Journal of Medical Internet Research

Journal Impact Factor (JIF) (2022): 7.4
Volume 6 (2004), Issue 3   ISSN 1438-8871   Editor in Chief: Gunther Eysenbach, MD, MPH

Contents

Editorials

Viewpoints

Original Papers

Editorial

Tackling Publication Bias and Selective Reporting in Health Informatics Research: Register your eHealth Trials in the International eHealth Studies Registry

Gunther Eysenbach[1,], MD, MPH

Centre for Global eHealth Innovation, Toronto, Canada

Corresponding Author:
Gunther Eysenbach, MD, MPHEditor-in-Chief
Associate Professor, Department of Health Policy, Management and Evaluation
Senior Scientist, Centre for Global eHealth Innovation
University of Toronto
University Health Network
190 Elizabeth Street
Toronto ON M5G 2C4
Canada
Phone: +1 416 340 4800 ext 6427
Fax: +1 416 340 3595
Email: geysenba@uhnres.utoronto.ca

Abstract

Beginning in July 2005, several major medical journals, including the Journal of Medical Internet Research, will only consider trials for publication that have been registered in a trial registry before they started. This is to reduce publication bias and to prevent selective reporting of positive outcomes. As existing clinical trial registers seem to be unsuitable or suboptimal for eHealth studies, a free International eHealth Study Registry (IESR) has been set up, allowing registration of trials (including non-randomized studies) in the field of health informatics and assigning an International eHealth Study Number (IESN). The IESR should meet the requirements of journal editors for a-priori registration of a study. We hope IESR will become the preferred choice for registration of eHealth studies and, as an secondary benefit, will become an international repository of ongoing eHealth projects, thereby enhancing global collaboration and reducing duplication of effort.

(J Med Internet Res 2004;6(3):e35) doi:10.2196/jmir.6.3.e35

KEYWORDS

Clinical protocols; publication bias; randomized controlled trials/standards; registries; information storage and retrieval

Compulsory Registration of Studies as Requirement for Publication

This month some of the world's leading medical journals under the umbrella of the International Committee of Medical Journal Editors (ICMJE) made an important and far-reaching announcement: they will not publish trials in the future unless they have been registered before they started [1]. To be considered for publication in these journals, trials that begin enrollment of patients after July 1, 2005 must register in a trials registry at or before the onset of enrollment. For trials that begin enrolment before this date, the journals will require registration by September 13, 2005. (See multimedia appendix for the ICMJE statement). With this measure, editors of journals hope to effect widespread registration of trials to counter selective reporting and publication bias. JMIR will join this initiative and will (after July 1, 2005) publish only randomized trials or cohort studies which have been registered before starting enrollment. JMIR has also created a registry for eHealth studies and urges all eHealth researchers to register their planned or ongoing projects, regardless of whether they intend to submit them to this or other journals.

The mandatory registration of clinical trials has been demanded for almost 20 years and is overdue [2-4]. The new requirement from many of the world's leading journals is a breakthrough for ensuring the quality of clinical research. It is long known that negative trials are less likely to be published than positive trials [4], and that this leads to a problem called “publication bias”, with somebody just appraising the published literature coming to a more positive conclusion about the effectiveness of an intervention than somebody who would be aware of all trial results. Although widespread use of trial registers will not prevent negative trials from remaining unpublished, it will at least help systematic reviewers identify unpublished trials and will improve the quality of published study reports. While the Internet has already been a very useful tool helping systematic reviewers discover ongoing and planned research, this has required tedious “detective work” for systematic reviewers to find clues on the homepages of researchers and funding agencies [5]. With Web-based trial registers, investigators will now leave digital trails on the Internet so that knowledge synthesis researchers can contact the investigators for further information. Furthermore – and perhaps even more importantly – registration of key data such as the primary outcome measures and trial duration before the trial starts may prevent post hoc “data dredging” (fishing for significance) or selective reporting.

A recent high-profile case of alleged selective reporting was the drug company- sponsored CLASS trial, which compared gastrointestinal toxicity of Celecoxib against other nonsteroidal anti-inflammatory drugs (NSAIDs) [6]. Investigators were accused of intentionally misleading readers by reporting only the more favourable 6-month outcomes for a trial that lasted 12 months – a fact that was not reported in the final publication [7,8]. According to critics of the publication, most of the ulcer complications occurred in the second half of the study period, and if 12-month outcome data had been compared, some of the drug's apparent safety advantage would have been diminished. The investigators deny any wrongdoing and said that the reported data “best reflected the comparisons they were trying to make [9].”

The prevalence of cases where pharmaceutical companies try to intentionally mislead peer reviewers and the public is unknown. However, investigator-driven, well-intentioned selective reporting is likely to be widespread. In an attempt to make their manuscripts more interesting and to increase their chances of acceptance by journals, investigators almost routinely highlight the positive findings and sometimes do not mention the negative outcomes. Not reporting all the negative findings is, of course, is a problem, as it conceals the fact that the positive result could be spurious finding: If investigators make 20 different comparisons (eg, measure 5 outcomes on 4 different points in time) at least one will be statistically significant on a 5% level by chance alone. If investigators report only this one “positive” comparison, without mentioning that they made 19 other comparisons which were all negative, the reader is misled. In one recent analysis, where the protocols of studies submitted to an institutional review board were systematically compared against publications of these studies, 62% of at least primary outcome was changed, introduced, or omitted. On average 50% of efficacy and 65% of harm outcomes per trial were incompletely reported; and statistically significant outcomes were more likely to be reported than non-significant results [10]. In health informatics, where researchers often do exploratory studies by measuring multiple outcomes, selective reporting is likely to be highly prevalent.

The Case for an eHealth Study Registry

Although the ICMJE initiative is exciting and is to be welcomed, those primarily interested in the evaluation of non-drug interventions (such as eHealth interventions) are left confused. The signatories of the ICMJE editorial define a clinical trial as “any research project that prospectively assigns human subjects to intervention or comparison groups to study the cause-and-effect relationship between a medical intervention and a health outcome.” Despite this seemingly broad definition, the ICMJE initiative and the surrounding discussion are focused on drug trials. This focus is demonstrated by the ICMJE's endorsement of clinicaltrials.gov as the preferred registry [11,12]. As others have pointed out [13], clinicaltrials.gov offers registration only to "(US) federal agencies sponsoring the clinical research studies (both interventional and observational trials), private sponsors that have submitted an Investigational New Drug Application (IND) to the Food and Drug Administration (FDA), such as pharmaceutical companies, and organizations representingIND sponsors.” Not only is the clinicaltrials.gov registry restricted to US-funded trials, it practically excludes most eHealth and health informatics trials, if they do not study regulated interventions such as drugs or medical devices.

Secondly, eHealth and medical informatics studies often look at more effective services, health services utilization or other variables related to the health care system as endpoints. It is uncertain whether such studies are covered by the definition of the ICMJE which focuses on “health outcomes”. To be on the safe side, and also to ensure eligibility for publication in JMIR, the British Medical Journal (BMJ) or other journals, we recommend that all researchers prospectively register their studies in a registry – but which one?

Although there are commercial trial registers available which provide alternatives to clinicaltrials.gov, these are not always the best choice for eHealth trials. One register, Current Controlled Trials (CCT), assigns, for a fee of about $150, an International Standard Randomized Controlled Trial Number (ISRCTN). This trial register does not meet the ICMJE requirements because it is private and for-profit and lacks backing by a public institution such as a university. Also, it does not meet some eHealth research community requirements, such as a health informatics-specific thesaurus to index the trials. Furthermore, the scope of CCT is “a clinical study in which two (or more) forms of care are compared, and in which the participants are allocated to one of the forms of care in the study, in an unbiased way, by using the play of chance.” Thus, this register focuses on “clinical care” (does this include home care?) and is restricted to randomized studies, while we think that other types of studies, which may be equally or more suitable in our field, should also be registered [14].

The International eHealth Study Registry (IESR)

To meet the requirements of the eHealth and medical informatics community, we have set up an eHealth study registry on the JMIR site, which should meet the requirements of most journals. Our non-profit International eHealth Study Registry (IESR) will assign a International eHealth Study Number (IESN) to each submitted study. We hope IESR will become the preferred choice for registration of eHealth studies and, as an secondary benefit, will become an international repository of ongoing eHealth projects, thereby enhancing global collaboration and reducing duplication of effort.

Does it make sense to create yet another registry? Yes, because it is unlikely that only a single endorsed trial register will serve for all trials in the world. It is more likely (and this is partly a current reality) that multiple domain-, funder- or country-specific registers will exist. All will be accessible on the Internet and made interoperable and cross-searchable forming a large "Meta-Register". In the end it will not matter where a trial or research project has been physically registered. This is similar to the Santa Fe Open Archives standards in Open Access publishing that enable harvesters to search across different archives. With this in mind, it seems important to add the criterion "interoperability" to the list of trial register requirements, which is neither mentioned by the ICMJE [1] nor the BMJ [13].

In addition to developing an eHealth study-specific thesaurus and indexing system based on registry submissions, other innovations distinguish IESR from generic registries such as clinicaltrials.gov or CCT. For example, we will provide a "results" field in the database, making it easy for registrants of the eHealth research to report their results in a very short form or to link to subsequent publications. In addition, the register will have a one-click "submit for publication" button to submit the protocol with the short results for publication to JMIR. The report will then be peer reviewed and can be published as a short report or letter to the editor, so that it can be indexed in bibliographic databases such as Medline. The rationale for this feature is that health informatics is an area in which a significant proportion of research regarding, for example, introduction of information technology in hospitals or provision of eHealth gadgets to consumers remains unpublished [11]. In many cases authors never write up research because of lack of time or motivation, and this "one-click-submit-for-publication" feature may encourage authors to publish their findings at least as a short report.

Scope of the IESR

It is important to understand that the scope of the registry is wider than registration of eHealth studies intended for publication in JMIR. We hope that the registry becomes a database of planned and ongoing research where all studies related to information and communication technologies (ICT) in health are submitted, regardless of where authors plan to submit the results for publication. We define an eHealth study as any type of empirical research, evaluation and development activity studying the effect of ICT interventions in a health or health services context. ICT includes Internet and Intranet applications, studies of Web-based interventions, telehealth, telemedicine, clinical informatics applications (Hospital Information Systems, decision support) and consumer health informatics. Apart from RCTs we expect also other types of longitudinal studies or even cross-sectional and qualitative studies to be submitted and registered.

We recommend registering only concrete projects (ie, those which have already secured funding or are about to be started) as opposed to mere ideas. As described in a separate editorial [16], we are also offering peer review and publication of complete protocols in JMIR, but registration of the study in the IESR and publication of the protocol are separate processes and take place independently of each other.

Registration Process

The registry (which is non-profit and hosted at the Centre for Global eHealth Innovation in Toronto, Canada) is a database which allows investigators (or their proxies, such as research associates or funding agencies) to publish their research protocol in an abbreviated format. The content will be reviewed by a registry editor, and the principal investigator [PI]) will be contacted to confirm the details of the study. Entries will not be copyedited or peer reviewed. The primary purpose is to disclose the important information from the protocol such as study question and endpoints to be measured prior to starting the trial. However, investigators can also add other information such as the profile of a desired collaborator.

The system will assign an unique International eHealth Study Number (IESR). The registry meets the criteria of journals such as JMIR or the British Medical Journal (BMJ). As clinicaltrials.gov does not accept non-US funded trials, it is anticipated that the signatories of the ICMJE editorial will also accept studies with protocols published in the IESR to meet their requirement of advance registration before a study can be published.

Investigators will be able (and will be encouraged) to continuously update their entries, with older versions being kept on file and retrievable for archival purposes.

The IESR database is designed to be complementary to other registries such as clinicaltrials.gov, not competitive. IESN will primarily contain studies that are not eligible for registration on clinicaltrials.gov. There will also be cross-links if a trial is also entered in other trial registers.

The Goal: "Openness" and Excellence in eHealth Research

A natural synergy exists between an Open Access eHealth journal and a trial registry; both journal and registry share the common vision of enhancing access to research information and promoting "openness" of research processes and results. In combination with JMIR's new feature of offering peer review of research protocols [16], we hope that these will be important steps in our quest to improve the quality of eHealth research and to generate and disseminate high-quality evidence in the field.

Appendix 1

Clinical Trial Registration: A Statement from the International Committee of Medical Journal Editors

[PDF file, 40 KB - jmir_v6i3e35_app1.pdf]

References

1. De Angelis C, Drazen JM, Frizelle FA, Haug C, Hoey J, Horton R, et al; International Committee of Medical Journal Editors. Clinical trial registration: a statement from the International Committee of Medical Journal Editors. CMAJ 2004 Sep 14;171(6):606-607 [FREE Full text] [Medline: 15367465] [doi: 10.1503/cmaj.1041281]
2. Dickersin K, Rennie D. Registering clinical trials. JAMA 2003 Jul 23;290(4):516-523. [doi: 10.1001/jama.290.4.516] [Medline: 22758720]
3. Chalmers I. Underreporting research is scientific misconduct. JAMA 1990 Mar 9;263(10):1405-1408. [Medline: 90156660] [doi: 10.1001/jama.263.10.1405]
4. Simes RJ. Publication bias: the case for an international registry of clinical trials. J Clin Oncol 1986 Oct;4(10):1529-1541. [Medline: 87010763]
5. Eysenbach G, Tuische J, Diepgen TL. Evaluation of the usefulness of Internet searches to identify unpublished clinical trials for systematic reviews. Med Inform Internet Med 2001;26(3):203-218. [Medline: 21563293] [doi: 10.1080/14639230110075459]
6. Silverstein FE, Faich G, Goldstein JL, Simon LS, Pincus T, Whelton A, et al. Gastrointestinal toxicity with celecoxib vs nonsteroidal anti-inflammatory drugs for osteoarthritis and rheumatoid arthritis: the CLASS study: A randomized controlled trial. Celecoxib Long-term Arthritis Safety Study. JAMA 2000 Sep 13;284(10):1247-1255. [Medline: 20440155] [doi: 10.1001/jama.284.10.1247]
7. Wright JM, Perry TL, Bassett KL, Chambers GK. Reporting of 6-month vs 12-month data in a clinical trial of celecoxib. JAMA 2001 Nov 21;286(19):2398-2400. [Medline: 21570345] [doi: 10.1001/jama.286.19.2398]
8. Hrachovec JB, Mora M. Reporting of 6-month vs 12-month data in a clinical trial of celecoxib. JAMA 2001 Nov 21;286(19):2398-2400. [Medline: 21570344] [doi: 10.1001/jama.286.19.2398]
9. Gottlieb S. Researchers deny any attempt to mislead the public over JAMA article on arthritis drug. BMJ 2001 Aug 11;323(7308):301 [FREE Full text] [Medline: 21389059] [doi: 10.1136/bmj.323.7308.301]
10. Chan AW, Hróbjartsson A, Haahr MT, Gøtzsche PC, Altman DG; Empirical evidence for selective reporting of outcomes in randomized trials: comparison of protocols to published articles. JAMA 2004 May 26;291(20):2457-2465. [Medline: 15161896] [doi: 10.1001/jama.291.20.2457]
11. Mccray AT, Ide NC. Design and implementation of a national clinical trials registry. J Am Med Inform Assoc 2000;7(3):313-323. [PMC: 10833169] [Medline: 20290766]
12. Mccray AT. Better access to information about clinical trials. Ann Intern Med 2000 Oct 17;133(8):609-614 [FREE Full text] [Medline: 20491847]
13. Abbasi K. Compulsory registration of clinical trials. BMJ 2004 Sep 18;329(7467):637-638 [FREE Full text] [Medline: 15374895] [doi: 10.1136/bmj.329.7467.637]
14. Kaplan B. Evaluating informatics applications--some alternative approaches: theory, social interactionism, and call for methodological pluralism. Int J Med Inform 2001 Nov;64(1):39-56. [Medline: 21528784] [doi: 10.1016/S1386-5056(01)00184-8]
15. Friedman CP, Wyatt JC. Publication bias in medical informatics. J Am Med Inform Assoc 2001;8(2):189-191. [PMC: 11230387] [Medline: 21143649]
16. Eysenbach G. Peer-review and publication of research protocols and proposals: a role for open access journals. J Med Internet Res 2004 Sep 30;6(3):e37 [FREE Full text] [Medline: 15471763] [doi: 10.2196/jmir.6.3.e37]

---

submitted 29.09.04; peer-reviewed by AW Chan; comments to author 29.09.04; revised version received 29.09.04; accepted 30.09.04; published 30.09.04.

Please cite as:
Eysenbach G
Tackling Publication Bias and Selective Reporting in Health Informatics Research: Register your eHealth Trials in the International eHealth Studies Registry
J Med Internet Res 2004;6(3):e35
URL: http://www.jmir.org/2004/3/e35/
doi:10.2196/jmir.6.3.e35
PMID:15471761

Editorial

Peer Review and Publication of Research Protocols and Proposals: A Role for Open Access Journals

Gunther Eysenbach[1], MD, MPH

Centre for Global eHealth Innovation, Toronto, Canada

Corresponding Author:
Gunther Eysenbach, MD, MPHEditor-in-Chief
Associate Professor, Department of Health Policy, Management and Evaluation
Senior Scientist, Centre for Global eHealth Innovation
University of Toronto
University Health Network
190 Elizabeth Street
Toronto ON M5G 2C4
Canada
Phone: +1 416 340 4800 ext 6427
Fax: +1 416 340 3595
Email: geysenba@uhnres.utoronto.ca

Abstract

Peer-review and publication of research protocols offer several advantages to all parties involved. Among these are the following opportunities for authors: external expert opinion on the methods, demonstration to funding agencies of prior expert review of the protocol, proof of priority of ideas and methods, and solicitation of potential collaborators. We think that review and publication of protocols is an important role for Open Access journals. Because of their electronic form, openness for readers, and author-pays business model, they are better suited than traditional journals to ensure the sustainability and quality of protocol reviews and publications. In this editorial, we describe the workflow for investigators in eHealth research, from protocol submission to a funding agency, to protocol review and (optionally) publication at JMIR, to registration of trials at the International eHealth Study Registry (IESR), and to publication of the report. One innovation at JMIR is that protocol peer reviewers will be paid a honorarium, which will be drawn partly from a new submission fee for protocol reviews. Separating the article processing fee into a submission and a publishing fee will allow authors to opt for “peer-review only” (without subsequent publication) at reduced costs, if they wish to await a funding decision or for other reasons decide not to make the protocol public.

(J Med Internet Res 2004;6(3):e37) doi:10.2196/jmir.6.3.e37

KEYWORDS

Access to information; information dissemination; Internet; publishing; research design

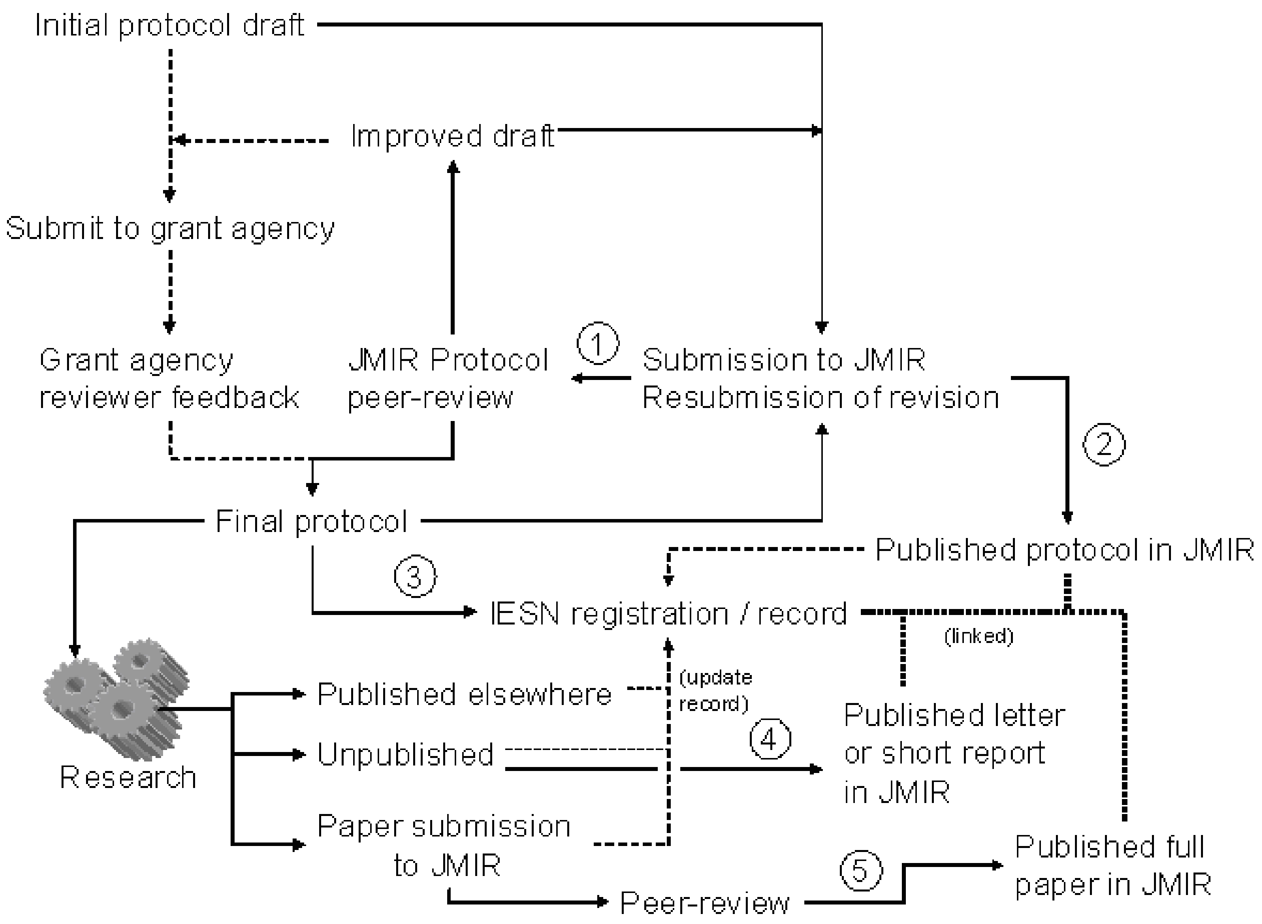
It has long been advocated that journals take on a more active role in the “primary prevention” of poor research not only by peer reviewing final reports but by becoming involved earlier in the process through reviewing research protocols [1-3]. Even though some protocols are reviewed at a funding agency, it is also a fact that many projects (in particular smaller projects in eHealth) are never subjected to this scrutiny. Even if projects receive funding agency assessment, researchers and society may still benefit from a prior peer review and possible subsequent Medline-indexed publication. The arguments for doing so include the following [1]:

- highlighting good-quality studies at an early stage
- contribution to a register of selected trials, to reduce publication bias against negative (neutral) or inconvenient findings
- promotion of recruitment of cooperating centres and trial participants
- helping researchers in funding applications
- prevention of poor research
- prevention of data dredging by documentation of intended analyses
- establishment of priority of an important idea

In addition, the current development of journal editors asking for trial registration prior to enrollment of participants [4] places a renewed emphasis on the quality of the research protocol. Research protocols will undergo more scrutiny in the future [5] as peer reviewers of trial reports, having access to some key points from the protocol through the trial registry entry, will be able to read the submitted paper in the context of what had been proposed originally.

JMIR now also encourages submissions of protocols for peer review and (optionally) subsequent publication. This, in conjunction with its newly established study register, will increase the possibility of other researchers (such as systematic reviewers) finding negative and ongoing studies. It is also part of a larger vision of making JMIR a one-stop-shopping site by offering services for eHealth researchers at all stages of the knowledge production and dissemination cycle.

Figure 1. Possible “workflow” from the conception of an eHealth study to its publication



The possible “workflow” from study conception to publication is shown in the figure. Authors have the opportunity of submitting a research protocol for peer review to JMIR (point 1 in figure) either before or after submitting it to the funding agency. Peer review at JMIR will encompass suggestions for improvement and an expert opinion on the value of the research plan. Authors may either incorporate the suggested changes and resubmit the revised version, or publish the unchanged protocol alongside the peer-review report (2), or opt to refrain from publication. In addition, authors are, under the new policy of most medical journals, now required to register their studies. This can be done at the new International eHealth Study Register (IESR) located at JMIR [4]. The registry will assign a unique IESN (International eHealth Study Number) to the study and create a database entry summarizing some of the study information, including links to the published protocol or subsequent publications. After study completion, authors may submit a full paper to JMIR (5) or other journals, or – if time-constraints prevent authors from writing a full paper – at least publish the database entry with a short comment on the results as a letter or short report in JMIR [4].

Peer reviewers of protocols will be asked to use different standards from those used for peer-reviewed articles. There will be no “accept” or “decline” decision except in cases where the protocol is off-topic (see journal scope) or is clearly ethically or scientifically flawed. Reviewers are asked to comment on the existence of potential flaws which might threaten the validity of the research, to make suggestions for overcoming these flaws if they exist, or to suggest minor improvements to the research plan or the writing.

The peer review and optional publication of protocols will be separate processes, in that the author may have the protocol peer reviewed only and not proceed to publication. The option of “peer review only” might be used by some investigators to obtain peer-review input before submission to a funding body while reserving disclosure of the research plan until after funding. Others might prefer to publish in order to be able to cite a fully peer-reviewed research protocol in a funding proposal, while some might wish to use the publication option after success of the funding applications in order to claim priority of the research ideas outlined in the protocol.

Peer review and publication of protocols will have a different cost structure from regular article submissions to JMIR. For normal research papers, authors' institutions or authors pay an article processing fee (currently set at $750, payable at step 5 in the figure) only if the article is accepted for publication. The fee covers costs incurred both at peer-review and at publication. For protocol submissions only, JMIR is introducing a separated fee. A $250 levy, payable upon submission, will cover the costs of honoraria to peer reviewers, and a separate $500 fee will cover the copyediting and typesetting costs of the optional publication. JMIR needs to recover the costs of peer reviews of protocols which are not published, while researchers might view the submission fee as payment for value received in the peer review.

To our knowledge, JMIR is the first Open Access journal taking this critical step of levying a submission fee. To encourage the sustainability and quality of Open Access journals, the Science and Technology Committee of the House of Commons of the United Kingdom has in fact recommended this step. In its Report the Committee stresses, “The introduction of a submission fee would be an important step towards ensuring the quality of scientific publications and we strongly recommend that author-pays publishers introduce this system [paragraph 174 and recommendation 67] [6].”

As peer reviewers may find review of protocols less appealing than review of finished research, we will offer an honorarium as a small incentive. This will help maintain the quality of reviews and promote a quick turnaround time. Authors will have the opportunity to nominate specific reviewers whom we will approach first, but we reserve the right to replace them if they decline or seem unsuitable.

This model is an experiment, but we think it is viable. Protocol review and publication may become an important role for Open Access journals. Clear advantages flow to all parties in the process. Authors obtain external expert opinions on their methods and are able to show funding agencies reviewed protocols. They are also able to document priority of ideas and methods and to solicit potential collaborators. Open Access journals because of their electronic form, openness for readers and author-pays business model are better suited than traditional journals to provide the sustainability and quality of protocol review and publication.

References

1. Chalmers I, Altman DG. How can medical journals help prevent poor medical research? Some opportunities presented by electronic publishing. Lancet 1999 Feb 6;353(9151):490-493. [Medline: 99142843] [doi: 10.1016/S0140-6736(98)07618-1]
2. Weiss DJ. An experiment in publication: advance publication review. Appl Psychol Meas 1989;13:1-7.
3. Mcnamee D. Protocol reviews at The Lancet. Lancet 1997;350(9070):6. [doi: 10.1016/S0140-6736(05)66237-X]
4. Eysenbach G. Tackling publication bias and selective reporting in health informatics research: register your eHealth trials in the International eHealth Studies Registry. J Med Internet Res 2004 Sep 30;6(3):e35 [FREE Full text] [Medline: 15471761] [doi: 10.2196/jmir.6.3.e35]
5. Chan AW, Hróbjartsson A, Haahr MT, Gøtzsche PC, Altman DG. Empirical evidence for selective reporting of outcomes in randomized trials: comparison of protocols to published articles. JAMA 2004 May 26;291(20):2457-2465. [Medline: 15161896] [doi: 10.1001/jama.291.20.2457]
6. ; House of Commons SaTC. Scientific Publications: Free for all? (Report #HC 399-I) . London: The Stationery Office Limited; 2004. URL: http://www.publications.parliament.uk/pa/cm200304/cmselect/cmsctech/399/399.pdf

Submitted 30.09.04; ###Reviewer names will be inserted here### published 30.09.04.

Please cite as:
Eysenbach G
Peer Review and Publication of Research Protocols and Proposals: A Role for Open Access Journals
J Med Internet Res 2004;6(3):e37
URL: http://www.jmir.org/2004/3/e37/
doi:10.2196/jmir.6.3.e37
PMID:15471763

Editorial

Will Web Surveys Ever Become Part of Mainstream Research?

Matthias Schonlau[1], PhD

[1] RAND Corporation, Santa Monica CA, USA

Corresponding Author:
Matthias Schonlau, PhD
RAND Corporation
1776 Main Street, P.O. Box 2138
Santa Monica CA 90407-2138
USA
Phone: +1 310 393 0411
Email: matt@rand.org

(J Med Internet Res 2004;6(3):e31) doi:10.2196/jmir.6.3.e31

This issue contains two interesting papers on Web survey methodology, which reach different conclusions about the potential of Web surveys. Particular attention is directed to relative response rates. A high response rate is commonly taken as an indicator of survey validity.

Leece et al used systematic sampling to assign one half of a list of orthopedic surgeons to a Web survey and the other half to a mail survey [1]. They observed that the Web survey produced a significantly lower response rate than the mail survey, and cautioned, “Researchers should not assume that the widespread availability and potential ease of Internet-based surveys will translate into higher response rates.” In contrast, Ritter et al, who recruited participants from the Internet and randomly assigned them either to a mail survey or to a Web survey, observed different results [2]. They found that participation was at least as good as if not better among the Web survey group than among those receiving questionnaires by mail. In addition the investigators found that the responses to 16 health-related questions did not differ significantly between the two study groups.

The different findings can be explained by the respective recruiting strategies. Ritter et al recruited participants over the Internet. Clearly, respondents recruited on the Web are more likely to respond to a Web survey than the general population. The finding is nonetheless interesting because it is not obvious that the response rate to a Web survey would be higher than to a mail survey even among Internet-savvy respondents. A Web survey typically achieves a higher response rate when respondents are contacted by e-mail rather than by mail [3]. Analogously, a mail survey typically achieves a higher response rate when respondents are contacted by mail rather than by e-mail. It is possible that recruiting respondents on the Web also reduces the response rate of a mail survey because the recruiting mode is different from the response mode.

Both Ritter et al and Leece et al survey special rather than general populations [1,2]. Ritter et al recruit respondents from the Internet [2]. Leece et al have a master list of orthopedic surgeons [1]. They also have e-mail addresses for 79% (all but 45 respondents) of the respondents in the Web survey arm. A much greater challenge would be to conduct a Web survey of a general population for which no master list of e-mail addresses is readily available. One approach, contacting respondents by mail and encouraging response by Web with a mail fallback option, is discussed in Schonlau et al [4]. This approach is not very practical because the second response mode requires additional resources and slows the survey down.

Ritter et al's survey and most Web surveys are conducted with convenience samples rather than with random samples [2]. In a convenience sample participants are selected, in part or in whole, at the convenience of the researcher. In a random sample the researcher ensures that each member of that population has a known probability (for example, equal probability) of being selected. For example, a sample of respondents recruited from newsgroup postings is a convenience sample for most populations of interest. Eysenbach and Wyatt note, “In 'open' web-based surveys, selection bias occurs … through self-selection of participants, …” [5]. Such selection bias implies a convenience sample because the probability of selection is unknown.

Whether Web surveys will develop into mainstream survey research tools depends on the possibility of drawing inferences from convenience samples. Conventional survey sampling wisdom holds that inferences cannot be drawn from convenience samples, thereby negating their use—with the possible exception of pilot studies. Still, convenience samples can be used to conduct experiments within that sample. Ritter et al have shown this with a nice properly-randomized experiment within a convenience sample; whether the larger sample is representative is secondary [2]. Ritter et al's finding would not hold for people without access to the Internet [2]. Other experiments can be conducted with a single convenience sample, including testing of response order effects (in visual response modes the first answer choice tends to be chosen more often) and of anchoring effects (the answer choice may be affected by the context, including what was asked in previous questions). Vignettes and factorial experiments could be inserted in Web surveys based on convenience samples. These are exciting research possibilities.

The possibility of drawing inferences from convenience samples is a contentious issue among survey researchers. The excitement needs to be tempered with rational skepticism.

Health service and biostatistical researchers have traditionally drawn conclusions from observational studies. The purpose of the ubiquitous “Table 1” of epidemiological cohort studies which displays demographical and other information on both experimental and control groups is to argue that experimental and control groups are not different with respect to important confounding variables, such as age and education. Therefore observed risk or outcome differences between the groups are indeed due to the exposure to the intervention (or treatment) and not to observed confounding factors. In a randomized study, the experimental design should “automatically” balance the covariates. For example, it is unlikely that participants in the exposed (intervention or treatment) group are significantly older than in the non-exposed (control) group. In a non-randomized study, such systematic differences are likely to occur due to selection bias. If in a non-randomized study one can show that the covariates are balanced, then there is little reason to distrust regression results or other inferences based on observational data.

Rubin's framework for causal inference goes further ensuring that the covariates in Table 1 are balanced [6]. Propensity scores are constructed from logistic regression on baseline variables that are thought to capture the difference between Web respondents and the general population. The propensity scores can be used to construct subclasses in which covariates are approximately balanced. One very important assumption is that no important unobserved variables affect treatment assignment. Rubin's approach is widely accepted.

Harris Interactive, a commercial Web survey company, has adapted Rubin's approach for drawing inferences from Web surveys [7]. Assignment to treatment or control corresponds to “assignment” of a respondent to a random or a convenience sample. Capturing the selection mechanism that distinguishes a random sample from the convenience sample allows for adjustment for it. While the selection approach of Harris Interactive is theoretically sound, the challenge is to ask the right questions to capture the difference between the online and offline populations. I am involved in a study which explores the feasibility of moving a portion of the Health and Retirement Survey (HRS), a large-scale US panel survey, onto the Internet in future survey waves. I have recently applied the propensity scoring approach to the HRS with early encouraging results [8].

Will inferences drawn from convenience samples achieve the rigor required by mainstream research? I am hopeful of this possibility. In the past researchers have rejected the possibility of drawing inferences from mail surveys because they were self-administered. Currently mail surveys are certainly considered “mainstream”. The possibility of inference based on convenience samples is one of several exciting research opportunities in Web survey research. Leece et al and Ritter et al have stimulated us to further consideration of the expanding research frontier [1,2].

References

1. Leece P, Bhandari M, Sprague S, Swiontkowski MF, Schemitsch EH, Tornetta P, et al. Internet versus mailed questionnaires: a randomized comparison (2). J Med Internet Res 2004 Sep 24;6(3):e30 [FREE Full text] [Medline: 15471756] [doi: 10.2196/jmir.6.3.e30]
2. Ritter P, Lorig K, Laurent D, Matthews K. Internet versus mailed questionnaires: a randomized comparison. J Med Internet Res 2004 Sep 15;6(3):e29 [FREE Full text] [Medline: 15471755] [doi: 10.2196/jmir.6.3.e29]
3. Schonlau M, Fricker R, Elliott M. Conducting Research Surveys via Email and the Web. Santa Monica, CA: RAND; 2002.
4. Schonlau M, Asch BJ, Du C. Web surveys as part of a mixed mode strategy for populations that cannot be contacted by e-mail. Soc Sci Comp Rev 2003; 21(2):218-222. [doi: 10.1177/0894439303021002007]
5. Eysenbach G, Wyatt J. Using the Internet for surveys and health research. J Med Internet Res 2002 Nov 22;4(2):e13 [FREE Full text] [Medline: 22442445] [doi: 10.2196/jmir.4.2.e13]
6. Rosenbaum PR, Rubin DB. The central role of the propensity score in observational studies for causal effects. Biometrika 1983;70:41-55.
7. Schonlau M, Zapert K, Payne SL, Sanstad K, Marcus S, Adams J, et al. A comparison between a propensity weighted web survey and an identical RDD survey. Soc Sci Comp Rev 2004;22(1):128-138. [doi: 10.1177/0894439303256551]
8. Schonlau M, Van Soest A, Couper M, Winter J, Kapteyn A. Attempting to adjust for selection bias in Web surveys with propensity scores: the case of the Health and Retirement Survey (HRS). In: Proceedings of the Section on Survey Statistics, American Statistical Association 2004. URL: http://www.schonlau.net/

submitted 31.08.04; peer-reviewed by G Eysenbach; comments to author 01.09.04; revised version received 13.09.04; accepted 14.09.04; published 23.09.04.

Please cite as:
Schonlau M
Will Web Surveys Ever Become Part of Mainstream Research?
J Med Internet Res 2004;6(3):e31
URL: http://www.jmir.org/2004/3/e31/
doi:10.2196/jmir.6.3.e31
PMID:15471757

Editorial

Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES)

Gunther Eysenbach, MD, MPH

Corresponding Author:
Gunther Eysenbach, MD, MPH
Editor-in-Chief, JMIR
Associate Professor, Department of Health Policy, Management and Evaluation
Senior Scientist, Centre for Global eHealth Innovation
University of Toronto
University Health Network
190 Elizabeth Street
Toronto ON M5G 2C4
Canada
Phone: +1 416 340 4800 ext 6427
Fax: +1 416 340 3595
Email: geysenba@uhnres.utoronto.ca

Related Article:

This is a corrected version. See correction statement: http://www.jmir.org/2012/1/e8

Abstract

Analogous to checklists of recommendations such as the CONSORT statement (for randomized trials), or the QUORUM statement (for systematic reviews), which are designed to ensure the quality of reports in the medical literature, a checklist of recommendations for authors is being presented by the Journal of Medical Internet Research (JMIR) in an effort to ensure complete descriptions of Web-based surveys. Papers on Web-based surveys reported according to the CHERRIES statement will give readers a better understanding of the sample (self-)selection and its possible differences from a “representative” sample. It is hoped that author adherence to the checklist will increase the usefulness of such reports.

(J Med Internet Res 2004;6(3):e34) doi:10.2196/jmir.6.3.e34

Introduction

The Internet is increasingly used for online surveys and Web-based research. In this issue of the *Journal of Medical Internet Research* we publish two methodological studies exploring the characteristics of Web-based surveys compared to mail-based surveys [1,2]. In previous issues we have published Web-based research such as a survey among physicians conducted on a Web site [3].

As explained in an accompanying editorial [4] as well as in a previous review [5], such surveys can be subject to considerable bias. In particular, bias can result from 1) the non-representative nature of the Internet population and 2) the self-selection of participants (volunteer effect). Often online surveys have a very low response rate (if the number of visitors is used as denominator). Thus, considerable debate ensues about the validity of online surveys. The editor and peer reviewers of this journal are frequently faced with the question of whether to accept for publication studies reporting results from Web surveys (or email surveys). There is no easy answer to this question. Often it “just depends”. It depends on the reasons for the survey in the first place, its execution, and the authors' conclusions. Conclusions drawn from a convenience sample are limited and need to be qualified in the discussion section of a paper. On the other hand, we will not, as many other journals do, routinely reject reports of Web surveys, even surveys with very small response rates, which are typical of electronic surveys, but decide on a case-by-case basis whether the conclusions drawn from a Web survey are valid and useful for readers. Web surveys may be of some use in generating hypotheses which need to be confirmed in a more controlled environment; or they may be used to pilot test a questionnaire or to conduct a Web-based experiment. Statistical methods such as propensity scores may be used to adjust results [4]. Again, it all depends on why and how the survey was done.

Every biased sample is an unbiased sample of another target population, and it is sometimes just a question of defining for which subset of a population the conclusions drawn are assumed to be valid. For example, the polling results on the CNN Web site are certainly highly biased and not representative for the US population. But it is legitimate to assume that they are “representative” for visitors to the CNN Web site who choose to participate in the online survey.

This illustrates the critical importance of carefully describing how and in what context the survey was done, and how the sample, which chose to reply, is constituted and might differ from a representative population-based sample. For example, it is very important to describe the content and nature of the Web site where the survey was posted in order to get an idea of the people who filled in the questionnaire (ie, to characterize the population of respondents). A survey on an anti-vaccination Web site run by concerned parents will have a different visitor structure than, for example, a vaccination clinic site. It is also important to describe in sufficient detail exactly how the questionnaire was administered. For example, was it mandatory that every visitor who wanted to enter the Web site fill it in, or were any other incentives offered? A mandatory survey is likely to reduce a volunteer bias.

Analogous to checklists of recommendations such as the CONSORT statement (for randomized trials), or the QUORUM statement (for systematic reviews), which are designed to ensure the quality of reports in the medical literature, a checklist of recommendations for authors is being presented by JMIR in an effort to ensure complete descriptions of e-survey methodology. Papers reported according to the CHERRIES statement will give peer reviewers and readers a better understanding of the sample selection and its possible differences from a “representative” sample.

The CHERRIES Checklist

We define an e-survey as an electronic questionnaire administered on the Internet or an Intranet. Although many of the CHERRIES items are also valid for surveys administered via e-mail, the checklist focuses on Web-based surveys.

While most items on the checklist are self-explanatory, a few comments about the “response rate” are in order. In traditional surveys investigators usually report a response rate (number of people presented with a questionnaire divided by the number of people who completed the questionnaire) to allow some estimation of the degree of representativeness and bias. Surveys with response rates lower than 70% or so (an arbitrary cut-off point!) are usually viewed with skepticism.

In online surveys, there is no single response rate. Rather, there are multiple potential methods for calculating a response rate, depending on what are chosen as the numerator and denominator. As there is no standard methodology, we suggest avoiding the term “response rate” and have defined how, at least in this journal, response metrics such as, what we call, the view rate, participation rate and completion rate should be calculated.

A common concern for online surveys is that a single user fills in the same questionnaire multiple times. Some users like to go back to the survey and experiment with the results of their modified entries. Multiple methods are available to prevent this or at least to minimize the chance of this happening (eg, cookies or log-file/IP address analysis).

Investigators should also state whether the completion or internal consistency of certain (or all) items was enforced using Javascript (ie, displaying an alert before the questionnaire can be submitted) or server-side techniques (ie, after submission displaying the questionnaire and highlighting mandatory but unanswered items or items answered inconsistently).

The hope is that the CHERRIES checklist provides a useful starting point for investigators reporting results of Web surveys. The editor and peer reviewers of this journal ask authors to ensure that they report the methodology fully and according to the CHERRIES checklist before submitting manuscripts.

Table 1. Checklist for Reporting Results of Internet E-Surveys (CHERRIES)

	Checklist for Reporting Results of Internet E-Surveys (CHERRIES)	
Item Category	***Checklist Item***	***Explanation***
Design		
	Describe survey design	Describe target population, sample frame. Is the sample a convenience sample? (In “open” surveys this is most likely.)
IRB (Institutional Review Board) approval and informed consent process		
	IRB approval	Mention whether the study has been approved by an IRB.
	Informed consent	Describe the informed consent process. Where were the participants told the length of time of the survey, which data were stored and where and for how long, who the investigator was, and the purpose of the study?
	Data protection	If any personal information was collected or stored, describe what mechanisms were used to protect unauthorized access.
Development and pre-testing		
	Development and testing	State how the survey was developed, including whether the usability and technical functionality of the electronic questionnaire had been tested before fielding the questionnaire.
Recruitment process and description of the sample having access to the questionnaire		
	Open survey versus closed survey	An “open survey” is a survey open for each visitor of a site, while a closed survey is only open to a sample which the investigator knows (password-protected survey).
	Contact mode	Indicate whether or not the initial contact with the potential participants was made on the Internet. (Investigators may also send out questionnaires by mail and allow for Web-based data entry.)
	Advertising the survey	How/where was the survey announced or advertised? Some examples are offline media (newspapers), or online (mailing lists – If yes, which ones?) or banner ads (Where were these banner ads posted and what did they look like?). It is important to know the wording of the announcement as it will heavily influence who chooses to participate. Ideally the survey announcement should be published as an appendix.
Survey administration		
	Web/E-mail	State the type of e-survey (eg, one posted on a Web site, or one sent out through e-mail). If it is an e-mail survey, were the responses entered manually into a database, or was there an automatic method for capturing responses?
	Context	Describe the Web site (for mailing list/newsgroup) in which the survey was posted. What is the Web site about, who is visiting it, what are visitors normally looking for? Discuss to what degree the content of the Web site could pre-select the sample or influence the results. For example, a survey about vaccination on a anti-immunization Web site will have different results from a Web survey conducted on a government Web site
	Mandatory/voluntary	Was it a mandatory survey to be filled in by every visitor who wanted to enter the Web site, or was it a voluntary survey?
	Incentives	Were any incentives offered (eg, monetary, prizes, or non-monetary incentives such as an offer to provide the survey results)?
	Time/Date	In what timeframe were the data collected?
	Randomization of items or questionnaires	To prevent biases items can be randomized or alternated.
	Adaptive questioning	Use adaptive questioning (certain items, or only conditionally displayed based on responses to other items) to reduce number and complexity of the questions.
	Number of Items	What was the number of questionnaire items per page? The number of items is an important factor for the completion rate.

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

Item Category	*Checklist Item*	*Explanation*
	Number of screens (pages)	Over how many pages was the questionnaire distributed? The number of items is an important factor for the completion rate.
	Completeness check	It is technically possible to do consistency or completeness checks before the questionnaire is submitted. Was this done, and if “yes”, how (usually JAVAScript)? An alternative is to check for completeness after the questionnaire has been submitted (and highlight mandatory items). If this has been done, it should be reported. All items should provide a non-response option such as “not applicable” or “rather not say”, and selection of one response option should be enforced.
	Review step	State whether respondents were able to review and change their answers (eg, through a Back button or a Review step which displays a summary of the responses and asks the respondents if they are correct).
Response rates		
	Unique site visitor	If you provide view rates or participation rates, you need to define how you determined a unique visitor. There are different techniques available, based on IP addresses or cookies or both.
	View rate (Ratio of unique survey visitors/unique site visitors)	Requires counting unique visitors to the first page of the survey, divided by the number of unique site visitors (not page views!). It is not unusual to have view rates of less than 0.1 % if the survey is voluntary.
	Participation rate (Ratio of unique visitors who agreed to participate/unique first survey page visitors)	Count the unique number of people who filled in the first survey page (or agreed to participate, for example by checking a checkbox), divided by visitors who visit the first page of the survey (or the informed consents page, if present). This can also be called “recruitment” rate.
	Completion rate (Ratio of users who finished the survey/users who agreed to participate)	The number of people submitting the last questionnaire page, divided by the number of people who agreed to participate (or submitted the first survey page). This is only relevant if there is a separate “informed consent” page or if the survey goes over several pages. This is a measure for attrition. Note that “completion” can involve leaving questionnaire items blank. This is not a measure for how completely questionnaires were filled in. (If you need a measure for this, use the word “completeness rate”.)
Preventing multiple entries from the same individual		
	Cookies used	Indicate whether cookies were used to assign a unique user identifier to each client computer. If so, mention the page on which the cookie was set and read, and how long the cookie was valid. Were duplicate entries avoided by preventing users access to the survey twice; or were duplicate database entries having the same user ID eliminated before analysis? In the latter case, which entries were kept for analysis (eg, the first entry or the most recent)?
	IP check	Indicate whether the IP address of the client computer was used to identify potential duplicate entries from the same user. If so, mention the period of time for which no two entries from the same IP address were allowed (eg, 24 hours). Were duplicate entries avoided by preventing users with the same IP address access to the survey twice; or were duplicate database entries having the same IP address within a given period of time eliminated before analysis? If the latter, which entries were kept for analysis (eg, the first entry or the most recent)?
	Log file analysis	Indicate whether other techniques to analyze the log file for identification of multiple entries were used. If so, please describe.
	Registration	In “closed” (non-open) surveys, users need to login first and it is easier to prevent duplicate entries from the same user. Describe how this was done. For example, was the survey never displayed a second time once the user had filled it in, or was the username stored together with the survey results and later eliminated? If the latter, which entries were kept for analysis (eg, the first entry or the most recent)?
Analysis		

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

Item Category	*Checklist Item*	*Explanation*
	Handling of incomplete questionnaires	Were only completed questionnaires analyzed? Were questionnaires which terminated early (where, for example, users did not go through all questionnaire pages) also analyzed?
	Questionnaires submitted with an atypical timestamp	Some investigators may measure the time people needed to fill in a questionnaire and exclude questionnaires that were submitted too soon. Specify the timeframe that was used as a cut-off point, and describe how this point was determined.
	Statistical correction	Indicate whether any methods such as weighting of items or propensity scores have been used to adjust for the non-representative sample; if so, please describe the methods.

References

1. Ritter P, Lorig K, Laurent D, Matthews K. Internet versus mailed questionnaires: a randomized comparison. J Med Internet Res 2004 Sep 15;6(3):e29 [FREE Full text] [Medline: 15471755] [doi: 10.2196/jmir.6.3.e29]
2. Leece P, Bhandari M, Sprague S, Swiontkowski MF, Schemitsch EH, Tornetta P, et al. Internet versus mailed questionnaires: a randomized comparison (2). J Med Internet Res 2004 Sep 24;6(3):e30 [FREE Full text] [Medline: 15471756] [doi: 10.2196/jmir.6.3.e30]
3. Potts HWW, Wyatt JC. Survey of doctors' experience of patients using the Internet. J Med Internet Res 2002 Mar 31;4(1):e5 [FREE Full text] [Medline: 21953333] [doi: 10.2196/jmir.4.1.e5]
4. Schonlau M. Will web surveys ever become part of mainstream research? J Med Internet Res 2004 Sep 23;6(3):e31 [FREE Full text] [Medline: 15471757] [doi: 10.2196/jmir.6.3.e31]
5. Eysenbach G, Wyatt J. Using the Internet for surveys and health research. J Med Internet Res 2002 Nov 22;4(2):e13 [FREE Full text] [Medline: 22442445] [doi: 10.2196/jmir.4.2.e13]

submitted 28.09.04; peer-reviewed by M Schonlau; comments to author 28.09.04; revised version received 29.09.04; accepted 29.09.04; published 29.09.04.

Please cite as:
Eysenbach G
Improving the Quality of Web Surveys: The Checklist for Reporting Results of Internet E-Surveys (CHERRIES)
J Med Internet Res 2004;6(3):e34
URL: http://www.jmir.org/2004/3/e34/
doi:10.2196/jmir.6.3.e34
PMID:15471760

Editorial

Disease Management and the Internet

George Demiris[1], PhD

Department of Health Management and Informatics, University of Missouri-Columbia, Columbia MO, USA

Corresponding Author:
George Demiris, PhDAssistant Professor
Director of the Health Informatics Graduate Program
Department of Health Management and Informatics
University of Missouri-Columbia
Columbia MO 65211
USA
Phone: +1 573 882 5772
Fax: +1 573 882 6158
Email: DemirisG@health.missouri.edu

(J Med Internet Res 2004;6(3):e33) doi:10.2196/jmir.6.3.e33

This issue contains three articles on the use of the Internet in disease management, the anticipated benefits and challenges associated with this concept, and emerging trends. The studies presented in this issue aim to determine whether/how the use of Web-based applications can assist in managing chronic conditions over time, improve clinical outcomes and lower costs both through patient education and physiological monitoring.

The health care sector is facing challenges such as rapidly-escalating medical costs, growing life expectancy rates and expanding segments of the population suffering from chronic conditions such as diabetes, obstructive pulmonary disease, and congestive heart failure. Several disease management initiatives aim to reduce the rate of inpatient hospitalization, the use of emergency room services, and the number of physician office visits—innovations that would allow people to stay at home enjoying increased quality of life and independence. A possible reduction of utilization rates would also lower both clinical and administrative costs.

Several challenges are associated with the diffusion of Web-based disease management initiatives. Such initiatives require an infrastructure that will enable efficient and timely communication among health care providers, case managers, health plan staff, and caregivers, and that will enable coordination of all related services. One of the most important factors, which will greatly affect the growth of such systems, is, obviously, reimbursement. In the United States in the year 2000, First Health, a national health benefits company based in Illinois, was one of the first health plans in the country to reimburse providers for electronic communication with patients under specific circumstances. Since then, additional insurance companies and health plans have been redefining their reimbursement policies for online services. In 2003 Blue Shield of California started reimbursing physicians for online consultations.

Many believe that the Internet can enhance a shift from institution-centric to patient-centric systems that empower individuals with chronic conditions to play an active role in the management of their diseases. A large portion of the population diagnosed with chronic conditions, however, is of lower socioeconomic status. Concerns have been expressed that these citizens might have limited access to the Internet and other electronic applications, and as a result might be excluded from disease management systems due to the so-called digital divide.

In this issue, three papers introduce new concepts for Web-based disease management or specific applications that have been pilot tested. One of these applications described by Anhøj and Nielsen is LinkMedica, a Web service for asthma patients and health care professionals [1]. Link Medica enables asthma patients to monitor their conditions using an online diary and enables health care providers to access the patients' diary data. The study describes the first three years of this project and outlines the reasons that patients seemed to underutilize the Web service after short periods. The study reports that patients felt after a while that the system was not easily integrated into their daily schedule. Issues of time and inconvenience as well as psychological factors were addressed. These findings raise an important ethical concern that is associated with the daily use of Web-based in-home applications for patients with chronic conditions, namely, the "medicalization" of the home environment or what Bauer calls turning the home into a "*de facto* ICU" [2]. Daily use of systems over longer periods of time are sometimes perceived as psychologically burdensome to patients. The second study by Anhøj and Jensen focuses on the use of the Internet as a tool to enhance lifestyle changes concerning diet and physical activity [3]. Patients and practitioners seem to appreciate such applications but the study illustrates the challenges for their successful implementation. One of the great challenges is the usability of the system interfaces. Furthermore, the study indicates that selecting the type and amount of information that become included in patient education systems needs to be customized to the specific needs of the target audience. Finally, the third paper by Wiecha and Pollard introduces us to the concept of an interdisciplinary e-health team [4]. The Internet is an appropriate platform for supporting interdisciplinary clinical teamwork. The authors argue that teamwork supported by properly-designed e-health applications could help create more effective systems of care for chronic disease.

As we discussed in the call for papers for this issue, the factors that will be critical for the diffusion of Internet-based disease management systems include the usability of the design, issues of privacy and confidentiality of data, patient and provider acceptance, development and maintenance costs, and reimbursement structures [5]. The studies presented in this issue provide us with a better understanding of these challenges and ways to address them.

References

1. Anhøj J, Nielsen N. Quantitative and Qualitative Usage Data of an Internet-based Asthma Monitoring Tool. J Med Internet Res 2004;6(3):e23 [FREE Full text] [doi: 10.2196/jmir.6.3.e23]
2. Bauer KA. Home-based telemedicine: a survey of ethical issues. Camb Q Healthc Ethics 2001 Dec;10(2):137-146. [Medline: 21197645] [doi: 10.1017/S0963180101002043]
3. Anhøj J, Jensen AH. Using the Internet for Life Style Changes in Diet and Physical Activity: A Feasibility Study. J Med Internet Res 2004;6(3):e28 [FREE Full text] [doi: 10.2196/jmir.6.3.e28]
4. Wiecha J, Pollard T. The interdisciplinary eHealth team: chronic care for the future. J Med Internet Res 2004 Sep 3;6(3):e22 [FREE Full text] [Medline: 15471748] [doi: 10.2196/jmir.6.3.e22]
5. Demiris G, Eysenbach G. Internet use in disease management for home care patients: A call for papers. J Med Internet Res 2002;4(2):e6 [FREE Full text] [doi: 10.2196/jmir.4.2.e6]

submitted 01.09.04; peer-reviewed by G Eysenbach; accepted 15.09.04; published 29.09.04.

Please cite as:
Demiris G
Disease Management and the Internet
J Med Internet Res 2004;6(3):e33
URL: http://www.jmir.org/2004/3/e33/
doi:10.2196/jmir.6.3.e33
PMID:15471759

Viewpoint

Online Health Information and Low-Literacy African Americans

Mehret S Birru[1], BA; Richard A Steinman[2], MD, PhD

[1]Department of Basic Research, University of Pittsburgh Cancer Institute, Pittsburgh PA, USA
[2]Departments of Medicine and Pharmacology, University of Pittsburgh School of Medicine, Pittsburgh PA, USA

Corresponding Author:
Richard A Steinman, MD, PhDAssociate Professor of Medicine
University of Pittsburgh
5117 Centre Avenue
Suite 2.18 Hillman Cancer Center
Pittsburgh PA 15213
USA
Phone: +1 412 623 3237
Fax: +1 412 623 7768
Email: steinman@pitt.edu

Abstract

African Americans with low incomes and low literacy levels disproportionately suffer poor health outcomes from many preventable diseases. Low functional literacy and low health literacy impede millions of Americans from successfully accessing health information. These problems are compounded for African Americans by cultural insensitivity in health materials. The Internet could become a useful tool for providing accessible health information to low-literacy and low-income African Americans. Optimal health Web sites should include text written at low reading levels and appropriate cultural references. More research is needed to determine how African Americans with low literacy skills access, evaluate, prioritize, and value health information on the Internet.

