interactive Journal of Medical Research

Impact Factor (2022): 2.0
Volume 2 (2013), Issue 1 ISSN 1929-073X

Contents

Brief Report

Does Socioeconomic Status Affect Patients' Ease of Use of a Touch-Screen (iPad) Patient Survey?

Saman Zarghom[1], B.Sc; David Di Fonzo[2]; Fok-Han Leung[3], B.Sc (Hons), MHSc, MD, CCFP

[1]University of Toronto, Faculty of Medicine, Toronto, ON, Canada

[2]University of Toronto, Faculty of Kinesiology and Physical Education, Toronto, ON, Canada

[3]University of Toronto, Department of Family and Community Medicine, Toronto, ON, Canada

Corresponding Author:
Fok-Han Leung, B.Sc (Hons), MHSc, MD, CCFP
University of Toronto
Department of Family and Community Medicine
St. Michael's Hospital, Health Centre at 80 Bond
80 Bond Street
Toronto, ON, M5B 1X2
Canada
Phone: 1 4168643011
Fax: 1 4168643099
Email: leungf@smh.ca

Abstract

Socioeconomic disparities influence the usage rate of advanced communication technologies in Canada. It is important to assess all patient interactions with computers and electronic devices based on these socioeconomic differences. This project studied the ease of use of a touch-screen interface program for collecting patient feedback. The interface collected feedback on physicians' communication skills, an important health concern that has been garnering more and more attention. A concurrent paper survey was used to gather information on the socioeconomic status and the usability of the touchscreen device. As expected, patients who were older, had lower annual household income, and had lower educational attainment were associated with more difficulty using the devices. Surprisingly, 94% of all users (representing a wide range of socioeconomic status backgrounds) rated the device as easy to use.

(Interact J Med Res 2013;2(1):e1) doi:10.2196/ijmr.2314

KEYWORDS

socioeconomic factors; age factors; medical informatics; computer-user interface

Introduction

Education and literacy are important determinants of health. Unemployment, poverty, and poor health are more common amongst Canadians with low literacy rates [1]. Income and educational level also influence the usage of the new communication technology. The use of the Internet by Canadians is influenced by income, education, and age [1]. This research project studied the usability of a new touch interface program for collecting patient feedback. The feedback focused on physician communication skills [2-5] as part of a larger initiative to target staff and resident education. Previous studies have demonstrated patient opinion as a reliable proxy for the strength of physician communication skills [2,3]. This current study looks at the feasibility of using touch screen interfaces for patients, examining touch screen use, and socioeconomic markers. We wanted to ensure that, prior to implementing touch screen interfaces more widely, that its use would be equitable.

Methods

The target population of this study was all of the English-speaking patients over 18 years of age who received medical care from the 80 Bond Street family clinic in Toronto, Canada, between January 1 and March 1, 2011. The local research ethics board approved the study. To assess the usability of the touch screen interface and to collect the socioeconomic status data of the sample population, a paper-based survey was developed and used in conjunction with the touch screen. Following routine registration, patients were approached in the waiting room with a touch screen device. A convenience sample was collected; every patient in the waiting room was approached. After consenting, patients used the touch screen

device to answer questions on physician communication skills. Patients were then provided a paper survey inquiring about device usability. Responses on the paper surveys were analyzed using Pearson's chi-square test without Yates correction. Statistical significance was set at $P<.05$.

Results

490 patients were approached for the study with a 72% response rate (N=353) representing a broad range of socioeconomic statuses, while 130 declined and 7 participants were excluded (non-responders, Table 1). All results were patient self-reported.

Table 1. Demographic information of electronic feedback users.[a]

Category	n (%)
Age	
<50	224/352 (63.6)
≥50	128/352 (36.4)
Gender	
Male	168/348 (48.3)
Female	180/348 (51.7)
Income	
<50k	168/329 (51.1)
≥50k	161/329 (48.9)
Education	
No university degree	172/348 (49.4)
University degree	176/348 (50.6)

[a]note variation in sum of numbers due to non-responders

Ease of Use

Ease of use was a patient self-reported measure. Older age (≥50 years), lower income (<$50,000), and lower educational status (P=.03) were associated with statistically significant difficulty using the touch screen device (Table 2). Conversely, younger age (<50 years) ($P<.001$), higher income (≥$50,000) ($P<.001$), and higher educational status (university/college degree completed) (P=.03) were associated with significant ease of use for the touch screen device (Table 2).

Table 2. Ease of use rating by patients.[a]

Category	Very easy/easy n (%)	Neutral/difficult n (%)	*P* value
Age			
<50	214/221(96.8)	7/221(3.2)	<.001
≥50	104/127(81.9)	23/127 (18.1)	<.001
Income			
<50K	114/138(82.6)	24/138 (17.4)	<.001
≥50K	188/192(97.9)	4/192 (2.1)	<.001
Education			
No university degree completed	154/175(88.0)	21/175 (12.0)	.03
University degree completed	160/169(94.7)	9/169 (5.3)	.03

[a]note variation in sum of numbers due to non-responders

Likelihood of Reuse

Older age (≥50 years), and lower educational status (no university/college degree completed) were associated with significant likelihood of not reusing the touch screen device (Table 3). Conversely, younger age (<50 years), and higher educational status (university degree) were associated with significant likelihood of reusing the touch screen device (Table 3).

Table 3. Likelihood of reuse rating by patients.[a]

Category	Very likely/likely n (%)	Neutral/unlikely n (%)	*P* value
Age			
<50	193/221(87.3)	28/221(12.7)	<.001
≥50	90/125(72.0)	35/125(28.0)	<.001
Income			
<50K	131/165(79.4)	34/165 (20.6)	.32
≥50K	133/159(83.6)	26/159(16.4)	.32
Education			
No university degree completed	133/173(76.9)	40/173 (23.1)	.02
University degree completed	146/169(86.4)	23/169 (13.6)	.02

[a]note variation in sum of numbers due to non-responders

Likelihood to Recommend

Older age (≥50 years) was associated with significant likelihood of not recommending use of the touch screen device (Table 4). Conversely, younger age (<50 years) was associated with significant likelihood of recommending use of the touch screen device (Table 4).

Table 4. Likelihood to recommend by patients.[a]

Category	Yes n (%)	No n (%)	*P* value
Age			
<50	213/217 (98.2)	4/217 (1.8)	.01
≥50	114/123 (92.7)	9/123 (7.3)	.01
Income			
<50K	152/162 (93.8)	10/162 (6.2)	.06
≥50K	153/156 (98.1)	3/156 (1.9)	.06
Education			
No university degree completed	164/170 (96.5)	6/170 (3.5)	.75
University degree completed	160/167 (95.8)	7/167 (4.2)	.75

[a]note variation in sum of numbers due to non-responders

Discussion

As one might intuit, our results show that older age, lower income, and lower educational attainment were factors associated with significant difficulty using the touch screen device when compared with those that are younger, with greater income, and with greater educational attainment. The surveyors observed that some of the older users, particularly those with motor difficulties (eg, tremor), seemed to struggle to adapt to the sensitivity and responsiveness of the touch screen. Older age was also associated with lower chances of using the program in future visits and recommending the program to others. These findings point to the importance of maintaining routes for patient feedback other than touch screens—while touch screens present significant efficiencies in the collection and collation of patient feedback data, patient equity must also be considered.

While there was a statistically significant difference in the patient ratings when considering age, income, and education, it should be noted that there was an overall high rating for ease of use. The participation/response rate was also very high. These findings very strongly suggest that touch screen technology can play an important role in acquiring successful patient surveys. While there is scant research on the use of touch screens in clinical waiting rooms, the existing literature on human computer interactions and interfaces supports the increased use of touch screens [6]. This study was performed in an inner city clinic, and given the overall high ratings (owing to the statistically significant findings), the results indicate that using touch screen technology for patient feedback is feasible. Furthermore, given the globally high participation rate and positive results, touch screen technologies might also play a role in encouraging health consumer equity.

In using a convenience sample, some selection bias could have been introduced. The study only considered one clinical setting. The sample size was also limited. Further study is warranted. However, this study answered an important feasibility question.

Touch screen interfaces can be easy to use, and can represent an accessible way for patients to provide feedback. This has implications for all clinics interested or engaged in quality initiatives to enhance patient satisfaction with their physicians.

Conflicts of Interest

None declared.

References

1. Monday, May 1, 2010. Public Health Agency of Canada. Ottawa: Public Health Agency of Canada; 2012 Aug 21. What Makes Canadians Healthy or Unhealthy URL: http://www.phac-aspc.gc.ca/ph-sp/determinants/determinants-eng.php#unhealthy [accessed 2010-11-02] [WebCite Cache ID 6DNJchOFe]
2. Stewart, Moira A. Effective Physician-patient Communication and Health Outcomes: a Review. Canadian Medical Association Journal 1995 May 01;152(9):1423-1433. [Medline: 7728691]
3. Bull SA, Hu XH, Hunkeler EM, Lee JY, Ming EE, Markson LE, et al. Discontinuation of Use and Switching of Antidepressants: Influence of Patient-Physician Communication. The Journal of the American Medical Association 2002 Sep 18;288(11):1403-1409. [Medline: 12234237]
4. Bogardus ST, Holmboe E, Jekel JF. Perils, Pitfalls and Possibilities in Talking About Medical Risk. The Journal of the American Medical Association 1999 Mar 17;281(11):1037-1041. [Medline: 10086441]
5. Stelfox TH, Gandhi TK, Orav EJ, Gustafson ML. The Relation of Patient Satisfaction with Complaints against Physicians and Malpractice Lawsuits. American Journal of Medicine 2005 Oct;118(10):1126-1133. [Medline: 16194644]
6. Hartson HR, Gray PD. Temporal Aspects of Tasks in the User Action Notation. Human Computer Interaction 1992 Mar;7(1):1-45.

Edited by G Eysenbach; submitted 16.08.12; peer-reviewed by P Rich, D Kaplan, A Ozok, S Porter, A Roundtree, V Isetta; comments to author 08.11.12; revised version received 14.12.12; accepted 17.12.12; published 11.01.13.

Please cite as:
Zarghom S, Di Fonzo D, Leung FH
Does Socioeconomic Status Affect Patients' Ease of Use of a Touch-Screen (iPad) Patient Survey?
Interact J Med Res 2013;2(1):e1
URL: http://www.i-jmr.org/2013/1/e1/
doi:10.2196/ijmr.2314
PMID:23612116

Viewpoint

Physio-Environmental Sensing and Live Modeling

Filippo Castiglione[1], Ph.D; Vanessa Diaz[2], Ph.D; Andrea Gaggioli[3,4], MS, Ph.D; Pietro Liò[5], Ph.D; Claudia Mazzà[6], Ph.D; Emanuela Merelli[7], Ph.D; Carel G.M Meskers[8], MD, Ph.D; Francesco Pappalardo[9], Ph.D; Rainer von Ammon[10], Ph.D

[1]Istituto per le Applicazioni del Calcolo, National Research Council of Italy, Rome, Italy

[10]Center of Information Technology Transfer GmbH, Regensburg, Germany

[2]Multiscale Cardiovascular Engineering Group, Department of Mechanical Engineering, University College London, London, United Kingdom

[3]Department of Psychology, Catholic University of Milan, Milan, Italy

[4]Applied Technology for Neuro-Psychology Lab, Istituto Auxologico Italiano, Milan, Italy

[5] Computer Laboratory, Department of Computer Science, University of Cambridge, Cambridge, United Kingdom

[6] Department of Human Movement and Sport Sciences, Università degli Studi di Roma "Foro Italico", Rome, Italy

[7]School of Science and technology, Computer Science Division, University of Camerino, Camerino, Italy

[8]Willem-Alexander Children's Hospital, Department of Rehabilitation Medicine, Leiden University Medical Center, Leiden, Netherlands

[9]Dipartimento di Scienze del Farmaco, Università degli Studi di Catania, Catania, Italy

Corresponding Author:
Filippo Castiglione, Ph.D
Istituto per le Applicazioni del Calcolo
National Research Council of Italy
Viale Manzoni 30
Rome, 00185
Italy
Phone: 39 067716452
Fax: 39 067716461
Email: f.castiglione@iac.cnr.it

Abstract

In daily life, humans are constantly interacting with their environment. Evidence is emerging that this interaction is a very important modulator of health and well-being, even more so in our rapidly ageing society. Information and communication technology lies at the heart of the human health care revolution. It cannot remain acceptable to use out of date data analysis and predictive algorithms when superior alternatives exist. Communication network speed, high penetration of home broadband, availability of various mobile network options, together with the available detailed biological data for individuals, are producing promising advances in computerized systems that will turn information on human-environment interactions into actual knowledge with the potential to help make medical and lifestyle decisions. We introduced and discussed a key scenario in which hardware and software technologies capable of simultaneously sensing physiological and environmental signals process health care data in real-time to issue alarms, warnings, or simple recommendations to the patient or carers.

(Interact J Med Res 2013;2(1):e3) doi:10.2196/ijmr.2092

KEYWORDS

personalized health care, mobile networks, computer models, telediagnosis

Introduction

Overview

A proper knowledge of the interaction between human physiology and daily living environmental conditions is essential to establish a connection between an individual's lifestyle and his/her health status. Understanding these connections will give insight to the effect of pollution on human health.

Most modern prevention or intervention approaches rely deeply on early, accurate, and broad diagnosis, followed by close monitoring of the outcomes. This latter task is carried out by occasional screening and typically produces a series of time dependent snapshots at different levels (eg, biochemical, mechanical, cellular, and molecular). From a biological point of view, every human individual has a different susceptibility to disease. This simple observation has resulted in the concept

of personalized medicine and procedures [1]. However, for a personalized treatment to be really effective, accurate individualized information obtained at various levels in a continuous fashion is needed, possibly extending to acquiring a screen of the patients' home environment.

The aging European Union (EU) population (and of all industrialized countries in general) and the increase in life expectancy are causing a rapid increase of the number of patients with multimorbidity and neurological diseases such as mild cognitive impairment or Alzheimer's. In this context, the above-described approach in which data are collected in a haphazard way will not suffice anymore. There is an urgent need to shift medical care from institutions to the daily living environment of patients to ensure a continuous follow-up. In addition to this clinical need, there is an economical urgency calling for care distributed differently than the traditional methods. The existing low ratio between care providers and care seekers will become even lower and the growing costs of assistance will soon become unsustainable. Information and communication technology (ICT) tools are already being proposed and studied to provide a solution to these problems, but much more is still expected.

One important aspect is that in general, elderly patients have a more limited capacity to deal with environmental challenges. Moreover, there is increasing evidence that the onset and course of highly prevalent diseases such as stroke, diabetes, and arthrosis are shaped by human environmental interaction (ie, mobility). Assessment and understanding of human-environmental interaction in daily life is therefore of vital importance to design targeted intervention paradigms that aim to optimize conditions such as muscle state, neural plasticity, sensorimotor integration, and internal physiological processes such as insulin metabolism or inflammation. This promotes healthy aging and self-dependency.

Technological Platforms and Services

The use of technological tools allowing setup of a one-to-many relationship between doctors and patients is potentially an effective strategy for ensuring the necessary quality and intensity of treatment at a sustainable cost [2]. Technological platforms, moreover, allow quantifying the specific progress of a patient, facilitating modulation and customization of treatments, and consequently, a faster recovery. In this respect, a growing number of Web services offer the possibility to track and compare health data. For example, CureTogether [3] allows users to anonymously track various health measures (including symptoms, treatment plans, and medication schedules) and share them with other individuals having the same conditions. Aggregated data can be then analyzed to identify trends and eventually highlight the most effective treatments. Other medical-oriented social networks are appearing, which provide users with tools to track their health status. Collected data, once anonymized, can be used for research purposes, in order to assess, for example, patterns of drug usage or investigate side effects. For instance, PatientsLikeMe [4] is an online platform for patients to share their experience using patient-reported outcomes, find other patients like them, and learn from others' data to improve their outcomes. The site has gathered a huge quantity of data, with nearly 125,000 members (as of January 2013) spanning a number of different disease communities, including epilepsy, fibromyalgia, and depression.

Personalization of Treatment and Decisions

Personal medical informatics offers the possibility to store and access data from our daily life and to improve self-knowledge. Insights gained from these measurements can be used, for example, to change life-threatening habits, adopt healthier lifestyle, or make better-informed treatment decisions. From this perspective, the Continua Health Alliance defines personal health system as an "ecosystem of connected technologies, devices, and services" that will enable an "exchange of fitness, health, and wellness information", in order to "build a community of care" [5]. The final objective of these interoperable personal telehealth solutions is to help health care providers and patients meet "their fitness goals, better manage their chronic diseases, and live independently as they age" [6]. This has been considered in a European-wide context and the EU is currently funding road-mapping exercises for the Digital Patient [7] for example. It is clear that this objective has to be accomplished using a sensitive, respectful, and non-invasive approach, which should not interfere with the patients' quality of life, and most importantly, should be based on the use of affordable and cost-effective solutions.

Luckily, this objective is within reach. Actually, much of the world now enjoys unprecedented network speed, high penetration of home broadband, and availability of various mobile network options. In this massively interconnected world, capillary information is potentially available to improve medical systems. However, several technical and non-technical issues need to be addressed for the realization of this vision. In particular, the present paper addresses the following key questions: (1) Is it possible to develop new hardware-software technologies capable of simultaneously sensing physiological and environmental signals (eg, temperature, noise), for prolonged times, with little or no invasiveness, and with a level of comfort that ensures wide acceptability? (2) Is it possible to process sensed data in real-time and feed them to integrative models to issue alarms, warnings, or simple recommendations to the subject or to the carers when needed?

Monitoring Devices

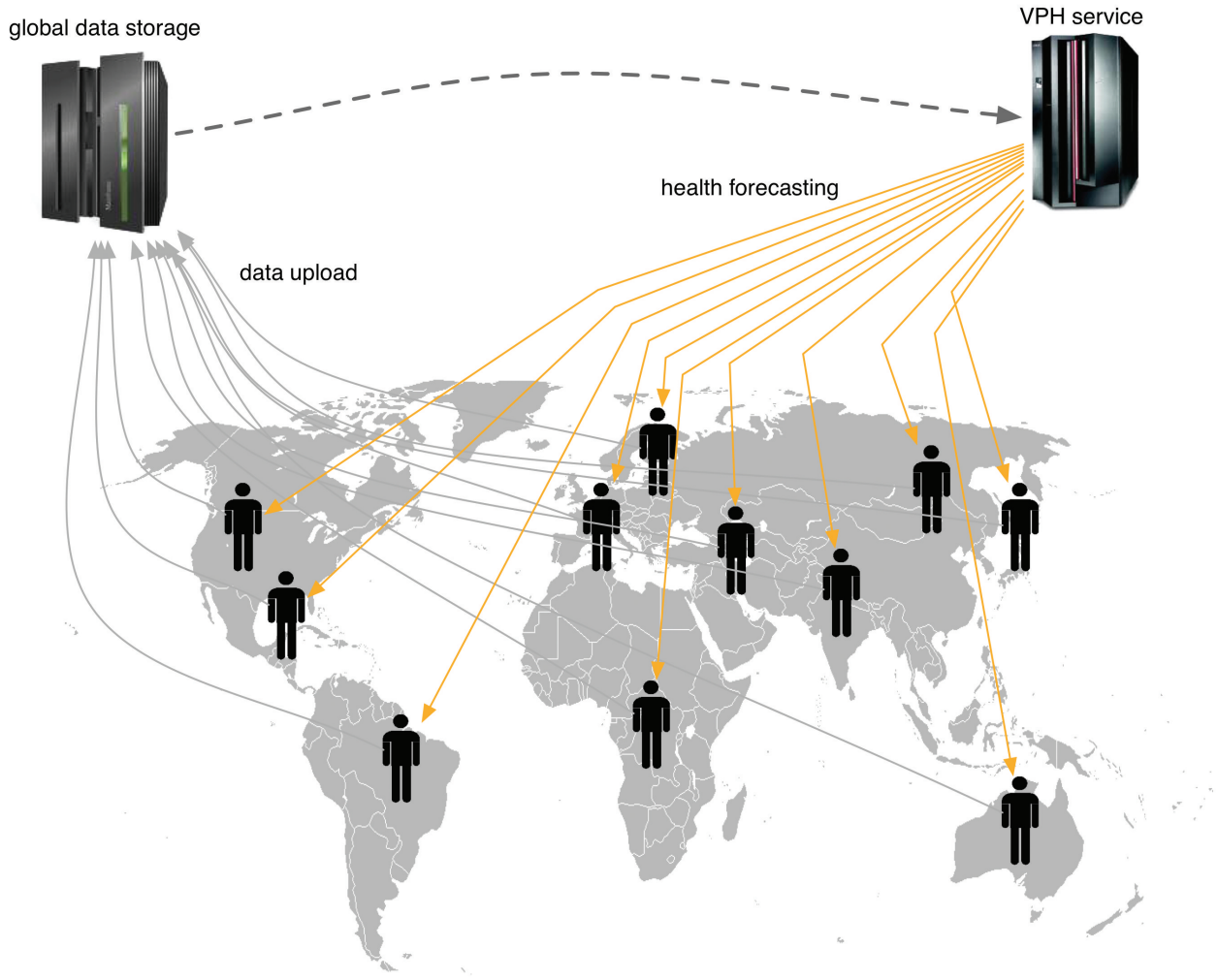
The last decade has witnessed a rapid surge of interest in sensing and monitoring devices for health care and in the use of wearable/wireless devices for a large number of biomedical applications. Body sensors are small pieces of little or non-invasive equipment that measure biophysical parameters (eg, heart beat rate or body temperature). Body sensor technology is growing rapidly (the first international workshop on body sensors was launched in 2004 [8], while the pHealth conference was, as of 2011, already at its 8th edition [9]) and it is becoming available at affordable prices. Similarly, home environments are becoming more and more instrumented, interconnected, and intelligent [10]. The possibility of connecting these data measurement devices with portable communication systems (ie, smartphones) allows for the development of smarter, connected personal health care systems,

with the aim to improve diagnosis, treatment, and condition management.

The emergence of body computing is an on-going revolution in hospitals where physicians, medical engineers, and technical personnel deploy handheld mobile devices as clinical computing tools [6,11-15]. The use of tablets and mobile devices coupled with wireless sensor systems (ie, electrocardiography, electroencephalography, electromyography) has the potential to improve quality of care by providing interactive information to institutionalized patients and by facilitating day-hospital and home monitoring activity.

However, despite its promises, this approach has found very limited applications. A key barrier is the low integration between mobile and sensor technologies, as different brands use proprietary software platforms for data monitoring and visualization systems. Besides that, a global architecture (or paradigm of data handling at large) for collecting, storing, and using this huge amount of data at a level that can potentially be worldwide, is still missing. A second bottleneck is data analysis. Nowadays, data are stored in databases and mainly analyzed offline, with delayed benefits for everybody, especially for the patients who actually provided the information (this obviously clashes with the personalized medicine concept). There is an urgent need for high frequency data mining, machine learning, and signal processing algorithms to integrate and translate large amounts of data into straightforward readable parameters. These data analysis tools should be based on constantly updated databases, on development of novel statistical methods of causal inference which will be applied to answer causal questions emerging from the data, and on improved pathophysiological models able to interpret data in a predictive, proactive, and possibly automatic, manner. Models predicting the occurrence of a certain event or the emergence of certain behaviour at individual or population level would provide an extraordinary instrument for real-time monitoring. Analytical programs monitoring the sensor data and using rules and logic constraints to describe both the environment and the patient health and to compare against targets, would allow tracking of progress against goals and send alerts when needed (Figure 1). Therefore, health monitoring solutions can become more intuitive, comprehensive, and affordable. Potentially useful applications of these sensor-model integrated systems include (but are not limited to): (1) monitoring patients with chronic diseases (eg, mild cognitive impairments, diabetes, epilepsy, chronic cardiac diseases, progressive renal diseases, and atherosclerosis), (2) monitoring patients that are hospitalized and need frequent probes, (3) monitoring patient's addiction recovery and long-term drug treatment, (4) monitoring of elderly patients in the daily assessment of generic health conditions. One may raise the point that from the perspective of a developing country, personalized applications might not be economically viable also because prevalent disease pattern differs. However, it is worth to note that the same devices and supportive infrastructure can be tweaked for both clinical and laboratory diagnosis at the health facility level [16]. Indeed, an initiative that is working to address this already exists—the MoDiSe [17].

Figure 1. Users upload data via mobile network devices. They get health forecast services through the Web or through ad hoc mobile applications.



Discussion

Sensors and Models Synergy

As there is a need of flexible ICT tools for supporting software developing in this new application domain, the synergy between computational models and body sensor technology is both imperative and easy to reach. On the one hand, sensors will feed realistic data-driven models for their calibration and validation in areas where this process has traditionally been difficult. On the other hand, predictive models will allow to assess the impact on the population, to optimize the allocation of resources and to devise mitigation and containment interventions to reduce economic and social disruption. Only a perfect intertwining of the two components will make the overall system efficient and efficacious. A crucial feature will be the easiness of use and accessibility to data. In fact, the success of this combined process of data collection, data analysis, and health forecasting will strongly depend on how easy it will be to share the data and to receive information back from the available servers.

The building blocks of such health care distributed system span across areas such as mobile devices, home-based devices, Web-based resources, electronic health records and personal health records. Hence, its development will involve alliances made up from device makers (electronics industry), health care industry, computational modellers (life science researchers) and ultimately also policy makers to institutionalize the integration of this system in the national health care one. It is worth considering the efforts of the Continua Alliance in creating a standardized platform for integrating multiple devices for personalized care [5].

The discussion can be broken down to the following research, technological, conceptual, and societal challenges: (1) developing a whole spectrum of wearable body sensors, (2) developing data communication systems that is secure and allows partial anonymous retrieval to third parties, (3) developing robust storage systems that is extensible and upgradable, (4) developing information systems including computational methods and models exploiting collected such data, (5) developing smart and self-adaptive systems for monitoring the human health.

Body Sensors

Developing a whole spectrum of wearable sensors capable of measuring cheaply and possibly non-invasively is one of the major challenges, entailing also the development of home-environment sensors that can seamlessly communicate with either public and private wireless or mobile networks to connect to personal data hubs.

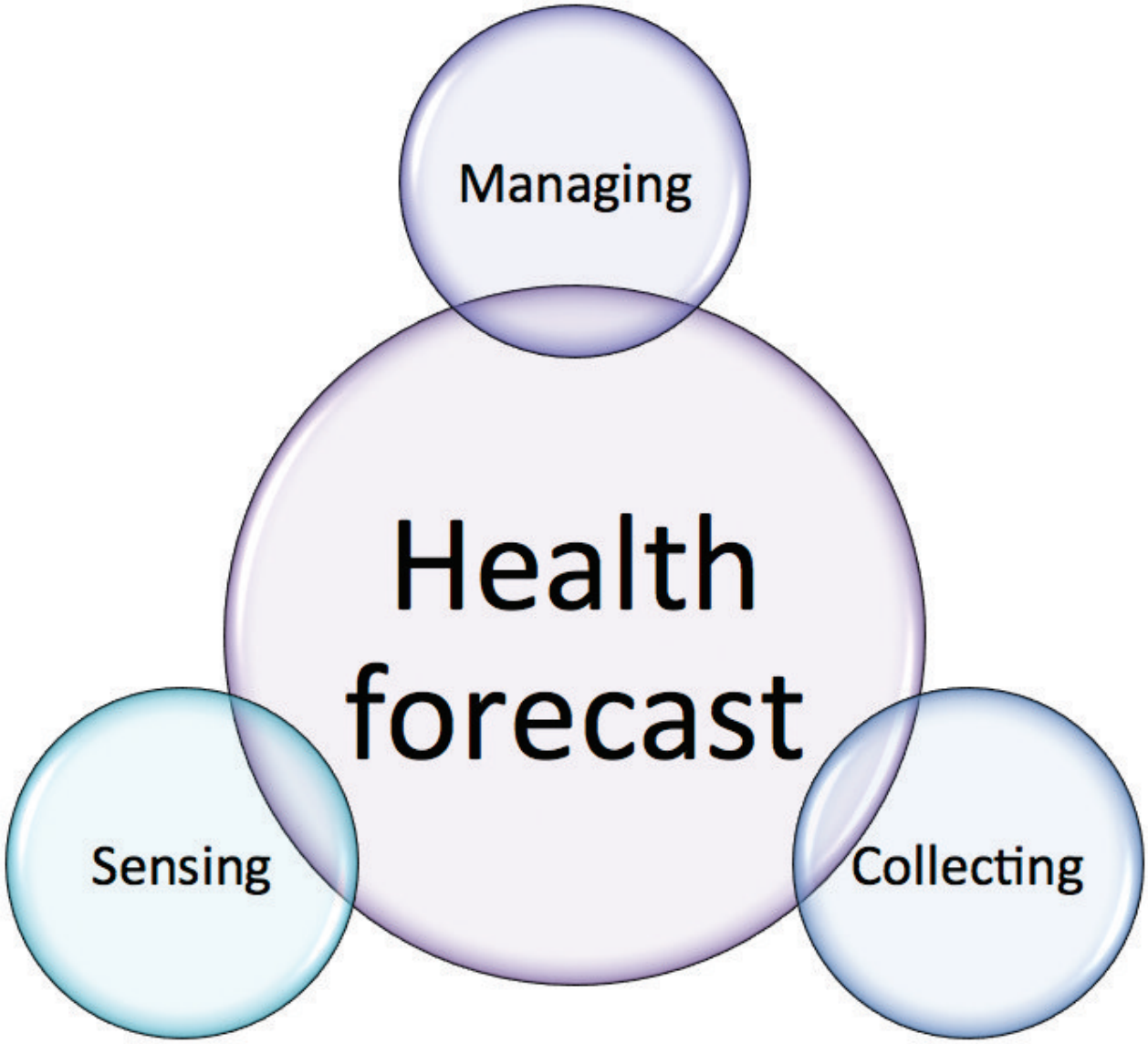
Body sensor research and manufacturing are in continuous and rapid evolution in terms of material, multiphysics, and multiscale physiological integration. Available sensors include electrochemical, optical, and gravimetric sensors and allow for measurements ranging from the whole body scale (inertial devices for movement measurements) to the body structure level (textile-based devices for biological signal monitoring), to the so-called bioelectric diagnostic chips able to scan bodily fluids for various markers of minor illness and disease [18]. See Figure 2 for examples of personal biomedical devices. New and most advanced protein-based sensors are especially interesting as environmental pollutants detectors (ie, sensors based on the folding of proteins, peptides, and DNA when they come into contact with compounds of interest).

Research on implantable in vivo monitoring devices faces problems such as long-term stability and biocompatibility, system integration, sensor miniaturization, low-power sensor interface circuitry design, wireless telemetric links, and on board signal processing. Apart from technological considerations, a lot of effort in this area is devoted to quality and trust of the service/device. In fact, the level of user acceptance strongly depends on how reliable, and hence useful, the proposed technology is, and on how noticeably its output improves his/her quality of life.

The degree of invasive surgery required to implant such devices depends on the type of user. While chronic patients or elder people are more likely to accept technology which promises an improvement in quality of life, healthy individuals might adverse it. This advocates the elderly to be targeted first.

Figure 2. Examples of personal biomedical devices (Source: Continua Health Alliance [4]).

Figure 3. The task of sensing, collecting, and managing the data gains a larger significance when combined together with the possibility to produce new and valuable information on the health status of single individuals or entire populations.



Data Communication Systems

The data communication network is already available, as it can rely on common data/voice network technology plus the Internet through use of smartphones and tablets. For what concerns the area of wireless sensor networks that could provide interesting solutions for the home and pollution detection sensors, it is necessary to develop wireless protocols, to address the problem of their security, as well as problems related to the performance of large distributed systems, fault tolerance, and anomaly detection.

What needs to be developed is a bulletproof communication workflow that goes from the individual to the storage facility in an anonymous and secure way. Whereas in principle the data could be stored locally on the device and only later uploaded through a secure connection, in general, embedded systems do not have the possibility to store a large amount of data. Hence the development of secure protocols for run-time measurements upload is required.

Imagine a physician's tool that could evaluate, in minutes or possibly seconds, a wealth of data from connected health devices plus the complete medical history of a patient and all available medical literature (such as medical records, texts, journals, research documents, and even on-going clinical trial results), much of which is unstructured information written in natural language. This application could suggest possible diagnoses complete with documented reasoning or, alternatively, request additional, seemingly unimportant information needed to test hypotheses.

This idea of tracking progress and stay motivated or to monitor chronic conditions and share data with the personal doctor was the original idea behind Google Health [19] that, unfortunately, has been discontinued (end of 2011) because an unexpected insufficient participation to the project. A similar effort (still operational at the time of this writing) is the Microsoft HealthVault [20].

Storage Systems

The data collection needs to be organized by using taxonomies that are well accepted within and beyond the community of experts dedicated to the development of computational models. For what concerns data standards there exist at least a couple of interesting projects going on. One is the standard for data storage and communication already developed and adopted by both Google Health and Microsoft HealthVault called Continuity of Care Record (CCR) [21] proposed by the American Society for Testing and Materials [22]. This standard is a core data set of the most relevant administrative, demographic, and clinical information facts about a patient's health care, covering one or more health care encounters. It provides a means for one health care practitioner, system, or setting to aggregate all of the pertinent data about a patient and forward it to another practitioner, system, or setting to support the continuity of care. The primary use case for the CCR is to provide a snapshot in time containing the pertinent clinical, demographic, and administrative data for a specific patient [21]. The second is Direct Project launched by the US department of Health and Human Services with the Nationwide Health Information Network initiative in March 2010 [23]. National Health Services (NHS) Interoperability Toolkit [24] in the UK and Healthcare Interoperability Testing and Conformance Harmonisation (HITCH) [25] in the EU are also similar on-going initiatives.

The driving philosophy behind these two efforts is in line with the matter of the present paper. In particular, communication of health information among health care organizations, providers, and patients is traditionally achieved by sending paper through the mail or fax. The development of a standard for data exchange seeks to benefit patients and providers by improving the transport of health information, making it faster, more secure, and less expensive. It will facilitate direct communication patterns with an eye toward approaching unprecedented levels of interoperability.

From an ICT point of view, the development of a general storage system consisting of large data warehouse facilities in charge of providing controlled access to users, does not express a challenge on its own. However, collected data needs to be organized in a strict but also extensible and upgradable manner. This finally comes down to the problem of adopting a standard for names and symbols of biological objects and the use of controlled vocabularies and ontologies to describe repository content [26].

The problem of how to combine data and models in a close synergistic effort to create new information in a way that is both accessible and secure is a stimulating challenge. Besides strictly technical issues, the realization of personal health informatics requires that a number of ethical issues to be addressed. For instance, data from which to derive epidemiological information at the level of geographical regions has an enormous strategic value for industrial sectors as the pharmaceuticals. Data security or integrity is most essential particularly if cloud computing is being considered.

To summarize, data needs to be kept private and secure. It should be shareable with health professionals and downloadable for use elsewhere (also accessible through mobile device). Data should be organized according to standardised ontologies and stored in digital formats that are well defined and already adopted.

Information Systems

A further challenge concerns the development of information systems (such as computational models embedded in web servers, internet resources, or mobile applications) that are able to exploit collected data and to provide distilled information in forms of predictions. This requires the foundation and development of mathematical and computational methods to achieve prediction on disorder conditions and of diseases spreading in our complex techno-social system. This prompts the development of new, or the adoption of old, large-scale, data-driven mathematical and computational models endowed with a high level of realism. Models enabled by ubiquitous sensors data will allow the forecast of critical events. Moreover, identified modelling needs to motivate the design and implementation of original data-collection schemes. In addition, the setup of computational platforms for disease forecast and data sharing will generate important synergies amongst different research communities and countries.

A critical issue is how to motivate individuals to share their personal data. In fact, as already discussed, the system should rely on the participation of the population to collect real-time information on the distribution of biological parameters or diseases by means of their personal body sensors and smartphone devices (Figure 1). How can individuals be rewarded for spending their time (and money if phone connection is not free) and for sharing personal information with research institutions? In principle, the potential savings that live modelling and continuous monitoring may lead to opens the possibility of applying novel forms of project financing for innovation. In the same way that many public works programs across Europe have been financed through a mix of public and private funds in conjunction with the agreement that the private investors would be entitled to a return on their investment through tolls or the equivalent for a sufficient period of time, cost reducing or controlling eHealth innovation may also attract substantial private investments, if a share of the potential reduction in the cost of treating patients can be passed back to the original private investors in the form an innovation dividend. In a contemporary setting, the value of the saving, from which the original private investors would be entitled a share of, could be derived from the reduction in the average cost of the care of a sufficiently large number of patients with a specific disease within a region that had been selected to trial the innovation in question for a pre-defined duration. This would result in an effective economic incentive for innovation that could attract a wide variety of health care providers, information technology companies, and investments institutions, whilst initially stabilizing (and later on reducing) the costs of health care delivery, management, and innovation.

In the future, scientifically justified health reference costs will be a product of a fully functioning innovative patient- and process-oriented care. This care will be based on live sensors-derived model-guided medicine and on consequent model-guided clinical workflows, spanning the entire health

continuum from prevention to diagnosis and treatment to rehabilitation and nursing care. As a result of the expected improvement in early diagnoses and preemptive care, the outcomes of such a system could favourably reflect, in terms of cost, on the contemporary average costs system that was described above. As a consequence, private investors will benefit from a significant return on their innovation investment and health care providers and patients will benefit from lower costs and higher quality of care. In the long run there is even the possibility that the traditional relationship between income (national or individual) and health care expenditure, making health care appear as a luxury good, could be broken and replaced by a relationship in which the core costs of health care delivery and quality are separate from income levels and more closely aligned with innovative solutions to fundamental health care needs. Finally, scientifically justified reference costs and evaluated outcomes-oriented management could replace the black-box (hidden, pragmatic) approaches to health care systems (including diagnostic, therapeutic, systemic, and managerial) and fully exert a role as potential change drivers.

Another critical issue may be the time lag between data collection and individual benefit, which may put extra demands on data collection and processing. The availability of meaningful, directly readable parameters can motivate patients and caregivers, and facilitate online feedback and coaching. This perfectly underlines the necessity to develop powerful data processing algorithms, based on pathophysiological models that are capable of extracting information at far greater speed than is performed nowadays on static databases. An inspiring example was provided by the recent societal and economical phenomena of social networks. These software systems are actually collecting an enormous amount of data without providing any financial reward to individuals. They collect data because people are willing to share information with other people. Note that this is indeed one of the possible reasons for the failure of the GoogleHealth project, as the enthusiasm in sharing personal health data possibly requires the relationship with an institutional partner rather than a software industry. This further suggests that the involvement of institutions in such vision is not optional but rather essential for the successful active support of a critical mass of citizens. HealthSpace, a personal health record platform operated by the NHS that is also suffering from the same disappointing low utilization, provides a suitable anecdote for reflection [27]. This suggests that direct incentives to the patients, citizens, or the population beyond just an institutional support are required.

On the one hand, the system could rely on a kind of social contract whereby motivated individuals have a clear return in term of health assistance. On the other hand, a business model could be adopted to gain from potential market opportunities. The question is whether a system as the one envisioned will prove to live up to user/patient expectations or the whole solution requires a concrete real market opportunity to exploit. Perhaps the answer lies half way between these two extremes in that sensor vendors and communication technology industry can exploit a market opportunity. The data exploitation and health forecast, although curiosity and research driven, will provide enough critical services to boost the interest of a part of the society that is interested and believes in technological advances, especially in the health system.

With respect to data collection, two interconnected points are at the core of the challenge: (1) how to collect the necessary data, and (2) how to ensure that there is no abuse regarding this data. Both questions need to be handled in unison and robust solutions need to be provided if we actually want to employ this technology. Also, this scenario will be markedly influenced by the growing use of electronic patient records that will be spread in the new few years to all clinical activities.

Finally, besides the technical challenges facing the body sensor technology (design, biocompatibility, invasiveness, reliability, energy consumption etc), there are a number of legal, societal, and ethical challenges that need to be addressed.

Smart and Self-Adaptive Systems

Strictly related to the above subject is the development of smart and self-adaptive systems, that is, intelligent environments for monitoring human health, regulating the uptake of medicaments, and predicting individual emergencies. This includes the development of notice network systems based on overall data able to issue warnings for the population in general.

Smart and self-adaptive systems based on two levels of abstraction, logical and physical, can allow real-time, long-term trend analysis, prediction, prevention, and support of basic daily behavioural and physiological data, building on unobtrusive sensing and advanced reasoning with humans-in-the-loop. The physical level consists of a self-adaptive and self-healing middleware that supports the ensemble of adaptive components and their interactive communication within shared contextual information. The logical level provides tools for automatic reasoning enabling the prediction of spatial/temporal object configurations determining dangerous interactions or physiological damages.

Impact on Biomedicine

Revolutions in biotechnology and information technology have produced enormous amounts of data and are accelerating the extension of our knowledge of biological systems. These advances are changing the way biomedical research, development, and applications are done. Clinical data complement physiological data, enabling detailed descriptions of various healthy and diseased states, progression, and responses to therapies. It is the availability of data representing various biological states, processes, and their time dependencies that enables the study of biological systems at various levels of organization, from molecule to organism, and even population levels.

Multiple sources of data support a rapidly growing body of biomedical knowledge; however our ability to analyze and interpret these data lags far behind data generation and storage capacity. Mathematical and computational models are increasingly used to help interpret biomedical data produced by high-throughput genomics and proteomics projects. Advanced applications of computer models that enable the simulation of biological processes are used to generate hypotheses and plan experiments. Computational models,

appropriately interfaced with biomedical databases, are necessary for rapid access to and sharing of knowledge through data mining and knowledge discovery approaches [28].

Computational biomedicine will provide the possibility of developing not just qualitative but truly quantitative analytical tools, that is, models, on the basis of the data available through the system just described. Information not available today (large cohort studies nowadays include thousands of individuals whereas here we are talking about millions of records) will be available for free.

Large cohorts of data will be available for online consultation and download. Integrative and multi-scale models will benefit from the availability of this large amount of data by using parameter estimation in a statistically meaningful manner. At the same time distribution maps of important parameters will be generated and continuously updated. Through a certain mechanism, the user will be given the opportunity to express his interest on this or that model so to set up a consensus model selection process. Moreover, models should be open for consultation and annotation.

Flexible and user friendly services have many potential positive outcomes. Some examples include simulation of case studies, tests, and validation of specific assumptions on the nature or related diseases, understanding the world-wide distribution of these parameters and disease patterns, ability to hypothesize intervention strategies in cases such as spreading of an infectious disease, and advanced risk modeling.

Notably, these applications are already appearing on the market, for example, a medical device maker company markets a diabetes management solution that combines and analyzes data from a patient's insulin pump, continuous glucose monitoring device, and blood glucose meter and makes it available to the individual's doctor. Having a real-time view of blood sugar and the ability to deliver insulin precisely when needed helps diabetics reduce the risks associated with erratic sugar levels.

Along the same lines, it is worth mentioning that the EU project DIAdvisor [29] is developing a prediction-based tool to optimize the therapy of diabetes. In this project, the Ubiquitous Complex Event Processing paradigm recently suggested [30,31] could be applied by using the developed biomarkers and biosensors as event adapters to build a bidirectional event processing communication, eventually into a global event cloud. This would allow a continuous monitoring of the biomarkers and a permanent management of the insulin adjustment, including automatically started processes in the case of specific event patterns (ie, in the case of an emergency).

What was just illustrated is a typical example of a data processing approach that provide direct feedback to the patients about their health status, allows them to be autonomous in the care, reduce the burden to the caregivers and help keep health care budgets within reasonable limits. One of the challenges will be to deal with the increasing complexity of comorbidities typical of the older age, in which it is not feasible anymore to guide interventions based a single parameter. Failure and function of various organ systems have to be taken into account simultaneously (eg, guidance of blood sugar levels with respect to organ damage or cognitive functions). These kinds of choices can only be made based on a thorough knowledge of different clinical phenotypes, on data reflecting the state of different organ systems, and on adequate data-processing algorithms based on pathophysiological models in which disease interactions are taken into account.

Conclusions

As we learned from a recent study [10], a number of interesting and related surveys have been conducted. One can discover that the rapid adoption of mobile interactive devices has provided a viable gateway for consumers to transmit health data [32]. A survey conducted in North America in 2010 among a sample of 3001 adults ages 18 and older reports that 17% of mobile phone owners (29% of those ages 18-29) use their phones to look up health or medical information. Nine percent of mobile phone owners (15% of those ages 18-29) have smartphone applications that help them track or manage their health [32]. In fact, 10% of all apps downloaded from the Apple iTunes store are related to health care, medical issues, and lifestyle [33]. One example is the Pfizer Mon Krono Santé application, which serves as a memory aid and offers a personal health record for chronic disease sufferers [34]. Gaming devices are viable conduits as well. Bayer's Didget, for example, is a plug-in for the Nintendo DS gaming system targeting children with diabetes [35]. On other aspects more related to the development of communication protocols for wearable or implantable devices, it is interesting to look at the coordination action of CA-RoboCom [36] that design and describe the Future and Emerging Technologies Flagship initiative, the Robot Companions for Citizens. The Robot Companions for Citizens envisions ecology of sentient machines that will help and assist humans in the broadest possible sense to support and sustain our welfare.

The growing number and increasing maturity of Web-based resources are providing more opportunities for consumer self-service and peer support. Bayer, for instance, offers a comprehensive support program called BETAPLUS for multiple sclerosis patients [37]. In addition to Bayer's application for the Apple iPhone mobile device that assists with Betaseron injection timing and site reminders, Bayer has also created a robust website with educational tools, forums, and access to solution-trained nurses. Worth mentioning are producers like LUCAS that has developed an innovative and low-cost microscopic appendage to smartphones that is currently being trialled for laboratory diagnosis in Africa [38]. Similar initiatives using microchips or sensors are currently under development by the EU [39].

Clearly, the building blocks are there and gaining traction; but the greater value comes in bringing the components together to provide a step change in diagnosis and treatment both in terms of patient outcomes as well as health care system efficiency. This technology will potentially provide a huge shareable collection of biomedical information worldwide. Devices will be most successful when they provide data that would not otherwise be available because of the measurement frequency required or the need to capture at the right time. This information will be live, meaning that it will be updated constantly and

instantaneously. Data crawler and analyzers will extract and produce refined data from the raw data, thus producing interesting distilled information. Mathematical or computational models will use the refined data to make predictions, and medical institutions can use this information to set up health care services such as monitoring systems, warning systems, or aid systems.

Mobile and home-based devices monitor vital signs and activities in real-time and communicate with personal health record services, personal computers, smartphones, caregivers, and health care professionals

Smarter health systems continually analyze information from multiple devices and other sources to derive insights and recommendations for the individual's health regimes. Here, two examples tackling different levels (or scales) are provided. At the epidemiological/population level, the EU future and emerging technologies (FET) project EPIWORK [40] proposes a multidisciplinary research effort aimed at developing the appropriate framework of tools and knowledge needed for the design of epidemic forecast infrastructures to be used by epidemiologists and public health scientists (also called Internet based surveillance). This pins down the application of the ideas described above, aside from clinical usage, as of potential interest for epidemiological modelling in times of pandemics such as Influence Flu, and epidemics in developing countries and during natural or environmental disasters. At the subject/individual level, another EU project called INTERSTRESS [41], aims at developing a set of personal system tools and services for the collection, classification, and aggregated representation of individual stress patterns.

The virtual physiological human (VPH) vision of the underlying future need focused on monitoring the health status of European citizenship, shares a common view with "The Future of the Internet" [42], that is, to exploit the true unprecedented connecting power of the Internet thanks to mobile and wireless networking and services in order to provide a bridge between market driven research and fundamental research to meet Europe's future needs. Lastly, the proposed vision can have a significant impact on the objectives of the JADE project in the EU [43]. As already mentioned, European citizens are getting older and are increasingly living with chronic diseases. This because although their health condition is better than that of earlier generations, they live longer as a result of advanced medical care and therefore many end acquire chronic conditions and minor disabilities that are well manageable by home care. This has highlighted shared concerns by regional governments about implications for future provision of welfare and health services. This demographic change poses significant challenges to Europe's society and economy. The JADE project concept is to develop and promote a common research agenda and joint action plan using one of the most promising cluster of ambient intelligence technology applications in everyday life, addressing the need of having independent living services and telecare in an ageing population. They embrace eHealth as an enabler for range activities, for instance, teleconsultations, transfer of records, telehomecare, telehealth, vital sign monitoring, interpersonal communication, remote care, and social support. Among the targeted objectives there are to define new research fields and technologies and to develop actions to improve the cost-effectiveness of research and policy coordination in order to foster transnational scientific cooperation. Finally, another goal of this project is to share and disseminate knowledge awareness on relevant understanding to enhance research, policy effort, and stimulate business actors.

Therefore, we are delighted to report that sensing technology for health is a thriving field of research. It has two immediate and important benefits: (1) the improved understanding of how information and communication technology is revolutionizing human health care, and (2) the investigation of the best conditions for simultaneously sensing physiological and environmental signals. In reaching these targets, it offers the chance to develop computerized systems that will turn this information into actual knowledge with the potential to help making medical and lifestyle decisions. As these questions tackle a range of technological challenges, we believe that combining medical health care meaningfulness, methodological novelties, and the interdisciplinary technological aspects described in this article can lead to ground-breaking applications.

Acknowledgments

The European VPH-FET project is kindly acknowledged for providing the context in which the authors could discuss the content of this article. We also wish to thank Andrea Remuzzi, Adesina Iluyemi, and Edwin Morley-Fletcher for the helpful discussions and suggestions. Pietro Lio' is supported by the FP7 EU project RECOGNITION: Relevance and Cognition for Self-Awareness in a Content-Centric Internet (257756). All authors contributed equally to this manuscript. Andrea Gaggioli is supported by the FP7 EU project INTERSTRESS: Interreality in the Management and Treatment of Stress-Related Disorders (247685)

Conflicts of Interest

None declared.

References

1. Burke W, Psaty BM. Personalized medicine in the era of genomics. JAMA 2007 Oct 10;298(14):1682-1684. [doi: 10.1001/jama.298.14.1682] [Medline: 17925520]
2. Eysenbach G. Medicine 2.0: social networking, collaboration, participation, apomediation, and openness. J Med Internet Res 2008;10(3):e22 [FREE Full text] [doi: 10.2196/jmir.1030] [Medline: 18725354]

3. CureTogether.com. URL: http://curetogether.com/ [accessed 2012-02-22] [WebCite Cache ID 65dzYJS06]
4. patientslikeme. URL: http://www.patientslikeme.com/ [accessed 2012-02-22] [WebCite Cache ID 65dzZpXbu]
5. Continua Health Alliance. URL: http://www.continuaalliance.org/index.html [accessed 2012-02-22] [WebCite Cache ID 65dzniqaP]
6. Vawdrey DK, Wilcox LG, Collins SA, Bakken S, Feiner S, Boyer A, et al. A tablet computer application for patients to participate in their hospital care. In: AMIA Annu Symp Proc. 2011 Presented at: AMIA 2011 Annual Symposium - Improving Health: Informatics and IT Changing the World; October 22-26, 2011; Washington DC p. 1428-1435 URL: http://europepmc.org/abstract/MED/22195206
7. Discipulus.: European Commission under the Seventh Framework Programme Roadmap for the digital patient URL: http://www.digital-patient.net/ [accessed 2013-01-23] [WebCite Cache ID 6DtCJNC4A]
8. The first International Workshop on body-sensors. BSN Workshop 2004. URL: http://vip.doc.ic.ac.uk/bsn/m196.html [accessed 2012-02-22] [WebCite Cache ID 65dzhgJBC]
9. International Conference on Wearable Micro and Nano Technologies for Personalised Health. URL: http://www.insavalor.fr/phealth2011/ [accessed 2012-02-22] [WebCite Cache ID 6DssxX2V0]
10. IBM Global Business Services. IBM Executive Report. The future of connected health devices URL: http://public.dhe.ibm.com/common/ssi/ecm/en/gbe03398usen/GBE03398USEN.PDF [accessed 2012-02-22] [WebCite Cache ID 65dpqNsaz]
11. Berger E. The iPad: gadget or medical godsend? Ann Emerg Med 2010 Jul;56(1):A21-A22. [Medline: 20677379]
12. Kubben PL. Neurosurgical apps for iPhone, iPod Touch, iPad and Android. Surg Neurol Int 2010;1:89 [FREE Full text] [doi: 10.4103/2152-7806.74148] [Medline: 21206897]
13. Doukas C, Pliakas T, Maglogiannis I. Mobile healthcare information management utilizing Cloud Computing and Android OS. In: Conf Proc IEEE Eng Med Biol Soc. 2010 Presented at: Engineering in Medicine and Biology Society (EMBC), 2010 Annual International Conference of the IEEE; Aug. 31 2010-Sept. 4 2010; Buenos Aires, Argentina p. 1037-1040. [doi: 10.1109/IEMBS.2010.5628061]
14. Aanensen DM, Huntley DM, Feil EJ, al-Own F, Spratt BG. EpiCollect: linking smartphones to web applications for epidemiology, ecology and community data collection. PLoS One 2009;4(9):e6968 [FREE Full text] [doi: 10.1371/journal.pone.0006968] [Medline: 19756138]
15. Sposaro F, Danielson J, Tyson G. iWander: An Android application for dementia patients. In: Conf Proc IEEE Eng Med Biol Soc. 2010 Presented at: Engineering in Medicine and Biology Society (EMBC), 2010 Annual International Conference of the IEEE; Aug. 31 2010-Sept. 4 2010; Buenos Aires, Argentina p. 3875-3878. [doi: 10.1109/IEMBS.2010.5627669]
16. Melo MR, Clark S, Barrio D. Miniaturization and globalization of clinical laboratory activities. Clin Chem Lab Med 2011 Apr;49(4):581-586. [doi: 10.1515/CCLM.2011.092] [Medline: 21175379]
17. Mobile Diagnostic Services. URL: http://www.modise.org/ [accessed 2012-02-22] [WebCite Cache ID 65dzmqjBP]
18. Jeremy L. techradar.com. Cutting edge: Intel's bioelectric wonder-chip URL: http://www.techradar.com/news/computing/cutting-edge-intel-s-bioelectric-wonder-chip-425788 [accessed 2012-02-22] [WebCite Cache ID 65dzs6bM3]
19. Google Health. URL: http://www.google.com/intl/en-US/health/about/index.html [accessed 2012-02-22] [WebCite Cache ID 65dwCAqvM]
20. Microsoft HealthVault. URL: http://www.microsoft.com/en-us/healthvault/default.aspx [accessed 2013-01-23] [WebCite Cache ID 6DsvmdeeO]
21. ASTM International. Standard Specification for Continuity of Care Record (CCR) URL: http://www.astm.org/Standards/E2369.htm [accessed 2013-01-23] [WebCite Cache ID 6Dsw7w4Xk]
22. ASTM International. URL: http://www.astm.org/ [accessed 2012-02-22] [WebCite Cache ID 65e03qSEA]
23. HealthIT.gov. Nationwide Health Information Network: Overview URL: http://healthit.hhs.gov/portal/server.pt/community/healthit_hhs_gov__nationwide_health_information_network/1142 [accessed 2012-02-22] [WebCite Cache ID 65e09tmBI]
24. NHS Connecting for Health. NHS Interoperability Toolkit URL: http://www.connectingforhealth.nhs.uk/systemsandservices/interop [accessed 2012-02-22] [WebCite Cache ID 65e0bx1Z9]
25. Health care interoperability testing and conformance harmonisation. URL: http://www.hitch-project.eu/about [accessed 2012-02-22] [WebCite Cache ID 65e0ecqFn]
26. Virtual Physiological Human Network of Excellence. URL: http://www.vph-noe.eu/ [accessed 2012-02-22] [WebCite Cache ID 65e0h5Ki3]
27. NHS Connecting for Health. HealthSpace URL: https://www.healthspace.nhs.uk/visitor/default.aspx [accessed 2012-02-22] [WebCite Cache ID 65e0j6nHo]
28. Halling-Brown M, Pappalardo F, Rapin N, Zhang P, Alemani D, Emerson A, et al. ImmunoGrid: towards agent-based simulations of the human immune system at a natural scale. Philos Transact A Math Phys Eng Sci 2010 Jun 13;368(1920):2799-2815 [FREE Full text] [doi: 10.1098/rsta.2010.0067] [Medline: 20439274]
29. The DiAdvisor project. Personal glucose predictive diabetes advisor URL: http://www.diadvisor.eu/ [accessed 2012-02-22] [WebCite Cache ID 65e4SFNcK]
30. Rainer VA. Complex Event Processing. Ubiquitous Complex Event Processing URL: http://www.complexevents.com/2010/05/16/ubiquitous-complex-event-processing-u-cep/ [accessed 2012-02-22] [WebCite Cache ID 65e0lSAHu]

31. Luckham D. The power of events: an introduction to complex event processing in distributed enterprise systems. Boston: Addison-Wesley; 2002.
32. Fox S. The Pew Internet & American Life Project.: Pew Internet & American Life Project Mobile Health 2010 URL: http://pewinternet.org/Reports/2010/Mobile-Health-2010.aspx [accessed 2012-02-22] [WebCite Cache ID 65dvNLB4y]
33. Lyall M. Know About Health. Health apps contribute 10% to 10 billion app downloads URL: http://www.knowabouthealth.com/health-apps-pitch-in-10-to-speedy-10-billion-downloads/7664/ [accessed 2012-02-22] [WebCite Cache ID 65dvUu1bU]
34. Tyer D. InPharm.com.: InPharm.com; 2010. Digital Pharma: Big pharma's iPhone apps (part one) URL: http://www.pharmafile.com/news/digital-pharma-big-pharma-iphone-apps-part-one [accessed 2013-01-23] [WebCite Cache ID 6DsyErsG3]
35. Bayer health care. Bayer Didget URL: http://www.bayerdidget.ca/About-Didget [accessed 2012-02-22] [WebCite Cache ID 65dvg6TAJ]
36. The CA-RoboCom project. Robot Companions for Citizens URL: http://www.robotcompanions.eu/ [accessed 2012-02-22] [WebCite Cache ID 65e0v8OxB]
37. PR Newswire. Bayer health care launches first iPhone application with personalized tools to assist people on Betaseron® (interferon beta-1b) in managing their multiple sclerosis treatment URL: http://www.bayerdidget.ca/About-Didget [accessed 2012-02-22] [WebCite Cache ID 65dvg6TAJ]
38. Aydogan Ozcan. SPIE. Smart technology for global access to healthcare URL: http://spie.org/documents/Newsroom/Imported/002568/002568_10.pdf [accessed 2012-02-22] [WebCite Cache ID 65dvu71g8]
39. Ruano-López JM, Agirregabiria M, Olabarria G, Verdoy D, Bang DD, Bu M, et al. The SmartBioPhone, a point of care vision under development through two European projects: OPTOLABCARD and LABONFOIL. Lab Chip 2009 Jun 7;9(11):1495-1499. [doi: 10.1039/b902354m] [Medline: 19458852]
40. The Epiwork project. Developing the framework for an epidemic forecast infrastructure URL: http://www.epiwork.eu/ [accessed 2012-02-22] [WebCite Cache ID 65e0o0H7t]
41. The interstress project. Interreality in the management and treatment of stress-related disorders URL: http://www.interstress.eu/ [accessed 2012-02-22] [WebCite Cache ID 65e0pqMMO]
42. Europe's information society thematic portal.: Information Society Thematic Portal - Designing our future Internet European research - designing our future Internet URL: http://ec.europa.eu/information_society/activities/foi/research/index_en.htm [accessed 2012-02-22] [WebCite Cache ID 65e0rJ6Uy]
43. The JADE project. JADE: joining innovative Approaches for the integration and Development of transnational knowledge of clusters policies related to independent of Elderly URL: http://www.jadeproject.eu/ [accessed 2012-02-22] [WebCite Cache ID 6DszhI5Jv]

Abbreviations

CCR: Continuity of Care Record
EU: European Union
FET: future and emerging technologies
HITCH: Healthcare Interoperability Testing and Conformance Harmonisation
ICT: information and communication technology
NHS: National Health Services
VPH: virtual physiological human

Edited by G Eysenbach; submitted 24.02.12; peer-reviewed by V Gay; comments to author 04.05.12; revised version received 15.06.12; accepted 01.08.12; published 30.01.13.

