectly promotes other appropriate and relevant NPS MedicineWise products and services to further assist consumers. The service offers a new medium for a quality use of medicines organization committed to promoting awareness about the correct and safe use of medicines in Australia.

## Introduction

Social networking sites (SNSs) are widely used and have changed the way people communicate. They are defined as Web-based services that allow individuals to create a profile within a bounded system, articulate that profile to a list of other users, and view and traverse that list and those made by others within that system creating a network [1]. There is a plethora of SNSs, but Facebook, founded in 2004, is the most popular with 1.35 billion monthly active users (or 864 million daily active users) as of September 30, 2014 [2]. The chief reasons for using SNSs are to connect with other people, keep in touch

and make plans with friends, locate old friends, learn about events, share photos, pass time, entertainment, and information gathering [3-6].

With all its functionalities and capabilities, it is not surprising that SNSs are used for health-related purposes. Consumers, particularly younger people with chronic diseases, are grouping themselves in Facebook to share and compare experiences with the disease and treatment in a supportive and readily accessible environment [7]. As the demographics of Facebook shifts to include more of those aged 50 and older [8], an increase in health-related activities might follow suit. It is expected that social media can help the delivery of patient-centered, high-quality, and affordable health care in the future [9].

Social media has changed the way the general public accesses health information [10] and it might represent an additional option consumers have to communicate with their providers while also enabling the providers to offer care to those who cannot or prefer not to come to them [11]. The provision of services to consumers using SNSs has potential to provide an efficient, consumer-friendly, and cost-effective channel for health care systems. It is believed that a Facebook service trial for pediatric medical consultations in Finland reduced the need for further contacts with a health care service in more than half of cases [12]. Additionally, a number of indicators, such as research papers in the field, demonstrate that the use of social media in the health care context is growing [13].

As the pharmacists' role in health care evolves, the way they communicate with their clients may change depending on the technologies available. Shcherbakova and Shepherd [14] showed in a statewide study in the United States that pharmacists providing medication therapy management services at their workplace are more likely to communicate with patients via text, email, or social media. Although SNSs could be used to provide pharmaceutical services to consumers, no research has been conducted so far to address the feasibility of this kind of service. Therefore, this study aimed to provide a detailed description and modus operandi of a public medicines information service provided to individual consumers through Facebook by a national not-for-profit Australian organization. It also aimed to discuss the pros and cons of the service and inform health and pharmacy stakeholders and researchers about the opportunities and challenges of providing a similar service.

## Methods

This exploratory study used a case study format. A case study is defined as an in-depth multifaceted investigation of a single social phenomenon using qualitative research methods [15]. It provides a holistic in-depth approach, which is particularly valuable in the generation of new ideas and theories in social science [15]. This qualitative methodology is of great value in health care because it can be used to inform professional practice or evidence-informed decision making in both clinical and policy realms [16].

The case in this paper does not represent a family or group of cases; instead, it was chosen because of its uniqueness. To our knowledge, it is the first time a public medicines information

service provided to individual consumers on a social networking site, namely Facebook, is described and discussed in a peer-reviewed journal. The data presented here were collected through an in-depth semistructured interview with the pharmacist in charge of the Facebook service and direct retrospective observation of the service during 12 months. The interview was conducted as part of a broader research study, which aimed to investigate the role and impact of social networks in the delivery of health care by pharmacists. The interview guide included pharmacists' understanding of social media, its use as part of their professional practice, and their perceptions of its use in health care and in the pharmacy profession by both pharmacists and consumers. During the interviews with one of the participants (SS), the researchers learned about the Facebook service as an example of the use of social media by pharmacists as part of their professional practice. The authors chose to specifically present the findings of the interview pertaining to the NPS MedicineWise Facebook service as well as further information about this service. This study received ethical approval from the Human Research Ethics Committee of the University of Sydney.

## Results

### The Organization: NPS MedicineWise

NPS MedicineWise, known as the National Prescribing Service prior to 2009, is an independent and not-for-profit organization committed to quality use of medicines, specifically improving the way health technologies, including medicines and medical tests, are prescribed and used in Australia. NPS MedicineWise provides evidence-based educational programs for general practitioners, pharmacists, nurses, and students. The educational activities are delivered online, face-to-face, or as group discussions. Participants are able to obtain continuing professional development points for participating in the activities. The activities include case studies, clinical e-audits, online courses, educational visits, and pharmacy practice reviews.

Since 2003, NPS MedicineWise has been committed to promoting discussions about basic medicine-related issues in the community via consumer education programs and conducting health campaigns, such as Be Medicinewise Week [17]. NPS MedicineWise has a website [18] where both health care professionals and consumers can access NPS MedicineWise materials for continuing education and self-management, respectively. Another service directed to consumers is Medicines Line [19], which is a telephone service aimed at providing information on prescription, over-the-counter, and complementary and alternative medicines. The Medicines Line Services team is staffed by registered pharmacists, employed by NPS MedicineWise, who have been trained to deliver medicines information to consumers. At any time, 3 to 5 pharmacists are on roster to manage incoming telephone calls. Medicines Line operates in collaboration with Healthdirect Australia in all Australian states and territories (except Queensland and Victoria) and promotes quality use of medicines and provides information that is independent, evidence-based, appropriate and safe, and encourages responsible use of

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medicines by increasing public awareness about medicines. Specific information provided includes how a medicine works, how to take medicines, adverse effects and interactions with other medicines, medicines during pregnancy and breastfeeding, medicines for children, storage of medicines, how to obtain consumer medicine information for prescription medicines, and referrals to reliable services and support organizations. Medicines Line does not provide emergency services, medical advice, or second opinions on the appropriateness of medicines recommended by health care professionals. NPS MedicineWise also provides consumers with a free smartphone app, called MedicineList+, with features such as reminders of how and when to take medicines, calendar alerts for refills, a barcode scanner to input medicines, and the ability to record details about medical test results which are displayed graphically.

## NPS MedicineWise and Social Media Presence

Social media represents a new opportunity to engage with consumers. NPS MedicineWise set up a social media team consisting of 2 staff: the social media coordinator and the manager of digital services / digital communications advisor. In 2011, it launched a Facebook page to target key demographics in the Australian population with health information. The organization's social media presence aims to "provide information to help people with their decisions about managing health, medicines, and medical tests" [20]. As of November 15, 2014, the NPS MedicineWise Facebook page had 45,700 followers (people who liked the page and see its posts on their newsfeed). The demographic breakdown was more than 85% women with the majority in the 25 to 54 years age bracket.

### The Pharmacist Hour Facebook Service

The initial aim of the Facebook page was to engage consumers through weekly topics. However, due to social media interactivity, consumers started to post medicine-specific questions related to their own needs. To fulfill the consumers' need for a more interactive presence on Facebook, NPS MedicineWise designed a free-of-charge public service called Pharmacist Hour. Followers of NPS MedicineWise's Facebook page were invited to post medicine-related questions, with a focus on a specific health topic suggested by the organization. Pharmacists from the Medicines Line team answered the Facebook questions, which were then posted online during the specified 1-hour period each week.

This new service posed new challenges to the clinical team; namely, a change in the mode of information transmission (ie, from verbal to written) and audience reach (ie, from one-to-one to unlimited viewers):

> We were all probably quite hesitant about it [Pharmacist Hour service] because we're used to dealing with so much one-on-one with people over

> the telephone, people were concerned about their writing skills. So they're used to talking, not putting information into a written form, so that was interesting...they were very concerned about the ramifications of the work...concerned about how much information can you give to someone on Facebook because it's not, even though you're answering a question, that question and answer is seen potentially by thousands of people.

Initially, when the service was implemented, formal staff training was not conducted. Any issue that arose was addressed through extensive team discussions until the team was completely comfortable in delivering the service and over time the service became part of the team's routine activities:

> [At the beginning] we would have big discussions before sending the answer to the social media team, you know...it's been interesting, but over the past 9 months I'd say it's become much more comfortable and it's sort of embedded now, as part of our weekly process.

Pharmacist Hour is considered an appropriate tool for consumer engagement on Facebook for a number of reasons. Firstly, it focuses medicines-related questions into a specific time period allowing the service to be responsive, but reduces the need to schedule Medicines Line staff outside this time period. Secondly, it is a service provided for people who follow the Facebook page. Thirdly, it provides an opportunity for NPS MedicineWise to partner with other health-focused organizations (eg, Asthma Australia and the Stroke Foundation) on specific health issues.

Generally, consumers posted questions before the specified time and the social media team posted a standard reply stating that the pharmacist would reply back during the Pharmacist Hour. Questions posted after the specified Pharmacist Hour were also addressed, but not with the same immediacy. The promotion of the Pharmacist Hour service reduced the frequency of nonscheduled questioning.

This weekly Facebook service first started in October 2013 and currently runs on Thursdays from 3 pm to 4 pm Australian Eastern Standard Time. Figure 1 shows an example of an NPS MedicineWise invitation post for the Facebook service. The direct public Facebook service complements the NPS MedicineWise social media presence promoting the safe use of medicines by the provision of evidence-based information. Additionally, this service provides insight into the types of questions posted and the type of language used by people to describe their issues online. The service also acts as an indirect advertisement about other NPS MedicineWise products and services that may be relevant and appropriate for the people posting medicine-related questions.

**Figure 1.** Screenshot of NPS MedicineWise Facebook advertising the Pharmacist Hour service.
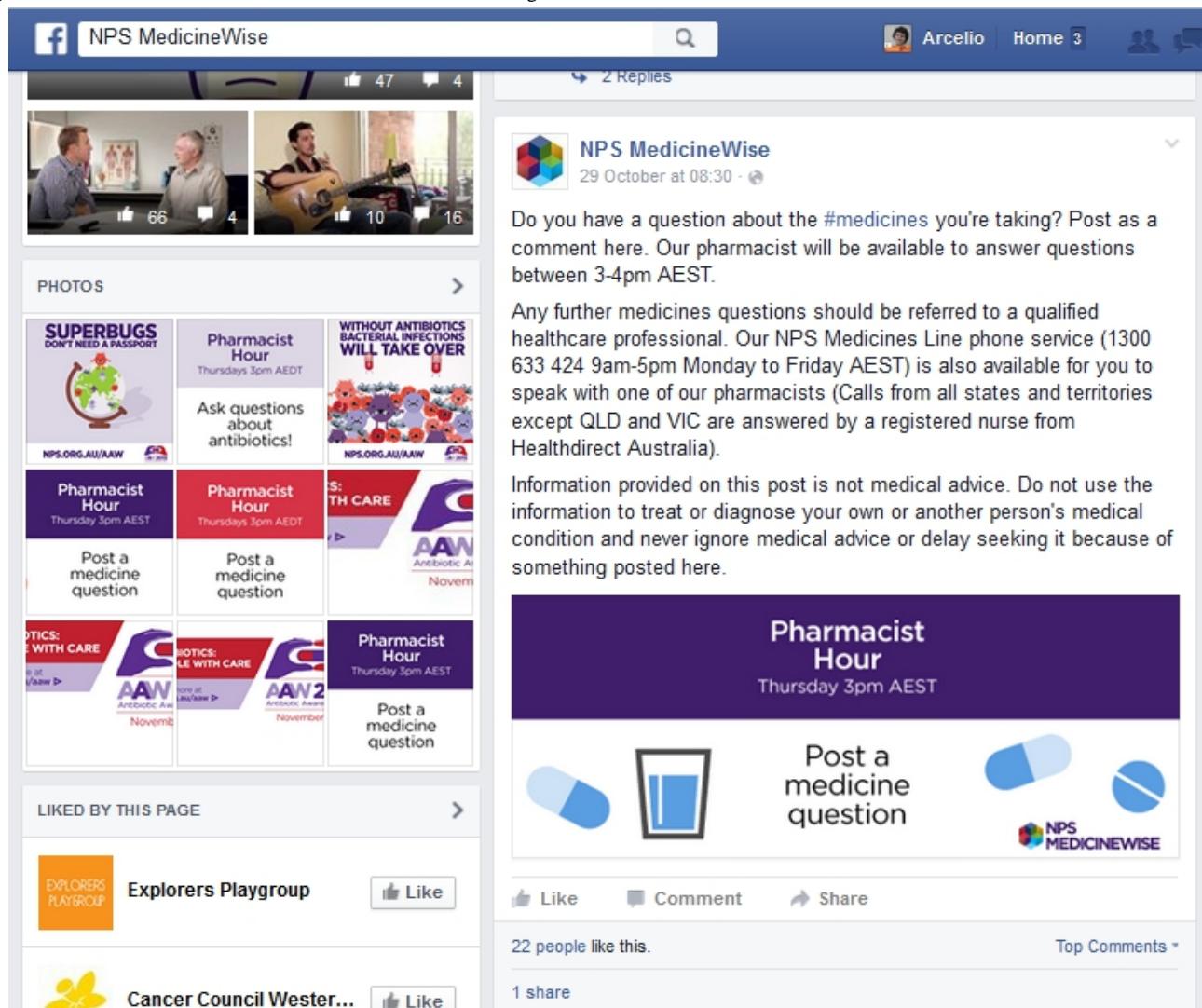


### Engagement With the Facebook Service and Types of Questions Posted

Data gathered from the Facebook page Insight [21], a tool that provides information about the page performance, revealed the engagement and reach of the Pharmacist Hour service (Table 1).

**Table 1.** Data obtained from Facebook Insight for the Pharmacist Hour posts during the first 12 months (October 18, 2013-October 30, 2014).

| Facebook page Insight (first 12 months) | Mean (SD) or n |
| --- | --- |
| Pharmacist Hour post reach per week, mean (SD) | 3776 (1595) |
| People engaged (shares and likes) with the Pharmacist Hour per week, mean (SD) | 38 (19) |
| Number of people sharing the Pharmacist Hour post per week, mean (SD) | 6 (7) |
| Number of questions per week, mean (SD) | 5 (3) |
| Total number of questions, n | 226 |

Over the first 12 months (October 2013-October 2014), the Pharmacist Hour had a mean reach of 3776 (SD 1595), indicating that 3776 different Facebook users saw the Pharmacist Hour posts in their newsfeed. In terms of engagement [22] (ie, number of unique people who liked or shared the Pharmacist Hour posts), the weekly mean was 38 (SD 19) Facebook users. This included a mean 6 (SD 7; median 3, IQR 1-7) people sharing the Pharmacists Hour post every week.

During this 12-month period, a total of 226 questions were posted with a mean number of 5 (SD 3) questions per week. Figure 2 details the prevalence of questions by topic according to the classification used by the organization for recording purposes. A total of 27 questions were found to contain content that belonged to more than one category. The categorization of the questions asked was conducted by NPS MedicineWise based on their internal procedures. Multiple categorization of Facebook

posts and other enquiries is used to ensure accurate categorization and maximal information retrieval when searching for posts. The most common topic was adverse effects of medicines followed by questions related to treatment options for conditions, drug interactions, and dose and administration.

**Figure 2.** Question categories in the Pharmacist Hour Facebook service in the first 12 months (October 18, 2013-October 30, 2014).
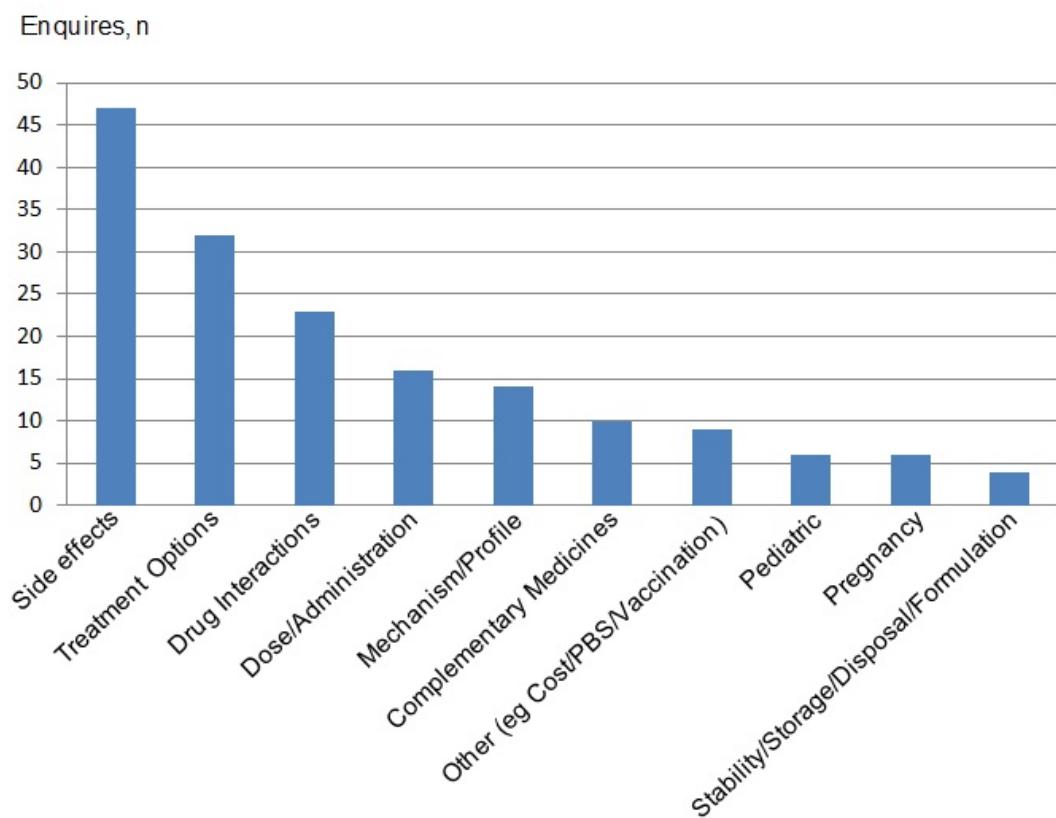


## Response Process

The social media team responsible for managing the Facebook page content was in charge of collecting the questions and posting the answers. As soon as a query was posted, a designated social media staff sent it privately to a designated pharmacist through corporate instant messaging systems or corporate email.

The reply followed a NPS MedicineWise–designed procedure. A flowchart of the service is provided in Figure 3. After the answer was formulated by a pharmacist, it was sent to a medical writer and social media staff for editing. This step aimed to reduce the amount of jargon and technical language to make all posts consumer-friendly and easy to understand, plus link to appropriate resources on the NPS MedicineWise website or other resources. The reply was checked again by the pharmacist

to certify the clinical content was not changed. Once the answer was approved, the pharmacist sent it with the corresponding question to the social media team for posting. Even though consumers sometimes would post queries before the specified time, all answers were posted during the stated Pharmacist Hour.

All answers followed the NPS MedicineWise protocol and procedures. This ensured that no medical advice or second opinions were given. Moreover, the replies were worded carefully to avoid any misinterpretation. The service followed a question-and-answer format and NPS MedicineWise did not engage in online discussions. There was no information gathering to clarify certain aspects when providing an answer; all replies were made with the information provided by the consumer.

**Figure 3.** Flowchart of the Pharmacist Hour Facebook service.
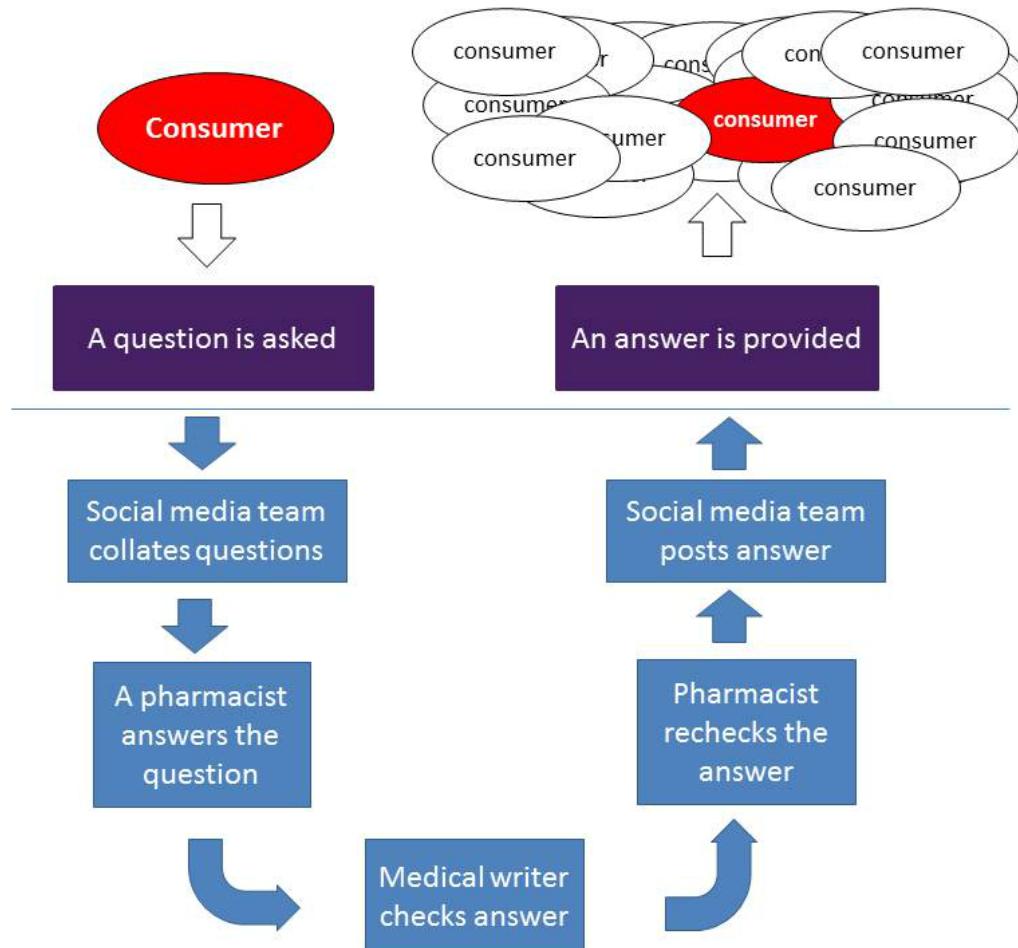


## Concerns and Limitations of the Facebook Service

The pharmacists at NPS MedicineWise were mindful that potentially thousands of people could see the questions and their respective answers through the Facebook service. Indeed, the first year of the service obtained a mean reach of 3776 unique viewers per week.

Because the Facebook page can serve as an open forum, any Facebook user can post answers or comments to the questions. This happened on rare occasions, in which technically correct answers were posted by other followers. To avoid confusion by less Facebook-savvy users, a disclaimer stating that NPS MedicineWise does not endorse anyone else's replies and that all answers are posted under its name only is included on the Facebook page and on each Pharmacy Hour post.

Another safety measure is that the pharmacist answering the questions is sent only one question at a time and does not see the actual Facebook posts on the live Facebook page. This strategy allows the pharmacist to focus on the question and avoid distraction by reading subsequent questions or comments. As previously mentioned, the collection of questions and posting of answers is the responsibility of the social media team.

Due to consumer safety concerns, the Pharmacist Hour Facebook service was more limited in the depth of information provided compared to the information delivered directly to individual consumers over the telephone. The Pharmacist Hour answers

are succinct and straightforward to avoid misinterpretations by both the person who posted the question and other readers. Another limitation is that because a dialog is not developed, it is not possible to gauge consumers' understanding. In cases in which further information is required to provide an answer, the consumer is advised to contact the Medicines Line service:

> In order to provide you with the safest and most appropriate information for your question, we need to gather further information about you and your medicines. By calling NPS Medicines Line on 1300 633 424, we will be able to do this in a much more efficient way.

Whenever appropriate, consumers were simply advised to see their doctor or pharmacist. This procedure also discouraged consumers from sharing private information online, further safeguarding their privacy.

Similarly, questions with few details prevented an answer altogether. For example, if the medication names were needed to answer a specific question, the consumer was advised to call the Medicines Line service. These occasions were seen as an additional opportunity to promote the flagship (telephone) service, Medicines Line.

All Facebook posts were researched, completed, and documented in the Medicines Line database in-line with all enquiries made to the Medicines Line service. They were

included in the internal quality assurance activities undertaken by the Medicines Line team regularly. Additionally, all email correspondence between pharmacists and the social media team as well as the responses to the questions posted were recorded and saved.

## Discussion

Although SNSs have the potential to increase communication between pharmacists and consumers, the literature on the professional use of social media by pharmacists is scarce with no mention of provision of clinical services [23]. Delivery of health and medicines information services through Facebook is in its infancy and one approach to developing appropriate and effective services through this popular SNS is to learn about the existing health and medicines information services being delivered, including the strengths and limitations of the approaches used. Therefore, we present a case study about the provision of a direct service to the public by an organization focused on quality use of medicines using Facebook as the medium. We believe that this case study can provide useful insights in the debate about using social networks as a medium in the overall care of patients by pharmacists.

Since the conception of pharmaceutical care in the 1990s [24], there have been huge efforts in moving the pharmacy profession from a product orientation to a patient/consumer orientation. The services that pharmacists offer are no longer restricted to supply of medicines, but also include the delivery of cognitive pharmaceutical services, which are patient-centered and aim to improve patient outcomes. This paradigm shift is being continuously implemented in varying degrees in the pharmacy profession globally. Digital technologies, such as social media, provide additional opportunities for the delivery of cognitive pharmaceutical services. Pharmacists, as experts on medicines, are well equipped and should be encouraged to contribute to these new online tasks.

This study has shown that SNSs, specifically Facebook, can be a medium for the delivery of a public medicines information service to individual consumers. The Pharmacist Hour service has been an effective way of engaging the broad community on the topic of medicines information. The Facebook Insight provided useful service metrics revealing its reach and engagement. Although a mean number of 5 questions were posted per week, a much higher number of people, 38, engaged with the service per week by liking or sharing each Pharmacist Hour post during the service's first year. The mean reach per week was 3776 (ie, the number of people who saw the post, this includes those who engaged with it). This highlights that consumers were both actively posting questions as well as passively receiving information. A particularly important interaction with the Pharmacist Hour in terms of dissemination was sharing of Facebook service posts on consumers' own Facebook timelines. This activity increased the reach of the service and can effectively drive more followers to both the Pharmacist Hour and the NPS MedicineWise Facebook page and website (and consequently its available resources).

A wide range of topics related to medicine usage were raised by "online consumers." Adverse effects was at the top of the list. This reflects consumers' desire to know about the adverse effects of their medicines [25]. A wish to better understand the pharmacological possibilities available to deal with health issues can also be inferred from the data because the second most popular topic was related to treatment options.

Another study that corroborates the idea presented in this case study, that medicines information can be delivered via the Internet to address individual consumer's needs, was recently reported in the form of a private chat-based telepharmacy service in Denmark, where answers to queries were not made public [26]. The service operated on behalf of a national pharmacy association and provided counseling services to consumers 24 hours a day, 7 days a week. The service was conceived to ensure quality use of medicines purchased online. However, it was found that the majority of enquiries (89.5%) were not directly related to online purchases.

It is possible that technology savvy consumers are increasingly realizing that the Internet in general, and SNSs in particular, can be used for health-related activities, including the delivery of customized medicines information. Moreover, those aged 50 years and older are increasingly joining Facebook [8], which can potentially contribute to an increased demand for online health services.

Consumers resorting to such innovative online services to obtain tailored medicines information may highlight the limited information they are currently receiving. It may also demonstrate their desire to obtain tailored information that addresses their specific needs rather than broad medicines information that may not be useful for them. Moreover, online services provide an opportunity to ask questions anonymously without attending a community pharmacy and at a time convenient to the consumer. Pharmacists should be encouraged to embrace new communication technologies and understand the possibilities of using them to better care for patients and provide tailored information. As health consumers change (ie, the way they communicate and access information), the pharmacy profession has to be open to adapt to fulfill their needs in terms of effective and safe use of medicines. However, pharmacists should be aware of challenges, limitations, disadvantages, and risks of engaging in the provision of a tailored service through these new media.

Although at first glance the Pharmacist Hour could be perceived as a simple and straightforward service, a more in-depth investigation of the service revealed not only the extensive efforts involved in providing a quality and safe service, but all the challenges. The primary challenge is to ensure that the written information provided is clear and understandable by a broader audience. Although formal training was not initially implemented, processes were put in place to ensure that the written advice provided is of high quality and comprehensible.

Patient confidentiality and professional liability were also issues that concerned the clinical team. Consequently, a well-defined policy for the service was implemented. No additional information is gathered online from the consumers posting the questions. Answers are formulated based only on the initial question and information provided by the consumer. This approach safeguards both the consumer and health care

professional. The former are spared from providing personal health information in an open forum and the latter from requesting such information and risking exposing the consumer's personal information to a broad group of people. This policy ensures users' confidentiality and privacy [27]. If further information is needed to formulate a reply, consumers are advised to access the Medicines Line service directly. The safety of consumers is also a priority. In addition to providing evidence-based information, when appropriate, the consumer is instructed to contact their doctor or pharmacist for additional advice.

Although the Pharmacist Hour service is free-of-charge, remuneration or a source of revenue to support online services is an important consideration for those planning to use SNSs as a medium for health care delivery. For example, if a community pharmacy decides to engage in the delivery of a service similar to the Pharmacist Hour, it would require a pharmacist dedicated to the task, which would mean extra costs for the pharmacy. Previous literature has identified the need for reimbursement for health care professionals delivering care via social media, such as e-consultations [28]. Because users might not be willing to pay for online services, the expansion of service delivered via mobile technologies might require a change in both culture and operations of health care providers who are used to existing reimbursement models for provision of episodic care [29].

## Limitations and Future Studies

The description and discussion of a single case of a public medicines information service on an SNS will not cover all possibilities that this relatively new communication medium affords. However, this methodological approach has allowed us to focus on understanding the dynamics present within a single setting [30]. Specifically it has allowed us to describe and discuss a medicines information service on Facebook and show health and pharmacy stakeholders that SNS is a new medium for the delivery of medicines information services to empower consumers and foster quality use of medicines.

This study did not focus on evaluating the opinions and perceptions of consumers using the Pharmacist Hour Facebook service or on providing a detailed analysis of the questions asked by the consumers. This information would add important insights about consumers' needs and preferences for health services sought online. This is a topic for future research.

Further studies about the use of social media to deliver health and medicines information services should be encouraged. All services and interventions should be evidence-based and their impact on consumer outcomes evaluated [31]. Consequently, further assessment of outcomes related to quality use of medicines afforded by social media services is needed.

## Conclusions

This study described and discussed the provision of a not-for-profit medicines information public service to individual consumers on Facebook by NPS MedicineWise, an Australian organization focused on promoting quality use of medicines. The Facebook service dubbed Pharmacist Hour has allowed consumers to post a wide range of medicine-related questions, primarily on adverse effects, treatment options for conditions, and drug interactions. This Facebook service is an additional channel that allows NPS MedicineWise to promote the safe use of medicines by the provision of evidence-based information.

An SNS can be a new medium for the provision of individualized health and medicines information services, in which pharmacists might play a prominent and significant role. Pharmacies and other health care providers planning to implement a similar SNS service to individual consumers should be wary of some challenges highlighted in this case study, such as careful service design, patient confidentiality and privacy, professional liability, quality and extent of information, and resources. To better understand the possibilities and challenges of an SNS in the provision of pharmacy services, the description and analyses of other services are needed.

## Conflicts of Interest

AB, TC, and PA have no conflicts of interest to declare. SS is currently and TB was previously employed by NPS MedicineWise. They have no other conflicts of interest to declare.

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XSL·FO

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## Abbreviations

**SNS:** social networking site

XSL•FO

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Original Paper

# Using Twitter Data to Gain Insights into E-cigarette Marketing and Locations of Use: An Infoveillance Study

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## Abstract

**Background:**    Marketing and use of electronic cigarettes (e-cigarettes) and other electronic nicotine delivery devices have increased exponentially in recent years fueled, in part, by marketing and word-of-mouth communications via social media platforms, such as Twitter.

**Objective:**    This study examines Twitter posts about e-cigarettes between 2008 and 2013 to gain insights into (1) marketing trends for selling and promoting e-cigarettes and (2) locations where people use e-cigarettes.

**Methods:**    We used keywords to gather tweets about e-cigarettes between July 1, 2008 and February 28, 2013. A randomly selected subset of tweets was manually coded as advertising (eg, marketing, advertising, sales, promotion) or nonadvertising (eg, individual users, consumers), and classification algorithms were trained to code the remaining data into these 2 categories. A combination of manual coding and natural language processing methods was used to indicate locations where people used e-cigarettes. Additional metadata were used to generate insights about users who tweeted most frequently about e-cigarettes.

**Results:**    We identified approximately 1.7 million tweets about e-cigarettes between 2008 and 2013, with the majority of these tweets being advertising (93.43%, 1,559,508/1,669,123). Tweets about e-cigarettes increased more than tenfold between 2009 and 2010, suggesting a rapid increase in the popularity of e-cigarettes and marketing efforts. The Twitter handles tweeting most frequently about e-cigarettes were a mixture of e-cigarette brands, affiliate marketers, and resellers of e-cigarette products. Of the 471 e-cigarette tweets mentioning a specific place, most mentioned e-cigarette use in class (39.1%, 184/471) followed by home/room/bed (12.5%, 59/471), school (12.1%, 57/471), in public (8.7%, 41/471), the bathroom (5.7%, 27/471), and at work (4.5%, 21/471).

**Conclusions:**    Twitter is being used to promote e-cigarettes by different types of entities and the online marketplace is more diverse than offline product offerings and advertising strategies. E-cigarettes are also being used in public places, such as schools, underscoring the need for education and enforcement of policies banning e-cigarette use in public places. Twitter data can provide new insights on e-cigarettes to help inform future research, regulations, surveillance, and enforcement efforts.

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## Introduction

Electronic cigarettes (e-cigarettes) have grown in popularity since their introduction into the marketplace in 2006. E-cigarette awareness is high among adults in the United States (73%) and abroad [1-3]. The proportion of US adults who have ever used e-cigarettes increased rapidly from 1.8% in 2010 to 10.0% in 2013, with use rates highest among young adults and current cigarette smokers [4]. Today, more US teens use e-cigarettes than traditional cigarettes [5-7]; nationally, 9% of 8th graders, 16% of 10th graders, and 17% of 12th graders reported e-cigarette use in the past 30 days compared with 4% of 8th, 7% of 10th, and 14% of 12th graders reporting cigarette use in the past 30 days [5].

Consumer interest in and use of e-cigarettes may be influenced by advertising and information sharing from social sources. E-cigarette advertising expenditures increased dramatically across media channels between 2010 and 2013, including television, magazines, outdoor, radio, and online [8-10]. E-cigarette television ads increased by 256% from 2011 to 2013 [9] and more than US $2 million was spent on e-cigarette and tobacco ads online from 2012 to 2013 [10]. Adults and youth are receptive to e-cigarette television ads [8,11] and exposure is associated with intentions to use e-cigarettes among youth [11]. However, studies show that most people heard about e-cigarettes online (41%) or from personal contacts (35%) [12] and that most consumers who try e-cigarettes do so out of curiosity or because a friend or family member offered it to them [13]. Recent studies have documented that e-cigarette information is widely available online from branded websites, e-cigarette user forums, marketing, and user-generated content on social media sites such as Twitter and YouTube [14,10]. Therefore, understanding how e-cigarettes are marketed and what information consumers share about them could help to inform ongoing surveillance and regulatory efforts.

Social media is an important source of information in our everyday lives. In the United States, nearly 81% of youth [15] and 74% of adults [16,17] use some form of social media. Twitter, a social networking microblog, has grown in popularity and currently (September 17, 2015) has more than 316 million active users [18]. Registered users can publish an unlimited number of 140-character posts ("tweets") that are by default visible to the public. As of September 2015, users are creating more than 500 million tweets daily [18]. Because tweets are publicly available, Twitter has become a rich data source for surveillance of public health issues and insights into emerging phenomena [19-26].

Researchers have begun to explore e-cigarette conversations on Twitter [27-29]. Huang and colleagues [29] analyzed e-cigarette tweets from May to June 2012 and found that 90% of tweets were commercial/advertising-related and that these tweets emanated from a relatively small subset of extremely active users. Also, most of these tweets (94%) included URLs, which in many cases were used for the promotion or sale of e-cigarettes. In another study, researchers found that Twitter was used to oppose passage of e-cigarette regulation [28]. The week before the Chicago City Council was scheduled to vote on regulating e-cigarettes as a tobacco product, most tweets mentioning the Chicago Department of Public Health (59%) were against the policy and framed e-cigarettes as healthier alternatives to cigarettes and as aids to smoking cessation. Findings from this study suggest that 14% of these tweets were created using accounts intended to create perceptions of consensus regarding an issue (eg, health benefits of e-cigarettes). These studies suggest that Twitter data may be useful for surveillance of e-cigarette marketing and policy issues.

E-cigarettes are currently not regulated by the US Food and Drug Administration (FDA), but the FDA has issued a deeming rule to extend their authority to regulate e-cigarettes. Researchers have argued that swift responses to e-cigarette advertising are needed [30]. If the FDA regulates the manner e-cigarettes are marketed, including the type of claims companies can make, ongoing surveillance of e-cigarette marketing practices and enforcement of potential violators is needed. Because e-cigarettes are advertised online, identifying and monitoring these entities will be critical to regulatory enforcement efforts, especially on platforms such as social media where multiple accounts can be opened with no verification of one's true identity. Therefore, identifying marketers who are advertising e-cigarettes online will be critical to these efforts.

There has been more active local and state government regulations including banning sales of e-cigarettes to minors [31] and prohibiting use of e-cigarettes in public places by amending clean indoor air laws to include e-cigarettes. However, the extent to which these laws are enforced is largely unknown. In an online survey of 1201 adult US adult smokers, we found that 35.0% reported seeing others use e-cigarettes "often" or "very often" in public places, such as restaurants (31.6%), parks and beaches (43.7%), and worksites (21.0%) [32]. Because social media is widely used by consumers, analyzing social media data may provide more insights into consumer behaviors and reactions to e-cigarette policies that could help inform future regulatory action.

Our study explored insights about e-cigarettes gleaned from mining Twitter data across multiple years (2008-2013) from the Twitter firehose (full sample of tweets). This study builds on previous research studying e-cigarette marketing on Twitter in several important ways [29]. First, our Twitter data and analyses represent a crucial period (2008-2013) for understanding rapid increases in e-cigarette marketing, advertising, sales, and use. These analyses capture tweets during the period when e-cigarette use began to increase in popularity. Second, this study identifies marketing trends that may be indicative of spamming or fake consumers (eg, purchasing followers), which has important implications for prioritizing regulatory efforts for e-cigarette marketing. Third, this study derives the places where people report using (and seeing others use) e-cigarettes from tweets, which helps to illuminate locations where policy makers should consider passing regulations to prohibit the use of e-cigarettes.

## Methods

### Data Source

Twitter data were obtained from Radian6 [33], a leading social media monitoring tool that collects data from more than 400 million sources across social networking sites (eg, Twitter, Facebook, YouTube), forums, blogs, and mainstream news. Radian6 offers historical Twitter data from July 1, 2008, and provides users full access to all available tweets from the Twitter firehose.

### Keyword Search

To identify tweets about e-cigarettes, we developed a search syntax that included 55 search keywords, including general e-cigarette terms (eg, electronic cigarette, eCig), specific e-cigarette brand names (eg, blu, NJoy, green smoke), and terms about e-cigarette use (eg, vaping). We reviewed the initial search results and amended the syntax to exclude other tobacco or drug terms (eg, marijuana, hookah). The final search syntax was entered into Radian6 to identify relevant tweets from July 1, 2008 to February 28, 2013 (when the search was conducted). The search results were downloaded into Microsoft Excel from Radian6, including the date and time of the tweet, Twitter handle, the entire text of the tweet (including URLs, hashtags), and the number of followers at the time the tweet was posted.

### Tweet Classification and Analysis

Data processing was done in the Python programming languages. We extracted hashtags and links from the text using regular expressions [34]. For hashtags, we used the regular expression #[a-zA-Z][a-z-A-Z0-9_]. For URLs, we used +:/{2}[-]+(.[-]+)(?:(?:/[^s/])) [34]. Because many links are URL shorteners (eg, bit.ly, t.co), we unshortened the URLs using the application programming interfaces (APIs) provided by unshort.me and Unshorten.It! [35].

### Classification of Advertising Tweets

We randomly selected 507 tweets from the Radian6 corpus and manually classified them as advertising or not advertising. A tweet was coded as advertising e-cigarettes if it mentioned specific brands or websites and listed a price, promotional offer, and words such as "buy." By using the scikit-learn module in Python [36], we built a classification algorithm to tag the remaining tweets as advertising or not. We used text content of the tweet and 5 metadata features in our classification algorithm: follower count at time of tweet, following count at time of tweet, number of tweets at time of tweet, a binary feature indicating whether or not the tweet contained a URL, and a binary feature indicating whether or not the tweet was a retweet.

To turn the tweet text into a feature matrix [37], we used scikit-learn's CountVectorizer method [36]. CountVectorizer creates a feature for each word and, in this case, a feature for every n-gram of length 1 to 4 [37]. For each tweet, the value of the feature for a given n-gram was one if the tweet contained the n-gram and zero otherwise. Initially, we had 15,313 n-gram features along with the 5 metadata features.

Because the number of features was 30 times the number of data points, we performed feature selection before training a classification model [38,39]. We trained an extremely randomized trees model [39] (implemented in scikit-learn as ExtraTreesClassifier) on our data and selected only the features with nonzero feature importance. This resulted in 2167 features. We then fit the reduced data with a random forest model (as implemented by scikit-learn) with 10 trees. We scored our model with a tenfold cross-validation according to the accuracy metric (proportion correctly classified). (Because we were concerned about correct classification in both classes, precision and recall were insufficient metrics here.) The mean accuracy across the 10 cross-validations was 0.907. Because 78% of the tweets in the training data were advertising, the naive classifier that labeled everything as advertising would result in an accuracy of 0.78. Our model was a 16% improvement over this baseline. The classifier had high precision (91%) and recall (93%).

### Classification of Where People Use E-Cigarettes

By using a combination of natural language processing and manual classification, we extracted prepositional phrases indicating where people used e-cigarettes or observed others using them. We started with the corpus of tweets that we classified as not advertising.

First, we selected a subset of the tweets containing the words *smoking*, *vaping*, *smokes*, *vapes*, *smoked*, and *vaped* that indicated active usage of e-cigarettes. Second, we cleaned each of these tweets according to a series of rules that were iteratively developed to maximize the number of prepositional phrases extracted. These rules included removing @-mentions and hashtags, removing various interjections (eg, "lol," "smh," and various expletives), removing common subordinate prepositional phrases (eg, "in the middle," "in front"), and correcting common misspellings and slang commonly used in text-based communication (eg, "ur" to "you're"). Third, we ran each cleaned tweet through the parts-of-speech tagger in the Natural Language Toolkit (NLTK) library [40]. The tagger attempted to label each word in a document (ie, tweet) with its part of speech. Fourth, to extract prepositional phrases from the tweets, we extracted each preposition and all subsequent words before the next verb, preposition, or "wh-" adverb (eg, "whenever," "where"). Statistical methods for extraction of prepositional phrases, such as the Stanford Parser [41] are available. However, because of the prevalence of poor spelling and bad grammar on Twitter, the Stanford Parser proved ineffective at correctly extracting prepositional phrases. Looking at a sample of 100 tweets containing prepositional phrases, we determined that the 3 primary prepositions indicating the location of e-cigarette use were "in" (62 tweets), "at" (12 tweets), and "on" (11 tweets). The next most frequent prepositions were "around" (3 tweets) and "during" (3 tweets). Thus, we restricted further analysis to tweets containing one of the top 3 prepositions. Finally, we manually compiled a list of nouns that commonly occur in prepositional phrases, but do not refer to a physical location (eg, at "night," in "life"). Prepositional phrases containing these words as objects were excluded from our analysis. Once prepositional phrases with these objects were excluded, we were left with a list of tweets containing references to e-cigarettes being used in physical locations.

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## Results

We identified a total of 1,669,123 tweets about e-cigarettes from July 1, 2008 to February 28, 2013 (Figure 1). The number of e-cigarette tweets increased from 82 in 2008 (May through December only) to 10,870 in 2009, 141,405 in 2010, 746,541 in 2011, 643,900 in 2012, and 64,734 in 2013 (January and February only) (Table 1). Of these 1.6 million tweets, 93.43% (n=1,559,508) were advertising e-cigarettes, whereas only 6.57% (n=109,615) were nonadvertising tweets (Table 1). Approximately 28.70% (447,579/1,559,508) of advertising tweets were retweeted, whereas 11.60% (12,715/109,615) of nonadvertising tweets were retweeted. As Figure 1 shows, advertising tweets increased dramatically over the period observed with periods of sharp increases and declines, whereas nonadvertising tweets increased minimally and at a relatively stable rate.

We are unaware of any events that could explain the spikes observed. We examined the spike around October/November 2011 and noticed an increase in the number of Twitter handles that started posting e-cigarette content at that time but stopped in early 2012. We think this may have been a coordinated marketing/spam effort because many of the Twitter accounts were random numbers and characters.

Table 1 summarizes characteristics of advertising and nonadvertising tweets. Approximately 10% of the advertising tweets described price-related promotions, including coupons (7.69%, 119,904/1,559,508), percent off (7.61%, 118,616/1,559,508), and discount offers (0.89%, 13,952/1,559,508). Approximately 14.99% (233,712/1,559,508) mentioned one of the 32 e-cigarette brands we coded for, with blu (5.99%, 93,405/1,559,508), V2 (2.05%, 31,983/1,559,508), and Green Smoke (1.78%, 27,778/1,559,508) being the most commonly mentioned brands. The 5 most active Twitter handles over the study period produced between 32,141 and 88,424 tweets. Two of the 5 handles included words related to e-cigarettes (eg, vapor and e-cigarettes). The most prolific handle belonged to an online e-cigarette vendor with the following Twitter profile: "Over 125 flavors of Ejuice to choose from at [Vapor God website]. We also offer a Flavor Lab where you can create your own ejuice flavors!" As of March 7, 2015, this handle had 15,601 followers and had posted 107,739 tweets, but only 10 tweets were posted since November 5, 2012. Many of their tweets were of the following form, with different flavors advertised: "Try our great-tasting vanilla cupcake flavored ecigarette eliquid! Get 20% off at checkout with coupon code-twitter [Vapor God website] (Nov 5, 2012)." In contrast, the other active Twitter handles had limited information on their profile (ie, no description, custom background, picture, or URL), and the name given for the account was generic (eg, "moou," "alejandro"). These Twitter handles also had few followers (132-1340) compared with the most prolific Twitter handle, yet they had a large number of total tweets (eg, one account posted 132,242 tweets as of March 7, 2015). Most tweets were short fragments of text promoting e-cigarettes (eg, "Review e-cigarette" and "Best vapor 7.5mm ecigs") often with a link that redirected to an inactive page at the time of last review (March 7, 2015). Tweets also contained e-cigarette promotional phrases within nonsensical strings of words (eg, "Buy Electronic smoke The e cigarette bass viol safeguarding brace the healthiness but the...e-Cigarettes On Sale"). This pattern suggests that an automated computer program, rather than a human, may have been generating tweet content and posting it online. None of these Twitter handles appeared to be active as of December 2013 and one account was suspended by Twitter. The most common links shared in advertising tweets are summarized in Table 1. The link to the VaporGod website [42] was shared in 89,068 tweets, mostly by the most prolific Twitter handle for e-cigarette advertising tweets. The top 3 links most commonly shared by unique Twitter handles [43-45] appeared to be affiliate sites with news and reviews about e-cigarettes, including advertisements for e-cigarette brands and links to free e-cigarette starter kits.

Characteristics of the 109,615 nonadvertising e-cigarette tweets are also summarized in Table 1. Specific brands were mentioned in 4244 nonadvertising tweets with top mentions being blu (979 tweets, 0.89%), Vapor4life (803 tweets, 0.73%), Volcano (718 tweets, 0.66%), NicStick (605 tweets, 0.55%), and eSmoke (311 tweets, 0.28%). The most active Twitter handles among the nonadvertising tweets produced between 424 and 1224 tweets. All these Twitter handles included e-cigarette–related terms in the handle (eg, vape, ecigs). The nonadvertising Twitter handles had substantially fewer followers (51-2705) and tweeted less content than the top e-cigarette advertising Twitter handles. According to its Twitter profile, the most prolific nonadvertising Twitter handle is a "global electronic cigarette manufacturer & retailer," but this retailer is tweeting about e-cigarette–related policies and news stories and interacting with followers, rather than advertising its products. Another profile notes that he is a "husband, father of 4, nurse and vaper" who "Love[s] technology and getting outside when I can. Spending time with my kids & fishing are my favorite things to do."

**Table 1.** Number and characteristics of e-cigarette tweets, May 1, 2008 to February 28, 2013 (N=1,669,123).

| Characteristic | Tweets |
| --- | --- |
| **Number of tweets, n** | |
| 2008 (July-December only) | 82 |
| 2009 | 10,870 |
| 2010 | 141,405 |
| 2011 | 746,541 |
| 2012 | 643,900 |
| 2013 (January-February only) | 64,734 |
| **Total, n (%)** | 1,669,123 (100) |
| Advertising tweets | 1,559,508 (93.43) |
| Nonadvertising tweets | 109,615 (6.57) |
| **Advertising tweets, n (%)** | |
| Promotion | 152,812 (9.80) |
| Coupon | 119,904 (7.69) |
| Percent Off | 118,616 (7.61) |
| Discount | 13,952 (0.89) |
| **Brands mentioned** | 233,712 (14.99) |
| blu | 93,405 (5.99) |
| V2 | 31,983 (2.05) |
| Green Smoke | 27,778 (1.78) |
| Premium | 11,112 (0.71) |
| Luci | 9337 (0.60) |
| **Most active Twitter handles** [a] | |
| Most active handle (16,160 followers) | 88,424 (5.67) |
| Second most active handle (1393 followers) | 50,651 (3.25) |
| Third most active handle (136 followers) | 41,032 (2.63) |
| Fourth most active handle (145 followers) | 36,694 (2.35) |
| Fifth most active handle (149 followers) | 32,141 (2.06) |
| **Most common links shared in tweets** | |
| VaporGod [42] | 89,068 (5.71) |
| http://aan.atrinsic.com/z/873949/9092/&subid1=9546 | 75,580 (4.85) |
| http://bestcelebrex.blogspot.com/p/e-cigarette.html | 42,751 (2.74) |
| South Beach Smoke | 14,718 (0.94) |
| http://ECigarettesStarterKits.com [43] | 8351 (0.54) |
| **Nonadvertising tweets, n (%)** | |
| **Brands mentioned** | 4244 (3.87) |
| blu | 979 (0.89) |
| Vapor4Life | 803 (0.73) |
| Volcano | 718 (0.66) |
| NicStick | 605 (0.55) |
| eSmoke | 311 (0.28) |
| **Most active Twitter handles** | |
| Most active handle (2705 followers) | 1224 (1.11) |

| Characteristic | Tweets |
| --- | --- |
| Second most active handle (646 followers) | 899 (0.82) |
| Third most active handle (702 followers) | 737 (0.67) |
| Fourth most active handle (51 followers) | 547 (0.50) |
| Fifth most active handle (246 followers) | 424 (0.39) |
| **Places mentioned in tweets** | 471 (0.43) |
| Class | 184 (39.07) |
| House/room/in bed | 59 (12.53) |
| School | 57 (12.11) |
| Public place | 41 (8.70) |
| Bathroom | 27 (5.73) |
| Work | 21 (4.46) |
| In front of someone | 12 (2.55) |
| Car | 11 (2.34) |
| Restaurant | 10 (2.1) |
| Movie theater | 9 (1.91) |
| Airplanes/airport | 8 (1.70) |
| Store | 7 (1.49) |
| Bars/clubs | 6 (1.27) |
| Dormitory | 6 (1.27) |
| Library | 4 (0.85) |
| Mall | 3 (0.64) |
| Bowling alley | 2 (0.42) |
| Café/coffee shop | 2 (0.42) |
| Hospital | 1 (0.21) |
| Locker room | 1 (0.21) |

[a]Number of followers as of December 12, 2013.

For a subset of the most active handles tweeting about e-cigarettes, we explored additional metadata for some insights into how to characterize these users. Specifically, we examined the number of followers accrued over time for the 7 most active tweeters (Figure 2). Amassing a large number of followers in a short time frame, which occurred for certain users, may be suggestive of a marketer or spammer who purchased a list of Twitter handles as followers compared to a legitimate brand or business that accrues followers steadily over time. Indeed, further exploration of historic activities on Twitter during the time in which tweets about e-cigarettes spiked to the highest levels (November 2011-February 2012) revealed that a large number of spam accounts with handles comprising random characters began tweeting around this time and were shut down by Twitter in early 2012.

We coded places where users mentioned using their e-cigarettes or seeing others use e-cigarettes. Of the 471 tweets that mentioned a specific place, 39.1% (184/471) mentioned e-cigarette use in class, whereas 12.5% 59/471) mentioned use in a house/room/bed, 12.1% (57/471) mentioned use in school, 8.7% (41/471) mentioned use in public, 5.7% (27/471) mentioned use in a bathroom, and 4.5% (21/471) mentioned use at work. Some tweets were indeed about individuals using e-cigarettes in public places such as schools (eg, "my teacher yells at me everyday for vaping in class..." and "Vaping in the bathroom #whatofit") and in the convenience of private spaces such as their bedrooms (eg, "I do love being able to smoke in my room again doe! #ecig"). However, most tweets were from people expressing disbelief at others using e-cigarettes in public places (eg, "Is this guy really smoking an electronic cigarette in class? #Yes #wtf"). People also noted that it was odd to see others use e-cigarettes in places where smoking has traditionally been banned (eg, "The guys in my office are smoking electronic cigarettes, its rather strange seeing smoke indoors, in an office, in the daytime") and were confused about whether using e-cigarettes in public places is allowed (eg, "My professor was just smoking his electronic cigarette in class, is that illegal?" and "High schoolers smoking e-cigarette in my #metro station. @Wmata Is that allowed? #narc #defnothealthy").

**Figure 1.** Number of e-cigarette tweets by type (advertising vs nonadvertising), weekly from July 1, 2008 to February 28, 2013.
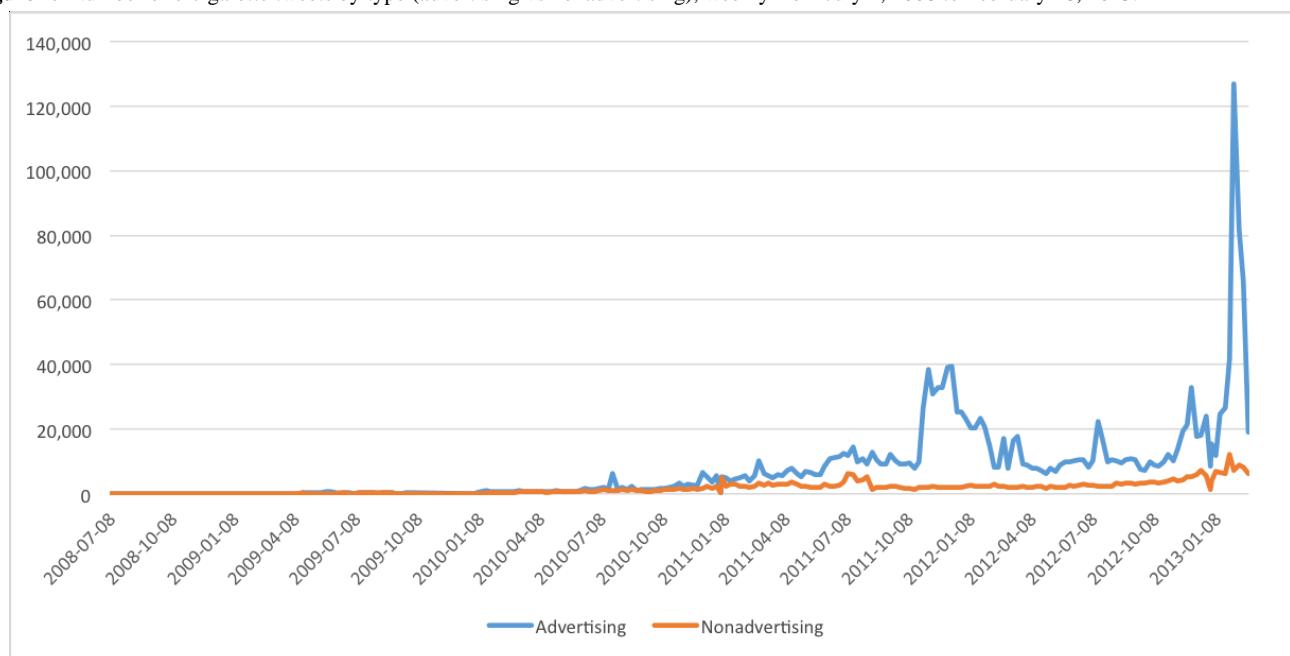


**Figure 2.** Follower counts of prolific e-cigarette advertising Twitter handles.
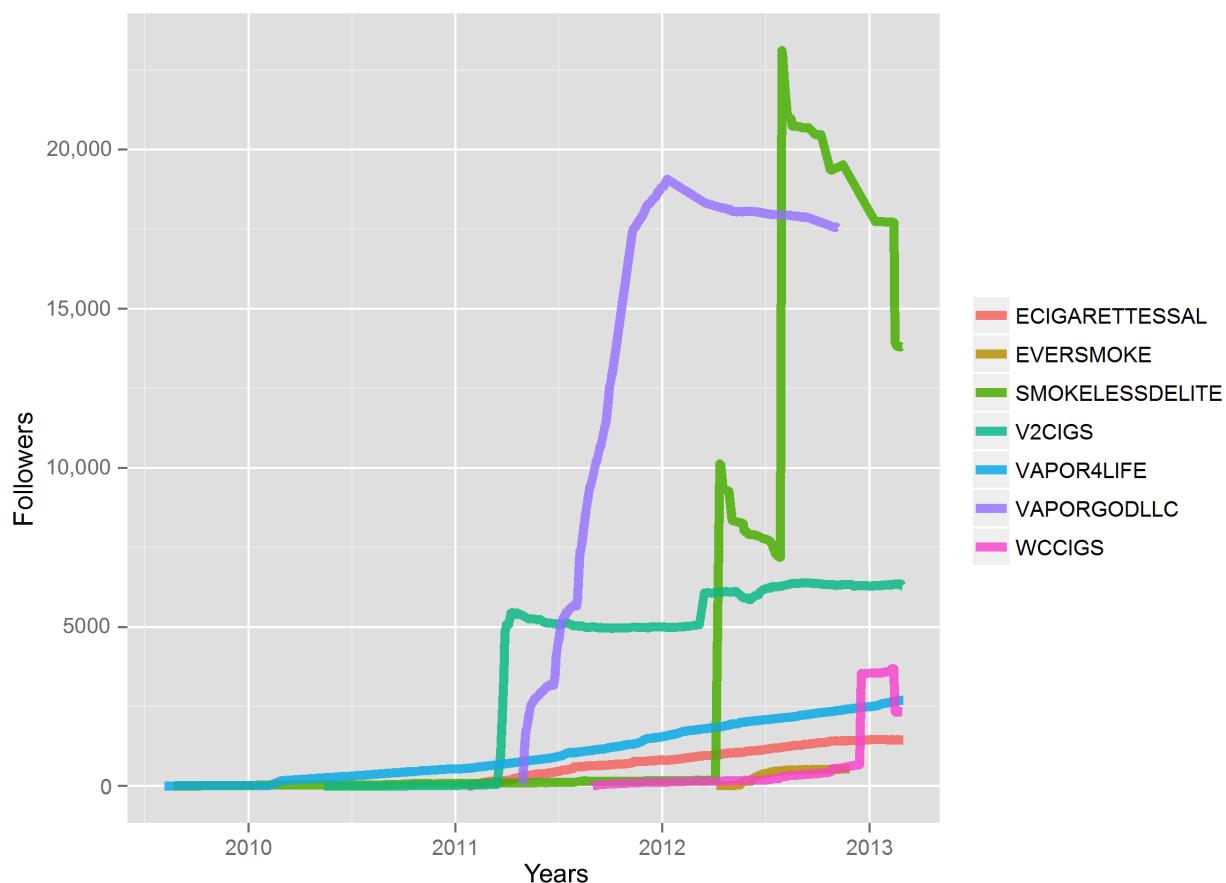
## Discussion

### Principal Results

In summary, we found that Twitter conversations about e-cigarettes have increased dramatically in recent years. This pattern is consistent with the recent rise in e-cigarette advertising expenditures [8] and e-cigarette use among youth [46] and adults [47]. It is not surprising that the majority of tweets appear to be advertising-related because in the early introduction of a new product claims are often made that new products are more cost-effective (eg, claims that e-cigarettes are cheaper than tobacco cigarettes and nicotine replacement therapy) [48]. Furthermore, because anyone can create a Twitter account and start posting content, e-cigarette vendors can freely "advertise" their products via tweets to the more than 316 million monthly active users with no advertising costs per se. This also means that anyone—whether a legitimate brand, an online-only vendor, an affiliate marketer, or an e-cigarette user/enthusiast—can post content. Indeed, our look at the most active Twitter handles suggests that actual online vendors and potential affiliate marketers are promoting e-cigarettes online, with some potentially using computer programs to generate and post tweet content automatically. This practice is not unique to e-cigarettes as evidenced by the fact that, for years, Twitter has been attempting to identify spam accounts that are generating automated content from computer programs and not actual individuals. This type of "spamming" suggests that there is an online marketplace for e-cigarettes whereby individuals can earn money by driving customers to visit an e-cigarette vendor website. This also means that the online marketplace is more diverse than traditional brick-and-mortar offerings; the top brands mentioned in tweets, except for blu eCigs, are not the leading brands advertised on other media channels (eg, television) or sold in retail stores [8].

The ease of posting user-generated content online and sharing this information across social media platforms such as Twitter suggests that Twitter users may be exposed to more e-cigarette brands and online vendors than non-Twitter users. Although only approximately 23% of the US adult population is on Twitter, use rates are highest among young adults aged 18 to 29 years [17] and have been increasing among youth in recent years [17,49]. Just because youth are on Twitter does not necessarily mean they are exposed to these tweets. One would have to follow these Twitter accounts or be exposed to the tweets through their social network (ie, followers or those they are following) or via searches. This study was not designed to examine audiences that may have been exposed to these e-cigarette tweets; however, recent studies suggest that e-cigarette users learn about e-cigarettes from sources such as the Internet. Therefore, monitoring how e-cigarettes are discussed on social media platforms such as Twitter is important, especially if frequent tweets about e-cigarettes from multiple Twitter handles may give consumers the false perception that e-cigarettes are readily available and use is more common than it really is. Previous research has shown that tactics of fostering a false sense of consensus have been used to oppose passage of e-cigarette policies [28]. We also know from the literature that youth overestimate the prevalence of youth smoking, so

exposure to frequent tweets about e-cigarettes and visual cues of people vaping their e-cigarettes via photos may influence their interest in and perceived social norms about e-cigarette use [50].

Our analysis of patterns of tweets among the most active Twitter users also revealed important patterns (eg, accounts gaining many followers during a short window of time) that suggest some of the most active accounts may be engaging in practices such as purchasing followers. Previous research has shown that abnormal patterns in posting behavior (eg, bursts of posts in a short period of time) are indicative of spamming or fake consumers [51]. In this context, a burst of followers for a particular e-cigarette-related Twitter handle likely suggests spamming. Additional work is needed in this area because distinguishing legitimate e-cigarette companies/vendors from spammers/affiliate marketers will help prioritize and inform future regulatory efforts.

Our analysis of nonadvertising tweets indicates that organic conversations about e-cigarettes are occurring online that can provide insights into consumer use behaviors. Interestingly, we find posts about e-cigarettes being used in public spaces, with class being the top mention. Although some of these tweets indicate that students (and staff in some cases) were using e-cigarettes in class, the majority of tweets were from nonusers who expressed surprise or disdain at seeing others using e-cigarettes in public and were confused as to whether this is allowed. We do not know from the tweets whether these were youth or young adults tweeting about a high school class or a college class, and future studies should examine ways to determine the demographics of tweeters. Regardless, these results suggest that youth and young adults may be exposed to e-cigarette use in their everyday lives, and the lack of action by staff may give them a sense that e-cigarette use is permissible and not as harmful as cigarettes. This is a concern among public health professionals and increasingly local governments have introduced [52] and passed [53] policies banning the use of e-cigarettes in public places and in schools (eg, [54]).

### Limitations

This study has several limitations. Although we attempted to identify the entire population of tweets about e-cigarettes using a comprehensive search strategy, we may have missed some relevant tweets. Additionally, we attempted to characterize the most active Twitter handles, but our analysis was based largely on posted information in their profile, which may not reflect who they truly are or their motivations for tweeting e-cigarette content. This is a general challenge in conducting Twitter research and more advanced computational methods are needed to mine the profile descriptions and tweet content of any given Twitter handle to determine the individuals' demographic characteristics. Additionally, we do not know the extent to which Twitter users were exposed to e-cigarette tweets. Finally, the data presented in this study may have limited implications today given likely changes in the e-cigarette marketplace, brands' advertising strategies, e-cigarette policies, and consumer behaviors.

## Comparison to Prior Work

This study builds on prior work assessing e-cigarette marketing on Twitter (eg [29]). A key strength is that we analyzed data across multiple years to characterize the emerging trend of e-cigarette conversations on Twitter. We used a data source with access to the full Twitter sample and historical tweets. In contrast, most studies using Twitter data have examined substantially shorter time periods (eg, months) using freely accessible data from the Twitter API, which only provides 1% of all tweets. The Twitter data and analyses presented here also helped us to understand a key period (2008-2013) for e-cigarette marketing when these devices began to increase in popularity. This study also identifies locations where e-cigarettes are being used and suggests the need for better enforcement of policies restricting e-cigarette use in public places such as schools.

## Conclusions

In conclusion, Twitter may provide valuable insights into how information about new products, such as e-cigarettes, are disseminated via social media. Our results suggest that Twitter is being used to promote e-cigarettes and that the online marketplace is more diverse than the offline brick-and-mortar product offerings and advertising strategies. Monitoring and regulating these entities online will be challenging given how easily anyone can set up multiple social media accounts with no verification of their identity before they advertise their products to consumers worldwide. Therefore, it will be important to not only examine the content of e-cigarette advertising tweets, but other characteristics of marketers, such as frequency of tweeting behavior and patterns of acquiring followers, to identify entities that state and federal governments may need to monitor and regulate. For example, enforcing advertising restrictions may have different implications for an actual e-cigarette brand company with brick-and-mortar presence versus an individual who is an affiliate marketer for an online e-cigarette retailer. Our results also highlight that e-cigarettes are being used in public places such as schools and underscore the need for education and enforcement of policies banning e-cigarette use in public places. In summary, Twitter data can provide new insights on a rapidly evolving public health phenomenon such as e-cigarettes to help inform future research, regulations, surveillance, and enforcement efforts.

## Authors' Contributions

AK conceptualized the study and led study implementation, interpretation of findings, and writing of the manuscript. TH led the data analysis and assisted with writing of the manuscript. SS assisted with data analysis. JN assisted with interpretation of findings and manuscript review. AL and HH assisted with data collection. JG and LP assisted with writing and review of manuscript.

## Conflicts of Interest

None declared.

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## Abbreviations

**API:** application program interface
**FDA:** Food and Drug Administration

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Original Paper

# Forecasting the Incidence of Dementia and Dementia-Related Outpatient Visits With Google Trends: Evidence From Taiwan

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## Abstract

**Background:** Google Trends has demonstrated the capability to both monitor and predict epidemic outbreaks. The connection between Internet searches for dementia information and dementia incidence and dementia-related outpatient visits remains unknown.

**Objective:** This study aimed to determine whether Google Trends could provide insight into trends in dementia incidence and related outpatient visits in Taiwan. We investigated and validated the local search terms that would be the best predictors of new dementia cases and outpatient visits. We further evaluated the nowcasting (ie, forecasting the present) and forecasting effects of Google Trends search trends for new dementia cases and outpatient visits. The long-term goal is to develop a surveillance system to help early detection and interventions for dementia in Taiwan.

**Methods:** This study collected (1) dementia data from Taiwan's National Health Insurance Research Database and (2) local Internet search data from Google Trends, both from January 2009 to December 2011. We investigated and validated search terms that would be the best predictors of new dementia cases and outpatient visits. We then evaluated both the nowcasting and the forecasting effects of Google Trends search trends through cross-correlation analysis of the dementia incidence and outpatient visit data with the Google Trends data.

**Results:** The search term "dementia + Alzheimer's disease" demonstrated a 3-month lead effect for new dementia cases and a 6-month lead effect for outpatient visits ($r=.503$, $P=.002$; $r=.431$, $P=.009$, respectively). When gender was included in the analysis, the search term "dementia" showed 6-month predictive power for new female dementia cases ($r=.520$, $P=.001$), but only a nowcasting effect for male cases ($r=.430$, $P=.009$). The search term "neurology" demonstrated a 3-month leading effect for new dementia cases ($r=.433$, $P=.008$), for new male dementia cases ($r=.434$, $P=.008$), and for outpatient visits ($r=.613$, $P<.001$).

**Conclusions:** Google Trends established a plausible relationship between search terms and new dementia cases and dementia-related outpatient visits in Taiwan. This data may allow the health care system in Taiwan to prepare for upcoming outpatient and dementia screening visits. In addition, the validated search term results can be used to provide caregivers with caregiving-related health, skills, and social welfare information by embedding dementia-related search keywords in relevant online articles.

**KEYWORDS**

# Introduction

## Background

Dementia is a clinical syndrome caused by neurodegeneration of brain tissue. It encompasses a variety of diseases, including Alzheimer's disease (AD), vascular dementia, Lewy body dementia, and frontotemporal dementia [1]. It is well known that dementia becomes more prevalent with increasing age, and that this increasing prevalence of dementia is significantly affecting the lives of a large and growing number of older adults around the world. Dementia also generates a substantial effect on public health, the social care system, and societal costs [2].

Worldwide, the number of people over the age of 60 is projected to increase to 1.25 billion by 2050, and will account for 22% of the total world population [3]. According to the World Alzheimer Report released by Alzheimer's Disease International (ADI), nearly 36 million people worldwide are believed to have been living with AD or other dementias in 2013; that number is expected to reach 66 million by 2030 and to increase to more than 115 million by 2050 [4]. ADI reported that overall payments for people aged 65 years and older with dementia—including health care, long-term care, and hospice services—are expected to reach US $203 billion in 2013, increasing to US $1.2 trillion by 2050 [1]. Additionally, the Aging, Demographics, and Memory Study (ADAMS), a nationally representative study taking place in the United States, recently reported that the yearly societal costs in the United States attributable to dementia amounted to US $41,689 per person, with 68% of the total costs stemming from direct costs for health and social care, and the remainder due to the cost of informal care [5].

Informal caregivers have recently become an important target group for long-term care policy making. The Organisation for Economic Co-operation and Development (OECD) and other researchers have suggested that informal caregivers need to learn and obtain more skills for care and more knowledge to avoid the depression and isolation which could potentially lead to more medical utilization [6-8]. However, a challenge that has been raised in much of the literature regarding caregivers has been identifying this group of informal caregivers and determining a way to reach out to them [9,10].

Although there is no known cure for dementia, some pharmaceutical drugs, treatments, and activity interventions may potentially help to improve or maintain the symptoms [11-13]. Thus, it has been suggested that these treatments and interventions be delivered at an earlier stage of dementia, rather than at a later stage, to achieve maximum benefits, including reduced direct medical costs [12,13], delayed institutionalization [3], and maintenance of lower symptom severity levels for longer periods [14,15]. However, current diagnoses tend to be made at a relatively later stage in the course of the disease, partly due to the lack of awareness of symptoms associated with dementia, as well as to the stigma and denial of its existence [16,17]. Under such serious financial burdens on society, all governments and the World Health Organization are set to establish dementia as a public health priority in order to reach

out to individuals with early-stage dementia and their caregivers through creative strategies [18].

One of the main challenges of dementia is the lack of appropriate tools and channels for helping individuals identify themselves as having symptoms of dementia, as well as for their family members to quickly examine those they care for. The stigma associated with dementia increases this challenge [17]. A dementia diagnosis is generally perceived negatively by both family members and patients. Stigma and stereotypes are significant obstacles to well-being and quality of life [18-21]. The high rates of Internet searches for health information have suggested that the Internet may be an important resource for patients and family members, who may try to access information for self-diagnosis first, rather than visit their physicians for a more formal diagnosis [22]. Thus, the possibility of reaching out to people with dementia and their family members through the Internet merits further study.