(J Med Internet Res 2004;6(3):e26) doi:10.2196/jmir.6.3.e26

KEYWORDS

Health; literacy; socioeconomic status (SES); African Americans; Internet; comprehension; health behavior

Introduction

Technologies such as the Internet could conceivably enhance the health knowledge of consumers, but have not adequately reached socioeconomic groups at highest risk for poor health. Disparities in income, education, and treatment account for most of this excess [1], but inaccessible health information also contributes to a higher burden of disease. Many groups encounter obstacles in accessing health information; we concentrate on some of the specific barriers encountered by low socioeconomic status (SES) African Americans with substandard literacy skills. While this group has been shown to suffer excessively from preventable complications of diseases such as breast cancer and diabetes [2,3], minimal research has been conducted to determine the utility of the Internet as a means of improving the accessibility of health information to this population. This paper identifies some of the difficulties related to Web usage many low-SES, low-literacy African Americans, and highlights areas of research that must be examined in order to optimally design resources for this population.

Background

Mainstream health information is profoundly inaccessible for millions of Americans with low functional literacy. Functional literacy, as defined in the National Literacy Act of 1991, reflects "an individual's ability to read, write, and speak in English and compute and solve problems at levels of proficiency necessary to function on the job and in society" [4]. However, a striking number of Americans are unable to achieve these most fundamental of aims. According to the American Medical Association [5], low literacy limits the ability of 90 million Americans to engage in disease screening or lifestyle modifying activities. People with low literacy are approximately twice as likely to be hospitalized as individuals with high literacy [5], and low literacy has been identified as a barrier to participation in clinical trials [6].

Our Focus

This paper will focus primarily on defining ways in which informational obstacles-including those found on the Web-may hinder health-seeking behaviors of low-SES and low-literacy African Americans.

While numerous studies have identified low SES as a contributor to the poor health outcomes presented by some African Americans, fewer studies of at-risk African Americans have analyzed their literacy level as another component of their overall health status. However, distinct linkages exist between low literacy, poverty, and poor health.

Literacy, Income Levels and Health Information

In the 1992 National Assessment of Adult Literacy (NAAL) [7] nearly half of all individuals who read at the lowest defined literacy level (Level 1) also reported the lowest income levels of all participants. Because reports of health complications generally are greatest among low income and undereducated people [7,8], low-SES African Americans are therefore, more likely than high-SES African Americans to present with poorer health.

The NAAL study [7] further reported that 38% of African-American participants were graded at Level 1 for prose literacy, and noted that African American families demonstrate poverty rates up to three times higher than other ethnic groups. The correlation between low literacy and poverty in this group suggests that many studies that describe the health behaviors of low-SES African.

Americans may actually be applicable to behavioral characteristics of African Americans with low functional literacy. Therefore, while there is a paucity of specific research on health-seeking behaviors of low-literacy African Americans, representative results may be found in studies that focus on low-SES African Americans.

However, available research has not clearly correlated functional literacy, SES, and health literacy as contributors to poorer health outcomes in this group. *Health* literacy is defined by researchers at the National Center for the Study of Adult Learning and Literacy as "the ability to use written materials to function in health care settings and to maintain one's health and the skills needed to advocate for and request needed clarification" [9]. Health literacy impacts the health status of some African Americans by hindering their comprehension of health-related topics and their ability to understand health education materials, brochures, and physicians' instructions. A study of African American patients with non-insulin-dependent diabetes in municipal hospital outpatient settings reported that health literacy, as measured by the Test of Functional Health Literacy in Adults, was adequate in only 25% of established patients [10]; this undermined the ability of patients to navigate the health care environment. A study by Morhmann et al [11] determined that "printed educational materials on breast cancer do not adequately provide information to undereducated, economically disadvantaged African-American women", an observation confirmed in other analyses of breast and prostate cancer-prevention materials [12,13].

Impact on Health Literacy

While the aggregate impact of functional literacy on health literacy has not been clearly identified by research, low functional literacy does limit the ability of individuals to read and comprehend health education materials. Therefore, poor reading skills are likely to limit health literacy and healthy practices supported by written health materials, and may impact health outcomes in the low-SES African-American population [9]. New nationwide initiatives, including the "Ask Me Three" Campaign by the Partnership for Clear Health Communication train the health community to better communicate with low-health literacy individuals; however, inadequacies persist in the development of educationally appropriate materials for African Americans with low incomes and literacy.

The Internet as an Accessible Health Tool

The Internet may comprise a more accessible, dynamic tool for improving health literacy than current health resources and interventions designed for this group. Internet health Web sites may circumvent some of the typical distribution concerns associated with print health materials. These Web sites may also incorporate multiple mediums to convey information; conceivably this could reinforce comprehension for the low-literacy individuals who access a site.

Is the Internet valued by low-SES African Americans as a source of health information? While no studies directly address this question, Zarcadoolas et al [14] found that health information would be the highest priority search category for low-SES White, Latino/a, and African Americans if they were to access the Internet. Robinson et al [15] further reported that while only 5% of multi-ethnic, low-SES individuals surveyed had used the Internet for health information, nearly half believed that they could find trustworthy and reliable medical information on the Internet . Moreover, home Internet access by low-SES African Americans rose more than three-fold between 1994 and 1998, and African Americans also comprise the largest category of Internet users who access the Web outside of their homes [16].

While these statistics are initially promising, a more comprehensive examination must be conducted to determine the utility of current online health materials for low-literacy, low-SES African Americans, and whether available online resources measurably impact the health literacy of this group. Because no such studies have yet been conducted within this area of research, it is difficult to ascertain whether online health materials are beneficial to this population. However, literacy may be the most daunting barrier to successful Internet access by low-SES, low-literacy African Americans. In one example, researchers noted that 91% of neurology information on the Web was written at a ninth grade or higher level [17]. Berland et al [18] determined that a collegiate reading level was the average required reading level for 25 English-language health Web sites. The Children's Partnership [19] further indicated that of 1000 Web sites evaluated, only 10 were appropriate for low-literacy adults. These numbers suggest that an alarming paucity of relevant sites exist for all low-literacy individuals. Wilson et al [20] studied ethnic cancer education materials on the National Cancer Institute's CancerNet Web site and demonstrated that the required reading level was 12th grade and cultural references were not adequately specific to the ethnic groups targeted. These results suggest that members of ethnic groups who have low or moderate reading skills may have unique difficulties accessing health information on reputable Web sites.

Health Web sites or pages that are culturally sensitive may, in fact, be particularly important for online African Americans and members of other cultural groups. Culturally sensitive materials present information in a format that reflects the beliefs, practices, and values of a target demographic population. Previous studies have underscored that while racial and ethnic groups consist of highly diverse individuals, visual cues (ie, pictures of African Americans) or lifestyle and historical references may add value to information targeted towards a specific population [21,22]. In one study, Brodie et al [23] sampled opinions of self-reported African Americans towards media health information. Nearly 80% of participants believed that African American individuals and families are visually underrepresented in media health information and 69% believed that inadequate media attention is given to African-American health issues. A 1998 study by Guidry and Fagan [13] supports these perceptions, maintaining that 54% of printed breast- and 40% of prostate-cancer education materials evaluated were not culturally sensitive to African Americans . More research is needed to determine the level of cultural sensitivity of current mainstream online health information resources, and whether it is adequately inviting for usage by low-SES, low-literacy African Americans.

While many mainstream health Web sites (including the American Cancer Society, American Red Cross, and National Institute of Health sites) have attempted to address issues of cultural sensitivity through their development of African-American focused Web pages, hyperlinks to some of these sites are buried and may be difficult to find by an individual with low literacy. For example, the African American pages of the American Diabetes Association are not listed on the homepage and must be accessed through two submenus. Other major disease-specific organizations (eg, cancer, heart disease) lack homepage and submenu linkages to African American-focused Web pages and documents. A mainstream government consumer health search engine, healthfinder.gov, includes hyperlinks to African-American interest sites. Though its hyperlinks to highly sophisticated sites are intact, many hyperlinks to simple health brochures are outdated or unavailable; this may frustrate low-literacy readers who believe their inability to reach selected sites derives from their improper usage of the Internet. In sum, the inclusion of culturally sensitive materials in Web sites may improve user-friendliness for low-literacy, low-SES African Americans, but cannot overshadow the necessity of providing easy-to-read, easy-to-access and easy-to navigate online health materials.

Overcoming Informational Obstacles on the Internet

Several initiatives seek to exploit the potential of the Internet to empower low-literacy individuals. For example Cyberstep, Inc, a consortium of four literacy organizations operates *thestudyplace.org*, an online educational resource for low-literacy adults. The Adult Literacy Media Alliance (ALMA) produces an online video program (TV411) for low-literacy adults; this addresses some health topics. However, these resources are not specifically developed to address health needs and concerns of poor African Americans.

The full potential of the Internet as a health-promoting medium for low-literacy African Americans cannot be realized with our current state of knowledge. More research needs to be done on the utility of Internet health resources for low-SES and low-literacy African Americans. Several key areas of research would be particularly valuable such as the direct impact of functional literacy on health literacy; search terms and navigation strategies used by low-SES African Americans seeking health information; the concordance between mainstream criteria used in creating/evaluating health Web sites and the criteria used by low-SES African Americans in rating these Web sites [24,25]; and the effectiveness of health information derived from the Internet compared with print medium in enhancing health-promoting behaviors by this population.

It is also critical for research to determine whether the greatest barriers to Internet usage by this group are literacy, socioeconomic status, mechanics related to Internet navigation/usage, cultural considerations, the physical accessibility of Internet resources, and/or other factors currently unidentified. A comprehensive Web site such as the National Cancer Institute's *Usability.gov*, which consolidates research-based conclusions about optimal Web design and usability, may eventually clarify site-design issues and usability needs unique to low-literacy, low-SES African Americans. These findings should eventually inform criteria for health Web site certification by initiatives such as MedCIRCLE [26].

Design and Content

Ultimately, however, the design and content of health Web sites should be guided by the input of those whom they are meant to serve. A vigorous research agenda is needed to fill in the gaps in our knowledge of how the Internet can best serve the health of low-SES African Americans and others confronting cultural and literacy barriers. Only with feedback from these groups can we understand how, when and why those at greatest risk for disease seek health information on the web, how that information is processed and whether it can help modify lifestyles to promote health. We must also increase our understanding of the criteria by which these groups value information they encounter on the Internet, including the relative value of traditional or alternative health information sources, and the importance of spiritual references, anecdotes or basic biology within health material.

Conclusion

The Internet offers a mechanism for self-directed health learning with the potential to either broaden health literacy or to spread misinformation. For our patients who bear an excess burden of disease and are willing to learn how to become healthy but are daunted by the complex jargon of medicine, it is time for medicine to speak their language both on the Web and in print.

Acknowledgments

We thank Dr. Vicki March, Derietra-Neal-Ferguson, and Nancy Hrynkiw for their comments and review of this manuscript.

Conflicts of Interest

None declared.

References

1. Grant EN, Lyttle CS, Weiss KB. The relation of socioeconomic factors and racial/ethnic differences in US asthma mortality. Am J Public Health 2000 Dec;90(12):1923-1925. [Medline: 20563104]
2. Lannin DR, Mathews HF, Mitchell J, Swanson MS, Edwards MS. Influence of socioeconomic and cultural factors on racial differences in late-stage presentation of breast cancer. JAMA 1998 Jun 10;279(22):1801-1807. [Medline: 98290675] [doi: 10.1001/jama.279.22.1801]
3. Klag MJ, Whelton PK, Randall BL, Neaton JD, Brancati FL, Stamler J. End-stage renal disease in African-American and white men. 16-year MRFIT findings. JAMA 1997;277(16):1293-1298. [Medline: 97263552] [doi: 10.1001/jama.277.16.1293]
4. ; Congress n. National Literacy Act. URL: www.nifl.gov/publiclaw.html [accessed 2 Jan 1991]
5. ; Ad Hoc Committee on Health Literacy for the Council on Scientific Affairs, American Medical Association. Health literacy: report of the Council on Scientific Affairs. JAMA 1999 Feb 10;281(6):552-557. [Medline: 99144710] [doi: 10.1001/jama.281.6.552]
6. Paasche-orlow MK, Taylor HA, Brancati FL. Readability standards for informed-consent forms as compared with actual readability. N Engl J Med 2003 Feb 20;348(8):721-726 [FREE Full text] [doi: 10.1056/NEJMsa021212] [Medline: 22482789]
7. Kirsch IS, Jungeblut A, Jenkins L, Kolstad A. Executive Summary of Adult Literacy in America: A First Look at the Results of the National Adult Literacy Survey: National Center for Educational Statistics; 1992.
8. Rudd R, Moeykens BA, Colton TC. Vol 1: Health and Literacy. National Center for the Study of Adult Learning and Literacy. .
9. Rudd R, Moeykens BA. Adult educator's perceptions of health issues and topics in adult basic education programs. In: National Center for the Study of Adult Learning and Literacy: US Dept. of Education; Aug 1999.
10. Nurss JR, El-kebbi IM, Gallina DL, Ziemer DC, Musey VC, Lewis S, et al. Diabetes in urban African Americans: functional health literacy of municipal hospital outpatients with diabetes. Diabetes Educ 1997;23(5):563-568. [Medline: 98017007]
11. Mohrmann CC, Coleman EA, Coon SK, Lord JE, Heard JK, Cantrell MJ, et al. An analysis of printed breast cancer information for African American women. J Cancer Educ 2000;15(1):23-27. [Medline: 20193042]
12. Guidry JJ, Fagan P. The readability levels of cancer-prevention materials targeting African Americans. J Cancer Educ 1997;12(2):108-113. [Medline: 97373233]
13. Guidry JJ, Fagan P, Walker V. Cultural sensitivity and readability of breast and prostate printed cancer education materials targeting African Americans. J Natl Med Assoc 1998 Mar;90(3):165-169. [Medline: 98211150]
14. Zarcadoolas C, Blanco M, Boyer JF, Pleasant A. Unweaving the Web: an exploratory study of low-literate adults' navigation skills on the World Wide Web. J Health Commun 2002;7(4):309-324. [Medline: 22243102] [doi: 10.1080/10810730290088157]
15. Robinson C, Flowers CW, Alperson BL, Norris KC. Internet access and use among disadvantaged inner-city patients. JAMA 1999 Mar 17;281(11):988-989. [Medline: 99184236] [doi: 10.1001/jama.281.11.988-a]
16. Shapiro R, Rohde G; US National Archives and Records Administration. Falling through the Net : toward digital inclusion : a report on Americans' access to technology tools (SuDoc C 60.2:N 38/2/2000). Washington, D.C.: U.S. Dept. of Commerce, Economic and Statistics Administration National Telecommunications and Information Administration; Oct 2000.
17. Murphy PW, Chesson AL, Berman SA, Arnold CL, Galloway G. Neurology patient education materials: do our educational aids fit our patients' needs? J Neurosci Nurs 2001 Apr;33(2):99-104. [Medline: 21224562]
18. Berland GK, Elliott MN, Morales LS, Algazy JI, Kravitz RL, Broder MS, et al. Health information on the Internet: accessibility, quality, and readability in English and Spanish. JAMA 2001;285(20):2612-2621. [Medline: 21262346] [doi: 10.1001/jama.285.20.2612]
19. Lazarus W. Online content for low-income and underserved Americans: The digital divide's new frontier : a strategic audit of activities and opportunities. Santa Monica: Children's Partnership; Mar 2002.
20. Wilson FL, Baker LM, Brown-syed C, Gollop C. An analysis of the readability and cultural sensitivity of information on the National Cancer Institute's Web site: CancerNet. Oncol Nurs Forum 2000 Oct;27(9):1403-1409. [Medline: 20512720]
21. Guidry JJ, Walker VD. Assessing cultural sensitivity in printed cancer materials. Cancer Pract 1999;7(6):291-296. [Medline: 20197077] [doi: 10.1046/j.1523-5394.1999.76005.x]
22. Fogel J. Internet use for cancer information among racial/ethnic populations and low literacy groups. Cancer Control 2003;10(5 Suppl):45-51 [FREE Full text] [Medline: 22942135]
23. Brodie M, Kjellson N, Hoff T, Parker M. Perceptions of Latinos, African- Americans, and Whites on media as a health information source. Howard Journal of Communications 1999;10(3):147-167. [doi: 10.1080/106461799246799]

24. ; Commission of the European Communities, Brussels. eEurope 2002: Quality Criteria for Health Related Websites. J Med Internet Res 2002 Nov 29;4(3):e15 [FREE Full text] [Medline: 22442447]
25. Eysenbach G, Powell J, Kuss O, Sa ER. Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. JAMA 2002;287(20):2691-2700. [Medline: 22016241] [doi: 10.1001/jama.287.20.2691]
26. Medcircle: The Collaboration for Internet Rating, Certification, Labeling and Evaluation of Health Information. URL: http://www.medcircle.org [accessed 5 Jan 2004]

---

submitted 09.01.04; peer-reviewed by D Hansen, C Zarcadoolas; comments to author 15.02.04; revised version received 15.03.04; accepted 15.04.04; published 03.09.04.

Please cite as:
Birru MS, Steinman RA
Online Health Information and Low-Literacy African Americans
J Med Internet Res 2004;6(3):e26
URL: http://www.jmir.org/2004/3/e26/
doi:10.2196/jmir.6.3.e26
PMID:15471752

Viewpoint

The Interdisciplinary eHealth Team: Chronic Care for the Future

John Wiecha[1], MD, MPH; Timothy Pollard[1], MD

Distance Education for Health, Department of Family Medicine, Boston University Medical Campus, Boston MA, USA

Corresponding Author:
John Wiecha, MD, MPH
Department of Family Medicine
Boston University Medical Campus
Dowling 5 South, 1 Boston Medical Center Place
Boston MA 02118
USA
Phone: +1 617 414 4465
Fax: +1 617 414 3345
Email: John.Wiecha@bmc.org

Abstract

An interdisciplinary clinical team is a consistent grouping of people from relevant clinical disciplines, ideally inclusive of the patient, whose interactions are guided by specific team functions and processes to achieve team-defined favorable patient outcomes. Teamwork supported by properly designed eHealth applications could help create more effective systems of care for chronic disease. Given its synchronous and asynchronous communication capacity and information-gathering and -sharing capabilities, the Internet is a logical platform for supporting interdisciplinary clinical teamwork. Research is needed to better understand how interdisciplinary eHealth team members can work together in everyday practice and to guide the development of effective and efficient eHealth software applications to support greater clinical teamwork.

(J Med Internet Res 2004;6(3):e22) doi:10.2196/jmir.6.3.e22

KEYWORDS

Patient care team; medical informatics; telemedicine; interdisciplinary communication; quality of health care; chronic disease

Introduction

Chronic diseases are the most common cause of mortality and morbidity in developed countries [1]. The increasing complexity of chronic disease managed in the ambulatory setting, and the expanding evidence base available to guide medical care, has led to calls for interdisciplinary team models of patient management [2] that include the patient [3].

The effective and efficient functioning of health care teams is predicated on two factors amenable to information technology solutions: patient data and a workable method of coordinating interactions among team members.

Teamwork supported by properly designed eHealth applications could help create more effective systems of care for chronic disease. However, new eHealth models have not emerged to reach this potential, nor has there been general recognition of the contribution that electronic technology can make to promoting clinical teamwork or the need to rigorously evaluate the facilitation of clinical teamwork via electronic means.

Team Theory

Although teamwork in health care has been promoted as beneficial since the turn of the century [4], consensus on a definition of clinical teamwork is not apparent in the literature.

Lorimer et al [5] suggest that "a team is a small number of consistent people committed to a relevant shared purpose, with common performance goals, complementary and overlapping skills, and a common approach to their work. Team members hold themselves mutually accountable, team results are outcomes."

This definition implies *interdisciplinary* interactions, in which all members participate in the team's activities and rely on one another to accomplish goals. In contrast, in the "multidisciplinary" team model, health care providers tend to treat patients independently and to share information with each other, while the patient may be a mere recipient of care. An interdisciplinary team aspires to a more profound level of collaboration, in which constituents of different backgrounds combining their knowledge mutually complete different levels of planned care [4].

There is growing advocacy for including patients as members of the teams that manage their chronic illness [6]. The burden of chronic illness is borne most heavily by patients and their families, as most care of chronically ill patients takes place in the home [7]. The U.S. Institute of Medicine [2] as well as other authorities have argued that for successful treatment of chronic illness, patients must be "well informed about their disease, know where they can access treatment, and have greater control over their treatment" [8]. There is good evidence that patients should be "partners in their care" [8]. Integrating patients into the virtual health care team is an obvious next step in this evolution.

eHealth Applications for Teamwork

Given its synchronous and asynchronous communication capacity and information-gathering and -sharing capabilities, the Internet is a logical platform for supporting interdisciplinary teamwork. This concept is not new. As early as 1968, two of the founders of the modern-day Internet wrote:

> *We believe that communicators have to do something nontrivial with the information they send and receive. And we believe that we are entering a technological age in which we will be able to interact with the richness of living information—not merely in the passive way that we have become accustomed to using books and libraries, but as active participants in an ongoing process, bringing something to it through our interaction with it, and not simply receiving from it by our connection to it. . . . We want to emphasize something beyond its one-way transfer: the increasing significance of the jointly constructive, the mutually reinforcing aspect of communication— the part that transcends 'now we both know a fact that only one of us knew before.' When minds interact, new ideas emerge [9].*

Defining how minds actually interact in a clinical team, and having a clear understanding of team structure and function, is essential to building successful interdisciplinary care teams that function electronically.

Four domains of team function have been described [10] that can guide interdisciplinary eHealth team development, evaluation, and research. These include structure (composition and representation), context (relationship to the larger institution), process (of team functioning), and productivity (measure of impact). The structure of teams refers to the membership composition and their hierarchic organization. The context is shaped by environmental structure and financial and organizational relationships. Team process is determined by which methods are used for team communication, by the hierarchic nature of the team, by the values of team members concerning power sharing, and by idiosyncratic relationships that develop within teams. Productivity can be understood in the same way as individual productivity. Of these four domains, the *process* of eHealth teams is likely to most differ from teams supported by non-electronic means of communication and information sharing, and so a deeper understanding of process is in order. Team process, based on the work of Heinemann [10] and others, can be characterized into what we call the "12 C's of teamwork":

The 12 C's Defining Teamwork:

1. Communication (this is the sine qua non of teamwork)
2. Cooperation (empowerment of team members)
3. Cohesiveness (team sticks together)
4. Commitment (investing in team process)
5. Collaboration (equality in the team)
6. Confronts problems directly
7. Coordination of efforts (insuring actions support a common plan)
8. Conflict management
9. Consensus decision making
10. Caring(patient centered outcomes)
11. Consistency (with one another and the environment)
12. Contribution (feeling this is being made)

Applying these 12 processes to a group might reasonably be expected to produce creative synergies among group members, producing new and perhaps unexpected ideas and solutions and resulting in a functional team. Diverse perspectives may contribute to creativity and learning, skill acquisition, and innovation.

In summary, a modern interdisciplinary team is a consistent grouping of people from relevant clinical disciplines, ideally inclusive of the patient, who interact guided by these 12 processes to achieve team-defined favorable patient outcomes.

Evidence for Effectiveness of Teamwork in Clinical Settings

The purported benefits of teamwork in health care are many, and include increased learning and development of people and organizations; better utilization of resources and planning for the future, ensuring the best use of resources and minimization of unnecessary costs; and improving job performance and work quality [11]. However, despite calls for reengineering health care processes to include greater teamwork, published studies on the effectiveness of teamwork provide conflicting results, and the state of research on teamwork has been rated poor [12].

In a 1999 review article, Schofield and Amodeo [13] analyzed research evaluating the impact of clinical teamwork. They reported significant weaknesses in research rigor, with great inconsistency in terminology and little empirical evidence for the efficacy of interdisciplinary teams at that time.

More recently, there has emerged some research evidence demonstrating teamwork benefit [10,14-18]. For example, Gittell et al [17] studied the effect of several key dimensions of coordination, including communication, shared goals, shared knowledge, problem solving, and mutual respect, on the quality of orthopedic surgical care. The more coordination the team demonstrated, the better the patients' postoperative functioning and the shorter the hospital stays.

Teamwork under the guise of "collaborative care" or "shared care" schemes has been described and evaluated and has improved patient outcomes [19].

Historically, psychiatric disorders have been managed by either psychiatrists, psychologists, or primary care physicians. Care models that include patient education, psychiatric and primary care co-management of drugs, and case management have been shown to improve patient outcomes 20]. Patients with depression rated the quality of their care more highly [21,22], were more adherent to medications [20,23], had fewer symptomatic days [24,25], and decreased depression scores [22,26] when treated collaboratively. Although the cost of care was higher in these models due mostly to increased patient compliance with visits and medicines [27,28], these costs were offset at the societal level by increased days of work [25]. Similar results have been reported with panic disorder [29]. How these collaborative models improve outcomes is not clear.

Limitations of Research on eHealth Teamwork

Although there is some evidence demonstrating improved clinical outcomes by virtue of good team performance, there has been little work on the relationship between team process and clinical outcomes [10]. In other words, we do not know why teamwork improves clinical outcomes, and therefore we do not know which processes ought to be electronically enhanced.

In fact, many of the assertions regarding effective attributes of a successful team do not have supporting evidence. Various attributes have been promoted as the essential qualities of a successful interdisciplinary team, including diversity of participants;

shared records; improved communication between doctors and patients; a clear role for the patient; specialist input; consensus on management; and close coordination [14]. It has also been argued that diversity of professional, cultural, and demographic characteristics provides varied perspectives on decision making and may improve problem solving and creativity [10].

New methods are needed to evaluate health care teams. Although there is a substantial body of literature on teamwork, methodological weaknesses are prevalent. Use of non-validated instruments, poorly defined methods and measures, lack of control groups, and inadequate isolation of specific teamwork effects upon outcomes contribute to our ignorance. There is little research at the clinical trial level evaluating various methods of online or conventional clinical teamwork, and there is limited research on interdisciplinary teamwork in community-based primary care settings. Most studies offer only "explanatory hypotheses or sociological theories" [30].

Although strong provider-patient relationships can positively influence patient satisfaction, adherence to treatment, and health care outcomes [31], few studies have addressed how to meaningfully integrate the patient into a more broadly constituted interdisciplinary clinical team, virtual or otherwise. There is considerable discussion in the literature on how to set up teams and manage them, but research explaining how interdisciplinary team members manage their concerns and work together in everyday practice is minimal [12]. Likewise, we know little about models and effectiveness of electronically supported team interactions. New communications processes augmented by advances in electronic technology provide fertile soil for further research.

McCallin [12] and Schofield [13] have called for more sophisticated research on conventional and electronically mediated teamwork, making such points as: (1) Articles need to be more analytic and meet a higher standard of conceptualization; (2) all variables need to be specified, and a more sophisticated research design used when possible; (3) comparison groups, almost entirely absent from the current literature, should be used; (4) researchers should compare interdisciplinary team interventions with one-on-one interventions; and (5) more research is needed to understand the processes used by clinical team members as they work [12].

We agree that "there is an urgent need for more research into patients' information needs and preferences and for the development and evaluation of decision support mechanisms to enable patients to become informed participants in treatment decisions" [6]. This work should include research and development of eHealth applications focused on how these goals can be met within a broader context of collaboration among health care professionals caring for the patient.

A new system for asthma care provides an opportunity for research into the impact of electronic teams on patient care. A Web-based tool has recently been introduced in Germany (Forum-Telemedizin, or FTM) [32] to promote the self-management behaviors of children with asthma. FTM as currently implemented uses disease-specific data acquisition in the patients' home, educational tools that include Web-based learning games, point-of-care tools for physicians and nurses, and computer-driven adaptation to individual patient treatment and assessment needs. It is designed to improve patient motivation and self-care in youths most severely affected by asthma in clinical practice.

FTM will be modified by the authors to support data-driven teamwork among all health care professionals responsible for the care of the child with asthma, including primary care physicians, asthma specialists, asthma nurses, and school nurses. The system will be transparent, in that child and parent will be encouraged to be bonafide participants in the management discussions. A randomized clinical trial in progress should help to answer questions about which aspects of these systems are producing positive clinical outcomes, including the relative impact of telemonitoring with electromedical devices, direct contact with the physician, co-management via online teams, patient education, or combinations of the above. Studies are also needed to assess the impact of such systems on adult patients with chronic illness, as well as for the prevention of illness via promotion of healthy lifestyles.

Conclusions

A recent review [33] noted the need for additional study of telemedicine in chronic conditions, with an emphasis on patient-centered approaches to care. The discourse ontelemedicine applications to date has not embraced the utility of telemedicine systems to promote clinical teamwork.

In the near future, we anticipate, the Internet and appropriately designed multifunctional software applications will enable teamwork to occur anywhere, at any time. The team could have access to real-time patient data sent from the home, and the patient could be fully integrated into a collaborative care process by accessing appropriate patient data and participating in communications between caregivers via asynchronous discussion threads. Ultimately, digital audio and video accessed over the Internet will be widely used to facilitate these communication processes.

A research agenda on the impact of eHealth applications should integrate investigations of clinical teamwork functionality. As we develop, implement, and evaluate new tools for integrated communication, remote patient education, and monitoring of patients with chronic diseases, we should be sure that facilitation and assessment of online clinical teamwork is an explicit functional goal. The current undeveloped state of research on the effectiveness and efficiency of clinical teamwork can be advanced by evaluating teamwork schemes that are facilitated electronically.

The research agenda should include development of models to guide the process by which effective and efficient teamwork can be promoted and supported online. Methods will need to be developed to measure the quantity and quality of online teamwork. A unique opportunity exists to assess the content of team interactions given the retrievable nature of online communication.

These records can provide a rich resource documenting teamwork characteristics and will be available for qualitative analyses, doing much to penetrate the "black box" of shared care. In the past, this work has been hampered by the lack of such enduring records and the impracticality of impartial observers accompanying health care providers to record team interaction.

To quote the president of the Association of American Medical Colleges when advocating rapid introduction of information technology into medicine and noting potential pitfalls, "One pitfall would be to embrace the technology, but to stop short of taking full advantage of its transforming potential" [34].

Acknowledgments

This work was supported by the Commonwealth Fund, via a grant to Dr. Wiecha.

References

1. ; US Dept of Health and Human Services. The burden of chronic diseases and their risk factors. URL: http://www.cdc.gov/nccdphp/burdenbook2002 [accessed 15 Sept 2002]
2. ; Institute of Medicine. Crossing the Quality Chasm: A New Health System for the 21st Century. Washington, DC: National Academies Press; Jun 1, 2001.
3. Wagner EH, Glasgow RE, Davis C, Bonomi AE, Provost L, Mcculloch D, et al. Quality improvement in chronic illness care: a collaborative approach. Jt Comm J Qual Improv 2001 Feb;27(2):63-80. [Medline: 21116124]
4. Bernard-bonnin AC, Stachenko S, Bonin D, Charette C, Rousseau E. Self-management teaching programs and morbidity of pediatric asthma: a meta-analysis. J Allergy Clin Immunol 1995 Jan;95(1 Pt 1):34-41 [FREE Full text] [Medline: 95122929]
5. Lorimer W, Manion J. Team-based organizations: leading the essential transformation. PFCA Rev 1996:15-19. [Medline: 96338048]
6. Coulter A. Partnerships with patients: the pros and cons of shared clinical decision-making. J Health Serv Res Policy 1997 Apr;2(2):112-121. [Medline: 98317737]
7. Von Korff M, Gruman J, Schaefer J, Curry SJ, Wagner EH. Collaborative management of chronic illness. Ann Intern Med 1997 Dec 15;127(12):1097-1102 [FREE Full text] [Medline: 98049719]
8. Davis RM, Wagner EG, Groves T. Advances in managing chronic disease. Research, performance measurement, and quality improvement are key. BMJ 2000 Feb 26;320(7234):525-526 [FREE Full text] [Medline: 20153329] [doi: 10.1136/bmj.320.7234.525]
9. Licklider JCR, Taylor RW. The computer as a communication device. Science and Technology 1968 Apr.
10. Heinemann GD, Zeiss AM, editors. Team Performance in Health Care: Assessment and Development (Issues in the Practice of Psychology). New York: Plenum US; Jan 1, 2002:400.
11. Ingram H, Desombre T. Teamwork in health care. Lessons from the literature and from good practice around the world. J Manag Med 1999;13(1):51-58. [Medline: 99407545] [doi: 10.1108/02689239910261354]
12. Mccallin A. Interdisciplinary practice--a matter of teamwork: an integrated literature review. J Clin Nurs 2001 Jul;10(4):419-428. [Medline: 21680180] [doi: 10.1046/j.1365-2702.2001.00495.x]
13. Schofield RF, Amodeo M. Interdisciplinary teams in health care and human services settings: are they effective? Health Soc Work 1999 Aug;24(3):210-219. [Medline: 99434907]
14. Mcghee SM, Mcinnes GT, Hedley AJ, Murray TS, Reid JL. Coordinating and standardizing long-term care: evaluation of the west of Scotland shared-care scheme for hypertension. Br J Gen Pract 1994 Oct;44(387):441-445. [Medline: 95267528]
15. Shortell SM, Zimmerman JE, Rousseau DM, Gillies RR, Wagner DP, Draper EA, et al. The performance of intensive care units: does good management make a difference? Med Care 1994 May;32(5):508-525. [Medline: 94238950]

16. Young GJ, Charns MP, Desai K, Khuri SF, Forbes MG, Henderson W, et al. Patterns of coordination and clinical outcomes: a study of surgical services. Health Serv Res 1998 Dec;33(5 Pt 1):1211-1236. [Medline: 99082737]
17. Gittell JH, Fairfield KM, Bierbaum B, Head W, Jackson R, Kelly M, et al. Impact of relational coordination on quality of care, postoperative pain and functioning, and length of stay: a nine-hospital study of surgical patients. Med Care 2000 Aug;38(8):807-819. [Medline: 20383818] [doi: 10.1097/00005650-200008000-00005]
18. Risser DT, Rice MM, Salisbury ML, Simon R, Jay GD, Berns SD. The potential for improved teamwork to reduce medical errors in the emergency department. The MedTeams Research Consortium. Ann Emerg Med 1999 Sep;34(3):373-383 [FREE Full text] [Medline: 99389521]
19. Katon W, Russo J, Von Korff M, Lin E, Simon G, Bush T, et al. Long-term effects of a collaborative care intervention in persistently depressed primary care patients. J Gen Intern Med 2002 Oct;17(10):741-748. [Medline: 22278582] [doi: 10.1046/j.1525-1497.2002.11051.x]
20. Katon W, Von Korff M, Lin E, Simon G, Walker E, Bush T, et al. Collaborative management to achieve depression treatment guidelines. J Clin Psychiatry 1997;58 Suppl 1(Suppl 1):20-23. [Medline: 97207612]
21. Katon W, Robinson P, Von Korff M, Lin E, Bush T, Ludman E, et al. A multifaceted intervention to improve treatment of depression in primary care. Arch Gen Psychiatry 1996 Oct;53(10):924-932. [Medline: 97010836]
22. Unützer J, Katon W, Callahan CM, Williams JW, Hunkeler E, Harpole L, et al; IMPACT Investigators. Improving Mood-Promoting Access to Collaborative Treatment. Collaborative care management of late-life depression in the primary care setting: a randomized controlled trial. JAMA 2002 Dec 11;288(22):2836-2845. [Medline: 22361863] [doi: 10.1001/jama.288.22.2836]
23. Liu CF, Hedrick SC, Chaney EF, Heagerty P, Felker B, Hasenberg N, et al. Cost-effectiveness of collaborative care for depression in a primary care veteran population. Psychiatr Serv 2003 May;54(5):698-704 [FREE Full text] [Medline: 22605690] [doi: 10.1176/appi.ps.54.5.698]
24. Katon W, Von Korff M, Lin E, Simon G, Walker E, Unützer J, et al. Stepped collaborative care for primary care patients with persistent symptoms of depression: a randomized trial. Arch Gen Psychiatry 1999 Dec;56(12):1109-1115. [Medline: 20057245] [doi: 10.1001/archpsyc.56.12.1109]
25. Schoenbaum M, Unützer J, Sherbourne C, Duan N, Rubenstein LV, Miranda J, et al. Cost-effectiveness of practice-initiated quality improvement for depression: results of a randomized controlled trial. JAMA 2001 Sep 19;286(11):1325-1330. [Medline: 21445326] [doi: 10.1001/jama.286.11.1325]
26. Katon W, Von Korff M, Lin E, Walker E, Simon GE, Bush T, et al. Collaborative management to achieve treatment guidelines. Impact on depression in primary care. JAMA 1995 Apr 5;273(13):1026-1031. [Medline: 95205543] [doi: 10.1001/jama.273.13.1026]
27. Simon GE, Von Korff M, Ludman EJ, Katon WJ, Rutter C, Unützer J, et al. Cost-effectiveness of a program to prevent depression relapse in primary care. Med Care 2002 Oct;40(10):941-950. [Medline: 22281977]
28. Von Korff M, Katon W, Bush T, Lin EH, Simon GE, Saunders K, et al. Treatment costs, cost offset, and cost-effectiveness of collaborative management of depression. Psychosom Med 1998 Mar;60(2):143-149. [Medline: 98221632]
29. Katon WJ, Roy-byrne P, Russo J, Cowley D. Cost-effectiveness and cost offset of a collaborative care intervention for primary care patients with panic disorder. Arch Gen Psychiatry 2002 Dec;59(12):1098-1104. [Medline: 22358246] [doi: 10.1001/archpsyc.59.12.1098]
30. Zwarenstein M, Reeves S. What's so great about collaboration? BMJ 2000 Apr 15;320(7241):1022-1023 [FREE Full text] [Medline: 20227648] [doi: 10.1136/bmj.320.7241.1022]
31. Stubblefield C, Mutha S. Provider-patient roles in chronic disease management. J Allied Health 2002 Dec;31(2):87-92. [Medline: 22037328]
32. Horn M, Lecheler J. Children's and teenagers' reception to asthma education on the Internet. Abstracts of MEDNET 2001, the 6th World Congress on the Internet in Medicine. Udine, Italy, 29 November-2 December 2001. Technol Health Care 2001;9(6):433-539. [Medline: 11894802]
33. Currell R, Urquhart C, Wainwright P, Lewis R. Telemedicine versus face to face patient care: effects on professional practice and health care outcomes. Nurs Times 2001 Aug 30;97(35):35. [Medline: 21955177]
34. Cohen JJ. Leading the information revolution. From the President. Acad Med 1997.

---

submitted 12.11.03; peer-reviewed by A Klemann; accepted 10.01.04; published 03.09.04.

Please cite as:
Wiecha J, Pollard T
The Interdisciplinary eHealth Team: Chronic Care for the Future
J Med Internet Res 2004;6(3):e22
URL: http://www.jmir.org/2004/3/e22/
doi:10.2196/jmir.6.3.e22
PMID:15471748

Original Paper

Using the Internet for Life Style Changes in Diet and Physical Activity: A Feasibility Study

Jacob Anhøj[1], MD, DIT; Anne Holm Jensen[2], MIMS

[1]AstraZeneca A/S, Albertslund, Denmark

[2]University of Aarhus, Department of Information and Media Studies, Helsingforsgade 14, DK-8200 Århus N, Denmark

Corresponding Author:
Jacob Anhøj, MD, DIT
AstraZeneca A/S
Roskildevej 22
DK-2620 Albertslund
Denmark
Phone: +45 43666275
Fax: +45 43666100
Email: jacob.anhoj@astrazeneca.com

Abstract

Background: LinkMedica-Heart is a novel Internet based program intended to support people who seek to improve their life style by means of changes in diet and physical activity. The program is currently under evaluation in a clinical study and the present study is a feasibility test of the LinkMedica-Heart Internet based program.

Objective: The aim of this study was to evaluate LinkMedica-Heart, an Internet based program we designed for support and maintenance of patient-led life style changes.

Methods: The feasibility study of LinkMedica-Heart presented here is a qualitative study. Nine general practitioners were invited to participate. Each practitioner was asked to introduce LinkMedica-Heart to not less than two patients, with a maximum of five patients per practitioner. Patients and general practitioners were both asked to participate in testing the program for a period of 6 months. At the end of 6 months, evaluation meetings were held with the general practitioners, and separate interviews took place with some of the participating patients who were selected by the GPs.

Results: Five general practitioners and 25 patients participated in the study. The general practitioners and the patients were enthusiastic about the prospect of an Internet based life style change program. However, the program was not able to sustain patient loyalty over an extended period. The doctors found that the program was much too complicated to navigate and that the results from the program could not be trusted. The patients in contrast had fewer complaints about the program design, but found that the advice given by the program was too elaborate and detailed and, in general, did not add to the patient's knowledge on life style change.

Conclusion: Our study confirms that there is a need for, and a receptive attitude toward a Web-based program that supports people who want to improve their life style and health. LinkMedica-Heart in its present form does not satisfy these needs. We suggest a number of design changes and improvements to the program.

(J Med Internet Res 2004;6(3):e28) doi:10.2196/jmir.6.3.e28

KEYWORDS

Internet; life style; self care; physician-patient relations; computer-assisted decision making; user-computer interface

Introduction

Obesity and physical inactivity are major causes of a number of diseases. Several studies prove that a change of life style towards a healthy diet and ample physical activity reduces the risk of a large number of diseases [1,2]. However, permanent life style changes are difficult to achieve for most people.

Individual and group based education of individuals for implementing life style changes are seldom possible due to often-limited resources. There is an enormous need for innovative ways to introduce and maintain life style changes in people at risk from life style related diseases.

The growth and extensive use of the World Wide Web presents a novel opportunity for mass communication and patient education (also referred to as e-learning). Taking advantage of the new medium, the Research Centre for Prevention and Health (RCP), Glostrup, Denmark, in cooperation with AstraZeneca (AZ), Denmark, created a novel Internet-based program called LinkMedica-Heart (LMH), for support and maintenance of life style changes in people at risk from life style related diseases. The program's effect on predictors of life style related diseases is currently under investigation in a clinical trial that compares changes in serum cholesterol in patients using the LMH program, with those of patients using a ‘placebo' program. We plan further studies on other predictors of life style related diseases that may be prevented with the LMH program.

The present study was originally intended to be a pilot test with a small number of general practitioners (GPs) testing the web pages, together with some of the practitioners' patients, in order to help us identify and correct errors in the program prior to beginning the actual clinical study mentioned above. The feedback we got from the GPs and some of the patients during the pilot study could be of interest for other researchers working on Internet-based patient education. Hence, we decided to expand the pilot study with some in-depth interviews with selected patients and present our findings on the feasibility of LinkMedica-Heart as an Internet-based program for support and maintenance of life style changes.

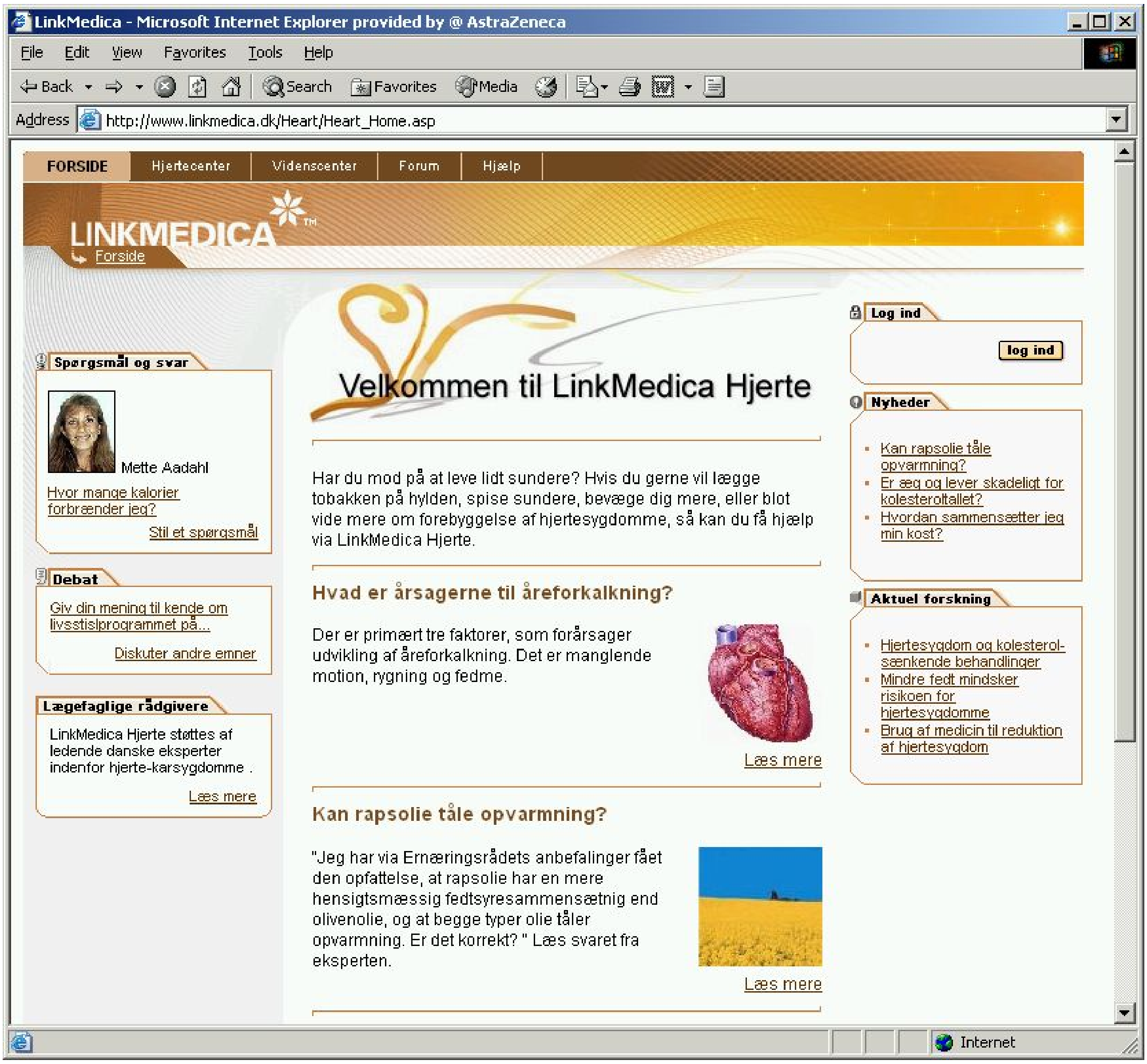
Methods

The aim of LinkMedica-Heart is to provide support and information for people trying to achieve a healthy life style through focus on diet and physical exercise. LMH is part of a closed Web site that is currently accessible only by people who participate in the study.

System Description

To use LMH, the patient must register and chose a username and a password. The patient is then required to enter his or her sex, height, weight, and E-mail address. A screenshot of LMH's home page is shown in Figure 1.

Figure 1. LinkMedica-Heart home page



Hvor mange kalorier forbrænder jeg?

Stil et spørgsmål

Giv din mening til kende om livsstislprogrammet på...

Diskuter andre emner

LinkMedica Hjerte støttes af ledende danske eksperter indenfor hjerte-karsygdomme .

Læs mere

Velkommen til LinkMedica Hjerte

Har du mod på at leve lidt sundere? Hvis du gerne vil lægge tobakken på hylden, spise sundere, bevæge dig mere, eller blot vide mere om forebyggelse af hjertesygdomme, så kan du få hjælp via LinkMedica Hjerte.

Hvad er årsagerne til åreforkalkning?

Der er primært tre faktorer, som forårsager udvikling af åreforkalkning. Det er manglende motion, rygning og fedme.

Læs mere

Kan rapsolie tåle opvarmning?

"Jeg har via Ernæringsrådets anbefalinger fået den opfattelse, at rapsolie har en mere hensigtsmæssig fedtsyresammensætnig end olivenolie, og at begge typer olie tåler opvarmning. Er det korrekt? " Læs svaret fra eksperten.

Læs mere

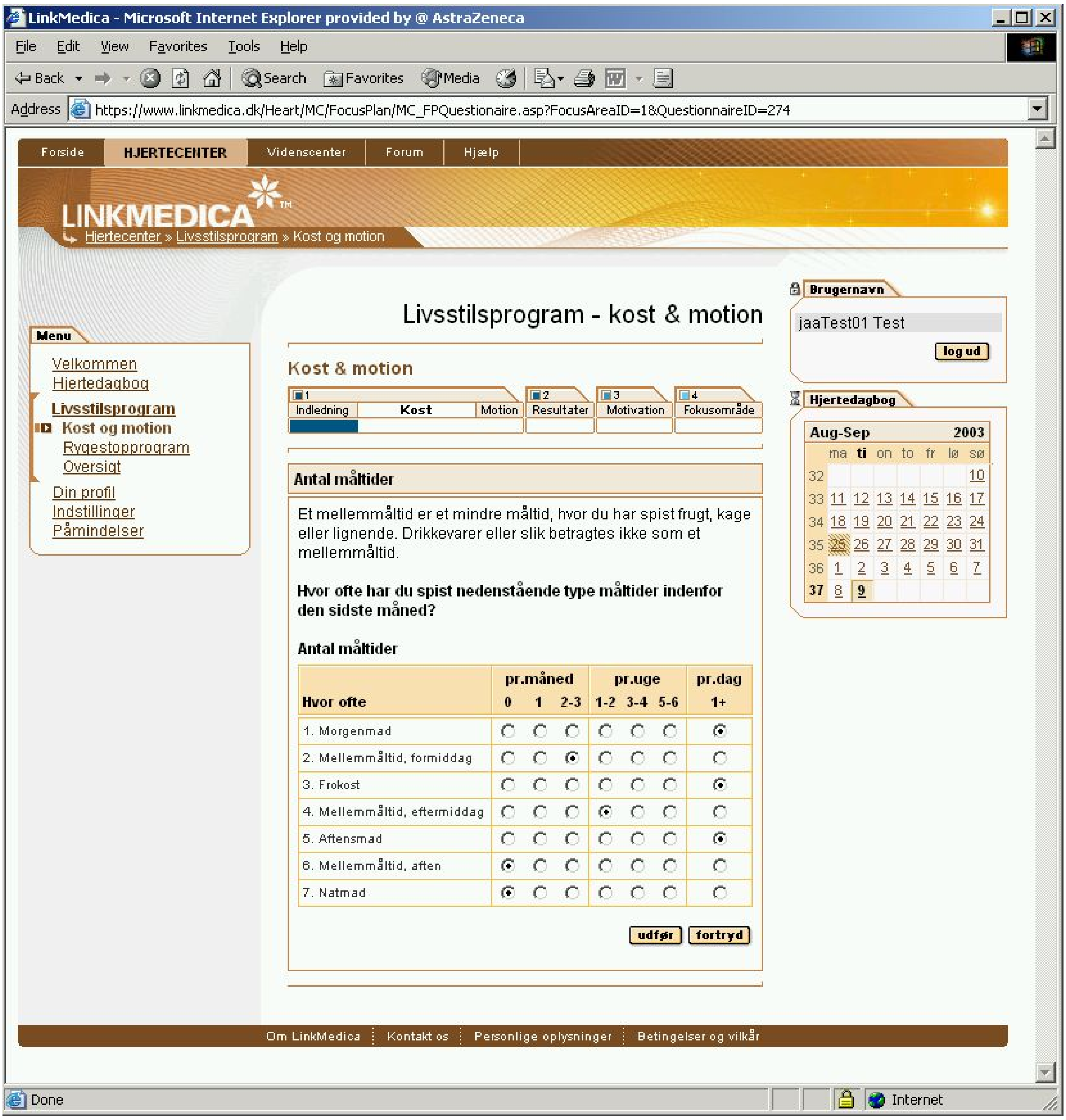
- Kan rapsolie tåle opvarmning?
- Er æg og lever skadeligt for kolesteroltallet?
- Hvordan sammensætter jeg min kost?

- Hjertesygdom og kolesterol-sænkende behandlinger
- Mindre fedt mindsker risikoen for hjertesygdomme
- Brug af medicin til reduktion af hjertesygdom

After registration, the user is asked to activate a life style change program. To do this, the patient must first fill-in two questionnaires: one about diet, and the other about physical activity (screenshots shown in Figure 2 and Figure 3).

The diet questionnaire is very detailed and asks the patient how often he or she has consumed different food items typical in a Danish diet in the last month. The LMH program then matches each answer with data stored in the program's database on the nutritional composition of the particular food item entered by the patient. The system assumes the size of an average serving of the particular food item and calculates the patient's intake of energy, fat, protein, carbohydrates, fibre, and alcohol. In total, there are 219 questions, and filling in the diet questionnaire for the first time takes approximately half an hour. The diet questionnaire is based on the Dankost 2000 computer program [3].

Figure 2. A page from the diet questionnaire. Each question, eg, “Morgenmad” (Breakfast) or “Frokost”(Lunch), requires patients to answer how often they have consumed an item during the previous month. Other questionnaire pages detail contents of each type of meal



jaaTest01 Test

Livsstilsprogram - kost & motion

Kost & motion

Antal måltider

Et mellemmåltid er et mindre måltid, hvor du har spist frugt, kage eller lignende. Drikkevarer eller slik betragtes ikke som et mellemmåltid.

Hvor ofte har du spist nedenstående type måltider indenfor den sidste måned?

Antal måltider

	pr.måned			pr.uge			pr.dag
Hvor ofte	**0**	**1**	**2-3**	**1-2**	**3-4**	**5-6**	**1+**
1. Morgenmad	○	○	○	○	○	○	●
2. Mellemmåltid, formiddag	○	○	●	○	○	○	○
3. Frokost	○	○	○	○	○	○	●
4. Mellemmåltid, eftermiddag	○	○	○	●	○	○	○
5. Aftensmad	○	○	○	○	○	○	●
6. Mellemmåltid, aften	●	○	○	○	○	○	○
7. Natmad	●	○	○	○	○	○	○

In the activity questionnaire, the patient must specify on average how much time he or she spends, during a typical day, on nine different activity levels that extend from sleep to hard physical activity. The total time must add up to 24 hours. The LMH program assigns each activity level a metabolic equivalent (ME) number. One ME corresponds to a person's energy expenditure when sitting relaxed. The ME of an activity times the patient's weight, the minutes spent per day on the particular activity, and a constant for the patient's sex, gives the amount of energy spent on the particular activity, per day. The total energy spent per day is a sum of energy spent on all activities in a day. The activity questionnaire takes only a few minutes to fill-in.

After filling-in both the diet and activity level questionnaire, the patient is presented with results that summarize energy intake, energy expenditure, and composition of diet with regard to protein, carbohydrate, fat, alcohol and fibre per day (Figure 4).

