Medicine 2.0

Official proceedings publication of the Medicine 2.0 Congress
Volume 2 (2013), Issue 2 ISSN 1923-2195

Contents

Original Papers

Acceptance of E-Learning Devices by Dental Students (e6)
Peter Schulz, Keyvan Sagheb, Harald Affeldt, Hannah Klumpp, Kathy Taylor, Christian Walter, Bilal Al-Nawas. . . . 3

How Twitter Is Studied in the Medical Professions: A Classification of Twitter Papers Indexed in PubMed (e2)
Shirley Williams, Melissa Terras, Claire Warwick. . . . 8

Developing a Framework to Generate Evidence of Health Outcomes From Social Media Use in Chronic Disease Management (e3)
Mark Merolli, Kathleen Gray, Fernando Martin-Sanchez. . . . 24

Health Care Social Media: Expectations of Users in a Developing Country (e4)
Amrita, Dhrubes Biswas. . . . 31

Live Long and Prosper: Potentials of Low-Cost Consumer Devices for the Prevention of Cardiovascular Diseases (e7)
Jochen Meyer, Andreas Hein. . . . 40

The Ligurian Human Immunodeficiency Virus Clinical Network: A Web Tool to Manage Patients With Human Immunodeficiency Virus in Primary Care and Multicenter Clinical Trials (e5)
Paolo Fraccaro, Valeria Pupella, Roberta Gazzarata, Chiara Dentone, Giovanni Cenderello, Pasqualina De Leo, Federica Bozzano, Giorgetta Casalino Finocchio, Andrea De Maria, Daniela Fenoglio, Gilberto Filaci, Michele Guerra, Antonio Di Biagio, Eugenio Mantia, Giancarlo Orofino, Giuseppe Ferrea, Claudio Viscoli, Mauro Giacomini. . . . 49

Validity and Reliability of the eHealth Analysis and Steering Instrument (e8)
Olivier Blanson Henkemans, Elise Dusseldorp, Jolanda Keijsers, Judith Kessens, Mark Neerincx, Wilma Otten. . . . 60

Development of a Questionnaire and Cross-Sectional Survey of Patient eHealth Readiness and eHealth Inequalities (e9)
Ray Jones. . . . 74

eHealth Technology Competencies for Health Professionals Working in Home Care to Support Older Adults to Age in Place: Outcomes of a Two-Day Collaborative Workshop (e10)
Ansam Barakat, Ryan Woolrych, Andrew Sixsmith, William Kearns, Helianthe Kort. . . . 93

Clinicians' Assessment of Mobile Monitoring: A Comparative Study in Japan and Spain (e11)
Shintaro Okazaki, José Castañeda, Silvia Sanz. . . . 105

Participatory Design With Seniors: Design of Future Services and Iterative Refinements of Interactive eHealth Services for Old Citizens (e12)

Isabella Scandurra, Marie Sjölinder. 110

Embedding a Learning Management System Into an Undergraduate Medical Informatics Course in Saudi Arabia: Lessons Learned (e13)

Nasriah Zakaria, Amr Jamal, Shekhar Bisht, Cristina Koppel. 120

Original Paper

Acceptance of E-Learning Devices by Dental Students

Peter Schulz[1], DMD; Keyvan Sagheb[1], MD, DMD; Harald Affeldt[2]; Hannah Klumpp[2]; Kathy Taylor[3]; Christian Walter[1], MD, DMD, PhD; Bilal Al-Nawas[1], MD, DMD, PhD

[1]Department of Oral and Maxillofacial Surgery, University Medical Center, Johannes Gutenberg University, Mainz, Germany
[2]Ressort Research and Teaching, University Medical Center, Johannes Gutenberg University, Mainz, Germany
[3]Institute for Medical Biometry, Epidemiology and Informatic, University Medical Center, Johannes Gutenberg University, Mainz, Germany

Corresponding Author:
Peter Schulz, DMD
Department of Oral and Maxillofacial Surgery
University Medical Center
Johannes Gutenberg University
Building 901
Augustusplatz 2,
Mainz, 55116
Germany
Phone: 49 613170 ext 38
Fax: 49 61316602
Email: schulzpe@uni-mainz.de

Abstract

Background: E-Learning programs and their corresponding devices are increasingly employed to educate dental students during their clinical training.

Objective: Recent progress made in the development of e-learning software as well as in hardware (computers, tablet PCs, smartphones) caused us to more closely investigate into the habits of dental students in dealing with these learning techniques.

Methods: Dental students during their clinical training attended a survey compiled in cooperation with biostatisticians. The questionnaire probands were asked to complete based on previous surveys of similar subjects, allowing single as well as multiple answers. The data, which were obtained with respect to the learning devices students commonly employ, were compared with their internet learning activities.

Results: The e-learning devices utilized are of heterogeneous brands. Each student has access to at least one hardware type suitable for e-learning. All students held mobile devices, about 90 percent employed laptops, and about 60 percent possess smartphones. Unexceptional all participants of the survey acknowledged an unlimited internet access. In contrast, only 16 percent of students utilized tablet PCs. A detailed analysis of the survey outcome reveals that an increasing use of mobile devices (tablet PC, smartphone) facilitates internet learning activities while at the same time utilization of computers (desktop, laptop) declines.

Conclusions: Dental students overwhelmingly accept e-learning during their clinical training. Students report outstanding preconditions to conduct e-learning as both their access to hardware and to the internet is excellent. Less satisfying is the outcome of our survey regarding the utilization of e-learning programs. Depending of the hardware employed only one-third to barely one-half of students comprise learning programs.

(Med 2.0 2013;2(2):e6) doi:10.2196/med20.2767

KEYWORDS

e-learning activity; computer; tablet PC; smartphone, Internet

Introduction

The use of electronic devices in dental medicine for patient care, teaching, and learning, respectively, has been widely accepted [1-3]. As consequence of this development it became evident in recent years that internet-based learning increased its attraction for students at large [4,5], including those of dental medicine [6,7]. However, utilization of these new media depends on several criteria, specifically on the availabilty of a convenient hard and software as well as access to a high speed internet [8]. In this context authors repeatedly refer to the Web 2.0 as a basic social software for a successful implementation of e-learning [9].

The new generation of mobile phones and tablet personal computers (PCs) appears to perfectly adapt to the general framework of e-learning techniques presently available [10]. Taking account of these facts this investigation pursues two major issues. First, we examined current e-learning activities of dental students with reference to their use of specific e-learning devices that are desktop computers, tablet PCs (iPads), and smartphones, respectively. Second, probands were also questioned regarding a preferred utilization of commonly available teaching programs, which can possibly be linked to special e-learning devices.

Methods

Dental students (n=141) in their second and third clinical semester of the University Mainz were asked to attend an optional survey, nobody refused. No student was excluded since all of them met essential criteria such as mastering the German language and complying with basic technological literacy regarding the electronic devices here under discussion. Probands were encouraged to request assistance in case they believe the questionnaire implies ambiguous issues. The participants were invited to independently complete a machine-readable form within 20 minutes. This procedure appears superior over online surveys as an increased reliability of results may be expected [11].

The queries put emphasis on different domains of learning preferences as well as on hardware devices individual students had access to. The inquiry schedule also considers previously conducted surveys regarding the percentage of internet-based learning [6], and allows single as well as multiple answers. Table 1 displays an outline of the questionnaire the probands were confronted with.

Further information was requested concerning the operation systems (OS) the devices are equiped with (Table 1, question 4), as 2 OSs are mainly installed on hardware devices. That is the OS introduced by Apple (Apple Inc., Cupertino, CA, USA) for iPhones or iPads (iOS), and the Android OS provided by Google (Google Inc., Mountain View, CA, USA). The market share for the year 2012 in Germany of both OSs reveals a 77% rate for iOS and 19% for Android OS [12]. Evaluation of question 2, considers the quantity of students in relation to the hardware (eg, tablet PCs, smartphones, laptops) each participant utilizes. The obtained data were correlated with the internet-based learning activities of the probands.

The questionnaire was compiled in cooperation with biostatisticians of the Center for Quality-Management and Development, Johannes Gutenberg University Mainz. These experts also conducted the machine read-out and processing of the completed questionnaires, employing the statistical analysis programme SPSS 16.0 (Statistical Package Social Sciences; IBM Inc., Chicago. IL, USA). The survey analysis did not differentiate between male and female participants as well as of their degree of clinical education.

Table 1. Outline of the questionaire provided to students.

Question #	Question
1	Do you have an Internet access from your home? If „yes“, which kind?
2	Define the percentage of your internet-based learning activity.
3	Which type of computer (desktop, notebook, netbook) are you utilizing?
4	Which kind of mobile device (tablet PC, smartphone) and operation system (OS) are you working with?
5	Are you mainly utilizing the university’s e-learning offers at home or where else?
6	Which medium (iOS apps, Android apps, computer programs) are you deploying for learning activities?

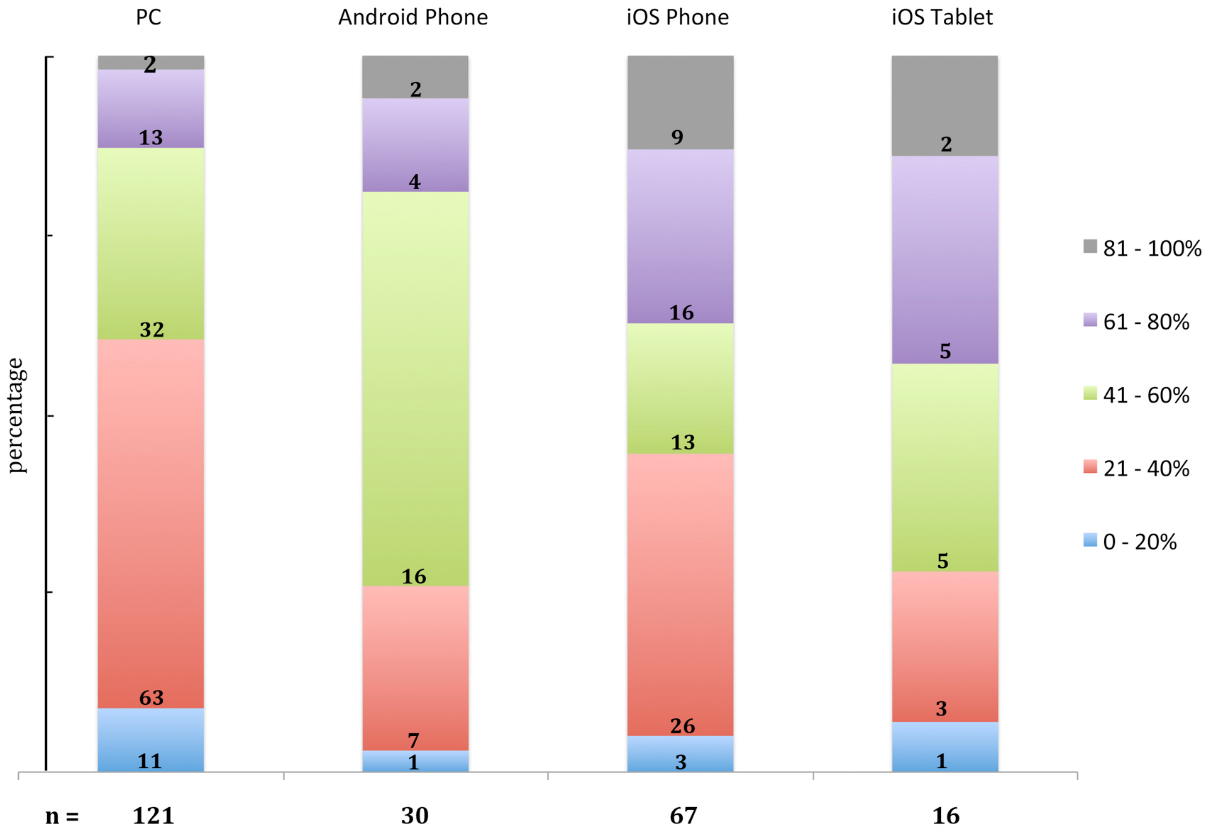
Results

The study comprises 141 students during their clinical education, 42 males and 99 females. The gender distribution roughly matches the notification (10% variance) officially provided [13]. Preliminary talks unveiled that each student participating in the survey employed any e-learning device and owned at least one device useful for e-learning activities. Analysis of the survey confirms this statement, and details that an overwhelming number of probands (125/141, 89%) utilized laptops for e-learning activities. Beyond that, all students reported an unlimited Internet access. Furthermore, all students hold mobile devices, although tablet PCs and smartphones employed for e-learning can be assigned to only 75% (106/141) of probands. Apparently, less than two-thirds (83./141, 59%) of students questioned own smartphones, and a minority (23/141, 16%) has tablet PCs at one's disposal. Examining the devices with respect to their OS it appears that iOSs prevail. The overall conclusion drawn from this data clearly demonstrates that at least with respect to the hardware (e-devices) clinical dental students are excellently equipped to accomplish e-learning requirements.

Internet-based learning activities are linked to specific e-learning devices as detailed in Figure 1. Analyzing the utilization of computers (PCs) for e-learning it became apparent that the range of 21 – 40 % of internet-based learning activity of students is linked to half (52%) of computers available. Interestingly, as the internet learning activity increases (range 41 – 100 %), the preference to utilize computers clearly declines. At the highest level of e-learning efforts (81 – 100 %) less students made use of computers (PCs). Noteworthy differences were observed to use tablet PCs and smartphones for e-learning. The documentation for tablet PCs (iOS Tablets) reveals that the e-learning activity (range from 21 to 80 % activity) is related to either 77 % tablet PCs equipped with iOS or to 100 % tablets equipped with Android OS. Remarkably, those students conducting almost entirely e-learning activities (81 – 100 %) during their clinical education preferred iOS tablets and iOS phones (27 %), only 8 % utilized PCs and Android phones. However, tablet PCs carrying iOS are most popular for internet-based learning activities. A break down of data compiled for smartphones (Android phone, iOS phone) displays some distinct differences when compared to the use of computers or iOS tablets. Again, slightly more than one-third of students performing e-learning activities (21 - 40 %) is using an iOS smartphone (39%). Smartphones equipped with Android OS are absolutely favored for e-learning. These devices are employed to 91 % by students performing e-learning activities in the range of 21 to 80 %. Our data do not allow to transfer percentages of users directly in an absolute number of probands as individual students utilize more than 1 e-device for e-learning activities. This is inferred from the number of students (n=141) participating in the survey compared with the total of e-learning devices students (n=234) employ (see Table 1).

Utilization of e-learning programs is allocated to specific hardware-types. Since e-learning hardware devices are without exception highly sophisticated technical allround tools one would not necessarily expect a preference of any type of device for a specific e-learning program. From 121 students using computers (PCs) for their e-learning activity, 37 % (n=5) took advantage of learning programs. A different outcome holds for tablet PCs. From students owning Tablet PCs equipped with iOS only 54% (n=9) employed e-learning programs. Marginal acceptance was found for tablets PCs furnished with Android OS, and only 1 proband used an assigned learning program. Data for smartphones are divergent from computers and tablets. Students employing iOS-smartphones about half of them (55%, n=37) practice appropriate e-learning programs. From Android smartphone users only 14 % (n=4) took advantage of e-learning programs. To avoid an overinterpretation of the data presented here we suggest that of all students questioned only one-third regulary uses e-learning programs, regardless of the different hard ware devices and OSs employed.

Figure 1. Activity of Internet based learning performance related to the internet devices PC, Android Phone, iOS Phone and iOS Tablet, respectively. The number of students utilizing a specific device is indicated by “n”. The application of each device employed for learning activities varies between students. This variation causes an alignment in 20 percent steps (see coloured boxes at the right). Thus, the absolute frequency is displayed in “grey” (81 – 100%), the lowest frequency in “blue” (0 – 20%). The actual number of students referring to the individual frequencies is given for each Internet device. This number directly relates to the variable size of coloured boxes and can be transferred in percentage (ordinate).



Discussion

Summary

The data collected from 141 dental students reveal that all utilize at least 1 internet hardware device such as PC, smart phone or tablet PC, and they have all unlimited access to the internet. The overwhelming part of probands (90%) employ laptops for e-learning, while only three-quarter of mobile device owners use this hard-ware for e-learning activities. The more intense students are engaged in e-learning, the more they use smart phones and tablets PCs. Students performing almost exclusively e-learning favour highly sophisticated e-learning hardware like smart phones and tablet PCs equipped either with Android OS or with iOS. e-Learning programs are less popular. Most students are operating PCs but only 30 % utilize e-learning programs. The acceptance for e-learning software increases to 50 % as high-class devices (iOS equipped tablet PCs, Android Phones) are employed.

This outcome of our survey conducted with 141 dental students during their clinical education describes a current state of hard and software employed for e-learning activities. Although the whole issue is subject to rapid developments, a comparison with previous data [6] discloses a clearly increased application of e-learning techniques. This holds both for the access to the Internet and to the availability of hardware devices. The data gathered here implicate that dental students overwhelmingly favour PCs (laptops) for e-learning activities, which we relate primarily to the formidable sales figures of this device. However, a trend is apparent that the availability of more sophisticated hardware, such as smart phones and tablet PCs equipped with efficient OSs, promotes the attractiveness of e-learning. In fact, students highly engaged in e-learning (81 - 100 %) favour for their efforts high-class devices. In general, this view is supported by our survey as the relative use of iOS equipped tablet PCs is increasingly employed for e-learning activities (range from 41 - 100%). A somewhat different result was obtained with respect to smartphones. About half e-learning activities of student relates to iOS smartphones. Smartphones equipped with Android OS often exhibit enlarged screens as compared to iOS phones, and this fact seems to attract students performing an intense internet-based learning activity. Again, the reliability of this result should be judged cautiously as the phone-purchasing behavior of students may change rapidly with new applications not confined to e-learning matters. Despite these conjectures we assume that high tech preconditions are most relevant to improve clinical education of dental students.

Utilization of e-learning programs was found mostly accepted by students owning iOS tablet PCs and iOS smartphones, respectively. This finding contrasts data for tablet PCs and smartphones equipped with Android OSs, exhibiting a moderate use (about 20%) of learning programs. Unfortunately, the responses obtained for tablet PCs is rather low impairing a reliable interpretation. Rather convincing appear the results regarding computers (desktop, laptop). About one third out of 141 students employs learning programs installed on computers. This supports the notion and let us suggest that affordable prices and an easy access to e-learning programs is eligible to promote their widespread dissemination. Regardless of the preferences dental students exhibit for e-learning devices, the trend continuous to an increased engagement in e-learning activities linked to contemporary techniques [14].

Conclusions

Our survey confirms recent suggestions that dental students increasingly accept e-learning offers. The essential preconditions to perform these studies are excellent, since all students have access to computers (desktop, laptop) and mobile e-learning devices (tablet PC, smartphone), respectively. A trend to tablet PCs and smartphones equipped with high performance operation systems appears evident. While the survey participants are overwhelmingly engaged in e-learning activities, only one-third to half of students deploys e-learning programs. We conclude that e-learning activities of dental students meanwhile represent an intergral part of clinical training at the University Mainz.

References

1. ShintakuWH, Scarbecz M, Venturin JS. Evaluation of interproximal caries using the iPad 2 and a liquid crystal display monitor. Oral and maxillofaxial Radiology 2012;113:40-44.
2. Chatterley T, Chojecki D. Personal digital assistant usage among undergraduate medical students: exploring trends, barriers, and the advent of smartphones. J Med Libr Assoc 2010 Apr;98(2):157-160 [FREE Full text] [doi: 10.3163/1536-5050.98.2.008] [Medline: 20428281]
3. Garritty C, El Emam K. Who's using PDA's? Estimates of PDA use by health care providers: a systematic review of surveys. J Med Internet Res 2006;8:7.
4. Wong G, Greenhalgh T, Pawson R. Internet-based medical education: a realist review of what works, for whom and in what circumstances. BMC Med Educ 2010;10:12 [FREE Full text] [doi: 10.1186/1472-6920-10-12] [Medline: 20122253]
5. Link TM, Marz R. Computer literacy and attitudes towards e-learning among first year medical students. BMC Med Educ 2006;6:34 [FREE Full text] [doi: 10.1186/1472-6920-6-34] [Medline: 16784524]
6. Sagheb K, Schulz P, Bemsch A, Al-Nawas B. Improving interactive Learning in dental education – ILKUM. Int Poster J Dent Oral Med 2010;12:503.
7. Gupta B, White DA, Walmsley AD. The attitudes of undergraduate students and staff to the use of electronic learning. Br Dent J 2004 Apr 24;196(8):487-492. [doi: 10.1038/sj.bdj.4811179] [Medline: 15105865]
8. Mattheos N, Stefanovic N, Apse P, Attstrom R, Buchanan J, Brown P, et al. Potential of information technology in dental education. Eur J Dent Educ 2008 Feb;12 Suppl 1:85-92. [doi: 10.1111/j.1600-0579.2007.00483.x] [Medline: 18289271]
9. Kerres M. Potenziale von Web 2.0 nutzen. In: Hohenstein A, Wilbers K, editors. Handbuch E-Learning. München: DWD; Aug 05, 2006.
10. Schönwetter DJ, Reynolds PA, Eaton KA, de Vries J. Online learning in dentristry: an overview of the future directions for dental education. J Oral Rehabil 2010;37:927-940.
11. Heervang E, Goodman R. Advantages and Limitations of web-based surveys: evidence from a child mental health survey. Soc Psyciatr Epidemiol 2011;46:69-76.

12. Net Applications I. Alisjo Viejo, CA, USA. 2012. URL: http://www.netmarketshare.com [WebCite Cache ID 1375886952751036]
13. Lehrbericht der Universitätsmedizin der Johannes Gutenberg Universität. Mainz: Universitätsmedizin Mainz; 2011. Source: URL: http://lehrbericht.um-mainz.de [accessed 2013-08-07] [WebCite Cache ID 1375886595157556]
14. Davies BS, Rafique J, Vincent TR, Fairclough J, Packer MH, Vincent R, et al. Mobile Medical Education (MoMEd) - how mobile information resources contribute to learning for undergraduate clinical students - a mixed methods study. BMC Med Educ 2012;12:1 [FREE Full text] [doi: 10.1186/1472-6920-12-1] [Medline: 22240206]

Abbreviations

PC: personal computers
OS: operation system
iOS: iPhone operating system

Edited by G Eysenbach; submitted 13.06.13; peer-reviewed by N Pombo, B Davies; comments to author 18.07.13; revised version received 26.07.13; accepted 29.07.13; published 14.08.13.

Please cite as:
Schulz P, Sagheb K, Affeldt H, Klumpp H, Taylor K, Walter C, Al-Nawas B
Acceptance of E-Learning Devices by Dental Students
Med 2.0 2013;2(2):e6
URL: http://www.medicine20.com/2013/2/e6/
doi:10.2196/med20.2767
PMID:25075241

Original Paper

How Twitter Is Studied in the Medical Professions: A Classification of Twitter Papers Indexed in PubMed

Shirley Ann Williams[1*], BSc, PhD; Melissa Terras[2*], MA, MSc, DPhil, CLTHE; Claire Warwick[2*], MA, MPhil, PhD

[1]School of Systems Engineering, University of Reading, Reading, United Kingdom

[2]Department of Information Studies, University College London, London, United Kingdom

[*]all authors contributed equally

Corresponding Author:
Shirley Ann Williams, BSc, PhD
School of Systems Engineering
University of Reading
Whiteknights
Reading, RG6 6AY
United Kingdom
Phone: 44 118 378 8613
Fax: 44 118 975 1994
Email: shirley.williams@reading.ac.uk

Abstract

Background: Since their inception, Twitter and related microblogging systems have provided a rich source of information for researchers and have attracted interest in their affordances and use. Since 2009 PubMed has included 123 journal articles on medicine and Twitter, but no overview exists as to how the field uses Twitter in research.

Objective: This paper aims to identify published work relating to Twitter within the fields indexed by PubMed, and then to classify it. This classification will provide a framework in which future researchers will be able to position their work, and to provide an understanding of the current reach of research using Twitter in medical disciplines.

Methods: Papers on Twitter and related topics were identified and reviewed. The papers were then qualitatively classified based on the paper's title and abstract to determine their focus. The work that was Twitter focused was studied in detail to determine what data, if any, it was based on, and from this a categorization of the data set size used in the studies was developed. Using open coded content analysis additional important categories were also identified, relating to the primary methodology, domain, and aspect.

Results: As of 2012, PubMed comprises more than 21 million citations from biomedical literature, and from these a corpus of 134 potentially Twitter related papers were identified, eleven of which were subsequently found not to be relevant. There were no papers prior to 2009 relating to microblogging, a term first used in 2006. Of the remaining 123 papers which mentioned Twitter, thirty were focused on Twitter (the others referring to it tangentially). The early Twitter focused papers introduced the topic and highlighted the potential, not carrying out any form of data analysis. The majority of published papers used analytic techniques to sort through thousands, if not millions, of individual tweets, often depending on automated tools to do so. Our analysis demonstrates that researchers are starting to use knowledge discovery methods and data mining techniques to understand vast quantities of tweets: the study of Twitter is becoming quantitative research.

Conclusions: This work is to the best of our knowledge the first overview study of medical related research based on Twitter and related microblogging. We have used 5 dimensions to categorize published medical related research on Twitter. This classification provides a framework within which researchers studying development and use of Twitter within medical related research, and those undertaking comparative studies of research, relating to Twitter in the area of medicine and beyond, can position and ground their work.

(Med 2.0 2013;2(2):e2) doi:10.2196/med20.2269

KEYWORDS

Twitter messaging; Twitter messenging; information science; Twitter; microblogging; papers; classification, social network systems

Introduction

Since their inception in 2006, Twitter and similar microblogging systems have provided data for research, with the first academic paper on the subject appearing in 2007 [1]. Articles in the popular news media highlight the potential of Twitter based research to meet a number of goals ranging from measuring public sentiment to spotting flu outbreaks [2]. However, there has been little work done beyond the headlines in understanding how or why people are using information gathered from Twitter systems for research, particularly around specific topic areas.

The terms microblog and Twitter are both widely used by authors, dating from the first paper on the subject [1]. The term microblogging is defined as:

> *A variant of blogging which allows users to quickly post short updates, providing an innovative communication method that can be seen as a hybrid of blogging, instant messaging, social networking and status notifications. The word's origin suggests that it shares the majority of elements with blogging, therefore it can potentially be described using blogging's three key concepts: the contents are short postings, these postings are kept together by a common content author who controls publication, and individual blog entries can be easily aggregated together.* [3,4]

Some writers hyphenate the term as "micro-blog" [5], while other do not [6]. We follow the majority and use the unhyphenated version, although while searching for papers on the topic we utilized both. Twitter is usually defined in terms as microblogging:

> *Twitter is a microblogging site, originally developed for mobile phones, designed to let people post short, 140-character text updates or "tweets" to a network of others. Twitter prompts users to answer the question "What are you doing?", creating a constantly- updated timeline, or stream, of short messages that range from humor and musings on life to links and breaking news. Twitter has a directed friendship model: participants choose Twitter accounts to "follow" in their stream, and they each have their own group of "followers".* [7]

PubMed is a free Web literature search service developed and maintained by the National Center for Biotechnology Information (NCBI) [8]. Since 1996, PubMed gives access to citation and abstracts of some 5400 biomedical journals covering the fields of medicine, nursing, dentistry, veterinary medicine, health care systems, and preclinical sciences. The intended users of PubMed are researchers, health care professionals, and the general public. For the intended users, PubMed serves as the primary tool for electronically searching and retrieving biomedical literature [9]. Fink [10] describes PubMed as "the best site for published medical and health research". PubMed uses the Medical Subject Headings (MeSH) controlled vocabulary to supplement searches. MeSH pre-dates PubMed with its origins in the 1960s as a set of catalog headings across medicine composed by the US National Library of Medicine [11]. Entries to MeSH are regularly updated to match changes in medicine and technology.

In common with many other papers, we used the term Twitter to encompass all microblogging systems. The work was not a traditional literature review [10]. Instead, only papers indexed by PubMed were considered and only those related to Twitter were reviewed then classified.

This work will provide a framework with which researchers studying Twitter related topics and their applications in medical related areas will be able to position and ground their work. It will provide a single point where current work on the medical use of Twitter can be compared and contrasted. Additionally it will help to understand the scope and reach of using PubMed as a data source.

Our analysis shows that Twitter related research can be classified in a variety of ways: whether it is Twitter-focused or part of a wider social media related study; whether it is based on data, and if so, the quantity of data considered; the domain in which the work is based; the methods used; and the aspect–or characteristic–of Twitter considered. These dimensions of classification provide a framework in which Twitter-related medical research can be positioned and compared with other work within the area and beyond.

Methods

Data Collection

Researchers normally identify papers on a topic in a number of different ways such as chaining from existing papers and database searches [12,13]. There are many databases and search engines available to researchers wanting to find papers on a particular topic [10], some of which are freely available, while others are available via individual or institutional subscription [14]. Researchers in areas of emerging technologies sometimes limit themselves to groups of publications [15], single journal sources [16], or concentrate around conferences [17]. While many studies do not indicate their identification method, Cormode et al [18], for example, classify Twitter papers providing examples of "first studies" and the "next set of papers". Within this work we wanted to investigate the area of Twitter based research in medicine, and for our data collection to be replicable we chose to make a structured search of journal articles.

Initial experimentation showed that for Google Scholar [19] the searches either had to be limited to searching the article's title or it is full text. Searches limited to articles title would not return "OMG U got flu? Analysis of shared health messages for bio-surveillance" [5] as it does not contain any words related to Twitter. Full text searches returned articles which had "share this on Twitter" buttons on the page even though the article was nothing to do with microblogging. Using our institutional library's facility to search freely available electronic resources for papers relating to Twitter in the biomedical field, we established that PubMed returned over 100 items while BioMed Central [20] returned around 20, and other databases returned very few papers, and almost all were already in the PubMed list.

Gold et al [21] faced a similar challenge when undertaking a systematic examination of the use of social networking sites for health promotion: from a systematic search of a range of databases they originally found 204 academic papers but closer investigation showed only one was relevant, a Web search revealed over 80 million electronic resources and an unknown number of social networking sites. Likewise Guse et al [22] investigated the use of digital media to improve adolescent sexual health searched a range of databases to identify 942 possible abstracts of which 10 met the inclusion criteria: while they do not indicate which databases they found each paper in, all the 10 studies can be found via PubMed.

It was determined for this study that a structured search using PubMed would be used to identify papers in journals. While this most certainly would not give an exhaustive list of papers on Twitter it does mean that the search is repeatable, by other researchers, allowing future studies to include papers added to PubMed. Using subscription based services (such as Scopus) would mean only some researchers could repeat the study limiting its usefulness as a benchmark.

The data collection was made for the papers that were first published between 2007 (the first year academic papers on Twitter appeared) and 2011 (the last complete year before this study); inclusive of papers available online as preprints ahead of the print version (epubs).

During 2010, the terms "Twitter messenging" and "Twitter messaging" were introduced into the MeSH controlled vocabulary under the headings Internet and Blogging respectively. There are no entries relating to the term microblog or its variants, although blogging is present. There are currently no papers within PubMed that are returned by searches on the MeSH terms: "Twitter messenging" or "Twitter messaging". It should be noted that where papers have keywords, not indexed by MeSH terms, PubMed does not store these and so it is not possible to search PubMed for papers with keywords such as "Twitter" or "microblog". Therefore, the terms Twitter, Tweet, Microblog, and Micro-blog were used as the basis for keyword searching across all fields in PubMed, and then cross-referenced and checked to remove spurious data. A total of 139 papers were initially identified which had used terms from the query in a medical context. Five of these were subsequently found to be only included in the results because one of the author's surnames or usernames included "tweet", and so a base corpus of 134 papers was created.

Data Classification

Previous research [23] showed that a number of dimensions could be identified and studied when Twitter-related academic papers and their abstracts are analyzed. These include:

1. *Focus*. Papers can be predominantly about Twitter or related microblogging such as the use of the Chinese microblog site Sina Weibo [24], or they can be partially about Twitter but predominantly about other things, for example considering a number of different social networking sites of which Twitter is just one [25]. There are also unknowns where a paper has no abstract. Additionally there are papers where the term twitter is used with its conventional meaning such as a noise made by birds.
2. *Data*. The data used in studies is varied, ranging from observations of small samples, through questionnaires, to collecting vast quantities of information via the Twitter API (an interface that allows technically skilled users to extract data). The date of the study also impacts on the timeliness, quantity and quality of data.
3. *Domain*. Studies are undertaken from a number of different standpoints and often within a domain or a group of domains.
4. *Method*. Researchers use a variety of methodological techniques when carrying out research into Twitter.
5. *Aspect*. The aspect or characteristic of Twitter considered. Many studies concentrate on looking at the message (tweets), while others study the user (tweeter), with smaller numbers look at the underlying technology and how it can be developed. A number of papers consider the concept of Twitter without any detail of its use.

The overarching approach to classification was based on the approach used in a study of research on microblogging in education [15], with independent coding and then discussion until consensus was reached. For each paper in our corpus, the focus was identified, based on close reading of the title and abstract. Those papers identified as Twitter-focused were subject to a qualitative classification on the title, abstract and full paper using open coded analysis to determine groupings for the data used in the work described. Corbin and Strauss [26] have shown how this methodology facilitates the breaking of corpora data into delineated concepts as well as featuring in grounded theory [27] where initial and focused line by line coding produces label variables from within the data itself. The approach has been previously used successfully to classify Twitter posts [4]. The grouping of method, domain and aspect was initially identified from the paper's title and abstract and verified by consulting the full paper.

Results

Focus

Multimedia Appendix 1 summarizes the flow of selection of papers from our base corpus of 134 papers. From this corpus thirty [5,6,28-55] were Twitter-focused. The papers had a significant proportion that was related to some aspect of microblogging. For example Chew and Eysenbach [31] in their paper entitled "Pandemics in the age of Twitter: content analysis of Tweets during the 2009 H1N1 outbreak" study how Twitter was used in relation to the spread of infection in a pandemic.

There were 57 corpora [21,56-111] that mentioned Twitter but were primarily about another topic. For example Turner-McGrievy and Tate [105] in their paper, "Tweets, Apps, and Pods: Results of the 6-month Mobile Pounds Off Digitally (Mobile POD) randomized weight-loss intervention among adults" study a combination of podcasts and other techniques including using Twitter in relation to weight loss.

Out of 134 papers, 36 [112-147] had no abstract, for example the article "Are you using Twitter for your next survey?" by

Pattillo [127]. Further investigation showed that this is a news article within the publication. Papers without abstracts are therefore not considered in any further detail, given that they were news reports rather than academic articles per se. News stories have been shown to be rated differently by medical professionals according to their authorship [148]. Wilson et al [149] took a similar decision to concentrate on academic papers when reviewing papers related to Facebook, and highlighting that while unpublished manuscripts, dissertations, position papers, and popular press articles offer thoughtful insights, their quality is variable.

Out of 134 articles, there were 11 [150-160] not related to microblogging, with 10 of these the term “twitter” being used with original, non-microblogging meanings. For example “Why do shrews twitter? Communication or simple echo-based orientation” [156] is about the noise made by shrews. Exceptional was a paper entitled “Plant twitter: ligands under 140 amino acids enforcing stomatal patterning” [159], as the paper is not about microblogging but in the area of plant research. The MeSH terms used to classify the paper support this, but interestingly the only appearance of “twitter” is in the title; a form of pun. These non-microblogging papers are not considered in any further detail.

Table 1 shows the number of Twitter-focused papers and the number of papers mentioning Twitter published each year between 2007 and 2011, and compares them with the numbers for general journals [23], found by searching Scopus [161] and Web of Science within Web of Knowledge [162]. Note there were no such papers published in medical fields in 2007 and 2008, although they were appearing in other disciplines. Since 2009 the number of papers has increased each year. This analysis suggests that although the use of Twitter in medical research came later than in some other disciplines, its use is growing and its importance is increasing as time progresses. Initial indications for 2012 suggest that the number of papers published both in the area of medicine and more generally will be greater than the numbers published in 2011.

The 2 papers in the corpus published in 2009 [28,29] and 3/8 published in 2010 [30,32,36] discussed the merits of Twitter and whether it should be used by medical professionals. The study of Twitter content for medical related terms was first seen within the corpus in 2010 papers [31,35], while general examination of terms was first presented in 2007 [1].

In the following we consider only the Twitter-focused papers in medical related disciplines. Those papers that use Twitter or other microblogs as a primary source and topic for research as identified via PubMed. Multimedia Appendix 2 combines the information presented in Tables 1-5 for all the Twitter-focused papers.

Data

Across the papers a number of different types of data sources were reported including surveys, user profiles, tweets (posts), and individual words in tweets. The size of data set examined ranged from small, with a few items, to large scale, with billions of individual data points. Some papers were not based on data, particularly those early papers that were introducing the concept of Twitter.

For some papers the abstracts indicated the data studied, for example in a paper “Use of Twitter to encourage interaction in a multi-campus pharmacy management course” [41] the abstract includes the following:

> *More than eighteen hundred tweets were made by students, guests, and the instructor... One hundred thirty-one students completed an optional evaluation survey.* [41]

Indicating the type of data and quantities, the full paper shows that the students posted 1775 tweets over 6 days, as well as indicating the use by other participants. The Twitter data was collected by graduate teaching assistants using a Twitter list in preference to hashtags, which the students are reported to have found cumbersome. In other papers, the abstract provides only partial information about the dataset. For example in a paper “Social media & stem cell science: examining the discourse” [38], the abstract indicates that Twitter posts are analyzed. But the full paper needs to be consulted to identify that the researchers used TweetDeck to collect 2 sets of tweets, one group of 35 using the term “DeGette” over a 6 day period, and a group of 50 using “trachea stem cells” over a 4 day period. Similarly, the paper “Diurnal and seasonal mood vary with work, sleep, and day length across diverse cultures” [43] indicates in the abstract that millions of Twitter messages are considered, the full paper provides more details:

> *Using Twitter.com’s data access protocol, we collected up to 400 public messages from each user in the sample, excluding users with fewer than 25 messages. The resulting corpus contained about 2.4 million individuals from across the globe and 509 million messages authored between February 2008 and January 2010.* [43]

The paper “Implementing Twitter in a health sciences library” [32] is a report on the establishing of a Twitter presence by the communications team within the library. The work is not based on data although in the evaluation section the authors do report on the number of followers (66) the account has gathered and classifying these in relationship to the library.

Stratifying across the different descriptions of data we identified 4 categories which can be used to describe the datasets used to study Twitter in a medical context.

1. *Large*. Studies looking at vast amounts of data that would require a team of researchers and the use of automated tools if the data is to be analyzed in a timely manner. Typically considering over a million tweets and/or a million accounts. The term “big data” is often used to describe the quantity of data in such studies
2. *Medium*. Studies using quantities of data that could realistically be analyzed manually by a dedicated researcher or a small team with limited tool support. Typically considering thousands of tweets or accounts.
3. *Small*. The data handled could be reasonably handled by a researcher alongside other tasks. Typically considering

surveys, groups, tweets, and user profiles, with up to a thousand items.

4. *Not data based*. Papers not based on data collection and analysis.

Table 2 shows the categorization of data in the Twitter related papers by year published. The early papers (2009 and 2010) were predominantly not based on data, typically explaining the affordances of Twitter. In 2011 all papers had a data element, while there were a range of papers using large, medium, and small scale datasets. There is an increase in large scale analysis of Twitter from 1 study in 2010 to 6 in 2011, indicating that computational analysis of large scale datasets of Twitter data are becoming more common.

Domain

All the papers in this study are from PubMed and so the broad domain is medical, however the researchers have a number of different standpoints. Consideration was given to the selection of domains from sub-area and disciplines of medicines, but typically there are only a few papers in each sub-area, see Table 3.

Based on an analysis of the contents of full papers we have identified the following broader topic, or domain, areas. Some papers are allocated to more than one of these domains:

- *Academic*. Seven papers in total [30,32,34,37,40,41,48] have an academic perspective ranging through education for professions, libraries, and scholarly publications, to an experimental use of Twitter with groups of students.
- *General Communication*. Fourteen papers [5,6,31,35,39,43-46,50-54] examine the general Twitter interface, and do not in any ways select individuals. These include all the papers which analyze large scale datasets.
- *Medical Professional Communication*. Nine papers [32,33,36,38,40,42,47,48,55] consider use by professionals within an area, both among themselves and with patients, as well as one way communication to the more general public (including marketing).
- *Targeted Communication*. Two papers [38,49] involve other identifiable groups not related to medical professionals. one was an analysis of accounts that were identified as related to quitting smoking [49].
- *Guides*. Four of the papers [28-30,36] are written primarily as guides: all of these concentrated on explaining the concept and purpose of Twitter.

Table 1. Number of Twitter related papers published per year.

Year	Mentions Twitter (Medical)	Twitter-focused (Medical)	Mentions Twitter (General)	Twitter-focused (General)
2007	0	0	3	3
2008	0	0	12	8
2009	6	2	70	36
2010	18	8	217	210
2011	33	20	248	320

Table 2. Data categorization of Twitter papers by year.

Year	Large	Medium	Small	Not data based
2009				2
2010	1	1	2	4
2011	6	7	7	

Table 3. Sub-areas and number of papers.

Sub-area	Number of papers
Psychology	5
General	4
Influenza	3
Neurology	3
Pharmacy	3
Administration	2
Happiness	2
Nursing	2
Dentistry	1
Health education	1
Information science	1
Natural science	1
Orthopaedics	1
Sociology	1

Methods and Aspects

Initially, the papers' titles and abstracts were read to try to identify the methodological approach use by the researchers. For the papers with structured abstracts and some others this clearly indicated the approach taken. For example a paper entitled "'What's happening?' A content analysis of concussion-related traffic on Twitter" [54] clearly used a content analysis approach. Following this initial pass, all papers were examined for details of methods used. An open coding approach was used to capture the diversity of approaches. This resulted in across the 30 papers 53 methods identified, and not all of which were distinct, see Table 4.

These methods were then stratified into 3 broad categories:

1. *Analytic*. Where the researchers had performed some type of analysis, which may be quantitative or qualitative. Sometimes these methods are supported by existing or new techniques from artificial intelligence, mathematics and statistics to facilitate knowledge discovery and mining of information. Many of the papers use the techniques of content analysis: for example in "Pandemics in the age of Twitter: content analysis of Tweets during the 2009 H1N1 outbreak" [31], while in "OMG U got flu? Analysis of shared health messages for bio-surveillance" [5] machine learning techniques are used alongside content analysis. Social network analysis is used in the paper "Modeling users' activity on twitter networks: validation of Dunbar's number" [44] to extract and analyze 25 million conversations from some 380 million tweets.
2. *Design and Development*. Where systems are proposed or built, to interact with Twitter, such systems are often demonstrators used by the authors within their own context. For example, in a paper entitled, "A new support system using a mobile device (smartphone) for diagnostic image display and treatment of stroke" [55], the method of the work is presented as the creation of a communication system that was piloted in the author's hospital, the system includes the capability to tweet to other professionals. While in "Machine intelligence for health information: capturing concepts and trends in social media via query expansion" [52], the authors develop information retrieval techniques to facilitate working with their Twitter corpus, and in "A visual backchannel for large-scale events" [33] they describe a system they have developed and trials that allows the tweets related to an event to be presented graphically.s
3. *Examination*. Where the authors had undertaken review and survey type works, including approaches such as: case studies, categorizations, essays, ethnographic studies, interviews, and investigation. For example in a paper entitled, "Twitter as a communication tool for orthopedic surgery" [42], they identified, categorized, and reviewed Twitter profiles of over 400 orthopedic professionals. While in a paper entitled "Should you be tweeting?" [28], interviews with scientists who use Twitter are presented. This paper would itself be classed as an examination paper.

Alongside the methods the aspect of Twitter primarily considered in research was identified according to the 4 categories:

1. The messages (tweets).
2. The users (tweeter).
3. The underlying technology and how it can be developed.
4. The concept of Twitter without any detail of its use.

For all medical related papers it was possible to identify a primary method and primary aspect considered by the researchers and these are summarized in Table 5. Some papers also were identified as having secondary aspects, as shown in Multimedia Appendix 2.

It is interesting to note that the majority of the papers report research using analytic methods, and the majority of this group look at the contents of the tweets sent, rather than the users. The 6 papers using examination methods such as reviews considering the concept of Twitter are the same as the 6 papers in Table 2 that are not based on data. A similar classification of general papers [23] identified proportionally many more papers using the design and development methods. The general papers 154 of the total 575 papers primarily using a design and development method on the message aspect. None of the PubMed papers took this approach. Otherwise the PubMed papers do have a similar spread to the general papers.

Table 4. Methodological approaches initially identified.

Methods identified	Number of papers
Content analysis	12
Review	4
Survey	4
Experimental	2
Graph	2
Machine intelligence	2
Mined	2
Statistical	2
System development	2
System implementation	2
Algorithmic	1
Analysis	1
Automation	1
Classification	1
Classification analysis	1
Comparative analysis	1
Correlation analysis	1
Evaluation	1
Examination	1
Investigation	1
Mathematical	1
Model	1
Normalisation	1
Qualitative	1
Simulation	1
Statistics	1
System design	1
Text analysis	1
Text mining	1

Table 5. Number of papers with primary method and aspect.

	Message	User	Technology	Concept	Total
Analytic	11	5	0	0	16
Design and development	0	0	4	2	6
Examination	1	1	0	6	8
Total	12	6	4	8	

Discussion

Principal Results

Across PubMed 123 papers were identified that were Twitter related; this is a very tiny proportion of the more than 21 million citations held in the database. The first papers indexed by PubMed were published in 2009, 3 years after the launch of Twitter and 2 years after the first Twitter papers appeared in other disciplines. The early Twitter focused papers introduced the topic and highlighted the potential, not carrying out any form of data analysis. However subsequent studies analyzed quantities of Twitter data and one of the principal findings of this study is the size of studies that are now possible based on Twitter in the medical field. The first of the large studies of over a million pieces of data was published in November 2010 [31]. Researchers are now reporting collecting billions of items of data over almost 3 years [6]. Collecting large quantities of data is challenging, as explained,

> *Our research material of tweets was gathered by using the Twitter4J … an open-source Java library for the Twitter Application Programming Interface (API). The tweets were stored locally as Twitter limits online search to one week. This strategy allowed an increased sample size improving the likelihood of detecting trends. Twitter API provided approximately one per cent of all real-time tweets. Our tweet corpus included English tweets over fourteen days. The data was gathered during 4 Jan 2011 at 13:36–20:10 EST with 300,000 tweets and 582,975 words.* [52]

The Edinburgh Twitter corpus of 97 million tweets was used in one paper [5], however that corpus is no longer available due changes to Twitter's current terms and conditions [163]. This means researchers are no longer able to share corpuses of Twitter data and so the handling of large sets of data need teams to include the expertise and capacity to extract, store and manipulate large quantities of information. Teams also need to be aware of limitations placed by Twitter on developer's access to Twitter data and the possibilities of changes during the lifetime of a project. Likewise the methods for understanding the data collected are moving on from what can be undertaken by lone researchers using qualitative approaches, and while the methods used are still broadly analytic they are using techniques from knowledge discovery and mining of information [40].

Limitations

Limiting the papers examined in this study to those indexed in PubMed between 2007 and 2011 means that there is a body of work published since the start of 2012 that is not considered. While PubMed indexes some 5400 journals there are journals not indexed, including those not in English. A lot of papers published on the subject of Twitter are in conference proceedings. For instance, the Scopus database [161] returns approximately twice as many conference papers as journal papers on the subject (across all fields not just medicine), and there are many conferences that are not indexed. Over and above papers there are many blog posts reporting medical use of Twitter. For example, Bottles [164] describes his personal use of Twitter, and Neylon [165] discusses links shared by nurses. However there is no reliable way of identifying all such posts, nor is it possible to guarantee the posts will remain available. The selection of a single data source does mean that the study is reproducible, and based on published, peer-reviewed research rather than accounts and reflections by individuals. Future comparison can be done on a year by year basis to trace the changing use of Twitter in the medical domain.

Searching on the MeSH terms did not prove useful in highlighting relevant papers. Given the terms "Twitter messaging" and Twitter messenging" were only added to the vocabulary during 2010 this is not totally surprising, although we did expect to see some use of these terms in the most recent publications. This indicates that the MeSH vocabulary system is not being adequately used by authors and publications writing about Twitter, which is problematic given that it is the only faceted search available in PubMed.

The word "twitter" is sometimes used in medical related research with its original meaning. Papers that did this were discounted from this study. Potentially papers may be incorrectly excluded, for example a paper that related both patients with twitters and who used microblogging. We do not believe this was the case in the papers considered here but it is certainly a potential limitation with the approach.

Given that this paper covers only the first few years of academic research in the area of Twitter, it is likely that some of the approaches reported upon are fledgling and that over the next years the methods applied will reach a degree of maturity that will impact on the broad methodological classification presented here.

Analysis of Papers' Findings

The papers reviewed and categorized here were diverse in their finding and conclusions. Of the findings many were closely linked to the domain of study rather than the use of Twitter or social media in general. For example, the findings and conclusions of Golder and Macy [43] all relate to mood change and day patterns. There was no discussion as to the use of Twitter as a source of data.

In the papers in the domain of professional communications, where usually papers concentrate on the concept of Twitter, rather than findings extrapolated from Twitter data, the approach was usually a review or other method classified above as examination. These tended to conclude that they had introduced Twitter and highlighted its potential. Although some were less enthusiastic.

> *Despite the growing popularity of social media across multiple disciplines, the majority of pharmacy preceptors surveyed were not willing to use these venues in professional practice.* [47]

Papers looking at medium and large data sets often included indications that their work illustrated the potential for studies in medical related area to use Twitter and other social media data.

> *The study adds to evidence supporting a high degree of correlation between pre-diagnostic social media*

> *signals and diagnostic influenza case data, pointing the way towards low cost sensor networks.* [5]

Also among these studies authors indicate that the abundance of data will change the way in which researchers approach their studies [6].

Conclusions

This work is to the best of our knowledge the first broad study of medical related research based on Twitter and related microblogging. We have identified that medical related research in this area was first published in 2009 and that the number of papers has increased in both the following years.

From the some 5400 journals indexed by PubMed, we have identified thirty papers that focus on Twitter and 57 that mention it. There are also a number of papers in which the term twitter is used with its original meaning and not at all related to microblogging. There are some papers indexed that appear to relate to Twitter but do not have abstracts further investigations shows these to be editorial or news type items as opposed to academic oriented papers. Further work will need to be undertaken to identify and classify work beyond the academic papers indexed by PubMed, this would include diverse sources such as book chapters, conference proceedings, and blog posts.

While the early Twitter-focused papers were predominantly introductory explaining to the readership what Twitter was about and considering its potential, we are now seeing work reported were researchers have examined large quantities of Twitter data, using these large data sets to obtain better understanding of topics within medicine. We have classified this usage of data into 4 categories: large, medium, small, and no data. This access to large amount of data stemming from individual tweets coupled with metadata of location, time of day, networks of followers holds potential for many future studies building on existing work such as identification of the spread of infectious diseases but it has also potential for the identification of previously impossible studies based on personal thoughts put into a public space. While most studies use methods that can be broadly classed as analytic, the large quantities of data mean that analysis techniques that facilitate knowledge discovery and mining of information are starting to be used. As the number of research papers grows, the dimension of domain will need to be revisited as other stratifications may become possible.

The results presented here will provide researchers with an insight into the medical domain and Twitter use, where there is work in related sub-areas that can be used to inform new studies and those that have still to be studied rigorously. The large data studies that have completed certainly have information on techniques for data collection and method for analysis that will be useful in other domains. Identifying areas where further research is needed is difficult, but we would suggest that the following are neglected areas within the realms of twitter and medicine:

- *Outreach and investigating the reach and scope of Twitter messages*. Although Prochaska et al [49] have reviewed the content of accounts related to Quitting Smoking, none of the studies have investigated the reach of such accounts, or the best ways to use them.
- *Public engagement*. While Adams et al [38] have investigated what is said about their subjects, there are no investigations where discussion is invited or prompted surrounding medical areas.
- *Legal and ethical issues*. While a number of papers (particularly the early ones [28,29]) discuss the general use there are no academic studies of the ethical issues of medical professionals using Twitter, nor any detailed studies of the legal implications of using Twitter in a medical context.

This study provides a framework within which researchers studying the development and use of Twitter within medical related research will be able to position their work and against those undertaking comparative studies of research relating to Twitter in the area of medicine and beyond will be able to ground their work. We have provided an analysis of the use and usefulness of microblogging within medical fields at a time when social media is being increasingly used for research purposes across many domain and in a reproducible manner, which can be built upon in future as more studies are published.

Acknowledgments

We are grateful to Anne Welsh, UCL Department of Information Studies, for her advice on the selection of databases. The anonymous reviewers provided valuable suggestions that improved the paper.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Flow diagram of search strategy.

[PDF File (Adobe PDF File), 37KB - med20_v2i2e2_app1.pdf]

Multimedia Appendix 2

Overview table.

[PDF File (Adobe PDF File), 97KB - med20_v2i2e2_app2.pdf]

References

1. Java A, Song X, Finin T, Tseng B. Why we twitter: understanding microblogging usage and communities. : ACM; 2007 Presented at: Joint 9th WebKDD and 1st SNA-KDD Workshop '07; August 12, 2007; San Jose, California , USA p. 56-65.
2. Savage N. Twitter as medium and message. Commun. ACM 2011 Mar 01;54(3):18-20. [doi: 10.1145/1897852.1897860]
3. Karger DR, Quan D. What would it mean to blog on the semantic web? In: McIlraith SA, Plexousakis D, van Harmelen F, editors. The Semantic Web – ISWC 2004, LNCS 3298. Berlin: Springer-Verlag; 2004:214-228.
4. Ross C, Terras M, Warwick C, Welsh A. Enabled backchannel: conference Twitter use by digital humanists. Journal of Documentation 2011;67(2):214-237. [doi: 10.1108/00220411111109449]
5. Collier N, Son NT, Nguyen NM. OMG U got flu? Analysis of shared health messages for bio-surveillance. J Biomed Semantics 2011;2 Suppl 5:S9 [FREE Full text] [doi: 10.1186/2041-1480-2-S5-S9] [Medline: 22166368]
6. Dodds PS, Harris KD, Kloumann IM, Bliss CA, Danforth CM. Temporal patterns of happiness and information in a global social network: hedonometrics and Twitter. PLoS One 2011;6(12):e26752 [FREE Full text] [doi: 10.1371/journal.pone.0026752] [Medline: 22163266]
7. Marwick AE, boyd D. I tweet honestly, I tweet passionately: Twitter users, context collapse, and the imagined audience. New Media & Society 2010 Jul 07;13(1):114-133. [doi: 10.1177/1461444810365313]
8. National Center for Biotechnology Information. PubMed. 2012. URL: http://www.ncbi.nlm.nih.gov/pubmed [accessed 2012-06-06] [WebCite Cache ID 68DTrarNf]
9. Lu Z. PubMed and beyond: a survey of web tools for searching biomedical literature. Database (Oxford) 2011;2011:baq036 [FREE Full text] [doi: 10.1093/database/baq036] [Medline: 21245076]
10. Fink A. Conducting Research Literature Reviews: From Internet to paper. In: Conducting Research Literature Reviews: From the Internet to Paper. Thousand Oaks, California: Sage Publications, Inc; 2010.
11. Lipscomb CE. Medical Subject Headings (MeSH). Bull Med Libr Assoc 2000 Jul;88(3):265-266 [FREE Full text] [Medline: 10928714]
12. Ellis D. A Behavioural Approach to Information Retrieval System Design. Journal of Documentation 1989;45(3):171-212.
13. Talja S, Maula H. Reasons for the use and non-use of electronic journals and databases: A domain analytic study in four scholarly disciplines. Journal of Documentation 2003;59(6):673-691.
14. Falagas ME, Pitsouni EI, Malietzis GA, Pappas G. Comparison of PubMed, Scopus, Web of Science, and Google Scholar: strengths and weaknesses. FASEB J 2008 Feb;22(2):338-342 [FREE Full text] [doi: 10.1096/fj.07-9492LSF] [Medline: 17884971]
15. Gao F, Luo T, Zhang K. Tweeting for learning: A critical analysis of research on microblogging in education published in 2008-2011. Br J Educ Technol 2012 Aug 24;43(5):783-801. [doi: 10.1111/j.1467-8535.2012.01357.x]
16. Barbera E, Gros B, Kirschner P. Temporal issues in e-learning research: A literature review. British Journal of Educational Technology 2012;43(2):E53-E55. [doi: 10.1111/j.1467-8535.2011.01255.x]
17. Cheong M, Ray S. A Literature Review of Recent Microblogging Developments. In. Victoria, Australia: Clayton School of Information Technology, Monash University; 2011.
18. Cormode G, Krishnamurthy B, Willinger W. A manifesto for modeling and measurement in social media. [online social networks; modeling; measurement. First Monday 2010;15(9) [FREE Full text] [doi: 10.5210/fm.v15i9.3072]
19. Google. Google Scholar. 2011. URL: http://scholar.google.co.uk/intl/en/scholar/about.html [accessed 2012-06-06] [WebCite Cache ID 68DV2qtiL]
20. BioMed. BioMed Central. 2012. URL: http://www.biomedcentral.com/about [accessed 2012-06-06] [WebCite Cache ID 68DZeLXXZ]
21. Gold J, Pedrana AE, Sacks-Davis R, Hellard ME, Chang S, Howard S, et al. A systematic examination of the use of online social networking sites for sexual health promotion. BMC Public Health 2011;11:583 [FREE Full text] [doi: 10.1186/1471-2458-11-583] [Medline: 21777470]
22. Guse K, Levine D, Martins S, Lira A, Gaarde J, Westmorland W, et al. Interventions Using New Digital Media to Improve Adolescent Sexual Health: A Systematic Review. Journal of Adolescent Health 2012;51(6):535-543. [doi: 10.1016/j.jadohealth.2012.03.014]
23. Williams SA, Terras M, Warwick C. What do people study when they study Twitter? Classifying Twitter related academic papers. Journal of Documentation 2013;69(3):384-410. [doi: 10.1108/JD-03-2012-0027]
24. Bamman D, O'Connor B, Smith NA. Censorship and deletion practices in Chinese social media. FM 2012 Mar 02;17(3). [doi: 10.5210/fm.v17i3.3943]
25. boyd D, Ellison NB. Social Network Sites: Definition, History, and Scholarship. Journal of Computer-Mediated Communication 2007;13(1):210-230. [doi: 10.1111/j.1083-6101.2007.00393.x]
26. Corbin J, Strauss AL. Basics of Qualitative Research: Techniques and Procedures for Developing Grounded Theory. Thousand Oaks, CA: Sage Publications, Inc; 2008.
27. Glaser BG, Strauss AL. The discovery of grounded theory; strategies for qualitative research. Chicago: Aldine Pub. Co; 1967.

