

# Journal of Medical Internet Research

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Original Paper

# Beyond Open Big Data: Addressing Unreliable Research

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## Abstract

The National Institute of Health invests US \$30.9 billion annually in medical research. However, the subsequent impact of this research output on society and the economy is amplified dramatically as a result of the actual medical treatments, biomedical innovations, and various commercial enterprises that emanate from and depend on these findings. It is therefore a great concern to discover that much of published research is unreliable. We propose extending the open data concept to the culture of the scientific research community. By dialing down unproductive features of secrecy and competition, while ramping up cooperation and transparency, we make a case that what is published would then be less susceptible to the sometimes corrupting and confounding pressures to be first or journalistically attractive, which can compromise the more fundamental need to be robustly correct.

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**KEYWORDS**

open data; unreliable research; collaborative learning; knowledge discovery; peer review; research culture

## *Under the Magnifying Lens: The Reliability of Medical Research*

*It ought to be remembered that there is nothing more difficult to take in hand, more perilous to conduct, or more uncertain in its success, than to take the lead in the introduction of a new order of things. Because the innovator has for enemies all those who have done well under the old conditions, and lukewarm defenders in those who may do well under the new.*  
[Niccolo Machiavelli]

The reliability of research is coming under increasing scrutiny. Over the past several years, editorials and entire issues of journals, including *British Medical Journal*, *The Lancet*, and even *The Economist* have highlighted the discordance between the amount of money invested in the biomedical research

enterprise with the lack of reliability in published studies [1-4]. Despite the peer-review process, there is a fundamental problem with the reliability of a disturbing amount of scientific, particularly biomedical, research. The problem is basically two-fold and lies in the unreliability of what does get published and the inability of other researchers to know what is not getting published. False positive research results are successfully published with alarming frequency. Replication is intrinsically difficult for a variety of reasons including limited access to original data, intellectual property issues, the general perception that replication is not doing original (and rewarding) work, and also the possible appearance of being defiant to more senior authority. Of course, work that is never published cannot be examined or replicated. When re-examination does occur, irreproducibility is surprisingly rampant. Furthermore, the peer-review system is less robust than often assumed, and there are enormous career structure-related pressures to publish. It is

remarkably easy for well-meaning but perhaps imperfectly objective researchers to be duped by false positive results that are generated by technical laboratory execution issues (including simple inconsistency) and faulty statistical analyses. The latter lies in inadequately powered studies, unlikely hypotheses being tested, lack of proper blinding, and the bias towards reporting and publishing something new. Wolfgang Pauli, the eminent physicist, might have classified this kind of work under his most brutal characterization of sloppy thinking, “It is not only not right, it is not even wrong,” or even better in the original German, “Das ist nicht nur nicht richtig, es ist nicht einmal falsch!” [5].

In the current research reward system, sensational positive findings—some, perhaps even the majority, of dubious reliability—are overvalued, while potentially important negative findings are underreported. In the words of a University of Virginia psychologist Brian Nosek, “There is no cost to getting things wrong. The cost is not getting them published” [6]. This underreporting may be due to several reasons including the reluctance of journals to publish negative results because they are perceived as intrinsically less interesting and important; the lower importance given to negative results in the sphere of promotions, awards, and grants; and unconscious or conscious self-censorship when negative results contradict a personal or industrial research agenda.

High-quality systematic reviews and meta-analyses are considered the strongest form of medical evidence. By including only published studies with sound methodology and robust analysis, the noise from irreproducible or improperly conducted research is diminished. However, systematic reviews do not adequately address publication bias. As exemplified by the drawn out Cochrane review of the neuraminidase inhibitors [7], this approach to evidence creation will be reliable only if there is access to all clinical trial data, and not only the ones that were analyzed and presented in publications. After finally getting access to previously unreleased studies (20 from Roche and 24 from GlaxoSmithKline), Cochrane Library found that the benefits of oseltamivir and zanamavir in the prevention and treatment of influenza had been overstated in previous meta-analyses [8].

More alarmingly, systematic reviews shed some light on the inefficiency of research in providing clinical guidelines. In a cross-sectional study of more than 1000 systematic reviews in the Cochrane Library across all 50 Collaborative Review Groups, 96% recommended further research to fully evaluate the intervention in question [9].

We have previously commented on the use of the vast amounts of data generated in the critical care setting to provide population-based data-driven care of individual patients [10]. Big data is an all-encompassing term for any collection of datasets so large and complex that it becomes difficult to process using traditional data processing applications. It has become an increasingly important element of research in many scientific areas such as astronomy [11], chemistry [12], microbiology [13], molecular biology [14], and physics [15]. Given the availability and use of these data and the dependency of a variety of enterprises, including clinical practice, on data analytics,

there is justifiable concern regarding the issue. In addition, the use of increasingly big(ger) data will only further augment the noise resulting from these biases and problems that currently plague the scientific literature. We share these concerns and propose measures to mitigate the risk and improve the reliability and efficiency of the research enterprise.

## *From Open Data to Collaborative Learning*

We suggest building on a system, previously described to some extent, where data and methods are freely shared among different groups of investigators addressing the same or similar questions [16,17]. Clearly, the infrastructure for this sharing process would rest extensively on carefully engineered Internet-based processes. The Internet has become such a quietly ubiquitous factor in our lives that we may forget to explicitly acknowledge the huge fundamental impact that it has had and is most likely to continue having on information storage and exchange, and in the process dramatically expanding our problem-solving ability and increasing our combined brainpower [18]. Such processes would be created and implemented to validate and build on each group’s findings. Complete data interoperability would be required; this has been a particular issue with clinical data that emanate from the silos of different vendors. An open culture of sharing data would require a paradigm shift whereby individual research groups no longer compete for publication and funding. Research would be conducted with laboratories cooperatively testing the hypotheses of others with the goal of joint publication rather than independently developing similar hypotheses, then working in silos towards separate publications. Web-based applications would be further developed for the specific purpose of supporting research cooperation. Telematik-Plattform für Medizinische Forschungsnet (TMF) in Germany, for example, offers an open-access platform for interdisciplinary exchange as well as cross-project and cross-location cooperation in order to identify and address organizational, legal, ethical, and technological problems of modern medical research [19].

This system enhancement will allow investigators to avoid the politics, secrecy, and inefficiencies that characterize the pursuit of publicly funded research in academic institutions. The current system actually inhibits advances by discouraging investigations in areas that appear to be already locked-up with funded but patented research. Those researchers who sought to restrict the use of their materials and methods in the reproduction of their experiments before, during, or after peer review, would be excluded, retrospectively if necessary, from the scientific research publication community. Researchers should be sufficiently confident in the merit and integrity of their work to provide this kind of cooperative transparency for the sake of facilitating scientific progress. We seek to systematically disassemble and revise the perception of laboratories conducting similar research as “competing” laboratories.

The best way to take down the wall between potentially competitive laboratories is to open the data gates [20]. By sharing data, competitors will transform into collaborators. Grants would generally be awarded to laboratories collaborating



in the same area, rather than to individual laboratories. Since results would be reported by more than one group, groups would review each other's data with great scrutiny because fabricated data would tarnish the reputations of all involved parties on publication. Furthermore, with the availability and use of more complete datasets from past studies, future studies could be more efficiently constructed. The "open access" data model would apply to both published as well as unpublished data. Data can remain unpublished for a variety of reasons that include lack of submission or rejection. Researchers may not want to share certain findings or they may not be able to publish important negative or confirmatory work. In either case, it is critical that these data also be accessible. While this access presents additional technical and administrative difficulties, in the current environment of continuously improving (and cheaper) data storage, it should not be insurmountable.

## *An Entrenched Culture of Competition*

Some may argue that competition, as opposed to cooperation, is the engine that drives scientific discovery. For example, one might maintain that fierce competition accelerated the process of Watson and Crick's solution of the structure of deoxyribonucleic acid (DNA). However, the competitive process can become counterproductive when secrecy transcends honest collegiality and an "end justifies any means" approach is adopted. Open collaboration with Pauling, Franklin, and Wilkins may well have *shortened* the discovery process. In addition, the credit would have been distributed differently or at least, more widely shared. Watson and Crick feared the possibility of Pauling's latching onto the solution first far more than they welcomed the potential contribution of Pauling's genius. Indeed, it was not until Watson and Crick obtained unauthorized and questionably ethical access to the crystallographic work of Rosalind Franklin that they were able to correctly deduce the double helical structure [21].

As biomedical science becomes less of an individualistic pursuit, as substantiated by the large author numbers listed for many publications, the primary driver for scientific knowledge must shift from individual glory to group accomplishment. Outstanding individuals can and will still be recognized and rewarded, but their roles may lie primarily in leading and coordinating groups rather than carrying out entire complex projects on their own. For example, promotion and tenure committees have adjusted to the shift to multi-authorship whereas in a prior era, such publications may have been significantly underweighted due to the small fractional contribution of each author.

## *Towards Open Continuous Peer Review*

All data from taxpayer-supported funding sources would truly be open and freely available to the public. This would include unpublished or privately published data as well as data from papers published in publicly available journals. This would create an environment where diverse groups could access the relevant database(s) to further investigate and validate (or invalidate) the published findings. Unpublished material may contain keys to interpreting the published results in both positive

and negative, reliable and unreliable lights. No research finding would be immune from query and possible challenge. The possibility that an investigator's published material might even be proven false by a very junior researcher or a layperson would spark the due diligence necessary for accurate data collection and a robust aversion to falsified or fabricated data—as well as to those individuals who engage in such practice. The academic promotion process would adjust to this new culture but, except for the recognized rare lone wolf genius, would actually require investigators to participate in research collaboratives. In addition, the reward system (eg, promotions, awards) would more strongly recognize the publication of important negative results and more negatively weigh the publication of research that proved to be unreliable, required retraction, etc. While it is more difficult and time consuming for evaluative bodies to do so, the content of articles should be carefully considered in detail by such committees. This may not be the case when the process rests on a more superficial count of publications along with the impact factors of the journals in which they are published.

Scholarly journals would need to work together in order to specifically prevent the publication of unreliable research. Post-publication vigilance for reliability on the part of journals (akin to the post-marketing life cycles of drugs) would become a fundamental element of the scholarly publication process. Those journals best at tracking research post publication might see their impact factors rise in a manner proportional to their engagement in the process. Even better, perhaps more valid and useful metrics than impact factors, such as a "collaboration index", could be developed to better represent journal quality. Post-publication vigilance on the part of journals would become a fundamental element of the scholarly publication process.

## *Shouldering the Cost of Reliability*

Without the unlikely *deus ex machina* intervention of a Gates or a Buffett to fund a new non-profit organization devoted to disinterested auditing for the sake of improving research reliability, the funding would likely have to derive from a consortium of the interested parties. The culture would need to develop the embedded philosophy that these costs are simply a part of "doing business" in the sense of producing reliably performed and reported research. The possible involved actors include the researchers themselves; the "payers", or the source of funding, including non-profit, governmental, and industrial agencies; journals; universities for academic researchers; and hospital systems and professional societies for medical research. We propose for a lean and efficient organization, perhaps an independent non-profit entity, funded in an acceptably fair fashion by the involved parties, whose mission would be to provide what increasingly appears to be much required oversight to the research enterprise.

There might also be an unintended educational benefit from the auditing system. These datasets could be used as exercise for graduate or undergraduate students in their respective fields to review and validate, and credit could be awarded to students who participate as a means of displaying their scholarship in the field. Such measures may be necessary as statistical and

machine learning methodologies continue to evolve, and a number of data and statistical expert types may be required to validate the findings. Current technology allows for the simple collection and transfer of vast amounts of data, and this portability should be a vehicle for broadening the base that view and validate research for publication, application, and dissemination.

There are examples of new journals that support and promote data sharing. *BMJ Open* was launched in 2011 and was the first medical journal to integrate its submission process with the Dryad digital repository, so that data deposition is part of authors' submission/workflow [22]. Data Dryad is a curated general-purpose repository that makes the data underlying scientific publications discoverable, freely reusable, and citable [23]. It now has integrated data submission for a growing list of journals. *Scientific Data* is a new open-access, online-only publication for descriptions of scientifically valuable datasets [24]. It is currently calling for submissions and was launched in May 2014. In fact, the traditional journal model may not be the only modality for the public transmission of scientific information: data may be provided freely online as in the Genomes Unzipped project [25].

With open-access data, research will be democratized and no longer confined within traditional academic environments or industry-funded laboratories. This will allow interacting groups of investigators to conduct research with varying methods on the same and/or related topics using the same data. This will mitigate false positives based on biases related to researchers' hypotheses, reduce unnecessary experimental reproduction, and open research fields to fuller participation.

## Crowdsourcing the Validation of Research Findings

Replication will not remove either bias or residual confounding. For observational studies, hidden variables, including provider bias and local medical culture issues, that confound the true relationship between an exposure and an outcome, tend to differ across heterogeneous settings. If the association between an intervention and an outcome remains strong across countries with very different practices, for example, then the probability that this association is noise rather than signal is reduced (vs an observation in a single locale).

A major challenge with observational studies that is not addressed by the size of the data is the presence of residual confounding: there may be characteristics of the patients or the diseases not captured in clinical databases that may explain why patients who got treatment A got better while those that got treatment B did not. The social determinants of health—the conditions in which people are born, grow, live, work, and age, and most importantly, the individual behaviors in response to these variables—are seldom captured in electronic health records (EHR). The sociological factors are becoming increasingly available as large cities build open data platforms. For example, the NYC Open Data repository [26] contains over 1100 datasets spanning Business, City Government, Education, Environment, Health, Housing and Development, Public Safety, Recreation,

Social Services, and Transportation. Behavioral data are likewise increasingly captured digitally through mobile phones, tracking of Internet usage (including social media), global positioning system (GPS) devices and other wireless sensors, purchases, and other financial transactions, etc. The challenge, needless to say, is to map these disparate data sources without significant risk to privacy and security.

For translational and clinical research, the additional research scrutiny would set the stage for the development of useful standard thresholds at which a research finding could be considered valid and reliable, for example, after  $n$  number of replications or after a particular statistical requirement is achieved. Within a bigger data framework, the threshold standardization would become progressively more valid due to the statistical confidence afforded by larger datasets.

A key ingredient to making this vision successful is efficient crowdsourcing. Models that may be emulated already exist and are efficiently being used by researchers today. The Multi-parameter Intelligent Monitoring in Intensive Care (MIMIC) database is one such successful initiative [27]. The MIMIC database, developed and maintained by the Laboratory of Computational Physiology at the Massachusetts Institute of Technology (MIT), contains health care metrics of over 60,000 de-identified intensive care unit patients admitted to the Beth Israel Deaconess Medical Center (BIDMC). Information is carefully de-identified to minimize identification risks without excessive deletion of information of clinical value. Natural language processing is used to correctly capture the correct and precise meaning of clinical entries that can be difficult to elucidate based on factors such as physician abbreviations and a plethora of contextual modifiers (eg, “rule out”, “suspect”, “history of”). The success of MIMIC at an admittedly relative small scale gives great hope for our ability to similarly use larger clinical databases for both dynamic and retrospective data mining purposes. This database has already been employed in several publications that have brought together frontline clinicians with data scientists and computer engineers, under the guidance of the authors. The Institutional Review Boards of both MIT and BIDMC have approved the use of MIMIC for research purposes. The authors also recently organized the Critical Data Marathon and Conference held at MIT in January 2014 [28]. The conference's theme was to address concerns that big data will only augment the problem of unreliable research. Professors Jeffrey Drazen, *New England Journal of Medicine* editor-in-chief, and John Ioannidis, director of the Meta-Research Innovation Center at Stanford, were the keynote speakers. The second MIMIC data marathon was held concurrently at MIT, in London and in Paris on September 2014 and attracted more than 200 participants.

The PCORnet is a new initiative by the Patient-Centered Outcomes Research Institute [29]. It is a database that will consist of 11 clinical data research networks across the country cataloguing primarily EHR data, with some degree of mapping to 18 patient-powered research networks archiving all types of data collected by patients. If all goes well, by September 2015 PCORnet will be a giant repository of medical information from 26–30 million Americans. In the United Kingdom, the National Institute for Health Research Health Informatics Collaboration

was launched in November 2013 [30]. Five National Health Service (NHS) trusts are working together to make NHS clinical data more readily available and accessible to researchers, industry, and the NHS community. The main objectives are to develop, design, and provide common infrastructure, standards, and services that will allow users to perform secondary analysis of EHR data in the fields of viral hepatology, acute coronary syndrome, ovarian cancer, renal transplantation, and critical care. But as we have previously emphasized, the value of these large databases hinges on the researchers' transparency in their methodology and the creation of a continuous and more effective peer review, leading to improvement in method quality with each iteration of analysis and resulting in more reliability.

Data marathons held around open data (including MIMIC) have attracted both students and postgraduate trainees [31]. Closed research networks would expand and evolve, removing the barriers that have made research activity accessible only to a limited group. In effect, research networks would expand exponentially breaking down the walls that have made much research activity accessible to only a relatively small group of academics.

## Open Big Data Hits and Misses

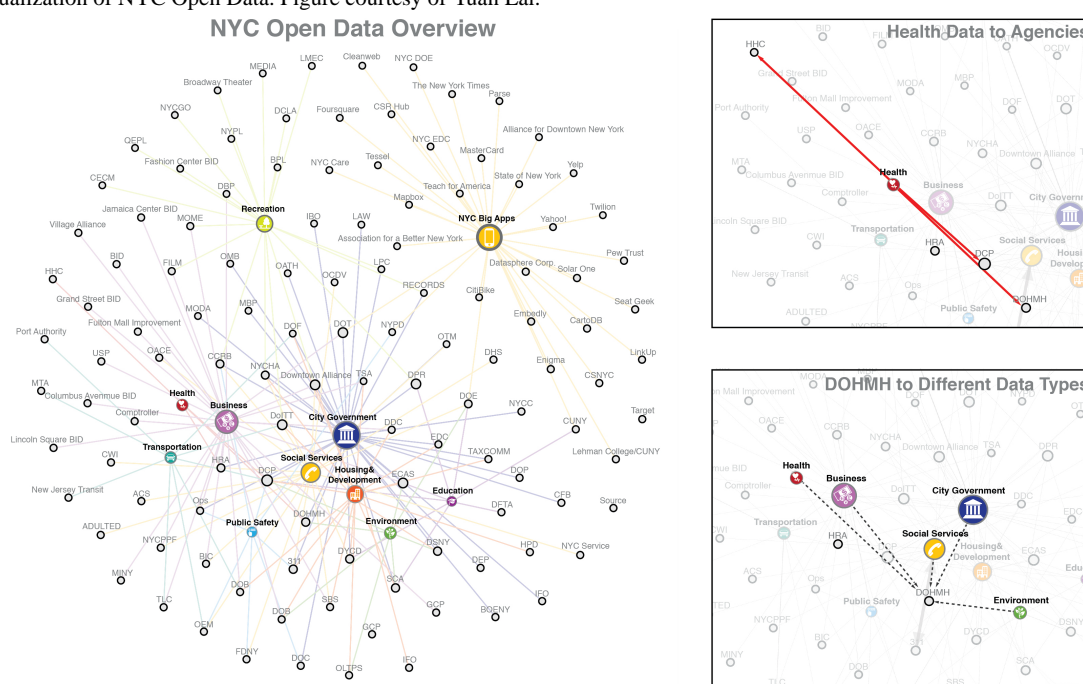
As impressive as it is, the NYC Open Data repository highlights some of the problems that we see in big data initiatives. For example, urban planning has to date not incorporated health care data to fully exploit the data's potential to inform public health policies. As shown in Figure 1, health data are directly shared only between the Health and Hospitals Corporation, the Department of City Planning, and the Department of Health and Mental Hygiene. Noticeably missing are direct data-sharing connections between these organizations and the New York Department of Sanitation, Department of Homeless Services, Department for the Aging, and the Office of Emergency

Management. The association map illustrates that organizations that would benefit from direct multidisciplinary collaboration appear to be operating in informational siloes, which is a recurring theme among big data projects.

But there have been success stories. In October 2012, GlaxoSmithKline announced that it would make detailed data from its clinical trials available to researchers outside its own walls [32]. For a company that spends \$6.5 billion a year on research and development, it was a surprising departure from the entrenched system of data secrecy. True to its word, the company began posting its patient-level clinical trial data online in May 2013 and then invited other pharmaceutical companies to do the same. Consequently the Clinical Trial Data Request project was launched [33]. Pharmaceutical companies that have so far committed to contribute (apart from GlaxoSmithKline) include Bayer, Boehringer Ingelheim, Lilly, Novartis, Roche, Sanofi, Takeda, Union Chimique Belge (UCB), and ViiV Healthcare. To date, more than 1000 clinical trials have been uploaded. Trial transparency is appealing because of a growing sense that it could make drug development more efficient, saving the industry billions while also getting breakthrough therapies to patients more quickly.

Finally, the Global Alliance for Genomics and Health was established in 2013 and consists of genomics researchers, funders, businesses, and advocates [34]. The coalition develops and implements technical, ethical, legal, and clinical guidelines to make it easier to share genomic data. This is an example of an international multidisciplinary collaboration around a big data initiative representing various sectors including academia, industry, and the government. The current focus of the group is the creation of a genomics application programming interface to enable the interoperable exchange of data in DNA sequence reads and a framework for data sharing to guide governance and research.

**Figure 1.** Visualization of NYC Open Data. Figure courtesy of Yuan Lai.





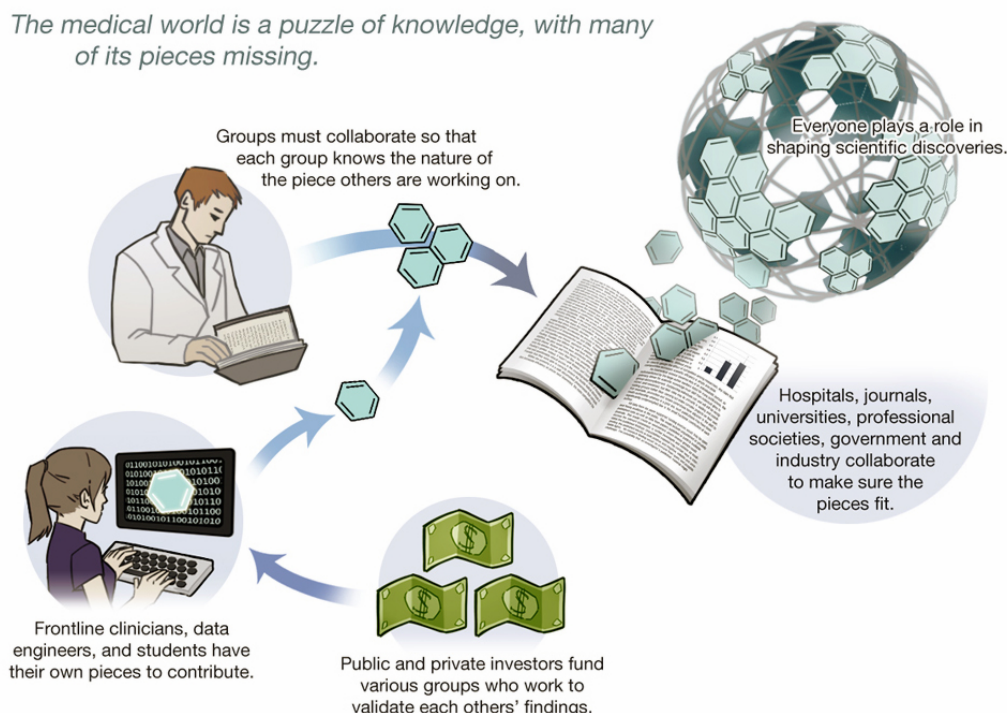
## Implementing Transparent Oversight Systems

Systems will need to be put in place to institute the replication and cross validation of experiments and analyses (Figure 2). Universities, professional societies, government agencies, and research-driven companies are examples of organizations that could develop and operate these systems. Regulatory boards such as the Food and Drug Administration (FDA) and European Medicines Association (EMA) will have to revise existing approval requirements; for example, trials backing a drug or device will require replication as well as validation by different groups. To renew approval, companies will be required to submit ongoing, regular reports that track the effectiveness of their products in the real world. A pharmacovigilance system has been described that proactively uses clinical database networks to accumulate safety and efficacy evidence when drugs are used in wider, more diverse patient populations than those typically examined during pre-market approval clinical studies [35]. Both the FDA and EMA have already proposed the expansion of data access submitted in regulatory applications [36,37]. In 2012, The Royal Society published a report on science as an open enterprise that mapped out the changes required of scientists, their institutions, and those that fund and support science in order to optimize the potential of the huge deluge of data created by modern technologies [38]. Last year, the AllTrials campaign was launched globally with a cross-sectoral support, calling for all clinical trials to be registered and all results reported [39]. The initiative pushes for researchers, funding bodies, institutions, ethics committees, and regulators to work together to ensure that the value from the resources used to produce research is maximized. In the United States, the Center for Open Science was inaugurated [40]. It is a non-profit technology organization whose mission is to increase the openness, integrity, and of scientific research. At the heart of the organization is the Open Science Framework, an open source

software that facilitates collaboration in science research. Most recently, the Meta-Research Innovation Center at Stanford was launched. Headed by Professors John Ioannidis and Steven Goodman, the center will undertake rigorous evaluation of research practices with the aim of optimizing the reliability of scientific investigations and the efficiency of the biomedical research enterprise [41].

With such systems in place, investors will be able to invest in a group of companies working on a related product or idea, rather than solely in individual companies. The ability to invest in a “fund” of related research initiatives should also reduce investor risk in a manner akin to the reduced risk associated with financial index investing versus individual stock picking. Perhaps in the future, new investment products would arise that focus on companies associated with a particular research subject. As noted, funding agencies like the National Institute of Health and the National Science Foundation would award grants to collaborative groups of laboratories. The extensive time and effort spent in preparing grants that may or may not be successfully funded would presumably be reduced, allowing scientists to focus their efforts on research.

The solution to the conundrum of unreliable research lies not only in complete transparency, but more importantly in cooperation among investigators, and with a more lateral distribution of investments, grant funding, and credit for scientific discoveries. We expect these proposals would bring about a culture of collaboration and shared data as well as more complete and accurate reporting of scientific findings. The added accuracy of the scientific findings is only one of the benefits of the systematization of data interrogation. Another will be the enhanced ability of individuals of every educational level and area of expertise to thrust themselves into the fray and contribute to science. We wish to echo the sentiments of Louis Pasteur when he stated, “Science knows no country, because knowledge belongs to humanity, and is the torch which illuminates the world.”

**Figure 2.** Graphic illustrating how to address unreliable research. Figure courtesy of Kai-ou Tang.

## Conflicts of Interest

None declared.

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## Abbreviations

**BIDMC:** Beth Israel Deaconess Medical Center  
**EHR:** electronic health record  
**EMA:** European Medicines Association

**FDA:** US Food and Drug Administration  
**MIMIC:** Multi-parameter Intelligent Monitoring in Intensive Care  
**MIT:** Massachusetts Institute of Technology  
**NHS:** National Health Service

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Original Paper

# The Change in Eating Behaviors in a Web-Based Weight Loss Program: A Longitudinal Analysis of Study Completers

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## Abstract

**Background:** Eating behaviors are essential components in weight loss programs, but limited research has explored eating behaviors in Web-based weight loss programs.

**Objectives:** The aim was to evaluate an interactive Web-based weight loss program on eating behaviors using the 18-item Three-Factor Eating Questionnaire Revised (TFEQ-R18) which measures uncontrolled eating, emotional eating, and cognitive restrained eating. Our Web-based weight loss program is comprised of information about healthy lifestyle choices, weekly chats with experts, social networking features, databases for recipe searches, and features allowing members to self-report and track their weight, physical activity, and dietary intake on the website.

**Methods:** On registering for the weight loss program, 23,333 members agreed to take part in the research study. The participants were then asked to complete the TFEQ-R18 questionnaire at baseline and after 3 and 6 months of participation. All data collection was conducted online, with no face-to-face contact. To study changes in TFEQ-R18 eating behaviors we restricted our study to those members who completed all 3 TFEQ-R18 questionnaires. These participants were defined as “completers” and the remaining as “noncompleters.” The relationships between sex, change in eating behaviors, and total weight loss were studied using repeated measures ANOVA and Pearson correlation coefficient.

**Results:** In total, 22,800 individuals participated (females: 19,065/22,800, 83.62%; mean age 39.6, SD 11.4 years; BMI 29.0 kg/m<sup>2</sup>; males: 3735/22,800, 16.38%; mean age 43.2, SD 11.7 years; BMI 30.8 kg/m<sup>2</sup>). Noncompleters (n=22,180) were younger and reported a lower score of uncontrolled eating and a higher score of cognitive restrained eating. Over time, completers (n=620) decreased their uncontrolled eating score (from 56.3 to 32.0;  $P<.001$ ) and increased their cognitive restrained eating (from 50.6 to 62.9;  $P<.001$ ). Males decreased their emotional eating (from 57.2 to 35.9;  $P<.001$ ), but no significant change was found among females. The baseline cognitive restrained eating score was significantly and positively associated with weight loss for completers in both men ( $P=.02$ ) and women ( $P=.002$ ).

**Conclusions:** To our knowledge, this is the largest TFEQ sample that has been documented. This Web-based weight loss intervention suggests that eating behaviors (cognitive restrained eating, uncontrolled eating, and emotional eating) measured by

TFEQ-R18 were significantly changed during 6 months of participation. Our findings indicate differences in eating behaviors with respect to sex, but should be interpreted with caution because attrition was high.

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## KEYWORDS

behavior; counseling; diet; eating; method; questionnaires; Internet; weight loss; TFEQ

## Introduction

Obesity has reached epidemic proportions globally [1] and effective strategies to prevent and improve this epidemic are continuously being discussed [2]. One intervention strategy that has increased in popularity is the Web-based weight loss program, probably due to its potential for a large reach [3] in a cost- and time-effective manner [4-6]. The Internet's potential to operate interactively makes it a valuable tool in weight loss interventions [7]. It allows for instant tailored health counseling based on the participants' reported health behaviors, personal interests, and goals [7-9].

In 2003, our research group developed the Swedish Web-based weight loss intervention program, the Weight Club [10]. We previously studied the characteristics of members participating continuously for 6 months in the Weight Club. We found an average weight loss of 7.7% among men and 6.8% among women [11]. This is in-line with a review by Neve et al [12], who documented a minimum achieved weight loss of at least 5% in 4 of 7 Web-based studies—a weight loss considered to be sufficient to provide clinically significant health benefits [13,14].

Although the results from Web-based weight loss programs have been promising, the chance for successful weight loss may not only result from the content of the intervention or the individual's adherence to the weight loss intervention [7,15,16], but may also be related to an individual's lifestyle behaviors [17]. It is not unreasonable to argue that a weight loss program of any kind may influence eating behaviors, which eventually will lead to weight loss. Conversely, some may argue that a change in eating behavior may be the primary mechanism that results in a loss of weight, independent of intervention.

However, only a few studies have examined the association between individuals' eating behaviors and weight loss or weight gain, with controversial results. Results from some studies suggest a relationship between high levels of restrained eating behavior, defined as an individual's conscious food restriction to control body weight [18], and lower body mass index (BMI) [19-22]. Although, in a review by Lowe et al [23], normal-weight individuals with high levels of restrained eating behavior or with a history of dieting seemed to be more susceptible to gain weight compared with those with low restrained eating or no history of dieting. Alternatively, other researchers found no associations between restrained eating and BMI [24].

Moreover, the tendency to lose control over eating when feeling hungry or being exposed to external stimuli [25,26] has been shown to correlate with an individual's overeating and impulsive eating, contributing to increased bodyweight [27,28]. This eating

behavior has previously been referred to as “disinhibited eating” [18], but has been revised to the term “uncontrolled eating behavior” [26]. It has been suggested that emotional eating, overeating in response to negative emotions or stimuli, is a learned response rather than a consequence or a mediator for overweight or obesity [29-31]. Koenders et al [32] stress that it is “emotional eating, rather than lifestyle behaviors, [that] drives weight gain” among people with overweight and obesity.

The possible change of eating behavior over time has not been fully investigated. Even less is known about how eating behavior may change over time while partaking in a Web-based weight loss program and if there is a relationship between eating styles and weight loss. To disentangle these matters, this study was designed to examine eating behaviors in a large cohort of members participating in the Swedish Web-based Weight Club for 6 months. We specifically studied the participants' eating behaviors over time, using the 18-item Three-Factor Eating Questionnaire Revised (TFEQ-R18).

## Methods

### Weight Loss Program

The participants were registered members of a Swedish Web-based weight loss program [10], who were invited through a media advertising campaign. The program was specifically tailored to the general Swedish population. The weight loss club was named the Weight Club (Swedish: Viktklubb) and was developed in collaboration with health professionals (physicians, dietitians, nurses, and researchers) at the Karolinska Obesity Unit, Karolinska University Hospital Stockholm, Sweden, and the Swedish newspaper *Aftonbladet* [33] (see Figure 1).

The Weight Club [10] was accessible on a 24-hour basis. At the start, members were asked to weigh themselves and to record and report their weight once a week. The recommended weight loss was  $\leq 1$  kg per week. Recommendations for daily energy intake were calculated using the Benedict formula [34]. Approximately 1000 meals and recipes by well-known Swedish chefs were accessible and regularly updated. All meals were based on guidelines from the national Swedish Food Agency. The participants had the opportunity to modify or create their own recipes and use the search feature to evaluate their food choices regarding nutritional content.

Members were instructed to frequently record their weight, food intake, and physical activity level using the online food and exercise diaries (see Figure 2). The members automatically received feedback. This feedback was communicated to the members through the website's interactive charts and figures presenting their progress (ie, with respect to weight loss and frequency of physical activity). Emails with tips and advice on how to change eating behaviors to encourage weight loss and

weight maintenance were sent on a regular basis. In addition, chats were available on the website allowing for exchange of knowledge, experiences, and social support during the weight loss process. The members could also use a personal blog—a feature used by 25% of the members. Additionally, members had the opportunity to participate in weekly online chats with

a physician or dietician for further personal advice and support. Questions and answers from the chats were published on the newspaper's website and at the Weight Club's website on a weekly basis. Members who had successfully managed to lose weight were interviewed by the Weight Club team and these interviews were posted online.

**Figure 1.** Home page for Viktklubb (Weight Club) with information about what is included in a membership, success stories, BMI calculator, and setting current and future goals.

**Viktklubb.** Hem | Mat | Motivation | Motion | Experter | Vi har lyckats Logga in

**DETTA ÄR VIKTKLUBB**

- ✓ Personlig kaloriplan & menyförslag
- ✓ Experthjälp & rådgivning
- ✓ Sveriges största viktforum

**MEDLEMSBERÄTTELSE**

**ANDREAS, 32**  
Andreas har fått mer energi och mindre smärtor. Målvikten nådde han på 8 månader

**FANNY, 30**  
Fanny fick en ny vikt och en hälsosam livsstil med hjälp av promenader och smärta kostnapp

**TESTA DITT BMI**  
Fyll i dina värden så räknar vi ut när du kan nå din målvikt.

Vikt: 100 kg  
Längd: 170 cm  
Målvikt: 90 kg

Testa nu

**Detta får du i Viktklubb**

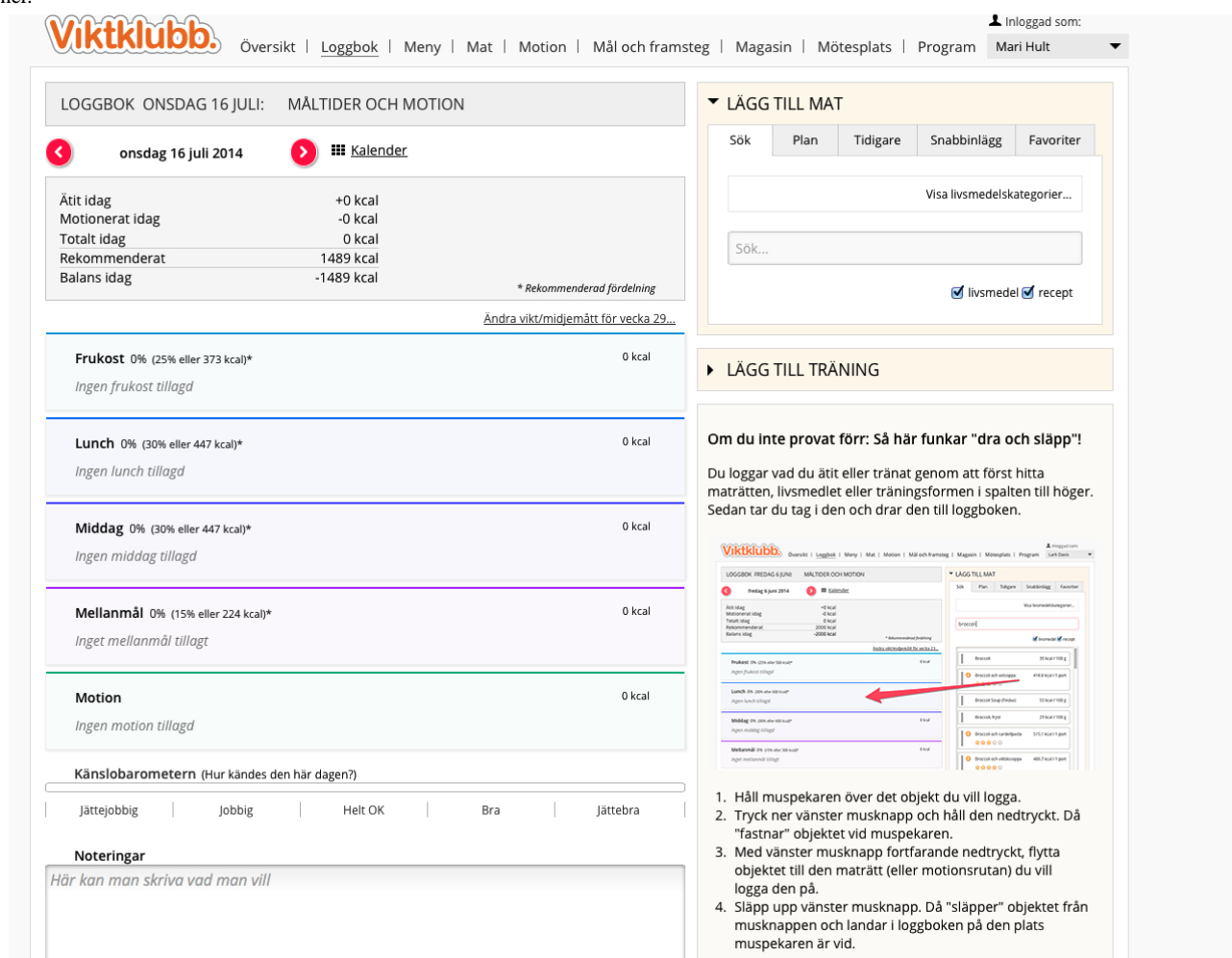
**En personlig kostplan**  
Du får en personlig kostplan baserat på din nuvarande vikt, hur mycket du rör dig och din bakgrund. Ditt dagliga kaloriintag räknas ut av en formel framtagen av Karolinska Institutet.

**Loggbok**  
Här loggar du allt som du äter och motionerar under en dag. Du kommer att upptäcka att loggboken är ett viktigt verktyg på din viktresa. Du söker upp vad du ätit och loggar det, vet du hur många kalorier du ätit går det också att logga direkt.

**Recept**  
Viktklubb har över 4000 kaloriberäknade recept som är väldigt uppskattade och populära bland våra medlemmar. Du kan även skapa dina egna recept.



**Figure 2.** A diary for daily food intake, level of physical activity, and additional private comments about the day (using a drag-and-drop function). The balance between actual energy intake minus energy expended through physical activity compared to suggested energy intake is seen in the upper left corner.



## Participants and Design

To access the weight loss program, the members had to subscribe to a 3-, 6-, or 12-month membership plan (prices ranging from €33 to €55) [10]. All members were asked to answer a questionnaire of sociodemographics and whether they were interested in participating in the research study. The consenting participants were then asked to answer questions about age, weight, and height and fill out the TFEQ-R18 at baseline, 3 months, and 6 months.

The TFEQ is a widely used validated questionnaire to measure eating behaviors among heterogeneous populations [26,30,35-37]. The TFEQ-R18 is an 18-item revised version [26] of the original questionnaire, developed by Stunkard and Messick, which was 51 items originally [18]. The TFEQ-R18 encompasses 3 concepts of eating behaviors including cognitive restrained eating (6 items), emotional eating (3 items), and uncontrolled eating (9 items) [26,37,38]. The TFEQ-R18 is based on scores, wherein each item has a score. The total scores are then summed and the results are presented on a scale of 0-100, where higher values indicate a greater degree of that particular behavior [39].

A total of 23,233 members agreed to participate in the study. Of these, 22,844 members submitted complete information on

sex, age, weight, and the TFEQ-R18 at baseline. Overall, 37 participants were excluded from the data analysis due to obviously conflicting answers (ie, unrealistic BMI and weight goal). Also, to prevent confounding due to bariatric surgery, cancer, or other reasons with the potential to alter eating behaviors, we omitted 7 participants because they reported a weight loss of more than 30% in 6 months.

To study members' eating behaviors (cognitive restrained eating, uncontrolled eating, and emotional eating) over time, we restricted our analyses to members who were participating continuously for 6 months because this was a typical time to sign up for the weight loss program. Because the Weight Club was open to the public (and not limited to solely study participants or patients), members entered and left the program on a voluntary basis. Hence, we only have data on those members who agreed to take part in the study and who submitted the research questionnaires.

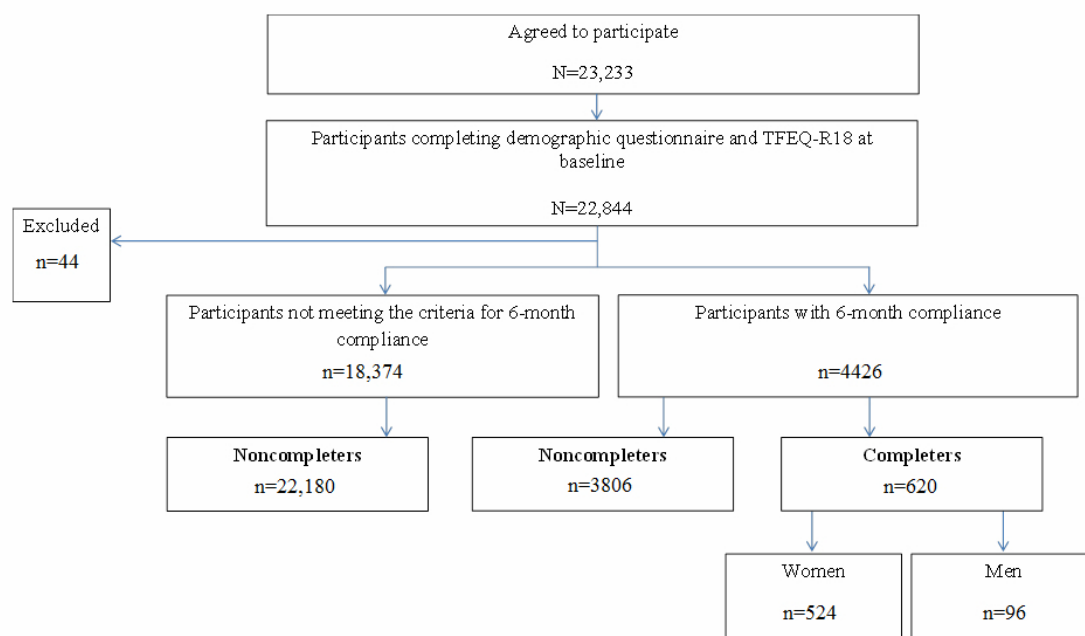
We defined 6-month compliance by restricting our analyses to participants who registered their weight at least once during the past month and logged on at least twice during the first 3 months and twice during the second 3 months of participation. As a result, 4426 participants were eligible for study.

To study changes in eating behaviors over time, we further restricted our analyses to those participants who had completed the baseline questionnaire and the TFEQ-R18 at baseline and at 3 and 6 months, leaving 620 participants from our primary study sample. Those participants who met these 2 criteria (1) 6-months compliance and (2) submitting complete data (baseline questionnaire and TFEQ-R18 at baseline and at 3 and 6 months)

were categorized as “completers.” Those participants not meeting these criteria were categorized as “noncompleters.” See Figure 3 for a flowchart of the study design.

All data were collected through the website’s database and sent to the researchers on a regular basis. The Ethics Committee of the Karolinska Institutet approved the study.

**Figure 3.** Flowchart of the study design.



## Statistics

Descriptive statistics (mean, SD) were computed to summarize the participants’ baseline characteristics (ie, age, BMI, TFEQ-R18 scoring, and years of education). Results were stratified by sex and by completers and noncompleters. The Mann-Whitney *U* test was computed to study possible differences between completers and noncompleters for continuous variables, such as age, BMI, and TFEQ-R18 scoring. The Pearson chi-square test was computed to test for differences in categorical variables (level of education) between completers and noncompleters.

The reported eating behaviors and weight level were summarized at baseline and at 3 and 6 months. We also summarized the total number of log-ins to the website during their 6-month participation.

We studied the participants change in eating behavior over time and potential differences between sexes using a repeated measures analysis of variance (ANOVA). In these analyses, the measured eating behavior at 3 time-points was analyzed as a within-subjects factor, whereas the participants’ sex was analyzed as a between-subjects factor. The interaction between sex and time was also tested. If significant, repeated measures ANOVA was carried out separately for men and women.

Pearson correlation coefficient (*r*) was used to study the relationship between change in eating behaviors over 6 months

and total weight loss percentage, computed as  $([\text{weight at the beginning} - \text{weight after 6 months}] / \text{weight at the beginning}) \times 100$ . We also studied the relationship between change in eating behaviors over 6 months and the total number of log-ins to the website using the same analysis.

*P* values less than .05 were considered statistically significant. All analyses were performed using SPSS 15.0 for Windows (SPSS Inc, Chicago, IL, USA).

## Results

At baseline, the mean age of the 22,800 study participants was 39.6 (SD 11.4) years for females and 43.2 (SD 11.7) years for males. More than 80% (19,065/22,800, 83.62%) of the participants were females. The mean BMI was 29.0 (SD 5.0) kg/m<sup>2</sup> for females and 30.8 (SD 4.3) kg/m<sup>2</sup> for males.

When studying differences in baseline data between completers and noncompleters, we found that both male and female completers were slightly older ( $P < .001$  and  $P = .002$ , respectively) compared to noncompleters. Female completers also had a higher BMI ( $P < .001$ ), and were more educated ( $P = .02$ ) compared to noncompleters, whereas no significant difference was found in BMI or education between male completers and noncompleters. (Table 1). The average weight loss for male completers was 7.0% (SD 5.1) and 5.8% (SD 5.0) for female completers.

**Table 1.** Baseline characteristics of the study participants (N=22,800).

Characteristics	Women			<i>P</i> <sup>a</sup>	Men			<i>P</i> <sup>a</sup>
	All n=19,065	Completers n=524	Noncompleters n=18,541		All n=3735	Completers n=96	Noncompleters n=3639	
Age (years), mean (SD)	39.6 (11.4)	43.4 (11.8)	39.5 (11.3)	<.001	43.2 (11.7)	46.6 (10.5)	43.1 (11.7)	.002
BMI (kg/m <sup>2</sup> ), mean (SD)	29.0 (5.0)	29.8 (4.9)	29.0 (5.0)	<.001	30.8 (4.3)	31.5 (4.3)	30.7 (4.3)	.07
<b>Eating behavior, mean (SD)</b>								
Uncontrolled eating	51.8 (15.1)	56.3 (14.4)	51.6 (15.1)	<.001	51.7 (14.8)	56.8 (13.6)	51.5 (14.8)	.001
Emotional eating	43.5 (30.3)	45.1 (28.6)	43.5 (30.4)	.14	55.3 (28.9)	57.2 (28.4)	55.3 (28.9)	.57
Cognitive restrained eating	48.6 (11.4)	50.6 (10.7)	48.5 (11.4)	.002	47.2 (12.2)	50.8 (10.9)	47.1 (12.2)	.09
<b>Education, n (%)</b>								
				.02				.56
≤9 years	1253 (6.6)	24 (4.5)	1229 (6.6)		312 (8.3)	6 (6.3)	306 (8.4)	
10-12 years	9176 (48.1)	235 (44.8)	8941 (48.2)		1840 (49.3)	45 (46.8)	1795 (49.3)	
≥13 years	8097 (42.5)	244 (46.6)	7853 (42.4)		1484 (39.7)	44 (45.8)	1440 (39.6)	
Unknown	539 (2.8)	21 (4.0)	518 (2.8)		99 (2.7)	1 (1.0)	98 (2.7)	

<sup>a</sup>*P* value based on Mann-Whitney *U* test (age, BMI, uncontrolled, emotional, and cognitive restrained eating behavior) or Chi-square test (education).

Both male and female completers reported higher baseline scores of uncontrolled eating compared to noncompleters (men:  $P=.001$ ; women:  $P<.001$ ), although no significant difference in baseline emotional eating score was found. Female completers reported higher baseline scores of cognitive restrained eating ( $P=.002$ ) compared to female noncompleters, whereas no significant difference was observed among men (Table 1).

The results from repeated measures ANOVA (Table 2) suggest no interaction between time and sex for uncontrolled eating behavior ( $P=.76$ ). The variable time was significant ( $P<.001$ ), and both male and female completers significantly decreased their uncontrolled eating score over time. For cognitive restrained eating behavior, there was no significant interaction

between time and sex ( $P=.12$ ), but the variable time was significant ( $P<.001$ ) with both males and females increasing their cognitive restrained eating over time (see Figure 4a-d).

An interaction between time and sex for emotional eating ( $P<.001$ ) was observed (Table 2). The effect of time was significant in men ( $P<.001$ ), but not in women ( $P=.98$ ). Males decreased their emotional eating score from 57.2 at baseline (SD 28.4) to 35.9 (SD 26.9) after 6 months participation. Females, conversely, had a constant emotional eating score (Figure 4e,f). Thus, our results suggest a difference in change of emotional eating behaviors over 6 months with respect to sex.

**Table 2.** Results of repeated measures ANOVA.

Eating behavior	<i>F</i> ratio ( <i>df</i> ) <sup>a</sup>	<i>P</i> value
<b>Uncontrolled eating behavior</b>		
Sex	0.30 (1, 618)	.58
Time	193.93 (1.17, 720.22)	<.001
Interaction (time×sex)	0.13 (1.17, 720.22)	.76
<b>Cognitive restrained eating behavior</b>		
Sex	2.72 (1, 618)	.10
Time	73.43 (1.64, 1016.24)	<.001
Interaction (time×sex)	2.24 (1.64, 1016.24)	.12
<b>Emotional eating behavior</b>		
Sex	1.58 (1, 618)	.21
Time	12.21 (1.16, 717.50)	<.001
Interaction (time×sex)	11.77 (1.16, 717.50)	<.001

<sup>a</sup> Degrees of freedom for time and interaction are adjusted according to Greenhouse-Geisser correction for nonsphericity.

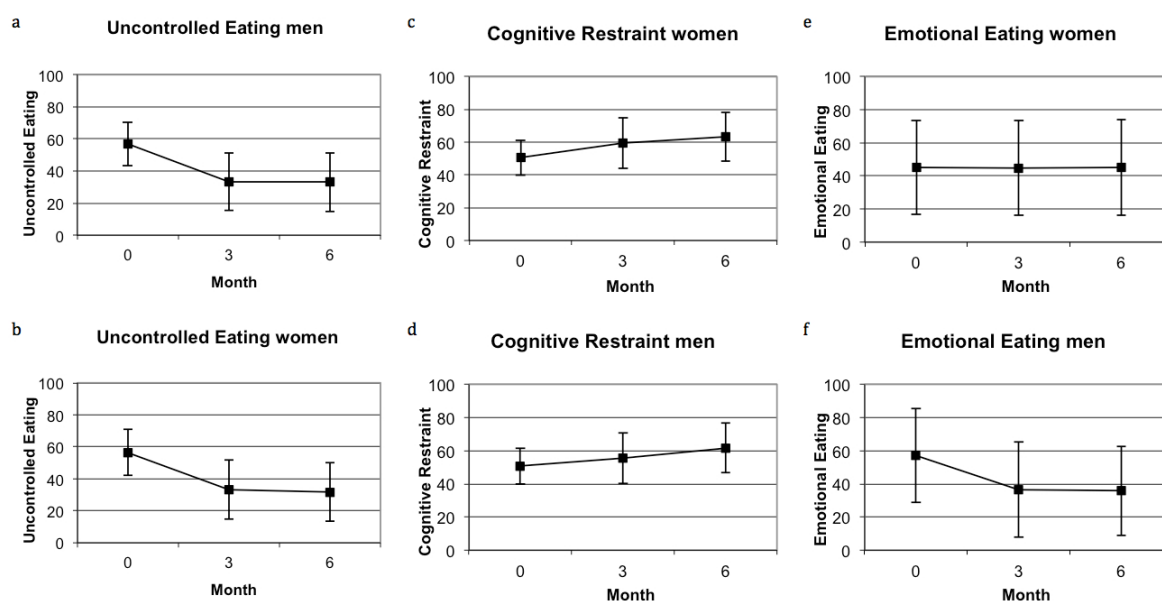
Our results suggest an association between change in eating behaviors and total weight loss among our completers. Weight loss was negatively correlated to changes in scores for emotional eating (women:  $r=-.12$ ,  $P=.01$ ; men:  $r=-.24$ ,  $P=.02$ ), suggesting

that reductions in emotional eating are associated with reductions in weight. Analogously, weight loss was negatively correlated to changes in scores for uncontrolled eating, although not significant for men (women:  $r=-.11$ ,  $P=.02$ ; men:  $r=-.19$ ,  $P=.07$ ), suggesting a possible association between reductions in uncontrolled eating scores and reductions in weight. Cognitive restrained eating scores increased during program participation and changes in the score were positively correlated to weight loss among our females ( $r=.11$ ,  $P=.01$ ), but not among males ( $r=.03$ ,  $P=.80$ ). Thus, results suggest a possible association

between reductions in weight and an increase in cognitive restrained eating score over 6 months in females.

We found no significant correlation for female or male completers between their total number of log-ins to the website and change in eating behaviors. The correlations were low between total log-ins vs change in emotional eating (women:  $r=-.02$ ,  $P=.63$ ; men:  $r=-.08$ ,  $P=.44$ ), uncontrolled eating (women:  $r=-.01$ ,  $P=.85$ ; men:  $r=-.09$ ,  $P=.36$ ), and cognitive restrained eating (women:  $r=-.01$ ,  $P=.80$ ; men:  $r=.01$ ,  $P=.89$ ).

**Figure 4.** Change over time in uncontrolled eating behavior a) among women (n=524) and b) among men (n=96). Change over time in cognitive restraint eating behavior c) among women (n=524) and d) among men (n=96). Change over time in emotional eating behavior e) among women (n=524) and f) among men (n=96).



## Discussion

In this Web-based weight loss program, eating behavior changed during the 6-month program participation. We found that male participants changed all eating behaviors; cognitive restrained eating scores increased over 6 months, whereas uncontrolled and emotional eating scores decreased. Among our female participants, cognitive restrained eating increased and uncontrolled eating decreased during the program.

The effect of sex with respect to emotional eating is controversial in existing research. In our cohort, there was no significant difference between male and female participants' emotional eating scores at baseline. We cannot exclude that an underlying selection process leading people to join the program may have affected baseline values, making them partially different from other cohorts in which different enrollment criteria were used. Interestingly, Ozier et al [40] found that men reporting high levels of emotional eating were almost 3 times as likely as women to be overweight. Because our participants were overweight at baseline, we were not able to make this comparison with respect to BMI and sex. However, Kontinen et al [41] reported greater tendencies among women to report higher emotional eating scores than men, a result also supported by Karlsson et al [26] in the Swedish Obese Subjects (SOS) study. In their study, half of all participants (n=4377) scored at

the top of the TFEQ emotional eating scale. Almost 40% of male participants and 60% of female participants reported high emotional eating [26]. Hence, prior literature is in disagreement regarding the effect of sex on emotional eating.

Interestingly, Péneau et al [42] reported that former or current dieters had higher scores of emotional eating compared to those who had never dieted. A possible explanation for this change is the tendency to restrict food intake during specific time periods with a high number of relapses, which may contribute to increased risk for overeating caused by emotional cues [42,43]. Presumably, the participants who took part in our Web-based weight loss intervention have had a similar history of dieting as those described previously. It is likely that our participants, before signing up to the Weight Club, characterized the behaviors of a dieter, which in turn may have contributed to the amplified emotional eating score at baseline. Our male participants scored 57.2 and our female participants scored 45.1 on the 100-point TFEQ scale. These scores are in-line with the scores of an obese Swedish sample (BMI 44.5 kg/m<sup>2</sup>) scoring eating behavior before gastric bypass with TFEQ [44]. Interestingly, in a community-based French cohort with leaner subjects who might have a different history of dieting (the average BMI among the male participant was 26 kg/m<sup>2</sup> and 25 kg/m<sup>2</sup> among the female participants) the scores for emotional eating were much lower in men (TFEQ score=22), whereas



women scored only slightly lower (TFEQ score=43) [37]. This may suggest that the background history of dieting should be considered in future weight loss interventions, particularly in men because it might affect the overall eating behavior and require personalized treatment methods to optimize weight loss.

Furthermore, the correlation between increased cognitive restrained eating behavior and weight loss for females that we found was put forward by Stunkard and Messick 30 years ago [18]. Other researchers proposed lowered BMI as a result of cognitive restrained eating behaviors [19-21]. Cognitive restrained eating has, for example, been reported to be associated not only with low energy intake in a randomized weight loss intervention study [45], but also with long-term weight loss [46]. An increased cognitive restrained eating behavior may generate an overall improved self-control over food intake [47,48]. However, it should be emphasized that our results on eating behaviors do not imply causality, although it is conceivable that behaviors related to cognitive restrained, uncontrolled, and emotional eating may have an impact on food intake and ultimately weight loss.

The present study comprised a baseline sample of 22,844 participants submitting data on baseline characteristics and TFEQ-R18. To our knowledge, this is the largest Web-based research study conducted on eating behaviors to date, even if our study demonstrates a high prevalence of participant attrition. Neve et al [49] reported that commercial Web-based weight loss programs generally show high attrition rates. The authors propose a relationship between higher nonusage attrition and age, exercise level, emotional eating habits, eating breakfast, and skipping meals. A careful drop-out analysis investigating when the participants left the study with respect to basic characteristics, health aspects, and TFEQ-scores would have strengthened our study. However, such an analysis is difficult to conduct in a commercial Web-based weight loss program due to our inability to control compliance.

The absence of a control group prevents us from concluding that the observed changes in eating behaviors actually occurred as a result of participating in our Web-based weight loss program. Besides, we did not see a statistical relationship between the frequency of log-ins and greater change in eating behavior. We cannot exclude the possibility that any dieting person would experience similar changes over a 6-month period. Or indeed, that the simple act of repeatedly answering questions about eating behavior may cause one to adjust one's eating behavior or cause an increased awareness of one's eating behavior, which would affect subsequent self-reports [50]. For example, recent evidence suggests that self-reports of emotional

eating reflect concern over emotional eating, rather than the actual act of eating when feeling emotional [22,51].

Our final analyses included a total of 620 participants, of which 96 were men. It is not surprising that more than 80% of our baseline participants were women; rather, this is a common phenomenon in health research [52]. Additionally, the completers in our study were older than the noncompleters, supporting previous research on age groups engaged in Web-based weight loss programs, in which older participants have shown higher compliance rates than younger ones [15,53,54].

According to recent statistics, Swedish citizens older than age 45 years are less likely to use the Internet on a daily basis compared to younger citizens, primarily due to lack of interest [55]. However, according to a report on Internet statistics, almost 90% of the Swedish population had access to the Internet in 2012 [55] suggesting high computer literacy in the Swedish population. Yet Web-based health interventions require certain levels of health technology literacy among the participants—the skills to read, understand, and personalize health information communicated via the Web and to be able to transform this information into action [56]. A selection of participants with high level of health technology literacy is thus possible in the present study. Therefore, older individuals who have access to the Internet may be an important target group in Web-based interventions because they seem more receptive to this type of intervention.

Although this study admits its limitations, our results add further understanding of baseline eating behaviors among overweight individuals and how eating behaviors changed during 6 months participating in a Web-based weight loss program. Enhanced knowledge about eating behaviors among individuals taking part in weight loss intervention programs might open opportunities for health professionals to personalize treatment and overall health care, meeting the needs and preferences of the target group.

This Web-based weight loss intervention suggests that eating behaviors (cognitive restrained eating, uncontrolled eating, and emotional eating) measured by TFEQ-R18 were significantly changed during 6 months of participation. Cognitive restrained eating scores increased and uncontrolled eating scores decreased among both male and female participants, whereas emotional eating scores only decreased among male participants. Our findings indicate differences in eating behaviors with respect to sex, but should be interpreted with caution because attrition was high.

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## Conflicts of Interest

Josefine Jonasson is employed part time by *Aftonbladet*, the Swedish newspaper the authors collaborated with to develop the weight loss program studied in this project. She was one of the dietitians in charge of the weight loss program. Stephan Rössner received consulting fees from *Aftonbladet* during the early development and design of the weight loss program.

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## Abbreviations

**BMI:** body mass index

**SOS study:** Swedish Obese Subjects study

**TFEQ:** Three-Factor Eating Questionnaire

**TFEQ-R18:** 18-item Three-Factor Eating Questionnaire Revised

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Original Paper

# Analyzing Engagement in a Web-Based Intervention Platform Through Visualizing Log-Data

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## Abstract

**Background:** Engagement has emerged as a significant cross-cutting concern within the development of Web-based interventions. There have been calls to institute a more rigorous approach to the design of Web-based interventions, to increase both the quantity and quality of engagement. One approach would be to use log-data to better understand the process of engagement and patterns of use. However, an important challenge lies in organizing log-data for productive analysis.

**Objective:** Our aim was to conduct an initial exploration of the use of visualizations of log-data to enhance understanding of engagement with Web-based interventions.

**Methods:** We applied exploratory sequential data analysis to highlight sequential aspects of the log data, such as time or module number, to provide insights into engagement. After applying a number of processing steps, a range of visualizations were generated from the log-data. We then examined the usefulness of these visualizations for understanding the engagement of individual users and the engagement of cohorts of users. The visualizations created are illustrated with two datasets drawn from studies using the SilverCloud Platform: (1) a small, detailed dataset with interviews (n=19) and (2) a large dataset (n=326) with 44,838 logged events.

**Results:** We present four exploratory visualizations of user engagement with a Web-based intervention, including Navigation Graph, Stripe Graph, Start-Finish Graph, and Next Action Heat Map. The first represents individual usage and the last three, specific aspects of cohort usage. We provide examples of each with a discussion of salient features.

**Conclusions:** Log-data analysis through data visualization is an alternative way of exploring user engagement with Web-based interventions, which can yield different insights than more commonly used summative measures. We describe how understanding the process of engagement through visualizations can support the development and evaluation of Web-based interventions. Specifically, we show how visualizations can (1) allow inspection of content or feature usage in a temporal relationship to the overall program at different levels of granularity, (2) detect different patterns of use to consider personalization in the design process, (3) detect usability issues, (4) enable exploratory analysis to support the design of statistical queries to summarize the data, (5) provide new opportunities for real-time evaluation, and (6) examine assumptions about interactivity that underlie many summative measures in this field.

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**KEYWORDS**

engagement; log-data analysis; data visualisation; Web-based interventions



## Introduction

Web-based interventions for improving health have burgeoned over the past 10 years as researchers aim to harness the reach and cost-effectiveness that the Internet promises [1-6]. However, obstinately high rates of attrition have kept them from reaching their potential [7,8]. As the corpus of research studies grows, there have been calls to develop a more scientific approach to the design and evaluation of Web-based interventions: a methodology that includes the analysis of engagement. One important aspect of such a methodology would be to support a more nuanced understanding of how users engage with Web-based interventions, or a science of engagement [9-11].

Previous research has focused on the summative measurement of engagement, such as level of adherence [12,13] or intervention exposure [14-16]. Researchers have also identified factors that correlate with adherence, including patient characteristics [17] (eg, gender), the context of delivery [18] (eg, classroom), aspects of the delivery [19] (eg, therapist support), and characteristics of the intervention itself [20] (eg, tailored content). Attempts to focus more directly on interactive technological elements of an intervention that may facilitate engagement have reported positive correlations between interactive feature inclusion and outcomes [21-24].

Such summative measures do not capture the temporal elements of engagement needed to provide insight into the design of Web-based interventions. This is echoed in recent work that has demonstrated that there is not a linear relationship between usage (either adherence or exposure) and outcome [25]. Rather, a substantial amount of variance seen in adherence between studies can be explained by the characteristics of the Web-based intervention, that is, interactive technological elements [26]. These two findings taken together suggest that it is essential to understand the temporal process of engagement or patterns of use.

Log-data analysis, similar to that used in the analysis of websites in other domains [27], provides a way to capture patterns of use. Log-data has been used, for example, to illustrate changes in frequency of feature usage over time (eg, feedback messages) as well as staged feature usage (eg, starting a mindfulness exercise, but not downloading it) [28]. These authors propose further work on how content/feature integration and intra-usability of features can enable engagement. Such work raises the question of how to capture patterns of use in a way that defines engagement as more than a sum of individual content or feature element usage.

The challenge of using log-data to understand the process of engagement lies in organizing it for productive analysis. In this paper, we present a set of visualizations that capture the process of engagement for individuals and cohorts. The aim of the paper is to stimulate a discussion on ways that log-data can be used to understand user engagement for the explicit purpose of Web-based intervention design.

## Methods

### Data Visualization: Information Visualization

Information visualization can be defined as “the use of computer-supported, interactive, visual representations of abstract data to amplify cognition” [29]. Information visualization can be used either to explore or communicate a set of data [30]. We apply exploratory sequential data analysis [31] to highlight sequential (or temporal) aspects of the data, such as time or module number, that can provide insights into engagement. While this approach has been applied to log-data analysis for session events grouped into a small number of distinct categories [32], there are no precedents for representation of continuous data.

When designing visualizations, it can be helpful to consider Schneiderman’s information seeking mantra: “Overview first, zoom and filter, then details-on-demand” [33]. This can be applied to a single visualization or to linking a series of visualizations. For example, a visualization that depicts navigation paths for an individual could show an overview of all sessions, enable zooming on a particular session, or selecting details of a specific event, or user action. Alternatively, a visualization of usage over time for an entire cohort could support filtering (eg, by gender or initial depression score), and details-on-demand linking to a visualization of an individual’s temporal navigation patterns.

### Data

Data used in the visualizations are drawn from two studies using the SilverCloud platform, which is described below. The first dataset is from a small pilot trial of the SilverCloud platform in a primary-care mental health setting in the United Kingdom [34]. Outcome data, log-data, and interview data were captured for 19 participants. The combination of data allows us to explore engagement patterns of individuals in depth. To complement this small, detailed dataset, we used a larger dataset drawn from the usage of the same intervention in a university setting [35]. The second dataset contains 326 participants, and over 44,838 logged events, which allows us to explore the issues surrounding visualization of a larger cohort.

### Data Transformation Steps

Exploratory sequential data analysis involves the successive transformation of raw data sequences until the product enables statements to be made that answer research or design questions [31]. In this case, the original log-dataset included user ID, time-stamp, and page URL (uniform resource locator) of every action completed, such as reading a content page, saving a journal entry, or updating an activity. The first data processing step was to transform the URLs into meaningful labels. Content page URLs were assigned labels that indicated sequential order. For example, a URL ending with “content/9/54/93/” can be mapped to “Module 2 Subsection 1” or more briefly “2.1”. URLs for features, such as “Journal” or “Mindfulness”, were renamed as such.

The next data processing step is to identify sessions, defined as repeated interaction with the system over an interval of time. To avoid counting periods when the user was not actively

engaged with the system, any period of inactivity longer than a threshold starts the count on a new session. The threshold is configurable, and for the examples presented here, a value of 60 minutes is used. The threshold has been set to make allowance for users watching videos repeatedly or taking time to compose longer textual entries for certain exercises. As session time is not a feature in these visualizations, the impact is only in the segmentation of the data into different sessions. A shorter threshold may be appropriate for some interventions or for visualizations where session time is the focus to avoid overestimation of session time.

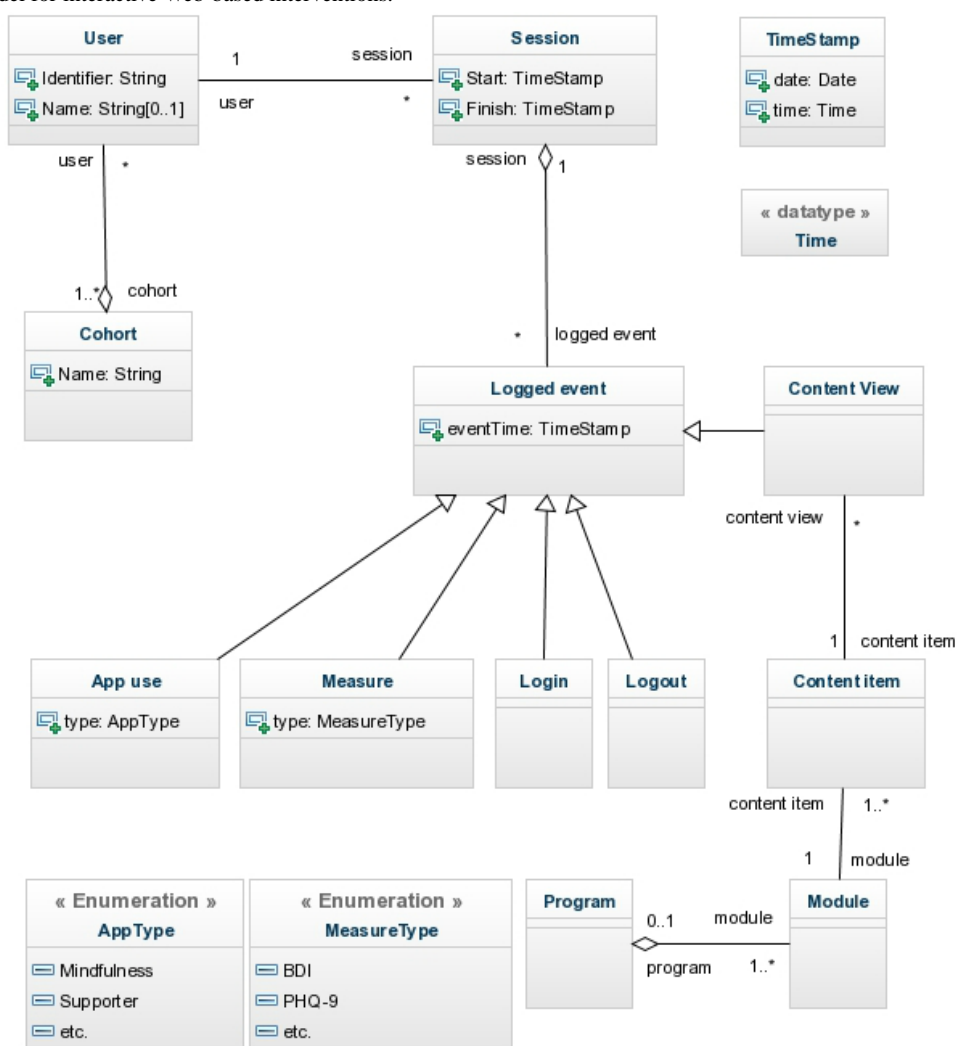
Each of the individual visualizations entail further transformations of this data, building on these first two steps. These included extracting usage days and first and last content-viewing events within each session for example.

## Visualization Tools

The programs used to produce the visualizations in this paper were developed in the *processing* language and have been made freely available. Applying these visualizations to another dataset requires two elements: (1) a data file that includes user ID, time-stamp, and event identifier (eg, URL), for all actions, and (2) a key file that maps event identifiers to meaningful labels and their intended sequential use, and differentiates between content and other features. The event identifiers will commonly be in the form of URLs, but other formats might be used. Identifiers do not need to be unique—several URLs might map to the same piece of content.

One program processes the data and outputs a number of spreadsheets that can be checked for correctness as detailed in the readme file. The other programs produce the visualizations presented below. Figure 1 is the data model underlying the visualizations considered in this paper. The full code and a small amount of test data are available in [Multimedia Appendix 1](#).

**Figure 1.** Data model for interactive Web-based interventions.



## Web-Based Intervention: The SilverCloud Platform

The data used to develop these visualizations are drawn from studies that used the SilverCloud platform. SilverCloud is a media-rich, Web 2.0 platform that can be used to quickly build

interactive Web-based interventions for common mental health problems. It is specifically designed to improve engagement through the following design strategies:

- **Personalization:** Users are encouraged to draw together all strands of the intervention and build their own plan or “toolbox” for staying well and managing current and future mood difficulties.
- **Interactive exercises:** Users can engage with the range of media, such as interactive quizzes, video presentation, Web-based exercises and activities, homework, and mobile diary-keeping. These are meant to encourage reflection and personalization of the information offered in the intervention.
- **Guidance and support:** Though mainly self-directed, each user in the program is assigned a supporter who provides feedback at specified intervals throughout the intervention on the activities that the user has chosen to share.
- **Social features:** Users can gain a sense of other people using the system by seeing how many people liked an activity, or by sharing answers to an activity that are visible to all after moderation.

Each module is structured in an identical way and incorporates introductory quizzes, videos, informational content, interactive activities, as well as homework suggestions and summaries. In addition, personal stories and accounts from other clients are incorporated into the presentation of the material.

SilverCloud is an interesting source of data as there are a variety of types of user interaction with the system to explore. As a platform, the focus is on the technology elements (design strategies) that structure the intervention, rather than the content.

The sample platform can be used to deliver a range of programs (eg, depression [36] and anxiety [37]). A more detailed description of the implementation for depression (MindBalance) is available in Sharry et al [35], including a video overview.

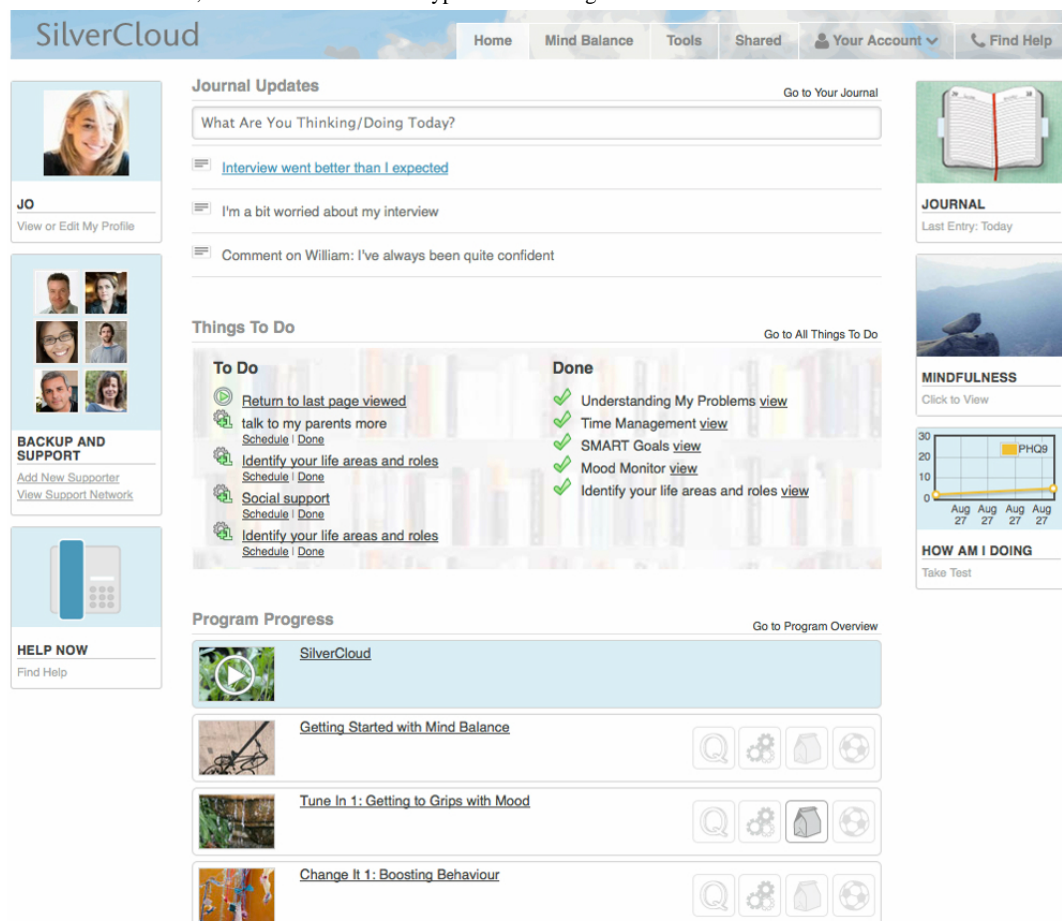
### Focus of Visualizations

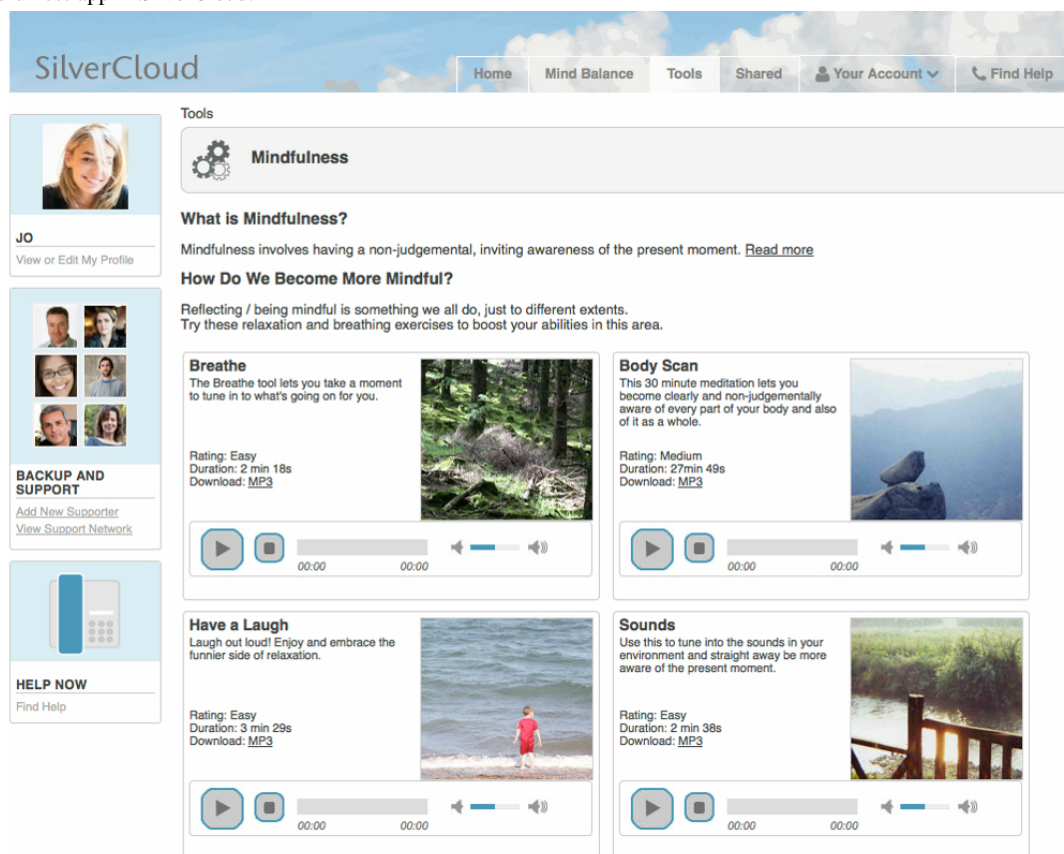
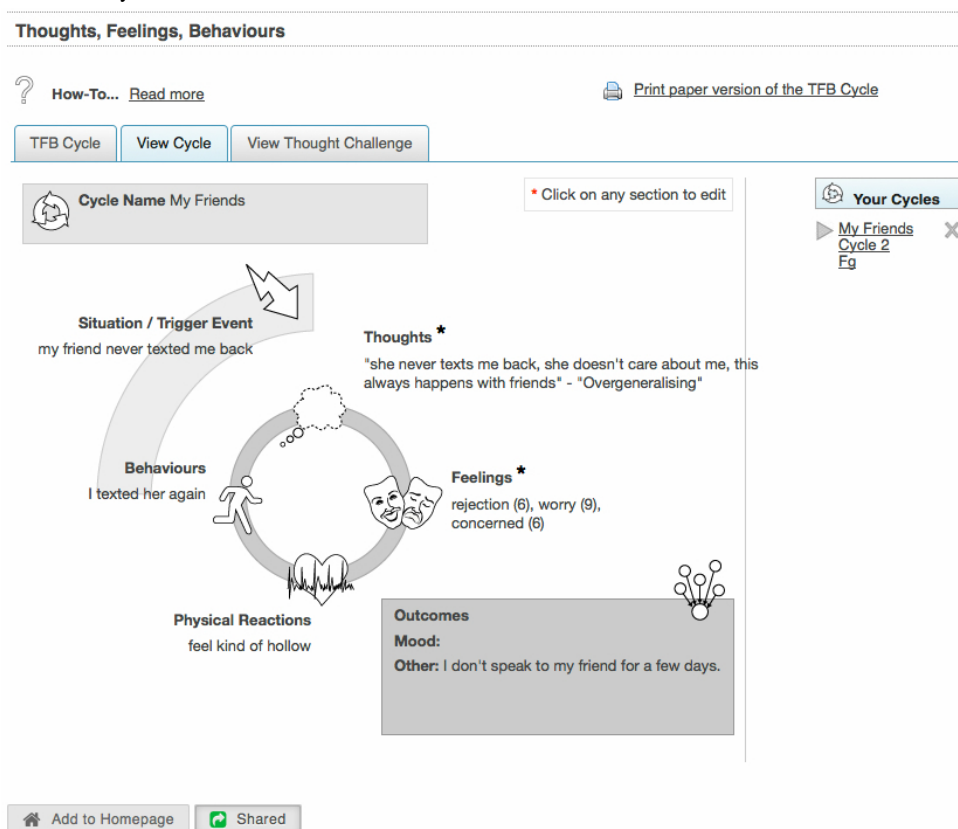
There are three aspects of the SilverCloud platform that feature prominently in the visualizations we discuss in this paper. First, user navigation possibilities are multiple. It is possible to take a linear approach, clicking the forward arrow to get to the next page or activity planned by the content designer. It is also possible to choose one's own path through the intervention, selecting which module and submodule to start with. The latter approach is similar to navigating a webpage.

Second, apps are used to support the engagement with content. These include an interactive journal, recordings of mindfulness activities, as well as interactive activities, such as creating a “Thoughts, Feelings, Behaviors” cycle. Some of the apps contain material that can be downloaded and used offline. Third, support is provided by weekly reviews. The client's supporter, generally a health professional, reviews the content that the client has shared and provides encouragement and guidance. A supporter might recognize and articulate the efforts a client has made, or suggest a particular content page or activity.

Figures 2-4 illustrate the three main aspects of the user interaction with SilverCloud just described that will be discussed in the example visualizations: (1) user navigation, (2) apps, and (3) reviews.

**Figure 2.** SilverCloud Home Screen, which enables different types of user navigation.



**Figure 3.** Mindfulness app in SilverCloud.**Figure 4.** Screenshot of an activity that can be shared for review.



## Results

### Overview

Four visualizations are presented in this section. The first, Navigation Graph Visualization, illustrates the temporal process of engagement by an individual. The second, third, and fourth visualizations aggregate specific aspects of this first one over an entire cohort. Stripe Graph Visualization illustrates the temporal pattern of use over the intervention period for individual users but is compact enough to be stacked, allowing usage across a cohort to be examined and compared. Start-Finish Visualization depicts the shape of users' sessions across a cohort, showing the starting and finishing content page of each session. Finally, Next Action Heat Map Visualization aggregates the navigation path through the intervention.

