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## Editorial

# "Is Cybermedicine Killing You?" - The Story of a Cochrane Disaster

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## Abstract

This editorial briefly reviews the series of unfortunate events that led to the publication, dissemination, and eventual retraction of a flawed Cochrane systematic review on interactive health communication applications (IHCAs), which was widely reported in the media with headlines such as "Internet Makes Us Sick," "Knowledge May Be Hazardous to Web Consumers' Health," "Too Much Advice Can Be Bad for Your Health," "Click to Get Sick?" and even "Is Cybermedicine Killing You?" While the media attention helped to speed up the identification of errors, leading to a retraction of the review after only 13 days, a paper published in this issue of JMIR by Rada shows that the retraction, in contrast to the original review, remained largely unnoticed by the public. We discuss the three flaws of the review, which include (1) data extraction and coding errors, (2) the pooling of heterogeneous studies, and (3) a problematic and ambiguous scope and, possibly, some overlooked studies. We then discuss "retraction ethics" for researchers, editors/publishers, and journalists. Researchers and editors should, in the case of retractions, match the aggressiveness of the original dissemination campaign if errors are detected. It is argued that researchers and their organizations may have an ethical obligation to track down journalists who reported stories on the basis of a flawed study and to specifically ask them to publish an article indicating the error. Journalists should respond to errors or retractions with reports that have the same prominence as the original story. Finally, we look at some of the lessons for the Cochrane Collaboration, which include (1) improving the peer-review system by routinely sending out pre-prints to authors of the original studies, (2) avoiding downplay of the magnitude of errors if they occur, (3) addressing the usability issues of RevMan, and (4) making critical articles such as retraction notices open access.

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## A Series of Unfortunate Events

*If you are interested in stories with happy endings, you would be better off reading some other story. In this story, not only is there no happy ending, there is no happy beginning and very few happy things in the middle. [-Lemony Snicket, A Series of Unfortunate Events]*

On October 16, 2004, three press releases from the University College London (UCL) ([Multimedia Appendix 1](#)), Wiley InterScience in the United Kingdom, publishers of The Cochrane Library, and the Center for the Advancement of Health (CFAH) in the United States were widely disseminated to announce the result of a just-published Cochrane review synthesizing "studies on Internet health" (UCL press release) or, more accurately,

interactive health communication applications (IHCAs) [1]. The Cochrane review seemed to arrive at stunning results that "confound conventional wisdom" (quote of the Principal Investigator, taken from the UCL press release): the Cochrane investigators found that these applications lead to an increase in knowledge and positive feelings of social support, but they had deleterious effects on health outcomes, that is, "may leave [users] in worse health" (UCL press release). These surprising results were immediately jumped on by the mass media and led to widely publicized news stories around the globe, with often sensationalistic and oversimplified headlines, such as "Internet Makes Us Sick," "Knowledge May Be Hazardous to Web Consumers' Health," "Too Much Advice Can Be Bad for Your Health," "Click to Get Sick?" and even "Is Cybermedicine Killing You?" (see [Figure 1](#), [Table 1](#), and [Multimedia Appendix 2](#)).

**Figure 1.** A collage of headlines reporting on the IHCA Cochrane review**Table 1.** Epidemic of misinformation: selected headlines from around the world reporting the results of the flawed Cochrane review, compiled in October 2004 (as of June 2005, most of these articles are still online, and not a single one carries a note on the retraction)

<b>Web Not Always Safe Health Source for Some</b> HON News (Health on the Net Foundation), Switzerland - Oct 21, 2004	<b>Internet medical advice risky</b> Big News Network.com, Australia - Oct 18, 2004
<b>Patients using the Net at risk: report</b> The Age, Australia - Oct 17, 2004	<b>Internet-based health information may be hazardous: study</b> CBC News, Canada - Oct 18, 2004
<b>Too Much Advice Could Be Bad for Your Health</b> HealthCentral.com - Oct 18, 2004	<b>Warning on internet health advice</b> Onlypunjab.com, India - Oct 18, 2004
<b>Too much information bad for your health, study shows</b> E-Health Insider, UK - Oct 18, 2004	<b>Click To Get Sick?</b> TIME - Oct 25, 2004
<b>Study: Internet Medical Advice Could Have Unintended Consequences</b> ihealthbeat, USA - Oct 18, 2004	<b>Internet makes us sick</b> The Times, UK - Oct 22, 2004
<b>Knowledge May be Hazardous to Web Consumers' Health</b> Newswise (press release) - Oct 17, 2004	<b>Warning on internet health advice</b> BBC News, UK - Oct 17, 2004
<b>Patient, don't try to heal thyself</b> DMeurope.com, Netherlands - Oct 19, 2004	<b>Beware of Internet health advises</b> Pravda, Russia - Oct 18, 2004
<b>Web Not Always Safe Health Source for Some</b> Forbes - Oct 21, 2004	<b>Warning over bad health advice online</b> Medical News Today, UK - Oct 18, 2004
<b>Logging on can make you sicker</b> ABC Science Online, Australia - Oct 19, 2004	<b>Fears over health 'cures' on the web</b> The Scotsman, UK - Oct 18, 2004
<b>Too much Internet advice is bad for your health: study</b> Canada.com, Canada - Oct 18, 2004	

Few reporters seemed to have read the review, which actually did not speak about health websites or "the Internet" (as suggested in the press release and subsequent media reports) but of "Interactive Health Communication Applications (IHCAs)." According to the Cochrane review, the defining feature of an IHCA is "that it does not simply provide health information, but combines such information with at least one (and frequently more than one) additional service [such as] decision support, behaviour change support or peer support" [1], which excludes information-only websites. Ignoring this, the press release spoke of the "Internet" and contained statements like "knowledge-seekers become so steeped in information from the Internet they make treatment choices on their own, contradicting advice from their doctors." Many news outlets reprinted the press release verbatim, which also stated that "people who use their computers to find health information often wind up in worse condition than if they had listened to their doctor," or rephrased this into "Some people with chronic health problems who seek online advice would be better off just listening to their doctors." Some journalists even condensed this to "Patient, don't try to heal thyself." Statements like this—emphasizing that people should better listen to their doctor rather than going on the Web—made consumers, patients,

self-care advocates, and eHealth experts wince, not only because they seemed factually questionable, but also because they were reminiscent of a dark pre-Internet era of paternalism and "doctor knows it all" mindsets, which many thought were long behind us [2-6].

Most eHealth researchers are driven by the belief that the Web and other interactive media applications play a major role in supporting patients with chronic conditions. At the same time, we are all for being on the cautious side, viewing eHealth applications with a critical eye, knowing that some people will not benefit from them, stressing that badly designed applications can harm patients, and monitoring unintended side effects and potentially negative outcomes [7]. Still, many eHealth researchers were surprised and angered by the sweeping and blatant comments stemming from this review, which seemed to ignore the growing literature on the effectiveness of many eHealth interventions, some of which have been published in this journal. Most researchers familiar with the literature know that the vast majority of such reports are actually positive—in fact, the proportion of positive studies is so overwhelming that it has been questioned whether negative studies are underreported [8].

**Figure 2.** The original (flawed) figure from the retracted Cochrane review [1], showing the reverted effect estimates favoring the control rather than IHCAs

The series of unfortunate events culminated when the scientific eHealth community debunked the Cochrane review as a "methodological disaster" [9]. Among several other flaws (outlined below), the review included severe extraction (or coding and data interpretation) errors leading to a complete reversal of the outcomes. Positive outcomes in the primary studies (such as reduction in encopresis [10]) were misinterpreted as negative (harmful) effects. As Per Egil Kummervold and colleagues listed in the feedback section of the Cochrane Library on October 28, 2004, at least 8 of 11 outcomes were reversed—letting the effect estimator appear on the left side ("favours control") instead on the right side ("favours intervention"). See [Figure 2](#), which shows the flawed figure from the Cochrane review, and [Multimedia Appendix 2](#), which shows corrections made by Kummervold et al.

These were stunning errors because anyone who read these primary reports could not possibly have come to the conclusion that any of these studies reported less favourable health outcomes in the IHCA groups. To date, it remains a mystery how respected and experienced investigators could arrive at these conclusions (unless investigators relied on research assistants or students to extract the data and did not bother to read the studies themselves, which is an unimaginable scenario for a Cochrane review). These errors were obviously magnified by aggressive marketing efforts of the investigators and publisher, who sent out three press releases that did not in any way caution readers about the results.

When the review was eventually retracted by the authors on October 29, 2004—only 13 days after the press release—the public hardly took notice. As illustrated in an article by Roy Rada in this issue of JMIR [11], the media remained quiet, too quiet. To date, many publications have not published any follow-up stories, and the impact will be long-lasting. As the Rada paper shows, the Web is still full of reports on the flawed Cochrane review, and Rada identified only one newspaper story about the retraction—the Canadian journalist said he found this out only by chance. (We are also aware of a report by Frith Rayner, published in the *Australian Doctor*, courtesy of Lee Ritterband.) The failure of the media to report the retraction has to do with either the fact that they simply did not know about it or with issues around how the media decides what will be newsworthy ("if it bleeds, it leads," "bad news are good news"). Another reason why it was not taken up could be that the press release reporting the retraction was not very clear in highlighting the magnitude of the error, and it contained little more than the message that the review was being reworked and that it was too early to say what the result would be. Few journalists would have understood that the errors invalidated the results completely, even reversed them.

Rada analyzes the impact of the review and draws a few lessons, some of which shall be complemented by this editorial, not least because the authors of this editorial were involved in the events that eventually led to a retraction.

## The Emperor Without Clothes

In a curious way, the media attention this review received—as detrimental as it was in sending out a false message to the

public—also had a positive side in that it probably also sped up the identification of the errors. Without the media frenzy the results would possibly have remained unnoticed for a while, but with the worldwide media attention, peers quickly heard about the review.

For example, the editor of this journal (Gunther Eysenbach) was contacted by a journalist when the press release came out, was among the first who looked closely at the original review on October 16, and was one of the first who blew the whistle, pointing out that this emperor did not have clothes. Having read many of the primary studies that were pooled in the review, having done several systematic reviews in this area, and knowing the results of another review which JMIR published around the same time [12], he told the journalist who contacted him that the study seemed flawed. On October 25, he also posted a message on the Medical Webmasters Mailing List (MWM-L), where some researchers had started to discuss the study, warning readers not to take the review at face value [9].

Around the same time, on October 24, another researcher, Lee Ritterband—whose research was cited in the review and who had not seen a pre-print of it prior to publication—was alarmed by media reports and commented in a mailing list for Internet health intervention researchers: "While it is possible that some people may be worse off, we know that our interventions are quite effective, and this kind of fear-inducing 'findings' are the types of comments which our research, in part, must debunk." (Ritterband, personal communication, June 15, 2005). On the other side of the Atlantic, Per Egil Kummervold and colleagues at the Norwegian Centre for Telemedicine had also noticed that the numbers did not add up. They started a thorough investigation, reviewing the original data material, and on October 28 they notified the Cochrane Collaboration that the authors had made almost inconceivable mistakes, including reverting the direction of the results. On October 29, 2004, the review was retracted.

## The Three Principal Flaws

### **Data Extraction and Coding Errors**

The most devastating (and most obvious) error was the previously discussed blatant mistake of misinterpreting positive outcomes as negative outcomes (and vice versa). Kummervold's original list of errors is documented in [Multimedia Appendix 2](#).

### **Pooling Heterogeneous Studies**

The second concern is that the studies were too heterogeneous to sensibly attempt a formal random effects meta-analysis using Cochrane's RevMan software. The resulting effect estimates are meaningless. The review guidelines of the Consumers and Communication Group state the following: "They [systematic reviewers] should also use caution when extracting and interpreting data, and when deciding whether to combine them statistically. Combining disparate data quantitatively may not always be appropriate, and qualitative synthesis may often be preferable" [13].

This is particularly true for pooling health outcomes, but equally problematic is to pool knowledge scores and behaviour change



and social support measures from studies with interventions that had very little in common except that they were delivered electronically. Comparing different IHCA against controls and pooling these results without paying any attention to the "ingredients" is like comparing all studies in which investigators used "blue pills" in the intervention arm—a pooling on the basis of the delivery mechanism rather than the "ingredient" is of limited value. And for every successfully IHCA-delivered intervention, one can probably find a similar intervention which is delivered on a badly designed IHCA, which does not mean that IHCA per se are inappropriate delivery mechanisms.

A richer, deeper qualitative analysis to answer questions like "what seem to be the success factors in terms of how the intervention and the trial should be designed" would have been more appropriate and more informative. Qualitative synthesis prevents us from drowning in a river that on average is only 3 feet deep.

As an aside, while the authors focused on extracting outcome measures which could support their postulated pathway of action, it would have been very informative to extract and report attrition rates as secondary outcomes (ie, the percentage of users who dropped out and/or did not use the application), not only because nonuse of the application may explain a lack of an effect, but also because such data from numerous studies could be useful in identifying some of the factors (predictors) for nonuse/dropout as postulated in the "Law of Attrition" [14]. In health informatics, issues around adoption are at least as important as health outcomes [15], and systematic reviews in this area should try to extract and synthesize adoption measures.

### Scope and Lack of Comprehensiveness

The third problem with the IHCA Cochrane review, which has not yet been discussed on the Cochrane feedback section, is the scope of the review and the lack of truly comprehensive searches within the scope the authors defined. The scope may be too broad in some respect (making the review unmanageable and confusing by lumping together too many different applications), and too narrow in others (eg, by excluding pure patient-doctor or peer-to-peer communication, or by focusing on chronic diseases).

In particular, the authors decided to exclude electronic decision aids and computer/Internet-delivered cognitive behavioural therapy (CBT) programs. High-quality CBT applications, such as ODIN (Overcoming Depression on the InterNet), were not cited in the review [16]. This creates a considerable bias, as CBT applications are among the most successful interventions. These important exclusions were neither mentioned in the press release nor in any media reports.

There is also some confusion about the scope of the review, in particular, whether applications that provide social support by enabling peer-to-peer communication were included. The original definition of the Science Panel on Interactive Communication and Health [17] of the term "IHC application" is as follows:

*[IHCA are] the operational software programs or modules that interface with the end user. This includes health information and support Websites and clinical*

*decision-support and risk assessment software (which may or may not be online), but does not include applications that focus exclusively on administrative, financial, or clinical data, such as electronic medical records, dedicated clinical telemedicine applications, or expert clinical decision-support systems for providers.*

However, the Cochrane review team narrowed this definition by only including studies on applications that, apart from delivering health information, had another component (eg, decision support, peer-to-peer support), thereby excluding simple information-only websites. The fact that simple health information sites were not in the scope of the review was not communicated properly in the press release and was widely misunderstood by the media. Journalists reported, for example, that "the study found no evidence that Web health information [*sic*] helps people with chronic diseases" (*HealthDayNews*) or that "people who use their computer to find out more about their condition end up in worse health than those who do not" (*The Times*). While the Cochrane investigators may have had good reasons to exclude simple health information websites, there was a remarkable divergence between what the public understood the review was about and the actual inclusion criteria. Leaving aside all other flaws, such as coding errors, it appears problematic to issue press releases that suggest that the Internet is harmful when the actual review excluded things like websites, Internet-based CBT programs, and possibly even peer-to-peer support groups.

On the latter point, the definition of IHCA used by the Cochrane review team leaves considerable ambiguity about whether or not "pure" peer-to-peer groups are in the scope of the review—and ambiguities at the protocol stage are often a recipe for disaster [18]. One may argue that peer-to-peer support on the Internet is always embedded in a wealth of health information on the Web and would therefore meet the definition and fall within the scope of this review.

A final concern is that a comparison with another systematic review [19] suggests that the searches were less than comprehensive or that the reference screening process was sloppy. In a systematic review on applications with peer-to-peer components [19] (which was not cited in the Cochrane review), 20 randomized controlled trials of IHCA (all of which had peer-to-peer components) were identified. Of these, only 6 studies were included in the Cochrane review, 3 were excluded, but more than half (as many as 11 studies [20-29]) were not cited or mentioned in the Cochrane review, although many of them appear relevant or should at least have been explicitly excluded (see [Multimedia Appendix 3](#)). While it is admittedly difficult (or impossible) to find all relevant papers in this area, the fact that more than half of the studies from a previously published systematic review were not cited is disturbing.

## *What the Various Parties Should Learn From This*

### **Retraction Ethics**

In the "publication ethics" literature, which deals with scientific misconduct such as duplicate publication, underreporting, and authorship issues, there is remarkably little discussion on how retractions due to error or misconduct should be handled by investigators and the media. In the case discussed here, the Cochrane Collaboration and the investigators were, as the Rada paper [11] shows, not very effective in getting word of the retraction out to the public. Obviously, there are also very little incentives for the investigators' organization or the publisher/editor to blare out an embarrassing error with the same vigour as the original report. One may argue that it is a matter of ethics to try to match the aggressiveness of the original dissemination campaign if errors are detected and a wrong story needs to be corrected. Researchers and their organizations may have an ethical obligation to track down journalists who reported the misinformation and to specifically ask them to publish an article correcting the error.

Similarly, in our view there is an ethical duty for journalists to respond to such requests and to react to reports on errors or retractions with stories that have the same prominence as the original story. In other words, if the original report was worth a space on the title page, the retraction should be reported on the same prominent spot. In cases for which it is possible to change or add something to the original story (online articles), this should also be done.

### **Responsibility of the Cochrane Collaboration**

#### *No Systemic Failures?*

The Cochrane press release that was issued when the original report was retracted contained the following statement: "The Cochrane Collaboration regrets that this particular review was found to contain inaccuracies, apologises unreservedly, has acted swiftly to mitigate both this error (which arose from individual error and not systemic failures) and the likelihood of it being repeated, and undertakes to ensure that the corrected results are published as soon as possible" (Cochrane press release).

What is interesting here is that it took the Cochrane Collaboration only a few days to determine that there were no "systemic failures," which, in our view, is questionable. Perhaps a better approach would have been to set up an independent group to analyze the mistakes made and to wait for them to come back with some recommendations, rather than swiftly dismissing any possibilities for systemic errors.

#### *Failure of the Pre-Publication Peer-Review System*

One remarkable and obvious "systemic" problem seems to be the apparent total failure of the pre-publication peer-review system. Most eHealth researchers (and certainly those whose work was cited in the review) state that it took them only minutes to figure out that something was wrong with the review, which suggests that the 4 peer reviewers who reviewed the manuscript were not intimately familiar with the work done in

this area. One potential policy change that the Cochrane Collaboration may have to make is a *requirement* to invite authors of the primary studies to comment on the systematic review, a sort of semi-open peer review. Rada suggests making the peer review completely open to the public, which is another consideration. One could for example use pre-print servers [30] to post drafts of reviews before they are published. However, this would diminish the newsworthiness of such reports [31] and, due to the Ingelfinger rule, may prevent such reports from being published in other academic journals [32].

#### *Has the Magnitude of the Errors Been Downplayed?*

As noted above, the Cochrane Collaboration and the investigators have not been successful in getting the word out about the error in a timely manner. It is not sufficient to wait for a corrected version to appear (which was promised for April 2005), hoping that the media and the public will remember the original story and correct their impressions of it. The press release issued by Cochrane seems to downplay the severity of the errors. It does not say that the errors were so grave that they literally led to a reversal of the conclusions, even though it was clear to any informed observer that the initial message Cochrane disseminated was the 180-degree opposite of what should have been reported.

The admittance of an error was half-hearted, and the marketers at Cochrane tried to use even the retraction press release as an opportunity to emphasize how good Cochrane reviews are compared with non-Cochrane reviews: "It has been demonstrated that Cochrane Systematic Reviews are of comparable or better quality and are updated more often than the reviews published in print journals" [33]. It would have been wiser in this situation to cite a paper with a very similar focus [12], which happened to appear in this journal (JMIR), rather than citing a paper that suggests that reviews developed outside of Cochrane are usually of worse quality, even though in this case the situation was exactly the opposite.

#### *Usability of RevMan*

Another issue Cochrane should carefully look at is the usability of RevMan, the software used to support meta-analyses. From the experience of one of the authors (GE), RevMan clearly has some usability issues, most notably that it is far too easy to accidentally "flip" the direction of outcomes. This may have been a contributing factor to the errors in this case. The principal investigator wrote in the Cochrane Communication Consumer and Communication Group newsletter that "RevMan has a mind of its own and I don't think I could have managed it without our very own IT whizzkid,...the lead research fellow on the review" [34]. If software is so difficult to use that it takes an "IT whizzkid" to enter the data (as opposed to the medical experts who understand the primary papers), errors seem to be pre-programmed.

#### *At Least Retractions Should Be Open Access!*

The Cochrane Library is (amazingly) still not an Open Access publication. This may have been a contributing factor to why the retraction remained largely unnoticed by the public and many fellow researchers. The UCL press release ([Multimedia Appendix 1](#)) refers readers to the Wiley website, which is

subscription-access only. Even the "Reason for Withdrawal" cannot be accessed by nonsubscribers (as of May 30, 2005). Shouldn't at least retraction statements be made open access,

and shouldn't this be a standard practice across all toll-access journals?

**Figure 3.** The "Reason for Withdrawal" behind closed doors—only subscribers have the privilege of learning about the retraction (as of May 30, 2005)



## The Damage Done

Fortunately, this particular Cochrane review warning patients to abstain from a specific type of intervention was not about a drug or other clinical intervention, whose withdrawal could have cost lives.

But damage was done: statements in the press release suggesting that "patients are better off listening to their doctor than going to the Internet" have outraged patient advocates (rightly so) and eroded the public's trust in the medical profession, which appeared to warn of the dangers of the Internet for selfish reasons. This was expressed in a posting by a patient on the BrainTalk forum, who wrote, "If the medical profession had its way this forum would be illegal" [35].

The myth of the Internet causing harm to your health may be here to stay, at least for a while, and policy makers and

researchers searching the Web for evidence on the effectiveness of IHCA's will inevitably run into media remnants of the Cochrane review and cite it without bothering to read the original or corrected version. While Rada [11] failed to find any citation to the review in the Web of Science database (which is not surprising since in most traditional journals [not JMIR] it takes many months or years from submission to publication), one of the authors (GE) has already seen, as a peer reviewer, one book chapter and one thesis citing the Cochrane review without mentioning the retraction status.

It is our hope that by publishing this editorial and the Rada paper we do our part in making the public and the research community aware of this series of unfortunate events. While much of the damage created in this case is irreversible, lessons should be learnt so that future disasters can be avoided.

## Acknowledgments

PEK wishes to thank Professor Per Hjortdahl for assistance in analyzing the source material of the Murray review and in communicating the errors found to the Cochrane Collaboration.

## Conflicts of Interest

Both authors have been involved in this case as whistleblowers. GE used to be involved in the Cochrane Consumers and Communication Group as the Cochrane Skin Group.

## Multimedia Appendix 1

UCL press release [[PDF File, 52K - jmir\\_v7i2e21\\_app1.pdf](#)]

## Multimedia Appendix 2

Errors in outcomes [[PDF File, 72K - jmir\\_v7i2e21\\_app2.pdf](#)]

## Multimedia Appendix 3

Potentially missed studies [[PDF File, 120K - jmir\\_v7i2e21\\_app3.pdf](#)]

## Multimedia Appendix 4

Media responses [[PDF File, 4.2M - jmir\\_v7i2e21\\_app4.pdf](#)]

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## Abbreviations

**IHCA:** interactive health communication application

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Tutorial

# The Information Architecture of Behavior Change Websites

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## Abstract

The extraordinary growth in Internet use offers researchers important new opportunities to identify and test new ways to deliver effective behavior change programs. The information architecture (IA)—the structure of website information—is an important but often overlooked factor to consider when adapting behavioral strategies developed in office-based settings for Web delivery. Using examples and relevant perspectives from multiple disciplines, we describe a continuum of website IA designs ranging from a matrix design to the tunnel design. The free-form matrix IA design allows users free rein to use multiple hyperlinks to explore available content according to their idiosyncratic interests. The more directive tunnel IA design (commonly used in e-learning courses) guides users step-by-step through a series of Web pages that are arranged in a particular order to improve the chances of achieving a goal that is measurable and consistent. Other IA designs are also discussed, including hierarchical IA and hybrid IA designs. In the hierarchical IA design, program content is arranged in a top-down manner, which helps the user find content of interest. The more complex hybrid IA design incorporates some combination of components that use matrix, tunnel, and/or hierarchical IA designs. Each of these IA designs is discussed in terms of usability, participant engagement, and program tailoring, as well as how they might best be matched with different behavior change goals (using Web-based smoking cessation interventions as examples). Our presentation underscores the role of considering and clearly reporting the use of IA designs when creating effective Web-based interventions. We also encourage the adoption of a multidisciplinary perspective as we move towards a more mature view of Internet intervention research.

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**KEYWORDS**

Health behavior; Internet; behavioral research; information architecture; cigarette smoking; tobacco

## Information Architecture Designs

Attracted by the Internet's tremendous reach, its economies of scale, as well as its ability to foster instantaneous interaction and individual tailoring, behavioral science and health care researchers are beginning to port their individual and group-based interventions to the Internet in increasing numbers [1,2]. These researchers are finding, however, that this translational process is not simple since they are faced with a new set of challenges inherent in adapting their content and interventions to take fuller advantage of the unique capacities of the Internet to encourage measurable behavior change. One of the critical dimensions worthy of greater scrutiny is a website's information architecture (IA), which Garrett defines as the structure of information space to facilitate intuitive access to content and task completion [3]. For example, how much of

an Internet-based behavior change intervention's success—or lack thereof—is due to the format, presentation, and quality of the website's IA apart from the soundness of the underlying theory and substance of the intervention? While the literature is currently lacking on this issue, a logical place to start is to examine common types of website IA and how these designs might best support behavior change processes.

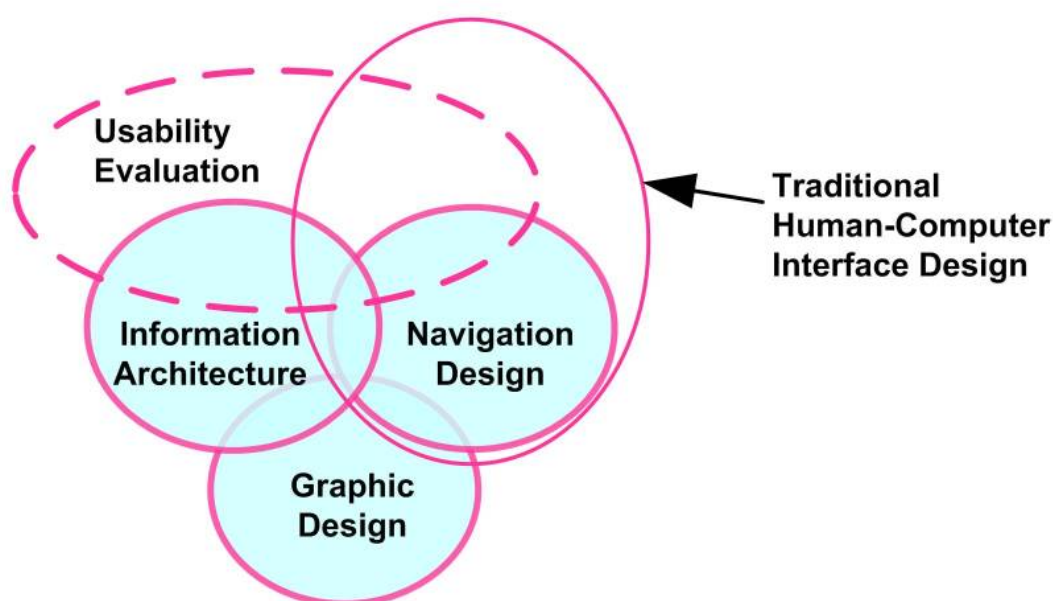
We acknowledge the important role played by reviews that attempt to rate the adequacy of behavior change websites [4-10]. However, we believe that the promise of using the Internet as a delivery channel or modality for behavior change programs also warrants parametric research that focuses on the interaction between website IA features and the requirements of successful behavior change [11].

## Website Design Elements

Rapidly emerging design principles that take into consideration current practices as well as empirical data that describe how users best interact with website content can serve as new guides to the design and information structuring of websites [12,13]. As website conventions become more widely adopted, users will be able to navigate websites successfully without having to process the underlying structural and usability “rules” in a

conscious manner [14-17]. Yet standardization will undoubtedly be a difficult goal to achieve in any final form since new website designs and browser capabilities that try to escape the limitations of today's browser experience inevitably emerge (see Garrett's discussion of Ajax [18]). As depicted in Figure 1, multiple disciplines contribute to the overall design of any website, including graphic design (the visual and aesthetic communication of information), navigation design (methods to help users find their way around a website), and IA (the coherent structure and display of content) [17].

**Figure 1.** Website design elements (used with permission [17])



Users of most websites typically enjoy considerable freedom when it comes to accessing content. For example, they can choose when they want to visit the site, what they want to browse, how much they want to see, how much time they want to spend seeing it, in what order their browsing will occur, what else they might be doing/viewing or listening to while browsing, and whether they want to copy, save, and/or print content as they review it. Some researchers have postulated that this type of unrestricted (*ad lib*) interaction between users and websites shares meaningful similarities with the manner in which wild animals forage for food. From this *information foraging* perspective, users are free to follow the “information scent,” which helps them determine if the effort of the search will be rewarded by finding desired nuggets or *chunks* of information [16,19-21]. “Novice users...perform a kind of *hill-climbing* with information scent as the heuristic for choosing the next step to take” [16].

In this report, we describe IA structures that appear to have particular relevance for websites intended to help users change their health behavior. In particular, we focus on four IA designs: (1) the free-form *matrix* design that offers little information structure, (2) a *hierarchical* design that provides the user with

information arranged in an organized fashion, (3) a *tunnel* design that defines a narrow path with a predefined series of steps, and (4) a *hybrid* design composed of a combination of modules that have their own IA design.

## Matrix Design

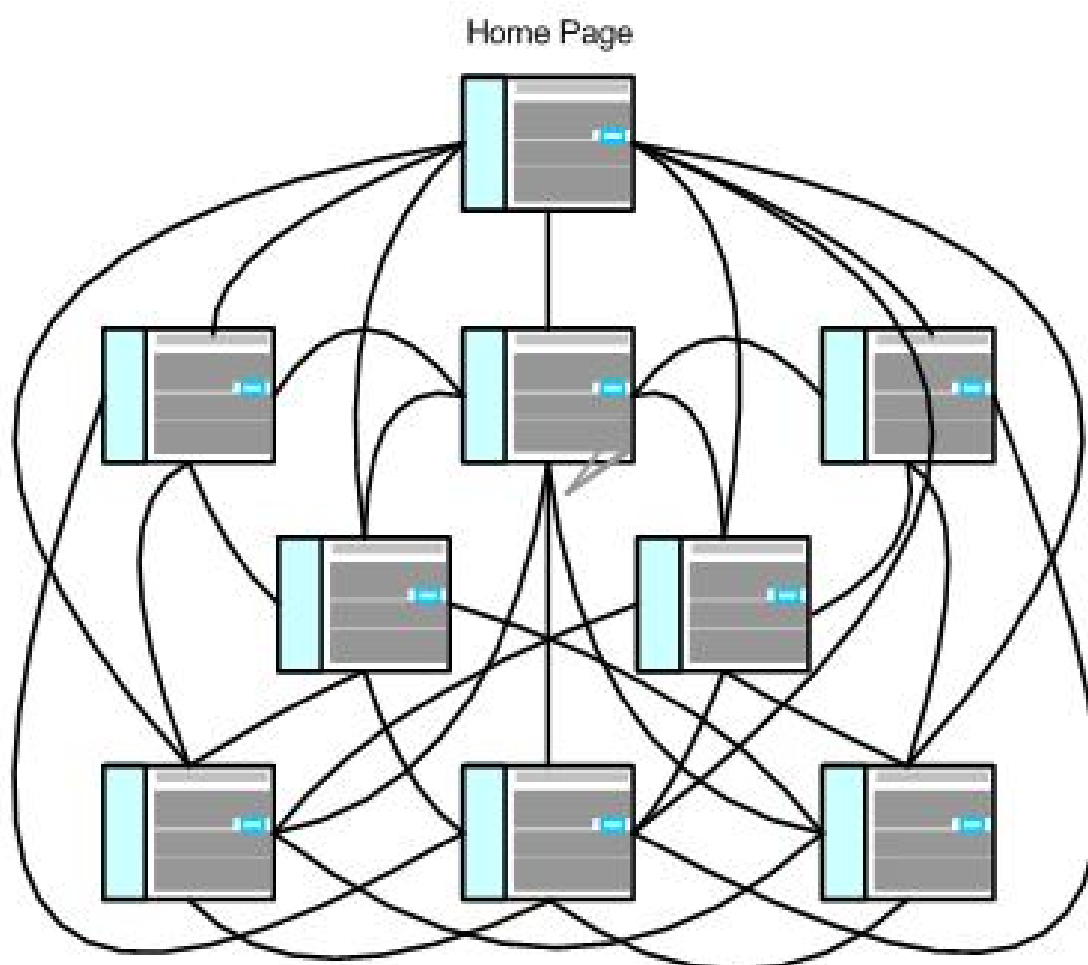
Websites with a matrix IA design embody the principles of the originators of hypertext, HTML, and the Web [22,23], and they take fullest advantage of HTML's hyperlink capabilities to allow users to review all website content (Figure 2). (Note that the lines in Figure 2 that connect Web page icons represent the multiple links that enable users to move from one Web page to another.) In the matrix IA design, users are free to pursue their idiosyncratic interests by using their own path through the available content. When properly created, this design can expedite a user's search of the content. When links are too numerous or do not anticipate a user's search pattern, then the user may well have to search through all available listings. Examples of the matrix design can be readily found in government sponsored websites focused on broad health topics.