In recent years, the Internet has become a popular medium for people searching for health-related knowledge and information for self-diagnosis [23]. A recent online health survey conducted in the United States reported that in 2012, 35% of US adults looked online to figure out medical conditions, and 72% of Internet users looked online for health information [22]. Of these online health seekers, 77% began at a search engine such as Google or Yahoo. About half of all online health searches are reportedly made on behalf of someone else [22]. These increasing numbers of online searches through search engines creates trend data which can be analyzed in real time [24].

## Previous Research

The use of aggregated search queries has considerable potential for syndromic surveillance, as proven by comparing the evidence found in the numbers of clicks on a keyword-triggered link in Google with the epidemiological data from the 2004-2005 flu season in Canada [25]. Since 2004, Google has provided two services for trend analysis: Google Flu Trends (GFT) and Google Trends (GT). In a landmark study published in the journal Nature, GFT has been identified as a powerful tool used in influenza surveillance in the United States, identifying influenza epidemics up to 7-10 days before detection by the Centers for Disease Control and Prevention's (CDC's) influenza surveillance network [26]. During periods of infectious disease prevalence, GFT has also been able to predict emergency department visit volumes [27,28].

However, GFT failed to correctly estimate the scale of the 2009 H1N1 pandemic in the United States. Several mistakes that led to GFT's overestimation of H1N1 incidence were caused by the limited transparency of Google's treatment of data and its dynamic algorithm, due to Google's business considerations [29,30]. To overcome this, GFT recently used aggregated Google search data in a model created in collaboration with the CDC to estimate influenza activity in the United States, and the results are available in the CDC's weekly US Influenza Surveillance Report [31].

Following the same logic, GT can be extended to any area for researchers to graph the frequency of searches for a specific term or phrase [24]. These graphs are normalized on a relative

basis and can also be restricted to specific time intervals or geographic regions [32]. GT data is available in the United States for city, country, or subnational areas; but for other countries worldwide, including Taiwan, GT data is mostly available on a national basis [24,33]. By tracking health-seeking behavior, GT has predictive capability to monitor the epidemic curve of food-borne illnesses, such as peanut butter-associated outbreaks of *Salmonella enterica* serotype Typhimurium [34], as well as the incidence of human immunodeficiency virus [19,35].

This tool has more recently been extended to study the relationships among macroeconomic conditions and mental illness. A recent study reported that a 5% rise in the unemployment rate is followed in the next 12 months by an approximate 14% increase in searches around problem drinking [36]. Another study showed that searches for key terms such as "divorce," "asthma," and "social welfare" led the suicide death data for 2 months [23]. Additionally, a previous study demonstrated how restaurant table availability has the potential to monitor the incidence of influenza-like illness [37]. Nowadays, this type of research has become a new discipline collectively termed *infodemiology* [25,38,39]. Based on GT's algorithm, mechanism, and research findings, it may be expected that what the general public searches for today will have predictive power for what will occur in the near future.

## Research Goals

To the best of our knowledge, most previous studies of GT data have been in the field of infectious diseases, and quite a few have been in the field of noncommunicable and chronic disease. Additionally, most of the previous studies took place in the United States. By contrast, such studies in Asia, and in Taiwan in particular, are more rare.

The first objective of this study was to investigate and validate the search terms that could be the best predictors of new dementia cases and outpatient visits. The second objective was to further evaluate the lead pattern of GT search trends related to new dementia cases and outpatient visits. The long-term goal is to contribute to developing a surveillance system for the early detection of dementia in Taiwan.

## Methods

### Data Sources

#### Overview

Data on dementia in Taiwan from January 1, 2009 to December 31, 2011, was obtained from the Longitudinal Health Insurance Database 2010 (LHID 2010), a subset of the National Health Insurance Research Database (NHIRD). These data were collected and maintained by the National Health Insurance Institutes [40]. The NHIRD has comprehensive claim data on outpatient and inpatient services from approximately 27.38 million individuals enrolled in Taiwan's National Health Insurance program. The LHID 2010 contains the entire original claim data of 1 million beneficiaries enrolled in the year 2010 and randomly sampled from the year 2010 Registry for Beneficiaries (ID) of the NHIRD.

### New Dementia Cases

Monthly figures of new dementia cases were obtained from a data file named Ambulatory Care Expenditures by Visits (CD), which is a subset database of the LHID 2010. Patients with a dementia diagnosis were identified using the International Classification of Disease, Ninth Revision, Clinical Modification (ICD-9-CM), including the diagnosis codes 290.x, 294.x, and 331.x. Patients aged 65 years or over who had received a dementia diagnosis between the years of 2009 and 2011 were included in this study. To avoid the miscounting of new case numbers, the data were reviewed and cases in which individuals had been diagnosed as dementia patients from 2005 through 2008 were excluded from the study. A total of 5383 new dementia cases were identified, with 2442 (45.37%) male cases and 2941 (54.63%) female cases.

### Dementia-Related Outpatient Visits

Dementia-related outpatient visits include both regular dementia-related clinical visits and clinical visits with new dementia diagnoses. Total visits from 2009 to 2011 were obtained from the CD data file. The numbers of monthly outpatient visits related to dementia and attributed to patients aged 65 years or older were calculated using the same ICD-9-CM criteria described above. A total of 113,710 outpatient visits were identified between the years of 2009 and 2011.

### Google Trends Search Terms and Trends

GT was provided by Google Inc starting in 2004 [24]. Search trends in GT over time are represented as a scaled number (0-100) which is normalized to the time of maximal value for those particular search terms, thus allowing for comparisons between the search terms.

To capture a broad sense of dementia-related conditions and services, 23 search terms were catalogued through GT. The relevant terms were derived from GT's explore function and included disease names, symptoms, care services, and hospital divisions. For example, disease names catalogued as search terms included "dementia," "Alzheimer's disease," and "Parkinson's disease" (see Table 1). GT only reports results above a certain threshold. When GT could not report the search volume for a term, the message displayed was "Not enough search volume to show graphs." Those search terms with insufficient search volume compared to GT's threshold were excluded. Data on the remaining three search terms from January 2009 to December 2011 (36 months) were accessed and downloaded from GT on December 28, 2013. Table 1 shows the list of dementia-related categories and search terms; Multimedia Appendix 1 shows these terms in Chinese, along with their English equivalents.

**Table 1.** List of dementia-related search terms.

| Category | Search terms[a] |
| --- | --- |
| Disease terms | Dementia; Alzheimer's disease; Parkinson's disease; senile dementia of the Alzheimer type; vascular dementia; amnesia; anxiety disorder; depression |
| Symptom terms | Dementia; senile dementia; geriatric dementia; sunset phenomenon; forgetful; memory; insomnia |
| Care terms | Dementia care; dementia respite; Taiwan Alzheimer dementia association; school of wisdom; dementia care; caregiver; long-term care |
| Division term | Neurology |

[a]Search terms are shown in their English equivalents; see Multimedia Appendix 1 for the terms in Chinese.

## Statistical Analyses

### Overview

Pearson correlation coefficient analysis is widely used in GT research [41-43]. To access the strength of the linear relationship between search trends and new dementia cases and outpatient visits, Pearson correlation coefficient analysis with 95% CI was performed for all the data. The two steps to the analysis are described below. All statistical analyses were conducted using IBM SPSS Statistics for Windows, version 20.0 (IBM Corp, Armonk, NY); a two-tailed $P$ value of less than .05 was required for statistical significance in all analyses conducted. This study was approved by the National Taiwan University Hospital (NTUH) Research Ethics Committee (REC).

### Step I: Temporal Trends

The temporal relationship between GT search trends and overall new dementia cases and outpatient visits was analyzed first. GT's lead pattern analysis was then analyzed by 1-month, 3-month, 6-month, 9-month, and 12-month intervals. For example, a 1-month lead evaluates the correlation of GT search trends from January 2009 with new dementia cases and dementia-related outpatient visits in February 2009.

### Step II: Correlation Analysis

To account for differences in the GT lead patterns influenced by gender, a correlation between GT search trends and new dementia cases and outpatient visits was first analyzed by gender, after which the analysis followed the lead pattern analysis described in Step I.

## Results

### Temporal Trends

Only three key terms—"dementia," "Alzheimer's disease," and "neurology"—came above the GT threshold and were recorded in GT. The other 20 terms either did not generate sufficient search volume, and thus were excluded from GT, or were not relevant to dementia. GT reported that searches for "dementia" and "dementia + Alzheimer's disease" steadily increased throughout the study period. Figures 1 and 2 illustrate the temporal relationship between search term trends and the number of new dementia cases (Figure 1) and outpatient visits (Figure 2). Scatterplots were constructed to compare new dementia cases and outpatient visits with data gathered from GT (see Figures 3 and 4).

**Figure 1.** Time series for the monthly counts of new dementia cases in Taiwan between January 2009 and December 2011 plotted with Google Trends search terms.
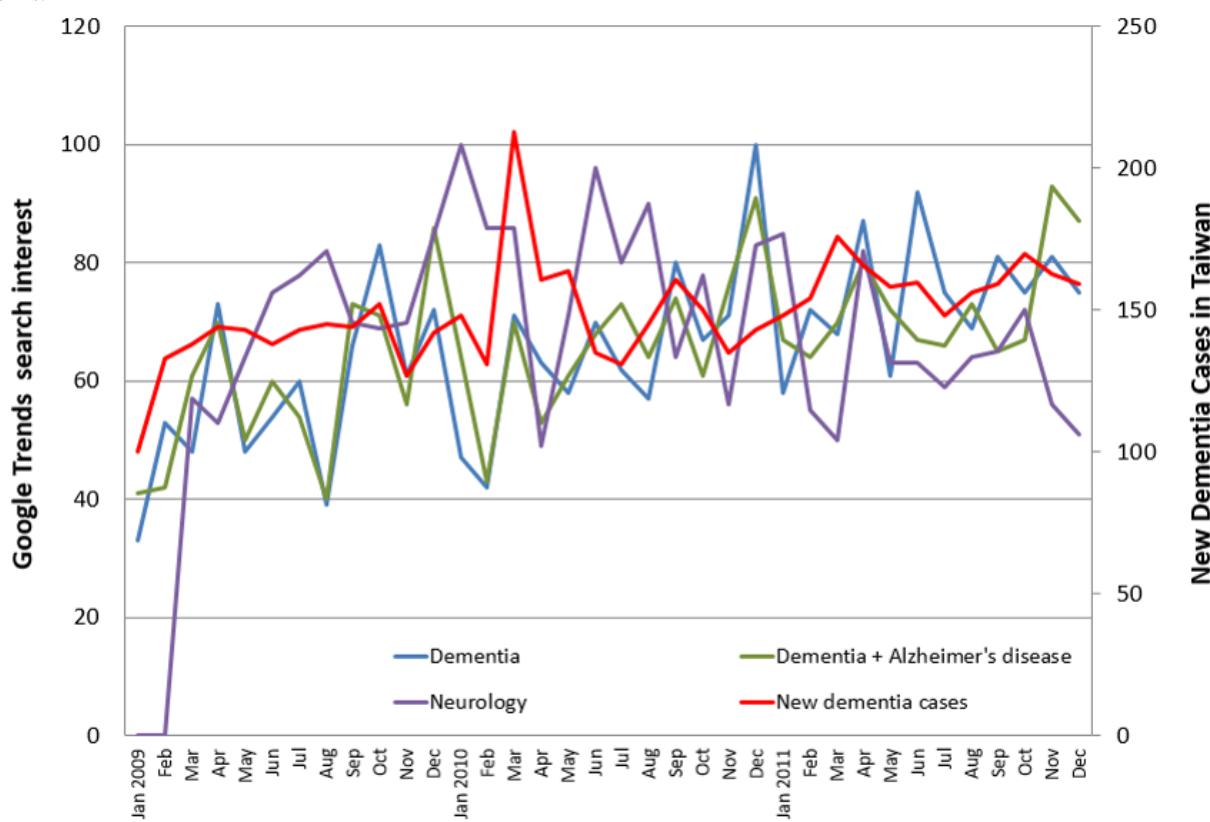


**Figure 2.** Time series for the monthly counts of outpatient visits between January 2009 and December 2011 plotted with Google Trends search terms.
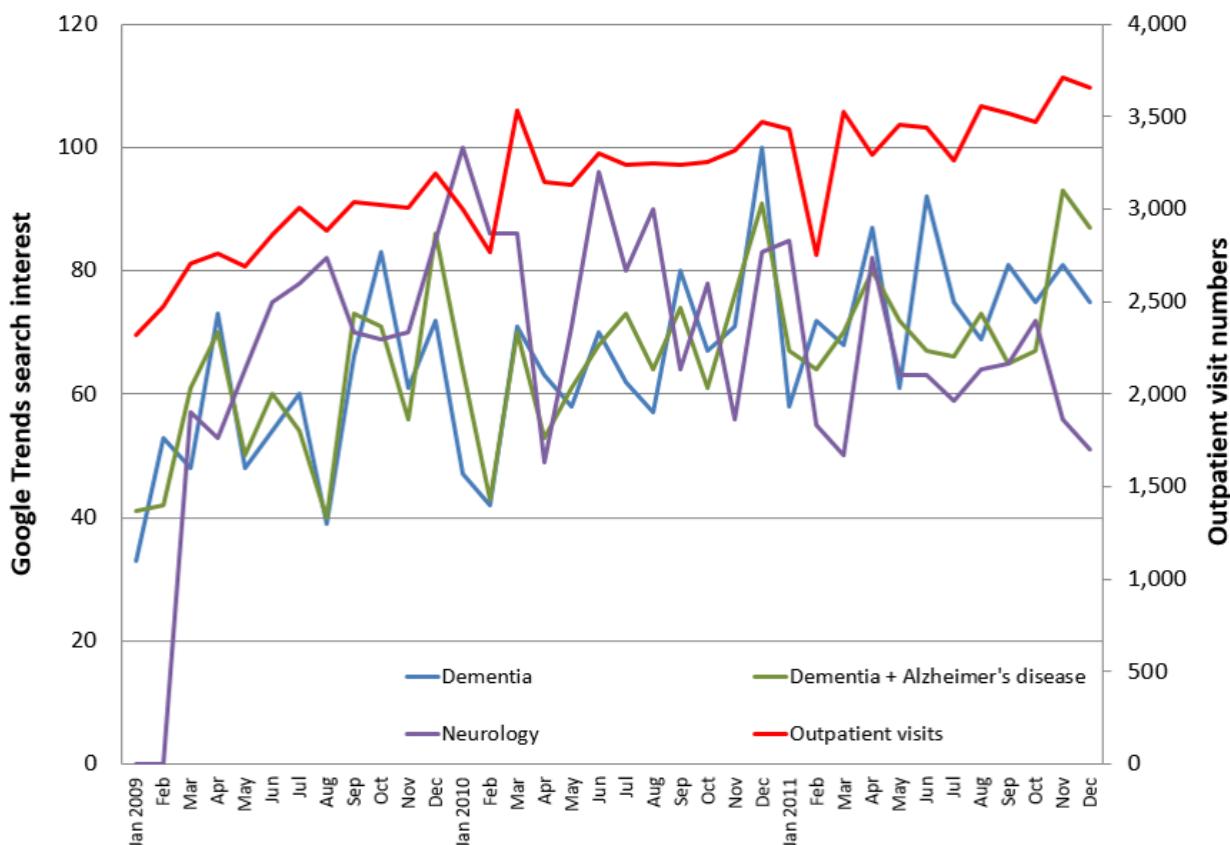
**Figure 3.** New monthly dementia cases and search trends of "dementia" in Taiwan from 2009 to 2011.
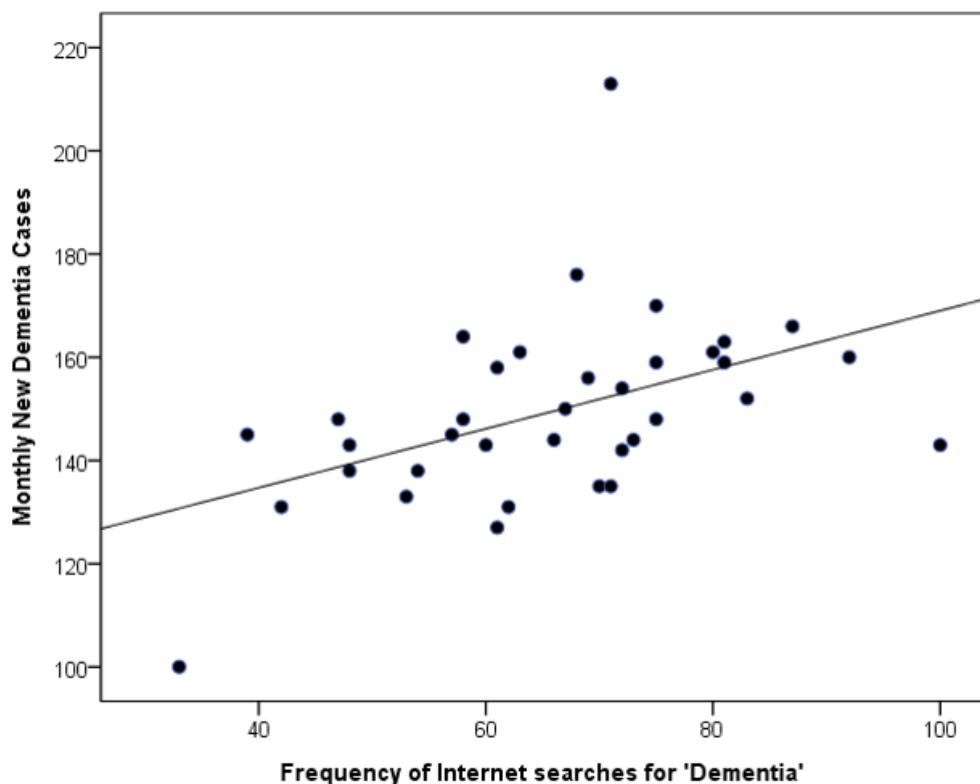


**Figure 4.** Monthly outpatient visits and search trends of "dementia" in Taiwan from 2009 to 2011.
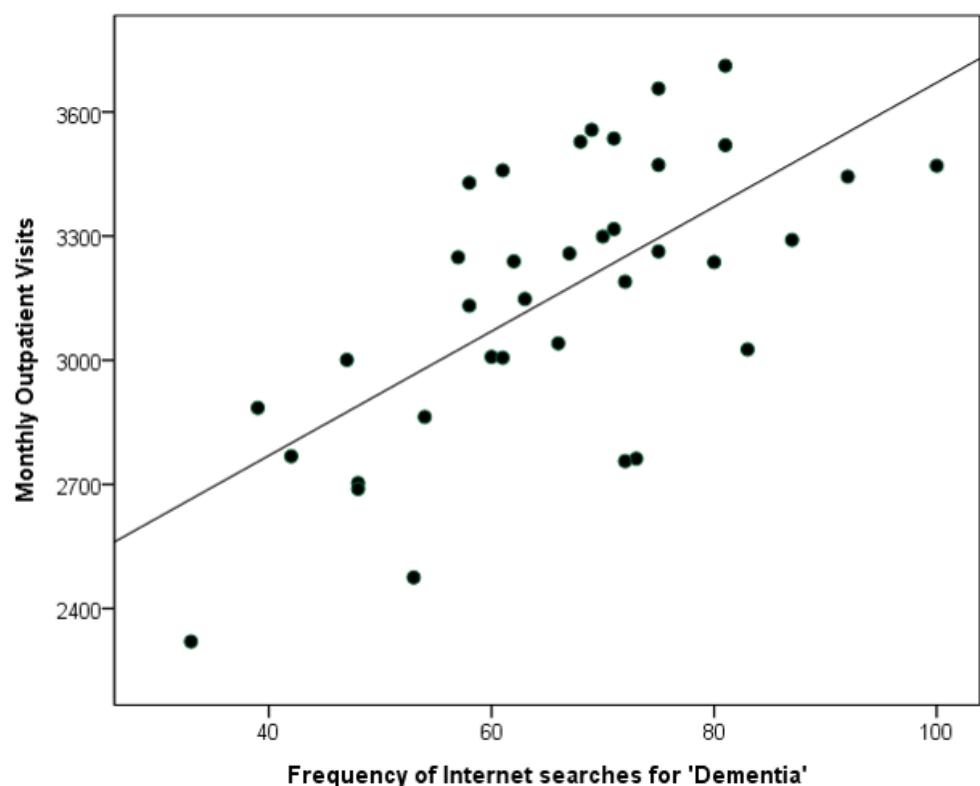


## Correlation Analysis

From the comparisons of new dementia cases and outpatient visits with search data gathered from GT, Pearson correlation coefficient analysis was conducted.

### Nowcasting Effect

*Nowcasting*, also known as contemporaneous forecasting, is a term used to describe predicting the present. Nowcasting has become widely popular in economics because of the significant time lag in statistical releases [44]. The results of the cross-correlation analysis of new dementia cases and GT data

suggested that the search term "dementia" moderately coincided with new dementia cases ($r$=.469, $P$=.004). For outpatient visits, the search terms "dementia" and "dementia + Alzheimer's disease" both indicated strong correlation ($r$=.658, $P$=.001; $r$=.727, $P$=.001, respectively; see Table 2) with outpatient visit numbers. When gender differences were considered, "dementia,"

but not "dementia + Alzheimer's disease," moderately coincided with new male dementia cases ($r$=.430, $P$=.009). These results demonstrate the possibility of monitoring the scale and the temporal and spatial patterns of online search behaviors that may plausibly be associated with future clinical diagnoses of dementia.

**Table 2.** Pearson cross-correlation analysis of new dementia cases, outpatient visits, and search trends, 2009-2011.

| Search term and variable | Pearson cross-correlation coefficient[a] ($P$) | | | | | |
|---|---|---|---|---|---|---|
| | Search preceded outpatient visit or new diagnosis by... | | | | | |
| | No lag | 1 month | 3 months | 6 months | 9 months | 12 months |
| **Dementia** | | | | | | |
| New dementia cases | .469 (.004) | .118 (.49) | .393 (.02) | .365 (.03) | .130 (.45) | .068 (.70) |
| New male dementia cases | .430 (.009) | .079 (.65) | .093 (.59) | .015 (.93) | .064 (.71) | -.059 (.73) |
| New female dementia cases | .297 (.08) | .100 (.56) | .489 (.002) | .520 (.001) | .131 (.45) | .152 (.38) |
| Outpatient visits | .658 (.001) | .542 (.001) | .554 (.001) | .349 (.04) | .331 (.048) | .365 (.03) |
| **Dementia + Alzheimer's disease** | | | | | | |
| New dementia cases | .385 (.02) | -.005 (.98) | .503 (.002) | .348 (.04) | .145 (.40) | .111 (.52) |
| New male dementia cases | .358 (.03) | -.065 (.70) | .257 (.13) | .109 (.53) | -.134 (.44) | -.102 (.55) |
| New female dementia cases | .239 (.16) | .052 (.76) | .502 (.002) | .410 (.01) | .332 (.048) | .255 (.13) |
| Outpatient visits | .727 (.001) | .394 (.02) | .514 (.001) | .431 (.009) | .228 (.18) | .317 (.06) |
| **Neurology** | | | | | | |
| New dementia cases | .263 (.12) | .304 (.07) | .433 (.008) | .112 (.52) | .227 (.18) | .154 (.37) |
| New male dementia cases | .340 (.04) | .371 (.03) | .434 (.008) | .081 (.64) | .121 (.48) | .216 (.21) |
| New female dementia cases | .077 (.66) | .108 (.53) | .240 (.16) | .090 (.60) | .223 (.19) | .030 (.86) |
| Outpatient visits | .393 (.02) | .421 (.01) | .613 (<.001) | .356 (.03) | .245 (.15) | .267 (.12) |

[a]Values represent cross-correlation coefficients where .8 was operationally defined as an excellent correlation, .6-.8 indicated good correlation, .4-.6 indicated a moderate correlation, and ≤.4 indicated a poor correlation.

## *Forecasting Effect*

Separate from nowcasting, the forecasting effect aims to catch how far in advance GT could help predict the future. The results of applying GT lead patterns to search terms suggested that the search terms "dementia + Alzheimer's disease" and "neurology" led the overall new dementia cases reported in the LHID 2010 by 3 months ($r$=.503, $P$=.002; $r$=.433, $P$=.008, respectively). For outpatient visits, two search terms—"dementia" and "neurology"—demonstrated a 3-month leading effect, and the search term "dementia + Alzheimer's disease" demonstrated a 6-month leading effect (see Table 2). Moreover, there was an interesting finding regarding gender differences. The search term "dementia" showed 6-month predictive power for the new female dementia cases ($r$=.52, $P$=.001), but not for the male cases. However, the search term "neurology" showed a 3-month predictive power for the new male dementia cases ($r$=.434, $P$=.008), but not for the female cases. This implies different Internet search behaviors, whether performed by individuals or caregivers, for male and female dementia patients.

# *Discussion*

## Principal Findings

This study contributes to an understanding of how GT search trends are related to dementia cases and outpatient visits by analyzing data gathered between the years of 2009 and 2011 in Taiwan. Furthermore, this study's results demonstrate the possibility of monitoring the scale and the temporal and spatial patterns of online search behaviors that may plausibly be associated with future clinical diagnoses of dementia.

Regarding nowcasting capability, findings showed that GT data temporally coincided with the number of new dementia cases and outpatient visits. This finding is consistent with prior research showing that GT provides near-real-time surveillance data up to 7-10 days in advance of CDC's influenza surveillance network [26]. As for long-term forecasting capability, three search terms—"dementia," "dementia + Alzheimer's disease," and "neurology"—had leading effects on reported new dementia cases and outpatient visits. This finding also confirms previous studies' results, which suggested that a set of suicide-related search terms, whose trends either temporally coincided with or preceded trends in suicide data, were associated with suicide death [23].

Another important finding in this study is that the search term "dementia" yielded more sensitivity in prediction power among women (with a 6-month leading effect) than among men. This finding may be reasonably explained by a recent study which suggested that women would be more likely than men to report subjective memory complaints (SMCs), which is one of the earliest symptoms observed in the prodromal phase of dementia, whereas men would be more likely to report difficulties or restrictions in instrumental activities of daily living (IADLs), which may become apparent at a later stage of the dementia diagnosis [45].

According to statistics from the Ministry of Health and Welfare Taiwan, in 2012, female patients generated more than 1.55 times the number of mental disorder clinical visits than male patients [46]. This indicates that female patients and their families may possibly take the step of going to see a doctor for complaints earlier than male patients do. In addition, men usually are not expected to fulfill IADLs such as housekeeping, cooking, and washing clothes, so once restrictions in instrumental activities are noted and reported, the dementia will likely be at a later stage [47]. Therefore, we interpreted the results of the search term "dementia" to indicate that families of women with dementia would search online for dementia-related information or knowledge at an earlier stage than would families of men with dementia. Conversely, owing to the stigma and stereotypes of dementia [18], men tended to search for "neurology" instead of "psychiatry" in Taiwan [46]. This may reasonably explain why the search term "neurology" yielded more sensitivity in prediction power among men (with a 3-month leading effect) than among women.

In Taiwan, dementia prevalence at ages 65-69 was 3.4% in 2013 [48]. In Taiwan in 2015, according to a survey by ClickForce [49], just 5.2% of adults aged 55 and over had at least one experience of searching on the Internet. Therefore, in this study we assumed that most searches were initiated by family members, whether before or after patient diagnosis. In addition, we anticipated that searches originating from dementia patients themselves would reflect concurrently in a *no lag* period after their outpatient visits, rather than precede a visit or a new diagnosis.

Most people in Taiwan have the basic knowledge to understand disease-related divisions in hospitals, such as neurology, and this is believed to be related to the increasing tendency for patients and family members to use Internet searches for health information prior to seeing a doctor. Such search trends can now be applied as leading indicators which are capable of predicting disease incidence and related increases in outpatient visits earlier than conventional surveillance [22,24,32].

In comparison with conventional surveillance methods, GT has several advantages. First, GT is a free and easily accessible search tool. Second, GT is now available for more than 70 countries worldwide, and thus allows for tracking of searches in different languages and regions. Last, GT is updated weekly, which permits more frequent monitoring of symptoms and could facilitate early detection of dementia. In this regard, GT can be used to notify health policy makers and hospital managers to get ready for upcoming outpatient visits, where screening work

is expected to achieve early detection and treatment and thus save more medical and care costs [50,51].

Additionally, from a public health point of view, health policy makers and health care professionals may consider using key search terms to inversely feed dementia-related information, such as health care resources, care skills, and social welfare information, to those formal and informal caregivers who are difficult to identify in the dementia care system. It is possible to embed dementia-related keywords in online articles, where they can be easily found and recorded by Googlebot—Google's Web-crawling bot that discovers new and updated pages to be added to the Google index—and thus delivered to users who search for these keywords on the Internet [52]. These users are likely to be the people conducting dementia-related searches on behalf of someone they care for. Using these inverse search strategies to deliver information may improve various aspects of caregivers' well-being, such as increasing confidence and reducing depression, as well as lowering the potential utilization of medical and health care services by caregivers of persons with dementia [6-8].

## Further Research and Limitations

Our research suggests the need for the following further research. First, further qualitative research is needed to validate the results of this study. In particular, an examination of the Internet search behaviors of caregivers for people diagnosed with dementia is necessary. Also, the gender difference reported in the argument on early report of SMC by female patients needs validation [45]. Second, additional research at different geographic scales would be worthwhile, in places where GT offers complete subnational data points. Third, aside from GT, Google AdWords and Baidu trends also have the potential to play similar roles in the surveillance of dementia, and research on these tools merit further study. Lastly, more dementia-related keywords and a longer period of data points merit further study to validate GT's lead pattern. This study contributes to the literature by expanding the GT research field to the disease of dementia. To the best of our knowledge, no existing empirical research addresses the relationship between GT and dementia or ways of estimating potential medical needs for people with Alzheimer's disease.

Several limitations of this study should be noted, mostly related to the GT algorithm. First, owing to insufficient and incomplete data sources, only 3 years of GT data were included in this study. Future research with longer periods of data points is recommended to validate the lead patterns. Second, there was difficulty in identifying search trends that were generated by true cases. In particular, GT tends to be influenced by media exposure of specific diseases (eg, drug advertisements), which drives more nonpatients to search related terms and thus increases the search volumes [53]. Lastly, the calculation of GT depends on Google's assumptions and normalization, which are not clearly reported.

## Conclusions

In conclusion, GT serves as an easily accessible, real-time surveillance tool. Despite the limitations, this study highlights GT as a useful tool for establishing a plausible relationship

between search terms and new dementia cases and dementia-related outpatient visits. This tool can lead to better management of medical resources and budgets in Taiwan's health and social care system. It is possible that GT could be further developed as a surveillance platform to help lower the individual and social costs of this troublesome disease associated with aging populations.

## Acknowledgments

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

List of Chinese dementia-related search terms and their English equivalents.

[PDF File (Adobe PDF File), 215KB - jmir_v17i11e264_app1.pdf ]

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## Abbreviations

**AD:** Alzheimer's disease
**ADAMS:** Aging, Demographics, and Memory Study
**ADI:** Alzheimer's Disease International
**CD:** Ambulatory Care Expenditures by Visits
**CDC:** Centers for Disease Control and Prevention
**GFT:** Google Flu Trends
**GT:** Google Trends
**IADLs:** instrumental activities of daily living
**ICD-9-CM:** International Classification of Disease, Ninth Revision, Clinical Modification
**ID:** Registry for Beneficiaries
**LHID 2010:** Longitudinal Health Insurance Database 2010
**NHIRD:** National Health Insurance Research Database
**NTUH:** National Taiwan University Hospital
**REC:** Research Ethics Committee
**SMC:** subjective memory complaint

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Review

# Empowerment of Cancer Survivors Through Information Technology: An Integrative Review

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## Abstract

**Background:**   Patient empowerment may be an effective approach to strengthen the role of cancer survivors and to reduce the burden on health care. However, it is not well conceptualized, notably in oncology. Furthermore, it is unclear to what extent information technology (IT) services can contribute to empowerment of cancer survivors.

**Objective:**  We aim to define the conceptual components of patient empowerment of chronic disease patients, especially cancer survivors, and to explore the contribution of existing and new IT services to promote empowerment.

**Methods:**  Electronic databases were searched to identify theoretical and empirical articles regarding empowerment. We extracted and synthesized conceptual components of patient empowerment (ie, attributes, antecedents, and consequences) according to the integrated review methodology. We identified recent IT services for cancer survivors by examining systematic reviews and a proposed inventory of new services, and we related their features and effects to the identified components of empowerment.

**Results:**  Based on 26 articles, we identified five main attributes of patient empowerment: (1) being autonomous and respected, (2) having knowledge, (3) having psychosocial and behavioral skills, (4) perceiving support from community, family, and friends, and (5) perceiving oneself to be useful. The latter two were specific for the cancer setting. Systematic reviews of IT services and our additional inventory helped us identify five main categories: (1) educational services, including electronic survivorship care plan services, (2) patient-to-patient services, (3) electronic patient-reported outcome (ePRO) services, (4) multicomponent services, and (5) portal services. Potential impact on empowerment included knowledge enhancement and, to a lesser extent, enhancing autonomy and skills. Newly developed services offer promising and exciting opportunities to empower cancer survivors, for instance, by providing tailored advice for supportive or follow-up care based on patients' input.

**Conclusions:**   We identified five main components of empowerment and showed that IT services may especially contribute to empowerment by providing knowledge. The components of empowerment could be used to develop IT services for cancer survivors. It is important to take into account patients' needs, follow up on these needs, and create a service that is attractive and easy to use.

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## Introduction

A popular approach to improve the involvement of patients in their care is to provide them with information on how to make a decision about medical treatment (ie, shared decision making) [1]. However, more aspects are important when fully engaging patients regarding their health. A concept that may be particularly relevant in this regard is patient empowerment, which is generally viewed as a multilevel construct with manifestations at the community, group, or individual level. Despite its popularity, patient empowerment has no generally accepted definition or conceptualization and it is a rather complex and multifaceted construct. This is illustrated by the differences in various questionnaires that have been developed to measure aspects of empowerment [2]. Nevertheless, there is convincing evidence for the effects of improving patient empowerment on health outcomes. Meta-analyses show that self-management interventions improve glycated hemoglobin levels (a marker of glycemic control), self-efficacy, and empowerment levels in patients with chronic metabolic diseases [3]. Moreover, these interventions reduce the number of readmissions due to heart failure [4] and emergency department visits due to asthma [4].

Because of better screening, detection, and treatment, the number of cancer survivors is growing rapidly. We will use the term cancer survivor as the National Coalition of Cancer Survivorship defines cancer survivorship: "from the time of diagnosis and through the balance of life." In 2008, 28.8 million people worldwide had survived cancer for at least 5 years [5]. Cancer and its treatment result in a wide range of physical and psychological challenges, some of which may even appear years later [6]. The current models of survivorship care are likely to lead to rapidly increasing and not sustainable use of health care [7]. Some claim that a stronger role of the patient might be helpful to control costs. New models are emerging that emphasize the importance of supporting patients to engage in self-management activities and to be able to make informed choices about the type of support they need. The challenge is to provide this in a cost-effective way that is either equally or more effective than traditional models of survivorship care [8]. It seems imperative that cancer survivors need to become more effective coactors in their health care. Existing theories and models of chronic disease management might be relevant to cancer survivors as well, but have not been tested rigorously [9,10]. In this review, we therefore focused on the *higher order* concept of patient empowerment.

Empowering interventions providing face-to-face support to patients require substantial resources and effort. A promising approach is the use of information technology (IT), which enables the provision of easily accessible, up-to-date, tailored information and automated feedback to patients. Many *empowering* Web-based interventions have been developed in the field of chronic diseases (eg, diabetes, heart failure, and chronic obstructive pulmonary disease), but relatively few seem to have been developed for, and rigorously tested in, cancer survivors [11].

The objective of this study is to identify conceptual components of patient empowerment in chronic patients and cancer survivors and to explore the contribution of existing and new IT services to promote their empowerment. This can guide the development of innovative and sustainable eHealth services that may improve empowerment in cancer survivorship care.

## Methods

### Overview

We conducted an integrative literature review using the methodology as proposed by Whittemore and Knafl [12] to conceptualize the construct of empowerment. An integrative review summarizes past empirical and theoretical literature to provide a more comprehensive understanding of a phenomenon or health care problem [12]. Accordingly, five steps were undertaken: (1) problem identification (already stated in the introduction), (2) literature search, (3) data evaluation, (4) data analysis, and (5) presentation. In addition, we searched for IT services that could support cancer survivors with regard to patient empowerment. The Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) statement was checked for relevant items that would aid the reporting of this review [13].

### Integrative Literature Review

#### Literature Search and Data Evaluation

We performed a literature search in PubMed (Medline), Scopus, and PsycINFO from January 1990 up to April 2014 to obtain definitions of patient empowerment in general, and specifically in cancer survivors. Search terms included "conceptual," "theory," and "cancer" either alone or combined, and always in combination with "patient empowerment." The search query for PubMed is presented in Multimedia Appendix 1. We selected publications for full-text review based on screening of titles and abstracts. Articles were selected for inclusion if they met the following criteria: (1) were written in English, (2) were published in a peer-reviewed journal, and (3) were a specific type of article. Specific article types included in the study were as follows: (1) articles providing a conceptual or theoretical description of patient empowerment, (2) articles providing empirical qualitative data on the concept of patient empowerment in chronic patients or cancer survivors, (3) articles describing the development of a questionnaire that aims to measure aspects of patient empowerment, both generic and disease specific, and (4) quantitative articles with empowerment as an outcome, which also extensively discuss the conceptual definition of patient empowerment in chronic patients or cancer survivors. Reference lists of selected full texts were screened for additional relevant papers. Two researchers (WG, WK) reviewed all articles for inclusion, and in case of disagreement a third researcher (WvH) was consulted for a definitive decision.

#### Data Analysis and Presentation

A predefined data sheet was used for data extraction. Data were extracted on study characteristics (ie, first author, year of publication, type of research, number of participants involved, and type of disease), defining attributes (ie, characteristics), antecedents (ie, events or circumstances that precede a concept),

and consequences (ie, phenomena that follow an occurrence of the concept) of empowerment [14]. In order to identify the main attributes, we coded qualifying text elements and these were integrated into common descriptions. A final check of the primary data sources was performed to verify the conceptualization [12]. Findings of the studies on cancer, specifically, were reviewed separately and compared to the findings of the literature on chronic diseases. All aspects of the procedure were verified by a second researcher (WK) to reduce potential bias. Data are presented narratively.

## Identification of Existing Information Technology Services and Their Potential to Support Patient Empowerment in Cancer Survivors

We searched the Medline (PubMed) database for papers in English that were published between January 2010 and January 2015. We used medical subject headings and free-text terms. A combination of any of the terms "cancer patient," "cancer survivor," "cancer survivorship," and "cancer" was combined with any combination of the terms "information and communication technology" (ICT), "ICT," "Web-based," and "Internet." The search query for PubMed is presented in Multimedia Appendix 1. Because there have been several recent, systematic reviews on this topic, we decided not to do a search for primary articles. One author (WG) checked titles and abstracts to determine if articles were sufficiently relevant to retrieve the full-text article. Reference lists were also searched for additional relevant papers. Full texts were screened by two reviewers (WG, WK) on the following criteria: (1) the paper described a literature review with a systematic and explicit search strategy, (2) the scope of the review concerned supportive IT services, (3) the services focused on adult cancer survivors, and (4) the paper contained information on the features and effects of the reported IT services or, when these were not reported, obtained this from primary articles.

Apart from the services described in the systematic reviews, there were also emerging services that were in an early phase of development and had not yet been rigorously tested. We therefore additionally searched Google and PubMed up to April 2014. To our knowledge, no formal guidelines exist for surveying eHealth systems and applications. We purposely selected three groups of these IT services that may be particularly relevant for cancer survivors (but may be designed for other diseases as well), namely: (1) patient portals, (2) electronic patient-reported outcome (ePRO) systems, and (3) IT services related to survivorship care plans for cancer patients. Major keywords used, either alone or in combination, were as follows: "patient portal(s)," "patient empowerment," "electronic medical record," "patient reported outcomes," "survivorship care plan," "cancer," and "information and communication technology." References in reports and articles were checked for citations leading to other possible relevant IT services (ie,

snowballing method). Suggestions from members of our project group were added to this inventory as well. Our inclusion criteria were as follows: (1) we included portal services that at least provided insight into the patient's medical record, (2) with regard to ePRO systems, we included systems that enable people with cancer to complete symptoms and/or quality-of-life questionnaires by computer, either at home or at the clinic, (3) for the survivorship care support services, we included those that were aimed at cancer survivors and provided an electronic survivorship care plan (SCP) or generated one from a digital registry, and (4) all IT services had to be in use and not only available as a test or beta version.

From the identified IT services, key features and user interaction aspects were collected from websites, published manuscripts, or by demos of the service when possible. Lastly, convenience sample-based site visits were made to developers of the OncoKompas system (Free University Medical Center, Amsterdam, Netherlands), the ChipSoft patient portal (University Medical Center [UMC] Utrecht, Netherlands), the digital in vitro fertilization (IVF) clinic (Radboud UMC, Nijmegen, Netherlands), and the electronic patient-reported outcome system of UMC Leiden, Netherlands. The developers of Care Companion (Sanofi Aventis, Gouda, Netherlands) visited us to demonstrate their application. Demo software of the Computer-based Health Evaluation System (CHES) for ePRO (Innsbruck, Austria) was obtained for review. References to the services can be found in Multimedia Appendix 2 [15-25].

The possible contribution of identified IT services to attributes of patient empowerment was determined by relating the reviewed features and effects to the attributes of empowerment as identified by the integrative review. Results are presented qualitatively and several exemplary IT services are described in detail.

## Results

### Integrative Literature Review

#### Overview

The initial search resulted in 2248 hits. After screening titles and abstracts, 94 papers were selected and read in full text. A total of 22 papers met our inclusion criteria and four articles were added by checking reference lists. A total of 11 reviews were included [26-36]. Nine manuscripts described the development and/or psychometric evaluation of a questionnaire on patient empowerment [37-45] and six qualitative studies described patient empowerment of chronic patients [46-51]. Figure 1 shows the literature search and selection procedure. Antecedents, attributes, and consequences of patient empowerment of chronic patients and cancer survivors are presented in Figure 2 and are described in more detail below. References to the most representative manuscripts are provided.

**Figure 1.** Flowchart of selection of articles according to PRISMA.



N=2248 Publications identified by database searching:

PubMed: n=1233
SCOPUS: n=638
PsycINFO: n=377

n=2154 publications excluded based on titles and abstracts and after removing duplicates

Full-text articles (n=94) assessed for eligibility

n=72 full text articles excluded based on:

- No full text could be obtained, n=5
- Not peer reviewed, n=2
- Not patients/healthy subjects, n=4
- Not primarily from patient perspective, n=8
- No clear contribution to conceptual definition of patient empowerment, n=53

n=4 articles identified via reference checking or via related article search

n=26 articles included in review:
- Theoretical/review article: n=11
- Questionnaire development articles n=9
- Qualitative studies n=6
- Quantitative studies n=0

### Antecedents

Antecedents that appeared from the literature were to a large extent based on the excellent review of Holmström et al [32]. Antecedents are events or circumstances that precede a concept [14]. An antecedent may contribute to the occurrence of the concept, it may be associated with its occurrence, or it may need to be present for the concept to occur. Several antecedents of patient empowerment are related to patients themselves. Having a long-term condition [35,40] is a first antecedent of empowerment. Further antecedents on the patient side are poor health behaviors that need to be changed, the presence of motivation for action toward desired goals(s), and the ability to self-reflect regarding benefits of behavior change [32].

There are several antecedents of patient empowerment that relate to health care providers (HCPs) and their approach to patients. When HCPs respect patients' beliefs and surrender their need to control and decide for patients, they create an atmosphere of mutual trust and respect [28,29,31] and shared responsibility [32], which facilitates patient empowerment. Finally, an antecedent to patient empowerment is HCPs' willingness to provide educational support to patients [28,32].

### Attributes

Three main attributes emerged from the literature review concerning chronic patients.

#### Being Autonomous and Respected (and Willingness of Health Care Providers to Support This)

Patients must have the opportunity to make their own decisions and choose their own health or life goals [26,28,30,34]. This attribute depends, in part, on external factors. For example, HCPs need to adjust their position of power to a level that provokes equal participation of the patient, and they need to act as a coach to work toward negotiated health goals [26,29-31,35,36]. Being respected also requires that HCPs share knowledge and resources in such a way that patients feel fully recognized [29,35].

**Figure 2.** Conceptual components of empowerment in chronic patients, including cancer survivors. HCP: Health care provider. A detailed overview of attributes is provided in Tables 1 and 2.
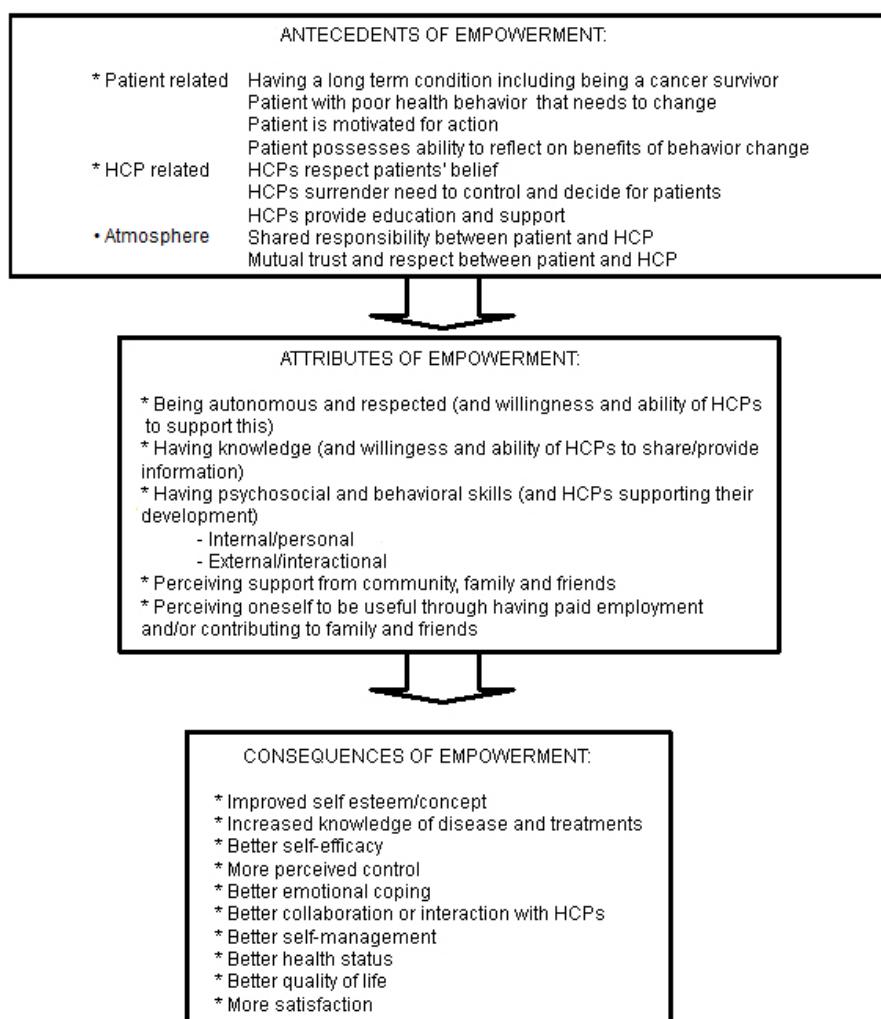


### Having Knowledge (and Willingness and Ability of Health Care Providers to Share/Provide This)

Having knowledge about one's health situation is another attribute of empowerment. It refers to having knowledge about one's disease [45,50,51], about oneself [30,34], and about available supporting resources [28,34]. Having more knowledge is expected to enable "better informed decision making," for example, about treatments or lifestyle changes [31,50,51].

### Having Psychosocial and Behavioral Skills (and Health Care Providers Supporting Their Development)

Nearly every article that we reviewed described having skills to positively influence one's situation as an attribute of patient empowerment. These skills could be subdivided into those related to internal thought processes (ie, internal/personal) and those more behaviorally and externally oriented (ie, external/interactional). Internal/personal skills are, in general, referred to as personal psychological strengths, such as having a sense of self-efficacy, self-esteem, optimism, and personal competence [41,49], as well as the ability to accept and cope with living with a chronic disease [40,45,49]. These skills are also related to building the capacity to identify one's needs, psychosocial problems, goal setting, and problem solving [36].

It also refers to the skill of patients to increase and maintain motivation to pursue their health goals [36].

External/interactional skills are needed to positively influence one's current situation by one's own behavior and/or by interaction with others. These skills are generally related to the effectiveness of patients in managing their disease through preventive self-management [30,34,38,39,42,45,50] and effective, collaborative interaction with HCPs, such as negotiating and asking for clarification [36,38]. Furthermore, being able to obtain emotional and practical support from family and friends is important [37,38,40,41,43,47,48]. Using or developing these skills may be a challenge for patients who have, or have had, a life-threatening disease such as cancer. Nevertheless, developing or reinforcing these skills is the hallmark of empowering interventions [36].

### Consequences

A diversity of consequences of empowerment was reported in the reviewed literature. Empowerment is associated with increased self-esteem and a better self-concept [27,28], increased knowledge about disease and treatments [32,35,36,40,46], more self-efficacy regarding disease and treatment-related behaviors [27,29,32,36,47], and more perceived control [27,28,36,40]. It is also associated with better interaction or collaboration with

HCPs [32,42], better disease self-management [32,35,36,42], and improved emotional coping [32,36,37,39]. In more general terms, empowerment is related to higher levels of satisfaction [27,29,32,36], better health status [29,32,36,39,42], and better quality of life [27,29,36,47].

**Table 1.** Identified attributes of patient empowerment and the possible contributing role of reviewed educational and patient-to-patient IT[a] services.

| Attributes of empowerment | Possible contributing role of reviewed IT services | |
|---|---|---|
| | Educational services | Patient-to-patient services |
| **Being autonomous and respected (and willingness and ability of HCPs [b] to support this)** | | |
| Patients make their own decisions and choose their own health or life goals | o[c] | +[d,e] |
| There is an atmosphere of mutual trust | o | o |
| HCPs bring their power to a level that provokes equal participation of the patient and act as coaches to work toward negotiated health goals | o | o |
| HCPs share knowledge and resources in such a way that patients feel fully recognized | ++[f,g] | o |
| **Having knowledge (and willingness and ability of HCPs to share/provide information)** | | |
| Having knowledge about one's disease and treatments and about oneself | ++[h] | +[i] |
| Having knowledge about available supporting resources | ++[h] | +[i] |
| **Having psychosocial and behavioral skills (and HCPs supporting their development)** | | |
| **Internal/personal** | | |
| Having self-efficacy, self-esteem, optimism, and personal competence | o | o |
| Ability to accept diagnosis and cope with emotions (eg, anxiety or depression) | +[j] | o |
| Capacity to identify one's needs and psychosocial problems and set goals to improve self-selected goals | o | o |
| Increase and maintain motivation to pursue health goals | o | o |
| **External/interactional** | | |
| Effectiveness of patients in managing their disease through preventive self-management | +[k] | o |
| Effective collaborative interaction with HCPs, such as negotiating, asking for clarification, etc | o | o |
| Being able to obtain emotional and practical support from family and friends | +[k] | o |
| Perceiving support from community, family, and friends | o | +[l] |
| Perceiving oneself to be useful through having paid employment and/or by contributing to family and friends | o | o |

[a]IT: information technology.

[b]HCP: health care provider.

[c]o: no positive contribution to empowerment.

[d]+: weak positive contribution to empowerment.

[e]Patients can ask questions regarding their most relevant issues in online communities.

[f]++: strong positive contribution to empowerment.

[g]Knowledge and resources are shared between HCPs and patients.

[h]Providing Information about, for example, diagnosis, treatments, side effects, late effects, follow-up scheme, and healthy lifestyle, and information on, or links to, supporting resources.

[i]Information could be obtained through online communities, however quality may be limited.

[j]Training programs could enhance coping with emotions.

[k]Providing information about diagnosis, treatments, side effects, late effects, follow-up scheme, and healthy lifestyle, and information on, or links to, supporting resources. Provision of skill-building programs to effectively obtain social support.

[l]Patients could perceive more support from community (ie, fellow patients).

**Table 2.** Identified attributes of patient empowerment and the possible contributing role of reviewed ePRO[a]services and patient portals.

| Attributes of empowerment | Possible contributing role of reviewed IT[b]services | |
|---|---|---|
| | ePRO services | Patient portals |
| **Being autonomous and respected (and willingness and ability of HCPs to support this)** | | |
| Patients make their own decisions and choose their own health or life goals | +[c,d] | o[e] |
| There is an atmosphere of mutual trust | o | o |
| HCPs bring their power to a level that provokes equal participation of the patient and act as coaches to work toward negotiated health goals | +[d] | o |
| HCPs share knowledge and resources in such a way that patients feel fully recognized | o | ++[f,g] |
| **Having knowledge (and willingness and ability of HCPs to share/provide information)** | | |
| Having knowledge about one's disease and treatments and about oneself | +[h] | ++[i] |
| Having knowledge about available supporting resources | o | ++[i] |
| **Having psychosocial and behavioral skills (and HCPs supporting their development)** | | |
| **Internal/personal** | | |
| Having self-efficacy, self-esteem, optimism, and personal competence | o | o |
| Ability to accept diagnosis and cope with emotions (eg, anxiety or depression) | o | o |
| Capacity to identify one's needs and psychosocial problems and set goals to improve self-selected goals | +[j] | o |
| Increase and maintain motivation to pursue health goals | +[j] | o |
| **External/interactional** | | |
| Effectiveness of patients in managing their disease through preventive self-management | o | o |
| Effective, collaborative interaction with HCPs, such as negotiating, asking for clarification, etc | ++[k] | +[l] |
| Being able to obtain emotional and practical support from family and friends | o | o |
| Perceiving support from community, family, and friends | o | o |
| Perceiving oneself to be useful through having paid employment and/or by contributing to family and friends | o | o |

[a]ePRO: electronic patient-reported outcome.

[b]IT: information technology.

[c]+: weak positive contribution to empowerment.

[d]ePROs give patients the opportunity to identify personally relevant issues and health goals.

[e]o: no positive contribution to empowerment.

[f]++: strong positive contribution to empowerment.

[g]Medical knowledge in the electronic medical record (EMR) is shared between HCPs and patients.

[h]Providing knowledge of personal symptoms and physical and psychosocial functioning by providing graphic overview of symptom and quality-of-life scores.

[i]Providing information about diagnosis, test results, treatments, etc, by providing access to parts of the EMR during and after treatment. Providing knowledge about available supporting resources through tailored patient educational material.

[j]Identification of personal needs and psychosocial problems by providing graphic overview of symptoms and quality-of-life scores, with or without reference values.

[k]When ePROs are fed back to patients with coaching statements, it may improve the effectiveness of the encounters with health professionals.

[l]E-consultations may enhance patient-provider interaction.

### Cancer-Specific Findings

Six papers were specifically aimed at cancer patients: three methodological papers describing the development and psychometric testing of a questionnaire designed to measure empowerment [37,38,41], and three very small-scale qualitative studies of which one—Bulsara et al [47]—was also included in a questionnaire development paper [46-48].

Taken together, the cancer-specific papers reflected many aspects already identified from literature on patients with a chronic disease. No cancer-specific antecedents or consequences could be identified from these studies. Most attributes were

related to having knowledge and having psychosocial and behavioral skills. Cancer-specific attributes that could be added to the three already described above are as follows:

1. Perceiving support from community, family, and friends [37,41,48]. This refers to perceived support from people close to the patient and feelings of acceptance and support from the social community. It is about the availability of support, which makes it slightly different from the earlier identified skill of seeking support from these sources.

2. Perceiving oneself to be useful through having paid employment and/or by contributing to family and friends [37]. This attribute refers to the patient's sense of self-worth through having a job or through having the feeling that one is contributing to family or friends, or that they may rely on him/her.

Also, one specific subattribute could be added to the attribute, *having skills*: being able to accept the diagnosis [37,47] and coping with emotions (eg, anxiety or depression) related to the disease [38].

## Identification of Existing Information Technology Services and Their Potential to Support Patient Empowerment in Cancer Survivors

### Identified Information Technology Services, Their Features, and Their Effects

The initial search identified 216 potentially relevant reviews. We selected 26 reviews for full-text screening and four met all of our inclusion criteria [52-55]. Two reviews were concerned with cancer in general [52,53], one was focused on breast cancer [54], and one on prostate cancer [55]. None of the included reviews performed a meta-analysis. The four reviews included 46 unique IT services (described in 74 studies). The additional search and expert input yielded additional information on five patient portal services, six ePRO services, and three electronic survivorship care plan support systems [15-25] (see Multimedia Appendix 2 for an overview). IT services could be divided into five categories: (1) educational services (including electronic survivorship care plan services), (2) patient-to-patient services, (3) ePRO services, (4) multicomponent services (which combine two or more of the former), and (5) patient portal services.

Below, we report on the main features of the services per category, including several examples and a summary of the evidence regarding the effectiveness or hypothesized benefits in supporting the attributes of patient empowerment, as identified in the previous step. For convenience, the possible contributions to attributes of empowerment are indicated as follows: being autonomous and respected (AR); having knowledge (HK); having skills (SK); and perceived support from community, family, and friends (PS). We felt that IT could not/hardly contribute to the attribute, *Perceiving oneself to be useful through having paid employment and/or by contributing to family and friends*; therefore, this attribute is not represented here. An overview is presented in Tables 1 and 2. Because the features of multicomponent services were very diverse, these are not presented in the tables.

### Educational Services

Educational services often are interactive systems provided via the Internet or offline via computer or CD-ROM. Many provide disease- and treatment-related information to improve knowledge of survivors (HK). Some are specifically aimed at improving decision making (SK), for example, regarding surgical treatment for breast or prostate cancer. An example is the Interactive Digital Education Aid (IDEA) intervention [56]: an interactive software program that includes high-quality, three-dimensional animated graphics, patient testimonials, before-and-after photographs, and video explanations from clinical specialists. It is designed to answer general questions about breast reconstruction and to provide detailed explanations of the various techniques, including advantages and disadvantages (HK). The intervention has been shown to increase the knowledge (HK) and satisfaction with treatment choice, compared to a control group.

Other services contain educational programs about symptoms and how to cope with them (HK and SK). For example, the Sleep Healthy Using The Internet (SHUTi) program is based on a well-validated, face-to-face cognitive behavioral therapy (CBT) program and includes six interactive modules [57]. It covers aspects of behavior, stimulus control, education, and problem prevention (SK). SHUTi provides a high degree of individual tailoring and feedback. Automated emails are sent throughout the program to inform the users about next steps, as well as to encourage adherence. A small-scale, two-arm randomized controlled trial (RCT) (n=14 per group) showed that the intervention significantly improved overall insomnia severity, sleep efficiency, sleep onset latency, soundness of sleep, restored feeling upon awakening, and general fatigue.

The electronic survivorship care plan support is based on the recommendation of the Institute of Medicine that survivors should be provided with a personalized structured overview of one's disease, treatments, and possible short- and long-term side effects (HK). Furthermore, it may include information on available resources, recommended follow-up visits, and on healthy lifestyle (AR and HK). Several electronic SCP initiatives exist. The LIVESTRONG Care Plan provides an online SCP based on the data that patients provide themselves [23]. Patients can then view and/or print their SCP. Other systems such as ROGY Care (Registrationsystem Oncological GYnecology) [25] and SCP Builder [24] enable health professionals to compose an SCP for survivors based on tumor registry data, manual input, or both. The electronic SCP initiatives are hypothesized to contribute to patient empowerment by increasing autonomy through HCPs sharing knowledge about available resources. Furthermore, it may enhance patients' knowledge of their current and future situation. With regard to skill development, SCPs appear to offer limited benefit. Patients might better prevent side effects and late effects by adopting a healthier lifestyle.

Beneficial effects of educational services related to patient empowerment include increased levels of knowledge, skill development through better decision making, increased levels of satisfaction, and, to a lesser extent, a better quality of life.

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However, the number of high-quality studies supporting those claims remains limited [52-55].

### Patient-to-Patient Services

Patient-to-patient services consist of online support groups or bulletin boards in which patients can exchange experiences with fellow patients and ask about their most bothersome issues (AR, HK, and PS). These services are quite unstructured and the quality of feedback may be limited because fellow patients may have different treatments and may lack proper medical knowledge. An example is the Internet peer support offered to a large group of cancer survivors as described by Hoybye et al [58]. The intervention contained a self-guided space for communication, including an Internet discussion forum, a live chat room, and a personal message system. Groups would form around a shared cancer diagnosis or a particular shared concern in relation to the experience of cancer (HK and PS). No therapeutic content or information services were offered within the groups. The intervention did not result in statistically significant improvements of self-reported mood disturbance, adjustment to cancer, or self-rated health.

Patient-to-patient services may contribute to empowerment through increased autonomy, because patients can ask questions about their most bothersome issues, and through increased knowledge about one's health/disease. Furthermore, it may improve perceived support from the community, in this case fellow patients. To date, however, there are few studies available to make firm claims on effectiveness related to patient empowerment. Results of controlled studies range from positive effects on depression, cancer-related trauma, and perceived stress [59] to no effects and even negative effects on psychosocial distress and quality of life [60].

### Electronic Patient-Reported Outcome Services

Several national and international services have been developed whereby cancer survivors can complete validated questionnaires about symptoms and/or quality-of-life issues at home or in the waiting room of the clinic. All identified systems possess the ability to graphically show questionnaire data to clinicians, and some have the feature of adding norm values derived from healthy individuals, such as the CHES [20]. Few services provide graphic feedback on scores or outcomes to patients themselves. Most of these systems are not directly integrated with the electronic medical record (EMR), but with freestanding database systems that can be linked via a standardized Health Level Seven (HL7) protocol. The Electronic Self-Report Assessment for Cancer (ESRA-C) system [61] enables patients to score their symptoms and quality of life and get tips for communicating about their most bothersome issues with HCPs (SK). Furthermore, patients can review all aspects of their symptoms and quality of life in charts with cutoff values (HK) and may be better able to identify their personal needs and psychosocial issues (SK). A promising new approach is the OncoKompas that provides survivors with an overview of one's health status in terms of a profile indicating whether the patient is either "on track" or "off track" [22]. This profile is based on a set of validated questionnaires and uses an internal algorithm and cutoff values. It also provides advice on how to address problems (HK) using a stepped-care algorithm, starting with

self-help options (SK) and gradually progressing to professional help. It has not been tested in a controlled study. Another promising system is the electronic patient self-assessment and management (SAM) framework which provides tailored information and graphical feedback to prostate cancer patients postsurgery based on their input [21].

ePRO systems are hypothesized to contribute to patient empowerment by enabling survivors to identify their most relevant issues (ie, increased autonomy) and by enhancing their knowledge of their current health status and patterns of change in their health over time. Having such information may also increase the effectiveness of the encounters of patients with their HCPs; both patients and their HCPs may be motivated to talk about the patients' most bothersome issues. Two RCTs of the ESRA-C have demonstrated its effectiveness in terms of the number of bothersome issues discussed (HK and SK) and a small improvement in symptom distress (SK) [61,62].

### Multicomponent Services

Many services contain a mix of the aforementioned features. Most services combine educational support with patient-to-patient support as described above. One such service is the Comprehensive Health Enhancement Support System (CHESS) [63]. This service provides access to many online services, including information services such as breast cancer information, personal stories of fellow patients, a resource guide, discussion groups, ask an expert, live chats, and coaching services [63].

Because this category of services is quite broad, the evidence regarding effects on enhancing empowerment is also variable. There is some evidence that these services contribute to enhanced knowledge and skills, mostly from studies of CHESS. However, other services also show improved knowledge [64] and coping [65] skill as a result of educational and patient-to-patient support.

### Patient Portal Services

Most patient portals offer patients access to their EMR (AR and HK) and provide additional services like tailored patient education (HK), questionnaire administration, posing questions electronically to clinicians (ie, e-consultation) (SK), making notes/keeping a diary for oneself (HK), ordering medication, and appointment keeping (SK). Most portals are directly integrated with the EMR, although some are separate applications that connect to the EMR and transfer data to a freestanding Web-based portal [6]. In the Netherlands, portals are secured via a two-way authorization procedure, meaning that patients have to provide a personal username and password, and consequently have to enter an additional code that is sent to their mobile phone.

No controlled studies have investigated the effect of patient portals on improving aspects of empowerment in cancer survivors, but they may contribute to patient empowerment in several ways. First, by accessing their EMR, patients have the same clinical information available as their clinicians, thus potentially enhancing perceptions of being respected and of autonomy. Second, portals may enhance patients' knowledge of their disease and treatments, either via access to their EMR

or via tailored patient education. To date, there appears to be limited contribution of patient portals to skill development. E-consultation might enhance the effectiveness of the interaction of patients with their HCPs.

## Discussion

### Overview

By using the integrative review methodology, we were able to identify conceptual components of patient empowerment of chronic patients including cancer survivors. We illustrated the various ways in which selected IT services may contribute to patient empowerment of cancer survivors. This is a first attempt to link empowerment theory to existing IT services for cancer survivors.

### Patient Empowerment of Cancer Survivors

We identified five main attributes related to patient empowerment. The first is *being autonomous and respected (and willingness and ability of HCPs to support this)*. For this attribute, a patient-centered approach seems imperative. Patients need to be regarded as a valuable source of information, and the goals that are set should be derived from the patients themselves. These goals could, but do not have to, correspond with the ones based on the health provider's values. When external factors are neglected (eg, how clinicians approach patients), it may be difficult to facilitate empowerment in patients. We cannot expect patients to take an active role when that is not supported by the health care environment. It is known that patients in general depend highly on their oncologists, which consequently leads to high levels of trust. This high dependency and need for trust might result in a more obedient attitude and reduced autonomy of patients [66].

The second attribute is *having knowledge (and willingness and ability of HCPs to share/provide this)*. For this attribute, we have to realize that some patients may not want to know all the details of their disease and treatments. For example, it is known that people can have different coping styles with regard to information. There are *monitors*—those who attend to threatening information—and *blunters*—those who avoid it. In general, monitors are more physiologically, behaviorally, and subjectively aroused than blunters, and these differences occur primarily under conditions of threat of the sort when cancer risk or diagnosis is at issue [67]. Patients with a blunting coping style may be unable to process the relevant information necessary to make informed decisions regarding treatment or self-care. It is thus important to match the amount of information to patients' coping styles to reduce their levels of stress, because telling patients either more or less than they want to know about a stressor will make it more stressful [67].

The third identified attribute is *having psychosocial and behavioral skills (and HCPs supporting their development)*. In the literature, many empowering interventions have been described to enhance survivors' skills. For example, one could think of a physical activity intervention with motivational interviewing technique [68] to enhance exercise behavior, or cognitive behavioral therapy to restructure dysfunctional ways of thinking to alleviate symptom burden (eg, CBT for

climacteric symptoms [69] or for cancer-related fatigue [70]). Physical activity may be a particularly promising intervention for patient empowerment because, in addition to its direct beneficial effects on physical and psychosocial outcomes in cancer [71], it may also function as a gateway behavior, such that improvements in physical activity behavior positively influence other health behaviors, like healthy eating [72]. It may therefore be particularly useful to emphasize physical activity promotion in cancer survivorship.

The fourth and fifth attributes were derived from cancer-specific studies. *Perceiving support from community, family, and friends* was highlighted by several papers and delineates the importance of patients not only having skills to obtain support, but also the a priori existence of such sources of support which are strong enough to be perceived as supporting by the patient. This attribute seems to very difficult to facilitate with the use of IT. *Perceiving oneself to be useful through having paid employment and/or by contributing to family and friends* highlights the importance of maintaining a sense of self-worth and the importance of returning to work. Return-to-work programs specifically aimed at cancer survivors exist but are still relatively rare [73]. These cancer-specific attributes are highly relevant but appear not to be very actionable by IT services.

Empowerment appears to be a relatively new concept in its application to cancer survivors. This may be due to a recent paradigm shift; many cancer types are no longer regarded as a deadly disease, but as a disease with a chronic nature, requiring ongoing support and care. This is highlighted by the fact that existing theories and models of chronic disease management, such as the Chronic Care Model (CCM) and the Chronic Disease Self-Management Program have recently been introduced to cancer survivorship [9,10]. Not surprisingly, much overlap exists between these models and our identified attributes of empowerment. Interestingly, researchers have recently related the CCM to ICT [74,75], and alterations to the CCM have been proposed to make it more appropriate for eHealth use [75]. These existing models may also be considered for future IT services for cancer survivors.

Recently, others have attempted to conceptualize patient empowerment by systematically reviewing questionnaires purporting to capture patient empowerment [76] and by using a mixed-methods approach combining literature review and focus groups [77]. Although these studies have taken a slightly different approach than ours, the findings show great overlap, which strengthens the confidence in our findings. We found that the attributes of empowerment do not differ much for cancer survivors compared to patients with a chronic disease, however further in-depth research is needed, especially on empowerment in dealing with symptom-specific aspects and with cancer worries.

### Using Information Technology to Support Patient Empowerment in Cancer Survivors

#### Overview

For patients with a chronic disease we previously found that there are many IT services available that are aiming to increase aspects of empowerment through Web-based interventions [11].

Positive effects regarding empowerment were found, mainly related to self-care behavior and measures of self-efficacy [11]. In this study, we additionally found IT services that could contribute to the empowerment of cancer survivors, specifically. When we related these services to the earlier identified attributes of empowerment it showed that they contribute to attributes of empowerment differently. Mainly, services were found to contribute to enhancing knowledge of patients regarding their situation, but the evidence for enhancing skills was limited. The contribution to the attribute of *being autonomous and respected* may be present in some tailored services, however, it is hardly ever a specific study end point, which makes it hard to substantiate it. For the different types of IT services, we will now discuss points of attention with regard to empowerment of cancer survivors.

## Educational Services

Educational services may greatly contribute to patient empowerment by providing patients with knowledge and skills. The approaches taken and the use of IT differs greatly, ranging from interactive decision tools to services that interactively deliver cognitive behavioral therapy to electronically provided survivorship care plans. Although appealing, the empowering potential of the latter service, either generated online or printed from an electronic tumor registry, seems to be mainly restricted to knowledge provision. To date, there is very little evidence of the effectiveness of providing patients with a survivorship care plan on aspects of patient empowerment [78]. From focus groups, we know that survivors anticipate that they would benefit from SCPs because they provide information about side effects that could occur in the long term and advice for a healthy lifestyle. They also value having an overview of diagnosis- and treatment-related information [79]. However, when focusing on the potential to empower cancer survivors, providing SCPs may be too passive an approach when it comes to enhancing skill levels. It is expected that when e-interventions are offered based on the input of patients (eg, as is done by the OncoKompas), cancer survivors will gain skills related to their problem areas. This hypothesis, however, needs to be tested in high-quality controlled trials. The use of SCPs could be valuable to facilitate information transfer from oncology centers to primary care and between several primary care physicians, especially in countries where the information transfer between these care providers is suboptimal.

## Patient-to-Patient Services

Patient-to-patient services seemed to offer little benefit in terms of empowerment and some negative effects have been reported as well. In focus group sessions, we found that some survivors would find such a service useful, mainly for practical tips such as where to find good wigs; however, in general, they did not endorse such a feature. Many doubted the quality of the information due to lack of moderation by an HCP, and they were also reluctant in sharing their emotions via this medium [79]. On the other hand, new peer-to-peer services, such as *PatientsLikeMe,* seem to grow in popularity, indicating there may be value in it for patients that has not been studied and recognized yet.

## Electronic Patient-Reported Outcome Services

A recent review shows that routine use of patient-reported outcomes (PROs) in clinical practice leads to better communication between patient and physician [80], and this benefit may also be expected from ePRO systems. These systems have the opportunity to immediately provide relevant, Web-based interventions to alleviate symptoms or improve coping ability for problems indicated on PROs. Of the reviewed IT services, these seem to be particularly promising as will be outlined in the following section.

## Multicomponent Services

It remains unclear what positive effects are related to what mix of components, but a study of Baker et al [63] comparing different versions of the CHESS—information only versus information and support services versus information, support, and coaching services—showed that emotional coping was only enhanced in the first two conditions, contrary to their expectations. The authors stated that the full CHESS version may be too complex for survivors and may reduce its effectiveness. In line with this finding, the WebChoice service [81] failed to show major benefits, despite the fact that it contained educational, patient-to-patient, and ePRO services.

## Patient Portals

Most portals that we reviewed are likely to make some contribution to patient empowerment. A recent systematic review questions the effectiveness of patient portals, as the data to date provide limited evidence for improved health outcomes or reduced costs [82]. Patient portals provide a technical basis for information exchange but still seem to be limited in their ability to really tailor content and feedback to patient input, which may limit their effectiveness in terms of skill development. Therefore, they may be enhanced by providing information and educational materials in a tailored way, for example, via intelligent algorithms that enable the tailoring according to the user's age, eHealth literacy, and coping style. Patient empowerment could also be enhanced by adding tailored interventions, such as online cognitive behavioral therapy.