### Navigation Graph Visualization

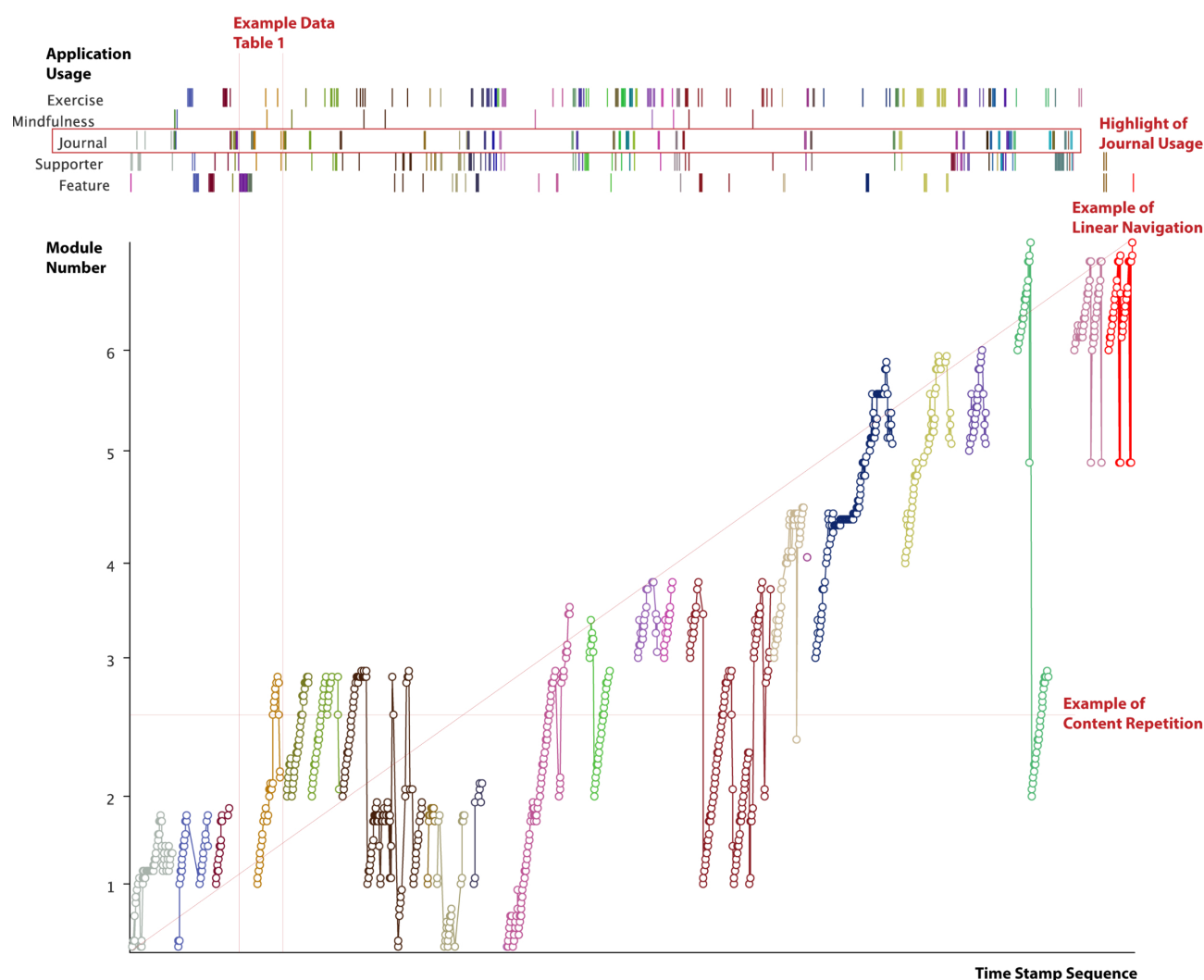
#### Description

The Navigation Graph Visualization in Figures 5-7 depicts an individual's temporal process of engagement with the content

and interactive features embedded in apps. It consists of two parts: a line graph of content usage and a stripe graph of application usage across the top. The interactive version includes a vertical bar cursor that enables one to line up events between the line and stripe graphs. The horizontal axis shows each content page viewed or app used in sequential order. Sessions are demarcated by space and color. Each content page is marked by module number followed by content page number. For example, 4.3 is the third content page in module 4. Across the top are five categories of apps in the SilverCloud platform: In-content exercise, Mindfulness applications, Journal usage, Review provided by a supporter, and Other interactive features (eg, quizzes). These are temporally sequenced with content usage. The data are taken from both datasets. Table 1 provides a sample of the log-data used to generate the visualization.

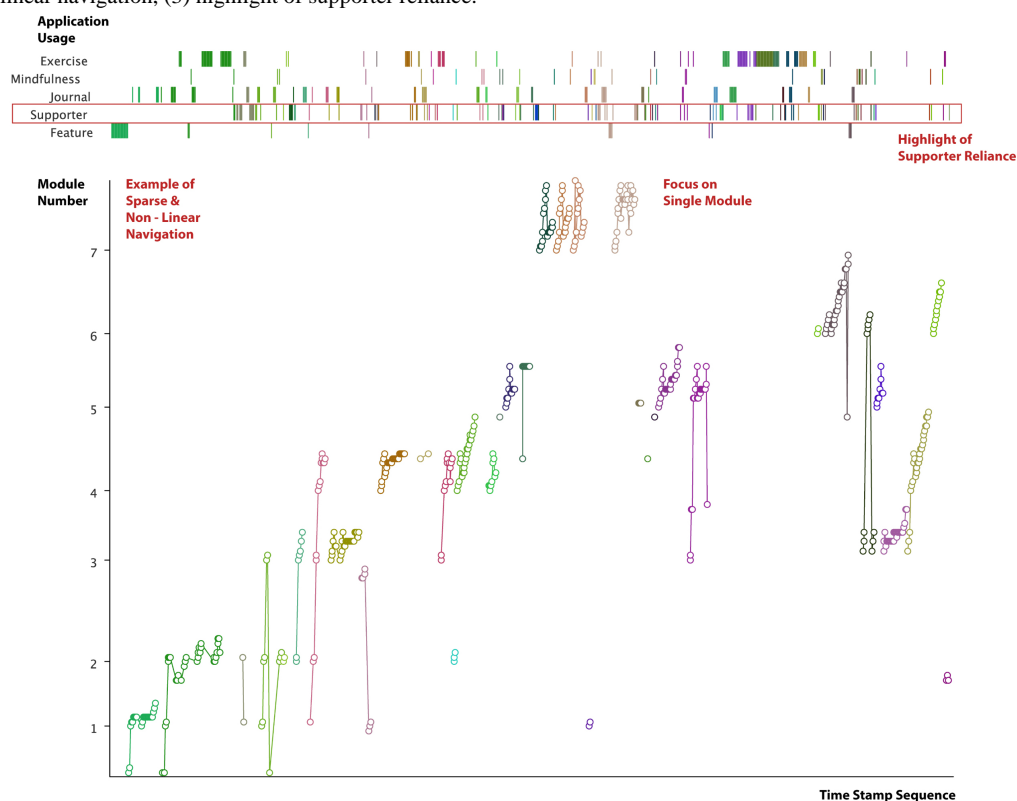
The Navigation visualization captures a substantial amount of information about an individual's pattern of use. At a glance, it is possible to see (1) range of content viewed in a session, (2) repetition of content in a session and across sessions, (3) linearity of content viewed within and across sessions, (4) app usage over time, and (5) interspersal of apps and content.

**Figure 5.** Navigation Graph Visualization showing pattern of use trajectory of a user through SilverCloud: (1) graph section that relates to example data in Table 1, (2) example of content repetition within and between sessions, (3) example of linear navigation, (4) highlighted journal usage.

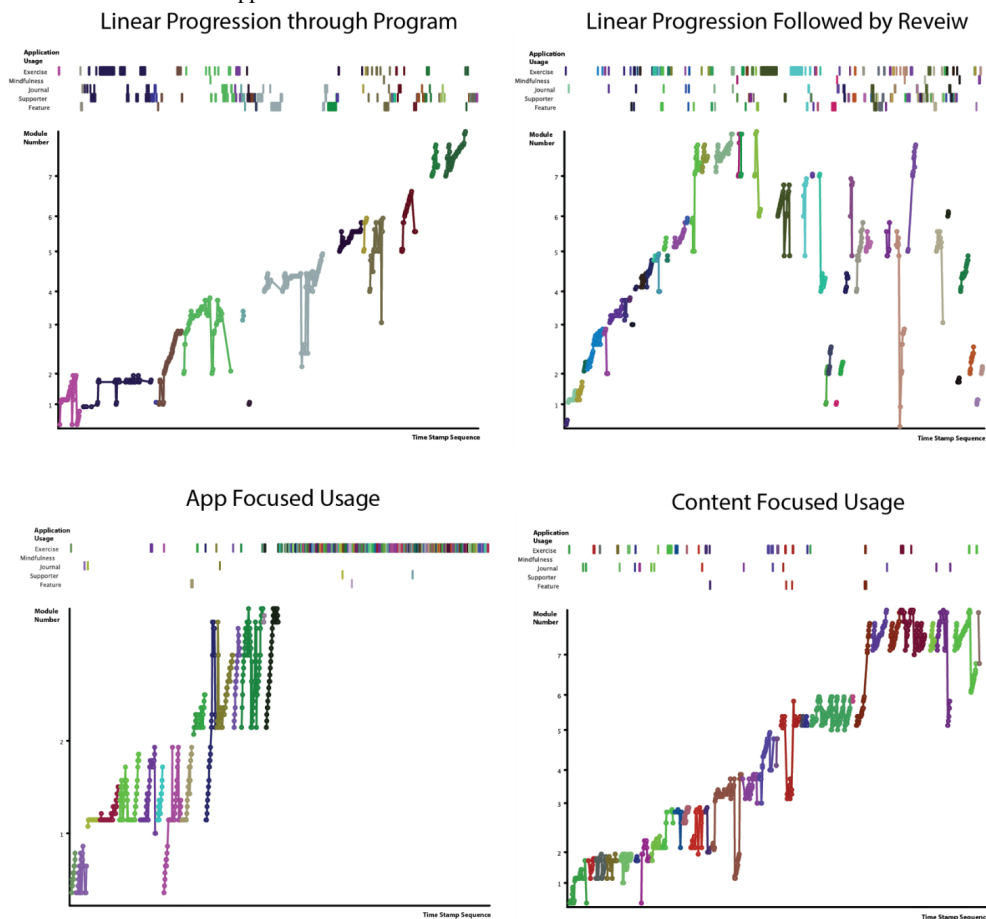




**Figure 6.** Navigation Graph Visualization showing pattern of use trajectory of a user through SilverCloud: (1) focus on a single module, (2) example of sparse and non-linear navigation, (3) highlight of supporter reliance.



**Figure 7.** Navigation Graphs Visualization showing 4 different pattern of use trajectories: the top two highlight linear progression versus exploration and review, and the bottom two contrast an app focus to a content focus.



**Table 1.** Log-data from one session of user Janet, as marked in Figure 1.

Raw log-data			Generated data	
D	Date and time	URL (website address omitted for brevity)	Sequence assign- ment	Session number
8	08/03/2012 12:47		Home	4
8	08/03/2012 12:47	bns/main/	Feature	4
8	08/03/2012 12:47	bns/1239/updateItem/	Feature	4
8	08/03/2012 12:47	bns/1230/updateItem/	Feature	4
8	08/03/2012 12:47	bns/1230/updateItem/	Feature	4
8	08/03/2012 12:47	bns/1228/updateItem/	Feature	4
8	08/03/2012 12:47	bns/1241/updateItem/	Feature	4
8	08/03/2012 12:48	journal/add/	Journal	4
8	08/03/2012 12:48	journal/	Journal	4
8	08/03/2012 12:49	journal/1537/delete/	Journal	4
8	08/03/2012 16:41		Home	4
8	08/03/2012 16:41	journal/	Journal	4
8	08/03/2012 16:47	journal/add/	Journal	4
8	08/03/2012 16:47	journal/	Journal	4
8	08/03/2012 16:47	apps/share	Supporter	4
8	08/03/2012 16:47		Home	4
8	08/03/2012 17:18	content/9/53/238/	1	4
8	08/03/2012 17:18	apps/40/i	1.0.1	4
8	08/03/2012 17:18	content/9/53/92/	1.1.0	4
8	08/03/2012 17:18	92-mind-balance-basics/#carousel11	1.1.0	4
8	08/03/2012 17:18	92-mind-balance-basics/#content2	1.1.1	4
8	08/03/2012 17:18	92-mind-balance-basics/#content3	1.1.2	4
8	08/03/2012 17:18	92-mind-balance-basics/#content4	1.1.3	4
8	08/03/2012 17:18	/content/9/53/98/	1.2.0	4
8	08/03/2012 17:18	98-personal-stories/#carousel1	1.2.0	4
8	08/03/2012 17:18	98-personal-stories/#carousel2	1.2.1	4
8	08/03/2012 17:18	98-personal-stories/#carousel3	1.2.2	4
8	08/03/2012 17:18	content/9/53/104/	1.3.0	4
8	08/03/2012 17:18	apps/42/i	1.3.0	4
8	08/03/2012 17:18	apps/41/i	1.3.1	4
8	08/03/2012 17:18	104-activity/#subconcept2	1.3.1	4
8	08/03/2012 17:20	apps/41/addItem	Exercise	4
8	08/03/2012 17:20	104-activity/#subconcept3	1.3.2	4
8	08/03/2012 17:21	apps/14/	Mindfulness	4
8	08/03/2012 17:21	apps/42/i	1.3.0	4
8	08/03/2012 17:21	apps/41/i	1.3.1	4
8	08/03/2012 17:21	104-activity/#subconcept2	1.3.1	4
8	08/03/2012 17:22	content/9/54/239/	2	4
8	08/03/2012 17:22	apps/33/i	2.0.1	4
8	08/03/2012 17:24	content/9/54/93/	2.1.0	4

Raw log-data			Generated data	
ID	Date and time	URL (website address omitted for brevity)	Sequence assignment	Session number
8	08/03/2012 17:24	apps/33/i	2.0.1	4
8	08/03/2012 17:25	apps/33/i	2.0.1	4
8	08/03/2012 17:27	apps/33/update	2.0.1	4
8	08/03/2012 17:27	content/9/54/93/	2.1.0	4
8	08/03/2012 17:27	content/9/54/99/	2.2.0	4
8	08/03/2012 17:27	content/27-tune-1/99-personal-stories/#carousel1	2.2.0	4
8	08/03/2012 17:30	content/27-tune-1/99-personal-stories/#carousel2	2.2.1	4
8	08/03/2012 17:30	content/27-tune-1/99-personal-stories/#carousel3	2.2.2	4
8	08/03/2012 17:30	content/27-tune-1/99-personal-stories/#carousel4	2.2.3	4
8	08/03/2012 17:31	content/27-tune-1/99-personal-stories/#carousel5	2.2.4	4
8	08/03/2012 17:31	content/9/54/105/	2.3.0	4
8	08/03/2012 17:31	content/9/54/105/	2.3.0	4
8	08/03/2012 17:31	apps/15/i	Exercise	4
8	08/03/2012 17:31	apps/2/i	2.3.1	4
8	08/03/2012 17:31	content/27-tune-1/105-activity/#subconcept1	2.3.0	4
8	08/03/2012 17:31	content/27-tune-1/99-personal-stories/#carousel1	2.2.0	4
8	08/03/2012 17:33	93-getting-grips-mood/#subconcept2	2.1.1	4
8	08/03/2012 17:35	93-getting-grips-mood/#subconcept3	2.1.2	4
8	08/03/2012 18:16	journal/add/	Journal	4
8	08/03/2012 18:16	apps/share	Supporter	4
8	08/03/2012 18:17		Home	4
8	08/03/2012 18:46		Home	4
8	08/03/2012 18:46	journal/	Journal	4

## Examples

Figures 5 and 6 show the Navigation Graph Visualization from Janet and Robert, respectively. Janet and Robert are two persistent users who had more than 58 sessions each. Both reported substantial benefit from using the intervention. Comparing the visualizations immediately shows that these two users had very different patterns of use.

Janet viewed all of the content pages in a module. We can also see that she repeated content both within a session, as in session 2, and across sessions, as with 2, 3, 4, 7, 10, and 14. Otherwise, Janet took a relatively linear path through the content, looking at the next recommended page. Looking at app usage, the Journal was used at the beginning or end of most sessions. Janet also used the Mindfulness apps and read the Reviews by her supporter.

Robert, on the other hand, had a very different pattern of use. App usage was more prevalent than content usage. The latter was sparse and jumped around across modules. There was, however, substantial focus on the Core Beliefs module, which was done four times in detail. The number of times a Review was viewed ( $n=28$ ) is striking as only 8 reviews were written.

The most interesting aspect of these visualizations is their diversity. Janet progressed in a more or less linear manner through the content, while Robert jumped around. Janet focused on content and Robert on apps. This difference emphasizes that not all users move through the content in the linear order planned but find their own pathways when allowed. This difference can be seen in a more extreme fashion in the 4 users portrayed in Figure 7.

These visualizations provide an interesting contrast with feedback garnered from interviews. Janet described her use of the application as reading every page but never looking back. Although the log-data indicate that she does indeed read every page, she also repeated a substantial amount of material. This would not be obvious without the visualization. Robert, in contrast, found it difficult to concentrate and said that he clicked around until he found something that he could relate to. Again, although this is indeed true, the log-data indicate that content in all modules was viewed. These examples indicate that people's usage may not be as straightforward as they describe.

There are some perspectives that the visualization cannot capture. Without interviewing users, we would not know that Janet treated the intervention like a course to be completed and

Robert saw it as his sanctuary to help him through sleepless nights. This explains their different patterns of engagement with the content. A further issue is that some of the apps, such as the Mindfulness exercises, could be run in the browser or downloaded. Robert reported listening to these exercises daily from downloaded versions. We cannot capture such elements of intervention use in the log-data.

The visualizations in Figure 7 make apparent very different pattern of use trajectories that would be hard to detect through manual inspection of the data. From these extreme cases, we can tease out important dimensions of patterns of use. The top two examples illustrate that content review is an important element of usage. In the left example, review is done per session, and in the right example, it is done after all the content has been viewed. These examples stand in contrast to enforced linear use in many Web-based interventions and suggests that some summative measures, such as module completion, may not always be appropriate.

The bottom two graphs of Figure 7, in conjunction with Figures 5 and 6, give us more insight into how people interweave content and interactive feature usage (referred to as intra-usability of features [28]). In Figure 7, we can see extreme cases of app-focused and content-focused usage showing the importance of preference in how people engage. Figures 5 and 6 also show these contrasting preferences to a lesser extreme with clear routines emerging quickly. Janet consistently used the diary at

the beginning or ends of most sessions for example. By looking at the data presented in the visualization, we get a fuller picture of engagement throughout the application.

These examples draw attention to avenues for future design as well as assumptions commonly made in the evaluation of Web-based interventions. For example, knowing that people return repeatedly to content they find relevant to them, we might look at ways of “refreshing” this content, by presenting new examples or personal stories. When evaluating interactivity, these graphs can help move beyond the idea of isolated feature usage. We could, for example, look at where in the session that features are being used to see if there are patterns that encourage either the quantity or perhaps quality of engagement.

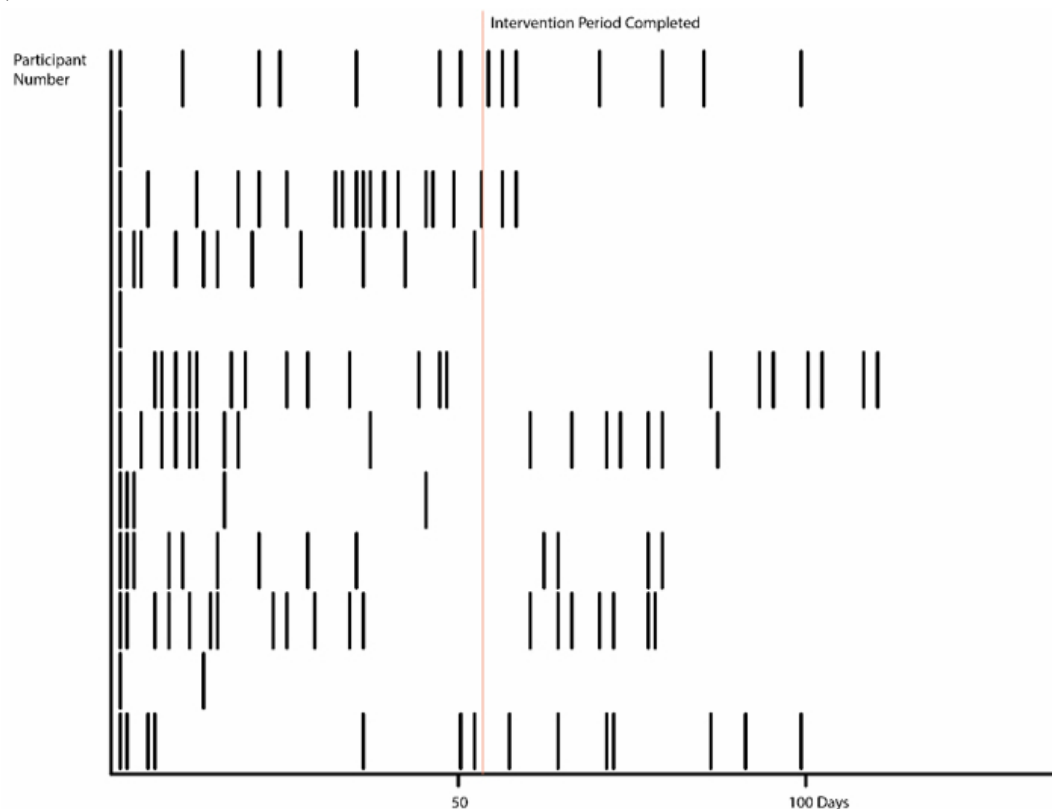
## Stripe Graph Visualization

### Description

The Stripe Graph Visualization in Figure 8 isolates temporal use of the Web-based intervention over the treatment period and makes it comparable in a cohort of users. The horizontal axis is days, and the users are stacked on the vertical axis. A bar is placed on each day of the treatment period in which the intervention is used. The data used to generate this graph are participant ID and date. The data are excerpted from the large dataset.

This visualization captures (1) length of use and (2) consistency of use.

**Figure 8.** Stripe Graph Visualization showing temporal representation of intervention use by individuals in a cohort (y-axis) over days in the treatment period (x-axis).



### Example

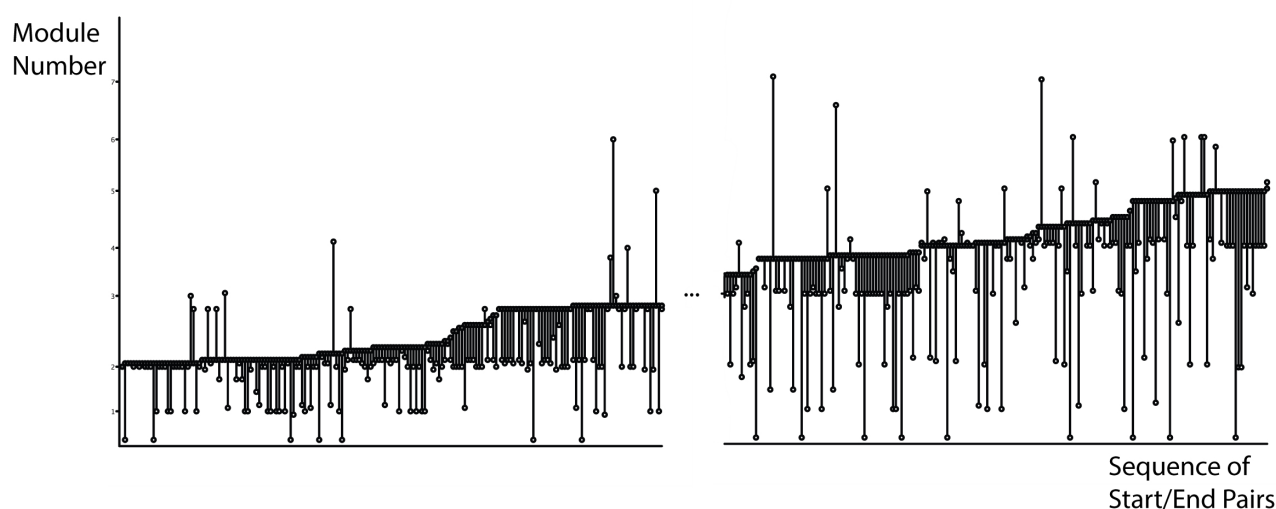
The example in Figure 8 shows 12 users. What is most striking about the visualization is that many people used the intervention

in bursts sometimes with long periods in between. This is a different pattern of usage than the consistency assumed in most adherence metrics. From a design perspective, this prompts

consideration of the engagement goal—is it to make users come back each week or is it to ensure that each burst leaves the user with something to do or think about that is likely to lead to changes in behavior?

It is also interesting to note the significant level of usage beyond the formally supported 8-week period. Most studies tend to focus on the formally defined usage period associated with their post-intervention outcome measures. This suggests that other ways of collecting post-intervention data may be relevant. The visualization is also interesting from a design perspective, suggesting that there may be value in exploring how people use SilverCloud without online guidance after the formal intervention period, in order to provide appropriate support.

**Figure 9.** Start-Finish Graph showing plot of start page (light circle) and end page (dark circle) for each session for all users sorted by end page.



### Example

This visualization does not have stepped rows that would suggest people complete one module in a sitting. Instead, we observe that many users did not start at the beginning of one module and stop at the end. Some took several sessions to complete a module, while others did several in one sitting. This is an interesting finding given that many interventions measure their usage through module completion.

This visualization can also support the design process by looking for common break points. We can see, for example, that more people seemed to stop at intermediate points between modules 4 and 5 than modules 2 and 3. This finding could prompt a usability evaluation at this point. Taken in conjunction with data in Figures 7, 8, and 10, which suggests that engagement wanes at the end of the intervention, we could also explore different engagement strategies at this point. In this case, the visualization is acting as pointer to further design and evaluation work.

### Next Action Heat Map Visualization

#### Description

The Next Action Heat Map Visualization explores the linearity of Web-based intervention use for an entire cohort. This visualization plots for any given content page the likelihood of going to another content page, creating a heat map. The

### Start-Finish Graph Visualization

#### Description

The Start-Finish Graph Visualization in Figure 9 plots each user's starting and finishing content page viewed for every session. It provides an aggregate visualization for session usage of the Web-based intervention. In this case, we have sorted the data points by module number of finishing page visited. The data are excerpted from the large cohort with sections removed to fit the page (the software version can be scrolled).

This visualization captures (1) amount of content covered in individual sessions, (2) direction of content usage, and (3) overlap of module completion.

horizontal axis is the module number identifying the content page and the vertical axis is that of the next page view. If participants were required to navigate the intervention in a single pre-defined manner, then a red diagonal line would form from the lower left corner. We would call this linear use. Places where the data points spread out indicate where users have taken alternative routes. The points across the top and right side are apps usage, showing how they intersperse with content.

This visualization captures (1) linearity of use and (2) potential usability problems.

#### Example

We can observe that in Figure 10, there was the strongest page-by-page usage in module 1, the first content module, with a similar trend to a lesser extent in modules 2 and 3. Many people did not complete module 0—the introduction to the intervention. The review and optional modules, 6 and 7 respectively, were also not done as frequently. The red dots that come at the beginning of modules 1, 2, and 3 in the top row, indicate that people were doing the interactive exercises in the modules consistently. On the other hand, we can see that people were taking advantage of the multiple routes in each module, focusing on content that was of most interest and moving back and forth from apps.

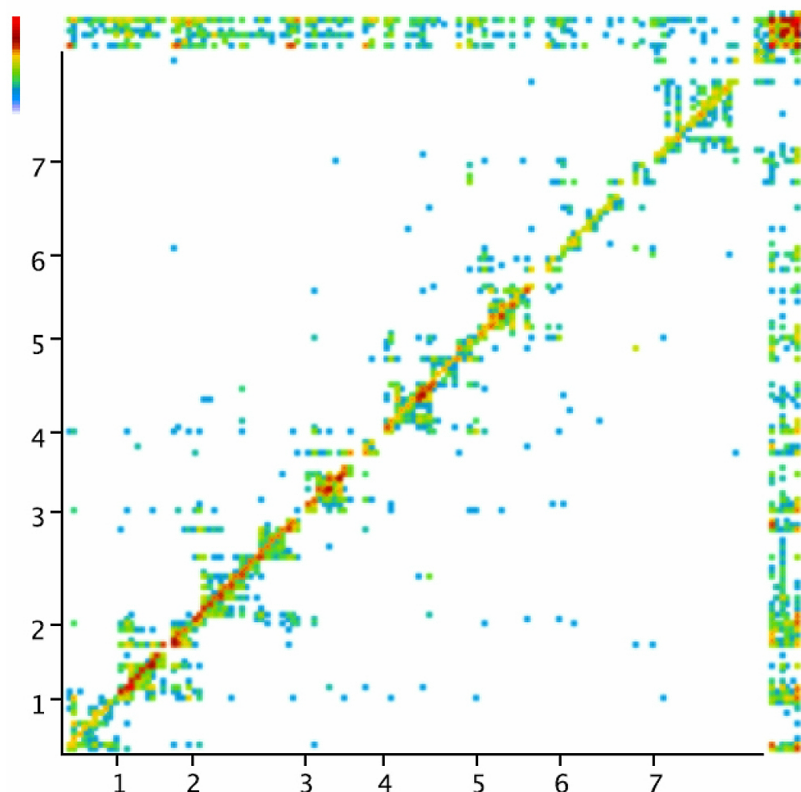
What we find most provocative about this visualization is the demonstration that people used the multiple navigation pathways



while still finding the proposed navigation useful. This visualization might have also indicated usability issues apparent with large gaps in the linear navigation. In this case, the gaps corresponded to optional content where multiple different examples were available in a carousel to illustrate the same point (up to 10 examples in some cases). While we did not identify any usability problems for this intervention, this is not surprising given the sustained iterative development process that was carried out before these visualizations were created.

The challenge of this kind of visualization is to organize the raw data in such a way that artefacts do not appear. In this example, we see blue dots (low frequency usage) at random points, jumping from modules 1 to 5 for example. While this may happen on occasion if someone is clicking around trying to re-find something, it can also happen because the Mindfulness app can be reached from a number of locations without any indication in the log-data. At the time of application development, it was not considered that apps accessed from multiple locations should have separate URLs for ease of tracking interaction.

**Figure 10.** Next Action Heat Map Visualization showing a plot of the likelihood of going from one content page to another: horizontal axis is the module number identifying the content page and the vertical axis the next page view. A red diagonal line would form from the lower left corner if the intervention could only be navigated in a single pre-defined manner.



## Discussion

### Principal Results

We have presented four visualizations of user engagement with a Web-based intervention: Navigation Graph, Stripe Graph, Start-Finish Graph, and Next Action Heat Map. These four visualizations provide a novel way to interrogate the patterns of use through log-data of individual usage and specific aspects of cohort usage. We offer these as an alternative view on user engagement with a Web-based intervention than more commonly used summative measures. In this discussion, we articulate how understanding the process of engagement through visualizations can support the design and evaluation of Web-based interventions.

### Design

The visualizations provide examples of how those authoring interventions can inspect the data at different levels of

granularity to improve engagement. The Navigation Graph draws attention to strategies that people employed to revisit material. Authors can inspect numerous examples to give them understanding of different ways that material is viewed with in the temporal relationship to the overall intervention. These patterns can then be inspected in the aggregate using the Heat Map Visualization. Alternatively, the intuition afforded by inspecting the data visually can provide the basis for constructing statistical queries on the log-data.

The visualizations of individual patterns of use afford the opportunity to consider personalization in the design process. It is striking how diverse individual patterns of use are in Figures 5-7. This finding indicates that a search for the “best” interactivity may be the wrong line of inquiry. Rather, Web-based interventions need to be designed to enable personalized usage without overwhelming the user with too many options or a lack of direction. It may also be possible to identify different styles of use that could support the tailoring

of specific aspects of the intervention. As in the previous example, these visualizations have helped articulate appropriate research questions for pursuing better engagement.

The visualization can also help detect usability issues that may mask the underlying effectiveness of the intervention. Both the Start–Finish Graph and the Next Action Heat Map quickly highlight large trends in cohort navigation. If many people are stopping mid-way through a module in the Start–Finish Graph, it suggests that people are losing interest at this point. It may be that the intervention designers need to consider strategies for engagement at this point. Similarly, large breaks in the Next Action Heat Map indicate that many people are following routes other than proposed, highlighting a potential usability or content issue.

Log-data visualization is likely to be most useful in conjunction with other types of data. For example, it can offer a representation to support the elicitation of experience through qualitative interviewing [38] to understand why people used the intervention a particular way. It could also be used as a method of exploratory analysis before the creation and calculation of engagement statistics, a technique currently being developed by Kelders & Gemert-Pijnen [39]. Log-data visualization can, with other methods, add to the richness of understanding engagement needed to support the iterative design approach for complex interventions [40].

## Evaluation

Log-data visualization offers a way to inspect the assumptions of usage embodied in evaluation metrics and criteria. The visualizations presented here question the implicit assumption of linear usage that underpins summative adherence metrics such as intervention completion or module completion. For example, the Stripes Graph shows the adherence is often not consistent but comes in bursts, suggesting that measures of adherence calculated based on weekly usage should not be considered in isolation. The Navigation Graphs and the Start–Finish Graphs both suggest that module completion may not be an accurate reflection of engagement either.

Usage visualizations also offer a different perspective on interactivity. The Navigation Graph, for example, illustrates the back and forth nature of content intake and interactive activities. Comparing different users, we can also see preferences for certain types of interactivity are highly specific to the individual. This view of the data enables a more nuanced conceptualization of engagement, shifting from what content people see, to what content people interact with. This is an important distinction for researchers concerned with the quality of engagement. It also provides a view of interactivity that goes beyond its reduction to individual feature usage.

Log-data visualization also provides new opportunities for evaluation. Summative clinical trials alone are unlikely to provide the flexibility needed to address the continuing ongoing refinement of Web-based interventions. Approaches are required that can adjust to the speed of technology evolution and provide outcome data appropriate to the varied settings and configurations in which a Web-based intervention may be used

in practice. Engagement visualizations can allow continual assessment of an intervention as it is changed to incorporate new technologies or adapted to new settings. Visualizations could potentially underpin a more dynamic model of evaluation. Further work would be needed to determine the best visualizations for this purpose.

## Conclusions

The science of engagement is in its infancy. There is much that could be done in the sphere of visualization depending on the size of dataset, granularity of analysis, and motivation for looking at the log-data. Understanding the experience of an individual user (perhaps correlating with qualitative feedback) is at one end of the spectrum, whereas understanding patterns of engagement for a particular demographic would be at the other end. Other uses, such as by clients themselves to reflect upon their own patterns in relationship to the intervention are also possible.

We offer these visualizations as a demonstration of some of the benefits of understanding engagement through log-data. Specifically, we show how visualizations can (1) allow inspection of content or feature usage in a temporal relationship to the overall program at different levels of granularity, (2) detect different patterns of use to consider personalization in the design process, (3) detect usability or content issues, (4) enable exploratory analysis to support the design of statistical queries to summarize the data, (5) provide new opportunities for real-time evaluation, and (6) examine assumptions about interactivity that underlie many summative measures in this field.

We do not suggest that these visualizations are the ultimate set. Indeed, visualization will need to some extent be specific to the design intent of the Web-based intervention as it is best suited to exploratory analysis. Therefore, it is unlikely for the research community to settle on a single set of visualizations for all interventions, but we felt that having a starting point would be useful. We have made the programs freely available to encourage others to explore these visualizations with their own data.

A shared toolset within the community, which allows exploratory and not just confirmatory analysis of data, will require some degree of standardization, for example through a common format for log-data from online interventions. Common fields such as event identifier (URL), timestamp, and user identifier are clearly required, other data points might also be considered, such as self-report measures and treatment events (eg, support sessions for clients receiving blended treatment). The model presented in Figure 1 illustrates one possible arrangement of such data. This would allow researchers developing different interventions to share a common set of tools for visualizing and analyzing log-data.

Future research in this area could help to provide the rigor of development for engagement currently sought to address the issues of adherence that stymie the regular use of Web-based interventions.

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## Conflicts of Interest

The SilverCloud platform was developed through a translational research project that led to the creation of SilverCloud Health. Gavin Doherty was principal investigator of this project and has an interest in the company.

## Multimedia Appendix 1

Processing code and test data for the four visualizations.

[[ZIP File \(Zip Archive\), 302KB - jmir\\_v16i11e252\\_app1.zip](#)]

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## Abbreviations

**NHS:** National Health Service

**NIHR:** National Institute for Health Research

**URL:** uniform resource locator

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Original Paper

# Web-Enhanced Tobacco Tactics With Telephone Support Versus 1-800-QUIT-NOW Telephone Line Intervention for Operating Engineers: Randomized Controlled Trial

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## Abstract

**Background:** Novel interventions tailored to blue collar workers are needed to reduce the disparities in smoking rates among occupational groups.

**Objective:** The main objective of this study was to evaluate the efficacy and usage of the Web-enhanced “Tobacco Tactics” intervention targeting operating engineers (heavy equipment operators) compared to the “1-800-QUIT-NOW” telephone line.

**Methods:** Operating engineers (N=145) attending one of 25 safety training sessions from 2010 through 2012 were randomized to either the Tobacco Tactics website with nurse counseling by phone and access to nicotine replacement therapy (NRT) or to the 1-800-QUIT-NOW telephone line, which provided an equal number of phone calls and NRT. The primary outcome was self-reported 7-day abstinence at 30-day and 6-month follow-up. The outcomes were compared using chi-square tests, t tests, generalized mixed models, and logistic regression models.

**Results:** The average age was 42 years and most were male (115/145, 79.3%) and white (125/145, 86.2%). Using an intent-to-treat analysis, the Tobacco Tactics website group showed significantly higher quit rates (18/67, 27%) than the 1-800-QUIT NOW group (6/78, 8%) at 30-day follow-up ( $P=.003$ ), but this difference was no longer significant at 6-month follow-up. There were significantly more positive changes in harm reduction measures (quit attempts, number of cigarettes smoked per day, and nicotine dependence) at both 30-day and 6-month follow-up in the Tobacco Tactics group compared to the 1-800-QUIT-NOW group. Compared to participants in the 1-800-QUIT NOW group, significantly more of those in the Tobacco Tactics website group participated in the interventions, received phone calls and NRT, and found the intervention helpful.

**Conclusions:** The Web-enhanced Tobacco Tactics website with telephone support showed higher efficacy and reach than the 1-800-QUIT-NOW intervention. Longer counseling sessions may be needed to improve 6-month cessation rates.

**Trial Registration:** Clinicaltrials.gov NCT01124110; <http://clinicaltrials.gov/ct2/show/NCT01124110> (Archived by WebCite at <http://www.webcitation.org/6TfKN5iNL>).

**KEYWORDS**

smoking cessation; intervention study; workplace; blue collar workers

## Introduction

Blue-collar workers (those who perform manual labor) are more likely to smoke than white-collar workers and are more likely to develop smoking-related diseases [1]. Despite the risks, blue-collar workers have limited access to smoking cessation interventions [2] and only half of construction workers were advised to quit smoking [3]. When provided with interventions, blue-collar workers are less likely to use proven tobacco cessation treatments compared to those of higher socioeconomic status (SES) [2]. Moreover, blue-collar workers do not benefit from worksite smoking bans and restrictions. While there is an understanding of factors that contribute to elevated tobacco use in blue-collar workers, little research has focused on cessation. Novel approaches to disseminate efficacious interventions are likely to reduce tobacco-related disparities and cancers among blue-collar workers [4].

One group of blue-collar workers, operating engineers (those who are responsible for the operation of heavy earth-moving equipment to construct buildings, bridges, and roads) showed a higher smoking rate [5]. Among workers in dusty occupations, such as operating engineers, smoking is particularly detrimental because of the exposure to occupational hazards, such as asbestos, cement dust, coal tar pitch, and diesel exhaust, which has a dose-response synergic effect with smoking to develop pulmonary diseases [6]. Thus, operating engineers are particularly at risk for smoking-related diseases, such as cardiovascular disease [7], pulmonary disease [7], as well as cancers of the lung [8], head and neck [9], and trachea and bronchus [10].

Our prior work with operating engineers has shown that 29% smoke [11] compared to 19% among the general population [12], over half are interested in quitting, and they have access to a computer during their regularly scheduled safety trainings [13]. Web-enhanced cessation interventions have been shown to reduce tobacco use [14-17], be more efficacious if they provide tailored messages [18], and enhance quit rates when in conjunction with NRTs [16,18,19]. To our knowledge, there are a few smoking cessation interventions targeting blue-collar workers [20,21], but none of them are Web-enhanced. The Tobacco Tactics website was built for operating engineers based on an efficacious face-to-face intervention [22]. The development of the website was described in detail in a previously published paper [23]. The specific aim of this paper was to compare the Tobacco Tactics website targeting operating engineers to the state-sponsored 1-800-QUIT-NOW telephone line on: (1) 30-day and 6-month self-reported quit rates, (2) 6-month cotinine levels, (3) number of quit attempts, (4) nicotine dependence, (5) number of cigarettes smoked/day, (6) smoking self-efficacy, (7) contacts with interventions, (8) medications used, (9) helpfulness of the interventions, and (10) willingness to recommend the interventions to others.

## Methods

### Design

The protocol of this study was described in a previously published manuscript [24]. In this randomized controlled trial (trial registration: ClinicalTrials.gov NCT01124110), operating engineers attending one of 25 safety training sessions from 2010 through 2012 were randomized either to the Tobacco Tactics website intervention or to the 1-800-QUIT-NOW state-supported telephone quit line. Since there was a high probability of cross-contamination within training sessions, randomization occurred at the training class level rather than individual level [17,25]. Institutional Review Board approval was received from the University of Michigan.

### Setting and Sample

At the Operating Engineers Local 324 Training Center, workers attending annual safety training sessions were invited to participate in this study. Inclusion criteria were operating engineers who were (1) older than 18 years of age, (2) current smokers, and (3) interested in participating in a cessation program. Exclusion criteria were operating engineers who were (1) non-English speaking (the interventions are only available in English), and (2) pregnant.

### Procedures

Operating engineers interested in the study were provided with an information sheet about the study and consent forms. Once participants completed a baseline survey, they were given time to make the first contact with the intervention. Training groups randomized into the Tobacco Tactics intervention group were provided with a computer with Internet access and those randomized into the 1-800-QUIT-NOW were offered a telephone at the training center.

Follow-up surveys were mailed at 30-days and 6-months asking about smoking status, covariates, and their opinions about the intervention. To increase response rates, those who did not return mail surveys were given the opportunity to complete the surveys on the phone. At 6-month follow-up, participants were also sent a NicAlert urinary cotinine test to return with their survey. Those who completed surveys received US \$15 for the baseline survey, US \$15 for the 30-day survey, and US \$20 for the 6-month survey and cotinine test. Data were collected from 2010 through 2012 and analyzed in 2013.

### Description of the Tobacco Tactics Website Intervention

The development of the Tobacco Tactics website is described in detail in an earlier publication [23]. The Tobacco Tactics website contains humorous graphics tailored to operating engineers, tailored cessation feedback, and follow-up nurse counseling offered by multimedia options including phone and/or email, and/or e-community (Figure 1 and Figure 2).

Figure 1. Screenshot of the intervention.

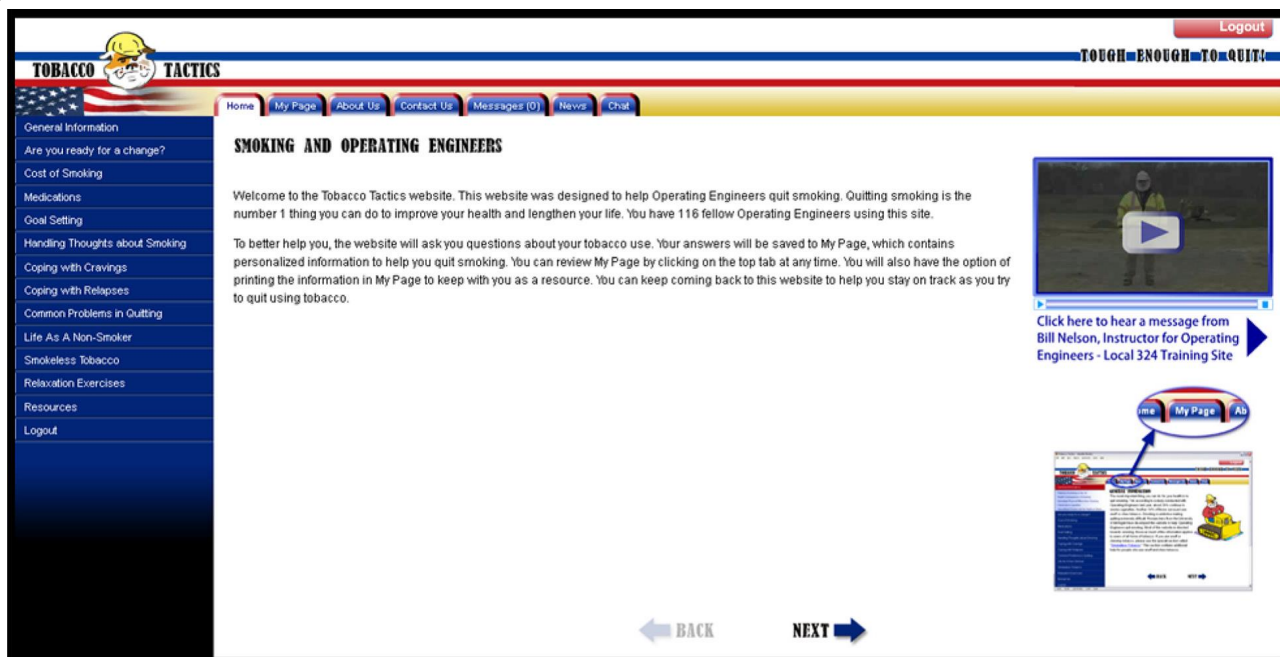


Figure 2. Screenshot of the intervention.



## COST OF SMOKING CALCULATOR

Enter the numbers and click Calculate Savings.

Cigarettes	Cigars	Pipe and Chewing Tobacco
How many cigarettes do you smoke per day? <input style="width: 80px;" type="text" value="0"/>	How many cigars do you smoke per day? <input style="width: 80px;" type="text" value="0"/>	Number of Pouches or Tins per week <input style="width: 80px;" type="text" value="0"/>
Price per Pack \$ <input style="width: 80px;" type="text"/>	Number of Cigars in a Pack <input style="width: 80px;" type="text"/>	Price per Pouch or Tin \$ <input style="width: 80px;" type="text"/>
	Price per Pack \$ <input style="width: 80px;" type="text"/>	



Calculate Savings

Weekly Total: \$

Yearly Total: \$

Save to My Plan

The content was written at an 8<sup>th</sup> grade reading level and provided interactive cognitive behavioral therapy exercises including a self-assessment of tobacco habit, calculation of a nicotine dependence score, identification of smoker type, calculation of money savings, tips for prepare for quitting (eg, cleaning the car of cigarette butts, etc), a change plan work sheet, and strategies for coping with relapses. Additional interactive components provide mechanisms for tobacco users to assess their smoking habit, set a quit date, and monitor weekly progress.

Since peer support has been shown to enhance behavioral interventions [26], there was also a nurse-monitored e-community. A research nurse served as a group moderator for the e-community three times per week, answered questions, and posted questions to stimulate group discussion. Upon each log-off, participants were asked to answer a few brief questions about their tobacco habit, which resulted in a graph that showed their progress in quitting over time. Operating engineers were offered their choice of a full supply of over-the-counter nicotine

patches, gum, lozenges, or a combination of these for highly addicted smokers.

Since studies have shown that telephone and nurse counseling is efficacious [27-29] and tailored telephone and regular postal mail cessation interventions have been found to be efficacious among construction workers [20], the nurse made follow-up telephone and/or email counseling contacts at 2, 7, 14, 21, and 30 days after the training. Follow-up contacts reinforced the initial website visit, promoted skill building, and monitored pharmacologic treatment.

### Description of the 1-800-QUIT-NOW Intervention

According to the recommendations for the design of control group conditions in clinical trials [30], the control group condition should be designed to be equivalent as much as possible on time spent, follow-up times, and attention given to participants. In keeping with the recommendations, the 1-800-QUIT-NOW intervention was chosen as a control condition since it was as equivalent as possible to the Tobacco



Tactics Web-enhanced intervention in terms of baseline counseling from the study nurse, numbers of follow-up calls, and medications available. Participants randomized to the 1-800-QUIT-NOW were counseled by the study nurse to call and were given time to do so at their safety training class. The first time participants called the quit line, they received a personal coach who assisted them in setting a quit date and making an individualized quit plan, followed by up to five telephone coaching sessions around the caller's quit date and free NRT (patches or gum), which were all equivalent to the Tobacco Tactics intervention.

## Measures

### Dependent Variables

The primary dependent variable was self-reported 7-day point prevalence smoking cessation rates at 30-day and 6-month follow-up by asking the well-validated question, "Have you used any tobacco products in the past 7 days?" [31]. The secondary dependent variable was a cotinine-verified 6-month smoking status using a mailed urinary cotinine test kit. Urinary cotinine assessment has excellent reproducibility and high sensitivity (92%) and specificity (91%) for identifying non-smokers from smokers [32]. Using an intention-to-treat analysis, participants who were not available for follow-up or did not return the survey were considered smokers and those who did not return the cotinine test or who had an unreadable cotinine strip were considered to test positive for smoking for the biochemical confirmation analyses.

Harm reduction was assessed including (1) quit attempts for at least 24 hours, (2) (changes in) nicotine dependence, (3) (changes in) number of cigarettes smoked/day, and (4) (changes in) smoking self-efficacy. Nicotine dependence was assessed using the Fagerstrom Test for Nicotine Dependence (FTND) [33] and the self-efficacy was measured by the Smoking Self-Efficacy Questionnaire (SEQ-12) [34].

As a process evaluation, both interventions were evaluated in terms of (1) percent that had contacts with intervention, and (2) percent that used medications. Participants were asked to rate the interventions on a scale of 1 to 5 (higher scores were better) in terms of (1) helpfulness of the phone calls and NRTs (extremely unhelpful to extremely helpful), (2) opinion about the number of calls (far too many to far too few), (3) comfort asking questions, level of support provided, and willingness to recommend the interventions to others (strongly disagree to strongly agree), and (4) satisfaction with answers (extremely unsatisfied to extremely satisfied).

Those randomized to the Web-enhanced Tobacco Tactics intervention only were asked to rate components of the website on a scale of 1 to 5 (with higher scores were better). Ease of use, enjoyability, navigation, feedback from interactive exercises, and satisfaction were rated from strongly disagree to strongly agree. The interactive exercises of smoking assessment, reasons to quit, smoking log, smoking triggers, cigarette substitutes, and medication were rated from extremely unhelpful to extremely helpful. The home page, title, and pictures and illustrations were rated from very poor to excellent. This

information was collected from an administrative component of the website, nurse logs of contacts, and survey data. Similar survey questions were asked of those randomized to the 1-800-QUIT-NOW quit line intervention.

### Independent Variables

The main independent variable was the Tobacco Tactics Web-enhanced intervention versus the 1-800-QUIT-NOW intervention. Covariates that might influence smoking were also examined. Alcohol use was measured by the Alcohol Use Disorders Identification Test (AUDIT) with scores of 8 or higher indicating problem drinking [35]. Social support was measured by the ENRICHED Social Support Instrument [36] and the Perceived Stress Scale was used to assess stress [37]. Depressive symptoms were assessed by the Center for Epidemiologic Studies Depression Scale (CES-D) with scores of 16 or higher indicating significant depressive symptoms [38]. Medical comorbidities were assessed by the validated measure [39] and questions about demographics were asked.

### Data Analysis

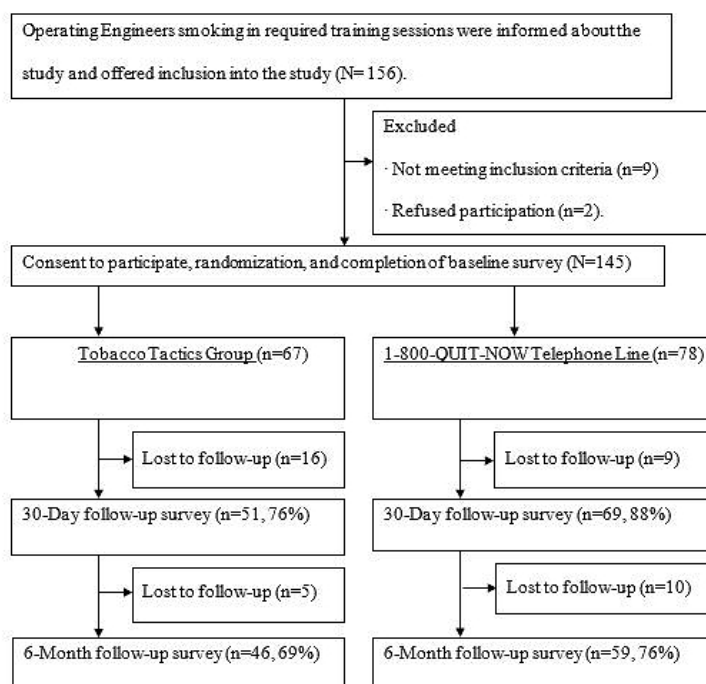
Descriptive statistics were computed for all variables. The equivalence of the two groups at baseline was tested using  $\chi^2$  tests or Fisher's exact tests for categorical variables and two-tailed  $t$  tests for quantitative variables. To compare the two interventions on efficacy and usage,  $\chi^2$  tests or Fisher's exact tests and  $t$  tests were conducted using an intention-to-treat analysis in which non-responders were considered smokers. These analyses for quit rates were repeated controlling for differences between the groups using logistic regression. Since the randomization occurred at the training group level, to test for cluster effects, tests of heterogeneity for smoking status at 30-day and 6-month follow-up were performed using mixed models. Since the sample size was small, if there was no significant heterogeneity, final analyses were conducted with chi-square tests or  $t$  tests not adjusting the clustering by training group. In all analyses, an alpha level of .05 two-tailed was used as the criterion for significance. Sample size may vary for selected variables due to missing data.

## Results

### Recruitment and Retention

Over the course of 3 years (2010 to 2012), 25 training groups were randomized with an average size of 6 participants per group, leading to 67 participants in the website group and 78 participants in the 1-800-QUIT-NOW group (N=145). A total of 83% of the sample (120/145, 82.8%) completed the 30-day survey and 73% (105/145, 72.4%) completed the 6-month survey. Those who were not thinking of quitting within the next 30 days ( $P=.029$ ) and reported higher numbers of snuff used in the past month ( $P=.003$ ) were more likely to drop out before 30-day follow-up. Those who reported that they were not thinking of quitting ( $P=.021$ ), were veterans ( $P=.044$ ), and were without hypertension ( $P=.033$ ) were more likely to drop out before 6-month follow-up. A CONSORT diagram can be found in Figure 3.



**Figure 3.** CONSORT Flowdiagram.

### Description of the Sample and Equivalency of the Groups

The description of the sample can be seen in [Table 1](#). The average age of the operating engineers was 42 (SD 9.5) years, most were male (115/145, 79.3%) and white (125/145, 86.2%). Just over half were married (80/145, 55.9%) and had a high school education or less (88/145, 61.1%). The most common comorbidities were high blood pressure (29/145, 20.4%), psychiatric problems (21/145, 14.7%), substance abuse problems (16/145, 11.2%), and lung disease (14/145, 10.1%). A total of

45.1% screened positive for problem drinking (60/133) and 35.4% (51/145) screened positive for significant depressive symptoms. The mean perceived stress score was 24.3 (SD 6.8) (range 9-43), which is comparable to mean scores in other populations such as students and community samples [37]. Just under one-third (42/145, 29.0%) of operating engineers reported low social support. While the groups were equivalent on most factors at baseline, subjects in the website group showed significantly higher body mass index (BMI) ( $P=.029$ ) and less motivation to quit smoking ( $P=.042$ ) compared to those in the 1-800-QUIT NOW group.

**Table 1.** Baseline characteristics of the Tobacco Tactics website and 1-800-QUIT-NOW participants.

Group	All (N=145)  mean (SD; range) or n (%)	Website (n=67)	1-800-QUIT-NOW (n=78)	P value
Age, years	42.0 (9.5; 20-61)	42.1 (9.3; 23-60)	41.8 (9.7; 20-61)	.837
BMI <sup>a</sup>	29.0 (5.7; 20-53)	30.1 (6.0; 21-53)	28.1 (5.3; 20-44)	.029
Years of regular smoking (n <sub>I</sub> =65; n <sub>C</sub> =77) <sup>b</sup>	21.5 (10.1; 1-47)	22.0 (10.3; 1-45)	21.2 (10.0; 1-47)	.651
Number of cigarettes smoked per day (n <sub>I</sub> =64; n <sub>C</sub> =74)	20.9 (9.9; 1-50)	22.2 (8.4; 3-50)	19.8 (11.0; 1-50)	.162
Nicotine dependence (FTND <sup>c</sup> ) (n <sub>I</sub> =63; n <sub>C</sub> =77)	4.7 (2.6; 0-10)	5.1 (2.4; 0-9)	4.4 (2.7; 0-10)	.149
Smoking self-efficacy (SEQ-12 <sup>d</sup> )	32.7 (10.5; 12-60)	33.5 (10.8; 12-60)	32.0 (10.3; 12-56)	.401
Perceived stress scale score	24.3 (6.8; 9-43)	24.3 (6.6; 9-43)	24.4 (6.9; 10-42)	.972
<b>Sex</b>				.063
Male	115 (79.3)	58 (86.6)	57 (73.1)	
Female	30 (20.7)	9 (13.4)	21 (26.9)	
Hispanic or Latino	6 (4.1)	2 (3.0)	4 (5.1)	.686
<b>Race</b>				.339
White	125 (86.2)	60 (89.6)	65 (83.3)	
Non-white (all others)	20 (13.8)	7 (10.4)	13 (16.7)	
<b>Marital status (n<sub>I</sub> =66; n<sub>C</sub> =77)</b>				.738
Married	80 (55.9)	38 (57.6)	42 (54.5)	
Not married	63 (44.1)	28 (42.4)	35 (45.5)	
<b>Educational level (n<sub>I</sub> =66; n<sub>C</sub> =78)</b>				.609
High school or less than high school	88 (61.1)	42 (63.6)	46 (59.0)	
More than high school	56 (38.9)	24 (36.4)	32 (41.0)	
Do you live alone? (n <sub>I</sub> =64; n <sub>C</sub> =78)	21 (14.8)	8 (12.5)	13 (16.7)	.636
<b>Medical comorbidities</b>				
High blood pressure (n <sub>I</sub> =65; n <sub>C</sub> =77)	29 (20.4)	13 (20.0)	16 (20.8)	1.000
Psychiatric problems (n <sub>I</sub> =66; n <sub>C</sub> =77)	21 (14.7)	9 (13.6)	12 (15.6)	.815
Substance abuse problems (n <sub>I</sub> =66; n <sub>C</sub> =77)	16 (11.2)	7 (10.6)	9 (11.7)	1.000
Lung disease (n <sub>I</sub> =63; n <sub>C</sub> =75)	14 (10.1)	7 (11.1)	7 (9.3)	.782
Diabetes (n <sub>I</sub> =65; n <sub>C</sub> =76)	7 (5.0)	5 (7.7)	2 (2.6)	.248
Heart disease (n <sub>I</sub> =64; n <sub>C</sub> =76)	7 (5.0)	4 (6.2)	3 (3.9)	.702
Arthritis (n <sub>I</sub> =62; n <sub>C</sub> =74)	7 (5.1)	2 (3.2)	5 (6.8)	.454
Cancer (n <sub>I</sub> =66; n <sub>C</sub> =77)	6 (4.2)	2 (3.0)	4 (5.2)	.678

Group	All (N=145)  mean (SD; range) or n (%)	Website (n=67)	1-800-QUIT-NOW (n=78)	P value
Stroke (n <sub>I</sub> =64; n <sub>C</sub> =77)	1 (0.7)	0 (0.0)	1 (1.3)	1.000
Alcohol problem (AUDIT ≥8) (n <sub>I</sub> =63; n <sub>C</sub> =70)	60 (45.1)	26 (41.3)	34 (48.6)	.486
Depressed (CES-D≥16) (n <sub>I</sub> =66; n <sub>C</sub> =78)	51 (35.4)	18 (27.3)	33 (42.3)	.080
Low social support	42 (29.0)	22 (32.8)	20 (25.6)	.364
<b>Thinking of quitting</b>				
Yes, within next 30 days	76 (52.4)	32 (47.8)	44 (56.4)	.042
Yes, within next 6 months	64 (44.1)	30 (44.8)	34 (43.6)	
No	5 (3.4)	5 (7.5)	0 (0.0)	
<b>Used in past month (yes/no)</b>				
Cigars	17 (11.7)	7 (10.4)	10 (12.8)	.854
Pipes	2 (1.4)	1 (1.5)	1 (1.3)	1.000
Cigarillos	2 (1.4)	2 (3.0)	0 (0.0)	.411
Snuff	21 (14.5)	7 (10.4)	14 (17.9)	.297
Smoking of closest person (n <sub>I</sub> =56; n <sub>C</sub> =64)	57 (47.5)	24 (42.9)	33 (51.6)	.365
Ever tried to quit	126 (86.9)	56 (83.6)	70 (89.7)	.328

<sup>a</sup>BMI: body mass index

<sup>b</sup>n<sub>I</sub>: intervention sample; n<sub>C</sub>: control sample

<sup>c</sup>FTND: Fagerstrom Test for Nicotine Dependence

<sup>d</sup>SEQ-12: Smoking Self-Efficacy Questionnaire

## Efficacy of the Interventions

The differences in 7-day point prevalence quit rates between the groups can be seen in Table 2. The Tobacco Tactics website group had significantly higher quit rates (18/67, 27%) than the 1-800-QUIT-NOW group (6/78, 8%) at 30-day follow-up ( $P=.003$ ). However, the differences were not significant at 6-month follow-up (12%, 8/67, vs 12%, 9/78). Repeating these analyses controlling for BMI and motivation to quit smoking, which differed across the two groups at baseline, produced similar results; the odds of non-smoking in the website group was 4.8 times as great as in the 1-800-QUIT NOW group (OR 4.8,  $P=.003$ ). Tests for heterogeneity for smoking status at 30-day and 6-month follow-ups among the training groups were not significant and hence training group was not controlled for in the analyses. Only 20.7% (30/145) of the operating engineers returned cotinine strips, hence cotinine-verified quit rates could not be determined.

Compared to the 1-800-QUIT-NOW group, more operating engineers in the Tobacco Tactics website group were able to quit for at least 24 hours: 69% (36/67) vs 23% (16/78) at 30-day follow-up ( $P<.001$ ) and 70% (32/67) vs 43% (26/78) at 6-month follow-up ( $P=.010$ ), yet the numbers of quit attempts were not significantly different between the groups. Moreover, the website group showed greater reductions in nicotine dependence ( $P=.006$  at 30-day follow-up and  $P=.014$  at 6-month follow-up) and the number of cigarettes smoked per day ( $P<.001$  at 30-day follow-up and  $P=.017$  at 6-month follow-up). Participants in the website group smoked significantly fewer cigarettes per day: 12.4 vs 17.7 at 30-day follow-up ( $P=.020$ ) and 13.6 vs 19.1 at 6-month follow-up ( $P=.046$ ). Similarly, those in the website group reported higher levels of smoking self-efficacy ( $P=.003$ ) and greater increases in smoking self-efficacy ( $P=.010$ ) at 30-day follow-up than those who were in the 1-800-QUIT-NOW group.

**Table 2.** Tobacco use among the Tobacco Tactics website and 1-800-QUIT-NOW participants.

Surveys completed	Baseline			30-day follow-up			6-month follow-up		
Group	Website (n=67)	1-800-QUIT-NOW (n=78)	<i>P</i> value	Website (n=67)	1-800-QUIT-NOW (n=78)	<i>P</i> value	Website (n=67)	1-800-QUIT-NOW (n=78)	<i>P</i> value
Non-smoking, n (%)				18 (27)	6 (8)	(n=145) <i>P</i> =.003	8 (12)	9 (12)	(n=145) <i>P</i> =1.000
Able to quit 24 hours, n (%)				36 (69)	16 (23)	(n=121) <i>P</i> <.001	32 (70)	26 (43)	(n=106) <i>P</i> =.010
Nicotine dependence score, mean (SD)	5.1 (2.4)	4.4 (2.7)	(n=140) <i>P</i> =.149	2.9 (2.7)	3.5 (2.8)	(n=103) <i>P</i> =.262	3.8 (2.8)	4.2 (2.9)	(n=74) <i>P</i> =.614
Changes in nicotine dependence, mean (SD)				-2.3 (3.0)	-0.8 (2.1)	(n=98) <i>P</i> =.006	-1.5 (2.3)	-0.2 (2.0)	(n=71) <i>P</i> =.014
Number of cigarettes/day, mean (SD)	20.4 (12.9)	18.3 (12.8)	(n=145) <i>P</i> =.336	12.4 (10.3)	17.7 (13.4)	(n=121) <i>P</i> =.020	13.6 (11.7)	19.1 (16.4)	(n=106) <i>P</i> =.046
Changes in number of cigarettes/day, mean (SD)				-9.2 (14.7)	0.3 (14.1)	(n=121) <i>P</i> <.001	-6.6 (17.6)	1.0 (14.5)	(n=106) <i>P</i> =.017
Number of quit attempts, mean (SD)				5.3 (7.8)	6.1 (7.8)	(n=43) <i>P</i> =.776	6.4 (7.8)	5.0 (7.1)	(n=44) <i>P</i> =.537
Smoking self-efficacy, mean (SD)	33.5 (10.8)	32.0 (10.3)	(n=145) <i>P</i> =.401	39.1 (10.0)	31.5 (10.4)	(n=76) <i>P</i> =.003	33.8 (12.6)	31.9 (12.1)	(n=70) <i>P</i> =.513
Changes in smoking self-efficacy, mean (SD)				9.5 (12.2)	1.1 (13.1)	(n=75) <i>P</i> =.010	1.5 (13.3)	0.3 (15.0)	(n=68) <i>P</i> =.748

## Usage of the Interventions

**Multimedia Appendix 1** compares the usage of the two interventions. Significantly more participants in the website group participated in the intervention than those in the 1-800-QUIT-NOW group ( $P<.001$ ). The majority of the participants (66/67, 99%) in the website group visited the Tobacco Tactics website at least once and the average was 2.7 (SD 3.7) visits. Compared to the 1-800-QUIT-NOW group (11/78, 14%), significantly more participants in the website group (60/67, 90%) participated in phone counseling ( $P<.001$ ). While 70% (48/67) of the website group received any kind of NRTs, only 5% (4/78) of the 1-800-QUIT-NOW group received NRT ( $P<.001$ ); patches, 40% (29/67) vs 3% (2/78) ( $P<.001$ ), gum, 60% (40/67) vs 1% (1/78) ( $P<.001$ ), lozenges, 9% (6/67) vs 0% (0/78) ( $P=.009$ ), and patches and gum or lozenges, 36% (24/67) vs 0% (0/78) ( $P<.001$ ).

Participants were asked to rate components of both interventions on a scale of 1 to 5 (higher scores were better). Overall helpfulness of the phone calls was rated significantly higher in the website group than the 1-800-QUIT-NOW group ( $P=.023$ ). There was no significant difference in the participants' opinions about the number of calls received (3.3 compared to 3.1,

$P=.604$ ). However, participants in the website group reported more comfort with asking questions ( $P=.010$ ), more satisfaction with the answers provided by the counselors ( $P=.003$ ), and felt more supported ( $P<.001$ ) than those in the 1-800-QUIT-NOW group. There was no difference between the groups in terms of tendency to recommend the intervention to someone else ( $P=.171$ ).

Individuals that were randomized to the Web-enhanced Tobacco Tactics intervention were asked to rate specific components of the website on a scale of 1 to 5, with higher scores being better (**Table 3**). The majority (33/44, 75%) thought that it was overall recommendable. The lowest rated items were "helpful feedback" (20/44, 47%), "medication assessment" (21/44, 48%), and "smoking log" (16/44, 36%). Additional analysis (not shown in Tables) revealed the number of contacts with the website was not correlated with quit rates. However, the higher number of phone calls the Tobacco Tactics intervention participants received by the study nurse was correlated with higher cessation rates ( $P<.001$ ). About 40% (27/67) attended the e-community chat room. The most common subjects discussed in the chat room included (1) checking/evaluating quitting process, (2) suggesting /sharing /encouraging strategies for smoking cessation, (3) NRTs, and (4) withdrawal symptoms.

**Table 3.** Percent of respondents that rated the Tobacco Tactics website as 4 or 5 on a 5-point scale, with higher numbers being better (n=44).

Rating	n (%)
<b>General evaluation of Tobacco Tactics: responded as Strongly Agree or Agree</b>	
Overall recommendable	33 (75)
Easy to navigate	30 (68)
Easy to read and understand	26 (67)
Easy to use of interactive exercises	27 (61)
Overall satisfactory	26 (59)
Enjoyable to visit	22 (50)
Helpful feedback	20 (47)
<b>Exercises of Tobacco Tactics: responded as Extremely Helpful or Somewhat Helpful</b>	
Reasons to quit	26 (59)
Smoking self-assessment	25 (57)
Cigarette substitutes	24 (55)
Smoking triggers	22 (50)
Medication assessment	21 (48)
Smoking log	16 (36)
<b>Design of Tobacco Tactics: responded as Excellent or Good</b>	
Main page	26 (59)
Title	24 (55)
Pictures and illustrations	22 (50)

## Discussion

### Principal Findings

The Tobacco Tactics Web-enhanced intervention for operating engineers produced three times higher quit rates at 30-day follow-up than the 1-800-QUIT-NOW quit line. Compared to other studies, the quit rate of 27% (18/67) is at the higher end of Internet-based smoking cessation interventions that reported successful results, which range from 11.0% to 27.7% [18,40,41]. There are several factors that led to the success of the Tobacco Tactics intervention. First, the Tobacco Tactics was developed to target operating engineers, featuring humorous cartoon characters of this population and containing tailored cessation feedback, which have been shown to increase quit rates [19,42]. All the content was written at an 8<sup>th</sup> grade reading level and was easy to understand, which was critical since almost two-thirds had a high school education or less.

Second, the Tobacco Tactics website was available anytime and accessed as frequently as desired. All but one of the operating engineers that were randomized to the intervention group was able to explore the website at least once at the training site and many operating engineers repeated their visits up to 26 times.

Third, recruiting participants during their regularly scheduled safety trainings, which they attend each winter, may have enhanced quit rates as they were given on-the-spot intervention. Even though individuals randomized to the 1-800-QUIT-NOW were given the same amount of time to make a first contact, the majority of them did not make phone calls and the low-reach

of the quit line intervention is consistent with previous studies [43]. As a result, the Tobacco Tactics website group received six times more phone counseling and 14 times more NRTs than the 1-800-QUIT-NOW group, which led to higher quit rates.

Unfortunately, the higher quit rates in the Tobacco Tactics Web-enhanced intervention group were not sustained at 6-month follow-up, which is consistent with a previous study with similar population [21]. A longer follow-up period may be needed to increase sustainability [44]. Previous studies have shown that obesity and concerns about weight gain can cause quit attempts to fail [45,46] and this may partially explain the non-significant quit rate at 6-month follow-up since the intervention group was significantly heavier than the control group, although an analysis controlling for obesity did not show different results. Nonetheless, future interventions may need to combine behavior change strategies targeting weight loss with those targeting smoking cessation [47].

Yet even among continuing smokers, compared to the 1-800-QUIT-NOW control group, those in the website group showed a significant reduction in number of cigarettes smoked per day and a reduction in nicotine dependence, suggesting that the Tobacco Tactics Web-enhanced intervention had a significant effect on harm reduction. Several studies acknowledged that the number of cigarettes smoked per day had a dose-response relationship with heart and lung disease [48,49] and that harm reduction decreases the risk of smoking-related diseases possibly through reductions in tobacco toxin exposure, such as carbon monoxide [50]. Since the average smoker makes seven quit attempts before actually quitting [51]



and past quit attempts strongly predicted future quit attempts [52], those operating engineers who did not quit made substantial progress in the direction of quitting.

Over three-quarters of respondents randomized to the Web-enhanced Tobacco Tactics intervention strongly agreed or agreed that it was recommendable to others. Yet there were components of the intervention that were rated lower. The Web-based medication assessment was among the lower-rated items, suggesting that a conversation may be needed to figure out the best medications for an individual based on their smoking habit. While there were interactive exercises that gave feedback, feedback was among the lower-rated items suggesting that a website cannot suffice for personal contact. Moreover, there was a positive correlation between number of phone calls in the intervention group and quit rates. Social support has been shown to enhance smoking cessation interventions [26,53]. While the e-community chat room provided some social support, just under half participated in the chat room and the number of calls received was correlated with quitting, albeit those participating in the calls may be more motivated to quit.

### Limitations

The sample was primarily white and male, but was representative of the sample of operating engineers in Michigan [11,54]. The sample size was a bit small to control for clustering of training groups, although this was less of a problem since tests for heterogeneity for smoking status at 30-day and 6-month follow-up among the training groups were not significant. Only one-third of the operating engineers completed the biochemical validation and we anecdotally heard that they felt biochemical verification was offensive, which is a limitation of the study, although our prior work has shown high sensitivity and specificity between self-report and biochemical verification in other populations of primarily male smokers [55]. Even though training groups were randomized, there were baseline

differences between the groups (such as BMI and motivation to quit), yet controlling for these factors in the analysis did not change the results. The Tobacco Tactics Web-enhanced intervention was composed of three parts (Tobacco Tactics website, phone counseling, and NRTs) and was tested as a whole, therefore the specific components of the Tobacco Tactics that led to success in smoking cessation and harm reduction could not be determined, which is often the case with multi-component interventions. The multi-component Tobacco Tactics intervention was provided by one study nurse, perhaps causing an intervener effect by increasing engagement in the intervention and impact on the outcomes, which may influence construct and the internal validity [56].

### Conclusions

The Web-enhanced Tobacco Tactics intervention for operating engineers showed a significantly higher efficacy and higher reach at 30-day follow-up compared to the 1-800-QUIT-NOW quit line. Among those who did not quit at 6-month follow-up, there were significant increases in harm reduction in the intervention group compared to the 1-800-QUIT-NOW telephone line. Web-enhanced smoking cessation interventions are cost effective [19] in that once a website is built, the cost of reaching 1 million tobacco users is not much more than reaching 1000 tobacco users [57]. Without considering the cost of medications, Web-enhanced smoking cessation interventions have been shown to cost less than US \$1 per smoker, which is a lot less than either telephone counseling or print product interventions [19]. Therefore, the Web-enhanced Tobacco Tactics smoking cessation intervention has the potential to have high reach and efficacy at a low cost. Based on our results, we will revise our strategy and explore the possibility of dissemination via the operating engineers National Training Center, which services North America (including the United States, Mexico, and Canada).

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### Conflicts of Interest

None declared.

### Multimedia Appendix 1

Usage and satisfaction with Tobacco Tactics and 1-800-QUIT-NOW interventions.

[PDF File (Adobe PDF File), 33KB - [jmir\\_v16i11e255\\_app1.pdf](#)]

### Multimedia Appendix 2

CONSORT-EHEALTH checklist V1.6.2 [58].

[PDF File (Adobe PDF File), 983KB - [jmir\\_v16i11e255\\_app2.pdf](#)]

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## Abbreviations

**AUDIT:** Alcohol Use Disorders Identification Test  
**BMI:** body mass index  
**CES-D:** Center for Epidemiologic Studies Depression Scale  
**FTND:** Fagerstrom Test for Nicotine Dependence  
**NRT:** nicotine replacement therapy  
**RCT:** randomized controlled trial  
**SES:** socioeconomic status  
**SEQ-12:** Smoking Self-Efficacy Questionnaire

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Original Paper

# Finding Collaborators: Toward Interactive Discovery Tools for Research Network Systems

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## Abstract

**Background:** Research networking systems hold great promise for helping biomedical scientists identify collaborators with the expertise needed to build interdisciplinary teams. Although efforts to date have focused primarily on collecting and aggregating information, less attention has been paid to the design of end-user tools for using these collections to identify collaborators. To be effective, collaborator search tools must provide researchers with easy access to information relevant to their collaboration needs.

**Objective:** The aim was to study user requirements and preferences for research networking system collaborator search tools and to design and evaluate a functional prototype.

**Methods:** Paper prototypes exploring possible interface designs were presented to 18 participants in semistructured interviews aimed at eliciting collaborator search needs. Interview data were coded and analyzed to identify recurrent themes and related software requirements. Analysis results and elements from paper prototypes were used to design a Web-based prototype using the D3 JavaScript library and VIVO data. Preliminary usability studies asked 20 participants to use the tool and to provide feedback through semistructured interviews and completion of the System Usability Scale (SUS).

**Results:** Initial interviews identified consensus regarding several novel requirements for collaborator search tools, including chronological display of publication and research funding information, the need for conjunctive keyword searches, and tools for tracking candidate collaborators. Participant responses were positive (SUS score: mean 76.4%, SD 13.9). Opportunities for improving the interface design were identified.

**Conclusions:** Interactive, timeline-based displays that support comparison of researcher productivity in funding and publication have the potential to effectively support searching for collaborators. Further refinement and longitudinal studies may be needed to better understand the implications of collaborator search tools for researcher workflows.

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**KEYWORDS**

translational medical research; cooperative behavior; interprofessional relations; interdisciplinary studies; information systems; information services



## Introduction

Building collaborative research teams is a critical challenge for biomedical scientists. Interdisciplinary research teams provide a breadth of expertise [1,2], shared workload [2,3], and greater advocacy for breakthroughs [2], often resulting in more frequent citations [4]. However, identifying appropriate collaborators is often difficult, particularly for junior investigators who lack extensive personal networks [5]. Research networking systems (RNSs) that model researcher activity, expertise, and collaborations have been developed to facilitate collaborator searches [6-9], particularly via federated search tools that provide preliminary demonstrations of cross-institution search facilities [10]. Emerging reports of RNS usage provide preliminary evidence of search and navigation patterns extracted from usage logs with deployed RNSs [11,12], but relatively little insight into how search tools should be designed to support the process of collaborator searches. The goal of this study was to conduct an iterative design and qualitative inquiry process to better understand scientists' needs and workflows, and how they might best be supported by software tools. These efforts led to the development of a functional prototype collaborator search tool, which was evaluated in a preliminary usability study.

Identifying collaborators is a time-consuming process that does not scale well [6]. Researchers seeking collaborators often want to find new collaborators through existing contacts, who can provide useful feedback on the suitability of potential collaborators for their colleagues [6]. Although this approach might be effective for senior scientists with well-established personal contacts, junior researchers often lack personal contacts with potential collaborators [6]. Geographic separation is also a potential concern for evaluating potential collaborators, particularly given experience demonstrating the importance of physical proximity for research groups [13,14].

Identifying appropriate collaborators for team and translational science was one of the key motivations for the emergence of RNSs. As social networks for scientists, RNSs organize researchers' interests, publications, funding, and collaborators in navigable formats designed to publicize research activity and support discovery of needed expertise. An assortment of commercial and academic RNSs provides a range of functionality, such as Digital Vita's ability to populate National Institutes of Health (NIH) biosketches from RNS data [9]. Academic RNSs are typically deployed separately at individual research institutions [7], with localized navigation and search tools. Currently, one of the most prominent is the VIVO system [8], which provides a detailed semantic metadata model for describing researchers. Other notable tools include Harvard's Profiles [15] and commercial tools, such as SciVal [16] and ResearchGate [17].

Concerns about the limitations of restricting searches to single institutions have led to the development of broader search tools. Direct2Experts uses a standard application programming interface convention to provide a federated multi-institution search interface [10]. Although Direct2Experts returns result counts that allow comparison across institutions, results are

presented in their native form as provided by each institution. This lack of common formats limits opportunities for comparison and contrast. The VIVO platform's use of semantic Resource Description Framework (RDF) markup and linked open data provides the possibility of cross-institutional searches, but this functionality is not well supported in current interfaces. The VIVO Searchlight browser plugin [18] demonstrates a possible approach to increasing the utility of RNS data by supporting links to individual VIVO profiles from multiple institutions through commonly used Web resources, such as PubMed entries [19,20].

Preliminary reports from institutional RNSs provide some insight into usage patterns and user goals. An analysis of 5 months of log data from an RNS at Columbia University found differences in usage patterns across user classes, with faculty performing more keyword searches than administrators [12]. A similar log-based analysis at the University of California, San Francisco, found that search engines were the source of almost 75% of initial visits, the number of return visitors increased over time, and that return visitors accessed a higher number of pages/visit compared to first-time users [11].

Relatively little attention has been paid to understanding how information tools might best support the process of searching for collaborators. Techniques such as contextual design [21] and scenario-based design [22] that rely on task modeling and work observation might be used to develop models of researcher goals, needs, and workflows, but the nature of collaborator search complicates these matters. As an occasional ad hoc task that generally lacks focused support from software tools, collaborator search use is not well suited for direct observation. This problem is particularly acute for RNS use. Given the incomplete penetrance of RNS systems [7] and a perceived lack of "critical mass" of participation for institutions where RNS systems have been deployed [23], ongoing use of these tools by researchers may be somewhat limited.

Preliminary investigations of user needs have identified some recurring themes in information needs and workflows. Schleyer et al [9] conducted retrospective interviews aimed at identifying researcher requirements for collaboration search tools, identifying themes such as compatibility of personal styles, rich communication needs including details beyond publications, high-quality data, and the importance of personal networks for the identification of collaborators. Bhavnani et al [24] conducted a qualitative study of researcher needs for tools for both collaboration identification and resource discovery, identifying the need for federated information, facilities for managing large volumes of information, and "humanized computing" tools that would favor user-controlled tools over algorithmic approaches that might use opaque processes to identify suggested resources. These suggestions are consistent with the observation from Boland et al [12] that different classes of RNS users may have different goals and workflows.

The goal of this study was to move beyond these descriptions of broad classes of user needs to explore specific features and designs, and to use these investigations to develop further understanding of user goals and preferences. Specifically, paper prototypes were used to elicit comments from researchers

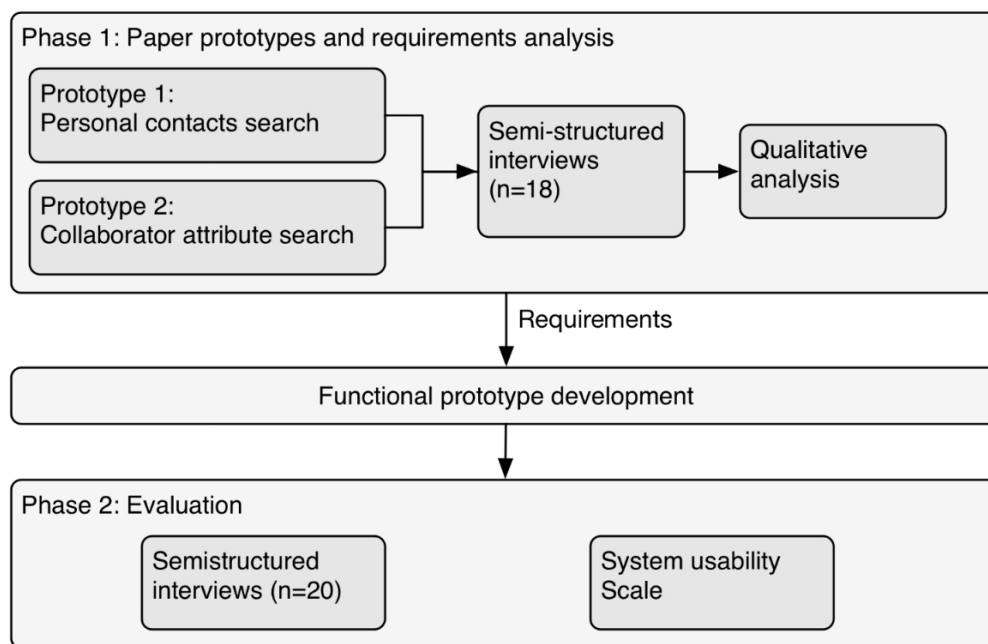
regarding their perceptions of preferences for interactive collaborative search tools. Qualitative analysis of responses to these prototypes was used to identify recurring requirements. These requirements informed the design of a functional prototype collaboration search tool, which was developed to provide preliminary evaluation of the feasibility and usability of interactive collaboration search tools. Results from these inquiries provided preliminary validation of the tool design while identifying areas of concerns that might need to be addressed in subsequent redesigns.

## Methods

### Summary

This study used a combination of prototyping, qualitative inquiry, and software development. Initial designs of paper prototypes were based on findings from earlier studies [9]. Semistructured interviews with potential users [25] provided qualitative feedback, including reactions to the paper prototypes. These responses were analyzed to identify specific requirements, which were used to drive the design and implementation of a functional prototype. This prototype was evaluated through a second set of qualitative interviews with potential users (Figure 1).

**Figure 1.** Overall study workflow.



## Paper Prototypes and Requirements Analysis

### Overview

The goal of the first inquiry was to explore user requirements for collaboration search tools. Pilot studies presented a conundrum: potential users were likely to be unfamiliar with the notion of collaborator search tools because of the relatively low adoption rates of RNSs. To effectively elicit participant input, we developed 2 paper prototypes illustrating hypothetical interfaces for collaborator search tools. We use the term “paper” here to informally refer to low-fidelity, nonfunctional prototypes. Using multiple prototypes provided the freedom to consider designs that covered a variety of perspectives on relevant information and to present participants with a range of options that might elicit more detailed feedback [26].

### Prototype 1: Personal Contacts Search

Researchers often seek new collaborators through existing contacts [6]. The first prototype explored the possibility of using

prior contacts from an external source such as an email contact list to begin a collaborator search (Figure 2). These contacts would then be matched to publications and author information found within an RNS.

Use of this tool begins with importing email contacts. Users then use keyword searches to explore topics of interest. These keyword searches leverage RNS publication and grant data, identifying possible collaborators who have relevant publications. Potential matches are listed in rows on the screen. Information about each candidate is arranged in chronological order along a horizontal timeline. Publications are marked with color codes to indicate individuals who are on the imported contact list, geographically close (within 10 miles of the user), and/or marked as interest for further follow-up. Checkbox filter selections can be used to filter out items based on any of the color-coded categories.

For candidates not found on the user’s contact list, coauthorship information can be used to identify current contacts who might have coauthored papers with them (Figure 3).

**Figure 2.** Personal contacts search: contact import screen. This screen allows users to import existing contacts from an external source (eg, email) and these contacts are then matched against publication data from the RNS.