## Rationale for use

The matrix design can be very efficient in that it offers the user the maximum amount of content within the confines of a Web page, and it uses multiple links that transport the user to content available on many different pages. It is particularly well-suited for finding information although its efficiency is associated with how well the links anticipate the user's search preferences. Moreover, the freedom of movement and exploration associated with the matrix design may come at a cost because users may become disoriented, quite literally *lost in hypertext*, and may

experience great difficulty when trying to retrace their steps to review what they have already seen [24]. As a result, Lynch and Horton [12,25] have suggested that a website with a matrix design may not be well-suited to helping users become familiar with a new content area. Instead, they recommend that the matrix design is most applicable to small websites that are designed for use by highly educated and experienced users who are already familiar with the basic organization of the content and who are visiting in order to obtain further education or enrichment.

**Figure 2.** Matrix design schematic



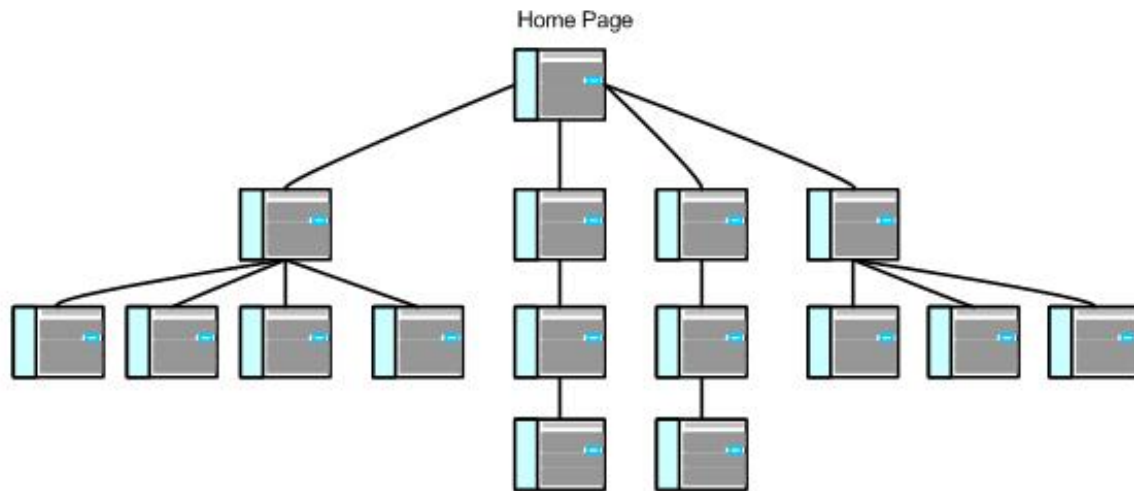
## Hierarchical Design

In hierarchical IA designs, information is organized in a *top-down* manner so that the user can review increasingly detailed content. The user is presented with small *chunks* of information that he/she can rapidly explore in a nonsequential manner. The design depicted in Figure 3 contains three instances of a *one-to-many relationship* in which a single Web page

contains links to the home page and two second-level pages. In contrast to the matrix design (Figure 2), the hierarchical design has significantly fewer links between pages [12,25]. Hierarchical IA designs help users find desired content by locating a broad theme and then *drilling down* into more detailed information. And it is relatively easy to find your way back through content already viewed because it simply involves moving back up the hierarchical structure.



Figure 3. Hierarchical design schematic



**Rationale for use**

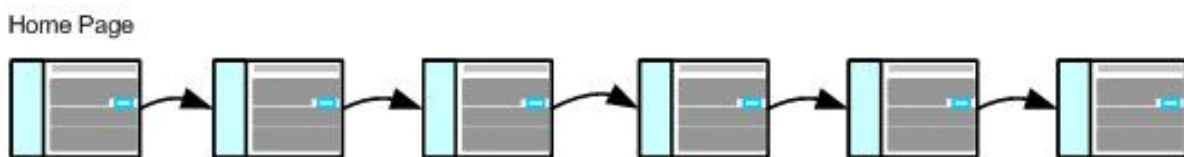
Websites with a hierarchical design tend to reduce the kind of confusion that comes from users being presented with too many links and options (as may be associated with the matrix design). In addition, many users are familiar with information arranged in hierarchical fashion since it is similar to a table of contents design and it mimics the tree-like file directory/subdirectory structure that operating systems use to organize files [26]. Businesses often use hierarchical models to organize information, workgroups, project plans, etc [12,26]. The usefulness of a hierarchical design diminishes if the content is nested too deeply (in too many levels). When this occurs, the burden on the user is increased because of the added effort required to drill down through so much content in order to locate

the desired information [21]. In addition, a user may become confused unless his/her mental model of the content grouping, and even the labels used to describe the content groups, corresponds to the way that content is organized on the website [16,20,25].

*Tunnel Design*

Websites based on a *tunnel* IA design represent the opposite end of the continuum from a matrix design. Instead of free access to content, the user follows a step-by-step (page-by-page) approach (Figure 4). This design eliminates access to any ancillary or related Web pages that are viewed as potential distractions.

Figure 4. Tunnel design schematic



An example of task-based tunnel design is encountered when purchasing items on the Internet. For example, when purchasing travel tickets online, the user typically follows a sequence of steps, each having its own Web page that shows the following: (1) day and time of flight choices, (2) hotel and car rental details, (3) credit card information, (4) purchase confirmation, and (5) booked reservation details. Note that van Duyne et al [17] refer to this online purchasing scenario as a *process funnel*. Another common use of the tunnel design can be found in online surveys [27].

have been derived from the instructional designs found in corporate multimedia CD-ROMs. Almost all e-learning courses adhere to a tunnel design. These typically have a series of lessons that present the content, test for comprehension, and provide remedial loops and other conditional branching [28].

While emerging website design conventions take into consideration matrix or hierarchical designs, there is relatively little agreement on how best to use tunnel IA designs. The structure of many websites with tunnel IA designs seems to

It should be noted that the tunnel IA design presents significant challenges since HTML was designed as hypertext markup for documents rather than a software interface for Web applications. Indeed, creating a tunnel essentially requires the designer to break the rules of the hypertext and the Web in order to guide the user's experience, as is clearly indicated in the guidelines that reviewers of tunnel IA designs have recommended [12,15,17]:

- Display extra information in pop-up windows instead of the browser in order to reduce the possibility that users will leave the tunnel.
- Remove all standard browser tools, including navigation bars, tab rows, location breadcrumbs, and embedded links.
- Limit navigation to “next” and “prior” buttons.
- Provide a progress bar to show users the context of where they are in the process.
- Make it clear how to proceed to the next step.
- Include error messages at the time the errors occur.

Little is currently known about how users accommodate the unfamiliar confines of a website based on a tunnel IA design. Nielsen, a noted Web usability authority, has argued that “...one of the Web's most powerful features is that it lets users control their own destiny. Users go where they want, when they want.... Websites that force users to sit through sequences with nothing to do will be boring and pacifying, regardless of how cool they look” [29].

The challenge may well be to design tunnel websites that encourage users to be patient long enough to become comfortable using an unfamiliar program interface that is designed to keep them from engaging in their typical information foraging behavior. Some may find this to be a frustrating experience. Users who are matriculating through an e-learning program (eg, students, employees receiving online training or obtaining career critical certification) may be more motivated to cope with the frustration and accept the constraints of tunnel designs than would most prospective participants of Web-based behavior change programs. Other users may greatly value the reduced complexity that the tunnel provides, avoiding the information anxiety that can accompany a program that offers a myriad of links and options from which to choose [30,31].

### Rationale for use

There are a number of arguments in favor of designing websites with a tunnel format. The linear model is familiar because it is consistent with the manner in which content is presented in movies [28,32], textbook narratives [26], academic classes, and multiple clinical sessions. Its use assumes that there is some optimal ordering and/or *dosage* of content that is associated with greater effectiveness. In contrast, a matrix design website

affords little control over the order and amount of content actually reviewed.

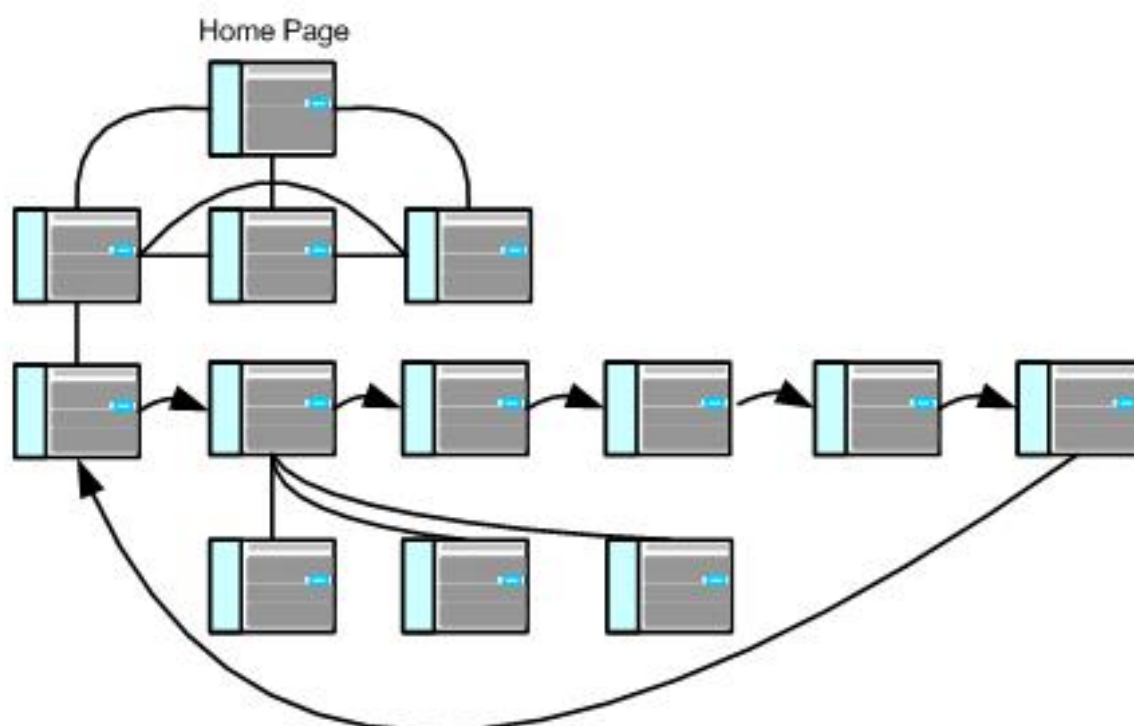
The tunnel IA design is particularly well-suited to fostering the type of *dialog* that can be associated with multi-session programs in which users are assigned tasks to do at home on their own in between online sessions. At the start of a subsequent session, users can be asked about any problems and the progress they experienced during the practice of these tasks. This dialog sets the stage for the program to provide tailored feedback and recommendations. In addition, programs using a tunnel IA design can more carefully titrate the amount of information a user is exposed to in order to reduce the sheer number of strategies and the amount of program content that the user learns and potentially uses.

Finally, it is important to acknowledge that tunnel programs are not, by definition, inflexible. For example, they can be targeted in the sense that content in the tunnel can be adapted to better address a particular demographic audience. They can also be tailored in the sense that the program can contain tests of knowledge as well as comprehension of key learning points, along with remedial loops as necessary.

### Hybrid Designs

Hybrid designs are composed of multiple IA *modules*, each of which can be described along the continuum from matrix and tunnel designs. It is possible to mix and match matrix, tunnel, and hierarchical designs. For example, the hybrid design depicted in Figure 5 uses a tunnel design combined with a module that adheres to a hierarchical IA design that offers users optional, but clearly defined, content while moving along the required sequence of steps. Note in Figure 5 that the user has free access to three Web pages from the home page (a matrix design). On one of these pages the user can choose to enter a program composed of a series of sequential steps (a tunnel design). On the second page of the tunnel design the user can sample from the content of any of three linked pages without interrupting the step-by-step flow of the process. This allows the user to explore content (engage in discovery learning) while still maintaining the focused forward movement of the tunnel program.

Figure 5. Hybrid design schematic #1



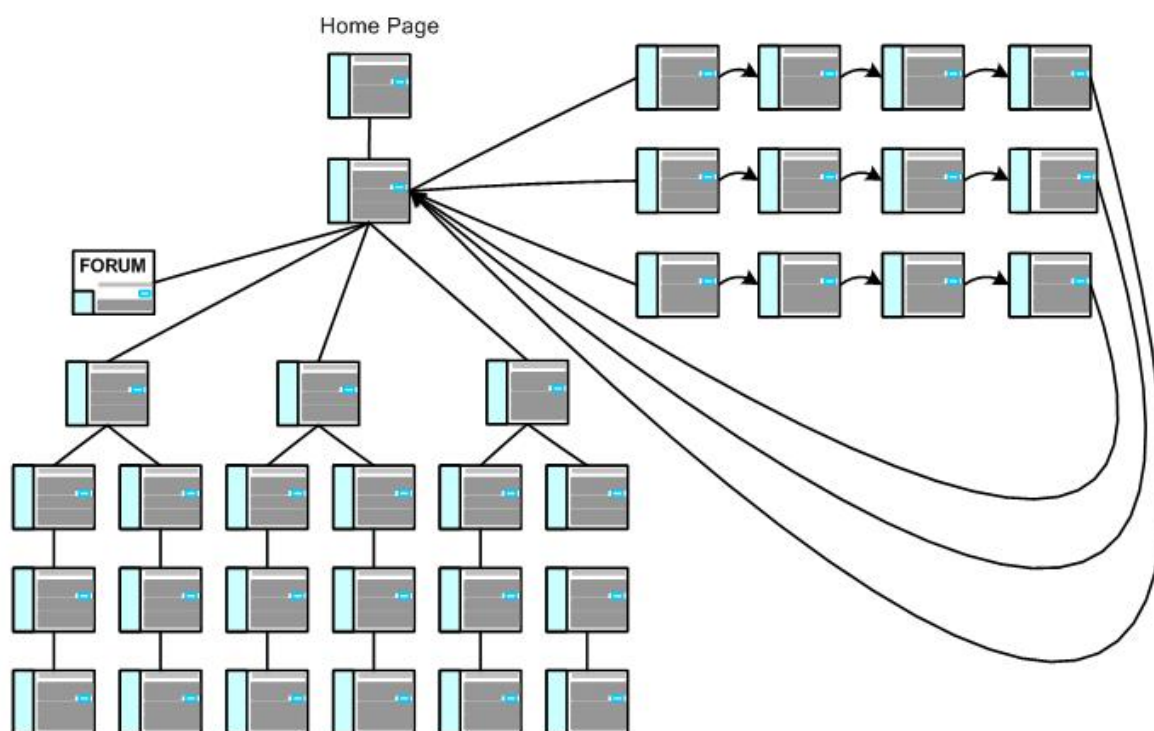
While tunnel designs require few navigational controls other than the *prior* and *next* buttons, ancillary Web pages may have far richer content that requires additional navigational controls (similar to those found in a matrix IA design). Changing navigational tools as users move from ancillary pages back to the sequential tunnel pages can present usability challenges. Similarly, if ancillary pages provide links to Web page resources outside of the behavior change program, some users might choose to leave the current session while others might not be able to find their way back to their point of departure [26].

It is also possible to adapt the tunnel design so that it morphs into a more flexible design once the user has completed a required step of content. When the user has seen *all* of the required content contained in a tunnel (accomplished all of the required steps in the required order), then the IA of that Web-based program can change from a tunnel to a matrix so that the user can freely access any of the available content. Note

that the ease of transforming a website from a tunnel to a matrix IA design is greatly improved when the sites are not created using hand-coded HTML. Instead, these transformations require the development of carefully modularized, data-driven websites that display content based on the interaction of logic scripts (eg, PHP, ASP, ColdFusion), SQL databases, and cascading stylesheets. By capturing and interpreting user data, and then manipulating scripts, databases, and stylesheets, it is possible to adapt the appearance and behavior of websites in real time.

A somewhat more complex hybrid design is depicted in Figure 6. In this example, the user starts out by accessing an initial Web page that contains a welcome and log-in that enables access to a page that provides matrix-like access to seven content areas, including a Web forum, three hierarchical IA designs used to present articles of content in increasing detail, and three tunnel IA design experiences that walk the user through the content in a step-by-step manner.

Figure 6. Hybrid design schematic #2



**Rationale for use**

Hybrid IA designs appear to have a number of distinct advantages over websites that offer only the more orthodox matrix or tunnel designs. For example, hybrid designs can give users more guidance than can be obtained from matrix IA designs. Hybrid designs also allow the user to break free from the lock-step sequence of pages found in a tunnel design. Offering alternative ways of interacting with content can be refreshing. It can spur the user to become more involved in his/her own learning rather than falling into a mode of a passive page turner. Depending upon what is contained on the ancillary Web pages, the user can have a far richer and more effective learning experience and outcome. For example, the potential

impact of ancillary pages in the hybrid design could enable the user to customize his/her experience by joining a Web forum, viewing pertinent video vignettes, or reviewing more in-depth articles.

It is also important to note that hybrid designs may well reduce attrition by users who find the tunnel experience to be too constraining. No matter how efficacious a tunnel-based program is found to be, its effectiveness can be seriously undermined if users find the experience too unfamiliar, inflexible, and, thus, unpalatable.

Table 1 presents an overview of the strengths and constraints of the IA designs discussed in this paper.

Table 1. Summary of IA design features

IA Design	Strengths	Constraints
Matrix	<ul style="list-style-type: none"> <li>• Can move freely through content</li> <li>• Encourages discovery learning</li> </ul>	<ul style="list-style-type: none"> <li>• Links may not anticipate user's search pattern</li> <li>• User can become disoriented</li> </ul>
Hierarchical	<ul style="list-style-type: none"> <li>• Familiar top-down organization</li> <li>• Provides a simplified view</li> <li>• Easy to retrace steps</li> </ul>	<ul style="list-style-type: none"> <li>• Deeply nested information may be difficult to find</li> <li>• Labels may not correspond to how user defines area</li> </ul>
Tunnel	<ul style="list-style-type: none"> <li>• Familiar step-by-step flow through content</li> <li>• Can control timing and amount of exposure to content</li> </ul>	<ul style="list-style-type: none"> <li>• Does not follow familiar website navigation conventions</li> <li>• May cause frustration and reduce follow-through</li> </ul>
Hybrid	<ul style="list-style-type: none"> <li>• Uses multiple IA designs that best fit content and purpose</li> </ul>	<ul style="list-style-type: none"> <li>• Moving between Web pages with different IA designs may present usability challenges</li> </ul>



## Behavior Change Examples: Tobacco Cessation

### Oregon Center for Applied Science

The most recent version of the 1-2-3 SmokeFree Web-based smoking cessation program developed by Oregon Center for Applied Science [33] uses a hybrid IA design in which the user moves through an extended tunnel containing more than 20 sequential steps that address the key topics of addiction, triggers, cravings, picking a quit date, and making a personal quit plan. Eight of these Web pages are based upon a hierarchical IA

design which allows the user to access additional cessation content on other pages. The screen capture of one of these Web pages depicted in Figure 7 shows how the user can either continue to move forward within the tunnel by pressing the *next* button, or, alternatively, can select any of the available links that provide additional tips for dealing with cravings. In this smoking cessation program, the user is able to reverse direction in the program (via the *prior* button or using the expand/collapse features of the left navigation bar) in order to review any of the content already covered. In keeping with the tunnel design, however, the user is encouraged to move forward to work with new content in a required order.

Figure 7. 1-2-3 SmokeFree Web page showing hybrid IA design (tunnel with links to optional ancillary content)



### National Cancer Institute

In another example, a National Cancer Institute (NCI) website on smokeless tobacco [34] presents general information adapted from a booklet into a series of six Web pages that adhere to a tunnel IA design. The user can click to move forward or backward from one page to the next as the content is presented in a linear manner.

Finally, another NCI website (Smokefree.gov) provides an “online guide to quitting” that uses a hybrid design [35]. More specifically, the Website uses a hierarchical IA design that enables users to click on headings in a table of contents that allows them to select and then drill down to learn more about any content area in any order. Once they arrive at more detailed information on deeper Web pages, users see links that allow them to break out of the hierarchy and leapfrog into another broad topic area using a variation on the tunnel IA design: “Move on the Preparing to Quit,” “Move on to Quitting,” and then “Move on to Staying Quit.”

## Discussion

The development of effective Internet-based behavior change programs presents a number of unique challenges. It is reasonable to assume, for example, that the best practice approaches drawn from office-based settings (see, for example, [36]) will need to be adapted to fit the strengths of Web delivery. In addition, the content of behavior change interventions must be presented in a way that is attractive as well as usable in order for it to have beneficial impact.

For example, the more free-form matrix IA designs might be particularly well-suited to a website (or portion of a large website) designed to help users resolve their ambiguity regarding whether or not to engage in a behavior change attempt [37]. Perhaps participants who are more committed and *ready* to change would be best matched with a tunnel IA design that guides them through the step-by-step change (see, for example, [38]). And perhaps any tunnel design behavior change program would be improved by the addition of a module that allows users to explore what is known about the risks and benefits of



making the behavior change as well as their feelings regarding the change.

The rationale for using any particular IA design is largely theoretical rather than validated or universally accepted. We anticipate a period of intriguing discussion and related empirical testing regarding the ways to take fullest advantage of Internet-based programs. Highly relevant topics abound, including websites that use different IA designs, the value of tailoring and targeting content, scheduling of homework tasks and the tracking of progress, roles of media and interactivity, structure and value of community components (eg, Web forums), impact of email and/or phone adjuncts, etc. Early examples exploring these and related research directions have already begun to emerge for different target behaviors, as in diabetes [39], eating disorders [40], post-traumatic stress (see tunnel IA design in [41]), depression [42], smoking cessation [43-46], caregiving [47], and also for tests of different program

components as in formats and user preference for multimedia [48,49].

The speed with which technology is evolving is staggering. The Internet has rapidly become an accepted part of daily life for hundreds of millions of people worldwide. As a result, it is reasonable to conclude that these revolutionary advances will act as a catalyst to expand the scope and impact of both persuasive technology, in general [30,50], and of Internet-based health behavior change programs [51]. We have highlighted the important role that IA designs can have upon the design and likely impact of online behavior change programs. We believe that a broad multidisciplinary perspective is needed in order to better understand the larger context of relevant creative thinking and empirical research, to define and test both theories and strategies, and to deliver more innovative and effective Internet behavior change programs.

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## Conflicts of Interest

None declared.

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## Abbreviations

**IA:** information architecture

**NCI:** National Cancer Institute

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Original Paper

# Overcoming Depression on the Internet (ODIN) (2): A Randomized Trial of a Self-Help Depression Skills Program With Reminders

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## Abstract

**Background:** Guided self-help programs for depression (with associated therapist contact) have been successfully delivered over the Internet. However, previous trials of pure self-help Internet programs for depression (without therapist contact), including an earlier trial conducted by us, have failed to yield positive results. We hypothesized that methods to increase participant usage of the intervention, such as postcard or telephone reminders, might result in significant effects on depression.

**Objectives:** This paper presents a second randomized trial of a pure self-help Internet site, ODIN (Overcoming Depression on the InterNet), for adults with self-reported depression. We hypothesized that frequently reminded participants receiving the Internet program would report greater reduction in depression symptoms and greater improvements in mental and physical health functioning than a comparison group with usual treatment and no access to ODIN.

**Methods:** This was a three-arm randomized control trial with a usual treatment control group and two ODIN intervention groups receiving reminders through postcards or brief telephone calls. The setting was a nonprofit health maintenance organization (HMO). We mailed recruitment brochures by US post to two groups: adults (n = 6030) who received depression medication or psychotherapy in the previous 30 days, and an age- and gender-matched group of adults (n = 6021) who did not receive such services. At enrollment and at 5-, 10- and 16-weeks follow-up, participants were reminded by email (and telephone, if nonresponsive) to complete online versions of the Center for Epidemiological Studies Depression Scale (CES-D) and the Short Form 12 (SF-12). We also recorded participant HMO health care services utilization in the 12 months following study enrollment.

**Results:** Out of a recruitment pool of 12051 approached subjects, 255 persons accessed the Internet enrollment site, completed the online consent form, and were randomized to one of the three groups: (1) treatment as usual control group without access to the ODIN website (n = 100), (2) ODIN program group with postcard reminders (n = 75), and (3) ODIN program group with telephone reminders (n = 80). Across all groups, follow-up completion rates were 64% (n = 164) at 5 weeks, 68% (n = 173) at 10 weeks, and 66% (n = 169) at 16 weeks. In an intention-to-treat analysis, intervention participants reported greater reductions in depression compared to the control group ( $P = .03$ ; effect size = 0.277 standard deviation units). A more pronounced effect was detected among participants who were more severely depressed at baseline ( $P = .02$ ; effect size = 0.537 standard deviation units). By the end of the study, 20% more intervention participants moved from the disordered to normal range on the CES-D. We found no difference between the two intervention groups with different reminders in outcomes measures or in frequency of log-ons. We also found no significant intervention effects on the SF-12 or health care services.

**Conclusions:** In contrast to our earlier trial, in which participants were not reminded to use ODIN, in this trial we found a positive effect of the ODIN intervention compared to the control group. Future studies should address limitations of this trial, including relatively low enrollment and follow-up completion rates, and a restricted number of outcome measures. However, the low incremental costs of delivering this Internet program makes it feasible to offer this type of program to large populations with widespread Internet access.

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**KEYWORDS**

Internet; depression; cognitive therapy; self-help; randomized trial

## Introduction

Several Internet interventions have emerged in recent years to treat mental and behavioral health problems. These interventions provide some of the basic skills training traditionally offered in face-to-face psychotherapies, particularly cognitive behavioral therapy (CBT). This recent trend extends the tradition of bibliotherapy with books, videos [1–3], and computer programs [4]. Mental health Internet interventions have targeted panic disorder [5,6], distress associated with tinnitus [7], and depression [8,9]. Nearly all of these “guided self-help” interventions [10] incorporate the Internet skills training with simultaneous professional staff counseling typically delivered by telephone or email.

Our Internet program, ODIN (Overcoming Depression on the InterNet) [11], shares a CBT approach with these other interventions. However, it is “pure self-help” [10] because it relies solely on skills training delivered by the Internet and eschews the therapist-delivered mental health counseling typical of the other programs. Both guided and pure self-help approaches merit consideration, but the much lower cost of the latter is a significant advantage.

Several of these interventions have been evaluated in randomized trials, with generally positive results on depression symptomatology for *guided* self-help programs [5,7,8]. However, initial trials of *pure* self-help Internet programs failed to impact depression symptoms [9], including our first investigation of the ODIN program [11]. In this earlier study, we randomized 299 adults with highly elevated depression symptoms to either access to the ODIN site, or no access. Participants in both conditions were free to receive treatment as usual (TAU) health care services, including depression medication and psychotherapy. This TAU control condition, consisting principally of antidepressant medication, distinguishes our research from that of most other trials of Internet mental health interventions, which have employed a waitlist control condition. Subjects reported depression symptoms at enrollment and at 4-, 8-, 16-, and 32-weeks follow-up. However, in that trial we found that participants in the intervention group used the ODIN Internet site very infrequently after their initial enrollment session, which may have contributed to the overall negative effects. We concluded that future studies should focus on increasing participant use of the Internet site.

This paper presents the second trial of our pure self-help ODIN program. This time, we added telephone and postcard reminders to the intervention group aimed at increasing participant use of ODIN, and we compared the intervention against a “no access” TAU control condition. We had no hypotheses regarding different website usage attributable to postcard or telephone reminders. However, the latter method required so much more staff time that we wanted to test whether brief telephone contact increased website usage beyond the less expensive postcard reminder. We hypothesized that persons randomized to the ODIN group would report greater reductions in depression

symptoms and greater improvements in mental and physical health functioning. We also report general medical and mental health care service utilization data of participants in the 12 months following randomization.

## Methods

### Subjects and Recruitment

We conducted the study in the Kaiser Permanente Northwest HMO, which has about 440000 members in northwest Oregon and southwest Washington. Our research center is located within the HMO and is scientifically autonomous. The Human Subjects Committee for the HMO approved study procedures.

We employed the HMO's electronic medical record to identify two recruitment groups in 2000: a “depressed” group of adults ( $n = 6030$ ), who received depression medication or psychotherapy in the previous 30 days and had a chart diagnosis of depression; and a “nondepressed” group of adults ( $n = 6021$ ), who did not receive such services and did not have an HMO diagnosis of depression but who was age and gender matched to the first group. We included the latter group to determine whether persons with previously undetected cases of depression might enroll in the study.

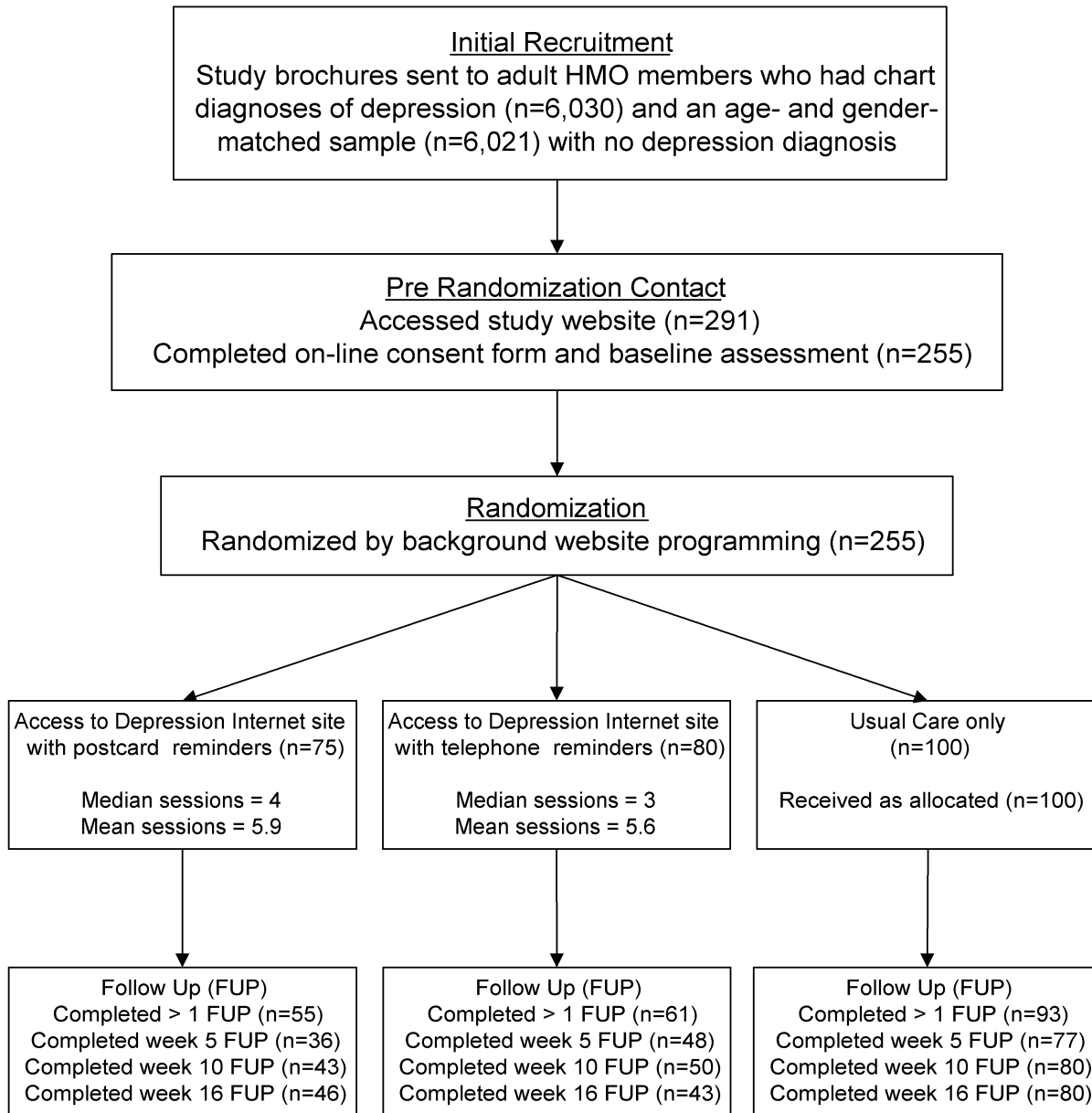
We mailed all potential participants a study recruitment brochure in a plain envelope. The brochure explained the study and provided the Internet address. It was up to the initiative of invited individuals to visit the study Internet site.

After receiving the study recruitment brochure, participants entered confirmed HMO membership numbers at the study home page and proceeded to the online consent form and baseline assessment battery. Subsequently, participants were automatically randomized by the website (using random sequence software) to one of the three groups. Participants in the TAU control group were denied access to the ODIN intervention. Instead, they were linked to an HMO health information website which provided information about depression but no interactive skills training. Participants in the remaining two intervention groups were given immediate access to the ODIN intervention and received either US mail postcards or brief (< 5 minutes) telephone reminders from non-clinician study staff at 2, 8, and 13 weeks after enrollment. The telephone reminder calls were scripted to convey information identical to that included on the postcard reminders. Staff first identified themselves and the study, then reminded participants of the ODIN website address and gave instructions for looking up forgotten passwords. They read a brief description of a feature of the website designed to entice the participant to make a return visit and then concluded the call. The reminder staff had no mental health background, and they were prohibited from engaging in any therapy-like activity. Staff were capable of, and limited to, answering questions only about basic website troubleshooting (eg, difficulty logging on or accessing questionnaires). [Figure 1](#) provides a summary of the study process.



Participants in all conditions were free to obtain any traditional mental or physical health care services and access any Internet health resources. Participants were not blind to their study condition.

Figure 1. Study flowchart



**Assessment Battery**

At baseline and at each follow-up, participants completed an online version of the Center for Epidemiological Studies Depression Scale (CES-D) [12], a self-report measure of 20 depressive symptoms. Participants also completed the Short Form 12 (SF-12), a measure of health-related functioning [13,14]. A Physical Component Summary (PCS) scale and a Mental Component Summary (MCS) scale were computed from the SF-12 items [15].