28. Bonetta L. Should you be tweeting? Cell 2009 Oct 30;139(3):452-453. [doi: 10.1016/j.cell.2009.10.017] [Medline: 19879830]
29. Bush H. Time to tweet? Hosp Health Netw 2009 Jun;83(6):46-51. [Medline: 19606626]
30. Bristol TJ. Twitter: consider the possibilities for continuing nursing education. J Contin Educ Nurs 2010 May;41(5):199-200. [doi: 10.3928/00220124-20100423-09] [Medline: 20481418]
31. Chew C, Eysenbach G. Pandemics in the age of Twitter: content analysis of Tweets during the 2009 H1N1 outbreak. PLoS One 2010;5(11):e14118 [FREE Full text] [doi: 10.1371/journal.pone.0014118] [Medline: 21124761]
32. Cuddy C, Graham J, Morton-Owens EG. Implementing Twitter in a health sciences library. Med Ref Serv Q 2010 Oct;29(4):320-330. [doi: 10.1080/02763869.2010.518915] [Medline: 21058176]
33. Dörk M, Gruen D, Williamson C, Carpendale S. A visual backchannel for large-scale events. IEEE Trans Vis Comput Graph 2010;16(6):1129-1138. [doi: 10.1109/TVCG.2010.129] [Medline: 20975151]
34. Qiu L, Leung AK, Ho JH, Yeung QM, Francis KJ, Chua PF. Understanding the psychological motives behind microblogging. Stud Health Technol Inform 2010;154:140-144. [Medline: 20543286]
35. Scanfeld D, Scanfeld V, Larson EL. Dissemination of health information through social networks: twitter and antibiotics. Am J Infect Control 2010 Apr;38(3):182-188 [FREE Full text] [doi: 10.1016/j.ajic.2009.11.004] [Medline: 20347636]
36. Schneider A, Jackson R, Baum N. Social media networking: Facebook and Twitter. J Med Pract Manage 2010;26(3):156-157. [Medline: 21243885]
37. Stieger S, Burger C. Let's go formative: continuous student ratings with Web 2.0 application Twitter. Cyberpsychol Behav Soc Netw 2010 Apr;13(2):163-167. [Medline: 20528272]
38. Adams A, Lomax G, Santarini A. Social media & stem cell science: examining the discourse. Regen Med 2011 Nov;6(6 Suppl):121-124. [doi: 10.2217/rme.11.82] [Medline: 21999274]
39. Bollen J, Gonçalves B, Ruan G, Mao H. Happiness is assortative in online social networks. Artif Life 2011;17(3):237-251. [doi: 10.1162/artl_a_00034] [Medline: 21554117]
40. Eysenbach G. Can tweets predict citations? Metrics of social impact based on Twitter and correlation with traditional metrics of scientific impact. J Med Internet Res 2011;13(4):e123 [FREE Full text] [doi: 10.2196/jmir.2012] [Medline: 22173204]
41. Fox BI, Varadarajan R. Use of Twitter to encourage interaction in a multi-campus pharmacy management course. Am J Pharm Educ 2011 Jun 10;75(5):88 [FREE Full text] [doi: 10.5688/ajpe75588] [Medline: 21829262]
42. Franko OI. Twitter as a communication tool for orthopedic surgery. Orthopedics 2011 Nov;34(11):873-876. [doi: 10.3928/01477447-20110922-21] [Medline: 22050252]
43. Golder SA, Macy MW. Diurnal and seasonal mood vary with work, sleep, and daylength across diverse cultures. Science 2011 Sep 30;333(6051):1878-1881 [FREE Full text] [doi: 10.1126/science.1202775] [Medline: 21960633]
44. Gonçalves B, Perra N, Vespignani A. Modeling users' activity on twitter networks: validation of Dunbar's number. PLoS One 2011;6(8):e22656 [FREE Full text] [doi: 10.1371/journal.pone.0022656] [Medline: 21826200]
45. González-Bailón S, Borge-Holthoefer J, Rivero A, Moreno Y. The dynamics of protest recruitment through an online network. Sci Rep 2011;1:197 [FREE Full text] [doi: 10.1038/srep00197] [Medline: 22355712]
46. Heaivilin N, Gerbert B, Page JE, Gibbs JL. Public health surveillance of dental pain via Twitter. J Dent Res 2011 Sep;90(9):1047-1051 [FREE Full text] [doi: 10.1177/0022034511415273] [Medline: 21768306]
47. Kukreja P, Heck Sheehan A, Riggins J. Use of social media by pharmacy preceptors. Am J Pharm Educ 2011 Nov 10;75(9):176 [FREE Full text] [doi: 10.5688/ajpe759176] [Medline: 22171104]
48. Mistry V. Critical care training: using Twitter as a teaching tool. Br J Nurs 2011;20(20):1292-1296. [Medline: 22068003]
49. Prochaska JJ, Pechmann C, Kim R, Leonhardt JM. Twitter=quitter? An analysis of Twitter quit smoking social networks. Tob Control 2012 Jul;21(4):447-449 [FREE Full text] [doi: 10.1136/tc.2010.042507] [Medline: 21730101]
50. Reips UD, Garaizar P. Mining twitter: a source for psychological wisdom of the crowds. Behav Res Methods 2011 Sep;43(3):635-642. [doi: 10.3758/s13428-011-0116-6] [Medline: 21701948]
51. Signorini A, Segre AM, Polgreen PM. The use of Twitter to track levels of disease activity and public concern in the U.S. during the influenza A H1N1 pandemic. PLoS One 2011;6(5):e19467 [FREE Full text] [doi: 10.1371/journal.pone.0019467] [Medline: 21573238]
52. Su XY, Suominen H, Hanlen L. Machine intelligence for health information: capturing concepts and trends in social media via query expansion. Stud Health Technol Inform 2011;168:150-157. [Medline: 21893923]
53. McNeil K, Brna PM, Gordon KE. Epilepsy in the Twitter era: a need to re-tweet the way we think about seizures. Epilepsy Behav 2012 Feb;23(2):127-130. [doi: 10.1016/j.yebeh.2011.10.020] [Medline: 22134096]
54. Sullivan SJ, Schneiders AG, Cheang CW, Kitto E, Lee H, Redhead J, et al. 'What's happening?' A content analysis of concussion-related traffic on Twitter. Br J Sports Med 2012 Mar;46(4):258-263. [doi: 10.1136/bjsm.2010.080341] [Medline: 21406451]
55. Takao H, Murayama Y, Ishibashi T, Karagiozov KL, Abe T. A new support system using a mobile device (smartphone) for diagnostic image display and treatment of stroke. Stroke 2012 Jan;43(1):236-239 [FREE Full text] [doi: 10.1161/STROKEAHA.111.627943] [Medline: 21998052]
56. Conde C. Medbloggers beware: watch what you say on the web. Tex Med 2009 May;105(5):29-32. [Medline: 19421922]

57. Eysenbach G. Infodemiology and infoveillance: framework for an emerging set of public health informatics methods to analyze search, communication and publication behavior on the Internet. J Med Internet Res 2009;11(1):e11 [FREE Full text] [doi: 10.2196/jmir.1157] [Medline: 19329408]
58. Gamble KH. Just a tweet away. Healthc Inform 2009 May;26(5):30, 32, 34 passim. [Medline: 19514237]
59. Hawn C. Take two aspirin and tweet me in the morning: how Twitter, Facebook, and other social media are reshaping health care. Health Aff (Millwood) 2009;28(2):361-368 [FREE Full text] [doi: 10.1377/hlthaff.28.2.361] [Medline: 19275991]
60. Lefebvre C. Integrating cell phones and mobile technologies into public health practice: a social marketing perspective. Health Promot Pract 2009 Oct;10(4):490-494. [doi: 10.1177/1524839909342849] [Medline: 19809002]
61. Vance K, Howe W, Dellavalle RP. Social internet sites as a source of public health information. Dermatol Clin 2009 Apr;27(2):133-136, vi. [doi: 10.1016/j.det.2008.11.010] [Medline: 19254656]
62. Cain J, Fink JL. Legal and ethical issues regarding social media and pharmacy education. Am J Pharm Educ 2010 Dec 15;74(10):184 [FREE Full text] [Medline: 21436925]
63. Cain J, Romanelli F, Fox B. Pharmacy, social media, and health: opportunity for impact. J Am Pharm Assoc 2010;50(6):745-751. [doi: 10.1331/JAPhA.2010.09190] [Medline: 21071322]
64. Clauson KA, Ekins J, Goncz CE. Use of blogs by pharmacists. Am J Health Syst Pharm 2010 Dec 1;67(23):2043-2048. [doi: 10.2146/ajhp100065] [Medline: 21098377]
65. Cooper PS, Lipshultz D, Matten WT, McGinnis SD, Pechous S, Romiti ML, et al. Education resources of the National Center for Biotechnology Information. Brief Bioinform 2010 Nov;11(6):563-569 [FREE Full text] [doi: 10.1093/bib/bbq022] [Medline: 20570844]
66. Daniel D. Engaging the masses. Aust Fam Physician 2010 Sep;39(9):615 [FREE Full text] [Medline: 20877760]
67. Donahue A. Google wave: have CTSA-minded institutions caught it? Evid Based Libr Inf Pract 2010 Jan 1;5(4):70-82 [FREE Full text] [Medline: 21461135]
68. Duffin C. Community service. Nurs Stand 2010;24(28):20-21. [Medline: 20391669]
69. Garven JJ. Social media: the word of mouth revolution. Northwest Dent 2010;89(6):33-35, 68. [Medline: 21287815]
70. Greysen SR, Kind T, Chretien KC. Online professionalism and the mirror of social media. J Gen Intern Med 2010 Nov;25(11):1227-1229 [FREE Full text] [doi: 10.1007/s11606-010-1447-1] [Medline: 20632121]
71. Hawker MD. Social networking in the National Health Service in England: a quantitative analysis of the online identities of 152 primary care trusts. Stud Health Technol Inform 2010;160(Pt 1):356-360. [Medline: 20841708]
72. Kaldy J. The social pharmacist: tweeting and posting the way to success. Consult Pharm 2010 Jan;25(1):26-30, 32. [doi: 10.4140/TCP.n.2010.26] [Medline: 20211814]
73. Kind T, Genrich G, Sodhi A, Chretien KC. Social media policies at US medical schools. Med Educ Online 2010;15 [FREE Full text] [doi: 10.3402/meo.v15i0.5324] [Medline: 20859533]
74. Landman MP, Shelton J, Kauffmann RM, Dattilo JB. Guidelines for maintaining a professional compass in the era of social networking. J Surg Educ 2010;67(6):381-386. [doi: 10.1016/j.jsurg.2010.07.006] [Medline: 21156295]
75. Miller RJ. Internet marketing 101. Facial Plast Surg Clin North Am 2010 Nov;18(4):509-516. [doi: 10.1016/j.fsc.2010.06.008] [Medline: 20974391]
76. Pujazon-Zazik M, Park MJ. To tweet, or not to tweet: gender differences and potential positive and negative health outcomes of adolescents' social internet use. Am J Mens Health 2010 Mar;4(1):77-85. [doi: 10.1177/1557988309360819] [Medline: 20164062]
77. Rozental TD, George TM, Chacko AT. Social networking among upper extremity patients. J Hand Surg Am 2010 May;35(5):819-823 e1. [doi: 10.1016/j.jhsa.2009.12.043] [Medline: 20227837]
78. van Manen M. The pedagogy of Momus technologies: Facebook, privacy, and online intimacy. Qual Health Res 2010 Aug;20(8):1023-1032. [doi: 10.1177/1049732310364990] [Medline: 20335498]
79. Angelle D, Rose CL. Conversations with the community: the Methodist Hospital System's experience with social media. Front Health Serv Manage 2011;28(2):15-21. [Medline: 22256507]
80. Baptist AP, Thompson M, Grossman KS, Mohammed L, Sy A, Sanders GM. Social media, text messaging, and email-preferences of asthma patients between 12 and 40 years old. J Asthma 2011 Oct;48(8):824-830. [doi: 10.3109/02770903.2011.608460] [Medline: 21864099]
81. Basak P. Development of an online tool for public health: the European Public Health Law Network. Public Health 2011 Sep;125(9):600-603. [doi: 10.1016/j.puhe.2011.05.006] [Medline: 21864871]
82. Chatterjee P, Biswas T. Blogs and Twitter in medical publications: too unreliable to quote, or a change waiting to happen? S Afr Med J 2011 Oct;101(10):712-714. [Medline: 22272866]
83. Dreesman J, Denecke K. Challenges for signal generation from medical social media data. Stud Health Technol Inform 2011;169:639-643. [Medline: 21893826]
84. Dubose C. The social media revolution. Radiol Technol 2011;83(2):112-119. [Medline: 22106386]
85. Evans P, Krauthammer M. Exploring the use of social media to measure journal article impact. AMIA Annu Symp Proc 2011;2011:374-381 [FREE Full text] [Medline: 22195090]
86. Folkestad L, Brodersen JB, Hallas P, Brabrand M. Laypersons can seek help from their Facebook friends regarding medical diagnosis. Ugeskr Laeger 2011 Dec 5;173(49):3174-3177. [Medline: 22142603]

87. Fortinsky KJ, Fournier MR, Benchimol EI. Internet and electronic resources for inflammatory bowel disease: a primer for providers and patients. Inflamm Bowel Dis 2012 Jun;18(6):1156-1163. [doi: 10.1002/ibd.22834] [Medline: 22147497]
88. Galloro V. Status update. Hospitals are finding ways to use the social media revolution to raise money, engage patients and connect with their communities. Mod Healthc 2011 Mar 14;41(11):6-7, 16, 1. [Medline: 21513035]
89. George DR, Dellasega C. Use of social media in graduate-level medical humanities education: two pilot studies from Penn State College of Medicine. Med Teach 2011;33(8):e429-e434. [doi: 10.3109/0142159X.2011.586749] [Medline: 21774639]
90. Giordano C, Giordano C. Health professions students' use of social media. J Allied Health 2011;40(2):78-81. [Medline: 21695367]
91. Juárez Giménez JC, Puyal González C, Valdivia Vadell C, Palacio Lacambra ME, Vidal Otero J, Cerqueira Dapena MJ. Application of the Technology Web 2.0 in a drug information centre. Farm Hosp 2011;35(6):315.e1-315315. [doi: 10.1016/j.farma.2011.07.001] [Medline: 22035600]
92. Kamel Boulos MN, Resch B, Crowley DN, Breslin JG, Sohn G, Burtner R, et al. Crowdsourcing, citizen sensing and sensor web technologies for public and environmental health surveillance and crisis management: trends, OGC standards and application examples. Int J Health Geogr 2011;10:67 [FREE Full text] [doi: 10.1186/1476-072X-10-67] [Medline: 22188675]
93. Keim ME, Noji E. Emergent use of social media: a new age of opportunity for disaster resilience. Am J Disaster Med 2011;6(1):47-54. [Medline: 21466029]
94. Kishimoto K, Fukushima N. Use of anonymous Web communities and websites by medical consumers in Japan to research drug information. Yakugaku Zasshi 2011;131(5):685-695 [FREE Full text] [Medline: 21532265]
95. Lee JY, Kang DH, Moon HS, Kim YT, Yoo TK, Choi HY, et al. Analysis of content legibility for smartphones of websites of the korean urological association and other urological societies in Korea. Korean J Urol 2011 Feb;52(2):142-146 [FREE Full text] [doi: 10.4111/kju.2011.52.2.142] [Medline: 21379433]
96. Liang BA, Mackey TK. Prevalence and Global Health implications of social media in direct-to-consumer drug advertising. J Med Internet Res 2011;13(3):e64 [FREE Full text] [doi: 10.2196/jmir.1775] [Medline: 21880574]
97. Locke PA. Communication of radiation benefits and risks in decision making: some lessons learned. Health Phys 2011 Nov;101(5):626-629. [doi: 10.1097/HP.0b013e3182299539] [Medline: 21979551]
98. Lyon A, Nunn M, Grossel G, Burgman M. Comparison of web-based biosecurity intelligence systems: BioCaster, EpiSPIDER and HealthMap. Transbound Emerg Dis 2012 Jun;59(3):223-232. [doi: 10.1111/j.1865-1682.2011.01258.x] [Medline: 22182229]
99. Melamud A, Otero P. [Facebook and Twitter, are they already in the pediatrician's office? Survey on the use of social networks]. Arch Argent Pediatr 2011 Oct;109(5):437-444 [FREE Full text] [doi: 10.1590/S0325-00752011000500011] [Medline: 22042075]
100. Nierenberg K, Hollenbeck J, Fleming LE, Stephan W, Reich A, Backer LC, et al. Frontiers in Outreach and Education: The Florida Red Tide Experience. Harmful Algae 2011 May 1;10(4):374-380 [FREE Full text] [doi: 10.1016/j.hal.2011.01.004] [Medline: 21532966]
101. O'Keeffe GS, Clarke-Pearson K, Council on Communications and Media. The impact of social media on children, adolescents, and families. Pediatrics 2011 Apr;127(4):800-804 [FREE Full text] [doi: 10.1542/peds.2011-0054] [Medline: 21444588]
102. Pletneva N, Cruchet S, Simonet MA, Kajiwara M, Boyer C. Results of the 10 HON survey on health and medical internet use. Stud Health Technol Inform 2011;169:73-77. [Medline: 21893717]
103. Sajadi KP, Goldman HB. Social networks lack useful content for incontinence. Urology 2011 Oct;78(4):764-767. [doi: 10.1016/j.urology.2011.04.074] [Medline: 21862115]
104. Tobias E. Using Twitter and other social media platforms to provide situational awareness during an incident. J Bus Contin Emer Plan 2011 Oct;5(3):208-223. [Medline: 22130339]
105. Turner-McGrievy G, Tate D. Tweets, Apps, and Pods: Results of the 6-month Mobile Pounds Off Digitally (Mobile POD) randomized weight-loss intervention among adults. J Med Internet Res 2011;13(4):e120 [FREE Full text] [doi: 10.2196/jmir.1841] [Medline: 22186428]
106. Wolpert Barraza E. [Physician retirement from clinical practice: how and when]. Gac Med Mex 2011;147(3):262-265. [Medline: 21743596]
107. Wong WW, Gupta SC. Plastic surgery marketing in a generation of "tweeting". Aesthet Surg J 2011 Nov;31(8):972-976. [doi: 10.1177/1090820X11423764] [Medline: 22065887]
108. Zhou T, Medo M, Cimini G, Zhang ZK, Zhang YC. Emergence of scale-free leadership structure in social recommender systems. PLoS One 2011;6(7):e20648 [FREE Full text] [doi: 10.1371/journal.pone.0020648] [Medline: 21857891]
109. Omurtag K, Jimenez PT, Ratts V, Odem R, Cooper AR. The ART of social networking: how SART member clinics are connecting with patients online. Fertil Steril 2012 Jan;97(1):88-94. [doi: 10.1016/j.fertnstert.2011.10.001] [Medline: 22088209]
110. Kamel Boulos MN, Sanfilippo AP, Corley CD, Wheeler S. Social Web mining and exploitation for serious applications: Technosocial Predictive Analytics and related technologies for public health, environmental and national security surveillance. Comput Methods Programs Biomed 2010 Oct;100(1):16-23. [doi: 10.1016/j.cmpb.2010.02.007] [Medline: 20236725]

111. Robinson M, Robertson S. Young men's health promotion and new information communication technologies: illuminating the issues and research agendas. Health Promot Int 2010 Sep;25(3):363-370 [FREE Full text] [doi: 10.1093/heapro/daq022] [Medline: 20427372]
112. Skiba DJ. Nursing education 2.0: Twitter & tweets. Can you post a nugget of knowledge in 140 characters or less? Nurs Educ Perspect 2008;29(2):110-112. [Medline: 18459627]
113. Chhanabhai P. A tweet a day keeps the doctor away. N Z Med J 2009 Apr 3;122(1292):97-98. [Medline: 19448781]
114. Coffsky J. Twitter, the lost years and the geeks. J Med Assoc Ga 2009;98(4):28. [Medline: 20131701]
115. Hamilton JA. It's Twitter time. Hosp Health Netw 2009 Aug;83(8):6. [Medline: 19764357]
116. Parslow GR. Commentary: Twitter for educational networking. Biochem Mol Biol Educ 2009 Jul;37(4):255-256. [doi: 10.1002/bmb.20307] [Medline: 21567747]
117. Reisman M. Will pharma twitter? P T 2009 Aug;34(8):421 [FREE Full text] [Medline: 20140105]
118. Thames G. Twitter as an educational tool. J Child Adolesc Psychiatr Nurs 2009 Nov;22(4):235. [doi: 10.1111/j.1744-6171.2009.00208.x] [Medline: 19930305]
119. van den Broek WW. The journal on Twitter. Tijdschr Psychiatr 2009;51(10):711-714 [FREE Full text] [Medline: 19821238]
120. Weissmann G. Walter Benjamin and Biz Stone: the scientific paper in the age of Twitter. FASEB J 2009 Jul;23(7):2015-2018 [FREE Full text] [doi: 10.1096/fj.09-0701ufm] [Medline: 19567372]
121. Williams N. High-level twitter. Curr Biol 2009 May 12;19(9):R350-R351. [Medline: 19455729]
122. anonymous. All a-Twitter about chemistry. Nat Chem 2010 Jul;2(7):511. [doi: 10.1038/nchem.732] [Medline: 20571557]
123. Atkinson L. Do you twitter and tweet? Iowa Med 2010;100(6):24-25. [Medline: 21387980]
124. Martens E. Twitter for scientists. ACS Chem Biol 2010 Feb 19;5(2):149. [doi: 10.1021/cb100033k] [Medline: 20166757]
125. Orsini M. Meet the Web 2010: interactive and informative. Caring 2010 May;29(5):44-45. [Medline: 20642188]
126. Parfitt T. Plant science. Pavlovsk's hopes hang on a tweet. Science 2010 Aug 20;329(5994):899. [doi: 10.1126/science.329.5994.899] [Medline: 20724614]
127. Pattillo R. Are you using Twitter for your next survey? Nurse Educ 2010;35(5):207. [doi: 10.1097/NNE.0b013e3181ed825a] [Medline: 20729679]
128. Williams B. Twitter, facebook and youtube: the TMA turns to social media to engage members. Tenn Med 2010 Feb;103(2):27-28. [Medline: 20345063]
129. Ali FR, Finlayson AE. Tweet to collaborate with poorer nations. Nature 2011 Jul 28;475(7357):455. [doi: 10.1038/475455d] [Medline: 21796195]
130. anonymous. Tweet me. Nat Methods 2011 Apr;8(4):273. [Medline: 21574277]
131. anonymous. Do you use Facebook or Twitter? MGMA Connex 2011 Oct;11(9):18. [Medline: 22379628]
132. Bottles K. Twitter: an essential tool for every physician leader. Physician Exec 2011;37(3):80-82. [Medline: 21675319]
133. Chretien KC, Azar J, Kind T. Physicians on Twitter. JAMA 2011 Feb 9;305(6):566-568. [doi: 10.1001/jama.2011.68] [Medline: 21304081]
134. Curioso WH, Alvarado-Vásquez E, Calderón-Anyosa R. Using Twitter to promote continuous education and health research in Peru. Rev Peru Med Exp Salud Publica 2011 Mar;28(1):163-164 [FREE Full text] [Medline: 21537792]
135. Duffy M. iNurse: Facebook, Twitter, and LinkedIn, oh my!. Am J Nurs 2011 Apr;111(4):56-59. [doi: 10.1097/01.NAJ.0000396558.32490.c1] [Medline: 21451299]
136. Kubben PL. Twitter for neurosurgeons. Surg Neurol Int 2011;2:28 [FREE Full text] [doi: 10.4103/2152-7806.77596] [Medline: 21451727]
137. Leow JJ, Groen RS, Sadasivam V, Kushner AL. Twitter and mobile technology as diagnostic aids in the Democratic Republic of Congo. Am Surg 2011 Nov;77(11):E242-E243. [Medline: 22196637]
138. Mandavilli A. Peer review: trial by Twitter. Nature 2011 Jan 20;469(7330):286-287. [doi: 10.1038/469286a] [Medline: 21248816]
139. McKee M, Cole K, Hurst L, Aldridge RW, Horton R. The other Twitter revolution: how social media are helping to monitor the NHS reforms. BMJ 2011;342:d948. [Medline: 21325389]
140. Miller G. Sociology. Social scientists wade into the tweet stream. Science 2011 Sep 30;333(6051):1814-1815. [doi: 10.1126/science.333.6051.1814] [Medline: 21960603]
141. Morris K. Tweet, post, share: a new school of health communication. Lancet Infect Dis 2011 Jul;11(7):500-501. [Medline: 21842546]
142. Peregrin T. Time to tweet: social networking for surgeons. Bull Am Coll Surg 2011 Feb;96(2):46-48. [Medline: 21452633]
143. Rajani R, Berman DS, Rozanski A. Social networks: are they good for your health? The era of Facebook and Twitter. QJM 2011 Sep;104(9):819-820 [FREE Full text] [doi: 10.1093/qjmed/hcr078] [Medline: 21642360]
144. Reich ES. Researchers tweet technical talk. Nature 2011 Jun 23;474(7352):431. [doi: 10.1038/474431a] [Medline: 21697922]
145. Spence D. All a-Twitter. BMJ 2011;343:d8122. [Medline: 22167796]
146. Trueman MS, Miles DG. Twitter in the classroom: twenty-first century flash cards. Nurse Educ 2011;36(5):183-186. [doi: 10.1097/NNE.0b013e3182297a07] [Medline: 21857333]
147. Weinberger S. Spies to use Twitter as crystal ball. Nature 2011 Oct 20;478(7369):301. [doi: 10.1038/478301a] [Medline: 22012368]

148. Wilson A, Robertson J, McElduff P, Jones A, Henry D. Does it matter who writes medical news stories? PLoS Med 2010 Sep;7(9) [FREE Full text] [doi: 10.1371/journal.pmed.1000323] [Medline: 20856907]
149. Wilson RE, Gosling SD, Graham LT. A Review of Facebook Research in the Social Sciences. Perspectives on Psychological Science 2012 May 16;7(3):203-220. [doi: 10.1177/1745691612442904]
150. Atencio CA, Blake DT, Strata F, Cheung SW, Merzenich MM, Schreiner CE. Frequency-modulation encoding in the primary auditory cortex of the awake owl monkey. J Neurophysiol 2007 Oct;98(4):2182-2195 [FREE Full text] [doi: 10.1152/jn.00394.2007] [Medline: 17699695]
151. Arai YC, Sakakibara S, Ito A, Ohshima K, Sakakibara T, Nishi T, et al. Intra-operative natural sound decreases salivary amylase activity of patients undergoing inguinal hernia repair under epidural anesthesia. Acta Anaesthesiol Scand 2008 Aug;52(7):987-990. [doi: 10.1111/j.1399-6576.2008.01649.x] [Medline: 18477078]
152. Kajikawa Y, de la Mothe LA, Blumell S, Sterbing-D'Angelo SJ, D'Angelo W, Camalier CR, et al. Coding of FM sweep trains and twitter calls in area CM of marmoset auditory cortex. Hear Res 2008 May;239(1-2):107-125 [FREE Full text] [doi: 10.1016/j.heares.2008.01.015] [Medline: 18342463]
153. Rochefort C. The FoxP2 gene makes humans speak and birds twitter. Med Sci (Paris) 2008 Nov;24(11):906-907 [FREE Full text] [doi: 10.1051/medsci/20082411906] [Medline: 19038086]
154. Walker KM, Ahmed B, Schnupp JW. Linking cortical spike pattern codes to auditory perception. J Cogn Neurosci 2008 Jan;20(1):135-152. [doi: 10.1162/jocn.2008.20012] [Medline: 17919084]
155. Chen HC, Kaplan G, Rogers LJ. Contact calls of common marmosets (Callithrix jacchus): influence of age of caller on antiphonal calling and other vocal responses. Am J Primatol 2009 Feb;71(2):165-170. [doi: 10.1002/ajp.20636] [Medline: 19026011]
156. Siemers BM, Schauermann G, Turni H, von Merten S. Why do shrews twitter? Communication or simple echo-based orientation. Biol Lett 2009 Oct 23;5(5):593-596 [FREE Full text] [doi: 10.1098/rsbl.2009.0378] [Medline: 19535367]
157. Bolhuis JJ, Okanoya K, Scharff C. Twitter evolution: converging mechanisms in birdsong and human speech. Nat Rev Neurosci 2010 Nov;11(11):747-759. [doi: 10.1038/nrn2931] [Medline: 20959859]
158. Jin T. Near-infrared fluorescence detection of acetylcholine in aqueous solution using a complex of rhodamine 800 and p-sulfonatocalix[8]arene. Sensors (Basel) 2010;10(3):2438-2449 [FREE Full text] [doi: 10.3390/s100302438] [Medline: 22294934]
159. Rychel AL, Peterson KM, Torii KU. Plant twitter: ligands under 140 amino acids enforcing stomatal patterning. J Plant Res 2010 May;123(3):275-280. [doi: 10.1007/s10265-010-0330-9] [Medline: 20336477]
160. Watson CF, Caldwell CA. Neighbor effects in marmosets: social contagion of agonism and affiliation in captive Callithrix jacchus. Am J Primatol 2010 Jun;72(6):549-558. [doi: 10.1002/ajp.20805] [Medline: 20131362]
161. Elsevier. SciVerse Scopus. 2012. URL: http://www.info.sciverse.com/scopus/about [accessed 2012-06-06] [WebCite Cache ID 68DkY1k64]
162. MIMAS. Web of Knowledge. 2012. URL: http://wok.mimas.ac.uk/ [accessed 2012-06-06] [WebCite Cache ID 68DksoIRC]
163. Twitter. API Terms of Service: Archive. 2012. URL: https://dev.twitter.com/terms/api-terms/archive [accessed 2013-01-27] [WebCite Cache ID 6Dz8UCjzA]
164. Bottles K. kevinmd.com. 2011. How Twitter changed the life of this physician executive consultant URL: http://www.kevinmd.com/blog/2011/05/twitter-changed-life-physician-executive-consultant.html [accessed 2012-07-11] [WebCite Cache ID 694bnDf5T]
165. Neylon C. Science in the open: the online home of Cameron Neylon. 2012 Jun 11. Tracking research into practice: Are nurses on twitter a good case study? URL: http://cameronneylon.net/blog/tracking-research-into-practice-are-nurses-on-twitter-a-good-case-study/ [accessed 2012-07-11] [WebCite Cache ID 694cdpAzb]

Abbreviations

NCBI: National Center for Biotechnology Information
MeSH: Medical Subject Headings

Edited by G Eysenbach; submitted 16.07.12; peer-reviewed by B McGowan, A Pedrana; comments to author 09.10.12; revised version received 27.01.13; accepted 12.05.13; published 18.07.13.

Please cite as:
Williams SA, Terras M, Warwick C
How Twitter Is Studied in the Medical Professions: A Classification of Twitter Papers Indexed in PubMed
Med 2.0 2013;2(2):e2
URL: http://www.medicine20.com/2013/2/e2/
doi:10.2196/med20.2269
PMID:25075237

Original Paper

Developing a Framework to Generate Evidence of Health Outcomes From Social Media Use in Chronic Disease Management

Mark Merolli[1]; Kathleen Gray[1], PhD; Fernando Martin-Sanchez[1], PhD

[1] Health and Biomedical Informatics Centre, The University of Melbourne, Melbourne, Australia

Corresponding Author:
Mark Merolli
Health and Biomedical Informatics Centre
The University of Melbourne
Level 1
202 Berkeley St, Parkville
Melbourne, 3010
Australia
Phone: 61 39035 4943
Fax: 61 39035 8873
Email: mmerolli@student.unimelb.edu.au

Abstract

Background: While there is an abundance of evidence-based practice (EBP) recommendations guiding management of various chronic diseases, evidence suggesting best practice for using social media to improve health outcomes is inadequate. The variety of social media platforms, multiple potential uses, inconsistent definitions, and paucity of rigorous studies, make it difficult to measure health outcomes reliably in chronic disease management. Most published investigations report on an earlier generation of online tools, which are not as user-centered, participatory, engaging, or collaborative, and thus may work differently for health self-management.

Objective: The challenge to establish a sound evidence base for social media use in chronic disease starts with the need to define criteria and methods to generate and evaluate evidence. The authors' key objective is to develop a framework for research and practice that addresses this challenge.

Methods: This paper forms part of a larger research project that presents a conceptual framework of how evidence of health outcomes can be generated from social media use, allowing social media to be utilized in chronic disease management more effectively. Using mixed methods incorporating a qualitative literature review, a survey and a pilot intervention, the research closely examines the therapeutic affordances of social media, people with chronic pain (PWCP) as a subset of chronic disease management, valid outcome measurement of patient-reported (health) outcomes (PRO), the individual needs of people living with chronic disease, and finally translation of the combined results to improve evidence-based decision making about social media use in this context.

Results: Extensive review highlights various affordances of social media that may prove valuable to understanding social media's effect on individual health outcomes. However, without standardized PRO instruments, we are unable to definitively investigate these effects. The proposed framework that we offer outlines how therapeutic affordances of social media coupled with valid and reliable PRO measurement may be used to generate evidence of improvements in health outcomes, as well as guide evidence-based decision making in the future about social media use as part of chronic disease self-management.

Conclusions: The results will (1) inform a framework for conducting research into health outcomes from social media use in chronic disease, as well as support translating the findings into evidence of improved health outcomes, and (2) inform a set of recommendations for evidence-based decision making about social media use as part of chronic disease self-management. These outcomes will fill a gap in the knowledge and resources available to individuals managing a chronic disease, their clinicians and other researchers in chronic disease and the field of medicine 2.0.

(Med 2.0 2013;2(2):e3) doi:10.2196/med20.2717

KEYWORDS
chronic disease; social media; Internet; evidence-based practice, affordances; patient-reported outcomes

Introduction

Overview

Presently, no rigorous frameworks exist informing how to generate evidence of improved health outcomes from social media use in chronic disease management based on robust research design. We wish to address this problem. The work presented in this paper is part of a larger research project, which has two aims. First, on a theoretical level it aims to develop a framework for generating evidence of improved health outcomes from social media use as part of chronic disease self-management. Second, on a practical level it aims to produce a series of recommendations for clinicians suggesting evidence-based decision making about social media use in the same setting (ie, best practice for using social media). We also recognize the shortcomings of much of the research in this domain. Namely, there is a failure to discuss and unpack fundamentals within the research context. In the case of this research, addressing the above study aims requires careful consideration of the following key concepts: social media, evidence-based practice (EBP), affordances, and patient-reported outcomes (PRO). They will be outlined and described in more detail.

Background

Social Media in Chronic Disease Management

Attempts to ratify definitions of social media remain problematic, partly because agreements remain elusive. However, the underlying principles of communication, participation, collaboration and user-centeredness are commonalities [1]. Social media are essentially the services that foster the aforementioned activities and examples of platforms include: social network sites (SNS), blogs, wikis, and video sharing services to name a few [2,3]. In their current form, they may be seen as more highly evolved relatives of Internet 1.0 applications, displaying high social functionality and interaction [4]. 1.0 Internet applications can be seen in simple email and basic websites designed essentially for sourcing information, not creation and sharing [4].

People dealing with chronic disease are increasingly communicating their health concerns online, with poorer health status, stigmatization, isolation, and disconnection outlined as major reasons [5]. Social media have created new opportunities for management, not only for the way in which patients self-manage their conditions but also for clinicians who treat them [5]. These platforms allow patients to choose how they share and receive health information, creating a greater user-centric, engaged, and collaborative experience [6].

Evidence-Based Practice

Despite the apparent infiltration of the social Web into chronic disease management, there is a challenge for clinicians who wish to use social media in patient management within an evidence-based practice (EBP) framework. The challenge is establishing robust recommendations for their use based on best available evidence, while also taking into consideration both clinician expertise and patient preferences [7,8]. We therefore pose the question: How can social media use in chronic disease be approached in a more evidence-based manner?

EBP refers to providing the most effective care to patients based on the best available evidence [7,8]. While this seems self-explanatory, in practice implementing EBP is not always so simple. Traditionally EBP requires clinicians to have the necessary skills, time and effort to sort through research and implement it with their patients. These factors are one possible reason that EBP is not always adhered to clinically [7].

A four-step process [7] suggests that to improve clinician adherence to EBP, the clinician: asks an answerable question about the problem, finds best evidence for management, critically appraises the evidence and integrates it with the unique needs of the patient in mind. However, in order to do this and satisfy EBP principles, a further set of steps [7] outlines that clinicians need to: be aware of valid evidence, accept the evidence to change practice preferences, correctly apply the evidence, have the necessary tools and resources available to do so, act upon the evidence, inform and agree upon treatment with the patient and have patients adhere to the course of action.

This conventional approach to EBP provides the scope for the current research and is applicable to how social media in clinical practice may be considered. As highlighted above, evidence-based decision making about social media use in chronic disease to improve health outcomes also relies not only on an efficient set of processes but on the best available information and guidance being available to clinicians, researchers and patients to make informed decisions [8]. However, the current problem faced with social media use is the relative paucity of high quality literature definitively examining its use in chronic disease management, specifically regarding their effectiveness to improve health outcomes and, therefore lack of research to reliably inform these decisions [9]. One might argue that our knowledge of social media use in chronic disease does not support EBP and needs further refinement.

Offline approaches to chronic disease management have been commonly “unidirectional”. This means they have emphasized clinical research findings above all else, suggesting research should inform clinical practice [8]. However, advancements in technology have caused such processes to evolve. Information flows are now more circular and incorporate information from a variety of sources to inform EBP. Such sources of information include clinician expertise, clinician experience, patient views and patient preferences as part of the decision-making process [8]. Social media use may be broached in the same way. The advent of the social Web represents a shift in how evidence of health outcomes in chronic disease can be generated, as patients are choosing how and when they access information to help manage their condition. It presents a culture of “shared responsibility” among multiple stakeholders [10].

Therapeutic Affordances

“Affordance” as a theory may be relatively foreign to health care and more specifically to this research in understanding how social media are used in chronic disease management to affect health outcomes. Notably, this is perhaps because its origins are from perceptual psychology. However, it has been appropriated to human-computer interaction [11,12]. The idea underlying affordance is that it attempts to explain how people perceive things in their immediate environment differently, perceiving what an object is potentially useful for, not simply what it is [11]. It is for this reason that people must first perceive what an object can be used for before they interact with it. Affordances are perceived uniquely by each of us, suggesting why some people use the same objects differently to others [11]. Within a technology setting, the affordance concept is further refined. While the idea behind an object’s actionable possibilities needing to be perceived is important, the emphasis is placed on the unique relationship that exists between the object and the individual [12]. Greater emphasis is therefore placed on past experiences, end goals for use and one’s belief/value system. Essentially the individual’s goal and context for use will lead to a different perception of the affordances [12,13].

Contemplating the importance of the therapeutic affordances of social media has been a key motivation behind our work. We theorize that different social media interactions can precipitate different effects for different people self-managing chronic disease. We anticipate that this approach may help to guide researchers when conducting research projects in this domain and also guide clinicians when deciding whether social media may form a meaningful part of patient management.

Patient-Reported Outcome Measurement

Patient-reported outcome (PRO) measurement has long been an accepted means to evaluate the success of medical interventions and present evidence of changes to health outcomes. This approach is intended to foster the patient’s perspective of an intervention via outcome measure questionnaires [14]. They provide quantitative data from a patient’s responses to allow the researcher to measure change from the patient’s own perspective, essentially providing a means to quantify qualitative information [14].

The chronic disease landscape in particular pushes us to establish valid PRO measurement research methodologies. The breadth of chronic conditions (eg, chronic pain, cancer, diabetes, arthritis, depression, fibromyalgia, etc) creates a relative lack of consistency in regards to the measures chosen to assess health outcomes. In chronic disease, PRO tools are generally designed to assess functional limitations, symptoms, health status and health-related quality of life (HRQL) [15]. Common questionnaires that have been utilized in studies of social media include: the visual-analogue pain rating scale, profile of mood states, depression anxiety and stress scales and the SF-36 [16]. This variety highlights the need for validated PRO tools to address this problem, allowing research findings to be standardized, generalized and comparable across a range of chronic diseases and different studies.

Methods

To consider how to generate evidence of health outcomes from social media use we propose a dual method that harnesses both qualitative and quantitative research findings and allows them to be combined.

The first part of the method focuses on *identification and examination of the therapeutic affordances of social media* that can help to explain how use of these platforms may underlie favorable health outcomes.

We feel that it is important to examine more closely by what mechanisms social media actually impact health outcomes. As implied in [9], research to date has not adequately examined patient perceptions towards different media and their effect on health outcomes. Propositions are made that future social media research in this domain should consider frameworks that may be used to approach and evaluate what components of social media interventions are best suited to different patient contexts and needs. This approach may help bolster a more effective combination of both online and offline support in chronic disease self-management [9]. It is here that we believe examination of the therapeutic affordances of social media may hold valuable information.

We have conducted an extensive review that has been published, of empirical and theoretical literature in order to define potentially therapeutic affordances of social media in chronic disease management [17]. The findings of this review formed the foundations for an online survey we have recently closed that targeted approximately 200-250 people with chronic pain (PWCP), recruited from large online health networks, smaller online pain support communities and chronic disease organizations, as well as international pain organizations. The survey and its findings will be an important next step in development of this framework, as it aims to refine our findings and understanding of individual perceptions towards health outcomes experienced from use of social media (specifically considering these therapeutic affordances).

Chronic pain has been selected as a suitable subset of chronic disease self-management for our study purposes. The reason is because while chronic pain is a recognized chronic disease in its own right, it is also a common manifestation or comorbidity of many other chronic diseases. This provides us an opportunity to generalize across various chronic diseases in the clinical setting. This is further highlighted in the same literature review we have conducted, presenting examples of various social Web-based interventions impacting health outcomes in chronic pain related studies [17].

The other part of the method focuses on *validated and appropriate outcome measurement* to reliably assess health outcomes from social media use (that more specifically considers these affordances).

Pertinent to our current research is that social media’s validity as chronic disease management tools is uncertain and still largely untested. Formal measurement of health outcomes is required to actively assess whether social media interventions are effective for improving health outcomes in chronic disease [15].

In our case, we refer to tailored interventions specifically taking into consideration the therapeutic affordances of social media. In order to measure effectiveness rigorously, both qualitative and empirical information about these affordances, combined with validated PRO measurement, are required to assess effect on health outcomes. We require an instrument that has been shown to be valid and reliable to assess PRO across a range of chronic diseases and for a range of different outcomes. We plan to test the ability of one such tool (to be further described in this paper) to produce clinically significant and replicable evidence of health outcomes from social media studies considering therapeutic affordances.

Results

Evidence of the Therapeutic Affordances of Social Media in Chronic Disease Management

Our literature review identified evidence of self-reported health outcomes and other effects seen from social media use in different chronic disease scenarios. This evidence is presented in full in the review, which has been published elsewhere [17]. To briefly summarize, we were able to highlight associations between various social platforms and improved health outcomes. However, relationships and linkages are more difficult to infer. Without closer evaluation, review tenuously explained the connection between platforms and outcomes, doing little to describe what patients attribute any improvements to or how social media meet their individual needs. Upon closer investigation it was possible to qualitatively identify a series of therapeutic affordances that we hypothesize may better explain mechanisms behind how social media have an effect on health outcomes. The affordances that appear significant in this regard we have labeled: identity, flexibility, structure, narration and adaptation [17]. These therapeutic affordances form the core information we are further exploring in the online survey. We will refine them and further examine their presence or absence via the aforementioned survey results to enable us to explore their perceived value in more detail before formal clinical effectiveness can add further validation via a planned pilot intervention. While we expect that different researchers and clinicians will have their own opinions and ideas regarding social media's affordances, we believe this structure presents a robust approach for generating evidence of health outcomes from social media use.

Measuring the Effectiveness of the Therapeutic Affordances of Social Media: PRO Measurement

We have decided to explore and utilize a particular instrument of PRO measurement, the Patient-Reported Outcomes Measurement Information System (PROMIS). We are doing this because PROMIS is an item bank system of commonly studied PROs that has been tested and calibrated, demonstrating good reliability and validity across a range of chronic diseases, and shows moderate to strong correlations with other common outcome measures [18]. PROMIS provides great scope for this research as its generalizability has the advantage of allowing comparability across a range of chronic diseases, as item banks are not designed to differentiate subtypes of symptoms from different diseases (ie, pain in fibromyalgia vs pain in arthritis for example) [18]. Rather, they aim to delineate based on severity of symptoms or impairment of function. The focus is on physical, mental, and social health (including sub domains of: physical function, pain, distress, fatigue, social function, global health, etc). The aim is that this would be appropriate for patients with a wide range of chronic diseases [18] and has the potential to address the generalizability and consistency issues that come from combining two complex areas—chronic disease and social media.

Discussion

Overview

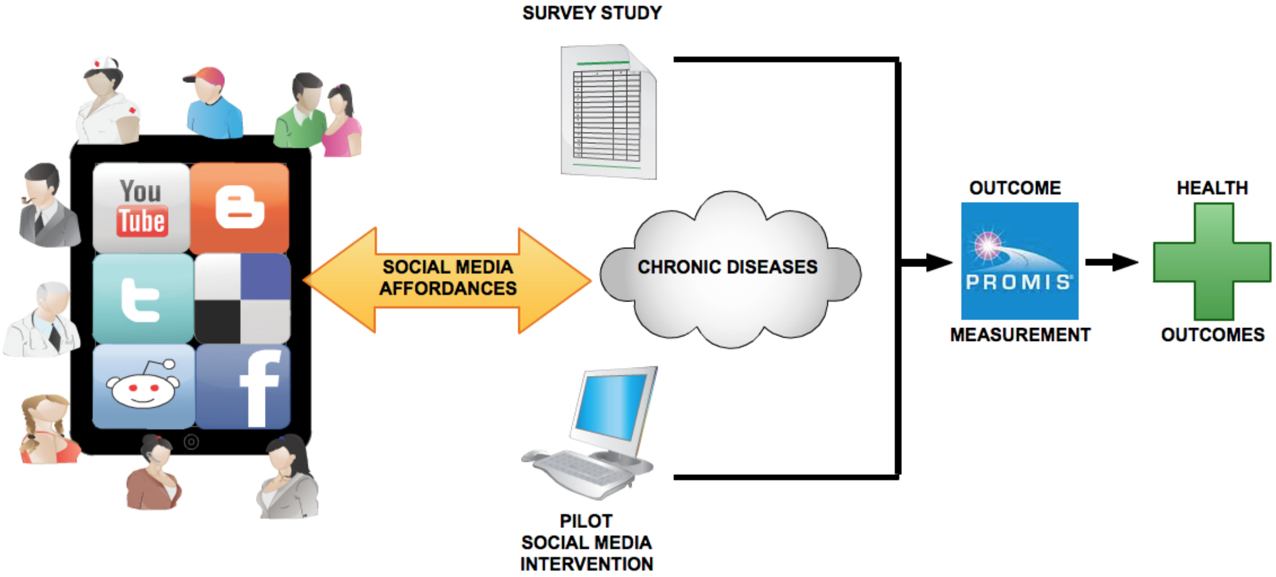
While literature exists outlining health outcomes from social media use, few attempts have been made to investigate how social media operate to meet the specific and individual needs of different chronic disease patients. As more social media uses emerge and further reports are published, researchers will require even more comprehensive methodologies and meta-analytic research designs to synthesize collective knowledge in the quest towards incorporating social media use into EBP [9,10]. The information presented in the results section forms the basis of our proposed framework below.

Our Proposed Framework

Our proposed framework represents a research approach for generating evidence of health outcomes from social media use in chronic disease management (Figure 1). Its design also provides the basis for evidence we expect to see of health outcomes from social media use; as well it forms the basis for informing practical recommendations for health professionals to assist them with their decision-making about social media use for patient self-management.

The proposed framework follows several steps. First, taking into account the uses and interactions social media affords people with chronic disease, the framework begins with a thorough review of the literature of social media use in chronic disease management [17]. Second, people with chronic disease are *surveyed* regarding their perceptions of the therapeutic affordances of social media and how social media use may lead to health outcomes. Then, they undergo an *online pilot intervention* testing how social media can be targeted (considering these affordances) to better tailor management to individual needs. Finally, PRO from both survey and online intervention are measured using specific item banks from PROMIS to provide empirical evidence of health outcomes. Using standardized PROMIS item banks allows for health outcome questions in the survey and online intervention to be tailored depending on the chronic disease being studied, as well as the primary outcome measure of interest (ie, pain interference, physical function, mood, cognition, sleep, QOL, etc) [18].

Figure 1. Generating evidence of health outcomes from social media use.



Progress to Date and Future Directions

As outlined, progress to date has expressed the complexities involved and how important it is to be systematic when approaching the study of health outcomes in chronic disease using social media. This is why we feel research would benefit from frameworks detailing the evidence synthesis process. We began our research by examining the chronic disease landscape to gain a deeper knowledge of management both offline and online. This enabled a more focused approach to then explore social media (culminating in the literature review that we have alluded to [17]). We emphasize and introduce the concept of "therapeutic affordances" of social media because current research lacks discussion of the connection between use and health outcomes. Despite affordances being a somewhat enigmatic construct, the affordance approach to social media has recently been studied in a similar fashion across other domains. For example, one study published in peer-reviewed literature describes affordances in organizational communication processes [13]. We bring the same concept to chronic disease management and hope that its applicability can be further explored within a variety of health scenarios.

The global online survey is now closed and recruited 231 participants. In the coming months we plan to present findings of the survey and describe them in a future paper, which is currently beyond the scope of the present paper. We anticipate the results will provide a refined understanding of both how social media affect health PROs and also how people with chronic pain perceive this to be so. The steady flow of contact and interest in the survey, and coherence of preliminary results indicates that participants have been able to follow and make sense of the work. This provides early evidence and validation supporting the theoretical basis of our framework. Unfortunately, this is not expected to be rigorous enough to inform decision-making about social media use in the clinical setting. Future plans of our research are to conduct a pilot intervention in order to further develop and validate our framework and bring us one step close to evidence-based decision making about social media use in chronic disease self management.

Strengths and Limitations

Standardized outcome measurement lies at the heart of bringing our research together and without it the reliability, validity, and generalizability of this project will be of limited value. For this reason we have selected and discussed PROMIS as the outcome instrument we are using to investigate the PROs in both our survey and also the pilot intervention. PROMIS has many strengths that suit this research. Its item banks (or outcome domains) can be translated into "short-forms" of targeted questions to suit any study, its item banks have been tested amongst large heterogeneous patient cohorts and they have been tested against other commonly used outcomes measures [18]. However, perhaps the biggest strength of PROMIS lies in its ability to be applied to a wide range of chronic conditions and to measure a wide range of functional outcome domains, correlating strongly with all. No questions are specific to any one cohort of patients, they are generalizable and therefore permit a large range of participants to supply PRO data without needing to be too disease specific [18]. For this reason we believe it is ideal as it can fit into the survey approach and then be cross-referenced to a pilot intervention. This also allows for researchers conducting future studies into the health outcomes from social media use in chronic disease to substitute the functional outcome domain to reflect their own study's interests and needs.

Conversely, we acknowledge that while initial PROMIS item banks have been shown to display reliability, validity and accuracy when compared to other common outcome measures, longitudinal data is still to be finalized. PROMIS researchers are confident however, that this will also be shown [18].

Future Considerations

As research and clinical practice progresses, the challenge for clinicians who plan to use social media in patient management or recommend them as part of individual self-management will persist. This will continue unless research into social media in this domain establishes evidence-based frameworks [8]. While we have previously found that there is a paucity of rigorous studies investigating the health outcomes of social media use [17], a 2013 study investigating Web 2.0 chronic disease self-management has been published that goes some way to addressing this [9]. The authors propose use of the Reach, Efficacy, Adoption, Implementation, and Maintenance (RE-AIM) framework for "evaluating" the effectiveness of Web 2.0 interventions in a methodical evidence-based fashion. The framework is described in [19] and is a five-step method that describes the reach, efficacy, adoption, implementation, and maintenance of social media interventions for chronic disease self-management. It is hypothesized that visiting the RE-AIM framework may be helpful to develop social media interventions that are more likely to be adopted in practice [9,19,20]. It is certainly worthy of further consideration. The aim of the current research is to support the same spirit of evidence-based Web 2.0 interventions in clinical practice, thus making social media use in chronic disease management more accountable. Evidence of the benefits and/or limitations of social media use will greatly enhance the potential of these technologies in the future. However, while the RE-AIM framework is used for study "evaluation" purposes, our research puts forward a unique "evidence-generation" framework for consideration in future studies. This is to aid in informing research design from the early research phases, not just at the intervention success evaluation stage.

Conclusions

Our research to date on framework development for conducting research into health outcomes in chronic disease centers on a deeper investigation of the therapeutic affordances of social media in this context. Second, we emphasize the importance of valid and standardized PRO measurement. Together, affordances and PRO form the basis of a novel methodological approach for how to generate evidence of health outcomes from social media use, as well as clinical recommendations for evidence-based decision-making about social media use in chronic disease management. With further work and collaboration, this research method and framework may aid research design for social media interventions and allow for greater improvements in health outcomes to be recognized.

Acknowledgments

The authors would like to thank the Institute for a Broadband Enabled Society (IBES) at the University of Melbourne, Australia for ongoing support of this research. Please note that any opinions and theories presented in this work are our own and do not represent those of IBES.

Conflicts of Interest

None declared.

References

1. Van De Belt TH, Engelen LJ, Berben SA, Schoonhoven L. Definition of Health 2.0 and Medicine 2.0: a systematic review. J Med Internet Res 2010;12(2):e18 [FREE Full text] [doi: 10.2196/jmir.1350] [Medline: 20542857]
2. Hesse BW, O'Connell M, Augustson EM, Chou WY, Shaikh AR, Rutten LJ. Realizing the promise of Web 2.0: engaging community intelligence. J Health Commun 2011;16 Suppl 1:10-31 [FREE Full text] [doi: 10.1080/10810730.2011.589882] [Medline: 21843093]
3. Schein RW, Wilson K, Keelan J. A Report for Peel Public Health: Ontario, Canada. 2010. Literature review on effectiveness of the use of social media URL: http://www.peelregion.ca/health/resources/pdf/socialmedia.pdf [WebCite Cache ID 6Ifu7G0Z9]
4. Cormode G, Krishnamurthy B. Key Differences Between Web 1.0 and Web 2.0. First Monday: Peer Reviewed Journal of the Internet 2008;13(6) [FREE Full text]
5. Seeman N. Web 2.0 and chronic illness: new horizons, new opportunities. Healthc Q 2008;11(1):104-8, 110, 4. [Medline: 18326388]
6. Kamel Boulos MN, Wheeler S. The emerging Web 2.0 social software: an enabling suite of sociable technologies in health and health care education. Health Info Libr J 2007 Mar;24(1):2-23. [doi: 10.1111/j.1471-1842.2007.00701.x] [Medline: 17331140]
7. Glasziou P, Haynes B. The paths from research to improved health outcomes. ACP J Club 2005;142(2):A8-10. [Medline: 15739973]
8. Dijkers MP, Murphy SL, Krellman J. Evidence-based practice for rehabilitation professionals: concepts and controversies. Arch Phys Med Rehabil 2012 Aug;93(8 Suppl):S164-S176. [doi: 10.1016/j.apmr.2011.12.014] [Medline: 22683207]
9. Stellefson M, Chaney B, Barry AE, Chavarria E, Tennant B, Walsh-Childers K, et al. Web 2.0 chronic disease self-management for older adults: a systematic review. J Med Internet Res 2013;15(2):e35 [FREE Full text] [doi: 10.2196/jmir.2439] [Medline: 23410671]
10. Bloomrosen M, Detmer DE. Informatics, evidence-based care, and research; implications for national policy: a report of an American Medical Informatics Association health policy conference. J Am Med Inform Assoc 2010;17(2):115-123 [FREE Full text] [doi: 10.1136/jamia.2009.001370] [Medline: 20190052]
11. Gibson J. The ecological approach to visual perception. Hillsdale, N.J: Lawrence Erlbaum Associates; 1986.
12. Norman D. The design of everyday things. London: MIT Press; 1998.

13. Treem JW, Leonardi PM. Social Media Use in Organizations: Exploring the Affordances of Visibility, Editability, Persistence, and Association. SSRN Journal 2012;36:143-189. [doi: 10.2139/ssrn.2129853]
14. Baldwin M, Spong A, Doward L, Gnanasakthy A. Patient-reported outcomes, patient-reported information: from randomized controlled trials to the social web and beyond. Patient 2011;4(1):11-17 [FREE Full text] [doi: 10.2165/11585530-000000000-00000] [Medline: 21766890]
15. Song H, Nam Y, Gould J, Sanders WS, McLaughlin M, Fulk J, et al. Cancer survivor identity shared in a social media intervention. J Pediatr Oncol Nurs 2012;29(2):80-91. [doi: 10.1177/1043454212438964] [Medline: 22472482]
16. Dworkin RH, Turk DC, Farrar JT, Haythornthwaite JA, Jensen MP, Katz NP, IMMPACT. Core outcome measures for chronic pain clinical trials: IMMPACT recommendations. Pain 2005 Jan;113(1-2):9-19. [doi: 10.1016/j.pain.2004.09.012] [Medline: 15621359]
17. Merolli M, Gray K, Martin-Sanchez F. Health outcomes and related effects of using social media in chronic disease management: A literature review and analysis of affordances. J Biomed Inform 2013 May 20. [doi: 10.1016/j.jbi.2013.04.010] [Medline: 23702104]
18. Cella D, Riley W, Stone A, Rothrock N, Reeve B, Yount S, PROMIS Cooperative Group. The Patient-Reported Outcomes Measurement Information System (PROMIS) developed and tested its first wave of adult self-reported health outcome item banks: 2005-2008. J Clin Epidemiol 2010 Nov;63(11):1179-1194 [FREE Full text] [doi: 10.1016/j.jclinepi.2010.04.011] [Medline: 20685078]
19. Glasgow RE, Vogt TM, Boles SM. Evaluating the public health impact of health promotion interventions: the RE-AIM framework. Am J Public Health 1999 Sep;89(9):1322-1327. [Medline: 10474547]
20. Glasgow RE, Dickinson P, Fisher L, Christiansen S, Toobert DJ, Bender BG, et al. Use of RE-AIM to develop a multi-media facilitation tool for the patient-centered medical home. Implement Sci 2011;6:118 [FREE Full text] [doi: 10.1186/1748-5908-6-118] [Medline: 22017791]

Abbreviations

EBP: evidence-based practice
HRQL: health-related quality of life
IBES: Institute for a Broadband Enabled Society
PRO: patient-reported outcome
PROMIS: Patient-Report Outcome Measurement Information System
PWCP: People With Chronic Pain
RE-AIM: Reach, Efficacy, Adoption, Implementation, and Maintenance
SNS: social network sites

Edited by G Eysenbach; submitted 15.05.13; peer-reviewed by N Diviani; comments to author 15.06.13; accepted 18.07.13; published 08.08.13.

Please cite as:
Merolli M, Gray K, Martin-Sanchez F
Developing a Framework to Generate Evidence of Health Outcomes From Social Media Use in Chronic Disease Management
Med 2.0 2013;2(2):e3
URL: http://www.medicine20.com/2013/2/e3/
doi:10.2196/med20.2717
PMID:25075238

Original Paper

Health Care Social Media: Expectations of Users in a Developing Country

Amrita[1*], BE (CS), PGDBA, MS; Dhrubes Biswas[1*], BTech (EEE), MS, PhD

Indian Institute of Technology (IIT), Rajendra Mishra School of Engineering Entrepreneurship (RMSOEE), Kharagpur, India

[*]all authors contributed equally

Corresponding Author:
Amrita, BE (CS), PGDBA, MS
Indian Institute of Technology (IIT)
Rajendra Mishra School of Engineering Entrepreneurship (RMSOEE)
Indian Institute of Technology
Kharagpur, 721302
India
Phone: 91 03222 ext 281091
Fax: 91 3222 255303
Email: iamthealchemist@gmail.com

Abstract

Background: Affordability, acceptability, accommodation, availability, and accessibility are the five most important dimensions of access to health services. Seventy two percent of the Indian population lives in semi-urban and rural areas. The strong mismatched ratio of hospitals to patients, rising costs of health care, rapidly changing demographics, increasing population, and heightened demands in pricing for technological health care usage in emerging economies necessitate a unique health delivery solution model using social media. A greater disease burden lies in the health care delivery in developing country like India. This is due to the lack of health care infrastructure in the majority of semi-urban and rural regions. New techniques need to be introduced in these regions to overcome these issues. In the present scenario, people use social media from business, automobiles, arts, book marking, cooking, entertainment, and general networking. Developed and advanced countries like the United States have developed their communication system for many years now. They have already established social media in a number of domains including health care. Similar practice incidences can be used to provide a new dimension to health care in the semi-urban regions of India.

Objective: This paper describes an extended study of a previous empirical study on the expectations of social media users for health care. The paper discusses what the users of social media expect from a health care social media site.

Methods: Multiple regression analysis was used to determine the significance of the affect of four factors (privacy, immediacy, usability, and communication) on the usage of health care social media. Privacy, immediacy, usability, and communication were the independent variables and health care social media was the dependant variable.

Results: There were 103 respondents who used the online questionnaire tool to generate their responses. The results from the multiple regression analysis using SPSS 20 showed that the model is acceptable, with P=.011, which is statistically significant on a P<.05 level. The observed F value (2.082) in ANOVA was less than the given value in the F table (2.61), which allowed us to accept the hypothesis that the independent variables influence the dependant variable. The users of social media in India expect that they can best utilize social media through emergency service information. They want to be able to learn the operations of the social media site quickly and expect to know about health camps and insurance collaborations. However, people like to become friends with people with similar interests based on their interests identified.

Conclusions: Health care social media requires intelligent implementation in developing economies. It needs to cater to the expectations of the users. The people in India, especially those in urban and semi-urban regions, are very interested in accepting the system.

(Med 2.0 2013;2(2):e4) doi:10.2196/med20.2720

KEYWORDS

health care; social media; developing economy; user expectations; networking; eHealth; online patient care; online medical advice

Introduction

Background

Social media is now a buzzword in the new generation of digital communications. Social networks are networks that link people and machines [1]. The way the world saw Web 1.0 during 1990's [2] has completely changed by the emergence of social media. Mobile and handheld devices having social networking applications at affordable prices have made people more conversant with social media usage. In the present scenario, people use social media right from business, automobiles, arts, bookmarking, cooking, entertainment, and general networking. It has created a highly collaborative virtual environment where individuals and communities share, and modify user-generated content. This process mostly employs mobile and Web-based technologies [3]. Social media has created a change in the society and is getting deployed in various domains. It is being tested for its effectiveness for different levels including health care. This change is dramatic in health care where the focus has shifted from costly high-tech health care to non-traditional health care using social media.

In developing countries, a number of attempts have been made to reform health care for the underprivileged. However, it is mostly the private sector players [4] who create a difference for the underprivileged. Besides the local players and entrepreneurs, there are other successful efforts in health care delivery for developing telemedicine like Voxiva, IBM health care solutions, De Novo Group, Arvind Eye Care System, Narayana Hrudayalaya, and Pilot Projects by Indian Space Research Organization (ISRO) with Apollo Hospital. Moreover, wide prevalence of mobile usage adds to the flexibility of the health care delivery system in India. Recent reports on mobile usage shows that India constitutes 10% of the total mobile usage in the world. This is very clear when we look at the 1.2 billion population residing in India out of which 72% belong to rural areas.

Moreover, technology has influenced the spread of information and the manner it can be disseminated to the world. Media and its landscape has seen significant transformation in the last decade and social media is increasingly replacing the traditional media [5-8]. The wide acceptance of social media for the last few decades has triggered research comparing traditional media and social media [9]. They have been analyzed for usefulness in various domains such as marketing communication, cost effectiveness, sales performance, health care and so on. An individual's social network is the one surrounded by network of relationships and its ties [10]. A general tendency of influence of social media has been noted from the online users, for instance, book reviews affects the sales [11,12]. However, researchers have also confirmed the interrelatedness of both the media [6,9,13].

The developed and advanced countries like the United States have developed their interrelated communication system many years from now. This includes the usage of social media in almost every domain including health care. Manhattan Research Group found long back in 2002 [14] that the total e-Patients zone of influence was 166.5 million Americans. The introduction of new technologies and interrelated media has made the society well informed about the happenings in the other parts the world too in various ways. The modern Indian society is now well informed of the new technologies being developed for health care too. Conversely, they are ignorant about the learning, usage, and outcomes of the same. There lies the issue of "Technology to Health (T2H)" Gap [15].

The world average of beds per 1000 patients is 2.6 where as in India it is only 0.7 [16]. This is just an example of poor infrastructure in India. Chaudhry et al, (2005) [17] has given a picture of Indian villages which has also revealed that households descent into poverty [18] due to three principal factors, that is, health expenses, high-interest private debt, and social and customary expenses of which health care expenses figured prominently in more than half of all cases of decline into poverty. Countries all around the world especially the BASIC (Brazil, South Africa, India, and China) are struggling to address the ever-increasing costs, poor or inconsistent quality, and inaccessibility to timely health care.

Everyone needs similar levels and quality of health care services particularly five dimensions of access to health services as affordability, acceptability, accommodation, availability, and accessibility [19,20]. The strong mismatch of ratio of hospitals to patients, rising costs of health care, rapidly changing demographics, increasing population and heightened demands in pricing for technological health care usage in emerging economies necessitate a unique health care reform. The health care system is getting unmanaged by the high-technology introduction as well as high price points of the interest groups. Furthermore, it is adding to the already existing realm of new and costly technologies in health care [21].

However, these challenges can be relieved for those who might use information technology to an extent by knowing about similar kinds of patients with same disease patterns, share their experiences and many more by the introduction of a one step ahead social media tool for health care. Thus, social media for health care as technology intervention strategy in information technology may exert their influence through both volume and price effects. Technological interventions at every stage in innovation will direct to sustainable health care system especially in the emerging economies context. Research has also confirmed the value addition and trust involved in a continuous online development of the contents for patients [22].

The augmentation of health care delivery system needs a large reform in the developing economy context. This is directly derived from the poor health care scenario presented in the semi-urban and rural regions. The reform through information and communication tools (ICT), that is, social media might be looked at provided the users are given training. This leads to various research issues. They are: What are the factors that determine the health care social media? Would the people in semi-urban and rural regions of developing countries prefer the intervention to other existing systems? How much information sharing would they be comfortable with? How much would they expect from the health care social media given to them? Hence, this leads to an organized and methodical study of these issues.

This paper makes an attempt to analyze the expectations for health care social media of the already existing users of the social media. The expectations are measured in terms of Privacy, Immediacy, Usability [23], and Communication [24,25].

Technology to Health Gap in India

It is true to state that these health care reforms are seen mostly in the developed countries. There are few instances of social media usage for health care in the metropolitan areas in India. The world average comparison is just an example of poor infrastructure in India. Amrita et al 2010, [15] mentions that the “T2H Gap” in health care originates from the adversities of affordability, accessibility, and availability. An adoption of proper ICT based health care model for cheaper and quality health care can alone solve this problem to a great extent.

It has also been observed that the wide prevalence of mobile usage adds to the flexibility of the health care delivery system in India. Recent reports on mobile usage shows that India constitutes 10% of the total mobile usage in the world. The Internet users in India are 11.4% [26], which shows information technology can provide a new platform for them.

The World Health Statistics 2012 [27] shows the inadequate health care infrastructure and workforce. The urban regions have four times more doctors and three times nurses than in the rural regions in India. Even though India has quality education and medical institutes, most of them are located in urban regions. This results in health care services deficits in semi-urban and rural regions. The private health sector is currently leading in the service delivery. The statistics show it has 80% of all doctors, 26% of nurses, 49% of beds, and 78% of ambulatory services and 60% of in-patient care. This leads to maximum out-of-pocket expenditure by the large semi-urban and rural population. The gap in health care demand and supply can be met when we implement unique service delivery models in health care using social media.

The motivation of this paper lies in the huge prevalence and acceptance of viral marketing and social media marketing by the people in India. It shows that they are open to new dimensions for comfortable lives. It has already been seen that the drug companies are using social-media to promote their brands. Research has reported positive inclination towards the belief levels for using wiki-based information for health care [28]. Hence, information technology through social media can be used to create better health care information in India.

Why Health Care Social Media in India?

There are a number of health care networks which includes doctors, patients, nurses, pharmacists and who so ever are interested in health care. There are also a number of applications in the Internet including Google health, medicine 2.0 and health 2.0. All of them target to the population who are already using Internet and can understand computer and information technology. It has been seen from the survey of Internet, that there are many social media networks which deal with doctor networks, nurses’ networks, popular disease support forums, health blogs, patients’ voices, and expert answers.

It might also be stated that various efforts have been made to make health care accessible for the rural and semi-urban population. These efforts are more towards the use of mobile and hand held devices for transferring patients’ information to the relevant doctors. Mobile hospitals and similar efforts have also been made in parts of Africa and Brazil.

The growing body of literature on social media and health care is generally concerned with the advertisers to find new customers. However, scarce literatures of social media for effectiveness of health care especially in developing countries have been viewed.

Mobile phones for health care are on the cusp of spurring an information revolution in such regions [29]. Studying the expectations and influencing variables of a social media network around the usage of mobile technology in coordination of a public-private-partnership might lead to the cost cutting of expenditure on health care. Lot of work is being done in social media domain for finding effectiveness of marketing, advertising and consumer relations. However, it has not been seen in the perspective of health care delivery in semi-urban setting in emerging economy. Authors present in this paper the expectations of the users of developing economy, who would intend to use such a health care social media. These expectations in future can be utilized to implement such system for the semi-urban and rural regions in such economies.

Objective

Social media provides an substantial amount of information, having the potential to attract significant audience [30]. The similar practice incidences can be used to provide a new dimension to the health care in Indian semi-urban regions. Before we move to the specifications of understanding what the semi-urban users of social media in India, it is required that we understand what the existing users expect. The factors that affect the users of health care social media were found in the previous work [24]. These factors are not tested to answer the key question: Which are the most influencing variables that affect the expectations of users of health care social media in a developing country?

There are a number of health care networks, which includes doctors, patients, nurses, and pharmacists, who are interested in health care. Most of them target to developed and advanced countries. There are not many studies that refer to the developing country perspective. Hence, the objective of the paper is aligned with the aim to understand the social media users in developing country. This might lead us the way to realize how we could proceed further for building any social media tool for developing countries.

Methods

Overview

Researchers on social media techniques have mentioned seven functional elements [3]: identity, conversations, sharing, presence, relationships, reputation, and groups. Many other researchers have confirmed and cited these building blocks of social media as attributes for online strategy, public affairs [31], product development through co-creation, tourism, health care [32], and many more not mentioned here.

This study is based on the primary data collected during January 2013 using a survey questionnaire form created in the Google forms in the Internet. This work is based on our previous published paper [24], where we determined significant components for health care social media. We reported in our previous work that: privacy, immediacy, and usability are most the significant factors for health care social media. The results showed that the users of social media have significant privacy value for their health care issues on the Internet. At the same time face-to-face meeting is rejected. The opinions only from doctors would have negative influence, at the same time also not being open for frank suggestions. However there is a preference to be viewed as part of interest columns on health issues. Simple user interface has a larger acceptance than the advanced user settings. Learning from the earlier work and having unstructured discussions with few of the respondents, we added one more factor, that is, communication for further investigation in this work.