**Initial Import**

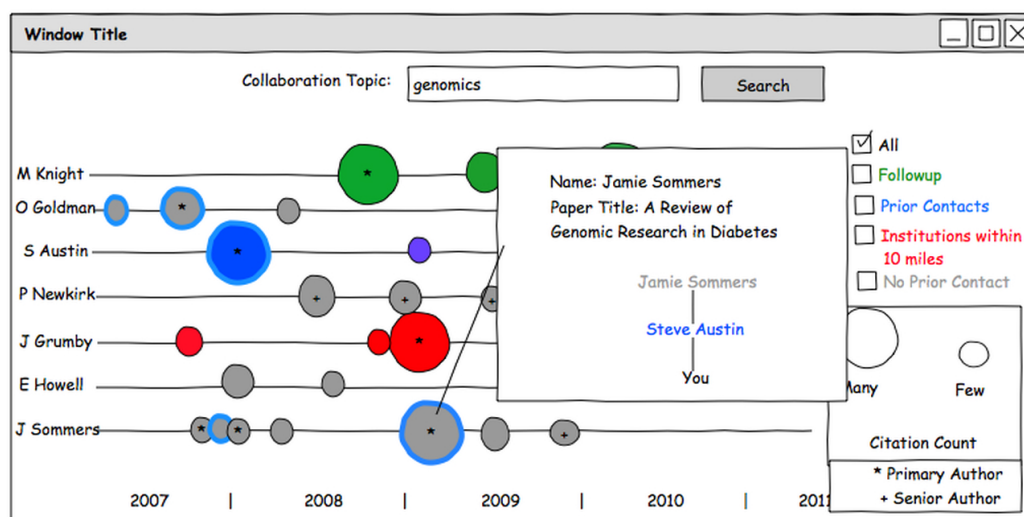
Step 1: Import Your Contacts

Step 2: Select Contacts

Select the email contacts you wish to include when searching for collaborators. The people chosen here will be ranked higher in lists compared to collaborators with similar levels of experience.

<input type="checkbox"/>	Name	Institution	Number of Emails	Most Recent	Keywords
<input checked="" type="checkbox"/>	Steve Austin	Texas	104	Jan 1, 2011	engineering, physics
<input type="checkbox"/>	Oscar Goldman	NIH	65	Jul 1, 2011	genomics, cancer, statistics
<input type="checkbox"/>	Jamie Sommers	PITT	23	Feb 1, 2011	diabetes, immunology

**Figure 3.** Personal contacts search results. This screen shows a list of collaborators who have published on the topic “genomics”. Their publications are color-coded: red indicates institutions within 10 miles of the user, blue means the author was on the user’s contact list, green means the user has marked the collaborator for future contact, and gray is the default color. Circles can be coded with blended colors to indicate multiple categories. Thus, purple indicates nearby (red) authors on the contact list (blue). The circles are sized to indicate the number of citations. The user has selected a paper and their relationship with the author is displayed.



### Prototype 2: Collaborator Attribute Search

Seniority can play a major role in collaborator search: junior researchers often seek junior collaborators, perhaps because more senior researchers often decline collaboration requests [5,24]. The second prototype uses a 2-step approach to support the use of seniority in identifying candidates. The use of this tool begins with the identification of a potential collaborator in an RNS, perhaps through browsing lists of participants. The data for this individual is used to formulate a “profile” for subsequent searches, quantifying different aspects of a researcher’s history (eg, overall number of publications, grant

funding) into measures that will be used for subsequent comparisons against other candidates. The user can then search the system for a topic of interest based on research keywords similar to those used in the first prototype.

Similar profiles are then computed for each candidate returned by the topic search and compared to the selected profile. The candidates who are most similar to the selected profile are shown on the screen. Thus, initial selection of a profile of a junior researcher might bias subsequent results to favor other junior researchers (Figure 4).

Search results are shown in a table containing researchers' names, institutions, total number of publications, number of publications matching the search term, the number of years of active publication (a proxy for seniority), an estimate of total research funding (based on grant information), and keywords summarizing their primary research interests. Interactive double-thumb sliders provide the ability to set upper and lower bounds on the attributes in the table ([Figure 5](#)) with histograms on the slider providing a display of the distribution of the given values across the currently active candidate profiles [27].

This prototype also differs from the first ([Figure 3](#)) in terms of both information provided and the representation of that information. Where the first prototype provides chronologically oriented feedback in graphical form along with contact-based information and geographic hints, the second provides tabular aggregate data. The collaborator attribute search prototype also provides affiliation information and additional matching keywords not available in the personal attributes search design. A summary of key features of the 2 prototypes is given in [Table 1](#).

These prototypes were used to elicit feedback from potential users, including both general preferences for collaborator search tools and specific responses to specific design features. Participant sessions consisted of a structured interview and unstructured discussion of the prototypes. The structured interview included questions concerning demographics, social networking applications usage, and workflows for finding collaborators (interview questions are given in [Multimedia Appendix 1](#)). Participants were asked to respond to all questions

that they felt were applicable to their work. The interviewer then described and presented each of the prototypes to the participants, using several screens that simulated possible uses of each system. Participants were asked to identify features of the prototypes that they thought would be particularly useful, to note features that appeared to be less worthwhile, and to describe new features that they might like to see added. Finally, they were asked to provide overall impressions, considering both of the prototypes. Each participant saw both of the prototypes with the order of presentation of the prototypes varied between participants.

Sessions were conducted online using the WebEx Web conferencing tool [28], which was used to present the prototype screens to the participants and to record the screenshots and audio from the sessions. Descriptive statistics were used to characterize participant background, education, and collaborator search behavior. Audio and screen capture recordings of the sessions were analyzed and coded using an open-coding approach [25,29]. Specifically, 1 author (CB) reviewed the audio recordings using descriptive codes to classify participant comments including reactions to the prototypes, statements about collaboration finding practices, preferences/requirements for collaboration finding software, etc. Initial codes were chosen based on content of the interactions and eventually categorized as patterns emerged. Higher-level themes identified during this process formed the basis for categorizing requirements for the functional prototypes. A second author (HH) reviewed all codes and categorization. This study was classified as exempt by the University of Pittsburgh Institutional Review Board, Study #PRO12060527.

**Table 1.** Feature comparison of both Phase 1 prototypes.

Functionality	Prototype 1: personal contacts search	Prototype 2: collaborator attribute search
Search mechanism	Keyword search and link to imported contacts	Browse/search for initial profile, keyword search identifies researchers with similar profiles
Display	Timeline with color-coded glyphs for publications	Tabular grids with aggregate displays of publications, grant funding, institutions, and other keywords
Controls	None	Interactive controls for selecting similarity values for publications, grants, and other values



**Figure 4.** Collaborator attribute search: selecting a profile. A selected profile (“John Logan”) forms the basis for a similarity search (“juvenile diabetes”) that constrains the candidates returned by subsequent keyword queries. Selecting the profile of a junior researcher might bias results of subsequent searches toward junior researchers.

**Prototype2**

**Instructions**

1. List potential collaborators using either a topic or search for a collaborator by name.
2. Select a name from the list.

The system will use the selected person's "profile" to find collaborators with similar profiles.

Current Profile: John Logan

Search Term:

Enter a topic (e.g. diabetes) or a person's name (e.g. John Smith)

	Name	Institution	Total Pubs	Pubs for Topic	Publication Years	Funding	Keywords
<input type="checkbox"/>	John Logan	Alberta	100	10	5	50,000	statistics, diabetes
<input type="checkbox"/>	John Tripper	UCLA	110	9	8	150,000	immunology, statistics
<input type="checkbox"/>	Burl Smith	Florida	85	14	7	75,000	immunology

**Figure 5.** Collaborator attribute search with dynamic filters. The sliders on the publication counts and years are double-sided allowing researchers to restrict the criteria in either direction. The sliders can adjust publication counts, publication years, funding, and number of publications related to the chosen topic (juvenile diabetes). Histograms on the sliders display distribution of the possible values across items in the currently active set [27].

**Prototype2**

Collaboration Topic:

**Instructions**

Click on the publication cells to see recent publications. Click on the funding cell to see recent funding.

Current Followup List: empty

Current Profile: John Logan

☐ Restrict to Followup List

**Sliders**

Publication Count

Publication Years

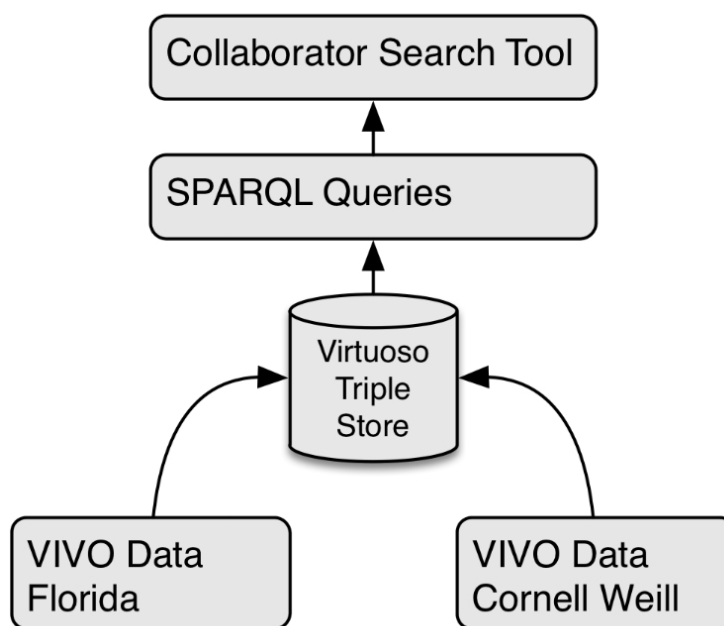
	Name	Institution	Total Pubs	Pubs for Topic	Publication Years	Funding
<input type="checkbox"/>	Jonas Grumby	NYU	123	50	10	500,000
<input type="checkbox"/>	Eunice Howell	Harvard	400	32	40	4,000,000
<input type="checkbox"/>	Peter Newkirk	Oxford	300	23	17	500,000
<input type="checkbox"/>	John Logan	Alberta	100	10	5	50,000

## Functional Prototype Development

Although paper prototypes can provide useful formative feedback for workflow and interface designs, static representations may fail to convey the dynamic nature of interactive tools. A functional prototype was implemented to provide a working example of a tool designed to satisfy the requirements derived from the initial qualitative inquiries. A Virtuoso Open-Source Edition triple store [30] was used to store RDF-formatted VIVO [8] data from the University of Florida

and Weill Cornell Medical College. Data from the triple store was retrieved through SPARQL Protocol and RDF Query Language (SPARQL) [31] queries. The Web-based prototype was developed using the D3 library [32], which uses scalable vector graphics and JavaScript to create interactive data visualizations. JavaScript code developed for the prototype issued SPARQL queries against the Virtuoso triple store, passing the results to the D3 library for visualization. The system architecture is illustrated in Figure 6.



**Figure 6.** Prototype architecture.

### Functional Prototype Evaluation

Evaluation of the functional prototype involved asking participants to use the tool to conduct collaborator search tasks. Each participant session began with a series of questions similar to those used in Phase 1 (see [Multimedia Appendix 2](#) for all questions). The participant then completed 2 collaborator search tasks, 1 using the prototype and the other using their choice of online search engines and repositories such as PubMed. Because the alternative online tools did not provide a directly comparable experience, they were used only to provide contrast to the prototype tool and we do not discuss these interactions here. One task asked participants to find collaborators familiar with Alzheimer's disease, the other specified researchers in Parkinson's disease. These were chosen to be fairly broad to avoid dependence on user expertise and to minimize risk of bias associated with participant familiarity with the research field. The order of both tasks and tools was varied across participants.

After completing the tasks, participants were interviewed regarding the impressions of the prototype. Participant responses to the tool were evaluated using the System Usability Scale (SUS) [33,34]. Additional Likert scale questions asked participants to respond to key features of the prototype on a Likert scale (1-5, 5 being best). Interviews were conducted via WebEx and demographic and search behavior data were analyzed as in the earlier phase of the study.

## Results

### Paper Prototypes and Requirements Analysis

#### Overview

Study participants represented 11 US-based research institutions and 1 European university. Participants included both principal investigators (PIs) and research facilitators (RFs)—members of institutional research offices and others who assist investigators in forming project teams. Most participants in both categories had doctoral degrees ([Table 2](#)).

**Table 2.** Demographics of study participants from the first (N=18) and second (N=20) studies according to research role, education, and gender.

Participant classification	Paper prototype participants (N=18)	Functional prototype participants (N=20)	Total (N=38)
<b>Research role and degree</b>			
<b>Principal investigators</b>			
BS/MS	5	3	8
PhD	6	9	15
PharmD	0	0	0
MD	1	1	2
MD/PhD	0	2	2
Total	12	15	27
<b>Research facilitators</b>			
BS/MS	3	3	6
PhD	3	0	3
PharmD	0	1	1
MD	0	1	1
MD/PhD	0	0	0
Total	6	5	11
<b>Gender</b>			
Male	5	11	16
Female	13	9	22

Responses to structured interview questions regarding collaboration behavior indicated that participants were active researchers with a range of strategies for identifying collaborators. Most respondents (12/18, 66.7% in the paper prototype sessions; 19/20, 95% in the functional prototype sessions) answered all questions completely. Respondents participated in a mean of 5.4 (SD 6.3) research projects in the previous 12 months, interacting with a mean of 31.9 (SD 29.4) unique collaborators. Participants were active collaborators, having been approached with a mean of 5.2 (SD 5.3) offers of collaboration during the 12 preceding months, and having contacted others a mean of 6.7 (SD 13.9) times on average during the same interval ([Table 3](#)).

The approach to finding collaborators most frequently cited was using existing social networks, selected by 72% (13/18) of respondents. Participants who used software tools reported using NIH resources, homegrown systems, a variety of commercial social networking tools, and search engines ([Table 4](#)).

Coding of responses to the paper prototypes led to the identification of several emergent themes, which were used to derive requirements. Specifically, we identified 3 key themes: measuring research productivity, tracking candidates identified as potential collaborators, and conducting complex searches. Specific requirements addressing each of these themes were also identified ([Table 5](#)).

**Table 3.** Participation in collaborations.<sup>a</sup>

Question	Prototype, mean (SD)		Overall, mean (SD)
	Paper (n=18)	Functional (n=20)	(n=38)
2. Approximately, how many funded research projects have you participated in during the past 12 months?			
Principal investigators	3.2 (1.8)	4.9 (3.8)	4.2 (3.2)
Research facilitators	10.3 (13.9)	7.8 (9.1)	8.9 (10.8)
Overall	5.1 (7.4)	5.6 (5.5)	5.4 (6.3)
3. Approximately, what was the average number of collaborators you directly interact with in each project?			
Principal investigators	18.5 (21.9)	13.2 (15.9)	15.6 (18.5)
Research facilitators	5.5 (0.7)	20.4 (33.4)	16.1 (28.3)
Overall	16.5 (20.6)	15.1 (21.0)	15.7 (20.5)
4. What is the total number of unique collaborators you have interacted with in the last 12 months?			
Principal investigators	27.1 (26.8)	29.0 (19.9)	28.3 (22.2)
Research facilitators	15.0 (7.1)	56.2 (51.8)	44.4 (46.9)
Overall	24.9 (24.6)	35.8 (31.7)	31.9 (29.4)
5. During the past 12 months, how many times have you been approached for a formal collaboration?			
Principal investigators	5.9 (3.6)	5.2 (2.9)	5.5 (3.1)
Research facilitators	1.0 (1.4)	5.6 (3.7)	4.3 (3.8)
Overall	5.1 (3.8)	5.3 (3.0)	5.2 (3.3)
6. During the past 12 months, how many times have you contacted someone about a potential collaboration?			
Principal investigators	5.1 (3.0)	3.1 (2.5)	3.9 (2.8)
Research facilitators	11.0 (12.7)	19.0 (34.1)	16.7 (28.6)
Overall	6.1 (5.2)	7.1 (17.3)	6.7 (13.9)

<sup>a</sup>Question 1 results reported in [Table 2](#).

**Table 4.** Tools used to find collaborations. Multiple responses for each question were allowed.<sup>a</sup>

Question	Prototype, n (%)		Overall, n (%)
	Paper (n=18)	Functional (n=20)	n=38
<b>7. How do you usually find collaborators?</b>			
Existing network	13 (72)	16 (75)	29 (76)
NIH resources	5 (28)	4 (20)	9 (24)
Research networking system	3 (17)	1 (5)	4 (11)
<b>8. Are there specific tools you use to find collaborators (eg, PubMed, NIH Reporter, Web of Science)?</b>			
NIH Resources	4 (22)	6 (30)	10 (26)
Homegrown System	4 (22)	2 (10)	6 (16)
Web of Science	3 (17)	1 (5)	4 (11)
SciVal	2 (11)	2 (10)	4 (11)
LinkedIn	2 (11)	0 (0)	2 (5)
Google	3 (17)	0 (0)	3 (8)
Community of Science	1 (6)	1 (5)	2 (5)
<b>9. Do you use general purpose networking applications for professional purposes (eg, FaceBook, LinkedIn, Google+)?</b>			
LinkedIn	5 (28)	7 (35)	12 (32)
Facebook	4 (22)	0 (0)	4 (11)
Google+	1 (6)	2 (10)	3 (8)
Twitter	1 (6)	2 (10)	3 (8)
Friendfeed	0 (0)	1 (5)	1 (3)
<b>10. Do you use a scientific collaboration tool (e.g., VIVO, CAP, Loki, ResearchGate)?</b>			
SciVal	4 (22)	5 (25)	9 (24)
VIVO	1 (6)	2 (10)	3 (8)
Digital Vita	0 (0)	1 (5)	1 (3)
Leo	1 (0)	0 (0)	1 (3)

<sup>a</sup>Users were allowed to select all appropriate values for each question.

**Table 5.** Themes derived from the paper prototypes mapped to the requirements used to design the prototype.

Theme and information needed	Associated requirement
<b>Measure impact</b>	
Which candidates are productive researchers?	1. Chronological display of grants and publications
Who are the leaders in the field?	1. Chronological display of grants and publications
Which candidates have had the most impact?	2. Robust impact measures
<b>Track candidates</b>	
Which individuals are under consideration?	3. Tools for tracking promising candidates
What additional information might be gathered about each candidate?	3. Tools for tracking promising candidates
<b>Conduct complex searches</b>	
Which candidates work in multiple fields?	4. Multiple keyword search

### **Requirement 1: Chronological Display Data of Grants and Publications**

The first prototype included a page that displayed publications on a horizontal timeline (Figure 3). Participants found this screen to be helpful when searching for collaborators, facilitating both

the comparison of candidates on the basis of the frequency and timeliness of their publication on topics of interest, and the identification of key leaders in specific subfields. Simultaneous presentation of both publications and grants was suggested as a possible improvement on the prototype designs.

### **Requirement 2: Robust Impact Measures**

Although participants were interested in seeing quantitative measures of research impact, there was no agreement on specific measures. Citation counts, h-index [35], and journal impact factors were discussed, but there was no consensus as to which would be preferred.

### **Requirement 3: Tools for Bookmarking Promising Candidates**

Both prototypes allowed users to maintain lists of potential collaborators. Participants were enthusiastic about this feature. In addition to a list, participants suggested allowing users to annotate candidates with free-text notes commenting on reasons for selection of each individual or other reminders relevant to the collaborator search tasks.

### **Requirement 4: Multiple Keyword Search**

Participants thought the single keyword presented in both prototypes was too limiting. Several ideas were suggested, including the addition of sliders to adjust the “weight” of keywords in a search, displaying primary/secondary keywords, and including additional keywords in searches.

Participants did not respond well to some proposed features. Contact lists were not viewed as being particularly useful. Some respondents questioned the utility of seeing existing contacts in a search tool because they already know who their contacts are; therefore, seeing them listed in the tool would not be helpful. Participants were ambivalent regarding the physical distance between the participants and their potential collaborators. Some of the participants said this was useful information whereas others said this information was not necessary. Comparison of responses from the 2 groups of users (PIs vs RFs) did not reveal any systematic differences between the groups in responses to the prototypes or requirements for collaborator search tools.

### **Functional Prototype Development**

The interactive prototype implemented most of the requirements identified from analysis of the paper prototype data (Table 6). Requirement 2 (robust impact measures) was not implemented in the prototype because participants were not able to agree on a single method for ranking authors based on bibliometric measures.

The prototype is based on a timeline-based view of candidates’ publication and grant history. The main view displays potential candidates’ names and institutions on the y-axis with each candidate’s grants and publications displayed in a horizontal line on the x-axis. The prototype employs distinct visuals for the grant and publication data. Pairs of green triangles are arranged on the timeline representing the start and end dates of the grants. Rectangles act as bar charts summarizing a candidate’s publications for a year. Keyword filters and a “bookmark” list of candidates identified for subsequent follow-up can be found on the right hand side of the screen (Figure 7).

To find collaboration candidates, the user types a keyword into the search box in the upper left corner (Figure 7). Autocomplete functionality matches user input against the list of all Medical Subject Headings (MeSH) topics from the publications found in the VIVO data. When a search term is selected, the prototype retrieves all candidates who have published articles associated with that term. Candidates are displayed in rows with each row displaying a timeline of the individual’s grants and annual publication counts (since 2000). Publications are indicated as bars, providing a histogram of publication counts categorized and color-coded by keyword for each year.

The height of each bar corresponds to the percentage of the candidates’ publications from a given year that correspond with the associated keyword. For example, given a user search for “neurons”, a candidate who had 6 of 10 publications for a given year matching that term would have a bar for that year that occupied 60% of the maximum possible height. Because mapping MeSH keywords to grant topics is not straightforward [36], all articles for each candidate are displayed even if they do not match the search term(s). Grants are displayed on the timeline as bracketed green arrows indicating the start and end of each grant. This design was chosen as being less cluttered than alternatives that drew lines for the complete duration of the grant.

The selection of a search term also generates the display of a list of additional keywords in a set of checkboxes on the right of the screen. The additional keywords represent the superset of all the terms in the publications retrieved during the initial keyword search. The keywords are arranged alphabetically and color-coded up to a maximum of 4 additional keywords. Clicking the checkbox for additional keywords creates new publication bars corresponding to those keywords providing an opportunity to visualize research activity in multiple areas, thus satisfying requirement 4 (multiple keyword search).

The prototype contains several interactive features. Hovering over the candidate’s name lists their top 8 publication topics and a research overview (if available from the VIVO datasets). Hovering over the publication bars leads to a display of the titles of the publications for a given color-coded keyword plus the summary (eg, 8 of 10 papers for 2012). To interact with grant information, users can move the mouse between the start and end date for a grant. When this happens, a green line connecting the start and end of the grant is displayed. A box above this line displays the title of the grant plus the candidate’s role in the grant (eg, principal investigator, coinvestigator). The dates on the x-axis and the green line allow the user to easily see the duration of the grant.

Users can put promising candidates on a bookmark list. To add a candidate to the bookmark list, the user clicks on a candidate’s name and optionally enters a note describing why the candidate was selected. The bookmark list is shown on the lower right side of the prototype. Source code for the prototype is available in a GitHub source code repository [37].



**Table 6.** Requirements mapped to prototype functionality included in the working prototype.

Requirement	Prototype feature(s)
1. Chronological display of grants and publications	X-axis used as a research history timeline Publications shown as rectangles Grants shown as triangles
2. Robust impact measures	Not implemented
3. Tools for tracking promising candidates	Candidate names can be added to a bookmark list shown alongside time-lines Users can record notes about candidates
4. Multiple keyword search	Users search for 1 keyword Checkboxes allow users to add up to 4 additional keywords

**Figure 7.** Screenshot of prototype. An initial search for the term “neurons” has been augmented by selection of additional terms (“pyramidal cells”, “Parkinson disease”, “neurodegenerative diseases”, and “neural pathways”) from the list of terms associated with neurons (right column). The rectangles represent the frequency of categorized publications, color-coded by each MeSH term. Green triangles represent the start/end dates for a collaborator’s grants. When the user mouses over an endpoint of a grant, a line is drawn showing the grant’s full extent and a tooltip describing the grant is also shown. Researchers of interest can be added to the follow-up list (lower right) by clicking on the name and adding a descriptive comment.

## Functional Prototype Evaluation

A total of 20 participants from 12 US-based institutions were recruited to evaluate the functional prototype (Table 2). Similar to the first phase of the study, recruitment included individuals involved in biomedical research. Participants were comparable to participants from the earlier inquiry in participation in funded projects and collaborator search patterns (Tables 3 and 4).

The participants evaluated the prototype using the SUS [33] (Table 7). The SUS employs a set of 10 Likert-type questions. The overall test is set on a scale from 0-100 (where 100 is represents the best possible score). The mean SUS score for all participants was 76.4 (SD 13.9). For PIs, the mean was 77.5 (SD 14.0), and the mean for RFs was 73.0 (SD 14.3). According

to Bangor [34], a score greater than 70 represents a passable system from a usability standpoint. Although small sample sizes ( $n=5$  for RFs) prevent statistical comparison, results across the 2 participant groups seem comparable. Examination of responses to individual questions revealed a mixed picture: although respondents generally agreed that the system would be learnable, responses to other questions suggested potential concerns regarding topics such as complexity, anticipated frequency of use, inconsistency, and the need for support in using the system (Table 7).

Additional Likert scale questions rated functionality of the prototype. On a scale of 1 to 5, with 5 indicating a most useful feature, all features (except 1) scored greater than 4 (Table 8).

**Table 7.** Functional prototype usability results: mean and standard deviations for the individual SUS questions used in the evaluation phase (1=strongly disagree, 5=strongly agree).

SUS question	PIs, mean (SD) (n=15)	RFs, mean (SD) (n=5)	Overall, mean (SD) (n=20)
I think that I would like to use this system frequently	2.9 (1.5)	3.6 (0.55)	3.1 (1.4)
I found the system unnecessarily complex	4.3 (1.0)	4.4 (0.89)	4.4 (0.99)
I thought the system was easy to use	4.3 (0.60)	4.3 (0.84)	4.3 (0.66)
I think that I would need the support of a technical person to be able to use this system	4.7 (0.60)	4.0 (1.1)	4.6 (0.83)
I found the various functions in this system to be well integrated	3.5 (0.76)	3.4 (0.81)	3.5 (0.76)
I thought there was too much inconsistency in this system	4.3 (0.87)	4.0 (1.0)	4.3 (0.86)
I would imagine that most people would learn to use this system very quickly	4.2 (0.66)	4.2 (0.45)	4.2 (0.62)
I found the system very cumbersome to use	4.1 (1.1)	4.0 (1.2)	4.2 (1.0)
I felt very confident using the system	3.9 (1.1)	3.6 (0.55)	3.9 (0.99)
I needed to learn a lot of things before I could get going with this system	4.3 (1.1)	3.8 (1.6)	4.2 (1.1)

**Table 8.** Mean and standard deviations of scores for Likert questions<sup>a</sup> regarding features within the prototype.

System functionality	PIs, mean (SD) (n=15)	RFs, mean (SD) (n=5)	Overall, mean (SD) (n=20)
Overall timeline format	4.7 (0.59)	4.4 (0.89)	4.65 (0.67)
Height of the publication bar	2.8 (0.94)	3.2 (0.83)	2.90 (0.91)
Document data available on hover	4.4 (0.91)	4.2 (0.45)	4.35 (0.81)
Grant title and role available on hover	4.8 (0.41)	4.0 (0.0)	4.60 (0.50)
Grant start and end dates indicated on timeline	4.7 (0.62)	3.0 (0.0)	4.25 (0.91)
Ability to add/remove collaborators to a list	3.9 (1.1)	4.4 (0.89)	4.05 (1.1)
Ability to add notes regarding candidates	3.9 (1.2)	4.4 (0.89)	4.05 (1.1)
Ability to add/remove additional keywords	4.3 (0.88)	3.8 (0.83)	4.2 (0.88)

<sup>a</sup>On a 5-point scale (1= useless, 5=useful).

Overall, the participant reaction to the working prototype was positive. The combination of publication and grant information in a single timeline scored the highest (mean 4.65, SD 0.67) of all the prototype features. Participants felt the interface provided insights into the candidate's research interests and past history. The timeline format allowed users to examine researchers' publication history, including both the recency and frequency of publications associated with search keywords. The publications allowed users to categorize a candidate as either a multidisciplinary researcher or a researcher with a single field of research. As with the SUS scores, responses from the 2 groups are roughly similar.

Several improvements to the application were suggested during the evaluations. Multiple participants requested hyperlinks to the PubMed and NIH Reporter records corresponding to items found in collaborator profiles. One evaluator felt that information regarding candidates' academic training (eg, MD or PhD) was important for assembling collaborative teams. Another evaluator observed that papers and grants do not fully describe the value a candidate brings to collaborations, particularly including unique expertise or access to crucial resources (eg, animal models, computing techniques). The

addition of research resource information [38–40] was suggested as a potential solution to this problem.

Anecdotal feedback from participants suggested that interest in collaborator search tools might differ based on the context in which researchers work. Two participants—one from a country with a smaller number of universities and another from a small US medical school (less than 200 faculty)—commented that the lack of resources at their institutions limited opportunities for local collaborations, potentially motivating greater interest in RNS tools.

## Discussion

### Principal Findings

Interactive visualizations may help researchers use RNSs to identify collaborators. Interviews with researchers used paper prototypes to stimulate discussion of desired functionality for collaborator search tools. A functional prototype providing many of these features, including chronological displays, bookmarking tools, and multiple keyword search, was well

received by users. Additional development and evaluation will be needed to gauge the utility of RNS collaborator search tools.

### Building Usable Collaborator Search Tools

Identifying appropriate collaborators is an important task in the increasingly interdisciplinary field of biomedical research. Although RNSs show great promise for aggregating and representing data describing researchers and their potential contributions, the success of these tools will require more than just infrastructure. If RNSs are to play a constructive role in facilitating collaboration, they will need to improve on the established method of using existing collegial contacts to find the “friend of a friend” who might provide needed expertise. To do this, they will need to provide easy access to high-quality data; in effect, they must provide added value unavailable through other means [6]. Furthermore, they must support the potentially different goals of different groups of users [12].

Although previous efforts have investigated collaborator search habits and preferences, relatively little attention has been paid to how interactive tools might meet these needs. Investigation of potential features and how they might be realized addressed requirements identified in earlier studies, including the importance of personal contact lists [6] and geographic location [14], along with others that were implied, if not explicitly discussed, such as the temporal histories of grants and publications. In contrast with computational methods that attempt to model researcher similarity [19,20], the designs considered in this study rely on term matching and visual displays, thus favoring clarity and simplicity at the potential expense of missing latent similarities. Further comparisons of this tradeoff might be an interesting area for future investigation.

Participants in the qualitative inquiries did not respond enthusiastically to some features that were identified as potentially important in prior work [5,6]. In response to the prototype based on personal social networks, participants were not particularly interested either in the use of their personal contacts as seed points or in the use of geographical distance as a criterion for selecting collaborators. However, in both cases participants may have missed the salient point. In the case of personal social networks, participants’ reaction that “they know these people already” may have overshadowed the fact that existing colleagues are important “gateways” to people they do not know. In the case of geographical distance, participants may not have been aware of the potential impact of proximity on collaborative productivity and of the possibility of discovering neighboring, but unknown, collaborators. Whatever the etiology, these findings suggest the likelihood of a range of preferences and styles for searching for collaborators. More fully realized tools might provide users with a range of starting points, views, and filtering options.

Positive responses to the prototype suggest the design provided useful functionality for collaborator searches. Participants found the timeline-based display of publications and grants to be useful for a variety of tasks, including identifying central people in fields, assessing researchers’ levels of activity and finding multidisciplinary collaborators. Timeline displays of publication activity have also been explored in other RNSs, most notably Profiles[15] and SciVal [16].

Participants in the first phase of the study were inconsistent in their comments regarding the role of impact measures in collaboration search processes. Although these metrics were generally found to be of potential use, there was little agreement on which specific measures might prove most useful. It is possible that this lack of consensus is a reflection of the ongoing discussion of the relative merits of different measures [41,42]. Potential design solutions might include displaying multiple impact measures, along with tools for filtering and ranking along individual measures or potentially some weighted aggregate measure.

The results for the SUS present both initial feedback on the usability of the functional prototype and indications of areas potentially in need of further work. The mean SUS score of 76.4 (SD 13.9) provides some validation of the usability of the tool, with particularly encouraging scores for questions regarding ease of learnability and confidence in using the system. Other questions suggest potential concerns regarding unnecessary complexity, potential need for technical support, inconsistency, and the need for training.

A relatively low score for the question involving frequency of use (“I think that I would like to use this system frequently”) is consistent with earlier observation that most researchers do not use online tools to find collaborators (see Table 4) and with the observation that finding collaborators may not be seen as a discrete or frequent task. Further study including empirical comparisons of metrics, such as learnability, would be needed to better understand these preliminary usability results.

Additional Likert questions assessing satisfaction with specific design elements gave generally encouraging results. The lowest score was given to the representation of the documents within the system (“height of the publication bar”), which scored 2.90. During the design phase of the working prototype, several approaches for representing the documents were considered. The initial design suggestion was to use absolute scales making the height of each bar proportional to the number of publications by a candidate that matched the keyword in each given year. This approach was rejected initially because it complicated rendering for candidates with keywords or bars that would contain low but nonzero counts. Furthermore, absolute counts might perpetuate biases against junior researchers, who might be less likely to have many publications matching a single topic in any given year.

Instead, we used a relative scaling approach normalizing the height of each bar to the percentage of that individual’s publications on the given topic for the given year. This design presents its own challenges because researchers with similar ratios but vastly different outputs on a given topic could be represented identically. Alternative representations with appropriate user controls might give users the option of selecting a preferred visual representation and further comparative user testing might be needed to better understand the usability implications of these different layouts.

Questions regarding initial design elements also provide preliminary validation of the requirements identified in the qualitative investigation of the paper prototypes (Table 6). Positive responses to the timeline (requirement 1), the list of

potential collaborators (requirement 3), and the multiple keyword search (requirement 4) suggest that these features might play important roles in production-quality collaborator search tools. However, the current list of requirements and themes is not definitive. Further exploration of user needs, involving a broader set of informants, is likely necessary to capture the possible variations in preferences and working styles for collaboration identification.

These inquiries identified several additional suggested features focusing on the presentation of richer information about potential collaborations. The addition of academic degrees, impact factors, and research resources [38-40] might provide additional perspective on the prominence of potential collaborators. Exploration of the relative utility of these comparative measures might be an interesting focus for future work.

Participant recruitment identified subpopulations of users with potentially different needs and goals for research collaborator search tools. Because recruitment involved a convenience sample [43] based on email solicitations to scientists interested in research networks and subsequent snowball sampling, participants are in no way representative. It is entirely possible that this convenience sample might have introduced biases in the results.

However, we did identify 2 distinct groups with different goals and perspectives. Although the nature of the sample limits generalizations that might be made, PIs appeared to rely more heavily on personal networks than RFs (Table 4). Because the facilitators are generally working on behalf of others, potentially in unfamiliar fields, they might benefit more from interactive tools. Other potential features, such as concept maps relating topics from different fields, might provide additional benefits for research facilitators.

Participants also suggested that contextual differences might make interactive tools more useful to certain classes of PIs. Researchers at institutions that lack opportunities for local collaborations and junior researchers, previously described as relatively impoverished with respect to personal networks of potential collaborators [5], may be those who stand to benefit most from research social network collaboration identification tools.

The concern that collaborator search is not a discrete task that users engage in is consistent with the observation that search engines may lead many users into RNS pages [11]. To be successful, collaborator search tools will have to work within this well-established dynamic, finding ways to engage users who arrive via search engines and providing value beyond simple ranked lists. The functional prototype provides an initial design exploration that might move in this direction, but additional work will be needed to fully integrate this vision within the context of functional RNSs.

Further work will be needed to develop a more complete understanding of the use of collaboration search tools. The small and nonrepresentative sample of participants limits the breadth,

depth, and generality of these preliminary results. Specifically, this study does not address the very real possibility that collaboration search practices and preferences may differ across the wide range of biomedical research collaborations. Differences in researcher backgrounds (basic researchers vs clinical researchers), number of collaborations, size of collaborations, local funding climate and incentives, and the extent to which research is interdisciplinary are just a few of the factors that might influence how researchers might identify potential collaborators and, therefore, how interactive tools might best support this practice.

## Limitations

This project's small sample size limits the generalizability of the results. The convenience sample of 38 participants may not be representative of the greater research community. Generality of the results might also be limited by the diversity of the participant pool, which contained a relatively small number of researchers with medical degrees. Descriptions of collaborator search behavior are limited by reliance on recall-based measures and respondents' definitions of the nature and extent of their collaborations. The limitations of the data used in the functional prototype (2 VIVO datasets) might have influenced users' responses to the tool.

## Conclusions

The landscape of RNSs continues to evolve as more systems are deployed throughout institutions providing researchers novel opportunities for scientific collaborations. RNSs have the potential to play an important role in enabling interdisciplinary science. However, these benefits will not be realized without highly usable and useful end-user applications. Successful collaboration support tools must provide enough value to convince researchers to change established habits, including traditional networking and Web searches. Effectively converting the previously manual and socially complex task of identifying collaborators into a computer search system requires analysis of user needs and how tools might change/impact their workflow.

This qualitative study used semistructured interviews with researchers to gauge responses to paper prototypes for collaboration search tools. This inquiry identified 2 distinct user groups (RFs and PIs), and 3 themes categorizing collaboration search software needs: measure impact, track candidates, and conduct complex searches. Four specific requirements—chronological display of research output, robust impact measures, tools for tracking promising candidates, and multiple keyword searches—were considered for inclusion in a functional prototype, which was reviewed by participants in a second round of qualitative inquiry. Responses on the SUS provided initial formative validation of the design.

Although further inquiry will be needed to understand the similarities and differences between these subgroups, these distinctions illustrate the importance of understanding user needs and of providing functionality that meets those needs.



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CDB developed the paper prototypes, conducted the participant interviews, coded and interpreted responses, developed the functional system, and drafted the manuscript. HH discussed designs, reviewed data coding, reviewed analyses of qualitative data, and revised the manuscript. TKS and MJB contributed to designs of the paper prototypes and of the functional tool. All authors reviewed and contributed to the manuscript. We thank all the participants in the study for their time and insights. We would especially like to thank Holly Falk-Krzesinski who was instrumental in our recruiting efforts. This publication was made possible, in part, by the Lilly Endowment, Inc Physician Scientist Initiative and by the University of Pittsburgh Clinical and Translational Science Institute, NIH Grants #5 UL1 TR000005-08 and #UL1 RR024153-06.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Semi-structured interview questions used in Phase 1.

[[PDF File \(Adobe PDF File\), 4KB - jmir\\_v16i11e244\\_app1.pdf](#)]

## Multimedia Appendix 2

Description: Semi-structured interview instrument for Phase 2 evaluation of functional prototype.

[[PDF File \(Adobe PDF File\), 15KB - jmir\\_v16i11e244\\_app2.pdf](#)]

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## Abbreviations

**MeSH:** Medical Subject Headings

**NIH:** National Institutes of Health

**PI:** principal investigator

**RDF:** Resource Definition Framework

**RF:** research facilitator

**RNS:** research networking system

**SPARQL:** SPARQL Protocol and RDF Query Language

**SUS:** System Usability Scale

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Original Paper

# An AIDS-Denialist Online Community on a Russian Social Networking Service: Patterns of Interactions With Newcomers and Rhetorical Strategies of Persuasion

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## Abstract

**Background:** The rise of social media proved to be a fertile ground for the expansion of the acquired immune deficiency syndrome (AIDS)-denialist movement (in the form of online communities). While there is substantial literature devoted to disproving AIDS-denialist views, there is a lack of studies exploring AIDS-denialists online communities that interact with an external environment.

**Objective:** We explored three research areas: (1) reasons for newcomers to come to an AIDS-denialist community, (2) the patterns of interactions of the community with the newcomers, and (3) rhetorical strategies that denialists use for persuasion in the veracity of their views.

**Methods:** We studied the largest AIDS-denialist community on one of the most popular social networking services in Russia. We used netnography as a method for collecting data for qualitative analysis and observed the community for 9 months (at least 2-3 times a week). While doing netnography, we periodically downloaded community discussions. In total, we downloaded 4821 posts and comments for analysis. Grounded theory approach was used for data analysis.

**Results:** Most users came to the community for the following reasons: their stories did not fit the unitary picture of AIDS disease progression translated by popular medical discourse, health problems, concern about HIV-positive tests, and desire to dissuade community members from false AIDS beliefs. On the basis of strength in AIDS-denialist beliefs, we constructed a typology of the newcomers consisting of three ideal-typical groups: (1) convinced: those who already had become denialists before coming to the group, (2) doubters: those who were undecided about the truth of either human immunodeficiency virus (HIV) science theory or AIDS-denialist theory, and (3) orthodox: those who openly held HIV science views. Reception of a newcomer mainly depended on the newcomer's belief status. Reception was very warm for the convinced, cold or slightly hostile for the doubters, and extremely hostile or derisive for the orthodox. We identified seven main rhetorical strategies of persuasion used by the denialists on the "undecided".

**Conclusions:** Contrary to the widespread public health depiction of AIDS denialists as totally irrational, our study suggests that some of those who become AIDS denialists have sufficiently reasonable grounds to suspect that "something is wrong" with scientific theory, because their personal experience contradicts the unitary picture of AIDS disease progression. Odd and inexplicable practices of some AIDS centers only fuel these people's suspicions. We can conclude that public health practitioners' practices may play a role in generating AIDS-denialist sentiments. In interactions with the newcomers, the experienced community members highlighted the importance of personal autonomy and freedom of choice in decision making consistent with the consumerist ideology of health care. The study findings suggest that health care workers should change a one-size-fits-all mode of counseling for a more complex and patient-tailored approach, allowing for diversity of disease progression scenarios and scientific uncertainty.

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**KEYWORDS**

consumer health information; Internet; online communities; AIDS denialists; quality of health information on the Internet; netnography; qualitative research

## Introduction

### Background

The rising role of new social media in the field of health can adequately be described as a “double-edged sword”. On one hand, new social media can deliver patients empowerment in doctor-patient relationships and be a medium of new evidence-based eHealth interventions and a platform for patient online support communities where they can share useful practical experience on coping with a chronic disease. In short, social media can help create a new type of patient, the ePatient, who is “equipped, enabled, empowered, and engaged in their health and health care decisions” [1]. In contrast, critics of techno-enthusiasts who embrace this new form of communication point out that the Internet in general, and new social media in particular, can help spread pernicious, antiscientific views on health (eg, social acceptance of anorexia [2] or anti-vaccination movement views [3-5]). Thus, the dubious or downright pernicious quality of some of the information circulating on the Internet has rightly been named as a major concern for eHealth [6], and for medicine as a whole as well [7].

### AIDS-Denialist Movement

While some of these antimedicine movements, such as the antivaccination movement, have been the object of extensive scientific research [3-5,8,9], the acquired immune deficiency syndrome (AIDS)-denialist movement has received little attention from social science despite its having been a focus of huge public controversies and a long-standing cause of trouble for medical and activist communities dealing with HIV/AIDS [10,11]. The “AIDS-dissident movement” as they call themselves denies either human immunodeficiency virus (HIV) existence or a connection between HIV and AIDS. The majority of the existing research (eg, [12-16]) is devoted to the analysis of the situation in South Africa where in the late 1990s and early 2000s then-president Mbeki banned use of antiretroviral therapy (ART) used for HIV treatment in state hospitals, which by some estimates resulted in more than 300,000 AIDS-related deaths and hundreds of thousands of new infections [17]. The other large part of the research to date is dedicated to disproving AIDS-denialists views as unscientific (one of the latest and brilliant examples of such studies is [18]). Few studies examine the AIDS-denialist movement as a *movement* and not just a system of *views* (with a notable exception of Kalichman’s [19] and Nattrass’s [20] studies), and to date we are not aware of a single study that explores this movement in Russia or Former Soviet Union (FSU) countries. This is deplorable as the AIDS-denialist movement is alive and well in these countries. While it is difficult to determine the exact extent of the AIDS-denialist movement’s influence on public health, some studies indicate that it is significant in some communities. A survey at minority gay pride events in four American cities in 2005 found that around one third of attendees doubted that HIV

caused AIDS [21]. A survey of people living with HIV (PLWH) of African-American background conducted by Kalichman et al [22] showed that one in five participants believed that there is no proof that HIV causes AIDS and that HIV medicines do more harm than good. AIDS denialism has proved to have a negative impact on those who endorse it. Thus, in the same study it was found that holding denialist beliefs about AIDS was related to refusing HIV treatments and poor health outcomes. AIDS conspiracy theories (see [23] for review of available evidence on AIDS conspiracy beliefs among African Americans) are also an obstacle for HIV prevention and treatment [22,24-26].

The rise and global penetration of the Internet has opened a large window of opportunities for AIDS denialists, who quickly jumped on the bandwagon. As the pro-denialist Group for the Scientific Reappraisal of the HIV/AIDS Hypothesis (“Reappraising AIDS”) wrote on its website: “Thanks to the ascendance of the Internet, we are now able to reinvigorate our informational campaign” (quoted in [10]). The works of Kalichman et al [22], Smith and Novella [10], Nattrass [11], and other scholars underscore the role of the Internet in dissemination of AIDS-denialist misinformation.

Although there are no reliable data on the influence of the AIDS-denialist movement in Russia and FSU countries (either online or offline), Russian PLWH community leaders both in public talks and in informal talks with the current project team members admit that the AIDS-denialist movement is on the rise and that proliferation of social networking services (SNS) in FSU countries contributes to its growing influence. As a leader of one of the most prominent PLWH communities in Russia (who regularly monitors AIDS-denialist activity on the Internet) put it, “we are losing the battle [with AIDS denialists] on the Internet”.

To summarize, the growing presence of the AIDS-denialist movement on SNS presents a serious public health threat, which contributes to higher morbidity and mortality from AIDS and HIV-related diseases, and further spread of HIV among the populace. All this warrants research of the AIDS-denialist movement on the Internet in general, and on the social networking services in particular. To our knowledge, this is the first study of its kind.

### Study Objectives

This is an explorative study of the most numerous AIDS-denialist online communities on one of the most popular social networking services in Russia (its users also include millions of people from other FSU countries). As the spread of denialists’ views and the recruitment of new members into the movement are particularly challenging for public health, we have decided to (1) examine the reasons people come to the group, (2) analyze how the community deals with the newcomers, and (3) describe rhetorical strategies employed by deniers for persuasion in the veracity of their views. Gaining such knowledge could be of significant value for designing



Internet interventions directed at counteracting the influence of AIDS denialists on the Internet.

## Methods

### Object of Study

We have chosen an SNS group (like Facebook groups) with a manifestly AIDS-denialist name, which is open for everybody who is willing to join. By community members, we can mean only those who have formally signed up for the SNS group: in the broadest “actionist” sense, those who participate in its activities regardless of formal belonging to the group; and finally, in the most restrictive sense, only those who formally belong to the community and also participate in its activities. We used the third definition when we drew a map of friendship in the group and the second when we calculated some statistics on activities in the community and for a qualitative analysis of the community posts and comments.

The group is highly visible to people who seek information about HIV and AIDS. Thus, searching the word “HIV” in Russian (at the moment of this paper’s submission) using Google’s search engine (the second most popular engine among Russian users—33.9% of users [27]) returns results that include the group’s name in the top ten list. Similar results are generated from searching “AIDS” on Google and searching either of these words on the SNS search engine. In turn, the group’s high visibility on search engines leads to a higher probability that users seeking information on HIV and AIDS will click the group’s hyperlink (according to the findings of Eysenbach and Kohler [28], online health information seekers inspect the first 10 search results 97.2% of the time).

During the project’s execution (March to November 2013), the group numbered around 13,000 members and had existed for almost 5 years, with the date of the first post being December 8, 2008. The primary group’s mission statements listed on its webpage are “saving peoples’ lives” from the “AIDS industry” and spreading the true word about the AIDS conspiracy. The group contains 21 hyperlinks, the majority of which are other AIDS-denialist groups or their websites on the Internet, other antimedicine groups such as “Vaccines kill”, and nationalistic groups. The group lists nine moderators who have played a crucial role in its functioning by heavily moderating its content. Like all groups in the studied SNS, the group contains a message board called “the wall”, the most visible discussion space that has become the main object of analysis. The “wall” is where most newcomers come and it is also the place where the most heated discussions take place—apparently because it is the best place to post for attracting attention. Besides that, the group site contains 104 documents, hundreds of videos, and 284 “themes” (ie, discussion threads that vary in length from one to thousands of posts). Videos mostly include pro-denialist ads, various news items, or heavily criticized antidenialist materials. Most are re-posted from regular media and YouTube, some of which were made in Russian, with others dubbed by the sources from which they were borrowed. The main topics in discussion threads include “scientific” justifications of AIDS-denialist assertions, legal advice, discussion of AIDS in terms of conspiracy theory, advice on how to deal with medical

institutions, advice for pregnant women, “harm and consequences of ART”, and direct advice topics such as “Don’t test for HIV!”. While antidenialist activists claim that such direct calls contradict Russia’s HIV laws, Russian legislation does not directly prohibit dissemination of false medical information.

### Data Collection

For outlining the group’s general picture, we used VKminer, a software developed in our lab that helped us map the friendships in the group. With this program, we also were able to download the content of the wall for the entire 2-year period and count the number of posts, comments, and likes for every participant in the “wall” activities.

We used netnography as a method for collecting data for qualitative analysis. Netnography is “a specialized form of ethnography adapted to include the unique computer-mediated contingencies of today’s social worlds” [29]. To put it more simply, netnography is ethnography on the Internet, which means that the observations are not quantified but analyzed in-depth using various qualitative data analysis methods. We observed the community during 9 months (at least 2-3 times a week and sometimes more frequently if there was “something up” in the community like a scandal or extremely frequent posting and commenting). The group is highly moderated, so in our case netnography, which implies frequent periods of continuous presence in the field, turned out to be particularly useful. Some posts and comments (especially those that were written by adherents of the scientific theory of HIV) lived for an hour or less before moderators removed them. Thus, we downloaded posts immediately in many cases, as there was substantial risk that we would not see them the next time we visited the community. Unable to monitor 24/7, we lost some posts and comments but were able to guess the gist from other posters’ later comments. In total, we downloaded 4821 posts and comments for qualitative analysis.

### Data Analysis

Social network analysis with NodeXL was used for mapping the group’s “quantitative portrait”, while for analysis of qualitative data we used Grounded Theory approach [30]. We used freeware QDA package Open Code 4.01 for computerized qualitative data analysis. While doing netnography, some notions that could be coded already cropped up, so when we started coding we had the initial set of codes (and memos indicating some potentially fruitful directions). Some of these codes did not work out; for instance, we thought the question of homosexuality would be controversial and actively debated but we were wrong. Only some members expressed homophobic attitudes, and their posts did not generate substantial reaction from other online community members. Also, at the start of the project our research questions were too broad to use as codes. So we started open coding, that is, coding fragments of text relevant to the research questions. In so doing, we started seeing some patterns in the texts, which we had not thought of at the start of the project. Thus emergent codes become apparent while, as we noted, some old codes turned out to be fruitless. As a result, we succeeded at achieving conceptual saturation, when



each category or theme relevant for our study was developed “fully in terms of its properties and dimensions” [30].

Some of the participants used their real names (or at least, positioned themselves this way), some fearing possible stigmatization used fictional names (and informed the community members about it), and some went by nicknames. We use pseudonyms in this paper when we present community members’ quotes.

## Results

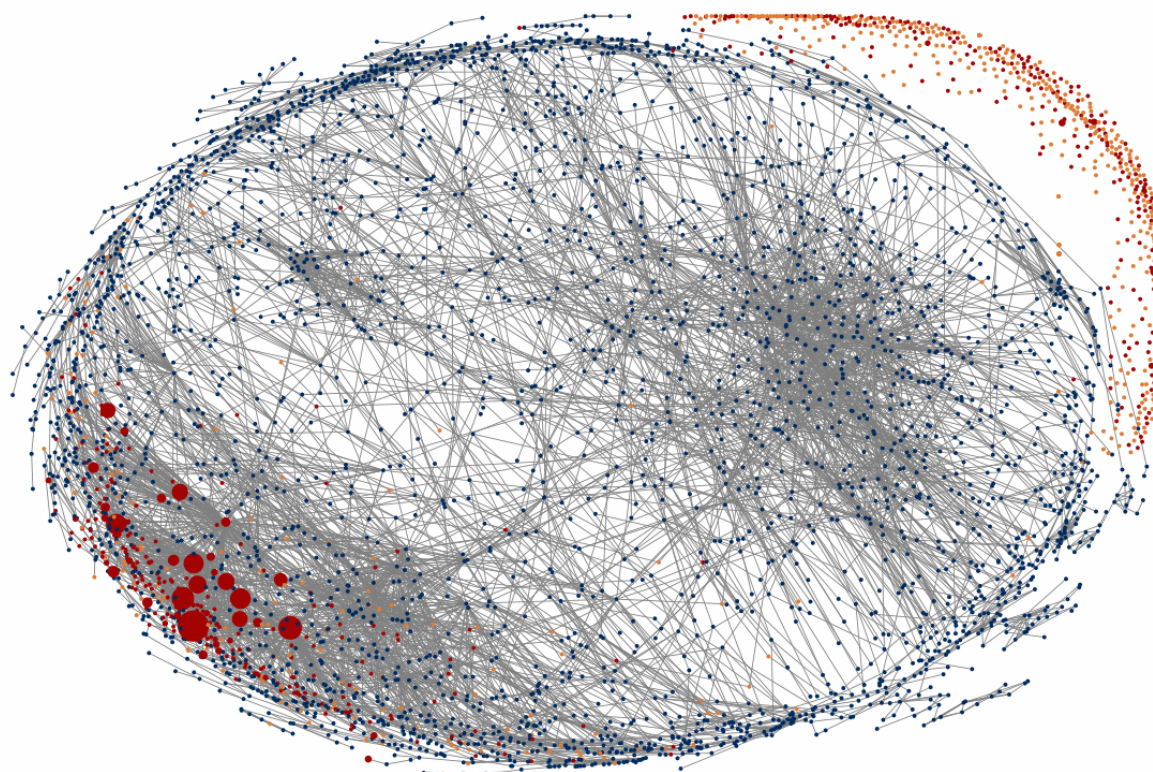
### Community Structure and Participants’ Activity

Analysis has shown that 61.31% (8051/13,131) of the group members were isolates, that is, they had no friends in the group. The majority (3425) of the non-isolated members belonged to the largest connected component, while the second largest component contained only 20 nodes. The visualization of the largest connected component and of the 700 active isolates is

represented in [Figure 1](#). By “active”, we mean the group members who participated in the group activity at least once in the form of a post, a comment, or a like. The size of nodes is proportional to the participants’ contribution to the content generation.

We found that the share of active online community members was 9.39% (1234/13,131). Only 4.32% (468/13,131) of group members generated content (posts or comments) while the rest, 5.07% (666/13,131), were only attention-givers in the form of “likes”. In sum, the community consists of a small core producing all the content and a large number of readers or potential readers, a small proportion of whom sometimes approves of what they read. Such community structure is not unique; however, it is not typical for inactive groups, where a dense core is seldom observed and the scarce activity is usually more evenly distributed among the moderately active members (unless such groups are “fanpages”). The dense core is therefore an indicator of intensive group dynamics and real communicative processes in the community.

**Figure 1.** Friendship network of the community (red: participants who post and/or comment; orange: those who only give likes; blue: non-active members; non-active isolates excluded).



### Reasons for Coming to the Group and Typology of Newcomers

Most people came to the community for the following reasons: their stories did not fit the general AIDS disease narrative (see below), curiosity, concern about HIV-positive tests, desire to dissuade the community members from false AIDS beliefs, or to support them in their struggle for truth. Many of the newcomers were in confusion and despair because of their diagnosis. Consider the following quote from a newcomer’s post that illustrates one of the most important reasons for coming to the group that we were able to pinpoint—a contradiction of

the newcomer’s life story with her vision of the disease progression:

*Here what I did when I was initiated into the caste of “the chosen”—I sought for anybody to talk about it openly and apart from psychological support counselor from AIDS-center I didn’t find anybody. After conversation with their psychologist I came to the conclusion I should get registered but for some reason someone inside told me: don’t rush...wait...My husband took the test and got a negative result! And from this moment the internal struggle began and*

*soul-searching, and I would say God helped me to find you because before that I hadn't even used [the name of SNS]. [Olga]*

From this quote we can see that Olga started to doubt the “official theory” after she had learned that her husband was negative despite their having unprotected sexual relations, which, as she sees it, contradicts the HIV science theory according to which positives infect negatives. Another group member tells how her viral load has decreased “by itself” and her immune status rose, interpreting it as evidence of the fallacy of the “official theory”:

*When I was pregnant I was diagnosed with HIV. And on the fifth month [of my pregnancy] my immune status is 350 cells – it is very little. it is thought that if less than 250, it is already AIDS. Viral load 85000...Next test: Immune status 750, viral load – 25000. That is, I did not take any medicines, and the viral load decreased by itself. According to the theory this is impossible. I asked them where did 60000 viruses go, one said “he doesn't know”, the second that “maybe they mixed up something in the lab”...At this point I stopped coming to the AIDS-center.*

Thus, from community members posts (old and new), we can see that their stories or lab tests results contradict (or seem to contradict) what we call the “AIDS-metanarrative”. Though each member writes about one or two contradictions with this metanarrative, combining our findings we can construct a schematic narrative, many elements of which are widely known to the public from popular and popular medical discourses. This metanarrative can be outlined as follows.

People get infected with HIV in situations of risk (such as needle sharing in injection drug use or unprotected sexual contact). Then in a certain period, their immune system (CD4 count) starts to lower and viral load starts to rise, and at a certain point their depleted immune system fails to defend them from a range of diseases and they die, unless they start taking highly active antiretroviral therapy (HAART). During the entire period of the disease progression, they are contagious and infect their sexual or injection partners. Pregnant women have a high chance of transmission of HIV to their children if they do not take antiretrovirals during pregnancy.

However, there are some points that contradict or seemingly contradict this AIDS-metanarrative that we saw in the community members' posts: (1) absence of a risk situation: “I couldn't get it because I have never used drugs or cheated on my partner, and I'm 100% sure that he didn't cheat on me either”, (2) nontransmission of HIV from a positive to a negative: “I live with my husband and we have unprotected sex, and still seven years later he's negative”, (3) nontransmission of HIV through sharing injection equipment: “My friend was a junkie and he shared needles with other junkies but he never caught HIV”, (4) lowering of the viral load without treatment: “My viral load dropped despite I faked taking HAART and threw out the pills”, (5) rise of the immune status without treatment: “My CD4 count rose even though I didn't take HAART”, and (6) death of HIV-positives despite taking HAART: “People take HAART and die nevertheless”.

On the basis of strength in the AIDS-denialist beliefs, we have constructed a simple typology of the newcomers that consists of the three ideal-typical groups: (1) the convinced: those who already had become deniers before coming to the group, (2) the doubters: those who presented themselves as undecided as to the truth of either HIV science theory or AIDS-denialists theory, and also often posed uncomfortable questions that cast doubt over denialist views, and finally (3) the orthodox: those who openly held HIV science views.

### Patterns of Interactions Between the Group's Experienced Members and the Newcomers

Reception of newcomers and the choice of a rhetorical strategy addressed to newcomers strongly depended on their presentation of self to the group. The decisive factor that determined the type of reception received by newcomers was, unsurprisingly, their “belief status” in the denialist views expressed in their post, although other factors such as confusion or self-confidence, cheerfulness, or a gloomy tone also mattered to some extent. Reaction of the group can be understood as positive, neutral, or negative depending on the comment's sentiment to the newcomer's post and also by the quantity of “likes” the post gets. Although we did not calculate “likes” formally for every newcomer's post, the difference in likes between the “convinced” and the other types of newcomers is striking. While the “convinced” often got from 10-20 likes, all other newcomers got 0-3 likes. The content of the post with the highest chance of getting many likes was the “thank you” message to the community or/and expressed despal of HAART. Consider the following post from Natalia that got 16 likes:

*Hey guys, thank you for your community! I got “+” on the tenth week of my pregnancy. Husband “-”!!! I thank him that he didn't turn his back on me, we together started to figure out what's going on, to enter into details. In AC [AIDS-Center] they prescribed inviraza, kombivir, and ritonavir. Two pills of each medicine twice a day! It's 12 pills a day!!!! Holy shit! Considering that even when I have a banal cold I have never taken anything. AC worked all my nerves!!! After visiting them I had a stomach pain! Having read all your posts, having watched the videos I got convinced that all this is a big swindle. I won't go to AC ever. The health of my child and my nerve cells are more important. P.S. I flushed the pills down the drain! Thank you so much!!!*

But apart from likes, community members gave a verbal welcome in their comments to her post. She received emotional support and welcome messages, such as, “Welcome to the group!”, “Good luck and patience!”, and “Keep us informed about your battle with AC”. We call this strategy “rhetoric of reinforcement” as the newcomer is already convinced in AIDS-denialist views and the community only supports and reinforces the views and the feeling of community belonging.

A different situation arises with the doubters. Any degree of doubt in the truthfulness of denialists tenets almost always caused an ostentatiously cold or hostile reaction. Nadia drove this point home in her answer to Jenia, a “doubter”:



*Jenia, I think that our group should be only for true dissidents, those, who have no qualms about their positions! And you create your own group for those, who're neither here, nor there. And you will persuade each other, whether the virus exists. Let's not interfere with each other. Sometimes one NEEDS necessary information—on lawyer's advice, refusal [from medical treatment], and this information is just impossible to find in the mumbo-jumbo of those who still need to be persuaded and seek an answer to the question "whether the virus exists?"*

By far the most popular answer that the doubters received to their questions was advice to "read the group's materials":

*There are a lot of materials in the group. Please, understand us, we can't answer the same questions every day, every day we are asked the same things, by familiarizing yourselves with the group materials you will understand who benefits and how, and there is a lot to benefit from. [Any]*

Such refusals to answer the questions and reluctance to interact (which can be dubbed "strategy of avoiding") met resistance from the doubters. Despite the cold reception and answer-dodging, the doubters tried to get answers to their questions by the following rhetorical devices: blaming the group, justification of their doubts, and appeal to the group's mission. For instance, Alena blamed the group and simultaneously appealed to the group's mission—spreading the word about HIV-conspiracy:

*Is it so hard to copypaste the specific links? Oh yes, it's much easier to write a derogatory message—10000 characters long—about the lack of intelligence of the one who's asked the question. Just be forewarned—after such hospitable reception I (and other interested people) have a right to think about you whatever we want. If you want to be heard and understood, learn tact and respect to the interlocutor. Aggression is inappropriate in preaching.*

The experienced group members to whom these requests and reproaches were addressed reacted in a defensive or even hostile manner. They explained their annoyance by denying allegations that they tried to "make" someone believe in anything, thereby appealing to the principle of "free choice". Thus, Georgiy responded to Alena's accusations: "This is not a place for preaching, and nobody makes you believe in anything. Actually, nobody owes you anything. You yourself choose what to believe in and whom to believe". Alisa supported him:

*Read the stories of people in the group. There are people here that have [been diagnosed with] HIV, and they have healthy children, don't drink tera [ART], don't infect their wives (husbands) —don't these facts seem to you striking? And whether believe us—healthy people or people who are dying from tera and advocate tera at that—is up to you.*

It is worth noting that newcomers often came to the community seeking advice, for instance, whether to take HIV test or not. Despite the experienced community members' main advice of referral to the group materials, they also did give direct advice.

It should be stressed that such advice in the overwhelming number of cases contradicted the seasoned community members' position on freedom of choice and unwillingness to "enforce" their own point of view as this advice was clearly based on the denialist dogma. The most frequently observed advice that the newcomers received were "Don't take HIV tests!", "Don't go to the AIDS-center!", "Don't take ART!", "Don't believe the HIV tests results!", "Treat real diseases, not test results", "Don't succumb to stress as stress causes real diseases", "Live on as though there was never HIV positive test, enjoy your life, you're not sick with anything", and "Live a healthy lifestyle and everything will be all right."

Finally, the last type of newcomer according to our typology, the orthodox, come to the group page either out of curiosity or willing to persuade the community members in the falsehood of their beliefs. As we wrote above, the overwhelming number of the posts and comments written by the orthodox were swiftly removed, but the netnography method allowed capturing interactions of the hard-core deniers with the orthodox. In this case, deniers realized "strategies of protection", and the orthodox were subjected, as a rule, to collective ridicule and insults. Marat responded to a newcomer, who presented himself as a doctor: "Kirill, the most amazing people are those, who got their education and still continue to push this HIV/AIDS scam, or some are ready to sell their souls for the money???"

Despite the experienced community members' reluctance to interact with the newcomers who were doubters, the latter often succeeded in dragging the former into conversations and overcoming the "strategy of avoiding". In this case, dedicated denialists exercised various rhetorical strategies in order to defend their position and simultaneously try to persuade doubters of the truthfulness of their ideas. Use of rhetorical strategies (ie, "strategies of persuasion") with the doubters and unwillingness to interact with them may sound like a contradiction, but we should be aware that these strategies are addressed not only to a particular doubter but to the wider audience—all those who watch these interactions without engaging in them. (According to the group's statistics, the daily average number of unique visitors from May 15 to June 15, 2013, was 381). Having analyzed and combined the denialists' arguments scattered on different discussions and disputes on the wall, we have determined the main rhetorical strategies of persuasion.

## Denialists' Rhetorical Strategies of Persuasion

### Scientific Arguments

Denialists present the scientific community as having no proof of HIV existence, and the evidence produced by scientists as unconvincing or fabricated. However, in the modern world it takes science to disprove science. This is why denialists engage in "selective distrust of scientific authority" [10], that is, discarding the findings on HIV/AIDS that are agreed on in the scientific community, but putting forth what Natrass calls "hero scientists" [20] who have evidence against this "concoction" but are silenced by those who take part in the global conspiracy (see below). Duesberg was by far the most popular "hero-scientist" referred to by the community members; others mentioned by the community members most frequently were

Nobel prize winner Kary Mullis, and two Russian medical professionals—general practitioner Irina Sazonova and autopsist Vladimir Ageiyev. It should be noted that none of the Russian hero-scientists possesses credentials comparable to those of Duesberg and Mullis.

### ***Ideological Arguments***

Denialists claim that the myth of HIV appeared as a result of a global conspiracy between a secret world government and “Big Pharma”, who enforced the acceptance of this myth first in the United States and then in all other countries.

### ***Underscoring the Importance of Personal Experience and Critical Thinking Compared to Unreflective Acceptance of Abstract Medical Knowledge***

Thus, Alla wrote to Kirill, who presented himself as a doctor: “There are people here, who came to these conclusions [HIV is a myth] not on the basis of propaganda but on the basis of PERSONAL experience”. As we have shown earlier, this personal experience in many cases contradicts the dominant AIDS-metanarrative. This strategy is similar to the one described by Natrass—the use of “living icons” [20] (ie, people living with “attributed” HIV diagnosis for prolonged periods seemingly without developing the disease symptoms) as the living proof of AIDS science’s fallacy (the most famous example being Christine Maggiore, an AIDS denialist who eventually died from AIDS). In our case, however, the living proof is not an AIDS-denialist celebrity from abroad but a regular person, that is, a group member who is present, thus making the denialist cause seem closer and more personal.

### ***Underlining Material Interest of “Aidsologists”, Who Aim to Sell as Many Pills as Possible, Compared to the Denialists’ Lack of Material Interests***

Cui bono argumentation is frequently used by AIDS-denialists, who constantly reiterate that they have no financial stake in the issue as opposed to “Aidsologists” who are materially interested in propagating the “AIDS-myth.”

### ***Pointing Out Suspicious Practices of AIDS Centers***

AIDS centers’ specialists obscure, which for denialists means that they have something to hide. They do not give health records and test results to the patients but read these results to them instead. Indeed, in many Russian AIDS centers, patients’ health records and tests results are not given to them, which generates suspicion on the part of some patients. Denialists interpret these practices as the evidence of doctors’ participation in the global conspiracy.

### ***Claims About Uselessness and Toxicity of Antiretroviral Therapy***

One community member, Luda, writes “HIV is a pseudoscientific terrorism. People die from...drugs or poisonous therapy they receive”.

### ***Use of “Morphed Science”***

Morphed science (unconnected statements from legitimate sources taken out of context that are dispersed throughout the text) is used, as well as an abundance of highly technical jargon

or as Kalichman calls it “technobabble” [19]. Kalichman writes about the purpose of this strategy: “Even scientifically trained readers will get lost in the illogic of morphed science. Morphed science can convince the untrained reader that the author is knowledgeable about AIDS while not understanding a word of what they are saying...The objective of technobabble in denialism is to present a façade of science within which it is easy to lose track of the details. Like morphing science, the goal is that readers render the material credible even if utterly unintelligible” [19].

### ***Doubter Reactions to Strategies***

We would like to conclude this section by describing the doubters’ reactions to rhetorical strategies of persuasion directed to them. In most cases, they remained undecided as illustrated by the following quote from newcomer-doubter Semen: “There is no point to delve into this heap of articles and video materials, as both sides have a lot of evidence”. We found only a few cases when a doubter thanked the group for clarifying the issue and dispelling doubts as to the veracity of the denialist tenets. However, we cannot conclude based on these findings that denialists’ rhetorical strategies are ineffective, after all, many experienced group members wrote that initially they themselves had had doubts that were later dispelled as they obtained deeper knowledge of denialist evidence. As to answering the question of how these rhetorical strategies affect “lurkers”, a study with a totally different design is required. We observed only a single case when after interaction with the community’s experienced members, a newcomer-doubter took a pro-scientific stance on HIV.

## ***Discussion***

### ***Principal Findings***

Contrary to the widespread public health depictions of AIDS denialists as “crazy”, “delusional”, or insulated from reason by psychological “denial” [19], our study suggests that some of those who become AIDS deniers have sufficiently reasonable grounds to suspect that “something is wrong” with the orthodox theory. This is mostly because their personal experience contradicts the AIDS-metanarrative taken from medical and popular discourses, and it is commonly considered to be quite reasonable to have doubts when empirical facts do not fit the theory. Admittedly, not everybody would reject the medical and scientific knowledge on the basis of some facts that do not seem to fit in commonly held theories. Other factors influencing people to become AIDS denialists are obviously in play (psychological traits and trust in medical institutions will probably be some of them), but to portray these people as utterly irrational would be equally fallacious. Of course, this contradiction occurs not because the scientific theory of AIDS is wrong but because the AIDS-metanarrative is an oversimplified form of this theory leaving no room for different disease progression scenarios and scientific uncertainty. Smith and Novella wrote to this effect: “Oversimplifying AIDS science to the public lends itself to exploitation by AIDS deniers who remain ‘alive and well’ years after diagnosis with HIV. Yet the reality behind the scenes is often quite different. Every medical field has its legitimate controversies and complexities, and the

process of science is often messy. Denial groups exploit the gap between public education and scientific reality” [10]. Odd and inexplicable (at least from the patients’ perspective) practices of some AIDS centers exploited by AIDS deniers for their own purposes only fuel suspicions of people who face this gap. Concordant to Blume’s [31] study of antivaccination movement, we can conclude that public health practitioners’ practices may play a role in generating AIDS-denialists’ sentiments.

We do not try to assert that understanding the multifaceted phenomenon of why some people become denialists can be achieved purely by analyzing their rational reasons for accepting denialist views. Obviously, there are deep psychological reasons for that. A well-known psychological concept of “being in denial” about one’s illness that brings both psychological (tranquility) and practical (one does need not to embark on a complex regimen of pill-taking) benefits is certainly a major factor in many cases of the denialist views. However, in this paper we tried to shift the focus from a traditional perspective of analyzing people’s psychological traits and their proclivity to being in denial to the question of social-structural production of denialism.

On a practical level, this means that in consultation with patients, practitioners should change a one-size-fits-all mode of counseling (the AIDS-metanarrative telling) to a more complex and patient-tailored approach, allowing for diversity of disease progression scenarios and open admission of scientific uncertainty on some HIV issues (when necessary) with concomitant emphasis that diversity and uncertainty do not undermine the basic principles and findings of HIV science. Elimination of the AIDS centers’ “shadow practices” could also be very helpful in building and/or sustaining trust in doctor-patients relationships and dispelling the conspiracy myth propagated by AIDS denialists.

Studying interactions of the experienced community members with the newcomers, we have also seen that the former do not try to recruit the latter by any means necessary (contrary to religious cults, eg, [32,33]) but instead highlight the importance of personal autonomy, critical thinking, and freedom of choice in decision making (again the picture that contradicts the familiar portrait of AIDS denialists as irrational fanatics). This finding is in accordance with the popular, or even dominant, consumerist ideology of health care, according to which patients are informed consumers that critically assess medical advice before accepting or rejecting it [3,31,34,35]. As Blume wrote about consumerist ideology in the case of the vaccination opponents: “As citizens, we were increasingly encouraged to think of ourselves as critical consumers, taking responsibility for our own health. Consumers, informed and empowered, have the right of choice...so why not here? Isn’t a critical stance towards vaccination, and hence the possibility of alternative viewpoints, a logical consequence of this ideological shift?” [31]. We may observe the same logic

with the AIDS denialists. While patients’ growing power in modern health care is certainly a laudable and useful phenomenon [36], it has its downside—the erosion of trust in medical and scientific institutions in general, and consequently, adoption of antiscientific and destructive views. The AIDS-denialist movement bears witness to this.

This is not to say that the AIDS-denialist community is not interested in recruiting new members. We saw that they provide emotional support to the “convinced” type of the newcomers. In addition, we know that, though without enthusiasm (the lack of which can probably be attributed to fatigue of the experienced members of constantly answering the same questions), denialists employ rhetorical strategies of persuasion, which target not only the doubters but undecided lurkers as well.

We have also seen that members of the AIDS-denialist online community are not a homogenous group as they vary in the extent of their involvement in the group activities and in their belief status in denialist tenets. Further research is needed in order to address the issue of stratification among AIDS-denialist communities. While there is little use debating with hard-core denialists, we suggest spending time and resources on the doubters who have doubts both in the HIV science and the denialist views. Social network analysis methods could be particularly useful for determining “susceptibles” (similar to what is done for identifying susceptibles in other fields [37–40]) with regards to which Internet interventions designed to combat denialist views could be effective and efficient.

## Future Considerations

Comparison of denialist rhetorical strategies of persuasion identified in this paper with rhetorical strategies of the antivaccination movement [3,31,41,42] reveals considerable similarity. Toxicity of science-based treatment, sagas of brave scientists challenging medical orthodoxy, and other rhetorical devices that are employed in both movements are all cases in point. A comparative project addressing the issues of similarity and difference between these movements (and other antiscientific movements) would allow us to discern specific features of each movement and to understand what these movements have in common in terms of sociodemographic characteristics of their participants, interpretative frames, modes of action, and collective identities.

Finally, we need to gain deeper insight into why some HIV-positive people become AIDS denialists. Although we have received some preliminary answers to this question based on qualitative analysis of posts in this research, more work needs to be done. In-depth biographical interviews with HIV-positive AIDS-denialist movement members would certainly shed light on this question. Understanding the factors influencing adoption of denialist views could be very useful for practical efforts to combat the spread of AIDS-denialist sentiments.

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**Conflicts of Interest**

None declared.

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## Abbreviations

**AC:** AIDS Center  
**AIDS:** acquired immune deficiency syndrome  
**ART:** antiretroviral therapy  
**HAART:** highly active antiretroviral therapy  
**HIV:** human immunodeficiency virus  
**PLWH:** people living with HIV  
**QDA:** qualitative data analysis  
**SNS:** social networking services

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Original Paper

# Understanding and Predicting Social Media Use Among Community Health Center Patients: A Cross-Sectional Survey

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## Abstract

**Background:** The use of social media by health care organizations is growing and provides Web-based tools to connect patients, caregivers, and providers.

**Objective:** The aim was to determine the use and factors predicting the use of social media for health care-related purposes among medically underserved primary care patients.

**Methods:** A cross-sectional survey was administered to 444 patients of a federally qualified community health center.

**Results:** Community health center patients preferred that their providers use email, cell phones for texting, and Facebook and cell phone apps for sharing health information. Significantly more Hispanic than white patients believed their providers should use Facebook ( $P=.001$ ), YouTube ( $P=.01$ ), and Twitter ( $P=.04$ ) for sharing health information. Use and intentions to use social media for health-related purposes were significantly higher for those patients with higher subjective norm scores.

**Conclusions:** Understanding use and factors predicting use can increase adoption and utilization of social media for health care-related purposes among underserved patients in community health centers.

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**KEYWORDS**

social media; community health centers; medically underserved area

## Introduction

Social media includes “Web-based and mobile technologies used to turn communication into interactive dialog between organizations, communities, and individuals” [1]. Health care organizations have begun to recognize the value of these technologies for connecting, communicating, and collaborating [2-8] with social media interactions categorized as patient-patient, clinician-patient, public health-consumer, researchers-patient, and corporate-consumer [9]. As they have been applied to health care, new terms such as Medicine 2.0, Health 2.0, and eHealth have emerged to describe the plethora

of Web-based tools of the second generation Internet (Web 2.0) used to connect patients, caregivers, and health professionals [10]. Eysenbach has defined Medicine 2.0 as “Web-based services for health care consumers, caregivers, patients, health professionals, and biomedical researchers that use Web 2.0 technologies and/or semantic Web and virtual reality approaches to enable and facilitate specifically (1) social networking, (2) participation, (3) apomediation, (4) openness, and (5) collaboration within and between these user groups” [11].

Several motives explain the application of social media in health care [12]. These motives include information seeking about disease treatment and medicines [12-14], social support between

2 or more people with the same illness [12,15,16], improved efficiency and quality of care [6,17], improved relationships with providers [5], and self-care and self-management [18]. Patients of clinical providers are increasingly likely to go online to find advice and share information about their condition through the Internet and social media platforms than ever before [19]. Fisher and Clayton [20] have assessed patient interest in social media for health care purposes. Their findings revealed that 83% of patients used some form of social media and more than half wanted their providers to use it for health care (ie, share health information updates, communicate, and/or help manage health problems).

In the United States, Federally Qualified Health Centers (FQHCs), such as community health centers, are an important part of the health care system. They provide comprehensive primary and preventive care most often to medically underserved and disadvantaged community members. As the Patient Protection and Affordable Care Act (PPACA) is implemented, FQHCs will be under greater pressure to achieve the “triple aim” of improving affordability, health status, and patient experience [21]. Recent studies have demonstrated the potential value of mobile technologies for promoting access, effective patient-provider communication, and adherence among the underserved [21-23]. Although social media use is promising for health care purposes, effective use among racially and ethnically underserved communities will require an understanding of the adoption and utilization barriers for providers as well as patients [24,25]. For minority patient populations, these barriers may include, but are not limited to, lack of perceived benefit, increased work and time required to use the technology, computer knowledge and skills, access to computers, technology fear/anxiety, lack of cultural relevance, and privacy and trust concerns [24].

Despite a recent call for additional research on social media and health information seeking among the underserved [26], no studies have explored social media use among those served by FQHCs. The purpose of this study was to determine use and

factors predicting intentions to use social media for health information and support among medically underserved primary care patients in a community health center. Research questions included:

1. To what extent do patients use social media?
2. What are patient preferences for how health care providers should use social media to communicate?
3. What factors from the theory of planned behavior (TPB) predict intentions use of social media for health care–related purposes?

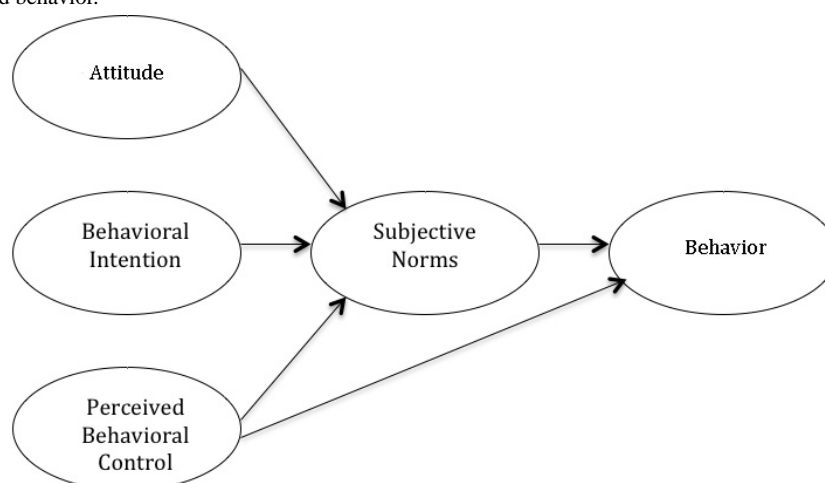
Although it is critically important to monitor race/ethnicity on health information seeking to reach those in most need [26], this study also compared social media use and theoretical constructs between the 2 largest groups in the sample: white and Hispanic patients.

## Methods

### Theoretical Framework

The TPB provided the theoretical framework through which contributing factors and intention to use social media were explored (see Figure 1). The TPB purports that individual behavioral intention is dependent on a number of determinants that include attitude toward the behavior, subjective norms, and behavioral control relative to the behavior of interest [27,28]. Attitudes originate from an individual’s belief that the behavior, if performed, will yield an outcome they value. Subjective norms are based on normative beliefs and motivation to comply with those beliefs. For example, if important referents to the individual believe the behavior is important and the individual is motivated to follow the referent’s opinion, the subjective norm for the behavior will be positive. Perceived behavior control is belief in the ability to perform the behavior. Together, attitudes, subjective norms, and perceived behavior control are important antecedents to an intention to perform a behavior. Ultimately, behavioral intention is the most important determinant of actual behavior [29].

**Figure 1.** Theory of planned behavior.



### Study Participants and Procedures

Participants in this study were patients aged 18 years or older of a community health center in the western United States.

Community health centers were first authorized in the United States in 1975 under the Public Health Service Act. They were permanently reauthorized in 2009 in the PPACA and must be located in medically underserved areas and populations. They



provide health care services that are adjusted based on ability to pay; have 51% consumer representation on their board of directors; provide medical, dental, and behavioral health care; and provide culturally competent care [26].

Following institutional review board approval from Brigham Young University, the survey questionnaire was administered using Apple iPads over a 6-week period. Each patient was invited to participate on checking in at the front desk for his or her appointment. A total of 444 patients participated in the study, the majority (302/444, 67.9%) being Hispanic followed by white (89/444, 20.2%). Qualtrics survey software was used to collect the data on Apple iPads while patients were waiting in the waiting area for appointments. A trained bilingual community health center staff member helped to administer the survey and assisted patients with any questions they had regarding the survey or use of the iPad. Every patient who checked in at the front desk of the community health center for an appointment during the study period was invited to participate. Therefore, initial contact with the patients was made in person. Patients who reported they did not have access to the Internet on a computer or cell phone were excluded from the survey.

## Measurement

This cross-sectional survey method employed the use of a 64-item closed survey questionnaire developed to assess demographics, social media use, and TPB constructs relative to social media use for obtaining health information and support. Four questions were included to collect patients' demographic information, which included the age, race/ethnicity, gender, and annual household income of the respondent. Questions related to social media use and health were adapted from Fisher and Clayton [20] and Steele [9] (see [Multimedia Appendix 1](#)). Included in the social media response options for this study were blogs, microblogs (Twitter), social networking services (Myspace, Facebook, LinkedIn), content communities (YouTube), online group discussions, mobile phone applications, email, and texting [20]. Questions related to TPB were taken from Cameron et al [30] and modified to assess social media use in receiving health information and support (see [Multimedia Appendix 1](#)). Each construct of the TPB was assessed from 3 questions using a 5-point Likert scale with options ranging from strongly disagree to strongly agree. Cronbach alpha was used to assess the reliability of the instrument with reported reliability of .90 for attitude, .88 for subjective norm, .91 for perceived behavioral control, .88 for behavioral intention, and .86 for behavior. A Cronbach alpha of .70 and above was considered acceptable [31].

A panel of experts who reviewed the preliminary draft helped to establish content validity. In addition, the instrument was

pilot tested among 50 community health center patients. Based on the feedback from experts and patients, modifications were made to several of the questions and response options. Two versions of questionnaire were created to accommodate both English and Spanish speakers. The English version was translated to Spanish, then back-translated to English to ensure that the nature of the questions were unchanged.

## Data Analysis

All statistical analyses were performed using Stata version 12.0 for Mac (StataCorp LP, College Station, TX, USA). Demographic characteristics were calculated, but nearly 23% (102/444) of demographic data were missing. Descriptive data of study variables had high response rates and statistics were calculated for each. Chi-square test statistics were computed to compare white and Hispanic respondents' reported preferences for communicating with health care providers. Responses from nonwhite and non-Hispanic respondents were excluded from this analysis because there was not sufficient representation of other races/ethnicities to warrant this type of comparison.

Regression analyses were used to explore factors predicting behavioral intentions to use social media and actual use of social media for health purposes. Two separate models were created, one using social media use behavior as a dependent variable and a second using behavioral intentions to use social media. Using the TPB as a guide, variables were added sequentially to the respective models by block based on their conceptual proximity to the dependent variable. The model using social media use behavior included 2 blocks, whereas the model using behavioral intentions to use social media had 2 blocks. The first block in both models was comprised of demographic items, age, and gender. In the model using social media behavior as an outcome, block 2 included behavioral intentions to use social media followed by block 3, which included attitudes, subjective norms, and perceived behavioral control. In the model using behavioral intentions to use social media as an outcome, block 1 included demographics, whereas block 2 included attitudes, subjective norms, and perceived behavioral control.

## Results

A total of 444 patients participated in the study. The demographic characteristics of the respondents are shown in [Table 1](#). More females (168/241, 69.7%) than males (73/241, 30.3%) participated with the majority being Hispanic (165/243, 67.9%) followed by white (49/243, 20.2%) and Asian (10/243, 4.1%). The majority of respondents were aged between 18 and 29 years (106/241, 44.0%) with an annual income less than US \$20,000 (127/238, 53.4%).

