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Original Paper

Moderating Effects of Voluntariness on the Actual Use of Electronic Health Records for Allied Health Professionals

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Abstract

Background: Mandatory versus voluntary requirement has moderating effect on a person's intention to use a new information technology. Studies have shown that the use of technology in health care settings is predicted by perceived ease of use, perceived usefulness, social influence, facilitating conditions, and attitude towards computer. These factors have different effects on mandatory versus voluntary environment of use. However, the degree and direction of moderating effect of voluntariness on these factors remain inconclusive.

Objective: This study aimed to examine the moderating effect of voluntariness on the actual use of an electronic health record (EHR) designed for use by allied health professionals in Hong Kong. Specifically, this study explored and compared the moderating effects of voluntariness on factors organized into technology, implementation, and individual contexts.

Methods: Physiotherapists who had taken part in the implementation of a new EHR were invited to complete a survey. The survey included questions that measured the levels of voluntariness, technology acceptance and use, and attitude towards technology. Multiple logistic regressions were conducted to identify factors associated with actual use of a compulsory module and a noncompulsory module of the EHR.

Results: In total, there were 93 participants in the study. All of them had access to the noncompulsory module, the e-Progress Note, to record progress notes of their patients. Out of the 93 participants, 57 (62%) were required to use a compulsory module, the e-Registration, to register patient attendance. In the low voluntariness environment, Actual Use was associated with Effort Expectancy (mean score of users 3.51, SD 0.43; mean score of non-users 3.21, SD 0.31; *P*=.03). Effort Expectancy measured the perceived ease of use and was a variable in the technology context. The variables in the implementation and individual contexts did not show a difference between the two groups. In the high voluntariness environment, the mean score of Actual Use was associated with Performance Expectancy (*P*=.03), Organization Facilitating Condition (*P*=.02), and Interest in Internet and Computer (*P*=.052) in univariate analyses. The only variable left in the logistic regression model was Organization Facilitating Conditions (mean score of users 3.82, SD 0.35; mean score of non-users 3.40, SD 0.48; *P*=.03), a variable in the implementation context. The factors affecting actual use were different in mandatory and voluntary environments, indicating a moderating effect of voluntariness.

Conclusions: The results of this study have provided preliminary supports of moderating effects of voluntariness on the use of EHR by allied health professionals. Different factors were identified to be associated with actual use: (1) Ease of Use in mandatory environment, and (2) Organization Facilitating Conditions in voluntary environment. More studies are needed to examine the direction of moderating effects. The findings of this study have potential practical implications. In sum, voluntariness can be a highly relevant and important moderating factor not to be ignored in the design and evaluation of EHR.

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KEYWORDS

health information technology; technology acceptance; user behavior; allied health; attitude towards technology

Introduction

Background

This research aimed to study the role of voluntariness on the actual use of electronic health records (EHR). According to the Unified Theory of Acceptance and Use of Technology (UTAUT) model, voluntariness moderates the effect of *social influence* on intention to use [1]. Other than social influence, a meta-analysis study [2] found that voluntariness also moderates the effects of *ease of use* and *usefulness* on the intention to use a new information technology. Although these factors have provided evidence to explain in part the reasons of technology acceptance among health professionals, researchers in the health care field have argued that the technology acceptance models developed in business settings have not included factors unique to health care professionals [3,4]. A model that is adapted specifically to the health care context is needed [5].

Different technology acceptance concepts have been adapted for use in health care settings. Chau and Hu studied the doctor's acceptance of telemedicine technology [3] and proposed a hierarchical conceptual structure of acceptance: the *individual context* in the inner core and the *technological context* in the middle layer, surrounded by the *implementation context* on the outermost layer. The concept emphasized the importance of individual context in order to predict doctor's adoption of technology. Chau and Hu's work was further adapted by Schaper and Pervan [4] in a study of allied health professionals' intention to use information communication technologies (ICT) at work. Integrating the conceptual structure of UTAUT and Chau and Hu's model, Schaper and Pervan [4] proposed a model that explains how *intention to use* is affected by three contexts of use: (1) *individual context* (computer anxiety, computer self-efficacy, computer attitude), (2) *technological context* (perceived usefulness and perceived ease of use), and (3) *implementation context* (social influence, compatibility, and organizational facilitating conditions). The model was validated using survey data of 2044 Australian occupational therapists. The study measured the self-reported use of ICT at work for the purposes of clinical, administrative, and professional development [6]. The results supported the direct effect of *effort expectancy* and *compatibility* on *behavior intention* but did not support the direct effect of *performance expectancy*, *social influence*, and *attitude* on intention. Recently, the UTAUT model was adapted by Venkatesh and colleagues to explain doctor's adoption and use of an EHR system [7]. The results showed that age moderated between the acceptance and use of EHR *and effect expectancy*, *performance expectancy*, *social influence* and *facilitating conditions*. The adapted UTAUT model explained the intention to use better than the original model when applied in the health care context. Different explanatory models have found differing conceptual constructs of the use behaviors in health care context. One possible explanation of the differences could be the moderating effects of voluntariness. A literature review on the moderating effects of voluntariness on use behaviors is presented in the next section.

Moderating Effects of Voluntariness on Actual Use in Technological, Implementation, and Individual Contexts

Figure 1 represents the conceptual model of the study of the moderating effects of voluntariness on actual use. The conceptual model includes the theoretical constructs from the UTAUT [1,8], Chau and Hu's framework [3], and Schaper and Pervan's model [4,6]. The three contexts that influence actual use are *technological context*, *implementation context*, and *individual context*. This study focuses on *actual use* instead of *intention to use* of EHR because there is limited empirical evidence of the moderating effect of voluntariness on actual use [2]. The model also proposed the moderating effects of voluntariness in each context.

In the technology context, *perceived usefulness* and *perceived ease of use* are two main factors that influence *actual use*. According to the UTAUT, *effort expectancy*, and *performance expectancy* are the main factors that influence *behavioral intention*, which in turn predicts *actual use* of technology systems. Voluntariness does not moderate the technology context according to UTAUT [1,8]. However, in a meta-analysis of studies conducted in education and business contexts, the results showed that voluntariness moderated the effects of *ease of use* and *usefulness* on intention to use [2]. Such effects were stronger in a highly volunteer-driven environment (voluntary use) than in a low volunteer-driven environment (mandatory use). Similar findings have been reported in studies conducted in health care settings. In highly volunteer-driven environment, studies showed that *perceived ease of use* but not *perceived usefulness* significantly predicted *intention to use* a new EHR by physicians [9], and a modified case management system by health and social service professionals [10]. In both studies, the results showed that *intention to use* was predicted by *perceived ease of use* ($P<.05$) but not *perceived usefulness* (P=ns). However, in a study of the mandatory use of a homecare telemonitoring system in Spain, Asua and colleagues [11] found that the intention to use the system by physicians and nurses was predicted by *perceived usefulness* ($P=.02$) but not *ease of use* (P=ns). Contrary to these studies, Gangnon and colleagues [12] found that neither *perceived usefulness* nor *perceived ease of use* was a predictor of *intention to use* of a telemonitoring system. On the other hand, the literature is more consistent when the studies were conducted in a low volunteer-driven environment. The findings showed that *perceived usefulness* and *perceived ease of use* had similar effects on *intention to use* [13-15]. The technologies evaluated in the studies included a barcode system for bed-side medication administration [13], e-ICU technology by nurses [14], mobile health record by homecare nurses in Ontario, Canada [15], an EHR system by doctors [7], and a health information system by administration and medical staff in Greece [16]. All four studies found that *intention to use* was predicted by *perceived usefulness* ($P<.05$). Only one study evaluated the actual use of an EHR system. The results showed that perceived usefulness ($P<.05$) but not perceived ease of use ($P<$ns) predicted actual use [9]. In sum, the literature supported the moderating effects of voluntariness in technology context. Although the direction of moderating effect in highly volunteer-driven environments remains inconclusive, their effects are likely to be stronger than those of low volunteer-driven environments.