The extensive use of social media has already perturbed the common understanding of the *privacy*, [3] though the privacy ideology remains the same as earlier. The users understand that the organization of information in such a way which maintains the individual decorum and independence. The immediacy and communication [3] are the vital parts for sharing information on health care interests. In the presence of above components, another important issue is *usability* preferences, which would determine how frequently the users like to visit the health care social media.

Hence, learning from the previous work and results, we designed the factors to: *privacy, immediacy, usability,* and *communication* in the current work. The first three items were confirmed from previous work. The last item emerged from the learning with unstructured interviews of more than 46 users.

Sampling Method

The paper is based on the premise that the health customer is able to choose from where and whom they get treated or prefer some close relatives advices for taking such decisions. The users are free to use and have their views on health information over the Internet or social media.

Since we have targeted the users of the social media as the target group, we did not define any premise of distance and place of stay. The only clause we have used for the respondents is that they should be Indian citizens staying in India. Hence we have relied on the snowball sampling method to spread the online survey link. This also helped us identify the few duplications and quality of information.

Questionnaire Design

Based on our previous experience of the published paper, we designed our questionnaire to remove as well as include the defining constructs for 4 identified factors. Additionally, we designed questions to know the social media presence, preference and health care social media. The distribution of the questions were as such that 42 items were created, 5 each for 4 independent variables and 4, 7, and 11 for social media presence, health care preference, and demography.

The questionnaire was designed as a webpage form using the Google forms available online. The link was shared online through emails, Facebook, Twitter, and interest forums. Sections A to D were designed using 5 point Likert scale. Options ranging from “Strongly Disagree” to “Strongly Agree” for A to C and “Never” to “Always” in the case of D was used. Sections from E to G were majorly multiple choices along with other few to enter themselves as well as select from given choices.

Data Collection

The response of the online Google form automatically got registered in the Excel format. The response rate was good during the first time intimation and dropped after a few days. After 5 to 6 reminders, 103 responses were generated. It is assumed that the sample is random attributing to the wide demography of the respondents. The data points count, that is, $n=103$ we can say referring to the Central Limit Theorem ($n>30$) that the sample size is large and normally distributed.

The idea of using online data collection was generated for the reason that our focus was more on the users of the social media and Internet. Moreover, the large audience, reduced cost of travel, quick time to gather responses, easy data management, and less item non-response led to the decision of online data collection.

The demographic profile of the respondents’ show that majority are between the age groups of 19 to 25. Qualification is majorly in graduation and post graduation. Occupation-wise most of them are professionals. Maximum belong to urban and semi-urban regions. The income shows that maximum have the average income between 1819 to 7273 USD but the next income group has more than 14,545 USD. The sample is representative of the social media users keeping in mind the domicile status. Conversely, maximum response is from the age group 25 to 30 years and below. This shows that the online social media users in India are mainly the younger generation.

Results

Variables

The four determinants—privacy, immediacy, usability, and communication of health care social media—have been taken as the predictor variables pertaining to multiple regressions. Health care social media has been considered as the dependent (outcome) variable.

Hypothesis

Our null hypothesis for determination of the regression has been taken such that the four independent variables (privacy, immediacy, usability, and communication) do not depend on the dependent variable health care social media. Hence, the null hypothesis was designed as health care social media is not dependent on privacy, immediacy, usability, and communication, and are not related. Therefore, the alternative hypothesis is that health care social media is dependent on the variables privacy, immediacy, usability, and communication.

Based on the null hypothesis, several propositions are drawn to form the conceptual model (Textbox 1).

The data obtained from survey was regressed using the SPSS 20 package for analysis. We present the results of the regression from Model fit statistics in Table 1.

Table 1 depicts the variability of the data through R^2. The value of .337 shows that a fair amount of variability lies in the dataset. However, the adjusted R^2 show a lesser amount of variability.

The significance value in ANOVA (Table 2, at 90% confidence interval) shows .011, which is less than 0.05. Hence the model is considered as significant. As per Table 1 results, we obtained the observed value of the $F_{20,82}$=2.082. However the test statistics from the F distribution table for $F_{20,82}$=2.61, which is greater than the observed value. Hence this rejects the null hypothesis.

So it can be said that the independent variables privacy, immediacy, usability, and communication has an influence on the dependent variable, health care social media. Accepting the alternate hypothesis, we proceed to explain the significant influences of the independent variable through the reporting of unstandardized coefficients (Table 3).

Textbox 1. Propositions of the conceptual model.

Proposition H1: the predictor variable “privacy” has no influence on health care social media.

Proposition H2: the predictor variable “immediacy” has no influence on health care social media.

Proposition H3: the predictor variable “usability” has no influence on health care social media.

Proposition H4: the predictor variable “communication” has no influence on health care social media.

Table 1. Reporting of the model summary.[a]

Model	R	R^2	Adjusted R^2	Standard error of the estimate
Statistics	.580[b]	0.337	0.175	1.104

[a] Dependent variable: Health care social media

[b] Predictors: (Constant), Communication 5, Communication 4, Privacy 1, Communication 2, Immediacy 1, Privacy 4, Usability 5, Immediacy 3, Usability 2, Immediacy 5, Communication 1, Communication 3, Privacy 5, Privacy 2, Usability 3, Immediacy 2, Usability 4, Privacy 3, Usability 1, Immediacy 4

Table 2. Reporting of ANOVA[a] statistics.

Model	Sum of squares	Degrees of freedom	Mean square	F	Significant difference
Regression	50.743	20	2.537	2.082	.011[b]
Residual	99.936	82	1.219	N/A	N/A
Total	150.68	102	N/A	N/A	N/A

[a] Dependent variable: Health care social media

[b] Predictors: (Constant), Communication 5, Communication 4, Privacy 1, Communication 2, Immediacy 1, Privacy 4, Usability 5, Immediacy 3, Usability 2, Immediacy 5, Communication 1, Communication 3, Privacy 5, Privacy 2, Usability 3, Immediacy 2, Usability 4, Privacy 3, Usability 1, Immediacy 4

Table 3. Reporting of coefficients.[a]

Model	Unstandardized coefficients		Standardized coefficients	*t*	Significant difference
	Beta	Standard error	Beta		
Constant	2.86	1.19		2.404	0.018
Privacy					
1	-0.009	0.1	-0.011	-0.093	0.926
2	0.001	0.114	0.001	0.005	0.996
3	-0.182	0.158	-0.14	-1.152	0.253
4	0.044	0.145	0.039	0.308	0.759
5	-0.222	0.126	-0.19	-1.76	0.082
Immediacy					
1	-0.104	0.102	-0.103	-1.023	0.309
2	0.154	0.117	0.148	1.322	0.19
3	0.007	0.127	0.006	0.054	0.957
4	-0.298	0.204	-0.202	-1.463	0.147
5	0.015	0.241	0.009	0.06	0.952
Usability					
1	0.457	0.184	0.316	2.48	0.015
2	0.003	0.104	0.003	0.03	0.976
3	-0.087	0.177	-0.059	-0.495	0.622
4	0.017	0.152	0.013	0.109	0.913
5	0.026	0.106	0.026	0.244	0.808
Communication					
1	0.116	0.132	0.094	0.883	0.38
2	-0.16	0.103	-0.153	-1.55	0.125
3	0.075	0.117	0.067	0.646	0.52
4	0.354	0.095	0.405	3.732	0
5	0.019	0.1	0.019	0.186	0.853

[a] Dependent variable: Health care social media

Looking at the smaller significance level of the model items in Table 3, we can see that privacy 5, usability 1, and communication 4 are highly influencing the dependant variable. We would also like to report the observation based on good difference between *t* value and significance value. The model items in underline are the ones we are interested into. Privacy 5 was intended to find the face-to-face meeting expectations of the users of social media. It has a negative influence on the dependant variable. Usability 1 was intended to know how quickly the users expect to learn a new health care social media launched. It has positive influence. Communication 4 was intended to learn from the users of how they would utilize a health care social media during the situation of emergency. This has very high significance level and positively influences the dependant variable.

Now considering the observations based on the good difference between *t* and significance level, we estimate the following points. Privacy 2 has a fair influence stating that the users expect to become friends with chain system of referrals through friends. Privacy 3 has considerable negative influence on the health care social media. This reveals that the users expect that they should not have control on the disclosure of the health care interests. Though the variable immediacy did not show a very high significance level, all the expectation constructs can be considered. Hence it shows somewhat influence on the dependent variable. Immediacy 1 and 4 has negative influence stating that the users expect not to get advices only from doctors and have cost comparisons of hospitals. Immediacy 2, 3, and 5 have positive influence showing the expectations of users to get opinions from experienced people, insurance companies collaboration with hospitals information and information about free health camps. Usability 2 shows a positive influence stating that they expect to get training from someone to learn the health care social media. Usability 3 has a negative influence that the users do not want to keep administering their settings. Communication 2 has a negative influence on the users where they expect that the physician-patient interaction is not very necessary to join each other in health care social media.

Discussion

Principal Findings

The implication of usefulness of social media has been well understood through its usage in marketing and other dominant domains. Social media has seen a good influence in the behaviors of the users in developing economies.

This paper is a contribution of how the users expect and understand the health care social media in India as a developing country. The majority of responses from urban and semi-urban domicile population show that they expect that health care becomes more accessible and available. We show how we can refer to the gap of understanding the impact of how the social media can help semi-urban and rural population in health care. The results would help the designers of health care social media to understand the expectations of the semi-urban and urban population in a developing economy. The results show that people would use the social media sites for health. However there is a need of good awareness and training for making it a successful implementation.

Limitations

The paper has used snowball sampling for online data collection. This method does not report the response rate of the survey. Even though the different online ways were used to distribute the survey link, getting a large population sample remained a problem same as in traditional data collection. Moreover, we do not know the conditions and setting of the respondents at the time of taking the survey.

The bias of the volunteer sample in the earlier work [24], led us to the introduction of a new independent variable, that is, communication, in the current work. Hence, the online data collection sometimes leads to the possibility of introducing new ideas and factors. This sometimes biases the selected sample. Furthermore, this sample might not include those respondents who use the social media sites less frequently due to the lack of good Internet availability. It is also worth mentioning that this type of survey might have some demographic related biases, such as younger people filling in the online survey.

Comparison With Prior Work

The current work shares the similar model of regression as the previous one for measuring the expectations of the users of health care social media. The users in the developing economy are conscious about the openness of the privacy in a public forum. There is a variation from the previous work in which we have tried to understand the communication influences between the users. The negative influence of communication for face-to-face patient-physician interaction shows that people are skeptic towards revealing their identity. This is again confirmed by the negative influence results of controlling identity settings. Both the work shows a positive influence of usability for simple and quick learning health care social media.

Conclusions

The openness of the privacy component was highlighted where it shows negative influence. Users are very skeptic towards keeping their identity and friend's list open. The less disclosure of health care interests is very prominent. Hence openness of privacy negatively influences the dependant variable. Respondents wish to get advices from experienced people and not only from health experts. Hence immediacy has a positive influence in terms of intermediary communications supported. Usability shows a positive influence where people want to be in directory listings. Communication has a strong positive influence where the users want emergency information over the health care social media.

Acknowledgments

The authors thank Partha Mukhopadhyay and Rana Basu for their contribution in proof reading the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Questionnaire.

[PDF File (Adobe PDF File), 57KB - med20_v2i2e4_app1.pdf]

References

1. Wellman B, Haythornthwaite CA. The Internet in everyday life. Malden, MA: Blackwell Pub; 2002.
2. Leiner BM, Cerf VG, Clark DD. Internet Society. A brief history of the Internet URL: http://www.internetsociety.org/internet/what-internet/history-internet/brief-history-internet [accessed 2013-07-08] [WebCite Cache ID 6HxW7CLoL]
3. Kietzmann JH, Hermkens K, McCarthy IP, Silvestre BS. Social media? Get serious! Understanding the functional building blocks of social media. Business Horizons 2011 May;54(3):241-251 [FREE Full text] [doi: 10.1016/j.bushor.2011.01.005]
4. Bhattacharyya O, Khor S, McGahan A, Dunne D, Daar AS, Singer PA. Innovative health service delivery models in low and middle income countries - what can we learn from the private sector? Health Res Policy Syst 2010;8:24 [FREE Full text] [doi: 10.1186/1478-4505-8-24] [Medline: 20630108]

5. Trusov M, Bucklin RE, Pauwels K. Effects of word-of-mouth versus traditional marketing: findings from an Internet social networking site. Journal of Marketing 2009 Sep;73(5):90-102 [FREE Full text] [doi: 10.1509/jmkg.73.5.90]
6. Mangold WG, Faulds DJ. Social media: The new hybrid element of the promotion mix. Business Horizons 2009 Jul;52(4):357-365 [FREE Full text] [doi: 10.1016/j.bushor.2009.03.002]
7. Kozinets RV, de Valck K, Wojnicki AC, Wilner SJS. Networked narratives: understanding word-of-mouth marketing in online communities. Journal of Marketing 2010;74(2):71-89 [FREE Full text]
8. Bruhn M, Schoenmueller V, Schäfer DB. Are social media replacing traditional media in terms of brand equity creation? Management Research Review 2012;35(9):770-790 [FREE Full text] [doi: 10.1108/01409171211255948]
9. Stephen AT, Galak J. The effects of traditional and social earned media on sales: a study of a microlending marketplace. Journal of Marketing Research 2012 Oct;49(5):624-639 [FREE Full text] [doi: 10.1509/jmr.09.0401]
10. Kawachi I, Berkman LF. Social integration, social networks, social support and health. In: Social Epidemiology. New York: Oxford University Press; 2000:137-173.
11. Keller KL. Building strong brands in a modern marketing communications environment. Journal of Marketing Communications 2009 Jul;15(2-3):139-155 [FREE Full text] [doi: 10.1080/13527260902757530]
12. Chevalier JA, Mayzlin D. The effect of word of mouth on sales: online book reviews. Journal of Marketing Research 2006 Aug;43(3):345-354 [FREE Full text] [doi: 10.1509/jmkr.43.3.345]
13. Naik PA, Raman K. Understanding the impact of synergy in multimedia communications. Journal of Marketing Research 2003 Nov;40(4):375-388 [FREE Full text] [doi: 10.1509/jmkr.40.4.375.19385]
14. Ferguson T. Robert Wood Johnson Foundation Quality Health Care Grant. e-patients: how they can help us heal healthcare URL: http://e-patients.net/e-Patients_White_Paper.pdf [accessed 2013-07-08] [WebCite Cache ID 6HxQhXPF2]
15. Amrita, Das P, Saurabh P, Biswas D. Determinants of success for private public partnership in filling technology to health (T2H) gap in terms of expectations. In: Co-Creation as a Way Forward. 2010 Presented at: Research Forum to Understand Business in Knowledge Society; 15-17 September 2010; Spa Hotel Rantasipi Eden, Nokia, Finland URL: http://www.ebrf.fi/_file/32879/EBRF2010-1.pdf
16. Organization WH. World health statistics 2011 (World Health Statistics Annual). 20 Avenue Appia, 1211 Geneva 27, Switzerland: World Health Organization; 2011.
17. Chaudhry PK, Vanduzer-Snow M. Book review: the regional roots of development politics in India: a divided Leviathan comparative political studies. In: Comparative Political Studies. B-42, Panchsheel Enclave, New Delhi, India: Sage Publications India Pvt Ltd; Nov 01, 2006:1161-1165.
18. Krishna A. Escaping poverty and becoming poor: who gains, who loses, and why? World Development 2004 Jan;32(1):121-136 [FREE Full text] [doi: 10.1016/j.worlddev.2003.08.002]
19. Adams J, Mounib E, Pai A, Stuart N, Thomas R, Tomaszewicz P. IBM Institute for Business Value. Somers, NY: IBM Global Services; 2006. Healthcare 2015: Win-win or lose-lose URL: http://www-935.ibm.com/services/us/gbs/bus/pdf/healthcare2015-win-win_or_lose-lose.pdf [accessed 2011-12-16] [WebCite Cache ID 63yLRYX3s]
20. Penchansky R, Thomas JW. The concept of access: definition and relationship to consumer satisfaction. Med Care 1981 Feb;19(2):127-140. [Medline: 7206846]
21. Thomas JW, Penchansky R. Relating satisfaction with access to utilization of services. Med Care 1984 Jun;22(6):553-568. [Medline: 6738145]
22. Nordfeldt S, Ängarne-Lindberg T, Berterö C. To use or not to use--practitioners' perceptions of an open web portal for young patients with diabetes. J Med Internet Res 2012;14(6) [FREE Full text] [doi: 10.2196/jmir.1987] [Medline: 23137767]
23. Callahan D. Taming the beloved beast: how medical technology costs are destroying our health care system. In: Journal of Health Politics, Policy and Law. Princeton, NJ: Princeton University Press; May 24, 2010:430-432.
24. Amrita, Bhowmick B, Biswas D. Determining social media components for scalable healthcare. In: Co-Creation of Enterprise for Problems Worth Solving. 2011 Presented at: EBRF; 14-15 December 2011; Aalto University, Espoo, Finland URL: http://www.ebrf.fi/_file/44088/EBRF11_1023.pdf
25. Biswas D, Amrita, Saurabh P, Das P. Contemporary views on business: partnering for the future. In: An entrepreneurship driven wellness business model for non-metro Indian cities. Conf. Proc. Combi. Vantaa, Finland: Laurea Publications; 2010 Presented at: COMBI2010; 7-10 October 2010; Vantaa, Finland p. 226-245 URL: http://www.laurea.fi/fi/tutkimus_ja_kehitys/julkaisut/julkaisuarkisto/Documents/A72.pdf
26. Internet users in Asia 2012 Q2. URL: http://www.internetworldstats.com/stats3.htm [accessed 2013-07-08] [WebCite Cache ID 6HxS7ba4I]
27. WHO Press. World health statistics 2012. In: World Health Organization. 20 Avenue Appia, 1211 Geneva 27, Switzerland: WHO Press; 2012.
28. Archambault PM, Bilodeau A, Gagnon MP, Aubin K, Lavoie A, Lapointe J, et al. Health care professionals' beliefs about using wiki-based reminders to promote best practices in trauma care. J Med Internet Res 2012;14(2):e49 [FREE Full text] [doi: 10.2196/jmir.1983] [Medline: 22515985]
29. DeRenzi B, Borriello G, Jackson J, Kumar VS, Parikh TS, Virk P, et al. Mobile phone tools for field-based health care workers in low-income countries. Mount Sinai Journal of Medicine: A Journal of Personalized and Translational Medicine, John Wiley and Sons 2011. [doi: 10.1002/msj.20256]

30. Schein R, Wilson K, Keelan J. Centre for Innovation in Complex Care & School of Public Health, University of Toronto, Toronto, Ontario, Canada. 2010. Literature review on the effectiveness of the use of social media: A report for peel public health URL: http://www.peelregion.ca/health/resources/pdf/socialmedia.pdf [accessed 2013-05-16] [WebCite Cache ID 6GdkktTT5]
31. Kietzmann JH, Hermkens K, McCarthy IP, Silvestre BS. Social media? Get serious! Understanding the functional building blocks of social media. Business Horizons 2011 May;54(3):241-251 [FREE Full text] [doi: 10.1016/j.bushor.2011.01.005]
32. Moorhead SA, Hazlett DE, Harrison L, Carroll JK, Irwin A, Hoving C. A new dimension of health care: systematic review of the uses, benefits, and limitations of social media for health communication. J Med Internet Res 2013;15(4) [FREE Full text] [doi: 10.2196/jmir.1933] [Medline: 23615206]

Abbreviations

BASIC: Brazil, South Africa, India, and China
ICT: information and communication tools
ISRO: Indian Space Research Organization
T2H: Technology to Health

Edited by G Eysenbach; submitted 15.05.13; peer-reviewed by D Carvalho; comments to author 11.06.13; revised version received 10.07.13; accepted 18.07.13; published 09.08.13.

Please cite as:
Amrita, Biswas D
Health Care Social Media: Expectations of Users in a Developing Country
Med 2.0 2013;2(2):e4
URL: http://www.medicine20.com/2013/2/e4/
doi:10.2196/med20.2720
PMID:25075239

Original Paper

Live Long and Prosper: Potentials of Low-Cost Consumer Devices for the Prevention of Cardiovascular Diseases

Jochen Meyer[1], Dipl-Inform; Andreas Hein[2], PhDEng, Prof

[1]R&D Division Health, OFFIS Institute for Information Technology, Oldenburg, Germany

[2]School of Medicine and Health Sciences, Carl von Ossietzky University Oldenburg, Oldenburg, Germany

Corresponding Author:
Jochen Meyer, Dipl-Inform
R&D Division Health
OFFIS Institute for Information Technology
Escherweg 2
Oldenburg, 26121
Germany
Phone: 49 4419722 ext 185
Fax: 49 4419722111
Email: meyer@offis.de

Abstract

Background: Cardiovascular diseases (CVD) are one of the major causes of death worldwide. Personal behavior such as physical activity considerably influences the risk of incurring a CVD. In the last years numerous products such as pedometers have become available on the mass market that allow monitoring relevant behaviors and vital parameters. These devices are sufficiently precise, affordable, and easy to use. While today they are mostly lifestyle oriented they also have considerable potential for health and prevention.

Objective: Our goal is to investigate how recent low-cost devices can be used in real-life settings for the prevention of CVD, and whether using these devices has an advantage over subjective self-assessment. We also examine whether it is feasible to use multiple of such devices in parallel.

Methods: We observe whether and how persons are willing and able to use multiple devices in their daily lives. We compare the devices’ measurements with subjective self-assessment. We make use of existing low-cost consumer devices to monitor a user's behavior. By mapping the devices' features with pre-defined prevention goals we ensure that the system collects meaningful data that can be used to monitor the individual's behavior. We conducted a user study with 10 healthy adults to measure usability and to identify problems with sensor use in real life. The participants used the devices' original portals to monitor their behavior. The subjects (age range 35-75) used an off-the-shelf pedometer and a sports watch for 4 weeks.

Results: The participants responded in principle positively to the use of the devices. Analyzing the sensor data, we found that the users had some difficulties in operating the devices. We also found that the participants' self-assessment of their health behavior was too optimistic compared to the monitored data. They rated the usability of the overall system with 71 of up to 100 points in the "System Usability Scale".

Conclusions: Our study indicates that today's devices are suitable for a long term monitoring of health for the prevention of CVD. Using the devices provides more precise data than a subjective self-assessment. However usability and acceptance of the systems are still major topics.

(Med 2.0 2013;2(2):e7) doi:10.2196/med20.2667

KEYWORDS

primary prevention; cardiovascular diseases; user-computer interface

Introduction

Background

Cardiovascular diseases (CVD) are the number one reason of death globally [1]. To a large extent they are caused by behavioral risk factors such as lack of physical activity or an unhealthy diet. A healthy lifestyle is a life-long effort that involves multiple facets such as daily activity, fitness, sleep, and many more. Monitoring is one of the key technologies of many persuasive health systems [2,3]. While many devices for monitoring one or more of these behaviors exist on the market already, it seems unlikely that the universal device that monitors everything and is liked by everybody will ever be available. Hence, a person who would wish to use a pervasive system for the prevention of CVD would have to permanently use multiple devices simultaneously.

We therefore investigated whether a person would be able to use multiple commercial off-the-shelf devices for a longer period of time in daily use for a reliable behavior monitoring for the prevention of cardiovascular diseases. We also examined whether the measured data from the devices provide added value over a simple subjective self-assessment.

Prevention of Cardiovascular Diseases

Overview

Risk factors for incurring CVD include vital parameters such as blood lipids or blood pressure, behaviors such as physical activity or nutrition, and other factors such as environmental factors or psychosocial stress (eg, [1,4,5]). For the scope of this study, we are focusing on 2 aspects that are of major interest to most concerned persons and that may be monitored using consumer devices, namely physical activity and sleep.

Physical Activity

All guidelines for heart-friendly lifestyle [5] recommend physical activity as a key behavior. Usually, 2 physiologically different types of activities are recommended, “daily activity” on a moderate level of intensity such as walking or slow cycling, and vigorous or “endurance sports” activity such as jogging or fast cycling. While the detailed specifications and wording may vary, there is a general consent that daily activity should be performed preferably daily for at least 30 minutes, and endurance sports should be performed at least twice a week.

Research [6] also indicates that endurance sport 3 times a week for at least 30 minutes each already achieves the maximum effect for cardiac health. Only if the user misses some of the trainings, he may partially compensate by daily activity. However, the daily activity does not have the same positive effects as a real training, so a lack of training cannot fully be compensated by daily activity. Moreover, in order to be effective for the heart at all, daily activity must happen in intervals of at least 10 minutes without a break [7]. With 30 minutes of activity each day of the week, the maximum effect has been reached. A lack of activity on one day cannot be compensated by more activity on subsequent days.

Sleep

Although sleep is not as unanimously part of the guidelines, there is a growing body of evidence [8] that sleep behavior has a major effect on cardiac health. A meta-study [9] has shown that people sleeping 6-8 hours a night have no increased risk of long-term health consequences, but people consistently sleeping 5h or less should be regarded as higher risk group for cardiovascular morbidity. On the other hand, sleeping 9h or more per night may be an indication for subclinical or undiagnosed co-morbidity. Home monitoring one’s sleep behavior may help to increase awareness for a good sleep behavior and to identify potential problems [10] and is therefore potentially a feasible tool for the prevention of CVD.

Pervasive Systems for Health Monitoring

With the availability of appropriate sensors and devices, in the last 10 years many systems have been developed that use monitoring as a basic technology in systems that aim to support a healthy lifestyle. Early such systems put a straightforward and actionable link between monitored data on the one hand and envisaged behavior or outcome on the other. Physical activity as a frequent example is measured using pedometers to count the number of steps, and the envisaged behavior is to achieve a minimum number of steps each day. Fish’n Steps [11] or Chick Clique [12] are examples that combine a playful interface and elements of competition. The UbiFitGarden system [13] was shown to induce an envisaged health behavior also over a period of several months. There is increasing evidence that mobile interventions are generally effective to encourage physical activity [14]. Such types of interventions have reached the market with sensor-based systems such as Fitbit or Nike FuelBand for daily activity, or Zeo for sleep.

Research is now addressing systems for more complex health questions that require monitoring multiple behaviors and need a more complex data analysis to identify health states and outcomes. Monarca [15] uses an interactive application and various sensing devices for identification of episodes in the treatment of bipolar disorder, based e.g. on a sentiment analysis of text messages, and on the frequency of phone calls. JogFalls [16] combines activity monitoring, diet logging, and monitoring of certain vital parameters for the management of diabetes. Such systems clearly have a high potential for the management of chronic diseases, also because they fulfill the user’s need to go beyond mere presentation of data [17]. However, by design they are not intended for everyday use by healthy persons aiming to stay healthy: They require interaction and use of specific, potentially obtrusive sensors. Mobile phones clearly are an important enabling platform [18], however they cannot be considered a universal solution.

As persuasive technology for prevention and well-being becomes more and more an aspect of our daily life, usability, user acceptance, and suitability for everyday use are increasingly important. In a workshop conducted at PervasiveHealth 2012 [19] we identified major points that distinguish the preventive use of persuasive health technologies from management of diseases: People will be using multiple and different devices; preventive systems are used over a long period of time, potentially over decades or even life long; people have complex goals that cannot easily be broken down into daily advice.

Rationale and Goal

The goal of our study is to identify user requirements for the use of multiple devices as part of a system on the prevention of cardiovascular diseases. Particularly we want to understand if the users are able to interact with different devices at the same time, if they would be able to interpret the gathered data, if these devices can be helpful for sustaining a healthy lifestyle, and if they can improve the self-assessment. We furthermore wanted to examine whether the effort of sensor-based monitoring has advantages over subjective self-assessment.

Therefore we conducted a 3 week study with 10 participants that used a small set of sensors to monitor multiple behaviors that contribute to a heart-friendly lifestyle.

Methods

Set-Up of the Study

We focused on 2 factors of heart-friendly living, physical activity and sleep. Physical activity is further broken down into daily activity and endurance training. To monitor these 3 behaviors, the participants received 2 different devices: A Fitbit Ultra pedometer, and a Garmin Forerunner 110 training watch. We chose these devices as they are widely available and prototypical representatives of products for monitoring personal activities. With prices ranging from about 50-150 Euro they are not particularly cheap but affordable for many persons. We decided not to use any of the available smartphone apps collecting this data since - in spite of their increasing popularity—the majority of people still do not own a smartphone that is powerful enough for monitoring. Moreover as a universal platform that is not tailored to the specific needs of collecting long-term activity data smartphones still face a number of issues including battery runtime and obtrusiveness of wearing the device.

The Fitbit Ultra is a lightweight electronic pedometer that may be worn in the pocket or attached to the clothes. It counts the steps taken per minute and transfers the data wirelessly and without interaction via a docking station on a local PC to the online platform fitbit.com. The Fitbit may also be used to monitor sleep. For the study we used sleep duration by manually marking start and end of the night by pressing a button on the device.

The Garmin Forerunner 110 is a sports watch with a breast belt to monitor the heart rate and an integrated GPS for monitoring the pace during the workout. The watch may also be used indoors without GPS, or it may be used without the heart rate belt. The watch may be connected to a PC using a special USB cable for uploading the data to a dedicated software or an online portal via a browser plug-in. We used the runkeeper portal to collect the user’s endurance training data.

With these devices we collect the following data:

- the step count of the user for each minute of the day
- the start time and duration of an endurance training
- the start and end time of sleep, as manually marked by the user

More detailed data is available in the portals but not used within the study.

Participants

Participants of our study were 10 subjects, 5 female, and 5 male, who were customers of a medically oriented gym. The age ranged from age class 35-44 to 65-74, average age was 54 (SD 12 years). In the group were 2 couples. All subjects already used a body scale (digital or analogue), 3 used a blood pressure monitor, one had used a pedometer and 3 had used a sports watch with heart rate monitor before. All subjects were under regular supervision of the gym’s physician. One participant had a previous cardiac condition.

All participants used a PC and the Internet fairly frequently, but had no particular interest in new technologies. They were very interested in healthy living and were doing sports regularly. They felt they had a fairly good knowledge about healthy living and a good self-assessment of their behavior. The main reason for participation was to learn about one’s own health behavior, other reasons were interest in new devices and intended health behavior change.

We piloted the system before with 3 persons who tested the system for one week each.

Conductance of the Study

The study took place during 3 weeks in November 2012 in North-West Germany. We had one kick-off meeting where we explained the study and instructed the participants in detail how to set up and use the devices as well as one closing meeting. In between, we contacted the users by phone or by email to solve potential issues.

The subjects’ mission for the study was to follow our selected guidelines for heart friendly living throughout the study: “Do a fitness training of at least 30 minutes at least 3 times a week. If that is not possible be active for at least 30 minutes each day in intervals of at least 10 minutes each. Sleep between 6 and 8 hours each night. Monitor and regularly review your behavior using the devices and systems.”

In the closing meeting, all participants filled out a 22-item questionnaire: The first section was the German version of the system usability scale (SUS). The next section asked for experiences using the system and for effects on the participants’ health behavior. We also asked for subjective self-assessment on how well they followed guidelines given. Possible answers ranged from “Perfect” (4 points) up to “not at all” (0 points). The questions in this section were adapted from the IPAQ questionnaire [20]. The last section of the questionnaire asked for potential future extension of the system. We discussed the participants’ experiences using the devices and portals and also the emerging difficulties they experienced.

Results

Data Collected

The 10 participants used the devices and collected data for an overall period of 225 days and 219 nights (see Multimedia Appendix 1).

On 224 days (99.55%) step data was collected using the Fitbit. The average number of steps per day was 10,045 (SD 3243, minimum average per person 4885, maximum 14,918).

The active minutes per day were estimated based on the minute-wise step data of the Fitbit: When for 10 minutes the step-count per minute was above a minimum threshold of 40 steps we would assume this to be an active interval. One minute with a lower value in between was allowed to reflect, for example, necessary traffic light stops when walking through a city. We chose the threshold based on our own experiments. According to our internal experiments the resulting assumptions are a fair estimation. The average active minutes per day were 41.4 (SD 22.2, minimum average per person 9.92, maximum 68.85).

The participants altogether recorded 45 endurance training sets. All of them were at least 30 minutes. Twelve (27%) had a duration of 30-60 minutes, 14 (31%) 1-2 hours. 10 (22%) had a duration of more than 12 hours.

For 180 nights (80%) sleep data was collected. 83 of the sleep records (46%) had a duration of 6-8 hours, 51 (28%) 8-9 hours, 6 (3%) 5-6 hours. 14 (8%) had a duration of more than 16 hours.

The participants' self-assessments on how well they followed the recommendations for daily activity, fitness trainings and sleep is shown in Table 1 below.

Qualitative Experiences From Using the Sensors

Setting up the devices mostly worked flawlessly, but some problems still were reported. Some participants had technical difficulties in the installation process. Some of the devices were faulty and had to be exchanged. Non-standard installations raised further questions. The concept of the local installation of the Fitbit service component in combination with the Fitbit portal was difficult to understand and caused confusion when one participant switched to a new PC at home.

In daily use, most participants were excited about the Fitbit for monitoring their daily activity. They very much appreciated the feedback on their daily activities and were sometimes quite surprised about the results in comparison to their self-assessment. The preferred level of detail of the data was quite heterogeneous: While some participants were very interested to understand the details and reviewed the data in the portal very carefully, others were happy just to see the number of steps per day on the device's display, and hardly looked into the portal. All in all, the participants found the Fitbit device very easy and intuitive to use, whereas the portal was considered more complex and difficult to use.

A number of negative points of the Fitbit were also discussed. The device was occasionally forgotten. Cycling as part of the daily activities was not well accounted for in terms of step count. Not everybody liked to keep the Fitbit in their pocket or clipped to the clothes. Particularly women said that the clothes they wear may not have pockets to store the device. Some participants forgot to take the Fitbit off their pocket when changing clothes throughout the day. Several persons suggested having, for example, a bracelet rather than a clip.

Although prior pilot tests had indicated that sleep behavior might be an issue of interest, most participants were in the end not particularly interested. They said they tended to forget to mark their sleep or wake-up times, and they did not get any further insights from it.

The feedback on the Garmin Forerunner was less positive. There were difficulties in getting the device to work. The general concepts of GPS monitoring and heart rate monitoring were not well understood. The required delay for getting a GPS fix outdoors was considered annoying. When used indoors the lack of GPS caused considerable confusion. In general, especially indoors, little added value was seen using the watch for heart rate monitoring. People liked using the watch rather outdoors. They would not just use it for monitoring the actual endurance trainings such as walking, but also take into account other activity such as their daily cycling or an occasional hiking tour.

Uploading the training data from the watch to the Runkeeper portal was considered to be slightly annoying, but in the end worked for most participants. However, the portal was not appreciated well. There was little advantage seen for entering the data into the system, and the results were only rarely used. The participants commented that they would in principle be interested to monitor their training, but that monitoring should be much better connected to their situation, for example, by directly linking it to their gym visits.

Table 1. Self-assessment of activities versus monitored behavior.

Participant	Daily activity self-assessed	Daily activity actual level by minutes	Actual activity level by steps	Fitness activity self-assessed	Fitness activity actual level	Sleep self-assessed	Sleep actual level
1	3	1.51	1.15	3	1.61	4	2.09
2	-	3.60	3.41	4	2.00	1	2.35
3	4	3.09	3.01	3	1.58	4	1.74
4	4	2.73	2.63	4	3.00	4	3.03
5	3	0.99	1.11	2	2.16	4	1.52
6	3	2.90	3.04	2	0.00	1	2.47
7	1	3.13	3.73	4	3.00	4	3.81
8	2	2.06	2.47	2	2.33	4	2.23
9	3	2.96	2.83	0	0.74	4	2.89
10	4	3.43	3.45	4	2.79	2	3.06

Usability and Users' Experiences

We asked the users for the usability of the overall system, for possible effects of the system on their health behavior, and for suggestions for future improvements.

The usability was measured using the German version of the System Usability Scale [21]. The average score is 71 (SD 17.7).

Most participants said that the devices helped them to better understand their own behavior and motivated them to a healthier lifestyle. The participants felt that using the system increased the awareness towards their personal activity. Many participants planned their activities more carefully. Some participants also felt that during the study they learned to better assess their behavior. Therefore they would be able to live healthier afterwards even without using the devices. However, the examples given by the participants were addressing mainly daily activities. Endurance workouts were only occasionally mentioned, and sleeping duration was not an issue at all.

One participant was generally more critical about self-monitoring, seeing also the risk of over-motivation and distorted feedback, since the devices just provide a very selective view on one's behavior.

Several participants explicitly mentioned that dealing with the multiple platforms was difficult and caused confusion. Therefore they suggested an integrated platform that would allow seeing all the data in one place.

Although all participants were strongly aware of the do's and don'ts of a healthy lifestyle, the goal to live heart friendly was not appealing to them. They understood the necessities of activity and sleep, but found little motivation in following this goal. Within the scope of the study they were much more eager to see their physical daily activity. Several participants suggested that other goals would be more interesting, including weight control and increasing fitness. They also suggested to include more monitoring options, for example, for weight, nutrition, or blood pressure.

Discussion

Sensor Use

The Fitbit was used by all participants virtually every day for monitoring daily activity. We therefore assume that this device is in principle well accepted. However, from the participants' feedback we also must assume that the device was occasionally not worn during some parts of a day. The step data per day is therefore likely to be incomplete. We conclude that the concept of the Fitbit as an easy to use device is well accepted, but different forms of pedometers such as a bracelet rather than a clip might have resulted in more complete data for some of the participants.

The participants recorded 45 workouts altogether. 14 of these (31%) were above 4 hours duration for 4 participants and 10 of these (22%) even above 16 hours duration for 2 of the participants. Longer durations might be cycling or hiking tours. However, trainings above 16 hours duration can only be explained by the participants forgetting to mark the end of the training.

Recording sleep required pressing a button in the evening and again in the morning. With 80% of the nights covered, sleep data was less complete than the data on daily activity. We therefore assume that occasionally the device was forgotten, or was not used intentionally. From the recorded sleep durations it is noticeable that a number of sleep records are overlong, above 12 hours (5 nights, 3%) or even above 16 hours (14 nights, 8%). Particularly in the latter case we can assume that pressing the button in the morning was forgotten.

Self Assessment Versus Monitored Behavior

We compared the participants' self-assessments with the measurements taken by the sensors. The self-assessment took place at the end of the study, after 3 weeks only, so there is likely a recall bias limiting the precision of the data. On the other hand, during the 3 weeks the participants got regular feedback on their actual behavior from the devices, which should increase their awareness for their behavior and mitigate the effects of the recall bias. The results are summarized in Table

1. For each of the 3 behaviors, the columns show from left to right the points as subjectively assessed by the participants, and the actual achieved points as monitored by the devices—for daily activity in 2 different methods. The details are subsequently described.

For daily activities we took into account the active minutes in intervals of 10 minutes each. We scaled this into a 0-4 scale from 0 (no active minutes) to 4 (30 minutes or more of activity). The participants had reported that they observed their daily step count with high interest, so we could expect quite a good estimation. However, 5 participants were too optimistic in their self-assessment, 3 were quite precise, and one was too pessimistic. One participant did not assess his activity.

We also used the daily step count sum as an alternative measurement to mitigate potential weaknesses of our approach for estimating the active daily minutes. By adopting the Tudor-Locke scale [22] we gave 0 points for 0 steps, 1 point for 5000 steps, 2 for 7500, 3 for 10,000 and 4 for 12,500 and more. We linearly interpolated points for step values in between. The resulting scores deviate only slightly from the one based on our own estimation (average deviation 0.04, SD 0.29) and do not change the overall picture.

For training, we counted for each day the number of fitness trainings the participant had recorded for this and the preceding 6 days. All trainings recorded were longer than 30 minutes For each day with at least 3 trainings on that and the preceding 6 days we scored 4 points, for 2 trainings 3 points, for 1 training 2 points and for no training 0 points. We compared this to the participants' self-assessment. 7 participants were too optimistic in their self-assessment, and 3 were slightly pessimistic.

For sleep, we scored 4 points for each night with 6-8 hours. We scored 0 points for 5 and 9 hours, 4 for 6 and 8 hours, and linearly interpolated values in between. 0 points were scored for nights shorter than 5 and longer than 9 hours. For calculating the participant's average sleep score, we omitted sleep records of more than 16 hours duration, as we assume a faulty use of the sensor. Compared to the participants' self-assessment, 6 participants were too optimistic, in 1 case the assessment was about correct, and in 3 cases it was too pessimistic.

Our comparison between self-reported and monitored data is partially in line with other studies. For physical activity [20] concludes that for vigorous activities there is a strong correlation between self-assessment and monitoring, while we found some deviations. For medium activities, [20] finds a fair to moderate correlation, which is quite in line with our observations. Differences could be explained in different self-assessment methods: We used only an ex-post questionnaire after 3 weeks, while [20] used a logbook. For sleep [23] finds that in average the self-assessment is close to the objective measurement, but there are considerable individual differences. This is well reflected by our observations. In general, our participants tend to assess themselves more positively. This might be explained by the fact that our participants had the mission to follow some specific guidelines. Not having succeeded in following these might therefore be considered a failure, so the participants might have had the trend to show themselves in a more positive light.

Limitations

The study has some limitations. The measured data may be partially wrong due to a non-identified faulty use or because participants didn't record all activities. Our measurement of active minutes based on analyzing the steps by the minute is not precise. And our mapping of the activities to 0-4 points scale compared to the participants' self-assessment scale 0-4 may be imperfect. Taking into account the relatively small sample size of 10 persons, the figures as outlined in Table 1 should be understood to underline our qualitative statements, not as quantitative results in themselves.

However, with 10 participants the sample is large enough to gain a better understanding of how people use pervasive health services and what the current problems are. The demographic of the participant group is rather broad with respect to age range and to participation of female and male persons, and it included 2 couples. The participants were in general just average technically skilled. The group was in general healthy and didn't suffer from a particular disease. The interest in healthy living was probably above average, but not exceedingly high. Therefore we think that our participants are fairly close to the "average target group"

Design Implications

Our results reveal a number of implications for the future design of systems for the prevention of cardiovascular diseases:

We gave 2 devices to the users, both of which were mass market products and should in principle be easy to install and use. We explained carefully the required procedures to the participants. Nevertheless, installing and operating the devices has shown to be a considerable effort for the users. We found that virtually every possible interaction with the devices required some training and lead to some faulty operations and possible errors in data. However we also found that the participants were quite eager to resolve the issues if their use promised personal advantages. Therefore, while it is basically always a good idea to keep a system as simple as possible, we also find that users are willing to accept some level of complexity provided that the promised advantage is high enough for them. However, faulty use and incomplete data will always happen, and any system using that data will have to cope with that.

Wearing and using the devices was rated differently by the participants. The Garmin watch was mostly liked for outdoor use, but it was too complex for indoor workouts. Also the Fitbit, in spite of its high acceptance, was not the perfect device for all the users. Some participants would have preferred a bracelet over a clip. Prevention devices are used for a longer period of time, so users must have the choice of devices they use, and they might want to use different devices for the same purpose, changing from day to day. A pervasive prevention system must therefore deal with heterogeneous devices and not focus on one or 2 specific products.

Our participants were very interested in healthy living and had probably an above-average degree of knowledge on that issue. The intention to live heart-healthy was generally understood and appreciated. Nevertheless our goal and guidelines were not particularly appealing to them. They found little motivation trying to live more heart-healthy in general, and were much more focusing on increasing daily activity. Moreover, the participants suggested goals such as weight control or increasing fitness. Therefore we conclude that general goals for healthy living must be broken down into concrete and actionable sub-goals that are personalized to match the individual user's needs and that may well change over time. A preventive system can then assist the user in following these sub-goals and guidelines.

All participants liked getting insights into their own behavior. However, the requested level of detail was different between the users. For the Fitbit some users were happy just seeing the number of daily steps they achieved, whereas others were keen to understand how different types of activities contribute to step counts and active minutes. Sleep duration was in general not considered interesting by the users. However, from pilot tests in slightly different set-ups we found that people may be interested in sleep quality. Therefore we think there is a mutual influence of the choice of devices and the definition of personalized goals. A device's properties obviously limit the possible level of detail of the monitored data: If the user's preferred pedometer doesn't allow monitoring active minutes, activity goals may need to be defined based on daily step counts rather than the more detailed active minutes. The other way around, the user's goals influence the choice of devices: If sleep quality is important, the user may wish to use a device like the Zeo, whereas for mere sleep duration the Fitbit approach would be fine.

Our participants had decent knowledge about healthy living and followed a healthy lifestyle. Nevertheless, when asked for their subjective self-assessment regarding their behavior during the study, the participants tended to over-estimate their own behavior. Therefore behavior monitoring using technical devices provides a more reliable base data for recommendations on healthy behavior than self-assessment alone.

Summary and Outlook

We investigated how low-cost monitoring devices can be used in the context of prevention of cardio-vascular diseases. We learned that using devices is a challenge to the user, but users are willing to cope with it if their advantage is clear. However, users prefer different devices therefore we believe that also in the future we will have heterogeneity of devices rather than the one universal product.

There was a tendency that a person's subjective self-assessment is more optimistic than the data monitored by the devices. Therefore the objective monitoring is potentially better suited for observing and reflecting health behavior than a subjective self-assessment.

We believe that preventive systems in the future will be platforms that integrate multiple data sources to provide the user with a unified view. One main challenge clearly is the analysis and interpretation of this heterogeneous data to infer medically valid conclusions on the user's health. However this is what we need to turn the existing personal data into personalized knowledge.

Acknowledgments

We would like to thank all the participants of the study, and particularly the team from "Corpus Gesundheit" gym for their support and for helping us finding participants. This work has been founded in part by the Hewlett Packard Innovation Research Programme.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Collected user data on daily activity, sleep and endurance training.

[XLS File (Microsoft Excel File), 478KB - med20_v2i2e7_app1.xls]

References

1. World Health Organization. Global Status Report on Noncommunicable Diseases 2010. Geneva: World Health Organization; 2010.
2. Fogg B. Persuasive Technology: Using Computers to Change What We Think and Do. Burlington, Massachusetts: Morgan Kaufmann; 2003.
3. Chatterjee S, Price A. Healthy living with persuasive technologies: framework, issues, and challenges. J Am Med Inform Assoc 2009;16(2):171-178 [FREE Full text] [doi: 10.1197/jamia.M2859] [Medline: 19074300]
4. Reissigová J, Tomecková M. State of the art coronary heart disease risk estimations based on the Framingham heart study. Cent Eur J Public Health 2005 Dec;13(4):180-186. [Medline: 16419382]
5. Pearson T, Blair SN, Daniels SR, Eckel RH, Fair JM, Fortmann SP, et al. AHA Guidelines for Primary Prevention of Cardiovascular Disease and Stroke: 2002 Update: Consensus Panel Guide to Comprehensive Risk Reduction for Adult Patients Without Coronary or Other Atherosclerotic Vascular Diseases. American Heart Association Science Advisory and Coordinating Committee. Circulation 2002 Jul 16;106(3):388-391 [FREE Full text] [Medline: 12119259]
6. Hollmann W, Strüder HK. Sports Medicine (Sportmedizin) (5th edition). Germany: Schattauer; 2009.

7. Graf C, Predel H, Bjarnason-Wehrens B. Physical activity in the primary prevention of coronary heart diseases (Körperliche Aktivität in der Primärprävention der koronaren Herzkrankheit). Kardiovaskuläre Medizin 2004;7:119-125.
8. Ayas NT, White DP, Manson JE, Stampfer MJ, Speizer FE, Malhotra A, et al. A prospective study of sleep duration and coronary heart disease in women. Arch Intern Med 2003 Jan 27;163(2):205-209. [Medline: 12546611]
9. Cappuccio FP, Cooper D, D'Elia L, Strazzullo P, Miller MA. Sleep duration predicts cardiovascular outcomes: a systematic review and meta-analysis of prospective studies. Eur Heart J 2011 Jun;32(12):1484-1492 [FREE Full text] [doi: 10.1093/eurheartj/ehr007] [Medline: 21300732]
10. Haakma R, Beun R. Unobtrusive Sleep Monitoring. 2012 Presented at: Measuring Behavior; August 2012; Utrecht, The Netherlands p. 28-31.
11. Lin J, Mamykina L, Lindtner S, Delajoux G, Strub HB. Fish'n'Steps: encouraging physical activity with an interactive computer game. In: UbiComp 2006: Ubiquitous Computing. Berlin, Heidelberg: Springer; 2006:261-278.
12. Toscos T, Faber A. Persuasive technology to motivate teenage girls to exercise. New York, NY, USA: ACM; 2006 Presented at: CHI Conference on Human Factors in Computing Systems; 2006; Montreal p. 1873-1878. [doi: 10.1145/1125451.1125805]
13. Consolvo S, Klasnja P, Mcdonald DW, Avrahami D, Froehlich J, Legrand L, et al. Flowers or a robot army? encouraging awareness & activity with personal, mobile displays. 2008 Presented at: International Conference on Persuasive Technology; 2008; Seoul p. 54-63.
14. Fanning J, Mullen SP, McAuley E. Increasing physical activity with mobile devices: a meta-analysis. J Med Internet Res 2012;14(6):e161 [FREE Full text] [doi: 10.2196/jmir.2171] [Medline: 23171838]
15. Marcu G, Bardram J, Gabrielli S. A framework for overcoming challenges in designing persuasive monitoring and feedback systems for mental illness. 2011 Presented at: International Conference on Pervasive Computing Technologies for Healthcare; May 23-26, 2011; Dublin, Ireland. [doi: 10.4108/icst.pervasivehealth.2011.246097]
16. Nachman L, Baxi A, Bhattacharya S, Darera V, Deshpande P, Kodalapura N, et al. Jog falls: A pervasive healthcare platform for diabetes management. 2010 Presented at: International Conference on Pervasive Computing; May 17-20, 2010; Helsinki, Finland p. 94-111.
17. Maitland J, Chalmers M. Self-monitoring, self-awareness, and self-determination in cardiac Rehabilitation. 2010 Presented at: CHI Conference on Human Factors in Computing Systems; 2010; Atlanta p. 1213-1222.
18. Klasnja P, Pratt W. Healthcare in the pocket: mapping the space of mobile-phone health interventions. J Biomed Inform 2012 Feb;45(1):184-198 [FREE Full text] [doi: 10.1016/j.jbi.2011.08.017] [Medline: 21925288]
19. Meyer J, Boll S, Lee YS, Mayora O, Siek K, Röcker C. Wellness interventions and HCI. SIGHIT Rec 2012 Sep 01;2(2):51-53. [doi: 10.1145/2384556.2384564]
20. Hagströmer M, Oja P, Sjöström M. The International Physical Activity Questionnaire (IPAQ): a study of concurrent and construct validity. Public Health Nutr 2006 Sep;9(6):755-762. [Medline: 16925881]
21. Brooke J. SUS: A Quick and Dirty Usability Scale. In: Jordan P, Thomas B, McClelland IL, Weerdmeester B, editors. Usability evaluation in industry. London: Taylor & Francis; 1996.
22. Tudor-Locke C, Craig CL, Brown WJ, Clemes SA, De Cocker K, Giles-Corti B, et al. How many steps/day are enough? For adults. Int J Behav Nutr Phys Act 2011;8:79 [FREE Full text] [doi: 10.1186/1479-5868-8-79] [Medline: 21798015]
23. Signal TL, Gale J, Gander PH. Sleep measurement in flight crew: comparing actigraphic and subjective estimates to polysomnography. Aviat Space Environ Med 2005 Nov;76(11):1058-1063. [Medline: 16313142]

Abbreviations

CVD: cardiovascular diseases
SUS: system usability scale

Edited by G Eysenbach; submitted 13.05.13; peer-reviewed by S Nylander, K Antypas; comments to author 11.06.13; revised version received 24.06.13; accepted 18.07.13; published 12.08.13.

Please cite as:
Meyer J, Hein A
Live Long and Prosper: Potentials of Low-Cost Consumer Devices for the Prevention of Cardiovascular Diseases
Med 2.0 2013;2(2):e7
URL: http://www.medicine20.com/2013/2/e7/
doi:10.2196/med20.2667
PMID:25075242

Original Paper

The Ligurian Human Immunodeficiency Virus Clinical Network: A Web Tool to Manage Patients With Human Immunodeficiency Virus in Primary Care and Multicenter Clinical Trials

Paolo Fraccaro[1]; Valeria Pupella[1]; Roberta Gazzarata[1]; Chiara Dentone[2,3]; Giovanni Cenderello[4]; Pasqualina De Leo[5]; Federica Bozzano[3]; Giorgetta Casalino Finocchio[6]; Andrea De Maria[3]; Daniela Fenoglio[3]; Gilberto Filaci[3]; Michele Guerra[7]; Antonio Di Biagio[8]; Eugenio Mantia[9]; Giancarlo Orofino[10]; Giuseppe Ferrea[2]; Claudio Viscoli[8]; Mauro Giacomini[1,3]

[1]Department of Informatics, Bioengineering, Robotics and System Engineering, University of Genoa, Genoa, Italy
[2]Department of Infectious Diseases, Sanremo Hospital, Sanremo, Italy
[3]Center of Excellence for Biomedical Research, University of Genoa, Genoa, Italy
[4]Department of Infectious Diseases, Galliera Hospital, Genoa, Italy
[5]Department of Infectious Diseases, San Paolo Hospital, Savona, Italy
[6]Department of Infectious Diseases, Pietra Ligure Hospital, Pietra Ligure, Italy
[7]Department of Infectious Diseases, La Spezia Hospital, La Spezia, Italy
[8]Department of Infectious Diseases, San Martino Hospital, Genoa, Italy
[9]Department of Infectious Diseases, Alessandria Hospital, Alessandria), Italy
[10]Department of Infectious Diseases, Torino Hospital, Torino, Italy

Corresponding Author:
Paolo Fraccaro
Department of Informatics, Bioengineering, Robotics and System Engineering
University of Genoa
MEDINFO
Via Opera Pia 13
Genoa, 16145
Italy
Phone: 39 010 3536546
Fax: 39 010 3532154
Email: paolo.fraccaro.dms@gmail.com

Abstract

Background: In recent years, Highly-Active Anti-Retroviral Therapies (HAARTs) have modified the Human Immunodeficiency Virus (HIV) life-cycle and the disease is now considered chronic. Consequently, a longitudinal and complex follow-up is now required for HIV positive patients during their lifetime. Moreover, patients often encounter various complications due to comorbidities, related to the immunodeficiency state and HAARTs' side effects. Thus, HIV positive patients are involved in multicenter clinical trials (MCTs) to improve treatments and discover a preventive vaccine. Therefore, physicians require proper instruments to access comprehensive patient data for managing patients during follow-ups, and tools for data collection and analysis in MCTs.

Objective: The Ligurian HIV Clinical Network aims to provide physicians with a Web-tool to administrate HIV positive patients' data within primary-care and to reuse the collected clinical information to perform MCTs in Northern Italy.

Methods: The key aspect of the system is a relational database which allows the storage of various types of clinical information (eg, related to HIV, cardiovascular, or hepatic diseases) in multiple formats. The modular design of the database permits a rapid insertion of new parameters without requiring any changes in the database structure. Furthermore, codes from biomedical ontologies controlled vocabularies ("Logical Observation Identifier Names and Codes", and "International Classification of Diseases 9") and ontologies ("Systematized Nomenclature of Medicine Clinical Terms"), units and normality ranges used by all partners participating in the project were collected to achieve a complete semantic interoperability. Accordingly, data can be automatically normalized through the *z* score formula and physicians can extract and correctly compare information with external statistical tools. Moreover, to respect patients' privacy and legal issues, a local identifier, determined through an HASH cryptography algorithm, is assigned to each patient during the registration process. The database is managed by a user-friendly Web-platform which allows quick access to information during medical examinations and the reusing of the collected data for present and future MCTs. Furthermore, a bidirectional middleware was created in order to import/export information through HL7 messaging. Hence, data can be manually entered by physicians or automatically collected within HL7-compliant Hospital Information systems.

Results: Presently, the direct storage of patients' information from the San Paolo Hospital (Savona, Italy), and San Martino and Galliera hospitals in Genoa is in a test phase. Currently, 8 centers of Infectious Diseases (located in Liguria and Piedmont) are participating in the project and almost 400 HIV positive patients have been recorded in the system. Patient data has been used for primary care and research purposes. Currently, there are 4 on-going MCTs and preliminary results have already been presented at International HIV congresses.

Conclusions: The Web-platform allows effective management, sharing and reuse of information within primary care and clinical research. In the future it is planned to share the clinical information from this network with other HL7-compliant workgroups and to extend the platform to other infective diseases (eg, hepatitis).

(Med 2.0 2013;2(2):e5) doi:10.2196/med20.2712

KEYWORDS

multicenter clinical trials; human immunodeficiency virus; health level 7; biomedical ontologies; z score

Introduction

Human immunodeficiency virus (HIV) infection is still a severe and current problem in modern society. Indeed, even if at the moment less attention is focused on HIV disease in comparison to the past, still globally, 34.0 million [31.4-35.9 million] people were living with HIV at the end of 2011 [1]. Currently, the primary HIV treatments, highly-active antiretroviral therapies (HAARTs), extend the life expectancy of patients and the disease is now considered chronic; therefore the overall number of people living with HIV has steadily increased. Moreover, even if the survival rate has sensibly improved, HIV positive patients need to be regularly monitored within primary care with a comprehensive approach throughout their life, through complex longitudinal follow ups [2]. Furthermore, HIV patients often encounter various types of complications due to the state of immunodeficiency and the side effects caused by HAARTs. Accordingly, HIV positive people are often concurrently involved in many multicenter clinical trials (MCTs), with the objective of improving HIV treatments and finding a preventive vaccine. Therefore, proper systems and software applications are needed to correctly store, manage, and analyse the large amount of data produced within this complex scenario, between primary care and clinical research, with the aim of supporting physicians during their work and consequently improving patients' health. First, such systems and software applications would have to allow physicians an easy access to overall patient information and the reusing of such information for multicenter clinical research. Second, operator usability and freedom of access and analysis, according to proper access rights, would have to be supported with user-friendly and intuitive applications. Finally, there should be the possibility of data sharing through standard instruments among different workgroups, and national and international institutions to stimulate collaborations and favour public health policies concerning HIV.

Generally, the benefits of the integration between primary care and clinical research has already been established [3,4] and many workgroups are focusing their strengths on achieving this objective [5,6]. However, vendors of electronic/medical health records systems are so far, still not working in the same direction. Consequently, a wide integration of administration and primary care applications with the research applications is not yet possible. Therefore, above all in the academic community where financial resources are lacking, physicians have to adopt craft-made or open source (eg, OpenClinica [7], OpenCDMS [8], PhOSCO [9], and REDCap [10]) solutions to manage their data within clinical research. This often generates substantial and repeated data copy operations which are time consuming and a possible source of errors.

Specifically, in the HIV domain, the efficacy of comprehensive systems to optimally treat the disease has already been proven [11]. In particular, the Orchestra program [11] is a computer-assisted HIV care and support tool implemented in the outpatient clinic of a University Hospital (Paris, France). The system aimed at providing physicians with information concerning 5 areas of actions (eg, cardiovascular risk factors and compliance to HAARTs). Nevertheless, even if its efficacy has been tested and its comprehensive approach proved, the Orchestra program is limited to only some aspects within the HIV scenario and above all, data cannot be reused for research purposes. Instead, Pugliese et al [12,13] presented NADIS which is an electronic medical record for HIV negative, hepatitis B virus (HBV) negative, or hepatitis C virus (HCV) negative infected adults seeking care in French public hospitals. NADIS satisfies many of the requirements introduced above, for an optimal management of the HIV infection. However, it has some drawbacks. First, it is a desktop application, which causes laborious maintenance operations and limited access for users. Second, physicians, also with appropriate viewing rights, are not free to consult and extract information for research purposes, but have to ask dedicated staff to perform these tasks. Finally, NADIS is only available within the French National Health Systems, consequently is not possible to participate in the project from outside France.

Due to the previously presented limitations, the authors decided to develop their own solution: “The Ligurian HIV Clinical Network”, which is a user-friendly Web-application which manages, shares, and analyses data within primary care and clinical research.

Methods

Overview

First, to ensure the satisfaction of all technical and clinical aspects and to guarantee high quality patient care and research within the HIV context, the system has been designed, developed, and tested through a close collaboration between health informaticians and HIV experts.

From a technical point of view, the core of the system is based on some general and scalable principles [14,15] which are suitable also for other clinical domains. The key aspect of the system is a relational database which, due to a high data structuring through a meta description approach, permits the archiving of various types of clinical information (eg, related to HIV, cardiovascular, or hepatic diseases) in multiple formats. The modular design of the database allows a quick addition of new parameters without any required modification to the database structure. Particularly, this aspect is essential within the HIV context because, as introduced above, HIV management and treatment are constantly evolving, consequently the inclusion of new criteria is often necessary. Furthermore, to achieve a complete semantic interoperability and ensure the participation of as many research groups as possible, the system allows the collection of codes from biomedical ontologies controlled vocabularies (“Logical Observation Identifier Names and Codes”, and “International Classification of Diseases 9”) and ontologies (“Systematized Nomenclature of Medicine Clinical Terms”), units and normality ranges concerning all parameters used by all partners participating in the project. Accordingly, data can be automatically normalized through the *z* score formula [16], extracted and correctly compared within external statistical tools. Moreover, to respect patients’ privacy and legal issues, a local identifier, determined through an HASH cryptography algorithm, is assigned to each patient during the registration process and a strict viewing rights policy was adopted. Furthermore, a bidirectional middleware was created in order to import/export information through health level 7 (HL7) messaging. Thus, data can be manually entered by physicians or automatically collected within HL7-compliant hospital information. The essential characteristic is that once data has been collected in the database the first time, it is then available, without any further copy operations, during primary care and for present and future MCTs according to specific research purposes.

To ensure a wide utilization and low costs, the database is managed through a Web-platform which dynamically builds webpage contents and reflects the modular structure described above [14,15]. Within the design and development of the Web-platform, physicians’ indications and suggestions had a particular importance in obtaining a result as user-friendly as possible, which could be effectively integrated into their workflow. Furthermore, a maintainance layer was developed to provide administrators with quick access and enable modification to all structural aspects of the platform. Finally, since one of the main objectives was to allow physicians to extract data for research purposes, a specific algorithm and extraction tool were developed. Such instruments permit physicians to access *z* score normalized information according to their criteria and to extract this data in a Microsoft Excel format.

Quantitative Results

The Ligurian HIV Clinical Network has been online from September 2011 and, after almost 1 year and 9 months, 8 Departments of Infectious Diseases among Ligurian and Piedmont regions are participating in the project. Furthermore, testing of the infrastructure, for direct storage of information from hospital information systems has been developing in 3 of the previous centers. Currently, out of a population of about 2500 HIV positive people in Liguria (total inhabitants 1,567,339, on 31/12/2011, calculated by ISTAT), almost 400 patients and their clinical data have been recorded in the database. Furthermore, 10 patients have been recorded from centers of the Piedmont region which participated in one of the MCTs. At the moment, 5 types of clinical events (historical information, blood sample examination, admission, discharge and therapy) are monitored and structured in more than 200 parameters in 7 different formats. The results of such parameters are collected within primary care and currently reused in 4 ongoing MCTs, which, even if with different research objectives (eg, starting from immunological to economical aspects), can correctly coexist within the platform and consider relevant information according to specific research purposes. Finally, preliminary results of some trials have already been presented to national [17,18] and international conferences [19]. Table 1 reports the quantitative results described previously in more detail.

Table 1. Summary of quantitative results of the project.