## Promising Developments and Research Priorities

Based on this study, we conclude that services that are able to elicit survivors´ most bothersome issues and provide them with guidance to improve these issues have great potential to empower them. Preferably, an active attempt to improve or reinforce skills (eg, their ability to cope with emotions or to deal with fatigue) is used. Services that are particularly promising in this regard are tailored ePRO systems such as SAM, ESRA-C, and OncoKompas [21,22,61]. A significant challenge will be defining thresholds (ie, cutoff values) for screening questionnaires of such services, and generating a decision tree with valid and acceptable interventions that align with existing care pathways. The stepped-care model, starting with self-management options and gradually progressing to professional help, is a promising approach. It is largely unknown what would be the optimal format for graphically presenting ePRO data to cancer survivors and their HCPs, but researchers are starting to look into this issue [83]. It may be useful to include question prompt sheets that enable patients to formulate

their specific questions prior to a medical visit, based on their ePRO results. Most ePRO systems make use of validated quality-of-life and symptom measures. From an empowerment perspective, it may be useful to supplement these measures with questions that ask patients to identify their most relevant health problems and goals, as does the ESRA-C [61]. Future challenges in this regard will be to make these services aimed truly at the patients' needs, effective in following up on the identified needs, and making these services attractive and easy to use for patients with varying levels of eHealth literacy and sociodemographic characteristics. An area that was not fully tapped into in this paper, but that also may be promising, is that of social media services such as Twitter and Facebook. There is, for example, recent literature indicating that Twitter may be valuable for patients to increase their knowledge [84] and their perceived support from the community [85].

Consequently, several research priorities can be pointed out. First, research needs to focus on how to best measure what survivors identify as key areas or goals that they want to work on regarding their health, and how these could be best met by existing health services, either on- or offline, in preferably a stepped-care manner. Second, research is needed to determine the optimal information provision to survivors given their informational coping styles. Third, it is important to determine the key skills that cancer survivors need, as well as the most effective ways to enhance these skills, possibly differentiated for different types of cancer. And finally, an important issue with health IT services is that there is a limited uptake. According to a large study in the United States (n=3959), overall use ranged from 3% to 78% for online diary keeping and health information seeking on the Internet, respectively. They also found that older persons, males, and those with a lower socioeconomic status were less likely to engage in a number of eHealth activities (odds ratio ~ 0.5) compared to their counterparts [86]. It may therefore be prudent to study ways to optimize the reach of such services in cancer survivors, for example, by using the Reach Effectiveness Adoption Implementation Maintenance (RE-AIM) framework that was developed to guide the widespread adoption and implementation of health interventions [87].

## Limitations and Strengths

First, regarding the integrative literature search on empowerment, we did not include or exclude articles based on quality criteria, which makes it impossible to objectively assign more weight to one article over another. Furthermore, it is an inherent limitation of this review that there is a limited number of studies specifically focusing on cancer patients. However, as findings with regard to patient empowerment in the larger body of literature on chronically diseased patient populations were also reflected in the more limited literature specifically focusing on patients with cancer, we can assume that the conceptualization of empowerment applies to the cancer setting as well. Second, the review of IT services may not include every IT service available at the time of this review. This is a rapidly developing area, and thus it is difficult to be comprehensive. Rather, we have provided an overview of some of the more widely publicized IT services that serve cancer survivors. Although there are no established methods for reviewing newly developed IT services, we have suggestions for future attempts. Reviews in this area may be strengthened by searching multiple databases (eg, PubMed and Scopus), having at least two persons evaluating the eligibility, extracting features/functionalities of the services, and relating the features/functionalities to predefined quality criteria when available. For example, Williams et al reviewed online decision aids and rated them on International Patient Decision Aid Standards (IPDAS) criteria [88]. Finally, our statements regarding the contribution of IT to patient empowerment have been based largely on hypothesized effectiveness, as the current evidence base in this area is quite small.

The major strength of this review is that it addresses both the literature on defining patient empowerment, and the literature on current IT services for cancer survivors and their possible contribution to enhancing empowerment. Another strength is the use of the integrated review method, which facilitates inclusion and integration of different sources and types of information (eg, theoretical and empirical manuscripts) in a single review [12].

## Conclusions

In this paper, we have identified the key attributes of the concept of patient empowerment for chronic disease patients including cancer survivors, and we have illustrated the ways in which IT services can contribute to enhancing empowerment of cancer survivors. We found that IT services were mainly related to knowledge provision (eg, about the patients' medical conditions) and that active approaches for skill development were limited. Future challenges will be to make these services aimed truly at the patients' needs, effective in following up on their identified needs, and making these services attractive and easy to use for patients with varying levels of eHealth literacy and sociodemographic characteristics.

## Conflicts of Interest

None declared.

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## Multimedia Appendix 1

Electronic PubMed searches.

[PDF File (Adobe PDF File), 22KB - jmir_v17i11e270_app1.pdf ]

## Multimedia Appendix 2

Examples of IT services with potential for empowerment of cancer survivors.

[PDF File (Adobe PDF File), 159KB - jmir_v17i11e270_app2.pdf ]

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## Abbreviations

**A-CaRe:** Alpe d'HuZes Cancer Rehabiliation
**AR:** being autonomous and respected

**CBT:** cognitive behavioral therapy
**CCM:** Chronic Care Model
**CHES:** Computer-based Health Evaluation System
**CHESS:** Comprehensive Health Enhancement Support System
**EMR:** electronic medical record
**ePRO:** electronic patient-reported outcome
**ESRA-C:** Electronic Self-Report Assessment for Cancer
**HCP:** health care provider
**HK:** having knowledge
**HL7:** Health Level Seven
**ICT:** information and communication technology
**IDEA:** Interactive Digital Education Aid
**IPDAS:** International Patient Decision Aid Standards
**IT:** information technology
**IVF:** in vitro fertilization
**KWF:** Dutch Cancer Society
**o:** no positive contribution to empowerment
**PRISMA:** Preferred Reporting Items for Systematic Reviews and Meta-Analyses
**PRO:** patient-reported outcome
**PS:** perceived support from community, family, and friends
**RCT:** randomized controlled trial
**RE-AIM:** Reach Effectiveness Adoption Implementation Maintenance
**ROGY:** Registrationsystem Oncological GYnecology
**SAM:** self-assessment and management
**SCP:** survivorship care plan
**SHUTi:** Sleep Healthy Using The Internet
**SK:** having skills
**UMC:** University Medical Center
**+:** weak positive contribution to empowerment
**++:** strong positive contribution to empowerment

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Original Paper

# Heart Failure Telemonitoring in Japan and Sweden: A Cross-Sectional Survey

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## Abstract

**Background:** Telemonitoring of heart failure (HF) patients is increasingly discussed at conferences and addressed in research. However, little is known about actual use in specific countries.

**Objective:** We aimed to (1) describe the use of non-invasive HF telemonitoring, (2) clarify expectations of telemonitoring among cardiologists and nurses, and (3) describe barriers to the implementation of telemonitoring in Japan and Sweden.

**Methods:** This study used a cross-sectional survey of non-invasive HF telemonitoring. A total of 378 Japanese (120 cardiologists, 258 nurses) and 120 Swedish (39 cardiologists, 81 nurses) health care professionals from 165 Japanese and 61 Swedish hospitals/clinics nationwide participated in the study (210 in Japan and 98 in Sweden were approached). Data were collected between November 2013 and May 2014 with a questionnaire that was adapted from a previous Dutch study on telemonitoring.

**Results:** The mean age of the cardiologists and nurses was 47 years and 41 years, respectively. Experience at the current position caring for HF patients was 19 years among the physicians and 15 years among the nurses. In total, 7 Japanese (4.2%) and none of the Swedish health care institutions used telemonitoring. One fourth (24.0%, 118/498) of the health care professionals were familiar with the technology (in Japan: 21.6%, 82/378; in Sweden: 30.0%, 36/120). The highest expectations of telemonitoring (rated on a scale from 0-10) were reduced hospitalizations (8.3 in Japan and 7.5 in Sweden), increased patient self-care (7.8 and 7.4), and offering high-quality care (7.8 and 7.0). The major goal for introducing telemonitoring was to monitor physical condition and recognize signs of worsening HF in Japan (94.1%, 352/374) and Sweden (88.7%, 102/115). The following reasons were also high in Sweden: to monitor effects of treatment and adjust it remotely (86.9%, 100/115) and to do remote drug titration (79.1%, 91/115). Just under a quarter of Japanese (22.4%, 85/378) and over a third of Swedish (38.1%, 45/118) health care professionals thought that telemonitoring was a good way to follow up stable HF patients. Three domains of barriers were identified by content analysis: organizational barriers "how are we going to do it?" (categories include structure and resource), health care professionals themselves "what do we need to know and do" (reservation), and barriers related to patients "not everybody would benefit" (internal and external shortcomings).

**Conclusions:** Telemonitoring for HF patients has not been implemented in Japan or Sweden. However, health care professionals have expectations of telemonitoring to reduce patients' hospitalizations and increase patient self-care. There are still a wide range of barriers to the implementation of HF telemonitoring.

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## Introduction

Management of heart failure (HF) poses substantial challenges to health care systems worldwide. Advances in modern telecommunication technologies have created new opportunities to provide telemedical care as an adjunct to the management of HF patients. Telemonitoring defined as "the remote monitoring of patients including the use of audio, video, other telecommunications, and electronic information processing technologies to monitor patient status at a distance" [1] might be an option for future HF management.

In several meta-analyses, telemonitoring for HF patients has been shown to reduce mortality and hospital admissions [2-4]. However, findings from recent studies are not consistent [5-8], raising doubts about the potential of telemonitoring in HF management. Because of this conflicting evidence, the HF guideline committee of the European Society of Cardiology has not recommended use of telemonitoring in regular HF care [9]. HF telemonitoring is, however, considered to be promising, and many HF telemonitoring studies are underway. In contrast, little is known about HF telemonitoring in daily practice. Only a few studies have examined the actual usage rate of telemonitoring, health care professionals' expectations of telemonitoring, and practical issues related to telemonitoring [10-12]. These aspects are vital for HF telemonitoring in future practice.

Sweden and Japan are two countries with advanced information technology, where HF management is a medical and financial challenge [13,14]. Findings on implementation and attitudes to telemonitoring in these two countries might make it possible to predict how HF telemonitoring will be used in other European and Asian countries in the near future. In addition, clarifying practical issues related to HF telemonitoring could lead to solutions for using the device in daily practice.

This study therefore aimed to (1) describe the use of HF telemonitoring, (2) clarify expectations of telemonitoring among cardiologists and nurses, and (3) describe barriers to the implementation of telemonitoring in Japan and Sweden. The findings were compared between the two countries, which could facilitate generalizability.

## Methods

### Design and Definition

This study used a cross-sectional survey of non-invasive HF telemonitoring. Non-invasive HF telemonitoring was defined as the remote, Internet-based monitoring of HF patients on weight, blood pressure, heart rate, and signs and symptoms that disclose the actual condition of HF patient [11]. The devices are used by the patient in their own home environment, and the generated data are communicated by the Internet to a telemonitoring center. Health care professionals receive the data in the center and provide feedback to the patients.

Telemonitoring by means of telephone, telephone support, telephone follow-up, or implantable devices was not included in this study as our focus was to investigate perceptions of using telemonitoring devices that required active user interaction.

### Study Procedure and Participants

Physicians and nurses working with HF patients in Japan and Sweden participated in this study. First, we made a list of potential hospitals. In Japan, a total of 210 public and private hospitals nationwide were randomly extracted from 994 hospitals that were recognized training facilities for cardiologists by the Japanese Circulation Society, based on each prefecture population. At least two hospitals from each of 47 prefectures (one university and one non-university hospital) were included. In Sweden, all 98 hospitals/primary care centers with a specialist HF clinic in all 21 county councils and regions were included.

Between November 2013 and May 2014, the questionnaire was sent to hospital departments responsible for HF patient care, for example, cardiology departments, HF clinics, or primary care centers with a specialized HF nurse, along with an information letter requesting their help. For each hospital/clinic, it was requested that the questionnaire be completed by 1 physician and 2 nurses working with HF patients on a regular basis. The questionnaires were given a code for each hospital/clinic so that it was possible to tell which hospitals returned the questionnaire. Respondent confidentiality was assured by omitting names and other personal information in the questionnaire.

### Instrument

To clarify health care providers' perceptions of HF telemonitoring, a questionnaire previously developed by de Vries et al was used [11]. Face validity of the original questionnaire has been confirmed by 10 cardiologists and 10 HF nurses. The original instrument was developed in Dutch [11] and then translated into English. In our study, 3 researchers who were native speakers of Dutch, Japanese, and Swedish respectively, translated the instrument from English into Japanese and from English to Swedish, while carefully verifying the semantic equivalence of the translation. Where there were difficulties understanding the intent of the original questionnaire, the translated versions were checked against the original Dutch questionnaire.

To examine availability of telemonitoring, study participants were asked if they used telemonitoring for HF patients at that time. Those who did were asked about the system they used. As for awareness of telemonitoring, the participants were asked if they were familiar with HF telemonitoring. They responded to this question with yes or no. For data about the participants' expectations of telemonitoring, we asked if the following four items could be main goals for telemonitoring: (1) monitoring physical condition and noticing declines, (2) monitoring effects of the treatment and adjusting it remotely, (3) remote drug

titration, and (4) patient education. Again, the participants responded to four items with yes or no. They were also asked about good ways to follow up on stable HF patients. They responded to the 8 ways of follow-up including telemonitoring, outpatient clinic, and implantable telemonitoring device with yes or no. As for reasons for introducing telemonitoring in HF patients, health care professionals were asked to rate the importance level for introducing telemonitoring (eg, reduced readmission, increased patient self-care, high quality of care, and improved adherence to HF guidelines) on a 10-point scale (0= "not important", 10="very important"). We asked about barriers for implementation of telemonitoring in HF patients to health care professionals who had not used HF telemonitoring in their hospitals or clinics with open-ended question such as "What are the important barriers to use of telemonitoring in your institutions?". Multimedia Appendix 1 shows the questionnaire used in the study.

We also examined characteristics of study participants, such as gender, age, experience of current position as physicians or nurses caring for HF patients, health care institutions, and computer skills and knowledge of, for instance, Word, Excel, and the Internet.

## Data Analysis

Data from all participants were included for analysis regardless of actual usage of HF telemonitoring at the time of the study. Descriptive analysis was used to present data. For continuous variables with a normal distribution, the mean and standard deviations are reported and were analyzed by Student $t$ test to compare data between Japan and Sweden. For continuous variables not normally distributed, the median and interquartile range (Q1-Q3) are reported and were analyzed with Mann-Whitney U test. Categorical variables are presented with numbers and percentages and were analyzed with chi-square test and in a few cases, the Fisher's exact test. All statistical tests were two-tailed, and statistical significance was defined as $P<.05$. All analyses were performed with SAS version 9.3.

Barriers for implementation of telemonitoring in HF patients were extracted by analyzing the participants' responses to the open-ended questions in the questionnaire. All responses were transcribed verbatim and analyzed using content analysis methodology [15]. First, descriptions were divided into domains by 3 researchers (NPK, PJ, TJ), which was the highest conceptual level identified in the study. Subsequently, the descriptions were categorized into subcategories in each domain. Then, the subcategories were merged into categories, based on topic similarities. Where there was no consensus, discussions took place between the researchers until consensus was achieved.

## Results

### Participants and Response Rate

A total of 165 Japanese hospitals and 61 Swedish hospitals/clinics participated in this study. The response rate at hospital/clinic level (meaning that at least one health care provider answered the questionnaire) was 79% in Japan and 62% in Sweden. In total, data from 339 nurses (258 Japanese, 81 Swedish, response rate=55%), and 159 physicians (120 Japanese, 39 Swedish, response rate=52%) were analyzed in the study.

Table 1 shows the characteristics of the study participants. The mean age of the physicians and nurses was 47 years and 41 years, respectively. Japanese nurses were significantly younger than Swedish nurses (39 years vs 51 years, $P<.001$). Experience at the current position caring for HF patients was 19 years among physicians and 15 years among nurses. Almost every respondent (over 96%) had experience with standard programs such as Word and Excel and were able to use email and Internet.

**Table 1.** Characteristics of physicians and nurses.

| | All physicians (n=159) | Japanese physicians (n=120) | Swedish physicians (n=39) | All nurses (n=339) | Japanese nurses (n=258) | Swedish nurses (n=81) |
|---|---|---|---|---|---|---|
| Male, n (%) | 137 (86) | 115 (96) | 22 (56) | 17 (6) | 11 (5) | 6 (8) |
| Age, mean (SD) | 47 (8) | 46 (7) | 49 (9) | 41 (10) | 39 (8) | 51 (9) |
| Experience at current position in years, mean (SD) | 19.0 (8.1) | 19.9 (7.5) | 16.5 (9.3) | 15.0 (8.7) | 15.1 (8.4) | 14.9 (9.7) |
| Time working with HF patients, hours/week, median (Q1-Q3) | 12 (6-20) | 15 (8-24) | 10 (5-15) | 30 (10-40) | 40 (16-40) | 14 (8-24) |
| University hospital, n (%) | 61 (38) | 56 (47) | 5 (13) | 113 (34) | 109 (42) | 4 (5) |

## Availability of Telemonitoring for Heart Failure Patients

### Actual Usage Rate of Telemonitoring for Heart Failure Patients

In total, 7 of 165 hospitals (4%) in Japan and none of the hospitals in Sweden used telemonitoring for HF patients at the time of the study. Of the Japanese hospitals, 6 used the same telemonitoring device (Karada Karute, Tanita Health Link, Inc.) since they were involved in a clinical trial of this equipment [16], and one hospital used devices made by Cyber Cross Japan Co. [17]. The functionality of the two systems used in Japan are similar. Physiological data generated at home, such as blood pressure and body weight, are transferred to a central Web server via the Internet. Nurses working at the center monitor the

acquired data on a secure website 7 days a week. If the data exceed the acceptable range, the nurses in the center contact the patients to check the patients' physical condition with the use of standard operating procedure. The patients were also contacted by physicians in accordance with the standard operating procedures [17,18].

### Awareness

In total, 24.0% (118/498) of health care professionals (21.6%, 82/378 in Japan and 30.0%, 36/120 in Sweden) were familiar with HF telemonitoring. There was a significant difference (*P*<.001) in familiarity between physicians (49.6%, 63/159) and nurses (16.2%, 55/339).

## Expectations of Heart Failure Telemonitoring

### Main Goals of Telemonitoring

As shown in Figure 1, the most frequent purpose for choosing HF telemonitoring in Japan (93.1%, 352/378) and Sweden (89.0%, 102/115) was "monitoring physical condition and noticing a decline". In Japan, the second most frequent purpose was "patient education" (60.6%, 229/378). In Sweden, the second most frequent purpose was "monitoring effects of the treatment and adjusting it remotely" (86.9%, 100/115), whereas the third was "remote drug titration" (79.1%, 91/115). These two Swedish figures were significantly higher than the Japanese ones (both *P*<.001).

Figure 2 shows what health care providers think is a good way to follow up on stable HF patients. Just under a quarter of Japanese (22.4%, 85/378) and over a third of Swedish (38.1%, 45/118) health care providers thought that telemonitoring was a good way to follow up on stable HF patients. The percentage differed significantly between the two countries (*P*=.001). "Outpatient clinic" was the most frequently chosen option for a good way to follow up stable HF patients, regardless of country. In Japan, "Home visit by nurses" (31.7%, 120/378) was the second most common option, whereas in Sweden, "Phone" (75.4%, 89/118) was the second most common choice. "Implantable monitoring device" was chosen in 12.2% of Japanese (46/378) and 14.4% of Swedish (17/118) health care professionals. Approximately 10% of health care professionals selected other options including "Video contact", "E-mail by mobile phone", and "Home visit by other person".

**Figure 1.** Main goals of heart failure telemonitoring according to the respondents. *P* < .01 Japan vs Sweden by chi-square test.
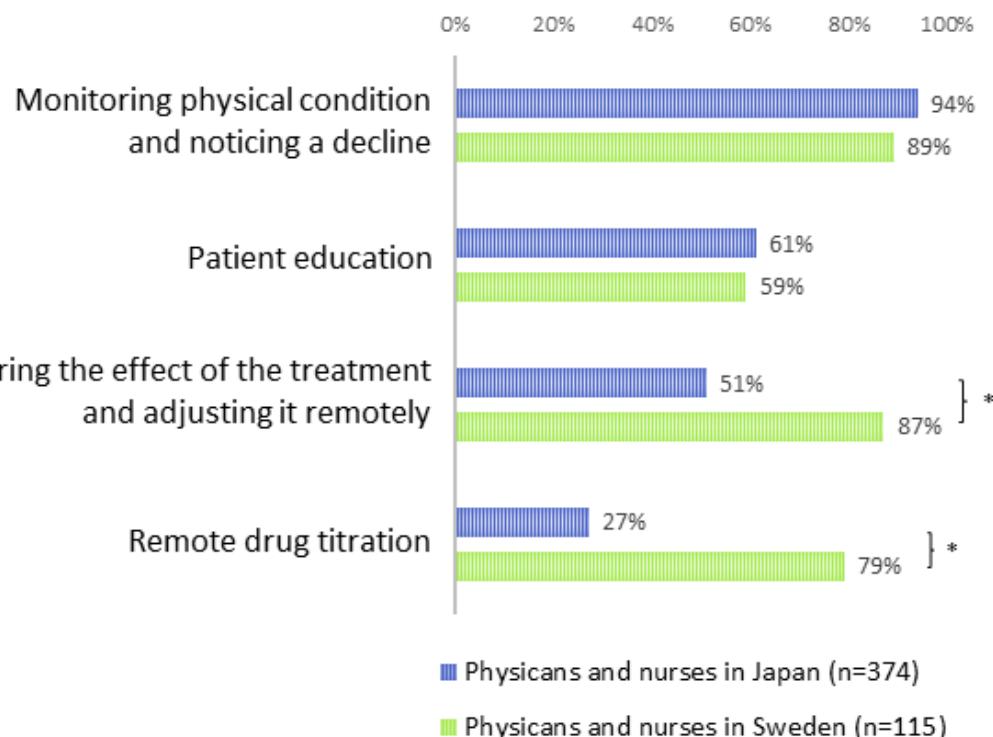
**Figure 2.** Good ways to follow up stable heart failure patients according to the respondents. *P < .01 Japan vs Sweden by chi-square test.
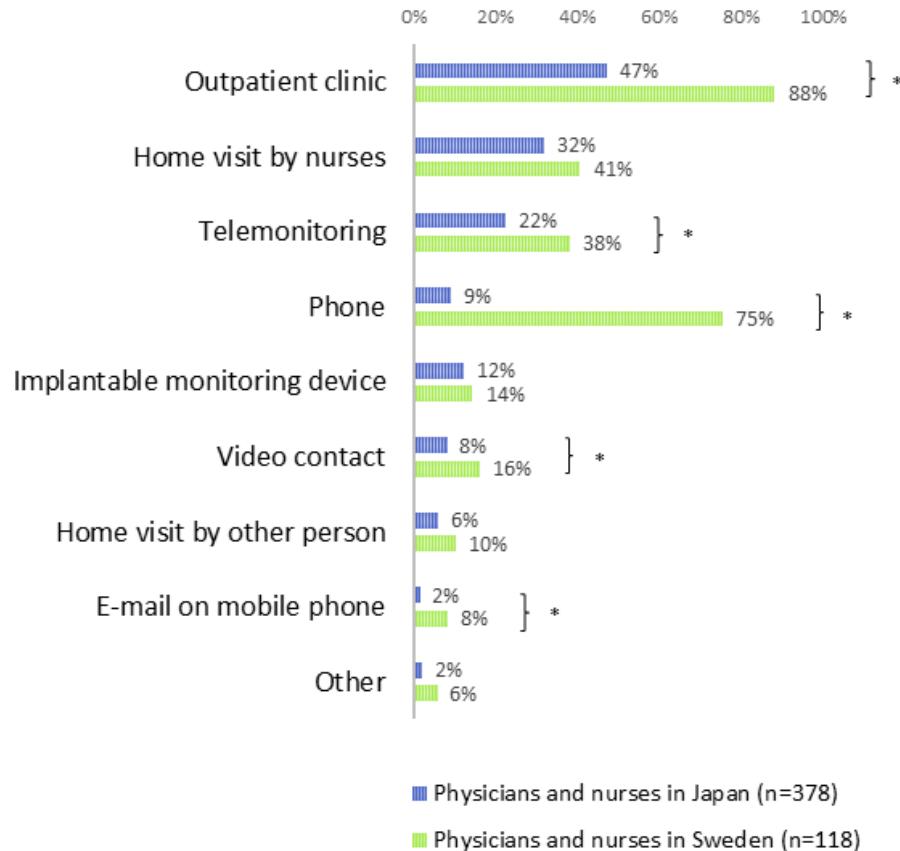


### Reasons for Introducing Telemonitoring for Heart Failure Patients

Figure 3 represents the expectations of HF telemonitoring. Regardless of country, the top 3 reasons for introducing telemonitoring to HF patients were "Reduce patients' admissions/readmissions" (Japan 8.3, SD 2.1; Sweden 7.5, SD 2.5), "Increasing patients' self-care" (Japan 7.8, SD 2.1; Sweden 7.0, SD 2.5), and "Offering higher quality of care" (Japan 7.8, SD 2.3; Sweden 7.0, SD 2.7). The items "Ability to treat more patients", "Reducing the work load on the HF clinic", and "Reducing cost" were not rated as high (range from 5.3-6.3).

## Barriers to the Implementation of Telemonitoring for Heart Failure Patients

All answers from all 498 participants on the open question were considered in the analysis of the data on the question regarding barriers. These answers were condensed into categories and subcategories as presented in Tables 2-4. The quotes of some of the participants are used to illustrate the subcategory. Not many differences in the barriers to the implementation of HF telemonitoring were found between Sweden and Japan; therefore, they were summarized as one result. The barriers were divided into three domains: (1) organization, "How are we going to do it?", (2) health care professionals, "What do we need to know and do?", and (3) patients, "Not everybody would benefit". The domain organization comprised two categories: resource and structures. In the health care professionals' domain, the category reservation was extracted. In the patients' domain, two categories (ie, internal and external shortcomings) were extracted.

**Figure 3.** Expectations of heart failure telemonitoring. Importance level for introducing telemonitoring was evaluated on a 10-point scale (0= not important, 10= very important). Mean±SEM, *P <.05 Japan vs Sweden by Student t test.
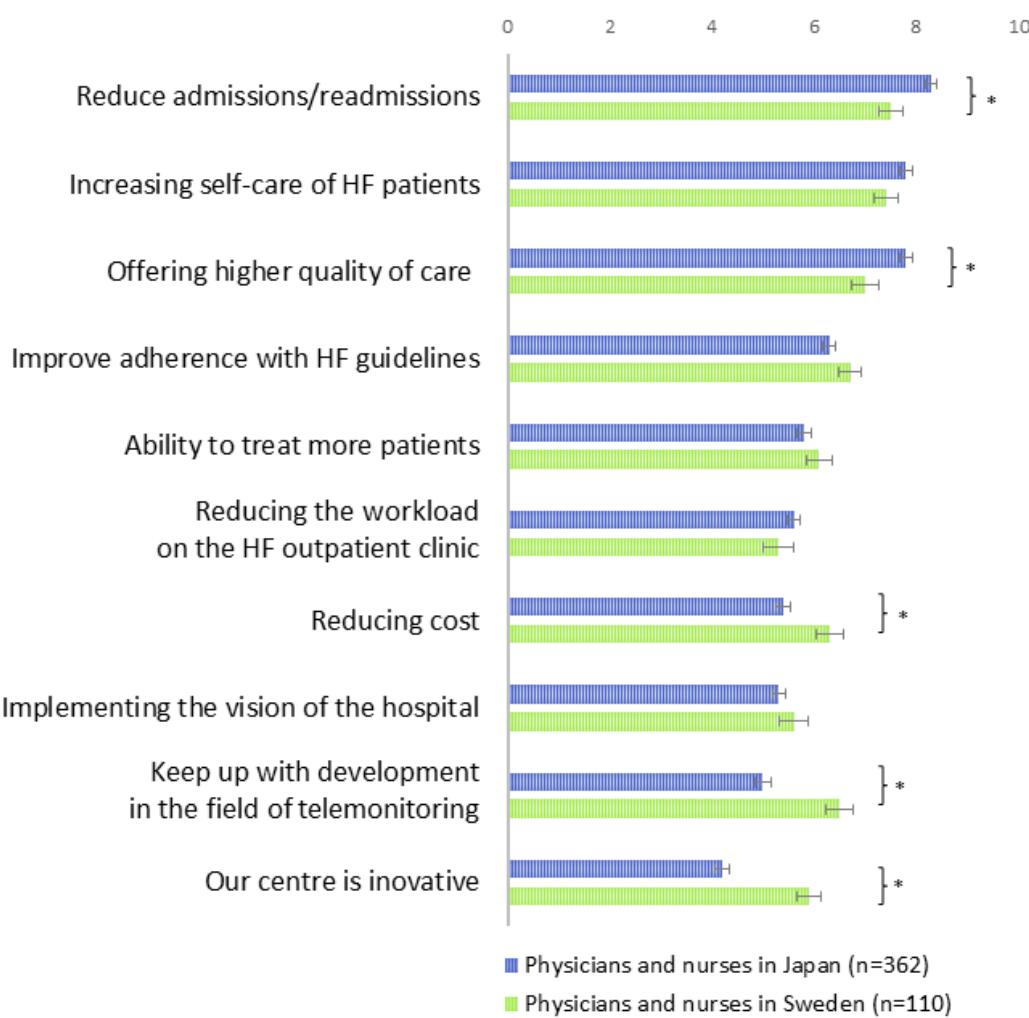


**Table 2.** Barriers to implementation of HF telemonitoring based on the content analysis of the open-ended answers in the survey—Domain 1. Organization, "How are we going to do it?".

| Category | Subcategory | Quote |
|---|---|---|
| Resource | Manpower | We have a shortage of medical staff, we have no time (Sweden, physician, male) |
| | | Difficulty securing medical staff who control overall data/system of telemonitoring (Japan, physician, male) |
| | Materials | There are no devices for HF telemonitoring (Japan, nurse, female) |
| | | There are no adequate network systems in our hospital (Japan, physician, male) |
| | Funding and priority setting | We have no money for this (Sweden, physician, male) |
| | | It depends on hospital policy (Japan, nurse, female) |
| Structure | Responsibilities | Who is responsible for telemonitoring? (Japan, physician, male) |
| | | Which professionals play a key role? (Japan, nurse, female) |
| | | What should we do if something happens? (Japan, nurse, male) |
| | Patients | What kind of patients can be a candidate for telemonitoring? (Japan, nurse, female) |
| | | How many patients need telemonitoring? (Japan, nurse, female) |
| | Protocols | When or how often do we check data from patients? (Japan, nurse, female) |
| | Collaboration | Information-sharing among medical staff is not sufficient (Japan, nurse, female) |
| | | It is difficult to collaborate with other hospitals/clinics (Sweden, physician, male) |
| | Safety | Support system and troubleshooting were not yet established (Japan, nurse, female) |

**Table 3.** Barriers to implementation of HF telemonitoring based on the content analysis of the open-ended answers in the survey—Domain 2. Health care professionals, "What do we need to know and do?".

| Category | Subcategory | Quote |
|---|---|---|
| Reservation | Lack of advantage | I do not feel the need for telemonitoring (Sweden, nurse, female) |
| | | We should prioritize self-care support rather than telemonitoring (Japan, physician, male) |
| | Skepticism about effects of telemonitoring/information technology | Some health care professionals have a resistance toward IT technology (Japan, nurse, female) |
| | | There is no strong evidence of telemonitoring (Sweden, physician, female) |
| | Poor knowledge and skills of telemonitoring | I do not have enough confidence to explain telemonitoring to patients (Japan, nurse, female) |
| | Lack of computer skills | Some health care professionals do not have enough skills to use a personal computer (Japan, nurse, female) |

**Table 4.** Barriers to implementation of HF telemonitoring based on the content analysis of the open ended answers in the survey—Domain 3. Patients, "Not everybody would benefit".

| Category | Subcategory | Quote |
|---|---|---|
| Internal shortcoming | Age-related conditions | Elderly patients cannot use the device (Japan, physician, male) |
| | Comorbidities | Patients with multiple diseases need additional monitoring (Sweden, nurse, female) |
| | Cognitive dysfunction | We cannot obtain correct information if patients have cognitive dysfunctions (Sweden, physician, female) |
| | Functional disability | Patients with impaired eyesight or hearing cannot use telemonitoring (Sweden, nurse, female) |
| | | Patients with difficulty standing up cannot use telemonitoring (Japan, nurse, female) |
| | Anxiety/depression/worries | Patients may be greatly worried because of slightly changed data (Japan, nurse, female) |
| | No support | Patients cannot send physical data because of lack of family support (Japan, nurse, female) |
| | Lack of motivation | Patients who cannot measure their weight even now would not send their physical data by Internet (Japan, physician, male) |
| | | Patients who do not have a cooperative relationship would not send data (Japan, nurse, female) |
| | Lack of acceptance | It is difficult to obtain acceptance of telemonitoring from patients (Japan, physician, female) |
| | Language problems | Non-Swedish speaking patients cannot understand the device (Sweden, nurse, female) |
| Environmental shortcoming | Lack of infrastructure | No/insufficient Internet connection and computers (Sweden, physician, female) |
| | | Patients who are not used to using computers may not be able to use the device (Japan, nurse, female) |
| | Financial problems | Patients on welfare might not be able to pay the telemonitoring fee (Japan, nurse, female) |

## Discussion

### Principal Findings

Despite increasing attention to telemonitoring for HF patients at professional conferences and some evidence being available in the literature [2-8], we found that only a few Japanese hospitals and no Swedish hospitals/clinics have introduced telemonitoring for HF patients. We also found that only a limited number (24%) of health care professionals were familiar with HF telemonitoring. However, at the same time we found that health care professionals could see a potential for using telemonitoring in their HF patients. In particular, they felt that it could reduce patients' hospitalization and increase patients' self-care, but they also identified a wide range of barriers for implementing telemonitoring at the level of organization, health care professionals, and patients.

When hospitals using telemonitoring for the purpose of clinical trials were excluded, we found that only one hospital in Japan used telemonitoring, and in Sweden it was not used at all. This was surprising since Japan and Sweden both have highly developed information technology and a high number of elderly HF patients [13,14]. In addition, Sweden has a long tradition of HF disease management programs. For these reasons, we assumed that many hospitals in the two countries had introduced a telemonitoring system in daily practice. However, our findings were completely different, especially when comparing them with a recently published study from the Netherlands, where 36% of hospitals were using telemonitoring [11] (and this was

still considered a low figure). No specific number on the uptake of telemonitoring in other countries is known, although in several European countries (eg, Poland, Germany, and the United Kingdom) research studies on the effect of telemonitoring have been performed [3,5,19].

Despite the low use of telemonitoring, health care professionals could imagine a place for this technology among HF patients. They expected telemonitoring to reduce hospitalization rates, increase patient self-care, and high quality of care. These potential purposes for telemonitoring were also described by de Vries et al as expectations of telemonitoring in the Netherlands [11]. In that study, these expectations were not met after introducing telemonitoring, triggering us to focus on realistic and unrealistic expectations before the actual implementation. If expectations are high and are not met, this might lead to frustration and a waste of resources. Similar to the Dutch study [11], most of the health care staff in our study reported that an important aim of using telemonitoring would be to monitor the physical condition of the patient and to monitor and adjust treatment after remote drug titration. In our survey, the latter aim was less often viewed as applicable by the Japanese nurses, compared to the Swedish HF nurses. This can be explained by differences in the health care system between Sweden and Japan. Although citizens of both countries have basic health insurance and patients can have easy access to HF clinics and hospitals, there are some differences in the organization of care, for example, Swedish nurses are allowed to be active in drug titration, whereas nurses in Japan are not. Therefore, it is important to consider differences and similarities in health care systems and cultures in order to develop HF telemonitoring models.

Consistent with previous studies [11,20,21], the organization was identified as a significant barrier to the implementation of HF telemonitoring. Lack of structure, such as clear descriptions of responsibilities and protocols, as well as a lack of resources, such as manpower and materials, were seen as barriers standing in the way of using telemonitoring in current practice. In general, organizational issues are a key in the implementation of comprehensive health care systems [22]. A lack of a clear protocol describing actions to be taken based on the data received from the device can make telemonitoring time-consuming or make the health care professional feel insecure [20]. With regard to organization, previous studies have described that health care professionals may expect telemonitoring to be one of the solutions for medical staff shortages [20]. However, some studies have reported that telemonitoring is perceived as more laborious and as increasing one's workload [23,24]. These findings suggest that the structure and resources in the organization go hand in hand, and therefore, implementation of telemonitoring should be considered as an organizational development and not merely a technical project.

Another barrier for implementation was the health care professionals' reserved attitude. Not all physicians and nurses could see the advantage of using telemonitoring in their current practice, whereas others were skeptical about telemonitoring or reported that they did not know enough about it. These barriers are partly in line with barriers described in other studies [20,25]. Lack of relative advantage represents the degree to which a

technology is perceived to be better than the existing alternatives [26]. It is one of the most important factors for adopting new technology [27]. In the case of telemonitoring in HF, it should be recognized that health care professionals might be confronted with mixed messages from research and industrial companies. A systematic review concluded that there was clear evidence of the clinical benefits in HF telemonitoring [2-4], while recent findings have not been consistent [5-8]. More evidence is still required on clinical benefits as well as the cost-effectiveness from a societal perspective. The finding that telemonitoring was not chosen as the best way to follow up on stable HF patients might be related to the perception of lack of advantage. Some industrial companies provide education and training, but a systematic educational support system regarding the concept, aims, and patient selection is necessary. Technology alone is not enough to create joined-up care pathways, and there is a need for continuous education of health care professionals at all stages of care.

Health care providers also had great doubts about the applicability of telemonitoring to certain patient groups or patients with certain characteristics or shortcomings. These included doubts about giving telemonitoring equipment to older patients, patients with physical and psychosocial impairments, or patients with no Internet/computer and who lacked computer skills. It is important to note that these are barriers as perceived by health care professionals, who had no experience of and/or lacked knowledge about HF telemonitoring. Thus, many of these barriers might be overcome by increased knowledge about telemonitoring and HF trajectory, but also clear instructions on how to use the devices and by improved design of equipment. Health care providers also expressed the concern that patients might get worried or anxious when using telemonitoring. However, these fears may disappear once they are using telemonitoring, as was shown in a study where such fear was reduced after patients began using telemonitoring devices. Patients had increased assurance and a sense of security [28,29]. Telemonitoring has been shown to enhance patients' self-management, but our findings indicate that further work is required to develop an approach on how to increase patients' acceptance and motivation to use HF telemonitoring.

## Limitations

There were several limitations to consider in this study. First, questions about barriers for implementing telemonitoring were asked, using open-ended question, which might limit our findings compared to using interviews. However, answers from nearly 500 health care providers were obtained. As for content analysis, all subcategories, categories, and themes were reviewed again to enhance conformability and minimize personal bias, which ensures trustworthiness of the findings. Second, as only a few hospitals had introduced telemonitoring for HF patients, it was not possible to describe health care professionals' experiences of working with telemonitoring. Third, the instrument used was developed on the basis of a previous, validated Dutch study. However, some items might need to be modified considering the low percentage of health care institutions that had introduced HF telemonitoring in Japan and Sweden.

## Conclusions

This study demonstrated that only a few Japanese hospitals and no Swedish hospitals/clinics have introduced non-invasive telemonitoring for HF patients. Only a quarter of health care professionals were familiar with HF telemonitoring. However, cardiologists and nurses in Japan and Sweden expected HF telemonitoring to reduce patients' hospitalization and increase patient self-care. There was, however, a wide range of barriers to implementing HF telemonitoring at the organizational, health care professional, and patient levels.

## Acknowledgments

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

A questionnaire in the study.

[PDF File (Adobe PDF File), 12KB - jmir_v17i11e258_app1.pdf ]

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## Abbreviations

**HF:** heart failure

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Original Paper

# A Patient Portal With Electronic Messaging: Controlled Before-and-After Study

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## Abstract

**Background:** Patients' access to their medical records, along with electronic messaging, offers an efficient means of information transition between patients and their caregivers. Easier access to information and interaction with health care professionals may reduce use of other services while increasing patients' activation in the management of their own health. Patient portals may therefore have a favorable impact on the cost-effectiveness of care.

**Objective:** The aim was to assess the benefits and risks of providing electronic messaging services to patients with chronic conditions. Using cost-effectiveness analysis, the outcomes and costs of providing access to an electronic patient portal were evaluated in a real-life treatment process in primary care.

**Methods:** A total of 876 chronically ill patients from public primary care were allocated to either an intervention group receiving immediate access to a patient portal that included their medical records, care plan, and secure messaging with a care team, or to a control group receiving standard care. Incremental direct heath care costs, health status based on the Short-Form Health Survey, version 2 (SF-36v2), and patient activation based on the short form of the Patient Activation Measure (PAM13) were compared to standard care in a 6-month follow-up. Incremental cost-effectiveness ratios were calculated using a sample of 80 patients in the intervention group and 57 patients in the control group; thus, a total of 137 patients were included in the final analysis. Propensity-score matching was used to assess the sensitivity of the results to the possible attrition bias.

**Results:** Patient activation improved more in the intervention group but the effect was not statistically significant. The effect on cost of care was ambiguous; costs decreased by an average of €91 in the unadjusted model, but increased by €48 in the adjusted model. Due to the controversial results on cost, the unadjusted analysis showed an 89% probability of cost-effectiveness with no willingness to pay for increased patient activation, whereas in the adjusted sample, the probability of the portal being more cost-effective than care as usual exceeded 50% probability at a willingness to pay €700 per clinically significant increase in patient activation score. There was no marked short-term impact on health status based on the SF-36v2 measure.

**Conclusions:** Offering the possibility to substitute health care visits with less costly contacts using self-management tools did not seem to compromise the health status or treatment of chronic care patients. Patient activation increased, and this could be achieved with moderate costs in a short-term experiment. In the long term, increased activation is proposed to lead to better health outcomes and eventually cut down resource use. Future studies should assess the long-term effects of patient portals on patients' health status and cost of care.

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## Introduction

Health maintenance and the restoration of functioning among the chronically ill requires repetitive interaction with the care provider and patient engagement in the management of their own condition [1]. To meet the needs of the growing population with chronic diseases, health care providers have begun efforts to engage chronically ill patients in monitoring and managing their own health. Supporting patients' self-management may impact patients' use of traditionally provided health services, but can also have an impact on health outcomes by increasing patients' activation in the management of their own health [2]. Activated patients are knowledgeable, skilled, and confident in the management of their condition, and are shown to engage in preventive behavior by following care recommendations and pursuing healthy lifestyles [3-5].

An electronic patient portal is one of the self-management tools suggested for increasing patient activation [6,7] by enabling efficient information sharing between a patient and the health care provider, and by improving patient access to communication with a health care professional [8-10]. Patient portals typically provide the patient with access to their own medical health records documented and managed by a health care institution [8,11]. Other common patient portal functionalities are secured electronic messaging with a health care professional, medication refills, and access to medical information [11]. In addition to the potential positive effect on patient activation, a patient portal may also relieve the need for health services offered through traditional channels, such as phone calls and face-to-face office visits [12].

Along with these positive expectations for the effects of a patient portal, there have also been doubts whether physician or nurse visits can be substituted with self-management and electronic messaging without adverse effects on health outcomes. Some concern has been expressed about the loss of interpersonal relationships between the patient and the caregiver and on the possible worry that seeing one's medical information might cause to the patient [13].

To decide on the adoption and implementation of new self-management tools, practitioners and policy makers need information on how effective—in terms of their impact on patient activation and health outcomes—the tools are relative to their impact on the cost of care provision. Previous studies on electronic patient portals have assessed either their effect on use of other health services [12,14] or their impact on care outcomes [7,15-17]. Limited attention has been paid to the simultaneous assessment of the additional costs and care outcomes of an electronic patient portal compared to standard care, namely the cost-effectiveness of an electronic patient portal. This paper reports the cost-effectiveness evaluation of

an electronic patient portal conducted along with a controlled before-and-after study. To account for possible changes in patient activation and in patient-assessed state of health, we report cost-effectiveness comparisons for both of these care outcomes.

## Methods

### Study Setting, Participants, and the Intervention

The setting was a controlled before-and-after study conducted in Finnish public primary care in 2012 [18]. Patients were recruited to the study by nurses and doctors during their visit to primary care. To be included in the study, patients had to meet the following eligibility criteria: (1) age of at least 18 years, (2) at least two treatable health conditions assessed by a health professional, (3) bank identifiers (ie, electronic credentials for online authentication provided by their bank) and access to the Internet, and (4) be willing and able, both according to themselves and to a health care professional, to engage in using the portal. The eligible patients were allocated either to the intervention group or the control group on the basis of their date of birth. Patients born on odd dates were assigned to the intervention group, and patients born on even dates were assigned to the control group. The ethical board of the local authority (Pirkanmaa Hospital District) approved the study protocol, and informed consent was obtained from all patients included in the study (see Figure 1).

The intervention group received immediate access to the patient portal, and participants in the control group were to receive delayed portal access after 6 months. Each study participant formed a personally tailored care plan together with a health care professional. Whereas the intervention group was given online access to their care plan through the portal, patients in the control group received a printed copy of their plan. In addition to the electronic care plan, the patient portal contained access to (1) the patient's own patient records, provided and maintained by the health care provider with diagnoses of chronic illnesses and permanent medication prescriptions, (2) laboratory results with statements from a health care professional, (3) vaccination history, and (4) electronic messaging with a health care professional. The names of diagnoses, medicines, and laboratory results were linked to relevant additional information in the online medical information service, Health Library [19], administered by The Finnish Medical Society, Duodecim. The users could visit the portal through the care provider's webpages. For secure identification, the patient used his or her bank identifiers to sign in. The patient portal studied was relatively simple as it contained no features for patient-produced information of their health management (eg, see Nagykaldi et al [6]) or interactive condition-specific health education (eg, see Solomon et al [7]).

**Figure 1.** Patient flow.
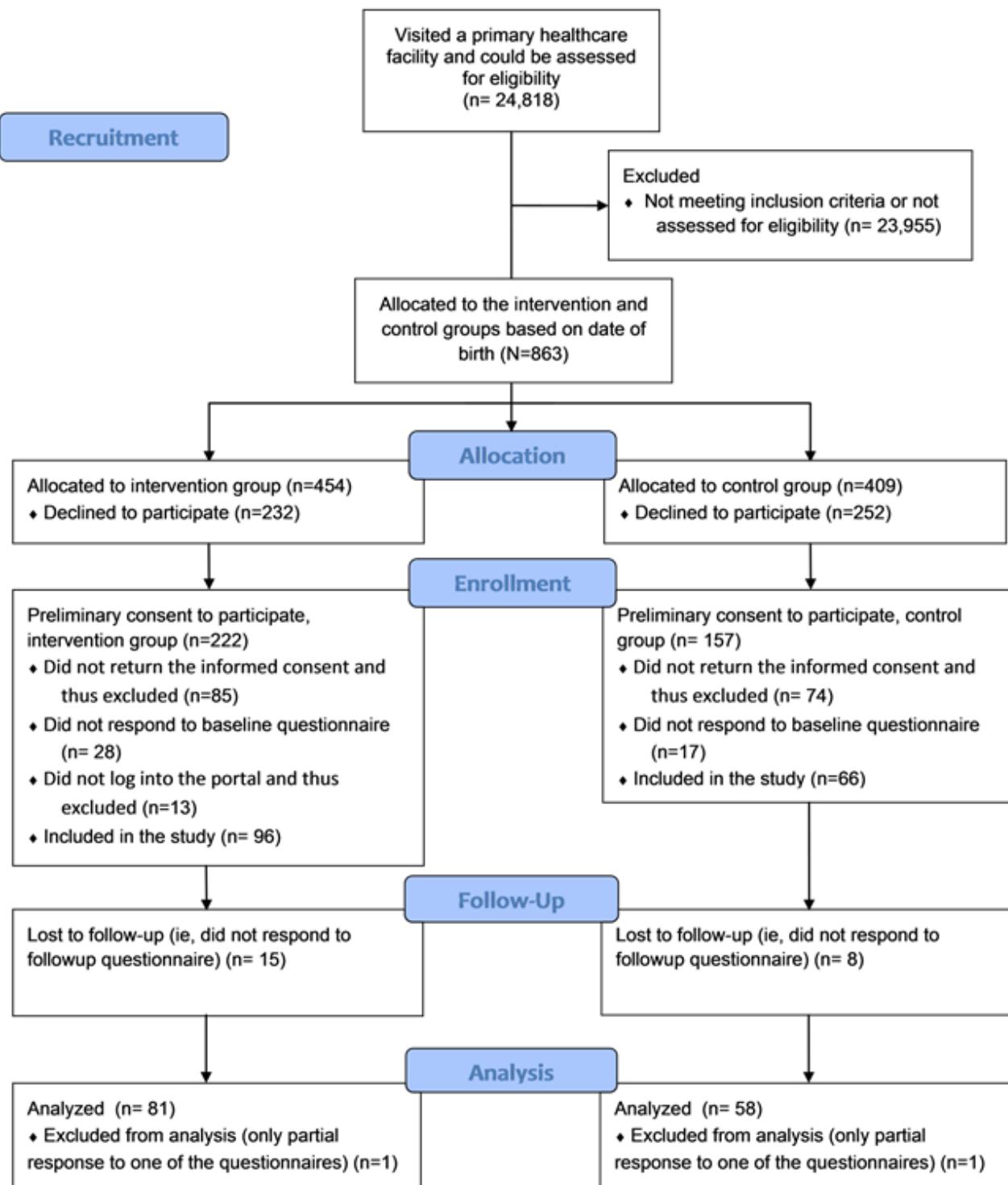


## Materials

### Outcome Data

The first measure of effectiveness in this study was patient activation, assessed using the short form of the Patient Activation Measure (PAM13, see Multimedia Appendix 1). The PAM13 was created by Hibbard and colleagues [20] and measures patients' knowledge of their diseases, skills to self-manage their diseases, and self-confidence in their abilities to manage their diseases. The validity assessment of the Finnish translation for the PAM13 instrument has been reported elsewhere [18]. The instrument consists of 13 statements, which are answered by the respondents with degrees of agreement or disagreement. The raw PAM13 scores (range 13-52) were linearly converted to activation scores ranging from zero (lowest activation) to 100 (highest activation) following established Patient Activation Measure (PAM) methodology [21]. Increases in the patient activation score have been shown to be followed by improved health behaviors [4,22]; thus, the measure can be

used as an intermediate outcome measure for self-management interventions [3].

The second measure of effectiveness was related to health status and quality of life. Here, patients self-assessed their physical and mental health based on the second version of the Short-Form Health Survey (SF-36v2). The Short-Form Health Survey (SF-36) was created by John E Ware and colleagues [23-25] to evaluate patient perception of their physical and mental well-being. In previous registered clinical trials, the SF-36 is the most broadly used instrument for evaluating patient-reported health outcomes in clinical trials [26]. Responses to the SF-36v2 were collected along with the PAM13 questionnaire from both the intervention and control groups at baseline and after 6 months from enrollment in the study. Age, gender, the number of chronic diseases, and the prevalence of the most common chronic conditions in the sample (ie, diabetes, hypercholesterolemia, and hypertension) were retrieved from the electronic patient records.

### Costs and Resource Use Data

The cost of primary health care contacts during the 6 months before the intervention and in the 6 months following were calculated for each individual, as were the costs of providing access to the portal. The use of primary health care resources was collected directly from the patient administration system (PAS), which contained patient-level data abstracts from the electronic patient records. The PAS data included contact types—such as visits, phone calls, or electronic messaging—the patient's age, the diagnoses (International Classification of Diseases, 10th revision [ICD-10]), the reason for the encounter (International Classification for Primary Care, version 2 [ICPC-2]), and the employee category of the health care professional in the contact.

Extracting the patient-level data from the patient administration systems—with diagnosis and activity information—made it possible to group each individual encounter type using the Ambulatory and Primary Care Related Patient Groups (APR) grouper software, a grouping system equivalent to diagnosis-related groups (DRG) used in hospital care [27]. The batch grouper software assigned each individual patient encounter to one of the 144 APR groups. After grouping, each of the 144 APR groups in the sample was assigned a cost weight, indicating the relative consumption of resources. APR cost weights were based on the same standard time measurements which are also used in the national unit price lists for health and social services [28] published by the National Institute for Health and Welfare (THL). The resource consumption of messages sent via the patient portal was also included in the costs. A secure message to the patient using the patient portal was considered to require the same amount of a health care professional's time as sending an email or a letter. Thus, the APR grouper used identical cost weights for these types of contacts.

The cost of providing access to the patient portal for this study was €6 per year per patient. This estimate was based on a 5-year depreciation plan of the portal deployment cost, on the expected average number of users during this period, and on the yearly maintenance cost (see Table 1). The number of patient portal users in 2014 after 2 years from portal adoption was 3527, and the number was expected to grow by 1000 users per year in 2015 and 2016.

**Table 1.** Cost of the patient portal.

| Components of cost | Year | | | | | 5-year average |
|---|---|---|---|---|---|---|
| | 2012 | 2013 | 2014 | 2015 | 2016 | |
| Depreciation of the deployment cost (€) | 3095 | 3095 | 3095 | 3095 | 3095 | 3095 |
| Maintenance cost (€) | 7068 | 11,120 | 11,902 | 12,780 | 13,380 | 11,250 |
| Total cost (€) | 10,163 | 14,215 | 14,997 | 15,875 | 16,475 | 14,345 |
| Number of users, n | 760 | 2315 | 3527 | 4527 | 5527 | 3331 |
| Cost per user (€) | 13.4 | 6.1 | 4.3 | 3.5 | 3.0 | 6.0 |

### Statistical Analysis

To examine the similarity of the intervention and control groups at baseline, we tested for differences in age, gender, number of chronic diseases, prevalence of the most common chronic conditions in the sample (ie, diabetes, hypercholesterolemia, and hypertension), doctor and nurse visits, cost of care, physical and mental health, and patient activation. Independent-sample *t* tests for continuous variables and chi-square tests for categorical variables were used.

Due to the possible selection bias resulting from the nonblinding of the participants [18], we used propensity-score matching [29] to adjust for the baseline differences between the intervention and control groups. Here, the propensity score is the predicted value from logistic regression, with portal access as the dependent variable. Brookhart and colleagues [30] advise to include the variables that may affect the outcomes of interest in the logistic regression. Therefore, in addition to age and gender, baseline measurements for all outcome variables followed; the cost of care, patient activation, and patient-reported health indicators were included in the logistic regression. After calculating the propensity scores, nearest-available matching [29] was used to pair each participant in the control group with a participant in the intervention group based on the propensity score similarities.

To assess the achieved balance between the matched groups, we tested for the standardized differences for each covariate at baseline. Standardized difference is the difference in means between the two groups in units of standard deviation [31]. A value of less than 20% is considered to indicate an adequate

balance and therefore good comparability between the groups [29].

To assess cost-effectiveness of the intervention, we used nonparametric bootstrapping to simulate 1000 incremental cost-effectiveness ratios (ICERs) for both the matched and nonmatched samples and plotted them on a cost-effectiveness plane. This method is widely used in health economics evaluations (eg, see Bos et al [32] and van Spijker et al [33]) to study the health effects of an intervention in relation to the cost of care induced by the intervention [34]. Here, ICER is the ratio between the incremental cost and the incremental effectiveness, which can be changes in patient activation or in health status. Each bootstrapped ICER falls into one of the four quadrants of the cost-effectiveness plane where differences in average effectiveness are displayed on the x-axis and differences in average costs on the y-axis. The quadrants represent four possible situations in relation to the incremental cost and incremental effectiveness of the intervention in comparison with care as usual. The proportion of bootstrapped ICERs that fall into a quadrant indicates the likelihood of the outcome represented by the quadrant. In addition to the cost-effectiveness plane, we calculated the cost-effectiveness acceptability curves (CEACs) for patient portal cost-effectiveness [35]. The acceptability curve indicates the probability for cost-effectiveness of the intervention at different levels of willingness to pay for the additional health outcome [36].

## Results

### Descriptive Characteristics

There were no significant differences in the baseline characteristics between the intervention and control groups (see Table 2). A slightly greater proportion of the patients in the intervention group were women (45/80, 56%) compared to the control group (26/57, 46%). The mean cost of care during the year before the intervention was somewhat higher for the intervention group (€935) in comparison to the control group (€756). Patient-reported physical and mental health and patient activation at baseline were similar in both groups.

**Table 2.** Descriptive characteristics of study participants.

| Characteristic | Portal access (n=80) | Control (n=57) | $t_{135}$ | $\chi^2_1$ | $P$ |
|---|---|---|---|---|---|
| Age (years), mean (SD) | 61 (9) | 63 (10) | -0.8 | | .40 |
| Female, n (%) | 45 (56) | 26 (46) | | 1.5 | .22 |
| Number of chronic diagnoses[a], mean (SD) | 1.3 (1.3) | 1.4 (1.4) | -0.6 | | .53 |
| **Diagnosis, n (%)** | | | | | |
| Type 1 or 2 diabetes[a,b] | 32 (40) | 22 (39) | | 0 | .87 |
| Hypertension[a,c] | 22 (28) | 21 (37) | | 1.3 | .25 |
| Hypercholesterolemia[a,d] | 37 (46) | 24 (42) | | 0.2 | .63 |
| Doctor visits[e], mean (SD) | 3.8 (3.3) | 3.0 (3.1) | 1.4 | | .18 |
| Nurse visits[e], mean (SD) | 3.5 (2.6) | 4.1 (2.5) | -1.3 | | .18 |
| Cost of care[e] (€), mean (SD) | 935 (767) | 756 (528) | 1.5 | | .13 |
| Patient activation, mean (SD) | 63.7 (15.4) | 63.4 (14.5) | 0.1 | | .89 |
| SF-36v2[f] Physical Health subscale, mean (SD) | 65.9 (19.3) | 63.8 (20.6) | 0.6 | | .55 |
| SF-36v2 Mental Health subscale, mean (SD) | 72.8 (21.1) | 73.5 (19.6) | -0.2 | | .85 |

[a]From the time before the beginning of the intervention.

[b]International Classification of Diseases, 10th revision (ICD-10) codes E10-E14 or International Classification for Primary Care, version 2 (ICPC-2) codes T89-T90.

[c]ICD-10 codes I10-I15 or ICPC-2 codes K85-K87.

[d]ICD-10 code E78 or ICPC-2 code T93.

[e]During the year before the intervention.

[f]SF-36v2: Short-Form Health Survey, version 2.

### Propensity-Score Matching

The matching reduced the sample size to 114 participants, with 57 participants in each of the intervention and control groups. Before matching, the standardized difference was over 20% for two of the covariates, namely gender and cost of care. After matching, this statistic was below 15% for each covariate, suggesting that the matching was successful (see Table 3). Standardized difference calculations for variables were based on Austin [37].

**Table 3.** Covariables at baseline before and after matching.

| Characteristic | Before matching | | | After matching | | |
|---|---|---|---|---|---|---|
| | Portal access (n=80) | Control (n=57) | Standardized difference[a] | Portal access (n=57) | Control (n=57) | Standardized difference[a] |
| Female, n (%) | 45 (56) | 26 (46) | 21.2 | 26 (46) | 26 (46) | 0 |
| Age, mean (SD) | 61 (9) | 63 (10) | -14.4 | 63 (7) | 63 (10) | 4.9 |
| Cost of care[b] (€), mean (SD) | 584 (516) | 468 (377) | 25.8 | 455 (327) | 468 (377) | -2.8 |
| Patient activation, mean (SD) | 63.7 (15.4) | 63.4 (14.5) | 2.3 | 65.2 (15.7) | 63.4 (14.5) | 12.3 |
| Physical health, mean (SD) | 65.9 (19.3) | 63.8 (20.6) | 10.4 | 63.7 (20.1) | 63.8 (20.1) | -0.4 |
| Mental health, mean (SD) | 72.8 (21.1) | 73.5 (19.6) | -3.4 | 73.1 (21.1) | 73.5 (19.6) | -1.7 |

[a]Standardized difference for continuous variables = $100(x_i-x_c)/(s_i^2+s_c^2)^{1/2}$, where $x_i$ and $x_c$ are sample means in the intervention and control groups, respectively, and $s_i^2$ and $s_c^2$ are sample variances in the intervention and control groups, respectively. Standardized difference for dichotomous variables = $100(P_i-P_c)/\{[P_i(1-P_i)+P_c(1-P_c)]/2\}^{1/2}$ where $P_i$ and $P_c$ denote the prevalence or mean of the dichotomous variable in treated and untreated subjects, respectively [37].

[b]During 6 months before the intervention.

## Unadjusted and Adjusted Effects of Portal Access on Cost of Care, Patient Activation, and Patient-Reported Health

In both matched and unmatched samples, none of the incremental changes in effectiveness measures and cost were statistically significant. In the adjusted sample, the incremental change in costs due to the intervention was €45 (95% CI -94 to 183), whereas in the unadjusted sample the incremental change in costs changed sign, being -€94 (95% CI -253 to 65). Results on patient activation and patient-reported health were less sensitive to the matching. The mean change in the patients' activation score was 2.8 points (95% CI -2.2 to 7.8) higher in the intervention group, compared to the control group in the adjusted sample, and 2.6 points (95% CI -1.8 to 7.1) higher in the intervention group, compared to the control group in the

unadjusted sample. The difference of 4-5 points in patient activation is considered clinically meaningful in terms of patients' health behavior [38,39]. The proportion of patients with clinically meaningful change (≥5 points) in patient activation was 7.0% higher in the intervention group in the matched sample and 5.7% higher in the intervention group in the unmatched sample. Differences in patient-reported physical and mental health changes were minor and changed sign from the matched (Physical Health, mean 1.2, 95% CI -3.3 to 5.7; Mental Health, mean 0.8, 95% CI -3.6 to 5.2) to the unmatched sample (Physical Health, mean -0.4, 95% CI -4.7 to 3.9; Mental Health, mean -0.4, 95% CI -4.8 to 4.0). Previous studies on the SF-36 Physical and Mental Health subscales have suggested a change of 4-5 points to be clinically significant in these measures [40,41] (see Table 4).

**Table 4.** Changes in outcome measures and incremental change due to the intervention: matched and unmatched samples.

| Outcome | Portal access, matched (n=57) | Portal access, unmatched (n=80) | Control (n=57) | Incremental change, matched sample (n=114) | Incremental change, unmatched sample (n=137) |
|---|---|---|---|---|---|
| Cost of care (€)[a], mean difference (95% CI) | 39 (-61 to 140) | -99 (-215 to 16) | -9 (-106 to 89) | 48 (-91 to 186) | -91 (-250 to 68) |
| Patient activation, mean difference (95% CI) | 1.2 (-2.3 to 4.8) | 1.1 (-1.8 to 3.9) | -1.6 (-5.2 to 2.1) | 2.8 (-2.2 to 7.8) | 2.6 (-1.8 to 7.1) |
| Patient activation, proportion of responders[b], n (%) or % | 20 (35) | 27 (34) | 16 (28) | 7.0 | 5.7 |
| Physical Health score, mean difference (95% CI) | -0.6 (-4.2 to 3.1) | -2.2 (-5.4 to 0.9) | -1.8 (-4.5 to 0.9) | 1.2 (-3.3 to 5.7) | -0.4 (-4.7 to 3.9) |
| Mental Health score, mean difference (95% CI) | 2.1 (-1.0 to 5.1) | 0.9 (-2.1 to 3.8) | 1.3 (-1.9 to 4.5) | 0.8 (-3.6 to 5.2) | -0.4 (-4.8 to 4.0) |

[a]Difference in cost of care 6 months before and after the intervention.

[b]Improvement of ≥5 points (scale 0-100).

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## The Cost-Effectiveness Analysis

The cost-effectiveness plane for patient activation after patient portal access shows greater uncertainty for the cost-effectiveness of the intervention in the matched sample compared to the unmatched sample. In the matched sample, 67.4% of the bootstrapped ICERs fall into the northeast quadrant, indicating increased activation at an incremental cost. In addition, 19.2% of the points fall into the southeast quadrant, 5.4% into the southwest quadrant, and 8.0% into the northwest quadrant. In the unadjusted sample, 71.9% of the simulated ICERs fall into the southeast quadrant, indicating that increased activation was generated with less cost by the intervention in comparison with care as usual (dominance). In addition, 9.4% of the ICERs fall into the northeast quadrant, suggesting increased activation at incremental cost, and 17.5% into the southwest quadrant, suggesting decreased activity at a lower cost. Only 1.2% of the data points fall into the northwest quadrant, suggesting a very small probability for decrease in patient activation at an incremental cost (see Figure 2).

The incremental cost-effectiveness acceptability curve (see Figure 3) for the matched sample shows that at a willingness to pay €18 per 1-point increase in patient activation, there is a 50% probability that the intervention is cost-effective. At a willingness to pay €40 per 1-point increase, the probability is 70%. In the unadjusted sample, at no willingness to pay for incremental patient activation points, the probability of intervention cost-effectiveness is 89%.

We also conducted a cost-effectiveness analysis for the proportion of clinically significant changes in patient activation (≥5-point increase). The results were parallel with the analysis for a 1-point increase in patient activation. In the adjusted sample, a majority (61.1%) of the bootstrapped ICERs fall into the northeast quadrant, indicating increased activation at an incremental cost. In the unadjusted sample, 57.7% of the simulated ICERs fall into the southeast quadrant, indicating that increased activation was generated for less cost by the intervention, in comparison with care as usual (dominance) (see Multimedia Appendix 2A). The incremental cost-effectiveness acceptability curve (see Multimedia Appendix 2B) for the adjusted sample shows that at a willingness to pay €700 per clinically significant change in patient activation, there is over 50% probability that the intervention is cost-effective. At a willingness to pay €2100 per clinically significant change in patient activation, the probability of cost-effectiveness rises to 70% in the adjusted sample. In the unadjusted sample, the probability of cost-effectiveness is 89% at a willingness to pay €0 per clinically significant change in patient activation. At a willingness to pay €2000 per clinically significant change in the PAM13, the acceptability was still as high as 82% in the unadjusted sample.

The cost-effectiveness planes for physical and mental health scores after patient portal access showed similar percentages of ICERs in the right-hand and left-hand quadrants, which confirms that there was no difference in these outcome measures between the intervention and care as usual (see Multimedia Appendices 2C and Multimedia Appendices 2D).

**Figure 2.** Distribution of bootstrapped incremental costs and activation with and without propensity-score matching adjustment.
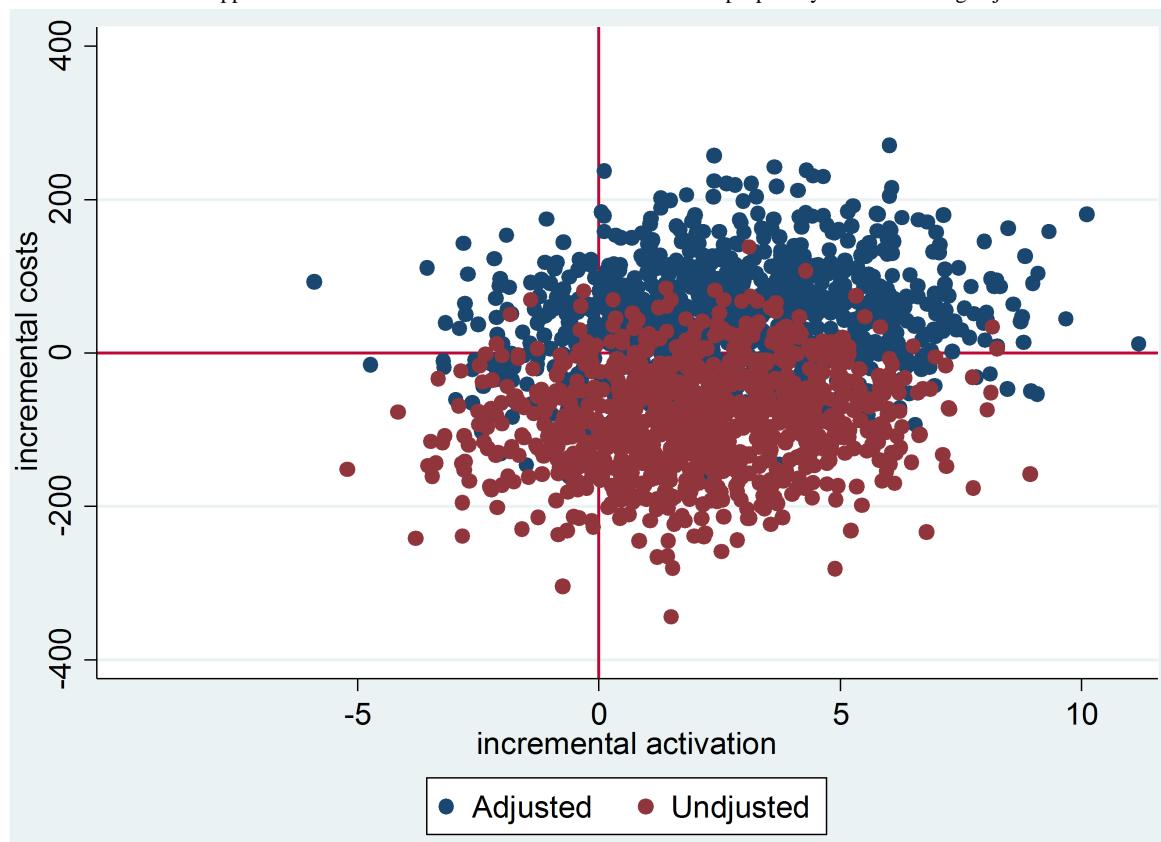
**Figure 3.** ICER acceptability curve based on willingness to pay for clinically significant change in patient activation gain.
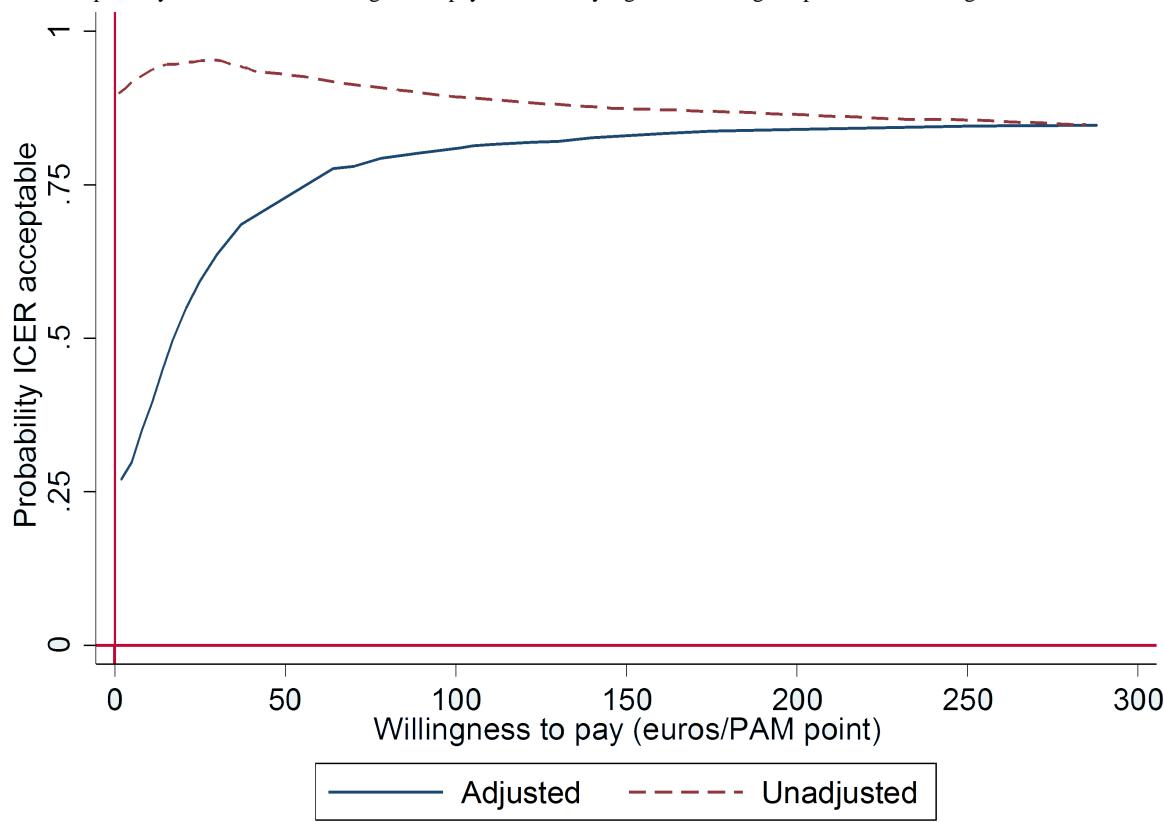


## Discussion

### Principal Findings

While patient activation increased more in the intervention group than in the control group, no significant effect of access to the patient portal on patient activation was detected in this study. This finding differs from previous findings on electronic patient portals [6,7]. Previous studies have also shown decreases in face-to-face visits due to patient portal use [6,12,42]. In this study, however, the effect of the portal access on cost of care was ambiguous, changing from more to less costly depending on the model used. Patient activation improved in both intervention and control groups. A plausible explanation for this may be the additional intervention delivered to both the intervention and control groups, namely the drafting of the care plan. Another explanation could be the patient activation survey itself, as it might encourage patients to rethink their role in the management of their condition.