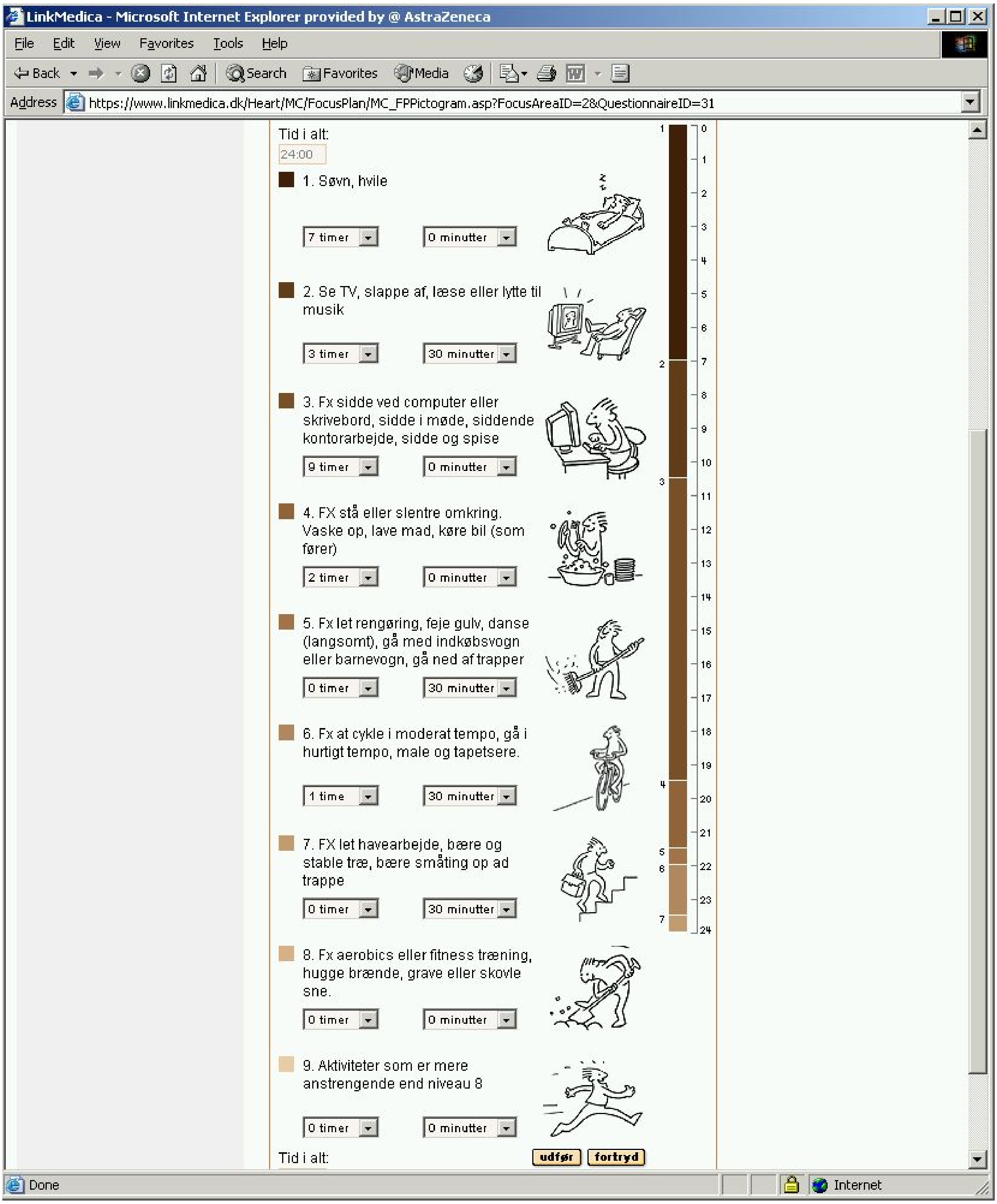
The patient is then asked to select one of five offered diet programs, and one of three activity programs. The patient can select a program based on how motivated the patient is for a life style change: a highly motivated patient might select an intensive program, while a less motivated patient may select a program that aims at creating the needed motivation.

After the patient has activated a program, he or she receives a computer-generated E-mail with results of the questionnaire and personalized advice on how to improve life style through changes in diet and physical activity. The activity questionnaire, the advice generator, and textual content were created by RCP.

After 4 weeks, patients received an E-mail asking them to update answers to the diet and physical activity questionnaires. When updating their answers, patients were only required to enter changes in diet or physical activity since the last questionnaire. This made updating much less demanding than the first entry. Again, the patient received results and advice based on the current life style change program. The patient could at any time change their program to a more or less intensive one. The content of E-mail advice changed according to the newly recommended program. Thus, the overall goal of the program was to introduce and maintain permanent changes in life style, rather than a radical short-term change in diet.

A single life style change program ran for 6 months. If the patient chose a different program in between, the new program would then take over for the next 6 months.

Figure 3. Screen-shot of the physical activity questionnaire. A cartoon accompanying each question illustrates the activity level. The patient needs to answer with the average time spent per day, in hours and minutes, on an activity level. The answers must total 24 hours



Address: https://www.linkmedica.dk/Heart/MC/FocusPlan/MC_FPPictogram.asp?FocusAreaID=2&QuestionnaireID=31

Tid i alt:
24:00

1. Søvn, hvile
7 timer | 0 minutter

2. Se TV, slappe af, læse eller lytte til musik
3 timer | 30 minutter

3. Fx sidde ved computer eller skrivebord, sidde i møde, siddende kontorarbejde, sidde og spise
9 timer | 0 minutter

4. FX stå eller slentre omkring. Vaske op, lave mad, køre bil (som fører)
2 timer | 0 minutter

5. Fx let rengøring, feje gulv, danse (langsomt), gå med indkøbsvogn eller barnevogn, gå ned af trapper
0 timer | 30 minutter

6. Fx at cykle i moderat tempo, gå i hurtigt tempo, male og tapetsere.
1 time | 30 minutter

7. FX let havearbejde, bære og stable træ, bære småting op ad trappe
0 timer | 30 minutter

8. Fx aerobics eller fitness træning, hugge brænde, grave eller skovle sne.
0 timer | 0 minutter

9. Aktiviteter som er mere anstrengende end niveau 8
0 timer | 0 minutter

Tid i alt:

Data Collection

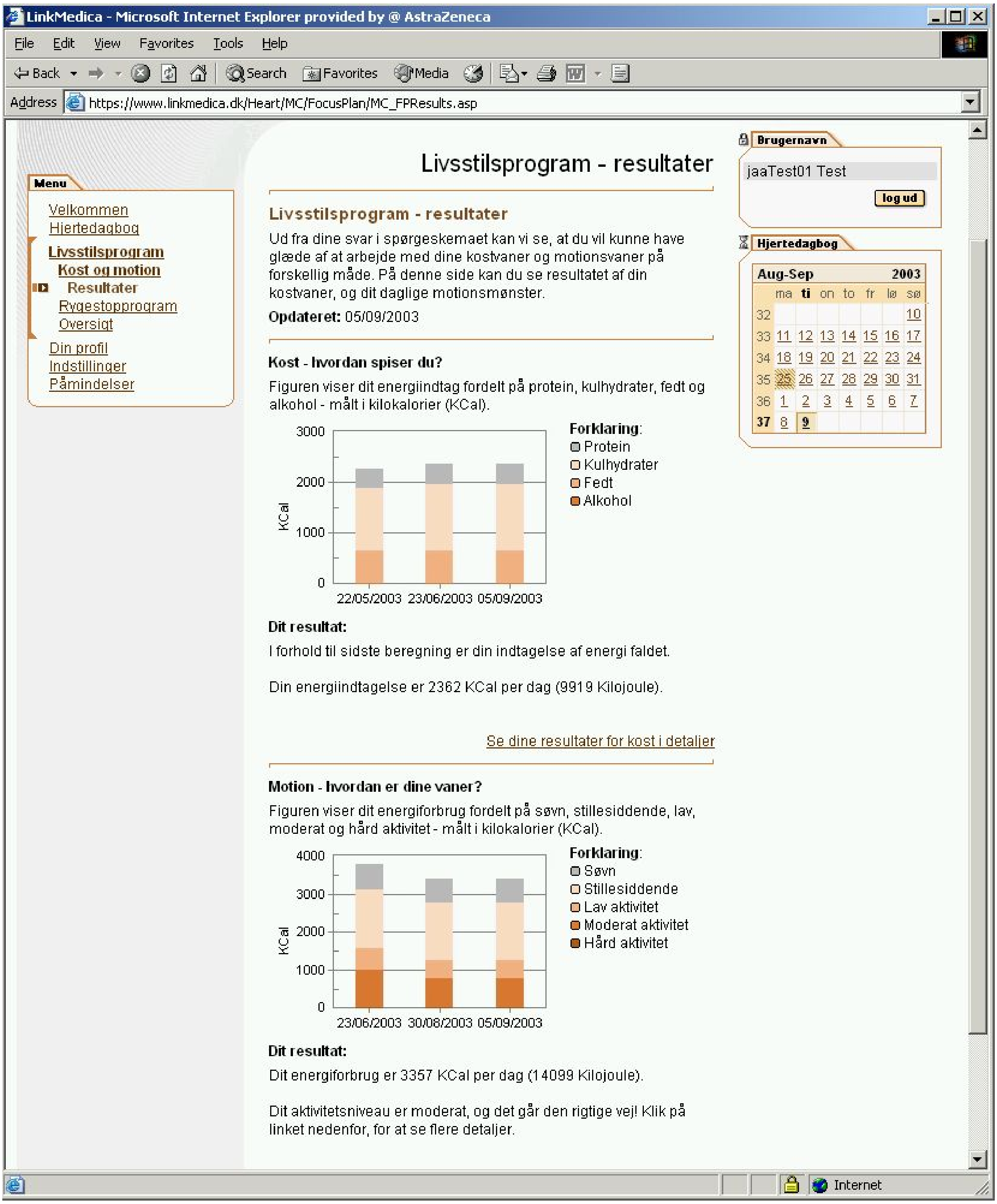
Nine GPs, selected by two AstraZeneca sales representatives, were invited to participate in the feasibility test of LMH. Each GP was asked to introduce between two to five patients to the LMH program. During the feasibility test, the GPs were asked to see each patient at least once after 3 to 6 months after the patient was introduced to the program. After 6 months, we held an evaluation meeting with the GPs. At this meeting, the GPs gave an oral summary of their own and their patients' experience with LMH. Two persons prepared separate minutes of these meetings.

We further asked two of the GPs to select a total of four patients who had participated in the feasibility test to participate in semi-structured in-depth interviews. We chose to interview patients as a qualitative research method, since the feasibility of the program could not be quantified or analysed by statistical methods. Qualitative research focuses on people's lives, their experiences, and emotions, as well as cultural phenomena and social movements [4].

One of the methods used in qualitative research is the semi-structured interview, the main source of empirical material in this study. According to Kvale, the purpose of the qualitative research interview is to describe and interpret themes in the patients' lifestyle that shape a continuum between description and interpretation [5].

In this study, the main research questions for which we sought answers in the patient interviews were: (a) how do patients use the lifestyle program, and (b) what do they learn about lifestyle when interacting with the program. To answer these questions, we made an interview guide which outlines three main themes for the patient interview sessions: the patients' (a) extent of involvement in the pilot study, (b) use of the LMH lifestyle change program, and (c) extent of putting into practice advice given by the program.

Figure 4. Result page. The two graphs show the daily energy intake and energy outflow of the patient. Each colour in the bars indicates a constituent of the diet, eg, protein, carbohydrate,fat, and alcohol, or an activity, eg, sleeping, sitting, low, moderate, and vigorous physical activity.



jaaTest01 Test

Aug-Sep							2003
	ma	**ti**	on	to	fr	lø	sø
32							10
33	11	12	13	14	15	16	17
34	18	19	20	21	22	23	24
35	25	26	27	28	29	30	31
36	1	2	3	4	5	6	7
37	8	**9**					

Livsstilsprogram - resultater

Livsstilsprogram - resultater

Ud fra dine svar i spørgeskemaet kan vi se, at du vil kunne have glæde af at arbejde med dine kostvaner og motionsvaner på forskellig måde. På denne side kan du se resultatet af din kostvaner, og dit daglige motionsmønster.

Opdateret: 05/09/2003

Kost - hvordan spiser du?

Figuren viser dit energiindtag fordelt på protein, kulhydrater, fedt og alkohol - målt i kilokalorier (KCal).

Dit resultat:

I forhold til sidste beregning er din indtagelse af energi faldet.

Din energiindtagelse er 2362 KCal per dag (9919 Kilojoule).

Se dine resultater for kost i detaljer

Motion - hvordan er dine vaner?

Figuren viser dit energiforbrug fordelt på søvn, stillesiddende, lav, moderat og hård aktivitet - målt i kilokalorier (KCal).

Dit resultat:

Dit energiforbrug er 3357 KCal per dag (14099 Kilojoule).

Dit aktivitetsniveau er moderat, og det går den rigtige vej! Klik på linket nedenfor, for at se flere detaljer.

Interviews were held by the second author in the patients' homes to help make them feel comfortable during the interview sessions. In addition, a student of psychology was present as an observer.

The interviews lasted between 45 and 60 minutes and were recorded on Minidisks. Immediately after each interview, the interviewer and the observer discussed their interpretations of the interview, and the patient's attitude towards the program. Later, the interviewer alone revised the interview recordings three times: the first was a general recall of the interview without a specific focus; the second time, the interviews were divided into sections by means of the Minidisk player's bookmark function. Each interview had at least 30 to 40 sections. From each section, significant words and statements were noted and used in the third revision to organize each interview into thematic units.

We also received some unsolicited E-mails and telephone calls from patients who participated in the study, conveying their experience with the program. In addition, one GP asked his patients to fill-in a questionnaire regarding four aspects about LMH: usability, reliability, suggestions for improvement, and relevance of the program for lifestyle change.

The minutes of the interviews, together with the E-mails, questionnaires and calls from patients comprise the data material of this study.

Results

Three GPs withdrew from the pilot test, one because of illness, and two because of time constraints. One GP was unable to get any patients signed up for the study due to technical problems with his Internet connection. Another GP could not participate in the evaluation meeting after the pilot test and sent his comments by E-mail. Table 1 summarizes the demography of the five GPs who participated in the study. The five GPs introduced a total of 25 patients (including 13 females and 12 males), between the ages 23 to 80 years (median age = 43 years) to the LMH pilot study.

Four patients were interviewed for the qualitative research interview. Table 2 profiles the patients interviewed.

Additionally, we received two unsolicited E-mails from two participating patients, and four anonymous filled-in questionnaires turned-in by patients of the GP who could not attend the evaluation meeting.

Table 1. Demography of general practitioners

General Practitioner (GP)	Description
GP1 (Jakob Dahl)	Male, 39 years of age, 5 years in general practice, urban area, 2 doctors in clinic
GP2 (Lars Dudal)	Male, 50 years of age, 13 years in general practice, rural area, 2 doctors in clinic
GP3 (Henning Skytte)	Male, 51 years of age, 17 years in general practice, rural area, 5 doctors in clinic
GP4 (Dennis Christoffersen)	Male, 47 years of age, 7 years in general practice, urban area, 4 doctors in clinic
GP5 (Jesper Holmelund)	Male, 47 years of age, 8 years in general practice, rural area, 3 doctors in clinic

Table 2. Demography of patient interviewees

Patient	Description
A	Female, 44 years old, married, 2 adult children, social worker, overweight
B	Male, 55 years old, married, 2 adult children, former bank employee, currently unemployed, diabetes, hypertension, hypercholesterolemia
C	Female, 43 years old, married, 2 children (1 adult), nursing aide, overweight
D	Male, 40 years old, married, 2 children, veterinary aide, overweight, hypertension

Results From Evaluation Meeting With GPs

Four topics came-up during discussions at the evaluation meeting:

- Program errors
- Initial perception of the program concept
- Program usability
- Program design.

Program Errors

Early on during patient inclusion in the feasibility test, we discovered that the E-mail service did not work, and advice and reminder E-mails were not mailed to patients. This error affected about half the patients for a month and a half, and clearly gave them the impression that the program was ‘dead'.

A small number of minor errors, primarily in algorithms controlling advice messages were also found and corrected.

Initial Perception of the Program Concept

Before they were introduced to the LMH program, the GPs, their nurses, and patients were enthusiastic about the idea of having a life style program available on the Internet. The GPs agreed that general practice needs new means to help introduce and maintain life style changes for patients at risk of life style related diseases. One GP (GP2) said, “The patients were happy when I asked them to participate in a test of a life style program. When I introduced the program to them, their eyes shined and they were ready to start immediately.”

An anonymous letter from a patient noted, “Unfortunately, I never got into the program, but I wanted to do it very much. I believe I would have benefited from it.”

However, during the feasibility test it became obvious from informal contacts (telephone conversations and E-mails) that most patients perceived the program as a *short-termdiet* program, rather than a program intended for long-term *permanent* changes in life style. For example, a middle-aged female expressing her expectations in an E-mail said: “It would have been great if you had to enter your diet every day instead of only once a month. This is important when you have to lose weight. In this way you get the feedback immediately and can correct your mistakes the day after.” We were surprised by this error in perception, since we had worked very hard to communicate LMH as a lifestyle change program rather than a diet reduction program during initial meetings with GPs and on the LMH Web site.

Program Usability

As expected, the GPs had different opinions regarding the LMH Web site layout: one GP found the site layout elegant; another GP found it boring with tiny fonts and too few graphics; and the other three GPs had no special opinion for or against the layout.

All GPs, however, agreed that the program was much too complicated to navigate. GP3 said, “The program is complicated, and navigation is confusing. It is difficult to navigate the site.” GP2 stated, “When a patient logs on for the first time, the program should be extremely simple with the possibility of adding more and more functionality as the patient gains experience.”

Interestingly, some patients did not agree with the GPs negative perception of the site's usability. The same patient who expressed her perception of the program as a diet-reduction program wrote in her E-mail, “First I want to say that the site is logically built, easy to navigate and has some very good information.”

Program Design

The term ‘program design' refers to the logical design of the LMH program—from the patient when first filling-in the questionnaires, viewing the results, then choosing a life style change program in keeping with the extent of personal motivation, and finally, receiving regular advice by E-mail.

The GPs agreed that the questionnaires, especially the diet questionnaire, were far too long. GP3 said, “The questionnaires are too long, and the patients lost interest very quickly.” The GPs also had doubts about the reliability of the results. As GP1 said, “The patients did not trust the results.” This view was supported by GP2 who tried the program himself and found that the results did not match his own observations on the balance between his energy intake and expenditure.

In general, there were surprisingly few comments on advice given via E-mail. This, of course, was partly due to the program error that withheld E-mails to patients for a month and a half. However, the advice was also available on-line on the LMH Web site and the patients did not seem to pay much attention to the available advice. GP3 told us, “Most patients said that they had not seen the advice content and if they had, they did not trust them because they were in conflict with their personal experience.”

An important observation from the study is that none of the patients completed their life style change program. Personal questionnaires were updated no more than a few times, if ever. The patients did not give any clear explanation why they lost interest in the program. They simply disclosed that they stopped using the program. In an anonymous questionnaire a patient wrote: “To be honest, I have not entered the site more than once.”

The GPs, too, agreed that the program was unable to sustain the patient's attention for more than a short period. GP3 said, “… when using the program, they lost interest quickly.” GP2 summed up, “At the beginning, the patients were highly motivated. But the program is much too complicated.” In the GPs opinion, one reason for the patients' loss of interest was that the program's interaction with the patients was too infrequent and meagre. As GP1 said, “It is crucial to have frequent contact with the patients, especially in the beginning.”

Results From Patient Interviews

From the analysis of patient interviews, four issues emerged:

- LMH did not provide patients with new information
- The feedback E-mail content was too detailed and elaborate
- Changes in life style do not come from using a computer based program alone
- Human support and contact are important if life style change programs are to succeed.

Although the content of advice based on the results from the questionnaires is highly detailed, the patients interviewed did not find that they were given any new information. This point became clear early in the interview sessions, as we noticed that the patients' knowledge of lifestyle and their general awareness of how to eat, drink, and exercise to stay healthy was high from the beginning. Consequently, the patients quickly lost interest the program since they felt that they already knew the outcome. Hence, the program was not able to establish a personal interaction with the patients. One of the patients, patient C, said, “I have loads of materials about healthy living. I don't need any more.” From the patients' viewpoint, the information on LMH is very basic and could be one of the reasons why the patients lost interest in the program. Patient A said in the beginning of the interview, “I have been on a diet since I was 11 years old, so I know a lot about what is healthy and what is not.” When another patient, patient D, was asked about his opinion of the program, his comment was, “I don't need the program to tell me that I eat less than I expend. I can see that on the scale – can't I?”

Regarding the texts being too broad and elaborate, patient D said that he spent too much time locating information on the LMH Web site and that he would rather call his doctor or nurse to get a quick answer. Another patient, patient B, preferred to have all information in print and said: “I spent 50 minutes printing everything, and I didn't even want to read it … it's too much. There is nothing wrong with the content, but it's too much.”

As for the third issue (i.e., changes in life style do not come from using a computer program alone), all patients agreed that the use of the program did not provide the necessary support in their struggle towards a healthy life style. They said that the program itself was merely a tool and that it could never replace support from a health care professional. One of the patients, patient C, noted that the computer could not keep an eye on her, as her nurse could, “I need another person to check my weight and say, ‘it's for your own good, it's not for me you are doing this.' The program may give me advice and ideas, but I need the nurse to coach me.”

Patients seemed to give a high value to personal relations with a health care professional. They expressed great conviction in the competence of the health care professionals, a trust that they could not seem to establish with the LMH computer based program. Hence, the patients were sceptical with the results that the LMH program provided. Patient A said, "… it's the doctor who is educated and knows things. You cannot expect a computer program to know what is good for you. However, if your doctor tells you to use a computer program, it might provide extra information." As a result, patient A acknowledges that when the doctor endorses a program it must be of some value for her as a patient.

Discussion

As stated in the introduction, this study was intended merely to be a test of the LMH program and to find software errors in the program. Data for the study was collected rather randomly from different sources: minutes from evaluation meetings with hand-picked GPs who reported their patients' experience with the LMH program; unsolicited E-mails and letters from patients; and issues appearing in interviews with selected patients. We acknowledge that the patients who where selected by the GPs to participate in the study, especially the patients selected for interviews, may not at all be a representative sample of the general population of people (not necessarily patients), needing life style changes. However, we believe that despite these limitations, our findings and conclusions may be of interest to other researchers working on internet based disease management or prevention.

Our pilot study confirms the need for, and an open attitude towards life style change programs delivered via the Internet. The doctors confirm the need to aid their patients starting a life style change program with a tool that complements the doctor's advice and direction. The patients, too, seem to be eager to get additional help and support in striving towards a healthy life. The Internet appears to be an ideal medium for providing the additional support that complements the doctor's counsel.

However, the present version of LinkMedica Heart does not seem to fulfil this need: the patients did not use the program more than a single, or a few times.

It is important to stress that the study was a real time study, with an aim to learn how GPs and their patients use and perceive LMH—after a relatively short interaction with the program. The objective was not to investigate the effect of the LMH program on patients using the program. Hence, we did not attempt to control either the GPs' or the patients' use of LMH during the test phase.

Our study identifies three issues that need to be addressed in order for the LMH program to be successful in bringing about patient lifestyle changes:

- Complicated user interface and navigation
- Reliability of questionnaire results and content of advice
- Lack of personal interaction between the program and the patient.

Interface

It is tempting to think that if the user interface and navigation were improved, it would be sufficient to sustain the patients' attention. Without any doubt, an improved interface would certainly help encourage new patients to enter the program for the first time—especially if they are attempting to join the program on their own without support from a healthcare professional. However, improvements to the interface may not necessarily sustain participant loyalty to the program for an extended period. The patients included in the study were handpicked by their GPs and were cautioned that they were testing a new program with many rough edges. In addition, the patients in the study had support of their GP's to help them get started with the program. Hence, we do not believe that simply improving the user interface would be enough for LMH to be a successful Internet based program.

Reliability

A lot of effort was put into creating the content and the logic behind the result and advice text for the LMH Web site. To make the results and advice precise and personal, a typical feedback message from LMH was almost as long as five printed pages. Nevertheless, some patients felt that the feedback was not in accordance with their own expectations. For example, the LMH program told some patients that their energy intake was *higher* than expenditure, when in fact they had been loosing weight. Some other patients were told that their intake was *lower* than their expenditure when in fact they were gaining weight. Moreover, patients were not inclined to read the lengthy textual content, either on the computer screen or as a print out of the text.

The accuracy of the energy calculations in the LMH program was not an issue in this study. However, accuracy of the calculations would be an issue and a major problem if patients were wary of the program overall. Any mistrust will inevitably lead the patients to stop using the program, even if it is the patient who is mistaken and not the program.

It might be a better idea to simplify the feedback function of the program engine with precise, qualitative advice in the form of concise messages based on a patient's own perception of his or her dietary habits, coupled with measured developments in weight and waist circumference. The questionnaires could also be similarly simplified.

The observation that patients are more likely to trust their own opinion than that of a computer program supports our previous findings from a similar Web service for asthma patients, LinkMedica-Asthma [6]. In the previous study, we found that, in general, asthma patients did not follow the advice given by the Web site, even if acknowledged asthma experts offered advice. When the advice was in disagreement with their own previous experience or attitudes, whether medically true or not, patients disregarded the advice

Personal Interaction

The diet questionnaire is intended to reveal the diet for the previous month. Therefore, it would be misleading to ask the patient to update the questionnaire more often. On the other hand, the study shows that in order to sustain patient attention, the program needs to interact with patient more frequently, preferably on a daily basis. Some patients wanted to enter their questionnaires every day, while others preferred a less demanding program. Consequently, the ideal program should be adaptable to the patient's preference. Combining succinct, qualitative questionnaires with concise advice delivered via

E-mail, and/or SMS (Short Message Service provided by wireless phone companies), could prove useful. Also, breaking up advice messages into small fragments, delivered on a daily basis might help patients who do not want to read long, all-inclusive texts.

Suggestion to Improve the Site

In summary, we suggest a number of improvements to the LMH Web site:

- A simplified diet questionnaire for a *qualitative* evaluation of the patient's dietary habits.
- Frequent (preferably daily), and concise feedback messages from the program to the patient in the form of E-mail and/or SMS messages. These messages can possibly contain practical advice about healthy living, and food recipes attuned to the patient's lifestyle profile.
- Suggestions to monitor weight and waist circumference. Physical measures of weight and waist circumference can be the patient's means of assessing whether there is any positive effect of his or her lifestyle change efforts.
- Removal of options in choosing a lifestyle change program. The LMH program in its current state prompts the patient to chose between several lifestyle change programs based on his or her degree of motivation. Our study suggests that patients are highly motivated from the beginning and that too many program options confuse them. Hence, the program should automatically select the most appropriate lifestyle change program based on the patient's profile.

Conclusion

This study confirms the need for, and a positive attitude towards Web-based programs for supporting people who want to improve their health through life style changes. In its present form, LinkMedica-Heart, our life style change program, does not address these needs. A number of design changes and improvements to the program are suggested.

Acknowledgments

AstraZeneca A/S, Roskildevej 22, 2620 Albertslund, Denmark sponsored this study.

The Research Centre for Prevention and Health, Copenhagen University Hospital Glostrup, Copenhagen, Denmark, a public research centre working in the field of public health and disease prevention, was responsible for content of the questionnaires and software algorithms for the feedback messages.

Jacob Lenau, e-Business Manager, AstraZeneca, Denmark reviewed and approved the manuscript.

Kirsten Broe Pedersen, AstraZeneca, Denmark proofread the manuscript.

Conflicts of Interest

The authors have no personal financial interests related to the subject matter discussed in the manuscript.

References

1. ; National Board of Health, Center for Health Promotion and Prevention. National Action Plan against Obesity, Recommendations and Perspectives, Short version. URL: http://www.sst.dk/ [accessed 2003 Sept 16]
2. ; WHO Technical Report Series. Diet, Nutrition and the Prevention of Chronic Diseases. URL: http://www.who.int/hpr/NPH/docs/who_fao_expert_report.pdf [accessed 2003 Sept 16]
3. ; Dansk Catering Center, Herlev, Denmark. Home page. URL: http://www.dankost.dk/ [accessed 2003 Sept 10]
4. Strauss A, Corbin JM. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory, 2nd edition. Thousand Oaks, CA, USA: SAGE Publications; Sep 22, 1998:11.
5. Kvale S. InterViews: An Introduction to Qualitative Research Interviewing. Thousand Oaks, CA, USA: Sage Publications; Mar 14, 1996.
6. Anhøj J, Nielsen L. Quantitative and Qualitative Usage Data of an Internet-based Asthma Monitoring Tool - From the user's point of view. J Med Internet Res 2004 Sep;6(3):e23 [FREE Full text] [doi: 10.2196/jmir.6.3.e23]

Abbreviations

GP: General Practitioner
HCP: Health Care Professional
SMS: Short Messaging System
LMH: LinkMedica-Heart
AZ: AstraZeneca
RCP: Research Centre for Prevention and Health

submitted 19.09.03; peer-reviewed by S Krishna, G Demiris; comments to author 08.11.03; revised version received 17.11.03; accepted 10.01.04; published 08.09.04.

Please cite as:
Anhøj J, Jensen AH
Using the Internet for Life Style Changes in Diet and Physical Activity: A Feasibility Study
J Med Internet Res 2004;6(3):e28
URL: http://www.jmir.org/2004/3/e28/
doi:10.2196/jmir.6.3.e28
PMID:15471754

Original Paper

The Role of the Internet in Patient-Practitioner Relationships: Findings from a Qualitative Research Study

Angie Hart[1], DPhil, MPhil, BA, Dip Psych Counselling; Flis Henwood[2], BA (Hons), MSc, PhD; Sally Wyatt[3], BA (Hons), MA, PhD

[1]Centre for Nursing and Midwifery Research, University of Brighton, UK
[2]School of Computing, Mathematical and Information Sciences, University of Brighton, UK
[3]Department of Communication Studies, University of Amsterdam, The Netherlands

Corresponding Author:
Angie Hart, DPhil, MPhil, BA, Dip Psych CounsellingPrincipal Lecturer
Centre for Nursing and Midwifery Research
Faculty of Health
University of Brighton
Room 264, Mayfield House
Falmer, East Sussex BN1 9RT
UK
Phone: +01273 644051
Email: a.hart@brighton.ac.uk

Abstract

Background: Studies suggest that there has been an increase in the use of the Internet by patients in many Western societies. However, despite the many texts available on health and the Internet, not much is known about how much patients actually use the Internet to look up health information in their daily lives. We know little about what meaning this activity has for their experience of health and illness, and for their relationship with health-care practitioners.

Objective: To explore patients' and practitioners' use of the Internet and to consider whether use of the Internet is changing relationships between patients and health-care practitioners.

Method: The study used qualitative interviews and observations of patient–practitioner interaction. Our purposive sample of 47 patients (32 women and 15 men) had all had contact with the health services for information/treatment in relation to hormone replacement therapy (HRT)/menopause and Viagra/erectile dysfunction. The setting for the research was in general practitioners' surgeries, specialist clinics and patients' homes in the United Kingdom. Participants reflected a wide range of socio-economic groups, but most were white and British born, which, given the ethnic make-up of the town in which we conducted the research, was not surprising. In addition to patients, we interviewed 10 health-care practitioners (4 consultant doctors, 3 GPs, 2 specialist nurses, and a psychologist) about their own health information seeking practices (HISPs) and those of their patients.

Results: Use of the Internet can increase patients' knowledge about their health conditions, although patients in our study were often too overwhelmed by the information available on the Internet to make an informed decision about their own care. Patients have a great deal of trust in their health-care practitioners. Health-care practitioners need to improve their own skills in Internet use. Hype around Internet use by patients appears to exceed the reality of Internet use.

Conclusions: Our qualitative study suggests that use of the Internet is contributing to subtle changes in the relationship between health-care practitioners and their patients, rather than effecting the dramatic transformation some people envisage for it.

(J Med Internet Res 2004;6(3):e36) doi:10.2196/jmir.6.3.e36

KEYWORDS

Information literacy; patient-practitioner relations

Introduction

The rapid rise in the use of the Internet as a source of health information, as part of a general rise in Internet use, has been well documented [1-3]. Claims from policy sources, academic researchers, and patients themselves are that the increase in the use of the Internet for health information will result in positive shifts towards more equitable, or even patient-controlled, relationships between practitioners and patients [4-8]. Therefore, an understanding of Internet use may lead to further shifts in the models of practitioner–patient interaction that are used in the educational preparation of new practitioners [9-11]. However, some have drawn attention to the dangers of patients using the Internet for health information. For example, some raise the potential for misdiagnosis and exploitation [12-14]. Others suggest that Internet use can erode patients' faith in the authority of health-care practitioners [15-17]. In response to such concerns, health-care providers have established classificatory systems for evaluating the scientific worth of Web information [18,19].

Methods

Over the past decade, the number of studies about the Internet has grown dramatically [20-24]. Some focus on particular Web sites, others on particular social groups' use of the Internet. Furthermore, we are now beginning to see a number of studies specifically about health information and the Internet [8,15,25]. However, these focus on specific groups of Internet users (for example, the “self-helpers”) and the practices they employ in such use [26], or on Internet use by patients under experimental conditions in computer laboratories [25]. These studies have illustrated well the potential for users to shape just what the Internet is or can be to individual users. However, they give us little idea of the overall significance of the Internet in relation to the other information media and sources these users are accessing, including health practitioners, in the course of their daily lives. In contrast, our research seeks to locate the Internet, for our particular sample, within a wider information landscape. Hence, the starting point for our research was people's own experience of finding information on a particular topic, using a “follow the user” approach. We focused broadly on participants' health information seeking practices (HISPs), including sources of information such as friends, health-care practitioners, NHS Direct, television, leaflets, etc. Because of this we are able to understand our participants' Internet use in the context of their other HISPs.

Our study of 47 patients (32 women, and 15 men) between the ages of 39 and 73, explored how far use of the Internet was changing the way in which they managed their health and their medical encounters. We received local research ethics approval for the study. The main method of enquiry was semi-structured interviews, each lasting between one and two hours. The interviews, which were conducted between November 2001 and November 2002, were undertaken by members of the project team and were tape-recorded and subsequently transcribed verbatim. They included questions about people's reasons for considering HRT or Viagra, their understanding of how these drugs work, and their perception of the advantages and disadvantages of their use. Participants were also asked about their awareness and use of alternative treatments. In addition, they were asked about whether and how they looked for health information generally, as well as for HRT, Viagra, and other treatments for their symptoms related to menopause or erectile dysfunction. People were asked where they look and where they find information, by what means they find it, and how they interpret and make sense of it both for themselves and in negotiation with others, including in consultation with health-care practitioners. If people used the Internet, they were asked for how long they had done so and what they used it for. If they used it for finding health information, they were asked how they did this, as well as about the advantages and disadvantages of the Internet as a source of information. Nearly half of the participants, 16 women and 5 men, were interviewed a second time, 6 to 9 months after the first interview, in order to discuss any changes in health, treatment, and information-seeking behaviour.

Descriptive statistics were generated through the use of Excel. Qualitative data were analysed using NVivo software. All the researchers were involved in coding the transcripts, and we jointly agreed the coding frame. During the initial stages of analysis we compared our transcription analyses in order to enhance the reliability of our coding.

Our sample included both Internet users and non-users. Of the 47 patients interviewed, 24 had access to the Internet: 19 of these 24 were women, and 5 were men. All participants were interviewed at least once, with a sub-section of 21 patients being interviewed at least twice (5 men and 16 women). Most interviews took place within participants' own homes, although some were conducted in offices located within health-care settings. We also observed 16 consultations between patients and health practitioners. Participants were recruited through a GP surgery and two specialist clinics (gynaecology and erectile dysfunction clinics).

We sought out patients who had had contact with the health service as a result of needing to know about two specific, but quite common, drugs/forms of treatment. For men, we chose Viagra in relation to erectile dysfunction, and for women, HRT in relation to menopause. All participants were interviewed about their HISPs in relation to their general health, and to these specific issues. Given the size and characteristics of our sample, we should point out that it may not be typical of the HISPs of patients with other health conditions. There is some evidence to suggest that patients with rare conditions are more active on the Internet [27]. Participants reflected a wide range of socio-economic groups, but most were white and British born, which, given the ethnic make-up of the town in which we conducted the research, was not surprising. In addition to patients, we interviewed 10 health-care practitioners (4 consultant doctors, 3 GPs, 2 specialist nurses, and a psychologist) about their own HISPs and those of their patients.

Of the 32 women interviewed, the average age was 55, with the youngest being 39 and the oldest 73. Eighteen were in relationships. The men were older, ranging from 54 to 81, with an average age of 66. Ten were in relationships at the time of the study. Our sample included people from a range of socio-economic groups, with varied educational experience and qualifications.

This overview of the study and the participants provides some clues as to the everyday life experiences of these people as they try to live with and inform themselves about different aspects of aging.

Results

Sources of Health Information

Amongst both the male and female participants in this study, medical situations were often complex. The range of symptoms, the prescribed treatments, and the after-effects experienced all varied. The possible sources of information were enormous. So, how did our participants inform themselves about health matters? All drew more or less actively on a range of sources. For both men and women, the family doctor was the most important source, and we explore this in more detail below. Family members, usually women, were the second most frequently cited source, with friends, pharmacists, and alternative practitioners also mentioned. The media used include magazines, television, World Wide Web, self-help books, newspapers, and other items such as leaflets from pharmacists or those provided by pharmaceutical companies with drugs. The most striking difference between the women and the men was that women had much more diffuse social networks, including family, friends, neighbors, and colleagues, which they drew upon to talk about their health, whereas men talked primarily with their doctors and sexual partners.

Of the 15 men in our study, 9 had access to the Internet, but only 3 used it to access health information. Of the 32 women, 24 had access to the Internet, but only 18 of them used it for this purpose. However, as we shall see below, the 21 participants who did use the Internet to look up health information did not find the experience trouble-free.

IT Literacy

Our study showed that most participants, both patients and practitioners, were not very IT literate when it came to looking up health information on the Web. Becoming informed involves skills and competencies that relate both to the information itself and to the medium used to access that information. Amongst our participants we found many who had very few information literacy skills and others who lacked general computer literacy skills and/or Web-searching skills. Most of those who wanted to access information from the Web relied on intermediaries, and we report on this elsewhere [28]. Interestingly, one of the most damning views on self-competence came from a practitioner, a specialist nurse, rather than from a patient: “I'm not very good at it. Somebody says ‘Internet' and I think [draws in breath]. I get lost on it. That's why it terrifies me” (specialist nurse, no.2).

Some patients were aware of their lack of search skills, while others seemed unaware of, and largely unconcerned about, their rationale for accessing information the way they did. One patient participant (female participant, no. 8), for example, showed little awareness of the sources of information (publisher, organization, etc.) she finds on the Web, and expressed no interest in issues of information validity or quality, tending to trust whatever she finds there, regardless of source. While this participant was our least information-literate Internet user, many other patients were similarly uninterested in information source and validity issues, displaying low levels of information literacy. Practitioners, on the other hand, were more aware of their own skill limitations, although many were inclined not to do anything about this. Time constraints and the lack of convenient Internet access were cited as major reasons for this.

No patients reported having been given information about Internet sites from practitioners. Of the practitioners we interviewed, only one actively encouraged patients to look up information in this way, although three said that in the past they had given out such information. In our observations of consultations, we saw no examples of information about Internet sites being given out. However, some practitioners we spoke to saw encouraging Internet information seeking as a potentially useful development of their role in the future. One nurse commented that she would like to see patient Internet access in her clinic. Others mentioned that they might provide Internet addresses in their clinic. Their own lack of IT skills, and perceived lack of time, probably had a hand in such developments being slow to get off the ground.

Patients' Trust in Practitioners

Our research confirms the view that that despite the negative publicity health practitioners have received of late in the UK (for example, the Shipman case, in which a GP murdered many of his elderly patients by deliberately giving them the wrong medication), trust in them remains very high. Most patient participants mentioned that they would go to a known health-care practitioner first to discuss a health issue, rather than use any other source, including those to be found on the Internet. Box 1 illustrates comments made by patient participants about the trust they have in health practitioners.

Textbox 1. Patients' trust in practitioners

> *You can do so much on the net, you can do so much on the phone, but it is eye-to-eye contact [with a health practitioner] that counts.* [male participant, no. 17]
>
> *Well, I have always trusted the doctor but then of course I grew up in the era, as I'm 60, I grew up when you did trust the doctor.* [female participant, no. 29]
>
> *I do trust dispensers, chemists, doctors. The medical profession. Basically professionals. That's where my basic trust is.* [female participant, no. 14]

Very few patients expressed views to the contrary; some of those who did mentioned friends and family as primary sources of health information. A minority expressed a sense of having been let down by health practitioners; however, being let down by one practitioner did not generally mean that patients developed a more diffuse sense of distrust.

Negative comments about health practitioners as information providers were rare in our research. As a result of this high level of trust, many patients did not feel the need to access alternative, or even complementary, sources of information such as those on the Internet.

The Symbolic Power of the Internet

Despite the strong sense of trust in practitioners as a main source of health information, and despite the low levels of IT literacy in our sample, it was striking to note that many patients reified the power of the Internet, for good or for ill. We refer to this as the Internet's symbolic power, and to some extent it applied also to the practitioners. There was a strong sense amongst many participants, even those who had never used the Internet, that they should be doing so, and that they were missing out in a profound sense if they were not. In some cases, both patient and practitioner participants were clearly embarrassed by the fact that they were not "Internet savvy." A number of participants had quite high expectations of what they would find there if only they acquired sufficient expertise. However, cases where the symbolic power of the Internet was implicitly referred to were rarely backed up by reference to actual experiences with it. Thinking specifically about the experiences of patients who reified the Internet, the quotes in Box 2 demonstrate a sense of needing to be online to reap the benefits of cheap deals, and email communication, rather than specifically to access health information. This was particularly the case for male participants. For example, one participant had used the Internet extensively to search for holidays, but when we asked him about looking up health information on the Internet, he said that he did not have time for that.

Textbox 2. Positive patients

> *I had heard of people looking things up on the Internet and finding out things. I thought I ought to be able to do that and I should try that.* [male participant, no. 11]
>
> *I want to be on the Internet, I'm missing out on a lot.* [male participant, no. 5]
>
> *[The Internet is] a marvellous medium and you just want to learn more and more about it. … You can get there instantly and if it doesn't give you exactly what you want there's usually a way of finding out more. …I think the Internet is marvellous…* [male participant, no. 17]
>
> *I haven't got it [the Internet] yet, but I've started this week a course on computers, to get to grips with the Internet and the email and buy one… you've really got to have one.* [female participant, no. 29]

For health practitioners, the symbolic role of the Internet specifically as a source of health information was more marked. Some felt that it was an incredibly useful source of information that they, and in some cases also their patients, should be accessing. For example, a specialist nurse with little Internet experience was enthusiastic: "…we'd love it [Internet access for patients in the clinic], absolutely."

However, it was far more common in our study for health practitioners to view the Internet as having profoundly negative powers. A few expressed their concern that Internet use would encourage patients to challenge their medical authority. Many were worried about inappropriate self-diagnosis, and about patients' taking advice from sites that did not concur with medical opinion. The Internet's role in feeding the anxieties of patients with hypochondria was raised by three practitioners, and problems with "all sorts of odd Web sites," and patients coming in armed with printouts were mentioned by a further two. One consultant was concerned that patients would act on individualised accounts from others who post their experiences on the Web.

For the most part, these anxieties were expressed in the context of a fairly balanced view of the Internet's threats and promises. However, this was not always the case: "I am sure people are ferociously searching the Internet for information," remarked one health-care practitioner who clearly did not approve of this (HCP, no. 1). The participant went on, "The Internet … you find yourself having to substantiate some really difficult scenarios where somebody has come armed with this information: you're on your back foot and you just don't know where to go. Can't argue about it, you are only a [HCP] and you haven't got the arguments against their specific topic which they find particularly interesting. And you are at a loss: it puts you on your back foot and makes you feel quite stupid." However, when we asked about how often people had actually come to this person with Internet information, "only three times" was the answer.

Patients reported that some health practitioners sought to assert their authority by dismissing the patient's acquired knowledge. For example, one woman said some health practitioners had made it clear that they thought she should not look things up for herself. She felt that the view was, "you're here with me now and I'm telling you this" (female participant, no. 29).

Consultations between practitioners and patients are inter-subjective experiences in that there are always at least two people involved. As such, psychodynamic factors, as well as professionally driven agendas, are at play. Consultant psychiatrist Jeremy Holmes suggests that "perhaps rather than being motivated by altruism and scientific integrity, we are merely using our patients to bolster our fragile sense of competence and health" [29]. This perspective can be linked to debates about the limits of professional knowledge and authority, and about ways in which practitioners emotionally protect themselves from their patients, both of which go back a long way [30-32]. The health-care practitioner we discussed above was a self-described beginner in Internet use. How much, then, were practitioners' concerns about the negative power of the Internet a reflection of their own insecurities in its use, and in their own medical competence? It did seem to us that IT literacy (in terms of sorting through Web sites and evaluating the reliability of information) was as much an issue for the health-care practitioners in our study as it was for patients.

This point may have wider application in our study and beyond, although we are cautious about this since we interviewed only

10 practitioners. Nevertheless, they came from different professions and IT literacy skills were an issue for most of them, as they are for many NHS professionals [33]. White and Stancombe's discourse analysis of encounters between patients and practitioners shows that medical decision-making in the moment is a complex combination of science, art, moral action, and psychodynamic process [34]. They argue for analysis of clinical decision-making to be made on what they describe as a “re-embodied” clinician. “Putting the mind back into a feeling body—that gets angry, has friends, enemies, loyalties, vendettas, has a past and an anticipated future, becomes weary or bored—forces us to consider how we may understand the processes of judgment and intuition more adequately” [34]. The use of the Internet in health needs to be understood in this light too, and not solely in relation to debates about information quality from largely biomedical understandings.

Discussion

To what extent, then, can our findings contribute to the debate about the changing relationships between patients and practitioners? First, our study reveals only a handful of patient participants actively challenge medical authority using the information they acquire on the Internet. Most patients articulated high levels of trust in health practitioners. Even those few who did look up health information on the Internet prior to their consultation, usually did not tell the practitioner they had done so. One way of understanding such covert practice is to see it, as Scott suggests, as “a weapon of the weak” [35] in a context where one party (the patient) significantly lacks the power to determine the actions of another (the practitioner).

Our study revealed very few examples of patients having acquired information from the Internet that actually resulted in an explicitly patient-controlled outcome. There are a number of potential reasons for this. Clearly, some practitioners were defensive about their own Internet competencies. As a result, they asserted their medical authority all the more, thereby dismissing the positive potential of the Internet, particularly if the information from it came via a patient. In other cases, and in corroboration of other studies [36,37], time limitations constrained the possibility of engaging in dialogue that might have led to a patient-controlled, or even a patient-centred, outcome. This was something that many participants in our study, both patients and practitioners, were aware of.

In their exploratory paper, Gerber and Eiser present a broad typology of how patient–physician relationships might fare in the Internet age [38]. What does our research suggest about the future of patient–practitioner relationships in the UK? If practitioners with poor IT skills do not improve their own IT literacy, use of the Internet by their patients may result in such practitioners defensively asserting their “expert opinion” all the more in the heated moment of the consultation. Relationships between patients and practitioners who are more Internet savvy can go in one of three ways. First, as we have seen, time constraints on the consultation (which studies have shown patients generally understand and respect), can lead to curtailment of opportunities for patients to become better informed. In this case, consultations are unlikely to move towards the patient-controlled end of a continuum. Rather, patients can be quickly and authoritatively steered towards the course of action preferred by the practitioner without any discussion of alternatives, even though the practitioner, and indeed the patient, might know of them.

A slightly different take on this first scenario presents us with the second one. This would involve practitioners using their technical skills to guide trusting patients to “approved sites,” information from which would reinforce the course of action favored by the practitioner—the “Internet prescription,” as Gerber and Eiser put it [38]. One doctor in our study reported steering patients' decision-making in this way. If it were to happen more widely, some may see this as Internet prescribing: information for compliance, rather than choice. However, the degree of trust patients in our study wanted to put in their practitioners potentially tempers this criticism. Clearly, some passive patients are content to be so.

The third scenario presents a view that moves more toward patient-controlled encounters. Here the privileging of practitioners' biomedical perspectives is not automatic. The perspective of one doctor in our study captures this. Thinking about the role of the Internet in relation to his dynamic with patients he suggested, “It's something about our role changing and it's something about our role becoming the processors of information rather than the providers of information” (HCP, no. 2). Other studies of HISPs suggest that the realization of this scenario is unlikely to be just around the corner for most patient–practitioner encounters [37,38]. Nevertheless, this doctor's view presents a challenge to traditional constructions of patient–practitioner relationships, and is firmly in keeping with policy shifts and the vision of the central role of patients and citizens in NHS (National Health Service) provision [40]. This doctor's view also reflects a popular discourse in the literature on health and the Internet: that relationships will be transformed [4-8,41]. Of course, the Internet is not the only mediator of information that may precipitate such a role transition from HCP-centred to patient-controlled consultations. Its symbolic importance, in drawing attention to the patient–practitioner relationship and throwing the issues of authority and trust into sharp relief, as we have explored above, is clear.

Despite the many texts available on health and the Internet, much is still unknown about how much patients actually use the Internet to look up health information in their daily lives, and what meaning this activity has for their experience of health and illness, and for their relationships with health-care practitioners [42]. Ours was a small-scale study and cannot be generalizable. At the very least though, it provides some evidence of the symbolic role of the Internet. Though slow to change, many patients and practitioners feel that they ought to be getting online. Also, whatever the future of relationships between patients and practitioners, our study demonstrates empirically, at least in one UK context, that Internet-mediated changes in their dynamics are discernible, if not dramatically so.

Acknowledgments

The authors are grateful to Julie Smith and Hazel Platzer for carrying out some of the interviews for this research. Grateful acknowledgement is also due to the Economic and Social Research Council and the Medical Research Council who jointly funded the study (Project Number L218252039). Thanks too to the patients and health professionals who participated in the research.

Conflicts of Interest

None declared.

References

1. ; BBC. Health websites gaining popularity. URL: http://news.bbc.co.uk/1/hi/health/2249606.stm [accessed 2002 Sep 19]
2. ; Datamonitor. Online consumer segmentation. URL: http://datamonitor-market-research.com/Merchant2/merchant.mvc?Screen=SFNT [accessed 2002 Oct 23]
3. Fox S, Rainie L. Vital decisions. How Internet users decide what information to trust when they or their loved ones are sick. Washington, DC: Pew Internet & American Life Project; May 22, 2002. URL: http://www.pewinternet.org/pdfs/PIP_Vital_Decisions_May2002.pdf
4. ; Department of Health. Building the information core implementing the NHS plan. London: Department of Health; Jan 2001. URL: http://www.dh.gov.uk/assetRoot/04/06/69/46/04066946.pdf
5. Graham W, Smith P, Kamal A, Fitzmaurice A, Hamilton N. Randomised controlled trial comparing effectiveness of touch screen system with leaflet for providing women with information on prenatal tests. BMJ 2000 Jan 15;320(7228):155-160 [FREE Full text] [PMC: 10634736] [Medline: 20100672] [doi: 10.1136/bmj.320.7228.155]
6. Hardey M. 'E-health': the internet and the transformation of patients into consumers and producers of health knowledge. Information, Communication & Society 2001; 4(3):388-405. [doi: 10.1080/13691180127053]
7. Ferguson T. Health online and the empowered medical consumer. Jt Comm J Qual Improv 1997 May;23(5):251-257. [Medline: 97323227]
8. Eysenbach G. Consumer health informatics. BMJ 2000 Jun 24;320(7251):1713-1716 [FREE Full text] [Medline: 20323060] [doi: 10.1136/bmj.320.7251.1713]
9. Balint M. The Doctor, His Patient And The Illness. London: Pitman Medical Pub. Co; 1966.
10. Gothill M, Armstrong D. Dr. No-body: the construction of the doctor as an embodied subject in British medical practice 1955-1997. Sociol Health Illn 1999; 21(1):1-12. [doi: 10.1111/1467-9566.00139]
11. Little P, Everitt H, Williamson I, Warner G, Moore M, Gould C, et al. Observational study of effect of patient centredness and positive approach on outcomes of general practice consultations. BMJ 2001 Oct 20;323(7318):908-911 [FREE Full text] [PMC: 11668137] [Medline: 21522822] [doi: 10.1136/bmj.323.7318.908]
12. Eysenbach G, Diepgen TL. Towards quality management of medical information on the internet: evaluation, labelling, and filtering of information. BMJ 1998 Nov 28;317(7171):1496-1500 [FREE Full text] [Medline: 99051215]
13. Heathfield H, Pitty D, Hanka R. Evaluating information technology in health care: barriers and challenges. BMJ 1998 Jun 27;316(7149):1959-1961 [FREE Full text] [Medline: 98306102]
14. Jadad AR, Gagliardi A. Rating health information on the Internet: navigating to knowledge or to Babel? JAMA 1998 Feb 25;279(8):611-614. [Medline: 98146162] [doi: 10.1001/jama.279.8.611]
15. Hardey M. Consumers, the internet and the reconfiguration of expertise. In: Harlow E, Webb SA, editors. Information and Communication Technology in the Welfare Services. London: Jessica Kingsley Publishers; Jan 1, 2003.
16. Harlow E, Webb SA, editors. Information and communication technologies in the welfare state. London: Jessica Kingley Publishers; 2003.
17. Oliver CW, Doward WA. Quality of patient information on the orthopaedic Internet. Clinical Medicine & Health Research 1999 Dec 17 [FREE Full text]
18. Impicciatore P, Pandolfini C, Casella N, Bonati M. Reliability of health information for the public on the World Wide Web: systematic survey of advice on managing fever in children at home. BMJ 1997 Jun 28;314(7098):1875-1879 [FREE Full text] [Medline: 97367429]
19. Silberg WM, Lundberg GD, Musacchio RA. Assessing, controlling, and assuring the quality of medical information on the Internet: Caveant lector et viewor--Let the reader and viewer beware. JAMA 1997 Apr 16;277(15):1244-1245. [Medline: 97256510] [doi: 10.1001/jama.277.15.1244]
20. Consalvo M, Paasonen S, editors. Women & Everyday Uses of the Internet: Agency & Identity (Digital Formations). New York: Peter Lang Publishing; Dec 1, 2002.
21. Katz JE, Rice RE. Social Consequences of Internet Use: Access, Involvement, and Interaction. Cambridge MA: The MIT Press; Sep 9, 2002.
22. Gauntlett D, editor. Web.Studies: Rewiring Media Studies for the Digital Age. London: Arnold Publishers; Oct 1, 2000.
23. Jones S, editor. Doing Internet research. London: Sage; 1999.
24. Loader B, editor. Cyberspace divide: equality, agency and policy in the information society. London: Routledge; 1998.

25. Eysenbach G, Köhler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. BMJ 2002 Mar 9;324(7337):573-577 [FREE Full text] [PMC: 11884321] [Medline: 21881326] [doi: 10.1136/bmj.324.7337.573]
26. Burrows R, Nettleton S, Pleace N, Loader B, Muncer S. Virtual community care? Social policy and the emergence of computer mediated social support. Information, Communication & Society 2000; 3(1):95-121. [doi: 10.1080/136911800359446]
27. Houlihan BV, Drainoni ML, Warner G, Nesathurai S, Wierbicky J, Williams S. The impact of Internet access for people with spinal cord injuries: a descriptive analysis of a pilot study. Disabil Rehabil 2003 Apr 22;25(8):422-431. [doi: 10.1080/0963828031000071750] [Medline: 22630435]
28. Wyatt S, Henwood F, Hart A, Platzer H. Transforming health? The internet, health and everyday life. Science Sociales et Sante (Social Science & Medicine) 2004 Mar;22(1):45-68.
29. Holmes J. Good doctor, bad doctor—a psychodynamic approach. BMJ 2002; 325(7366):722 [FREE Full text] [doi: 10.1136/bmj.325.7366.722]
30. Friedson E. Professional Dominance: the Social Structure of Medical Care. Chicago: Aldine de Gruyter; 1970.
31. Illich I. Disabling Professions (Ideas in Progress). London: Marion Boyars Publishers; Sep 1, 1978.
32. Menzies-Lyth I. The functioning of social systems as a defence against anxiety. Report to the Centre for Applied Social Research. London: Tavistock Institute of Human Relations; 1960.
33. Majeed A. Ten ways to improve information technology in the NHS. BMJ 2003 Jan 25;326(7382):202-206 [FREE Full text] [PMC: 12543838] [Medline: 22430637] [doi: 10.1136/bmj.326.7382.202]
34. White S, Stancombe J. Clinical Judgement in the Health and Welfare Professions: Extending the Evidence Base. Buckingham: Open University Press; Jul 1, 2003:38.
35. Scott J. Domination and the Arts of Resistance : Hidden Transcripts. New Haven: Yale University Press; Oct 24, 1990.
36. Pollock K, Grime J. Patients' perceptions of entitlement to time in general practice consultations for depression: qualitative study. BMJ 2002 Sep 28;325(7366):687 [FREE Full text] [PMC: 12351362] [Medline: 22238280] [doi: 10.1136/bmj.325.7366.687]
37. Stapleton H, Kirkham M, Thomas G. Qualitative study of evidence based leaflets in maternity care. BMJ 2002 Mar 16;324(7338):639 [FREE Full text] [PMC: 11895821] [Medline: 21892614] [doi: 10.1136/bmj.324.7338.639]
38. Gerber BS, Eiser AR. The patient physician relationship in the Internet age: future prospects and the research agenda. J Med Internet Res 2001 Apr 9;3(2):e15 [FREE Full text] [Medline: 21578022] [doi: 10.2196/jmir.3.2.e15]
39. Payne SA. Balancing information needs: dilemmas in producing patient information leaflets. Health Informatics Journal 2002; 8(4):174-179 [FREE Full text]
40. ; Department of Health. The NHS Plan. A Plan for Investment, a Plan for Reform. White Paper: Cm 4818-I. Department of Health, HMSO: London; 2000.
41. Anderson JG, Rainey MR, Eysenbach G. The impact of CyberHealthcare on the physician-patient relationship. J Med Syst 2003 Feb;27(1):67-84. [Medline: 22504063] [doi: 10.1023/A:1021061229743]
42. Henwood F, Wyatt S, Hart A, Smith J. 'Ignorance is bliss sometimes': constraints on the emergence of the 'informed patient' in the changing landscapes of health information. Sociol Health Illn 2003 Sep;25(6):589-607 [FREE Full text] [Medline: 22801649] [doi: 10.1111/1467-9566.00360]

submitted 04.02.04; peer-reviewed by J Anderson, R Mrtek; comments to author 03.03.04; revised version received 16.08.04; accepted 17.08.04; published 30.09.04.