Parameter	Result
Time online	1 year and 9 months (since September 2011)
Participating centers	Pietra Ligure Hospital (Pietra Ligure, Italy); San Paolo Hospital (Savona, Italy); San Martino Hospital (Genoa, Italy); Galliera Hospital (Genoa, Italy); Sanremo Hospital (Sanremo, Italy); La Spezia Hospital (La Spezia, Italy); Alessandria Hospital (Alessandria, Italy); Turin Hospital (Turin, Italy)
Testing of direct storage in HL7 format	San Paolo Hospital (Savona, Italy); San Martino Hospital (Genoa, Italy); Galliera Hospital (Genoa, Italy)
Recorded patients	410
Type of clinical events	Historical information; Blood sample; Admission; Discharge; Therapy
Monitored parameters	216
Possible formats	Integer; Float; Categorical; Boolean; Dates; String; Code
Ongoing MCTs	4
Clinical Studies' preliminary results presented to conferences by clinicians	3

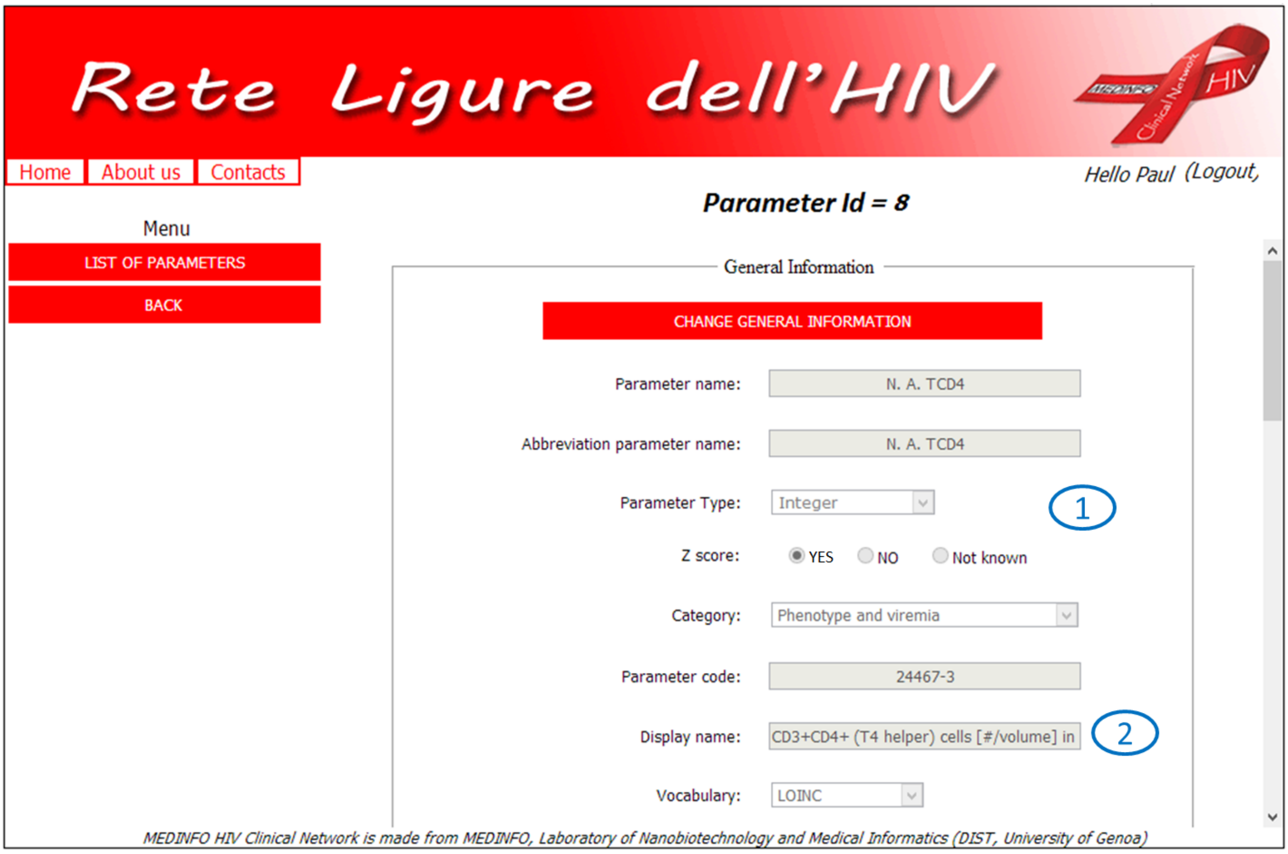
Qualitative Results: Examples of the Most Significative Webpages

Each parameter has its own detail page (Figures 1 and 2), where administrators can set up all the necessary information to correctly manage clinical data and achieve a complete semantic interoperability within all centers which are participating in the project. In particular, this example refers to CD4 Lymphocites number (one of the most important variables within HIV context), which pertains to the phenotyping and viremy aspects, and label 2 (Figure 1) highlights the related standard code and controlled vocabulary. The type of parameter is integer and *z* score normalization is required (label 1, Figure 1) furthermore, it is possible to archive all different units and normality ranges used by centers (label 3, Figure 2). Finally, there is the possibility to set up the MCTs in which researchers wish to consider the parameter (label 4, Figure 2). Therefore, it is possible to customize the considered parameters according to specific research purposes, and the practical results of this option are shown in Figures 3-5.

Specifically, Figures 3-5 report snapshots of the results concerning the phenotype and viremy aspects, for the same patient and same blood sample (dotted circles in the Figures) for primary care and two different MCTs. Obviously, all possible parameters are present in the list which refers to primary care (Figure 3), as in order to optimally treat the HIV positive patients, as much information as possible is required. Instead, the other two lists contain less parameters and are customized according to specific research objectives. Therefore, the MARHIV study [17,18] (Figure 4) considers many aspects as it is focused on immunological and clinical aspects; on the contrary, the ACTEA I study, which is mainly concentrated on economical aspects, examines only the essential immunological information of HIV positive patients (Figure 5). Furthermore, the Figures show two other main characteristics of the platform. First, users can work with their own instruments since units and normality ranges are related to centers and data is normalized only during the extraction process. Second, even if considered parameters are different in the three lists and data has been recorded only once, where it is possible common information is reused and integrated. For example, as highlighted by solid circles, some results are available in all the snapshots.

As reported in the introduction, one of the main objectives was to allow physicians to independently extract data according to their needs. Figures 6 and 7 underline the results which have been obtained concerning this aspect. In fact, the snapshots report examples of how physicians can enter specific extraction criteria (Figure 6), and how the obtained information can be exploited (Figure 7). Referring to Figure 6, label 5 shows the possibility of defining particular thresholds, both inclusive and exclusive, for numeric parameters. Obviously, there is also the possibility to indicate specific requirements for all other formats, such as positivity/negativity for Booleans or equality to a cert value for categorical. Once all the criteria has been entered, physicians can extract information through two different modalities. The first one allows authorized users to access information and extract z score normalized data in Excel format. Conversely, the second extraction mode can be used during the recruitment phase of MCTs. In fact, it is possible to know how many patients in each center, within the whole cohort, respect specific criteria (Figure 7). It is important to emphasize that, due to a strict viewing rights policy, the physicians who is extracting data in this case cannot directly access information; however, there is the possibility to send the centers a request for the participation of the patients in the selected MCT.

Figure 1. Parameter details page: name, type (label 1), and code (label 2).



Parameter Id = 8

Parameter name: N. A. TCD4

Abbreviation parameter name: N. A. TCD4

Parameter Type: Integer

Z score: ● YES ○ NO ○ Not known

Category: Phenotype and viremia

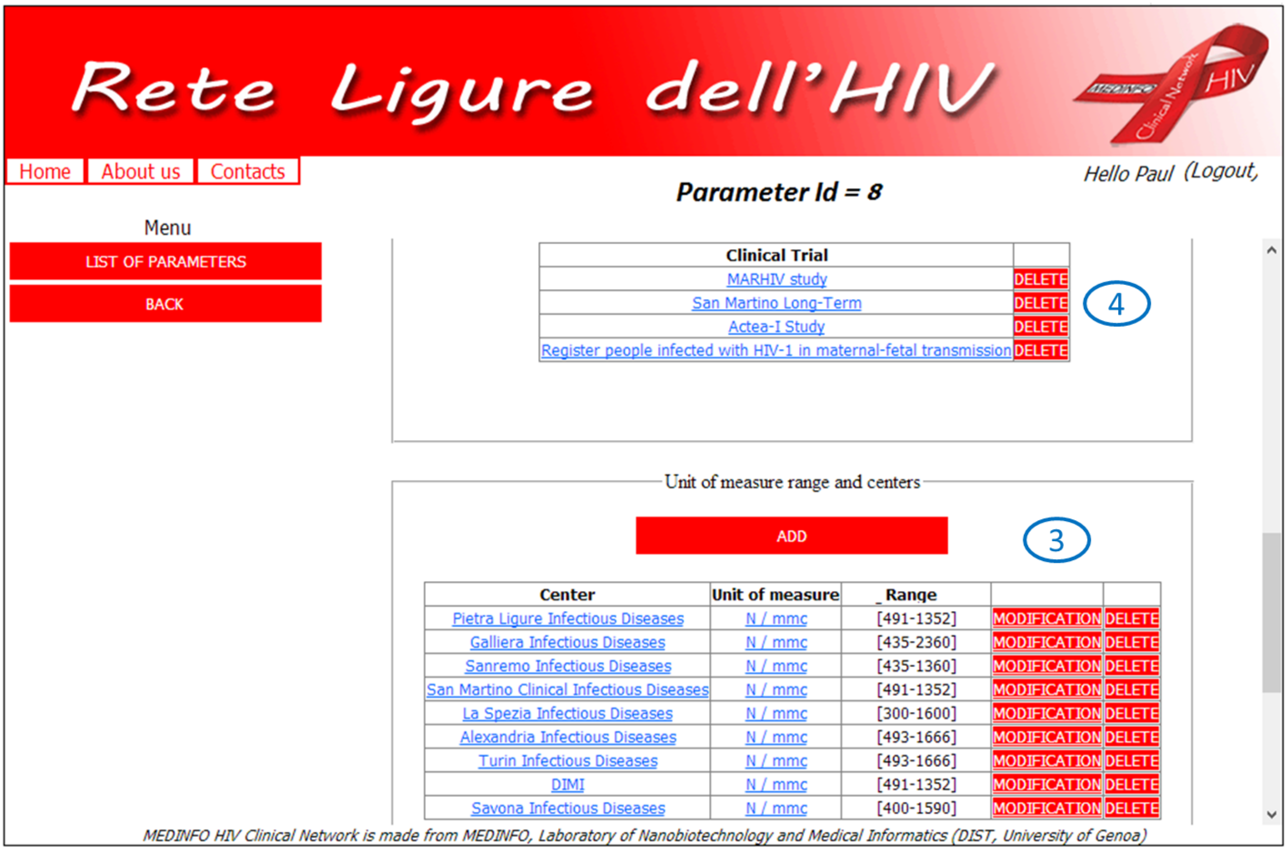
Parameter code: 24467-3

Display name: CD3+CD4+ (T4 helper) cells [#/volume] in

Vocabulary: LOINC

MEDINFO HIV Clinical Network is made from MEDINFO, Laboratory of Nanobiotechnology and Medical Informatics (DIST, University of Genoa)

Figure 2. Parameter details page: studies in which the parameter is considered (label 3) and, centers' units and normality ranges (label 4).



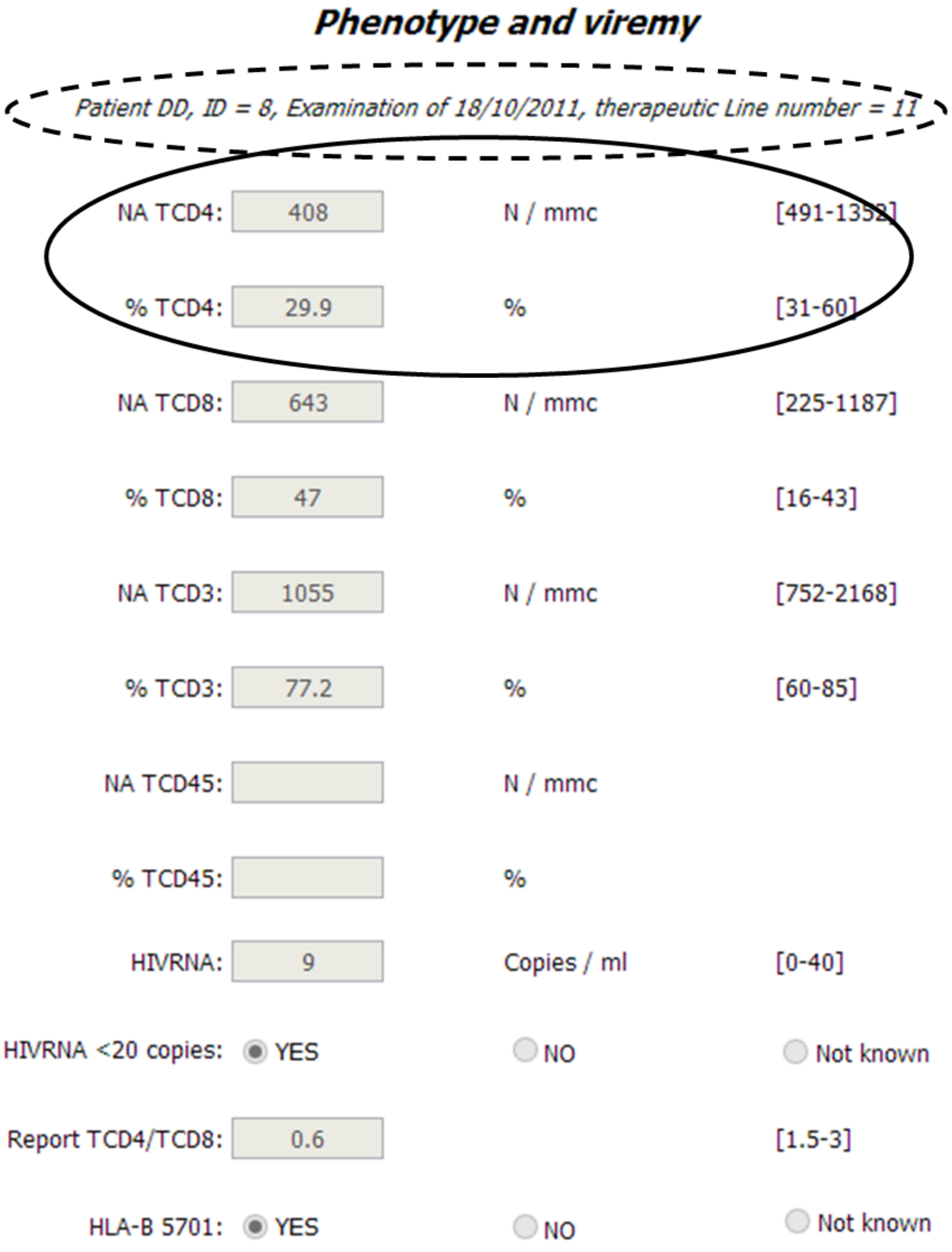
Parameter Id = 8

Clinical Trial	
MARHIV study	DELETE
San Martino Long-Term	DELETE
Actea-I Study	DELETE
Register people infected with HIV-1 in maternal-fetal transmission	DELETE

Center	Unit of measure	Range		
Pietra Ligure Infectious Diseases	N / mmc	[491-1352]	MODIFICATION	DELETE
Galliera Infectious Diseases	N / mmc	[435-2360]	MODIFICATION	DELETE
Sanremo Infectious Diseases	N / mmc	[435-1360]	MODIFICATION	DELETE
San Martino Clinical Infectious Diseases	N / mmc	[491-1352]	MODIFICATION	DELETE
La Spezia Infectious Diseases	N / mmc	[300-1600]	MODIFICATION	DELETE
Alexandria Infectious Diseases	N / mmc	[493-1666]	MODIFICATION	DELETE
Turin Infectious Diseases	N / mmc	[493-1666]	MODIFICATION	DELETE
DIMI	N / mmc	[491-1352]	MODIFICATION	DELETE
Savona Infectious Diseases	N / mmc	[400-1590]	MODIFICATION	DELETE

MEDINFO HIV Clinical Network is made from MEDINFO, Laboratory of Nanobiotechnology and Medical Informatics (DIST, University of Genoa)

Figure 3. List of parameters concerning phenotype and viremy aspects for primary care.

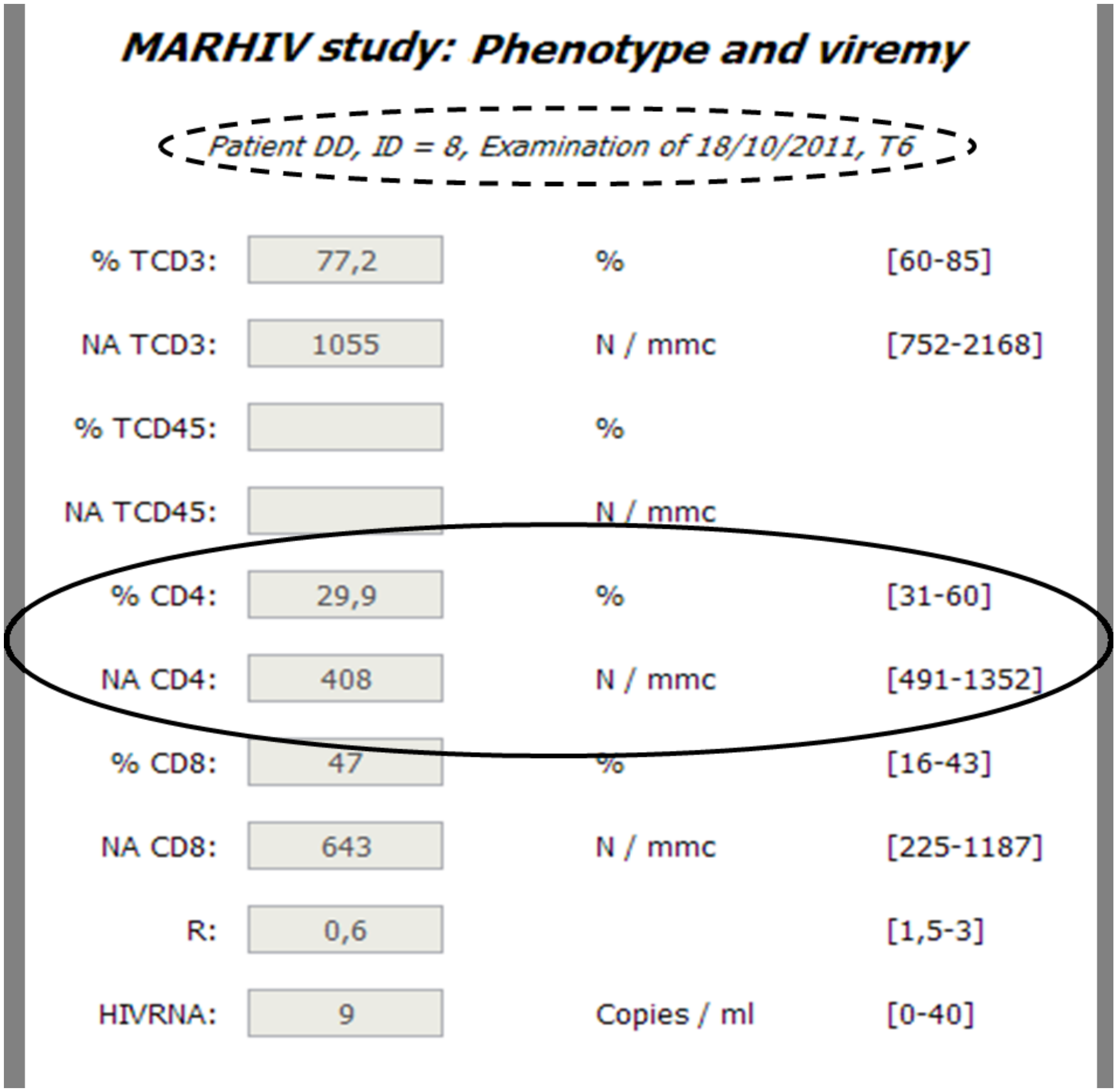


Phenotype and viremy

Patient DD, ID = 8, Examination of 18/10/2011, therapeutic Line number = 11

NA TCD4:	408	N / mmc	[491-1352]
% TCD4:	29.9	%	[31-60]
NA TCD8:	643	N / mmc	[225-1187]
% TCD8:	47	%	[16-43]
NA TCD3:	1055	N / mmc	[752-2168]
% TCD3:	77.2	%	[60-85]
NA TCD45:		N / mmc	
% TCD45:		%	
HIVRNA:	9	Copies / ml	[0-40]
HIVRNA <20 copies:	● YES	○ NO	○ Not known
Report TCD4/TCD8:	0.6		[1.5-3]
HLA-B 5701:	● YES	○ NO	○ Not known

Figure 4. List of parameters concerning phenotype and viremy aspects for MARHIV study.

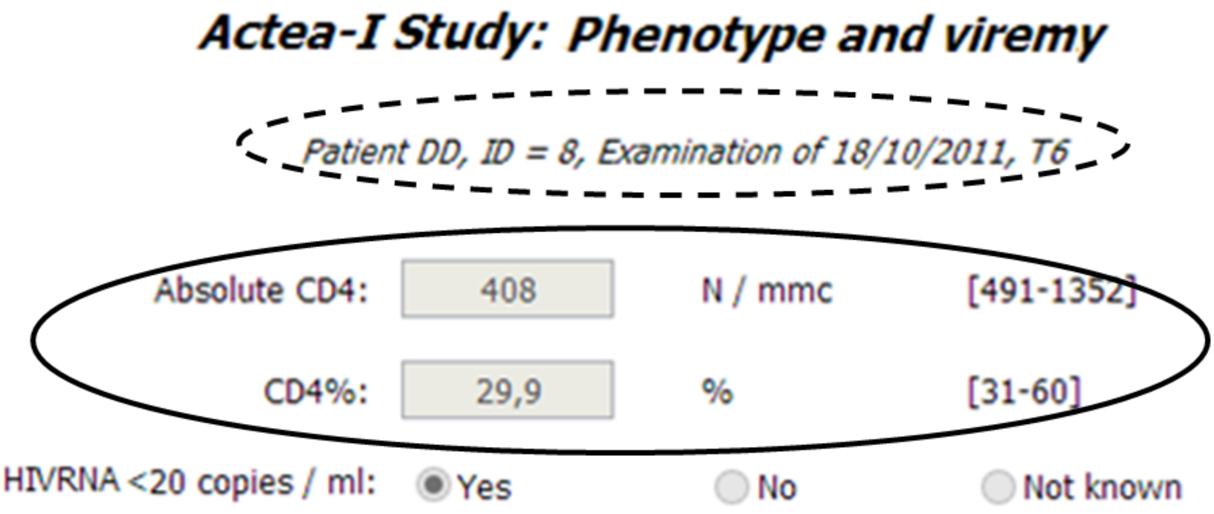


MARHIV study: Phenotype and viremy

Patient DD, ID = 8, Examination of 18/10/2011, T6

% TCD3:	77,2	%	[60-85]
NA TCD3:	1055	N / mmc	[752-2168]
% TCD45:		%	
NA TCD45:		N / mmc	
% CD4:	29,9	%	[31-60]
NA CD4:	408	N / mmc	[491-1352]
% CD8:	47	%	[16-43]
NA CD8:	643	N / mmc	[225-1187]
R:	0,6		[1,5-3]
HIVRNA:	9	Copies / ml	[0-40]

Figure 5. List of parameters concerning phenotype and viremy aspects for ACTEA I-study.



Actea-I Study: Phenotype and viremy

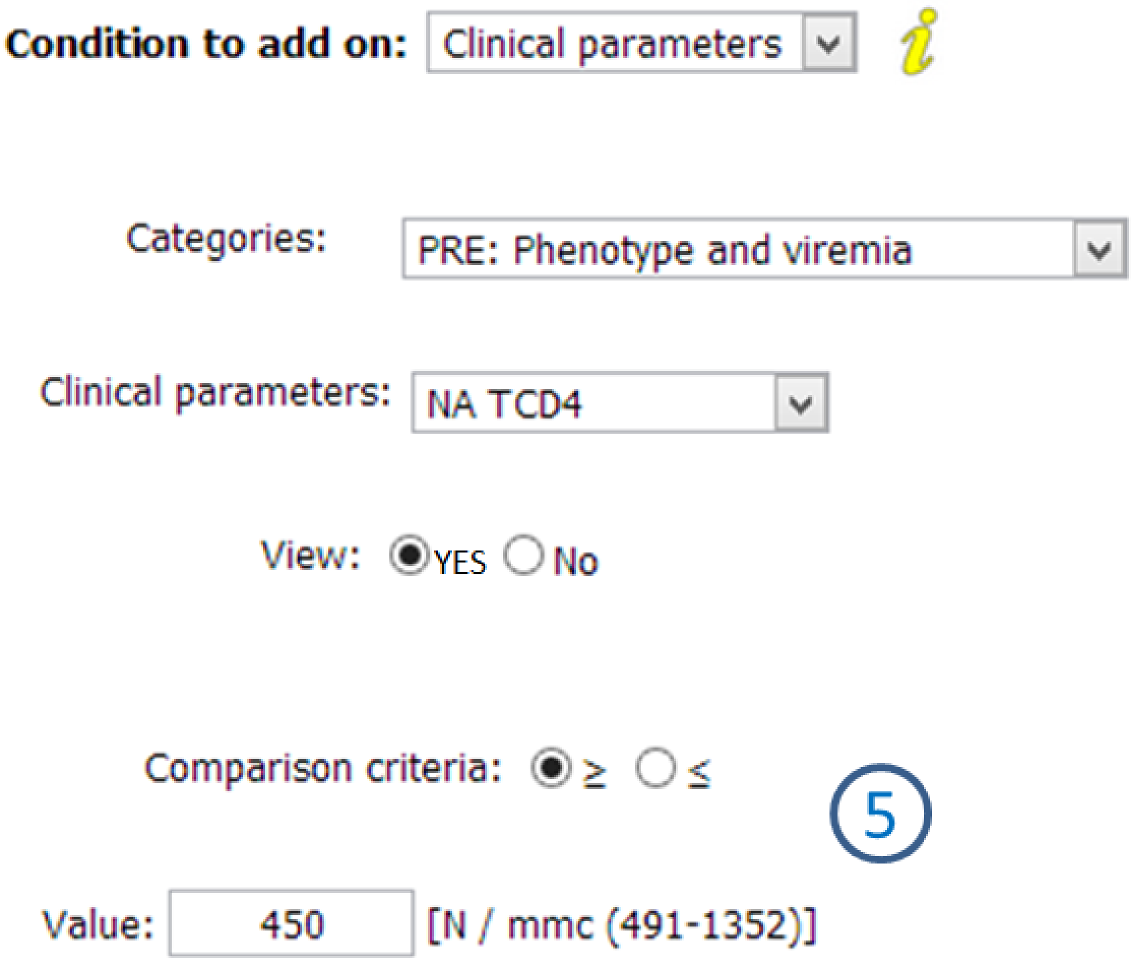
Patient DD, ID = 8, Examination of 18/10/2011, T6

Absolute CD4: 408 N / mmc [491-1352]

CD4%: 29,9 % [31-60]

HIVRNA <20 copies / ml: ● Yes ○ No ○ Not known

Figure 6. Data extraction tool: example of extraction criteria entering.



Condition to add on: Clinical parameters

Categories: PRE: Phenotype and viremia

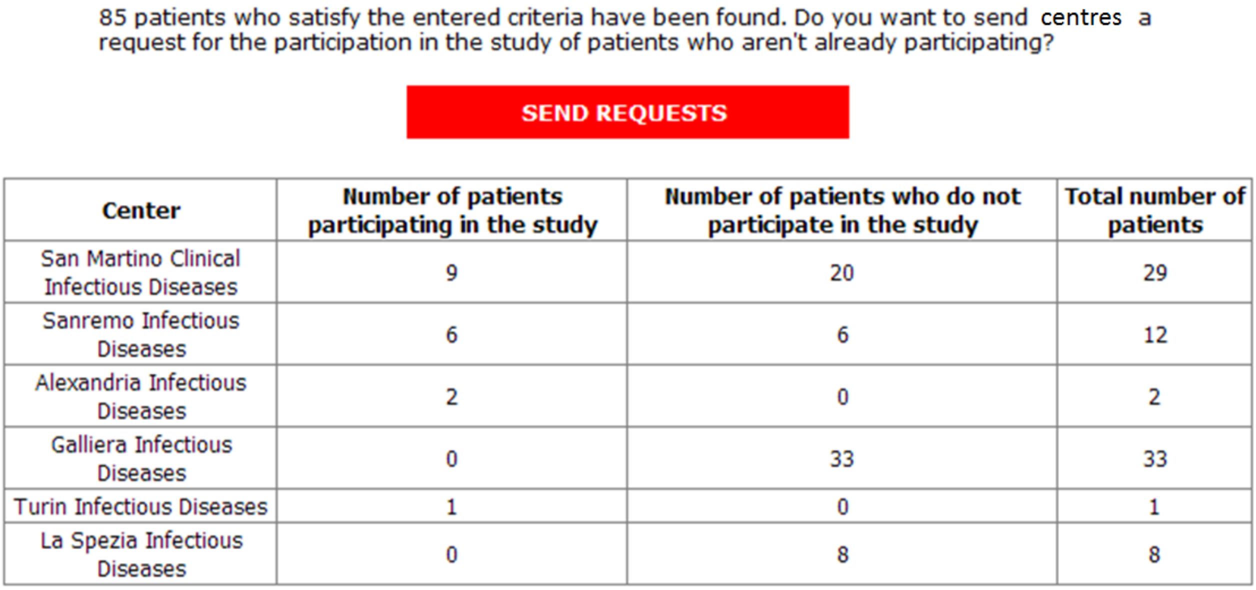
Clinical parameters: NA TCD4

View: ● YES ○ No

Comparison criteria: ● ≥ ○ ≤

Value: 450 [N / mmc (491-1352)]

Figure 7. Data extraction tool: extraction tool used for patients’ recruitment.



85 patients who satisfy the entered criteria have been found. Do you want to send centres a request for the participation in the study of patients who aren't already participating?

Center	Number of patients participating in the study	Number of patients who do not participate in the study	Total number of patients
San Martino Clinical Infectious Diseases	9	20	29
Sanremo Infectious Diseases	6	6	12
Alexandria Infectious Diseases	2	0	2
Galliera Infectious Diseases	0	33	33
Turin Infectious Diseases	1	0	1
La Spezia Infectious Diseases	0	8	8

Discussion

The Ligurian HIV Clinical Network, through standard and general methods which are applicable also in other medical domains, provides physicians with all the necessary instruments to perform high quality care and collaborative research in the field of HIV. In addition, it overcame some of the drawbacks of the previously proposed solutions. First, as reported in the Results section, a wide range of parameters are considered in order to extend the area of actions analysed within the Orchestra program [11] and the adoption of an approach as comprehensive as possible during primary care with the possibility of easily adding new clinical aspects was applied. Furthermore, instead of NADIS [12,13] the proposed solution is a Web-platform to ensure low maintenance costs and wide access. From the multicenter research perspective, a high level of semantic interoperability was achieved and data is effectively managed and shared within MCTs among different regions in Italy.

Moreover, due to the nature of the presented structure, the project potentially is not limited to NorthernItaly. In fact, new centers and research groups could join this initiative on a national and international base; the only requirement is the collection of all relevant information concerning the work environment (such as standard codes; normality ranges and units). Furthermore, unlike within NADIS [12,13], physicians can independently extract and compare information according to their needs in an effective way, without any necessary dedicated staff. In addition, the developed extraction tool can sensibly improve and speed up the patients’ recruitment which usually is one of the most time consuming operations in MCTs.

However, since some aspects are still being developed, our system still has some limitations. First, at the moment a statistical analysis tool is missing. We plan to develop such a tool in the near future, but it is important to underline that the majority of physicians prefers to use their own statistical packages. Accordingly, the creation of a statistical tool within the platform does not represent a priority at the moment. In fact, the most important and innovative aspect is to have provided physicians with the possibility of normalizing and extracting data which can be correctly analyzed by their own statistical packages. Second, specific alghorithms for patient recruitment are missing at this stage. However, the developed tool selects the patients according to the user requirements (eg, value of last cluster of differentiation 4 [CD4] lymphocytes count), consequently physicians can identify suitable patients for their research purposes. Finally, the percentage of recorded patients in the system is just a part of the overall Ligurian HIV positive population in the considered area. Though, since the information has been recorded manually so far, physicians actively used the system and about the 16% of the whole Ligurian HIV positive population (400/2500 patients) has been collected within the system. Moreover, since testing processes for the direct storage of information are in an advanced phase in three hospitals, the quantity and the quality of recorded data are destined to increase. Furthermore, the already published works [17-19] evidence the effectiveness of the platform also from a research point of view.These results are a direct consequence of the close collaboration between health informaticians and physicians, adopted during all the phases of the project which has permited the creation of a tool that satisfies s physicians needs in both primary care and clinical research.

As far as the future is concerned, operations to extend the platform to other chronic infective diseases (hepatitis B and C) have already begun and this could be extremely important in supporting physicians’ work, as many HIV positive patients have also these coinfections. Furthermore, we planned to exchange our information with other HL7 compliant research groups. Concerning this aspect, links have previously been developed to perform, in the future, an automatic exchange of data with Antiretroviral Resistance Cohort Analysis (ARCA) [20], which is one of the biggest HIV research databases in Italy.

Acknowledgments

The authors would like to thank Moyra Watson for the English revision.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Summary of quantitative results of the project.

[PNG File, 37KB - med20_v2i2e5_app1.png]

References

1. Unaids Association. UNAIDS Corporate publications. 2012. 2012 UNAIDS report on the global AIDS epidemic URL: http://www.unaids.org/en/resources/publications/2012/name,76121,en.asp [accessed 2013-08-01] [WebCite Cache ID 6IXsEsI5h]
2. European AIDS Clinical Society. European AIDS Clinical Society Guidelines Version 6.1. 2012 Nov 1. URL: http://www.europeanaidsclinicalsociety.org/index.php?option=com_content&view=article&id=59&Itemid=41 [accessed 2013-08-01] [WebCite Cache ID 6Ig4CNBBb]
3. Williams JG, Cheung WY, Cohen DR, Hutchings HA, Longo MF, Russell IT. Can randomised trials rely on existing electronic data? A feasibility study to explore the value of routine data in health technology assessment. Health Technol Assess 2003;7(26):iii, v-iix, 1 [FREE Full text] [Medline: 14499049]
4. Dugas M, Lange M, Müller-Tidow C, Kirchhof P, Prokosch HU. Routine data from hospital information systems can support patient recruitment for clinical studies. Clin Trials 2010 Apr;7(2):183-189. [doi: 10.1177/1740774510363013] [Medline: 20338903]
5. Ohmann C, Kuchinke W. Future developments of medical informatics from the viewpoint of networked clinical research. Interoperability and integration. Methods Inf Med 2009;48(1):45-54. [Medline: 19151883]
6. Prokosch HU, Ganslandt T. Perspectives for medical informatics. Reusing the electronic medical record for clinical research. Methods Inf Med 2009;48(1):38-44. [Medline: 19151882]
7. Open Clinica-Open source for clinical research. URL: https://community.openclinica.com/ [accessed 2013-08-01] [WebCite Cache ID 6IXseps6u]
8. openCDMS - The open source clinical data management system. URL: http://opencdms.org/ [accessed 2013-08-01] [WebCite Cache ID 6IXsrvO0i]
9. PhOSCo - the pharma open source community. URL: http://www.phosco.com/ [accessed 2013-08-01] [WebCite Cache ID 6IXsx8Nq7]
10. Harris PA, Taylor R, Thielke R, Payne J, Gonzalez N, Conde JG. Research electronic data capture (REDCap)--a metadata-driven methodology and workflow process for providing translational research informatics support. J Biomed Inform 2009 Apr;42(2):377-381 [FREE Full text] [doi: 10.1016/j.jbi.2008.08.010] [Medline: 18929686]
11. Fonquernie F, Lacombe K, Vincensini JP, Boccara F, Clozel S, Ayouch Boda A, et al. How to improve the quality of a disease management program for HIV-infected patients using a computerized data system. The Saint-Antoine Orchestra program. AIDS Care 2010 May;22(5):588-596. [doi: 10.1080/09540120903280893] [Medline: 20401768]
12. Pugliese P, Cuzin L, Enel P, Agher R, Alfandari S, Billaud E, et al. [NADIS 2000, development of an electronic medical record for patients infected by HIV, HBV and HCV]. Presse Med 2003 Feb 22;32(7):299-303. [Medline: 12610445]
13. Pugliese P, Cuzin L, Cabié A, Poizot-Martin I, Allavena C, Duvivier C, Nadis Group. A large French prospective cohort of HIV-infected patients: the Nadis Cohort. HIV Med 2009 Sep;10(8):504-511. [doi: 10.1111/j.1468-1293.2009.00719.x] [Medline: 19486189]
14. Fraccaro P, Giacomini M. A web-based tool for patients cohorts and Clinical Trials management. Stud Health Technol Inform 2012;180:554-558. [Medline: 22874252]
15. Fraccaro P, Dentone C, Fenoglio D, Giacomini M. Multicentre clinical trials' data management: A hybrid solution to exploit the strengths of Electronic Data Capture and Electronic Health Records systems. Informatics for Health and Social Care (in press) 2014.
16. Chuang-Stein C. Summarizing laboratory data with different reference ranges in multi-center clinical trials. Therapeutic Innovation & Regulatory Science 1992 Jan 01;26(1):77-84. [doi: 10.1177/009286159202600108]
17. Dentone C, Fraccaro P, Fenoglio D, Firpo E, Cenderello G, Piscopo R, et al. Utilizzo di Maraviroc nella pratica clinica: studio multicentrico osservazionale (MARHIV study). In: 6° Workshop Nazionale CISAI. 2013 Presented at: 6° Workshop Nazionale CISAI; 2013; Genoa.

18. Cenderello G, Dentone C, Artioli S, Penco G, Fraccaro P, Giacomini M, et al. Liguria: risultati preliminari dello studio ACTEA. In: 6° Workshop Nazionale CISAI. 2013 Presented at: 6° Workshop Nazionale CISAI; 2013; Genova.
19. Dentone C, Fraccaro P, Fenoglio D, Firpo E, Cenderello G, Piscopo R, et al. Use of maraviroc in clinical practice: a multicenter observational study. Journal of the International AIDS Society 2012 Nov 11;15(6(Suppl 4)):18265. [doi: 10.7448/IAS.15.6.18265]
20. The ARCA (Antiretroviral Resistance Cohort Analysis) database. URL: http://www.hivarca.net/hiv_resistance.asp [accessed 2013-08-01] [WebCite Cache ID 6IXuJ2jnL]

Abbreviations

ARCA: Antiretroviral Resistance Cohort Analysis
CD4: cluster of diffrentiation 4
HAARTS: highly-active antiretroviral therapies
HBV: hepatitis B virus
HCV: hepatitis C virus
HIV: human immunodeficiency virus
HL7: health level 7
MCT: multicenter clinical trial

Edited by G Eysenbach; submitted 14.05.13; peer-reviewed by W Brown, E Afari-kumah, I Adeleke, H Alanazi; comments to author 15.06.13; accepted 18.07.13; published 13.08.13.

Please cite as:
Fraccaro P, Pupella V, Gazzarata R, Dentone C, Cenderello G, De Leo P, Bozzano F, Casalino Finocchio G, De Maria A, Fenoglio D, Filaci G, Guerra M, Di Biagio A, Mantia E, Orofino G, Ferrea G, Viscoli C, Giacomini M
The Ligurian Human Immunodeficiency Virus Clinical Network: A Web Tool to Manage Patients With Human Immunodeficiency Virus in Primary Care and Multicenter Clinical Trials
Med 2.0 2013;2(2):e5
URL: http://www.medicine20.com/2013/2/e5/
doi:10.2196/med20.2712
PMID:25075240

Original Paper

Validity and Reliability of the eHealth Analysis and Steering Instrument

Olivier A Blanson Henkemans[1], PhD; Elise ML Dusseldorp[1], PhD; Jolanda FEM Keijsers[1], PhD; Judith M Kessens[1], PhD; Mark A Neerincx[1], PhD; Wilma Otten[1], PhD

Nederlandse Organisatie voor Toegepast Natuurwetenschappelijk Onderzoek (TNO), Department Lifestyle, Leiden, Netherlands

Corresponding Author:
Olivier A Blanson Henkemans, PhD
Nederlandse Organisatie voor Toegepast Natuurwetenschappelijk Onderzoek (TNO), Department Lifestyle
Room 208
Wassenaarseweg 56
Leiden, 2333AL
Netherlands
Phone: 31 888666186
Fax: 31 715181918
Email: olivier.blansonhenkemans@tno.nl

Abstract

Background: eHealth services can contribute to individuals' self-management, that is, performing lifestyle-related activities and decision making, to maintain a good health, or to mitigate the effect of an (chronic) illness on their health. But how effective are these services? Conducting a randomized controlled trial (RCT) is the golden standard to answer such a question, but takes extensive time and effort. The eHealth Analysis and Steering Instrument (eASI) offers a quick, but not dirty alternative. The eASI surveys how eHealth services score on 3 dimensions (ie, utility, usability, and content) and 12 underlying categories (ie, insight in health condition, self-management decision making, performance of self-management, involving the social environment, interaction, personalization, persuasion, description of health issue, factors of influence, goal of eHealth service, implementation, and evidence). However, there are no data on its validity and reliability.

Objective: The objective of our study was to assess the construct and predictive validity and interrater reliability of the eASI.

Methods: We found 16 eHealth services supporting self-management published in the literature, whose effectiveness was evaluated in an RCT and the service itself was available for rating. Participants (N=16) rated these services with the eASI. We analyzed the correlation of eASI items with the underlying three dimensions (construct validity), the correlation between the eASI score and the eHealth services' effect size observed in the RCT (predictive validity), and the interrater agreement.

Results: Three items did not fit with the other items and dimensions and were removed from the eASI; 4 items were replaced from the utility to the content dimension. The interrater reliabilities of the dimensions and the total score were moderate (total, κ=.53, and content, κ=.55) and substantial (utility, κ=.69, and usability, κ=.63). The adjusted eASI explained variance in the eHealth services' effect sizes (R^2=.31, P<.001), as did the dimensions utility (R^2=.49, P<.001) and usability (R^2=.18, P=.021). Usability explained variance in the effect size on health outcomes (R^2=.13, P=.028).

Conclusions: After removing 3 items and replacing 4 items to another dimension, the eASI (3 dimensions, 11 categories, and 32 items) has a good construct validity and predictive validity. The eASI scales are moderately to highly reliable. Accordingly, the eASI can predict how effective an eHealth service is in regard to supporting self-management. Due to a small pool of available eHealth services, it is advised to reevaluate the eASI in the future with more services.

(Med 2.0 2013;2(2):e8) doi:10.2196/med20.2571

KEYWORDS

self-care; psychometrics; validity; reliability; scale analysis; effectiveness; self-management support

Introduction

Background

eHealth services, contributing to self-management, are developed and implemented on a daily basis. The Internet is flooded with websites and apps, which offer support for individuals to perform lifestyle-related activities and decision making, to maintain a good health, or to mitigate the effect of an (chronic) illness on their health. For example, Apple offers more than 200 apps, which provide information about healthy habits, offer the possibility to keep a diet, help monitoring physical activity, and facilitate managing an illness, such as diabetes. These websites and apps all claim that they can help to maintain a healthy lifestyle and contribute to a person’s health. But how effective are these eHealth services?

Various randomized controlled trials (RCTs) examined the effectiveness of eHealth services on self-management, with a large variety in effectiveness. For example, Norman et al. reported heterogeneity of studies with respect to participants, type of intervention and outcomes, and mixed findings related to the outcome [1]. As a result, it is difficult to generalize these findings to all eHealth services supporting self-management. In addition, many new health services are developed and should the effectiveness of each of these be examined empirically in an RCT?

Conducting an RCT takes extensive time and effort. Enrolling and studying people using an eHealth service for a longer period of time to examine its effectiveness may take a year or more. In addition, one has to deal with high levels of attrition when people use eHealth services [2]. Meanwhile, when the results are published, general knowledge and technological developments about eHealth are already a number of steps ahead [3]. Although considered the “gold standard” in empirical research on medical interventions, these RCTs are not an efficient way to answer our question how effective an eHealth service is at this time. Moreover, when evaluating eHealth services it is suggested to apply “methodological pluralism” (ie, undertaking combined quantitative and qualitative work) [4] and to examine changes and effects of using the eHealth service on various levels, such as the micro-level (eg, user health service), meso-level (eg, health organization), and macro-level (eg, society) [5]. Accordingly, there is a need for a rating instrument which can be used efficiently, provides an agenda to discuss how an eHealth service can contribute to self-management, and finally which is valid and reliable to provide a forecast on the effectiveness of an eHealth service on self-management, that is, an instrument which collects data “quick, but not dirty”.

The present literature does not provide such an instrument. Most instruments are concerned with rating the quality of the content of health websites (eg, Health Website Rating Instrument, HWRI [6] and for an overview see [7]), standards to report studies on eHealth devices (eg, Consolidated Standards of Reporting Trials of Electronic and Mobile HEalth Applications and online TeleHealth, CONSORT-EHEALTH [8]), or toolkits to promote the implementation of eHealth (eg, eHealth implementation toolkit, e-hit [9]). However, we need an instrument that not only evaluates the quality of the content of a website, description of the study, or implementation of the service, but that judges if the eHealth device effectively supports changing health-related behavior (ie, se-management).

eHealth Analysis and Steering Instrument: Dimensions and Categories

The eHealth Analysis and Steering Instrument (eASI) is developed to measure the expected effectiveness of eHealth services on self-management, without necessitating the endeavors of an RCT or more formative research on various levels (ie, micro-, meso-, and macro-level). The eASI is based on a literature review, examining definitions and operationalization of the effectiveness of eHealth [10]. This review covered the literature on health promotion, self-management and self-regulation, human-computer interaction, usability, and the development and implementation of health-promoting interventions, including interactive health technologies (ie, eHealth) [11-20]. The review elicited various techniques and strategies contributing to the effectiveness of health innovations. Examples are providing feedback to create health awareness, offering decision aids, and goal setting. In addition, it elicited usability aspects contributing to the effectiveness of technology in general. Only one paper looked at evaluation of usability in eHealth services. In this paper, the usability guidelines, as originally introduced by Norman and Nielsen, are used as principal evaluation items, because no new evaluation items have been specifically developed for testing interactive health technologies. The guidelines for usability include interface consistency, error prevention, and tailoring to user characteristics. Finally, the review elicited aspects related to the content of the technological health-promoting intervention, which contribute to its effectiveness. Here, aspects cover analyzing the health problem, identifying causes of the health problem and the extent to which the intervention attends to these factors, and the constituency for the intervention.

These resulting aspects were integrated in a conceptual framework consisting of 3 dimensions, contributing to the effectiveness of eHealth supporting self-management. These dimensions are: (1) utility, a scale of how functional the service is (ie, what is self-management and how is it operationalized in the rated eHealth services), (2) usability, a scale of how usable the service is (ie, how easy and enjoyable is it to perform self-management with this service), and (3) content, a scale of the quality of the content of the service (ie, does this service contain content, which succeeds in convincing why it is important for the user to perform self-management.).

These dimensions were operationalized in 3 subscales by formulating Likert-type items. The dimensions contain different categories, which in turn cover 43 items, which are rated dichotomously.

The face validity of this 43-item version of the eASI was evaluated by a group of Dutch experts (n=28) in a Delphi procedure [21]. Through this Delphi study, we reached consensus that 35 items were considered relevant for measuring the effectiveness of eHealth (see Table 1). The 35 items are divided across 12 categories, which in turn are divided across the three dimensions: utility, usability, and content. For an overview of the items, see Multimedia Appendix 1.

The eASI is developed for intermediates, such as health care insurance companies, health care givers, and eHealth developers. This target group can directly act based on the eASI outcomes. They can reimburse, buy and apply services, or determine how to (re)develop them. A first application of the eASI showed that it can be used to analyze the expected effectiveness of eHealth services and provide steering for improvement [10]. However, there are no data on its validity and reliability. Therefore, our study has 3 aims to address these issues: First, the construct validity: the degree to which the scores of eASI are consistent with our hypotheses, regarding internal relationships between items within the different dimensions—utility, usability, and content [22]. Second, the interrater reliability: the degree of agreement among the raters for each item of the eASI, the total score on the eASI, and the three dimensions [22]. Third, the predictive validity: the degree to which the scores on eASI (ie, total score and dimensions) predict the effect sizes of the rated eHealth services observed in RCTs [23].

Table 1. Dimensions and categories defined in the eASI and the number of items they contain.

Dimension	Categories	Number of items
Utility	Insight in health condition	3
	Self-management decision making	3
	Performance of self-management	4
	Involving the social environment	4
Usability	Interaction	4
	Personalization	3
	Persuasion	4
Content	Description of health issue	2
	Factors of influence	2
	Goal of eHealth service	3
	Implementation	2
	Evidence	1
Total		35

Methods

Focus

To examine the validity and reliability of the eASI, various eHealth services needed to be rated using the eASI. These ratings served to examine the construct validity and interrater reliability. In order to study the predictive validity of the eASI, the effectiveness of these eHealth services had to be assessed in an RCT. Although the RCT is sometimes criticized as too limited to assess the effectiveness of eHealth services [4,5], we consider the RCT as a suitable and conservative approach to examine the effects of stand-alone eHealth services to support individual users in their self-management. To demonstrate the predictive validity, the effect sizes of the eHealth services found in an RCT needed to be compared with the eASI rating result of that eHealth service.

Selection of eHealth Services

Systematic literature searches in electronic databases (Pubmed, MEDLINE, CINAHL, and PsycInfo) were conducted for RCTs of eHealth services, which aimed at increasing self-management. We used the search phrase (online OR Internet OR eHealth) AND (self-management OR self-care OR health-promotion) AND (randomized controlled trial OR RCT) as title and abstract words or MeSH terms. Article reference lists were examined for additional papers. A total of 14,531 papers were identified.

Subsequently, titles and abstracts of the papers were screened using the following criteria: First, the RCT evaluated an eHealth service (ie, online or Web-based or Internet-based therapy, treatment, or intervention) and the outcome measure was self-management behavior (ie, behavior conducted by the user to improve or maintain health or minimize impact of illness on health). Second, the results of the full trial were published or in press. This screening elicited 64 studies. Finally, we screened if the studied eHealth service used the Dutch, English, French, or German language and was available to be rated by the eASI in our study. This screening elicited 16 services (see Table 2).

Table 2. Overview of the eHealth service and RCT evaluation (N=16).

eHealth service (country)	Study	Service characteristics[a]
1. Drinktest (Netherlands)	Boon et al [24]	Problem drinkers Assessment and advice SA Reduce alcohol consumption
2. Moodgym (Australia)	Powell et al [25]	People with (early signs of) a depression Web-based cognitive behavioral therapy (CBT) SA Reduce depression and anxiety
3. Interapy (Netherlands)	Ruwaard et al [26]	People with a depression Online assessment, diagnosis by phone and Web-based CBT BC Reduce symptoms of depression and anxiety
4. Gripp (Netherlands)	Genugten et al [27]	People who are overweight Web-based modular treatment focusing on goal setting, self-monitoring, and feedback SA Reduce weight gain
5. Alcoholdebaas (Netherlands)	Postel et al [28]	Problem drinkers Asynchronous communication with therapist, health information, and forum BC Reduce alcohol consumption
6. Diep (Netherlands)	Heinrich et al [29]	People with diabetes Interactive information on diabetes SA Improve diabetes regulation
7. Diabetergestemd (Netherlands)	Bastelaar [30]	People with diabetes and depression Web-based, guided self-help program based on CBT BC Reduce depressive symptoms
8. Fitnet (Netherlands)	Nijhof et al [31]	Teenagers with chronic fatigue syndrome Web-based CBT BC Improve school presence and physical functioning and reduce fatigue
9. Gezondgewichtassistent (Netherlands)	Kelders et al [32]	People who are overweight Website to set and achieve personal health goals and tailored health information SA Maintaining a healthy lifestyle and improve body mass index (BMI)
10. Kleurjeleven (Netherlands)	Graaf et al [33]	People with (early signs of) a depression and anxiety Web-based CBT BC Reduce symptoms of depression and anxiety

eHealth service (country)	Study	Service characteristics[a]
11. 113online (Netherlands)	Spijker et al [34]	People with suicidal ideations Online services, covering self-test and consultation through chat, phone and email, forum, and self-help course BC Reduce suicidal ideations
12. Patientcoach (Netherlands)	van der Meer et al [35]	People with chronic obstructive pulmonary disease (COPD) and asthma Web-based application for health information, self-monitoring, and eConsult BC Improve COPD and asthma regulation
13. Diabeter (Netherlands)	Blanson Henkemans et al [36]	People who are overweight Online lifestyle diary, setting personal goals and feedback from an avatar SA Maintaining a healthy lifestyle and improve BMI
14. Minderdrinken.nl (Netherlands)	Riper et al [37]	Problem drinkers Web-based CBT SA Reduce alcohol consumption
15. Alles onder controle (Netherlands)	Warmerdam et al [38]	People with (early signs of) a depression and anxiety Web-based CBT BC Reduce symptoms of depression and anxiety
16. Active online (Switzerland)	Wanner et al [39]	People who want to increase physical exercise Individually tailored counseling and motivational feedback SA Improved physical exercise

[a] Target group, intervention description, stand-alone (SA) or blended care (BC), and goals.

Rating eHealth Services With eASI

Population

The eASI target user group consists of health care insurance employees in charge of acquiring eHealth services, health care givers applying eHealth, and eHealth developers. These persons are generally highly educated and use computers and Internet daily. In our study, to fit the profile of the target group, we recruited a sample of 16 men and women, aged 20-25 years, highly educated (ie, BA or MA degree), and with above average experience with computers and Internet.

Persons were recruited through the participants' database of the Dutch Organization for Applied Sciences (TNO) through an invitational email. Computer experience of the persons, who signed up for the study, was assessed with a computer experience survey. This survey consisted of a 5-point Likert scale, ranging from low (little computer and Internet experience) through high (extensive computer and Internet experience, including programming). All participants scored at least 4 points. Participants were invited to rate eHealth services and they received a small fee for their participation. They did not have prior experience with the eASI.

eASI Instrument

The eASI is based on a literature review of factors related to the effectiveness of eHealth services, regarding self-management and health outcomes [10]. For the study, we applied the eASI, which was tested on face validity and improved accordingly. The eASI contained 35 items, which were rated dichotomously (item is applicable or not applicable to eHealth service). An eHealth service could score 0-35 points in total, 0-14 points for utility, 0-11 points for usability, and 0-10 points for content. The higher the score, the more effective an eHealth service is expected to be.

Procedure

The rating sessions lasted approximately 2.5 hours and started with a short questionnaire assessing demographics (ie, gender, year of birth, and education level) and use of eHealth (on a

4-point scale: never, sometimes, regularly, and often). Further, the participants received a short training on how to rate with the eASI. The training covered the goal of the eASI, explanation of the three dimensions, and instructions on how to use the eASI to rate the eHealth services. These instructions were also available on paper during the rating. The rated eHealth services were presented on a PC and the eASI was filled in on paper. Finally, we surveyed how the raters experienced rating eHealth services with the eASI. The raters were surveyed after each rated service, using a 5-point Likert scale and an open question, on the experienced clarity of the items, the effort to answer them, and the ability to rate a service with the eASI. In addition, we posed an open question about the positive and negative features of the eASI.

It would be too demanding for each participant to rate all eHealth services with the eASI. Therefore, each eHealth service was rated by 3 participants. They were randomly selected from the pool of 16 participants in such a way that each of the 16 participants rated 3 eHealth services. For example, the eHealth service by Postel et al was rated by raters 1, 12, and 14. The score of each service on the eASI was calculated as follows: First, we computed the services' total eASI score and score per dimensions, per rater (ie, sum score). Second, we averaged the three raters' sum scores.

Statistical Analysis

Construct Validity

To determine the construct validity, that is, to confirm the existence of the predefined three dimensions, we conducted confirmatory factor analysis (ie, the oblique multiple group method) [40,41]. We tested if the eASI ratings fit the hypothesized structure. For each dimension, we calculated the reliability statistic (ie, Cronbach alpha) and for each item 3 correlations: the correlation with the dimension it is assumed to belong to (with an item-rest correlation) and the correlations with the other two dimensions. If the first correlation (the item-rest correlation) was larger than the latter two, the predefined structure was confirmed.

Because we had scores from 3 raters per item, we calculated the Cronbach alpha from 3 random samples in regard to the rater (ie, we randomly selected one score per item; and this was repeated 3 times). On the basis of the results, an alternative structure of the eASI was considered.

Interrater Reliability

As an index of the interrater reliability, a generalized kappa was computed (ie, Light's kappa) [42]. For the analysis, we assumed that the raters were interchangeable (ie, each of the raters could "act" as the first, second, or third rater), and we organized the data for each item accordingly. We permuted the order of the values in each row 1000 times, resulting in 1000 data sets. For each permuted data set, we computed Light's kappa, resulting in 1000 values of kappa. As summary statistics, we used the computed mean kappa of these 1000 values, and the minimum and maximum. We used the interpretation of kappa, as listed in Table 3 [43].

Predictive Validity

To determine the predictive validity, we first analyzed how the RCTs measured the effectiveness of the eHealth services. Self-management behavior is influenced by personal and environmental determinants (eg, intention, attitude, and subjective norm). In turn, self-management behavior results in health outcomes. This behavioral model is based on, among others, the theory of reasoned action and the theory of planned behavior [44]. These social cognitive theories of behavior distinguish 3 elements of behavior: (1) the determinants of an individual's behavior, (2) the intention to perform a behavior, and (3) the actual behavior itself. Many health outcomes are linked to specific behaviors, thus a fourth step that can be distinguished, which is the impact of the behavior on an individual's health. This enabled us to categorize the measures of the different studies and compare effect sizes. First, we calculated the effect sizes (ie, Hedges *g*) of each service in regard to (1) determinants of behavior, (2) self-management behavior, and (3) health outcomes [45]. Second, we conducted a regression analysis in which we studied the relation between the eHealth services' effect size in regard to determinants, health behavior and health outcomes, and their averaged sum scores on the eASI in total and per dimension. For example, the analysis showed that the eHealth service "Alcohol de baas" (Look at your drinking) had an effect size of 1.15 regarding self-management behavior. The sum score of the three raters on average was 31.67 on the eASI total (90% of maximum total score), 13.00 on utility (93% of maximum total score), 9.33 on usability (85% of maximum total score), and 9.33 on content (93% of maximum total score). In our regression analysis, we analyzed if eHealth services with a high effect score also had a high eASI score, just as Alcohol de baas, and *vice versa*.

Computational Note

The construct validity analyses were performed in SPSS (version 20.0); the predictive validity analyses were performed in Comprehensive Meta-Analyses (version 2) [46], and the interrater reliability analyses were performed using the package "psy" in the R software environment [47,48].

Table 3. Interpretations of kappa [43].

Kappa statistic	Strength of agreement
<.00	Poor
.00-.20	Slight
.21-.40	Fair
.41-.60	Moderate
.61-.80	Substantial
>.80	Almost perfect

Results

Participants

The study sample consisted of 7 male and 9 female participants, between the age of 20 and 25 years (mean 22.06, SD 1.57). They had a Bachelor (BA) or Master (MA) degree. They sometimes used eHealth services.

Construct Validity

A first step in the construct validity is the internal consistency of the items belonging to a construct. The dimensions utility, usability, and content had a Cronbach alpha of .53,.41, and .49, respectively. An inter-item correlation analysis of items in own dimension versus items in other dimensions showed that items 5 and 35 had a negative correlation with their own dimension (−.35 and −.27, respectively) and a weak correlation with the other two dimensions. Therefore, we followed a number of steps to come to a new structure and to improve the overall inter-item correlation.

First, we discarded items 5 and 35 and redid the inter-item correlation analysis. The correlation improved, but showed that items 11-14 better correlated with the dimension content than with utility (.30 vs .06, .68 vs .49, .51 vs .04, and .12 vs −.11, respectively). Second, we discarded items 5 and 35 and placed items 11-14 in the dimension content and redid the inter-item correlation analysis. The result was that item 30 had a negative correlation with its own dimension (−33). Third, we discarded item 30 and redid the inter-item correlation analysis. Internal consistency statistics of the new version of eASI with 32 items, with items 5, 30, and 35 discarded and items 11-14 placed in the dimension content, were as follows. The dimensions utility, usability, and content had a Cronbach alpha of .61, .56, and .62, respectively. This new and final version is listed in Multimedia Appendix 1.

Interrater Reliability

The interrater reliability of most items was moderate to almost perfect (κ>.41 and κ>.81, respectively), except for the following 6 items: 14, 15, 17, 28, 29, and 31. For 3 items (16, 25, and 30), Light's kappa could not be computed, because there was no variability in the scores among the raters. All raters scored a “1” (ie, yes) on these eASI items.

The interrater reliabilities of the dimensions and the total score varied between moderate (total and content) and substantial (utility and usability). The interrater reliabilities of the initial structure were comparable to the ones of the new structure. The improvement of the construct validity did not go at the cost of the reliability.

Predictive Validity

As shown in Table 4, 10 RCTs studied the effect of their eHealth service on self-management behaviors (eg, maintain diet, performing physical activity, adhering to the low-risk drinking guideline, and controlling corticosteroid). As shown in Table 5, 12 RCTs studied the effect of their eHealth service on health outcomes (ie, physical and mental health). Only 4 RCTs studied the effect of their eHealth service on determinants for self-management (eg, attitude, beliefs, knowledge, and skills). This number was too small for our predictive validity analysis. As we wanted to evaluate the eASI and not the eHealth services, we have anonymized the studies; however, services in Tables 4 and 5 are similarly denoted.

Figure 1 shows the correlation between the eASI total score with 32 items (see Multimedia Appendix 1) and self-management behavior. The correlation was significant. The eASI total score predicted 31% of the variance in the effect sizes of the studied eHealth services ($F_{1,28}$=12.56, P<.001). Furthermore, the separate eASI utility scores and eASI usability scores on self-management behavior were significant. They predicted 49% and 18% of the effect sizes ($F_{1,28}$=27.37, P<.0001; $F_{1,28}$=6.01, P=.021), respectively. The eASI content score was not significant (R^2=.05; $F_{1,28}$=.54, P=.22).

The total score on eASI did not have a significant effect on health outcome measures (R^2=.05; $F_{1,34}$=1.64, P=.21). Of the separate dimensions, usability (ie, new scale with 11 items) predicted 13% of the variance in the effect sizes ($F_{1,34}$=5.28, P=.028). The other two dimensions utility and content predicted 0% and 2% variance, respectively.

Table 4. eHealth services' effect sizes in RCTs of self-management behavior and sum scores on eASI total, utility, usability, and content (N=10).

eHealth services[a]	Hedges *g* (*P* value)	Score eASI total	Score eASI utility	Score eASI usability	Score eASI content
Range (min-max)	−1-1	0-32	0-9	0-11	0-12
A	.378 (.257)	19.33	7.00	4.67	6.67
B	.562 (.004)	22.00	7.00	4.33	10.33
C	.727 (.002)	22.67	8.00	7.33	7.67
D	.645 (.000)	12.33	5.00	3.67	3.67
E	.223 (.256)	22.00	8.00	6.33	7.33
F	.300 (.257)	19.67	5.00	6.00	8.33
G	.183 (.462)	19.33	4.00	7.33	8.00
H	1.151 (.000)	28.67	8.00	9.33	11.00
I	.170 (.141)	20.33	7.00	4.00	9.00
J	1.215 (.000)	21.00	7.00	7.33	6.33
Overall	.556 (.000)	20.73	6.60	6.03	7.83

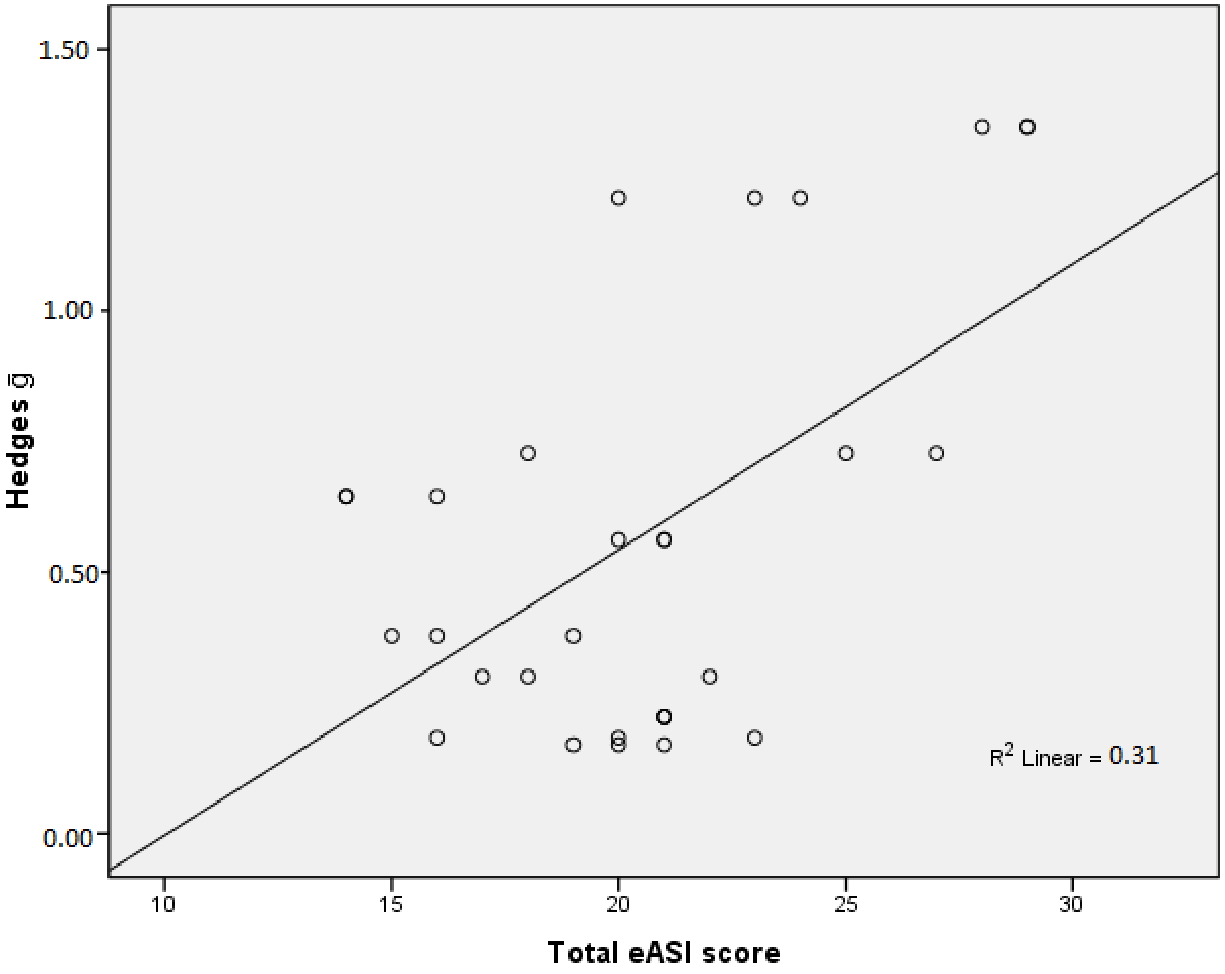
[a]eHealth services have been anonymized.