Computerized depression instruments generally yield psychometrics equivalent to paper versions [16]; both versions of the CES-D correlate highly ( $r = .96$ ) [17]. Patients often

prefer computerized methods for reporting sensitive health topics [16].

Subjects in all conditions were sent email reminders to complete the online follow-up questionnaires at 5, 10, and 16 weeks after enrollment. Study staff telephoned participants who failed to respond to two email reminders for any assessment. Participants received US \$5, \$10, \$15, and \$20 gift certificates to Amazon.com for completing the baseline and subsequent assessments.

**Intervention**

The ODIN Internet intervention (www.feelbetter.org) was a pure self-help program offering training in cognitive

restructuring [18,19]. (See the Multimedia Appendix of our previous report [11] for screenshots.) We did not employ any behavioral therapy or behavioral activation techniques. Intervention content was adapted from CBT psychotherapy manuals [20,21] successfully employed in randomized trials [22–25]. The intervention was organized in seven “chapters,” each presenting a new technique via interactive examples and practice opportunities. Tutorials included the self-assessment of mood, identification of unrealistic thoughts, and generation of realistic counter-thoughts. Participants randomized to the intervention conditions were able to use the program at any time.

A representative module was the “Thought Helper.” Participants typed their personal negative or irrational thought into a text box and then clicked on a search button. The Web server searched a predefined list of 300 negative thoughts for examples that best matched the negative thought submitted by the participant and returned a list of the most likely matches. Participants selected the displayed negative thought that they thought was closest to their original. The program then returned a list of several possible realistic counter-thoughts relevant to that belief. Users were encouraged to create a personalized counter-thought using relevant portions of the provided examples and enter it into the website for storage. Users could later retrieve their own personal counter-thoughts, unrealistic beliefs, and activating situations.

We did not actively monitor the participant interactions for suicidal thoughts or behaviors, but instead provided links to the non-research HMO psychiatric emergency services staffed by professional mental health providers.

### Health Care Utilization

HMO computer systems provided data for inpatient and outpatient services, prescriptions, emergency room visits, and other utilization. Non-HMO health care services were not assessed.

### Analysis Plan

We examined CES-D and SF-12 scores using random effects regression analyses, modeling an unstructured covariance matrix, with slope and intercept as random effects. The test of difference between groups is a test of the difference in these slopes over time. The random effects modeling includes all data on all participants (an intent-to-treat analysis), but it preserves the measurement time for each observed response (rather than carrying last observations forward). It does so by computing maximum likelihood estimates of the slope over time given the data observed and the covariance structure within subjects. This method, which conditions out the missing data, is called restricted (or residual) maximum likelihood estimation (REML). The REML methods for dealing with missing data are superior in efficiency and are considered less biased than the last observations carried forward (LOCF) method [26,27]. For all outcomes analyses (except for health care utilization), we conducted planned comparisons of (a) the two intervention conditions combined versus the control condition; and (b) the mail versus the telephone intervention conditions. We ran separate models for each predictor/outcome combination: the

linear slope, both linear and quadratic trends, and a third that included linear, quadratic, and cubic trends. The linear trend indicates the direction and rate of change, while the quadratic and cubic trends indicate how the rate of change increased or decreased at some point during the observation period. We report results from the best fitting of these three models for each predictor/outcome combination. All tables and figures present observed unimputed data.

For health care utilization data, we employed chi-square analyses to compare proportions of participants in each condition who had at least one instance of each type of health care service. We then conducted logistic regression analyses predicting use of each type of health care service from study condition and baseline CES-D score.

## Results

### Recruitment, Randomization, and Follow-Up

Of 12051 total study recruitment brochures mailed to depressed and nondepressed HMO members, 291 participants (2.4%) entered confirmed HMO membership numbers at the study home page and proceeded to the online consent form and baseline assessment battery. Subsequently, 255 members (87.6%) were automatically randomized by the website (using random sequence software) to one of three groups: 100 to the TAU control group, 75 to the ODIN intervention with postcard reminders group, and 80 to the ODIN intervention with telephone reminders group.

Fifty-five of the 255 enrolled participants were from the nondepressed recruitment group (0.9% of those invited), and 200 were from the depressed recruitment group (3.3% of those invited). The randomized sample was more likely to be female (77% vs 71% of the non randomized sample,  $P = .03$ ) and older (64% were 45 years or older vs 52% of the non randomized sample,  $P < .001$ ).

Follow-up completion rates for all groups combined were 64% ( $n = 164$ ) at 5 weeks, 68% ( $n = 173$ ) at 10 weeks, and 66% ( $n = 169$ ) at 16 weeks. Overall, 209 participants (82%) completed at least one post-baseline assessment. Compared to participants completing at least one follow-up (baseline CES-D mean = 28.9, SD = 13.0), subjects who were lost to follow-up had higher baseline CES-D scores (mean = 33.3, SD = 12.6;  $t = 2.08$ ,  $P = .04$ ) and were slightly older (average age 47.7 vs 42.9,  $P = .006$ ), but they did not differ with respect to gender ( $P = .08$ ). Participants in the control condition were more likely to have completed at least one follow-up assessment (93%) than participants in either the telephone reminder intervention (76%) or the mail reminder intervention conditions (73%,  $P = .001$ ).

### Comparability of Conditions

Table 1 presents the frequency of participant log-ons for the mail and telephone reminder intervention conditions and the same data from our earlier randomized trial [11]. Participants in the two intervention groups with different reminder modes did not differ in the number of log-ons to the website ( $t = .45$ ,  $P = .65$ ), but both groups together did access the website significantly more often ( $t = 5.74$ ,  $P < .001$ ) than participants

in our initial study [11], which was nearly identical in design except for the lack of reminders.

Study conditions did not differ with respect to recruitment group, gender, or baseline CES-D and SF-12 scores; however, participants in the control group were more likely to be college graduates and were significantly older (Table 2).

**Table 1.** Frequency of ODIN website usage for mail and telephone reminder participants, and participants from the 1999 study [11] with no reminders

	Mode (Modal Frequency*)	Median	Mean (SD)	Range
Mail reminder	1 (28%)	4	5.9 (6.2)	1–33
Telephone reminder	1 (25%)	3	5.6 (5.8)	1–27
No reminder†	1 (41%)	2	2.6 (2.5)	1–20

\* The modal frequency is the percent of participants in each condition who had the modal (most frequent) number of log-ons, which was 1.

† From the initial ODIN study [11], with no reminders to use the Internet site

**Table 2.** Comparison of experimental condition on baseline demographics

	ODIN Group with Mail Reminder (n = 75)		ODIN Group with Phone Reminder (n = 80)		Control (n = 100)		Significance*
	Mean	SD	Mean	SD	Mean	SD	
Age	50.3	10.8	44.4	10.5	45.0	10.6	< .001
Female	72.0%		83.8%		76.0%		.20
Minority	6.7%		5.1%		6.0%		.91
Married	49.3%		60.3%		67.0%		.06
College graduate	38.7%		38.0%		56.0%		.02
“Depressed” at case-finding	72.0%		83.8%		79.0%		.20

\* Participant age was compared with an ANOVA. All other comparisons were made with chi-square analyses.

## Depression

Figure 2 shows that participants in the intervention conditions improved more than those in the control group on self-reported depression ( $F_{1,523} = 4.93$ ,  $P = .03$  for the linear slope), with an estimated difference in effect size of 0.277 standard deviation units. The graph displays the group means for each participant's change in CES-D from their baseline score, across all assessment points. The random effect regression parameter estimate was 0.25 (95% CI = 0.03–0.58). This effect held up even when controlling for baseline differences in age and education. We did not find any difference between the two treatment conditions.

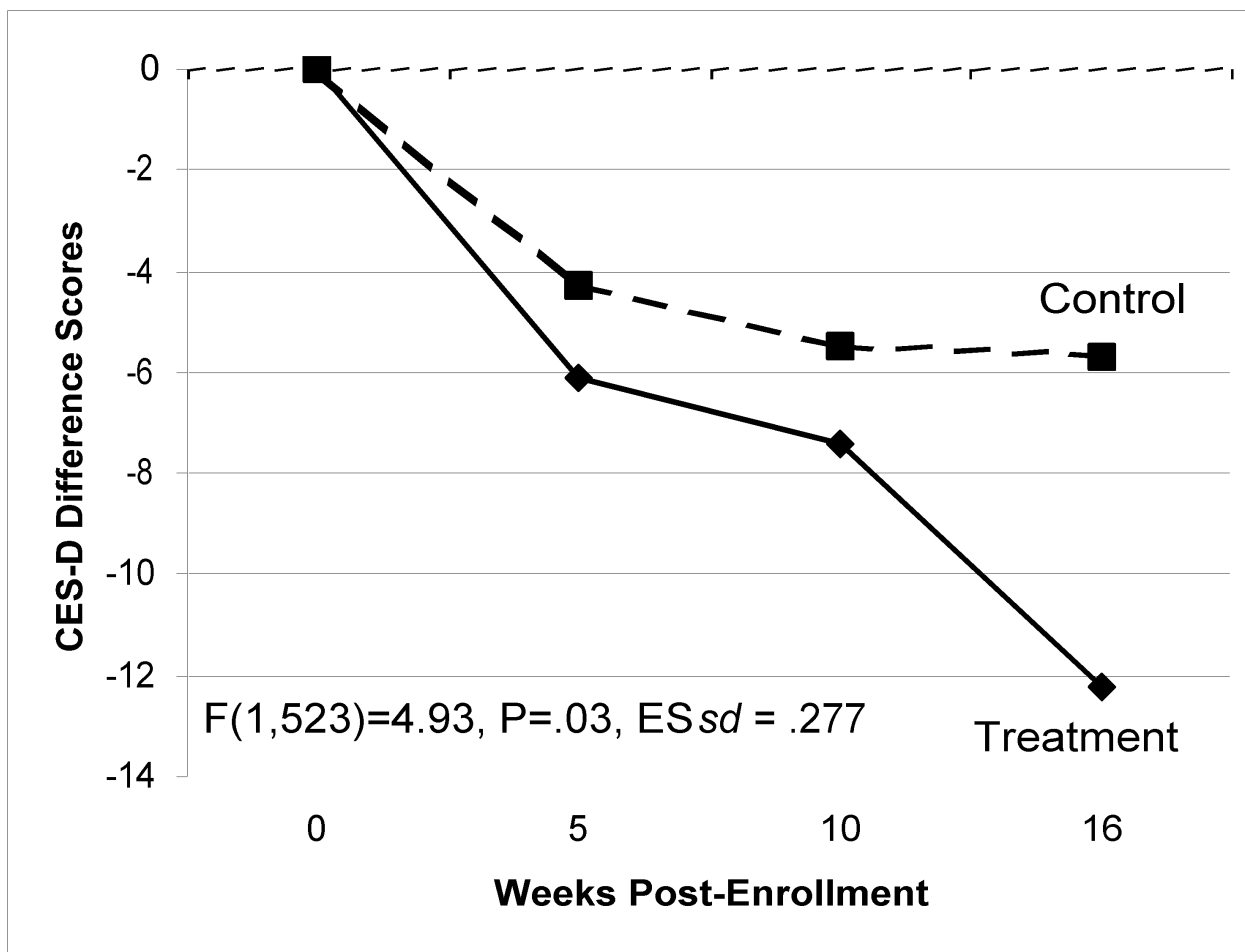
We tested clinical significance [28] by examining how many cases moved over time from the “disordered” to the “non disordered” CES-D ranges. The CES-D has two cutoff scores: a score of  $\geq 16$  is considered “moderately depressed,” and a score of  $\geq 28$  is considered “severely depressed” [12,29]. We compared the intervention conditions (combined) against the control condition using these categories. A total of 211 participants were above the lower of the two CES-D cutoff scores ( $\geq 16$ ) at baseline (75 control and 136 treatment). Of these moderately depressed participants, 137 completed the 16-week follow-up. At that final follow-up, 56% ( $n = 42/75$ ) of these participants in the treatment group were still in the moderately depressed range, compared to 76% ( $n = 47/62$ ) of the control sample ( $\chi^2 = 5.8$ ,  $P = .02$ ).

We also examined the 149 participants who were above the severely depressed cutoff score ( $\text{CES-D} \geq 28$ ) at baseline (53 control and 96 treatment). Of these, 93 participants completed the 16-week assessment; 42% ( $n = 20/48$ ) of the intervention cases were still in the severely depressed range at this final follow-up, compared to 62% ( $n = 28/45$ ) of the control cases ( $\chi^2 = 3.9$ ,  $P = .05$ ). Using either moderate or severely depressed scoring criteria, significantly more treatment participants (20%) moved from the clinical to normal range by the end of the study.

Because control participants were more likely to have completed at least one follow-up assessment than intervention participants, we examined whether the significant outcome results may have been a function of bias in the followed sample. This is a consideration because random effects regression methods yield unbiased estimates of missing follow-up data only if the missingness is ignorable (ie, can be predicted from patient characteristics and is unrelated to the study outcome). If loss to follow-up is a function of study outcome, the analyses conducted with imputed but possibly biased data may not accurately reflect the true outcomes. Therefore, we ran a repeated measures analysis predicting follow-up completion at each time point from baseline depression severity, age, sex, recruitment group, and educational attainment. In this model, younger age, male gender, and ODIN intervention assignment all increased the likelihood of missing a follow-up assessment. None of these factors predicted treatment outcome, suggesting they would be unlikely to contribute to the treatment outcomes that we found. However, it is not possible to completely prove that imputed

follow-up data are unbiased. Therefore, our results clearly need replication in a sample with minimal and nonsystematic attrition.

**Figure 2.** CES-D scores over time by condition (both treatment conditions combined)



**Table 3.** Self-reported depression outcomes (CES-D) for the total sample and selected subsamples

Group	Study Condition	N	Baseline		5-Week		10-Week		16-Week		P value*
			Mean	SD	Mean	SD	Mean	SD	Mean	SD	
Total Sample	Mail reminder	75	30.3	11.9	23.0	10.8	21.7	12.4	18.2	12.8	.03
	Phone reminder	80	31.3	13.2	26.3	13.3	24.9	13.1	19.0	13.1	
	Control	100	28.0	13.6	23.7	12.9	22.5	13.1	22.3	13.8	
Depression Recruitment Cases	Mail reminder	54	31.4	11.8	24.7	11.6	22.3	12.9	18.5	13.1	.08
	Phone reminder	67	31.3	13.4	24.8	13.3	24.4	13.2	20.0	13.8	
	Control	79	28.8	13.6	23.0	12.8	22.6	12.7	22.9	13.8	
High Baseline CES-D	Mail Reminder	58	35.2	8.4	26.5	10.0	25.3	11.8	19.7	12.3	.02
	Phone reminder	64	36.2	9.2	29.8	12.3	28.6	11.7	20.1	12.1	
	Control	69	35.4	9.1	28.1	12.0	26.1	12.6	26.7	13.1	
Female	Mail reminder	54	31.3	12.3	23.5	11.1	21.6	12.6	17.8	13.4	.17
	Phone reminder	67	30.1	13.5	26.7	14.0	24.8	13.2	20.0	13.4	
	Control	76	28.9	13.4	24.2	12.6	22.6	13.5	22.3	14.0	

P value for the random effects regression comparing two treatment conditions combined vs the control condition

Table 3 presents depression results for several subgroups, to generate hypotheses for future studies. We limited these exploratory analyses to subgroups with larger samples. These

included female participants (n = 197; linear model fit best, time × treatment  $F_{1,419} = 1.92, P = .17$ ); participants with higher

baseline CES-D scores (CES-D > 20; n = 191; quadratic model fit best, time × time × treatment  $F_{1,381} = 5.14, P = .02$ ; effect size = 0.537 standard deviation units); and participants recruited from among HMO members with depression diagnoses in their medical records (n = 200; linear model fit best, time × treatment  $F_{1,403} = 3.09, P = .08$ ).

### Functioning

We did not find any statistically significant intervention effects on the physical components (PCS) or mental components (MCS) subscales of the SF-12 (Table 4).

**Table 4.** Self-reported SF-12 physical components scale (PCS) and mental components scale (MCS) for the total sample

Subscale	Study Condition	N	Baseline		5-Week		10-Week		16-Week		Significance*
			Mean	SD	Mean	SD	Mean	SD	Mean	SD	
PCS	Mail reminder	75	46.5	7.2	45.0	7.6	47.2	7.1	47.2	7.7	.92
	Phone reminder	80	44.9	7.5	45.4	6.9	45.9	6.9	47.3	6.9	
	Control	100	45.0	7.7	45.5	6.8	45.0	7.3	46.3	7.4	
MCS	Mail reminder	75	34.5	6.9	33.7	7.5	34.9	6.9	34.7	8.9	.18
	Phone reminder	80	35.3	9.1	35.1	7.0	33.7	7.8	32.3	7.6	
	Control	100	34.4	7.2	34.8	7.8	34.4	8.0	35.5	8.8	

\* The significance column displays the alpha for the random effects regression analyses comparing the two intervention conditions combined vs the control condition.

### Dose-Adjusted Effects

We failed to find statistically significant interactions between the total number of ODIN sign-ins (our measure of dose) and CES-D or SF-12 outcomes (data not shown).

### Health Care Utilization

In the 12 months following randomization, we found no differences in the use of mental health or general medical services or psychoactive medications across all conditions (Table 5).

**Table 5.** Health care services in the 12 months post-randomization, by study condition

	TAU Condition (n = 100)			Mail Reminder Condition (n = 75)			Telephone Reminder Condition (n = 80)			Significance†
	Mean	SD	N (%) > 0 *	Mean	SD	N (%) > 0	Mean	SD	N (%) > 0	
<b>Mental Health Services</b>										
Outpatient visits	4.2	7.2	49 (49%)	3.1	5.7	35 (47%)	6.2	9.3	46 (57%)	.61
Total Rx dispenses	8.1	7.4	85 (85%)	7.7	6.2	68 (91%)	9.5	7.9	72 (90%)	.20
TCA dispenses	0.8	3.2	14 (14%)	0.3	1.4	7 (9%)	0.4	1.5	9 (11%)	.37
SSRI dispenses	4.0	4.1	65 (65%)	3.1	3.3	46 (60%)	3.4	3.7	46 (61%)	.48
Any MH Service			90 (90%)			71 (95%)			75 (94%)	
<b>General Health Services</b>										
Outpatient visits	9.7	9.5	95 (95%)	7.8	7.2	78 (97%)	8.5	7.1	73 (97%)	.31

Rx = any prescribed medication; TCA = tricyclic antidepressant; SSRI = selective serotonergic reuptake inhibitor antidepressant; MH = mental health  
 \* N (%) > 0 is the number and percent of the sample that had at least some level (> 0) of each type of treatment service.

† The significance column displays the alpha for chi-square analyses comparing the proportion with any of each type of health care services, for the two intervention conditions combined vs the control condition.

## Discussion

We detected a modest but statistically and clinically significant advantage for the two treatment conditions relative to the control group on self-reported depression, but not on functioning. To the best of our knowledge, this study is the first to find significant effects for a pure self-help or “unattended” Internet

program, where the intervention was delivered without any adjunct person-to-person contact.

This study is also the first to find Internet intervention effects in the context of a TAU control condition. TAU was essentially another potentially active treatment, with 93% of participants receiving at least some traditional mental health care in the year following randomization (84% through the week 16 follow-up), the majority of which was antidepressant medication. This high



background level of depression treatment and other health care had the potential to obscure differences between conditions. Nonetheless, we still observed an advantage for the ODIN intervention.

While the magnitude of this outcome was relatively modest, it compares favorably with other traditional, stand alone bibliotherapy interventions such as self-help books [3]. More importantly, the potential public health implications of these findings are considerable. The low incremental costs of delivering this Internet program makes it feasible to offer this or similar programs to very large populations (health plans, large employer groups, universities) where Internet access is widespread. Interventions with a small average effect may have substantial public health impact when applied to a large number of people, as a modest but meaningful number of patients will not develop the target disorder as a result of this small, average improvement [30].

Is the observed effect size of 0.277 standard deviation units (0.537 in cases with higher baseline depression) of sufficient magnitude to merit much enthusiasm? In meta-analyses of depression evidence-based psychotherapy *efficacy* randomized controlled trials (where the control condition is typically an easily surmounted no treatment or waitlist control), the difference in effect size is typically much higher, averaging around 1.56 standard deviation units [31]. However, when (as in this randomized controlled trial) the evidence-based psychotherapy is provided in the context of TAU [32], this effect size advantage typically shrinks substantially. Gaffan [31] and Gloaguen [33] find only small to medium mean effect sizes favoring CBT when it is compared to behavioral therapy (0.27), “other” psychotherapy (0.23), or pharmacotherapy (0.27). In this context, our TAU control condition is best thought of as a blend of evidence-based and non-evidence-based psychosocial and pharmacotherapy treatments [34]. Therefore, the observed effect size of 0.277 standard deviation units is roughly consistent with the effect sizes of this meta-analysis when traditional, face-to-face CBT is compared to these other treatments.

The mail and telephone reminders similarly increased the frequency of visits to the ODIN site, relative to our first study with no reminders [11]. We are therefore inclined to use postcard reminders in the future because they are much less costly than telephone reminders.

Our failure to detect effects on health care utilization was not unexpected. A follow-up period of two years or more is typically needed to detect impacts of an intervention on health care utilization [35]. Further, because health care utilization typically has very high variance (a small number of patients use an extreme amount of health care), very large samples are typically needed for adequate power [36].

### Limitations

This study had several limitations. First, despite providing gift certificates for completed assessments, follow-up rates averaged around 66%—although 82% of participants completed at least one follow-up assessment. These rates are comparable to the follow-up rates obtained in our earlier study [11] and are similar

to, if not better than, rates seen in other Internet intervention trials (reviewed by Eysenbach [37]).

Second, subjects lost to follow-up were slightly more depressed, slightly older, and less likely to be in the control group. All these factors, but particularly the interaction between experimental condition and attrition, limit our confidence in our results, although post-hoc analyses suggest that confounding effects were unlikely to have accounted for the observed results.

Our enrollment rates were also quite low, with 3.3% of the “depressed” recruitment sample and 0.9% of the “nondepressed” recruitment sample enrolling in the study, respectively. We have no information on why so many declined to enroll. Because the majority of the “depressed” recruitment sample was receiving traditional depression care (all had depression diagnoses in their medical charts), perhaps they felt no need to augment their traditional care with our self-help program. Among the nominally “nondepressed” recruitment sample, we had hoped to enroll previously unrecognized cases of depression [38]. However, the 1% “nondepressed” enrollment rate suggests that only a small minority of these undetected cases found our study of interest. Perhaps some of these individuals did not recognize their own depression and thus would not have seen the program as applicable. Still others may have been receiving other depression care outside of this HMO, which we could not know about from the HMO records. Regardless of the reasons for the low enrollment, these rates are not an indication of the *acceptability* of this intervention or any Internet program offered outside of a research trial. The unique features of randomized trials (a chance of being assigned to the no-access control group, repeated reminders to complete assessments over time, burdensome questionnaires) create barriers to participants that likely contribute to lower research enrollment rates, but which have no counterparts in usual clinical care implementation of these types of programs.

This study was also limited by its reliance on a single, self-reported measure of depression. We decided against using research diagnostic interviews because the accompanying in-person or telephone interview contacts had the potential to impart quasi-therapeutic benefits that, in turn, might have swamped the small benefit expected from the ODIN intervention. Further, the target population for the ODIN website includes persons who may have low level or subdiagnostic depression symptoms, as well as individuals who meet full diagnostic criteria for major depression or other DSM mood diagnoses. Relying on DSM mood diagnosis as a primary outcome might have missed the effects of the ODIN intervention on depression symptoms below the level of a full diagnosis.

Finally, our follow-up period of 16 weeks was extremely brief. We must examine this intervention's longer term impacts on depression, health care utilization, and quality of life. Future studies should include a much longer follow-up and a broader range of assessment domains.

### Conclusions

The lessons we have learned from this investigation are guiding our development of a completely new Internet intervention for depressed young adults. This new program emphasizes

behavioral activation, or increasing pleasant activities, as the main therapeutic technique [39].

We are encouraged by the results of this study, while acknowledging the positive effects are modest in magnitude. Nonetheless, we view low intensity, widely available interventions as an important piece of an overall,

population-based strategy for reducing depression disorder and symptomatology. The marginal costs of delivering this pure self-help Internet program to each additional individual are very minimal, given that there is no staff time associated with the delivery of the intervention content. Therefore, it is feasible to offer this type of program to entire populations where Internet access is widespread, such as universities and large employers.

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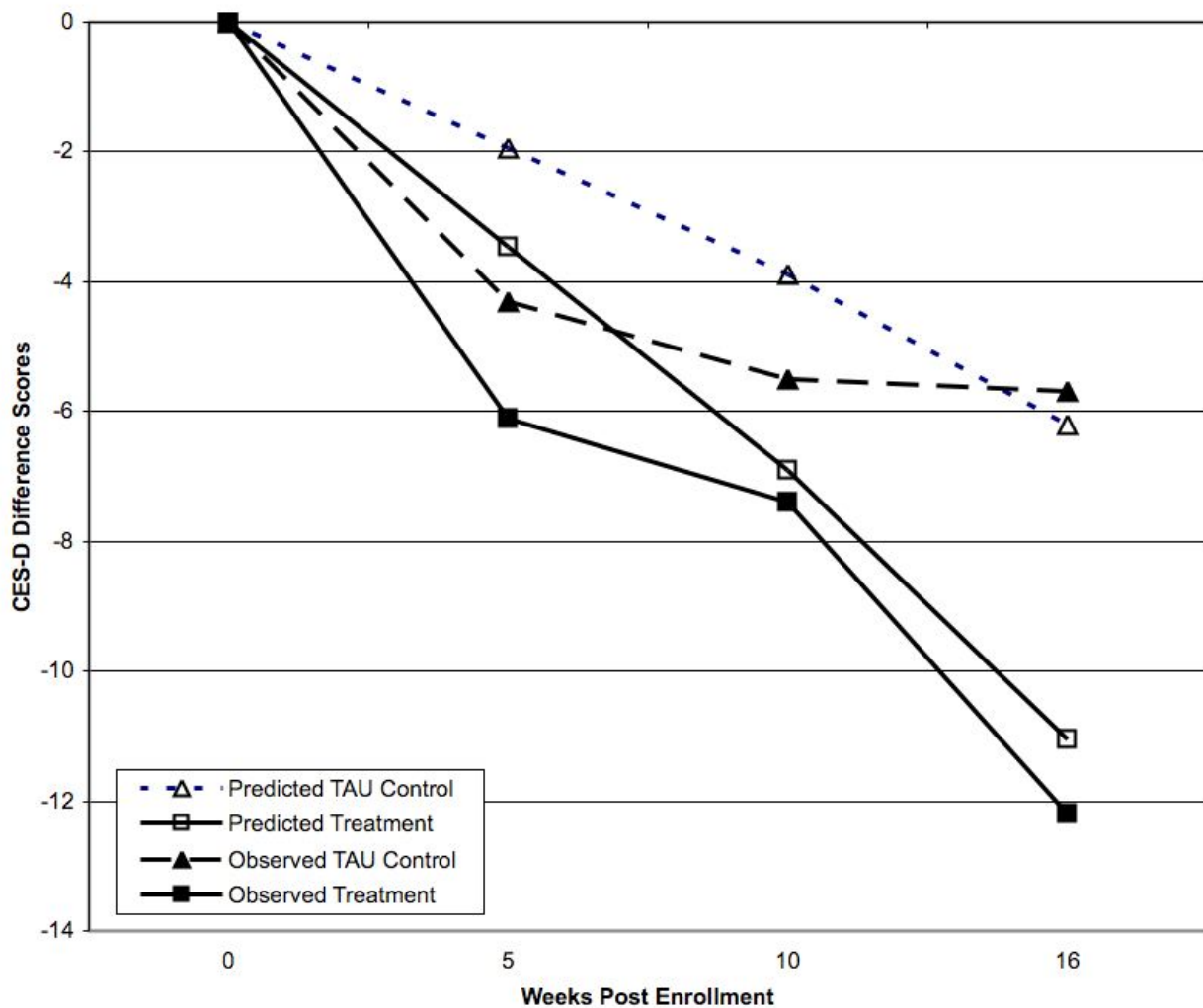
**Conflicts of Interest**

None declared.

**Appendix**

Additional figure (complementing figure 2) showing both the predicted and observed data for the main outcome measure, the CES-D. (added 08 June 2005)

**Figure 2a.** Predicted and observed data for the main outcome measure, the CES-D



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## Abbreviations

**CES-D:** Center for Epidemiological Studies Depression Scale

**CBT:** cognitive behavioral therapy

**HMO:** health maintenance organization

**MCS:** Mental Component Summary

**ODIN:** Overcoming Depression on the InterNet

**PCS:** Physical Component Summary

**SF-12:** Short Form 12

**TAU:** treatment as usual

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Original Paper

# Vaccine Criticism on the World Wide Web

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## Abstract

**Background:** The incidence of vaccine-preventable diseases is directly related to the number of unvaccinated children. Parents who refuse vaccination of their children frequently express concerns about vaccine safety. The Internet can influence perceptions about vaccines because it is the fastest growing source of consumer health information. However, few studies have analyzed vaccine criticism on the Web.

**Objective:** The purposes of this paper are to examine vaccine criticism on the Internet and to analyze the websites in order to identify common characteristics and ethical allegations.

**Methods:** A structured Web search was conducted for the terms “vaccine,” “vaccination,” “vaccinate,” and “anti-vaccination” using a metasearch program that incorporated 8 search engines. This yielded 1138 Web pages representing 750 sites. Two researchers reviewed the sites for inclusion/exclusion criteria, resulting in 78 vaccine-critical sites, which were then abstracted for design, content, and allegations.

**Results:** The most common characteristic of vaccine-critical websites was the inclusion of statements linking vaccinations with specific adverse reactions, especially idiopathic chronic diseases such as multiple sclerosis, autism, and diabetes. Other common attributes ( $\geq 70\%$  of websites) were links to other vaccine-critical websites; charges that vaccines contain contaminants, mercury, or “hot lots” that cause adverse events; claims that vaccines provide only temporary protection and that the diseases prevented are mild; appeals for responsible parenting through education and resisting the establishment; allegations of conspiracies and cover-ups to hide the truth about vaccine safety; and charges that civil liberties are violated through mandatory vaccination.

**Conclusions:** Vaccine-critical websites frequently make serious allegations. With the burgeoning of the Internet as a health information source, an undiscerning or incompletely educated public may accept these claims and refuse vaccination of their children. As this occurs, the incidence of vaccine-preventable diseases can be expected to rise.

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## KEYWORDS

Vaccines; Internet; immunization; vaccine safety; vaccine criticism; anti-vaccine

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## Introduction

The number of unvaccinated children is rising in the United States; the estimated number of unvaccinated children aged 19 to 35 months increased from 14719 in 1995 to 24073 in 2000 [1]. The number of unvaccinated children plays an important

role in the incidence of vaccine-preventable diseases. For example, the frequency of abstainers from vaccination has been associated with the incidence of measles and pertussis among both vaccinated and unvaccinated children [2].

## Parental Concerns About Vaccine Safety

A number of studies have documented parental concerns about vaccine safety [1,3-5]. A 2004 online survey showed that half of parents are concerned that a child might develop a long-term medical condition as a result of vaccination [6]. One tenth of parents are uncomfortable having their child vaccinated due to health concerns [6]. Another US national survey found that the majority of parents of young children support the use of immunization, but about one quarter are concerned that children receive more vaccines than are good for them, and that, as a result, their immune systems could be weakened [7]. About one fifth (19%) do not think vaccines are proven safe prior to use in the United States [7]. A third study comparing responses from parents of unvaccinated versus vaccinated children found that parents of the unvaccinated were significantly more likely to ask that their child not be vaccinated, to believe that the MMR (measles, mumps, rubella) vaccine causes autism, to be concerned about side effects, and to believe that children receive too many vaccines [4]. In Colorado, the percentage of children with philosophical exemptions to immunization increased from 1.02% to 1.87% from 1987 to 1998 [2]. Thus, many parents are concerned about vaccine safety, and a growing number are expressing this by refusing vaccination of their children.

The media, both print and electronic, are frequently used to educate the public about health issues. Similarly, the media have been used to discourage uptake of known public health measures such as vaccination. For example, an international study examined anti-vaccine campaigns in the media, pertussis vaccine coverage, and disease incidence in the United States and several European countries [8]. Those countries with concerted anti-vaccine campaigns as reported in contemporary news stories had significantly higher incidence of pertussis compared with countries with few or no media reports on alleged vaccine adverse events. The latter countries, in general, maintained high vaccination levels with low disease incidence.

## Influence of the Internet and Purpose to Study Vaccine-Critical Websites

The Internet, the newest electronic news medium, has the potential to influence perceptions about vaccines because it is the fastest growing source of consumer health information. In fact, most (67%) US adults use the Internet, and of these, 40% to 80% use it to access health information [9-11]. With the rapid expansion of the Internet (an estimated 19000 websites in 1995 to 36 million websites in 2001 [12]) and the increasing number of people seeking health information on the Web (an estimated 110 million adults [10]), frequent updates of the health information being disseminated via the Internet are necessary.

The vaccine criticism movement has taken advantage of the Internet and its ability to reach parents seeking information on vaccines and vaccine safety. Parents can find this information with just a few key strokes. Three studies, conducted from 1999 to 2001, provide some insight into the vaccine criticism movement on the Internet, describing the content and design attributes of "anti-vaccination" websites [13-15]. The purpose of this paper is to more broadly examine vaccine criticism on the Internet in 2004 and update previous findings. This is the largest study of such websites conducted in the United States

to date. This update will enable health providers to better understand the arguments against vaccination and the questions regarding vaccination that parents and patients may present to them.