Please cite as:
Hart A, Henwood F, Wyatt S
The Role of the Internet in Patient-Practitioner Relationships: Findings from a Qualitative Research Study
J Med Internet Res 2004;6(3):e36
URL: http://www.jmir.org/2004/3/e36/
doi:10.2196/jmir.6.3.e36
PMID:15471762

Original Paper

Internet Versus Mailed Questionnaires: A Randomized Comparison

Philip Ritter[1], PhD; Kate Lorig[1], DrPH; Diana Laurent[1], MPH; Katy Matthews[1], MPH

Stanford University School of Medicine, Palo Alto CA, USA

Corresponding Author:
Philip Ritter, PhD
Stanford University School of Medicine
Patient Education Research Center
Suite 204, 1000 Welch Rd
Palo Alto CA 94304-1811
USA
Phone: +1 650 725 8004
Fax: +1 650 725 9422
Email: philr@stanford.edu

Abstract

Background: The use of Internet-based questionnaires for collection of data to evaluate patient education and other interventions has increased in recent years. Many self-report instruments have been validated using paper-and-pencil versions, but we cannot assume that the psychometric properties of an Internet-based version will be identical.

Objectives: To look at similarities and differences between the Internet versions and the paper-and-pencil versions of 16 existing self-report instruments useful in evaluation of patient interventions.

Methods: Participants were recruited via the Internet and volunteered to participate (N=397), after which they were randomly assigned to fill out questionnaires online or via mailed paper-and-pencil versions. The self-report instruments measured were overall health, health distress, practice mental stress management, Health Assessment Questionnaire (HAQ) disability, illness intrusiveness, activity limitations, visual numeric for pain, visual numeric for shortness of breath, visual numeric for fatigue, self-efficacy for managing disease, aerobic exercise, stretching and strengthening exercise, visits to MD, hospitalizations, hospital days, and emergency room visits. Means, ranges, and confidence intervals are given for each instrument within each type of questionnaire. The results from the two questionnaires were compared using both parametric and non-parametric tests. Reliability tests were given for multi-item instruments. A separate sample (N=30) filled out identical questionnaires over the Internet within a few days and correlations were used to assess test-retest reliability.

Results: Out of 16 instruments, none showed significant differences when the appropriate tests were used. Construct reliability was similar within each type of questionnaire, and Internet test-retest reliability was high. Internet questionnaires required less follow-up to achieve a slightly (non-significant) higher completion rate compared to mailed questionnaires.

Conclusions: Among a convenience sample recruited via the Internet, results from those randomly assigned to Internet participation were at least as good as, if not better than, among those assigned mailed questionnaires, with less recruitment effort required. The instruments administered via the Internet appear to be reliable, and to be answered similarly to the way they are answered when they are administered via traditional mailed paper questionnaires.

(J Med Internet Res 2004;6(3):e29) doi:10.2196/jmir.6.3.e29

KEYWORDS

Questionnaire design; evaluation; methodology; instruments; Internet

Introduction

The purpose of the study was to test the reliability for Internet use of 16 existing self-report instruments that can be used in Internet health services research and intervention studies. Participants in the study were randomized to answer questionnaires on the Internet or via a mailed (paper-and-pencil) questionnaire.

Although we and others have been using these instruments in Internet-based studies for a few years [1], neither these nor most similar instruments had previously been tested for Internet use.

This lack of psychometric testing might cause some to question the outcomes of Internet-based health studies.

In searching the literature, we found a number of studies testing particular Internet measures, especially within the field of psychology. For example, Lin et al (2003) studied a measure of self-assessment of depression [2], while Farvolden et al (2003) looked at screening for clinical depression [3]. An increasing number of studies have directly compared paper-and-pencil–administered questionnaires with an Internet-mediated questionnaire. In a study of a 13-item quality of life scale, the Foundation for Accountability [4] found that while there was some variation in individual items, the mean scores for mail and Internet collection were similar. Buchanan and Smith (1999) [5] compared a Web-based personality assessment to a paper-and-pencil version, and using confirmatory factor analyses, found similar psychometric properties in the two tests. Davis (1999) [6] also compared Web and paper-and-pencil versions of a personality measure (rumination), and concluded that “findings from Web-based questionnaire research are comparable with results obtained using standard procedures.” Riva et al (2003) [7] compared attitudes regarding the Internet and concluded that if sampling control and validity assessment is provided, the Internet is a suitable alternative to traditional paper-based methods. Joinson (1999) reported that both anonymity and Web usage (compared to paper-and-pencil) resulted in lower scores on a social desirability measure [8]. And Buchanan (2003) [9] reported that even when Internet-based versions of instruments are reliable and valid, normative data from paper-and-pencil versions may not always compare directly with Internet-mediated psychological testing. A recent overview entitled “Using the Internet for Surveys and Health Research” (Eysenbach & Wyatt 2002, [10]), barely touched on instruments (referring readers to the Quality of Life Instruments Database at Quality of Life Instruments database [11]) and did not discuss validity or reliability of Internet-based questionnaires. Although progress is being made, there remains a need to evaluate Internet versions of most of the health-behavior and outcome instruments useful to researchers evaluating patient intervention programs.

Information is presented on the distributions of the responses using both methods of questionnaire delivery, as well as on the differences between the two sets of responses. The intent is to allow researchers to make an informed decision as to whether each variable is appropriate for Internet use when compared to use via traditional mailed paper self-report questionnaires.

Methods

Sample

Over a period of two months, subjects were recruited via the Internet using messages on health discussion groups, community servers, Web-site links, medical e-newsletters, and online support groups. Potential subjects were invited to visit a study Web site and thus all subjects had Internet access. Seven hundred and ninety-one potential subjects expressed interest by leaving contact information at the project Web site, and were invited to participate. Of these, 462 agreed to proceed, were randomized, and were either sent a paper questionnaire or invited to return to a Web site to complete the questionnaire online. Ultimately, 397 were enrolled and filled out questionnaires. We compared the refusal rates of those randomized to the Internet versus those randomized to mailed questionnaires using chi-squares. We also examined the amount of follow-up required for each group.

Instruments

Information was collected on 16 self-report instruments and well as on demographic variables and types of disease conditions. These instruments have been used extensively in our and others' research, and their mailed paper questionnaire version responses have been previously examined and validated (eg, Lorig et al 1996 [12], also see the research instruments page of the Stanford University Patient Education Research Center's Web site [13]). The criteria for choosing instruments were that they 1) had previously been validated, 2) represented key outcome in studies of one or more chronic conditions, 3) had been used in past studies, 4) were relatively short, and 5) were sensitive to change in the range of .3 effect size. The variables selected were the following instruments.

- Self-Rated Health (1 item). This item comes from the National Health Survey and has been found to be predictive of future health status (Idler & Angel, 1990) [14].
- Health Distress measures worry and concern caused by chronic illness (5 items) (Lorig et al, 1996) [12].
- Number of times per week practice mental stress management and relaxation techniques (1 item) (Lorig et al, 1996) [12].
- Health Assessment Instrument measures disability and is used in the National Health Survey (20 items) (Fries et al, 1980) [15].
- Illness Intrusiveness. Instrument measures how chronic illness affects role function in 5 domains: physical well being and diet, work and finances, marital, sexual and family relations, recreational and social relations, other (13 items) (Devins, 1990) [16].
- Activity limitations, measures role function (4 items) (Lorig et al, 1996) [12].
- Visual numeric instruments for pain, shortness of breath, and fatigue are adaptations of visual analogue instruments that have been found to be easy for subjects to complete (4 items) (González et al, 1995) [17].
- Self-efficacy for managing chronic disease measures the confidence one has in managing chronic conditions and has been found to be predictive of future health status (5 items) (Lorig et al, 1996) [12].
- Self-reported exercise measures minutes/week of aerobic (5 items) and minutes/week stretching and strengthening exercise (1 item) (Lorig et al, 1996) [12].
- Health care utilization (MD visits, hospitalization, hospital days, ER visits) (Lorig et al, 1996; Ritter et al, 2001) [12,18].

Many of the instruments tested were developed by the authors, and all are available for free public use. Detailed information and paper questionnaire-based psychometrics for each of the instruments can be found at the Stanford University Patient Education Research Center Web site [13].

Data Analyses

We first checked to see if the randomization process had been successful by compared the demographic and disease variables using t-tests. The means for the 16 instruments were then compared using t-tests, Wilcoxin, and analyses of covariance (ANCOVAs). ANCOVAs were run controlling for demographic variable and for the disease variables that were found to differ between the two groups. Confidence intervals were also computed to provide a sense of how much overlap there might be between the answers from the two randomized groups. This information is presented in a way that allows an informed researcher to determine if a particular instrument is appropriate for Internet use and for comparison to results obtained from a traditional paper questionnaire. The standard .05 criterion for determining if there is a significant difference may not be appropriate when one is asserting that there is likely little difference. That criterion is intended to avoid the error of claiming there is a difference when it may only be the result of statistical fluctuation (type I error). But we also wish to avoid the error of claiming there is no difference when there may well be (type II error). Thus we also discuss trends (p=.05 to .10) and slight trends (p=.10 to .20) in case these may indicate a real, albeit small, difference in how the instruments are answered using the two methods.

For multi-item instruments, internal consistency reliability was computed separately within the paper questionnaire and within the Web-based questionnaire groups using Cronbach alpha.

A separate sample was used to compute test-retest correlations. A group of subjects enrolled in an online chronic disease self-management workshop was asked to return to the Web site to fill out a second questionnaire one day after completing a 12-month follow-up questionnaire as part of their study participation. Thirty subjects completed the second questionnaire within one week of completing the first questionnaire. The results of the two sets of answers to the 16 instruments were compared using both Pearson and Spearman correlations.

All subjects received a $10.00 Amazon.com certificate for their participation.

Results

Four hundred and sixty-two people with chronic disease were invited to participate. If they did not return a mailed questionnaire or fill out the Internet questionnaire after approximately 10 days, they were sent a postcard or follow-up email. As might be expected, many of the mailed questionnaires were not returned within 10 days, and 63.6% were sent a follow-up postcard. Only 27.3% of those randomized to the Internet required a follow-up email (chi square=<.0001). After an additional 10 days with no response, a phone call was made to those randomized to the mailed questionnaire and a reminder email was sent to the Internet group. Of those randomized to mailed questionnaires, 29.4% required a follow-up phone call, and of those assigned to Internet participation, 16.0% required a reminder email (chi square=.0006). Finally, after an additional one to two weeks, a follow-up letter went to 20.3% of those randomized to mail, and a second email was sent to 13.4% of those randomized to the Internet (chi square=.064). Of the participants randomized to mail, 83.1% eventually returned their questionnaires, as did 87.5 % of those randomized to the Internet (chi square=.189). This return rate is defined as those who actually returned their questionnaires or who logged on and filled out a questionnaire divided by the number who agreed to participate and were randomized.

When we compared the demographic characteristics of those who answered their questionnaires on the Internet versus those who used mailed paper questionnaires, we found two slight differences (Table 1). The Internet subjects were slightly more likely to be married than the paper questionnaire subjects (P=.043). In addition, the mailed questionnaire subjects had a slightly higher incidence of asthma (p=.096). Thus, the asthma and marital status variables, as well as the other demographic variables, were included as covariates in the ANCOVA models.

Table 2 presents the means for the 16 instruments and the probability that there are differences in those means, comparing those who answered questionnaires on the Internet with those who used mailed paper questionnaires. Only shortness of breath showed a trend toward being statistically significantly different when the two groups were compared using t-test (p=.074) or Wilcoxin test (p=.081). However, there was also a trend toward the mailed questionnaire sample having higher levels of asthma (Table 1), and when ANCOVAs were used to control for asthma and other demographic variables, the significance rose to p=.254.

Although there were no other differences approaching significance, there were slight trends (less than .20) for ER Visits (p=.146) and health distress (p=.116). The ER visits are very skewed in distribution (with most participants reporting 0), and when the differences were tested using Wilcoxin, the p value rose to .330. Health distress continued to show a slight trend toward a difference, regardless of the test (p=.111 with Wilcoxin, p=.193 from ANCOVAs).

Table 2 also provides information on the distributions of each variable. Standard deviations and 5% to 95% confidence intervals for each randomized group are shown. These illustrate the considerable overlap found between those answering the questionnaires using Web questionnaires and those using mailed questionnaires for all instruments with the possible exception of the Shortness of Breath Visual Numeric Scale.

Internal consistency reliability (Cronbach alpha) was nearly identical for multi-item instruments, whether administered via the Internet or by paper questionnaire (Table 3).

Table 3 also includes the test-retest reliability scores. We saw consistently high correlations, whether Pearson or Spearman correlations were used. This is in spite of the fact that some items such as pain, fatigue and shortness of breath were asked regarding the preceding two weeks, and could have been expected to change in the time between the two questionnaires. The relaxation variable specifically asked about the preceding week (How many times did you do mental stress management or relaxation techniques in the last week?), and might have been expected to produce lower test-retest correlations, which it does.

Table 1. Demographic and disease variables

Variable	Percent or Mean (Standard Deviation)		Probability of Difference p (t-test)
	Web N=205	Questionnaire N=192	
Percent male	29.8%	25.7%	.364
Mean years of education	16.1	15.7	.119
% less than 12 years	(3.41)	(3.54)	
% 12 years	range: 3-23	range: 1-23	
% 13-15 years	2.9%	4.7%	
% 16 years	8.2	15.1	
% more than 16 years	31.7	27.1	
	19.5	20.3	
	37.6	32.8	
Mean age	45.9	44.6	.369
	(14.3)	(13.5)	
	range: 19-89	range: 19-82	
% Non Hispanic White	79.0%	72.3%	.117
% Black	4.9	5.2	(chi-square, p= .324)
% Hispanic	6.8	7.9	
% Asian	5.4	11.1	
Ethnic category			
% Married	58.1%	47.9%	.043
% with Diabetes	26.3%	26.6%	.960
% with Hypertension	29.8%	33.9%	.382
% with Asthma	20.0%	27.1%	.096
% with COPD or other lung disease	14.2%	14.1%	.981
% with heart disease	9.8%	13.0%	.468

Table 2. Comparison of tested variables

Variable	Internet N=205			Mailed Questionnaire N=192			Probability of Difference		
	Mean (Standard Deviation)	Confidence Intervals	Observed Range	Mean (Standard Deviation)	Confidence Intervals	Observed Range	p (t-test)	p (Wilcoxin)	p (ANCOVA)
Self-reported health	3.26 (0.890)	3.26-3.39	1-5	3.20 (1.05)	3.05-3.35	1-5	.548	.543	.403
Pain VNS	4.74 (3.26)	4.29-5.19	0-10	4.50 (3.14)	4.05-4.95	0-10	.465	.625	.402
Shortness of Breath VNS	3.35 (3.04)	2.93-3.77	0-10	3.91 (3.16)	3.46-4.36	0-10	.074	.081	.254
Fatigue VNS	6.11 (2.53)	5.76-6.46	0-10	5.94 (2.69)	5.56-6.33	0-10	.530	.489	.421
MD visits	4.69 (5.29)	3.96-5.42	0-35	5.59 (11.6)	3.94-7.24	0-150	.325	.269	.306
ER visits	0.534 (1.43)	0.338-0.731	0-10	0.938 (3.57)	0.429-1.45	0-32	.146	.330	.120
Hosp nights	1.82 (8.83)	0.600-3.04	0-10	2.04 (13.7)	0.090-3.99	0-10	.849	.812	.875
Hospitalizations	0.319 (1.07)	0.172-0.466	0-90	0.307 (0.989)	0.167-0.448	0-180	.913	.819	.883
Illness intrusiveness	13.1 (4.64)	12.4-13.7	4-21	13.1 (4.52)	12.5-13.8	3-21	.892	.893	.897
Health distress	2.25 (0.297)	2.09-2.44	0-5	2.46 (1.30)	2.28-2.65	0-5	.116	.111	.193
Self efficacy	5.92 (1.24)	5.60-6.23	1-10	6.01 (2.32)	5.68-6.34	1-10	.687	.684	.580
HAQ disability	0.284 (0.390)	0.230-0.338	0-1.63	0.254 (0.393)	0.198-0.310	0-2.13	.450	.306	.363
Doctor comm.	3.02 (1.27)	2.85-3.20	0-5	3.13 (1.19)	2.96-3.30	0-5	.379	.487	.208
Relaxation	1.70 (3.65)	1.19-2.20	0-20	1.61 (3.29)	1.14-2.08	0-25	.804	.461	.820
Range of motion exercise	37.1 (51.1)	30.1-44.2	0-180	34.4 (46.8)	27.7-41.0	0-180	.577	.793	.667
Aerobic exercise	84.5 (96.7)	71.1-97.8	0-420	86.6 (102.9)	71.9-101.2	0-585	.836	.580	.770

Table 3. Reliability

Variable	Internet Test-retest Reliability, N=30		I-C Reliability, Cronbach alpha	
	Pearson r	Spearman r	Web (N=204)	Questionnaire (N=191)
Self-reported health	.884	.890	single item	single item
Pain VNS	.847	.832	single item	single item
Shortness of Breath VNS	.968	.940	single item	single item
Fatigue VNS	.864	.827	single item	single item
MD visits	.784	.783	single item	single item
ER visits	.999	1.000	single item	single item
Hosp nights	.992	.999	single item	single item
Hospitalizations	1.000	1.000	single item	single item
Illness intrusiveness	.869	.880	.668	.658
Health distress	.935	.930	.935	.931
Self efficacy	.906	.870	.912	.922
HAQ disability	.930	.931	.874	.879
Doctor communication	.874	.865	.775	.750
Relaxation	.684	.802	single item	single item
Range of motion exercise	.829	.878	single item	single item
Aerobic exercise	.765	.921	n/a	n/a

Discussion

The group randomized to mailed questionnaires required more follow-up effort than those randomized to Internet questionnaires. Although there was a slightly higher return rate among the Internet group (87.5% versus 83.1%), that difference was not statistically significant. We can conclude that among a population recruited through the Internet, participation among those assigned to the Internet was at least as good as, if not better than, participation among those assigned mailed questionnaires, with less recruitment effort required. However, the same results might not have occurred among a population less familiar and less comfortable with the Internet.

Our sample was a volunteer (convenience sample) drawn from a population who had access to and who were familiar with the Internet. Thus the results particularly apply to such populations and may not be representative of a broader-based population. However, Gosling et al [19] have argued that Internet samples may actually be more representative than traditional samples. Paper-and-pencil questionnaires will remain useful in target populations who have limited experience with or access to the Internet, while Internet surveys may allow researchers to reach more geographically diverse populations with less expense.

The results showed few differences between Internet-based and mailed paper questionnaires. None were significantly different at the .05 level when appropriate tests were used. With 16 instruments tested, we might expect to find several significantly different at the .20 level or lower, even if the two groups were more or less identical in how they answered the questions. And we did find a consistent difference at that level for one variable, health distress. Further testing on health distress might be warranted to determine if this slight trend toward Internet-based questionnaires showing more health distress could be replicated. Health distress did have high internal consistency reliability and high test-rest reliability, which was nearly identical for both Internet-based and mailed questionnaires. Thus we can be confident that health distress is reliable when administered via the Internet, even though there may be a possibility of slight differences in the normative values of the two different modes of administration.

Shortness of breath also showed a trend toward being significantly different when evaluated using bivariate statistics (t-tests and Wilcoxin). But when the presence of asthma was included as a covariate in an analyses of covariance model, the significance rose to a level indicating minor differences. This was because of the higher level of asthma in the mailed questionnaire group compared to the Internet group. The Shortness of Breath Visual Numeric Scale might also benefit from being tested in a new sample that did not show differences in asthma between the two randomized groups.

In summary, the instruments administered via the Internet appear to be reliable and appear to be answered similarly to the way they are answered when they are administered via mailed paper questionnaires.

Acknowledgments

The research was supported by the Robert Wood Johnson Foundation e-health initiative program. Data collection and preparation was assisted by Christiana Lum.

Conflicts of Interest

None declared.

References

1. Lorig KR, Laurent DD, Deyo RA, Marnell ME, Minor MA, Ritter PL. Can a Back Pain E-mail Discussion Group improve health status and lower health care costs?: A randomized study. Arch Intern Med 2002 Apr 8;162(7):792-796. [Medline: 21924399] [doi: 10.1001/archinte.162.7.792]
2. Lin C, Li YC, Bai YM, Tsai SJ, Hsiao MC, Wu CH, et al. The validity of an Internet-based self-assessment program for depression. In: Proc AMIA Symp 2003:911. [Medline: 14728417]
3. Farvolden P, Mcbride C, Bagby RM, Ravitz P. A Web-based screening instrument for depression and anxiety disorders in primary care. J Med Internet Res 2003 Sep 29;5(3):e23 [FREE Full text] [Medline: 22879622] [doi: 10.2196/jmir.5.3.e23]
4. ; The Foundation for Accountability. Compare your care, a web-based strategy for consumer activation website. URL: http://www.facct.org/facct/doclibFiles/documentFile_279.pdf [accessed 2004 June 8]
5. Buchanan T, Smith JL. Using the Internet for psychological research: personality testing on the World Wide Web. Br J Psychol 1999 Feb;90 (Pt 1)(1):125-144. [Medline: 99185469] [doi: 10.1348/000712699161189]
6. Davis RN. Web-based administration of a personality questionnaire: comparison with traditional methods. Behav Res Methods Instrum Comput 1999 Nov;31(4):572-577. [Medline: 20099793]
7. Buchanan T. Internet-based questionnaire assessment; appropriate use in clinical contexts. Cognitive Behavior Therapy 2003; 32(3):100-109 [FREE Full text] [doi: 10.1080/16506070310000957]
8. Riva G, Teruzzi T, Anolli L. The use of the internet in psychological research: comparison of online and offline questionnaires. Cyberpsychol Behav 2003 Feb;6(1):73-80. [Medline: 22537076] [doi: 10.1089/109493103321167983]
9. Joinson A. Social desirability, anonymity, and Internet-based questionnaires. Behav Res Methods Instrum Comput 1999 Aug;31(3):433-438. [Medline: 99432484]
10. Eysenbach G, Wyatt J. Using the Internet for surveys and health research. J Med Internet Res 2002 Nov 22;4(2):e13 [FREE Full text] [Medline: 22442445] [doi: 10.2196/jmir.4.2.e13]
11. QOLID, the Quality of Life Instruments Database. URL: http://www.qolid.org/ [accessed 2004 June 8]
12. Lorig K, Stewart A, Ritter P, Gonzalez V, Laurent D, Lynch J. Outcome Measures for Health Education and Other Health Care Interventions. Thousand Oaks, CA: SAGE Publications; Jan 15, 1996.
13. Stanford University Patient Education Research Center Web site. Research Instruments Page. URL: http://patienteducation.stanford.edu/research/ [accessed 2004 June 8]
14. Idler EL, Angel RJ. Self-rated health and mortality in the NHANES-I Epidemiologic Follow-up Study. Am J Public Health 1990 Apr;80(4):446-452. [Medline: 90196421]
15. Fries JF, Spitz P, Kraines RG, Holman HR. Measurement of patient outcome in arthritis. Arthritis Rheum 1980 Feb;23(2):137-145. [Medline: 80153563]
16. Devins GM, Mandin H, Hons RB, Burgess ED, Klassen J, Taub K, et al. Illness intrusiveness and quality of life in end-stage renal disease: comparison and stability across treatment modalities. Health Psychol 1990;9(2):117-142. [Medline: 90235800] [doi: 10.1037//0278-6133.9.2.117]
17. González VM, Stewart A, Ritter PL, Lorig K. Translation and validation of arthritis outcome measures into Spanish. Arthritis Rheum 1995 Oct;38(10):1429-1446. [Medline: 96017441]
18. Ritter PL, Stewart AL, Kaymaz H, Sobel DS, Block DA, Lorig KR. Self-reports of health care utilization compared to provider records. J Clin Epidemiol 2001 Feb;54(2):136-141. [Medline: 21104096] [doi: 10.1016/S0895-4356(00)00261-4]
19. Gosling SD, Vazire S, Srivastava S, John OP. Should we trust web-based studies? A comparative analysis of six preconceptions about internet questionnaires. Am Psychol 2004 Feb;59(2):93-104. [Medline: 14992636] [doi: 10.1037/0003-066X.59.2.93]

submitted 12.07.04; peer-reviewed by M Schonlau, G Riva; comments to author 22.07.04; revised version received 12.08.04; accepted 17.08.04; published 15.09.04.

Please cite as:
Ritter P, Lorig K, Laurent D, Matthews K
Internet Versus Mailed Questionnaires: A Randomized Comparison
J Med Internet Res 2004;6(3):e29
URL: http://www.jmir.org/2004/3/e29/
doi:10.2196/jmir.6.3.e29
PMID:15471755

Original Paper

Internet Versus Mailed Questionnaires: A Randomized Comparison (2)

Pam Leece[1], BSc; Mohit Bhandari[1,2], MD, MSc; Sheila Sprague[1], MSc; Marc F Swiontkowski[3], MD; Emil H Schemitsch[4], MD; Paul Tornetta III[5], MD; PJ Devereaux[1,6], MD; Gordon H Guyatt[1,6], MD, MSc

[1]Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton ON, Canada
[2]Department of Orthopaedic Surgery, Department of Clinical Epidemiology and Biostatistics, McMaster University, Hamilton ON, Canada
[3]Department of Orthopaedic Surgery, University of Minnesota, Minneapolis MN, USA
[4]Department of Orthopaedic Surgery, St. Michael's Hospital, Toronto ON, Canada
[5]Department of Orthopaedic Surgery, Boston University, Boston MA, USA
[6]Department of Medicine, McMaster University, Hamilton ON, Canada

Corresponding Author:
Mohit Bhandari, MD, MSc
McMaster University Health Sciences Centre
Department of Clinical Epidemiology and Biostatistics
Room 2C9, 1200 Main Street West
Hamilton ON L8N 3Z5
Canada
Phone: +1 905 525 9140 ext 22825
Fax: +1 905 524 3841
Email: bhandari@sympatico.ca

Related Articles:

This is a corrected version. See correction statement: http://www.jmir.org/2004/4/e39/

Letter: http://www.jmir.org/2004/4/e38/

Abstract

Background: Low response rates among surgeons can threaten the validity of surveys. Internet technologies may reduce the time, effort, and financial resources needed to conduct surveys.

Objective: We investigated whether using Web-based technology could increase the response rates to an international survey.

Methods: We solicited opinions from the 442 surgeon–members of the Orthopaedic Trauma Association regarding the treatment of femoral neck fractures. We developed a self-administered questionnaire after conducting a literature review, focus groups, and key informant interviews, for which we used sampling to redundancy techniques. We administered an Internet version of the questionnaire on a Web site, as well as a paper version, which looked similar to the Internet version and which had identical content. Only those in our sample could access the Web site. We alternately assigned the participants to receive the survey by mail (n=221) or an email invitation to participate on the Internet (n=221). Non-respondents in the mail arm received up to three additional copies of the survey, while non-respondents in the Internet arm received up to three additional requests, including a final mailed copy. All participants in the Internet arm had an opportunity to request an emailed Portable Document Format (PDF) version.

Results: The Internet arm demonstrated a lower response rate (99/221, 45%) than the mail questionnaire arm (129/221, 58%) (absolute difference 13%, 95% confidence interval 4%-22%, P<0.01).

Conclusions: Our Internet-based survey to surgeons resulted in a significantly lower response rate than a traditional mailed survey. Researchers should not assume that the widespread availability and potential ease of Internet-based surveys will translate into higher response rates.

(J Med Internet Res 2004;6(3):e30) doi:10.2196/jmir.6.3.e30

KEYWORDS

Survey; methods; mail surveys; Internet surveys; response rate

Introduction

Health-care surveys are an important research tool to study the attitudes, beliefs, behaviors, practice patterns, and concerns of physicians [1]. Response rates to surveys, especially among physicians, have been suboptimal (mean response rates=62%, SD=15%) [2]. Investigators have attributed the lower response rates to increasing physician workloads and to the low priority physicians place on survey completion. The return rates have been especially low in surveys of surgeons, who have responded at rates from 15%-77% [3-6]. Low response rates threaten the validity of a survey by increasing the risk of a non-response bias [1,7,8].

Dillman's Tailored Design Method is the current standard for conducting mail and Internet surveys [9]. A recent Cochrane Methodology Review verified the success of these strategies for achieving reproducible response rates in the general population [10,11]. Another systematic review also confirmed that some of these methods are effective in physician surveys: monetary incentives, stamps on outgoing and return envelopes, and short questionnaires [1].

The suboptimal response rates among surgeons calls for exploration of alternative survey administration strategies. Internet technology has the potential to decrease the time and cost involved in conducting a health-care survey. Couper presents a review of issues and approaches to Web surveys, and suggests that Web surveys may improve the response rate and lower the cost of surveys [12]. While some Internet-based surveys have shown promising response rates (up to 94% [13]), their potential has not been realized in other studies (response rates ranged from 11%-70%) [14-17]. To date, no studies have evaluated the response rates to Internet surveys among orthopaedic surgeons.

We hypothesized that orthopaedic surgeons who were given the opportunity to participate in an Internet-based questionnaire would respond at a higher rate than surgeons who were mailed a paper copy of the survey. We tested this hypothesis in a survey of orthopaedic surgeons on their views about managing hip fractures.

Methods

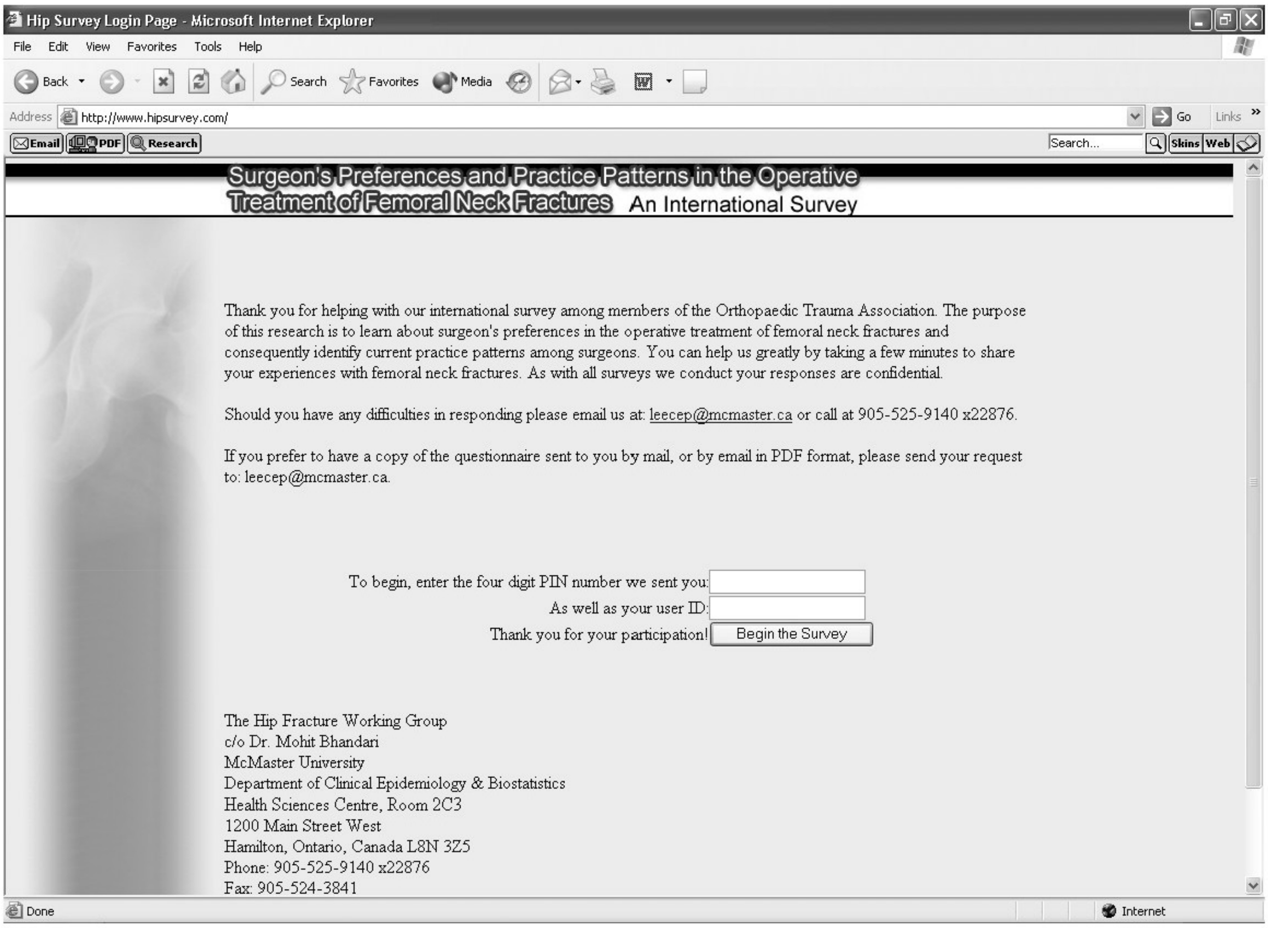
Questionnaire Development

We developed an 8-page self-administered questionnaire to identify the preferences and practice patterns of orthopaedic traumatologists in the operative treatment for femoral neck fractures. Using previous literature, focus groups with orthopaedic surgeons, and key informants, using sampling to redundancy techniques, we identified items that fell into six domains: 1) surgeon experience; 2) classification of fracture types; 3) treatment options; 4) technical considerations in the operative technique; 5) predictors of patient outcome; and 6) patient outcomes. We pre-tested the 8-page questionnaire to establish its comprehensibility, face validity, and content validity [18].

Study Sample

Of the 453 members of the Orthopaedic Trauma Association (OTA) listed on the 2002 membership list, we included all active, international, emeritus, and associate members, but excluded 11 members who are not surgeons. Therefore, we included all 442 surgeon–members of the OTA. We obtained the email addresses for the surgeons in the Internet group from the OTA's online directory.

Figure 1. Welcome screen for Internet questionnaire



Surgeon's Preferences and Practice Patterns in the Operative Treatment of Femoral Neck Fractures An International Survey

Thank you for helping with our international survey among members of the Orthopaedic Trauma Association. The purpose of this research is to learn about surgeon's preferences in the operative treatment of femoral neck fractures and consequently identify current practice patterns among surgeons. You can help us greatly by taking a few minutes to share your experiences with femoral neck fractures. As with all surveys we conduct your responses are confidential.

Should you have any difficulties in responding please email us at: leecep@mcmaster.ca or call at 905-525-9140 x22876.

If you prefer to have a copy of the questionnaire sent to you by mail, or by email in PDF format, please send your request to: leecep@mcmaster.ca.

To begin, enter the four digit PIN number we sent you:
As well as your user ID:
Thank you for your participation! Begin the Survey

The Hip Fracture Working Group
c/o Dr. Mohit Bhandari
McMaster University
Department of Clinical Epidemiology & Biostatistics
Health Sciences Centre, Room 2C3
1200 Main Street West
Hamilton, Ontario, Canada L8N 3Z5
Phone: 905-525-9140 x22876
Fax: 905-524-3841

Development of Web Questionnaire

We hired a professional Web designer to create an Internet version of the questionnaire on a Web site. The questions were displayed in the same order and format as they were in the paper version. The “welcome screen” of the Web site invited participants to enter their assigned personal identification number (PIN) and user identification (user ID) before beginning the questionnaire, so that only those in the Internet group had access to the questionnaire (Figure 1).

We also included our contact information, as well as the option to request a questionnaire by mail, fax, or email as a Portable Document Format (PDF) attachment. The Web questionnaire was 6 pages long (1 page per section), took approximately 5 minutes to complete, and had 38 questions. The responses to the Internet questionnaire were automatically entered into a database.

Study Design and Allocation

We alternately assigned the surgeon–members of the OTA to receive a postal or an Internet questionnaire. One of us (PL), who did not know the surgeons, prepared the allocation schedule for each of the 442 surgeon–members of the OTA by using the association's membership list and, starting at the top of the alphabetical membership list, alternately assigning each name to the mail or Internet group using a systematic sampling approach. Of the 221 surgeons originally assigned to the Internet group, 45 did not have email addresses and thus received the mail version and reminders in the same way as those in the mailed questionnaire group. We selected 45 surgeons from the mail group known to have email addresses to receive the electronic questionnaire.

One of us (PL) recorded the costs associated with development and implementation of the mail and Internet-based surveys to assess the feasibility of each method. Our costs included labor, supplies, postage, Web-site administration, and our domain name. These costs were calculated and compared between groups.

Questionnaire Administration

We planned five points of contact for the questionnaire administration: 1) advanced notification by post (mail group) or email (Internet group) 2 to 5 days prior to receiving the survey; 2) a mailed copy of the survey, or an email with a link to the Internet survey; 3) another mailed copy or email with a link to the survey at 6 weeks; 4) a further copy or link at 12 weeks; and 5) a copy of the survey sent by mail only to all non-respondents in both groups (22 weeks for the mail group and 19 weeks for the Internet group). We conducted the final mail-out to non-responders in both groups at the same time, and stopped the study for both groups at the same time, although the mail group had started three weeks before the Web site was ready for the Internet group. We calculated our primary response rates based on the number of responses received before the final mail-out; it was at that final mail-out that we changed our method of administration.

Our University Research Ethics Board reviewed and approved this research.

Statistical Analysis

We analyzed all participants according to their final group (per protocol analysis) and the group to which they were originally assigned, following the intention to treat (ITT) principle. We summarized response rates by the proportion of respondents at each time point. Chi-square analyses were used to compare the proportion of respondents in the mail group with the proportion in the Internet group using the MINITAB version 14.0 statistical software package. All statistical tests were two-sided, at a pre-determined alpha level of 0.05.

Results

Of the 442 surgeons, 221 received a copy of the questionnaire by mail, and 221 received an email invitation to complete the survey online. Characteristics of respondents (age, geographic location, type of practice, and the proportion who had completed a fellowship in trauma) were not different between groups (Table 1).

Table 1. Characteristics of the surgeons who responded to the survey before the final mailing (Intention to Treat Analysis)

Physician Characteristic		Mail (n=129)	Internet (n=99)	P-Value
Age	Under 40	25/129 (19%)	19/99 (19%)	>0.99
	41-50	64/129 (50%)	42/99 (43%)	0.31
	51-60	33/129 (26%)	25/99 (26%)	0.99
	Over 60	11/129 (9%)	6/99 (6%)	0.49
Geographic location (% North America)		104/129 (81%)	78/99 (79%)	0.73
Type of practice (% academic)		104/129 (81%)	73/99 (74%)	0.22
Trauma fellowship (% yes)		88/129 (68%)	73/99 (74%)	0.36

Figure 2. Participant flow (Intention to Treat Analysis)

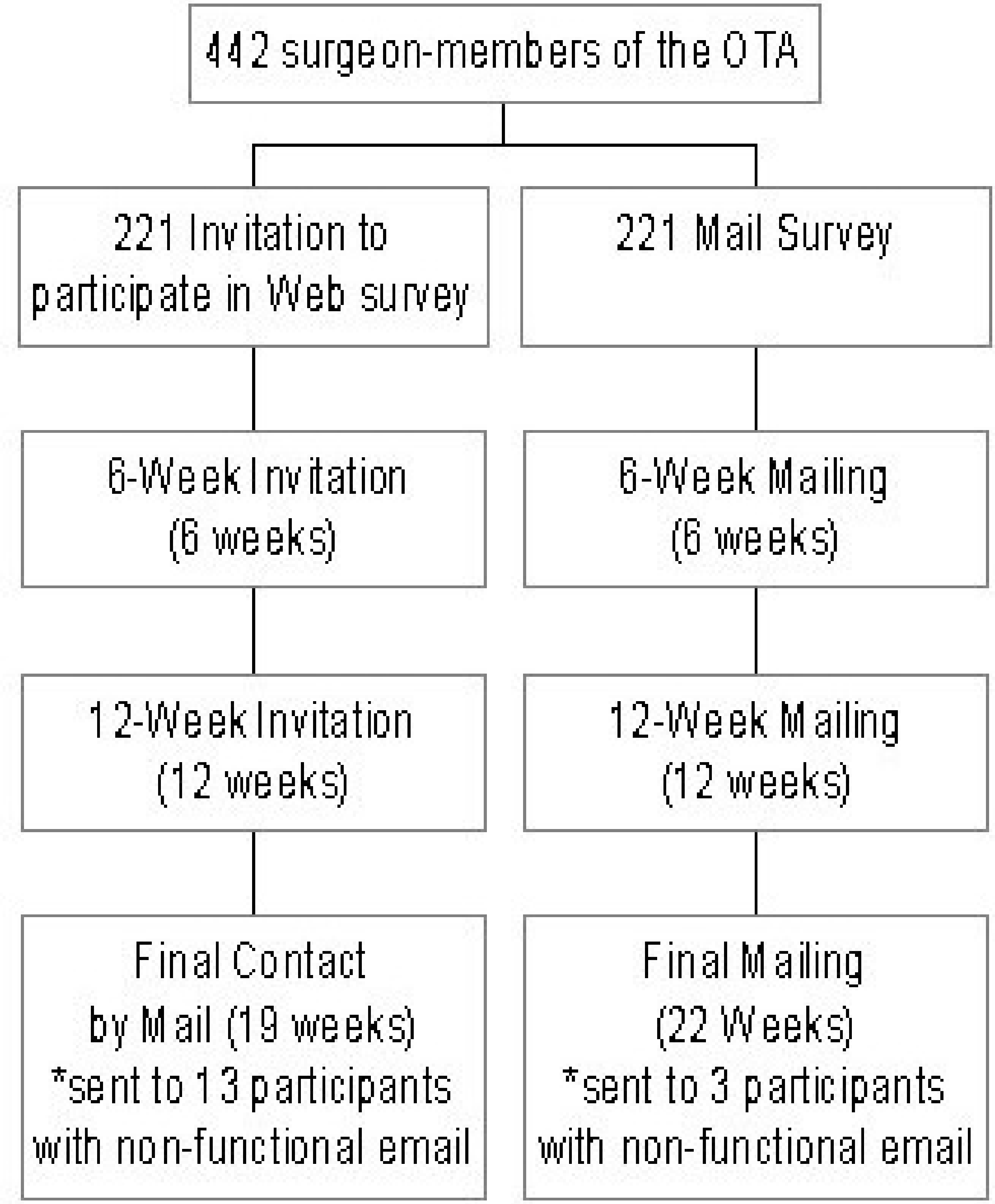


Table 2. Geographical location of the surgeons who responded to the survey before the final mailing (Intention to Treat Analysis)

	Mail (n=129)	Internet (n=99)	Total (n=228)
Africa	1	0	1
Asia	4	3	7
Australia	0	1	1
Europe	19	16	35
North America	104	78	182
South America	0	1	1

The surgeons who responded live in 17 countries on 6 continents; 80% of all respondents before the final mailing lived in the USA (Table 2).

In the original mail group, 9 surveys were returned to sender (ie, wrong address), 3 email addresses were non-functional, and 19 surgeons explicitly refused to participate by the time we closed the study. In the original Internet group, 2 surveys were returned to sender, 13 email addresses were non-functional, and 20 people explicitly refused to participate by the end of the study (Figure 2).

There was no significant difference between the proportion of respondents who switched from the mail to the Internet group and those who switched from the Internet to the mail group (27/45 vs 22/45, P=0.287).

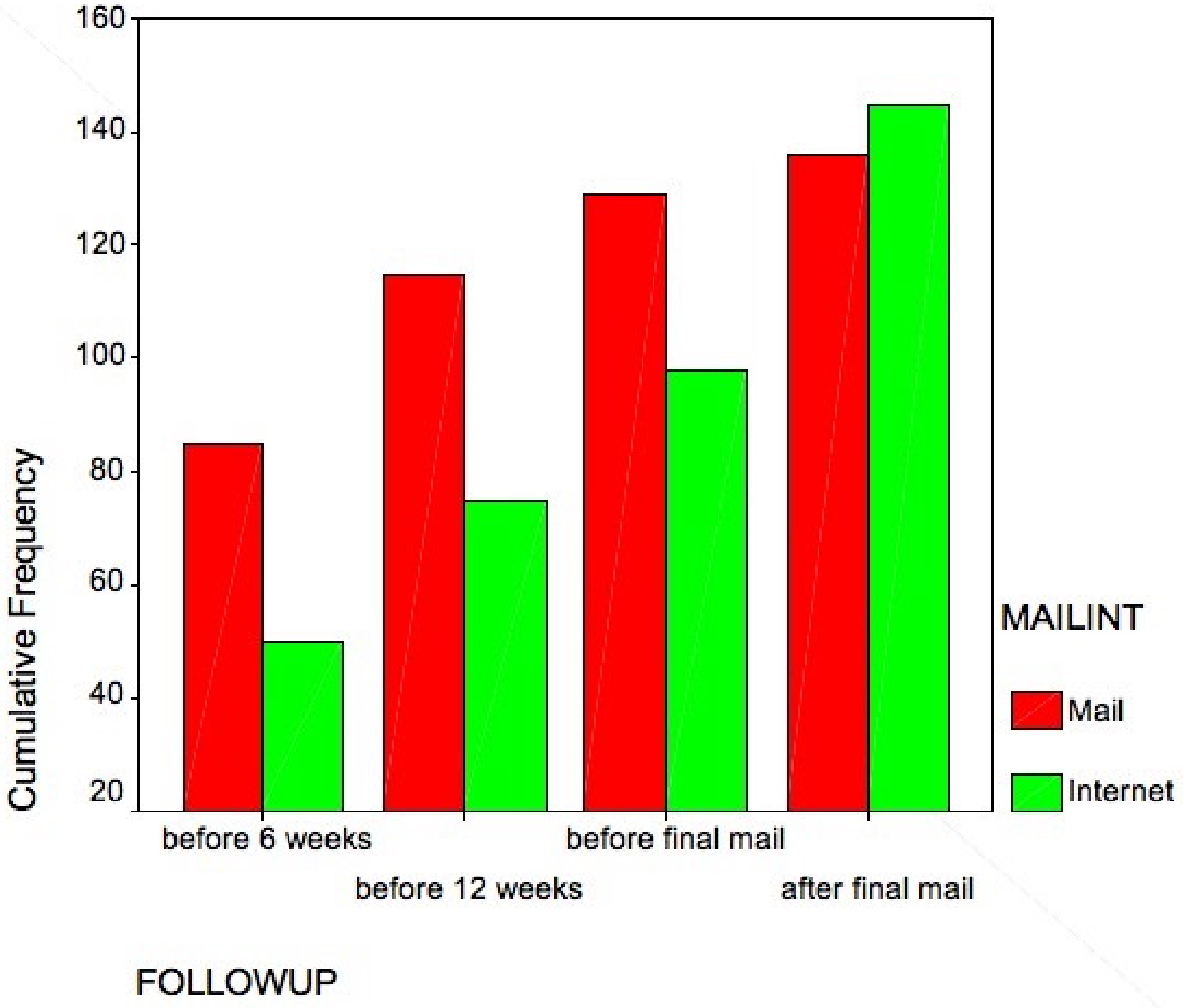
Table 3. Response rates over time (Intention to Treat Analysis)

		Mail (N=176)	Internet (N=221)	Overall (N=442)	P-Value
RESPONSES	6 weeks	75 (43%)	52 (24%)	135 (30%)	<0.01
	12 weeks	98 (56%)	77 (35%)	190 (43%)	<0.01
	22 weeks (mail) 19 weeks (Internet)	109 (62%)	99 (45%)	227 (51%)	<0.01
	32 weeks (mail) 29 weeks (Internet)	113 (64%)	141 (64%)	281 (64%)	>0.99

Table 4. Cost of administering survey by group

	Mail (Can $)	Internet (Can $)
Survey mailing materials	1319.41	215.78
Web administration (programming and domain name)	N/A	2413.51
Labor for mailing/ emailing ($20/hr, 5 min per mailed survey, 1 min per emailed survey)	1181.66	392.68
Labor for data entry ($20/hr, 5 min per survey)	238.33	80.00
TOTAL	2739.40	3101.95

Figure 3. Response rates over time (per protocol analysis)



The overall primary response rate was 228/442 (51%). A significantly greater proportion of participants in the mail group responded (129/221, 58%) compared with the Internet group (99/221, 45%) (absolute difference 13%, 95% confidence interval: 4%-22%, P<0.01). The per protocol analysis similarly favored the mail group (absolute difference 14%, 95% confidence interval: 5%-23%).

The final response rate for the survey, after we had used a mixture of administration methods to raise the response rate, was 64% (281/442). Response rates did not differ significantly between the mail and Internet groups either in the intention to treat (Table 3) or per protocol analysis (Figure 3) (absolute difference: 0%, versus 4%, 95% confidence interval: -13% to 5%, respectively).

The Internet-based survey was more costly to implement than the mail survey (Can $3101.95 and Can $2739.40, respectively) (Table 4).

Had we utilized an existing Web site for developing surveys [19], the Internet costs could have been reduced to Can $968.46 for the Internet group; however, we would have been constricted in the format and design of the Web page.

Discussion

It is important to achieve the highest response rate possible in order to limit non-response bias in health-care surveys. Previous research has demonstrated that monetary incentives, stamped return envelopes, telephone reminders, shorter surveys, and high interest can sometimes increase response rates [1,2]. Currently, there are very few data comparing response rates between postal and Internet surveys.

We hypothesized that we might receive a higher response rate among surgeons to the Web questionnaire than to the conventional paper version. We expected that surgeons with busy schedules might find the Web questionnaire would take less time and eliminate the inconvenience of dealing with paper or mailing. Additionally, we believed that widely available Internet access throughout operating suites, hospital wards, and surgeons' offices would facilitate the early completion and return of Internet-based surveys. Finally, the novelty of participating in a Web questionnaire might have interested participants who would not have completed a mailed questionnaire.

Contrary to our hypothesis, but consistent with previous studies [14,17], we found a lower response rate to the Internet questionnaire. Raziano et al randomized 2 cohorts of geriatric division chiefs to receive a survey either by electronic mail (n = 57) or by conventional postal mail (n = 57) [17]. The aggregate response rate was 58% (n = 31) for the email group versus 77% (n = 44) for the postal mail group. In another study, Kim and colleagues sent postal or email surveys to 2502 members of the American Urological Association [15]. From the postal group (n = 1000), 419 responses were obtained (42%); from the email group (n = 1502), 160 (11%) responses were obtained [15]. McMahon and colleagues compared email and postal survey response rates in a survey of physicians listed in the membership directory of the Georgia Chapter of the American Academy of Pediatrics [14]. The response rate after the first 2 mailings (2 weeks and 4 weeks) was 41% (59/143) for postal and 26% (33/125) for email surveys [14]. Harewood distributed a survey to patients about their experience after routine outpatient endoscopy. Patients were randomized to receive the questionnaire by standard mail or email. The email version of the survey resulted in a 15% lower response rate (70% vs 85%) (Table 5) [16].

Table 5. Response rates in previous surveys comparing mail and Internet surveys

Authors	Participants	Groups	Response
Raziano et al [17]	Geriatric division chiefs (n=114)	Email (n=57) Mail (n=57)	Email 58% (31/53)* Mail 77% (44/57)
Kim et al [15]	American Urological Association (n=2502)	Email (n=1502) Mail (n=1000)	Email 11% (160/1502) Mail 42% (419/1000)
McMahon et al [14]	Georgia Chapter of the American Academy of Pediatrics (n=268)	Email (n=125) Mail (n=143)	Email 26% (33/125) Mail 41% (59/143)
Harewood et al [16]	Patients after routine outpatient endoscopy (n=43)	Email (n=23) Mail (n=20)	Email 70% (16/23) Mail 85% (17/20)
Present study	Orthopaedic surgeon– members of the Orthopaedic Trauma Association (n=442)	Email (n=221) Mail (n=221)	Email 45% (99/221) Mail 58% (128/221)* after final mailing to all: Email 64% (141/221) Mail 63% (140/221)

* 4 individuals had incorrect or no email address

This is also consistent with Couper's caution that for using a probability-based method, with a list-based sample of high-coverage populations, non-response remains a concern. People will usually choose a paper version over an Internet version of a survey [12].

We found a lower response rate to the Internet questionnaire despite efforts to make the Internet version of our questionnaire easy to use, and despite the inclusion of a link to the Web site in the invitation email. We followed closely the recommendations for conducting Web surveys made by Dillman, who reported comparable electronic and postal mail response rates [9]. We have also avoided many of the common problems with Internet surveys noted by Zhang: our design used a population that has easy access to the Internet and that is relatively comfortable with it; we eliminated self-selection bias and increased the validity of responses by using ID; we used a personalized survey; and we blocked participants from entering multiple responses [20].

However, we were probably able to achieve similar final response rates for those who originally received the survey by Internet only because we used mixed modes (ie, sent by email, offered PDF, and finally sent a paper copy by mail), as shown by our response rates up until the final reminders (Table 3).

There are several possible explanations for why the response rate was lower for the Web questionnaire. It may be that participants tend to be worried about computer viruses and delete emails that are unsolicited or from someone they do not know. In fact, it may be easier to delete an email than it is to ignore a mailed survey. It may also be that more paper surveys sent to the incorrect address may have been forwarded to participants, whereas emails would not be re-directed (however, we did not find a significant difference in the number of returned emails versus paper surveys). Having to enter a user ID and PIN to access the Internet questionnaire may have deterred participants. Several participants who used Netscape as their browser contacted us to report that they had trouble navigating through the pages of the survey. We expected that the level of computer literacy in this group would be quite high, although this may not have been the case. The use of different versions or types of browsers and different operating platforms can result in the questionnaire being displayed differently on the designer's computer and the respondent's computer [9]. Other differences in the respondent's computer equipment can affect the appearance of the questionnaire or the ease of using it. Differences include the configuration of the user's screen resolution, Internet connection speed, memory resources, and software applications [9].

In the end, the cost of using the Web site was higher than mailing the survey (Can $3101.95 vs Can $2739.40) because of the cost of Web programming and the monthly cost of the domain name. Our decision to design a custom Web page for the survey led to the increased cost of the Internet survey. Had our sample size been larger, the cost of the Web survey would have been less than the cost of the mailed survey: set-up costs for the Web survey were high, but the cost per additional participant was low [21].

In retrospect, excluding those without email addresses and randomizing the remainder represents a superior design to the one we chose, which requires separate consideration of per protocol and intention-to-treat analyses. However, results were very similar in the two analyses. Our allocation method was "pseudo-random" because we did not use a random number generator to allocate participants to each group. However, our method probably produced the same effect as randomization because we alternately assigned participants to groups using an alphabetical list. Therefore, the assignment of participants was not based on any factor that could plausibly affect their inclination to respond.

We also did not pre-determine whether participants were regular Internet users, or ask non-responders why they did not complete our questionnaire. Thus, it remains possible that more selective use of Internet users would lead to higher response rates. We do not feel that the email group's receiving the final mail-out three weeks later than the mail survey group had much effect on the response rates. Because email communication is much faster than postal mail, we found that after each reminder, responses from the Internet group stopped coming in much earlier than those from the postal mail group. Although one might also challenge the generalizability of our results to surgeons beyond the membership of the OTA, the similar findings of other studies suggest the results may be broadly generalizable. Another limitation of this study is that we cannot precisely measure the reception of the survey by mail and Internet: if the reception differs by the mode, the response rate could be confounded if those who did not receive the survey were included in the denominator. To be conservative we have included in the denominator all those we tried to reach.

We conclude that postal surveys still result in higher initial response rates than Internet-based surveys. Researchers should not assume that the widespread availability and potential ease of Internet-based surveys will translate into higher response rates. Future research should focus on how to refine our techniques in conducting Internet surveys so that they are more accessible and easier to use. Asking non-respondents to Internet-based surveys why they did not respond will inform this work. As our expertise increases in the area of conducting Internet surveys, we will be able to make a more informed evaluation of whether they constitute a valuable tool for conducting health research.

Acknowledgments

This study was funded, in part, by a grant from the Department of Surgery, McMaster University, Hamilton, Ontario, Canada.

Conflicts of Interest

None declared.