**Table 1.** Demographic characteristics of the study participants (N=444).

Demographics	n (%)
<b>Gender</b>	
Male	73 (30.3)
Female	168 (69.7)
<b>Age (years)</b>	
18-29	106 (43.9)
30-39	64 (26.6)
40-49	37 (15.4)
50-59	20 (8.3)
60-69	13 (5.4)
≥70	1 (.4)
<b>Race/ethnicity</b>	
African American	4 (1.7)
American Indian	3 (1.2)
Asian	10 (4.1)
Hispanic	165 (67.9)
Pacific Islander	5 (2.1)
White	49 (20.2)
Other	7 (2.9)
<b>Annual income (US\$)</b>	
<\$20,000	127 (53.4)
\$20,000-\$34,999	73 (30.7)
\$35,000-\$49,999	25 (10.5)
\$50,000-\$74,999	4 (1.7)
≥\$75,000	9 (3.8)
<b>Own computer with Internet access</b>	
Yes	315 (71.0)
No	129 (29.1)
<b>Own cell phone</b>	
Yes	280 (92.1)
No	24 (7.9)

## Social Media Use

Texting on a cell phone was the most common form of social media used by patients (202/274, 73.7%), followed by Facebook (152/279, 54.5%), email (123/236, 52.1%), cell phone apps (85/229, 37.1%), and YouTube (74/242, 30.6%). LinkedIn was

the social media app used the least among patients (3/205, 1.5%). Compared to white patients, Hispanic patients reported more daily use of Facebook (91/155, 59%), YouTube (48/130, 36.9%), Twitter (12/108, 11.1%), online group discussions (7/106.6, 7%), LinkedIn (2/99, 2.0%), and MySpace (6.0%) (see [Table 2](#)).

**Table 2.** Daily social media use among community health center patients (N=214).

Social media type	White, n (%)	Hispanic, n (%)	P
Facebook	23 (46.9)	91 (58.7)	.15
MySpace	1 (2.2)	6 (55.8)	.34
LinkedIn	0 (0.0)	2 (2.0)	.33
Blogs	3 (6.5)	6 (6.2)	.94
Online group discussions	1 (2.2)	7 (6.6)	.26
Twitter	2 (4.4)	12 (11.1)	.18
YouTube	11 (22.5)	48 (36.9)	.07
Email	27 (56.3)	58 (47.2)	.29
Cell phone for texting	39 (79.6)	118 (76.1)	.62
Cell phone apps	20 (44.4)	42 (34.2)	.22

### Patient Preferences for Social Media Use in Health Care

When asked about their preference for their health care provider using social media to help them stay healthy, white respondents preferred that the provider use cell phone for texting (26/45, 57.8%), Facebook (23/45, 51.1%), and cell phone apps (20/42, 47.6%) (see [Table 3](#)). Hispanic respondents preferred cell phone for texting (89/125, 71.20%), followed by email (83/124, 66.9%) and Facebook (75/132, 57%).

With regard to sharing health information through social media, white respondents preferred email (27/45, 60.0%) and cell phone for texting (28/47, 59.6%). Hispanic respondents preferred cell phone for texting (99/137, 72.3%) followed by email (82/123, 66.7%) and Facebook (92/145, 63.5%). Analysis revealed a significant difference between white and Hispanic respondents for Facebook (16/46, 34.8% and 92/145, 63.5%,  $P<.001$ ), Twitter (5/44, 11.4% and 31/117, 26.5%,  $P=.04$ ), and YouTube (7/46, 15.2% and 41/116, 35.3%,  $P=.01$ ).

**Table 3.** Number and percentage of whites and Hispanic patients who prefer that their provider use various social media to help them stay healthy and share health information (N=214).

Social media type	Help them stay healthy			Share health information		
	White, n (%)	Hispanic, n (%)	P	White, n (%)	Hispanic, n (%)	P
Facebook	23 (51.1)	75 (56.8)	.51	16 (34.8)	92 (63.5)	.001
MySpace	6 (13.6)	16 (14.7)	.87	2 (6.7)	14 (12.6)	.28
LinkedIn	3 (6.8)	12 (11.4)	.39	5 (11.1)	12 (11.4)	.96
Blogs	11 (25.0)	27 (24.6)	.95	9 (20.0)	26 (23.4)	.64
Online group discussions	14 (34.2)	22 (19.8)	.07	13 (28.9)	30 (25.6)	.68
Twitter	6 (14.6)	17 (16.4)	.80	5 (11.4)	31 (26.5)	.04
YouTube	14 (34.2)	37 (33.0)	.90	7 (15.2)	41 (35.3)	.01
Email	32 (71.1)	83 (66.9)	.61	27 (60.0)	82 (66.7)	.42
Cell phone for texting	26 (57.8)	89 (71.2)	.10	28 (59.6)	99 (72.3)	.11
Cell phone apps	20 (47.6)	47 (43.1)	.62	18 (40.9)	51 (43.9)	.73

### Factors Predicting the Use of Social Media

Mean scores of behavioral constructs revealed that Hispanics reported more intention (mean 3.07, SD 1.06) to use social media for health-related purposes than white patients did (mean 2.58, SD 0.74,  $P=.005$ ) (see [Table 4](#)). Response options included

1=strongly disagree, 2=disagree, 3=neither disagree nor agree, 4=agree, 5=strongly agree. In addition, Hispanic respondents had a higher mean score for subjective norms (mean 3.44, SD 1.11) compared to white respondents (mean 2.92, SD 0.73,  $P=.003$ ).

**Table 4.** Mean scores of behavioral constructs for Hispanic and white participants (N=189).

Construct	Hispanic, mean (SD)	White, mean (SD)	P
Behavioral intentions	3.07 (1.06)	2.58 (0.74)	.005
Attitudes	3.58 (1.29)	3.52 (0.99)	.79
Subjective norms	3.44 (1.11)	2.92 (0.73)	.003
Perceived behavioral control	3.58 (1.14)	3.66 (0.94)	.68

To explore factors that predict the use of social media within the next week for health-related purposes, a hierarchical multiple regression analysis was used in the analysis in which blocks of variables were added to the regression equation sequentially.  $R^2$  refers to the overall regression equation after each block has been entered into the model;  $F$  for change in  $R^2$  describes the contribution of each individual block (see Table 5). For block 1, the variables age and gender did not significantly account for any variance. Adding the variable behavioral intentions in block 2 accounted for 64% of the variance ( $F_{3,165}=0.63$ ,  $P<.001$ ). For block 3, the addition of attitudes, subjective norms, and perceived behavioral control accounted for 70% of the variance

( $F_{6,166}=0.06$ ,  $P<.001$ ). When considering all the variables entered in the model that were significant, the beta score was highest for subjective norms followed by perceived behavioral control, behavioral intention, and age.

When considering behavioral intentions to use social media for health-related purposes, hierarchical multiple regression analysis revealed that block 1 variables of age and gender did not account for any of the variance (see Table 6). The addition of attitudes, subjective norms, and perceived behavioral control variables increased the proportion of the variance to 51% ( $F_{5,169}=0.51$ ,  $P<.001$ ). With all variables in the model, subjective norms was the only significant predictor.

**Table 5.** Predictors of social media use: contributions of each variable block to changes in  $R^2$  (N=173).

Variable	Block 1 ( $df=2/170$ )				Block 2 ( $df=3/169$ )				Block 3 ( $df=6/166$ )			
	B	SE	t	P	B	SE	t	P	B	SE	t	P
Age	-.10	.07	-1.52	.13	-.07	.04	-1.73	.09	-.08	.04	-1.97	.05
Gender	-.10	.17	-0.58	.56	.05	.10	0.50	.61	.07	.09	0.70	.49
Behavioral intentions					.84	.05	17.46	.001	.61	.06	9.69	.001
Attitudes									-.07	.05	-1.38	.17
Subjective norms									.23	.08	3.10	.002
Perceived behavioral control									.19	.06	2.99	.003
$R^2$		.01				.64				.70		
F for change in $R^2$		—				.63		.001		.06		.001

**Table 6.** Predictors of intentions to use social media: contributions of each variable block to changes in  $R^2$  (N=175).

Variable	Block 1 ( $df=2/172$ )				Block 2 ( $df=5/169$ )			
	B	SE	t	P	B	SE	t	P
Age	-.04	.06	-0.65	.52	-.08	.05	-1.75	.08
Gender	-.17	.16	-1.07	.29	-.16	.11	-1.39	.17
Attitudes					.11	.06	1.88	.06
Subjective norms					.59	.08	7.49	.001
Perceived behavioral control					.08	.07	1.09	.28
$R^2$		.00				.51		
F for change in $R^2$		—				.51		.001

## Discussion

The purpose of this study was to determine use and factors predicting use and intentions to use social media for

health-related purposes among medically underserved primary care patients. The first aim of the study was to determine to what extent patients used social media. Findings indicated that social media use is common among this underserved population. The most common social media tools used were cell phones for

texting (73.7%) followed by Facebook (54.5%), email (52.1%), cell phone apps (37.1%), and YouTube (30.6%). These findings are consistent with other research among non-FQHC family practice patients who reported email, cell phone for texting, Facebook, and YouTube as most commonly used sources of social media [20]. Further analysis of our findings revealed that Hispanic respondents reported greater use of 7 of 10 social media tools. These findings are similar with other research that indicates Hispanics are using social media and mobile devices at higher rates than whites [32]. The Pew Research Hispanic Trends Project reports that 68% of Latino Internet users use Facebook, Twitter, or other social networking sites compared to 58% or all Internet users in the United States [33]. A total of 86% of Latino adults own a cell phone compared to 84% of whites and 90% of blacks. Additionally, 49% of Latino adults own a smartphone compared to 46% of whites [33].

The second aim of the study was to determine patient preferences for how their health care provider should use social media to share health information and to help them stay healthy. The use of various technologies, such as emailing, texting, and smartphone apps, can enhance patient-provider relations among the underserved primary care patients [34]; however, the prevalence of health care providers' use of various social media for communicating with patients is limited. In a survey of US doctors, 49% reported using email in the past 6 months to communicate with their patients [35]. A study in the Netherlands showed that patients' motives for using social media for patient-provider communication were low, including only 18% for Twitter and 10% for Facebook. Similar results were found among providers; 28% said they use Twitter to communicate with patients and 14% used Facebook [12].

In general, patient preferences for their health care providers social media use are consistent with their own personal daily use of these same apps. For example, Hispanic respondents preferred their provider use cell phones for texting; using cell phones for texting was the most common social media tool used daily. For conveying health information, both groups preferred texting and email. Although the study did not specifically ask respondents what type of health information they would like to be conveyed through email or texting, personal health information may be best communicated in these ways due to privacy concerns [36]. Previous research from the Pew Internet Project has revealed that privacy concerns have led to more than half of mobile phone users uninstalling or not installing apps on their phones [37].

For sharing information to help them stay healthy, again the majority preferred texting and email, with the addition of Facebook and cell phone apps. This suggests that patients may be limited in their understanding of how providers could use a variety of social media apps to help them stay healthy. This may be because few providers have used social media for interactions with patients or that patients just have not explored that possibility. The only statistically significant differences seen between Hispanic and white respondents were related to sharing of health information using Facebook, Twitter, and YouTube, with Hispanic respondents reporting greater preferences. These differences may reflect that Hispanics use these apps more often than whites [33]. This lack of differences

between the 2 groups also suggests that a social media communications strategy may not need to be based on race and ethnicity. However, a study evaluating the success of using social media to reach Hispanic cancer survivors found that this audience is very receptive to these technologies [38].

For those health care providers working to reach medically underserved community health center patients with important health information, cell phone texting and email are important to patients for health care purposes. Facebook, Twitter, and YouTube provide promising avenues of communication, especially for Hispanics. These social media applications offer an opportunity for providers to connect with underserved patients where many are interested in getting health information through social media channels. Although these avenues are promising, few studies have evaluated the use of social media for health care purposes among Hispanics [38]. Future research might explore its use in greater detail for these and other underserved populations.

A third aim of the study was to determine what factors influence the use of social media for health care-related purposes. As outlined in the TPB, attitude, subjective norms, and perceived behavioral control are important to one's behavioral intention and behavior. Understanding the TPB factors predicting intention to use social media among patients can help to provide valuable understanding that can increase adoption of these technologies for obtaining health information. Studies have demonstrated the prominent role of social factors (ie, influence of others/groups) in predicting the use of computer technologies for health information seeking, exchange, decision making, social and emotional support, and behavior change among patients [39]. Findings from the current study revealed that subjective norms significantly predict use and intentions to use social media for health-related purposes. That is, patients in this study had higher use and intentions to use social media if important people in their lives felt the technology was important and use it for health care-related purposes. Strategies aimed at increasing the use of social media for obtaining health information and support should emphasize that important people in their life (eg, friends, family members) use social media for this purpose.

Perceived behavioral control predicted social media use but not intentions to use suggesting obtaining health information through social media channels is easier for those who are capable of using the technologies. This finding is consistent with other studies on patient use of computer technologies for health care [39] and might indicate that individuals experience barriers related to using technology to access and share health information. Barriers of this nature could include a lack of knowledge in using social media apps, costly data plans, language barriers, or health care providers that do not engage patients in such settings. Future research efforts could corroborate these findings and, if true, design strategies to minimize barriers.

Because patients are using social media as identified in this study, ignoring social media may come with risks to community health centers. These risks could come in the form of inaccurate information being shared among patients while they are online,



not being aware of threats to organizational reputation, and lack of clear social media policies that can protect against liability and violation of the Health Insurance Portability and Accountability Act (HIPPA) [40]. Social media tools should be implemented by health care organizations following a planning process that includes understanding target audiences and fitting the best social media apps to meet identified communication needs [3]. Health care providers should also have clear internal and external social media use policies that guide both patient and staff involvement with the social media apps [3,41].

Although this study provides valuable insights for social media use among underserved populations, findings should be interpreted based on the following limitations. First, this study is cross-sectional and, therefore, cause cannot be assigned to any particular independent variable. Second, the study only included those individuals who reported that they had access to a computer and used the Internet. Not all patients receiving care through community health centers will benefit from a social media plan. However, many of those that are connected see value to its use for health care-related purposes. Furthermore, individuals with missing values were excluded from each analysis, which accounts for differences in the sample sizes used in each table. Missing values are not uncommon in datasets collected in locations such as FQHCs that primarily serve underprivileged individuals. Third, although reliability measures

of internal consistency were acceptable, we lacked sufficient validity evidence for these scales as measures of intention to use social media for health-related purposes. Future research can help to strengthen validity evidence beyond that achieved by an expert panel. Lastly, the age range of participants included in this study included mostly individuals younger than 40 years of age. A true comparison of age would include a greater proportion of older participants. Nevertheless, we included age in multivariate analyses, but it was not significant, which may be attributable to its lack of variance. Future studies of this nature may benefit from ensuring participation from older individuals.

This study helps to demonstrate the use and factors predicting intentions to use social media among community health center patients. Community health centers deliver affordable, comprehensive, patient-centered care that is close to communities in need [42]. Optimizing primary care as motivated by the PPACA requires greater attention to advancing patient-centered medical homes, a model that community health centers value [43]. Although social media can provide another tool for primary health care providers to be even more patient-centered and provide greater personalized care [10], understanding use and factors predicting use can increase adoption and utilization of these technologies among underserved and disadvantaged patients.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Theoretical constructs and survey questions.

[PDF File (Adobe PDF File), 40KB - [jmir\\_v16i11e270\\_app1.pdf](http://www.jmir.org/2014/11/e270_app1.pdf)]

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## Abbreviations

**FQHC:** Federally Qualified Health Centers

**PPACA:** Patient Protection and Affordable Care Act

**TPB:** theory of planned behavior

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Original Paper

# Use of Social Media Across US Hospitals: Descriptive Analysis of Adoption and Utilization

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## Abstract

**Background:** Use of social media has become widespread across the United States. Although businesses have invested in social media to engage consumers and promote products, less is known about the extent to which hospitals are using social media to interact with patients and promote health.

**Objective:** The aim was to investigate the relationship between hospital social media extent of adoption and utilization relative to hospital characteristics.

**Methods:** We conducted a cross-sectional review of hospital-related activity on 4 social media platforms: Facebook, Twitter, Yelp, and Foursquare. All US hospitals were included that reported complete data for the Centers for Medicare and Medicaid Services Hospital Consumer Assessment of Healthcare Providers and Systems survey and the American Hospital Association Annual Survey. We reviewed hospital social media webpages to determine the extent of adoption relative to hospital characteristics, including geographic region, urban designation, bed size, ownership type, and teaching status. Social media utilization was estimated from user activity specific to each social media platform, including number of Facebook likes, Twitter followers, Foursquare check-ins, and Yelp reviews.

**Results:** Adoption of social media varied across hospitals with 94.41% (3351/3371) having a Facebook page and 50.82% (1713/3371) having a Twitter account. A majority of hospitals had a Yelp page (99.14%, 3342/3371) and almost all hospitals had check-ins on Foursquare (99.41%, 3351/3371). Large, urban, private nonprofit, and teaching hospitals were more likely to have higher utilization of these accounts.

**Conclusions:** Although most hospitals adopted at least one social media platform, utilization of social media varied according to several hospital characteristics. This preliminary investigation of social media adoption and utilization among US hospitals



provides the framework for future studies investigating the effect of social media on patient outcomes, including links between social media use and the quality of hospital care and services.

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## KEYWORDS

social media; Internet; health information

## Introduction

Nearly three-quarters of adult Internet users in the United States use social networking sites [1]. Businesses have invested considerable resources in engaging consumers through these online platforms to enhance their reputation, brand recognition, and consumer loyalty. Similar strategies may be taken by hospitals, yet little is known about the extent to which hospitals use social media platforms [2-4].

Hospitals may adopt social media strategies to improve market share, profitability, or to advance their missions in health and health care [5-7]. A strong social media presence may support hospitals' reputations and ability to attract patients. For example, patients may perceive hospitals with social media activity to be more likely to offer advanced technologies and cutting-edge therapies.

However, hospitals may not have control over the conversation on social media that surrounds their Web presence [8]. Much of the content on social media is generated by hospitals' communities, including patients and their families, neighbors, employees, and potentially even competitors [9]. For example, social media sites such as Facebook and Yelp have empowered patients and their families to publicly rate their health care experience [10-17]. Although such ratings lack the systematic collection and analysis of data possible with carefully designed surveys, they happen organically, create no additional cost, and may provide some valuable signals about the markets or missions of health care organizations [7,18]. Indeed, Facebook "likes" in 1 urban region were associated with patients' recommending a particular hospital and negatively associated with 30-day mortality rates [17]. Another study demonstrated that consumer ratings for hospitals on the social media website Yelp were associated with the more traditional hospital performance measures of patient experience of care generated by the Hospital Consumer Assessment of Healthcare Providers and Systems (HCAHPS) survey [10].

The relationships between hospital-associated social media activity, patient choices, clinical processes and outcomes, and hospital profit margins are unknown and almost certainly evolving rapidly. At the same time, it has become increasingly critical to find effective ways of communicating with patients outside of clinical settings. Mail and telephone communication channels that dominated the past are being supplemented or replaced by new media channels, and this is occurring faster in some demographic segments and hospitals than others [4,19]. In this study, we sought to describe the adoption and utilization of social media among US hospitals and determine whether adoption and utilization varied by hospital characteristics. This lays the groundwork for relating hospital social media adoption

and utilization to other outcomes, including health care quality, market share, and profitability.

## Methods

### Study Design

We conducted a cross-sectional review of hospital-related activity on 4 of the most popular social media platforms: Facebook, Twitter, Foursquare, and Yelp. For each platform, we reviewed the adoption and utilization of social media among US hospitals.

### Study Population

We included all US hospitals reporting complete data to both the Centers for Medicare and Medicaid Services (CMS) HCAHPS survey and the 2010 American Hospital Association Survey (AHAS) [20,21]. The study cohort included 3371 US hospitals. We excluded hospitals operated by the federal government and those not classified as general medical and surgical centers, such as pediatric hospitals, psychiatric hospitals, specialty surgery centers, and long-term acute care hospitals. Because these hospitals provide care for specific subpopulations of patients, social media adoption and utilization may reflect specific types of care from different types of patients than the general population receiving care from hospitals that provide a wide range of services. Hospital characteristics were derived from the AHAS, including ownership/profit status (public, private nonprofit, private for-profit), teaching status (yes/no), urban designation (yes/no), bed count (small: less than 99 beds; medium: 100 to 299 beds; large: 300 or more beds), and region (northeast, midwest, west, south).

We extracted data for each hospital from the 4 social media platforms. Data included whether each hospital had an account (adoption) and, if so, activity on each social media account (utilization). These platforms were selected because of their widespread popularity, free public access, and availability of posted usage metrics.

Webpages on Facebook and Twitter are created by hospitals. Hospitals can create accounts and then post messages and pictures through these accounts to their followers. Facebook is a social networking platform that allows individuals and organizations to post and discuss content [22]. This content can be "liked" by users and shared with others. Facebook has 1.19 billion monthly active users worldwide [23]. Twitter is a microblogging site that allows individuals and organizations to post 140-character messages, or "tweets" [24]. Twitter has more than 230 million monthly active users who collectively generate 500 million tweets each day [25].

Webpages on Foursquare and Yelp, however, are not created by hospitals. Social media users create and generate the content



of webpages for hospitals on these platforms. Foursquare is a location-based service application that allows individuals to “check-in” and indicate their presence at a geographic location [26]. Foursquare has more than 45 million users and more than 5 billion posted check-ins [27]. Yelp is an online rating platform where individuals can post reviews and comments about businesses [28]. Yelp has more than 100 million monthly unique users and over 47 million local reviews [29].

### Data Collection

To extract data from the 4 social media platforms, we first identified the home page for each hospital through an Internet search engine using hospital names from the HCAHPS and AHAS surveys. We then followed posted links to social media webpages. If the hospital website did not feature links to social media webpages, direct searches using the hospital name were performed on the search function provided by the social media platform. In these cases, the identity of each hospital’s social media webpage was confirmed by matching the address of the hospital on the social media page with the known address of the hospital from the HCAHPS and AHAS surveys.

We defined *adoption* to be whether or not a hospital had a social media account. We defined *utilization* to be metrics of social media user activity or content that could be extracted from each social media webpage. These included number of likes (Facebook), number of followers (Twitter), number of check-ins (Foursquare), and number of reviews (Yelp).

For social media webpages attributed to multiple hospitals in a consortium or network, adoption and utilization of the network social media page was attributed to each network hospital. For hospitals with multiple social media pages on 1 platform, we selected either the page endorsed by the hospital or the page with the greatest volume of social media activity. Social media webpages were reviewed over a 1-month period (August 2014).

### Statistical Analysis

We report the percentage of hospitals having Facebook, Twitter, Foursquare, and Yelp to show the adoption of social media platforms across hospitals. Because of the right-skewed distribution of utilization (likes, followers, check-ins, and reviews), we report medians and IQRs. We used the Mood median test to determine differences in the magnitude of social media utilization between groups of hospitals with different characteristics. We used ordinary least squares (OLS) regressions to assess the independent associations of hospital

characteristics on the magnitude of social media activity. Due to the skewed nature of utilization, we used the log transformation of social media utilization to approximate the normal distribution. The variance inflation factor and normality of residuals indicated OLS regression was appropriate for these outcomes. For all analyses, a  $P$  value  $<.05$  was considered statistically significant. We performed sensitivity analyses to assess the effect of attributing 1 hospital’s social media page adoption and utilization characteristics to all hospitals in a network and all associations presented were unchanged. Therefore, data are presented such that each webpage represents a unique hospital. All statistical analyses were performed using STATA version 10.0 (StataCorp, College Station, TX, USA). To display the geographic distribution of social media utilization across hospitals, we geocoded each hospital based on street address in ArcGIS version 10.1 (ESRI, Redlands, CA, USA).

## Results

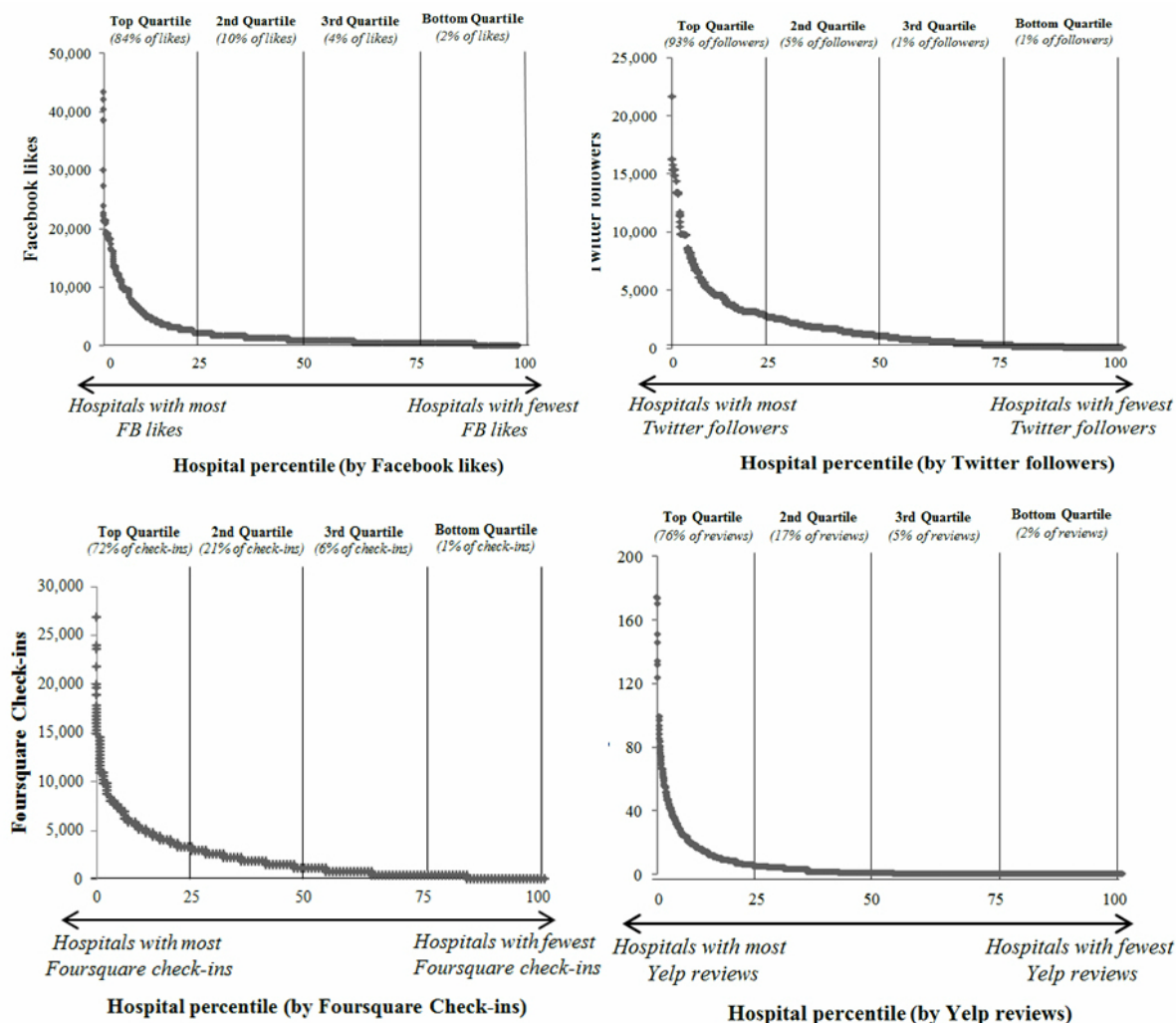
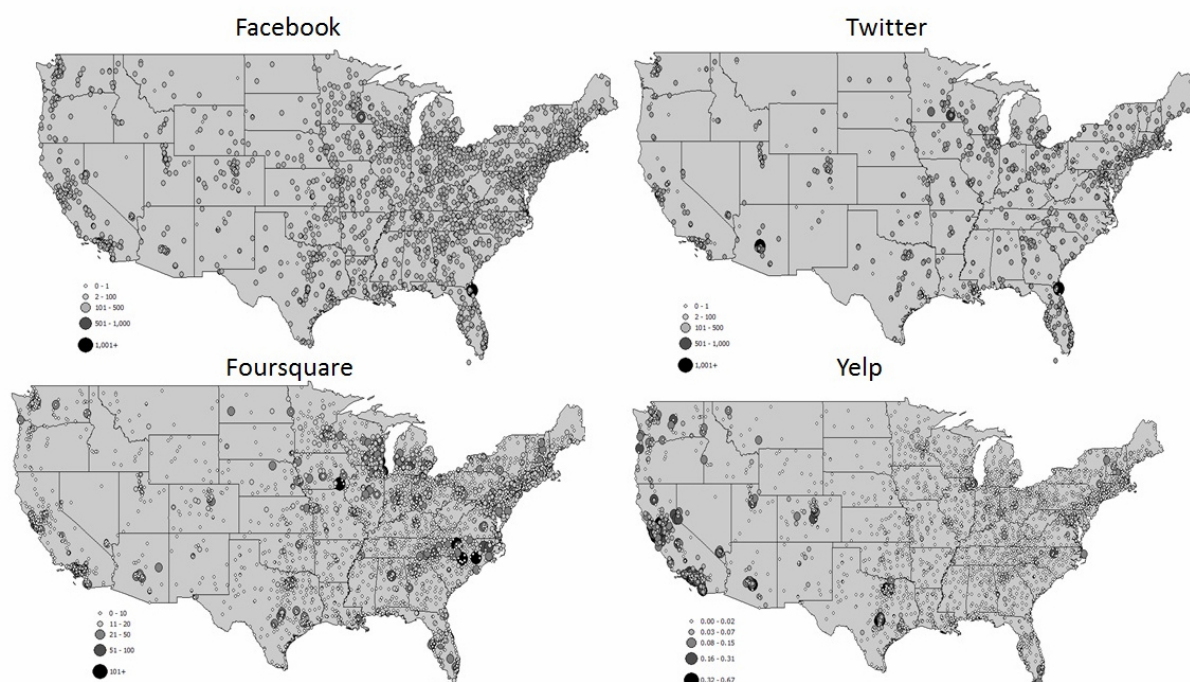
### Adoption

Of the total 3371 US hospitals identified, the adoption of social media websites varied across platforms, with 3351 (99.41%) having a Facebook, 1713 (50.82%) having a Twitter, 3351 (99.41%) having a Foursquare, and 3342 (99.14%) having a Yelp account. Overall, 1699 (50.40%) hospitals had accounts on all 4 platforms. Few hospitals (42/3371, 1.25%) used just 1 or 2 types of social media platform.

### Utilization

The distribution of social media utilization for US hospitals was right-skewed for all social media platforms (Figure 1). Hospitals in the top quartile accounted for more than 68% of likes, followers, check-ins, and reviews. This figure shows the relationship between utilization (likes, followers, check-ins, and reviews) on the y-axis and hospital percentile on the x-axis.

The geographic distribution of social media utilization adjusted for the size of the hospital (using bed count) also varied (Figure 2). All social media platforms appeared widely spread across the United States with a higher density of hospitals using social media in urban areas. The northeast United States had a large cluster of hospitals using social media, but the west also had clusters of hospitals with high Foursquare and Yelp utilization. This figure illustrates the number of likes, followers, check-ins, and reviews by hospital (each dot represents a hospital location).

**Figure 1.** Distribution of utilization of social media across US hospitals.**Figure 2.** Maps of social media utilization for hospitals adjusted by bed count.

To better understand hospital characteristics associated with this variation, [Tables 1](#) and [2](#) display the magnitude of social media utilization differentiated by hospital characteristics.

Larger, urban, private nonprofit, and teaching hospitals had significantly more social media utilization than their comparison groups across all 4 social media platforms. For example, large hospitals (>300 beds) compared to the smallest hospitals (<99 beds) had a median 2817.5 (IQR 1289-5533) versus median 425.5 (IQR 133-1127) Facebook likes, median 1409 (IQR

525-3115) versus median 753 (IQR 164-2381) Twitter followers, median 4595 (IQR 2383-7321) versus median 212 (IQR 79-539) Foursquare check-ins, and median 5 (IQR 1-17) versus median 0 (IQR 0-1) reviews on Yelp. Urban hospitals had a median 1409 (IQR 509-3453) versus median 518 (IQR 151-1199.5) Facebook likes for rural hospitals, median 1130 (IQR 392.5-2860.5) versus median 491 (IQR 118-1771) Twitter followers, median 2027.5 (IQR 765.5-4180.5) versus median 211 (IQR 79-537) Foursquare check-ins, and median 2 (IQR 0-9) versus median 0 (IQR 0-0) Yelp reviews.

**Table 1.** Magnitude of social media utilization relative to hospital characteristics: Facebook and Twitter.<sup>a</sup>

Social media platform	Facebook likes (n=3351)		Twitter followers (n=1713)	
	Median	IQR	Median	IQR
<b>Region</b>				
Northeast	1248	451-3015	825	251-2748
Midwest	931	332-2780	1200.5	367.5-2818
West	813	261-1971	882	283-2673
South	1060	276-2767	854	268-2411
<b>Urban</b>				
Yes	1409	509-3453	1130	392.5-2860.5
No	518	151-1199.5	491	118-1771
<b>Bed count</b>				
Small (<99)	425.5	133-1127	753	164-2381
Medium(100-299)	1062	418.5-2196.5	779	250-2390
Large(300+)	2817.5	1289-5533	1409	525-3115
<b>Profit status</b>				
Public	712	227-2023	650	136-220
Private nonprofit	1302	473-3240	1202	409-3104
Private for-profit	426.5	151-1302	415	120-1019
<b>Teaching hospital</b>				
Yes	4155	1854-8715	2706	1078-5093
No	900	281-2203	817	261-2381

<sup>a</sup> Within each characteristic, Mood median tests indicate at least one median is significantly different at the alpha .05 level.

**Table 2.** Magnitude of social media utilization relative to hospital characteristics: Foursquare and Yelp.<sup>a</sup>

Social media platform	Foursquare check-ins (n=3351)		Yelp Reviews (n=3342)	
	Median	IQR	Median	IQR
<b>Region</b>				
Northeast	2324	847-4865	2	0-7
Midwest	851	223-2941	0	0-2
West	1083	271-2655	1	8-27.5
South	673.5	155.5-2124.5	0	0-3
<b>Urban</b>				
Yes	2027.5	765.5-4180.5	2	0-9
No	211	79-537	0	0-0
<b>Bed count</b>				
Small (<99)	212	79-539	0	0-1
Medium (100-299)	1437	560-2633	1	0-6
Large (300+)	4595	2383-7321	5	1-17
<b>Profit status</b>				
Public	375	109.5-1623	0	0-2
Private nonprofit	1465	349-3550	1	0-6
Private for-profit	732	185-1733		
<b>Teaching hospital</b>				
Yes	2698	1032-4913	4	1-15
No	809	245-2323	0	0-3

<sup>a</sup> Within each characteristic, Mood median tests indicate at least one median is significantly different at the alpha .05 level.

Tables 3 and 4 report the results of OLS regressions to assess the independent associations between hospital characteristics and the magnitude of social media utilization. Each regression model explained significantly more variance in the outcome than was left unexplained (Facebook:  $F_{9,3068}=106.44$ ,  $P<.001$ ; Twitter:  $F_{9,1549}=32.84$ ,  $P<.001$ ; Foursquare:  $F_{9,3334}$ ,  $P<.001$ ; Yelp:  $F_{9,3330}=293.43$ ,  $P<.001$ ). Hospital characteristics explained 23.8% of the variation in Facebook, 16.0% of Twitter, 53.82%

of Foursquare, and 38.95% of Yelp utilization. Urban and teaching hospitals tended to have more social media utilization. Different regions displayed different utilization of the 4 social media platforms. The magnitude of social media activity increased with hospital size, significantly for Yelp and Facebook. Private for-profit hospitals had significantly fewer Facebook likes compared to public ( $P<.001$ ) or private nonprofit hospitals compared to public hospitals ( $P<.001$ ), and this association was the same for the number of Twitter followers.

**Table 3.** Ordinary least squares regression of social media utilization relative to hospital characteristics: Facebook and Twitter.

Social media platform	Facebook likes (n=3351)			Twitter followers (n=1713)		
	Coefficient	SE	<i>P</i>	Coefficient	SE	<i>P</i>
<b>Region</b>						
Northeast (ref)						
Midwest	0.388	0.084	<.001	0.470	0.107	<.001
West	0.003	0.092	.97	0.397	0.117	<.001
South	0.467	0.085	<.001	0.521	0.110	<.001
<b>Urban</b>						
Yes	0.546	0.066	<.001	0.693	0.100	<.001
No (ref)						
<b>Bed count</b>						
Small (ref)						
Medium	0.639	0.066	<.001	−0.014	0.095	.88
Large	1.176	0.088	<.001	0.123	0.114	.28
<b>Profit status</b>						
Public (ref)						
Private nonprofit	0.494	0.077	<.001	0.759	0.117	<.001
Private for-profit	−0.465	0.094	<.001	−0.430	0.146	.003
<b>Teaching hospital</b>						
Yes (ref)						
No	−0.792	0.112	<.001	−0.835	0.128	<.001
Constant	6.091	0.143	<.001	5.945	0.187	<.001
<i>R</i> <sup>2</sup>	0.238			0.160		



**Table 4.** Ordinary least squares regression of social media utilization relative to hospital characteristics: Foursquare and Yelp.

Social media platform	Foursquare check-ins (n=3351)			Yelp Reviews (n=3342)		
	Coefficient	SE	P	Coefficient	SE	P
<b>Region</b>						
Northeast (ref)						
Midwest	−0.118	0.065	.07	−0.254	0.077	<.001
West	−0.463	0.071	<.001	1.190	0.074	<.001
South	−0.566	0.065	<.001	−0.084	0.076	.27
<b>Urban</b>						
Yes	1.179	0.051	<.001	0.910	0.079	<.001
No (ref)						
<b>Bed count</b>						
Small (ref)						
Medium	1.251	0.051	<.001	0.495	0.071	<.001
Large	2.015	0.069	<.001	0.829	0.083	<.001
<b>Profit status</b>						
Public (ref)						
Private nonprofit	0.361	0.060	<.001	0.269	0.078	<.001
Private for-profit	0.082	0.073	.26	0.121	0.093	.19
<b>Teaching hospital</b>						
Yes (ref)						
No	−0.564	0.088	<.001	−0.544	0.085	<.001
Constant	5.461	0.111	<.001	0.374	0.128	.004
R <sup>2</sup>	0.538				0.390	

## Discussion

### Principal Findings

In this study, we examined the extent to which US hospitals had social media platforms and then determined utilization of each social media platform by systematically extracting data from hospital social media webpages. This paper has 3 central findings: (1) adoption of social media is widespread among US hospitals, (2) hospitals are adopting different social media platforms, and (3) social media utilization is variable with larger, urban, private nonprofit, and teaching hospitals tending to demonstrate more activity. Laying the exploratory foundation for future research regarding hospital social media use, this study can inform the potential link between social media use and hospital quality.

### Adoption of Social Media by Hospitals Is Widespread

Compared to the results of prior studies, our results demonstrate a dramatic growth of social media adoption among hospitals. In a random sample of US hospitals, 21% of hospitals used social media in 2010 [4]. At the time, 18% of hospitals maintained a Facebook account and 16% had a Twitter account [4]. Three years later, our study demonstrates significantly higher percentages of hospitals with social media accounts—more than 90% have Facebook, Foursquare, and

Yelp accounts, and approximately 40% have a Twitter account. In particular, a significantly higher proportion of hospitals in rural locations (93.9%) and smaller hospitals (94.4%) have a Facebook account compared to the 2010 report [4]. Additionally, a study of hospitals in Western Europe showed that social media use is growing, with Facebook being the most popular social media platform—67.0% of hospitals in Western Europe had a Facebook account [30]. This dramatic increase in social media use may show the increasing value of social media to hospitals to potentially improve market share, engage with patients, increase profitability, or advance their missions in health and health care [5-7].

### Hospitals' Adoption of Social Media Varies Across Social Media Platforms

Our study also demonstrates that adoption varied by social media platform, with more hospital-generated accounts on Facebook than Twitter, and more public-generated accounts for Foursquare and Yelp. As adoption in this context reflects whether or not a hospital set up an account, utilization (measured by likes and followers) allows for a better understanding of how actively hospitals are using their accounts and how actively the public is responding to their content.

Although it is unknown which platform may best connect hospitals with patients and for what purpose, it is probable that

users will continue to interact with hospitals through social media, even with the continual introduction of new social media portals, such as Instagram, Pinterest, and Snapchat. Particularly for Facebook and Twitter, these accounts may enable hospitals to engage in dialog with patients, share knowledge, and solicit patient opinions [2,11].

Yelp presents an interesting platform for hospitals to gauge patient and public experiences and opinions, which may be helpful when thinking about hospital quality and patient perception [10]. Because Yelp reviews can be collected in real time, hospitals can collect reviews and relate them to quality and quality surveys, including the HCAHPS. Yelp reviews are related to traditional hospital performance measures [10]; therefore, reviews may also be helpful to find measures that are more important to patients. Also, reviews may highlight potential areas that hospitals are not surveyed about but are still important to patients, such as how family members perceive quality of care.

Facebook is also an interesting social media platform that hospitals may use to increase reputation and attract patients. With the ability of hospitals to respond to comments made by Facebook users on the hospital's website, dialogs between hospitals and patients could foster important conversations regarding quality of care that traditional surveys may not have the ability to do [17]. Also, the ability to respond to patients in real time and collect data in real time for not only Facebook but all social media platforms provides the ability for hospitals to potentially assess quality and other metrics faster than traditional survey formats.

### Social Media Use Varies Widely Across Hospital Characteristics

Additionally, the utilization of social media among hospitals varies across hospital characteristics. Large, urban, private nonprofit, and teaching hospitals tend to have more likes, followers, check-ins, and reviews. These hospitals may have more hospital communications personnel dedicated to social media presence and engagement, different policies regarding social media use by the hospital, or more resources dedicated to outreach and communication via social media. As a way to increase social media presence and extend reach in social media, hospitals could be more active, such as increase tweeting on Twitter or posting to Facebook. Specific to Twitter, the number of followers is significantly correlated with the number of tweets ( $\rho=.113$ ,  $P<.001$ ), so more activity could lead to more followers,

resulting in greater social media presence. Future research could investigate why some hospitals tend to post more than others do and social media use as a patient engagement tool.

Additionally, certain hospitals are outliers with comparatively higher social media activity. For example, several hospitals had more than 400,000 Facebook likes and Twitter followers. A potential explanation for high numbers of likes and followers may be the popularity and frequency of content disseminated on these pages, which the public deems valuable enough to share with their own social networks. Social media engagement may provide a measure of the value of information services that hospitals offer to patients, providers, policymakers, and their online community. A better understanding of the benefits of social media engagement and the approaches used by outliers to increase visibility could be useful for hospitals at the early stages of creating social media accounts.

### Limitations

This study has several limitations. Our findings represent a snapshot of hospital adoption and utilization. Social media are changing rapidly and so are the media channels themselves. The same speed with which these channels are adopted and new channels are developed reveals the importance of examining how they are used by hospitals. In addition, some hospitals in networks share social media accounts. In this case, we attributed the social media account adoption and utilization to all hospitals within the network. However, after conducting sensitivity analyses that included and excluded all the hospitals in networks, the results remained the same. Lastly, there may be hospital social media webpages that we did not locate using our search methods. This may lead to underestimation of social media adoption. Our search method, however, mimics the strategy that the public might use to search for the social media webpage for a particular hospital.

### Conclusion

Adoption of certain social media platforms is widespread among US hospitals, is greater than in previous reports, and remains varied. The functional purpose of social media use by hospitals and its opportunity and impact on patients and populations remains largely unknown. Nevertheless, the tremendous reach of these new media and their ability to harness existing networks with established trust relationships suggests they have the potential to become dominant communication channels for health care.

### Conflicts of Interest

None declared.

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## Abbreviations

**AHAS:** American Hospital Association Survey

**HCAHPS:** Hospital Consumer Assessment of Healthcare Providers and Systems

**OLS:** ordinary least squares

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Original Paper

# The Reliability of Tweets as a Supplementary Method of Seasonal Influenza Surveillance

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## Abstract

**Background:** Existing influenza surveillance in the United States is focused on the collection of data from sentinel physicians and hospitals; however, the compilation and distribution of reports are usually delayed by up to 2 weeks. With the popularity of social media growing, the Internet is a source for syndromic surveillance due to the availability of large amounts of data. In this study, tweets, or posts of 140 characters or less, from the website Twitter were collected and analyzed for their potential as surveillance for seasonal influenza.

**Objective:** There were three aims: (1) to improve the correlation of tweets to sentinel-provided influenza-like illness (ILI) rates by city through filtering and a machine-learning classifier, (2) to observe correlations of tweets for emergency department ILI rates by city, and (3) to explore correlations for tweets to laboratory-confirmed influenza cases in San Diego.

**Methods:** Tweets containing the keyword “flu” were collected within a 17-mile radius from 11 US cities selected for population and availability of ILI data. At the end of the collection period, 159,802 tweets were used for correlation analyses with sentinel-provided ILI and emergency department ILI rates as reported by the corresponding city or county health department. Two separate methods were used to observe correlations between tweets and ILI rates: filtering the tweets by type (non-retweets, retweets, tweets with a URL, tweets without a URL), and the use of a machine-learning classifier that determined whether a tweet was “valid”, or from a user who was likely ill with the flu.

**Results:** Correlations varied by city but general trends were observed. Non-retweets and tweets without a URL had higher and more significant ( $P < .05$ ) correlations than retweets and tweets with a URL. Correlations of tweets to emergency department ILI rates were higher than the correlations observed for sentinel-provided ILI for most of the cities. The machine-learning classifier yielded the highest correlations for many of the cities when using the sentinel-provided or emergency department ILI as well as the number of laboratory-confirmed influenza cases in San Diego. High correlation values ( $r = .93$ ) with significance at  $P < .001$  were observed for laboratory-confirmed influenza cases for most categories and tweets determined to be valid by the classifier.

**Conclusions:** Compared to tweet analyses in the previous influenza season, this study demonstrated increased accuracy in using Twitter as a supplementary surveillance tool for influenza as better filtering and classification methods yielded higher correlations for the 2013-2014 influenza season than those found for tweets in the previous influenza season, where emergency department



ILI rates were better correlated to tweets than sentinel-provided ILI rates. Further investigations in the field would require expansion with regard to the location that the tweets are collected from, as well as the availability of more ILI data.

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## KEYWORDS

Twitter; tweets; infoveillance; infodemiology; syndromic surveillance; influenza; Internet

## Introduction

### Overview

Surveillance systems that are in place by the Centers for Disease Control and Prevention (CDC) and through state surveillance have the potential to reduce morbidity and mortality due to a disease and to improve health; however, their usefulness has not been established [1]. Traditionally, surveillance for disease incidence and prevalence is ongoing and systematic, generally relying on laboratory-confirmed cases, as reported by a clinical physician, laboratory, or emergency department. Between the reporting of cases and compiling of data into surveillance reports, a time delay of 1 to 2 weeks is often present, impacting the response of health departments to a possible outbreak.

The Internet's potential as a source of public health information has not been overlooked in the past decade. It has been hypothesized that the routine use of informal electronic information, typically user-generated, can reduce the time needed to recognize an outbreak, prevent governments from suppressing outbreak information, and facilitate public health interventions [2]. With the increasing popularity of social media websites and people publicly sharing many aspects of their days, syndromic surveillance systems, which rely on the use of real-time data in order to provide quick analysis and feedback for a potential outbreak, now have a new source of data [3]. Infodemiology, where user-generated data on Internet-based venues has allowed for the possibility to mine, aggregate, and analyze text to inform public health practitioners and public policy, is an emerging field that has applications toward disease outbreak detection [4]. Infoveillance, where information gleaned from infodemiology is used as a method of surveillance [4], can be used to enhance syndromic surveillance and can be applied to influenza activity.

Among vaccine-preventable illnesses, seasonal influenza in adults has the greatest impact in the United States [5]. Although it has similar symptoms to the common cold, infection with the influenza virus can lead to symptoms ranging in severity and can lead to death in susceptible persons [6]. Financially, the annual national economic burden of influenza attributable to adults can amount to US \$83.3 billion according to a study from 2007 [7]. While the ever-changing nature of influenza viruses enables new sources of the flu season every year, predictions of the onset of infections and the number of people affected are nearly impossible to make with traditional surveillance methods. Through the implementation of a supplementary surveillance tool focused on real-time trends gathered from social media and the fast release of that data, public health agencies may be better prepared and able to stifle a potentially debilitating outbreak in a community.

### Related Work

More recent disease surveillance websites are Web application hybrids that are capable of mining, categorizing, filtering, and visualizing epidemic information while using geographic information systems (GIS) in real time so that delays are minimized and updates are constant [8-14]. HealthMap, organized by the Children's Hospital of Boston, has between 1000 and 150,000 users daily and provides real-time updates for public health reports related to all types of outbreaks across the world in many languages [2]. Social media on the Internet has also identified foodborne-illness outbreaks faster than traditional methods as many of those affected opt to not seek medical attention and instead post their symptoms online [15]. Google Flu Trends collects the 50 million most common search queries in Google as they relate to flu symptoms, remedies, and complications and compares them with the CDC's reported national influenza-like illness (ILI) rates [16]. The benefits of using the Internet are multiple as these Internet tools could aid public health officials to underscore the importance of vaccination and prevention measures, or guide physicians in their medical decision making [2]. However, the lack of specificity of signals, noisy data, false reports, and unusual events like drug recalls or popular cold or flu remedies can overload the tool with irrelevant data that can lead to inaccuracy during analysis [2].

Twitter, a microblogging site where users generate tweets, or texts of 140 characters or less, has already shown its value in forecasting box-office revenues, earthquake reporting, meme tracking, large-scale fire emergencies, downtime on services, live traffic updates, national moods, currency trading [17], and even election results [18]. The real-time updates on Twitter are useful for a variety of fields—whether to increase knowledge, predict consumer trends, or to determine what users are discussing in general. For example, researchers at the University of Michigan were able to use Twitter as a tool to understand the effects of a migraine in real-time by collecting tweets and categorizing them by prevalence, life-style impact, linguistic, and timeline of the self-reported migraine headache, finding that the study avoided memory bias and experimenter-induced error, and highlighted migraine colloquialisms as they related to modern characteristics and descriptions used by migraine sufferers [19].

Multiple studies have been done to find correlations between tweets and ILI data, however the searches tend to be very wide. One study analyzed over 500 million tweets from an 8-month period and found that tracking a small number of flu-related keywords and combinations of keywords allowed forecasting of future rates with a 95% correlation [20]. Signorini et al also found that Twitter can be used descriptively, as a way to ascertain users' interests and concerns related to influenza, and

can capture real-time disease activity [21]. During the influenza A (H1N1) pandemic, hundreds of thousands of tweets were collected in the United Kingdom over a period of 24 weeks to search for symptom-related statements [22]. The method proved to be inexpensive as well as timely by utilizing a stream of data created within only a few hours whereas traditional surveillance would take 1 to 2 weeks to release a report; however, it was determined that it would be necessary to separate media hype and discussion from reporting of actual flu cases if the goal is to use Twitter as a predictive tool for influenza [22]. Chew and Eysenbach reached similar conclusions after performing content analysis from tweets during the 2009 H1N1 outbreak and found that over 90% of their tweets were linked to mainstream and local news websites, but the proportion that were linked to more opinion-based or experience-based sites (blogs, social networks, web pages) also increased over the time of collection [23].

## Objectives

This study builds on previous exploratory research conducted by the Department of Geography at San Diego State University that demonstrated that the content of social media messages and searches was correlated with actual surveillance reports of influenza in the 2012-2013 US influenza season [24]. The objectives of this study were threefold. The first objective was to investigate the ability to improve the correlation of Twitter social media content with traditional sentinel ILI surveillance reports by using a machine-learning classifier and keyword-based search techniques to filter tweets to make them more “valid”. Second, we sought to compare mentions of influenza in social media content to emergency department ILI records, and third, to do a small pilot study comparing tweets related to influenza to laboratory-confirmed influenza cases in San Diego, California. Unlike previous research with Twitter and influenza surveillance, our study is unique in that we compared ILI rates from specific cities to tweets that contained the word “flu” that originated from that respective city, thereby focusing on city-specific correlations. By comparing tweets from a city with the city-specific ILI rates, we are able to view trends in the spread of influenza on a much smaller scale than in previous studies.

## Methods

### Data Collection

Using a geo-targeted social media search tool created by Tsou et al [18], information mining can be conducted in conjunction with the Twitter Search Application Programming Interface (API). With over 200 million active users, Twitter is a large resource of publicly available data in the form of millions of tweets. By first specifying a keyword, the research group’s frameworks in combination with the Twitter API yield a Microsoft Excel spreadsheet of tweets that originate from within a certain geographical location (determined by the user’s global positioning system coordinates, if enabled, or listed hometown) and are associated with the keyword either through the text of the tweet, or the username. The spreadsheet also includes additional data include time of tweet creation, location of origin, who the tweet was directed to if it was part of a conversation, the number of followers, and people following the user who

tweeted, as well as the number of total tweets of that user. Of interest to this study were the tweet text and the geographic location of the tweet was posted.

Based on our previous study indicating that non-retweets and tweets without a URL containing the keyword “flu” were much more highly correlated with sentinel influenza surveillance than other words such as “influenza” [24], tweets that contained the keyword “flu” were collected and aggregated once every 7 days starting on August 25, 2013 and ending on March 1, 2014. Tweets were collected from users who resided within a 17-mile radius from the center of 11 different cities (Boston, Chicago, Cleveland, Columbus, Denver, Detroit, Fort Worth, Nashville-Davidson, New York, San Diego, and Seattle). Tweets were collected from a 17-mile radius as it was the minimum distance between two neighboring cities, thus ensuring there were no tweets that could have overlapped in their city of origination. These cities were chosen for their availability of sentinel influenza-like illness (ILI) surveillance data either from the city or county health department. An influenza-like illness is defined as a fever equal to or greater than 100° F and a cough and/or sore throat in the absence of a known cause other than the influenza virus. The ILI is reported as the percent of patients seen for ILI symptoms compared to all patient visits for the week [25]. Because the CDC does not report ILI data below the state level, ILI reports were found on either county or city level health department websites and for San Diego, through a contact at the County of San Diego Health and Human Services Agency. For a subset of five cities (Boston, Chicago, Cleveland, Columbus, and San Diego), both sentinel ILI and emergency department ILI were collected.

At the end of the collection period, 159,802 tweets contained the word “flu” and were used for filtering and analysis. Depending on when ILI data became available by city, the focus was on tweets from Week 40 in 2013 through Week 9 in 2014 (the week starting on September 29, 2013 to the week ending on March 1, 2014), as determined by the CDC’s Morbidity Mortality Weekly Report (MMWR). Correlations and significance of correlation values between the weekly number of yielded tweets and the weekly sentinel ILI or emergency department ILI as reported by the corresponding city or county department were calculated.

### Analysis

Pearson’s correlation coefficients for the association between week-specific tweet volume and influenza-like illness rates were calculated in R (R Foundation for Statistical Computing, Vienna, Austria, version 3.0.0) for each of the cities for tweets containing “flu.” Tweets were also subdivided into non-retweets, retweets, tweets without a URL, and tweets with a URL. These categories were not mutually exclusive, for instance, non-retweets could contain tweets that had a URL or tweets without a URL. This was done to determine whether there were higher correlations based on the type of tweet. Pearson’s correlation coefficients were performed as an easy way to compare groups of tweets with the ILI and in order to readily identify tweets that would be most useful for infoveillance in the future. For each week, the tweeting rate, or the number of tweets per 100,000 individuals, in each city was also calculated. To determine the

population of each city that tweets were collected from, census tracts whose centers fell within the 17-mile radius from the city center were identified and their population counts summed. “Flu” tweeting rates were compared weekly for each city and visualized through bar graphs that also displayed the reported ILI rate for each week in each city. The goal of scaling by population was to observe if there would be differing trends in flu activity by city.

Separately, a machine-learning classifier was coded in Python (Python Software Foundation, Delaware, USA, version 2.7.6) and its “scikit-learn” software. We used a support vector machine (SVM) classifier to filter out noise from the data set. To train the classifier, we used 1500 randomly sampled tweets containing the keyword “flu” from the 2012-2013 season as inputs. Each of these 1500 training tweets was manually inspected and tagged as valid or invalid according to the likelihood that they indicated actual cases of influenza. This hand-tagged training set was converted to vector representation using their term-frequency-inverse document frequency (TF-IDF) scores, which is a measure of the statistical significance of each term in a text document. These TF-IDF

vectors were then input to the SVM for training. Tweets posted by a user whose username contained the word “flu” were removed because they were collected regardless of tweet content and would introduce noise into the sample size. Tweets that were determined to be representative of a user who was likely ill with the flu were labeled as valid, while other tweets that did not score the minimum were classified as invalid and thereby eliminated before conducting correlation analyses. Examples of the types of tweets the algorithm labeled as valid or invalid are listed in [Table 1](#).

To evaluate the classifier, we manually tagged a test set containing 1000 tweets and ran the classifier to get two performance measures: recall, the portion of tweets that were hand-tagged as valid in the test set that were also correctly classified as valid by the classifier, and precision, the portion of classified “valid” tweets that were also manually tagged as valid. The recall for the classifier was calculated to be 0.9369, and the precision was 0.6859. This means that the classifier was able to correctly identify most manually tagged valid tweets as being valid, but it had difficulty identifying invalid tweets and would mark some as valid.

**Table 1.** Examples of valid and invalid tweets from the machine-learning classifier.

Tweet text	Valid or Invalid
“I hate being sick with the flu”	Valid
“Not a good time to be hit by a flu”	Valid
“Been home sick with the flu the last 2 days”	Valid
“Getting my flu shot”	Invalid
“Now it’s my turn to have the stomach flu. Ugh”	Invalid
“Recipes for Foods That Fight The Flu [URL]”	Invalid

## Results

### Sentinel-Provided ILI

Weekly ILI rates as reported by sentinel physicians to city and county health departments were available for Boston, Chicago, Cleveland, Columbus, Denver, Detroit, Fort Worth, Nashville-Davidson, New York, and San Diego. [Table 2](#) shows correlation coefficients between the sentinel-provided ILI for each city and the number of weekly tweets containing the keyword “flu” that originated in each city before filtering and after filtering for each of the categories of tweets.

Correlations for each category of tweets (non-retweets, retweets, tweets without a URL, tweets with a URL) with sentinel ILI by city can be seen in [Table 2](#). Correlations in the table that had a significance of  $P < .05$  are denoted with an *e* superscript. Denver, Fort Worth, Nashville-Davidson, and San Diego had significant correlations ( $P < .001$ ) for each category, including all tweets. Cleveland and Detroit both had significant correlations for undivided tweets (Column 1) and all categories with the exception of retweets (Column 3). New York was the only city observed to have a significant correlation with all tweets, and all other categories were shown to have insignificant correlations. With the exception of Boston and Denver, non-retweets (Column 2) had higher correlations than retweets.

Tweets without a URL (Column 5) also had a higher correlation than tweets with a URL (Column 6) except for Columbus, Detroit, New York, and San Diego. Column 4 displays the Fisher’s *z* transformation *P* values for the comparison of correlations between non-retweets and retweets, while Column 7 contains the Fisher’s *z* transformation *P* values for the comparison of correlations between tweets without a URL and tweets with a URL. Fisher’s *z* transformations were calculated to demonstrate whether there was a difference between categories of tweets.

[Table 3](#) shows the correlations for all tweets, the number of tweets, *P* values for the correlations, and then the same information for the tweets that were labeled as valid by the Python machine-learning classifier. Using the valid tweets, the correlations were greater and more significant in 5 cities than the correlations for all tweets (Column 1). Column 7 in [Table 3](#) contains Fisher’s *z* transformation *P* values for the comparison of correlations between the undivided tweets and valid tweets. With the exception of Cleveland, the differences between correlations were significant ( $P < .001$ ).

[Figure 1](#) shows a visual representation of the weekly tweet rates per 100,000 for the valid tweets in each city alongside the sentinel-provided ILI. The x-axis is the week number, starting at Week 36 and going through Week 9, with two Y-axes: one

is tweet rate per 100,000 and the other is the ILI for that week, often reported as a percentage. Correlations from Table 2 are listed and bolded if the significance for the correlation was at  $P < .05$ , alongside the number of valid tweets for each city. Tweet rates are shown in pink and ILI rates in blue. Yellow bars indicate missing ILI data and were calculated by averaging the ILI rate from the week before and after the week of missing data. To ensure better visualization, maximum ILI rates for each city were rescaled.

Trends in valid tweets containing the word “flu”, or tweets identified to be posted by a user who is likely ill with the flu, and sentinel-provided ILI are displayed in bar charts for each city. Tweeting rates are in pink, ILI rates in blue, and yellow indicates a week during which ILI rates were missing. Both of the tweeting and ILI rates were rescaled for each city in order to show trends on the same scale to account for differences in population. Correlation coefficients between valid tweets and the sentinel-provided ILI rate as well as the total number of valid tweets are listed for each city. Significant correlations ( $P < .05$ ) are bolded.

**Table 2.** Correlations between tweets and sentinel-provided ILI<sup>a</sup> rates.<sup>b</sup>

	1. All tweets	2. Non- retweets	3. Retweets	4. Fisher's $z$ transformation <sup>c</sup>	5. Tweets without a URL	6. Tweets with a URL	7. Fisher's $z$ transformation <sup>d</sup>	8. Total number of tweets
	<i>r</i>	<i>r</i>	<i>r</i>	<i>P</i>	<i>r</i>	<i>r</i>	<i>P</i>	
Boston	-.05	-.19	.08	<.001	.04	-.13	<.001	17,370
Chicago	.33	.50	.04	<.001	.49 <sup>e</sup>	.25	<.001	21,655
Cleveland	.63 <sup>e</sup>	.74 <sup>e</sup>	.42	<.001	.56 <sup>e</sup>	.55 <sup>e</sup>	.703	6632
Columbus	.01	.05	-.06	.019	-.04	.08	.001	3206
Denver	.76 <sup>e</sup>	.64 <sup>e</sup>	.74 <sup>e</sup>	<.001	.81 <sup>e</sup>	.63 <sup>e</sup>	<.001	5706
Detroit	.81 <sup>e</sup>	.84	.44	<.001	.62 <sup>e</sup>	.78 <sup>e</sup>	<.001	8417
Fort Worth	.69 <sup>e</sup>	.73 <sup>e</sup>	.45 <sup>e</sup>	<.001	.81 <sup>e</sup>	.62 <sup>e</sup>	<.001	4755
Nashville- Davidson	.77 <sup>e</sup>	.74 <sup>e</sup>	.54 <sup>e</sup>	<.001	.70 <sup>e</sup>	.66 <sup>e</sup>	<.001	5805
New York	.44 <sup>e</sup>	.42	.39	<.001	.32	.44	<.001	64,340
San Diego	.78 <sup>e</sup>	.73 <sup>e</sup>	.41 <sup>e</sup>	<.001	.69 <sup>e</sup>	.73 <sup>e</sup>	<.001	8002

<sup>a</sup>ILI: influenza-like illness

<sup>b</sup>Correlation coefficients of all tweets and tweet categories with sentinel-provided ILI rates for each city. Comparisons between tweets and ILI began in Weeks 36-49 (weeks starting September 1, 2013 to starting November 24, 2013) as ILI data became available by city and ended in Week 9 (ending March 1, 2014).

<sup>c</sup>This column displays the  $P$  values from Fisher's  $z$  transformation comparing the correlation coefficients of non-retweets to retweets.

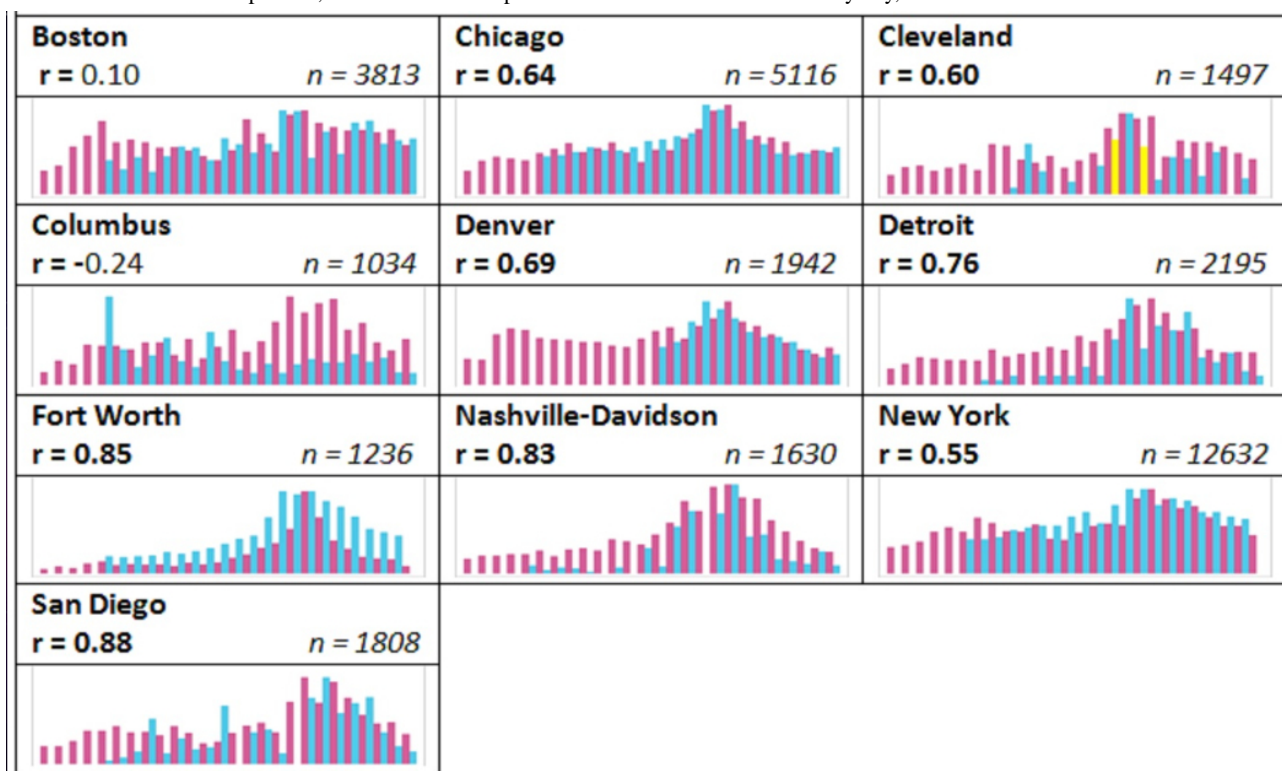
<sup>d</sup>This column displays the  $P$  values from Fisher's  $z$  transformation comparing the correlation coefficients of tweets without a URL to tweets with a URL.

<sup>e</sup>Significant correlation coefficient ( $P < .05$ ).



**Table 3.** Correlations between valid tweets and sentinel-provided ILI<sup>a</sup> rates.<sup>b</sup>

	1. All tweets, <i>r</i>	2. Number of all tweets	3. <i>P</i> -value for all tweets	4. Valid tweets, <i>r</i>	5. Number of valid tweets	6. <i>P</i> -value for valid tweets	7. Fisher's <i>z</i> transformation, <i>P</i>
Boston	-.05	17,370	.834	.10	3813	.67	<.001
Chicago	.33	21,655	.139	.64	5116	.002	<.001
Cleveland	.63	7152	.002	.60	1497	.003	.064
Columbus	.01	3288	.978	-.24	1034	.274	<.001
Denver	.76	5706	.003	.69	1942	.009	<.001
Detroit	.81	8417	.001	.76	2195	<.001	<.001
Fort Worth	.69	4755	.001	.85	1236	<.001	<.001
Nashville-Davidson	.77	5805	.001	.83	1630	<.001	<.001
New York	.44	64,340	.047	.55	12632	.01	<.001
San Diego	.78	8002	.001	.88	1808	<.001	<.001

<sup>a</sup>ILI: influenza-like illness<sup>b</sup>Correlation coefficients between all tweets and valid tweets, as identified by the machine-learning classifier, with sentinel-provided ILI rates for each city. Comparisons between tweets and ILI began in Weeks 36-49 (weeks starting September 1, 2013 to starting November 24, 2013) as ILI data became available by city and ended in Week 9 (ending March 1, 2014).**Figure 1.** "Valid" Tweet rates per 100,000 versus sentinel-provided influenza-like illness rates by city, 2013-14 influenza season.

### Emergency Department ILI Rates

Emergency department ILI rates were available for six cities: Boston, Chicago, Cleveland, Columbus, San Diego, and Seattle. Health departments reported hospital emergency department ILI rates for every city, with the exception of Boston, where data was made available through the Boston Public Health Commission. Table 4 contains the correlations for tweets with the same tweet categories as Table 2: all tweets, non-retweets

and retweets, tweets without a URL, and tweets with a URL. In general, non-retweets (Column 2) had higher correlations than retweets (Column 3), and tweets without a URL (Column 5) had higher correlations than tweets with a URL (Column 6) when comparing to the emergency department ILI rates of each city. Fisher's *z* transformations in Column 4 comparing correlations of non-retweets to retweets and Fisher's *z* transformations in Column 7 comparing correlations of tweets without a URL to tweets with a URL were significant for all



cities for which emergency department ILI rates were available ( $P<.05$ ).

Tweets marked as valid by the classifier were more highly correlated to the emergency department ILI rates than all tweets for all of the cities, as shown in Table 5, with the correlation for tweets and ILI data increasing from .23 ( $P=.41$ ) to .61 ( $P=.02$ ) in Boston alone, and similar increases in correlations observed in the other five cities. The Fisher's  $z$  transformation  $P$  values in Column 7 comparing the correlations of unfiltered tweets and valid tweets to the emergency department ILI rates were all significant ( $P<.001$ ).

Figure 2 shows a visual representation of available emergency department ILI data to rescaled valid tweet rates for each city. The x-axis is the week number, starting at Week 36 and going through Week 9, with two Y-axes: one is tweet rate per 100,000 and the other is the ILI for that week, often reported as a percentage. Pink columns depict tweet rates per 100,000, blue columns show ILI rates, and yellow columns indicate an averaged ILI rate from the week before and the week after a week for which an emergency department ILI rate was not made available.

**Table 4.** Correlations between tweet rates and emergency department ILI<sup>a</sup> rates by city.<sup>b</sup>

	1. All tweets	2. Non- retweets	3. Retweets	4. Fisher's $z$ transforma- tion <sup>c</sup>	5. Tweets without a URL	6. Tweets with a URL	7. Fisher's $z$ transforma- tion <sup>d</sup>	8. Total number of tweets
	$r$	$r$	$r$	$P$	$r$	$r$	$P$	
Boston	.23	.47	-.004	<.001	.03	.41	<.001	17,370
Chicago	.51 <sup>e</sup>	.54 <sup>e</sup>	.23	<.001	.59 <sup>e</sup>	.45 <sup>e</sup>	<.001	21,655
Cleveland	.68 <sup>e</sup>	.87 <sup>e</sup>	.39	<.001	.62 <sup>e</sup>	.58 <sup>e</sup>	.005	7152
Columbus	.62 <sup>e</sup>	.54	.61	.018	.62 <sup>e</sup>	.47 <sup>e</sup>	<.001	3288
San Diego	.80 <sup>e</sup>	.92 <sup>e</sup>	.40 <sup>e</sup>	<.001	.88 <sup>e</sup>	.79 <sup>e</sup>	<.001	8002
Seattle	.72 <sup>e</sup>	.71 <sup>e</sup>	.67 <sup>e</sup>	.001	.62 <sup>e</sup>	.71 <sup>e</sup>	<.001	9735

<sup>a</sup>ILI: influenza-like illness

<sup>b</sup>Correlation coefficients of all tweets and tweet categories with emergency department ILI rates for each city. Comparisons between tweets and ILI began in Weeks 40-41 (weeks starting September 29, 2013 to starting October 6, 2013) as ILI data became available by city and ended in Week 9 (ending March 1, 2014).

<sup>c</sup>This column displays the  $P$  values from Fisher's  $z$  transformation comparing the correlation coefficients of non-retweets to retweets.

<sup>d</sup>This column displays the  $P$  values from Fisher's  $z$  transformation comparing the correlation coefficients of tweets without a URL to tweets with a URL.

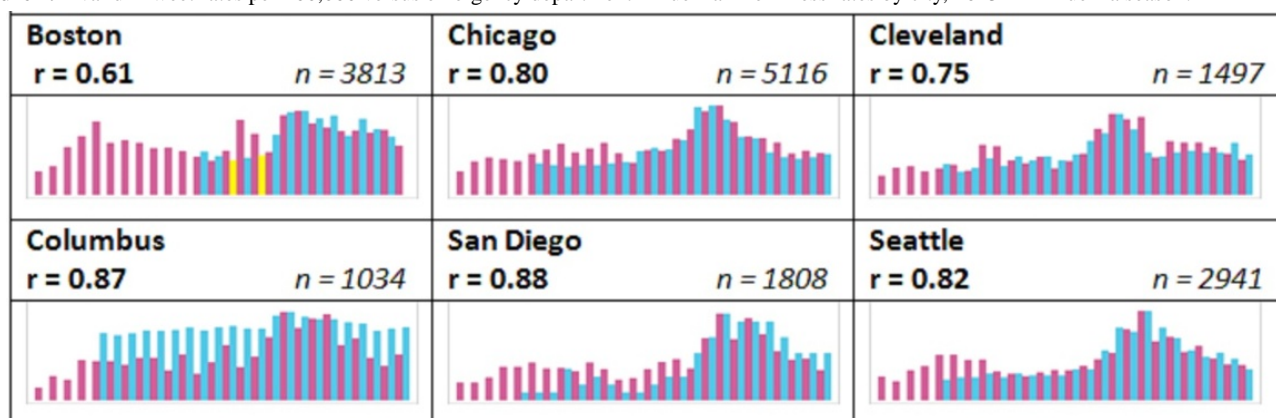
<sup>e</sup>Significant correlation coefficient ( $P<.05$ ).

**Table 5.** Correlations between valid tweets and emergency department ILI<sup>a</sup> rates by city.<sup>b</sup>

	1. All tweets	2. Number of all tweets	3. All tweets	4. Valid tweets	5. Number of valid tweets	6. Valid tweets	7. Fisher's $z$ transformation
	$r$		$P$	$r$	$r$	$P$	$P$
Boston	.23	17,370	.411	.61	3813	.016	<.001
Chicago	.51	21,655	.017	.80	5116	<.001	<.001
Cleveland	.68	7152	<.001	.75	1497	<.001	<.001
Columbus	.62	3288	.002	.87	1034	<.001	<.001
San Diego	.80	8002	<.001	.88	1808	<.001	<.001
Seattle	.72	9735	<.001	.82	2941	<.001	<.001

<sup>a</sup>ILI: influenza-like illness

<sup>b</sup>Correlation coefficients between all tweets and valid tweets, as identified by the machine-learning classifier, with emergency department ILI rates for each city. Comparisons between tweets and ILI began in Weeks 40-41 (weeks starting September 29, 2013 to starting October 6, 2013) as ILI data became available by city and ended in Week 9 (ending March 1, 2014).

**Figure 2.** “Valid” Tweet rates per 100,000 versus emergency department influenza-like illness rates by city, 2013-14 influenza season.

### Laboratory-Confirmed Influenza Cases in San Diego

As a small pilot study, the San Diego Health and Human Services Agency was able to provide the number of laboratory-confirmed influenza cases from Week 40 through Week 9 of the 2013-2014 flu season. Correlations were calculated using the number of weekly tweets in San Diego for

all tweets and for each of the tweet categories. Table 6 shows the  $r$  correlations for all subdivisions of tweets, along with the  $P$  value for each. All were significant ( $P < .001$ ) with tweets marked as valid by the classifier having the highest correlation value ( $r = .93$ ), followed by non-retweets, tweets without a URL, and all tweets. Retweets had the lowest correlation value at  $r = .40$ .

**Table 6.** Correlations between tweets and number of laboratory-confirmed influenza cases in San Diego.<sup>a</sup>

All tweets	All tweets	Non-retweet	Non-retweets	Retweets	Retweets	Tweets without a URL	Tweets without a URL	Tweets with a UR	Tweets with a URL	Valid tweets	Valid tweets
$r$	$P$	$r$	$P$	$r$	$P$	$r$	$P$	$r$	$P$	$r$	$P$
.88	<.001	.92	<.001	.40	<.001	.88	<.001	.79	<.001	.93	<.001

<sup>a</sup>Correlation coefficients for all tweets and all categories of tweets, including valid tweets with the number of laboratory-confirmed influenza cases in San Diego starting Week 40 (beginning October 6, 2013) through Week 9 (ending March 1, 2014).

## Discussion

### Principal Findings

This study is a continuation of the exploratory research conducted for the 2012-2013 flu season by researchers at San Diego State University that used Twitter as a possible method for identifying trends in influenza incidence in 11 cities. The specific ILI rates per city are not included in this paper because we wanted to establish the correlations between tweets and ILI rates, regardless of how high or low they were, and not the progression of the spread of influenza in the cities themselves. The 2013-2014 influenza season was less severe than the 2012-2013 influenza season: ILI rates were lower and fewer people were infected with a strain of the influenza virus. Across the 11 cities that tweets were collected from, tweet rates and ILI rates peaked around between Week 50 (ending December 14, 2013) and Week 2 (ending January 11, 2014). Tweets, sentinel, and emergency department ILI rates all followed the same general trend of increasing or decreasing at roughly the same time. Boston was the only city for which the tweet rate peaked before the ILI rate, for both sentinel-provided and emergency department ILI. However, in Boston the correlation between tweet rate and ILI rate was only significant when looking at valid tweets and emergency department ILI ( $P = .02$ ) and other correlations were low and insignificant for that city.

Separate analyses by tweet category suggest methods to improve ILI rate approximation. Non-retweets had higher and more significant correlations than retweets for the majority of the cities, and tweets without a URL also had higher and more significant correlations than tweets with a URL. Non-retweets are completely original tweets and are posted from the user's location, whereas retweets are the tweets of others re-posted by a user. Even if a tweet is posted from an area outside of collection, retweets can still be acquired because of the location of the user who re-posted it. For this reason, retweets are likely not as reflective of the user's own health and illness. Tweets with a URL are likely used to share information from a news source or blog and are more probably representative of the user's opinion or sentiments rather than their actual health condition.

Correlations of tweets with emergency department ILI rates were higher for all of the cities than the correlations of tweets and sentinel-provided ILI rates, with the exception of San Diego. This was observed not only for all tweets, but also for all of the categories of tweets. Emergency department ILI is often reported mandatorily to health departments whereas sentinel-provided ILI is voluntary and based on sentinel physicians within an area. The number of physicians who report weekly can vary widely and lead to inconsistency of rates on a week-by-week basis. Patients who visit a sentinel physician may be more likely to have received an influenza vaccination and so lower ILI rates are reported. Throughout the season, correlations to emergency

department ILI activity were very high compared to sentinel-provided ILI activity, though by the end of the study period, the gap in correlations had closed.

Use of the machine-learning classifier yielded the highest correlations for many of the cities when using either sentinel-provided or emergency department ILI activity data, as well as the number of laboratory-confirmed influenza cases in San Diego. We expected to see highest correlations using the valid tweets and the ILI activity, for both sentinel and emergency department ILI rates, because by identifying valid tweets, or ones that were more likely to indicate that the user has an influenza-like illness, much of the noise caused by tweets that are not retweets or do not have a URL can be eliminated. In future infoveillance activities, we recommend the use of non-retweets and tweets without a URL that have been filtered through a machine-learning classifier to improve validity for the highest levels of correlation with sentinel ILI and emergency department ILI findings.

The observation of high correlation values ( $r > .80$ ) and at such high significance ( $P < .001$ ) to laboratory-confirmed influenza cases is another promising aspect of this study. Influenza-like illness rates are based on syndromes and thus provide an idea of the number of illnesses before they can actually be confirmed with laboratory evidence. Nevertheless, the delay that occurs before the reports are released can and does create a large problem for surveillance. Our results show a high correlation between tweets and laboratory-confirmed cases, which may add another source of current information to public health professionals. However, there is growing concern in the field about the effect of large sample sizes on  $P$  values. It is a possibility that users tweeting about the flu were younger and largely teenagers, who were taken to a physician and tested for the influenza virus because of greater access and their parents taking them, accounting for the especially high  $P$  value observed in our study between laboratory-confirmed cases and influenza.

An advantage to using social media to survey influenza incidence is that it would quicken response time for public health departments and health care providers. This case study only looked at how well tweets correlated to ILI as reported by emergency departments and sentinel physicians. By observing how both ILI and tweets were increasing together around Weeks 48 through Week 52, a responsive measure to the outbreak could have been instated, whether through notifying neighboring communities of a growing number of flu cases or reminding the population of ways to steer clear of the flu.

## Limitations

The greatest limitation in this study was experienced in the ILI disease reporting surveillance systems. The start dates for the weekly ILI reports varied by city and although some report year-round and others start during MMWR week 40, Denver did not release an ILI rate until MMWR week 49. Reporting by city was also variable with the type of data shared—while some cities had both sentinel-provided and emergency department ILI data, others only had sentinel-provided or, in the case of Seattle, only emergency department ILI data. The optional nature of ILI reporting by sentinel providers meant that cities of similar populations could be gathering data from a differing

number of sentinel providers. For instance, Columbus generally had only two or fewer sentinel providers reporting weekly ILI rates and so had unreliable ILI rates for a city of over 800,000 residents. Boston and Chicago also had low correlations between tweets and ILI rates from either source, whether a sentinel provider or emergency department. It is difficult to ascertain why this may be the case because reports from Boston and Chicago did not contain the number of sentinel providers or emergency departments surveyed. As both Boston and Chicago are very large in population size, it may be that there was too much noise in the collected tweets where even tweets that were not posted by news sources were opinion-based, not illness-based, as observed by Chew and Eysenbach [23]. Although correlations improved for both cities when comparing tweets identified as valid to ILI rates, questions remain as to how to utilize Twitter as a tool for Boston and Chicago specifically. One method that would aid our research, as well as surveillance in these cities, would be to perhaps review what qualifies as an ILI and also seek out more sentinel providers willing to report cases, as well as student health centers, as both cities have large student populations who may be accessing their university resources rather than a primary care physician or emergency department. The accuracy of ILI reporting has been brought into question before, but it only increases the need for another method that can be used, such as tweets.

Although information such as username, location, number of followers, number of people being followed, and user profiles can be collected along with the tweet text, demographic information such as age, gender, and race cannot be collected through tweets, making it difficult to determine who is tweeting about the flu and to whom public health efforts should be directed. A total of 31% of Twitter users in 2013 reported their age as between 18-29 years old [26], an age group that can be heavily affected by the flu; although, for many flu strains we are often more concerned about the very young and the elderly. The fact that tweets were highly correlated to ILI surveillance in the 2013-2014 flu season might be due to the fact that a strain of the H1N1 virus was circulating, a strain to which those in 15-24 year age group are considered to be vulnerable. It is hard to know whether or not the correlations would be stronger or weaker if younger and older age groups used Twitter. There was also only one keyword used in this study (“flu”) rather than the large number of keywords used in our first case study. In the previous study, it was found that tweets containing the word “flu” were more highly correlated to ILI rates than tweets that contained the keyword “influenza” or other related terms [24]. However, even with only one keyword, using the machine-learning classifier yielded such high correlations between weekly numbers of tweets and ILI data that it may only be necessary to refine the classifier rather than to include more keywords that would introduce more noise into the data. Other refinements to the classifier would also include fine-tuning the degrees of separation in the tweet. Currently, if a tweet mentions “my sister”, “son”, or “classmate” as having the flu, it is identified as valid. However, if people are tweeting about a celebrity or other popular figure who has the flu, the numbers could be quite skewed. To prevent this issue, more training would be required as a way to modify the algorithm.

## Conclusions

Social media is a growing platform used by millions of people and holds great potential as a resource for public health through infodemiology and infoveillance research. This study demonstrated reproducibility in using Twitter as a supplementary surveillance tool for influenza, as better filtering and classification methods yielded higher correlations than those found for tweets in the previous influenza season. Non-retweets and tweets identified as valid by our machine classifier were both highly correlated to reported ILI rates in many of the cities and specify which tweets should be collected in the future.

Further investigations in this field should include expansion beyond these 11 cities, however more ILI data would need to be available to allow for a possible association to be detected. Our study was restricted as ILI data was available from only 11

cities, but if more cities would publish a weekly ILI rates, either sentinel or emergency room, or both, more refinement could be made in our methods and more knowledge obtained for the reliability of tweets as an indicator of seasonal influenza trends. Existing traditional influenza surveillance efforts have been long-lasting and well-developed, but if correlations to user-generated data on social media continue to increase through improved methods, a real-time estimate of influenza cases would be valuable not only to public health efforts in containing an outbreak and in predicting ILI rates in real time, but also to the general population vulnerable to illness. More credibility should be given to using Twitter as a supplementary large-scale surveillance tool for identifying the spread of local disease in an effort to detect outbreaks earlier and provide more time for the development and implementation of interventions designed to halt the spread of diseases.

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## Conflicts of Interest

None declared.

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## Abbreviations

**API:** application programming interface  
**CDC:** Centers for Disease Control and Prevention  
**ILI:** influenza-like illness  
**MMWR:** Morbidity Mortality Weekly Report  
**SVM:** support vector machine  
**TF-IDF:** term-frequency-inverse document frequency score



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Original Paper

# Using a Geolocation Social Networking Application to Calculate the Population Density of Sex-Seeking Gay Men for Research and Prevention Services

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## Abstract

**Background:** In the United States, human immunodeficiency virus/acquired immunodeficiency syndrome (HIV/AIDS) continues to have a heavy impact on men who have sex with men (MSM). Among MSM, black men under the age of 30 are at the most risk for being diagnosed with HIV. The US National HIV/AIDS strategy recommends intensifying efforts in communities that are most heavily impacted; to do so requires new methods for identifying and targeting prevention resources to young MSM, especially young MSM of color.

**Objective:** We piloted a methodology for using the geolocation features of social and sexual networking applications as a novel approach to calculating the local population density of sex-seeking MSM and to use self-reported age and race from profile postings to highlight areas with a high density of minority and young minority MSM in Atlanta, Georgia.