## Methods

Web pages about vaccination were identified using Copernic Agent Professional version 6.11 (Copernic Technologies Inc, Saine-Foy, Quebec, Canada), which is an Internet search program designed to simultaneously submit searches on numerous engines and return unduplicated results. The search engines used were AltaVista, FAST Search (alltheweb.com), Google (which also powers Yahoo! and AOL), HotBot, Lycos, MSN Web search, Netscape Netcenter, and Teoma. The search was conducted on December 5, 2003, using the terms "vaccine," "vaccination," "vaccinate," and "anti-vaccination." Previous research showed that sites critical of vaccination were much more likely to be found with these terms rather than "immunization" [15]. The result was 1138 Web pages representing 750 sites.

The exclusion criteria were as follows: (1) listserv or newsgroup containing online conversation; (2) information applicable primarily to animals; (3) posts of brief notices about content on other sites; (4) online commercial news service, health/medical journal, or library; (5) non-English language site; (6) exclusively adult immunization; and (7) inactive links. The inclusion criterion was content encouraging vaccine refusal or emphasizing the dangers of vaccines.

Two researchers independently reviewed the sites and agreed that 662 were excluded and 22 were included, but they disagreed on 66 sites. A third reviewer reviewed these and determined inclusion or exclusion, leading to a final count of 78 sites.

## Data Collection/Website Review

The websites meeting the exclusion and inclusion criteria were downloaded in 2004 onto a CD using Aeria Leech 3.3 software (Tampa, FL), which downloads Web content. In this way, all the reviewers accessed identical information, as content of the websites may change over time. Criteria for evaluation of the sites were adapted from published criteria for evaluating health related websites, design and attribute characteristics used in previous studies in 2000 (eg, links to other vaccine-critical websites and sale of books, tapes, CDs from the site), specific vaccine safety concerns (eg, association with autism, multiple sclerosis), and ethical allegations (eg, conspiracy, civil liberty violations) [13,16,17]. A list of variables was defined and, after data collection, was refined. In particular, fifty variables were defined in detail to minimize interpretation differences. For each variable, 2 reviewers (1 clinician and 1 social scientist) independently examined all pages of each website to determine if the attributes were present (coded as 1) or absent (coded as 0).

## Data Analysis

Interrater reliability for each variable was determined using the kappa statistic. Variables with a kappa value less than 0.5, indicating a low level of agreement between the two reviewers, were not included in further analyses (4 variables). Of the

remaining 46 variables, 16 were retained as collected, and 30 were combined into 12 variables using logical groupings (eg, sites promoting alternative therapies, herbal remedies, or homeopathy as adequate protection against infectious disease were combined). For combined variables, if a website was found to have at least one of the individual attributes present, then the combined variable was coded as being present for that website. The kappa statistic was calculated for the combined variables.

To determine the percentage of websites containing each of the attributes, it was necessary to average the two reviewers' coded values (ie, if both reviewers coded an attribute as present, the average was 1; if one reviewer coded the attribute as present and one reviewer coded it as absent, the average was 0.5; and if both coded the attribute as absent, the average was 0). These scores were summed and divided by the total number of websites.

Variable groupings were then created by combining the 28 variables into the following clusters: promotion of vaccine criticism, emotive appeals, alternative medicine, disease risk/vaccine safety, and ethical allegations. Spearman correlations compared total percent presence of attributes in

each cluster to assess whether certain groups of attributes were frequently found together in vaccine-critical websites. Analyses were performed using SPSS 12.0 (SPSS Inc, Chicago, IL).

## Results

In total, 78 websites were reviewed. Table 2 lists the website characteristics, the frequency with which they appeared, and the interrater reliability for website reviews. The single most common characteristic of vaccine-critical websites was the inclusion of statements linking vaccinations with specific adverse reactions, especially idiopathic chronic diseases such as multiple sclerosis, autism, and diabetes.

Other common ( $\geq 75\%$  of websites) characteristics were links to other vaccine-critical websites, charges that vaccines contain contaminants that cause adverse events, allegations of conspiracies to hide the truth about vaccine safety and efficacy, appeals for responsible parenting through education and resisting the establishment, and claims that vaccines provide only temporary protection and are therefore not worth the risk. Examples of the types of vaccine criticism on the Internet are provided in Table 1.

**Table 1.** Types and examples of vaccine criticism on the Web

Type of Information	Example
Promotion of vaccine criticism	<p>"Then one word can describe this new video, 'Vaccines: What CDC Documents and Science Reveal,' by world-renowned vaccine expert Dr. Sherri Tenpenny: essential. To put it simply, if you are dedicated to protecting and enhancing your life, your family's, or your patients', but you have not been exposed to the often startling but thoroughly documented information in this video, there is a dangerous gap in your knowledge. Whether you have explored the issue of the dangers of vaccines extensively or not at all, I more than recommend you watch this video—I implore you to do so. Available on VHS. Just \$24.95."</p> <p>(<a href="http://www.mercola.com/forms/vaccine_video.htm">www.mercola.com/forms/vaccine_video.htm</a>)</p>
Alternative medicine	<p>"Homeopathic Medicine for counteracting the effects of vaccination: while not as good as NOT getting vaccinated, I have been told by a number of healers that the homeopathic medicine Thuja was very helpful."</p> <p>(<a href="http://www.relife.com/vaccine.html">www.relife.com/vaccine.html</a>)</p> <p>"For those that decide not to immunize their children, naturopathic medicine does offer several alternatives. For those that wish to have some sort of protection, there are homeopathic mixtures of the vaccines which can be used. Constitutional homeopathy can also be used to strengthen the vital force of your children."</p> <p>(<a href="http://www.naturdoctor.com/Chapters/Articles/vaccinate.html">www.naturdoctor.com/Chapters/Articles/vaccinate.html</a>)</p>
Emotive appeals	<p>"I helplessly watched my daughter suffer an excruciatingly slow death as she screamed and arched her back in pain, while the vaccine did as it was intended to do and assaulted her immature immune system. The poisons used as preservatives seeped through her tiny body, overwhelming her vital organs one by one until they collapsed. It is an image that will haunt me forever and I hope no other parent ever has to witness it. A death sentence considered too inhumane for this county's most violent criminals was handed down to my beautiful, innocent, infant daughter, death by lethal injection."</p> <p>(<a href="http://www.mercola.com/2002/aug/7/vaccine_death.htm">www.mercola.com/2002/aug/7/vaccine_death.htm</a>)</p>
Vaccine safety	<p>"Vaccination causes significant death and disability at an astounding personal and financial cost to families and taxpayers."</p> <p>(<a href="http://www.relife.com/vaccine.html">www.relife.com/vaccine.html</a>)</p> <p>"Personal stories of vaccine damage, as told by sad parents who lost a child to the shots, remind us that real families, and real children, are being affected."</p> <p>(<a href="http://thinktwice.com/risk.htm">http://thinktwice.com/risk.htm</a>)</p>
Ethical allegations	<p>"Adverse reactions to vaccines are more common than many people realize. In fact, the US government operates a secret database that contains the names of several thousand children who were healthy and alive just prior to receiving the vaccines." (<a href="http://thinktwice.com/risk.htm">http://thinktwice.com/risk.htm</a>)</p>

**Table 2.** Types of information on vaccine-critical websites

Type of Information	Websites With This Attribute (%)	Interrater Reliability (Kappa)*
<b>DESCRIPTIVE CONTENT</b>		
<b>Vaccine Criticism</b>		
Links to other sites critical of vaccines	80	0.718
Information for legally avoiding immunizations	47	0.719
Information on reporting adverse events	35	0.661
Vaccine critical books, tapes, compact discs for purchase from site	33	0.738
Email listserv or chat room (eg, to discuss vaccine dangers)	28	0.558
Solicitations for contributions for website support or anti-vaccine cause or organization	21	0.654
Links to attorneys	20	0.800
<b>Disease Risk/Vaccine Safety</b>		
Specific illnesses are attributed to vaccination, (eg, multiple sclerosis, autism, asthma, sudden infant death syndrome)	91	0.529
Vaccines contain contaminants, mercury, or there are “hot lots” of vaccine that cause adverse events	83	0.687
Vaccines afford only temporary protection and/or outbreaks occur despite vaccination	79	0.688
Diseases prevented by vaccines have declined, are not contagious, or are relatively mild illnesses	74	0.702
Physicians under-report adverse reactions	62	0.677
<b>Alternative Medicine</b>		
Encourages “back to nature” alternatives to vaccination such as homeopathy, vitamins/minerals/supplements, chiropractic services	67	0.565
Conventional medicine is wrong; some physicians disagree with vaccination	63	0.531
Physicians are misinformed about vaccines	58	0.606
Sells herbal and/or homeopathic products	16	0.575
<b>RHETORICAL APPEAL</b>		
<b>Emotive Appeals</b>		
Responsible parenting mandates educating oneself; parents must stand together against the establishment	76	0.540
Pictures and/or stories of children allegedly harmed by vaccinations	37	0.573
Pictures or diagrams of needles	22	0.522
<b>Ethical Allegations</b>		
Safety and efficacy information is false; cover-up and conspiracy about safety is alleged	76	0.528
Civil liberties are violated by taking away parental choice	70	0.666
Conflict of interest exists between vaccine manufacturers and doctors or policy makers	66	0.630
Vaccine mandates infringe on parental rights; totalitarianism is suggested	63	0.561
Immorality argument—vaccines are grown on cell lines derived from abortions; universal vaccination is a form of utilitarianism which sacrifices a few for the benefit of many	46	0.555
Government protects doctors and manufacturers from liability for harm caused by vaccines	33	0.601

$P < .001$  for kappa for each attribute

Of the 25 website characteristics in Table 2, the average number of characteristics per website was  $13.5 \pm 5.3$  (range 1.5–23.5). In order to assess the way in which groups of characteristics were related in vaccine-critical websites, correlation analyses for nonparametric data were performed. Although all were significantly correlated ( $P < .019$ ), the highest correlation coefficients were for the relationships between the ethics group and the disease risk/vaccine safety group ( $\rho = .637$ ;  $P < .001$ ),

the ethics group and the emotion group ( $\rho = .542$ ;  $P < .001$ ), and the alternative medicine group and the disease risk/vaccine safety group ( $\rho = .554$ ;  $P < .001$ ). Three content design attributes were identified: 62% of sites contained references to scientific literature ( $\kappa = .60$ ;  $P < .001$ ); 28% provided links to vaccine proponents' websites ( $\kappa = .68$ ;  $P < .001$ ); 26% provided information on or links to states' immunization requirements ( $\kappa = .66$ ;  $P < .001$ ).



## Discussion

We found that websites critical of vaccines claim that vaccines cause illness, claim that vaccines are contaminated, promote the idea that the vaccines are only temporarily effective, encourage alternative medicine, claim conventional medicine is wrong, make emotive appeals, and make ethical allegations about conspiracy, cover-up, civil liberty violations, totalitarianism, and immorality.

The Institute of Medicine reviewed the scientific evidence for a number of vaccine controversies, published multiple texts on the issues, and has generally found vaccines to be safe, albeit with rare risks such as anaphylaxis [18-23]. A published review of the veracity of claims by websites critical of vaccination reports many “fabrications and distortions” and misrepresentation of the data from reputable medical journals [24].

The number of vaccine-critical websites may be increasing. We found 78 sites in 2004, whereas Nasir found 51 sites in 1999, and Wolfe et al found 22 in 2000 [13,14].

### Relativism, Logic Fallacies, and Heuristics

We believe that there is a link between the claims we evaluated about conventional medicine being wrong, about physicians being misinformed about vaccination, and about the promotion of “back to nature” alternatives and homeopathy. These are all common in post-modern thought, which considers truth to be relative and which questions established points of view. Thus, the viewpoint of a homeopath or herbalist may be considered as legitimate, or more legitimate, than the opinion of traditional authorities such as physicians and scientists. Evidence of this was seen in an analysis of parents of unvaccinated children in the National Immunization Survey, which found that 71% said that a doctor is not influential in shaping vaccination decisions for their children [1].

We found that personal stories or pictures of children allegedly injured by vaccines appeared on 37% of websites. Information from the disciplines of logic and debate may help in analyzing and responding to such allegations. The linking of such alleged adverse reactions with vaccination appears to commit two logic fallacies. One is *post hoc ergo propter hoc*, which translates into “occurring afterwards, therefore occurring because,” in other words, confusing temporal association with causality. The second logic fallacy is *faulty dilemma*. In this case, the argument forces a choice between two options, both of which are contrary to a third position, which is not mentioned as an option. For example, given a description of a disabled child, the choice is either the vaccine caused the disability or the child is not disabled; the third option that the disability was genetically determined or occurred in utero is not mentioned as a possibility.

Several other heuristic processes may be involved in parental analyses of vaccine risks, including compression, omission bias, and ambiguity aversion. Compression is the overestimation of rare risks, such as vaccine reactions, but an underestimation of common risks, such as the morbidity and mortality of vaccine-preventable diseases [25]. The news media tend to overemphasize risk of death from infrequent causes and to

under-represent risk of death from more common causes [26]. Omission bias is the tendency to favor errors of omission over errors of commission, even though a distinction between them may be irrelevant [27,28]. Ambiguity aversion applies to cases in which parents tend to avoid ambiguity and may find a greater risk from a known disease more acceptable than a smaller, more ambiguous risk from a new vaccine [25,28]. Ambiguity aversion also applies to a situation in which there is debate about the reliability of vaccine information. One study found that those opposed to vaccination were more strongly opposed after being shown a table comparing the risks of pertussis disease with the risks of whole cell DTP (diphtheria, tetanus, pertussis) vaccine, suggesting that they focused on information that supported their previous beliefs even when presented a balanced picture [28].

### Ethical Allegations

The ethical allegations of conspiracy, cover-up, civil liberty violations, totalitarianism, and immorality that we found frequently in websites critical of vaccination are particularly troubling, given the serious nature of the charges. The handling of the rare cases of intussusception following vaccination with rhesus monkey-derived rotavirus vaccine (RRV) challenges the conspiracy and cover-up allegations. In this case, personnel from the Centers for Disease Control noted a signal in the vaccine adverse events reporting system (VAERS), instituted a study, and rapidly found an association between RRV and intussusception. RRV was withdrawn within weeks [29-31].

Exemptions to states' mandatory vaccination laws are a counter-argument to the aforementioned ethical allegations. Although state laws require vaccination prior to school entry, all states allow exemptions for medical reasons, 48 allow them for religious reasons, and 17 for philosophical reasons [32]. States that allow philosophical exemptions to laws mandating vaccination for school entry have significantly higher rates of unvaccinated children [1].

An analysis of vaccine immorality allegations based on the fact that a few vaccines are grown in self-propagating cell lines originally obtained from two abortions in the 1960s was recently published [33]. The paper used strategies to analyze moral complicity (eg, principle of double effect) and found that vaccination is ethical [33]. The abortions were past events separated in time, agency, and purpose from vaccine production. Indeed, the ethics of altruism and herd immunity argue for widespread vaccination, although concerns about autonomous decisions and personal conscience should be respected [33].

### Historical Context

Since the introduction of smallpox vaccine and compulsory vaccination, there have been small but vocal movements against vaccinations which share many similarities with criticisms of the past. First, vaccine criticism of the past and present capitalizes on the public's lack of understanding of medical science and investigation and their limited ability to confirm or refute claims. The general public is not skilled in interpreting statistical results, in differentiating between causality and temporal association, or in assessing the validity of findings based on appropriate study design. Second, many of the arguments in use today parallel those used in the past. For



instance, during the late 19th century, objections to smallpox and typhoid vaccinations included the following: vaccination is against the laws of nature, good hygiene provides adequate protection against disease, vaccines can transmit other diseases, and compulsory vaccination is a violation of one's liberty [34,35]. These arguments are similar to those espoused by current vaccine critics who hold that natural therapies and alternative medicine are preferable for prevention of infectious disease, vaccines cause idiopathic illness, and school entry vaccination requirements violate civil liberties [13,14]. Furthermore, the ethical allegations remain quite strident, including purported collusion among government, the medical establishment, and pharmaceutical companies that is motivated by profit [35]. Finally, opponents of vaccination dramatize relatively rare adverse events to overshadow vaccination's enormous public health benefits [15]. This is an especially effective tactic now, as the toll from a number of infectious diseases fades from the public memory (as a result of universal vaccinations).

Differences between vaccine criticism of today and the past are principally a matter of degree. There are now more vaccines and therefore more available to criticize. Secondly, there are many more resources for dissemination of health information, including television, radio, and the World Wide Web.

### Strengths and Limitations

This is the largest study conducted by US investigators on this topic and the most complete and current in the literature. In addition, our design builds on prior studies by quantifying ethical allegations on the reviewed websites.

As was the case in prior studies, non-English sites were not reviewed, which limits the ability to generalize results. Also, interrater reliability was good but not excellent. We believe that this primarily reflects inherent individual differences in the interpretation of website content when determining the presence or absence of value-related issues such as conspiracy, immorality, and civil liberties violations. The complexity and

size of websites are other factors that may have affected the interrater reliability.

### Solutions

There are several strategies to encourage openness to vaccination among parents who are concerned about the risk of causing their children harm from vaccines. These strategies can be used in mass education campaigns or in discussions between a clinician and parents. One strategy is to share personal experiences with diseases such as pertussis, which can cause serious illness and disability and which still circulates in the United States. Pictures [36,37] and testimonials [38] of children suffering from vaccine-preventable diseases may be helpful.

A second strategy is to explain the communicable nature of most vaccine-preventable diseases and their recurrence in industrialized countries when vaccination rates decline. For instance, pertussis returned after immunization rates decreased in Sweden, England, Wales, and Japan [39-41]. Third, some websites that are critical of vaccination sell products, including homeopathic and herbal products, raising the possibility of conflict of interest in these particular sites—an important point to raise with parents. Finally, non-profit websites such as the Vaccine Education Center [42] and the National Network for Immunization Information [43] provide useful information for parents and providers that is free from commercial and federal funding.

### Conclusions

In summary, websites critical of vaccines allege serious adverse reactions, vaccine failure, and serious ethical violations, including cover-up, conspiracy, and civil liberties violations. As physicians encounter an increasing number of parents and patients who have searched the Internet for vaccine information, they need to be aware of the medical and ethical allegations being made against vaccination. Strategies such as encouraging parents to take the child's perspective, sharing the physician's experience of treating patients with vaccine-preventable diseases, and providing pictures and testimonials of persons affected by vaccine-preventable diseases may be useful.

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### Conflicts of Interest

None declared.

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Original Paper

# Information Needs and Visitors' Experience of an Internet Expert Forum on Infertility

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## Abstract

**Background:** Patients increasingly use health portals and Web-based expert forums (ask-the-doctor services), but little is known about the specific needs of Internet users visiting such websites, the nature of their requests, or how satisfied they are with Internet health experts.

**Objective:** The aim of this study was to analyze the information requests of (mostly female) patients visiting an Internet expert forum on involuntary childlessness and their satisfaction with the experts' feedback.

**Methods:** We posted an electronic questionnaire on a website hosting an expert forum on involuntary childlessness. The questionnaire was "activated" whenever a visitor sent a question or request to the expert forum. The survey focused on the reasons for visiting the expert forum and whether the visitors were satisfied with the experts' answers to previously posted questions. The free-text questions of visitors who answered the survey were analyzed using Atlas-ti, a software program for qualitative data analysis.

**Results:** Over a period of 6 months, 513 out of 610 visitors (84%) answered the questionnaire. The majority of respondents (65.5%) expected general information about involuntary childlessness, conception, or an evaluation of drugs. Others were concerned about their actual treatment (40.6%) and therapeutic options (28.8%). Out of 225 respondents who had previously contacted the forum, 223 had received an answer, and 123 (55.2%) were satisfied with the experts' answers. About half (105/223) of those users who had previously received an answer from the expert forum stated that they had discussed it with their own doctor. More of these users were satisfied with their subsequent care in fertility clinics than users who did not talk to their doctor about their Internet activities (93.9% vs 76.1%;  $P = .015$ ). According to the qualitative analysis, many requests ( $n = 194$ ) were more or less trivial, especially those for information on basic aspects of reproduction. More than one-third of visitors ( $n = 199$ ) sent detailed results of diagnostic tests and asked for a first or second opinion. Requests to the expert forum were also sent in order to obtain emotional support (17%) or to complain about a doctor (15%).

**Conclusions:** Visitors who sent their laboratory findings to receive a thorough evaluation or a second opinion had a good command of the opportunities that an expert forum offers. One important expectation of the forum was emotional support, indicating psychological needs that were not met by medical providers. Future websites must find a compromise in order to protect experts from being overwhelmed by general, nonspecific requests while supporting patients with individualized answers.

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**KEYWORDS**

Consumer health informatics; telemedicine; Internet; e-health; infertility; remote consultation



## Introduction

Both healthy and sick people increasingly use electronic media to get medical information and advice [1]. One out of four Europeans search the Internet to receive information about health, and more than 40% consider this a reliable way to obtain information [2]. In a survey of nearly 5000 Internet users drawn from the US Research Household Panel, 40% used the Internet for advice or information about health, and 6% used it to communicate with health professionals [3].

The Internet has the potential to help patients to become active and well informed, instead of being passive health care consumers [4,5]. Van Woerkum [6] considers this in terms of a sender-receiver model: the Internet user is not only a receiver, but is active in solving a problem via the Internet. The user actively exchanges information with others about a subject of interest.

There are several reports about why consumers visit certain websites or expert forums. In their analysis of electronic mail sent to the webmaster of a cardiac website, Widman and Tong [7] found that most inquiries were about therapy and diagnosis, and only a few were about patient education. A content analysis of unsolicited electronic mail sent to a dermatological website concluded that emails contained questions about a particular treatment (30%), new therapies (12%), or about specialists for the treatment of a specific disease (15%). Most inquiries pertained to general information about a specific disease (34%) [8]. It appears that many visitors seem to consult a website looking for a second opinion [7,8].

According to a recent study on the Swedish public health service Infomedica [9,10], most people consulted the Internet expert forum "Ask the Doctor" to receive a second opinion (31%), especially because they were unsatisfied with their doctor (25%). Few (15%) consulted the forum for a primary evaluation of a medical problem. Accessing this service at their own convenience was the feature most appreciated by visitors (52%). Based on a qualitative content analysis of visitors' questions, information and advice were the most frequent reasons to visit a University of Washington health education website offering information about orthopedics and sports medicine [11].

Even with all this research, we still know very little about the specific needs of Internet users visiting medical websites, the nature of their requests, or how satisfied they are with the Internet service. Therefore, it is difficult to form valid conclusions about consumer health informatics or electronic communication services and their impact on personal health, patient information, and the clinician-patient relationship. More detailed information, derived from qualitative and quantitative methods, could help to reveal health needs not covered by traditional outpatient or hospital services [12].

In this study we used a qualitative approach to analyze in detail the needs and expectations of patients visiting a specialized health website. Furthermore, we investigated the visitors' experience and satisfaction with the offered service using a quantitative method. For these analyses, we chose a website about involuntary childlessness for two reasons:

1. The burden of involuntary childlessness is high [13] and so is the number of patients using the Internet as an outlet for talking about infertility [14].
2. There are numerous therapeutic options for treating infertility; therefore, patients are often confronted with the question of which treatment might be most successful in their specific situation [15].

## Methods

The study design comprised two phases:

- a Web-based survey of visitors who sent a request to the Internet expert forum, and
- a content analysis of these requests.

### Setting

The study was conducted on the German website [www.rund-ums-baby.de](http://www.rund-ums-baby.de), which provides information for parents and potential parents. The site consists of several sections, such as reproduction, pregnancy, birth, and parenting. In each section, visitors can refer to a group of medical experts (expert forum) and ask questions directly via a Web-based interface or by email. In the section "Wish for a Child," the expert team consists of six to eight experts who are board certified in gynecology, urology, andrology, or embryology. Some of them work in an outpatient department, some in reproductive clinics, and some in university hospitals. The experts' work with the forum is on a voluntary, unpaid basis. It is possible for visitors to find the experts' addresses on the website but, to our knowledge, it is unusual for them to personally visit an expert in his or her surgery or clinic. Until 2003 (including the study period), visitors did not have to pay to ask a question. At the time of writing, a nominal fee of 2 euros is charged.

If visitors send a request to one of the experts, the request (without any email address) and the answer are openly published on the website. Further comments from any visitor to the site are welcome and are also published. The structure of these dialogues resembles, for example, The Heart Forum of the Cleveland Clinic Foundation [16]. A PowerPoint presentation about the website can be found in [Multimedia Appendix 1](#). There are several other online sources for infertility-related problems in Germany, but until 2003, [www.rund-ums-baby.de](http://www.rund-ums-baby.de) was the only one combining general information and expert advice.

To date, more than 10000 electronic messages have been published on the website. Of these, 3840 could be identified as original requests to the expert forum (excluding expert answers, comments, demands, or requests that had nothing to do with involuntary childlessness). The first names of the visitors indicated that only 69 requests (1.8%) were from men.

### Open Survey

We posted a questionnaire on the website from August 27, 2001 to February 28, 2002. The questionnaire was "activated" whenever a visitor sent a request to the expert forum. Right at the beginning of the questionnaire, visitors were informed that they were not obliged to answer the questionnaire (informed consent) and were told how they could exit the questionnaire.



The questionnaire was designed for adaptive questioning. The request of the visitor and his or her answers to the questionnaire were immediately separated from each other so that the expert team did not know whether a visitor had answered the questionnaire or what the answers were.

The questionnaire comprised 22 items. First, visitors were asked whether they had filled out a questionnaire in the past. Then, in the first set of questions, participants were asked to explain their reasons for visiting the website and the expert forum, whether they had previously sent a request and, if so, how they had used the information and how satisfied they were with the experts' answers. The second set of questions related to the actual treatment situation of the participant. At the end of the questionnaire, participants were asked for some sociodemographic details.

The questionnaire was pilot tested with 30 visitors to the website. They were asked at the end of the questionnaire whether they had any difficulties in answering the questions and whether they had any technical problems handling the questionnaire. None of the respondents reported any problems. The final version of the questionnaire is available in [Multimedia Appendix 2 and 3](#). A non-edited English translation is also provided.

Descriptive statistics were applied to analyze the survey data, including absolute and relative frequencies and cross-tabulations, using SAS 8.2 [17]. Differences between nominal variables were tested for statistical significance using the Pearson chi-square test, with alpha set at  $P < .05$ .

### Analysis of Requests

Requests of those visitors who had answered the survey were analyzed using Atlas-ti [18], a software program for qualitative

data analysis. Single phrases or the whole request were coded according to a list of categories and subcodes that we had developed in a retrospective analysis of former requests to the expert forum. These categories were developed and refined by a multidisciplinary group, consisting of two physicians, an expert in reproductive medicine, and a sociologist (JM, MMK, HWM, WH). In detail, HWM suggested a broad spectrum of categories from his work and experience in the expert forum, which JM transformed into a hierarchy of general expectations of the expert forum and different special requests ("codes"; see [Table 4](#)). JM coded the requests according to this list, supervised by WH. To ensure a valid coding process, a list of different examples and their respective codes was produced by JM and adjusted by HWM and WH. Problems in coding were discussed with all authors. Most importantly, we not only coded the "official" request but also implicit messages and expectations regarding the expert forum.

### Data Security

The webmaster for the expert forum was responsible for the handling of the data. He administered all requests and all questionnaires during the study period. Afterwards, the data were securely transmitted via a SSL (secure sockets layer) connection to the Department of General Practice without using any email addresses.

The study was approved by the local ethics committee of the University of Goettingen.

## Results

A total of 513 answers from participants were analyzed. These users had visited the Internet forum, sent a request to one of the experts, and answered the survey.

**Table 1.** Study characteristics compared with the German population\*

	Percent of Study Sample Age: 18–43 (N = 513)	Percent of German Population Age: 20–45 (N = 29551600)
<b>Sex</b>		
Female	99.2	48.7
Male	0.8	51.3
<b>Family Status</b>		
Married	72.5	49.6
Partnership	26.7	-
Single, divorced, widowed	0.8	50.4
<b>Education</b>		
Less than 10 y	12.3	33.6
10 y	40.9	24.6
More than 10 y	19.6	17.3
University degree	27.2	11.3
Other		13.6

\* Federal Statistics Office [19]

During the study period, the survey was activated by 1305 visitors, of whom 632 (48.4%) declared that they had already visited the website several times and had previously filled in the questionnaire. Because 53 visitors (4.1%) had no wish for a child, they were excluded from further analysis; 97 visitors refused to participate, giving a response rate of 84.1% (513/610). Nearly all respondents were women. Compared to the German reference population, many more of the respondents lived in stable partnerships and were better educated (Table 1).

### Survey Results

At the beginning of the survey, the visitors were asked how they found the website. About 43% (220/509) found the Internet forum by chance, and 83 visitors had systematically searched the Internet for such a website. Only 6 visitors had received this, or a similar, Internet address from their doctor. More than half of the respondents (276/501) sent a question to the expert forum for the first time, and 225 persons had previously consulted the expert forum.

Most of the respondents who reported suffering from involuntary childlessness had already contacted a gynecologist (361/484). For 15%, however, the expert forum was the first professional contact from which they hoped to receive information. Table 2 presents the respondents' reasons for visiting the expert forum. Most of them asked for general information about involuntary childlessness and conception or had questions about their actual treatment.

Of 225 visitors who had previously contacted the forum, 223 received an expert answer. More than half (55.2%; n = 123) were satisfied with the experts' answers, 7 were unhappy with the reply, and the remainder were undecided. Additional comments about the quality of the expert forum were provided by 65 respondents. Apart from many positive reactions, 31 of these respondents expressed dissatisfaction because they either did not receive a previous answer to their question (n = 13), waited too long for an answer (n = 12), or considered the answers superficial (n = 9), inadequate (n = 5), or difficult to understand (n = 3).

**Table 2.** Self-reported reasons for visiting the Internet expert forum (n = 505)\*

Reason	Percent
General information	72.9
Questions about current treatment	45.1
Questions about different treatment options	32.1
Questions about causes of infertility	25.5
Questions about diagnostic data	22.0
Other	7.7

\* Multiple answers possible

About half of the users who received a previous answer from the expert forum (105/223) discussed it with their own doctors, some with their fertility clinic doctor, some with their gynecologist, and some with their general practitioner. Of these users, more of them were satisfied with their subsequent medical treatment and/or consultation than visitors who had not talked

to their doctor about their Internet experience. This difference was only significant for patients in fertility clinics (Table 3). A quarter of respondents (51/221) changed their doctor or consulted a specialist because of the experts' answers, and 56 started treatment following the experts' advice.

**Table 3.** Satisfaction with medical provider (% of patients who said they were satisfied with treatment or consultation)

Medical Provider	Talked With Doctor About Expert Answer		P value *
	Satisfied Among Those Who Talked	Satisfied Among Those Who Did Not Talk	
Fertility clinic (n = 95)	93.9	76.1	.015
Gynecologist (n = 155)	80.5	74.4	.36
General practitioner (n = 47)	72.4	66.7	.68

\* Significance of chi<sup>2</sup> test

Many respondents to the survey were disappointed that they could not talk with their doctors about psychological problems (n = 79), sexual problems (n = 37), somatic complaints (n = 30), or difficulties in their partnership (n = 30). Those who described complaints about their doctors in detail most often mentioned lack of time during consultation (n = 28) and inadequate information (n = 28). Of the women, 20 were upset about "being treated as a number," being reduced to their abdomen, or being considered a "laying hen."

### Content Analysis of Types of Requests

We categorized the requests according to the type of help that visitors sought from the expert forum. Each category had several subcategories (Table 4). Most people sought information about conception, reasons for childlessness, evaluation of drugs, diagnostic procedures, and therapeutic options. Many of these requests were very basic.

*With the help of an ovulation calendar I have ascertained my fertile days. But what does that mean?*

*If they are, for example, from Sunday to Thursday should I have intercourse every day from Sunday to Thursday or is it better to do so every second day? Or what should I do to become pregnant as soon as possible? Sorry to ask but I heard totally different things. [110; FB 382.txt]*

Many visitors sent their diagnostic tests results in detail and asked for a second opinion as a check or for decision making.

*Our doctor recommends assisted hatching. [A process that may help embryos implant in the uterus during an IVF cycle.] What do you think about this technique? Allegedly it should increase pregnancy rate. I am unsure and afraid of course that if implantation occurs, a malformed child may be the consequence. Do you also use this method? [24; FB 12.txt]*

**Table 4.** Types of requests, according to qualitative analysis (n = 513)\*

Expectation of the Expert Forum	Categories of Requests*	n	Total
Information and explanation	General information	194	343
	More detailed questions	333	
	How to find information	2	
Independent medical advice	Second opinion	199	226
	Treatment options	116	
	Diagnostic options	26	
	Cost of treatment	16	
	Other	15	
Compliance authority	Criticizing doctors	76	76
Guidance	Requests whether to change a doctor	13	36
	Requests whether to consult of doctor	11	
	Recommendation of specialists	10	
	Recommendation of clinics	10	
Emotional support	Expression of feelings	80	90
	Looking for new hope	8	
	Looking for fellow sufferer	6	

\* Multiple classifications possible

The expert forum was also utilized as a sort of guide to finding an adequate specialist or to getting an answer to the question of whether medical help was necessary at all.

The need for information and the complaints about doctors were often intermingled, giving the expert forum a role of reassurance.

*According to a new hormonal analysis, my gynecologist told me that my progesterone values were disastrous. A value of 1000-2800 (???) would be normal, but mine was 47. This is why a pregnancy can be excluded. Unfortunately, those values were not explained to me and no treatment was recommended. Can you please explain this? Maybe I do not ovulate and are my values really so catastrophic? Certainly, I will never consult this doctor again. Do you recommend that I visit a fertility clinic or can I do something myself? [196; FB 565.txt]*

*I have the right to know what happened in the operating theatre, or am I wrong?...I only received a copy of the findings from the material which was sent in (from the abrasion). Please explain this to me; I don't understand anything. I have the feeling he kept something back...because the doctor told me, I was as fit as a fiddle...I am even more disturbed, because he refused to give me the surgery report. [105; FB 377.txt]*

Furthermore, the expert forum provided emotional support. Visitors sometimes expressed their feelings by using the words “help” or “cry for help” or other expressions which they wrote in capital letters.