Table 5. eHealth services' effect sizes in RCTs of health outcomes and sum and sum scores on eASI total, utility, usability, and content (N=12).

eHealth services[a]	Hedges *g* (*P*value)	Score eASI total	Score eASI utility	Score eASI usability	Score eASI content
Range (min-max)	−1-1	0-35	0-14	0-11	0-10
A	.080 (.620)	19.33	7.00	4.67	6.67
C	.137 (.219)	22.67	8.00	7.33	7.67
E	.224 (.185)	22.00	8.00	6.33	7.33
F	.611 (.024)	19.67	5.00	6.00	8.33
G	.831 (.001)	19.33	4.00	7.33	8.00
H	.562 (.001)	28.67	8.00	9.33	11.00
J	1.194 (.000)	21.00	7.00	7.33	6.33
K	.171 (.185)	15.67	4.00	5.67	6.33
L	.541 (.000)	22.00	8.00	6.67	7.67
M	.390 (.012)	19.67	5.00	6.00	8.33
N	.227 (.515)	18.00	8.00	5.33	5.00
O	.220 (.092)	20.00	4.00	6.67	9.00
Overall	.369 (.000)	20.67	6.33	6.56	7.64

[a]eHealth services have been anonymized.

Figure 1. Regression of eASI total score and eHealth services' effect size in regard to self-management behavior (Hedges g; n=10; R^2=.31; $F_{1,28}$=12.56, P<.001).



Qualitative Evaluation of eASI

In regard to the experienced ability to rate a service with the eASI, on a scale of 1 (not at all able) through 5 (very able), the raters, on average, scored 4.06 (SD .75) after 1 rating and 3.38 (SD 1.05) after 3 ratings.

In regard to the experienced clarity of eASI, on a scale of 1 (not clear at all) through 5 (very clear), the raters, on average, scored 3.94 (SD .66) after 1 rating and 4.06 (SD .43) after 3 ratings. The items that were least clear (ie, this item was mentioned more than 6 times by the raters as not clear) were "the eHealth service aids making a decision about how to cope with a health problem in agreement with personal preferences", "the eHealth service aids translating chosen coping strategies to a personal goal," and "the eHealth service can be used on different platforms."

In regard to the experienced effort to rate services with eASI, on a scale of 1 (no effort at all) through 5 (very much effort), the raters, on average, scored 2.25 (SD .66) after 1 rating and 1.94 (SD .43) after 3 ratings. The items that took most effort to rate (ie, this item was mentioned more than 6 times by the raters as difficult to rate) was "the eHealth service can be used on different platforms."

Finally, when asked about the positive and negative features of the eASI, the raters mentioned that the eASI helped them to look at websites more accurately and systematically (n=4) and that the examples provided helped them to understand the rating items (n=3). In addition, they mentioned that it is important to bear in mind how the services is used (eg, once or continuously) (n=1) and that in some cases a caregiver is involved in the use of the service (n=2). This could affect the effectiveness. Finally, the raters suggested a rating scale instead of yes/no rating (n=3).

Discussion

Construct Validity

After discarding 3 items and shifting 4 items to another dimension, the three dimensions of eASI are moderately reliable (internal consistency, Cronbach alpha between .56 and .62) and the items are grouped in three distinctive dimensions. These results partly confirm our hypothetical and theory-based dimensions [10]. Accordingly, the results show that the eASI says something about the "what and how" of self-management through eHealth (utility), the ease and enjoyment using an eHealth service (usability), and why it is relevant (content).

Still, the reliability of the dimensions and especially that of content could be improved. We have two suggestions for improvement. The first suggestion is of a technical nature, namely changing the existing “Applicable/Not applicable” response scale into a 3-point rating scale. The methodological benefit of a 3-point rating scale is that there is more room for variation, which could lead to stronger correlations. The second suggestion is of a substantive nature, namely creating additional items for the content dimension or rewriting existing ones. These additional items should help discriminate the content dimension from the other two dimensions and mainly from utility, whereby the content items focus on the “why” of self-management and utility on the “what and how”. Our aim is to look for items in these two domains that are more discriminating.

Interrater Reliability

Six items of the eASI showed a poor interrater reliability. We suggest that these items are improved in the following way. First, the formulation of the item should be made less ambiguous. In addition, the examples provided with each item should fit with the specific target group of the rated service. For example, in the case of item “Personal health data can be entered in the eHealth services (eg, BMI, blood pressure, HbA_{1c})”, the exemplary measure becomes “BMI” if the target group is overweight and “HbA_{1c}” if the target group has diabetes. This requires the instrument to be adaptive. Second, the instruction for the raters should be further clarified and they could be trained. In this case, it is advisable to study if there is a learning curve and how this affects interrater reliability.

The interrater reliability could not be computed for 3 items. This finding may imply that eHealth programs in general do not vary on these items (and so the items are not informative) or that the specific sample of eHealth programs used in this study is not diverse enough. More data are needed to investigate this in more detail.

Predictive Validity

The eASI total score predicted the impact of eHealth services on self-management behavior and health outcomes, which were assessed in RCTs. Specifically, the dimensions utility and usability were related to these effects, but content was not. These results show that the eASI is a valid instrument to predict the effectiveness of eHealth services with regard to self-management. However, the associations were small to moderately high (ie, R^2 between .05 and .31). This implies that the selection and application of eHealth services should not only be based on the eASI rating.

The total score of eASI did not predict the impact of eHealth services on health outcomes in RCTs. A possible cause is that these studies evaluated self-management among (chronically ill) patients, whereas we also looked at preventive self-management (ie, keep people healthy). It would be worth the effort to study the difference in predictive validity of the eASI for eHealth supporting healthy users or patients.

Clarity, Ease of Use, and Considerations

The qualitative evaluation shows that the eASI scored high on clarity and ease of use. Nevertheless, there are some items, which are challenging to understand and to rate. Specifically, the item “the eHealth service can be used on different platforms” was evaluated both as unclear and challenging to rate. More and more applications are offered on mobile platforms, such as smartphones and tablet pc. These platforms have the benefit of always being at hand. Still, none of the rated services offers a mobile version (eg, app). Possibly, the services work well through mobile Internet. To rate this item, one needs to have such a platform at hand. Accordingly, as mHealth is on the rise, we feel this is an important item when rating eHealth, but also suggest reexamining the validity and reliability of this item.

The qualitative evaluation also provided some consideration in regard to how to rate eHealth services. In the rated eHealth services, we found a variation in how they are used. For example, services are used once, continuously, or in modules. In addition, some services work stand-alone, while others are part of blended care (ie, human and computerized care are alternated). To date, no study has compared these new ways of using eHealth, and they are not differentiated in the eASI. However, these aspects could very well affect the effectiveness of eHealth. Taking into account how eHealth services are operated offer direction for the possible improvement of the eASI’s predictive validity. For example, the rater could indicate in the eASI what the context of the eHealth services is (eg, who is the end user and how is it used). In addition, the rater could indicate if the rating is based on the functionality of the eHealth service itself or on services offered by a remote caregiver. These parameters (context, type of use, and blended care) could be used as covariates for the rating results.

Online Version of eASI

Currently, an online version of eASI is developed with different functionalities (see Multimedia Appendix 2) [49]. These functionalities could enhance the validity and reliability. In addition, they could contribute to the effectiveness of eASI, regarding analysis and steering. Examples of enhancing functionalities (some of which are already implemented based on the qualitative data elicited in the study) are as follows:

- Using a rating scale instead of dichotomous rating
- Displaying the context of the eHealth service, including the type of use and the involvement of a caregiver
- Adapting the examples, accompanying the items, to the context of the service
- Providing an ontology which clarifies the terminology used in the eASI
- Providing examples of services which score high or low per items of the eASI
- Summarizing rating results and suggesting improvements for the service
- Offering the rater the possibility to provide an overall personal grade for the rated service
- Sharing results among raters

In a future study, we will evaluate if these functionalities further contribute to the reliability and validity.

Steering eHealth to Greater Effect on Self-Management

The results show that the eASI can analyze eHealth services, but also can provide directions for improvement of eHealth services. While developing eHealth services, developers could bare the items of eASI in mind. The more items are fulfilled, the greater the chance that the eHealth service will be effective in regard to stimulating self-management. However, specific eASI items could be at odds. For instance, when implementing cognitive behavioral therapy (CBT) in an eHealth service, the item "The eHealth service contains game elements" is unconventional. Still, through challenge and development of competencies, games can greatly contribute to long-term interaction. Stimulating behavior (ie, develop new healthy behavior or stop unhealthy behavior) takes time and gaming could stimulate people to use eHealth longer. Thus, we recommend developers not to rigidly adhere to the items of eASI, but incorporate the instrument in a conscious decision-making process, during the design of the service.

These results also show that the eASI has added value in terms of scientific contributions to eHealth evaluations. Greenhalgh and Russell [5] point out that "assumptions, methods, and study designs of experimental science, whilst useful in many contexts, may be ill-suited to the particular challenges of evaluating eHealth programs" (p. 2). They provide an alternative set of guiding principles for eHealth evaluation based on traditions that view evaluation as social practice rather than as scientific testing. In the light of this paper, the eASI facilitates applying the suggested guiding principles related to the creation of interpersonal and analytic space for effective dialog, the consideration of the meso-level contexts (eg, organizations, professional groups), and the consideration of the individuals (eg, clinicians, managers, and service users) through whom the eHealth innovation(s) will be adopted, deployed, and used. Illustratively, the eASI provides a theory-based reference for the dialog between stakeholders, who are involved in the buying (insurers), providing (caregivers), and developing (developers) of eHealth for a variety of end users, for example, people who are overweight or cope with a chronic illness. With the eASI, these stakeholders have a starting point to jointly determine what, on the one hand, can theoretically contribute to the effectiveness of eHealth on the level of the intervention itself (ie, utility, usability, and content). On the other hand, it can help translate eASI rating outcomes to implications for among other insurance companies, care organizations, and patient associations to come to an overall improved eHealth. The eASI can aid decision making in regard to reimbursing and/or providing an eHealth service or not and further development or not. This in the end goes at the benefit of the ehealth user.

When using the eASI, it is important to also consider other instruments, which can contribute to improve the effective application of eHealth, such as HWRI, e-hit, and CONSORT-EHEALTH [6,8,9]. The eASI showed to have multiple unique qualities to be an addition to the domain of eHealth evaluation, that is, a quick, but not dirty way to forecast eHealth effectiveness in regard to self-management. However, other instruments could be more suitable depending on the phase of development (eg, reporting the evaluation or implementation).

Limitations

This study has a number of limitations. First, the sample size of the study is a major limitation. We were restricted by the amount of services, which on the one hand were trialed in an RCT and, on the other hand were available to rate. However, to compute a correlation the sample size was sufficient. A minimum of 15 observations is recommended [50]. Second, we did not evaluate the RCTs of eHealth services on methodological quality. As a result, it is possible that included studies that found smaller effect sizes actually were more methodologically sound than other included studies. Third, 13 of the 16 studied and available eHealth services were from the Dutch origin. This could be explained as follows. We selected the eHealth service using the Dutch, English, French, or German language to enable rating the services. This diminishes the inclusion of services from the regions Asia, South-America, and Africa. The second explanation is that within the remaining regions (the United States, Australia, and Europe) the Netherlands is the front-runner in the evaluation of eHealth services. Other meta-analyses on eHealth and self-management show that a large number of the services are from the Dutch origin [51,52]. Despite these explanations and as research has found that culture affects the way a person formulates self-management strategies and how a health profession can support these strategies [53], one should recognize the predictive validity of eASI could be different in other countries. Regarding these limitations, it is desirable to continue rating eHealth services, especially from different countries, which are evaluated in high quality RCTs, and further analyze the predictive validity of eASI.

Conclusions

The eASI is a valid and reliable instrument to predict how effective an eHealth service is in regard to self-management (eg, maintaining diet, performing physical activity, adhering to the low-risk drinking guideline, and controlling corticosteroid). Analysis of an eHealth service with eASI can be conducted quickly and independently of the eHealth user group, which decreases the prerequisite to conduct RCTs. Moreover, the score on eASI and its dimensions utility, usability, and content provide steering how to improve the effectiveness of the service. Although evaluating eHealth is a relatively new and complex field of research, the current results provide an important first step in the development of an instrument to measure the effectiveness of eHealth services supporting self-management. In addition, the eASI can contribute to the dialog regarding to the challenges of evaluating eHealth programs. Specifically, the eASI contributes to "methodological pluralism" suggested to evaluate eHealth by introducing new possibilities to systematically determine and discuss which aspects of eHealth could contribute to effective development, evaluation, and implementation of eHealth for self-management.

Acknowledgments

This research was funded by the Dutch Ministry of Economic Affairs and Health Insurance Cooperation VGZ.We would like to thank the collaborating researchers and developers of the included eHealth services.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Items of the final version of eASI with 3 dimensions, 11 categories, and 32 items.

[PDF File (Adobe PDF File), 10KB - med20_v2i2e8_app1.pdf]

Multimedia Appendix 2

Interfaces of the online version of eASI: rating, summary, and diagnosis.

[PNG File, 219KB - med20_v2i2e8_app2.png]

References

1. Norman GJ, Zabinski MF, Adams MA, Rosenberg DE, Yaroch AL, Atienza AA. A review of eHealth interventions for physical activity and dietary behavior change. Am J Prev Med 2007 Oct;33(4):336-345 [FREE Full text] [doi: 10.1016/j.amepre.2007.05.007] [Medline: 17888860]
2. Eysenbach G. The law of attrition. J Med Internet Res 2005;7(1):e11 [FREE Full text] [doi: 10.2196/jmir.7.1.e11] [Medline: 15829473]
3. Blanson Henkemans OA, Otten W, Boxsel JV, Hilgersom M, Rövekamp T, Alpay LL. Nieuwe technologie en zelfmanagement: twee handen op een buik? New technology and self-management: two heads, one heart? KIZ Special issue on Self-management 2011;2:22-26.
4. Lilford RJ, Foster J, Pringle M. Evaluating eHealth: how to make evaluation more methodologically robust. PLoS Med 2009 Nov;6(11):e1000186 [FREE Full text] [doi: 10.1371/journal.pmed.1000186] [Medline: 19956674]
5. Greenhalgh T, Russell J. Why do evaluations of eHealth programs fail? An alternative set of guiding principles. PLoS Med 2010;7(11):e1000360 [FREE Full text] [doi: 10.1371/journal.pmed.1000360] [Medline: 21072245]
6. Breckons M, Jones R, Morris J, Richardson J. What do evaluation instruments tell us about the quality of complementary medicine information on the Internet? J Med Internet Res 2008;10(1):e3 [FREE Full text] [doi: 10.2196/jmir.961] [Medline: 18244894]
7. Wilson P. How to find the good and avoid the bad or ugly: a short guide to tools for rating quality of health information on the internet. BMJ 2002 Mar 9;324(7337):598-602 [FREE Full text] [Medline: 11884329]
8. Eysenbach G, CONSORT-EHEALTH Group. CONSORT-EHEALTH: improving and standardizing evaluation reports of Web-based and mobile health interventions. J Med Internet Res 2011;13(4):e126 [FREE Full text] [doi: 10.2196/jmir.1923] [Medline: 22209829]
9. MacFarlane A, Clerkin P, Murray E, Heaney DJ, Wakeling M, Pesola UM, et al. The e-Health Implementation Toolkit: qualitative evaluation across four European countries. Implement Sci 2011;6:122 [FREE Full text] [doi: 10.1186/1748-5908-6-122] [Medline: 22098945]
10. Mikolajczak J, Keijsers JFEM, Blanson Henkemans OA. eHealth Analyse en SturingsInstrument (eASI). TSG 2011;2:78-82.
11. Maes S, Karoly P. Self-regulation assessment and intervention in physical health and illness: a review. Appl Psychol 2005 Apr;54(2):267-299. [doi: 10.1111/j.1464-0597.2005.00210.x]
12. Leventahl H, Halm E, Horowitz C, Leventahl E, Ozakinci G. Living with chronic illness: a contextualized, self-regulation approach. In: Sutton S, Baum A, Johnston M, editors. The Sage Handbook of Health Psychology. London: Sage; 2004.
13. Lorig K, Holman H, Sobel D, Laurent D. Living a Healthy Life with Chronic Conditions: Self-Management of Heart Disease, Arthritis, Diabetes, Asthma, Bronchitis, Emphysema and Others. Boulder, CO: Bull Pub. Company; 2006.
14. Rollnick S, Miller WR, Butler C. Motivational Interviewing in Health Care: Helping Patients Change Behavior (Applications of Motivational Interviewin). New York: The Guilford Press; 2008.
15. Ryan RM, Deci EL. Self-determination theory and the facilitation of intrinsic motivation, social development, and well-being. Am Psychol 2000 Jan;55(1):68-78. [Medline: 11392867]
16. Nielsen J. Usability Engineering. Boston: Academic Press; 1993.
17. Norman DA. The Psychology of Everyday Things. New York: Basic Books; 1988.
18. Jaspers MW. A comparison of usability methods for testing interactive health technologies: methodological aspects and empirical evidence. Int J Med Inform 2009 May;78(5):340-353. [doi: 10.1016/j.ijmedinf.2008.10.002] [Medline: 19046928]

19. Bartholomew LK, Parcel GS, Kok G, Gottlieb NH. Planning Health Promotion Programs: An Intervention Mapping Approach. San Francisco, Calif: Jossey-Bass; 2011.
20. Fogg BJ. Persuasive Technology: Using Computers to Change What We Think and Do. Amsterdam: Morgan Kaufmann; 2003.
21. Linstone, Harold A. The Delphi Method: Techniques and Applications. Reading, MA: Addison-Wesley Pub. Co., Advanced Book Program; 1975.
22. Mokkink LB, Terwee CB, Patrick DL, Alonso J, Stratford PW, Knol DL, et al. The COSMIN study reached international consensus on taxonomy, terminology, and definitions of measurement properties for health-related patient-reported outcomes. J Clin Epidemiol 2010 Jul;63(7):737-745. [doi: 10.1016/j.jclinepi.2010.02.006] [Medline: 20494804]
23. Cronbach LJ, Meeh PE. Construct validity in psychological tests. Psychol Bull 1955 Jul;52(4):281-302. [Medline: 13245896]
24. Boon B, Risselada A, Huiberts A, Riper H, Smit F. Curbing alcohol use in male adults through computer generated personalized advice: randomized controlled trial. J Med Internet Res 2011;13(2):e43 [FREE Full text] [doi: 10.2196/jmir.1695] [Medline: 21719412]
25. Powell J, Hamborg T, Stallard N, Burls A, McSorley J, Bennett K, et al. Effectiveness of a web-based cognitive-behavioral tool to improve mental well-being in the general population: randomized controlled trial. J Med Internet Res 2013;15(1):e2 [FREE Full text] [doi: 10.2196/jmir.2240] [Medline: 23302475]
26. Ruwaard J, Broeksteeg J, Schrieken B, Emmelkamp P, Lange A. Web-based therapist-assisted cognitive behavioral treatment of panic symptoms: a randomized controlled trial with a three-year follow-up. J Anxiety Disord 2010 May;24(4):387-396. [doi: 10.1016/j.janxdis.2010.01.010] [Medline: 20227241]
27. Genugten L. van. Prevention of Weight Gain Among Overweight Adults: Development and Evaluation of a Computer-Tailored Self-Regulation Intervention. Rotterdam: Erasmus University; 2012.
28. Postel MG, de Haan HA, ter Huurne ED, Becker ES, de Jong CA. Effectiveness of a web-based intervention for problem drinkers and reasons for dropout: randomized controlled trial. J Med Internet Res 2010;12(4):e68 [FREE Full text] [doi: 10.2196/jmir.1642] [Medline: 21163776]
29. Heinrich E, de Nooijer J, Schaper NC, Schoonus-Spit MH, Janssen MA, de Vries NK. Evaluation of the web-based Diabetes Interactive Education Programme (DIEP) for patients with type 2 diabetes. Patient Educ Couns 2012 Feb;86(2):172-178. [doi: 10.1016/j.pec.2011.04.032] [Medline: 21616626]
30. Bastelaar KMP. Web-Based Cognitive Behaviour Therapy for Depression in Adults with Type 1 or Type 2 Diabetes. Amsterdam: Vrije Universiteit; 2011.
31. Nijhof SL, Bleijenberg G, Uiterwaal CS, Kimpen JL, van de Putte EM. Effectiveness of internet-based cognitive behavioural treatment for adolescents with chronic fatigue syndrome (FITNET): a randomised controlled trial. Lancet 2012 Apr 14;379(9824):1412-1418. [doi: 10.1016/S0140-6736(12)60025-7] [Medline: 22385683]
32. Kelders SM, Van Gemert-Pijnen JE, Werkman A, Nijland N, Seydel ER. Effectiveness of a Web-based intervention aimed at healthy dietary and physical activity behavior: a randomized controlled trial about users and usage. J Med Internet Res 2011;13(2):e32 [FREE Full text] [doi: 10.2196/jmir.1624] [Medline: 21493191]
33. de Graaf LE, Gerhards SA, Arntz A, Riper H, Metsemakers JF, Evers SM, et al. Clinical effectiveness of online computerised cognitive-behavioural therapy without support for depression in primary care: randomised trial. Br J Psychiatry 2009 Jul;195(1):73-80 [FREE Full text] [doi: 10.1192/bjp.bp.108.054429] [Medline: 19567900]
34. Spijker B. Reducing the Burden of Suicidal Thoughts Through Online Self-Help. Amsterdam: Vrije Universiteit; 2012.
35. van der Meer V, van Stel HF, Bakker MJ, Roldaan AC, Assendelft WJ, Sterk PJ, SMASHING (Self-Management of Asthma Supported by Hospitals, ICT, NursesGeneral practitioners) Study Group. Weekly self-monitoring and treatment adjustment benefit patients with partly controlled and uncontrolled asthma: an analysis of the SMASHING study. Respir Res 2010;11:74 [FREE Full text] [doi: 10.1186/1465-9921-11-74] [Medline: 20537124]
36. Blanson Henkemans OA, van der Boog PJ, Lindenberg J, van der Mast CA, Neerincx MA, Zwetsloot-Schonk BJ. An online lifestyle diary with a persuasive computer assistant providing feedback on self-management. Technol Health Care 2009;17(3):253-267. [doi: 10.3233/THC-2009-0545] [Medline: 19641261]
37. Riper H, Kramer J, Smit F, Conijn B, Schippers G, Cuijpers P. Web-based self-help for problem drinkers: a pragmatic randomized trial. Addiction 2008 Feb;103(2):218-227. [doi: 10.1111/j.1360-0443.2007.02063.x] [Medline: 18199300]
38. Warmerdam L, van Straten A, Twisk J, Riper H, Cuijpers P. Internet-based treatment for adults with depressive symptoms: randomized controlled trial. J Med Internet Res 2008;10(4):e44 [FREE Full text] [doi: 10.2196/jmir.1094] [Medline: 19033149]
39. Wanner M, Martin-Diener E, Braun-Fahrländer C, Bauer G, Martin BW. Effectiveness of active-online, an individually tailored physical activity intervention, in a real-life setting: randomized controlled trial. J Med Internet Res 2009;11(3):e23 [FREE Full text] [doi: 10.2196/jmir.1179] [Medline: 19666456]
40. Holzinger KJ. A simple method of factor analysis. Psychometrika 1944;9:257-262.
41. Stuive I, Kiers HA, Timmerman ME. Comparison of methods for adjusting incorrect assignments of items to subtests: oblique multiple group method versus confirmatory common factor method. Educ Psychol Meas 2009 Mar 11;69(6):948-965. [doi: 10.1177/0013164409332226]

42. Conger AJ. Integration and generalization of kappas for multiple raters. Psychol Bull 1980;88(2):322-328. [doi: 10.1037/0033-2909.88.2.322]
43. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics 1977 Mar;33(1):159-174. [Medline: 843571]
44. Ajzen I. The theory of planned behavior. Org Behav Human Decision Process 1991 Dec;50(2):179-211. [doi: 10.1016/0749-5978(91)90020-T]
45. Hedges LV. Distribution theory for glass's estimator of effect size and related estimators. J Educ Stat 1981;6:107-128 [FREE Full text]
46. Development Core Team. A Language and Environment for Statistical Computing. Vienna, Austria: Foundation for Statistical Computing; 2011. URL: http://www.lsw.uni-heidelberg.de/users/christlieb/teaching/UKStaSS10/R-refman.pdf [accessed 2013-01-17] [WebCite Cache ID 6Djz8vKmc]
47. Borenstein M, Hedges L, Higgins J, Rothstein H. Comprehensive Meta-Analysis Version 2. Englewood, NJ: Biostat; 2005.
48. Falissard B. Package version 1. 2009. Various procedures used in psychometry URL: http://cran.r-project.org/web/packages/psy/psy.pdf [accessed 2013-07-25] [WebCite Cache ID 6INM0g3Wt]
49. TNO. eASI: eHealth Analysis and Steering Instrument URL: http://www.tno.nl/content.cfm?context=thema&content=prop_case&laag1=891&laag2=902&laag3=70&item_id=1888&Taal=2, [accessed 2013-08-19] [WebCite Cache ID 6DjzDTZIw]
50. Stevens JP. Applied Multivariate Statistics for the Social Sciences. New York, NY: Routledge; 2009.
51. Riper H, Spek V, Boon B, Conijn B, Kramer J, Martin-Abello K, et al. Effectiveness of E-self-help interventions for curbing adult problem drinking: a meta-analysis. J Med Internet Res 2011;13(2):e42 [FREE Full text] [doi: 10.2196/jmir.1691] [Medline: 21719411]
52. Broekhuizen K, Kroeze W, van Poppel MN, Oenema A, Brug J. A systematic review of randomized controlled trials on the effectiveness of computer-tailored physical activity and dietary behavior promotion programs: an update. Ann Behav Med 2012 Oct;44(2):259-286 [FREE Full text] [doi: 10.1007/s12160-012-9384-3] [Medline: 22767052]
53. Furler J, Walker C, Blackberry I, Dunning T, Sulaiman N, Dunbar J, et al. The emotional context of self-management in chronic illness: a qualitative study of the role of health professional support in the self-management of type 2 diabetes. BMC Health Serv Res 2008;8. [doi: 10.1186/1472-6963-8-214]

Abbreviations

BMI: body mass index
CBT: cognitive behavioral therapy
CONSORT-EHEALTH: Consolidated Standards of Reporting Trials of Electronic and Mobile HEalth Applications and onLine TeleHealth
COPD: chronic obstructive pulmonary disease
eASI: eHealth Analysis and Steering Instrument
HWRI: Health Website Rating Instrument
RCT: randomized controlled trial

Edited by G Eysenbach; submitted 11.02.13; peer-reviewed by L Gemert-Pijnen, van, P Cipresso, W van Ballegooijen; comments to author 28.04.13; revised version received 25.07.13; accepted 12.08.13; published 22.08.13.

Please cite as:
Blanson Henkemans OA, Dusseldorp EML, Keijsers JFEM, Kessens JM, Neerincx MA, Otten W
Validity and Reliability of the eHealth Analysis and Steering Instrument
Med 2.0 2013;2(2):e8
URL: http://www.medicine20.com/2013/2/e8/
doi:10.2196/med20.2571
PMID:25075243

Original Paper

Development of a Questionnaire and Cross-Sectional Survey of Patient eHealth Readiness and eHealth Inequalities

Ray Jones[1], PhD

University of Plymouth, Faculty of Health, Education, and Society, Plymouth, United Kingdom

Corresponding Author:
Ray Jones, PhD
University of Plymouth
Faculty of Health, Education, and Society
3 Portland Villas
Plymouth, PL4 8AA
United Kingdom
Phone: 44 7972563340
Fax: 44 7972563340
Email: ray.jones@plymouth.ac.uk

Abstract

Background: Many speak of the digital divide, but variation in the opportunity of patients to use the Internet for health (patient eHealth readiness) is not a binary difference, rather a distribution influenced by personal capability, provision of services, support, and cost. Digital divisions in health have been addressed by various initiatives, but there was no comprehensive validated measure to know if they are effective that could be used in randomized controlled trials (RCTs) covering both non-Internet-users and the range of Internet-users.

Objective: The aim of this study was to develop and validate a self-completed questionnaire and scoring system to assess patient eHealth readiness by examining the spread of scores and eHealth inequalities. The intended use of this questionnaire and scores is in RCTs of interventions aiming to improve patient eHealth readiness and reduce eHealth inequalities.

Methods: Based on four factors identified from the literature, a self-completed questionnaire, using a pragmatic combination of factual and attitude questions, was drafted and piloted in three stages. This was followed by a final population-based, cross-sectional household survey of 344 people used to refine the scoring system.

Results: The Patient eHealth Readiness Questionnaire (PERQ) includes questions used to calculate four subscores: patients' perception of (1) provision, (2) their personal ability and confidence, (3) their interpersonal support, and (4) relative costs in using the Internet for health. These were combined into an overall PERQ score (0-9) which could be used in intervention studies. Reduction in standard deviation of the scores represents reduction in eHealth inequalities.

Conclusions: PERQ appears acceptable for participants in British studies. The scores produced appear valid and will enable assessment of the effectiveness of interventions to improve patient eHealth readiness and reduce eHealth inequalities. Such methods need continued evolution and redevelopment for other environments. Full documentation and data have been published to allow others to develop the tool further.

(Med 2.0 2013;2(2):e9) doi:10.2196/med20.2559

KEYWORDS

eHealth readiness; eHealth inequalities; digital divide; questionnaire development

Introduction

Definitions and Literature

The term eHealth is used in various ways, some (eg, World Health Organization) [1] using it as an over-arching term incorporating health informatics, telehealth, e-learning, and mHealth, while others think of eHealth as a patient-centered subset of health informatics [2-8]. This paper uses the term "patient eHealth readiness" to refer to the opportunity of patients to use the Internet and apps for health, and eHealth inequalities to mean differences in patient eHealth readiness.

In developing the ideas for this study, literature was first reviewed in November 2010 and updated in May 2013 from Web of Knowledge, PubMed, and Google Scholar using the terms (1) [E-health OR ehealth OR telehealth* OR telemedicine OR (ICT AND health) OR (technology AND health <in topic>) AND (readiness OR preparedness OR (implementation AND measure*) <in title>], (2) E-health literacy, (3) (Digital divide OR digital inclusion OR digital exclusion OR e-health inequalities) AND health, and (4) Inequality AND measure <in title> AND health. Web of Knowledge was used to examine citations of this literature for further relevant studies.

Benefits From Patient eHealth Interventions

There is evidence that direct use of the Internet by patients can benefit patients [9]. For example, systematic reviews show improvements in health-related knowledge, attitudes, intentions and behaviors [10,11], and reduced health service use [12,13]. Studies showing the benefits of patient eHealth interventions, however, are nearly always carried out on populations of Internet users and the effectiveness of any intervention may depend on the skills and opportunities of the population recruited [10].

Barriers to Patient eHealth Opportunity

There are four domains of barriers to eHealth opportunity that were identified (1) provision of eHealth opportunity, (2) personal abilities of the patient, (3) the support from others they may have to use eHealth, and (4) economic barriers.

Provision of eHealth opportunity varies. For example, while some British general practices [14] provided information, repeat prescribing, appointment booking, online advice, and patient access to their medical records, other practices had no website [15]. Internationally, many US practices use preconsultation computer-interviews [16], but these are rarely used in Britain. In secondary care, most British renal patients have access to their renal medical records online [17], but few stroke patients have such facility. Even use of globally available websites may show marked regional variation because of varied rates of recommendation to patients. For example, use of an online cognitive behavioral-therapy site for depression varied 30-fold by postcode area [18].

Physical and psychological attributes of patients contribute to digital divisions in health. Someone may have problems from sight or hearing impairment, arthritis, or lack of mobility in their hands. They may have no prior experience or find it difficult to learn Internet use, have limited literacy or health literacy, or lack confidence either in their Internet use or in making decisions using health information. They may distrust the Internet [19]. Someone's current health may increase motivation to use the Internet for health [20], but may restrict Internet use; 81% of those with no recent health problems had used the Internet compared to 65% with recent health problems [21].

Some factors limiting personal use of eHealth may be diminished if people have support from others. For example, anonymous e-mail support may help people with long-term conditions use the Internet [22,23] and volunteers may help older people start using the Internet [24]. Without such support people may struggle to go online or make the best use of resources.

Finally, economic factors may affect digital divisions in health [25]. Although homes may be capable of Internet connection, families may not be able to afford it. Someone relying on accessing the Internet at their local library may be restricted by transport costs. Some groups, such as those with substance use problems, may be particularly susceptible, and in times of economic recession, barriers to eHealth use may increase. In the United States, broadband use is clearly related to income with 43% of families with incomes between $15,000 and $25,000 compared to 86% of those with incomes between $100,000 and $149,000 having home broadband [26]. However, with appropriate provision even the poorest can get access; a US study among homeless found that 47% reported computer use in the past month [27]. Economic factors are relative to the cost of alternative actions in health.

Others have examined barriers to eHealth use and the eHealth readiness of organizations or health services [28-51] through measures involving contact with staff or observation of process. The aim of this study was to develop a patient-completed tool giving patients' perceptions of their opportunity that could be combined with their personal abilities, their support networks, and economic barriers.

Do Digital Divisions in Health Deserve Action?

Should governments or health services address digital divisions in health? Some argue that it is just a matter of time before everyone has Internet access and that digital divisions will disappear. Others remind us that in the diffusion of technology [52,53], there are always earlier and later adopters, so there will always be inequalities. Others argue that as technology and eHealth progress, differences in opportunities for patients to use the Internet for health may increase, ultimately leading to worse health inequalities [54]. Even without the ethical argument for addressing inequality, eHealth inequalities make the adoption of more cost-effective health delivery difficult. If health services must provide eHealth and more traditional services, this diversity of service provision may be expensive. The digital divide has received attention with British government promoted organizations such as Race Online 2012, national regular reporting of digital use [55,56], and other specialized reports [57]. The current British government is committed to the idea that services should be “digital by default” [58], which may impact on those without good Internet access or skills.

What Level of eHealth Inequality Is Important?

Like the seven-year difference in life expectancy by social class in England [59], the size of eHealth inequality needs to be large enough to be of concern. Some differences are binary; if houses in rural areas are not connected to the Internet, then those families cannot use eHealth. Other factors, such as eHealth literacy, will follow a distribution and we need to ask whether the standard deviation of that distribution is unacceptably large. In some cases relatively small differences are worth addressing if that can be done at low cost. A single numerical measure of eHealth inequality would help to judge the effectiveness of interventions.

How Have eHealth Inequalities Been Addressed?

Initially, physical access to eHealth received a good deal of attention. From the late 1980s, there were experiments with public access kiosks [60] and initiatives to make the Internet available in public libraries. In the United States, 95% of public libraries provided Internet access by the year 2000 [61]. The third sector, through organizations such as Age UK, have provided both physical access and support using computers for older people [62]. In the English National Health Service (NHS), NHS Choices had a social and digital inclusion team from 2007 to 2012 [63], now lost in recent government cuts. There are no quality targets requiring NHS Trusts to provide eHealth services.

Various studies have addressed eHealth inequalities or tried to ameliorate their impact. For example, Kerr et al [64] explored the effectiveness of a web-based intervention in decreasing inequalities in access to self-management support in patients with coronary heart disease. Jones et al piloted anonymous personal online email support for patients with long-term conditions [22]. In the United States, an experiment offering older adults computer training in public libraries on finding health information via the Internet was successful [65]. In England, Fisher et al aim to improve uptake of patient access to their records by supporting general practices [66].

Digital divisions caused by physical disability have been subject to legislation. Web accessibility laws and regulations have encouraged developers to make websites accessible to those with visual, auditory, motor, neurological, or cognitive impairments. In Britain, the Disability Discrimination Act 1995 [67], Special Educational Needs and Disability Act 2001 [68], and the Equality Act 2010 [69] resulted in organizations reviewing website functionality and causing some organizations [eg, Royal National Institute for the Blind (RNIB)] [70] to have units aiming to make digital information accessible to those with physical disability. In the United States, section 508 of the Rehabilitation Act of 1973 [71] required federal agencies to ensure that federal employees with disabilities have equal access to information unless an undue burden would be imposed on the agency.

Why Do We Need to Measure eHealth Inequalities?

Projects and national initiatives such as those described above need to measure eHealth inequalities to know (1) if action is needed, (2) what is the main cause of inequality, and (3) if inequalities are addressed, if the intervention was successful and cost effective. But inequality cannot be directly measured; it has to be measured as a difference in another variable, namely eHealth readiness. To compare eHealth inequality over time, we need a measure of “patient eHealth readiness” that is comprehensive, valid, and reliable. A measure that is also “diagnostic,” allows development of interventions tailored to the needs of populations.

Tools to Assess eHealth Readiness

Others have considered the “readiness” of practitioners, organizations, or communities to adopt telehealth or eHealth [34,35,37,38,44-46,72]. Legare in 2010 [38] identified six eHealth readiness tools [28,29,31,32,34,44], five of which assessed organizational readiness. Legare developed one of these [34] further, translating it into French [37] and validated its use with staff. However, no suitable tool that assessed patients’ opportunities to participate in eHealth was identified.

There are two groups of literature that exist at the “patient level” (1) the “digital divide” and (2) eHealth literacy. The digital divide-as the term implies-tends to be measured as a binary division. For example, whether someone has or does not have access to the Internet or has or has not used the Internet in the last three months [73]. The digital divide has usually been assessed and reported by factual measures of Internet use or availability rather than attitudes or psychometric assessment. Work on measures of eHealth literacy [in particular the eHealth Literacy Scale (eHEALS)] [74] recognized that physical access to the Internet was only part of the story and that personal abilities to use the Internet were important. However, by adopting a more sophisticated examination of eHealth literacy, the basic ideas of digital divide and limitations of access to the Internet were lost.

Simple measures of whether or not someone has Internet access are insufficient as even among Internet users some may be more ready to make progress in using eHealth if they have access to support and are not struggling with the cost of access. In particular, interventions at patient and community levels need tools that can measure their impacts.

Objectives

The aim of this project was to get the benefits of a scaled (rather than binary) approach (like eHEALS), but to include eHealth provision, support, and economics in the scale. In particular, the study aim was to develop and validate a self-completed questionnaire and scoring system for use in intervention studies hoping to improve eHealth readiness and reduce eHealth inequalities.

Methods

PERQ Stages

The Patient eHealth Readiness Questionnaire (PERQ) and related scores have been developed in two stages. First, four domains (1) provision (from the digital divide literature), (2) personal (from the eHealth literacy literature), (3) support, and (4) economic were used to draft a self-completed questionnaire and take it through three stages of piloting (January-March 2012). Second, a cross-sectional population survey was carried out (April-August 2012) and proposed scoring systems checked and iteratively refined to ensure construct validity.

Physical

Although there are good national statistics on home Internet access [55,75,76] that allow a check on face validity, similar questions need to be included in patient-completed questionnaires to allow comparison before and after interventions. Provision of eHealth services is more difficult to assess as this will depend on the health conditions of interest to respondents and will be country-specific. Nearly all British respondents have a family doctor so asking about General Practice (GP) website provision is applicable to all. Some surveys have only asked about Internet “information” and respondents may not consider using the Internet to contact people. PERQ, therefore, included questions about personal contact.

Personal

The most frequently used [77-80] measure of personal skills is eHEALS [74], using eight items to assess eHealth literacy. A Dutch translation of eHEALS was found reliable, but its validity questioned [81]. Van Deursen and Van Dijk [82] criticized eHEALS because respondents were not always accurate at estimating their real levels of skill [83]. Others have noted that self-efficacy may not accurately reflect ability. For example, nursing students' self-efficacy in numeracy decreased if they had previously been asked to carry out an actual drug calculation [84], and patients with long-term conditions may be confident in what they do on the Internet, but lack a sense of adventure to try new things [22]. Van Deursen suggested that incorporation of basic Internet skills is needed to measure all aspects of eHealth literacy [85]. However, having to "test" whole populations to produce a measure of eHealth literacy is not feasible.

Prior to the Dutch studies [81,82,85], Hargittai [86] examined survey measures of Web-oriented digital literacy to serve as proxies for observed skill measures. They studied both observations and survey questions, and recommended measures as survey proxies of observed web-use skills. Their results suggested some composite variables of survey knowledge items were better predictors of people's actual digital literacy based on performance tests than the usual method of asking users' self-perceived abilities. Hargittai's approach seemed a reasonable compromise towards the gold standard of Van Deursen. The first version of PERQ included the eight eHEALS questions and a single self-efficacy question, [22] based on [87], both "grounded" by using questions based on self-assessment (Hargittai's approach) of the skills identified by Van Deursen and Van Dijk.

Interpersonal and Economic Measures

Although interpersonal support to help people start using the Internet was a major component of the Race Online 2012 campaign [88], no "measure" of support in using the Internet was identified. Simple questions about who is available to support participants and if there are barriers (eg, of disclosure, or "being a bother") can be used. Similarly, although economic differences in being able to use eHealth are clearly important, there did not appear to be any standard measures. To ground questions about the perception of cost of Internet access, PERQ included comparative questions about cost of access to health services and the perceived cost of Internet provision.

Moderators

Whether or not someone uses the Internet for their health depends on whether they are motivated to do so [89]. So if patient eHealth readiness is to be an indicator of digital divisions, it needs to be "standardized" for motivation, similar to the distinction between digital choice and digital exclusion [90].

PERQ Development and Initial Piloting

Three pilots (PERQ1-3) including repeatability were followed by a baseline survey. (PERQ4):

1. The first had 15 people (work colleagues and friends). Questions from eHEALS [74] were initially included following the four skills questions [85] and followed by a single self-efficacy question [22]. eHEALS score and the single self-efficacy rating showed quite good agreement (rho=0.61, *P*=.02), the single question showed good face validity (see Multimedia Appendix 1), and eHEALS was not well understood by one older person. Given the need to shorten the questionnaire, the eHEALS questions were subsequently omitted and the single self-efficacy question, following the four skills questions, retained.
2. The second had 20 friends and family of a research assistant; 17 of these were subsequently asked to complete PERQ4 to assess repeatability (reported below).
3. The third had a convenience sample of 103 houses likely to have a high proportion of more elderly residents. This was used to test the survey method, response rate, completeness of data, and that non-Internet users would respond. The response rate was 44% and data were reasonably complete. It was found that 5 out of 43 (12%) respondents had not used the Internet.

After each stage, revised questionnaires were circulated among colleagues to check readability (see Multimedia Appendix 1). The questionnaire was reviewed and approved by the university ethics committee between pilots two and three.

Baseline Population Survey

As one intended use of PERQ was in a geographically based cluster randomized controlled trial (RCT), it was appropriate to test that mode of use. The aim was to use a sample representative of urban, suburban, and semirural postcodes and different levels of affluence to pilot the questionnaire, its distribution, and methods for construction of eHealth readiness and inequality scores. The 2001 census included 14,279 postcodes for the PL postcode area, with a total population of 510,223. There were seven postcodes (total population 3243) with very high populations (being either military camps or university halls of residence) that were excluded. The remaining postcodes were "ordered" by population and a 1% systematic sample (142 postcodes) was taken. Each postcode was "looked up" on the free Zoopla website service giving estimated property values to find current average property values and number of properties in each postcode. To achieve a "practical" sample of just fewer than 1000 properties, all postcodes further than 12 miles from Plymouth University were excluded, leaving 79 postcodes. These 79 postcodes were again ordered by Zoopla average property values, and a further systematic sample of 53/79 postcodes was taken with a total of 975 properties.

The final sample therefore comprised 53 postcodes within 12 miles of Plymouth University, with a total of 975 properties, population of 2126, and an average of 2.18 people per house. Average property prices (January 2012) per postcode ranged from British £78,163 to £459,360. The sample was representative of the range of property prices. Number of properties per postcode (a crude measure of rurality) varied from 1 to 53.

We attempted to deliver questionnaires by hand to all 975 properties in April 2012. There were thirty houses no longer in use, leaving 945 occupied houses as our sample. The research assistant called at each house and if someone answered, she explained the purpose of the survey and if possible handed the resident a questionnaire and covering letter (24 refused to take the questionnaire). If there was no response at the house, the questionnaire and covering letter were posted through the letterbox. In June 2012, reminders were posted through the letterbox of 658 who had not responded. The instructions on the questionnaire, and explained by the research assistant, were for the person with the next birthday in the house to complete the questionnaire.

Analysis and Refinement of Scoring Systems

Survey data were used to assess the ability of PERQ to collect good quality data, and used to develop and iterate a scoring system suitable for use in intervention studies, particularly RCTs. This required that only questions that contributed to the score were included, collected data were complete, consistent, and valid, scales must not have floor or ceiling effects, and must reflect meaningful changes.

Scales that combine a number of “Likert style” attitude questions normally assess reliability using Cronbach alpha. In this study, the construction of the eHealth readiness scale relied on pragmatic combinations of factual questions with some ratings, so assessing scale properties such as repeatability, face, and construct validity, was also pragmatic. Questions were cross checked for consistency and reviewed for their contribution to eHealth readiness scores, face validation against other information sources, or description of sample demographics. Comparisons of scores between subgroups were made using Mann Whitney U tests for groups less than 100 and *t* tests for groups of 100 or more.

The contribution of each question was checked. Not all questions made direct contributions to scores, some were asked to ground respondents to give them the “right frame of mind” for subsequent questions. Other questions were used as consistency checks.

Scores for each constructed variable were essentially arbitrary, but to have some way of measuring change before and after interventions, an overall score is needed that is at least ordinal, and if possible approximates to a cardinal scale. Similarly, overall scores need to combine component variables in a sensible manner. A pragmatic and iterative approach was taken to examine construct validity of scores by examining the scores of sampled individual respondents with a range of scores. If the order and difference in scores between individuals did not match with an understanding of the barriers to adopting eHealth, the weights of scores were adjusted.

Scoring was also adjusted after examining the repeatability of scores and to cope with occasional missing values. This process of tuning scoring weights continued until all components seemed internally consistent. Various methods of combining the four subscales to produce an overall readiness scale were tried, checking for construct validity by examining differences between Internet users and non-Internet users.

Questionnaire Review

Once the scoring system was finalized, questionnaires and dataset were again reviewed to check that all questions and answers were useful either as contributors to the score, as “grounding” for other questions, or as consistency checks (see Multimedia Appendix 1).

Modeling of Performance in Measuring Change

Finally, data from the survey were used to model possible changes to participants “states” and to check the ability of the scoring system to measure those changes. Comparisons of scores between subgroups were made using Wilcoxon Signed Rank tests for groups less than 100 and *t* tests for groups of 100 or more.

This provided a further check that the subscores and weights seemed sensible, and to allow an assessment of methods of analysis and estimation of sample size for possible RCTs.

Results

Dataset

The anonymized dataset from the cross-sectional survey is available from the author.

Response Rate and Possible Biases

Figure 1 shows by August 2012, 344 (36.4%) of the 945 occupied houses in the sample had returned completed questionnaires. Those 323/945 (34.2%) houses where the research assistant was able to speak to someone were more likely to have returned questionnaires (56% versus 27%) (χ^2_4=90.4; P<.001). The 344 houses providing respondents had higher estimated values than those with no respondent (£176,998 versus £142,019; t_{925}=-6.2; P<.001).

Data Completeness, Consistency, and Contribution

Despite care in design and three stages of piloting, PERQ still had missing and some inconsistent data (see Multimedia Appendix 1), for example 29/344 (8.4%) people did not complete their age and 6/344 (1.7%) their gender. All questions contributed (see Multimedia Appendix 1).

Sample

Figure 1 shows the sample was disproportionately female (231/344 ,67.2% women; 107/344, 31.1% men; 6/344, 1.7% gender unknown), and older (mean age 55) than the Plymouth population.

Constructed Variables

Figure 2 shows the eight sections of the questionnaire (A-H). Non-Internet users answered A, B, C, G, and H and Internet users A, B, and D-H. There were six sets of variables created by scoring or combining responses to questions (1) Need, (2) Internet-Use including range of uses and the four subscales of “eHealth readiness,” (3) Provision including physical provision of Internet and provision of health on Internet, (4) Personal (ie, the individual’s capability to use the Internet for health), (5) Interpersonal Support, and (6) Economic. A “short score” (of half the score) was used in some comparisons and figures.

Figure 1. Sample response and characteristics.

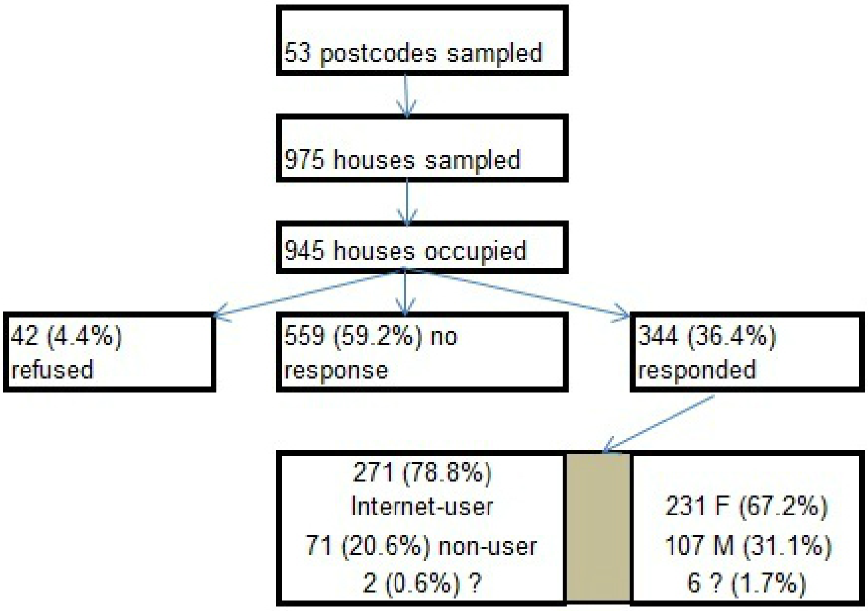
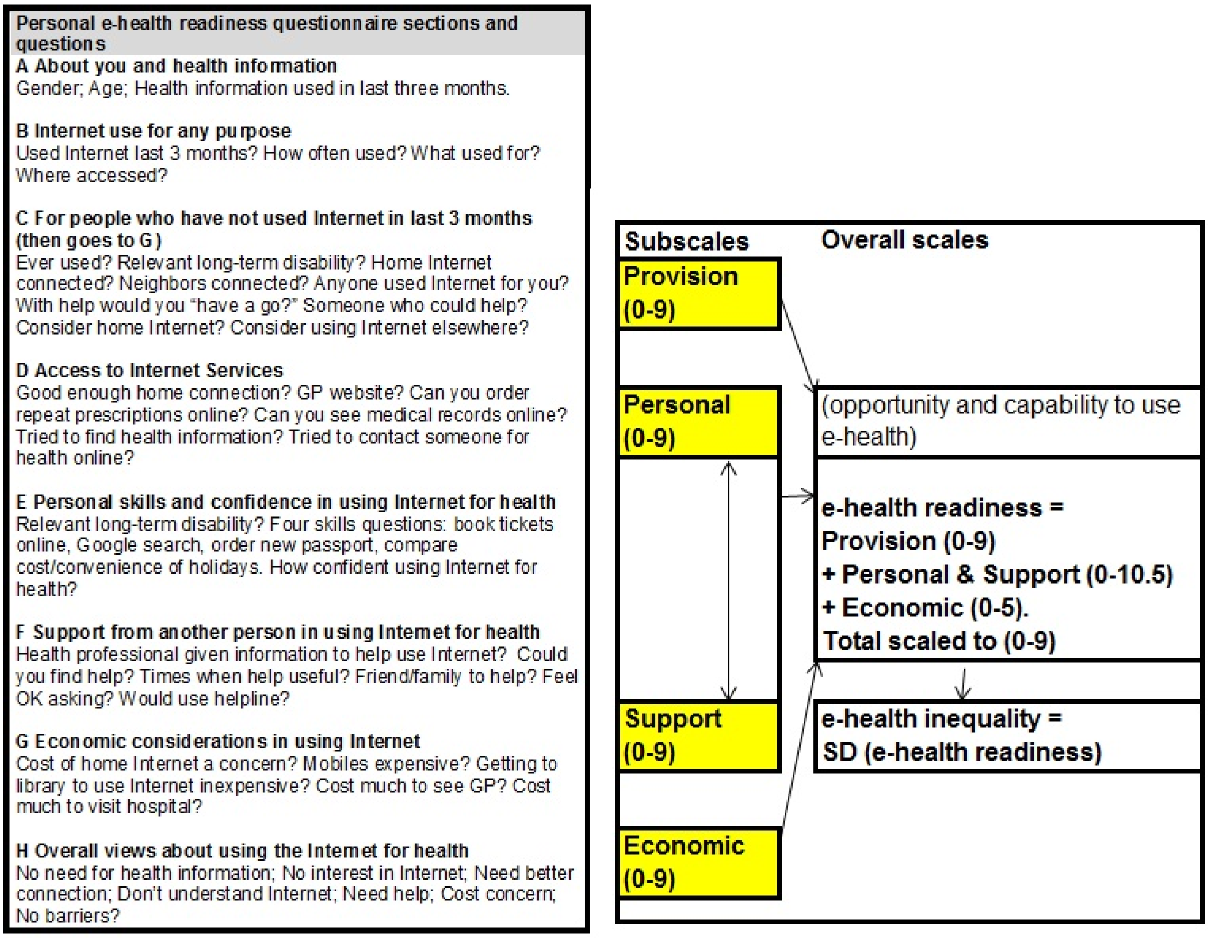


Figure 2. Personal eHealth readiness questionnaire and scale.



Personal e-health readiness questionnaire sections and questions

A About you and health information
Gender; Age; Health information used in last three months.

B Internet use for any purpose
Used Internet last 3 months? How often used? What used for? Where accessed?

C For people who have not used Internet in last 3 months (then goes to G)
Ever used? Relevant long-term disability? Home Internet connected? Neighbors connected? Anyone used Internet for you? With help would you “have a go?” Someone who could help? Consider home Internet? Consider using Internet elsewhere?

D Access to Internet Services
Good enough home connection? GP website? Can you order repeat prescriptions online? Can you see medical records online? Tried to find health information? Tried to contact someone for health online?

E Personal skills and confidence in using Internet for health
Relevant long-term disability? Four skills questions: book tickets online, Google search, order new passport, compare cost/convenience of holidays. How confident using Internet for health?

F Support from another person in using Internet for health
Health professional given information to help use Internet? Could you find help? Times when help useful? Friend/family to help? Feel OK asking? Would use helpline?

G Economic considerations in using Internet
Cost of home Internet a concern? Mobiles expensive? Getting to library to use Internet inexpensive? Cost much to see GP? Cost much to visit hospital?

H Overall views about using the Internet for health
No need for health information; No interest in Internet; Need better connection; Don’t understand Internet; Need help; Cost concern; No barriers?

Need

Scores (0-10) representing “need for health information and support” were constructed from one multi-part factual question (A3), by adding 2 points for each professional contact and health-information seeking behavior in the last three months. Scores had face validity, for example, women had higher Need scores than men. Need was used as a modifier of Provision scores.

Internet Use

Personal use of the Internet in the last three months was similar to national figures (271/342, 79.2% versus 77% from Office for National Statistics, ONS) [91]. As expected, younger people and those from more affluent areas were more likely to use the Internet. Nearly half used it for health (mainly to search for information), but few used discussion forums or social media for health purposes. Most Internet users (262/271, 96.7%) used the Internet at home, at work (94/271, 34.7%), or on mobile (93/271, 34.3%). This section (B) was used for subsequent questionnaire section choice, face validity check, and as a consistency check with other parts of the questionnaire.

Provision

For Internet users, provision scores comprised two parts (section D) (1) General Internet Provision (4 points) ascertained by questions about what opportunities there are to access the Internet, and (2) Health Internet Provision (5 points) ascertained by questions on GP website (3.5 points), and Internet condition specific information and support (1.5 points). Provision of online information and support may vary by condition (eg, there are many resources for breast cancer, but fewer for stroke). However, not everyone has a need for health information or support and so may never have had reason to look for their GP website or for health information. So the Need score was used to moderate Provision; more was added to Health Internet Provision if Need was equal to zero (see Multimedia Appendix 1).

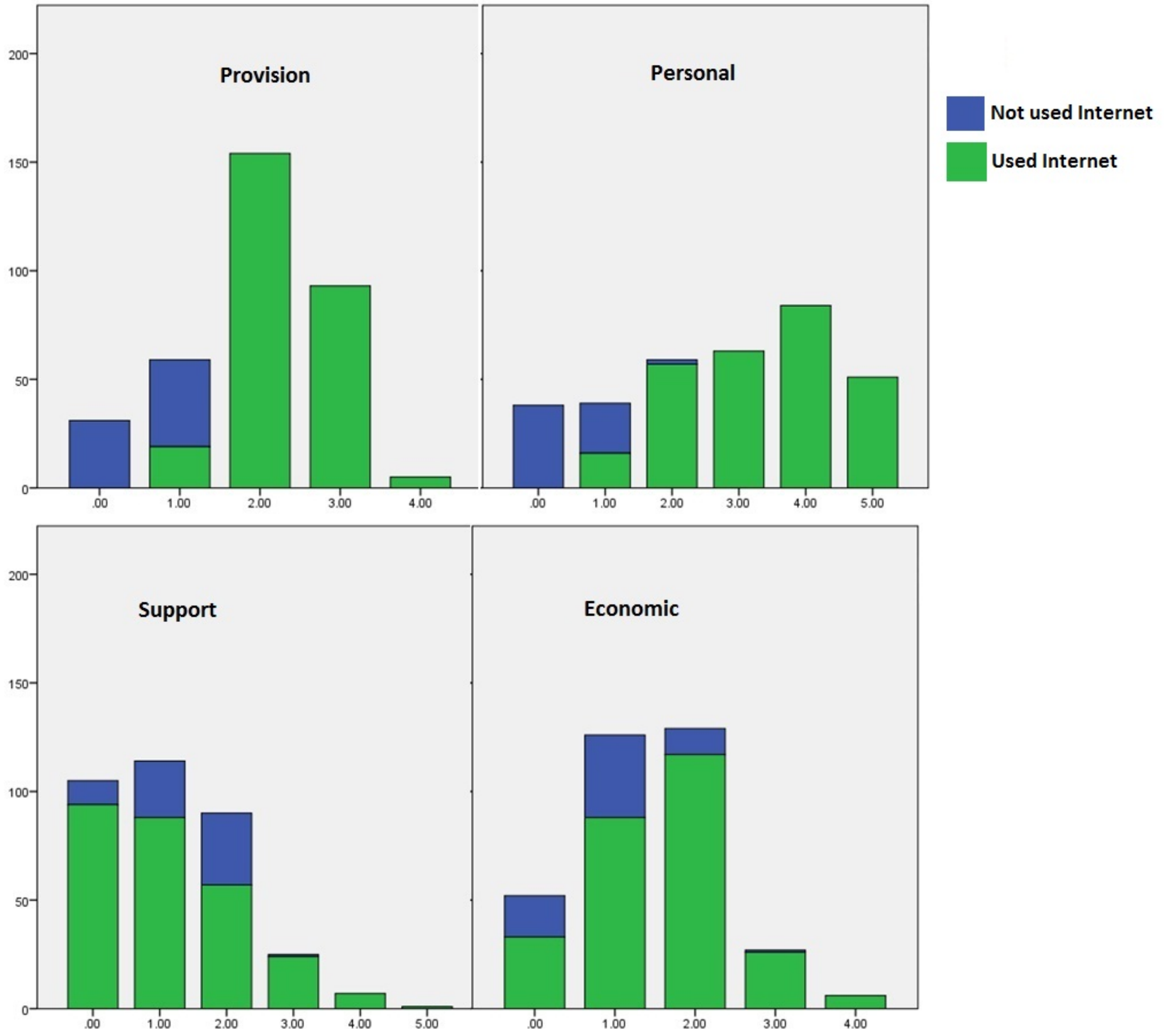
Figure 3 shows the mean Provision score for Internet users was 4.5. There were 18 Internet users who had relatively low General Internet Provision (<1.5/3.5 max) including those who used the Internet only in places other than the home. Individual records were checked for participants with extreme scores and appeared to have face and construct validity (see Multimedia Appendix 1).

Component questions showed that nearly half (30/71) of non-Internet users had an Internet connected computer at home. Of 271 Internet users, 249 people had used it at home, but 3 said they had no home Internet connection, of these, 2 had used a mobile device and so it is possible that questions about “home Internet use” need to be clarified. There were 3 other people who had accessed the Internet at home, but did not apparently know if they had an Internet connection, may have not known about the “speed” of their home Internet, so some clarification may be needed for that question. A substantial minority (33/243,13.6%) thought their home Internet connection was not fast enough, a third of these said it was because they would need to pay more, a third because their provider did not offer a faster connection, and a third did not know.

Of 271 Internet users 89/271 (32.8%) had looked at their GP’s website, 51/271 (18.8%) thought their GP had a website, but had not seen it, 7/271 (2.6%) thought their GP did not have a website, and nearly half (122/271, 45.0%) did not know. Of the 89 who had looked at their GP’s website, 64 knew they could order repeat prescriptions online, 6 said their GP did not offer this service, and 14 did not know. Only 1 person knew they could see their medical record online, 20 knew they could not, but 66 did not know. Half (143/271, 52.8%) of Internet users had tried to find information on health topics with all but 9 having found what they wanted, but only 27/271 (10.0%) people had tried to contact an organization or forum or other people online connected with health.

The internal consistency of Provision scores was addressed by comparison of answers to sections B (where people had used the Internet) and D (home Internet provision and use for health). Figure 3 shows that no one had a short score of 5, so there was room for improvement and no ceiling effect.

Figure 3. Four sub-scales of Provision, Personal, Support, and Economic presented as "short scales" of 0-5, showing Internet-users and non-Internet-users, including mean and standard deviation (SD) for full (0-9) scales.



Personal

Personal scores comprised moderated confidence scores for Internet users (section E) and the willingness to try using the Internet for non-Internet users. Internet users rated their skills on four tasks from which skills scores (0-12) were constructed. Users then rated their overall Internet confidence (0-10). This sequence of questions aimed to ground their confidence rating in the reality of their ability and to provide a consistency check on their confidence rating. Skills scores correlated with confidence self-ratings (Spearman's Correlation=0.60, *P*<.001) with some outliers; four people rated their skills low, but confidence high and 13 people rated their skills high, but confidence low (see Multimedia Appendix 1). However, to produce more consistent Personal scores, "moderated" confidence scores of skills*original confidence score/12 were calculated.

Component questions showed that just under half of non-Internet users said they would try using the Internet if they had help, would have a home Internet connection if they had help and it was cheap, and would use the Internet for health at some other place (most frequent choice public library). Questionnaires asked about disabilities. Six non-Internet users and six Internet users said they had disabilities (including arthritis, eye problems, hearing impairment, learning difficulty, and dyslexia) that made using computers difficult, but this information was not used in Personal score calculations on the assumption that respondents would themselves make that adjustment.

The face validity of Personal scores was assessed by exploring associations with frequency, range, and ubiquity of Internet use. As expected there were strong associations between frequency of use and moderated confidence (χ^2_{12}=81, *P*<.001). Nevertheless there were outliers, one person who was very confident despite using the Internet less than once a week and four people who used the Internet many times daily, but had low confidence. The latter is more believable as they may use it for limited purposes. Similarly, as would be expected, there were strong associations between range of use and moderated confidence (χ^2_{12}=61.5, P<.001), but similarly there were some "outliers." Personal scores had a strong association with "ubiquity," [ie, the places where people accessed the Internet (χ^2_{16}=81, P<.001)]. Some might argue that range of health uses should be the outcome measure of any intervention, but this will be dependent on someone's need for health information. So overall PERQ scores include moderated confidence as Personal score, being a "cleaner concept," but will additionally report range of health uses.