Please cite as:
Castiglione F, Diaz V, Gaggioli A, Liò P, Mazzà C, Merelli E, Meskers CG, Pappalardo F, von Ammon R
Physio-Environmental Sensing and Live Modeling
Interact J Med Res 2013;2(1):e3
URL: http://www.i-jmr.org/2013/1/e3/
doi:10.2196/ijmr.2092
PMID:23612245

Original Paper

Health Care Provider Adoption of eHealth: Systematic Literature Review

Junhua Li[1,2], PhD; Amir Talaei-Khoei[3], PhD; Holly Seale[2], PhD; Pradeep Ray[1], PhD; C Raina MacIntyre[2,4], PhD

[1]Asia-Pacific ubiquitous Healthcare research Centre (APuHC), The University of New South Wales, Sydney, Australia

[2]School of Public Health and Community Medicine, Faculty of Medicine, The University of New South Wales, Sydney, Australia

[3]Discipline of Informatics, Faculty of Arts and Business, University of the Sunshine Coast, Sunshine Coast, Australia

[4]National Centre for Immunization Research and Surveillance of Vaccine Preventable Diseases (NCIRS), Sydney, Australia

Corresponding Author:
Junhua Li, PhD
Asia-Pacific ubiquitous Healthcare research Centre (APuHC)
The University of New South Wales
Room 1039, Quadrangle Building, University of New South Wales
Sydney, 2052
Australia
Phone: 61 (2) 9931 9308
Fax: 61 (2) 9662 4061
Email: junhua.li.syd@gmail.com

Abstract

Background: eHealth is an application of information and communication technologies across the whole range of functions that affect health. The benefits of eHealth (eg, improvement of health care operational efficiency and quality of patient care) have previously been documented in the literature. Health care providers (eg, medical doctors) are the key driving force in pushing eHealth initiatives. Without their acceptance and actual use, those eHealth benefits would be unlikely to be reaped.

Objective: To identify and synthesize influential factors to health care providers' acceptance of various eHealth systems.

Methods: This systematic literature review was conducted in four steps. The first two steps facilitated the location and identification of relevant articles. The third step extracted key information from those articles including the studies' characteristics and results. In the last step, identified factors were analyzed and grouped in accordance with the Unified Theory of Acceptance and Use of Technology (UTAUT).

Results: This study included 93 papers that have studied health care providers' acceptance of eHealth. From these papers, 40 factors were identified and grouped into 7 clusters: (1) health care provider characteristics, (2) medical practice characteristics, (3) voluntariness of use, (4) performance expectancy, (5) effort expectancy, (6) social influence, and (7) facilitating or inhibiting conditions.

Conclusions: The grouping results demonstrated that the UTAUT model is useful for organizing the literature but has its limitations. Due to the complex contextual dynamics of health care settings, our work suggested that there would be potential to extend theories on information technology adoption, which is of great benefit to readers interested in learning more on the topic. Practically, these findings may help health care decision makers proactively introduce interventions to encourage acceptance of eHealth and may also assist health policy makers refine relevant policies to promote the eHealth innovation.

(Interact J Med Res 2013;2(1):e7) doi:10.2196/ijmr.2468

KEYWORDS

technology acceptance; eHealth; health care provider; adoption

Introduction

Poor health care outcomes lead to increased levels of morbidity and mortality, and obstruct countries' prosperity and business profitability (eg, [1,2]). eHealth is an application of information and communication technologies (ICT) across health-related functions [3]. The benefits of eHealth, such as improved operational efficiency, higher quality of care, and positive return on investments have been well documented in the literature [4-6].

eHealth is an emerging field at the intersection of medical informatics, public health, and business, and refers to health services and information delivered or enhanced through the Internet and other related technologies [7,8]. Different eHealth applications have been used across countries, corresponding to their health needs and priorities. The World Health Organization (WHO) eHealth for Health Care Delivery (eHCD) program, for example, targeted primary health care in a number of countries in the Asia-Pacific region. Some of these countries have instigated telemedicine as a means of bringing specialist health care to rural communities, whereas some others have endeavoured to improve the safety and continuity of patient care through the use of electronic health records (EHR).

While there has been high interest in eHealth, the adoption and acceptance rates have not been high enough for health care systems to experience the maximal benefits eHealth has to offer [8]. Past experience of eHealth adoption in the United States, for example, informed us that the low adoption rate could be attributed to both macro-level factors (eg, supportive policies) from the perspective of the public, health care organization, and system, and micro-level barriers from the perspective of health care providers (eg, physicians' perception about technological complexity, [9]).

A broad spectrum of research methodologies have been used to study eHealth adoption and acceptance factors based on information provided in published studies [9]. The methodologies include quantitative surveys [10], observations [11], qualitative focus groups [12], ethnographic studies [13], and personal intuition and experience [14]. According to the results of these studies, different eHealth adoption factors may have led to difficulty for decision makers to explicitly understand, measure, and decrease inhibiting factors or enhance facilitating forces [9]. Hence, there is a need to synthesize those insights and provide decision makers with a holistic view of eHealth adoption.

Health care providers are the key driving force in pushing eHealth initiatives [14]. eHealth implementation represents a disruptive change in the health care workplace. The change does not occur simply from the introduction of ICT infrastructure but may also require remodelling of the job design of interconnected health professionals to effectively and efficiently incorporate technology [15]. Without the presence of motivational forces (eg, health care providers' dissatisfaction with the status quo), it is unlikely that the innovation process would be initiated. If health care providers resist change or do not possess attributes necessary for change (eg, adaptability and growth-orientation), the change process is less likely to proceed [16]. The objective of this paper was to identify and synthesize the factors influential to health care providers' acceptance of various eHealth applications.

Methods

Overview

In light of the guidelines originally proposed by [17,18] and already applied in several systematic reviews (eg, [19]), we conducted a systematic literature review on eHealth adoption. For the specific objective of this study, the guidelines have been modified and 4 steps were taken: (1) identification of resources, (2) selection of relevant papers, (3) data extraction, and (4) data analysis and validation.

Identification of Resources

A literature search was conducted between October and November 2011 using 8 online databases: Medline, Cinahl, Web of Science, PubMed, PsychInfo, ERIC, ProQuest Science Journals, and EMBASE. These databases were thought to be the most likely to publish eHealth adoption related work [20]. All search fields available from each search service were used. In each database, the search was repeated 3 times using the following phrases (operators came before keywords): ["e-Health" AND "Adoption" OR "User Acceptance"] or ["eHealth" AND "Adoption" OR "User Acceptance"] or ["EMR" AND "Adoption" OR "User Acceptance"] or ["EHR" AND "Adoption" OR "User Acceptance"].

The terms "electronic medical records" (EMR) and EHR were separately used to search papers. This is because the EMR/EHR consists of patient health related information and forms the core of eHealth systems [8]. The inclusion of those papers increased the validity of the findings. Table 1 lists the number of papers found in each database using the search phrases. In summary, a total of 3315 papers were found, of which 420 papers were duplicated. The selection process excluded the repeated papers from the archive and produced a list of 2895 papers.

Selection of Relevant Articles

The full texts of the selected papers were reviewed for relevance. Papers with the following criteria were filtered out:

1. articles not written in English
2. articles that did not directly use the terms "adoption" and "eHealth" or related terms in the title, abstract, or entire text, with casual referencing of eHealth adoption related issues.
3. articles without empirical evidence
4. articles which discussed adoption or user acceptance of eHealth but not from the health care provider's perspective

This examination process had two iterations. Finally, 93 relevant papers were selected.

Data Extraction

The key information was extracted from the 93 papers. The extracted data included: (1) characteristics of the study (eg, year of publication and health care settings where the studies were conducted), (2) the study results and output—eHealth adoption factors. Relevant text was extracted or retyped verbatim and was added to a database.

Table 1. Identification of papers for review from 8 online databases.

Keywords	Medline	Cinahl	Web of Science	PubMed	PsycInfo	ERIC	ProQuest Science Journals	EM-BASE (1980+)	Total	Duplicated results
User acceptance AND eHealth	2	3	15	2	2	1	73	2	100	-
User acceptance AND eHealth	6	0	7	8	3	0	45	2	71	20
User acceptance AND EMR	9	5	8	9	2	0	93	10	136	17
User acceptance AND EHR	13	2	15	12	3	0	57	10	112	20
Adoption AND eHealth	31	15	47	34	24	1	244	36	432	39
Adoption AND eHealth	29	9	29	44	28	1	155	30	325	74
Adoption AND EMR	89	30	67	97	12	3	395	101	794	87
Adoption AND EHR	165	83	106	187	17	1	607	179	1345	163
Total unrepeated articles retrieved									2895	-

Data Analysis and Validation

Figure 1 illustrates the analysis process of the data collected in Step 3. Based on the terminologies or terms utilized in the papers, 49 eHealth adoption/acceptance factors were initially extracted. All citations used to identify the results were noted. The next activity was to study the definitions used in the papers. Factors with close relevance were combined, generating a list of 40 factors. For example, “time required to select, purchase, and install the eHealth system”, “time involved in learning to use the eHealth system and additionally required to become familiar with the system operation”, and “the degree to which use of the innovation is perceived as being time consuming” were all grouped to “time cost”.

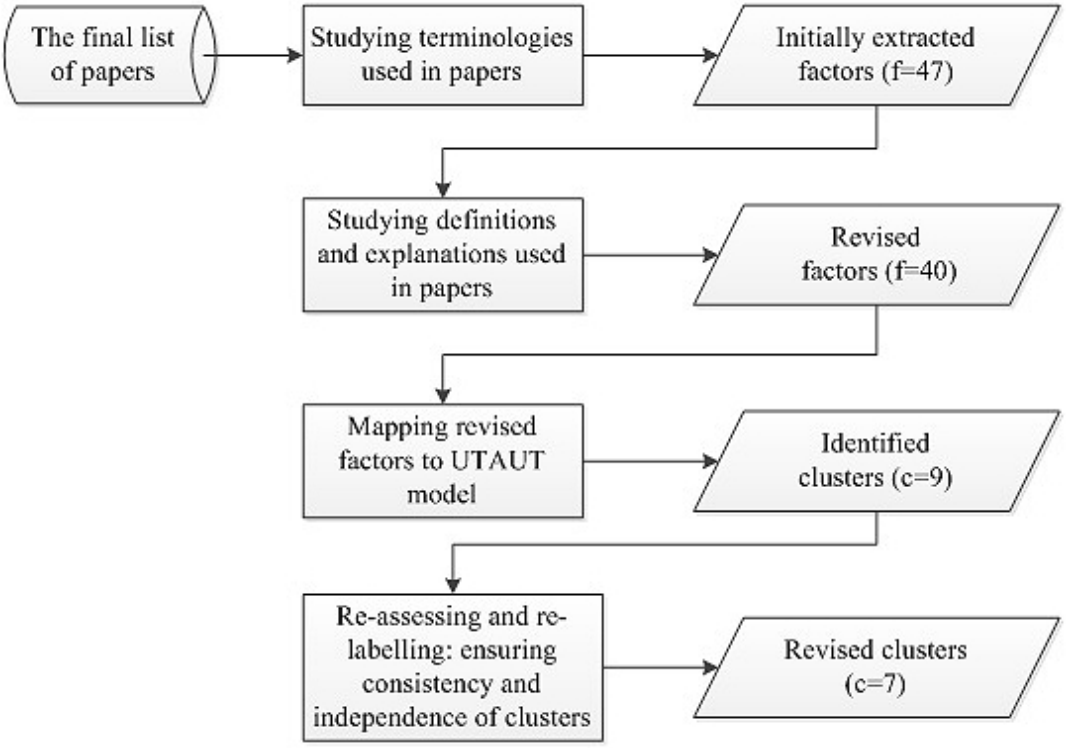
Based on the perceived commonality of the themes, the 40 factors were analyzed and organized according to the Unified Theory of Acceptance and Use of Technology (UTAUT) by Venkatesh et al [21]. The UTAUT set out to integrate the fragmented theory and research on individual acceptance of information technology into a unified theoretical model, which highlights the importance of contextual analysis in developing strategies for technology implementation within organizations. This model accounts for 70% of the variance in usage intention—a substantial improvement over any of the original 8 models and their extensions. Within the UTAUT, 3 core constructs that impact on behavioral intention, and consequently use behavior, are *performance expectancy, effort expectancy,* and *social influence*, whereas the other core construct *facilitating conditions* has a direct impact upon use behavior. Four moderators (ie, *gender*, *age*, *voluntariness of use*, and *experience*) have also been incorporated in the UTAUT. Apart from the 4 core constructs and 4 moderators, another cluster of eHealth adoption factors, which could not be mapped against the UTAUT, was identified. Accordingly, the factors were initially grouped into 9 clusters (Figure 1).

To search for convergence among multiple sources of information and methods of data collection and analysis, a validity procedure was applied [22,23]. First, the eHealth adoption factors were reanalyzed within and across the clusters to ensure consistency and independence. The factors were regrouped into 7 clusters:

1. health care provider characteristics (eg, IT experience and knowledge, gender, age, and years in practice)
2. medical practice characteristics (eg, practice size and teaching status)
3. voluntariness of use
4. performance expectancy (eg, perceived usefulness and needs)
5. effort expectancy (eg, perceived ease of use)
6. social influence (eg, subjective norm)
7. facilitating or inhibiting conditions (eg, legal concerns)

The clusters were then given labels and reviewed once more for consistency. Reassessment and relabelling were performed for some papers. This step was repeated until a consensus was reached on the labels for clusters. In the final analysis, papers were reassigned to appropriate clusters. The resulting clusters represented another level of abstraction.

Figure 1. Data analysis process. f=number of factors; c=number of clusters.



Results

Characteristics of Selected Studies

This section presents the results of statistical analyzes on the characteristic data extracted from the 93 papers, including: (1) the growth of publications by years, (2) distribution by geographical areas, (3) types of research methodologies employed, (4) eHealth applications studied, (5) health care settings selected, and (6) study participants.

Growth of Publications

Figure 2 shows the growth in the publications. The growth represented by the curve was not linear, with a dramatic rise in the number of papers published after 2005.

Geographical Areas

The majority of the studies (72/93, 77%) were conducted in North America, followed by Europe (9/93, 10%), and Asia (7/93, 8%).

Research Methodologies

Quantitative methodology was predominately used by 57/93 studies. The number was nearly twice as large as that of qualitative studies.

eHealth Applications

The 93 papers addressed a wide range of eHealth applications. 57 targeted the EHR/EMR, which was defined as computerized medical information systems that collect, store, and display patient information [24]. Telemedicine/Telehealth was the second most popular application studied (addressed by 7/93 studies). Telemedicine frequently referred to the use of a wide array of technologies to deliver a range of medical services to persons at some distance from a health care provider [25]. The remnant studies examined the acceptance of other eHealth applications such as Intensive Care Information System (ICIS) [26], e-discharge which helps inpatient physicians to track pending tests at hospital discharge [27], Anesthesia Information Management System (AIMS) [28], and electronic logistics information system [29].

Health Care Settings

The majority of the studies were conducted in hospitals and office-based clinics (primary care). In some studies, multiple health care settings of different types were chosen to examine the eHealth acceptance issue. For example, Jha et al used survey data from stratified random sample of all medical practices in Massachusetts in 2005 to determine rates of EHR adoption and perceived barriers to adoption [30].

Study Participants

The majority of the studies (ie, 68/93) focused on physicians. Nurses and other health workers were recruited in 25 research projects on eHealth adoption and acceptance.

eHealth Acceptance Factors

Through the data analysis and validation process, 40 factors were identified to be influential to the health care providers' acceptance of eHealth and grouped into 7 clusters (Figure 3 and Table 2). A brief description of each cluster is provided below.

A health care provider's characteristics included his/her information technology (IT) experience and knowledge, years in medical practice, professional role, age, gender, and race. Characteristics in relation to a health care provider's medical practice included the practice size, teaching status, location, single or multi-specialty, practice level, types of third party

payers, and patient age range. Voluntariness of use was defined as "the degree to which use of the innovation is perceived as being voluntary or of free will" [21]. Performance expectancy was defined as the degree to which a health care provider believes that using the eHealth system will help him or her to attain gains in job performance [21]. It included the perceived usefulness and needs, relative advantage, job-fit, and reimbursement and financial incentive. Effort expectancy was defined as the degree of ease associated with the use of the eHealth system [21]. It included perceived ease of use, ease of use, and complexity. Social influence was defined as the degree to which a health care provider perceives that important others believe he or she should use the new eHealth system [21]. It included the subjective norm, competition, supportive organizational culture for change, and friendship network. Facilitating or inhibiting conditions were defined as the degree to which a health care provider believes that an organizational and technical infrastructure exists to support use of the eHealth system [21]. It included the computer self-efficacy, computer anxiety, legal concerns, financial constraints, availability of ICT infrastructure, time cost, eHealth interoperability, IT support, eHealth and business process alignment, end user involvement, management commitment and support to change, uncertainty about IT vendor, professional autonomy, interference with the health care provider and patient relationship, and patient privacy concerns.

Figure 2. Growth of publications (based on our selected articles).

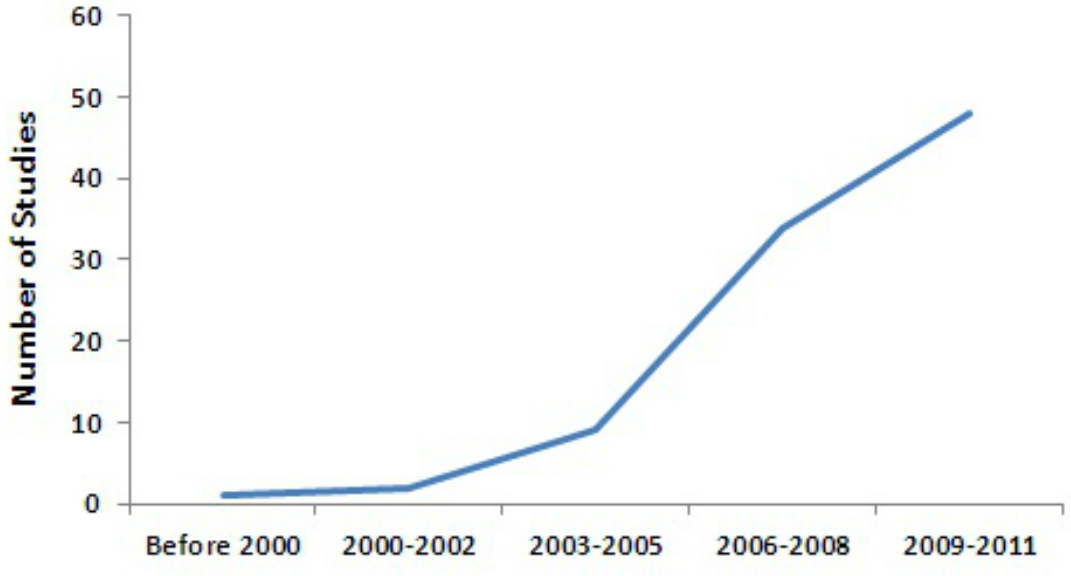


Figure 3. eHealth acceptance factors and clusters.

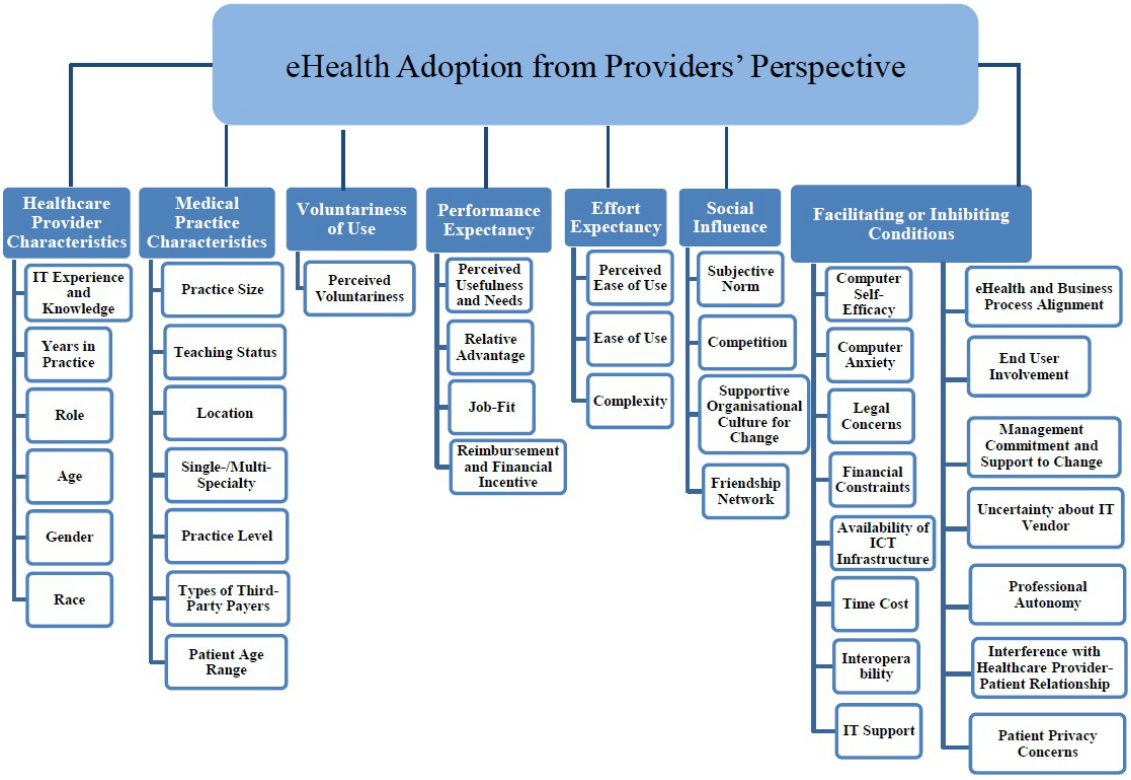


Table 2. eHealth acceptance factors under 7 clusters.

Cluster and factors	Definitions and citations
Health care provider characteristics	
IT experience and knowledge	Generic IT skills (eg, typing skills) and experience [24,30-47]
	Those who had little experience with computers were challenged by the process of learning how to use the computer in addition to learning the software [43]
	Previous experience of computer use in medical practice or training in using particular eHealth systems [48-56]
	Respondents with an electronic health record (EHR) were more likely to e-prescribe than those who did not have an EHR, and to have patients take a computer-generated prescription to the pharmacy [55]
Years in practice	Total years in practice since medical school graduation [32,48,57-61]
	Based on the comments offered by those in practice for longer than 25 years in our study, it did not make sense to invest time or money at this point in their careers [32]
Role	Variation between physicians and other health professionals [53]
	Physicians use most of the advanced features more than nonphysicians [53]
	Variation between specialists and others [59,62,63]
	high-end specialists, such as obstetrician-gynecologists, are less likely to be using EHR in their practice [63]
Age	Physical age [36,39,46,59,61,64-67]
	EMR use was inversely associated with physician age [65]
Gender	Biological sex [39]
	Females were less likely to use PDAs [39]
Race	A group of people of common ancestry, distinguished from others by physical characteristics [39]
	African American and Hispanic physicians were more likely than Caucasian to indicate routine PDA use; Asian physicians reported using email with patients significantly less frequently than their Caucasian counterparts [39]
Medical practice characteristics	
Practice size	Number of physicians in the medical practice [36,39,48,57,58,60,61,65,67-72]
	Physicians in practices with 11 or more physicians were most likely to use any EMR system, whereas physicians in solo practice were least likely to use EMRs [65]
	Number of patient visits [24,32,61,72,73]
	who saw fewer than ten patients per day, reviewed fewer than 20 medical records per day and handled fewer than ten calls daily, were statistically less likely to want to use a computer during a consultation; Those seeing fewer than ten patients daily were the most receptive to the use of handwriting [32]
Teaching status	Practices affiliated with academic institutions [58,70-72]
	There was a statistically significant association between presence of students and residents in a practice and the practice's use of an her [71]
Location	The medical practice in a rural setting or urban setting [40,61,68,72-74]
	urban settings were significantly more likely to have adopted AIMS [72]

Cluster and factors	Definitions and citations
Single/Multi-specialty	Difference between those in a single-specialty practice and in a multi-specialty practice [39,65,66,68,75] *those in a multi-specialty group were more likely than those in a single specialty practice to routinely use EHRs* [39]
Practice level	Distinctions between Primary, Secondary and Tertiary health care [36,58,60] *physicians whose practice consisted of a specialty other than primary care were more likely to use an EHR* [60]
Types of third-party payers	Proportion of patients who are privately insured, Medicaid, Medicare, or uninsured [48,66,73,76] *Physicians with the highest percentage of Medicaid patients in their practices were significantly less likely to indicate using an EHR system when compared with those in the low-volume Medicaid group* [76]
Patient Age Range	The age range of served patients' [67] *doctors who treat HVE[a] were significantly less likely to adopt EHR* [67]
Voluntariness of use	
Perceived voluntariness	The degree to which use of the innovation is perceived as being voluntary, or of free will [77] *Perceived voluntariness had a negative causality on behavioral intention to use telemedicine. These findings contradict those from prior IS literature that found a positive relation between voluntariness of use and intention to adopt* [77]
Performance expectancy	
Perceived usefulness and needs	The degree to which a health care provider believes that using the eHealth system would enhance his or her clinical or non-clinical job performance [24,25,28,29,33,35,36,38,41,43,46,50,56,75,77-91]
	Perceived needs of adopting the eHealth system [42,79,92-94] *Participants from private hospitals or who owns a private practice reported that most of their patients are one-time customers and they do not expect them to come back. For private hospitals, about 30% of their patients are from out of the state (mostly from near towns and villages). Therefore, they do not keep their past medical records* [93]
Relative advantage	The degree to which using an innovation is perceived as being better than using its precursor of practices [5,45,59-61,72,93,95,96] *physicians who used electronic prescribing were significantly more likely to view it as saving time than those who have not adopted the technology* [5]
Job-fit	How the capabilities of the eHealth system enhance a health care provider's clinical job performance [24,40,97] *no mechanism of alerting inpatient physicians that finalized test results were available for viewing (eg, by email or by an alert in the inpatient computer system* [97]
Reimbursement and financial incentive	The degree of a health care provider's perception of uncertainty over return on monetary investment [5,24,26,31,40,73,86,90,91,95,98]
	Availability of financial reward for a health care provider's time investment in learning and using the eHealth system [36,54,70,86,92,99] *the availability of incentives for adoption of HIT were more likely to have EHRs than practices without such incentives* [70]
Effort expectancy	

Cluster and factors	Definitions and citations
Perceived Ease of use	The degree to which a health care provider believes that using the eHealth system would be free of effort [5,25,28,29,38,40,46,47,52,54,56,68,74,75,81,84,87,88,90] *co-existence of paper and electronic records at the transition period, as an important barrier to EMR adoption* [74]
Ease of use	The degree to which using the eHealth system is perceived as being difficult to use [5,27,28,35,41,45,46,52-54,64,77,84-86,89,91,97,100-103] *a perception that technical system deficiencies reduce the quality of clinical routines can result users' resistance* [103]
	Location of ICT equipment for convenient use of the eHealth system [41,45,49,96,101,102] *Sometimes the physician practice does not have appropriate equipment to facilitate use of the e-Prescribing system as part of the existing workflow. For example, if they do not have a handheld device or computer in the examination room, the busy clinician needs to use a PC outside the examination room, adding an extra step to the workflow* [49]
Complexity	The degree to which the eHealth system is perceived as relatively difficult to understand and use [24,26,35,37,45,46,54,79,84,86,89,93,96,100,101] *this study indicated that the EMR systems are very complex and difficult to learn, and this affects their attitude towards using the EMR systems* [93]
Social influence	
Subjective norm	The health care provider's perception that most people who are important to him or her thinks he or she should or should not adopt the eHealth system in question [40,59,77,91] *Patient resistance or not wanting their physicians to use EHR* [40]
Competition	Perceived competitive advantage with eHealth [48,86,94] *adopt mobile technologies to gain a competitive advantage; adopting IS creates a competitive advantage by giving businesses new ways in which to outperform their rivals* [94]
Supportive organizational culture for change	Leadership and presence of champions for the eHealth system adoption within a health care setting [24,35,38,43-45,74,79,86,96,104] *Health care professionals were likely to accept and participate in the process of eHealth adoption when the programs were introduced and promoted by a peer with considerable authority and influence and familiarity with the practices* [79]
	The degree of a health care provider's perception of organizational culture (eg, learning culture) supportive to eHealth adoption [33,105] *The culture of the organization, including its supportive elements, influences both implementation and persistence of the work innovation* [33]
Friendship network	Personal intimacy and interactions with personal friends [47] *Social influence affecting physician adoption of EHR was predominantly conveyed through interactions with personal friends rather than interactions in professional settings* [47]
Facilitating or inhibiting conditions	
Computer self-efficacy	A health care provider's self-judgment of his or her ability to use the eHealth system to accomplish clinical jobs or tasks [46,48,67,77,86]

Cluster and factors	Definitions and citations
Computer anxiety	Evoking anxious or emotional reactions when it comes to adopting the eHealth system [24,33,40,77,80,92,106] *They are concerned that under certain circumstances, or as time passes, the systems will reach their limitations, become obsolete and will no longer be useful* [24]
Legal concerns	The availability of the policy, regulation, and protocol supportive to using the eHealth system [31,54,74,78,79,82,93,95] *Regulation regarding sharing of clinical information between the various EMR users across settings of care could represent a complex issue. During interviews, some respondents expressed concern with respect to the application of the law related to patients' consent in the context of EMR implementation* [74]
Financial constraints	The degree of a health care provider's perception of high monetary cost for adopting the eHealth system (ie, start-up costs and ongoing maintenance costs) and of the availability of financial resources to cover the cost [5,25,27,28,30-33,35,37,39,41,50,52,53,58,60,62,69,71-75,79,80,85-87,91,93,94,107-110] *respondents noted the lack of capital to invest in EHRs as an important or very important barrier to adoption* [73]
Availability of ICT infrastructure	The degree of a health care provider's perception of the availability of ICT infrastructure required for using the eHealth system [24,35,38,49,51,79,81,91,107]
Time cost	Time required to select, purchase, and install the eHealth system [5,24,37,40,59,61,86,90] *Implementing an EMR means switching from paper-based to electronic based systems, and this involves transferring records between the two systems* [24]
	Time involved in learning to use the eHealth system and additionally required to become familiar with the system operation [25,28,31,32,37-39,41,44,46,50,53,55,57,60,62,71,72,74,85,87,91,92,109,110] *the time and effort involved in learning to use these technologies as a significant barrier* [31]
	The degree to which use of the innovation is perceived as being time consuming [24,35,84,86,90,93,97,99-101] *takes too much time to enter data in real time* [93]
Interoperability	The degree of a health care provider's perception of the ability of the eHealth system to exchange and use relevant clinical data within and across the health care setting [24,26,31,32,38,49,72,73,86,91,92,103,104] *Lack of ability to exchange clinical data with laboratories and hospitals is a major barrier for smaller physician practices* [31]
IT support	The degree of a health care provider's perception of the availability of experienced IT personnel for technical support (eg, troubleshooting emergent problems during actual usage of the eHealth system, and providing instructional and/or hand-on support to users before and during usage) [24,26,28,30,31,34-38,54,57,72,74,79,81,84,91,94,100] *the provision of good maintenance and user support systems greatly increases user acceptance of a new system* [84]
	The degree of a health care provider's perception of the adequacy of training for the usage of the eHealth system [24,27,35,38,41,43,44,50,53,71,75,78,79,92,100,103,108] *This study found that inadequate training limits EMR utilization* [108]
eHealth and business process alignment	The degree of a health care provider's perception of the fitness of the eHealth system into the clinical workflow [29,32,77,96,97,99,103]
End user involvement	The involvement of end users in the planning and implementation process of the eHealth system [24,38,75,83,84,86-88,103,104] *Clinicians' resistance was also related to whether or not they had been involved in the design and implementation process* [103]

Cluster and factors	Definitions and citations
Management commitment and support to change	The presence of management commitment and availability of management support for adoption of the eHealth system [24,33,45,75,79,81,82,87,88,91,92,103,109] *the implementers' responses were supportive and addressed the issues related to the real object of resistance; the severity of resistance decreased* [109]
Uncertainty about IT vendor	The degree of a health care provider's perception of the availability of reputable and trustworthy external IT service providers in the market [24,29,49,52,106]
Professional autonomy	The degree to which using the eHealth system is perceived by a health care provider as losing professional control over the conditions, processes, procedures, or content of his or her work according to the individual judgment in the application of his or her profession's body of knowledge and expertise [24,42,75,86-89,91,110,111] *With the implementation of EMRs, physicians are concerned about the loss of their control of patient information and working processes since these data will be shared with and assessed by others. Physicians' perceptions of the threat to their professional autonomy are very important in their reaction to EMR adoption* [24]
Interference with health care provider-patient relationship	The degree to which using the eHealth system is perceived as interfering the health care provider-patient relationship during their encounter [24,33,36,46,50,75,86-88,91,92,112] *physicians who value a close patient relationship have less positive attitudes about the EMR* [33]
Patient privacy concerns	The degree of a health care provider's perception of the security of patient information and protection of patient privacy [24,30,31,40,79,89,111,112]

[a]high volume of elderly

Discussion

Comparative and Gap Analysis

Of the 93 papers, 57 examined the adoption/acceptance issue of EHR/EMR. EHR/EMR is a repository of health information in relation to a subject of care (ie, patient) in a computer processable form [113]. Li et al explained that electronic patient records form the core of any other eHealth applications and thus the success of these is very much dependent on the EHR/EMR adoption [114]. Although EHR/EMR can be utilized by all groups of health care providers (eg, physicians, nurses, and pharmacists), physicians were study participants among an overwhelmingly large number of publications.

After 2002-2004, there was a sharp increase in the number of publications. A majority of these studies were conducted in the United States. According to Burt et al [115], EHR adoption in the United States was significantly low until 2005, with less than 18% of physicians used EHR at their office. After 2005, there was a great increase in EHR adoption levels across the United States [115], making more health care settings available for eHealth acceptance research.

Most of the 93 studies used a quantitative research methodology to measure eHealth adoption/acceptance variables and test hypotheses. A small percentage applied models or theories on individual acceptance of information technology (eg, Technology Acceptance Model, TAM [116-118]). The results supported the models in predicting the adoption behavior in the health care context. The most applied model was the TAM, which proposed a method of evaluating user acceptance through his/her beliefs, attitudes, intentions, and actual technology adoption behavior. Within these studies [25,29,41,42,75,77,79,81,83-85,87,88,102], the factors influential to health care providers' acceptance of eHealth included their perceived usefulness and needs, perceived ease of use, and all of the facilitating or inhibiting conditions.

Few studies (eg, [41]) have successfully tested the applicability of the UTAUT model by Venkatesh et al [21]. Using the definition of the UTAUT constructs, we analyzed and organized the eHealth acceptance factors that we found. The mapping work demonstrated that the UTAUT model is a useful framework for applying and organizing literature, which is of great benefit to readers interested in learning more on the topic [119]. Nevertheless, it was found that half of the health care provider characteristics (years in practice, role, and race) as well as medical practice characteristics identified from this literature review have not yet been covered in the UTAUT. Further, some studies also showed significant correlations among the identified factors. Perceived usefulness had the strongest impact on health care providers' behavior intention [88], whereas their perceived usefulness was influenced by the perceived ease of use, eHealth and business process alignment, end user involvement, management commitment and support to change, health care provider-patient relationship, and IT experience and knowledge [25,28,33,56,77,83,86-88]. The variance of the perceived ease of use was associated with the computer self-efficacy, end user involvement, management commitment and support to change, as well as health care provider-patient relationship [77,88]. These correlations have not been incorporated in the UTAUT. Our efforts to map eHealth acceptance research results against the UTAUT model suggested that health care settings could potentially extend theories on information technology adoption due to their complex contextual dynamics.

In some of the papers, significant correlations were not necessarily found between acceptance factors on the list (particularly those of individual characteristics and medical practice characteristics) and health care providers' usage intention or actual use of eHealth. Chavis's study [105], for example, did not demonstrate a significant positive correlation between individual characteristics (ie, job role and age) and technology adoption. This result can be explained with the UTAUT model: the age acts as a moderator rather than a factor directly impacting upon the behavioral intention or use behavior. Russell et al found that health care providers in large practices were not more likely to use an EMR [112]. Others [24,40,57,69,120] argued against that, suggesting that larger practices tended to "have access to the potentially greater resources" (financial and human resources) required for the eHealth system delivery and adoption, and have extensive internal IT assistance and training.

Apart from the contradicting findings among these studies, some acceptance factors can also be context sensitive. Given that most of the 93 studies were conducted in the United States, the types of third-party payers (which is by definition the proportion of patients who are privately insured, Medicaid, Medicare, or uninsured), for example, reflects the health insurance scheme specifically in the United States context. In the future, further studies particularly in health care settings of other countries, are required in order to improve the understanding of eHealth adoption phenomenon in a global context, as well as to extend the theory and research on individual acceptance of information technology.

Limitations

Here are a few major limitations of this literature review. Although efforts were made to include all research papers on health care providers' acceptance of various eHealth applications, some may not have been identified due to selected search phrases. In order to at least include those papers, which can help us increase the validity of the findings, the supplementary search keywords "EHR" and "EMR" were both used as previously discussed.

The review was limited also due to the selection of the databases. Although they are the outlets that were deemed most likely to publish eHealth acceptance-related work, some papers may have been missed. We tried to compensate for this potential loss by ensuring that all selected databases were searched to their full extent.

Mapping the identified eHealth adoption factors against the UTAUT model can be subjective. We attempted to maximize the accuracy and appropriateness of our mapping work by applying the validity procedure.

Practical Implications

To Decision Makers at Health Care Settings

The study results could help decision makers at the health care setting systematically understand facilitating forces and inhibiting factors influential to the health care providers' acceptance of eHealth, and thus proactively introduce interventions for the adoption success. For example, health care providers may lack the adequate computer skills to use eHealth systems or had previous negative technology experiences [49,121]. IT support before, during, and after initial eHealth implementation can provide a smooth transition to their reengineered job routine and overcome their technology phobia, hence facilitating eHealth acceptance and use (eg, [27,78,81]). IT support includes, but is not limited to training, provision of guideline documents, and troubleshooting [50,123,124].

Training can take various forms such as group training or one-on-one training, which is ideal in all circumstances [122]. One-on-one training needs to set expectations, teach health care providers about the eHealth system features, customize the technology for each particular specialty, and help them to integrate the system (eg, e-Prescribing) into their medical practice workflow [49].

Guideline documents as a knowledge source promote authentic translation of domain knowledge and reduce the overall complexity of the implementation task [123]. Each care provider should be provided with a manual containing step-by-step instructions for the system's use [124].

Real time troubleshooting (especially through internal resources) facilitates the effective use of the eHealth system and becomes essential to the system success in terms of actual usage [49,124]. Health care providers need to know how to access it when required [124]. A feedback mechanism (eg, online help) allows health care providers to document a problem that they are having with the system and then to receive prompt feedback [13,125]. Compared with external support services from the IT vendor, internal IT staff is more familiar with the work environment and related needs, and may respond more quickly to an urgent request [124].

Another example is eHealth/business process alignment. Workflow is associated with routine processes, characterized by a fixed definition of tasks and an order of execution [126]. The eHealth system needs to be designed in close collaboration with health care providers so that it truly assists their medical practice [122,127,128]. The collaboration between IT vendors and clinical sites is to understand the site's workflow and determine the most suitable IT solution [124,129]. After the workflow is analyzed thoroughly with health care providers' involvement, their participatory process is also essential to fine-tune the system's capabilities [128]. Extensive software testing of the vendor's claims for the baseline functionality and system adaptability to local needs is critical before the implementation, as health care providers' frustration from software problems can promptly escalate and result in resistance to continue using the system [128].

To Policy Makers at the Health Sector

By synthesizing the evidence from the literature, our study may also assist policy makers at the health sector in refining or developing relevant policies to push eHealth innovation. eHealth adoption and ongoing maintenance requires a large capital investment [131-133]. While the government in some cases funds the start-up cost of an eHealth project (eg, the EMRX system in Singapore), health care providers may still need to undertake the operation and enhancement cost of their system

[8]. In small or independent medical practices, there is lack or absence of internal capacity for system maintenance; eHealth vendors alternatively provide all these services but often charge high fees. Due to financial constraints, system maintenance represents a vulnerable spot for the entire effort of eHealth and many practices underperform [130]. To address this challenge, the development of programs such as zero-interest or revolving loans that make capital available to health care provider groups at low interest rates is essential, particularly in small or independent practices [48,106,130].

Another important issue is interoperability. Bates commented that the interoperability between eHealth applications and seamless and reliable clinical information exchange is a key to making EHR use a cornerstone of practice [130]. Even if physicians started to use an EHR system, they might still be unable to seamlessly share some other patient information (such as laboratory and radiology results stored in Laboratory Information Systems, LIS, and Picture Archiving and Communication Systems, PACS) for clinical decisions [130]. According to a recent analysis, $77.8 billion USD could be saved annually by interoperable clinical information exchange among key stakeholders in the health care delivery system [131]. The government should take stronger position to create a database of eHealth vendors whose products meet certain standards and enable clinical information exchange and to certify these products [31,82]. The certification effort would also minimize health care providers' uncertainty over the selection of a viable and sustainable product from hundreds of IT vendors in the market [68,106].

Legal and regulatory changes can be required to address eHealth adoption related issues [130,132]. For example, the Medicines Regulations (1984) and the Misuse of Drugs Regulations (1977) in New Zealand, which governs respectively the form of medication prescriptions and controlled substances, stated that indelible text and practitioners' handwritten signature was required for a legitimate prescription. To facilitate the adoption of electronic prescribing and dispensing of medicines, the Health Department of Commonwealth has amended the National Health (Pharmaceutical Benefits) Regulations [8]. These amendments came into effect from March 1, 2007 and the electronic prescribing and dispensing process has been additional and separate to the already existing paper-based process. The states and territories have continuously been taking steps to remove any legal barriers to the adoption of the electronic process in each jurisdiction.

Concluding Remarks

In this 4-step literature review, 40 factors were identified to be influential to health care providers' acceptance of eHealth and organized in accordance with the UTAUT model. The findings may help decision makers at health care settings and policy makers at the health sector to better understand eHealth adoption issues and take action to facilitate the eHealth innovation process. Our work also suggests further studies to extend theories on information technology adoption.

Conflicts of Interest

None declared.

References

1. World Health Organization. Global tuberculosis control: surveillance, planning, financing: WHO report 2008 URL: http://www.who.int/tb/publications/global_report/2008/en/index.html [accessed 2013-03-21] [WebCite Cache ID 6FIVL6O2T]
2. New Delhi: Central TB Division, DGHS, Ministry of Health and Family Welfare. RNTCP Status report 2010 URL: http://tbcindia.nic.in/pdfs/TB%20India%202010.pdf [accessed 2013-03-21] [WebCite Cache ID 6FIVcB95f]
3. Silber D. European Commission, Information Society, eHealth Conference. Atlanta, Belgium; 2003. The case for ehealth URL: http://ec.europa.eu/information_society/eeurope/ehealth/conference/2003/doc/the_case_for_eHealth.pdf [accessed 2013-03-21] [WebCite Cache ID 6FIViFwJR]
4. Grieger DL, Cohen SH, Krusch DA. A pilot study to document the return on investment for implementing an ambulatory electronic health record at an academic medical center. J Am Coll Surg 2007 Jul;205(1):89-96 [FREE Full text] [doi: 10.1016/j.jamcollsurg.2007.02.074] [Medline: 17617337]
5. Schade CP, Sullivan FM, de Lusignan S, Madeley J. e-Prescribing, efficiency, quality: lessons from the computerization of UK family practice. J Am Med Inform Assoc 2006;13(5):470-475 [FREE Full text] [doi: 10.1197/jamia.M2041] [Medline: 16799129]
6. Thakkar M, Davis DC. Risks, barriers, and benefits of EHR systems: a comparative study based on size of hospital. Perspect Health Inf Manag 2006;3:5 [FREE Full text] [Medline: 18066363]
7. 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]
8. Li J, Land L, Ray P. Humanitarian Technology Challenge (HTC)-electronic health records perspective. A Report of Joint Project of IEEE and United Nations Foundation 2008.
9. Vishwanath A, Scamurra SD. Barriers to the adoption of electronic health records: using concept mapping to develop a comprehensive empirical model. Health Informatics J 2007 Jun;13(2):119-134. [doi: 10.1177/1460458207076468] [Medline: 17510224]

10. O'Connell RT, Cho C, Shah N, Brown K, Shiffman RN. Take note(s): differential EHR satisfaction with two implementations under one roof. J Am Med Inform Assoc 2004;11(1):43-49 [FREE Full text] [doi: 10.1197/jamia.M1409] [Medline: 14527978]
11. Patterson ES, Nguyen AD, Halloran JP, Asch SM. Human factors barriers to the effective use of ten HIV clinical reminders. J Am Med Inform Assoc 2004;11(1):50-59 [FREE Full text] [doi: 10.1197/jamia.M1364] [Medline: 14527974]
12. Wallis K, Rice RE. Technology and health information privacy: consumers and the adoption of digital medical records technology. Mahwah, NJ: Erlbaum; 2006.
13. Saleem JJ, Patterson ES, Militello L, Render ML, Orshansky G, Asch SM. Exploring barriers and facilitators to the use of computerized clinical reminders. J Am Med Inform Assoc 2005;12(4):438-447 [FREE Full text] [doi: 10.1197/jamia.M1777] [Medline: 15802482]
14. Wickramasinghe NS, Fadlalla AMA, Geisler E, Schaffer JL. A framework for assessing e-health preparedness. Int J Electron Healthc 2005;1(3):316-334. [Medline: 18048213]
15. Ford EW, Menachemi N, Phillips MT. Predicting the adoption of electronic health records by physicians: when will health care be paperless? J Am Med Inform Assoc 2006;13(1):106-112 [FREE Full text] [doi: 10.1197/jamia.M1913] [Medline: 16221936]
16. Lehman WE, Greener JM, Simpson DD. Assessing organizational readiness for change. J Subst Abuse Treat 2002 Jun;22(4):197-209. [Medline: 12072164]
17. Kitchenham B. 2004. Procedures for performing systematic reviews URL: http://www.researchgate.net/publication/228756057_Procedures_for_performing_systematic_reviews [accessed 2013-03-27] [WebCite Cache ID 6FQuFqucY]
18. Kitchenham B, Pearl Brereton O, Budgen D, Turner M, Bailey J, Linkman S. Systematic literature reviews in software engineering - A systematic literature review. Information and Software Technology 2009;51:7-15. [doi: 10.1016/j.infsof.2008.09.009]
19. Ghapanchi AH, Aurum A. Antecedents to IT personnel's intentions to leave: A systematic literature review. J Syst Softw 2011;84:238-249. [doi: 10.1016/j.jss.2010.09.022]
20. Li J, Land L, Ray P. Evaluation criteria for frameworks in e-health domain. 2009 Presented at: The 15th American Conference on Information Systems; 2009 6-9 August; San Francisco, California United States.
21. Venkatesh V, Morris MG, Davis GB, Davis FD. User acceptance of information technology: toward a unified view. MIS Quarterly 2003;27:425-478.
22. Patton MQ. Qualitative research and evaluation methods. Thousand Oaks, Calif: Sage Publications; 2002.
23. Creswell JW, Miller DL. Determining validity in qualitative inquiry. Theory into Practice 2000;39(3):124-131.
24. Boonstra A, Broekhuis M. Barriers to the acceptance of electronic medical records by physicians from systematic review to taxonomy and interventions. BMC Health Serv Res 2010;10:231 [FREE Full text] [doi: 10.1186/1472-6963-10-231] [Medline: 20691097]
25. Djamasbi S, Fruhling AL, Loiacono ET. The influence of affect, attitude and usefulness in the acceptance of telemedicine systems. Journal of Information Technology Theory and Application 2009;10(1):41-58.
26. Colpaert K, Vanbelleghem S, Danneels C, Benoit D, Steurbaut K, Van Hoecke S, et al. Has information technology finally been adopted in Flemish intensive care units? BMC Med Inform Decis Mak 2010;10:62 [FREE Full text] [doi: 10.1186/1472-6947-10-62] [Medline: 20958955]
27. Pagliari C, Donnan P, Morrison J, Ricketts I, Gregor P, Sullivan F. Adoption and perception of electronic clinical communications in Scotland. Inform Prim Care 2005;13(2):97-104. [Medline: 15992494]
28. Tsiknakis M, Kouroubali A. Organizational factors affecting successful adoption of innovative eHealth services: a case study employing the FITT framework. Int J Med Inform 2009 Jan;78(1):39-52. [doi: 10.1016/j.ijmedinf.2008.07.001] [Medline: 18723389]
29. Tung FC, Chang SC, Chou CM. An extension of trust and TAM model with IDT in the adoption of the electronic logistics information system in HIS in the medical industry. Int J Med Inform 2008 May;77(5):324-335. [doi: 10.1016/j.ijmedinf.2007.06.006] [Medline: 17644029]
30. Jha AK, Bates DW, Jenter C, Orav EJ, Zheng J, Cleary P, et al. Electronic health records: use, barriers and satisfaction among physicians who care for black and Hispanic patients. J Eval Clin Pract 2009 Feb;15(1):158-163. [doi: 10.1111/j.1365-2753.2008.00975.x] [Medline: 18759752]
31. 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]
32. Arvary G. A primary care physician perspective survey on the limited use of handwriting and pen computing in the electronic medical record. Informatics in Primary Care 2002;10(3):161-172.
33. Dansky KH, Gamm LD, Vasey JJ, Barsukiewicz CK. Electronic medical records: are physicians ready? J Healthc Manag 1999;44(6):440-54; discussion 454. [Medline: 10662431]
34. Guida K, LaVenture M. EHR adoption and use. Results from the 2010 Minnesota ambulatory clinic survey. Minn Med 2011 Apr;94(4):33-36. [Medline: 21560880]

35. Holden RJ. Beliefs about health information technology: an investigation of hospital physicians' beliefs about and experiences with using electronic medical records. In: Dissertation International: Section B: The Sciences and Engineering. Ann Arbor, MI, USA: Proquest, Umi Dissertation Publishing; 2010:4413.
36. Kaushal R, Bates DW, Jenter CA, Mills SA, Volk LA, Burdick E, et al. Imminent adopters of electronic health records in ambulatory care. Inform Prim Care 2009;17(1):7-15. [Medline: 19490768]
37. Ludwick DA, Doucette J. Primary care physicians' experience with electronic medical records: barriers to implementation in a fee-for-service environment. International Journal of Telemedicine and Applications 2009 [FREE Full text]
38. McAlearney AS, Schweikhart SB, Medow MA. Organizational and physician perspectives about facilitating handheld computer use in clinical practice: results of a cross-site qualitative study. J Am Med Inform Assoc 2005 May;12(5):568-575 [FREE Full text] [doi: 10.1197/jamia.M1816] [Medline: 15905482]
39. Menachemi N, Brooks RG. EHR and other IT adoption among physicians: results of a large-scale statewide analysis. J Healthc Inf Manag 2006;20(3):79-87. [Medline: 16903665]
40. Menachemi N, Langley A, Brooks RG. The Use of Information Technologies Among Rural and Urban Physicians in Florida. J Med Syst 2007 Aug 2007;31(6):483-488. [doi: 10.1007/s10916-007-9088-6]
41. Ruxwana NL, Herselman ME, Conradie DP. ICT applications as e-health solutions in rural healthcare in the Eastern Cape Province of South Africa. HIM J 2010;39(1):17-26. [Medline: 20335646]
42. Tamblyn R, Huang A, Kawasumi Y, Bartlett G, Grad R, Jacques A, et al. The development and evaluation of an integrated electronic prescribing and drug management system for primary care. J Am Med Inform Assoc 2006;13(2):148-159 [FREE Full text] [doi: 10.1197/jamia.M1887] [Medline: 16357357]
43. Terry AL, Thorpe CF, Giles G, Brown JB, Harris SB, Reid GJ, et al. Implementing electronic health records: Key factors in primary care. Can Fam Physician 2008 May;54(5):730-736 [FREE Full text] [Medline: 18474707]
44. Terry AL, Giles G, Brown JB, Thind A, Stewart M. Adoption of electronic medical records in family practice: the providers' perspective. Fam Med 2009;41(7):508-512 [FREE Full text] [Medline: 19582637]
45. Whittaker AA, Aufdenkamp M, Tinley S. Barriers and facilitators to electronic documentation in a rural hospital. J Nurs Scholarsh 2009;41(3):293-300. [doi: 10.1111/j.1547-5069.2009.01278.x] [Medline: 19723278]
46. Whittaker L, Van Zyl J, Soicher AS. What is the point of the point-of-care? A case study of user resistance to an e-health system. Telemed J E Health 2011;17(1):55-61. [doi: 10.1089/tmj.2010.0008] [Medline: 21294686]
47. Zheng K, Padman R, Krackhardt D, Johnson MP, Diamond HS. Social networks and physician adoption of electronic health records: insights from an empirical study. J Am Med Inform Assoc 2010;17(3):328-336 [FREE Full text] [doi: 10.1136/jamia.2009.000877] [Medline: 20442152]
48. Abdolrasulnia M, Menachemi N, Shewchuk RM, Ginter PM, Duncan WJ, Brooks RG. Market effects on electronic health record adoption by physicians. Health Care Manage Rev 2008;33(3):243-252. [doi: 10.1097/01.HMR.0000324904.19272.c2] [Medline: 18580304]
49. Halamka J, Aranow M, Ascenzo C, Bates DW, Berry K, Debor G, et al. E-Prescribing collaboration in Massachusetts: early experiences from regional prescribing projects. J Am Med Inform Assoc 2006;13(3):239-244 [FREE Full text] [doi: 10.1197/jamia.M2028] [Medline: 16501174]
50. Ludwick D, Manca D, Doucette J. Primary care physicians' experiences with electronic medical records: implementation experience in community, urban, hospital, and academic family medicine. Can Fam Physician 2010 Jan;56(1):40-47 [FREE Full text] [Medline: 20090083]
51. Marques A, Oliveira T, Martins MFO. Adoption of medical records management system in European hospitals. 2010 Presented at: ECIME; September 9-10; Lisbon, Portugal.
52. Randeree E. Exploring physician adoption of EMRs: a multi-case analysis. J Med Syst 2007 Dec;31(6):489-496. [Medline: 18041282]
53. Rockswold PD, Finnell VW. Predictors of tool usage in the military health system's electronic health record, the Armed Forces Health Longitudinal Technology Application. Mil Med 2010 May;175(5):313-316. [Medline: 20486501]
54. Samoutis G, Soteriades ES, Kounalakis DK, Zachariadou T, Philalithis A, Lionis C. Implementation of an electronic medical record system in previously computer-naïve primary care centres: a pilot study from Cyprus. Inform Prim Care 2007;15(4):207-216. [Medline: 18237477]
55. Siracuse M, Galt K, Drincic A, Bramble J, Fuji K, Paschal K. E-prescribing: Are Medicare incentive payments enough to encourage adoption by physicians? Journal of the American Pharmacists Association 2010;50(2):249-250.
56. Vogel EW, Gracely EJ, Kwon Y, Maulitz RC. Factors determining the use of personal digital assistants among physicians. Telemed J E Health 2009 Apr;15(3):270-276. [doi: 10.1089/tmj.2008.0112] [Medline: 19382865]
57. Bramble JD, Galt KA, Siracuse MV, Abbott AA, Drincic A, Paschal KA, et al. The relationship between physician practice characteristics and physician adoption of electronic health records. Health Care Manage Rev 2010;35(1):55-64. [doi: 10.1097/HMR.0b013e3181c3f9ad] [Medline: 20010013]
58. Grant RW, Campbell EG, Gruen RL, Ferris TG, Blumenthal D. Prevalence of basic information technology use by U.S. physicians. J Gen Intern Med 2006 Nov;21(11):1150-1155 [FREE Full text] [doi: 10.1111/j.1525-1497.2006.00571.x] [Medline: 16879417]