*Treatments: 1. ICSI follicular puncture 09.2000: 14 oocytes, all fertilized, 3 cryopreserved, 2 transferred, NEGATIVE ... 5. ICSI follicular puncture; 7 oocytes, 5 fertilized, no cryo!, 3 transferred, NEGATIVE.*

*Maybe this happened because of my endometriosis?????. Could you recommend down regulation over a three month period? Maybe an HLA analysis should be done. HELP!!! I don't know how to go on, I am devastated and totally helpless. [478; FB 1248.txt]*

Some visitors also hoped to receive help concerning problems in their relationship.

*My boyfriend always tells me that nothing will happen if my life is so much dominated by the wish for a child. This always dampens my hopes. He does not understand how I feel. All day long I only think about having a baby. [67;FB 294.txt]*

Compared to the requests from women, the few requests from men differed in only one respect—they were usually much shorter.

## Discussion

Visitors to the Internet site [www.rund-ums-baby.de](http://www.rund-ums-baby.de) not only required detailed medical advice on specific matters of infertility diagnosis and treatment, but they also asked for general information about reproduction and for second opinions. Furthermore, they considered this forum as a source of emotional support and as a place where they could complain about their current treatment. Though the majority of visitors were satisfied with the experts' work, 44.8% were not fully convinced.

## Limitations

When visitors to the website were presented with the survey, some may have left the site instead of declaring their unwillingness to participate in the study. Others may have claimed that they had already responded to the survey, even though this was their first visit to the website since the survey was offered. Since we did not use cookies or check the IP address to register site visits or to identify potential duplicate entries from the same user—due to the demands of the ethics committee and the highly sensitive issue of involuntary childlessness—it was not possible to calculate exact view rates or participation rates. The reported figure of 84% may overestimate the true response rate.

Because study participants wanted an answer to their requests at the same time as being asked to complete to questionnaire, there may have been some social pressure to respond to the survey. Although we informed the participants that the experts would receive only their requests and not their answers to the survey, some visitors might have evaluated the experts' responses in a more positive light for fear of jeopardizing future requests.

Another source of bias may be that satisfaction with the experts' answers could only be assessed by people who visit the site at least twice; however, those who were highly dissatisfied would have been less likely to visit the site again.

## Study Implications

The most striking result of this study is the broad variety of reasons why visitors contacted the forum and the different types of requests:

1. One group of visitors made full use of the opportunities offered by the expert forum: those who sent their laboratory data to the experts to receive a thorough evaluation or a second opinion. This is in line with other studies on reasons for Internet consultations [8,20]. Many of the visitors explained their condition using medical terms and concepts before asking their question.
2. Many requests were not suited to the expertise of the team of specialists. This was especially true in relation to general information about basic aspects of human reproduction. Obviously, patients contacting this website were not satisfied with the information they received from doctors, partners, parents, school, and the mass media, which resembles findings from an earlier study [8]. As access to the Internet expands, the volume of requests may increase and become a strain on the experts [7].
3. One important expectation of the forum was emotional support, which was the main reason for some requests or which appeared embedded in other requests. Involuntary childlessness often results in stress, anxiety, and insecurity about whether or not to choose an artificial reproductive technology [21]. Epstein et al [14] are sure that expert forums can support infertile people by giving them the chance to communicate their feelings of depression, anxiety, or anger. In contrast, Baur [12] doubts whether email and the Internet are appropriate media for counseling. Therefore, many participants in our study may have adapted to the “technical imperative” of the Internet to exchange or to ask for technical information. Most of them described their request as information seeking. Only our more in-depth analysis made us aware of implicit emotional problems and needs in some of the requests.

The use of the Internet to get medical information and advice reflects a lack of patient information. Patients may not receive adequate information from their doctors because doctors have insufficient time to answer all questions or are unwilling to spend adequate time with the patient [6]. About one-third of respondents in our study were dissatisfied with the information they received from their family doctor or gynecologist, and they complained about their own doctor's professional or emotional incompetence. This was also true in an analysis of emails addressed to a university dermatology hospital, in which 17% of patients expressed frustration with their own doctors [8]. Distrust was also a strong concern in a patient survey in primary care practices in Rhode Island, USA [22]. More than 57% of the patients expressed an interest in using the Internet to find out if their health care provider was giving them the tests and treatments they need, although, to date, only 17.3% reported ever doing this on the Internet. Consequently, 53% of the visitors in our study did not talk with their doctor about the experts' answers. More of these patients were dissatisfied with their further medical treatment compared to those who did talk with their doctors about their Internet activities. However, this association was only significant for patients in fertility clinics,

and we should emphasize that visitors who have a good relationship with their doctor may be more likely to both share the answer from the expert forum and rate their subsequent treatment as satisfactory. Further research should clarify whether there is evidence for a causal relationship between the discussion of Internet information with the doctor and satisfaction with further medical treatment.

About half of the visitors were also not fully satisfied with the expert forum. According to Kedar et al [23], a strong motive for using the Internet is the dissatisfaction patients have with the fact that they have to wait too long for treatment to start. Some visitors even reacted disquietingly towards a delay of a few days when waiting for an answer to their requests. Expanding Internet opportunities of this kind may result in even more visitors who are dissatisfied with their doctor's information, and who either get lost in a maze of Internet information or wait for an adequate answer longer than tolerated.

There is some concern that regular use of the Internet is highly correlated with income level and education [24]. This "digital divide" [25] was also evident in our study. One explanation could be that better educated people tend to delay having children and may therefore encounter more infertility problems

[26]. It is more likely that this population has more experience in the use of the Internet and is more familiar with writing Internet requests. As appropriate information is crucial for making health care decisions, especially about new treatment options, Internet-based expert forums may amplify the digital divide.

### Conclusions

Internet-based expert forums are well suited to give medical advice in difficult situations, to provide help in making decisions, and to offer second opinions. There is no legitimate reason why doctors should not support their patients' use of the Internet for this purpose. In addition, doctors should offer their patients an open discussion about all the information they have received.

The Internet seems to be a seismograph for psychological needs that are not met by doctors and which, on the other hand, can hardly be fulfilled by virtual experts. Further research is necessary to find out whether dialogues between visitors in a chat room, for example, would be more supportive in cases of emotional stress [27,28] and would stimulate visitors to take on a more active role by exchanging information with like-minded people.

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### Authors' Contributions

WH and HWM wrote the study proposal and designed the study. JM designed the questionnaire, managed the fieldwork, and collected the data. WH and JM analyzed the data and discussed problems in coding with MMK and HWM. MMK provided advice during study design and co-interpreted the data. WH wrote the original and successive drafts of the paper and acts as guarantor for the study. HWM co-wrote the article. All authors reviewed and commented on the paper.

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### Conflicts of Interest

HWM serves as 1 of 6 Internet doctors of the expert forum on [www.rund-ums-baby.de](http://www.rund-ums-baby.de), working on an unpaid basis.

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### Multimedia Appendix 1

Screenshots of [www.rund-ums-baby.de](http://www.rund-ums-baby.de) [[PPT File, 504K - jmir\\_v7i2e20\\_app1.ppt](#)]

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### Multimedia Appendix 2

Questionnaire in German [[DOC File, 92K - jmir\\_v7i2e20\\_app2.doc](#)]

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### Multimedia Appendix 3

Questionnaire (translated into English by the authors, unedited) [[DOC File, 96K - jmir\\_v7i2e20\\_app3.doc](#)]

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### Multimedia Appendix 4

Patient Quotes in German [[DOC File, 24K - jmir\\_v7i2e20\\_app4.doc](#)]

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Original Paper

# Teaching Elderly Adults to Use the Internet to Access Health Care Information: Before-After Study

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## Abstract

**Background:** Much has been written about the Internet's potential to revolutionize health care delivery. As younger populations increasingly utilize Internet-based health care information, it will be essential to ensure that the elderly become adept at using this medium for health care purposes, especially those from minority, low income, and limited educational backgrounds.

**Objective:** This paper presents the results of a program designed to teach elderly adults to use the Internet to access health care information. The objective was to examine whether the training led to changes in participant's perceptions of their health, perceptions of their interactions with health care providers, health information-seeking behaviors, and self-care activities.

**Methods:** Participants attended a 5-week training course held in public libraries and senior community centers within the greater Pittsburgh and Allegheny County region. Classes within each seminar lasted 2 hours and consisted of lecture and hands-on training. Baseline surveys were administered prior to the course, 5-week follow-up surveys were administered immediately after the course, and final surveys were mailed 1 year later. Instruments included the Multidimensional Health Locus of Control (MHLC) Scale, which measures three domains of locus of control (internal, external, and chance); the Krantz Health Opinion Survey (HOS); and the Lau, Hartman, and Ware Health Value Survey. Two additional questionnaires included multiple choice and qualitative questions designed to measure participants' Internet utilization and levels of health care participation. The Health Participation Survey was administered with the baseline survey. The Internet Use Survey was administered at the 1-year mark and contained several items from the Health Participation Survey, which allowed comparison between baseline and 1-year responses.

**Results:** Of the 60 elderly adults who began the training course, 42 (mean age 72) completed the entire 5-week training program and the 5-week follow-up questionnaire administered immediately after the program, and 27 completed the 1-year follow-up survey. Statistically significant differences were found between baseline and 5-week follow-up results for MHLC chance subscores in males ( $P = .02$ ) and females ( $P = .05$ ), as well as total HOS information seeking scores ( $P = .05$ ). However, these statistically significant findings disappeared when all 60 original participants were included using a "last observation carried forward" imputation. No statistically significant changes were found between baseline and 5-week follow-up surveys for MHLC external ( $P = .44$ ) and internal ( $P = .97$ ) locus of control scores in both genders, or for the HOS behavioral involvement subscale ( $P = .65$ ).

**Conclusions:** We failed to show robust before-after effects for most of the outcomes measured. Elderly adults may be willing to use the Internet as a source for general health information; however, when making decisions about their health care, our participants seemed to adhere to a physician-centered model of care. Demographic and situational variables may play a large role in determining which seniors will use the Internet for making behavioral decisions about their health care and in which scenarios they will do so.

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**KEYWORDS**

Aged; health; patient participation; health information system; Web-based services; Internet; attitude to health; physician-patient relations

## *Introduction*

The days of the physician-centered, paternalistic model of health care [1], when physicians seemingly provided all answers and all direction, are rapidly fading. Although many health care systems in industrialized countries continue to move toward a shared decision-making model, many seniors learned to interact with their health care providers when the paternalistic model was prevalent. To become independent consumers of health care, seniors must learn to find the health information needed in order to participate in the shared decision-making model. As increasing numbers of seniors go online, the Internet can provide needed health information, but seniors must become both health and health information literate. More research is needed to determine whether Internet use increases seniors' levels of participation, alters their decision-making processes, and most importantly, whether it has a positive impact on seniors' overall health.

### **The Digital Divide**

Use of the Internet continues to grow exponentially across all age groups in the United States. Fox [2] reports that overall, 77% of 18- to 29-year-olds, 75% of 30- to 49-year-olds, 58% of 50- to 64-year-olds, and 22% of adults 65 and older have access to the Internet. Furthermore, Fox and Fallows [3] report that more than 80% of adult users (or 93 million) have searched the Internet for health information. Of that 93 million, roughly 5 million adults age 65 and older have used the Internet to access and use health care information. Although the discrepancy in Internet use among age groups decreases each year, a large gap exists between seniors who frequently use the Internet to find health care information and those who do not. This gap is of grave concern because the move toward managed care places a greater burden on patients to make decisions about their own health care. Furthermore, US government agencies are now beginning to place an increasing amount of information relevant to Medicare and other programs on the Internet (eg, one option to sign up for the Medicare drug benefit card is to register via the Internet). Seniors who lack access to the Internet as well as the skills necessary to find, retrieve, and evaluate information are at a distinct disadvantage in managing their health care.

Of the 22% of US adults aged 65 and older using the Internet, it is estimated that 66% use the Internet to locate health information [2]. Initial studies suggest the majority of senior users are highly educated white females, with high economic standing, who own personal computers connected to the Internet [2,4,5]. Elderly males and elderly members of ethnic minority groups lag behind in using the Internet to locate health care information. In 2003, only 11% of African Americans aged 65 and older reported using the Internet for any purpose [2].

### **A Cause for Concern**

Providing seniors with the requisite skills to use the Internet to locate health information is important for four reasons:

1. Of all medical expenditures in the United States, 40% are for persons 65 and older [6]. With the senior population expected to rise from its current proportion of 12.4% to more than 20% in the year 2030, medical expenditures for seniors will continue to grow.
2. Research by Wenger [7] shows that care for seniors for conditions such as dementia, mobility disorders, pressure ulcers, urinary incontinence, and end-of-life care falls well short of practice guidelines.
3. Americans 65 and older are at constant risk of functional decline by either having to live with a disability or suffering from a chronic illness.
4. The Institute of Medicine [8] and Bach [9] report that substantial disparities exist in the quality of care delivered to ethnic minority patients, who are more susceptible to cardiovascular disease and cancer [10].

The ability to locate relevant health care information benefits seniors by helping them to ask better questions of their health care providers. Several studies show that patients who ask questions, elicit treatment options, express opinions, and state preferences during physician office visits have measurably better health outcomes than those who do not [11-16]. Exposing seniors to Internet-based practice guidelines and standards of care should increase the likelihood that they will receive the proper treatment and take preventive measures.

The question of seniors using the Internet is acutely important in Pittsburgh and the surrounding Allegheny County. Among US counties with populations over 1 million, Allegheny County has the second highest concentration of seniors in the United States, with 17.8% of residents being 65 and older [17,18]. Additionally, research by the University of Pittsburgh Graduate School of Public Health shows that seniors living in Allegheny County have lower levels of computer ownership and Internet access as compared to other demographic groups [19].

The authors hypothesized that teaching seniors to use the Internet to search for health care information and to evaluate the quality of information found would result in (1) reduced reluctance to use computers and increased willingness to use the Internet to find health care information; (2) increased willingness to use external health care information to manage their health care; (3) adoption of a more active role in managing their health care; and (4) increased perception of control over their own health and wellness.

## *Methods*

This study began in September 2001 with recruitment of volunteers to participate in 5-week training seminars, which lasted through November 2002. One year after completion of the training, participants received follow-up surveys, which concluded in December 2003.

## Training Seminars

One of the authors partnered with Pittsburgh's public library system, a large suburban library, and two senior community centers to sponsor a series of seminars designed to teach seniors to search the Internet for health care information. Holding the sessions in libraries and community centers afforded Internet access to seniors who do not own computers or have Internet access at home. The choice of training centers provided access to a wide range of individuals from varied ethnic groups and socioeconomic status [4]. Participants met for 2 hours, once a week, for 5 weeks. The presenters focused on helping participants use the Internet to learn more about diseases, treatment options, and the health care system, covering the following topics:

- Using a computer and Web browser to access the Internet
- Locating health related information using search engines
- Evaluating health information found on the Internet
- Finding specific types of health information (eg, treatments, medications, physician background and education)
- Using various relevant, high-quality websites (eg, MedlinePlus, ClinicalTrials.gov, OncoLink, IntelliHealth, American Medical Association)

The sessions used constructivist teaching techniques and self-directed learning with a focus on practicing problem-solving skills. Class size was limited to 12 participants to enable instructors to provide more personalized attention.

The overarching goal of the instruction was to encourage seniors to learn more about their health problems, evaluate their health care, and take a more active role in managing it.

## Participant Recruitment

Participants were recruited using posters and flyers targeted to seniors and were available at libraries, senior centers, and other training sites. Ads were placed in senior newsletters and regional publications, and community newspapers. Notices for the sessions were placed in senior center catalogs and program announcements. Also, library and senior center staff members, as well as past participants, were encouraged to spread the word about the program. Any interested senior was allowed to attend the sessions.

## Data Collection, Instruments, and Analysis

As participants began the training sessions, they were asked to complete a baseline questionnaire composed of the Multidimensional Health Locus of Control (MHLC) Scale, the Krantz Health Opinion Survey (HOS), and the Lau, Hartman, and Ware Health Value Survey, as well as the Health Participation Survey. At the end of the 5-week training sessions, participants were asked to complete the same battery of instruments, with the exception of the Health Participation Survey. One year after the training, the 42 participants who completed the training were mailed paper copies of a questionnaire, including the HOS, Lau, Hartman, and Ware Health Value Survey, and Health Participation Survey, as well as 10 additional questions comprising an Internet Use Survey. MHLC was not included in the 1-year follow-up in order to make the questionnaire less daunting to participants. The mailing

included a cover letter with instructions and a pre-addressed, postage-paid envelope to return the completed surveys.

## Statistical Analysis

Unless otherwise noted, paired *t* tests were used to compare participants' (completers') baseline scores to 5-week follow-up scores. Where indicated, to account for the missing data from the 18 participants who did not complete the training program, a last observation carried forward imputation was used to analyze all significant results.

## Multidimensional Health Locus of Control (MHLC) Scale

The MHLC Scale [20] was adopted to assess the participants' perception of control over their own health and wellness, or locus of control. The concept "locus of control" was first derived from Rotter's social learning theory, which states that behavior is a function of the expectancy that a specific action will lead to a specific goal or outcome, combined with the reinforcement value of that goal or outcome [21]. Locus of control has three domains: internal, external, and chance. In terms of personal health, an individual with an *external* locus of control believes that the actions of another individual determine her health status. A person with an *internal* locus of control believes her own actions determine her health status. An individual with a *chance* locus of control believes that chance plays a major role in her overall health status.

Previous research found that senior women who used the Internet to locate health information already had an internal health locus of control [4]. However, it was hypothesized that most participants would have an external health locus of control because research shows that older adults generally allow physicians and other health professionals to control their health care [22-28].

## Krantz Health Opinion Survey (HOS)

The HOS [29] was used to measure seniors' desire for more health information, as well as their desire to engage in self-treatment. This survey consists of 16 items yielding scores for health information seeking, behavioral involvement, and an overall score which measures composite attitudes toward treatment approaches. High scores on each subscale represent an individual's desire to be informed on issues regarding their health and a desire to engage in self-care activities. It was hypothesized that participants would initially score low on each subscale as well as the overall score. It was also predicted that scores would increase once participants received instruction on how to use the Internet to locate health information. Furthermore, the authors anticipated that scores would remain stable over the course of a year from the time participants received initial Internet training.

## Health Value Survey

The four-item Lau, Hartman, and Ware Health Value Scale [30] was used to measure the value participants place on their health. Health value is important because, as Wallston and Wallston explain, "There is no theoretical reason to expect health locus of control to predict health behavior, unless it is used in combination with a measure of health value" [31]. Individuals



who value their health, whether healthy or suffering from chronic illness, will be more likely to use the Internet to locate and use health information.

### Health Participation Survey

This survey was administered to measure seniors' levels of participation in managing their health care. For example, the first question asked them to rate their level of participation during their last visit with their primary care provider. Question two asked participants to identify the role they played at their last office visit: did they let their health care provider make all the decisions, did they make all the decisions and ask their health care provider to state his/her opinions, or did they take a collaborative role with their provider? Other questions included whether or not they prepared a list of questions for their office visit, how many questions they asked at the last office visit, did they do any research to prepare for their last office visit, and whether they had ever used the Internet to locate health information.

### Internet Use Survey

This survey was administered only at 1-year follow-up. It was designed to measure the impact the Internet had on participants' health care behaviors. Five questions from the Health Participation Survey appeared on this survey but used slightly different wording. Participants were asked to evaluate, on a 5-point scale, their levels of participation with physicians and their use of health information to prepare for physician office visits, change personal behaviors, and make health care decisions.

Ten of the questions were based on a national survey conducted by Baker et al [32]. The questions evaluated the influence Internet-based health information had on participant understanding and decision making regarding a health-related issue. Responses to these questions included a 6-point scale from "Strongly Disagree" to "Strongly Agree."

## Results

### Participants

A total of 60 participants began the Internet training program, and 42 completed the 5-week training seminar. These 42 participants also completed the baseline and 5-week follow-up MHLC and HOS surveys. Participant makeup consisted of 34

(81%) females and 8 (19%) males. The average age of participants was 72 years, and 34 participants (81%) reported that they were retired. The respondents showed a much higher percentage of computer ownership than typically found in senior populations. Of the 42 participants, 30 (71%) owned a home computer, 25 (60%) reported having used the Internet, and 24 (57%) had used email. Seventeen (40%) respondents reported that they used the Internet to find health care information prior to the study, and 1 (2%) reported using the Internet to join an online support group. Prior to the study, 27 (64%) participants reported having some type of illness, with a subset of 19 (45%) reporting a chronic illness.

Only 27 participants responded to the 1-year follow-up survey, which included the Internet Use Survey. The attrition rate from the 5-week follow-up to the 1-year follow-up was worse for the women than for the men, with 7 of the 8 males responding at 1-year but only 20 of the 34 females.

### Before-After Analysis of Outcomes

#### Krantz Health Opinion Survey (HOS)

HOS health information seeking scores for the 42 participants showed a statistically significant increase from baseline to 5-week follow-up (mean = 28.0 vs 29.6;  $P = .05$ ). Higher scores on the HOS indicate a greater desire for health information and self-treatment. In a sensitivity analysis, to address nonresponse bias due to the 18 participants who did not complete the training or the 5-week follow-up, a last observation carried forward imputation was used, which included all original 60 participants and assumed that the HOS information seeking scores remained at baseline level for the 18 participants who dropped out. This analysis changed the level of significance slightly ( $P = .051$ ). No statistically significant differences were found for the behavioral involvement subscale ( $P = .65$ ).

#### Multidimensional Health Locus of Control (MHLC) Scale

Male ( $P = .02$ ), female ( $P = .05$ ), and overall participants' ( $P = .005$ ) MHLC chance scores showed statistically significant differences between observed baseline and 5-week follow-up results, suggesting that participants' perceptions of the role chance plays in their health declined (Table 1). Other MHLC scores showed movement after participation in the course, but the differences were not statistically significant.

Table 1. MHLC mean scores

	n	Internal			External			Chance		
		Baseline (SD)	5-Week Follow-Up (SD)	P value	Baseline (SD)	5-Week Follow-Up (SD)	P value	Baseline (SD)	5-Week Follow-Up (SD)	P value
Male	8	22.25 (3.694)	24.00 (2.673)	.33	22.63 (2.669)	21.75 (3.615)	.61	19.00 (2.619)	15.88 (2.997)	.02
Female	34	24.06 (3.931)	24.12 (3.724)	.90	19.15 (5.040)	19.38 (4.599)	.73	16.44 (4.717)	15.29 (4.131)	.05
All	42	23.71 (3.909)	24.10 (3.519)	.44	19.81 (4.855)	19.83 (4.488)	.97	16.93 (4.485)	15.40 (3.914)	.005

In a sensitivity analysis, we included the 18 participants who did not complete the training or 5-week follow-up, assuming unchanged baseline values for the 5-week follow-up of the dropouts. This changed the previously statistically significant MHLIC chance findings to insignificant levels for males ( $P = .43$ ), females ( $P = .75$ ), and overall participants ( $P = .53$ ).

### Health Value Survey

Baseline mean scores from the Health Value Survey were 18.02 and increased only slightly and nonsignificantly during the 5-week follow-up (18.12,  $P = .80$ ). Of the 27 participants who

completed the 1-year follow-up, no statistically significant differences were found from baseline to 1-year follow-up ( $P = .22$ ), or from 5-week follow-up to 1-year follow-up ( $P = .10$ ).

### Health Participation Survey

The Health Participation Survey asked participants to identify the role they played on their last visit to their physician. There were very few changes from baseline to 1-year follow-up (Table 2). Interestingly, none of the participants reported working together with their physicians to make important decisions.

**Table 2.** Health participation survey (n = 27)

	Baseline No. (%)	1-Year Follow-Up No. (%)	Chi <sup>2</sup>	P value
<b>Role played on last visit to physician</b>				
I let the doctor make all the decisions and I followed them	7 (26)	4 (15)	.021	.89
I made all the decisions and asked the physician to state his/her opinions	0 (0)	1 (4)	-	-
I played a collaborative role with my physician	20 (74)	21 (78)	1.122	.29
Other	0 (0)	1 (4)	-	-
<b>How do you prepare for physician visits</b>				
Prepared a list of questions before visit	16 (59)	8 (30)	1.167	.28
Used Internet to locate information prior to visit	3 (11)	6 (22)	2.220	1.1

The Health Participation Survey also asked participants to report how they prepared for physicians' visits. Although fewer respondents in the 1-year follow-up indicated preparing a list of questions prior to their last visit, they did, on average, ask their health care provider more questions than at baseline (mean = 3 vs 4 questions at baseline vs 1 year, data not shown).

### Internet Use Survey

Administered at 1-year follow-up, the Internet Use Survey asked participants to rate their levels of participation during their last physician office visit. Ratings were based on a 5-point scale from (1) for "No participation" to (5) for "High participation." Although the median score increased from 3 at baseline to 4 at 1-year follow-up, a Wilcoxon signed rank test used to compare participant responses showed no statistically significant increase in participation ( $P = .38$ ).

Twenty-one of 27 (78%) respondents to the 1-year follow-up survey indicated that they had used the Internet to find health-related information; 11 respondents reported using the Internet for health information at least weekly. Another 10 respondents indicated that their frequency of use was "other," which provided an open-ended opportunity for further explanation. Responses included as needed, 3 to 4 times per year, 10 times per year, or no additional information.

Ten questions of the Internet Use Survey focused on the impact Internet-based health information had on participants' decision making. The first four questions related to participants' feelings regarding general health information retrieved from the Internet (Table 3). The remaining six questions (Table 4) were aimed only at the 18 participants who said they were suffering from a chronic condition.

**Table 3.** Internet use survey: general health information, 1-year follow-up survey (n = 27, multiple answers possible)

Question	Agree or Strongly Agree	
	No.	%
1. Did the Information you found on the Internet improve your understanding of the symptoms, conditions, or treatments in which you were interested?	18	67%
2. Did the information you found on the Internet provide you with the ability to manage your health care needs?	5	19%
3. Did the information you found on the Internet challenge you to seek care from another health care provider or health care facility?	9	33%
4. Did the information you found on the Internet challenge you to change the way you eat or exercise?	11	41%

**Table 4.** Internet use survey: patients reporting chronic illnesses, 1-year follow-up survey (n = 18, multiple answers possible)

Question	Agree or Strongly Agree	
	No.	%
1. Did the information you found on the Internet help you better understand your chronic condition?	13	72%
2. Did the information you found on the Internet help you manage your chronic condition by yourself?	3	17%
3. Did the information you found on the Internet affect the treatments you use for your chronic condition?	6	33%
4. Did the information you found on the Internet help you manage other health problems without visiting a health care provider?	3	17%
5. Did the information you found on the Internet challenge you to seek care from a different physician, health care provider, or health care facility?	3	17%
6. Did the information you found on the Internet challenge you to change the way you eat or exercise?	7	39%

The majority, 18 of 27 (67%) participants, agreed that the information improved their understanding of a health care topic, but most participants also felt that the information did not help them manage their health care needs, challenge them to seek care from another health provider or facility, or challenge them to change their diet or exercise habits. A similar pattern was observed for participants with chronic conditions, with a majority agreeing that the information allowed them to better understand their health problem, but only a minority reporting that the retrieved health information helped them to manage their chronic condition, affected treatments used to control their condition, helped to manage other conditions, or challenged them to change their diet or exercise.

## Discussion

This study explored the impact of training seniors to use the Internet to locate health information. In examining the viability of this endeavor, the authors chose to focus on four research questions (as stated in the Introduction) to explore how Internet usage may or may not affect a group of seniors' decision-making processes.

### Willingness to Use Computers and Internet

The first question to be answered was whether or not participants would experience a reduced reluctance to use computers and an increased willingness to use the Internet to find health care information. Although 30 of the 42 participants already owned a personal computer at the onset of the study, only 17 (40%) reported having used the Internet to locate health information. A year after receiving Internet training, 21 of the 27 respondents (78%, or 50% of the 42 course completers) reported using the Internet, either weekly or as needed, to locate health information. This suggests that older adults are willing to use personal computers to locate health information.

However, since participants for this study were self-selected, it is likely that they had a greater interest in using the Internet prior to the study than the average senior.

A high number of participants (18 of 60, 30%) did not complete the course (n = 18). Reasons for attrition varied. Some examples included family illnesses, difficulty getting to training sites, and frustration in learning to use computers. Several of the participants were not willing to provide reasons for dropping

out of the study. Given that the demographic characteristics of the 18 dropouts were similar to the 42 who completed the study, it seems unlikely that the findings would have been substantially different if the 18 participants had completed the 5-week follow-up survey.

### Willingness to Use External Health Information

The second question sought to determine whether there was an increased willingness among participants to use external health information to manage their health care. The HOS score showed a significant ( $P = .05$ ) increase from baseline to 5-week follow-up, indicating a greater desire for health information as well as for self-treatment. However, the majority of participants did not use the Internet or any information source to prepare for health care provider office visits or to review information after office visits. These results suggest that use of the Internet to locate health information did not increase participants' willingness to use the information to manage their health care. Since the number of participants in this study was relatively low, topics for future research include the following: What factors determine a senior's likelihood to prepare for physician office visits? What factors determine whether seniors value finding and using information in support of their health care?

### Active Role in Managing Their Health

A third question focused on whether Internet use allowed participants to adopt a more active role in managing their health. When asked what role they played with their physician during an office visit, 78% of the participants indicated that they played a collaborative role. Yet, as mentioned above, the participants did not use the Internet to prepare for an office visit or to verify information provided by their physicians after an office visit. Furthermore, participants reported that the Internet did not necessarily help them manage either a general health concern or a chronic condition. The results suggest that, if participants were collaborating with their physicians, they were not using information found on the Internet to promote this process. Future research needs to determine whether this observation indicates a problem with the training methodology or suggests other factors are at work, such as seniors' beliefs about how they should interact with physicians. Another possibility is that, although participants indicate that they collaborate with their physicians, they really are not collaborating, whether due to illness or other situational variables [33-44].

## Locus of Control

A final question examined whether Internet use increased participants' perception of control over their health and wellness. The statistically significant reduction in MHLC chance scores from baseline to 5-week follow-up suggests that health care providers or educators can intervene and shift perceptions about seniors' ability to manage their own health care. However, it may also be that those participants who believed that chance plays a major role in their overall health status were more likely to discontinue the course, biasing the analysis of the observed results. Indeed, inclusion of the 18 participants who dropped out (assuming baseline values for the missing follow-up data) eliminated the significant finding.

It is interesting to note that female participants had a higher internal locus of control score than men, starting with the baseline surveys and continuing through 5-week and 1-year follow-ups. The study results suggest that the Internet is one more tool women can use to maintain their internal health locus of control [4]. It also matches past research showing that women take a more active role in their health care, while men are generally more passive [23,25,33,45,46]. Further research is needed to determine why this gender difference exists.

## Limitations

Results from this study seem to suggest that the training sessions are having a positive impact on participants in several ways. However, the rather small sample size limits the power of this study to detect differences. There was a substantial attrition, with only 42 of 60 participants continuing the course over 5 weeks, and only 27 responding to the 1-year follow-up survey. To determine whether the training sessions yield statistically significant positive changes, it will be necessary to increase the total number of participants as well as the response rate after the sessions. Some possible methods to increase response rates include the following:

1. Decreasing the time between the end of the sessions and the follow-up questionnaires
2. Providing incentives for participants to follow up
3. Asking participants to make a long-term commitment to the study

The biggest limitation was the lack of a control group. Participants in this study were self-selected and could potentially have had a greater inclination to engage in information-seeking behaviors as well as preparation for physician office visits.

## Conclusions

The results of this study suggest that the participants experienced an increased willingness to use personal computers to locate health information. However, it did not translate into a willingness to take a more active role in their health care or to use the Internet when making important health care decisions. Further studies will need to specifically address whether use of the Internet to locate health information is a behavior determined by variables such as gender, computer ownership, economic status, and academic background, or whether situational variables, such as health status, type of office visit, and preferences for participation in one's health, play a significant role.

Finally, future studies should examine the qualitative impact of teaching seniors to use the Internet for health care information. Although the instruments used can show how seniors' behaviors and perceptions are changing in aggregate, it would be equally important to attempt to determine how the participants' attitudes toward their health and health care providers change as they gain information-seeking skills. That seniors' health will decline over time is axiomatic. However, the authors believe that increased understanding of their health can lead seniors to have an increased sense of empowerment, self-worth, and dignity. Studies that address these and other issues would be equally worthwhile.

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## Conflicts of Interest

None declared.

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## Abbreviations

**HOS:** Health Opinion Survey

**MHLC:** Multidimensional Health Locus of Control

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Original Paper

# Expectations of Patients and Physicians Regarding Patient-Accessible Medical Records

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## Abstract

**Background:** Middle class populations have supported shared medical records, including Internet-accessible medical records. The attitudes of lower income populations, and of physicians, are less clear.

**Objectives:** The objective of this study was to compare the attitudes toward shared outpatient medical records among (1) socioeconomically disadvantaged patients in community health centers, (2) insured patients in primary care offices, and (3) a broad range of physicians in outpatient practice.

**Methods:** Written questionnaires were provided to patients in the waiting rooms of six primary care practices in the metropolitan Denver, Colorado area. Three practices were community health centers, and three practices were primary care clinics of an academic medical center. Questionnaires were also mailed to primary care physicians in the state of Colorado.