Empirical investigations on electronic patient portals have predominantly assessed either their effect on the use of other health services [12,14] or their impact on care outcomes [7,15-17]. Only a few studies have assessed both the effects on care outcomes and service use [6] and, to our knowledge, this is the first study to assess the cost-effectiveness of a patient portal.

The results of the cost-effectiveness analysis, in which both effects on patient activation and cost of care were assessed simultaneously, show some support for the cost-effectiveness of a simple electronic patient portal that provides patients access to their own health records and secure messaging with the health care provider. Although no statistically significant improvement (>90% probability) in cost-effectiveness was detected in the sample adjusted for plausible attrition bias, the results indicated over 50% probability for cost-effectiveness of the intervention at a willingness to pay €18 per 1-point increase in the patient activation score. For a clinically significant improvement in patient activation, that is, a more than 5-point increase in patient activation score, the probability exceeded 50% probability at €700 per clinically significant change. To assess whether these investments in patient activation are acceptable from the service provider's perspective, information on the consequences of the improvements in patient activation are needed.

In previous research, an increase in activation score has been shown to result in improved self-management behavior [4] and better health outcomes [3]. Further, an association between low patient activation and high cost of care [43], as well as between high patient activation and low cost of care after 2 years of activation assessment [44], have been found. Although the causal relationship between patient activation change and the change in cost of care has not been studied to date [44], increased patient activation may, indeed, decrease cost of care in the long term. These findings suggest that monetary investments in activating patients may well be acceptable in terms of the achieved patient activation and the proposed following health outcomes. Further longitudinal studies are needed to set acceptable thresholds for willingness to pay for improvements in patient activation.

### Strengths and Limitations

The main strengths of this study are the experimental setting with longitudinal design, the simultaneous assessment of cost

and effectiveness of the intervention, and the use of scientifically validated measures for assessment of (1) patient-reported health outcomes (SF-36v2) and (2) patient activation (PAM13). Patient activation serves as "an intermediate outcome of care that is measurable and linked with improved [health] outcomes" [3].

Our study also has several limitations. As the service was to be offered in a timely manner to all of the customers of the target-study organization, time periods for the recruitment and follow-up were limited. Sample size remained modest, and this likely reduced the statistical significance of the effects. Further, the 6-month follow-up period might have been too short to capture the full benefits of the portal. According to the professionals working in the study organization, both professionals and patients spent part of the intervention time learning how to use the portal effectively, despite the fact that a small-scale pilot study with a restricted group of patients had been organized to test the portal before this investigation began.

In this study, the patients and the study recruiters (nurses and physicians) could not be blinded from the allocation of the participants to the intervention and control groups, and this has plausibly caused attrition bias in the study arms [18]. Whereas blinding the patients from receiving the intervention would solve the attrition bias problem, it may be challenging to execute in a self-management intervention study where patients are active participants in the intervention and when informed consent from the patient is required for ethical approval. In Web-based intervention studies, Samoocha and colleagues [45] suggest the use of "sham" websites to blind participants from not receiving the actual intervention. In this study, a "sham" portal could not be offered for practical reasons. To control for the plausible attrition bias [18], propensity-score matching, a widely used statistical method for reducing the effects of confounding in observational studies [37], was applied.

In this study, socioeconomic factors were not controlled for and this may compromise the generalization of the study findings in populations with highly varying socioeconomic status. Sarkar and colleagues [46] found that patients with lower levels of education may be less likely to use patient portals. In this study, each eligible participant was explicitly offered access to the portal and support for portal use was available, if needed. This may have mitigated some differences in patients' ability and willingness to participate and use the portal. The usability of the portal or patient perceptions of the portal content were not assessed in this study. Further research should address the implementation of patient portals in health service organizations and assessments of patient and care team perceptions of the portal to better understand why some patient portals may be cost-effective and some not. Similarly, further research should investigate who benefits most from access to and use of patient portals. A previous study published on this topic found that the portal had the greatest effect on activation among patients starting at the highest level of patient activation [18]. It has also been reported previously [47] that previous care received by the patient, rather than state of health, age, gender, or patient activation, is an important factor predicting the attractiveness of electronic patient portal use. Among patients with similar disease burden, those who chose not to use the portal had received more services from primary care in the previous year than those who had used the portal [47].

Finally, when assessing cost of care, only the costs for the providing primary care organization could be assessed in this study. Access to an electronic patient portal may also have a comparative advantage in terms of opportunity cost to the patients' time.

## Conclusions

In this controlled before-and-after study with 6-month follow-up, the effect of an electronic patient portal with secured messaging on an intermediary health outcome, patient activation, and cost of care were assessed to evaluate the cost-effectiveness of the intervention. The results suggest that a patient portal with secured messaging may be more cost-effective than care as usual among chronically ill patients. Considering the favorable effect of patient activation on patients' final health outcomes and cost of care shown in previous research, increased patient activation was gained with moderate cost in this study. Further, no reverse effect of the intervention on patient-reported health was detected.

As efforts are made to increase patients' active participation in the management of their own care, suitable and valid measures for assessing the short-term effectiveness of self-management interventions, such as the Patient Activation Measure, are needed. These measures for "intermediary health outcomes" should be validated by longitudinal studies with several years of follow-up that can grasp the causalities between both the intermediary and final health outcomes, and between the intermediary health outcomes and cost of care. This will aid in setting acceptable thresholds for willingness to pay for intermediary health outcomes.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

The short form of the Patient Activation Measure (PAM13).

[PDF File (Adobe PDF File), 26KB - jmir_v17i11e250_app1.pdf ]

## Multimedia Appendix 2

(A) Distribution of bootstrapped incremental costs and proportion of significant changes in activation with and without propensity-score matching adjustment. (B) ICER acceptability curve based on willingness to pay for a clinically significant change in patient activation gain. (C) Distribution of bootstrapped incremental costs and Mental Health subscale score with and without propensity-score matching adjustment. (D) Distribution of bootstrapped incremental costs and Physical Health subscale score with and without propensity-score matching adjustment.

[PDF File (Adobe PDF File), 203KB - jmir_v17i11e250_app2.pdf ]

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## Abbreviations

**APR:** Ambulatory and Primary Care Related Patient Group
**CEAC:** cost-effectiveness acceptability curve
**DRG:** diagnosis-related group
**ICD-10:** International Classification of Diseases, 10th revision
**ICER:** incremental cost-effectiveness ratio
**ICPC-2:** International Classification of Primary Care, version 2
**PAM:** Patient Activation Measure
**PAM13:** the short form of the Patient Activation Measure
**PAS:** patient administration system
**Pc:** the prevalence or mean of the dichotomous variable in untreated subjects
**Pi:** the prevalence or mean of the dichotomous variable in treated subjects
**sc2:** sample variance in control group
**SF-36:** Short-Form Health Survey
**SF-36v2:** Short-Form Health Survey, version 2
**si2:** sample variance in intervention group
**THL:** National Institute for Health and Welfare
**xc:** sample mean in control group
**xi:** sample mean in intervention group

<u>Original Paper</u>

# The Impact of an eHealth Portal on Health Care Professionals' Interaction with Patients: Qualitative Study

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## *Abstract*

**Background:**    People who undergo weight loss surgery require a comprehensive treatment program to achieve successful outcomes. eHealth solutions, such as secure online portals, create new opportunities for improved health care delivery and care, but depend on the organizational delivery systems and on the health care professionals providing it. So far, these have received limited attention and the overall adoption of eHealth solutions remains low. In this study, a secure eHealth portal was implemented in a bariatric surgery clinic and offered to their patients. During the study period of 6 months, 60 patients and 5 health care professionals had access. The portal included patient information, self-management tools, and communication features for online dialog with peers and health care providers at the bariatric surgery clinic.

**Objective:**    The aim of this study was to characterize and assess the impact of an eHealth portal on health care professionals' interaction with patients in bariatric surgery.

**Methods:**    This qualitative case study involved a field study consisting of contextual interviews at the clinic involving observing and speaking with personnel in their actual work environment. Semi-structured in-depth interviews were conducted with health care professionals who interacted with patients through the portal. Analysis of the collected material was done inductively using thematic analysis.

**Results:**    The analysis revealed two main dimensions of using an eHealth portal in bariatric surgery: the transparency it represents and the responsibility that follows by providing it. The professionals reported the eHealth portal as (1) a source of information, (2) a gateway to approach and facilitate the patients, (3) a medium for irrevocable postings, (4) a channel that exposes responsibility and competence, and (5) a tool in the clinic.

**Conclusions:**    By providing an eHealth portal to patients in a bariatric surgery program, health care professionals can observe patients' writings and revelations thereby capturing patient challenges and acting and implementing measures. Interacting with patients through the portal can prevent dropouts and deterioration of patients' health. However, professionals report on organizational challenges and personal constraints related to communicating with patients in writing online. Further development of guidelines and education of health care professionals about how to handle, prioritize, communicate, and facilitate patients online is required in addition to increased attention to the organizational infrastructures and incentives for enabling such solutions in health care.

**KEYWORDS**

## Introduction

Given the limited time for face-to-face consultations, health care professionals and patients experience considerable challenges in setting priorities to address clinical concerns. New approaches to organize and deliver health services are being explored and eHealth technologies are one of the key elements to address this. Promises about improved cost-effectiveness by the use of such may reduce the pressure on the health care system and improve the quality of care for the recipients [1-3].

### Weight Loss Surgery

The number of people suffering from obesity and obesity-related comorbidities has increased significantly the last couple of decades [4,5] entailing enormous economic and health costs [6]. The effects of obesity are reversible and have led to a rising demand for weight loss interventions [4,7-9]. Bariatric surgery (weight loss surgery) is currently one of the most effective interventions to produce initial weight reduction [7,10] and the number of performed surgeries has increased dramatically over the past decade [7,8]. Most surgeries nowadays are performed with short hospital stays. A number of aspects prove that this is both cost-effective and considered beneficial for the individual [9,11,12]. Bariatric surgery procedures are no exception because patients are procedurally discharged a couple of days after surgery if no complications have incurred [11]. Accordingly, the outcomes depend on the patients' adherence to recommended treatment regimens and on their abilities for self-care management.

### Challenges Related to Bariatric Surgery

Even though bariatric surgery is one of the most effective interventions to produce initial weight reduction, there are many challenges related to the treatment. Patients commonly experience difficulties, particularly the first period after surgery because of the immediate impact of the surgical procedure on their physical well-being. The purpose of the surgery is to restrict food intake and involves removing and bypassing parts of the intestine. The operation contributes to reduced absorption, leading to poor digestion and reduced nutritional uptake. As a consequence, the patients must follow a particular dietary regimen and, in some cases, are required to take lifelong vitamin supplements to prevent nutritional deficiencies with severe outcomes [13-16].

The surgery alone does not suffice to achieve successful outcomes; the patients need to change their lifestyle, addressing dietary habits and physical activity in order to accomplish results [17,18]. Research shows that bariatric surgery patients experience challenges after some time because the recommended lifestyle and behavior changes are difficult to maintain [19,20] and many patients regain weight [20-24]. The underlying reasons for weight regain are multifactorial: the causative factors are patient-related (mental health and behavior) and surgery-related (anatomical alterations and complications) [25]. Weight regain is an important public health issue with significant consequences to the patient as to the recurrence of obesity-related comorbidities and to the health care system due to the economic costs of obesity and societal impacts of recalcitrant obesity. In an effort to manage and prevent weight regain, an organized and systematic approach is essential [25].

Most bariatric surgery clinics offer some kind of follow-up to their patients; these are typically telephone conversations, individual face-to-face consultations, or group-based meetings. However, this group of patients commonly experience stigma and shame [26,27], and restrain from making contact with health care professionals trough traditional means, such as by telephone or meeting in person [28]. In worst-case scenarios, this might result in fatal consequences because complications or other challenges might not be acknowledged and adequately handled. Therefore, the need to facilitate bariatric surgery patients in connection to their treatment program is critical to provide sufficient health care delivery and clinical care to this patient group. Toussi et al [20] pointed out that having more contact with patients and requiring adherence to behavioral changes, especially with respect to exercise and dietary restrictions, may improve the long-term outcomes for bariatric procedures.

### eHealth Portals in Health Care

eHealth solutions, such as secure online portals, hold great potential if offered to patients in conjunction with their treatment program because they create new opportunities for improving health care delivery and follow-up of clinical care [1,29]. eHealth portals offer a number of potential benefits to providers, including administrative efficiencies, improved responsiveness to patients' needs, decreased utilization of health services, more effective care, and cost savings [30]. Despite the potential advantages, the adoption of eHealth solutions and portals has been low [30,31]. The success depends on the degree of acceptance by its users, where health care professionals are key stakeholders to adoption and use [32,33]. A number of barriers to adoption have been identified, such as concerns about costs, added workload and workflow demands, technology literacy, liability issues, and confidentiality and privacy risks [30,34,35]. To our knowledge, few studies have explored Internet-based tools such as eHealth portals in bariatric surgery. A number of studies have been done in other areas of chronic disease management, such as in diabetes care, chronic obstructive pulmonary disease (COPD), and asthma [36-41]. eHealth portals in diabetes and COPD show that access to information and support via online patient-centered tools improves patient engagement and health outcomes, but there are unclear results when it comes to the effectiveness of follow-up [37,38]. In diabetes care, studies show that providers often are reluctant to adopt these technologies due to lack of knowledge about the Internet or information technology systems [40,42]. There are few, if any, studies exploring health care providers' perspectives on the use of eHealth portals in bariatric surgery. Because the impact and success of such solutions depends on the organizational delivery systems and the professionals' acceptance and adaptation of the solutions, the need to explore their views is important.

### Objective

The objective of this study was to characterize and assess the impact of an eHealth portal on health care professionals' interaction with bariatric surgery patients. The aim was to develop a better understanding and insights relevant for using

such solutions for health care delivery and care in bariatric surgery programs.

## Methods

### Study Setting

In this research project, an eHealth portal for bariatric surgery patients was established in 2011 in collaboration with a bariatric surgery clinic in Norway. The portal was developed through a human-centered development process [43] and according to the security and privacy concerns that are required for such solutions in Norway. Access to the portal required log-on procedures with username, password, and entering of a one-time personal identification number (PIN) sent to the user's mobile phone. The features of the eHealth portal included:

1. Patient information (eg, validated information about the surgery, pre- and postsurgical recommendations, food and diet, nutritional facts, lifestyle recommendations, physical activity)
2. Self-management tools (eg, personal diary, calendar, reminders via short message service [SMS] text messaging)

3. Communication features (for dialog with peers and providers)
4. Online discussion forum
5. Personal messaging

The eHealth portal (Figure 1) was implemented in the bariatric surgery clinic, where 5 health care professionals (all women; 2 nurses, 1 clinical dietician, 1 psychiatric nurse, and 1 administrative leader) at the clinic received access to facilitate the patients and respond to their requests. In addition, one person from the research team, educated in nursing, had the overall responsibility to moderate the forum and could comment on postings that were within her field of competence. The patients received access to the eHealth portal for approximately 6 months. In total, 60 bariatric surgery patients (75%, 45/60 women and 25%, 15/60 men) received access and 80% (48/60) of them logged on to the system one time or more. The study was approved by the Regional Ethics Committee [44] and by the Norwegian Social Science Data Service [45]. All participants provided written informed consent when included to the study.

**Figure 1.** Screenshot of the eHealth portal.



### Data Collection and Analysis

Data collection involved a field study and in-depth interviews with health care professionals. The field study was conducted at the clinic, consisting of contextual interviews with professionals at the clinic during the 6-month study period. Such interviews involve observing the people in their actual work environment and speaking with them about their work and actions [46]. The contextual interviews typically lasted 20 to 60 minutes, were informal, and notes were taken. At the end of the study period, the 5 health care professionals were requested to give in-depth interviews [47], but not all could participate. Semi-structured in-depth interviews were conducted with 3

health care professionals. The interviews were conducted in Norwegian, lasted 1 hour each, were sound recorded, and transcribed verbatim before analysis. The two first authors conducted the analysis, which was done inductively using thematic analysis, and used English terms and concepts. HyperRESEARCH software was used to facilitate the process, involving a stepwise process in which both researchers reviewed the material and created codes individually. Next, the codes were collated and concepts were generated in a mutual process. These were compared, contrasted, and discussed in light of relevant literature and theory, and the final themes were achieved via consensus. The quotes in this paper are translated

from Norwegian to English and the names reported are pseudonyms.

# Results

The analysis revealed two main dimensions of using an eHealth portal in bariatric surgery: the transparency it represented and the responsibility that followed by providing it. The personnel reported the eHealth portal as (1) a source of information, (2) a gateway to approach and facilitate the patients, (3) a medium for irrevocable postings, (4) a channel to expose responsibility and competence, and (5) a tool in the clinic.

## The eHealth Portal as a Source of Information

The health care professionals reported the eHealth portal to be a source of information in regards to gaining awareness about the unique challenges of the individual patients and as a learning source about the group of bariatric surgery patients. With access to the portal, the patients could write and post whatever they wanted, whenever they wanted. Most of their postings were stories and narrations about personal experiences; they shared thoughts about daily ups-and-downs, often without specific questions requiring attention. Some patients used the online forum as an arena to post their "personal diaries." The professionals reported that the length of the postings and/or the number of threads related to a particular topic could signify a problem that needed attention; therefore, they read most postings even though they were not addressed to them in particular. "Linda" described "reading between the lines" to identify if anything was out of the ordinary: "Even though it's there as part of a diary, and there is not a single [direct] question there, you understand that something isn't how it should be." During the field study, we observed how she handled such postings: if she considered that the patient needed facilitation by the clinic, she would approach the patient by sending a personal message through the portal to identify if there were issues that needed further investigation. All professionals who had access to the portal reported that they were surprised about the vast and rich amount of information about the patients that became available through the portal. Some issues and themes were recurring, posted by several patients, signifying what information this group of patients searched for and needed:

> We have learned a lot as well. So we need this type of patient contact. [Linda]

The patients posted a great number of questions; some were meant for their peers, others were addressed to the health care professionals. The professionals reported becoming aware of issues they previously had not considered significant. They knew that the patients experienced challenges in adjusting their lifestyle, but they were not aware of how complicated this turned out to be. The insights that became evident by reading the postings concerned the patients' unique experiences postsurgery, the psychosocial aspects that came to pass, and the enormous challenges they experienced related to the new lifestyle and diet. These understandings benefited the patient group:

> We can capture the information they write. In addition, we can learn a bit more about how to facilitate the patients. [Bente]

The information they attained was important for their occupational behavior, knowing what to emphasize in contact with the patients:

> In relation to the need of feeling cared for as patients, it is probably useful. And it's educational for us as well. Because learning goes both ways. [Fride]

The knowledge gained was further enabled to customize the patient information and contents in their patient education program.

## The eHealth Portal as a Gateway to Approach and Facilitate the Patients

The eHealth portal worked as a lowered threshold solution for the patients to seek advice, guidance, and help, and as a gateway for the health care professionals to approach and facilitate the patients.

### Lowered Threshold Solution

By following the patients' writings, the professionals got an overall impression about the patients' daily lives as opposed to the selected issues they were presented during time-limited face-to-face consultations:

> But it's obvious that one can capture things in the portal that I cannot capture during a consultation. [Fride]

In the patients' online writing, their information was described in greater detail compared to oral contexts:

> You get more information about them here [online] than on the phone. [Bente]

This was considered to be relevant in order to identify patient symptoms and needs: "...because, in the portal they are more laid back and at home...and they are closer to what is relevant for them there and then."

They found that some patients had difficulties in revealing their actual problems in face-to-face settings:

> Those who come for consultation and sit in that chair and talk to the person in white coat, I don't think it's always that easy for the patient to come with his or her request to me. [Fride]

In the field study, we observed that the patient consultations often ran overtime and other patients were kept waiting. The professionals described that some patients' required significant time during the consultations because they needed time to feel confident and had complex needs. However, because other patients were waiting for their turn, the personnel had to end the consultations even though they knew that the patients had more on their mind. The professionals reported that factors such as time constraints, shame, and fear of stigma could influence the oral dialog and thereby restrict what the patients were comfortable in sharing in face-to-face settings. These issues were not as prevalent for the patients when communicating online. The personnel quickly learned that some patients found it easier to take contact with the clinic through the eHealth portal: "Yes...they give their notice here instead of calling..." Also, they observed that some preferred to express themselves in writing via the portal and, therefore, it became a lowered

threshold solution: "...they are at home, it's easier to send a message online than to call, and that's why we get so many questions."

### Dropouts

When undergoing bariatric surgery, the patients were offered a 5-year follow-up program at the clinic consisting of a combination of group-based and individual outpatient consultations. These consultations occur at specific intervals after surgery: at 3 months, 6 months, and 12 months after surgery, and at yearly intervals for the following 4 years. The health care professionals reported that a number of patients failed to show up to these scheduled (face-to-face) consultations, something we also observed in the field. Even though they rescheduled the appointments, sent letters, and tried to achieve contact by phone, some patients still did not show up, thereby dropping out of the follow-up program. This represented a challenge for the clinic because they were left with no data about the cause or how these patients coped after the surgery. "Linda" observed patients having difficulties in achieving their expected outcomes:

> The operation, it is kind of their last chance. And if they don't succeed with that either...they say that they think, "Oh my God, now I got this operation costing 100,000 NOK, and all that help and follow-up, and still it doesn't work".

The personnel stated that several patients refrained from taking contact with the clinic by traditional means when necessary because of shame:

> If this can be that place where those who struggle and who do not want to show up in person because of shame...because it is shameful not to be able to make it [lose weight], right? One had great expectations and then it did not go as planned...If we can get hold of them through this, then it's really good. Because we want everyone to succeed. [Fride]

As a consequence, the clinic could not follow up and provide health care to patients they perceived needed it:

> In reality, I think that there are more people that struggle than those who say they do. Who need help, and yes...they are ashamed. [Linda]

They detected that some of those who excluded themselves from the traditional follow-up program were active on the website:

> And not everybody who are in here [the portal] makes contact with us by phone...because not everybody, I don't think that everyone that are in here would take contact with us otherwise. [Bente]

"Linda" discovered that one of their patients failed to show up to her scheduled consultations, but posted considerably on the forum. By following her postings, she understood that the patient needed help and initiated contact through the portal. They communicated in private messaging and identified that she needed additional medical investigations and scheduled her for further follow-up to the endocrinologist at the clinic. Later, this patient expressed gratitude about receiving the care she needed

due to the portal because she would not have taken contact with the clinic directly. The portal became an important asset as it represented an additional approach for the professionals to reach out to the patients:

> I think that this can be, if we are going to [continue] using it, then this might be a place where we can get hold of them. The people who do not dear to take contact...yes, or who are to shameful to show up at the traditional programs we offer, to meet in person. [Fride]

## The eHealth Portal as a Medium for Irrevocable Postings

Interacting with patients in writing online was a new way of communicating and represented other aspects than in an oral dialog. "Fride" reported that this signified uncertainty about how to deal with this new kind of interaction:

> I have chosen to read what I have found to be related to my area of competence, and I think that has been okay. Occasionally I have felt that some have disclosed themselves. And I don't know if that is okay.

"Bente" expressed concerns about the degree of self-disclosure she observed: "They expose themselves too much for the others that are in and have access to read..." The personnel were concerned about what the patients exposed online and were equally apprehensive about their own postings:

> It's just that you have to consider that this can be used against you later in some way, it remains there. [Linda]

This was a shared understanding among all the professionals. The awareness about how to communicate online became particularly significant when their posting would be available to many people:

> It is about practice—to practice to write short and concise, and dare to be...not vague. At least I am very afraid of writing to concluding, particularly when I am in such a forum, when it will be standing there written. It gets a lot of readers and you try to ensure that what you write is correct. [Fride]

When online, nonverbal cues, such as body language, tone of voice, and gaze, that were present in face-to-face conversations disappeared. "Fride" contrasted online communication with a face-to-face dialog, where she continuously would assess whether the patient actually understood what she said and the information she provided. When communicating in writing she had to be particularly aware in order to avoid misinterpretations: "And what I said before, that you have to be sure about that what you say is correct, and that it cannot be understood differently."

"Linda" shared this understanding:

> It's okay, but you have to consider what you say, when it's written...I have to be aware about how I articulate myself. It's almost like when you get an SMS from someone, and "What!? Bad mood today, or what is it?" If I talk to them (patients) on the phone for

*instance, I hear if someone misunderstands something. Yes, and that you don't here...have to think carefully, can't just [write].*

She had become used to communicating with family and friends in writing by using SMS text messaging and social media forums, and stated that this transition needed to be undertaken in the professional sphere as well: "Thus, there is something about getting used to communicate this way, and you are in your personal life." All assumed that with time and practice the clinic would adapt to communicating online with their patients.

## The eHealth Portal as a Channel to Expose Responsibility and Competence

According to the professionals, the questions they received online differed from the ones they traditionally received in oral contexts: "Maybe more specific in the portal. And maybe it is those who are interested, or who try [who ask]." The patients' access to other information sources seemed to have an impact:

> *But then the questions here, it's clearly that the questions that have been posted, those are from patients that have read all the information that is available here [in the portal], and they have also talked to others that have undergone surgery.*

Also, the patients' context when articulating the questions influenced the topics:

> *Because here they are at home in peace and quiet, and can use—can get information from other arenas as well obviously...The questions have not only been experiential.* [Linda]

The personnel reported being unprepared for the advanced level of questions they would receive: "Thus, the questions have been really good, often so advanced that we have been required to speak with a specialist." This represented a challenge for the level of expertise required to provide an appropriate response: "...so there have been many questions that I have not been able to answer, have needed to talk to the specialist." They could not refer the patient to another professional through the portal because not everyone at the clinic had access. Neither could they ignore the patients' requests because the presence of unanswered questions could create an impression about not doing their job. As a result, it became necessary to provide high quality answers to the patients' posts. In cases when the personnel having portal access could not respond themselves, they made contact with other professionals at the clinic, such as the physician, physiotherapist, pharmacologist, surgeon, and endocrinologist, to get quality assured information for redistribution to the patients. The fact that they needed to make contact with other professionals became more obvious when using the portal compared to an oral context:

> *Now we get quite some calls about that they have pain or...We can't give the diagnosis [stating her profession] over the phone. And I couldn't have done that here either.* [Bente]

When delivering the response in writing, the caregivers felt obliged to take contact with others to ensure a qualified response:

> *Like "why can't they take NSAIDs?" That resulted in that our pharmacologist didn't want to answer, needed a statement from the chief over there.* [Linda]

"Linda" explained that the activities triggered by this one question required considerable efforts: the process required resources in regards to have expertise in knowing the right addressee, time effort to contact them, have them write a statement, and get the information validated before they could finally post the statement online. In the field study, we observed that the process could take quite some time and effort, which verified the personnel's experiences. Even though the patients' requests were specific, the answers from the professionals would not necessarily correspond in level of detail because they delivered an answer based on the information they had available there and then:

> *When you are in a face-to-face consultation, you have access to much more medical information and about the patients' history, and you aren't supposed to give advice without knowing, without knowing the underlying cause. So it's, call it whatever you want to, but it's a weakness as well, and then you have to give more general advice, less specific advice, because you don't know.* [Fride]

In the field study, we observed that some of the professionals would search the electronic patient record and look up test results if necessary to answer the patients' requests as best as possible. But the professionals experienced that the online communication had its limitation in cases where they found it necessary to go deeper into the matters to provide sufficient help:

> *Particularly those who have posted a lot, then it's preferable that you have read what they have posted before, and not only answer the question. Like the one I just answered, I think it's a lot, and then there is no use to just answer the last one there, then it's better to get them to come to a consultation when [you understand] it's complex.* [Linda]

Therefore, in some instances, the patients' postings worked as triggers for further communication, occasionally leading to face-to-face consultations.

## The eHealth Portal as a Tool in the Clinic

In the beginning, when introducing the portal in the clinic, the professionals expected that it would become an integrated tool in their daily occupational practice. They talked about their intentions for using the portal in peace and quiet, focusing on the patients' posts, and responding to their requests. They assumed that the opportunity to communicate with the patients in an asynchronous manner would give them more flexibility in when to do the work, but the reality turned out to be different from expected and factors such as normal work routines, time constraints, and prioritizations became evident in the daily clinical practice:

> *Then I can sit down whenever I have time, but on the other hand, I probably have shown that I don't have the time, or do other stuff, right? So you need to get accustomed to use it.* [Bente]

The professionals described their work routines to be hasted, characterized by fully booked calendars with appointments and patient consultations, and often interrupted by unexpected telephone calls and other emergent tasks. Thus, their intentions failed to materialize:

> It is just that the days are filled with patient lists, and suddenly it is 4 o'clock, and then you are off to home. We haven't organized the time for it, and we should have. It hasn't been a priority because when a patient is physically here, then you have to attend to him. If the phone rings, you have to pick up. And then this is what we postpone to use. Unfortunately. [Linda]

Enabling a tool that the personnel were unfamiliar with proved to be a restraining factor in getting it integrated into their daily work routines. Using the portal became an extra task in addition to their current duties, which we observed that they prioritized to complete:

> It is the time pressure we have at work, we don't have time for anything. I have to put everything aside, and when I get time I have to catch up [the other work]. So one can say that it has to do with priorities. [Bente]

The lack of incentives became prevalent when using the eHealth portal:

> It does not give us any incomes because we got feedback about that from our boss that if it does not give us any incomes...we have to register it some way. Because our leader go in and check how many patients we have every day. And then surely you get feedback if you haven't reported any patients, then you would have gotten some questions. [Bente]

It was difficult to justify using the portal when they knew that their work was evaluated based on other criteria:

> To be honest, this has not been something I could prioritize. You prioritize those that are on your patient list. Those are the ones you are counted for...how many notes [in the electronic patient record] that are in progress and incomplete and so on. That is something my leaders go inn and check. So that is what you are counted for. [Fride]

The organizational infrastructures and economic incomes that the professionals perceived to be important for getting such a tool integrated into their current work routines were nonexistent at the time of this study. These were reported by the personnel to limit portal use and redeem the opportunities it presented.

## Discussion

### Principal Findings

The findings suggest that health care professionals experience a number of benefits from interacting with bariatric surgery patients through a secure eHealth portal while it also poses a distinct set of challenges. The two dimensions of transparency and responsibility that follows by providing an eHealth portal to this patient group became decisive for how the professionals enabled the portal. The transparency to both the patients' lives and the professionals' online actions influenced the professionals' roles and responsibilities toward the patients. The success of implementing such a portal into bariatric surgery care appears to depend on how confident the professionals are in communicating in writing and using online tools as well as organizational infrastructures and incentives. Yet, such online communication portals may place greater demands on the caregivers because it appears to be a solution that the patients both prefer and benefit from using. Traditional communication arenas between bariatric surgery patients and their health care providers seem to have their shortcomings. Thus, professionals must learn how to communicate online and enable eHealth tools as a complement to traditional care for this patient group in order to follow up and facilitate patients in need and consequently enhance patients' outcomes after treatment.

### Transparency

The eHealth portal provides transparency to the patients' daily life, their challenges, and their needs, and it became an information source about the patient group. The narratives that patients create and share outside the constraints of time-limited consultations can help professionals develop a more comprehensive view of the situation of their patients, thereby enabling them to individualize the care to the patient's particular needs. But the transparency goes both ways: an eHealth portal that make the patients' requests and the health care professionals' postings available for all to read makes professionals spend more time in preparing comprehensive, thought-through answers compared to communicating in oral contexts. This is a fact that is important to consider when introducing additional tasks for the personnel. Given the fact that their postings would remain online and the fear of publishing information that can be perceived as incorrect, results in the professionals acting carefully and deliberately in their online acts and written communication. Also, each health care professional's competence becomes evident when using a written communication form, resulting in that they become particularly aware about what they are eligible and comfortable on posting.

### Responsibility

The online portal represents responsibility to follow up and provide high quality health care to the patients. This become particularly evident for following up the patients' postings because these signalize the professionals' work; if they do not respond, this can signify poor quality and work. The responsibility can be seen at two levels: with the competence and skills to identify the patients' challenges and needs, the professionals are obliged to act and implement measures accordingly. On the second level, the responsibility to provide correct and quality assured information becomes evident when communicating online in writing; it becomes an absolute of no discussion when it stands in text. The fact that the professionals "monitor" the patients by accessing their writings and narrations means that they can identify if and when patients experience signs and symptoms of health deterioration that need professional follow-up and care. Given that the professionals, based on their clinical expertise, can identify patient symptoms and needs at an early stage, makes them responsible to act and implement measures accordingly. The prevention of health

deterioration can have great impact on both the patients' health status and quality of life, and to society as a whole considering the health care expenses of treatment costs and hospitalizations.

## Implications

Bariatric surgery is often a "last chance" solution to patients who have tried and failed various approaches to achieve weight reduction, which leaves them with unrealistic expectations toward the outcomes of surgery [48,49]. The informants report that patients' inadequate adherence to the follow-up program were due to unsuccessful outcomes and shame, resulting in restraints in making contact with the clinic when in need and dropouts. These findings correspond with earlier research that show that inadequate adherence to follow-up programs in bariatric surgery is associated with poor weight loss and maintenance, poorer control of obesity-related comorbidities, and the development of postoperative complications [50]. Attrition to bariatric surgery aftercare and weight loss intervention programs is associated with greater presurgical weight, psychological and behavioral patient factors, processes associated with the treatment, and greater travel distance to the follow-up center [50,51]. The portal proves to be a possible gateway for the professionals to communicate and interact with patients, particularly as a channel to a subgroup of patients who for various reasons do not use traditional communication forms currently in use at the clinic and would have been lost to follow-up. Bariatric surgery patients report that they experience difficulties in communicating with professionals in face-to-face meetings [28]. This underlines the need to offer new solutions. The personnel report that some patients prefer to communicate online rather than face-to-face, which implies that they experienced a benefit of using such an eHealth portal. For those who reject participation in the traditional aftercare program, eHealth portals for online communication can be a substitute and be valuable for addressing clinical needs and care. Adherence to scheduled visits (and compliance to recommended rules) predicts success of bariatric surgery [52], where health care professionals can use eHealth portals in communicating and promoting recommended postsurgical regimens. This might be an additional approach or even a substitute for face-to-face visits to selected patients. Better contact between health care providers and patients may improve the long-term outcomes for bariatric procedures [20]; this study has shown that an eHealth portal can be one approach to achieve this.

Despite the potential advantages of using the eHealth portal, the professionals report a number of organizational challenges, such as time constraints, busy working hours, and lack of incentives as underpinnings for their work. These findings are similar to the ones of Hanberger et al [53] who found that practitioners in diabetes care had a hard time starting to make use of an eHealth portal in their practice due to obstacles such as deep-routed working habits and too many working tasks. Enabling and using the portal was more time consuming than anticipated, a finding that is opposed to previous envisions about more efficient use of clinical time by the use of Web-based tools [54]. The professionals had difficulties in justifying the use of a work tool that did not give the clinic income because, in the end, their occupational behavior depends on giving the clinic sufficient earnings. The lack of incentives drives the prioritization of the personnel's activities and, for increased adoption and use of technology, incentives at both the individual level and organizational level should be considered. At the individual level, remuneration for work efforts can be either financial (eg, reimbursement for activity) or nonfinancial (eg, workload credit for activity) [55]. When introducing a personal health record at the Department of Veterans Affairs, a workload code for secure messaging was implemented to enable workload credit for secure messaging activity, providing incentives at the individual level to foster increased adoption and use of the technology [55].

## Implications for Practice

The findings of this study have demonstrated the feasibility of an eHealth portal for patient care and communication in bariatric surgery, which provides both clinical benefits and challenges. The health care professionals imply that an eHealth portal has great potential and impact in bariatric surgery, but that there are a number of aspects that need to be addressed in order to take full advantage of the benefits. A portal for communicating and interacting with bariatric surgery patients can be a useful complement for most patients, but for selected patients it might be a substitute to traditional postsurgery care. Even though the practitioners are motivated to use the new solution, the fact that they are evaluated by their economic income to the clinic makes them prioritize their work accordingly and the necessity to implement incentives is therefore crucial.

Based on these findings, we present some practical implications that need to be considered when introducing and implementing eHealth portals into clinical practice:

1. Establishment of clinical rationale. Define why and for what purpose the eHealth portal is implemented. What are the major motivations and how should these be communicated to the personnel?
2. Clinical skills and competences. Identify if the personnel have sufficient competencies to identify patients' symptoms and needs. Are other competencies or skills than those currently available required?
3. Decision support and multidisciplinary team. Assess whether the personnel who will facilitate the patients have sufficient decision support. Do they have a multidisciplinary team available for questions?
4. Individual motivation. Explore the personnel's individual motivation. Are the personnel motivated to use the eHealth tools? Are they satisfied with the information, training, etc, they have received in order to enable the solution in an efficient manner?
5. Communication skills. Identify the personnel's competences and experiences with communicating in writing/online. Are the personnel comfortable in communicating in writing? If not, do they need practice or education?
6. Organizational infrastructures. Identify barriers to enable the technology. Do the personnel have time and resources to use the technology? Do they have access to sufficient infrastructures (eg, computers, Internet) and dedicated time when they can use the technology?
7. Clinical workflow. Identify how enabling of the new technology corresponds with the established workflow at

the clinic. Which adjustments are required for satisfying integration between current and new tasks?

8. Incentives. Identify which incentives are required for enabling the technology. Is it necessary with economic incentives? Does it require incentives at the individual or organizational level, or both?

## Study Limitations and Future Work

This study is limited due to its qualitative approach, restricted to a case study, and the results cannot be generalized. The results might be different if other informants were involved, a different patient population, another Web portal, or setting was studied.

In this project, the patients had no restrictions about length, topic, or timing for their postings. Because our findings show that the professionals experienced that the time and competence required for handling the postings were significant, this suggests that more structured forms of communication should be investigated in future projects: patients can fill-in predefined categories or answer a particular set of questions. The need to investigate which categories and contents these should include are subject for future investigations. Also, further studies considering quantitative measures and cost-efficiency studies are required when it comes to eHealth portals in bariatric surgery. Our study reveals that communicating with patients and facilitating them online requires certain clinical skills and competences to capture their symptoms and needs. This underlines that not just anyone can be a moderator and recipient to patient requests, but that it requires particular health education in order for the patients' to be adequately handled. Also, skills in communicating in writing with patients are required when providing such eHealth solutions. The need to acknowledge that these are required competences and educate professionals about how to communicate and interact with patients online is an underestimated issue that needs further attention.

This study revealed a number of aspects that are not directly evident when introducing eHealth portals, but that are extremely important for the tools to be appropriately implemented and adopted in bariatric surgery practices. When considering the use of an eHealth portal in clinical care, the motivation and clinical rationale for the implementation should be established. Our findings imply that the integration of technology into busy working hours requires alignment with clinical workflow, incentives to justify the work, and organizational infrastructures, all crucial and underpinning factors for successful implementation and adaptation of eHealth portals in clinical care.

## Conclusion

The findings of this study show that by providing an eHealth portal to patients in a bariatric surgery program, health care professionals can observe patients' writings and revelations, thereby capturing patient challenges and acting and implementing measures. Interacting with patients through the portal can prevent dropouts and patients' health deterioration, factors that predict the success of the surgery. However, professionals report on organizational challenges and personal constraints related to communicating in writing with patients online. Further guidelines and education of professionals about how to handle, prioritize, communicate, and facilitate patients online is required, in addition to increased attention to organizational infrastructures, incentives, and rationales for enabling eHealth solutions in health care.

## Authors' Contributions

AD, DS, AF contributed in designing the study and preparing the manuscript. AD planned and performed data collection and analysis, and wrote and revised the manuscript. AF performed analysis of collected material and contributed in writing and revising the manuscript. DS critically reviewed the manuscript. All authors approved the final manuscript.

## Conflicts of Interest

None declared.

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## Abbreviations

**COPD:** chronic obstructive pulmonary disease
**PIN:** personal identification number
**SMS:** short message service

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Original Paper

# Usability and Acceptance of the Librarian Infobutton Tailoring Environment: An Open Access Online Knowledge Capture, Management, and Configuration Tool for OpenInfobutton

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## Abstract

**Background:** The Librarian Infobutton Tailoring Environment (LITE) is a Web-based knowledge capture, management, and configuration tool with which users can build profiles used by OpenInfobutton, an open source infobutton manager, to provide electronic health record users with context-relevant links to online knowledge resources.

**Objective:** We conducted a multipart evaluation study to explore users' attitudes and acceptance of LITE and to guide future development.

**Methods:** The evaluation consisted of an initial online survey to all LITE users, followed by an observational study of a subset of users in which evaluators' sessions were recorded while they conducted assigned tasks. The observational study was followed by administration of a modified System Usability Scale (SUS) survey.

**Results:** Fourteen users responded to the survey and indicated good acceptance of LITE with feedback that was mostly positive. Six users participated in the observational study, demonstrating average task completion time of less than 6 minutes and an average SUS score of 72, which is considered good compared with other SUS scores.

**Conclusions:** LITE can be used to fulfill its designated tasks quickly and successfully. Evaluators proposed suggestions for improvements in LITE functionality and user interface.

## Introduction

### Infobutton, OpenInfobutton, Meaningful Use and Librarian Infobutton Tailoring Environment

Studies show that clinicians raised about 1 question for every 2 patients seen and that over 60% of these questions are not answered [1-4]. Meeting clinicians' information needs in a timely manner at the point of care helps them make more informed decisions and provide better quality care to patients [1]. An infobutton is a clinical decision support tool embedded within electronic health record (EHR) systems that has been shown to be an effective tool to meet such information needs [5,6].

Infobuttons are enabled within EHR systems through a Web service known as *infobutton manager*. An infobutton manager is an application accessible from within EHR systems that

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provides EHR users with context-specific links (CSLs) to external knowledge resources when an EHR user clicks on an infobutton in a particular clinical context. An infobutton manager uses a knowledge base to manage all CSLs. An example of an infobutton manager is available in OpenInfobutton [7], which consists of a suite of open source tools to help various health care organizations and EHR developers to implement HL7-compliant infobuttons.

Meaningful Use [8] is a US government incentive program to encourage health care organizations to adopt certified EHR technology and demonstrate its usage in meaningful ways. Two of the core measures of Meaningful Use regulations for eligible professionals and hospitals are to deliver patient-specific education materials and to utilize clinical decision support interventions to improve performance. Both measures can be achieved using infobutton functionality encompassed in certified EHR systems, which are compliant with the *HL7 Context-Aware Knowledge Retrieval (infobutton) Standard* [9,10]. There are over 1000 certified EHR products with HL7-compliant infobutton functionality. However, how to populate, manage, and customize infobutton managers' knowledge bases easily and in bigger scale to optimize infobutton's performance after implementation have not yet been solved.

Librarian Infobutton Tailoring Environment (LITE) [11], a part of OpenInfobutton, is the tool that enables knowledge resource experts (eg, medical librarians) to populate, manage, and customize infobuttons' knowledge bases via graphical user interfaces according to different health care organizations' characteristics.

OpenInfobutton is maintained by the University of Utah and the Veterans Health Administration and is freely available to entities such as health care organizations and EHR developers. LITE is an essential piece of OpenInfobutton, because it enables individuals with no information technology (IT) background to maintain the infobutton manager's knowledge base. Although LITE is now being used to support infobutton implementation at several institutions, it is still very much a work in progress. To study users' acceptance of LITE and to improve the usability of LITE, we conducted a multipart evaluation.

## Technical and Functional Background of LITE

LITE allows its users to define profiles of health care knowledge resource (such as MedlinePlus or UpToDate) and then define generic CSLs that describe the EHR contexts for which particular resources may be useful. A CSL is represented as a URL with a set of parameters specific to the resource. These parameters are defined in the HL7 Infobutton Standard and include information about the clinical settings (eg, inpatient unit or outpatient); EHR tasks (eg, medication order entry or problem list review); patient's demographics (eg, gender, age, or language); user types (eg, physicians, nurses, or medical students); and a clinical concept of interest (eg, a medication, a problem, or a laboratory test result). Upon receiving a request from an EHR system, CSLs configured in LITE are used by OpenInfobutton's infobutton manager to generate HL7-compliant URLs to various knowledge resources.

Figure 1 shows the relationships among LITE, the infobutton manager, EHR systems, LITE users, and EHR systems' users. A simplified workflow of an infobutton includes the following steps: (1) an EHR user clicks on an infobutton within an EHR; (2) the infobutton evokes a Web browser that, in turn, evokes the parameters that were included by the EHR in the infobutton link and transmits the EHR context information to the infobutton manager; (3) the infobutton manager compares the EHR context with the CSLs in its knowledge base; (4) the infobutton manager selects CSLs that match the EHR context; (5) the infobutton manager instantiates the CSL with context-specific information (such as the concept of interest and patient demographics); and finally, (6) the infobutton manger passes a set of relevant and customized CSLs back to the Web browser in a standard XML format. LITE is used to build and manage a CSLs knowledge base in an easy-to-use and Web-based environment. LITE can be utilized by different institutions. The CSLs and the knowledge resource profiles can be exported from LITE to the infobutton manager for integration with various EHR systems, which increase CSLs' portability.

LITE has the following main functions, which correspond to the steps a user must complete to provide CSLs for the infobutton manager:

1. *Define institutional profiles:* Each institution may have different knowledge resource subscriptions, different preferences, and different types of EHR systems.
2. *Define resource profiles:* To create profiles for external knowledge resources. This includes the resource-base URL, whether the resource is HL7 compliant or not, and the context parameters and standard terminologies that are supported by the resource.
3. *Create CSLs:* To identify the contexts (ie, clinical tasks and patient's characteristics) in which the infobutton manager should select a particular resource.
4. *Test CSLs in a simulated EHR environment:* A functional test application allows users to set up HL7 infobutton requests, submit requests to the infobutton manager, and inspect the response.

Wizard-like applications guide the user through the creation of institutional profiles, resource profiles, and CSLs within LITE. Each step has a specific purpose, such as giving a name and a resource-base URL. An LITE user can review the content before saving the profile, and may modify the profiles after saving them. Figure 2 shows the main workflow within LITE and the relationships among the main components of LITE. Figure 3 shows the main functionalities and structure of LITE.

LITE is managed by Drupal, an open source content management platform. PHP and MySQL are used on the front end and back end, respectively, to support necessary programming functions.

To evaluate the usability and acceptance of LITE and more importantly to guide future development, we conducted a multiple parts evaluation and here we report how the evaluation was conducted and the related findings.

**Figure 1.** Diagram of Librarian Infobutton Tailoring Environment (LITE) and its clinical applications. EHR: electronic health record.
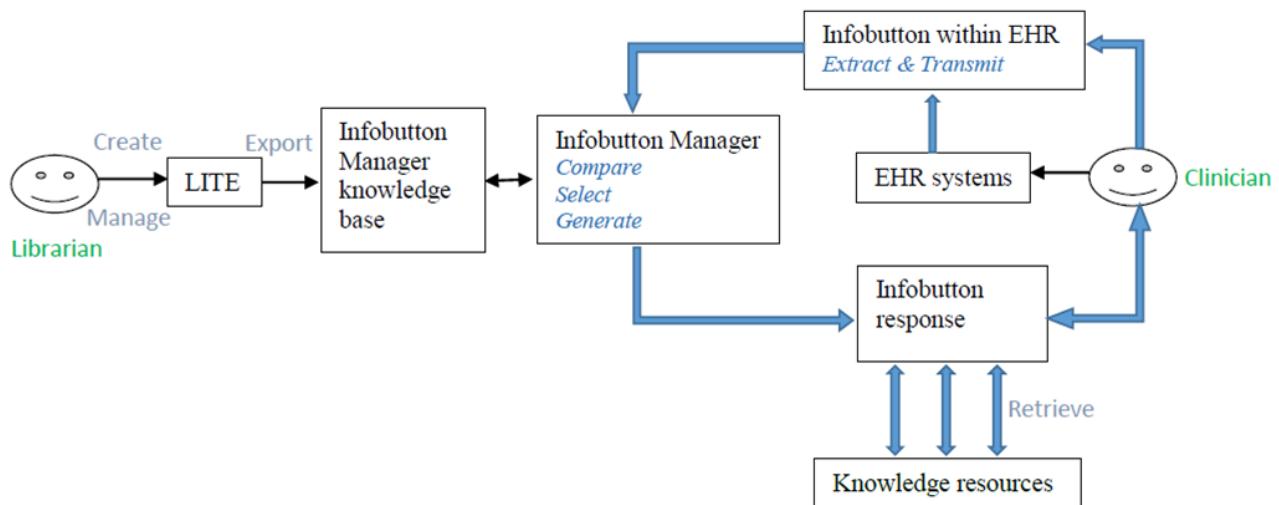


**Figure 2.** Librarian Infobutton Tailoring Environment (LITE) workflow diagram and the relationships among its main components. CSL: context-specific link.
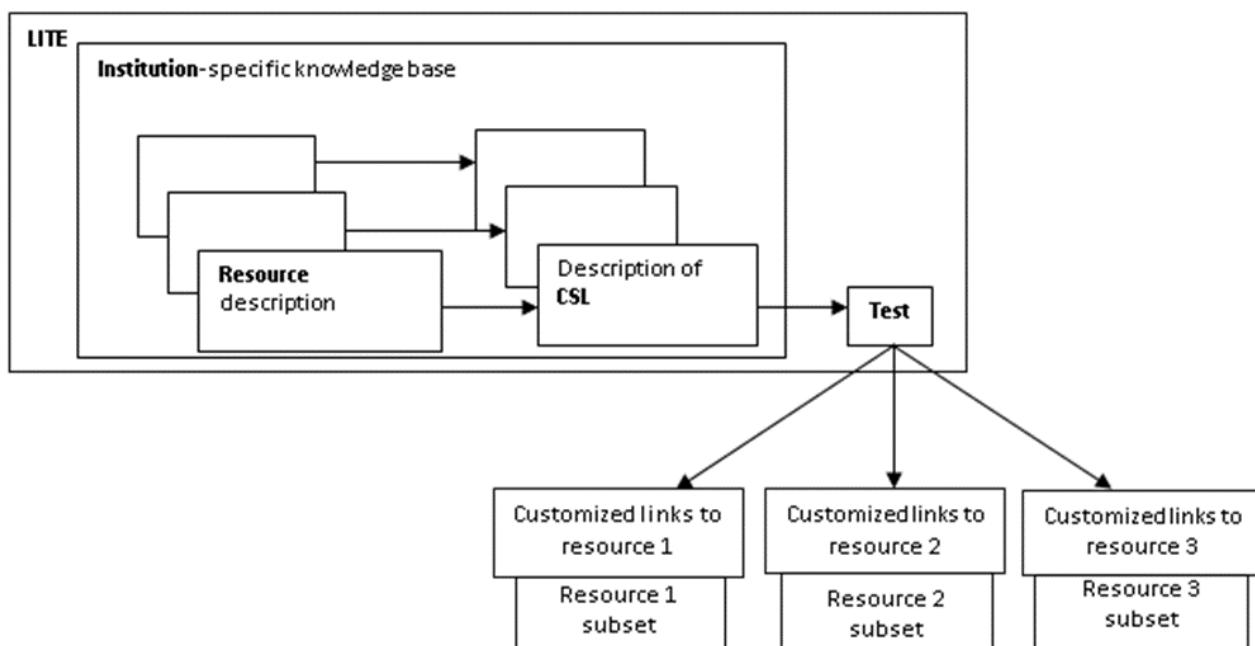


## Methods

The LITE evaluation has 2 main objectives: (1) to determine whether LITE fulfills its role as designed and (2) to identify ways to improve LITE's usability. To achieve our objectives, we first surveyed users' attitudes and usage experience about LITE. We then gathered direct and detailed feedback by observing actual usage of LITE on predetermined tasks, which corresponded to the 4 main components of LITE, and by interviewing users for their feedback about the ambiguous or less ideal parts. We also asked users their opinions about the current HL7-compliant parameters used in LITE for resource profiles and CSLs, which were selected by 3 field experts.

We used Kushniruk and Patel's methodology [12] for the evaluation of clinical information systems. We also included follow-up questions to identify the specific reasons/problems that lead to negative comments in questionnaires and in observational study.

We conducted a pilot study before the formal evaluation: a semistructured interview and mock observational study (n=2). The pilot study helped identify LITE bugs, provided valuable information about the evaluation flow, and helped fine-tune the formal evaluation procedures.

**Figure 3.** An overview of the main functionalities and structure of the Librarian Infobutton Tailoring Environment (the yellow highlighted fields are shared cross both resources and context-specific links [CSLs]).
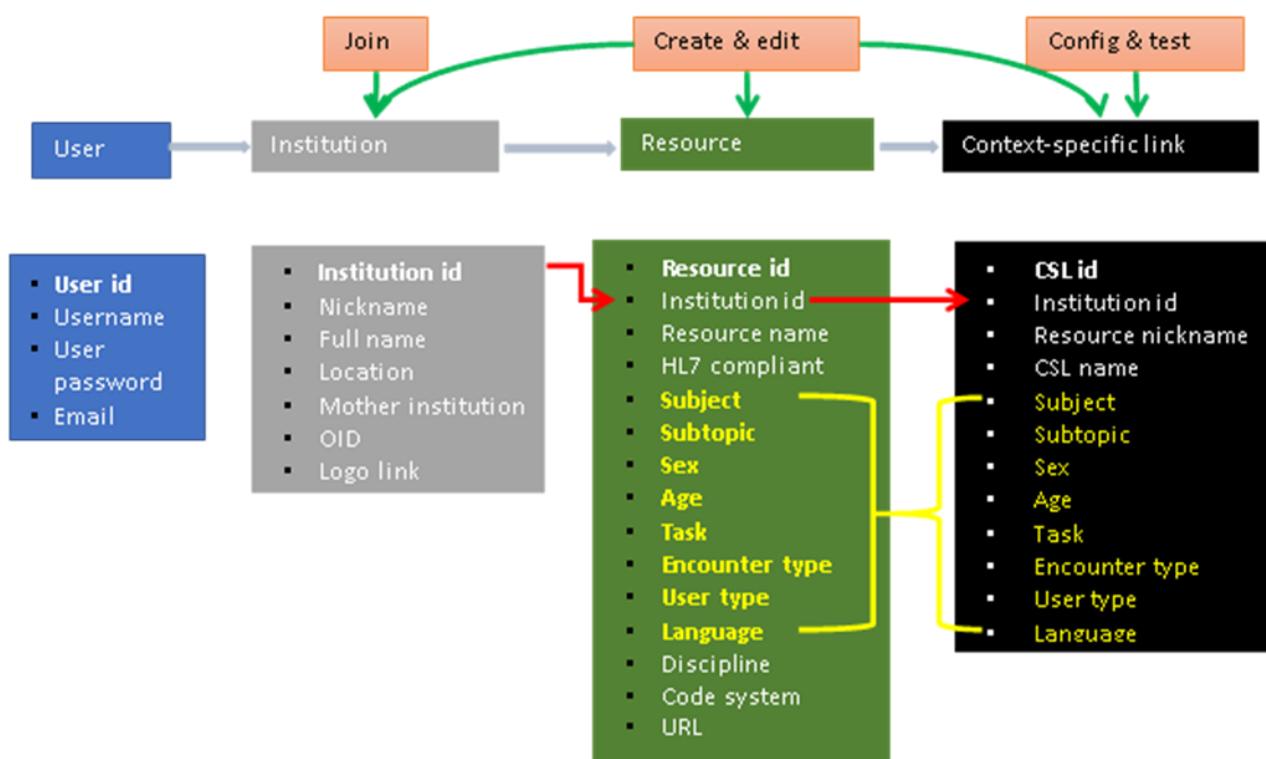


The formal LITE evaluation study was composed of 3 parts: a general survey, an observational study, and a System Usability Scale (SUS) survey. Figure 4 shows the study flow and includes the number of individuals who participated in each component of the study.

The LITE general survey focused on users' experiences, their opinions about currently available functionalities, and their requirements and preferences for future development. In the observational study, we focused on the usability of the current version of LITE and identified specific functions with which users expressed dissatisfaction.

We invited all LITE users to participate in both parts of the evaluation. LITE users who completed the survey and expressed interest were recruited to participate in the observational study. Most LITE users are from the United States, but there are a few international users. Users include medical librarians, software engineers, hospital administrators, researchers, etc. All participants are recruited on a voluntary basis by 2 invitation emails without any incentives. Observational study participants received instructions regarding evaluation beforehand. The observational study was conducted via online sessions using WebEx, a Web conference tool. During the observational study, the researcher (XJ) reiterated the general purpose of LITE and the 4 designated tasks (define an institute, a resource, a CSL, test a CSL). Then the participant conducted the tasks one by one while sharing their work screen via WebEx. All the screen activities were recorded via BB FlashBack [13]; audio recording

was optional. The researcher observed the whole process and was available to provide assistance during the study. The researcher also asked questions if the evaluator expressed hesitation, confusion, or interest at any point to identify the specific reason for confusion and capture every possibility that may improve LITE in future. A modified SUS survey followed the observational study. The main modification to SUS occurred if the evaluator had a negative answer; in this case, the SUS asked a follow-up question to specify the reason. The calculation of the SUS score was derived from the method described by John Brooke [14]. The general survey, SUS, and the evaluation instructions are attached as appendices to the manuscript. Both surveys were generated and managed within Survey Monkey.

For the video analysis, we used the following time-measurement criteria (using seconds as the measurement unit):

- *Start point:* The participant entered the first page to conduct a designated task;
- *End point:* The participant exited the last page for the designated task.

There were optional tasks (eg, modify an existing resource) in the evaluation, so not every participant conducted exactly the same number of tasks. The counts were based on tasks only, not on participants. For example, one participant might have created 2 or 3 CSLs, in which case each creation was counted independently. Therefore, final counts were task counts, not participant counts.

**Figure 4.** Librarian Infobutton Tailoring Environment (LITE) evaluation workflow (SUS: System Usability Scale survey; n refers to participants).
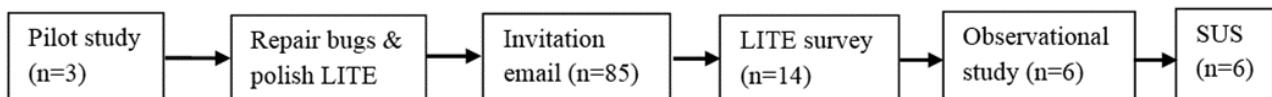


## Results

The response rate for the LITE general evaluation survey was 17% (14/85). The general evaluation survey results are summarized in Figure 5. Some of the original questions used numeric scales (1-10); however, for presentation purposes, we combined them into "yes/no" categories. For example, the original answers for "if LITE is easy to use?" and "if LITE meets your needs?" are a score from 1 (extreme negative) to 10 (extreme positive). We categorized the scores into yes (7-10), no (1-4), and neutral (5 and 6). The original answers about overall impression of LITE are free text, and we categorized them into yes (eg, it is wonderful, useful tool, looks great), no (eg, difficult to navigate, not clear to me...), and N/A (irrelevant answers).

For the observational study, all the designated tasks were conducted successfully except for one in which the participant did not successfully conduct a test of CSL due to an LITE server outage. Table 1 summarizes the time needed for completing each of the designated tasks. The average SUS score of LITE was 72.

**Table 1.** Time spent completing designated tasks in the observational study.[a]

| Tasks | Min | Max | Average | SD | Median | Count |
|---|---|---|---|---|---|---|
| **Institution** | | | | | | |
| Create | 0:58 | 8:06 | 2:58 | 2:22 | 2:27 | 7 |
| Change/verify | 0:06 | 0:19 | 0:11 | 0:04 | 0:11 | 9 |
| **Resource** | | | | | | |
| Create | 2:20 | 13:48 | 5:35 | 4:41 | 3:57 | 5 |
| Modify | 0:28 | 4:34 | 1:50 | 1:40 | 1:33 | 5 |
| Verify | 0:05 | 4:05 | 1:02 | 1:19 | 0:34 | 8 |
| **Context-specific link** | | | | | | |
| Create | 2:05 | 8:37 | 4:27 | 2:47 | 3:08 | 6 |
| Modify/verify | 0:27 | 2:46 | 1:31 | 1:10 | 1:18 | 3 |
| Test of context-specific link | 1:00 | 6:23 | 3:30 | 2:02 | 3:00 | 9 |

[a]Data are presented as minutes:seconds.

In Table 2, we summarize evaluators' suggestions about LITE functionalities and interface presentation features from the general survey, observational study, and SUS survey. The frequent suggestions can be classified into the following categories: navigation, content layout and organization, functionalities, annotations and instructions, interface presentation features, and suggestions not specific to LITE. The main suggestions on improving LITE focused on consolidating information on one single page, sharing knowledge resources usage statistics information for decision making, providing more training and instructional materials, giving users more control of information display and organization, making required fields more evident in testing of CSLs module, providing additional documentation, and troubleshooting tips and giving more explanations about URL styles.

**Table 2.** Summarized suggestions from LITE evaluation studies.

| Categories | | | Verbal suggestions/comments/feedback |
|---|---|---|---|
| **Navigation** | | | A little too much blending of information/hard to quickly pick my target |
| | **Content** | | |
| | | Organization | Available institutions (resources and CSLs) should be listed in the first page[a] |
| | | | It would be nice to have them all on 1 page in collapsible divisions so that you could jump between settings faster |
| | | Adjustment | Performer discipline is probably unnecessary |
| | | | Race, ethnicity should be included |
| | | | Timestamps should be local to the user (or institution location) |
| | **Interface** | | |
| | | Visibility | Required fields need to be more evident in the test CSL module[a] |
| | | | Button fonts are too small |
| | | | Input boxes should be bigger with an obvious border |
| | | Graphical design | To add visual connections between resources, CSL, and testing CSL |
| | | | "Continue" and "Previous" buttons should be switched |
| | | Words usage preference | Prefer "Cancel" to "Quit" |
| | **Functionalities** | | |
| | | To make LITE more intelligent | Need more feedback in the testing component |
| | | | Be able to customize the views of resources and CSLs to show more fields from which data are being collected |
| | | | An editable table format as an alternative view for changing certain values or adding ones |
| | | To improve LITE's technical performance | Export resource/CSL profiles |
| | | | Can URLs be listed beside CSLs for troubleshooting purpose, with the search terms and other details? |
| Annotations | | | Subject (subtopic, URL style) needs a more comprehensive definition |
| Instructions | | | Progress bars for each wizard |
| | | | Additional documentation and troubleshooting tips[a] |
| Education and support | | | Can the webinar be recorded and make the webinar available online as a tutorial to help people learn how to use LITE? |
| | | | Need more help in defining resources and understand the technical features |
| Outside of LITE scope | | | Implementation of OpenInfobutton locally |
| | | | EHR integration forum, content, and videos |

[a]The comments appeared repeatedly.

All general comments, such as "need an intuitive guidance," that did not articulate the specific questions or problems were excluded from these tables. These are some positive comments by the evaluators: "LITE displayed all the information that was necessary in a clean interface"; "The ability to customize resources and create specific context situations around them is great"; "This greatly simplifies configuring resources for use with OpenInfobutton. It did a good job walking me through all the necessary setup steps"; "It's straightforward and easy to use."

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**Figure 5.** General Librarian Infobutton Tailoring Environment (LITE) evaluation survey results.
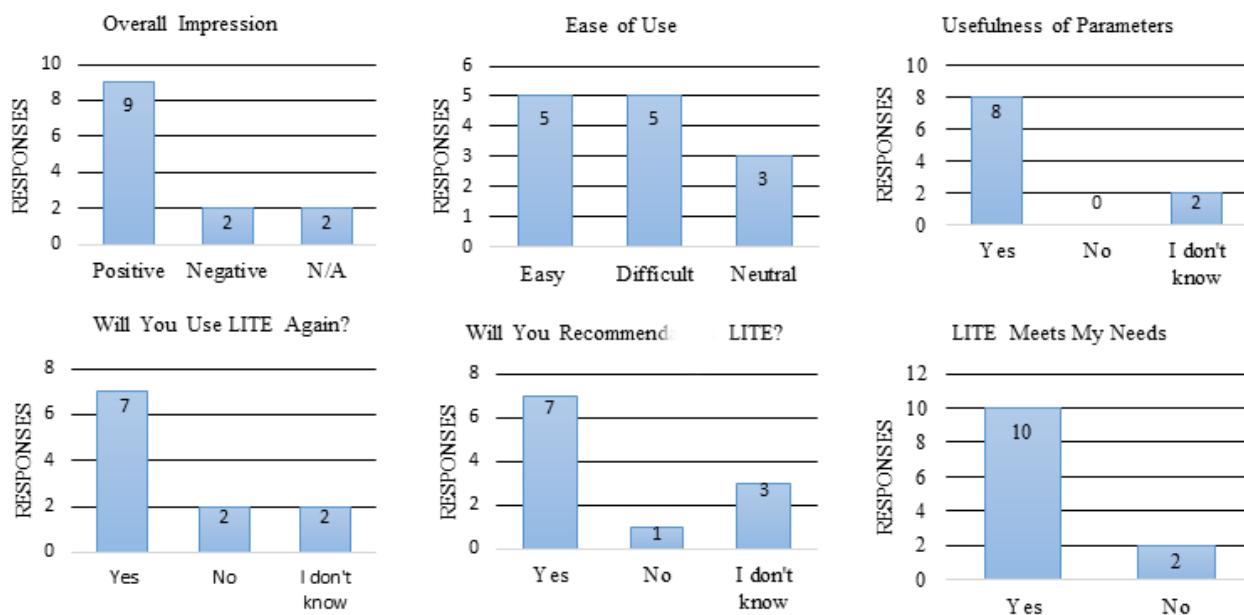


## Discussion

### Interpretations of the Evaluation Results

The evaluators' general impressions about LITE were quite positive. As a group, they thought that LITE allowed users to complete the main tasks successfully and quickly. The average time for observed users to complete each task was less than 6 minutes under a very relaxed test atmosphere. The time provides an objective measure for usage of LITE. Interview questions were common during the tests. The average SUS score of LITE was 72 (the average SUS score from literature is 68 [15]). According to Bangor et al [16] and Brooke [17], who examined more than 1000 SUS scores from different applications and technologies, the SUS 72 is in the good range (worst imaginable, awful, poor, OK, good, excellent, best imaginable). In our study, SUS is one measurement dimension we used to give readers a more comprehensive view about LITE and our main goal was to find evidence to guide future LITE development. Of the current infobutton standard parameters, users felt that age, sex, EHR task, subject, subtopic, encounter type (eg, inpatient, outpatient); user type (eg, provider, patient); and language were useful but that performer discipline was not necessary. Evaluators suggested that "race or ethnicity" and "geographic locations" should be added as new parameters. The latter has been included in the latest version of the HL7 Infobutton Standard and will be included in future versions of LITE.

LITE fulfills its primary role to build and manage CSLs for external resources in a user-friendly environment. The high rates of completion of designated tasks and positive feedback from evaluators confirm our confidence about LITE.

After we thoroughly read and analyzed the suggestions and comments, we classified them into the following categories: (1) users expected LITE to be more intelligent with a higher level of interaction, such as more feedback or troubleshooting tips

from LITE during CSL tests; (2) users expected more control of the Web page display, such as the ability to customize the view of fields for resources and CSLs; (3) users desired data definitions of some data elements used in LITE to clarify the terminology; and (4) users desired education and support, such as troubleshooting tips.

### Significance of LITE

OpenInfobutton is one of the open-access resources that allows EHRs to comply with Infobutton standard to meet meaningful use requirements. Although meaningful use requirements are clearly defined, there still are gaps between implementation of certified EHR systems and meeting meaningful use requirements. One of them is how to populate and tailor infobutton manager's knowledge base to optimize infobutton to suit the local health care settings. As part of the OpenInfobutton suite, LITE provides a mechanism for individuals at the EHR's home institution to create and manage CSLs for OpenInfobutton's infobutton manager. LITE is especially useful and helpful for clinical practices that lack sufficient IT support and professional health sciences librarians due to the graphical user interfaces. The centralized service, the graphical user interfaces, and wizard-like setup steps of LITE aim to save individual resources and efforts across different practices or institutions. Improving the user interface and usability of LITE will have a direct impact on helping practitioners and clinical settings adopting infobutton functionality within EHR systems to meet the meaningful use requirements.

### Significance of the Evaluation Study: Methods and Findings

We used multiple evaluation approaches (including 2 surveys, an interview, and an observational study) to gain a comprehensive view of LITE. In addition to multiple approaches, we gave evaluators opportunities to specify

problems they encountered. Using this strategy, we obtained relatively high-quality input and feedback although we did not have a large sample size for the evaluation. Research shows that 5 participants can find at least 55% of the problems in usability tests and 10 participants can reveal over 80% of the problems [18] so further evaluation of LITE, when it has more users, is warranted.

Our analysis of the results revealed that users expect more interaction with LITE and more control of the interface display. A possible solution is to make LITE more intelligent, so that certain features, especially layouts and interfaces, are more readily adjustable according to users' preferences. Because of the small sample size, the findings of the observational and usability sessions need to be considered with caution.

Although LITE does not contribute to evidence-based practice directly, LITE does play a critical role in configuring infobutton managers. Infobuttons are effective clinical decision support tool to help clinicians to conduct evidence-based practices. HL7 infobutton standard is required for EHR product certification and Infobuttons have been implemented in multiple sites [19,20]. A previous study [6] demonstrated that infobuttons can support clinicians in answering questions more efficiently, enhancing clinical decisions, and improving their knowledge with high positive impacts at the point of care. Therefore, LITE contributes to evidence-based practice in an indirect but necessary manner.

## Limitations of the Evaluation Study

One of the main limitations of this evaluation study is the low response rate. Two invitation emails are not sufficient to recruit evaluators. After the first invitation email, we should add incentives to attract more participants, which may help to recruit more participants. Because of the low response rate, we have a small sample size, and therefore, there are many limitations about how we can analyze the results and interpret them. For example, different age groups, different computer literacy levels, and different levels of LITE users (beginners and advanced users) may affect the evaluation results. We would be able to look at the factors that are associated with the evaluation results if we have a bigger sample size.

Another limitation can be introduced by the way we recruited evaluators: biased participants. Currently, all evaluators are recruited on a voluntary basis and the voluntary samples do not necessarily represent the real user population comprehensively. Well-stratified user groups and representations from each group may mitigate this type of bias; however, a larger sample size is a preliminary condition for such analysis.

How to measure the time and efforts saved using LITE cannot be answered by this evaluation study. To define a resource profile from scratch needs at least two tasks to be completed in LITE (to define an institute and to define a resource); and to define a CSL from scratch needs 3 tasks (to define an institute, a resource, and a CSL). This means that an LITE user would spend on average less than 18 minutes for each CSL configuration within LITE. Currently, we do not have a standard measurement of time that will be needed for an experienced knowledge expert to define a CSL usable by OpenInfobutton without LITE, such as to define XML file directly. Otherwise,

the impacts of LITE can be claimed more specifically. For most nontech savvy users, dealing with graphical user interfaces may be far more pleasant than dealing with XML files directly. To find out how long it takes for an experienced knowledge expert to define a resource and a CSL can be an interesting separate study, which can be used as baseline data to evaluate the comprehensive impacts of LITE. Conservative estimation of LITE's impacts should include the number of librarian-hours saved and not the level of work days saved.

Demographic data of the study participants are not available. We did not collect demographic data in surveys or in LITE registration. Now when we look back, computer literacy level may be a factor that is related to the evaluation results. A standard computer literacy test may thus be helpful before performing an SUS study.

## Challenges for Next-Stage Development

Prioritizing different suggestions and harmonizing controversial or contrasting opinions from different evaluators in a systematical manner create challenges as we consider ways to use this feedback in the next stage of LITE development. For example, having LITE break a task into detailed steps for the user to go through one by one is not as efficient for a tech-savvy user as completing all the steps within 1 page; however, other users complain that too much information increases the difficulty of navigation. Users' computer literacy, their familiarity with LITE and background knowledge about LITE, infobutton managers, and EHR systems are all critical factors that may affect their views about LITE. However, how to deal with the challenges will be unavoidable for next-stage development. We may need a matrix to measure, prioritize, and calculate the different features and suggestions to guide the further development in a systematic manner.