59. Pizzi LT, Suh DC, Barone J, Nash DB. Factors related to physicians' adoption of electronic prescribing: results from a national survey. Am J Med Qual 2005;20(1):22-32. [Medline: 15782752]
60. Simon SR, Kaushal R, Cleary PD, Jenter CA, Volk LA, Orav EJ, et al. Physicians and electronic health records: a statewide survey. Arch Intern Med 2007 Mar 12;167(5):507-512. [doi: 10.1001/archinte.167.5.507] [Medline: 17353500]
61. Tucker MT. Dissertation International: Section B: The Sciences and Engineering. 2009. Application of the diffusion of innovations theory and the health belief model to describe EMR use among Alabama family medicine physicians: A rural and urban analysis URL: http://free-doc-lib.com/book/application-of-the-diffusion-of-innovations-theory-among-alabama.pdf [accessed 2013-03-27] [WebCite Cache ID 6FRAgvCt9]
62. Hoffman T. Computerworld. 2007 Mar 26. What's Plaguing E-health? URL: http://www.wpmassociates.com/healthcare/articles/plaguing_hit.html [accessed 2013-03-27] [WebCite Cache ID 6FR009TX3]
63. Menachemi N, Lee SC, Shepherd JE, Brooks RG. Proliferation of electronic health records among obstetrician-gynecologists. Qual Manag Health Care 2006;15(3):150-156. [Medline: 16849986]
64. Chiu TM, Eysenbach G. Stages of use: consideration, initiation, utilization, and outcomes of an internet-mediated intervention. BMC Med Inform Decis Mak 2010;10:73 [FREE Full text] [doi: 10.1186/1472-6947-10-73] [Medline: 21092275]
65. Hing E, Hsiao CJ. Electronic medical record use by office-based physicians and their practices: United States, 2007. Natl Health Stat Report 2010 Mar 31(23):1-11. [Medline: 20632518]
66. Menachemi N, Powers TL, Brooks RG. Physician and practice characteristics associated with longitudinal increases in electronic health records adoption. J Healthc Manag 2011;56(3):183-197. [Medline: 21714373]
67. Yeager VA, Menachemi N, Brooks RG. EHR adoption among doctors who treat the elderly. J Eval Clin Pract 2010 Dec;16(6):1103-1107. [doi: 10.1111/j.1365-2753.2009.01277.x] [Medline: 21176000]
68. Menachemi N. Barriers to ambulatory EHR: who are 'imminent adopters' and how do they differ from other physicians? Inform Prim Care 2006;14(2):101-108. [Medline: 17059699]
69. Simon JS, Rundall TG, Shortell SM. Drivers of electronic medical record adoption among medical groups. Jt Comm J Qual Patient Saf 2005 Nov;31(11):631-639. [Medline: 16335064]
70. Simon SR, Kaushal R, Cleary PD, Jenter CA, Volk LA, Poon EG, et al. Correlates of electronic health record adoption in office practices: a statewide survey. J Am Med Inform Assoc 2007;14(1):110-117 [FREE Full text] [doi: 10.1197/jamia.M2187] [Medline: 17068351]
71. Stream GR. Trends in adoption of electronic health records by family physicians in Washington State. Inform Prim Care 2009;17(3):145-152. [Medline: 20074426]
72. Trentman TL, Mueller JT, Ruskin KJ, Noble BN, Doyle CA. Adoption of anesthesia information management systems by US anesthesiologists. J Clin Monit Comput 2011 Apr;25(2):129-135. [doi: 10.1007/s10877-011-9289-x] [Medline: 21728057]
73. Shields AE, Shin P, Leu MG, Levy DE, Betancourt RM, Hawkins D, et al. Adoption of health information technology in community health centers: results of a national survey. Health Aff (Millwood) 2007;26(5):1373-1383 [FREE Full text] [doi: 10.1377/hlthaff.26.5.1373] [Medline: 17848448]
74. Gagnon MP, Desmartis M, Labrecque M, Légaré F, Lamothe L, Fortin JP, et al. Implementation of an electronic medical record in family practice: a case study. Inform Prim Care 2010;18(1):31-40. [Medline: 20429976]
75. Morton ME, Wiedenbeck S. EHR acceptance factors in ambulatory care: a survey of physician perceptions. Perspect Health Inf Manag 2010;7:1c [FREE Full text] [Medline: 20697466]
76. Menachemi N, Matthews MC, Ford EW, Brooks RG. The influence of payer mix on electronic health record adoption by physicians. Health Care Manage Rev 2007;32(2):111-118. [doi: 10.1097/01.HMR.0000267791.02062.3f] [Medline: 17438394]
77. Kifle M, Payton FC, Mbarika V, Meso P. Transfer and adoption of advanced information technology solutions in resource-poor environments: the case of telemedicine systems adoption in Ethiopia. Telemed J E Health 2010 Apr;16(3):327-343. [doi: 10.1089/tmj.2009.0008] [Medline: 20406120]
78. Cherry B, Carter M, Owen D, Lockhart C. Factors affecting electronic health record adoption in long-term care facilities. J Healthc Qual 2008;30(2):37-47. [Medline: 18411891]
79. Baroud RM. Dissertation International: Section B: The Sciences and Engineering. 2008. How ready are the stakeholders in the Palestinian healthcare system in the Gaza strip to adopt e-health? URL: http://dspace.ucalgary.ca/jspui/bitstream/1880/46329/1/Baroud_Thesis_2008.pdf [accessed 2013-03-27] [WebCite Cache ID 6FRAvBXl2]
80. Bennani A, Belalia M, Oumlil R. As a human factor, the attitude of healthcare practitioners is the primary step for the e-health: First outcome of an ongoing study in Morocco. Communications of the IBIMA 2008;3(4):1943-7765.
81. Bhattacherjee A, Hikmet N. Reconceptualizing organizational support and its effect on information technology usage: evidence from the health care sector. Journal of Computer Information Systems 2008;48(4):69-76.
82. Chang IC, Hwang H, Yen DC, Lian JW. Critical factors for adopting PACS in Taiwan: Views of radiology department directors. Decision Support Systems 2006;42:1042-1053. [doi: 10.1016/j.dss.2005.08.007]
83. Ernstmann N, Ommen O, Neumann M, Hammer A, Voltz R, Pfaff H. Primary care physician's attitude towards the German e-health card project--determinants and implications. J Med Syst 2009 Jun;33(3):181-188. [Medline: 19408451]
84. Handy J, Hunter I, Whiddett R. Erratum. Therap Adv Gastroenterol 2012 Sep;5(5):371-107 [FREE Full text] [doi: 10.1177/1756283X10363751] [Medline: 22973420]

85. Hewitt B. Exploring how security features affect the use of electronic health records. IJHTM 2010 2010;11(1/2):31-49. [doi: 10.1504/IJHTM.2010.033273]
86. McGinn CA, Grenier S, Duplantie J, Shaw N, Sicotte C, Mathieu L, et al. Comparison of user groups' perspectives of barriers and facilitators to implementing electronic health records: a systematic review. BMC Med 2011;9:46 [FREE Full text] [doi: 10.1186/1741-7015-9-46] [Medline: 21524315]
87. Morton ME, Wiedenbeck S. A framework for predicting EHR adoption attitudes: a physician survey. Perspect Health Inf Manag 2009;6:1a [FREE Full text] [Medline: 20169013]
88. Morton ME. Dissertation International: Section B: The Sciences and Engineering. Philadelphia, Pennsylvania, USA: Drexel University; 2009. Use and acceptance of an electronic health record: factors affecting physician attitudes URL: http://idea.library.drexel.edu/bitstream/1860/2905/1/Morton_Mary.pdf [accessed 2013-03-28] [WebCite Cache ID 6FSYNd3oQ]
89. Rudin RS, Simon SR, Volk LA, Tripathi M, Bates D. Understanding the decisions and values of stakeholders in health information exchanges: experiences from Massachusetts. Am J Public Health 2009 May;99(5):950-955. [doi: 10.2105/AJPH.2008.144873] [Medline: 19299671]
90. Gans D, Kralewski J, Hammons T, Dowd B. Medical groups' adoption of electronic health records and information systems. Health Aff (Millwood) 2005;24(5):1323-1333 [FREE Full text] [doi: 10.1377/hlthaff.24.5.1323] [Medline: 16162580]
91. Vishwanath A, Scamurra SD. Barriers to the adoption of electronic health records: using concept mapping to develop a comprehensive empirical model. Health Informatics J 2007 Jun;13(2):119-134. [doi: 10.1177/1460458207076468] [Medline: 17510224]
92. Fitzgerald G, Piris L, Serrano A. Identification of benefits and barriers for the adoption of e-health information systems using a socio-technical approach. 2008 Presented at: 30th International Conference on Information Technology Interfaces; 2008 Jun 23-26; Cavtat/Dubrovnik, Croatia p. 601-606.
93. Gómez Reynoso JM, Tulu B. Electronic Medical Records Adoption Challenges in Mexico. 2007 Presented at: AMIA 2007 Symposium Proceedings; 2007 Nov 10-14; CHICAGO IL, United States p. 1093.
94. Hsiao S, Li Y, Chen Y, Ko H. Critical factors for the adoption of mobile nursing information systems in Taiwan: the nursing department administrators' perspective. J Med Syst 2008 Aug 2008;33(5):369-377. [doi: 10.1007/s10916-008-9199-8]
95. Al-Qirim NA. Teledermatology: the case of adoption and diffusion of telemedicine health Waikato in New Zealand. Telemed J E Health 2003 Jun;9(2):167-177. [doi: 10.1089/153056203766437507] [Medline: 12855039]
96. Helitzer D, Heath D, Maltrud K, Sullivan E, Alverson D. Assessing or predicting adoption of telehealth using the diffusion of innovations theory: a practical example from a rural program in New Mexico. Telemed J E Health 2003;9(2):179-187. [doi: 10.1089/153056203766437516] [Medline: 12855040]
97. Dalal AK, Poon EG, Karson AS, Gandhi TK, Roy CL. Lessons learned from implementation of a computerized application for pending tests at hospital discharge. J Hosp Med 2011 Jan;6(1):16-21. [doi: 10.1002/jhm.794] [Medline: 21241037]
98. Grigsby B, Brega AG, Bennett RE, Devore PA, Paulich MJ, Talkington SG, et al. The slow pace of interactive video telemedicine adoption: the perspective of telemedicine program administrators on physician participation. Telemed J E Health 2007 Dec;13(6):645-656. [doi: 10.1089/tmj.2007.0090] [Medline: 18092926]
99. Halifax NV, Cafazzo JA, Irvine MJ, Hamill M, Rizo CA, McIssac WJ, et al. Telemanagement of hypertension: a qualitative assessment of patient and physician preferences. Can J Cardiol 2007 May 15;23(7):591-594 [FREE Full text] [Medline: 17534469]
100. Granlien MF, Hertzum M, Gudmundsen J. The gap between actual and mandated use of an electronic medication record three years after deployment. Stud Health Technol Inform 2008;136:419-424. [Medline: 18487767]
101. Hier DB, Rothschild A, LeMaistre A, Keeler J. Differing faculty and housestaff acceptance of an electronic health record. Int J Med Inform 2005 Aug;74(7-8):657-662. [doi: 10.1016/j.ijmedinf.2005.03.006] [Medline: 16043088]
102. Ilie V, Slyke CV, Parikh MA, Courtney JF. Paper versus electronic medical records: the effects of access on physicians' decisions to use complex information technologies. Decision Sciences 2009;40(2). [doi: 10.1111/j.1540-5915.2009.00227.x]
103. Rahimi B, Vimarlund V, Timpka T. Health information system implementation: a qualitative meta-analysis. J Med Syst 2008 Aug 2008;33(5):359-368. [doi: 10.1007/s10916-008-9198-9]
104. Sicotte C, Paré G, Moreault MP, Paccioni A. A risk assessment of two interorganizational clinical information systems. J Am Med Inform Assoc 2006;13(5):557-566 [FREE Full text] [doi: 10.1197/jamia.M2012] [Medline: 16799130]
105. Chavis VD. Dissertation International Section A: Humanities and Social Sciences. 2010. Organizational learning and large-scale change: adoption of electronic medical records URL: http://udini.proquest.com/view/organizational-learning-and-large-goid:520286516/ [accessed 2013-03-27] [WebCite Cache ID 6FR8BuZBg]
106. Rao SR, Desroches CM, Donelan K, Campbell EG, Miralles PD, Jha AK. Electronic health records in small physician practices: availability, use, and perceived benefits. J Am Med Inform Assoc 2011 May 1;18(3):271-275 [FREE Full text] [doi: 10.1136/amiajnl-2010-000010] [Medline: 21486885]
107. Chattopadhyay S. A framework for studying perceptions of rural healthcare staff and basic ICT support for e-health use: an Indian experience. Telemed J E Health 2010;16(1):80-88. [doi: 10.1089/tmj.2009.0081] [Medline: 20070160]
108. Elekwachi AO. Limitations to the utilization of electronic medical records by healthcare professionals: a case study of small medical practices. In: Dissertation International Section A: Humanities and Social Sciences. Ann Arbor, MI, USA: ProQuest; 2008:793.

109. Lapointe L, Rivard S. Getting physicians to accept new information technology: insights from case studies. CMAJ 2006;174(11).
110. Ross S. Results of a survey of an online physician community regarding use of electronic medical records in office practices. J Med Pract Manage 2009;24(4):254-256. [Medline: 19288653]
111. Nash K. Urologists wary of mandatory EMR system. Urology times 2009;37(5):34.
112. Russell SC, Spooner SA. Barriers to EMR adoption in internal medicine and pediatric outpatient practices. Tenn Med 2004 Oct;97(10):457-460. [Medline: 15536973]
113. ISO Technical Report. 2004. Health informatics - Electronic health record – Definition, scope and context URL: http://sl.infoway-inforoute.ca/downloads/infostand_V0.4_ISO_DTR_Defn_Scope_Context_e.pdf [accessed 2013-03-21] [WebCite Cache ID 6FIZEAjHO]
114. Li J, Land L, Ray P, Chattopadhyaya S. E-Health readiness framework from Electronic Health Records perspective. IJIEM 2010 2010;6(4):326. [doi: 10.1504/IJIEM.2010.035626]
115. Burt CW, Hing E. Use of computerized clinical support systems in medical settings: United States, 2001-03. Adv Data 2005 Mar 2(353):1-8. [Medline: 15759905]
116. Davis F. Perceived Usefulness, Perceived Ease of Use, and User Acceptance of Information Technology. MIS Quarterly 1989;13:319-340. [doi: 10.2307/249008]
117. Davis FD, Bagozzi RP, Warshaw PR. User Acceptance of Computer Technology: A Comparison of Two Theoretical Models. Management Science 1989 Aug 1989;35(8):982-1003. [doi: 10.1287/mnsc.35.8.982]
118. Davis FD. User acceptance of information technology: system characteristics, user perceptions and behavioral impacts. International Journal of Man-Machine Studies 1993 Mar 1993;38(3):475-487. [doi: 10.1006/imms.1993.1022]
119. Hennington AH, Janz BD. Information systems and healthcare XVI: physician adoption of electronic medical records: applying the UTAUT model in a healthcare context. Communications of the Association for Information Systems 2007;19:60-80.
120. Mattocks K, Lalime K, Tate JP, Giannotti TE, Carr K, Carrabba A, et al. The state of physician office-based health information technology in Connecticut: current use, barriers and future plans. Conn Med 2007 Jan;71(1):27-31. [Medline: 17288104]
121. Kemper AR, Uren RL, Clark SJ. Adoption of electronic health records in primary care pediatric practices. Pediatrics 2006 Jul;118(1):e20-e24 [FREE Full text] [doi: 10.1542/peds.2005-3000] [Medline: 16818534]
122. Ash JS, Bates DW. Factors and forces affecting EHR system adoption: report of a 2004 ACMI discussion. J Am Med Inform Assoc 2005;12(1):8-12 [FREE Full text] [doi: 10.1197/jamia.M1684] [Medline: 15492027]
123. Shiffman RN, Michel G, Essaihi A, Thornquist E. Bridging the guideline implementation gap: a systematic, document-centered approach to guideline implementation. J Am Med Inform Assoc 2004;11(5):418-426 [FREE Full text] [doi: 10.1197/jamia.M1444] [Medline: 15187061]
124. Fullerton C, Aponte P, Hopkins RIII, Bragg D, Ballard DJ. Lessons learned from pilot site implementation of an ambulatory electronic health record. Proc (Bayl Univ Med Cent) 2006 Oct;19(4):303-310 [FREE Full text] [Medline: 17106488]
125. Lee F, Teich JM, Spurr CD, Bates DW. Implementation of physician order entry: user satisfaction and self-reported usage patterns. J Am Med Inform Assoc 1996;3(1):42-55 [FREE Full text] [Medline: 8750389]
126. Xu L, Liu H, Wang S, Wang K. Modelling and analysis techniques for cross-organizational workflow systems. Syst. Res 2009 May 2009;26(3):367-389. [doi: 10.1002/sres.978]
127. Kamadjeu EM, Tapang EM, Moluh RN. Designing and implementing an electronic health record system in primary care practice in sub-Saharan Africa: a case study from Cameroon. Inform Prim Care 2005;13(3):179-186. [Medline: 16259857]
128. Scott JT, Rundall TG, Vogt TM, Hsu J. Kaiser Permanente's experience of implementing an electronic medical record: a qualitative study. BMJ 2005 Dec 3;331(7528):1313-1316 [FREE Full text] [doi: 10.1136/bmj.38638.497477.68] [Medline: 16269467]
129. Darroch K, Ellis B. Development and use of integrated electronic records. Community Practitioner 2003;76(2):53-55.
130. Bates DW. Physicians and ambulatory electronic health records. Health Aff (Millwood) 2005;24(5):1180-1189 [FREE Full text] [doi: 10.1377/hlthaff.24.5.1180] [Medline: 16162561]
131. Walker J, Pan E, Johnston D, Adler-Milstein J, Bates DW, Middleton B. The value of health care information exchange and interoperability. Health Aff (Millwood) 2005;Suppl Web Exclusives:W5-10 [FREE Full text] [doi: 10.1377/hlthaff.w5.10] [Medline: 15659453]
132. Jha AK, Ferris TG, Donelan K, DesRoches C, Shields A, Rosenbaum S, et al. How common are electronic health records in the United States? A summary of the evidence. Health Aff (Millwood) 2006;25(6):w496-w507 [FREE Full text] [doi: 10.1377/hlthaff.25.w496] [Medline: 17035341]

Abbreviations

AIMS: Anesthesia Information Management System
eHCD: eHealth for Health Care Delivery
EHR: electronic health records
EMR: electronic medical records

HVE: high volume of elderly
ICIS: Intensive Care Information System
ICT: information and communication technologies
IT: information technology
LIS: Laboratory Information Systems
PACS: Picture Archiving and Communication systems
TAM: Technology Acceptance Model
UTAUT: Unified Theory of Acceptance and Use of Technology
WHO: World Health Organization

Edited by G Eysenbach; submitted 09.12.12; peer-reviewed by H Siadat, T Solvoll, D Keeling; comments to author 22.01.13; revised version received 04.02.13; accepted 09.03.13; published 16.04.13.

Please cite as:
Li J, Talaei-Khoei A, Seale H, Ray P, MacIntyre CR
Health Care Provider Adoption of eHealth: Systematic Literature Review
Interact J Med Res 2013;2(1):e7
URL: http://www.i-jmr.org/2013/1/e7/
doi:10.2196/ijmr.2468
PMID:23608679

Original Paper

Evaluation of User Interface and Workflow Design of a Bedside Nursing Clinical Decision Support System

Michael Juntao Yuan[1], PhD; George Mike Finley[2], MD; Ju Long[3], PhD; Christy Mills[2], RN; Ron Kim Johnson[1], MBA

[1]Ringful Health, Austin, TX, United States

[2]CHRISTUS St Michael's Health System, Texarkana, TX, United States

[3]Texas State University - San Marcos, Department of Computer Information Systems, San Marcos, TX, United States

Corresponding Author:
Ju Long, PhD
Texas State University - San Marcos
Department of Computer Information Systems
601 University Drive
San Marcos, TX,
United States
Phone: 1 512 245 3231
Fax: 1 512 245 1452
Email: julong@txstate.edu

Abstract

Background: Clinical decision support systems (CDSS) are important tools to improve health care outcomes and reduce preventable medical adverse events. However, the effectiveness and success of CDSS depend on their implementation context and usability in complex health care settings. As a result, usability design and validation, especially in real world clinical settings, are crucial aspects of successful CDSS implementations.

Objective: Our objective was to develop a novel CDSS to help frontline nurses better manage critical symptom changes in hospitalized patients, hence reducing preventable failure to rescue cases. A robust user interface and implementation strategy that fit into existing workflows was key for the success of the CDSS.

Methods: Guided by a formal usability evaluation framework, UFuRT (user, function, representation, and task analysis), we developed a high-level specification of the product that captures key usability requirements and is flexible to implement. We interviewed users of the proposed CDSS to identify requirements, listed functions, and operations the system must perform. We then designed visual and workflow representations of the product to perform the operations. The user interface and workflow design were evaluated via heuristic and end user performance evaluation. The heuristic evaluation was done after the first prototype, and its results were incorporated into the product before the end user evaluation was conducted. First, we recruited 4 evaluators with strong domain expertise to study the initial prototype. Heuristic violations were coded and rated for severity. Second, after development of the system, we assembled a panel of nurses, consisting of 3 licensed vocational nurses and 7 registered nurses, to evaluate the user interface and workflow via simulated use cases. We recorded whether each session was successfully completed and its completion time. Each nurse was asked to use the National Aeronautics and Space Administration (NASA) Task Load Index to self-evaluate the amount of cognitive and physical burden associated with using the device.

Results: A total of 83 heuristic violations were identified in the studies. The distribution of the heuristic violations and their average severity are reported. The nurse evaluators successfully completed all 30 sessions of the performance evaluations. All nurses were able to use the device after a single training session. On average, the nurses took 111 seconds (SD 30 seconds) to complete the simulated task. The NASA Task Load Index results indicated that the work overhead on the nurses was low. In fact, most of the burden measures were consistent with zero. The only potentially significant burden was temporal demand, which was consistent with the primary use case of the tool.

Conclusions: The evaluation has shown that our design was functional and met the requirements demanded by the nurses' tight schedules and heavy workloads. The user interface embedded in the tool provided compelling utility to the nurse with minimal distraction.

(Interact J Med Res 2013;2(1):e4) doi:10.2196/ijmr.2402

KEYWORDS

clinical decision support systems; user-computer interface; software design; human computer interaction; usability testing; heuristic evaluations; software performance; patient-centered care

Introduction

Usability Issues in Clinical Decision Support Systems

Clinical decision support systems (CDSS) are important tools to improve health care outcomes and reduce preventable medical adverse events [1,2]. In the US, CDSS is one of the key requirements for the government mandated meaningful use of electronic medical record (EMR) adoption [3]. It was suggested that smart, portable, point-of-care, and interoperable technology solutions could help reduce inefficiencies and improve patient safety and outcomes for nurses [4].

However, the effectiveness and success of CDSS depend on their implementation context and usability in complex health care settings (eg, [5]). Studies have shown that different CDSS implementations often yield very different clinical outcomes (eg, [6,7]). A study found that a home grown CDSS designed specifically for a hospital out-performed 31 other similar CDSS deployments included in the study [8]. A multi-site study indicated that nurses routinely over-ride CDSS recommendations that do not fit their local practice, leading to a potential increase of errors [9].

In particular, CDSS implementations often suffer from poor usability, which directly impacts their adoption and effectiveness. For instance, user interface (UI) workarounds have been shown to greatly diminish the effectiveness of widely used CDSSs [10,11]. While many CDSSs rely on alert/reminder-based user interactions to prompt the clinician correct potential guideline violations, alert fatigue was a common issue for those systems (eg, [12]). A study showed that physicians who receive CDSS alerts were only slightly more likely to take appropriate actions than those who do not [13]. In the area of diagnostic decision support, it has been demonstrated that the accuracy of diagnostic aid tools depends on their UI. Tools that require simple copying and pasting from free text medical records yield more accurate results than tools that require the physician to extract and categorize information from the medical records [14,15]. As a result, usability design and validation, especially in real world clinical settings, are crucial aspects of successful CDSS implementation.

In this study, we developed a novel CDSS for the CHRISTUS St. Michael health system (a 350 bed acute care hospital) to help frontline nurses better manage critical symptom changes in hospitalized patients. The CDSS is currently undergoing clinical pilots inside the hospital. The goal of the CDSS was to reduce preventable failure to rescue (FTR) cases in the hospital. Since the nursing work environment is subject to constant interruptions and is error prone [16], a robust UI and implementation strategy that fit into the existing workflow was crucial to the success of the system.

In this paper, we will discuss the design, evaluation, implementation, and validation of the CDSS UI. We will present several innovations in nursing CDSS UI design, especially on large touch screen devices. The internal algorithmic design and the validation of decision rules, however, are beyond the scope of this paper. In the next section, we will start with a brief clinical background of the nursing CDSS tool.

Nursing Decision Support for Early Detection of Critical Changes

Early Symptom Recognition and Response

The FTR is a leading patient safety indicator with the highest incident rates among all indicators according to a recent large-scale study [17]. In 2010, FTR measure was included as one of the Inpatient Prospective Payment System measures by the Center for Medicare and Medicaid Services, which directly affects hospitals' reimbursements [18].

FTRs are often considered preventable because the symptoms of a deteriorating patient could present hours before the rescue starts. Examples of such critical symptom change include patient complaint of a new pain, mental status change, and difficulty breathing etc. Studies have indicated that many FTRs could have been averted if the critical symptoms in patients were captured, evaluated, and communicated early.

It was suggested that the nurses' early recognition, evaluation, and decision making of symptom signs could play an important role in FTR [19,20]. A study conducted in a surgical oncology population indicated that many complications are detectable by nurses and can be managed with timely intervention [21]. It was suggested that 23,000 in-hospital cardiac arrests in the UK could be prevented every year if early signs of symptoms were detected and acted upon [22]. A 2009 study demonstrated that an early symptom recognition and response system could help improve outcome of sepsis and septic shock, which have hard-to-detect symptoms [23].

Simply detecting and evaluating the critical symptom changes is not enough. The potential complication must be communicated to the rest of the clinical team, and be escalated to the right team members in order to organize effective interventions. It was argued that FTRs are often caused by the failure to communicate [24]. Interventions such as the rapid response team (RRT) have demonstrated effectiveness in reducing FTRs when the issues are escalated on time [25,26]. In fact, the national deployment of RRT has the explicit purpose of supporting nurses in managing critical changes before coding arrest [27]. It was also suggested that escalating to surgical residents could improve rescue success rates [28], indicating that the optimal path of escalation needs to be selected by the nurses as part of the decision-making process.

Role of Frontline Nurses in Symptom Evaluations and Rapid Response Interventions

Frontline nurses are often the first to notice critical symptom changes. Their decisions at the point-of-care are crucial factors determining whether FTR events can be reduced. However, at

the same time, nurses are ill equipped to manage critical symptom changes in hospitals.

The frontline nursing staff in most hospitals have very high workloads, need to manage extensive multitasking, and are fatigued [16,29]. The fatigue has been demonstrated to negatively impact nurses' cognitive performance [30], including symptom evaluations. In fact, studies have shown a strong anti-correlation between nursing staffing levels and medical error rates [31].

The average skill and training levels of nurses do not adequately prepare them to evaluate potentially complex symptom changes. A study found that a 10% increase in the proportion of nurses holding a bachelor's degree was associated with a 5% decrease in the odds of FTR [32]. Furthermore, most diagnostic aid CDSSs, such as differential diagnostic tools and diagnostic reminder tools, were designed for physicians to use in office settings, as opposed to nurses at the bedside.

While the RRT is a proven effective intervention for FTR, RRT resources can be under-utilized [33] because the nurses do not feel comfortable activating the RRT. Better communication has been shown to improve RRT utilization [34]. It has been suggested that mandatory RRT activation helps reduce cardiorespiratory arrests outside of critical care areas in a hospital [35].

The hieratical structure in hospitals is known to impede nurse decision-making process [36]. Nurses are often discouraged from communicating and escalating problems. While hospitals across the nation have implemented teamwork frameworks, such as the TeamSTEPPS [37], the emergency communication between nurses and physicians is still often error prone and require standardization [38].

Design of CDSS

A specially designed CDSS could potentially help the nurse address the above issues related to critical symptom changes and FTRs. Such CDSS requires special design considerations for two reasons.

First, the system must be tailored to the nurses' training and cognitive levels, and generate action items that are appropriate for the nurse. Most floor nurses have gone through less than 4 years of medical training after high school, and they do not have independent authority to treat the patient without the physician's prescription.

Second, the system must be adapted to the fast paced workflow during a rescue operation. The tool must be ubiquitous, instant on, and provides useful feedback in merely minutes. The application should enhance real-time communication across team members, as opposed to bringing in another computer that impedes face-to-face communication.

Both challenges highlight the need for a novel design, and formal evaluation of the system UI and workflow.

Cognitive Design of UI

Human-computer interaction and workflow designs are crucial for the success of clinical informatics projects. A large body of research has been devoted to study methods and techniques to evaluate usability of systems.

Early efforts focused on creating human models and breaking down tasks into small pieces that could be directly measured and optimized for user performance. For instance, the goals, operators, methods, and selection rules family of frameworks [39-41] are widely used to model human users as information processors. They break down user actions (eg, every key stroke), and measure time consumed in each step to evaluate the overall effectiveness of the UI. However, such frameworks do not take into account the intrinsic difficulty of the task and the functionality of the UI. They are very good at evaluating systems that predominantly require movement operations, but are less effective in evaluating systems with heavy cognitive tasks.

For cognitive systems, analysis of the UI itself is a key aspect of usability design, because UI design often has a deterministic effect on user performance. Research in cognitive theory has indicated that different visual representation of the same underlying work problem could produce dramatically different user performance in terms of ability to complete tasks correctly and productivity [42,43]. A well-known example is that Arabic numerals are much easier to add and multiply than their equivalent Roman numerals.

Furthermore, complex work often requires collaboration of multiple users. It was demonstrated that cognition can be distributed across multiple users working on the same system [44-46]. Hence, another important aspect of usability design is to evaluate each user's goals and functions, and then translate them into a cohesive UI.

A popular design approach that works with the above cognitive design principles is the work-centered design (WCD) [47,48]. WCD treats the UI as an aid for the user to achieve a specific work task. It conceptualizes steps for knowledge capture, requirement analysis, aiding design, and evaluation, which is a process followed closely in modern software development.

A particularly interesting application of distributed cognition and WCD in the medical informatics field is the UFuRT (user, function, representation, and task analysis) [49-51] framework. For this project, we decided to use the UFuRT framework as a guide for usability design. The primary reason for us to choose UFuRT is its successful track record in design and evaluation of medical information technology (IT) products [52-54]. Its usability evaluation process consists of 4 major steps:

1. User analysis is used to identify users and stakeholders of the work product, and document their needs and objectives. The user requirements are translated into system design requirements in this process.
2. Function analysis aims to generate an essential description of the work. The UFuRT process calls for a 4-step analysis to detail the dimensions, constraints, relations, and finally operations.
3. Representational analysis is the design process to identify and determine the implementation representations of relations among the dimensions identified in the functional analysis. The representation includes UIs and workflows for different types of users of the system. Representational

analysis is a crucial step of the design process since it has been convincingly demonstrated that different representations of the same task can have very different impacts on the user's efficiency and productivity [55]. The ease-of-use of the UI is also one of the major factors driving adoption of any technology product [56].

4. Task analysis is to identify steps by a specific user on a specific representation in order to carry out an operation.

In the context of our project, we used UFuRT framework to analyze software requirements and inform the specification. Hence, we focused on user analysis and UI design aspects of representation analysis. We performed a high-level functional analysis and did not perform task analysis in the design stage. The reason was that complete functional and task analysis require full knowledge of every detail of the product, which would not provide enough flexibility for our iterative software development process.

Methods

Design Goals and System Requirements

The overall objective of the system was to help prevent patient safety events during critical changes. Through interviews with hospital-based clinicians, we have specifically identified symptom evaluation and escalation as the 2 main functional goals of the CDSS.

Improve Symptom Recognition and Evaluation

Existing Procedures

While nurses do not make diagnoses, they are the first to recognize and evaluate the patient symptom changes. Based on their evaluation, they would decide how to (or whether to) coordinate further care, and their evaluation results are often accepted by the team as the basis of a formal diagnosis.

Existing diagnostic CDSS tools provide a proven framework to help reduce errors in diagnostic evaluation, and improve documentation of the clinical findings that lead to diagnoses. Specially, the CDSS needs to provide 2 core functionalities.

Provide Just-in-Time Medical Content to the Nurse

For many critical symptom changes, there are multiple possible diagnoses. An example is that a hospitalized patient suddenly feels chest pain. The chest pain could be an indicator of heart attack, which needs to be attended to by a cardiologist or surgery team immediately; or the chest pain could indicate reflux or indigestion, which is a rather common condition that is simple to treat.

The frontline nurses typically do not have enough medical training and experience to thoroughly evaluate those potential diagnostic outcomes. The CDSS should provide specific instructions for the nurse to follow, and then make recommendations on what to do next. For instance, it should provide specific instructions on whom to call and what to say during the call for each potential diagnosis. The system does not replace human decision-making or training, but it provides support to help nurses deal with complicated emergent situations to the best of their capabilities.

Reduce Common Cognitive Errors

Common cognitive errors that lead to diagnostic errors include premature closure, anchoring, confirmatory bias, and framing [57]. Those errors happen because the clinicians ignore certain findings or give certain other findings too much weight. Studies have indicated that cognitive errors such as premature closure are the most common cause of diagnostic errors made by clinicians [58]. A key design goal of the CDSS was to help reduce those common cognitive errors.

To reduce framing and premature closure, the CDSS should encourage and prompt the clinicians to check all possible diagnostic outcomes, especially severe outcomes that lead to FTRs. The CDSS should also prompt the clinicians to verify all important symptoms and findings related to major diagnostic outcomes to minimize missed diagnoses.

To reduce anchoring or confirmatory bias, the CDSS should present an objective estimate of likely diagnoses and suggested clinical actions based on the current findings. The objective probability estimate could reduce the user's reliance on reconceived decision biases.

Facilitate Team Communication

Teamwork

Teamwork is one of the few proven approaches to improve patient safety and care quality in hospitals [37,59]. Particularly, our system should be designed to increase the utilization of the RRT, and improve communication between nurses and physicians.

RRT Utilization

As we discussed in the clinical background, RRT is an effective approach to help reduce FTR when it is deployed correctly. Our CDSS aimed to improve the effectiveness of the RRT by activating RRT early and making RRT mandatory when the nurse detects certain warning signs.

The CDSS needs to provide an easy and non-intrusive way to automatically alert the RRT at appropriate times. The RRT consists of more experienced clinicians, and they can decide whether or when to respond to those alerts. At the same time, it is important for the CDSS to clearly notify the nurse when it sends alerts to the RRT and the status of the alerts. The user must feel that he/she is in full control in order to effectively utilize the system.

Nurse-Physician Communication

If the floor nurse determines that the patient needs assistance from a physician, he/she would call the physician and explain the situation. The conversation could be a frustrating experience for both the nurse and the physician due to different expectations. That could result in the physician losing confidence in the nursing staff, and nurses delaying calls to physicians. The system should provide tools to help nurses communicate better with physicians in emergency situations.

Development of the Software Specification

Design

We used the UFuRT framework as a conceptual guide to develop the software specification for the CDSS tool. Specifically, we identified users of the system, and documented use case stories for each user (ie, user analysis). We identified high-level functions the system must perform to meet the user requirement (ie, functional analysis). And finally, we created visual representations of the UI that can best accomplish those functions (ie, representational analysis). The UFuRT task analysis was not conducted at the design stage. Instead, the tasks were evaluated as part of the user evaluation process described later in this article.

User Analysis

Users of the proposed CDSS were members of the clinician team responsible for rescuing patients in the hospital. They included floor nurses, RRT nurses, and physicians. The user roles described in this section were based on interviews with hospital clinicians.

The primary users of the CDSS were the floor nurses. The system presented information and actions that were appropriate to the floor nurses. Specifically, the system could not present medical content that required MD-level training to understand, or ask nurses to make diagnostic decisions on their own. The CDSS also could not instruct the nurse to perform clinical actions that he/she was not authorized or qualified to do, such as performing advanced examinations, ordering labs, or writing prescriptions. Furthermore, a key characteristic in the floor nurse's work environment is that they are very busy and have established workflows. The system added minimal overhead to the existing workflows.

If the floor nurse detected a potential problem, the RRT nurse was the next escalation step. RRT nurses are typically paged by the hospital internal communication system, and hence the CDSS must support paging the RRT. The system should give RRT nurses more options as they have the authority to perform standing orders on patients. Finally, when the RRT nurse arrived at the bedside, in order to minimize errors at the hand-off of care, it was important for the CDSS to have clear documentation on the findings and actions that have been performed by the floor nurse so far.

The physician in charge of the patient should be notified when there is a probable problem with the patient. The system should provide accurate and concise summaries of the patient condition for the nurse to read to the physician when talking on the phone.

Functional Analysis

Once the user requirements were determined, we developed a list of high-level functions the system must perform. Please note that we did not create a detailed catalog of functions at this stage of development. Instead, we focused on high-level operations in order to provide implementation flexibility. Key operations of the system include the following:

- Identify the symptom change that triggers the use of the system
- Identify a list of potential diagnoses
- Identify a list of potential clinical findings that will reject or affirm those diagnoses
- Enter clinical findings
- Re-evaluate the probabilities for each diagnosis after each finding
- Repeat for all finds until a diagnosis becomes highly likely
- Identify the action items for this diagnosis
- Identify the escalation path for this diagnosis
- Perform operations required in the action items list

In addition, we have also identified non-essential operations that were related to the specific design of the system. Such operations included user login to the system with badge number, synchronization of the device content with online repositories, user entry of the patients' room number, and user configuration of the device for display options.

UI Design

Overview

The UI of the product was designed to address operations listed in the previous section. It aimed to present a familiar and non-intrusive interface to the user at the point-of-care. In this section, we describe key features of the UI.

Mobility Through a Consumer Tablet Device

We decided to implement the UI on a touch screen consumer tablet device. The reason behind choosing a tablet device was that it can be accessed anytime, anywhere, and could be carried around by the clinician or be made available at the bedside. The tablet device was connected to the hospital secure WiFi system to access medical records, alert RRT and other teams, and update clinical content as needed.

The choice of a consumer tablet, as opposed to a dedicated medical device, was due to two reasons. First, the consumer device was much cheaper to deploy. A consumer iPad costs less than one third of a special purpose tablet PC on the market. Second, the consumer device featured an UI that the nurses were already familiar with due to his or her use of similar devices at home.

The most widely used and user-friendly consumer tablet device on the market is the Apple iPad, which we chose as the implementation platform for the CDSS device.

Dynamic Checklist Design

Most existing diagnostic decision support tools use decision trees [60] or text-based free form search [15] to generate potential diagnoses. We determined that neither approach was suitable for nurses in emergence situations. Decision trees are slow and hard to recover from accidental typos. Text-based data entry is very slow on a mobile device.

Instead, we decided to use another UI metaphor that is commonly used in hospital environments—the medical checklist. The main UI of the system was a dynamic checklist for the nurse to go over and examine clinical findings related to the patient. Checklists have been shown to reduce medical errors [61,62], and could help prevent several categories of cognitive errors (outlined in Section 3.1.2 of [63]). UI is

important for checklists. Effective checklists need to be prioritized, short, highly usable, and integrated into the clinician workflow [64].

Figure 1 shows a split panel screen with 2 lists. This is the screen that the nurses see when he/she selects a critical change (eg, "chest pain" or "mental status change"). The checklist to the right is a list of measurements and observations the nurse needs to perform in order to evaluate the patient. The list was ordered based on the priority and potential impact of each finding. The nurses were encouraged to work on the high priority tasks at the top of the list first.

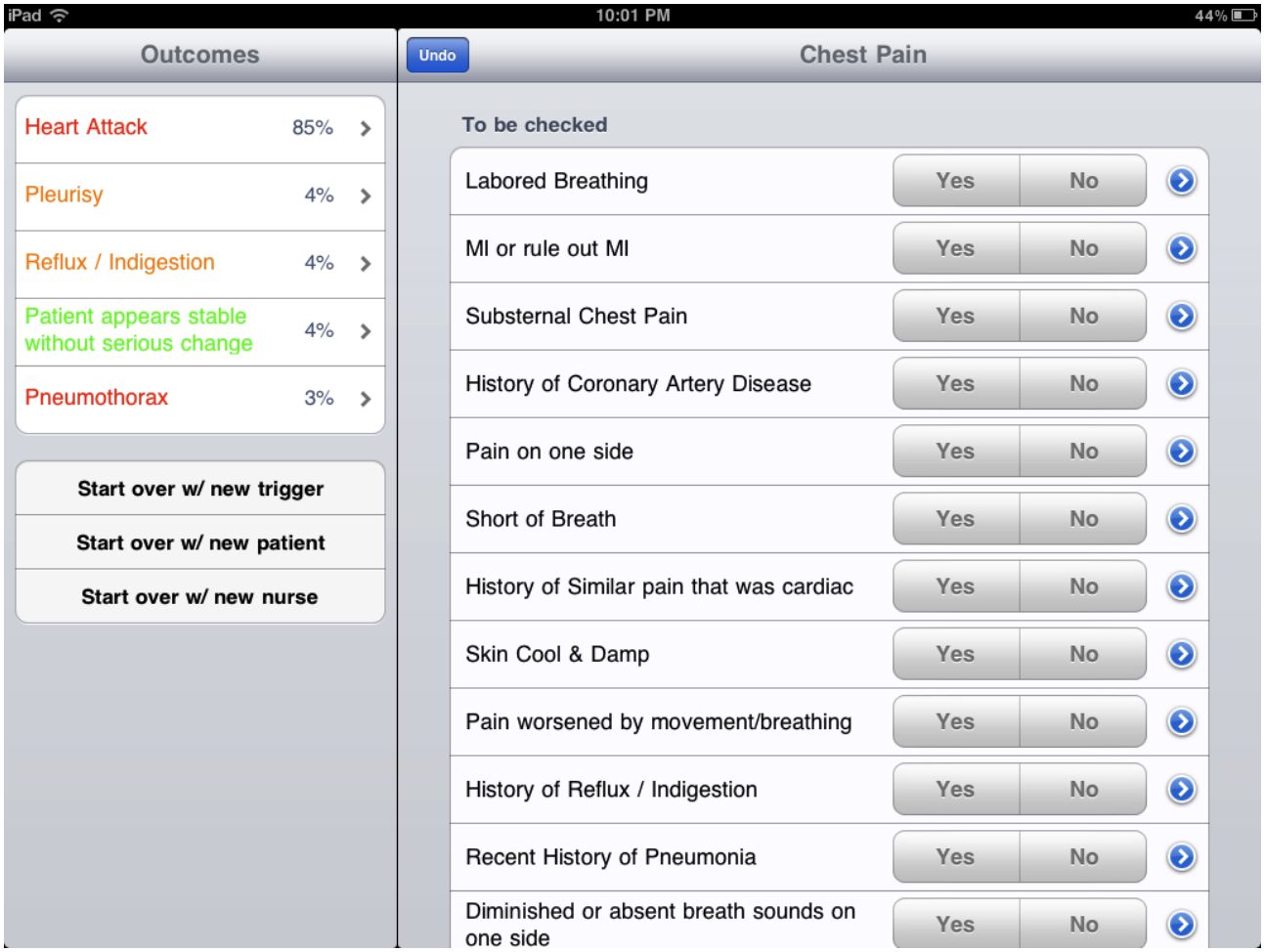
The list on the left shows potential causes for the patient's critical change (ie, the diagnostic outcomes). The causes were listed in order of their probabilities based on the current findings from the checklist items on the right panel.

All the user needed to do was to follow the checklist and enter a simple yes/no answer to the findings. With each yes/no answer, the system automatically recalculated and redisplayed the diagnostic outcome probabilities and the priorities of the remaining checklist items.

The nurses could go through the findings checklist in any order. The nurses could also undo any choices to go back to any previous state. That allowed the nurses to pick and choose tasks that happen to fit the existing workflow at any point of the process. There was no need to interrupt the flow just to provide a finding required by the software.

This is different than the typical decision tree or flow chart decision models, where the workflow is dictated by the software system.

Figure 1. The main split screen user interface of the decision support system.



RRT Integration

The CDSS was connected to the hospital communication system, and it automatically sent out pages to the RRT as the nurse works on the patient. The RRT members could then decide whether to intervene depending on how severe the patient condition was as reported by the nurse through the device.

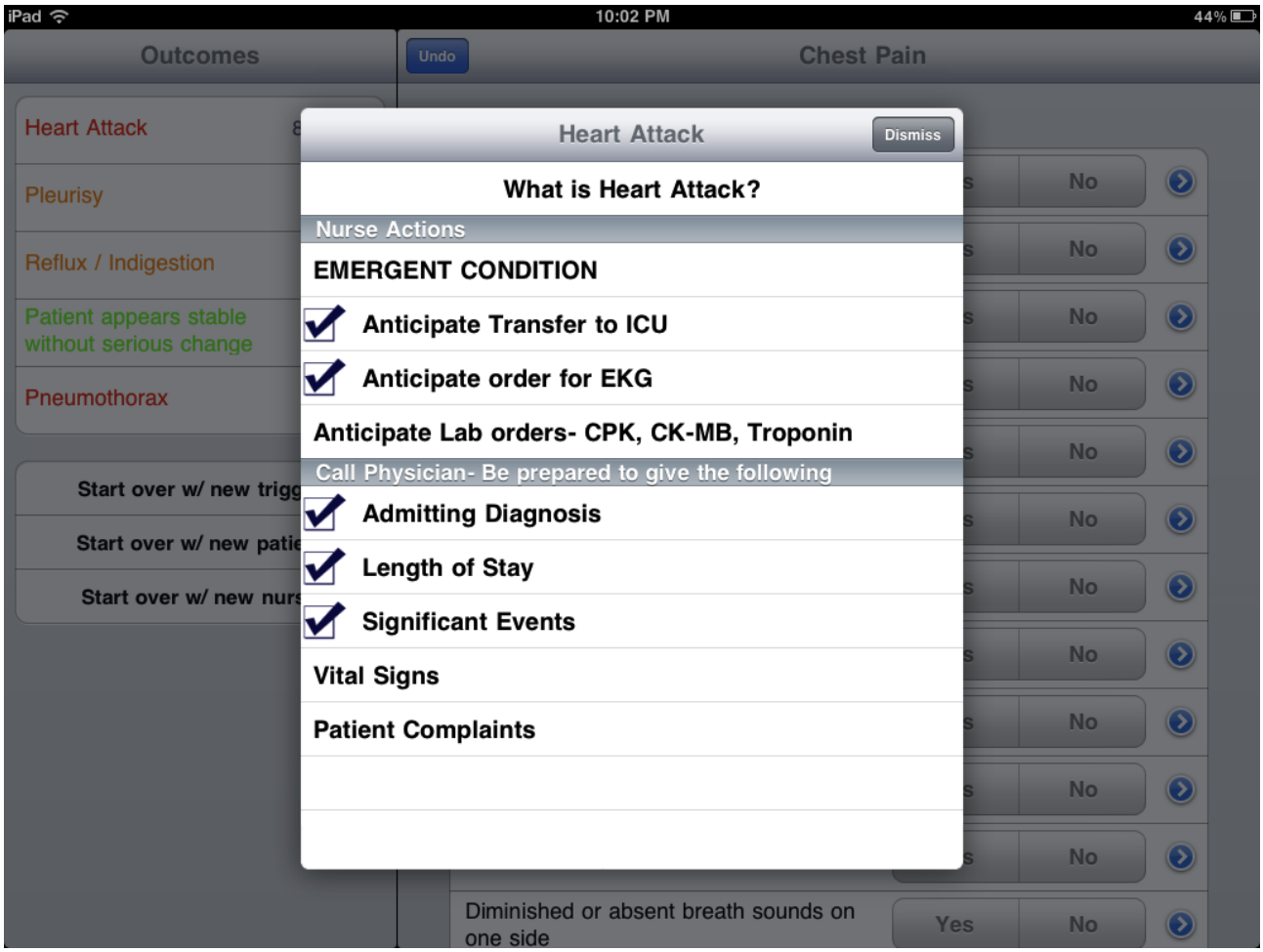
If the RRT decided to intervene, they could simply take over the CDSS device, which has documentation of the findings the nurse had already completed.

Communication Checklist

The CDSS provided a standard list of items for the nurses to go through with the physicians when a likely diagnosis emerged (Figure 2). The nurse action lists were customized for each diagnostic outcome, and included orders the nurses should anticipate from the physicians. The nurses could get a head start by preparing for those orders while trying to reach the physician, saving time for the patient rescue.

The action items were reviewed and approved by the physicians in the hospital, and they were designed to enable physicians to make quick decisions over the phone.

Figure 2. The action items for the nurse after a likely outcome is reached.



Implementation of the CDSS

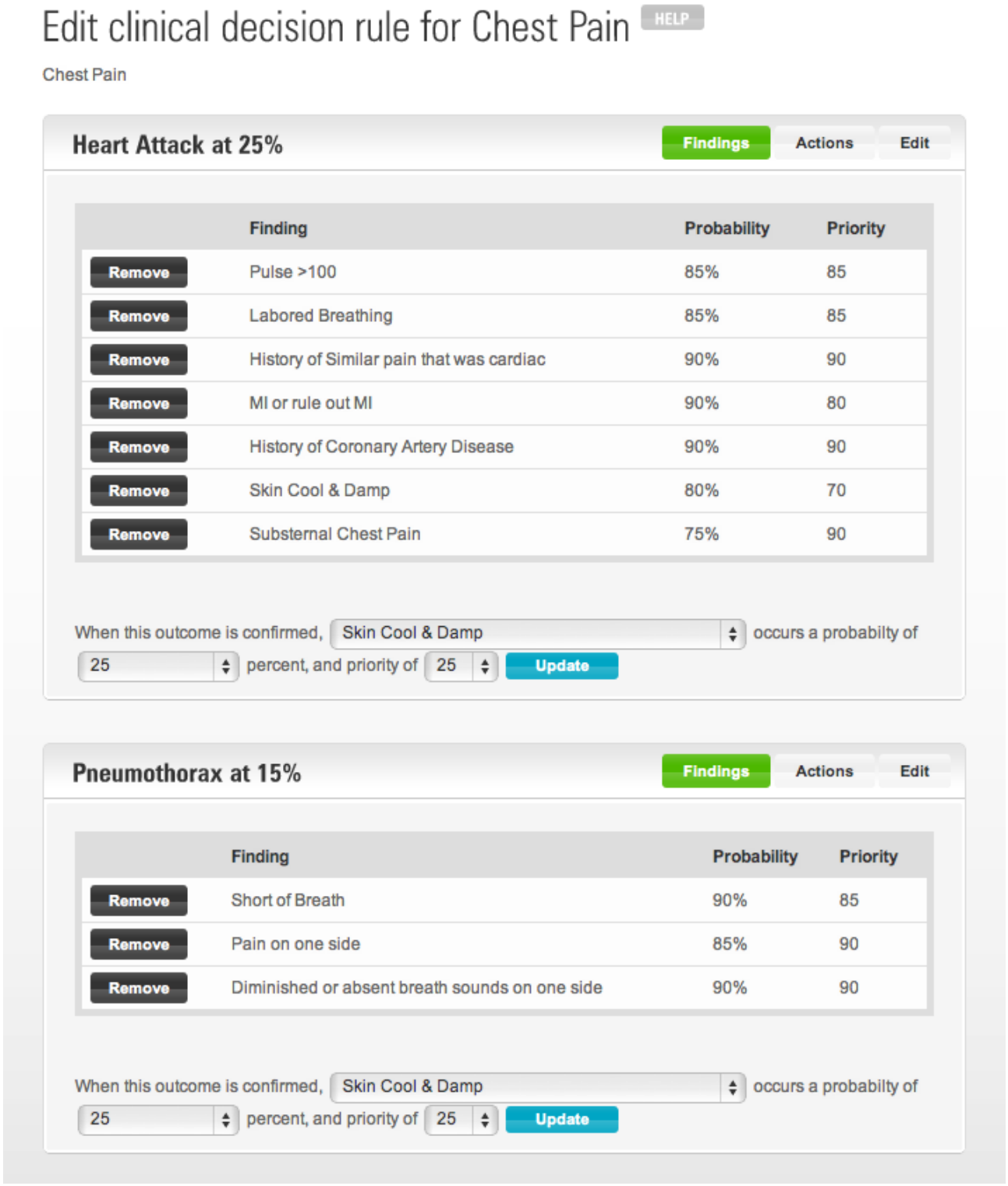
The CDSS system was implemented as a client-server computer application. The main component of the system was an iPad application developed in Objective C using the Apple iOS software development kit. The iPad application provided all the UI elements described in the design, and it was the only UI device the nurses needed to interact with during the patient evaluation process. The iPad application contained a SQLite-based relational database to store decision rules, medical content, user credentials, and usage logs. The application required access to the hospital's secure WiFi network in order to send paging messages to the RRT members. Except for the RRT page, the iPad device could function entirely without network connectivity, and only needed to occasionally synchronize with the backend database for content updates.

The second component of the system was an online content management system (CMS) to manage the decision rules, medical contents, and authorized users and devices. The system was designed as a Web application built on Java Enterprise Edition running on Tomcat and MySQL database servers. The interface with the iPad device was programmed as RESTful XML Web services. The CMS had a human UI that visualized the content and allowed CRUD (create, retrieval, update, and delete) operations of the content items from any Web browser. Proper user authorization was enforced in the CMS so that only users with certain roles (eg, physicians and managers) could update the content. Figure 3 shows a screenshot of the CMS Web page that allowed reviewers to associate findings and actions with diagnoses into clinical rules.

The CMS also provided an interface for the physician reviewers to review cases based on the usage log of the iPad device. That supplemented the brief information recorded in formal medical records and provided insights into how to improve the system in the future.

In the next two sections, we will discuss evaluations and validations we performed on the CDSS, especially the iPad UI.

Figure 3. The clinical rule editor in the Web-based CMS.



Evaluation Methods

Evaluation Process

The UI and workflow design of the product was evaluated using heuristic evaluation and performance-based end user evaluation. The heuristic evaluation was done after the first prototype, and its results were incorporated into the product before the performance-based evaluation was conducted.

Heuristic Evaluation

Heuristic evaluation is a formal UI evaluation method designed to uncover potential problems in a product [65-68]. It is particularly well suited for prototype and early stage products as a discounted alternative to full usability testing [68]. A heuristic study is typically conducted by 3-5 independent expert evaluators who are trained on UIs. Studies have suggested that 3 expert evaluators can uncover 80-90% of usability problems that would have been uncovered by a full usability study from

end users [69]. In health care IT, heuristic evaluation has been successfully used to evaluate UIs for products ranging from EMRs [70] to medical devices [68,71].

In this project, we incorporated heuristic evaluation into the iterative product design and development process. Based on the functional requirements outlined earlier in this paper, we built a first prototype, conducted heuristic evaluation, and then improved the prototype by addressing the heuristic violations identified by the evaluators.

It was demonstrated that the evaluators who are experts in both UI design and the specific application domain tend to be most effective in identifying heuristic violations [69]. Since a key requirement in our product was to cause minimal disruption to the clinical workflow, we believed that evaluators with strong domain expertise are crucial. We recruited 4 evaluators to study the initial prototype. JL is an information scientist trained in usability evaluation and technology adoption. She is an associate professor at the Texas State University. CM is a registered nurse and hospital quality management specialist. She has over 5 years of experience with RRTs in hospitals. She received training by JL to conduct heuristic evaluation. RM is a registered nurse of 20 years of experience with 5 years in the RRT. She received training from JL to conduct heuristic evaluation. CE is a registered nurse of 15 years of experience with 5 years in the RRT. He received training from JL to conduct heuristic evaluation.

The evaluators went through all UI elements in the application, and used the 10 heuristics in the computer software for evaluation [65]. The heuristic violations were coded and documented. They were then rated for severity by all evaluators in the team. The severity was rated on the scale of 0 to 4, where a score of 0 meant that it is not a usability problem at all, 1 was a cosmetic problem only that did not need to be fixed unless extra time was available, 2 was a minor usability problem and fixing this was given low priority, 3 was a major usability problem that was important to fix and was given high priority, and 4 was related to release block issues and was imperative to fix before the product could be released.

The heuristic violations were entered into an issue tracking system for the engineering team. The product reached its first release after all heuristic violations rated 3 and above were fixed.

Performance-Based Evaluation

Overview

Once the first release of system was developed, we assembled a panel of nurses to evaluate the UI and workflow via simulated use cases. The panel consisted of 10 nurses from our target user group in the hospital. The panelists had varied education background and experience levels. There were 3 licensed vocational nurses and 7 registered nurses on the panel. All of them were non-rapid response nurses working full time on the floor. Their work experience ranged from 1 to 39 years, with a median of 23 years. The simulation study was conducted as follows.

1. The nurse enters a patient room to meet the study monitor. The monitor gives a trigger symptom verbally to the nurse.
2. The nurse goes back to the station and fetches the tablet device. On the way, he/she will enter badge number, room number, and select the trigger symptom from a list.
3. When the nurse enters the room again, he/she can go through the checklist in any order. The nurse will verbally ask the monitor questions on the checklist, and the monitor will provide a yes/no answer.
4. When the nurse has received enough information, he/she decides on a likely diagnostic outcome for the patient.
5. The nurse will read out aloud each of the action item associated with the diagnostic outcome.

The process was repeated 3 times for each nurse. The tablet device automatically logged usage during the sessions.

Task Completion

We recorded whether each nurse successfully completed each session. The first session for each nurse was considered a training session to get the nurse familiar with the device, and was not included in the evaluation results. The success criterion was to have the nurse walkthrough the entire process and reach the action items without external help.

Completion Time Evaluation

For each session, we recorded the entire duration from the time the nurse walked into the room to the point where the nurse finished reading the action items. The completion time was an estimate of how much overhead time the use of the device added to the whole workflow. Since the product was designed to help nurses make quick decisions in urgent situations, it was crucial that the tool does not introduce too much overhead on its own. The evaluation criterion for the tool was that it should add less than 5 minutes of overhead to the existing clinical workflows.

NASA Task Load Index

After each session, the nurse was asked to use the National Aeronautics and Space Administration (NASA) Task Load index [72] to self evaluate the amount of cognitive and physical burden associated with using the device. The NASA task load index is a validated instrument for evaluating the burden of multiple tasks a user has to perform in parallel. It is well suited for the use scenario of this application where the user is required to multitask. The NASA Task Load Index has been successfully applied in evaluating health care IT products in the past [73]. The evaluation criterion for the released product was that the task load introduced by the tool should be minimal.

Results

Key Issues Identified in Heuristic Evaluation

In Table 1, we list a few examples of the heuristic violations identified by the evaluators. Each issue was categorized into one of the 10 common software application heuristics [65], identified by the place in the software product where it occurs, and assigned a severity based on the consensus rating by the evaluators.

A total of 83 heuristic violations were identified in the studies. Tables 2 to 4 list the distribution of the heuristic violations and their average severity.

The released version of the product had all heuristic violations rated 3 and above fixed. In this study, heuristic evaluation conducted by experts improved the usability of the product.

Performance-Based Evaluation Results

The 10 nurses on the panel successfully completed all 30 sessions of the performance evaluations. All nurses were able to use the device after a single training session with the instructor.

For each nurse, we took the median completion time from the 3 sessions, and then calculated the mean and standard deviation across the 10 nurses. On average, the nurses took 111 seconds (SD 30 seconds) to complete the simulated task. That is well within the 5 minutes overhead goal that we had set.

The NASA Task Load Index results indicated that the work overhead on the nurses was low. In fact, most of the burden measures were consistent with zero, as seen in Table 5. The only potentially significant burden was temporal demand, which is consistent with the primary use case of the tool. The tool was designed for the nurses to go over the symptom and vital signs checklists quickly, hence it exerts natural temporal pressure to its users.

Table 1. Example heuristic violations.

Heuristics violated	Place of occurrence	Severity	Usability problem description
Visibility of system status	Start	3.8	When syncing the application, there was no way to know if it will take 15 seconds or 10 minutes. It would be nice to know that it will take approximately 1 minute or show a percent completion.
Match between system and the real world	Outcome	3.4	List the outcomes as percentages instead of just a number without percentages.
User control and freedom	Checklist	4	The user should have the ability to change an answer once it has gone down to the list of answered questions. I can see frustration with the process if you have to completely start over to change an answer.
Consistency and standards	Outcome	1	Color code should be far apart along the visible spectrum so that the outcome can be clearly distinguished.
Error prevention	Checklist	4	Have the user confirmation when backing out of a screen that would cause the user to have to reenter all data.
Recognition rather than recall	Checklist	2	Abbreviations are used in the checklist. It should follow a simple primary rule.
Flexibility and efficiency of use	Checklist	3	If we add future triggers, there needs to be a way to ensure that when the keyboard displays that it does not cover the last triggers. Currently it is not a problem but should build this into system now.
Aesthetic and minimalist design	Outcome	3	There were too many "start over" displays currently. It would be simpler to have 1 button with a drop down screen listing the options: trigger, patient, or user. The questions also need to be reviewed by Dr. Finley and the RRT as currently there are a few questions that ask the same thing, but are just worded differently, and duplicating the questions is unnecessary.
Help user Recognize, diagnose, and recover from errors	Start	4	When a user accidentally hit the home button on iPad, the system will close without any warning and all data will be lost. Restarting within 1 minute allows you to get back to where you were. Otherwise the program will close.
Documentation and help	Outcome	3	The outcomes are in different colors. I am not sure that the staff will know what the color-coding means. Define the color scheme.

Table 2. Number of the heuristic violations across the heuristics.

Heuristics violated	Count of usability problem description
Aesthetic and minimalist design	4
Consistency and standards	10
Documentation and Help	13
Error prevention	6
Flexibility and efficiency of use	4
Help user recognize, diagnose, and recover from errors	12
Match between system and the real world	10
Recognition rather than recall	4
User control and freedom	8
Visibility of system status	12
Grand total	83

Table 3. Severity of the heuristic violations.