**Results:** There was a 79% response rate for patient surveys (601 surveys returned) and a 53% response rate for physician surveys (564 surveys returned). Academic medical center patients and community health center patients were equally likely to endorse shared medical records (94% vs 96%) and Internet-accessible records (54% vs 57%). Community health center patients were more likely than academic medical center patients to anticipate the benefits of shared medical records (mean number of expected benefits = 7.9 vs 7.1,  $P < .001$ ), and they were also somewhat more likely to anticipate problems with shared records. Significant predictors of patient endorsement of Internet-accessible records were previous use of the Internet (OR = 2.45, CI 1.59–3.79), the number of expected benefits (OR = 1.12 per unit, CI 1.03–1.21), anticipation of asking more questions between visits (OR = 1.73, CI 1.18–2.54), and anticipation of finding the doctors' notes to be confusing (OR = 1.50, CI 1.01–2.22). Physicians were significantly more likely than patients to anticipate that access to records would cause problems. Physicians were significantly less likely than patients to anticipate benefits (mean number of expected benefits = 4.2 vs 7.5,  $P < .001$ ).

**Conclusions:** Interest in shared medical records is not confined to a white, middle class population. Shared medical records are almost universally endorsed across a broad range of ethnic and socioeconomic groups. A majority of patients are also interested in Internet-accessible records, but a substantial minority is not. The primary determinants of support of Internet-accessible records are not age, race, or education level; rather, they are previous experience with the Internet and patients' expectations of the benefits and drawbacks of reading their medical records. Physicians have more concerns about shared medical records and see less potential for benefit. The attitudes of patients and physicians may need to be reconciled for widespread adoption of shared medical records to be achieved.

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**KEYWORDS**

Patient access to records; medical records systems, computerized; questionnaires; physician-patient relations; medical records

## Introduction

As the Health Insurance Portability and Accountability Act (HIPAA) has clarified the rights of patients to review their medical records [1], there has been increasing interest in sharing records with patients, particularly in an online format [2-6]. These clinical trials and other studies of shared paper records [7] have suggested that patient-accessible medical records may improve doctor-patient communication, patient adherence to treatment, patient education, and patient empowerment, all with little risk. Nonetheless, concerns remain, particularly among physicians, that patient-accessible medical records might increase physician workload or disrupt the doctor-patient relationship [8].

Several recent surveys have evaluated patients' interest in shared records. A study of patients in Minnesota found that 79% of patients were "very interested" or "somewhat interested" in reading their clinic medical record [9]. Roughly half were interested in reading a paper copy of their medical record at home, and roughly half were interested in an online version. The authors noted a "strong polarity" of opinion about the latter, with one patient threatening to sue if records were made available online. A study of patients in the United Kingdom had similar findings, with 83% of patients endorsing of patient-accessible records and roughly half expressing interest in viewing records using a computer [10]. It remains unclear to what extent this interest in shared medical records currently extends to patients of lower socioeconomic status in the United States, particularly those in "safety-net" medical programs. Similarly, although physician attitudes towards shared records have been assessed in small samples [11-13], broad attitudes of practicing physicians remain undefined.

We addressed these issues through two related survey projects. In one project, we assessed the attitudes of a broad sample of physicians in the state of Colorado using a mailed questionnaire. In a follow-up project, we assessed patient attitudes in multiple primary care offices in the metropolitan Denver area. Half of these offices were associated with a community health center for socioeconomically disadvantaged patients, and half were primary care clinics of an academic medical center that provided services for a more middle class clientele. Our objectives were to compare the attitudes of patients in the two groups and to compare the attitudes of patients as a whole to those of doctors in the region.

## Methods

### Questionnaire Design

Physician and patient questionnaires included demographic items and 16 questions assessing the potential benefits and concerns of sharing medical records (Multimedia Appendix). Key themes were identified from a review of previous studies of patient-accessible medical records [7]. Most of the questions had been used before in a clinical trial of patient-accessible medical records [6]. In that study, pilot testing was performed one-on-one with patients to ensure comprehensibility and lack of ambiguity in the questions.

Patients also answered two additional questions regarding their attitudes about shared medical records in general, and two additional questions regarding shared *online* medical records. As the primary intent of the survey was to assess attitudes towards shared medical records regardless of format, the latter two questions were the only ones in either survey to mention online medical records. Both the patient and physician surveys were approved by the Colorado Multiple Institutional Review Board.

### Patient Survey

The survey population represented outpatients to primary care practices in metropolitan Denver, Colorado. The sample frame consisted of adult patients (18 years of age and older) presenting for outpatient appointments to one of six primary care sites between September 1, 2003 and April 27, 2004. Three primary care practices associated with a teaching hospital (University of Colorado Hospital) represented patients typical of a private practice. Three neighborhood community health centers associated with the safety-net hospital (Denver Health) represented a financially disadvantaged and ethnically diverse population. A convenience sample was obtained from patients in the waiting rooms of these practices. All patients with appointments were potentially eligible. Because the medical records were written in English and we intended to study the attitudes of patients who would be reading their own medical records, patients who did not speak English were not approached for the survey.

Questionnaires were given to patients by a research assistant stationed in the waiting rooms of the practices. Surveys were anonymous, but the research assistant tracked how many patients declined to complete the survey. Surveys were abstracted and double-entry verified.

### Physician Survey

The survey of physicians was performed in July 2002. The survey population represented Colorado physicians in primary care (family practice, general internal medicine, and general practice) and in internal medicine specialties. The sample frame was derived from a list of Colorado physicians supplied by the Colorado Commission on Family Medicine. The original sample frame contained 4351 physician records with information on degree, specialty, age, gender, and street address. The database was cleaned to eliminate specialties not of interest to this study (615), duplicate entries (417), and entries without the full complement of information (50 due to missing age information, 6 due to missing gender information). This resulted in a cleaned database containing 3263 records. A probability sample was created by randomly selecting one fourth of the physicians in the primary care group and one half of the physicians in the internal medicine specialty group. This produced a sample of 1059 physicians, 580 in primary care and 479 in internal medicine specialties.

Questionnaires were mailed to physicians in July 2002. Potential respondents were initially mailed a postcard describing the survey. A written questionnaire was mailed one week later with a business reply envelope. A reminder card was sent two weeks

later. A second questionnaire was mailed to those who did not respond within four weeks.

### Statistical Methods

Statistical analyses were performed using SAS Version 9.1 (SAS Institute, Cary, NC). Differences in dichotomous outcomes were compared using chi-square tests, and differences in continuous outcomes were compared using *t* tests. Internal consistency was evaluated by Cronbach alpha. Logistic regression was used for multivariate analysis. All tests were considered significant at the 0.05 level. Because the proportion of missing values was less than 5% for every questionnaire item, we did not incorporate adjustment or imputation for missing values in the multivariate analysis.

## Results

### Sample Size and Response Rate

For patients, 601 surveys were returned, 295 from the community health centers (response rate 71%) and 306 from

the academic primary care clinics (response rate 88%). For physicians, 340 questionnaires were returned from the primary care group (response rate 59%) and 224 from the specialist group (response rate 47%).

### Demographics

The majority of respondents in both patient groups were female, with a mean age in the 40s (Table 1). Twenty-one percent of the patients were African American, and 13% were Hispanic. Patients in the community health center were less likely to be white, non-Hispanic, and they had a lower socioeconomic status than those in the academic primary care clinics. Although patients in the community health center were less likely to have Internet access at home or work, half of them did have such access, and the majority of patients in both patient groups had used the Internet before. A substantial minority of patients in the community health center (48%) and a majority of patients in the academic primary care clinics (63%) answered “yes” to “Have you reviewed parts of your medical records before?”

**Table 1.** Patient demographics

	Community Health Center Patients (n = 306) No. (%)	Academic Primary Care Clinic Patients (n = 295) No. (%)	P value
Age (years), mean (SD)	42 (15)	49 (18)	< .001
Male gender	75 (28)	108 (37)	.02
White, non-Hispanic	95 (35)	222 (75)	< .001
Household income > \$45000 per year	16 (6)	145 (52)	< .001
College graduate	53 (20)	165 (56)	< .001
Insurance other than Medicaid, Medically Indigent, or uninsured	57 (22)	263 (89)	< .001
More than three physician visits per year	120 (41)	95 (31)	.01
Used Internet before	182 (67)	241 (82)	< .001
Have Internet access at home or work	148 (54)	242 (83)	< .001
Interested in communicating with doctor by email	129 (48)	190 (66)	< .001
Reviewed parts of their medical records before	131 (48)	187 (63)	< .001

For physicians, the age and gender distribution of the respondent sample was representative of the sample frame (Table 2). The mean age for the respondent sample was within one year of the

overall group, and the percentage of males in the respondent sample was within 1% of the overall group.

**Table 2.** Physician demographics

	All Physicians (N = 564) No. (%)
Age (years), mean (SD)	48 (10)
Male	421 (75)
Office-based practice	535 (97)
Already routinely send notes to patients	45 (8)

### Patient Attitudes in the Two Settings

The responses of patients in the community health centers were compared with those from patients in the academic primary care clinics. Because the responses to the nine questions about potential benefits of access to the medical record were highly correlated (Cronbach alpha = 0.90), the count of the number of questions which were answered “strongly agree” or “agree” was created, which we termed the number of expected benefits.

In general, the patients in the community health centers (CHCs) were more likely to anticipate benefits (Table 3), but they were also more likely to anticipate encountering difficulties with shared records (Table 4). The number of expected benefits was high in both patient groups, modestly higher in the CHC patients. The CHC patients were particularly more likely to anticipate that they would better understand their doctors' instructions, better adhere to their doctors' recommendations,

and feel more in control of their medical care. These positive expectations were noted in spite of the fact that the CHC patients were also more likely to anticipate being confused by various parts of the medical record and being embarrassed or offended by the doctors' notes.

Patients were also asked two summary questions about shared records, in general, and about shared records online, in particular. Ninety-five percent of all patients agreed with the statement, “Overall, I think it is a good idea for patients to be able to routinely review their outpatient medical records” (96% of CHC patients vs 94% of academic primary care clinic patients,  $P = .31$ ). Fifty-six percent of all patients agreed with the statement, “Overall, I think it is a good idea for patients to be able to review their outpatient medical records using the Internet” (57% of CHC patients vs 54% of academic primary care clinic patients,  $P = .37$ ).

**Table 3.** Expected benefits of shared medical records

	Community Health Center Patients (n = 295) No. (%) in agreement	Academic Primary Care Clinic Patients (n = 306) No. (%) in agreement	P value	All Patients (N = 601) No. (%) in agreement	All Physicians (N = 564) No. (%) in agreement	P value
Would improve understanding of medical conditions	263 (90)	249 (82)	.01	512 (86)	220 (40)	< .001
Would improve understanding of doctors' instructions	258 (89)	230 (76)	< .001	488 (83)	290 (53)	< .001
Would improve patient adherence	255 (90)	216 (72)	< .001	471 (81)	257 (47)	< .001
Would prepare patients for visits	253 (86)	243 (80)	.04	496 (83)	209 (38)	< .001
Would be reassuring	258 (90)	257 (85)	.06	515 (88)	260 (47)	< .001
Would increase patients' sense of control	263 (91)	252 (83)	.003	515 (87)	388 (70)	.001
Would increase trust in doctors	242 (83)	223 (75)	.02	465 (79)	279 (52)	< .001
Would increase patient satisfaction	254 (89)	244 (82)	.01	498 (85)	240 (44)	< .001
Patients would identify errors in the medical record	231 (83)	253 (85)	.55	484 (84)	177 (32)	< .001
Number of expected benefits, mean (SD)	7.9 (2.0)	7.1 (2.6)	< .001	7.5 (2.3)	4.2 (3.0)	< .001

**Table 4.** Other expectations of shared medical records

	Community Health Center Patients (n = 295) No. (%) in agreement	Academic Primary Care Clinic Patients (n = 306) No. (%) in agreement	P value	All Patients (N = 601) No. (%) in agreement	All Physicians (N = 564) No. (%) in agreement	P value
Lab and x-ray reports would be confusing	146 (50)	109 (36)	< .001	255 (43)	421 (76)	< .001
Doctors' notes would be confusing	130 (44)	84 (28)	< .001	214 (36)	274 (49)	< .001
Would increase patient worry	84 (29)	68 (22)	.07	152 (26)	448 (81)	< .001
Would cause offense or embarrassment	55 (19)	29 (10)	< .001	84 (14)	248 (45)	< .001
Would increase questions between visits	198 (69)	142 (47)	< .001	340 (58)	385 (70)	< .001



## Logistic Model

To assess the determinants of patient attitudes towards Internet-accessible medical records, we created a logistic model. The dependent (outcome) variable was agreement with the statement, "Overall, I think it is a good idea for patients to be able to review their outpatient medical records using the Internet." Bivariate analyses were performed and demographic variables (listed in Table 1), anticipated benefits, and anticipated concerns that were significant at or below a *P* value of 0.25 were included in the logistic regression. These variables were college graduate (Yes/No), ever used the internet before (Yes/No), anticipating finding doctors' notes confusing (Yes/No), anticipating asking more questions between visits (Yes/No), anticipating being embarrassed or offended (Yes/No), and the number of expected benefits. The variable representing the type of clinic (CHC or academic primary care clinic) the patient was from was also included to account for any difference between the groups. In this model, significant predictors were the following:

1. Previous use of the Internet (OR = 2.45, CI 1.59–3.79)
2. The number of expected benefits (OR = 1.12 per question, CI 1.03–1.21). The mean number of expected benefits for those who endorsed Internet-accessible records was 7.8 vs 7.1 for those who did not endorse them.
3. Anticipating asking more questions between visits (OR = 1.73, CI 1.18–2.54)
4. Anticipating doctors' notes being confusing (OR = 1.50, CI 1.01–2.22)

## Patient Attitudes Compared with Physician Attitudes

The patient responses in aggregate were compared with the responses from the physician survey. Of note, the responses of primary care and specialist physicians were combined, as were responses of patients at the community health centers and the academic clinics, since the differences between patients and physicians was much greater than the differences within physician and patient subgroups. Because the inter-item correlations of the expected benefits was also high among physicians (Cronbach alpha = 0.87), we used the number of expected benefits as for patients.

Physicians were significantly more likely to anticipate concerns than patients (Table 4). Physicians were also significantly less likely to anticipate that shared medical records would be empowering for patients (Table 3).

Physicians were also asked two additional questions about their expectations if patients could routinely review their outpatient medical records. Sixty-three percent anticipated that their "workload would increase substantially," and 45% anticipated that they "would document things differently in the medical record."

## Discussion

### Principal Findings in Relation to Previous Studies

This survey confirms the primary results of the surveys in Minnesota [9] and the United Kingdom [10]: the vast majority of patients endorse the concept of patient-accessible medical

records, and about half support online access. This survey further demonstrates that these attitudes are shared even by patients in ethnically diverse and socioeconomically disadvantaged populations. On multivariate analysis, demographic features such as age, gender, race, and education did not predict an interest in online patient-accessible records. The primary predictor was previous experience with the Internet, followed by expectations of the benefits and drawbacks of reading the medical record.

Our survey also extends these findings by comparing patient attitudes to the significantly different attitudes of physicians. Patients are particularly likely to anticipate that shared records will be empowering, and particularly unlikely to anticipate that access to their medical records will be embarrassing. Physicians, by contrast, are especially likely to anticipate that laboratory results will confuse patients and that shared records will make patients worry more.

In addition to our quantitative findings, our anecdotal experience in conducting the survey confirmed the strong polarity of opinion towards Internet-accessible records that was reported in the Minnesota survey [9]. After pilot testing our survey for one week, our research assistant was informed by clinic staff that several patients had angrily complained to them after mistakenly inferring that plans were already underway to make their medical records available online. In contrast, in the United Kingdom, where plans *are* underway to give patients online access to their primary care records in 2005, patient attitudes seem to be more favorable, although concerns about security and confidentiality remain [10].

Our results also complement the findings of Hassol et al in the Geisinger Health System in Pennsylvania [4]. In their survey, the experiences of a large group of actual patient users of Geisinger's online health care record were assessed. This system gave patients access to the 25 most frequently ordered laboratory tests with an explanation of the results. This system did not provide access to clinical notes. While less educated patients found test results to be less understandable than higher educated patients, all groups rated understandability as good (71–88 on a scale from 0–100). Although it might be hypothesized that the good general understandability observed in the Geisinger patient group was the result of patient self-selection (patients opting not to use the system if they are concerned about comprehensibility), our own survey suggests that this is not the case. About half of the patients we surveyed in the CHCs, and fewer in the academic primary care clinics, anticipated finding the laboratory and radiographic reports in the medical record to be confusing, but this concern was not a predictor of whether a patient would endorse online shared records. In fact, patients who anticipated finding doctors' notes to be confusing were actually *more* likely to endorse online access. Therefore, the general understandability of Geisinger's health care record is less likely to be the result of self-selection and may be more likely related to other factors (such as the explanations of the test results that were provided by the system).

In addition, Hassol's study reported that Geisinger physicians and system administrators expressed particular concern that patients would be worried about test results that were available

online. This information was only anecdotal, however, because their clinician response rate (13%) was too low for statistical analysis. The larger response rate in our statewide physician survey confirms that the majority of physicians are concerned about the potential for shared medical records to confuse or worry their patients.

### Strengths and Limitations of the Study

The different sampling strategies we used for the physician and the patient surveys appear to have been successful in obtaining a representative response of the populations. The response rate for the physician survey is typical of mailed surveys of physicians [14]. The convenience sampling used in the patient survey was successful in recruiting a large sample of ethnically diverse, socioeconomically disadvantaged patients with an excellent response rate. The proportion of patients using the Internet in our sample was comparable to national data from the Pew Internet and American Life project [15]. About half of low-income patients used the Internet, while roughly three quarters of those with higher incomes did. We were surprised, however, by the large proportion of patients (53%) who reported that they had previously reviewed parts of their medical records. This is in sharp contrast to previous reports that only 0.4% of patients spontaneously request their records [16,17] and also to the United Kingdom survey in which only 3.3% of patients reported having seen their records before [10]. We infer that previous surveys assessed whether patients reviewed the full medical record, which few patients have done, while many have reviewed at least part of their medical record. Thus, while patients have limited experience with their medical records, most are not completely naive about the contents.

Several limitations of this study are noted. The attitudes of Colorado physicians and metropolitan Denver patients are only incomplete representations of broader national opinions. Because

the patient and the physician surveys were conducted over a year apart, secular changes in attitudes may have affected the comparisons. Also, while the questions in the patient survey and the physician survey were linked, the differences in the way the questions were framed may have accounted for some of the differences observed in the physician and the patient responses.

### Conclusions

Overall, our survey confirms that nearly all patients value having access to their medical records. Clearly, patient-accessible medical records are not something valued only by a privileged elite or by patients with idiosyncratic relationships with the medical system [16]. At the same time, while most patients endorse Internet-accessible records, a substantial minority does not endorse this practice, and many have very strong feelings about it. Presumably, those patients with strong negative feelings are motivated by security and privacy concerns, particularly those without previous experience using the Internet. For Internet-accessible medical records to be more widely adopted, those concerns will need to be thoroughly addressed. Meanwhile, physicians remain more skeptical of the potential benefits of patient-accessible medical records and more sensitive to the potential risks. For physicians to be supportive of programs to increase patients' access to records, the potential benefits of these programs will need to be demonstrated more definitively, and it may be particularly important to address physicians' concerns that these programs may confuse patients or make them anxious. Small trials have suggested that these programs can be implemented without causing harm [2-6]. Larger trials will better define how to enhance the experience of patient-accessible records to promote the benefits that patients expect, and how to mitigate any rare but serious problems that may arise as information from the medical record becomes not only an artifact for medical professionals but a tool for patients as well.

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### Conflicts of Interest

The authors have no financial interests in patient-accessible medical records. Dr. Ross and Dr. Lin practice at University of Colorado Hospital, which has sponsored pilot programs of online patient-accessible medical records.

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### Multimedia Appendix

Overview of questions asked in physician and patient questionnaires assessing the potential benefits and concerns of sharing medical records. [[WinWord \(.doc\) File, 40KB - jmir\\_v7i2e13\\_app1.doc](#) ]

Actual physician questionnaire. [[WinWord \(.doc\) File, 48KB - jmir\\_v7i2e13\\_app2.doc](#) ]

Actual patient questionnaire. [[WinWord \(.doc\) File, 124KB - jmir\\_v7i2e13\\_app3.doc](#) ]

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## Abbreviations

**CHC:** community health center

**OR:** odds ratio

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Original Paper

# Shoestring Budgets, Band-Aids, and Team Work: Challenges and Motivators in the Development of a Web-Based Resource for Undergraduate Clinical Skills Teaching

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## Abstract

**Background:** Learning how to conduct a medical interview and perform a physical examination is fundamental to the practice of medicine; however, when this project began, the methods used to teach these skills to medical students at the University of Toronto (U of T) had not changed significantly since the early 1990s despite increasing outpatient care, shorter hospital stays, and heavy preceptor workloads. In response, a Web-based clinical skills resource was developed for the first-year undergraduate medical course—The Art and Science of Clinical Medicine I (ASCM I).

**Objectives:** This paper examines our experiences with the development of the ASCM I website and details the challenges and motivators inherent in the production of a Web-based, multimedia medical education tool at a large Canadian medical school.

**Methods:** Interviews and a focus group were conducted with the development team to discover the factors that positively and negatively affected the development process.

**Results:** Motivating factors included team attributes such as strong leadership and judicious use of medical students and faculty volunteers as developers. Other motivators included a growing lack of instructional equivalency across diverse clinical teaching sites and financial and resource support by the Faculty of Medicine. Barriers to development included an administrative environment that did not yet fully incorporate information technology into its teaching vision and framework, a lack of academic incentive for faculty participation, and inadequate technical support, space, and equipment.

**Conclusions:** The success of electronic educational resources such as the ASCM I website has caused a significant cultural shift within the Faculty of Medicine, resulting in the provision of more space, resources, and support for IT endeavours in the undergraduate medical curriculum.

(*J Med Internet Res* 2005;7(2):e14) doi:[10.2196/jmir.7.2.e14](https://doi.org/10.2196/jmir.7.2.e14)

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**KEYWORDS**

Undergraduate medical education; Internet; clinical skills; medical history taking; teaching methods; training techniques; qualitative research; focus groups; interviews



## Introduction

*The life so short, the craft so long to learn...* [– Hippocrates]

*No one has time to sit down and teach people how to do a history anymore, but it is the most important thing you have to learn.* [– Physician contributor to the ASCM I website]

Learning how to conduct a medical interview and perform a physical examination is fundamental to the practice of medicine. Documentation of the history and physical is critical for communication between medical personnel and for the long-term recording of patient data. The methods used to teach these skills to students at the University of Toronto (U of T) had not changed significantly since the early 1990s despite changes in the practice of medicine that included increasing outpatient care, shorter hospital stays, and heavy preceptor workloads. As a result, the traditional teaching and learning of clinical skills appeared to be increasingly inadequate in today's health care environment [1,2], a concern that is now being recognized and addressed nationally by the Association of Faculties of Medicine of Canada (formerly known as the Association of Canadian Medical Colleges).

### The Art and Science of Clinical Medicine (ASCM I)

In the medical program at the U of T, clinical skills training begins in the second week of first year with the course The Art and Science of Clinical Medicine I (ASCM I). This course is taught at six affiliated teaching hospital sites by approximately 90 volunteer physician tutors, who teach groups of five to seven students. Like many other medical schools, the U of T teaches a standardized clinical curriculum [3-5] and is faced with many challenges. For example, the clinical learning experience varies between hospital sites and small groups, and student course evaluations have repeatedly identified a need for standardized teaching methods and expectations. Similarly, tutors have requested faculty development to aid their understanding of the level of expertise necessary in the clinical encounter in order for a first-year student to meet the course objectives.

### Origin of the ASCM I Website

To address these concerns, a medical student proposed the development of a computer-based tool to meet the demand for instructional equivalency across clinical sites, to standardize the expectations of both students and tutors, to assist the teaching of clinical skills to undergraduate medical students, and to supplement the course content. In response, a research and development team was formed to create the ASCM I website, an interactive, multimedia online resource for both student education and faculty development in clinical skills training [6]. Such online resources are playing an increasingly important role in the delivery of medical education programs [7-15].

A Web-based platform was chosen to supplement the hands-on clinical curriculum due to the following benefits of the Internet:

(1) increasingly wide availability to students and tutors at home, school, and hospital; (2) on-demand and round-the-clock access; (3) increasing popularity; (4) expanding interactive and multimedia capabilities; (5) ability to accommodate many learning styles; and (6) ease of website updates and expansions. A lack of physical examination sites suitable for our local and Canadian context was also a factor in choosing a Web-based platform. The course director and three medical students developed the password-protected website over two years. Formative and summative evaluations of the site by a medical educator and member of the Wilson Centre for Research in Education have been ongoing. Summer student scholarships and Faculty of Medicine funding supported basic budget requirements.

### Focus of This Study

In this paper we share our experience of the development of the ASCM I website in order to detail some of the challenges and motivators inherent in the production of a Web-based, multimedia medical education tool at a large Canadian medical school. The experiences, practical knowledge, understanding, and expectations that individuals (eg, faculty and students) brought to the information technology (IT) development process clearly influenced the final product. Similarly, the institutional context (eg, established roles, norms, and mandated practices of the medical school) and the broader social context (eg, political and economic) in which the electronic resource was embedded also strongly shaped the development process. Therefore, this study examines the factors influencing the development, implementation, and evaluation of e-based resources in our setting. Ultimately, it aims to generate both qualitative and quantitative data for explanatory theory building [16]. By discussing individual, structural, and political issues that impinged upon the development and implementation of the ASCM I website, we also hope to assist others who are contemplating or developing similar projects in their own settings.

## Methods

### Website Description

The website was developed in two phases: the history home page was developed in 2000, and the physical examination home page was developed in 2001. The complete site has been in operation since September 2001 [17,18]. Selected portions of the website may be accessed at <http://ascm.med.utoronto.ca/examples/>.

The history section (Figure 1) consists of (1) a video interview (26 minutes) conducted by a first-year medical student with a standardized patient, (2) eight interactive modules outlining key components of medical history taking, (3) case report assignment modules to improve case report writing skills, and (4) activity modules to improve verbal and nonverbal communication skills and to increase student comfort with patient visitation on the wards.

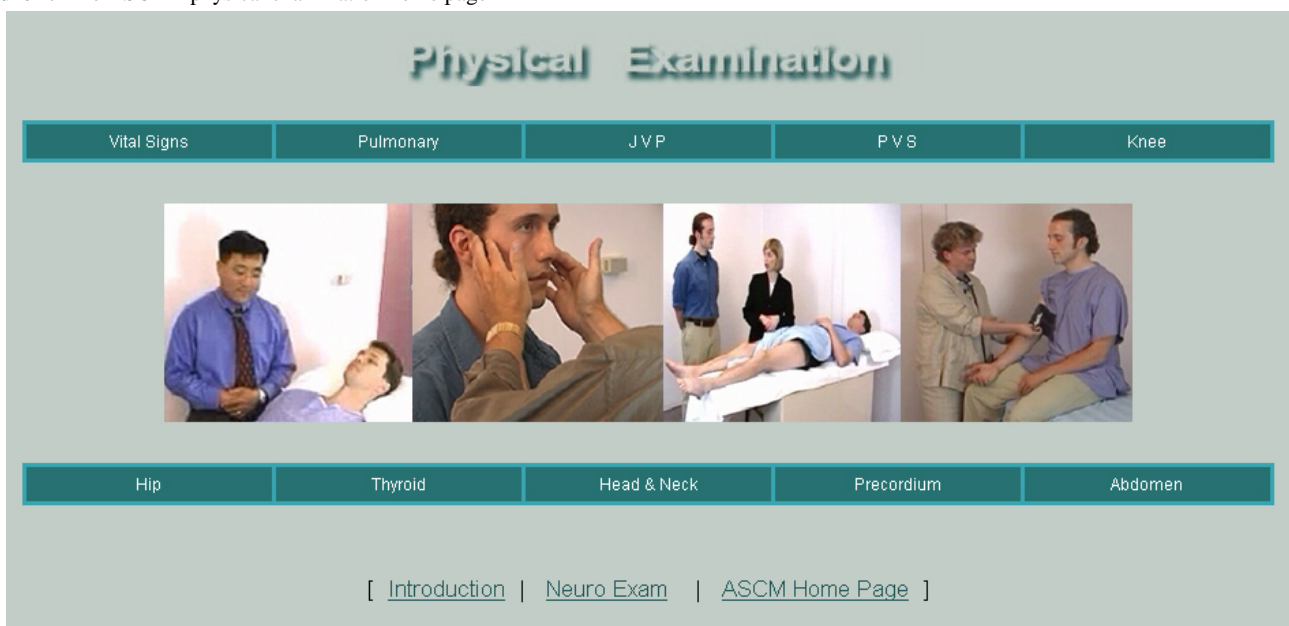
Figure 1. The ASCM I history home page



The physical examination section (Figure 2) contains 10 modules for the physical skills (excluding the neurological exam, which has its own separate website) taught in ASCM I. Each module includes a video demonstration performed by a faculty member, accompanied by explanatory graphics and text. The modules include demonstrations of draping and positioning, inspection, palpation, percussion, auscultation, and special maneuvers as they apply to the specific examinations. Subsections of the modules can be viewed separately or together

as a continuous piece. Graphics and notes specific to the subsections of the examinations provide information on anatomy, physiology, and the mechanics of the examination. Several modules include unrehearsed examinations performed by a first-year student that are accompanied by faculty feedback in order to address common challenges students face when learning particular examinations and to illustrate for physician tutors how to give immediate formative feedback to students.

Figure 2. The ASCM I physical examination home page



## Focus Group

Following completion of the website prototype, a focus group of 10 participants (physicians, standardized patients, medical students, and production staff involved in the creation of the site) was held in July 2002 to discuss the motivators, challenges, and barriers to the development of the ASCM I site. A funnel technique of questioning was used to identify broad question areas first and then to progressively discuss specific domains of interest. Initial probes fell into four main domains: technical, content, and contextual issues and future directions for site development. The focus group discussion was audio taped and transcribed.

## Interviews

Semi-structured interviews ( $N = 5$ ) were conducted with the remaining members of the development team and university staff (eg, course coordinators, clinical faculty, and administrative staff) in order to garner their insights on the website development and maintenance. As in the focus group, participants were asked to identify the difficulties and challenges they faced, along with their successes and lessons learned.

Data arising from the interviews and focus group were analyzed using the methods previously described by Miles and Huberman [19] and Krueger [20]. Each transcript was read recursively by

at least two readers to code the data and create thematic categories representing trends in the perceptions, attitudes, and experiences of the participants. Patterns were then jointly identified. The jointly coded data underwent a process of increasingly finer categorization until all trends and variations were accounted for and cross-referenced. Finally, the completed academic manuscript was presented to participants for review to ensure the accuracy and comprehensiveness of the data interpretation (ie, interpretive validity). This study received ethical approval from the Research Ethics Board of the University of Toronto.

## Results

All participants involved in the development of the ASCM I website shared an interest in and a commitment to innovation in the undergraduate medical curriculum, as well as a willingness to contribute a great deal of their own personal time to realize that goal. They discussed their motivations for joining the development team, the importance of team leadership for project completion, the impact of a lack of resources (eg, space, finances, and personnel), and the need for institutional support for IT. These themes are discussed below and are summarized in the [Table 1](#).

**Table 1.** Motivators and barriers experienced by the ASCM I development team

Motivator	Description/Characteristics
Curriculum gap	<ul style="list-style-type: none"> <li>Expressed need of faculty and students for contextually relevant, uniform curriculum available at all times across the university and its diverse affiliated hospitals</li> </ul>
Team leadership	<ul style="list-style-type: none"> <li>Vision to develop ASCM I website and improve the medical curriculum</li> <li>Vocal project champion and advocate</li> <li>Strong team recruitment and team building skills</li> <li>Ability to capture funding</li> </ul>
Medical students	<ul style="list-style-type: none"> <li>Posses in-depth knowledge of curriculum content, student learning needs, and target audience perspective</li> <li>Intelligent, altruistic, hard working, and cost-effective</li> </ul>
Faculty	<ul style="list-style-type: none"> <li>Investment of substantial personal and academic time</li> <li>Altruism</li> <li>Strong content and teaching expertise</li> <li>Commitment to improving medical education</li> </ul>
Teamwork	<ul style="list-style-type: none"> <li>Team members with different motivations all united in their desire to improve the clinical curriculum</li> <li>Strong grassroots and hands-on approach to resource development</li> </ul>
Financial resources	<ul style="list-style-type: none"> <li>Financial support from the U of T key to project initiation and completion</li> </ul>
Space	<ul style="list-style-type: none"> <li>Dedicated research and development space (Educational Innovation Lab)</li> </ul>
<b>Barrier</b>	
Administrative structure of institution	<ul style="list-style-type: none"> <li>Educational IT new, expensive, and not fully incorporated into the academic institution</li> <li>Lack of centralized IT policy, support, and resources leading to redundancy and inefficiency</li> </ul>
Development mandate	<ul style="list-style-type: none"> <li>Lack of a faculty level champion able to assume site ownership and maintenance responsibility</li> </ul>
Faculty	<ul style="list-style-type: none"> <li>Little academic incentive for faculty to contribute to IT innovations (eg, no protected or paid time for clinicians to develop educational resources)</li> </ul>
Support staff	<ul style="list-style-type: none"> <li>Lack of support staff and expertise (eg, for user helpline, IT development and maintenance)</li> </ul>
Equipment	<ul style="list-style-type: none"> <li>Outdated equipment lacking user support</li> </ul>

### Motivations for Joining the Development Team

In the focus group, team members explained their motivations to contribute. Medical students selected from the ASCM I course to construct the site the following summer were intrigued by the project's informatics focus ("Well, isn't this different and neat!") and were motivated to join by altruism. They "wanted to improve the course" and felt that "the university was lagging behind in terms of using Internet computing." As newly graduated members of the course's target audience, the medical students could readily identify difficult curriculum topics from a student's perspective and focus the teaching content of the site accordingly. The students showed tremendous enthusiasm, creativity, and dedication to the project [3,21]. According to other team members, the students "worked marvelously well together," had complementary skills, and appeared to "live" in the computer facilities where they studied at night while developing the site and solving user problems and programming glitches. Together they "created something that is absolutely amazing."