References

1. Kellerman SE, Herold J. Physician response to surveys. A review of the literature. Am J Prev Med 2001 Jan;20(1):61-67. [Medline: 20578654] [doi: 10.1016/S0749-3797(00)00258-0]
2. Asch DA, Jedrziewski MK, Christakis NA. Response rates to mail surveys published in medical journals. J Clin Epidemiol 1997 Oct;50(10):1129-1136. [Medline: 98034896] [doi: 10.1016/S0895-4356(97)00126-1]
3. Matarasso A, Elkwood A, Rankin M, Elkowitz M. National plastic surgery survey: face lift techniques and complications. Plast Reconstr Surg 2000 Oct;106(5):1185-1195 discussion 1196. [Medline: 20492514] [doi: 10.1097/00006534-200010000-00033]
4. Almeida OD. Current state of office laparoscopic surgery. J Am Assoc Gynecol Laparosc 2000 Nov;7(4):545-546. [Medline: 20501434]
5. Khalily C, Behnke S, Seligson D. Treatment of closed tibia shaft fractures: a survey from the 1997 Orthopaedic Trauma Association and Osteosynthesis International--Gerhard Küntscher Kreis meeting. J Orthop Trauma 2000 Nov;14(8):577-581. [Medline: 21024225] [doi: 10.1097/00005131-200011000-00011]
6. Bhandari M, Guyatt GH, Swiontkowski MF, Tornetta P, Hanson B, Weaver B, et al. Surgeons' preferences for the operative treatment of fractures of the tibial shaft. An international survey. J Bone Joint Surg Am 2001 Nov;83-A(11):1746-1752. [Medline: 21558474]
7. Cummings SM, Savitz LA, Konrad TR. Reported response rates to mailed physician questionnaires. Health Serv Res 2001 Feb;35(6):1347-1355. [Medline: 21115791]
8. Sibbald B, Addington-hall J, Brenneman D, Freeling P. Telephone versus postal surveys of general practitioners: methodological considerations. Br J Gen Pract 1994 Jul;44(384):297-300. [Medline: 94347414]
9. Dillman DA. Mail and Internet Surveys : The Tailored Design Method. New York, NY: Wiley; Nov 19, 1999.
10. Edwards P, Roberts I, Clarke M, Diguiseppi C, Pratap S, Wentz R, et al. Increasing response rates to postal questionnaires: systematic review. BMJ 2002 May 18;324(7347):1183 [FREE Full text] [PMC: 12016181] [Medline: 22011649] [doi: 10.1136/bmj.324.7347.1183]
11. Edwards P, Roberts I, Clarke M, et al. Methods to influence response to postal questionnaires (Cochrane Methodology Review). In: The Cochrane Library, Issue 3. Oxford: Chichester, UK: John Wiley & Sons, Ltd, Update Software; 2002.

12. Couper M. Web surveys: a review of issues and approaches. Public Opin Q 2000;64(4):464-494. [Medline: 11171027] [doi: 10.1086/318641]
13. Braithwaite D, Emery J, De Lusignan S, Sutton S. Using the Internet to conduct surveys of health professionals: a valid alternative? Fam Pract 2003 Oct;20(5):545-551. [Medline: 22870876] [doi: 10.1093/fampra/cmg509]
14. Mcmahon SR, Iwamoto M, Massoudi MS, Yusuf HR, Stevenson JM, David F, et al. Comparison of e-mail, fax, and postal surveys of pediatricians. Pediatrics 2003 Apr;111(4 Pt 1):e299-e303 [FREE Full text] [Medline: 12671142] [doi: 10.1542/peds.111.4.e299]
15. Kim HL, Gerber GS, Patel RV, Hollowell CM, Bales GT. Practice patterns in the treatment of female urinary incontinence: a postal and internet survey. Urology 2001 Jan;57(1):45-48. [Medline: 21113880] [doi: 10.1016/S0090-4295(00)00885-2]
16. Harewood GC, Yacavone RF, Locke GR, Wiersema MJ. Prospective comparison of endoscopy patient satisfaction surveys: e-mail versus standard mail versus telephone. Am J Gastroenterol 2001 Dec;96(12):3312-3317. [Medline: 21630680] [doi: 10.1016/S0002-9270(01)03893-X]
17. Raziano DB, Jayadevappa R, Valenzula D, Weiner M, Lavizzo-mourey R. E-mail versus conventional postal mail survey of geriatric chiefs. Gerontologist 2001 Dec;41(6):799-804. [Medline: 21579802]
18. Feinstein AR. The theory and evaluation of sensibility. In: Clinimetrics. New Haven, CT: Yale Univ Press; Jun 1, 1987.
19. ; SurveyMonkey.com LLC. Home page. Portland, OR URL: http://www.surveymonkey.com/ [accessed 2004 Sep 14]
20. Zhang Y. Using the Internet for survey research: a case study. JASIS 1999;51(1):57-68. [doi: 10.1002/(SICI)1097-4571(2000)51:1<57::AID-ASI9>3.0.CO;2-W]
21. Jones R, Pitt N. Health surveys in the workplace: comparison of postal, email and World Wide Web methods. Occup Med (Lond) 1999 Nov;49(8):556-558. [Medline: 20122771]

---

submitted 10.06.04; peer-reviewed by H Potts, M Schonlau, S Lee; comments to author 24.06.04; revised version received 19.07.04; accepted 17.08.04; published 24.09.04.

Please cite as:
Leece P, Bhandari M, Sprague S, Swiontkowski MF, Schemitsch EH, Tornetta P III, Devereaux PJ, Guyatt GH
Internet Versus Mailed Questionnaires: A Randomized Comparison (2)
J Med Internet Res 2004;6(3):e30
URL: http://www.jmir.org/2004/3/e30/
doi:10.2196/jmir.6.3.e30
PMID:15471756

Original Paper

Quantitative and Qualitative Usage Data of an Internet-Based Asthma Monitoring Tool

Jacob Anhøj[1], MD, DIT; Lene Nielsen[2], MA, PhD Student

[1]AstraZeneca A/S, Business Communication, Albertslund, Denmark

[2]Copenhagen Business School, Department of Informatics, Frederiksberg, Denmark

Corresponding Author:
Jacob Anhøj, MD, DIT
AstraZeneca A/S
Business Communication
Roskildevej 22
DK-2620 Albertslund
Denmark
Phone: +45 43666275
Fax: +45 43666100
Email: jacob.anhoj@astrazeneca.com

Abstract

Background: In May 2000, AstraZeneca launched a Web service for asthma patients and health-care providers called LinkMedica, which includes an asthma diary for monitoring and self-management. In the diary, the patient enters his or her peak flow, number of doses of rescue medication, and if there have been any asthma symptoms during the previous 24 hours. The patient receives an immediate response from LinkMedica, telling him or her if the asthma is under control and what to do if not, eg, increase the dose of inhaled steroid. Health-care providers have access to the patient diary.

Objectives: The primary objective of the study was to describe patients' and health-care providers' use of LinkMedica. Secondary objectives were to evaluate their perception of the system and how the users' interaction with the system is influenced by their everyday lives.

Methods: Site statistics regarding number of registered users and diary usage were analyzed. An online survey among users (85 respondents), a mailed questionnaire to health-care providers (131 respondents; response rate 26.8%), as well as in-depth interviews with 10 patients and 5 general practitioners, elicited further quantitative and qualitative data on users' perceptions.

Results: In February 2003, a total of 7653 users had registered. During 2002, the growth in registered users averaged 50 per month. In the same period, the number of unique diary users per month decreased from 307 to 138. Patients usually stopped using the diary after a short time; the doctors were reluctant to introduce the diary to patients because of time constraints. Several user subtypes were identified among patients and their relatives.

Conclusion: The self-selected survey responses and in-depth interviews indicated that LinkMedica is generally considered a trustworthy and reliable site by both patients and doctors. However, there was a contrast between users' positive perception of LinkMedica and their unwillingness to use the site for more than short periods. The primary reason for this was that LinkMedica did not fit into their everyday lives because of technical and psychological aspects. A number of recommendations to improve LinkMedica are suggested.

(J Med Internet Res 2004;6(3):e23) doi:10.2196/jmir.6.3.e23

KEYWORDS

Internet; asthma; self care; physician-patient relations; computer-assisted decision making; human-computer interaction

Introduction

The cornerstone of modern asthma care is self-management, allowing the patient to monitor his or her disease severity continuously and to adjust the dose of inhaled corticosteroid based on symptoms, lung function, and use of rescue medication [1]. A recent Cochrane Review concluded that self-management might improve asthma outcomes significantly [2]. Several strategies have been developed, including patient education and written actions plans.

With the appearance of the World Wide Web, new opportunities for communication and interaction between patients and health-care providers have emerged. The Internet has been suggested as a tool for monitoring and for self-management of a number of chronic diseases, eg, diabetes, hypertension, and asthma, and a small number of studies has been reported [3-8].

LinkMedica DK was launched in May 2000 as a Web service for asthma patients and health- care providers. The service enables asthma patients to monitor their condition using an electronic asthma diary, and allows health-care providers to access their patients' diary data. LinkMedica was sponsored and designed by AstraZeneca Denmark in cooperation with the Danish Asthma and Allergy Association and an independent advisory board of asthma specialists.

To our knowledge, LinkMedica was one of the first publicly available services taking advantage of the Internet for self-management of asthma and allowing health-care providers to access patient diary data online, thus improving and facilitating the cooperation between health-care providers and patients.

The LinkMedica Web site is currently available in Denmark [9]. Until 31 March 2004 LinkMedica was also available in the UK [10]. Besides different languages, the main difference between the two sites was different algorithms controlling feedback messages to patientsin the diary. This reflects the fact that LinkMedica is prepared for localized set-ups in different countries with different clinical guidelines and treatment practices.

Below, LinkMedica is briefly described. Readers are encouraged to visit www.linkmedica.dk (Danish) for personal study. Fig. 1 shows a screenshot from linkmedica.co.uk

Figure 1. Screenshot from linkmedica.co.uk

Welcome to LinkMedica

LinkMedica is a new way to link asthma patients with their Doctors and nurses. It is designed to support patients' asthma care by creating an easy way to update and access daily information about their asthma. LinkMedica is a shared tool, available to both patients and Doctor/Nurse.

- LinkMedica helps patients by giving them more control of their asthma and a greater understanding of its causes.
- LinkMedica helps Doctors/Nurses by giving them detailed access to their patients' asthma status and the tools to support their patients on a daily basis.

LinkMedica Services

Asthma Management Centre
This is a shared tool where patient and Doctor/Nurse work together to monitor the patient's asthma. The site contains an automated diary providing immediate feedback on the level of asthma control and allows the level of control to be monitored over time.

Read More

Knowledge Centre
Here you will find information that can help you to increase your understanding of asthma. You can find information about the latest clinical research and news from leading journals and opinion sources. Information is aimed at both patients and Doctors/Nurses. The Knowledge Centre also has regular news feeds, an asthma glossary and pollen & pollution forecasts for the whole of the UK.

Read More

Subscribe to the LinkMedica News Letter

Advisory Board
LinkMedica is endorsed by leading asthma experts. They take an active part in the selection of the Evidence Based Content articles and have supported the development of the Asthma Management Centre.

Read More

EFA

The European Federation of Asthma and Allergy Associations endorses the LinkMedica website.

Read more

HON

LinkMedica is in compliance with the HONcode (Health On the Net).

Read More

Register

Doctor/Nurse
If you already have a PIN access code you can register right now.

Register as a Doctor/Nurse

If you do not yet have a PIN access code and you want information on how to establish an online clinic please contact LinkMedica.

Contact LinkMedica

Patient
As a patient, you can start using the service now or wait for your Doctor/Nurse to establish an online clinic – once the clinic is up and running, you can connect to the clinic and give your Doctor/Nurse access to your asthma data.

Register as a patient

Opinion Poll
Are asthma action plans useful?

○ Yes
○ No
○ Don't know

Previous polls

Latest News
- Anti-allergen covers "ineffective"

System Description

LinkMedica has three main sections: Asthma Management Centre (AMC), Knowledge Centre (KC), and Forum. KC and Forum are immediately available to everyone, whereas AMC requires the user to register and create a user name and a password. Patients are able to create their own accounts online, while health-care providers are required to contact AstraZeneca to get registered. This is to confirm the identity of doctors and nurses available to patients on LinkMedica. When a patient has registered, he or she may select one or more doctors or nurses from the list of available health-care providers. This grants the health-care providers access to the patient's asthma diary if he or she accepts the patient. This procedure ensures that both parties have accepted their collaboration via LinkMedica. After the doctor or nurse has accepted or rejected a patient, the patient receives a notification about this at next login.

LinkMedica Asthma Management Centre

AMC contains the asthma diary. The intention is that the patients log on every day and enter their asthma values: morning peak flow, number of doses of rescue medication, and whether they have had asthma symptoms at night. After submitting diary values, the patient receives an immediate response saying whether or not his or her asthma is under control and, if it is not, providing detailed instructions on what to do. For example, the user may be instructed to double the dose of inhaled corticosteroids for a period of two weeks if he or she has reported asthma symptoms on two consecutive nights. AMC also has graphics that show trends in peak flow and symptoms coupled with environmental factors such as pollen counts and air pollution.

When a health-care provider logs on to LinkMedica, he or she is shown the list of patients who have permitted him or her to access their diary data. By clicking on a patient's name, the health-care provider can see that patient's diary data and graphs.

LinkMedica Knowledge Centre

In KC, users can find a large number (>100) of articles and news about asthma and allergies. The article section contains summaries of evidence-based scientific papers from peer-reviewed journals. These summaries are presented in two formats: 1) "In summary," a user-friendly summary of scientific papers, written in consumer language, and 2) "In detail," a fuller version of the scientific paper and link to the published paper abstract.

The following process is used to select papers: A project coordinator appointed by a subcontractor (Foresight Links Corporation) oversees the selection process. The coordinator, who has professional expertise in evidence-based decision-making, is the main liaison between Foresight Links Corporation, the LinkMedica team and the advisory board.

First, the coordinator conducts a search of the databases of "distilled" evidence using "asthma" as the only keyword, and produces a list of the citations yielded by the search.

Databases used include The Cochrane Database of Systmatic Reviews, Best Evidence, Database of Abstracts or Reviews of Evidence (DARE), Clinical Evidence, and Bandolier.

These databases have been built up over the last 10 years by internationally recognized initiatives (including professional and governmental organizations such as the American College of Physicians, the British Medical Association, and the Cochrane Collaboration), engaged in the collection, appraisal, and synthesis of the best available evidence from clinical research.

As a second step, this list of citations is sent to the advisory board members, together with the list of topics identified as relevant to patients and health professionals. The members of the advisory board are asked to select articles covering as many of the topics on this list as possible. When there are no articles on the list to address topics, members of the advisory board are invited to identify "classic" or recent articles published in peer-reviewed journals, based on their own content knowledge and expertise. These articles are retrieved from the Cochrane Controlled Trials Database and PubMed, and are included only if they meet the selection criteria used by ACP Journal Club. The full article selection process was done before launch of LinkMedica UK in summer 2001. Every four or five years, articles will be reviewed again by the advisory board members who are responsible for ensuring the content is up-to-date.

In addition, news from Danish and international media of interest to asthma and allergy patients is being added on a regular basis from Observer Denmark [11].

LinkMedica Forum

In the Forum section, users may participate in unmoderated discussion groups and ask questions, which are dealt with by experts. The experts are advisers from the Danish Asthma and Allergy Association, a specialist in environmental medicine, a pediatrician, a dermatologist, and a general practitioner [12]. AstraZeneca and the Danish Asthma and Allergy Association selected the experts.

Objectives of This Study

The primary objective of this study was to describe patients' and health-care providers' use of LinkMedica. Secondary objectives were to evaluate users' perception of LinkMedica and how their everyday lives interact with the system.

Methods

A total of four user studies (two surveys, two interview rounds) were launched in summer/fall 2002. Site statistics were evaluated in February 2003.

Site Statistics

Site statistics are available to the site administrator online from LinkMedica's back end based on Web site log files. Total number of registered users at the end of each month and number of unique diary users each month (number of users entering diary values at least once per month) were extracted and plotted against time for visual inspection.

Surveys

Two user surveys were carried out. The first was an online pop-up survey targeted at all users visiting the site from April 29 to May 30, 2002. When visiting LinkMedica during this period, the user was presented with a pop-up window asking the user if he or she was willing to participate in an online survey. Except for the introductory text, a yes and a no button were the only elements on the pop-up form. If the user pressed the no button, the window was closed. If the user pressed the yes button, he or she was redirected to the survey form. Regardless of the button pressed, a cookie was set on the user's hard disk to prevent the pop-up window appearing on subsequent visit. If the pop-up window was closed by other means-eg, by clicking the cross in the upper right corner-no cookie was set. No attempts were made to prevent users from submitting more than one survey form by filling in the form on different computers or by deleting the cookie from their own hard disk. We assumed, however, that the risk of a significant number of users doing this was negligible.

The response rate was not monitored, but the number of submissions was compared with the number of unique visitors (by IP-address) in May 2002.

The survey questionnaire contained 17 questions. In this article we present the results of 7 selected questions: "Your age?"; "Your gender?" (male, female); "What is your background?" (patient, relative, health care professional); "What is your primary reason for visiting LinkMedica?" (seeking information, seeking advice, asthma diary); "How often do you visit LinkMedica at present?" (daily, weekly, monthly, less than monthly); "How often do you intend to visit LinkMedica in the future?" (daily, weekly, monthly, less than monthly); "How do you rate the quality of LinkMedica?" (very good, good, poor, don't know). The last question was asked for each subsection of LinkMedica (diary, knowledge centre, forum).

Complete results from the full questionnaire are available in an internal AstraZeneca report, which is available free (in Danish) to anyone interested.

Males and females were compared with respect to age distribution, reason for visiting LinkMedica (information, advice, diary), and user's background (patient, relative, health-care provider).

The second survey, a mailed questionnaire, was sent to all health-care providers that- according to AstraZeneca's customer database-had received a user name and password for LinkMedica. The questionnaire was in two sections. The first section of 4 questions was intended for all respondents. The second section of 15 questions was intended for those who, in their own opinion, had ample experience in using LinkMedica. Only the results from the first section are presented in this article. The full report (in Danish) is available free to anyone interested. The questions from the first section were: "Your profession?" (physician, nurse, secretary, other); "Have you heard of LinkMedica?" (yes; no); "Do you think that there is a need for Internet tools like LinkMedica in medical practice?" (yes, no); "Do you ever use LinkMedica in collaboration with your patients?" (Yes-frequently, Yes-sometimes, I have looked at it-but did not find it useful, No, No-but I would like to try).

The questionnaire results allowed us to select persons representing different types of LinkMedica users for interviews; respondents of both surveys were asked to provide name, address, and phone number if they were interested in being interviewed.

Semi-structured Interviews

> *To seek to understand the social world as it is for those people whose social world it is, is possible only if one practices the art of listening to them in their own terms and attends to the social world they construct for themselves. (Zaner [13])*

In-depth qualitative interviews were conducted with users in order to get an understanding of the patients' approach to their illness and their use of the Internet and the doctors' approach to the use of Web-based monitoring systems.

A total of 15 users were selected from respondents who were willing to be interviewed for semi-structured interviews: 8 patients, 2 mothers of children with asthma, and 5 GPs. They were selected to represent: 1) male and female users, 2) users of AMC and of KC and Forum, 3) frequent visitors and occasional visitors, and 4) health-care providers, patients, and relatives.

The interviews were designed to address three issues:

- Who are the users?
- How do the users use LinkMedica?
- How do the users' everyday lives interact with LinkMedica?

The perspective of the qualitative method is to understand the world as inter-subjective-to understand the world from the point of view of those who live in the world. The purpose of this interpretative approach is to understand social phenomena-to understand the lived experience and the complex world this experience takes place in [14,15].

All interviews were conducted as semi-structured qualitative interviews according to Kvale's criteria for conducting and analyzing qualitative interviews [16]. They were taped and transcribed. Each interview was broken down into thematic units and these were compared across interviews. As the qualitative method provides insight into the inter-subjective world, it is not possible to quantify the data: they are interpreted as themes from the lived experience of those interviewed.

The starting point of the interviews was the patients' relation to their disease, and both doctors' and patients' strategies for information seeking and use of the Internet. Themes that appeared during the first interviews were pursued in later interviews.

Results

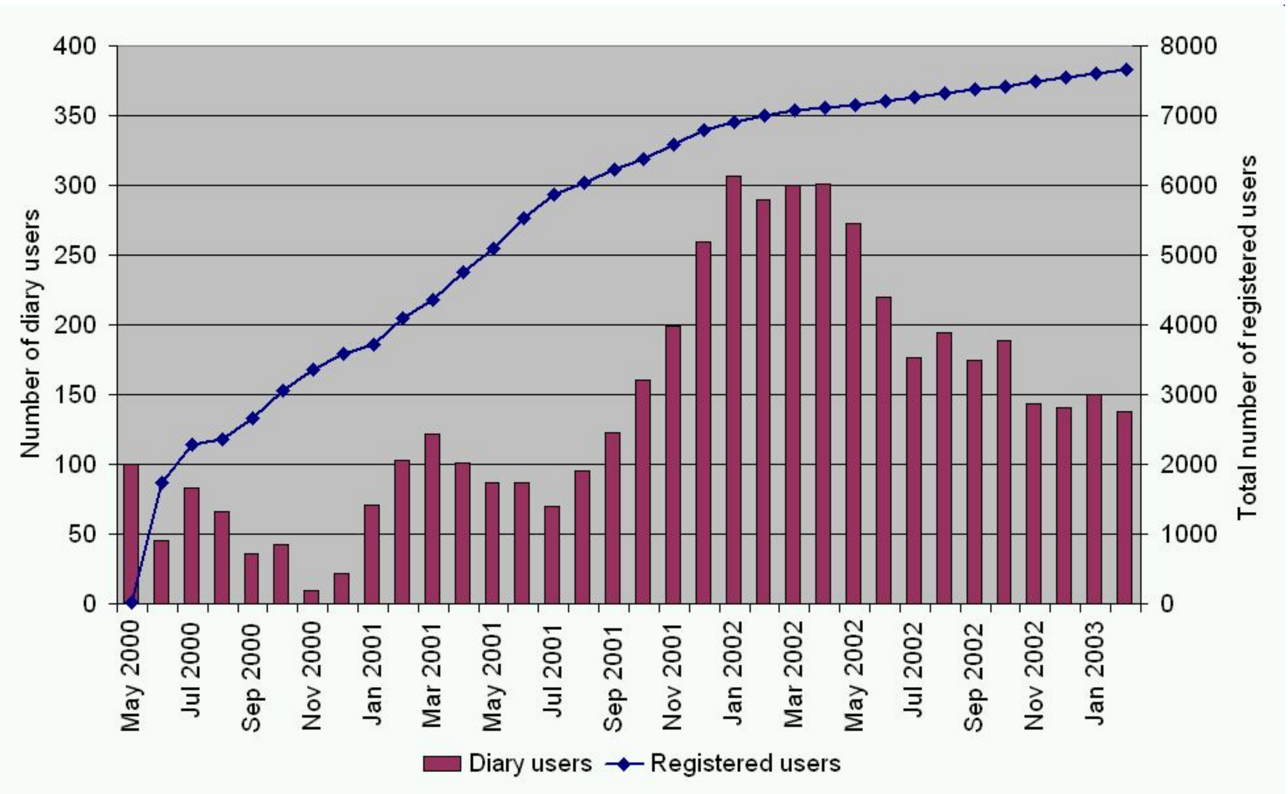
Trends in Number of Registered Users and Diary Users

In February 2003, a total of 7653 diary users were registered on LinkMedica. The number of unique diary users at that time was 138 per month.

Figure 2 shows that the growth rate of user numbers falls into three phases: In the first 3 months after launch, more than 2000 new users registered. During the next year and a half approximately 4000 users registered, and during the last year there was a growth of approximately 50 new users per month.

The trend in unique diary users is more uneven. After a peak of 100 diary users in May 2000, the number decreased until November 2000, when only 9 users kept an online diary. During the next year the number of diary users increased (with a decrease during holiday seasons) to a maximum of 307 in January 2002. This increase occurred at the same time as AstraZeneca started marketing LinkMedica. After this, the number of unique diary users was steady for a period of about 4 months. However, in February 2003, the diary user number had declined to 138 per month.

Figure 2. Number of unique users that have entered their diary per month (bars) and total number of registered users (line)



User Survey

Between April 29 and May 30, 2002, 85 users responded to the online pop-up survey. Compared to a total of 3689 unique visitors in May 2002, this gives an estimated response rate of 2.3%. Of these 59 (69%) were patients, 12 (14%) were mothers of children with asthma and 8 (9%) were health-care providers (see Table 1). Inter-quartile age range was 29 to 43 years.

Because of a programming error in the survey, gender was not recorded for 13 users. Of those remaining, two thirds were female. Mean age was 36 years for females and 41 years for males. This difference was not statistically significant (p=0.12). The age distribution for males and females respectively is shown in Figure 3.

User background and reason for visiting LinkMedica differed somewhat between males and females. Most females were seeking information and advice (49%), while the majority of males gave the asthma diary as primary reason (56%) (Table 2). Only 1 of 7 health-care providers was female. This difference between male and female users with respect to their background (patient, relative, health-care provider) and their reason for visiting LinkMedica (information, advice, diary) was statistically significant (p<0.05, chi square test).

Seventy-two percent reported that they visited LinkMedica at least once a month, and 92% reported that they expected to visit LinkMedica at least monthly in the future.

When asked how they perceived the quality of LinkMedica, the majority of users answered that the quality was good or very good. However, for each main section a rather large percentage of users answered that they did not know (Table 3).

Table 1. Demographics of respondents to pop-up online survey

Background	**All**	**Males**[**]	**Females**[**]
Patient	59 (69%)	17 (68%)	32 (68%)
Relative	12 (14%)	0 (0%)	11 (23%)
Health care professional	8 (9%)	6 (24%)	1 (2%)
Other	6 (7%)	2 (8%)	3 (6%)
Total	85 (99%)[*]	25 (100%)	47 (99%)

[*] Because of a programming error in the survey, gender could not be accounted for in 13 users

[**] p = 0.04, chi square test

Table 2. Response to the online pop-up survey question "What is your primary reason for visiting LinkMedica?"

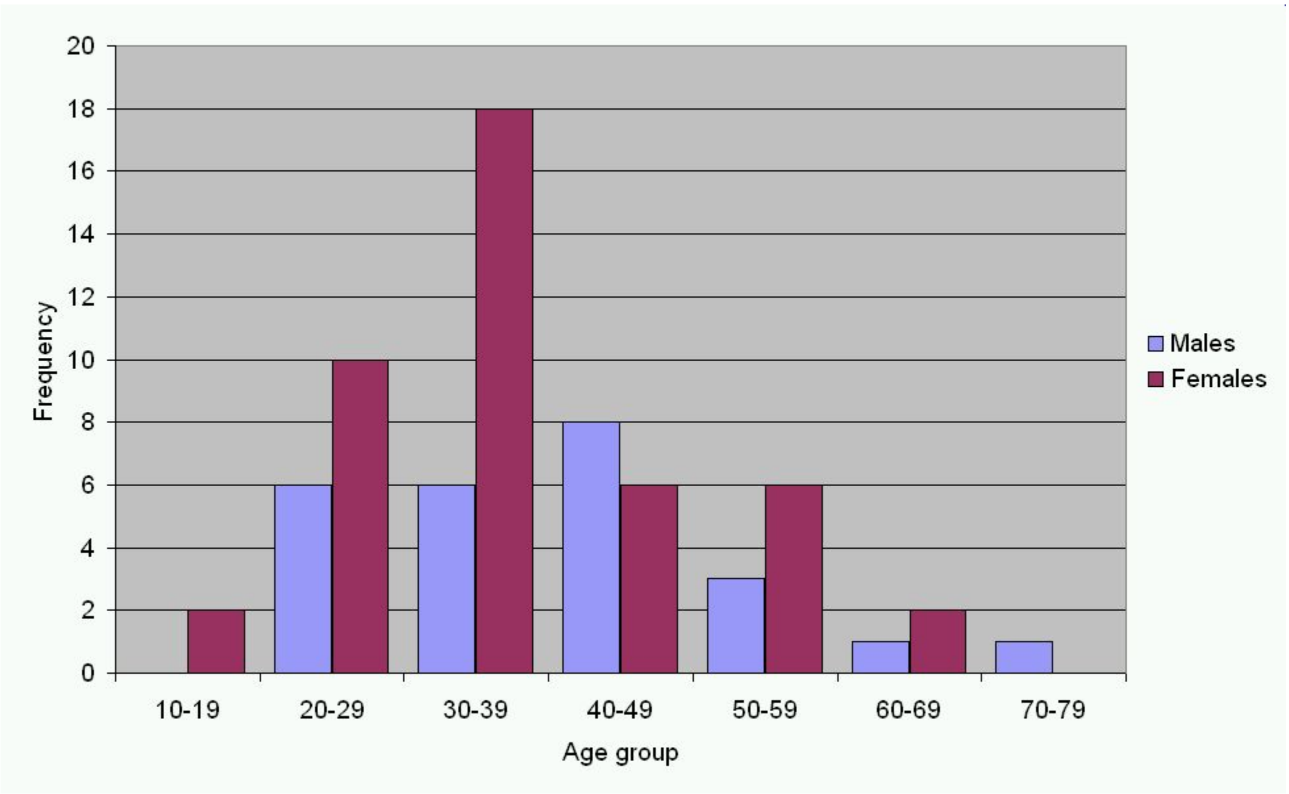
Reason	**All**	**Males**[*]	**Females**[*]
Information (Knowledge Centre)	23 (27%)	4 (16%)	18 (38%)
Advice (Forum)	6 (7%)	0 (0%)	5 (11%)
Asthma diary (Management Centre)	39 (46%)	14 (56%)	18 (38%)
Other	17 (20%)	7 (28%)	6 (13%)
Total	85 (100%)	25 (100%)	47 (100%)

[*] Because of a programming error in the survey, gender could not be accounted for in 13 users

Table 3. Users' responses to the online pop-up survey question: "How do you rate the quality of Asthma Management Centre, Knowledge Centre, and Forum respectively?"

Assessed quality	**Asthma Management Centre**	**Knowledge Centre**	**Forum**
Very good	27 (33.7%)	15 (18.7%)	8 (10.3%)
Good	28 (35%)	33 (41.2%)	24 (30.8%)
Poor	2 (2.5%)	2 (2.5%)	2 (2.6%)
Don't know	23 (28.7%)	30 (37.5%)	44 (56.4%)

Figure 3. Age distribution of users



Health Care Providers Survey

Out of 489 questionnaires mailed to health-care providers that-according to AstraZeneca's customer database-had been given user name and password for LinkMedica, 131 were returned (response rate 26.8%). Among the respondents there were 127 (97%) physicians and 4 (3%) nurses. Fifty-one (39%) used LinkMedica intermittently or frequently for their asthma patients. Questionnaire results are summarized in Table 4 and Table 5.

Table 4. Health-care providers' answers to two questions from the mailed questionnaire

Question	Yes	No	Total
Have you heard of LinkMedica?	113 (86%)	18 (14%)	131 (100%)
Do you think that there is a need for Internet tools like LinkMedica in medical practice?	96 (73%)	35 (27%)	131 (100%)

Table 5. Health-care providers' answers to the question: "Do you ever use LinkMedica in collaboration with your patients?" (from mailed questionnaire)

Answer	Frequency
Frequently	4 (3%)
Sometimes	47 (36%)
I have looked at it-but did not find it useful	4 (3%)
No	46 (35%)
No-but I would like to try	29 (22%)
Total	130 (99%)

Interviews

A total of 15 one-to-one in-depth interviews, each lasting approximately 60 minutes, were conducted.

Who Are the Users?

Five thematic types of users were identified among the interviewees. Characteristics are summarized and compared in Table 6.

Table 6. Interviewees

User	Demography
Patient 1	Male, 28, severe asthma, uses the diary. Has posed questions to expert.
Patient 2	Female, 37, asthma, diary user, mother of two, one has asthma.
Patient 3	Female 33, asthma, mother of a child with asthma, does not use the site.
Patient 4	Female 53, severe asthma and allergy, diary user.
Patient 5	Female 43, asthma and allergy, has used the site for information.
Patient 6	Male, 40, asthma, diary user.
Patient 7	Female, 35, asthma, diary user, pregnant with first child.
Patient 8	Female, 38, daughter with allergy, has posed questions to expert.
Patient 9	Female, 38, son with severe asthma, uses the whole site.
Patient 10	Male 48, asthma, diary user.
GP 1	Female 40, been a GP for 3 years, uses the diary.
GP 2	Male 53, been a GP for 18 years, uses the diary.
GP 3	Male 52, been a GP for 26 years, uses the diary.
GP 4	Male 52, been a GP for 20 years, does not use the diary.
GP 5	Male 58, been a GP for 20 years, working part time, uses the diary.

Patients

We identified a thematic difference amongst the patients. We labeled the two distinctly different types of patients as *controllers* and *neglecters*.

The **controllers** wish to gain control of their disease. They establish daily routines to control and monitor the disease so they do not have to worry about it. Their homes are designed to prevent asthma attacks. They use AMC to monitor their condition.

The following is an excerpt from a patient interview. Interviewees are listed and characterized in Table 7.

> *Interviewer: "Almost everybody in the family suffers from asthma. Does it influence your everyday life?"*
>
> *Patient 2: "No, not really. It influences us in that way-as you can see-that we do not have carpets, just the bare floor. And our son cannot have the pets that he would like to have. And we have installed a ventilating system in order to try and reduce the humidity. So in that way it has influence on our surroundings. We have chosen to hire a cleaner to clean the house because we realize that we cannot do it properly ourselves. So it does influence our lives, but we do not think about it on a daily basis."*

The **neglecters** do not want to think about their disease. By not focusing on it, they feel better. In this way they do not use mental energy on the disease, and they consider this to be good for their health. To feel secure, they just need to carry their rescue medication with them. This excerpt from an interview reflects this attitude.

> *Patient 4: "Then I must figure out myself what is good for me.*
>
> *Interviewer: "Instead of exploring and reading?"*
>
> *Patient 4: "Yes-you can get so focussed on it at times. Sometimes it is better to pretend nothing is wrong. It's a balance, you know."*

There was no distinction between the sexes in these attitudes.

We also observed that different user types might very well be expressed within the same person at different times and that most users possess traces of both the controller and the neglecter types. Thus, a person could say that he or she did not pay attention to the disease and at the same time talk about refurbishing the entire house or about being highly aware of things that might provoke an attack.

Mothers

The two mothers of children with asthma or allergy interviewed were different in their needs and response patterns to information. One motherexpressed an urgent need for information and responded emotionally to the information. She was mainly interested in guidelines that could help her in her present situation. She was not interested in abstract knowledge such as research results or scientific information.

The other mother used all her energy to control her child's disease. She subscribed to news and was active in the Forum. She was empowered by the use of AMC and strived to control her child's disease. She did not think this behavior influenced her family life. The following excerpt is an example of this.

> *Interviewer:" I can see you spend a lot of time looking for information. How does that influence your everyday life?"*
>
> *Patient 9: "It does not-in any negative way. I think it is good that I don't have to spend all day reading newspapers. Now I can use the Internet if there is anything I need to know."*

These two mothers were comparable to the neglecter and the controller types. They will be referred to as the **emotional** and the **professional** mother respectively.

General Practitioners

The typical GP user is a male around fifty years old who works at a GP clinic with a small number of other doctors. Two thematic subgroups were identified: the *user*, who had experience in monitoring asthma patients with LinkMedica and the *interested*, who was considering using LinkMedica in the future.

The **user** was introduced to AMC through participation in a clinical trial. He finds the system of great value for the patients, but he doesn't use it himself now the trial has ended. He finds that AMC has too many functions-more than he needs. He finds the system to be complex with a complicated login procedure.

The **interested** has no experience in using LinkMedica but has heard about it. He believes that both he and his patients might benefit from using the system.

The typical GP user is not a confident user of either the Internet or a PC. The GP knows his own electronic patient record system, but he doesn't use the PC for anything else. He is connected to the Internet through an integrated services digital network (ISDN) connection. This creates obstacles for a smooth login procedure and prevents him from being online all the time.

Table 7. Thematic user segmentation

User segmentation	Patient: The disease controller	Patient: The disease neglecter	Relative: the emotional mother	Relative: the professional mother	The GP
Cause & action	Causal (it is possible to find the cause for an attack/rash)	Deterministic (the causes can be found but they are not important to find)	Causal (it is possible to find the cause for an attack/rash)	Causal (it is possible to find the cause for an attack/rash)	No focus on the causal relationship
Relation to disease	Instrumental	Ad hoc information seeking according to need	Instrumental	Ad hoc information seeking according to need	Patient must learn to accept their asthma
Knowledge	Disseminated information.Active search for information	Experienced information.Information is sought when acute needs appear.	Disseminated information.Active search for information	Experienced information.Information is sought when acute needs appear.	Courses arranged by the Danish Medical Association or the medical industry
Information type	Research articles, news, etc.	Funny information, clarifying information.	Instructive information	Research articles, news, etc.	Medical journals, easy read articles
Relation between GP and patient	The GP is perceived as ignorant on subjects concerning asthma and allergy	The GP is perceived as ignorant on subjects concerning asthma and allergy	The GP is perceived as ignorant on subjects concerning asthma and allergy	The GP is perceived as ignorant on subjects concerning asthma and allergy	The GP is a consultant for the patient

How Do Users Use LinkMedica?

From the interviews we found that the user's perspective plays an important role in how the system is perceived and used.

In the **outside-in** perspective, the users have a problem that arises in the outside world and expect to find answers in LinkMedica. These users have an acute need for information and browse the site to fulfill this need. They ask questions, and they expect a quick reply. It is mainly women who have the outside-in perspective.

In the **inside-out** perspective, the users focus on the use of the diary. They do not read or look for articles and news. But once in a while, an interesting headline may catch their attention. They expect the system to operate as smoothly and as quickly as possible. They have high expectations to the usability of the system. Most of the users who used the diary participated in another research project. It is more often males that have the inside-out perspective. This also applies to GPs.

How Does the User's Everyday Life Interact With LinkMedica?

Most patients interviewed found it easy to use LinkMedica and to enter diary data. In spite of this, none of them used the diary as intended, ie, entering diary values immediately after measuring morning peak flow. All patients wrote the values on a piece of paper and entered the values in LinkMedica whenever it was convenient. Some had access to the Internet at work while others used their home computer in the evenings or during the weekends.

In general, we found that the users were satisfied with LinkMedica; some expressed a will to continue using the site to monitor their asthma over time and to identify asthma triggers. But even though they were motivated, most of the users believed that they would not continue using the site. This excerpt shows a typical behavior:

> *Patient 2: "I do not enter diary values every day. I do it in batches. On the other hand, you should enter values every day in order to benefit from the system. I really want to, but I never get it done."*

As a system, AMC is seen as a reliable tool. However, when the patient receives an unexpected message, one that contradicts his or her previous experience, the patient reacts with disbelief. The patients that had experienced a red alert instructing them to increase the dose of inhaled steroid did not understand why this was important, and none of them took the prescribed action.

In general, the patients were reluctant to use medication on a regular basis. It was difficult for them to accept the fact that a daily dose of medicine is better than using medicine only when experiencing symptoms, as this excerpt shows:

> *Patient 6: "I thought it was a high dose. I did follow the instructions on the Internet-but not the dose."*
>
> *Interviewer: "Why not?"*
>
> *Patient 6: "I might have had a low peak flow for a couple of days. But it kept instructing me to increase the dose, and I did not think it was necessary.*
>
> *Interviewer: How much would be reasonable?"*
>
> *Patient 6: It should have said a little bit more.... I do not know the side effects [talking to the microphone]-do I?*

When asked to consider the ideal patient for the system, the GPs generally described a young man who does sports and has an interest in computers, as expressed here:

> *GP 4: "I imagine a young man around 20 who is troubled by his asthma and knows about computers. So I don't have to explain everything to him. I think it is complicated and I would rather not explain it."*

The GPs said that their relations with the patients are currently in transition. From being considered experts, doctors are now more like consultants who identify problems and cures in collaboration with the patients**.** The GPs find that this is a positive development. But resources are limited, and the consultations still have to fit the 10-minute slots GPs can make available for appointments. This puts a strain on the GPs. Furthermore, as most GPs themselves are not confident PC users, they find it very difficult to instruct the patients in the system. The consultant role requires confidence as well as technical insight, and most GPs do not feel they have this insight.

From the GP's point of view, the patients benefit from using LinkMedica. The system helps patients understand their disease, improves compliance, and reduces symptoms. Furthermore, LinkMedica stresses the patient's own responsibility for his or her disease, as this GP says:

> *GP 5: "It is really motivating. The first of my patients who used the system came back to me and said: I'm so happy I tried this. I went hill-walking in Norway, and you know what? I went all the way to the top and back down again. I haven't been able to do that for many years."*

None of the GPs reported that the patients had difficulties in using the system. The GPs themselves, however, found that using LinkMedica was difficult. The login procedure, especially, was perceived as an obstacle. A GP expressed it like this:

> *"It is an obstacle. I think it is important that the computer logs you in automatically by remembering your login information. All that about changing your password: Forget it! People don't do it."*

From the GP's perspective, AMC is a useful tool, especially for things that computer systems do well: record keeping and performing calculations. This is the major advantage of the system. The disadvantage is that it takes time to log in and to instruct the patients. Also, the GPs found that the system has more functions than necessary.

Even though the GPs have a positive attitude towards the system, their use of it is influenced by external factors such as time and economy. As the GPs put emphasis on these factors, they do not use the system.

Discussion

Survey and interview data indicate that users are happy with LinkMedica in general. Patients find that the asthma diary helps them manage their disease, and doctors find that the diary improves asthma control in patients using it. This observation is supported by preliminary data from a clinical trial. These data, which are currently under evaluation and have been published in abstract form**,** suggest that LinkMedica improves lung function, asthma severity score, and bronchial hyperreactivity compared to traditional treatment regimens initiated by either a GP or a pulmonologist [17].

LinkMedica as a whole is considered a reliable system that offers information of high quality about asthma and allergy. Furthermore, doctors and patients haveexpressed a need for improved tools for asthma monitoring and management. In this respect, the users consider the Internet a medium of high interest.

Interestingly, however, we also found that despite their positive attitude and readiness, both doctors and patients usually stop using LinkMedica after a short period of time. From site statistics and informal user contacts we were already aware of this problem before the project started. The project, however, has given us insight into possible reasons forthis evident paradox:

- Users are inexperienced with the Internet and computers.
- Access to the Internet is limited and cumbersome.
- Users' everyday lives interact with LinkMedica in unpredictable ways.
- Different user types have conflicting needs.
- Internet information may support but not change users' inherent attitudes.
- The benefits of using an asthma diary are not recognized immediately.

Users Are Inexperienced With Internet and Computers

Surprisingly, we found that the users having most difficulties with LinkMedica were the doctors, whom we expected to be confident computer and Internet users. None of the patient users expressed any difficulties whatsoever using LinkMedica. The main complaint from doctors was that the login procedure is complicated and time consuming. The doctors have difficulties managing different user names and passwords for different services. Even though changing user name and password to something easy to remember is straightforward in LinkMedica, none of the doctors did this.

From training sessions with GPs, it is our personal experience that doctors find it difficult to use more than one application at a time. In general, doctors are satisfied with their electronic patient record system available from their desktop, but they do not feel confident in "windows juggling." This prevents them from having LinkMedica at hand whenever an asthma patient comes to the clinic.

In this sense, lack of practice and confidence hinders the use of LinkMedica. But surprisingly, only doctors seem to have this problem. This observation could be the result of a selection bias, leaving only computer literate patients for survey and interview. Although this may be partially true, we do not believe this fully explains why patients apparently have fewer problems than doctors accessing LinkMedica. It may be that doctors have higher demands and are more critical because of time constraints in their work. The fact that doctors on average are older, have less experience with the Internet, and seem to use the Internet less than patients for general information seeking may also play a role.

Access to Internet Is Limited and Cumbersome

Easy access to the Internet is critical for users' experience with LinkMedica. In 2002, 76% of Danes had access to the Internet either from work or home, and 56% used the Internet at least weekly (38% daily) [18]. Thus, in Denmark, Internet availability is hardly a barrier. But speed of connection may be. In the surveys, we did not ask how the users connected to the Internet. But in the interviews, some users complained that the connection and logon time through an analog modem was an obstacle. Although our impression is that LinkMedica loads faster than many other Web sites with comparable content, booting the computer and dialing up with a modem may take several minutes. In comparison, it usually takes less than 20 seconds to fill in the diary and receive the feedback message. As broadband connections become more available and affordable in the future, we expect these problems to diminish.

Users' Everyday Lives Interact With LinkMedica in Unpredictable Ways

In our opinion, an interesting finding from this study is how much users' everyday lives interact with LinkMedica. As an example, take the doctors' time schedules. They have about 10 minutes per patient. This, together with the fact that most doctors do not feel confident in using the Internet, or even their computers, has an enormous impact on how the doctors look at LinkMedica. The end result is that not a single one of the doctors that we interviewed used LinkMedica on a regular basis, despite their positive attitude. Furthermore, the doctors were mistaken in their views of who would use LinkMedica. According to the doctors, the typical LinkMedica user would be a young, sporty man, when in fact, the typical user is a mother around 40 years of age.

The following is another example of how everyday life influences the use of LinkMedica: Typically, the diary users measure their peak flow in the morning and write down the value. They collect the values for a week and type them in later, during the weekend. This way, feedback messages are received days after the condition that triggered them, and the whole idea of immediate dose adjustments due to changes in symptoms or peak flow is lost.

We are convinced that this problem has something to do with the Internet still being separate from the rest of people's everyday lives. The Internet is something you actively connect to, not something that is just there like the telephone or the television. In this sense, LinkMedica and other Internet-based disease management systems are ahead of their time, and we would expect these programs to gain popularity and usability as the Internet gets more integrated into our everyday lives. Currently, we are investigating other means of connecting to LinkMedica, eg, short messaging system (SMS) and general packet radio service (GPRS). These technologies have the advantage of being closely integrated into people's everyday lives and are immediately available to anyone, anywhere without the inconvenience of having to start the computer or wait for slow dial-up connections.

Different User Types Have Conflicting Needs

A number of patient subtypes were identified: controllers, neglecters, professional mothers and emotional mothers. The doctors came in two groups: users (or more correctly, former users) and potential users, who had no prior experience with LinkMedica but who were interested in trying it. During the interviews, it became obvious that these highly different user types have very different requirements and expectations of LinkMedica.

Different parts of LinkMedica (AMC, KC, Forum) are considered important depending on the user's perspective: inside-out or outside-in. The doctor and the controller, together with the professional mother, expect the diary (AMC) to function without a hitch. News, discussion forums, and ask-the-expert sections are merely distracting elements preventing them from having fast access to the diary. If they ask for information, they want it to be as complete as possible, enabling them to decide for themselves how to act. They prefer evidence-based articles and expert opinions to news and advice from other users. The neglecter and the emotional mother, on the other hand, seek information only when they need it. They expect concise information and concrete advice to help them in their current situation. They usually avoid scientific articles and expert opinions unless they are directly applicable to their current needs. They are not interested in monitoring their disease using the diary.

Creating a Web site that seeks to satisfy such conflicting needs and user perspectives may not be a good idea. For future Web projects like LinkMedica, we suggest that the target users be defined clearly from the very beginning. For existing Web sites of complex nature like LinkMedica, it may be worthwhile considering a split into several more focused sites, which may, of course, be interlinked.

Internet Information May Support but Not Change Users' Inherent Attitudes

It is an interesting observation that diary users (controllers) were the ones least likely to follow the advice in the feedback messages. As mentioned previously, not a single interviewee who received an alert message instructing him or her to increase the dose of steroid followed this advice. This observation calls into question the whole idea of the diary design as it is today. If the users most likely to use the diary are also the users least likely to follow specific advice from feedback messages, it might be worthwhile reconsidering the format and the content of the feedback messages.

The idea of having an electronic asthma diary with an "intelligent" feedback system was to support and educate asthma patients in self-management. In this respect, the diary may serve as a daily consultation with a virtual asthma expert. This study taught us, however, that an important difference between virtual and real experts is that patients do not readily accept advice from a virtual expert if this advice conflicts with the patient's own previous experience and attitudes in general, eg, that they are opposed to the use of steroids. The lesson learned is that no matter how intelligent and how well supported by acknowledged experts, a computer system cannot replace real face-to-face contact between doctor and patient. In future versions of LinkMedica and similar systems, we suggest that the very detailed (and complicated) feedback system be replaced by a simple "traffic light" approach. For example: "If your asthma diary says green, all is well. If it says yellow two days in a row or more, or red on a single day, contact your asthma doctor."

The Benefits of Using an Asthma Diary Are Not Recognized Immediately

From classical behavioral psychology we know that in order to reinforce certain behavior, the latency time between behavior and reward must be short. This phenomenon has great implications for treatment of asthma.

In general, it takes time to achieve asthma control. The effect of inhaled steroids on symptoms and exacerbations resulting from previously inadequate treatment may be delayed weeks or months after start of treatment. Furthermore, relapse after cessation of treatment may also be delayed. Since the reward (improved health) is delayed, it can be difficult for the patient to understand why taking regular medication is important. This latency problem is probably one of the reasons that inhaled steroids are being used much less than recommended [19] and also a main reason why patients tend to stop using LinkMedica after a short time.

As with medical treatment, self-management using an electronic asthma diary may take some time to prove its value to the patient. The immediate advantage of measuring peak flow, turning on the computer, connecting to the Internet, logging on LinkMedica, and entering diary values is simply not big enough for the patient to continue doing this for longer periods. Even if a patient has experienced improved asthma control from using LinkMedica, the advantage of continuing use may not (from the patient's viewpoint) justify the inconvenience.

In principle, there are two ways to solve this problem: by improving the accessibility of the diary, which could be achieved by, for example, improved Internet connections, mobile phones, or wireless devices (peak flow meters, electronic dispensing devices, etc.); or by increasing the immediate advantage of diary entry. There may be several ways to achieve the latter. Further studies need to be carried out to reveal whether it is the technology or the lack of immediate advantages that creates obstacles. User studies and explorative design methods [20] can help to clarify the users' needs.

As an example, teenagers would probably adhere more to the diary if they were permitted a small number of free SMS messages for their mobile phones after each diary entry, while others would be encouraged by reimbursement of a portion of their medicine costs linked to how often they entered their diary values. The decrease in unscheduled doctor visits, days off work, etc. resulting from the improved health of users would probably offset the cost of such reimbursement programs. Rewards may also be "virtual": small games where points earned from filling in the diary give access to new game levels might encourage children (and some adults) to adhere to the diary. General information on the user's health-eg, weekly or monthly messages with overall information about the user's asthma, whether it has improved or worsened, and what to do about it-might also prove useful.

What Can Be Done to Support the Use of LinkMedica and Similar Web Sites?

Given 3 years of experience developing and marketing LinkMedica together with the results of this study, we are able to suggest improvements that would make new users more likely to hold onto their Web-based asthma diaries for longer periods:

- Split LinkMedica into two sites, one for the diary and one for information, discussion groups and ask-the-expert sections.
- The diary should be developed after the "lean-mean-machine" principle, completely free of distracting elements like news, flashy graphics, opinion polls, etc. Fields for login and diary values should preferably be available on the front page, allowing for one-click access and diary entry.
- Redesign the feedback messages to merely *inform* about asthma status, rather than give concrete *advice* regarding dosage etc.
- Remove peak flow from the diary. The value of peak flow monitoring in asthma care is debatable [21], and many users find peak flow measurements cumbersome, which hinders the use of the diary. Alternatively, recording peak flow should be optional.
- Explore other methods for data entry and feedback than conventional Web forms. A combination of daily data entry via mobile phone and occasional Web access for diary overview and graphing facilities could prove valuable.
- Consider how to "reward" users immediately after diary entry. This is essential. Users of the diary must have some sort of immediate reward after dairy entry in order to continue using it for longer periods.

Conclusion

In general, LinkMedica is regarded as a very reliable and advantageous system by both patients and doctors. However, only a few users are using LinkMedica as intended, and most users, patients as well as doctors, stop using the diary after a short time. There are several reasons for this, the main reason being that the Internet in general and LinkMedica in particular are still not integrated into people's everyday lives. Consequently, if LinkMedica is to become more popular, it needs to be adapted to the conditions of the users, so it becomes a natural and integrated part of their everyday lives.

Acknowledgments

AstraZeneca A/S, Roskildevej 22, 2620 Albertslund, Denmark sponsored this study.

The Danish Asthma-Allergy Association, Astma-Allergiforbundet, which was involved in the design of the website, is a private, independent, non-profit organization whose aim it is to promote better health for people with asthma and allergy in Denmark. Astma-Allergiforbundet is a member of the European Federation of Asthma and Allergy Associations (www.efanet.org).

The members of the International and the Danish advisory board are: Martyn Partridge, UK; Paul O'Byrne, Canada; Søren Pedersen, Denmark; David Price, Scotland; John Haughney, UK; Lone Agertoft, Denmark; Klaus Phanareth, Denmark; Carsten Vrang, Head of the Department of Pediatrics, Storstrøms Sygehus, Næstved, Denmark; Jørgen Vestbo, UK; Asger Dirksen, Denmark.

Jacob Lenau, e-Business Manager, AstraZeneca, reviewed and approved the manuscript.

Kirsten Broe Pedersen, AstraZeneca, did proofreading and translated citations of the interviewees.

Torkild Clemmensen, TCPsych, and Claus Bornemann, Kamene Research, participated in planning and evaluation of the online user survey.

Thomas Dunk, frontAvenue A/S, programmed the online survey.

Conflicts of Interest

Jacob Anhøj is employed by AstraZeneca. Lene Nielsen has worked as a freelance consultant for AstraZeneca.
The authors have no personal financial interest in the subject matter discussed in the manuscript.

References

1. Global strategy for asthma management and prevention. GINA Workshop Report (NIH Publication No. 02-3659). 2002 Apr. URL: http://www.ginasthma.com/workshop.pdf
2. Gibson PG, Powell H, Coughlan J, Wilson AJ, Abramson M, Haywood P, et al. Self-management education and regular practitioner review for adults with asthma. Cochrane Database Syst Rev 2003(1):12535399. [Medline: 12535399]
3. Baker AM, Lafata JE, Ward RE, Whitehouse F, Divine G. A Web-based diabetes care management support system. Jt Comm J Qual Improv 2001 Apr;27(4):179-190. [Medline: 21190149]
4. Glasgow RE, Boles SM, Mckay HG, Feil EG, Barrera M. The D-Net diabetes self-management program: long-term implementation, outcomes, and generalization results. Prev Med 2003 Apr;36(4):410-419. [Medline: 22536406] [doi: 10.1016/S0091-7435(02)00056-7]
5. Patel AM. Using the Internet in the management of asthma. Curr Opin Pulm Med 2001 Jan;7(1):39-42. [Medline: 21020678] [doi: 10.1097/00063198-200101000-00007]
6. Finkelstein J, Cabrera MR, Hripcsak G. Internet-based home asthma telemonitoring: can patients handle the technology? Chest 2000 Jan;117(1):148-155 [FREE Full text] [Medline: 20098433] [doi: 10.1378/chest.117.1.148]
7. Finkelstein J, Hripcsak G, Cabrera M. Telematic system for monitoring of asthma severity in patients' homes. Medinfo 1998;9 Pt 1:272-276. [Medline: 99312454]
8. Finkelstein J, Hripcsak G, Cabrera MR. Patients' acceptance of Internet-based home asthma telemonitoring. Proc AMIA Symp 1998:336-340. [Medline: 99123142]
9. ; AstraZeneca. LinkMedica Denmark home page. URL: http://www.linkmedica.dk/ [accessed 2003 Sept 29]
10. ; AstraZeneca. LinkMedica home page UK. URL: http://www.linkmedica.co.uk/ [accessed 2003 Sept 29]
11. ; Observer Denmark. Home Page. URL: http://www.observer.dk/ [accessed 2004 July 8]
12. ; LinkMedica DK Experts. Home Page (in Danish). URL: http://www.linkmedica.dk/Asthma/Forum/AskTheExpert/Forum_ATE.asp [accessed 2003 Sept 29]
13. Zaner R. Solitude and society: the critical foundations of social science. In: Psathas G, editor. Phenomenology and Sociology: Theory and Research (Current Continental Research). New York: University Press of America; Sep 1, 1989:25-46.
14. Schwandt TA. Constructivist, interpretivist approaches to human inquiry. In: Denzin NK, Lincoln YS, editors. The Landscape of Qualitative Research: Theories and Issues. Thousand Oaks: Sage Publications; Mar 9, 1998.