Heuristics violated	Average of severity
Aesthetic and minimalist design	2.25
Consistency and standards	1.49
Documentation and Help	3.01
Error prevention	3.88
Flexibility and efficiency of use	2.88
Help user recognize, diagnose, and recover from errors	2.48
Match between system and the real world	2.50
Recognition rather than recall	2.20
User control and freedom	3.13
Visibility of system status	2.93

Table 4. Places of the heuristic violations occurrence.

Places of occurrence	Count of heuristics violated
Action	13
Checklist	33
Outcome	13
Start	24
Grand total	83

Table 5. The task burdens measured by the NASA Task Load Index.

Task burden	Average out of 100 (SD)
Mental demand	10.0 (7.4)
Physical demand	1.8 (2.1)
Temporal demand	20.4 (24.8)
Performance	10.7 (11.3)
Effort	4.5 (4.9)
Frustration	1.6 (2.5)

Discussion

We have demonstrated that the usability of the CDSS is suitable for nurses in hospital environments. However, the ultimate success of the CDSS tool depends on many factors beyond usability, such as training and culture. In the next phase of the project, we have received generous funding from the Center for Medicare and Medicaid Innovations and CHRISTUS Health System to deploy the CDSS in 17 acute and long care facilities in a 3-year clinical deployment. The direct measurement of FTR cases and preventable complications at the deployment sites will provide the ultimate validation of the efficacy of the tool in improving patient safety and hospital care.

In this paper, we discussed the UI design and evaluation of a new decision support tool for nurses. The system was designed to help nurses recognize and escalate early warning signs of patient deterioration in acute care settings. The system will be used by floor nurses to evaluate patients on a daily basis. It will automatically alert the RRT when probable diagnoses are reached.

Using established cognitive design framework UFuRT as a guide, we were able to identify key requirements for the product, create a high-level functional specification, and then translate those functions into UI designs. During the implementation of the product, we performed heuristic evaluation to iteratively identify 83 usability issues, and fixed all issues rated as severe. These design and implementation approaches can be widely used in many different types of software development projects.

After the product was developed, we validated the design by performing end user usability tests, including performance tests and NASA Task Load Index evaluation. The evaluation has shown that our design was functional and met the requirements demanded by the nurses' tight schedules and heavy workloads.

UI design and implementation were critical factors contributing to successful deployment of the CDSS tools, but they were not the only factors. In follow-up research, we will deploy the solution in a working hospital environment, and evaluate the clinical outcome measures to determine the barriers and efficacy of the overall solution.

Conflicts of Interest

None declared.

References

1. Osheroff JA, Teich JM, Middleton B, Steen EB, Wright A, Detmer DE. A roadmap for national action on clinical decision support. J Am Med Inform Assoc 2007 Apr;14(2):141-145 [FREE Full text] [doi: 10.1197/jamia.M2334] [Medline: 17213487]
2. Bryan C, Boren SA. The use and effectiveness of electronic clinical decision support tools in the ambulatory/primary care setting: a systematic review of the literature. Inform Prim Care 2008;16(2):79-91. [Medline: 18713524]
3. Centers for Medicare and Medicaid Services. 2011. Eligible Professional Meaningful Use Core Measures URL: http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/downloads/13ClinicalSummaries.pdf [accessed 2012-10-16] [WebCite Cache ID 6BSxLsZfC]
4. Bolton LB, Gassert CA, Cipriano PF. Technology solutions can make nursing care safer and more efficient. J Healthc Inf Manag 2008;22(4):24-30. [Medline: 19267016]
5. Mack EH, Wheeler DS, Embi PJ. Clinical decision support systems in the pediatric intensive care unit. Pediatr Crit Care Med 2009 Jan;10(1):23-28. [doi: 10.1097/PCC.0b013e3181936b23] [Medline: 19057443]
6. Ammenwerth E, Schnell-Inderst P, Machan C, Siebert U. The effect of electronic prescribing on medication errors and adverse drug events: a systematic review. J Am Med Inform Assoc 2008 Oct;15(5):585-600 [FREE Full text] [doi: 10.1197/jamia.M2667] [Medline: 18579832]
7. Wolfstadt JI, Gurwitz JH, Field TS, Lee M, Kalkar S, Wu W, et al. The effect of computerized physician order entry with clinical decision support on the rates of adverse drug events: a systematic review. J Gen Intern Med 2008 Apr;23(4):451-458 [FREE Full text] [doi: 10.1007/s11606-008-0504-5] [Medline: 18373144]
8. Shojania KG, Jennings A, Mayhew A, Ramsay C, Eccles M, Grimshaw J. Effect of point-of-care computer reminders on physician behaviour: a systematic review. CMAJ 2010 Mar 23;182(5):E216-E225 [FREE Full text] [doi: 10.1503/cmaj.090578] [Medline: 20212028]
9. Dowding D, Mitchell N, Randell R, Foster R, Lattimer V, Thompson C. Nurses' use of computerised clinical decision support systems: a case site analysis. J Clin Nurs 2009 Apr;18(8):1159-1167. [doi: 10.1111/j.1365-2702.2008.02607.x] [Medline: 19320785]
10. Zhou X, Ackerman MS, Zheng K, Schoville R. A case study of CPOE adoption and use: work-arounds and their social-technical implications. In: AMIA Annu Symp Proc. 2008 Presented at: p. 1195.
11. Koppel R, Wetterneck T, Telles JL, Karsh BT. Workarounds to barcode medication administration systems: their occurrences, causes, and threats to patient safety. J Am Med Inform Assoc 2008 Aug;15(4):408-423 [FREE Full text] [doi: 10.1197/jamia.M2616] [Medline: 18436903]

12. Shah NR, Seger AC, Seger DL, Fiskio JM, Kuperman GJ, Blumenfeld B, et al. Improving acceptance of computerized prescribing alerts in ambulatory care. J Am Med Inform Assoc 2006 Feb;13(1):5-11 [FREE Full text] [doi: 10.1197/jamia.M1868] [Medline: 16221941]
13. Judge J, Field TS, DeFlorio M, Laprino J, Auger J, Rochon P, et al. Prescribers' responses to alerts during medication ordering in the long term care setting. J Am Med Inform Assoc 2006 Aug;13(4):385-390 [FREE Full text] [doi: 10.1197/jamia.M1945] [Medline: 16622171]
14. Berner ES, Webster GD, Shugerman AA, Jackson JR, Algina J, Baker AL, et al. Performance of four computer-based diagnostic systems. N Engl J Med 1994 Jun 23;330(25):1792-1796. [doi: 10.1056/NEJM199406233302506] [Medline: 8190157]
15. Graber ML, Mathew A. Performance of a web-based clinical diagnosis support system for internists. J Gen Intern Med 2008 Jan;23 Suppl 1:37-40 [FREE Full text] [doi: 10.1007/s11606-007-0271-8] [Medline: 18095042]
16. Kalisch BJ, Aebersold M. Interruptions and multitasking in nursing care. Jt Comm J Qual Patient Saf 2010 Mar;36(3):126-132. [Medline: 20235414]
17. Reed K, May R. HealthGrades. 2011 Mar. HealthGrades Patient Safety in American Hospitals Study URL: https://www.cpmhealthgrades.com/CPM/assets/File/HealthGradesPatientSafetyInAmericanHospitalsStudy2011.pdf [accessed 2012-10-16] [WebCite Cache ID 6BT0xK0p8]
18. Centers for MedicareMedicaid Services. 2011. Overview Acute Inpatient PPS URL: https://www.cms.gov/Medicare/Medicare-Fee-for-Service-Payment/AcuteInpatientPPS/index.html?redirect=/AcuteInpatientPPS/ [accessed 2012-10-16] [WebCite Cache ID 6BSyEFjMR]
19. Tait D. Nursing recognition and response to signs of clinical deterioration. Nurs Manag (Harrow) 2010 Oct;17(6):31-35. [Medline: 21137705]
20. Sandroni C, Ferro G, Santangelo S, Tortora F, Mistura L, Cavallaro F, et al. In-hospital cardiac arrest: survival depends mainly on the effectiveness of the emergency response. Resuscitation 2004 Sep;62(3):291-297. [doi: 10.1016/j.resuscitation.2004.03.020] [Medline: 15325448]
21. Friese CR, Aiken LH. Failure to rescue in the surgical oncology population: implications for nursing and quality improvement. Oncol Nurs Forum 2008 Sep;35(5):779-785 [FREE Full text] [doi: 10.1188/08.ONF.779-785] [Medline: 18765323]
22. Hodgetts TJ, Kenward G, Vlachonikolis IG, Payne S, Castle N. The identification of risk factors for cardiac arrest and formulation of activation criteria to alert a medical emergency team. Resuscitation 2002 Aug;54(2):125-131. [Medline: 12161291]
23. Funk D, Sebat F, Kumar A. A systems approach to the early recognition and rapid administration of best practice therapy in sepsis and septic shock. Curr Opin Crit Care 2009 Aug;15(4):301-307. [doi: 10.1097/MCC.0b013e32832e3825] [Medline: 19561493]
24. Classen JL. Is failure to rescue really failure to communicate? Champion the move from reactive process to proactive model. Nurs Manage 2010 Jul;41(7):38-41. [doi: 10.1097/01.NUMA.0000384034.25176.a2] [Medline: 20581600]
25. Chen J, Bellomo R, Flabouris A, Hillman K, Finfer S, MERIT Study Investigators for the Simpson Centre, ANZICS Clinical Trials Group. The relationship between early emergency team calls and serious adverse events. Crit Care Med 2009 Jan;37(1):148-153. [doi: 10.1097/CCM.0b013e3181928ce3] [Medline: 19050625]
26. Schmid A, Hoffman L, Happ MB, Wolf GA, DeVita M. Failure to rescue: a literature review. J Nurs Adm 2007 Apr;37(4):188-198. [doi: 10.1097/01.NNA.0000266838.23814.65] [Medline: 17415106]
27. Berwick DM, Calkins DR, McCannon CJ, Hackbarth AD. The 100,000 lives campaign: setting a goal and a deadline for improving health care quality. JAMA 2006 Jan 18;295(3):324-327. [doi: 10.1001/jama.295.3.324] [Medline: 16418469]
28. Goldfarb M, Cavaretta M. Surgical resident bedside rescue successes. J Surg Educ 2010 Apr;67(2):95-98. [doi: 10.1016/j.jsurg.2010.02.001] [Medline: 20656605]
29. Surani S, Murphy J, Shah A. Sleepy nurses: are we willing to accept the challenge today? Nurs Adm Q 2007 Jun;31(2):146-151. [doi: 10.1097/01.NAQ.0000264863.94958.40] [Medline: 17413508]
30. Graves K, Simmons D. Reexamining fatigue: implications for nursing practice. Crit Care Nurs Q 2009 Jun;32(2):112-115. [doi: 10.1097/01.CNQ.0000348198.16788.df] [Medline: 19300075]
31. Kane RL, Shamliyan TA, Mueller C, Duval S, Wilt TJ. The association of registered nurse staffing levels and patient outcomes: systematic review and meta-analysis. Med Care 2007 Dec;45(12):1195-1204. [doi: 10.1097/MLR.0b013e3181468ca3] [Medline: 18007170]
32. Aiken LH, Clarke SP, Cheung RB, Sloane DM, Silber JH. Educational levels of hospital nurses and surgical patient mortality. JAMA 2003 Sep 24;290(12):1617-1623 [FREE Full text] [doi: 10.1001/jama.290.12.1617] [Medline: 14506121]
33. Bagshaw SM, Mondor EE, Scouten C, Montgomery C, Slater-MacLean L, Jones DA, Capital Health Medical Emergency Team Investigators. A survey of nurses' beliefs about the medical emergency team system in a canadian tertiary hospital. Am J Crit Care 2010 Jan;19(1):74-83 [FREE Full text] [doi: 10.4037/ajcc2009532] [Medline: 19542059]
34. Cziraki K, Lucas J, Rogers T, Page L, Zimmerman R, Hauer LA, et al. Communication and relationship skills for rapid response teams at hamilton health sciences. Healthc Q 2008;11(3 Spec No):66-71 [FREE Full text] [Medline: 18382164]
35. Jones CM, Bleyer AJ, Petree B. Evolution of a rapid response system from voluntary to mandatory activation. Jt Comm J Qual Patient Saf 2010 Jun;36(6):266-70, 241. [Medline: 20564888]

36. Leach LS, Mayo A, O'Rourke M. How RNs rescue patients: a qualitative study of RNs' perceived involvement in rapid response teams. Qual Saf Health Care 2010 Oct;19(5).
37. Stead K, Kumar S, Schultz TJ, Tiver S, Pirone CJ, Adams RJ, et al. Teams communicating through STEPPS. Med J Aust 2009 Jun 1;190(11 Suppl):S128-S132. [Medline: 19485861]
38. Mackintosh N, Sandall J. Overcoming gendered and professional hierarchies in order to facilitate escalation of care in emergency situations: the role of standardised communication protocols. Soc Sci Med 2010 Nov;71(9):1683-1686. [doi: 10.1016/j.socscimed.2010.07.037] [Medline: 20850919]
39. Card, Thomas PM, Newell A. The Psychology of Human Computer Interaction. In: The Psychology of Human Computer Interaction. N/A: Lawrence Erlbaum Associates; 1983.
40. Schrepp M, Fischer P. GOMS models to evaluate the efficiency of keyboard navigation in web units. Eminds-International Journal of Human Computer Interaction 2007;1(2):33-46.
41. Gray WD, John BE, Atwood ME. The Precis of Project Ernestine or an overview of a validation of GOMS. 1992 Presented at: SIGCHI conference on Human factors in computing systems; 1992; Monterey, California, US.
42. Simon HA, Hays JR. The understanding process: Problem isomorphs. Cognitive Psychology 1976;8:165.
43. Marr D. Vision. In: Vision. San Francisco, CA: W. H. Freeman; 1982.
44. Zhang J, Norman DA. Representations in distributed cognitive tasks. Cognitive Science 1994(18):87.
45. Zhang J, Norman DA. A representational analysis of numeration systems. Cognition 1995 Dec;57(3):271-295. [Medline: 8556844]
46. Wright P, Fields R, Harrison M. Analyzing Human-Computer Interaction as distributed cognition: The resources model. Human Computer Interaction 2000;15(1):1.
47. Eggleston RG. Work-centered design: a cognitive engineering approach to system design. 2003 Presented at: Human factors and ergonomics society 47th annual meeting; 2003; Denver, Colorado, US p. 263.
48. Butler K, Zhang J, Esposito C, Bahrami A, Hebron R, Kieras D. Work-centered design: A case study of a mixed initiative scheduler. 2007 Presented at: CHI; 2007; San Jose, California, US.
49. Zhang J, Butler K. UFuRT: A work-centered framework and process for design and evaluation of information systems. In: Proceedings of HCI International. 2007 Presented at: HCI International; 2007; Beijing, China.
50. Zhang J, Patel VL, Johnson KA, Malin J, Smith JW. Designing human-centered distributed information systems. IEEE Intelligent Systems 2002;17(5):42-47.
51. Butler K, Zhang J, Esposito C, Bahrami A, Hebron R, Kieras D. Work-centered design: A case study of a mixed initiative scheduler. 2007 Presented at: CHI; 2007; San Jose, California, US p. 747-756.
52. Nahm M, Zhang J. Operationalization of the UFuRT methodology for usability analysis in the clinical research data management domain. J Biomed Inform 2009 Apr;42(2):327-333 [FREE Full text] [doi: 10.1016/j.jbi.2008.10.004] [Medline: 19026765]
53. Saitwal H, Feng X, Walji M, Patel V, Zhang J. Assessing performance of an Electronic Health Record (EHR) using Cognitive Task Analysis. Int J Med Inform 2010 Jul;79(7):501-506. [doi: 10.1016/j.ijmedinf.2010.04.001] [Medline: 20452274]
54. Zhang Z, Walji M, Patel VL, Gimbel R, Zhang J. Functional Analysis of Interfaces in US Military Electronic Health Record System using UFuRT Framework. 2009 Presented at: AMIA; 2009; San Francisco, California, US.
55. Zhang J, Norman DA. Representations in distributed cognitive tasks. Cognitive Science 1994;18:87-122.
56. Davis FD. Perceived usefulness, perceived ease of use, and user acceptance of information technology. MIS Quarterly 1989;13(3):319-340.
57. Amundson DE, Seda G. Look out doctor, you may be getting framed: heuristics in medical decision-making. Mil Med 2008;173(9):2-5.
58. Graber ML, Franklin N, Gordon R. Diagnostic error in internal medicine. Arch Intern Med 2005 Jul 11;165(13):1493-1499. [doi: 10.1001/archinte.165.13.1493] [Medline: 16009864]
59. Weaver SJ, Rosen MA, DiazGranados D, Lazzara EH, Lyons R, Salas E, et al. Does teamwork improve performance in the operating room? A multilevel evaluation. Jt Comm J Qual Patient Saf 2010 Mar;36(3):133-142. [Medline: 20235415]
60. Barnett GO, Cimino JJ, Hupp JA, Hoffer EP. DXplain. An evolving diagnostic decision-support system. JAMA 1987 Jul 3;258(1):67-74. [Medline: 3295316]
61. Hales B, Terblanche M, Fowler R, Sibbald W. Development of medical checklists for improved quality of patient care. Int J Qual Health Care 2008 Feb;20(1):22-30.
62. Pronovost P, Needham D, Berenholtz S, Sinopoli D, Chu H, Cosgrove S, et al. An intervention to decrease catheter-related bloodstream infections in the ICU. N Engl J Med 2006 Dec 28;355(26):2725-2732.
63. Ely JW, Graber ML, Croskerry P. Checklists to Reduce Diagnostic Errors. Acad Med 2011 Jan 18.
64. Winters BD, Gurses AP, Lehmann H, Sexton JB, Rampersad CJ, Pronovost PJ. Clinical review: checklists - translating evidence into practice. Crit Care 2009;13(6):210.
65. Nielsen J, Molich R. Heuristic evaluation of user interfaces. 1990 Presented at: ACM CHI; 1990 p. 249-256.
66. Nielsen J, Mack R. Usability inspection methods. In: Usability inspection methods. New York: Wiley; 1994.
67. Nielsen J. Usability engineering. In: Usability engineering. Boston: AP Professional; 1994.

68. Zhang J, Johnson TR, Patel VL, Paige DL, Kubose T. Using usability heuristics to evaluate patient safety of medical devices. J Biomed Inform 2003;36(1-2):23-30. [Medline: 14552844]
69. Nielsen J. Finding usability problems through heuristic evaluation. 1992 May Presented at: ACM CHI Conference; 1992; Monterey, CA, US p. 373-380.
70. Sox CM, Gribbons WM, Loring BA, Mandl KD, Batista R, Porter SC. Patient-centered design of an information management module for a personally controlled health record. J Med Internet Res 2010;12(3):e36 [FREE Full text] [doi: 10.2196/jmir.1269] [Medline: 20805091]
71. Graham MJ, Kubose TK, Jordan D, Zhang J, Johnson TR, Patel VL. Heuristic evaluation of infusion pumps: implications for patient safety in Intensive Care Units. Int J Med Inform 2004 Nov;73(11-12):771-779. [doi: 10.1016/j.ijmedinf.2004.08.002] [Medline: 15491928]
72. NASA. NASA Task Load Index (TLX) Version 1.0 User's Guide. Moffett Field, CA: NASA Ames Research Center; 1985.
73. Sox CM, Gribbons WM, Loring BA, Mandl KD, Batista R, Porter SC. Patient-centered design of an information management module for a personally controlled health record. J Med Internet Res 2010;12(3):e36 [FREE Full text] [doi: 10.2196/jmir.1269] [Medline: 20805091]

Abbreviations

CDSS: clinical decision support systems
CMS: content management system
EMR: electronic medical record
FTR: failure to rescue
IT: information technology
NASA: National Aeronautics and Space Administration
RRT: rapid response team
UFuRT: user, function, representation, and task analysis
UI: user interface
WCD: work-centered design

Edited by G Eysenbach; submitted 16.10.12; peer-reviewed by O Anya; comments to author 09.11.12; revised version received 10.12.12; accepted 29.12.12; published 31.01.13.

Please cite as:
Yuan MJ, Finley GM, Long J, Mills C, Johnson RK
Evaluation of User Interface and Workflow Design of a Bedside Nursing Clinical Decision Support System
Interact J Med Res 2013;2(1):e4
URL: http://www.i-jmr.org/2013/1/e4/
doi:10.2196/ijmr.2402
PMID:23612350

Viewpoint

Understanding Electronic Medical Record Adoption in the United States: Communication and Sociocultural Perspectives

Priya Nambisan[1], PhD; Gary L Kreps[2], PhD; Stan Polit[3], MA

[1]George Mason University, Department of Health Administration & Policy, Fairfax, VA, United States

[2]Center for Health and Risk Communication, Department of Communication, George Mason University, Fairfax, VA, United States

[3]University of Pennsylvania, University of Pennsylvania Law School, Philadelphia, PA, United States

Corresponding Author:
Priya Nambisan, PhD
George Mason University
Department of Health Administration & Policy
4400 University Drive, MS 1J3
Fairfax, VA, 22030
United States
Phone: 1 703 993 8571
Fax: 1 703 993 1953
Email: pnambisa@gmu.edu

Abstract

Background: This paper adopts a communication and sociocultural perspective to analyze the factors behind the lag in electronic medical record (EMR) adoption in the United States. Much of the extant research on this topic has emphasized economic factors, particularly, lack of economic incentives, as the primary cause of the delay in EMR adoption. This prompted the Health Information Technology on Economic and Clinical Health Act that allow financial incentives through the Centers of Medicare and Medicaid Services for many health care organizations planning to adopt EMR. However, financial incentives alone have not solved the problem; many new innovations do not diffuse even when offered for free. Thus, this paper underlines the need to consider communication and sociocultural factors to develop a better understanding of the impediments of EMR adoption.

Objective: The objective of this paper was to develop a holistic understanding of EMR adoption by identifying and analyzing the impact of communication and sociocultural factors that operate at 3 levels: macro (environmental), meso (organizational), and micro (individual).

Methods: We use the systems approach to focus on the 3 levels (macro, meso, and micro) and developed propositions at each level drawing on the communication and sociocultural perspectives.

Results: Our analysis resulted in 10 propositions that connect communication and sociocultural aspects with EMR adoption.

Conclusions: This paper brings perspectives from the social sciences that have largely been missing in the extant literature of health information technology (HIT) adoption. In doing so, it implies how communication and sociocultural factors may complement (and in some instances, reinforce) the impact of economic factors on HIT adoption.

(Interact J Med Res 2013;2(1):e5) doi:10.2196/ijmr.2437

KEYWORDS

electronic health records adoption; communication; systems approach

Introduction

The slow adoption of electronic medical records (EMR) has become a critical challenge in the health care industry of the United States. [1]. Quicker adoption of EMR is necessary to streamline key processes in the health care industry, integrate activities across health care organizations, reduce overall health care costs, and improve care quality.

The US Government has made considerable efforts to improve the rate of EMR adoption [2-4]. The most recent effort was to provide financial incentives to health care organizations to implement these technologies under the Health Information Technology on Economic and Clinical Health (HITECH) Act [5]. This has led to a marginal improvement in the EMR implementation rate, but the adoption lag persists [6]. The financial incentives for adoption are available only if health

care organizations agree to meet the “meaningful use” criteria set forth by the Centers of Medicare and Medicaid Services (CMS), which outlines a set of requirements (classified under stage1, stage 2, and stage 3) that would demonstrate meaningful use of the certified EMR technology. Failure to meet those criteria will lead to loss of financial incentives with detrimental effects on the successful adoption of EMR [7]. A recent study reports that many health care organizations that are getting such incentives do not plan on implementing meaningful use stage I [8]. Further, a significant number of long-term health care providers such as nursing homes, home health agencies, long-term acute care hospitals, and inpatient rehabilitation hospitals are not eligible for incentives given their lack of Medicare and Medicaid patient mix, leaving the overall EMR adoption rate “dismally low” [7]. The latest report from the Centers for Disease Control and Prevention and other studies show that another major part of the health care sector, small practice physicians, also has a very low EMR adoption rate [6,9]. Thus, despite all recent efforts, the EMR adoption lag persists.

Even among those health care organizations (HCOs) that have made efforts to implement EMR, there is a very high failure rate—studies show that up to 80% of EMR implementations fail [10,11]. Accurate estimates of implementation failures are difficult to find, as many HCOs are reluctant to report it. Approximately 19% of EMRs are uninstalled after implementation, and approximately 30% are not used to their full potential by the care staff [12]. Further, many hospitals, especially Critical Access Hospitals, were found to be lacking the technological pre-conditions required for achieving meaningful use [13]. Thus, it is clear that despite the financial and other incentives provided by the government, the adoption of EMRs remain quite problematic. A major reason for this is the lack of a clear understanding of all the factors that are likely to affect EMR adoption.

The extant research on EMR adoption suffers from a “silo” effect, typically focusing on variables drawn from a single theoretical perspective or on adoption barriers that affect a limited set of EMR’s diverse and numerous stakeholders [14]. For example, a large set of studies had drawn on Rogers’ [15] diffusion model (which focuses on individual level factors) and consequently employed a “physician as adopter” perspective to examine physician resistance to EMR [2-4,16-18]. Findings from these studies indicated several individual factors impeding EMR adoption, including concerns over computers affecting work flow, concerns about computers interfering with physician-patient interactions, limited computer literacy of physicians, and apprehension about the often unclear benefits of the new technology. At the same time, these studies seem to have ignored the existence of important organizational level factors impeding adoption such as limited return on investment, high cost of technology adoption, lack of resources, and misaligned incentive structures [2-4,19,20]. Similarly, another set of studies [11,21-23] adopted an economic perspective and institution level focus, ignoring the potential impact of non-economic and individual level factors. Most of these studies ignored the importance of environmental (or sector level) factors such as the adoption of technology and process standards in the health care industry [19]. Hence, we need a systems perspective to understand the impact of each factor at the macro or environmental level, meso or organizational level, as well as at the micro level [24].

While there is extant research on many organizational and individual factors, the studies focusing on *economic factors* received the most attention. These studies indicated that adoption is dependent on the cost effectiveness of the innovation (ie, EMRs) [3,11,21-23] and on economic incentives [25]. However, from the communication literature, we know that an innovation may not get adopted even when offered free of cost, if the adopters have inadequate information or knowledge regarding the innovation or if they do not understand the benefits of adopting the innovation [15,24,26]. Such a communication perspective (that also incorporates knowledge transfer) could shed light on the current state of EMR adoption that is lagging even after providing financial incentives [27-30]. Similarly, the sociological (or sociocultural) perspective emphasizes that innovation adoption is situated in a social (cultural) context and implies that the norms and values of the individual, the larger community of the individual, and the organization that the individual belongs to, all can influence adoption [15,31,32]. Hence, to understand the impediments of EMR adoption fully, it is necessary to incorporate complementary theoretical perspectives—particularly behavior science and sociocultural perspectives. In this paper, we apply the systems approach to analyze how communication and sociocultural factors may influence EMR adoption and offer important new insights beyond those provided by the economic perspective.

The systems approach [33] can provide an appropriate framework to develop an integrative understanding of EMR adoption—one that incorporates multiple levels of analysis. The systems approach (first proposed as the "General System Theory" by the biologist Ludwig von Bertalanffy) looks at the system as a whole instead of focusing only on individual parts. The systems perspective examines interdependent interactions among system parts as well as the interactions between the system and the environment, both in terms of system inputs and system outputs. In the context of health care, the systems approach has been successfully applied to understanding issues such as patient safety, quality of care, and health outcomes [24,34]. The systems approach is also valuable for examining the ways EMR adoption involves multiple stakeholders, multiple levels of application, and highly complex technologies (ie, multiple “parts” with complex interconnections both within and across systems).

Thus, the primary objective of this paper was to apply the systems approach to examining the communication and sociocultural issues that operate at multiple levels and shape EMR adoption. Our goal was to provide an integrative framework (developed via the systems approach) that could serve as a template for guiding future studies of EMR adoption.

A Systems Approach to EMR Adoption

In applying the systems approach here, we draw on the nested model developed by Ferlie and Shortell [35] and Kimberly & Evanisco [36]. Ferlie and Shortell’s model classified the health

care system into 4 nested levels: (1) individual (patients), (2) group level (care team), (3) organization level (health care delivery system), and (4) macro level (political and economic environment). Kimberly & Evanisco classified factors that influence hospital innovation adoption on the individual, organizational, and contextual (outside forces that influence innovation adoption) levels, and stressed the importance of examining the combined effects of adoption variables across these 3 levels instead of examining them separately. Following these studies, we focused our attention on factors at 3 levels: macro (environmental), meso (organizational), and micro (individual) levels.

Conceptual Framework and Proposition Development

At each level (micro, meso, and macro), we examined the issues and challenges from communication and sociocultural perspectives and formulated propositions that link these factors to EMR adoption. Later, we considered how the insights derived from these propositions complement those available from the economic perspective.

Micro Level (Individual) Factors

General

For a hospital, the most important customers are the physicians who bring their patients to the facility, but may not work full-time on the premises. Most physicians belong to independent physician practices, small group practices, ambulatory clinics, rehabilitation clinics, or other micro level entities that are not part of a larger health care organization. Hence, many factors at the hospital organizational level do not directly influence the decisions made by individual physicians regarding technology adoption. Micro or individual level factors have received much focus in the adoption literature, especially in the area of physician resistance, lack of computer skills, cost and return on investment of EMRs, loss of productivity caused by EMRs, and the characteristics of the technology itself (eg, [17,37]). However, there has not been much focus on key communication and cultural factors that could influence the adoption of EMRs by physicians.

Micro Level Communication Factors

Overview

Physicians are trained to be independent, authoritative, and decisive. They are often hard to reach through advertisements and promotions. Sometimes they resist innovation as a group, which makes mass communication methods ineffective. They may not be working in any health care organization or hospitals and hence organizational level methods are not applicable to many of them [38]. Some physicians run small practices where they interact with a few people in their profession and attend professional conferences once a year. They may also participate in training programs that offer continuing professional education (CPE) credits. As such, current communication methods and strategies may not effectively address this target population [39]. Adoption starts at the grassroots level and these physicians form the grassroots of the physician community [40-42].

Social contagion and social cohesion theory can be used to develop insights that apply at the micro level (eg, with physicians). Social contagion theory states that when people are in the proximity of others who have adopted a particular innovation, there will be an enhanced tendency to adopt [43]. The mere physical proximity transfers significant information regarding the innovation to the adoption laggard. Social cohesion theory implies the significance of the social interaction between the adopter and the non-adopter. According to this theory, if there is more empathetic communication between these two entities (the adopter and the non-adopter), then there is a higher chance of adoption of the innovation by the laggard. This has been shown to be quite effective in the classic adoption of tetracycline [44,45]. The autonomous nature of physicians often makes it difficult to precipitate peer-to-peer discussions about issues regarding technology adoption. Nevertheless, social networks, virtual communities, and social media can be used in the diffusion of innovation among this group [40].

The establishment of 62 Regional Extension Offices through the 2009 HITECH Act was a significant step forward in employing communicative approach to promoting adoption of EMRs. The objective of this program was to reframe the national issue of technology adoption, and facilitate dialogue on a regional level, thus encouraging discussion of unique local factors influencing EMR adoption. However, we are not sure whether these extension offices are effectively communicating EMR information availability, as many regional websites do not even provide the required information for meeting meaningful use criteria (eg, Alabama regional extension center opened in 2010 does not contain this information).

The regional extension offices, if used effectively, could have multilayered benefits for diffusing relevant information about the need for EMRs. These offices can place physicians in the role of “leaders”, allowing them to become what Rogers [15] referred to as “change agents”, or individuals who have the ability to influence the decisions of others. Even though the federal government is facilitating and funding this program, having physicians disseminate technology adoption messages and facilitate discussions of the benefits and barriers to EMR will create a more authentic and convincing argument. Because physicians can share practical and implementation concerns among themselves, physicians are the key players to stir initial interest regarding technology. The federal government can then serve their role in supplying tools and incentives to further facilitate the technology promotion and implementation process. This process is referred to as the social cognitive method, using a socially mediated pathway to connect audiences through social networks that provide continued reinforcements for desired change [46]. Rogers [15] also advocated for this diffusion strategy because familiar interpersonal sources are more effective in inspiring individuals to accept new ideas than when discussions from more distant sources. The use of identifiable change agents could also promote further diffusion of EMR adoption by encouraging continuous recruitment of new opinion leaders to carry EMR messages from each physician-physician communication cycle.

Proposition 1

Communication tools such as social media (which is the fastest tool for the social contagion and social cohesion methods) will be positively related to the adoption and diffusion of EMRs among independent physicians in small practice settings.

Proposition 2

Implementation of communication mechanisms that function at the grassroots level and target independent physicians to promote and facilitate EMR use will be positively related to the adoption and sustained use of EMR by small practice physicians.

Micro Level Cultural Factors

Overview

Despite a considerable number of studies addressing other factors associated with EMR adoption, research on the topic has often overlooked the readiness of physicians to serve as the key implementers of EMR systems [21]. For physicians, there currently exists a culture of apprehension and distrust that permeates the adoption of EMR technology [47]. Shachak and Reis [48] elaborated that these feelings make it highly pertinent to understand how the cognitive elements of implementation shape perceptions of barriers.

Some individual cultural impediments to adoption stem from physician perceptions that these systems may challenge their authority as autonomous decision makers in the delivery of care. A key part of the physician psyche is how they cherish and protect their role as the expert in the care provider scenario. Unfortunately, a lack of understanding regarding technology, specifically how they should integrate EMR systems into their work, often leads physicians to view themselves as novices in this area. The juxtaposition between concurrent roles of “expert” and “novice” creates a high degree of cognitive dissonance for physicians [49]. One proposed solution is to place physicians at the forefront of efforts to address the cognitive impediments to technology adoption [50]. A benefit of this approach is that physicians begin to develop a sense of psychological ownership over the development and use of EMRs [51]. Ludwick and Doucette [47] advocated for this kind of approach by explaining how the most effective changes in the health care system occur when physicians are at the helm. Thus, framing physicians as leaders in adoption efforts allow them to become the principle force influencing the future of medical practice.

Cultural issues involving small practice physicians follow closely with the needs of independence and autonomy. While many physicians are attracted to the autonomy and independence small practices provide, they are also wary of the challenges of sustainability, with many small practices across the country going bankrupt or getting bought by large health care organizations [52,53]. Issues such as rising business expenses and administrative costs are cited for the demise of many small practices. However, many of these practices have not changed much in the past several decades in the way they practice or conduct business. Competition from new models of care such as walk-in clinics and practices run by large health care centers require that small physician owned practices keep up with the changing health care environment as well as with changing consumer needs. Consumers are likely to increasingly seek care at walk-in clinics and urgent care centers attracted by their convenient hours and quick service. Many walk in clinics and urgent care centers tout that their patients are using them for primary care and many of them provide continuity of care by relying on technologies such as EMRs. The lack of entrepreneurship skills, lack of customer orientation, and lack of understanding that technologies such as EMR are soon going to be a necessary infrastructure rather than a luxury [54], could be some of the reasons why small practice physicians are lagging behind in EMR adoption. Many experts also believe that small medical care practices that survive would need to stay connected or affiliated with other small practices through mechanisms such as shared EMRs [53].

One of the key issues that need to be addressed is the need for change in the ‘culture of small medical practice’ businesses. Many small practice owners need entrepreneurship skills and training on how to conduct business in the Internet era. Cultural change in customer orientation, entrepreneurship orientation, and perceptions regarding new technologies could be some of the factors that could lead to higher adoption of EMRs among this group.

Proposition 3

The level of physician involvement at the grassroots level in the initial adoption process will be positively related to the overall adoption and sustained use of EMRs by physicians. The decision-making power of physicians during these initial adoption stages is crucial for the success of EMR adoption.

Proposition 4

Cultural change in customer orientation, entrepreneur orientation, and change in perception of new technologies will be positively related to the adoption of EMRs among small practice physicians.

Meso Level (Organizational) Factors

General

Organizational researchers have studied a multitude of factors that could influence the adoption of new technological innovations in organizations [31,32,36,55]. These factors range from characteristics of the organization itself to the composition of its employees to organizational leadership and resource availability.

Organizational Level Communication Factors

Overview

The adoption of complex technologies such as EMR calls for effective communication among adopters and the potential for transferring experiential knowledge and learning. Such a communication and knowledge transfer perspective of technology adoption also ties in well with the notion that health care organizations need to increasingly become learning organizations to enforce radical changes and bring about transformation in services, practices, and processes [56]. There are several barriers to establishing a learning culture in health care organizations [57,58], ranging from the complex hierarchical work structure to physician resistance towards learning and sharing knowledge.

An important factor that affects learning is the mode of communication in the health care organization. Much of the information flow within a hospital involves health care workers communicating directly with one another [59]. In fact, face-to-face communications constitute half of such communications, while communication through electronic devices (pagers, phones, etc) accounts for the other half [59,60]. With the increasing number of staff and hospital workers, this type of communication (face-to-face or phone) has been found to be highly interruptive and is a leading cause of errors. Coiera and Tombs [60] observed that communication among employees in a hospital environment often leads to interruption-driven work contexts, where miscommunication or ineffective communication is the norm. Thus, in this kind of environment, getting physicians and other staff to communicate with one another and engage in knowledge sharing becomes challenging and potentially makes EMR adoption very difficult.

There is a critical need for health care organizations to implement good communication policies that are engaging and productive rather than disruptive [59]. The provision of a communication infrastructure that utilizes new communication technologies may enable health care workers to not only communicate important task-related messages, but also take part in other productive conversations. Evidence indicates that online communities and communities of practice where physicians can share information through online forums have the potential to address many of the deeply rooted cultural factors that inhibit the development of a learning culture in health care organizations [61-63]. Such forums allow adopters of new technology to not only share their experiences related to the new technology, but also describe their own innovations or reinventions.

It is well established that adopters of new innovations often learn by using the innovation [64,65] or reinvent the technology to adapt it to their own context [66,67]. The ability to share such user innovations and experiences are invaluable during the adoption of new technologies such as EMR. There are some online forums such as the Paperless Practice Groups that provide user support for EMR adoption issues, but this could be supplemented by online support groups within the organization where users can share issues and problems while using the new technology at their specific institution to help each other. Here we suggest that the availability of such diverse communication forums can enhance learning related to EMR deployment and lead to faster EMR adoption.

Proposition 5

Facilitating a learning environment by offering diverse knowledge sharing facilities such as online forums will be positively related to EMR adoption at the organizational level.

Organizational Level Cultural Factors

Overview

An organizational culture that fosters leadership and support is a critical factor when it comes to technology adoption. For example, Rogers' authority innovation-decision model [15] shows that leaders use their authority to enforce change. Peter Senge's [68] concept of leadership in a learning organization also illustrates how leaders are supposed to steward and teach members, thereby driving adoption. Further, in the innovation adoption literature, characteristics of key organizational actors have been found to be critical in influencing the innovative behavior of people within the organization and thereby their willingness to engage in adoption processes [69-71].

In the case of EMR, "adoption by fiat" has been found to be quite effective. The classic example was the Veterans Administration (VA) system, where the top leadership decided to adopt and implement EMRs and the physicians and other staff members were required to comply as system employees [72]. Unfortunately, such a scenario is unlikely to exist in most EMR adoption contexts since in most health care organizations, physicians (who are the users/adopters) are partners or stakeholders, instead of employees.

Prior research [73] indicated that a key factor that could facilitate adoption in such contexts is the extent of *user involvement* in the adoption process. Several examples clearly show that involving physicians and other administrators during the EMR adoption decision-making process can go far in enhancing their motivation to adopt [74]. Practices such as listening to stakeholder concerns, inviting physicians, and other staff to make adoption recommendations, and including having users as implementation team members, have all been found to enhance the adoption rate [75]. Palacio et al [75] suggested that a forum for multidisciplinary information planning committees could encourage such user-driven discussions. By bringing together various types of health care stakeholders, it becomes possible to uncover a wide range of experiences regarding the institutional integration of technology into care delivery.

Another critical adoption factor is at the level of organizational commitment and support. In the context of EMR, organizations could invest in support facilities such as help desks and online user communities that help organization members address implementation concerns. Additionally, the level of technology training offered by management is another important factor cited for successful adoption of EMRs. For example, the VISTA system at the VA, is considered to be one of the most successful EMR implementations, touts its training program as a critical success factor in implementation [72]. Similarly, organizational leaders need to develop and communicate a shared vision and understanding of EMR adoption and use within the organization—a vision that connects EMRs with the organizational (or business) mission and objectives. Such a shared vision could bring congruence to the activities associated with EMR adoption across different functions or departments within the organization and enable faster and smoother adoption.

Proposition 6

Development of a participatory work environment that promotes organizational members' active involvement in the EMR adoption and implementation process and decision-making will be positively related to the adoption and sustained use of EMRs.

Proposition 7

The commitment and support of organizational leaders (through deployment of explicit support mechanisms and the

communication of a shared vision for EMR adoption) will be positively related to the adoption and sustained use of EMRs.

Macro Level (Environmental) Factors

General

In the area of EMR adoption, the key macro level entity is the federal government which influences EMR adoption through reimbursement practices of Medicare/Medicaid and direct funding of EMR implementation.

Macro Level Communication Factors

Overview

Many new technologies and products experience an initial spurt of adoption (eg, products such as the iPod, iPhone, etc). The primary reason for such a high rate of early adoption is advertisements in mass media such as TV and magazines. This applies to EMRs as well. Many new technologies often do not catch on due to a lack of promotional efforts. For example, physician portals were developed purely out of demand from physicians who wanted to access patient records remotely. Many health care organizations developed these systems, but unfortunately, did not promote or market them [76], so the potential of this technology was never fully understood by physicians. In essence, even the cool products will not sell if there is inadequate marketing and promotional efforts emphasizing the products' attributes.

Two factors assume importance here: the *content* of the communication and the *target* of the communication efforts [77]. The content of the communication should be able to address the complex changes and upheavals faced by health care providers, which is leading to the delay in their EMR adoption. There are a lot of new changes being implemented in the area of health care by programs such as Accountable Care Organizations (ACOs) and Patient Centered Medical Homes (PCMH) in addition to the impending changes brought down by the Affordable Care Act. Such complex changes and uncertainties could put physicians under a lot of stress and strategic communication is critical to provide clarifications. For example, one effective communication strategy would be to convey to physicians it is critical to adopt an EMR—the new models such as ACOs and PCMH depend on physician practices and hospitals that have already implemented EMRs. Hence, strategic communication efforts at the macro level should focus on both promoting EMRs (ie, its benefits and payoffs) as well as addressing the potential issues and complexities of EMR adoption.

Second, is to understand the target of the communication efforts. It is important to understand that there are multiple types of stakeholders who can influence EMR adoption by health care providers. Currently, promotional efforts primarily target physicians through medical journals and medical conferences, although, it is mostly done by the vendors who want to sell their EMR products. However, marketing and advertising efforts need not be just physician-focused. These strategies could also target additional stakeholders of care delivery. For example, direct consumer marketing has been long adopted by pharmaceutical companies and has been found to be a very effective method in not only increasing the awareness of a particular drug, but also in stirring demand for the drug and eventual sales [78]. Improving awareness among consumers about the quality difference of care by providers who have adopted EMR versus those who have not adopted EMR could be one way to increase the adoption rate among providers. The potential for implementing EMR systems that can provide relevant health information to patients is likely to be very attractive to consumers [79]. The growth of mobile health products and mHealth applications for smart phones has provided new gateways for communication between physicians and patients, which, through telemedicine, will definitely necessitate increased use of EMRs. While patient markets for mHealth apps have been aggressively marketed, the use of EMRs for hospitals has not been promoted similarly. In short, the implications of adopting EMRs go beyond one set of stakeholders and involve a diverse set of stakeholders. Therefore, mass communication campaigns that target these different stakeholders, and in some cases when targeted together, rather than separately, are likely to enhance EMR adoption rates.

Proposition 8

Effective communication at the macro level that focuses on both the benefits of EMRs as well as the likely challenges and complexities of EMR adoption will be positively related to the adoption of EMRs.

Proposition 9

Mass communication strategies at the macro level that targets not only the direct users (physicians and providers), but also other stakeholders or beneficiaries of EMR systems (including insurance companies as well as indirect users such as patients and pharmacists) will be positively related to the adoption of EMRs.

Macro-Level Cultural Factors

Overview

Currently, the macro culture in the health care industry related to EMR adoption can be described as very negative, focused on blaming individuals and institutions attributed with preventing the promotion and adoption of EMR systems. For example, Bleich and Slack [80] explained how marketing-based approaches to change physician behaviors and attitudes regarding the use of EMR technology have proven ineffective because they tend to frame physicians themselves as one of the main impediments to adoption efforts. The existence of this culture of negativity is quite evident, based on the number of articles pertaining to physician resistance and that physicians themselves are a central barrier to adoption efforts [2,17,21,80-82]. Conversely, physicians also fuel this culture by blaming insurance companies for advocating EMRs because they are the institutions most likely to reap the financial benefits of technology adoption, at least initially [19,47]. As a result of this blame shifting, altering the current dynamics of the situation requires reframing of the relationships between all stakeholders involved in the adoption process. These stakeholders include, but are not limited to, physicians, care providers, health care organizations, and government institutions that have vested interests in the development and spread of EMRs. In addition,

there has been a lot more focus on implementation failures than success stories and this adds to the negative perceptions regarding EMR.

Counteracting this negative culture requires an understanding of the institutional and product related goals that perpetuate hostility towards all aspects of EMR adoption. Recognizing physicians as the end users of EMRs pushes policy makers to assure that supply-side institutions are developing products that adequately function within highly regulated and complicated medical environments. For example, O'Malley et al [83] explained that when physicians are perceived as the central barrier to EMR adoption, it only exacerbates the gap between physicians' experiences with EMRs and policy makers' expectations. Ludwick and Doucette [47] elaborated that not acknowledging these gaps results in supporters of EMR, possibly promoting dysfunctional systems. EMR advocates who promote technology that is misaligned with physicians' expectations and needs, which may precipitate a vicious cycle in which ineffective systems become the gold-standard upon which all systems are associated and compared [47].

A critical challenge that physicians face when attempting to adopt EMR systems is the unwillingness of product developers and manufacturers to match their products to the individualized needs of physicians and medical groups [47]. Perceived attributes of any new innovation can influence the rate of adoption [15]. Not only do physicians struggle to find EMR systems that match their specific needs, but these systems can also be ineffective in delivering one of the most widely touted benefits, increased physician coordination. Jha et al [84] articulated how the plethora of EMR products offered to physicians often lead to use of incompatible systems between different care providers. Due to a lack of congruency between proposed EMR goals and functionality, physicians are concerned that the switch to an electronic product may create problems associated with patient privacy, physician-patient power relationships, and quality of care delivery [47,85].

Vendors should focus on not just advertising the potential benefits of EMR adoption but also ensuring that the innovation (ie, EMRs) is compatible with the broader cultural setting (ie, physician practice setting) in which it will be deployed. For example, efforts to enhance the overall compatibility of EMRs with the macro culture would likely enhance the adoption rate. Similarly vendor efforts to enhance the observability and the demonstrability of EMR technology (how will it work and what will be the potential outcomes) will likely reduce the cultural resistance to EMR adoption that is largely fueled by ignorance and suspicion. It has been found that physicians do adopt medical technologies like diagnostic tools (where the technology has immediate effects on their job outcomes) and other consumer technologies in their personal life but not EMRs, which are perceived as highly complicated, costly, and cumbersome [85]. Another source of negativity stems from stories of implementation mishaps and well-publicized implementation failures in the health care industry [10,86]. These implementation disasters are highly avoidable as their root causes are typically due to vendors' poor understanding of the health care environment, lack of user involvement in the implementation process, and severe lack of user training that should be provided by the vendors.

Proposition 10

Vendor efforts to understand and align EMR technology vis-à-vis the cultural factors associated with technology adoption in the health care field as well as the work context of health care professionals will be positively related to the adoption of EMRs.

Discussion and Implications

Understanding EMR adoption from the communication and sociocultural perspectives is very important, as there is a limit to enhancing adoption through economic or financial incentives alone. There are implications for researchers, practitioners as well as for policy makers. From a research perspective, it implies the need to further explore and investigate the communication and sociocultural factors that are relevant to EMR adoption.

The nature of EMR implementation is inherently complicated. As this study indicates, the impediments to these adoption efforts involve not only a diverse set of actors but also a complex set of interactions between these stakeholders across a variety of levels. Navigating through these barriers require advocates of technology adoption to acknowledge that these challenges cannot be isolated to any one set of variables. There needs to be more studies conducted about how we can address the myriad multi-level communication challenges and sociocultural challenges within the health care industry. While proponents of financial incentives are quick to note that there has been an increase in the rate of adoption after the implementation of the HITECH Act, it does not mean that the early adopters are going to complete the EMR implementation process, as many have raised doubts whether they will be able to meet the meaningful use criteria. However, there definitely is higher momentum than before in EMR adoption, partly due to the financial incentives and partly due to the influx of younger and more tech savvy care providers. This indicates that more research in understanding the range of key adoption and implementation factors would play a critical role in promoting or helping the adoption momentum set off by the financial incentives.

For practitioners, it is important to understand that all the issues with health information technology (HIT) adoption cannot be addressed with financial incentives alone and that it is critical to take a holistic perspective and address issues not only at the organizational level, but also at the macro and individual levels, and devise appropriate incentives at the different levels. Many organizations spend a lot of unnecessary money on EMRs due to a lack of information regarding the kind of information systems they require, lack of understanding of the needs and requirements of different types and levels of users, lack of promotional efforts after implementation, or a lack of understanding of the sociocultural aspects of users at different levels. The communication gap within and between various actors and stakeholders creates an even more complex situation, where solutions at one level or for one set of actors is rejected by another set. Hence, it is critical at this time to invest in understanding the communication/knowledge needs as well as the sociocultural factors that are relevant to technology adoption.

For policy makers, it is important to understand that while financial incentives may produce some positive results, without addressing the need for broader promotional and educational efforts, such advances in HIT, adoption may not be sustainable. At the macro level, there is some understanding of these factors and hence the provision of health information exchanges (HIEs). However, many of these HIEs are not promoted well as some do not have websites or any information that they are supposed to provide and there has been minimal formal evaluation of the effectiveness of these HIEs. HIEs will not be effective if physicians and other users do not know about the existence of these exchanges and the purpose of their existence.

Financially-oriented issues are not just found in the "carrot" of incentive-based efforts, but also in the affiliated "stick" of punishments for not meeting EMR adoption standards. A goal of federally-sponsored EMR incentives is to boost US physician adoption rates to 90% by 2020 [9,87]. To ensure that physicians are willing to utilize these incentives, the federal government will begin levying penalties on noncompliant physicians starting in 2015. These penalties will come in the form of a progressive fine starting at one percent of a physician's Medicare receipts and increase an additional one percent each year [88]. A noted problem with this kind of approach to EMR implementation is that, as research indicates, when a hardline approach to changing physicians' behaviors is implemented, the reaction is usually emboldened resistance [51].

Clearly, there needs to be more research on how to address the proverbial "what is in it for me" question. Instead of focusing on the cash value of adoption, there needs to be more focus on benefits other than those that are purely economic in nature [85]. Non-economic returns have driven the success of many consumer products that even physicians are attracted to and use in their daily lives [85]. Similar benefits are evident in some of the EMR technologies too, for example, in the adoption of Picture Archiving Communication Systems (PACS). Radiologists can see medical imaging pictures digitally, enlarge them on the computer screen and make more accurate diagnoses, and above all, they can do this from their own home. As a consequence of the convenience and technical advantages brought by this new technology, PACS has a high adoption rate. The example of the success of PACS adoption illustrates how vendors can promote health information technology products that deliver specific broad benefits (eg, improve quality of care, reduce errors, enhance satisfaction, reduce stress, or enhance subjective well-being) and also provide good financial investments. Mandl and Kohane [85] question the need for promotion of EMR systems to be overly complicated and call for promotion of applications similar to consumer IT products that physicians use in their daily lives.

In conclusion, financial incentives may have helped with getting the momentum started for EMR adoption to some extent, but there is a limit to the influence of such incentives. EMRs implemented without complying with meaningful use criteria will not lead to full realization of the potential of EMRs for health care practices and is not going to fully benefit patients in terms of transparency and access to records. Further, by focusing on culture and communication perspectives, we understand that monetary incentives may play only a limited role in the larger scheme of EMR adoption. Without integrating a broad range of communication and cultural factors into the promotion of EMR adoption (eg, administrative, marketing, and lifestyle benefits), it might be over ambitious to expect high results with the current financial incentives offered by the Federal government.

Acknowledgments

Publication of this article was funded in part by the George Mason University Libraries Open Access Publishing Fund.

Conflicts of Interest

None declared.