All physician contributors were already involved in the ASCM I course as tutors or hospital coordinators, had a personal interest

in medical education, and volunteered considerable personal time and energy to the project, often as a personal favor to the course director. One clinician explained, "[The course director] motivated me very strongly, but I also have an interest in undergraduate education and looking at different ways of teaching the musculoskeletal exam. This project seemed like a perfect fit." Similarly, the support staff on the project all had strong track records in multimedia and medical education along with a willingness to contribute extensive personal time.

Together, these players formed an enthusiastic and committed team that worked well together. Focus group participants said, "The team work here was unbelievable!" and they recalled late night work sessions with pizza and beer to keep creativity flowing. Mutual support of team members was critical when it seemed that the fledgling project would collapse and was crucial to its ultimate success. As one student put it, "[Success] is when you learn to work as a team. It is when you know that if you start to slip, someone else is going to back you up or say, 'No, don't give up yet!'"

Such volunteer-driven resource development requires a very dedicated and motivated team of faculty, staff, and students



who recognize the importance of the project. Unfortunately, the majority of clinicians do not have protected time for teaching and have difficulty finding time for educational work [4]. As one physician explained, “My teaching is unsupported, ie, I do it by generating my income with the other 75% of my time.” Similarly, Berge and Muilenberg [22] identified lack of faculty time and compensation as the most frequently identified barrier to the development of distance education strategies. However, another clinician asserted, “You make time for this. You make the time!” Unfortunately, in general, there appears to be little incentive for clinical faculty to contribute to or create innovative projects [22]. In spite of personal interest, clinician respondents in the focus group felt unable to spearhead resource development projects “because of the time and energy it would require.” One clinician noted, “The University has to realize that anybody you could get has other commitments.” The U of T partially addresses this concern by making “creative professional activity” and teaching platforms viable routes for faculty promotion.

### Team Leadership

Interviewed participants discussed the importance of the course director as an e-learning innovator and project champion, thereby highlighting his role as a promoter of organizational change. The team leader had a vision of the project and the passion to see it through. As one interviewed administrator noted, “The only way things get developed in the faculty is that the key teachers say ‘I want to do something,’ and ways are found to do it. It certainly doesn’t come from the top down.” The course director had “a good reputation as a teacher,” “had never been involved in anything like this before,” “really got excited about it,” and was then able to move the project forward to completion “on time, on budget.” This project arose from the grassroots rather than from a university-mandated approach to curriculum development.

An ability to deal with and adapt to uncertainty and a lack of resources (including protected time) was an important leadership quality discussed in the focus group. This innovative project was very vulnerable to disruptions in its early days (eg, loss of a key team member). The team leader created a unified team that capitalized on the personal strengths of the individual members. Important project management skills included the ability to spearhead the development process, to network and partner with members of other medical programs such as the Standardized Patient Program and the Wilson Centre for Research in Education, and to bring together, support, and motivate a diverse and talented development team [4,23]. The course director provided the project’s cohesive leadership by working on multiple administrative levels to secure support for the project. He expended energy and time recruiting and supporting team members, advocating for project funding, and facilitating product evaluation. He observed that an ongoing motivator for him was the encouragement and financial support of the Associate Dean of Undergraduate Medicine and the Director of Teaching Labs and Educational Computing.

### Lack of Resources

The project was initially hindered by a lack of resources as the Faculty did not yet have the necessary infrastructure or IT support. As one respondent noted, “In these kinds of projects

we are always trying to find a little help here and a little help there. So they are put together from lots of little bits and fragments.” The entire website was produced for less than \$25000 Canadian (primarily salary support for students). Others in the focus group stated bluntly, “We were all putting this together with scotch tape,” and were “doing things on a shoestring budget and [with] Band-Aids.” Developers faced outdated and limited computer and audiovisual equipment and minimal support staff. Students had to teach themselves audiovisual skills and were frequently “bogged down in” technical issues, resulting in “frustrations” and much wasted time and effort. Technical tasks such as film editing initially took weeks to learn and accomplish, compared with one afternoon the following year after the necessary equipment was purchased. One student recalled, “There was no one there to show me the ropes. I was just learning as I went. . . . There was no personnel support.” Another observed, “Everyone was just kind of thrown together, and we made do with what we had.”

Innovative work on a low budget without technical support means making mistakes. According to one focus group physician, the visuals of the student interview with a standardized patient “are pretty poor” due to inexperience with the camera, “but the content was fantastic.” The necessary technical skills gradually developed within the team, and by the second summer, new students could rely on pre-existing expertise by “standing on the shoulders” of the previous students. Experience taught the team valuable (and, in hindsight, simple) lessons about the usefulness and cost-effectiveness of pre-production meetings in which the different needs and styles of clinicians and the production staff were anticipated and reconciled. Simple but effective tricks to simplify editing and improve video quality were passed down. In particular, practical tips for the filming (eg, camera setup, lighting, and sound) and selection of audio and video codecs were most helpful.

### Site Maintenance

Once the website was completed and was online (hosted on a faculty server), a lack of university IT infrastructure to support this new resource became apparent. The course director recalled, “We found out in the middle of September, when the first glitch occurred, that there was no one...to look after this. We spent all these hundreds of hours doing this, and now it was ready to go, but I didn’t know how to fix the little problems—I am the course director!... There was nobody to look after the damn thing!” As a temporary solution, one of the students came in regularly to back up and maintain the database. Furthermore, the students did “all the tech support” for users, including staffing an electronic user help line. An instruction package and online instructions were provided to all students currently enrolled in ASCM I; however, the course administrative staff also devoted significant time to dealing with password concerns and questions from both students and faculty.

### Institutional Support for IT

Interviewees noted that, since 1999, support for IT innovation increased steadily among key stakeholders (eg, upper administration, academic deans), and there was increased accountability for technological innovation that falls within



academic portfolios. Greater numbers of people are taking responsibility for and promoting innovation. Interview participants recognized a growing shift in thinking within the university hierarchy, from very little evidence of support from administration for online education to attitudes of “This is what is coming and there is a definite move in that direction,” and “Hey, you can get a lot of research funds by doing something like this.” One person noted, “They realized subsequently that, in fact, good research came out of it.” This evolution in thinking was termed “big C change” by one interview respondent, signaling the beginning of the acceptance of IT as a teaching and learning tool by the university hierarchy. Interviewees also noted, however, that the funding necessary to maintain already developed projects and to provide student computer infrastructure was still seriously insufficient. As one focus group participant observed, “Another frustration with developing this resource was there was really no precedent that U of T will look at another project and say, well, they went through this. These were their pitfalls, so we should avoid making the same mistakes.”

## Discussion

Effective development of a multimedia education tool requires a multidisciplinary team with diverse skills and creative talents. The effective use of technical non-experts, such as students and clinicians, for the development and implementation of IT products requires readily available technical support personnel (see also [5]). Ideally, collaboration of IT experts, content experts, and developers allows the content to be conceptualized by content specialists, enacted and captured by a production crew, and placed and maintained in an electronic framework by technical staff.

This study used qualitative methods (a focus group and individual interviews) to investigate the complex social factors involved in the development of the ASCM I website. Limitations to these methods can include recall bias by the participants and a potential social desirability bias in the focus group, as participants may not have wished to sound negative about the website or the development process in front of their colleagues. However, private individual interviews resulted in similar discussions of the motivators and challenges experienced during site development. All participants appeared very open, thoughtful, and concerned about the future of university-based electronic resource development. Future research can assess the transferability of our findings to other situations and development teams.

### Institutional Context

The administrative and support structure of most educational institutions were created well before the computer and Internet revolutions, and established medical schools appear less likely to accommodate innovation within their organizations' structure [22,25]. Therefore, although computers have permeated educational administration, in many schools they are still ancillary in education itself [26], and few medical schools have developed a strategic approach to the use of technology in medical education [27]. As was experienced here, the lack of acceptance and integration of computer-based education in the

mindset of an institution hinders both the development and the use of computer-based educational tools. For institutions that do use distance education for mission critical goals, other barriers include a lack of technical expertise and support, and concerns regarding resource evaluation and effectiveness. In the absence of a unified academic plan on IT and medical education, independent projects and resources may be poorly developed, uncoordinated, and not well integrated into the curricula [5]. An effective, IT-supported medical curriculum requires an accompanying organizational change strategy to adopt and develop technology suitable for that context and to prepare and support e-learners [24]. For example, an institution needs to develop an “institutional memory” of IT trailblazing by its faculty and students so that they are not forced to continually reinvent the wheel.

Fortunately, since the start of this project in 2000, the Faculty of Medicine has taken important steps to improve the IT development climate. In January 2002, the Medical Alumni Association sponsored an Education Innovations Lab to provide space and hardware for faculty, staff, and students to develop new IT applications for educational purposes. One full-time and one part-time staff member have been hired to assist in the design and maintenance of the educational tools created. Two internal sources of funding are now available for the development of IT courseware: The Dean's Excellence Fund in Medical Education and the Information Technology Courseware Development Fund. We believe that the value of the electronic educational projects developed to date has triggered these improvements and will continue to prompt changes necessary for IT to be more fully utilized in the future.

A medical faculty committed to e-education requires an environment and policies that are conducive to IT development and use. For example, the ASCM I website remains password protected in the absence of a broader university policy or official disclaimer to protect participants from liability claims. In our experience, fundamental development support for in-house creation of multimedia resources necessitates provision of physical space, technical support, hardware, and software and licensing. The budget of a single medical course cannot support even one of these requirements. Moreover, Internet-based educational tools require long-term basal funding because of the need for evaluation, technical support for users, and site housing and maintenance. In order that projects such as this one can be incorporated into the Faculty funding scheme, changes in administrative policy and structure are required. Research and dissemination of effective IT development practice and theory are integral to the continued growth of the field. In order to promote such dissemination, the Faculty of Medicine sponsors a yearly Educational Achievement Day to network and share new developments.

### National Context

As we were implementing the first electronic iteration of the ASCM I website to increase standardization of clinical skills teaching across our own curriculum, a national discussion of undergraduate clinical skills teaching in Canada was being initiated by the Association of Faculties of Medicine of Canada (AFMC). In 2002, the Canadian National Clinical Skills

Working Group was formed to standardize the curriculum content and evaluation methods across Canadian medical schools and to specify the clinical skills Canadian medical students should master by graduation. Electronic and Web-based teaching and learning tools such as the ASCM I website are ideally suited for promoting nationally recognized clinically useful and evidence-based clinical skills, and for addressing many of the objectives put forth at the national AFMC clinical skills meeting. A similar website for all Canadian medical schools would be an ideal forum for the presentation of standardized history taking, physical examinations, and technical skills, and it could positively affect the practices of both students and teachers. The ASCM I website can be considered a successful pilot project for the feasibility of a Canada-wide, online resource for clinical skills training.

### Conclusions

This study investigated the climate surrounding the creation of an Internet-based learning tool for medical education at a major Canadian medical school. Capitalizing on strong leadership and the skills of a multidisciplinary team of collaborators, we developed an effective and widely used resource for students. The enthusiasm, creativity, sense of ownership and altruism, and content knowledge of the students and faculty involved with this grassroots project were key to its development (see also [28]). We found that, when information technology has not yet been incorporated into the fundamental educational structure

of an academic institution, the resource development process can be arduous and can result in challenges around funding, personnel, and resource allocation for electronic curriculum development. At the heart of the difficulties experienced at our institution was lack of a centralized policy on the use of information technology in medical education. This barrier hampers financial support for educational information technology as part of the medical school's core curriculum. For the effective development of future electronic resources, the barriers documented in this paper must be addressed, and the key motivators capitalized on and enhanced.

### Future Directions

Systematic evaluation of innovative electronic teaching and learning initiatives is crucial in order to ensure continued excellence and user-centered program development [16,29]. We believe that our website is a positive educational resource, and a future publication will document our formative and summative evaluation strategies. In ASCM I, our strategy of ongoing formative evaluation has allowed continued resource development to be driven by user (and other stakeholder) feedback on the site's strengths and weaknesses [18,30]. Continued formative and summative evaluation of the ASCM I learning tool is proving key to its expansion to address the requirements of the second-year ASCM course, which teaches more complicated history taking and examination skills.

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### Conflicts of Interest

None declared.

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**Abbreviations**

**ASCM I:** The Art and Science of Clinical Medicine, year one

**IT:** information technology

**U of T:** University of Toronto

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Original Paper

# Privacy vs Usability: A Qualitative Exploration of Patients' Experiences With Secure Internet Communication With Their General Practitioner

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## Abstract

**Background:** Direct electronic communication between patients and physicians has the potential to empower patients and improve health care services. Communication by regular email is, however, considered a security threat in many countries and is not recommended. Systems which offer secure communication have now emerged. Unlike regular email, secure systems require that users authenticate themselves. However, the authentication steps per se may become barriers that reduce use.

**Objectives:** The objective was to study the experiences of patients who were using a secure electronic communication system. The focus of the study was the users' privacy versus the usability of the system.

**Methods:** Qualitative interviews were conducted with 15 patients who used a secure communication system (MedAxess) to exchange personal health information with their primary care physician.

**Results:** Six main themes were identified from the interviews: (1) supporting simple questions, (2) security issues, (3) aspects of written communication, (4) trust in the physician, (5) simplicity of MedAxess, and (6) trouble using the system. By using the system, about half of the patients (8/15) experienced easier access to their physician, with whom they tended to solve minor health problems and elaborate on more complex illness experiences. Two thirds of the respondents (10/15) found that their physician quickly responded to their MedAxess requests. As a result of the security barriers, the users felt that the system was secure. However, due to the same barriers, the patients considered the log-in procedure cumbersome, which had considerable negative impact on the actual use of the system.

**Conclusions:** Despite a perceived need for secure electronic patient-physician communication systems, security barriers may diminish their overall usefulness. A dual approach is necessary to improve this situation: patients need to be better informed about security issues, and, at the same time, their experiences of using secure systems must be studied and used to improve user interfaces.

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## KEYWORDS

Internet; patient-physician communication; electronic mail; qualitative research

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## Introduction

It has been claimed that advances in information technology and computer literacy among the public have the potential to empower patients and transform health care [1]. The emergence

of Internet and electronic communication links between physicians and patients is believed to have many potential benefits. Health portals, physician Web pages, and email channels for exchange of personal medical information allow for more complete and thoughtful health communication. This



may, in turn, foster a new “breed” of health care consumers who slowly redefine the physician-patient relationship. Spielberg has suggested that use of email may enhance the level of intimacy shared between physician and patient, making their respective private spheres more accessible. For instance, patients who are reluctant to raise sensitive topics face-to-face or who seek a quick opinion between office visits may find electronic communication inviting [2]. Web-based programs may also provide chronic disease management support [3]. Moreover, many researchers have proposed that email has improved both access to and continuity of care [4] and has increased patients' involvement in their own care [5].

### **Ambiguous Evidence on Electronic Patient-Physician Communication**

Health care providers who generally experience a high demand for their services fear that their workload may reach an unsustainable level if they open a new communication channel [6,7], and they have also been worried about reimbursement issues [5]. Physicians communicate by email with only a very small proportion of their patients [8], but the selection criteria remain unclear [4]. Also, very few patients with email access actually use it to communicate with their general practitioner (GP) [9], and there is no unambiguous evidence to indicate for which purposes this communication is used. Yet, email has been used to communicate causes of symptoms, diagnostic test results, therapeutic interventions, and to obtain second opinions as well as general information on a specific disorder, treatment, or medication without reference to a specific patient [10]. According to Sittig, email messages from patients to providers include various requests for both information and action [11]. There is a possibility that some of these communications may have replaced a number of office visits [12]. However, the major problems with patient-physician communication via the Internet are the issues of trust, privacy, and legal concerns [13], even though it has been found that patients have been only mildly concerned with these issues [14].

### **The Issue of Trust in Electronic Patient-Physician Communication**

With the acknowledgement of the potential benefits of electronic communication, it has become an important aim for health care providers and government authorities to establish services that offer secure channels for health communication [15]. In order to be regarded as secure, a communication system must have mechanisms for message protection during transfer and storage. Further, it is mandatory that the users explicitly prove their identity (authentication). In electronic communication, those who participate cannot rely on the recognition of voices and faces to establish trust. It does not suffice to simply log on to one's household computer and start the email application. In practice, the user must go through a set of actions that establish a system user identity and link that identity to the actual identity of the user. The creation of a system user identity usually requires that the users physically identify themselves in front of a person who is authorized to register new users into the system. “The credentials” are a password, smartcard, or software token that is chosen or generated that the user will need in order to gain access to the system. The credentials must be transferred

to a user before he or she can apply them to verify his or her identity with the system. A communication session can then be initiated.

### **Secure Web-Based Communication Is Underused but Well Received**

Communication systems that possess the above-mentioned security properties are gradually becoming available. Since they are quite new, little research that addresses their use by patients and providers is available. An electronic Internet link called the Patient Gateway has been identified as one system that offers a safe solution [8], and it has been well received by primary care clinicians [16]. In their study of a Web message service between GPs and patients, Liederman and Morefield reported favorable experiences of both care providers and patients [17]. A recent Norwegian study has reported on another secure Web-based solution called PasientLink [12]. In that study, however, only 48% of the intervention group had used the modality, while the non-users reported that they had felt no need for a doctor during the study period and that they did not regard the system as appropriate for the actual request [12].

### **The Need for Addressing Patient Experiences**

If care is not taken during the design and testing of systems that are developed for secure information exchange, the procedures required for authentication may become barriers that reduce use and, hence, overall utility of the system, although some “challenge” might be acceptable [7] since most patients are willing to accept a certain barrier for security reasons. Faced with applications that have poorly designed interfaces or that otherwise appear unfamiliar, appropriate and effective use by patients may not be achieved. Our aim was to explore the experiences of patients using a Web-based patient-physician communication system, with MedAxess as an example of such a system. We asked how participants used MedAxess, for what purposes, and what the results of that use were. We wanted to focus on information security issues from the users' perspectives and on how users perceived MedAxess as opposed to ordinary email in the same context. We were also interested in how strict regulations limit the use of MedAxess.

### **Computer and Internet Availability and Use in Norway**

Norway is well off into the information age. In the second quarter of 2004, as many as 60% of Norwegians had an Internet-connected personal computer (PC) available at home. Half of these people also had a broadband connection. A total of 79% of respondents had used a PC during the last three months [18]. On an average day in 2003, 42% of Norwegians were connected to the Internet for an average of 72 minutes [19]. In 2002, 45% of the Norwegian adult population reported that they might like to contact their family doctor over the Internet [20]. With regard to computer availability, skills, and a willingness to use electronic communication, the Norwegian population is similar to that of other industrialized countries [21].

### **Patients and GPs in Norway**

Most Norwegian GPs work in privately owned group practices. Primary medical care in Norway is organized through a patient list system that entitles every Norwegian citizen to be

permanently listed with a local GP. The financial reimbursement is a mixture of a per capita annual fee from the National Health Services and a fee for service for individual consultations. Norwegian GPs have between 1100 and 2500 patients on their list, with an average of about 1280 patients [22].

## Methods

### The MedAxess System

MedAxess is a software system for secure exchange of information between a health care provider and a patient. It was developed in Norway by Deriga and has been piloted in primary care since 2002. The system has been approved by the

Norwegian Data Inspectorate. In order to become a user, the patient must be registered as a list patient at the GP's office. Further, to be registered as a MedAxess user, the patient must choose a password from the GP's office. In addition to a PC connected to the Internet, the patient must also have a cell phone. Access to the system requires the user to open a Web browser and log on to the MedAxess "client" from the home page of the physician's office. After submitting the first password and passing the first log-on, in the second page, the user must request the system to generate a second, instant password to be sent to his or her cell phone as an SMS message. Once this procedure has been completed successfully, the user can transmit and receive messages with the GP. The MedAxess log-in, inbox, and message screens can be seen in Figures 1-3.

Figure 1. MedAxess log-in screen

**MedAxess** Logg inn Hjelp

**Innlogging**

Kun for pasienter som har opprettet Pasientkonto

Fødselsnummer:

Passord:

**Logg inn**

■ **Opprett Pasientkonto**  
■ **Mistet passord**

NOK 1,- for PIN-kode mottatt på SMS

**Navneendring til Minhelse.no fra 20.02.05**  
Velkommen til Minhelse.no. Med virkning fra 20.02.05 har MedAxess skiftet navn til Minhelse.no. Tjenesten har også fått flere betydelige oppgraderinger. [Les mer >>>](#)

**Hvordan fungerer Minhelse.no? Hvordan få Pasientkonto?**  
Hvordan skaffer du deg en Pasientkonto? Hvilken sikkerhet har du på Minhelse.no? Hvilken informasjon blir lagret om deg? [Les mer >>>](#)

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Figure 2. MedAxess inbox screen

**Meldingsmapper**

- Innboks
- Sendte meldinger
- Mine mapper

**Ny melding...**

- Generell melding
- Timebestilling
- Reseptfornyelse
- Legeattest

Logg ut

Kontorets hjemmeside

Du blir aut. logget ut om: 15 minutter

## Innboks

- Flytt til mappe -

Avsender	Tittel	Tidspunkt
<input type="checkbox"/> <input checked="" type="checkbox"/> Legen, Din	Prøvesvar - microbiologi	2005-05-11
<input type="checkbox"/> Legen, Din	SV: Mulige allergiproblemer	2005-05-11

<< Forrige   Neste >>

= Besvart melding  
 = Ulest melding  
 Intet ikon = Lest melding

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Figure 3. MedAxess message screen

**Meldingsmapper**

- Innboks
- Sendte meldinger
- Mine mapper

**Ny melding...**

- Generell melding
- Timebestilling
- Reseptfornyelse
- Legeattest

Logg ut

Kontorets hjemmeside

Du blir aut. logget ut om: 15 minutter

## Innboks: melding 2 av 2

Til: Aaaasen, Ivaar  
 Fra: Legen, Din  
 Dato: 2005-05-11

### SV: Mulige allergiproblemer

*Melding:* I følge beskrivelsen med rennende nase og røde øyne, er det sannsynligvis pollenallergi du reagerer på.

For å være sikker på dette, ønsker jeg at du møter opp på kontoret til time. Bestill selv time på våre nettsider.

**Send svar tilbake:**

*Svarmetode:* Avsender får svar tilbake via **MedAxess** når du trykker **Send**.

*Melding*

--- Mottatt melding: ---  
 I følge beskrivelsen med rennende nase og røde øyne, er det sannsynligvis pollenallergi du reagerer på.

Send

## Study Design

This study was based on interviews of MedAcess users who were listed as patients at one GP office in an urban setting in Trondheim, Norway. When the study took place in October 2002, 70 listed patients were registered as MedAcess users; however, four months after it had been implemented, only 35 of them had actually used the system. Based on availability when the GP's secretary called, 15 patients who expressed their willingness to participate were selected and recruited from among these 35 users. When the interviews took place during the spring of 2004, the 15 selected patients would have used MedAcess for about 12 to 18 months.

All respondents were interviewed using a semi-structured design. The interviews took place at the Norwegian Research Centre for Electronic Patient Records (NSEP) (13/15) or at the patient's workplace (2/15). They lasted from 15 to 40 minutes, with a typical duration of 30 minutes.

All interviews were tape recorded, fully transcribed, and, initially, manually analyzed by the second author. The first author then analyzed the interview transcripts independently using the NUD-IST qualitative analysis software and applying a grounded theory approach by which empirical data are thematically categorized by induction [23]. To increase validity, results of the two independent empirical-analytical approaches were compared by all authors. In the first analysis, five main themes were directly identified from the transcripts: (1) patients' attitudes toward security, (2) aspects concerned with exchanging information with MedAcess, (3) easier access to the doctor, (4) unwanted incidents, and (5) perception of ease of use. In the second analysis, 38 themes (or categories) were initially identified and then sorted into six main themes: (1) supporting simple questions, (2) security, (3) aspects of written communication, (4) trust in the GP, (5) simplicity of MedAcess, and (6) trouble with MedAcess. The themes from the first and second analysis, although differently grouped, extract the same issues from the empirical material. This was taken as a confirmation of the grounding of the analysis in the data.

This paper reports on all themes, using the six-theme grouping from the second analysis. Extracts from interviews are indexed pX/Y, where X is the informant (patient) number and Y is the text segment number within that interview. These numbers are used for internal tracking purposes in order to be able to refer interview extracts back to the context of raw data, for example, in relation to later discussions of the paper.

## Results

Six different but related findings could be extracted from the interviews: (1) patients experienced easier access to their GP by using MedAcess, (2) patients tended to solve minor problems with their GP, (3) patients elaborated on larger issues with their GP, (4) patients did not worry too much about information confidentiality, (5) patients experienced the log in as awkward and a barrier to use, and (6) some patients preferred plain email instead of MedAcess.

## Patients Experienced Easier Access to Their GP

An overall reason to use MedAcess is that patients gain easy access to their GP. Through MedAcess patients may get in touch with their GP without having to wait on the phone or arrange a consultation. In particular, for users with significant travel distance to their GP's office, the possibility to communicate in this manner is "an extra bonus."

*I live in another part of town than the GP's office. And, in addition, I would rather not leave work to sit and wait in his office, like it used to be, to have a prescription or an appointment or something else. Now I can do all these tasks on the net, and I have a response the same day. I think it works great. [p14/8]*

Patients mostly have limited direct phone access to their doctor since most physicians spend their time in consultations and have secretaries to answer and screen the majority of incoming calls. Some practices have organized certain telephone time slots during the day when GPs will answer questions directly from patients. However, since a vast number of patients will try to contact the doctor during that short time slot, such telephone hours often result in long waiting times or no response whatsoever.

*Then it is very hard to get the GP on the phone. The hours with telephone access is very limited, so I have tried to use it, but you have to plan carefully. It is one hour, maybe two or three times per week, and then you must be sure to call during that hour. And the line is not necessarily available. Now you just have to write and then he will answer when it suits him.... So it [MedAcess] is very convenient. [p5/36]*

Most of the MedAcess users (10/15) reported that their GP responded surprisingly quickly to their questions and requests. This means that the patient may contact the doctor asynchronously, without having to wait on the phone, and still get an answer to short questions within minutes. As a consequence, a number of the users (8/15) felt that the GP was more easily accessible through MedAcess than he or she would be otherwise. However, 2 of the 15 respondents reported that they did not get any response from their GP on MedAcess, without being able to explain why.

## Patients Solved Minor Health Problems by Using MedAcess

Although there was a tendency for patients to prefer using MedAcess for minor problems, some patients reported that it was convenient to use it for specific problems that they felt were too complicated to explain on the phone or that required some interaction back and forth between patient and doctor. The time constraints in regular office and telephone consultations rarely allow for in-depth discussions, and they tend to limit the opportunity for the patients to reflect on the GP's suggestions.

*You are supposed to say everything on as little time as possible and be very precise right then. But via that system [MedAcess], you could ask for advice and perhaps a bit of background and spend some more time when you want to ask a question, and to present what is important to get through. [p12/8]*



MedAcess may help users to reflect on suggestions given by the GP since it provides asynchronous communication. Also, the written communication may make a significant difference in establishing a dialogue between the patient and physician.

*It is much easier than going [to the GP] to sit down to wait for an appointment. So I think I feel that the contact with the doctor somehow has been better because you have more dialogue, so to speak, on the small matters. Then you are a little more confident about the larger matters. [p14/32]*

Even though any text-based communication like that of MedAcess is qualitatively different from a face-to-face or telephone interaction, it is the asynchronous nature of the text-based communication that gives users the chance to take the care and time to present a more comprehensive request or question to the doctor.

### Patients Used MedAcess to Elaborate on Complex Health Problems

One of the most interesting aspects with an asynchronous communication system like MedAcess is the potential not only for short questions but also for longer descriptions of health problems. Patients reported that, with MedAcess, they were able to elaborate on illness experiences and also make their own suggestions without feeling that they used too much of the physician's time.

*When you call the doctor in the telephone time you know you have limited time. One is supposed to speak only briefly and be very concise there and then. But through the MedAcess system, you could ask for advice and perhaps a bit more background and take your time to ask questions and get through with important matters and so on.... I try to include everything that is relevant. The other day I wrote that I had such and such symptoms and I needed to include some background history, that I have been examined for this that year. Then I try to give a complete picture of my health, then and now, enough for the physician to sort of grasp the continuity. [p12/8]*

Many patients reported that the written communication gave them the opportunity to think carefully through their message, for example, their illness history, as described by the informant above. Using text to communicate provided a less stressful situation, allowing patients to produce a full illness narrative. Some patients felt that there was always too little time to talk with the GP during office consultations.

*You have a feeling that things move fast here [at the GP's office]...and that, even if the doctor does not think that way, you think since you got a consultation in between other patients...he is in a hurry. And it ends up in such a way...that you think afterwards, "Oh, I should have said that. I forgot!" But when I use the Net, I have time to think through how to formulate and describe things. [p14/36]*

Other users reported that using MedAcess for complex medical problems was useless since text-based communication is not a rich enough medium to reach an understanding between doctor

and patient. These users meant that electronic communication was too impersonal for substituting the face-to-face consultation. However, users would, at the same time, argue that patients who knew the doctor well would be able to use electronic communication with greater success.

Another aspect with the written communication that was reported by the MedAcess users was the chance to suggest a medical analysis themselves. Patients with chronic illness, especially, are often well educated and may have the ability to suggest some therapeutic interventions to the doctor.

*I have so-called autoimmunity and have had to learn to refer to my own illness or health. So, because of that, I guess I have internalized a terminology and an attitude towards not going to the doctor just to tell him that I have some pains. I try to analyze, myself, so therefore I am a bit specific in my descriptions. [p15/28]*

A question related to privacy issues is how users think about sensitive issues being communicated via the MedAcess system. This is slightly ambivalent: many patients perceived MedAcess as useful for simple messages regarding appointments, prescriptions, and so on; however, other patients utilized the tool to discuss sensitive matters.

*It becomes more private. You know, you want to discuss in private with a doctor; and you can write, and you feel that it is more directly from you to him.... You, in a way, dare to write a bit more on such [a system]. [p8/7]*

*I do not think it is a problem to write about things that I am worried about. It has not been a problem at all.... Even in some cases, I would think that if there is something that is really difficult to talk about, perhaps it would be easier to write about it. [p7/26]*

The potential of the MedAcess system to let patients elaborate on illness experiences, even those where a high level of privacy is expected, might be an important finding in a time when complex chronic illnesses that might need to be thoroughly discussed between patient and provider represent a large portion of health care provision.

With the MedAcess system, it was also found that the GPs had more time to respond to difficult questions (as long as time was available to spend). GPs were in control of the response time and, therefore, in the long run, were also in control of the patients' expectations of response time. The doctor was therefore able to either think thoroughly through alternatives or use additional resources to make a decision.

*I had a question regarding some natural medicine that I had started using without consulting the doctor. And then I was told that I should not use it and it was in a way a bit acute [urgent]. [The system] was very convenient because I explained the situation and received a very thorough answer that I would not get if I asked him in a consultation. He had forwarded the question to a research institute for natural medicine and received a response that he forwarded to me. So I received information from this source*



*directly, with an answer, and it went quite fast.*  
[p5/20]

In summary, the fact that MedAxess let patients communicate with their GP through text provided an opportunity for patients to present illness experiences in a more relaxed way, with possibilities to elaborate on sensitive topics and include historical and contextual information, as well as patient hypotheses. The GP would also have the chance to check with external expert resources before providing an answer to the patient. Some users would argue that a personal relationship between the doctor and patient should have been established before an extensive use of electronic communication substituted telephone and face-to-face communication.

### **Patients Were Not Too Concerned About Information Confidentiality**

One main achievement of MedAxess is that it satisfies the strict health information security regulations in Norway and other European states, as mentioned previously. The interviews have documented, however, that patients were, in general, not especially worried about confidentiality. When the patients personally assessed the information security of MedAxess, they often made a comparison with economic transactions on the Internet. Many MedAxess users had favorable experiences with several years of Internet use, and one patient compared MedAxess with the use of Internet banking services.

*We are used to transferring money over the Internet...in and out of Internet banking services. So, if you are afraid of being watched—I am not, but I understand that people might have problems with that—it seems paralyzing. That fear may be paralyzing for information transfer in general.... So, MedAxess is a good thing, to my opinion. And then you have to take chances [laughs].* [p3/80]

One important aspect of the users' perceptions of security (ie, confidentiality) was that their immediate experience with the rigorous log-in procedure elicited the feeling of a high security level. The users expected that the only reason for the awkward procedures must be security issues, and that these issues were necessarily addressed by the procedures.

*I feel that it is safe because it is like this: I receive a new password every time, which they transmit to my mobile phone. So I hope that this means it is safe...that the passwords are stored in another system.* [p13/9]

Most respondents were conscious about the security problems on the Internet and thought that information transactions could never be 100% safe. There are several reasons why users were relaxed about using MedAxess. First, they regarded personal health information as of limited interest to the potential hacker. Second, the users were extra cautious not to elaborate their most intimate details during communications via MedAxess.

*It has only been questions about when to start with [an] allergy medication and that kind of general matters. I do not care if people should learn about that.... When it is something serious, that is something you don't email.* [p11/92-95]

*I would not like to discuss my health over the Internet; I never would have. That confidence in the net, I would never have. But that is not the point either. If you are really sick and need to talk to the doctor, then you should talk to the doctor and not sit there chatting on email, sort of. So I think it's fine.* [p10/29]

However, some patients were uncertain about a potential misuse of information transmitted through MedAxess. Also, the fact that communication is logged and stored in a database made the situation quite different from that of, for instance, telephone conversations. If such written communication is stored for a very long time, it is difficult to foresee who will have access to the information in years to come.