The second challenge is finding a balance between fixed workflow and more alternatives (eg, to provide singular or multiple ways to access a specific page for initiating a task, to modify resources or CSLs). To increase its flexibility, LITE was designed to give users multiple ways to initiate creation and modification of resources and CSLs. However, this flexibility makes the workflow less simple, which may, in turn, confuse some LITE users who prefer a singular way for a task with few alternatives.

The third challenge is reaching a balance between trusting rational design decisions and relying on users' feedback. When we designed LITE's wizards for creating new CSLs or resources, every page (ie, step) has a "Continue" and a "Previous page" button, which let users navigate among different pages. For most LITE users, when they create a new CSL or a new resource, they have to click "Continue" to move forward. We placed "Continue" on the left of "Previous page" to make most of the clicks convenient. However, one evaluator pointed out that the 2 buttons should switch positions. Valid evidence about the optimal positions of the 2 buttons may need a large-scale observational study, which can detect the percentages of clicks for each button to complete 1 task precisely.

LITE is an important tool for furthering the adoption of infobuttons in EHR systems to meet meaningful use

requirements. The evaluators were quite positive about LITE. LITE can be used to fulfill the original designated purposes successfully and quickly. The average time to complete a task is shorter than 6 minutes. It is an important challenge to meet all levels of users' requirements within 1 output, so different layout plans for different users' preferences (ie, more intelligent, information intense and more users' control for advanced users and simpler, fixed workflow, and step-by-step wizards for beginners) may be a future direction for LITE.

## Acknowledgments

## Conflicts of Interest

None declared.

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## Abbreviations

**CSL:** context-specific link
**EHR:** electronic health record
**LITE:** Librarian Infobutton Tailoring Environment
**SUS:** System Usability Scale

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<u>Original Paper</u>

# Measuring Use of Health-Related Support on the Internet: Development of the Health Online Support Questionnaire (HOSQ)

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## *Abstract*

**Background:** Social support plays an important role for the perceived health in people with health problems and chronic diseases. Provision of different kinds of support during the disease trajectory is crucial for many people. Online support is ubiquitous and represents a promising modality for people with chronic diseases. There are no existing instruments that measure various aspects of online support.

**Objective:** The objective of this study was to create a generic questionnaire regarding health-related support online that can be applied to people with various health problems and illnesses. Additionally, we wanted to test the questionnaire in a cancer population to assess its adequacy in the context of severe disease.

**Methods:** Initial items for the Health Online Support Questionnaire (HOSQ) were inspired by sociologist James House regarding social support. An exploratory factor analysis was conducted in healthy persons or with minor health problems (n=243) on 31 initial items. The scale was reduced to 18 items and the internal consistency and reliability of the scale was examined along with content validity. Further validation was conducted by a confirmatory analysis on the 18-item scale in a cancer population (n=215). In addition, data on demographics, health problems experienced, and Internet use were collected.

**Results:** The exploratory factor analysis on the final 18-item scale resulted in 2 factors. After scrutinizing the content, these factors were labeled "reading" and "interacting" and they demonstrated good internal consistency (Cronbach alphas .88 and .77, respectively). The factors were confirmed in the cancer population. The response pattern revealed expected differences both between the interaction and reading scales and according to age, gender, education, and health problems thereby supporting the validity of the HOSQ.

**Conclusions:** The HOSQ may be a reliable and valid instrument for measuring the use of online support for people with health problems, but the results ought to be replicated in more studies to confirm the results for different diagnoses. If the results of this study are corroborated by future studies, the HOSQ may be used as a basis for the development of different forms of support on the Internet.

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## Introduction

During the past 2 decades, the use of the Internet as a tool for health-related support has increased [1]. People turn to the Internet for health-related informational support as well as other types of support, both to find out about health problems and to share in other people's experiences in a similar situation [2,3]. For persons faced with illness, Internet-delivered interventions can be efficient in providing information, appraisal, and emotional support, thus alleviating psychological distress [4-7]. It is important to investigate the diverse needs and expectations of patients to develop such Internet interventions.

### Social Support

Since the mid-1970s, there has been an increasing interest in the role of social support as a coping resource during stressful life events, generating extensive research [8]. The concept of social support has been analyzed in different models and widely elaborated in studies showing that aspects of social support influence health-related quality of life, stress symptoms, and health [8-10]. A theory developed by James House [11] states that social support can be divided into 4 broad classes or types of supportive behaviors or acts: informational, instrumental, emotional, and appraisal. Informational support is advice or counseling that is helpful for coping with personal and environmental problems. Instrumental support takes the form of practical help or economic help. "Appraisal" means information that individuals use in evaluating themselves, such as feedback on performance or information that facilitates social comparison, etc. Emotional support involves empathy, caring, love, and trust. In an online context, the overall label "social support" could be questioned, but the different classes of support described by House could most likely also be found on the Internet [12-14].

### Health-Related Support Online

Health-related support online differs from face-to-face support. Online support can offer anonymity and greater flexibility regarding time and place. However, the support offered face-to-face involves contact with another human being which could imply experiences with other benefits [15]. Factors associated with an increased use of the Internet for health purposes are youth, female sex, higher education, white collar work, visits to a general practitioner during the past year, and long-term illness or disability [1,16]. Being faced with a health problem can be a challenging situation associated with different levels of psychological distress [17] and research suggests that people with chronic disease can benefit from using the Internet for health purposes [18,19].

An increasing trend in health-related Internet use among cancer survivors has been identified [20]. In a recent study in which an online questionnaire with open-ended questions was used describing why cancer patients choose the Internet as a source of social support, it was found that the incentives were, among others, the need for informational and emotional support, lack of support outside the Internet, and the ease of online communication [14].

### Social Support Measures

In an offline context, measures of social support have been developed and applied over the past few decades [21]. Regardless of the underlying model, they typically fall into structural measures, including the network size, frequency or density, and functional measures including emotional, appraisal, informational, and instrumental support. The general finding that stronger social support networks are beneficial has remained relatively constant [21].

Because the use of eHealth services is growing, there is a need to improve our knowledge about how these services are used, by whom they are preferred, and for what reasons. With that information, adequate interventions can be developed and implemented by health providers. To date, however, no questionnaire exists that captures the previously mentioned aspects of support in an online context. Therefore, the development of such a questionnaire is important because the Internet has become such a potentially significant source of health-related support [1,13,22-24]. There is a need for more studies in various contexts to further investigate the incentives for using the Internet for support.

### Aim

The overall aim of this study was to create a generic questionnaire regarding health-related support online that can be applied to people with various health problems and illnesses. Additionally, we wanted to test the questionnaire in a cancer population to assess its adequacy in the context of severe disease.

## Methods

### Questionnaire Development

The development of the Health Online Support Questionnaire (HOSQ) was inspired by the theory of social support developed by House [11] in that his categorization of 4 different classes of support—instrumental, informational, emotional, and appraisal—was used as a tool to guide the nature of the questions.

The first step was to go through the literature regarding support online and search for existing questionnaires measuring aspects of seeking online support. Searching the databases PubMed, PsycINFO, and Scopus resulted in many citations regarding the search for informational support, but no citation mentioning any questionnaire capturing various kinds of potential forms of online support. The second step was to do a comprehensive review of websites related to cancer health issues. With the inspiration of all these sources, we began the process of generating a set of questions encompassing aspects of House's classes of social support applicable to online support. Three of the authors, independently of one another, scrutinized the suggested questions to see if any aspect of potential support was missing or if there was unnecessary overlap. This yielded the preliminary HOSQ consisting of 31 items regarding the purpose of health-related Internet use (see Multimedia Appendix 1). They were all scored on a 6-point Likert scale describing the frequency of use ranging from zero (not relevant/never) to 5 (on a daily basis).

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The first draft of the questionnaire was tested with the so-called "think-aloud method" [25]. Three women with a former breast cancer and 5 men with a former prostate cancer answered the questionnaire while speaking out loud about what they were thinking. They were also given the instruction to share their opinions regarding whether they thought the questionnaire was missing something essential related to the topic and whether it contained anything that was irrelevant or that could easily be misinterpreted. Thus, face and content validity was evaluated. Five of these individuals tested the questionnaire initially and a small revision of the questionnaire was made. Thereafter, another 3 individuals tested the revised version of the questionnaire according to the same procedure, whereupon the final revision before the psychometric testing was done.

After finalizing the draft, an exploratory factor analysis (EFA) using principal axis factoring (PAF) was conducted in a sample from a nonclinical population to investigate whether there was a relevant factor structure underlying the item responses.

In the EFA, reduction of items was guided by the response pattern and statistical considerations, as well as the theoretical constructs. The content of every item was inspected to avoid overlap and items not matching the core aspects of the suggested factors. Further, the explained variance of the questionnaire was balanced against its length to make the HOSQ as clinically acceptable and easy to use as possible (see Multimedia Appendix 1).

## Psychometric Testing

### Sample and Procedure

To reach out to a heterogeneous group of individuals who were healthy or had minor health problems, we tested the HOSQ in a convenience sample that consisted of staff at a factory in a rural area in central Sweden (n=176) and staff at Uppsala University (n=67). At the factory, we could reach both laborers and clerks; at the university, we could reach a group of individuals with the highest level of education. That way we could compare differences between groups found in previous studies [13,16]. Data were collected from March to May 2014. Paper copies of the HOSQ were handed out in the job mailbox to the sample at the university and outside the canteen at the factory. In total, approximately 500 questionnaires were handed out and 243 (48.6%) were completed. Participants' median age was 44 (range 20-71) years and there was a preponderance of men (67.9%, 165/243). In all, 66 (27.1%) participants were single and 177 (72.8%) were living in cohabitation. Regarding education, 105 (43.2%) had a university degree and 123 (50.6%) had high school or elementary school education; 5 (2.1%) did not answer the question relating to education. Those who reported no use of the Internet during the last 2 years (n=6) were excluded from all analyses.

A confirmatory factor analysis (CFA) was done in a sample of adult patients (age>18 years) with different cancer diagnoses (n=215). They were recruited at an oncology or urology clinic at a hospital in Uppsala, Sweden. The inclusion criteria were that they could read and understand Swedish and that they had completed the initial treatment (surgery and/or chemotherapy and/or radiotherapy) or were undergoing active surveillance,

hormone, or other medical treatment. This was so they had gained some perspective on how they had used the Internet after being diagnosed. Exclusion criteria were that it was their first visit at the clinic and that they were participating in an ongoing Internet-based psychosocial intervention at the hospital, U-CARE [26], that could have an impact on the answers. The data were collected from November 2014 to February 2015. Patients were given a paper copy of the HOSQ in the waiting room and could chose to either answer it at the clinic or complete it at home and return it by mail in a prepaid envelope. Approximately 350 questionnaires were handed out and 285 patients answered the questionnaire. Of these, 70 reported that they had not used the Internet and were consequently excluded from the CFA. The age range in the cancer group was 20 to 84 years and the median age was 63 years. There were slightly more men (120/285, 55.8%). A majority were living in cohabitation (181/285, 84.1%); 31 (14.4%) were single and 105 (48.8%) had a university degree.

In addition to the HOSQ, the participants answered some questions about demographic variables, whether they had used the Internet during the last 2 years, and, in the nonclinical population, whether they had any health problems.

Ethical approval was granted by the Regional Ethical Review Board in Uppsala (November 20, 2013; diary number 2013/436).

### Statistical Analyses

Exploratory factor analysis with PAF was used to investigate the factor structure of the questionnaire in the nonclinical group. To determine the number of factors to extract, we used parallel analysis. Because factors were hypothesized to correlate, oblique promax rotation was used to retain factors. The criteria for retaining an item were (1) a loading >0.30 on either factor and (2) a loading difference >0.15 between the 2 factors. Items with both factor loadings <0.30 were excluded. To confirm the extracted factor structure, a CFA was then conducted on data from the cancer group. The CFA was conducted with structural equation modeling using robust maximum likelihood estimation and the asymptotic covariance matrix. In the measurement model of the CFA, error terms of measurements loading on the same latent variable were allowed to covary. To estimate model fit, the Satorra-Bentler scaled chi-square, the root mean square error of approximation (RMSEA), the nonnormed fit index (NNFI), and the comparative fit index (CFI) were used. Values for RMSEA <0.08 and NNFI and CFI values >0.95 indicated acceptable model fit [27,28].

The response patterns in relation to the demographic variables were analyzed with the Mann-Whitney $U$ test and Spearman rho because the distributions were positively skewed. This was done on the HOSQ total score with a maximal possible score (range 0-90) and subscales (range 0-45) calculated.

## Results

Two of the 31 items yielded a very narrow response range, >90% of the responses being zero (not relevant/never). These items were removed from further analysis. Correlations between the remaining 29 items ranged from $\rho=.01$ to $\rho=.65$ and the

lowest eigenvalue in a preliminary analysis was 0.174; therefore, the risk of singularity or multicollinearity was considered low.

After an EFA using PAF of the remaining 29 items, results indicated that 2 items should be removed based on the exclusion criteria: (1) a loading <0.30 on either factor and (2) a loading difference <0.15 between the 2 factors. Five items with a difference <0.30 between the factor loadings were removed to further trim the instrument. Another 2 items were excluded after content analysis because they were considered deviant from the core content of the factors. Finally, 2 items considered superfluous were removed to make the 2 subindexes equal in length. The final factor loadings after promax rotation for the remaining 18 items, accounting for 45.3% of the variance, can be seen in Table 1. The Kaiser-Meyer-Olkin measure of 0.85 confirmed sample adequacy. Bartlett's test for sphericity was significant ($\chi^2_{153}$=1582; $P$<.001), indicating that the interitem correlations were adequate.

**Table 1.** Factor loadings of the exploratory factor analysis (EFA) of the final 18-item version of the Health Online Support Questionnaire (HOSQ) in the nonclinical group (n=229).

| I do health-related Internet research... | Factor 1: reading | Factor 2: interacting |
|---|---|---|
| To search for information that can improve my health | 0.616[a] | 0.034 |
| To share information about a disease treatment that I've been through | –0.083 | 0.393[a] |
| To read about other people's experience of disease/bad health/a treatment | 0.502[a] | 0.198 |
| To be able to make more well-informed decisions regarding my health | 0.720[a] | 0.065 |
| To stay in touch with my friends and colleagues when I'm sick or not feeling well | 0.078 | 0.598[a] |
| To share practical advice and suggestions regarding my health | –0.054 | 0.685[a] |
| To search for information that enables me to better understand physicians and other health staff | 0.528[a] | 0.083 |
| To search for encouragement from others when I'm stricken by disease or not feeling well | –0.070 | 0.690[a] |
| To express my opinion regarding health/disease/care | 0.043 | 0.420[a] |
| To search for information from different sources to enable the best care | 0.730[a] | 0.085 |
| To search for compassion when I'm not feeling well | 0.093 | 0.445[a] |
| To get feedback from others who have, or have had, the same health problem as I have | 0.137 | 0.443[a] |
| To search for scheduled appointments, addresses or phone numbers to health care | 0.619[a] | –0.017 |
| To search for information when I feel worried | 0.763[a] | –0.124 |
| To keep friends and relatives informed on how I feel | 0.030 | 0.507[a] |
| To get feedback from friends and relatives on how I'm handling my health situation | –0.038 | 0.586[a] |
| To search for the latest research regarding my health situation | 0.647[a] | –0.045 |
| To find out whether symptoms that I've experienced are dangerous or not | 0.890[a] | –0.116 |
| % variance | 33.9 | 11.4 |
| Cronbach alpha | .88 | .77 |

[a] Indicates factor membership.

After scrutinizing the items, the 2 factors were conceptualized and labeled "reading" (9 items) and "interacting" (9 items). Therefore, the final instrument contained 18 items and 2 subscales. The mean value in the nonclinical sample (n=229) was 12.0 (SD 9.1) for the total score, mean 9.1 (SD 6.5) for the reading subscale, and mean 2.8 (SD 3.9) for the interacting subscale (see Table 1).

The CFA was conducted with the 18 measurements loading on 2 latent variables, "reading" and "interacting," and resulted in a significant Satorra-Bentler chi-square ($\chi^2_{79}$=169.6, $P$<.001), RMSEA of 0.073, NNFI of 0.98, and CFI of 0.99 (see Figure 1). Taken together, this indicates an adequate fit for the model

and there were no indexes that suggested a potential substantial improvement of the model (see Figure 1).

Women in the nonclinical group scored statistically significantly higher on the HOSQ total score and reading subscale compared to men (Table 2). In the cancer group, women scored significantly higher on the interacting subscale and the HOSQ total score. Participants in the nonclinical sample who reported having a health problem scored significantly higher on the reading subscale and had a significantly higher total score compared with others. Participants with a university education scored higher on the reading subscale in the nonclinical group and on both subscales and the total HOSQ score in the cancer

group. There were no differences between single or cohabiting participants. Younger age was correlated with higher scores on the reading and interacting subscales and the total HOSQ score in both the nonclinical and the cancer group (nonclinical group: $R=-.34$ to $-.38$; cancer group: $R=-.19$ to .27; all $P<.001$).

## Discussion

The HOSQ was found to provide useful information regarding health-related support online and a meaningful 2-factor structure with good internal consistency. The factors represent reading versus interactive eHealth behaviors. This structure was confirmed in a second population with cancer and is, therefore, considered to be robust. The response pattern revealed expected differences both between the interaction and reading scales and

according to age, gender, education, and health problems and thereby supports the validity of the HOSQ [22].

### Psychometric Testing

The EFA did not result in the 4 classes suggested by House [11]. A plausible explanation is that the factor structure identified tapping reading and interaction is more salient even though the classes of support suggested by House are embedded in the 2 appearing factors. A majority of the questions measuring instrumental support were removed. This was because of bad fit with the 2 factors derived in the HOSQ. The need for instrumental support should not be overlooked or underestimated in a group of individuals with health alterations or problems, although not central in the HOSQ.

**Figure 1.** Confirmatory factor analysis of the 18-item Health Online Support Questionnaire with factor loadings, factor covariances, and error variances. Left column: each item of the questionnaire; right column: the two latent variables.
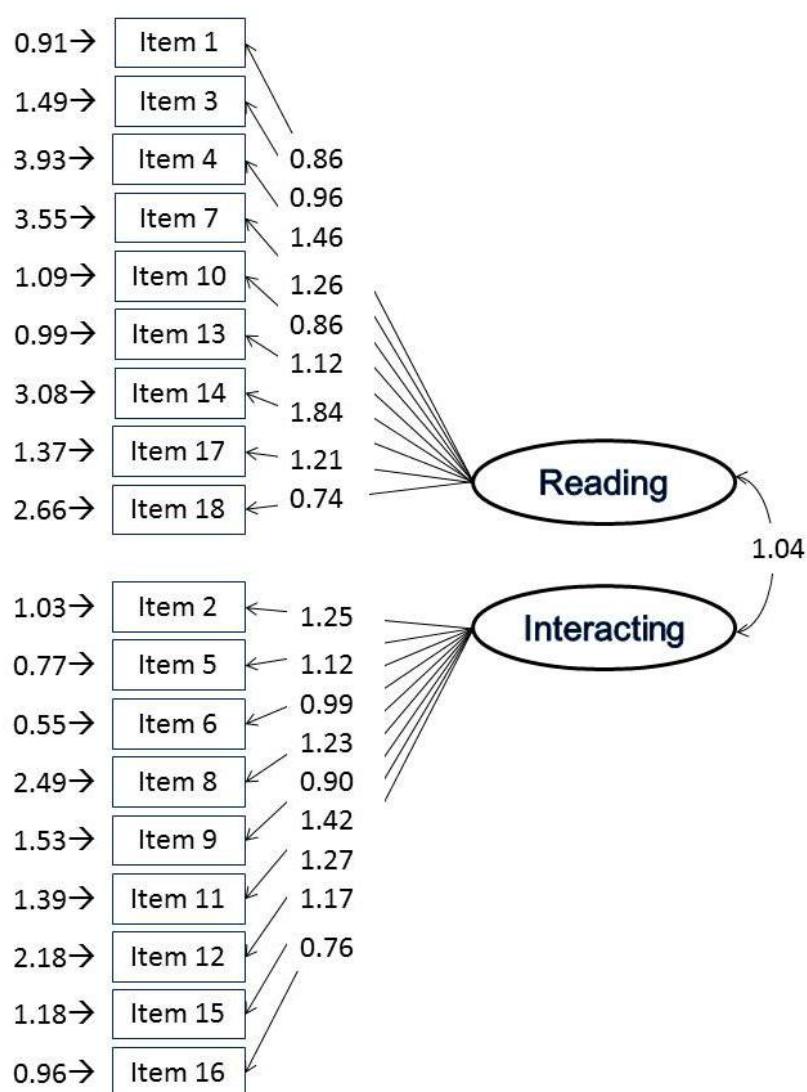
**Table 2.** Medians, third quartiles (Q3), and differences between groups of participants.

| Nonclinical population | HOSQ Reading, median (Q3) | P [a] | HOSQ Interacting, median (Q3) | P [a] | Total score, median (Q3) | P [a] |
|---|---|---|---|---|---|---|
| **All (N=229)** | 9 (14) | | 1 (4) | | 11 (18) | |
| **Gender** | | | | | | |
| Women (n=74) | 11 (17) | .006 | 2 (6) | .06 | 14 (20) | .003 |
| Men (n=155) | 8 (13) | | 1 (4) | | 10 (16) | |
| **Health problems** | | | | | | |
| No health problem (n=108) | 6 (11) | .001 | 1 (4) | .17 | 8 (16) | .001 |
| Health problem (n=119) | 11 (15) | | 1 (5) | | 13 (19) | |
| **Marital status** | | | | | | |
| Married/cohabitating (n=168) | 8 (13.5) | .28 | 1 (4) | .41 | 10.5 (17) | .22 |
| Single (n=61) | 9 (15) | | 1 (6) | | 11 (19) | |
| **Education** | | | | | | |
| University education (n=100) | 10 (15.50) | .02 | 1 (4) | .98 | 12 (19) | .06 |
| ≤High school (n=125) | 7 (13) | | 2 (4) | | 10 (17) | |
| **Cancer population (n=190)** | 8 (17) | | 2 (6.75) | | 12 (23) | |
| **Gender** | | | | | | |
| Women (n=88) | 8 (17.5) | .17 | 4 (10) | .006 | 14.5 (26) | .02 |
| Men (n=102) | 7 (14.5) | | 1 (4) | | 9 (19) | |
| **Marital status** | | | | | | |
| Married/cohabitating (n=160) | 8 (16) | .93 | 2 (6) | .63 | 12 (22.75) | .89 |
| Single (n=29) | 8 (18) | | 1 (8) | | 12 (26) | |
| **Education** | | | | | | |
| University education (n=99) | 11 (19) | .001 | 3 (10) | .005 | 16 (28) | .001 |
| ≤High school (n=88) | 5 (11) | | 1 (5) | | 7 (16.5) | |

[a] Mann-Whitney $U$ test.

## Health-Related Support

People suffering from a disease primarily search for information, but also visit online networks that offer the opportunity to share in other people's experiences and to talk about their own experiences. One study examining the exchange of information on Twitter among people with cancer found that it was emotional support rather than information and news that was exchanged [12]. It has been found that those who interact in online networks, rather than just read, report a higher level of mental well-being [29]. Therefore, it is desirable to further investigate the differences between just reading and reading combined with interacting to be able to offer support in accordance with what is searched for.

## Demographic Variables

Women seemed to use the Internet for health-related purposes, especially for interaction, more than men do. Other studies that have shown that women seek health information online more often and have a lower dropout rate in online self-help interventions compared with men [30,31]. Women are also more willing to go online to figure out a possible diagnosis [22] and use social media and blogging for this purpose [32]. Younger

people used the Internet for health-related purposes more often than older people in both groups. This is in-line with other research that has found that Internet use is not as high among older adults. Internet use is increasing in the older age group, internationally and in Sweden [22,32,33], potentially meeting the needs in a health care consumer group.

## Health Problems and Online Support

Participants who reported having a health problem searched for health-related information and interaction to a greater extent compared with participants who did not report a health problem. In her theory of online support, LaCoursiere [34] elaborates on the incentives for searching online support. She claims that the search process begins with initiating events, such as an alteration in health status and an alteration in perceived health. Our results for the nonclinical group support her theory. On the other hand, another study found that those who reported poor health used the Internet less for health purposes compared with those who did not [1]. Maybe this has to do with cultural differences in the way that the threshold for health-related Internet use is higher in countries where the access to Internet is relatively low and is correlated to a higher socioeconomic status and better

health. In Sweden, approximately 90% of the population older than 12 years have access to the Internet at home [32]. And more than 90% of the population are Internet users, which makes Swedes one of the most Internet-using people in the world.

## Reading Versus Interacting

According to a large survey on Internet use and chronic illness, approximately one-third of a group with chronic disease who consumed health information online reported that they read other people's comments or about others' medical/health experiences on online newsgroups, blogs, or websites [18]. Of those, only 6% reported that they posted health-related comments themselves. In that study, the ones who shared knowledge and experiences and interacted with others were a minority compared with the ones who read and took part in what other people shared [18]. People who share information report more benefits from online social support groups and a higher mental well-being than those who do not share [29,35]. The HOSQ may be used in future studies to find out whether individuals or groups tend to be primarily interested in reading only or also to interact. It may also be used together with other instruments to investigate how these different behaviors correlate with other variables. That information might increase the opportunities to offer adequate support online.

## Strengths and Limitations

The confirmatory analysis showed adequate model fit and there was no indication that the model could be further improved. Because CFA can only be used to compare different models, it is important to note that the results of the CFA should be interpreted with caution. Moreover, the sample size used in the CFA was at the lower end of the suggested range, but the model was deemed simple enough to allow for analysis. The factor structure should be confirmed in other, and larger, samples in the future.

One of the limitations of this study is that it was difficult to assess the response rate in all participants because the questionnaire was handed out via the mailboxes of the staff employed at the university. This was easier to control among participants working at the factory and in the cancer group. The vast majority of the participants in both these groups answered the questionnaire; hence, the response rate was high. The minor missing data indicate that the questionnaire was fairly uncomplicated to answer.

Another limitation is that this study used convenient samples and caution should be taken in generalizing the findings to the general population. However the questionnaire was tested in 3 groups: initially in a group of persons with no health problems and in a group with minor health problems (ie, they were not on sick leave) and then in a group diagnosed with a severe disease. Almost half of the nonclinical sample reported having health problems. In other words, the questionnaire was administered to 2 groups experiencing health problems. The same 2 factors appeared in the nonclinical group and the cancer group, indicating that the HOSQ may be a valid as a generic questionnaire examining the search for health-related support online in a population experiencing health problems.

There was a majority of men in both groups. Most of them were well-educated in the nonclinical group, whereas among the women there was a preponderance of well-educated individuals in both groups. This is not fully representative of the overall online population and may have led to higher scores. Women and men with high education are more frequent Internet users [22]; hence, this may have affected the outcome.

Further, we could have used focus group or individual interviews in the initial development process of the questionnaire. Early involvement of key informants is regarded as an important part of questionnaire development and lack of interviews could have influenced the selection of questions. However, the think-aloud method involving patient experts did not indicate a lack of important aspects. Hence, it is reasonable to assume that the HOSQ may have fairly good content validity, but this needs to be more thoroughly tested in future studies.

Construct validity needs to be further evaluated. Having health problems, younger age, and female gender were expected to predict higher total HOSQ scores. This is in-line with other studies measuring searches of health-related information on the Internet. Because the HOSQ is a questionnaire also measuring other types of support, the "known group validity" is not completely applicable. Therefore, there is uncertainty about its construct validity at this point.

Regarding reliability, one limitation is that the questionnaire was administered only once in both the nonclinical and the cancer group. On the other hand, the HOSQ measures behavior. Had we administered the questionnaire twice, there is a risk that the answers could have changed due to altered behavior between the 2 observation points, which would have made it difficult to assess test-retest reliability. Therefore, it is crucial to repeat the testing of the questionnaire in other groups.

## Conclusion

Because of the similar factor structure and salient Internet behaviors in both the nonclinical and the cancer group in this study, the HOSQ may be a promising first step in the development of a generic questionnaire for individuals in various groups with health alterations. However, further tests of the HOSQ's validity and reliability in other groups are needed to strengthen the presented results. Many people today use the Internet as a tool to help themselves (and others) better understand and handle what is ailing them. Although the Internet is a potentially productive source of health-related support, it is not certain that everyone can benefit from using it. The HOSQ may be used in future research regarding purposes of Internet use and studies regarding reading versus interacting. With the help of that information, tailored support can be developed for different groups or individuals.

## Acknowledgments

## Authors' Contributions

SM contributed to the study design and the development of the questionnaire and drafted the manuscript. EO contributed to the study design and the development of the questionnaire and helped to draft the manuscript. BJ contributed to the study design and helped to draft the manuscript. SA contributed to the development of the questionnaire and helped to draft the manuscript. MC contributed to the study design and the development of the questionnaire and helped to draft the manuscript. All authors read and approved the final manuscript.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Item reduction overview.

[PDF File (Adobe PDF File), 41KB - jmir_v17i11e266_app1.pdf ]

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## Abbreviations

**CFA:** confirmatory factor analysis
**CFI:** comparative fit index
**EFA:** exploratory factor analysis
**HOSQ:** Health Online Support Questionnaire

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**PAF:** principal axis factoring
**RMSEA:** root mean square error of approximation

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Original Paper

# Web-Based Immersive Virtual Patient Simulators: Positive Effect on Clinical Reasoning in Medical Education

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## Abstract

**Background:**   Clinical reasoning is based on the declarative and procedural knowledge of workflows in clinical medicine. Educational approaches such as problem-based learning or mannequin simulators support learning of procedural knowledge. Immersive patient simulators (IPSs) go one step further as they allow an illusionary immersion into a synthetic world. Students can freely navigate an avatar through a three-dimensional environment, interact with the virtual surroundings, and treat virtual patients. By playful learning with IPS, medical workflows can be repetitively trained and internalized. As there are only a few university-driven IPS with a profound amount of medical knowledge available, we developed a university-based IPS framework. Our simulator is free to use and combines a high degree of immersion with in-depth medical content. By adding disease-specific content modules, the simulator framework can be expanded depending on the curricular demands. However, these new educational tools compete with the traditional teaching

**Objective:**   It was our aim to develop an educational content module that teaches clinical and therapeutic workflows in surgical oncology. Furthermore, we wanted to examine how the use of this module affects student performance.

**Methods:**   The new module was based on the declarative and procedural learning targets of the official German medical examination regulations. The module was added to our custom-made IPS named ALICE (Artificial Learning Interface for Clinical Education). ALICE was evaluated on 62 third-year students.

**Results:**   Students showed a high degree of motivation when using the simulator as most of them had fun using it. ALICE showed positive impact on clinical reasoning as there was a significant improvement in determining the correct therapy after using the simulator. ALICE positively impacted the rise in declarative knowledge as there was improvement in answering multiple-choice questions before and after simulator use.

**Conclusions:**   ALICE has a positive effect on knowledge gain and raises students' motivation. It is a suitable tool for supporting clinical education in the blended learning context.

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## Introduction

One important part of clinical education is learning and mastering medical workflows, which is the basis for mastering clinical workflows in diagnosis and therapy (clinical reasoning). Nowadays, many workflows are based on standard operation procedures (SOPs) that enable performance uniformity in the clinical daily routine [1]. A key basis of these procedures is the learning of the underlying (declarative) knowledge, which is nowadays often supported by e-learning programs [2]. Mastering SOPs require the ability to transfer declarative knowledge (what to do) into practical or procedural knowledge (how to do it). This is most effective in attending courses, preferably in small groups where students' preexisting knowledge is on the same level [3]. In current medical curricula, new educational approaches such as problem-based learning, skills lab, and mannequin simulators [4,5] play an increasing role. By repetitive training of standardized clinical settings, procedural knowledge can be internalized, which ensures a certain knowledge level before working with real patients.

The rapid development of computer technology enables implementation of new educational approaches for teaching and internalizing medical workflows in diagnosis and therapy even on home computers. Immersive patient simulators (IPSs) enable a representation of a virtual counterpart in a three-dimensional "game-like" virtual environment where students can freely interact in real time with virtual patients [6]. Playful immersion in the digital environment provides virtual experience as students can face the consequences of different decisions (trial and error) without putting real patients at risk. Repetitive training allows internalization and consolidation of the scripts that are relevant for the necessary procedural performance [7]. Furthermore, Web-based IPS combines immersion with the advantages of distance learning [8].

In a thematic review, we summarized the available immersive virtual patient simulators and found that the use of such simulators in clinical education is still rare. Furthermore, there was no IPS available that combined high technical quality with an in-depth level of medical content and that was freely accessible for all students [9]. Therefore, we developed a university-based IPS prototype called "ALICE" (Artificial Interface for Clinical Education) that is free to use, available to all interested teachers, and that enjoys high student acceptance [10]. However, application of this new educational approach requires knowledge about the impact on knowledge gain as clinical teachers may ask whether using a simulator of this kind can really support clinical education.

We formulated the hypothesis that repetitive training with ALICE consolidates clinical reasoning and has a positive impact on knowledge gain. Therefore, we implemented a teaching module that simulates patients with a complex oncological disease. It was our aim to perform a validation of this novel educational approach and to examine whether the use of ALICE has positive impact on clinical reasoning and is a suitable tool for supporting the clinical teacher.

## Methods

### Immersive Virtual Patient Simulator: ALICE

Design and technical realization were previously described by our group [10]. In brief, ALICE is a Web-based IPS that enables the student to navigate through a virtual environment from a first-person perspective similar to a video game (Figure 1). ALICE simulates a small outpatient clinic with a treatment room where the user can interact with nonplayer characters such as nurses, patients, and other doctors (Figure 1). The simulator starts with a short instructional case where the basic controls and functions are explained. The user is able to freely interact with the virtual patient and choose the different options (medical history, examination, diagnostic tests). The student instantly receives the desired result either as a table (eg, laboratory values), image (eg, x-ray, electrocardiogram), or video (eg, computed tomography scans, ultrasound, gastroscopy). When choosing a medically nonindicated examination, the test shows a normal finding. Once the student makes a diagnosis, he or she initiates the necessary treatments and finishes the case. The models of Miller's pyramid [11] and Bloom's taxonomy were used as a scaffold for planning and assessing our simulator (Figure 2). Level of competence was assessed on level one (factual test), level two (clinical context-based test), and partly on level three of Miller's pyramid (performance assessment in simulated patients). ALICE helps students gain and understand knowledge and offers the opportunity to apply this knowledge on virtual patients, which are important steps in Bloom's taxonomy in the cognitive domain [12] (Figure 3).

**Figure 1.** Screenshot of ALICE. Students can freely navigate an avatar through a virtual outpatient clinic (upper left) and freely interact with the virtual patient via a dynamic graphical user interface (GUI) (upper right). Students can communicate with the virtual patient (lower left) via the GUI and choose different medical examinations. Results of these examinations are presented either as image, text or video and remain uncommented at this point (lower right).
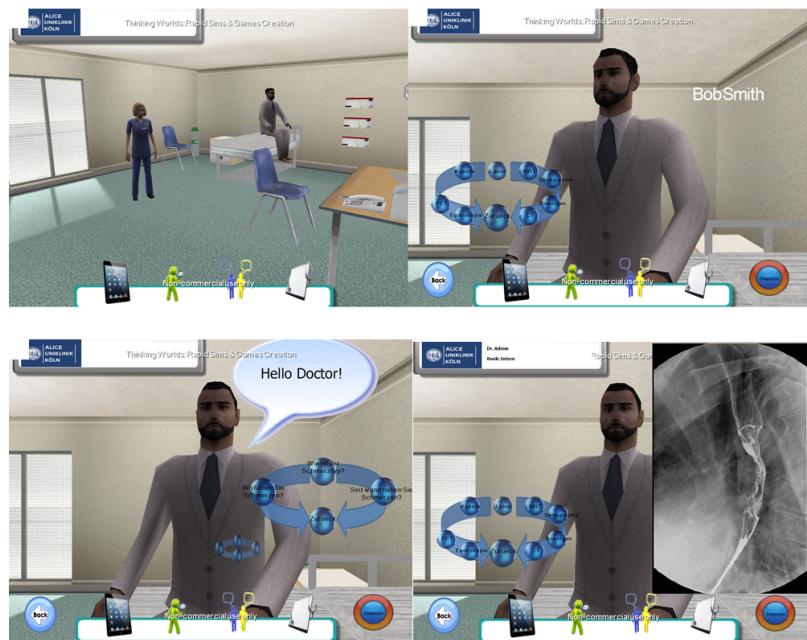


**Figure 2.** Simulator design is based on the concept of Miller's pyramid (upper part) and was developed to support clinical education in the first two steps. Modified from Miller 1990 [11].
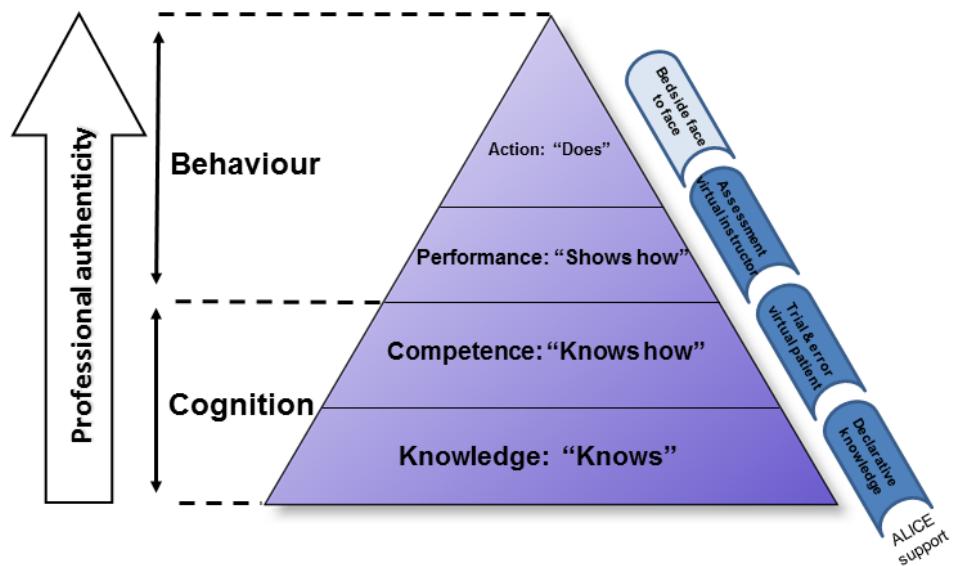
**Figure 3.** Bloom's taxonomy of the cognitive domain: ALICE supports learning on the first three steps (Foundation Thinking).
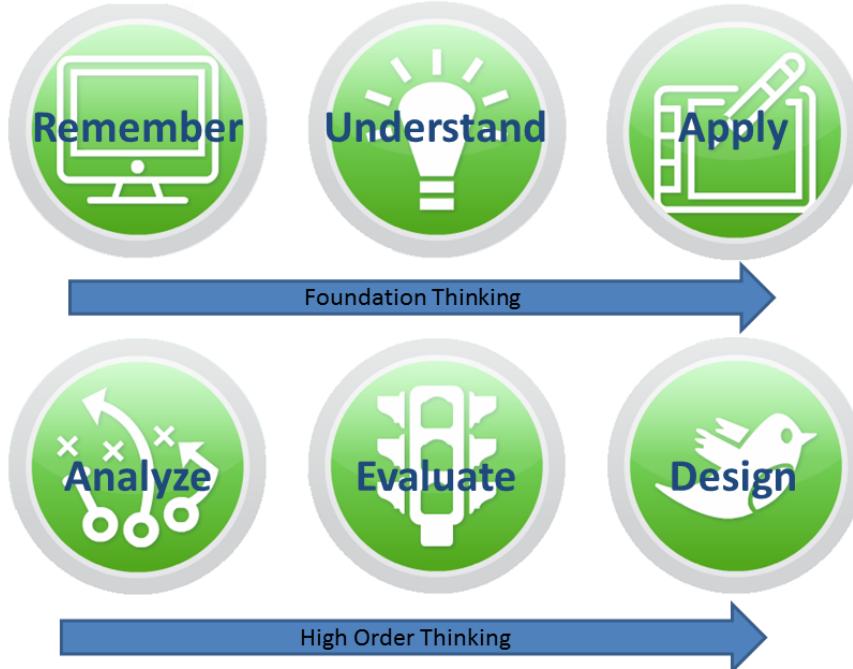


## Adding Medical Content

ALICE can easily be expanded by adding content modules that include a specific disease. These teaching modules contain all information about the underlying declarative and procedural knowledge as well as patient characteristics and images. These modules can be added via a special editor. Determination of impact on clinical reasoning required the development of a new simulator module. To support or reject the hypothesis that repetitive simulator use can consolidate clinical reasoning, the following requirements were defined: The simulator should mimic a disease with a standardized workflow in diagnosis and therapy. It is mandatory that there are concurrent therapeutical concepts that depend on specific clinical findings. Moreover, this specific disease should not have been a focus in the previous clinical curriculum, to minimize the influence of already obtained knowledge.

## Study Design

The module was evaluated in the context of a surgical seminar held at the surgical faculty of the University of Cologne. A total of 62 third-year students were taught in a small group (<5 students), each accompanied by an experienced board-certified surgeon. Each student received the patient files from 2 real patients diagnosed with esophageal cancer. Students were not aware of the diagnosis. Students were asked to summarize the findings in a clinical reasoning summary. This included diagnosis, diagnostic tests, and suggested therapy. In addition, students answered multiple-choice questions taken from the official state examination board to determine the preexisting declarative knowledge about the underlying disease. This presimulator questionnaire was stored for later analysis. After completion of the presimulator questionnaire, students worked with ALICE. Students' performance was reviewed immediately after each case as procedural review of students' performance immediately after training is known to be an effective incentive for knowledge gain [13]. A virtual instructor summarizes the performance based on a short comparison of the students' choices and stored SOPs. Furthermore, the virtual instructor summarizes the underlying declarative knowledge and optimal procedural pattern. The debriefing ends with a video presentation of the corresponding surgical procedure and a summary of the underlying declarative knowledge (Figure 4).

After completing the simulator cases, students had to perform a reassessment of the clinical reasoning of the 2 patients and complete a postsimulator questionnaire that contained the same questions as before. Cases were recapped and summarized after simulator evaluation by the clinical teacher in a small-group, face-to-face learning.

**Figure 4.** Debriefing scene represents a virtual instructor who explains and summarizes the different findings. Debriefing ends with a video presentation of the specific surgical procedure and a summary of the underlying declarative knowledge.



## Evaluation

To test the hypothesis that simulator use has an impact on knowledge gain and students' motivation, ALICE was validated in the form of an experimental study. The variable, simulator performance, was measured using the following parameters: correct order of the diagnostic pathway, correct or incorrect diagnosis, and correct therapy. ALICE stored the user behavior at the server level, logging students' decisions. Students' acceptance and their opinion about the effectiveness and applicability were determined by means of a questionnaire using a (forced choice) 6-point Likert scale (Figure 5). The variable "impact on future performance (predictive validity)" is an important parameter for simulator quality [14,15]. It was tested on several levels: (1) by comparison of pre- and postsimulator

clinical reasoning files, (2) by comparison of simulator performance between Cases 1 and 3, and (3) by comparison of pre- and postsimulator multiple-choice questions. Student feedback was measured using a descriptive Likert scale. Evaluation was approved as a pilot project by the Educational Committee of the Medical Faculty at the University of Cologne. The Institutional Review Board was informed and there were no objections.

Evaluation of simulator acceptance and students' opinions were analyzed using descriptive methods such as the Likert scale. Simulator performance was analyzed using the McNemar test. Performance in the pre- and postquestionnaire multiple-choice questions was analyzed using the Student $t$ test. $P$ .05 was considered significant. Data were analyzed using the SPSS software package version 20.

**Figure 5.** Acceptance, effectiveness, and applicability and preexisting computer affinity were determined using a Likert scale questionnaire where students had to mark one of 6 checkboxes for each question: 1: very reasonable, 2: mainly reasonable, 3: reasonable, 4: partially reasonable, 5: hardly reasonable, 6: not reasonable.
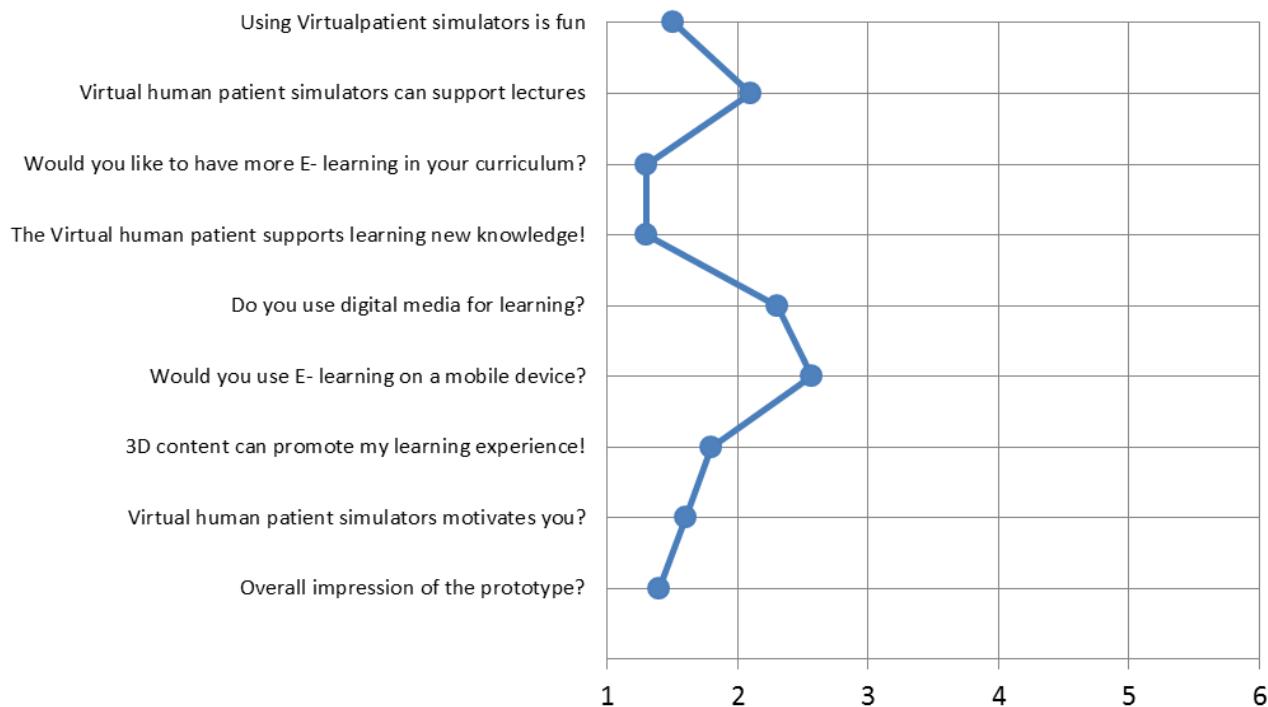


## Results

### Module Development

The content module contains the declarative and procedural knowledge of patients diagnosed with esophageal cancer. The diagnostic and therapeutic workflow of this disease is standardized. However, this disease requires an individual risk analysis as the chosen therapy depends on the tumor stage [16] and functional factors [17]. Although esophageal cancer is a rare disease in Europe, it is a common disease at our hospital. As a Center of Excellence for Surgery of the Esophagus and Stomach, we see more than 400 such patients and perform more than 160 esophagectomies annually. Because the topic of esophageal cancer was not part of the previous curriculum until

that point, we were able to minimize influence of preexisting knowledge.

The esophageal cancer module was added to the ALICE framework and included 3 cases with different tumor stages and different therapeutic options (Table 1). More patients can easily be added when necessary. Declarative and procedural learning targets were based on the German medical examination regulations and served as a template for the procedural content. The correct diagnostic and treatment patterns were defined in process charts (Figures 6 and 7) by 2 different experienced clinical teachers and served as templates for the analysis of student performance. Clinical findings as well as corresponding images, videos, and tables from real patients were collected. Radiological images were interpreted by an experienced radiologist while gastroscopy videos were interpreted by an experienced endoscopist.

**Table 1.** Three cases with patients diagnosed with esophageal carcinoma.[a]

|             | Case 1       | Case 2                      | Case 3                  |
|-------------|--------------|-----------------------------|-------------------------|
| Diagnosis   | Adenocarcinoma | Adenocarcinoma            | Squamous cell carcinoma |
| Tumor stage | T3 Nx M0     | T4 Nx M1                    | T2 Nx M0                |
| Diagnostics | Standard     | Plus PET computed tomography | Plus bronchoscopy      |
| Therapy     | Neoadjuvant  | Palliative                  | Surgery                 |
|             | Restaging    |                             |                         |
|             | Surgery      |                             |                         |

[a]The 3 cases differ in tumor stage and histology, and thus require a slightly different diagnostic pathway and therapeutical approach.

**Figure 6.** Therapeutic workflow based on German evidence-based guidelines. Parameters are tumor depth (T1 to T4), lymph node manifestation (N+ or N-), and metastasis (M1 or M0).
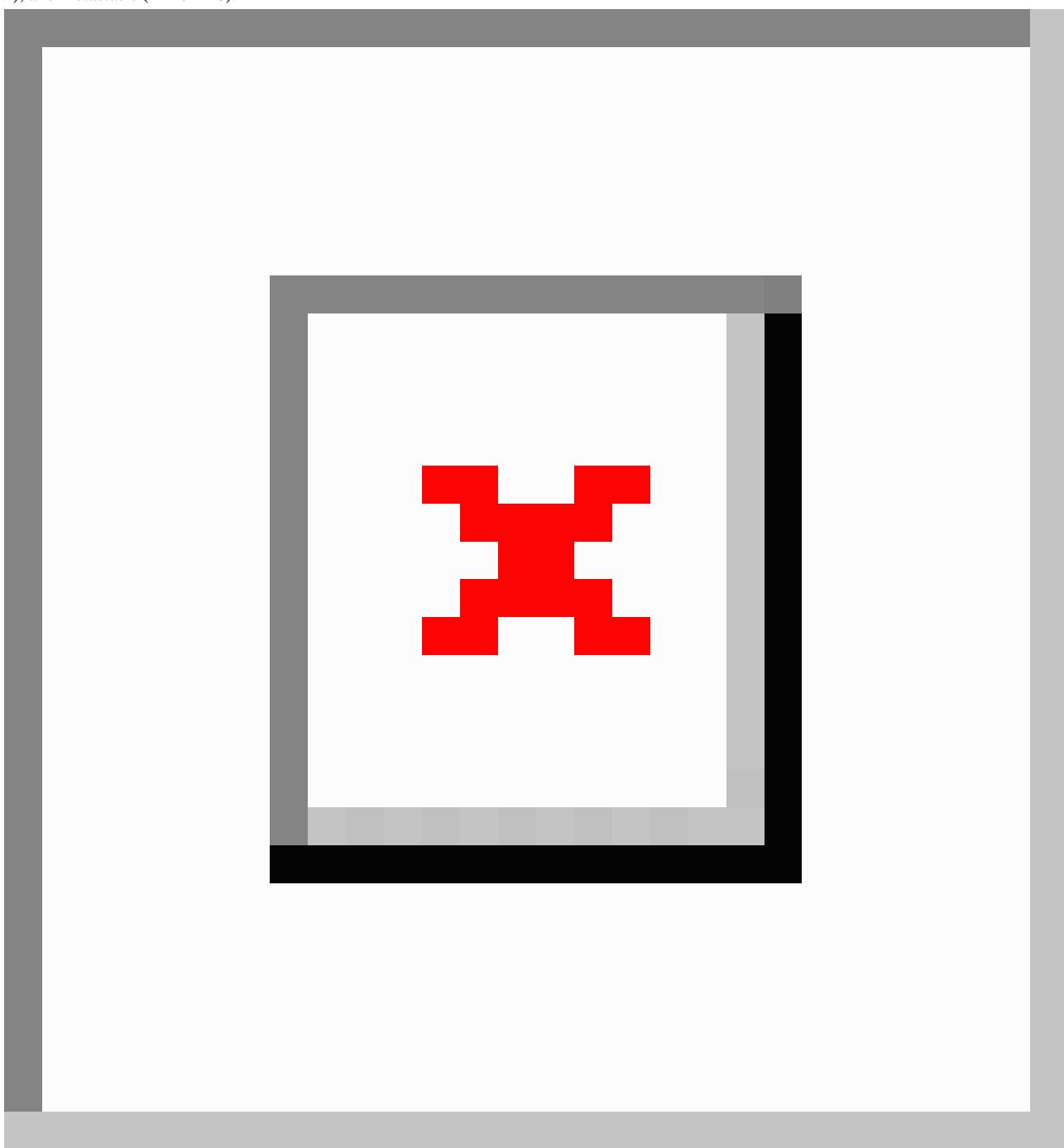


## Evaluation

A total of 62 students participated in the survey. Students' acceptance and their opinion about the effectiveness and applicability were determined using a (forced choice) 6-point Likert scale. Six response categories were intentionally chosen because learning performance in Germany is traditionally measured on a 6-point scale and participating students were therefore familiar with a 6-level grading system. Likert scale assessment was averaged and is summarized in Figure 5. Students showed a high level of motivation when using the simulator as most of them had fun using it. Most of the students demand more e-learning in their medical curricula. These students showed a high acceptance of the simulator prototype and would frequently use a simulator of this kind. Most of the students use computers on a daily basis. The majority of the students agreed that ALICE taught new knowledge.

Predictive validity was tested by measuring the impact of simulator use on declarative knowledge. Ten multiple-choice questions that were asked before and after the simulation were correlated. In the prequestionnaire, the mean number of correct answers was 5 out of 10 (SD 1). In the postquestionnaire, the students achieved 7 out of 10 correct answers (SD 1). Hence, ALICE showed a significant impact on declarative knowledge gain ($P<.01$).

The impact of simulator use on future clinical decision making was tested by comparing clinical decision making before and after simulator use (Table 2). Students were asked to write down the most probable diagnosis and the suggested therapy. These answers were compared by the tutor and evaluated as "right" or "wrong." In the prequestionnaire, 65% (40/62) of students chose the right diagnosis whereas after simulator use, 92% (57/62) of students chose the right diagnosis. In the prequestionnaire, only 32% (20/62) of students chose the right therapeutic concept, and in the postquestionnaire, 76% (47/62) of students prescribed the suitable therapy. As this improvement was significant, simulator use had a positive impact on clinical decision making.

**Figure 7.** Template of an "optimal" diagnostic process (light and dark blue subitems can be freely chosen). Staging tests are again subdivided into more precise tests (eg, CT into "CT Abdomen," "CT Thorax," "PET CT").
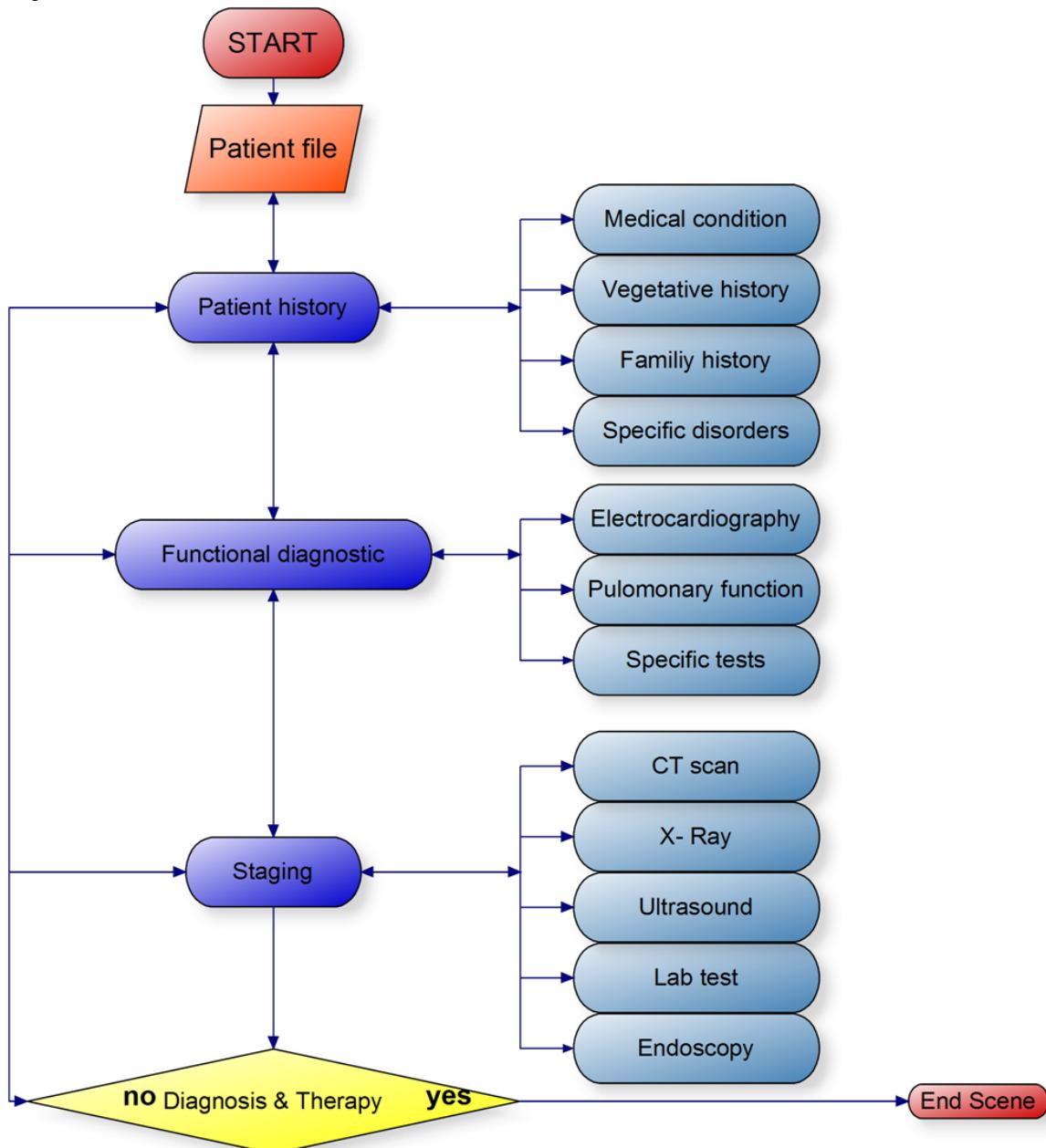
**Table 2.** Detailed results from the pre- and postquestionnaire where the mean number of correct answers rose from 5/10 to 7/10 (*P*<.01).

| Parameters | Correct answers, n | | *P* value |
|---|---|---|---|
| | Presimulator | Postsimulator | |
| Number of multiple-choice questions (out of 10) | 5 (SD 1) | 7 (SD 1) | <.01 |
| Students who made correct diagnosis (full text) | 40 | 57 | <.01 |
| Students who choose right therapy (full text) | 20 | 47 | <.01 |
| Students who made correct simulator diagnosis | 48 | 52 | Not significant |
| Students who chose correct simulator therapy | 27 | 44 | <.01 |
| Students who chose correct pathway | 23 | 21 | Not significant |

Reproduction of trained content was determined by comparing the simulator performance in Case 1 with Case 3 as these cases dealt with a similar diagnosis but different tumor stagings and different therapies. The correct pathway parameter was based on the flow diagram shown in Figure 6. Medically nonindicated tests as well as wrong sequence of performed tests resulted in a negative rating. Simulator use showed no positive impact on the correct pathway parameter. The diagnosis and therapy parameters were compared on students' choices based on pull-down menus with single statements. The diagnosis parameter showed no significant improvement between the two simulator cases. However, students showed an improvement in performance for the right therapy parameter (*P*<.01).

## Discussion

### Principal Findings

This study describes the successful establishment of a simulator (ALICE) for learning decision making in oncological patients. Previous studies revealed that using virtual patient simulators can have a positive impact on learning success [18]. Immersive patient simulators enhance virtual patient simulators thanks to an immersive environment where the user becomes part of the simulation. There is evidence that immersion plays a fundamental role in virtual reality simulators, as identification with the avatar impacts motivation and improves learning success [7]. However, the degree of immersion is influenced by many factors and furthermore probably not all students are equally suited to this learning style [19].

For clinical teachers, information about validity and usability are important as new educational concepts compete against the established courses. Knowledge of the SOPs in diagnosis and therapy is essential when treating oncological patients [20]. Simulator design is based on the concept of Miller's pyramid [11] (Figure 2) and was developed to support clinical education in the first three steps. Miller's pyramid gives a vivid impression of the necessary steps in acquiring and assessing knowledge. While our simulator is designed to address levels one and two, level four (Action: Does) is assessed in vivo (eg, bedside teaching), and therefore cannot be addressed by our simulator. For level three (Shows how), the parameter on reproduction of trained content was used. However, performance on this level is usually assessed in vitro, for instance, in simulated patients in an Objective Structured Clinical Examination (OSCE)

environment. It is questionable whether virtual patients can replace simulator patients in an OSCE environment. We cannot answer this question with this study as this would require a comparison of two randomly assigned groups (virtual versus OSCE patients).

However, clinical reasoning includes not only knowledge of SOPs but is also influenced by many other factors, as also summarized in Bloom's learning taxonomy [12], which reveals the limitations of immersive virtual patient simulators in clinical education. In the cognitive domain, ALICE focuses on supporting foundation thinking (Figure 3) as training of critical thinking is hard to implement within a simulation.

Moreover, two other domains of Bloom's taxonomy are not addressed by ALICE: in the affective and psychomotor domains, weighting clinical findings and evaluating different hypotheses, professional attitude, and behavior are key in clinical education and depend on the experience of the teacher. These skills are very difficult to impart using immersive virtual patient simulators. Therefore, the gold standard on clinical education is the small-group attendance learning [3] accompanied by a medical teacher [4,5].

Learning in small groups is impaired by the increasing workload of hospital doctors [21] and restrictive working time directives. Small-group learning is most effective when students have a similar knowledge level. Here, ALICE can potentially support clinical education as the simulator can prepare students for the attendance-based courses. Students can learn the reasoning of a practitioner at their own individual pace with repetition as required. Moreover, a performance-based assessment can test the students' problem-solving skills [22] and ensure sufficient student preparation.

ALICE showed an impact on knowledge gain as students displayed a significant improvement in finding the right therapeutic concept after working with the simulator. This is also supported by other studies for different validity levels [18,23]. As these assessments are often focused on a specific part of procedural knowledge [24], we also measured knowledge gain in terms of declarative knowledge. The comparison of pre- and posttest performance revealed an increase in declarative knowledge.

ALICE uses a three-dimensional engine similar to computer games and enables an immersion that is known to have a positive

impact on students' motivation [25] and even learning performance [7]. In this study, students were enthusiastic and motivated while learning with ALICE. This was to be expected as this concept meets the expectations of Generation Y [26]. Nevertheless, this enthusiasm is a pitfall when it comes to analyzing student performance. Contrary to reality, students tended to deliberately select all available technical examination methods one after another as they were fascinated by the high number of images and videos. As students did not exclude nonmedically indicated tests, the comparison of simulator performance in terms of the correct pathway parameter between Cases 1 and 3 was not successful. Even when students were briefed before simulator use to select only the indicated tests, this behavior was detectable. Future simulator modification is necessary to motivate students to find the optimal way instead of clicking all available tests.

## Conclusion

ALICE is an appropriate educational tool for teaching procedural knowledge. It has a positive effect on knowledge gain and boosts student motivation. When used as required preparation in education, it can possibly lead to more efficient bedside teaching.

## Conflicts of Interest

None declared.

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## Abbreviations

**ALICE:** Artificial Interface for Clinical Education
**IPS:** immersive patient simulator
**OSCE:** Objective Structured Clinical Examination
**SOP:** standard operating procedure

Original Paper

# Impact of Scientific Versus Emotional Wording of Patient Questions on Doctor-Patient Communication in an Internet Forum: A Randomized Controlled Experiment with Medical Students

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## Abstract

**Background:** Medical expert forums on the Internet play an increasing role in patient counseling. Therefore, it is important to understand how doctor-patient communication is influenced in such forums both by features of the patients or advice seekers, as expressed in their forum queries, and by characteristics of the medical experts involved.

**Objective:** In this experimental study, we aimed to examine in what way (1) the particular wording of patient queries and (2) medical experts' therapeutic health concepts (for example, beliefs around adhering to a distinctly scientific understanding of diagnosis and treatment and a clear focus on evidence-based medicine) impact communication behavior of the medical experts in an Internet forum.

**Methods:** Advanced medical students (in their ninth semester of medical training) were recruited as participants. Participation in the online forum was part of a communication training embedded in a gynecology course. We first measured their biomedical therapeutic health concept (hereinafter called "biomedical concept"). Then they participated in an online forum where they answered fictitious patient queries about mammography screening that either included scientific or emotional wording in a between-group design. We analyzed participants' replies with regard to the following dimensions: their use of scientific or emotional wording, the amount of communicated information, and their attempt to build a positive doctor-patient relationship.

**Results:** This study was carried out with 117 medical students (73 women, 41 men, 3 did not indicate their sex). We found evidence that both the wording of patient queries and the participants' biomedical concept influenced participants' response behavior. They answered emotional patient queries in a more emotional way (mean 0.92, SD 1.02) than scientific patient queries (mean 0.26, SD 0.55; $t_{74}$=3.48, $P$<.001, $d$=0.81). We also found a significant interaction effect between participants' use of scientific or emotional wording and type of patient query ($F_{2,74}$=10.29, $P$<.01, partial $\eta^2$=0.12) indicating that participants used scientific wording independently of the type of patient query, whereas they used emotional wording particularly when replying to emotional patient queries. In addition, the more pronounced the medical experts' biomedical concept was, the more scientifically (adjusted β=.20; $F_{1,75}$=2.95, $P$=.045) and the less emotionally (adjusted β=−.22; $F_{1,74}$=3.66, $P$=.03) they replied to patient queries. Finally, we found that participants' biomedical concept predicted their engagement in relationship building (adjusted β=−.26): The more pronounced their biomedical concept was, the less they attempted to build a positive doctor-patient relationship ($F_{1,74}$=5.39, $P$=.02).

**Conclusions:** Communication training for medical experts could aim to address this issue of recognizing patients' communication styles and needs in certain situations in order to teach medical experts how to take those aspects adequately into account. In

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addition, communication training should also make medical experts aware of their individual therapeutic health concepts and the consequential implications in communication situations.

## Introduction

Internet communication enables both medical experts [1-5] and laypeople [3-6] to perceive as well as produce and communicate health-related information online. At the same time, knowledge in the field of health and medicine is very complex, often contradictory, highly sophisticated [7,8], and therefore often difficult to evaluate. One way in which laypeople deal with this situation is to consult medical experts in expert online forums [9-13]. Although their legal assessment is disputed, medical expert forums are increasingly used for purposes of counseling patients and other people who seek medical advice [13-18]. It is characteristic of medical expert forums that patients and doctors have never seen each other before and, therefore, have no established doctor-patient relationship. This is relevant because a good doctor-patient relationship has a significant impact on various variables that support therapeutic success [19], such as patient adherence [20,21] or informed decision making [22].

Medical expert forums as a special communication channel create new challenges for medical experts arising from that particular kind of communication. Such text-based communication differs strongly from real-life counseling situations. This includes reduced audiovisual and social context clues [23-25]. Often, there is only a short period of time to establish a trustful relationship between physicians and patients; however, in computer-mediated situations, people need even more time to establish a trustful relationship than in face-to-face scenarios [26]. In addition, medical experts have to communicate with unknown and largely anonymous patients. So far, the factors have been strongly underexposed that might have an impact on how medical experts manage to be responsive to advice seekers in text-based Internet forums. Because online consultation should fulfill the same criteria of doctor-patient communication as in real-life counseling (in particular, information exchange and relationship building [27,28]), it is highly relevant to examine how potential factors of influence affect these aspects.

Previous research about medical expert forums has shown that patients consult an Internet physician for many different reasons. Typically, patients want to receive both general and individualized information as well as professional advice and/or emotional support [9,10,29,30]. So far, some studies have been published about patient expectations [9,13,29] and patient communication behavior [30-33] in health-related online forums. But very little is known about how features of the advice seekers, as expressed in their forum queries, and characteristics of the medical experts influence information exchange and relationship building between patients and doctors. Most research on expert forums has been merely based on surveys [14,15,29] or qualitative analyses of field observations [13,30,31,33]. In this study, we address this research gap both methodologically and with regard to content by investigating the communication of medical experts in an online forum in a randomized controlled experiment.

In the following sections, we discuss the potential impact of both patients' and doctors' characteristics on the experts' communication behavior. In particular, we consider the role of the wording of patient queries in terms of scientific versus emotional phrasing and of the experts' beliefs about medicine (ie, their individual therapeutic health concept).

## Impact of Patient Queries

As in all text-based communication, an expert online forum offers a reduced communication setting [25] in which the post or query of another user is the crucial external stimulus that triggers the communication process. For this reason, the wording of the queries may play a very important role. It is plausible that the response behavior of medical experts in such forums is affected by the patient requests themselves. In communicating with patients, the capability of a medical expert to adapt his or her own communication style to that of a patient is an important conversational skill. Research about tailored health communication shows that the fit between health messages and the individual characteristics of patients or advice seekers influences how they handle those messages [34-39]. Tailored messages are processed more deeply, for instance [36], and are better learned [34] than nontailored messages. This illustrates the great theoretical and practical relevance of this aspect of communication.

It is well established that people often imitate the behavior [40] and the communication style of their interaction partners [41,42]. This is particularly conveyed in people's ability to mimic emotional expressions [43-45]. Recent research has found that laypeople tend to reply more emotionally to forum queries containing personal experiences than to fact-oriented queries [32]. In conversation research, the concept of *lexical entrainment* [46-48] refers to overlaps between conversational partners in their choice of words. Research about written communication between medical experts and laypeople found that the answer of a medical expert to a patient query was influenced by the word choice in the query [46,48]. Accordingly, medical experts are also assumed to apply a conversation technique of imitating conversational partners' word choice to text-based communication in expert online forums. Thus, we expect that medical experts will reply in a more emotional way to emotional patient queries (Hypothesis 1a) and in a more scientific way to scientific patient queries (Hypothesis 1b).

## Impact of Medical Experts' Therapeutic Health Concept

In addition to the impact of the communication partner, the communication process is also influenced by individual characteristics, such as personal values, attitudes, or beliefs. Medical experts' beliefs about medicine (ie, about the relevant aspects of health, diagnosis, and therapy in medicine) are strongly triggered by the *International Classification of Diseases* (*ICD*), which is the most common classification catalog in conventional medicine [49]. The *ICD* is clearly based on a biomedical conception of diagnostic and therapeutic approaches. A biomedically oriented therapeutic health concept (hereinafter called "biomedical concept") adheres to a distinctly scientific understanding of diagnosis and treatment and a clear focus on evidence-based medicine [50-52]. At the same time, it is occasionally recorded that personal and emotional aspects of doctor-patient relationships are largely disregarded in communication that is derived from the biomedical perspective [53]. Medical students, for instance, state that they feel insufficiently prepared regarding psychosocial skills [54]. Even though psychology is considered to be an integral part of medical professionalization, psychosocial aspects are often not regarded as important from a biomedical point of view [55]. We assume that the strength of the individual biomedical concept of medical experts will have an impact on their communication style in patient counseling. This should apply to communication in online forums as well. Accordingly, we expect that the more pronounced the medical experts' biomedical concept, the more scientifically they will reply to patient queries (Hypothesis 2a). We also assume that the more pronounced the medical experts' biomedical concept, the less emotionally they will reply to patient queries (Hypothesis 2b).

## Interaction Effects of Patient Queries and Medical Experts' Biomedical Health Concept

An interesting research question is whether the style of patient requests and the medical experts' biomedical concept will interact in having an impact on physician-patient communication. Individuals tend to be more attracted to people who they perceive to have similar attitudes or beliefs to their own [56,57]; for example, when patients perceive similarities between themselves and their doctor, they are more satisfied with the medical care [58]. There is also a positive relationship between information-sharing behavior and similarity [59]. It has been found that information transfer is more likely between individuals who display similar attitudes. Accordingly, we assume that medical experts with a pronounced biomedical concept who encounter patient queries that express some sort of like-mindedness (ie, include scientific wording) will be willing to provide more information to those patients than to others without that fit (Hypothesis 3).