In the *implementation context*, *social influence* and *facilitating conditions* are two factors that influence *actual use*. According to the original UTAUT [1], voluntariness moderates the relationship between *social influence* and *behavioral intention*. However, when the UTAUT model was adapted to examine the use of EHR by doctors, *age* but not *voluntariness* was found to moderate the relationship between *social influence* and *behavior intention* [7]. Contrary to the UTAUT model, studies conducted in highly volunteer-driven environments have shown different relationships. Studies showed that *intention to use* was not influenced by *social influence* but *facilitating conditions* [11,12]. Ausa and colleagues [11] found that the intention to use a system by physicians and nurses was predicted by *facilitating conditions* (P<.001) but not *social norm* (P=ns). Gagnon and colleagues [12] studied the compulsory use of a telemedicine system in a clinical trial conducted in Spain and reported that the only factor remained in the final model of logistic regression was *facilitating condition* (P<.001), indicating the exclusion of *social influence* (P=ns) from the model. On the other hand, studies conducted in low volunteer-driven environments showed that *social influence* and *facilitating conditions* had similar effects on *intention behavior* [7,13,15], and *actual use* [16]. Aggelidis and colleagues [16] reported that both *social influence* (P<.05) and *facilitating conditions* (P<.05) predicted *actual use* of a health information system. Vanketash and colleagues [7] found significant effects of social influence on intention to use (P<.01) and facilitating conditions on actual use (P<.05). Holden and colleagues [13] reported a significant predictive effect of social influence on intention to use (P<.01). Zhang et al also [15] found an indirect effect of subjective norm on intention to use. In sum, the literature supported the moderating effects of voluntariness in implementation context. Such effects would likely be stronger in a highly volunteer-driven environment than in a low volunteer-driven environment.

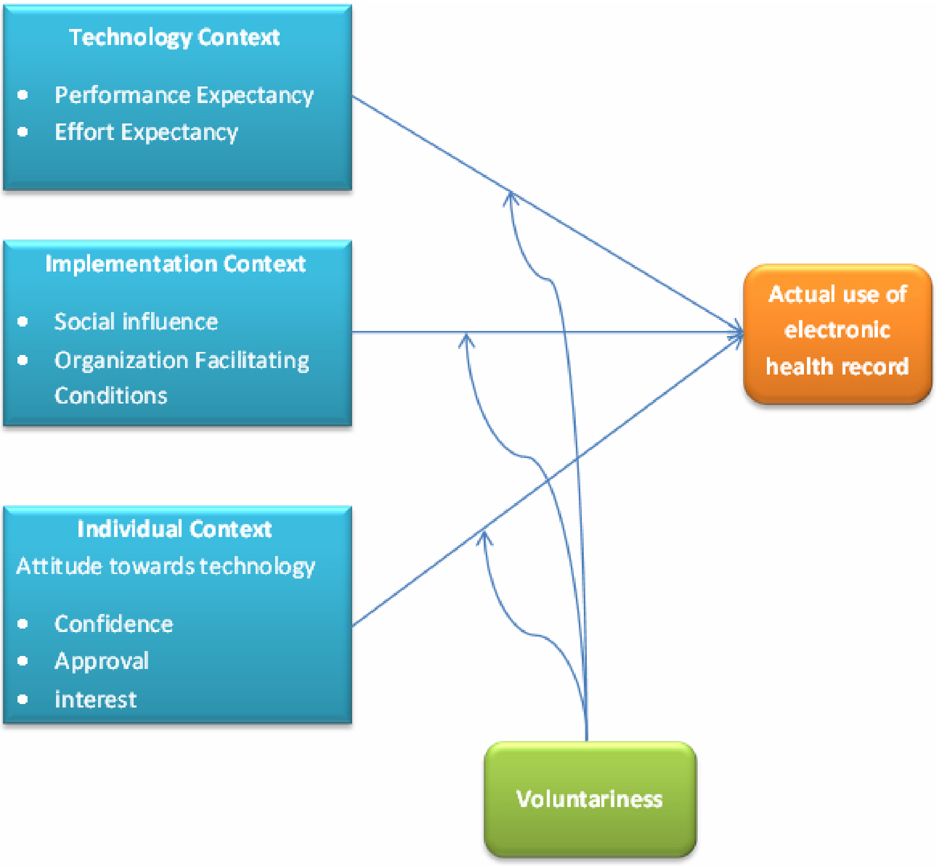
The individual context refers to a person's attitude towards technology in general. In highly volunteer-driven health care environment, individual context seemed to have limited impact on intention to use. Gagnon and colleagues [9] reported that *computer self-efficacy* (P=ns) did not predict *intention to use*. Schaper and Pervan [4] also found that *attitude towards computer* (P=ns) did not have an impact on *intention to use*. On the other hand, individual context was found to have a positive influence on intention to use in a low volunteer-driven environment. Aggelidis and Chatzoglou [16] found that *self-efficacy* (P=.05) and *attitude* (P=.05) to use computer had significant impact on the actual use of a health information system by administration and medical staff. Although there are limited studies that examine attitude towards technology in health care settings, the literature has suggested a moderating effect of voluntariness on individual context. The effect of attitude towards technology on use behavior would likely be present in a highly volunteer-driven environment but absent in a low volunteer-driven environment.

Even though the literature supported the moderating effects of voluntariness on the use of health technology, the degree and direction of its moderating effect remains inconclusive especially in the technology and individual contexts. This study aimed to address the knowledge gap and to examine its moderating effect on the actual use of an EHR for use by allied health professionals in Hong Kong. Specifically, this study explored the voluntariness and compared the mandatory and voluntary use behaviors in technology, implementation, and individual contexts (Figure 1). Table 1 presents the research hypotheses in the three contexts.

Table 1. Hypotheses of moderating effects of voluntariness on technology, implementation, and individual contexts.

Hypothesis	Supported literature
Technology context	
In high voluntariness environment,	
H1 - Performance expectancy is not associated with use H2 - Effort expectancy is associated with use	[9-12]
In low voluntariness environment	
H4 - Effort expectancy is associated with use H3 - Performance expectancy is associated with use	[7,13-16]
Implementation context	
In high voluntariness environment,	
H5 - Social influence is not associated with use H6 - Facilitating condition is associated with use	[11,12]
In low voluntariness environment,	
H7 - Social influence is associated with use H8 - Facilitating condition is associated with use	[7,13,15,16]
Individual context	
In high voluntariness environment,	
H9 - Attitude towards technology is not associated with actual use	[6,9]
In low voluntariness environment	
H10 - Attitude towards technology is associated with actual use	[16]

Figure 1. Conceptual model of the moderating effects of voluntariness on actual use.