**Methods:** We collected data from a geographically systematic sample of points in Atlanta. We used a sexual network mobile phone app and collected application profile data, including age, race, and distance from each point, for either the 50 closest users or for all users within a 2-mile radius of sampled points. From these data, we developed estimates of the spatial density of application users in the entire city, stratified by race. We then compared the ratios and differences between the spatial densities of black and white users and developed an indicator of areas with the highest density of users of each race.

**Results:** We collected data from 2666 profiles at 79 sampled points covering 883 square miles; overlapping circles of data included the entire 132.4 square miles in Atlanta. Of the 2666 men whose profiles were observed, 1563 (58.63%) were white, 810 (30.38%) were black, 146 (5.48%) were another race, and 147 (5.51%) did not report a race in their profile. The mean age was 31.5 years, with 591 (22.17%) between the ages of 18-25, and 496 (18.60%) between the ages of 26-30. The mean spatial density of observed profiles was 33 per square mile, but the distribution of profiles observed across the 79 sampled points was highly skewed (median 17, range 1-208). Ratio, difference, and distribution outlier measures all provided similar information, highlighting areas with higher densities of minority and young minority MSM.

**Conclusions:** Using a limited number of sampled points, we developed a geospatial density map of MSM using a social-networking sex-seeking app. This approach provides a simple method to describe the density of specific MSM subpopulations (users of a particular app) for future HIV behavioral surveillance and allow targeting of prevention resources such as HIV testing to populations and areas of highest need.

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**KEYWORDS**

Internet; HIV; MSM; sampling, location services

**Introduction**

In the United States, human immunodeficiency virus (HIV) continues to have a heavy impact on men who report having sex with men (MSM) [1,2]. Although HIV incidence is increasing among MSM overall, there are pronounced disparities in both prevalence and incidence in the United States within the MSM HIV epidemic by race/ethnicity. A Centers for Disease Control and Prevention surveillance study conducted in 2008 [3] found that black non-Hispanic MSM were significantly more likely to be living with HIV than were white non-Hispanic MSM (28% vs 18%), and among those living with HIV, blacks were also significantly more likely to be unaware of their HIV infection (59% vs 26%). The disparity in HIV prevalence is consistent with a marked difference in estimated incidence of new infections for young minority MSM. From 2006-2009, black MSM under age 30 experienced a 47% increase in the estimated annual number of new infections and in 2009, there were more new infections in black MSM under age 30 than in white MSM under age 39 and more than all Hispanic MSM [4].

As a result, there is renewed emphasis [5] on identifying reasons for these disparities [6,7] and developing and providing interventions specifically for young minority MSM. However, the number of HIV prevention interventions implemented and evaluated with young minority MSM remains relatively low [8,9]. One reason for the lack of interventions specifically targeted to black MSM may be difficulty identifying a sampling frame for this population [6,8]. Stigma experienced by black MSM [10-12] may pose particular challenges in enumerating and accessing these men for provision of services [11]. A variety of sampling methods have been developed to access hidden or marginalized populations [13-18], with varying degrees of success [17-24].

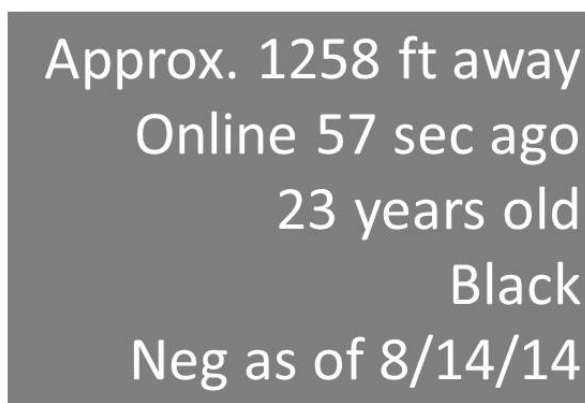
Social networking websites and apps represent novel means for individual communication. A variety of new social networking tools designed for MSM are now available for most smartphones [25-28], and combined, these apps have more than 6 million users and 10,000 new users added daily. Many of these apps build their services on the ability to use the geolocation features

available on most phones and other communication devices (iPods, iPads, and tablets) to provide location information for other app users, including their geographic proximity (in feet or miles) to the user's location. In this paper, we describe a methodology for using the geolocation features of one of these apps as a novel approach to calculating the population density of men using the app at given times and describe how to use this density measure to highlight areas with a high-density of minority and young minority MSM.

**Methods****Overview**

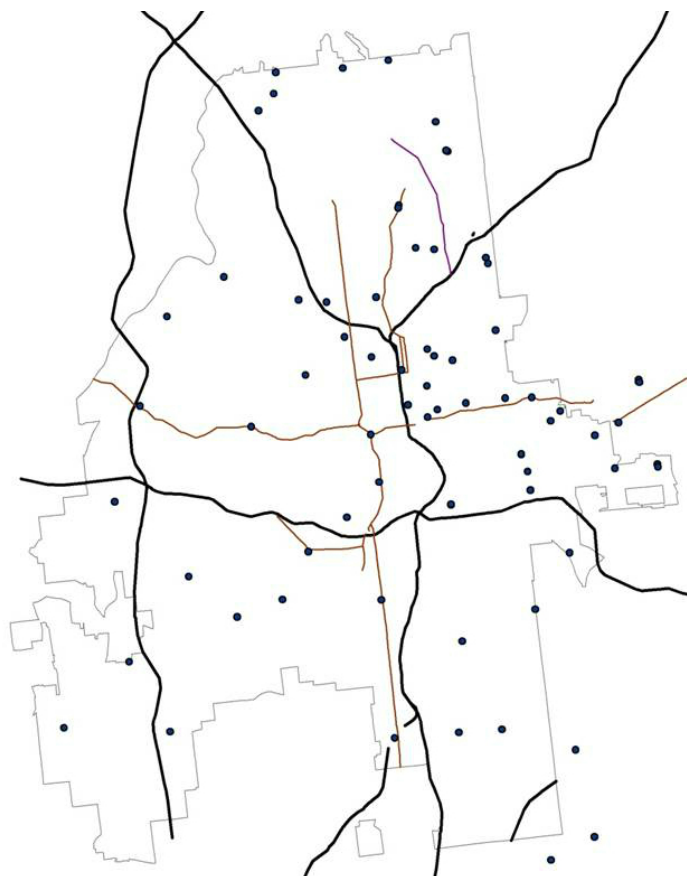
To pilot the study methodology, we chose a sexual networking app and collected data from publicly available profiles at sampled locations around the city of Atlanta, Georgia. App profiles (see Figure 1 for a hypothetical example showing the types of data typically included in user profiles) include information on the linear distance from the user to each other member, in feet for distances less than one mile, and miles for larger distances. For example, the person whose profile is represented in the first panel in Figure 1 was 1258 feet from our sampling location when the profile was viewed. Although we piloted this approach with several of the available apps [25-28], data generated for this paper were from a single app whose name is not revealed at the request of the developer. App profiles indicate the distance but not the direction of the person in question. In order to develop measures of density of users, we began by establishing a grid over Atlanta and selecting points within the grid at which to collect information (Figure 2). Points were selected systematically with the following protocol: we selected a starting point near one author's (KPD) home and drove along major roads to sample at roughly 2-mile intervals through most of the city. In areas with a high density of app users, we used a sampling strategy designed to collect data more frequently at closer intervals (see below). At each point where profile data were observed, study staff used the "GeoLocation" app [29] to pinpoint the location of data collection to latitude and longitude.

**Figure 1.** Hypothetical example of social networking application profile data provided by application users (we used age, race, and distance in feet from our location in this analysis).



Approx. 1258 ft away  
Online 57 sec ago  
23 years old  
Black  
Neg as of 8/14/14

**Figure 2.** Map of Atlanta (gray outline) including major interstates (black lines) and selected major roads (dark red lines); points in the figure represent 79 data collection locations.

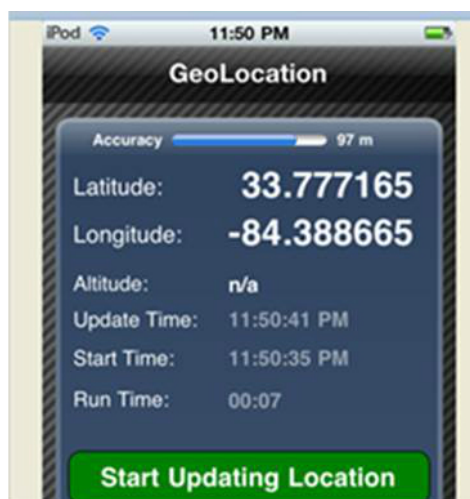


### Validation of Geolocation Data

In order to assess the accuracy of the geolocating app, we also recorded the global positioning system (GPS) location at a subset of the same points at several different days/times using both GeoLocation and a GPS unit (Garmin model GPSmap 60CS [30]). The GeoLocation app was found to be consistent with the GPS unit, with the mean of the difference between them of 144 feet (range 7-344 feet) over a total of 25 sampled points. The GeoLocation app was also used at the same 10 locations 6

months apart and found to give consistent results with a mean of the difference in location coordinates of 76 feet (range 0-232). Thus we found it sufficient to use the free GeoLocation latitude and longitude data available on the same device as the social networking app for our purposes, rather than using two different devices for data collection. See Figure 3 for a screenshot from the GeoLocation iPhone app, available from [29]. Similar tools available for Android devices [31] were not evaluated in this study.

**Figure 3.** Example of the GeoLocation app used in this study, which relies on cell towers and an Internet connection and provides latitude and longitude in decimal degrees.



## Data Collection

At each sampling point, study staff collected screenshots of user profiles. These apps sort profiles based on distance from the user to other users. We collected profile data for either the 50 closest users or for all users within 2 miles of the sampling point, whichever was less. Profiles were saved on a password-protected iPod Touch. These data were entered into a database after field collection of the screenshots. Staff also recorded the day and time of data collection at each point. We calculated the total time spent collecting data as a process measure for this pilot study.

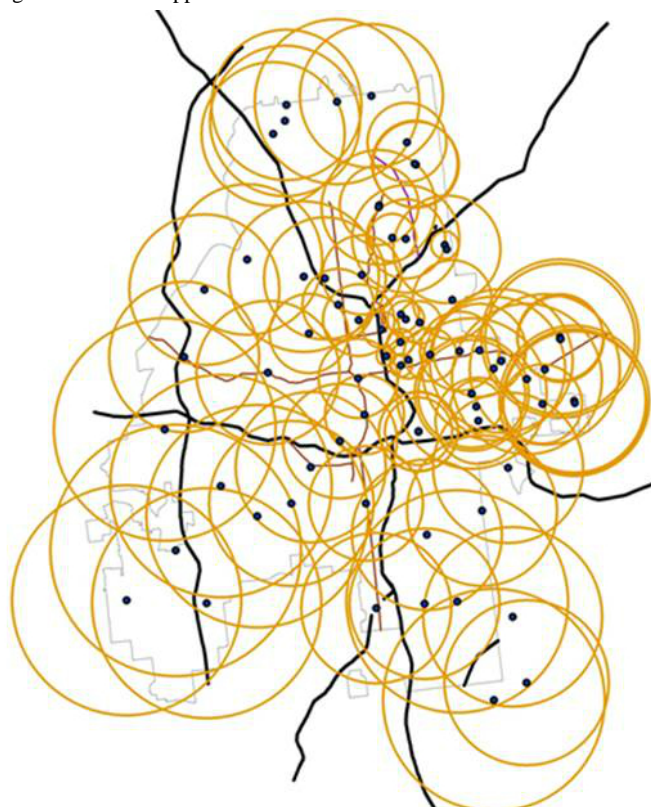
For each profile recorded, we extracted self-reported race and age, and the reported distance from the sampled point (see Figure 1). Race was categorized as “white”, “black”, or “other”, and age was recorded as a continuous variable. If a profile included no information on race or age, this was indicated with a missing value in the database. Because the main objective was to compare the distribution of persons reporting their race as white to those reporting their race as black, when either race or age were missing, we recorded missing race as “other” and missing age as missing. Individual profile data from each sampled point were aggregated as the number of users by

self-reported race (grouped as white, black, and other) and self-reported age group (grouped as 18-24, 25-30, >30, or unknown), and summary measures comparing those reporting black or white race in their profiles (further described below) were calculated for Atlanta.

## Sampling Strategy

At points where there were greater than 50 users within less than a 2-mile radius, we recorded the maximum distance to the 50<sup>th</sup> closest user (ordered by distance) and moved this same distance along city streets to establish the next sample point. Thus smaller radii were used in areas with a higher density of users. Figure 4 shows the sampling radii for each point: the smaller circles represent the areas of Atlanta with the highest density of users, and thus larger numbers of individual profiles available within a given (eg, 2 mile) radius. Because we collected different numbers of users from circles of different radii, we chose to standardize these measures to a common area, for example, converting each observation into the number of users within 1 mile of the point (thus describing a circle with a mile radius and/or an area of  $\pi$  square miles), and stratifying these measures by race and age group.

**Figure 4.** Map of Atlanta showing 79 data collection points from profiles on a sex-seeking networking app; radii of yellow circles represent distance to user sample at the maximum distance from the sample point, and overlapping circles completely cover Atlanta, with smaller circular areas used for data collection where there were the largest numbers of application users.



## Analysis

The data in this study provide a somewhat unique challenge to geospatial statistical methods because they combine the characteristics of point and area processes [32-37]. Data are collected at points on a grid, but the data at that point represent a density over an area of sampling in a concentric circle around

that point. Still, the data are more analogous to point data, with the measure collected at each point representing an area rather than an individual data point. Thus we chose to treat these densities of users per square mile as the measure of interest but use point data statistics [32,38,39] to summarize over the entire study area. ArcGIS [39] performs kernel smoothing to estimate the density measured at each sample point where each sample



point is weighted by the observed population density at that point. In our case, the Kernel Density smoother [34] counts every white and black user observed at that location. For example, a point at which we observed 12 profiles within 2 miles, including 8 white and 4 black users, would be counted 8 times in the white density measure and 4 times in the black density measure. Next, these weighted values for each point are also averaged with other points within a specified radius [32,36,37], resulting in a smoothed surface representing the density of users, by race, in the sample space. The kernel approach may place non-zero density in areas where no data were collected, but only as a result of averaging between points separated by the area with no data. We also experimented with methods for interpolation of spatial data such as kriging [32,38] and found similar results. We focus on kernel density estimates here. As noted above, sampling was conducted at different times and days of the week over a 6-month period (see [Multimedia Appendix 1](#) for documentation of days and times sampled). While an in-depth analysis of time of day and day of week variability is of interest for future research, to illustrate our approach, we present the kernel densities calculated here as averages over sampled days and times.

After estimating the population density, we used ArcGIS to compute the mean and standard deviation for the calculated density measure over the entire sample space. We compared density surfaces through ratio and difference measures via the Map Algebra tool in ArcGIS, which solves standard algebraic equations at each point in a grid across the density surface and creates a new map displaying the results of these calculations. When comparing the density of users, the difference between surfaces for different races, for example, (density of black users – density of white users) has the property that its null value (no difference) is zero, and if positive, it identifies an area with a higher density of black users than white users. This represents an absolute difference in the densities of the two groups. When positive, this approach identifies areas where it might be easier to recruit black users because the density of black users is greater in absolute terms (ie, the number of excess individuals). We note that this example says nothing about the magnitude (size of the density of black and/or white users), only that one number is bigger than the other. To capture areas where there are relatively more black users than white users (ie, the ratio of black to white users is higher), we also calculated the ratio of the two density surfaces.

As a further exploration of the possibilities with the approach, we also considered a measure to highlight areas with the largest densities for each race and then compare these areas as follows. First, for each density surface (eg, the density of black users <25 years of age) we identified areas with the highest density values (density value > mean + 2 SD). For example, if the estimated mean density for white users was 14/square mile with standard deviation of 7, we would ask ArcGIS to select points with a density of white users greater than 28. We then used Map Algebra to calculate the difference between the surfaces including these highest density points for each race according to the following formula:

$$I(\text{Density of black users} > \text{mean} + 2\text{SD of estimated kernel density distribution}) - I(\text{Density of white users} > \text{mean} + 2\text{SD of estimated kernel density distribution})$$

where  $I(\text{statement})$  represents an indicator function with value 1 if the statement is true and zero otherwise. This equation takes only three values: zero when a point is greater than mean + 2SD of both distributions or neither is greater than mean + 2SD; 1 when a point is greater than the mean + 2SD for only the first distribution; and -1 when the point is only greater than the mean + 2SD of the second distribution. This measure identifies not only locations with more users of a given race, but also locations with the highest density areas overall. Similar measures can be constructed to highlight other features of interest, for example, comparing densities by age group or combinations of race and age. Finally, to provide some context to our results, we present them in relation to the location of recruitment sites seeking to enroll MSM for two ongoing HIV prevention studies in Atlanta.

## Results

Over a 2-week period, we spent a total of 21 hours traversing Atlanta, collecting data at the 79 sample points ([Figure 2](#)) covering 883 square miles of area ([Figure 4](#)) in order to collect overlapping circles of data and cover the entire 132.4 square miles in the city of Atlanta. The average radius of data collection at each sample point was 1.65 miles, with smaller radii resulting from the more densely populated areas.

We extracted profile data (race and age) for 2666 user profiles. Of these, 1563 (58.63%) were white, 810 (30.38%) were black, 146 (5.48%) were some other race, and 147 (5.51%) did not report a race in their profile. The mean age was 31.5 years, with 591 (22.17%) between the ages of 18-25, and 496 (18.60%) between the ages of 26-30. Age was more likely than race to be missing from profile information with 593 (22.24%) of profiles sampled not providing age information. The remaining 37% of profiles reported ages greater than 30; whites were more likely to report being >30 years of age than blacks (46% vs 25%,  $P < .001$ ). Black users were younger than white users (median 28 vs 33 years,  $P < .001$  via the Wilcoxon Sign rank test).

Across the 79 sampled points, the mean number of users was 33 per square mile, but the distribution of users across points was highly skewed with median of 17 and range 0.86-208 ([Figure 5](#)).

[Figure 6](#) shows the density of app users, smoothed using a kernel density function with a 2-mile radius, for white (A) and black (B) users. A 2-mile radius was chosen as the smoothing parameter because it was the next largest integer that covered the average radius of 1.6 miles in the sampled points and also was the maximum distance to which we sampled data when a sample point had fewer than 50 users. [Multimedia Appendix 1](#) shows the analogs of [Figures 6](#) and [7](#) with a 1-mile kernel density smoothing parameter for comparison; the results were not qualitatively different. The highest density of white users (the darkest blues in the first panel in [Figure 6](#)) concentrates in Midtown Atlanta (roughly bounded by the yellow rectangle on the map). While much of the highest density of black users also

concentrates in this area, it is clear that there are areas with high densities of black users further south and to the west (to the lower left) of Midtown. The kernel approach smooths observations according to a two-dimensional distribution centered at the observed point and declining out to the radius used to define the search area, essentially “spreading” observations from sample points across the study area. For example, the density values for white users over the 79 sample points ranged from 0.3 to 154 profiles per square mile, but the range of values for the smoothed density shown in the first panel in [Figure 6](#) was 0-57 profiles per square mile. For the 1-mile smoothed density ([Multimedia Appendix 1](#)) the range (0-138) was closer to the observed values, but with many more points with density estimates of zero (ie, observations were not “spread” as far).

There are several ways to compare surfaces to illustrate local differences between the densities of white and black users. [Figure 7](#) shows two similar but nonidentical ways to compare these densities. Panel A in [Figure 7](#) shows the difference between the two surfaces, colored so that areas with higher absolute density of white users are blue and areas with higher density of black users are red. Panel B in [Figure 7](#) shows the relative difference, with areas where the ratio of black to white profile densities is higher than one as red and lower than one as blue.

The ratio measure shows that most of Southwest Atlanta has relatively more black user profiles observed than white profiles,

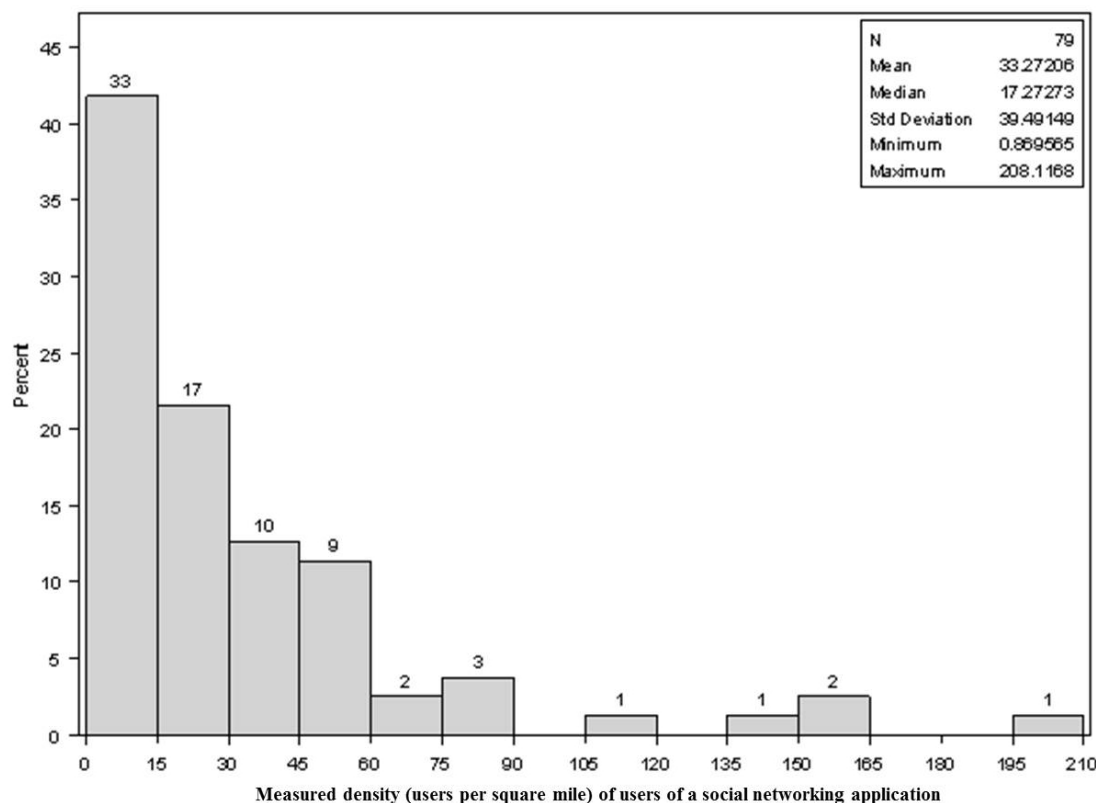
but when we compare the map with that of the overall number of black users, we find a much smaller region in which to focus efforts, that is, south and west of Midtown, shown with a yellow band in [Figure 7](#).

A third way to visualize differences between the surfaces is to focus on the areas with extreme values. This provides a within-density comparison: over the entire surface of the density of black user profiles, where is the density the greatest? In [Figure 8](#), we highlight the regions with density greater than the mean+2 standard deviations over the entire map, separately for all white (A), all black (B), and young black (<25 years old, C) users based on data in their observed profiles. This approach again highlights Midtown Atlanta (yellow rectangle) as the region with the most users observed in each graph.

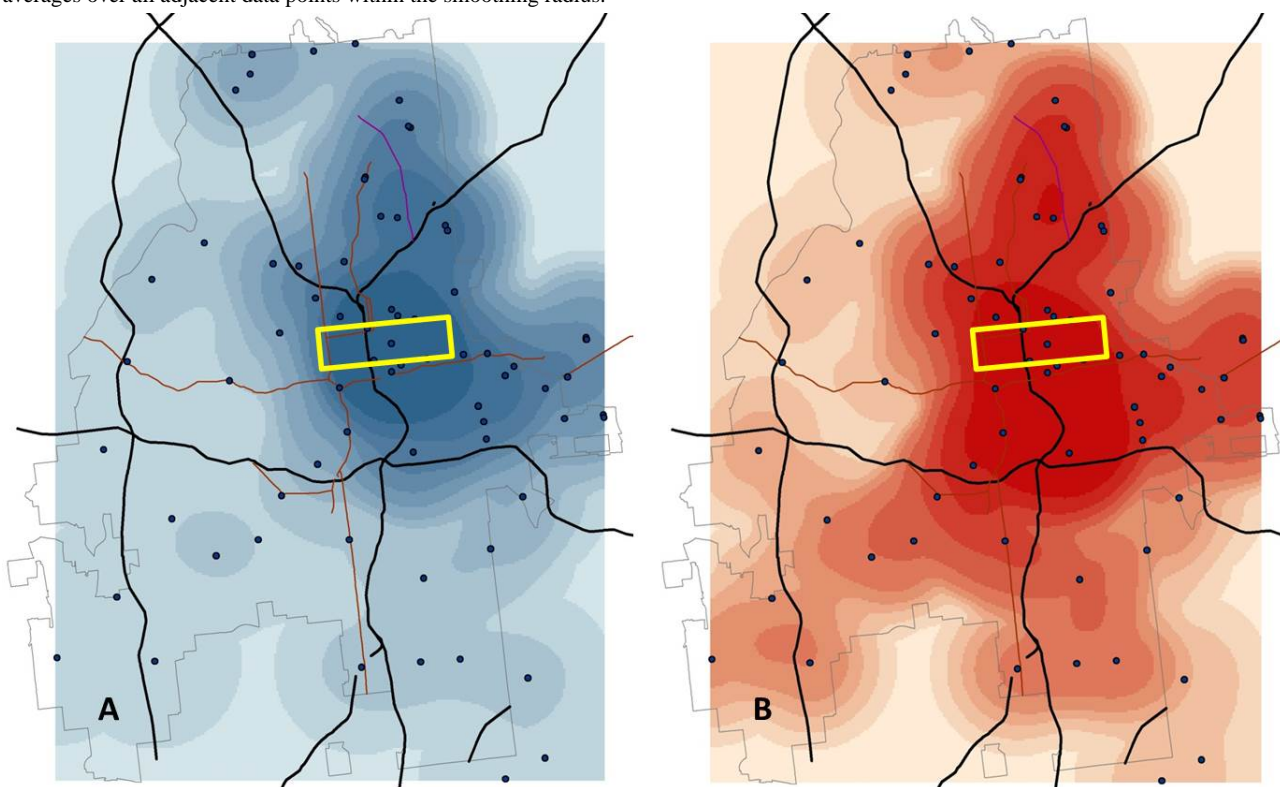
[Figure 9](#) calculates the difference between the first two panels in [Figure 8](#) and shows that black user profiles have high density much further south than white profiles.

The third figure included in [Multimedia Appendix 1](#) compares the difference between the 1-mile smoothed densities for young black and all black users (an analog to [Figure 9](#) but comparing panels B and C of [Figure 8](#)). Overall the results are similar, but there are a few additional areas (highlighted in [Multimedia Appendix 1](#) figure) with extreme densities of young black users that did not appear in the 2-mile estimates shown in [Figure 8c](#) or [9](#).

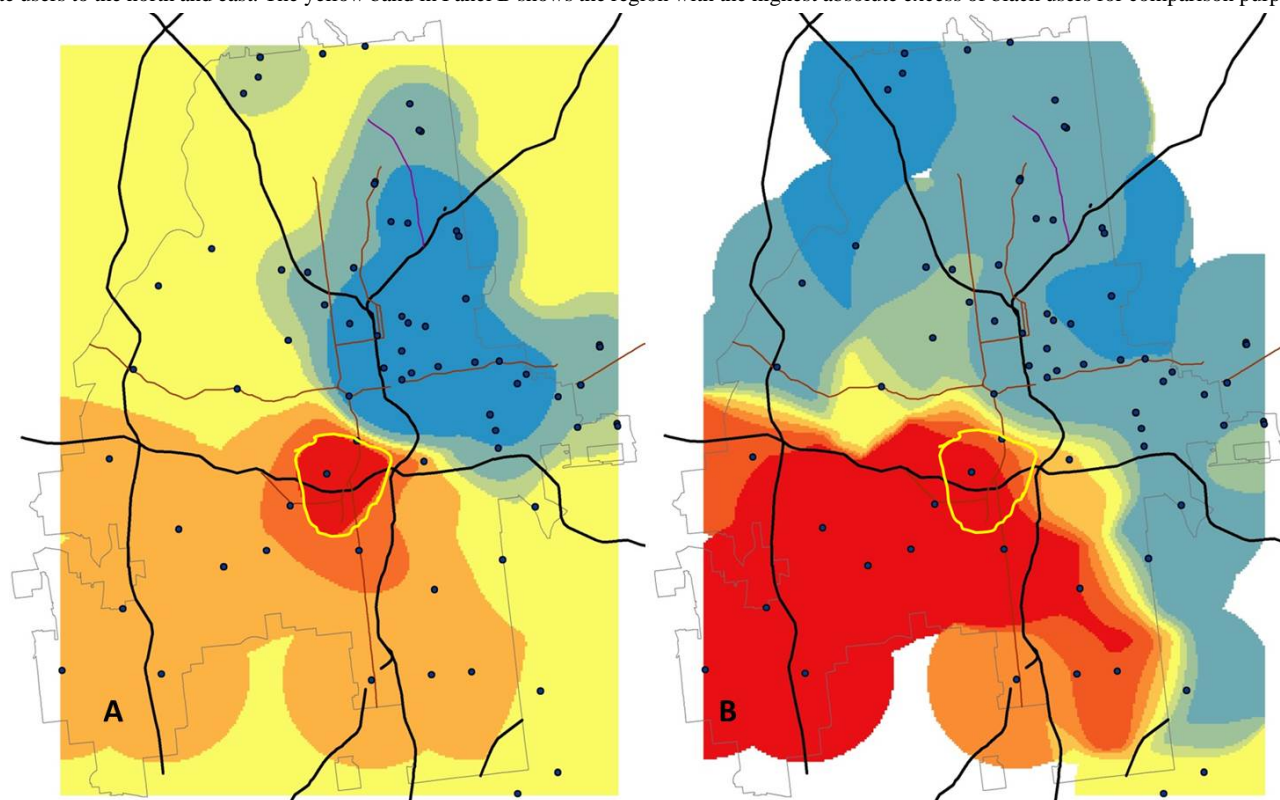
**Figure 5.** Histogram showing distribution of observed density of social network application users per 1-mile circle for the 79 sampled locations in Atlanta (inset includes statistics for the distribution, which is highly skewed with SD estimated to be larger than the mean; numbers above bars are the number of sample points with density along the X axis and the Y axis representing the percent of all points with this density).



**Figure 6.** Estimated density of white (A) and black (B) social network application users in Atlanta (gray outline), showing major highways (black lines) and roads (dark red lines) and highlighting the “Midtown” area of Atlanta (yellow rectangle); kernel densities estimated from sample data standardized to 1-mile circular radii and smoothed to 2 miles using a Gaussian smoother that concentrates the majority of the density at the sample point and averages over all adjacent data points within the smoothing radius.

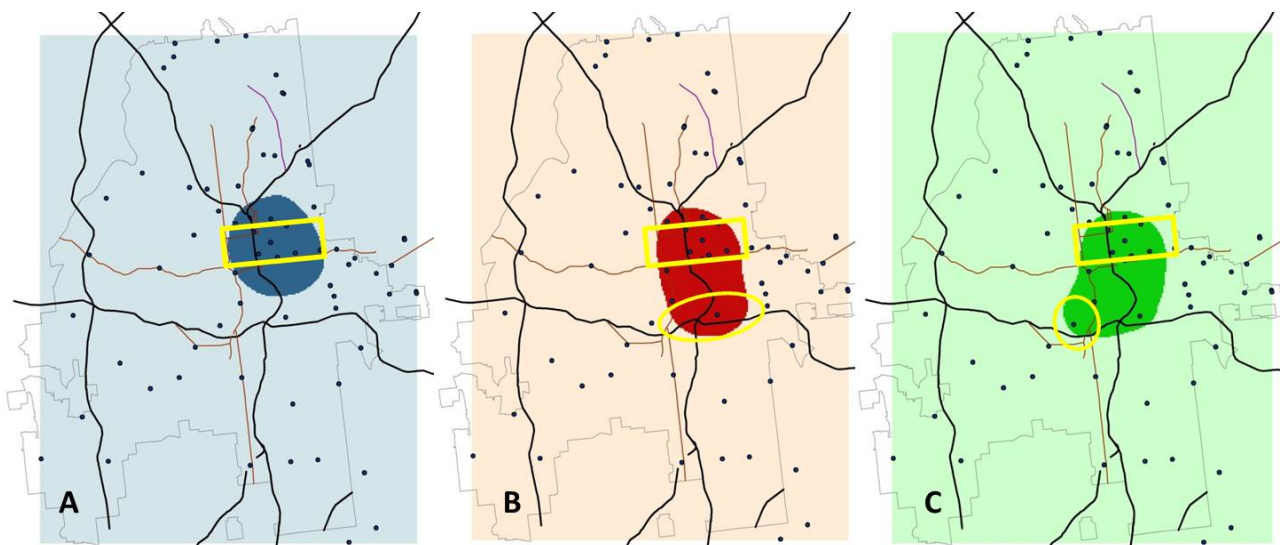


**Figure 7.** Comparison of the density of black and white social networking application users in Atlanta. Panel A shows the absolute difference in users (Density of black users – Density of white users) color-coded so that areas with more black users appear red and those with more white users appear blue. Yellow regions are areas where the two densities are similar. Panel A highlights a small section of the city (the area shaded the darkest red) where there are many more black than white application users. Panel B shows a comparison of the relative size of the densities of black and white users (Density of black users/Density of white users). With this measure, Atlanta is divided nearly in half, with relatively more black users in the southwest and more white users to the north and east. The yellow band in Panel B shows the region with the highest absolute excess of black users for comparison purposes.

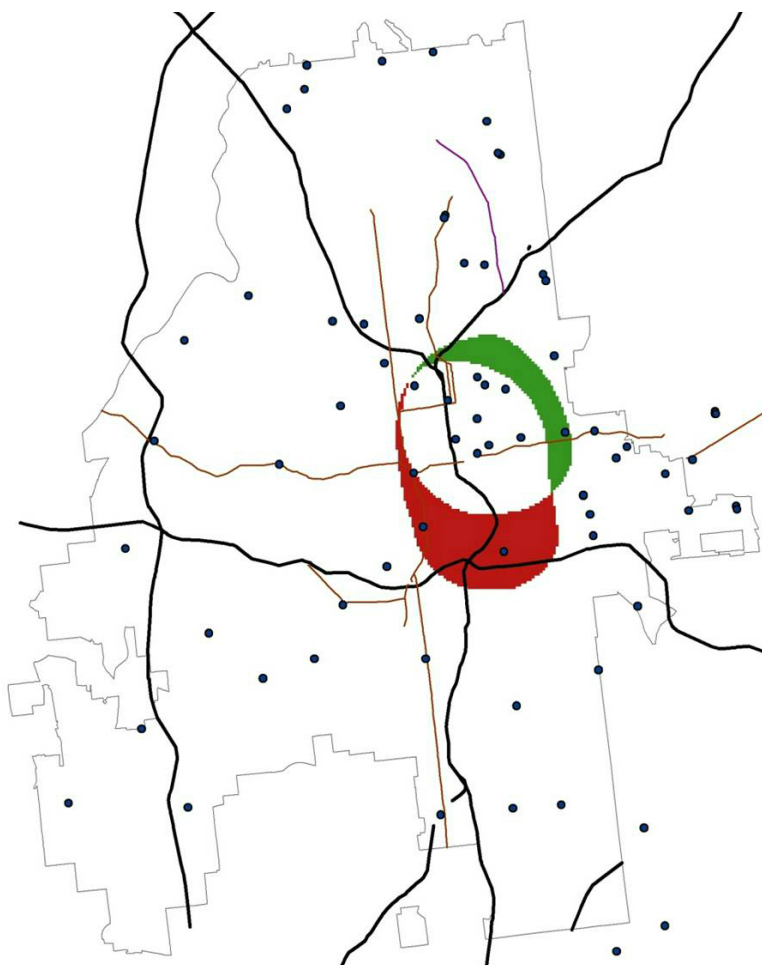




**Figure 8.** Density of social networking application users in Atlanta, highlighting points with values >95th percentile of estimated kernel densities for white (Panel A), black (Panel B), and young black (<25 years of age, Panel C) users. For Panel A, points with an estimated density >17.2 users/mile<sup>2</sup> are highlighted dark blue; for Panel B those >5.65/mile<sup>2</sup> are dark red, and for Panel C >2.8/mile<sup>2</sup> are dark green. The yellow rectangle highlights the midtown area of Atlanta for reference. The yellow oval in Panel B highlights an area with high density of black users but not white users. The yellow circle in Panel C highlights an area with a high density of young black users, but not black users overall (ie, an area highlighted in Panel C but not Panel B).



**Figure 9.** Difference between extreme values of estimated kernel densities of white and black users of a social networking application. We use the formula  $I(\text{Density of black users} > \text{mean} + 2 \text{ standard deviations}) - I(\text{Density of white users} > \text{mean} + 2 \text{ standard deviations})$ . Figure shows regions where the values of this equation are -1 (green shading, indicating areas with extremes of density for white but not black users), 1 (red shading, indicating areas with extremes of the density for black but not white users), and 0 (white shading indicating areas that are either not extremes of either density or are extremes for both races).



## Discussion

### Principal Findings

We sampled 2666 profiles from a mobile phone-based social networking app at 79 sites in Atlanta and, under our sampling protocol, observed a mean of 33 app users per square mile. We also identified areas where there were more black and young black user profiles observed compared to white user profiles, describing three different summary measures of the density of profiles in a sampling frame. Finally, we showed the impact of the choice of the kernel radius in construction and interpretation of such data.

### Application of the Proposed Methods

The goal of this study was primarily descriptive, in that we sought to describe a method for calculating the density of user profiles by race and age in Atlanta, and to compare and contrast the information provided by different outcome measures that can be constructed from these data. In addition, the methods described here may have practical application in HIV prevention research. The results are promising and illustrate how the use of self-reported location data can provide information on the geographic distribution of users in time and space. The study methodology could provide a more efficient way to identify locations for recruitment of MSM in future studies. Significant time and effort is spent on formative research to develop sampling frames for studies of MSM [15,21]. The goal of such formative research is to identify locations for sampling MSM using time space sampling methods [15]. Our methodology, based on the geolocation data incorporated into popular social networking apps, allowed us to quickly describe the density of sex-seeking MSM in Atlanta. Furthermore, we were able to use profile information to stratify these density measures by race and age. This might allow for oversampling or exclusive sampling in areas of the city that are expected to yield a particular subset of the population, for example, young black MSM. As an example, Figure 10 illustrates how these data can inform study implementation in practice. Figure 10 shows Panel B of Figure 7 and a variation of Figure 9, along with recruitment venues currently in use for two HIV prevention studies in Atlanta (green triangles). Panel A in Figure 10 shows that, to date, there have not been very many sampling locations in the southwestern part of Atlanta, where, based on the ratio of the density of black to white app users, there are relatively more black users than white users. However, Panel B in Figure 10 shows the difference between extremes for the densities of young white and young black users of the social networking app, using a formula similar to that used to calculate Figure 9. Looking at this representation of the data, we see that we have identified recruitment venues in an area of the city where there are the most young black app users and not that many white users. In this case, while going further into the areas of higher relative densities of black users might yield additional recruitment sites, we seem to have covered the areas with the highest number of both black and white users. Also, we find that there are not many recruitment sites outside of the area with the highest densities of white users, black users, or both, confirming that past recruitment sites were located in parts of the city where there are the most app users overall. Further

potential applications of this methodology include identification of areas with need for prevention services, for example, overlaying HIV testing locations on the density grid to identify local areas with greatest unmet need.

Since the early 2000s, there has been a significant rise in Internet usage by MSM [40-43] and young minorities [44-46]. Three different groups have found that gay men now report meeting the majority of their sex partners online [40,47-49], and many [43,47-49] but not all [50] studies of sex behavior have shown increased reports of behaviors associated with higher HIV risk among partners met online compared to offline. The most popular and well-studied of these location-based social networking apps is Grindr [51-53], which is currently being used by over 4 million men worldwide [25] and is likely to continue to grow in popularity. MSM use this app for a variety of purposes, but a survey of Grindr users in Los Angeles found that 76% have had sex with someone they met on Grindr [51], suggesting that Grindr users are using the app to help find sex partners. Many other similar apps exist such as Adam-4-Adam, Jack'd, and BoyAhoy [26-28], and our methodology can be applied to any such app that provides data on race and age as well as distance to the user within member profiles. In our research, we have found that users of these apps vary by race and less so by age, with, for example, a greater proportion of white men reporting using Grindr and more black men reporting using Jack'd (unpublished Emory University data). In this study, although we illustrate our approach using only one app (and have chosen not to identify the specific app used to generate these data), we did validate the methodology with more than one app. Any of the apps that report race, age, and other characteristics of interest (eg, HIV serostatus), as well as geographic distance from the user's present location, could be used to make density maps and calculate summary statistics using the methods we report in this paper. In some cases, it may be useful to calculate one or more density measures with more than one app to try to get a better overall picture of the spatial distribution of men using sex-seeking apps in a given location.

Because users of these apps make both their profile information and their location public, it was possible to simply observe these publically available data without contacting the users directly for this research. However, there is still an ethical requirement to protect individually identifying information when the information is collected for research purposes. In this study, we used screen captures to record profile information, storing these pictures on a password-protected iPod Touch until the data of interest (age, race, and location information) could be entered into a database with no identifiers. Because we were recording only publically available data from user profiles without identifiers, the Institutional Review Board at Emory University considered the study to be research exempt from review.

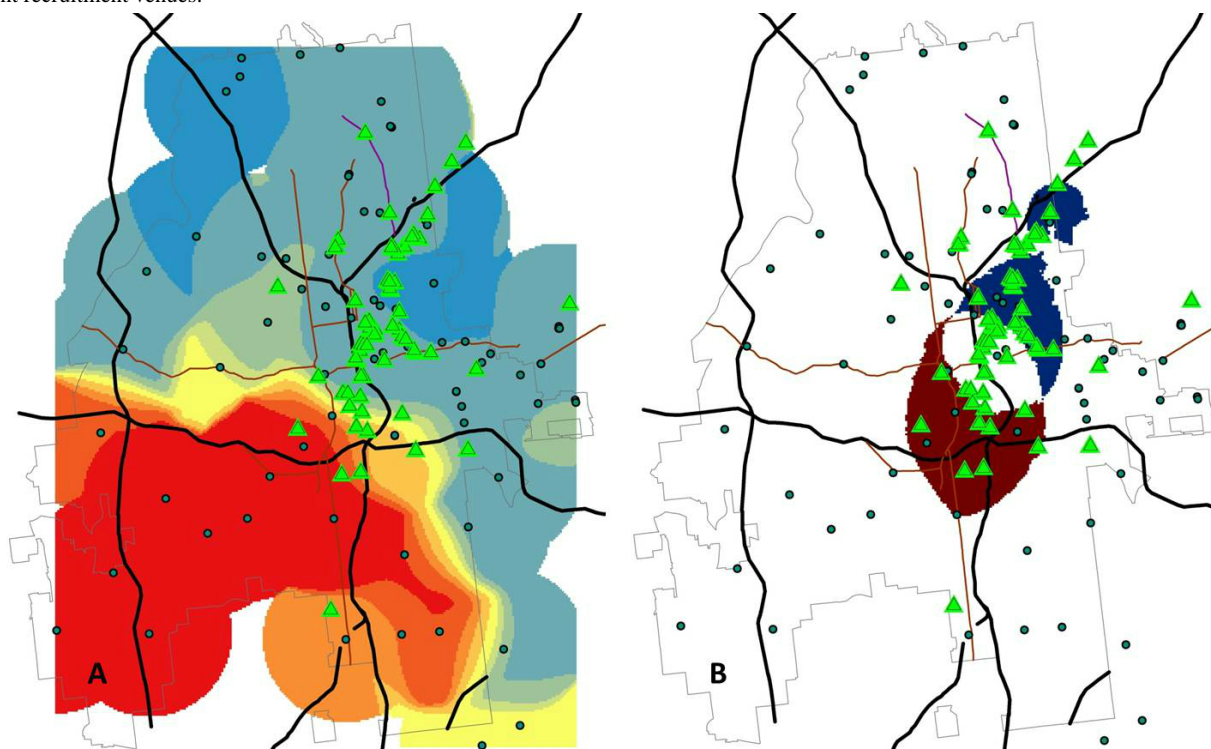
More generally, using social networking apps for HIV prevention is likely a key strategy for future research [52-54] but comes with new ethical and methodological questions. Our study only sought to summarize the data publically available within these apps, but social media apps may themselves serve as an important public health communications tool. Recently, public health agencies have sought to partner with Grindr and use its built-in advertisements as a medium for disseminating



prevention information and recruit MSM for research studies [52,53]. Future research might adapt our methodology further to establish a sampling frame and then use the density information to sample app users and contact them to either conduct a cross-sectional survey or recruit them into a follow-up

study. At that time, one would have to develop mechanisms for consenting study participants, as well as a way to keep sensitive information, such as sex and drug use behavior, protected and ideally separate from any identifying online profile information.

**Figure 10.** Application of two density metrics to evaluate recruitment for HIV prevention studies in Atlanta, showing recruitment venues currently in use for two HIV prevention studies (green triangles). Panel A shows few recruitment locations in the southwestern part of Atlanta, where there are relatively more young black application users than white users. Panel B uses the formula (Density of young black users > mean+2 standard deviations) – (Density of young white users > mean+2 SD). Regions where the values of this equation are -1 (blue shading, indicating areas with extremes of density for young white but not young black users), 1 (red shading, indicating areas with extremes of the density for young black but not young white users), and 0 (white shading indicating areas that are either not extremes of either density or are extremes for both races) can then be compared to the locations of current recruitment venues.



### Limitations of the Current Work and Opportunities for Future Research

Piloting this methodology in Atlanta exposed other challenges as well. Atlanta is geographically large and contains both densely settled neighborhoods in the inner city along with a large amount of semi-urban and even rural areas with less dense populations. Atlanta also exhibits a large degree of geospatial segregation by race, both in the population overall [55] and in the relative measures of the distribution of social-network app users (Panel B in Figure 7). However, although the overall black population density is low in Midtown Atlanta [55,56], it still represented the area with the highest concentration of black users of the sex-seeking application (Figure 4). To obtain a picture of the distributions of both black and white app users, we therefore had to sample enough points with a sufficiently wide radius to cover the entire city. We also found the density of users to vary widely within the city, and we therefore had to adapt our sampling strategy. We chose to collect either the first 50 profiles and record the distance to the 50<sup>th</sup> user, or to sample out to a 2-mile radius if there were less than 50 profiles observed in that area. In areas with large numbers of users, we had to collect data at more closely sampled points. For example, if

there were 50 profiles within a half mile, we moved only that short distance before collecting more data. If there were only 13 users within the 2 mile radius, we moved the full 2 miles between sample points. This allowed us to cover the whole city, but despite collecting data at 79 points that represented an area equivalent to 882 square miles, there were still areas of the city where we did not directly sample any users.

This makes the choice of the smoothing parameter (radius) for the kernel smoothing algorithm important because it provides a balance between too much interpolation of data between sampling points and presuming that the data collected at a particular sampling point occur only at the point and do not represent an area defined by the radius of a circle based on the linear distance to the person whose profile is being observed. Using our sampling plan, we collected data from concentric circles with an average radius of 1.65 miles and then fit weighted kernel densities smoothed to 1 and 2 miles. Both of these smoothing parameters provided similar interpretations of density of black, white, and young black individuals, with the 1-mile radius leaving more areas of the city with no estimates for the density of app users. The 2-mile radius covers the whole city, but as a result it reduces the emphasis of several points which,

when using a 1-mile radius are considered to have a particularly high density of black users.

Some questions remain about the precise interpretation of the density of social-network app users. For example, are users simply a subset of all MSM seeking sex on the Internet? Is the population that uses any one of these apps different by important characteristics (race, age, sex behavior with persons met through a social-network app or with sex partners generally) from the underlying population? Are persons who use specific services (eg, Adam-4-Adam, Jack'd, Grindr) different by one or more of these characteristics than those that use other online apps [47-49]? Future studies [54] will seek to quantify the density and characteristics of men who use each of these apps and compare the characteristics of men who use each of the apps exclusively, while also capturing information about men who use more than one service to describe whether their behaviors vary when using different services.

It would be useful to test the methodology in other cities with significant minority MSM populations (eg, Washington, DC, or Los Angeles, CA) and also to assess the utility of the method in less densely populated areas (eg, in rural areas of Georgia), to describe the extent to which the utility of the methods vary by characteristics of the geography of the region. We have already identified that Atlanta is a challenging place to conduct this kind of study because of its racial distribution, which was

borne out in the social-network app user density data. In areas with sparse numbers of users, our adaptive sampling methodology, which sampled a maximum of 50 users or to a 2-mile radius, might help to stabilize density estimates, but this needs further testing. Additionally, although we averaged over day and time of sampling in our current analysis, the method could be refined to capture spatiotemporal trends in density. For example, it would be possible to select points to be sampled multiple times over a grid of specific times and days [14,15]. This modification could provide a clear description of how the user profile's population density changes over the course of a week. This last component may identify trends in the spatial and temporal clustering of app users, for example on weekend nights, as compared to mid-day during the work week.

## Conclusions

We have found that it is possible to use a limited number of sample points to develop a geospatial density of men using a social-networking app to seek sex in the city of Atlanta. Such a density could serve as a sampling frame for future cross-sectional or longitudinal research. We also describe several methods to compare two densities with a goal of identifying areas with a high density of a particular subset of the population. We hope that this novel methodology and its further adaptations will prove useful to future research and prevention efforts that can be tailored to areas of the community where they will be most effective.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Kernel density calculations and days/times of data collection.

[PPTX File, 992KB - [jmir\\_v16i11e249\\_app1.pptx](#)]

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## Abbreviations

**HIV:** human immunodeficiency virus

**MSM:** men who have sex with men

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Original Paper

# Assessment of a New Web-Based Sexual Concurrency Measurement Tool for Men Who Have Sex With Men

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## Abstract

**Background:** Men who have sex with men (MSM) are the most affected risk group in the United States' human immunodeficiency virus (HIV) epidemic. Sexual concurrency, the overlapping of partnerships in time, accelerates HIV transmission in populations and has been documented at high levels among MSM. However, concurrency is challenging to measure empirically and variations in assessment techniques used (primarily the date overlap and direct question approaches) and the outcomes derived from them have led to heterogeneity and questionable validity of estimates among MSM and other populations.

**Objective:** The aim was to evaluate a novel Web-based and interactive partnership-timing module designed for measuring concurrency among MSM, and to compare outcomes measured by the partnership-timing module to those of typical approaches in an online study of MSM.

**Methods:** In an online study of MSM aged  $\geq 18$  years, we assessed concurrency by using the direct question method and by gathering the dates of first and last sex, with enhanced programming logic, for each reported partner in the previous 6 months. From these methods, we computed multiple concurrency cumulative prevalence outcomes: direct question, day resolution / date overlap, and month resolution / date overlap including both 1-month ties and excluding ties. We additionally computed variants of the UNAIDS point prevalence outcome. The partnership-timing module was also administered. It uses an interactive month resolution calendar to improve recall and follow-up questions to resolve temporal ambiguities, combines elements of the direct question and date overlap approaches. The agreement between the partnership-timing module and other concurrency outcomes was assessed with percent agreement, kappa statistic ( $\kappa$ ), and matched odds ratios at the individual, dyad, and triad levels of analysis.

**Results:** Among 2737 MSM who completed the partnership section of the partnership-timing module, 41.07% (1124/2737) of individuals had concurrent partners in the previous 6 months. The partnership-timing module had the highest degree of agreement with the direct question. Agreement was lower with date overlap outcomes (agreement range 79%-81%,  $\kappa$  range .55-.59) and lowest with the UNAIDS outcome at 5 months before interview (65% agreement,  $\kappa$ =.14, 95% CI .12-.16). All agreements declined after excluding individuals with 1 sex partner (always classified as not engaging in concurrency), although the highest agreement was still observed with the direct question technique (81% agreement,  $\kappa$ =.59, 95% CI .55-.63). Similar patterns in agreement were observed with dyad- and triad-level outcomes.

**Conclusions:** The partnership-timing module showed strong concurrency detection ability and agreement with previous measures. These levels of agreement were greater than others have reported among previous measures. The partnership-timing module may be well suited to quantifying concurrency among MSM at multiple levels of analysis.

**KEYWORDS**

HIV; sexual networks; questionnaires; concurrency; MSM; sexual network measurement; online questionnaire

## Introduction

### Background

Men who have sex with men (MSM) have long been the most heavily impacted risk group in the United States' human immunodeficiency virus (HIV) epidemic [1]. In 2010, MSM accounted for an estimated 66% of new HIV infections in the United States; since 2000, MSM have been the only transmission group for whom incidence has been increasing [2,3]. Emerging evidence suggests that the biological realities of differential transmission probabilities for anal and vaginal sex and heterosexual role segregation play a larger role in the HIV incidence disparities between MSM and heterosexuals than do differences in individual-level risk behavior [4-6]. The role of differential network-level factors may also be important, yet this remains insufficiently explored [6,7].

### Concurrency Accelerates HIV Transmission but Measurement Varies

One such factor is sexual concurrency, defined as "overlapping sexual partnerships where sexual intercourse with 1 partner occurs between 2 acts of intercourse with another partner" [8]. Concurrency has the potential to catalyze transmission in populations by increasing both sexual network connectivity and the likelihood of transmission during acute HIV infection [9,10]. Simulation-based, couples-based, and ecological studies have provided theoretical and empirical evidence of concurrency's causal role in amplifying HIV epidemics [11-14].

Differences in the level and patterns of sexual concurrency between MSM and heterosexuals in the United States remain insufficiently understood. High levels of concurrent sex have been recently documented among MSM in the United States (18%-78% prevalence in previous year) [7,15,16], substantially greater than among heterosexual men (10%-11% in previous year) [7,17]. These reports all used differing methods of measuring concurrency, a common issue in concurrency research [18,19]. To properly describe the role concurrency might play in transmission among MSM, an improved understanding of the appropriateness of concurrency measures is needed.

It is important to differentiate between the tools used to elucidate sexual timing information and the concurrency measures derived from these tools because these 2 notions are subject to different limitations that have been conflated in critical examinations of concurrency measurement [8,20,21]. Two approaches, date overlap and direct question, are primarily used to gather concurrency responses, both of which involve assessment on a partner-by-partner basis for a given number of recent sex partners. On the other hand, a variety of individual-level concurrency measures have been calculated using data from these approaches.

### Date Overlap Method

In the date overlap method, the dates of first and last sex with each partner are gathered with the purpose of inspecting for overlapping partner intervals. Although seemingly powerful and precise if exact dates are used, this approach is subject to poor date recall and missing or illogical responses [20,22,23]. Variants of this measurement technique intended to alleviate these issues have been to gather date information at the month/year level only and as the number of days/weeks/month/years preceding the interview [8,17]. These alternatives come with potential temporal ambiguities for single-month interval overlaps ("ties"), which may be more common in populations with more short-term partnerships.

From these date collection techniques, multiple individual-level concurrency cumulative prevalence measures have been employed: having any exact date overlaps [24], any month resolution overlaps and including ties as concurrent [20,21,23,25], and, most commonly, any date overlaps but conservatively excluding ties [8,17,21,25]. These have been typically computed for a 12-month recall period.

The Joint United Nations Programme on HIV/AIDS (UNAIDS) working group has introduced a measure of concurrency, the point prevalence of concurrency at 6 months before interview, to be calculated as a month resolution overlap during this month and excluding ties [8,19]. This measure was chosen to emphasize longer-term relationships and overlaps, which are expected to contribute more greatly to the risk of concurrency in the sub-Saharan African context for which the measure was developed [8,19]. Yet this also creates the potential to drastically undercount the occurrence of concurrency in a population with frequent short-term sexual contacts, resulting in low sensitivity for screening those who engage in concurrent sexual partnerships.

### Direct Question Method

The direct question data collection method assesses, for each partnership, how many other sex partners were had during that partnership in the recall period. An individual-level period prevalence measure is then derived from inspection for any partnership with 1 or more outside partner [23]. This method is simple to administer, may be easier for recall, typically yields fewer missing data, and is less limited by the total partners able to be described in the survey [20,26]. Yet it is potentially impacted more by biases related to social desirability and in the perception of concurrency [21].

The few published comparisons have shown varied performance of these measures, partly due to the differences and limitations discussed. Nelson et al [20] found similar levels of concurrency among US heterosexuals, but only fair agreement, using month resolution date overlap (inclusive of ties) and direct question measures. Glynn et al [21] found lower agreement across a broader set of these measures and the most concurrency per

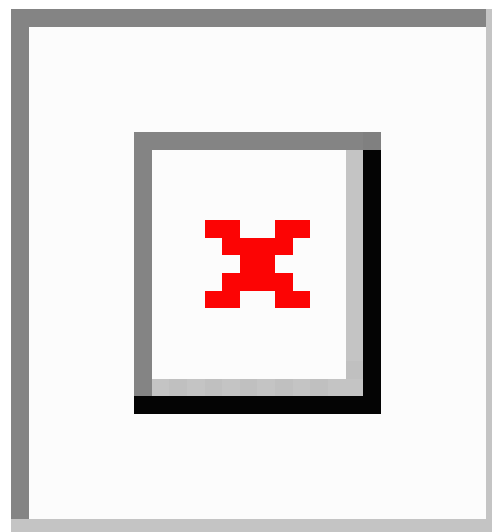
direct question in Malawian heterosexuals. Maughan-Brown and Venkataramani [26] have reported similar findings in a South African comparison of the direct question and UNAIDS measures. Because no gold-standard method exists, it is unclear if the highest levels of concurrency measured by the direct method correspond to best detection.

### Levels of Analysis Are Important but Seldom Considered

Absent from previous discussions of concurrency measurement techniques are considerations of which levels of analysis they enable. Individual-level concurrency is important for the surveillance of those who engage in concurrent sex. Yet it offers a limited analytical perspective for the research purposes of empirically understanding the types, correlates, and implications of concurrency. This is because the fundamental unit at which concurrency operates is the triad, composed of an individual and 2 sex partners [27]. Individuals may contribute multiple triads (see Figure 1), and summarizing triads to form individual-level measures discards information about the partnership-level factors associated with concurrency. Recently published triadic results have described the prevalence of unprotected sex with both members among concurrent triads and the association between triadic concurrency and unprotected sex [15,28]. Of these measures, only those based on cumulative date overlap data permit triadic analysis.

The dyadic, or partner, perspective is another important level for understanding concurrency [29]. An individual's concurrency does not impact one's own risk of infection acquisition, but rather that of one's partners, a distinction that has long stymied empirical analyses of concurrency [27,30]. Ideally, empirical analyses of infection risk due to concurrency would consider the types of partners involved and would quantify partners' increased exposure and/or infection due to concurrent sex. We recently assessed such increased dyadic exposure among MSM [31]. Both date overlap and direct question approaches can be used to measure dyadic concurrency, although the latter is limited by the absence of data on other partners with whom the respondent was concurrent. UNAIDS-type point prevalence measures are insufficient for triadic and dyadic analyses because they are designed to detect only a subset of concurrent partnerships.

**Figure 1.** The number of possible triads among an individual's sex partners.



### Challenges in Measuring Concurrency Among MSM and the Need for Appropriate Tools

The majority of empirical concurrency measurement research has been in sub-Saharan African [21,25,32,33] and US heterosexual [23,34,35] settings, rather than among MSM, whose partnership patterns are distinct from these populations [7]. Compared to heterosexuals, MSM report more shorter-term casual partners on average [7,36]. This presents several challenges to concurrency measurement among MSM. First, to the extent that these partnerships are 1-time or are contained within a single month, substantial misclassification would be likely if month resolution date overlap measures are used, with disparate results seen depending on the inclusion of ties. Because MSM are more likely to report more than 1 sex partner and, thus, have more opportunity for concurrency, fewer individuals would be automatically classified as nonconcurrent by all measures compared to heterosexuals. This would be expected to result in higher estimated concurrency prevalence among MSM and a lower agreement between concurrency measures.

In this paper, we describe a novel, Web-based concurrency measurement tool used in 2 recent analyses [15,31]. It is designed to remedy reporting biases, enables triadic and dyadic analyses, and is tailored to the sexual activity patterns of MSM. This tool employs a compromise between date overlap and direct question methods, and is consistent with calls for improved computer- and calendar-aided concurrency measurement techniques [8]. Its Web-based implementation allows for real-time logical evaluations, which are not possible with the other methods and they improve data quality and are accessible in a variety of locations by a range of devices. At multiple analysis levels, we assess the agreement of concurrency prevalence measures from this technique with those computed based on the date overlap and direct question methods.

## Methods

### Study Design

Data are from participants' baseline responses in a 12-month prospective online study of HIV behavioral risks among MSM



in the United States, described previously [15,37,38]. Internet-using MSM were recruited from August to December 2010 through selective placement of banner advertisements on social networking websites. Eligibility criteria for participation in the baseline questionnaire were being male, age at least 18 years, and having a male sex partner in the past 12 months. Following online screening and consent, participants completed a 60-minute questionnaire, developed in and hosted on SurveyGizmo 2.6 [39]. The study was reviewed and approved by the Institutional Review Board of Emory University (IRB #00031326).

### Dyadic Data Collection

As part of the online questionnaire, participants who had  $\geq 1$  sex partner in the 6 months before the interview were asked to provide nicknames for up to 5 of their most recent anal, oral, or vaginal sex partners within the previous 6 months. This was followed by a novel partnership-timing module, described previously [15,40], which was designed to interactively collect data on concurrency in a method that improved on the existing, passive date overlap and direct question methods. Participants were provided a calendar-like grid of check boxes that displayed the previous 6 months in columns, and partner nicknames on the rows. Participants were asked to indicate the months in which they had sex with each partner (Figure 2). A response pattern that showed 2 or more common months of sex between 2 partners resulted in the triad being later classified as concurrent, consistent with all date overlap techniques. In the case where responses indicated a tie, follow-up direct questions (Figure 2) were asked to clarify whether the participant was with the 2 partners serially or concurrently during the indicated month. This method inherits the easier recall afforded by month

resolution dates and direct questioning approaches, but gains the unambiguous sequencing information provided by day resolution dates [40]. Recall is further aided by the ability to visualize all partnerships simultaneously on a calendar, rather than report timing per partnership [8,20]. The partnership-timing module additionally enables concurrency measurement at the individual, dyad, and triad levels. This module has been implemented in multiple studies, with questionnaires administered via desktop computers, laptop computers, and iPads. A demonstration of the partnership-timing module is available [41].

Following the partnership-timing module, participants completed an in-depth demographic and behavioral inventory for each partner. For repeat, rather than 1-time (1-off) sex partners, standard direct concurrency questions were asked [23], along with questions about the partnership's first and last dates of sex. To help alleviate common problems with missing or invalid dates [19], a flexible series of date questions were asked, with tight logical controls applied. Initially, month/year resolution dates were requested, but participants could opt-in to provide the exact date, if known. If the month was unknown, participants were prompted to select quarters of the year and were shown reminders of familiar events during those seasons to aid recall. If the year of first sex was unknown, ranges of years in the past were provided. Out-of-sequence or invalid (ie, future dates or last sex  $>6$  months prior to interview) first and last sex dates (or approximate dates/quarters) were detected in real time. Participants were then shown their logical error and prompted for correction. Due to the multiple allowances for indicating partial/unknown responses, the date questions could collectively be set as required, further reducing the potential for missing data.

**Figure 2.** Screenshots of the online partnership timing module illustrating the method for offering follow-up clarification questions.

Now we'd like to ask you about the times you had sex with your partners over the last 6 months.

For each sex partner, click a box for each month during which you had sex with that partner

	July '13	August '13	September '13	October '13	November '13	December '13
Chris	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>
Tim	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
DJ	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>
Enrique	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>
Party	<input type="checkbox"/>	<input checked="" type="checkbox"/>	<input checked="" type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>	<input type="checkbox"/>

**A.** For each partner, the participant indicates the months in which the two had sex. For each month, each pair of partners is examined. Ambiguously concurrent overlaps between partners (red), are selected for further questioning. Concurrent overlaps that are obvious (green) are not selected.

**I** You indicated that you had sex with both Tim and DJ in the month of November '13. Which of these statements about November '13 is most correct? (required)

- ☐ I last had sex with DJ before I had sex with Tim.
- ☐ I was having sex with both Tim and DJ during the same time period.
- ☐ Don't know

**II** You also indicated that you had sex with both Enrique and Party in the month of August '13. Which of these statements about August '13 is most correct? (required)

- ☐ I last had sex with Enrique before I had sex with Party.
- ☐ I last had sex with Party before I had sex with Enrique.
- ☐ I was having sex with both Enrique and Party during the same time period.
- ☐ Don't know

**B.** For each ambiguous overlap, the participant indicates the correct serial ordering of the partners, or that sex was concurrent with both.

### Focus Group and Facebook Pilot

In December 2009, a focus group with 13 MSM was conducted to evaluate the partnership-timing module in comparison to the direct question and date-based data collection methods. A high degree of acceptability was indicated for the partnership-timing module, which participants felt facilitated recall more than the

date collection. Focus group feedback resulted in refinements to the partnership-timing module placement and follow-up question wording. An additional online pilot study was conducted with 1077 Facebook-recruited MSM, with the purpose of testing and refining the questionnaire's logic.

## Concurrency Measures

Measures of concurrency were calculated at the triadic, dyadic, and participant levels. Each unique combination of a respondent and 2 reported sex partners comprised a triad; each respondent could contribute 0-10 triads based on the number of sex partners in the past 6 months about whom he reported information (5 partners choose 2 triads=10 triads total). Triads were considered concurrent using partnership-timing module responses if the months of sex with both partners overlapped by  $\geq 2$  months (criterion A), if they overlapped by 1 month and 1 partner's interval entirely contained the 1 month relationship of the other partner (criterion B), or based on a response to the clarification questions that affirmed concurrency for a 1-month tie (criterion C). Using the date information for each partner described, triadic date overlap was evaluated by the 3 methods described previously: exact date overlap, month resolution date overlap excluding ties (using criteria A and B) [17,19,21,25], and including ties [20,21,23,25].

At the dyad level, concurrency was classified using direct question responses, dichotomized at  $\geq 1$  other sex partners during the relationship being queried [23]. These triadic and dyadic measures were summarized by participant to yield individual-level binary measures of the cumulative occurrence of any concurrency in the previous 6 months.

Lastly, we computed UNAIDS measures of the point prevalence of concurrency before the interview [8,19]. The questionnaire's 6-month recall period precluded its calculation at 6 months before interview; instead, 5 and 3 months were chosen to represent the closest time to 6 months and the midpoint of the recall period, respectively [25].

## Analytical Methods

We previously described concurrency among 3471 participants who completed the partnership-timing module [15] and in this report we include the 2737 who completed the partner inventory for all partners (2737/3471, 78.85%), consistent with recommendations for concurrency outcome computation [8]. For this restricted sample, we computed the distribution of demographic characteristics. Next, the prevalence of individual-level concurrency was computed for all concurrency measures. The percent agreement of concurrency classifications was computed pairwise between the partnership-timing module and the other methods (direct question, all 3 date overlap, and both UNAIDS outcomes). Agreement in excess of chance was assessed by the kappa statistic ( $\kappa$ ) and its 95% confidence interval (CI); values from .80-.99 indicate very high, .61-.80 good, .40-.60 moderate, and 0-.40 low agreement [42]. The degree to which discordant concurrency classifications favored the partnership-timing module was quantified by the matched odds ratio (matched OR) and its 95% CI; values  $>1$  indicate more concurrency classified by the partnership-timing module, whereas those  $<1$  indicate more concurrency by the comparison method.

Several participant subsets were examined to further resolve the partnership-timing module's ability to accurately classify concurrency. To understand whether limiting the partnership inventory to 5 partners constrained concurrency measured by

the partnership-timing module relative to the direct method (which has no upper bound), we compared these 2 methods after excluding participants who reported  $>5$  total partners in the previous 6 months. Because participants with only 1 sex partner are automatically classified as not concurrent by all measures, thereby inflating their agreement, we next performed these computations restricted to participants with multiple sex partners [33]. Dates of sex were not collected for 1-time sex partners, which may potentially lower agreement for the date-based methods. To address this, we conducted an analysis restricted to participants who reported multiple and exclusively repeat sex partners, and later discuss the role of 1-time partners in the agreement of concurrency measures.

We additionally assessed the prevalence and agreement of these measures at the dyad and triad levels of analysis. This is because these levels are the ones at which concurrency data are primarily collected (dyadic by direct question, triadic by date methods) and these levels contribute to understanding different aspects of concurrency.

## Results

Among the 2737 participants who completed the partnership inventory, 55.97% (1532/2737) identified as white non-Hispanic, 16.00% (438/2737) as black non-Hispanic, 14.32% (392/2737) as Hispanic, and 13.70% (375/2737) as other race/ethnicity. The median age was 27 years (IQR 22-38) and a median of 2 sex partners (IQR 1-5) was reported in the previous 6 months.

Table 1 displays individual-level prevalence measures of concurrency in the previous 6 months. Using the partnership-timing module, 41.07% (1124/2737) of participants reported at least 1 concurrent triad and thus had concurrent partners. More individual concurrency was identified using the direction question (49.33%, 1333/2702) and lower levels were classified using the date-based measures. The pairwise agreement between the partnership-timing module and the other concurrency measures is displayed in Table 1. Overall, a large degree of agreement was observed (agreement range: 64.82%-85.60%), although substantial variation was seen in agreement that was in excess of chance ( $\kappa$  range .14-.71).

The most agreement was observed with the direct question technique, with 85.60% and a kappa of .71, although the direct question method significantly classified more concurrency (matched OR 0.27, 95% CI 0.21-0.34,  $P<.001$ ). The exclusion of 388 participants with more than 5 total partners reduced both methods' concurrency prevalences by 7%, but resulted in a negligible change in their agreement (87% agreement,  $\kappa=.72$ ).

Concurrency prevalences were 27.52% (753/2736) and 25.73% (704/2736) using overlapping day and month resolution (excluding ties) date measures, respectively. Although these levels were less than that detected with the partnership-timing module, these date measures had nearly identical and moderate agreement with the module (79% agreement,  $\kappa=.55$ ). Where the methods differed, the partnership-timing module was more than 4 times more likely to classify individual concurrency (matched OR 4.8 and 6.8 compared to day- and month-level dates methods, respectively). A 32.64% (893/2736) concurrency

prevalence was measured by overlapping month-level dates that included ties. Levels of agreement with the partnership-timing module were similar to those of the other date measures, although a lower matched OR of 2.6 (95% CI 2.1-3.1) was observed.

The lowest levels of concurrency were observed using the 2 modified UNAIDS point prevalence measures. A total of 5.34% (146/2736) of participants reported concurrent partnerships at 5 months before interview, and 6.76% (185/2736) did so at 3

months beforehand. Similarly, the agreements between these measures and the partnership-timing module were lowest ( $\kappa=.14$  and  $.17$  at 5 and 3 months, respectively). Additionally, the 2 modified UNAIDS measures had high agreement with one another (96.97% agreement,  $\kappa=.73$ ). To assess the degree to which the use of month-level dates with the exclusion of ties might have diminished the UNAIDS measure estimates, we calculated these point prevalences using day resolution date information and found prevalences of 16.11% (411/2737) and 17.32% (474/2737) at 5 and 3 months, respectively.

**Table 1.** Individual-level concurrency by partnership-timing module and alternative measures of concurrency among 2737 men who have sex with men.

Concurrency measure	Concurrency prevalence		Agreement with partnership-timing module			
	Concurrent, n (%)	Missing, n	Agreement, n (%)	Both methods concurrent, n	$\kappa$ (95% CI)	Matched OR (95% CI)
Partnership-timing module	1124 (41.07)	0	—	—	—	—
Direct question	1333 (49.33)	35	2313 (85.60)	1026	.71 (.69-.74)	0.27 (0.21-0.34)
Date overlap, day resolution <sup>a</sup>	753 (27.52)	1	2171 (79.35)	656	.55 (.52-.58)	4.8 (3.9-6.0)
Date overlap, month resolution, excluding ties	704 (25.73)	1	2172 (79.39)	632	.55 (.52-.58)	6.8 (5.4-8.8)
Date overlap, month resolution, including ties	893 (32.64)	1	2209 (80.74)	745	.59 (.56-.62)	2.6 (2.1-3.1)
UNAIDS, 5 months before interview <sup>b</sup>	146 (5.34)	1	1746 (64.82)	140	.14 (.2-.16)	164.0 (78.6-405.5)
UNAIDS, 3 months before interview	185 (6.76)	1	1781 (65.10)	177	.17 (.15-.20)	118.4 (62.1-255.6)

<sup>a</sup>Date overlaps measures exclude 1-time partners, for whom dates of sex were not asked.

<sup>b</sup>UNAIDS point prevalence measures modified to 5 and 3 months from typical 6 months.

Table 2 displays these same metrics for those participants who reported  $\geq 1$  sex partner. Among these participants, the prevalence of concurrency as measured by the partnership-timing module was 60.30% (1124/1864). As anticipated, this restriction also caused all other prevalence measures to increase (range: direct question 70.09%-UNAIDS 5 months 7.84%) and their agreement with the partnership-timing module to decrease ( $\kappa$  range: direct question .59-UNAIDS 5 months .09). For this subgroup, the agreement between the direct question and the tie-inclusive overlapping dates methods were fair ( $\kappa=.44$ ), similar to that reported among US heterosexuals ( $\kappa=.40$ ) [20] and higher than that among Malawian heterosexuals ( $\kappa=.23$ ) [21].

A further restriction to participants with exclusively repeat partners is shown in Table 2. A 73.94% (227/307) concurrency prevalence was observed using the partnership-timing module. High and similar levels of agreement were observed for the direct question and date overlap methods compared to the partnership-timing module (agreement range 86.60%-90.13%,  $\kappa$  range .65-.72). Despite high agreement, very low matched OR were seen for the direct question (matched OR 0.07, 95% CI 0.01-0.26) and tie-inclusive date overlap methods (matched

OR 0.03, 95% CI 0.00-0.15). In contrast, poor agreement was seen between the UNAIDS and partnership-timing module measures (% agreement: 48.69%, 149/306 and 50.98%, 156/306,  $\kappa$  range .17 and .20 for 5 and 3 months, respectively).

The measurement of concurrency at each method's primary unit of measurement is shown in Table 3. Participants indicated concurrent partners during 56.71% (2667/4703) of partnerships involving repeat partners using the partnership-timing module. Using the direct question module, this was 67.29% (2927/4703) with a substantial level of agreement (83.66%,  $\kappa=.66$ ). Discordantly classified partners were 5 times as likely to be considered concurrent by the direct question method (matched OR 0.20, 95% CI 0.16-0.24). Among triads involving 2 repeat partners, 63.65% (1879/2962) of those involving 2 repeat partners were concurrent. Agreement was consistent and moderate with the 3 overlapping dates measures (agreement range 78.62%-80.96%,  $\kappa$  range .48-.59). By the tie-inclusive overlapping dates method, triadic concurrency prevalence was high (81.77%, 2378/2962), with high tendency to classify discrepant triads as concurrent compared to the partnership-timing module (matched OR 0.08, 95% CI 0.06-0.10).

**Table 2.** Individual-level concurrency by partnership-timing module and alternative measures of concurrency among subsets of men who have sex with men.

Concurrency measure	Concurrency prevalence		Agreement with partnership-timing module			
	Concurrent, n (%)	Missing, n	Agreement, n (%)	Both methods concur, n	$\kappa$ (95% CI)	Matched OR (95% CI)
<b>Participants with multiple partners (n=1864)</b>						
Partnership-timing module	1124 (60.30)	0	—	—	—	—
Direct question <sup>a</sup>	1291 (70.09)	22	1495 (81.16)	1026	.59 (.55-.63)	0.31 (0.24-0.40)
Date overlap, day resolution <sup>b</sup>	753 (40.42)	1	1298 (69.67)	656	.42 (.38-.45)	4.8 (3.9-6.0)
Date overlap, month resolution, excluding ties	704 (37.79)	1	1299 (69.73)	632	.42 (.39-.46)	6.8 (5.4-8.8)
Date overlap, month resolution, including ties	893 (47.93)	1	1326 (71.18)	745	.44 (.40-.48)	2.6 (2.1-3.1)
UNAIDS, 5 months before interview <sup>c</sup>	146 (7.84)	1	873 (46.86)	140	.09 (.08-.11)	164.0 (78.6-405.5)
UNAIDS, 3 months before interview	185 (9.93)	1	908 (48.74)	177	.12 (.10-.14)	118.4 (62.1-255.6)
<b>Participants with multiple and exclusively repeat partners (n=307)</b>						
Partnership-timing module	227 (73.94)	0	—	—	—	—
Direct question <sup>a</sup>	250 (82.24)	3	274 (90.13)	222	.72 (.62-.81)	0.07 (0.01-0.26)
Date overlap, day resolution <sup>b</sup>	231 (75.49)	1	268 (87.58)	210	.67 (.57-.77)	0.81 (0.42-1.5)
Date overlap, month resolution, excluding ties	224 (73.20)	1	265 (86.60)	205	.65 (.56-.75)	1.2 (0.62-2.2)
Date overlap, month resolution, including ties	260 (84.97)	1	271 (88.56)	226	.65 (.55-.76)	0.03 (0.00-0.15)
UNAIDS, 5 months before interview <sup>c</sup>	76 (24.84)	1	149 (48.69)	73	.17 (.12-.23)	51.3 (18.6-203.8)
UNAIDS, 3 months before interview	83 (27.12)	1	156 (50.98)	80	.20 (.14-.26)	49.0 (17.7-194.6)

<sup>a</sup>3% (n=42) of those who indicated concurrency by the direct question also named only 1 sex partner. Accordingly, the 42 individuals are included in Table 1, but are excluded from the subsets of participants with multiple partners in Table 2.

<sup>b</sup>Date overlaps measures exclude 1-time partners, for whom dates of sex were not asked.

<sup>c</sup>UNAIDS point prevalence measures modified to 5 and 3 months from typical 6 months.

**Table 3.** Dyad- and triad-level concurrency by partnership-timing module and alternative measures of concurrency among subsets of men who have sex with men.

Concurrency measure	Concurrency prevalence		Agreement with partnership-timing module			
	Concurrent, n (%)	Missing, n	Agreement, n (%)	Both methods concurrent, n	$\kappa$ (95% CI)	Matched OR (95% CI)
<b>Dyad level, repeat partners (n=4703)</b>						
Partnership-timing module	2667 (56.71)	0	—	—	—	—
Direct question	2927 (67.29)	353	3639 (83.66)	2334	.66 (.64-.68)	0.20 (0.16-0.24)
<b>Triad level, repeat partners (n=2962)</b>						
Partnership-timing module	1879 (63.65)	10	—	—	—	—
Date overlap, day resolution	1986 (68.29)	54	2291 (78.76)	1608	.53 (.50-.56)	0.63 (0.54-0.74)
Date overlap, month resolution, excluding ties	1842 (63.34)	54	2355 (80.96)	1568	.59 (.56-.62)	1.0 (0.86-1.2)
Date overlap, month resolution, including ties	2378 (81.77)	54	2287 (78.62)	1802	.48 (.45-.52)	0.08 (0.06-0.10)

For the set of participants with multiple partners considered in Table 2, we examined individual-level correlates of agreement with the partnership-timing module (Table 4). Agreement in

classifying concurrency between each of the 6 alternative methods and the partnership-timing module did not significantly vary by race/ethnicity, age, or annual income (kappa values not



significantly different). Agreement significantly differed by education level for the day resolution and month resolution, excluding ties methods, with those reporting some college education having the highest agreement.

**Table 4.** Individual-level concurrency and correlates of agreement between the partnership-timing module and alternative measures of concurrency among men who have sex with men reporting multiple partners.

Concurrency measure	Participants, n (%) (n=1864)		Concurrency prevalence, %	Agreement with partnership-timing module, κ					
				Direct question	Date overlap			UNAIDS	
					Day resolution	Month resolution, excluding ties	Month resolution, including ties	5 months before interview	3 months before interview
Race/ethnicity									
	White	1035 (55.53)	62.03	.60	.41	.41	.44	.08	0.11
	Black	309 (16.58)	58.58	.52	.42	.45	.46	.12	0.12
	Hispanic	283 (15.18)	57.60	.55	.42	.42	.41	.10	0.13
	Other	237 (12.71)	58.23	.66	.43	.44	.43	.12	0.14
	<i>P</i> value			<i>P</i> =.16	<i>P</i> =.98	<i>P</i> =.85	<i>P</i> =.93	<i>P</i> =.57	<i>P</i> =.84
Age (years)									
	18-19	195 (10.46)	47.69	.61	.47	.48	.46	.11	0.11
	20-24	529 (28.38)	55.77	.60	.43	.43	.46	.07	0.12
	25-29	344 (18.45)	61.34	.55	.37	.37	.37	.07	0.09
	30-39	376 (20.17)	60.90	.62	.39	.39	.47	.08	0.11
	40-49	273 (14.65)	72.53	.54	.38	.41	.40	.12	0.13
	≥50	147 (7.89)	66.67	.52	.46	.46	.42	.12	0.13
	<i>P</i> value			<i>P</i> =.67	<i>P</i> =.67	<i>P</i> =.64	<i>P</i> =.64	<i>P</i> =.42	<i>P</i> =.83
Education									
	College/post-graduate	748 (40.17)	65.51	.59	.36	.35	.38	.08	0.09
	Some college/associate degree	761 (40.87)	56.24	.60	.49	.50	.49	.13	0.15
	High school or GED	298 (16.00)	54.55	.52	.37	.42	.44	.07	0.11
	Less than high school	55 (2.95)	59.06	.70	.42	.46	.41	.09	0.15
	<i>P</i> value			<i>P</i> =.37	<i>P</i> =.02	<i>P</i> =.004	<i>P</i> =.11	<i>P</i> =.06	<i>P</i> =.05
Annual income									
	≤\$14,999	574 (32.50)	54.53	.55	.41	.43	.43	.09	0.11
	\$15,000-\$39,999	543 (30.75)	59.48	.61	.41	.43	.42	.09	0.13
	\$40,000-\$74,999	383 (21.69)	65.80	.62	.41	.40	.43	.09	0.11
	≥\$75,000	266 (15.06)	71.80	.53	.40	.36	.44	.10	0.12
	<i>P</i> value			<i>P</i> =.41	<i>P</i> =.99	<i>P</i> =.62	<i>P</i> =.99	<i>P</i> =.95	<i>P</i> =.83

## Discussion

In this comparison of extant concurrency measures and measures derived from a new partnership-timing module, a wide range

was seen in the overall prevalence of concurrency among our sample of MSM, which may help to explain the sizeable variability seen in published estimates of concurrency prevalence among MSM [7,16]. Overall, the observed levels of agreement between the partnership-timing module with date overlap and

direct question cumulative prevalence measures are higher than we and others have found among these latter 2 types of measures [20,21]. Further, the prevalences of concurrency measured by the partnership-timing module were between those resulting from these 2 measurement types. This is consistent with our expectations, as aspects of the partnership-timing module are borrowed from these techniques.

The greatest degree of agreement was seen with the direct question measures, which consistently yielded the highest frequency of concurrency consistent with what others have reported [21]. That this highest prevalence was seen despite restricting to individuals with less than 5 partners corresponds to either better concurrency detection abilities of the direct question method or its inadequate validity. Because direct question concurrency was seen among 3%-7% of those with 1 named partner, this approach likely has limited specificity. Others have attributed this to underreporting in partner histories and priming effects of the direct questions [21,26,43]; however, we observed this phenomenon even more frequently when considering 6-month partner counts (not dyadic section partners) provided earlier in the questionnaire. Due to potential overclassification and the previously described analytical limitations for the direct question measures, the high levels of agreement between the techniques and that the partnership-timing module retains direct questioning where critical, we feel the partnership-timing module seems like an appropriate alternative to the direct question approach.

More individuals were classified as having concurrent partners using the partnership-timing module than with all date overlap methods. Examining those with exclusively repeat partners, agreement was markedly improved. Some of this is likely explained by our study's limitation of not asking dates of 1-time partners, who represented almost half of partners described in this sample (45%, 3907/8610), and may be involved in a substantial proportion of concurrent triads among MSM. This pattern is less common and has been generally disregarded as unimportant for concurrency-related HIV transmission in other contexts [8]. However, the role of 1-time partnerships in MSM concurrency transmission is yet to be determined and may be broader, given the greater HIV transmission risks per sexual act and the documentation of transmission bursts among MSM [4,44]. The inclusion of sex date for 1-time partners would increase date overlap measure prevalence, yet it is unclear whether the agreement of these measures would be substantially improved compared to the partnership-timing module for several reasons. Poor recall for ongoing partnerships has led to the seldom use of day resolution concurrency measures. Although the enhanced date collection methods used may have improved date recall and quality, data quality would likely be worse for 1-time partners. The more commonly used month resolution measures showed a greater disparity in the degree of concurrency detected, owing to differential classification of repeat "tie" partnerships of short duration but within 1 calendar month. The influx of 1-time partners would necessarily inflate the number of 1-month partnerships and cause the agreement of the 2 month resolution measures to diverge further, representing upper and lower bounds of the true date-based concurrency estimate. Indeed, the partnership-timing module

was designed precisely to alleviate this ambiguity among MSM partnerships.