15. Guba EG, Lincoln YS. Competing paradigms in qualitative research. In: Denzin NK, Lincoln YS, editors. The Landscape of Qualitative Research: Theories and Issues. Thousand Oaks: Sage Publications; Mar 9, 1998.
16. Kvale S. InterViews : An Introduction to Qualitative Research Interviewing. Thousand Oaks: Sage Publications; Mar 14, 1996.
17. Rasmussen L, Backer V, Phanareth K. Preliminary data from a clinical trial: does use of an Internet based asthma-monitoring tool increase lung function and asthma control? 2003 Presented at: American Thoracic Society 99th International Conference; May 16-21; Seattle, Washington, USA.
18. ; Statistics Denmark. Use of the Internet by households (in Danish). 2003 Apr 4. URL: http://www.dst.dk/pukora/view/pdf.asp?id=4740 [accessed 2003 Aug 18]
19. Rabe KF, Vermeire PA, Soriano JB, Maier WC. Clinical management of asthma in 1999: the Asthma Insights and Reality in Europe (AIRE) study. Eur Respir J 2000 Nov;16(5):802-807 [FREE Full text] [Medline: 21026428] [doi: 10.1183/09031936.00.16580200]
20. Nielsen L. Constructing the user. Proceeding of 10th International Conference on Human-Computer Interaction; 2003 June 22-27; Crete, Greece. Mahwah: Lawrence Erlbaum Associates, Inc; 2003.
21. Mcgrath AM, Gardner DM, Mccormack J. Is home peak expiratory flow monitoring effective for controlling asthma symptoms? J Clin Pharm Ther 2001 Oct;26(5):311-317. [Medline: 21536953] [doi: 10.1046/j.1365-2710.2001.00374.x]

Abbreviations

AMC: Asthma Management Centre
GP: General Practitioner
ISDN: Integrated Services Digital Network
KC: Knowledge Centre
SMS: Short Messaging System
GPRS: General Packet Radio Service

---

submitted 26.08.03; peer-reviewed by S Krishna, G Demiris; comments to author 19.09.03; revised version received 03.10.03; accepted 09.10.03; published 03.09.04.

Please cite as:
Anhøj J, Nielsen L
Quantitative and Qualitative Usage Data of an Internet-Based Asthma Monitoring Tool
J Med Internet Res 2004;6(3):e23
URL: http://www.jmir.org/2004/3/e23/
doi:10.2196/jmir.6.3.e23
PMID:15471749

Original Paper

Internet Usage by Low-Literacy Adults Seeking Health Information: An Observational Analysis

Mehret S Birru[1], BA; Valerie M Monaco[2], PhD, MHCI; Lonelyss Charles[3], MLIS; Hadiya Drew[3], MLIS; Valerie Njie[4], MS; Timothy Bierria[4], BA; Ellen Detlefsen[3], DLS; Richard A Steinman[1,2], MD, PhD

[1]Department of Basic Research, University of Pittsburgh Cancer Institute, Pittsburgh PA, USA
[2]Department of Medicine, University of Pittsburgh, Pittsburgh PA, USA
[3]University of Pittsburgh School of Information Sciences, Pittsburgh PA, USA
[4]Bidwell Training Center, Pittsburgh PA, USA

Corresponding Author:
Richard A Steinman, MD, PhDAssociate Professor of Medicine and Pharmacology
Hillman Cancer Center
5117 Centre Avenue
Suite 2.18 UPCI Research Pavilion
Pittsburgh PA 15213
USA
Phone: +1 412 623 3237
Fax: +1 412 623 7768
Email: steinman@pitt.edu

Abstract

Background: Adults with low literacy may encounter informational obstacles on the Internet when searching for health information, in part because most health Web sites require at least a high-school reading proficiency for optimal access.

Objective: The purpose of this study was to 1) determine how low-literacy adults independently access and evaluate health information on the Internet, 2) identify challenges and areas of proficiency in the Internet-searching skills of low-literacy adults.

Methods: Subjects (n=8) were enrolled in a reading assistance program at Bidwell Training Center in Pittsburgh, PA, and read at a 3rd to 8th grade level. Subjects conducted self-directed Internet searches for designated health topics while utilizing a think-aloud protocol. Subjects' keystrokes and comments were recorded using Camtasia Studio screen-capture software. The search terms used to find health information, the amount of time spent on each Web site, the number of Web sites accessed, the reading level of Web sites accessed, and the responses of subjects to questionnaires were assessed.

Results: Subjects collectively answered 8 out of 24 questions correctly. Seven out of 8 subjects selected "sponsored sites"-paid Web advertisements-over search engine-generated links when answering health questions. On average, subjects accessed health Web sites written at or above a 10th grade reading level. Standard methodologies used for measuring health literacy and for promoting subjects to verbalize responses to Web-site form and content had limited utility in this population.

Conclusion: This study demonstrates that Web health information requires a reading level that prohibits optimal access by some low-literacy adults. These results highlight the low-literacy adult population as a potential audience for Web health information, and indicate some areas of difficulty that these individuals face when using the Internet and health Web sites to find information on specific health topics.

(J Med Internet Res 2004;6(3):e25) doi:10.2196/jmir.6.3.e25

KEYWORDS

Literacy; health; reading; Internet; health education; health promotion; socioeconomic factors

Introduction

Although a tremendous volume of educational health materials is disseminated in the United States, not all Americans find this information accessible or usable. In particular, adults with poor health and low functional literacy face great risks of poor health outcomes and preventable disease progression [1-4]. While many low-literacy adults could benefit from enhanced health knowledge, most current health education materials are written at a 10th grade or higher reading level [3]. Inability to access or understand health education materials inhibits important preventive or treatment measures, and may decrease the likelihood of identifying a symptom of disease. Low *health* literacy is also a barrier to enrollment in clinical trials [5,6] and minimizes adherence to instructions given by health professionals [7]. These obstacles are compounded by low income levels pervasive in the undereducated population [1], which can prevent individuals from pursuing regular primary care, paying health insurance premiums, or purchasing medications when prescribed. Collectively, these factors help to explain why low-literacy adults are twice as likely to be hospitalized as individuals with high functional literacy [8].

The expense of poor health and low functional literacy on the health system is estimated at $73 billion each year [9]. High cost estimates have encouraged many health-care providers to search for innovative ways to improve health literacy. The Internet has been embraced as an easy-to-use, convenient, and comprehensive clearinghouse for information on diseases, disorders, treatments, and preventions. Even when receiving physician care, between 40% and 54% of medical patients use the Internet to learn about treatment options and tobetter understand their medical conditions [10].

However, the low-literacy population has largely been excluded from the veritable boom of Internet health resources. The expense of Internet services and personal computers may be too high for this population. In addition, most text-based health information on the Internet is too advanced to be optimally effective for low-literacy populations. On average, Internet health-education materials are written at a 10th grade or higher reading level, and 100% of English-language health Web sites examined in a 2001 study required at least high school-level reading proficiency [11,12]. Another study concluded that of 1000 Web sites reviewed, only 10 had a level of writing and content accessible to low-literacy adults [13]. Kalichman et al suggest that individuals who read English below a 6th grade level are not likely to make effective use of the Internet [14]. Further, Zarcadoolas et al report that complex Web features, such as animated links, may be challenging for low-literacy adults to identify and utilize [15]. The 1992 National Adult Literacy Survey (NALS) revealed that more than 90 million Americans either read at a low-literacy level or are functionally illiterate [1]; the paucity of Internet health resources appropriate for these individuals perpetuates discrepancies in health outcomes between the educated and undereducated.

While no studies to date have determined how many low-literacy adults regularly use the Internet to find health information, the dearth of educational materials suitable for these individuals may impair optimal usage and navigation. One study has reported interventions that enabled low-income HIV-positive individuals to use the Internet and to critically evaluate information that they encountered [16]. Health-related Internet use has also been shown to enhance knowledge about HIV and to be correlated with active coping in a study of HIV-positive patients [17]. Although these studies focus on low-income status rather than low-literacy status, the established correlation between these two factors suggests that low-literacy adults may likewise benefit from augmented health education via the Internet.

We conducted an observational study of low-literacy adults to assess how they searched for Internet health information in as close to a natural setting as possible. Our investigative questions include the following: if low- to mid-level literacy adults are given access to the Internet, can they find basic health information that they can understand? Will their search strategies be effective in identifying information that they can use and comprehend? How do they rate current health Web sites in relation to their needs and interests? Will they be able to conduct successful self-directed searches? In our investigation, we also categorized navigational strategies used by low-literacy adults and the reading level of materials they accessed.

Methods

We enrolled 13 adult literacy students (3rd to 8th grade reading levels) from Bidwell Training Center, a vocational school in Pittsburgh, Pennsylvania. The protocol used was approved by the University of Pittsburgh Institutional Review Board. Bidwell students are organized individually and/or in small groups for reading instruction; they meet together once a week for program announcements. The literacy program coordinator introduced the study to 20 students in this large-group setting. Thirteen interested students then self-selected into the study. All subjects participated in a computer skills workshop in May 2003, where they were presented with basic search and navigation strategies and learned how to use the Google search engine. We selected Google because it is a widely used search engine and has a "Did You Mean…" feature that corrects misspelled search terms. We anticipated that this might be a feature that low-literacy subjects would find particularly helpful. Among other topics, subjects were taught how to use the "Back" button and the "Forward" button, how to scroll down a page, how to identify links, and how to conduct basic searches. Each subject also filled out a brief questionnaire to give insight on their educational background, ethnicity, health insurance status, and previous experience with computers and the Internet. The questionnaire was written at a 3rd grade reading level (Flesch-Kincaid Reading Scale).

An investigator met individually with each of the participants within 3 weeks of the computer skills course for the observational portion of the study. Participants were 1) administered the REALM test (Rapid Estimate of Adult Literacy in Medicine) [18] to assess their health literacy level; 2) asked several questions to gauge their comfort level on the Internet and prior Internet experiences; and 3) taught how to "think aloud," or continually express their thoughts while using the computer. Investigators engaged each participant in several think-aloud examples in order to actively illustrate this process.

The investigator then asked the participant to use the Internet and Google search engine and think aloud while finding information on a subject of his or her choice. This preliminary question allowed participants to practice and review their Internet searching techniques. Participants were permitted to ask the investigator technical and navigation-related questions during this part of the study. These questions included, but were not limited to, whether to put spaces between words in search terms and how to initiate a search once a search term had been specified.

Participants were then asked to find answers on the Internet to 3 health-related questions developed by members of the research team. Participants were instructed to use the Google search engine so that their answers could be standardized. A committee consisting of a physician, a faculty member specializing in human-computer interactions, a community health educator, and an information sciences specialist compiled various answers to these questions that would qualify as accurate and complete. Subjects who were able to generate any of these answers during their online searches were considered to have answered the questions correctly; subjects who were not able to generate these answers were determined to have answered the question either incorrectly or incompletely. Examples of responses for each question that would have been considered correct are included in the *Results* section

The investigator read the 3 questions aloud and also provided them to the participant in written form (Arial font, 20 pt):

1. Think of a health question you are interested in for yourself or for someone you know. Find out information about this question on the Internet.

2. Imagine that someone you care about has lung cancer. This person would like to know about treatments for lung cancer. Can you find out the three main types of treatments using the Internet?

3. Imagine that you are at a doctor's office and you are told you have a disease called diabetes (sometimes called sugar). You are given a pill called Metformin to take for it. What does Metformin do?

Subjects identified answers to the investigator, who then asked them to articulate the answers in their own words. Participants who seemed frustrated or unreceptive, or who asked to move to a new question were directed to the next task. Participants were allowed to use any Web sites they felt would help them answer the questions. Participants also were not provided with dictionaries-our objective was to examine how they navigated the Internet without assistance from external sources. Subjects were given up to 15 minutes to complete each task, as measured by the investigator. To minimize anxiety, they were not informed of the time limitation. After the 15-minute period, investigators used a series of prompts to gradually guide subjects, if necessary, to the next task.

Next, investigators accessed the colon and rectum cancer Web page on the American Cancer Society (ACS) Web site [19]. Participants were asked to navigate through links on this page and find 2 ways to help prevent colon and rectum cancer. Investigators recorded the amount of time spent answering this question and the number of links participants clicked on to find the answers. After this task was completed, investigators asked the participants several subjective questions to qualify their experience on the Internet. Participants were then given $25 compensation, which ended their direct involvement in the study.

Investigators wrote notes on each participant's progress, and asked for participant feedback about the Internet both before and after searching the Internet. Investigators did not coach subjects on proper technical or navigational techniques after the initial practice question until subjects had completed their tasks. In 2 cases, investigators directed subjects to Google's "Did You Mean…" search term correction option in order to adjust for spelling mistakes; these subjects had repeatedly demonstrated very poor spelling proficiency before this intervention.

Camtasia Studio screen-capture software recorded individual keystrokes and think-aloud recordings. Questionnaires and think-aloud methods were used to ascertain the criteria used by participants in evaluating Internet health Web sites. Investigators also calculated the 1) literacy levels of Web sites accessed by the participants, 2) the amount of time spent on each Web site, 3) the number of questions answered thoroughly and correctly by each participant according to pre-determined standards, 4) the average number of sites used to answer each question, and 5) the number of participants who accessed sponsored sites, or paid advertisements appearing on the Google retrievals page, and how many used that information to answer questions.

Results

Qualitative and quantitative results were analyzed in this study.

Participants

In this study, the subject population was reduced from 13 to 8. Two participants were excluded because they did not attend the one-on-one searching session with the investigator. Two other participants were excluded because they were non-native English speakers who did not understand the tasks presented to them. One participant was later excluded because technical problems prohibited the retrieval of her computer searches.

The average age of our 8 remaining participants was 41.5 years. Five subjects were male and 3 were female. Seven identified themselves as African Americans and 1 self-identified as of Asian descent. The Asian participant was an English-as-a-second language (ESL) speaker with a university education from his native country. Seven of the 8 participants reported having health insurance. Seven of the 8 also had at least some high school or trade school education; 1 participant did not report educational experience on the intake questionnaire.

Of these subjects, 2 reported on the intake questionnaire that they had never previously used a computer or the Internet. Two reported that they had previously used a computer, but had not used the Internet. Subjects generally used computers with greater frequency than they used the Internet. Three participants reported on the questionnaire that they used the Internet 2 or more times a week; they later said verbalized that their main online interests were news, sports, cars, and/or entertainment information. The other 5 participants reported on the questionnaire that they used the Internet either occasionally or not at all. Usage reports from the intake questionnaires are provided in Table 1.

Table 1. Self-reported, written questionnaire responses about prior Internet and computer usage by subjects (n=8)

Subject	*Have you ever used a computer? If so, how often?*	*Where do you use computers?*	*Do you use the Internet? If so, how often?*	*Where do you use the Internet?*
1	No	"No where" [sic]	No	"I've never used the Internet"
2	Less than once a month	"When I was in jail"	No	(N/A)
3	2 or more times a week	"At school, Bidwell Training Center in Ms. Cooper's class."	No	"At the Carnegie Library in Beechview where I live"
4	No	"No"	No	"No"
5	2 or more times a week	"To type"	Yes; Less than once a month	"In school"
6	No; 2 or more times a week	"At home"	Once a week	"At home"
7	2 or more times a week	"Home"	2 or more times a week (at home)	"Home"
8	Once a week	"Different location"	2 or more times a week	"Different location"

As seen in Table 1, the self reports of prior Web and computer experiences are unclear in several cases. Subject 3 reported no prior Internet usage in one part of the questionnaire, but reported in a subsequent answer Web usage at a local public library. In addition, as Table 1 indicates, subject 8 reported more frequent usage of the Internet than of computers; subject 6 (ESL student) first indicated no prior computer usage, then later reported on the questionnaire computer usage of twice a week. Because there were seemingly divergent perceptions of what constitutes a computer or Internet experience, perceived computer/Web adeptness cannot be correlated with our participants' experience using this technology. Therefore, while this study will indicate differences in results between the 3 people with frequent Internet experiences (defined in this study as usage of at least once a week) and the 5 individuals without, the study will not attempt to conclude whether the skill level of subjects in the study correlated with the sustainability of their prior computer and Web experiences.

Search Engine Usage

Participants reviewed their navigational skills during their preliminary question, where they were encouraged to look for information on any subject that interested them. They used Google to search for a variety of topics, ranging from entertainment to health-related information. Participants occasionally searched for information on more than one topic.

Participants used the search items listed in Table 2 in order to answer the preliminary question and questions 1 to 3. Semicolons between words or phrases separate multiple search terms used by a subject to answer a question. The subjects are listed in Table 2 in the same order (ie, 1, 2, 3…) as they appeared in Table 1.

Table 2. Search terms used by subjects to answer preliminary questions and questions 1 to 3 (n=8)

Subject	Preliminary	Question 1	Question 2	Question 3
1	lena horn[†]	Lung cancer	Lung cancer	Metformin
2	health care;health care mental	Sports and health	health care about lung cancer	A pill called metformin
3	*(no clear search topic)*	Herpes	Cancer	Metformin
4	Wwwsoulfood; wwwsoulfoodcom; soulfood	AIDS	lung caner[†]	Diabetes
5	Will Smith; sipers[†]; spiders	High blood	Lung cancer	Metformin
6[**]	Bi;;;dwell training center[†]	Health	health lung caner[†]	Health diabetes
7	sonny Rollins	Tuberculosis	Treatments for lung cancer	Metformin
8	Babyface recording artist	Pain	Cancer	Pdr[*]

[*] Physicians' Desk Reference

[**] English-as-a Second Language subject

[†] misspellings for: "lena horne," "bidwell training center," "lung cancer," and "spiders"; the Google correction option was used in two instances when the subject was prompted by investigators to amend search terms.

Questions 1 to 3 were given to our participants in writing, as well as orally; this may have affected their selection of search terms. For question 2, one participant wrote "treatments for lung cancer" in the search term box, a phrase that is written explicitly in that question. Another participant was similarly prompted by the wording of question 3 to write "a pill called metformin" as his search term.

Individuals who used the Internet at least once a week are labeled in Table 1 and subsequent tables as subjects 6 to 8. Search terms generated by these frequent Internet users did not differ greatly from search terms generated by individuals who had little Internet experience. The one exception was subject 8, who attempted to answer question 3 by using the online *Physicians' Desk Reference*, a site about which she had once heard good reviews.

In general, this group found generating original search terms to be somewhat challenging. Many did not initially remember whether to put spaces between the words in search terms. Even a subject who reported using the Internet once a week hesitated when writing the search term for question 1, finally stating, "*Yeah, you do have to space [between words]… I had to remember if you had to space.*" With one exception, participants were able to correct their terms by inserting the proper spaces.

Spelling of search terms was generally a problem for only 2 participants, one of whom (subject 7) spoke English as a second language. Subjects tended to self-correct for spelling in the search term box before pressing the "Google Search" button or Enter key. Several participants also had difficulty understanding what type of terms to put in. When conducting a preliminary search for information on the television show, *Soul Food*, one participant typed into the search term box, "wwwsoulfood." When this retrieved no results, the subject looked at the URL for guidance and then typed "wwwsoulfoodcom" into the Google search term box. This again did not yield any results. The participant next entered "soulfood" into the search term box. The investigator finally directed the subject to Google's "Did You Mean…" option so that the subject could answer the question. However, this participant had continued difficulties generating correct search terms; later in the study, he used "lungcaner" as a search term to find information about lung cancer.

Nearly all participants retained skills such as scrolling and clicking on links from the computer workshop or previous Internet experiences. They also learned other navigational strategies through repetition and practice. For example, one participant who was conducting a preliminary search for information about Will Smith looked at the Google retrievals and stated, "*So it [search engine] must go to other Smiths ... I wonder if I was supposed to put in 'Will Smith the actor'?*" Quickly, the subject had learned that increasing the specificity of search terms generally improves the specificity of results.

Six of the 8 participants did not venture past page 1 of the Google retrievals. One participant was surprised by the number of search results, saying, "*You find a lot of stuff on this thing [the Internet].*" Another participant explained why she stayed on page 1: "*Oh boy, I've got a lot to choose from. I don't want to go to the other ten [pages of retrievals] because it might give me other information I don't really need ... the first page gives me just enough of what I need to know.*" This participant had deduced that first-page retrievals typically have the most relevant sites to the particular search term used. Later, this subject stated, "*I didn't answer the questions, but I looked up the information, and it [Internet] gave me what it wanted me to have.*" This statement implies that the subject believed that the Internet was more in control of the searching than the subject, revealing a possible belief that the search engine and search terms selected are not the primary determinants of what type of information is retrieved.

Sites Accessed

Ability to Answer Questions

In question 1, participants were asked to use information on the Internet to find the answer to a health-related query of their choice. Most participants identified only a subject area, and did not clearly articulate a specific question despite verbal prompting by the investigators. Several participants initially stated a topic, but changed it as they retrieved unrelated material that they found more interesting. While recordings from the think-alouds would have been helpful in designating the search topics, we found that despite investigators' prompts and encouragement, subjects were very reluctant to verbally report their real-time experiences navigating through the Web. As one subject stated, "*Shucks, I can't think aloud.*" It is therefore difficult to gauge whether participants were able to find adequate information for which they searched, especially during the unstructured searching period required to answer the first question.

Question 2 required participants to locate the 3 main types of lung cancer treatments (acceptable answers: chemotherapy, surgery, radiation). This question models the navigation of a typical Internet health-information seeker who searches for disease-related information. Of all 8 participants, only subject 5 was able to answer this question accurately and completely. Subject 3 verbalized one viable option-chemotherapy-based on information accessed online. The remaining participants either did not answer the question or identified an alternative medicine as one of the principal types of lung cancer treatments available.

Question 3 required participants to find out the role of metformin, or Glucophage, in diabetes treatment (one acceptable answer: metformin lowers sugar in the blood). This question models a doctor-patient interaction in which a patient who is prescribed an unfamiliar medication independently searches for information about its effects. Six of 8 participants were unable to find information on the Internet to answer the question. The 2 participants, subjects 3 and 7, who found the information, read directly from text on the site and did not articulate the information in their own words.

Surprisingly, subjects who reported sustained prior Internet experience in the questionnaire were no more successful at answering questions than subjects with little Internet experience. This could have been a result of the generalized search terms that they used to look for answers. Prior Internet experience does not seem to lead to satisfactory search/navigation skills for members of this group in searching for health information.

Information Accessed

Sites used by subjects 3, 5, and 7 to successfully answer questions 2 and 3 were written at a 12th grade reading level (Flesch-Kincaid). It is noteworthy that these subjects were able to identify the answer in the text and read it aloud. In 2 out of 3 cases, they were unable to express these answers in their own words, which suggests a minimal comprehension of the material accessed.

Seven of the 8 participants accessed sponsored site information while attempting to answer questions. Businesses pay a service fee to Google to have their site names appear as sponsored sites when triggered by a particular search term or keyword. Sponsored sites are outlined in color and/or appear in boxes on the right side and heading of the Google retrievals page. In general, alternative treatments and commercial therapies and medications appear under this listing; many of these sites may contain information that is uncorroborated by legitimate scientific sources.

Five participants used information provided by the sponsored sites to answer questions. Two out of 3 of the subjects who used the Internet at least once a week also used this information to answer questions. Half of the participants searching for lung cancer cures arrived at the same site: an Asian dietary supplement site claiming to cure cancer by removing free radicals from the body [20]. Another popular sponsored site promoted a radio frequency technique to hinder cancer progression [21]. The titles of these sites as they appeared in the sponsored sites submenu were: "New Cancer Treatment" and "Cancer Treatment." The Flesch-Kincaid formula indicated that the information on both sites was written at a 12th grade or higher reading level. Information on sponsored sites, therefore, was not necessarily any easier to read or interpret than information on non-sponsored sites accessed by subjects in this study.

General Site Profiles

Observational logs and records on the Camtasia software show little correlation between our subjects' ability to identify answers and the amount of text on a page; analysis using the Camtasia software also showed little conclusive difference in the amount of time that the subjects spent on each site despite variances in the amount of text on the pages accessed. Therefore, subjects did not seem to prefer or navigate towards Web pages/sites with less text.

Participants, on average, used between 1 and 2 Web sites to answer questions 1 to 3. Table 3 records the number of links from the Google retrievals page that were selected by subjects. The results for subjects 1 to 5-the participants with minimal prior Internet experience-are also presented separately from the results for participants with sustained prior Internet experience (subjects 6 to 8).

The Flesch-Kincaid reading scale used in this study scores text at a 1st to 12th grade reading level. Given this scale, sites ranked at the 12th grade level require *at least* that level of reading ability. That is, material scored at a 12th grade level may actually be written at a college level. In our study, the average site accessed required at least a 10th grade reading level.

Table 3. Average number of links used to answer questions

	Avg. Number of Links Used (Average Total)	Avg. Number of Links Used (Subjects 1-5)	Avg. Number of Links Used (Subjects 6-8)
Preliminary	1.875	2.4	1.0
Question 1	1.14	1.2	1.67
Question 2	1.82	1.8	2
Question 3	1.5	1.6	1.33
AVG.	1.58	1.75	1.5

Table 4. Average (rounded) reading level of sites accessed

	Avg. Reading Level of Sites Accessed	Avg. Reading Level of Sites Accessed (Subjects 1-5)	Avg. Reading Level of Sites Accessed (Subjects 6-8)
Preliminary	10.50	10.7	10.0
Question 1	10.50	9.4	11.2
Question 2	11.1	11.3	11.0
Question 3	11.8	11.8	11.9
AVG.	11.0	10.8	11.0

Table 5. Average time spent on sites

	Avg. Total Time Spent Per Site (min)	Avg. Total Time Spent Per Site (Subjects 1-5)	Avg. Total Time Spent Per Site (Subjects 6-8)
Preliminary	7.2	8.7	4.7
Question 1	10.3	10.6	9.8
Question 2	8.7	8.7	8.7
Question 3	6.6	8.3	5.8
AVG.	8.2	9.1	7.25

Participants spent an overall average of 8.2 minutes on individual sites. All participants voluntarily finished answering questions 1 to 3 before the 15-minute time limit was reached.

After completion of these first 3 questions, subjects were directed to a specific site; question 4 was posed about information directly linked to that site. We chose to use the ACS colon and rectum cancer Web page site, which contains links to a variety of prevention resources written at 6.3-12.0 grade levels (Flesch-Kincaid Reading Scale). The page to which we directed subjects consists of a listing of links to defined topic areas, one of which was closely related in wording to question 4. On the ACS site, 5 out of 8 people were able to answer question 4 correctly. Three of the 5 reported prior Internet experience; 2 reported none. These subjects used 3.8 links on average to answer the question. The 3 subjects who did not access the material used 6.5 sites on average before they were either stopped by the investigator or quit voluntarily. Two of these subjects had never used the Internet prior to enrollment in the study.

Attitudes and Self-reporting

While most participants were unable to answer all of the questions asked, 7 out of 8 reported feeling very comfortable or comfortable with their Internet searching experience. The eighth participant felt moderately comfortable. Also, 5 out of 8 found it at least moderately easy to find readable and understandable information on the Internet. Two of the remaining participants found it very difficult to find readable information, and one participant reported that finding understandable information is easy if the Web user has strong reading skills.

Despite their dependence on sponsored sites and alternative Web sites to answer questions, 7 out of 8 subjects reported that they found it very easy to locate trustworthy information on the Internet. The eighth subject noted that it is moderately easy to find information that is trustworthy on the Internet. However, one subject said, "*I believe that on the Internet, you have your shysters ... just like anything.*"

Subjects felt positive about continuing their online experiences, and all expressed some enthusiasm about improving their skills. One participant stated, "*I'm getting a computer ... it can help your typing skills.*" Another subject said, "*The computer is real interesting. I'm a see if I can get one so I can learn [how to use it].*" After the study was completed, many participants asked investigators to continue teaching them Internet skills or to continue helping them locate Internet resources on a variety of subjects.

Discussion

This observational study is the first to examine Internet use by low-literacy adults seeking health information [11]. Irrespective of prior experience using the Internet and/or computers, low-literacy adults participating in our study did not use optimal search terms to answer questions, encountered difficulties finding health information at the appropriate reading level, and were unable to successfully interpret Internet health information as it was presented. While basic navigational skills (eg, using the "Back" button) were easily retained, areas that required reading and comprehension were problematic for most subjects-evidenced by their inability to answer questions and comments made during their think-alouds. Therefore, the literacy level needed to read health information on the Internet does appear to inhibit information-seeking efforts of low-literacy adults.

Searching strategies were sub-optimal in several respects. First, the search terms used by subjects were predominately non-specific (Table 2). Although we anticipated that subjects who used the Internet more often would generate more specific search terms than did their peers, we did not observe this in the study.

Difficulty Generating Search Terms

Without guidance, subjects had difficulty generating original search terms that would yield specific results. A recent study reveals that adolescents used similarly general search terms when searching the Internet for health information [22]; this corroborates results from another study, which found that among subjects with an average of 33 months of Internet experience, self-selected search terms to find health information were unexpectedly general [23]. These observations highlight search terms as a potential barrier to specific, targeted Internet health information for different types of Internet users with varying levels of Web expertise. A categorizing search engine might be particularly effective for use by these groups; it minimizes the need for individuals to both create a specific search term and independently read and assess all retrievals. A sample search to answer question 2 was conducted using the Vivisimo search engine [24]. The search term "lung cancer" yielded a series of folders about lung cancer separated by subject matter; one folder specifically focused on lung cancer treatments. Individuals clicking on that option could access all sites on lung cancer treatments retrieved by the engine, circumventing the need to sift through thousands of retrievals to locate treatment-focused sites. A future study could monitor the ease with which low-literacy individuals could conduct self-directed searches using an automatically sorting search engine.

Reluctance to Use Links

Search strategies observed in this study were also sub-optimal because most subjects exhibited some unwillingness to click on links to Web sites on the Google retrievals page. On average, subjects clicked on one to two links to answer questions. Even when the subjects did not appropriately answer questions or only partially answered questions, most seemed reluctant to click on additional links on the Google retrievals page, and 7 of 8 did not go to subsequent retrievals pages. These results did not seem to correlate with prior Internet experience. Subjects also rarely re-typed search terms in order to access more relevant retrievals. These results differ from those of a previous observational Internet study, whose participants preferred to choose links from page-one retrievals and then re-type original search terms if they were unable to find appropriate information [23]. As stated earlier, our subjects had such difficulty generating original search terms, figuring out appropriate spelling, and determining whether to place spaces between words in search terms, it is conceivable that this is why they avoided this strategy.

Another reason why subjects' generation of search terms and selection of links were so limited may have been because the subjects were not interested in the health materials or the questions. Subjects may have also found the Google retrievals page confusing and intimidating. While the think-alouds are inconclusive about which of these factors contributed most to the weak search strategies observed, the post-session questionnaire reveals that the majority of participants reported that it was easy to search the Internet. Future research may help to illuminate the factors that contribute to the inconsistencies between subjects' perceived unwillingness to explore the Internet's health resources and their positive feedback about navigating through these resources.

High Literacy Levels of Health Web Sites

The *health* sites participants accessed to answer questions 1 to 3 had, on average, an 11th grade reading level (Flesch-Kincaid Reading Scale), which was consistent with the findings of previous studies [3,25]. Clearly, all of our subjects experienced difficulties using these sites to answer questions. The literacy level of the materials that the subjects did access may have limited their ability to read and understand materials as presented to them, and may have also impaired their ability to select the appropriate links for finding information. However, a majority of subjects were able to find specific information on the ACS Web site. As one subject reported about the site, "*This is a real good one 'cause it breaks it right down for you*." This Web page consisted of a series of links: general links on the left and right sides of the page and links to colorectal cancer in the center. Subjects who were unable to answer the questions seemed to find the lists of links on the page confusing, and picked links that took them to unrelated pages on the ACS site rather than to specific pages containing colon and rectum cancer information. While the selection of only 1 link on the colon and rectum cancer Web page was necessary in order to answer the question, these subjects on average picked more than 6 separate links before quitting. Therefore, layout of health Web sites evidently affects the ability of low-literacy adults to find pertinent health information.

Despite the navigational difficulties observed on the ACS Web page, the ability of 5 subjects to correctly answer question 4 probably resulted from the fact that the information needed to answer question 4 was written at an 8th grade reading level-significantly lower than the11th grade reading level required on average to read information retrieved in the first 3 searches. This suggests that low-literacy individuals can identify and utilize easier-to-read materials on Web sites. The Internet may indeed be a useful health resource to this population if materials are written at an appropriate reading level. Considering the navigational struggles of our subjects, the actual process of locating low-literacy sites on the Web may prove a more daunting challenge to this population.

Difficulty Measuring Participants' Comprehension of Information

While most were able to competently navigate through lower literacy materials, subjects' comprehension of Internet health information was difficult to measure in our study. Some participants found correct answers and read them to the investigators directly from the Web text, but none were able to articulate the answer in their own words when prompted. In their analysis of the1992 National Adult Literacy Survey (NALS) results, Kirsch et al reported that low-literacy adults may successfully perform simple comprehension exercises such as locating a single piece of information from text, but often find it more difficult to integrate and synthesize that information [1]. Furthermore, subjects in our study may have been able to use cues from sentence structure to locate an answer, and then relied on their pronunciation skills in order to read the answer as written. However, their ability to identify relevant health information within text is not necessarily a measure of their ability to comprehend that information.

In addition, several subjects seemed to compensate for their low literacy skills by using external information resources. One subject who examined a Web site on mental health law (12th grade level) expressed great enthusiasm about a particular topic that he said was presented on the site. A perusal of the site after the session showed that this topic was not addressed on any of the pages he had accessed. This participant may have compensated for his struggles in reading the site by citing facts with which he was personally familiar. Another subject used a similar approach when accessing a lung cancer site. When asked about the type of information he was reading, the subject responded that the page focused on smoking cessation. However, there were no smoking-related topics on the pages examined by the subject. The subject was able to correlate lung cancer with smoking, and may have relied on this information in order to answer the investigator's query. Overall, some subjects may have been able to rely less on actual comprehension skills and more on background knowledge in order to infer answers.

Positive Web-site and performance feedback reported by most of the participants could have also been fueled by a desire to compensate for reading and comprehension difficulties. Participants were aware that the majority of the investigators were affiliated with a local hospital system; some may have felt compelled to answer positively about Internet health information because they were reporting to health-care professionals. Additionally, the participants may have been unwilling or ashamed to admit that they had difficulty understanding the information on the Internet. Individuals with low literacy tend to be embarrassed by their reading inadequacies [26]. Participants may have felt compelled to report more positively about their Internet experiences in order to de-emphasize their difficulties navigating the Web. These considerations might begin to explain that while most participants struggled when using the Internet, most 1) felt they did a good job searching for information, and 2) found information on the Internet readable and understandable. Collectively, then, poor comprehension of health information on the Internet coupled with a desire to compensate for self-perceived inadequacies in reading may have negatively affected the ability of our subjects to objectively evaluate Web sites. In this study, these factors may also have diminished the accuracy of their think-alouds and feedback in relation to their actual Internet experiences.

Inaccurate Self-assessment

An alternative reason why subjects reported positive experiences on the Internet could be that subjects were unaware of the magnitude of their Internet searching difficulties. A study by Moon et al indicates that 70% of subjects told investigators that they read "really well," while in actuality, their mean REALM scores reflected a 7th to 8th grade reading level [27]. This suggests that individuals may actually overestimate their reading ability in relation to standard educational parameters; it may also relate to a similarly heightened perception of Internet competence. Furthermore, because the majority of our subjects had minimal Internet experience, they may not have been able to objectively gauge the limitations of their Internet skills in relation to the skills of more advanced users. While the investigators were able to categorize their searching as sub-optimal, our participants could have considered their searching strategies to be adequate, if not standard.

Preference for Sponsored Sites

Subjects' reliance on sponsored-site information to answer questions, regardless of the high literacy level required to read those sites, suggests that other factors promote the selective advantage of sponsored sites over non-sponsored sites. In fact, the design of sponsored sites on the Google retrieval page follows many of the guidelines for creating optimal layouts for health information targeted to low-literacy adults [28]. First, the sponsored sites are organized by topic, and are also segmented in colored boxes that stand out from the rest of the Google retrievals. They do not contain the "teaser information" and keywords associated with normal Google links, and minimize the amount of text used. Most are easier to read than the normal Google links, are automatically categorized by subject, and are visually stimulating. In addition, despite misspellings of search terms, sponsored sites are often applicable to the intended subject. For example, a search of "lung caner" instead of "lung cancer" yields sponsored sites on lung cancer, though most of the non-sponsored Google retrievals are irrelevant. When individuals misspell search terms, which the low-literacy subjects in our study did fairly commonly, they might easily gravitate to sponsored-site information to answer their health questions.

Of concern is that subjects did not seem to differentiate between the information on the sponsored sites and information on non-sponsored sites. Subjects used these sites interchangeably to answer questions. One study suggests that critical interpretation of Web sites is based on the Internet acumen and interests of the information-seeker; if coupling the *motivation* to find a topic and the *ability* to do so successfully, the information-seeker will be well-equipped to evaluate Web sites objectively and perceptively [29]. This approach offers 3 possible explanations for our results. First, our questions may have been of little interest to our subjects; this may have diminished their motivation in answering questions and affected impacted their critical analysis of sites. Second, many of our subjects had little sustained exposure to various Web sites before the study. Those subjects in particular may not have been able to critically compare Web sites as readily as individuals who had previously seen both good and bad Web sites and developed their own rating system. In this context, most health information on the Internet may have seemed trustworthy and interchangeable to some of the subjects. Third, the searching problems observed even among those subjects with previous Internet experience underscore the fact that none of these subjects reported that their prior Web usage included searches for health information. While these subjects had successfully found items of personal interest in previous Web searches, they were unable to navigate to health materials that were any more accurate or easy-to-read than those found by the rest of the subjects. Therefore, health searches may present unique challenges to a low-literacy population that counter the ability to find accurate, trustworthy health information. This may result from the high literacy level required for reading health information and health Web sites in addition to the complexity of health terminology.

Limitations of Methodology

Standard methodologies used in this study to determine health literacy and to generate continual feedback were sub-optimal. First, REALM test results were inconclusive. Subjects were placed into the literacy program at Bidwell Training Center after taking the national Tests for Adult Basic Education (TABE). However, in our study, these subjects tested significantly higher on the REALM than expected for individuals with the reading levels indicated by their TABE scores as reported by Bidwell Training Center (3rd to 8th grade reading skills). Subjects may have strong phonetic skills that help compensate for poor word recognition and comprehension. This observation is supported in a study by Wilson et al [30], which similarly noted that lower literacy participants who used the REALM tested at several grade levels above their actual reading level. The REALM may not be an optimal tool for accurately determining the health literacy of low-literacy adults.

Whereas complete think-alouds could have helped us better understand subjects' navigational priorities and comprehension levels, the protocols we used in this study were ineffective at prompting verbalization. None of the participants consistently articulated their step-by-step navigational process at all points during their searching session. Investigators continually prompted the subjects through the exercise, but were unable to stimulate free-thinking, consistent, and self-motivated think-alouds. One potential explanation originates from the observation that our study population was not uniformly familiar with the Internet. Therefore, some subjects may have felt overly challenged by simultaneously learning how to use the Internet and verbalizing their navigational strategies. According to previous studies [31], these subjects were probably in an "acquisition role." Such studies disclosed that a learner who is new to a certain task focuses primarily on acclimatization, and finds it overwhelming to concurrently think aloud. Since traditional think-aloud protocols may be ineffective for this group, an interactive protocol may be of assistance for future studies. In such a protocol, subjects would directly be asked about specific site features, and asked to rate and make comparisons between health sites. This may highlight precise preferences the subjects might have for Web-site information, content, design, and presentation, and may result in a more cohesive rating system.

Overall, however, our subjects were very enthusiastic about learning how to use the Internet, and all indicated an interest in improving their skills for future use. In this study and other studies [13,15], members of the low-literacy population have expressed excitement about using the Internet. In order for the Internet to further empower these individuals to make informed health decisions, the development of easy to read *and* easy to comprehend health materials is imperative. If Google's sponsored sites are usedas a guide, low-literacy adults prefer information that is aesthetically pleasing, has minimal text, and is organized by subject matter. Search engines that are able to consolidate these features for searches will probably be of greater use to this population. However, low-literacy adults must improve their navigation and searching skills to efficiently locate low-literacy materials on the Internet. With sufficient practice, they are likely to develop the skills to use the Internet to find specific health information, and learn to critically evaluate the information they access.

Indications for Future Research

One caveat to the present study is that our sample size precluded the analysis of factors besides low literacy that could influence the results we observed. We believe, however, that our findings with this sample group in an observational study were representative of the way low-literacy adults interact with the Internet. It will be important to validate and analyze in a larger study the appeal of sponsored sites (as opposed to other retrieved links) to low-literacy adults. It will also be worthwhile to determine the relative importance of limited literacy in comparison to socioeconomic and cultural factors in effective use of the Internet by this population. Future work will identify the exact components of sites that engage and promote learning by low-literacy adults. Greater understanding of these factors will hasten the day when the Internet becomes an effective vehicle for optimizing the health knowledge and acumen for those at high risk of poor health outcomes.

Acknowledgments

We thank Derietra Neal Ferguson for helpful comments and advice.

The study was supported in part by the University of Pittsburgh Cancer Institute, and publication by NLM grant LM008302.

Conflicts of Interest

None declared.

References

1. Kirsch IS, Jungeblut A, Jenkins L, Kolstad A. Executive summary of adult literacy in America: a first look at the results of the National Adult Literacy Survey. National Center for Education Statistics. 1992. URL: http://nces.ed.gov/naal/resources/execsumm.asp
2. Rudd R, Moeykens BA, Colton TC; National Center for the Study of Adult Learning and Literacy. Health and literacy: a review of medical and public health literature. 1999. The annual review of adult learning and literacy URL: http://www.gse.harvard.edu/~ncsall/ann_rev/vol1_5.html URL: http://www.gse.harvard.edu/~ncsall/ann_rev/chap5.rev.htm
3. Michielutte R, Alciati MH, El Arculli R. Cancer control research and literacy. J Health Care Poor Underserved 1999 Aug;10(3):281-297. [Medline: 99365781]
4. Baker DW, Gazmararian JA, Williams MV, Scott T, Parker RM, Green D, et al. Functional health literacy and the risk of hospital admission among Medicare managed care enrollees. Am J Public Health 2002 Aug;92(8):1278-1283. [Medline: 22139605]
5. Kim SP, Knight SJ, Tomori C, Colella KM, Schoor RA, Shih L, et al. Health literacy and shared decision making for prostate cancer patients with low socioeconomic status. Cancer Invest 2001;19(7):684-691. [Medline: 21461555] [doi: 10.1081/CNV-100106143]
6. Paasche-orlow MK, Taylor HA, Brancati FL. Readability standards for informed-consent forms as compared with actual readability. N Engl J Med 2003 Feb 20;348(8):721-726 [FREE Full text] [doi: 10.1056/NEJMsa021212] [Medline: 22482789]

7. Schillinger D, Piette J, Grumbach K, Wang F, Wilson C, Daher C, et al. Closing the loop: physician communication with diabetic patients who have low health literacy. Arch Intern Med 2003 Jan 13;163(1):83-90. [Medline: 22411742] [doi: 10.1001/archinte.163.1.83]
8. ; Committee on Communication for Behavior Change in the 21st Century. Improving the Health of Diverse Populations, Board on Neuroscience and Behavioral Health. Speaking of health: assessing health communication strategies for diverse populations. Washington, DC: National Academies Press; 2002.
9. ; National Academy on an Aging Society. Low health literacy skills increase annual health care expenditures by $73 billion. Washington, DC: National Academy on an Aging Society and Center for Health Care Strategies [fact sheet]; 1998. URL: http://www.agingsociety.org/agingsociety/publications/fact/fact_low.html
10. Meric F, Bernstam EV, Mirza NQ, Hunt KK, Ames FC, Ross MI, et al. Breast cancer on the world wide web: cross sectional survey of quality of information and popularity of websites. BMJ 2002 Mar 9;324(7337):577-581 [FREE Full text] [PMC: 11884322] [Medline: 21881327] [doi: 10.1136/bmj.324.7337.577]
11. Fogel J. Internet use for cancer information among racial/ethnic populations and low literacy groups. Cancer Control 2003 Sep;10(5 Suppl):45-51 [FREE Full text] [Medline: 22942135]
12. Berland GK, Elliott MN, Morales LS, Algazy JI, Kravitz RL, Broder MS, et al. Health information on the Internet: accessibility, quality, and readability in English and Spanish. JAMA 2001 May 23;285(20):2612-2621. [Medline: 21262346] [doi: 10.1001/jama.285.20.2612]
13. Lazarus W. Online content for low-income and underserved Americans: The digital divide's new frontier : a strategic audit of activities and opportunities. Santa Monica: Children's Partnership; Mar 2000. URL: http://www.childrenspartnership.org/
14. Kalichman SC, Benotsch EG, Weinhardt LS, Austin J, Luke W. Internet use among people living with HIV/AIDS: association of health information, health behaviors, and health status. AIDS Educ Prev 2002 Feb;14(1):51-61. [Medline: 21896777] [doi: 10.1521/aeap.14.1.51.24335]
15. Zarcadoolas C, Blanco M, Boyer JF, Pleasant A. Unweaving the Web: an exploratory study of low-literate adults' navigation skills on the World Wide Web. J Health Commun 2002 Jul;7(4):309-324. [Medline: 22243102] [doi: 10.1080/10810730290088157]
16. Kalichman SC, Weinhardt L, Benotsch E, Cherry C. Closing the digital divide in HIV/AIDS care: development of a theory-based intervention to increase Internet access. AIDS Care 2002 Aug;14(4):523-537. [doi: 10.1080/09540120220133044] [Medline: 22193370]
17. Kalichman SC, Benotsch EG, Weinhardt L, Austin J, Luke W, Cherry C. Health-related Internet use, coping, social support, and health indicators in people living with HIV/AIDS: preliminary results from a community survey. Health Psychol 2003 Jan;22(1):111-116. [Medline: 22445387] [doi: 10.1037//0278-6133.22.1.111]
18. ; REALM. Rapid Estimate of Adult Literacy in Medicine. URL: http://www.healthsystem.virginia.edu/internet/health-education/images/realm.gif [accessed 2004 Jan 9]
19. Society AC. Colon and Rectum Cancer. URL: http://www.cancer.org/docroot/CRI/CRI_2_3x.asp?dt=10 [accessed 2004 Jan 9]
20. ; Tien Hsein Liquid. Home page. URL: http://www.tienhsien.com/ [accessed 2003 Nov 13]
21. ; Radiofrequency Ablation. Home page. URL: http://www.rfalung.com/ [accessed 2004 Jul 8]
22. Hansen DL, Derry HA, Resnick PJ, Richardson CR. Adolescents searching for health information on the Internet: an observational study. J Med Internet Res 2003 Oct 17;5(4):e25 [FREE Full text] [Medline: 14713653] [doi: 10.2196/jmir.5.4.e25]
23. Eysenbach G, Köhler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. BMJ 2002 Mar 9;324(7337):573-577 [FREE Full text] [PMC: 11884321] [Medline: 21881326] [doi: 10.1136/bmj.324.7337.573]
24. ; Vivisimo Company, Pittsburgh, PA. The Vivísimo Clustering Engine. URL: http://www.vivisimo.com/ [accessed 2004 Jul 2]
25. Payne S, Large S, Jarrett N, Turner P. Written information given to patients and families by palliative care units: a national survey. Lancet 2000 May 20;355(9217):1792. [Medline: 20290432] [doi: 10.1016/S0140-6736(00)02272-8]
26. Parikh NS, Parker RM, Nurss JR, Baker DW, Williams MV. Shame and health literacy: the unspoken connection. Patient Educ Couns 1996 Jan;27(1):33-39. [Medline: 96380734] [doi: 10.1016/0738-3991(95)00787-3]
27. Moon RY, Cheng TL, Patel KM, Baumhaft K, Scheidt PC. Parental literacy level and understanding of medical information. Pediatrics 1998 Aug;102(2):e25 [FREE Full text] [Medline: 98356248] [doi: 10.1542/peds.102.2.e25]
28. Coyne C, Halvorson H, Riley K, Schneider L. Beyond the brochure: alternative approaches to effective health communication. AMC Cancer Research Center & Centers for Disease Control: Denver, Colorado; 1994. URL: http://www.cdc.gov/cancer/nbccedp/bccpdfs/amcbeyon.pdf
29. Eastin M. Credibility assessments of online health information: the effects of source expertise and knowledge of content. JCMC 2001 Jul;6(4):1-14 [FREE Full text]
30. Wilson FL, Racine E, Tekieli V, Williams B. Literacy, readability and cultural barriers: critical factors to consider when educating older African Americans about anticoagulation therapy. J Clin Nurs 2003 Mar;12(2):275-282. [Medline: 22492631] [doi: 10.1046/j.1365-2702.2003.00711.x]

31. Meichenbaum D, Biemiller A. In search of student expertise in the classroom: a metacognitive analysis. In: Pressley M, Harris KR, Guthrie JT, editors. Promoting academic competence and literacy in school. San Diego, CA: Academic Press; 1992:3-56 URL: http://www.slis.ualberta.ca/cais2000/branch.htm

Abbreviations

ACS: American Cancer Society
NALS: National Adult Literacy Survey
REALM: Rapid Estimate of Adult Literacy in Medicine
TABE: Tests for Adult Basic Education

---

submitted 09.01.04; peer-reviewed by D Hansen, C Zarcadoolas; comments to author 17.02.04; revised version received 15.03.04; accepted 15.04.04; published 03.09.04.

Please cite as:
Birru MS, Monaco VM, Charles L, Drew H, Njie V, Bierria T, Detlefsen E, Steinman RA
Internet Usage by Low-Literacy Adults Seeking Health Information: An Observational Analysis
J Med Internet Res 2004;6(3):e25
URL: http://www.jmir.org/2004/3/e25
doi:10.2196/jmir.6.3.e25
PMID:15471751

Original Paper

The Effect of Top-Level Domains and Advertisements on Health Web Site Credibility

Joseph B Walther[1], PhD; Zuoming Wang[1], MA; Tracy Loh[1], MSc

Department of Communication, Cornell University, Ithaca NY, USA

Corresponding Author:
Joseph B Walther, PhD
Department of Communication
Cornell University
303 Kennedy Hall
Ithaca NY 14853
USA
Phone: +1 607 255 2798
Fax: +1 607 254 1322
Email: joe.walther@cornell.edu

Abstract

Background: Concerns over health information on the Internet have generated efforts to enhance credibility markers; yet how users actually assess the credibility of online health information is largely unknown.

Objective: This study set out to (1) establish a parsimonious and valid questionnaire instrument to measure credibility of Internet health information by drawing on various previous measures of source, news, and other credibility scales; and (2) to identify the effects of Web-site domains and advertising on credibility perceptions.

Methods: Respondents (*N* = 156) examined one of 12 Web-site mock-ups and completed credibility scales in a 3 x 2 x 2 between-subjects experimental design. Factor analysis and validity checks were used for item reduction, and analysis of variance was employed for hypothesis testing of Web-site features' effects.

Results: In an attempt to construct a credibility instrument, three dimensions of credibility (safety, trustworthiness, and dynamism) were retained, reflecting traditional credibility sub-themes, but composed of items from disparate sources. When testing the effect of the presence or absence of advertising on a Web site on credibility, we found that this depends on the site's domain, with a trend for advertisements having deleterious effects on the credibility of sites with .org domain, but positive effects on sites with .com or .edu domains.

Conclusions: Health-information Web-site providers should select domains purposefully when they can, especially if they must accept on-site advertising. Credibility perceptions may not be invariant or stable, but rather are sensitive to topic and context. Future research may employ these findings in order to compare other forms of health-information delivery to optimal Web-site features.

(J Med Internet Res 2004;6(3):e24) doi:10.2196/jmir.6.3.e24

KEYWORDS

Internet; credibility; Web sites; domains; advertising

Introduction

One of the most interesting aspects of the diffusion of the Internet is its use by millions to access and to discuss information related to health and medicine. Surveys estimate that 55% of Americans with Internet access seek health information online [1]. This phenomenon prompts both praise and concern. Praise, because individuals can access information to help them address physical and psychological maladies at any time for no cost, once they have computer access. Concern, especially from health professionals, that information freely distributed online is subject to no professional authorization and there is no way of verifying the credentials of those who post the information; thepossibility exists for amateurs to misinform one another, with harmful consequences. The credibility of health information on the Internet is also a concern to users themselves. Eighty-six percent of health-information seekers are concerned that online sources are unreliable. Fifty-two percent of users who have visited health sites think that "almost all" or "most" health information that they see on the Internet is credible, and 44% think that they can believe only "some" online health information. Fifty-eight percent of health-informationseekers checked to see who was providing the information on the Web sites they visited [1].

Some steps have been taken in order to address this concern. Bona fide medical organizations such as the American Medical Association have formulated Web-site design recommendations intended to facilitate understanding and certify authenticity [2]. Pharmacies hand out lists of questions (oddly, without answers) that Web surfers should ask when perusing medical Web sites to help them decide about the utility and authenticity of information online. In some cases, medical experts rated the content of health-related Internet sources; in one trial they rated information as poor to potentially dangerous, although Craigie et al [3] found that the experts "showed a low agreement when rating the postings." A meta-analysis by Turow and his colleagues [4] revealed, among medical and academic researchers alike, "a startling lack of consensus among (medical and academic) researchers regarding the meaning of basic terms as quality, accuracy, and depth of detail when it comes to a website."

In contexts other than health and medicine, the credibility of Web sites has been explored, but whether the principles uncovered in e-commerce or other Web transactions apply as well to medical information seeking is an issue that is just beginning to come into focus. Little is actually known about how end-users of online health and medical information evaluate the credibility and utility of such information, and it appears that users themselves have limited awareness of how they find and evaluate Internet-based information on health and medicine [5].

In this study, we examine historical approaches to the study of credibility, the challenges facing the application of these approaches to Internet information, and new aspects related to credibility that Internet channels introduce. We then describe an empirical research project in which we developed a parsimonious instrument to measure how users assess health-information credibility online, and how they evaluate it with respect to different features of health-related Web sites-domain and advertising-to assess whether these attributes affect the credibility users ascribe.

Credibility

In the last fifty years, credibility has been conceptualized and studied in a variety of ways. Much research has been directed towards studying credibility, mostly in terms of its various sub-dimensions of source, message, and medium credibility. There tends to be considerable overlap between the various dimensions of credibility on which research has focused [6,7,8,9].

Source Credibility

Traditionally, credibility research focuses on the question of what makes a communicator believable and persuasive. While analysis of this kind dates back to Aristotle, one of the most important theoretical formulations divided source credibility into the two dimensions of *expertise* and *trustworthiness* [10]. Expertise is defined as a communicator's qualifications and/or ability to know the truth about a topic. Trustworthiness relates to a judgment about the communicator's motivation either to tell the truth about a topic, or to bias information for self-serving motives (such as commercial gain). This dynamic emerges in recent focus group research assessing how consumers search and appraise Internet information about medicines: While some respondents regard pharmaceutical companies as the "official" information source, others prefer government agencies, organizations, and educational institutions as information sources, considering them to be impartial [5].

The history of credibility research suggests that a variety of theoretical dimensions and empirical measures may be relevant to assessing credibility. These dimensions include safety, qualification, and dynamism [11], authoritativeness, sociability, character, competence, composure, and extroversion [12,13], and other similar dimensions [14,15].

In addition, the relationship between the receiver and the source has been identified as an important factor in determining the degree of credibility accorded to the source [16,17]. How Internet users relate to experts may affect credibility assessments. Perception and measurement of source credibility may differ depending upon the type of source being evaluated as well as the context in which the evaluation occurs [14,18,19,20,21].

The factor-analytic approach to defining dimensions of credibility has been criticized on a number of grounds. For instance, characterizations of the research as atheoretical and data-driven have been made. Cronkhite and Liska [18] argued that factor structures depend on a number of aspects, including the rating scale used, the speakers chosen, the raters chosen, and the method of factor analysis. Delia et al [22] found that attitudes toward a source were based more on context-relevant beliefs than on generalized evaluations. In different contexts, different dimensions of evaluation became more relevant.

These concerns both reject the adoption of one set of existing factors over another, and highlight the need to identify the relevant factors based on the content and audience for each research setting, an approach that has also been adopted in the present study.

Media Characteristics

The concept of credibility has been widely explored in the domain of traditional media, with research investigating the relative believability of particular forms of communication (eg, newspapers vs television), where cross-medium comparisons of credibility dimensions have been regularly examined. To make such comparisons, "the credibility of various media has been measured by comparing perceptions of the believability, accuracy, fairness, bias, trustworthiness, ease of use, completeness, reliability, or attractiveness, for example, of the media themselves…" [23]. For instance, some studies on the credibility of print and television reveal that television is more believable than print media; others demonstrate that only newspapers are especially credible when compared to magazines and other print media (for review, see [24]).

Gaziano and McGrath [25] developed a 12-item media credibility scale, comprising the following items: is fair, is unbiased, tells the whole story, is accurate, respects people's privacy, watches out for the public's interest, is concerned about the community's well-being, separates facts from opinions, can be trusted, is concerned about the public's interest, is factual, and has well-trained reporters. Meyer [26] reduced the scale to five items**:** fairness, bias, completeness, accuracy, and trust.

Internet Credibility Issues

The Internet's ability to combine aspects of and collapse barriers between traditional source, message, and media studies has opened up new vistas in credibility research. The Internet is a uniquely versatile medium of numerous communication and information functions and ought to be treated as such [27]. As traditional forms converge, new measures of credibility arise in addition to the numerous measures already established.