Methods

Design and Procedure

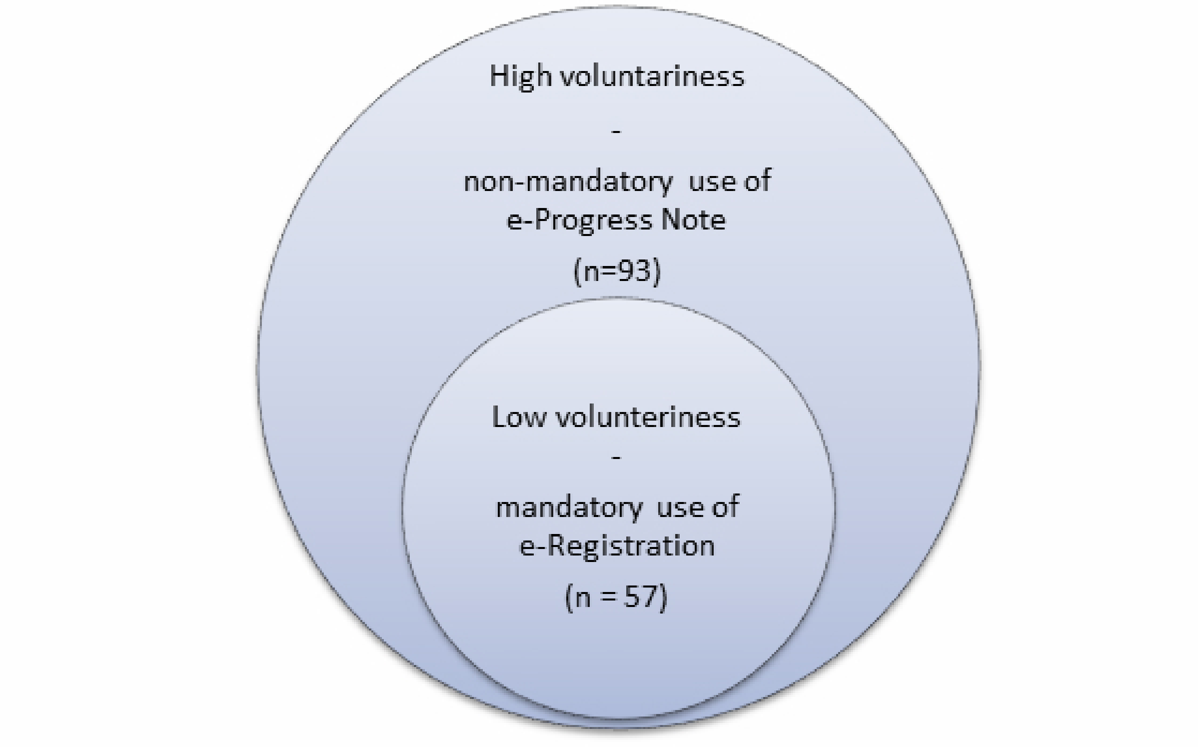
The study was conducted in the Hospital Authority, the Hong Kong Special Administration Region. The EHR system of the Hospital Authority introduced a module called Allied Health Progress Note (AHPN) that was designed for the allied health professionals including physiotherapists, occupational therapists, and other allied health professionals. Between September 2011 and January 2012, a survey was conducted to invite physiotherapists who had taken part in the implementation of the AHPN. During the study, there were 135 physiotherapists who worked in eight hospitals that participated in the trial and implementation of the AHPN, and were all invited to take part in the survey. Ethics approvals were obtained from the Hospital Authority and the Hong Kong Polytechnic University.

Variables/Instruments

Level of Voluntariness

Two modules of the AHPN, *e-Registration* and *e-Progress Note*, were provided to the allied health professionals to enter health information onto the EHR system. Figure 2 presents the relationship between the two study groups in the low and high levels of voluntariness. The voluntariness scale developed by Moore and Benbasat [17] was used to define the levels of voluntariness in this study.

Figure 2. The sample distribution in the high and low voluntariness environments.



High Voluntariness Environment

The *e-Progress Note* was a nonmandatory module for all participants (n=93). Therapists had the autonomy to record the progress of their patients either using the e-Progress or paper-based health records. The nonmandatory use of the e-Progress Note module formed a high voluntariness environment in this study.

The *e-Progress Note* module was designed to support data entry in a free-text format. Designated computers with the AHPN installed were available for the therapists to type the progress notes onto the system. Multimedia Appendix 1 is a screenshot of the module.

Low Voluntariness Environment

The *e-Registration* was a compulsory module in in-patient units in the study sites. A subsample of physiotherapists (n=57) who worked in in-patient settings were included. The physiotherapists in the other units, such as outpatient, chose to use the e-Registration module on a voluntary basis. The mandatory use of e-Registration module by the subsample of physiotherapists formed a low voluntariness environment in this study. The e-Registration module was designed to record daily workload using electronic data entry. Instead of typing the data onto the AHPN, the therapists prepared a list of patients they have treated by affixing labels containing the hospital identity number of the patients on a paper form. The therapists then scanned the form to electronically enter the data onto the e-Registration module. Alternatively, they could delegate the scanning task to the clerical staff in the department. Multimedia Appendix 2 is a screenshot of the module.

Actual Use of the EHR

Actual use was measured based on self-reported frequency of use. In the e-Progress Notes module, actual use was defined as the self-reported frequency of using the module in the past month. *Users* referred to the participants who selected “All of my cases”, “Most of my cases” or “About Half of my cases”.

Non-users referred to those who selected “A few of my cases” or “None of my cases”.

In the e-Registration module, actual use was defined as the self-reported frequency of completing the scanning task in the past month. *Users* referred to participants who completed the scanning process by themselves most of the time. *Non-users* referred to those who delegated the scanning task to clerical staff.

Technological Context

Performance expectancy was defined as the degree to which an individual believes that the use of the AHPN will help him/her to improve job performance [1]. In addition to the four original UTAUT items, four new items specific to the allied health workflow in the Hospital Authority in Hong Kong were added. Table 2 presents the Cronbach alpha of each measurement.

Effort expectancy was defined as the degree to which a person perceives the system as easy to use [1]. The four original UTAUT items were used in the study.

Table 2. Measurement and Cronbach alpha.

Context	Measurement	Cronbach alpha
Technology context	Performance expectancy (8 items)	.89
	Effort expectancy (4 items)	.65
Implementation context	Social influence (4 items)	.65
	Organizational Facilitating Condition (4 items)	.73
Individual context	Confidence (10 items)	.82
	Approval (10 items)	.83
	Interest (10 items)	.87

Implementation Context

Social influence was defined as the degree to which an individual perceives that important others believe he/she should use an information system [1]. The original UTAUT items were used in the study.

Organizational facilitating condition was defined as the degree to which an individual believes an organizational and technical infrastructure exists to support the use of the system [1]. This includes factors such as management support, training, and provision of computer support. The original UTAUT items were used in the study.

Individual Context

Individual context referred to an individual’s attitude towards the use of information technology in general. It was measured using the Technology Profile Inventory [18], which is consisted of three subscales. *Confidence* was defined as an individual’s confidence when working with computers and information systems. *Approval* was defined as the degree to which an individual feels positively about information technology as a tool to accomplish various tasks. *Interest* was defined as the intrinsic interest of an individual toward the use of information technology [19].

Data Analysis

Univariate analysis was conducted using independent sample *t* test to compare each factor between the user and nonuser groups. Factors with *P* value less than .10 were entered to the multiple logistic regression model for analysis [20]. The SPSS (Statistical Package for the Social Sciences) software program version 19.0 was used to analyze the data.

Results

Participant Characteristics

A total of 93 out of 135 eligible physiotherapists participated in the study, representing a 69% response rate. Among the 93 participants, 65 of them (70%) were 31 to 50 years old and 47 (51%) were male therapists. Sixty-three (68%) had 11 to 30 years of experience, and 57 worked in in-patient settings (61%). Seventy participants reported that they spent less than 20 hours per week using personal computer (75%). Figure 2 shows the relationship of the samples in the high and low voluntariness environments. All participants (n=93) had access to the e-Progress Note module of the AHPN for use on a voluntary basis (high voluntariness environment). A subsample of the participants (n=57) who worked in in-patient units must use the e-Registration module of the AHPN (low voluntariness environment).