Relatively low levels of concurrency were detected by the UNAIDS-style point prevalence measures at 5 and 3 months, suggesting low sensitivity in this population. The 2 prevalence measures were consistently similar, implying that the precise time-point may be arbitrary, and suggesting a plausible range for the 6-month indicator, if it were computable. A portion of the low detection may be explained by the exclusion of 1-time partners. However, the UNAIDS method always excludes ties and many 1-time partnerships would manifest as single-month ties, rather than being fully "contained" within another multimonth partnership. The degree to which classification was impeded by excluding ties was quantified by substituting day resolution point prevalence (a nonstandard measure), which resulted in modestly increased classification and a nearly identical change in estimate to that observed among Kenyan heterosexuals [25]. This method by definition excludes all 1-time partners, except for those on the exact day being assessed, and the inclusion of 1-time partner dates would not change the estimates of 16% and 17%. Nonetheless, the month resolution measures we found are in the range of those reported among most samples of sub-Saharan African heterosexual men [21,33,45]. This implies a false equality in concurrency patterns between these 2 populations, given the documentation of substantially different concurrency cumulative prevalence [7,15], which is likely partially due to differences in partner duration among MSM. The UNAIDS measure accordingly appears to be ill suited for detecting concurrency among MSM in either surveillance or research contexts, unless momentary degree is specifically required for dynamic modeling.

In addition to the measure-specific limitations discussed, this report is subject to several broad limitations. Participants were sampled from social network sites and may not represent the broader MSM population in the United States, although recent analyses have suggested the relative comparability of men sampled through social websites compared to through MSM venues [46]. Participant dropout in the partnership inventory, likely owing to the nonincentivized and online nature of the study, may have biased observed results, specifically lowering concurrency estimates because those with more partners were more likely to not complete the questionnaire. We earlier reported 45% individual-level concurrency among 3519 men who began, but did not necessarily complete, this section [15]. This is similar to the 41% observed in this report and partly allays these concerns. We also recognize that concurrency measured on subsets, such as those with multiple partners, do not necessarily make valid population-wide estimates because their validity is tied to the occurrence of those subsets. These subsets should be used only to weigh the relative merits of measurement approaches. Last, we have only considered the performance of these concurrency tools and measures among MSM. In other at-risk populations, particularly those with longer-term concurrently overlapping relationships, fewer differences between measures are expected. Nonetheless, the desire to conduct analysis at other levels should be considered in selecting the appropriate concurrency measure. Compared to other measurement approaches, the partnership-timing module

requires that more complex computer programming logic be executed in real time to be implemented. This may impede its application in some surveillance contexts. Yet as technologically enhanced data collection modalities become sophisticated and normative, this limitation will become less prominent.

Across a range of comparisons, the partnership-timing module showed strong concurrency detection ability and agreement with extant measures among an online sample of MSM. The

technique overcomes known limitations of other concurrency collection approaches and measures, and may be well suited to MSM partnership patterns. Furthermore, its placement before detailed partnership questions may help to avoid priming participants for socially desired responses [26], while providing the benefit of generally reorienting participants to their sexual histories. Further research of concurrency among MSM should consider the incorporation of this new measurement technique.

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## Conflicts of Interest

None declared.

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## Abbreviations

**HIV:** human immunodeficiency virus

**MSM:** men who have sex with men

**UNAIDS:** The Joint United Nations Programme on HIV/AIDS

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Original Paper

# Seeking Health Information and Support Online: Does It Differ as a Function of Engagement in Risky Health Behaviors? Evidence From the Health Information National Trends Survey

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## Abstract

**Background:** The Internet is an important tool to deliver health behavior interventions, yet little is known about Internet access and use of health-related information, or support, by the intended intervention recipients.

**Objective:** Our aim was to evaluate whether health-related Internet use differed as a function of common health-risk behaviors (excessive alcohol consumption, smoking, low fruit/vegetable intake, inactive/sedentary lifestyle, unprotected sun exposure, or obesity).

**Methods:** Sociodemographic, health behavior characteristics, and information on Internet access and use were assessed in the nationally representative US Health Information National Trends Survey (HINTS) 4. Data from 3911 participants collated in 2011/12 were included.

**Results:** Of the 78.2% (95% CI 76.1-80.1) of participants who had ever accessed the Internet, approximately three-quarters (78.2%, 95% CI 75.4-80.7) had obtained health-related information online last year. About half had used the Internet as the first source of health-related information (47.8%, 95% CI 44.8-50.7) or to access behavioral support (56.9%, 95% CI 53.7-60.0) in the last year. Adjusting for sociodemographic determinants of going online (being younger, white, female, with at least college education) revealed few differences in Internet access and use between health-risk behaviors. Participants with inadequate sun protection were less likely to access the Internet (OR 0.59, 95% CI 0.04-0.88) and those with low fruit/vegetable intake were less likely to have gone online to obtain health-related information last year (OR 0.60, 95% CI 0.45-0.80). Smokers in particular were likely to use the Internet to obtain behavioral support (OR 1.90, 95% CI 1.35-2.68).

**Conclusions:** Internet access and use to obtain health-related information and support is widespread and mostly independent of engagement in various health-risk behaviors. However, those with low fruit/vegetable intake or inadequate sun-protective behaviors may be more difficult to reach with Internet-based interventions. In addition, when developing online health promotions, relevant sociodemographic determinants of Internet use need to be targeted to maximize their impact.

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**KEYWORDS**

health-risk behavior; online support; Internet-based intervention; information seeking; health information and national trends survey (HINTS)

## Introduction

Over the last decade, global access to the Internet has dramatically increased such that over 80% of the US population now uses the Internet [1]. A similar proportion access the Internet in other developed countries such as in the United Kingdom [2], and worldwide one in three people are now connected online [3]. This has been accompanied by a proliferation of online sources of health-related information and support [4]. The use of the Internet to promote health and deliver interventions can engage those reluctant to use face-to-face support by providing an anonymous environment that ensures confidentiality and reduced stigma. Internet-based interventions offer a convenient means of helping those who would otherwise struggle to access face-to-face support due to mobility or geographical barriers, while offering a cheaper and more scalable alternative to offline health interventions [5].

Health interventions try to modify health-risk behaviors, which can be defined as actions that cause preventable morbidity and mortality. Tobacco smoking and overeating alone contribute to 8 million avoidable global deaths every year [6], and over a third of cancer cases are attributable to health-risk behaviors [7]. The proportion of US adults meeting daily recommendations for fruit and vegetable intake [8] and physical activity is inadequate [9], and tobacco smoking prevalence remains above 18% [10]. Despite decades of large-scale health promotion campaigns and interventions, the number of deaths attributable to health-risk behaviors is projected to increase even further [11]. Therefore, there is a continued need to tackle these behaviors.

It is encouraging that Internet-based interventions, as a novel way to engage those who persist with health-risk behaviors, have been shown to have a small but clinically significant effect on promoting health behavior change [12]. For instance, there is evidence from controlled trials that interactive, online interventions for tobacco use that personalize information and provide tailored feedback can increase 6-month abstinence rates by 17% [13]. Similarly, online interventions that provide personalized feedback and normative information have been shown to reduce weekly alcohol consumption by around 0.5 standard (10 mg) units [14]. Web-based exercise interventions that involve goal setting and online coaching can result in small but positive increases in physical activity [15]. Online interventions for obesity that provide behavior therapy and e-counseling have yielded weight loss of up to 7 kg over 6 months to 1 year [16]. Internet-based interventions also have the potential to address social health inequalities within and between countries [17] that are attributable to health-risk behaviors [18]. Interest in online support appears to be equally spread across the social spectrum [19], and there is evidence of a decreasing digital divide [20]. The universal ease of accessing Internet-based interventions is therefore a potential asset in the quest towards decreasing inequality and improving the health outcomes of the poorest in society.

However, despite the recent proliferation of eHealth, relatively little is known about the actual reach of Internet interventions [21], and there remains a need to increase exposure to health

life-style interventions delivered online [22]. For instance, it is currently unclear whether the Internet, and Internet-based health-related information and support, are accessed to the same degree and in a similar manner by people who do or do not engage in health-risk behaviors. Given that overall intervention impact is determined by both efficacy and reach, this information is important for evaluating the potential of interventions to improve health behaviors.

It is possible that the Internet and Internet-based support are accessed either more or less frequently by those who are the intended target. If the former is the case, then this further adds to the potential of the Internet as a preferred medium to deliver health interventions. Yet, if the latter is the case, then Internet-based interventions may not be as beneficial as assumed and may have suboptimal real-world effectiveness at population level despite proven efficacy in clinical trials. This would require that dissemination channels for Internet-based interventions be changed, for instance, by making intended users aware of such interventions through their health care providers or by using targeted marketing. Additionally, knowing more about what kind of person does or does not engage with eHealth can inform intervention design, for example, in terms of providing adequate or enhanced functionality and effective tailoring based on user characteristics to encourage those who are currently not making the most of the Internet to use this resource to improve their health [23].

Data are therefore needed on access to and reach of Internet-based interventions as well as sociodemographic determinants of use to aid development and optimization of online material. As North America has one of the highest rates of penetration of Internet access [3] and most mature online markets for eHealth [4], we sought to provide these data in a US sample. We addressed the following research questions:

1. What is the prevalence of general Internet use, and does this differ as a function of sociodemographic characteristics and engagement in specific health-risk behaviors?
2. What is the prevalence of Internet use to access health-related information and support online, and does this differ as a function of sociodemographic characteristics and engagement in specific health-risk behaviors?

## Methods

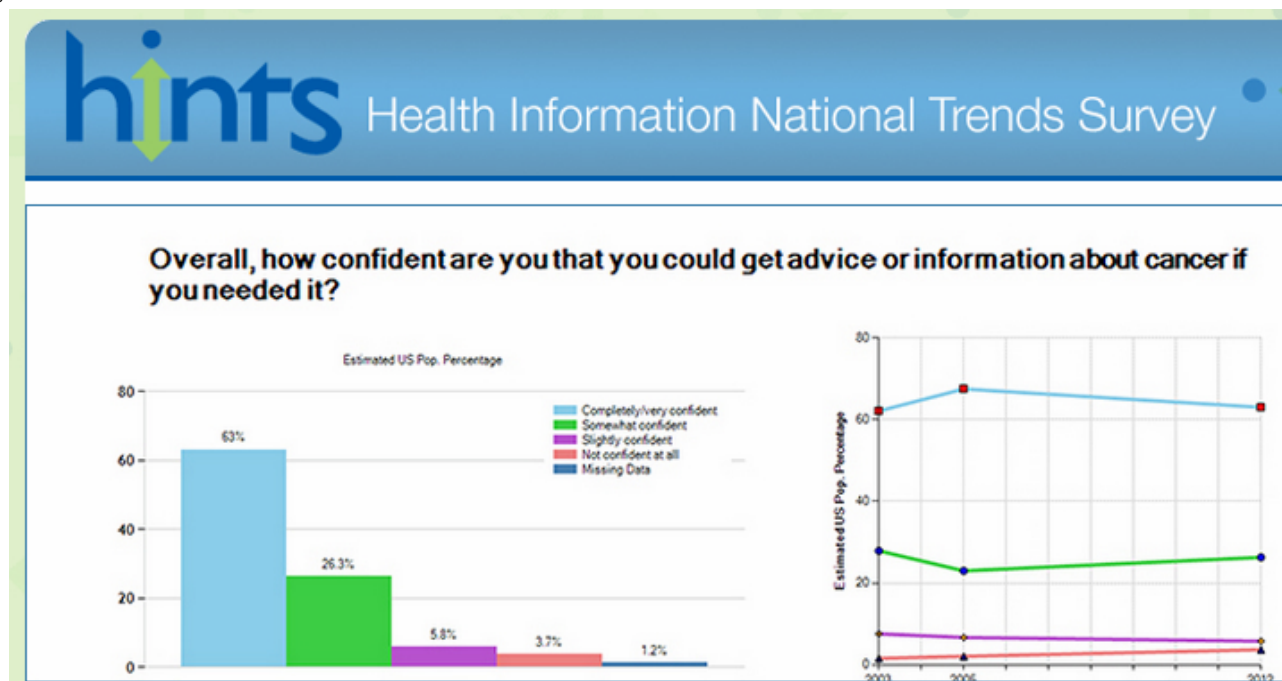
### Study Population and Design

Data come from Health Information National Trends Survey (HINTS) 4 (Cycle 1), a national probability survey of adults aged 18 or older in the civilian non-institutionalized population of the United States that assesses usage and trends in health information access and understanding (Figure 1). This study uses data from the fourth data collection wave, carried out between October 2011 and February 2012 by the National Cancer Institute. A full description of HINTS methodology is available elsewhere [24,25]. Briefly, the latest iteration used a two-stage stratified sample of addresses present on the Marketing Systems Group database to which questionnaires were mailed for self-administration (in both English and Spanish). This was followed by a reminder card and an

additional three mailings of the questionnaire depending on non-response. The sampling frame of addresses was divided into high and low ethnic/racial minority strata, with high minority areas oversampled to provide more exact estimates for minority populations. For each selected household, participants were identified by randomly allocating household

to one of two selection methods. In the next-birthday method, the adult in the household whose birthday is soonest completes the survey, and in the all-adult method, any adult in the household can complete the survey. Response rates for the two methods were 37.9% and 35.3% respectively, yielding an overall response rate of 36.7%.

**Figure 1.** HINTS screenshot.



## Measures

### Sociodemographics

Age, employment status (employed; yes/no), marital status (married; yes/no), ethnicity (white; yes/no), and educational attainment (college education or above; yes/no) were recorded. General health was assessed with an established single item asking participants to rate their health as “excellent”, “very good”, “good”, “fair”, or “poor” [26]. The latter two and former three categories were respectively combined to create a binary health status variable (poor health; yes/no).

### Health-Risk Behaviors

Alcohol consumption was determined by asking on how many days per week during the last 30 days participants had at least one drink of an alcoholic beverage (defined as a standard measure of alcohol in beer, wine, wine cooler, cocktail, or other liquor). Participants were also asked how many drinks they consumed on the days they did drink. US guidelines for alcohol consumption state that moderate alcohol consumption constitutes an average of one drink per day for women and two drinks per day for men [27]. This information was used to calculate a binary variable reflecting alcohol consumption above these levels (excessive alcohol use; yes/no).

Cigarette smoking was assessed by asking participants whether they had smoked at least 100 cigarettes in their lifetime, and if so, whether they smoked every day, some days, or not at all nowadays. This information was used to calculate a binary

variable reflecting any current (daily or non-daily) cigarette use (current smoking; yes/no).

Diet was assessed by asking participants how many cups of fruit (including 100% pure fruit juice) or vegetables (including 100% pure vegetable juice) they consumed each day. Examples of what a cup means (eg, one large banana, 12 baby carrots) were provided. Based on standard guidelines recommending at least 5 servings (roughly equivalent to 2.5 cups) of fruit and vegetables per day [28], a binary variable reflecting restricted dietary intake was computed (low fruit/vegetable intake; yes/no).

Physical activity was determined by asking on how many days a week participants engaged in bouts of exercise of at least moderate intensity, and how long a typical bout lasted. In addition participants were asked how many hours per day on average they sat and watched TV or movies, surfed the Web, or played computer games (excluding active gaming). US guidelines recommend at least 30 minutes of moderate physical activity on 5 days a week [29] and accumulating evidence links excessively inactive leisure time behavior to increased mortality [30]. This information was therefore combined into a binary variable (inactive/sedentary lifestyle; yes/no) to identify those with both inadequate physical activity (no moderate activity/exercise) and high “screen time” ( $\geq 4$  hours per day).

Sun-protective behavior was assessed by asking participants how many times they had used a tanning bed or booth in the last year, as well as whether and how often they use sunscreen when outside for more than one hour on a sunny day (always, often, sometimes, rarely, never; do not go out on sunny days).



Following sun-safe guidelines that recommend minimizing exposure to ultraviolet radiation [31] by avoiding tanning beds and always wearing sunscreen, responses were used to compute a binary variable of sun-safe behavior (unprotected sun exposure; yes/no).

Participants also self-reported anthropometric measures that were converted into Body Mass Index (BMI in  $\text{kg}/\text{m}^2$ ) and used to compute obesity ( $\text{BMI} \geq 30$ ; yes/no).

Internet use and access to health information online were measured by the following:

- Ever use of Internet: Access to the Internet was established by asking participants whether they ever went online to access the Internet or to send and receive emails.
- Internet use for health-related information last year: Access to online health information was determined by asking whether participants had used the Internet in the last year to look for health or medical information for themselves.
- Internet first source for health-related information: Participants were asked to pick one item from a list to indicate where they would first go if they had a strong need to get information about health or medical topics. The list comprised family, friends/co-workers, doctors/health care professionals, books, brochures, libraries, specialized organizations, magazines/newspapers, complementary/alternative practitioner, telephone helpline, or the Internet. This list was used to create a variable to denote use of the Internet as a first port of call for health-related information.
- Internet use for behavioral support last year: Participants were prompted to indicate various specific uses of the Internet over the last year (eg, to buy medicine or vitamins online, to look for health care providers, to write an online diary or blog on health topics). This list of uses was used to create a variable denoting use of the Internet for behavioral support (use of websites to help with diet,

weight, smoking cessation, or physical activity; participation in online support groups for people with similar health or medical issues; downloading of health-related information to a mobile device or visiting “a social networking” site to read and share about medial topics).

## Analysis

Out of a total of 3959 participants, only those who provided information on Internet use and at least one health-risk behavior (3911/3959, 98.79%) were included in the analytic sample. In univariable analysis, differences in categorical and continuous variables between those who did and did not access the Internet, or between those who did and did not use online resources for health-related information and support, were compared with chi-square and *t* test, respectively. In multivariable analysis that controlled for sociodemographic characteristics, the association between health behaviors and Internet access and use was determined with logistic and linear regressions. Sampling weights based on the Horvitz-Thompson estimator to account for sample design and non-response (jackknife with 50 replicates) were applied to all analyses to calculate accurate standard errors of estimates [32]. This was implemented using the `svyset` command in STATA version 12 to declare the appropriate survey design.

## Results

### Overview

As shown in Table 1, poor sun-protective behavior was by far the most prevalent of the health-risk behaviors; nearly nine out of ten participants did not follow sun-safe guidelines (87.7%, 95% CI 86.4-88.9). This was followed by low fruit/vegetable intake (56.0%, 95% CI 53.6-58.3), obesity (28.9%, 95% CI 26.9-31.0), current smoking (17.8%, 95% CI 15.8-20.0), excessive alcohol consumption (15.1%, 95% CI 12.8-17.7), and having a sedentary life-style (14.5%, 95% CI 12.5-16.9).

**Table 1.** Univariable associations of health-related Internet use with sociodemographic, health characteristics, and health-risk behavior.

	Total <sup>a</sup> (N=3911)	Ever use of Internet		Internet use for health-related information last year <sup>b</sup>		Internet first source for health-related information <sup>b</sup>		Internet use for behavioral support last year <sup>b</sup>	
		Yes (n=2886)	No (n=1025)	Yes (n=2222)	No (n=650)	Yes (n=1318)	No (n=1459)	Yes (n=1321)	No (n=1236)
Sociodemographic & health characteristics									
Age in years, mean (SD)	46.35 (18.01)	42.88 (15.57)	58.91 (21.00) <sup>c</sup>	42.48 (15.69)	44.06 (17.04)	42.30 (14.82)	43.71 (16.94)	39.78 (13.99)	47.59 (17.70) <sup>c</sup>
Male, % (n)	48.50 (1576)	47.87 (1130)	50.76 (446)	45.38 (841)	57.14 (286) <sup>c</sup>	50.00 (524)	45.95 (568)	45.02 (449)	51.78 (550) <sup>c</sup>
White, % (n)	80.54 (2819)	82.05 (2183)	74.87 (636) <sup>c</sup>	82.41 (1689)	82.00 (486)	81.39 (1023)	83.09 (1089)	79.11 (978)	84.83 (964)
Married, % (n)	51.23 (2015)	52.75 (1604)	45.66 (411) <sup>c</sup>	52.79 (1241)	53.54 (359)	52.85 (732)	54.30 (816)	49.96 (697)	58.53 (732) <sup>c</sup>
Employed, % (n)	55.90 (2036)	61.28 (1756)	36.26 (280) <sup>c</sup>	61.93 (1396)	59.82 (354)	63.08 (854)	59.53 (837)	62.83 (878)	60.74 (678)
College education, % (n)	64.10 (2672)	73.88 (2311)	28.08 (361) <sup>c</sup>	77.47 (1835)	61.83 (467) <sup>c</sup>	78.13 (1111)	71.79 (1118) <sup>c</sup>	77.51 (1103)	72.73 (972)
Poor health, % (n)	15.04 (623)	12.36 (343)	25.00 (280)	12.97 (268)	9.97 (71)	14.19 (156)	10.82 (174)	13.92 (161)	9.93 (132)
BMI, mean (SD)	27.66 (6.53)	27.51 (6.32)	28.25 (7.27)	27.50 (6.35)	27.59 (6.99)	27.52 (6.36)	27.55 (6.73)	27.82 (6.77)	27.07 (6.39)
Health-risk behavior, % (n)									
Excessive alcohol consumption	15.06 (484)	15.47 (368)	13.57 (116)	15.52 (286)	15.34 (80)	14.84 (178)	15.66 (181)	15.89 (190)	15.87 (141)
Current smoking	17.78 (615)	16.15 (419)	23.71 (196) <sup>c</sup>	15.34 (316)	19.34 (101)	16.65 (199)	15.32 (206)	19.84 (240)	11.70 (130) <sup>c</sup>
Low fruit/ vegetable intake	55.98 (2066)	54.85 (1492)	60.06 (574)	52.54 (1115)	63.72 (369) <sup>c</sup>	58.20 (706)	52.20 (732) <sup>c</sup>	54.91 (676)	54.67 (640)
Inactive/ sedentary lifestyle	14.54 (545)	11.74 (324)	25.25 (221) <sup>c</sup>	10.93 (229)	14.70 (94)	13.01 (154)	11.09 (158)	12.10 (137)	11.91 (151)
Unprotected sun exposure	87.69 (3309)	86.97 (2414)	90.29 (895) <sup>c</sup>	86.60 (1853)	88.33 (549)	86.97 (1119)	86.86 (1208)	87.48 (1101)	85.67 (1035)
Obese	28.88 (1122)	27.69 (819)	33.40 (303) <sup>c</sup>	27.94 (638)	27.07 (177)	26.51 (356)	28.76 (434)	28.64 (417)	24.49 (299)

<sup>a</sup>All counts in table are unweighted.<sup>b</sup>Restricted to those who have ever used the Internet.<sup>c</sup> $P < .05$ .

### Prevalence of General Internet Use and Differences as a Function of Sociodemographic Characteristics and Engagement in Risky Health Behaviors

General Internet use was common as nearly four out of five participants indicated that they had ever used it (78.2%, 95% CI 76.1-80.1). Univariable analysis showed that participants who engaged in any health-risk behaviors (with the exception of excessive alcohol consumption and low fruit/vegetable intake)

were significantly less likely to have ever used the Internet (see Table 1).

However, after controlling for sociodemographic and other characteristics in multivariable analysis, only participants with unprotected sun exposure remained less likely to have ever used the Internet (Table 2). Younger age, being female, married, of white ethnicity, and having a college education were all independently associated with ever using the Internet (Table 2).

**Table 2.** Multivariable associations of health-related Internet use with sociodemographic, health characteristics, and health-risk behavior.

	Ever use of Internet	Internet use for health-related information last year <sup>c</sup>	Internet first source for health-related information <sup>c</sup>	Internet use for behavioral support last year <sup>c</sup>
<b>Sociodemographic &amp; health characteristics<sup>a</sup>, OR (95% CI)</b>				
Age	0.94 (0.92-0.95) <sup>d</sup>	0.99 (0.98-1.00)	1.00 (0.99-1.00)	0.97 (0.96-0.98) <sup>d</sup>
Male	0.65 (0.47-0.89) <sup>d</sup>	0.64 (0.45-0.90) <sup>d</sup>	1.11 (0.56-1.44)	0.69 (0.50-0.93) <sup>d</sup>
White	2.15 (1.44-3.20) <sup>d</sup>	0.92 (0.57-1.49)	0.90 (0.56-1.47)	0.71 (0.46-1.10)
Married	1.69 (1.25-2.28) <sup>d</sup>	1.06 (0.78-1.44)	0.95 (0.77-1.17)	0.99 (0.74-1.34)
Employed	1.40 (0.89-2.21)	1.11 (0.77-1.60)	1.19 (0.90-1.56)	1.00 (0.69-1.45)
College education	7.40 (5.47-10.0) <sup>d</sup>	2.17 (1.40-3.36) <sup>d</sup>	1.42 (0.97-2.08)	1.41 (1.01-1.98) <sup>d</sup>
Poor health	0.79 (0.51-1.22)	1.77 (1.03-3.05) <sup>d</sup>	1.40 (0.83-2.37)	1.43 (0.93-2.21)
BMI	0.99 (0.95-1.02)	1.00 (0.97-1.03)	1.00 (0.98-1.02)	1.03 (1.00-1.05) <sup>d</sup>
<b>Health-risk behavior<sup>b</sup>, OR (95% CI)</b>				
Excessive alcohol use	0.61 (0.34-1.08)	0.86 (0.54-1.36)	0.83 (0.53-1.31)	0.86 (0.59-1.24)
Current smoking	0.62 (0.38-1.02)	0.78 (0.47-1.29)	0.97 (0.67-1.39)	1.90 (1.35-2.68) <sup>d</sup>
Low fruit/vegetable intake	1.03 (0.70-1.52)	0.60 (0.45-0.80) <sup>d</sup>	1.32 (1.04-1.68) <sup>d</sup>	0.97 (0.69-1.36)
Inactive/ sedentary lifestyle	0.80 (0.36-1.75)	0.62 (0.37-1.05)	1.22 (0.80-1.87)	0.94 (0.53-1.68)
Unprotected sun exposure	0.59 (0.40-0.88) <sup>d</sup>	0.94 (0.66-1.35)	0.97 (0.75-1.26)	1.01 (0.67-1.53)
Obese	0.91 (0.60-1.38)	1.03 (0.72-1.49)	0.91 (0.67-1.24)	1.32 (1.00-1.75)

<sup>a</sup>Estimates from model including all sociodemographic & health characteristics but no health-risk behaviors. <sup>b</sup>Estimates in separate models for each health-risk behavior, including sociodemographic & health characteristics covariates (BMI omitted from models with “Obese” as health-risk behavior).

<sup>c</sup>Restricted to those who have ever used the Internet.

<sup>d</sup> $P < .05$ .

### Prevalence of Internet Use to Access Health-Related Information and Support Online and Differences as a Function of Sociodemographic Characteristics and Engagement in Risky Health Behaviors

Among those who had ever accessed the Internet, over three-quarters of participants (78.2%, 95% CI 75.4-80.7) had used it to obtain health-related information during the last year. Participants with low fruit/vegetable consumption were less likely to have sought health-related information online in the last year both in univariable analysis (Table 1), and after controlling for sociodemographic and other confounders in multivariable analysis (Table 2). Being female, in poor health, and having a college education were independently associated with use of the Internet to access health-related information in the last year (Table 2).

Nearly half of Internet users reported that they would look online first whenever they urgently required health-related information (47.8%, 95% CI 44.8-50.7). A higher proportion of those with, rather than without, low fruit and vegetable intake said they would use the Internet as a first source for information on health and medical topics. This was the case both in univariable analysis (Table 1) and when adjusting for potential confounders in multivariable analysis (Table 2).

Over half of all those who had ever been online also reported using the Internet to access some sort of health-related behavioral support in the last year (56.9%, 95% CI 53.7-60.0). Both univariable (Table 1) and multivariable (Table 2) analysis showed that smokers were nearly twice as likely as non-smokers to have used the Internet to obtain behavioral support during last year. Presumably this was primarily due to getting support for stopping smoking as this difference disappeared when information seeking for quitting smoking was excluded from the definition of behavioral support (OR 1.10, 95% CI 0.71-1.69). Participants who were younger, female, college educated, and with higher BMI were also more likely to have accessed behavioral support online during the last year (Table 2).

## Discussion

### Principal Findings

Our findings provide up-to-date information on Internet access in the United States and demonstrate its widespread use to obtain health-related and medical information and support. In agreement with other national data [3,33], we find that over three-quarters of adults in the United States have ever gone online. Of these, the same proportion has used the Internet to look for health or medical information in the last year and nearly half to obtain behavioral support. This study is the first to show

that there are few differences in Internet access and use for health-related support and information between people who do or do not engage in specific health-risk behaviors. This provides empirical evidence that Internet-based interventions to change health-risk behaviors generally reach those who are the intended target of health promotion and lends further credence to the potential of the Internet as a platform for improving public health [21].

Nonetheless, the findings also suggest that the Internet may not be equally effective for addressing all types of health-risk behaviors. In particular, the Internet may be less effective for promoting sun-protective behaviors and related awareness campaigns as Internet access is lower in the at-risk population, even after taking sociodemographic confounders into account. The reasons for this are unclear. It may in part reflect lower Internet penetration of rural areas where poor sun-protective behavior can be more prevalent [34,35], though the extent to which an area was urban or rural was not directly assessed in the current study. Among those with access to the Internet, participants with a diet low in fruit and vegetables were more likely to report using the Internet as the first source for health-related information but were less likely to have used the Internet to obtain health-related information in the last year. This finding is in agreement with work from the United Kingdom, which suggests that daily recommended intake of fruit and vegetables is associated with consistent Internet use after controlling for known confounders [36]. Our results also indicate that the Internet may be particularly effective for providing behavioral support for smoking cessation as current smokers were nearly twice as likely to seek support online, primarily for help with stopping smoking. However, even then, few use intensive online support to aid quit attempts [19].

There were also sociodemographic correlates of Internet use that were mostly independent of health-related behaviors. Access to the Internet and gaining health-related information and support online was associated with being younger, female, having at least college level education and less so with white ethnicity and being married. Importantly, the observed associations of health-risk behaviors with reduced access to the Internet were attenuated but not eradicated when controlling for sociodemographic determinants. Although this suggests that the Internet may be a good medium to deliver health promotion messages and interventions to those with health-risk behaviors, it also indicates a need to be aware that older, male, non-white, and less educated people could be less likely to benefit from the availability of online health-related support. Indeed, many of the characteristics that were associated with limited access or use of the Internet to obtain health-related and medical information in this study such as unemployment, worse education, and being single are also linked with detrimental health behaviors (eg, [37,38]).

Our results have a number of implications. The Internet appears to have sufficient reach to engage people who display various risky health behaviors and, given its other advantages, is therefore a good medium to deliver online interventions to address excessive alcohol use, overeating, and physical inactivity. Based on our findings, smoking cessation interventions in particular may benefit from being delivered online. However, as access to the Internet and its use for obtaining health-related information is more limited among people with inadequate sun protection and with low fruit and vegetable intake, Internet-based interventions to change these behaviors may be less effective and require additional promotion. For instance, it may be important to supplement such interventions with print material and tailored advertising in health care outlets to reach the target population. Moreover, even though access to the Internet has grown exponentially over the last 15 years, this access is not equal across all population characteristics [39], and our results highlight the need to be aware of sociodemographic determinants of Internet use for health information. In order to avoid increasing health inequalities and decreasing effectiveness, online material will need to be tailored to characteristics such as male gender, older age, and lower educational attainment to engage these users. This can be done successfully, for instance, in the area of online support for smoking cessation [40,41].

## Limitations

The study has a number of limitations inherent to most surveys. Findings rely on self-reported data, and this may have introduced biases due to systematic misreporting or forgetting. For instance, participants may underreport their alcohol [42] and tobacco consumption [43] due to social desirability concerns. Moreover, given the cross-sectional nature of the study, no causal interpretations can be made, and we cannot exclude the possibility that unmeasured confounding factors explain some of the observed associations. For example, particular trait characteristics that influence health-risk behaviors (such as greater impulsivity, which is associated with alcohol use and smoking [44]) may also determine use of the Internet to access health-related information. Notwithstanding these limitations, given the anonymous nature of data collection, misreporting is unlikely to have made a substantial contribution to results, and common confounders in the analysis were controlled. Strengths of the study include its representativeness of the US population and its large sample size. However, findings will need to be replicated in longitudinal analyses and other countries to confirm and clarify the reported associations.

## Conclusions

Overall, our results suggests that the Internet has a wide reach and should be an effective tool to provide support and information for improving most health-risk behaviors but that sociodemographic characteristics of users need to be taken into consideration when developing online health promotion material.

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## Conflicts of Interest

None declared.

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**Abbreviations****BMI:** Body Mass Index**HINTS:** Health Information National Trends Survey

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Original Paper

# Patients Who Share Transparent Visit Notes With Others: Characteristics, Risks, and Benefits

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## Abstract

**Background:** Inviting patients to read their primary care visit notes may improve communication and help them engage more actively in their health care. Little is known about how patients will use the opportunity to share their visit notes with family members or caregivers, or what the benefits might be.

**Objective:** Our goal was to evaluate the characteristics of patients who reported sharing their visit notes during the course of the study, including their views on associated benefits and risks.

**Methods:** The OpenNotes study invited patients to access their primary care providers' visit notes in Massachusetts, Pennsylvania, and Washington. Pre- and post-intervention surveys assessed patient demographics, standardized measures of patient-doctor communication, sharing of visit notes with others during the study, and specific health behaviors reflecting the potential benefits and risks of offering patients easy access to their visit notes.

**Results:** More than half (55.43%, 2503/4516) of the participants who reported viewing at least one visit note would like the option of letting family members or friends have their own Web access to their visit notes, and 21.70% (980/4516) reported sharing their visit notes with someone during the study year. Men, and those retired or unable to work, were significantly more likely to share visit notes, and those sharing were neither more nor less concerned about their privacy than were non-sharers. Compared to participants who did not share clinic notes, those who shared were more likely to report taking better care of themselves and taking their medications as prescribed, after adjustment for age, gender, employment status, and study site.

**Conclusions:** One in five OpenNotes patients shared a visit note with someone, and those sharing Web access to their visit notes reported better adherence to self-care and medications. As health information technology systems increase patients' ability to access their medical records, facilitating access to caregivers may improve perceived health behaviors and outcomes.

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**KEYWORDS**

open access to information; caregivers; health behavior; information sharing



## Introduction

Patients are often cared for in the home by informal caregivers. In the United States, approximately 39% of adults are caregivers for an adult or child with significant health issues [1]. The care provided by these informal caregivers is valued at US \$196 billion per year, in contrast to a cost nationally of US \$32 billion for formal home health care, and US \$83 billion for nursing homes [2]. As Americans age, with more patients with comorbid complex conditions and the prevalence of dementia likely to triple by 2050 [3,4], provision of care by family members and other close relations will likely become increasingly common. Caregivers will be called on to assist with improving quality and containing health care costs.

OpenNotes is an initiative that gives patients access to the visit notes written by their doctors, nurses, or other clinicians. In the OpenNotes study, one third of patients with easy Internet access to their primary care doctors' notes were concerned about privacy [5]; however, they were not deterred from accessing notes and reported feeling more in control of their health care and being better able to care for themselves [6]. Access to provider documentation serves as a reminder of the clinical interaction and potentially enhances patients' engagement with the plan of care and therapeutic regimens [6]. Additionally, providing access to paper visit notes [7,8] and electronic medical records may improve patient outcomes [9,10], making open access to visit notes a compelling intervention.

Health policy encourages patient access to their electronic health information. The Medicare and Medicaid Electronic Health Care Record (EHR) Incentive Program provides incentive payments to eligible professionals and hospitals as they adopt, implement, or show meaningful use of certified EHR technology. Stage 2 of Meaningful Use advocates electronic engagement of patients and their families [11]. A core requirement is to provide patients with electronic access to portions of their medical record, specifically after visit summaries [12]. Informal caregivers are incorporated into a framework for evaluation of the patient portal, My HealtheVet, used by the Department of Veteran's Affairs [13]. However, the focus of policy and research interventions to date has primarily been on providing individual patients access to their own health information: the impact of sharing electronic records with informal caregivers is largely unknown.

Large medical systems, including the Veterans Administration (VA), Geisinger Health System, Mayo Clinic, Beth Israel Deaconess network, and MD Anderson Cancer Center are offering open records to increasing numbers of patients, and in some circumstances also to their delegates [6,14]. Prior patient surveys suggest interest in shared electronic medical records, including low income populations [15] and veterans [16]. My HealtheVet participants indicated that 79% of the predominantly elderly, male population was interested in sharing access to their electronic medical record laboratory results and medication refill information with someone else, most commonly with their spouse or partner [16]. In a single-site qualitative study of veterans and their delegates who had Internet access to clinical data, including visit notes, participants noted predominantly

positive experiences [17], but no prior studies have focused on how patients share their visit notes with others outside of the patient-doctor dyad.

Decreasing barriers to communication of important medical information and recommendations with caregivers has the potential to improve patient outcomes and decrease medical errors. The OpenNotes study invited patients in three US states to access their visit notes for one year. Here we evaluate the characteristics of patients who reported sharing their visit notes during the course of the study, including their views on associated benefits and risks.

## Methods

### Overview

The study was a quasi-experimental intervention that invited patients to access their primary providers' visit notes via Web-based, secure patient portals for a year between the summer of 2010 and fall of 2011. Study populations included urban and suburban primary care practices associated with Beth Israel Deaconess Medical Center (BIDMC), an academic health center with urban and suburban practices, Geisinger Health System (GHS) in central, largely rural Pennsylvania, and Harborview Medical Center (HMC), an urban safety-net teaching medical center affiliated with the University of Washington. At HMC, both the general medical clinic and a primary care clinic for patients with human immunodeficiency virus (HIV) participated in the study. Patients were initially surveyed about their expectations at the time of enrollment, and a year later surveys focused on their experiences with the intervention. The details of the study are previously described [18].

### Protection of Human Subjects

All study procedures were approved by the institutional review boards of BIDMC, GHS, and the University of Washington.

### Study Population and Survey Content

Patients of volunteering primary care physicians were invited electronically to participate at BIDMC and GHS, where portals already existed, and were approached individually at HMC, where an existing electronic health record was modified and made available to study participants [19].

Pre-intervention baseline surveys assessed patients' demographic data, including education, self-reported health, how the patients felt about gaining electronic access to visit notes [19]. It also measured patient-doctor communication using the Ambulatory Care Experiences Survey score of patient-doctor interactions (range of 0-6 with a higher score indicating better communication), and the Perceived Efficacy of Patient-Physician Interactions score, which assesses the patient's level of confidence communicating with their physician (range 5-50 with a higher score indicating greater confidence) [20,21]. The post-intervention survey asked participants about sharing their notes: "Did you show or discuss your visit notes with other people?" and "With whom did you share or discuss the note? (Check all that apply)". Participants also responded to statements about the results of reading their visit notes: "I take better care of myself", "I do better with taking my medications as

prescribed”, “I am concerned about my privacy”, with response options including disagree, somewhat disagree, somewhat agree, agree, and don’t know. The full pre- and post-test surveys are available on the OpenNotes website [22].

### Statistical Analysis

Data from the baseline and post-intervention survey were analyzed for participants who viewed at least one visit note and responded “yes” or “no” to the sharing question on the post-intervention survey. The proportion of participants reporting that they showed or discussed their note with someone else during the study (sharers) was compared to those who did not (non-sharers). Sharers and non-sharers were compared by patient characteristics from the baseline survey, including demographics, self-reported health, patient-doctor communication measures, and from the post-intervention data, including number of notes available during the study, frequency of portal use, and behavioral perceptions (better self-care, better adherence to medications, concern about privacy) using chi-square tests and Mann Whitney tests when appropriate.

Modified Poisson regression with robust error variance was used to determine perceived relative risks of sharing notes for each of the aforementioned patient characteristics in univariate models. Characteristics were found statistically to be significantly associated with sharing visit notes were then included in multivariable models. The resulting characteristics associated significantly with sharing visit notes: age, gender, employment status, and study site were incorporated into relative risk models to assess the association between sharing, frequency of portal access, and behavioral perceptions, respectively. Data analyses were performed using SAS software, version 9.3.

## Results

Across the three study sites, 22,703 patients were invited to participate, 19,371 (85.32%) completed the intervention, and

11,155 of those (57.59%) had at least one note available during the study period [18]. Of those with at least one note available, 4516 (40.48%) completed the post-intervention survey and responded “yes” or “no” to the sharing survey question.

Over half (55.43%, 2503/4516) of post-intervention survey respondents agreed that they would like the option of letting family members or friends have their own access to their visit notes. In fact, 21.70% (980/4516) of participants reported showing or discussing their visit note with someone else. Among those that shared their visit notes, the persons with whom they shared included (the survey allowed reporting of more than one individual) a family member, friend, or relative who takes care of them (349/980, 35.61%), another family member (554/980, 56.53%), another friend (95/980, 9.69%), another doctor (87/980, 8.88%), a nurse or health professional (83/980, 8.47%), or someone else (107/980, 10.92%).

Multiple characteristics were significantly associated with sharing visit notes during the intervention in unadjusted analyses: being 60 years of age and older, male, having less than or equal to a high school education, being retired or unable to work, having poor or fair self-reported health, and participating at a study site other than BIDMC (Tables 1 and 2). In unadjusted analyses, those who shared were more likely to respond affirmatively to taking better care of themselves and doing better with taking their medication as prescribed and were neither more nor less likely to report concern about their privacy than non-sharers (Table 3). The median number of days that the portal was accessed during the study was 30 for those who shared their notes, compared to 28 for non-sharers. Both sharers and non-sharers had a median of three visit notes available during the study.

**Table 1.** Characteristics of patients who reported sharing or did not report sharing their visit notes with someone else during the study.

	Did share visit notes		Did not share visit notes		
Patient characteristics <sup>a</sup>	n	%	n	%	<i>P</i> value <sup>b</sup>
Total number of participants (N=4516)	980		3536		
<b>Age at baseline</b>					
18-39	97	9.9	488	13.8	<.001
40-49	154	15.7	691	19.5	
50-59	284	29.0	1189	33.6	
60-69	292	29.8	849	24.0	
≥70	153	15.6	319	9.0	
<b>Gender</b>					
Women	466	47.6	2256	63.8	<.001
Men	514	52.5	1280	36.2	
<b>Race</b>					
White	758	77.4	2781	78.7	.41
Black or African American	15	1.5	78	2.2	
Other or multiracial	50	5.1	169	4.8	
Unknown	157	16.0	508	14.4	
<b>Education</b>					
High school/GED or less	158	16.1	429	12.1	<.001
Some college	181	18.5	616	17.4	
College graduate	106	10.8	543	15.4	
Post college	257	26.2	1047	29.6	
Unknown	278	28.4	901	25.5	
<b>Employed</b>					
No (Retired/unable to work)	311	31.7	746	21.1	<.001
Yes (Employed/self-employed/homemaker)	374	38.2	1843	52.1	
Unknown	295	30.1	947	26.8	
<b>Self-reported health</b>					
Poor/Fair	118	12.0	323	9.1	.001
Good/Very Good	523	53.4	2005	56.7	
Excellent	61	6.2	308	8.7	
Unknown	278	28.4	900	25.4	
<b>Study site</b>					
<b>Harborview</b>					
HIV clinic	21	2.1	33	<1	<.001
Adult medicine clinic	10	1.0	12	<1	
GHS	460	49.9	1567	54.4	
BIDMC	489	46.9	1924	44.3	

<sup>a</sup>Patient characteristics were obtained from the pre-intervention survey, response rate 51.90% (5789/11,155).

<sup>b</sup>*P* values derived from chi-square tests unless otherwise noted.

**Table 2.** Patient-doctor interaction and patient confidence in communication with doctor scores for patients who did share or did not share visit notes with someone else during the study.

Measures of interaction	Did share visit notes		Did not share visit notes		P value
	Mean (SD)	Median (IQR)	Mean (SD)	Median (IQR)	
Ambulatory care experiences survey score <sup>a</sup>	5.2 (0.9)	5.6 (4.8, 6.0)	5.1 (0.9)	5.4 (4.6, 5.8)	.009 <sup>b</sup>
Perceived efficacy of patient-doctor interactions score <sup>c</sup>	42 (7)	44 (23, 24)	42 (7)	43 (23, 24)	.42 <sup>b</sup>

<sup>a</sup>Patient report of patient-doctor interactions; range of 0-6, with a higher score indicating better communication.

<sup>b</sup>P value obtained from Mann-Whitney test.

<sup>c</sup>Patient level of confidence about communicating with his or her physician; range of 5-50, with a higher score indicating more confidence.

**Table 3.** Behavioral perceptions of patients who reported sharing their visit notes with someone else during the study (N=4516).

	Did share visit notes (n=980)		Did not share (n=3536)		<i>P</i> value <sup>a</sup>
Behavioral perceptions	n	%	n	%	
In thinking about what it was like to read your doctor's visit notes					
<b>I take better care of myself</b>					
Agree/somewhat agree	843	86.02	2737	77.40	<.001
Disagree/somewhat disagree/don't know	137	13.98	799	22.60	
<b>I do better with taking my medications as prescribed</b>					
Agree/somewhat agree	698	71.22	2103	59.47	<.001
Disagree/somewhat disagree/don't know	203	20.71	1058	29.92	
Do not take medications	79	8.06	375	10.61	
<b>I am concerned about my privacy</b>					
Agree/somewhat agree	347	35.41	1345	38.04	.13
Disagree/somewhat disagree/don't know	633	64.59	2191	61.96	

<sup>a</sup>P values derived from chi-square tests.

When demographic, health, and study site characteristics were placed into a multiple adjusted regression model, the characteristics that remained independently associated with sharing visit notes were being male, being retired or unable to work, and attending the general medicine clinic at Harborview Medical Center, an urban safety-net hospital (Table 4). After adjusting for age, gender, employment, and study site, the probability of sharing increased by 4% for each visit note

available during the study (RR 1.04, 95% CI 1.03-1.06) (data not shown). After adjustment for the same demographic and study site characteristics, participants who shared were statistically significantly more likely to report taking better care of themselves (RR 1.45, 95% CI 1.20-1.76) and taking their medication as prescribed (RR 1.49, 95% CI 1.25-1.76), they were no more or less concerned about their privacy than were non-sharers (Table 5).



**Table 4.** Unadjusted and adjusted association between patients who shared visit notes and demographic characteristics, self-reported health, and study site.

Characteristic	Unadjusted RR <sup>a,b</sup>	95% CI	Adjusted RR <sup>a,b</sup>	95% CI
<b>Age at baseline</b>				
18-39	1		1	
40-49	1.10	0.87-1.38	0.96	0.72-1.28
50-59	1.16	0.94-1.43	0.97	0.75-1.26
60-69	1.54	1.25-1.90	1.09	0.83-1.44
≥70	1.95	1.56-2.44	1.22	0.89-1.66
<b>Gender</b>				
Men	1.67	1.50-1.87	1.61	1.41-1.85
Women	1		1	
<b>Education</b>				
High school/GED or less	1.37	1.15-1.62	1.19	0.97-1.46
Some college	1.15	0.97-1.36	1.10	0.92-1.32
College graduate	0.83	0.67-1.02	0.86	0.70-1.05
Post college	1		1	
<b>Employment</b>				
No (Retired/unable to work)	1.74	1.53-1.99	1.39	1.18-1.64
Yes (Employed/homemaker)	1		1	
<b>Self-reported health</b>				
Poor/Fair	1		1	
Good/Very good	0.77	0.65-0.92	0.88	0.74-1.05
Excellent	0.62	0.47-0.81	0.78	0.59-1.04
<b>Study site</b>				
<b>Harborview</b>				
HIV clinic	1.92	1.36-2.71	1.35	0.90-2.01
Adult medicine clinic	2.24	1.41-3.57	1.67	1.01-2.76
GHS	1.12	1.00-1.25	0.96	0.82-1.13
BIDMC	1		1	

<sup>a</sup>Estimates derived from modified Poisson regression with robust error variance.<sup>b</sup>Adjusted for age, gender, education, employment, self-reported health and study site.**Table 5.** Behavioral perceptions in patients who shared visit notes.

Behavioral perceptions	Unadjusted RR <sup>a</sup>	95% CI	Adjusted RR <sup>a,b</sup>	96% CI
<b>In thinking about what it was like to read your doctor's visit notes</b>				
I take better care of myself	1.61	1.36-1.90	1.45	1.20-1.76
I do better with taking my medications as prescribed	1.55	1.34-1.78	1.49	1.25-1.76
I am concerned about my privacy	0.91	0.81-1.03	0.94	0.82-1.08

<sup>a</sup>Estimates derived from modified Poisson regression with robust error variance.<sup>b</sup>Adjusted for age, gender, employment, and study site.

## Discussion

### Principal Findings

Health care systems, prodded by policy drivers and consumer demand, are increasingly moving forward with opening records to patients [6,18,25], but how these records are shared with others is not well understood. In this study of open access to doctors' visit notes in three disparate outpatient settings, one-fifth of participants reported sharing their notes with a variety of individuals over the course of a year, and 55% reported interest in allowing family or friends their own access to their visit notes. This potentially indicates that with a longer study duration, more patients might have shared notes or shared with people who are geographically distant. Those who shared were more likely to report taking better care of themselves and taking their medications as prescribed. They were also more likely to be older, male, less educated, unemployed, and have poorer self-reported health than were those who chose not to share. While a sizable minority of patients surveyed expressed concerns about loss of privacy, we found no difference in such worries between the sharers and those choosing to keep notes to themselves.

A large proportion of persons in the United States are informal caregivers [1,26], and caregiver support groups encourage them to take notes and actively participate in doctors' visits, including accessing patient information via portals [27]. "Care partners" who do not provide day-to-day care but do help patients navigate the health care system and facilitate communication with providers, sometimes from a distance, would also benefit from access to online patient portals [28]. However, formal study of patients' and caregivers' desires around sharing notes is limited. Data from a predominantly older, male Veteran population suggest that their interest in sharing medical records is high [16]. In the OpenNotes study, conducted among a younger, more diverse population with a larger number of female patients, the majority of participants similarly desired the option to share notes. As more health care institutions offer access to patient records and notes, it is likely that more and more patients will share their health information with others.

Integrating caregivers of frail patients into each step of patient care will likely become increasingly important for providing high-quality and cost-effective care for these medically complex patients [29]. Nearly half of caregivers perform tasks typically carried out by professional health care workers, such as wound care or intravenous medication administration [30]. Similarly caregivers for the burgeoning number of patients with dementia [3] often need to acquire skills of professional medical personnel. For all members of a medical team, rapid and open communication can be vital, and the visit note can serve as an expedient and effective platform. It should help both patients and their caregivers engage, communicate, develop and demonstrate trust, and assist with the implementation of the care plan. Further investigation regarding the interaction within patient-caregiver dyads has substantial implications for the safe and effective implementation of patient portals and the requirements that health information technology vendors need to consider in the development of this technology.

Accessing medical information via the Internet has been postulated to increase the "digital divide" between those who are facile with technology and those who are not [31]. Patients who reported improved health behaviors after the OpenNotes study were more likely to have shared their notes. Given this, it is noteworthy that the patients attending the Harborview clinics, which have a specific mission to care for the community's most vulnerable patients, were more likely to have shared their notes than those from the other clinical sites. Moreover, older and unemployed patients, and those who reported poorer health were also more likely to do so. This suggests that those with greater medical comorbidity and potentially less health literacy may value and benefit most from the ability to share their notes by seeking help from support persons. As patients turn to caregivers for help, the opportunity for patients to share their notes may help diminish a digital divide.

Clinicians often record intimate details of patients' lives. Electronic access to such information for persons outside of the patient-doctor relationship raises concerns about privacy. Substance use, mental health, and sexual history, for example, are areas that many patients could be reticent to share with caregivers. However, we found that those who shared their visit notes were neither more nor less concerned about privacy than were non-sharers. While this is reassuring for those who advocate open access to patient notes, perhaps the proportion of those who shared would have been greater if elements of the "social history" were restricted. Health information technology vendors need to consider how to protect patients' privacy while facilitating access to pertinent medical information and recommendations. Currently there are no clear standards for caregiver access to patient portals, and authentication procedures vary widely [28]. Additional study of how to document sensitive personal history, while potentially allowing patients to not disclose the social history to caregivers or family, would benefit patients and caregivers.

Caregiver stress is well documented [2]. While access to the patient's visit notes may decrease stress by facilitating communication and clarifying the plan, it could also induce stress. The chasm between a caregiver's experience of the patient's illness and the physician's understanding of the diagnosis and science may trigger tension between caregiver and doctor [32], and how concepts are communicated in a visit note could alienate the caregiver. Content within an electronic medical record, which frequently includes both data and repetition designed primarily for billing and administrative purposes, as well as medical jargon and speculative diagnostic scenarios that could include frightening diagnostic possibilities, may in itself increase caregiver stress. In the OpenNotes study, some physicians reported changing the way they phrased potentially sensitive information related to malignancy, mental health, or substance use [18]. Viewing both patients and caregivers as integral members of the health care team, doctors and EHR vendors should maximize clear, direct communication in visit notes, and hopefully diminish stress and anxiety that caregivers might feel.

As patients share notes with caregivers, they may also consider sharing their notes more broadly, such as posting them on social

media platforms. Divulging sensitive information, wittingly or unwittingly, could affect personal relationships, job opportunities, or litigation. A doctor's note freely accessible on the Internet could generate positive or negative comment from a wide variety of viewers. As social media evolve hand in hand with health care transparency, the consequences for the doctor-patient relationship are largely unknown, and adding caregivers to the mix may introduce even more complexity.

### Strengths and Limitations

This study's strengths include the large number of patients granted access to their visit notes in geographically and socioeconomically diverse settings. These participants may represent early adopters of technology that may quickly become standard of practice. But limitations derive from a sample that nevertheless represents a small subset of Americans, so these findings cannot be considered widely generalizable. The data are self-reported survey data, without input from caregivers.

### Conclusions

We have undergone a revolution in the way personal electronic data are accessed and shared. Future patient portals will need to integrate the preferences of patients, caregivers, and health

care providers. Developing separate secure portals for caregivers may help limit access to components that the patient prefers to keep private. Vendors will need to add features allowing patients to share specific information with caregivers based on patient preferences. Policies for organizations seeking to enable "delegation" for patients are needed to address aspects such as authentication of patient delegates and how control of specific access to patient information is supported. Protections against inadvertent over-sharing must also be considered.

Coordinating care for patients is both a tremendous challenge and a core competency for effective care organizations [33]. When given the opportunity, 22% of OpenNotes patients shared their visit notes with someone over a year's time. Those who shared reported that they took better care of themselves, were more likely to take their medications, and were not more or less concerned about privacy than non-sharers. Sharing visit notes to engage caregivers and family as active members of the health care team could be critical for many patients if clinical outcomes are to improve and costs are to be contained. Open access to visit notes offers exciting opportunities to engage a patient's family and social support members, and now is the time to establish standards and develop the technology to open these portals.

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### Conflicts of Interest

None declared.

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## Abbreviations

**BIDMC:** Beth Israel Deaconess Medical Center



**EHR:** Electronic Health Records  
**GED:** General Educational Development  
**GHS:** Geisinger Health System  
**HIV:** human immunodeficiency virus  
**HMC:** Harborview Medical Center  
**VA:** Veterans Administration

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Original Paper

# The Effect of a Patient Portal With Electronic Messaging on Patient Activation Among Chronically Ill Patients: Controlled Before-and-After Study

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## Abstract

**Background:** It has been suggested that providing patients with access to their medical records and secure messaging with health care professionals improves health outcomes in chronic care by encouraging and activating patients to manage their own condition.

**Objectives:** The aim was to evaluate the effect of access to a patient portal on patient activation among chronically ill patients. Further, the relationship between temporal proximity of a severe diagnosis and patient activation were assessed.

**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 usual care. Patient Activation Measure (PAM) at baseline and at 6-month follow-up was obtained from 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.

**Results:** No significant effect of access to patient portal on patient activation was detected in this study ( $F_{1,133}=1.87$ ,  $P=.17$ ,  $\eta^2=0.01$ ). Patients starting at a lower level of activation demonstrated greater positive change in activation compared to patients starting at higher levels of activation in both the intervention and control groups. Further, patients diagnosed with a severe diagnosis during the intervention showed greater positive change in patient activation compared to patients whose last severe diagnosis was made more than 2 years ago. The results also suggest that the intervention had greatest effect on patients starting at the highest level of patient activation (difference in change of patient activation=4.82,  $P=.13$ ), and among patients diagnosed within a year of the intervention (difference in change of patient activation=7.65,  $P=.12$ ).

**Conclusions:** Time since last severe diagnosis and patient activation at baseline may affect changes in patient activation, suggesting that these should be considered in evaluation of activating chronic care interventions and in the specification of possible target groups for these interventions. This may be relevant in designing services for a heterogeneous group of patients with a distinct medical history and level of activation.

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**KEYWORDS**

chronic illness; patient activation; self-management; diagnosis

## Introduction

Approximately 40% of the population in Europe and the United States suffer from at least 1 chronic disease, and this number is expected to grow [1]. Such conditions currently account for between 70% and 80% of health care costs in these regions. To ease the burden of growing demand and restricted resources, health care providers have begun developing and implementing practices to engage the most underutilized asset of health care—the patient—in the care process. By engaging chronically ill patients in monitoring and managing their health, care providers can shift to the patients some aspects of the work previously performed by professionals. However, diminishing resource use is not the only expected benefit of activating patients. Activated patients who are knowledgeable, skilled, and confident in the self-management of their condition are shown to engage in preventive behavior by following care recommendations and a healthy lifestyle [2-4]. Engaging patients in self-management of their conditions may, therefore, also improve health outcomes and quality of care.

A growing body of research shows that sharing information regarding the state and goals of care and improving access to communication with a health care professional can strengthen a patient's active role in the management of their own condition [5-7]. Along with the recent progress in information technology, new channels of communication between the patient and the professional, and opportunities for the care providers to effectively share information on the care process with the patient have emerged. One of the outputs of this progress is the electronic patient portal which offers the patient access to the health information that is documented and managed by a health care institution [7,8]. Typically, the available information consists of the medical records of the patient, but other services and applications, such as electronic messaging with a health care professional, medication refills, and access to medical information, may also be offered [8]. Although previous studies [9,10] have shown positive effects of access to electronic patient portals on patient activation (knowledge, skills, and confidence in managing one's condition), further empirical evidence is still required [2,8]. Moreover, little is known of the contextual factors that may promote or diminish the effect of patient portals and other self-management interventions.

We address 2 essential factors that may promote or dilute the effect of self-management interventions; namely, the level of a patient's activation when entering an intervention and the temporal proximity of a diagnosis. Patient activation may have an impact on self-management intervention outcomes, especially when the intervention requires some level of patient participation. Temporal proximity of a diagnosis is related to a patient's perception of their health and the consequential interest in managing their health. The health belief model by Rosenstock and colleagues [11] hypothesizes that a threat perceived by the patient of falling ill motivates health-related action if the patient believes that they may reduce the perceived threat. A strong indication of falling ill, even when the symptoms are mild, is the diagnosis made by a health care professional: "...from a patient's perspective, [a diagnosis] is the starting point for an altered life situation" [12]. In this study, we analyzed the

independent effect of time since a patient's new diagnosis on patient activation and the moderating effect that the temporal proximity of a diagnosis may have on the activating effect of a patient portal. The more severe the disease is, the more its onset will affect patients' attitudes toward managing their health [13]. In this study, we limited the analysis of time since diagnosis to diagnoses considered severe (eg, cancer) in contrast to diagnoses considered less severe (eg, hypertension).

This paper describes the results of a controlled before-and-after study in which the effect on patient activation of a simple patient portal with access to personal clinical information and electronic messaging with clinicians was examined. In addition, we assessed the effects of patient activation at baseline and time since severe diagnosis on change in patient activation. The study was conducted among the chronically ill patients in public primary care in a medium-sized town in Finland (approximately 68,000 citizens). Because it has been suggested that the benefits of a patient portal apply to all regular primary care customers, we did not restrict study participation on the basis of specific diagnoses, but instead based it on a professional's perception of the chronic, but treatable, nature of a patient's condition.

## Methods

### Study Setting, Participants, and the Intervention

This was a controlled before-and-after study conducted in Finnish public primary care. Patients visiting 1 of the 10 health centers in the town of Hämeenlinna during the recruitment phase from October 2011 to March 2012 were considered potential study participants. To study the impact of a patient portal among those most likely to become users of such a service in the future, the following eligibility criteria were applied: (1) age at least 18 years, (2) at least 2 treatable health conditions assessed by a health professional, (3) bank identifiers (electronic credentials for online authentication provided by their bank) and access to the Internet, (4) willing and able, both according to themselves and to a health care professional, to engage in using the portal.

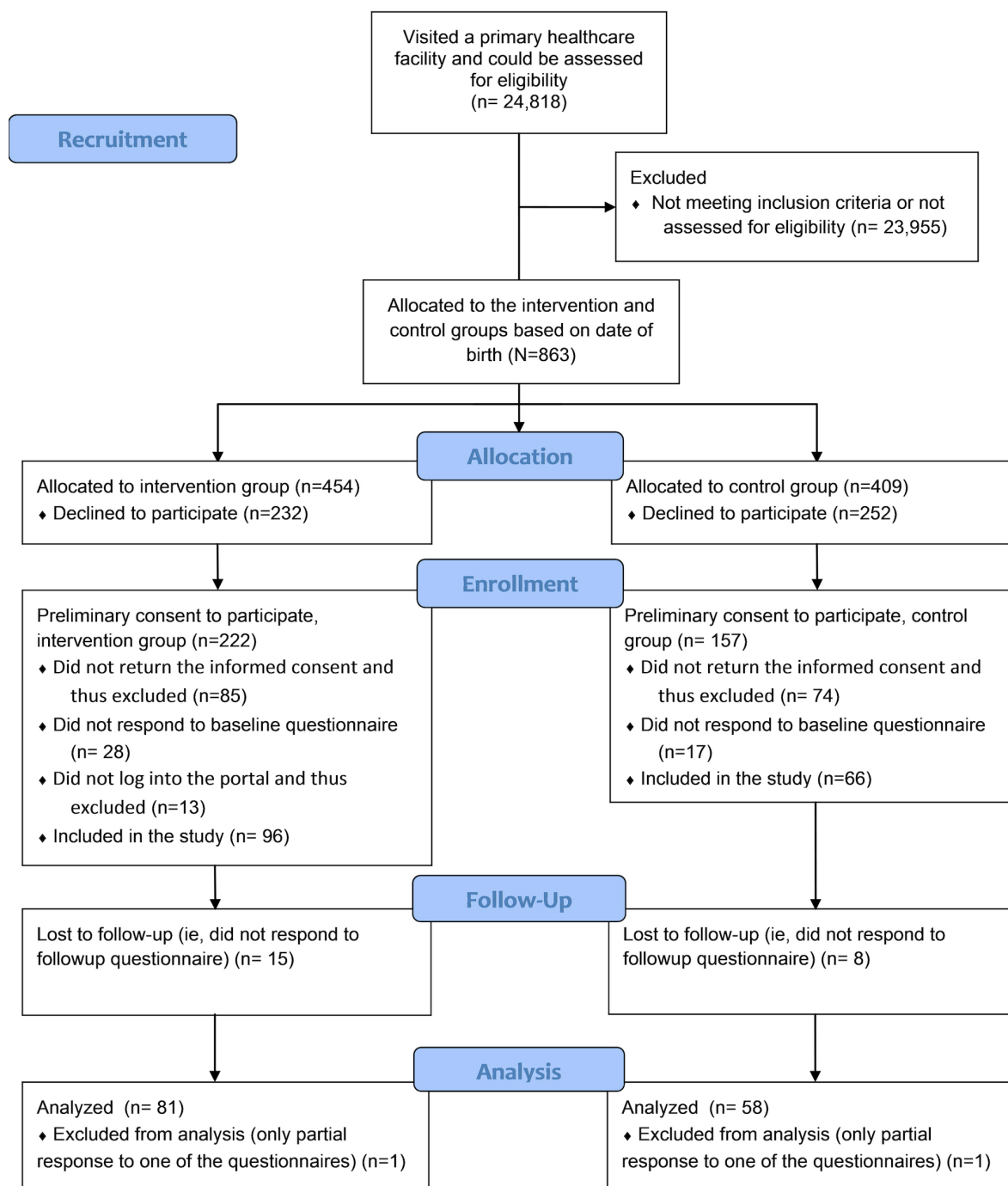
The eligible patients were approached during their visits to primary health care facilities. The nurses and doctors were advised to consider each patient as a potential participant. Once a patient was found eligible, invited to participate, and showed interest in taking part in the study, they were allocated 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 intervention group received immediate access to the patient portal and participants in the control group were to receive delayed portal access after 6 months. Ethical approval was granted by the ethical board of the local authority (Pirkanmaa Hospital District). Patients who returned the informed consent to participate were included in the study, whereas patients who did not return the informed consent were considered to have declined to participate (Figure 1).

Once a patient enrolled in the study, they formed a care plan together with a health care professional. The plan was personally tailored for each patient to holistically care for their health and to involve them in the planning of their own health care.

Although a care plan was created for all study participants, only the patients in the intervention group were given online access to their care plan through the portal. Patients in the control group received a printed copy of their plan. Other features of the patient portal were access to (1) customer's own patient records provided and maintained by the health care provider with diagnoses of chronic illnesses and permanent medication prescriptions (Figure 2), (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 [14], 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 their bank identifiers to sign in. Whenever the customer received a message or a laboratory result through the portal, a text message reminder was sent to their mobile phone. A reminder was also sent if changes to their next follow-up appointment were made.

**Figure 1.** Patient flow.





**Figure 2.** Screenshot of the patient portal.

## Materials

Patient activation was studied through the short form of Patient Activation Measure (PAM13) created by Hibbard and colleagues [15]. PAM13 assesses a patient's knowledge of their diseases, skills to self-manage their disease, and self-confidence in their abilities to manage their disease [15]. The concept of patient activation draws on psychological theories of health locus of control [16], self-efficacy in self-managing behaviors [17], and readiness to change health-related behaviors [18], but it also incorporates competency elements specifically related to the self-management of a chronic illness [19]. The measure was developed using Rasch analysis and has been validated through several studies [3,4,20]. Increases in patient activation score have been shown to be followed by improved health behaviors [3]; thus, the measure can be used as an intermediate outcome measure for self-management interventions [2].

The PAM13 instrument consists of 13 statements, such as "When all is said and done, I am the person who is responsible for taking care of my health" (see [Multimedia Appendix 1](#)). Respondents answer the items with degrees of agreement or disagreement. The raw PAM scores (range 13-52) were linearly converted to activation scores ranging from zero (lowest activation) to 100 (highest activation) following established PAM methodology [19]. The converted PAM score was further categorized to 4 developmental levels of activation described earlier [21]. In previous studies, high PAM scores have been associated with high quality, cost-effective care [4], and an increase in activation score has also been shown to result in improved self-management behavior [3], better health outcomes [2], and a decrease in use of hospital services [2]. To collect the responses to the PAM13 questionnaire, an email with a link to an online questionnaire was sent to the participants at baseline and at 6-month follow-up.

Because a Finnish translation of PAM13 has not been used in previous studies, the translation was conducted in collaboration

with an expert panel of 3 researchers with expertise in health service research. An independent Finnish translator first translated the questionnaire to Finnish, after which each member of the expert panel made their translations of the instrument. Discrepancies were discussed and a single translation of the PAM13 was agreed upon.

Diagnoses of the participants from 5 years before the intervention were gathered from the electronic patient records to examine the temporal proximity of a diagnosis. Because the effect of diagnosis on patient activation is assumed to depend on diagnosis severity [13], we defined a list of severe chronic diagnoses using the Charlson Comorbidity Index (CCI). The CCI is a widely used system for characterizing patient comorbidities drawing on information regarding 17 chronic medical conditions [22] ([Multimedia Appendix 2](#)).

## Statistical Analysis

Independent sample *t* tests for continuous variables and chi-square tests for categorical variables were used to examine the differences between the intervention and control groups at baseline. An analysis of covariance (ANCOVA) with patient activation score at baseline as a covariate was used to assess the effect of patient portal access on patient activation score at 6-month follow-up.

To examine the main effect of (1) patient activation level at baseline and (2) severe diagnosis proximity on the change in activation score, we used post hoc tests for group comparisons. In the post hoc tests, we employed the Tukey honestly significant difference (HSD) method to compare the change in patient activation between groups with different times since severe diagnosis (0-1 year, 1-2 years, over 2 years, severe diagnosis during the intervention, and no severe diagnoses), and between groups with different levels of patient activation at baseline (1-2, 3, and 4).

To test the moderating effect of (1) patient activation level at baseline and (2) severe diagnosis proximity on intervention

outcome, we used linear regression modeling. Estimates (linear predictions) for changes in patient activation are presented for each category of the moderating variables.

To verify the reliability of the translated Finnish PAM13 instrument, we analyzed item response rate, internal consistency (Cronbach alpha), and item-rest correlations at both baseline and follow-up. All statistical analyses were performed using Stata version 13 (StataCorp LP, College Station, TX, USA). We used a CHARLSON Stata module by Stagg [23] to identify the CCI conditions from patient records.

## Results

### Descriptive Characteristics

A total of 24,818 unique patients visited the health care facilities during the recruitment phase and could be assessed for eligibility. Of the assessed patients, 863 met the inclusion criteria

and were allocated to intervention and control groups. In the end, informed consent and responses to baseline and follow-up questionnaires were obtained from 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 (Table 1).

None of the differences in patients' baseline characteristics were statistically significant. There were slightly fewer women in the control group (45.6%, 26/57) than in the intervention group (56.3%, 45/80). More patients in the intervention group had a CCI of zero (52.5%, 42/80) than in the control group (47.4%, 27/57); accordingly, a greater number of patients in the control group (21.1%, 12/57) had a CCI of 2 than patients in the intervention group (15.0%, 12/80). In addition, more patients in the control group had diagnosed hypertension (36.8%, 21/57) than patients in the intervention group (27.5%, 22/80). The mean age and the baseline score for mental health were similar in both groups as were the proportions of patients with diabetes and hypercholesterolemia.

**Table 1.** Baseline characteristics of study participants (N=137).

Characteristic	Portal access (n=80)	Control (n=57)	<i>t</i> <sub>135</sub>	$\chi^2(df)$	<i>P</i> value
Age (years), mean (SD)	61 (9)	63 (10)	-0.8		.40
Female, n (%)	45 (56.2)	26 (45.6)		1.5 (1)	.22
<b>Diagnosis, n (%)</b>					
Type 1 or 2 diabetes <sup>a,b</sup>	32 (40.0)	22 (38.6)		0.0 (1)	.87
Hypertension <sup>a,c</sup>	22 (27.5)	21 (36.8)		1.3 (1)	.25
Hypercholesterolemia <sup>a,d</sup>	37 (46.3)	24 (42.1)		0.2 (1)	.63
<b>Charlson comorbidity index, n (%)</b>				0.9 (2)	.64
0	42 (52.5)	27 (47.4)			
1	26 (32.5)	18 (31.6)			
2	12 (15.0)	12 (21.1)			

<sup>a</sup>From before the beginning of the intervention.

<sup>b</sup>ICD10 codes E10-E14 or ICPC codes T89-T90.

<sup>c</sup>ICD10 codes I10-I15 or ICPC codes K85-K87.

<sup>d</sup>ICD10 codes E78 or ICPC T93.

### Validation of PAM

To verify the psychometric properties of the translated instrument, internal consistency and item-rest correlations were examined at both baseline and follow-up (Multimedia Appendix 3).

The item response was high, with at most 0.7% (1/137) missing values at baseline and 1.5% (2/137) at follow-up. Question 12 was scored as "not applicable" by 9.5% (13/137) of the participants at baseline and by 12.4% (17/137) at follow-up. The overall mean PAM score in this Finnish sample was 63.59 (SD 15.00) at baseline and 63.55 (SD 14.80) at follow-up, and these are similar to the Danish (64.2) [24] and Dutch (61.3) [25] mean scores.

Internal consistency was assessed as the Cronbach alpha for the sum scale, which was .87 at baseline and .86 for the follow-up sample. These are similar to the Danish (.89) [24] and Dutch

(.88) [25] versions and considered to be good levels of internal consistency.

Item-rest correlation per item to the sum scale was .32 to .73 at baseline and .33 to .70 at follow-up. For several items, these values were only moderate ( $\leq .50$ ), which indicates that they may not be absolutely true to 1 dimension.

### Use of the Patient Portal Functionalities

The view to patient's own health information containing diagnoses, medication prescriptions, and laboratory results was the starting page encountered by the patient once they logged in to the portal. On average, this information was viewed 10.8 times per patient during the 6-month study period. The second most popular feature of the portal, used 3.2 times on average, was viewing one's personal care plan. Patients sent 1.5 messages to their care team and viewed their vaccination record 1.3 times

on average. Only 0.3 prescription renewals, on average, were made through the portal during first year after access (Table 2).

**Table 2.** Mean use of patient portal functionalities per patient in the intervention group (n=80) during the 6-month study period.

Functionality	Mean (SD)	Range
Viewing personal health record	10.8 (9.8)	1-43
Viewing personal care plan	3.2 (3.2)	0-16
Messages to the care team	1.5 (2.0)	0-9
Viewing vaccination record	1.3 (1.5)	0-7
Prescription renewal	0.3 (0.6)	0-3

### Patient Portal Effect on Patient Activation

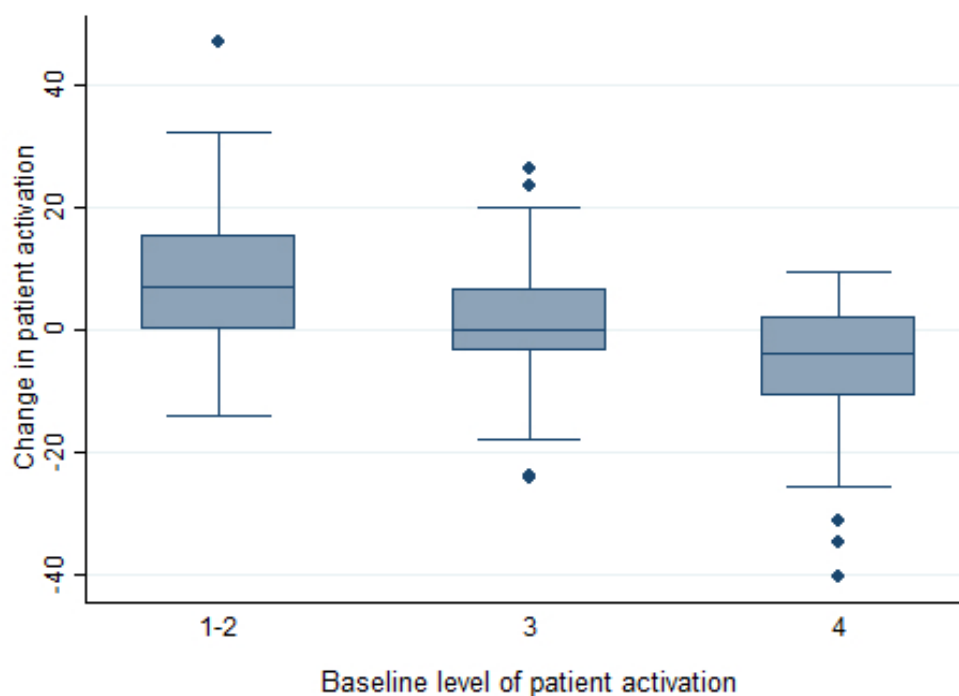
In analysis of variance, no significant effect of access to patient portal on patient activation was detected ( $F_{1,133}=1.87$ ,  $P=.17$ ,  $\eta^2=0.01$ ). The mean activation score increased by 1.05 (SD 12.61), from 63.74 (SD 15.37) to 64.79 (SD 15.20), in the intervention group and decreased by 1.58 (SD 13.71), from 63.39 (SD 14.51) to 61.80 (SD 14.17), in the control group. The group difference at follow-up adjusted for baseline activation score was 2.77 (95% CI -1.24 to 6.79). As the difference of 4 to 5 points in patient activation is considered meaningful in terms of patients' health behavior [26,27], the adjusted difference is minor.

### Main Effect of Baseline PAM Level on Change in PAM Score

The 1-way analysis of variance showed a significant difference in mean change in patient activation score across the 3 groups

starting from different levels of patient activation ( $F_{2,137}=17.90$ ,  $P<.001$ ,  $\eta^2=0.21$ ). Patients starting at low levels of patient activation (1-2) demonstrated greater positive change (mean change 8.5, SD 12.3) in activation score than patients starting at level 3 (mean change 0.7, SD 11.7) and 4 (mean change -6.1, SD 11.3; Figure 3). Pairwise post hoc comparisons using the Tukey HSD test further supported the statistical significance of the differences. Patients starting at the combined level 1-2 had significantly greater mean change scores than patients starting at level 3 (mean difference in change 7.8,  $P=.01$ ) and level 4 (mean difference in change 14.6,  $P<.001$ ). Furthermore, patients starting at level 3 showed a significantly greater mean change in patient activation than patients starting at level 4 (mean difference in change 6.8,  $P=.01$ ). The difference of 4 to 5 points in patient activation is considered meaningful in terms of patients' health behavior [26,27] and, thus, the differences between groups are considerable.

**Figure 3.** Changes in patient activation scores within groups starting at different levels of patient activation (n=137).

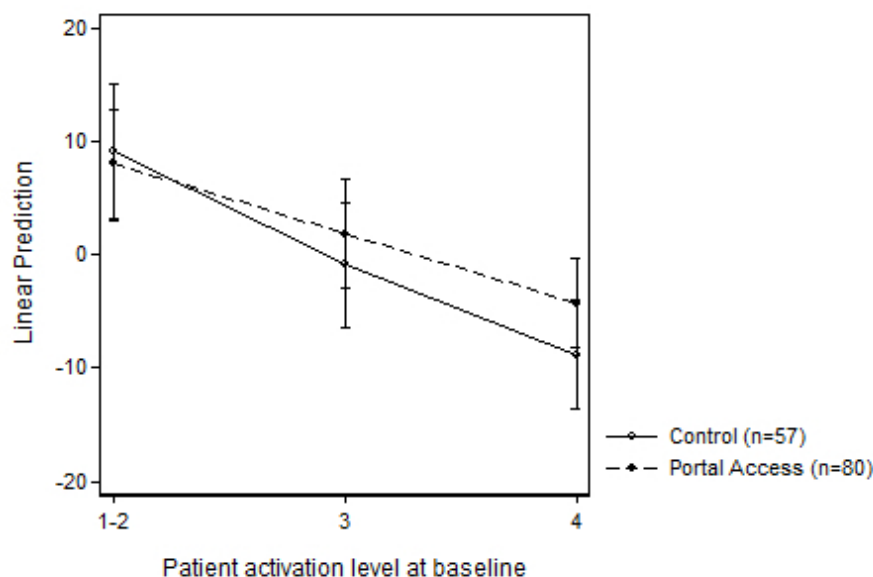


### Interaction Effect of Portal Access and Baseline PAM Level on Change in PAM Score

No statistically significant interaction effect on change in patient activation was detected between portal access and baseline PAM level ( $F_{2,137}=0.62$ ,  $P=.54$ ,  $\eta^2=0.009$ ). Figure 4 presents the linear

regression estimates (linear predictions) for change in patient activation by patient activation level at baseline. The most notable difference between the intervention and control groups was among patients starting from the highest level of patient activation (marginal effect=4.82,  $P=.13$ ; Figure 4).

**Figure 4.** Intervention and control group estimates for mean change in patient activation (0-100 points) at different baseline levels of patient activation.

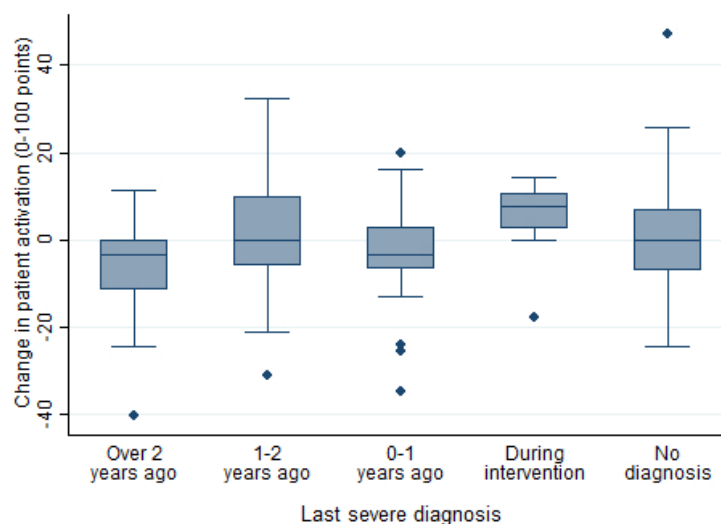


### Main Effect of Time Since Last Diagnosis on Change in PAM Score

The 1-way ANOVA revealed a significant difference in mean change in patient activation scores across the 5 groups with different temporal proximity of a severe diagnosis ( $F_{2,137}=17.90$ ,  $P<.001$ ,  $\eta^2=0.21$ ). Patients diagnosed with a severe diagnosis during the intervention showed greatest positive change in patient activation (mean change 5.4, SD 8.4). In addition, patients diagnosed 1-2 years ago (mean change 2.3, SD 15.7) and patients with no severe diagnoses (mean change 1.6, SD

13.1) showed a positive change in patient activation. The greatest decrease in patient activation change was observed for patients with a severe diagnosis made more than 2 years before the intervention (mean change -7.1, SD 12.3), and the change was also negative for patients diagnosed less than 1 year before the intervention (mean change -3.0, SD 11.5), as shown in Figure 5. Pairwise post hoc comparisons using the Tukey HSD test showed a significant difference between patients diagnosed with a severe condition more than 2 years before the intervention and patients diagnosed during the intervention (mean difference in change 12.4,  $P=.02$ ). The differences between the other groups were not statistically significant.

**Figure 5.** Changes in patient activation scores by time since last severe diagnosis (n=137).

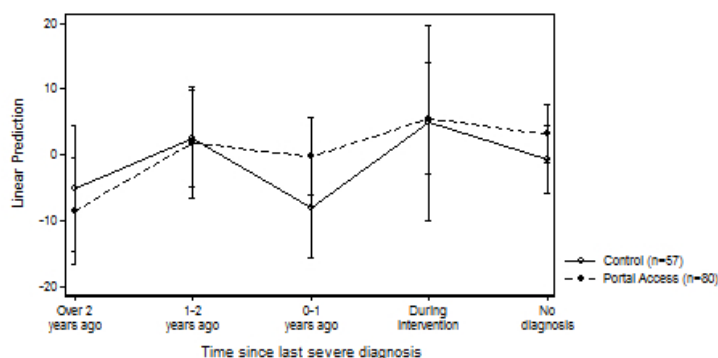


### Interaction Effect of Portal Access and Time Since Last Diagnosis on Change in PAM Score

No statistically significant interaction effect on change in patient activation was detected between portal access and baseline activation level ( $F_{2,137}=0.62$ ,  $P=.64$ ,  $\eta^2=0.02$ ). Figure 6 presents

the linear regression estimates (linear predictions) for change in patient activation by time since diagnosis. The most notable difference between the intervention and control groups was observed among patients diagnosed within a year of the intervention (marginal effect=7.65,  $P=.12$ ; Figure 6).

**Figure 6.** Group estimates for mean change in patient activation (0-100 points) in groups with different time since last severe diagnosis.



## Discussion

### Principal Findings

The psychometric assessment of the translated Finnish PAM13 instrument supported the reliability of the measure, and replicated to a great extent the findings from the previous Danish [24] and Dutch [25] versions. However, some rephrasing of question 12 may be required because more than 10% of participants scored the item as “not applicable” at follow-up.

No significant effect of access to patient portal on patient activation was detected in this study unlike previous research [9,10]. The heterogeneous results may be because of the different sets of functionalities provided through the portals studied. Nagykalai and colleagues’ cluster randomized controlled trial [9] and Solomon and colleagues’ randomized controlled trial [10] both found a significant positive effect of an electronic patient portal on patient activation. Unlike the patient portal studied here, the interventions included features for patient-produced information of their health management [9] and interactive condition-specific health education [10]. The patient portal in the present study was relatively simple, so the addition of a greater number of activating functionalities might fortify its effect.

As has been observed in previous studies, the change in patient activation was greater among patients starting at a lower level of activation [10]. This pattern was similar in the intervention and control groups; thus, the effect of access to the patient portal was not greater for less-activated patients entering the intervention. In fact, the comparison of activation change between the intervention and control groups revealed that the positive effect of the intervention was greater among the patients starting at a higher level of patient activation. In the present study, the regression toward the highest score in the entire sample might be because of 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, in that it might encourage patients to

rethink their role in the management of their condition. The latter alternative would call for the use of control groups to distinguish between the survey instrument effect and the actual intervention effect on changes in patient activation.

To our knowledge, this is the first study to examine the effect of time since diagnosis on patient activation. In both the intervention and control groups, a greater positive change in patient activation was identified among patients diagnosed with a severe condition during the intervention than among patients whose last severe diagnosis was made more than 2 years ago. This suggests that a severe diagnosis may have an independent immediate effect on patient activation. The intervention, in turn, appears to have made the greatest impact on the group diagnosed with a severe condition up to 1 year before the intervention. Among the few studies addressing the effect of time since diagnosis on care outcomes other than patient activation are those by Karter and colleagues [28], Blaum and colleagues [29], and van den Arend and colleagues [30], which were all conducted among diabetic patients. Karter and colleagues [28] found a connection between time since diagnosis and adherence to self-monitoring of blood glucose levels among diabetic patients by comparing patients diagnosed less than and more than 10 years ago, although the connections were inconsistent by diabetes type and severity of disease. Blaum and colleagues [29] discovered that time since type 2 diabetes diagnosis was longer for a group of patients with poor glycemic control compared with a group of patients with good control suggesting that the care outcomes may deteriorate as time since diagnosis increases. Van den Arend and colleagues [30] compared 4 different primary care programs for structured care of diabetes, and found that the longer patients had the diagnosis, the less their disease knowledge increased as a result of the programs. The somewhat incoherent results of the associations between time since diagnosis and different care outcomes suggest that the association may be dependent on the type of diagnosis, the outcomes measured, and the type of the performed self-management intervention. Understanding the effect of temporal proximity of a diagnosis may aid in identifying the sensitive periods in chronic care when “an exposure [to a



specific chronic care intervention] has a stronger effect on development and hence disease risk than it would at other times” [31].