References

1. Anderson GF, Frogner BK, Johns RA, Reinhardt UE. Health care spending and use of information technology in OECD countries. Health Aff (Millwood) 2006;25(3):819-831 [FREE Full text] [doi: 10.1377/hlthaff.25.3.819] [Medline: 16684749]
2. Poon EG, Jha AK, Christino M, Honour MM, Fernandopulle R, Middleton B, et al. Assessing the level of healthcare information technology adoption in the United States: a snapshot. BMC Med Inform Decis Mak 2006;6:1 [FREE Full text] [doi: 10.1186/1472-6947-6-1] [Medline: 16396679]
3. Berner ES, Detmer DE, Simborg D. Will the wave finally break? A brief view of the adoption of electronic medical records in the United States. J Am Med Inform Assoc 2005;12(1):3-7 [FREE Full text] [doi: 10.1197/jamia.M1664] [Medline: 15492029]
4. Cutler DM, Feldman NE, Horwitz JR. U.S. adoption of computerized physician order entry systems. Health Aff (Millwood) 2005;24(6):1654-1663 [FREE Full text] [doi: 10.1377/hlthaff.24.6.1654] [Medline: 16284040]
5. Centers for Medicare & Medicaid Services. EHR incentive programs URL: http://www.cms.gov/Regulations-and-Guidance/Legislation/EHRIncentivePrograms/index.html?redirect=/EHRIncentivePrograms/01_Overview.asp [accessed 2012-11-09] [WebCite Cache ID 6C31hwIxp]
6. Rao SR, Desroches CM, Donelan K, Campbell EG, Miralles PD, Jha AK. Electronic health records in small physician practices: availability, use, and perceived benefits. J Am Med Inform Assoc 2011 May 1;18(3):271-275 [FREE Full text] [doi: 10.1136/amiajnl-2010-000010] [Medline: 21486885]

7. Wolf L, Harvell J, Jha. Hospitals ineligible for federal meaningful-use incentives have dismally low rates of adoption of electronic health records. Health Aff (Millwood) 2012 Mar;31(3):505-513. [doi: 10.1377/hlthaff.2011.0351] [Medline: 22392661]
8. IVANS. 2012 Healthcare provider survey key findings on revenue cycle management, audits and automation URL: http://www.ivans.com/news/news_detail.aspx?id=107 [accessed 2012-11-09] [WebCite Cache ID 6C31pTKaS]
9. Hsiao CJ, Hing E, Socey TC, Cai B. Electronic health record systems and intent to apply for meaningful use incentives among office-based physician practices: United States, 2001-2011 URL: http://www.cdc.gov/nchs/data/databriefs/db79.pdf [accessed 2012-11-09] [WebCite Cache ID 6C31ySJjE]
10. Keshavjee K, Bosomworth J, Copen J, Lai J, Kucukyazici B, Lilani R, et al. Best practices in EMR implementation: a systematic review. 2006 Presented at: AMIA Annu Symp Proc; 2006; Washington DC.
11. Blumenthal D. Stimulating the adoption of health information technology. N Engl J Med 2009 Apr 9;360(15):1477-1479. [doi: 10.1056/NEJMp0901592] [Medline: 19321856]
12. Lorenzi NM, Novak LL, Weiss JB, Gadd CS, Unertl KM. Crossing the implementation chasm: a proposal for bold action. J Am Med Inform Assoc 2008;15(3):290-296 [FREE Full text] [doi: 10.1197/jamia.M2583] [Medline: 18308985]
13. McCullough J, Casey M, Moscovice I. Flex Monitoring Team. Critical access hospitals and meaningful use of health information technology, policy brief, flex monitoring team URL: http://www.flexmonitoring.org/documents/Hospital-Compare-PolicyBrief-Year7.pdf [accessed 2012-11-09] [WebCite Cache ID 6C32BTHGP]
14. Chandrasekaran D, Tellis G. A critical review of marketing research on diffusion of new products. Review of Marketing Research 2007;3:39-80. [doi: 10.1108/S1548-6435(2007)0000003006]
15. Rogers EM. Diffusion of innovations, 5th edition. New York: Free Press; 2003.
16. Bower AG. The diffusion and value of healthcare information technology. Santa Monica, CA: Rand Corp; 2005.
17. Meinert DB. Resistance to electronic medical records (EMRs): A barrier to improved quality of care. Issues in Informing Science and Information Technology 2005;2:493-504.
18. Khoury A. Finding value in EMRs (electronic medical records). Health Manag Technol 1997 Jul;18(8):34-36. [Medline: 10169803]
19. Middleton B, Hammond WE, Brennan PF, Cooper GF. Accelerating U.S. EHR adoption: how to get there from here - recommendations based on the 2004 ACMI retreat. J Am Med Inform Assoc 2005;12(1):13-19 [FREE Full text] [doi: 10.1197/jamia.M1669] [Medline: 15492028]
20. Simborg DW. Promoting electronic health record adoption. Is it the correct focus? J Am Med Inform Assoc 2008;15(2):127-129 [FREE Full text] [doi: 10.1197/jamia.M2573] [Medline: 18096904]
21. Selder A. Physician reimbursement and technology adoption. J Health Econ 2005 Sep;24(5):907-930. [doi: 10.1016/j.jhealeco.2005.03.004] [Medline: 15927287]
22. Wang SJ, Middleton B, Prosser L, Bardon CG, Spurr CD, Carchidi PJ, et al. A cost-benefit analysis of electronic medical records in primary care. Am J Med 2003 Apr 1;114(5):397-403. [Medline: 12714130]
23. Kaushal R, Jha AK, Franz C, Glaser J, Shetty KD, Jaggi T, et al. Return on investment for a computerized physician order entry system. J Am Med Inform Assoc 2006;13(3):261-266 [FREE Full text] [doi: 10.1197/jamia.M1984] [Medline: 16501178]
24. Harris LM, Kobb R, Ryan P, Darkins A, Kreps GL. Research as dialogue: a window into the dynamics of communicating systems and change. In: Whitten P, Cook D, editors. Understanding Health Communications Technologies: A Case Study Approach. San Francisco: Jossey-Bass; 2004:91-100.
25. Landro L. EBM Brief. Doctors need incentives to embrace technology URL: http://www.imakenews.com/ebmsolutions/e_article000168561.cfm [accessed 2012-11-09] [WebCite Cache ID 6C32Imc1l]
26. Haider M, Kreps GL. Forty years of diffusion of innovations: utility and value in public health. J Health Commun 2004;9 Suppl 1:3-11. [doi: 10.1080/10810730490271430] [Medline: 14960400]
27. Abraham JM, McCullough JS, Parente ST, Gaynor MS. Prevalence of electronic health records in U.S. hospitals. Journal of Healthcare Engineering 2011;2(2):121-142.
28. Kreps GL. Enhancing access to relevant health information. In: Carveth R, Kretchmer SB, Schuler D, editors. Shaping the network society: Patterns for participation, action, and change. Palo Alto, CA: CPSR; 2002:149-152.
29. Kreps GL. Health communication and information technology. The Electronic Journal of Communication/La Revue Electronique de Communication 2002 [FREE Full text]
30. Kreps GL. Evaluating new health information technologies: expanding the frontiers of health care delivery and health promotion. Stud Health Technol Inform 2002;80:205-212. [Medline: 12026130]
31. Damanpour F. The adoption of technological, administrative and ancillary innovations: impact of organizational factors. Journal of Management 1987;13:675-688.
32. Damanpour F. Organizational innovation: a meta-analysis of effects of determinants and moderators. Academy of Management Journal 1991;34:555-590.
33. Bertalanffy L. General system theory. New York: George Braziller; 1969.
34. Shortell SM, Singer SJ. Improving patient safety by taking systems seriously. JAMA 2008 Jan 30;299(4):445-447. [doi: 10.1001/jama.299.4.445] [Medline: 18230782]

35. Ferlie EB, Shortell SM. Improving the quality of health care in the United Kingdom and the United States: a framework for change. Milbank Q 2001;79(2):281-315 [FREE Full text] [Medline: 11439467]
36. Kimberly JR, Evanisko MJ. Organizational Innovation: The influence of individual, organizational, and contextual factors on hospital adoption of technological and administrative innovations. Academy of Management Journal 1981;24(4):689-713.
37. Yan H, Gardner R, Baier R. Beyond the focus group: understanding physicians' barriers to electronic medical records. Jt Comm J Qual Patient Saf 2012 Apr;38(4):184-191. [Medline: 22533131]
38. Ash JS, Bates DW. Factors and forces affecting EHR system adoption: report of a 2004 ACMI discussion. J Am Med Inform Assoc 2005;12(1):8-12 [FREE Full text] [doi: 10.1197/jamia.M1684] [Medline: 15492027]
39. Brooks R, Grotz C. Implementation of electronic medical records: How healthcare providers are managing the challenges of going digital. Journal of Business & Economics Research 2010;8(6):73-84.
40. Ayers DJ, Menachemi N, Ramamonjiarivelo Z, Matthews M, Brooks RG. Adoption of electronic medical records: the role of network effects. Journal of Product & Brand Management 2009 2009;18(2):127-135. [doi: 10.1108/10610420910949022]
41. Davidson E, Heslinga D. Bridging the IT Adoption Gap for Small Physician Practices: An Action Research Study on Electronic Health Records. Information Systems Management 2006 Dec 2006;24(1):15-28. [doi: 10.1080/10580530601036786]
42. Felt-Lisk S, Johnson L, Fleming C, Shapiro R, Natzke B. Toward understanding EHR use in small physician practices. Health Care Financ Rev 2010;31(1):11-22. [Medline: 20191754]
43. Friedkin N. Social Cohesion. Annu. Rev. Sociol 2004 Aug 2004;30(1):409-425. [doi: 10.1146/annurev.soc.30.012703.110625]
44. Burt RS. Social contagion and innovation: cohesion versus structural equivalence. American Journal of Sociology 1987;92(6):1287-1335.
45. Coleman JS, Katz E, Menzel H. Medical innovation: a diffusion study. Indianapolis: The Bobbs-Merril Company, Inc; 1966.
46. Bandura A. Social cognitive theory of mass communication. Media Psychology 2001;3:265-299.
47. Ludwick DA, Doucette J. Primary Care Physicians' Experience with Electronic Medical Records: Barriers to Implementation in a Fee-for-Service Environment. Int J Telemed Appl 2009;2009:853524-853529 [FREE Full text] [doi: 10.1155/2009/853524] [Medline: 19081787]
48. Shachak A, Reis S. The impact of electronic medical records on patient-doctor communication during consultation: a narrative literature review. J Eval Clin Pract 2009 Aug;15(4):641-649. [doi: 10.1111/j.1365-2753.2008.01065.x] [Medline: 19522722]
49. LeTourneau B. Managing physician resistance to change. J Healthc Manag 2004;49(5):286-288. [Medline: 15499802]
50. Boonstra A, Broekhuis M. Barriers to the acceptance of electronic medical records by physicians from systematic review to taxonomy and interventions. BMC Health Serv Res 2010;10:231 [FREE Full text] [doi: 10.1186/1472-6963-10-231] [Medline: 20691097]
51. Ilie V. How to influence physicians to use electronic medical records (EMR)? Social influence tactics and their effects on EMR implementation effectiveness. 2009 Presented at: ICIS Proceedings; December; Phoenix, Arizona.
52. Jones, Greg. MDLinx. MDLinx doc survey: 26% of small private practices say they could close within a year URL: http://usa.m3.com/pressdetail.cfm/691/mdlinx-doc-survey-26-of-small-private-practices-say-they-could-close-within-a-year [accessed 2012-11-01] [WebCite Cache ID 6Bqr0ZMzE]
53. Elliott, Victoria Stagg. amednews. 2011. Small practices: adapting to survive URL: http://www.ama-assn.org/amednews/2011/06/27/bisa0627.htm [accessed 2012-11-01] [WebCite Cache ID 6BqrPoJtJ]
54. Bohmer RM. Managing the new primary care: the new skills that will be needed. Health Aff (Millwood) 2010 May;29(5):1010-1014. [doi: 10.1377/hlthaff.2010.0197] [Medline: 20439899]
55. Aiken M, Hage J. The organic organization and innovation. Sociology 1971;5:63-82.
56. De Burca S. The learning health care organization. International Journal for Quality in Health Care 2000;12(6):457-458.
57. Argyris C. Teaching smart people how to learn. Harvard Business Review 1991(May-June).
58. Ash J. Organizational factors that influence information technology diffusion in academic health sciences centers. J Am Med Inform Assoc 1997;4(2):102-111 [FREE Full text] [Medline: 9067876]
59. Coiera E. When conversation is better than computation. J Am Med Inform Assoc 2000;7(3):277-286 [FREE Full text] [Medline: 10833164]
60. Coiera E, Tombs V. Communication behaviours in a hospital setting: an observational study. BMJ 1998 Feb 28;316(7132):673-676 [FREE Full text] [Medline: 9522794]
61. Brown JS, Duguid P. Organizational Learning and Communities-of-Practice: Toward a Unified View of Working, Learning, and Innovation. Organization Science 1991 Feb 1991;2(1):40-57. [doi: 10.1287/orsc.2.1.40]
62. Parboosingh JT. Physician communities of practice: where learning and practice are inseparable. J Contin Educ Health Prof 2002;22(4):230-236. [doi: 10.1002/chp.1340220407] [Medline: 12613058]
63. Wenger E. Communities of practice: learning, meaning, and identity. Cambridge, U.K: Cambridge University Press; 1998.
64. Arrow K. The economic implications of learning by doing. Review of Economic Studies 1962;29(3):155-173.
65. Rosenberg N. Inside the black box: technology and economics. Cambridge: Cambridge University Press; 1982.
66. Rice RE, Rogers EM. Reinvention in the innovation process. Knowledge 1980;1:499-514.

67. Orlikowski WJ. The Duality of Technology: Rethinking the Concept of Technology in Organizations. Organization Science 1992 Aug 1992;3(3):398-427. [doi: 10.1287/orsc.3.3.398]
68. Senge P. The leader's new work: building learning organizations. Sloan Management Review 1990;32(1):7-24.
69. Baldridge JV, Burnham RA. Organizational innovation: individual, organizational, and environmental impacts. Administrative Science Quarterly 1975;20(June):165-176.
70. Sapolsky H. Organizational structure and innovation. Journal of Business 1967;40:497-510.
71. Hage J, Dewar R. Elite values vs organization structure in predicting innovation. Administrative Science Quarterly 1973;18:279-290.
72. Venkatesh V, Bala H, Venkatraman S, Bates J. Enterprise architecture maturity: the story of the Veterans Health Administstration,. MIS Quarterly Executive 2007;6(2):79-90.
73. Yusof MM, Stergioulas L, Zugic J. Health information systems adoption: findings from a systematic review. Stud Health Technol Inform 2007;129(Pt 1):262-266. [Medline: 17911719]
74. Agarwal R, Anderson C, Crowley K, Kannan PK. Understanding development methods from other industries to improve the design of consumer health IT: background report. AHRQ Publication No. 11-0065-EF. Rockville, MD: Agency for Healthcare Research and Quality 2011.
75. Palacio C, Harrison JP, Garets D. Benchmarking electronic medical records initiatives in the US: a conceptual model. J Med Syst 2010 Jun;34(3):273-279. [Medline: 20503611]
76. Grossman JM, Bodenheimer TS, McKenzie K. Hospital-physician portals: the role of competition in driving clinical data exchange. Health Aff (Millwood) 2006;25(6):1629-1636 [FREE Full text] [doi: 10.1377/hlthaff.25.6.1629] [Medline: 17102188]
77. Kreps GL. Annals of Family Medicine. 2006. One size does not fit all: Adapting communication to the needs and literacy levels of individuals URL: http://www.annfammed.org/content/4/3/205/reply [accessed 2013-02-12] [WebCite Cache ID 6EOJQrByo]
78. Donohue JM, Cevasco M, Rosenthal MB. A decade of direct-to-consumer advertising of prescription drugs. N Engl J Med 2007 Aug 16;357(7):673-681. [doi: 10.1056/NEJMsa070502] [Medline: 17699817]
79. Wen KY, Kreps GL, Miller S. Consumers' perceptions about and use of the Internet for personal health records and health information exchange: analysis of the 2007 health information national trends survey. Journal of Medical Internet Research 2010;12(4) [FREE Full text]
80. Berger RG, Kichak JP. Computerized physician order entry: helpful or harmful? J Am Med Inform Assoc 2004;11(2):100-103 [FREE Full text] [doi: 10.1197/jamia.M1411] [Medline: 14633934]
81. Baldwin FD. Physician conservatism may be stalling technology. Physician's Management 1998;38(7):8.
82. Eger MS, Godkin RL, Valentine SR. Physicians' adoption of information technology: a consumer behavior approach. Health Mark Q 2001;19(2):3-21. [doi: 10.1300/J026v19n02_02] [Medline: 11873454]
83. O'Malley AS, Grossman JM, Cohen GR, Kemper NM, Pham HH. Are electronic medical records helpful for care coordination? Experiences of physician practices. J Gen Intern Med 2010 Mar;25(3):177-185 [FREE Full text] [doi: 10.1007/s11606-009-1195-2] [Medline: 20033621]
84. Jha AK, DesRoches CM, Campbell EG, Donelan K, Rao SR, Ferris TG, et al. Use of electronic health records in U.S. hospitals. N Engl J Med 2009 Apr 16;360(16):1628-1638. [doi: 10.1056/NEJMsa0900592] [Medline: 19321858]
85. Mandl KD, Kohane IS. Escaping the EHR trap--the future of health IT. N Engl J Med 2012 Jun 14;366(24):2240-2242. [doi: 10.1056/NEJMp1203102] [Medline: 22693995]
86. Han YY, Carcillo JA, Venkataraman ST, Clark RSB, Watson RS, Nguyen TC, et al. Unexpected increased mortality after implementation of a commercially sold computerized physician order entry system. Pediatrics 2005 Dec;116(6):1506-1512 [FREE Full text] [doi: 10.1542/peds.2005-1287] [Medline: 16322178]
87. Richards MM. Electronic medical records: confidentiality issues in the time of HIPAA. Professional Psychology: Research and Practice 2009;40(6):550-556.
88. D'Avolio LW. Electronic medical records at a crossroads: impetus for change or missed opportunity? JAMA 2009 Sep 9;302(10):1109-1111. [doi: 10.1001/jama.2009.1319] [Medline: 19738097]

Abbreviations

ACO: Accountable Care Organization
CMS: Centers for Medicare and Medicaid Services
CPE: continuing professional education
EMR: electronic medical record
HCO: health care organizations
HIE: health information exchange
HIT: health information technology
HITECH: Health Information Technology on Economic and Clinical Health
PACS: Picture Archiving Communication Systems

PCMH: patient centered medical homes
VA: veterans administration

Edited by G Eysenbach; submitted 15.11.12; peer-reviewed by L Harris, S Godin; comments to author 06.12.12; revised version received 31.12.12; accepted 23.01.13; published 26.03.13.

Please cite as:
Nambisan P, Kreps GL, Polit S
Understanding Electronic Medical Record Adoption in the United States: Communication and Sociocultural Perspectives
Interact J Med Res 2013;2(1):e5
URL: http://www.i-jmr.org/2013/1/e5/
doi:10.2196/ijmr.2437
PMID:23612390

Original Paper

Health Care Transformation Through Collaboration on Open-Source Informatics Projects: Integrating a Medical Applications Platform, Research Data Repository, and Patient Summarization

Jeffrey G Klann[1,2,3], MEng, PhD; Allison B McCoy[4], MS, PhD; Adam Wright[1,5], PhD; Nich Wattanasin[6], MS; Dean F Sittig[4], MS, PhD, FHIMSS, FACMI; Shawn N Murphy[1,2,3], MD, PhD

[1]Harvard Medical School, Boston, MA, United States

[2]Laboratory of Computer Science, Department of Medicine, Massachusetts General Hospital, Boston, MA, United States

[3]Research Computing, Information Systems, Partners Healthcare System, Inc, Boston, MA, United States

[4]The University of Texas School of Biomedical Informatics at Houston, Houston, TX, United States

[5]Department of General Medicine, Brigham and Women's Hospital, Boston, MA, United States

[6]Research Computing, Information Systems, Partners Healthcare System, Inc., Boston, MA, United States

Corresponding Author:
Jeffrey G Klann, MEng, PhD
Laboratory of Computer Science
Department of Medicine
Massachusetts General Hospital
One Constitution Center
2nd Floor
Boston, MA, 02129
United States
Phone: 1 617 643 5879
Fax: 1 617 643 5280
Email: jklann@partners.org

Abstract

Background: The Strategic Health IT Advanced Research Projects (SHARP) program seeks to conquer well-understood challenges in medical informatics through breakthrough research. Two SHARP centers have found alignment in their methodological needs: (1) members of the National Center for Cognitive Informatics and Decision-making (NCCD) have developed knowledge bases to support problem-oriented summarizations of patient data, and (2) Substitutable Medical Apps, Reusable Technologies (SMART), which is a platform for reusable medical apps that can run on participating platforms connected to various electronic health records (EHR). Combining the work of these two centers will ensure wide dissemination of new methods for synthesized views of patient data. Informatics for Integrating Biology and the Bedside (i2b2) is an NIH-funded clinical research data repository platform in use at over 100 sites worldwide. By also working with a co-occurring initiative to SMART-enabling i2b2, we can confidently write one app that can be used extremely broadly.

Objective: Our goal was to facilitate development of intuitive, problem-oriented views of the patient record using NCCD knowledge bases that would run in any EHR. To do this, we developed a collaboration between the two SHARPs and an NIH center, i2b2.

Methods: First, we implemented collaborative tools to connect researchers at three institutions. Next, we developed a patient summarization app using the SMART platform and a previously validated NCCD problem-medication linkage knowledge base derived from the National Drug File-Reference Terminology (NDF-RT). Finally, to SMART-enable i2b2, we implemented two new Web service “cells” that expose the SMART application programming interface (API), and we made changes to the Web interface of i2b2 to host a “carousel” of SMART apps.

Results: We deployed our SMART-based, NDF-RT-derived patient summarization app in this SMART-i2b2 container. It displays a problem-oriented view of medications and presents a line-graph display of laboratory results.

Conclusions: This summarization app can be run in any EHR environment that either supports SMART or runs SMART-enabled i2b2. This i2b2 "clinical bridge" demonstrates a pathway for reusable app development that does not require EHR vendors to immediately adopt the SMART API. Apps can be developed in SMART and run by clinicians in the i2b2 repository, reusing clinical data extracted from EHRs. This may encourage the adoption of SMART by supporting SMART app development until EHRs adopt the platform. It also allows a new variety of clinical SMART apps, fueled by the broad aggregation of data types available in research repositories. The app (including its knowledge base) and SMART-i2b2 are open-source and freely available for download.

(Interact J Med Res 2013;2(1):e11) doi:10.2196/ijmr.2454

KEYWORDS

clinical information systems; medical informatics; knowledge bases; user-computer interface; data display; diffusion of innovation

Introduction

Substitutable Medical Apps

The burden for development of innovative views of the medical record has, until recently, rested largely on the core software architects of electronic health record (EHR) systems. Local innovation on those systems has functionally been restricted to a small number of academic research hospitals with large research budgets [1], and their tools are frequently designed only for local use (eg, [2]). Transfer of local innovation to the larger medical community has often been slow and complex. For example, the WizOrder order-entry system, developed at Vanderbilt, is used widely within their hospital system and has been the source of much interesting research. However, WizOrder itself was unavailable to others until a commercial EHR vendor purchased it in 2001 [3], and it is now available only to users of that vendor system.

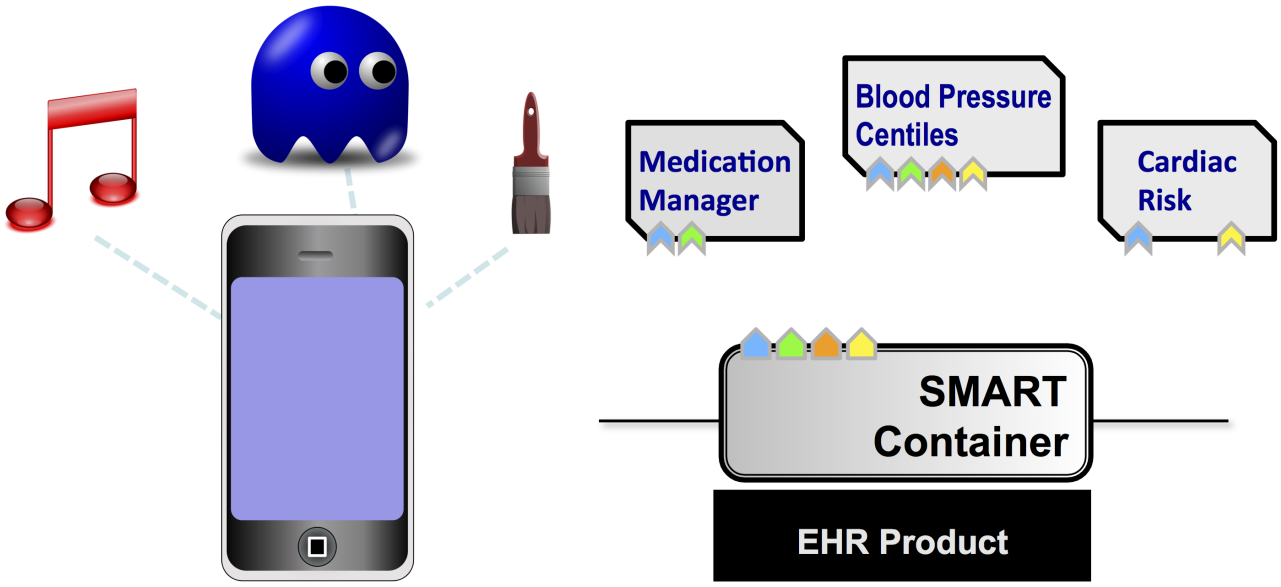
A new allocation of resources is emerging which will directly support distribution, modularity, and interoperability of local innovation. In 2009, Kohane and Mandl proposed that EHRs be designed as platforms for supporting modular third-party applications rather than as monolithic systems [4]. They drew analogies to "app stores" found in the smartphone market, where specialized applications are developed and purchased to meet niche or not-widely-understood needs, without compromising the basic integrity of the device. Such an ecosystem of apps, they suggested, would foster innovation without sacrificing compatibility. Users with particular information needs could become app developers and contribute innovative insights from their local environment to the larger medical informatics community.

In 2010, the United States Office of the National Coordinator for Health Information Technology (ONC) launched a four-year, $60 million government initiative: the Strategic Health IT Advanced Research Projects (SHARP) program. SHARP seeks to conquer well-understood challenges in medical informatics through breakthrough research. ONC funded four SHARP centers, one to study each of four challenge areas: information security, cognitive support, reusable applications, and secondary use of EHR data [5].

The Substitutable Medical Apps Reusable Technologies (SMART) center at Harvard Medical School is attempting to make Kohane and Mandl's ecosystem for user-interface innovation a reality. SMART defines an application programming interface (API) and provides core software components so that health care information technology (HIT) systems' developers can implement a SMART "container" interface to provide access to the data in EHRs in a standardized resource description framework (RDF) format. Apps written to conform to the container interface will run without modification on all EHRs and HIT systems that provide a SMART container. Apps can be written for patients, providers, and researchers, and all are backed by EHR data. The high level design is shown in Figure 1.

At the beginning of 2012, SMART leadership reported on their progress 14 months into the contract [6]. SMART had defined its initial API and had begun container development for three HIT platforms: an electronic health record system (OpenMRS), a personal health record system (Indivo), and a clinical research repository (Informatics for Integrating Biology and the Bedside, i2b2). They also developed a suite of charter apps. Most notably, SMART developers took a user-friendly conceptualization of a cardiac risk app that appeared in Wired magazine and converted it into a live SMART app in about a week [7]. SMART is extending its reach, recently implementing some of the SMART container interface on Cerner's public API and developing an app to monitor trends in blood pressure and flag hypertension in pediatric patients [8]. This app has now been running at Children's Hospital in Boston for several months and is seeing increased adoption each month. SMART hosted a national "app challenge", which was won by HIT innovator Polyglot Systems for their "Meducation app", providing multilingual, user-friendly medication instructions for patients [9,10]. A similar app challenge has just concluded for Indivo. The winner, Indivo WebNotes, allows users to integrate snippets from webpages directly into their personal health record [11]. Other SMART containers are also in development, including Mirth corporation's work with SMART to enable two Health Information Exchanges [12]. SMART has also recently been supporting best practices in Continuity of Care Documents with a "report card" app that includes terminology validation and "soft" rubrics not included in the official validator [13].

Figure 1. SMART enables an ecosystems of apps in medical systems, just as app stores enable this on smartphones. Portions adapted with permission from [4].



Patient Summarization

One potentially important use-case for SMART-style user-interface innovation is in clinical decision support (CDS). There is substantial evidence to suggest that CDS can be a powerful tool to improve the quality of patient care, yet commercial EHR systems have highly variable and underutilized CDS capabilities [14-16]. The Patient-Centered Cognitive Support SHARP, housed at the National Center for Cognitive Informatics and Decision Making (NCCD) in Houston, Texas, has the high-level goal of utilizing HIT to support clinician decision-making.

Its "automated model-based clinical summarization of key patient data" project seeks to make EHR data more easily digestible, particularly by transforming it from pages of disconnected data into a concise problem-oriented medical record (POMR). Clinical summarization is becoming particularly important given the overwhelming amount of information present in today's EHRs. Sifting through these data present an added burden to already-overwhelmed clinicians, who admit to making mistakes due to hurry and distractions [17]. The POMR, first described by Weed in 1968, puts patients' problems at the center of the record and organizes data around those problems [18]. Users have found this format facilitates quicker understanding and review, improved team communication, and faster auditing, among other advantages [19-23]. Although most commercial EHRs have some summarization capability, such summarizations focus on organizing each type of clinical data, rather than synthesized views of the patient record [24]. One evaluation study concluded that developing a suitable POMR "is not easy," and that physicians have become accustomed to the standard time-oriented view [25], which suggests some of the reasons for sluggish change.

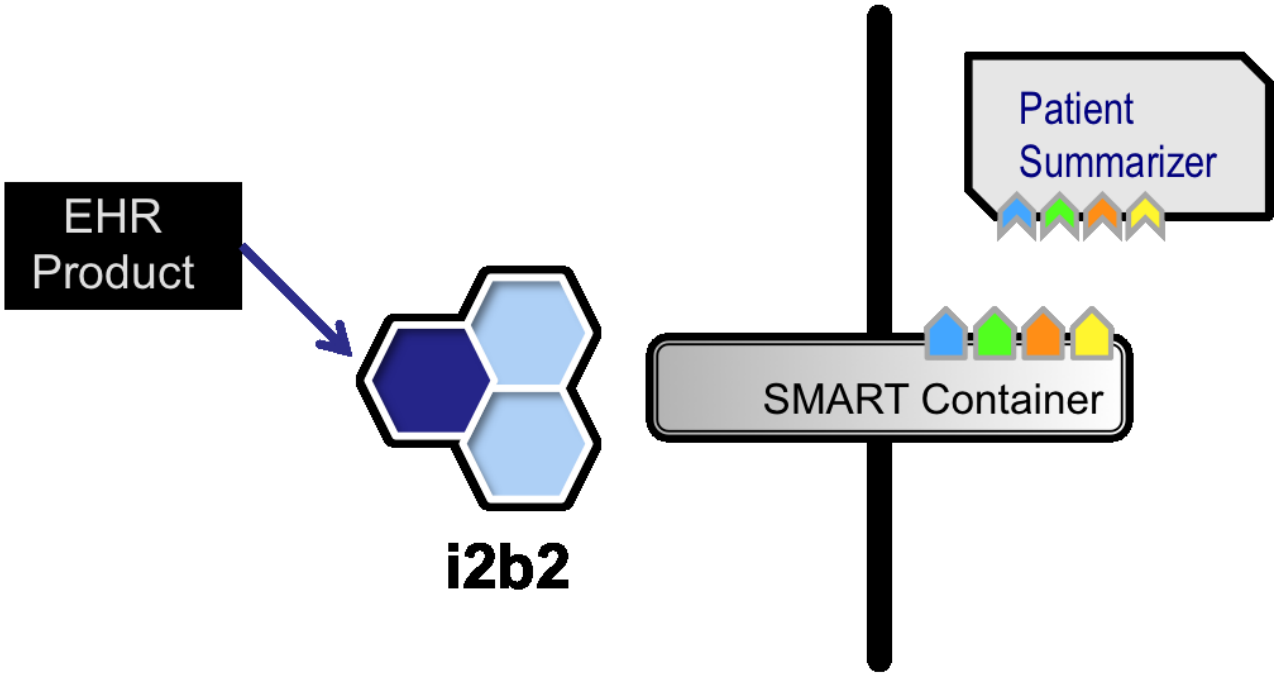
SMART-i2b2

SMART's app approach offers the ability to integrate a POMR view with traditional views of clinical data, and it also overcomes the difficulty of integrating new, vendor-independent applications with many vendor products. Therefore, we had previously turned to SMART and developed a proof-of-concept POMR SMART app [26]. However, SMART is not yet supported by many EHRs, which limited the utility of this line of development. In early 2012, we became aware of the SMART-i2b2 project. i2b2 is a flexible, componentized clinical data warehousing system that now enjoys widespread adoption as a research and population management data repository at over 100 sites worldwide. It is being developed as part of a National Institutes of Health (NIH)-funded center charged with developing a national computational infrastructure for biomedical computing [27]. SMART-enabling i2b2 has been underway for some time, but it has primarily focused on clinical research support, such as a patient-centric view for clinical trial recruitment selection [28].

We theorized that i2b2's popularity and the wealth of data available in i2b2 instances would make it a useful "clinical bridge", to support SMART apps prior to large EHR vendors developing SMART containers. This led us to an architecture in which the patient summarization app runs in SMART-i2b2, shown in Figure 2. In this architecture, SMART-i2b2 would be launched as a webpage on the EHR workstation to run SMART clinical apps.

In this paper, we describe the results of our collaborative endeavor between i2b2 and the cognitive support and reusable apps SHARP centers, focused on creating more intuitive views of the EHR. Our goal was to facilitate development of intuitive, problem-oriented views of the patient record using NCCD knowledge bases that would run in any EHR.

Figure 2. The overall architecture of the patient summarizer running in the SMART-i2b2 "clinical bridge".



Methods

Collaboration

To assist effective collaboration among sites, we used an Amazon virtual machine [29] to host our deployment of SMART-i2b2 with patient summarization, GitHub [30] to support collaborative development of the patient summarization app, DropBox [31] for sharing miscellaneous items such as notes and diagrams, and Google+ [32] to support multi-way real-time video conferencing. Tools like these will certainly become more important as collaborative, multi-site research is increasingly occurring [33].

Patient Summarization

The National Drug File Reference Terminology (NDF-RT) contains "may_treat" linkages between diagnoses and medications [34] which have been explored as a knowledge source for enhancing the problem list [35]. We have previously developed a proof-of-concept problem-medication linkage SMART app using an NDF-RT derived knowledge base [26]. For this work, we extended that app. Within the Unified Medical Language System (UMLS), there exist links between RxNorm (a SMART-approved terminology) and NDF-RT medication codes. From these medication codes, we traversed the "may_treat" linkages and then converted the linked NDF-RT diseases to the Systematized Nomenclature of Medicine-Clinical Terms (SNOMED-CT, another SMART-approved terminology) using the UMLS, expanding all levels of the problem hierarchy to create the most inclusive possible knowledge. The resulting knowledge base consists of over 7 million problem-medication links. An illustration of the knowledge base construction is shown in Figure 3. We stored our knowledge base as tuples of a related RxNorm medication concept unique identifier (CUI) and a SNOMED-CT problem code. To access this database from our Web application, we wrote a Web service in PHP Hypertext Preprocessor (PHP) to retrieve a list of SNOMED-CT problems given an RxNorm CUI. The NDF-RT approach is limited by knowledge gaps, in part due to data loss from incomplete mappings. However, this knowledge base is currently our most mature and it already uses SMART-required terminologies (SNOMED-CT and RxNorm). The SMART container handles mapping to these terminologies, so this knowledge base is "SMART ready."

We are developing other knowledge bases using other techniques, each with strengths and weaknesses. One knowledge base utilizes probabilistic linkages in the medical record, an approach first suggested more than a decade ago [36]. This approach is able to detect correct linkage very accurately on medications used for one very specific purpose (eg, glycopyrrolate) and for non-clinical problems (eg, tube feeding, taking medication). As an example, our initial work with this method found the 50 strongest linkages in a dataset of 100,000 patients were all clinically accurate and the majority were for a very specific purpose [37]. This method does not require any effort by clinical experts, but the knowledge base must be recompiled in each setting, and it is less accurate on common diseases and interventions. Another knowledge base uses a form of crowdsourcing, which takes advantage of manually asserted links between problems and medications or laboratory results and is more accurate than probabilistic linkage on some multivariate associations, especially commonly prescribed medications with secondary problems (eg, metformin and polycystic ovarian syndrome [38-40]). While the crowdsourcing approach requires little effort to capture knowledge, methods must be applied to filter out noise (eg, patient data linked to a problem to facilitate billing and not medical care). A final approach utilizes a manually constructed knowledge base [41]. The manual approach had the highest accuracy but required the most effort and still only covered a relatively small number of common clinical conditions. Work has also been done on literature mining (such as PubMed and Food and Drug Administration product labels) to develop knowledge bases,

though we have not yet incorporated this technique [42-45]. None of these knowledge bases have yet been sufficiently mapped to SMART-approved terminologies, so we used the NDF-RT approach for this work.

When the app is launched, it makes asynchronous JavaScript SMART API calls to retrieve demographics, medications, problems, allergies, lab results, encounters, vital signs, and immunizations. Each API call returns a SMARTResponse object containing a RDF graph containing that component of the patient record. For all objects except problems and medications, the app iteratively traverses each graph as it is retrieved to generate HTML display data. The app does not process problem and medication objects until both are loaded, because they must be handled together. When both are loaded, the app traverses the medication graph, retrieves all possibly related problems through the PHP Web service, and then traverses the problem graph, adding the current medication to the HTML output for all matching problems.

We modeled our summarization app's user interface on a previously designed prototype interface of a problem-oriented view for OpenVista, which was evaluated using the Task, User, Representation, and Function framework for EHR usability [46,47]. We developed the app using HTML and JavaScript, facilitated by the Bootstrap front-end framework and the Google Visualization API [48]. The originally-developed proof-of-concept summarization SMART app showed all problems and medications on one screen, which can prove unwieldy for complex patients, and displayed output in a rigid HTML table. The new app, modeled after the prototype, features a responsive cascading style sheet, fluid grid design that ensures proper proportions for key screen resolutions and devices.

The app user interface displays the list of active problems on the left. Users may select a problem from the list to display associated medications on the right side. The user can also click the "All Medications" text to toggle a list of all prescribed medications for the patient. We have not yet integrated a knowledge base with lab results, so the app displays all historical lab results and vital signs in a list below the problems and medications. Users may click a lab result or vital sign to toggle display of the values; any lab result with multiple values is shown as a graph, generated using the Google Visualization API. See the Results section and Multimedia Appendix 1 for an example. The app is open-source and available for free download [30].

SMART-i2b2

i2b2 is a "hive" of "cells" (software modules), where each cell provides a set of Web services. New cells can be added to the hive and communicate with the other cells via Web service calls. The standard hive has the blue cells shown in Figure 4. Adding SMART functionality involved three changes to i2b2 [49].

First, we developed a new cell, the SMART container, which implements the SMART API and securely sends RDF messages to SMART apps as specified by the OAuth protocol. SMART places the burden of constructing valid SMART-RDF messages on the container developer. Therefore, we developed a flexible way in the SMART cell to transform an i2b2 XML message into a SMART-RDF XML message using stylesheets.

Second, in i2b2, one methodologically challenging piece is flexibly translating from the variety of i2b2 terminologies to the expected terminologies of SMART. To facilitate this translation, we developed a Mapper cell, which supports customizable mappings between terminologies and can be jumpstarted with existing linkages such as those in the UMLS. A set of about 2000 most used "target terms" for mapping, which covers 85% of terms used in the Partners Health care System [49,50], has been created and is distributed with the SMART-i2b2 container. These "target terms" are SNOMED-CT, RxNorm, and Logical Observation Identifier Names and Codes (LOINC) terms that can be loaded into the Mapper cell to provide guidance when an institution maps its local codes to the SMART preferred coding systems. Additionally, the i2b2 demonstration data's terminology dictionary, which includes terms in the 9th edition of the International Classification of Diseases (ICD-9), NDF-RT, and several demographic value sets, was also mapped to SNOMED-CT and RxNorm. Although each i2b2 instance can choose which terminologies to support and therefore might require a custom mapping, many sites have adopted variations of the demonstration terminology.

The final change to i2b2 was an upgrade to the Web interface. The i2b2 Web interface supports plugins, and so a plugin was developed for the "SMART Patient Centric view", shown on the right side of Figure 4. This EHR-like view in turn can be configured to run any number of SMART apps simultaneously, hosted locally and remotely. The Patient Centric view allows per-user organization of these apps into multiple views suited to the user's needs.

With these aforementioned components, any SMART app can reside inside i2b2, communicating with i2b2 via the SMART container. These SMART-enabling components are freely available and can be installed as an add-on to any i2b2 installation [51].

Figure 3. SMART RxNorm medications are mapped to SNOMED CT problems using the NDF-RT "may treat" linkage as intermediary. Adapted from [26]; used with permission.

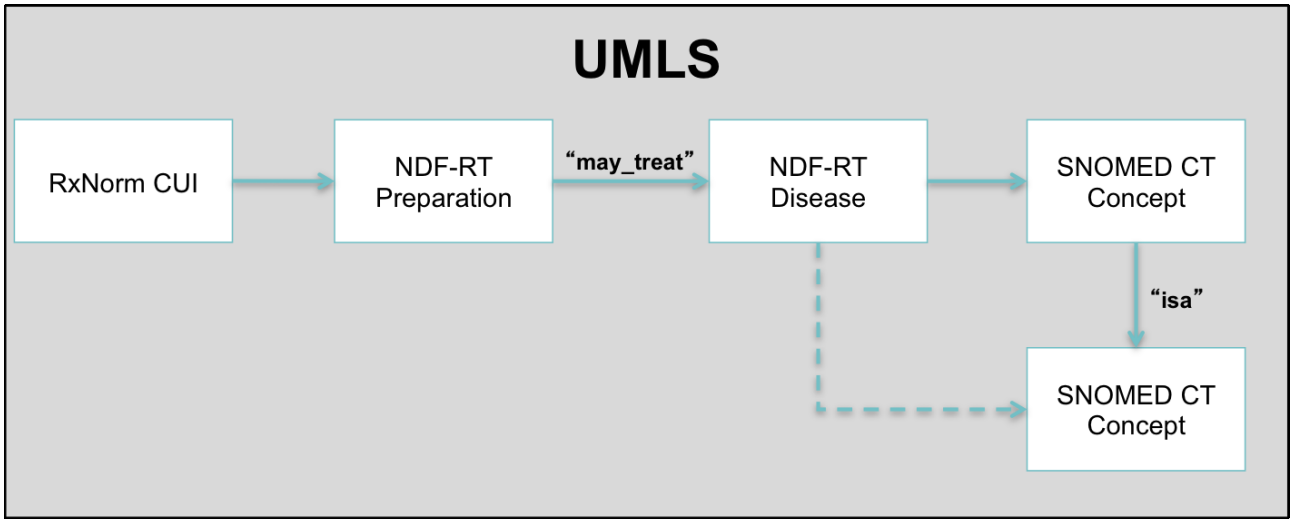
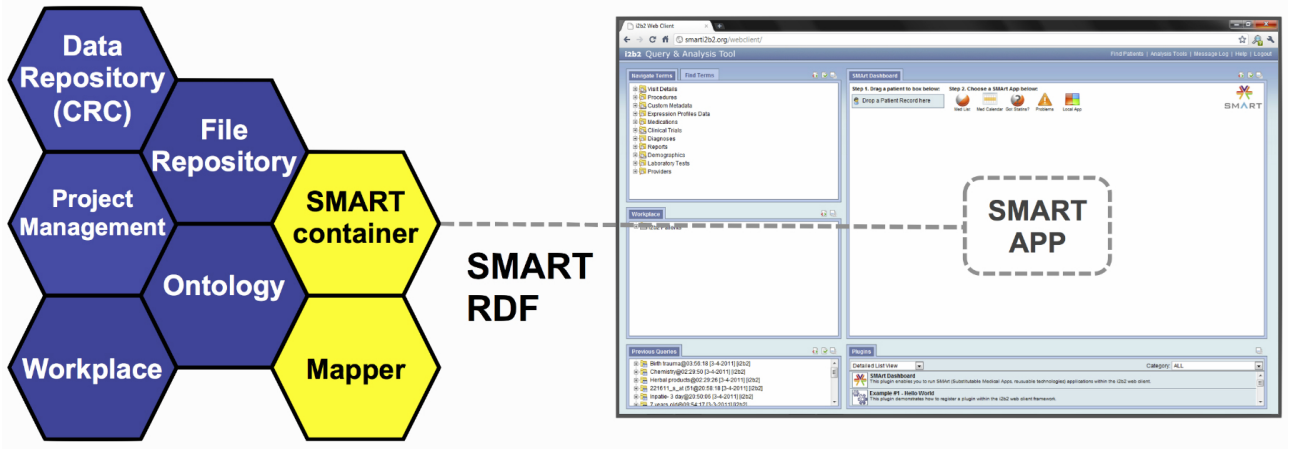


Figure 4. Left: i2b2 hive (blue) with SMART container and Mapper cells (yellow). Right: SMART Patient Centric view for the i2b2 Web interface.



Results

We deployed i2b2 v1.6 in an Amazon-hosted virtual machine with the demonstration terminology dictionary and the 133 fake demonstration patients included in the standard release of i2b2. We then installed the SMART Web client plugin and SMART cells using the previously described "target mapping terms" list that was populated with mappings from this demonstration terminology dictionary. We were able to deploy our summarization app by adding it to the Web server hosting i2b2 and making a few small configuration changes.

To run the app, a user chooses the SMART plugin inside the i2b2 Web client and drags the patient of interest into the Patient Centric view. One can either drag a patient from a customizable patient list (eg, the set of patients for which the user provides care), or from a previously executed research query. The two different options are shown in Figure 5. Once a patient is dragged into the Patient Centric view, the patient summarization app fills the screen (presuming the user has access to this patient's data). The app is shown in Figure 6, and a demo is also included in Multimedia Appendix 1.

During development, we found that the engineered demonstration patients distributed with i2b2 tended to have uncorrelated problems and interventions, probably because they are not based on real patient data but only to meet the goal of testing research queries. Therefore, we developed a new test patient. Because we developed this test patient in i2b2 (using non-SMART terminologies like NDC and ICD-9), she was a patient who utilized the full translation pipeline from i2b2 to SMART, including the Mapper cell. Therefore, although she is still a test patient, we believe she comes close to a real-world i2b2 scenario, where local terms are dynamically mapped to SMART terminology. The app correctly found the problem-medication linkages shown in Table 1.

By SMART-enabling i2b2, we were able to develop a patient summarization app that can run in any i2b2 instance, reusing research data extracted from EHRs for clinical care. SMART-enabled i2b2 could then be launched as a webpage on an EHR workstation to run the summarization app on the current patient. We are finalizing a more streamlined workflow, in which the Patient Centric view can be launched for a particular patient separately from the full i2b2 Web client. This will allow easier access to clinical apps for a patient but still backed by the i2b2-SMART infrastructure.

Table 1. Problem-medication linkages found by the patient summarization app on our i2b2 test patient.

Problem	Medication
Acute bronchitis	Aminophylline 200 mg oral tablet
Pernicious anemia	Vitamin B12 1 mg/ml injectable solution
Seizure	Lamotrigine 100mg oral tablet
Urinary incontinence	Oxybutynin chloride 5 mg oral tablet

Figure 5. The i2b2 Web application with the SMART container activated. A patient can be dragged from a patient list in the workplace (first oval) or from a previous query result (second oval).

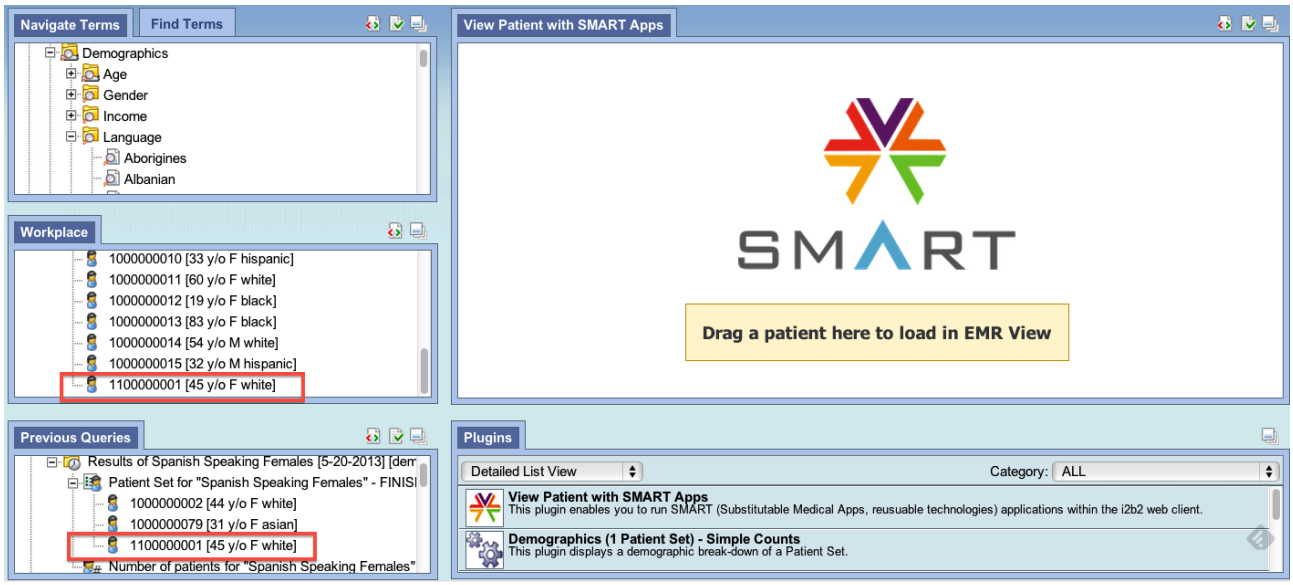
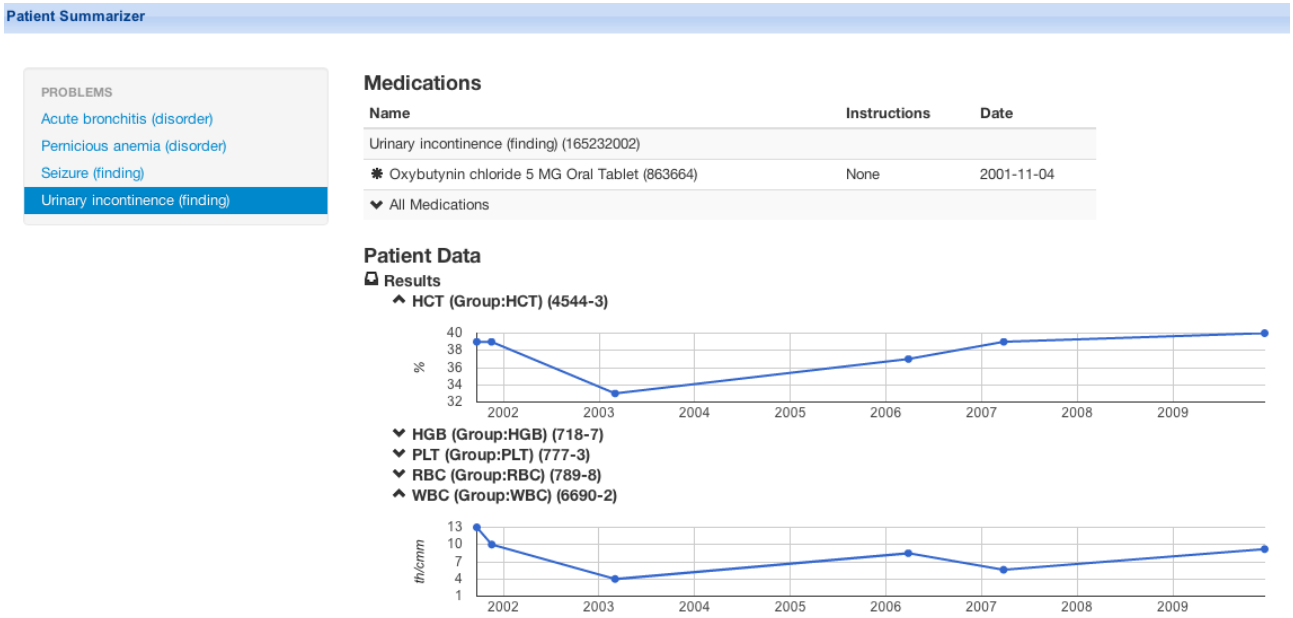


Figure 6. The patient summarization app running inside the SMART-i2b2 container. Shown here: urinary incontinence is highlighted and a relevant medication (oxybutynin) is displayed to the right; lab results are shown as line graphs below.



Discussion

Principal Findings

We successfully created a patient summarization app based on a validated NCCD knowledge base that can be run in nearly any EHR environment. For SMART-enabled EHRs, the app can be run directly within the EHR. In other cases, a SMART-enabled i2b2 instance can be used as a "sidecar" to the EHR, extracting data from it for research and clinical apps like this one. SMART-enabled i2b2 can run in a webpage alongside the EHR. This is certainly beneficial to more than 100 sites using i2b2 worldwide. We also found that online tools

like Google+, GitHub, DropBox, and a cloud-hosted virtual machine increased our ability to collaborate effectively.

SMART has accelerated the implementation and testing of our patient summarization work. This step of our research was previously impeded by the need to maintain multiple apps for various clinical systems, thereby needing to adapt to each system's local ontologies and local API. By choosing SMART, we can now test our knowledge bases using a single clinical app that will run in all SMART-enabled environments. At Partners' Healthcare, this includes both i2b2 data repositories and directly in the outpatient medical record system. We are hopeful that supporting a single SMART app will allow us to disseminate our results both as a raw knowledge bases and as an executable tool.

Broad interest in SMART puts it in a good position to spread in the coming years, either through the demands and requirements of hospital systems, or through smaller EHR vendors implementing it in anticipation of gaining market share. Our hope is that this "sidecar" approach of running clinical apps through i2b2 will help foster SMART, by supporting SMART app development until EHRs adopt the platform. Furthermore, the i2b2 approach might provide SMART-specific functionality that are absent in other clinical systems.. Because i2b2 aggregates many systems' data, it is able to provide more information than individual clinical systems, at the expense of real-time data. A SMART clinical app backed by i2b2 could allow clinicians to, for example, perform comparative effectiveness research on the fly to make treatment decisions for rare combinations of comorbidities [52].

Writing our SMART app was not particularly time-consuming; the majority of the work was developing the SMART-i2b2 container and NCCD knowledge bases. This indicates that SMART might be an ideal platform for quick dissemination of innovative tools. It is also notable that SMART apps will naturally become easier to write as general Internet innovation flourishes, because SMART apps can leverage freely available Web development toolkits such as Bootstrap and the Google Visualization API. While only about a dozen SMART apps have been developed to date, SMART has already enabled small software shops to innovate on EHR data through the SMART "app challenges".

Whether SMART becomes the de facto standard for EHR apps remains to be seen as the platform matures. Already it has several points in its favor. First, it lessens the learning curve of app development by leveraging existing Web standards (eg, JavaScript Object Notation data structures and Web service interfaces). Second, the current API is a straightforward RDF data model designed to meet the needs of app development without trying to solve all use-cases for external views of clinical data. This avoids the steep learning curve of formats such as the Clinical Document Architecture, a health care data standard used for representing all types of clinical data. Third, SMART's current read-only approach will be extended in the future with methods to write data back to the record. SMART enables clinical app innovation by giving app developers access to clinical data elements on individual patients, and it is complemented by data analytical platforms such as i2b2 (for aggregate, research-oriented data repositories and reporting).

Challenges

The greatest challenges we faced in this endeavor occurred in "gluing" the pieces together. The downloadable source code [51], which was in its early stages during development, did not include usable default configuration files and provided scant documentation. However, this has since been resolved. Some user-interface changes were necessary in the app. For example, the SMART-i2b2 container provides a panel of demographic information that the "SMART sandbox" implementation does not. We also modified the app to only display one instance of a problem, because i2b2 returns all historical diagnoses of that problem. We further hid the allergies and vitals sections, which were not supported in SMART-i2b2 when we deployed the app. As discussed, we discovered the developer-engineered i2b2 sample patients were not suitable for problem-oriented analysis, which required that we develop our own. Finally, the SMART API changed several times during development, requiring frequent minor changes to the app. All these issues were associated with platform development, and are not expected to recur.

As the technology matures, installing and developing containers and deploying apps will become simpler. The longer-term challenge for SMART deployments will be terminology mappings. This is a barrier to interoperability in general, and it appears in almost all health information exchange problems in medical informatics—from generating conformant continuity of care documents to consuming quality measure queries. Advanced methods for mapping terminologies are necessary. The i2b2 platform utilizes a mapping tool that extracts terms from the National Center for Biomedical Ontology. This is freely available and has been integrated into the SMART-i2b2 platform [53]. Drawing from tools like these and those provided by the UMLS will be a good starting point, but it is possible that other methods, such as crowdsourcing or probabilistic linkage, will become important in terminology mapping as well.

Future Plans

Previous testing of ontology-based knowledge bases on real patient data showed poor sensitivity [26], which could be partially attributed to information loss during mapping. Once mapped to SMART-approved terminologies, our other knowledge bases (those developed through crowdsourcing, probabilistic linkage, and expert design) could be integrated into the summarization app. We suspect that by combining these knowledge bases (eg, by joining them or with a probabilistic-weighting approach) the coverage of our app will far exceed what we have demonstrated here. At that point, a new evaluation using real patient data would be appropriate.

Also, although we have extended the SMART app beyond the original prototype, it does not yet have the full functionality of the usability-tested prototype interface, nor does it currently have a particularly compelling "look and feel". Beyond further refinement of the user interface, the app will need improvements of its handling of SMART patient data. Our current app simply displays the most recent problem and medication instance rather

than a summary of that problem or medication's history. Also, methods should be developed to incorporate unencoded data into the summary, as SMART does not require every problem or medication to have an associated code.

For the SMART platform as a whole, there are several open questions. One is the level of programming expertise needed to build an app. SMART supports app distribution in an interoperable environment and it lowers the entry threshold for those interested in developing innovative apps. However, we have not yet evaluated what average EHR users can accomplish with SMART. Currently available SMART apps have been written by groups with significant prior programming experience. A second open question is the appropriate distribution model for these apps. The iPhone app store has a certification process, whereas the Android app store does not. Because SMART's goal is to foster innovation, it does not seem wise to restrict distribution of apps. Instead, some type of certification for apps performing key clinical functions might be needed. Currently, the ONC's certification criteria for EHR systems require that any component performing a function for which certification exists must be certified for that function [54]. One approach moving forward might include ONC certification of SMART apps through similar testing mechanisms. However, stringing together many certified technological components does not necessarily mean that the entire system would perform correctly. For example, even if i2b2, its SMART container, and a patient summarization app were all somehow certified, an improper deployment or poor mappings could still cause the app to miss important information in its synthesis. This is a challenging problem that might require more complicated certification criteria.

Conclusions

We have successfully deployed a patient summarization app in the i2b2 clinical data repository platform. This provides a problem-oriented view of the medical record by combining a previously developed knowledge base and the SMART medical apps platform. It leverages co-occurring work in building a SMART-i2b2 container for research, so that this clinical app can be available to the many clinicians whose information systems include i2b2 but do not otherwise have access to SMART. This technical work lays the foundation for a broader ecosystem of reusable apps to provide innovative summary views of the health record. It also provides a "clinical bridge" an i2b2-based pathway for reusable app development that does not require EHR vendors to immediately adopt the SMART API. We hope this will support SMART app development until EHRs adopt the platform.

All software components discussed here are freely available for download, including i2b2, SMART, the SMART-i2b2 integration, and the patient summarization app [30,51].

Acknowledgments

We would like to thank the senior leadership and the software engineers of all three initiatives, who have made this work possible, and SMART's lead architect Josh Mandel, MD, who provided us with portions of Figures 2 and 3. Sponsored by ONC SHARP contracts 10510592 (Patient Centered Cognitive Support) and 90TR0001/01 (Healthcare Application and Network Design).

Conflicts of Interest

None declared.

Multimedia Appendix 1

Screencast demo of patient summarization app running inside SMART-i2b2. This is a primarily a technical demonstration of the system, and the patient shown in the example does not necessarily have comorbidities that are realistic or clinically interesting.