Factors Associated With Actual Use in Low and Highly Volunteer-Driven Environments

Out of the 93 respondents in the high voluntariness environment 8 individuals (9%) used the e-Progress Notes. The univariate analysis results (Table 3) showed that *actual use* was associated with three factors: *performance expectancy* (*P*=.03), *organization facilitating condition* (*P*=.02), and *interest in Internet and computer* (*P*=.05). There were no association between *actual use* and the following variables: *effort expectancy*, *social influence*, and *the confidence*, *interest*, and *approval* of information technologies. The multiple logistic regression analysis showed that *organization facilitating conditions* (*P*=.02) was the only factor left in the final model and explained 16.5% of variance.

Table 3. Factors associated with actual use in high and low voluntariness environments (n=93).

	High voluntariness environment – e-Progress Note (n=93)			Low voluntariness environment – e-Registration (n=57)		
Variables	Users (N=8) Mean (SD)	Non-users (N=85) Mean (SD)	*P* value (*t* test)	Users (N=44) Mean (SD)	Non-users (N=13) Mean (SD)	*P* value (*t* test)
Technological context						
Performance expectancy	3.72 (.19)	3.21 (.64)	.03[a]	3.29 (.60)	3.15 (.48)	.47
Effort expectancy	3.68 (.52)	3.44 (.41)	.13	3.51 (.43)	3.21 (.31)	.03 [a]
Implementation context						
Social influence	3.53 (.51)	3.38 (.55)	.45	3.44 (.61)	3.21 (.44)	.22
Facilitating condition	3.82 (.35)	3.40 (.48)	.02 [a]	3.44 (.53)	3.35 (.41)	.59
Individual context						
Confidence	3.38 (.29)	3.40 (.49)	.93	3.38 (.53)	3.24 (.39)	.38
Interest	3.60 (.26)	3.24 (.50)	.05 [a]	3.27 (.46)	3.11 (.48)	.28
Approval	4.05 (.50)	3.89 (.51)	.39	3.91 (.52)	3.66 (.44)	.12
TPI scale	3.68 (.26)	3.51 (.41)	.26	3.52 (.41)	3.33 (.34)	.15

[a] *P*<.1 in univariate analysis; A higher score indicates a more positive rating

In the low voluntariness environment, 44 out of 57 participants (77%) completed the scanning task of the e-Registration module. The remaining participants (n=13) completed the scanning task with the help of a clerical staff. Table 3 shows the univariate analysis results. *Actual use* was associated with *effort expectancy* (*P*=.03) but not the following variables: *performance expectancy, social influence, organization facilitation condition,* and the *confidence, interest,* and *approval* of information technologies. A logistic regression of Effort Expectancy on Actual Use explained 34.6% of variance.

Moderating Effects of Voluntariness on the Associations Between Actual Use and Technology, Implementation, and Individual Contexts

The study proposed a stronger moderating effect in a high voluntariness environment than in a low voluntariness environment within technology context. The results showed that the two hypotheses related to high voluntariness environment (e-Progress Note) were not supported. H1 hypothesized that performance expectancy would not be associated with use but the results showed an association between them (*P*=.03). Users of the e-Progress Note perceived the module as more useful than nonusers. H2 hypothesized an association of effort expectancy with use but the results showed no association (*P*=ns). Another two hypotheses were tested in the low voluntariness environment (e-Registration). H3 hypothesized an association between effort expectancy and use and the results supported the hypothesis and found a positive association (*P*=.03). Users of e-Registration perceived the module as more easy to use than nonusers. However, H4 hypothesized an association between performance expectancy and use behavior but the results showed no association (*P*=ns). Only one out of four hypotheses was supported. Although not all hypotheses were supported, voluntariness showed a moderating effect opposite to the proposed direction.

Another four hypotheses were proposed to test the moderating effects of voluntariness in implementation context. The study expected that the effects would be stronger in a high voluntariness environment than in a low voluntariness environment. The results supported H5 and H6 that were tested in the high voluntariness environment (e-Progress Note). H5 hypothesized no association between social influence and use, and the results showed no association as hypothesized (*P*=ns). H6 hypothesized an association between facilitating condition and use. The results supported the hypothesis and found an association as hypothesized (*P*=.02), indicating that users perceived more facilitating conditions than non-users for the use of the e-Progress Note. However, the two hypotheses tested in the low voluntariness environment (e-Registration) were not supported. H7 hypothesized that social influence was associated with use, but the results showed no association (*P*=.22). H8 hypothesized that facilitating condition was associated with use, but the results showed no association (*P*=.59). In sum, two out of four hypotheses were supported by the findings. Although the direction of association in the low voluntariness environment (H7 & H8) was opposite to the hypothesized direction, voluntariness moderates the implementation context on use behavior. The moderating effect was present but in an opposite direction as proposed.

The last two hypotheses were tested in the individual context. H9 hypothesized that in high voluntariness environment (e-Progress Note) attitude towards technology would not be associated with actual use. The results showed that there was no association (*P*=ns) in the total TPI scale but an association in the Interest subscale (*P*=.05). Users of the e-Progress Note had a greater interest in information technologies in general than non-users. H6 hypothesized that in low voluntariness environment (e-Registration) attitude towards technology would be associated with actual use. The results found no association (*P*=ns). Although both hypotheses were not supported, the impact of attitude on use behavior was likely to be present in voluntary environment and absent in mandatory environment. The results supported the presence of moderating effect but in an opposite direction.

Discussion

The study had several limitations. The sample size was small, especially the subsample of the low voluntariness environment (e-Progress Note). If a larger sample was available, some factors might show an association with actual use such as the attitude towards technology (*P*=.15) and the approval subscale (*P*=.12). The small sample size could not provide sufficient power to confirm the moderating effects of voluntariness on the factors being tested. Furthermore, the sample was recruited from hospitals that were early adopters of the APHN. The use behavior and the moderating effect of voluntariness of early adopters may be different from that of early majority, late majority, or laggards [21]. Another limitation was that only physiotherapists were involved. The study did not include other allied health professionals such as occupational therapists, speech therapists, etc. The generalizability of the findings to other allied health professionals remains unclear. These limitations could be addressed if further studies include a representative sample of other allied health professions from more hospitals undergoing full implementation.

Despite the limitations, the study has provided some preliminary evidence that voluntariness moderates the factors affecting the actual use of APHN. Specifically, such effects were present in all three contexts but showing a moderating effect opposite to the proposed direction. The findings were most consistent with the studies in high voluntariness environment within the implementation context. The studies conducted in mandatory environment showed an association between intention to use and social influence but not facilitating conditions [11,12]. Several findings were unexpected because the moderating effect was found to be presented in an opposite direction. For example, in the voluntary use of e-Progress Note, users perceived it as more useful than nonusers, and the perceived ease of use ratings were similar in both groups. However, the literature showed that perceived ease of use but not perceived usefulness predicted intention to use in high voluntariness context [9,10]. A possible explanation of the opposite direction is that the literature measured intention to use and not actual use. The perceived ease of use may attract an initial intention to use. But after gaining some experience of using a system, the continuation of using an EHR system is motivated by the usefulness of the system instead of ease of use. Most studies reported the testing of the technology acceptance in either mandatory or voluntary situations, and few include both levels of voluntariness in the same study. Future studies of the moderating effect of voluntariness can involve the same user group that use health technology in both high and low voluntariness environments like this study.