### Strengths and Limitations

The main strengths of this study are the experimental setting with longitudinal design and the use of scientifically validated measures for assessment of patient activation (PAM13) as well as in defining time since diagnosis (CCI).

As in any study, there are also several limitations. Three main limitations are related to the natural experimental setting. First, because the recruitment of the patients was conducted by clinical professionals and the time period for recruitment was limited, the sample size remained modest, reducing the statistical significance of the effects. The second limitation concerns the allocation of the patients in the intervention and the control groups. Although birth date itself is not expected to affect the outcomes of the intervention, the allocation method is deterministic in the sense that the assigned intervention could be predicted before the allocation [32]. This may have influenced the recruitment of the patients and may have contributed to the attrition imbalance between the intervention and control groups. Another likely reason for the attrition imbalance that could not have been avoided by randomization was the inability to blind the patients from receiving or not receiving access to the portal. An informed consent from the patients to participate was required for the ethical approval of the study. Therefore, the patients were aware of their assignment, which may have induced the greater dropout rate in the control group at the allocation phase (Figure 1). The third limitation of the study was the duration of the intervention. The intervention period of 6 months 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 effectively use the portal, 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. However, a longer intervention period would have been difficult to justify in a publicly funded health care organization, the central duty of which is to provide equal services to all its patients.

In this study, the participants formed a diagnostically heterogeneous group. Because there may be differences in

activation and its development in different diagnostic groups, further research is needed to assess the association of different diseases and patient activation. Furthermore, CCI, used in defining time since severe diagnosis, is restricted to a set of typical severe diagnoses; thus, some relevant diagnoses that might affect change in patient activation may possibly have been omitted. Broadening the set of diagnoses may further specify the relationship between time since diagnosis and patient activation.

### Conclusions

In this study, we created a Finnish translation of the validated PAM13 to evaluate the benefits of giving patients access to their medical records and secure messaging with health care professionals. Patient activation serves as “an intermediate outcome of care that is measurable and linked with improved [health] outcomes” [2].

No significant effect of a patient portal on patient activation was detected in this study. This result concerning a simple form of a patient portal differs from previous studies in which more interactive functionalities were included in the portal studied.

In addition to the functionalities offered through a patient portal, the activating effect of the portal is dependent on the characteristics of the patient who uses the portal. In this study, 2 patient-related factors, namely patient activation level at baseline and time since last severe diagnosis, were considered. Both variables were shown to be associated with changes in patient activation. Thus, it is suggested that these are considered in any evaluation of activating chronic care interventions. Further studies on the effect of time since diagnosis may identify sensitivity periods during which patients can benefit the most from specific chronic care self-management interventions. Findings on the factors affecting patient activation may aid in designing effective services for a heterogeneous group of patients with a distinct medical history and level of activation.

Patient portals are complex interventions in the way that their outcomes depend on multiple patient-related factors, such as recontacts with their health care provider during the intervention period, but also on the characteristics of the portal itself, such as the set of functionalities offered through the portal. We encourage further conceptual and empirical research on the mechanisms ignited by different patient portal functionalities and on the contextual factors that may moderate the effect of these mechanisms on patient outcomes.

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## Authors' Contributions

Riippa was responsible for the design of the study, participated to the collection of the data, analyzed and interpreted the data, and drafted the paper. Linna participated in the design of the study and the interpretation of the results, and continuously revised the paper during drafting. Rönkkö participated in the collection of the data and provided insight into the implementation of the intervention and the collection of the data in the target organization.

## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Patient Activation Measure.

[PDF File (Adobe PDF File), 26KB - [jmir\\_v16i11e257\\_app1.pdf](#)]

## Multimedia Appendix 2

Charlson Comorbidity Index conditions.

[PDF File (Adobe PDF File), 2KB - [jmir\\_v16i11e257\\_app2.pdf](#)]

## Multimedia Appendix 3

Data quality and item-rest correlations of the Finnish 13-item PAM (N = 137) at baseline and 6 months' follow-up.

[PDF File (Adobe PDF File), 24KB - [jmir\\_v16i11e257\\_app3.pdf](#)]

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## Abbreviations

**CCI:** Charlson Comorbidity Index  
**HSD:** honestly significant difference  
**PAM:** Patient Activation Measure

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Original Paper

# Characteristics of Patient Portals Developed in the Context of Health Information Exchanges: Early Policy Effects of Incentives in the Meaningful Use Program in the United States

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## Abstract

**Background:** In 2014, the Centers for Medicare & Medicaid Services in the United States launched the second stage of its Electronic Health Record (EHR) Incentive Program, providing financial incentives to providers to meaningfully use their electronic health records to engage patients online. Patient portals are electronic means to engage patients by enabling secure access to personal medical records, communication with providers, various self-management tools, and administrative functionalities. Outcomes of patient portals have mainly been reported in large integrated health systems. This may now change as the EHR Incentive Program enables and supports the use of patient portals in other types of health systems. In this paper, we focus on Health Information Exchanges (HIE): entities that facilitate data exchange within networks of independent providers.

**Objective:** In response to the EHR Incentive Program, some Health Information Exchanges in the United States are developing patient portals and offering them to their network of providers. Such patient portals hold high value for patients, especially in fragmented health system contexts, due to the portals' ability to integrate health information from an array of providers and give patients one access point to this information. Our aim was to report on the early effects of the EHR incentives on patient portal development by HIEs. Specifically, we describe the characteristics of these portals, identify factors affecting adoption by providers during the 2013-2014 time frame, and consider what may be the primary drivers of providers' adoption of patient portals in the future.

**Methods:** We identified four HIEs that were developing patient portals as of spring 2014. We collected relevant documents and conducted interviews with six HIE leaders as well as two providers that were implementing the portals in their practices. We performed content analysis on these data to extract information pertinent to our study objectives.

**Results:** Our findings suggest that there are two primary types of patient portals available to providers in HIEs: (1) portals linked to EHRs of individual providers or health systems and (2) HIE-sponsored portals that link information from multiple providers' EHRs. The decision of providers in the HIEs to adopt either one of these portals appears to be a trade-off between functionality, connectivity, and cost. Our findings also suggest that while the EHR Incentive Program is influencing these decisions, it may not be enough to drive adoption. Rather, patient demand for access to patient portals will be necessary to achieve widespread portal adoption and realization of potential benefits.

**Conclusions:** Optimizing patient value should be the main principle underlying policies intending to increase online patient engagement in the third stage of the EHR Incentive Program. We propose a number of features for the EHR Incentive Program



that will enhance patient value and thereby support the growth and sustainability of patient portals provided by Health Information Exchanges.

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## KEYWORDS

medical informatics; meaningful use; electronic health records; patient-centered care

## Introduction

### The Meaningful Use Program

Passed into legislation in 2009, the Health Information Technology for Economic and Clinical Health (HITECH) Act included US \$30 billion for accelerating and mainstreaming the use of health information technology [1]. The Act incentivizes the adoption of electronic health records (EHRs) by hospitals and physician practices and sets targets for the “meaningful use” of these EHRs to significantly improve patient care [2]. The EHR Incentive Program, also known as the Meaningful Use (MU) program, is a cornerstone of the HITECH Act. The program, which is regulated by the National Coordinator for Health Information Technology (ONC) and administered by the Center for Medicare & Medicaid Services (CMS), authorizes incentive payments through the Medicare and Medicaid Programs [3]. Through three stages, the program rewards providers that meaningfully use ONC-certified EHRs by meeting designated objectives and levies a financial penalty on those providers that fail to meet the objectives [4].

Stage 1 of MU, which was implemented in 2011, provided incentives for eligible physicians and hospitals to adopt EHRs with basic functionalities, such as capturing data electronically and exchanging information among care providers [5]. Subsequent to Stage 1 implementation, the number of providers meeting MU1 criteria with their EHRs sharply increased [6,7]. Up from 4% in 2010, 42% of hospitals surveyed in the 2012 American Hospital Association Health Information Technology Supplement fulfilled core Stage 1 requirements [8,9]. Further, it was estimated that by May 2012, 12.2% of US office-based physicians had successfully restructured their IT systems and practices to meet Stage 1 requirements [10,11].

Stage 2 of MU went into effect in 2014 for providers that demonstrated Stage 1 MU in 2011 [12]. In addition to using EHRs for continuous data capture and enhanced interprofessional information exchange, the second stage of the program emphasizes building online patient engagement capabilities on top of these EHRs [13,14]. One core objective specific to online patient engagement is that providers give at least 50% of their patient population the ability to view online, download, and transmit their health information within 4 days of the office visit (for physicians) and 36 hours of discharge (for hospitals). Of these patients, the provider must attest that 5% actually access their records online to view, download, or transmit information. Providers must also be able to securely message their patients and provide patient-specific educational resources to at least 10% of patients after office visits [15].

### Patient Portals in Light of Meaningful Use

Patient portals are vehicles for meeting these particular MU2 objectives by enabling secure messaging with health care providers and by giving patients access to their personal health records (PHRs) [16,17]. A PHR is a patient-centered tool used for managing health information and engaging in health promotion and management. The individual patients control their own PHR and may also insert information into the record that is not contained in an EHR [18]. A patient portal that is linked to a provider's EHR is called a tethered patient portal [19]. Early evaluations of tethered patient portals suggest that they can improve chronic disease management, patient adherence to medications and preventive services, patient-provider communication, patient empowerment, and patient satisfaction [20]. These outcomes have so far been reported from portals within large and integrated delivery systems, such as Kaiser Permanente and the Veterans Affairs health system, with system-wide EHRs. Through a combination of their comprehensive coverage of a defined eligible population and EHR integration, these portals give patients one access point through which they can view their information and interact with all of their providers in the system. Due to this comprehensiveness and integration, these portals can trigger mechanisms such as enhanced patient insight into their complete health information, interpersonal continuity of care, and patient convenience, which are instrumental to achieving the outcomes listed above [21].

However, as MU2 introduces financial incentives for online patient engagement, the program is now enabling and stimulating the development of patient portals in health system contexts other than these large integrated delivery systems, including Health Information Exchanges (HIEs).

### Patient Portals in the Context of Health Information Exchanges

Regional or statewide HIEs facilitate information transfer among participating hospitals and physicians' independent and non-interoperable EHRs. In 2013, 90 community-based and 45 statewide HIEs were reported in the United States [22]. By facilitating information transfer among independently operating clinicians, laboratories, hospitals, pharmacies, and health plans, these HIEs play an important role in connecting providers in fragmented contexts [23]. According to a Robert Wood Johnson Foundation report [8], by the end of 2012, 30% of US hospitals and 10% of ambulatory practices sent and received data through HIE efforts. This number has increased significantly over the last years, up from 14% and 3% in 2010 for hospitals and ambulatory practices respectively [8]. With information transfer being an ever more crucial component of the ONC's agenda, many HIEs will continue to receive start-up grants,

demonstration project grants, and ongoing operational support from the Department of Health and Human Services [24].

As health service providers that participate in these HIEs now seek ways to capture the MU2 incentives, some HIEs will play an increasing role in developing patient portals. Such HIE-sponsored patient portals may enable online patient engagement opportunities not previously seen outside of integrated health delivery systems. By consolidating information, which is typically spread across a range of independent providers' EHRs, patient portals that are developed by HIEs in fragmented contexts can give patients an overview of their health information. Since some patients—especially patients with complex conditions—see multiple providers [25], this single access point alleviates for patients the hassle of accessing their records and using other health care services through different portals, each with their own passwords, usernames, and interfaces. By achieving comprehensiveness and integration, patient portals in these systems may create patient value comparable to that observed in integrated systems, and thereby trigger outcomes similar to those reported from these systems. As pointed out by Otte-Trojel et al (2014) the patient value of portals that develop in fragmented systems may even exceed that of portals in integrated systems by breaking down siloes in fragmented provider-centric systems [21].

The achievement of this value from HIE-sponsored portals is challenged by the reality that only 10-30% of providers are currently linked to an HIE. However, as HIE participation rates grow each year, the coverage of HIE-sponsored portals will likely increase at a proportional rate.

## Study Aim

The potential of HIE-sponsored patient portals to deliver patient value in fragmented health system contexts is significant, especially for patients who see multiple providers. Yet, realizing this potential depends on physicians and hospitals that are members of the HIEs adopting the portals into their practices. The aim of this study is to report on the development and rollout of the first HIE-sponsored portals and to explore the early effects of the MU incentives on these developments. Specifically, we

examined the following questions: (1) What are the characteristics of early-stage HIE-sponsored portals?; (2) What are the major factors affecting providers' adoption of HIE-sponsored portals?; and (3) What factors will drive the further development and adoption of patient portals in the HIE context?

## Methods

Based on the list of HIEs in the 2013 eHealth Initiative report [22], we identified the HIEs that on their websites announced that they were either developing or offering a patient portal. As of early 2014, such activity was seen in HIEs in Pennsylvania, Kansas, California, and Texas. One of these patient portals has been implemented in a small set of provider practices, one is currently being rolled out in a few practices, and two are still in the piloting phase. Although being a relatively small sample, the four HIEs represent the HIEs that are developing patient portals at present and provide useful experience and information for other HIEs that intend to develop portals as well as for policy makers interested in the effects of MU criteria and incentives on patient portal development. Key characteristics of the four front running HIEs are presented in Table 1.

We contacted the directors of these four HIEs in February and March 2014, and all directors agreed to participate in our study. We asked all four HIE directors to refer us to other relevant HIE staff or providers that were in the process of implementing the portals in their practices. We collected data in March and April 2014. As part of our data collection, we obtained documents and conducted 10 in-depth interviews with 8 people, including 4 HIE directors, 2 HIE project managers from two different HIEs, and 2 providers participating in one of these HIEs. The 2 providers were from the HIE that had implemented the patient portal in a small set of provider practices at the time of the data collection. In addition, the HIEs provided us with relevant documents, including presentations, training and installation guides, and annual reports. We conducted content analysis [26,27] of the interview transcripts and acquired documents to extract information relevant to our research questions.

**Table 1.** Characteristics of HIEs implementing patient portals.

	Kansas Health Information Network (KHIN)	Healthcare Access San Antonio (HASA)	Keystone Health Information Exchange (KeyHIE) <sup>a</sup>	Santa Cruz Health Information Exchange
Date founded	2010	2005	2005	1998
Service area	Statewide	22 counties around San Antonio	53 counties in Pennsylvania	Santa Cruz county
Penetration	6000+ providers, 700+ organizations	683,000 providers, 29 organizations	1,500 providers, 40 organizations	400 providers, 200 organizations
Unique patients	2+ million	860,000	3,7 million	300,000
Patient portal name	MyKSHealth eRecords (previously My Health eRecord)	MyHASA	MyKeyCare	Santa Cruz HIE patient portal
Patient portal vendor	NoMoreClipboard	Mana Health	Get Real Health	NoMoreClipboard
Current patient portal users			2400+	

<sup>a</sup>Only KeyHIE had active patient portal users at the time of data collection in spring 2014.

## Results

### Characteristics of Early-Stage Patient Portals Sponsored by Health Information Exchanges

To meet the MU2 requirements, the portals that are currently being developed by HIEs focus on enabling patients to view and download summary of care documents and transmit them to other providers. The HIE-sponsored portals are untethered, since they are not directly linked to an EHR. For two of the HIEs, data will be transferred to each patient's PHR through the ONC's secure emailing system, *Direct*. As their technical capabilities expand, the plan is to enable automatic population of the PHRs with data, including summary of care documents, lab results, immunization reports, etc. The other two HIEs already have such automatic transfer capacities, meaning that data can be pulled directly into the PHR. The HIEs have set up procedures to allow providers to flag information in their EHRs that they would not like to share with patients or that they would prefer to discuss with patients before making accessible.

At this early stage of development, patients will be able to store documents and enter information (eg, about their diet or exercise) in their PHRs, but as the portals evolve, the plan is to also enable transmission of such patient-generated information to relevant health care providers. To comply with MU, secure messaging between patients and providers is a standard feature in all the portals.

In addition, individual providers may choose to offer EHR-linked features, such as appointment scheduling, bill payment, patient preregistration, and prescription refill through the portals. In fact, one of the interviewed providers mentioned that they were discussing ways to add a scheduling component and a bill payment component to the portal. However, since the portals are untethered, this will require the providers to install such applications at their end and subsequently integrate these applications with the patient portal. As several HIE directors and project managers explained, incorporating such features into the portal would require extensive collaboration between the provider and the HIE to achieve the necessary technical and workflow integration. Requiring far less integration work, at least two of the HIEs are also planning to provide non-EHR-linked features through the portals, such as various educational, self-management, and wellness applications.

All four portals will be accessible through both the websites of participating providers and a central HIE website. The providers may choose to brand the portal to fit their organization, in which case the portal's interface may differ across these providers. One of the HIEs aired intentions to eventually also make its portal available on mobile devices, such as mobile phones and iPads.

All of the HIEs are planning to incorporate the cost of their portal into the overall HIE provider participation fee, while at least one is considering assigning some of the cost to patients in the form of a US \$3-5 monthly service fee. That HIE had conducted several focus group interviews with patients in the region to learn about their willingness to pay and had concluded that this reimbursement model was feasible. A number of studies

have examined patients' willingness to pay for access to patient portals. Results from these studies indicate that 40-70% of patients with Internet access would be willing to pay a small fee for use of standard patient portal features such as viewing their medical records and secure emailing with their providers [28,29].

While all the HIEs see vast potential for their patient portals to improve patient health and provider workflow in their state or region, at the time of the interviews none of the HIEs had set specific targets on these areas. The critical milestone for all four HIEs is to be able to attest MU by the start of their providers' reporting periods in either July or October 2014. Afterwards, the most important success factor is to attain a certain level of provider adoption and patient use of their portals.

### Factors Affecting Providers' Adoption of Portals Sponsored by Health Information Exchanges

#### Overview

The main issue limiting HIE-participating providers' uptake of HIE-sponsored portals is the difficulty HIE leaders have in convincing providers that the value of the HIE portal exceeds that of the EHR-tethered portal that most providers are offered by their EHR vendor. As a result of this competition from the EHR vendors' portals, an HIE-participating provider's decision to adopt the HIE-sponsored portal seems to largely be a trade-off between functionality, connectivity, and cost.

#### Functionality

From our interviews with HIE directors and managers, we identified three main challenges that currently limit the HIE-sponsored portals' degree of functionality. It should be noted that the reported significance of these challenges varies across the four HIEs.

First, the missing linkage between providers' EHRs and the HIE limits the capacities of the HIE-sponsored portals compared to their tethered counterparts in several ways. As noted above, in this early stage, EHR-linked features of convenience for patients (such as appointment scheduling) may not be available through the HIE-sponsored portals. Until full integration between providers' EHR and the HIE-sponsored portal is realized, one HIE director noted that a solution could be to simply refer patients to relevant providers' EHR features through the portal. However, accessing such features would require patients to use a separate login for each individual provider feature, thus contradicting the rationale behind a shared portal. Furthermore, for the HIEs that are still working on enabling automatic flow of information from the HIE to the patients' records, providers or their administrative staff will have to manually perform this step by sending relevant documents via an email function. While this may be feasible in small practices with small patient volumes, for bigger practices, manually transferring data after each patient visit or discharge is an unsustainable solution.

Second, all the HIEs are challenged by creating the reporting formats required for providers to attest MU. This challenge is augmented by the fact that the HIEs are not tied to the providers' EHRs, which contain administrative data on patient contacts



such as when an office visit or discharge took place. Such information is necessary, for example, to generate reports certifying that information was made available to patients in a timely manner. According to the HIEs, no perfect solution is in place yet. For now, attesting MU2 requires that the providers themselves link the data generated by the HIE with information in their own EHR. Since clinical documents are generated through the EHR, many providers have turned to their EHR vendors for advice on meeting MU2. Since these vendors could guarantee only that providers would meet the requirements through the vendors' portals, directors and project managers in two HIEs reported that many providers in their network came to believe that their EHR vendor's tethered portal was a better option than the HIE-sponsored portal.

Third, to varying degrees, the HIEs have yet to fully resolve issues regarding patient matching [23]. When data are exchanged among providers in a given HIE network, data from different providers are matched to a given patient using probabilistic matching algorithms [30]. If available, these algorithms take into account various patient identifiers, such as name, gender, date of birth, social security number, address, and phone number. In fact, one HIE uses 17 patient identifier options for matching. Since the data are being sent only to providers, the threshold for what is considered an adequate match for data with a patient is less than 100% and varies by HIE. When in doubt the providers are able to double-check the data with the patient at the time of a patient visit. However, this situation is different when it comes to populating PHRs, which can be accessed by patients via their portals. Ideally there should be a 100% match of patient identifiers so that patients never receive incorrect data in their PHR. In cases where it is not possible to achieve a match, data cannot be sent to the PHR. This challenge is especially prominent if there is considerable variation in how participating providers' EHRs format names and addresses, in the quality of data entered in the system at the point of patient registration, and if there are duplicate records for the same patient [31]. Providers with EHR-tethered portals do not share the same challenge, since they can always achieve a full match based on patients' medical record numbers generated within their systems.

### **Connectivity**

The core value of HIE-sponsored portals is their connectivity. According to the MU specifications, to meet the 5% target of patients that view, download, or transmit their information, a provider must have contributed some of the information to the shared portal, but not necessarily the particular information that was viewed, downloaded, or transmitted by the patient. There is consensus among the interviewees that the network externality of sharing credit for patient contacts and thereby collaborating to reach the 5% target is the main selling point of the HIE-sponsored portals to the HIE member provider organizations. As the directors and managers in all four HIEs explained, for many clinics and hospitals this shared incentive makes it more feasible to achieve the 5% target through the shared HIE-sponsored portal compared to having their patient population view records generated only in their respective office, clinic, or hospital. A manager from one medical center pointed out that a positive consequence of this incentive mechanism

could be that providers will encourage each other to adopt the HIE-sponsored portal.

### **Cost**

A notable advantage of the HIE-sponsored portals is lower costs to providers of acquiring a portal. As explained earlier, most HIEs plan to roll the portal costs into the overall HIE participation fee, regardless of whether a provider actively uses the portal. Smaller practices are especially sensitive to the high cost of EHR-tethered portals and may prefer this more affordable option. Moreover, one HIE director pointed out that the shared portals can operate with a lower overhead, since providers can share certain functions, such as a helpdesk to register patients and respond to patient inquiries.

Nevertheless, this cost incentive is not available for providers that have already implemented a patient portal as part of their EHR. Due to the ONC's certification of "complete EHRs" that include patient portals, many providers have already implemented an EHR-tethered portal. The "complete EHR" certification has meant that EHR vendors can guarantee only that their EHRs meet MU requirements if a patient portal is included in the package. For providers who have purchased a patient portal as part of their EHR package, the added value of participating in an HIE-sponsored portal would have to compensate for the (sunk) cost of having an already-purchased portal remain unused (one might note that if the cost of the HIE-sponsored portal is included in the overall participation fee, the expense on a non-used HIE-sponsored portal could also be considered a waste). As one project manager expressed: "MU is kind of the best and the worst of worlds at the same time".

### **Factors Likely to Impact the Further Development and Adoption of Portals Sponsored by Health Information Exchanges**

As outlined above, for HIE-participating providers that are considering implementing a patient portal, their decision to adopt a HIE-sponsored portal may largely be a trade-off between functionality, connectivity, and cost. Yet, according to the interviewed HIE directors and managers, the widespread uptake of patient portals is also inhibited by a general lack of provider interest in sharing information and communicating with patients online. The HIE directors and managers noted that a considerable share of their members express concerns with respect to patient portals, with the main points of concern being that secure messaging will lead to a boost in patient contacts and that patients will not be able to interpret or cope with the clinical data in their records. It is worth noting that the literature provides a mixed account of secure messaging's effect on health service utilization. Some studies show that secure emails increase utilization of hospitalizations, in-person visits, and telephone contacts [32-35], while one has demonstrated the opposite [36]. There are no good estimates of the proportion of providers that are interested in online patient engagement, and this proportion may vary by state and county. However, the perception among the HIE directors and managers that we interviewed is that a large proportion of providers in their network are not highly motivated by the MU incentives. This perception is supported by reports of the uptake of MU2 requirements. By June 2014, only eight eligible hospitals and

447 eligible professionals had attested to Stage 2 meaningful use [37,38]. Thus, although the HIEs develop patient portals to help their members comply with MU2, this financial incentive may not be enough to guarantee widespread uptake among providers.

Nonetheless, the notion among the HIEs is that as more and more providers include a patient portal in their service portfolio, patients will start demanding that their non-compliant providers offer similar capabilities for online engagement. If the HIEs' predictions about such network externalities hold true, the MU financial incentives may encourage HIEs to provide the infrastructure for patient portals, but ultimately the patients will have to drive the widespread incorporation of the portals into their providers' practices. Most patients recognize the benefits of patient portals: in a 2011 nationwide survey, 70% of patients indicated that they would want to access portals with comprehensive PHRs if they were made available to them [39].

## Discussion

### Principal Findings

MU2 incentives have ignited interest among some health service providers in fragmented systems to install or further develop patient portals. Such arrangements can be made via EHR-tethered portals within individual provider practices or via portals shared by the HIE network. While both arrangements enable online patient engagement, the latter may lead to more patient value by simulating the connectivity of portals in larger and integrated systems from which outcomes have mainly been reported thus far. Indeed, conversely, development of patient portals solely at the individual provider level could result in sustained fragmentation of patient information. As explained earlier, this fragmentation may have the most serious implications for patients receiving care from multiple providers, who would have to access several patient portals to view all their personal health information and interact with all their providers. However, the functionality of early stage HIE-sponsored portals may be lower than EHR-tethered portals, limiting their adoption. As we have explained, the MU incentives reward connectivity by allowing patient contacts to count towards all providers that contribute to a shared HIE-sponsored portal. Yet, it is still too early to conclude whether this incentive mechanism will be enough to ensure provider adoption of shared portals over individual portals. However, according to our informants, due to a general disinterest among providers to engage their patients online, financial incentives alone may not be enough to drive the widespread adoption of patient portals. Instead, by making online engagement tools a market differentiator, patients themselves may ultimately be the driving force behind patient portal adoption.

Hence, a focus on patient value will be imperative to drive the development of patient portals, and more importantly, to realize the outcomes possible through the use of portals [40]. If the patient portals do not deliver sufficient functionality and meaning to patients, they will likely not be able to generate traction among patients, caregivers, and health care consumers to create the necessary demand. Further, if the portals do not

adequately engage patients, patients may not capitalize on their online capabilities to spur quality, efficiency, and patient safety outcomes envisioned in the EHR Incentive Program [41]. Patient engagement is dependent on patients' perceptions that portal services enrich their current care and patient-provider relationship [42,43]. Thus, identifying ways to optimize and embed patient-valued portal capacities and functionalities into their health care services is crucial to achieving desired outcomes, since achieving these outcomes relies on patients to co-produce the outcomes by appropriately using the services [44]. We argue that portals that connect with multiple providers to give patients only one highly connected portal have the highest value to patient. The improvement of certain process and health outcomes is especially critical for patients with complex or chronic conditions who receive care from multiple providers and who account for an increasingly large part of the burden of disease [45]. Indeed, these patients will likely benefit most from a shared portal that allows them to interact and access information from their entire network of providers.

### Limitations

This study has a number of limitations. First, our principal findings and policy recommendation are based on experiences of a small number of HIEs. However, these HIEs represent the first ones developing patient portals to take part in MU in early 2014. Second, only early results from MU implementation on HIE portal development are assessed at this time. In fact, only one of the HIEs had a fully operational portal at the time of study, whereas the other three were in the implementation or pilot phases. Thus, a follow-up study 2-3 years from now would be relevant to understand the longer-term effects of the MU program on patient portal development, adoption, and use. Third, since we do not have information from patients, our results are constrained to the perceptions of the barriers and facilitators of patient portal development from HIE manager's perspective. A follow-up study could benefit from including patient users and non-users as research subjects.

### Policy Recommendations

Due to the importance of patient interest and engagement for the success of the program, an important question is whether the prevailing patient portal development that emphasizes provider-centric benefits will lead to portals that rouse the necessary patient demand. We argue that optimizing patient value should be a prime principle underlying efforts to promote online patient engagement in the third stage of the MU program, which is set to start in 2017. The Stage 3 program specifications are now under development, informed by the experience of 12 projects funded by the Agency for Healthcare Research and Quality that will propose relevant revisions to the program's overall objectives and specific measures [46]. In the following, we point to some MU Stage 3 program features identified in our research that could enhance the feasibility and success of HIE-sponsored portals, including Stage 3 financial incentives, guidelines, and technical requirements.

Shared portals can be promoted through financial incentives that further reward connectivity by strengthening incentives to portals that cross multiple providers. According to one HIE director, "MU3 ought to focus on giving the patients just one



portal". The degree of connectivity will also benefit from financial initiatives aimed at increasing the overall rates of HIE participation; as noted earlier, the potential connectivity possible through HIE-sponsored portals may be limited unless HIE participation rates increase. Furthermore, similar incentives could be targeted towards establishing links with other data repositories, particularly the federal Blue Button [47]. Developed as part of the ONC's Standard and Interoperability framework, Blue Button gives, among others, veterans and Medicare beneficiaries access to their electronic records and the ability to transmit them to other providers or family members [48]. A link with Blue Button may enhance the value of portals by providing a critical mass of data and thus higher connectivity of patient information in a state or region.

Guidelines and other technical and organizational support mechanisms could assist other organizations and networks in developing shared, untethered portals and thereby mitigate some of the challenges faced by the pioneering HIEs. Specifically, the existing ONC specifications for reporting MU poorly match the HIE situation, and further guidance on how to create accurate reporting formats could facilitate this process. Similarly, solving issues around patient matching could also increase the likelihood that providers will adopt HIE-sponsored portals. More generally,

such initiatives can be supported by the creation of an HIE collaborative, specifically aimed at disseminating and exchanging successful innovations from HIEs that are developing and implementing patient portals.

Technical requirements could focus on features and capabilities that enhance the functionality of untethered portals to patients. In addition to promoting further integration with providers' EHRs, this could entail giving patients access to more sections of their medical record or more options to interact with providers. Moreover, but likely further down the line, portals could leverage mobile technology to allow for integration with various wellness and health management applications that could further personalize the portal services. On a more urgent note, the ONC's proposed certification requirements for 2015 [49], which involve revoking the "complete EHR" certification in favor of a more modular approach, should be put into force to level the playing field between tethered and untethered portals.

Finally, on a broader level, in consultation with patient representatives, the ONC, CMS, and the patient portal-developing HIEs could engage in a dialogue to define realistic targets for developments and outcomes of the HIE-sponsored portals and weave time-specific goals into forthcoming ONC/CMS strategies.

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## Conflicts of Interest

None declared.

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## Abbreviations

**CMS:** Center for Medicare & Medicaid Services  
**EHR:** electronic health record  
**HASA:** Healthcare Access San Antonio  
**HIEs:** Health Information Exchange  
**HITECH:** Health Information Technology for Economic and Clinical Health  
**KeyHIE:** Keystone Health Information Exchange  
**KHIN:** Kansas Health Information Network  
**MU:** meaningful use  
**ONC:** National Coordinator for Health Information Technology  
**PHR:** personal health record

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Original Paper

# Reasons and Barriers for Using a Patient Portal: Survey Among Patients With Diabetes Mellitus

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## Abstract

**Background:** The use of a Web portal for patients with diabetes mellitus to access their own personal health record may result in improved diabetes outcomes. However, the adoption by patients is slow. This may be caused by patient characteristics, but also by the content, layout, and promotion of the portal. Detailed knowledge about this could help increase patients' participation in Web portals.

**Objective:** The aim was to study the opinions of patients with diabetes and identify perceived barriers to using a Web portal to optimize its use.

**Methods:** We conducted a survey among patients with type 1 and type 2 diabetes mellitus from 62 primary care practices and 1 outpatient hospital clinic in the central area of the Netherlands who all used the same electronic health record with a Web portal. Questionnaires about patient characteristics, opinions about reasons for use or nonuse, and about portal content were sent to 1500 patients with a login and 3000 patients without a login to the Web portal. Patient groups were stratified according to login frequency. Demographic and diabetes-related variables were analyzed with multivariable regression analysis.

**Results:** The total response rate was 66.63% (2391/4399); 1390 of 4399 patients (31.60%) were eligible for analysis. There were 413 regular users (login frequency more than once) and 758 nonusers (no login). Most nonusers (72.4%) stated that the main reason for not requesting a login was that they were unaware of the existence of the portal. Other barriers reported by patients were disinterest in managing their own disease (28.5%, 216/758) and feelings of inadequacy with the use of computers and Internet (11.6%, 88/758). Patients treated by a general practitioner were more frequently nonusers compared to patients treated by an internist (78.8%, 666/846 vs 28.3%, 92/325;  $P<.001$ ) and more users than nonusers became aware of the Web portal through their physician (94.9%, 392/413 vs 48.8%, 102/209;  $P<.001$ ). Nonusers perceived specific portal content as not as useful as regular users did, especially access to laboratory values (71.7%, 383/534 vs 92.3%, 372/403), rereading clinic visits (61.3%, 320/522 vs 89.6%, 360/402), e-messaging (52.0%, 262/504 vs 74.6%, 299/401), and uploading results to the glucose diary (45.3%, 229/506 vs 74.0%, 288/400; all  $P<.001$ ).

**Conclusions:** Our study shows that unawareness of the patient portal is the main barrier of enrollment. Users and nonusers perceive the usefulness of the portal differently and do not have the same recommendations for additional functionalities. To increase patients' participation in a Web portal, the unawareness of its existence and its possibilities need to be addressed by their health care professionals.

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**KEYWORDS**

diabetes mellitus; telemedicine; Internet; electronic health record; cross-sectional studies; patient preference; patient access to records

**Introduction**

The use of eHealth in disease management has been studied, especially in chronic diseases such as diabetes mellitus. In these studies, the focus was on patient Web portals where patients have access to their medical health record and can use the Web portal for communication with their health care provider. The use of a Web portal has several benefits. It can enhance communication between patient and health care professionals [1], allow patients to play a more active role in their own treatment and self-management [2], increase self-efficacy [3], and patients can feel that other nonacute concerns are valued because of an email function [4]. The use of Web portals shows promising results in diabetes outcomes, such as improved HbA<sub>1c</sub>, blood pressure, weight, and cholesterol levels [5-9]. With the growing number of people with diabetes mellitus worldwide [10], the use of patient portals for diabetes management becomes more important to cope with the burden on health care.

However, the adoption of Web portals is slow by both patients [11] and health care professionals [12]. We previously showed that patient characteristics play an important role in nonadoption [13]. Simply promoting eHealth is ineffective without addressing the differences in patient characteristics.

In the Netherlands, 96% of all inhabitants have access to Internet. Men and women have equal access and more than 95% of people up to age 65 years have access; the access rate is lower (81%) for people older than that age. Access ranges from 90% in lower education groups to 99% in the groups with the highest education. Of the people with Internet access, 87% use it daily [14]. Therefore, Internet access itself should not be a barrier for use of patient portals by most patients with diabetes mellitus.

For both patients and providers, there are several barriers in the adoption of a Web portal. Health information privacy and security are major concerns [15]. In addition, the use of medical terms and abbreviations [15,16] and problems arising due to the design [11], such as navigational problems and unmet expectations about functionality, may also play a role. There is a difference in the potential and actual usefulness of certain features of a Web portal [17]. Before using a Web portal, patients have certain expectations about how the portal may help them with their disease management and which features may be useful for them. These opinions may change when patients actively use the portal.

However, it remains unclear what reasons patients with diabetes have for using a Web portal or not. Previous research has not fully considered the steps that need to be taken before patients decide whether a patient portal can be of personal use. If we want to increase the involvement of patients in their own treatment, the barriers for using a Web portal must be addressed. More information is needed about the opinions that patients have when deciding to login for a Web portal or not and about

their first experiences with its use. With this knowledge, the initial barriers of using a Web portal could be reduced. This study aims to study the opinions and barriers of patients with diabetes to request a login and to use a patient Web portal. The following research questions were addressed:

1. In what respect do regular users and nonusers of the portal differ?
2. What are the reasons for (or not) requesting a login?
3. How did patients become aware of the portal?
4. Are there any differences in perceived usefulness of the portal between users and nonusers?
5. Are there recommendations for new functionalities?

**Methods****Design**

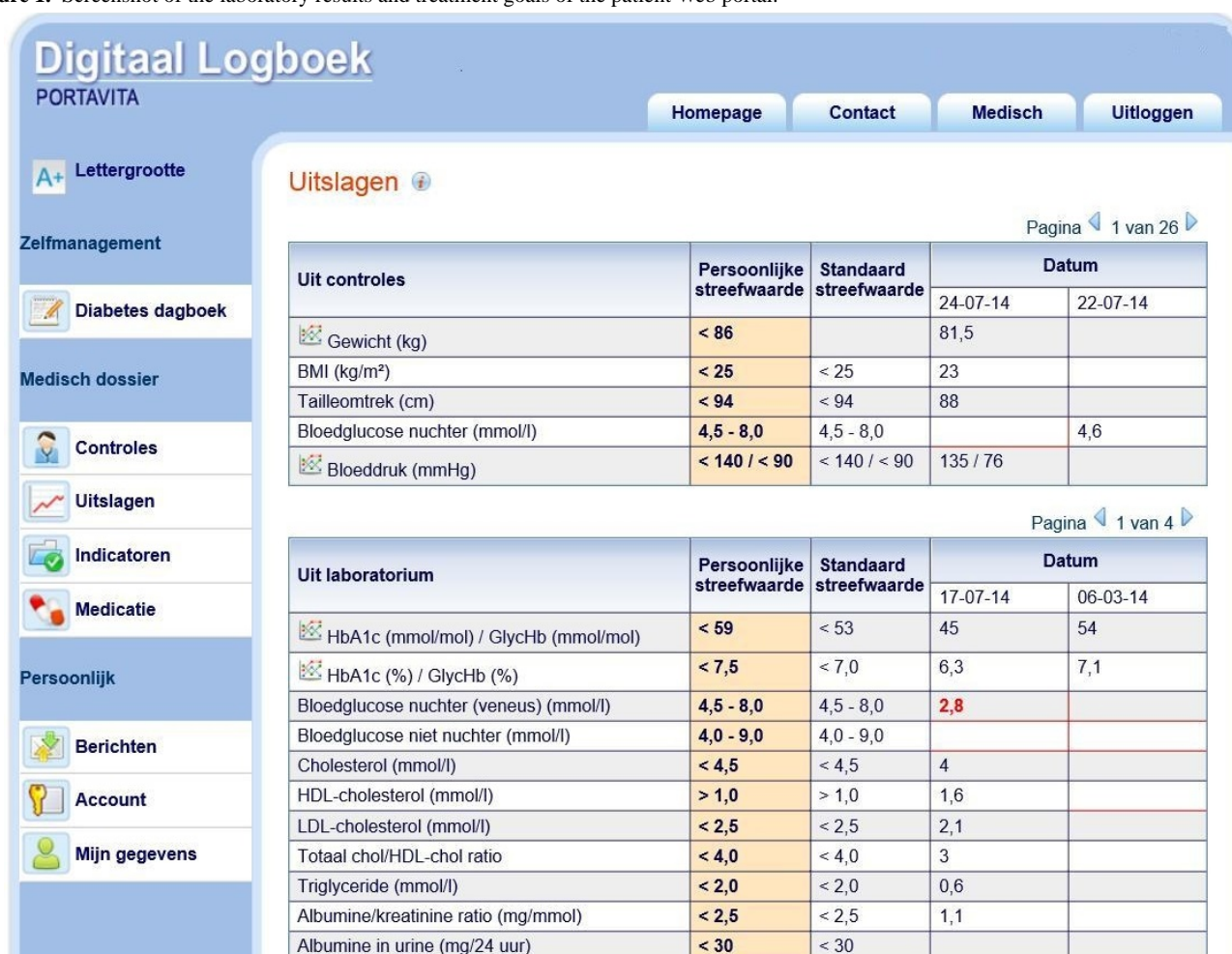
We conducted a survey among a sample of 12,793 patients with diabetes by randomly selecting patients aged 18 to 85 years and asking 1500 patients with a login to the Web portal and 3000 patients without a login to participate. Patients were sent a set of questionnaires and a reminder letter twice if necessary. Patients who did not want to participate were asked to state the reason. The survey was approved by the Medical Research Ethics Committee of the University Medical Center Utrecht (protocol number 11-296/C).

**Setting**

Primary care practices and the regional hospital joined together in an organization called “Diamuraal” to coordinate the care of patients with diabetes in a defined geographical area in the center of the Netherlands. Currently, Diamuraal comprises 62 independent primary care practices and 1 hospital outpatient clinic. All physicians and nurses who participate in the care of patients with type 1 and type 2 diabetes in Diamuraal use the same electronic health record and patients can request a login to access their personal electronic health records. When a patient wants access to the Web portal, he or she needs to sign a registration form which the physician has to cosign. The portal is called “Digitaal Logboek” and was developed by Diamuraal and a private company (Portavita). Patients have access to their diabetes-specific medical records, including information provided by their physician during medical consultation, such as physical examination, laboratory results, problem lists, and treatment goals (Figure 1). Laboratory results are accessible as soon as the laboratories report them in advance of a medical consultation. The Web portal also provides access to general diabetes information and to an overview of all personal diabetes-related examinations and consultations that are needed and/or scheduled. Patients can import and upload the glucose levels measured at home and contact their physician or diabetes nurse through secured electronic messaging. The portal is supplementary; patients who do not request access still receive diabetes care according to the Dutch guidelines. At the start of

our survey, 12,793 patients with diabetes were treated in Diamuraal, of whom 9791 (76.53%) never requested a login.

**Figure 1.** Screenshot of the laboratory results and treatment goals of the patient Web portal.



## Measures

We collected information through a set of questionnaires and by extracting data from the electronic health records. Patient characteristics were obtained from the patients' electronic health records (age, gender, type of diabetes, duration of diabetes, setting of diabetes treatment, HbA<sub>1c</sub>, and total cholesterol) and from the questionnaires (educational level, ethnicity, living status, employment, medication, smoking, drinking, fluency in the Dutch language, and access to computer and Internet). We did not take blood pressure into account because it was not a determinant for portal use [13].

## Questionnaires

We designed 2 separate questionnaires: 1 for patients with a login and 1 for patients without a login. They were based on characteristics found previously on the use of eHealth in literature [18,19].

The questionnaire for patients with a login contained multiple choice questions about (1) reasons for requesting a login (influence in disease and management of disease, to reread information at home, others thought it would be useful, discontent with current care, other); (2) the way people were informed about the portal's existence (by a health care provider, a poster, an information pamphlet, through friends or relatives,

other); (3) the frequency of portal use (from daily to monthly); (4) the duration of portal use (from less than 15 minutes to more than 1 hour); and (5) the person who added the information to the portal (the user/self, family, friends, or others).

The questionnaire for patients without a login contained questions about their awareness of the patient Web portal and, if applicable, how people were informed about its existence (see above) as well as the reasons for nonuse (all yes/no questions). There was room for free text as well.

Both questionnaires contained questions about the use of the Internet for other purposes than the Web portal, with regard to frequency and duration and the use of the Internet for searching information about diabetes (from never to monthly). The 9 questions about the perceived usefulness of specific portal components were answered on a 5-point Likert scale ranging from very important to unimportant.

The final question regarded possible improvements to the portal. All recommendations were scored on a 5-point Likert scale ranging from very important to unimportant. There was room for free text.

Questions about specific portal components and the question about recommendations regarding possible improvements were,



in case of nonusers, addressed as how nonusers expected the usefulness of that particular component to be.

In addition to these specifically designed questionnaires, the set of questionnaires contained additional validated questionnaires, including the Problem Areas in Diabetes (PAID) questionnaire to measure diabetes-specific distress [20,21], the Diabetes Treatment Satisfaction Questionnaire (DTSQ) to measure satisfaction with diabetes treatment [22], the Diabetes Management Self-Efficacy Scale (DMSES) to measure self-efficacy [23], and the Brief Diabetes Knowledge Test (BDKT) to measure diabetes knowledge [24,25].

### Statistical Analysis

Reason for regular use or nonuse, the answers about content and usefulness of the portal, and about the recommendations were expressed as percentages. The answer categories useful and very useful were combined. The question about reason for nonuse was misread by some patients. We asked for the main reason (1 reason) why a patient did not request a login and provided multiple answers. A total of 59 patients gave more than 1 reason. We used all these answers in the analysis.

We compared patients who requested a login and used it 2 or more times (regular users) and patients who did not request a login at all (nonusers). We decided to perform the analysis only on the regular users instead of all patients with a login because we wanted to compare the patients without a login to a group of patients with actual experience with the patient portal. Based on previous research, we considered the group of nonusers too different from patients who had requested a login but never logged in or logged in only once, the so-called “early quitters.” Indeed, early quitters differed from nonusers: they were younger (mean 61.9, SD 12.7 years vs mean 64.7, SD 10.0 years;  $P=.001$ ), more often male (63.9%, 140/219 vs 56.5%, 428/758;  $P=.049$ ), and had a higher educational level (39.4%, 84/213 vs 28.2%, 519/723;  $P=.002$ ).

Age and gender of nonparticipants (patients who responded but declared that they did not want to participate) and nonresponders (patients who did not respond to the invitation to fill out the questionnaire) of the study are described elsewhere [13].

We used chi-square tests for all categorical variables and unpaired  $t$  tests for all normally distributed continuous variables and Mann-Whitney tests for nonnormally distributed continuous variables. Categorical variables were expressed as numbers with percentages and continuous variables as means with standard deviation (SD) or with median and interquartile range (IQR) when not normally distributed. Multivariable logistic regression analysis, using the enter method, was used to determine the adjusted association between patient characteristics and not requesting a login. We used a  $P$  value of  $<0.2$  in the univariable analysis to select variables for further multivariable analysis. These determinants were expressed as odds ratios (ORs) with corresponding 95% confidence intervals (95% CI). Data was analyzed using SPSS for Windows version 20 (SPSS Inc, Chicago, IL, USA).

## Results

### Overview

From the 4500 questionnaires, 101 were not answered because 33 patients died and 68 had incorrect contact information. From the remaining patients, 2931 (66.63%) responded; 1541 of these 2931 patients (52.59%) declared that they did not wish to participate. In total, 1390 (31.60%) patients were eligible for analysis (“participants”) because they returned a completed questionnaire and signed a consent form. Their mean age was 63.9 (SD 12.2) years (nonparticipants: mean 64.5, SD 13.8 years;  $P=.11$ ) and 826 of 1390 (59.42%) were male (nonparticipant group: 1539/3009, 51.15% male patients;  $P<.001$ ). Of the 1390 participants, 632 (45.47%) had a login and 758 (54.53%) did not (“nonusers”).

### Differences Between Nonusers and Regular Users

The login frequency of the patients with a login was a mean 10.4 (SD 23.0) times and 413 of 632 (65.3%) patients accessed the patient Web portal 2 or more times (“regular users”). The latter category differed in many characteristics from nonusers (Table 1). Of the 94 patients with type 1 diabetes, only 13 (14%) were nonusers, whereas 745 of 1077 (69.17%) patients with type 2 diabetes were nonusers ( $P<.001$ ). There was also a difference in treatment setting: 666 of 846 (78.8%) patients treated by a general practitioner were nonusers, whereas only 92 of 325 (28.3%) patients treated by an internist were nonusers ( $P<.001$ ).

The use of the Internet differed between both groups: 321 (77.9%) of the 413 regular users used the Internet daily versus 346 (67.6%) of the 512 nonusers with Internet access ( $P<.001$ ). When using the Internet, 184 (44.6%) of the 413 regular Web portal users were online for more than an hour per day compared with only 140 (27.3%) of the 512 nonusers ( $P<.001$ ). Furthermore, 206 (51.1%) of the regular users declared that they used the Internet for searching for information about their disease compared with only 126 (25.4%) of the nonusers ( $P<.001$ ).

Of the 413 regular users, 328 (79.4%) patients declared that they were the main user of the Web portal themselves and 79 (19.1%) declared that someone else had access to the Web portal and usually accessed the portal. Of the 758 nonusers, 162 (21.4%) patients stated that they would consider using the Web portal if someone would help them, 262 (34.6%) did not know if they would use the portal if someone would help, and 293 (38.7%) would not consider using the portal even if someone would help.

Multivariable analysis showed that increasing age and smoking were associated with not using the Web portal. On the contrary, a higher educational level, treatment by an internist, using insulin, polypharmacy, better diabetes knowledge, and more hyperglycemic episodes were less likely to be associated with not using the Web portal (Table 2).



**Table 1.** Characteristics of the study participants (N=1171).

Patient characteristics	Regular users (n=413)	Nonusers (n=758)	<i>P</i>
Age (years), median (IQR)	60.2 (51.3-67.5)	68.1 (60.7-75.3)	<.001
Gender (male), n (%)	259 (62.7)	428 (56.5)	.04
Caucasian (yes), n (%)	383 (93.6)	652 (89.3)	.02
Educational level (high), n (%)	188 (46.2)	204 (28.2)	<.001
<b>Work status, n (%)</b>			<.001
Paid job	193 (47.1)	157 (21.1)	
Retired	153 (37.3)	479 (64.5)	
Other	64 (15.6)	107 (14.4)	
Living arrangement (alone), n (%)	65 (15.9)	193 (25.9)	<.001
Fluency in speaking Dutch (yes), n (%)	407 (99.3)	695 (93.0)	<.001
Access to computer (yes), n (%)	413 (100)	525 (70.5)	<.001
Access to Internet (yes), n (%)	413 (100)	516 (84.7)	<.001
<b>Treatment setting, n (%)</b>			<.001
General practitioner	180 (43.6)	666 (87.9)	
Internist	233 (56.4)	92 (12.1)	
<b>Type of diabetes, n (%)</b>			<.001
Type 1	81 (19.6)	13 (1.7)	
Type 2	332 (80.4)	745 (98.3)	
Duration of diabetes (years), median (IQR)	11.3 (5.5-17.4)	7.4 (3.7-11.4)	<.001
<b>Blood glucose lowering medication, n (%)</b>			<.001
None	21 (5.1)	91 (12.1)	
Oral	131 (31.7)	507 (67.2)	
Oral and insulin	126 (30.5)	93 (12.3)	
Insulin	135 (32.7)	64 (8.5)	
Polypharmacy (yes)	204 (52.7)	277 (43.6)	.02
HbA <sub>1c</sub> (mmol/mol), median (IQR)	54.0 (48.0-62.0)	49.0 (44.0-56.0)	<.001
Total cholesterol (mmol/L), mean (SD)	4.4 (1.0)	4.5 (1.0)	.35
Smoking (yes), n (%)	47 (11.5)	116 (16.4)	.03
Drinking alcohol (yes), n (%)	208 (52.8)	294 (42.7)	.004
<b>Validated questionnaires, <sup>a</sup> mean (SD)</b>			
PAID	31.0 (11.8)	27.2 (11.2)	<.001
DMSES	80.7 (15.5)	72.9 (18.0)	<.001
BDKT standard	78.7 (14.7)	62.4 (20.0)	<.001
BDKT insulin	61.4 (20.6)	42.2 (21.5)	<.001
DTSQ status	30.2 (5.0)	30.8 (5.5)	.10
DTSQ hyperglycemic episodes	2.7 (1.9)	1.6 (1.7)	<.001
DTSQ hypoglycemic episodes	2.0 (1.7)	1.1 (1.5)	<.001

<sup>a</sup> PAID: Problem Areas in Diabetes Questionnaire; DTSQ: Diabetes Treatment Satisfaction Questionnaire (with treatment satisfaction status, perceived hypoglycemic and hyperglycemic episodes) ; DMSES: Diabetes Management Self-Efficacy Scale; BDKT: Brief Diabetes Knowledge Test (one with standard items and one with only insulin-related questions).

**Table 2.** Independent determinants of nonusers compared to users.

Independent determinant	OR (95% CI)	P value
Age	1.04 (1.00-1.08)	.03
Educational level (high)	0.59 (0.36-0.95)	.03
Treatment setting (internist)	0.27 (0.14-0.54)	<.001
<b>Blood glucose lowering drugs</b>		
None	0.59 (0.21-1.63)	.31
Oral	Reference	
Oral and insulin	0.33 (0.15-0.70)	.004
Insulin	0.31 (0.12-0.78)	.01
Polypharmacy (yes)	0.58 (0.36-0.95)	.03
Smoking (yes)	2.53 (1.30-4.91)	.006
Diabetes knowledge (standard)	0.98 (0.96-0.99)	.008
DTSQ (hyper)	0.79 (0.68-0.92)	.002

### Reasons for Requesting or Not Requesting a Login

The main reason for not requesting a login was that 549 of 758 (72.4%) patients were not aware of the portal's existence. Another 216 of 758 (28.5%) stated that the main reason for not requesting a login was that they preferred to leave the disease management to the physician (Table 3).

The reasons for requesting a login among the regular users were to reread information of the consultation at home (312/413, 75.5%), the feeling that the portal use would give them influence on their disease and treatment (132/413, 32.0%), the fact that the physician or someone else thought the Web portal could be useful for them (74/413, 17.9%), dissatisfaction with the current care (2/413, 0.5%), and other reasons (27/413, 6.5%).

**Table 3.** Reasons for not requesting a login to the patient Web portal.

Reasons for not requesting a login	Nonusers, n (%) (n=758)
Was not aware that the portal existed	549 (72.4)
Prefers to leave disease management to physician	216 (28.5)
Feels inadequate with computer or Internet	88 (11.6)
No access to computer or Internet	62 (8.2)
Web portal is difficult to use	58 (7.7)
Privacy reasons	46 (6.1)
Concern for less personal attention by physician	48 (6.3)
Physician/other advised against portal use	20 (2.6)
Language barriers	18 (2.4)

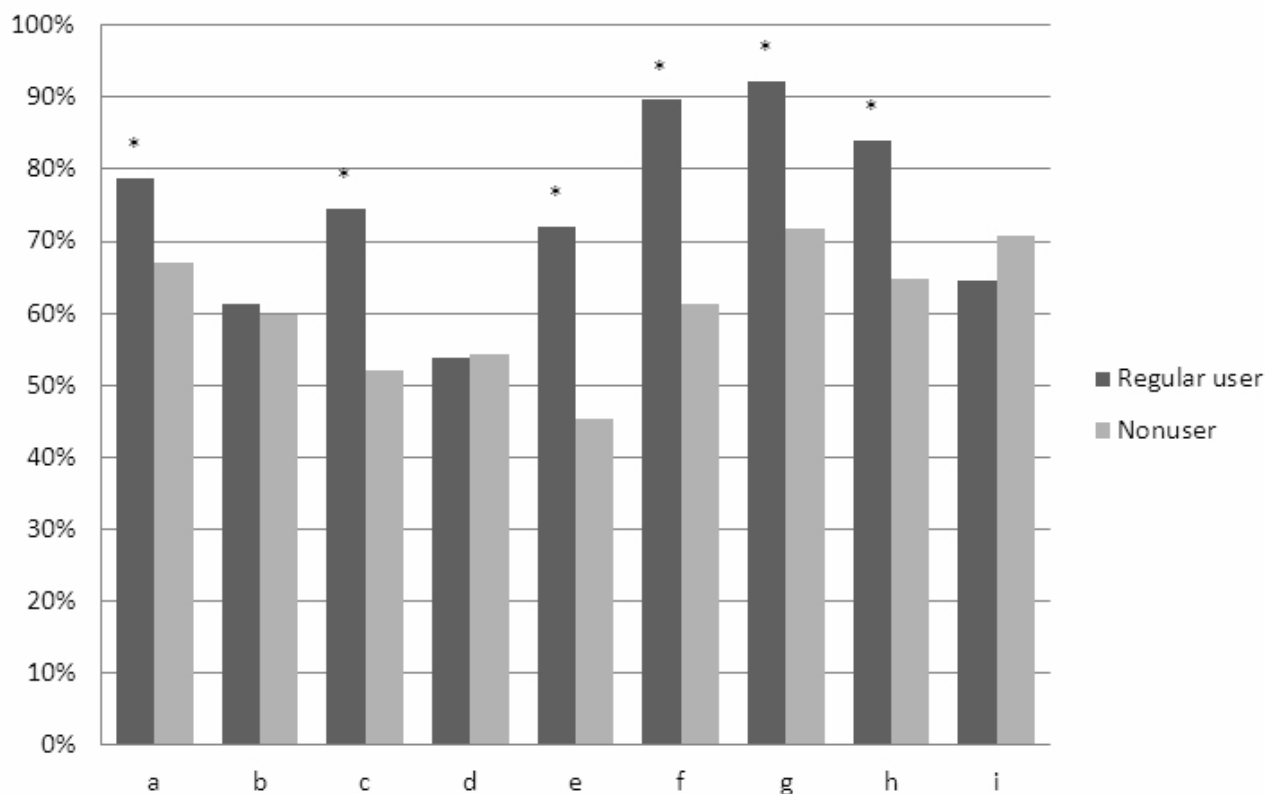
### How Patients Became Aware of the Web Portal

Of the 209 patients without a login who stated they were aware of the existence of the portal, 102 (48.8%) knew about the portal because their health care provider told them. In comparison, 392 (94.9%) of the 413 regular users were informed about the portal by their health care provider ( $P<.001$ ). Other sources of information about using the Web portal were posters in the clinic waiting area (nonusers: 10/209, 4.8%; regular users: 7/413, 0.7%;  $P<.001$ ), a pamphlet (nonusers: 4/209, 1.9%; regular users: 15/413, 3.6%;  $P=.24$ ), friends or relatives who used the portal themselves (nonusers: 20/209, 9.6%; regular users: 4/413, 1.0%;  $P<.001$ ), and other reasons (nonusers: 29/209, 13.9%; users: 9/413, 2.2%;  $P<.001$ ).

### Perceived Usefulness

Regular users perceived the usefulness of specific portal content in a different way compared to nonusers (Figure 2). Users perceived access to the laboratory values with treatment targets, the possibility of rereading clinic consultations, and having a summary of all controls as the most useful features of the portal. We asked the nonusers if they could speculate on the possible usefulness of portal features for their own disease management. They suggested a summary of upcoming consultations and a summary of their medication to be the most useful parts of a Web portal.

**Figure 2.** Differences between regular users (n=413) and nonusers (n=758) regarding the perceived usefulness (very useful or useful) of the content items of the patient Web portal. (a) overview of upcoming consultations, (b) summary of all health care physicians involved in treatment, (c) e-messaging, (d) general information about diabetes, (e) using the portal to upload the glucose levels measured at home, (f) rereading medical record after consultation, (g) access to laboratory values and treatment goals, (h) a summary of all consultations (history and future), (i) overview of medication. \* P<.001.

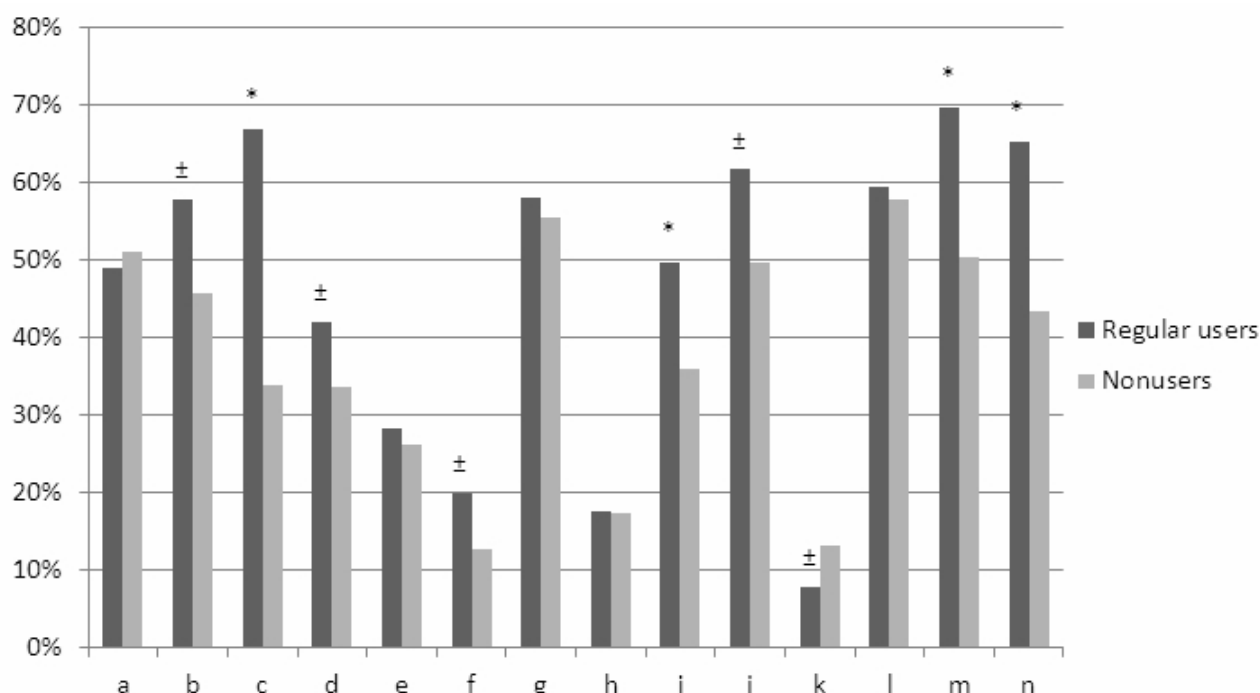


### Recommendations About Functionalities Added to the Web Portal

Regular users and nonusers appreciated additional functionalities that could improve the Web portal differentially (Figure 3). Regular users wanted to be able to add their injected insulin units to the glucose diary and to use the portal for supportive

care, such as scheduling an appointment and receiving reminders about upcoming consultations. Nonusers felt that a diabetes Web portal could benefit mostly from more information about medication and side effects and they wanted to use the portal for medication refills. Overall, regular users scored more possible features as useful or very useful than nonusers did except for information provided in different languages.

**Figure 3.** Differences between regular users (n=413) and nonusers (n=758) regarding usefulness of functionalities (very useful or useful) that could be added to the Web portal. (a) Automatic signal to physician when uploading glucose diary, (b) automatic upload from glucose meter to portal, (c) adding insulin units to glucose diary, (d) links to websites with information about diabetes, (e) links to websites with lifestyle interventions, (f) portal on mobile device, (g) request for medication refills, (h) forum functionality, (i) printing functionality, (j) news sites about diabetes, (k) information in different languages, (l) information about medication and side effects, (m) reminder function about upcoming consultation, (n) using the portal for scheduling a consultation with physician. \*  $P<.001$ ;  $\pm P<.05$ .



## Discussion

The main reason for patients with diabetes not requesting a login for a patient Web portal was that they were not even aware of its existence. This was previously found in a smaller group (3 of 13 respondents) of patients with diabetes mellitus type 2 [26]. Earlier studies have provided information on difficulties in usability [11,15,16] and reasons for not using the portal after receiving a login [27], but not on reasons for use or nonuse before requesting a login. In our study, it seems obvious that many health care providers, especially in the primary care setting, often did not communicate the possibility of using the shared electronic health record with their patients clearly enough. We can only speculate about the reasons. In the Netherlands, more than 99% of the primary care physicians and nurses work with an electronic medical system. However, it might be that they have not included a communication protocol about the Web portal for their patients with diabetes; they may not want to share data in a Web portal; they may have assumptions about capabilities, skills, and wishes of their patients that do not enhance the Web portal's promotion [28]; or that they may not be satisfied with the Web portal itself [29]. Whatever the reasons, before trying to get a Web portal used by a substantial number of patients with diabetes, such a Web portal should be discussed in detail about requirements with all diabetes care providers. The same held true in telemonitoring of patients with heart failure; without transparent and predefined criteria of user requirements, health professionals' expectations did not meet actual experiences, leading to disappointment [30]. Another possibility for the patients' ignorance of the Web portal

is that health care providers did communicate about the portal with their patients, but the latter did not recollect the physician telling them about it, perhaps because they did not understand the topic.

In a previous study, one of the main obstacles of enrollment in a general Web portal was that a quarter of the patients did not remember discussing the portal with their providers [31]. In that study, even despite remembering a discussion about the portal, another 63% of patients did not attempt to enroll mainly due to lack of motivation and negative attitudes toward the patient portal [31]. In the 6 years Diamuraal has been in use, 76.5% of the patients who could request a login never did. This percentage is more or less similar with other patient portals. In the literature, the actual percentage of users is approximately 32% to 37% for patients with chronic diseases such as diabetes [31,32]. In a general population, there is even less inclination to activate an account [11]. Better strategies have to be found to inform patients about a Web portal, how to request a login, and what benefits a patient portal may offer. One study in the general population found a threefold increase in Web portal enrollment with the use of aggressive marketing strategies, defined as using more than 5 different means of recruitment, including posters in the waiting area and onsite enrollment with a computer kiosk [33], illustrating the importance of the health care provider.

Some patients who did not request a login did so because they preferred to leave the disease management to the health care provider. On the other hand, regular users wanted to reread the information given by the diabetes care provider at home and they felt the portal gave them influence in the management of



the disease. This illustrates the difference in opinions about who should be responsible for the management of the disease. In a previous study, we found that only 62% of patients with diabetes agreed to take full responsibility for their disease [34]. Therefore, we cannot expect that all patients will use and benefit from a diabetes patient Web portal.

Fear for privacy and security of the Web portal did not seem to pose a large barrier in our study in contrast to previous studies [35]. After patients have received access to their health care record, worries about the security may drop, for example, from 47% before to 4% after login when patients were reassured about the use of passwords and unique login numbers [15]. Health technology developers have to warrant the patient's privacy without making the login process a barrier on itself and diabetes care providers should address the fears by informing patients about security measures.

Nonusers were older, had lower education [26,36], and had less diabetes knowledge. Diabetes care providers need to pay extra attention to this group of patients to help them becoming familiar with a different approach to diabetes care. At least one-fifth of the nonusers stated that they would use the portal if someone else could help them and another third of participants would at least consider using it. Many regular users stated that someone else used the portal as well to read the information provided by the physician. This access to the Web portal by family members has been shown to be effective and desirable in cardiac surgery [37] and in pediatric patient portals [27]. For all patients, the joint use of the Web portal by the patients themselves and a family member or friend should be discussed.

Patients can encounter difficulties in navigating through a portal to find the information they seek and have problems with interpretation of data [16,29,38]. This study does not provide any information in this respect because we sent questionnaires to nonusers who never logged in to the portal and could not comment on its attractiveness and ergonomics. However, if we want more patients using a portal, this is a concern that needs to be addressed. We are currently studying the influence of design and ease of use of the portal on persistent use or early discontinuation.

Not only actual barriers can prevent patients from requesting a login; nonusers perceived the usefulness of a patient Web portal differently compared to users. Although more users found the features that helped them with their disease control (very) useful, such as laboratory results and treatment goals, fewer nonusers scored those features as useful. Before using a Web portal, patients have certain expectations about which features are useful for them with regard to disease management and these expectations and opinions may change after actively using it

[17]. The results of our study are another illustration of the fact that we need to inform patients better about what a patient portal can mean for them. To interpret our results correctly, we should keep in mind that we analyzed patients who had logged in 2 or more times. These regular users have other demographics than patients who cease to use the portal in an early stage and are not comparable to regular users or nonusers. Although there are differences between patients with type 1 and type 2 diabetes in requesting a login to the Web portal [13], we did not distinguish between type 1 and type 2 diabetes in the present study.

To our knowledge, this is the first study about the barriers of the use of a Web portal for patients with diabetes, before and during its use. The Web portal is used by patients with both type 1 and type 2 diabetes in primary care and also in secondary care. The Web portal under study has been used for 6 years, which underpins the relevance of the patients' opinions. Furthermore, we studied a large group of nonusers of a patient Web portal for diabetes mellitus, not previously done in the literature.

However, there are some limitations. The first is due to the design of the questionnaire. Several patients gave multiple reasons for not requesting a login instead of 1 main reason, whereas other patients only gave 1 answer as per the instructions of the questionnaire. We are aware that patients can have multiple reasons for not requesting a login, but because most participants were careful in following instructions, they did not mention other reasons even if there were any. This means that our results are likely to be an underrepresentation of reasons for not requesting a login.

Secondly, there was a response rate of 66%; 31.6% of all people who were sent a questionnaire were eligible for analysis. This is comparable with other studies in this area [39,40]. Our participants did not differ in age from nonparticipants, but they were more frequently male. Gender was not a determinant for being a nonuser; therefore, the selective participation will not have influenced our outcomes.

Our study showed that unawareness of the patient portal is the main barrier of enrollment. All patients who were aware of the existence of the Web portal were made aware by their health care provider. Users and nonusers perceive the usefulness of the portal differently and do not have the same recommendations for additional functionalities. Currently, the Web portal is not communicated at all or not communicated clearly enough by health care providers. To increase participation, the unawareness of its existence and usefulness needs to be addressed by informing the physicians of the possible benefits and subsequently encourage them to discuss the Web portal with their patients.

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## Conflicts of Interest

None declared.

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## Abbreviations

**BDKT:** Brief Diabetes Knowledge Test  
**DMSES:** Diabetes Management Self-Efficacy Scale  
**DTSQ:** Diabetes Treatment Satisfaction Questionnaire  
**PAID:** Problem Areas in Diabetes

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Original Paper

# Emotional Approach Coping and the Effects of Online Peer-Led Support Group Participation Among Patients With Breast Cancer: A Longitudinal Study

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## Abstract

**Background:** Previous research on the effects of online peer support on psychological well-being of patients with cancer showed mixed findings. There is a need for longitudinal studies explaining if and when online peer-led support groups are beneficial. How patients cope with emotions that come along with the cancer diagnosis might influence effectiveness of online participation. Emotional approach coping is a construct encompassing the intentional use of emotional processing and emotional expression in efforts to manage adverse circumstances.

**Objective:** In this longitudinal study, we hypothesize that mixed findings in previous research are partly caused by individual differences in coping with emotions, which may moderate the effects of online support group participation on patients' well-being.

**Methods:** A total of 133 Dutch patients with breast cancer filled out a baseline (T0) and a follow-up (T1, 6 months later) questionnaire assessing intensity of online participation within the online support community, emotional approach coping (ie, actively processing and expressing emotions), and psychological well-being (depression, emotional well-being, and breast cancer-related concerns). There were 109 patients who visited an online support community at both points in time. Repeated measures ANOVAs assessed change in well-being over time.

**Results:** Results showed 3-way interactions of time, online intensity of participation, and emotional approach coping on emotional well-being ( $F_{1,89}=4.232$ ,  $P=.04$ ,  $\eta^2_p=.045$ ) and depression ( $F_{1,88}=8.167$ ,  $P=.005$ ,  $\eta^2_p=.085$ ). Online support group participation increased emotional well-being over time for patients who scored low on emotional approach coping at T0, provided that they were highly active online. Patients who were highly active online with a high score on emotional approach coping reported no change in sense of well-being, but showed the highest score on well-being overall. Participating less frequently online was only beneficial for patients who scored high on emotional approach coping, showing an increase in well-being over time. Patients participating less frequently and with a low score on emotional approach coping reported no significant change in well-being over time.

**Conclusions:** This study extends previous findings on the effects of online peer support in two ways: by testing changes in well-being as a function of intensity of online support group participation and by examining the role of individual differences in emotional coping styles. Findings showed no negative effects of intense support group participation. Participating frequently online was especially helpful for patients who approach their emotions less actively; their emotional well-being increased over time. In contrast, frequent online users who actively approach their emotions experienced no change in well-being, reporting highest levels of well-being overall. For patients who participate less intensively within the support community, coping style seems to outweigh effects of online participation; over time, patients who actively approached emotions experienced an increase



in psychological well-being, whereas patients with a low score on emotional approach coping reported no change in depression and emotional well-being.

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## KEYWORDS

Internet; breast neoplasms; self-help groups; social support; online systems; emotions

## Introduction

An increasing amount of individuals are diagnosed with breast cancer, and this number is expected to grow over the coming years due to early diagnosis, average increase in human life expectancy, and more survivors due to improved treatment [1]. A growing number of patients turn to the Internet to search for illness-related information and seek support among peers. Patients with breast cancer are among the most active online seekers compared to other patient groups [2]. Therefore, the question if such online communities are beneficial for patients becomes increasingly important.

The lack of longitudinal studies testing causal effects of online peer-led support group participation is most likely due to its uncontrolled setting. Testing effects is difficult because patients participate anonymously and autonomously—they determine when and how much they want to participate. Participants become members at different time points, frequency and length of visits vary among patients, and some patients are active posters whereas others only read messages from others (ie, lurkers) [3]. Perhaps as a result, studies covering peer-led support communities are often descriptive in nature (ie, interview studies, content analyses, cross-sectional surveys). These studies point to the presence of empowering and therapeutic processes, such as emotional and informational support, recognition, and understanding, but also disempowering processes such as being confronted with negative sides of the disease and complainers [4-8]. However, effects are rarely tested although these peer-led platforms are easily accessible and common online.

Current outcome studies on online peer support mostly concern online interventions set up by health professionals, showing positive effects, such as decreased depression, posttraumatic stress, and perceived stress [9-12]. However, it has been discussed that these online interventions often include several other therapeutic aspects besides peer support (eg, decision-making tools, skill training, or professional moderation). It is unclear if improvements among patients are specifically caused by the sheer support from peers or by other aspects of the intervention [13]. Only a few studies empirically tested the effects of online peer-led support communities. For example, Lieberman and Goldstein [14] showed a positive change in emotional well-being, depression, and posttraumatic growth. However, other studies reported no significant major effects [15,16] or negative effects [17]. If we assume that null findings may not always get published due to publication bias [13], the meager evidence for a direct relationship between online peer support and well-being may even be an overrepresentation. This requires more studies testing when and why online peer support is beneficial. Therefore, the first goal

of the present research was to provide a robust test of changes in patients' psychological well-being over time due to patients' intensity of online peer-led support group participation.

We put forward that patients' intensity of online participation is important to assess when we aim to test the effectiveness of online peer support group participation because differences in patients' online behavior might affect health outcomes. For example, a cross-sectional study showed that posters felt that they received more benefits (ie, emotional support, helping others, and emotional expression) from online communities than lurkers, and only for posters were higher levels of emotional support/helper therapy and advice related to lower levels of anxiety [3]. In this longitudinal study, we aim to reveal if patients who are more active within a peer-led support community (in terms of frequency and length of visits and amount of posts) benefit more in terms of health outcomes than patients who are less active online.

Apart from intensity of online participation, patients also differ on aspects outside the online environment, which may affect online behavior and effectiveness of online support group participation as well. For example, recent studies suggest that individual differences in health self-efficacy [18], emotional communication competence [19], and differences in coping with emotions [20] might be moderating factors. In this study, we focus on patients' level of emotional approach coping (ie, actively processing and expressing emotions). Evidence from related fields such as clinical psychology shows substantial differences between patients in coping with cancer-related emotions, which significantly affect ones' well-being. Because online support platforms are merely used to share illness-related experiences (ie, patients write about their experiences and related thoughts and emotions), variations in patients' emotional coping styles might be one of the reasons why a direct relation between online participation and well-being is not always found. Studies showed that actively coping with emotions (ie, recognizing and feeling the meaning of losses) [21] is often related to better well-being. For example, actively approaching emotions is related to decreased depressive symptoms, distress, increased vigor, improved perceived health status, and fewer medical appointments [22-25]. Hence, how patients cope with emotions that come along with the cancer diagnosis might influence effectiveness of online participation as well.

Our presumption that the relationship between intensity of online participation and well-being might be moderated by patients' emotional coping style is substantiated by 2 studies on writing style within online peer-led support communities and a cross-sectional study on emotional approach coping. The first 2 studies showed that the use of words related to expression of emotions and to learning and understanding was related to changes in well-being [26,27]. However, whether word use

caused changes in well-being or was a reflection of well-being remains unclear. Nevertheless, these findings show that patients differ in how they deal with illness and emotions in online environments. Another recent cross-sectional study showed that emotional approach coping was especially relevant for patients who participated frequently within an online peer-led support group (ie, for patients who visit the online community and post messages relatively often). Patients who actively dealt with their emotions and frequently participated online reported higher psychological well-being than patients who were frequent users but approached their emotions less actively. No difference in well-being was found for patients who participated less often within the online support group [20].

Although these findings underscore the importance of individual differences in emotional approach coping when assessing effects of online support group participation, they provide no conclusive evidence regarding causal patterns. Therefore, we aimed to extend these cross-sectional findings by tracking patients over an extended period of time to further assess individual emotional coping differences. In-line with previous cross-sectional findings, we expected that patients who actively deal with emotions may benefit especially from online support groups. Because online support communities often confront patients with emotionally distressing content from peers [28], patients who participate intensely but cope with emotions less actively, might experience additional stress ending up in a downward spiral. However, one might also argue that over time online support and the recognition patients find in stories from others might be especially helpful for patients with more repressive coping styles because they need it most.

In this research project, we conducted a 2-wave longitudinal study among Dutch patients with breast cancer participating in online peer-led support communities, in which we assessed individual differences in emotional coping style. Specifically, we assessed patients' intensity of online support group participation, emotional approach coping [25], and 3 measures of well-being that are generally associated with breast cancer diagnosis at 2 points in time: emotional well-being [29], depression [30], and breast cancer-related concerns [31]. We included potential covariates (ie, factors often associated with the psychological well-being of patients with breast cancer), such as social support from family and friends [32,33], disease status, and received professional psychological help. Based on previous findings regarding emotional approach coping, we propose an interaction effect of emotional coping style and the intensity of patients' online participation. With our longitudinal approach, we aim to reveal the long-term effects of this interaction on patients' psychological well-being.

## Methods

### Participants and Procedure

We searched the Internet with Google to identify all online support communities for patients with breast cancer in the Netherlands. Criteria for inclusion were (1) the website was in the Dutch language, (2) the website was purely designed as 24-hour available message boards or part of the website was designed as a 24-hour available message board, and (3) the

discussion board was still active (new messages were posted within the past month). With approval of the website owners, we posted a request to participate in an online survey about Internet use of patients with breast cancer on 7 support websites. Participants filled out a baseline (T0) survey in June 2011, including demographics, disease status, the intensity of online support group participation, and psychological well-being (the specific measurements used in this study are described subsequently). After 6 months, we sent this group of patients a follow-up (T1) questionnaire (December 2011) to reassess their psychological well-being and intensity of online support group participation.

This survey was part of a more extensive research project on online peer support among Dutch patients with breast cancer. The research was carried out in accordance with the American Psychological Association's ethics guidelines [34] and complied with European Union legislation [35] and Dutch legislation [36] on data protection. All procedures were approved by the Department of Communication Science at VU University Amsterdam.

The introduction page of the survey included the length and purpose of the survey, contact information of the investigator, and ensured anonymity. A sample of 134 Dutch breast cancer survivors filled out both questionnaires. Because this sample included 133 females and only 1 male, we decided to exclude this male from the data analyses to keep a homogeneous group. Response rates are unknown because we had no access to page views of the participating websites. The online survey tool tracked Internet protocol (IP) addresses to prevent users from retaking the survey. Responses to questions were obligatory, but participants were provided with an "I don't know" or "not applicable" option.

### Measurements

#### *Demographics, Illness Characteristics, and Control Variables*

The T0 baseline questionnaire included questions on patients' age, gender, education level, and working status (ie, if patients were currently working). We measured current disease status (ie, if cancer cells were currently detected in the patient's body or not), the number of medical appointments in the past 3 months regarding breast cancer, and if patients were under treatment at the moment. Because social support from resources other than online peers may affect psychological well-being, we asked if patients received any psychological help from a professional and assessed the social support they received from their friends and family based on the 6 social well-being items from the Functional Assessment of Cancer Therapy-Breast (FACT-B) [29]. Items referring to support from friends were adjusted into items that clearly referred to offline friends. Respondents rated on a 5-point scale if the statements applied to them, ranging from "not at all" to "totally" (Cronbach alpha=.753).

#### *Intensity of Online Support Group Participation*

At both T0 and T1, patients' intensity of online support group participation was assessed by 4 different questions regarding frequency of visits, average length of visits, contribution (ie,

reading, responding, starting new topics or questions), and frequency of posts in the last 4 weeks [20,37]. Frequency of visits was assessed on a 7-point scale; the other items were assessed on a 4-point scale. To merge these different scales into 1 index, all items were transformed into *z* scores. The scale was internally consistent at T0 (Cronbach alpha=.799) and T1 (Cronbach alpha=.796). See [Multimedia Appendix 1](#) for the specific items.

### ***Emotional Approach Coping***

At T0 the emotional approach coping scale [25] was used to measure participants' coping style concerning emotions, including 4 items referring to emotional processing (eg, "I realize that my feelings are justified and important") and 4 items regarding emotional expression (eg, "I take the time to express my emotions"). Participants rated on a 4-point scale if the statements applied to them. The mean scores (emotional processing: mean 2.85, SD 0.63; emotional expression: mean 2.85, SD 0.57) were comparable to those of a sample of patients with breast cancer from a previous study (emotional processing: mean 3.00, SD 0.72; emotional expression: mean 2.95, SD 0.84 [23]) and a group of healthy women (emotional processing: mean 2.85, SD 0.63; emotional expression: mean 2.79, SD 0.73 [25]).

Because factor analyses showed that all factors loaded between 0.58 and 0.86 on 1 component and explained 44% of the variance, we created 1 index for emotional approach coping with all 8 items. Ratings were summed and averaged across items (Cronbach alpha=.864).

### ***Psychological Well-being***

At both T0 and T1, we assessed psychological well-being with 3 different concepts: depression, breast cancer-related concerns, and emotional well-being. Depression was measured with the CES-D10 [30]. The scale consisted of 10 items (eg, "I felt that everything I did took me quite some effort"). Participants rated on a 4-point scale if the statements applied to them the past week from "less than 1 day" to "5 to 7 days." The scale was internally consistent in both questionnaires (T0: Cronbach alpha=.740; T1: Cronbach alpha=.815), but was positively skewed at T1. A log transformation was performed for depression T0 and T1 to meet the assumptions of multiple regression analysis [38]. Breast cancer-related concerns (Profile of Concerns about Breast cancer [31]) were measured with an index of 28 items assessed on a 5-point scale (eg, "As you think about your illness, how much are you concerned that

chemotherapy or radiation therapy will damage your body in some way?"). The index showed consistency (T0: Cronbach alpha=.909; T1: Cronbach alpha=.918). Emotional well-being was measured according to 6 items from the FACT-B on a 5-point scale (eg, "I'm proud of how I am coping with my illness" [29] and showed scale consistency at T0 (Cronbach alpha=.821) and T1 (Cronbach alpha=.876).

### **Analyses**

We conducted repeated measures ANOVAs on the 3 measures of psychological well-being with intensity of online participation at T0 (-1 SD vs +1 SD) and emotional approach coping (-1 SD vs +1 SD) at T0 as between-subjects factors and time (T0 vs T1) as a within-subjects factor (see [39] for this specific regression analysis). This estimation procedure allows tests of differences between participants with low vs high levels of online support group participation and participants with low vs high levels of emotional approach coping without conducting a median split, thus retaining all observations in the analysis [40]. We added the intensity of online participation at T1 as covariate in our model to control for changes in online participation over time. In addition, we also included disease status at T1 as control variable into the model. Finally, all other variables that correlated significantly with the independent and dependent variables (ie, intensity of online participation T0, emotional approach coping T0 or psychological well-being T0 and T1) were entered into the model as covariates (see Results).

## **Results**

### **Sample Characteristics**

[Table 1](#) presents the patients' characteristics. Our sample of 133 patients with breast cancer included women with a mean age of 48.44 years (SD 8.60). Most patients had an average to high level of education (86/132, 65.2%), and more than half (79/133, 59.4%) were (still) actively performing their job. Of the sample, 67.5% reported that no cancer cells were detected at the moment. Slightly more than half of the participants (68/133, 51.1%) were under treatment, the other half (65/133, 48.9%) were not under treatment or only monitored by a physician at the moment. The average number of breast cancer-related medical appointments in the previous 3 months before participating in this study was 3.6 appointments. Less than half of the participants received psychological guidance during the period of illness (57/132, 43.2%).

**Table 1.** Demographics and health characteristics of participants.

Characteristic	Participants
<b>Age (n=133)</b>	
Mean (SD)	48.44 (8.60)
Range	23-67
<b>Highest education level <sup>a</sup> (n=132), n (%)</b>	
Primary school	4 (3.0)
<b>Secondary school</b>	
Low (junior general secondary school)	20 (15.2)
Middle (senior general secondary school)	12 (9.1)
High (pre-university)	1 (0.8)
<b>Vocational school</b>	
Low <sup>b</sup> (LBO/LTS)	9 (6.8)
Middle (MBO)	36 (27.3)
High (HBO) (Bachelor's degree)	41 (31.1)
Scientific degree (Bachelor/Master's degree)	9 (6.8)
<b>Working status (n=133), n (%)</b>	
Not working	53 (40.2)
Working	79 (59.8)
<b>Disease status (n=123), n (%)</b>	
No cancer cells	83 (67.5)
Cancer cells	40 (32.5)
<b>Under treatment (n=133), n (%)</b>	
Yes	68 (51.1)
No	65 (48.9)
<b>Number of cancer-related medical appointments in the past 3 months</b>	
Mean (SD)	3.61 (6.34)
Range	0-40
<b>Psychological help during period of illness (n=132), n (%)</b>	
Yes	57 (43.2)
No	75 (56.8)

<sup>a</sup> Levels within the Dutch education system: education is divided over 3 schools for different age groups, which are divided in streams for different educational levels.

<sup>b</sup> LBO/LTS (ie, lowest level of vocational school) existed until 1992.