Recently, Sundar and Nass [28] experimentally examined how people identified and evaluated sources of news, all of which came through Internet channels. Subjects were exposed to news stories presented by computers and appearing to be transmitted via the Internet. Subjects were led to believe that the stories were chosen by a corporate news organization, by the computer, by a peer discussion group, or by the subject himself or herself. While there were no differences on a measure of credibility, significant differences on other measures suggest that computer users make distinctions about information quality, and prefer different information sources, based on the institutional nature of the source.

Web Credibility

The convergence of genres of information via the Web makes it problematic to assess online credibility. As Metzger et al [23] pointed out, Web-site expertise can be reflected in the site's informativeness, the display of the appropriate credentials, the site sponsor's reputation, or the type of site sponsor (ie, institutional vs individual). *Trustworthiness* may be communicated through explicit policy statements or a lack of advertising and commercial content; and attractiveness or dynamism can be presented through dimensions of the Web site's appearance (eg, layout, graphics, font, color, etc). According to Eastin [29], *dynamism* also plays a key role in perception of online content, which can be affected when a message or a Web site's presentational features are highly dynamic. Fogg et al [30] found that commercial associations (eg, more advertisements) and a feeling of amateurism (eg, broken links) decreased credibility, while a real-world feel (eg, a physical address listed in site), perceived integrity (eg, explicit policy statement), and tailoring (eg, site sends emails confirming transactions) can increase credibility. Novel credibility concerns may also arise when evaluating Web sites. For instance, issues of security, consumerism, and usability, which usually are not the concerns of the traditional media credibility, arise in various Web contexts.

Medical Information

In the specific domain of health information on the Web, a few studies are notable. Following arguments about variable attention to content cues versus heuristic cues as a function of topical knowledge, Eastin [29] explored the same dynamics in users' evaluation of online health information. Eastin's study experimentally varied source expertise (high, medium, low) and subjects' knowledge about the topic (HIV vs syphilis) among a sample of college students. Participants tended to rate all information as relatively credible, with effects obtaining for content knowledge and source expertise. There was no interaction effect among these variables.

Eysenbach and Köhler [31] examined what characteristics of health Web sites users purported to use in evaluating credibility, and also observed the discrepancy in subjects' actual search and evaluation behaviors. Users indicated a variety of symbols that would enhance believability in online health information, including the scientific or institutional source of the information, site owner credentialing, and content updating. In their actual search behavior, however, users almost entirely neglected such resources, relying on search engines (and top-to-bottom ordering of search results) to select sites to browse, spent a median of 37 seconds on a site, and remembered the domain of the sites from which they gleaned information only 23% of the time. These results from the health domain mirror more general tendencies for users not to check or verify the veracity of Web information in other kinds of research [32].

Dutta-Bergman [33] recently found that the completeness of information affected attitudes of health-information users. While credibility was not a specific construct of concern in this study, the outcome of credibility-persuasion-was. Dutta-Bergman offered two levels of information completeness and argument quality on experimental sites offering heart-and-diet information. The completeness variable affected the attitudes of both casual readers and readers prompted to imagine they had heart disease.

Health Care and the Internet

According to Pew Research, the Internet is being used by many Americans (55% of those with Internet access) to gain health or medical information. Seventy percent of those who said they have been swayed by what they read online the last time they sought health information said that the information they obtained online influenced their decision about how to treat an illness or condition, 50% said that the information led them to ask a doctor new questions or get a second opinion from another doctor, and 28% said that the information they found online affected their decision about whether or not to visit a doctor.

Hypotheses

Given the lessons of the factor analytic approaches to credibility, we needed to develop a parsimonious and appropriate scale with which to measure credibility in the context of online health information, and to assess it using adults who were actual or prospective health-information users. Second, we sought to ascertain what characteristics enhanced or detracted from health-information Web-site credibility. In order to develop an instrument, we collected those measures used in previous research and subjected them to the treatments described below. In order to identify Web-page characteristics affecting credibility, we developed the following hypothesis based on the literature reviewed above:

H1: Different top-level domains (*.org*, *.com*, *.edu*, *.gov*) influence the credibility of the Web site.

Because Web sites with explicit commercial natures are more likely to be associated with greater self-interest, we also posited the following:

H2: The *.com* domain reduces the credibility of a Web site.

H3: The presence of advertisements reduces the credibility of a Web site.

Methods

Data were collected in two phases using two samples and two parallel sets of stimulus materials.

Stimulus Materials

A number of health-related Web sites were reviewed for typical features in order to generate plausible-looking Web pages containing the manipulations of interest to this study. Commonalities were noted with respect to the size of the headers and text, and the presence of graphics depicting couples or individuals who appeared to be doctors. Typical-looking Web-page mock-ups were created that resembled many of these sites' home pages.

The mock-ups varied with respect to operationalizations of several variables. First, two topical health issues were identified for use as examples in this research on the basis of their popularity as online health topics, both as Web-related information sources and as subjects of peer (Usenet) discussion topics: arthritis and depression [34]. Second, the headers were varied to reflect differences in the following domain types: arthritis.com, arthritis.edu, arthritis.gov, and arthritis.org (with parallel differences for depression). Third, within each of these conditions, half the mock-ups featured advertisements, in this case, for consumer-level pharmacological books, while the other half did not. All of the mock-ups featured a photo copied from an actual health-information Web site depicting a smiling middle-aged couple, which was common on such sites, in order to make the mock-ups look like typical Web pages of this nature. All mock-ups contained the same text. Thus the stimulus conditions comprised variations according to a 2 (topic) x 4 (domain) x 2 (advertising/no advertising) design, resulting in 16 different versions. A sample is featured in Figure 1, but for purposes of publication, the photo and advertisment titles have been blurred.

Figure 1. Web site mock-up

Welcome to

Depression.com

—your premier online resource for depression information.

Depression is a major unrecognized health issue.

Depression is among the most common and destructive of illnesses prevalent in the United States today. 35 million Americans suffer from depression during their lives.

Depressive illness is treatable.

More than 80 percent of those suffering from depression can be treated successfully with medications, therapy or counseling.

I'm done looking at this site. Take me to the questions.

Measures

Although credibility has been conceptualized and measured in many ways in various contexts, it is not clear whether the dimensions and operationalizations of credibility in previous research provide the most parsimonious and applicable dimensions of this construct for the specific domains of health communication via the Internet [23]. In order to discern the most applicable measures, which was a major focus of this study, a number of existing measures were collected that bore some conceptual connection to one aspect or another of online health-information credibility. These existing measures included source credibility [11,12], and news credibility (excluding items specifically referencing reporters [25]). All of these measures exist as semantic differential items.

Items from all of these measures were gathered on one questionnaire and arrayed on a common 7-interval scaling. Items that were duplicated from different sources were used only once.

Participants and Procedures

For research related to health issues it is often important to obtain a sample that has a wider age range than typically is found among college students. Extending from principles of elaboration likelihood theory [35], adults who are more likely to be concerned about health issues on a first- or second-hand basis will attend to features of a presentation differently than will younger and presumably healthy individuals whose experience with health topics is less personal. In order to attract a sample of adult respondents, researchers employed an intercept survey technique at a local shopping mall in a northeastern US suburban city for several weekends in November, a busy holiday shopping season. Researchers were asked to limit their activity to a relatively constrained location in the mall, from which they approached passersby who appeared to be greater than college aged.

Stimulus materials were printed as color copies on paper. When a researcher approached a passerby and the prospective respondent indicated willingness to be questioned, researchers screened participants using several questions about whether they had ever used the Internet, had an email address, or used online discussion systems. Negative responses to these qualifying questions terminated the intercept, and the prospective respondent was thanked and dismissed. Upon qualification, participants were asked to examine one of the 16 versions of the mock-up Web page, which were randomly distributed. Each participant was asked to examine the top page-the mock-up-for as long or as short a time as he or she wished, and then to turn to the subsequent pages to complete a self-administered questionnaire. Participants were asked not to turn back to the first page after moving on. Participants were offered a place to sit at a table and a confection if they wished.

The first item on the questionnaire asked respondents to write down the name of the Web site the home page of which they had just seen. This question was used in order to track participants' awareness of the domain name, although it was unclear at the outset how much difference there might be in their overall responses due to their cognizance of domain type. Following this item, the credibility items were presented for self-administered completion, with demographic items at the end of the questionnaire.

The first phase of data collection yielded 111 participants, with a median age of 32, 46% of whom indicated they were male, and 53% female.

In order to increase the sample size for more robust analysis, a second phase of data collection was undertaken. A different strategy, more efficient than the field intercept method, was used in this phase to attract an adult sample. In this phase, a snowball sampling strategy was employed: Students taking an introductory communication course were addressed in class and sent an email message that they were asked for forward to their parents, who in turn were asked to participate in the research. The email message contained a URL for a Web page, which introduced the purpose of the study, instructed participants that they would soon see a home page for a Web site that they might examine for as long or as short a time as they wished, and told them they would be asked to answer a series of questions if they clicked a button to continue. When they clicked this button, a JavaScript routine randomly redirected the participant to one of 16 versions of a Web-site mock-up. These mock-ups were identical to those used in the paper version of the study in phase 1. However, another button was made to float over the site content so that, no matter where on the page the participant might scroll, the prompt to click to move to the questionnaire was always present. When participants clicked this button, the same semantic differential items were presented using a Web form, with radio buttons for each scale on which to record responses. Participation was anonymous in every way. This sample yielded 45 individuals, with a median age of 50 and the gender composition of 68% female. Concerns over the possible differences in participant responses due to the two data collection methods are addressed in the hypothesis test results, below.

Results

Scaling

The first objective of this study was to create a reliable and parsimonious measure for Web credibility related to online health information. Data from the questionnaire were subjected to a principal component factor analysis with Varimax rotation to identify the items and dimensions of online health-information credibility from otherwise disparate but potentially overlapping measures. In order to identify the most parsimonious measure, we employed very conservative criteria for selecting a factor solution: (1) All factors had to have eigenvalues of 1.5 or better; (2) the Scree test indicated reasonable incremental improvement in variance accounted for by the addition of a given factor; (3) all retained factors had to contain at least three items with primary loading of 0.60 or better and secondary loadings below 0.40; (4) among solutions meeting the first three criteria, the one accounting for the most variance was to be selected. Initial results show up to six factors with eigenvalues greater than 1.5, accounting for 60% of the variance. However, after the application of the above criteria, the results indicated an optimal three-factor solution explaining 48.6% of the variance.

After applying these criteria, we conducted cross-tab analysis to examine the discriminating validity of items within each dimension. It is often the case that factor analysis clusters items together that show little variance (ie, scores are not high or low, but huddled around the mid-point of the scales [36]), and such items reduce the overall utility of the measure. Following procedures articulated in Klingle et al (1995), we identified the cut-off scores associated with the bottom quartile (23%) and the top quartile (78%) of the dimensional totals by summing up the values of all items within a dimension. Values in the scale below 23% were coded as 1, and values above 78% were coded as 2. Then for every item, we calculated the item-specific cut-offs by treating 5-7 scores as high and 1-3 as low. If the score on the original item was 3 or below, it was coded as 1, and if its score was 5 or above on the original item, it was coded as 2. Cross tabs were used to test the item-to-scale correspondence, and the phi coefficient was used to see whether a high score on an item also showed a high score on the total. Any item that failed in this aspect was dropped from the scale. Only one item, "friendly," did so, and it was subsequently removed from further analysis.

The first factor appeared to represent *safety* (Cronbach α= .91). *Trustworthiness* is the second factor (α= .82). The last factor is *dynamism* (α = .77). The factor structure and item means and standard deviations appear in Table 1. These dimensions have conceptual overlap with previously articulated credibility dimensions, although the combination of items comprising the factors is unique.

Table 1. Factor structure, means, and standard deviations: 16-item measure for Internet health credibility *

Factors and Items	*M*	*SD*	Factor Loadings		
1. Safety					
Just/Unjust	4.50	1.415	.787	.302	.097
Friendly/ Unfriendly	5.29	1.332	.771	.128	.149
Safe/Dangerous	4.98	1.421	.762	.309	.114
Kind/Cruel	5.15	1.229	.761	.156	.075
Nice/Awful	4.79	1.259	.737	.289	.001
Good-natured/Irritable	4.80	1.078	.670	.174	.128
2. Trustworthiness					
Can be trusted/Cannot be trusted	4.31	1.448	.310	.743	.078
Accurate/Inaccurate	4.37	1.278	.149	.714	.036
Factual/Opinionated	4.25	1.511	.225	.700	.008
Concerned (not concerned) about the community's well-being	4.75	1.506	.150	.624	.067
Does (not) watch after reader's interests	4.35	1.416	.082	.609	.112
3. Dynamism					
Active/Passive	4.43	1.245	.061	.011	.727
Energetic/Tired	4.27	1.175	.169	.156	.718
Verbal/Quiet	4.20	1.194	.099	.167	.656
Bold/Timid	4.29	1.069	.028	.065	.634
Aggressive/Meek	3.86	1.277	.266	.088	.608

* Based on 1 to 7 scales.

Hypothesis Tests

Several preliminary tests were conducted before the hypotheses were tested. Omnibus analysis of variance (ANOVA) tests were run in order to detect unanticipated interaction effects between these hypothesized factors (domain and advertising) and the arthritis/depression topics. No three-way interactions emerged on any dependent variables, nor were there any two-way interactions involving the discussion topics. In order to address concerns about potential differences in scores due to the two data collection methods (paper-based vs Web-based), an additional ANOVA was conducted involving method, domains, and advertising. No significant three-way interactions or two-way interactions involving the hypothetical factors of interest obtained. The scores from paper-based version (*M* = 30.96, *SD* = 6.2) were somewhat higher on the *safety* dimension of credibility only than were scores obtained from the Web version of the same stimuli (*M* = 27.31, *SD* = 6.15), *t* (151) = 3.33, P = .001, but this main effect occurred across the board, and thus the findings reported below are not affected by data gathering method. The final analysis is based on the combined samples.

We predicted that different domains influence Web-site credibility (H1), and that both the *.com* domain and the presence of advertising reduce Web-site credibility (H2 and H3, respectively). Reduced, two-factor analyses were conducted involving domains and advertisements on the three dimensions of credibility.

On the *safety* dimension, ANOVA yielded a two-way interaction between domains and advertising, *F* (3, 145) = 2.73, P = .046, η^2 = .05. The descriptive statistics for each cell are reported in Table 2. Inspection of the means indicated a disordinal interaction effect. Thus, no further main effects analyses were appropriate. The interaction indicates that for different domains, there were differences in perceived safety depending on the presence or absence of advertising.

Table 2. Impact of advertisement and domain on safety dimension

Ads Presence	Domain	*M*	*SD*	*n*
No ads	.org	32.60	5.66	20
	.com	28.70	6.29	20
	.edu	28.63	5.34	22
	.gov	31.32	7.05	19
With ads	.org	27.88	6.75	16
	.com	32.31	6.62	16
	.edu	28.58	5.48	21
	.gov	30.39	7.31	19

Most dramatically, the *.org* page received the highest mean when no advertising appeared, but when advertising was present, *.org* had the lowest mean, and the two versions were significantly different, *t* (34) = 2.29, P = .03. The *.com* site without advertising was among the lowest in safety, but just as low as both versions of the *.edu* site, which was low whether there was advertising or not. Interestingly, and contrary to hypotheses, the *.com* site with advertising on it was not the lowest rated among the versions that had advertising on them, although they were not significantly different using post hoc Newman Kuels tests. Both the *.gov* sites were both moderately high in safety. It is unclear which domain was seen as connoting the most safety; the *F* test seemed to obtain because of the difference between *.org* sites due to advertising.

On the *trustworthiness* dimension, the omnibus ANOVA revealed a two-way interaction effect also, *F* (3, 145) = 2.81, P = .041, η^2 = .06. The pattern of the means was similar to that of the safety dimension. The *.org* page with advertising was the lowest scoring domain, but the same *.org* domain without advertising was the highest, *t* (34) = 2.80, P = .008. The scores for the *.edu* pages approached the scores of the *.com* with no advertising page; both were relatively low, whereas the *.gov* pages were relatively high on trustworthiness. The *.com* with advertising was not lower than *.com* without advertising; the difference between these two versions of *.com* was not statistically significant. However, among the pages that showed advertisements, the *.org* page was significantly lower in trustworthiness than the *.com* page as shown using Newman Kuels tests. Means and standard deviations for the two-way interaction are reported in Table 3.

Table 3. Impact of advertisement and domain on trustworthiness dimension

Ads Presence	Domain	*M*	*SD*	*n*
No ads	.org	23.50	4.30	20
	.com	22.45	5.35	20
	.edu	20.59	5.67	22
	.gov	23.11	5.88	19
With ads	.org	18.94	5.48	16
	.com	24.16	6.58	16
	.edu	22.10	4.86	21
	.gov	21.42	5.01	19

The *dynamism* dimension was not affected by any main or interaction effects across the board. However, between just the two *.edu* sites, the one without advertising (*M*= 19.59, *SD* = 3.96, *n* = 22) was significantly lower on dynamism than the *.edu* site with advertising, (*M* = 22.48, *SD* = 3.89, *n* = 21), *t* (41) = -2.41, P = .021, contradicting H3.

Discussion

The present study sought to identify a parsimonious and appropriate set of measures to assess the way Internet users determine the credibility of health information online, and to examine some superficial yet common Web components that may affect credibility. While a plethora of measures and competing dimensions exist, past research has shown, and the present results reaffirm, that the measurement of credibility may shift because of the nature of the topic and other characteristics. In this research, scales drawn from a variety of potentially relevant sources and administered to adult samples resulted in a set of three dimensions, with similarity to dimensions found in previous research but unique with respect to the precise combination of scales.

Previous research conducted in non-health contexts has implicated domains and advertising as credibility variables. We hypothesized differences due to the domain of the site (H1), and this hypothesis was partially supported on two dimensions of credibility: *safety* and *dynamism*, but the effects were not straightforward. Specifically, for the *safety* dimension, the *domains* effect interacted with the presence or absence of advertising. Likewise, for *trustworthiness*, an interaction overrode main effects. Only on the *dynamism* dimension did domain and advertising not interact. However, there were no main effects on *trustworthiness* either.

There is also inconsistent support for our hypothesis that advertising has deleterious credibility effects (H3). Only in the cases of *.org* did trends go in this direction on two of the three dimensions of credibility: The opposite trends emerged, marginally for *.com*, and significantly (on *dynamism*) for *.edu*.

Findings differ from research on Web credibility in other domains, reaffirming the need to re-examine measurement in this context. In one sense, it confirms the criticism of the factor approach to source credibility that credibility perceptions may not be invariant or stable, but rather are sensitive to topic and context. It was not expected that the two predicted effects would interact, but the results indicate this is the case. This suggests that findings from research on one kind of Web site-non-health-related-may not generalize to other information contexts.

The *.com* domain was originally posited to elicit low credibility assessments because of the implied commercial self-interest of the site's sponsors. The *.com* domain elicited inconsistent responses, however. It may be that a commercial *.com* site without advertising may not appear as legitimate, ie, as deserving of additional commercial investment by means of advertising, as one in which advertisers have invested. Based on all the above findings, we notice that the effects of domains and advertising on Web-site credibility are not simple and straightforward. The domain and the presence of advertising are important factors in predicting the credibility of health Web sites, although they are important through their mutual interplay rather than individually.

These findings in particular sharply contrast with previous work on perceptions ofWeb-site credibility due to domain and advertising [30]. It is apparent from these results that the credibility of health-information presentations online is evaluated differently than previous findings on non-health Web sites.

It is also possible that the top-level domain of a site alone is not as important as it once was. If users find sites via search engines, the quality of the "hit" or search accuracy may be more important than the site's actual sponsor in most cases [31]. Users will probably be more likely to visit sites recommended by peers, and are more likely to find them credible, than sites they might find by other means. This is known to be the case with educationally useful site referrals among student peers [37].

The practical applications of this research are straightforward. When it is possible to choose the top-level domain for a health-information site, investing in an *.org* domain name appears to be worthwhile. Those affiliated with educational institutions, for whom an *.edu* Web site may be simple to create, are advised to establish an alternative. However, for those who must offset the costs of their efforts through online advertising, *.org* should be avoided. The credibility of other domains is not as strongly affected by the advertising decision.

Research applications may also be discerned from this investigation. Studies intended to test alternative forms of health information against Web-borne advice should include Web sites deliberately chosen on the basis of credibility, so that deficits in the persuasive aspects of alternative stimuli are not confused with the persuasive potential of the Web overall. Future research may broaden the question of how people are influenced by online health information, and compare the influence of source credibility to source homophily (ie, perceived similarity between source and user). Such comparisons hold promise for distinguishing the influence mechanisms that may differ between Web-site information and information exchanged through peer-to-peer support groups, harkening back to the distinction Hovland et al [10] made between expertise and trustworthiness as alternative and orthogonal sources of influence.

Finally, since credibility is not and end-goal in and of itself, but a facilitator of persuasion, attitude, and behavior, additional measures should be investigated that assess the likely adoption of information as a result of the two kinds of online presentations. In this regard, recent work by Dutta-Bergman [33] offers useful and validated scales for the evaluation and persuasiveness of online health information and its effect on attitude about, and intention toward, health-related behavior. The inclusion of such research methods will offer a more comprehensive and meaningful approach to a growing understanding of the impact of online health information in its various forms.

Acknowledgments

The authors are grateful to a number of individuals who have assisted in various aspects of this project with literature summaries, data collection, or in other aspects, including Shelly Campo, Janie Diels, Rayna Jhaveri, Aaron Kemp, and Elizabeth Goulding. Portions of this research have been presented at the April 2004 NIH/NCI meeting, The Search for an Interdisciplinary Understanding of Online Cancer Services, in Tampa, FL, and at the August 2004 annual meeting of the Communication Technology and Policy division of the Association for Education in Journalism and Mass Communication in Toronto.

Conflicts of Interest

None declared.

References

1. Fox S, Rainie L. The online health care revolution: how the Web helps Americans take better care of themselves. Washington, DC: Pew Internet & American Life Project; Nov 26, 2000. URL: http://www.pewinternet.org/pdfs/PIP_Health_Report.pdf
2. Winker MA, Flanagin A, Chi-lum B, White J, Andrews K, Kennet RL, et al. Guidelines for medical and health information sites on the Internet: principles governing AMA Web sites. American Medical Association. 2003. URL: http://www.ama-assn.org/ama/pub/category/1905.html
3. Craigie M, Loader B, Burrows R, Muncer S. Reliability of health information on the Internet: an examination of experts' ratings. J Med Internet Res 2002 Jan 17;4(1):e2 [FREE Full text] [Medline: 21953330] [doi: 10.2196/jmir.4.1.e2]
4. Turow J, Coluccio K, Hersh A, Humphreys L, Jacobsohn L, Sawicki N, et al. Discussions of health websites in medical and popular media. Report to Consumer WebWatch. 2003 May. URL: http://www.consumerwebwatch.org/news/health/Turow_Report.pdf
5. Peterson G, Aslani P, Williams KA. How do consumers search for and appraise information on medicines on the Internet? A qualitative study using focus groups. J Med Internet Res 2003 Dec 19;5(4):e33 [FREE Full text] [Medline: 14713661] [doi: 10.2196/jmir.5.4.e33]
6. Chaffee SH. In: Gumpert G, Cathcart R, editors. Inter/Media: Interpersonal Communication in a Media World. New York: Oxford Univ Pr (Sd); Jan 1, 1986:57-77.
7. Kiousis S. Public trust or mistrust? Perceptions of media credibility in the information age. Mass Communication & Society 2001;4(4):381-403 [FREE Full text] [doi: 10.1207/S15327825MCS0404_4]
8. Slater MD, Rounder D. How message evaluation and source attributes may influence credibility assessment and belief change. Journalism Mass Comm 1996;73:974-991.
9. Smith RG. The message measurement inventory: A profile for communication analysis. Bloomington: Indiana University Press; 1978.
10. Hovland CI, Janis IL, Kelley JJ. Communication and Persuasion: Psychological Studies of Opinion Change,. New Haven, CT: Yale University Press; 1953.
11. Berlo DK, Lemert JB, Mertz RJ. Dimensions for evaluating the acceptability of message sources. Public Opin Q 1969; 33(4):563-576. [doi: 10.1086/267745]
12. McCroskey J. Scales for the measurement of ethos. Speech Monogr 1966;33:65-72.
13. McCroskey JC, Young JT. Ethos and credibility: the construct and its measurement after three decades. Cent States Speech J 1981;32:24-34.
14. Gass RH, Seiter JS. Persuasion, Social Influence, and Compliance Gaining (2nd Edition). Boston, MA: Allyn & Bacon; Sep 10, 2002.
15. Jurma WE. Evaluations of credibility of the source of the message. Psychol Rep 1981;49:778.
16. Aune RK, Kikuchi T. Effects of language intensity similarity on perceptions of credibility, relational attributes, and persuasion. J Lang Soc Psychol 1993;12:224-237.
17. O'keefe DJ. Persuasion: Theory and Research (Current Communication). Newbury Park, CA: SAGE Publications; Mar 1, 1990.
18. Cronkhite G, Liska J. A critique of factor analytic approaches to the study of credibility. Commun Monogr 1976; 43:92-107.
19. Delia JG. A constructivist analysis of the concept of credibility. Q J Speech 1976;62:361-375.
20. Gunther A. Attitude extremity and trust in media. Journal Q 1988;65:279-287.
21. Stamme K, Dube R. The relationship of attitudinal components to trust in media. Communic Res 1994;21:105-123.
22. Keefe DJ. The dependency of interpersonal evaluations on context-relevant beliefs about the other. Speech Monogr 1975;42:10-19.
23. Metzger MJ, Flanagin AJ, Eyal K, Lemus DR, McCann RM. Bringing the concept of credibility into the 21st century: integrating perspectives on source, message, and media credibility in the contemporary media environment. In: Kalbfleisch PJ, editor. Communication Yearbook 27 (Communication Yearbook). Mahwah, NJ: Lea; May 1, 2003:293-335.
24. Flanagin A, Metzger M. Perceptions of Internet information credibility. Journalism Mass Comm 2000;77:515-540.
25. Gaziano C, McGrath K. Measuring the concept of credibility. Journal Q 1986;63:451-462.
26. Meyer P. Defining and measuring credibility of newspapers: developing an index. Journal Q 1988;65:567-574.
27. Flanagin A, Metzger M. Internet use in the contemporary media environment. Hum Commun Res 2001; 27(1):153-181. [doi: 10.1093/hcr/27.1.153]
28. Sundar SS, Nass C. Conceptualizing sources in online news. J Commun 2001;51(1):52-72. [doi: 10.1093/joc/51.1.52]

29. Eastin MS. Credibility assessments of online health information: the effects of source expertise and knowledge of content. J of Computer-Mediated Comm 2001 Jul;6(4).
30. Fogg BJ, Marshall J, Laraki O, Osipovich A, Varnma C, Fang N, et al. What makes web sites credible? A report on a large quantitative study. Presented at: ACM CHI 2001 Conference on Human Factors in Computing Systems; 2001 Mar 31-Apr 5; Seattle, WA.
31. Eysenbach G, Köhler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. BMJ 2002 Mar 9;324(7337):573-577 [FREE Full text] [PMC: 11884321] [Medline: 21881326] [doi: 10.1136/bmj.324.7337.573]
32. Metzger MJ, Flanagin AJ, Zwarun L. College student Web use, perceptions of information credibility, and verification behavior. Comput Educ 2003;41(3):271-290. [doi: 10.1016/S0360-1315(03)00049-6]
33. Dutta-Bergman MJ. Health communication on the web: the roles of web use motivation and information completeness. Commun Monogr 2003;70:264-274.
34. Walther JB, Boyd S. Attraction to computer-mediated social support. In: Lin CA, Atkin DJ, editors. Communication Technology and Society: Audience Adoption and Uses (The Hampton Press Communication Series). Cresskill, NJ: Hampton Press; Jan 1, 2002:153-188.
35. Petty RE, Cacioppo JT. The elaboration likelihood model of persuasion. In: Berkowitz L, editor. Advances in Experimental Social Psychology. New York: Academic Press; Jan 1, 1986, Vol. 19:123-205.
36. Klingle RS, Burgoon HM, Afifi WA, Callister M. Rethinking how to measure organizational culture in the hospital setting: the hospital culture scale. Evid Based Ment Health 1995;18:166-186.
37. Gay G. , Stefanone M, Grace-Martin M, Hembrooke H. The effects of wireless computing in collaborative learning environments. Int J Hum Comput Interact 2001; 13(2):257-276. [doi: 10.1207/S15327590IJHC1302_10]

Abbreviations

ANOVA: Analysis of Variance

submitted 28.04.04; peer-reviewed by M Dutta-Bergmann, B Fogg; comments to author 10.05.04; revised version received 17.06.04; accepted 17.06.04; published 03.09.04.

Please cite as:
Walther JB, Wang Z, Loh T
The Effect of Top-Level Domains and Advertisements on Health Web Site Credibility
J Med Internet Res 2004;6(3):e24
URL: http://www.jmir.org/2004/3/e24/
doi:10.2196/jmir.6.3.e24
PMID:15471750

Original Paper

HIV-Positive Youth's Perspectives on the Internet and eHealth

Sarah Flicker[1], MPH; Eudice Goldberg[1,2,3], MD; Stanley Read[2,3], MD; Tiffany Veinot[4], MLS; Alex McClelland[5]; Paul Saulnier[5]; Harvey Skinner[1], PhD

[1]Department of Public Health Sciences, University of Toronto, Toronto ON, Canada
[2]Department of Paediatrics, The Hospital for Sick Children, Toronto ON, Canada
[3]Faculty of Medicine, University of Toronto, Toronto ON, Canada
[4]Canadian AIDS Treatment Information Exchange, Toronto ON, Canada
[5]Positive Youth Outreach, AIDS Committee of Toronto, Toronto ON, Canada

Corresponding Author:
Harvey Skinner, PhD
Department of Public Health Sciences
McMurrich Building, Faculty of Medicine
University of Toronto
Toronto ON M5S 1A8
Canada
Phone: +1 416 978 8989
Fax: +1 416 978 8299
Email: Harvey.Skinner@utoronto.ca

Abstract

Background: Globally, half of all new HIV infections occur among young people. Despite this incidence, there is a profound lack of resources for HIV-positive youth.

Objective: To investigate Internet access, use and acceptability as a means for health promotion and health service delivery among HIV-positive youth.

Methods: A community-based participatory approach was used to conduct a mixed methods research study. Thirty-five qualitative in-depth semi-structured interviews were conducted with youth (ages 12-24) living with HIV in Ontario. Also, brief structured demographic surveys were administered at the time of the interview. A stakeholder group of youth living with HIV, professionals and researchers collaboratively analyzed the data for emerging themes.

Results: Five main themes were identified with respect to the youth's use of and interest in the Internet as a health promotion strategy. These include: (1) high rates of Internet use and access; (2) issues around public and private terminals; (3) their use of the Internet primarily for communication and entertainment; (4) the rarity of health information seeking behavior in this group; and (5) wanting "one-stop shopping" from an e-health site. HIV-positive youth were enthusiastic about the possibility of content that was developed specifically to target them and their needs. Also, they were keen about the possibilities for increased social support that youth-specific online chat rooms and message boards might provide.

Conclusion: Given high rates of use, access and interest, the Internet provides an important way to reach young people living with HIV using health services and health promotion programs. The onus is on e-Health developers to understand the particular needs of HIV-positive youth and create relevant content.

(J Med Internet Res 2004;6(3):e32) doi:10.2196/jmir.6.3.e32

KEYWORDS

Youth; HIV; Internet; health promotion

Introduction

Globally, half of all new HIV infections occur among young people [1]. Currently there are an estimated 11.8 million youth aged 15-24 years living with HIV/AIDS [1]. In Canada, youth, particularly young women aged 15-29, represent a growing population who are being infected with HIV and AIDS [2,3]. As of June 2002, 13279 youth and young adults under the age of 29 had tested positive for HIV in Canada [4]. Due to under-reporting and under-diagnosis, as well as a long asymptomatic period, the actual prevalence of HIV in youth is likely much higher than indicated in official statistics.

Surveillance data in the United States shows that although AIDS incidence is declining, there has not been a comparable decline in the number of newly diagnosed HIV cases among youth [5].

Despite this prevalence and incidence, there is a profound lack of resources for HIV-positive youth [6]. In particular, youth--accessible resources outlining treatment options are scarce. Although material is available to help adults make treatment decisions, many of these resources are not appropriate for youth because they fail to address their unique clinical and developmental challenges. Furthermore, texts written for adults are often intimidating to younger audiences both because of language and literacy barriers and the less engaging ways in which information has traditionally been presented.

While many HIV-positive adolescents are at early stages in the course of their disease, health promotion messages are very important for them. Studies of adolescents living with HIV have shown high morbidity and mortality rates [7,8]. Other studies looking at the subjective health experience have documented that a quarter of those interviewed described their health as "fair" or "poor." [9] These findings illustrate the importance of treatment, self-care and prevention of co-infections for this population.

Treatment and Self-care Needs

HIV-positive youth are unique in their treatment and self-care needs. Many youth for whom antiretroviral medications are clinically indicated choose not take them [10]. Many do not access health care services. Youth may have perceptions of treatment that differ from adults [11], favoring a present quality of life over improving biological markers. In contrast to adults, peer influence has been identified as one of the key factors affecting youth treatment decision making [12,13]. Thus, there is a strong need for peer-driven resources about HIV/AIDS treatment, which are presented in youth-friendly formats. Moreover, these resources need to be sensitive to the ways in which self-care and treatment decisions are contextualized within the broader scope of these youth's lives.

Adolescence and early adulthood are the stages when lifelong health and social behavior patterns are formed. HIV-positive youth are particularly vulnerable during this period, as they experience disproportionate rates of: homelessness [14,15]; sexual and physical abuse [16,17]; financial difficulties [18,21]; addictions [22]; legal concerns [20,23]; social isolation and stigma [9,23]; and mental health concerns [16,24]. Often, the immediacy of these social and structural determinants of health may overshadow worries about HIV infection [20]. This results in a need for information that is sensitive to the unique situations of HIV-positive youth, while framing their experiences within the perspective of normal youth development to avoid further marginalization and stigmatization.

Potential of the Internet

There is a growing literature that emphasizes the potential of the Internet, not only for health promotion [25,26], but also as a community development tool [27,28]. The Internet provides innovative ways of engaging youth, allowing opportunities to assess and address their needs and to provide them with a means of offering each other support. Research has demonstrated that computers can attract young adults to participate in health assessments and behavior change programs, in ways and numbers that are not possible using traditional approaches [29,30]. Internet technology can be easily updated, is available 24 hours per day, and enables self-directed learning. It can be reached by those in remote and isolated settings, facilitates repeat use and can be anonymously accessed. Finally, information presented online can be of a highly graphical, interactive nature, and thus be able to reach users who may not have age-appropriate literacy skills [30].

In 1994, only 17% of young people were estimated to be using the Internet. Data from 2000 however, suggest that between 92% and 99% of Canadian youth used the Internet regularly [31]. Indeed, the digital divide in Canada is narrowing. Among households with less than $20,000 incomes, 77% of youth reported regular Internet use in 2000. Given the rapid growth of Internet use, this number has probably grown considerably [31]. American youth are also online: 73% of 12-17 year olds in the US use the Internet regularly [32], and 95% of all teens have ever been online [33]. Generally, youth are more likely than their adult counterparts to use the Web and are 'early adopters' of technology [34].

Research with adult populations living with HIV has demonstrated that computer-based health services can improve a patient's quality of life and promote more efficient use of health care systems [35-37]. Furthermore, qualitative studies have shown that HIV-positive adults use the Internet for a wide variety of functions including communication, advocacy and commerce [38,39]. Kalichman found that individuals with HIV who used the Internet were more likely to be better informed about HIV treatment and self-care than those who did not [40,41]. However, he also found that there was a "digital divide": those accessing the Internet were more likely to be better educated and report higher incomes [40-41].

Despite the growing popularity of the Internet as a health information resource [43], little research has been conducted on the feasibility of using the Internet as a health promotion strategy with HIV-positive youth. One of the aims of this study was to investigate Internet access, use and acceptability among this vulnerable and marginalized population.

Methods

A community-based participatory research model [44,45] was used to assess the needs of Canadian HIV-positive youth. A stakeholder group of HIV-positive youth (trained as community researchers) and supporting professionals collaboratively developed the research design, instruments and protocol. Qualitative methods were selected for their ability to explore issues 'in-depth' and allow participants to express their thoughts and feelings 'in their own words.' Thirty-five interviews were conducted with a diverse group of HIV-positive youth across Ontario. The interviews were semi-structured and probed around four main areas of interest: a) future goals; b) social support; c) treatment and self-care issues; and d) online interests and behaviors. In addition, brief structured surveys were administered at the conclusion of each interview. Surveys asked about demographics (e.g., age, sex, sexuality, etc.) and Internet use. This paper will focus on the online component (other findings have been reported elsewhere).

Using a maximum variation sampling scheme, a sampling frame was developed that ensured diversity in age, sex, sexuality, age of diagnosis, ethno-racial identity and geographic region [46]. Youth were recruited through AIDS-serving organizations, youth-serving organizations, hospitals, and health clinics. In some cases, youth workers and health care providers approached young people in their case load and told them about the study. In other cases, recruitment flyers were simply posted. Also, young people who had already participated were encouraged to tell other HIV-positive youth who they knew about the study (snowball recruitment).

In all cases, youth approached the research team directly. Participation was limited to youth who: a) were between the ages of 12 and 24 years; b) were identified as HIV-positive through self-report; c) had the ability to communicate in either English or French; and d) had lived in Ontario for the last three months. Each received a $20 honorarium for participation. Standard procedures were employed for obtaining informed consent (approved by the University of Toronto Human Subjects Ethical Review Committee and the Research Ethics Review Board at The Hospital for Sick Children). Two interviews were conducted in French; 33 interviews were conducted in English. Table 1 provides a breakdown of our final sample.

Table 1. Sample characteristics

Characteristic	Number Interviewed (Percentage)
Gender	
Male	22 (63%)
Female	13 (37%)
Age	
12-15	6 (17%)
16-19	12 (34%)
20-24	17 (49%)
Sexuality	
LGBTQ[1]	8 (23%)
Heterosexual	27 (77%)
Diagnosis	
Last 12 months	15 (43%)
Longer than 12 months	13 (37%)
Perinatal	7 (20%)
History of Street Involvement	
Yes	24 (68%)
No	11 (31%)
Ethno-Racial Identity	
White, European, Canadian	19 (54%)
African/Caribbean	10 (29%)
First Nation/Aboriginal	3 (9%)
Unknown/Other[2]	3 (9%)
Geographic Location	
Large Urban	28 (80%)
Small Urban/Rural	4 (11%)
Northern	3 (9%)

[1] Lesbian, Gay, Bisexual, Transsexual, Queer or Questioning

[2] Unspecified, Chinese, South-East Asian

Interviews lasted between 35 and 95 minutes. Generally, they were taped and transcribed verbatim. In one case, a youth did not want to be audio-taped and copious notes were taken during the interview. In another case, a youth wanted to write out his own answers rather than talking into a tape-recorder. At the conclusion of each interview, youth were asked to fill out a brief demographic survey and invited to continue to participate in the research project. In addition, they were provided with a list of youth-friendly health and service agencies in their area.

A modified grounded theory interpretive approach guided the analyses [47-49]. A sub-sample of 10 transcripts, stripped of identifying names and places, were returned to the stakeholder group of HIV-positive community youth researchers and professionals for preliminary analysis. Based on emerging themes, commonalities and major differences, a preliminary coding framework was developed [50]. Data were coded by two youth community researchers using Nud*istqualitative data analysis software [51]. After coding the first 10 transcripts, issues with the coding scheme were brought back to the larger stakeholder group and the scheme was refined and subsequently applied to the remaining transcripts.

Coded data were returned to the larger team for analysis. Members of the team were asked to fill out a work sheet for each code asking:

1. What was the range of experience here? What are the different ways that youth talked about their experience?
2. What are the general patterns that emerged? Generally how would you summarize what most young people had to say?
3. Which one or two quotes best summarize what you see here?

Weekly meetings were held to go over worksheets and discuss main themes, relevance and implications for each code. Collectively, the team's notes were discussed and summary tables constructed to capture the most common themes, gaps and issues.

Results

Five main themes were identified with respect to the youth's use of and interest in the Internet as a health promotion strategy. These include: (1) high rates of Internet use and access; (2) issues around public and private terminals; (3) their use of the Internet primarily for communication and entertainment; (4) the rarity of health information seeking behavior in this group; and (5) wanting "one-stop shopping" from an e-health site.

High Rates of Internet Use and Access

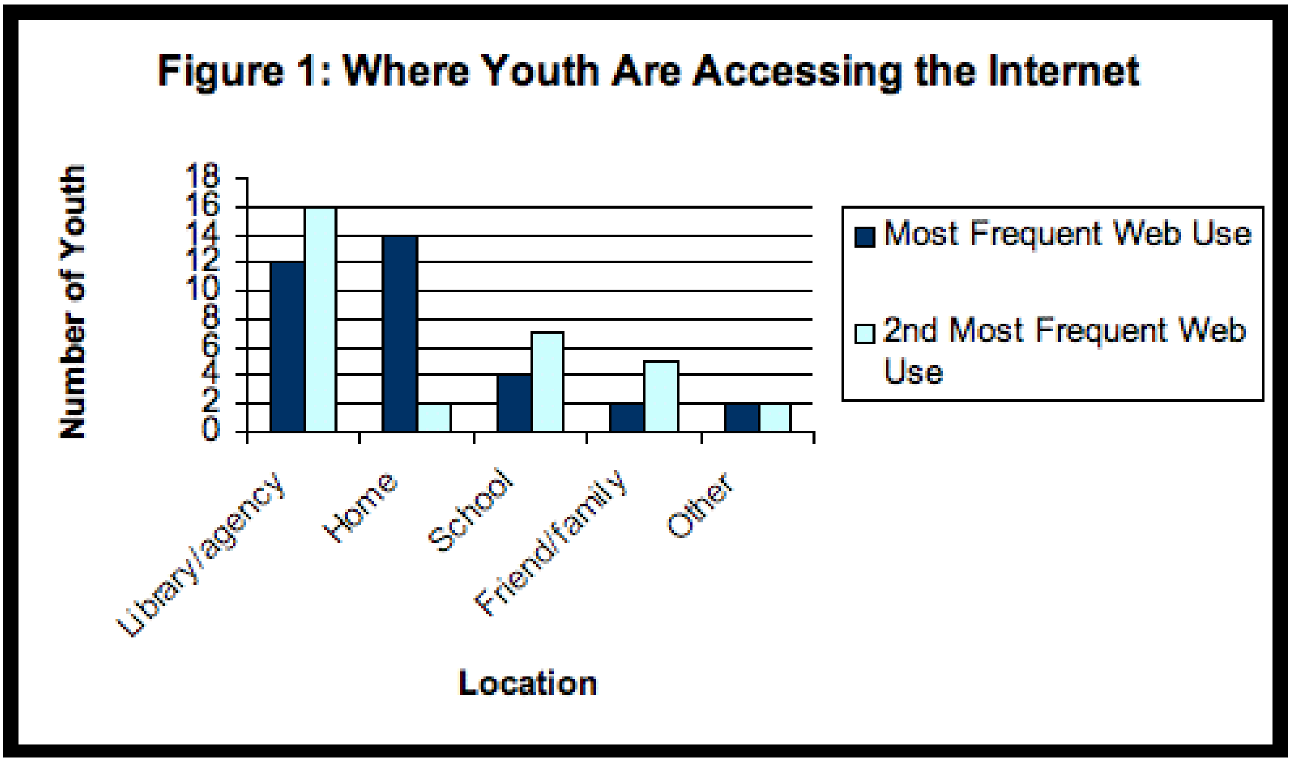
"I'm online like all the time." – young man

All of the youth we interviewed had used the Internet. Thirty four percent reported being online daily, 37% weekly and 29% said they were online monthly or occasionally. In addition, nearly half the youth we spoke with used instant messaging programs and two-thirds of the youth documented that they used e-mail at least once per week (Table 2).

Table 2. Frequency of technology use

Technology Use	Web	Instant Messaging	Email
Daily	12 (34%)	8 (23%)	13 (37%)
Weekly	13 (37%)	9 (26%)	10 (29%)
Occasionally or monthly	10 (29%)	10 (29%)	9 (26%)
Never	0 (0%)	8 (23%)	3 (9%)

Figure 1. Where youth are accessing the Internet



These young people logged on from a wide range of public and private locations (Figure 1). Community centers, youth-serving organizations, AIDS-serving organizations, shelters, and public libraries were important points of Internet access both among housed and street-involved youth. Those who were actively street involved discussed the importance of using the Internet, particularly e-mail, as a vital communication mechanism. Nearly all the youth with a history of street involvement cited being online daily or weekly. While the quality of access (in terms of speed, privacy and freedom to surf) varied across locations, most youth were active users of public Internet terminals and access points.

Youth who documented lower rates of Internet use did not see access as the major barrier. Rather, these young people simply preferred other modes of communication and/or gathering information. As one young woman stated: "Ah, well honestly, this is nothing to do with HIV, but I rarely use it... I don't really have the patience for the Internet. I only use it on real necessity." She preferred using the telephone for communication and reading books for gathering information.

Issues Around Public and Private Terminals

For many youth, private Web access was not a reality. Many were street-involved, some lived in subsidized housing and others lived in low income environments where Web access was not available at home. Thus, youth primarily talked about accessing the Web from public locations (Table 3).

Table 3. Public and private access

Benefits of public access • Free access • Anonymous • Freedom	*"I wouldn't care, because Internet is used for so many things, it could be research for school..."* *"So many people use it -- they don't know who went on their sites. It doesn't matter. You go to Web station and it's the same thing, like, a thousand people might touch the same keys as you so..."* *"It's nobody's business anyway, you know. Like... why are you talking to me? I don't even know your name. Why would I care what you have to say, you know?"* *"I don't care where I go online. Nothin' really bothers me like that."*
Drawbacks of Public Access • No real privacy • Don't want to be publicly 'outted' as HIV positive • Fear of emotional responses and having to 'deal' with others • Usernames limit confidentiality	*"Never checked out health sites... Because usually when I go... either in a library or a cyber cafe I don't want people seeing what I'm looking up, just in case they take it the wrong way." The thing that would make him feel safe is an area where no one can see.* *"I don't like doing things in a library other than like check out books or something like that. People look over your shoulder. Or you're sitting--the computers are like right next to each other, and it's like--I've always felt uncomfortable even researching certain books, looking at a certain book. It's like can you see the title I'm typing in, don't look. You know I don't want, like, you to know, even if people aren't that nosy, I just don't want to risk it."* *"Really worried about checking out health info online... In the library I was always looking over my shoulder...What can you do, right? Somebody tell you - what's wrong, what's wrong' and you can't really say and you want to lash out so you have to leave."* *"Due to the fact that I don't have a computer at home and I use my computer from school. I have to sign in every time I use the computer and accessing sites like that leaves traces, so it leaves information behind... and I don't like that."*
"Private" Access • better, but not 'totally' safe	*"I use the Internet from home, so I don't worry about stuff like that."* *"No. From a public in--no. Always my private. Because public, if you're going to a public library somewhere else, a little sign will pop up, 'information that you use or may enter may be seen by other people within this facility'. I don't like that. On my computer at least it will be like may be seen by people over the other--on the Internet and it's just like okay, I don't really like that either, there's not really big much of a difference, but at least it's a lot better when you're in the privacy and nobody can really pinpoint you..."*

Youth had mixed feelings about public access. Some saw the public portals as having an added sense of security and anonymity. In terminals where usernames were not required, they could feel free to browse the Web and search for confidential information without fear that they would be 'tracked down,' 'discovered' or 'outted' as being HIV-positive. They felt that because so many people used public access terminals all the time, their information or 'log histories' would be lost in the mix. One young person that had Internet access at home described searching for sensitive information at the library so her dad would not find out.

By contrast, other young people complained about the lack of privacy in public terminals. In particular, in libraries or shelters where computers were close together or peer networks were close-by, searching for sensitive or confidential information was not considered a possibility. Many youth were extremely leery about issues of confidentiality and were afraid that if they searched for information about HIV in public, others would find out about their status. Youth who needed special usernames or ID codes to access public terminals (e.g., at school) were extremely reluctant to search for confidential information.

Generally, youth that had home access often felt safer using private Internet access points than public ones. However, some youth acknowledged that even in the "privacy" of their own homes – they were not totally 'safe.' These youth were worried that their parents, friends or siblings might be able to trace their 'online movements.' Others worried that through the use of 'cookies' and other new technologies, others might be able to find out confidential information about them. As such, even 'safer' spaces were not seen as completely 'safe' or 'private.'

Youth Use the Internet for Communication and Entertainment

"I use it for everything and anything you can possibly think about in the world, and some things I'm not going to mention over tape." – young man

Overwhelmingly, these young people used the Internet for communication (chat, message boards, e-mail, instant messaging). They talked at great length about their love of these Internet communication tools. Many of them had multiple e-mail addresses, and some talked about having multiple Internet identities.

These youth also spent a good deal of time surfing the Internet for entertainment purposes (e.g., games, music, sports, movies, pornography). For many, the Internet was seen as 'something to do' or a good alternative to television. Many of the young men mentioned interactive gaming. Generally, the Internet was seen as a way to have fun. As one young man put it, "I guess, like, the Internet for me is just like a time for playing games and chatting on the net."

These youth also documented using the Internet to search for information for school and work. Many were savvy Internet users and were able to describe complex search strategies for finding the information that they were looking for. Despite being sophisticated Internet users, few used to Internet to seek out health information.

Health Information Seeking Behavior is Rare

"Cause half the time I don't really know I have HIV because I don't think about it, 'cause it's not like something you really think about 'cause I'm doing well." – young woman

Youth rarely talked about the Internet as a place where they sought health information (Table 4). A few young people described using the Internet regularly to learn about HIV, treatment options and community resources. These youth were 'expert' searchers; they were online regularly and knew how to access the information they were looking for. One young man in particular, was on HIV peer support sites regularly and saw his 'virtual friends' as important sources of social support and health information. However, these youth were in the minority.

Table 4. Searching for health information

Many youth do not use the Internet for health information	
• Too early in diagnosis	*"I really haven't checked that stuff out yet."*
• The Internet is a place to 'escape'	*"Because it is not interesting to me."* *"I guess, like, the Internet for me is just like a time for playing games and chatting on the net."*
• Confidentiality	*"Because usually when I go to either a library or a cyber café, I don't want people seeing what I'm looking up, just in case they take it the wrong way."*
• Prefers other methods of getting information (e.g., talking to health care providers, books)	*"Well, once in a while but hardly ever because I go to [Special school for street involved youth] and there's like a healthcare place you can go to so, if anything, I just go there if I have questions..."*
• Doesn't like the Internet or computers	*"I don't really have the patience for the Internet...I just can't stand looking at computer screens, using the mouse, it feels so awkward so I don't like it."*
• Doesn't know how	*"How do you find sites?"*
Some youth have limited experience using the Internet for health information	
• A first stop for information	*"Yeah, when I first found out I had it, I went on sites, a few sites to find out what I wanted to do. I wanted to read up on some of it. Couldn't believe it, did a lot of crying the first few months. It was all so overwhelming."* *"I did like a couple of times like when I first found out but now it's just, I try not to think about it and try not to read much about it. Everything else is basically for adults."*
• Some needed help negotiating information (friends, parents)	*"I did one time, yeah. It was helpful...Yeah. I had two of my other friends look with me, ahm, health information like different medications, how to take care of yourself, things like that, and I got a whole bunch of information on it."* *"When I first was diagnosed, I checked stuff out on the Websites. And then just all kinds of stuff...It was helpful because my dad was there. If I had been by myself, I probably wouldn't have understood anything. That's why you need to direct stuff towards teens."*
• An available resource	*"I have been doing a lot of it recently, but I don't know, I'm still trying to take it all in. It's all like, thinking. I go to the site, I read it, like I don't know, a paragraph or two and I get psyched out of it, like, okay, I don't want to think about it, I don't want to think about it and I go off and play a new game. Then I go back to the site and read the next paragraph and then click off of it."*
A small minority were expert searchers	
• Online daily, getting peer support	*"I always check this site out and there's a lot of people with HIV on there too, around the world. And I ask them questions... . (There's) Questions and answers, side effects on drugs, I mean, hundred medications, the whole nine yards."*
• Savvy searchers	*"You just search google or yahoo and tons of stuff comes up."*

When probed about why most did not use the Internet to access health information, they had a variety of responses. For some, the Internet was a place to 'escape' to. They saw the Internet as being primarily about entertainment (e.g., "I use the Internet to play card games and interact with other people.") For others, seeking health information was not seen as a priority because HIV was a relatively small part of their identity. As one young man explained, "It is, after all, only three letters." A small subset of youth worried that if they searched for health information about HIV online, someone (their ISP provider or others around) might find out about their HIV status. One young woman had adopted strategies for managing these issues, "[at the agency] the computers are so close and there are a lot of people I know there...but at the library I feel safer." Other reasons that youth provided included: preferring other methods of getting information; hating computers; not knowing how to access appropriate information; and not being ready yet to find out more information (i.e., too early after diagnosis).

Other youth who had experimented with using the Internet for health information complained that: a) there was too much out there and it was hard to prioritize and figure out "what's what"; b) most of the information that was out there was unintelligible and c) they found the experience somewhat overwhelming. Some adopted strategies of asking friends or family to search with them and act as translators or interpreters. As one young man described, "It was helpful because my dad was there. If I had been by myself, I probably wouldn't have understood anything. That's why you need to direct stuff towards teens."

Youth Want "One-Stop Shopping" From an eHealth Site

"Like basically, one-stop information location for positive youth. Like everything and anything you can put in there, but put it into a format that youth can understand, right? Something to create and have some fun with!" – young man

Despite the Internet's rare use for health information, when asked if they would visit a Website specifically designed by and for HIV-positive youth, most of the young people we interviewed were extremely enthusiastic about the possibilities of the Internet for health promotion. Nine percent said they would use a site specifically developed for positive youth everyday. Twenty-nine percent said they would use it regularly, 43% said they would use it once in awhile and 20% said they would never use such a site. Youth in the "once in awhile" category were generally enthusiastic about the concept. While they did not see their HIV status as being a major part of their identity, they were nevertheless interested in being able to access relevant content when appropriate (e.g., when they had specific questions). The minority of youth that would not access these resources gave the following reasons. They were either: (a) not interested in HIV health information resources generally; (b) unenthusiastic about the Web; or (c) concerned about privacy.

Table 5. What youth want from an eHealth site

Social Support & Communication Opportunities	
Chat Rooms	*"Chat rooms where people can chat about how they're feeling, how they're doing... they can write to each other and stay in contact..."*
Message Boards	*"Message boards... for people to connect with each other - you feel so alone, you want to talk about stuff and share ideas... you can post your feelings, a poem or something..."*
Information	
Treatment	*"Information about medication, information about other options out there, information about doctors that are youth oriented or they are good with you, so basically an investigation on doctors."*
Resources	*"Like you know, there's a whole bunch of agencies or services that you have to know. We all don't know of things that are out there."*
HIV/AIDS	*"Like about how you get it and stuff."*
Harm reduction	*"Like how to make sure you don't spread it and stuff."*
'Health' generally	*"How to maintain your health and be good to your body."*
Interactive Components	
Games, quizzes	*"Funkiness, coolness... make it fun and comfortable."*
Q & A	*"Like ask the doctor."*
Privacy Protected	
Nicknames	*"If you don't want to use your real name, you should be able to use a code."*
Password	*"Password is a big thing."*
Confidentiality Agreements	*"[You should have] a privacy or confidentiality agreements... so youth will understand that their information is not going to go out to somebody else on the net."*
Discreet Look	*"Why do all you guys use big, red letters? Big- big red bubble letters [that say HIV] all over the site!?"*
Protection from prowlers	*"It might not be a good idea because the older guys might go in there and start going after the youth. And it might be a really uncomfortable situation for those youth."*

Youth were extremely specific about what they wanted from e-health strategies targeted towards them (Table 5). First and foremost, young people wanted an opportunity to share and connect with each other; chats and message boards were seen as the main attraction to heading towards a site specifically for HIV-positive youth. Nearly every young person we spoke with recommended the creation of a chat space. Many youth described feelings of isolation and loneliness and felt that the opportunity to connect with other youth in similar circumstances could be extremely valuable. They talked about the importance of connection and prioritized chats and message boards over other possible Internet information applications (e.g., didactic information). Many of them worried, however, about "prowlers" and sexual solicitations in sites that were geared towards youth audiences and were concerned about how those might be managed.

Youth embraced the concept of "one-stop shopping" or one site that would be able to answer all their questions. Many talked with frustration about how so many sites 'out there' that dealt with HIV were not 'youth-friendly' or 'user-friendly' and were hard to understand. They did not enjoy getting 'lost' in complicated links.