[MOV File, 17MB - ijmr_v2i1e11_app1.mov]

References

1. Chaudhry B, Wang J, Wu S, Maglione M, Mojica W, Roth E, et al. Systematic review: impact of health information technology on quality, efficiency, and costs of medical care. Ann Intern Med 2006 May 16;144(10):742-752. [Medline: 16702590]
2. McDonald CJ, Overhage J, Tierney WM, Dexter PR, Martin DK, Suico JG, et al. The Regenstrief Medical Record System: a quarter century experience. Int J Med Inform 1999 Jun;54(3):225-253. [Medline: 10405881]
3. Miller RA, Waitman LR, Chen S, Rosenbloom ST. The anatomy of decision support during inpatient care provider order entry (CPOE): empirical observations from a decade of CPOE experience at Vanderbilt. J Biomed Inform 2005 Dec;38(6):469-485 [FREE Full text] [doi: 10.1016/j.jbi.2005.08.009] [Medline: 16290243]
4. Mandl KD, Kohane IS. No small change for the health information economy. N Engl J Med 2009 Mar 26;360(13):1278-1281. [doi: 10.1056/NEJMp0900411] [Medline: 19321867]
5. Office of the National Coordinator for Health IT. About the Strategic Healthcare IT Advanced Research Projects (SHARP) URL: http://www.healthit.gov/policy-researchers-implementers/strategic-health-it-advanced-research-projects-sharp [accessed 2012-11-14] [WebCite Cache ID 6CB6KAcOq]

6. Mandl KD, Mandel JC, Murphy SN, Bernstam EV, Ramoni RL, Kreda DA, et al. The SMART Platform: early experience enabling substitutable applications for electronic health records. J Am Med Inform Assoc 2012;19(4):597-603 [FREE Full text] [doi: 10.1136/amiajnl-2011-000622] [Medline: 22427539]
7. Leckart S. Wired Magazine. 2010 Nov 29. The blood test gets a makeover URL: http://www.wired.com/magazine/2010/11/ff_bloodwork/3/ [accessed 2013-05-08] [WebCite Cache ID 6GTBLG5JM]
8. SMART Platforms. BP Centiles URL: http://smartplatforms.org/smart-app-gallery/bp-centiles/ [accessed 2012-11-14] [WebCite Cache ID 6CAmDtg4c]
9. SMART Platforms. 2011. SMART app challenge winner announced URL: http://smartplatforms.org/2011/06/smart-app-challenge-winners-announced/ [accessed 2012-11-14] [WebCite Cache ID 6CAmdD5cJ]
10. Polyglot Systems. Meducation SMART app URL: http://smartapp.meducation.com/ [accessed 2012-11-14] [WebCite Cache ID 6CB63U5al]
11. Thakkar H. The Health 2.0 Developer Challenge. 2012 Aug 07. SMART-Indivo App Challenge URL: http://www.health2con.com/devchallenge/smart-indivo-app-challenge/ [accessed 2013-02-26] [WebCite Cache ID 6Ej9vvdVa]
12. SMART Platforms. 2012 Mar. SMART Health Information Exchanges URL: http://smartplatforms.org/2012/03/smart-health-information-exchanges/ [accessed 2012-11-14] [WebCite Cache ID 6CB6D7le6]
13. SMART Platforms. SMART C-CDA scorecard URL: http://ccda-scorecard.smartplatforms.org/static/ccdaScorecard/ [accessed 2013-05-08] [WebCite Cache ID 6GT4pX5Nj]
14. Wright A, Sittig DF, Ash JS, Sharma S, Pang JE, Middleton B. Clinical decision support capabilities of commercially-available clinical information systems. J Am Med Inform Assoc 2009 Jun;16(5):637-644 [FREE Full text] [doi: 10.1197/jamia.M3111] [Medline: 19567796]
15. Simon SR, Kaushal R, Cleary PD, Jenter CA, Volk LA, Orav EJ, et al. Physicians and electronic health records: a statewide survey. Arch Intern Med 2007 Mar 12;167(5):507-512. [doi: 10.1001/archinte.167.5.507] [Medline: 17353500]
16. Zhou L, Soran CS, Jenter CA, Volk LA, Orav EJ, Bates DW, et al. The relationship between electronic health record use and quality of care over time. J Am Med Inform Assoc 2009;16(4):457-464 [FREE Full text] [doi: 10.1197/jamia.M3128] [Medline: 19390094]
17. Ely JW, Levinson W, Elder NC, Mainous AG, Vinson DC. Perceived causes of family physicians' errors. J Fam Pract 1995 Apr;40(4):337-344. [Medline: 7699346]
18. Weed LL. Medical records that guide and teach. N Engl J Med 1968 Mar 14;278(11):593-600. [doi: 10.1056/NEJM196803142781105] [Medline: 5637758]
19. Hurst JW. Ten reasons why Lawrence Weed is right. N Engl J Med 1971 Jan 7;284(1):51-52. [doi: 10.1056/NEJM197101072840114] [Medline: 5538590]
20. Hurst JW, Walker HK, Hall WD. More reasons why Weed is right. N Engl J Med 1973 Mar 22;288(12):629-630. [doi: 10.1056/NEJM197303222881210] [Medline: 4568846]
21. Bayegan E, Tu S. The helpful patient record system: problem oriented and knowledge based. Proc AMIA Symp 2002;2002:36-40 [FREE Full text] [Medline: 12463782]
22. De Clercq E. Problem-oriented patient record model as a conceptual foundation for a multi-professional electronic patient record. Int J Med Inform 2008 Sep;77(9):565-575. [doi: 10.1016/j.ijmedinf.2007.11.002] [Medline: 18248847]
23. Zeng Q, Cimino JJ, Zou KH. Providing concept-oriented views for clinical data using a knowledge-based system: an evaluation. J Am Med Inform Assoc 2002;9(3):294-305 [FREE Full text] [Medline: 11971890]
24. Laxmisan A, McCoy AB, Wright A, Sittig DF. Clinical summarization capabilities of commercially-available and Internally-developed electronic health records. Appl Clin Inform 2012 Feb 22;3(1):80-93 [FREE Full text] [doi: 10.4338/ACI-2011-11-RA-0066] [Medline: 22468161]
25. Bossen C. Evaluation of a computerized problem-oriented medical record in a hospital department: does it support daily clinical practice? Int J Med Inform 2007 Aug;76(8):592-600. [doi: 10.1016/j.ijmedinf.2006.04.007] [Medline: 16769244]
26. McCoy AB, Wright A, Laxmisan A, Singh H, Sittig DF. A prototype knowledge base and SMART app to facilitate organization of patient medications by clinical problems. AMIA Annu Symp Proc 2011;2011:888-894 [FREE Full text] [Medline: 22195147]
27. Murphy SN, Weber G, Mendis M, Gainer V, Chueh HC, Churchill S, et al. Serving the enterprise and beyond with informatics for integrating biology and the bedside (i2b2). J Am Med Inform Assoc 2010;17(2):124-130 [FREE Full text] [doi: 10.1136/jamia.2009.000893] [Medline: 20190053]
28. Murphy SN, Wattanasin N, Mendis M, Simons W, Churchill S, Kohane I. Supporting multisite clinical trials with software and policy in i2b2. In: AMIA Summit on Clinical Research Informatics Proc. 2012 Mar Presented at: AMIA Summit on Clinical Research Informatics; 2012; San Francisco p. 147.
29. Amazon.com. Amazon Elastic Compute Cloud (Amazon EC2), cloud computing servers URL: http://aws.amazon.com/ec2/ [accessed 2013-02-27] [WebCite Cache ID 6EkTyTGD9]
30. McCoy AB. GitHub. Smart-summarization URL: https://github.com/allisonbmccoy/smart-summarization [accessed 2012-11-16] [WebCite Cache ID 6CEYPMUMp]
31. Dropbox. Dropbox: Simplify your life URL: https://www.dropbox.com/ [accessed 2013-02-27] [WebCite Cache ID 6EkUHdyEw]

32. Google. Google+ URL: http://plus.google.com [accessed 2013-02-27] [WebCite Cache ID 6EkUXal78]
33. Nagarajan R, Kalinka AT, Hogan WR. Evidence of community structure in biomedical research grant collaborations. J Biomed Inform 2013 Feb;46(1):40-46. [doi: 10.1016/j.jbi.2012.08.002] [Medline: 22981843]
34. Carter JS, Brown SH, Erlbaum MS, Gregg W, Elkin PL, Speroff T, et al. Initializing the VA medication reference terminology using UMLS metathesaurus co-occurrences. Proc AMIA Symp 2002;2002:116-120 [FREE Full text] [Medline: 12463798]
35. Burton MM, Simonaitis L, Schadow G. Medication and indication linkage: a practical therapy for the problem list? AMIA Annu Symp Proc 2008;2008:86-90 [FREE Full text] [Medline: 18999215]
36. Brown SH, Miller RA, Camp HN, Guise DA, Walker HK. Empirical derivation of an electronic clinically useful problem statement system. Ann Intern Med 1999 Jul 20;131(2):117-126. [Medline: 10419428]
37. Wright A, Chen ES, Maloney FL. An automated technique for identifying associations between medications, laboratory results and problems. J Biomed Inform 2010 Dec;43(6):891-901. [doi: 10.1016/j.jbi.2010.09.009] [Medline: 20884377]
38. McCoy AB, Wright A, Laxmisan A, Ottosen MJ, McCoy JA, Butten D, et al. Development and evaluation of a crowdsourcing methodology for knowledge base construction: identifying relationships between clinical problems and medications. J Am Med Inform Assoc 2012;19(5):713-718. [doi: 10.1136/amiajnl-2012-000852] [Medline: 22582202]
39. McCoy AB, Wright A, McCoy JA, Sittig DF. Use of the crowdsourcing methodology to generate a problem-laboratory test knowledge base. In: AMIA Annual Symp Proc. 2012 Nov Presented at: AMIA Annual Symposium; 2012; Chicago p. 1859.
40. McCoy AB, Wright A, Sittig DF. Comparison of association rule mining and crowdsourcing for automated generation of a problem-medication knowledge base. 2012 Sep Presented at: The 2nd Annual IEEE International Conference on Healthcare Informatics, Imaging and Systems Biology (HISB); 2012; San Diego p. 125 URL: http://ieeexplore.ieee.org/xpl/articleDetails.jsp?arnumber=6366152 [doi: 10.1109/HISB.2012.50]
41. Wright A, Pang J, Feblowitz JC, Maloney FL, Wilcox AR, Ramelson HZ, et al. A method and knowledge base for automated inference of patient problems from structured data in an electronic medical record. J Am Med Inform Assoc 2011;18(6):859-867 [FREE Full text] [doi: 10.1136/amiajnl-2011-000121] [Medline: 21613643]
42. Chen ES, Hripcsak G, Xu H, Markatou M, Friedman C. Automated acquisition of disease drug knowledge from biomedical and clinical documents: an initial study. J Am Med Inform Assoc 2008 Oct;15(1):87-98 [FREE Full text] [doi: 10.1197/jamia.M2401] [Medline: 17947625]
43. Kilicoglu H, Fiszman M, Rodriguez A, Shin D, Ripple A, Rindflesch TC. Semantic MEDLINE: a Web application for managing the results of PubMed Searches. 2008 Presented at: Third international symposium for semantic mining in biomedicine; 2008; Turku, Finland p. 69-76 URL: http://www.lhncbc.nlm.nih.gov/publication/lhncbc-2008-062
44. Elkin PL, Carter JS, Nabar M, Tuttle M, Lincoln M, Brown SH. Drug knowledge expressed as computable semantic triples. Stud Health Technol Inform 2011;166:38-47. [Medline: 21685609]
45. Duke JD, Friedlin J. ADESSA: A real-time decision support service for delivery of semantically coded adverse drug event data. AMIA Annu Symp Proc 2010;2010:177-181 [FREE Full text] [Medline: 21346964]
46. Mohammad M, Espinosa G, Murphy D, Zhang J. Design and evaluation of a problem-oriented view for OpenVista EHR using UFuRT framework. 2011 Presented at: AMIA Annual Symposium; 2011; Washington, DC p. 1891.
47. Zhang J, Walji MF. TURF: toward a unified framework of EHR usability. J Biomed Inform 2011 Dec;44(6):1056-1067. [doi: 10.1016/j.jbi.2011.08.005] [Medline: 21867774]
48. Google. Google visualization API reference-Google chart tools URL: https://developers.google.com/chart/interactive/docs/reference [accessed 2012-11-16] [WebCite Cache ID 6CEYGf1yB]
49. Wattanasin N, Porter A, Ubaha S, Mendis M, Phillips L, Mandel J, et al. Apps to display patient data, making SMART available in the i2b2 platform. AMIA Annu Symp Proc 2012;2012:960-969 [FREE Full text] [Medline: 23304371]
50. Wright A, Bates DW. Distribution of problems, medications and lab results in electronic health records: the Pareto principle at work. Appl Clin Inform 2010;1(1):32-37 [FREE Full text] [doi: 10.4338/ACI-2009-12-RA-0023] [Medline: 21991298]
51. SMART Platforms. SMART i2b2 demo site URL: http://smarti2b2.org/ [accessed 2012-11-16] [WebCite Cache ID 6CEYL9EsD]
52. Frankovich J, Longhurst CA, Sutherland SM. Evidence-based medicine in the EMR era. N Engl J Med 2011 Nov 10;365(19):1758-1759. [doi: 10.1056/NEJMp1108726] [Medline: 22047518]
53. i2b2 Community Wiki. NCBO ontology tools-i2b2 sponsored project URL: https://community.i2b2.org/wiki/display/NCBO/NCBO%20Ontology%20Tools [accessed 2013-02-27] [WebCite Cache ID 6Ekgu7ENb]
54. Health and Human Services. 77 Federal Register 54163:54163–292. 2012 Sep 04. Health information technology: standards, implementation specifications, and certification criteria for electronic health record technology, 2014 edition; revisions to the permanent certification program for health information technology URL: https://www.federalregister.gov/articles/2012/09/04/2012-20982/health-information-technology-standards-implementation-specifications-and-certification-criteria-for [accessed 2013-05-09] [WebCite Cache ID 6GUkA1FPv]

Abbreviations

API: application programming interface

CDS: clinical decision support
CSS: cascading style sheet
CUI: concept unique identifier
EHR: electronic health records
HIT: health care information technology
HTML: hypertext markup language
i2b2: Informatics for Integrating Biology and the Bedside
ICD-9: International Classification of Diseases, 9th edition
LOINC: Logical Observation Identifier Names and Codes
NCBO: National Center for Biomedical Ontology
NCCD: National Center for Cognitive Informatics and Decision-making
NDF-RT: National Drug File - Reference Terminology
NIH: National Institutes of Health
ONC: Office of the National Coordinator for Health Information Technology
PHP: PHP Hypertext Preprocessor
POMR: problem-oriented medical record
RDF: resource description framework
SHARP: Strategic Health Information Technology Advanced Research Projects
SMART: Substitutable Medical Apps, Reusable Technologies
SNOMED-CT: Systematized Nomenclature of Medicine-Clinical Terms
UMLS: Unified Medical Language System

Edited by G Eysenbach; submitted 09.12.12; peer-reviewed by R Waitman, B Macleod; comments to author 28.01.13; revised version received 28.02.13; accepted 08.05.13; published 30.05.13.

Please cite as:
Klann JG, McCoy AB, Wright A, Wattanasin N, Sittig DF, Murphy SN
Health Care Transformation Through Collaboration on Open-Source Informatics Projects: Integrating a Medical Applications Platform, Research Data Repository, and Patient Summarization
Interact J Med Res 2013;2(1):e11
URL: http://www.i-jmr.org/2013/1/e11/
doi:10.2196/ijmr.2454
PMID:23722634

Original Paper

Severe Loss of Appetite in Amyotrophic Lateral Sclerosis Patients: Online Self-Assessment Study

Teresa Holm[1], MD; André Maier[1], MD; Paul Wicks[2], PhD; Dirk Lang[3], Dipl.-Psych.; Peter Linke[1], MD; Christoph Münch[1], MD; Laura Steinfurth[1], B.Sc; Robert Meyer[1], MD; Thomas Meyer[1], MD

[1]Department of Neurology, Charité, University Hospital, Berlin, Germany

[2]PatientsLikeMe, London, United Kingdom

[3]Department of Psychiatry and Psychotherapy III, University Hospital Ulm, Ulm, Germany

Corresponding Author:
Thomas Meyer, MD
Department of Neurology, Charité
University Hospital
Augustenburger Platz 1
Berlin, 13353
Germany
Phone: 49 30 450 660032
Fax: 49 30 450 560907
Email: Thomas.Meyer@charite.de

Abstract

Background: Undesirable loss of weight is a major challenge in amyotrophic lateral sclerosis (ALS). However, little is known about loss of appetite in ALS patients.

Objective: We investigated loss of appetite in ALS patients by means of an online self-assessment and whether ALS-related symptoms were associated with it.

Methods: Loss of appetite in 51 ALS patients was assessed using the Council on Nutrition Appetite Questionnaire (CNAQ). Loss of appetite is defined as a CNAQ-score of 28 or less with a predicted weight loss of at least 5% within 6 months. We developed an Internet portal to facilitate self-assessment.

Results: Approximately half of the ALS patients (47%, 24/51) suffered from severe loss of appetite; after 6 months this increased to nearly two-thirds (65%, 22/34). An average weight loss of 5% was found in the group with severe loss of appetite as compared to only 2% of patients with normal appetite. Interestingly, loss of appetite was associated with respiratory dysfunction (P=.001, R^2=.223).

Conclusions: Loss of appetite was more common and more severe than expected. It was found to be an independent risk factor for unintended weight loss and may be related to dyspnea. The impact of severe loss of appetite on survival and quality of life should be established in further studies.

(Interact J Med Res 2013;2(1):e8) doi:10.2196/ijmr.2463

KEYWORDS

amyotrophic lateral sclerosis; nutrition; loss of appetite; weight loss; online self-assessment

Introduction

Amyotrophic lateral sclerosis (ALS) is a neurodegenerative disease resulting from the progressive degeneration of upper and lower motor neurons of the spinal cord, the brainstem and the cerebral cortex.

In the course of the disease, 15-55% of patients suffer from clinically severe weight loss [1-4]. Nutritional status is an important prognostic factor for survival in ALS [5-8]; weight loss that leads to a body mass index (BMI) below 18.5 kg/m^2 results in a 7.7 times higher mortality rate, compared to patients with normal weight [5]. The underlying causes of weight loss associated with ALS are heterogeneous [1,6] but are likely to include malnutrition, hypermetabolism, cachexia, and loss of appetite [9-11]. Loss of appetite is a multifactorial syndrome resulting from a number of symptoms such as changes in

controlling eating behavior, depression, and psychological distress [12].

The revised ALS Functional Rating Scale (ALSFRS-R) is an established and internationally used self-assessment questionnaire measuring physical functions of ALS patients in activities of daily living [13]. Based on its simplicity and ability to reflect disease progression, the ALSFRS-R is routinely applied in most clinical trials and in clinical practice. The instrument primarily focuses on the functional impact of muscle weakness, and does not attempt to capture important symptoms such as loss of appetite.

In the clinical setting, ALS patients reported regularly from changes in presenting appetite associated with a decline in caloric intake (with a reduction of the portion size) during the course of the disease. The aim of the present study was to determine the frequency of loss of appetite in ALS patients. This investigation does not claim to validate the Council on Nutrition of Appetite Questionnaire (CNAQ) in ALS. We used an online patient portal to field the CNAQ—a patient reported outcome that records loss of appetite [14]. CNAQ was developed as a short, simple appetite assessment tool in long-term care in institutionalized and community-dwelling adults. The CNAQ has not been deployed in ALS before. Within our study population, we grouped patients according to their ALS-related symptoms to identify risk factors that would be associated with decrease in appetite. We hypothesized that loss of appetite might be associated with dyspnea or dysphagia which are common symptoms in ALS.

Methods

Overview

Between April and November 2010, 51 patients were consecutively recruited at the Department of Neurology at the Charité University Hospital of Berlin. Patients gave written informed consent for their participation. Patients with possible, probable, or definite ALS (according to the revised El Escorial Criteria [15]) were enrolled in the study. Exclusion criteria included lack of Internet access in the patients' environment, patients suffering from consumptive disease or from eating disorder, and patients with enteral feeding. However, patients without Internet connection were able to participate in the trial if the next caregivers provided an alternative Internet access for the online self-assessment. Also patients presenting clinical criteria for cognitive impairment, especially frontotemporal dementia, were not included. These symptoms however, were not explicitly tested. Patients underwent neurological examination and measurements for slow respiratory vital capacity, height, and body weight were taken throughout from ALS outpatients. The ALSFRS-R was obtained during Web visits for monitoring the individual disease progression.

Nutritional Assessment

BMI was calculated by using the formula BMI = weight (kg) / height $(m)^2$. Malnutrition was defined by a BMI less than 18.5 kg/m^2 in ALS patients up to the age of 65 years, a BMI of <20 kg/m^2 in patients over 65 years [2,5], severe weight loss of 3.5% in 3 months, 5% in 6 months, or 10% in 1 year [2,5,16].

Appetite Assessment

The CNAQ was used for measuring loss of appetite. This assessment tool has not been specifically developed and validated for ALS. The CNAQ contains 8 single domain items, each rated on a 5-point scale. Thus, the total score can range between a minimum of 8 and a maximum of 40 points. While lower scores indicate deterioration in appetite, a total score of 28 or less is defined as "severe loss of appetite" and predicts a weight loss of at least 5% within the next 6 months [14]. This prospective questionnaire was developed as a short, simple appetite assessment tool for patients in long-term care in institutionalized and community-dwelling adults. Given the lack of appetite-related sub-scores within the established ALS rating scales, we decided to use the CNAQ, which does not include any motor symptom related items. Therefore, the CNAQ is unlikely to directly reflect difficulty in chewing and swallowing or the motor disability of patients to care for themselves. The CNAQ score contains one question concerning the mood of the patient. Although this item contributes to loss of appetite, it may interfere with other ALS related symptoms since anxiety and depression occasionally occur in ALS.

Online Self-Assessment

In the course of ALS, patients need alternative ways of communicating, especially because of dysarthria and progressing physical impairment. An increasing number of patients rely on novel methods, such as the Internet, for communication; therefore we chose the Internet self-assessment method for completion of questionnaires. The Internet portal ALShome was created as a safe Web application for collecting patient-related data and has been described previously [17]. Patients had controlled access to this website using an automatically generated username and password. Participants were asked to perform online self-assessments once a week over a period of 6 months. The study period was based on the ability of the CNAQ to predict weight loss after 6 months. We used monthly average CNAQ scores for data analysis.

Approval was obtained from the ethical review committee and Data Security Officer from the Ethikkommission der Charité, Universitätsmedizin Berlin, for online self-assessment.

Classification of Patients

The study population was clustered by the occurrence of ALS-associated symptoms. Functional impairment was assessed by the ALSFRS-R; the score contains 12 items, each scored from 0 to 4. According to our hypothesis, we clustered patients into 2 groups based on the following 4 categories within the ALSFRS-R: (1) swallowing impairment (mild to severe vs without), (2) dyspnea (mild to severe vs without), (3) orthopnea (mild to severe vs without), and respiratory insufficiency (using non-invasive ventilation, NIV, vs without NIV). Patients scoring between 0 to 3 points on each single ALSFRS-R item displayed mild to severe physical impairment and were thus classified as '"mild to severe", while patients scoring 4 points were classified as "not functionally affected". Within the group of patients suffering from mild to severe swallowing difficulties, individuals

with percutaneous endoscopic gastrostomy (PEG) were excluded because the CNAQ was, by definition, not applicable in these patients [14].

Data Analysis

Relevant data was recorded via the Web-based database and analyzed with PASW Statistics version 19.0 for Windows. Regarding the CNAQ independent two-sample *t* tests with between subject factor group (patients with "mild to severe" symptoms vs patients "not affected") and within subject factor symptoms (swallowing impairment, dyspnea, orthopnea, and respiratory insufficiency) were performed at baseline. For further analysis a multiple linear regression was applied. For analyzing the BMI data and mean CNAQ scores (baseline vs follow-up) we used the dependent *t* test for paired samples. The significance level was tested using a two-tailed test at P=.05. Mean values and SD are given.

Results

A total of 51 patients were enrolled in this study, including 34 males with the mean age of 58.4 (SD 9.4, range 37-73) years and 17 females with the mean average age 59.1 (SD 7.7, range 42-73) years. The mean disease duration was 31.7 (SD 24.9, range 3-125) months. We included patients with spinal (36/51, 71%), bulbar (13/51, 26%), and axial (2/51, 4%) onset. The baseline characteristics of the 51 patients including neurological, nutritional, and respiratory examination status are presented in Table 1.

During the study period of 6 months, 8 patients underwent PEG. 9 patients died within the observation period. The majority of patients followed the study protocol including self-assessment throughout the 6 months of observation. Because of missing compliance and/or uncertain clinical course, 8 patients terminated the self-assessment prematurely. At baseline, assessment of appetite using the CNAQ revealed a severe loss of appetite (CNAQ≤28) in 47% (24/51) of the participants. The mean CNAQ score was 28.1 (SD 3.9, range 20-33). Participant flow is shown in Figure 1.

Severe loss of appetite (CNAQ≤28) was identified in 59% (17/29) of patients suffering from mild to severe dyspnea (29/51), in contrast to only 32% (7/22) of patients without dyspnea (22/51; t_{49} = 2.610, P=.012, Table 2 and Figure 2).

The multiple linear regression analysis revealed that dyspnea (P=.001, R^2=.223) and age (P=.038, R^2=.223) were significantly correlated with loss of appetite. A similar (though non-significant) trend was found for orthopnea. Among 17 patients with mild to severe orthopnea, 59% (10/17) suffered from loss of appetite, compared to 41 % (14/34) of patients without orthopnea (t_{49}=1.974, P=.060). 12 of our 51 patients were treated with NIV. Fewer NIV-treated patients (5/12, 42%) had severe loss of appetite than patients not treated with NIV (19/39, 49%). However, due to small sample numbers, these results should be interpreted with caution and further study is warranted.

Surprisingly, there was no significant difference on mean CNAQ score within the ALSFRS-R item, swallowing impairment (see Table 2).

Table 1. Descriptive characteristics of the study population during baseline visit. Numbers show mean, SD, and range.

Characteristic	Total n (%) or mean (SD, range)	Male n (%) or mean (SD, range)	Female n (%) or mean (SD, range)
n (%)	51 (100)	34 (67)	17 (33)
Age at onset in years, mean (SD, range)	56.3 (9.2, 36-72)	55.7 (9.5, 36-71)	57.3 (8.5, 38-72)
Duration of disease (months), mean (SD, range)	31.7 (24.9, 3-125)	31.0 (25.6, 3-125)	32.9 (24.2, 9-104)
ALSFRS-R score, mean (SD, range)	33.0 (8.1, 16-47)	32.5 (7.5, 19-47)	34.2 (9.3, 16-44)
Weight (kg), mean (SD, range)	72.5 (14.3, 42-105)	77.9 (13.3, 57-105)	61.8 (9.7, 42-84)
BMI (kg/m^2), mean (SD, range)	23.6 (3.5, 17-32)	24.2 (3.5, 19-32)	22.4 (3.2, 17-29)
Vital capacity, % mean (SD, range)	65.6 (25.4, 14-107)	60 (25.6, 14-107)	75.5 (22.6, 23-107)
Spinal onset, n (%)	36 (71)	26 (77)	10 (59)
Bulbar onset, n (%)	13 (26)	6 (18)	7 (41)
Axial onset, n (%)	2 (4)	2 (6)	0 (0)
NIV, n (%)	12 (24)	9 (27)	3 (18)

Table 2. Descriptive characteristics of the study population during baseline visit and after 6 months divided into CNAQ scores (CNAQ ≤ 28 and CNAQ >28). Numbers show mean, SD, and range.

Characteristics	CNAQ≤28 n (%) or mean (SD, range)	CNAQ>28 n (%) or mean (SD, range)
Female: Male	7:17	10:17
Age at onset, mean (SD, range)	57.8 (10,0, 36-72)	54.4 (8.1, 37-69)
Duration of disease (months), mean (SD, range)	27.7 (23.8, 3-125)	35.1 (25.8, 4-104)
ALSFRS-R score at baseline, mean (SD, range)	33.1 (8.0, 16-47)	33 (8., 16-44)
ALSFRS-R score after 6 months, mean (SD, range)	25.9 (8.5, 15-40)	30.6 (9.0, 17-44)
BMI (kg/m^2) at baseline, mean (SD, range)	23.1 (3.5, 19-32)	24.1 (3.4, 17-32)
BMI (kg/m^2) after 6 months, mean (SD, range)	21.6 (3.3, 17-29)	23.2 (3.7, 18-30)
Vital Capacity at baseline, % mean (SD, range)	64.8 (23.2, 24-103)	70.7 (26.4, 23-107)
Spinal onset, n (%)	20 (83)	16 (59)
Bulbar onset, n (%)	3 (13)	10 (37)
Axial onset, n (%)	1 (4)	1 (4)
NIV, n (%)	4 (17)	8 (30)
Deceased, n (%)	7 (29)	2 (7)

At baseline, malnutrition was diagnosed in 46% (26/51) of the total study population [2,5,16]. 12% (7/51) had an abnormally low BMI and 40 % (23/51) had suffered from severe weight loss in the time leading up to baseline as defined in the methods section.

Loss of appetite worsened over time, with the average value of the CNAQ (mean 28.1, n=51 at baseline) decreasing to a mean of 26.5 (n=31) after 6 months (t_{30}= 3.433, *P*=.002, Figure 3).

At baseline, severe loss of appetite was detected in 47% (24/51) of the patients; after 6 months this increased to 65% (22/34). During the observation period of 6 months, loss of appetite (CNAQ≤28) was associated with weight loss. The mean BMI in the severe loss of appetite group decreased significantly from 22.9 to 21.6 kg/m^2 (t_{15}=3.829, *P*=.002); a significant reduction was also found in the group without loss of appetite (CNAQ>28) with BMI reducing from 24.4 to 23.4 kg/m^2 (t_{17}=3.055, *P*=.007).

However, the high degree of dysphagia in patients may have accounted for changes in the second group (ie, necessitating PEG within the study period). Repeating the analysis only in patients without high degree of dysphagia, the mean BMI in the loss of appetite group (CNAQ≤28) decreased from 23 to 21.8 kg/m^2 (t_{14}=3.467, *P*=.004; Figure 4), whereas in patients without loss of appetite (CNAQ>28; Figure 5) and no severe dysphagia, there was no significant weight loss (BMI 25.0 kg/m^2 at baseline, 24.4 kg/m^2 at follow-up; t_{12}=1.961, *P*=.073).

In conclusion, after correcting for high degree of dysphagia, an average weight loss of 5% occurred after 6 months in the group of patients with a severe loss of appetite (CNAQ≤28), compared to 2% of weight loss in patients with a CNAQ score greater than 28. Additionally, in 24 patients presenting severe loss of appetite at baseline, 7 patients died during the observation period. In contrast, 2 patients of 27, who rated their CNAQ scores higher than 28 at baseline, died.

Figure 1. Flowchart of appetite assessment and main results after 6 months.

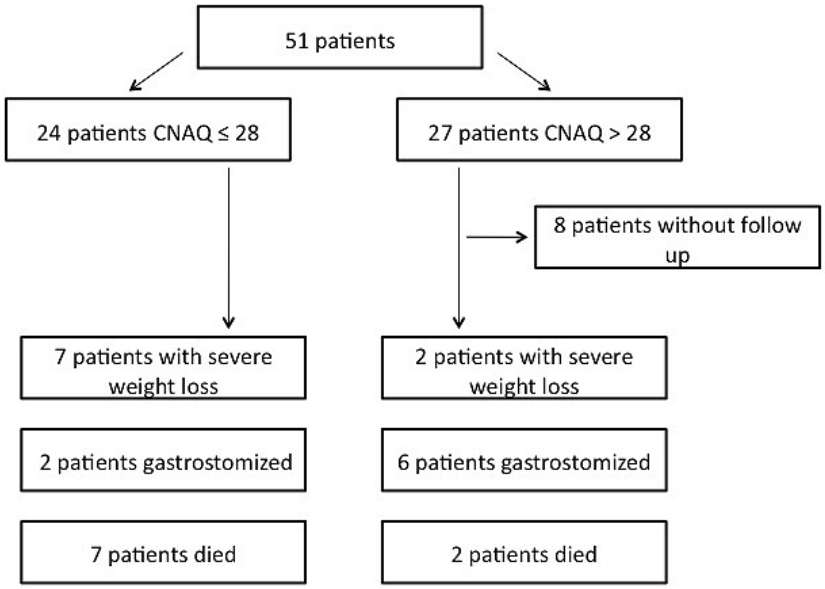


Figure 2. Box plots of CNAQ scores in relation to accordance of dyspnea.

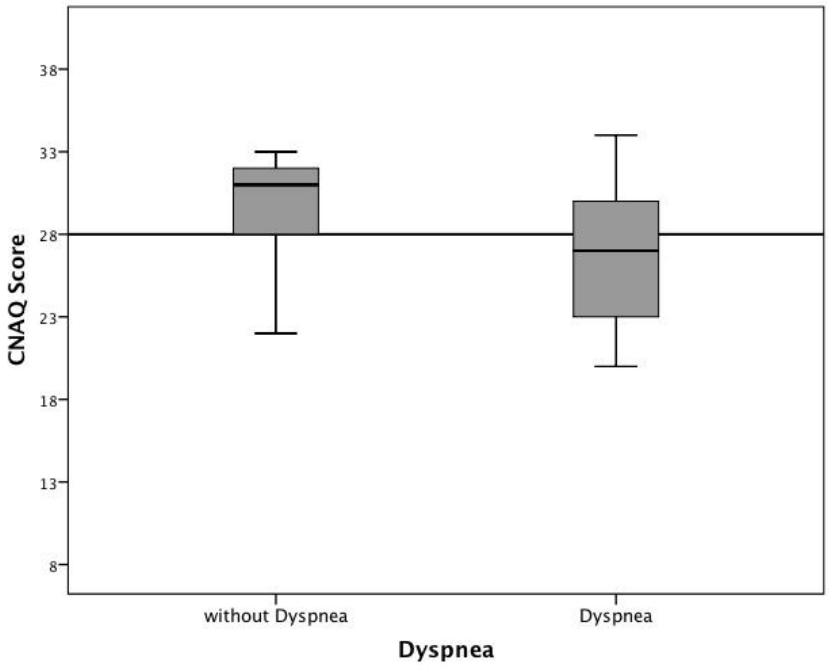


Figure 3. Box plots of CNAQ scores in the course of 6 months; patients receiving PEG (n=8) were excluded in the follow-up.

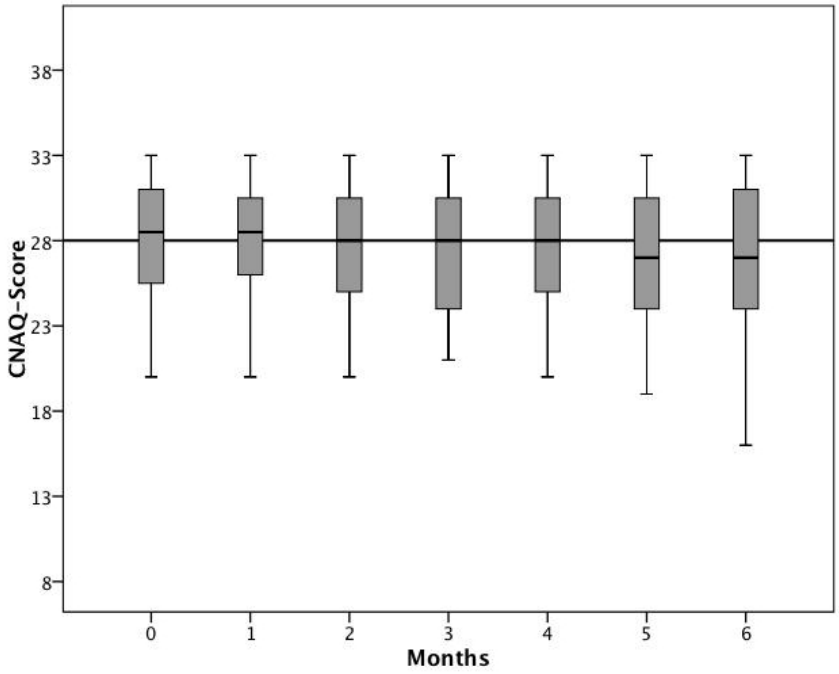


Figure 4. Changes in body weight over the course of 6 months in ALS patients suffering from severe loss of appetite (CNAQ ≤ 28).

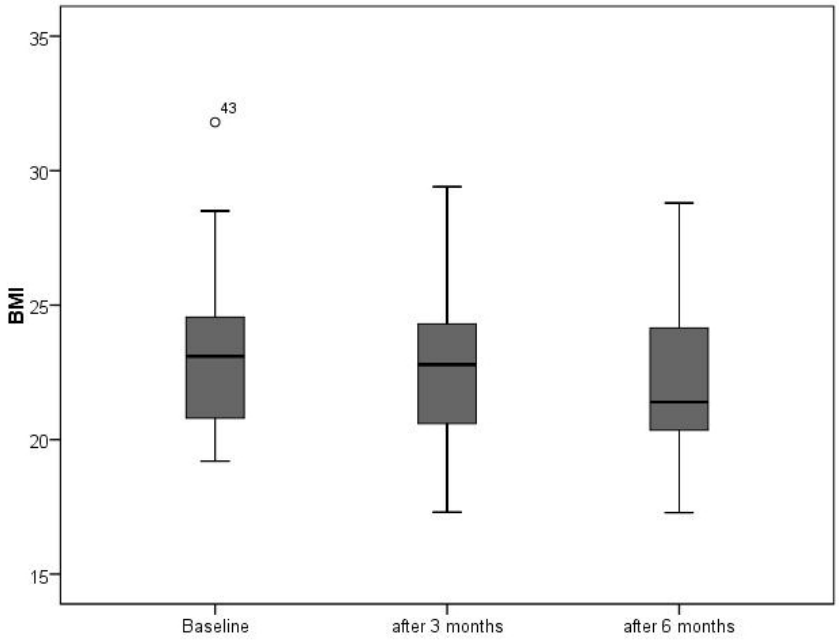
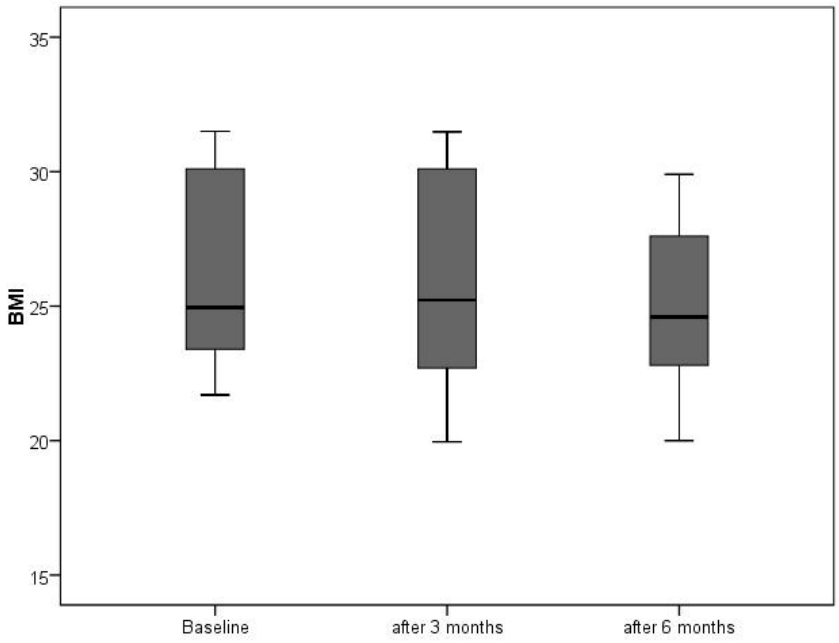


Figure 5. Changes in body weight over the course of 6 months in ALS patients with a CNAQ score > 28.



Discussion

Principal Findings and Conclusions

Appetite is defined as a pleasurable sensation or a desire to eat. For the first time we wanted to measure this feeling in the course of ALS, as it is an important part of quality of life especially in chronic diseases. There have been an increasing number of ALS patients reporting lack of appetite leading to reduced food intake during medical care. Using a combination of clinical examination and online self-assessment, about half of the study population showed severe loss of appetite, defined by a CNAQ score of 28 or less. During the course of the disease, both the prevalence and severity of appetite loss worsened. Our findings contributed to the notion that reduced appetite is a common ALS-associated symptom which may impair the individual capacity to maintain adequate nutrition. Previous reports have estimated weight loss exceeding 15-25% of body weight [3,4]. In fact, malnutrition is one of the most common symptoms and occurs in up to 50% of ALS patients [2]. Our finding of frequent loss of appetite in ALS appears to be in line with the previously reported malnutrition studies in ALS. Earlier work on nutritional status in ALS examined indicators of malnutrition such as weight loss, muscle wasting, body composition, and energy expenditure, but appetite has received little attention. Reduced appetite is a multifactorial syndrome due to changes in physiological eating behavior, but is also reinforced by depression [12]. Reportedly, about 10-20% of ALS patients suffer from depression [18-23]. Although potentially relevant, it is unlikely that depression alone explains the high prevalence of severe loss of appetite. However, it would be useful for future studies to assess depression in ALS to clarify its association with appetite. To our surprise, we did not found a significant correlation of appetite to dysphagia; swallowing impairment is not the leading cause of severe loss of appetite.

In general, the CNAQ was not validated for ALS or other neurological disorders, however, we have chosen this assessment tool because of the absence of motor items. During the past several years, the interest in patient reported outcomes (PRO) has increased. The US Food and Drug Administration released different recommendations for the use of PRO in order to measure the health status, the quality of life, or the evaluation of treatments. There is a need for computer-based symptom related self-assessment from the patients' perspective in order to optimize the treatment, to support the caregivers, and maintain the quality of life in patients better than using surrogate markers. To improve compliance and acceptance in patients, the use of an online self-assessment tool at home in a calm setting may help facilitate communication between the clinicians and their patients. Especially for immobilized patients with chronic diseases or patients in palliative care, an online tool for measuring symptoms and reporting PROs are useful tools for future treatments and studies. Further advantages of an online assessing tool are reliable storage, ubiquitous access, fast transmission, and immediate processing of data. In the sense of already established telemedicine and future infrastructural developments, it would be desirable to have a live interaction between patients and clinicians, with the possibility that clinicians could respond to critical patient information instantly via the Internet.

Our findings correspond with the clinical experience that many patients present with unintentional weight loss and a declining nutritional status, independent of dysphagia. Muscle wasting and cachexia may occur in the early course of ALS, without the presence of bulbar symptoms. Dysphagia was replaced by severe loss of appetite as the independent risk factor for unintended weight loss in ALS. The cause of appetite loss in ALS is not completely understood. Previous studies proposed a correlation between resting energy expenditure and respiratory function [24,25]. In fact, we found a significant association between dyspnea and loss of appetite. Loss of appetite occurred more

often in patients with dyspnea compared to patients without dyspnea. Our observations suggested that increased respiratory effort promotes a loss of appetite. This result may be explained by early satiety after eating small amounts due to ALS-related weakness of the patients' diaphragm [26], supported with evidence from patients with paralysis of the diaphragm who developed peri- or postprandial dyspnea and fatigue [26]. More speculatively, the known change of inflammatory status related to respiratory failure may reduce appetite [12,27-30].

The observed effect of respiratory disturbances is unlikely to be related solely to modifications of patients´ diet due to bulbar dysfunction, since dysphagia was not a risk factor for loss of appetite. In our study, 12 patients using NIV were enrolled. Severe loss of appetite occurred less frequently in the NIV group (42%, 5/12) as compared to patients without NIV (49%, 19/39). Although it is well-known that NIV may reduce energy expenditure and prevent negative effects of dyspnea on satiety, the data of our study did not reach statistical significance and was limited by small sample numbers. However this might be an area worthy of development alongside studies of NIV effectiveness.

Limitations and Further Research

Limitations of the current study included recruitment of patients from a single specialist ALS center, a relatively small sample size (particularly for subgroup analysis), and the absence of detailed dietary or metabolic assessments. Despite the fact that the CNAQ has not been validated in the context of ALS, our results point towards the same direction as the prediction of at least 5% weight loss within 6 months [14]. For validation of the CNAQ within ALS, it would be necessary to examine the quality criteria objectivity, reliability, and validity. It would also be essential to standardize the CNAQ-based results in a representative cohort of ALS patients and to compare them with an equivalent assessment tool. Furthermore, the results of the validation of the CNAQ in ALS patients should be compared with those of the applied CNAQ in long-term care in institutionalized and community-dwelling adults. Additional weaknesses of the paper are the missing assessment of depression as one reason for appetite loss as well as possible cognitive impairments regarding answering the relevant questionnaires during our investigation. These should be addressed in further trials investigating loss of appetite.

However, the results of the study had benefitted from a longitudinal time course, enabled in part by the novel use of an online patient portal to collect clinically validated health data. Such systems have the potential to accelerate clinical research in ALS, whether fielded in the context of clinical management (such as ALSHome. [17]) or an independent platform such as PatientsLikeMe [31,32] because once the infrastructure is in place, there is little or no incremental cost for fielding research surveys, which patients can do at home and in their own time.

Because the etiologies of severe loss of appetite are heterogeneous, several approaches to treatment of reduced appetite have been reported. However, most of the studies have been performed in the context of malnutrition from cachexia in patients with cancer [33]. Pharmacological agents have been investigated in an attempt to favorably affect appetite including progestagens, corticosteroids, cannabinoids, olanzapine, and mirtazapine [33,34]. In ALS, these agents have been rarely used. There are still many questions with regard to the implication of severe loss of appetite and its direct effect on nutritional status, survival, or most importantly, quality of life. Given the open questions, the impact of early satiety and reduced appetite has to be investigated in larger studies. From these studies, we will conclude whether interventions such as appetite-stimulating pharmacotherapy are justified and potentially successful. The timely detection and treatment of loss of appetite may contribute to improved palliation for patients with ALS.

Acknowledgments

The authors thank the study nurses Kerstin Krause, Dorit Strassenburg, and Birgit Koch, the institute for Biometry and Epidemiology under the leadership of Dr. Peter Martus, and the ALS patients for their participation and support.

This study received funding from the German Federal Ministry of Education and Research and the AirBerlin Funds for ALS Research.

Conflicts of Interest

None declared.

References

1. Ludolph AC. 135th ENMC International Workshop: nutrition in amyotrophic lateral sclerosis 18-20 of March 2005, Naarden, The Netherlands. Neuromuscul Disord 2006 Aug;16(8):530-538. [doi: 10.1016/j.nmd.2006.04.005] [Medline: 16701996]
2. Desport JC, Couratier P. [Nutritional assessment in amyotrophic lateral sclerosis patients]. Rev Neurol (Paris) 2006 Jun;162 Spec No 2:4S173-4S176. [Medline: 17128107]
3. Slowie LA, Paige MS, Antel JP. Nutritional considerations in the management of patients with amyotrophic lateral sclerosis (ALS). J Am Diet Assoc 1983 Jul;83(1):44-47. [Medline: 6863783]
4. Mazzini L, Corrà T, Zaccala M, Mora G, Del Piano M, Galante M. Percutaneous endoscopic gastrostomy and enteral nutrition in amyotrophic lateral sclerosis. J Neurol 1995 Oct;242(10):695-698. [Medline: 8568533]
5. Desport JC, Preux PM, Truong TC, Vallat JM, Sautereau D, Couratier P. Nutritional status is a prognostic factor for survival in ALS patients. Neurology 1999 Sep 22;53(5):1059-1063. [Medline: 10496266]

6. Marin B, Desport JC, Kajeu P, Jesus P, Nicolaud B, Nicol M, et al. Alteration of nutritional status at diagnosis is a prognostic factor for survival of amyotrophic lateral sclerosis patients. J Neurol Neurosurg Psychiatry 2011 Jun;82(6):628-634. [doi: 10.1136/jnnp.2010.211474] [Medline: 21097551]
7. Paganoni S, Deng J, Jaffa M, Cudkowicz ME, Wills AM. Body mass index, not dyslipidemia, is an independent predictor of survival in amyotrophic lateral sclerosis. Muscle Nerve 2011 Jul;44(1):20-24. [doi: 10.1002/mus.22114] [Medline: 21607987]
8. Jawaid A, Murthy SB, Wilson AM, Qureshi SU, Amro MJ, Wheaton M, et al. A decrease in body mass index is associated with faster progression of motor symptoms and shorter survival in ALS. Amyotroph Lateral Scler 2010 Dec;11(6):542-548. [doi: 10.3109/17482968.2010.482592] [Medline: 20500116]
9. Desport JC, Preux PM, Magy L, Boirie Y, Vallat JM, Beaufrère B, et al. Factors correlated with hypermetabolism in patients with amyotrophic lateral sclerosis. Am J Clin Nutr 2001 Sep;74(3):328-334 [FREE Full text] [Medline: 11522556]
10. Desport JC, Torny F, Lacoste M, Preux PM, Couratier P. Hypermetabolism in ALS: correlations with clinical and paraclinical parameters. Neurodegener Dis 2005;2(3-4):202-207. [doi: 10.1159/000089626] [Medline: 16909026]
11. Bouteloup C, Desport JC, Clavelou P, Guy N, Derumeaux-Burel H, Ferrier A, et al. Hypermetabolism in ALS patients: an early and persistent phenomenon. J Neurol 2009 Aug;256(8):1236-1242. [doi: 10.1007/s00415-009-5100-z] [Medline: 19306035]
12. Muscaritoli M, Anker SD, Argilés J, Aversa Z, Bauer JM, Biolo G, et al. Consensus definition of sarcopenia, cachexia and pre-cachexia: joint document elaborated by Special Interest Groups (SIG) "cachexia-anorexia in chronic wasting diseases" and "nutrition in geriatrics". Clin Nutr 2010 Apr;29(2):154-159. [doi: 10.1016/j.clnu.2009.12.004] [Medline: 20060626]
13. Cedarbaum JM, Stambler N, Malta E, Fuller C, Hilt D, Thurmond B, et al. The ALSFRS-R: a revised ALS functional rating scale that incorporates assessments of respiratory function. BDNF ALS Study Group (Phase III). J Neurol Sci 1999 Oct 31;169(1-2):13-21. [Medline: 10540002]
14. Wilson MM, Thomas DR, Rubenstein LZ, Chibnall JT, Anderson S, Baxi A, et al. Appetite assessment: simple appetite questionnaire predicts weight loss in community-dwelling adults and nursing home residents. Am J Clin Nutr 2005 Nov;82(5):1074-1081 [FREE Full text] [Medline: 16280441]
15. Brooks BR, Miller RG, Swash M, Munsat TL, World Federation of Neurology Research Group on Motor Neuron Diseases. El Escorial revisited: revised criteria for the diagnosis of amyotrophic lateral sclerosis. Amyotroph Lateral Scler Other Motor Neuron Disord 2000 Dec;1(5):293-299. [Medline: 11464847]
16. Kotler DP. Cachexia. Ann Intern Med 2000 Oct 17;133(8):622-634. [Medline: 11033592]
17. Maier A, Holm T, Wicks P, Steinfurth L, Linke P, Münch C, et al. Online assessment of ALS functional rating scale compares well to in-clinic evaluation: a prospective trial. Amyotroph Lateral Scler 2012 Feb;13(2):210-216 [FREE Full text] [doi: 10.3109/17482968.2011.633268] [Medline: 22292842]
18. Wicks P, Abrahams S, Masi D, Hejda-Forde S, Leigh PN, Goldstein LH. Prevalence of depression in a 12-month consecutive sample of patients with ALS. Eur J Neurol 2007 Sep;14(9):993-1001. [doi: 10.1111/j.1468-1331.2007.01843.x] [Medline: 17718691]
19. Taylor L, Wicks P, Leigh PN, Goldstein LH. Prevalence of depression in amyotrophic lateral sclerosis and other motor disorders. Eur J Neurol 2010 Aug;17(8):1047-1053. [doi: 10.1111/j.1468-1331.2010.02960.x] [Medline: 20158515]
20. McElhiney MC, Rabkin JG, Gordon PH, Goetz R, Mitsumoto H. Prevalence of fatigue and depression in ALS patients and change over time. J Neurol Neurosurg Psychiatry 2009 Oct;80(10):1146-1149. [doi: 10.1136/jnnp.2008.163246] [Medline: 19762902]
21. Rabkin JG, Albert SM, Del Bene ML, O'Sullivan I, Tider T, Rowland LP, et al. Prevalence of depressive disorders and change over time in late-stage ALS. Neurology 2005 Jul 12;65(1):62-67 [FREE Full text] [doi: 10.1212/01.wnl.0000167187.14501.0c] [Medline: 16009886]
22. Trail M, Nelson ND, Van JN, Appel SH, Lai EC. A study comparing patients with amyotrophic lateral sclerosis and their caregivers on measures of quality of life, depression, and their attitudes toward treatment options. J Neurol Sci 2003 May 15;209(1-2):79-85. [Medline: 12686407]
23. Rabkin JG, Wagner GJ, Del Bene M. Resilience and distress among amyotrophic lateral sclerosis patients and caregivers. Psychosom Med 2000 Apr;62(2):271-279 [FREE Full text] [Medline: 10772408]
24. Kasarskis EJ, Berryman S, Vanderleest JG, Schneider AR, McClain CJ. Nutritional status of patients with amyotrophic lateral sclerosis: relation to the proximity of death. Am J Clin Nutr 1996 Jan;63(1):130-137 [FREE Full text] [Medline: 8604660]
25. Shimizu T, Hayashi H, Tanabe H. [Energy metabolism of ALS patients under mechanical ventilation and tube feeding]. Rinsho Shinkeigaku 1991 Mar;31(3):255-259. [Medline: 1909943]
26. Golaszewski A. Nutrition throughout the course of ALS. NeuroRehabilitation 2007;22(6):431-434. [Medline: 18198428]
27. Moreau C, Devos D, Brunaud-Danel V, Defebvre L, Perez T, Destée A, et al. Elevated IL-6 and TNF-alpha levels in patients with ALS: inflammation or hypoxia? Neurology 2005 Dec 27;65(12):1958-1960. [doi: 10.1212/01.wnl.0000188907.97339.76] [Medline: 16380619]

28. Moreau C, Gosset P, Brunaud-Danel V, Lassalle P, Degonne B, Destee A, et al. CSF profiles of angiogenic and inflammatory factors depend on the respiratory status of ALS patients. Amyotroph Lateral Scler 2009 Jun;10(3):175-181. [doi: 10.1080/17482960802651725] [Medline: 19177252]
29. Braun TP, Marks DL. Pathophysiology and treatment of inflammatory anorexia in chronic disease. J Cachexia Sarcopenia Muscle 2010 Dec;1(2):135-145 [FREE Full text] [doi: 10.1007/s13539-010-0015-1] [Medline: 21475703]
30. Laviano A, Seelaender M, Sanchez-Lara K, Gioulbasanis I, Molfino A, Rossi Fanelli F. Beyond anorexia -cachexia. Nutrition and modulation of cancer patients' metabolism: supplementary, complementary or alternative anti-neoplastic therapy? Eur J Pharmacol 2011 Sep;668 Suppl 1:S87-S90. [doi: 10.1016/j.ejphar.2011.06.060] [Medline: 21810420]
31. Wicks P, Massagli MP, Wolf C, Heywood J. Measuring function in advanced ALS: validation of ALSFRS-EX extension items. Eur J Neurol 2009 Mar;16(3):353-359. [doi: 10.1111/j.1468-1331.2008.02434.x] [Medline: 19364363]
32. Wicks P, Vaughan TE, Massagli MP, Heywood J. Accelerated clinical discovery using self-reported patient data collected online and a patient-matching algorithm. Nat Biotechnol 2011 May;29(5):411-414. [doi: 10.1038/nbt.1837] [Medline: 21516084]
33. Mantovani G, Madeddu C. Cancer cachexia: medical management. Support Care Cancer 2010 Jan;18(1):1-9. [doi: 10.1007/s00520-009-0722-3] [Medline: 19688225]
34. Serretti A, Mandelli L. Antidepressants and body weight: a comprehensive review and meta-analysis. J Clin Psychiatry 2010 Oct;71(10):1259-1272. [doi: 10.4088/JCP.09r05346blu] [Medline: 21062615]

Abbreviations

ALS: amyotrophic lateral sclerosis
ALSFRS-R: amyotrophic lateral sclerosis functional rating scale revised
BMI: body mass index
CNAQ: Council on Nutrition Appetite Questionnaire
NIV: non-invasive ventilation
PEG: percutaneous endoscopic gastrostomy
PRO: patient reported outcomes

Edited by G Eysenbach; submitted 03.12.12; peer-reviewed by A Chio, W Brown; comments to author 25.01.13; revised version received 01.02.13; accepted 10.02.13; published 17.04.13.

Please cite as:
Holm T, Maier A, Wicks P, Lang D, Linke P, Münch C, Steinfurth L, Meyer R, Meyer T
Severe Loss of Appetite in Amyotrophic Lateral Sclerosis Patients: Online Self-Assessment Study
Interact J Med Res 2013;2(1):e8
URL: http://www.i-jmr.org/2013/1/e8/
doi:10.2196/ijmr.2463
PMID:23608722

Original Paper

Prevalence of Insomnia Among Residents of Tokyo and Osaka After the Great East Japan Earthquake: A Prospective Study

Hiroaki Sugiura[1*], MD, PhD; Manabu Akahane[1*], MD, PhD; Yasushi Ohkusa[2*], PhD; Nobuhiko Okabe[2*], MD, PhD; Tomomi Sano[1*], MD, PhD; Noriko Jojima[3*], MSN; Harumi Bando[3*], MS; Tomoaki Imamura[1*], MD, PhD

[1]Health Management and Policy, Department of Public Health, Nara Medical University School of Medicine, Kashihara, Japan

[2]National Institute of Infectious Diseases, Infectious Disease Surveillance Center, Tokyo, Japan

[3]Faculty of Nursing, Nara Medical University School of Medicine, Kashihara, Japan

[*]all authors contributed equally

Corresponding Author:
Hiroaki Sugiura, MD, PhD
Health Management and Policy
Department of Public Health
Nara Medical University School of Medicine
840 Shijo-cho
Kashihara, 634-8521
Japan
Phone: 81 744 22 3051 ext 2224
Fax: 81 744 25 7657
Email: tomomarie@smn.enjoy.ne.jp

Abstract

Background: The Great East Japan Earthquake occurred on March 11, 2011. Tokyo and Osaka, which are located 375 km and 750 km, respectively, from the epicenter, experienced tremors of 5.0 lower and 3.0 seismic intensity on the Japan Meteorological Agency scale. The Great East Japan Earthquake was the fourth largest earthquake in the world and was accompanied by a radioactive leak at a nuclear power plant and a tsunami. In the aftermath of a disaster, some affected individuals presented to mental health facilities with acute stress disorder (ASD) and/or post-traumatic stress disorder (PTSD). However, few studies have addressed mental stress problems other than ASD or PTSD among the general public immediately after a disaster. Further, the effects of such a disaster on residents living at considerable distances from the most severely affected area have not been examined.

Objective: This study aimed to prospectively analyze the effect of a major earthquake on the prevalence of insomnia among residents of Tokyo and Osaka.

Methods: A prospective online questionnaire study was conducted in Tokyo and Osaka from January 20 to April 30, 2011. An Internet-based questionnaire, intended to be completed daily for a period of 101 days, was used to collect the data. All of the study participants lived in Tokyo or Osaka and were Consumers' Co-operative Union (CO-OP) members who used an Internet-based food-ordering system. The presence or absence of insomnia was determined before and after the earthquake. These data were compared after stratification for the region and participants' age. Multivariate analyses were conducted using logistic regression and a generalized estimating equation. This study was conducted with the assistance of the Japanese CO-OP.

Results: The prevalence of insomnia among adults and minors in Tokyo and adults in Osaka increased significantly after the earthquake. No such increase was observed among minors in Osaka. The overall adjusted odds ratios for the risk of insomnia post-earthquake versus pre-earthquake were 1.998 (95% CI 1.571–2.542) for Tokyo, 1.558 (95% CI 1.106–2.196) for Osaka, and 1.842 (95% CI,1.514–2.242) for both areas combined.

Conclusions: The prevalence of insomnia increased even in regions that were at a considerable distance from the epicenter. Both adults and minors in Tokyo, where the seismic intensity was greater, experienced stress after the earthquake. In Osaka, where the earthquake impact was milder, disturbing video images may have exacerbated insomnia among adults.

(Interact J Med Res 2013;2(1):e2) doi:10.2196/ijmr.2485

KEYWORDS

insomnia; Web-based survey; population surveillance; disaster; nuclear accidents; earthquakes

Introduction

On March 11, 2011, the Japanese islands sustained a 9.0-magnitude earthquake. Unlike previous major earthquakes in Japan [1,2], this earthquake was followed by a tsunami that devastated the affected areas [3]. More than 20,000 individuals were recorded as dead or missing. The tsunami also caused extensive damage to the Fukushima Daiichi nuclear power plant, resulting in a level 7 nuclear accident [4,5]. This induced considerable anxiety among residents living near the nuclear power plant and among people living as far away as the Tokyo metropolitan area [6]. Images of the tsunami and scenes of the nuclear accident were shown repeatedly on television and the Internet.

In the aftermath of a disaster, people may experience not only physical disorders but also acute stress disorder (ASD), which can persist for up to 4 weeks. Furthermore, chronic post-traumatic stress disorder (PTSD) is common among individuals who have faced such situations [7]. Studies of disaster-related mental disorders typically include an assessment of the prevalence of PTSD, follow-up of patients diagnosed with ASD [8], and a comparison of the numbers of new and previous cases of PTSD in a given area. However, because these studies are usually planned after a disaster, pre-disaster prevalence must be determined retrospectively. A recollection of previous insomnia is likely to be less accurate than the prospective reporting of current symptoms of insomnia, especially during the traumatic aftermath of a disaster.

The current study made use of a daily health survey that was administered to 3128 participants in Tokyo and 1925 participants in Osaka (Table 1) from January 20 to April 30, 2011. One question on the survey specifically asked about the presence or absence of insomnia. Because the Great East Japan Earthquake occurred during the course of this survey, this was a rare opportunity to prospectively assess the impact of an earthquake on the prevalence of insomnia among residents of Tokyo and Osaka.

Table 1. Number of participants according to sex and age group.

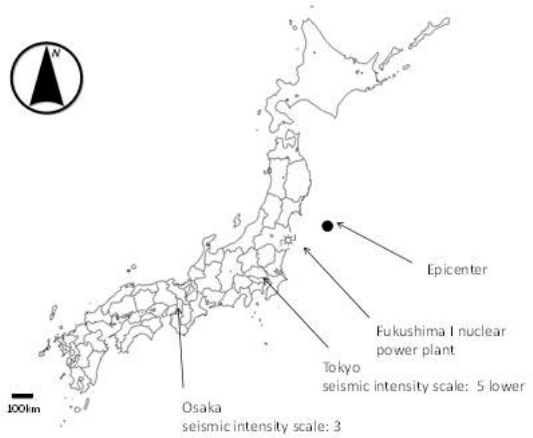
	Tokyo N (male/female)	Osaka N (male/female)
Adults (≥20 years of age)	2073 (999/1074)	1182 (564/618)
Minors (<20 years of age)	1055 (575/480)	743 (373/370)

Methods

Study Period and Locations

This survey began on January 20, 2011 and continued for 101 days until April 30, 2011. The questionnaire collected data related to the individual's health status on the day of the survey, and participants were instructed to complete the survey every day for the duration of the study period. The survey was conducted via an Internet-based questionnaire among residents of the Tokyo metropolitan area and Osaka, the largest city in western Japan. Tokyo is located approximately 375 km from the epicenter of the earthquake (N 38°06′ E 142°51′) and approximately 200 km from the Fukushima Daiichi nuclear power plant (N 37°42′ E 141°03′). The seismic intensity of the main shock in the center of Tokyo, as recorded by the Japan Meteorological Agency (JMA), was 5.0 Lower on the JMA scale [9]. The JMA scale is comprised of 5 phases from 1 to 5. Grades 5 and 6 are further classified into 2 subcategories: upper and lower. During an earthquake with an intensity of 5.0 Lower, people may find it difficult to move around, but major destruction is generally not expected. In contrast, many people find it hard to move during earthquakes with an intensity of 5.0 Upper [9]. Shinjuku Ward, where the offices of the Tokyo Metropolitan Government are located, was subsequently hit by 10 aftershocks that continued until April 16, 2011. The seismic intensity of the aftershocks was ≥3.0, strong enough to be felt by most people inside buildings [9]. Osaka, the other area investigated in the survey, is situated 750 km from the epicenter of the earthquake. The seismic intensity of the main shock was recorded as 3.0 in the offices of the Osaka Prefectural Government. Osaka did not receive any aftershocks with a seismic intensity ≥3.0 (Figure 1).