In conclusion, the study attempted to answer the question of whether the factors predicting use behavior would differ in voluntary versus mandatory use of an EHR designed for use by allied health professionals in Hong Kong. The results have provided preliminary support of moderating effects of voluntariness on use behavior in the technology, implementation and individual contexts. Two unique factors have been identified to be associated with actual use but in different voluntariness contexts: (1) *ease of use* (technological context) in mandatory environment (low voluntariness) and (2) *organization facilitating conditions* (implementation context) in voluntary environment (high voluntariness). Interestingly, the direction of moderating effects was opposite to that reported in the literature. The literature suggested that in a mandatory environment, perceived usefulness has a greater impact on intention to use than ease of use. Further studies are needed to examine the direction of moderating effects in each context. The findings of this study have potential practical implications. A strategy that works in a mandatory environment may not work in a voluntary environment. Different strategies might be needed to promote use behavior in high and low levels of voluntariness environments. Voluntariness can be a highly relevant and important moderating factor that requires more attention in the design and evaluation of the EHR.

Acknowledgments

Special thanks go to managers and therapists of the Physiotherapy Departments of the Hospital Authority who supported and participated in this study.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Screenshot of the e-Registration of the electronic health record (with fictitious names).

[JPG File, 450KB - medinform_v3i1e7_app1.jpg]

Multimedia Appendix 2

Screenshot of the e-Progress of the electronic health record (with fictitious names).

[JPG File, 457KB - medinform_v3i1e7_app2.jpg]

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Abbreviations

AHPN: Allied Health Progress Note
EHR: electronic Health Record
UTAUT: Unified Theory of Acceptance and Use of Technology

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Review

Adoption of Clinical Decision Support in Multimorbidity: A Systematic Review

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Abstract

Background: Patients with multiple conditions have complex needs and are increasing in number as populations age. This multimorbidity is one of the greatest challenges facing health care. Having more than 1 condition generates (1) interactions between pathologies, (2) duplication of tests, (3) difficulties in adhering to often conflicting clinical practice guidelines, (4) obstacles in the continuity of care, (5) confusing self-management information, and (6) medication errors. In this context, clinical decision support (CDS) systems need to be able to handle realistic complexity and minimize iatrogenic risks.

Objective: The aim of this review was to identify to what extent CDS is adopted in multimorbidity.

Methods: This review followed PRISMA guidance and adopted a multidisciplinary approach. Scopus and PubMed searches were performed by combining terms from 3 different thesauri containing synonyms for (1) multimorbidity and comorbidity, (2) polypharmacy, and (3) CDS. The relevant articles were identified by examining the titles and abstracts. The full text of selected/relevant articles was analyzed in-depth. For articles appropriate for this review, data were collected on clinical tasks, diseases, decision maker, methods, data input context, user interface considerations, and evaluation of effectiveness.

Results: A total of 50 articles were selected for the full in-depth analysis and 20 studies were included in the final review. Medication (n=10) and clinical guidance (n=8) were the predominant clinical tasks. Four studies focused on merging concurrent clinical practice guidelines. A total of 17 articles reported their CDS systems were knowledge-based. Most articles reviewed considered patients' clinical records (n=19), clinical practice guidelines (n=12), and clinicians' knowledge (n=10) as contextual input data. The most frequent diseases mentioned were cardiovascular (n=9) and diabetes mellitus (n=5). In all, 12 articles mentioned generalist doctor(s) as the decision maker(s). For articles reviewed, there were no studies referring to the active involvement of the patient in the decision-making process or to patient self-management. None of the articles reviewed adopted mobile technologies. There were no rigorous evaluations of usability or effectiveness of the CDS systems reported.

Conclusions: This review shows that multimorbidity is underinvestigated in the informatics of supporting clinical decisions. CDS interventions that systematize clinical practice guidelines without considering the interactions of different conditions and care processes may lead to unhelpful or harmful clinical actions. To improve patient safety in multimorbidity, there is a need for more evidence about how both conditions and care processes interact. The data needed to build this evidence base exist in many electronic health record systems and are underused.

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KEYWORDS

decision support systems, management; systematic review; multiple chronic diseases; multiple pathologies; multiple medications

Introduction

Background

Patients affected by multiple diseases are acknowledged to be one of the greatest challenges for modern health care, especially as populations age [1]. Different terms have been used in the medical literature to refer to coexistent pathologies; the most accepted are [2] *comorbidity*, defined in 1970 as "any distinct additional clinical entity that has existed or may occur during the clinical course of a patient who has the index disease under study" [3], and *multimorbidity*, later defined as "the coexistence of 2 or more chronic conditions, where 1 is not necessarily more central than others" [4]. In this review, we look at the presence of simultaneous medical conditions as the decision-making context without emphasizing the prominence of any 1 condition, and we follow the European General Practice Research Network, which defines multimorbidity as "any combination of chronic disease with at least 1 other disease (acute or chronic) or bio-psychosocial factor (associated or not) or somatic risk factor" [5]. Here we use multimorbidity in a broad sense to infer comorbidity as well.

Impact of Multimorbidity on Public Health

Estimates of the prevalence of multimorbidity emanate from countries with detailed primary care records. A national population study carried out in the Netherlands estimated an overall prevalence of 29.7%, ranging from 10% in those younger than 20 years to 78% in those older than 80 years [6]. Another population study in Scotland found an overall prevalence of 23.2% [7]. The prevalence of multimorbidity in a population increases with age [8]. Thus, a growing proportion of the population is affected by multimorbidity as populations age [9], particularly in countries with demographic patterns like the United Kingdom [10]. Previous studies [11-13] most commonly reported the following disease groups as likely to concur: cardiovascular diseases, diabetes mellitus, chronic kidney disease, chronic musculoskeletal disorders, chronic lung disorders, and mental ill health (particularly dementia and depression). There is also a greater burden of multimorbidity at younger ages (younger than 65 years) in deprived areas [7]. Thus, the public health and economic impact of multimorbidity is large [14]. In the United States, 84% of total health expenditure involves patients with more than 1 condition [15], whereas multimorbid patients in England account for the majority of primary care encounters [16] and this is expected to rise [15].

Patient-Centered Care and Iatrogenic Risks

The model of care in multimorbidity is changing, from a disease- and organization-centered approach [3] to patient-centered holistic care [17]. Patient-centeredness considers psychological and physiological needs, the patient's concerns and priorities for care, self-care, and coordination between different professions and organizations, with primary care as an integrator [17]. Although patient-centered care is ideal for managing complex, chronic conditions, it is challenging to implement [5]; therefore, at present, patients with multimorbidity are commonly underserved by poorly integrated care systems [18,19]. This fragmentation reduces the safety, effectiveness, and efficiency of care [1]. A previous study reported that 10% to 20% of unscheduled care among older multimorbid adults is iatrogenic (eg, medication-related harm) [20].

Self-Management and Continuity of Care

The presence of simultaneous care plans for multiple conditions leads to confusion and, in turn, generates safety hazards. Clear care plans, blending clinical care with self-management, are essential in multimorbidity [21]. Such plans need to incorporate not only biomedical but also psychosocial factors, such as mood, informal care network, and patient income/finances [21]. Communication between patients/carers and health professionals over complex care plans can be challenging; therefore, self-care may be unreliable [21,22]. For example, it was estimated an average Medicare patient in the United States with 1 chronic condition sees 4 different health care professionals in 1 year and this number increases to 14 in the presence of 5 different chronic conditions [22]. Increasing the number of health professionals involved creates a combinatorial explosion of communication interfaces and, for the patient, greater difficulty in understanding, remembering, and recalling guidance [22]. The most common problems arising from this miscommunication are duplication of tests and harmful decisions made on the basis of incomplete or incorrect information [23,24]. Primary care and general practitioners, in particular, are seen as a nexus of coordination for complex care such as this [24]. However, general practitioner workload is increasing beyond its capacity with the rising prevalence of chronic diseases and multimorbidity [25].