Study participants wanted the look and feel of a site geared towards them to be discreet and not 'obviously' about HIV so that they could access it in public forums. In order to protect their privacy, youth did not want to be asked for their real names. They were happy to provide nicknames and felt that passwords provided added protection. Also, they wanted to see privacy or confidentiality agreements that assured them that their confidentiality and anonymity would not be compromised.

Discussion

Our study found that HIV-positive youth are online and are Web savvy users. A surprising finding was that the youth who were perhaps most impoverished and marginalized (those who were either currently or had a history of being street involved) demonstrated high rates of Internet use. This is in sharp contrast to American findings of adult populations living with HIV [41,42].

This study supports evidence from investigations of adults living with HIV that communication is a primary reason that people living with HIV use the Internet. However, unlike adults, our study did not identify advocacy as something that youth did online. Information seeking was secondary [38,39].

Although they go online with regularity, the HIV-positive youth in our study rarely searched for health information. This was due to personal and institutional barriers including: lack of interest; difficulty assimilating information geared towards adults; fear of disclosure; and inadequate private access. Our findings that youth living with HIV use the Internet primarily for communication and entertainment is consistent with other studies that have looked at Internet use among more general youth populations [52]. In addition, the problems documented around quality of access are also found among other youth populations [53].

Results of a national needs assessment conducted by the Canadian AIDS Society in 2000 concluded that, "Nationally...there was a huge lack of services for HIV-positive youth. These missing services ranged from support groups, to accessible treatment information, and basic living necessities for positive youth." [6] Similarly, Toronto's Positive Youth Outreach 2000 Survey found that youth ranked treatment information amongst their top six most pressing needs [18]. Furthermore, they cited the Internet as one of the best ways to give them information. Identifying a need for further venues of social support, these youth documented that Chatrooms/Listserves, phone lines and social events were the top three services they wanted. This study confirmed that, indeed, the Internet may be a viable way to impart health and treatment information, provided the content, look and feel of such materials were created and presented in 'youth friendly' formats.

One limitation of this study is that we recruited young people from youth- and AIDS-serving organizations and health care settings. As such, the youth we spoke to were generally well connected to health and/or social services, which may have provided them higher rates of public Web access. The qualitative nature of our study also makes it difficult to generalize our results to all HIV-positive youth.

Nevertheless, this study suggests that if content were developed specifically for HIV-positive youth and marketed to them, they would be interested. Targeting young HIV-positives for health promotion messaging may be both feasible and desirable [54]. Given the success of computerized and online health promotion strategies with other populations, this may prove to be an important health promotion strategy.

Health care providers should be aware of the need for providing information to HIV positive youth in non-traditional formats. Health care providers may want to familiarize themselves with youth-friendly resources that are already available (e.g., http://www.livepositive.ca or http://www.youthhiv.org/). Referring youth clients to appropriate Web sources may be an important additional tool for health care providers and health promoters for supplementing 'regular care'. Finally, the onus is on e-health developers to better understand the needs of this vulnerable population and continue to expand and create appropriate, relevant and up-to-date content.

Acknowledgments

The authors thank the youth and community partners for their assistance in the data collection. This study was supported by a grant from the Ontario HIV Treatment Network.

Conflicts of Interest

None declared.

Appendix 1

Interview Guide

Goals: How can youth living with HIV be supported in achieving their goals?

- What are your hopes, goals, and aspirations for the future?
- What might help you to achieve your goals? What could you do for yourself?
- Have your goals changed as a result of learning your HIV status? How?
- What kinds of programs do you wish were around for young people like you?

Treatment: How can youth living with HIV be supported in making treatment or self-care decisions?

- How prepared do you feel to take care of your health?
- What kinds of problems do you face when taking care of your health?
- Do you feel like you have choices about treatment? Do you know what your choices are?
- What kind of information would you like on different treatment options for young people living with HIV/AIDS?
- What are some of the 'health topics' that you feel like learning more about?
- How can you be supported in making treatment or self-care decisions?
- What advice would you have for other HIV positive youth that are trying to make treatment decisions?

Support: How can youth living with HIV be supported?

- Where do you feel comfortable going for health information?
- Who do you turn to for moral/social support?
- How open are you about your HIV status with people in your life?
- Do you ever feel lonely or excluded because of your HIV status?
- Even though you are a diverse group of individuals - what common experiences do you think HIV+ youth might share?

Internet: How do youth living with HIV use the Internet?

- Do you ever use the Internet? What for? (Do you ever use it to get health info?)
- Do you know about any sites are out there for HIV+ youth? Do you use them? For what? Do you feel safe using them? Why/why not?
- If we were going to create a new Website for HIV positive youth in Canada - what sorts of things should we be sure to include? (What content/information would you like to see on the site? e.g. counselors, chat rooms, information)
- What would make you feel safe accessing it? Do you have a safe place to access it from? What sorts of things could we do to protect your privacy? (Would you feel safer accessing the site if it had a privacy/password age before you get to the homepage?)

Appendix 2

Coding Scheme

1. **Relationships**
    1. **To parents and family**
        1. Loving and supportive
        2. Antagonistic
        3. Abusive, dysfunctional
        4. Other
    2. **To health care providers**
        1. Faith - they know best
        2. Frustration
        3. Other
    3. **To other youth**
        1. Friends
        2. Other youth generally
        3. To other youth with HIV
        4. Other
    4. **To partners, lovers (boyfriend/girlfriend)**
    5. **To other institutions**
        1. Church & Spirituality
        2. ASO's
        3. Youth Orgs
        4. Youth Shelters
        5. Counsellors, Case workers
        6. Hospital clinics
        7. School
        8. Kids Help Phone
        9. Other
2. **Isolation, loneliness**
3. **Future**

   1. Living day by day (not future oriented)
   2. Uncertainty (in general)
   3. Long term vs. short term
   4. About health
   5. About relationships, partners
   6. About family of origin
   7. About starting own family
   8. About school
   9. About career, employment
   10. About financial stability
   11. About housing

4. **Goals changed**
   1. Yes - why
   2. No - why

5. **Feelings about HIV**
   1. I'm a normal kid - no big deal
   2. Regrets, Guilt
   3. Grief
   4. Shame - HIV as "dirty" or "foreign" or "bad"
   5. Angry, resentful
   6. Small part because I am overwhelmed with everything else
   7. Just is a small part of me
   8. "death sentence", feeling mortal
   9. conspiracy theories
   10. Stigma
   11. Acceptance or integration of HIV in life
   12. Other

6. **Life in shelters/Street Issues**
   1. Prostitution
   2. Drug use
   3. Abuse
   4. Hygiene
   5. Feelings about living in shelters
   6. Rules
   7. Panhandling
   8. Respect
   9. Other

7. **Issues around disclosure**
   1. Confidentiality
   2. Bad experiences/Stigma/Discrimination
   3. Good experiences
   4. Why should I tell you? (I wouldn't if I had a growth on my foot)
   5. Other

8. **Advice for other youth**
   1. Stay positive
   2. Think before you act
   3. Find people you trust
   4. Other

9. **Information**
   1. Want to know more about..
   2. Fear of finding out more...
   3. Lack of interest...
   4. Saturated (savvy about what is out there, accessing services)
   5. Where I go to get info

10. **Other health issues**

    1. Eating disorders
    2. Hygiene
    3. Vitamins, nutrition
    4. Addictions & substance use
    5. Violence/abuse
    6. Mental health issues
    7. Asthma
    8. STDs
    9. Cancer
    10. SARS
    11. Other

11. **Self-care stuff**
    1. Diet, vitamins, nutrition
    2. Exercise
    3. Sleep
    4. Choosing healthy, supportive relationships
    5. Taking care of yourself is tiring, exhausting, hard work
    6. Getting help
    7. Apathetic around self-care
    8. Alternative therapy (e.g., acupuncture)
    9. Other

12. **Knowledge, Attitudes & Behavior Around Medication**
    1. Why take it?
    2. Knowledgeable/Informed
    3. Have no choice
    4. Side effects & concerns
    5. Taking medicine as a young person
    6. Not ready for it
    7. Barriers to accessing meds
    8. Figuring out what is credible
    9. Avoiding it
    10. Adherence, interruption
    11. Other

13. **Coping Strategies**
14. **Level of Internet Usage, what people do (and don't do) online**
    1. Chat/communicate
    2. Entertainment
    3. Work (job or school)
    4. Health info

15. **Ideas for Website**
16. **Privacy, Safety and the Internet**
    1. Public Access Good
    2. Public Access Bad
    3. Private access
    4. Presentation of site
    5. Passwords and confidentiality
    6. Protection from prowlers
    7. The Internet as anonymous, safe
    8. The Internet as unsafe

References

1. ; UNAIDS. Report on the global HIV/AIDS epidemic. Geneva: UNAIDS; 2002.
2. ; UNICEF. Young People and HIV/AIDS: Opportunity in Crisis. New York: World Health Organisation (WHO); Oct 8, 2002.

3. ; Division of HIV/AIDS Epidemiology and Surveillance. HIV and AIDS in Canada: Surveillance Report to December 31, 2001. Ottawa: Health Canada Division of HIV/AIDS Epidemiology and Surveillance, Bureau of HIV/AIDS, STD and TB, Population and Public Health Branch; 2001.
4. ; Division of HIV/AIDS Epidemiology and Surveillance, Health Canada. HIV and AIDS in Canada, surveillance report to June 30, 2002. Ottawa: Division of HIV/AIDS Surveillance, CIDPC, Health Canada; 2002.
5. ; Center for Disease Control. Young People at Risk: HIV/AIDS Among America's Youth. Atlanta: Center for Disease Control; 2002:1-2.
6. ; Canadian AIDS Society. HIV/AIDS and Youth: assessing current activities and identifying partners for strategic planning. Survey Results. Ottawa: Canadian AIDS Society; 2000.
7. Wilson CM, Houser J, Partlow C, Rudy BJ, Futterman DC, Friedman LB; Adolescent Medicine HIV/AIDS Research Network. The REACH (Reaching for Excellence in Adolescent Care and Health) project: study design, methods, and population profile. J Adolesc Health 2001 Sep;29(3 Suppl):8-18. [Medline: 21421239] [doi: 10.1016/S1054-139X(01)00291-9]
8. Woods ER, Samples CL, Melchiono MW, Keenan PM, Fox DJ, Chase LH, et al. Boston HAPPENS Program: a model of health care for HIV-positive, homeless, and at-risk youth. Human immunodeficiency virus (HIV) Adolescent Provider and Peer Education Network for Services. J Adolesc Health 1998 Aug;23(2 Suppl):37-48. [Medline: 98376070] [doi: 10.1016/S1054-139X(98)00048-2]
9. Huba G, Hodgins A, Woods E, Kipke M, Fuedo R, Lothrop J, et al. A profile of adolescent women with or at high risk for HIV: personal and services needs. Presented at: The National Conference on Women with HIV; 1997 May; Los Angeles p. 178 (abstract no P2.24).
10. Rogers AS, Schwarz D, English A, Weissman G. Adolescent participation in clinical research: Eleven sites, one common protocol, eleven IRBs. J Adolesc Health 1998 Mar; 22(2):133.
11. Martinez J, Bell D, Sell R. Identifying HIV-positive youth and transitioning them into the health care system: Chicagoland HIV Risk Reduction Partnership for Youth (CHRRPY), Cook County Hospital. In: , editor; HIV/AIDS BureauHIV/AIDS Bureau. Lessons Learned: Innovations in the delivery of HIV/AIDS Services. Rockville: Human Resources and Services Administration (HRSA), The Special Projects of National Significance Program (SPNS); 2001. URL: ftp://ftp.hrsa.gov/hab/lessonslearned5.pdf
12. Huba GJ, Betru R, Hodgins A, Gelfand J, Kawata AK, Panter AT, et al. Adherence to protease inhibitor combination therapy among youth: a report from a focus group on issues for youth living with HIV. Culver City: The Measurement Group; 1997. URL: http://www.themeasurementgroup.com/pifocus.htm
13. ; PYO. Focus Group Responses. Toronto: Positive Youth Outreach, AIDS Committee of Toronto; 2000.
14. Dematteo D, Major C, Block B, Coates R, Fearon M, Goldberg E, et al. Toronto street youth and HIV/AIDS: Prevalence, demographics and risks. J Adolesc Health 1999 Nov; 44(5):358-366. [doi: 10.1016/S1054-139X(99)00059-2]
15. Elliott L, Blanchard J, Dinneer KI, et al. The Winnipeg injection drug epidemiology (WIDE) study. Canadian Journal of Infectious Diseases 1999; 10:46B.
16. ; Harder & Company Community Research. Mental Health Services and the Changing Needs of Youth. San Francisco: Health Initiatives for Youth; 1998.
17. Tenner AD, Trevithick LA, Wagner V, Burch R. Seattle YouthCare's prevention, intervention, and education program: a model of care for HIV-positive, homeless, and at-risk youth. J Adolesc Health 1998 Aug;23(2 Suppl):96-106. [Medline: 98376075] [doi: 10.1016/S1054-139X(98)00057-3]
18. Tan D. Needs Assessment for HIV-positive Youth: Final Report. Toronto: Positive Youth Outreach; Oct 2000:13.
19. Murphy DA, Moscicki AB, Vermund SH, Muenz LR. Psychological distress among HIV(+) adolescents in the REACH study: effects of life stress, social support, and coping. The Adolescent Medicine HIV/AIDS Research Network. J Adolesc Health 2000 Dec;27(6):391-398. [Medline: 20544782] [doi: 10.1016/S1054-139X(00)00158-0]
20. Remafedi G, Lauer T. The health and psychosocial status of HIV-seropositive youth in Minnesota. J Adolesc Health 1996 Apr;18(4):263-269. [Medline: 97013955] [doi: 10.1016/1054-139X(95)00170-W]
21. Rogers AS, Futterman DK, Moscicki AB, Wilson CM, Ellenberg J, Vermund SH. The REACH Project of the Adolescent Medicine HIV/AIDS Research Network: design, methods, and selected characteristics of participants. J Adolesc Health 1998 Apr;22(4):300-311. [Medline: 98222246] [doi: 10.1016/S1054-139X(97)00279-6]
22. Hymel MS, Greenberg BL. The Walden House Young Adult HIV project: meeting the needs of multidiagnosed youth. J Adolesc Health 1998 Aug;23(2 Suppl):122-131. [Medline: 98376078] [doi: 10.1016/S1054-139X(98)00060-3]
23. Travers R, Paoletti D. Responding to the support needs of HIV-positive lesbian, gay and bisexual youth. Can J Hum Sex 1999 Dec; 8(4):271-283.
24. Schultz JR, Butler RB, Mckernan L, Boelsen R; Haemophilia Behavioral Intervention Evaluation Project. Developing theory-based risk-reduction interventions for HIV-positive young people with haemophilia. Haemophilia 2001 Jan;7(1):64-71. [Medline: 21065425] [doi: 10.1046/j.1365-2516.2001.00458.x]
25. Milio N. Engines of Empowerment: Using Information Technology to Create Healthy Communities and Challenge Public Policy. Chicago: Health Administration Press; Feb 1, 1996.
26. Milio N. Public policy. Information technology and community health--invitation to innovation. J Prof Nurs 1991 May;7(3):146. [Medline: 91286564] [doi: 10.1016/8755-7223(91)90043-K]

27. Schuler D. New Community Networks: Wired for Change. New York: Addison-Wesley Pub (Sd); Apr 1, 1996.
28. James M, Rikert L. Working Together Online. Toronto: Web Networks; 1997.
29. Skinner H. Promoting Health through Organizational Change. San Francisco: Benjamin Cummings; Sep 14, 2001:404.
30. Skinner HA, Morrison M, Bercovitz K, Haans D, Jennings MH, Magdenko L, et al. Using the Internet to engage youth in health promotion. Int J Health Promot Educ 1997; IV:23-25.
31. Dryburgh H. Changing our ways: why and how Canadians use the Internet. Statistics Canada Catalogue no. 56F0006XIE. URL: http://www.statcan.ca/english/research/56F0006XIE/56F0006XIE.pdf
32. Lenhart A. Teenage life online: The rise of the instant-message generation and the Internet's impact on friendships and family relationships. Washington DC: Pew Internet & American Life Project; 2001. URL: http://207.21.232.103/PPF/r/36/report_display.asp
33. ; Kaiser Family Foundation. Generation Rx.com: How Young People Use the Internet for Health Information . Menlo Park: Kaiser Family Foundation; 2001. URL: http://www.kaisernetwork.org/health_cast/hcast_index.cfm?display=detail&hc=405
34. ; Environics Research Group. Young Canadians in a Wired World: the Students' View. Ottawa: Environics Research Group; 2001:1-97.
35. Gustafson DH, Hawkins R, Boberg E, Pingree S, Serlin RE, Graziano F, et al. Impact of a patient-centered, computer-based health information/support system. Am J Prev Med 1999 Jan;16(1):1-9. [Medline: 99111919] [doi: 10.1016/S0749-3797(98)00108-1]
36. Gustafson DH, Hawkins RP, Boberg EW, Mctavish F, Owens B, Wise M, et al. CHESS: 10 years of research and development in consumer health informatics for broad populations, including the underserved. Int J Med Inform 2002 Nov 12;65(3):169-177. [Medline: 22301851] [doi: 10.1016/S1386-5056(02)00048-5]
37. Brennan PF, Ripich S. Use of a home-care computer network by persons with AIDS. Int J Technol Assess Health Care 1994 Dec;10(2):258-272. [Medline: 94307832]
38. Reeves PM. Coping in cyberspace: the impact of Internet use on the ability of HIV-positive individuals to deal with their illness. J Health Commun 2000;5 Suppl(Suppl):47-59. [Medline: 20394543] [doi: 10.1080/10810730050019555]
39. Reeves PM. How individuals coping with HIV/AIDS use the Internet. Health Educ Res 2001 Dec;16(6):709-719. [Medline: 21639064] [doi: 10.1093/her/16.6.709]
40. Kalichman SC, Benotsch EG, Weinhardt L, Austin J, Luke W, Cherry C. Health-related Internet use, coping, social support, and health indicators in people living with HIV/AIDS: preliminary results from a community survey. Health Psychol 2003 Jan;22(1):111-116. [Medline: 22445387] [doi: 10.1037//0278-6133.22.1.111]
41. Kalichman SC, Weinhardt L, Benotsch E, Cherry C. Closing the digital divide in HIV/AIDS care: development of a theory-based intervention to increase Internet access. AIDS Care 2002 Aug;14(4):523-537. [doi: 10.1080/09540120220133044] [Medline: 22193370]
42. Kalichman SC, Weinhardt L, Benotsch E, Difonzo K, Luke W, Austin J. Internet access and Internet use for health information among people living with HIV-AIDS. Patient Educ Couns 2002 Feb;46(2):109-116. [Medline: 21856977] [doi: 10.1016/S0738-3991(01)00134-3]
43. Fox S, Rainie L. Vital decisions: How Internet users decide what information to trust when they or their loved ones are sick. Washington, DC: Pew Internet & American Life Project; 2002. URL: http://www.pewinternet.org/report_display.asp?r=59
44. Israel BA, Schulz AJ, Parker EA, Becker AB. Review of community-based research: assessing partnership approaches to improve public health. Annu Rev Public Health 1998;19(1):173-202. [Medline: 98274551] [doi: 10.1146/annurev.publhealth.19.1.173]
45. Minkler M, Wallerstein N, Hall B. Community-Based Participatory Research for Health. San Francisco: Jossey-Bass; Nov 15, 2002.
46. Kuzel A. Sampling in qualitative inquiry. In: Crabtree BF, Miller WL, editors. Doing Qualitative Research (Research Methods for Primary Care). Newbury Park: SAGE Publications; Apr 6, 1992:33-44.
47. Taylor SJ, Bogdan R. Introduction to Qualitative Research Methods: The Search for Meaning 2nd ed. New York: John Wiley and Sons; 1984.
48. Strauss AL, Corbin J. Grounded Theory Methodology: An Overview. In: Denzin NK, Lincoln YS, editors. Handbook of Qualitative Research. Thousand Oaks: SAGE Publications, Ltd: Thousand Oaks; 2000.
49. Strauss A, Corbin JM. Basics of Qualitative Research : Grounded Theory Procedures and Techniques. Newbury Park: Sage Publications; Sep 1, 1990.
50. Merriam SB. Qualitative Research and Case Study Applications in Education : Revised and Expanded from I Case Study Research in Education/I (Jossey Bass Education Series). San Francisco: Jossey-Bass; Sep 1, 1997.
51. Weitzman E, Miles MB. Computer programs for qualitatitve data analysis: a software sourcebook. Newbury Park: Sage Publications; 1994.
52. Skinner HA, Biscope S, Poland B. Goldberg, E. How Adolescents Use Technology for Health Information: Implications for Practitioners. J Med Internet Res 2003;5(4):e32 [FREE Full text] [doi: 10.2196/jmir.5.4.e32]
53. Skinner H, Biscope S, Poland B. Quality of internet access: barrier behind internet use statistics. Soc Sci Med 2003 Sep;57(5):875-880. [Medline: 22736020] [doi: 10.1016/S0277-9536(02)00455-0]

54. Kok G. Targeted prevention for people with HIV/AIDS: feasible and desirable? Patient Educ Couns 1999 Mar;36(3):239-246. [Medline: 22891259] [doi: 10.1016/S0738-3991(98)00141-4]

---

submitted 25.01.04; peer-reviewed by S Kalichman, J Gillett; comments to author 17.03.04; revised version received 21.06.04; accepted 22.06.04; published 29.09.04.

Please cite as:
Flicker S, Goldberg E, Read S, Veinot T, McClelland A, Saulnier P, Skinner H
HIV-Positive Youth's Perspectives on the Internet and eHealth
J Med Internet Res 2004;6(3):e32
URL: http://www.jmir.org/2004/3/e32/
doi:10.2196/jmir.6.3.e32
PMID:15471758

Original Paper

Reformulation of Consumer Health Queries with Professional Terminology: A Pilot Study

Robert M Plovnick[1], MS, MD; Qing T Zeng[1], PhD

Decision Systems Group, Brigham and Women's Hospital, Harvard Medical School, Boston MA, USA

Corresponding Author:
Robert M Plovnick, MS, MD
Brigham and Women's Hospital
Decision Systems Group, Thorn 310
75 Francis Street
Boston MA 02115
USA
Phone: +1 617 732 4950
Fax: +1 617 739 3672
Email: plovnick@dsg.harvard.edu

Abstract

Background: The Internet is becoming an increasingly important resource for health-information seekers. However, consumers often do not use effective search strategies. Query reformulation is one potential intervention to improve the effectiveness of consumer searches.

Objective: We endeavored to answer the research question: "Does reformulating original consumer queries with preferred terminology from the Unified Medical Language System (UMLS) Metathesaurus lead to better search returns?"

Methods: Consumer-generated queries with known goals (n=16) that could be mapped to UMLS Metathesaurus terminology were used as test samples. Reformulated queries were generated by replacing user terms with Metathesaurus-preferred synonyms (n=18). Searches (n=36) were performed using both a consumer information site and a general search engine. Top 30 precision was used as a performance indicator to compare the performance of the original and reformulated queries.

Results: Forty-two percent of the searches utilizing reformulated queries yielded better search returns than their associated original queries, 19% yielded worse results, and the results for the remaining 39% did not change. We identified ambiguous lay terms, expansion of acronyms, and arcane professional terms as causes for changes in performance.

Conclusions: We noted a trend towards increased precision when providing substitutions for lay terms, abbreviations, and acronyms. We have found qualitative evidence that reformulating queries with professional terminology may be a promising strategy to improve consumer health-information searches, although we caution that automated reformulation could in fact worsen search performance when the terminology is ill-fitted or arcane.

(J Med Internet Res 2004;6(3):e27) doi:10.2196/jmir.6.3.e27

KEYWORDS

Information retrieval; consumer informatics; Internet

Introduction

An ever-increasing number of patients and their family members are turning to the Internet for health information [1]. Recent survey reports suggest that at least half of the adults in the United States have searched for health information online [2]. Careful analysis of consumer information needs and preferences through the field of consumer health informatics is increasingly important to ensure that the information retrieval process is positive and effective [3]. Specifically, studying the variably effective search strategies and their associated performance could provide valuable insight for the development of future consumer health-information retrieval tools.

At present, it appears that most people who search the Internet are not using the most effective strategies. Spink et al analyzed one million queries from the log data of a popular Internet search engine and found that most people used short (mean 2.4 terms) and unmodified queries [4]. The one billion queries analyzed by Silverstein et al had a similarly small mean number of terms (2.35) [5]. Further, 77% of these search sessions consisted of just one query; this means a small minority of searchers modified their query after the first search. Although it cannot be ascertained what percentage of the logged searches were performed by humans rather than search robots, it is likely safe to conclude that Internet searchers are using short and therefore imprecise queries. Also, searchers are likely to quit after one search iteration instead of modifying their search to improve the results. Observational studies have shown that consumers specifically searching for health-care information employ the same suboptimal search strategies [6-8].

One potential tactic to address the problem of short and imprecise queries is to automatically alter the initial query for better returns, either by reformulation or expansion. Previous research, including a study that mapped consumer terms to an established medical vocabulary, has shown that there is a significant mismatch between consumers' health vocabulary and the terminology of the content [8]. Tse and Soergel's review of postings to online health discussion forums showed that a majority of consumer terms, although overlapping with professional terminology conceptually, often do not take the same form as technical terms [9]. This mismatch of consumer and medical content terminology could be partially bridged using query expansion, which has been shown to improve search performance both inside [10] and outside [11,12] the medical domain. Search behavior research has also demonstrated the difficulty that end-users have selecting query terms and illustrates the potential benefit of providing a thesaurus to suggest alternative queries and improve search [13,14]. Similarly, we theorize that reformulating queries to replace lay terms with the terminology more commonly used in medical content could potentially facilitate the delivery of relevant content to consumers.

To investigate the effect of query reformulation using standardized medical terminologies, we utilized original consumer health-information queries with explicit information needs and the Unified Medical Language System (UMLS) Metathesaurus [15], as the terminology source. We collected our search queries through interviews with consumers, and were thus able to ascertain the specific intention that led to the resulting free-text queries. This enabled a more objective assessment of the success of a given search. We studied the effect of reformulation in two different search spaces: the broad scope of a commercial search engine and the more limited scope of a single consumer health-information site. Survey data [16] and research [2,6] have shown that most consumers initiate their search for health information using a general search engine. However, although more limited in content, the information provided by a consumer information source like MedlinePlus [17] is of a more consistent quality, and the site receives 2 million queries per month by our own calculation of its log data. We were therefore interested in the effect of query reformulation in both of these settings. The research question addressed in this study is whether reformulating original consumer queries with preferred terminology from UMLS Metathesaurus lead to better search results.

Methods

Collection of Consumer Queries and Search Goals

Consumer queries and search goals were collected through an ongoing study we were conducting with patients and visitors recruited from public areas of Brigham and Women's Hospital, a large teaching hospital in Boston. Subjects described their health-information needs to the interviewer (RP). Each participant was then given the opportunity to search the Internet on a laptop computer to find the answer to his or her specific question or questions. The free-text queries generated by participants for these searches were recorded for further analysis. Search goals were recorded by the researcher based on interviews with the consumers.

Selecting Queries for Further Testing

Suitable substitutions for user-generated queries were generated using the UMLS Metathesaurus (release 2003AB). The Metathesaurus stores information about biomedical concepts compiled from numerous vocabularies and sources. Synonyms and inter-concept relationships are among the many attributes recorded for each concept, with one term chosen as the preferred English name for each concept. In this study, the search queries generated by consumers were hand-mapped to Metathesaurus-preferred concept names. For example, the consumer query "stroke" was deemed to be a synonym of the Metathesaurus concept "cerebrovascular accident." Some of the consumers' queries (eg, "chronic pain") were identical to the primary term used in the Metathesaurus. Only queries that were not equivalent to Metathesaurus preferred terms, and that therefore could be reformulated, were selected for this study.

Gold Standard Answer Generation

For each consumer question, a gold standard answer specific to the consumers' information needs was generated by an investigator with medical training (RP). Harrison's Online and MDConsult were the main resources used to create these answers. Gold standard answers were used to assess and compare the results generated from the Internet searches conducted for this study.

Query Reformulation

User queries were mapped to concepts in the UMLS Metathesaurus. Only queries that had at least one term found to be in the list of synonyms for a preferred concept name were selected for reformulation. Queries were reformulated by replacing the user term with the preferred synonym. Terms within queries that already corresponded to preferred concepts were left unaltered. For instance, the word "thyroid" was unchanged in the reformulation of the user query "thyroid abs test." Only one concept name was altered at a time. User queries that contained n-terms that could be mapped to preferred concepts thus led to the generation of n-reformulations, each with one user term replaced by the corresponding professional phrase. For example, two reformulations were generated from the user query "herbal treatment cancer": "herbal therapeutic aspects cancer" and "herbal treatment malignant neoplasms."

Query reformulation (altering the initial query), rather than query expansion (adding synonyms to the initial query), was the methodology chosen for this study. Metathesaurus-based query expansion has been shown to cause a decline in search performance [18]. Imprecise or arcane synonyms such as "blastoma, NOS" for the concept "malignant neoplasms" and "apoplectic fit" for the concept "cerebrovascular accident" could dilute the original intention of a given query and decrease retrieval performance.

Internet Search Using Original Consumer Queries and Reformulated Queries

Both the original consumer-generated queries and the reformulated queries were used to initiate controlled searches in two different search spaces: the more health-specific MedlinePlus and the broader range of content covered by a Google search.

MedlinePlus is a high-quality consumer-health site provided by the National Library of Medicine. The continuously updated content of this noncommercial site, organized by health topic, includes information on over 600 diseases and conditions, as well as a medical encyclopedia and information on prescription drugs [17]. Links to additional resources from the National Institutes of Health and other trusted sources are also presented.

Google [19] is currently a leading search engine. It provides access to over 3 billion indexed Web pages. Its proprietary search algorithm ranks the relevance of Web pages based in part on the number of links made to the page from other sites, and on characteristics of the page itself. The authority of referring pages is also considered in determining the rank of a page [20]. Among advanced search features available is the ability to limit searches using the Google engine to specific Web sites; this feature was employed for our study.

We used both the consumers' original queries and the modified queries to conduct Internet searches. Quotation marks were placed on each end of the query text (eg, the search query for flat head was "flat head"). The Google search engine was used to search both the consumer health-oriented site (MedlinePlus) and the general Internet (Google). Searches using the search engine included on the MedlinePlus site yielded several lists of results organized by health topic, whereas Google-initiated searches yielded a single list ordered by relevance. The Google search engine was utilized so that search results would be identically formatted and therefore more suited for comparison. Every search was limited to English language pages using Google's "Advanced Search" language feature.

Standard information, such as the date and the total number of results, was recorded for every search. The first 30 hits of every search, the number of documents that users are reasonably willing to look at after a search [18], were assessed for the presence of the gold standard answer to the participant's original question. A result page was considered to contain the gold standard answer if

1. the answer could be found by following no more than one link from the initial page
2. at least 90% of the established gold standard answer was present (for questions whose answers were lists, such as stroke risk factors)
3. for questions whose goal was to obtain general information about a topic, the page contained at least one correct fact pertinent to the health topic.

The total number of assessed hits containing the gold standard answer was recorded and the fraction of the assessed hits containing the gold standard answer (out of no more than 30) was calculated. This figure was used as an estimate of precision and was used for comparison of searches. Queries that returned no result or results that contained no gold standard answer failed to satisfy users' information needs, although we do recognize that there can be true negatives and returning results that do not contain the right information may misinform users and cost time to process. For the convenience of performance comparison of all queries, when no result was returned, the top 30 precision was assigned 0 in this study. True negative rates, however, are examined for those queries that failed to return any result. To determine true negative rates, the investigators conducted numerous searches of MedlinePlus and Google and browsed the concept-specific content of MedlinePlus to search for the gold standard answer. Substitutions that seemed to improve results versus those that did not were examined for reasons. Additionally, the queries and search results were examined for general qualitative trends.

Results

A total of 16 queries were selected for substitution from an initial pool of 46 queries. Eighteen replacement queries were generated. The original queries and their substitutions are summarized in Table 1. Each query (consumer or reformulation) was used to conduct two Internet searches, for a total of 68 searches: 34 in MedlinePlus and 34 in Google. In all, 926 individual search result pages were examined. Of the 68 searches, 23 did not yield any results. The text of these queries is listed in Table 2, and the distribution of the searches in MedlinePlus and Google is illustrated in Figure 1. Nine of these empty searches were generated using the consumers' original queries and 14 were based on reformulated queries; 19 were in MedlinePlus and 4 were in Google. In other words, using original queries in Google resulted in the least number of searches (only 1) with no returns. To put this result into perspective, we found that MedlinePlus contained the gold standard answer for 15 of the 19 failed queries (79%), and Google contained the answer for all 4 of the searches that had no returns (100%). In other words, among the queries that did not return any result, the true negative rate is 21% for MedlinePlus and 0% for Google.

Table 1. Consumer queries (n=16) with reformulated queries (n=18) and search goals

Participant's Question	**Query Text** *(reformulated queries in italics)*	**Precision of Search** *0 - No retrieved documents with gold standard answer* *Ø - No retrieved documents*
		MedlinePlus Google
Are there any natural substitutes for the hormone replacement therapy agent Prempro?	natural alternative hrt *natural alternative hormone replacement therapy*	
	natural hrt *natural hormone replacement therapy*	
Are there support groups for restless legs syndrome?	restless leg syndrome *restless legs syndrome*	
General information about heart transplants	heart transplant *heart transplantation*	
General information about petit mal seizures	petit mal seizure *epilepsy, absence*	
General information about plagiocephaly	flat head *plagiocephaly*	
How are arrhythmias treated?	heart arrhythmia treatment *arrhythmia treatment* *heart arrhythmia therapeutic aspects*	
How are the results of the anti-TPO thyroid lab test interpreted?	thyroid abs test *thyroid antibody studies*	
How do problems with the heart's electric system lead to shortness of breath?	heart electric *heart conduction system*	
Is there treatment for restless legs syndrome?	restless leg syndrome *restless legs syndrome*	
What are scientifically validated treatments for cancer?	herbal treatment cancer *herbal therapeutic aspects cancerherbal treatment malignant neoplasms*	
What are the risk factors for stroke?	stroke *cerebrovascular accident*	
What are the side effects of Lexapro?	ssri *selective serotonin re-uptake inhibitor*	
What causes heart flutters (palpitations)?	heart flutters *fluttering heart*	
What foods should be avoided to prevent cavities in children?	cavity *dental caries*	
Why can't you have an MRI with a pacemaker?	contraindications mri *contraindications magnetic resonance imaging*	

Figure 1. Distribution of searches with no returns (n=23) (M = MedlinePlus, G = Google)

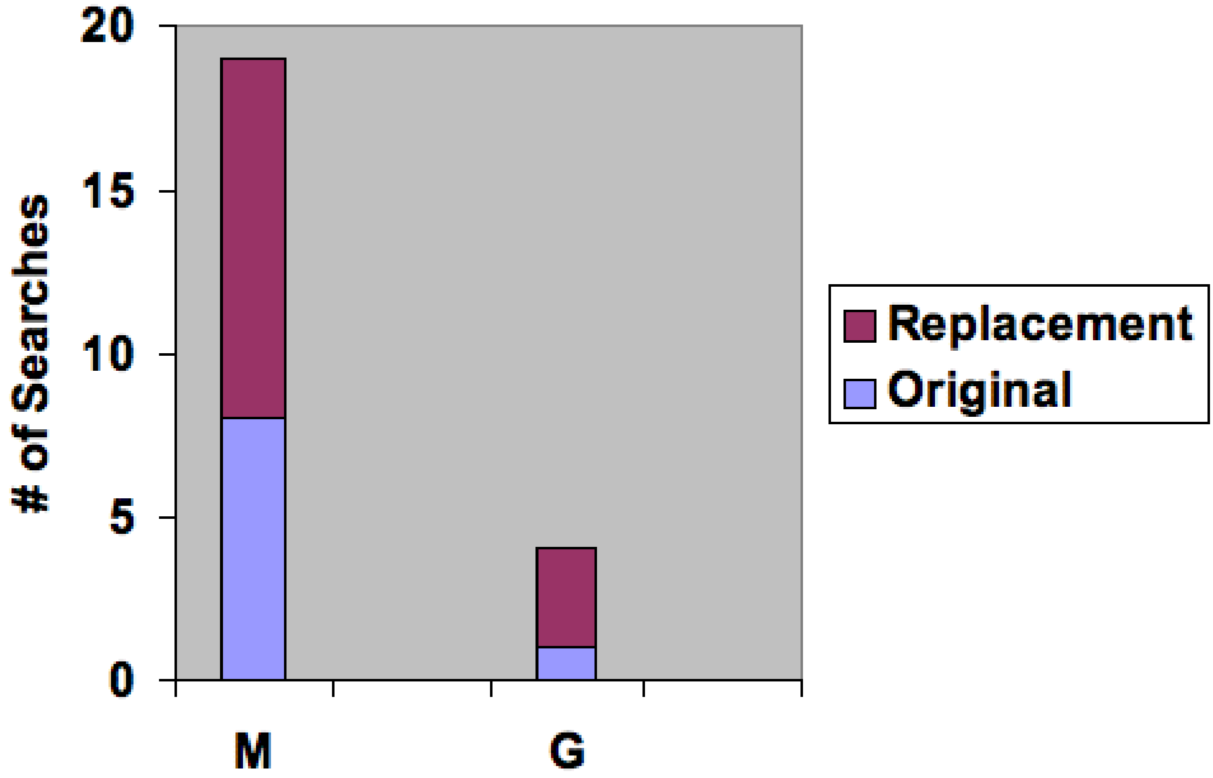
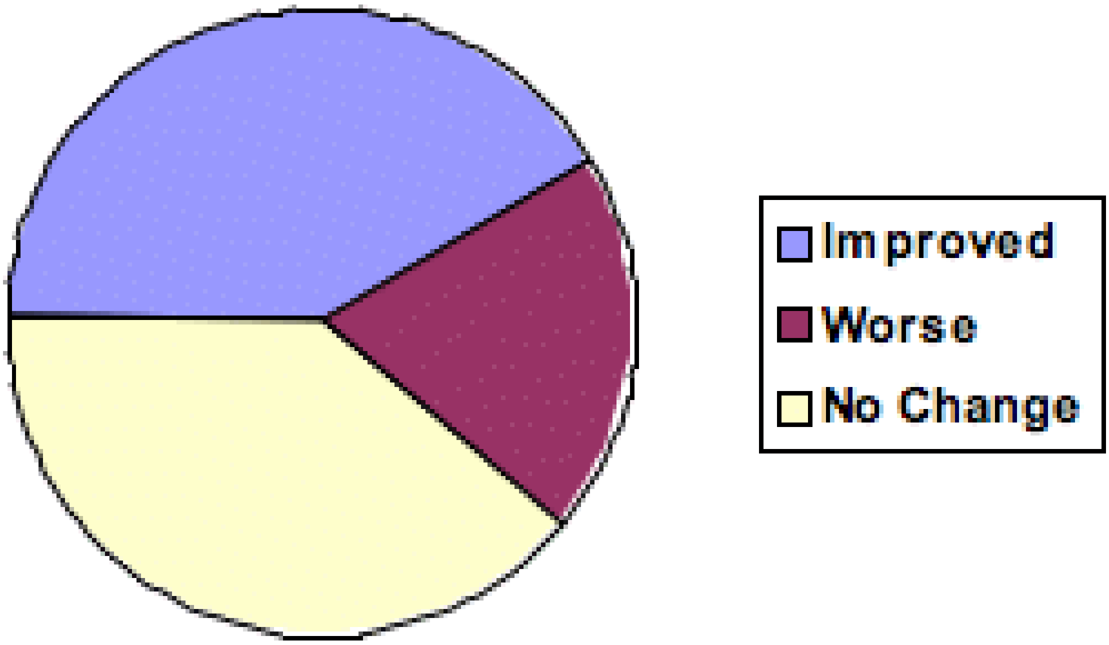


Table 2. Searches that did not yield any returns (n=23) G signifies search in Google, and M indicates a search of MedlinePlus

Query Text	Original (O) or Replacement (R)?	Search Scope
"contraindications mri"	O	M
"heart arrhythmia treatment"	O	M
"heart electric"	O	M
"heart flutters"	O	M
"herbal treatment cancer"	O	M
"natural alternative hrt"	O	M
"natural hrt"	O	M
"thyroid abs test"	O	M, G
"arrhythmia treatment"	R	M
"contraindications magnetic resonance imaging"	R	M
"epilepsy, absence"	R	M
"fluttering heart"	R	M
"heart arrhythmia therapeutic aspects"	R	M, G
"herbal therapeutic aspects cancer"	R	M, G
"herbal treatment malignant neoplasms"	R	M, G
"natural alternative hormone replacement therapy"	R	M
"natural hormone replacement therapy"	R	M
"selective serotonin re-uptake inhibitor"	R	M
"thyroid antibody studies"	R	M

Figure 2. Performance of reformulated queries (n = 36)



The main measure of the success of a search was the percentage of the first 30 resulting pages that contained the gold standard answer (top 30 precision). For example, 10 of the first hits of the MedlinePlus search for "stroke" contained enough of the established stroke risk factors to qualify as gold standard. The search had precision of 33% (10/30). By contrast, the Google search for "thyroid antibody studies" yielded only 11 hits. Of these 11, 3 contained the requested information regarding the anti-TPO lab test. This search therefore had a precision of 27% (3/11). As mentioned previously, when a query generated no result, its top 30 precision was set to 0. The precision values for all 68 searches (mean = 0.22, SD = 0.32) are presented in Table 1. The mean precision for all searches in MedlinePlus was 0.23 (SD = 0.37) and the mean precision for searches in Google was 0.21 (SD = 0.26).

Using precision as a performance indictor, 15 of the 36 searches using reformulated queries yielded better returns than their associated original queries (5 in MedlinePlus and 10 in Google). Seven of the searches using reformulated queries showed a worse performance than the original substitution as indicated by precision (4 MedlinePlus and 3 Google). The performance of the remaining 14 searches was unchanged by reformulation. Table 3 shows how the individual queries performed, and Figure 2 summarizes the relative performance of the reformulated queries.

Table 3. Search performance after reformulation. Original queries are listed either as improved, worse, or no change with substitution. G signified search in Google and M indicates a search of MedlinePlus

Query Text	Replacement Text	Search Space(s)
Improved with Reformulation		
"cavity"	"dental caries"	G, M
"flat head"	"plagiocephaly"	G, M
"heart arrhythmia treatment"	"arrhythmia treatment"	G
"heart electric"	"heart conduction system"	M
"heart transplant"	"heart transplantation"	G
"natural hrt"	"natural hormone replacement therapy"	G
"restless leg syndrome"	"restless legs syndrome"	G, M
"restless leg syndrome"	"restless legs syndrome"	G
"ssri"	"selective serotonin re-uptake inhibitor"	G
"stroke"	"cerebrovascular accident"	G, M
"thyroid abs test"	"thyroid antibody studies"	G
Worse with Reformulation		
"heart electric"	"heart conduction system"	G
"heart transplant"	"heart transplantation"	M
"petit mal seizure"	"epilepsy, absence"	G, M
"restless leg syndrome"[2]	"restless legs syndrome"	M
"heart arrhythmia treatment"	"heart arrhythmia therapeutic aspects"	G
"ssri"	"selective serotonin re-uptake inhibitor"	M
No Change with Reformulation		
"contraindications magnetic resonance imaging"	"contraindications mri"	G, M
"heart arrhythmia treatment"	"arrhythmia treatment"	M
"heart arrhythmia treatment"	"heart arrhythmia therapeutic aspects"	M
"heart flutters"	"fluttering heart"	G, M
"herbal treatment cancer"	"herbal therapeutic aspects cancer"	G, M
"herbal treatment cancer"	"herbal treatment malignant neoplasms"	G, M
"natural alternative hrt"	"natural alternative hormone replacement therapy"	G, M
"natural hrt"	"natural hormone replacement therapy"	M
"thyroid abs test"	"thyroid antibody studies"	M

Three reasons for changes in retrieval performance (precision) were identified: First, several consumer searches using ambiguous lay terms were improved when reformulated with professional terminology. This trend was noted both in MedlinePlus and in Google. Second, searches based on queries utilizing acronyms were improved in the Google scope when they were expanded to full phrases. Third, certain queries containing professional terms that were arcane or contextually ill-fitted to the users' original search goals performed worse than the original queries.

Discussion

Significance and Implication

Conducting Internet searches with reformulated consumer queries allowed us to note qualitative trends in query reformulation with professional terminology: it often helped to improve query performance by reducing ambiguity and increasing distinguishing power, but sometimes reduced query performance when the professional terms were arcane or ill-fitted. The reformulated queries also often had no impact on performance. Approximately 35% of the consumer queries we collected did not use UMLS-preferred names for concepts and were thus suitable for reformulation. This represents a substantial portion of the original sample queries that could potentially be affected by the reformulation approach.

Benefit of Query Reformulation

In 15 of 36 instances, the replacement queries yielded better results than the originals (as indicated by top 30 precision and taking into account the queries that did not generate any results). Searches using queries that utilized ambiguous lay terms such as "cavity," "flat head," and "stroke," were improved when replaced with professional terms ("dental caries," "plagiocephaly," and "cerebrovascular accident," respectively). These searches improved in both the health-specific scope of MedlinePlus and the broader Google domain. One participant used the ambiguous query "flat head" to search for information about plagiocephaly (infant cranial asymmetry). Many of the sites listed after the "flat head" search in Google utilized non-medical interpretations of the phrase (screwdrivers, screws, and even a guitar). In fact, only 2 of the first 30 hits contained contextually appropriate information. The search for "plagiocephaly," however, yielded better results than the ambiguous term "flat head": 25 of 30 hits were contextually correct.

It is important to note that many medical sites do employ lay terms. However, professional terms tend to have better distinguishing power in locating medical contents. For example, many of the "plagiocephaly" pages contained the phrase "flat head," while sites about screwdrivers or guitars do not contain the word "plagiocephaly." These medical sites using "flat head" were clearly outnumbered by pages using "flat head" in a non-medical context, and were therefore almost entirely absent from the "flat head" Internet search.

Acronyms or abbreviations are likely to introduce ambiguity to queries and thus can benefit from reformulation. Searches composed of acronyms or initialisms (eg, "SSRI" for selective serotonin reuptake inhibitor and "HRT" for hormone replacement therapy) or abbreviations (eg, "abs" for antibodies) fared better when reformulated with the full phrase. This trend was noted only in the broader Google domain. This is not surprising because there is a much greater chance of the existence of a non-medical meaning of these short terms in the broader scope of Google than in the exclusively medical scope of MedlinePlus. For instance, in addition to being a drug class, SSRI is also a pop band, an institute, and a stock abbreviation. Links interpreting SSRI in all of these ways were found in the first 30 Google search results. The search for "selective serotonin re-uptake inhibitor," by contrast, eliminated pages with these alternatives. The MedlinePlus search for "selective serotonin re-uptake inhibitor," however, yielded no results, due in part to the lack of an exact text match with the hyphenated spelling of the work "reuptake." Removing the ambiguity of acronyms and abbreviations from queries improved the performance of Internet searches conducted with the general search engine.

Disadvantage of Query Reformulation

In 7 of 36 instances, search performance was worse when the original consumer queries were replaced with alternate phrases. Four of these were conducted in the MedlinePlus domain, and three were in Google. It is not surprising that one of these searches, "petit mal seizure," performed worse when replaced with "epilepsy, absence," the Metathesaurus-preferred term. The consumer's question was about a medical event, a seizure, and the reformulated query referred to the disease that causes the event. Although altered less dramatically, the queries "heart transplant" and "restless leg syndrome" also performed considerably worse when reformulated. The arcane term "therapeutic aspects" replaced "treatment" in the query "heart arrhythmia treatment," which contributed to a decrease in precision in the Google search. We are aware of other concepts, not among the 16 consumer queries, with arcane preferred names in UMLS. For instance, "pes," is the Metathesaurus preferred term for "foot." These examples illustrate that an automated query-replacement process would have the potential for flawed substitutions. Presenting a search term that produces worse results than an information seeker's original query could lead to great frustration for the seeker.

Content Scope and Quality

The role of query reformulation appears to be more significant for a large content scope that for a health-care specific site simply because there is more room for ambiguity when the scope is extremely large. However, an aspect that we did not measure in this study is the rate of misinformation. Combing through almost 1000 sites allowed for general observations about the reliability and quality of the information presented to consumers after an Internet search. Using a general search engine like Google, we encountered a great number of sites with misleading or biased information. For instance, the Google search for "natural hormone replacement therapy" resulted in several pages selling "cures" for aging. Similarly, Web sites promoting alternative therapies for cancer have been found to be of dubious quality [21].

Unfortunately, searching within the domain of a single high-quality consumer site is not without disadvantages. Because a single site contains a small fraction of the information available on the general Internet, the chance of a finding the desired information is diminished. In this study, for example, although all searches were conducted in both MedlinePlus and Google, there were twice as many searches with at least one result in Google (n=30) as in MedlinePlus (n=15). The true negative rate for MedlinePlus (21%) was considerably higher than that for Google (0%), further emphasizing that medical sites, though providing a more consistent quality of information, will not contain the answer a percentage of consumers' queries. We have written a manuscript comparing medically specific and general search scopes, which discusses the pros and cons of each based on a separate study. Resolving the trade-off between quality and breadth of information remains a major challenge to successful consumer information retrieval.

Advantages to Queries With Known Goals

There are advantages to assessing health-related Web searches in this manner. The information needs of the consumer are explicit because they have been obtained from direct interviewing. When queries are obtained from log data, the intentions of the consumer are open to conjecture. The information needs of the query "flat head," for example, would prove difficult to guess without the context of an interview.

Although many of the users had very precise goals, the queries they formulated contained little more than the name of the disease or condition in question. In one search, the participant had a question specific to the medication Lexapro but did not even include the drug name in the search. Without the interview, it would be impossible to guess that the consumer searching with the query "restless leg syndrome" was specifically looking for pharmacologic treatment of that condition. These observations provide further evidence to the reported observation that consumers are producing short, imprecise queries. The type of detailed analysis employed in this study provides a more precise picture of the needs of health-information seekers in the hope of facilitating well-informed system development.

Limitations

The relatively small number of available sample queries with known goals limited the analysis to qualitative review instead of a statistically significant quantitative measure of search precision. The numbers of queries available for reformulation was further limited by the requirement that the original term not be a Metathesaurus preferred concept name. Not surprisingly, many participants used preferred concept drug and disease names for their initial searches. Further, even with a direct interview, some of the participants' information needs could not be expounded beyond the general desire for more information.

The gold standard answer presents another limitation. Because each site presents information differently, it is not possible to apply identical standards from site to site. This form of assessment, though time-consuming, is far more detailed than merely searching for the presence of the term.

Using quotation marks for queries was a major factor contributing to the number of searches that did not return results. We chose to utilize quoted query phrases so we could assess the impact of the phrase as a whole rather than the individual words, which each play a separate part in the search when not contained by quotation marks.

The method used to search MedlinePlus had one further limitation. This site was searched using Google instead of the search engine included with the site. The search results are not the same when the MedlinePlus search mechanism is used instead of Google. We did not intend to assess the performance of MedlinePlus but rather to study the impact of query reformulation in the narrower and specifically medical scope of a consumer health-information site as well as the much broader swath of the Internet covered by Google.

Further Study

We are in the process of

1. expanding our database of user queries with known intent
2. conducting a study with similar methods of patients in an asthma center to assess the specific information needs and search strategies of a specific health consumer population
3. developing a search tool that provides suggested search queries based on the initial search entered by a user.

Conclusion

We investigated the effect of reformulating consumer health queries using professional terminology. This study has shown some qualitative evidence that reformulating queries with professional terminology may be a promising strategy to improve consumer health-information searches. After taking original queries with clearly defined goals from health-information consumers and replacing the search text with phrases from medical vocabulary, we noted a trend towards increased precision when providing substitutions for lay terms, abbreviations, and acronyms. This improvement was noted both in searches conducted in the narrower scope of a consumer health site and in searches of a much broader portion of the Internet using the popular search engine Google. We caution, however, that automated reformulation could in fact worsen search performance when the terminology is ill-fitted or arcane.

Acknowledgments

This work was funded by training grant LM07092 and grant R01 LM07222, both from the National Library of Medicine.

Conflicts of Interest

None declared.

References

1. Cline RJ, Haynes KM. Consumer health information seeking on the Internet: the state of the art. Health Educ Res 2001 Dec;16(6):671-692. [Medline: 21639062] [doi: 10.1093/her/16.6.671]
2. Fox S, Fallows D. Internet health resources: Health searches and email have become more commonplace, but there is room for improvement in searches and overall Internet access. In: Pew Internet & American Life Project Jul 16, 2003. URL: http://www.pewinternet.org/pdfs/PIP_Health_Report_July_2003.pdf
3. Eysenbach G. Consumer health informatics. BMJ 2000 Jun 24;320(7251):1713-1716 [FREE Full text] [Medline: 20323060] [doi: 10.1136/bmj.320.7251.1713]
4. Spink A, Wolfram D, Jansen BJ, Saracevic T. Searching the Web: the public and their queries. J Am Soc Inf Sci Tec 2001;52(3):226-234.
5. Silverstein C, Henzinger M, Marais H, Moricz M. Analysis of a very large web search engine query log. SIGIR Forum 1999;33(3):6-12.

6. Eysenbach G, Köhler C. How do consumers search for and appraise health information on the world wide web? Qualitative study using focus groups, usability tests, and in-depth interviews. BMJ 2002 Mar 9;324(7337):573-577 [FREE Full text] [PMC: 11884321] [Medline: 21881326] [doi: 10.1136/bmj.324.7337.573]
7. Kogan S, Zeng Q, Ash N, Greenes RA. Problems and challenges in patient information retrieval: a descriptive study. Proc AMIA Symp 2001:329-333. [Medline: 21684201]
8. Zeng Q, Kogan S, Ash N, Greenes RA, Boxwala AA. Characteristics of consumer terminology for health information retrieval. Methods Inf Med 2002;41(4):289-298. [Medline: 22312863]
9. Tse T, Soergel D. Exploring medical expressions used by consumers and the media: An emerging view of consumer health vocabularies. Proc AMIA Symp 2003:674-678 [FREE Full text]
10. Aronson AR, Rindflesch TC. Query expansion using the UMLS Metathesaurus. Proc AMIA Annu Fall Symp 1997:485-489. [Medline: 98020544]
11. de Lima EF, Pedersen JO. Phrase recognition and expansion for short, precision-biased queries based on a query log. In: Proc SIGIR. Berkley, CA; 1999:145-152.
12. Alemayehu N. Analysis of performance variation using query expansion. J Am Soc Inf Sci Tec 2003;54(5):379-391. [doi: 10.1002/asi.10217]
13. Shiri AA, Revie C, Chowdhury G. Thesaurus-enhanced search interfaces. J Inform Sci 2002;28(2):111-122.
14. Shiri AA, Revie C, Chowdhury G. Thesaurus-assisted search term selection and query expansion: a review of user-centered studies. Knowl Organ 2002;29(1):1-19.
15. ; National Library of Medicine. UMLS Metathesaurus. URL: http://www.nlm.nih.gov/research/umls/ [accessed 2003 Oct-Nov]
16. Fox S, Rainie L. The online health care revolution: How the Web helps American take better care of themselves. Pew Internet & American Life Project. 2000 Nov 26. URL: http://www.pewinternet.org/pdfs/PIP_Health_Report.pdf
17. ; National Library of Medicine. Medline Plus. URL: http://www.nlm.nih.gov/medlineplus/ [accessed 2003 Nov]
18. Hersh W, Price S, Donohoe L. Assessing thesaurus-based query expansion using the UMLS Metathesaurus. Proc AMIA Symp 2000:344-348 [FREE Full text] [Medline: 21027376]
19. ; Google. Google. URL: http://www.google.com/ [accessed 2003 Nov]
20. De GG. Perspectives on the Web and Google: Monika Herzinger, Director of Research, Google. Journal of Internet Cataloging 2002;5(1):17-28.
21. Ernst E, Schmidt K. 'Alternative' cancer cures via the Internet? Br J Cancer 2002 Aug 27;87(5):479-480. [doi: 10.1038/sj.bjc.6600513] [Medline: 22176340]

Abbreviations

UMLS: Unified Medical Language System

submitted 26.04.04; peer-reviewed by T Tse; comments to author 17.05.04; revised version received 11.06.04; accepted 15.06.04; published 03.09.04.

Please cite as:
Plovnick RM, Zeng QT
Reformulation of Consumer Health Queries with Professional Terminology: A Pilot Study
J Med Internet Res 2004;6(3):e27
URL: http://www.jmir.org/2004/3/e27/
doi:10.2196/jmir.6.3.e27
PMID:15471753

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org