Another important aspect of a doctor-patient interaction is the development of a positive relationship between physicians and patients [27]. With regard to the restrictions of text-based communication in an online forum (eliminating large parts of nonverbal and paraverbal communication channels), one means of relationship building for physicians is to verbally express their respect and acceptance of a communication partner, for

instance, through courtesy or polite expressions of salutation and valediction [60,61]. In line with our previous reasoning, we assume that perceived similarity will also have an impact on that kind of communication behavior. Therefore, we expect that medical experts with a pronounced biomedical concept who encounter scientifically phrased patient queries will engage more strongly in relationship building than without that fit (Hypothesis 4).

## This Study

We set up an experimental study to investigate how advanced medical students with a more- or less-pronounced biomedical concept reacted to patient queries presented to them in an expert online forum. Those patient queries had either scientific or emotional wording. The goal of the study was to examine how the particular wording of the patient queries and the strength of the medical students' biomedical concepts affected participants' response behavior in the online forum. We also aimed to examine how the biomedical concept and the patient queries would interact. Outcome variables of interest were (1) participants' use of scientific and emotional wording, (2) the amount of communicated information, and (3) engagement in relationship building in their reply posts.

We created an online forum that participants used as a part of communication training that was embedded in a gynecology class. This forum was developed using the open-source server-side scripting language PHP. It was divided into a shared discussion forum and individual (password-protected) subforums where participants had the opportunity to respond to patient queries. For the study, each participant replied to a particular patient query about mammography screening in her or his individual subforum (time limit for reply: 15 minutes). These queries either included scientific or emotional wording in a between-group design.

# *Methods*

## Sample

This study was carried out with 117 medical students in the Faculty of Medicine of the University of Tuebingen (Germany). All participants were students in the ninth semester of medical training. All medical students in the ninth semester who attended the communication training were allowed to participate in the study because this was part of their gynecology education. We considered advanced medical students to be medical experts [48,62] according to the definition of an expert as "a person with training in a particular field who is able to tackle complex problems because of this training and additional practical experience" (p 317 [62]). The students were divided into groups of 8 to 10 participants. Each week, one group passed through the study. The inquiry period lasted 13 weeks. In each group, half of the students were randomly assigned to one experimental condition and the other half to the other experimental condition (scientific vs emotional wording of patient queries). The randomization was ensured by a computer-generated assignment of individual log-in information (anonymous code and password). By logging in, the students were automatically guided to one of the 2 experimental conditions. At this point, participants were not aware of the fact that there were different

kinds of patient queries. After the study was completed, students were debriefed by the instructor of their class.

## Procedure and Experimental Material

First, we collected demographic data. Then, we measured the strength of the participants' biomedical concept. Subsequently, each participant responded to one fictitious patient request in the online expert forum in the doctor's role. We recorded their individual reply posts and analyzed them regarding the use of scientific and emotional wording, the amount of communicated information, and engagement in relationship building.

Half of the participants answered patient queries that were written using scientific wording and the other half replied to a request written in an emotional style. The scientific queries included terms such as "scientifically proven," "evidence," and "study." The emotional queries contained wordings such as "I am concerned," "makes me anxious," and "my feelings." In order to ensure that it was not an unintended aspect of a particular query that triggered participants' replies, we created 6 different patient queries (3 with scientific and 3 with emotional wording). The queries were comparably long (scientific queries: mean 74.67 words, SD 28.75; emotional queries: mean 81.00 words, SD 15.13). The scientific queries contained a mean 3.67 scientific words (SD 1.53) and the emotional queries contained a mean 3.00 emotional words (SD 1.00). The scientific queries did not contain any emotional words and the emotional queries did not contain any scientific words. Both types of queries asked the medical experts for information about mammography screening. With regard to content, the patient queries addressed questions such as whether and why a mammogram was suitable for their individual situation or asked about the risks and benefits of mammography and other diagnostic methods.

## Measures

To measure the strength of participants' biomedical concept, we used the biomedical subscale of the Therapeutic Health Concepts Scale [63]. Participants were asked to rate the importance of 5 characteristic biomedical terms (diagnosis, science, evidence-based methods, standardized tests, and medical guidelines) on 6-point Likert scales ranging from 1 (not important) to 6 (very important). Internal consistency for that scale was acceptable ($\alpha$=.66).

To capture the outcome variables, we analyzed the answers of the participants in coding-and-counting procedures. The coders of participants' answers were blinded to the experimental condition. This was accomplished by downloading only the answers of the participants from the online forum—and not the corresponding patient query. This ensured that the raters had no hint as to the experimental condition. Based on a post hoc qualitative content analysis, we identified 19 scientific and 18 emotional keywords on the basis of a subset of replies. The identification of keywords was performed by the first author and validated by the third author following existing literature [49,64]. Examples of scientific keywords were "statistic," "evident," or "to prove." Examples of emotional keywords were "anxiety," "sorrow," or "to calm." The whole set of scientific and emotional words is presented in Multimedia Appendix 1.

In our analysis, we counted how often these words were used in total in each of the answers of the individual medical students.

Regularly, several units of information were provided in one reply post, for example, information about organizational issues, about risk factors, or advice for further diagnostic course of action. In a first step, every unit of information was coded using the codes "advice," "organizational information," "information about mammography," "information about other methods," "information about breast cancer," and "information about risk factors." To measure the amount of information provided by the participants in their reply posts, we calculated a total score of all given units of information. Half of the reply posts were coded by 2 independent raters for units of information. Interrater reliability was $r$=.85. Because of this high level of agreement, the remaining reply posts were coded by one rater.

To measure the participants' attempts to build a positive doctor-patient relationship, we also applied a coding-and-counting procedure. Two independent coders identified wording in which participants attended to patients' needs and wants (eg, "If you have further questions, please do not hesitate to contact me") and situations in which participants thanked the patients for their interest, request, or trust. Interrater reliability was $r$=.67.

## Statistical Analysis

We used 2 independent sample $t$ tests to examine the impact of patient queries on the use of scientific and emotional wording, respectively. We also conducted a mixed model analysis of variance (ANOVA) with patient queries as the between-subject factor and the use of scientific and emotional wording as the within-subject factor. To examine the influence of medical experts' biomedical concept on the use of emotional and scientific words, we calculated linear regression models. Finally, we calculated moderated regression analyses to test main and interaction effects of patient queries and biomedical concept on the amount of communicated information and on the participants' attempt to build a positive doctor-patient relationship. The sample size was calculated to detect moderate to large effects ($d$=0.65, $f$=0.35, $f^2$=0.15) with 90% power at the 5% significance level using G*Power 3.1.7 [65]. This procedure resulted in a total sample size requirement of 84 for independent sample $t$ tests, 68 for ANOVAs, and 59 for linear regression analyses.

## Ethical Considerations

This research was performed in accordance with the Declaration of Helsinki. The study was approved by the head of the gynecology program at the University Hospital Tuebingen and the Faculty of Medicine as well as by the Competence Centre for University Teaching in Medicine. All students participated voluntarily and anonymously. They gave informed consent and were informed about privacy protection, their right to terminate participation at any time without disadvantages, and about the general purpose of the study.

# *Results*

## Participant Characteristics

Four students missed the training session where the study took place. In addition, because of technical difficulties (eg, server failure), activity data of 37 participants were not properly recorded and could not be used for further analysis. Nevertheless, we were able to collect the demographic data of 38 of these 41 participants. Included and excluded participants did not differ regarding age ($P=.46$) or sex ($P=.86$) and both conditions were equally affected by the loss of participants. Thus, the following results refer to the data of the remaining 76 participants (potential consequences of this reduced sample are discussed subsequently). In all, 38 of those participants were assigned to the scientific and the other 38 participants were assigned to the emotional wording condition. Table 1 shows participants' characteristics (sex and age) in both conditions as well as the characteristics of the participants with missing data. The loss of participants is also illustrated in Figure 1.

**Table 1.** Participant characteristics (N=117).

| Participants | Participants in the scientific wording condition n=38 | Participants in the emotional wording condition n=38 | Participants with incomplete data n=41 |
|---|---|---|---|
| **Sex, n** | | | |
| Women | 25 | 23 | 25 |
| Men | 13 | 15 | 13 |
| N/A | — | — | 3 |
| **Age, n** | | | |
| 19-22 | 2 | 1 | 4 |
| 23-26 | 26 | 24 | 18 |
| 27-30 | 7 | 9 | 13 |
| >31 | 3 | 4 | 3 |
| N/A | — | — | 3 |

**Figure 1.** Participants' progress through the phases of the study.
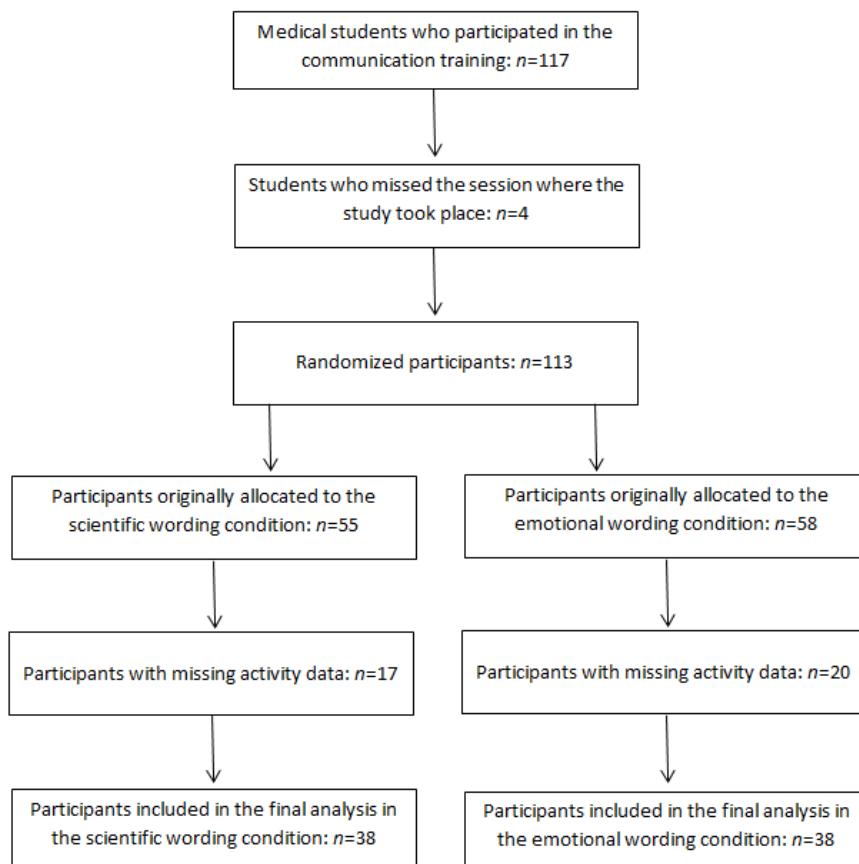
## Impact of Patient Queries

In Hypothesis 1a, we assumed that medical experts would reply in a more emotional way to emotional patient queries than to scientific queries. The results supported this hypothesis ($t_{74}=3.48$, $P<.001$, $d=0.81$). Emotional patient queries were answered in a more emotional way (mean 0.92, SD 1.02) than scientific patient queries (mean 0.26, SD 0.55).

According to Hypothesis 1b, we assumed that health care professionals would reply in a more scientific way to scientific patient queries than to emotional patient queries. Even though the descriptive data hinted toward this hypothesis (scientific patient queries: mean 1.11, SD 1.25; emotional patient queries:

mean 0.82, SD 1.04), it was not statistically supported by the data ($t_{74}=1.10$, $P=.14$).

To further explore the basis of these (absent) effects, we calculated a mixed model ANOVA. We found that, in general, scientific terms were used more frequently (mean 0.96, SD 1.15) than emotional terms (mean 0.59, SD 0.88; $F_{1,74}=6.23$, $P=.02$, partial $\eta^2=0.08$). In addition, we found a significant interaction effect between use of scientific and emotional wording and the type of the patient query ($F_{2,74}=10.29$, $P=.002$, partial $\eta^2=0.12$), indicating that participants used scientific wording quite independently of the type of patient query, whereas they used emotional wording particularly in replying to emotional patient queries (see Figure 2).

**Figure 2.** Interaction effect between type of patient query and use of scientific and emotional wording. Standard errors are represented by error bars attached to each column.
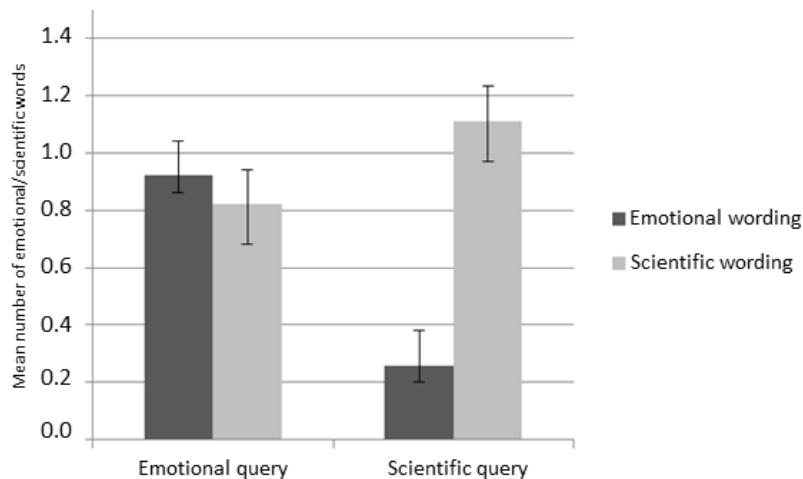


## Impact of the Biomedical Concept

As a first step, we analyzed how pronounced the participants' biomedical concept was. Their rating (mean 4.88, SD 0.63) was significantly higher than the midpoint (3.5) of the 6-point scale ($t_{75}=19.07$, $P<.001$, $d=2.19$). This indicates that the participants had a strong biomedical orientation.

Hypothesis 2a stated the expectation that the more pronounced the medical experts' biomedical concept, the more scientifically they would reply to patient queries. This hypothesis was supported by the data: a greater level of medical experts' biomedical concept was significantly associated with using scientific terms (adjusted β=.20). A linear model with biomedical concept as predictor explained 4% of the variance ($R^2=.04$, $F_{1,75}=2.95$, $P=.045$).

In Hypothesis 2b, we assumed that the more pronounced the medical experts' biomedical concept, the less emotionally they would reply to patient queries. This hypothesis was also supported by the data: a greater level of medical experts' biomedical concept was significantly associated with using emotional terms to a lesser extent (adjusted β=−.22). A linear model with biomedical concept as predictor explained 5% of the variance ($R^2=.05$, $F_{1,74}=3.66$, $P=.03$).

## Interaction Effects of Patient Queries and Biomedical Concept

According to Hypothesis 3, we assumed that medical experts with a pronounced biomedical concept who encountered patient queries worded scientifically would be willing to provide more information to those patients than to others without that fit. To test this assumption, we conducted a moderated regression analysis. The overall model with biomedical concept, type of patient query, and the interaction term between biomedical concept and type of patient query was not significant ($R^2=.06$, $F_{3,71}=1.52$, $P=.22$) and so the hypothesis did not hold.

In Hypothesis 4, we expected that medical experts with a pronounced biomedical concept who encountered scientifically phrased patient queries would engage more strongly in relationship building than they would without that fit. To test this assumption, we conducted a further regression analysis. The overall model with biomedical concept, type of patient query, and the interaction term was not significant ($F_{3,71}=2.44$, $P=.07$). The overall model explained 9% of the variance ($R^2=.09$). As shown in Table 2, the biomedical concept of medical experts was the only significant predictor for relationship building: a greater level of medical experts' biomedical concept was significantly associated with less engagement in relationship building ($r=−.26$, $P=.01$).

**Table 2.** Model showing impact of biomedical concept, type of patient query, and the interaction term between biomedical concept and type of patient query on relationship building.

| Predictor | Regression coefficient | Standard error | Standardized β | $P$ |
|---|---|---|---|---|
| Biomedical concept | −.36 | 0.13 | −.28 | .04 |
| Patient query | .18 | 0.18 | .11 | .33 |
| Biomedical concept × patient query | .18 | 0.18 | .17 | .34 |

## Discussion

### Main Findings

In this experimental study, we examined in what way the particular wording of patient queries and medical experts' therapeutic health concepts had an impact on the communication behavior of the medical experts in an Internet forum. We found evidence that both the wording of patient queries and the strength of medical experts' biomedical concept influenced their response behavior. Our study showed that medical experts replied in a more emotional way to emotional patient queries than to scientific patient queries. However, there was no significant main effect of scientific patient queries on scientific wording in the experts' replies. The activity data of 41 participants were not available for the analysis; thus, the required sample size for an independent $t$ test was not fully achieved. Therefore, we cannot be sure whether there was indeed no effect of scientific patient queries or whether we were not able to detect this effect due to a slightly underpowered analysis.

An interaction effect between the use of scientific and emotional wording and the type of the patient query also pointed out why there was a significant result for emotional but not for scientific queries: the participants, in their responses as medical experts, used scientific terms independently of the type of the patient query, whereas emotional terms were particularly used in replying to emotional patient queries, but seldom in replying to scientific queries. This finding shows that medical experts did not automatically adapt their communication style to that of their patients in the online forum. It seems that the participants were firmly attached to the scientific orientation and the communication style of a mainly biomedically oriented field. Seen from the patients' perspective, it seems that patients who made their inquiry in a scientific way were more likely to receive an answer apparently adjusted to their individual point of view, whereas patients who asked in an emotional way had a better chance of receiving an answer that integrated scientific and emotional aspects. Research about the adaptation of experts' communication style to laypeople has found that this adaptation may occur in an active, conscious, and targeted way—as it is usually in research about tailored communication [34-37]. However, this adaptation may also happen in a less conscious and rather automatic fashion. One explanation for a less conscious adaptation is the availability hypothesis, which states that the wording that is used by the conversational partner is simply easier to access and therefore used more frequently [46]. The results of our study are partly in line with the availability hypothesis, but also show that there was no complete adaptation to the communication style of the patients. If this had been the case, medical experts would have been using less scientific words when replying to emotional patient queries.

We also investigated to what extent the communication process was influenced by medical experts' biomedical concept. We found that a stronger biomedical orientation was significantly associated with using scientific words more. Additionally, we found that a greater level of medical experts' biomedical concept was significantly associated with using less emotional words and engaging less in relationship building. It is necessary to point out, however, that medical experts' biomedical concept made only a small contribution to the explanation of variance. But we may conclude that even in an anonymous forum setting, medical advisors' personal therapeutic health concepts tend to influence the communication process. This is also remarkable in view of the fact that scientific convictions are, of course, far from excluding emotional, empathetic, and relationship-oriented communication styles. But it can occasionally be observed that personal and emotional aspects of a doctor-patient relationship are largely disregarded in the biomedical perspective [54-56]. This state of affairs appears to be reflected in these results.

### Limitations and Future Work

A potential limitation of this study is that the generalizability of the findings to the whole population of medical experts and to real online forums has to be handled with care. The study was carried out with medical students and was embedded in a seminar at the Faculty of Medicine. In addition, we cannot entirely rule out that the loss of the activity data of 41 participants has potentially changed the results of our study. It has been found in previous research that a loss of participants can change the interpretation of study results [66]. It also remains unclear to what extent the results are influenced by the scientific orientation of the medical field in general and whether medical doctors with many years of working experience would show comparable response behavior to patient queries. Additionally, we cannot be sure whether medical students would answer in the same way if they were faced with patient queries in a real forum on the Internet because the behavior of individuals may be strongly influenced by their particular environment. To examine this, the response behavior of medical experts in actual online forums should be analyzed in future studies according to the criteria presented here. Another limitation is that we focused only on the biomedical concept and on one medical topic (mammography). It is possible that other health professionals, such as physiotherapists, who possess a biopsychosocial therapeutic health concept [63,67], would show different response behaviors in replying to patient queries.

Moreover, this study focused only on the response behavior of medical experts and did not consider the reception and information procession of laypeople. It would be very interesting to apply an extended study design in which laypeople with various levels of scientific orientation or with particular

emotional needs would rate the experts' answers regarding understandability, usefulness, empathy, or importance to their own decision [68,69]. In addition, one could test laypeople's knowledge acquisition after reading the reply posts in order to examine whether they learn more from particular wordings or understand them more easily. It would also be relevant for future studies to consider other particular features of the quality of the information provided by medical experts in online forums, for instance, correct versus incorrect information. Finally, it would be interesting to examine how biomedically oriented medical experts would respond to scientific or emotional queries in alternative medical online forums [70,71].

## Conclusions

This study points out that the particular wording of patient queries and medical experts' therapeutic health concept had an impact on the communication behavior of the medical experts in an Internet forum. The results of the study demonstrated that advanced medical students already possessed key competences in Web-based communication with laypeople. We found that the participants replied in a more emotional way to emotional patient queries than to scientific patient queries. The result that they always used scientific terms—independently of the type of patient query—could be understood as an indispensable course of action in communicating about an evidence-based procedure such as mammography screening. This finding, however, could also be interpreted as a kind of communication

deficit because medical experts did not entirely adapt their communication style to that of their patients in the online forum. In addition, we found that even in an anonymous forum setting, medical advisors' personal therapeutic health concepts tend to influence the communication process. A greater orientation toward a biomedical perspective was significantly associated with using scientific words to a higher degree and using emotional terms to a lesser degree. This shows that medical experts tended to adhere to their own science-oriented communication style in conversations with laypeople. Finally, we found that medical experts who were highly oriented toward biomedicine engaged in relationship building to a lower degree than medical experts who had less orientation toward biomedicine. Accordingly, communication training for medical experts could set addressing the issue of recognizing patients' communication style and needs in a given situation as a learning objective in order to teach them how to take those aspects into account adequately. Furthermore, communication training should include making medical experts aware of their individual therapeutic health concept and the implications of having that concept in communication situations. On the whole, communication training should emphasize the importance of providing scientific, evidence-based information adapted to patients' particular communication styles in a perceptive manner, regardless of the medical expert's own therapeutic health concept.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

List of scientific and emotional wordings in participants' reply posts.

[PDF File (Adobe PDF File), 308KB - jmir_v17i11e268_app1.pdf ]

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## Abbreviations

**ICD:** International Classification of Diseases

Original Paper

# The Association Between Online Health Information–Seeking Behaviors and Health Behaviors Among Hispanics in New York City: A Community-Based Cross-Sectional Study

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## Abstract

**Background:**   Hispanics are the fastest-growing minority group in the United States and they suffer from a disproportionate burden of chronic diseases. Studies have shown that online health information has the potential to affect health behaviors and influence management of chronic disease for a significant proportion of the population, but little research has focused on Hispanics.

**Objective:**   The specific aim of this descriptive, cross-sectional study was to examine the association between online health information–seeking behaviors and health behaviors (physical activity, fruit and vegetable consumption, alcohol use, and hypertension medication adherence) among Hispanics.

**Methods:**   Data were collected from a convenience sample (N=2680) of Hispanics living in northern Manhattan by bilingual community health workers in a face-to-face interview and analyzed using linear and ordinal logistic regression. Variable selection and statistical analyses were guided by the Integrative Model of eHealth Use.

**Results:**   Only 7.38% (198/2680) of the sample reported online health information–seeking behaviors. Levels of moderate physical activity and fruit, vegetable, and alcohol consumption were low. Among individuals taking hypertension medication (n=825), adherence was reported as high by approximately one-third (30.9%, 255/825) of the sample. Controlling for demographic, situational, and literacy variables, online health information–seeking behaviors were significantly associated with fruit (β=0.35, 95% CI 0.08-0.62, *P*=.01) and vegetable (β=0.36, 95% CI 0.06-0.65, *P*=.02) consumption and physical activity (β=3.73, 95% CI 1.99-5.46, *P*<.001), but not alcohol consumption or hypertension medication adherence. In the regression models, literacy factors, which were used as control variables, were associated with 3 health behaviors: social networking site membership (used to measure one dimension of computer literacy) was associated with fruit consumption (β=0.23, 95% CI 0.05-0.42, *P*=.02), health literacy was associated with alcohol consumption (β=0.44, 95% CI 0.24-0.63, *P*<.001), and hypertension medication adherence (β=–0.32, 95% CI –0.62 to –0.03, *P*=.03). Models explained only a small amount of the variance in health behaviors.

**Conclusions:**   Given the promising, although modest, associations between online health information–seeking behaviors and some health behaviors, efforts are needed to improve Hispanics' ability to access and understand health information and to enhance the availability of online health information that is suitable in terms of language, readability level, and cultural relevance.

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## Introduction

Hispanics are the fastest-growing minority group in the United States and they suffer from a disproportionate burden of chronic diseases compared with non-Hispanics groups [1,2]. For instance, Hispanics have similar or lower levels of hypertension compared to non-Hispanic whites; however, their high blood pressure is less likely to be treated or controlled [3,4]. To manage illnesses and associated health problems, it is especially important for people with chronic diseases to engage in health-promoting behaviors [5-7]. However, studies have shown that there are disparities in health behaviors between Hispanics and non-Hispanics; Hispanics, as a group, spend less time on healthy behaviors than other ethnic groups [8-10]. For example, Hispanics report less physical activity time than non-Hispanics and have high rates of diseases related to sedentary lifestyle [9]. Also, compared with other ethnic groups, the rise in nutrition-related chronic diseases among Hispanics reflects an unequal burden of health issues [10].

As the number of Internet users has grown, the Internet has become an important resource for chronic disease management [11]. Studies have shown that online health information has the potential to affect health behaviors and health outcomes for a significant proportion of the population [12,13]. Dutta-Bergman [14] demonstrated that online health information seekers reported higher levels of health behaviors, including physical activity, diet, alcohol consumption, medication, and smoking. In addition, online health information enables people to manage chronic diseases more effectively and improve their quality of life [15-17]. Because patient participation in health care decision making across the illness continuum is increasing, online health information–seeking behaviors are an important strategy for successful health interventions that inform decision making [18-20].

Hispanics' interest in online health information is increasing. In 2011, the Pew Internet & American Life Project reported that 45% of Hispanic Internet users had sought health information from the Internet; this increased to 66% in 2013 [21,22]. Compared with other ethnic groups, Hispanics are more likely to seek health information from the Internet or other social media rather than from a physician because they often lack access to a regular health care provider [23,24]. However, current studies have been limited to information seeking and its influence on health behaviors among the general public. Given the growth of Hispanic online health information seekers [25,26], examining the relationships between online health information–seeking behaviors and health behaviors in Hispanics is warranted.

Our previous study focused on the correlates of online health information–seeking behaviors in Hispanics [27]. This study builds on that research by examining the association between online health information–seeking behaviors and 5 health behaviors (physical activity, fruit and vegetable consumption, alcohol use, and hypertension medication adherence) of relevance to Hispanics [2,14,28,29].

## Methods

### Study Design and Hypotheses

Data were collected during an in-depth community survey as part of the Washington Heights Inwood Informatics Infrastructure for Comparative Effectiveness Research (WICER) project. Five hypotheses were tested. Controlling for situational, sociodemographic, and literacy factors, online health information–seeking behaviors would be (1) positively associated with fruit consumption, (2) positively associated with vegetable consumption, (3) positively associated with physical activity, (4) negatively associated with alcohol consumption, and (5) positively associated with hypertension medication adherence. In addition, the associations between situational, sociodemographic, and literacy factors and fruit consumption, vegetable consumption, physical activity, alcohol consumption, and hypertension medication adherence were examined.

### Setting

The survey catchment area included 5 ZIP codes (10031, 10032, 10033, 10034, and 10040) comprising the Washington Heights Inwood community of northern Manhattan, which has been designated a medically underserved area by the Centers for Medicare and Medicaid Services because it meets the criteria related to the level of poverty, elderly, and infant mortality, and the ratio of primary care providers in the community [30,31]. Currently, 71% of Washington Heights and Inwood area residents are Hispanic and 51% of residents are immigrants [32].

### Recruitment

After approval by the Institutional Review Board of Columbia University Medical Center, recruitment of eligible participants was initiated using multiple methods. Participants were recruited from households or other places in the community (eg, schools, grocery stores, hair salons). The household sample started as a probability sample that evolved, as planned, to snowball sampling based on participants' social networks and convenience sampling. For the probability sample, we randomized 68,000 dwelling units (ie, households) in the 5 ZIP codes and selected a weighted sample from each of the 8 New York City Department of Health and Mental Hygiene districts in the community. The sample size of each health district was weighted by the distribution of the population. Once we enrolled a household member and finished the survey, we asked participants if they would introduce the research team to members of their social network to ascertain interest in completing the survey (ie, snowball sampling). Other participants were recruited through direct contact with community health workers in community settings.

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## Sample

The sample consisted of those who completed the WICER community survey between April 2012 and November 2012. Participants who were 18 years or older, English or Spanish speaking, and Hispanic were eligible to participate in this study.

## Data Collection

Data were collected via in-person interviews by bilingual community health workers in households or places in the community (eg, schools, grocery stores). For consistency of data collection across interviewers, community health workers received a combination of didactic and practical training in responsible conduct of research and specific study procedures including informed consent. Their performance was monitored by the project coordinator on a weekly basis. Before conducting the survey interview, bilingual study personnel obtained informed consent from the participant in their language of choice (English or Spanish). The process required approximately 45

to 60 minutes for completion and participants received US $25 compensation in the form of subway cards, grocery coupons, or movie tickets.

## Study Variables

After WICER survey data collection was completed, Bodie and Dutta's Integrative Model of eHealth Use [33] was applied to inform selection of correlates and related health outcomes for online health information–seeking behaviors from among the WICER variables and to guide the data analysis. This model includes demographic information, situational factors, health literacy, computer literacy, online health information–seeking behaviors, and health behavior variables. Table 1 summarizes the definitions of model concepts and operationalization of the concepts through WICER study variables and measures. As described in more detail in study measures, only selected dimensions of health literacy and computer literacy were measured in the study (ie, the available WICER variables were more narrow than the broad concepts in the model).

**Table 1.** Conceptualization and measurement of study variables.

| Concept/Definition | WICER Variable/Measure |
| --- | --- |
| Situational factors: the specific health situations faced by a patient and his or her subsequent consumer health information needs [34] | Hypertension: "Have you ever been told by a doctor, nurse, or other health professional that you had hypertension also called high blood pressure or pressure?" [35] |
| | General health status: "Would you say that in general your health is...?" [36] |
| | Serious health problems: "Have you experienced any serious personal health problems that have lasted for at least 6 months?" [37] |
| Demographic information | Age, gender, employment, immigrant status, marital status, educational level, insurance |
| Health literacy: the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions [38] | Health literacy: Chew's 1-item health literacy screening question "How often do you have problems learning about your medical condition because of difficulty understanding written information?" [39] |
| Computer literacy: computer skills and ability to use technology to improve learning, productivity, and performance [40] | Social networking site membership: "Do you belong to any social networking sites like Facebook, Myspace, or Twitter?" |
| Online health information–seeking behaviors: the interaction of an individual with or through an electronic device or communication technology to access or transmit health information or to receive guidance and support on a health-related issue [41] | Online health information–seeking behaviors: "In the past 12 months, have you (1) participated in an online support group for people with similar health or medical issues, (2) used email or the Internet to communicate with a doctor or doctor's office, or (3) used the Internet to look up health or medical information?" [42] |
| Health behaviors | Physical activity, fruit consumption, vegetable consumption |
| | Alcohol use: New York City Health and Nutrition Examination Survey (NY-CHANES) [43] |
| | Medication adherence: Morisky 8-Item Medication Adherence Scale (MMAS-8) [44] |

Bodie and Dutta [33] suggest that disparities in social structures, such as sociodemographic factors, lead to individual-level differences in online health information–seeking ability. This model also incorporates health literacy and computer literacy as predictors of online health information–seeking behaviors and health behaviors. In addition, it proposes that differences in health literacy are related to sociodemographic factors, such as age, race, birthplace, education level, and income, which also influence online health information–seeking behaviors [25,45]. Ultimately, this difference in online health information–seeking behaviors causes disparities in lifestyle that are related to health

outcomes and continue to contribute to health care disparities [33].

### Demographic and Situational Factors

As summarized in Table 1, situational and demographic data were obtained during the interview. For situational variables, hypertension was measured by the question "Have you ever been told by a doctor, nurse, or other health professional that you had hypertension also called high blood pressure or pressure?" [35]. The presence of serious health problems was measured by the question "Have you experienced any serious personal health problems that have lasted for at least 6 months?" from the Chronic Burden Scale [37]. Self-reported general health

status was recorded in 5 categories: excellent, very good, good, fair, and poor. General health status was measured on a 5-point Likert scale (1=excellent, 5=poor) from the Short Form-8 Health Survey (SF-8) [36]. Demographic data included age, gender, employment, marital status, immigrant status, educational level, and type of insurance.

### Health Literacy

Although the Institute of Medicine definition of health literacy is broad and encompasses accessing and processing as well as understanding and applying information, [38] we selected understanding as the focus of our health literacy measurement. To assess health literacy, we used a one-item health literacy screening measure: "How often do you have problems learning about your medical condition because of difficulty understanding written information?" Response options were always, often, sometimes, occasionally, and never. Criterion-related validity with Short Test of Functional Health Literacy in Adults (S-TOFHLA) was established by the area under the receiver operating characteristic curve (0.76) in a study of Veterans Affairs clinic patients [38]. Evidence for the reliability and validity of the 3 one-item scales from Chew et al [39] have been demonstrated in other populations, including females, African Americans [46], Turkish speakers [47], and Spanish speakers [48], This one-item scale was selected for the analysis in this paper instead of other WICER health literacy variables (eg, Newest Vital Sign which includes numeracy) because of its relevance to online health information–seeking behaviors. Moreover, Sarkar and colleagues [48] revalidated this single health literacy item among English and Spanish speakers and found similar test characteristics to previous studies; thus, it was appropriate for our primarily Spanish-speaking Hispanic participants. Per the method described by Chew and colleagues [39], the responses of always, often, and sometimes were coded as inadequate literacy; occasionally and never were coded as adequate literacy.

### Social Networking Site Membership

There was no direct question regarding computer literacy in the WICER survey. The US Department of Education defines *computer literacy* as "computer skills and ability to use technology to improve learning, productivity, and performance" [40]. However, the definition of computer literacy changes as technology evolves [49] and several studies have included "using networked communication" as a component of computer literacy [50-52]. Use of social networking sites (SNS), whether by mobile device or desktop computer, requires a certain level of computer literacy as a foundation [53]. Therefore, based on the variables available in the WICER survey, one dichotomous question related to SNS membership was used to measure one dimension of computer literacy: "Do you belong to any social networking sites like Facebook, Myspace, or Twitter?" WICER survey variables specific to online health information–seeking behaviors also imply a level of computer literacy, but based on the Bodie and Dutta [33] model, were used to measure online health information–seeking behaviors.

### Online Health Information–Seeking Behaviors

Robinson et al [41] defined *interactive health communication* as "the interaction of an individual—consumer, patient, caregiver, or professional—with or through an electronic device or communication technology to access or transmit health information or to receive guidance and support on a health-related issue." Based on the definition, this study considered participation in an online support group, email communication with physicians, and using the Internet to look up health or medical information as online health information–seeking behaviors in this study. An affirmative response to at least 1 of 3 questions was coded as "yes" on online health information–seeking behaviors (no=0, yes=1).

### Health Behaviors

Physical activity, fruit and vegetable consumption, and alcohol consumption were measured using items from New York City Health and Nutrition Examination Survey (NYCHANES) [43]. Moderate physical activity was measured by the question "Over the past 30 days, did you do moderate activities for at least 10 minutes that caused only light sweating or a slight to moderate increase in breathing or heart rate?" Answers were standardized into weekly rates. Similarly, fruit, vegetable, and dark vegetable consumption were standardized as number of servings per day. Alcohol use was first measured by the dichotomous question "Have you ever had alcoholic beverages such as beer, wine, champagne, or liquor at least once per month for 6 months or more?" If yes, the respondents were asked to select from among 9 frequencies of drinking. Responses were clustered into 3 categories: 1, 1-19, or ≥20 drinks per month [54]. Those who answered "no" to the initial question were categorized as <1.

Hypertension medication adherence was measured by the Morisky 8-Item Medication Adherence Scale (MMAS-8) [44] with respondents explicitly instructed to limit the type of medication to those taken for hypertension. Three questions were dichotomous (no=0, yes=1) and 5 questions had 4 response options: (1) never or rarely, (2) once in a while, (3) sometimes, and (4) often. The former 2 were coded as "no" and the latter 2 as "yes." One dichotomous item, "Did you take your high blood pressure medication yesterday?" required reverse coding. The responses were summed and adherence was defined as high (0), medium (1-2), or low (>2) [44]. Internal consistency reliability was good ($\alpha$=.75) for the study sample.

### Statistical Analysis

Data were analyzed using SPSS version 20.0 software. Univariate analyses were used to examine the frequency and distribution of study variables, calculating mean and standard deviation, range, frequency, and percentage as appropriate. The statistical analyses were guided by Bodie and Dutta's Integrative Model of eHealth Use [33]. First, the relationships between demographics, situational and literacy (health literacy, SNS membership) variables, and online health information–seeking behaviors were examined using chi-square tests, *t* tests, and binary logistic regression with online health information–seeking behavior as the dependent variable. Although we previously conducted analyses of the variables associated with online health information–seeking behaviors in the larger WICER sample

[27], analysis in this smaller sample was required to determine which variables should be controlled for in the hypothesis testing. Second, to test the study hypotheses, variables found to be significant in online health information–seeking behavior analyses were controlled for in regression models that examined the influence of online health information–seeking behaviors on health behaviors. Linear regression was used for continuous health behavior variables (physical activity and fruit and vegetable consumption). Ordinal regression models were used for alcohol use and hypertension medication adherence because those were coded as ordered categorical data. For each health behavior regression, 3 models were run: (1) demographic and situational variables only, (2) demographic and situational variables plus literacy variables, and (3) demographic, situational, and literacy variables plus online health information–seeking behaviors. The level of significance for testing of each model was set to an alpha of .05.

# Results

## Characteristics of Respondents

### Sample Characteristics

The characteristics of the sample (N=2680) are summarized in Table 2. The mean age was 50.0 years (SD 17.1, range 18-100). Most were female (71.60%, 1919/2680) and immigrants (87.65%, 2349/2680). More than half of the respondents were unemployed (63.17%, 1693/2680), not married (64.33%, 1724/2680), and approximately half of the respondents had less than high school education (49.81%, 1335/2680). In all, 75.82% (2032/2680) of the participants were Medicare or Medicaid beneficiaries. Most respondents reported that their general health status as at least "good" (74.40%, 1994/2680) and that they did not have serious health problems (92.20%, 2471/2680). A total of 36.79% (986/2680) of respondents answered that they had been diagnosed with hypertension. More than the half of respondents (57.95%, 1553/2680) had inadequate health literacy and only 22.20% (595/2680) of respondents answered that they were a SNS member. Regarding online health information–seeking behaviors, only 7.38% (198/2680) of respondents reported that they had sought health information through the Internet. This was 29.0% (198/682) of the 682 respondents who reported using the Internet.

### Health Behaviors

Respondents reported consuming fruit (mean 0.8, SD 1.5) and vegetables (mean 0.8, SD 1.7) less than once per day. The mean frequency of moderate physical activity was 1.6 times per week (SD 11.4). More than half of respondents (69.07%, 185/2680) reported consuming less than one alcoholic drink per month and a small percentage (2.0%, 54/2680) answered that they consumed more than 20 alcoholic drinks per month. Among individuals taking hypertension medication (n=825), adherence was reported as high (30.9%, 255/825), medium (26.3%, 217/825), and low (42.8%, 353/825).

## Relationships Between Demographic, Situational, and Literacy Variables and Online Health Information–Seeking Behaviors

In bivariate analyses related to demographic and situational variables and respondents' online health information–seeking behaviors, there were statistically significant differences in age (P=.001), education (P<.001), employment status (P<.001), hypertension (P<.001), insurance (P=.005), immigrant status (P<.001), general health status (P<.001), health literacy (P<.001), and SNS membership (P<.001). Other demographic and situational variables were also significant in the binomial logistic regressions: older age (OR 1.68, 95% CI 1.29-2.20, P<.001), a high level of education (OR 3.07, 95% CI 1.99-4.80, P<.001), being born in the United States (OR 1.68, 95% CI 1.10-2.56, P=.02), worse health status (OR 0.39, 95% CI 0.27-0.57, P<.001), and lack of hypertension (OR 0.64, 95% CI 0.42-0.99, P=.047) were associated with participants' online health information–seeking behaviors. Controlling for these variables, respondents with adequate health literacy (OR 2.13, 95% CI 1.52-2.99, P<.001) and SNS members (OR 4.21, 95% CI 2.86-6.19, P<.001) had increased odds of online health information–seeking behaviors.

## Hypotheses Testing: Relationships Between Online Health Information–Seeking Behaviors and Health Behaviors Controlling for Demographic, Situational, and Literacy Factors

Models 1 and 2 in Tables 3-7 are displayed to reflect the relationships between the final regressions and the eHealth use framework that guided the analysis. Model 1 shows the results of the demographic and situational variables regressed on the health behaviors and Model 2 adds the literacy variables. In terms of hypothesis testing, controlling for demographic, situational, and literacy factors (as shown in Model 3 in Tables 3-7), online health information–seeking behaviors were positively associated with fruit consumption (β=0.35, 95% CI 0.08-0.62, P=.01; Table 3), vegetable consumption (β=0.36, 95% CI 0.06-0.65, P=.02; Table 4), and physical activity (β=3.73, 95% CI 1.99-5.46, P<.001; Table 5). Thus, hypotheses 1-3 were supported. Other variables significantly related with health behaviors in Model 3 were age (β=–0.12, 95% CI –0.23 to –0.01, P=.04), immigrant status (β=–0.33, 95% CI –0.56 to –0.10, P=.01), general health status (β=–0.24, 95% CI –0.41 to –0.08, P=.01), and SNS membership (β=0.23, 95% CI 0.05-0.42, P=.02) for fruit consumption; immigrant status for vegetable consumption (β=–0.33, 95% CI –0.59 to –0.08, P=.01); and age (β=–0.87, 95% CI –1.60 to –0.13, P=.02), general health status (β=–1.92, 95% CI –3.00 to –0.83, P=.001), and education level (β=1.28, 95% CI 0.29-2.27, P=.01) for physical activity. However, each model explained only a small amount of the variance in each health behavior.

**Table 2.** Descriptive characteristics of Hispanic participants (N=2680).

| Variables | Respondents |
|---|---|
| **Demographic factors** | |
| **Gender, n (%)** | |
| Men | 747 (27.87) |
| Women | 1919 (71.60) |
| **Employment status, n (%)** | |
| Employed | 987 (36.83) |
| Unemployed | 1693 (63.17) |
| **Marital status, n (%)** | |
| Married/living as | 935 (34.89) |
| Otherwise | 1724 (64.33) |
| **Education, n (%)** | |
| <High school graduate | 1335 (49.81) |
| ≥High school graduate | 1298 (48.43) |
| **Birthplace, n (%)** | |
| Born in the United States | 323 (12.05) |
| Born in the other countries | 2349 (87.65) |
| **Insurance, n (%)** | |
| Medicare/Medicaid | 2032 (75.82) |
| Others (VA, private, etc) | 392 (14.63) |
| None | 356 (13.28) |
| Age (years), mean (SD) | 50.0 (17.1) |
| **Situational factors** | |
| **General health status, n (%)** | |
| <Good | 612 (22.84) |
| ≥Good | 1994 (74.40) |
| **Hypertension, n (%)** | |
| Yes | 986 (36.79) |
| No | 1662 (62.01) |
| **Serious personal health problems, n (%)** | |
| Yes | 187 (6.98) |
| No | 2471 (92.20) |
| **Literacy factors** | |
| **Health literacy, n (%)** | |
| Adequate literacy | 1009 (37.65) |
| Inadequate literacy | 1553 (57.95) |
| **SNS membership, n (%)** | |
| Yes | 595 (22.20) |
| No | 1750 (65.30) |
| **Online health information–seeking behaviors, n (%)** | |
| Yes | 198 (7.39) |
| No | 2471 (92.20) |
| **Health behaviors** | |

| Variables | Respondents |
|---|---|
| Physical activity (times/week), mean (SD) | 1.6 (11.4) |
| Fruit consumption (times/day), mean (SD) | 0.8 (1.5) |
| Vegetable consumption (times/day), mean (SD) | 0.8 (1.7) |
| **Alcohol consumption, n (%)** | |
| <1 per month | 1851 (69.07) |
| 1-19 per month | 660 (24.63) |
| ≥20 per month | 54 (2.01) |
| **Medication adherence, [a] n (%)** | |
| High adherence | 255 (30.9) |
| Medium adherence | 217 (26.3) |
| Low adherence | 353 (42.8) |

[a] Sample size for medication adherence is n=825.

**Table 3.** Linear regression: association between online health information–seeking behaviors and fruit consumption.

| Variables | Model 1[a] | | | Model 2[b] | | | Model 3[b] | | |
|---|---|---|---|---|---|---|---|---|---|
| | β (SE) | 95% CI | P | β (SE) | 95% CI | P | β (SE) | 95% CI | P |
| **Demographic and situational factors** | | | | | | | | | |
| Immigrant status[c] | –0.24 (0.12) | –0.47, –0.01 | .04 | –0.31 (0.12) | –0.54, –0.08 | .01 | –0.33 (0.12) | –0.56, –0.09 | .01 |
| Age | –0.14 (0.06) | –0.26, –0.03 | .01 | –0.11 (0.06) | –0.22, 0.01 | .07 | –0.12 (0.06) | –0.24, –0.01 | .04 |
| General health status | –0.27 (0.09) | –0.44, –0.10 | .002 | –0.27 (0.09) | –0.44, –0.10 | .002 | –0.24 (0.09) | –0.41, –0.08 | .01 |
| Hypertension[d] | –0.01 (0.08) | –0.17, 0.15 | .92 | 0.02 (0.08) | –0.14, 0.18 | .81 | 0.03 (0.08) | –0.13, 0.19 | .70 |
| Education level | 0.13 (0.08) | –0.03, 0.28 | .10 | 0.08 (0.08) | –0.08, 0.23 | .32 | 0.05 (0.08) | –0.10, 0.21 | .50 |
| **Literacy factors** | | | | | | | | | |
| Health literacy | | | | –0.03 (0.07) | –0.15, 0.14 | .97 | –0.02 (0.07) | –0.17, 0.12 | .76 |
| SNS membership[d] | | | | 0.28 (0.09) | 0.10, 0.47 | .01 | 0.23 (0.10) | 0.05, 0.42 | .02 |
| Online health information–seeking behaviors[d] | | | | | | | 0.35 (0.14) | 0.08, 0.62 | .01 |

[a] Adjusted $R^2$=.01, P=.001.

[b] Adjusted $R^2$=.01, P<.001.

[c] Birthplace was coded as 0=foreign born or 1=US born.

[d] Coded as 0=no or 1=yes.

**Table 4.** Linear regression: association between online health information–seeking behaviors and vegetable consumption.

| Variables | Model 1[a] | | | Model 2[b] | | | Model 3[c] | | |
|---|---|---|---|---|---|---|---|---|---|
| | β (SE) | 95% CI | P | β (SE) | 95% CI | P | β (SE) | 95% CI | P |
| **Demographic and situational factors** | | | | | | | | | |
| Immigrant status[c] | –0.28 (0.13) | –0.53, –0.02 | .03 | –0.31 (0.13) | –0.57, –0.06 | .02 | –0.33 (0.13) | –0.59, –0.08 | .01 |
| Age | –0.10 (0.06) | –0.22, 0.02 | .11 | –0.07 (0.06) | –0.19, 0.06 | .28 | –0.09 (0.06) | –0.21, 0.04 | .19 |
| General health status | –0.09 (0.09) | –0.28, 0.09 | .31 | –0.11 (0.09) | –0.29, 0.08 | .26 | –0.08 (0.09) | –0.26, 0.11 | .41 |
| Hypertension[d] | –0.04 (0.09) | –0.21, 0.14 | .68 | –0.02 (0.09) | –0.19, 0.16 | .85 | –0.01 (0.09) | –0.18, 0.17 | .95 |
| Education level | 0.11 (0.08) | –0.06, 0.27 | .21 | 0.07 (0.09) | –0.10, 0.24 | .40 | 0.05 (0.09) | –0.12, 0.22 | .60 |
| **Literacy factors** | | | | | | | | | |
| Health literacy | | | | –0.12 (0.08) | –0.28, 0.04 | .14 | –0.14 (0.08) | –0.30, 0.02 | .08 |
| SNS membership[d] | | | | 0.20 (0.10) | –0.001, 0.40 | .05 | 0.15 (0.11) | –0.06, 0.36 | .15 |
| Online health information–seeking behaviors[d] | | | | | | | 0.36 (0.15) | 0.06, 0.65 | .02 |

[a] Adjusted $R^2$=.002, $P$=.12.

[b] Adjusted $R^2$=.004, $P$=04.

[c] Adjusted $R^2$=.006, $P$=.009.

[c] Immigrant status was coded as 0=foreign born or 1=US born.

[d] Coded as 0=no or 1=yes.

**Table 5.** Linear regression: association between online health information–seeking behaviors and physical activity.

| Variables | Model 1[a] | | | Model 2[a] | | | Model 3[b] | | |
|---|---|---|---|---|---|---|---|---|---|
| | β (SE) | 95% CI | P | β (SE) | 95% CI | P | β (SE) | 95% CI | P |
| **Demographic and situational factors** | | | | | | | | | |
| Immigrant status[c] | –0.90 (0.75) | –2.36, 0.57 | .23 | –1.19 (0.76) | –2.68, 0.30 | .12 | –1.40 (0.76) | –2.89, 0.08 | .06 |
| Age | –0.83 (0.37) | –1.54, –0.11 | .02 | –0.70 (0.38) | –1.43, 0.04 | .002 | –0.87 (0.38) | –1.60, –0.13 | .02 |
| General health status | –2.30 (0.55) | –3.37, –1.21 | <.001 | –2.22 (0.56) | –3.23, –1.12 | <.001 | –1.92 (0.55) | –3.00, –0.83 | .001 |
| Hypertension[d] | 0.47 (0.52) | –0.56, 1.45 | .37 | 0.58 (0.53) | –0.45, 1.61 | .27 | 0.71 (0.53) | –0.32, 1.74 | .18 |
| Education level | 1.75 (0.50) | 0.78, 2.72 | <.001 | 1.55 (0.50) | 0.56, 2.54 | .002 | 1.28 (0.51) | 0.29, 2.27 | .01 |
| **Literacy factors** | | | | | | | | | |
| Health literacy | | | | 0.99 (0.47) [a] | 0.07, 1.91 | .04 | 0.77 (0.47) | –0.1, 1.70 | .10 |
| SNS membership[d] | | | | 1.16 (0.60) | –0.02, 2.34 | .05 | 0.67 (0.61) | –0.53, 1.86 | .28 |
| Online health information–seeking behaviors[d] | | | | | | | 3.73 (0.88) | 1.99, 5.46 | <.001 |

[a] Adjusted $R^2$=.01, $P$<.001.

[b] Adjusted $R^2$=.02, $P$<.001.

[c] Immigrant status was coded as 0=foreign born or 1=US born.

[d] Coded as 0=no or 1=yes.

The hypotheses related to the association between online health information–seeking behaviors and alcohol consumption (Table 6) and hypertension medication adherence (Table 7) were not supported. For other variables in Model 3, health literacy (β=0.44, 95% CI 0.24-0.63, $P$<.001) was significantly associated with alcohol consumption and the final model explained 2.0%

of the variance in alcohol consumption ($R^2$=.02, $P$<.001). Age ($\beta$=–0.27, 95% CI –0.51 to –0.02, $P$=.04), education level ($\beta$=–0.58, 95% CI –0.90 to –0.25, $P$<.001), and health literacy ($\beta$=–0.32, 95% CI –0.62 to –0.03, $P$=.03) were significantly associated with hypertension medication adherence and Model 3 explained 5.0% of the variance ($R^2$=.05, $P$<.001).

**Table 6.** Ordinal logistic regression: association between online health information–seeking behaviors and alcohol consumption.

| Variables | Model 1[a] | | | Model 2[b] | | | Model 3[b] | | |
|---|---|---|---|---|---|---|---|---|---|
| | $\beta$ (SE) | 95% CI | $P$ | $\beta$ (SE) | 95% CI | $P$ | $\beta$ (SE) | 95% CI | $P$ |
| **Demographic and situational factors** | | | | | | | | | |
| Immigrant status[c] | 0.24 (0.14) | –0.04, 0.52 | .10 | 0.25 (0.16) | –0.05, 0.55 | .11 | 0.23 (0.16) | –0.07, 0.54 | .13 |
| Age | 0.07 (0.07) | –0.07, 0.21 | .33 | 0.13 (0.08) | –0.03, 0.28 | .10 | 0.11 (0.08) | –0.04, 0.27 | .16 |
| General health status | 0.24 (0.11) | 0.02, 0.46 | .03 | 0.20 (0.12) | –0.03, 0.43 | .09 | 0.21 (0.12) | 0.02, 0.45 | .08 |
| Hypertension[d] | –0.03 (0.10) | –0.24, 0.17 | .75 | –0.03 (0.11) | –0.25, 0.19 | .78 | –0.02 (0.11) | –0.24, 0.20 | .87 |
| Education level | 0.08 (0.10) | –0.11, 0.27 | .39 | 0.05 (0.11) | –0.16, 0.26 | .61 | 0.04 (0.11) | –0.17, 0.26 | .68 |
| **Literacy factors** | | | | | | | | | |
| Health literacy | | | | 0.46 (0.10) | 0.26, 0.65 | <.001 | 0.44 (0.10) [c] | 0.24, 0.63 | .<001 |
| SNS membership[d] | | | | 0.17 (0.13) | –0.08, 0.41 | .19 | 0.13 (0.13) [c] | –0.12, 0.39 | .29 |
| Online health information–seeking behaviors[d] | | | | | | | –0.17 (0.18) | –0.52, 0.19 | .35 |

[a] Adjusted $R^2$=.01, $P$=.07 .

[b] Adjusted $R^2$=.02, $P$<.001.

[c] Immigrant status was coded as 0=foreign born or 1=US born.

[d] Coded as 0=no or 1=yes.

**Table 7.** Ordinal logistic regression: association between online health information–seeking behaviors and hypertension medication adherence (n=825).

| Variables | Model 1[a] | | | Model 2[b] | | | Model 3[c] | | |
|---|---|---|---|---|---|---|---|---|---|
| | $\beta$ (SE) | 95% CI | $P$ | $\beta$ (SE) | 95% CI | $P$ | $\beta$ (SE) | 95% CI | $P$ |
| **Demographic and situational factors** | | | | | | | | | |
| Immigrant status[d] | 1.31 (0.53) | 0.27, 2.34 | .01 | 0.89 (0.57) | –0.23, 2.00 | .15 | 0.90 (0.57) | –0.22, 2.02 | .12 |
| Age | –0.29 (0.12) | –0.51, –0.06 | .01 | –0.28 (0.13) | –0.52, –0.03 | .03 | –0.27 (0.13) | –0.51, –0.02 | .04 |
| General health status[e] | 0.33 (0.14) | 0.05, 0.61 | .02 | 0.22 (0.15) | –0.08, 0.52 | .15 | 0.24 (0.16) | –0.01, 0.54 | .13 |
| Education level | –0.40 (0.15) | –0.69, –0.11 | .01 | –0.55 (0.16) | –0.87, –0.23 | .001 | –0.58 (0.17) [c] | –0.90, –0.25 | <.001 |
| **Literacy factors** | | | | | | | | | |
| Health literacy | | | | –0.32 (0.15) | –0.61, –0.03 | .03 | –0.32 (0.15) | –0.62, –0.03 | .03 |
| SNS membership[e] | | | | 0.44 (0.29) | –0.14, –1.00 | .13 | 0.41 (0.29) | –0.17, 0.98 | .17 |
| Online health information–seeking behaviors[e] | | | | | | | –0.64 (0.40) | –1.42, 0.14 | .11 |

[a] Adjusted $R^2$=.03, $P$<.001.

[b] Adjusted $R^2$=.04, $P$<.001.

[c] Adjusted $R^2$=.05, $P$=.

[d] Immigrant status was coded as 0=foreign born or 1=US born.

[e] Coded as 0=no or 1=yes.

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## Discussion

### Principal Results

Only 7.38% (198/2680) of respondents reported that they had sought health information through the Internet; this was 29.0% (198/682) of the 682 respondents who indicated that they used the Internet. This is significantly different than the 66% of Hispanic Internet users who reported online health information–seeking behaviors according to the Pew Internet & American Life Project in 2013 [21]. The difference may be a reflection of the low socioeconomic status of the Washington Heights and Inwood area in this study that may have limited participants' ability to pay for Internet access. Alternatively, we did not specifically ask about accessing the Internet via cellular telephone and respondents may have failed to consider this mode of access in their response. Thus, the actual rate of online health information–seeking behaviors in our sample may be higher than we captured in the WICER survey.

Guided by Bodie and Dutta's Integrative Model of eHealth Use [33], demographic, situational, and literacy factors were examined to determine which variables were significantly correlated with online health information–seeking behaviors as a preliminary step to determine which variables to control for in hypothesis testing of the relationship between online health information–seeking behaviors and health behaviors. Significant demographic variables associated with online health information–seeking behaviors were older age, higher level of education, and being born in the United States. Education level and immigrant status were consistent with previous studies [55-58]; however, the relationship of age to online health information–seeking behaviors contrasted with existing studies [55-57]. This may be explained by the increasing interest in online health information among older adults. More than half of our sample was older than age 40 years (1850/2680, 69.03%), and 19.70% (528/2680) were older than age 65 years. Consistent with our prior analysis using the larger WICER sample [27], worse health status and lack of hypertension were associated with participants' online health information–seeking behaviors.

Previous research has provided evidence that online health information seekers tend to improve their health behaviors [59-61]. Controlling for demographic, situational, and literacy factors, this study tested 5 hypotheses about the association between Hispanics' online health information–seeking behaviors and health behaviors: fruit consumption, vegetable consumption, physical activity, alcohol consumption, and hypertension medication adherence. Although only a small proportion of the sample reported online health information–seeking behaviors, online health information–seeking behaviors were positively associated with fruit and vegetable consumption and physical activity. Our study showed that online health information seekers were likely to consume more fruits and vegetables and report more physical activity than nonseekers. However, the average fruit and vegetable consumption and physical activity levels were significantly less than the Centers for Disease Control and Prevention guidelines [62]. Moreover, the models explained only a small portion of the variance. Consequently, these findings, although promising, must be interpreted cautiously.

In contrast, online health information–seeking behaviors were not significantly associated with alcohol consumption or adherence to hypertension medication, which is inconsistent with previous studies [63-66]. There are several possible reasons for this. First, other studies did not include a large number of immigrant Hispanics and findings may vary according to these demographic characteristics. Second, there may be lack of online content on medication adherence and alcohol consumption targeted for Hispanics, who were the focus of our study, and that could limit the motivation to seek such information online. Third, a study by Shabab et al [66] suggested that online health information may not be equally effective for all types of health behaviors, which may shed light on why our findings differed for various health behaviors.

In addition to the hypothesis testing, the study revealed relationships between the demographic, situational, and literacy factors, which served as control variables in the regressions related to the 5 health behaviors. There were significant relationships between health behaviors and the demographic characteristics of age (fruit and vegetable consumption, medication adherence), education level (physical activity, hypertension medication adherence), and immigrant status (fruit and vegetable consumption). In terms of immigrant status, consistent with previous research [67,68], foreign-born Hispanic participants were likely to eat more fruit and vegetables than US-born participants. Our results showed that younger people were likely to eat more fruit and have higher physical activity levels than older people, which contrasts with existing literature [69-71]. Our findings also showed that individuals with higher education were more likely to engage in physical activity and more likely to adhere to hypertension medication regimens. In regards to the latter, findings related to education level and age were inconsistent with existing literature [72,73] that showed that lower educational attainment and older age were positively associated with medication adherence. One reason for the differences may be that our study specifically focused on hypertension medication adherence rather than medication adherence in general.

In terms of situational factors, poor health status was associated with more fruit consumption and physical activity. This is consistent within Shim's [74] finding that people who perceived their health status as low were more likely to change their behavior after searching for health information online. Although a previous study showed having hypertension was significantly associated with health behaviors such as alcohol consumption and physical activities [75], our study did not show a significant association between hypertension and health behaviors.

Additionally, literacy factors were associated with some health behaviors: SNS membership was associated with fruit consumption and health literacy was associated with alcohol consumption and medication adherence. Previous research has reported that study participants who frequently visit SNS were willing to communicate with others about health-related issues and exchange health information through those sites [76-78]. A large survey based on 23,000 people in the United States indicated that 41% of respondents had used any social media as a health information resource; 94% of those users chose Facebook to seek health-related information [77]. Consequently,

one explanation for the association between SNS membership and health behaviors is that SNS members may use those sites to find or discuss health information related to healthy diet, such as eating fruit. SNS have the potential be used as a channel to convey health information to promote health behavior, especially tailored to SNS members through user profiles, forums, blogs, comments, search queries, and tags [79].

Moreover, our study findings that participants with higher health literacy were more likely to consume less alcohol [80-82] and to adhere to hypertension medication were consistent with previous studies [83,84]. Differences in health literacy are often related to sociodemographic factors that also influence health behaviors [33,45]. Hispanics are an important target in efforts to improve health literacy due to their lower health literacy levels when compared to other ethnic groups [85]. Adequate health literacy is a prerequisite to directly influence health behaviors and to affect online health information–seeking behavior as a strategy for improving health behaviors [86]. In fact, although we conceptualized it separately in our study, effective health information–seeking behavior is one dimension of the Institute of Medicine definition of health literacy [38].

The significant associations in our study between online health information–seeking behaviors and some health behaviors as well as between our measures of literacy factors (health, SNS membership) and fruit consumption, alcohol consumption, and hypertension suggest that strategies are needed in 2 areas to promote use of online health information by Hispanics. First, skills related to health literacy and online health information–seeking behaviors must be strengthened. Finding health information online challenges those with poor health literacy and limited skills related to online health information–seeking behaviors [87-89] and most existing search tools require high levels of computer literacy for optimal use [90,91]. Second, understandable online health information is necessary to fulfill the information needs of Hispanics so that online health information is perceived as useful [92-94]. More than half of our sample had difficulty understanding written information related to their medical problems. Moreover, online health information is rarely provided in Spanish [95] and Spanish online health information is often either at an advanced reading level or of poor quality [88]. Several authors suggest that the reading level for online information should be at the grade 7 or 8 level [93,94], but that may be too high for those with low health literacy. Additionally, although not explicitly examined in this study because all participants were Hispanic and predominantly from the Dominican Republic, experts recommend that the cultural beliefs and values of the designated population also should be reflected in the content of online health information to encourage ease of use and health behavior change [96,97]. Our study may provide a foundation to understand the characteristics of Hispanics living in the Washington Heights and Inwood community, which may support the dissemination of online information more strategically [11].

## Limitations

This study has several potential limitations. First, the generalizability is limited due to the nonprobability sample and the fact that the Hispanics in our sample were primarily from the Dominican Republic; our sample does not reflect the heterogeneity of socioeconomic status, culture, and health of Hispanics in the United States [11,34,98,99]. Second, the ratio of Internet users who reported online health information–seeking behaviors may be artificially high; the number of Internet users is most likely underestimated because it was not directly asked in the WICER survey. Rather, it was calculated from the unique number of respondents who indicated either online health information–seeking behaviors or SNS use. Third, the data were cross-sectional rather than longitudinal, thus it is not possible to draw causal inferences between online health information–seeking behaviors and health behaviors. Fourth, because all measures were self-reported, recall bias and social desirability bias [100] may have influenced participants' responses. Fifth, our measures of health literacy and computer literacy were narrower than the broader definitions in the conceptual model used for selection and analysis of variables. In particular, SNS membership alone in the absence of measurements of use may not accurately reflect overall level of computer literacy. Sixth, the survey was conducted by face-to-face interview by multiple community health workers. Although the interviewers were carefully trained and monitored, differences among interviewers may have affected the survey result [101]. However, face-to-face survey administration by bilingual community health workers was critical to the success of the WICER study given the documented underrepresentation of Hispanics in research and the low levels of health literacy in the study sample. Lastly, the questions related to online health information–seeking behaviors did not explicitly query the use of cellular phones and participants may not have considered this avenue of accessing the Internet in their response. This may be particularly important given that Hispanics are more likely to access the Internet from mobile phones than from desktop computers [21]. For example, the Pew Hispanic Center reported that Hispanics are more likely to access the Internet through mobile devices compared to non-Hispanics; 76% of Hispanics access the mobile Internet compared to 60% of non-Hispanics [102]. Because we only asked participants about the use of "Internet" there is the possibility that participants did not count the use of mobile Internet as the use of Internet. Therefore, this study may have underestimated online health information–seeking behaviors among the survey respondents.

## Conclusions

To our knowledge, this is the first large-scale study to examine the relationship between online health information–seeking behaviors and health behaviors in the Hispanic population. Although conclusions from a single study should be interpreted carefully, the data in this study suggest potential avenues for informatics-based health interventions. Given the promising, although modest, associations between online health information–seeking behaviors and 3 health behaviors (fruit and vegetable consumption and physical activity) efforts are needed to improve Hispanics' ability to access and understand health information and to enhance the availability of online health information that is suitable in terms of language, readability level, and culture.

## Acknowledgments

## Conflicts of Interest

None declared.

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## Abbreviations

**MMAS-8:** Morisky 8-Item Medication Adherence Scale
**NYCHANES:** New York City Health and Nutrition Examination Survey
**SNS:** social networking site
**WICER:** Washington Heights Inwood Informatics Infrastructure for Comparative Effectiveness Research

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Original Paper

# Do Patients Treated for Colorectal Cancer Benefit from General Practitioner Support? A Video Vignette Study

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## Abstract

**Background:**  Patients who have been treated for colorectal cancer in Australia can consult their general practitioner (GP) for advice about symptoms or side effects at any time following their treatment. However, there is no evidence that such patients are consistently advised by GPs, and patients experience substantial unmet need for reassurance and advice.

**Objective:**  To explore the patient management options selected by GPs to treat a set of patients describing their symptoms following treatment for colorectal cancer.

**Methods:**  This was an Internet-based survey. Participants (GPs) viewed 6 video vignettes of actors representing patients who had been treated for colorectal cancer. The actor-patients presented problems that resulted from their treatment. Participants indicated their diagnosis and stated if they would prescribe, refer, or order tests, based on that diagnosis. These responses were then rated against the management decisions for those vignettes as recommended by a team of colorectal cancer experts.

**Results:**  In total, 52 GPs consented to take part in the study, and 40 (77%) completed the study. Most GPs made a diagnosis of colorectal cancer treatment side effects/symptoms of recurrence that was consistent with the experts' opinions. However, correct diagnosis was dependent on the type of case viewed. Compared with radiation proctitis, GPs were more likely to recognize peripheral neuropathy (odds ratio, OR, 4.43, 95% CI 1.41-13.96, $P$=.011) and erectile dysfunction (OR 9.70, 95% CI 2.48-38.03, $P$=.001), but less likely to identify chemotherapy-induced fatigue (OR 0.19, 95% CI 0.08-0.44). GPs who had more hours of direct patient care (OR 0.38, 95% CI 0.17-0.84, $P$=.02), were experienced (OR 9.78, 95% CI 1.18-8.84, $P$=.02), and consulted more patients per week (OR 2.48, 95% CI 1.16-5.30, $P$=.02) suggested a management plan that was consistent with the expert opinion.

**Conclusions:**  In this pilot study, years of experience and direct patient contact hours had a significant and positive impact on the management of patients. This study also showed promising results indicating that management of the common side effects of colorectal cancer treatment can be delegated to general practice. Such an intervention could support the application of shared models of care. However, a larger study, including the management of side effects in real patients, needs to be conducted before this can be safely recommended.

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## Introduction

Colorectal cancer is the second most commonly diagnosed adult cancer in Australia [1]. One in 12 people in Australia will develop colorectal cancer in their lifetime [2]. Most people with colorectal cancer survive more than 5 years and die of unrelated causes [3]. The treatment of colorectal cancer may include surgery, radiotherapy, and chemotherapy. In the months and years following treatment, people may experience a number of troublesome side effects or symptoms and signs related to cancer recurrence. Many patients may experience bowel dysfunction, sexual dysfunction, urinary dysfunction, and fatigue, among other difficulties [4].

Post-treatment follow-up is provided in secondary settings in some instances; however, this follow-up may only be for a short period for some patients, after which they are encouraged to see their general practitioner (GP) about any ongoing problems [5]. Previous studies have demonstrated that cancer patients consult a GP routinely in the months and years after treatment for colorectal cancer, even those with scheduled follow-up visits at the hospital [6]. Colorectal cancer patients may contact their GP for a range of symptoms, such as radiation proctitis, urinary incontinence/urgency, fatigue, erectile dysfunction, and symptoms of recurrence [7]. To address the needs of patients treated for colorectal cancer, the GP needs to be knowledgeable about the recommended treatment for side effects of colorectal cancer treatment and the signs and symptoms that merit referral for further specialist treatment.

In this pilot video vignette study, we aim to explore the impact of a variety of clinical and respondent characteristics of GPs' decisions to treat colorectal cancer patients experiencing treatment side effects or symptoms of recurrence of their cancer.

## Methods

### Participants

Ethical approval was obtained from the Curtin Human Research Ethics Committee (HR 42/2012). Participants were then recruited from a network of 100 GPs across Australia. GPs were emailed invitations and the initial emails were supplemented with follow-up personal invitations to the invitees who did not initially respond. Participants were remunerated with AUD $50 for their contribution.

### Video Vignettes

Six video vignettes were developed, each presenting a potential side effect related to treatment for colorectal cancer or features of cancer recurrence (see Multimedia Appendix 1 for an example). The range of scenarios was based on the most common side effects reported by colorectal cancer patients (see Multimedia Appendix 2). The identification and validation of these side effects were reported in a different phase of this project [8]. Each vignette depicted a patient with clear indications for specific management, including referral, prescription, reassurance, and/or investigation. The vignettes were developed by 4 GPs, a radiation therapist, a medical oncologist, and a surgeon. This expert panel also suggested the management of each case, with details of prescription, referral for specialist treatment, and laboratory investigations (see Multimedia Appendix 3).

The vignettes were then prepared as a short video monologue by an actor-patient. The video included an off-camera commentary by an actor-doctor describing relevant signs to be found on clinical examination. Participation in the study was via the Internet. Information on the actor-patient's medical history, family history, medication history, and physical assessment was offered at the onset of each video. Participants were asked the following 4 questions after watching each video vignette:

1. "What is your diagnosis?"

2. "Would you prescribe something? If so, what would you prescribe?"

3. "Would you refer the patient? If so, to whom?," and

4. "Would you order tests? If so, which tests?"

The participants' responses were then assessed by a team of 2 researchers (IN and GP) against the experts' opinion. Where differences arose, the third researcher (MJ) validated the assessment.

### Sample Size and Statistical Analysis

The main aim of this study was to evaluate the treatment GPs offer to standardized patients presenting with side effects of colorectal cancer treatment or symptoms of recurrence. Each GP reviewed the same set of 6 video vignettes and responded to the 4 aforementioned binary (Yes/No response) questions regarding prescription of medication, referral for further treatment, or ordering of tests. Each of these 4 questions was analyzed in a separate general estimating equation (GEE) model, with the binary response as the dependent variable, and the subject named as the "random effect." The GEE model is appropriate to this design as it takes into account the correlation between responses from the same GP across the 6 vignettes.

The estimated sample size required to give adequate power to detect associations with the independent variables is difficult to estimate, but depends on the expected response proportions (proportions of positive responses) and the correlations between responses belonging to the same respondent. In the absence of pilot data on which these quantities might have been estimated, a sample of 40 GPs was sought (who would provide 240 observations in total). This projected number cannot be mathematically justified in the absence of pilot data. However, in a standard regression model, a sample of 120 uncorrelated measurements should be adequate to identify an independent variable exhibiting a moderate effect size with 80% power [9]. It was assumed that doubling the number of observations would be adequate to compensate for the internal correlations in the dataset.

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Each of the GEE models initially included the following independent variables: age, years of GP experience, recognized specialty qualification with the Royal Australian College of General Practitioners (RACGP) (Fellowship of the RACGP or FRACGP), number of patients consultations per week and patient consultations hours per week. A backward elimination method was used to arrive at the final model. This method involved dropping the least variable, one at a time, until all variables remaining in the model were ly associated with the outcome.

SPSS Version 21 software was used to perform the analysis. Following convention, a *P* value less than .05 was taken to indicate a statistically association in all tests.

## Results

### Demographics

In total, 52 GPs participated in the project, but only responses of participants who completed the entire survey (40 GPs) were considered for analysis of the primary outcomes. Those who participated in the study were younger than Australian GPs generally (mean age 36.9 years vs 50.5 years), and a greater proportion were females (57.7%, 30/52, vs 39.1%). The demographic details of the respondents are shown in Table 1.