Clinical Practice Guidelines and Polypharmacy

Clinical research processes tend to focus narrowly on a single disease, mechanism, or treatment. This parsimony is reflected in the production of clinical practice guidelines; therefore, interactions between diseases are barely touched upon in care pathways (even if they are referred to as "integrated") [26]. More recently, organizations such as the National Institute for Health and Care Excellence (NICE) have started to address multimorbidity explicitly [27] and a framework of principles for system-wide action to deal with comorbidities has been developed in England by the Department of Health and the National Health Service (NHS) [28]. Most current guidelines, however, do not consider interactions between diseases or between treatments [29]. Therefore, potential synergies or conflicts between different care pathways operating for the same patient may be missed [30]. For example, Boyd et al [29] applied clinical practice guidelines to a hypothetical case of a 79-year-old woman with multiple moderately severe chronic conditions (osteoporosis, osteoarthritis, diabetes mellitus, hypertension, and chronic obstructive pulmonary diseases). The guideline-derived treatment regimen was extremely complex and potentially harmful—comprising 14 nonpharmacologic treatments (ie, self-monitoring, diet, exercise, health care visits, and laboratory testing) and 12 unique medications with 19 doses of medication per day [29]. Even in simpler cases, such as the presence of 2 diseases and 2 related treatments, researchers report 16 possible exposure patterns (half relevant for clinical practice guidelines) and 4 possible interaction combinations [26]. The 2 previous examples precipitate a "prescribing cascade" whereby drugs are prescribed to treat the adverse effects of other drugs, which is common in polypharmacy (the use of multiple medications) [31].

Even the most primary care-focused of health care systems, such as the NHS [27], do not deal safely, effectively, or efficiently with multimorbidity and polypharmacy [32]. In the future, with an aging population, most health care system resources will be stretched by the care needs of multimorbid patients [33].

Informatics Implications

Multimorbid health care requires complex communication, analysis, summarization, and presentation of heterogeneous clinical information from multiple sources. It is acknowledged that electronic health records (EHRs), especially in primary care, require enhanced functionality to support decisions in these complex care processes [34]. A clinical decision support (CDS) system provides "clinicians, patients, or individuals with knowledge and person-specific or population information, intelligently filtered or presented at appropriate times, to foster better health processes, better individual patient care, and better population health." [35]. Despite notable failures [36], CDS systems have the potential to improve clinical outcomes [37,38]. Indeed, multimorbidity was defined as one of the "grand challenges in clinical decision support" by Sittig et al [39]; however, this area remains underinvestigated [40,41], with concerns raised over the unmet needs in primary care [40]. Some of the current challenges are lack of provision of integrated clinical practice guidelines, disease-centered rather than patient-centered approaches, difficulties in embedding CDS into clinical systems, and lack of training to make best use of CDS [40]. EHRs and computerized physician order entry systems include rules that deal with drug-drug interactions; however, the whole patient context is not considered and the system may "overalert" physicians [42]. The overalert is another main risk in multimorbidity, which is known as *alert fatigue*: "the mental state provoked by managing too many irrelevant alerts from the system, which consume physical and psychological energies and lead the user to ignore also the relevant alerts resulting in potential harm for the patient" [43]. Prescribing alerts are especially important in polypharmacy, which has well-established risks of harm [44]. However, in some situations, multiple prescriptions are valid [30] and should not be dissuaded by inappropriate alerts. Context awareness, such as an "application's ability to adapt to changing circumstances and respond according to the context of use" [45], is crucial in decision support interventions [46], especially for multimorbidity where many variables are in place. However, a greater understanding of which information and sociotechnical factors of the context have to be taken into account in health care has still to be established [47].

Previous reviews have investigated specific aspects of CDS in multimorbidity; for example, prescribing in the elderly [48] and chronic disease management [49]. We could find no satisfactory review of CDS in multimorbidity from a technical/methodological perspective to guide the engineering of future systems. This interdisciplinary review plugs that gap.

Aim and Objectives

The aim was to review the current state of the art of CDS in multimorbidity. The objectives were to review the aspects of decision support target, contextual information about patients/practitioners/services, decision support technology, user interface considerations, decision maker(s), diseases, and evaluation. These aspects were analyzed to identify what works and what does not in CDS for multimorbidity, why systems failed to produce the expected outcomes, and what solutions might be adopted to address the problems.

Methods

Overview

This review follows the guidelines from Preferred Reporting Items for Systematic reviews and Meta-Analyses (PRISMA) framework [50]. PRISMA consists of a list of 27 items and a 4-phase flow diagram to complete that was identified as the optimal way to perform and report systematic reviews and meta-analyses about health care interventions by an experienced group of researchers and methodologists [50].

Eligibility

Inclusion Criteria

Studies that linked the concepts of multimorbidity, comorbidity, or polypharmacy to the concept of CDS, referring to the definitions provided previously, were selected from the literature.

The studies included in this literature review are articles about CDS systems that (1) address general issues about the multimorbid population, (2) support care for a particular subpopulation of multimorbid patients, (3) manage comorbidities related to a main disease, (4) deal with multiple concurrent medications in multimorbid population, and (5) describe statistical or machine-learning methods for clinical prediction in which the multimorbid patients' data feed the modeling/learning and an holistic approach is adopted.

Exclusion Criteria

Studies excluded from this literature review were about (1) CDS characteristics in general, without describing a CDS system in detail; (2) economic evaluations of CDS; (3) CDS systems in which multimorbidity was not a key feature; (4) social and operational research into CDS with no reference to clinical outcomes; (5) statistical or machine-learning approaches in which comorbidities were part of the model, but the patient-centered approach was not considered; and (6) systems that checked drug-drug interactions by means of simple rules, without taking into account multimorbidity or comorbidities.

Information Sources

MEDLINE and Scopus [51] were selected as the source indexes because they conform to the Cochrane requirement [52] of being "searched electronically both for words in the title or abstract and by using the standardized indexing terms, or controlled vocabulary, assigned to each record." We used the PubMed [53] interface to MEDLINE, which also includes up-to-date citations not yet indexed in MEDLINE [52]. In addition, Scopus can use Medical Subject Headings (MeSH) terms for structured queries [54].

Some target studies could only be found in the grey literature, such as theses and conference proceedings. Scopus allows search restrictions to some categories of grey literature, such as conference proceedings. This wider searching aimed to reduce publication bias.

The searches were performed in December 2013 and January 2014 without any restriction in the publication date.

Search

For the search, we followed 3 key points from the Cochrane Handbook [52]:

1. Searches should seek high sensitivity—this may result in poor precision.
2. Too many different search concepts should be avoided, but a wide variety of search terms should be combined with "or" within each concept.
3. Both free-text and subject headings should be used (eg, MeSH) [55].

The focused clinical question that drove this systematic review was: What is the current level of adoption of CDS in multimorbidity? To answer this question, 3 different search concepts were selected:

1. Decision support: it has many related MeSH descriptors, such as "decision support systems, management" or "decision support techniques." Examples of individual hyponyms manually selected are "clinical decision support system," "decision support software," and "decision support tool."
2. Multimorbidity: it has zero related MeSH descriptors. Semantically, the closed concept comorbidity has 1 MeSH descriptor. Examples of synonyms manually selected are "concurrent conditions," "multiple chronic diseases," and "multiple pathologies."
3. Polypharmacy: it has just 1 MeSH descriptor and it should not be confused with the concept polypharmacology. Examples of synonyms manually selected are "several prescriptions," "poly-prescriptions," and "multiple medications."