Figure 1. Map of the locations relevant to this study.



Participants

This study was conducted with the assistance of the Japanese Consumers' Co-operative Union (CO-OP). All respondents who completed the questionnaire lived in Tokyo or Osaka and resided in households that included CO-OP members who placed food orders via the CO-OP website.

Survey Method

This study was conducted with the approval of the Ethics Committee of Nara Medical University (authorization code: 220). The general health condition of the participants, including their sleeping patterns, was investigated using an Internet-based questionnaire. The original aims of this survey were to determine the impact of biological factors, such as infectious diseases, and abiotic factors, such as climate, on the physical condition of residents during the study period. The survey method and data processing methods were described in detail in our previous study [10].

Registration Method

Respondents were recruited through a banner advertisement on the CO-OP's website. Each participant was rewarded with 500 yen (US $1=91.15 yen on the first day of the survey) upon registration for participating in the survey. No remuneration, in the form of cash, was given for providing answers on a daily basis.

Daily Survey Method

The original research plan was to send a reminder email to all the respondents on each day of the survey that would direct them to the website where they could provide their responses. The email was distributed as planned until day 50 of the survey. The Great East Japan Earthquake occurred on day 51 of the survey. The reminder emails were discontinued, as it was decided that the participants, who were recovering from the disaster, should not be burdened. Further responses were left to the participants' discretion during a hiatus period from March 14 to April 5, 2011, when the reminders were reinstituted. After the earthquake, respondents were able to submit descriptions of their physical condition by voluntarily visiting the website.

The daily survey procedure was designed to be simple. After confirming the everyday health condition of the family, participants were asked to access the survey website and answer several questions. The first question asked whether any family member was in poor health. If the participant answered "no", they were excluded from the survey. If the participant answered "yes", they were asked to answer additional "yes" or "no" questions on 19 symptoms; these questions pertained to the individual filling out the questionnaire as well as each member of his or her family [10]. The presence or absence of insomnia was prospectively investigated for 50 days before and 51 days after the Great East Japan Earthquake (including the day of the earthquake).

Statistical Analysis

In both surveyed areas, the prevalence of insomnia was calculated on a daily basis (the number of people reporting symptoms of insomnia divided by the number of responses per day) among people aged <20 years and those aged ≥20 years. Using a chi-square test, the presence or absence of insomnia before and after the earthquake was investigated for any correlation with region or participant age. A multivariate analysis was carried out using logistic regression analysis and a generalized estimating equation. The presence or absence of insomnia was the dependent variable. The independent variables included insomnia occurring after the earthquake, sex, age, region of each participant, the status of reminder emails (sent or not), and the incidence of pollinosis, which plagued approximately 30% of adults in those urban areas during the spring [11]. The statistical analyses were carried out using SPSS version 19.0 (IBM, Chicago, IL, USA).

Results

Response Rate

The mean (SD) daily response rate during the period when reminder emails were sent was 64.17% (5.78%) for Tokyo and 68.31% (5.18%) for Osaka. The response rate did not decline significantly over the course of the study. The response rate during the period when no reminder emails were sent (March 14 to April 5, 2011) was 24.47% (12.97%) for Tokyo and 27.82% (13.55%) for Osaka.

Daily Prevalence of Insomnia

Figures 2 and 3 illustrate the daily prevalence of insomnia in Tokyo and Osaka, respectively, according to age. The figures also indicate the dates of the main earthquake and the aftershocks with seismic intensity ≥3.0. Before the earthquake, the average daily prevalence of insomnia in Tokyo was 1.05% (0.18%) for adults (age ≥20 years) and 0.53% (0.22%) for minors (age <20 years); after the earthquake, this value increased to 2.35% (0.65%) for adults and 1.90% (1.17%) for minors. The maximum seismic intensity of the main earthquake was 5.0 Lower in Tokyo (Figure 2).

Before the earthquake, the average daily prevalence of insomnia in Osaka was 1.25% (0.25%) for adults and 0.092% (0.14%) for minors; after the earthquake, this value increased to 1.83% (0.51%) for adults but remained approximately the same at 0.089% (0.17%) for minors. The maximum seismic intensity of the main earthquake was 3.0 in Osaka (Figure 3).

A chi-square test was conducted to analyze the data according to region and age group. There was a significant increase in the number Tokyo residents who reported symptoms of insomnia after the earthquake (P<.001 for both adults and minors) compared with that before the earthquake. The same findings were reported for adults in Osaka after the earthquake (P<.001). No significant difference was observed among minors in Osaka (Table 2). We conducted a similar chi-square test that excluded the period during which no reminder emails were sent and similar results were obtained.

Table 2. Chi-square analysis according to sex and age.

Region		Chi-square value	Degrees of freedom	*P*	Odds ratio	95% CI
Tokyo	Adults	246.63	1	<.001	2.107	1.916–2.317
	Minors	128.52	1	<.001	2.763	2.301–3.319
Osaka	Adults	34.65	1	<.001	1.438	1.273–1.623
	Minors	0.087	1	.77	1.096	0.595–2.020

Figure 2. Prevalence of insomnia in Tokyo. The prevalence of insomnia increased after the earthquake for both adults and minors in Tokyo.

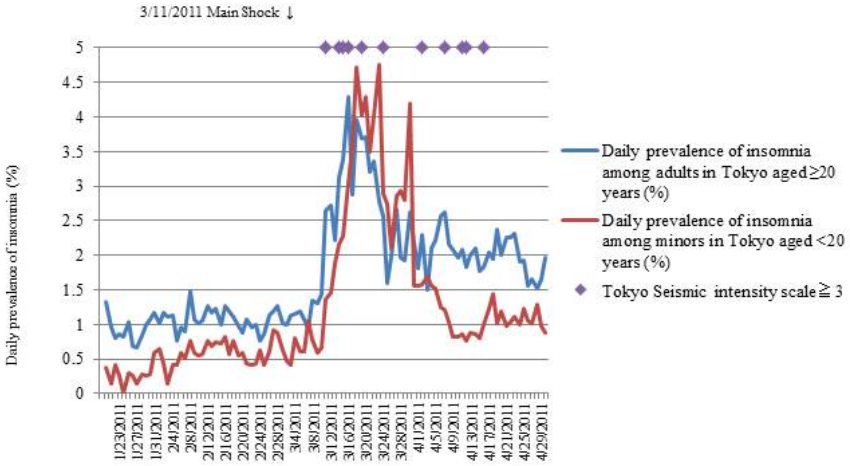
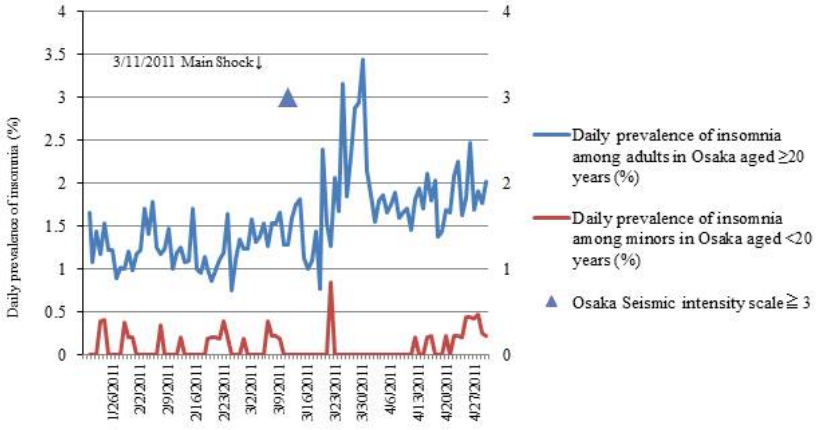


Figure 3. Prevalence of insomnia in Osaka. The prevalence of insomnia among adults increased after the earthquake. The prevalence of insomnia among minors remained approximately the same as that before the earthquake.



Analysis of Factors Associated with the Prevalence of Insomnia

Multivariate analysis was conducted to determine the odds ratios for insomnia (Table 3). The adjusted odds ratios for insomnia after versus before the earthquake were 1.998 (95% CI 1.571–2.542, *P*<.001) for Tokyo, 1.558 (95% CI 1.106–2.196, *P*=.011) for Osaka, and 1.842 (95% CI1.514–2.242, *P*<.001) for the 2 areas combined. Table 3 presents the factors analyzed in this study and their associations with the prevalence of insomnia.

Table 3. Multivariate analysis of factors associated with the prevalence of insomnia.

	Odds ratio	*P*	95% CI
Predictor for sleeplessness [a]			
Post-earthquake vs pre-earthquake	1.842	<.001	1.514–2.242
Age ≥20 years vs age <20 years	2.246	.027	1.095–4.605
Female vs male	1.510	.109	0.912–2.501
Presence vs absence of pollinosis	2.334	.001	1.437–3.791
Tokyo vs. Osaka	1.404	.187	0.848–2.323
No reminder email vs reminder email	1.303	.016	1.050–1.617
Predictor of sleeplessness			
Tokyo			
Post-earthquake vs pre-earthquake	1.998	<.001	1.571–2.542
Age ≥20 years vs age <20 years	1.378	.421	0.631–3.010
Female vs male	1.670	.903	0.90–3.087
Presence vs absence of pollinosis	2.437	.005	1.317–4.509
No reminder email vs reminder email	1.435	.004	1.121–1.838
Osaka			
Post-earthquake vs pre-earthquake	1.558	.011	1.106–2.196
Age ≥20 years vs age <20 years	13.987	<.001	6.408–30.530
Female vs male	1.285	.554	0.554–2.983
Presence vs absence of pollinosis	2.193	.047	1.012–4.751
No reminder email vs reminder email	1.005	.983	0.658–1.535

[a] values are total counts from Tokyo and Osaka

Discussion

Overall

This study examined the prevalence of insomnia among residents in areas that were at different distances from the epicenter of the Great East Japan Earthquake. This is a unique study in that it analyzes the effect of a great earthquake on the rates of insomnia and includes a pre-event baseline in the same group.

Great East Japan Earthquake and Its Impact

Major earthquakes have been common throughout the Asia-Pacific region over the past 2 decades [12,13], with more major earthquakes occurring in Japan than in any other country. In recent decades, 4 particularly large earthquakes have hit Japan, including the Great Hanshin Earthquake of 1995, which hit the Osaka region [1,2,14,15]. The Great East Japan Earthquake was the fourth largest earthquake in the world and was accompanied by 2 major events that could have occurred only in a modern society. First, the earthquake caused a radioactive leak at a nuclear power plant. Second, video images of the ensuing tsunami were recorded, and the footage was shown repeatedly on television; they were also available on the Internet. These images had a profound psychological impact on viewers. In the aftermath of a disaster, affected individuals may present to mental health facilities with ASD and/or PTSD [16-19]. However, few studies have addressed mental stress problems other than ASD or PTSD among the general public immediately after a disaster. Although ASD and PTSD tend to draw greater research attention in studies related to a major disaster, the effects of such a disaster on residents living at considerable distances from the most severely affected area have not been examined. This study revealed an increase in the prevalence of insomnia among the general public immediately after the occurrence of a major earthquake. To our knowledge, this is the first study conducted in Japan that presents longitudinal data on the persistence of insomnia in 2 age groups.

Daily Prevalence of Insomnia in Tokyo and Osaka

The daily prevalence of insomnia increased among both adults and minors in Tokyo after the Great East Japan Earthquake. Although the daily prevalence of insomnia increased among adults in Osaka, a similar increase was not observed among minors. The adjusted odds ratios for insomnia after versus before the earthquake were 1.998 (95% CI 1.571–2.542) for Tokyo, 1.558 (95% CI 1.106–2.196) for Osaka, and 1.842 (95% CI 1.514–2.242) for the 2 areas combined. These results demonstrate an increased prevalence of insomnia among residents in regions located at considerable distances from the immediate zone of the disaster. In Tokyo, where there was no observable infrastructure damage due to the tsunami, 7 people died as a result of the initial tremor. In addition, many people in Tokyo experienced considerable psychological strain for a

prolonged period. Many commuters were stranded because of interrupted transportation services, and there was a high risk of radioactive contamination associated with the nuclear accident. The increased prevalence of insomnia among minors in Tokyo, who are generally less susceptible to stress induced by indirect sources such as media coverage, may be attributable to the effects of the aftershocks. In contrast, the seismic intensity of the main shock in Osaka was 3.0; therefore, direct feelings of fear were likely to be less common, and there was an absence of palpable aftershocks. The prevalence of insomnia among minors in Osaka following the earthquake was not increased, which can be explained by the residents' exposure to fewer direct and local effects. However, an increased number of adults in Osaka reported insomnia. This may have stemmed from exposure to information reported by the media. Other possible causes of insomnia among these adults include anxiety about their future and memories of the disaster caused by the Great Hanshin Earthquake of 1995.

Questionnaire Survey and Its Advantages

A Web-based questionnaire survey was used in the current study because more data are acquired with Internet-based epidemiological surveys than with conventional, paper-based surveys [20,21]. This method was effective in targeting general residents and enabling the acquisition of information from people with medical complaints deemed very mild to warrant a visit to a medical facility. In addition, this survey method was successful because the participants were required to respond only to simple questions regarding the presence or absence of symptoms, thus, the input burden was low. Although a meta-analysis of 68 studies [22] indicated that the normal response rate to Internet-based surveys is low (39.6%), the daily response rate for this study during the period when reminder emails were sent was 64.17% (5.78%) for Tokyo and 68.31% (5.18%) for Osaka. The survey questions were not specifically designed to detect post-disaster psychological conditions, and insomnia was only 1 of several conditions investigated. Participants' responses were limited to the presence or absence of insomnia, and there was no attempt to determine the severity of the condition. Because insomnia was investigated as only 1 of several conditions, participants were unaware that their responses would be used in a study on post-disaster stress, even after the earthquake struck. It is possible, therefore, that the participants were less inclined to answer "yes" to the question about any experience of insomnia symptoms. This possibility is supported by the fact that the average daily prevalence of insomnia among adults before the earthquake was 1.1% in Tokyo and 1.3% in Osaka; these rates are lower than the values reported by an earlier survey on the prevalence of insomnia among Japanese adults [23].

Limitations

Immediately after the earthquake struck, an ethical decision was made to refrain from sending reminder emails. Therefore, the response rate was low during this period. However, no significant difference in the daily prevalence of insomnia correlated with the use of these reminder emails in either Tokyo or Osaka. The chi-square test results were similar between analysis including and excluding this time period. Although the reminder emails were included in the logistic regression analysis as an independent variable, the presence or absence of the reminder emails inevitably remains a limitation of this study and a potential source of bias. However, we believe that this factor had a negligible effect on the results.

Conclusions

This study examined the prevalence of insomnia among residents in areas distant from the epicenter of the Great East Japan Earthquake. In Tokyo, where the seismic intensity was higher, both adults and minors experienced increased rates of insomnia as a direct result of the earthquake and its aftershocks. Further, mental stress induced by information broadcast by the media may have influenced the prevalence of insomnia. In Osaka, where the seismic intensity was lower, only adults exhibited an increased prevalence of insomnia. Health care practitioners should be aware that individuals might experience mental stress, including insomnia, even in areas distant from those that are directly affected by a natural disaster.

Acknowledgments

Financial support for this study was provided by a grant from the Ministry of Health, Labour and Welfare, Japan. We thank the many members of CO-OP for their cooperation with this survey. We also thank Yoshiko Miyake and Mamiko Yoshimura (Department of Public Health, Health Management and Policy, Nara Medical University School of Medicine) for their help with data analysis.

Conflicts of Interest

None declared.

References

1. Maruyama S, Kwon YS, Morimoto K. Seismic intensity and mental stress after the Great Hanshin-Awaji Earthquake. Environ Health Prev Med 2001 Oct;6(3):165-169 [FREE Full text] [doi: 10.1007/BF02897965] [Medline: 21432256]
2. Sekizuka N, Sakai A, Aoyama K, Kohama T, Nakahama Y, Fujita S, et al. Association between the incidence of premature rupture of membranes in pregnant women and seismic intensity of the Noto Peninsula earthquake. Environ Health Prev Med 2010 Sep;15(5):292-298 [FREE Full text] [doi: 10.1007/s12199-010-0142-5] [Medline: 21432558]
3. Shibahara S. The 2011 Tohoku earthquake and devastating tsunami. Tohoku J Exp Med 2011;223(4):305-307 [FREE Full text] [Medline: 21478655]

4. Hirose K. 2011 Fukushima Dai-ichi nuclear power plant accident: summary of regional radioactive deposition monitoring results. J Environ Radioact 2012 Sep;111:13-17. [doi: 10.1016/j.jenvrad.2011.09.003] [Medline: 22119330]
5. Ohnishi T. The disaster at Japan's Fukushima-Daiichi nuclear power plant after the March 11, 2011 earthquake and tsunami, and the resulting spread of radioisotope contamination. Radiat Res 2012 Jan;177(1):1-14. [Medline: 22059981]
6. Goodwin R, Takahashi M, Sun S, Gaines SO. Modelling psychological responses to the Great East Japan earthquake and nuclear incident. PLoS One 2012;7(5):e37690 [FREE Full text] [doi: 10.1371/journal.pone.0037690] [Medline: 22666380]
7. Bryant RA. Acute stress disorder as a predictor of posttraumatic stress disorder: a systematic review. J Clin Psychiatry 2011 Feb;72(2):233-239. [doi: 10.4088/JCP.09r05072blu] [Medline: 21208593]
8. Mills MA, Edmondson D, Park CL. Trauma and stress response among Hurricane Katrina evacuees. Am J Public Health 2007 Apr;97 Suppl 1:S116-S123. [doi: 10.2105/AJPH.2006.086678] [Medline: 17413068]
9. Japan Meteorological Agency. accessed-12-12. 2012. Tables explaining the JMA Seismic Intensity Scale URL: http://www.jma.go.jp/jma/en/Activities/inttable.pdf [accessed 2012-12-12] [WebCite Cache ID 6CrJ8Z3mU]
10. Sugiura H, Ohkusa Y, Akahane M, Sano T, Okabe N, Imamura T. Development of a web-based survey for monitoring daily health and its application in an epidemiological survey. J Med Internet Res 2011;13(3):e66 [FREE Full text] [doi: 10.2196/jmir.1872] [Medline: 21946004]
11. Kaneko Y, Motohashi Y, Nakamura H, Endo T, Eboshida A. Increasing prevalence of Japanese cedar pollinosis: a meta-regression analysis. Int Arch Allergy Immunol 2005 Apr;136(4):365-371. [doi: 10.1159/000084256] [Medline: 15746556]
12. Chen CH, Tan HK, Liao LR, Chen HH, Chan CC, Cheng JJ, et al. Long-term psychological outcome of 1999 Taiwan earthquake survivors: a survey of a high-risk sample with property damage. Compr Psychiatry 2007 Jun;48(3):269-275. [doi: 10.1016/j.comppsych.2006.12.003] [Medline: 17445522]
13. Roy N. The Asian Tsunami: PAHO disaster guidelines in action in India. Prehosp Disaster Med 2006 Oct;21(5):310-315. [Medline: 17297900]
14. Hyodo K, Nakamura K, Oyama M, Yamazaki O, Nakagawa I, Ishigami K, et al. Long-term suicide mortality rates decrease in men and increase in women after the Niigata-Chuetsu earthquake in Japan. Tohoku J Exp Med 2010 Feb;220(2):149-155 [FREE Full text] [Medline: 20139666]
15. Shinfuku N. Disaster mental health: lessons learned from the Hanshin Awaji earthquake. World Psychiatry 2002 Oct;1(3):158-159 [FREE Full text] [Medline: 16946841]
16. Cairo JB, Dutta S, Nawaz H, Hashmi S, Kasl S, Bellido E. The prevalence of posttraumatic stress disorder among adult earthquake survivors in Peru. Disaster Med Public Health Prep 2010 Mar;4(1):39-46. [Medline: 20389194]
17. Neria Y, Nandi A, Galea S. Post-traumatic stress disorder following disasters: a systematic review. Psychol Med 2008 Apr;38(4):467-480. [doi: 10.1017/S0033291707001353] [Medline: 17803838]
18. Pyari TT, Kutty RV, Sarma PS. Risk factors of post-traumatic stress disorder in tsunami survivors of Kanyakumari District, Tamil Nadu, India. Indian J Psychiatry 2012 Jan;54(1):48-53 [FREE Full text] [doi: 10.4103/0019-5545.94645] [Medline: 22556437]
19. Varela E, Koustouki V, Davos CH, Eleni K. Psychological consequences among adults following the 1999 earthquake in Athens, Greece. Disasters 2008 Jun;32(2):280-291. [doi: 10.1111/j.1467-7717.2008.01039.x] [Medline: 18380855]
20. Ekman A, Dickman PW, Klint A, Weiderpass E, Litton JE. Feasibility of using web-based questionnaires in large population-based epidemiological studies. Eur J Epidemiol 2006;21(2):103-111. [doi: 10.1007/s10654-005-6030-4] [Medline: 16518678]
21. Schleyer TK, Forrest JL. Methods for the design and administration of web-based surveys. J Am Med Inform Assoc 2000 Aug;7(4):416-425 [FREE Full text] [Medline: 10887169]
22. Cook C, Heath F, Thompson RL. A meta-analysis of response rates in web- or internet-based surveys. Educ Psychol Meas 2000 Dec;60:821-836. [doi: 10.1177/00131640021970934]
23. Kim K, Uchiyama M, Okawa M, Liu X, Ogihara R. An epidemiological study of insomnia among the Japanese general population. Sleep 2000 Feb 1;23(1):41-47. [Medline: 10678464]

Abbreviations

ASD: acute stress disorder
CO-OP: Consumers' Co-operative Union
JMA: Japan Meteorological Agency
PTSD: post-traumatic stress disorder

Edited by G Eysenbach; submitted 14.12.12; peer-reviewed by M Keim, J Brice; comments to author 07.01.13; revised version received 13.01.13; accepted 13.01.13; published 18.01.13.

Please cite as:
Sugiura H, Akahane M, Ohkusa Y, Okabe N, Sano T, Jojima N, Bando H, Imamura T
Prevalence of Insomnia Among Residents of Tokyo and Osaka After the Great East Japan Earthquake: A Prospective Study
Interact J Med Res 2013;2(1):e2
URL: http://www.i-jmr.org/2013/1/e2/
doi:10.2196/ijmr.2485
PMID:23612152

Viewpoint

Growing Concerns With the Flow of Misinformation From Electronic Books

Kenzo Takahashi[1,2*], MD, MHS, PhD; Hideyuki Kanda[1*], MD, MPH, PhD; Shunsaku Mizushima[1*], MD, PhD

[1]Department of Epidemiology and Public Health, Graduate School of Medicine, Yokohama City University, Yokohama, Japan

[2]Advanced Medical Research Center, Yokohama City University, Yokohama, Japan

[*]all authors contributed equally

Corresponding Author:
Kenzo Takahashi, MD, MHS, PhD
Department of Epidemiology and Public Health
Graduate School of Medicine
Yokohama City University
3-9 Fukuura, Kanazawa-ku
Yokohama, 236-0004
Japan
Phone: 81 45 787 2610
Fax: 81 45 787 2609
Email: kt_intl_@ja2.so-net.ne.jp

Abstract

In 2012, several kinds of electronic books (e-books) became available in Japan. Since several major book retailers launched e-book businesses, it is expected that e-books will become a popular source of information in the country. However, we are concerned that e-books may also be a source of misinformation. In examining 24 available materials published by anti-vaccinists, "atopy businesses", and "wellness maintenance" authors, each was found to contain inaccuracies or misinformation. Thus far, such information is only available in printed books. If these books are scanned and circulated, or published in e-book format, this misinformation may circulate rapidly as e-book devices are becoming popular, and, consequently, harm people's health. We think that it is important for the government to formulate ethical guidelines for the publishing e-books with due consideration to freedom of expression.

(Interact J Med Res 2013;2(1):e10) doi:10.2196/ijmr.2541

KEYWORDS

misinformation; e-book; ethical guideline; anti-vaccinists; atopy business; wellness maintenance

Introduction

In 2012, several electronic book (e-book) devices became widely available in Japan [1]. Even though several e-book devices were previously available, it is expected that newly introduced e-books will become more popular because the devices are sold by some of the more popular book retailers in Japan who provide free access to retail websites. Their business model is designed to provide easier access to e-books than ever before. The only thing that a user has to do is to register a payment method. In 2016, it is expected that the number of e-book users will grow to 5 million (via e-book reader), 27 million (via tablet devices), and 80 million (via smartphone) [2]. Thus, it is expected that e-books will make access to information media more convenient.

In this regard, we are concerned that e-books may be a source of misinformation. Now that several self-publishing manuals are available, circulation of individual ideas without any scientific evidence via e-books is easy. In this article, we reviewed 3 topics of misinformation circulated by printed books that have been observed in Japan, and finally conclude that an ethical guideline for e-book publications should be considered.

We searched and examined all the printed books written in Japanese that were accessible via the Internet (in total 24 books). In this paper, we will discuss the 3 major topics of concern.

Vaccination

The first example of concern is vaccination (8 books). Japan has long history of distrust of vaccines [3-5]. Several anti-vaccinists, some with medical licenses and others without, published books that suggest that it is inappropriate for readers to vaccinate their children. Their structure of argument usually

contains both correct information and false recommendations and concluded that government recommendations are unsound. For example, some publications asserted that mumps vaccine is not recommended and natural infection is better than vaccine for acquiring immunity. They stand on the fact that low quality mumps vaccines caused severe side effects with poor prognosis including death. The current vaccine is recognized as safe. However, the aforementioned authors asserted that the data quality is not reliable. In addition, they did not alert readers to the risk of permanent hearing loss attached to mumps infection, for example. They asserted that severe consequences seldom occur since the number of reported cases is decreasing. They also claimed that even the measles vaccine is not necessary. Their point is that children can still be infected by measles even if they received the measles vaccine because immunity may diminish within several years after injection. In addition, they introduced a case of subacute sclerosing pan encephalitis that may have been caused by the measles vaccine and pointed out that the measles vaccine should not be recommended to all children because of its severe side effects. However, available epidemiological data including genotyping data do not suggest the measles vaccine virus as a possible cause of subacute sclerosing pan encephalitis [6]. The problem with this publication is that their discussions lack stochastic consideration. However, readers who do not recognize this flaw may follow these anti-vaccine recommendations, leaving their children vulnerable to vaccine targets.

Atopy Businesses

The second example is the "atopy businesses" (8 books) [7,8]. As the term "business" implies, books containing "atopy business" information are published for commercial reasons. They try to sell alternative therapy products such as specially treated foods, specially treated creams, and hot spring waters. They would show examples of rare cases of severe atopic dermatitis in a sensationalistic manner, and then conclude that steroids are a cause of severe diseases and should not be applied to human skin. Some of these publications claimed that, if the patients were left untreated by their products or treated by steroids, they would be sure to suffer from atopic dermatitis. An alternative therapy, that is, their own products, would be recommended. To high information seekers such as parents who worry about their children with or acquiring allergies [9], these texts look impressive and trustworthy. However, these alternatives are not medically evaluated and are generally expensive. Patients following these unproven treatment regimens would suffer financially and physically, as their conditions may worsen with these new treatments.

Wellness Maintenance Books

The third example is "wellness maintenance books"(8 books). These books are written by qualified medical doctors and demonstrate how to live a healthy life by following some extreme life habits. In one example, the author recommended that readers eat food only once a day, leaving one's body fasted. The possibility and concerns related to the consequence of hypoglycemia or hypoalbuminemia, for example, were not thoroughly discussed. In addition, they claimed that malnutrition could be averted by eating foods in their natural state, including unpeeled vegetables and unprocessed fish with the fish head or internal organs because the authors maintain that they are perfect nutritional foods in their natural form.

Ethical Publishing Guidelines

Some of the above mentioned content is already sold in e-book format [10]. However, in cases where they are not sold in an electronic format, used books are still sold through the Internet [11]. People may take advantage of the convenience of e-books due to the availability of self-publishing manuals, scan these books, and sell them illegally (sale of scanned books is illegal in Japan). To make matters worse, the public may write and publish their own e-books with misleading content, thus facilitating the dissemination of misinformation.

As Geraldine et al observed, “written information on medicines can be interpreted by consumers in ways that may lead to anxiety or apprehension, and a refusal of prescribed medicines” [12]. Thus, the prevalence of e-books may have a detrimental impact on human health. Fortunately, at the time of writing this paper, these books are not yet published electronically. While it is an ideal time to create legislation to punish publishers/authors who caused harmful effects to people’s health, it is difficult to judge the causal relationships between published books and health effects. We recommend that the government should promptly formulate ethical guidelines targeted at the content of e-books, listing that disputable information that should not be allowed in e-books with due consideration to freedom of expression/publication. Publishing associations should be watchful of the material that they publish based on the stated ethical guidelines and control the distribution of disreputable e-books.

Acknowledgments

This work was partly supported by the grant for Research and Development Project III (No. 13) of Yokohama City University, Japan.

Conflicts of Interest

None declared.

References

1. White paper information and communications in Japan. Tokyo: Ministry of internal affairs and communication; 2012 Mar 9. URL: http://www.soumu.go.jp/main_sosiki/joho_tsusin/eng/Releases/Telecommunications/130305_02.html [accessed 2013-05-22] [WebCite Cache ID 6GoMUQHKF]
2. Institute of Internet Media. eBook Marketing Report 2012 (Japanese). Tokyo, Japan: Impress R&D company; Jul 26, 2012.
3. Parry J. No vaccine for the scaremongers. Bull World Health Organ 2008 Jun;86(6):425-426 [FREE Full text] [Medline: 18568268]
4. Igarashi T. Science Links Japan. 2008 Feb. A vaccination system below the global standard URL: http://sciencelinks.jp/content/view/607/241/ [accessed 2013-05-09] [WebCite Cache ID 6GU06eCTO]
5. Takahashi K, Ohkusa Y, Kim JY. The economic disease burden of measles in Japan and a benefit cost analysis of vaccination, a retrospective study. BMC Health Serv Res 2011;11:254 [FREE Full text] [doi: 10.1186/1472-6963-11-254] [Medline: 21978107]
6. World Health Organization. Subacute sclerosing panencephalitis and measles vaccination. Weekly Epidemiological Records 2006;81(2):17-18.
7. Takehara K. [Modification evil drug of topical steroid and atopy business]. Arerugi 2001 Aug;50(8):654-656. [Medline: 11579516]
8. Kaburagi Y, Shimada Y, Takehara K. An investigation of the views about atopy business in atopic dermatitis patients. Jpn J Dermatol 2000;110(8):1277-1282.
9. Bernhardt JM, Felter EM. Online pediatric information seeking among mothers of young children: results from a qualitative study using focus groups. J Med Internet Res 2004 Mar 1;6(1):e7 [FREE Full text] [doi: 10.2196/jmir.6.1.e7] [Medline: 15111273]
10. Nagumo Y. [Hunger makes people healthy]. Tokyo: Sun Mark publishing; 2012.
11. Ogawa H. [Understanding how to treat atopic dermatitis-Parol evidence by 3500 patients who recovered from steroid epidemic]. Tokyo: Kanki-publishing; 1994.
12. Peterson G, Aslani P, Williams KA. How do consumers search for and appraise information on medicines on the Internet? A qualitative study using focus groups. J Med Internet Res 2003 Dec 19;5(4):e33 [FREE Full text] [doi: 10.2196/jmir.5.4.e33] [Medline: 14713661]

Edited by G Eysenbach; submitted 21.01.13; peer-reviewed by C Bermúdez-Tamayo, D Zulman; comments to author 13.02.13; revised version received 18.03.13; accepted 27.04.13; published 24.05.13.

Please cite as:
Takahashi K, Kanda H, Mizushima S
Growing Concerns With the Flow of Misinformation From Electronic Books
Interact J Med Res 2013;2(1):e10
URL: http://www.i-jmr.org/2013/1/e10/
doi:10.2196/ijmr.2541
PMID:23709125

Original Paper

Identifying Measures Used for Assessing Quality of YouTube Videos with Patient Health Information: A Review of Current Literature

Elia Gabarron[1,2], MS(Psycho); Luis Fernandez-Luque[3], MSc; Manuel Armayones[4], PsyD; Annie YS Lau[5], PhD

[1]NST-Norwegian Centre for Integrated Care and Telemedicine, University Hospital of North Norway, Tromsø, Norway

[2]Department of Clinical Medicine, Faculty of Health Sciences, University of Tromsø, Tromsø, Norway

[3]Norut, Tromsø, Norway

[4]PSiNET Research Group, Internet Interdisciplinary Institute (IN3), Open University of Catalonia, Barcelona, Spain

[5]Centre for Health Informatics, Australian Institute of Health Innovation, University of New South Wales, Sydney, Australia

Corresponding Author:
Elia Gabarron, MS(Psycho)
NST-Norwegian Centre for Integrated Care and Telemedicine
University Hospital of North Norway
P.O. Box 35
Tromsø, 9038
Norway
Phone: 47 07766
Fax: 47 77 75 40 98
Email: elia.gabarron@telemed.no

Abstract

Background: Recent publications on YouTube have advocated its potential for patient education. However, a reliable description of what could be considered quality information for patient education on YouTube is missing.

Objective: To identify topics associated with the concept of quality information for patient education on YouTube in the scientific literature.

Methods: A literature review was performed in MEDLINE, ISI Web of Knowledge, Scopus, and PsychINFO. Abstract selection was first conducted by two independent reviewers; discrepancies were discussed in a second abstract review with two additional independent reviewers. Full text of selected papers were analyzed looking for concepts, definitions, and topics used by its authors that focused on the quality of information on YouTube for patient education.

Results: In total, 456 abstracts were extracted and 13 papers meeting eligibility criteria were analyzed. Concepts identified related to quality of information for patient education are categorized as expert-driven, popularity-driven, or heuristic-driven measures. These include (in descending order): (1) quality of content in 10/13 (77%), (2) view count in 9/13 (69%), (3) health professional opinion in 8/13 (62%), (4) adequate length or duration in 6/13 (46%), (5) public ratings in 5/13 (39%), (6) adequate title, tags, and description in 5/13 (39%), (7) good description or a comprehensive narrative in 4/13 (31%), (8) evidence-based practices included in video in 4/13 (31%), (9) suitability as a teaching tool in 4/13 (31%), (10) technical quality in 4/13 (31%), (11) credentials provided in video in 4/13 (31%), (12) enough amount of content to identify its objective in 3/13 (23%), and (13) viewership share in 2/13 (15%).

Conclusions: Our review confirms that the current topics linked to quality of information for patient education on YouTube are unclear and not standardized. Although expert-driven, popularity-driven, or heuristic-driven measures are used as proxies to estimate the quality of video information, caution should be applied when using YouTube for health promotion and patient educational material.

(Interact J Med Res 2013;2(1):e6) doi:10.2196/ijmr.2465

KEYWORDS

YouTube; patient education; Internet; health education; quality of information

Introduction

Founded in February 2005, YouTube is a free video-sharing site that allows people to find, view, and share videos [1]. It also provides new opportunities for people to connect, collaborate, create, circulate, and disseminate original media creations [2].

Currently, YouTube has over 100 million videos, and has become a valuable resource to find videos containing personal stories about health and illnesses [3]. Its power to disseminate personalized health education and health communication messages cannot be underestimated [4]. One of the main features of YouTube is that anyone can publish a video, regardless of their background, medical qualifications, professionalism, or intention, and therefore health information available on YouTube can range from high quality to sales propaganda or pseudo-scientific scams [5-8].

Taking into account the exponential growth and popularity of YouTube, it has been suggested this video-sharing site could be considered an effective channel and a powerful tool for health education. While the most popular use of YouTube at present is primarily for entertainment sources, as people become increasingly comfortable and familiar with social media sites, the number of people using social media for health purposes will likely rise. In fact, a recent report from the Pew Internet & American Life Project showed that 72% of online 18-29 year olds use social networking websites, and that 31% of online teens (aged 12-17) get their information on health, dieting, or physical fitness from the Internet [9]. Coupled with the recent review which found that there are at least 5 areas of safety concerns identified in health-related videos on YouTube [7], it is important to identify how quality of information is currently being assessed in social media for health purposes.

Studies are emerging to recognize the role and relevance of YouTube for health promotion [10,11] or educating patients on specific conditions [12-15]. Efforts have been made to standardize publication of health videos on YouTube; for example, the Centers for Disease Control and Prevention (CDC) has a specific guideline for publishing on YouTube and other online video sites [4]. However, different users may have different concepts of information quality. As Purcell et al observed, "the quality of information, like beauty, is in the eye of the beholder, and it is users' views we should be seeking" [16]. On the Internet, measures to standardize the thoroughness and reliability of medical information websites has been developed, such as the certificate of quality Health on the Net Foundation Code of Conduct (HONcode) [17] in which an expert committee checks that ethical principles are met, and if so, this website can display the logo accrediting its quality. Research on this certificate showed that it represents a guarantee for consumers regarding trustworthy, ethical, quality, and transparent health information [18,19]. But, at present, a similar system of trustworthy or a reliable description of what could be considered quality information for patient education on YouTube is absent. The objective of this review was to identify topics associated with the concept of quality information for patient education on YouTube in the scientific literature.

Methods

Overview

A conscientious literature review by adapting the systematic review approach was performed on the concept of quality of information for patient education on YouTube. The electronic databases consulted were MEDLINE, ISI Web of Knowledge, Scopus, and PsychINFO. Since research on the use of YouTube for patient education is limited, we gave priority to primary sources that were published in peer-reviewed journals providing outcome data.

Search Strategy

Two search strategies were used in MEDLINE, one based on the use of only Medical Subject Headings (MeSH) and the second based on text-word searches. For the first search, researchers used the following MeSH terms: Internet; Health Communication; Health Literacy, Personal Satisfaction; Information Literacy; Access to Information; Consumer Health Information; Communications Media; and Computer Communication Networks. These terms were combined with the word "YouTube" limited to publications in English. For the second search, free terms were used: YouTube; and quality of information; health; healthcare; and patient education in combination with YouTube, and also limited to publications in English.

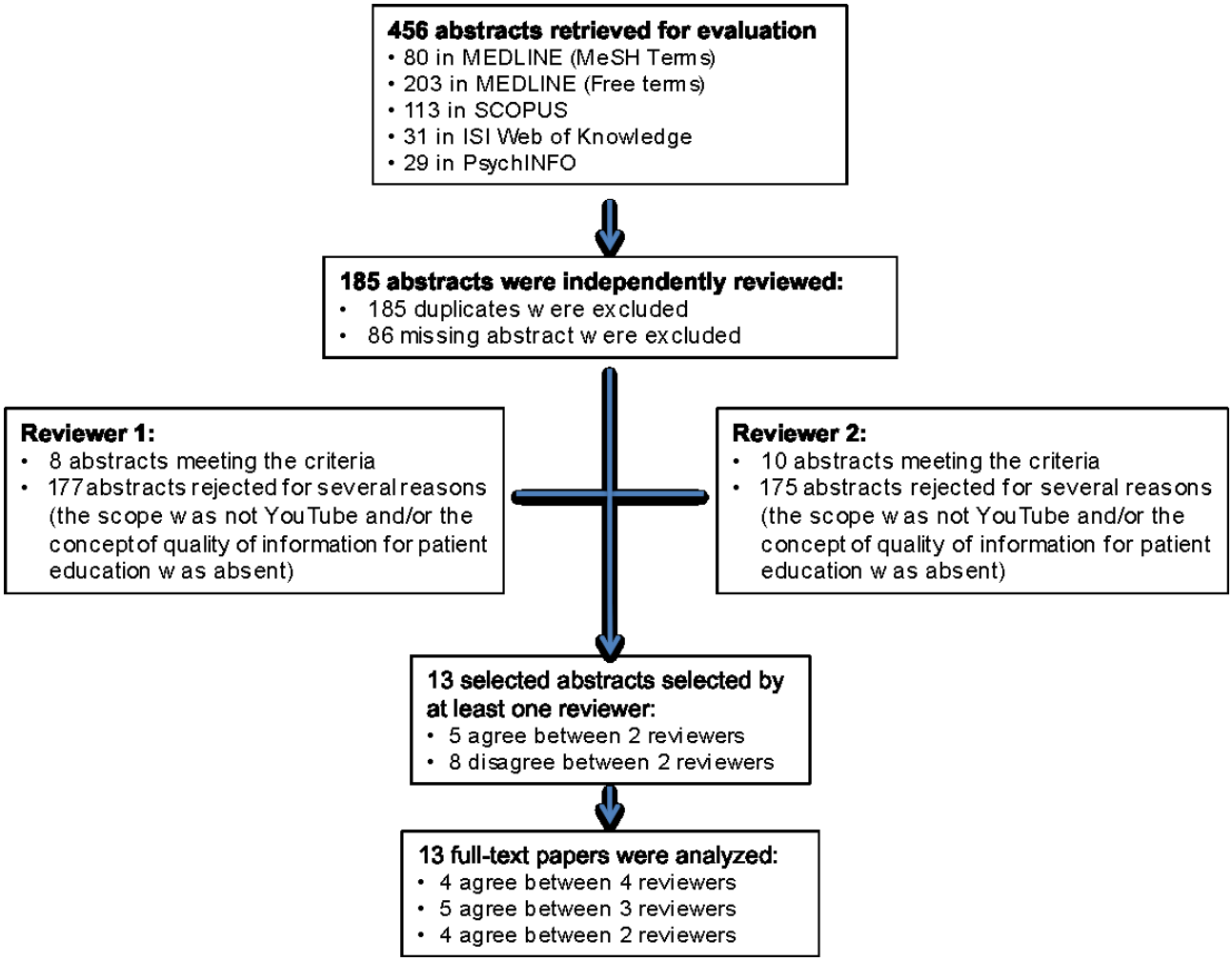
Similar search strategies were applied in other databases, and all publications containing the concepts "YouTube" and "Quality of information" in ISI Web of Knowledge, Scopus, and PsychINFO were also included. All searches were performed in November 2011.

Study Selection Process and Data Extraction

Titles and abstracts identified in the bibliographic databases were reviewed by two researchers (AL and EG) independently in the first abstract review. Duplicated studies and those with missing abstracts were excluded. Abstracts meeting any of the following exclusion criteria were also excluded: (1) the scope was not YouTube, and/or (2) the concept of quality of information for patient education was absent. A second abstract review was performed, where discrepancies between the first two reviewers were discussed with two additional independent reviewers (LF and MA) until consensus was reached. Full text of studies with agreement from at least two reviewers were retrieved for careful data extraction of the concepts, definitions, and topics used by its authors on the quality of information on YouTube for patient education. Search results are summarized in Figure 1.

The complete data extraction process and analysis was performed adapting the PRISMA recommendations for systematic reviews [20]. We excluded the statements referring to characteristics related specifically with clinical trials, as the trial registration code or the assessment and data were at risk of bias (ie, statements 4,5,11,12,15,16,19-23) as they are not applicable to the studies that were retrieved. Inter-rater reliability was obtained for the first abstract review. A 95% confidence interval was found using the generic formula for 95% confidence intervals (estimate ± SE 1.96).

Figure 1. Literature search and study selection process of quality of information for patient education on YouTube.



Results

Abstract Review

We retrieved 456 references from scientific databases (Figure 1). After removing 185 duplicates and 86 references missing an abstract, two independent reviewers (AL and EG) analyzed a total of 185 different abstracts, which were then classified independently for being included or by reason for being excluded according to pre-determined criteria. In this first abstract review, 13 abstracts were selected by at least one of the reviewers. The inter-rater reliability for the raters was found to be Kappa=0.73 (P<.001), 95% CI (0.662-0.792), and considered “moderate” [21].

The 13 abstracts selected in the first round were analyzed by two additional independent reviewers (LF and MA), who classified them as included or excluded using the same pre-determined criteria. After this second abstract review, 4 references were considered for inclusion by two reviewers, 5 references by three reviewers, and 4 references by all four reviewers. Overall, 13 abstracts that were selected by at least two reviewers were incorporated for full text analysis.

Data Extraction

A careful review of the selected papers were performed by EG and LF, looking for concepts related to (1) quality of information for patient education, (2) characteristics analyzed by authors to consider if a video had “quality”, (3) the dimensions used to classify quality, and (4) who was involved in conducting the classification. We also considered metadata of a video (eg, labels, title, description) as part of the video. Recurrent topics linked to quality of information for patient education are summarized in Table 1.

Table 1. Topics linked to quality of information for patient education on YouTube.

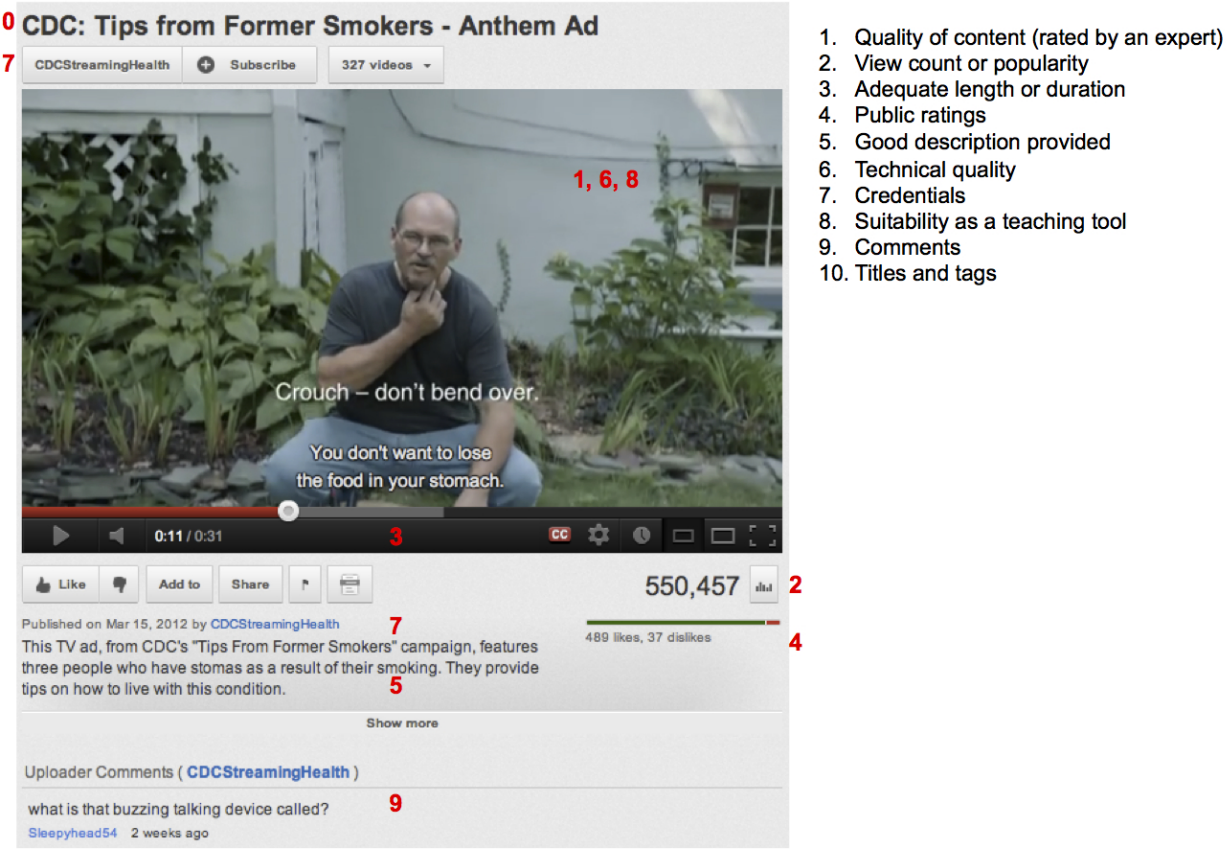
	Ameda et al [22]	Bakinger et al [10]	Dawson et al [11]	Figueiredo et al [23]	Figueiredo et al [24]	Lim et al [12]	Gooding and Gregory [25]	Murugiah et al [26]	Pandey et al [15]	Sajadi and Goldman [27]	Sood et al [13]	Steinberg et al [14]	Tian [28]	Frequency N=13 n (%)
Quality content (includes accuracy-credibility of content, scientifically correct information, and/or evidence-based practices)		✓	✓			✓	✓	✓	✓	✓	✓	✓	✓	10 (77%)
View count / popularity	✓	✓	✓			✓	✓	✓	✓		✓		✓	9 (69%)
Rated by expert (medical staff)		✓	✓			✓		✓	✓	✓	✓	✓		8 (62%)
Adequate length / duration							✓	✓	✓		✓	✓	✓	6 (46%)
Public ratings		✓				✓					✓	✓	✓	5 (39%)
Good description / comprehensive narrative provided	✓			✓	✓		✓							4 (31%)
Technical quality (light, sound, angle, resolution)						✓	✓					✓	✓	4 (31%)
Further contact info provided / credentials							✓	✓		✓	✓			4 (31%)
Suitability as a teaching tool						✓			✓	✓			✓	4 (31%)
Comments (by viewers)	✓			✓			✓						✓	4 (31%)
Title and tags	✓			✓	✓									3 (23%)
Amount of content / enough information to identify its objective	✓			✓	✓									3 (23%)
Viewership share (number of links to the video and/or number of shares in other social media)									✓		✓			2 (15%)
Description of video	✓			✓										2 (15%)
Health professional(s) and patient(s) seen in video							✓							1 (8%)
Mention intended target audience								✓						1 (8%)
Judgment include patients/parents/users			✓											1 (8%)

Measures Related to Quality of Information for Patient Education

Overview

Figure 2 summarizes selected measures identified in this review, which were used for analyzing the quality of YouTube videos for patient education. However, these measures were not consistently used throughout the papers, and we did not find a uniform definition or standard on how to assess quality of videos on YouTube. In this review, we classified these measures into 3 main categories: expert-driven, popularity-driven, or heuristic-driven.

Figure 2. Examples of criteria used to judge quality of health information for patient education on YouTube.



Expert-Driven Measures

The most frequently-used concept to assess patient education information in a video is the quality of its content, assessed by experts such as health professionals, IT researchers, and other researchers [10-15,24-28]. This concept was referred to as (1) accuracy-credibility of content, and/or (2) scientifically correct information, and/or (3) evidence-based practices. In 8 of 13 publications (62%), videos considered having quality information for patient education involved assessment from an expert, such as medical staff [10-15,26,27]. In 7 of 13 publications (54%), elements of quality information were identified from the opinions of two or three health professionals [10-15,26,27]. In 3 of 13 publications (23%), quality assessment was derived from a panel of IT researchers [22-24], and in 2 of 13 publications (15%) elements were assessed by two researchers [25,28] but their specialty was not outlined. Yet, judgment of patients/parents/users jointly with health professionals as quality criteria was mentioned in only one publication (8%) [11]. No publications reported solely relying on the judgment of patients (or consumers) to assess the quality of information found on YouTube videos for patient education.

Popularity-Driven Measures

The next most frequently used criteria for quality assessment was *view count (*ie, number of counts this video has been viewed by users on YouTube*)*, and was mentioned in 9 of the 13 papers (69%) [10-13,15,22,25,26,28]. Some papers analyzed the mean number of views per day since the video was posted, with means ranging between 37 [26] and 62 [15]. Other criteria included *public ratings*, considered in 5 of the 13 selected papers (39%) [10,12-15,28]. Public ratings were also assessed via the average rating score (0 was the lowest and 5 was the highest). Those considered “quality videos” had a mean of 3.1 (SD 2.1) [14], with public ratings ranging from 3.6 to 4.7 [12]. In addition, *viewership share* (number of links to the video and/or number of shares in other social media) was also mentioned in 2 papers for quality assessment [13,15].

Heuristic-Driven Measures

Heuristic measures based on metadata and other attributes of a video were also used to assess quality. For example, *adequate length* or *duration of the video* was a frequently-used criteria to estimate the quality of the video [13-15,25,26,28]. The mean duration of videos considered in these papers ranged from 1:37 to 4:26 minutes [13-15,25,26,28]. *Title and tags* [22-24] were also used in 23% (3/13) of papers selected for quality assessment. Other video concepts that were used for quality assessment included: (1) *good description* or *a comprehensive narrative* [22-25], (2) *evidence-based practices* or *efficacy used as clinical example* in video [11,13,15,26], (3) *suitability as a teaching tool* [12,15,27,28], (4) *technical quality* (light, sound, angle, resolution) [12,14,25,28], (5) *credentials* or *contact information* provided in video [25-27], (6) *amount of content* or *the presence of enough information* [22-24], and (7) *ability to identify its objective* [22-24].

Discussion

Overview

Unlike medical and health information websites where it is possible to guarantee the quality and trustworthiness of its

contents through certificates, measuring quality of health videos on YouTube is an under-developed area, requiring much attention. Only 13 papers focused specifically on YouTube have reported on quality measures of online videos for patient education, covering a wide spectrum of 17 quality measures.

Moreover, 10 of these selected papers were published in journals related to health and medicine, and generally referring to chronic conditions. We did not find any paper that reported on the potential of YouTube for educating consumers and patients on disease prevention, where knowledge could potentially influence behaviors and decrease risks, such as obesity or sexually transmitted diseases.

Key Results

There are 3 main ways that researchers used as quality assessment measures on YouTube: expert-driven [29], popularity-driven [30], and heuristic-driven (based on video metadata features) [29], where each presents its set of problems.

Expert Judgment as Quality Measure

Related to YouTube, content rated by an expert (such as medical or health professional staff) is the most frequently used criterion for assessing quality when referring to videos focused on health education. In fact, health and medical websites are increasingly being encouraged to apply for quality certificate assessments as proof of evidence that they are reliable sources of information which have been evaluated by experts [17]. However, as the volume of online videos grows exponentially (72 hours of video uploaded every minute [1]), using only expert evaluation to assess the quality of all videos posted on YouTube could not represent a sustainable long-term solution.

Alternative solutions, such as using the social networking approach, could represent a sustainable approach, taking the advantage of collective intelligence to assess the trustworthiness of social media content on YouTube [31]. Like other areas in public health, preventing access and production of unhealthy material on the Internet is likely to be a more cost-effective approach than providing treatment to those who have already accessed harmful content. Peer reviews by the crowd, such as online communities of patients, have been found to be able to filter misleading and incorrect information [32]. In addition, Fernández-Luque et al found a correlation between the quality of diabetes videos and social network metrics [31]. In social networks, peers have an important role on endorsing the quality of content via ratings and flagging harmful content. Health consumers and content producers can be encouraged to endorse or flag misleading content aiming at increasing the visibility of high quality content.

Popularity as Quality Measure

Popularity is the second most frequently cited concept in assessing quality on YouTube, often referred to as view count and/or public ratings. Unlike the focus on the assessment of the quality of content, which relies on human judgement and evaluation, view count or video views per day are quantitative measures that are readily accessible for each video on YouTube. However, some videos have higher view counts due to marketing campaigns, viral effects, because the video has been posted for a longer period of time, or was linked from several webpages. Users need to be aware that frequency of views may be manipulated by parties with specific agendas to achieve its "perceived" popularity.

Although video popularity is often used as a proxy to assess for quality, previous research has shown that online crowd influence can potentially lead consumers to making unsafe health decisions [7,33]. When consumers lack confidence, they have shown to be 28.5% more likely to change their decision after receiving online social feedback [34]. Yet, few to no studies have systematically studied the impact of social influence facilitated by YouTube on consumer health decisions. Similarly, public ratings (such as the like/dislike criteria) and inappropriate flags can be misleading as there are examples of gruesome and misleading videos (eg, videos promoting anorexia or featuring gruesome amputations) that are very popular.

As YouTube becomes one of the major outlets for organizations, news sources, and consumers alike for channelling and expressing their opinions and points of view [35], it is crucial to consider the way content is disseminated and the viral nature of the online community. The CDC has published guidelines on how to address risks in viral situations and offered advice to mitigate them in their context. Perhaps some of these recommendations could also be considered in YouTube or in other social media settings [36]. Unsolicited comments, even from a small number of individuals, can have detrimental effects on the effectiveness of public health campaigns, which are often expensive to run and costly to repair. For example, the first review paper on human papillomavirus (HPV) vaccination on YouTube conducted in 2008 found that most of the videos on the HPV vaccination were positive [37]. It appears that negative user comments and posts about HPV vaccine later emerged and the majority of videos are now negative in tone, disapproving of the HPV vaccine [35].

Other Video Features for Measuring Quality

Although researchers have used video metadata such as adequate length of the video to assess its quality, there are no evidence-based justifications on why these features could be used as quality measures. These measures should be considered as *heuristics* to determine the likelihood that these videos would be "viewed" by consumers, not as substitute for quality. Videos with high quality content, without appropriate metadata, could be dismissed as poor quality material. Similarly, videos with poor educational or misleading content, but contain appropriate metadata (such as adequate length, duration, captivating tags, titles, technical quality, and description), may be misinterpreted as good quality videos.

Given the exponential growth of YouTube videos, a multi-faceted approach that utilizes a social network approach [31], combined with expert-driven (layperson, professionals, and organizational-endorsement) and heuristic-driven criteria, could potentially be an ideal framework for assessing quality on YouTube.

Limitations

Our main focus was to identify (not evaluate) the different quality features related to the quality of information for patient

education on YouTube, which have been reported by researchers in the literature. The focus on peer-reviewed journal papers (and not on grey literature) in our approach was to ensure that the literature extracted that informs our view was peer-informed and of quality standard. We conducted a preliminary search for other video platforms (eg, Vimeo) but did not find any publications, thus we focused primarily and specifically on YouTube. Literature assessing health information on the Internet that includes presentations presented in video format was not considered in this review.

As YouTube is relatively new (started in 2005, although its popularity came quickly), there are only a handful of studies analyzing its quality for patient health education. Although 20% of traffic on YouTube comes via mobile devices [30], we did not find any published papers about quality of YouTube videos viewed on mobile devices, or the device where videos were watched. In fact, YouTube features are changing constantly, and the characteristics of video quality for patient education found in this review must be interpreted with care as new features become available to users on YouTube.

We must emphasize that although our search was limited to publications in English, we found that one of them was written in Brazilian Portuguese [23], and it was maintained in our analysis. The 13 papers selected for analysis in this review were published between 2009 and 2011, where authors' country of origin were mostly from the United States [10,11,14,25-28], Brazil [22-24], and India [13,15,26]. It must be noted that of the 13 selected papers, 5 belonged to two research groups—3 to a Brazilian research group [22-24] and the other 2 to an Indian research group [13,15]—raising questions on the representativeness and generalizability of these quality measures across different settings.

Conclusion

Our review confirms that the current topics linked to quality of information for patient education on YouTube are unclear and not standardized. Studies assessing quality on YouTube are few but emerging, with a variety of measures (such as expert-based, popularity-based, and heuristics-based) proposed to clarify and expand the concept of quality. Future research should investigate the types of measures that consumers and patients would actually use and/or find beneficial when assessing quality for health purposes on social media sites.