### Diagnosis Consistent With Expert Opinion

The colorectal cancer video vignettes were presented 240 times in the study (40 GPs × 6 vignettes). Of the 240 diagnoses made by the GPs, 168/240, 70.0% (range 35-95%), were consistent with the expert diagnosis. This consistency was observed more for erectile dysfunction (38/40, 95%), peripheral neuropathy (36/40, 90%), and tumor recurrence (31/40, 78%), compared with urinary dysfunction (23/40, 58%) and cancer-related fatigue (14/40, 35%). A higher proportion of correct diagnoses were made by GPs who worked more than 60 patient-care hours per week (15/18, 83%), those who held a GP fellowship (101/138, 73.2%), and those who had less than 10 years of experience (1-2 years 71/96, 74%; 3-10 years 53/72, 74%).

A multivariate GEE analysis was carried out to determine whether a correct diagnosis depended on the case itself or characteristics of the GP. There were some statistically differences in the diagnosis of the cases. Compared with radiation proctitis, GPs were more likely to identify cases with chemotherapy-induced peripheral neuropathy (odds ratio, OR, 4.43, 95% CI 1.41-13.96, *P*=.01) or erectile dysfunction (OR 9.70, 95% CI 2.48-38.03, *P*=.001), but were less likely to recognize chemotherapy-induced fatigue (OR 0.19, 95% CI 0.08-0.44, *P*=.001). In addition, younger GPs (<30 years of age; OR 2.64, 95% CI 1.12-6.22, *P*=.03) and those who held a GP fellowship (OR 3.26, 95% CI 1.62-6.62, *P*<.001) were more likely to identify cases consistent with the expert opinion. The demographic characteristics of the GP did not have any influence on their ability to recognize colorectal cancer treatment side effects or symptoms of recurrence. Details of the factors associated with correct diagnosis are displayed in Table 2.

**Table 1.** Participant demographic information (N=52).

| Characteristics | | | Study sample | National population[a] Mean/% |
|---|---|---|---|---|
| **Demographics** | | | | |
| | Age (years), mean (SD) | | 36.9 (10.5) | 50.5 |
| | Years of GP experience, mean (SD) | | 7.0 (9.7) | |
| | **Gender, n (%)** | | | |
| | | Male | 22 (42.3) | 60.9 |
| | | Female | 30 (57.7) | 39.1 |
| | Registrars (GPs in training), n (%) | | 17 (32.7) | 3.8 |
| | FRACGP, n (%) | | 28 (53.8) | 56.8 |
| **Practice demographics** | | | | |
| | Practice accredited, n (%) | | 52(100.0) | 88.6 |
| | **Clinic remoteness, n (%)** | | | |
| | | Major city | 36 (69.2) | 71.1 |
| | | Nonmajor city | 16 (30.8) | 28.9 |
| | **Clinic location, n (%)** [b] | | | |
| | | Capital | 27 (51.9) | |
| | | Other metropolitan | 14 (26.9) | |
| | | Large rural | 6 (11.5) | |
| | | Small rural | 4 (7.7) | |
| | | Remote center | 1 (1.9) | |
| **GP position in the practice, n (%)** | | | | |
| | | Principal | 8 (15.4) | |
| | | Nonprincipal | 35 (67.3) | |
| | | Others | 9 (17.3) | |
| **Patient consultations** | | | | |
| | **Patient consultations per week, n (%)** | | | |
| | | <100 | 22 (42.3) | |
| | | 100-149 | 21 (40.4) | |
| | | ≥150 | 9 (17.3) | |
| | **Patient consultations hours per week, n (%)** | | | |
| | | <11 | 10 (19.2) | 1.2 |
| | | 11-20 | 4 (7.7) | 12.2 |
| | | 21-40 | 24 (46.2) | 53 |
| | | 41-60 | 14 (26.9) | 33.5 |
| | **Non-English consultations, n (%)** | | | |
| | | No | 45 (86.5) | |
| | | Yes, <25% | 7 (13.5) | 24.5 |

[a]Sourced from national data when available [10].

[b]Classification based on Rural, Remote and Metropolitan Area classification [11,12].

**Table 2.** Factors associated with correct diagnosis (outcome consistent with expert opinion).[a]

| Variable | | n/N (%) | Odds ratio | 95% CI | P |
|---|---|---|---|---|---|
| **Age** | | | | | |
| | 31 years or older | 103/156 (66.0) | 1 (reference) | | |
| | 30 years or younger | 67/84 (79.8) | 2.64 | 1.12-6.22 | .0262 |
| **Years of practice** | | | | | |
| | 1-5 | 101/132 (76.5) | 1 (reference) | | |
| | 5 or more | 69/108 (63.9) | 0.42 | 0.20-0.87 | .0189 |
| **GP holds a fellowship** | | | | | |
| | No | 69/102 (67.6) | 1 (reference) | | |
| | Yes | 101/138 (73.2) | 3.26 | 1.62-6.54 | .0009 |
| **Case vignette** | | | | | <.0001[b] |
| | 1. Peripheral neuropathy | 36/40 (90.0) | 4.43 | 1.41-13.96 | .0110 |
| | 2. Erectile dysfunction | 38/40 (95.0) | 9.70 | 2.48-38.03 | .0011 |
| | 3. Urinary dysfunction | 23/40 (57.5) | 0.54 | 0.20-1.46 | .2227 |
| | 4. Tumor recurrence | 31/40 (77.5) | 1.55 | 0.48-5.06 | .4663 |
| | 5. Cancer-related fatigue | 14/40 (35.0) | 0.19 | 0.08-0.44 | .0001 |
| | 6. Radiation proctitis | 28/40 (70.0) | 1 (reference) | | |

[a]The independent variable was a correct response. For example, in the first analysis, respondents who were aged 30 or younger were ly more likely (OR 2.64) to give a correct diagnosis than the older participants. The numbers in the third column show the number and percentage of correct responses within the group defined by the row. For example, 80% (67/84) of the diagnoses from people aged 30 or under were correct compared with 66% (103/156) for the older group.

[b]P value for the variable as a whole.

## Management Consistent With Expert Opinion

Management of the cases according to the expert opinion was categorized into 3 domains, namely, (1) refer, (2) prescribe, and (3) order tests.

### Refer

Only 5/6 cases were deemed by the experts to require referral. The analysis of this variable used only the records relating to these vignettes (n=200 observations), as it was far more important that the GP should refer when a referral was considered important than they should do so when it was considered unimportant. Of these 200 observations, only 86/200, 43% (range 18-60%), were consistent with the expert opinion (so 57%, 114/200, did not refer, when it was considered appropriate to do so). This inconsistency occurred more frequently for the cases of erectile dysfunction, radiation proctitis, and peripheral neuropathy, with only 18% (7/40), 38% (15/40), and 43% (17/40) of these cases correctly referred, respectively.

Similarly, only 38% (15/40) of the referrals made by GPs who worked more than 60 patient care hours per week and 33% (26/80) of those made by GPs who had 1-2 years of experience were consistent with expert opinion. The results of the regression analysis revealed that the number of patient contact hours done by a GP per week and years of practice influenced GPs' decisions to refer. Compared with GPs who worked up to 40 hours, GPs who worked more than 40 hours per week were more likely (OR 0.38, 95% CI 0.17-0.84, P=.02) to refer the

patient, in agreement with the expert opinion. GPs with 1 year of experience (OR 0.30, 95% CI 0.13-0.66, P=.003) were less likely to refer according to expert opinion. Details of the factors associated with correct referrals are displayed in Table 3.

### Prescribe

Of the 120 observations made by the GPs to correctly prescribe, only 39% (n=47; range 27-70%) of the prescriptions were consistent with the expert opinion. The only cases with higher proportion of GPs who gave prescriptions that were consistent with expert opinion were erectile dysfunction (28/40, 70%).

The results of the regression analysis show that, compared with radiation proctitis, GPs were more likely to offer a prescription for erectile dysfunction that was consistent with expert opinion (OR 1.27, 95% CI 0.47-3.42, P=.63). However, this association was not statistically .

Details of the factors associated with correct prescription are displayed in Table 3.

### Order Tests

Of the 160 observations made by the GPs to order tests, at least 50% (80/160) were consistent with the expert opinion (average 36, range 10-85%). This consistency was observed more for chemotherapy-induced fatigue (33/40, 83%) and tumor recurrence (32/40, 80%) compared with radiation proctitis (4/40, 10%) and urinary dysfunction (16/40, 40%). Sixty-four percent (23/36) of tests ordered by GPs who had more than 150 patient

consultations per week (OR 2.48, 95% CI 1.16-5.30, *P*=.02) were consistent with the expert opinion.

Regression analysis results showed that compared with ordering tests for radiation proctitis, GPs were more likely to order tests for urinary dysfunction (OR 6.33, 95% CI 1.58-25.42, *P*=.01), tumor recurrence (OR 40.02, 95% CI 10.29-155.68, *P*<.001), and chemotherapy-induced fatigue (OR 47.29, 95% CI 11.47-195.00, *P*<.001). Details of the factors associated with correct ordering of tests by GPs are displayed in Table 3.

**Table 3.** Factors associated with management that is consistent with expert opinion.[a]

| Outcome | Variable | | n/N (%) | Odds ratio | 95% CI | *P* value |
|---|---|---|---|---|---|---|
| **Prescribe** | **FRACGP** | | | | | |
| | | No | 33/51 (64.7) | 1 (reference) | | |
| | | Yes | 32/69 (46.4) | 0.41 | 0.17-1.00 | .0508 |
| | **Case vignette** | | | | | <.0001[b] |
| | | 1. Peripheral neuropathy | 11/40 (27.5) | 0.19 | 0.08-0.47 | .0003 |
| | | 2. Erectile dysfunction | 28/40 (70.0) | 1.27 | 0.47-3.42 | .6388 |
| | | 6. Radiation proctitis | 26/40 (65.0) | 1 (reference) | | |
| **Refer** | **Years of practice** | | | | | |
| | | 1 | 15/55 (27.3) | 0.30 | 0.13-0.66 | .0027 |
| | | 2 or more | 71/145 (49.0) | 1 (reference) | | |
| | **Hours of patient contact per week** | | | | | |
| | | Up to 40 | 69/145 (47.6) | 1 (reference) | | |
| | | 41 or more | 17/55 (30.9) | 0.38 | 0.17-0.84 | .0165 |
| | **Case vignette** | | | | | .0005[b] |
| | | 1. Peripheral neuropathy | 17/40 (42.5) | 1.26 | 0.58-2.71 | .5632 |
| | | 2. Erectile dysfunction | 7/40 (17.5) | 0.33 | 0.10-1.04 | .0582 |
| | | 3. Urinary dysfunction | 23/40 (57.5) | 2.44 | 0.94-6.35 | .0680 |
| | | 4. Tumour recurrence | 24/40 (60.0) | 2.73 | 0.98-7.60 | .0542 |
| | | 6. Radiation proctitis | 15/40 (37.5) | 1 (reference) | | |
| **Order tests** | **Number of patients seen per week** | | | | | |
| | | Less than 150 | 62/124 (50.0) | 1 (reference) | | |
| | | 150 or more | 23/36 (63.9) | 2.48 | 1.16-5.30 | .0191 |
| | **Case vignette** | | | | | <.0001[b] |
| | | 3. Urinary dysfunction | 16/40 (40.0) | 6.33 | 1.58-25.42 | .0092 |
| | | 4. Tumour recurrence | 32/40 (80.0) | 40.02 | 10.29-155.68 | <.0001 |
| | | 5. Cancer-related fatigue | 33/40 (82.5) | 47.29 | 11.47-195.00 | <.0001 |
| | | 6. Radiation proctitis | 4/40 (10.0) | 1 (reference) | | |

[a]The table shows the results of 3 GEE models. For each analysis, the dependent variable was a correct response. The numbers in the third column show the number and percentage of correct responses within the group defined by the row.

[b]*P* value for the variable as a whole.

## Discussion

### Preliminary Findings

In this study, we have explored the impact of a variety of clinical and respondent characteristics on GPs' decisions to treat patients with treatment side effects or symptoms of recurrence of colorectal cancer. Peripheral neuropathy, fatigue, bowel dysfunction, urinary dysfunction, tumor recurrence, and sexual dysfunction are common presentations of patients with colorectal cancer in general practice [13]. Our data indicate that GPs correctly diagnosed most of these conditions, with the exception of chemotherapy-induced fatigue. This would be expected, as in most cases, fatigue presents as a manifestation of other underlying conditions and it is also difficult to diagnose [14]. Although participating GPs did not recognize fatigue, the

regression results showed that they ordered tests to explore underlying conditions that were consistent with the expert suggestions. Our results also indicate that younger GPs (<30 years of age) and those who held a GP fellowship were more likely to identify cases consistent with the expert opinion. The recency of training may have contributed to their level of awareness of colorectal cancer treatment-related problems. However, given the modest sample size we are cautious about drawing firm conclusions on this point.

Suggestions for management plans for these conditions were, however, not consistent with expert opinion in all the applicable categories of management (refer, prescribe, and order tests) for the specific cases. From the regression analysis, we were able to conclude that compared with radiation proctitis, tumor recurrence, fatigue, and urinary dysfunction were more likely to be managed according to the experts' opinions. There were marked deviations from the experts' suggestions for the cases of erectile dysfunction and peripheral neuropathy. For example, for erectile dysfunction, practitioners were less likely to refer back to the specialist, but offered appropriate medication. Similarly, there were deviations from expert management for peripheral neuropathy and urinary dysfunction. Such deviations from expert opinion have been reported previously in similar studies with prostate cancer patients [15].

The differences in management between the participants and the expert panel were less marked for the management of tumor recurrence. This may be expected, as most patients first present to a GP before the cancer diagnosis [16] or with symptoms of recurrence even with ongoing management by their specialist [6]. It is therefore plausible that the GPs were well experienced in recognizing and making appropriate decisions related to tumor recurrence.

Regression analysis also suggested that there were other influential variables that had an impact on the management of these conditions. These were some of the demographic characteristics of the participants; in particular, the number of patient contact hours and years of experience. GPs with less than 1 year of experience were less likely to manage patients according to expert opinion. This was expected for patients treated for colorectal cancer, because many of these problems are likely to present infrequently when patients are still being followed by their specialist. Few doctors will have encountered them previously unless they work full-time and/or have been practicing for a longer period.

A number of approaches have been reported in the literature to promote consistent and reliable management of chronic conditions in primary care [6,15,17]. A few of these have focused specifically on the knowledge of GPs [15], and others have reported that attitudes and beliefs are important in the context of a cancer diagnosis [6]. These issues were not evaluated in this study. For example, we were unable to report on the participants' attitude to the management of patients following treatment and whether they felt this role extended to investigating and treating conditions that may have resulted from specialist treatment.

Finally, we could not identify any practitioners who had any specialist training in colorectal cancer. However, all participants were working as GPs when they participated in this study and it is reasonable to assume that there were a negligible number with specialist training in a specific cancer.

This pilot study had a modest sample size of 240 observations, which was chosen on the basis that this number would be adequate to estimate the proportion of occasions on which at least one problem was correctly identified or managed with a reasonable precision (approximately ±10%). This was not true of all management modalities. In some cases, the number of observations was very low, as evidenced by very wide confidence limits, as shown in Table 3. Therefore, a much larger randomized study would be required to test our objectives robustly. In addition, some of the participants' demographic characteristics differed from the national average and this may limit generalizability of the findings.

## Conclusions

In this pilot study, years of experience and direct patient contact hours had a more and positive impact on the management of patients. This study also showed promising results that management of the common side effects of cancer colorectal treatment could be delegated to general practice. Such an intervention could support the application of shared care models of care. However, a larger study, including the management of side effects in real patients, needs to be conducted before it can be safely recommended.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

An Example of the Video Vignettes Used (.mov Movie File).

[MOV File, 111MB - jmir_v17i11e249_app1.mov ]

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## Multimedia Appendix 2

Details of Patients Presented in the Video Vignettes.

[PDF File (Adobe PDF File), 12KB - jmir_v17i11e249_app2.pdf ]

## Multimedia Appendix 3

Specific Recommendations for Management of Cases.

[PDF File (Adobe PDF File), 8KB - jmir_v17i11e249_app3.pdf ]

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## Abbreviations

**CRC:** colorectal cancer
**FRACGP:** Fellowship of the RACGP

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**GEE:** general estimating equation
**GP:** general practitioner
**OR:** odds ratio
**RACGP:** Royal Australian College of General Practitioners

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Original Paper

# Analysis of Documentation Speed Using Web-Based Medical Speech Recognition Technology: Randomized Controlled Trial

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## Abstract

**Background:** Clinical documentation has undergone a change due to the usage of electronic health records. The core element is to capture clinical findings and document therapy electronically. Health care personnel spend a significant portion of their time on the computer. Alternatives to self-typing, such as speech recognition, are currently believed to increase documentation efficiency and quality, as well as satisfaction of health professionals while accomplishing clinical documentation, but few studies in this area have been published to date.

**Objective:** This study describes the effects of using a Web-based medical speech recognition system for clinical documentation in a university hospital on (1) documentation speed, (2) document length, and (3) physician satisfaction.

**Methods:** Reports of 28 physicians were randomized to be created with (intervention) or without (control) the assistance of a Web-based system of medical automatic speech recognition (ASR) in the German language. The documentation was entered into a browser's text area and the time to complete the documentation including all necessary corrections, correction effort, number of characters, and mood of participant were stored in a database. The underlying time comprised text entering, text correction, and finalization of the documentation event. Participants self-assessed their moods on a scale of 1-3 (1=good, 2=moderate, 3=bad). Statistical analysis was done using permutation tests.

**Results:** The number of clinical reports eligible for further analysis stood at 1455. Out of 1455 reports, 718 (49.35%) were assisted by ASR and 737 (50.65%) were not assisted by ASR. Average documentation speed without ASR was 173 (SD 101) characters per minute, while it was 217 (SD 120) characters per minute using ASR. The overall increase in documentation speed through Web-based ASR assistance was 26% (*P*=.04). Participants documented an average of 356 (SD 388) characters per report when not assisted by ASR and 649 (SD 561) characters per report when assisted by ASR. Participants' average mood rating was 1.3 (SD 0.6) using ASR assistance compared to 1.6 (SD 0.7) without ASR assistance (*P*<.001).

**Conclusions:** We conclude that medical documentation with the assistance of Web-based speech recognition leads to an increase in documentation speed, document length, and participant mood when compared to self-typing. Speech recognition is a meaningful and effective tool for the clinical documentation process.

**KEYWORDS**

electronic health record; automatic speech recognition; randomized controlled trial

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## Introduction

The diagnostic and therapeutic procedures of medical professionals lead to a vast number of observations and decisions, which must be documented correctly to ensure the documentation of the medical course, fulfillment of legal aspects, quality reporting, and billing. The electronic health record (EHR) system plays a critical role in documenting the clinical treatment procedure. The electronic availability of clinical data improves readability, administration, safety, and communication during the course of treatment. On the other hand, electronic health records can interrupt clinical workflows and the treatment procedure, conceivably because of limited availability at bedside. These aspects lead to different beliefs and experiences of health care professionals concerning the general quality of electronic health record systems, clinical day-to-day usability, and user satisfaction [1].

Automatic speech recognition (ASR) systems are believed to facilitate documentation while using the EHR. In clinical specialties with high demands for structured documentation (eg, radiology, pathology), ASR systems are a standard tool today although several studies on ASR in the field of radiology reflect a large amount of heterogeneity [2]. In general, when using a current front-end ASR system, the dictated text immediately appears in visible characters on the screen, and medical documentation can be finalized as soon as it has been entered. As a result, the report is available without delays due to corrections or transport of the report.

Without the availability of a front-end ASR system, the user is forced to wait for a transcriptionist to enter content, to wait for a back-end ASR system to finish the job, or to enter it manually through a keyboard, mouse, or touch screen including all necessary corrections. This already leads to an avoidance of individual documentation by inserting copied text blocks (ie, copy and paste). In an analysis of clinical documentation of an intensive care unit, 82% of documentation contained at least 20% inserted text blocks [3]. Clinical information can be lost due to insufficient adaptation and weighting of the inserted content. Besides, unforeseeable legal issues could be suspected [4].

Front-end ASR systems require the user to interact directly. Since ASR systems compare the user's audio information with predefined patterns, recognition accuracy depends on correct grammar, consistent pronunciation, and constant feedback on new words or abbreviations. Therefore, users are urged to correct errors during report generation interactively in order to feed machine learning mechanisms.

Comparative analysis and synthesis of studies covering the usefulness of ASR in various clinical settings is challenging due to a narrative presentation of the results [5]. In 2003, a randomized controlled trial was undertaken outside radiology to compare back-end speech recognition with standard transcription, which failed to find an overall benefit [6]. Now, with the advent of new technologies, front-end ASR is available instantly in all areas and specialties of medicine in different languages [7]. But the effects of using current front-end ASR in a clinical setting on documentation speed, document length, and physician satisfaction are not known, thereby indicating the need for explorative studies on the topic.

We hypothesize that the addition of a Web-based, front-end ASR system to the clinical documentation process leads to an increase in documentation speed and documentation amount, and thereby increased physician satisfaction. To measure the effects of using a Web-based, front-end ASR system on documentation speed, document length, and physician satisfaction, we conducted a prospective randomized controlled trial. Documentation time, the number of documented characters, and physician satisfaction have been analyzed for keyboard and speech input in the German language. No changes have been made to any other aspect of the clinical documentation process.

## Methods

The study was not registered in a World Health Organization (WHO)-accredited trial registry since there was no applicable biomedical or health outcome conforming to any human subject or ethics review regulations, or regulations of the national or regional health authority.

### Study Design

Physicians from the Department of Pediatrics and the Department of Trauma Surgery, Düsseldorf University Hospital, Germany, were asked to participate in morning meetings. Two participants were asked to participate via personal communication. Enrollment was possible over a period of 30 days. The inclusion criteria were clinical activity of the participating physicians and documentation of at least two clinical reports within the study period.

All participants signed their informed consent forms. Each participant was known to the study team in person. Through the enrollment, the physician chose an individual username and password, not known to the study team, to access the study website. Thereafter, the users identified themselves using a username and a password. After written informed consent was obtained and the privacy policy signed, the password-protected, browser-based, study analysis home page was activated. The username was replaced with a number when storing study information in the database. The study was conducted by approval from, and according to requirements of, the Health Privacy Commissioner of Düsseldorf University Hospital (see Multimedia Appendix 1 for the CONSORT-EHEALTH checklist).

During a short, standardized technical training session, all participants documented a uniform standard text once using speech and once using a keyboard to assess individual speed levels. After that, no further contact between the study team and the participants occurred until the end of the study period of 120 days.

All participants were asked to do everyday clinical documentation in a browser's text area. To complete a study step, the participant opened a webpage, logged in, and documented the clinical finding, report, or discharge letter in the browser's text area. After completion, the text was manually copied into the EHR. For each study step, the length of the text,

documentation time including necessary corrections, correction-associated usage of keyboard, and physician's moods were captured using JavaScript. Each participant received the intervention in a random sequence. For each study step, log-in, or refresh of the webpage, a randomization occurred between the availability of speech recognition and the keyboard, or the keyboard alone.

After all necessary corrections (misspellings, misrecognitions, etc) to achieve a correct text, the study step (ie, the clinical report) was finished by hitting one of three smileys to indicate the mood. The physician's mood was measured using a 3-point scale (1 = good, 2 = moderate, 3 = bad) by online self-assessment on the study webpage. Hitting one of three smileys lead to the appearance of a copy button. Finalization of a study step and the transfer of captured data to the storage database were achieved by hitting the copy button. This action placed the text in the clipboard and simultaneously triggered a new randomization. Depending on the randomization result, the browser loaded a script that enabled medical speech recognition in addition to conventional keyboard text entry. Closing the session without hitting the copy button or direct log-out lead to exclusion of the report for further analysis (see Figure 1).

Writing speed was calculated by the number of characters per minute. The underlying time frame was the text entry time and corrections until finalization of the document. Numerical measures are mentioned in the text as mean (SD). To reduce the impact of technical artifacts (eg, by inserting text blocks or by interrupting text entry without finalizing the study documentation step), documentations with greater than 1000 characters per minute, more than 1-hour documentation time, or fewer than 10 characters have been excluded.

During the study period, a Web-based medical speech recognition system has been used (Nuance SpeechAnywhereServices Browser SDK, SpeechAnywhereServices 1.6/ SpeechMagic Version 7 Release 4 FP4, MultiMed 510.706). The system was available on any clinical desktop computer having a microphone, Microsoft Silverlight installed, and access to the network. No modifications to the physician's computer were made except the addition of a USB microphone (Samson Go Mic clip-on USB microphone). The only limitation was the restriction of usage for medical documentation only. The participants conducted their documentation based on their own needs. They were not allowed to use the system for private communication. It was not possible to insert text blocks by voice commands.

For each report, information including a time stamp had been saved for further analysis. The study information contained the following: current number, user ID, time stamp, session time, delete key count, backspace key count, arrow key count, mouse left-click count, total number of characters, self-assessment of mood, and type of session (intervention or control). The information was transmitted to a database using a Secure Sockets Layer (SSL) protocol. The end point of the study was the end of the study period.

**Figure 1.** Completion of a study step (ie, clinical report), webpage layout of intervention and control, randomization procedure, and time measurement. Please note the existence of a speech plug-in during the intervention (grey bar, lower left corner of intervention webpage). Starting time count also starts the other counters used (ie, delete key, backspace key, arrow keys, mouse left click). The copy button will appear after the participant hits a smiley for self-assessment of mood. This action copies the text onto the clipboard for further usage in the EHR.
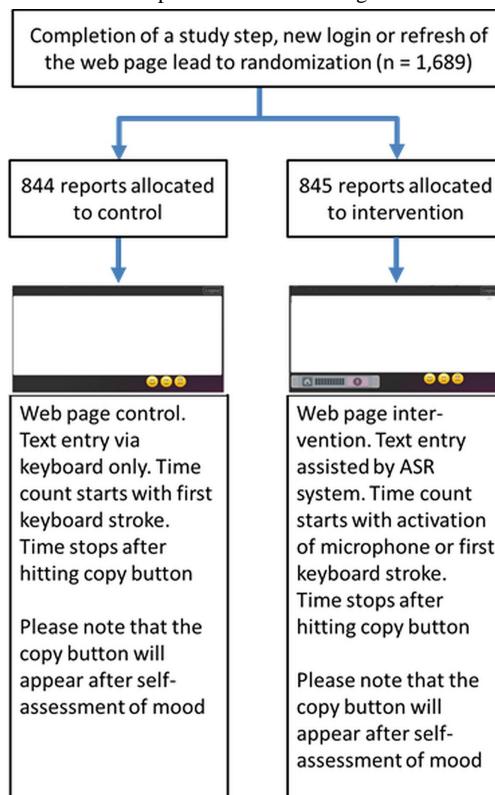
## Statistical Analysis

Calculation of numerical results, statistical tests, and creation of images were performed using R version 3.2.1 (The R Foundation, Vienna, Austria) [8] using a permutation test.

# Results

During the recruitment period, 40 physicians asked for participation. Out of 40 physicians, 37 (93%) met the inclusion criteria. Out of 37 participants, 7 (19%) could not participate after initial enrollment because of organizational reasons. Out of 30 participants, 2 (7%) were excluded later because fewer than two documents were completed using the study system.

The 28 (100%) final participants were comprised of 21 (75%) interns and 7 (25%) senior physicians. A total of 17 out of 28 (61%) participants were male and 11 (39%) were female. A total of 22 out of 28 (79%) participants were from a nonsurgery department and 6 (21%) were from a surgery department (see Table 1). All participants were native German speakers. No participant was a trained typist or had professional exposure to speech recognition systems before (see Figure 2).

**Table 1.** Participant characteristics (n=28).

| Participant characteristics | n (%) |
|---|---|
| All participants | 28 (100) |
| Male | 17 (61) |
| Female | 11 (39) |
| Number of senior physicians | 7 (25) |
| Surgery | 6 (21) |
| Nonsurgery | 22 (79) |

Over a period of 120 days, 1455 of 1689 (86.15%) recorded clinical reports from 28 participants met the inclusion criteria. A total of 234 reports out of 1455 (16.08%) were excluded because documentation speed was greater than 1000 characters per minute, documentation time was more than 1 hour, or the report contained fewer than 10 characters (see Figure 2). A total of 718 out of 1455 (49.35%) clinical reports were done using speech and 737 (50.65%) were done using the keyboard alone. Figure 3 shows the number of documentations per participant.

The average documentation speeds until the finalization of the report, including all corrections, were 173 (SD 101) characters per minute in the keyboard only (control) group, and 217 (SD 120) characters per minute in the speech-assisted (intervention) group. The documentation speed was increased by 25.7% in the speech group (P=.04, permutation test). The distribution of speed values is shown in Figure 4. Using the keyboard exclusively, an average of 356 (SD 388) characters per report were entered compared to 649 (SD 561) characters using speech entry. After the documentation, the physicians' average mood ratings were 1.6 (SD 0.7) using keyboard alone and 1.3 (SD 0.6) when using speech recognition (P<.001, permutation test). Table 2 shows a complete reference of captured data for productive use during the study period, and Table 3 shows a complete reference of captured data of standardized text.

**Table 2.** Captured data during productive use (n=1455)[a].

| Captured data: productive use | Keyboard only | Speech assisted |
|---|---|---|
| Number of reports/documentations, n (%) | 737 (50.65) | 718 (49.35) |
| Total number of characters | 262,080 | 465,785 |
| Total documentation time | 37h 18min | 55h 24min |
| Number of characters per report, mean (SD) | 356 (388) | 649 (561) |
| Number of delete key strokes[b], mean (SD) | 0.3 (1.2) | 4.2 (9.5) |
| Number of backspace key strokes[b], mean (SD) | 25.7 (41.8) | 10.3 (16.5) |
| Number of arrow key strokes[b], mean (SD) | 3.0 (7.1) | 5.8 (15.2) |
| Number of mouse left clicks[b], mean (SD) | 2.8 (4.0) | 11.4 (13.6) |
| Mood rating (1=good, 2=moderate, 3=bad), mean (SD) | 1.6 (0.7) | 1.3 (0.6) |

[a]Please note the absolute numbers in Table 2 versus the relative numbers in Figure 6.

[b]The listed key strokes are necessary correction events to produce a final report.

**Table 3.** Captured data during standard text entry (n=60)[a].

| Captured data: standard text[b] | Keyboard only (n=30), mean (SD) | Speech assisted (n=30), mean (SD) |
|---|---|---|
| Duration (s) | 376 (176) | 339 (175) |
| Number of characters | 939 (10) | 956 (8) |
| Number of delete key strokes | 0.8 (2.3) | 5.6 (8.0) |
| Number of backspace key strokes | 26.8 (15.0) | 14.8 (15.7) |
| Number of arrow key strokes | 6.2 (10.6) | 13.9 (22.5) |
| Number of mouse left clicks | 3.8 (4.4) | 11.3 (10.1) |
| Mood rating (1=good, 2=moderate, 3=bad) | 1.6 (0.7) | 1.3 (0.6) |

[a]Please note the absolute numbers in Table 3 versus the relative numbers in Figure 6.

[b]Each participant entered the standard text twice (control method and intervention method) and applied corrections to generate a correct text.

While documenting a standardized text, 17 out of 28 (61%) participants were faster using speech. During productive use, 22 out of 28 participants (79%) were faster when using speech recognition (see Figure 5). The individual rate of corrections—sum of correction actions (delete, backspace, arrow keys, and mouse left click) per number of characters per report—was lower for speech-assisted documentation. The total number of characters per report was higher in the intervention group (speech recognition) (see Figure 6).

The measured total time of documentation was 37 hours and 18 minutes for the control group and 55 hours and 24 minutes for the intervention group. Using keyboard alone, 262,080 characters were entered into the study system compared to 465,785 characters during speech recognition availability. Tables 1 and 2 show an overview of captured data, including correction effort which is defined as the recorded keyboard strokes of the delete, backspace, and arrow keys, as well as mouse left clicks. Comparing control and intervention groups, the results show a significant increase in documentation speed, document length, and physician satisfaction. They also show a decreased correction rate and an increase in total documentation time secondary to the increased documentation amount.

**Figure 2.** CONSORT-EHEALTH flowchart of enrollment, participants, and report status.
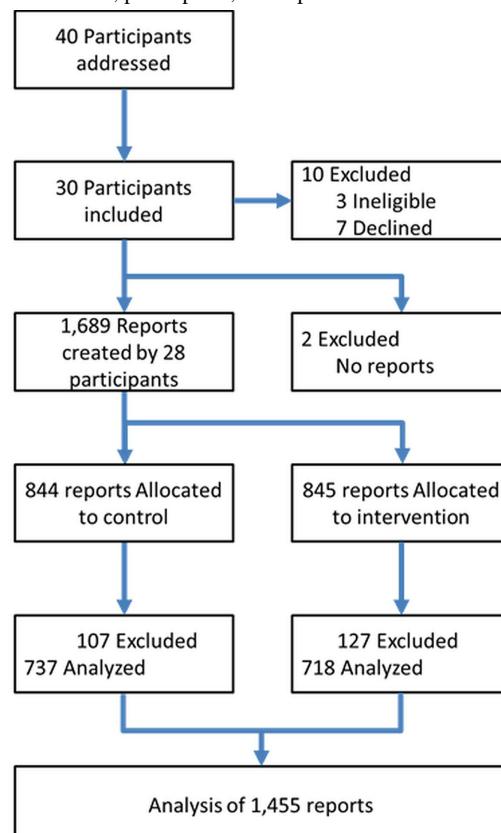
**Figure 3.** Box plot of the number of documentations per participant (total n=1455).
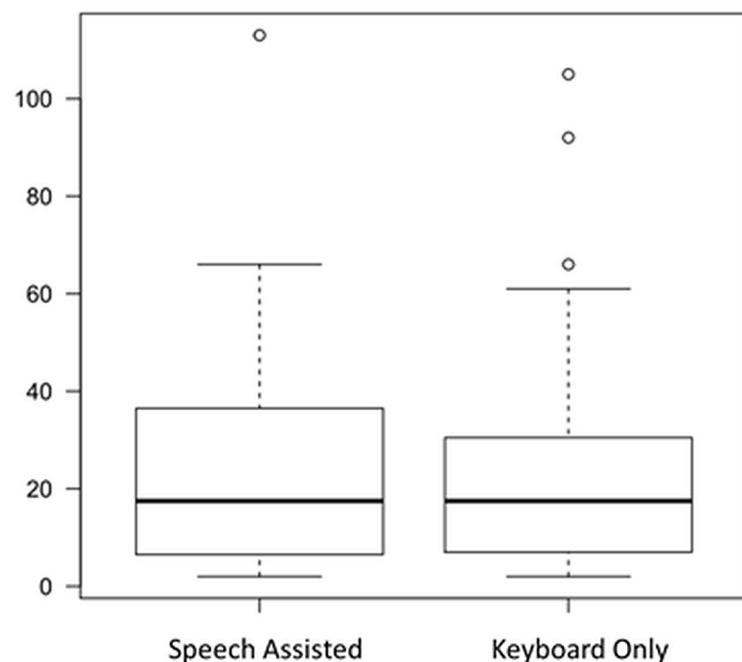


**Figure 4.** Distribution of documentation speed in characters per minute.
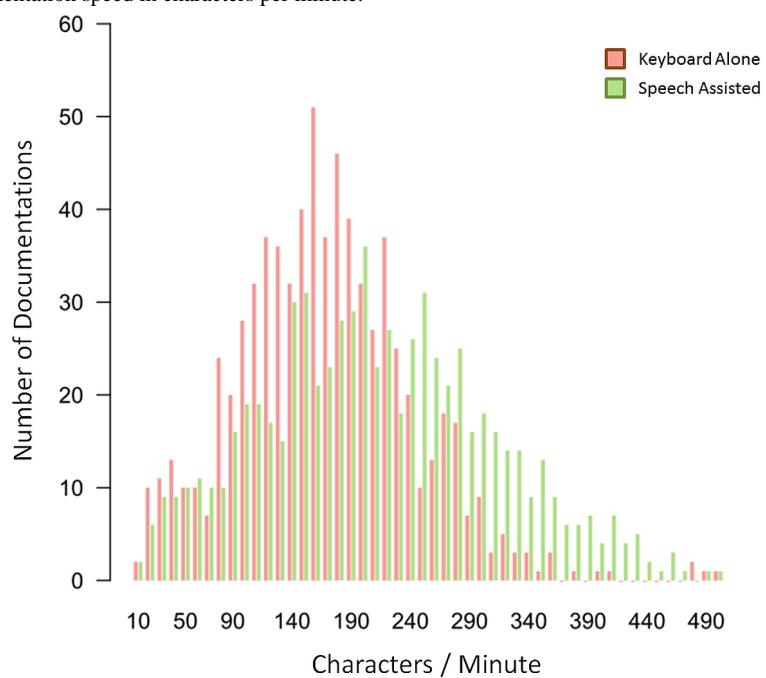
**Figure 5.** Per person analysis of documentation speed while documenting a standard text and during productive use in characters per minute. Each dot represents one participant. The location of the dot indicates the documentation speed of control and intervention. A location above the dotted line indicates a gain in speed using the intervention (speech-assisted documentation). The dots representing the standard text consist of one initial documentation pair while the dots representing productive use consist of all available data for each participant. The labeling of dots with numbers is for better comparison of both plots within the figure. Please note that documentation of the standard text reflects the individual's typing capabilities on the x-axis and the individual's initial capabilities in using the ASR system on the y-axis.
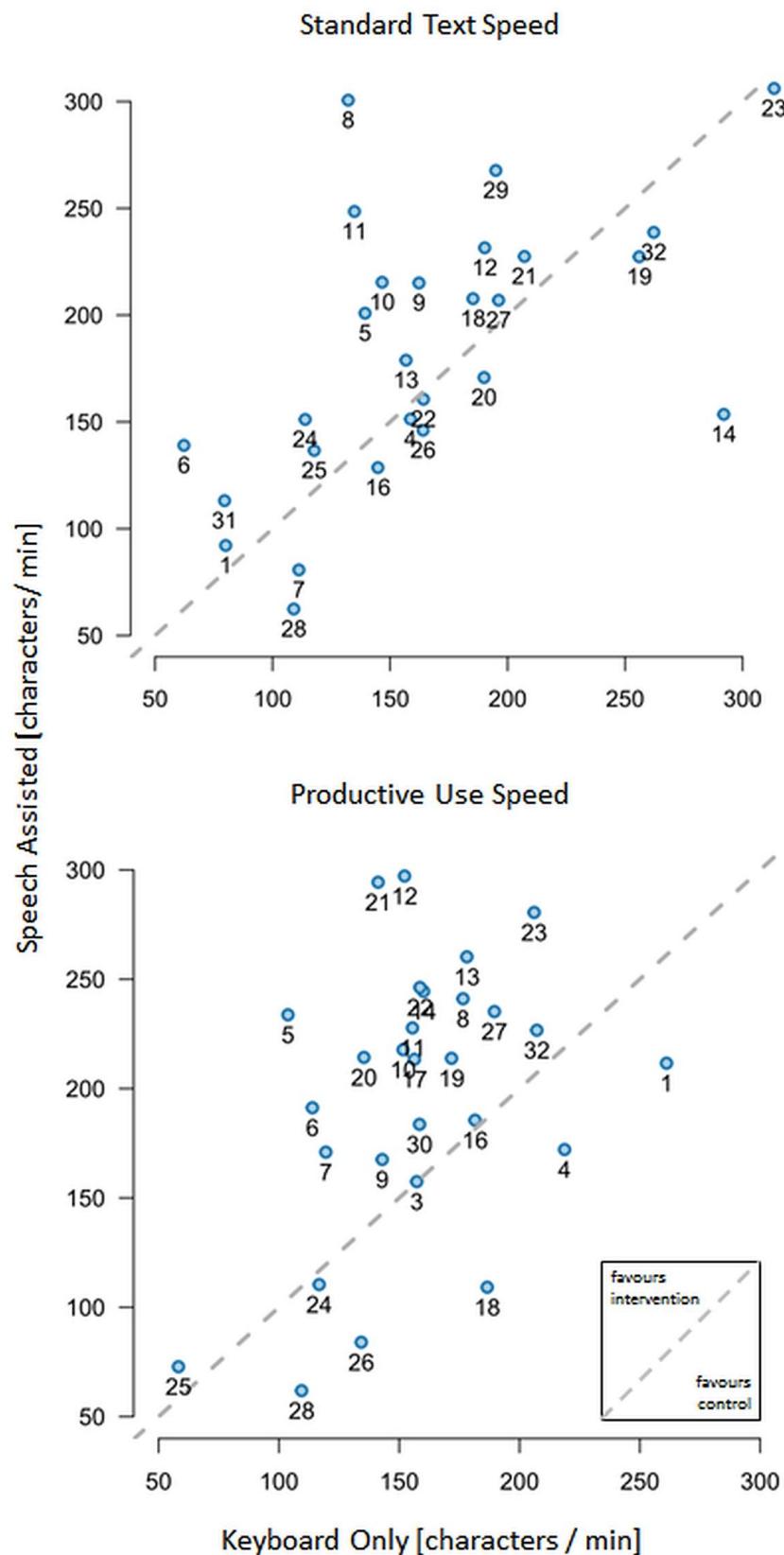
**Figure 6.** Per person analysis of correction rate and number of characters. Each dot represents one participant. The location of the dot indicates the sum of corrections per documented character (see text for further details) of control and intervention and the number of characters per report of control and intervention. A location above the dotted line indicates increased correction effort and increased number of characters per report when using the intervention.
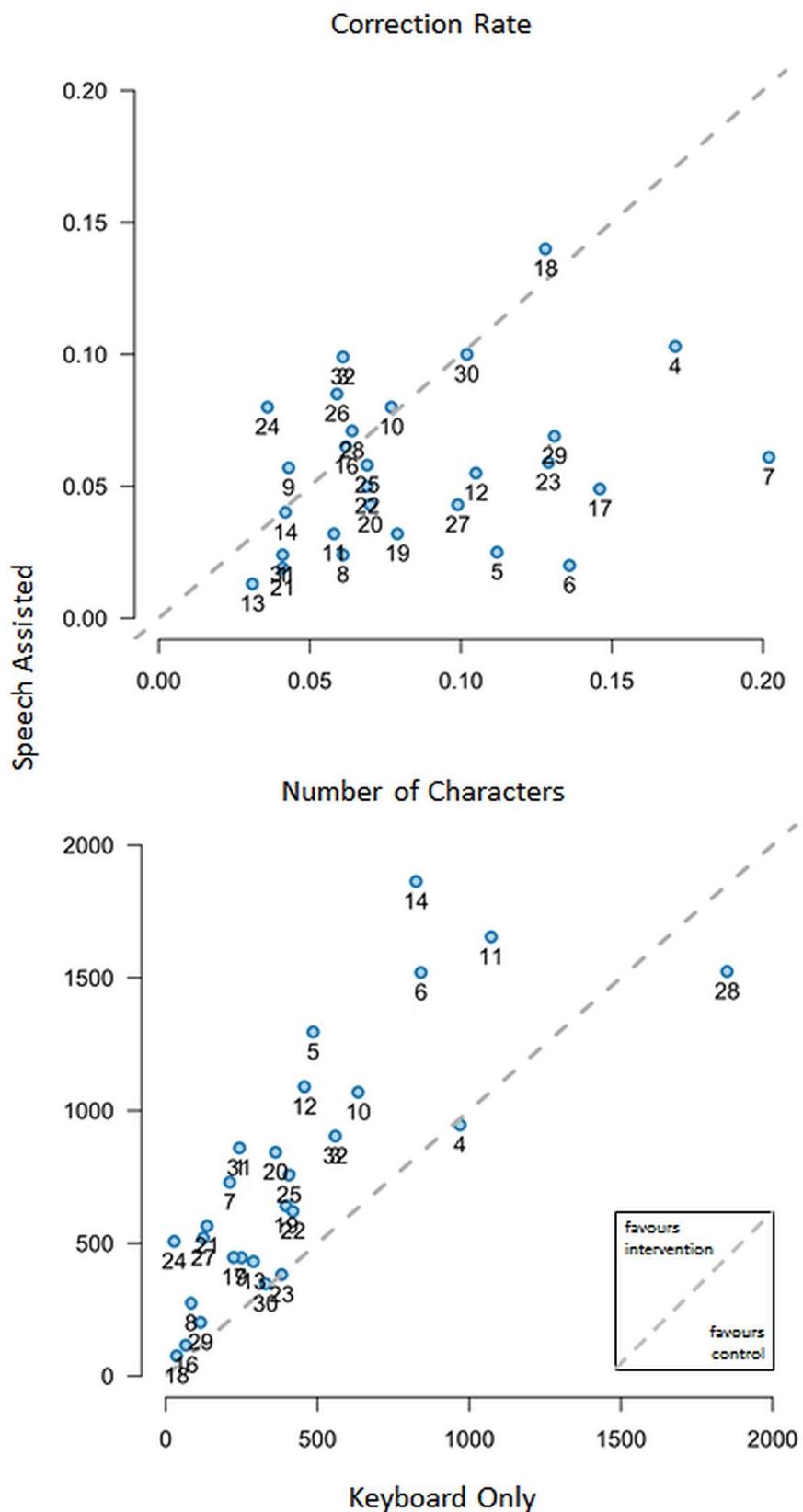
## Discussion

### Principal Findings

Digital communication and electronic information exchange have become a part of everyday communication. Clinical documentation is a core aspect of the clinical profession and is more than a tool for efficient, maximized billing [9]. Nevertheless, in medicine the emphasis lies on paper-based documentation, being only assisted by electronic documentation. The reasons for this are the deficient quality and usability of electronic clinical documentation tools [1].

To enter information into the EHR, physicians rely on their ability to type or on the assistance of transcriptionists, but medical transcriptionists are a limited resource (eg, usually not available at the point of care or during nighttime). Therefore, the only alternatives for clinicians are pen-and-paper documentation, self-typing, or avoidance of documentation.

The objective of this study was to compare the impact of electronic speech recognition with self-typing based on measurement of documentation speed and volume, and user satisfaction. This explorative study based on 1455 captured medical documents demonstrated that the availability of Web-based medical speech recognition led to increased documentation speed, increased documentation amount, and higher physician satisfaction.

The study group consisted of native German speakers which favors good results in this German-based speech recognition system. Due to the correct grammar of a native speaker, word chains can be predicted by an ASR system thereby enhancing the recognition result. Foreign speakers face difficulties in using ASR systems mainly because of using incorrect grammar versus having an accent [10].

The study group was more satisfied when speech recognition was used in documentation. The reasons for increased satisfaction could be individual physiological factors like hand posture and typing speed. These factors greatly influence fatigability, finger pain, and various physiological aspects, which could explain different satisfaction levels [11]. On the other hand, due to the study group's explorative composition, blocking and selection as well as stratification bias cannot be precluded.

### Requirements for Extensive Automatic Speech Recognition Usage in Clinical Routine

Electronic documentation tools are available on any desktop computer in hospitals. But the usual technical requirements for using speech recognition drastically reduce availability. The Web-based design of the study made speech recognition available on virtually any microphone-equipped desktop computer with a network connection. Documentation which is available everywhere in a hospital (also at the point of care) and simplified by suitable electronic tools leads to rapidly available individual texts. At the point of care, ASR systems have the greatest advantage over audio recordings since the documented text is electronically available day and night in real time [12].

Assuming availability issues were to be solved, remaining obstacles for widespread use of ASR in hospital settings include

insufficient identification of employees with the new technology, slow learning curve, correction efforts, costs, and limited availability of microphones. Individual barriers and different usage types are reflected in the different gains when analyzing Web-based study ASRs on an individual level [2,13-15].

Improved human-machine interfaces, such as speech recognition or touch screen entry, could change the paradigm of paper-based documentation to full electronic documentation. This study addresses the question of whether typing alone or a combination of typing and speaking is a suitable human-machine interface in a general clinical setting. Autonomous clinical observations documented in real time are of utmost importance for the treatment process, and the acceptance of electronic documentation depends on the availability of these observations [16].

### Electronic Documentation

Despite obvious advantages, the change to complete electronic documentation is a matter of ongoing discussion; on one hand, electronic documentation promises increased efficiency and improvements in patient treatment through availability and readability. On the other hand, there are concerns of exchanging information electronically, such as the tracking of data to an individual, general data security, or compliance with local regulatory requirements [4]. An insufficient adaptation of systems for specific clinical requirements (eg, in pediatrics) immediately reduces the clinical usefulness, leading to avoidance and thereby manifesting the status quo [17].

In general, the use of electronic documentation in creating a clinical document is a multistage process that starts even before the patient has been seen by the physician: copying and pasting of personal information, importing of lab values, importing of the radiologist's reports, or findings and reports of colleagues [18]. This can lead to fast but insufficiently individualized documentation, which can be troublesome. It is likely that certain clinical documentation tasks like informed consent will be exclusively documented electronically in the near future [19]. Electronic documentation may lead to a more complete documentation [20]. Consistent with this finding, the availability of a tool for the production of more complete documentation may be an explanation for the observed increase in documentation volume in our study.

### Strengths and Limitations

The strength of this study was being able to describe the effects of ASR availability on the clinical documentation process based on detailed data recorded by a computer program. This contrasts a significant number of studies on the topic which rely on perception-based data [1]. We present no proposal for a generally optimized clinical documentation process. The intervention affected only the self-typing by the medical personnel [2]. Provision via browser windows limited ASR availability issues to the presence of microphones. For study purposes, all computers involved in the study were equipped with a clip-on USB microphone.

Until recently, ASR training phases for new users were common. This was not done in this study system. Corrective user actions induce ASR system adaptation. Depending on the dictation style

and the contents of the dictation, the errors made by ASR can be numerous. Therefore, different correction efforts and usage types could explain the scattering in Figure 6. This scattering was induced by the user, and the reaction of the system to the user. The reports created by the study participants were not evaluated for typos or misspellings. It was not the intention of the study to check the grammar quality of a medical report directly; this might be an objective for a follow-up trial. Another strength of the study was being able to measure the correction effort indirectly by counting correction-related user interactions. Effects resulting from insertion of text blocks were eliminated by limiting documentation speed to a physiologically sensible range.

As part of the personalization process, corrections have great impact on speech recognition systems. They modify statistical models and potentially add new words to the system. Corrective actions include deletion and insertion of words, replacement of system errors, inserting correct words through the keyboard, and modifying and changing text because of errors caused by voice. Personalization is the basis for good recognition results that are superior to the general recognition results of mobile devices [21]. The different usage patterns of using the mouse left-click button and the delete, backspace, and arrow keys were taken as an indicator of errors within the documentation. We emphasize that all necessary corrections, either using keyboard alone or ASR-assisted keyboard usage, were captured and included in the speed measurements. Maximum increased productivity can be reached if a trained system causing few errors is readily available [12,22].

Any study on the topic has to consider recruitment-induced biases. For this study, no staff groups or specializations were selected—recruitment was based on voluntary participation. A bias can arise easily owing to different specialties, different clinical knowledge, and different experiences with dictation in general [10]. Figure 5 illustrates the individual loss or gain when using the speech recognition system compared to self-typing. Overall, 6 individuals lost speed during the study period (productive use speed) while using the speech recognition system. Users 1 and 4 increased speed during productive use compared to standard text when using speech recognition, but due to high typing speed, there was no overall speed effect. User

28 was consistently slow compared to the rest of the group. For Users 18, 24, and 26, both typing speed and speech speed decreased. The underlying reasons for these observations were not explored. Although these 6 participants individually did not increase documentation speed, there was still an overall time-saving effect. Individual factors like slurred speech, dictation style, and dictation content may heavily influence the recognition result.

Together, all participants documented 727,865 characters (total documentation volume). Documenting this amount by the study group using the keyboard alone would have taken 104 hours. By adding speech to the documentation process, this time decreased to 87 hours. Therefore, the gain on the total documentation time would have been 17 hours. Despite this gain in documentation speed, the notable effect might not be decreased documentation time, but increased documentation volume.

Tools for efficient capturing of patient data and clinical observations are still underrepresented in clinical practice [23]. Even a trained typist will not achieve the same efficiency in capturing patient data on a mobile device's touch screen as speech recognition or a digitizer pen could do day and night.

## Conclusions

We conclude that medical documentation with the assistance of Web-based speech recognition leads to an increase in documentation speed and amount, and enhances the participant's mood when compared to self-typing. The remarkable effect might not be the time savings, but the increase in documentation volume. This study may be a starting point for further investigations where the overall efficiency of the documentation process, differences due to personal preferences, as well as aspects concerning quality of care and patient safety related to clinical documentation are explored.

The way medical documentation influences treatment quality needs to be understood better to choose the right mode of documentation and to help both the doctor and the patient. The continued exchange between health care personnel and technicians can facilitate a technological change in hospitals, and encourage technical advances leading to a more patient-centered treatment.

## Authors' Contributions

MV was the principal investigator of the study. MV, WK, RW, and EM were responsible for the study conception and design, interpretation of data, revising the manuscript for intellectual content, and final approval of the published version. MV and WK were responsible for the acquisition of data. WK performed data analysis and MV and WK drafted the paper. MV is the guarantor of this work and, as such, had full access to all the data in the study and takes responsibility for the integrity of the data and the accuracy of the data analysis.

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## Conflicts of Interest

MV works as a clinical consultant at Nuance Healthcare International.

## Multimedia Appendix 1

CONSORT-EHEALTH (v. 1.6.1) checklist.

[PDF File (Adobe PDF File), 579KB - jmir_v17i11e247_app1.pdf ]

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## Abbreviations

**ASR:** automatic speech recognition
**EHR:** electronic health record
**SSL:** Secure Sockets Layer
**WHO:** World Health Organization

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Original Paper

# e-CBT (myCompass), Antidepressant Medication, and Face-to-Face Psychological Treatment for Depression in Australia: A Cost-Effectiveness Comparison

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## Abstract

**Background:** The economic cost of depression is becoming an ever more important determinant for health policy and decision makers. Internet-based interventions with and without therapist support have been found to be effective options for the treatment of mild to moderate depression. With increasing demands on health resources and shortages of mental health care professionals, the integration of cost-effective treatment options such as Internet-based programs into primary health care could increase efficiency in terms of resource use and costs.

**Objective:** Our aim was to evaluate the cost-effectiveness of an Internet-based intervention (myCompass) for the treatment of mild-to-moderate depression compared to treatment as usual and cognitive behavior therapy in a stepped care model.

**Methods:** A decision model was constructed using a cost utility framework to show both costs and health outcomes. In accordance with current treatment guidelines, a stepped care model included myCompass as the first low-intervention step in care for a proportion of the model cohort, with participants beginning from a low-intensity intervention to increasing levels of treatment. Model parameters were based on data from the recent randomized controlled trial of myCompass, which showed that the intervention reduced symptoms of depression, anxiety, and stress and improved work and social functioning for people with symptoms in the mild-to-moderate range.

**Results:** The average net monetary benefit (NMB) was calculated, identifying myCompass as the strategy with the highest net benefit. The mean incremental NMB per individual for the myCompass group was AUD 1165.88 compared to treatment as usual and AUD 522.58 for the cognitive behavioral therapy model.

**Conclusions:** Internet-based interventions can provide cost-effective access to treatment when provided as part of a stepped care model. Widespread dissemination of Internet-based programs can potentially reduce demands on primary and tertiary services and reduce unmet need.

## Introduction

Depressive disorders are highly prevalent [1], with an average lifetime prevalence of 14.6% [2]. The effects of these disorders extend beyond mental health to include diminished quality of life and functioning and increased mortality and medical morbidity for individuals [3], and substantial economic loss for society [4,5]. Antidepressant medication and cognitive behavior therapy (CBT) are established treatments for depressive disorders; however, current effective coverage is low and the

economic burden attributable to preventable depressive disorders is substantial [6,7]. This situation necessitates alternative cost-effective models of care for people with depressive disorders.

Internet-delivered psychological interventions can facilitate broad access to evidence-based treatments and are popular with users and clinically effective, with outcomes equivalent to face-to-face therapies [8-10]. With large effect sizes and reduced human resource demands (ie, no or minimal therapist input), these interventions are also likely to substantially reduce treatment costs for individuals and society [11,12]. Nevertheless, research into the economic consequences of Internet-delivered interventions is in its infancy. While evidence supports the low marginal costs of providing therapy via the Internet [13-16], the cost-effectiveness of treatment models incorporating Internet-delivered psychotherapies remains largely unexplored. This lack of evidence provides a major impediment to the integration of Internet-delivered interventions into mainstream models of health service provision for depressive disorders.

Current international guidelines recommend a "stepped-care" approach to treatment of depressive disorders. In a stepped-care model, low-intensity interventions are offered to people initiating treatment for persistent subthreshold depressive symptoms or mild-to-moderate depression [17,18], and antidepressant medication and/or face-to-face psychological therapy are offered to those with moderate or severe depression or with ongoing symptoms following an initial low-intensity program. Low-intensity programs include CBT-based guided and unguided self-help, for example CBT delivered via the Internet.

In a recently conducted large-scale randomized controlled trial (RCT), Proudfoot et al [8] showed that a fully automated CBT-based public health intervention combining mobile phone and Web technology, myCompass, effectively reduced symptoms of depression, anxiety, and stress and improved work and social functioning for people with symptoms in the mild-to-moderate range compared with waitlist and placebo controlled conditions. Details of the myCompass trial have been published elsewhere [8]. In this study, we used data from the trial to examine the cost-effectiveness of myCompass when incorporated into a stepped-care approach to depression treatment. Specifically, we compared the cost-effectiveness of myCompass to treatment as usual (TAU; in Australia this is antidepressant medication) and face-to-face CBT, with a view to understanding the cost implications of incorporating this type of intervention into a stepped-care plan for community-based depression management. To our knowledge, this is the first direct comparison of this type undertaken using Australian health system costs and structure.

## Methods

### The Clinical Model

The chosen stepped-care model reflects international and Australian guidelines. International guidelines refer to specific criteria to define treatment response and symptom remission [19]; "response" is generally defined as >50% reduction in symptoms from commencement of treatment per standardized rating scale [20]. "Remission" is generally defined as an asymptomatic state [20]. However, major international guidelines are vague on the specific methods and measures used to track treatment progress [18,21-23]. In the myCompass trial, symptoms were measured using the Depression Anxiety Stress Scale (DASS) [24]. In the trial, an outcome of 27 on the DASS scale reflected a normal (asymptomatic) profile and is assumed here as equivalent to remission on the Hamilton Rating Scale for Depression (0-7) [20]. Probabilities for the "remission" and "maintenance" states in the model were derived from the proportion of myCompass trial participants with scores on the DASS in the normal range at the post-treatment and follow-up assessments.

As described previously, for stepped-care models all patients with mild-to-moderate symptoms start with the same low-intensity intervention. Symptom progress is monitored, and only those with inadequate improvement are offered a higher-intensity intervention. International guidelines recommend that when mild or moderate depression is non-responsive to low-intensity treatments, then antidepressant or face-to-face psychological therapy (eg, CBT or interpersonal psychotherapy) should be offered [17,18,25]. However, due to service delivery barriers, including insufficient psychological services and low workforce numbers, patients are commonly offered antidepressants in the initial stages of treatment [26,27].

In accordance with these guidelines, we examined a stepped-care model that included myCompass as a first step. While current Australian guidelines do not make explicit reference to Internet-delivered therapies, the self-guided nature of myCompass means that it fits very well with current definitions of low-intensity interventions (ie, self-help therapy). In the Australian health system, most people seeking treatment for depression are referred to services by a general practitioner, so this is also reflected in our model.

### Decision-Analytic Model

A decision tree model (Figure 1) for the treatment of mild-to-moderate depression was constructed using a cost utility framework to show both costs and health outcomes over a period of 6 months based on each intervention. Quality-adjusted life years (QALYs) are the most commonly used outcome metric in international economic evaluation studies. The selected interventions include (1) TAU, in this case drug treatment with a prescribed antidepressant for an acute depressive episode, plus a 21-week maintenance phase of drug therapy after remission of symptoms, (2) CBT (face-to-face) with a clinical psychologist for an acute depressive episode, plus a 21-week maintenance phase of monthly booster sessions after remission of symptoms, and (3) the myCompass program for an acute depressive episode, plus a 21-week maintenance phase consisting of a booster Internet-delivered program (eg, mobile monitoring of symptoms, behaviors, and lifestyle factors).

The assumptions of the model are as follows. Individuals can move sequentially between mutually exclusive health states: depressive episode, remission, and maintenance [18]. All patients begin in the "episode" state and receive either myCompass, TAU (antidepressant therapy), or face-to-face

CBT over the course of a 7-week period. During maintenance therapy, all patients have consultations with a general practitioner (GP) at prescribed intervals to monitor symptoms, side effects, and compliance. Active relapse prevention in primary care is considered effective [25]. Patients not complying or not responding to either myCompass or CBT discontinue treatment or switch to receive TAU for the remaining cycles in line with accepted stepped-care protocols, that is, from a low-intensity to a higher-intensity level of intervention. Patients receiving first line antidepressants may switch to a different type if they are non-responsive to initial treatment or if treatment is discontinued for any reason (ie, non-response, adverse events). Those who switch treatment from CBT, TAU, or myCompass may either enter the remission state or discontinue treatment. Patients may become non-compliant or drop out due to side effects or lack of response from any state.

The model was constructed in TreeAge Pro Version 2013 (TreeAge Software Inc.). To estimate QALYs generated by each cohort (people receiving myCompass, face-to-face CBT, antidepressants), the time spent in each health state was multiplied by a health-state utility weight corresponding to a quality of life adjustment for a given state of health, where one is perfect health and zero is death. Utility data were obtained from a published study in which patient-assigned health state utilities were reported by clinical response [15]. Estimated resource utilization data were then combined with the relevant unit cost information to give the reference cost associated with each treatment. All treatment costs were adjusted for patients not completing treatment.

The time horizon for evaluating the benefits and costs of interventions for depression was 28 weeks to capture the initial phase of treatment (7 weeks of the myCompass program, up to a maximum of 10 sessions of CBT, or antidepressants at recommended initial dosages), followed by treatment maintenance after remission, based on current depression treatment guidelines recommending 6 months of treatment at sufficient level to maintain remission [19]. Limited information from published trials on the longer-term consequences of online intervention use was available beyond this timeframe. Additionally, the length of time to continue antidepressant treatment beyond 6 months after recovery from a depressive episode remains unclear [28]. In Australia, Internet-delivered or e-mental health (e-MH) programs can be accessed directly by the public through specialized or general online portals. Alternatively, e-MH can be recommended as a first step by GPs. Our model takes the latter route into consideration. Model input parameters are listed in Table 1 [8,15,20,29-37] (see Multimedia Appendix 1 for calculation methods indicated).

**Figure 1.** Partial decision tree structure (subtree is repeated for each arm of the model).
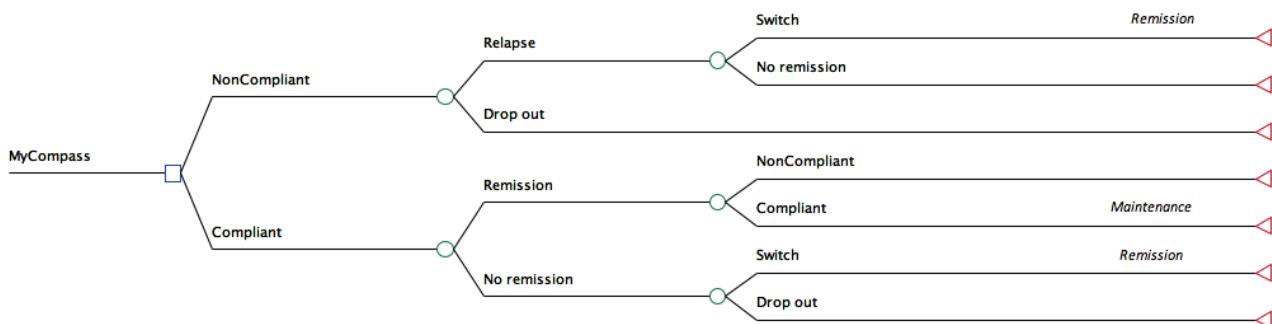
**Table 1.** Model input parameter values and sources of information.

| Parameter | Value | Uncertainty distribution | Sources and assumptions |
|---|---|---|---|
| **Effect size – Initial** | | | |
| Antidepressants | 0.462 | Beta (121, 140) | [29] Review of clinical trials |
| CBT | 0.479 | Beta (127, 139) | [29] Review of CBT clinical trials |
| *MyCompass* | 0.449 | Beta (202, 247) | [8] Clinical trial data |
| **Effect size – Maintenance** | | | |
| Antidepressants | 0.374 | Beta (1075, 1801) | [30] Clinical trial data |
| CBT | 0.559 | Beta (146, 115) | [31] Meta-analysis of CBT clinical trials |
| myCompass (follow-up) | 0.349 | Beta (122, 228) | [8] Clinical trial data |
| Return to treatment | 0.4 | | [37] |
| **Probability of remission after switch** | | | |
| Second line antidepressants | 0.306 | Beta (440, 999) | [20] Clinical trial data |
| After CBT | 0.585 | Lognormal (-0.713, 0.188) | [32] Meta-analysis results |
| **Non-adherence** | | | |
| Antidepressants | 0.163 | Beta (599, 3072) | [20] Clinical trial data |
| CBT | 0.222 | Beta (59,206) | [20] Review of clinical trial data |
| myCompass | 0.279 | Beta (201, 519) | [8] Clinical trial data |
| **Non-adherence (maintenance)** | | | |
| Antidepressants | 0.336 | Beta (1436, 2839) | [34] Values from retrospective database analysis |
| CBT | 0.184 | Beta (962, 4268) | [33] Meta-analysis of discontinuation trial data |
| myCompass (follow-up) | 0.486 | Beta (350, 370) | [8] Clinical trial data |
| Resource use | | | |
| GP visits/cycle | | | |
| Episode | 2.48 | | [35] Average number of visits per patient; Longitudinal database analysis[b] |
| Remission | 1.89 | | [35] Average number of visits per patient; Longitudinal database analysis[b] |
| Psychiatrist visits/episode | 0.056 | | [36] Average number of psychiatric consultations for depression; Population survey data[b] |
| **Utility for depression** | | | |
| Mild | 0.78 (0.20) | Beta (15.74, 4.44) | [15] |
| Moderate | 0.58 (0.31) | Beta (0.88, 0.65) | [15] |
| Maintenance | 0.88 (0.22) | Beta (1.44, 0.19) | [15] |

[a]Weighted average annual costs of combined services.

[b]See Multimedia Appendix 1 for calculation method.

## Costs

With respect to cost inputs, estimates were made of the costs of each arm (myCompass, CBT, and TAU). Estimates of resource use and the unit costs of these resources were obtained from the literature and administrative data and are shown in Table 2. A provider-based perspective, that of the Australian health provider (Medicare and the Pharmaceutical Benefits Scheme), was adopted and thus only direct costs (medication, health service use) were considered. Intervention costs included service provision costs and medication costs (Table 2). This assumes that development and maintenance costs of running e-MH programs are either transferred from current providers to government or are subsidized. Costs for each health state (depressive episode, remission, and maintenance) were estimated by multiplying the number of units of each resource consumed by the estimated unit cost of each resource and then summing the products across different resources. All cost data were for

the year 2013/14. No discounting of costs or benefits was necessary since the overall time horizon of the analysis was less than 12 months.

**Table 2.** Resource unit costs.

| Model input | Unit cost | Source | Assumptions |
|---|---|---|---|
| GP Mental Health Plan | 71.70 | MBS items 2700, 2712 (review)[a] | *Mental Health Plan items (initial and review). Statistics are based on relevant MBS items processed from April 2013 to March 2014 [38]* |
| GP consultation | 36.88 | MBS item 3, 23[a] | *Cost of a standard GP consultation [38][b]* |
| Psychiatric consultation | 367.80 | MBS items 291, 293[a] | |
| Psychologist | 141.87 | MBS items 80000, 80010[a] | Cost of a single session, based on weighted average cost of CBT items [36,38] |
| Course of CBT | 737.72 | MBS items 80000, 80010[a] | Based on weighted average cost of CBT MBS items processed from April 2013 to March 2014 multiplied by average number of sessions attended [36,38,39] |
| myCompass | 56.39 | | Cost of delivery, derived from budgeted delivery costs per user as is currently dispensed (12-month costs) |

[a]Weighted average annual costs of combined services (MBS=Medicare Benefits Schedule).

[b]Cost of a follow-up consultation once mental health plan has been implemented.

The costs input for the myCompass arm of the model were derived from the costs associated with delivery of the myCompass program (including enhancements, debugging, server licence, security adjustments, and administration) per user as it is currently dispensed, and service delivery costs. For TAU as a first or second line of therapy, medication costs were varied by averaging the least and most costly medication among the most commonly prescribed antidepressants according to administrative data (Australian Government, 2012) [40]. Services provided by clinical psychologists were assumed to be funded by the public insurance scheme (Medicare) and costed according to the average weighted cost per session multiplied by the median number of sessions attended based on reported findings from an administrative dataset [36,38]. Although myCompass is designed to be a self-help program, for the purposes of this analysis, we took a conservative approach. All three interventions were assumed to require an initial visit to a GP for a mental health plan and referral to either a psychologist or psychiatrist, with a follow-up GP consultation at the conclusion of a course of treatment thus incurring the respective costs for preparation of a mental health plan and standard GP consultation. Those in the CBT arm incur costs related to psychology consultations, that is, for either a course of CBT or single booster sessions during the maintenance phase of treatment. Although mild depression is far more prevalent than moderate or severe depression in the general population, the degree of severity influences the proportion of people presenting to health services for treatment, with those with moderate symptoms presenting to services at approximately twice the rate (68.8% versus 31.2%) [41]. These proportions were factored in to QALY calculations by multiplying these proportions by their respective utility values. Additionally, based on Australian survey data, people with depression present for psychiatric consultations at a rate of between 0.3% and 10.6% on a monthly basis [36]. We used this data to estimate the rate at which depressed patients would be referred for psychiatric services [42]. Resource use is related to the response level for each

intervention and the resulting state transition (to remission, maintenance, or relapse to episode). For parity, we assumed an equal likelihood of acceptability to patients for each intervention in the model, although in reality levels of acceptability may differ. To determine costs for each state, we assumed the same mix of providers and respective resource use as reported in longitudinal database and population survey data [35,36,38]. For example, patients experiencing an acute depressive episode require on average between 2-3 GP visits per cycle.

## Model Assumptions

The model relied on a number of assumptions. First, if an initial treatment was ineffective, the patient was switched to TAU, which in this case was antidepressant medication. Second, success rate was independent of previous treatment exposure. This assumption is consistent with current depression treatment guidelines, which have shown that response to one antidepressant does not help predict responses to another class of drug [21]. Therefore, we assume the same efficacy for all antidepressants.

## Analysis of Uncertainty and Sensitivity Analyses

Probabilistic sensitivity analyses (PSA) were conducted to determine the effect of all variable uncertainty simultaneously within the model using data described in Table 1. The probability distributions around the input variables are based on either standard errors or a range of parameter values as published in or calculated from the literature. A simulation of 10,000 runs generated a joint distribution of cost and effect pairs. The effectiveness of treatments was expressed in terms of QALYs. All patient-level data (transition probabilities, costs, utility values) were entered as prior distributions and not as point estimates, enabling random re-sampling and the characterization of parameter uncertainties.

Incremental costs and effects were calculated for the intervention and the comparators, and incremental cost-effectiveness ratios (ICERs) determined to compare costs and effects using the

formula, ICER = ΔC/ΔE. This describes the ratio of the change in costs of the intervention compared to each comparator to the change in the effects of the intervention [43]. As ICERs can compare only two groups, Net Monetary Benefit (NMB) was calculated for each group by multiplying the change in QALYs by AUD 50,000 per QALY and then deducting change to costs using the formula, NMB = E*WTP-C (where E represents effectiveness, C represents cost, and WTP is the decision makers' threshold ICER) [43]. This threshold is somewhat arbitrary; in Australia, the Pharmaceutical Benefits Advisory Committee does not explicitly state a cost-effectiveness threshold value. An approximate value of AUD 64,000 has been suggested [44] but may vary [45-47]. The average NMB across 10,000 simulations was calculated along with 95% credible intervals to represent the uncertainty in the decision. A decision that returns a positive NMB is considered to be cost-effective [48], and the optimal strategy is defined as the strategy with highest expected net benefit.

For the three strategies considered in this study, results of the PSA are presented graphically by cost-effectiveness acceptability curves (CEAC). The CEAC of each strategy was obtained by evaluating the percentage of simulated values where the strategy had the highest NMB, as a function of the willingness to pay (WTP), λ.