In essence, the search created for the focused clinical question that drove this systematic review was based on 3 different search concepts and the hyponyms and synonym terms combined with "or." Conceptually, our clinical query was the following: *<decision support> AND (<multimorbidity> OR <polypharmacy>).*

In Scopus, the query created imposed that the relevant terms selected appear in the title, abstract, or keywords. The search yielded 954 articles (see Figure 1). Only literature from the social sciences, arts, and humanities was excluded from the search, and no restriction on the type of publication was imposed. Therefore, a wider selection of articles beyond the grey literature was retrieved.

Because multimorbidity is underrepresented in MeSH (ie, no MeSH descriptor), we created a PubMed query that looked for the relevant terms selected in the title/abstract. The search created yielded 10,223 articles (ie, 10 times more document results than in Scopus). We investigated the origin of this high number by looking at the query as it appeared under search details when using the PubMed search engine. Some of the synonyms manually selected for multimorbidity were not recognized; thus, they were split up automatically by PubMed [56]. The query as executed in PubMed contained overly general terms, such as "conditions," "diseases," and "pathologies." This severely affected the performance of the query. To further illustrate this, a subquery automatically generated by PubMed as part of the original query "decision support[Title/Abstract] AND conditions[Title/Abstract]" yielded 420 results. However, this subquery did not reflect our focused clinical question and it was very unlikely that it retrieve the articles that we were interested in. Because the quality of any search depends on all constituents, we recognized that our original query was unsuitable for the PubMed search engine. More importantly, we became aware of the difficulties of constructing a PubMed query tailored to the medical question being investigated. Next, we tried to create more focused queries for the PubMed search engine, such as "multimorbidity[Title/Abstract] AND decision support[Title/Abstract]," which yielded only 6 articles. The low number of articles retrieved made us suspect that a substantial amount of articles were missing.

Knowing other researchers who were also conducting systematic reviews in the area of CDS, we thought of a search intended for a global evidence map [57] (ie, a search that sought to address broader questions about a particular area rather than focused clinical questions). Global evidence maps are similar to systematic reviews because they are both conducted in a formal process; however, the time taken for a global evidence map is longer (in excess of 2 years [58]). We were interested in decision support related to electronic clinical documentation systems and safety surveillance, so we created a new PubMed query to provide a better context of the area under study where our clinical query should focus on. The new query as it appeared under search details when using the PubMed search engine was "decision support[Title/Abstract] OR (safety[Title/Abstract] AND surveillance[Title/Abstract]) OR electronic health record[Title/Abstract] OR electronic medical record[Title/Abstract] OR electronic patient record[Title/Abstract]." This approach was adopted to guarantee the inclusion of all relevant articles even when CDS functionalities were described in studies about EHRs or safety surveillance systems without using CDS-related terms. To identify articles relevant to our focused clinical question, we used automatic annotation of all articles' excerpts retrieved by the broader query using the hyponyms and synonym terms that appeared in the original clinical query for the 3 different search concepts originally selected. For details, see the next subsection.

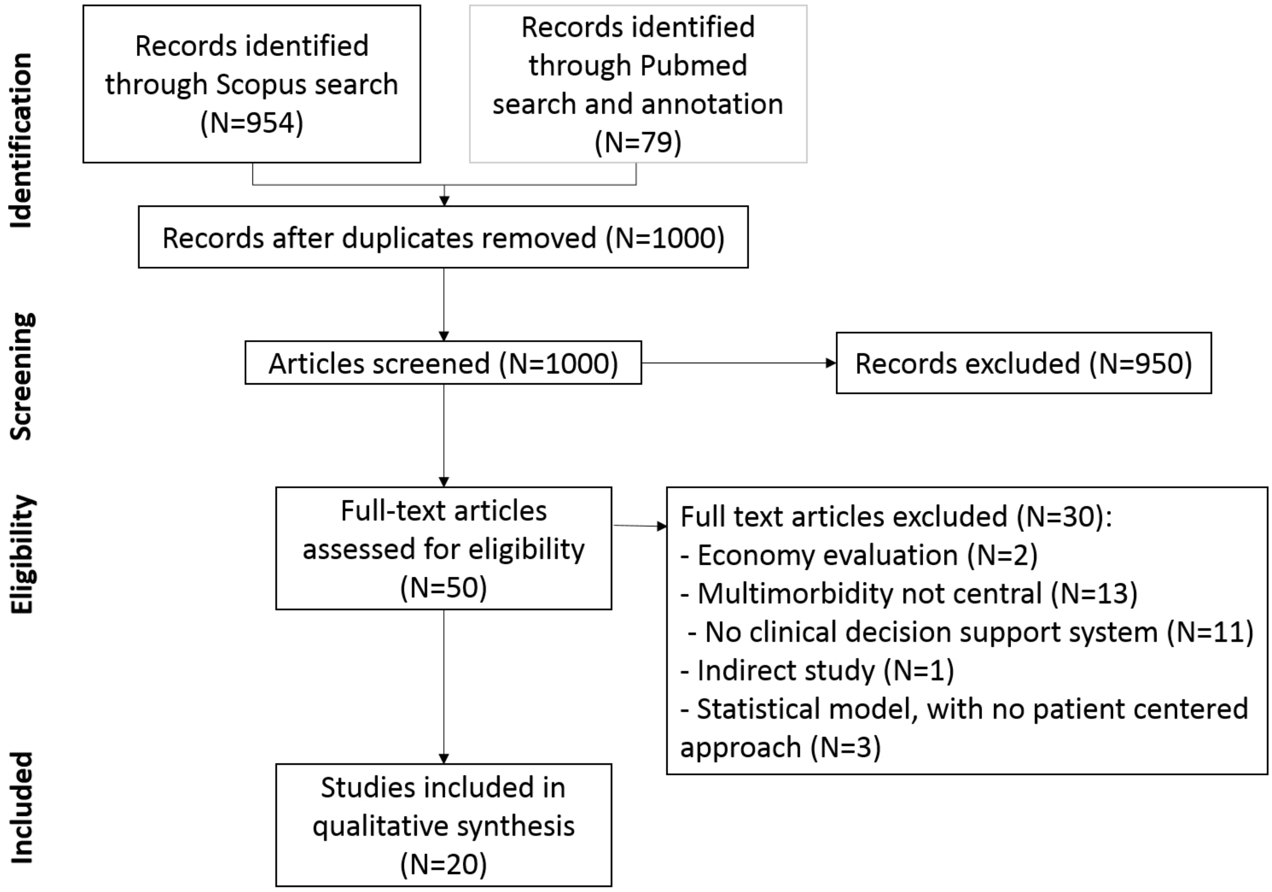

Figure 1. Review flow diagram.

Study Selection

For the PubMed article excerpts retrieved out of the broad query, we modified the manual approach to screening citations for systematic reviews and adopted some automation. In the area of automated document classification, there is an emerging body of research that uses machine-learning methods to help with the process of citation screening (eg, [59]). We adopted a simpler, but well-founded, type of automation for prescreening PubMed article excerpts, which did not classify article excerpts as "relevant" or "irrelevant." We used automatic annotation of text (title and abstracts) based on a controlled vocabulary known beforehand and tailored to our study. This method is analogous to the bioinformatics practice of relating genes that have been annotated using a common schema, such as an ontology [60,61], which is directly relevant to systematic reviews [62,63]. We note that the Cochrane Collaboration is considering ontologies to support evidence synthesis [62].