With the role of the Internet as a social network, typified by growing interest in Medicine 2.0 and Health 2.0, patients and consumers are increasingly seeking health information and advice from online peer networks. Although YouTube has the potential to be used for health education and health promotion [15,38,39], as well as a platform for teaching professionalism in the medical field [11], we must take into account that it is a social platform, and thus the quality of health-related information, is constantly changing [27]. Further, other video platforms are emerging, introducing new features that may constantly challenge and redefine the criteria used to assess quality of information for patient education. As we witness the first steps towards patient education through the use of social media, one needs to consider the growing safety concerns that are also present on video-sharing platform [6,7,14], especially given the salient nature of online videos.

Acknowledgments

The authors acknowledge the contributions of J. Artur Serrano for his support, advice and suggestions for improving the manuscript. This work was supported by the Norwegian Centre for Integrated Care and Telemedicine, University Hospital of North Norway. LFL's work is supported by the Tromsø Telemedicine Laboratory co-funded by the Research Council of Norway (Project 174934). And at the time of writing, AL was supported by the National Health and Medical Research Council Centre of Research Excellence in Informatics and E-Health (1032664).

Conflicts of Interest

None declared.

References

1. YouTube. 2012. About YouTube URL: http://www.youtube.com/t/about_youtube [accessed 2013-02-07] [WebCite Cache ID 68R5rzMUd]
2. Chau C. YouTube as a participatory culture. New Dir Youth Dev 2010;2010(128):65-74. [doi: 10.1002/yd.376] [Medline: 21240954]
3. Chou WY, Hunt Y, Folkers A, Augustson E. Cancer survivorship in the age of YouTube and social media: a narrative analysis. J Med Internet Res 2011;13(1):e7 [FREE Full text] [doi: 10.2196/jmir.1569] [Medline: 21247864]
4. Centers for Disease Control and Prevention. Social media guidelines and best practices. YouTube and other online video URL: http://www.cdc.gov/SocialMedia/Tools/guidelines/pdf/onlinevideo.pdf [accessed 2013-02-07] [WebCite Cache ID 68R5wVvEG]
5. American Public Health Organization. Criteria for assessing the quality of health information on the Internet. American Journal of Public Health 2001;91(3):513-514.
6. Coiera E, Aarts J, Kulikowski C. The dangerous decade. J Am Med Inform Assoc 2012;19(1):2-5 [FREE Full text] [doi: 10.1136/amiajnl-2011-000674] [Medline: 22116642]

7. Lau AYS, Gabarron E, Fernandez-Luque L, Armayones M. Social media in health - what are the safety concerns for health consumers? Health Information Management Journal 2012;41(2):30-35.
8. Syed-Abdul S, Fernandez-Luque L, Jian WS, Li YC, Crain S, Hsu MH, et al. Misleading Health-Related Information Promoted Through Video-Based Social Media: Anorexia on YouTube. J Med Internet Res 2013;15(2):e30 [FREE Full text] [doi: 10.2196/jmir.2237] [Medline: 23406655]
9. Pew Internet & American Life Project 2010. Social media & mobile Internet use among teens and young adults URL: http://www.pewinternet.org/~/media//Files/Reports/2010/PIP_Social_Media_and_Young_Adults_Report_Final_with_toplines.pdf [accessed 2013-02-08] [WebCite Cache ID 6EHSnSyJN]
10. Backinger CL, Pilsner AM, Augustson EM, Frydl A, Phillips T, Rowden J. YouTube as a source of quitting smoking information. Tob Control 2011 Mar;20(2):119-122. [doi: 10.1136/tc.2009.035550] [Medline: 20966132]
11. Dawson AL, Hamstra A. , Huff LS, Gamble RG, Howe W, Kane I. Online videos to promote sun safety: results of a contest. Dermatology Reports 2011;3(1):17-19.
12. Lim Fat MJ, Doja A, Barrowman N, Sell E. YouTube videos as a teaching tool and patient resource for infantile spasms. Journal of Child Neurology 2011 Jul;26(7):804-809.
13. Sood A, Sarangi S, Pandey A, Murugiah K. YouTube as a source of information on kidney stone disease. Urology 2011 Mar;77(3):558-562. [doi: 10.1016/j.urology.2010.07.536] [Medline: 21131027]
14. Steinberg PL, Wason S, Stern JM, Deters L, Kowal B, Seigne J. YouTube as source of prostate cancer information. Urology 2010 Mar;75(3):619-622. [doi: 10.1016/j.urology.2008.07.059] [Medline: 19815255]
15. Pandey A, Patni N, Singh M, Sood A, Singh G. YouTube as a source of information on the H1N1 influenza pandemic. Am J Prev Med 2010 Mar;38(3):e1-e3. [doi: 10.1016/j.amepre.2009.11.007] [Medline: 20171526]
16. Purcell GP, Wilson P, Delamothe T. The quality of health information on the Internet. BMJ 2002 Mar 9;324(7337):557-558 [FREE Full text] [Medline: 11884303]
17. Health On the Net Foundation. 2013. HON code URL: http://www.hon.ch/HONcode/ [accessed 2013-02-07] [WebCite Cache ID 6BBl97vxJ]
18. Laversin S, Baujard V, Gaudinat A, Simonet MA, Boyer C. Improving the transparency of health information found on the Internet through the honcode: a comparative study. Stud Health Technol Inform 2011;169:654-658. [Medline: 21893829]
19. 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]
20. Liberati A, Altman DG, Tetzlaff J, Mulrow C, Gøtzsche PC, Ioannidis JP, et al. The PRISMA statement for reporting systematic reviews and meta-analyses of studies that evaluate health care interventions: explanation and elaboration. PLoS Med 2009 Jul 21;6(7):e1000100 [FREE Full text] [doi: 10.1371/journal.pmed.1000100] [Medline: 19621070]
21. Landis JR, Koch GG. The measurement of observer agreement for categorical data. Biometrics 1977 Mar;33(1):159-174. [Medline: 843571]
22. Almeida JM, Figueiredo F, Pinto H, Minas UFD. On the quality of information. IEEE Internet Computing 2010:47-55.
23. Figueiredo F, Belem F, Pinto H, Almeida J, Gonçalves M, Fernandes D, et al. Caracterizando o Uso e a Qualidade dos Atributos Textuais da Web 2.0. 15º Simpósio Brasileiro de Sistemas Multimídia e Web. 2009 Presented at: WebMedia'09; October 5-7, 2009; Brazil.
24. Figueiredo F, Belém F, Pinto H, Almeida J, Gonçalves M, Fernandes D, et al. Evidence of quality of textual features on the Web 2.0. 2009 Presented at: 18th ACM Conference on Information and Knowledge Management, CIKM; November 2-6, 2009; Hong Kong, China p. 909-918.
25. Gooding LF, Gregory D. Descriptive analysis of YouTube music therapy videos. J Music Ther 2011 Jan;48(3):357-369. [Medline: 22097103]
26. Murugiah K, Vallakati A, Rajput K, Sood A, Challa NR. YouTube as a source of information on cardiopulmonary resuscitation. Resuscitation 2011 Mar;82(3):332-334. [doi: 10.1016/j.resuscitation.2010.11.015] [Medline: 21185643]
27. 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]
28. Tian Y. Organ donation on Web 2.0: content and audience analysis of organ donation videos on YouTube. Health Commun 2010 Apr;25(3):238-246. [doi: 10.1080/10410231003698911] [Medline: 20461609]
29. Eysenbach G, Powell J, Kuss O, Sa ER. Empirical studies assessing the quality of health information for consumers on the world wide web: a systematic review. JAMA 2002;287(20):2691-2700. [Medline: 12020305]
30. Metzger MJ, Flanagin AJ, Medders RB. Social and heuristic approaches to credibility evaluation online. Journal of Communication 2010;60(3):413-439.
31. Fernandez-Luque L, Karlsen R, Melton GB. HealthTrust: a social network approach for retrieving online health videos. J Med Internet Res 2012;14(1):e22 [FREE Full text] [doi: 10.2196/jmir.1985] [Medline: 22356723]
32. Esquivel A, Meric-Bernstam F, Bernstam EV. Accuracy and self correction of information received from an internet breast cancer list: content analysis. BMJ 2006 Apr 22;332(7547):939-942 [FREE Full text] [doi: 10.1136/bmj.38753.524201.7C] [Medline: 16513686]
33. Lau AYS, Kwok TMY, Coiera E. How online crowds influence the way individual consumers answer health questions. Applied Clinical Informatics 2011;2:177-189.

34. Lau AY, Coiera EW. Impact of web searching and social feedback on consumer decision making: a prospective online experiment. J Med Internet Res 2008;10(1):e2 [FREE Full text] [doi: 10.2196/jmir.963] [Medline: 18244893]
35. Briones R, Nan X, Madden K, Waks L. When vaccines go viral: an analysis of HPV vaccine coverage on YouTube. Health Commun 2012 Jul;27(5):478-485. [doi: 10.1080/10410236.2011.610258] [Medline: 22029723]
36. CDC. 2009. Social media security mitigations URL: http://www.cdc.gov/socialmedia/Tools/guidelines/pdf/securitymitigations.pdf [accessed 2013-02-07] [WebCite Cache ID 68R65T0Zr]
37. Ache KA, Wallace LS. Human papillomavirus vaccination coverage on YouTube. Am J Prev Med 2008 Oct;35(4):389-392. [doi: 10.1016/j.amepre.2008.06.029] [Medline: 18675530]
38. Lau AY, Siek KA, Fernandez-Luque L, Tange H, Chhanabhai P, Li SY, et al. The role of social media for patients and consumer health. Contribution of the IMIA consumer health informatics working group. Yearb Med Inform 2011;6(1):131-138. [Medline: 21938338]
39. Gabarrón E, Fernández-Luque L. eSalud y vídeos online para la promoción de la Salud. Gaceta Sanitaria 2012 May;26(3):197-200.

Abbreviations

CDC: Centers for Disease Control and Prevention
HONcode: Health on the Net Foundation Code of Conduct
HPV: human papillomavirus
MeSH: Medical Subject Headings

Edited by G Eysenbach; submitted 17.12.12; peer-reviewed by D Topps, C Camm; comments to author 31.01.13; revised version received 10.02.13; accepted 10.02.13; published 28.02.13.

Please cite as:
Gabarron E, Fernandez-Luque L, Armayones M, Lau AYS
Identifying Measures Used for Assessing Quality of YouTube Videos with Patient Health Information: A Review of Current Literature
Interact J Med Res 2013;2(1):e6
URL: http://www.i-jmr.org/2013/1/e6/
doi:10.2196/ijmr.2465
PMID:23612432

Original Paper

Developing Electronic Cooperation Tools: A Case From Norwegian Health Care

Eli Larsen[1]; Per Kristen Mydske[2], Dr.sc.soc

[1]Norwegian Centre for Integrated Care and Telemedicine, University Hospital of North Norway, Tromsø, Norway

[2]Department of Political Science, Faculty of Social Sciences, University of Oslo, Oslo, Norway

Corresponding Author:
Eli Larsen
Norwegian Centre for Integrated Care and Telemedicine
University Hospital of North Norway
Sykehusvn. 23
Tromsø, 9019
Norway
Phone: 47 90778661
Fax: 47 77 75 40 98
Email: eli.larsen@telemed.no

Abstract

Background: Many countries aim to create electronic cooperational tools in health care, but the progress is rather slow.

Objective: The study aimed to uncover how the authoritys' financing policies influence the development of electronic cooperational tools within public health care.

Methods: An interpretative approach was used in this study. We performed 30 semistructured interviews with vendors, policy makers, and public authorities. Additionally, we conducted an extensive documentation study and participated in 18 workshops concerning information and communication technology (ICT) in Norwegian health care.

Results: We found that the interorganizational communication in sectors like health care, that have undergone an independent development of their internal information infrastructure would find it difficult to create electronic services that interconnect the organizations because such connections would affect all interconnected organizations within the heterogenic structure. The organizations would, to a large extent, depend on new functionality in existing information systems. Electronic patient records play a central role in all parts of the health care sector and therefore dependence is established to the information systems and theirs vendors. The Norwegian government authorities, which run more than 80% of the Norwegian health care, have not taken extraordinary steps to compensate for this dependency–the government's political philosophy is that each health care institution should pay for further electronic patient record development. However, cooperational tools are complex due to the number of players involved and the way they are intertwined with the overall workflow. The customers are not able to buy new functionalities on the drawing table, while the electronic patient record vendors are not willing to take the economic risk in developing cooperational tools. Thus, the market mechanisms in the domain are challenged. We also found that public projects that were only financed for the first steps of project management could partially explain why many initiatives did not get past the initial planning and specification stages, but were stopped before further development could be made. Vendors were often unwilling to provide further own contribution without guaranteed return.

Conclusions: We propose that the authorities take a coordinating role and provide financial help for development of electronic cooperational tools for health because the regular market mechanisms are insufficient to push these developments to the market. It is, however, critical that the role of users be considered, and for users to decide which developments should go forward.

(Interact J Med Res 2013;2(1):e9) doi:10.2196/ijmr.2346

KEYWORDS

health communication; public policy; communication barriers

Introduction

Overview

Many studies of health care information systems have taken place [1], focusing on the successes, failures, and application of such systems without calling attention to the process that led to the design of the system. In this paper "information systems" are defined as a combination of hardware, software, infrastructure, and trained personnel organized to facilitate planning, control, coordination, and decision making in an organization. We believe that the development process (from the idea to the completed, implemented system) and the incentives that contribute to making innovations are also important components of information systems that should be understood in addition to the systems' functions. This paper focuses on issues in the development of electronic cooperation tools/services that allow different health care organizations , such as hospitals, general practitioners, and home care services, to cooperate electronically when patient information is stored in several organizations. Referrals, x-ray pictures, prescriptions, discharge letter, and laboratory requisition are examples of information entities that could be exchanged electronically and thus create new ways of cooperation. Our case was drawn from Norwegian health care, but we believe that our analysis can be applied to other countries and sectors. We examined the position of the vendors and customers in the health care market and the role that Norwegian authorities' financing policies play in the development of electronic cooperation tools for health care organizations.

To better understand authorities' strategies concerning information and communication technology (ICT) issues in health care, we described the philosophy behind neo-liberalism, the widespread political philosophy driving most policy decisions in Western countries today. Further, we outlined the use of ICT in health care and how these health care institutions have built separate information infrastructures. The characteristics of such infrastructures are explained in this paper using the Information Infrastructure Theory and elaborated with our research methods. We began with a description of the Norwegian health care sector and its level of ICT adoption, followed by two case descriptions, and finally explained the vendors', health care users', and authorities' perspectives. In the discussion, we analyzed the market within information systems in health care and how the authorities' financing model effects the development of cooperational electronic tools. A conclusion and recommendations rounds off the paper.

Health Care Spending, Political Philosophy, and Trade Regulations

Statistics from the Organization for Economic Cooperation and Development showed that 34 countries that reported to the organization spent, on average, 5.8% of their Gross Domestic Product on public health in 2007 [2]. Public expenditures on health measured as a percentage of total health expenditures ranged from 45% (eg, in the United States) up to more than 80% (eg, in the Scandinavian countries) [3]. The way that health care is organized and financed is often a central issue in election campaigns in democratic countries. As a result, improved electronic cooperation and integration of the health care sector has become an essential part of authorities' strategies in Western countries [4-6]. Strategies for streamlining health care have differed among Western countries, due to the differing ways in which health care is organized and differing approaches to ICT development in health care. It is however, usual that ICT in health care is developed and maintained by private players, representing a vendor category that is not a part of the public ownership [7]. In order to analyze the elements that influence these varying approaches to ICT in health care, we will first shed light on the dominant political philosophy in Western states today—namely, neo-liberalism [8].

Neo-liberalism is a set of economic policies that have become widespread during the last 25 years. The American economist Milton Friedman is widely known for laying the foundation of neo-liberal [9]. The term "neo-liberalism" is comprised of two root words, "neo" meaning new and "liberal" meaning free from authorities' intervention. Neo-liberalism is characterized by the desire to intensify and expand the market by increasing the number, frequency, repeatability, and formalization of transactions [10]. To obtain this outcome, the market should be based on the free flow of services, goods, manpower, and capital. Friedman maintained that free markets create the best conditions for democracy; when people have power over their own economic choices, they will acquire power over those who exercise state authority. The existence of free and autonomous individuals and organizations and a strong private sector with only limited state interference is key to neo-liberalism. Neo-liberalism justifies the limitation of authorities' intervention in the market by maintaining that markets are complex and unpredictable, thus making it impossible for the state alone to provide regulatory authority [10].

Political action in a neo-liberal government aims to maintain order and security and construct frameworks to shape society. Public properties and services should be run based on market economic principles. Reforms based on this principle have been advanced according to the principle of indirect governance. This means that autonomous organizations have to find ways to adjust their practices in accordance with political expectations. For instance, a public hospital can receive income in the form of grants based on the number of patients it treats. Thus, public hospitals strive to manage themselves effectively and attract patients (or consumers in market economic terms).

Neo-liberal reforms contain two aspects, privatization and market mechanisms within the public sector [11-13]. Neo-liberal reforms in Norway are characterized mainly by a trend to use market mechanisms within the public sector rather than privatization [12]. This implies devolution of public organizations and tasks to be run by strengthened efficiency goals at the lowest efficiency level: a New Public Management structure. This favors a decentralized and fragmented system with narrow business goals.

Central aspects of neo-liberal reforms in Norway are generally split between *ownership* and *management*, and between *infrastructure* and *management* [11]. When public ownership is preserved, management is located to autonomous institutions within the public sector, but with business efficiency goals

within a narrower local organizational rationality. This means that central steering is weakened in the sense that the distance between political leadership and implementing unit is longer, and the steering concerns more frames than concrete targets. The neo-liberal concept presupposes that this kind of reform makes the whole system more rational and efficient. But it is doubtful if the sum of local efficiency results in fact actively adds up to an improved total efficiency at a higher level.

In the literature of public management reform in a neo-liberal perspective, a distinction between different kinds of reform effects is defined, for instance between *operational*, *process*, and *system* effects [14]. Operational effects may be efficiency and productivity. Process effects include service quality, customer satisfaction, administrative culture etc. System effects mean capacity of the political-administrative system, such as coordination and innovation.

This means that if operational effects are strengthened in a narrow sense, as more weight on business and efficiency goals to make the single local unit more sustainable, other effects are weakened, as customer satisfaction (process effects) and coordination and innovation (system effects, see also [11,12]). The reforms may change towards a single-purpose orientation and weaken a multi-purpose orientation. A multi-purpose orientation more easily includes interests and goals which are not strictly in line with the main purpose of the organization, while the single-purpose orientation generates the opposite effect.

The basic idea in neo-liberalism concerning free flow of services, goods, manpower, and capital is usually not absolute. In practice, several countries cooperate and create internal markets where this free flow principle functions. Comprehensive negotiations result in detailed agreements about trade practices within the internal market and between the internal market and the rest of the market. Regulations and threats of sanctions position the trading bodies as significant players. The European Economic Area (EEA) [15] with its European Free Trade Association (EFTA) Court [16] is a prime example.

Due to the trade agreements that exist in an internal market such as the EEA, customers and vendors have to act within the legislative framework. For instance, if a public organization wants to buy a product, service, or software, a national request for tenders must be extended when the investment exceeds 60,000 euros, and a request for tenders must be extended to the entire internal European market when the investment exceeds 120,000 euros. Rigid regulations control the whole transaction process between vendors and customers from announcement to signed contract. Thus the regulation itself becomes an obligatory passage point [17]. The tender legislation is intended to ensure the effective use of public funds through cost-effective purchasing, and encourage the development of competitive business.

Information Infrastructure in Health Care

In health care, the patient record is the key tool for many activities, both medical and mercantile. From a medical perspective, the health care provider needs to record relevant information about the patients and is obliged to document diagnoses, interventions, and planned procedures. Similarly, the patient record contains information fundamental to logistics, billing, and statistics, which in turn plays a critical role in planning, financial management, and control. The potential for ICT to integrate all this information into a single record has proven highly attractive to policy-makers, promising to improve quality and cut costs, and providing a technological fix to the structural crises of exponentially increasing demand and limited public funding that face most public sector health systems [7]. Several commercial vendors provide electronic patient records. According to Porter [18], good competitors and customers are the key to success for any company in any industry.

Health care institutions have built infrastructures that support their local activity and are typically present in the specter from big hospitals to general practitioners offices [19,20]. Transforming cooperation routines *between* such institutions from, for instance telephone or letters sent by post over to electronic services, require attention to the fundamentally composite nature of these practices. Electronic services must play along with all of the people, processes, procedures, tools, facilities, and technology, which exists in the involved institutions and must be able to support the creation, use, transport, storage, and destruction of information.

Information Infrastructure Theory

To analyze topics concerning electronic cooperation in the health care context, we referred to the information infrastructure theory which Hanseth and Lyytinen [21] defined as a shared, evolving, heterogeneous installed base of information technology capabilities among a set of user communities based on open and/or standardized interfaces. Such an information infrastructure, when appropriated by a community of users, offer a shared resource for delivering and using information services in a (set of) community [21]. In the definition, three elements are especially important to highlight:

1. Evolving: Information infrastructures are not “stagnant”, but evolves continually, in response to innovation. This means that a cooperation service will be an expansion of the existing infrastructure. Radically, changes cannot occur in a single instance, but this change will occur over time.
2. Heterogeneous: Infrastructures consist of different elements, such as technology, users, and organizations, in large networks. A cooperation tool will therefore require more than just the technological component. The heterogeneity is extraordinary within health care. For instance the number of related professions and health care users is overwhelming.
3. Installed base of information, systems, artifacts, practices, and organizational structures are seldomly created from scratch but are expansions of existing bases. Health care has existed for a very long time and during this time the installed base has grown. The installed base exists in each health care unit and within clusters of health care units (where a unit is defined as an organization, department, or office).

Creating cooperational services in health care can address the issues highlighted by the information infrastructure theory. In fact, developers of cooperational electronic services attempt to

interconnect infrastructures that are established and have evolved for years

Contribution and Research Question

The study contributes with empirical insight into the development of electronic cooperation tools in health care. Our paper tries to combine two domains that are rarely combined, namely political philosophy and "down to earth" aspects within information systems. We elaborate on how development of cooperational services put both the vendors and customers in a difficult situation and we also point out that the neo-liberalistic policy do not give the authorities the tools they need to stimulate the process. Given this knowledge, we address the following research question: How does the Norwegian authorities' financing policy influence the development of electronic cooperational tools within health care?

Methods

The research questions that we wanted to answer during this study, were "how" questions within a complex area. A qualitative approach was recommended by Yin [22], while an interpretative method [23] could be used to get a better understanding of the mechanisms influencing the development of electronic cooperation tools in the health care sector. The empirical material for this study was gathered through a longitudinal process, starting in 2004 and continues today in Norway. Over this period of time, the first author has collected empirical knowledge from a number of information sources, including 30 semi-structured interviews of 60-180 minutes with vendors, policy makers, and public authorities, 18 workshops concerning ICT in Norwegian health care, strategic documents and evaluation reports for ICT in Norwegian health care for the period 1997 onwards, project documentation of 4 national ICT health care projects, parlament minutes, speeches by the Minister of Health, management documents from the Ministry of Health, and meetings minutes between the Ministry of Health and Regional Health Authorities.

The analysis of the collected material was based on the principle within the hermeneutic to understand the totality of the object to interpret based on sections and a section based on the totality [24]. The hermeneutic circle entails a continuous fluctuation and shift in understanding between sections and the totality. Every section relates to other sections and to the totality, and the section becomes different after we have perceived something in a new way. The totality of the object to interpret also changes when sections acquire new meaning. What seemed to be the reason for the slow progress within development of cooperational tools turned out to be something completely different when we analyzed our material throughout the hermeneutic circle.

The information from the interviews were transcribed and sorted into themes. By combining all informational elements, it was possible to understand the viewpoints of the different players and how these viewpoints have affected progress in the field. The perspectives of the users (health care personnel that use the information systems), electronic patient record vendors, and authorities are presented in the form of a synthesis statement in the case description in order to help visualize the complex situation.

Due to the long timescale of this study, important events were placed in a timetable in order to understand the context of the different events and how they have interfered with each other. These events are for instance, reorganization of hospital sector, introduction of new legislations, and publication of new political strategies.

The first author was formerly a project member in the Core Health Record project that failed and terminated in 2009. This insider background [25] has given her valuable insight into the processes in question. It also allowed for privileged appointments and contact with key players in conducting this research.

The second author was involved in several research projects on public innovation and policy reforms and has acted as a discussion partner with the first author throughout the study.

Results

Cooperational ICT in Norwegian Health Care

The following section explains the basic structure of health care in Norway and the adoption of ICT in the sector. Then, we present issues concerning service development in the domain and explain how two public projects were run. Finally, we present how the users (health care personnel), electronic patient record vendors, and authorities experience the climate for developing new services.

Health Care Structure

The main players in clinical health care in Norway are hospitals, general practitioners, home care services, and nursing homes. This structure has been stable for several decades. The sector is mainly public, but subject to various ownership and funding structures. General practitioners run private offices, as public funds are strictly regulated by the government. Most general practitioners have been using electronic patient records since the 1990s. Homecare services and nursing homes are run by municipalities, receiving funding from local authorities. The municipal sector slowly began to use electronic patient records for their patients in the 1990s, first for administrative purposes and then for statistical purposes. In 2002, a reform transferred the responsibility for Norwegian hospitals from the counties to 4 regional health authorities, centralizing ownership under the Ministry of Health. The reform was intended to make the hospitals more efficient by introducing a business-modeled framework of political control. The reform also set up new management principles for the hospitals based on a decentralized enterprise model. Lack of internally integrated ICT systems in the hospitals was accompanied by a lack of all kinds of other electronic communications such as communication between different hospitals, between general practitioners and hospitals, between the municipality and the hospitals, and so on. The need for communication extended to all levels of the health care system, including authorities (in cases dealing with refunds, applications, submission of statistics, etc).

Service Development

The Norwegian authorities had outlined clear strategies for ICT in the health care sector as early as 1997. "Seamless electronic cooperation" was stressed in all strategy documents published by the Ministry of Health. After 2000, electronic referrals, discharge letters, x-ray photos, and other records were sent within the Norwegian health care sector, but the scale of this electronic communication was limited compared to expectations. The authorities supported some development activities but did not coordinate them. Over the last few years the Directorate of Health has taken charge of an increasing number of national ICT projects. Three big projects have already started. The following table gives a short introduction to some of the public projects underway in Norway recent years.

Table 1. Public projects underway in Norway since 2005.

Project	Cost (million euros)	Project owner	Time and status	Goal	Characteristics
ePrescription First version.	60	Directorate of Health	2005-2008 pilot terminated in 2008 Failed	establish electronic transmission of prescriptions	There were many players. One electronic patient record vendor participated. The vendor received 30% funding.
ePrescription Second version	15	Directorate of Health	2008-2011 ran pilots in 2010 about to be rolled out	establish electronic transmission of prescriptions	Two electronic patient record vendors participated. The vendors received 100% funding.
Core Health Record	3	Trondheim City Council	2005-2009 project terminated before any kind of testing	create a patient summary available on the Norwegian Health Net	There were many players. Struggled to involve electronic patient record vendors due to vague requirements. Struggled to get some funding to the electronic patient record vendors.
Elin-K	2	Norwegian Nurses Organization	2005-2011 most planned functions have been established delayed several years	establish electronic communication between Home Care Services and general practitioners s and hospitals	There were many players. About 8 electronic patient record vendors were involved. The vendors received about 30 % funding. Continuing project management.
Core Health Record	>15	Directorate of Health	2009-ongoing prestigious project initiated on political level	create a patient summary available on the Norwegian Health Net	There were many players. Avoiding electronic patient record vendors. Functionality based on ePrescription.

Development Processes

In order to describe the problems encountered by a typical project creating an interorganizational service, we describe two project processes. These are the Core Health Record project owned by Trondheim City Council and ePrescription owned by the Directorate of Health. The description focus on 4 issues: (1) The health care needs, (2) project financing, (3) challenging work with requirement specifications, and (4) dependence on electronic patient record vendors.

Core Health Record

In the Trondheim municipality, their professionals in the home care service struggled to gain updated information about the medicine that their nurses were administering to their clients, and the city council applied for funding to run a project creating a Core Health Record with the purpose of reducing adverse medicine events and contribute to better resource use in health care sector. The aim was to create a cooperational tool that both the general practitioners and the home care service could use. They got 650,000 euros in founding funds from the Directorate of Health. However, the funding was only for project planning and project management. It did not include funding to any vendor or the users which would do the pilot testing.

> *The general practitioners are those who are responsible for our clients' medication as long as they are not hospitalized, and our Core Health Record will show the medication that the general practitioners have in their system, together with new prescriptions that other physicians, in the hospital or at the emergency service, have prescribed. In this way our nurses will know what kind of medicine the patients should have.* [Project manager]

The project group considered it peremptory to integrate the Core Health Record with the electronic patient records both in the Home Care Sector and the general practitioners'. This was critical to make a user-friendly service and the general practitioners' electronic patient record system should be the most significant information source for Core Health Record.

From a technical point of view, the Core Health Record service should consist of two major elements: (1) a database containing the Core Health Records, and (2) read/write functionalities in the electronic patient records in Home Care Sector and general practitioners'. Trondheim City put out a limited tender and bought the database based on pre-specified requirements. Basically, the project team wanted to include as few electronic patient record vendors as possible, but felt obligated to include all the 9 vendors, and to produce a national solution, because

funding from Innovation Norway (a public business funding organization) would otherwise be unavailable. However, the electronic patient record vendors wanted to have national specifications on such a service to reduce risk. After applying for more than one year, the project managed to receive funding to cover some of the vendors' expenses from integration work.

User workshops and technical workshops were arranged and specifications were further developed. The project was administered by well-trained managers, but due to the complexity in the specification work, experts from Norwegian Centre for Informatics in Health and Social Care were hired to run the process. The specification work concerning integration with the electronic patent record was a difficult task and the electronic patient record vendors did not find the specifications suitable.

> *It is not possible to start some kind of development based on the specifications—we must rewrite the whole damn thing. It is on such a theoretical level that all of it needs to be explained in a practical frame.* [Electronic patient record vendor]

None of the electronic patient record vendors started to make integrations in their systems for the Core Health Record because of the poor user specifications that was made and they were not willing to take the economic risk by developing the Core Health Record functionality.

> *I can't imagine that our doctors will pay anything extra for the Core Health Record.* [Electronic patient record vendor]

Without any effort from the electronic patient record vendors, the project made no progress and was terminated in 2009 without achieving any testing.

ePrescription

In 2004, the Ministry of Health initiated a project called ePrescription (ie, electronic prescriptions). The most important argument for this was a regulation that instructed the National Insurance Administration to document all prescriptions handled by the pharmacies. However, implementing electronic prescriptions was also expected to provide benefits for pharmacies, which could handle prescriptions faster and with fewer errors. The doctors saw the potential for decision support, improved quality, and less time spent on writing prescriptions. The patients could have their prescription distributed to any pharmacy, and the authorities could distribute changes to regulations more efficiently. The project was to be completed in 2009.

The following groups were included in the project: Norwegian Pharmacist's Union, National Insurance Administration (NIA), Norwegian Medical Association (representing physicians), and Norwegian Medicines Agency (NMA), which concerns all information concerning medicine in Norway. The project was managed by the Directorate of Health.

The ePrescription project was established with funding valuing 30 million euros from the parliament. From the outset, the funding for this project was not intended to help fund the electronic patient record vendors in integrating the electronic prescription functionality into the electronic patient record or to help fund pilot users.

The authorities wanted an electronic prescription system to document the use of medicine and control the public financing aspect of medicine distribution. In the beginning of the project, the management targeted its efforts toward this end. However, the physicians' representative was dissatisfied with the system that had been outlined, as the physicians' perspectives were lacking. The system did not allow for support during the prescription phase, such as interaction control and product information. The physicians are vital in the prescription process. Without their goodwill, prescriptions would probably still be in a paper-based format, and this would have undermined the concept of substantial electronic cooperation concerning prescriptions.

Another problem was that the 3 vendors of the hospital-based electronic patient records demanded better requirement specifications before agreeing to develop any measure. As a result, the project initiated with working groups in the hospitals developing user requirements for hospitals. It was difficult to launch an initiative and recruit volunteers in large institutions like hospitals, and about 2 years passed before the working group was able to deliver.

Due to the slow progress in hospital sector, only one of the electronic patient record vendors in this sector developed an electronic prescription functionality. The project funding was able to offer the vendor 175,000 euros, which was about 0.6% of the total project budget. The remaining two vendors were not able to participate because they had recently introduced new electronic patient record systems that needed a great deal of attention and personnel in the development department.

The specification process took place with much involvement from doctors in the form of interviews, meetings, and workshops. The electronic patient record vendor participated in much of this work. During this process, the specification was ambiguous and was changed extensively.

> *The technical specification of the message we were supposed to get from the Norwegian Medicine Agency was only ten percent OK when we started developing…They had defined classes and stuff that they wanted to use in the message but the message itself was not defined. And there were a lot of changes in the class structure afterwards.* [Electronic patient record vendor]

The Norwegian standardization organization, Norwegian Centre for Informatics in Health and Social Care, was included in the project in order to guide the vendors, yet, a great deal of testing and error detection was necessary in order to communicate seamlessly between the players. The workload necessary for establishing communication between the electronic patient record and the rest of the players, was very time-consuming, several times greater than initially expected.

A pilot test was launched by the Minister of Health in a small municipality in Norway in May 2008. The electronic patient record vendor insisted that it should be postponed for a few months, but this was refused.

> *Those who manage the [ePrescription] project have obviously decided to keep it on schedule, and this is said in such a way that you understand that there is a lot of prestige in the project—as if there is somebody who will rap them over the knuckles if they don't.* [Profiled health player]

The electronic patient record system that was integrated with ePrescription was a completely new system, but unfortunately the vendor had not had time to test it sufficiently in-house. The ePrescription was installed just a few days after the installation of the new electronic patient record. This caused even more trouble for the pilot users, who received too much experimental software to test in a busy working day. As a result, the combined functionality offered to users was not good enough and was characterized as a "living hell" in the Norwegian media. The pilot was aborted after only 3 months. A pilot user claimed to have lost a considerable amount of income during the pilot testing. The multi-million top-managed project was about to come to a complete stop. In order to make it more tempting for the two remaining electronic patient record vendors in the general practioner market, they got funding from the authorities that nearly matched their commitment costs. This funding was however, considered as extraordinary and do not represent a new practice.

A new version of the ePrescription was developed and tested in general practitioners' offices in a pilot 2 years after the first test, this time with much more successful outcome.

The service started running as a regular service throughout Norway in 2013, however the hospital sector is still not included.

Perspectives

Overview

We will now zoom in on 3 player groups that play significant roles in the case at hand and explain separately the experience of the 3 groups on the current situation. The 3 player groups are electronic patient record vendors, electronic patient record users, and authorities. Their perspectives provide insight to explain why the players act as they do.

Electronic Patient Record Vendors' Perspective

The vendors run a commercial enterprise, that means that they need to make some money in order to survive and hopefully give their owners some income on the investment made in the company. If they are not capable of that, they cannot stay in this business. All their development efforts are based on the needs of their customers who pay for their products in form of a yearly license and support services.

> *Our customers are our most important partners and we hope to keep them happy with our product, ensuring that they do not change suppliers. The challenge of dealing with our customers is that they do not speak with one voice—the wish lists they come up with are infinite and they prioritize their wishes differently. We prioritize improvements by compromising between the number of customers that want a specific improvement, the priority of this improvement among the customers, and the effort required to develop the improvement. However, the most challenging lists of improvements we get are the ones that come from the authorities every year. These lists influence the electronic patient record dramatically.* [Electronic patient record vendor]

The authorities use information in the electronic patient record for two reasons. First, they use this information as the basis for payments to hospitals and general practitioners. Second, they are interested in a variety of statistics, and the electronic patient record is a natural source of that kind of information. The vendors are required to comply with the list of demands from the authorities. For instance, health care institutions are obliged to send a certain amount of information when they send an electronic medical certificate to the authorities. Every time the authorities make a change in the information required, the electronic patient record system must be changed in order to fetch or assemble the necessary information. The vendor's estimations indicate that complying with the requirements advanced by the authorities takes up about 30 percent of their development resources. In addition to requirements from the authorities and orders and requests from their customers, the vendors get regular requests from a number of projects in Norway. These projects, most of them public, include many good ideas about new services they want to create in the health care sector. As soon as these planned services include some kind of patient information, the electronic patient record becomes a necessary communication object. However, those with the good ideas about new services seldom or never have any money to pay the electronic patient record vendors in order to integrate the service they want to create.

> *We experience this all the time! Well, it is one exception—when the pilot of the first version of ePrescription failed, we got an invitation to participate in the next version and this time we were promised good payment and offered a bonus payment if development was completed before a fixed date. I believe that the Directorate of Health had a bit panic due to the fiasco in the first version. However, the normal situation is that the authorities pay a lot of money to consultants and project groups to run the projects, but they do not pay those who are going to turn the idea into a reality. I find it strange. I wonder how many kilos of paper are produced without achieving any kind of implementation.* [Electronic patient record vendor]

Another problem the vendors have experienced with public projects is that they come up with specifications/requirements that are either too vague or quite specific. The vendors have to work extensively with these projects in order to understand what they actually mean by their specification. Even once they get an understandable specification, it is often not possible to implement it in the electronic patient record because it does not fit with the users' workflow. What appears to be an easy job often turns out to be complex and difficult. The vendors have also experienced that the initiatives from different public project groups seem not to be coordinated. The requirements are often so interwoven that they cannot be treated separately.

> *I wish that the authorities could coordinate their health care development efforts.* [Electronic patient record vendor]

Users' Perspective (Users in Terms of Health Care Personnel)

In health care, the electronic patient record is the most important ICT tool in use. Almost all information flow between different health organizations concerns patients. Because the health care system is divided into levels, the patients are moved between the levels depending on what kind of health care they receive. Moving patients include of cause moving patient information. This is stored in the electronic patient record, and a seamless electronic information flow is thereby an integral part of the electronic patient record system. The health care sector has become very dependent of this record because it contains enormous amounts of patient information and is woven into the work practice. Replace the electronic patient record is considered to be a huge task. Even general practitioners think twice before changing electronic patient records because of the considerable amount of work required to transfer the most important information from the old system to the new one and additionally, and a new system requires a new workflow.

Today, patient information is shared between different health care institutions on paper or in more "innovative" ways. X-ray photos are, for instance, transported in taxies between hospitals in some places in Norway. Health care personnel would like to have electronic seamless communication because they would avoid a lot of manual typing of information between the systems and could have a more efficient and safe exchange of patient information.

> *Creating new services between health organizations is very difficult task! I know—because I have been part of a group that pre-specified a new service and I must say I felt stupid. It is one thing to discuss how a new service or function should work in principle—but it is very difficult to imagine how it will meld together with the rest of the system. The final specification must be done during real testing, because we do not see the range of the new system before we test it in our setting.* [Health care personnel]

There are a lot of public projects going on, but the health care institutions must limit their involvement, because their patients are their first priority both in terms of ethical and economic issues. They understand that some of the services that are on the drawing table are so complex that it will takes years and years before they see any real results. In that case they find it difficult to get involved.

> *I think that the first time I heard that we were supposed to have electronic prescriptions was more than eight years ago. This service has recently been tested at full scale. It took years and years even though the project was run by the Directorate of Health. Our electronic patient record vendor devoted all their developers for more than a year just to complete the electronic prescription functionality. It was impossible to discuss anything other than prescriptions during that year!* [Health care personnel]

Developing new electronic services has also another important element, and that is the pilot testing. Health care personnel express that it costs blood, sweat, and tears to be a pilot user.

> *I would prefer not to think about how many hours we have spent during the test period we participated in. You must be mad to say "yes" to tests and experiments like these. The organizations that join this kind of test will experience drops in productivity, that's for sure.* [Health care personnel]

Health care institutions that have high efficiency find it difficult to participate in pilot testing, which is ironic because they should absolutely influence the ICT tools that they use every day.

> *My impression is that the developers do not understand how we work in practice, so you can't expect them to create something useful without our involvement. I have been in direct contact with the developer at our electronic patient record vendor, and I can really recommend that kind of cooperation. It is during the testing of the new functionalities that you really understand how it integrates with your work.* [Health care personnel]

Authorities' Perspective

The Norwegian authorities have worked intensively to create effective ICT for the health care sector and their strategy plans have been published regularly since late nineties. During the first years, they drew up the goals and tried to influence the sector by supplying it with a range of financing and allocated funds of diverse categories. Municipalities and others were encouraged to apply for these funds. The money has mainly been channeled through two organizations: Innovation Norway and the Directorate of Health. Innovation Norway is the Norwegian Government's most important instrument for the innovation and development of Norwegian enterprises and industry. The Directorate of Health is responsible for ensuring that policies are implemented in the health care sector, and they administer some money that is intended to stimulate electronic cooperation in the sector. This kind of funding has been largely based on competition, but some national projects have been able to include all the electronic patient record vendors (for general practitioners, municipalities, and hospitals) with funding from Innovation Norway. The idea is that the product (applying a function in an existing application) should be attractive to users and will create income in form of new sales and increased license income.

> *We are not willing to pay the electronic patient record vendors to make them develop functionality. The authorities should not be a partner in such trading.* [Member of the Ministry of Health]

Despite the various initiatives, the development within ICT in health care generally happens extremely slowly. Based on the evaluations that have been carried out during the last 10 years, it is clear that the health care sector do not often reach the goals set within electronic cooperation in the sector and still have yet to meet goals that were set many years ago. Due to this concern,

the authorities have decided to take charge of more of the ongoing work. The electronic prescription project was the first project that was managed from the directorate level, and there are more to come. These projects that are established in the directorate but still require approval from the government, so it is politicians that finally determine the commissioning of these projects. Norwegian Health Care Authorities do not have any unrestricted funds that the health care as one complete sector can spend on ICT development.

From the authorities' perspective, it looks like the electronic patient record vendors are the weak point in the chain, because all the projects that involved electronic patient record vendors were delayed.

> *We have in fact decided that a new service, the Core Health Record, should not be integrated with the electronic patient record in the initial versions. We cannot rely on the electronic patient record vendors because that will delay our goal of having a new Core Health Record within a few years. We do know that the clinicians will prefer, or even demand, to have the service integrated with their electronic patient records, but for the meantime we plan to avoid this problem area.* [Member of the Directorate of Health]

The authorities believe that the users of the cooperational tools must play the leading role by defining for their vendors how their information systems should work. It is also expressed by the authorities that the users of the systems should pay for the development of new functionalities.

> *If we just pay the vendors, they will not feel committed to the product they deliver. They will just develop it and leave it, without taking any kind of ongoing responsibility. If the vendors risk a great deal of equity capital, then I believe they will put a lot of effort into the product they are making, which will become attractive for their customers. There are so many vendors that the authorities cannot pay them all.* [Member of the Directorate of Health]

Moreover, the authorities must follow the international trading regulations in public procurement.

Discussion

Overview

In the following section we will elaborate on how the authorities' financing policies have affected the development process of information systems in the health care domain. First, we describe the unique position of the electronic patient record in health care. Second, we show how new legislations and big projects run by the authorities shift the focus away from the development of users wish list. Third, we describe the difficulty of navigating the customer/vendor relationship in the development of cooperational tools. Finally we summarize the effect of neo-liberalism within the focused topic.

The Electronic Patient Record: an Item That Does Not "Flow Freely"

The core idea driving the neo-liberalism is that vendors will create a diversity of products and will struggle to satisfy the market. In this way, the market will expand and the customers will be able to choose their preferred goods at any time. In the following section, we will explain why it is so difficult to equate information systems to any ordinary consumer product, thus presenting a challenge to market mechanisms.

In our study, we found that private companies develop and sell the most essential information systems in health care, namely the electronic patient records. Design issues are of concern between vendors and their customers [18]. The vendors spend a lot of resources in shaping the electronic patient records according to their customers' requests, and new versions are released regularly. The electronic patient record is a fundamental part of the information infrastructure in health care institutions. Replacing such a system is resource-intensive because of its heterogeneity [21]. It contains an enormous amount of data and is intertwined with working methods. Changing the electronic patient record in a hospital is a process with significant costs that normally takes years to complete, due to the necessity of transforming data from old to new systems and the organizational changes that the new system may cause [26]. The flow of interorganizational information in health care is mainly concerning patients. Since each institution has an electronic patient record, exchanging patient information has to be integrated with each record system. Otherwise, this will require extra work to manually transform data into the record system. Developing a new service between two or more levels in health care will, according to Information Infrastructure Theory, imply a pairing of two (or more) information infrastructures, which further implies that the heterogenic structure in all organizations are affected. This includes all electronic patient record vendors that deliver the systems and all the system users in all organizations involved.

Due to language issues, country-specific regulations, and health care structure, the electronic patient record is a product that is tailored to meet each country's specifications.

Within health care this means that (1) the electronic patient record is an item that customers seldom replace, (2) the electronic patient record is an obligatory passage point when it comes to the interchange of patient information, and (3) electronic patient record vendors act as gatekeepers in the development of electronic cooperation within health care systems.

Our findings may however be transformed into other domain than the health care sector. Electronic cooperation between organizations that have undergone independent development of their internal information infrastructure will most certain meet the same challenges that the health care sector has. Such critical information systems, like the electronic patient record, and their vendors will hold a unique position.

Interference From the Authorities: Clinical Issues Lose Priority

Neo-liberalism emphasizes that customers are powerful market players and declares that the authorities should not regulate the market because it is complex and unpredictable. We will now show how Norwegian authorities interfere with the electronic patient record market in such a way that customers' requests are given lower priority.

Electronic patient record vendors are regular commercial players that must profit to survive. Income is always one of the most important goals for a commercial player. Corporate board members will not accept recurring weak annual profits. Thus, electronic patient record vendors must balance payouts in relation to the effort they put into development, both over the short and long term. The long time frame refers mainly to the receipt of license revenues from their customers. Making a product that keeps old customers and attracts new ones therefore becomes crucial. The development department is staffed with the number of developers that the company's income justifies and the number is kept stable. The wish list concerning improvements of electronic patient records is, at any moment, always much longer than the development department can deal with, and it is always a matter of priority. Authorities' interference in the relationships between electronic patient record vendors and their customers has consequences for electronic patient record development—both in terms of functionality and priority. We found that the authorities have two powerful ways of influencing development of electronic patient record, through regulations and through funding. Through regulations, the vendor contracts with their health care customers obliges them to change the electronic patient record system according to any new regulations introduced by the authorities. Most of the newly adopted regulations are a result of economic and/or statistics concerns. Thus, the vendors have developers constantly working on regulatory compliance issues. Through funding, the authorities can buy the functionalities that they prioritize by contracting vendors, as in the second version of ePrescription, for example. Depending on the degree of funding, the electronic patient record vendors will prioritize the order from the authorities over the wish lists of their customers. The wish list will not disappear while working on well-paid orders from the authorities. In our case we found that the electronic patient record vendors spent more than a year producing the functionality that such an order demanded. As a result, the wish lists from their customers containing more basic functionalities were put on hold.

From the Norwegian health care case, we can suggest a more general result. When the authorities use regulations or well-paid assignments to interfere with information system development, the vendors' attention is drawn to the authorities' requests at the expense of the customers' requests. By doing so, the authorities interfere with a complex market and act contrary to the neo-liberal philosophy, which further implies that the users' requirement is downgraded.

So Much Planning and So Few Real Outcomes

Norwegian authorities need, according to the trading agreement with the European Union, to put out greater than 135,000 euros on public tenders before procurement. Grants to vendors and users for actually developing a new functionality in information systems are not in line with regulations and do not fit into the neo-liberalistic philosophy. We will now show how this impedes progress in establishing electronic cooperation within health care systems. Additionally, we will explain how the authorities have tried to initiate the development of cooperational functionalities. This investment actually wasted public money.

From the customers' perspective, we see that purchasing unfinished cooperational functionality is very difficult for the health care institutions to do, because it is impossible for them to invest money in something of unknown utility that will take years to develop. They also experience that pilot testing is very time consuming and affect the productivity. The users also describe that preparing requirements of a new cooperational service is extremely difficult because the new service have to fit into their own complex workflow and it is difficult to explain and understand how the new service is suppose to interplay with users in other organizations. The users are aware of the tight coupling between cooperation and how their work is infiltrated with the infrastructure in their job and in this way underpins some of the essence in Information Infrastructure Theory. To summarize, users find it difficult to order cooperational services due to weak economic incentives and that these services are extremely difficult to describe in advance. Thus, these users are not powerful players that are able to expand the aforementioned market that the basic philosophy of neo-liberalism assumes. Based on the vendors' perspective, we found that they often find that the effort required for development in public projects is much more than initially estimated. Underestimation often results from vague or poorly adapted design requirements. This matches the users' perspective and is a result of the complexity in information infrastructures. When the development of new services or functionalities include cooperation with other vendors, the oversight of the development phase decreases dramatically. No single vendor has control over the end product. Users do not pay for the new functionality in advance and public funding is rare and usually insufficient. ePrescription was the only exception. This means that the vendors are expected to take the economic risk when it comes to development of electronic cooperation within health care, but this often is a risk that they are not willing to take.

We found that several projects within new electronic collaboration tools in Norwegian health care have been financed with public money. What characterizes these projects is that vendors and pilot users are not included in the financing budget. Projects have been established and cooperational tools have been specified. These public projects find that it is extremely difficult to enroll electronic patient record vendors due to the situation described in the previous section. If the vendors do not have reason to believe that the new functionality will bring money to their company, the development will be put on hold. Thus the money invested in public projects will lead to money spent on planning and specification without any development and can be considered a waste of public money.

The concept of funding public projects to prepare user specification and order (or put out on a tender) is in line with the regulations concerning public procurements in the European

Economic Area market. However, these procedures are not well-suited for procurements that should end up with electronic services between information infrastructures.

Summary: Cooperational Electronic Tools in Health Care

In this paper we focused on the challenge to develop electronic communication between health care institutions. This kind of cooperation in the health care sector is an expressed goal from the sector itself and the authorities have underlined such strategies in a last 15 years through their strategy documents. Electronic patient record vendors are dependent on satisfied customers and are in this respect positive to interorganizational electronic information flow as well. All three groups that are focused in this study want to achieve innovation within the current topic but the progress is limited. The discussion showed the mechanisms that oppose the innovation. Our findings are summarized in Table 2, representing the effects of the funding policy for innovation within electronic cooperation in Norwegian health care using Pollitt's definition [14].

Developing electronic communication between separate players involves system innovations across organizational borders. This requires long term coordination of activities to achieve common goals and interests. The new public management and neo-liberal reforms have created a system that counterworks such aims. Strengthened weight on operational effects as business efficiency and local sustainability on a decentralized level create negative effects on a processing and systems level. The different players in this case are fenced within their local rationality; health care service institutions are linked to daily activity to fulfill the needs of their clients, the private firms have to fulfill business goals, and the public authorities' steering is restricted to the role of a distant and passive owner, with instruments/incentives adapted to a limited market situation. A main general result is incongruence and distance between uncoordinated players, unable to obtain a common innovation result.

Table 2. Effect of neo-liberalistic policy concerning innovation of electronic cooperation tools in Norwegian health care.

Player	Operational effects	Process effects	System effects
Electronic patient record vendors	business efficiency	insufficiently financed	innovation deficit
Health care institutions	high efficiency	difficult participation	innovation unable
Authorities	reduced steering	partly financing	innovation not obtained

Limitations

This study did not included issues like standardization, legalization, security, and development techniques.

Conclusion

In this study, we found several reasons why there has been little progress in establishing electronic cooperation within Norwegian health care despite the common desire from health care users and authorities, who pay for more than 80% of health care expenses. We found that health care institutions have established separate information infrastructures and that cooperational services will be the interconnection of information structures. Such interconnections will be a very difficult due to the intertwining between workflow, information system, and organizational issues in each organization. In the health care sector, the electronic patient record has a unique position in the information structure, because information and cooperation is centralized to this information system. Essential information systems, like the electronic patient record, will be difficult for customers to switch and are not easily changed to the best available in the market. If public health care plans for new cooperational services or functionalities that involve the electronic patient record, the initiatives will be stopped by the vendors of these systems that do not foresee the possibility of their customers (general practitioners, hospitals, municipalities) paying extra for the service or functionality. However, electronic patient record customers will find it difficult to pre-order something that will take years to develop and to do so without knowing, up front, the user friendliness of the new service and functionality. The authorities who, to a large extent practice neo-liberalistic principles, have not taken extraordinary steps to compensate for this. The philosophy is that the users of electronic patient records should pay for further electronic patient record development. Public projects in the case at hand, which just finances project management, will lead to money spent on planning and specification without any further development toward convenience because vendors and user are not willing to spend resources without compensation.

We found also that the authorities are interfering with the development of functionality in electronic patient records as they have come up with new legislation and in one occasion, paid for development in a project that was ran by the Directorate of Health. In this way, the electronic patient record vendors' attention is drawn to the authorities' requests at the expense of the customers' requests.

Recommendation

To obtain innovation across borders between different and separate players, 2 strategies may be discerned: (1) either specific incentives tailored to the specific criteria of the innovation object and its target, inserted externally from higher level, or (2) the system should be reformed to suit a broader set of goals and functions, while satisfying the type of innovation needed. Due to the nature of ICT in health care, the reform strategy is not suitable because such information infrastructure needs to be expanded stepwise [27]. We will therefore recommend the strategy based on incentives tailored to ICT in health care. It is, however, critical that the goals are inserted by actual health care users. ICT in health care is a very complex domain so the users must *not* play the role of consultants, but of deciders. An improvement would be to prolong planning and elucidation to implementation, expand public financing to cover implementation, and create a common institutional structure

between the group of players to include them as joint implementators.

Acknowledgments

This study has been partly funded by grants from the Health North Authorities and The Norwegian Centre for Integrated Care and Telemedicine. We want to express our thanks to interview subjects that have contributed their experience and opinions.

Conflicts of Interest

None declared.

References

1. Greenhalgh T, Potts HW, Wong G, Bark P, Swinglehurst D. Tensions and paradoxes in electronic patient record research: a systematic literature review using the meta-narrative method. Milbank Q 2009 Dec;87(4):729-788 [FREE Full text] [doi: 10.1111/j.1468-0009.2009.00578.x] [Medline: 20021585]
2. OECDiLibrary. 2010. Public social expenditure as a percentage of GDP URL: http://www.oecd-ilibrary.org/social-issues-migration-health/public-health-spending_20743904-2010-table4 [accessed 2013-03-22] [WebCite Cache ID 6FJJX9l1F]
3. OECDiLibrary. 2011. Public expenditure on health As a percentage of total expenditure on health URL: http://www.oecd-ilibrary.org/social-issues-migration-health/public-expenditure-on-health-2011_hlthxp-pub-table-2011-1-en [accessed 2013-03-22] [WebCite Cache ID 6FJJsXNyF]
4. Danish National Strategy. National strategy for digitalisation of the Danish healthcare service 2008-2012. Digital Health Connected Digital Health in Denmark 2007 Dec [FREE Full text]
5. Nationell eHälsa-strategin för tillgänglig och säker information inom vård och omsorg.: Swedish Social Departement; 2009. URL: http://regeringen.se/sb/d/108/a/148429 [accessed 2013-03-23] [WebCite Cache ID 6FKsPCThj]
6. Department of Health, UK. National Strategic Programme. 2002 Jun 11. Delivering 21st century IT support for the NHS URL: http://webarchive.nationalarchives.gov.uk/+/www.dh.gov.uk/en/Publicationsandstatistics/Publications/PublicationsPolicyAndGuidance/DH_4008227 [accessed 2013-04-23] [WebCite Cache ID 6G65NX8gi]
7. Halford S, Lotherington AT, Obstfelder A, Dyb K. Getting the whole picture? Information, Communication & Society 2010 Apr;13(3):442-465. [doi: 10.1080/13691180903095856]
8. Dean M. Governmentality: power and rule in modern society. London: Sage Publications; 1999.
9. Friedman M, Friedman RD. Capitalism and freedom. Chicago: University of Chicago Press; 2002.
10. Miller PN, Foucault M, Burchell G, Gordon C. Governmental rationality: an introduction. In: The Foucault effect: studies in governmentality: with two lectures by and an interview with Michel Foucault. Chicago: University of Chicago Press; 1991.
11. Claes DH, Mydske PK. Forretning eller fordeling?. Oslo, Norway: Universitetforlaget; 2011.
12. Mydske P, Claes DH, Lie A. Nyliberalisme: ideer og politisk virkelighet: Universitetsforlaget. Oslo, Norway: Universitetsforlaget; 2007.
13. Harvey D. A brief history of neoliberalism. Oxford: Oxford University Press; 2007.
14. Pollitt C, Bouckaert G. Public management reform: a comparative analysis. Oxford: Oxford University Press; 2004.
15. European Union. 1994. URL: http://eeas.europa.eu/eea/ [accessed 2013-04-02] [WebCite Cache ID 6FaO5Sbcn]
16. The EFTA Court. 1992. URL: http://www.eftacourt.int/ [accessed 2013-04-02] [WebCite Cache ID 6FaO7AUJu]
17. Biagioli M. Some elements of a sociology of translation: domestication of the scallops and the fishermen of St Brieuc Bay. In: The science studies reader. New York: Routledge; 1999.
18. Porter M. The competitive advantage of nations: with a new introduction. New York: Free Press; 1998.
19. Laerum H, Ellingsen G, Faxvaag A. Doctors' use of electronic medical records systems in hospitals: cross sectional survey. BMJ 2001 Dec 8;323(7325):1344-1348 [FREE Full text] [Medline: 11739222]
20. Ellingsen G. Global reach, local use: design and use of electronic patient record systems in large hospitals. Trondheim: Norwegian University of Science and Technology; 2002.
21. Hanseth O, Lyytinen K. Theorizing about the design of information infrastructures: design kernel theories and principles. Sprouts: Working Papers on Information Environments, Systems and Organizations 2004;4(4):207-241 [FREE Full text]
22. Yin RK. Case study research: design and methods (applied social research methods). California: Sage Publications, Inc; 2008.
23. Walsham G. Interpretive case studies in IS research: nature and method. Eur J Inf Syst 1995 May 1995;4(2):74-81. [doi: 10.1057/ejis.1995.9]
24. Schleiermacher F. In: Kimmerle H, editor. Hermeneutics: the handwritten manuscripts. Missoula, Mont: Scholars Press for the American Academy of Religion; 1977.
25. Walsham G. Interpreting information systems in organizations. Chichester, West Sussex, England: Wiley; 1993.

26. Ellingsen G, Monteiro E. Big is beautiful: electronic patient records in large Norwegian hospitals 1980s-2001. Methods Inf Med 2003;42(4):366-370. [doi: 10.1267/METH03040366] [Medline: 14534635]
27. Hanseth O, Monteiro E. Defining information infrastructures. In: Understanding information infrastructures. Oslo, Norway: University of Oslo; 1998.

Abbreviations

EEA: European Economic Area
EFTA: European Free Trade Association
ICT: information and communication technology
NIA: National Insurance Administration
NMA: Norwegian Medicines Agency

Edited by G Eysenbach; submitted 12.09.12; peer-reviewed by M Aanestad; comments to author 03.10.12; revised version received 22.11.12; accepted 10.02.13; published 19.06.13.

Please cite as:
Larsen E, Mydske PK
Developing Electronic Cooperation Tools: A Case From Norwegian Health Care
Interact J Med Res 2013;2(1):e9
URL: http://www.i-jmr.org/2013/1/e9/
doi:10.2196/ijmr.2346
PMID:23782708

Publisher:
JMIR Publications
130 Queens Quay East.
Toronto, ON, M5A 3Y5
Phone: (+1) 416-583-2040
Email: support@jmir.org