## Correlations

We first ran a correlation matrix (Tables 2 and 3) to assess associations between independent and dependent variables, and to detect potential covariates. No direct correlations between the intensity of online participation at T0, emotional approach coping at T0, breast cancer-related concerns (at both T0 and

T1), emotional well-being (at both T0 and T1), and depression (at both T0 and T1) were found. Because of significant correlations with the independent or dependent measures, we added age, education level, disease status, offline social support, and psychological help from a professional into our models as covariates.

**Table 2.** Means, standard deviations, and intercorrelations of independent variables, covariates, and dependent variables (part 1).

Variables	N	Mean (SD)	1	2	3	4	5	6	7
1 Intensity of online participation T0 <sup>a</sup>	125	0.00 (0.78)	–						
2 Intensity of online participation T1 <sup>a</sup>	113	–0.01 (0.79)	.70 <sup>c</sup>						
3 Emotional approach coping	132	2.86 (0.50)	.04	–.03					
4 Age	133	48.44 (8.60)	–.23 <sup>c</sup>	–.21 <sup>d</sup>	–.14				
5 Education	132	6.38 (1.95)	–.06	–.07	.06	–.21 <sup>d</sup>			
6 Working status <sup>b</sup>	132	0.60 (0.49)	–.06	–.02	–.05	–.21 <sup>d</sup>	.37 <sup>c</sup>		
7 Offline social support	133	3.80 (0.62)	.04	.01	.04	.04	.24 <sup>c</sup>	.14	
8 Psychological help <sup>b</sup>	132	0.43 (0.50)	–.01	–.01	.12	–.45 <sup>c</sup>	.08	.15	–.23 <sup>c</sup>
9 Disease status T1 <sup>b</sup>	123	0.33 (0.47)	.03	.11	.03	–.07	–.09	–.13	–.06
10 Under treatment <sup>b</sup>	133	0.51 (0.50)	.13	.17	.03	–.10	–.02	–.07	.09
11 Medical appointments	132	3.61 (6.34)	.15	.22 <sup>d</sup>	.12	.02	–.11	–.20 <sup>d</sup>	.09
12 Depression T0 (log)	132	0.25 (0.11)	–.04	–.04	.01	–.13	–.20 <sup>d</sup>	–.13	–.41 <sup>c</sup>
13 Depression T1 (log)	133	0.22 (0.13)	.05	.09	–.16	–.12	–.23 <sup>c</sup>	–.16	–.37 <sup>c</sup>
14 Emotional well-being T0	133	3.53 (0.80)	–.04	–.04	–.08	.12	.18 <sup>d</sup>	.20 <sup>d</sup>	.43 <sup>c</sup>
15 Emotional well-being T1	133	3.70 (0.90)	–.08	–.12	.11	.13	.18 <sup>d</sup>	.12	.37 <sup>c</sup>
16 Breast cancer–related concerns T0	133	2.61 (0.60)	.09	.13	.09	–.18 <sup>d</sup>	–.23 <sup>c</sup>	–.24 <sup>c</sup>	–.46 <sup>c</sup>
17 Breast cancer–related concerns T1	133	2.52 (0.63)	–.03	–.01	–.03	–.10	–.26 <sup>c</sup>	–.26 <sup>c</sup>	–.41 <sup>c</sup>

<sup>a</sup> Standardized into Z scores.<sup>b</sup> Coded 0=no, 1=yes.<sup>c</sup> Correlations significant at the .01 level.<sup>d</sup> Correlations significant at the .05 level.**Table 3.** Means, standard deviations, and intercorrelations of independent variables, covariates, and dependent variables (part 2).

Variables	8	9	10	11	12	13	14	15	16
9 Disease status T1 <sup>a</sup>	.00								
10 Under treatment <sup>a</sup>	–.12	.28 <sup>b</sup>							
11 Medical appointments	.05	.17	.10						
12 Depression T0 (log)	.34 <sup>b</sup>	–.08	–.12	.04					
13 Depression T1 (log)	.30 <sup>b</sup>	.14	–.01	.09	.54 <sup>b</sup>				
14 Emotional well-being T0	–.29 <sup>b</sup>	–.10	.13	–.11	–.57 <sup>b</sup>	–.48 <sup>b</sup>			
15 Emotional well-being T1	–.27 <sup>b</sup>	–.10	.07	–.05	–.39 <sup>b</sup>	–.62 <sup>b</sup>	.65 <sup>b</sup>		
16 Breast cancer–related concerns T0	.32 <sup>b</sup>	.01	–.09	.001	.51 <sup>b</sup>	.50 <sup>b</sup>	–.60 <sup>b</sup>	–.42 <sup>b</sup>	
17 Breast cancer–related concerns T1	.29 <sup>b</sup>	.02	–.01	–.003	.50 <sup>b</sup>	.57 <sup>b</sup>	–.52 <sup>b</sup>	–.55 <sup>b</sup>	.65 <sup>b</sup>

<sup>a</sup> Coded 0=no, 1=yes.<sup>b</sup> Correlations significant at the .01 level.

## Effects Testing

From the 133 patients, 125 patients reported they were visiting an online breast cancer support community at T0; 8 patients were not. The study participants only had access to the

questionnaire by visiting the online support community; therefore, they might have misunderstood our question. Furthermore, because these 8 patients claimed they did not visit an online support group, they also did not fill out our questions



on intensity of participation and were excluded from data analyses.

At T1, 113 patients claimed they were visiting an online support group. From T0 to T1, 16 participants stopped visiting the online support community and 4 participants started visiting an online community after the first survey. To measure the change in psychological well-being over time caused by the intensity of online support group participation, we only included the patients that were visiting an online support community at both time points ( $n=109$ ). To prevent our study from unnecessary data loss, 1 of the reviewers recommended adding an additional lowest category to the items measuring intensity of online participation T1 to include the forum users who stopped visiting the forum from T0 to T1. However, this new variable violated the normal distribution norms for regression analyses. Therefore, we could not include these support group dropouts for data

analyses. Nevertheless, when including this new variable in the analyses, the 3-way interactions were still significant (depression:  $F_{1,105}=6.360$ ,  $P=.01$ ; emotional well-being:  $F_{1,105}=4.232$ ,  $P=.04$ ).

Of the 109 participants who visited an online community at T0 and T1, 9 participants were not aware of their disease status, 1 participant did not report her level of education (see Table 1), and the level of depression at T0 was missing for 1 participant. Because we included these variables as covariates, SPSS excluded these participants from the ANOVA analyses.

Table 4 shows the within-subjects ANOVAs, indicating a 3-way interaction of time, intensity of online participation at T0, and emotional coping T0 on depression and emotional well-being. No 3-way interaction effect on breast cancer-related concerns was found.

**Table 4.** Repeated measures ANOVAs on well-being measures at T0 and T1.

Independent variables	Depression ( $n=98$ )			Emotional well-being ( $n=99$ )			Breast cancer concerns ( $n=99$ )		
	$F_{1,88}$	$P$	$\eta^2_p$	$F_{1,89}$	$P$	$\eta^2_p$	$F_{1,89}$	$P$	$\eta^2_p$
<b>Between-subjects effects, (mean T0 and T1)</b>									
Intensity of online participation T0	0.429	.51	.005	1.197	.28	.013	0.343	.56	.004
Emotional approach coping	4.620	.03	.050	1.285	.26	.014	0.017	.90	.000
Education	6.032	.02	.064	3.278	.07	.036	4.295	.04	.046
Offline support	7.358	.008	.077	10.684	.002	.107	17.834	<.001	.167
Psychological help	14.095	<.001	.138	8.174	.005	.084	7.033	.009	.073
Age	0.181	.67	.002	0.005	.95	.000	0.814	.37	.009
Intensity of online participation T1	0.564	.45	.006	3.428	.07	.037	1.295	.26	.014
Disease status	0.103	.75	.001	0.288	.59	.003	0.470	.50	.005
Intensity of online participation T0 $\times$ emotional approach coping	1.738	.19	.019	1.568	.21	.017	0.049	.83	.001
<b>Within-subjects effects</b>									
Time	0.773	.38	.009	1.041	.31	.012	2.355	.13	.026
Time $\times$ intensity of online participation T0	0.104	.75	.001	0.102	.75	.001	0.272	.60	.003
Time $\times$ emotional approach coping	1.185	.28	.013	1.166	.28	.013	0.612	.44	.007
Time $\times$ education	0.343	.56	.004	0.104	.75	.001	0.031	.86	.000
Time $\times$ offline support	0.107	.11	.745	0.664	.42	.007	2.552	.11	.028
Time $\times$ psychological help	0.282	.28	.597	0.068	.80	.001	0.334	.57	.004
Time $\times$ age	0.663	.42	.007	0.027	.87	.000	0.409	.52	.005
Time $\times$ intensity of online participation T1	1.231	.27	.014	0.711	.40	.008	2.352	.13	.026
Time $\times$ disease status	9.210	.003	.095	0.084	.77	.001	0.489	.49	.005
Time $\times$ intensity of online participation T0 $\times$ emotional approach coping	8.167	.005	.085	4.232	.04	.045	2.450	.12	.027

## Depression

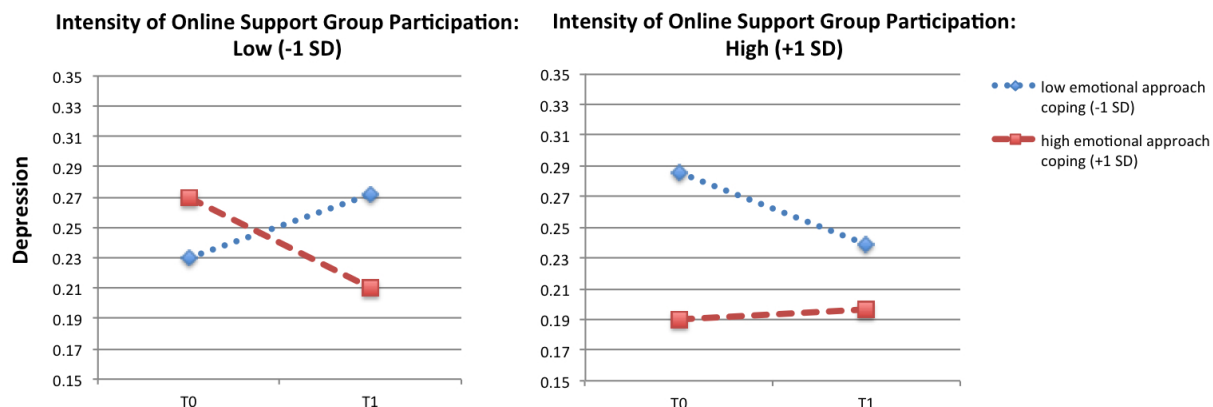
No main effect of time on depression was found; overall depression did not change significantly from T0 to T1 (see Table 4). Concerning covariates, only disease status caused a change in depression. However, education, offline social support, and professional psychological help were related to the average

score of depression at T0 and T1. No 2-way interactions of time and intensity on online participation, or time and emotional approach coping on depression were found. However, a 3-way interaction effect of time, the intensity of online participation, and emotional approach coping was found. Pairwise comparisons revealed that patients who scored low on online

participation and high on emotional approach coping showed a significant decrease in depression over time (mean difference 0.060, SE 0.027,  $P=.03$ ) (see Figure 1). In addition, online frequent users who scored high on emotional approach coping

did not show a change in depression over time ( $P=.80$ ), but showed lowest overall levels of depression at both points in time (Figure 1).

**Figure 1.** Depression over time (T0, T1) as a function of intensity of online participation at T0 (low vs high) and emotional approach coping (low vs high).

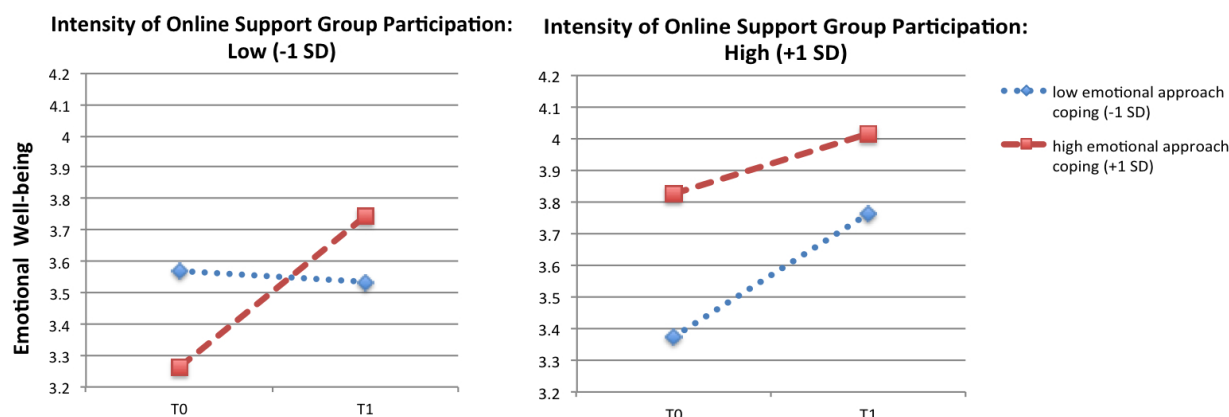


## Emotional Well-Being

Table 4 shows no main effect of time on emotional well-being; overall emotional well-being did not change significantly from T0 to T1. No covariates were related to changes in well-being, although offline social support and receiving professional psychological help were related to the average score of emotional well-being. No 2-way interaction of time and intensity of online participation, or time and emotional approach coping were found. However, a significant 3-way interaction of time, online intensity of participation, and emotional approach coping on emotional well-being was found. Pairwise comparisons showed that emotional well-being increased over time for

patients who scored low on intensity of participation but high on emotional approach coping (mean difference 0.479, SE 0.169,  $P=.006$ ; see Figure 2). No significant change in well-being was observed among patients who scored low on online participation and low on emotional approach coping ( $P=.86$ ). In addition, for patients who scored high on online participation and low on emotional approach coping, emotional well-being increased over time (mean difference 0.391, SE 0.181,  $P=.03$ ; see Figure 2). For frequent online users who scored high on emotional approach coping, no significant change in well-being was found, but showed highest levels of well-being at both points in time ( $P=.22$ ).

**Figure 2.** Emotional well-being over time (T0, T1) as a function of intensity of online participation at T0 (low vs high) and emotional approach coping (low vs high).



## Breast Cancer–Related Concerns

Only education, psychological help from a professional, and offline social support were related to the average score of breast cancer–related concerns. No other main or interaction effects were found.

## Discussion

### Principal Findings

This 2-wave longitudinal study extends previous findings on the effects of online peer support in 2 ways: by testing changes in well-being as a function of intensity of online support group participation and by examining the role of individual differences in emotional coping styles. Findings showed that participating

frequently online was especially helpful for patients who approach their emotions less actively; their emotional well-being increased over time. In contrast, frequent online users who actively approach their emotions experienced no change in well-being, reporting highest levels of well-being overall. For patients who participate less intensively within the support community, coping style seems to outweigh effects of online participation; over time, patients who actively approached emotions experienced an increase in psychological well-being, whereas patients with a low score on emotional approach coping reported no change in depression and emotional well-being.

This study was stimulated by findings from a previous cross-sectional study that showed that approaching one's emotions was especially relevant for patients who were highly active within an online support community [20]. Specifically, frequent users with a low score on emotional processing and expression reported significantly lower psychological well-being than equally active patients but with a high score on emotional processing and expression. In contrast, current longitudinal findings showed that especially the frequent users who approach emotions less actively benefit from intense online participation; they experienced an increase in emotional well-being over time. An explanation might be that frequent online participation compensates for the negative effects of not approaching emotions. Patients may benefit from several therapeutic processes within the online support group, such as the support from peers, empowerment by the provision of relevant illness-related information, and recognition in stories from others. These helpful processes might compensate for negative effects of not actively approaching emotions and cause a positive change in patients' well-being.

These results reconcile previous null findings of support group participation on well-being. We found no main effect of the level of online participation on changes in well-being; we only found interactions of online participation with patients' emotional coping style. This underscores the importance of considering individual differences in dealing with illness when examining health outcomes of online support communities. Although we found no negative effects for highly frequent users, researchers should be careful not to treat an online support community as a "one-cure-fits-all" solution because, apparently, they are not.

The present findings also showed the importance of other factors outside the online environment. We found, for example, correlations between patients' well-being and offline social support and professional psychological help. Patients who felt supported by family and friends reported a higher well-being than patients' feeling less supported, and patients receiving professional help reported a lower well-being. Although such covariates showed no influence on well-being change (except for disease status), we should be careful not to overestimate the effects of online peer support. Since no direct relation between online intensity of participation and well-being was found, such "offline" factors seem to have a stronger influence on patients' well-being than the level of online participation within an online peer support group. Online peer support might contribute to patients' well-being, but it probably does not compensate for

the potential negative effects of other important factors, such as a lack of support from relatives and deteriorated health status.

Regarding practical implications, with caution we could state that patients might be encouraged to participate actively in online peer communities. Although we cannot compare the current participating group with patients who decide not to visit online support communities, for the present sample frequent participation was beneficial to patients' well-being in the long run, regardless of their coping style, and did not cause harm to any patient group. Especially patients who occasionally visit an online community and approach their emotions less actively should be stimulated to participate more frequently because they seem to benefit most from frequent participation.

### Limitations and Future Research

No interaction effects of our key independent variables on breast cancer-related concerns were found. One explanation might be that breast cancer-related concerns are no accurate measure for well-being. Although the other psychological well-being measures were related to breast cancer-related concerns, concerns might be less appropriate to use as an outcome measure because concerns might intensify online participation. To be more specific, concerns may induce the need for online information and support, and for some patients online peer support, in turn, increases well-being over time. Another explanation is that concerns depend mostly on disease factors rather than online peer support. For example, current treatment, physical well-being, or recurrence might induce concerns. Such factors might intensify concerns at different (shorter) time points; therefore, concerns may fluctuate more intensively over time than more "stable" measures of well-being, such as depression. Future studies should include a more detailed assessment of the disease process patients are in and the number of months they have been participating in an online forum to test this assumption.

In this study, we measured emotional approach coping only in the baseline questionnaire because coping style is merely viewed as an aspect of one's personality that is rather stable over time and, therefore, often measured just once in longitudinal studies (eg, [23]). However, studies with a cognitive-behavioral approach suggest that specific treatment has the potential to teach patients certain coping skills [41]. Although peer-led support communities do not include professional guidance, it might still be possible that online conversations stimulate approaching emotions, which has a positive influence on their well-being. From a modeling or skills perspective [42], frequent participation in online support communities may help patients with more repressive coping styles to learn over time how to approach illness-related emotions. In future studies, we recommend to reassess coping style to test if patients learn to cope with emotions due to online participation.

Examining peer-led online communities is difficult because of its' anonymity and "fluidness" (ie, patients come and go whenever they like). Because participating patients were anonymous, there is no record of what participants did before T0, no information on dropouts, and the findings rely on self-report (ie, there is no actual information on what they precisely did online). We have no information on participants'

starting date of online participation. Possibly, advantages of online participation might particularly occur for patients who just started to participate online, for example because they are recently diagnosed and especially in need of support. It is possible that changes in well-being might be less pronounced in patients who are part of the community for a longer period. Future research should examine this possibility.

Furthermore, we may have encountered selection bias. Patients who were willing to participate in the current study might also be more involved in online support and, therefore, already behave differently than patients less active online. With respect to the current limitations, in future research it would be interesting to track patients' actual online behavior. Although it is rather difficult when it comes to anonymous peer-led online communities, investigating patients' online writings and connecting these findings to measures of well-being and individual characteristics would provide a better understanding of online processes and its effects. For instance, it would be interesting to see if certain coping skills reflect online writing style.

Although this is one of the rare attempts to investigate longitudinal effects of peer-led support communities, tracking patients for an even longer period with more points of measurement might answer more questions on this topic. For

example, online participation may not only influence well-being, patients' level of well-being might also incite online participation. For instance, patients' negative experiences lower well-being, which may stimulate online support seeking and, in turn, online interactions with peers helping patients to cope with the current situation, which in turn increases well-being.

Furthermore, in this study we investigated emotional approach coping. However, other individual differences might be of interest as well. For instance, are patients satisfied with the support they receive online and how does this affect well-being? Or how do patients compare their own situation to the condition of peers and how does this affect them? Future research should address other underlying psychological mechanism that could influence the effects of online support group participation.

## Conclusions

To our knowledge, this study is one of the first studies to examine the effects of online peer-led support group participation, taking into account individual differences in emotional coping style. Over time, frequent participation in an online peer support community increased emotional well-being, in particular for patients low on emotional approach coping. Findings suggest that intense support group participation may be especially helpful for patients who approach emotions less actively.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Scale construction: intensity of online support group participation.

[PDF File (Adobe PDF File), 53KB - [jmir\\_v16i11e256\\_app1.pdf](#)]

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## Abbreviations

**IP:** Internet protocol

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Original Paper

# eHealth Literacy Interventions for Older Adults: A Systematic Review of the Literature

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## Abstract

**Background:** eHealth resources offer new opportunities for older adults to access health information online, connect with others with shared health interests, and manage their health. However, older adults often lack sufficient eHealth literacy to maximize their benefit from these resources.

**Objective:** This review evaluates the research design, methods, and findings of eHealth literacy interventions for older adults.

**Methods:** A systematic review of peer-reviewed research articles from 28 databases in 9 fields was carried out in January 2013. Four rounds of screening of articles in these databases resulted in a final sample of 23 articles.

**Results:** Findings indicated a significant gap in the literature for eHealth literacy interventions evaluating health outcomes as the outcome of interest, a lack of theory-based interventions, and few studies applied high-quality research design.

**Conclusions:** Our findings emphasize the need for researchers to develop and assess theory-based interventions applying high-quality research design in eHealth literacy interventions targeting the older population.

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## KEYWORDS

health literacy; aging; computers

## Introduction

### Overview

Electronic health information plays a growing role in how individuals manage their health and interact with the health care system [1]. Online tools enable individuals to connect with others sharing similar health interests [2], participate in interventions [3], or find health services [4]. For instance, 72% of adult Internet users in the United States (US) have searched for health information online, while 35% of *all* US adults diagnosed a health condition online [1]. eHealth resources can help older adults manage chronic health issues, make informed health decisions, or communicate with their providers [3,4].

Problematically, older adults often lack the skills and knowledge necessary to use online health resources [5], and disability, chronic disease, or handicaps can make technology difficult to use. eHealth literacy refers to the “set of skills and knowledge that are essential for productive interactions with technology-based health tools” [6]. While 59% of adults age 65 and above go online, almost 29% of adults 65 and older perceived that a disability or chronic disease made technology use difficult [7], and only 3% of older adults have proficient health literacy [8]. Lower age and higher educational attainment correlate to higher eHealth literacy [9], suggesting that lower socioeconomic status (SES) older adults are particularly susceptible to low eHealth literacy. This disparity is significant because recent evidence indicates low health literacy correlates to poor health outcomes [10].

eHealth literacy interventions offer one solution for increasing older adults' ability to access and use eHealth resources such as electronic health records, patient portals, online support groups, and self-management tools [3,4]. Prior reviews examined health literacy interventions for older adults [11], eHealth literacy among younger adults [12], health and eHealth literacy combined [13], and online health literacy interventions for all age groups that use experimental designs [14]. However, no known article has systematically reviewed eHealth literacy interventions for older adults. This article addresses this gap in the literature by providing a systematic review of the literature on eHealth literacy interventions for older adults.

### eHealth and Health Literacy

Health literacy is "the degree to which individuals [can] obtain, process, and understand basic health information and services needed to make appropriate health decisions" [15]. This definition of health literacy contains two important elements: an individual's ability to (1) comprehend health information, and (2) make appropriate decisions with health information. Health literacy evolved from the two distinct perspectives of clinical care and public health [16]. The clinical perspective positions health literacy as a causal factor that influences health outcomes [16]. From this perspective, poor health literacy influences patients' adherence to clinical recommendations, which affects clinical outcomes [16]. In contrast, the public health perspective situates health literacy as an outcome of interest [16].

Building on the concept of health literacy, eHealth literacy emphasizes information and communication technologies' (ICTs) growing role in health information. Examples of ICTs relevant to individuals' health management include patient portals, telehealth systems, and online support systems. eHealth literacy requires a mix of health, information, scientific, media, computer, and Internet literacy [6]. Given ICTs' rapid development, the skills, knowledge, and literacies that constitute eHealth literacy continually evolve [17]. As a result, individuals must continue to develop their skills and knowledge to maintain their eHealth literacy.

In this new (but growing) field, few studies have yet developed and tested eHealth literacy specific theories. Rather, eHealth interventions often use learning theory to guide interventions (eg, Xie [18-20]). These interventions consistently prove effective at improving older adults' eHealth literacy, but their results suggest further theoretical development is necessary to advance the field. For instance, Xie [18,20] found no significant difference for learning outcomes between collaborative and individualistic learning conditions, despite the prediction of social interdependence theory (SIT) that suggested the superiority of collaborative learning over individualistic learning. Similarly, a cognitive theory of multimedia learning (CTML) predicts that tutorials presenting information in one modality (eg, visual only) should outperform tutorials presenting redundant information in multiple modalities (eg, visual and audio) [21]. However, an intervention testing this hypothesis with an eHealth tutorial for older adults found no significant difference for learning outcomes between two presentation methods (visual and audio; visual only) [20]. In both examples

of interventions guided by learning theory, outcomes did not align with predicted outcomes, suggesting further theoretical development is necessary.

### Aging-Related Issues

Older adults' distinct characteristics may explain why learning theories have not generalized to eHealth literacy interventions. Cognitive aging examines age-related changes in cognition, such as reduced information processing speed or a diminished ability to coordinate and integrate information [22]. Cognitive aging studies consistently find negative linear associations between chronological age and cognitive performance [22]. Learning theories developed with younger adults (eg, SIT and CTML) do not account for the influence of cognitive aging, which may explain why these theories have not generalized to older adults. For instance, a Web-based tutorial that provides redundant information (eg, visual text and audio narration that present identical instructional content) may help compensate for age-related declines in working memory [23,24]. However, CTML does not account for the effects of cognitive aging and predicts redundant information decreases learning outcomes [25].

Diversity within the older population may also affect intervention outcomes. This diversity includes chronological age, along with race and ethnicity. Chronological age can range from 50 to over 100, while racial and ethnic minorities comprise 21% of the US population over age 65 [26]. This diversity suggests interventions effective for one portion of the aging population (eg, Hispanic adults over 80) may not generalize to other segments (eg, African-American adults under 65). Tailoring interventions offers one approach for ensuring instructional content matches each participant's specific characteristics. Tailoring is "any combination of strategies and information intended to reach one specific person, based on characteristics that are unique to that person, related to the outcome of interest, and derived from an individual assessment" [27]. Tailored interventions have outperformed non-tailored interventions for participants with type 2 diabetes, hypertension, and physical activity [28,29]. However, no known study investigated tailored eHealth literacy interventions, indicating a significant opportunity exists for improving the efficacy of interventions.

A systematic review of eHealth literacy interventions for older adults can provide a foundation for improving intervention outcomes. A recent systematic review investigated health literacy interventions for older adults [11] but excluded large-scale experimental eHealth studies for older computer learners (eg, Xie [18-20]) and sampled only computer literate older adults [11]. Similarly, a prior review examined online health literacy interventions but is distinct from this systematic review in several key aspects [14]. First, the Car et al [14] review included only studies using randomized controlled trials (RCTs) or controlled before and after studies (CBA). In comparison, our systematic review analyzed a more comprehensive sample of studies including but not limited to RCTs or CBAs. Our broad scope is justified given the small number of existing studies on this topic. Second, the Car et al [14] review included only two studies in their study sample.

This small sample size led Car et al [14] to conclude that they could not “draw any conclusions about the implications of [their systematic review] for the content or delivery of consumer Internet skill interventions” [14]. Third, the Car et al [14] review applied no exclusion criteria for study participants. In contrast, this systematic review focuses explicitly on the older population and excludes studies with participants age 50 and below. Our systematic review thus makes new contributions to the literature.

We address a significant gap in the literature by providing a more comprehensive review that includes eHealth literacy interventions with both computer literate and illiterate older adults. This approach is necessary because (1) many older adults lack computer literacy [7], (2) excluding computer illiterate older adults may exclude studies with SES participants because of this population’s low computer literacy levels [5], and (3) limiting the review to eHealth literacy interventions excludes health literacy interventions that use ICTs but do not use the term eHealth (eg, Neafsey et al [30]). The following research questions guide this review: (1) What intervention strategies have been used to improve older adults’ eHealth literacy?, (2) What strategies are found to be effective in improving older adults’ eHealth literacy?, and (3) What evidence supports the effectiveness of eHealth literacy interventions for older adults?

## Methods

### Article Selection

We performed four rounds of systematic selection in January 2013 to identify relevant articles: (1) database selection, (2) keyword search, (3) screening the titles and abstracts, and (4) screening the full text.

#### Round 1: Database Selection

We conducted search queries with electronic databases accessible at the University of Texas at Austin. Database selection involved two steps. First, we identified academic fields pertinent to the literature review, resulting in a list of nine fields with a total of 159 databases (see [Multimedia Appendix 1](#) for the identified fields). Second, we evaluated the databases for these fields with inclusion criteria to confirm their relevance (see [Multimedia Appendix 2](#) for inclusion criteria). This process produced a set of 28 databases (see [Multimedia Appendix 1](#) for selected databases).

#### Round 2: Keyword Search

The following keywords were used to search the 28 selected databases: “health literacy” OR “eHealth literacy” OR “e-Health literacy” OR “information literacy” OR “computer literacy”

AND “old\* adult\*” OR “senior\*” OR “elder\*” OR “aging” OR “ageing” OR “babyboomer\*” OR “retiree\*”.

To ensure an inclusive selection of results, we applied no additional limiting criteria in the second round. Due to differences among the 28 databases, the keywords were used to search the articles’ full text, abstract, or title. This process produced a total of 253 articles.

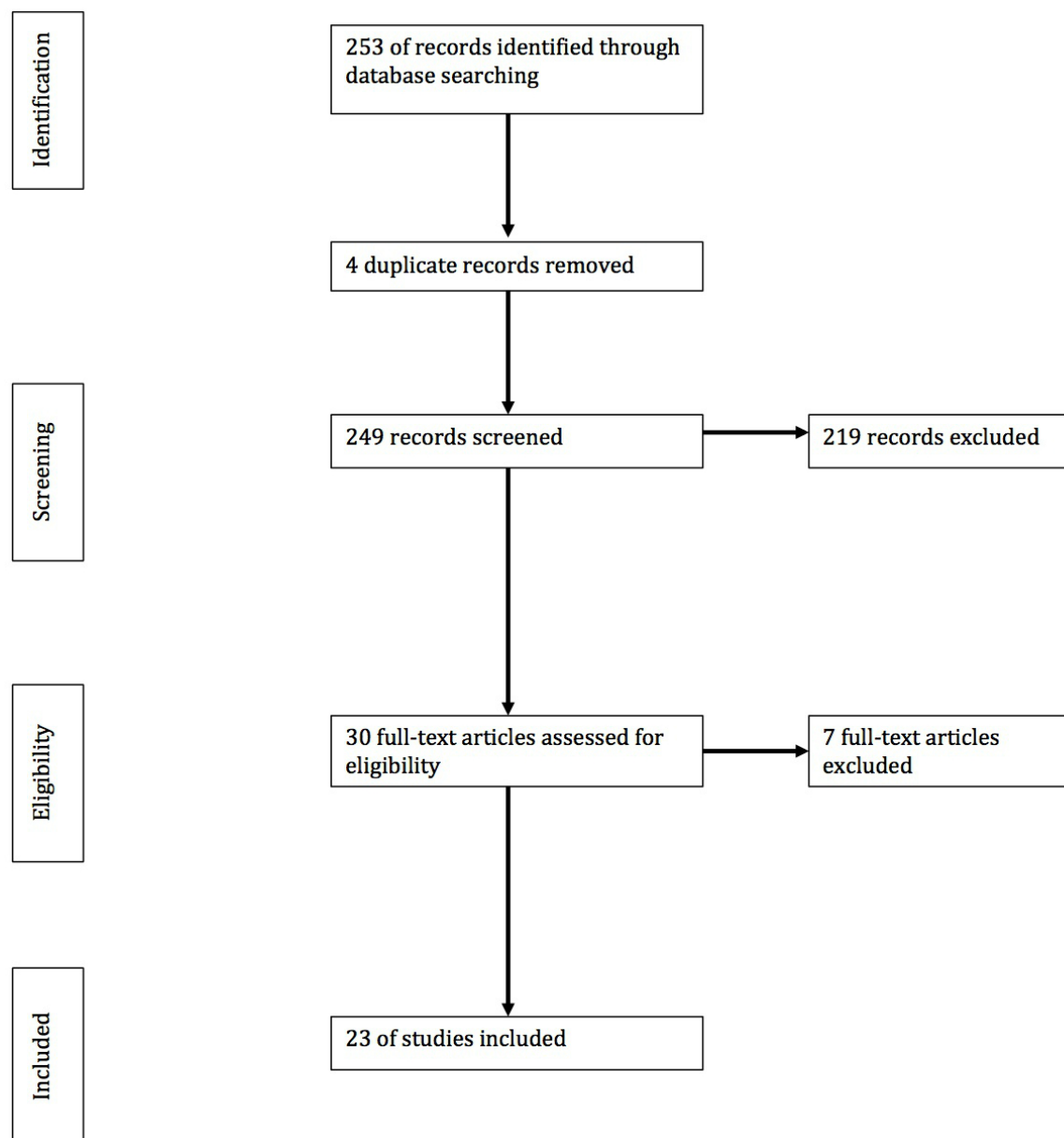
#### Round 3: Screening the Titles and Abstracts

One author (IW) screened the titles and abstracts for the 253 articles to ensure each study included *older adults* and involved an *eHealth literacy* intervention. Round 3 produced 30 articles that met the following criteria:

1. *Older adults* must make up a significant proportion of study participants. For the purpose of this study, older adults are defined as individuals age 50 years and above. This definition expands the scope of the review and is consistent with growing appreciation of the role that health behavior interventions play in healthy aging for those under age 65 [31]. Studies including no older adults in their samples (eg, Cormier et al [32]) were eliminated.
2. The study involved evaluation of an *intervention* using empirical data. To expand the scope of the review, we included qualitative studies and studies with a non-experimental research design, provided that these studies evaluated an intervention. Studies not reporting original and empirical data, such as literature reviews [11] (eg, Echt [33]), were excluded from our sample.
3. The intervention must have focused on improving *eHealth literacy* or improving a health outcome by improving *eHealth literacy*. To be more inclusive, we included interventions focused on health literacy related to specific health conditions, such as mental health literacy (eg, Walker [34]) or oral health literacy (eg, Hjertstedt, Barnes, Sjostedt [35]), or a single condition, such as ulcers (eg, Hartigan, Murphy, Hickey [36]).

#### Round 4: Screening the Full-Text

One author (IW) reviewed the full text of the remaining 30 articles to confirm consistency with the three criteria applied to review article titles and abstracts during the third round. We eliminated another 7 articles in Round 4. Articles were eliminated for not reporting empirical data [37-39], not including older adults [40,41], not focusing on health literacy [42], or providing no information on the intervention content or materials [43]. The final sample contained 23 articles. [Figure 1](#) summarizes this four-round selection process.

**Figure 1.** Four-round selection process.

## Results

### Overview

The 23 articles were published between 2003 and 2013 and report results from 23 independent studies [18-20,30,34-36,44-59]. These articles' key characteristics appear in [Multimedia Appendix 3](#). We report below these articles' use of theory (or a lack of it), research design, measures, participant characteristics, outcomes, intervention materials, and whether or not they involved tailored interventions.

### Themes That Emerged From Key Findings

#### *Intervention Strategies for Improving Older Adults' eHealth Literacy*

We identified several intervention strategies among the sampled studies, including collaborative learning and tailored intervention content. Collaborative learning "involves the construction of

meaning through interaction with others and can be characterized by a joint commitment to a shared goal" [60]. Three studies [18-20] used collaborative learning strategies to teach participants eHealth literacy.

Similarly, four studies (17%) tailored intervention content [30,44,45,61]. Tailored intervention materials "are intended to reach a specific person, are based on characteristics that are unique to that person, are related to the outcome of interest, and have been derived from an individual assessment" [27]. Of the four studies, three studies disseminated tailored content to participants in print [30,44,45], while one study disseminated tailored content by telephone [61].

#### *Effectiveness of Strategies*

Interventions applying collaborative learning strategies significantly improved participants' computer and Web knowledge and skill [18,20], eHealth literacy self-efficacy [18,19], and eHealth literacy skill [19]. Similarly, findings from



the four studies that applied tailoring as an intervention strategy provided evidence for the effectiveness of this strategy [30,44,45,61]. These studies found that tailored educational interventions significantly improved participants' blood pressure control [30,61], medication self-efficacy [30], and medication adherence [44,45].

### ***Evidence Supporting the Effectiveness of eHealth Literacy Interventions for Older Adults***

The sampled studies provided evidence for the effectiveness of eHealth literacy interventions for older adults. The studies that conducted RCTs all found significant improvement for outcome measures from pre- to post-intervention [18,20,34,44,46,47,61]. Likewise, the studies using a one group, pretest and posttest research design all identified significant improvements for outcome measures [19,30,35,36,48-54]. The remaining five studies [45,55-58] used a variety of research designs (eg, quasi-experimental design [56] and post-hoc analysis of an RCT [45]) or relied on qualitative data [55]. Each of these studies found evidence supporting the effectiveness of eHealth literacy interventions for older adults [45,55-58]. See [Multimedia Appendix 3](#) for key findings from each of these studies.

### **Use of Theory**

About half of the studies (12/23, 52%) applied no theoretical framework. The 11 studies that applied a theoretical framework drew on two fields: (1) health behavior (seven studies) and (2) education (4 studies). Of these 11 studies, 7 (30%) used health behavior theories: three studies (13%) used the Transtheoretical Model [34,50,55], two studies (9%) used the Health Belief Model [46,61], and two studies (8.7%) used Social Cognitive Theory [30,49]. Of the four studies (17%) using a learning theory, three studies (13%) used Social Interdependence Theory [18-20], one study (4%) used a Cognitive Theory of Multimedia Learning [20], and one study (4%) used Transformative Learning [51].

### **Research Design**

The studies used a variety of research designs, consistent with the broad selection criteria used in our searches. Just under half (11/23, 48%) used designs with pretest and posttest of a single condition [19,30,35,36,48-54], while one study used a quasi-experimental design [56]. RCTs defined as "trials that include at least one experimental condition, along with a control condition, and randomize the assignment of participants to a condition" [59], were used in seven studies (30.4%) [18,20,34,44,46,47,61]. One study (4.3%) conducted a post-hoc analysis of RCT data [45], while another study (4.3%) was an observational study that used survey questionnaires and in-depth interviews to evaluate participants from the experimental group of an RCT [55]. The two remaining studies (9%) were cross-sectional survey studies [57,58].

### **Health Literacy Measures**

Five studies (22%) used either the Test of Functional Health Literacy in Adults (TOFHLA) or the Short Test of Functional Literacy in Adults (S-TOFHLA) [45-47,50,51], two studies (9%) used a version of the Rapid Estimation of Adult Literacy in Medicine (REALM) [35,61], and three studies (13%) used the eHealth Literacy Scale (eHEALS) [18-20]. More than half

(13/23, 57%) used no standardized or validated instrument to measure literacy [30,34,36,46,48,49,52-58].

### **Sample Characteristics**

Sample size varied between 11 participants in a pilot study and 909 participants for an RCT (a notable outlier is Olson, Sabogal, and Perez [56], which examined secondary survey data collected from 57,104 Medicare beneficiaries). More than half of the studies (13/23, 57%) had over 100 participants [18-20,34,45-47,49,52-56,61], five studies (22%) had between 30 and 99 participants [35,36,48,57,58], and four studies (17%) had fewer than 30 participants [30,44,46,51]. One study reported the percentage of participants for two age ranges, but did not report the total sample size [54]. About one third (34%) of that study's participants were 65-79 years, while another 41% were over age 80 [54]. Overall, participant age varied considerably across the studies, with mean participant age ranging between mean 61 and mean 84. Many studies (17/23, 74%) were majority female [18-20,30,34-36,48-58]. Of studies reporting race or ethnicity, five studies (22%) reported majority African-American participants [18-20,49,51], four studies (17%) reported majority white participants [30,35,50,56], and one study reported a Latino/Hispanic majority [52]. The six studies (26%) with majority racial/ethnic minority participants targeted older adults of lower SES or a specific racial/ethnic minority group in the United States (one exception is Williams, Manias, Liew, Gock, Gorelik [46], who focused on Greek and Italian immigrants to Australia).

Only seven studies (30%) reported data on participants' income [18-20,45,49,50,61]. Of those studies, four studies reported that at least 20% of their participants earned less than \$20,000 per year [18-20,49], one study reported that 71% of participants earned less than \$25,000 per year [50], one study reported that 37% of participants had "low household income" [45], and one study reported that 19% of participants had "inadequate incomes" [61]. Only 11 studies (48%) reported data on educational attainment [18-20,30,34,35,45,47,50,51]. Of those studies, six reported that more than 10% of participants had less than a high school education [18,30,35,45,50,51], three studies reported less than 10% of participants had less than a high school education [19,20,49], two studies reported a mean of more than 10 years of formal education [34,47], and one study reported that 23.9% of participants had a high school education or below [35].

### **Outcomes of Interest**

Ten studies (43%) targeted a specific health outcome or behavior as the outcome of interest, with health literacy serving as an independent variable [30,45-47,53,55,56,61]; 13 studies (57%) targeted some form of literacy as an outcome of interest. Of these studies, eight studies (35%) targeted eHealth literacy [18-20,48,49,54,57,58] while five studies (22%) targeted health literacy [34-36,51,52]. Of the 10 studies targeting a health outcome or behavior with health literacy serving as an independent variable, four studies (17%) targeted medication management [45-47], two studies (9%) targeted hypertension management [30,61], two studies (9%) targeted diabetes management [55,56], and one study (4%) each targeted mental health [53] and pharmacist-patient communication [50].

## Intervention Materials

Most (6/8) of the eHealth literacy interventions used instructional materials developed by the National Institute on Aging (NIA) of the National Institutes of Health (NIH) [18,19,48,49,57,58]. Additionally, one study used a multimedia tutorial developed by the National Library of Medicine of the NIH [20], and one study developed a website with stroke information through a collaborative partnership between various Pennsylvania healthcare providers [54]. The six studies that used NIA materials all adapted materials from the NIH Senior Health “Training the Trainers Toolkit”, freely available on the NIH Senior Health website [18,19,48,49,57,58]. This toolkit provides lesson plans for instructing older adults on how to locate reliable health information online using desktop or laptop computers [62]. In contrast with the uniformity among the eHealth literacy studies in terms of the instructional materials they used in their interventions, the 15 health literacy interventions drew on a wide range of materials, such as those developed by non-profits or researchers themselves.

## Research Setting and Location

Fourteen studies (61%) occurred in informal learning settings (eg, public libraries or senior centers) [18-20,35,47-54,57,58]; four studies (17%) in clinical settings [34,44,45,61], four studies (17%) were administered remotely via ICTs including three by telephone [34,55,61] and one by tablet computer [30]. One study (4%) involved an intervention carried out via broadcast public service announcements on radio and television [56]. Data collection for 18 studies (78%) took place in the United States [18-20,30,35,48-52,54,56,59,61-65], three studies (13%) in Australia [34,46,53], one study (4%) in England [55], and one study (4%) in Ireland [36].

## Discussion

### Principal Findings

eHealth literacy interventions can provide older adults with the skills and knowledge necessary to benefit from eHealth resources [18-20]. However, this review highlights the need for theory-based interventions that apply high-quality research design. The eHealth interventions in our final sample most closely aligned with the public health perspective of health literacy [16], a trend not identified by prior reviews. These interventions were consistent with the public health perspective in that they viewed eHealth literacy as an asset that increases individuals’ ability to access, assess, understand, and apply health information to make health-related decisions [16]. These eHealth literacy interventions targeted eHealth literacy as an outcome of interest, similar to how health literacy interventions consistent with the public health perspective target health literacy as an outcome of interest [16]. This approach could potentially address a vital need among underserved segments of the older population, such as those with low SES, that are most likely to have poor health literacy [5]. However, of the eight studies with eHealth literacy as an outcome of interest, only those conducted by Xie [18-20,49] reported data on either participants’ income or education, making it difficult to determine whether the other eHealth interventions targeted low SES participants.

The sampled eHealth interventions were inconsistent with the clinical perspective in that none of the interventions included a health outcome as an outcome measure [16]. Including health outcomes as outcome measures is important because this can clarify the relationship between eHealth literacy and health outcomes for older adults. Another characteristic of the clinical perspective is that interventions are evaluated in clinical settings [16]. None of the sampled eHealth interventions occurred in a clinical setting. Investigating eHealth interventions in clinical settings could generate important knowledge by removing environmental distractions, such as noise, that can occur in informal learning settings such as a public library [18-20]. Additionally, clinical settings present distinct challenges, such as reliably measuring health literacy without causing patients embarrassment, stress, or discomfort [63]. Objective measures of eHealth literacy skill, such as those used by Xie [20], could be difficult to administer in clinical settings because they require participants to use a computer. Subjective measures, such as the self-reported eHealth literacy scale (eHEALS) [64], offer an alternative but must be updated for new Internet technologies, such as social media, to ensure their validity [17,65].

Similarly, developing and applying theory could enhance the quality of research on eHealth literacy interventions. Theory development advances emerging fields by shifting the research focus away from simply discovering new facts to explaining facts, predicting outcomes [66], and generalizing results [67]. A review examining the use of theory in the emerging field of Web 2.0 found the limited use of theory slowed the advancement of scientific knowledge on Web 2.0-associated social phenomena [68]. Consistent with prior reviews of health and eHealth literacy [13], most studies in this review applied no theory. Among the theory-based studies, eHealth literacy studies used only learning theory (eg, Xie [18-20]), while health literacy interventions used various health behavior theories (eg, Miller et al [50], Bosworth et al [61]). The limited range of theories for eHealth studies likely resulted from the small number of researchers investigating eHealth literacy interventions for older adults. As the number of researchers contributing to the field grows, greater variability in the application of theory may be expected.

None of the sampled studies used an eHealth literacy-specific theoretical framework, such as the Lily model or Chan and Kaufman’s [6] proposed framework. As a relatively new construct, it is not surprising that only a limited number of theoretical frameworks for eHealth literacy has been proposed. However, hypothesizing and testing the relationship between theoretical constructs is essential to theory development in intervention research [69]. As a result, using eHealth literacy-specific theoretical frameworks to guide eHealth intervention research with older adults can support the development and improvement of interventions. Theoretical development will be especially important as mobile technologies, such as smartphones and tablet computers, continue to grow as a source of digital health information [1].

While the Lily model describes the skills and knowledge necessary for eHealth literacy, it includes no cognitive, social, or environmental variables and lacks empirical validation. The Chan and Kaufman [6] framework mapped cognitive demands

onto this model but also lacks empirical validation. Combined, these two models demonstrate a need for future eHealth literacy research to empirically evaluate eHealth literacy theories. Such an evaluation is necessary to determine the extent to which these models generalize to the older population.

Along with a lack of theory, poor research design makes evaluating intervention outcomes problematic. Consistent with recent health literacy reviews [11,13], most sampled studies used non-experimental, cross-sectional, or quasi-experimental designs that tested a single condition without a control condition. RCTs, known to produce the highest quality evidence in health-related research by systematically limiting potential biases [70], are used in only a few studies. Several studies also used post-intervention surveys to assess outcomes (eg, Susic [57]). These surveys used only self-reported data without objective measures of eHealth literacy. Recent reviews found the lack of standardized health literacy measures decreases the generalizability of findings from health literacy interventions [11,13]. A similar issue emerged in the results from this review, where over half of the examined studies lacked measures of eHealth literacy. Further, several studies measured a health outcome without measuring eHealth literacy. For example, a mental health literacy intervention with community-dwelling older adults measured depression and physical activity (the outcomes of interest) but did not measure eHealth literacy as an outcome [34]. As a result, the study offers little information on the relationship between eHealth literacy and health outcomes.

A notable distinction between health literacy and eHealth literacy appeared in the intervention materials. The health literacy interventions used various materials, including condition-specific materials, such as an ulcer pamphlet [36]. In contrast, eHealth literacy interventions used NIH materials, with the exception of Gross et al [54], which used materials developed locally. Of studies using NIH materials, only Xie [20] did not use the NIH Senior Health training materials (that study used a tutorial developed by the National Library of Medicine of NIH). Again, this uniformity reflects eHealth literacy's status as an emerging field studied by a handful of researchers—Xie [18-20,49] alone conducted half of the sampled eHealth literacy studies. This uniformity raises several issues. First, the NIH Senior Health materials teach skills and knowledge specific to desktop or laptop computers. The contemporary ICT environment features a growing variety of devices, including smartphones and tablets, and almost one third of adults access health information on a mobile device [1]. As a result, literacy with these newer devices will become increasingly important. Second, the NIH Senior Health materials do not address Web 2.0 or social networking applications. Adults increasingly go online to connect with others over health issues, such as soliciting peers for health advice [1]. Ignoring the impact of new ICTs on health—and the associated skills required to use them—could negatively impact older adults' eHealth literacy. Last, the NIH Senior Health materials teach eHealth as a general skill applicable to many health issues. Teaching eHealth literacy for specific health issues of particular interest to individuals could potentially improve learning by making intervention content more personally relevant. Only one eHealth

literacy intervention focused on a specific health issue—stroke [54]. That intervention, however, did not report pretest and posttest data for participants' stroke knowledge, so the intervention's effectiveness is unclear.

The studies examined in this systematic review included participants that varied considerably in age, but most of these studies did not report participants' income, education, race, or ethnicity. Mean participant age ranged from 61-84 years, raising the question of whether interventions effective for the "younger" segment of the older population can generalize to the "oldest" old. The failure to report participants' income or education is problematic given the low median income of older adults in the United States [26,71] and the association of low SES with poor health literacy [9]. As with age, interventions effective for one group may not generalize to others, so reporting participants' income, education, race, or ethnicity is essential to understanding the implications of an intervention's results.

Tailoring offers a solution for addressing the influence of individual characteristics on health outcomes. While tailoring has been proven effective in health interventions [29,72], only four of the sampled studies involved tailoring. For eHealth literacy interventions with older adults, tailoring could adjust intervention content for factors like participants' computer experience, health literacy, income, educational attainment, age, race, ethnicity, language, or health issues. However, tailoring requires knowledge of how these factors affect outcomes. As noted above, most studies did not report data on participants' income, education, race, or ethnicity. Also, administering individual assessments necessary to tailoring typically demands significant resources [28]. New ICTs, such as tablet computers, can provide just-in-time intervention content based on individuals' reported behavior, though applications for new ICTs, such as tablets, can also present potential usability challenges for older adults [73]. Among the sampled studies, only one used tablets [30]. Notably, that study collected participant data using tablets but disseminated the tailored intervention content in print.

## Limitations and Future Directions

This systematic literature review contains several limitations. The keyword search did not use a controlled vocabulary (eg, Medical Subject Headings, Cumulative Index to Nursing and Allied Health) and was restricted to the title, keywords, and abstract for each article. This inclusion criterion may have excluded studies that deal with aspects of eHealth literacy but do not contain these exact keywords we used. Only studies with full text written in English were included in the sample, which excluded articles in non-English journals. Also, this review did not include studies that may have contributed to the development of the eHealth literacy construct (that pre-dated it and thus did not use the exact terms to be included in our searches). Nonetheless, this review identified important gaps in the literature that require future research. These gaps include (1) What is the relationship between eHealth literacy and health outcomes for older adults?, (2) Which theoretical frameworks are effective for developing and assessing eHealth literacy interventions for older adults, and which are more effective than others in what context?, (3) What is the relationship between



eHealth literacy interventions conducted in clinical settings and those conducted in informal learning settings, and what factors should be considered when implementing eHealth literacy interventions in clinical settings?, (4) What instructional materials best facilitate older adults' improvements in their eHealth literacy, and how can materials stay current given ICTs' rapid development?, and (5) Which individual characteristics, such as health literacy level, computer experience, or SES, should be considered in interventions to tailor the health content and delivery strategies?

## Conclusions

This paper reports findings from a systematic review of 23 articles on health literacy interventions and eHealth literacy interventions for older adults drawn from 28 relevant databases

in nine fields. The eHealth literacy interventions in the sampled articles used eHealth literacy as an outcome of interest, applied learning theories, and occurred in informal learning settings such as senior centers and public libraries. In contrast, health literacy interventions (that involved ICTs as a key aspect of their interventions) often targeted specific health outcomes, applied health behavior theories, and occurred in both informal learning and clinical settings. These results indicate a significant gap in the literature on eHealth literacy interventions that use health outcomes for outcome measures. Additionally, most of the studies used no theoretical framework, and only seven studies were RCTs. These results highlight a great need to develop and assess theory-based interventions applying high-quality research design.

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## Conflicts of Interest

None declared.

## Multimedia Appendix 1

Selected databases organized by field.

[PDF File (Adobe PDF File), 4KB - [jmir\\_v16i11e225\\_app1.pdf](#)]

## Multimedia Appendix 2

Database inclusion criteria.

[PDF File (Adobe PDF File), 2KB - [jmir\\_v16i11e225\\_app2.pdf](#)]

## Multimedia Appendix 3

Selected articles.

[PDF File (Adobe PDF File), 29KB - [jmir\\_v16i11e225\\_app3.pdf](#)]

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## Abbreviations

**CBA:** controlled before and after studies  
**CTML:** cognitive theory of multimedia learning  
**ICT:** information and communication technology  
**NIH:** National Institutes of Health  
**RCT:** randomized controlled trial  
**SES:** socioeconomic status  
**SIT:** social interdependence theory

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## Original Paper

# Exploring the Efficacy of Replacing Linear Paper-Based Patient Cases in Problem-Based Learning With Dynamic Web-Based Virtual Patients: Randomized Controlled Trial

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## Abstract

**Background:** Problem-based learning (PBL) is well established in medical education and beyond, and continues to be developed and explored. Challenges include how to connect the somewhat abstract nature of classroom-based PBL with clinical practice and how to maintain learner engagement in the process of PBL over time.

**Objective:** A study was conducted to investigate the efficacy of decision-PBL (D-PBL), a variant form of PBL that replaces linear PBL cases with virtual patients. These Web-based interactive cases provided learners with a series of patient management pathways. Learners were encouraged to consider and discuss courses of action, take their chosen management pathway, and experience the consequences of their decisions. A Web-based application was essential to allow scenarios to respond dynamically to learners' decisions, to deliver the scenarios to multiple PBL classrooms in the same timeframe, and to record centrally the paths taken by the PBL groups.

**Methods:** A randomized controlled trial in crossover design was run involving all learners (N=81) in the second year of the graduate entry stream for the undergraduate medicine program at St George's University of London. Learners were randomized to study groups; half engaged in a D-PBL activity whereas the other half had a traditional linear PBL activity on the same subject material. Groups alternated D-PBL and linear PBL over the semester. The measure was mean cohort performance on specific face-to-face exam questions at the end of the semester.

**Results:** D-PBL groups performed better than linear PBL groups on questions related to D-PBL with the difference being statistically significant for all questions. Differences between the exam performances of the 2 groups were not statistically significant for the questions not related to D-PBL. The effect sizes for D-PBL-related questions were large and positive (>0.6) except for 1 question that showed a medium positive effect size. The effect sizes for questions not related to D-PBL were all small (≤0.3) with a mix of positive and negative values.

**Conclusions:** The efficacy of D-PBL was indicated by improved exam performance for learners who had D-PBL compared to those who had linear PBL. This suggests that the use of D-PBL leads to better midterm learning outcomes than linear PBL, at least for learners with prior experience with linear PBL. On the basis of tutor and student feedback, St George's University of London and the University of Nicosia, Cyprus have replaced paper PBL cases for midstage undergraduate teaching with D-PBL virtual patients, and 6 more institutions in the ePBLnet partnership will be implementing D-PBL in Autumn 2015.

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**KEYWORDS**

problem-based learning; decision making; education, medical; virtual patients; curriculum

## Introduction

### Overview

The early years of medical training have seen a progressive move away from curricula organized around single-discipline bioscience material and the use of passive forms of instruction [1]. Problem-based learning (PBL) has been widely adopted as a way of integrating knowledge acquisition, teamwork, and problem-solving skills using active learning techniques within small-group settings [2]. However, PBL has remained relatively unchanged since it was introduced with paper cases—the principal medium around which PBL activities are organized. Even the use of the Internet has, at least so far, had limited impact on the design of the PBL case or the activities that are structured around it.

There are a number of educational technologies that share certain characteristics with PBL. For instance, virtual patients are on-screen learning resources that typically present a clinical problem for learners to solve or manage, and in doing so involve aspects of both PBL and simulation [3]. Although virtual patients can come in many forms, one of the more common forms is the branched case where learners select the best available course of action from predefined options [4]; each decision the learner makes can have consequences and lead to different outcomes.

St George's University of London (SGUL) replaced paper PBL cases for midstage undergraduate teaching with decision-PBL (D-PBL) cases. These are Web-based branching virtual patients that require learners to discuss, debate, and make patient management decisions to negotiate the case [5]. This paper describes the efficacy of this approach using results from a controlled trial comparing end-of-year face-to-face exam performance for learners in PBL groups who worked with linear or branched cases. The paper closes with a consideration of the implications of this approach to teaching tomorrow's doctors.

### Background

PBL involves a combination of students working in small groups with a facilitator and independent research. Each group works through a predefined patient case, discussing the information provided and implied, exploring possible diagnoses, suggesting investigations and treatments, and identifying the research they need to undertake to be able to resolve the case [6]. Learners then undertake their research before the next face-to-face session. The case may be resolved in the second face-to-face session or a second round of research may be identified which is then resolved in a third and final session. Groups of learners are typically given 1 PBL case per week. The pattern is repeated each week with different cases over a semester, term, or year. Although each PBL group will approach a case in different ways, the group facilitator directs the proceedings using the predefined PBL case outline (that the learners do not see) that sets out the key issues, anticipated learning objectives, and other intended features of the case, that allows them to keep learners

from straying too far from the intended learning outcomes for each case.

PBL has been deployed in many different contexts [7] and although the efficacy and effectiveness of PBL continues to be debated [8-11], research into PBL indicates that its benefits come from key components of the PBL activity that tend to be obscured if PBL is considered as a single indivisible intervention [12,13]. These components include the construction of the PBL case, the behavior of the facilitator, and the curriculum context for the activity [14-16]. A key limitation of using paper-based cases is that they can only unfold in a single direction giving learners little or no opportunity to influence the outcome of the case.

There are other teaching modalities in medical education that employ cases, including simulation, case-based learning, and virtual patients, reflecting the role of the patient case as “the primary, vicarious means of shaping clinical judgment for new learners and experienced practitioners alike” [17]. Simulation differs from PBL in that the former is directed more to skills training and teamwork, but there are also similarities [18,19]. Virtual patients are interactive computer simulations of “real-life clinical scenarios for the purpose of medical training, education, or assessment” [20]. Although virtual patients can take many forms, they are intended usually for individual study [4]. The use of virtual patients for PBL has not previously been the focus of PBL developers although a number of schools have placed their paper-based PBL cases online as static documents [21].

The study presented here explored the efficacy of D-PBL in terms of student exam performance. Our working hypothesis was that D-PBL experiences would lead to better exam performance than linear PBL experiences. A randomized controlled trial in crossover design was run to compare aggregate learner performance in those learners who had D-PBL with those who had linear PBL with supplementary PBL “triggers” to compensate for the absence of D-PBL. The trial analyzed students' performance on questions related to D-PBL decision points compared with their performance on questions not related to D-PBL. For each comparison cohort the learning activity was different, but the learning objectives were the same.

## Methods

### Study Context

SGUL is located in South London in the United Kingdom and runs a multiple stream medical education program. The undergraduate entry stream undertake a 5-year program and the graduate entry stream undertake a 4-year program. SGUL has employed PBL since the 1990s [21] and at the time of this study the 140 graduate entry learners (who were the participants in this study) completed 2 years of full PBL and then completed the 2 remaining years of clinical attachments.

A project was initiated in 2007 to rewrite the second year graduate entry paper PBL cases as branching virtual patients (D-PBL) and to modify the facilitation model to stimulate debate

around predefined choices, and their consequences, at key points in the D-PBL virtual patient case [5]. The objective was to make PBL more engaging for learners with prior PBL experience by adding structured options and alternative outcomes to the linear PBL activity model, and encouraging robust debate around structured patient management options and the consequences of pursuing a particular course of action. This was called decision-PBL (D-PBL).

### Study Intervention

A D-PBL virtual patient case is designed as a series of interconnected nodes, each of which is presented as a Web page. Each node represents a step in the unfolding of the case. Some nodes are connected in chains; others have multiple nodes linked to them that allow learners to choose which path they will follow. Learners can only take 1 path through a case and they need to deal with the consequences of their decisions as the D-PBL case unfolds. The small-group facilitator encourages learners to consider the options and to debate different courses of action at each D-PBL decision point. Tutors report increased student engagement at option points and students express the value of simulating the experience of managing cases in real life, including the stresses that can lead to poor decisions [22,23].

The use of a Web-based virtual patient delivery system was essential to creating and running D-PBL activities. The virtual patient cases were to be delivered to multiple PBL classrooms in the same time frame, the scenarios were required to respond to the choices of different learner groups dynamically and independently, and the paths taken by the individual groups were tracked and logged centrally. The latter would permit later analysis and research into the paths that groups took to better understand the effectiveness of the option steps and to iteratively improve the cases.

To minimize the impact on the curriculum as a whole, D-PBL was designed to only differ from traditional linear PBL in a few key areas. D-PBL (like PBL) involved small-group (6 to 8) learners, face-to-face sessions at the start and end of the week, independent research and study between face-to-face sessions, scaffolding by a case with triggers based around problems, and 1 case worked on per week. The differences were the replacement of static paper cases with dynamic Web-based virtual patient cases and the periodic debates and decision making when alternative paths were presented (within face-to-face sessions).

The 5-week Life Protection module (covering immunology, pathology, hematology, and microbiology material) in the second-year SGUL graduate entry stream was selected as the

context for the study. All 5 cases within the Life Protection module were rewritten both as linear PBL cases and as D-PBL cases using the same virtual patient software; the only difference being the addition of different routes through the case for the D-PBL versions.

The faculty committee for each module reviewed the completed D-PBL cases to make sure that the modified cases still fell within the range of the existing learning objectives (options were based on management issues that were already described in the learning objectives). Then the linear PBL cases were supplemented by trigger questions that would cover the same area of learning emphasized by the options. For example, in the anaphylaxis case shown in Figure 1, which focused on problems caused by a rapid intravenous injection of adrenaline. The 4 options would appear only after the students had read and discussed the text (which has been shortened in this figure, for reasons of clarity). This scenario, based on a real-life incident, describes a patient presenting in Accident and Emergency with anaphylactic shock. The scenario is written to elevate stress (“Toni is in poor condition, you have to think quickly what to do”), which in turn can lead them to follow their instinctive response to give a rapid intravenous injection, as happened in real life. This proved fatal. Students have previously noted that serious consequences such as this are particularly memorable [5].

In this way, the study sought to ensure that the D-PBL provided different learning opportunities rather than additional learning opportunities. The development of the D-PBL cases has been discussed more fully elsewhere [5], although the additional prompts were not included in the linear PBL in the earlier study. Students agreed that the group would take a majority view on their chosen direction through the case.

A preliminary analysis of D-PBL in 2007 compared student engagement between learners in paired cohorts who had either a linear version of the case (without options) or a branched version (with optional routes through the case; D-PBL). Cohorts alternated between branched and linear over the first 4 weeks, with a fifth case delivered in the branched version to both cohorts. It was noted that students had performed markedly better than in previous years to a question that was related to 1 of the D-PBL decision points in the week 5 case. However, the D-PBL deployment was not designed as an experiment and there was no control group or any other means to systematically assess the impact of using D-PBL on summative assessment in this first year of using D-PBL. Therefore, a study was developed and run in the following academic year (2008) analyzing the exam performance of students with questions that had been previously encountered in either a D-PBL or linear PBL format.

**Figure 1.** An example of a D-PBL page seen by the student PBL group at a decision point in a branching case in the authoring application OpenLabyrinth [24].

Patient Presentation	Case Information	
<p>You are the Casualty officer in Accident and Emergency when Toni Hutchinson, a 26 year old, is brought in by ambulance with severe breathing difficulties and covered in an urticaria rash. She had been eating in a nearby restaurant, and then complained of breathing difficulties, hoarseness and dizziness and then collapsed. She is very frightened and difficult to understand clearly.</p> <p>She says she develops mild rashes after take-away meals and vigorous exercise. She had eczema as a baby and still gets patches of eczema, sometimes needing steroid creams. She steers clear of nuts.</p> <p>Blood pressure: 85/50</p> <p>Pulse: 130 beats per minute, regular</p> <p>Respiration: 26 breaths per minute</p> <p>Toni is in poor condition. You have to think quickly what to do.</p>	<p>Case Toni and Dave Hutchinson (1054) ID: 35396</p> <p><a href="#">Restart Case</a></p>	
	<th>Case Pathway</th>	Case Pathway
	<p><a href="#">Review your pathway</a></p>	
	<th>Case Score</th>	Case Score

## Study Design

All 81 students (50 male and 31 female) in the graduate entry class in 2008 were entered in to the study. The SGUL Teaching and Learning Committee reviewed the study protocol, noting that the study did not require further ethical review because the early test of the system had not raised any serious concerns and the intervention was restricted to relatively small changes in the execution of PBL sessions.

Students were randomly allocated to 11 tutorial groups (4 groups of 8 and 7 groups of 7) by the SGUL Registry as part of its standard protocol for student assignments. The 11 PBL groups were separated into 2 cohorts: C1 with 5 PBL groups and C2 with 6 PBL groups. During weeks 1, 3, and 5, cohort C1 ran linear PBL cases and C2 ran the branching D-PBL cases. During weeks 2 and 4, C1 ran branching D-PBL cases and C2 ran linear PBL cases. Blinding to the intervention was not possible; both the participants and the investigators were aware which style of case they received. The material in both groups of questions was encountered in both D-PBL and linear PBL cases. The difference was that D-PBL cases required a learner to select a choice that may have had negative consequences, whereas there were no alternative paths or consequences in the linear PBL case. The flow of participants through the study is illustrated in the Consolidated Standards of Reporting Trials (CONSORT) diagram in [Figure 2](#).

Two weeks after the closure of the Life Protection module, the students were given a Short-Answer Question Summative Module Exam. Of the 81 students in the study, 80 took the face-to-face examination. Within the short-answer questions

section of the exam, 5 questions were chosen which were significantly linked to individual options and consequences points within the relevant D-PBL case. This represented our test set of questions. Another 5 questions were deemed to have no relevance to options within the cases, and these represented a comparison set. Questions were not identified to the students as relating to the study or D-PBL within the exam. For each question, the relevant subject specialist submitted criteria for assessment and a marking scheme to the module team for review. The subject specialist had no role in the creation of the relevant option point. The module team reviewed each item and then estimated the proportion of minimally competent examinees that would correctly answer the item.

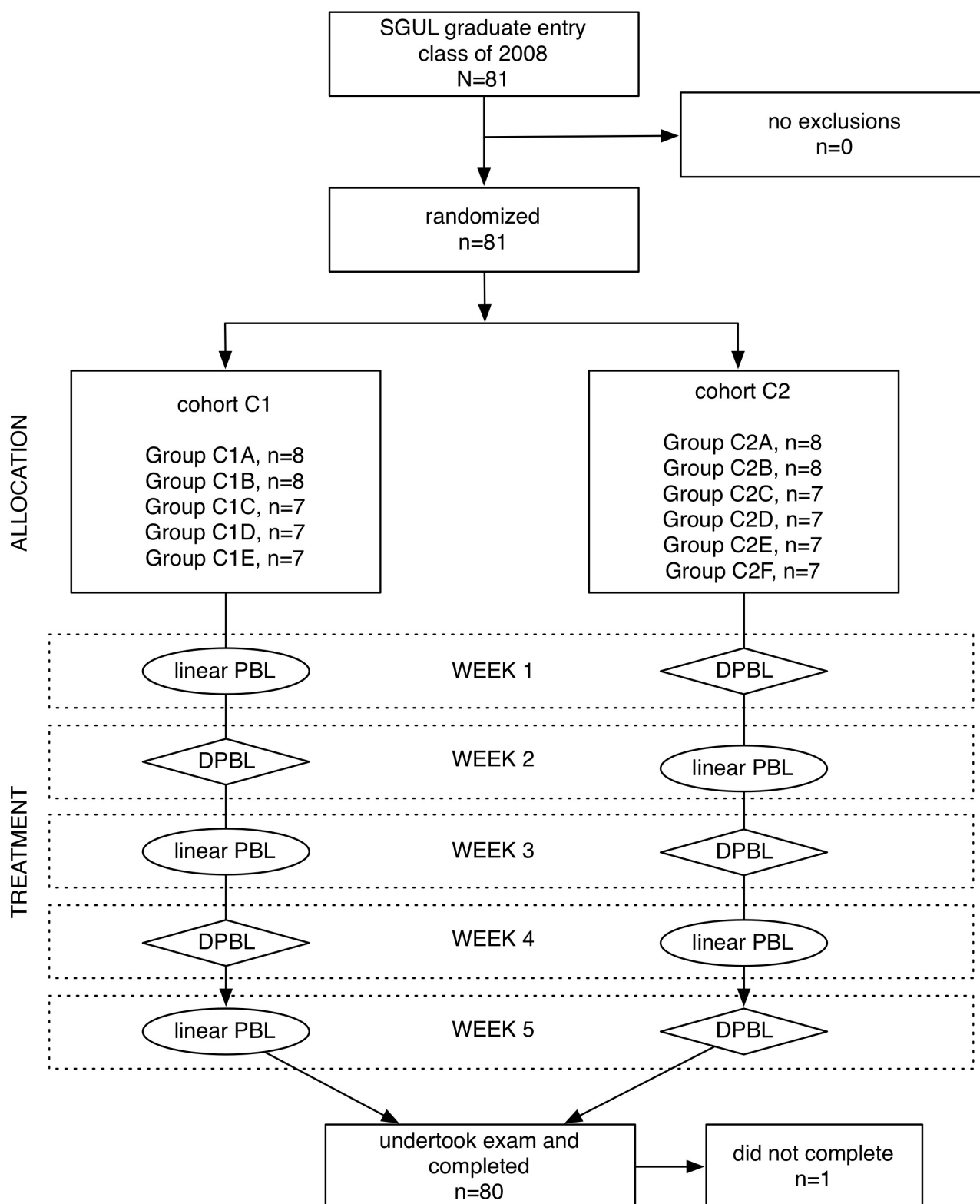
Scripts were marked in each case by the relevant subject specialist and reviewed by another marker. Maximum points for each SAQ varied from 10 to 12 marks. The Module Organizing Team ratified the validity of these 2 sets of questions and rejected 1 question for which the study team agreed did not fit cleanly into either of the 2 question categories. This reduced the comparison set to 4 questions. The examination office passed the final results to the study team who added tags to indicate which groups and cohorts they were in. The mapping between the type of PBL case, the exam questions, and the 2 cohorts are shown in [Table 1](#).

Because the exam results for the 9 questions were found to follow a nonnormal distribution, statistical significance was tested comparing the results for each question between the D-PBL and linear PBL cohorts as independent samples employing a Mann-Whitney *U* test using SPSS v21 (IBM Corp, Armonk, NY, USA). Tests were run to evaluate these

hypotheses: (1) learners who had not encountered key material related to D-PBL decisions would score lower, on average, than those who had and (2) learners who had worked with D-PBL

would score the same, on average, than those who had not on material not related to D-PBL decisions. Effect sizes were calculated for the 2 cohorts using Cohen's *d*.

**Figure 2.** CONSORT flow diagram for the trial showing the distribution of students within the cohorts and a flow diagram of their progress through the 5 weeks of the controlled trial.





**Table 1.** Exam questions used in the study mapped to the problem-based learning (PBL) case week in the Life Protection module and to the 2 cohorts' PBL modality (linear or decision-PBL; D-PBL) in each week of the module demonstrating a spread of questions over time and between cohorts.

Week	PBL modality		Questions		Topic
	Cohort C1	Cohort C2	Related to D-PBL activity	Unrelated to D-PBL activity	
1	Linear PBL	D-PBL	0	1	Leukemia
2	D-PBL	Linear PBL	1	2	Bacterial infection
3	Linear PBL	D-PBL	1	0	Viral infection
4	D-PBL	Linear PBL	2	1	Solid tumors
5	Linear PBL	D-PBL	1	0	Allergies

## Results

The mean scores for the D-PBL cohort's results were found to be consistently higher than for linear PBL cohort for those questions linked to D-PBL activities. The mean scores for the D-PBL cohort's results showed no consistent pattern relative to the linear PBL cohort for those questions not linked to D-PBL choice-discussion activities. The results of the statistical analyses are shown in Table 2. Questions 1-5 were related to D-PBL and all showed a statistically significant higher level of performance for the D-PBL cohort over the linear PBL cohort. Questions 6-9 were not related to D-PBL and showed no statistically significant differences in performance between the 2 cohorts. Note  $P < .05$  rejects the null hypothesis. The 80 learners in 2 cohorts were exposed to either a branching case D-PBL or linear PBL case each week (Figure 3). Each learner's performance in

the end-of-module assessment was tracked back to which cohort they had been part of in each week. This exam contained questions that were related to the option points and questions that were unrelated to option points.

The differences between the exam performance of the D-PBL and linear PBL groups were found to be statistically significant for all questions related to D-PBL. The differences between exam performances of the 2 groups were not found to be statistically significant for any of the questions not related to D-PBL. The effect sizes for D-PBL-related questions were all large ( $>0.6$ ) and positive except for question 2, which had a medium effect size (0.6-0.3) and was positive. The effect sizes for the questions not related to D-PBL were all small ( $<0.3$ ) except for question 8, which had a medium effect size. Overall, there was a mix of positive and negative values.

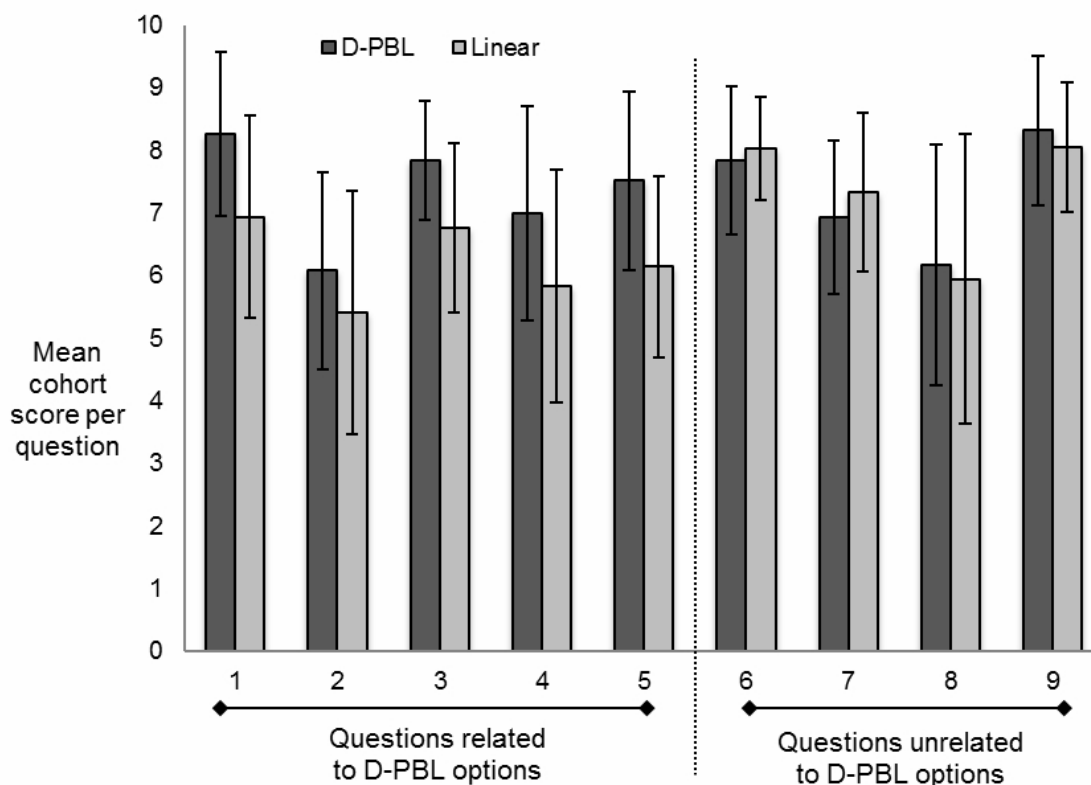
**Table 2.** Exam question results analysis.

Question	D-PBL (n=37)		Linear PBL (n=43)		<i>U</i>	<i>Z</i>	<i>P</i> <sup>a</sup>	Effect size
	Mean (SD)	Median (range)	Mean (SD)	Median (range)				
Related to D-PBL								
1	8.26 (1.31)	8.50 (5.50-10.00)	6.94 (1.62)	7.00 (3.50-10.00)	443.0	−3.419	<.001	0.814
2	6.08 (1.58)	6.00 (2.00-10.00)	5.41 (1.94)	5.50 (1.00-10.00)	593.5	−1.958	.02	0.345
3	7.84 (0.95)	8.00 (5.00-9.50)	6.76 (1.35)	7.00 (4.00-10.00)	391.5	−3.929	<.001	0.800
4	7.00 (1.72)	7.50 (3.00-10.00)	5.83 (1.86)	6.00 (0.50-10.00)	497.0	−2.895	.002	0.629
5	7.52 (1.42)	7.50 (4.30-9.50)	6.15 (1.45)	6.30 (2.30-9.30)	394.0	−3.882	<.001	0.945
Unrelated to D-PBL								
6	7.84 (1.18)	8.00 (3.00-9.00)	8.04 (0.82)	8.00 (6.00-9.00)	751.5	−0.437	.33	−0.244
7	6.94 (1.23)	7.50 (4.00-10.00)	7.34 (1.27)	7.00 (2.00-9.50)	677.5	−1.153	.12	−0.315
8	6.18 (1.92)	6.50 (0.00-9.00)	5.95 (2.31)	6.0 (1.00-10.00)	770.5	−0.242	.41	0.099
9	8.12 (1.20)	8.00 5.00-10.00)	8.06 (1.04)	8.00 (5.00-10.00)	729.5	−0.644	.26	0.058

<sup>a</sup> 1-tailed, exact.



**Figure 3.** Exam question results analysis. For questions related to D-PBL option points, in each case students who had been part of the D-PBL cohort for that week performed statistically significantly better than those who were part of the linear PBL cohort. For questions unrelated to option points, there was no significant difference between the 2 groups.



## Discussion

### Principal Results

The results confirmed the study hypothesis that learner performance was higher for those who had learned with D-PBL than for those who had learned with linear PBL on questions related to D-PBL experiences and there were no significant differences between D-PBL and linear PBL cohort performance on questions not related to D-PBL experiences. This suggests that the use of D-PBL leads to better midterm learning outcomes than linear PBL. However, we should clarify a number of contextual factors that underpin this assertion.

Firstly, participants were midstage undergraduate learners with some limited clinical exposure. Our background hypothesis was that the D-PBL approach suited learners who already have some PBL experience and who had enough clinical knowledge to work with the patient management challenges that D-PBL involves. Secondly, it should be made clear that the intervention was the whole activity, involving the use of particular artifacts (branching virtual patient cases) in a particular way (facilitated debate and discussion at decision points) within an otherwise traditional small-group PBL setting. Research is continuing into the conduct of D-PBL activities and the experiences of those involved. It is also important to note that the Web-based D-PBL did not detract from the process of discussion, enquiry, and problem solving in PBL. Options only appeared after the preceding steps in the case had been discussed fully. Moreover, there was no need for students to find the “correct” path through a case (or to be guided in doing so) because all paths were designed to engender equivalent learning opportunities and the

scenario itself provided excellent feedback in the context of the patient. If the students take poor options, the changes in the scenario are sufficient guidance to encourage students to review their choices and re-evaluate new optional routes for continuation. Therefore, careful scenario construction and testing were essential and all case writers were trained with a formal set of guidelines on scenario construction.

Because of the specificity of the activity, the type of virtual patient used within it, and the provisional nature of these current findings, no assertions can be made regarding the efficacy of virtual patients in general. We acknowledge the importance of the activity that is constructed around a virtual patient [24], something that has yet to be substantially explored [25]. This makes it somewhat difficult to compare our findings with other studies. For instance, although Nalesnik et al [26] found that exam results for groups that had PBL compared with no PBL failed to show significant efficacy for the PBL intervention, this study found little to indicate that different kinds of PBL components are more efficacious in ways that are reflected in student performance. However, D-PBL was designed for students who already had some experience with traditional linear PBL and who had acquired sufficient knowledge and expertise to be able to tackle patient management problems and deal with the consequences of their decisions. Therefore, we propose D-PBL as a modality suited to intermediate learners and this will be explored further in subsequent studies.

### Limitations

There are a number of limitations to this study. Firstly, only the 1 class iteration has been tested. Although these findings are

considered strong enough to justify publication at this stage, at least to encourage others to explore the D-PBL approach, further replication studies are planned to test the efficacy of D-PBL using a wider range of learning and curriculum contexts. Secondly, an experimental approach was taken to investigate the efficacy of the D-PBL activity at the single-item level. Although this has proved useful, there is much work to be done in exploring the nature of the activity and the ways in which students experience it. Finally, it is acknowledged that the cognitive aspects of D-PBL and the links between students' actions in small-group settings have not been explored. The nature of learning that follows from these actions and its retention and application also need further exploration.

### Comparison With Prior Work

Although our work is a hybrid of PBL and virtual patient instructional models, there are connections with studies that explore the importance of scaffolding and learner agency in PBL [27] as well as the role of collaboration and facilitation in learning [28]. The role of structured debate and the connection to clinical decision making within PBL is a departure and although there is an extant literature on decision making in medical education [29] and some consideration of the use of virtual patients to teach decision making [30], the combination of PBL, virtual patients, and clinical decision making would seem to be a significant innovation, one that shows great potential to enhance the efficacy of medical education. Although it has been proposed that virtual patients "should be designed and used to promote clinical reasoning skills" [25], we have demonstrated the efficacy (on the single-item level) of using virtual patients that require learners to engage in clinical reasoning and decision making only within a PBL activity context. We continue to explore the dynamics of D-PBL and its dependence on particular instructional contexts. D-PBL also exemplifies the importance of considering medical educational technologies in the context of the activities within which they are used [31]. Although D-PBL was only made possible by using Web-based virtual patients, much of the value of the activity was realized in the interactions between learners. The log data from the use of the D-PBL virtual patients has not yet been explored although it is expected to provide a rich area for future exploration [32]. Clearly, D-PBL has much potential as an emerging technology-enabled learning activity type.

Before this study was completed, SGUL decided to implement D-PBL in both its graduate and undergraduate (school-leaver) curricula in the common transitional year between campus-based learning and clinical attachments. This decision was based solely on tutor and student feedback. D-PBL is now running in both SGUL and the University of Nicosia, Cyprus (UNic), and in 2015 it will be implemented in the curricula of 6 further institutions in the ePBLnet consortium, a European Commission-funded program [33] implementing SGUL-style PBL. This will broaden the opportunity for further studies exploring the impact of D-PBL.

With successful implementation of the D-PBL model, our attention has turned to where the decision-making capabilities

of virtual patients in PBL can be further improved. There are 3 Web-based developments in this issue that describe alternative approaches, each of which has the potential to add to the model we describe here. Kononowicz et al [34] described a method that extends the options and consequences model by permitting students to make management choices and then augmenting the interactivity of virtual patients with computational models of physiological and pathological processes. The study proposes a conceptual framework for the integration of computational models within virtual patients, discusses pilot implementations of this approach, and considers critical factors in integrating systems in this way.

Antoniou et al [35] considered the ways in which multimedia-rich 3-dimensional multi-user virtual environments (MUVE) may provide more authentic and immersive experiences for learners. The study considers the suitability of the Second Life MUVE as a virtual patient deployment platform for undergraduate dental education and explores the challenges for the successful repurposing of virtual patients from the Web to the MUVE, including case complexity, decreased textual narration, and allowing learners to go beyond narrative questions and answers.

Salminen et al [36] took a different direction and focused more on reflective practice and communication training. Rather than being based on a series of options, their model features more open-ended questions allowing free-text answers rather than the branched options used in this study.

All 3 of these interventions have been received favorably by students. The model we have described in this study has relatively low resource implications and further work is needed to establish which interventions can be widely introduced to achieve improved pedagogic value at reasonable cost.

### Conclusions

This study investigated the efficacy of D-PBL, a variant form of Web-based PBL that replaced linear PBL cases with branched virtual patients to present medical learners with alternative patient management decisions and having made a decision to deal with the consequences. Learners were encouraged to consider and discuss courses of action before taking them and to explore the consequences of their actions once they had been taken. Efficacy was measured in exam performance after a semester of weekly D-PBL sessions. It was found that D-PBL led to statistically significant improvement in student performance on key questions linked to the D-PBL process.

If the promise of our findings are borne out and D-PBL proves to be a more efficacious way of structuring learning, at least for students who have already had a year or more of traditional PBL, then this has the possibility of being a major contribution to medical education. Although our findings are provisional pending further studies in and around the D-PBL model, we propose Web-based D-PBL as a candidate activity model for improving medical education through the inclusion of structured debate and decision making in small-group learning.

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## Conflicts of Interest

None declared.

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## Abbreviations

**D-PBL:** decision–problem-based learning

**MUVE:** multi-user virtual environments

**PBL:** problem-based learning

**SGUL:** St George's, University of London

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