Univariate sensitivity analysis was completed for all of the model input parameters in order to investigate the effect of individual assumptions on each intervention on the uncertainty around model outcomes. This enables the identification of which parameters are the key drivers of the model's results. The list of model parameters and their associated sampling uncertainty included in the 1-way sensitivity analysis are shown in Table 1.

## Scenario Analysis

The cost of providing myCompass in the model is an average based on estimates of support costs and numbers of program users from 2012-2014. Thus costs of delivering an e-MH intervention can vary—volume savings arise as the number of

patients treated increases over time. As such, we performed a threshold analysis to determine the maximum cost at which the implementation of myCompass is no longer cost effective.

## Value of Information Analysis

We conducted an evaluation of the Expected Value of Perfect Information (EVPI). The EVPI estimates the difference between the expected value of a decision with perfect information and the expected value of a decision given the current evidence base (at a WTP threshold of AUD 50,000 per QALY) over a period of 1 year. This gives an estimate of the maximum value of further research [49]. Decision makers faced with the findings of research have to appraise the available evidence base and decide if a new technology should be adopted into clinical practice on the basis of existing information due to the opportunity costs of making the wrong decision when the evidence base is not sufficiently certain [49]. We then estimated the Expected Value of Perfect Partial Information (EVPPI) to assess the value of uncertainty around model parameters. To estimate the EVPPI with accuracy [50], we ran an optimal number of iterations for each analysis.

## *Results*

### Sensitivity Analysis

The average NMB across 10,000 simulations was calculated along with 95% credible intervals to represent the uncertainty in the decision. Table 3 provides the estimates of the costs and QALYs generated by the baseline configuration, identifying myCompass as the strategy with the highest net marginal benefit. The resulting cost-effectiveness plane can be viewed in Figure 2. The mean incremental NMB per individual (ie, the average NMB for myCompass minus average NMB for comparator) for the myCompass group compared to the TAU group was AUD 1165.88 for the TAU model and AUD 522.58 for the CBT model. The incremental cost relative to myCompass was AUD 190 per individual for the model using TAU as the first line of treatment and AUD 1995 per individual for the CBT model (Table 4).

**Table 3.** Results of PSA, showing differences in costs, health benefits gained, and net monetary benefits.

| Model statistic | TAU<br>Mean (95% credible interval) | CBT<br>Mean (95% credible interval) | myCompass<br>Mean (95% credible interval) |
|---|---|---|---|
| Cost | 524.91 (457.05-619.77) | 2330.51 (2201.10-2408.40) | 334.96 (332.01-338.75) |
| QALYs | 0.24 (0.15-0.32) | 0.29 (0.16-0.37) | 0.26 (0.15-0.34) |
| Av. CER | 2187.13 | 8036.24 | 1288.33 |
| NMB | 11308.61 (6881.53-15514.74) | 11951.91 (5158.75-16254.58) | 12474.49 (6521.75-16599.58) |

**Table 4.** Incremental results, myCompass versus comparators.

| | TAU | CBT |
|---|---|---|
| Incremental costs | 158 | 1996 |
| Incremental QALYs | -0.02 | 0.03 |
| ICER | -8425.37 | 2966.37 |
| Incremental NMB | -1165.88 | -522.58 |

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Figure 3 presents the PSA results in the form of a CEAC, showing the proportion of the costs and effects pairs that are cost-effective for a range of values. This gives an estimate of the proportion of the simulated distribution of cost and effect pairs that lie below a given threshold of AUD 50,000 (the maximum value a decision maker is prepared to pay for a unit of effect), that is, the proportion that generates positive net (monetary) benefits. Figure 3 shows the probability that myCompass is cost-effective compared with CBT and TAU at a WTP threshold of AUD 50,000 (75.5%). The probability that CBT is the most efficient strategy increased as the threshold value increased, whereas myCompass is the favored strategy

for 96.7% of threshold values when compared to TAU. At a WTP of 0, there is a 100% likelihood that myCompass is the most cost-effective strategy. At the selected WTP threshold, a proportion of iterations were less costly but also less effective than comparators (22.9% versus CBT, 1.6% versus TAU). Thus the CEAC moves from 100% toward a minimum of 17%—a decreasing function of the WTP. The CEAC corresponding to TAU forms a horizontal line at close to 0%, representing the dominated case. Conversely, in the case of CBT, the CEAC reaches a maximum value of 80.3% and becomes the most efficient option at a WTP of AUD 65,000.

**Figure 2.** Sensitivity analysis - cost-effectiveness plane.



**Figure 3.** Cost-effectiveness acceptability curve: myCompass versus CBT and TAU.
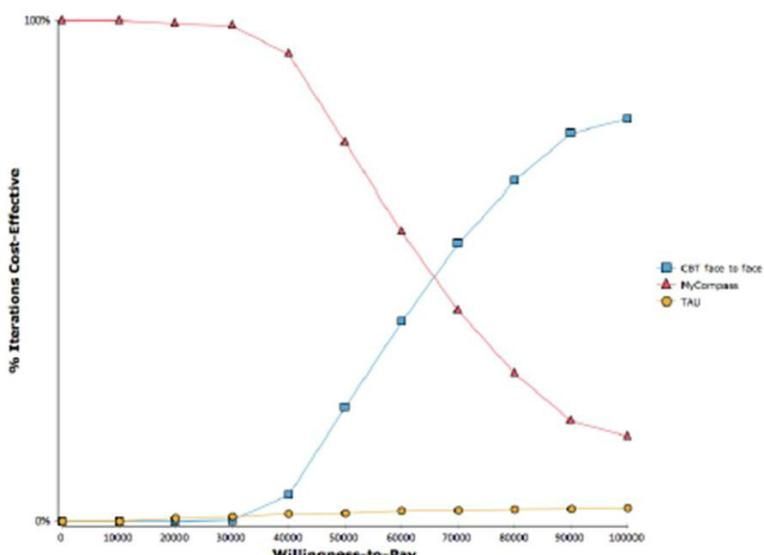
## Uncertainty Analysis

The variables with the greatest impact on the NMB are shown in Table 5. The sensitivity analysis with most deviation from the base-case analysis was the non-adherence rate of myCompass, followed by the cost of delivering the intervention. In univariate analysis, myCompass was no longer cost-effective at AUD 50,000/QALY when the cost of delivering CBT dropped below AUD 309.50 per patient. The average cost of providing myCompass had to rise approximately 5-fold before significant changes in cost-effectiveness comparisons were noted. Table 5 shows the lowest and highest expected value for the model based on the optimal strategy at each point.

The distribution of cost-effectiveness results is summarized by the cost-effectiveness acceptability curve (Figure 3).

**Table 5.** Results of uncertainty analysis.

| | Range in variation of parameter | Low expected value (NMB) | High expected value (NMB) | Threshold at which myCompass is no longer the most efficient strategy |
|---|---|---|---|---|
| Probability of non-adherence myCompass | 0.0-0.35[a] | 12,365.63 | 13,059.98 | — |
| Cost of delivering CBT (AUD) | 0.0-619[a] | 12,421.34 | 13,034.60 | 309.50[b] |
| Cost of delivering my-Compass | 0.0-564 | 12,005.16 | 12,682.00 | 281.95[b] |

[a]Based on 95% confidence intervals for non-adherence and remission rates and 0 to +20% of base-case value for cost of delivery of CBT.

[b]myCompass less efficient below this value.

## Expected Value of Information

Results of the EVPPI analyses suggested that the rate of non-adherence for myCompass was the single parameter for which value of further information might be obtained. Other parameters had an EVPPI of 0. The reasonably high level of confidence in the cost-effectiveness results at the WTP threshold reflect this finding. We estimated the expected per-patient value of perfect information to be AUD 79.37. We extrapolated this to a population level by estimating the number of patients that would be likely to receive the intervention over a 1-year period. The current estimates of the prevalence of mental illness in Australia is 20.1 % across all age groups (4.4 million) [51]; of those, 20.6% have a mood disorder [41]. Approximately 2 million people with a current mental disorder present to health services [51]. Treatment rates for people seen by health services by level of severity is around 25% for mild and 59% for moderate [41]. Hence, based on these data, assuming that both the prevalent and incident population are treated, based on an acceptability rate scenario of 2%, we estimate the eligibility for the intervention to be ((25%+59%)*(20.6%)*4.4 million) at total coverage. Assuming a scenario with a low acceptability rate of 2% [52] (of those with mild-to-moderate levels of disorder), at a population level, the EVPI for the intervention is approximately AUD 1,208,608. This represents a maximum estimate of the value of further research if perfect information were achievable for all model inputs.

## Discussion

### Main Findings

This study shows that implementation of the myCompass program is potentially cost-effective in the Australian setting, reducing treatment costs to providers without evidence of diminished treatment efficacy. Internet-based stepped care, and the impact of such care for depressive symptoms, has not been extensively studied and economic evaluations of this type of model are scarce. Our findings show that a stepped-care approach, with Internet-delivered, unguided self-help as the first step, may be a useful and cost-effective way to improve access to treatment for depression.

The cost of delivering CBT remains relatively high. Because of the cost benefits, research into the factors that influence use of Internet-delivered programs is urgently needed. Meta-analyses and reviews show that outcomes and adherence rates vary widely depending on the method of program delivery, that is, whether the intervention is clinician-assisted, has administrative support, or is unsupported [10,53-58]. However, patient variables are likely to be influential also. For example, patients with higher levels of motivation and less severe depression may be more suited to Internet-delivered treatments because they have the requisite cognitive skills, learning style, and self-regulation needed to complete a treatment course. Non-adherence to the myCompass program was an issue in the trial and hence the cost-effectiveness analysis. Although non-adherence may have implications for upscaling this intervention, qualitative evidence has shown that in many cases, patients withdraw for personal reasons such as improvement in symptoms (known as "e-attainers") [59,60], not because of problems with the technology or the social environment [61]. Including programs such as myCompass as part of an integrated model allows clinicians to monitor interim outcomes and inform decisions on patient treatment pathways, in case some patients are negatively affected by the limitations in effectiveness of low-intensity treatments. In this way, public health programs become more comprehensive, strategically leveraging existing knowledge, infrastructure, and resources to improve health outcomes.

Our analysis was, however, exploratory, and some caution is warranted in interpreting our findings as the model had several limiting assumptions. In this study, a series of univariate sensitivity analyses explored the impact of varying all resource costs, probabilities, and utilities on the incremental cost-effectiveness of myCompass compared to TAU and CBT. The cost-effectiveness of myCompass in this model was largely dependent on the probability of discontinuation of myCompass

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and, to a lesser degree, the delivery cost of the program, as opposed to findings from other literature where delivery costs of CBT were major cost drivers [14,62]. The EVPPI analyses suggested that at a WTP threshold of AUD 50,000 per QALY, there is reasonable certainty that myCompass will be cost-effective, regardless of which parameter value is taken within the bounds of the modeled distribution. Although the cost of delivery of myCompass in our model was considerably lower than other similar programs, such as that offered by the US National Stress Clinic [63], threshold analysis showed that even a substantial rise in the implementation cost of myCompass had little impact on cost-effectiveness. Our EVPI analysis suggested that the non-adherence rate for myCompass is the factor that would benefit from future research. High rates of discontinuation from Internet therapy programs have been noted in several studies [13,64-67], with lack of motivation in depression remediation being a possible contributor. On the other hand, there is evidence that participants who show early symptom improvements may discontinue program use because they feel it is no longer needed [40]. The estimated remission rate for myCompass was characterized using a Beta distribution. The parameters of this distribution were based on completer analysis and thus may be subject to attrition bias as it is possible that some of those lost to follow-up may have experienced a relapse in their depression (or a remission). Consequently, while our PSA characterized the uncertainty observed in the myCompass trial, the characterization of some parameters and the resultant dispersion of the distributions may have been affected by incomplete data.

## Implications

In line with previous studies, our findings showed modest but comparable effectiveness for myCompass versus CBT, and favorable QALY outcomes versus TAU. Previous studies have found similarly moderate results in incremental effectiveness to those reported here [11,13,14,16] but also found that the majority of costs were attributable to productivity and societal costs, with higher ICERs. The association between depression, disability, and lost productivity due to illness is well established [68]; days missed from work due to mental illness decline significantly when remission of depression is attained. Given the high incidence of depression among people of working age, precluding productivity costs could be considered a limitation of the study as interventions that have a strong effect on the productivity of the working population may produce productivity costs that reflect a large part of total costs. Thus, the inclusion of productivity costs may cause incremental costs to change from positive to negative, or vice versa, depending on study design factors such as time horizon, methodology used to measure lost productivity, and type of treatment. Only one study [13] analyzed the variations in societal cost calculations but found this produced similar CEACs. When considered from the perspective of the provider (as taken here), lower health services costs among those recovering from depression are commonly observed [69]. Considered from the societal perspective (that is, considering indirect costs such as lost productivity), a trend toward lower health services costs and reductions in lost work due to illness were noted.

This being the case, it is reasonable to assume that with reduced costs of care, lower implementation costs, greater efficiencies due to minimal therapist contact, and increased reach and access, implementation of e-MH interventions into routine care may have collateral benefits such as reductions in direct costs to stakeholders and greater treatment parity. Further cost savings are likely to arise due to the extended reach and fidelity conferred by Internet-based interventions, and the reasonable probability (based on current uptake of available programs [12], plus unmet need for services) that such interventions will find a sizeable target population. As Internet-based interventions have shown to be generally acceptable to patients [70], greater adherence might also arise with increased familiarity and changing perceptions and attitudes (therapeutic alliance, confidentiality) among health professionals and the general public. Potential indirect cost savings may include increased health knowledge in users and ability for self-care. These additional outcomes need to be tested empirically. However, the data presented here are sufficient to indicate that e-MH programs as treatments for depression could have a clinically meaningful and cost-advantageous impact at a larger scale. Thus, the cost-effectiveness of e-MH programs could fall well below the current WTP threshold for implementation than demonstrated in this analysis. Analysis of a United Kingdom stepped-care program similar to that proposed here concluded that it was cost-effective within the National Institute of Clinical Excellence threshold range of £30,000 per QALY; the program continues to form an important part of mental health care provision [71].

## Strengths and Limitations

Our findings are based on data derived from a large community-based RCT, in which participants were recruited nationally via a range of media, including websites, social media channels, print media, and corporate and government organizations. That the data have high external validity with respect to extrapolation of effectiveness at the population level is a strength of this research. The model chosen to examine the relative cost-effectiveness of these interventions was one based on stepped care. We acknowledge that a stepped-care approach may not be optimal for all individuals, particularly those in crisis, or those with comorbid, or complex needs. Nevertheless, the stepped-care model represents an accepted approach for people with mild-to-moderate common mental health disorders. It would be possible to do more sophisticated modeling of different scenarios into the future.

A number of important sources of costs associated with depression were not included in our model. For example, the model did not include the potential utility decrements associated with adverse effects of antidepressants, inclusion of which may have reinforced the cost-effectiveness of both psychologically based therapies. A narrow provider perspective was adopted and did not include drug dispensing costs or downstream cost offsets. Indirect costs of depression such as productivity losses, presenteeism, and intangible costs to patients (eg, unrestricted access to treatment) were also not considered, although these values are important from a societal perspective and may have led to an underestimation. The short 6-month timeframe of the model was limited by data available from the existing clinical

trial of myCompass. With regards to structural uncertainty, our model may represent a simplification of the progression of disease and clinical presentation in primary care. As depression can be a chronic condition, four cycles may not depict the full scope of cost-effectiveness comparisons between the three interventions. For example, our model did not allow for treatment enhancement such as combining medication and CBT, which would otherwise be part of a stepped-care strategy. However, without additional data, the use of a longer timeframe would require assumptions on the outcomes of the intervention and introduce further uncertainty. As myCompass is designed to be used without clinician consultation, it is possible that costs were overestimated. However, a recent meta-analysis found larger effect sizes for psychological therapies in patients referred by their GP as opposed to those recruited through screening [72]; it is possible that users are more adherent when interventions are integrated into primary care, impacting on costs. We did not include costs associated with introducing stepped care such as training of primary care providers and the establishment of referral networks between mental health care providers, despite research showing that factors such as unfamiliarity with eHealth instruments and websites,

appropriateness of interventions, and uncertainty around multidisciplinary collaboration provide major barriers to uptake in international settings [73]. We did not factor in lag times to treatment that are likely to occur in clinical practice.

## Conclusion

Health services internationally are currently challenged in disseminating care for depression. Internet-delivered interventions can provide access to treatment to those who would otherwise either not receive it or be placed on waiting lists or ineffective medications.

Widespread dissemination of e-MH interventions can potentially reduce demands on primary and tertiary services and reduce unmet need. This analysis adopted a decision tree model to estimate how the adoption of e-MH would impact the costs and outcomes of allocation of treatments to patients in routine care in the Australian health system. We found that implementation of an e-MH program (myCompass) was cost-effective compared to usual care and face-to-face CBT. Further research is needed to determine other related factors including population effectiveness and how implementation costs would be distributed across various stakeholders.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Calculation of resource use.

[PDF File (Adobe PDF File), 3KB - jmir_v17i11e255_app1.pdf ]

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## Abbreviations

**CBT:** cognitive behavior therapy
**CEAC:** cost-effectiveness acceptability curve
**e-MH:** e-mental health
**EVPI:** expected value of perfect information
**EVPPI:** expected value of perfect partial information
**GP:** general practitioner
**ICER:** incremental cost-effectiveness ratio
**MBS:** Medicare Benefits Schedule
**NMB:** net monetary benefit
**RCT:** randomized controlled trial
**TAU:** treatment-as-usual
**WTP:** willingness-to-pay

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Original Paper

# Using the Consolidated Framework for Implementation Research to Identify Barriers and Facilitators for the Implementation of an Internet-Based Patient-Provider Communication Service in Five Settings: A Qualitative Study

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## Abstract

**Background:**    Although there is growing evidence of the positive effects of Internet-based patient-provider communication (IPPC) services for both patients and health care providers, their implementation into clinical practice continues to be a challenge.

**Objective:**    The 3 aims of this study were to (1) identify and compare barriers and facilitators influencing the implementation of an IPPC service in 5 hospital units using the Consolidated Framework for Implementation Research (CFIR), (2) assess the ability of the different constructs of CFIR to distinguish between high and low implementation success, and (3) compare our findings with those from other studies that used the CFIR to discriminate between high and low implementation success.

**Methods:**    This study was based on individual interviews with 10 nurses, 6 physicians, and 1 nutritionist who had used the IPPC to answer messages from patients.

**Results:**    Of the 36 CFIR constructs, 28 were addressed in the interviews, of which 12 distinguished between high and low implementation units. Most of the distinguishing constructs were related to the inner setting domain of CFIR, indicating that institutional factors were particularly important for successful implementation. Health care providers' beliefs in the intervention as useful for themselves and their patients as well as the implementation process itself were also important. A comparison of constructs across ours and 2 other studies that also used the CFIR to discriminate between high and low implementation success showed that 24 CFIR constructs distinguished between high and low implementation units in at least 1 study; 11 constructs distinguished in 2 studies. However, only 2 constructs (patient need and resources and available resources) distinguished consistently between high and low implementation units in all 3 studies.

**Conclusions:**    The CFIR is a helpful framework for illuminating barriers and facilitators influencing IPPC implementation. However, CFIR's strength of being broad and comprehensive also limits its usefulness as an implementation framework because it does not discriminate between the relative importance of its many constructs for implementation success. This is the first study to identify which CFIR constructs are the most promising to distinguish between high and low implementation success across settings and interventions. Findings from this study can contribute to the refinement of CFIR toward a more succinct and parsimonious framework for planning and evaluation of the implementation of clinical interventions.

**ClinicalTrial:**    Clinicaltrials.gov NCT00971139; http://clinicaltrial.gov/ct2/show/NCT00971139 (Archived by WebCite at http://www.webcitation.org/6cWeqN1uY)

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## Introduction

Internet-based patient-provider communication (IPPC) services provide patients and their health care providers with the opportunity for secure email contact over the Internet and can be a valuable supplement to traditional health services [1,2]. An increasing number of studies indicate that IPPC services can help patients manage their illness better, improve health outcomes [3-5], address unmet communication needs in health care [6-8], and improve quality of care [8,9]. Health care providers who have used IPPC services to communicate with their patients report a high level of positive attitude [7,9,10]. They find IPPC services convenient and useful for selected patients [1], and perceive them as a safe and efficient way of communicating with patients [1,10]. No studies were found that reported any harmful effects for either patients or health care providers [1,11], and utilization of IPPCs is increasingly becoming part of health care policies [12].

Despite the growing evidence that the use of IPPC services has positive outcomes for patients and health care providers [1], studies also report challenges when making use of IPPC services in clinical practice. This new form of patient-provider communication has raised health care provider concerns regarding integration of the tools into daily working routines [13] and increased workload [10,11,14]. Health care providers have been concerned that patients would pose questions not suitable for this form of communication, such as urgent or sensitive themes [15]. Concerns about technology, confidentiality, security, and liability have also been raised [7,15].

Studies have illuminated what is needed for successful implementation of evidence-based practice [16], health care improvement [17], and new technology [18] into clinical practice. Until now, studies within eHealth have focused on patient and provider outcomes and effectiveness, but have had less emphasis on understanding *why* interventions succeed or fail [19]. In this study, *eHealth* is defined as "the transfer of health resources and health care by electronic means" [20]. A recent review argues that attention should be given now to the development and evaluation of strategies to implement effective eHealth initiatives, rather than to further strengthen the evidence of effectiveness that is already available [21]. Furthermore, it is recommended to include several sites in implementation studies because an apparently similar intervention may be implemented and accepted in different ways in different settings [22] and different professions may have varying perceptions about implementation success [23]. Yet few studies report on the factors relevant for successful implementation of tools such as IPPC services in clinical practice [10], across settings, which is important to increase transferability of results.

Theoretical frameworks in implementation studies are underused [24] and evaluations of eHealth implementation require good theoretical frameworks. Use of theory in implementation studies can help identify factors that predict the likelihood of implementation success and help develop better strategies to achieve more successful implementation, thus strengthening the understanding and explanation of how and why implementation succeeds or fails (eg, what works, for whom, under what circumstances, and why) [25]. Theories, frameworks, and models can help identify appropriate outcomes, measures, and variables of interest for implementation studies. Theory can also help organize studies when collecting, analyzing, interpreting, explaining, and presenting data [26]. In preparation for this study, which identified barriers and facilitators influencing the implementation of an IPPC service in 5 hospital units, the appropriateness of several theories and frameworks was assessed. A number of implementation frameworks and theories exist and were considered, such as the Reach Effectiveness Adoption Implementation Maintenance (RE-AIM) framework [27], the Promoting Action on Research Implementation in Health Services (PARiHS) framework [28], Technology Acceptance Model [29], and Normalization Process Theory [30]. The Consolidated Framework for Implementation Research (CFIR) [31] was chosen based on its comprehensiveness and ability to manage both breadth and depth of data for capturing the complexity of IPPC implementation. The meta-theoretical basis of CFIR includes a broad number of aspects related to implementation and is thus considered a helpful framework for illuminating barriers and facilitators influencing IPPC implementation. CFIR is derived from 19 theories about dissemination, innovation, organizational change, implementation, knowledge translation, and research uptake [31]. CFIR synthesizes the spectrum of terminologies, definitions, and constructs into a consolidated framework. It is described as a "determinant framework" meaning that it specifies determinants that can act as barriers and facilitators to influence implementation outcomes [25]. CFIR is described as well-suited for implementation research on health service delivery [31,32]. It addresses the need to assess and maximize the effectiveness of implementation within a specific context and to promote dissemination to other contexts. CFIR comprises 39 constructs sorted under 5 domains [31]: (1) intervention characteristics, (2) outer setting, (3) inner setting, (4) characteristics of individuals, and (5) process.

An increasing number of implementation studies have used CFIR, some as an evaluation framework [24,32-36], some for detecting factors influencing implementation [32,37,38], and some for classifying these influencing factors as facilitators or barriers [34,35,39]. To date, only a few studies have had the evaluation of CFIR as a specific aim [40-42]. So far, we found only one other study that used the CFIR developers' method to identify and compare distinguishing constructs between high versus low implementation settings [43]. Therefore, there was

a need for more studies to assess and further develop CFIR's applicability in explaining what factors influence implementation success. Furthermore, in CFIR, all constructs have equal weight and the framework does not distinguish between the relative importance of its different constructs. It would, therefore, add strength to the framework to increase the predictive ability of CFIR's different constructs to discriminate between implementation success, so that the framework could become more succinct, parsimonious, and thus more easily applicable.

The aim of this study was threefold: (1) to identify and compare barriers and facilitators influencing the implementation of IPPC in 5 hospital units using CFIR as the conceptual framework, (2) to assess the ability of the different constructs of CFIR to distinguish between high and low implementation success, and 3) to compare our findings with those from other studies that have used CFIR to discriminate between high and low implementation success.

## Methods

### Intervention

The IPPC service in this study was an Internet-based communication service in which patients could send messages to and receive answers from hospital nurses, physicians, nutritionists, and social workers. The IPPC system had a high security level, requiring both patients and health care providers to log in the system by means of strong authentication keys. The message from the patient was received in the mailbox of the coordinating nurse, who had expertise on the respective diagnoses and treatments and had access to the patients' medical record at the hospital. The nurse could address the question directly or forward the message to the mailbox of another provider who was in a better position to answer the question. This health care provider could either answer the patient directly or give comments back to the coordinating nurse, who formulated an answer to the patient (see Figure 1). The development and testing of an IPPC service is described elsewhere [44].

**Figure 1.** Internet-based patient-provider communication (IPPC) message flow between patients and health care providers.
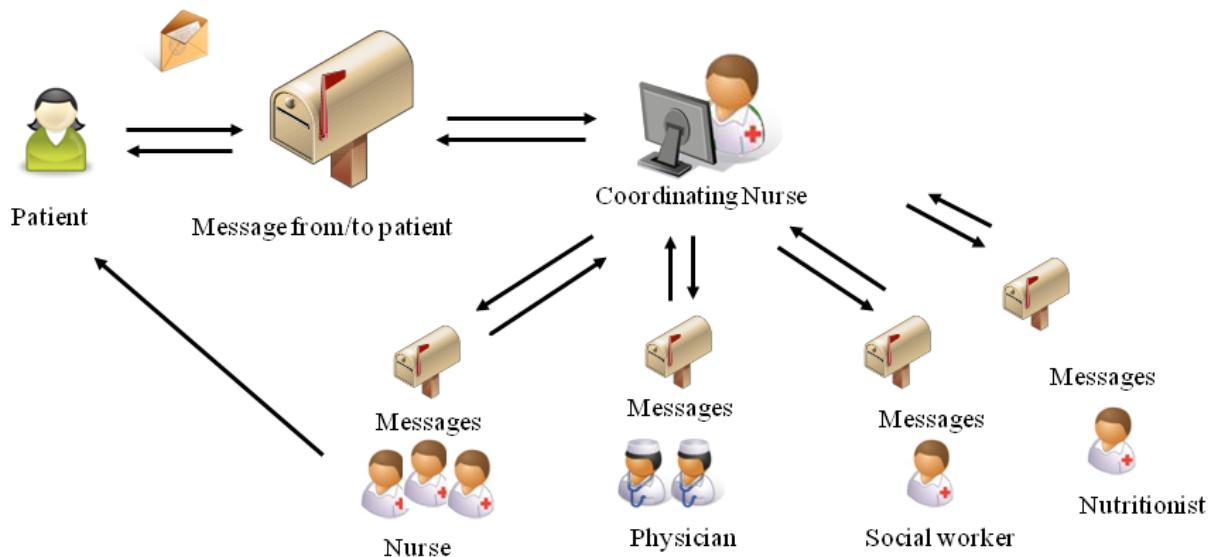


### Procedures

This paper reports on the identification of barriers and facilitators influencing the implementation of IPPC in 5 units treating patients with cancer or diverse medical diagnoses at a university hospital in Norway. Analysis of messages and interviews with patient users and nonusers has been reported elsewhere [6,45,46].

After initial information meetings between the unit management at each unit and the head of the research center, an agreement for implementing the IPPC service as part of a research study was signed. IPPC was not a mandatory intervention within the hospital, but was voluntarily implemented as part of routine care at these 5 units. The first step of the implementation was that the management of the units designated in total 16 nurses, 8 physicians, 4 social workers, and 1 nutritionist to the implementation and use of IPPC. Next, all contributing health care providers received thorough information about the IPPC

service and one-on-one training on how to operate the system. In addition, the nurses received training on how to refer eligible patients to the research assistants for potential study inclusion, who subsequently introduced the patients to IPPC, asked for informed consent, and filled out the demographic and baseline questionnaires. The patients received a brief introduction with information about how to log in and use the IPPC service. They were informed that they could send messages with questions and concerns related to their illness and would receive advice and support from hospital health care providers in between and after their hospital admissions. The patients were informed that they could use the IPPC service as much as they wanted over the study period, which lasted for 6 or 8 months dependent on unit affiliation [45].

At each unit, the health care providers agreed among themselves who should hold the different roles in answering the patients' messages (Figure 1) and set up routines to fill in for one another when absent. Routines were pilot-tested to streamline

recruitment procedures and solve initial technical problems with the IPPC service, and this was followed up with health care provider interviews 1 month after start-up. Only small insignificant obstacles that already had been solved were found. Throughout the study, participating health care providers and unit managers received monthly emails with the number of patients recruited so far and the number of received and answered messages in the IPPC system. The research team was also available if technical IPPC system problems occurred.

During the study period of 19 to 23 months (dependent on unit), 38 of 171 patients included in the study (22%) sent 133 messages (range 1-13). The health care providers wrote 133 responses to the patients (range 0-27). Four units identified and offered more than approximately 60% of their eligible patients to the IPPC service. The fifth unit, however, did not offer more than approximately 15% to the IPPC service. Based on the unit differences in the proportion of available patients who were offered information about IPPC, we labeled the 4 units as *high implementation units* and the fifth unit as a *low implementation unit*.

## Study Design and Participants

To identify barriers and facilitators influencing the implementation of IPPC, we conducted a qualitative study [47] based on individual interviews or written feedback from nurses, physicians, and a nutritionist at the end of the IPPC implementation period. The study was planned and performed in compliance with the principles outlined in the Declaration of Helsinki [48] and was approved by the Regional Committee for Medical and Health Research Ethics in Norway and the Privacy Protection Committee at Oslo University Hospital. Written informed consent was obtained from all participants.

Ten nurses, 6 physicians, and 1 nutritionist from the 5 units answered messages from the patients in the IPPC and were, therefore, included in the interview study. One of the respondents preferred to receive and answer interview questions in writing, whereas the others participated in individual interviews. The nurses were a mean age of 40 (median 40, range 26-55) years with a mean of 16 (median 13, range 3-32) years nursing practice since graduating from nursing school and a mean of 11 (median 7, range 0.5-32) years of experience with the current diagnostic patient group. Half had a clinical specialization in nursing. The physicians and nutritionist were a mean age of 50 (median 54, range 41-58) years with a mean of 23 (median 22, range 15-31) years since graduating from medical/nutritionist school and a mean of 14 (median 16, range 2-23) years of experience with the patient diagnostic group. Five respondents among the physicians and the nutritionist had a PhD degree, 4 had clinical specialization, and 3 had both. Most respondents were women (13/17, 76%; Clinical Trial NCT00971139).

## Interview Procedure

A semistructured interview guide was developed containing questions based on the 5 domains of CFIR [31]. The 39 constructs of CFIR supported the research team in defining topics for the interviews and ensured that all major domains in the framework that influence implementation were addressed. Operationalization of CFIR domains for the current study were:

1. Intervention characteristics: the IPPC service
2. Inner setting: 5 units treating patients with cancer or diagnoses within internal medicine
3. Outer setting: the patients who were offered IPPC
4. Characteristics of individuals involved: the nurses, physicians, and nutritionist who operated the IPPC service
5. Process: the process when IPPC was implemented

The interviews were conducted by the first author either at the interviewees' office or at a meeting room at the hospital based on the interviewee's preference. The interviews lasted between 10 and 75 minutes; they were recorded with a digital voice recorder and transcribed verbatim, except for one of the interviews in which notes were taken by the interviewer during the interview because the respondent did not allow use of a voice recorder.

## Analysis

The transcripts were analyzed using techniques of qualitative content analysis, inspired by a deductive directed approach, deemed applicable because we wanted to analyze our data in light of an existing framework [49]. The analysis was performed by the first (CV) and the second authors (ME) in a stepwise interactive process. The first step in the analysis, after reading all transcripts, notes, and written responses to obtain an understanding of the whole, was to develop initial coding nodes and subnodes based on the domains and constructs of the CFIR framework [31]. In the second step, units of analysis, such as sentences or longer semantic units, were deductively coded into the nodes and subnodes. Third, the coded text was then subjected to a rating process based on the recommended method described by Damschroder and Lowery [50], the authors of CFIR. In the rating process, a deliberated consensus process was used to assign a rating to each construct obtained from each hospital unit. The ratings reflected the valence (positive or negative influence) and the magnitude or strength of each construct that emerged in each hospital unit based on the coded text. When all constructs obtained from all hospital units were rated, we compared ratings for each construct across hospital units [50]. Constructs were coded either as missing too much data to discern a pattern (missing), not distinguishing between high and low implementation units (0), or weakly (+1/-1) or strongly (+2/-2) distinguishing low from high implementation units. Table 1 provides definitions of the criteria used to guide assignments of the ratings. For more details, see the method paper of the CFIR developers [50].

**Table 1.** Criteria used to assign ratings to constructs.

| Rating | Criteria |
| --- | --- |
| –2 | The construct is a negative influence in the organization, an impeding influence in work processes, and/or an impeding influence in implementation efforts. The majority of respondents describe explicit examples of how the key or all aspects (or the absence) of a construct manifests itself in a negative way. |
| –1 | The construct is a negative influence in the organization, an impeding influence in work processes, and/or an impeding influence in implementation efforts. Respondents make general statements about the construct manifesting in a negative way but without concrete examples: (1) the construct is mentioned only in passing or at a high level without examples or evidence of actual, concrete descriptions of how that construct manifests; (2) there is a mixed effect of different aspects of the construct but with a general overall negative effect; (3) there is sufficient information to make an indirect inference about the generally negative influence; and/or (4) judged as weakly negative by the absence of the construct. |
| 0 | A construct has neutral influence if: (1) it appears to have neutral effect (purely descriptive) or is only mentioned generically without valence; (2) there is no evidence of positive or negative influence; (3) credible or reliable respondents contradict each other; and/or (4) there are positive and negative influences that balance each other out, the construct has some positive influence whereas other influences are negative and, overall, the effect is neutral. |
| +1 | The construct is a positive influence in the organization, a facilitating influence in work processes, and/or a facilitating influence in implementation efforts. Respondents make general statements about the construct manifesting in a positive way but without concrete examples: (1) the construct is mentioned only in passing or at a high level without examples or evidence of actual, concrete descriptions of how that construct manifests; (2) there is a mixed effect of different aspects of the construct but with a general overall positive effect; and/or (3) there is sufficient information to make an indirect inference about the generally positive influence. |
| +2 | The construct is a positive influence in the organization, a facilitating influence in work processes, and/or a facilitating influence in implementation efforts. The majority of respondents describe explicit examples of how the key or all aspects of a construct manifests themselves in a positive way. |
| Missing | Respondent(s) were not asked about the presence or influence of the construct or, if they were asked about a construct, their responses did not correspond to the intended construct and were instead coded to another construct. Respondent(s)' lack of knowledge about a construct does not necessarily indicate missing data and may instead indicate the absence of the construct. |

To enhance trustworthiness [51], CV and ME analyzed data separately. Throughout the analysis, findings were examined and discussed among all authors until a common understanding of the final classifications of the coding categories and ratings into the constructs of CFIR was reached. To organize and manage the large amount of data [52], we used the software program NVivo version 9 (QSR International, Doncaster, Victoria, Australia). To increase the transparency of the interpretation, coding categories are illustrated with quotations in the presentation of the results subsequently.

# Results

## Evaluation of the Implementation of Internet-Based Patient-Provider Communication Using the Consolidated Framework for Implementation Research

The main results presented subsequently address identified barriers and facilitators influencing the implementation of IPPC in 5 hospital units using CFIR as the conceptual framework (aim 1) and the applicability of CFIR to identify determinants distinguishing between high and low implementation success (aim 2). As shown in Table 2, 6 constructs strongly distinguished between high and low implementation units. Six constructs weakly distinguished units and 16 constructs were mixed across units (Table 2). A description of findings on CFIR constructs follows subsequently.

**Table 2.** Ratings assigned to CFIR constructs by unit based on the rating criteria.[a]

| Domains and constructs of CFIR | High implementation units | | | | Low implementation unit | Distinguishing constructs[b] |
|---|---|---|---|---|---|---|
| | Unit 1 | Unit 2 | Unit 3 | Unit 4 | Unit 5 | |
| **1. Intervention characteristics** | | | | | | |
| Intervention source | External | External | Missing | Missing | External | |
| Evidence strength & quality | Missing | Missing | Missing | Missing | Missing | |
| Relative advantage | +2 | +2 | 0 (mix) | +1 | 0 | Weak |
| Adaptability | +1 | +2 | +1 | +1 | +1 | |
| Trialability | +2 | +2 | +2 | +2 | –1 | Strong |
| Complexity (reverse rated)[c] | +1 | +1 | +1 | +1 | +1 | |
| Design quality and packaging | +1 | +1 | +1 | –1 | 0 | |
| Cost | 0 (mix) | 0 | –1 | –2 | Missing | |
| **2. Outer setting** | | | | | | |
| Patient needs & resources | 0 | +1 | 0 | 0 | –1 | Weak |
| Cosmopolitanism | Missing | Missing | Missing | Missing | Missing | |
| Peer pressure | Missing | Missing | Missing | Missing | Missing | |
| External policies & incentives | Missing | Missing | Missing | Missing | Missing | |
| **3. Inner setting** | | | | | | |
| Structural characteristics | 0 | 0 | 0 | 0 | –1 | Weak |
| Networks & communications | +1 | 0 (mix) | +1 | +2 | +1 | |
| Culture | –1 | –1 | +1 | –1 | –2 | Weak |
| Implementation climate | | | | | | |
| Tension for change | +1 | +1 | 0 (mix) | +1 | –2 | Strong |
| Compatibility | Missing | +1 | 0 (mix) | +2 | –2 | Strong |
| Relative priority | 0 | Missing | 0 | +1 | –2 | Strong |
| Organizational incentives & rewards | 0 | +1 | 0 | Missing | Missing | |
| Goals & feedback | Missing | Missing | Missing | 0 (mix) | 0 | |
| Learning climate | +1 | +1 | Missing | Missing | +1 | |
| Readiness for implementation | | | | | | |
| Leadership engagement | +1 | 0 | +1 | 0 | +1 | |
| Available recourses | +2 | +2 | +2 | +2 | –1 | Strong |
| Access to information and knowledge | +2 | +1 | +2 | +2 | Missing | |
| **4. Characteristics of individuals** | | | | | | |
| Knowledge and belief about the intervention | +2 | +2 | 0 (mix) | +2 | –1 | Weak |
| Self-efficacy | +1 | +1 | +2 | +2 | +1 | |
| Individual stage of change | –1 | +2 | –1 | –1 | –1 | |
| Individual identification with organization | Missing | Missing | Missing | Missing | Missing | |
| Other personal attributes | Missing | Missing | Missing | Missing | Missing | |
| **5. Process** | | | | | | |
| Planning | Missing | +1 | Missing | +1 | –2 | Strong |
| Engaging | | | | | | |
| Opinion leaders | Missing | Missing | Missing | Missing | –2 | |

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| Domains and constructs of CFIR | High implementation units | | | | Low implementation unit | Distinguishing constructs[b] |
|---|---|---|---|---|---|---|
| | Unit 1 | Unit 2 | Unit 3 | Unit 4 | Unit 5 | |
| Formally appointed internal implementation leaders | 0 | 0 | +1 | 0 | –1 | Weak |
| Champions | Missing | Missing | Missing | Missing | Missing | |
| External change agents | –1 | +2 | +1 | +2 | –1 | |
| Executing | Missing | Missing | Missing | Missing | Missing | |
| Reflecting & evaluating | 0 | Missing | Missing | 0 | Missing | |

[a]–2: Construct found to have a strong negative influence; –1: construct found to have a weak negative influence; 0: construct found to have neutral influence; 0 (mix): construct had mixed positive and negative influences, which balanced each other; +1: construct found to have a weak positive influence; +2: construct found to have a strong positive influence; Missing: not asked or miscoded.

[b]Weak: construct weakly distinguished between high and low implementation units; Strong: construct strongly distinguished between high and low implementation units.

[c]Reverse rated: a positive rating means a less complex implementation.

## Intervention Characteristics

### Intervention Source (Not a Distinguishing Construct)

Regarding the respondents' perception about whether the IPPC service was externally or internally developed, respondents in 3 units described the IPPC service as externally developed with the research center taking the initiative for the IPPC implementation. This was viewed as a barrier for the implementation of IPPC at the low implementation unit. They said that the engagement for IPPC could have been increased if the implementation had been internally initiated either from the hospital administration as a mandatory intervention or from a person who was known in the unit beforehand:

> When someone comes from the outside, you know, it's got nothing to do with the person, and there could well be a project, but it may well be that people would be more dedicated if it were someone they knew in the department who was running it, that they said: "Oh yes, the woman over there, she has a project, yes, we will help her."

### Relative Advantage (Weakly Distinguishing Construct)

Related to their professional responsibility, the respondents described the relative advantage of communication with the patients via IPPC compared with face-to-face and telephone communication within 4 areas: (1) quality improvement, in that they could provide a better service to their patients; (2) patient safety, by bridging information gaps and discovering serious symptoms; (3) knowledge development, in that IPPC could provide insight into patients' problems and act as a repository for frequently asked questions and responses; and (4) time-saving and focused, in that they could answer patients' messages without interruptions when they had available time. They said that IPPC was a supplement and could not be the only means of communication. A disadvantage described by staff at the low implementation unit was the lack of important nonverbal communication in IPPC: "We lose voice, tone of voice, and pitch as well as catching undertones, reading between the lines." They said that IPPC was not suited for communication about complex issues, such as expected life span or complicated medication.

### Adaptability (Not a Distinguishing Construct)

Respondents reported that the IPPC service had been well adapted to the staff's other duties in all units. The respondents described how they answered messages from the patients and cooperated with the other IPPC team members. They wanted the patients to get an answer as soon as possible and they could become stressed if they could not give the patient the answer fast enough.

### Trialability (Strongly Distinguishing Construct)

According to respondents in all units, the IPPC service was tested in a well-run and exciting study:

> I knew that it was limited, but I had actually hoped that it could continue because the trend we saw was so positive, really, that it has worked very well.

However, at the low implementation unit there was a slightly negative perception of the way the study was performed and how the respondents perceived the study's research questions:

> I don't know, if there were too many questions, there were too many quality indicators versus the quantitative data that we are used to.

### Complexity (Not a Distinguishing Construct)

The IPPC service was described by all units as not very complex to implement. Factors that decreased implementation complexity included the limited number of patients and health care providers involved at each unit and the limited number of questions that the patients posted through IPPC. However, the shift from oral to written communication was described as challenging by respondents in the low implementation unit and by 2 of the high implementation units.

### Design Quality and Packaging (Not a Distinguishing Construct)

At all units, IPPC was described as easy for the health care providers to use. However, there had been some log-in problems

for both health care providers and patients related to server issues and a cumbersome log-in procedure.

### Cost (Not a Distinguishing Construct)

The respondents at 4 units were focused on the units' financial status and these respondents were conscious that funding was an issue for implementation of new interventions, such as an IPPC system, into clinical practice. Three high implementation units considered cost-effectiveness in terms of how many patients they thought should use IPPC before it was appropriate to offer it as a regular intervention and they said patient use in the current implementation was too low to introduce it as a regular service. However, some respondents said that if patients wanted it, and if those patients who used it were satisfied, they believed IPPC should nevertheless be offered as a regular service.

## Outer Setting

### Patient Need and Resources (Weakly Distinguishing Construct)

Respondents from all high implementation units said that the IPPC service would benefit the patients. Therefore, they were surprised, and to some degree disappointed, that only a few patients used the IPPC service:

> I'm a little disappointed that the patients didn't use it [IPPC]. I think it's sad that the patients didn't appreciate the project more.

Nevertheless, they thought that patients felt the IPPC service was good to have even if they did not use it. Four explanatory factors for patients' nonuse were described: (1) patient characteristics, such as diagnosis, health condition (too sick or too healthy), age, and eHealth experience; (2) not in need of IPPC due to not having any questions, experiencing a good follow-up in the regular service, or preferring other forms of communication; and (3) barriers, such as information overload, inappropriate treatment phase, cumbersome log-in, forgetting about the IPPC, too many forms to fill out as part of the study, or not wanting to disturb the health care providers. In the low implementation unit, respondents said that the patients at their unit had less need of the IPPC service than others because the patients received very close face-to-face and telephone follow-up, and that the frontline health care providers at the unit regarded it as too burdensome for the patients to participate in the IPPC study:

> And they are patients with severe crisis reactions. It's not important for them, you know, and then it gets difficult for us to come with this [IPPC] on top of everything else.

## Inner Setting

### Structural Characteristics (Weakly Distinguishing Construct)

All units were specialized in their medical discipline and were staffed with highly qualified health care providers. The structure and organization varied between the units with respect to professional autonomy. At the low implementation unit and 2 high implementation units, the nurse management was peripheral

and the frontline health care providers independently collaborated with one another at the unit. At the other 2 high implementation units, the management had a stronger presence in a hierarchical structure in the unit. For the low implementation unit, the peripheral nurse management had a negative impact on the implementation of IPPC (see Leadership Engagement).

### Networks and Communication (Not a Distinguishing Construct)

Arenas for discussion of individual patients' treatment and follow-up were described by all units. One of the high implementation units had a well-functioning team where all professional groups met every week and the IPPC system had been on the meetings' agendas. In one of the other high implementation units, staff members felt they were working on their own with too few arenas for meetings between the different professional groups. In terms of operating the IPPC system, the procedures were viewed as suitable at all units with nurses coordinating the messages from the patients and the other professional groups answering messages when they received them from the nurses.

### Culture (Weakly Distinguishing Construct)

A conservative culture toward implementation of new interventions was described by all units. The respondents said their units were slow to introduce new things and that health care providers liked to do things the way they always had done them:

> It's relatively conservative; we're a bit protective about our own things.

Respondents at the low implementation unit also described many individualists and strong personalities among the health care providers, who did not want to be told to do something different. At this unit, they were used to conducting research studies; however, they did not have experience in research led by nurses and had a view of nursing research as not being "real." This IPPC study had low status compared with clinical trials performed by physicians at the unit, which hindered some of the unit staff from taking the study seriously:

> This wasn't a medical study, after all. This was a nursing study and that's something we have never worked with and that, I mean, there were no heavyweight pharmaceutical companies behind it and there were no heavyweight professors behind it [which was not true].

At one of the high implementation units, they described the culture as a little more open to new ideas explained by a young staff at the unit open to changes.

### Implementation Climate

Six subconstructs in CFIR illuminate the implementation climate for IPPC and the units' capacity for change:

1. Tension for change (strongly distinguishing construct), the perception of a need for a change, was reflected in the respondents' view of IPPC as a possible future medium in health care. This was described by respondents in 3 of the high implementation units, which were enthusiastic about

using IPPC: "Today, our everyday work is just getting even more challenging with all these phones ringing, so I'm convinced that this [IPPC] will need to be offered to everyone because it will ease people's burden at work." Respondents at the low implementation unit, however, did not express a need for IPPC, either for themselves or for patients. The respondents said they had well-established follow-up with patients face-to-face and by telephone: "I believe there is a great need for extra communication, much less here because we make such clear arrangements and they have an open telephone line to the nurses...So I guess that's my conclusion, that perhaps our unit wasn't the one with the greatest need."

2. Compatibility (strongly distinguishing construct) between the health care providers involved and IPPC was expressed by 3 of the high implementation units in terms of being well adapted to the hospital's overarching philosophy of being open and accessible to patients: "The basic concept [of IPPC] is very good, so I feel it fits very well with the profile of the hospital." In the low implementation unit, respondents said that IPPC had poor fit because the patients had complicated problems, which meant that the health care providers needed to talk to the patients face-to-face anyway: "These medical questions; often they take a bit more follow-up than what one might be able to do by email, you might need to talk to the patient, and listen to the patient to find out how poorly are you really doing?" They said they had tried to communicate to the management that IPPC would not fit the unit and that the number of eligible patients originally estimated for the study was too high.

3. Relative priority (strongly distinguishing construct) for introducing patients to IPPC was described as good at 3 of the high implementation units. They talked about enrolling patients to IPPC in a neutral or positive way: "It was not so difficult to recruit patients; it actually went reasonably well." At the low implementation unit, introducing IPPC to patients was poor. The general view was that staff did not want to put effort into the implementation of IPPC and, thus, omitted to inform most of the patients about IPPC: "It did not fit in, you know, and then suddenly the patient has left, and then you have forgotten about it, because there were so many other things, and then, demands from all sides, you know, and then this comes on top of everything else."

4. Organizational incentives and rewards (not a distinguishing construct) were not given to either health care providers or units in the form of monetary rewards or other incentives. However, at one of the high implementation units, respondents felt proud to have the IPPC service and felt it could increase their professional status.

5. Goals and feedback (not a distinguishing construct) that the respondents had received during the IPPC service implementation were not much discussed at either of the units. Those who mentioned it did so in a neutral way, except one of the high implementation units, which expressed a wish for more feedback regarding the results from the questionnaires the patients had filled out as part of the study over the implementation period.

6. The learning climate (not a distinguishing construct) was described as good by both high and low implementation units. They aimed to offer evidence-based health care and the frontline nurses were offered nursing supervision and coaching.

### Readiness for Implementation

The units' commitment to the implementation of IPPC was illuminated in CFIR through 3 subconstructs:

1. Leadership engagement (not a distinguishing construct) was described as strong and involved in the early phases of the implementation of IPPC at both high and low implementation units, but respondents said that the managers had not followed up later during the implementation. Two of the respondents at the high implementation units said that their manager did not even know about the IPPC service, but that the respondents had an independent role and therefore did not miss it either: "So, to be perfectly honest, I haven't had any contact with management regarding this project at all. I don't know whether they are aware that I have been involved in the project." At the low implementation unit, the nurse manager was peripheral, which the respondents described as negative because the unit did not have a manager who led the implementation. Even if the management had been enthusiastic about IPPC, the anchoring to the frontline health care providers was missing: "So the thing is this, if you are going to have a project, the whole department must agree on it, and that didn't happen here. Because management thought this was great, but further down, they thought this was an extra burden." The respondents expressed a lack of consistency between the nurse manager's goal and the frontline health care providers' perception of what was realistic to conduct.

2. Available resources (strongly distinguishing construct) were perceived as sufficient in terms of available time at all high implementation units: "We haven't spent a lot of time on it...We have just answered in between the other things we do. We haven't needed to have any time set aside to sit with it." At the low implementation unit, respondents were worried about not having enough time for both patient recruitment and answering patient messages: "It does mean that you must have allocated time for it because you can't just do it on the side, at least not all the time."

3. Access to information and knowledge (not a distinguishing construct) in terms of information and training were expressed as satisfactory by all high implementation units.

## Characteristics of Individuals

The personal perception of IPPC of the respondents is illuminated through 3 subconstructs:

1. Knowledge and beliefs about the intervention (weakly distinguishing construct) were described with positive statements at the high implementation units where they were positive and enthusiastic about IPPC: "I feel very positive about this. I think it is a very good service." They said that IPPC was modern and future-oriented and that they thought it should be a permanent service. One of the

respondents at a high implementation unit had a different view than the others and preferred personal contact with the patients, so this unit was coded as a "mix" (0). At the low implementation unit, they said that the idea was good, but that IPPC would fit better into other parts of the health care system than their own unit. The respondents preferred personal contact with the patients: "I like the personal contact with the patient...And I sort of like having some eye contact and like to, there's so much that also gets said in the pauses you know."

2. Self-efficacy (not a distinguishing construct) was high at all units in that they were able to answer the questions from the patients without much difficulty.

3. Individual stage of change (not a distinguishing construct) was affected by the fact that the operation of IPPC was not yet fully incorporated. All felt some inconvenience using the IPPC because they seldom received messages. Only one of the respondents at a high implementation unit viewed IPPC as an integrated part of the daily work: "For me, it has in a way become like something ordinary in my everyday life. I have never thought that 'oh goodness, this thing is the research project'."

## Process

### *Planning (Strongly Distinguishing Construct)*

At 2 high implementation units, they were satisfied with the planning of the study and by participating in meetings with the research center they felt that they were able to have an impact on the implementation: "It was very good for those who followed the meetings, that you felt you could influence something." At the low implementation unit, not being part of the planning led to less engagement among the nurses involved and a more critical attitude to the implementation: "Perhaps all the nurses should have been more involved from the start, so that everyone was prepared to be included and to share the load, and then I think one would have been more committed to finding these patients and more dedicated to the study, because I felt that was lacking."

### *Engaging*

The engagement of different actors in the implementation of IPPC affected the process in different ways:

1. Opinion leaders (not a distinguishing construct) were illuminated only in the low implementation unit and there they had had strong negative views of IPPC, which affected the entire unit: "And then there may be some strong personalities who send signals, that is, who are highly verbal, and then that spreads around a bit in the unit...The counterculture isn't so strong when someone is obviously waving the negative flag."

2. Formally appointed implementation leaders (weakly distinguishing construct) were specially selected by their managers to operate the IPPC system based on their experience, role, and position in the unit: "There were a handful who were picked out for it, based a little bit on having worked for a few years and getting some experience and knowing the patient group and so on. I don't think I would assign a newcomer to this, no." At all units except

the low implementation unit, the selected nurses felt comfortable that they had been chosen to operate the IPPC system. At the low implementation unit, respondents described that the other frontline health care providers in the unit were highly independent and that the formally appointed implementation leaders were put in a difficult position because they did not have the authority to instruct the other nurses and physicians what to do: "It was up to the individual nurse to take responsibility for and ask [the patient about IPPC]. For us, that's the way it is with everything. And then I didn't have capacity to go and ask 'have you asked?' I mean, that's not how it works...No, I don't want to take on that kind of role, no. That would be wrong."

3. External change agents (not a distinguishing construct) in this implementation were the research center that was responsible for the implementation and managing the study. Three high implementation units were satisfied with the follow-up from the research center, except one of the respondents who did not feel informed about being a part of the research study and participating in interviews, but thought the only task was to answer some messages in the IPPC. The last high implementation unit and the low implementation unit said that the person from the research center had changed in the middle of the process and that this influenced the process negatively because the continuity was lost. At the low implementation unit, respondents also said that the person from the research center should have been in the unit more frequently to push the process.

### *Reflecting and Evaluating (Not a Distinguishing Construct)*

At 2 high implementation units, respondents looked forward to receiving a summary from the research center about how the patients viewed having a IPPC system and also how the other units had operated the IPPC system and their view on it.

### Comparison of Distinguishing Factors Across Studies

To identify distinguishing factors across studies (aim 3), we compared the 12 CFIR constructs found in our study that distinguished between high and low implementation units with the results from 2 other studies that also found constructs distinguishing between high and low implementation units (Table 3). One of the studies aimed to explain the variation in implementation success of MOVE!, a program for obesity management in medical centers and community-based outpatient clinics. This is also the study of the CFIR developers on which we based our analysis method [50]. The other study aimed to describe variation in implementation of California's Full Service Partnerships, a service delivery model for supported housing among persons with serious mental illness [43]. Across the 3 studies, 24 of 39 CFIR constructs distinguished between high and low implementation units in at least one of the studies. Eleven constructs distinguished between units in 2 of 3 studies. Two constructs distinguished between units in all 3 studies. Constructs that did not distinguish between high and low implementation units were reported in only one of the other studies with which we compared our results [50]. Across that study and our study, 8 constructs did not distinguish between

high and low implementation units in both studies and 15 constructs did not distinguish between high and low implementation units in one of the studies (Table 4).

**Table 3.** CFIR constructs distinguishing between high and low implementation units across studies that reported them.

| Domains and constructs of CFIR | Damschroder & Lowery [50] | Gilmer et al [43] | Our study | Studies with over-lapping distinguishing constructs, n |
|---|---|---|---|---|
| **1. Intervention characteristics** | | | | |
| Relative advantage | Yes | | Yes | 2 |
| Trialability | | | Yes | 1 |
| **2. Outer setting** | | | | |
| Patient needs & resources | Yes | Yes | Yes | 3 |
| Cosmopolitanism | | Yes | | 1 |
| External policies & incentives | Yes | Yes | | 2 |
| **3. Inner setting** | | | | |
| Structural characteristics | | | Yes | 1 |
| Networks & communications | Yes | Yes | | 2 |
| Culture | | Yes | Yes | 2 |
| Implementation climate | | | | — |
| Tension for change | Yes | | Yes | 2 |
| Compatibility | | Yes | Yes | 2 |
| Relative priority | Yes | | Yes | 2 |
| Goals & feedback | Yes | | | 1 |
| Learning climate | Yes | | | 1 |
| Readiness for implementation | | | | — |
| Leadership engagement | Yes | Yes | | 2 |
| Available recourses | Yes | Yes | Yes | 3 |
| Access to information and knowledge | | Yes | | 1 |
| **4. Characteristics of individuals** | | | | |
| Knowledge and beliefs about the intervention | | Yes | Yes | 2 |
| Other personal attributes | | Yes | | 1 |
| **5. Process** | | | | |
| Planning | Yes | | Yes | 2 |
| Engaging | | | | — |
| Opinion leaders | | Yes | | 1 |
| Formally appointed internal implementation leaders | | Yes | Yes | 2 |
| Champions | | Yes | | 1 |
| External change agents | | Yes | | 1 |
| Reflecting & evaluating | Yes | | | 1 |
| Distinguishing constructs in each study, n | 12 | 15 | 12 | |

**Table 4.** Constructs nondistinguishing between high and low implementation units across studies that reported them.

| Domains and constructs of CFIR | Damschroder & Lowery [50] | Our study | Studies with overlapping nondistinguishing constructs, n |
|---|---|---|---|
| **1. Intervention characteristics** | | | |
| Intervention source | Yes | Yes | 2 |
| Evidence strength & quality | Yes | | 1 |
| Adaptability | Yes | Yes | 2 |
| Trialability | Yes | | 1 |
| Complexity | Yes | Yes | 2 |
| Design quality and packaging | Yes | Yes | 2 |
| Cost | Yes | Yes | 2 |
| **2. Outer setting** | | | |
| Cosmopolitanism | Yes | | 1 |
| Peer pressure | Yes | | 1 |
| **3. Inner setting** | | | |
| Networks and communication | | Yes | 1 |
| Implementation climate | | | — |
| Compatibility | Yes | | 1 |
| Organizational incentives and rewards | Yes | Yes | 2 |
| Goals and feedback | | Yes | 1 |
| Learning climate | | Yes | 1 |
| Readiness for implementation | | | — |
| Leadership engagement | | Yes | 1 |
| Access to information and knowledge | Yes | Yes | 2 |
| **4. Characteristics of individuals** | | | |
| Self-efficacy | | Yes | 1 |
| Individual stage of change | | Yes | 1 |
| **5. Process** | | | |
| Engaging | | | — |
| Opinion leaders | | Yes | 1 |
| Formally appointed internal implementation leaders | Yes | | 1 |
| Champions | Yes | | 1 |
| External change agents | Yes | Yes | 2 |
| Reflecting and evaluating | | Yes | 1 |
| Nondistinguishing constructs in each study, n | 15 | 16 | |

## Discussion

### Evaluation of the Implementation of Internet-Based Patient-Provider Communication in Five Hospital Units

We identified barriers and facilitators influencing the implementation of IPPC in 5 units at a university hospital by means of the CFIR framework (aim 1). We found 12 constructs distinguishing between high and low implementation units. Half of the distinguishing constructs were related to the inner setting domain of CFIR and showed that structural characteristics of

the units, available resources, culture, and implementation climate influenced the implementation of IPPC. Thus, our results support claims that the context requires attention in itself and not only as a background description of a study [24].

This study also found that the constructs relative advantage, patient needs and resources, and knowledge and belief about the intervention were tied together, and that they distinguished between high and low implementation units. This indicates that the health care providers' perception of IPPC as useful either for themselves in their professional work or for the patients affects the implementation. This is consistent with another study

that found that clinical need and usefulness of an intervention may be crucial factors for successful implementation [53]. In information technology implementation, addressing the technology is also recommended [33] but, in this study, IPPC was regarded neither as complex nor technically challenging. This might imply that the usability of the IPPC system was good or that the professionals involved had high technical skills or both and, thus, technology demanded less attention.

Finally, the process domain included constructs distinguishing between high and low implementation units in this study and revealed that, in particular, the planning phase of an implementation is critical. In addition, the engagement of health care providers who are enthusiastic and can support the implementation throughout the process proved important for the implementation outcome. In this implementation, it was up to the individual nurses whether the patients were offered IPPC or not. Automatically offering all patients information about IPPC in a standardized introduction might have increased the number of patients enrolled in the study. By identifying and addressing the barriers beforehand, the implementation interventions could be tailored to meet and overcome the barriers toward a more successful implementation outcome [54]. If nurses at the low implementation unit had been more involved in the planning phase, it would likely contribute to more insights about the unit and the health care providers working there. Interventions that are tailored to prospectively identified barriers are more likely to improve practice [55].

## Consolidated Framework for Implementation Research's Ability to Distinguish Between High and Low Implementation Success

The CFIR provides a comprehensive overview of all aspects that can affect implementation and was helpful in creating the interview guide to ensure that all relevant aspects were covered in the interviews. However, the strength of CFIR as broad and comprehensive can also be its weakness. In our study, we had a number of constructs that were not illuminated through the interviews because the allotted time for the interviews did not allow for all constructs to be illuminated. Others have also found that the number of CFIR domains covered in a single study varies between 4 and 25 [36,56]. Even in the study of Damschroder and Lowery [50], where this method is described, the CFIR developers reported constructs that were not addressed. Therefore, CFIR may be too broad to capture all constructs through one set of individual interviews. By trying to capture the "big picture" in as many domains as possible, the depth and specificity in terms of details that may be crucial for a successful implementation may be lost. To capture all aspects of CFIR, a series of interviews may be needed. In contrast, a focus on specific facilitators or barriers, with a limited sample of sites or participants, would benefit from choosing a restricted sample of constructs that had been shown to distinguish between successful and weak implementation outcomes. Small studies can target discrete but significant questions and thereby speed knowledge translation [57].

The CFIR is institution-centric in that patients are placed under the outer setting domain, thus indicating their peripheral role in the implementation process. Although this is natural for many traditional implementations, it is somewhat unintuitive for patient-centric interventions. With the increasing emergence of patient-centric models of care, including models for homes and communities [58-60], it may be worth exploring implications for the appropriateness of all current CFIR domains. For example, patients are given only one single construct, intended to capture both their needs and their resources. In comparison, the health care providers have 2 whole domains, both the inner setting domain with 12 constructs and characteristics of individuals with 5 constructs. This applies not only for CFIR; others also have pointed out the need for greater consideration of the patient role in implementation theory [32,33,42].

Some of the constructs of CFIR are concrete and relatively easy to measure, whereas others are broad and abstract and more difficult to capture. Some of the constructs in the domain of characteristics of individuals were missing in our study (individual identification with organization and other personal attributes) and the same is seen in other studies using CFIR [39,61]. The question then is if these constructs are providing new information or if they are overlapping with other constructs. Probably they would have been used more if CFIR developers [31,50,62] had described and explained them more specifically.

## Consolidated Framework for Implementation Research Use Across Studies

To increase the knowledge about CFIR's applicability to compare implementation across settings and interventions, we compared our results with results from 2 other studies that also found CFIR constructs that distinguished between high and low implementation units (Table 3) or did not distinguish between them (Table 4).

In all 3 studies, the CFIR constructs patient need and resources and available resources distinguished between high and low implementation units. This indicates that factors essential for successful implementation is the health care providers' belief in the intervention as useful for their patients and their experience of having the necessary resources to make use of the new intervention. Eight of 12 distinguishing constructs in our study also appeared in one of the 2 other studies. This may suggest that in total 10 of the constructs we found in our study deserve particular attention because they also appeared in settings and for interventions quite different from ours.

Three distinguishing constructs were found in the 2 other studies that did not appear in our study. One of them, leadership engagement, is pointed out as important for successful implementation in several other studies [63,64]. One possible reason for the absence in our study is that many of the units in our study were staffed by nurses who were working independently led by their own self-management rather than by a unit manager. Therefore, there is no reason to question the importance of leadership even if it did not occur in our study. Inner motivation and own belief and perceived advantage of the intervention for the professionals involved and their patients played a more crucial role than leadership engagement. This may indicate that the characteristics of individuals are more influential when the management is peripheral. This is consistent with another study that found that management was not always

necessary if the planning and conducting of the implementation were taken care of by other means [17].

Constructs that did not distinguish between high and low implementation units were obtained from only 2 studies because it was not addressed in the third study and, therefore, they are too limited to draw conclusions about. However, across the 2 studies, most of the nondistinguishing factors were related to the intervention characteristics domain, indicating that implementation success was related to other aspects than the intervention itself.

## Strengths and Limitations

There are a number of limitations to our study. The study was conducted at a single university hospital and the results may not be representative of other practice settings. However, the inclusion of 5 units and comparisons across the units, which revealed that there were clear differences among the units, increases the transferability to other settings.

There is a limitation to the study in that it compares 4 high implementation units to only one low implementation unit. With only one low implementation unit, it is difficult to know whether its characteristics can be representative of other low implementation contexts or whether they are merely idiosyncratic to that one unit. However, the majority of CFIR constructs distinguishing between high and low implementation units in our study were also shown in other studies (Table 3) indicating that the characteristics for low implementation units are present across studies.

Another weakness of this study is that we were not able to present the exact number of available patients from all 5 units who could have been offered information about IPPC. At 2 units there were too many health care providers involved in the identification and first information about IPPC to the patients, so we did not manage to develop a complete reporting routine for patients who were not approached. However, the difference between the high and low implementation units regarding patients offered information about IPPC was prominent and also supported through the interviews.

Another limitation in this study is that one respondent did not allow use of a voice recorder during the interview and that another preferred to respond in writing. Even if these 2 respondents did not want to be included in the interview procedure designed for the study, their contributions were considered too crucial for the study to be omitted based on the departure in methodology. However, a strength of the study is

that it includes all the health care providers who had played an active role in the implementation of IPPC and all who were asked were also willing to participate.

## Suggestions for Further Research

Next step recommendations for CFIR research are to continue comparing high and low implementation units. In addition, longitudinal studies could provide insight into how an implementation process evolves over time and which factors are of special importance during the different phases of an implementation. Further, in light of increases in patient-centric models of care, we suggest to strengthen the patient-related constructs. These types of studies could help develop a next edition of the CFIR framework with refined parsimony and testability of its constructs. Finally, adding practical guidelines for implementation based on CFIR will make the framework more user-friendly not only for researchers, but also for the health care providers who are conducting implementations in clinical practice.

## Conclusion

This study adds insights into the barriers and facilitators influencing the implementation of an IPPC system and the differences between high and low implementation units by using the CFIR framework. We found 12 CFIR constructs distinguishing between high and low implementation units in our study, most from the inner setting domain, indicating that institutional factors are of particular importance for the implementation success in the given context. The health care providers' belief in the intervention as useful for themselves and the patients and the conduct of the implementation process, including engagement of key personnel, were also identified as important for the implementation of IPPC.

Comparison of CFIR constructs across 3 studies identified 2 constructs as particularly important in all 3 studies (patient needs and resources and available resources of health care providers) and an additional 11 constructs in 2 studies. CFIR was helpful in guiding the study and ensuring that all main aspects were covered during the interviews. Although CFIR's strength is being broad and comprehensive, this also limits its usefulness because it does not distinguish between the relative importance of its many constructs. This is the first study to identify which constructs in the CFIR are the most promising to distinguish between high and low implementation success. Thus, this study can contribute to the refinement of CFIR to become a more succinct and parsimonious framework for planning and evaluation of eHealth implementation studies.

## Authors' Contributions

CV, DG, and CMR conceived the idea for this paper, designed the study, and developed the interview guide. CMR was the principal investigator of the study. CV conducted the interviews. CV and ME coded and analyzed the data. Findings were examined

and discussed among all authors and all authors were involved in drafting and revising the manuscript for important intellectual content. All authors read and approved the final version.

## Conflicts of Interest

CMR is the developer of IPPC, but has no financial or ownership rights to the IPPC service. All authors are affiliated with the research center, but have no financial or nonfinancial interest to declare in relation to this study.

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## Abbreviations

**CFIR:** Consolidated Framework for Implementation Research

**IPPC:** Internet-based patient-provider communication
**PARiHS:** Promoting Action on Research Implementation in Health Services
**RE-AIM:** Reach Effectiveness Adoption Implementation Maintenance

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Corrigenda and Addenda

# Table Correction: Parent Engagement With a Telehealth-Based Parent-Mediated Intervention Program for Children With Autism Spectrum Disorders: Predictors of Program Use and Parent Outcomes

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**Related Article:**

Correction of: http://www.jmir.org/2015/10/e227

The authors of "Parent Engagement With a Telehealth-Based Parent-Mediated Intervention Program for Children With Autism Spectrum Disorders: Predictors of Program Use and Parent Outcomes" (http://www.jmir.org/2015/10/e227/) have inadvertently reversed the percent of participants completing the program for the self-directed and therapist-assisted group in Table 2 during the final proofreading process. The percent of participants completing the program for the self-directed group should be 69% and the percent of participants completing the program for the therapist-assisted group should be 100%. Table 2 has now been updated with the correct values in the online version of JMIR, and a corrected version was sent to Pubmed Central.

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Corrigenda and Addenda

# Metadata Correction: Impact of Educational Level on Study Attrition and Evaluation of Web-Based Computer-Tailored Interventions: Results From Seven Randomized Controlled Trials

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**Related Article:**

Correction of: http://www.jmir.org/2015/10/e228

The authors of the paper entitled "Impact of Educational Level on Study Attrition and Evaluation of Web-Based Computer-Tailored Interventions: Results From Seven Randomized Controlled Trials" [J Med Internet Res 2015;17(10):e228] inadvertently omitted Eline Suzanne Smit, PhD [CAPHRI, Department of Health Promotion, Maastricht University, Maastricht, Netherlands Amsterdam School of Communication Research (ASCoR), Department of Communication Science, University of Amsterdam, Amsterdam, Netherlands] from the list of authors during the copy-editing process. The author Eline Suzanne Smit was originally listed after Daniela Nadine Schulz in the list of authors. Additionally, a degree (PhD) has now been added for Hein de Vries. These errors have been corrected in the online version of the paper on the JMIR website on November 2, 2015, together with publishing this correction notice. Because these were made after submission to PubMed and other full-text repositories, the correction notice has been submitted to PubMed, and the original paper has been resubmitted to PubMed Central. The corrected metadata have also been resubmitted to CrossRef.

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Corrigenda and Addenda

# Correction: Parent Engagement With a Telehealth-Based Parent-Mediated Intervention Program for Children With Autism Spectrum Disorders: Predictors of Program Use and Parent Outcomes

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**Related Article:**

Correction of: http://www.jmir.org/2015/10/e227

The authors of "Parent Engagement With a Telehealth-Based Parent-Mediated Intervention Program for Children With Autism Spectrum Disorders: Predictors of Program Use and Parent Outcomes" (http://www.jmir.org/2015/10/e227/) have overlooked errors in participant demographics during the submission and proofreading process. In the Abstract, the sentence "Of the 27 parent participants, the majority were female (26/27, 96%), married (22/27, 81%), with a college degree or higher (18/27, 66%), and less than half were employed outside of the home (10/27, 37%)" should read as follows: "Of the 27 parent participants, the majority were female (26/27, 96%), married (22/27, 81%), with a college degree or higher (*15*/27, *56%*), and less than half were not employed outside of the home (10/27, 37%)." In the Results, the statement "As shown in Table 1, the majority of parent participants were female (26/27, 96%), married (22/27, 81%), with a college degree or higher (18/27, 66%). Less than half of parents were employed outside of the home (10/27, 37%)" should read as follows: "As shown in Table 1, the majority of parent participants were female (26/27, 96%), married (22/27, 81%), with a college degree or higher (*15*/27, *56%*). Less than half of parents were not employed outside of the home (10/27, 37%)." In Table 1, "Employment status (% employed)" should read as follows: "Employment status (% not employed)" and the percent of participants in the study with a college degree should be *56%* instead of 66%. These errors have now been updated with the correct values in the online version of JMIR, and a corrected version was sent to PubMed Central.

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