Figure 3 shows there were some ceiling effects on Personal score. Figure 3 also shows that despite grounding the estimates of confidence by asking about skills, there was still a large minority (51/200, 25.5%) of the sample with maximum scores, being able to do all four Internet tasks and being totally confident in their use of the Internet. This means that these people would not be able to increase their Personal score during the course of a study. This suggests that some "harder" tasks should be included in the skills question, and to focus the questionnaire better on eHealth, this should perhaps include some health-focused questions.

Support

Support scores were largely based on factual questions. There were 22 out of 271 Internet users that did not complete the section on support, half of these (10/22) said (H1) that they had no barriers to Internet use and were confident in using the Internet for health (E3).

Component questions showed that among Internet users, only 58/271 (21.4%) had been given information by health professionals to help them use the Internet. Just under half (117/271, 43.2%) knew where they could find help locally in using the Internet; many of these (78) cited their local library. A quarter (68/243, 28.0%) said there had been times when help would have been useful, and of these, 50 had someone they could ask, of which 47/50 could ask about health. Nearly three-quarters (49/71, 73%) of non-Internet users had someone use the Internet for them. There were 40/71 (65%) that had someone that could help if they wanted to try using the Internet.

That Support scores were less differentiated between Internet users and non-Internet users "made sense" in the way that questions were asked and answered. Exploration of how Support and Personal scores were associated led to a pragmatic combination, using the Personal score to moderate the Support score in the overall Readiness score (see below). There were no ceiling effects on Support.

Economic

The Economic subscale was constructed slightly differently to the other three subscales, relying on comparison of perceptions of the cost of using the Internet compared to other health activities such as visiting their GP or local hospital. Internet users and non-Internet users answered the same questions.

Considering the component questions, there were significant differences on the two Internet questions and on the cost of visiting the hospital between Internet users and non-Internet users. For the two Internet questions, this was dominated by the "don't knows" among non-Internet users; 45% (29/64) of non-Internet users did not know about the cost of home access and 57% (35/61) about the cost of mobile access compared to 4.8% (13/269) and 32.8% (87/265) of Internet users. There was no difference between Internet users and non-Internet users in perceptions of cost in getting to the local library or GP. Most (195/325, 60.0%) did not think it cost much to get to a public library, but a large minority (95/325, 29.2%) did not know. The vast majority (317/337, 94.1%) agreed that visiting their GP cost nothing or very little. Non-Internet users were more likely to think that visiting their nearest hospital cost nothing or little (55/67, 82% versus 185/268, 69.0%; χ^2_4=15.7; P=.003); this may be because more had free bus passes and may be an important reason why the Internet appears relatively more expensive to older non-Internet users.

Figure 3 shows that overall, non-Internet users were likely to have lower Economic scores indicating more barriers to using the Internet (χ^2_8=39; P<.001). There were no ceiling effects so improvements could be measured.

Overall View on Using the Internet for Health

Question H1 sought to identify the most important issue in using or not using the Internet for health. The original intention was to use this question to weight subscale scores in their combination to produce an overall readiness score. This idea was abandoned when it was realized that there was a close relationship between the Support and Personal subscales and an alternative combination method was developed. However, H1 remained a useful consistency check on the subscale scores. Table 1 shows that most Internet users (185/271, 70%) thought they had no real barriers to using the Internet for health. Among non-Internet users, 61% (40/66) said they had no interest in using the Internet.

Further breakdown of the groups in Table 1 show the range of different situations and attitudes. Of the 52 with "no interest in using the Internet," 12 had used it in the last three months, 11 had home Internet access and had not used it personally, but most had someone else use it for them. Relatively few chose connectivity, economic reasons, or need for support as the main barrier to Internet use for health.

To test the construct validity of subscales, constructed variables were compared to answers to question H1 (Table 1). All but two answers, "would use Internet more if could get a better connection" and "would use Internet more if could get someone to help" showed significant differences on the expected variable. Short scores were compared between Internet users and non-Internet users and examples of where non-Internet users had higher scores or the same scores as Internet users were selected and reviewed. These showed construct validity.

Combining the Four Subscales into an Overall eHealth Readiness Score

The initial intention was to create an overall eHealth readiness score by taking the mean of the four subscales, that is (Provision + Personal + Support + Economic)/4. However, exploration of the data led to recognition that Support was much more important for non-Internet users. Those who were already competent Internet users for health needed little support and scored low on Support. This reduced their overall eHealth readiness score and was misleading. Support was therefore added to eHealth readiness in inverse proportion to that person's Personal score, (ie, people with a higher Personal score had less weight given to their Support score). Through a process of iteration considering whether the impact on overall eHealth readiness made sense, the term 3*Support/(Personal+Support) was added as a "Modified Support" term. This Modified Support score can range from 0 to 3 and the sum of Personal and Modified Support can range from 0 to 10.5. The Economic score also seemed less important in being "eHealth ready" than Personal and Provision scores, so the short score (range 0-5) was used as the contribution to eHealth readiness. So,

eHealth readiness= Provision (0-9) + (Personal + Modified Support) (0-10.5) + Short economic (0-5)

It was then multiplied by 9/24.5 to scale to the range 0-9. Figure 3 shows in this sample scores ranged from 0-7 with mean 4.1 (SD 1.79). Non-Internet users had, as expected, lower scores than Internet users.

Table 1. Numbers choosing statements (in section H) that best summarized their view of using the Internet for health and Mann Whitney *U* or *t* independent sample tests to assess correspondence between those statements and appropriate constructed scores. (15 missing values).

Overall View	Non-Internet user		Internet user	Total	"Nearest" variable	Mean score for those who chose this item versus rest (*t* test)
	Home access	No home access				
(H11) No need for health information.	1	3	34	38	NEED	1.8 versus 3.3 *U*=3336, *P*<.001
(H12) No interest in using the Internet.	11	29	12	52	PERSONAL	1.1 versus 6.2 *U*=774, *P*<.001
(H13) Would use the Internet more for health if could get a good Internet connection.	0	2	3	5	PROVISION	2.8 versus 3.8 nsd
(H14) Don't understand the Internet that much.	9	4	17	30	PERSONAL	2.7 versus 5.7 *U*=1710, *P*<.001
(H15) Would use the Internet more for health if could get someone to help.	0	0	10	10	SUPPORT	2.1 versus 2.1 nsd
(H16) Would use the Internet more for health if money were no object.	1	2	2	5	ECONOMIC	0.8 versus 2.5 *U*=353, *P*=.024
(H17) Uses or would use the Internet for health and have no real barriers to that use.	4	0	185	189	PERSONAL	7.2 versus 3.2 *t*=16.8, *P*<.001
					ECONOMIC	3.0 versus 1.9 *t*=6.3, *P*<.001
					PROVISION	4.0 versus 1.9 *t*=13.7, *P*<.001
					SUPPORT	3.1 versus 2.3 *t*=4.6, *P*<.001
					READINESS	4.4 versus 2.3 *t*=16.1, *P*<.001
Total	26	40	263	329		

[a] *U*=Mann Whitney *U*

[b] nsd=no statistically significant difference *P*>.05

Repeatability and Change of Scores Over Time

Seventeen of the 20 people who completed the second-stage pilot (January 2012) completed PERQ4 in September 2012. Of these, four non-Internet users were excluded as the questions in section C had changed too much between the earlier and later version of PERQ to be comparable. For 13 Internet users their January data was converted to the September version of the questionnaire to allow a comparison and some assessment of "repeatability" and change over time. Each pair of questionnaires was examined for changes to answers and the impact on the scoring system to see if it made sense and if the scoring system was appropriate. This check resulted in some changes to the scoring system. With the final scoring system there was reasonable consistency in scores between January and September 2012 (see Multimedia Appendix 1) with changes in scores making sense with known changes in personal circumstances for those respondents.

Is PERQ Suitable to Assess Interventions?

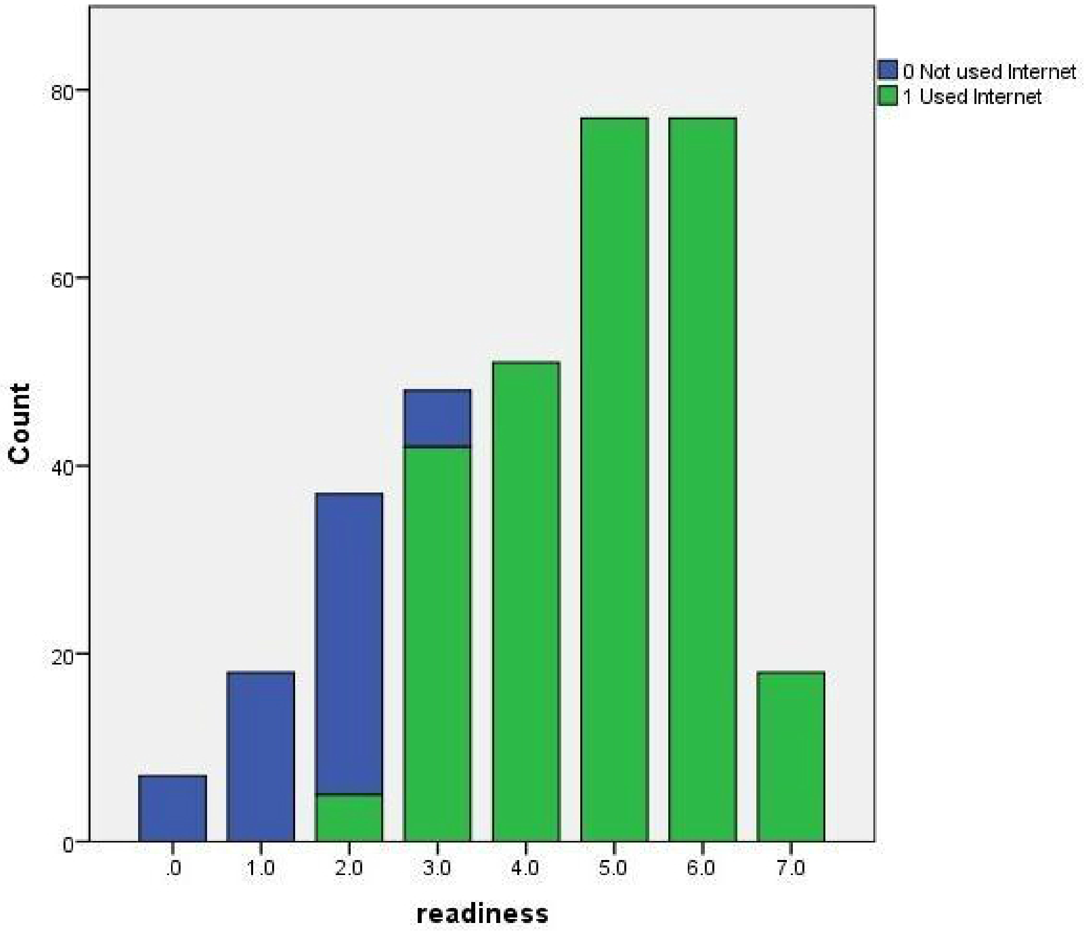
Figure 4 shows that PERQ did not have floor or ceiling effects. PERQ produces two scores, eHealth readiness and eHealth inequalities (SD of readiness). The aim of interventions would be to improve overall eHealth readiness (ie, increase the mean score) while keeping variation (SD) the same or reduced. With this sample, the mean eHealth readiness score was 4.24 with standard deviation 1.73, (4.9 for Internet users versus 1.6 for non-Internet users; $t_{4.24,1.73}$=-25.8; *P*<.001). Statistically significant changes in mean scores must represent practically (clinically) significant changes. To assess whether this scoring system can measure an attainable and useful improvement in eHealth readiness and what this would mean in terms of individual changes, changes were modelled using the dataset.

Table 2 shows four feasible changes resulting from interventions or further development in Internet use, modelled using the dataset. The first shows that if 20 non-Internet users get online and access health information there is a substantial increase in score for subgroup and whole sample as well as a reduction in inequality (SD of readiness). While the decrease in SD is not statistically significant (confidence intervals are 1.73-6.38 and 1.50-5.53) [92] the decrease is at least “heading in the right direction.” The second shows the impact of existing Internet users gaining more routes to access via mobile and learning about patient access to their GP record. Mean readiness is increased, but again, although not statistically significant, it is tending to increase inequality. The third scenario might result from better Internet provision, such as the implementation of faster broadband as is happening in Cornwall. If the level of statistical significance is set at *P*=.05, then the increase in readiness is significant, but policy makers may consider the actual change of just 20 people getting faster access relatively unimportant. With this sample size it appears relatively easy to achieve a statistically significant change in mean PERQ. The fourth scenario shows the possible impact of GPs in the area starting to engage more in recommending websites to their patients, as has been the case with “information prescription” projects [93-99]. PERQ therefore appears to be sufficiently sensitive to change.

Table 2. Modelled results of interventions, showing impact on subgroup and whole sample on eHealth readiness score and eHealth inequality and Wilcoxon signed ranks test (*z* statistic) or paired *t* test with original data.

Assumed changes	Impact on sub group mean readiness score	Impact on whole sample	
		Mean readiness score	Inequality (standard deviation of readiness)
20 non-Internet users are supported in getting online. They have not looked at the GP website, but have found other health information online.	Increase 1.8 to 5.0 *z*=4.0; *P*<.001 n=20	Increase 4.24 to 4.44 *t*=4.48; *P*<.001 n=333	Decrease 1.73 to 1.61
20 Internet users who previously used computer at home and at work got mobile access and became aware of GP services including patient access to records.	Increase 4.9 to 6.2 *z*=4.1; *P*<.001 n=20	Increase 4.24 to 4.32 *t*=4.34; *P*<.001 n=333	Increase 1.73 to 1.79
20 Internet users who said their Internet connection was too slow who got a faster connection and many of who used it to contact someone about health.	Increase 4.2 to 4.6 *z*=2.8; *P*=.005 n=20	Increase 4.24 to 4.27 *t*=2.86; *P*=.005 n=333	No change 1.73
80 Internet users who previously had not had advice on using Internet from HCP, recommended websites by GP.	Increase 4.5 to 4.7 *z*=4.0; *P*<.001 n=80	Increase 4.24 to 4.29 *t*=4.09; *P*<.001 n=333	No change 1.73

Figure 4. Distribution of eHealth readiness scores on possible scale 0-9 showing Internet-users and non-Internet-users.



Discussion

Questionnaire and Scoring

A questionnaire (PERQ) and scoring system has been developed comprising four components of patient eHealth readiness (1) provision of Internet and Internet for health, (2) personal capacity to use it, (3) support in using it, and (4) economic barriers to use. The scoring system appears consistent, to have face and construct validity, and to produce a score that can be used to assess interventions that improve eHealth readiness. By examining the standard deviation of scores, eHealth inequalities can be reviewed to ensure that interventions have not worsened inequalities. The questionnaire is being used in two studies locally [24,100].

Although national cross-sectional data from the ONS and Oxford Internet Survey (OIS) show the uptake of the Internet, and sometimes include questions on health, there is a need for a tool to measure the impact of interventions in the context of RCTs. Although there are widely used measures of eHealth literacy, these were not sufficiently comprehensive in their scope; in particular they only “worked” for Internet users. Initially the eHEALS questionnaire on eHealth literacy was included within the PERQ questionnaire, but was then dropped as the single self-efficacy question seemed adequate and took less space. There was a need for a measure that covered the full range of individuals from non-Internet users through to frequent Internet users.

Limitations in Scoring System

This pragmatic scoring system has many limitations, but is published with full details and data so that others can refine or continue to develop it. One problem with any measure of eHealth readiness is continually changing technology such as the current shift to smart phones [101]. If measures are to be used for any length of time they need to cope with changing technology. One solution may be to have a framework of generic questions that remain the same over time, but “situate” these by inserting questions related to the “state of the technology.” These questions will change over time as technology changes. The first stage of using a measure of eHealth inequality for a study would be to gain consensus on the current “State of Technology.” This has not been achieved in the development of this questionnaire and scoring system, but remains a future goal.

Second, the scale and scoring rely on self-report. Although one dimension of the proposed scale is provision of eHealth services, and although this could be measured fairly objectively [15,18], to have a method consistent with the other dimensions, this is best measured by asking patients (ie, the pragmatic solution of “perception of provision.)” Self-reported measures, such as self-efficacy, as discussed earlier, may not be good predictors of actual ability. PERQ tries to compensate by using "grounding" questions and by pragmatic "constructs" such as "modified confidence."

Third, having four dimensions makes having one summative number for eHealth readiness difficult. As described, the original plan to make the four components additive either in equal proportion or, using the ideas of Paterson et al [102-105] in measures of quality of life, by asking respondents to nominate what is most important. However, when the close connection between the Personal and Support terms was noted, this determined how the four terms should be combined. The final scoring system appears to have face and construct validity, but is nevertheless arbitrary. Others may wish to explore alternatives.

Fourth, the eHealth readiness scale is at best ordinal and not cardinal. This compares to, for example, a difference in mortality that can be expressed as a difference in years of life. While some may argue that 10 years of life at age 20 is "worth more" than 10 years of life at age 70, "years of life" is essentially a cardinal scale. Self-reported questions used to construct an ordinal scale will always have limitations and should be used cautiously.

Fifth, the weights used for individual items were arbitrary. For example, Internet Health Provision included questions about whether patients could access their medical records (weighted 1.5) and could order repeat prescriptions online (weighted 1.0). These weights reflect the judgements of the author in the "difficulty" or "sophistication" of provision. Clearly other weights could be used and the dataset and analysis syntax are provided for others to explore, but this pragmatic approach seems to provide a way of scoring and measuring change.

Sixth, people whose opportunities to use the Internet are less because of limited English will not be identified by this approach, using an English language questionnaire.

Lastly, it is not possible to directly measure eHealth inequalities, but instead to examine the spread of eHealth readiness scores. Those implementing eHealth interventions are interested in improvements in mean score (eHealth readiness) over time, but should also consider the standard deviation of scores (eHealth inequality). In other fields, for example, income inequality, measures such as the Gini coefficient directly measure inequality. Health inequalities are typically measured by differences in mortality, expressed in absolute numbers of life expectancy at birth or some other age between two groups. In this case, we hope that an intervention will improve eHealth readiness, but also reduce the standard deviation. It was important therefore in the construction of this score that a reduction in standard deviation was not artificially induced by a "ceiling effect" on the score. Given the natural progression of the Internet we are unlikely to see eHealth readiness reduce, so "floor effects" are less important. The modelling of possible interventions suggests that the eHealth readiness score is quite sensitive to relatively modest changes in Internet use for health. In determining sample size and setting significance levels, therefore, it is suggested that $P<.001$ is appropriate. On the other hand, achieving a statistically significant reduction in eHealth inequality may be difficult, but researchers' and policy makers' may be able to decide that interventions are at least not making inequality worse.

Social Determinants

Clarity is needed about the role of social determinants of eHealth inequalities. Should associations between eHealth use and demographic and social variables be explored, or should the focus be on the immediate "cause" of eHealth inequality? Demographics are clearly important in use of the Internet [76]. Answers to questions on the personal and interpersonal components of a measure may be predicted by social determinants and act as a test of face validity, but should not be part of any eHealth readiness scoring system.

Representativeness of the Sample

That the nonresponders in the baseline survey were more likely to live in lower value houses will have biased this sample towards Internet users [76]. On the other hand, using households as the sampling unit biased the sample towards older people and females (as there are more single, older, female households), so biasing the sample towards non-Internet users. Lower response rates from younger people, particularly from student households, will also bias the sample towards older people and non-Internet users. Overall, the baseline survey overrepresented older people. As the purpose of the sampling was to have a "test bed" for the questionnaire and to develop the scoring system, this may have been an advantage rather than disadvantage. The selection of households and respondents for this survey was pragmatic using easily available open data sources, but was similar in principle to the methods used in the OIS. The OIS used 175 randomly selected "Output Areas" in England, within which 10 addresses were selected at random from the Postal Address File. Interviews aimed to interview the person with the next birthday.

The baseline survey response rate was fairly poor (36%) compared to the 59% achieved by ONS [55] and to the OIS (49% successful interviews for 4160 houses visited) [76]. But, with bigger budgets, the data for both were collected by interview (rather than returned self-completed questionnaire) and allowed multiple visits to find a respondent at home. In this survey, the response rate for houses where the research assistant was able to speak to the resident before leaving a questionnaire for self-completion and return was 56%. Greater variation in time of calling/delivery and a budget allowing more persistence should achieve a better response rate.

"Diagnostic" Uses of PERQ

More detailed analysis of PERQ results could indicate the most appropriate interventions for individuals or subgroups. For example, groups that would most benefit from faster access, or support, or for whom economics was the main barrier could have interventions chosen appropriately. It is possible that a "stages of change" approach to classifying individuals might be useful, although the different dimensions (personal, provision, economic, support) need to be taken into account.

Further Work

The support section of the questionnaire was the least successful. This had proved difficult throughout piloting. In particular, we had sought ways of getting those people who had never needed or sought help to answer the questions by wording the questions about "people in general," and by stressing that we wanted everyone to answer this section. Nevertheless, 21/271 (7.8%) Internet users failed to answer this section. The second part of the "support section" (F) of PERQ probably did not collect particularly useful information, and given the desire to shorten the questionnaire, could possibly be dropped in further developments.

Conclusions

There was previously no measure of personal eHealth readiness or eHealth inequalities. The concept of a patient eHealth readiness based on provision, personal ability, support, and economic considerations with eHealth inequality as the standard deviation seems to "work" and be acceptable in a British context. The scores produced appear valid and sufficiently sensitive to enable assessment of the effectiveness of interventions to improve eHealth readiness and reduce eHealth inequalities. With suggested modifications PERQ is now being used in two other local studies. It could also be used to help identify interventions addressing eHealth readiness. Such methods need continued evolution; full documentation and data have been published to allow others to develop the tool further. In particular with changes to the "provision section," PERQ might be adapted for use in nonBritish settings.

Acknowledgments

The author wishes to thank the following people for their assistance with this paper: the reviewers for their helpful comments on the original submission, Liz Baker who delivered questionnaires, entered the data from the questionnaires, as well as recruiting family and friends for one round of the piloting, Paul Hewson for statistical advice, Jeremy Hobart and Michael Hyland for advice on scale construction, Lesley Goldsmith, Emily Ashurst, Tess Lomax, Jane Grose, Julia Frost, Anita Slade, Phil Abbott-Garner, and Jo Atkey for comments on drafts of the paper, and finally various colleagues, family members, residents of Wesley Court retirement apartments, students of Central Saint Martins, and others for the completion of and comments on early drafts of the questionnaire. The literature review, research for this paper, development and early piloting was unfunded. Sentinel Community Interest Company (GP-Co-operative for Plymouth) funded the costs of data collection for the pilot study of the questionnaire. Analysis and write-up was funded by Plymouth University (in terms of RJ's time).

Conflicts of Interest

None declared.

Multimedia Appendix 1

Initial piloting, more details on baseline survey, questionnaire development (versions 1-4), variables, SPSS syntax, dealing with inconsistent and missing data.

[PDF File (Adobe PDF File), 791KB - med20_v2i2e9_app1.pdf]

References

1. World Health Organisation. World Health Organisation. Trade, foreign policy, diplomacy and health: E-health URL: http://www.who.int/trade/glossary/story021/en/ [accessed 2013-05-24] [WebCite Cache ID 6GrG0O3zn]
2. Pagliari C, Sloan D, Gregor P, Sullivan F, Detmer D, Kahan JP, et al. What is eHealth (4): a scoping exercise to map the field. J Med Internet Res 2005;7(1):e9 [FREE Full text] [doi: 10.2196/jmir.7.1.e9] [Medline: 15829481]
3. Oh H, Rizo C, Enkin M, Jadad A. What is eHealth?: a systematic review of published definitions. World Hosp Health Serv 2005;41(1):32-40. [Medline: 15881824]
4. Eysenbach G. What is e-health? J Med Internet Res 2001;3(2):E20 [FREE Full text] [doi: 10.2196/jmir.3.2.e20] [Medline: 11720962]
5. Della Mea V. What is e-health (2): the death of telemedicine? J Med Internet Res 2001;3(2):E22 [FREE Full text] [doi: 10.2196/jmir.3.2.e22] [Medline: 11720964]
6. Oh H, Rizo C, Enkin M, Jadad A. What is eHealth (3): a systematic review of published definitions. J Med Internet Res 2005;7(1):e1 [FREE Full text] [doi: 10.2196/jmir.7.1.e1] [Medline: 15829471]
7. Ahern DK, Kreslake JM, Phalen JM. What is eHealth (6): perspectives on the evolution of eHealth research. J Med Internet Res 2006;8(1):e4 [FREE Full text] [doi: 10.2196/jmir.8.1.e4] [Medline: 16585029]
8. Jones R, Rogers R, Roberts J, Callaghan L, Lindsey L, Campbell J, et al. What is eHealth (5): a research agenda for eHealth through stakeholder consultation and policy context review. J Med Internet Res 2005;7(5):e54 [FREE Full text] [doi: 10.2196/jmir.7.5.e54] [Medline: 16403718]
9. Jones R, Goldsmith L. Final Report to NHS Choices. Plymouth: University of Plymouth; 2009. What is the evidence for the benefits and outcomes for digital health services? Final Report to NHS Choices URL: http://www.plymouth.ac.uk/files/extranet/docs/FoH/NHSChoices_2009.doc [accessed 2013-01-31] [WebCite Cache ID 6E5HQAaKY]
10. Portnoy DB, Scott-Sheldon LA, Johnson BT, Carey MP. Computer-delivered interventions for health promotion and behavioral risk reduction: a meta-analysis of 75 randomized controlled trials, 1988-2007. Prev Med 2008 Jul;47(1):3-16 [FREE Full text] [doi: 10.1016/j.ypmed.2008.02.014] [Medline: 18403003]

11. Wantland DJ, Portillo CJ, Holzemer WL, Slaughter R, McGhee EM. The effectiveness of Web-based vs. non-Web-based interventions: a meta-analysis of behavioral change outcomes. J Med Internet Res 2004 Nov 10;6(4):e40 [FREE Full text] [doi: 10.2196/jmir.6.4.e40] [Medline: 15631964]
12. Moeinedin F, Moineddin R, Jadad AR, Hamid JS, To T, Beyene J. Application of biomedical informatics to chronic pediatric diseases: a systematic review. BMC Med Inform Decis Mak 2009;9:22 [FREE Full text] [doi: 10.1186/1472-6947-9-22] [Medline: 19416540]
13. Sanders DL, Aronsky D. Biomedical informatics applications for asthma care: a systematic review. J Am Med Inform Assoc 2006;13(4):418-427 [FREE Full text] [doi: 10.1197/jamia.M2039] [Medline: 16622164]
14. Hannan A. Medeconomics. 2013. Self Care - Inform patients via your website URL: http://m.gponline.com/article/1064630/Self-Care---Inform-patients-via-website [accessed 2013-01-31] [WebCite Cache ID 6E5II842H]
15. Jones R. Inequalities in general practice website provision. Br J Gen Pract 2011 Nov;61(592):663 [FREE Full text] [Medline: 22167899]
16. Wenner A. University of Plymouth Webinar. 2013. Patient Entered Data Using Instant Medical History (Recorded webinar) University of Plymouth 2008 URL: http://www.plymouth.ac.uk/pages/view.asp?page=29272 [accessed 2013-01-31] [WebCite Cache ID 6E5InHbah]
17. Renal Association. Webcite. Which Units have Renal Patient View? Accessed from 31 January 2013 URL: http://www.renal.org/whatwedo/JointActivitiesSection/RIXGSection/RenalPatientView/RIXGWhere.aspx [accessed 2013-01-31] [WebCite Cache ID 6E5JC735A]
18. Jones RB, Goldsmith L, Hewson P, Williams CJ. Recruitment to online therapies for depression: pilot cluster randomized controlled trial. J Med Internet Res 2013;15(3):e45 [FREE Full text] [doi: 10.2196/jmir.2367] [Medline: 23462072]
19. Lenhart, Horrigan J, Allen K, Boyce A, Madden M, O'Grady E. Pew Internet and American Life Project. Washington, DC: Pew Charitable Trusts; 2003. The ever-shifting Internet population: a new look at Internet access and the digital divide URL: http://www.pewinternet.org/Reports/2003/The-EverShifting-Internet-Population-A-new-look-at-Internet-access-and-the-digital-divide/01-Summary-of-Findings.aspx [accessed 2013-01-31] [WebCite Cache ID 6E5JYor0c]
20. Rice RE. Influences, usage, and outcomes of Internet health information searching: multivariate results from the Pew surveys. Int J Med Inform 2006 Jan;75(1):8-28. [doi: 10.1016/j.ijmedinf.2005.07.032] [Medline: 16125453]
21. Renahy E, Parizot I, Chauvin P. Health information seeking on the Internet: a double divide? Results from a representative survey in the Paris metropolitan area, France, 2005-2006. BMC Public Health 2008;8:69 [FREE Full text] [doi: 10.1186/1471-2458-8-69] [Medline: 18291024]
22. Sheaves B, Jones RB, Williamson GR, Chauhan R. Phase 1 pilot study of e-mail support for people with long term conditions using the Internet. BMC Med Inform Decis Mak 2011;11:20 [FREE Full text] [doi: 10.1186/1472-6947-11-20] [Medline: 21466699]
23. Jones RB, O'Connor A, Brelsford J, Parsons N, Skirton H. Costs and difficulties of recruiting patients to provide e-health support: pilot study in one primary care trust. BMC Med Inform Decis Mak 2012;12:25 [FREE Full text] [doi: 10.1186/1472-6947-12-25] [Medline: 22458706]
24. Plymouth SeniorNet. 2013. URL: http://www.routeways.org.uk/index.php?page=silver-dreams [accessed 2013-08-29] [WebCite Cache ID 6JEhZXMHk]
25. Lorence D, Park H. Group disparities and health information: a study of online access for the underserved. Health Informatics J 2008 Mar;14(1):29-38. [doi: 10.1177/1460458207086332] [Medline: 18258673]
26. National Telecommunications and Information Administration. Published by U.S. Department of Commerce Accessed from 31 January Webcite. 2013. Digital Nation: Expanding Internet Usage (NTIA Research Preview) URL: http://www.ntia.doc.gov/report/2011/digital-nation-expanding-internet-usage-ntia-research-preview [accessed 2013-01-30] [WebCite Cache ID 6E5K4KNWT]
27. Eyrich-Garg KM. Sheltered in cyberspace? Computer use among the unsheltered ‘street’ homeless. Computers in Human Behavior 2011 Jan;27(1):296-303 [FREE Full text] [doi: 10.1016/j.chb.2010.08.007]
28. Demiris G, Patrick T, Khatri N. Assessing home care agencies' readiness for telehealth. AMIA Annu Symp Proc 2003:825 [FREE Full text] [Medline: 14728330]
29. Oliver DR, Demiris G. An assessment of the readiness of hospice organizations to accept technological innovation. J Telemed Telecare 2004;10(3):170-174. [doi: 10.1258/135763304323070832] [Medline: 15165444]
30. Wittenberg-Lyles E, Shaunfield S, Oliver DP, Demiris G, Schneider G. Assessing the readiness of hospice volunteers to utilize technology. Am J Hosp Palliat Care 2012 Sep;29(6):476-482. [doi: 10.1177/1049909111429559] [Medline: 22144658]
31. Lehman WE, Greener JM, Simpson DD. Assessing organizational readiness for change. J Subst Abuse Treat 2002 Jun;22(4):197-209. [Medline: 12072164]
32. Snyder-Halpern R. Development and pilot testing of an Organizational Information Technology/Systems Innovation Readiness Scale (OITIRS). Proc AMIA Symp 2002:702-706 [FREE Full text] [Medline: 12463915]
33. Snyder-Halpern R. Indicators of organizational readiness for clinical information technology/systems innovation: a Delphi study. Int J Med Inform 2001 Oct;63(3):179-204. [Medline: 11502432]

34. Jennett P, Jackson A, Ho K, Healy T, Kazanjian A, Woollard R, et al. The essence of telehealth readiness in rural communities: an organizational perspective. Telemed J E Health 2005 Apr;11(2):137-145. [doi: 10.1089/tmj.2005.11.137] [Medline: 15857254]
35. Li JH, Ray P. E-Health Readiness Assessment Methodology (EHRAM). In: Dössel O, Schlegel WC, editors. World Congress on Medical Physics and Biomedical Engineering September 7 - 12, 2009 Munich, Germany: Vol. 25/XII General Subjects (IFMBE Proceedings). Berlin: Springer; 2009:151-154.
36. Chattopadhyay S, Ray P, Land L, Li J. A Framework for Assessing ICT Preparedness for e-Health Implementation. In: Proceedings of 10th IEEE Intl. Conf. on e-Health Networking, Applications and Service. Singapore: IEEE; 2008:147-152.
37. Légaré E, Vincent C, Lehoux P, Anderson D, Kairy D, Gagnon MP, et al. Developing and validating the French-Canadian version of the practitioner and organizational telehealth readiness assessment tools. J Telemed Telecare 2010;16(3):140-146. [doi: 10.1258/jtt.2009.090514] [Medline: 20386034]
38. Légaré E, Vincent C, Lehoux P, Anderson D, Kairy D, Gagnon MP, et al. Telehealth readiness assessment tools. J Telemed Telecare 2010;16(3):107-109. [doi: 10.1258/jtt.2009.009004] [Medline: 20386031]
39. Wilson EV, Lankton NK. Modeling patients' acceptance of provider-delivered e-health. J Am Med Inform Assoc 2004;11(4):241-248 [FREE Full text] [doi: 10.1197/jamia.M1475] [Medline: 15064290]
40. Kutlu B, Ozturan M. Determinants of E-Health Readiness of End-Users. International Medical Journal 2012;19:287-291 [FREE Full text]
41. Li J, Seale H, Ray P, Wang Q, Yang P, Li S, et al. e-Health preparedness assessment in the context of an influenza pandemic: a qualitative study in China. BMJ Open 2013;3(3) [FREE Full text] [doi: 10.1136/bmjopen-2012-002293] [Medline: 23485719]
42. Zapka J, Simpson K, Hiott L, Langston L, Fakhry S, Ford D. A mixed methods descriptive investigation of readiness to change in rural hospitals participating in a tele-critical care intervention. BMC Health Serv Res 2013;13:33 [FREE Full text] [doi: 10.1186/1472-6963-13-33] [Medline: 23360332]
43. Wilkowsk W, Ziefle M, Alagöz F. How user diversity and country of origin impact the readiness to adopt E-health technologies: an intercultural comparison. Work 2012;41 Suppl 1:2072-2080. [doi: 10.3233/WOR-2012-0433-2072] [Medline: 22317022]
44. Khoja S, Scott RE, Casebeer AL, Mohsin M, Ishaq AF, Gilani S. e-Health readiness assessment tools for healthcare institutions in developing countries. Telemed J E Health 2007 Aug;13(4):425-431. [doi: 10.1089/tmj.2006.0064] [Medline: 17848110]
45. Jennett P, Jackson A, Healy T, Ho K, Kazanjian A, Woollard R, et al. A study of a rural community's readiness for telehealth. J Telemed Telecare 2003;9(5):259-263. [doi: 10.1258/135763303769211265] [Medline: 14599328]
46. Jennett P, Bates J, Healy T, Ho K, Kazanjian A, Woollard R, et al. A readiness model for telehealth is it possible to pre-determine how prepared communities are to implement telehealth? Stud Health Technol Inform 2003;97:51-55. [Medline: 15537230]
47. MacFarlane A, Clerkin P, Murray E, Heaney DJ, Wakeling M, Pesola UM, et al. The e-Health Implementation Toolkit: qualitative evaluation across four European countries. Implement Sci 2011;6:122 [FREE Full text] [doi: 10.1186/1748-5908-6-122] [Medline: 22098945]
48. Touré M, Poissant L, Swaine BR. Assessment of organizational readiness for e-health in a rehabilitation centre. Disabil Rehabil 2012;34(2):167-173. [doi: 10.3109/09638288.2011.591885] [Medline: 21936712]
49. Chipps J, Mars M. Readiness of health-care institutions in KwaZulu-Natal to implement telepsychiatry. J Telemed Telecare 2012 Apr;18(3):133-137. [doi: 10.1258/jtt.2012.SFT103] [Medline: 22362834]
50. Rezai-Rad M, Vaezi R, Nattagh F. E-health readiness assessment framework in iran. Iran J Public Health 2012;41(10):43-51 [FREE Full text] [Medline: 23304661]
51. Sharifi M, Ayat M, Jahanbakhsh M, Tavakoli N, Mokhtari H, Ismail WK. E-health implementation challenges in Iranian medical centers: a qualitative study in Iran. Telemed J E Health 2013 Feb;19(2):122-128. [doi: 10.1089/tmj.2012.0071] [Medline: 23374035]
52. Rogers EM. Diffusion of innovations. New York: Free Press; 1995.
53. Fenn J. Gartner Webcite. 2013. Understanding Gartner's Hype Cycles URL: http://www.gartner.com/id=1398413 [accessed 2013-01-31] [WebCite Cache ID 6E5LJFlWg]
54. Viswanath K, Kreuter MW. Health disparities, communication inequalities, and eHealth. Am J Prev Med 2007 May;32(5 Suppl):S131-S133 [FREE Full text] [doi: 10.1016/j.amepre.2007.02.012] [Medline: 17466818]
55. Office for National Statistics. Office for National Statistics. 2012. Households and Individuals, 2012 URL: http://www.ons.gov.uk/ons/rel/rdit2/internet-access---households-and-individuals/2012/stb-internet-access--households-and-individuals--2012.html [accessed 2013-01-31] [WebCite Cache ID 6E5FIJ77b]
56. Ofcom. Ofcom. 2010. Digital Participation: 2010 Metrics Bulletin URL: http://stakeholders.ofcom.org.uk/market-data-research/media-literacy/archive/medlitpub/medlitpubrss/2010-metrics-bulletin/ [accessed 2013-01-31] [WebCite Cache ID 6E5HCS4gw]

57. Milligan C, Passey D. Current Engagement and future Needs. Ageing and the use of the internet URL: http://www.nominettrust.org.uk/sites/default/files/NT%20SoA%20-%20Ageing%20and%20the%20use%20of%20the%20internet_0.pdf [accessed 2013-01-31] [WebCite Cache ID 6E5GzRxcu]
58. Cabinet Office. Cabinet Office. Digital services so good that people prefer to use them (Government Digital Strategy) Accessed from 31 January 2013 Webcite URL: http://publications.cabinetoffice.gov.uk/digital/ [accessed 2013-01-31] [WebCite Cache ID 6E5LU99hQ]
59. Department of Health. A review of tacking health inequalities in England over the last 10 years. Tackling health inequalities: 10 years on URL: http://www.bris.ac.uk/poverty/downloads/keyofficialdocuments/Tackling%20HE%2010%20years%20on.pdf [accessed 2013-01-31] [WebCite Cache ID 6E5LmSiRJ]
60. Jones R. The role of health kiosks in 2009: literature and informant review. Int J Environ Res Public Health 2009 Jun;6(6):1818-1855 [FREE Full text] [doi: 10.3390/ijerph6061818] [Medline: 19578463]
61. John Carlo B, Paul TJ, Lesley AL, Charles RM. First Monday. 2006. Public access computing and Internet access in public libraries: The role of public libraries in e-government and emergency situations URL: http://www.firstmonday.org/ojs/index.php/fm/article/view/1392/1310 [accessed 2013-08-30] [WebCite Cache ID 6JFxzPu5x]
62. Information Daily. 2013. Age Concern launches its Digital Inclusion Network Accessed from on 31 January 2013 Webcite URL: http://www.theinformationdaily.com/2007/05/01/age-concern-launches-its-digital-inclusion-network [accessed 2013-01-31] [WebCite Cache ID 6E5M9d1lg]
63. Gita Mendis (Head of Digital Inclusion NHS Choices) (2007-2011). 2013. Webcite URL: http://www.linkedin.com/pub/gita-mendis/6/4aa/438 [accessed 2013-01-31] [WebCite Cache ID 6E5OqIARc]
64. Kerr C, Murray E, Noble L, Morris R, Bottomley C, Stevenson F, et al. The potential of Web-based interventions for heart disease self-management: a mixed methods investigation. J Med Internet Res 2010;12(4):66-80 [FREE Full text] [doi: 10.2196/jmir.1438] [Medline: 21156471]
65. Xie B, Bugg JM. Public library computer training for older adults to access high-quality Internet health information. Libr Inf Sci Res 2009 Sep 1;31(3):155-162 [FREE Full text] [doi: 10.1016/j.lisr.2009.03.004] [Medline: 20161649]
66. Health Foundation. Health Foundation Inspiring Movement. 2013. Patient record access: turning it on, sharing the learning URL: http://www.health.org.uk/areas-of-work/programmes/closing-the-gap-through-changing-relationships/related-projects/patient-record-access/ [accessed 2013-01-31] [WebCite Cache ID 6E5PDwUHX]
67. National Archives. Legislation.gov.uk. 2013. Disability Discrimination Act 1995 URL: http://www.legislation.gov.uk/ukpga/1995/50/contents [accessed 2013-01-31] [WebCite Cache ID 6E5PQSCgd]
68. National Archives. Legislation.gov.uk. 2013. Special Educational Needs and Disability Act 2001 URL: http://www.legislation.gov.uk/ukpga/2001/10/contents [accessed 2013-01-31] [WebCite Cache ID 6E5Pc7xq5]
69. National Archives. Legislation.gov.uk. 2013. Equality Act 2010 URL: http://www.legislation.gov.uk/ukpga/2010/15/contents [accessed 2013-01-31] [WebCite Cache ID 6E5Po3j6i]
70. RNIB Digital Accessibility Team. Tiresias. 2013. Making ICT accessible URL: http://www.tiresias.org/index.htm [accessed 2013-01-31] [WebCite Cache ID 6E5PxHgAz]
71. United States Government. United States Government. 2013. Resources for understanding and implementing Section 508 Accessed from on 31 January 2013 Webcite URL: http://www.section508.gov/index.cfm [accessed 2013-01-31] [WebCite Cache ID 6E5QEZr8G]
72. Khoja S, Scott R, Gilani S. E-health readiness assessment: promoting "hope" in the health-care institutions of Pakistan. World Hosp Health Serv 2008;44(1):36-38. [Medline: 18549033]
73. Office for National Statistics. Office for National Statistics. 2013. Internet Access - Households and Individuals, 2012 URL: http://www.ons.gov.uk/ons/rel/rdit2/internet-access---households-and-individuals/2012/stb-internet-access--households-and-individuals--2012.html [accessed 2013-01-31] [WebCite Cache ID 6E5FIJ77b]
74. Norman CD, Skinner HA. eHEALS: The eHealth Literacy Scale. J Med Internet Res 2006;8(4):e27 [FREE Full text] [doi: 10.2196/jmir.8.4.e27] [Medline: 17213046]
75. Fox S. Pew Internet and American Life Project. Washington, DC: Pew Internet and American Life Project; 2005. Health Information Online URL: http://www.pewinternet.org/~/media/Files/Reports/2005/PIP_Healthtopics_May05.pdf.pdf [accessed 2013-01-31] [WebCite Cache ID 6E5QUFfiN]
76. Dutton WH, Blank G. Oxford Internet Surveys. Oxford: Oxford University; 2001. Next generation users: the Internet in Britain URL: http://www.oii.ox.ac.uk/downloads/index.cfm?File=publications/oxis2011_report.pdf [accessed 2013-08-30] [WebCite Cache ID 6JFz9aW61]
77. Robinson C, Graham J. Perceived Internet health literacy of HIV-positive people through the provision of a computer and Internet health education intervention. Health Info Libr J 2010 Dec;27(4):295-303. [doi: 10.1111/j.1471-1842.2010.00898.x] [Medline: 21050372]
78. Xie B. Experimenting on the impact of learning methods and information presentation channels on older adults' e-health literacy. J. Am. Soc. Inf. Sci 2011 Jun 06;62(9):1797-1807. [doi: 10.1002/asi.21575]
79. Knapp C, Madden V, Marcu M, Wang H, Curtis C, Sloyer P, et al. Information seeking behaviors of parents whose children have life-threatening illnesses. Pediatr Blood Cancer 2011 May;56(5):805-811. [doi: 10.1002/pbc.22674] [Medline: 21370415]

80. Horvath KJ, Courtenay-Quirk C, Harwood E, Fisher H, Kachur R, McFarlane M, et al. Using the Internet to provide care for persons living with HIV. AIDS Patient Care STDS 2009 Dec;23(12):1033-1041. [doi: 10.1089/apc.2009.0163] [Medline: 20025513]
81. van der Vaart R, van Deursen JAMA, Drossaert HCC, Taal E, van Dijk AMGJ, van de Laar AFJM. Does the eHealth Literacy Scale (eHEALS) measure what it intends to measure? Validation of a Dutch version of the eHEALS in two adult populations. J Med Internet Res 2011;13(4):e86 [FREE Full text] [doi: 10.2196/jmir.1840] [Medline: 22071338]
82. Deursen AJAMV, van Dijk JAGM. Measuring Internet Skills. International Journal of Human-Computer Interaction 2010 Sep 17;26(10):891-916 [FREE Full text] [doi: 10.1080/10447318.2010.496338]
83. Dunning D, Johnson K, Ehrlinger J, Kruger J. Why people fail to recognize their own incompetence. Current Directions in Psychol Sci 2003 Jun;12(3):83-87. [doi: 10.1111/1467-8721.01235]
84. McMullan M, Jones R, Lea S. Math anxiety, self-efficacy, and ability in British undergraduate nursing students. Res Nurs Health 2012 Apr;35(2):178-186. [doi: 10.1002/nur.21460] [Medline: 22261975]
85. van Deursen AJ, van Dijk JA. Internet skills performance tests: are people ready for eHealth? J Med Internet Res 2011;13(2):e35 [FREE Full text] [doi: 10.2196/jmir.1581] [Medline: 21531690]
86. Hargittai E. Survey Measures of Web-Oriented Digital Literacy. Social Science Computer Review 2005 Aug 01;23(3):371-379. [doi: 10.1177/0894439305275911]
87. Barnoy S, Volfin-Pruss D, Ehrenfeld M, Kushnir T. Factors affecting nurses' attitudes in Israel toward patients who present them with Internet medical information. Nurs Outlook 2008;56(6):314-321. [doi: 10.1016/j.outlook.2008.05.008] [Medline: 19041453]
88. Go ON UK Ltd. Webcite. London; 2013. URL: http://www.go-on.co.uk/ [accessed 2013-01-31] [WebCite Cache ID 6E5RJJgWW]
89. del Hoyo-Barbolla E, Kukafka R, Arredondo MT, Ortega M. A new perspective in the promotion of e-health. Stud Health Technol Inform 2006;124:404-412. [Medline: 17108554]
90. Eynon R, Helsper E. Adults learning online: Digital choice and/or digital exclusion? New Media & Society 2010 Dec 06;13(4):534-551 [FREE Full text] [doi: 10.1177/1461444810374789]
91. Office for National Statistics. Office for National Statistics. 2012. Internet Access Households and Individuals 2011 URL: http://www.ons.gov.uk/ons/dcp171766_256200.pdf [accessed 2013-08-29] [WebCite Cache ID 6JEuFFPhm]
92. Rizzo M. Computational Statistics with R. In: Statistical Computing with R (Computer Science and Data Analysis). London: Chapman & Hall/CRC; 2008.
93. Beaudoin DE, Longo N, Logan RA, Jones JP, Mitchell JA. Using information prescriptions to refer patients with metabolic conditions to the Genetics Home Reference website. J Med Libr Assoc 2011 Jan;99(1):70-76 [FREE Full text] [doi: 10.3163/1536-5050.99.1.012] [Medline: 21243058]
94. Brewster L, Sen B. 'Quality signposting': the role of online information prescription in providing patient information. Health Info Libr J 2011 Mar;28(1):59-67. [doi: 10.1111/j.1471-1842.2010.00912.x] [Medline: 21314895]
95. Burke M, Carey P, Haines L, Lampson AP, Pond F. Implementing the information prescription protocol in a family medicine practice: a case study. J Med Libr Assoc 2010 Jul;98(3):228-234 [FREE Full text] [doi: 10.3163/1536-5050.98.3.011] [Medline: 20648257]
96. Chamberlain D, Heaps D, Robert I. Bibliotherapy and information prescriptions: a summary of the published evidence-base and recommendations from past and ongoing Books on Prescription projects. J Psychiatr Ment Health Nurs 2008 Jan;15(1):24-36. [doi: 10.1111/j.1365-2850.2007.01201.x] [Medline: 18186826]
97. Koonce TY, Giuse NB, Storrow AB. A pilot study to evaluate learning style-tailored information prescriptions for hypertensive emergency department patients. J Med Libr Assoc 2011 Oct;99(4):280-289 [FREE Full text] [doi: 10.3163/1536-5050.99.4.005] [Medline: 22022222]
98. Oliver KB, Lehmann HP, Wolff AC, Davidson LW, Donohue PK, Gilmore MM, et al. Evaluating information prescriptions in two clinical environments. J Med Libr Assoc 2011 Jul;99(3):237-246 [FREE Full text] [doi: 10.3163/1536-5050.99.3.011] [Medline: 21753916]
99. Ritterband LM, Ardalan K, Thorndike FP, Magee JC, Saylor DK, Cox DJ, et al. Real world use of an Internet intervention for pediatric encopresis. J Med Internet Res 2008;10(2):e16 [FREE Full text] [doi: 10.2196/jmir.1081] [Medline: 18653440]
100. Abbott-Garner P. slideshare. Plymouth University: Plymouth University; 2012. Do superfast broadband and community interventions improve use of e-health and reduce health related car travel? Factorial cluster randomised controlled trial URL: http://www.slideshare.net/OnlineCentresFoundation/phils-phd-presentation [accessed 2013-08-29] [WebCite Cache ID 6JEhthz3V]
101. Boulos MN, Wheeler S, Tavares C, Jones R. How smartphones are changing the face of mobile and participatory healthcare: an overview, with example from eCAALYX. Biomed Eng Online 2011;10:24 [FREE Full text] [doi: 10.1186/1475-925X-10-24] [Medline: 21466669]
102. Paterson C, Thomas K, Manasse A, Cooke H, Peace G. Measure Yourself Concerns and Wellbeing (MYCaW): an individualised questionnaire for evaluating outcome in cancer support care that includes complementary therapies. Complement Ther Med 2007 Mar;15(1):38-45. [doi: 10.1016/j.ctim.2006.03.006] [Medline: 17352970]

103. Paterson C. Measuring outcomes in primary care: a patient generated measure, MYMOP, compared with the SF-36 health survey. BMJ 1996 Apr 20;312(7037):1016-1020 [FREE Full text] [Medline: 8616351]
104. Paterson C. Seeking the patient's perspective: a qualitative assessment of EuroQol, COOP-WONCA charts and MYMOP. Qual Life Res 2004 Jun;13(5):871-881. [Medline: 15233501]
105. Paterson C. Measuring changes in self-concept: a qualitative evaluation of outcome questionnaires in people having acupuncture for their chronic health problems. BMC Complement Altern Med 2006;6:7-7 [FREE Full text] [doi: 10.1186/1472-6882-6-7] [Medline: 16539737]

Abbreviations

GP: General Practice
OIS: Oxford Internet Survey
ONS: Office for National Statistics
PERQ: Patient eHealth Readiness Questionnaire
RCT: randomized controlled trial

Edited by G Eysenbach; submitted 01.02.13; peer-reviewed by H Durrani, M Duplaga; comments to author 12.05.13; revised version received 24.05.13; accepted 16.08.13; published 02.09.13.

Please cite as:
Jones R
Development of a Questionnaire and Cross-Sectional Survey of Patient eHealth Readiness and eHealth Inequalities
Med 2.0 2013;2(2):e9
URL: http://www.medicine20.com/2013/2/e9/
doi:10.2196/med20.2559
PMID:25075244

Original Paper

eHealth Technology Competencies for Health Professionals Working in Home Care to Support Older Adults to Age in Place: Outcomes of a Two-Day Collaborative Workshop

Ansam Barakat[1], MSc; Ryan D Woolrych[2], PhD; Andrew Sixsmith[2], PhD; William D Kearns[3], PhD; Helianthe SM Kort[1,4], PhD

[1]Demand Driven Care, Research Centre for Innovations in Healthcare, Faculty of Healthcare, University of Applied Sciences Utrecht, Utrecht, Netherlands

[2]Gerontology Research Centre, Simon Fraser University, Vancouver, BC, Canada

[3]Department of Rehabilitation and Mental Health Counselling, University of South Florida, Tampa, FL, United States

[4]Building Healthy Environments for Future Users, Department of the Built Environment, Building Physics and Services, Eindhoven University of Technology (TU/e), Eindhoven, Netherlands

Corresponding Author:
Helianthe SM Kort, PhD
Demand Driven Care, Research Centre for Innovations in Healthcare
Faculty of Healthcare
University of Applied Sciences Utrecht
Bolognalaan 101
Utrecht, 3508 AD
Netherlands
Phone: 31 884815342
Fax: 31 884815936
Email: helianthe.kort@hu.nl

Abstract

Background: The demand for care is increasing, whereas in the near future the number of people working in professional care will not match with the demand for care. eHealth technology can help to meet the growing demand for care. Despite the apparent positive effects of eHealth technology, there are still barriers to technology adoption related to the absence of a composite set of knowledge and skills among health care professionals regarding the use of eHealth technology.

Objective: The objective of this paper is to discuss the competencies required by health care professionals working in home care, with eHealth technologies such as remote telecare and ambient assisted living (AAL), mobile health, and fall detection systems.

Methods: A two-day collaborative workshop was undertaken with academics across multiple disciplines with experience in working on funded research regarding the application and development of technologies to support older people.

Results: The findings revealed that health care professionals working in home care require a subset of composite skills as well as technology-specific competencies to develop the necessary aptitude in eHealth care. This paper argues that eHealth care technology skills must be instilled in health care professionals to ensure that technologies become integral components of future care delivery, especially to support older adults to age in place. Educating health care professionals with the necessary skill training in eHealth care will improve service delivery and optimise the eHealth care potential to reduce costs by improving efficiency. Moreover, embedding eHealth care competencies within training and education for health care professionals ensures that the benefits of new technologies are realized by casting them in the context of the larger system of care. These care improvements will potentially support the independent living of older persons at home.

Conclusions: This paper describes the health care professionals' competencies and requirements needed for the use of eHealth technologies to support elderly adults to age in place. In addition, this paper underscores the need for further discussion of the changing role of health care professionals working in home care within the context of emerging eHealth care technologies. The findings are of value to local and central government, health care professionals, service delivery organizations, and commissioners of care to use this paper as a framework to conduct and develop competencies for health care professionals working with eHealth technologies.

(Med 2.0 2013;2(2):e10) doi:10.2196/med20.2711

KEYWORDS

competencies; nurses; professionals; technology; CanMEDS; health care; eHealth; health information technologies; ambient assisted living; mobile health

Introduction

Background

The world population continues to age [1], and the prevalence of chronic diseases is increasing [2], introducing complex societal challenges about how best to provide care to seniors. One in 5 workers will be employed in the health care sector by 2025, to meet the care demands of an aging population while supporting the independence, autonomy, and quality of life of older adults living at home [3,4]. To compensate for the anticipated shortfall in trained health care professionals, policymakers have advocated for the development and application of eHealth technologies as a potential tool to improve efficiencies in care [5]. While the application and deployment of eHealth technology has continued at a rapid pace, this has outstripped discussions on the skills and competencies that health care professionals are required to possess to successfully utilize the technology to support workplace practices.

eHealth involves the use of electronic communication and information technology to improve the access, efficiency, effectiveness, and quality of clinical and business processes utilized by health care organizations, health care professionals, and patients [6]. The term “eHealth” encompasses a broad range of technologies, including electronic/personal health records, telehealth, telecare, telemedicine, patient self-monitoring, ambient assisted living (AAL), and smart systems [6,7].

This paper focuses on health care skills and competencies required to utilize those technologies that support older adults aging in place: remote telecare and AAL, mobile health, and fall detection systems. This paper does not focus on health information technology (HIT) such as telemedicine or electronic health records. While there are differing occupations subsumed under the term “health care professional”, this paper refers to those who are future nurses (students) and current nurses. All types of nurses fall into this category including certified nurse assistants, licensed vocational/practical nurses, and registered nurses as key actors who will interface with eHealth in the future.

Advantages of eHealth

Research indicates that eHealth technologies can yield substantial benefits for older people seeking to age-in-place by promoting independence and well-being while promoting efficiency and cost savings by reducing unnecessary hospital visits and delaying admission to long-term care [8,9]. Telehealth technologies, for example, facilitate remote patient consultations and monitoring of chronic health conditions at a distance [10]. Remote telecare technologies offer the potential to monitor and assist older adults with routine tasks and everyday home activities while enhancing their independence and autonomy [11]. As an example, simple automated reminders help and encourage older people to take medications or follow exercise programmes [12]. Other assistive and monitoring technologies, such as mobile health, environmental and body area networks in home, and health and activity monitoring, permit frequent serial patient observations of conditions or behaviors that assist caregivers by providing a more complete picture of patient status [13]. Technologies that facilitate the delivery of care in the home remove 3 barriers—stigma, access, and cost, which may prevent older people from presenting themselves to health care professionals [14,15].

eHealth interventions have the potential to alleviate the burden on health care professionals who have patients with complex care requirements or who currently manage high caseloads by providing the opportunity to monitor the condition of an older person remotely [16]. eHealth technologies have demonstrated success in allowing health care professionals to telemonitor blood pressure, pulse rate, and blood sugar levels, obviating the need for personal visits [17,18].

Education and Training: Competencies

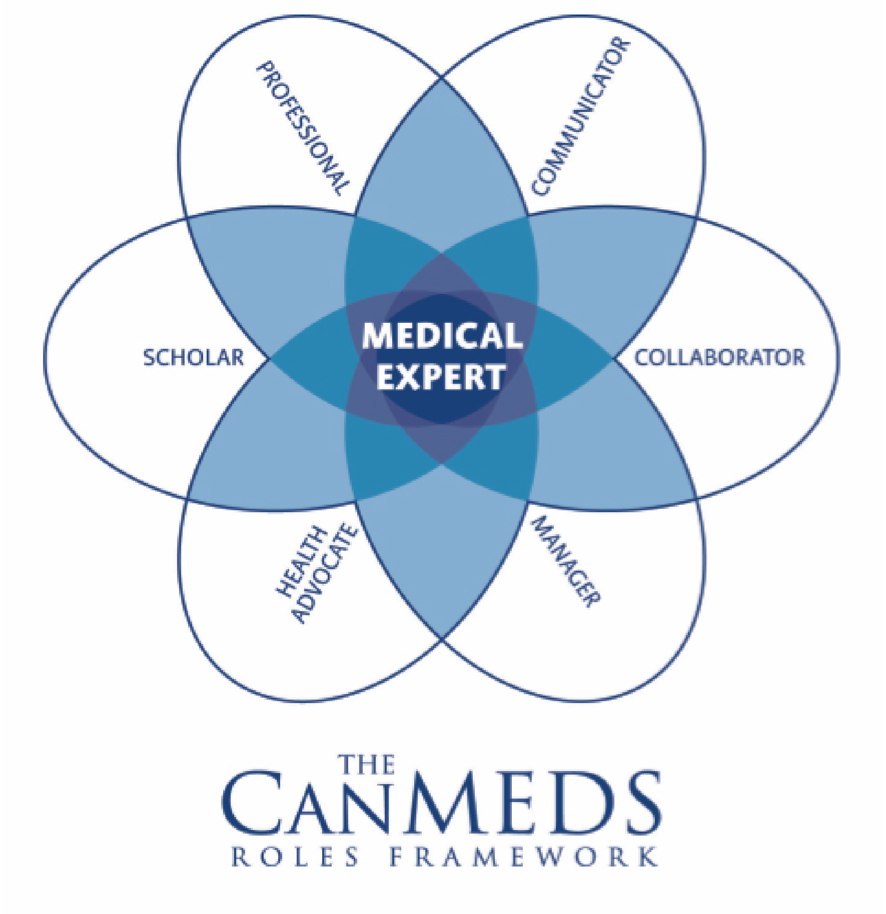
The advantages of eHealth technologies for health care professionals stem from a system that coordinates the collection, use and sharing of information to support health care delivery, known as health informatics [19]. Health informatics has developed rapidly in the last decade, becoming increasingly complex as technological advances and mechanisms for generating and sharing information have transformed clinical service delivery [20]. To ensure that these advances are translated into a service context, health care organizations must educate and train health care professionals in the latest tools and methods to accelerate the evolution of health care and affirm the acceptance of technology.

The “Diffusion of Innovations” theory seeks to explain why, and how fast new ideas and technology spread through cultures [21]. The model introduces 4 key elements that influence the adoption of a new idea: (1) the innovation, (2) communication channels, (3) time, and (4) social system. Diffusion is the process by which an innovation is communicated through certain channels over time among the members of a social system. Rogers explained that individuals progress through 5 stages of adopting new technology: knowledge, persuasion, decision, implementation, and confirmation. The first step in the process of adaptation to and acceptance of technology is to enhance professionals’ knowledge about eHealth in their everyday work. Knowledge can be categorized according to minimum competencies that health care professionals are required to possess prior to applying eHealth technologies. The typology of skills adopted by the CanMEDS Physician Competency Framework presents 6 key roles for professionals when engaging in health care delivery, including advocate, communicator, collaborator, manager, scholar, and professional [22]. Figure 1 illustrates the central role of the medical expert and its interconnectedness with the other CanMEDS framework roles.

This competency framework has been applied across different countries [23]; in the Netherlands, the CanMEDS framework is widely used in nursing education. The CanMEDS describes the composite roles required of health care professionals within generalized care delivery only and is not specific to eHealth. This highlights a potential disconnect between the increasing complexity of eHealth technology and the need to establish the composite skills required of health care professionals to make the best use of technology within a care context.

A systematic review indicated that end users' HIT competencies and skills represent implementation barriers to eHealth [24]. In the Netherlands, competencies and skills have been identified as facilitators for the implementation of remote telecare to best support frontline nurses in the workplace context [25]. A description of competencies would ensure uniform quality of remote telecare service delivery with the potential to apply these skills to a broad range of health care decision-makers, including nurses, professions allied with medicine, social workers, health care managers, and caregivers.

Figure 1. The CanMEDS framework.



Early Research

In the Netherlands, van Merwijk [26] has described Information Communication Technology (ICT) as a fundamental component of remote nursing care delivery. However, eHealth training is not a core component for care professionals [27], although several studies have suggested that eHealth instruction should be integral to nursing education, with the responsibility for implementation falling on university educators, placement supervisors, and regulators [28,29].

There is a long history of development of competencies in the area of health informatics, nursing informatics, and (bio)medical informatics [30-34]. Peterson and Gerdin-Jelger [34] started in 1988 with the recommendations of the international medical informatics, which has been recently updated to accommodate the current developments on education in biomedical and health informatics [31]. Hasman and Albert [30] succeeded in suggesting a guideline for the European curricula in health informatics that apply to health care professionals and administrative staff. In the Netherlands, on-going work on competencies address nursing education and nursing informatics more specifically [35,36]. However, there is still little or no education for health care professionals in the use of technology to support older adults to age in place such as remote telecare, patient self-monitoring, and AAL. We contend that the current competencies must be adjusted to fully realize the benefits of eHealth.

Edirippulige et al [37] and Dattakumar et al [38] identified the absence of systematic nursing education and training in eHealth care as the reason for the emergence of under-skilled and ill-equipped eHealth practitioners. Other studies suggest that the skills gap has undermined confidence among nurses in eHealth technologies, with many stating they are not in a position to use these technologies effectively within the scope of their work [39,40].

The Aim

In discussing the competencies of health care professionals working at home care organizations, 2 questions arise. First, which eHealth competencies are required for health care professionals to support older adults to age in place? Second, what is the nature of the supportive framework required to develop eHealth competencies? The goal of this paper is to present findings from a collaborative workshop tasked with exploring the basic eHealth competencies required of health care professionals working in home care, with eHealth technologies such as remote telecare, AAL, mobile health, and fall detection systems. In addition, we present a supportive framework that is required to establish these competencies in the field. This framework is an adapted framework to that used for HIT competencies.

Methods

Collaborative Workshops

In March 2012, the Department of Rehabilitation and Mental Health Counselling at the University of South Florida (USF) hosted an international group of academics in a set of collaborative workshops to discuss and explore eHealth competencies. Group discussion has been practiced extensively in participatory research to facilitate active dialog among individuals or groups to achieve the cross-fertilization of ideas [41]. Feldman [42] argued that engaging in collaborative dialog provided an opportunity to share and reflect upon experiences and to situate them within their broader context and meaning. Collaborative discussion allows for the transfer of knowledge, thoughts, and feelings about a topic of interest through a process of cooperative inquiry that enables new understandings to emerge (ie, a dialectical process). The workshops were funded as part of the Expanding eHealth Knowledge (iKOP) project, which investigates eHealth systems for their ability to support older adults living independently at home for as long as possible. The main research question of the iKOP project was “What criteria must eHealth fulfil to be understandable to professionals and to be used by older adults to reduce the burden of care and to reinforce independent living?” The workshops were designed to partly address the professional component of this question.