*You have that feeling, when you push the send button, "Well, well"; you hope what has been said about it being absolutely secure is really true.* [p12/33]

*But it is obvious that the incidences stay there, the history, and you may see which questions were asked one year ago. And the doctor has the same log. But I guess you have to trust that nobody else has access.... Since [communication] is stored...the thing about security and safety strikes me.... You are aware that it is not erased, you know.* [p12/75-76]

Being sceptical of applying MedAxess for complicated or intimate health issues is not only related to the security concern. Some users reported that the limits of text-based electronic communication make MedAxess less useful for comprehensive discussions. They would rather elaborate on personal issues with the GP face-to-face, watching the doctor's verbal and physical response closely, than to have immediate feedback.

### **Logging In to MedAxess Was Awkward Compared to Email**

As reported by the users, the awkward log-in procedure was a main problem with MedAxess. Users had to submit a message from their computer, wait for a pin code to be sent as an SMS message to their mobile phone, and then submit that pin code on the computer to get access to the system. The trouble of "passing the security obstacles" seemed to limit the amount of frequent users of MedAxess.

*I had been to the doctor to take some tests. I wanted to have the results and had problems with accessing MedAxess.... So I called the GP's office and then got a combination of numbers.... I tried one more time, without success. I asked again at the office and they told me to call them or those [technically] responsible. I can't remember their name. It became too awkward. Since then, I haven't thought too much about it.* [p15/112]

To comply with the Data Protection Act, MedAxess is based on a Web interface instead of an ordinary email account. This means that users cannot just check responses during the same operation as when they check their other email. Thus, they have to log on to MedAxess separately to check for answers from the GP's office. In particular, users who read email as part of their regular work could have saved a lot of time if they were

able to access their communication with the GP by using ordinary email.

*When you use such Net-based systems that have nothing to do with your email account, you have to access it separately. And I read so much email for the rest of the day or do so many other things, that to log on to check if I have had a response today—I don't bother. Then, it is much better to use an email account that I use on a daily basis. [p13/58]*

These problems have led many patients to use ordinary email instead of MedAxess. The GP offices in this project had communicated non-sensitive issues by email with some of their patients for many years before MedAxess was introduced. Beforehand, some patients had therefore been used to email communication with their care provider in a way they had found useful.

*If it is those quick things that I need, I just send an email to the reception. If I need a prescription...I send an ordinary email because they have some sort of prescription ordering where it is just [necessary] to contact the office desk. So, I use MedAxess more directly when it concerns my disease. [p14/24]*

The preferred use of email rather than MedAxess may be understood as a reaction to the awkward security procedures related to the system. It may also be a result of a patient's well-established routine of using email with the doctor.

*It was the last week or the one before that. It was a... patient record note that was written by a psychologist that was totally far out, the way I saw it, that [my doctor] got a copy of...and I sent her an email where I asked her to look at the note and give some feedback if she agreed. She would look at the matter. And she replied after two days. That was rather quick, I think. [p13/30]*

Moreover, a reasonable interpretation of patients' use of email instead of MedAxess is their relatively relaxed attitude toward confidentiality problems with email in general. Although the patients acknowledge that these security issues have been solved within MedAxess, they often make their own judgment as to whether the content of their communication is suitable for email even when they have access to MedAxess. It is quite interesting that the users assessed on their own behalf the privacy content of the information they transmitted. Thus, it challenges the role of the Information Security Act as well as the security functions of systems like MedAxess. To avoid too much hassle with logging in, some patients selectively preferred to use email for "small practical matters."

*I actually sent an email once more. I took that road again, the question related to a test result on my daughter that I was supposed to report. But then I didn't try [MedAxess]. I used ordinary email because it was much easier, since I knew there had been some trouble getting access the last time. But if I had the chance, I would rather use [MedAxess]. Because I regard it as a more secure and direct access to the doctor than the GP office's email address. [p12/17]*

The patients are not especially concerned about security issues on the receiver side (ie, at the GP's office), and they regard the GP as reliable when it comes to who reads the office email.

*Those simple things like ordering Paracet or asthma medicine, I could of course use [MedAxess] for that. But it hasn't turned out that way. I have sent [my doctor] an email.... It...seemed easier for me, at least. And I got a reply at once. Certainly, I hope they have a safe email system, that it is encrypted so that it is not possible to hack the system. So I had to rely on that. It is a [technologically advanced] GP office...to my experience, so I hope that's in place. Anyway, I got a response, very quick. [p13/15]*

The main reason for using email is the awkward log-in procedure of MedAxess. In addition, regular email is convenient for the respondents who use email on a daily basis at work.

*I have sent...an ordinary email, yes, because I sit in front of the computer all day at work, and at first I discovered that I could send an email to request an appointment. [p2/18-20]*

It is interesting to note that email seems to have established itself as an ideal standard for user-friendly computerized communication.

*And if it turns out to work as fast as email, I will use it for matters for which I could have used email. [p12/72]*

Our empirical data have shown that 5 of the 15 users preferred email for communication with their GP. In doing so, they avoided some of the log-in hassle and also made it possible to integrate their communication with the GP with other email-based work activities. Of special interest here is the finding that users made a self-assessment of their privacy need to distinguish between different kinds of communication media use. Even though they regarded email as less secure than MedAxess, they chose to use email because of its ease. At the same time, however, they made sure that the information they submitted via email was of a less private nature.

## Discussion

This study was limited to a qualitative approach with a focus on the various experiences of patients using MedAxess. Thus, we have taken an explorative approach to identify issues concerning how users perceive information privacy matters and how they act accordingly.

### Reasons for Using MedAxess

Patients used MedAxess for "small matters," which they did not regard as particularly sensitive. They avoided the most intimate details and therefore reduced the relevance of confidentiality worries. Examples of reasons for using MedAxess included the following: to ask for recent test results, to request documentation such as renewed prescriptions and certificates, and to give feedback on results of medications taken at home.

In addition, patients found MedAxess useful for elaborating on larger issues, for example, concerning their experiences of

changes in a chronic illness situation. The fact that MedAxess provided an asynchronous text-based medium gave patients an opportunity to present their story without feeling stressed because they were using the GP's time.

Users regarded MedAxess as making access to the GP easier. They did not have to travel to the GP's office or queue up in a long phone line. They felt that they did not have to disturb the GP with small questions. The response time from the GP was reported to be fast, sometimes surprisingly fast.

### Reasons for Not Using MedAxess

Several users (6/15) regarded MedAxess as not quite user friendly and therefore used MedAxess quite infrequently. This resulted in difficulties recalling the cumbersome log-in procedure. Some of these users ended up using ordinary email for communication with their GP, thus avoiding some of the log-in hassle and making it possible to integrate electronic communication with their GP with other email-based work activities. Users who relied on regular email regarded it as safe enough for the kind of information they communicated to their GP.

### Security Issues

About half of the users (7/15) in this study perceived MedAxess as secure because of the awkward password system ("Why else would one have it this way?"), because it was planned with information security in mind (and supposed to be more secure than email), and because it had passed the strict regulations of the Information Security Act. Users had already used Web-based banking services without many second thoughts and therefore knew that Web services might be safe. Supporting the findings of Hassol et al [14], patients in this study were only mildly concerned with information security issues.

### Privacy Issues

As expected, we identified that users were interested in applying MedAxess for small, practical issues, and that they found their

GP to be easily available through this system. However, the perception of privacy issues among users was more surprising. To avoid the log-in hassle of MedAxess, they preferred to use ordinary email, avoiding security problems through some self-assessed adjustment of the information they transmitted. It seemed to bother patients less that it is illegal for doctors in Norway to give medical advice to their patients via ordinary email. According to Norwegian regulations, the doctor is responsible for responding to such messages if it is expected that the problem described needs medical attention or treatment. In that situation, the GP would have to ask the patient to make an appointment or use a secure system, such as MedAxess, if the Internet is the obvious avenue to discuss the problem at hand. Or, the GP could simply call the patient on the telephone or ask the patient to call.

### Conclusions

With email as an ideal, the challenge for secure Web-based communication systems is to establish log-in procedures that users will find easy, effective, and feel familiar with. As mentioned by Masys et al, safety comes with a price in usability, which might even be acceptable [7]. Moreover, as we have demonstrated in support of the findings of Masys et al [7], the technical challenge of using the system contributes to the perception of safety.

On the other hand, our results clearly show that the usability of the log-in procedure has an impact on patients' actual use of the system. Only half of those patients who registered as users of MedAxess actually started using the system. Our results are based on responses from these patients; therefore, patients in our convenience sample might have more positive attitudes towards MedAxess than the average patient. Taken together, these results emphasize the need to address usability issues when developing and testing such systems. Perhaps there might be a need to educate users more on security issues before it is possible to widely implement systems that cannot necessarily be as easy to use as regular email.

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### Conflicts of Interest

None declared.

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Original Paper

# A Case Study of a Retracted Systematic Review on Interactive Health Communication Applications: Impact on Media, Scientists, and Patients

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## Abstract

**Background:** In October 2004, a flawed systematic review entitled "Interactive Health Communication Applications for People with Chronic Disease" was published in the Cochrane Library, accompanied by several press releases in which authors warned the public of the negative health consequences of interactive health communication applications, including the Internet. Within days of the review's publication, scientists identified major coding errors and other methodological problems that invalidated the principal conclusions of the study and led to a retraction. While the original study results and their negative conclusions were widely publicized in the media, the retraction seemed to go unnoticed.

**Objective:** This paper aims to document an unprecedented case of misinformation from a Cochrane review and its impact on media, scientists, and patients. As well, it aims to identify the generic factors leading to the incident and suggest remedies.

**Methods:** This was a qualitative study of the events leading to the retraction of the publication and of the reactions from media, scientists, and patients. This includes a review and content analysis of academic and mass media articles responding to the publication and retraction. Mass media articles were retrieved in May 2005 from LexisNexis Academic and Google and were classified and tallied. The extended case method is employed, and the analysis is also applied to comparable publishing events.

**Results:** A search on LexisNexis Academic database with the query "Elizabeth Murray AND health" for the period of June 2004 to May 2005 revealed a total of 15 press reports, of which only 1 addressed the retraction. Google was searched for references to the review, and the first 200 retrieved hits were analyzed. Of these, 170 pages were not related to the review. Of the remaining 30 pages, 23 (77%) were reports about the original publication that did not mention the retraction, 1 (3%) was a bibliography not mentioning the retraction, and 6 (20%) addressed the retraction, of which only 1 was a non-Cochrane-related source.

**Conclusions:** Analyzed retrievals showed that the mass media gave more coverage to the Cochrane review than to the retraction or to a related systematic review with a similar scope but a different conclusion. Questionable results were prematurely disseminated, oversimplified, and sensationalized, while the retraction was hardly noticed by the public. Open commentary by scientists and patients helped to rapidly identify the errors but did not prevent or correct the dissemination of misinformation.

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**KEYWORDS**

Retraction of publication; online systems; mass media; patients; medical errors; editorial policies

## Introduction

### Publication of the Review

On October 18, 2004, the Cochrane Collaboration, a organization which produces and disseminates systematic reviews of health care interventions [1], published a review entitled "Interactive Health Communication Applications for People with Chronic Disease" [2], which from this point on will be referred to as the "IHCA review." The IHCA review was edited by the Cochrane Consumers and Communication Review Group [3]. Those who prepare reviews volunteer to work in one of many Collaborative Review Groups, with editorial teams overseeing the preparation and maintenance of the reviews.

Interactive health communication applications (IHCAs) were defined in the IHCA review as "computer-based, usually Web-based, health information packages for patients that combine information with social-, decision-, or 'behavior change'-support" [2]. The results of the IHCA review showed that IHCAs had a positive effect on knowledge and on social support, no effect on behavioral outcomes, and a negative effect on clinical outcomes.

The principal conclusion of the review was "consumers whose primary aim is to achieve optimal clinical outcomes should not use an IHCA" [2]. This conclusion was the focus of a press release which the mass media widely circulated (as will be documented later). However, only days later, the IHCA review was found to be flawed and was retracted.

### Retractions

The National Library of Medicine (NLM) is a leader in the bibliographic handling of retractions. The Medical Subject Headings (MeSH) contain the concept "retracted publication," which identifies a citation previously published and now retracted through a formal issuance from the author, publisher, or other authorized agent. In January 2005, the PubMed query "Retracted Publication[Publication Type] AND 1971:2004[edat]" retrieved 619 retracted citations that entered PubMed between 1971 and 2004. Since the query "1971:2004[edat]" retrieves approximately 12.5 million citations, less than 1 in 10000 publications have been retracted.

Friedman [4] studied 60 fraudulent articles by one scientist. Journals in which the scientist had published were notified of the fraud. Only 7 articles were subsequently tagged in PubMed with "Retracted Publication." The delay between publication of a paper and its retraction often has deleterious effects [5]. Furthermore, journals and institutions are hesitant to issue a statement of errors in published work unless the author of the work confesses to the error, which authors may resist doing because such an admission can be career-damaging.

While very few publications are officially retracted, the concern about factors related to retractions is substantial. The study of retractions itself might be indexed with MeSH concepts such as "scientific misconduct," although the fraction of retractions that stem from error as opposed to scientific misconduct is not known. The query "Scientific Misconduct[majr] AND 1971:2004[edat]" in PubMed retrieved 1840 citations. This body of literature recommends that medical researchers

constructively criticize the research practices of others in their institution to reduce the likelihood of misconduct [6].

The objective of this paper is to document the IHCA review as an event in the history of medical publishing, to identify the factors leading to the publicizing of a retracted publication, and to assess the implications.

## Methods

The objectives of this research called for various study methods. The author employed the following three methods: (1) historical processes of collecting documents about a contemporary event and organizing them thematically; (2) ethnographic processes of author participation in the event, personal communication with other participants in the event, interpretation of communications, and construction of models; (3) content analyses based on bibliographic database and Internet searches, coding of the retrieved documents, and tallying of the code frequencies.

The ethnographic method employs the extended case method, and the extended case method applies reflexive science to ethnography. Buroway describes reflexive science as follows: "Reflexive science starts out from dialogue, virtual or real, between observer and participants, embeds such dialogue within a second dialogue between local processes and extralocal forces that in turn can only be comprehended through a third, expanding dialogue of theory with itself" [7].

Various database and Internet searches were employed to study the impact of the review and to quantify the difference between mass media coverage of the original publication and its retraction. LexisNexis Academic databases of health news and general news were searched, as was Google. The queries were designed in an iterative process that began with keywords from the question to be addressed but refined the query based on study of the query retrieval results. The retrieved results were coded, and the coding language was also developed in an iterative process. First, the obvious codes "about the review" and "about the retraction" were introduced. Each retrieved document was classified into a single code by the author. If the retrieved document was not appropriately described by an existing code, then the coding language was augmented. The Web of Science was also queried to identify academic citations, but no citations were identified (data not shown). Most database and Internet searches were conducted in May 2005.

To better understand how special the publicity accorded the IHCA review was, this study was extended to three other publications: 2 of these were retracted publications tagged as "Retracted Publication" (1 Cochrane review, but not eHealth related, and 1 non-Cochrane review, but eHealth related), and 1 was a meta-analysis with a scope similar to that of the IHCA review. These 3 reports were identified through PubMed searches.

## Results

The following qualitative results on the impact of the IHCA review are organized into three main sections: scientist reaction, mass media reaction, and patient reaction.

The section on scientist reaction considers Cochrane reviewers' reactions and how eHealth scientists responded to the IHCA review in the comment section of the Cochrane database. The mass media section provides the Cochrane retraction and then explores, via LexisNexis and Google results, the reaction of the mass media to the IHCA review. The patient reaction section shares dialogue from patient-patient online discussions that reveals the reactions of patients to the IHCA review.

### Scientist Reaction

The Cochrane Collaboration allows anyone to submit comments to the published reviews. Two scientists' comments on the IHCA review appeared independently on October 28, 2004. Kummervold and Eysenbach criticized the IHCA review for both its protocol and its coding.

Kummervold explained in detail how the coding of the meta-analysis was incorrect: "We can't get the numbers to add up, it looks like they are reversed in 8 of the 11 studies..." [8]. He delineated the facts and the interpretation for each of the 8 studies at issue; for example, regarding the HbA1c measurement in the Lehmann 2003 paper, he stated that Lehmann reported a reduction in HbA1c of 0.8 for the intervention group, and 0.1 for the control group, which should be interpreted as a positive result for the intervention group. Kummervold added: "We also find it strange that you focus so much on the overall estimates when there is so much heterogeneity in the material. The conclusion seems to be overstated" [8].

Eysenbach had similar comments, stressing that a formal meta-analysis of these heterogeneous studies was problematic, and that the three studies which contributed most to the "negative" result were in fact positive: "Apart from the fact that I do not think that it is legitimate to do a formal meta-analysis using papers measuring totally heterogeneous outcomes with different types of interventions, I also notice that the overall effect estimate is 'negative' (eg, 'favoring control') because of three studies.... However, when I read these three studies I cannot find that their result[s] are negative.... If my suspicion is correct, then this is quite a catastrophic error, and quite an embarrassment for Cochrane to let such an error slip through peer-review" [9].

On November 10, 2004, the Cochrane Consumers and Communication Review Group reacted to the discovered errors [10] with a notice that included the following: "The review will be withdrawn as soon as possible.... As the corrections to the review have not been completed yet, it would be premature to announce any reversal of the review's findings at this stage.... The original press releases regarding this review were made not by the Cochrane Collaboration itself but by University College London...."

John Wiley & Sons (the publisher of the Cochrane Database) released to EurekAlert a retraction on December 6, 2004: "The

review originally determined that...chronically ill people using interactive programmes had worse clinical outcomes than those who did not. Regrettably, errors in data analysis meant that these outcomes were reported incorrectly.... It is expected that the revised results will be published in April 2005" [11].

The April 2005 edition of the Cochrane Systematic Reviews did not mention the IHCA review. Royle, the chief executive officer of the Cochrane Collaboration, said that further review of the revised report was ongoing and no date could be given as to when the review might be published (personal communication, April 25, 2005).

### Mass Media Reaction

The Cochrane Database of Systematic Reviews is not read by the typical consumer. However, Murray's employer, the University College London (UCL), worked with Murray to widely publicize the result. UCL posted a news bulletin on its website on October 18, 2004 that remained there as of May 25, 2005. The bulletin was titled "Knowledge may be hazardous to web consumers' health" and stated the following: "People who use their computers to find information about their chronic disease often wind up in worse condition than if they had listened to their doctor, according to a UCL review of studies on internet health.... One reason...might be because knowledge-seekers become so steeped in information from the Internet they make treatment choices on their own, contradicting advice from their doctors" [12].

Most significantly, the UCL bulletin was circulated to information intermediaries that are considered the main entrance to the world's mass media, including AlphaGalileo and EurekAlert.

A search on LexisNexis Academic with the query "Elizabeth Murray AND health" for the period June 2004 to May 2005 revealed a total of 15 relevant press reports, in the following categories:

- Medical and Health News: There were 9 publications with titles such as UCL's press release title of "Knowledge may be hazardous to web consumers' health." The publications appeared in places like *Life Science Weekly*, *Law and Health Weekly*, and *Health and Medicine Week*.
- General News—Major Papers: There were 5 relevant articles, such as one entitled "Why medical advice from the internet can be bad for your health" in the British *The Daily Telegraph* and another entitled "Medical Web sites may be unhealthy places to learn about ills" in the *Omaha World Herald*. Only 1 article was about the retraction, published in the *Ottawa Citizen* on October 18, 2004.
- Time Incorporated Publications: There was 1 article in the November 1, 2004 issue of *Time* entitled "Click to Get Sick?" [13].

Among the 15 results from the LexisNexis Academic database, only 1 newspaper report, authored by Tom Spears, dealt specifically with the retraction [14]. Spears, in personal communication with this author (November 18, 2005), said, "I was fairly stunned today to learn that it [IHCA review] has been withdrawn; I found out only because I was looking up the study for my daughter, a science student. Now I'm covering the sequel

for tomorrow's paper... I scan EurekAlert faithfully, as many reporters do, and never saw a hint of anything there."

To further test whether the media emphasized the false negative result but minimally covered the retraction, a content analysis on Google was performed on May 24, 2005. The query was "health AND Cochrane AND Murray AND (interactive OR web OR internet)" for English pages, within the past year. Of the first 200 retrieved hits, 170 pages were not related to the IHCA review. Of the remaining 30 pages, 23 (77%) were reports about the original publication that did not mention the retraction, and an additional page was a bibliography (at a UCL site) that included a citation to the IHCA review, again without mentioning the retraction. All reports (except the bibliography) used a title such as "Click to Get Sick?" and emphasized the negative impact on clinical outcomes of using the Web. The reports came from such reputable sources as the *British Broadcasting Corporation* and *US News and World Report*. In contrast, only 6 pages (20%) addressed the retraction: 2 were the original press releases now marked with "retraction" but still emphasizing in their particulars the negative health impact, 3 were Web pages at Cochrane sites, and 1 was an announcement from *MedicalNews* entitled "Updated press release to October 2004 Cochrane Review." The latter was the only non-Cochrane-related page primarily addressing the retraction.

The grey literature reported on the mass media. For example, *The Neuroscience for Kids Newsletter* summarized [15] the "Click to Get Sick?" *Time* article by Sanjay Gupta, and a Web archive for patient education at the Samaritan Health Center pointed patients to Gupta's article. This author wrote to Gupta and asked him to write about the retraction, but Gupta did not reply.

NLM indexed the IHCA review and entered the citation for it (including its abstract) in PubMed on October 21, 2004. The "Retracted Publication" tag did not, however, appear in PubMed until March 24, 2005.

### Patient Reaction

Some patients reported the news about the IHCA review to their patient-patient online discussion groups. In a neurology patient discussion group [16], a patient posted the entire BBC news story. Patients responded in two ways. Some rejected the IHCA review result and added strong comments, such as "I have gotten more help and answers for problems from knowledgeable people on this Internet Forum than I have from any of the multitude of doctors I have seen over the last 12 years." Others accepted the conclusion but insisted that patients could filter bad information from good and benefit in the end from the web. These patients were not aware of the retraction of the IHCA review.

This author reported the *Time* "Click to Get Sick?" article to two head-and-neck cancer patient discussion groups to which he belongs. A day later he reported the retraction from the Cochrane Database. One member of the discussion group replied: "Thanks for the update—the negative findings seemed odd to me when I read it, so I'm glad it's being revised." This author, in his role as a cancer patient, also formally commented on the IHCA review at the Cochrane Database site [17].

The typical patient with a chronic disease has no formal medical training and is ill prepared to critique a meta-analysis of clinical trials. However, the typical patient is vulnerable to cultural pressures, as they are partially shaped by and reflected in the mass media.

### Comparison With Another Cochrane Retraction

For comparison, a search for further retracted Cochrane reviews using the PubMed query "Cochrane Database Syst Rev[TA] AND Retracted Publication[PT] AND 1971:2005/5/25[edat]" was conducted. One reference, in addition to the IHCA review already discussed, was identified, which was a retracted review by Brewster et al [18] about antihypertensives. The retraction for the Brewster et al review is explained on the Cochrane website as follows: "This systematic review has been withdrawn temporarily because its contents are potentially misleading."

A search on LexisNexis with the query "Brewster AND antihypertensive" for the period November 2004 to May 2005 retrieved no articles in either the "General News—Major Papers" category or the "Medical and Health News" category.

A search on Google for "Brewster antihypertensive" followed by an examination of the first 100 retrieved pages identified 23 relevant pages, which had a very different content pattern than the hits for the IHCA review. They all contained citations of papers from Brewster et al, who have published elsewhere on the same subject as in their review. The Brewster et al publication attracting the most attention was an article [19] in the *Annals of Internal Medicine* that was not retracted but has the same title as the Cochrane review. Thus, the only other retracted Cochrane review had a very different mass media, scientific, and web impact than the IHCA review.

### Comparison With Other Retracted Articles Related to eHealth

To determine whether other articles on a similar topic to the IHCA review have been retracted, a search was first made for articles on a similar subject that had been MeSH indexed in PubMed. The article by Demiris [20] seemed relevant, and its two MeSH index terms were "Disease Management" and "Internet." A search on PubMed for "Retracted Publication[PT] AND Disease Management[majr] AND Internet[majr] AND 1995:2005/5/25[edat]" returned no citations. When the search was broadened by removing the term "Disease Management," 1 retracted reference was retrieved, entitled "The quality of surgical information on the Internet" [21]. As previously described in the *Journal of Medical Internet Research*, this article was retracted due to a case of cyberplagiarism, with large sections of the paper having been lifted from different websites [22].

A search on LexisNexis Academic with the query "McKinley and surgical and Internet" for the period 1995 to May 2005 revealed no relevant press reports, neither in the "General News—Major Papers" category (three hits were all not relevant to the McKinley article) or in the "Medical and Health News" category.

A search on Google for English pages with the query "McKinley surgical Internet" revealed 96 irrelevant pointers in the first 100



results. Of the remaining 4 relevant hits, 1 was the article about the plagiarism [22], which precipitated the retraction of the McKinley et al manuscript, and 3 were academic references to the McKinley et al article, which did not note it being retracted.

Thus, the only other retraction of a published article appearing in PubMed similar in topic (the Internet) to the IHCA review had a very different pattern of reactions than the IHCA review.

### A Similar Meta-Analysis on eHealth

The IHCA review addressed a topic that the mass media found interesting. Have any other recent publications also been a meta-analysis on the impact of interactive applications on health, and, if yes, what was the mass media reaction? Using the query “Meta-analysis AND Web AND Chronic Illness” in PubMed, we found only 1 citation: Wantland et al [23] did a meta-analysis on Web-based health interventions that was published (in the Journal of Medical Internet Research) about the same time as the IHCA review. The paper concluded that “the effect size comparisons in the use of Web-based interventions compared to non-Web-based interventions showed an improvement in outcomes for individuals using Web-based interventions to achieve the specified knowledge and/or behavior change for the studied outcome variables.”

What has been the impact of the Wantland et al paper and how does that compare to the impact of the IHCA review? The Wantland et al paper was not announced with a press release in EurekAlert. A search on LexisNexis Academic for newspaper articles about the Wantland et al paper retrieves no articles. The queries performed were similar to those performed for the IHCA review and included “Wantland AND health” for 2004 through 2005 in General News/Major Papers.

A search was done on Google for “Wantland health Web” on May 24, 2005. Of the first 200 returns, 182 were not relevant. Of the remaining 18 hits, 15 pages contained academic citations to Wantland et al, 2 announced the appearance of the article, and 1 was a personal blog that commented on the article.

Thus, most of the Google returns that gave Wantland et al citations are academic in character and very different from the mass media coverage afforded the IHCA review.

## Discussion

As shown, the IHCA review provides a perhaps unprecedented case from which lessons should be drawn. Only one other Cochrane review (about antihypertensives) has been retracted, and that one received negligible mass media attention. The only retracted publication in PubMed that is indexed under the MeSH concept of “Internet” (the IHCA review did not have time to get indexed before it was withdrawn) received no newspaper coverage. The paper most similar to the IHCA review in topic and method (the Wantland et al report [23]) received considerable academic attention but no newspaper coverage. In other words, special circumstances must have come together for the IHCA review situation.

This section next presents a framework based on tiers of response. The first tier is medical scientists. The second tier is the mass media spreading medical press releases. The third tier

is the patient community reacting to the mass media and the scientists.

### First-Order Problem

In an effort to critique the problem that occurred, one might build on the analysis of misconduct in toxicology by Purchase. Purchase [24] identified four roots of misconduct:

- Intention of the work
- Conduct of the studies
- Design and interpretation of studies
- Bias from conflict of interest

In the case of the IHCA review, the intention was scientifically appropriate, namely to gain further insight about IHCA through a systematic review. In the other three categories, fault can be found:

- The errors in the coding of data should not have been made. The coauthors Nazareth and Tai, who are credited with doing the coding, have good enough credentials to not lay the blame on lack of experience: Nazareth is a Professor at UCL and is Scientific Director of the British Medical Research Council's General Practice and Research Framework, and Tai has coauthored several articles over the past two decades that appeared in refereed medical journals. An explanation for the miscoding in terms of experience of the coders is not apparent.
- The design of the study has been criticized as lumping together studies which are too heterogeneous in their design, interventions, and outcomes [8,9]. The protocol might have been more rigorously vetted by the Cochrane Review Group, and the authors should have been more cautious in their interpretation of results and emphasized the weakness of the design in their publicity.
- The reporting of the work suggests possible bias. The authors and their employers have sensationalized a result that catches the media's attention. For some observers, the review appeared biased in that the authors, who are affiliated with medical institutions, concluded that patients should listen to their doctor, instead of seeking help on the Internet.

Purchase [24] claims that a partial solution to this first-order problem is the institutionalization of quality controls. In the 1970s, good laboratory practice regulations were introduced, but comparable regulations do not exist for meta-analyses. For quality control of a meta-analysis the scientific community relies on the research team, the researchers' institution, and the referees. A medical research institution, such as the UCL Medical School, presumably embraces results from its researchers that can earn mass media coverage and is not the appropriate institution to prevent sensationalizing. Referees can not be expected to detect when laboratory data are intentionally modified [25]; however, in this case they could have been expected to detect when data available to them are miscoded. Problems with refereeing have been frequently noted and in particular for the Cochrane Database [26].

Open commentary, as exists for the Cochrane Database after a publication, is one way to identify flaws. Extending the open commentary to the refereeing phase might reduce the likelihood



of something going to press with errors. A submitted article might be available to the public and a community of hundreds of registered scientists could be invited to make anonymous comment. Submissions online would require extensive online commenting that reached a consensus before a submission could be considered “published.” Other approaches to increase the commentary on the research process include refereeing the protocol phase [27], which is done by the Cochrane Collaboration but apparently not with the necessary rigor or topic expertise.

### Second-Order Problem

The second-order problem is a press release and subsequent mass media coverage of the release. Winsten's classic study of science and the media shows how the truth is repeatedly misrepresented by journalists and researchers: “The most striking finding which emerged from the interviews [of medical journalists] is the dominant distorting influence of the competitive force in journalism.... As economic competition among hospitals has intensified, they have begun to compete aggressively for publicity.... With increasing frequency...scientists...are using the media to attach their names to important findings before their competitors do.... The result has been a spiraling competition, sometimes characterized by exaggerated claims” [28].

Online media have stimulated further competition [29]. The case of the IHCA review reflects these pressures. The UCL press release contained inaccuracies, even if the review would have been scientifically sound, in order to gain mass media attention. For instance, the subtitle of the press release was “Knowledge may be hazardous to web consumers' health.” In truth, the IHCA review was not about Web applications, per se, but about IHCAs, which are defined more broadly than “Web applications.” However, writing a news article about IHCAs is less likely to catch attention than an article about the Web. The UCL press release did not introduce and define the term IHCA, and Murray issued statements that implied the Web was the issue. By the time the information from the press release made it into the mass media, the material had been modified enough to lose any mention of IHCAs. For instance, the *Time* article said, “People who use the Web to get information about their chronic diseases often wind up in worse shape than before they logged on.”

One way for researchers to prevent the mass media from misrepresenting the truth is for researchers to understand how the media work and to interact with the media accordingly [28]. Murray should have known that her words might be twisted to emphasize what would sell newspaper space and should not have wildly speculated. The reputations of the Cochrane Collaboration and UCL partially account for the wide dissemination of the original press release. Yet, neither organization has taken adequate steps to undo the impact of the media reporting on the IHCA review.

The honesty of the press could be improved with the Internet [30]. Online health care mass media publications could allow

the public to make comments on news articles. Rating techniques, such as employed at eBay and Slashdot, might be used to give prominence to quality feedback [31].

### Third-Order Problem

The third-order problem concerns the long-term impact of the mass media. While electronic publications might be erased from a computer or marked as retracted, this does not consistently happen. Furthermore, some of the mass media coverage of the IHCA review is on paper and sits on people's bedside tables with no practical way to be retracted [32].

Although this author did not (yet) find any citations to the IHCA review in Web of Science, previous studies have confirmed that a retracted scientific publication may continue to have impact without readers recognizing its retracted status. For instance, one study [33] tracking the citation pattern of 82 retracted articles revealed that, together, they were cited 733 times after their retraction, but only a small fraction of the citations referred to the retraction. In the case of the mass media, retracted publications might be read by people without them seeing the separate retraction notice.

If and when the revised IHCA review is published, what could it say that would undo the effect of the original publication? If the conclusion is that IHCAs result in improved clinical outcomes, then the medical profession will want to closely study the protocol and might have grounds to discredit the conclusion. The media trumpeted the IHCA review conclusion partly because it was counterintuitive but was backed by top-notch institutions. If the conclusion becomes intuitive, then the media are unlikely to be interested in it.

The reactions to the IHCA review in patient online discussions highlight the importance of virtual communities in helping patients deal with published information. Simple extensions to Web-based, patient, discussion systems could help patients connect to Web-based publications. For instance, when a patient posts a message to a Web-based discussion board, the Web system could parse the message and provide links from the message to relevant articles on the Web. Patients might follow the links and engage in discourse about the validity and implications of the literature. This might lessen the potential ill effects of publications that are wrong or misleading.

### Conclusions

This special medical publishing event was marked by incorrect coding and a desire for maximum publicity. The IHCA review authors, their employers, and the Cochrane Collaboration were responsible for quality control, and failed. The mass media played their part by widely publicizing a sensational message but not reacting to the notice that that sensational message was false. The false result that patients are clinically harmed by interactive applications was very strongly delivered to patients worldwide. The broad lesson to be re-learned is that potentially sensational results should be carefully scrutinized before being sensationalized.

## Conflicts of Interest

None declared.

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## Abbreviations

**IHCA:** interactive health communication applications

**UCL:** University College London

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