Research Question

The aims of the collaborative workshops were as follows:

- The first aim is to share knowledge and expertise in the application of eHealth technologies with health care professionals through a process of collaborative learning.
- The second aim is to engage in collaborative discussion regarding the competencies required of health care professionals in the use of eHealth technologies.
- The third aim is to propose a set of skills and requirements for health care professionals to adopt eHealth technologies within their everyday working practices.

Stakeholders

To develop the transdisciplinary dialog, 11 academics spanning the domains of biology, nursing, psychology, sociology, engineering, gerontology, and health management engaged in the collaborative workshops.

The participants were drawn from 3 academic institutions. First, academics from the USF included the chair and an associate professor of the Department of Rehabilitation and Mental Health and the interim dean of the College of Behavioral and Community Sciences (representing medical educators). Participants from USF also included a professor at the College of Nursing (representing medical educators and nurses), a research associate professor of the Department of Rehabilitation and Mental Health Counselling, and a courtesy professor at the School of Aging Studies (representing academics, professionals, and older adults). Second, academics from Utrecht University of Applied Sciences included a full professor and chair of the research group Demand Driven Care, Department of Health care, Research Centre Innovation Health Care, and a PhD candidate (representing older adults, professionals, home care settings, and academics). Third, academics from the Gerontology Research Centre at Simon Fraser University included a research fellow and a professor (representing professionals, home care settings, and academics).

In addition, two other organizations, the James A Haley Veterans Administration Hospital Centre of Excellence (JAHVA) and the Creative Action Limited Liability Company (CAL), were involved. From the JAHVA, a research health science specialist with interests in health disparities research and efficacy trials of health care technologies to inform translational research and system-wide implementation represented professionals (nurses) and academics. The Vice President of Research at CAL represented the interests of older adults, trainers, and software developers.

The participants had previous experience working with or evaluating the impact of eHealth technologies across a broad range of care contexts including home care and institutional care settings. A number of the participants have experience of developing technology with a focus on end user involvement and working alongside health care professionals to evaluate their experience of using eHealth technologies.

Setting of the Workshops

The workshop consisted of two days of presentations and collaborative discussions to clarify the role of health care professionals in the application, development, and integration of eHealth technologies to support older adults to age in place. The presentations included a literature review on remote telecare competencies and requirements of health care professionals, feedback on the application and development of eHealth technologies in the homes of older people through funded research, and improvement of clinical research through the use of mobile technology. Three specific forms of eHealth technologies were addressed within the workshops: remote telecare and AAL, mobile health, and fall detection systems. These were the specific areas of expertise for the group of academics. Each presentation was followed by collaborative discussion in the group concerning the roles of health care professionals in using and delivering care through these different technologies and the specific competencies they might require.

At the end of each day of the workshop, a summary of the issues that were highlighted by all professionals was presented to the group for agreement. At the beginning of the second day of the workshop, a presentation was given about the key discussion points from the prior workshop day to refresh the participants' memory. The competencies and requirements were selected by voting and ranking in importance while considering the diffusion of innovations theory by Everett Rogers and the CanMEDS Physician Competency Framework concerning how the competency or requirement aligns with new technology. The two-day workshop concluded with a presentation summarizing the workgroup's recommended eHealth competencies and a discussion of future research directions. A number of participants kept written notes of the discussions, which were analysed thematically and presented in the results section.

Results

Necessary Competencies

During the workshop, eHealth products and possible necessary competencies were discussed. Participants agreed to structure the discussion as follows: (1) the requirements for basic ICT, proficiency, quantitative analysis, and interpretation skills, (2) communication skills, (3) support and guidance for the patient (both for care support, computer, and ICT use), (4) knowledge of best practices, and (5) legal requirements concerning patient privacy and confidentiality. Although health care professionals are required to possess a number of these skills within their current work role, the skills must be re-interpreted within the eHealth care context. Table 1 summarizes the competencies identified in the analysis of the workshop discussions.

ICT Attitudes and Skills

The concept of eHealth is predicated upon sharing and communicating information through ICT technologies [6]. A desirable prerequisite for health care professionals is an abiding interest in the eHealth technology field. With little interest in eHealth technology, there will be scant enthusiasm to learn and adapt eHealth technologies for work roles or to apply learning obtained through formal training. Venkatesh et al [43] and Davis et al [44] showed in the technology acceptance model that intension to use is highly correlated to actual use. Moreover, an interest in eHealth care promotes sharing and learning within the workplace, establishing the foundation for positive cultural attitudes to develop toward the technology.

A crucial competency for health care professionals involves the basic skills for using technology and hardware, such as accessing the Internet or using a personal computer or mobile device [30,45]. Formal caregivers must have an aptitude for the devices used to collate, store, and display patient information in their new work routines [31]. Just as other researchers have found that basic skills in ICT are necessary [30,31], we agreed that professionals must be adept in using the software application to access patient information, to properly display and manipulate patient data and to ensure that information is interpreted correctly [30,31]. Developing competencies in using hardware and software are integral to ensuring the usability and acceptability of the device. Without these basic skills and aptitudes, care workers are likely to continue to rely on the traditional mechanisms of observation and monitoring, which they feel are more usable and familiar.

The key to developing trust in a specific system is for health care professionals to know the *how* and *why* of what specific technologies are designed to achieve within the homes of older people. Smith [46] has shown that for a system to be implemented successfully, it needs to yield benefits for the users. For example, developments in the area of smart and assistive technologies are increasingly reliant upon a suite of sensors and alarms to monitor the older person. During the workshop, we agreed that there is a need to translate the purpose of these sensors into easily understood, jargon-free language with the specific objective of understanding how a sensor collects, shares, and distributes information and why it is useful to the professional to know that information. For example, the use of door sensors helps to monitor patient activity, which informs the caregiver about how many bathroom visits the person has performed. This is important for understanding how technologies can support the health care professional's everyday working practices. Another key area that can undermine the acceptance of eHealth technologies is the reliability of the technology [47]. Telephone technology operates with "Five 9s" reliability; in other words, it is available 99.999% of the time, with infrequent outages resulting from events such as severe weather [48]. Computers and Internet-based technologies are somewhat less reliable, and Internet protocols are termed "best effort" service delivery functions. Best effort service is, by definition, not perfect, nor should it expected to be. Information packets can be dropped or delayed, resulting in an incomplete delivery of eHealth services [49]. Mobile devices that rely upon the eHealth professional to properly charge the battery and maintain the Internet service provider account may find that access in a given region is not accessible due to poor network coverage or a discharged battery, meaning that the eHealth technology does not function when it should. The competent eHealth service provider must be cognizant that the failure of technology is not an infrequent event and that its successful resolution hinges upon the professional exercising a combination of tact, grace under fire, and patience. Technology failures undermine the confidence of the patient and the professional who uses them. With the expansion of mobile technologies into the everyday lives of citizens, we find that the general population has become somewhat more tolerant of service interruptions due to computer viruses, lack of cellular telephone service, and incorrectly configured networks [50]. Nevertheless, the willingness to use technology decreases if it is perceived as being more trouble than it is worth.

Interpretation and Analysis of eHealth Solutions and Data

It is necessary to ensure that health care professionals have the skills to interpret patient information gathered with eHealth technology. The presentation of information clearly, concisely, and in an interpretable way is a technological requirement, but eHealth care may require a different instrument to interpret information for health care professionals so that it makes sense in the context in which it was generated. The type of data generated through e-technologies may vary from longitudinal monitoring data to more immediate observations of a patient's condition, and the health care professional must competently interpret the new data. Another skill required of the health care professional is translating the data into meaningful information for effective clinical decision making by combining the data with the professional's knowledge of the patient's health condition and the health care domain to derive the most appropriate, least burdensome, and most cost-effective intervention.

Support and Guidance

If eHealth is to produce efficiency savings through economies of scale, then care will need to be increasingly delivered remotely, through mobile consultations or networked care delivery that obviates the need for direct contact. Given that the caregiver will not have face-to-face contact with the older person, good support and clear guidance to the patient will be important to ensure that health problems can be effectively diagnosed and treated at a distance [50].

The professional caregiver will be required to provide on-going support and guidance in the use of the technology to the patient. For example, where remote self-monitoring provides patients with access to their own data, health care professionals must educate users in the functionality of the system and in interpreting the readings so that they feel empowered in the decision-making process. In the expansion of e-telecare, the role of the health care professional as an educator and facilitator for the patient is important if eHealth technology is to become accepted in the home environment. The empowering role of the health care professional has been observed in the development of the expert patient programme in the United Kingdom and within the broader role of case management [51]. Evaluations of AAL technologies have highlighted the importance of community nurses in facilitating the benefits of technology when making care-related decisions. Here, community nurses possess tacit knowledge of the end user and their own expert knowledge in health care delivery and clinical decision making, which, when combined with data generated through assistive technology, can improve the usefulness and usability of eHealth care interventions [52].

Communication Skills

eHealth Care

eHealth care has the potential to change the dynamics of care and to bring about changes to the types and intensity of verbal and nonverbal communication in the care dyad. In the following sections, adjustment and modification of the communication between two caregivers or between the caregiver and the client is described.

Communication Skills Between Health Care Professionals and Clients

Effective communication skills are a current requirement for health care professionals, but eHealth care technologies have changed the traditional modes of interaction between caregivers and clients. Different technologies present alternative ways for health care professionals to project themselves into the care setting, such as by email, telephone, mobile devices, or teleconferencing. In doing so, health care professionals must be aware of how technology nuances their communications to deliver the type of care and person-centred support the end user requires.

The health care professional must ensure clear and transparent communication between the professional and the user. Voice intonation, listening skills, and clarity of two-way communication are important when delivering messages via technology because face-to-face prompts and supports are absent. As an example, remote telecare health care professionals communicate *synchronously* via an audio/video connection. Specific competencies are required for remote telecare, including presenting a professional appearance, sensitivity to maintaining eye contact with the client, adopting an engaging facial expression, and having a well-developed ability to recognize changes in client behaviors or environmental surroundings via the telecommunications link. These aspects may be conveyed differently through teleconferencing. It is worth noting that colors may not be correctly translated by all video devices in use in telecare situations and that high ambient noise levels may cause the professional to miss subtle cues that might be present in the individual's voice. These environmental considerations are classed broadly in the telecommunications as "production values" and subtly affect the recipient of the communication. When completing observations or encouraging patients to undertake a task, the professional cannot support the client by physically guiding them through the process but instead need to rely primarily upon verbal communication and nonverbal gestures, such as nodding or facial expressions to express satisfaction. The communication must be individually tailored because some persons require more frequent contact depending on their cognitive capacities and their specific social and emotional support needs.

Communication Skills Between Health Care Professionals

The health care professional may be required to engage other health care professionals when making care-related decisions and must ensure that patient health information is shared responsibly [53-56]. eHealth technologies should be set up to facilitate sharing information between and across organizations, but professionals need to engage in regular communication to facilitate joint working with other stakeholders who are responsible for delivering care to the older person, such as informal caregivers, health care delivery organizations, and community and voluntary groups. Therefore, an adjusted version of the health level 7 standards and the ISO 13606 could be used to apply to specific eHealth technologies [53-56]. However, health care professionals must be aware of the far-ranging implications of eHealth solutions across the broader integrated spectrum of care.

Privacy and Confidentiality

The sharing of patient information across an integrated eHealth system raises questions about patient privacy and confidentiality [57]. Health care professionals must be aware of the specific ways in which eHealth technologies have the potential to compromise the privacy and confidentiality of the patient and of the rights of the patient to know how these data are shared and viewed.

Even though there are standards for data and information sharing [58,59], eHealth care changes the ways in which health care professionals observe, view, and share information, leading to unique requirements for how patient data are retained and kept secure from others when using mobile devices and online tools. Moreover, if eHealth draws upon multiple professionals from various service providers, there is a need to be aware of who is allowed access to what information. Unfettered access to patient information is neither desirable nor, in some countries, legal, but there is a need to ensure the effective sharing of information across service providers while taking into account (inter)national privacy law and legislation rules.

Table 1. Skills and competencies of health care professionals.

Theme	Competencies	Requirements	Skills
ICT attitudes and skills	Competent in the use of necessary telehealth technologies and software and adopts a positive attitude toward their use in the workplace	Have an abiding interest in the eHealth technology field	Know specific skill sets in eHealth technologies being applied
			Have basic skills for using technology and hardware, such as accessing the Internet or using a personal computer or mobile device
			Have an aptitude for the devices used to collate, store, and display client information
			Know and be able to translate the benefits of eHealth technologies to end users
Interpretation and analysis of eHealth data	Competent in interpreting end user data and applying these data to effective clinical decision making	Knowledge of the client's health condition and the health care domain	Ability to interpret output data generated by eHealth care technologies
			Translate the data effectively within the context of the client with a positive outcome
Support and guidance	Ability to provide on-going support and guidance to end users to increase the acceptability of eHealth technologies	Possess tacit knowledge of the end user and their own expert knowledge in health care delivery and clinical decision making	Educate end users in the operation and functionality of the technology
			Ability to diagnose and treat effectively at a distance
			Effectively combine clinical knowledge with eHealth data in decision making
Communication skills	To communicate effectively with both end users and formal care providers	Have general communication skills	Ability to have clear and transparent communication between the professional and user, such as voice intonation, listening skills, and clarity of two-way communication
		Be aware of the far-ranging implications of eHealth solutions across the broader integrated spectrum of care	Ability to interpret verbal and nonverbal cues, such as nodding or facial expressions, in interaction with end users
			Facilitate information sharing and transferral across formal care providers
Privacy and confidentiality	To maintain the privacy and confidentiality of the end user	Be aware of the privacy and confidentiality rules of data exchange	Need to secure all personal health data for the patient
			Ensure that information transferral and exchange takes place within a secure platform; apply the concept of least privileged access to other practitioners sharing confidential information

Discussion

Principal Findings

In this paper, we described the competencies and requirements needed by health care professionals for the use of eHealth technologies to support older adults to age in place. The results of this paper are in good agreement with those of Kulikowski et al [32], IMIA group [31], Hasman and Albert [30], Goossen et al [35,36], and Ayres [45] with regard to general competencies (ie, computer skills and informatics knowledge). We expanded those competencies to extend to the more specific use of technologies such as remote telecare and AAL, mobile health, and fall detection systems. Moreover, this paper proposes a supportive framework required to establish these competencies, other than the HIT competencies, in the field of professionals working in health care to support older adults to age in place. In addition to the described competencies, this paper highlights a number of barriers and facilitators to applying and developing these competencies within the health care profession beyond ensuring that they are a fundamental aspect of training and education [21-24]. However, there are still a number of strengths, weaknesses, opportunities, and threats in the internal and external work environment that must be mapped for the adoption of eHealth technologies.

Strengths include those skills that health care professionals currently possess when delivering care to clients or patients and that can be capitalized upon in the integration of eHealth care, including the ability to analyse and interpret data from existing monitoring mechanisms, tacit knowledge of the client and the home environment, and clear and transparent verbal and nonverbal communication skills to establish trust and reciprocity with clients. In the Netherlands, based on the CanMEDS systematic the seven following workplace skills for nurses are described: clinical performance, communication, cooperation, organization, social performance, knowledge and science, and professionalism [26]. With this in mind, the theme “ICT attitudes and skills” as described in this paper can be seen as knowledge and science skills, whereas skills described under the theme “interpretation and analysis of eHealth data and support and guidance” might be seen as clinical or social performance. Further, the themes “communication and privacy, and confidentiality” can be seen as communication and professionalism skills, respectively. Moreover, communication skills have always been important in establishing rapport and trust with patients, and these are equally important within the context of eHealth care. These strengths can ensure that the benefits of eHealth technologies can be maximized to bring about improvements to the delivery of care (positive outcomes) and to realize efficiencies for the health care professional (better management of caseloads). All of these skills are integral to ensuring that eHealth technologies become widely adopted within the home environment. Existing skills, such as the ability to review paper-based patient case notes, can be transferred to eHealth solutions by utilizing different instruments to collect and display that information. A tacit understanding of the client enables eHealth data to be interpreted within the context in which they were generated, ensuring that interventions are appropriate. This implies organizational skills. Ensuring appropriate interventions has already been achieved for health information technology such as ICT and electronic public records, however not yet realized for remote telecare and assistive living technology.

In recognizing the strengths that health care professionals possess, there is also a need to recognize the weaknesses that must be addressed. eHealth technologies will bring about changes to the health care profession. The very notion of eHealth supporting or replacing tasks that the health care professional traditionally undertakes may evoke hostility within the profession slowing widespread adoption [25]. Interventions need to be integrated in an appropriate and sensitive manner and adapted to the existing workplace practices and workflow of the health care professional [25]. Moreover, although the benefits of eHealth care technologies have been documented, there is a dearth of large-scale evaluation studies of their long-term impact. This lack of an evidence base undercuts the argument that eHealth care technologies are necessary for the health care professional.

Opportunities

Despite these weaknesses, there are a number of opportunities available to ensure that eHealth care becomes a fundamental part of care delivery to support aging-in-place, and these opportunities require a number of changes at the organizational level. Following Rogers’ model for adopting new technology, we argue that first, although knowledge can be derived through the training and education of health care professionals, there must be systematic mechanisms in place for reviewing training needs and requirements within the context of emerging and changing technologies. Second, for persuasion, organizational commitment is needed to ensure the development of a culture of working with eHealth technologies, encouraging health care professionals within organizations to share their experiences with other professionals when using technologies. This will help in identifying and working through barriers while exploring the unanticipated benefits of using technology within the profession. Third, to support organizations in their decision of using eHealth, organizations must demonstrate that eHealth solutions are an essential part of delivering care in the future and must instill this within the cultural ethos of the organization, which challenges the traditional approaches to delivering care. Fourth, for a successful implementation, the benefits of using eHealth solutions need to be mapped and translated to caregivers. If eHealth technologies can enable health care professionals to accomplish their everyday tasks more efficiently, and if professionals can see the benefits in terms of assisting them in their roles, then professionals are more likely to give their confirmation to use eHealth technology within their everyday working practices.

Threats

A number of existing threats to the successful integration of eHealth care prevent the strengths and opportunities of eHealth care technologies from being realized. These include the conservatism inherent in the care delivery system, existing ways of commissioning care, traditional approaches to care delivery, and a lack of flexibility within health care systems to accommodate innovation and change. Care delivery is complex and involves multiple providers at the local level, the architecture of which differs across jurisdictions but involves a number of health care professionals. eHealth technologies must be sufficiently flexible to facilitate integration across jurisdictions; otherwise, health care professionals will be asked to work within complex circumstances. Ultimately, eHealth technology must be seen as part of the broader cultural system of delivering care to ensure that eHealth care becomes part of an integrated system of delivery.

An additional threat to the integration of eHealth care is the low level of funding for eHealth-based care delivery [60] and the lack of standardization in the field of eHealth. The ISO 13131, Health Informatics-Quality criteria for services and systems for telehealth, focuses on establishing standards for eHealth, allowing payment schemes to be defined [61].

Conclusion

Advances in eHealth technology have the potential to bring about efficiency savings in terms of delivering care to older people and to support self-management by older adults. To facilitate this scenario, there is a need to ensure that the pace of technology development is reflected in the abilities and skills of health care professionals working in home care organizations. In the eHealth world, professionals are required to collate, share, and manage multiple forms of information and to interact with different types of technology in their everyday working practices. This requires that the role of the health care professional be revisited to examine the existing skills gap and to identify professional development opportunities and educational needs. Technologists and engineers have been concerned with developing technological solutions to health and social care problems, but much of the research so far has been limited in terms of real-world products and services [61,62]. A number of barriers to effective implementation exist. In particular, there has been insufficient attention paid to the ways in which technology can be integrated into the working practices and workflow of care professionals [25]. Further work must be undertaken to examine the experiences of health care professionals when using the broad range of technologies on the market and to remove the barriers and establish facilitators to the realization of these technologies within an organizational context. The findings presented in this paper are exploratory and are limited in that they draw upon the opinions of academics as opposed to stakeholders involved in the commissioning of care. Future work should consider the perspectives of a broad range of stakeholders and actors involved in designing and commissioning technologies that change the way health care professionals remotely access patient information to support them to live independently at home.

Acknowledgments

We acknowledge the Department of Rehabilitation and Mental Health Counselling, University of South Florida, for hosting the workshop in March 2012. We thank the other participants in the workshop, Anthony Sterns, Mary Elizabeth Bowen, Prof. Meredeth Rowe, Profs James Fozard, and Prof. Tennyson Wright. We also acknowledge Jessika van Kammen, Jacqueline Dijkstra, and Coralien Merkens for the contribution of their literature search on nursing competencies. We would like to also thank the three health management students, Eline, Rico, and Anouk, for taking notes during the workshops. This paper is a part of the IKOP project. IKOP is cofinanced by the Foundation Innovation Alliance (SIA—Stichting Innovatie Alliantie), Regional Attention and Action for Knowledge circulation (RAAK) (project number: 2009-1-5-INT). We would like to thank SIA RAAK for the financial support.

Authors' Contributions

Ansam Barakat contributed to study conception, intellectual content, figures/tables, and drafting of the manuscript. Ryan Woolrych contributed to study conception, intellectual content, tables, and critical revision of the manuscript. Both Andrew Sixsmith and William Kearns contributed to study conception, intellectual content, and critical revision of the manuscript. Helianthe Kort contributed to design, study conception, intellectual content, and critical revision of the manuscript.

Conflicts of Interest

None declared.

References

1. United Nations, World Population Prospects: The 2008 Revision. 2009 URL: http://www.un.org/esa/population/publications/wpp2008/wpp2008_highlights.pdf [WebCite Cache ID 6FcpvjWkn]
2. Christensen K, Doblhammer G, Rau R, Vaupel JW. Ageing populations: the challenges ahead. Lancet 2009 Oct 3;374(9696):1196-1208 [FREE Full text] [doi: 10.1016/S0140-6736(09)61460-4] [Medline: 19801098]
3. Hope P, Bamford S, Beales S, Brett K, Kneale D, Macdonnell M, et al. Report of the Ageing Societies Working Group. Creating sustainable health and Care systems in ageing societies URL: https://workspace.imperial.ac.uk/global-health-innovation/Public/GHPS_Ageing_Societies_Report.pdf [WebCite Cache ID 6FcqW5MQk]
4. Country Report: Dutch. Ruimte voor arbeidsbesparende innovatie in de zorg; Den Haag: Raad voor de Volksgezondheid en Zorg (RVZ). RVZ Raad URL: http://rvz.net/uploads/docs/Advies_-_Ruimte_voor_arbeidsbesparende_innovaties_in_de_zorg2.pdf [WebCite Cache ID 6Fcqqcbcl]
5. Stefanov DH, Bien Z, Bang WC. The smart house for older persons and persons with physical disabilities: structure, technology arrangements, and perspectives. IEEE Trans Neural Syst Rehabil Eng 2004 Jun;12(2):228-250. [doi: 10.1109/TNSRE.2004.828423] [Medline: 15218937]
6. Oh H, Rizo C, Enkin M, Jadad A. What is eHealth (3): a systematic review of published definitions. J Med Internet Res 2005;7(1):e1 [FREE Full text] [doi: 10.2196/jmir.7.1.e1] [Medline: 15829471]
7. Augusto JC, Huch M, Kameas A, Maitland J, McCullagh P, Roberts J, et al. Handbook of Ambient Assisted Living---Technology for Healthcare, Rehabilitation and Well-being (Ambient Intelligence and Smart Environments), Vol. 11. Amsterdam: IOS Press; 2012.
8. Sixsmith A, Gutman G. Technologies for Active Aging. New York: Springer; 2013.

9. Haigh J. Information technology in health professional education: why IT matters. Nurse Educ Today 2004 Oct;24(7):547-552. [doi: 10.1016/j.nedt.2004.07.008] [Medline: 15465170]
10. Glascock A, Kutzik D. Essential Lessons for the Success of Telehomecare, Why It's Not Plug and Play(Assistive Technology Research Series). Amsterdam, Netherlands: IOS Press; 2012.
11. Ludwig W, Wolf KH, Duwenkamp C, Gusew N, Hellrung N, Marschollek M, et al. Health-enabling technologies for the elderly---an overview of services based on a literature review. Comput Methods Programs Biomed 2012 May;106(2):70-78. [doi: 10.1016/j.cmpb.2011.11.001] [Medline: 22115611]
12. Sixsmith A, Meuller S, Lull F, Klein M, Bierhoff I, Delaney S, et al. A user-driven approach to developing Ambient Assisted Living systems for older people: The SOPRANO Project. In: Soar J, Swindell R, Tsang P, editors. Intelligent Technologies for Bridging the Grey Digital Divide. Hershey, PA: Information Science Reference; 2011.
13. Tachakra S, Wang XH, Istepanian RS, Song YH. Mobile e-health: the unwired evolution of telemedicine. Telemed J E Health 2003;9(3):247-257. [doi: 10.1089/153056203322502632] [Medline: 14611692]
14. Barlow J, Singh D, Bayer S, Curry R. A systematic review of the benefits of home telecare for frail elderly people and those with long-term conditions. J Telemed Telecare 2007;13(4):172-179. [doi: 10.1258/135763307780908058] [Medline: 17565772]
15. Botsis T, Hartvigsen G. Current status and future perspectives in telecare for elderly people suffering from chronic diseases. J Telemed Telecare 2008;14(4):195-203. [doi: 10.1258/jtt.2008.070905] [Medline: 18534954]
16. Ball MJ, Lillis J. E-health: transforming the physician/patient relationship. Int J Med Inform 2001 Apr;61(1):1-10. [Medline: 11248599]
17. Verhoeven F, van Gemert-Pijnen L, Dijkstra K, Nijland N, Seydel E, Steehouder M. The contribution of teleconsultation and videoconferencing to diabetes care: a systematic literature review. J Med Internet Res 2007;9(5):e37 [FREE Full text] [doi: 10.2196/jmir.9.5.e37] [Medline: 18093904]
18. Del Prato S, Nicolucci A, Lovagnini-Scher AC, Turco S, Leotta S, Vespasiani G, ELEONOR Study Group. Telecare Provides comparable efficacy to conventional self-monitored blood glucose in patients with type 2 diabetes titrating one injection of insulin glulisine---the ELEONOR study. Diabetes Technol Ther 2012 Feb;14(2):175-182. [doi: 10.1089/dia.2011.0163] [Medline: 22013886]
19. Academy of Medical Royal Colleges. 2011. EHealth competency framework, defining the role of the expert clinician URL: http://www.physio-pedia.com/images/f/f0/EHealth_Competancy_Framework.pdf [WebCite Cache ID 6FcrML3ih]
20. Tachakra S, El Habashy A, Dawood M. Changes in the workplace with telemedicine. J Telemed Telecare 2001;7(5):277-280. [Medline: 11571082]
21. Rogers EM. Diffusion of Innovations. 5th edition. New York: Free Press; 2003.
22. Frank JR. The CanMEDS 2005 Physician Competency Framework: Better Standards, Better Physicians, Better Care. Ottawa: The Royal College of Physicians and Surgeons of Canada; 2005.
23. Moodley S, Kasangaki A, Macnab AJ. Education in global health: experience in health-promoting schools provides trainees with defined core competencies. ISRN Educ 2012;2012:1-7. [doi: 10.5402/2012/718303]
24. Lluch M. Healthcare professionals' organisational barriers to health information technologies---a literature review. Int J Med Inform 2011 Dec;80(12):849-862. [doi: 10.1016/j.ijmedinf.2011.09.005] [Medline: 22000677]
25. Kort HSM, Van Hoof J. Telehomecare in The Netherlands: barriers to implementation. Intl J Ambient Comput Intelligence 2012;4(2):64-73. [doi: 10.4018/jaci.2012040105]
26. van Merwijk C. Country report: Dutch. Beroepsprofiel verpleegkundige Utrecht: Verpleegkundigen & Verzorgenden. Deel 2. 2012. URL: http://www.venvn.nl/LinkClick.aspx?fileticket=I-rONg4bS1A%3D&tabid=5302 [WebCite Cache ID 6JKZrv4fE]
27. Flim C. Nictiz, Betere zorg door betere informatie. 2009. Zorg op afstand. Het perspectief van de zorgprofessional in de langdurige zorg. 2009. URL: http://www.venvn.nl/LinkClick.aspx?fileticket=KokF1G4AfOY%3D&tabid=3299 [WebCite Cache ID 6Fcrnsv7B]
28. Clark J, Baker B, Baker D. Getting eHealth into basic nursing education: report of the RCN information in nursing project. Stud Health Technol Inform 2009;146:534-539. [Medline: 19592900]
29. Utley-Smith Q. 5 competencies needed by new baccalaureate graduates. Nurs Educ Perspect 2004;25(4):166-170. [Medline: 15387509]
30. Hasman A, Albert A. Education and training in health informatics: guidelines for European curricula. Int J Med Inform 1997 Jun;45(1-2):91-110. [Medline: 9291024]
31. Mantas J, Ammenwerth E, Demiris G, Hasman A, Haux R, Hersh W, IMIA Recommendations on Education Task Force. Recommendations of the International Medical Informatics Association (IMIA) on education in biomedical and health informatics. First revision. Methods Inf Med 2010 Jan 7;49(2):105-120. [doi: 10.3414/ME5119] [Medline: 20054502]
32. Kulikowski CA, Shortliffe EH, Currie LM, Elkin PL, Hunter LE, Johnson TR, et al. AMIA board white paper: definition of biomedical informatics and specification of core competencies for graduate education in the discipline. J Am Med Inform Assoc 2012;19(6):931-938. [doi: 10.1136/amiajnl-2012-001053] [Medline: 22683918]

33. Norton M, Skiba DJ, Bowman J. Teaching nurses to provide patient centered evidence-based care through the use of informatics tools that promote safety, quality and effective clinical decisions. Stud Health Technol Inform 2006;122:230-234. [Medline: 17102254]
34. Peterson HE, Gerdin-Jelger U. Preparing Nurses for Using Information Systems: Recommended Informatics Competencies. IMIA Working Group 8 Nursing Informatics, SHSTF. Recommended Informatics Competencies. New York: National League for Nursing; 1988.
35. Goossen WT, Biesheuvel W. Past, present and future of health and nursing informatics education at Noordelijke Hogeschool Leeuwarden. Stud Health Technol Inform 2000;57:57-65. [Medline: 10947671]
36. Goossen WT, Goossen-Baremans AT, Hofte L, de Krey B. ROC van Twente: nursing education in care and technology. Stud Health Technol Inform 2007;129(Pt 2):1396-1400. [Medline: 17911943]
37. Edirippulige S, Smith A, Beattie H, Davies E, Wootton R. Pre-registration nurses: an investigation of knowledge, experience and comprehension of eHealth. Austr J Adv Nursing 2007;25:78.
38. Dattakumar A, Gray K, Henderson KB, Maeder A, Chenery H. We are not educating the future clinical health professional workforce adequately for e-health competence: findings of an Australian study. Stud Health Technol Inform 2012;178:33-38. [Medline: 22797016]
39. Ellaway RH, Graves L, Greene PS. Medical education in an electronic health record-mediated world. Med Teach 2013 Apr;35(4):282-286. [doi: 10.3109/0142159X.2013.773396] [Medline: 23464893]
40. Bryson M, Tidy N, Smith M, Levy S. An online survey of nurses' perceptions, knowledge and expectations of the National Health Service modernization programme. J Telemed Telecare 2005;11 Suppl 1:64-66. [doi: 10.1258/1357633054461732] [Medline: 16035999]
41. Fouche C, Light G. An invitation to dialogue: 'The World Cafe' in social work research. Qual Social Work 2010 Nov 22;10(1):28-48. [doi: 10.1177/1473325010376016]
42. Feldman A. The role of conversation in collaborative action research. Educ Action Res 1999 Mar;7(1):125-147. [doi: 10.1080/09650799900200076]
43. Venkatesh V, Morris MG, Davis FD, Davis GB. User acceptance of information technology: toward a unified view. MIS Quarterly 2003;27(3):425. [doi: 10.2307/30036540]
44. Davis FD, Bagozzi RP, Warshaw PR. User acceptance of computer technology: a comparison of two theoretical models. Manage Sci 1989;35(8):982. [doi: 10.1287/mnsc.35.8.982]
45. Ayres EJ, Greer-Carney JL, Fatzinger McShane PE, Miller A, Turner P. Nutrition informatics competencies across all levels of practice: a national Delphi study. J Acad Nutr Diet 2012 Dec;112(12):2042-2053. [doi: 10.1016/j.jand.2012.09.025] [Medline: 23174690]
46. Smith AP. Design a clinical information system. BMJ 1992 Aug 15;305(6850):415-417 [FREE Full text] [Medline: 1392927]
47. Mannan R, Murphy J, Jones M. Is primary care ready to embrace e-health? A qualitative study of staff in a London primary care trust. Inform Prim Care 2006;14(2):121-131. [Medline: 17059701]
48. Jin L, Robey D. Bridging social and technical interfaces in organizations: An interpretive analysis of time-space distanciation. Inform Org 2008 Jan 12;18(3):177-204. [doi: 10.1016/j.infoandorg.2007.12.001]
49. International Telecommunication Union. Series E: overall network operation, telephone service, service operation and human factors. Article number: E 33932. URL: http://www.itu.int/rec/T-REC-E.800-200809-I/en [WebCite Cache ID 6Fd4RxvZM]
50. Kaminsky E, Rosenqvist U, Holmström I. Telenurses' understanding of work: detective or educator? J Adv Nurs 2009 Feb;65(2):382-390. [doi: 10.1111/j.1365-2648.2008.04877.x] [Medline: 19040692]
51. Murphy E. Case management and community matrons for long term conditions. BMJ 2004;329(7477):1251-1252. [doi: 10.1136/bmj.329.7477.1251]
52. Sixsmith A, Woolrych R, Bierhoff I, Mueller S, Byrne P. Ambient assisted living: From concept to implementation. In: Glascock A, Kutzik D, editors. Essential Lessons for the Success of Telehomecare, Why It's Not Plug and Play. Assistive Technology Research Series. Amsterdam, Netherlands: IOS Press; 2012:259-286.
53. Khan WA, Hussain M, Afzal M, Amin MB, Lee S. Healthcare standards based sensory data exchange for Home Healthcare Monitoring System. Conf Proc IEEE Eng Med Biol Soc 2012;2012:1274-1277. [doi: 10.1109/EMBC.2012.6346170] [Medline: 23366131]
54. Corepoint Health. 2010. White paper: The HL7 Evolution Comparing HL7 Version 2 to Version 3, Including a History of Version 2 URL: http://www.corepointhealth.com/whitepapers/evolution-hl7 [WebCite Cache ID 6FcsG9wqO]
55. The Health Level Seven International website. URL: http://www.hl7.org/about/index.cfm [WebCite Cache ID 6FcscLBTW]
56. The EN 13606 Association site. URL: http://www.en13606.org/ [WebCite Cache ID 6FcseK6F6]
57. Katsikas S, Lopez J, Pernul G. The challenge for security and privacy services in distributed health settings. Stud Health Technol Inform 2008;134:113-125. [Medline: 18376039]
58. Health Insurance Portability and Accountability Act (HIPAA). URL: http://www.cms.gov/Regulations-and-Guidance/HIPAA-Administrative-Simplification/HIPAAGenInfo/Downloads/HIPAALaw.pdf [WebCite Cache ID 6FcsnGyNV]
59. The Freedom of Information and Protection of Privacy Act. URL: http://www.e-laws.gov.on.ca/html/statutes/english/elaws_statutes_90f31_e.htm [WebCite Cache ID 6Fcsy9aD1]

60. Anderson JG. Social, ethical and legal barriers to e-health. Int J Med Inform 2007;76(5-6):480-483. [doi: 10.1016/j.ijmedinf.2006.09.016] [Medline: 17064955]
61. IOS/DTS 13131: Health Informatics---Quality criteria for services and systems for telehealth. URL: http://www.iso.org/iso/home/store/catalogue_tc/catalogue_detail.htm?csnumber=53052 [WebCite Cache ID 6Fct0hTHT]
62. Meyer I, Muller S, Kubitschke L. AAL markets---knowing them, reaching them: evidence from European research. In: Augusto J, et al. , editors. Handbook of Ambient Assisted Living. Amsterdam: IOS Press; 2012:346-368.

Abbreviations

AAL: ambient assisted living
CAL: Creative Action Limited Liability Company
HIT: health information technology
ICT: Information Communication Technology
iKOP: Expanding eHealth Knowledge
JAHVA: James A Haley Veterans Administration Hospital
USF: University of South Florida

Edited by G Eysenbach; submitted 14.05.13; peer-reviewed by N Choi, M Kim; comments to author 11.06.13; revised version received 10.07.13; accepted 18.07.13; published 05.09.13.

Please cite as:
Barakat A, Woolrych RD, Sixsmith A, Kearns WD, Kort HSM
eHealth Technology Competencies for Health Professionals Working in Home Care to Support Older Adults to Age in Place: Outcomes of a Two-Day Collaborative Workshop
Med 2.0 2013;2(2):e10
URL: http://www.medicine20.com/2013/2/e10/
doi:10.2196/med20.2711
PMID:25075233

Original Paper

Clinicians' Assessment of Mobile Monitoring: A Comparative Study in Japan and Spain

Shintaro Okazaki[1], PhD; José Alberto Castañeda[2], PhD; Silvia Sanz[3], PhD

[1]Department of Marketing, College of Economics & Business Administration, Universidad Autónoma de Madrid, Madrid, Spain
[2]Department of Marketing, College of Economics & Business Administration, University of Granada, Granada, Spain
[3]Department of Marketing, College of Economics & Business Administration, University of Valencia, Valencia, Spain

Corresponding Author:
Shintaro Okazaki, PhD
Department of Marketing
College of Economics & Business Administration
Universidad Autónoma de Madrid
Cantoblanco
Madrid,
Spain
Phone: 34 914972872
Fax: 34 914978725
Email: shintaro.okazaki@uam.es

Abstract

Background: The gradual but steady shift toward telemedicine during the past decades is a clear response to important health problems that most industrialized countries have been facing. The growing elderly population and changing dietary habits have led to an increase in people with chronic diseases and overall health care expenditures. As more consumers use their mobile device as their preferred information and communication technology (ICT) device, mobile health monitoring has been receiving increasing attention in recent years.

Objective: This study examines clinicians' perception of factors determining mobile health monitoring acceptance in Japan and Spain. The study proposes a causal model consisting of innovation seeking, new ICT attributes (perceived value, time-place flexibility, and compatibility), and usage intention. In addition, cross-country differences are posited for the hypothesized relationships among the proposed constructs.

Methods: A questionnaire survey was performed to test our research model and hypotheses. The sample consisted of clinicians from various medical specialties. In total, 471 and 497 usable responses were obtained in Japan and Spain, respectively.

Results: In both countries, the collected data fit the model well with all the hypothesized paths among the constructs being supported. Furthermore, the moderating effects of psychic distance were observed in most of the paths.

Conclusions: Our study demonstrates the importance of new ICT attributes, namely perceived value, time-place flexibility, and compatibility, in the clinicians' adoption of mobile health monitoring. In particular, our results clearly indicated that perceived medical value and ubiquitous nature of the tool are the two main benefits clinicians are likely to perceive (and appreciate) in both countries. This tendency will be stronger for those with a greater propensity to seek innovation in ICT. In terms of cross-country comparison, the strength of the path from innovation seeking to perceived value was greater in Japan than in Spain. Since the number of clinicians per 10,000 residents is substantially fewer in Japan compared with Spain, clinicians with a greater propensity to seek innovation in ICT may have perceived greater value in using mobile health monitoring to improve remote patient care.

(Med 2.0 2013;2(2):e11) doi:10.2196/med20.2874

KEYWORDS

comparative study; health monitoring; personal innovativeness; smartphone; psychic distance

Introduction

As more consumers employ information and communication technology (ICT) to manage their health and fitness, mobile health monitoring has received much attention from the health care industry [1]. Compared with other ICT tools, mobile monitoring enables clinicians more personalized and flexible control of patients' health at a distance. One of the advantages of this monitoring system for patients is the unobtrusive, prolonged ambulatory monitoring, which allows for improved quality of life and faster response in the case of emergencies [2]. However, little attention has been paid to clinicians' perception on this technological breakthrough. In addition, it is virtually unknown how mobile health monitoring has been accepted across borders. To fulfill this research gap, this study examines clinicians' motivations to use mobile health monitoring in two industrialized countries, Japan and Spain.

We propose a causal model consisting of clinicians' innovation seeking, new ICT attributes (perceived value, time-place flexibility, and compatibility), and usage intention.

The model is based on Rogers' [3] diffusion of innovation theory, mainly focusing on relative advantage and compatibility. We envisage the relative advantage of mobile health monitoring as two main factors, perceived value and time-place flexibility, while retaining compatibility as a characteristic of a new ICT that must fit not only clinicians' work routines, but also their medical beliefs that remote control of chronic disease is beneficial [4]. These new ICT attributes turn out to be the main causes of usage intention. In addition, we posit full mediation hypotheses of new ICT attributes, since Yi et al [5] found that the impact of innovation seeking on intention to use a personal digital assistant was hardly significant in the presence of the new ICT attributes indicating full mediation. Several past studies reported similar results on the importance of individual propensity to seek innovation in directly determining user perceptions of new ICT attributes [6]. We posit that psychic distance between clinicians and patients would moderate the relationships among these constructs.

Japan and Spain were chosen for two reasons. First, both countries have developed a comprehensive public health care system that fully covers basic medical costs, with very similar medical expenditure as a percentage of gross domestic product and per capita. Second, the number of clinicians per 10,000 residents or per hospital bed is notably greater in Span than in Japan. By increasing health care costs, a lack of clinicians would drive a serious need for ICT-based health care monitoring.

Methods

Overview

Professional marketing research firms recruited participants in Japan and Spain. In both countries, quota sampling was applied. In an attempt to ensure a sample representative of the nation, the respondents were collected from all geographical regions, assigning a quota of clinicians per region. In Japan, 471 respondents were collected from 47 prefectures, and in Spain, 497 respondents were drawn from 17 autonomous communities. The sample consists of clinicians in diverse specialties, since the number of those specialized in diabetics is rather limited. The age ranged from 25 to 65 in Japan, and 25 to 80 in Spain.

Statistical Analysis

Measurement Assessment

Before proceeding with the estimation of the structural model, we performed a full-sample confirmatory factor analysis (CFA) with six latent constructs using AMOS 19.0 [7]. Time-place flexibility was conceptualized as a second-order construct, thus time flexibility and place flexibility were added as separate first-order constructs. To take into account the recommendations by Bagozzi and Yi [8] and Bollen [9], multiple indices were used to assess the goodness of fit of the overall model: χ^2_{242}=1883.75, comparative fit index (CFI)=.93, Tucker-Lewis index (TLI)=.92, and root mean square error of approximation (RMSEA)=.084.

In a model with "good" fit, the chi-square statistic should not be significant at the 5% level. However, the literature suggests that this index becomes too sensitive in larger sample sizes [10]. The values of the CFI and TLI indices should be close to 1, although values between .90 and .95 are considered adequate [8,9]. The RMSEA index should be close to 0 [7]. Thus, all the indices, except the chi-square statistic, were in an acceptable range. In addition, all items exhibited highly standardized loadings on their intended factors. Thus, convergent validity was established.

Reliability and Validity

Based on the CFA results, we computed composite reliability (CR) and average variance extracted (AVE) to assess the internal consistency of the multiple measures [11]. As a benchmark, researchers generally recommend .70 and .50 as an appropriate level for the CR and AVE, respectively, in an exploratory study. All the multiple reflective constructs exceeded these criteria.

Discriminant validity is the extent to which a construct truly differs from neighboring constructs [10]. This was assessed from the latent constructs correlations matrix, where the square roots of the AVE along the diagonal are reported. The correlations between the constructs are reported in the lower left off-diagonal elements in the matrix. Fornell and Lacker [11] suggested that the average variance shared between a construct and its measures should be greater than the variance shared between the construct and other constructs in the model. Thus, discriminant validity is satisfied when the diagonal elements (square root of AVE) are greater than the off-diagonal elements in the same row and column.

Invariance Structure

Given our comparative purpose for the path strengths between Japan and Spain, we examined the measurement invariance across the samples, following the procedure suggested by Steenkamp and Baumgartner [12]. We tested the invariant factor loadings across the models, restricting factor loadings equally across countries. The chi-square difference between the full metric invariance model and the baseline model was significant (*P*=.008), although the other fit indices were acceptable. Thus, full metric variance was not achieved.

Yet, prior research suggests that full metric invariance is rather unrealistic and only partial invariance is required for cross-country model comparison [13]. On this basis, we next tested a series of partial measurement invariance models by sequentially relaxing the factor loadings of the items. The resulting model did not differ significantly from the baseline model (P=.07). Therefore, we confirmed evidence of partial metric invariance that enabled us to assess relations in the structural model.

Results

Main Paths

Our structural model was examined for the full sample with the maximum likelihood method using AMOS 19.0 [7]. Most of the indices indicated an adequate model fit, except for the chi-square statistic. As explained before, the difficulty of passing this stringent test has been noted elsewhere [9]. Thus, it was judged that the multiple indices sufficiently justified the adequacy of the model's fit to the sample data. The resulting fit indices were CFI=.93, TLI=.92, and RMSEA=.086. All the hypothesized relationships between the proposed constructs were statistically significant.

Moderation Analysis

To test moderating effects of the country, multigroup analyses were performed using AMOS 19.0 with the maximum likelihood method. The multigroup baseline model was estimated across the two countries simultaneously, without placing any equality constraints on the hypothesized paths. Their fit indices served as initial points of comparison in addressing whether the proposed structural relationships would hold in the same way across the two groups. The chi-square value of the unconstrained or baseline model was 2572.36 (P<.001), with 511 degrees of freedom. In the equal path model, the path between innovation seeking and perceived value was constrained to be equal in both Spain and Japan. The difference in chi-square values between the constrained and equal path models (χ^2_1=3.12) suggests that the direct path between innovation seeking and perceived value was marginally greater for the Japanese sample, compared with their Spanish counterpart. This test was repeated for the path between innovation seeking and compatibility, and the one between innovation seeking and time-place flexibility. Two out of three paths were statistically greater in Japan than in Spain. As for the path between perceived value and usage intention, the difference was only marginally significant; this path was greater for the Japanese sample.

Discussion

Principal Results

Our structural equation modeling results indicate that, regardless of the country, innovation seeking is a strong determinant of new ICT attributes of mobile health monitoring in terms of perceived value, time-place flexibility, and compatibility. In the comparison of the relationships among the constructs across the countries, we found that Japanese clinicians, compared with their Spanish counterparts, perceived the paths between innovation seeking and perceived value and between innovation seeking and time-place flexibility. We believe that this may be, at least partially, due to the difference in psychic distance between clinicians and patients, which is operationalized as the number of clinicians per 10,000 residents.

Limitations

We should recognize two important limitations. First, there may be factors other than psychic distance that may have affected the cross-country differences between Japan and Spain. For example, the technology readiness may vary across countries and may have affected clinicians' perceptions on a new monitoring tool. By the same token, this study did not take into account negative factors, such as perceived risk or information security. Second, most of the respondents in both countries have not used the system before, thus their responses were based on their limited knowledge and experience.

Conclusions

Our study serves as an initial stepping-stone in research exploring cross-country differences in clinicians' perceptions on mobile health monitoring. Our results clearly demonstrated the importance of new ICT attributes, namely perceived value, time-place flexibility, and compatibility, in adopting mobile health monitoring in both Japan and Spain. Our study crystallized the importance of relative advantage in the framework of the Rogers' diffusion of innovation theory [3]. Clinical value and time-place flexibility are the main benefits clinicians may perceive and appreciate from this new tool.

With regard to the cross-country comparison, the path from innovation seeking to perceived value was viewed more strongly in Japan than in Spain. This could potentially be explained by the smaller ratio of clinicians per 10,000 residents in Japan compared with Spain. Clinicians with a greater propensity to innovate ICT may have perceived greater value to use mobile health monitoring to improve remote patient care. For the same reason, the path from innovation seeking to time-place flexibility was more accentuated in Japan than in Spain, probably because Japanese clinicians are more willing to take advantage of the most important utility in mobile health monitoring—the ubiquitous nature of the device. On the other hand, there was no difference in the paths between compatibility and innovation seeking and between compatibility and usage intention.

Future Research Suggestions

Future extension should not only overcome the limitations recognized previously, but also address additional issues directly related to mobile health monitoring adoption. For example, the concept of psychic distance between clinicians and patients has seldom been documented in prior research. Perhaps the most crucial issue here is the indicator that would represent psychic distance. The number of clinicians per bed could be a practical measure but the concept needs to be developed further. In addition to innovation seeking, there are other personal characteristics that would affect new technology adoption. For example, risk aversion, ease of use, usability, and design aesthetics, might be important factors to be considered. Furthermore, future research should examine more countries so that the obtained results can be more generalizable.

Acknowledgments

This research was funded by a grant from the Spanish Ministry of Science and Innovation (National Plan for Research, Development and Innovation ECO2011-30105).

Conflicts of Interest

None declared.

References

1. Okazaki S, Castañeda JA, Sanz S, Henseler J. Factors affecting mobile diabetes monitoring adoption among physicians: questionnaire study and path model. J Med Internet Res 2012 Dec;14(6):e183 [FREE Full text] [doi: 10.2196/jmir.2159] [Medline: 23257115]
2. Istepanian R, Jovanov E, Zhang YT. Introduction to the special section on M-Health: beyond seamless mobility and global wireless health-care connectivity. IEEE Trans Inf Technol Biomed 2004 Dec;8(4):405-414. [Medline: 15615031]
3. Rogers EM. Diffusion of innovations. New York: Free Press; 1983.
4. Sanson-Fisher RW. Diffusion of innovation theory for clinical change. Med J Aust 2004 Mar 15;180(6 Suppl):S55-S56. [Medline: 15012582]
5. Yi MY, Fiedler KD, Park JS. Understanding the role of individual innovativeness in the acceptance of IT-based innovations: comparative analyses of models and measures. Decision Sciences 2006 Aug;37(3):393-426. [doi: 10.1111/j.1540-5414.2006.00132.x]
6. Lu J, Yao JE, Yu CS. Personal innovativeness, social influences and adoption of wireless Internet services via mobile technology. The Journal of Strategic Information Systems 2005 Sep;14(3):245-268 [FREE Full text] [doi: 10.1016/j.jsis.2005.07.003]
7. Byrne BM. Structural Equation Modeling With AMOS: Basic Concepts, Applications, and Programming (Multivariate Applications Series). Mahwah, New York: Taylor and Francis; 2001.
8. Bagozzi RP, Yi Y. On the evaluation of structural equation models. JAMS 1988 Mar;16(1):74-94 [FREE Full text] [doi: 10.1007/BF02723327]
9. Bollen KA. Structural equations with latent variables. New York: Wiley; 1989.
10. Hair JF, Black WC, Babin BJ, Anderson RE, Tatham RL. Multivariate data analysis. Upper Saddle River, N.J: Prentice Hall PTR; 2006.
11. Fornell C, Larcker DF. Evaluating structural equation models with unobservable variables and measurement error. J Marketing Res 1981;18(1):39-50 [FREE Full text]
12. Steenkamp JBEM, Baumgartner H. Assessing measurement invariance in cross-national consumer research. J Consum Res 1998;25(1):78-90 [FREE Full text]
13. Netemeyer RG, Brashear-Alejandro T, Boles JS. A Cross-National Model of Job-Related Outcomes of Work Role and Family Role Variables: A Retail Sales Context. j acad market sci 2004 Jan 01;32(1):49-60 [FREE Full text] [doi: 10.1177/0092070303259128]

Abbreviations

AVE: average variance extracted
CFA: confirmatory factor analysis
CFI: comparative fit index
CR: composite reliability
ICT: information and communication technology
RMSEA: root mean square error of approximation
TLI: Tucker-Lewis index

Edited by G Eysenbach; submitted 12.08.13; peer-reviewed by M Rozano, S Kitsiou; comments to author 11.09.13; revised version received 13.09.13; accepted 13.09.13; published 18.09.13.

Please cite as:
Okazaki S, Castañeda JA, Sanz S
Clinicians' Assessment of Mobile Monitoring: A Comparative Study in Japan and Spain
Med 2.0 2013;2(2):e11
URL: http://www.medicine20.com/2013/2/e11/
doi:10.2196/med20.2874
PMID:25075234

Original Paper

Participatory Design With Seniors: Design of Future Services and Iterative Refinements of Interactive eHealth Services for Old Citizens

Isabella Scandurra[1*], MSc(Comp Sci), Dr med univ; Marie Sjölinder[2*], BSc, PhD(Psych)

[1]Division of Visual Information and Interaction, Department of Information Technology, Uppsala University, Uppsala, Sweden

[2]SICS Swedish ICT, SICS, Stockholm, Sweden

[*]all authors contributed equally

Corresponding Author:
Isabella Scandurra, MSc(Comp Sci), Dr med univ
Division of Visual Information and Interaction
Department of Information Technology
Uppsala University
Box 337
Uppsala, 75105
Sweden
Phone: 46 703681299
Fax: 46 703851559
Email: isabella.scandurra@it.uu.se

Abstract

Background: There is an increasing social isolation among the elderly today. This will be an even larger issue in the future with growing numbers of elderly and less resources, for example, in terms of economy and staff. Loneliness and social isolation can, however, be addressed in several ways using different interactive eHealth services.

Objective: This case study investigated novel eHealth services for the elderly, and their usage of a social interactive device designed especially for them.

Methods: In this work, we used an innovative mobile communication device connected to the television (TV), which worked as a remotely controlled large interactive screen. The device was tested by 8 volunteers who visited a senior center. They were between 65 and 80 years of age and lived in their own homes. Throughout the 1.5 year-long project, 7 design workshops were held with the seniors and the staff at the center. During these workshops, demands and preferences regarding existing and new services were gathered. At the end of the project the participants' experience of the device and of the services was elaborated in 3 workshops to get ideas for improved or new meaningful services. During the data analyses and development process, what seniors thought would be useful in relation to what was feasible was prioritized by the development company.

Results: Regarding daily usage, the seniors reported that they mainly used the service for receiving information from the senior center and for communication with other participants in the group or with younger relatives. They also read information about events at the senior center and they liked to perform a weekly sent out workout exercise. Further, they played games such as Memory and Sudoku using the device. The service development focused on three categories of services: cognitive activities, social activities, and physical activities. A cognitive activity service that would be meaningful to develop was a game for practicing working memory. In the social activities category, the seniors wanted different quizzes and multi-player games. For physical activities, the seniors desired more workout exercises and suggestions for guided walking routes. A new category, "information and news", was suggested since they lacked services like senior-customized global and local news.

Conclusions: This study showed the importance of input from a group of seniors when designing new services for elderly citizens. Besides input to interactive eHealth service development for seniors, this study showed the importance of a social context around such work. The seniors were very engaged throughout the project and workshops were frequently visited and the seniors became friends. The high amount of input from the seniors could be explained in terms of social inclusion; they belonged to a group and each member was considered important for the work. The friendly workshop atmosphere facilitated new ideas and redesign of the services.

(Med 2.0 2013;2(2):e12) doi:10.2196/med20.2729

KEYWORDS

Internet; community-based participatory research; systems analysis; interdisciplinary communication; community networks; professional-patient relations; seniors; elderly users; television; social inclusion

Introduction

Background

There is increasing social isolation among the elderly today. Loneliness and social isolation can, however, be addressed in several ways using different interactive eHealth services. One of the most important issues in reducing social isolation is the existence of social networks [1]. The possibilities to communicate with friends and relatives through computers and the Internet can increase the social network, and social isolation can be reduced [1,2]. Several studies have shown the importance for older adults to be able to communicate with family members and friends enabled through new communication technology [2,3]. Although it may seem different, the Internet usage pattern does not differ between older and younger daily users; Internet is mostly used for emailing, searching news, and gathering practical information [3]. This technology also provides opportunities for older adults to gain new knowledge from other generations. The possibility to communicate with children and grandchildren through the Internet and email, for example, is important for older adults and has already become one of the most important reasons for older adults to purchase a computer at the end of the last century [4]. Older adults using the Internet have also reported that they experience a higher level of social support [5]. Among many elderly, Internet has also become an important source for getting medical information. This opportunity increases the feeling of controlling the own health. It empowers people in terms of being more educated in the area, and having the possibility to share experiences with others [6].

The quick development in the area of mobile communication in the last decade has provided many new possibilities for communication and sharing our everyday life with each other. Many new services and applications are also targeted towards the elderly and have interfaces that are considered easy to use. In Sweden, however, where Internet access is common and accessible almost everywhere, daily usage decreased from generation to generation as a function age (Table 1).

Table 1 clearly reveals that Internet use decreases with increasing age. These data show as well a longitudinal measure of three user groups. Following a specific group of seniors horizontally, it is noticeable that daily use of Internet increased from 2009 to 2011. In 2011, the daily Internet use was 51% for the age group 65-74 years old and 22% for those 75 years old and up, which was the oldest measured group [7].

The low rate of usage at high ages could become a society problem, where more and more public services are accessed via different communication technology tools. This is also valid for eHealth services, where for example, time booking and contact information to care providers, as well as access to own health and social care data is found on the Internet and difficult to access elsewhere. It is therefore imperative to develop user- and situation based eHealth services that are thoroughly tested with and accepted by the intended users.

Table 1. Daily Internet use in Sweden during three years and displayed in three groups of users [7].

Age group	2009	2010	2011
55-64 years old, %	53	57	64
65-74 years old, %	37	43	51
75 years old and up, %	12	16	22

Objective

This case study aimed to investigate novel eHealth services for elderly citizens together with seniors, using an interactive device designed for seniors.

The Project: “Quadruple Helix”

This study was set for 1.5 years, financed by the Swedish agency for innovation systems, Vinnova. The goal with the project was to jointly develop a range of services that correspond to the society’s need for new sustainable and quality assured services in elderly care. The work in this project can be described as a kind of innovation procurement in which municipalities raise their competence, and where the Information Technology (IT) development companies increase their knowledge of the end users. By collaborating with researchers, the company gets a chance to strengthen their methodological approaches. By involving seniors, the project model is raised from being a Triple Helix (society working closely with industry and academia) to an even stronger quadruple helix model with the main stakeholder actively involved as potential end users [8]. In this environment, problem-owners, health informatics researchers, elderly users, and developers of novel IT services worked together in a user-centered and participatory design approach.

Research Approach

This research study adheres to cooperative design [9,10], which is a human-computer interaction (HCI) research theory that regards system development with user participation and considers designing a social process. From research literature, we know that usability aspects should be brought in early in the development process [9,11]. Previous research also presents several methods to engage users in the future, for example, future workshops [12]. Other methods to bring future needs analysis into system development are iterative prototyping and scenario-based design, preferably applied together with potential users in a collaborative approach [13,10].

The degree of user participation may vary. Regardless of activity degree, in cooperative design developers and practitioners/users are seen as actively cooperating partners. Together they aim to reduce uncertainty and risk in the development of novel systems, where a detailed conception of exactly which future needs should be supported, is often lacking [9,12]. Moreover, using older people's extensive experience when trying to meet their needs can be more successful for promoting a new product or service, rather than relying on interaction patterns based on the computer paradigm [14]. This fact increased the interest to further study how novel eHealth services could be designed to reach a heterogeneous target group of elderly people, spreading over an entire country, across different ages, education, health status, and interests. This case study is one of four aiming to extract new knowledge based on user experiences of different older citizen groups using this device and testing its interactive eHealth services [8]. It was conducted together with seniors healthy enough to frequently visit a senior center.

Methods

Device and Test Participants

Research suggests that use of a TV as the platform would reduce new users' uncertainty [15,2]. Based on this previous research, the TV platform was believed to have a relative advantage over computers and mobile phones in terms of users' self-reported motivations for starting and continuing to use the system. Hence, this study used an innovative mobile communication device (Figure 1) connected to the TV, which worked as an interactive large screen controlled remotely.

When the device was connected to an ordinary TV, the TV could receive and send photos, videos, sounds, and text messages from mobile phones and computers. The technology behind this was based on the mobile phone network for communication. There was a subscriber identity module (SIM) card in the device, requiring the device to be placed within global system for mobile communications (GSM) coverage. It was also possible to send email through the device.

The device was considered easy to install in the home. It was plugged into the TV and to the power connector. When a message has been received, the device flashed like an answering machine. The message could be opened with one press on the main button of the remote control. The user of the device could answer the message by writing a text or by sending a voice message. The device could be used for communication between friends and relatives, but also for caregiving purposes, for example to inform the senior which nurse from social care service was scheduled to come, the task to be performed, or medication to be taken.

This prototype, not widely commercialized yet, has been iteratively developed over the last three years. The studied (and latest) version consisted of three different user modes addressing different user groups. User mode 1 aimed to address the basic needs of the elderly without technology experience living at nursing homes. User mode 2 was targeted to a more active user group that still lived on their own, but with nursing or home help support. Some of the most advanced functionalities had been closed to make the device easy to use for people without technology experience. The aim with user mode 3 was to provide full possibilities for mobile communication (text messages, email, sending pictures, etc) for a cognitively active senior living on their own, with or without support from the municipality. These target groups were handled in different studies.

The participants were not randomly selected from the intended user population. Instead, the recruitment process of the participants of this study was handled by the senior center, following the stated requirements: the seniors should be capable of using the functionalities of a computer or a mobile phone, but for different reasons not wanting to communicate through these devices. Some technological skills and experiences were required as this participant group was selected to provide the development company with as much input as possible to the design phase of new services. A total of 8 seniors volunteered and fitted the description of user mode 3. They were between 65 and 80 years of age and lived alone in their own homes. The seniors were not acquainted, but they lived in the neighborhood of the senior center and had visited the center previously, where the advertisement for this project was posted. They all volunteered to test the services and they consented to participate in the study.

Figure 1. The communication device, a prototype called ippi, connected to the TV-set.

The Study

Setup

The participants were recruited by the senior center where an information booklet about the project and one device had been placed. Interested seniors could read about the project and try out the device before deciding to participate. Before the participants were given a device to bring home, they were offered introductory information and an education meeting aiming to create comfort and curiosity of the device and its services. Each participant was given a device, installed it at home, and started to use it with full access to all functionality. There was also one device at the senior center that was used when the group met at the center. The staff at the senior center also used their device for communication with the senior user group.

Most of the seniors installed the device at home by themselves. The ones that needed help had plugs on the TV set in places that were difficult to reach. At the beginning, support was given by staff from the senior center. Second line support was given by the development company during the entire project.

Throughout the 1.5 year-long project, 10 evaluation workshops were held with the seniors and the staff at the center. Two development workshops were held with the development company and researchers. Formative qualitative evaluations consisted of two parts:

1. Design workshops (n=7) to evaluate existing services and suggest improved functionality of the device and interaction with the services.
2. Future workshops (n=3) to get user contributions for the design of new meaningful services.

Part 1: Design Workshops

The seven design workshops were held approximately once a month and lasted for two hours including a coffee break. Seniors, researchers, staff from the senior center, and representatives from the developing company participated. The design workshops were entirely user-centered and the main goal was to gather the seniors' demands for improved functionality and interaction with respect to existing services. The seniors and the staff were very active during the workshops, where a large focus was placed on the participants' questions and demands regarding the device and its services.

All workshop occasions started with a discussion where the participants had the opportunity to ask questions about the device and its usage. Feedback was given by the developers both by explanations and on-site education of existing services and by iteratively shown refinements in new demos of the services. Improvements related to ease of use were accepted by the senior group after individual hands-on testing.

The participants also used questionnaires to describe daily usage of the provided services. The questions covered topics such as how they had used the device, who/how many people they communicated with through the device and what they had learned since last meeting. These questions were walked through during the workshop and all participants answered or commented from their perspective. During the discussions, one researcher took notes and wrote down the participants' answers and other issues that evolved in the discussion. At each workshop, data gathered in the previous workshop was discussed. The aim was to establish a correct understanding of the participants' ideas and issues. At the end of the design sessions a longer questionnaire was filled in. It gathered information about the participant's present usage and bridged to the desired future usage. The questionnaire also contained questions about how often/when they used the device, about attitudes towards usage (eg, if it was fun to use the services and why).

The main goal with the workshops was to gather user information in order to improve the device and its functionality. The discussions did not contain sensitive or personal questions, so we are rather persuaded that the participants shared their thoughts with the only intention to improve the product. Many suggestions for improvements were given, and it is not likely that biases like the "Hawthorne effect" played a major role. On the contrary, the focus was on improvement of a novel device and the users were aware of that their mistakes and misunderstandings were valuable information for the developers. The frequent meetings also contributed to an atmosphere were the participants felt comfortable when being negative towards the technology.

The approach was qualitative and analyses were inspired by the constructivist grounded theory method [16]. The material was analyzed and coded based on gathered notes and written answers from the participants. Concepts were interpreted and categorized by the researchers and handed over as summarized improvement opportunities to the developers.

Part 2: Future Workshops

Overview

In the last three workshops, the main focus was to move from improvements of existing services to the design of new communication or social inclusion services.

The future workshops were conducted to cover the process from user requirements to prioritization of suggested services by the seniors. They consisted of five phases, performed with different participant groups, both with seniors and with the project management group. To visualize new services for other users than "myself" more easily, the seniors were instructed to create three "personas" [17], which they later used as representations of other types of seniors.

Phase 1: Future Workshop at the Senior Center

The first phase consisted of a brainstorming session on how to use the device in the future using post-it notes with seniors and the project team. The only limitation of the exercise was that the proposed services should fall within the following areas: cognitive activities, social activities, and/or physical activities.

Phase 2: Categorization and Detailing of Future Workshop Material

The material from phase one was categorized and subgroups of services were created. Where needed, details were added to concretize the services. The categorization was performed by the project management team and led to over 50 proposals for various new services based on the suggestions from the seniors.

Phase 3: Feasibility Prioritization

The third phase consisted of a project in-house seminar on project priorities among suggested services with a focus on feasibility, with respect to content and cost.

Phase 4: Future Services Prioritization Based on Potential Value for the Seniors

The fourth phase regarded prioritization by the seniors. Based on the 17 services that passed phase 3, the purpose was to let seniors choose the services that they considered most valuable to realize.

Phase 5: Concluding Validation Workshop

As the last phase of the future workshops, both participants of the workshop series and other senior stakeholders were invited to prioritize amongst the 17 services left. The results of this concluding validation workshop are described below.

Results

Part 1: Design Workshops

Usage

The device itself was tuned during the workshop period, and the users considered it "stepwise more easy to use", both regarding functionality of the device and the interaction with the services. Regarding daily usage, the seniors reported that they mainly used the service of receiving and replying to invitations of events from the senior center. The staff at the center sent out a schedule for each week and the messages provided a direct contact with the seniors. This also helped the center to plan and improve publicly given events.

Furthermore, the participants used the device for communication with other study participants or with younger relatives. They also played games as Memory and Sudoku, and they liked to answer quizzes. Finally, the seniors enjoyed performing the weekly-distributed workout exercises.

Both the weekly workout exercises and the quizzes were services that were introduced and tested during the project. These services were developed in an iterative way based on suggestions from the seniors, aiming to encourage individual physical and cognitive wellness.

To Increase Future Usage

The seniors desired multiple services that they found attractive, in order to use the device more often. The hardware of the device was criticized by some users as being too old-fashioned. The text input mode was too cumbersome and the navigation within and between the services could be made more explicit. Finally, the participants pointed out the importance of keeping intact the already existing possibilities to communicate with children, grandchildren, and friends.

Attitudes Towards Acceptance and Usage

One of the questionnaires regarded the seniors' attitudes towards using the device and its services (Table 2). The questions were inspired by factors known to contribute to acceptance of an innovation [15]. The questionnaire used a numeric scale and the results are presented in a descriptive statistical manner. The generated results are not generalizable as such, instead they can be regarded as indicators of how the device was accepted and used by these novel users.

The results regarding attitudes towards acceptance and usage showed that the seniors thought it was quite easy to use the device and they managed to perform the actions they wanted to do. However, this could to some extent be explained by the frequent sessions at the senior center were they could get support. Nevertheless, a positive result was that the device was used and that the seniors felt that it fulfilled its purpose. Finally there were questions regarding to which extent they talked to others about the device and their usage. The aim with these questions was to understand whether the seniors were proud of having this device. The answers here were highly rated (4 of 5) and a conclusion could be that the seniors felt they had access to something new and useful, and that being a part of this development process was something they wanted to tell other people about.

Table 2. Attitudes towards using the device and its services.

Question	Scale: 1=low ; 5=high	Rating
Degree of fun to use the device	1=Not fun at all; 5=Very fun	3.3
Degree of easy/hard to use the device	1=Very easy; 5=Very hard	1.7
Degree of success in doing what they wanted to do with the device	1=Not at all; 5=To a great extent	4.0
Degree of telling others that they had this device	1=not at all; 5=To a great extent	4.0
Degree of telling others why/ how they used the device	1=not at all; 5=To a great extent	3.3

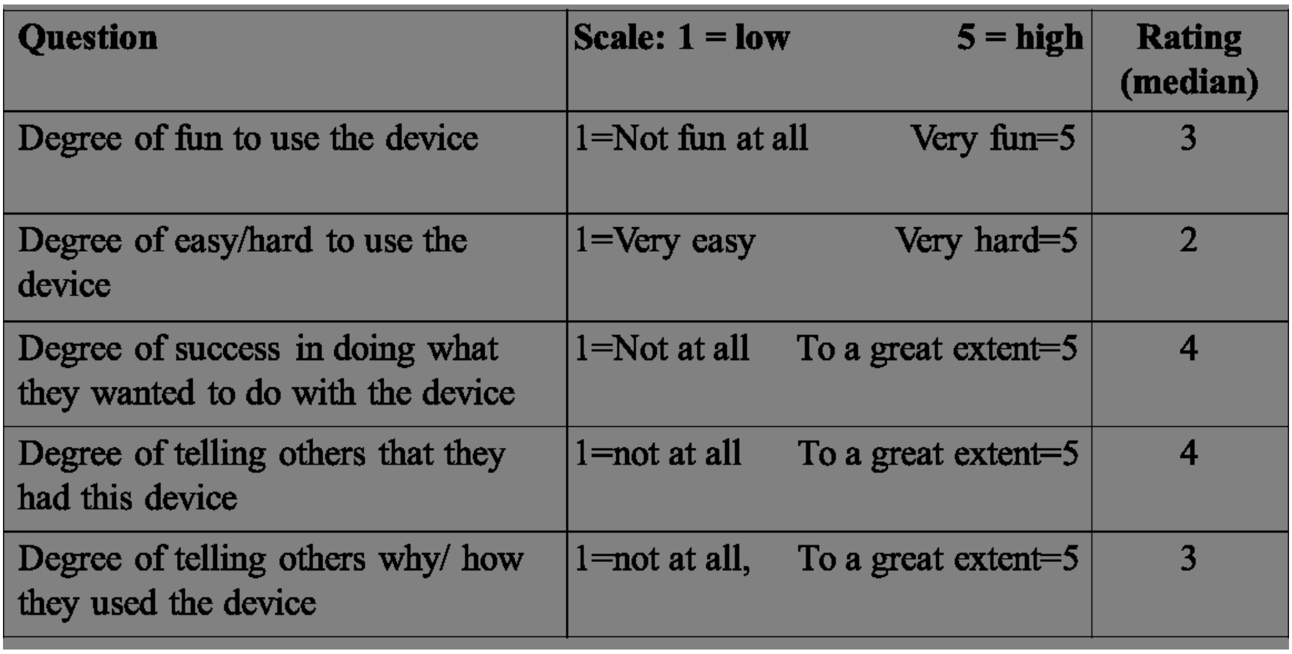
Part 2: Future Workshops

The requirement list of new future services resulted in improvements of three categories of services: cognitive, social, and physical activities. Desired future services contained news in general but in particular local news, about events to happen, or recaps of happenings. Therefore the participants also invented a new category "information and news", since they lacked senior-customized global and local news services, as well as municipality information about local events like lectures or cultural events, suitable for seniors. The entire future workshop process resulted in the high-priority proposals highlighted in Table 3.

Table 3. High-priority proposals from the future workshops.

Category	Details
Cognitive activities	Memory matrix: a game for practicing the working memory
Social activities	Quizzes with stepwise clues (like in magazines)
	Different multi-player games: to compare yourself with other users' results
	Cooking tips: daily or weekly menus.
Physical activities	Low impact workout: gymnastic exercises for seniors/elderly (Figure 2)
	Guided walking routes: discover your neighborhood
Information and news	Senior-customized news from the municipality (or other service providers)

Figure 2. An example of a workout instruction for seniors; push-ups. This kind of illustration of the workout exercises (using a baby instead of an adult) was appreciated by the seniors.



Question	Scale: 1 = low 5 = high	Rating (median)
Degree of fun to use the device	1=Not fun at all Very fun=5	3
Degree of easy/hard to use the device	1=Very easy Very hard=5	2
Degree of success in doing what they wanted to do with the device	1=Not at all To a great extent=5	4
Degree of telling others that they had this device	1=not at all To a great extent=5	4
Degree of telling others why/ how they used the device	1=not at all, To a great extent=5	3

Discussion

Principal Findings

To summarize the results regarding daily usage, the seniors reported that they used the service for communication with the participants in the group or with younger relatives. This is in line with previous results showing that the use of information technology increases social interaction [1,2]. The seniors also reported that they used the service for receiving information from the senior center, and to read information about events at the senior center. Furthermore they liked to perform a weekly-distributed workout exercise, and they played games such as Memory and Sudoku using the device. The service development focused on three categories of services: cognitive activities, social activities, and physical activities. The material was prioritized based on the seniors' ideas of usefulness and the developers' feasibility studies. A cognitive activity service, found meaningful to develop, was a game for practicing the working memory. In the social activities category the seniors wanted different quizzes and multi-player games. For physical activities the seniors desired more workout exercises and suggestions for guided walking routes. A new category "information and news" was suggested since they lacked services like senior-customized global and local news.

Reflections Regarding the Study Setup

As already mentioned, the participants iteratively filled in questionnaires during the project. At the concluding workshop the participants described their overall experiences, both with respect to the latest version of the device and with respect to the overall impressions about the project.

Hands-on work with innovations is never easy and often time-consuming in the start of a user-centered project, but it pays off in the long run if the user feedback is thoroughly handled. The group format with the senior participants was a good method to learn about what worked and how to improve the intervention. In each workshop the users' reflections were gathered and brought into the development process. Both this study and other research [14,18] showed the importance and the benefits of using older people's knowledge and experience in the development of new products.

Developers from the company participated in all workshops with the seniors. When working closely with researchers and users, the developers improved their understanding of the potential users and the real usage context. In this case the researchers' work was to support direct communication between users and developers rather than gather material to hand over to the non-present developers. If the developers would not be present at the workshops, much explanation time would be consumed and a real understanding for the users' needs and preferences could be lost.

It is imperative to let the refining and detailing work of the services take its time in the project management group (developers and researchers) in order to avoid misunderstandings, based on different views of what the seniors actually desired. It is difficult to put one's technical skills aside to fully understand the needs and wishes of so-called non-technical users. Feedback from the seniors was necessary to ensure that their needs were properly understood, as well as the need of an iterative development method to handle suggestions of improvements and new services. During the project, new services such as workout exercises, memory training, and quizzes were implemented thanks to the demands from the seniors.

The seniors' usage of the device and the services were also practical hands-on work. They had an own device at home and access to the device at the senior center for learning purposes, either together with the staff or with other participants in the group. In short, the seniors had access to both the technology any time they wanted at home, and several channels to get support. We are persuaded, that having access to the technology at any time, the possibility to get support easily, and frequent sessions with the developers are most important aspects in successful technology development.

Furthermore, it is crucial to have frequent access to the technology to be able to integrate the usage in one’s life [15,5]. Only when the technology is used in a realistic way, based on specific needs, will useful and correct feedback be given [18]. The frequent meetings also provided the possibility to get to know each other and created an environment where all participants in the quadruple helix-team could suggest changes freely. It was evident that this team was working hard together towards a common goal to improve the device as much as possible.

It was also evident that a novel device cannot be perfect from the beginning. It has to be iteratively refined, tested by relevant user groups, and evaluated by future users. Often technology can be rejected based on a tiny aspect. Good communication with future users and usage observations makes it easier to detect these aspects and remove potential problems. A benefit of the work in a quadruple helix-constellation like this is that the developers get a deeper understanding of why certain changes need to be performed to reach good usability of a product.

Social Inclusion

This work provided input to the development of different social services and it showed increased social contacts, especially with grandchildren. Besides input to the design of new services, for example providing local information and support for physical activity, this work showed the importance of a social context around such a study. The seniors were very engaged throughout the project. The amount of input from the seniors could be explained in terms of social inclusion; they belonged to a group and each member was considered important for the work. The friendly workshop atmosphere facilitated new ideas and the work with redesigning the services.

Between the monthly held workshops, the seniors decided to meet on their own for doing their “homework” and to share new knowledge. The seniors appreciated that they could learn the technology together with other participants who were at the same level. The user group has also been welded together socially and, thanks to the project, they now socialize privately and agree on having made new friends.

The perception among the seniors was that it was exciting to participate in a process where new technology was designed and developed. Participation also seems to have opened up the participants' interest in technology beyond this device and its services. One of the participants believed that she had become more confident to handle the DVD to the TV, a spillover effect of daring and learning new things within this project.

The importance of active participation in the society, even without using a computer, has also been identified in the project. A senior got a job via the device because she had an email address through which she was contacted. Using an email address connected to the TV, non-computer users are also represented in the digital world. Regarding development of digital cultures, there is a possibility to decrease the amount of “socially and technically excluded” (no access available) or “expelled” (forced to live without Internet) groups of people, as defined by Wyatt [19], just by providing devices like the one tested in this study.

Future Work

In this project we gained insight on a number of positive social aspects. Some were planned for and others not. One future interesting design aspect to be further investigated is how social benefits (and other benefits) can be used in the design process in a more structured way, and how the process itself can fulfill human needs. This will in the end also lead to even more engaged participants managing to provide improved input to the design process.

We have earlier been working with similar settings in other case studies (eg, [13]) and again, we noticed how valuable the researchers’ mediation is during communication between different stakeholders. The translation or mediating activities create a mutual understanding. An interesting area to be further investigated is how the direct communication between participants and developers can be taken one step further.

We would also like to study how the method for prioritization could be refined. In this work we had a number of services that the users rated on a usefulness scale and the developers on a feasibility scale. The results were put in a diagram with two axes. We believe that this process/method could be further developed towards an efficient tool for service development and evaluation.

Another interesting task will be to ensure creation of win-win situations in the beginning of a quadruple helix project. It is evident when a project like this ends, that it has increased knowledge in the various stakeholders’ organizations. However, being able to actually measure project goals related to the benefit and win-win situations is rare as that kind of project goals often lack in a project plan. Stated and measurable win-win situations and explicit benefit would probably aid when spreading this method further.

The work performed in this study, together with the other three studies in this project, tried to define potential users based on specific user requirements for this novel device [8]. It would be interesting to test this device in another context, for example, in stroke patients’ care and rehabilitation. In rehabilitation, it is common that elderly patients’ contacts with caregivers after some time become less frequent. Both parties suffer when they receive too little information and consequently proper follow-ups are missed [20]. New channels of receiving information and new ways to communicate will probably increase the possibilities for elderly to be more active in their own care and rehabilitation.

Concluding Remarks

The aim with the project was to develop services and functionalities that meet the needs among seniors, both today and in the future. Throughout the project new services have been introduced with the purpose of being useful for seniors or elderly people living in their own homes. Based on a user-centered approach and an iterative development process, the services and the functionalities were a result of this specific context, with this group of seniors, developers, and researchers. The outcome was specific for this context and hence, the results are not generalizable. However, use of personas and a careful recruitment process seeking to find representatives of potential future users is in line with previous research [10,17]. Therefore it is fair to claim that the results can be regarded as important indicators of a useful development approach where the aim is to develop technology that is of instant benefit for the user group. The local recruitment of seniors that were interested in the device also placed a focus on the motivational aspects. One explanation to the participants' engagement is that they were individuals that found this task relevant and interesting. People are different and have different needs; we believe it is important to develop technology with and for people that find the services meaningful rather than trying to develop towards specific target groups, without their engagement in the development process.

Another important aspect in the development is to actually understand the context around the users and make sure that the developers understand this context as well. Our results seem to be cost-effective when developers meet groups of users rather than getting second-hand information. When the developers are a part of the workshop, a source for rich information about context and needs arises that can only be conveyed by similar approaches. Participation makes it easier to develop the right product from start, or at least getting as close as possible.

To summarize the successful outcome of the project, the seniors were given a number of new, essential, services as described above. Most important from a socio-technical development perspective is that the participants enjoyed using the device, they participated to further develop it and they wanted to continue using it after the end of the project.

Acknowledgments

This project was financed by Vinnova, The Swedish Agency for Innovation Systems within a 'Research & Grow program' aiming to support industry by the involvement of researchers in the project. In this case, the development company was Ippi AB. We would like to thank Ippi AB and the development team and all the participants in the workshops, hosted by the senior center in Täby Municipality.

Authors' Contributions

The authors contributed equally to the study conception, intellectual content, study performance, and drafting of the manuscript. Isabella Scandurra contributed with final critical revision of the manuscript. Marie Sjölinder contributed with critical revision of the manuscript.

Conflicts of Interest

The authors have no current financial involvement with the company Ippi AB.

References

1. McConatha D. Aging online: toward a theory of e-quality. In: Morrell RW, editor. Older adults, health information, and the World Wide Web. New Jersey: Lawrence Erlbaum Associates; 2002:21-41.
2. Östlund B, Lindén K. Turning older peoples' experiences into innovations: Ippi as the convergence of mobile services and TV viewing. Gerontechnology 2011;10(2):103-109. [doi: 10.4017/gt.2011.10.2.003.00]
3. Findahl O. Older Swedes and the Internet 2010. Stockholm: World Internet Institute; 2011:10-11.
4. Östlund B. Images, users, practices - senior citizens entering the IT-society. In: Report 9. Stockholm, Sweden: Kommunikationsforskningsberedningen; 1999.
5. Cody MJ, Dunn D, Hoppin S, Wendt P. Silver surfers: training and evaluating Internet use among older adult learners. Communication Research 1999;48(4):269-286. [doi: 10.1080/03634529909379178]
6. O'rourke K, Heckman J, Elwood D. Development and exploration of a multifaceted social platform to improve patient education, communication, and activity. 2012 Presented at: Medicine 2.0 2012; September; Boston URL: http://www.medicine20congress.com/ocs/index.php/med/med2012/paper/view/1247
7. Findahl O. The Swedes and the Internet 2011. Stockholm: World Internet Institute; 2011:14-31.
8. Scandurra I. Sustainable and quality-based communication services in elderly care. In: Report #3 (in Swedish). Stockholm, Sweden: R&D Seniorium; 2011.
9. Greenbaum JM, Kyng M. Introduction: situated design. In: Design at work: cooperative design of computer systems. Hillsdale, NJ: L Erlbaum Associates; 1991:1.
10. Schuler D, Namioka A. Participatory design: principles and practices. Hillsdale, NJ: L Erlbaum Associates; 1993.
11. Constantine LL, Lockwood LAD. Software for use: a practical guide to the models and methods of usage-centered design. New York: Addison-Wesley Professional; 1999.
12. Jungk R, Mullert N, Edwards NA. Future workshops: how to create desirable futures. London: Institute for Social Inventions; 1996.

13. Scandurra I, Hägglund M, Koch S. From user needs to system specifications: multi-disciplinary thematic seminars as a collaborative design method for development of health information systems. J Biomed Inform 2008 Aug;41(4):557-569. [doi: 10.1016/j.jbi.2008.01.012] [Medline: 18394969]
14. Dickinson A, Dewsbury G. Designing computer technologies with older people. Gerontechnology 2006;5(1):1-3. [doi: 10.4017/gt.2006.05.01.001.00]
15. Rogers EM. Diffusion of innovations. New York: Free Press; 2003.
16. Charmaz K. Grounded theory: objectivist and constructivist methods. In: Denzin NK, Lincoln YS, editors. The SAGE Handbook of Qualitative Research. California: Sage Publications, Inc; 2011:359-381.
17. Mulder S, Yaar Z. The user is always right: a practical guide to creating and using personas for the Web. Berkeley, CA: New Riders; 2007.
18. Östlund B. Teknik, IToch åldrande - Hur fungerar det för patienter, omsorgstagare och äldre medborgare? (Technology, IT and ageing: how does it work for patients, social care receivers and old citizens?). Stockholm: Liber AB; 2012.
19. Wyatt S. Non-users also matter: the construction of users and non-users of the Internet. In: Oudshoorn N, Pinch T, editors. How users matter: the co-construction of users and technologies. Cambridge: MIT Press; 2003:67-80.
20. Hägglund M, Davoody N, Bolin P, Winsnes C, Lundberg N, Vimarlund V, et al. Stroke patients' needs for access to care process related information. 2012 Presented at: Medicine 2.0; September; Boston URL: http://www.medicine20congress.com/ocs/index.php/med/med2012/paper/view/1083

Abbreviations

GSM: global system for mobile communications
HCI: human-computer interaction
IT: information technology
SIM: subscriber identity module
TV: television

Edited by G Eysenbach; submitted 23.05.13; peer-reviewed by L Ashley, D Thompson, I Rootman; comments to author 18.07.13; revised version received 18.08.13; accepted 16.09.13; published 08.10.13.

Please cite as:
Scandurra I, Sjölinder M
Participatory Design With Seniors: Design of Future Services and Iterative Refinements of Interactive eHealth Services for Old Citizens
Med 2.0 2013;2(2):e12
URL: http://www.medicine20.com/2013/2/e12/
doi:10.2196/med20.2729
PMID:25075235

Original Paper

Embedding a Learning Management System Into an Undergraduate Medical Informatics Course in Saudi Arabia: Lessons Learned

Nasriah Zakaria[1,2*], BSc, MSc, PhD; Amr Jamal[1*], BSc, MBBS, MD, MSc; Shekhar Bisht[1*], MBA, PhD; Cristina Koppel[3*], BSc, MBBS

[1]Medical Informatics and E-learning Unit, Medical Education Department, College of Medicine, King Saud University, Riyadh, Saudi Arabia

[2]School of Computer Sciences, Universiti Sains Malaysia, Penang, Malaysia

[3]Department of Medicine, Imperial College, London, United Kingdom

[*]all authors contributed equally

Corresponding Author:
Nasriah Zakaria, BSc, MSc, PhD
Medical Informatics and E-learning Unit
Medical Education Department, College of Medicine
King Saud University
PO Box 2925 (37)
Riyadh, 11461
Saudi Arabia
Phone: 966 530231826
Fax: 966 4690821
Email: nzakaria@ksu.edu.sa

Abstract

Background: Public universities in Saudi Arabia today are making substantial investments in e-learning as part of their educational system, especially in the implementation of learning management systems (LMS). To our knowledge, this is the first study conducted in Saudi Arabia exploring medical students’ experience with an LMS, particularly as part of a medical informatics course.

Objective: This study investigates students’ use of various features of the LMS embedded in a recently implemented medical informatics course.

Methods: A mixed methodology approach was employed. Survey questionnaires were distributed to all third year medical informatics students at the end of the course. In addition, two focus group sessions were conducted with twelve students. A thematic analysis of the focus group was performed.

Results: A total of 265 third year medical student surveys (167/265, 63% male and 98/265, 37% female) were completed and analyzed. Overall, 50.6% (134/265) of the students agreed that the course was well planned and up-to-date, had clearly stated objectives and clear evaluation methods, appropriate course assignment, and that the LMS offered easy navigation. Most of the students rated the course as good/fair overall. In general, females were 10.4% more likely to prefer the LMS, as revealed by higher odd ratios (odds ratio [OR] 1.104, 95% CI 0.86-1.42) compared to males. Survey results showed that students’ use of LMS tools increased after taking the course compared to before taking the course. The full model containing all items were statistically significant (χ^2_{25}=69.52, P<.001, n=243), indicating that the model was able to distinguish between students who had positive attitudes towards LMS and those who did not. The focus group, however, revealed that the students used social networking for general use rather than learning purposes, but they were using other Internet resources and mobile devices for learning. Male students showed a higher preference for using technology in general to enhance learning activities. Overall, medical student attitudes towards the LMS were generally positive. Students also wanted a reminder and notification tool to help them stay updated with course events. Interestingly, a subset of students had been running a parallel LMS of their own that has features worth exploring and could be integrated with an official LMS in the future.

Conclusions: To our knowledge, this was the first time that an LMS was used in a medical informatics course. Students showed interest in adapting various LMS tools to enhance their learning and gained more knowledge through familiarity with the tool.

Researching an official LMS also revealed the existence of a parallel student-created LMS. This could allow teacher-led and student-led platforms to be integrated in the future for an enhanced student-centered experience.

(Med 2.0 2013;2(2):e13) doi:10.2196/med20.2735

KEYWORDS

medical education; medical informatics; learning management systems (LMS)

Introduction

Around the world, medical schools are embracing e-learning technology in their curriculum. In 2011, the forum “A 2020 Vision of Faculty Development across the Medical Education Continuum” addressed how medical schools should prepare for the changing role of medical education [1], and concluded that a key focus should be the digital environment. This was based on factors such as the explosion of new information, digitization of both medical knowledge and paper-based records, students who are digital learners, and the emergence and proliferation of instructional technologies [1].

The study of e-learning focuses on the use of computer and communication technology to deliver teaching and foster learning [2]. A learning management system (LMS) is a type of software that allows educators to provide course materials and monitor, manage, and interact with students. An LMS can increase the effectiveness and efficiency of teaching in medical schools [1,3] through ease of access, better utilization of content, increased retention rate [3], cost-effectiveness [2], and learner satisfaction. In this study, it is not our intention to compare traditional and online learning approaches; rather, we want to emphasize the fact that the LMS is complementary to traditional face-to-face learning and is best used in a blended approach.

In the Kingdom of Saudi Arabia, public universities are making substantial investments in e-learning as part of their educational system. King Saud University (KSU) introduced the Deanship of e-learning and Distance Learning in 2010 [4,5]. All courses became available through the LMS via Blackboard (a commercial LMS system) in the same year. Subsequently, the College of Medicine established the medical informatics and e-learning Unit (MIELU) [6] to introduce and promote the use of e-learning among medical educators and students. Training was conducted in stages, but there was still a lack of enthusiasm among educators for full-fledged embedding of the LMS in their courses. Although most courses do now use LMS to upload lecture notes, post announcements, and deliver test grades, most do not take advantage of the other interactive tools offered by LMS, such as conferencing facilities, chat rooms, discussion boards, and evaluation tools for tests and surveys [6].

As such, our unit, MIELU, undertook an initiative to revamp the Introduction to Medical Informatics course, a third year compulsory course, in order to incorporate and exploit the full range of tools offered by the LMS. The revised course applies “blended learning”, meaning that it combines both face-to-face and online learning [2]. We injected other LMS tools such as online discussions and online quizzes to maximize the learning experience for students.

Despite the supportive environment, instructors found that integrating an e-learning approach continued to pose various challenges, despite medical students being assumed to be “digital natives”. Thus, the other important aspect of our study was to explore the extent to which Saudi students use digital technologies in their daily lives.

Prensky coined the term “digital native” to refer to people who were born into the digital era and have been exposed to computing technologies since childhood [7]. The digital native works with and around technology almost constantly; this generation may therefore be far more adaptable to e-learning technologies than the “digital immigrant,” which describes most current instructors’ generation.

A study by Jhaveri et al showed that medical students who are digital natives explore different search engines when doing coursework, use various social media to stay current with medical knowledge, and participate in blogging to promote medical discussions [3]. There is also a support from recent study among dental students that indicate they are using smartphone and tablets to learn [8]. There is an assumption that all students are of this new generation of learners and so, as they enter higher education, universities are employing online learning technologies to meet the presumed needs and expectations of these “digital natives” and enhance their learning experience [1].

Although in general there has been a shift towards e-learning within this “digital native” generation, Prensky further matured his concept to “digital wisdom” [9], described as the ability to use digital technology to complement existing abilities and decision-making. Today’s health care learners embrace online learning due to convenience and usability factors [10]. Digital wisdom de-emphasizes age and implies that it is a skill that can be learned by anyone. This is a better match to our experience in the medical informatics course, wherein students seemed to demonstrate their mastery in informatics when they have completed their final project in this course.

Implementing LMS tools in a medical informatics course is a novel study in the Gulf region because only a few medical schools here include medical informatics in their medical curriculum. The medical education curriculum environment is ever changing and evolves from year to year. Together with the e-learning tools revolution, this makes the present study highly relevant to the body of literature. The present study also clarifies areas that should be targeted in order to further promote embedding the LMS in the College of Medicine.

In this study, we investigated the use of an LMS among medical students on a medical informatics course and the issues and challenges they faced. To our knowledge, there were no previous evaluations of how well medical students are adapting to and using these tools. We also explore how our students use online tools in their daily life to better understand their translation into an educational environment.

Methods

Research Context: Medical Informatics Course

The introduction of medical informatics into the medical curriculum is relatively new in the Gulf region. This course was introduced as a compulsory course for medical students at KSU two years ago. Its goals are (1) to inform students about current trends in medical informatics as it applies to health care, and (2) to expand students' awareness of the ways in which information technology is used in day-to-day medical work. Two factors made medical informatics ideal to incorporate the LMS. The first is the nature of the medical informatics field itself, which involves information and communication technology; the second is that most of the instructors for this course have a strong technical background and are experienced with various e-learning tools.

The course is taught through face-to-face lectures over 20 weeks. We deliver one online lecture through Flash presentation. All course materials, assignments, and quizzes are delivered via the LMS. The LMS is accessible via PC, laptop, and mobile devices (Figure 1). It is also available in both Arabic and English.

In terms of pedagogical approach, the course uses problem-based and hands-on learning. Students participate in live and online discussions, complete an article review assignment, conduct a field study, and attend workshops. We distributed 5 discussion questions (scenario- and problem-based) and students conducted small group discussions using the LMS. For one of these, the group summarizes their discussion and posts in the common forum area. This way, all groups can participate in discussions without interrupting the small group dynamics. Using the virtual class space, students were able to critically discuss pertinent topics by posting their writings, justifying their opinions, and commenting on their classmates' ideas in a systematic manner [11]. Article review assignments were also completed on an individual basis. We posted 100 relevant medical informatics papers and each student summarized and critically assessed an article.

The LMS plagiarism checker tool was used to monitor the article review assignment. Students received instant plagiarism results, including links to similar texts found online. Online quizzes were conducted, allowing students to take the quiz anywhere within a prescribed date range and length of time. Students also had to conduct a field study project in groups. Each group visited one department or organization that used informatics and they conducted interviews to gain insight into the usage of the system and its challenges. The projects took the whole of the second semester and at the end each group presented their work formally to the instructors and invited panels from outside the university for evaluation [11]. In addition, students attended five compulsory workshops covering DxR Clinician, a Web-based simulation software for medical education, picture archiving and communication system (PACS), the hospital information system, and a mobile version of evidence based medicine.

Survey and Statistical Analysis

We employed a mixed methodology approach, beginning with a course-wide survey of all third year students studying at the College of Medicine, KSU, Riyadh.

The survey was administered at the end of the final examination in the medical informatics course. The instrument was a structured questionnaire in English. We were not able to find similar work on LMS and medical informatics courses; however, we adapted some existing course evaluation forms. The survey included the following sections: (1) general demographic and academic information, (2) course rating, (3) perceptions about the course, (4) e-learning (LMS-Blackboard) utilization, (5) attitudes towards e-learning, and (6) proficiency in Internet/online tools. Each of the 6 sections contained 3 to 11 questions using a 5-point Likert scale (strongly disagree to strongly agree).

The survey data were collected and entered into a computer using standardized entry codes. For all tests, statistical significance was set at $P<.05$. Descriptive statistics were used to generate means, standard deviations, and percentages. In addition, *t* test (unpaired and paired) was employed to compare group variables by gender. Variables were then re-categorized into fewer groups to conduct further tests so that results could be interpreted meaningfully. We assessed the relationships of student attitudes towards e-learning using binary unconditional multiple logistic regression analysis based on gender. All the selected variables were converted into binary data (disagree/agree).

For multiple variable analyses using logistic regression, we constructed a dataset that contained only complete responses (n=243) for all relevant variables, discarding any surveys that had missing values for any of the variables involved in the regression analysis. This strategy was adopted to maintain comparability between models so that they could be developed from the same denominator. All analyses were conducted using SPSS version 21 (SPSS Inc, Chicago, IL). Logistic regression models were presented in graphical form using OpenMeta[analyst] version 4.24.13.

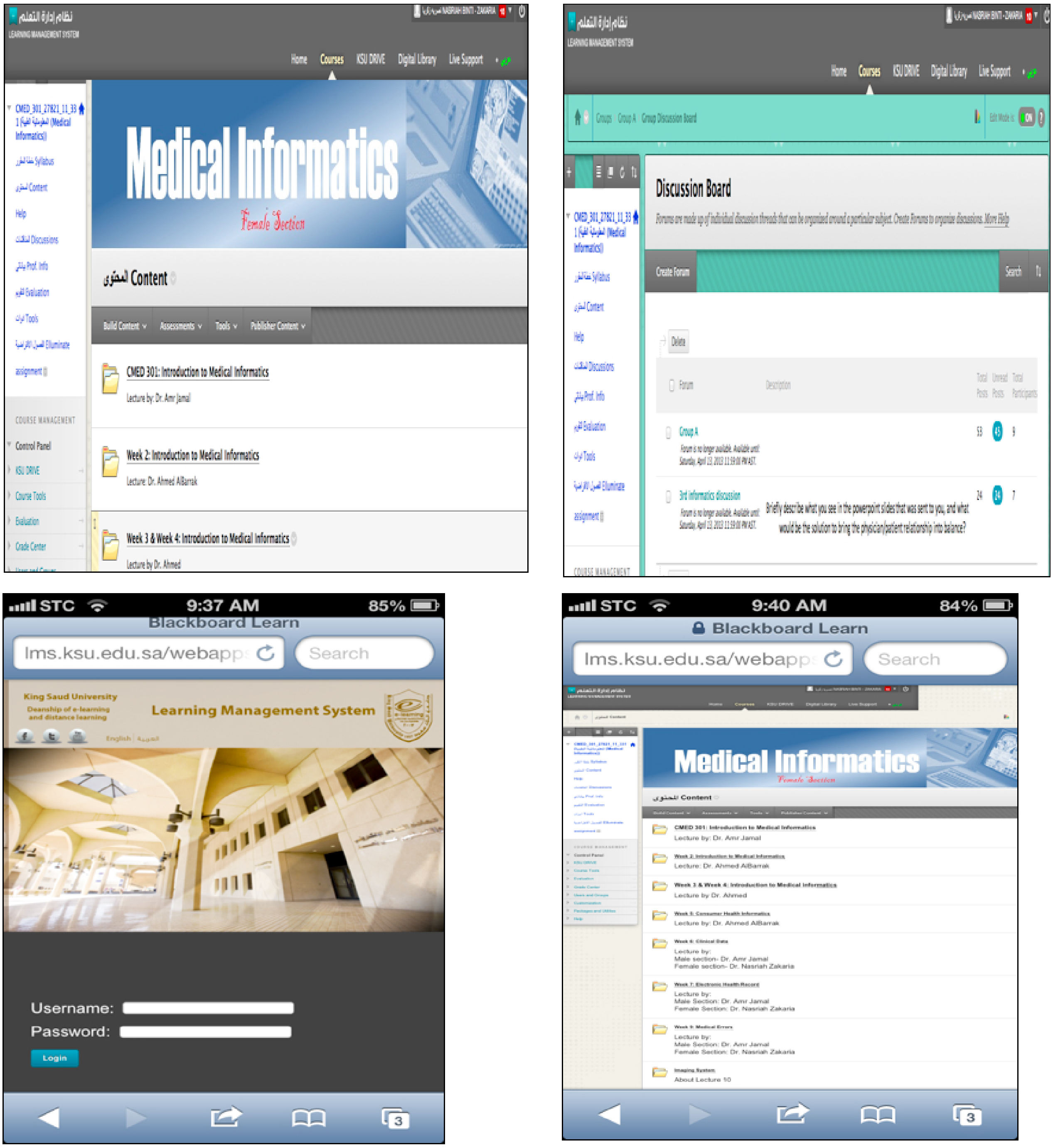
Focus Group

To complement the survey, in-depth focus group sessions were conducted. Arrangements were made with student leaders to recruit 10 to 16 students in two separate sessions. The purpose of these was to investigate how students used the LMS in medical informatics; the open format allowing participants to debate the pros and cons. Focus groups also allowed us to observe the interaction among group members [12,13]. Participants were encouraged to communicate freely with each other, exchanging their experiences and commenting on each other's stories [12,13]. Kitzinger stated that the number of focus groups can vary from 6 to 50 for a research study; however, some studies conduct only a few focus groups [12,13].

In preparation, we created a topic guide for the focus group moderator. The first author, NZ, served as moderator. The topics for discussion included issues and challenges of using the LMS, and how students overcame any struggles. We used a digital recorder to capture the focus group sessions.

The focus group session began by asking participants to fill out a form containing three questions asking them whether LMS can help achieve their educational goals, what the important skills required to use LMS are, and what challenges they faced when using the LMS. The moderator then gave a briefing on what was expected from the respondents during the focus group discussions. Next, the students discussed various interactive LMS features such as the group discussion board, online quizzes, plagiarism checker, and grade center. Students were encouraged to discuss the challenges encountered with each component and what steps they took to overcome the challenges. Thematic analysis was employed to elicit important themes that would represent the issues and challenges faced by medical students when using LMS.

Figure 1. Top panels: A snapshot of LMS page for Medical Informatics course via laptop. Bottom panels: A snapshot of LMS page for Medical Informatics course via mobile device.



CMED 301: Introduction to Medical Informatics
Lecture by: Dr. Amr Jamal

Week 2: Introduction to Medical Informatics
Lecture: Dr. Ahmed AlBarrak

Week 3 & Week 4: Introduction to Medical Informatics
Lecture by Dr. Ahmed

Forums are made up of individual discussion threads that can be organized around a particular subject. Create Forums to organize discussions. More Help

Group A
Forum is no longer available. Available until: Saturday, April 13, 2013 11:59:00 PM AST.

3rd informatics discussion
Forum is no longer available. Available until: Saturday, April 13, 2013 11:59:00 PM AST.
Briefly describe what you see in the powerpoint slides that was sent to you, and what would be the solution to bring the physician/patient relationship into balance?

Results

Statistical Results

For this study, there were 265 third-year medical students who participated (167/265, 63.0% male and 98/265, 37.0% female). The mean age of all students was 20.3 years (SD 3.7), although mean female age (mean 21.2, SD 0.66) was significantly higher than mean male age (mean 20, SD 4.32) (Table 1). The average score achieved in the medical informatics final examination and overall cumulative GPA were 15.58 (SD 2.25) and 4.37 (SD 0.43) respectively for both genders combined (Table 1). On the other hand, female students had statistically significant higher scores in the medical informatics course (*P*<.001) as well as overall cumulative grade point average (Table 2). The student ratings indicate that about, 84.9% (225/265) found the overall course is “fair” and above. When asked about the course content, 83.8% (222/265) students agreed the content is “fair” and above (Figure 2). For the overall medical informatics course, only 14.0% (37/265) students said the course was “poor” (Figure 2). Overall, almost half of the class (50.6%, 134/265) agreed the course was well planned and up-to-date, course expectations were clearly stated, clear evaluation methods were used, course assignment were appropriate, and navigation on the LMS was easy (Figure 3-6).

Students in the present study did not show any significant difference with regard to gender or uses of the LMS except in downloading content and in sending email via the LMS. These features, however, were not frequently used (Tables 3 and 4). The online quiz was the LMS feature most often used by the students, as it was compulsory. It can clearly be observed that students’ LMS use and its incorporation into their learning significantly increased after introduction of the medical informatics course into the curriculum.

In order to understand the attitudes of medical students towards LMS based on gender, we performed multiple logistic regressions. The model contained 25 independent variables (attitudes and digital natives section). The full model containing all items were statistically significant (χ^2_{25}=69.52, *P*<.001, n=243), indicating that the model was able to distinguish between students who had positive attitudes towards LMS and those who did not and correctly classified 83.7% of cases. The model is presented in Figure 7, and shows that, out of 25 items, 13 were more positively received (rated as highly agreeable) by female students as compared to male students.

The highest agreement among female students was on “using e-learning”. Analysis found that e-learning (specifically LMS-Blackboard) was 6.27 times (odds ratio [OR] 6.27, 95% CI 1.75-22.40) more likely to be used by female students as compared to male students. Similarly “course content” and “course assignments” were generally liked by female students. One interesting finding was that female students primarily used the Internet to chat with friends and family and to learn new activities other than medical education, while male students used the Internet primarily for learning activities. Male students also used Blackboard more for learning as compared to female students. Male students’ attitudes showed that they liked the e-learning (LMS) aspects of the course and reported LMS as beneficial (Figure 7).

Table 1. Student performance in medical informatics course.

Item	Mean (SD)	*P* value
Age	20.32 (3.73)	.012
Cumulative GPA	4.37 (0.43)	<.001
Final score in medical informatics course	15.58 (2.25)	<.001

Table 2. Student performance in medical informatics course by gender.

Item	Male, mean (SD)	Female, mean (SD)
Age	20.0 (4.32)	21.2 (0.66)
Cumulative GPA	4.25 (0.47)	4.5 (0.28)
Final score in medical informatics course	15.23 (5.3)	17.24 (1.63)

Table 3. Student use of LMS features after the medical informatics course.

Item	Mean (SD)	*P* value
Discussion board to ask questions	3.32 (1.37)	.991
Discussion board to get answers	3.16 (1.4)	.653
Safe assign to check work	3.55 (1.21)	.291
Online quizzes	4.13 (0.91)	.533
Read announcements	3.39 (1.31)	.202
Upload content (HW, Project, Papers)	3.89 (1.14)	.231
Download content (HW, Project, Papers)	3.72 (1.19)	.029
Play Flash presentation	2.35 (1.41)	.262
Send emails via Blackboard	1.77 (1.30)	.042
Receive emails via Blackboard	1.71 (1.3)	.116
Overall	3.1 (1.25)	.340

Table 4. Student (by gender) use of LMS features after the medical informatics course.

Item	Male, mean (SD)	Female, mean (SD)
Discussion board to ask questions	3.33 (1.45)	3.34 (1.34)
Discussion board to get answers	3.12 (1.5)	3.2 (1.34)
Safe assign to check work	3.67 (1.27)	3.5 (1.2)
Online quizzes	4.1 (0.92)	4.16 (0.92)
Read announcements	3.55 (1.3)	3.33 (1.31)
Upload content (HW, Project, Papers)	4.01 (1.16)	3.83 (1.13)
Download content (HW, Project, Papers)	3.95 (1.12)	3.61 (1.22)
Play Flash presentation	2.24 (1.4)	2.45 (1.14)
Send emails via Blackboard	1.57 (1.18)	1.91 (1.36)
Receive emails via Blackboard	1.57 (1.18)	1.91 (1.36)
Overall	3.11 (1.25)	3.12 (1.23)

Figure 2. Students' perception about the course.

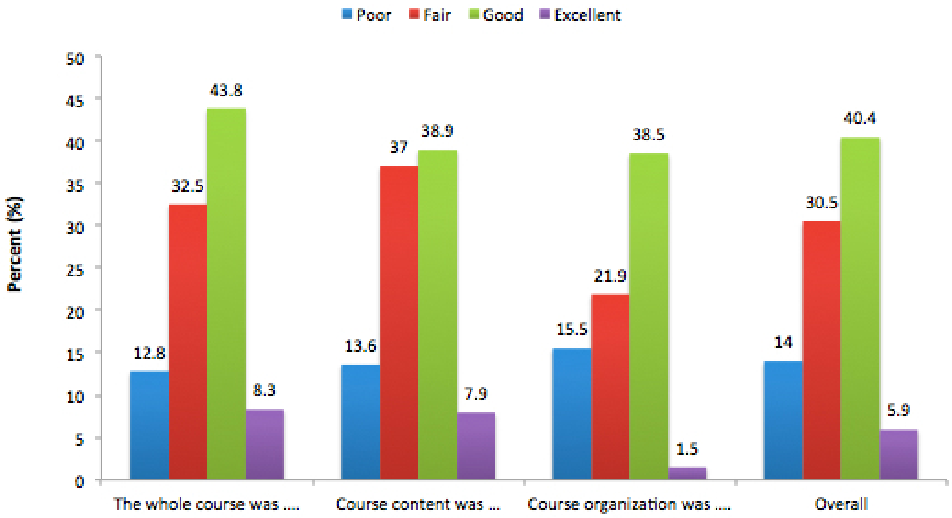


Figure 3. Course planning and uptodate, pertinent & comprehensiveness of content.

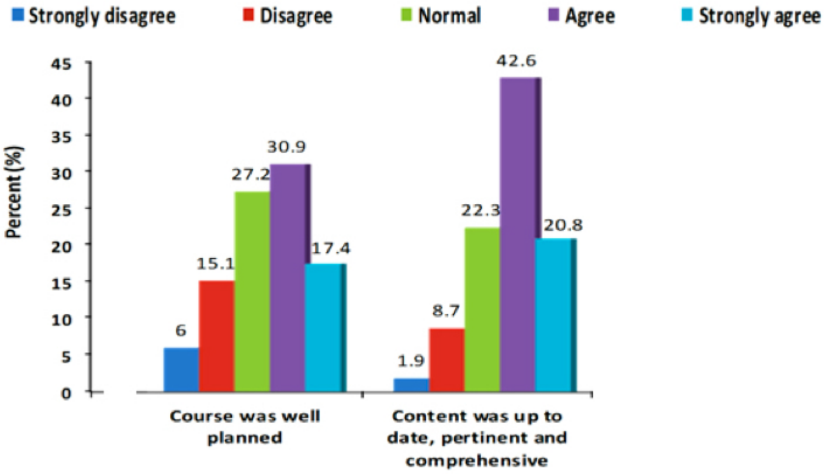


Figure 4. Course Expectation and evaluation methods.

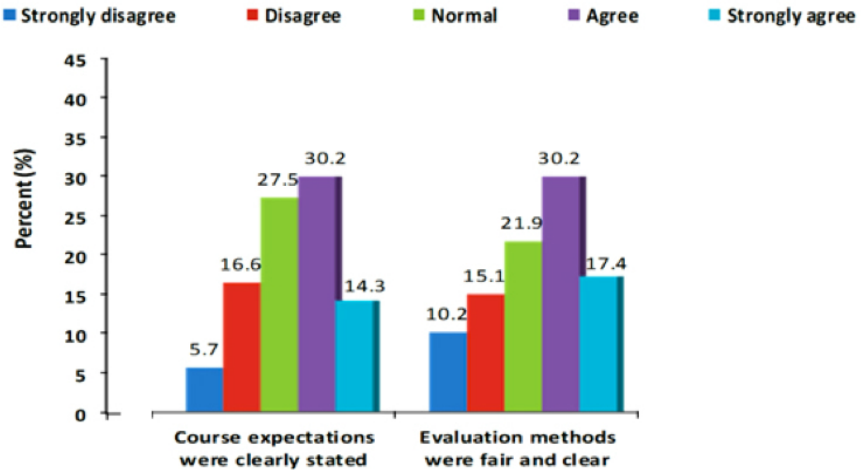


Figure 5. Appropriateness of course & navigation of LMS.

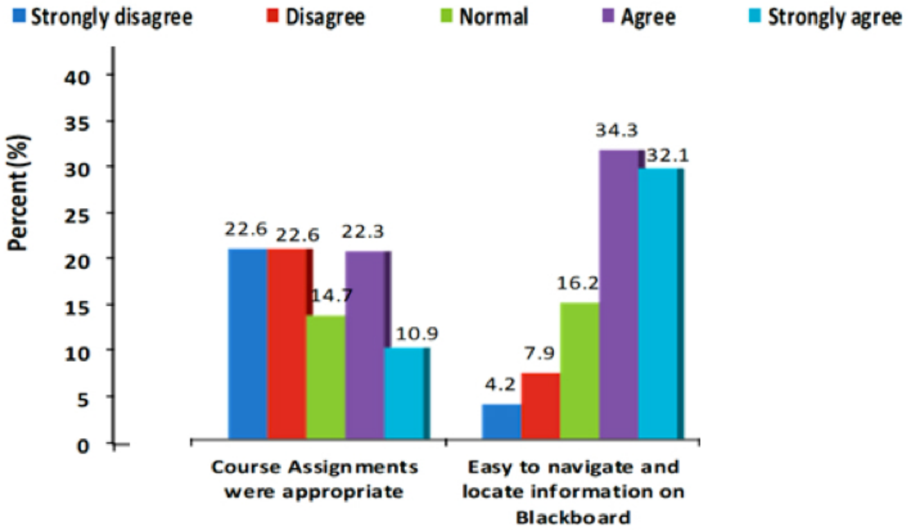


Figure 6. Overall perception about the course.

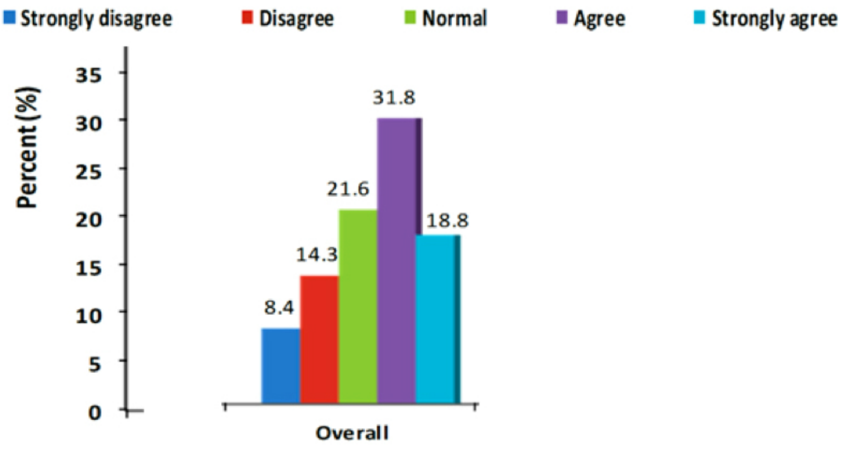
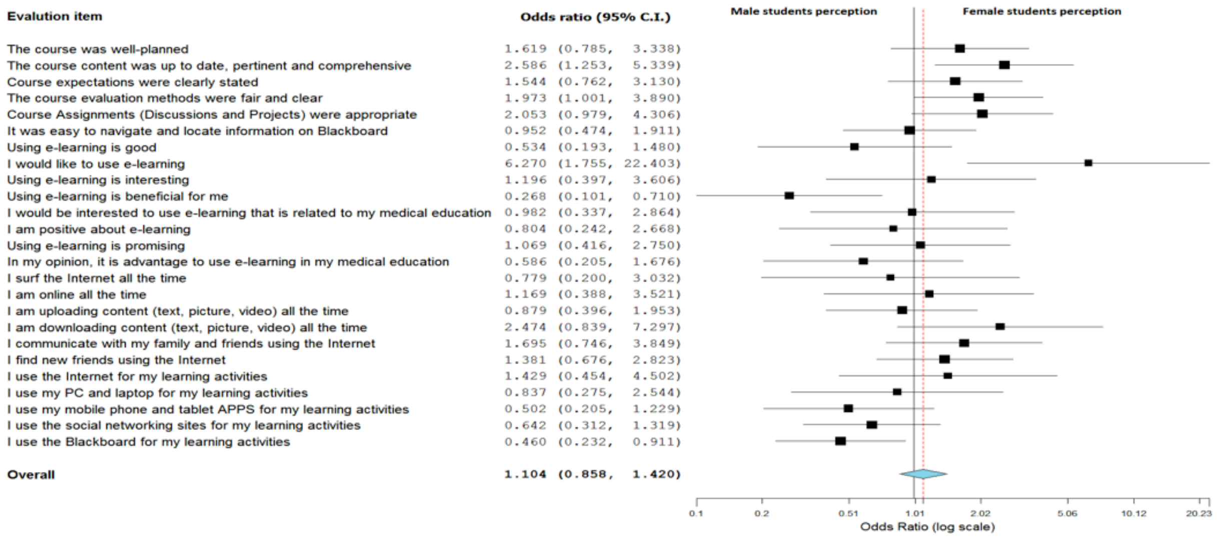


Figure 7. Relationships between student attitudes towards LMS and their Internet proficiency (Logistic Regression model [OR 95% CI, N=243 full case data only] modeling odds for female vs male).



Evalution item	Odds ratio (95% C.I.)
The course was well-planned	1.619 (0.785, 3.338)
The course content was up to date, pertinent and comprehensive	2.586 (1.253, 5.339)
Course expectations were clearly stated	1.544 (0.762, 3.130)
The course evaluation methods were fair and clear	1.973 (1.001, 3.890)
Course Assignments (Discussions and Projects) were appropriate	2.053 (0.979, 4.306)
It was easy to navigate and locate information on Blackboard	0.952 (0.474, 1.911)
Using e-learning is good	0.534 (0.193, 1.480)
I would like to use e-learning	6.270 (1.755, 22.403)
Using e-learning is interesting	1.196 (0.397, 3.606)
Using e-learning is beneficial for me	0.268 (0.101, 0.710)
I would be interested to use e-learning that is related to my medical education	0.982 (0.337, 2.864)
I am positive about e-learning	0.804 (0.242, 2.668)
Using e-learning is promising	1.069 (0.416, 2.750)
In my opinion, it is advantage to use e-learning in my medical education	0.586 (0.205, 1.676)
I surf the Internet all the time	0.779 (0.200, 3.032)
I am online all the time	1.169 (0.388, 3.521)
I am uploading content (text, picture, video) all the time	0.879 (0.396, 1.953)
I am downloading content (text, picture, video) all the time	2.474 (0.839, 7.297)
I communicate with my family and friends using the Internet	1.695 (0.746, 3.849)
I find new friends using the Internet	1.381 (0.676, 2.823)
I use the Internet for my learning activities	1.429 (0.454, 4.502)
I use my PC and laptop for my learning activities	0.837 (0.275, 2.544)
I use my mobile phone and tablet APPS for my learning activities	0.502 (0.205, 1.229)
I use the social networking sites for my learning activities	0.642 (0.312, 1.319)
I use the Blackboard for my learning activities	0.460 (0.232, 0.911)
Overall	**1.104 (0.858, 1.420)**

Focus Group Results

From the focus group, we found that most of the medical students reported that they used multiple resources to help with their learning. Referring to recommended textbooks was a core resource, but they also reported using search engines such as Google to familiarize themselves with the course content. When asked about the interactive tools on the LMS, the participants said it allowed them to learn new computer skills and writing skills. For computer skills, even though they reported being used to computers, they discovered new and useful tools in the LMS. They learned on their own and sought help from peers to resolve any technical issues.

In terms of writing skills, they felt that through the online discussion group they were able to write on specific topics and give comments to their peers. Students did report some technical issues when using the discussion tool, such as difficulties in creating new threads for new discussions, visibility of group members, and formatting of text in the discussion group posts. Again, they found technical solutions through their classmates. One method of getting help from their classmates was to forward screenshots of the LMS site problem to their classmates via email.

The students found the online quiz feature helped them to appreciate the LMS in their studies. They felt that the freedom to take the quiz anywhere and at any time within a particular window made it less stressful and they felt less panicked about taking quizzes. They liked the fact that there were no disturbances (eg, no proctors reminding them about the time), and reported that this helped them to complete their quizzes with ease. They also liked the fact that they were able to get their results immediately after the quiz. However, even though most of them preferred online quizzes to paper-based quizzes, they also said that when they encountered technical difficulties while taking the online quiz, they felt panicked. Another feature they liked was the PowerPoint with audio (using Flash) whereby they could view the slides multiple times and at their convenience to review the lecture content.

In general students said that after some time using the LMS, they were able to cope with this new online environment. They emphasized the importance of getting training on the system early in the semester and of the course coordinator clarifying the expectations regarding online assignments. They expressed the hope that all courses in the College will eventually use the LMS so that they can continue to adapt it into their daily academic lives. Some of them mentioned that they prefer lecturer-student communication to be done within the LMS email system so that they can better organize their learning in a single place, while others prefer using their regular email system. The one feature that they wanted was a notification service that would inform them about updates and announcements on the LMS.

Interestingly, it emerged through the focus group that some students had been running a parallel LMS of their own. The student representative would approach staff for the latest or supplementary files to upload onto an independent non-commercial server that was accessed by a subset of students to support their learning.

Discussion

Principal Findings

The overall attitude towards the LMS was positive among medical students in this institution. A significant odds ratio was found among the female students in regard to their preference for using the LMS. Interestingly, male students also showed high agreement in that they reported using LMS for their learning. Students were clearly using more LMS interactive tools (eg, taking online quizzes, uploading assignments, participating in discussion boards, and reading announcements) by the end of the course than before they took this course. These positive findings agree with other studies that found that an LMS was useful when introduced in medical education [8,14,15].

Significantly, medical students in Saudi Arabia were found to use mobile phones as much they were using PCs. This is consistent with previous study results, which showed that this population have access to mobile phones and find them effective for learning [15]. It also relates to the study of dental students who showed to be engaged with e-learning software using sophisticated high-end devices such as smartphones and tablets [8]. However, the present study found that students were using neither the LMS nor social networking for learning despite using the Internet, PCs, and mobile phones for this purpose. Even though these students gained digital wisdom through their use of LMS tools, we found that they take time to adapt new technologies to learning. Based on the focus group analysis, students are not as engaged in the LMS because not all courses in their medical curriculum are using the system. They would like to see all courses embedded in LMS and official communications made more readily available. Some of the students liked the idea of using email within LMS rather than their personal email. They also wanted a reminder and notification service that would update them with any news announcements, assignments and deadlines.

It is possible that the positive attitude of medical students in embracing LMS was due to the fact that the course content itself included various technologies that will help them in their medical careers. For example, electronic health records, clinical decision support systems, and computerized physician order entry, all of which are technologies that have been shown to increase efficiencies in health care. In addition, during the learning process, the instructors in this course (authors AJ and NZ) applied various technologies such as Flash video and e-voting to capture students’ attention to the subject matter.

The discovery of a parallel student-run LMS is not surprising, given the abilities of our digitally wiser students. Described as “Edupunk”, using free technology to address specific needs has previously been incorporated into large university environments [16]. In addition, prior studies also indicate that students prefer to have online repositories for efficient access to learning resources [10]. This is an exciting opportunity for further research work to explore by us. Exploring which features students are duplicated as well as identifying additional LMS features will give more insight into their utility and student preferences. The teacher-led and student-led LMSs could also be integrated in the future in order to better serve all students. This would also enable the more digitally wise students to contribute to the delivery of the course and expand their skills, thus providing a more student-centered approach and maximizing learning across students of varying ability.

Graz University in Austria propose a combined Student Centered e-Learning (SceL) approach where students explore e-learning tools by themselves in a supportive enviroment [17]. Through this, students have been shown to gain “personal values” such as flexibility, self-confidence, and social skills. They present a case study of a computer science course to highlight how both students and teachers gain from SceL. The researchers emphasize “personalization” and “creativity” as the important ingredients for the LMS. Personalization focuses on user needs while creativity allows educators to explore new pedagogical approaches [16].

Limitations

First, the study was conducted in only one medical college, though it is a well-reputed medical college in the middle-eastern region and includes students from all of Saudi Arabia as well as regional students. This could be considered a limitation. Second, due to the lack of related studies and standardized surveys on this topic, we had to design our own questionnaire. Since this is the first time the questionnaire has been used, that could also be considered a limitation. The questionnaire could be expanded to yield a more precise evaluation of student attitudes, perception, and feedback regarding e-learning and LMS .

Another aspect that we did not explore in this research is the extent to which students have been previously exposed to technology [18]. We did not measure what other devices they may be familiar with and how this impacts LMS usage. Holzinger et al [18] describe how elderly users are able to accept new technology when they can relate to it through metaphors and to technology they have previously been exposed to.

Conclusions

The present study's findings indicate that most of the students found the medical informatics course to be organized and has good content. Female students preferred this course more strongly than male students. Overall, we found students were successful in adapting various learning technologies and continuously experimenting to make better utilization of the LMS for their learning. This includes some students using their own online tools to maintain a parallel LMS. In future, we expect students will expand their use of the LMS when all medical courses are fully integrated in LMS. We intend to further investigate the student-led LMS in order to optimize the tools we offer our students and involve them in their delivery for an enhanced student-centered experience.

Acknowledgments

This study was funded by the College of Medicine Research Center, Deanship of Scientific Research, King Saud University, Riyadh, Kingdom of Saudi Arabia. It covers all editorial fees, conference fee, and travel fee.

Conflicts of Interest

None declared.

References

1. Robin BR, McNeil SG, Cook DA, Agarwal KL, Singhal GR. Preparing for the changing role of instructional technologies in medical education. Acad Med 2011 Apr;86(4):435-439. [doi: 10.1097/ACM.0b013e31820dbee4] [Medline: 21346506]
2. Ruiz JG, Mintzer MJ, Leipzig RM. The impact of E-learning in medical education. Acad Med 2006 Mar;81(3):207-212. [Medline: 16501260]
3. Jhaveri KD, Malieckal D, Israel E, Vachharajani T. Nephrology education in the electronic era: A case based review. Open Urol Nephrol J 2012;5:29-32.
4. College of Medicine, King Saud University, Riyadh. 2010. KSU establishes deanship in e-learning and distance learning URL: http://enews.ksu.edu.sa/2010/03/20/saudi-arabia-ksu-deanshipe-learning-and-distance-learning/ [accessed 2013-11-02] [WebCite Cache ID 6KoHXTO54]
5. College of Medicine, King Saud University, Riyadh. 2010. Deanship of e-learning announces Blackboard exemplary course program URL: http://enews.ksu.edu.sa/2010/12/06/blackboard-competition/ [accessed 2013-11-02] [WebCite Cache ID 6KoHnKdbV]
6. Medical Education Department, College of Medicine, King Saud University. 2013. Medical Informatics and E-learning Unit (MIELU) URL: https://www.facebook.com/Ksumielu [accessed 2013-11-02] [WebCite Cache ID 6KoIMjDZk]
7. Prensky M. Digital natives, digital immigrants Part 1. On the Horizon 2001;9(5):1-6 [FREE Full text] [doi: 10.1108/10748120110424816]
8. Schulz P, Sagheb K, Affeldt H, Klumpp H, Taylor K, Walter C, et al. Acceptance of e-Learning devices by dental students. Med 2.0 2013;2(2):e6-e5 [FREE Full text] [doi: 10.2196/med20.2767]
9. Prensky M. H Sapiens digital: From digital immigrants and digital natives to digital wisdom. Journal of Online Education 2009;5(3) [FREE Full text]
10. Maloney S, Chamberlain M, Morrison S, Kotsanas G, Keating JL, Ilic D. Health professional learner attitudes and use of digital learning resources. J Med Internet Res 2013;15(1):e7 [FREE Full text] [doi: 10.2196/jmir.2094] [Medline: 23324800]
11. College of Medicine, King Saud University, Riyadh. 2013. Medical informatics: Integrating tech key to physician education URL: http://enews.ksu.edu.sa/2013/04/16/medical-informatics-integrated-tech-key-to-physician-education/ [accessed 2013-11-02] [WebCite Cache ID 6KoIiNj65]
12. Salkind NJ. Exploring research. Upper Saddle River, N.J: Pearson/Prentice Hall Higher Education; 2009.
13. Kitzinger J. Qualitative research. Introducing focus groups. BMJ 1995 Jul 29;311(7000):299-302 [FREE Full text] [Medline: 7633241]
14. Schopf T, Flytkjær V. Doctors and nurses benefit from interprofessional online education in dermatology. BMC Med Educ 2011;11:84 [FREE Full text] [doi: 10.1186/1472-6920-11-84] [Medline: 21999114]
15. Fahad NF. Students' attitudes and perceptions towards the effectiveness of mobile learning in King Saud University. Turkish Online Journal of Education Technology 2009;8(2):111-119 [FREE Full text] [doi: 10.1007/1-84628-248-9_18]
16. Ebner M, Holzinger A, Scerbakov N, Tsang P. Edupunks and learning management systems- conflicts or chance? In: Kwan R, editor. Hybrid Learning. Berlin: Springer Berlin Heidelberg; Aug 10, 2011:224-238.
17. Motschnig-Pitrik R, Holzinger A. Student-centered teaching meets new media: Concept and case study, educational technology and society. Journal of Educational Technology & Society 2002;5(4):1-18 [FREE Full text]
18. Holzinger A, Searle G, Wernbacher M. The effect of previous exposure to technology on acceptance and its importance in usability and accessibility engineering. Univ Access Inf Soc 2010 Oct 8;10(3):245-260 [FREE Full text] [doi: 10.1007/s10209-010-0212-x]

Abbreviations

DxR: Diagnostic Reasoning

KSU: King Saud University
LMS: Learning Management System
MIELU: medical informatics and e-learning Unit
OR: odds ratio
PACS: picture archiving and communication system
SceL: student centered e-learning

Edited by G Eysenbach; submitted 27.05.13; peer-reviewed by L Sherman, A Holzinger, M Masoni; comments to author 18.07.13; revised version received 20.08.13; accepted 08.10.13; published 27.11.13.

Please cite as:
Zakaria N, Jamal A, Bisht S, Koppel C
Embedding a Learning Management System Into an Undergraduate Medical Informatics Course in Saudi Arabia: Lessons Learned
Med 2.0 2013;2(2):e13
URL: http://www.medicine20.com/2013/2/e13/
doi:10.2196/med20.2735
PMID:25075236

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org