The annotation was performed using a controlled vocabulary (ie, the list of the hyponyms and synonym terms manually created for our clinical query). This annotation can coexist with native annotations from PubMed article excerpts based on MeSH and/or authors' keywords. The concrete details of the annotation process are out of the scope of this paper. Once the annotation was performed, a selection of articles were selected based on our clinical query "<decision support> AND (<multimorbidity> OR <polypharmacy>)." Thus, only article excerpts with at least 1 term in title/abstract related to decision support and at least 1 term in title/abstract related to multimorbidity or polypharmacy were identified as related to our clinical question.

Articles obtained by the preceding procedure were combined with the ones from the Scopus search and, after removing duplicates, screened based on title and abstract. Relevant articles were assessed through full-text analysis to select the articles to be included in the systematic review.

Data Collection Process and Data Items

Overview

A careful selection of relevant features was agreed on by the authors (PF, JA, and IB) and data on the following aspects were collected. A summary was generated for each data item and study.

Decision Support Target

This included clinical tasks supported by the CDS system: prevention, diagnosis, care pathway guidance (ie, management of patients according to clinical practice guidelines), medication (eg, prescription, medication review), patient education, patient self-management, and care continuity (supporting communication between health care professionals involved in multimorbid patients).

Contextual Information

Information was collected regarding the context processed or taken into account by the system to provide support: patient clinical notes (ie, demographics or family history), laboratory results, comorbidities, medications, clinical practice guidelines, and clinicians’ knowledge.

Decision Support Technology

These data included:

1. Mode of delivery: type of technical solution used to deliver the system: desktop application, Web application, and mobile application.
2. Methodology: methods used to perform the CDS intervention: data visualization techniques [64] (ie, providing intuitive interfaces to minimize errors); social network techniques; international communication and coding standard, such as Health Level Seven International (HL7) [65] to communicate information and Systematized Nomenclature of Medicine Clinical Terms (SNOMED CT) [66] or International Classification of Diseases (ICD9-10) [67], to store data; machine-learning techniques [68]; natural language processing [69]; knowledge-based systems [70] (ie, using rules or based on ontologies [71]); and mobile technologies.
3. User interface considerations: reported considerations about techniques to enhance and make easier user utilization of the system: interactivity, user-centered design, summarization, and workflow graphs.
4. Decision maker(s): user(s) of the CDS system: nurse, specialist doctor, pharmacist, generalist doctor (ie, general practitioner or family doctor), and patient.
5. Diseases/conditions: CDS target conditions: obesity, diabetes mellitus, cardiovascular diseases, chronic respiratory diseases, chronic kidney disease, neurological conditions, mental health disorders, chronic musculoskeletal diseases, etc.
6. Evaluation: type of evaluation of system’s effectiveness: uncontrolled impact studies (eg, surveys or health services measurements before/after CDS), controlled comparisons (eg, comparing new vs old/no CDS), and no evaluation.

Synthesis of Results

The results of the review were summarized in a table. The table was organized by the aspects of CDS defined previously and provides a qualitative summary for each included study. An additional quantitative summary to highlight general trends over time and patterns of evidence is also provided.

Results

Study Selection

The search via Scopus retrieved 954 articles. We retrieved 17,145 articles via PubMed by using the broad search and annotation introduced previously; 79 results were recalled. After removing duplicates and screening the title and abstract, 50 articles were selected for in-depth analysis of the full text. A total of 20 studies were included in the review. The PRISMA process was followed and is reported in Figure 1.

Study Characteristics

Table 1 contains the summary of all data items collected for each study included in the review along with its reference.

Table 1. Summary of collected items for included studies.

Authors	Decision support target	Contextual information	Decision support methods/delivery	User interface considerations	Decision maker/diseases	Evaluation
Abidi [72]	Pathways (merging clinical practice guidelines for different diseases into 1 personalized guideline)	Patient clinical notes & clinical practice guidelines	Knowledge-based system (ontology) & international standards/—	—	—/—	—
Abidi et al [73]	Diagnosis & pathways (alignment of care pathways in a patient-specific comorbid combination) & patient education	Patient clinical notes & clinical practice guidelines	Knowledge-based system (ontology based)/desktop application	Interactivity & summarization	Generalist doctor/chronic cardiovascular diseases	Controlled comparison-expert panel (revision by 2 generalist doctors and 1 specialist doctor)
Bindoff et al [74]	Medication (review)	Patient clinical notes & medications & laboratory results	Knowledge-based system (rule based)/ —	—	Pharmacists/—	Controlled comparison-human vs system comparison (system identified more problems)
Dassen et al [75]	Medication (prescription)	Patient clinical notes & medications & clinical practice guidelines & comorbidities & laboratory results	Knowledge-based system (ontology based) & international standards/desktop application	Interactivity & workflow graphs	Specialist doctor/cardiovascular diseases	—
de Wit et al [76]	Medication (review)	Patient clinical notes & clinical practice guidelines & clinician knowledge & laboratory results	Knowledge-based system (rule based)/—	—	Nurses/other (home care for the elderly)	No evaluation
Duke et al [77]	Medication (review)	Medications & clinician knowledge	Knowledge-based system & data visualization techniques & natural language processing/Web platform	Interactivity & summarization	Specialist doctor & generalist doctor/—	Controlled comparison-new vs old system (same accuracy but decreasing in time of 60%)
Farkas et al [78]	Diagnosis (comorbidities)	Patient clinical notes	Natural language processing/—	—	—/obesity	Controlled comparison-simulations (Fβ=1 score of 97% for classification based on textual evidence and 96% for intuitive judgments; Fβ=1 score of 76% for classification based on textual evidence and 67% for intuitive judgments)
Georg et al [79]	Medication (prescription)	Patient clinical notes & clinical practice guidelines	Knowledge-based system (rule based)/—	—	Generalist doctor/cardiovascular diseases	—
Grando et al [80]	Medication (prescription)	Patient clinical notes & clinical practice guidelines	Knowledge-based system (ontology based)/—	—	Generalist doctor/chronic respiratory diseases & diabetes & cardiovascular diseases & chronic musculoskeletal diseases & others	—

Authors	Decision support target	Contextual information	Decision support methods/delivery	User interface considerations	Decision maker/diseases	Evaluation
Jafarpour et al [81]	Pathways (merging clinical practice guidelines for different diseases into 1 personalized guideline)	Patient clinical notes & clinical practice guidelines & clinician knowledge	Knowledge-based system (ontology based)/—	—	Generalist doctor/cardiovascular diseases	No evaluation
Martínez-García et al [82]	Care continuity & pathways	Patient clinical notes & clinical practice guidelines & clinician knowledge	International standards & social network techniques/Web application (linked to electronic health record)	—	Nurse, generalist doctor, specialist doctor/—	Controlled comparison-survey (positively judged)
Michel et al [83]	Medication (prescription)	Patient clinical notes & clinical practice guidelines & clinician knowledge & medications & laboratory results & comorbidities	Knowledge-based system & data visualization techniques & international standards/desktop application (linked to electronic health record)	Summarization	Generalist doctor/chronic pain (opioid treated)	—
Naureckas et al [84]	Diagnosis & pathways	Patient clinical notes & clinical practice guidelines	Knowledge-based system & data visualization techniques/desktop application (linked to electronic health record)	User-centered design	Generalist doctor/child obesity and related diseases (eg, diabetes, cardiovascular diseases, chronic kidney disease)	Impact evaluation-service performance metrics & survey
Riaño et al [85]	Diagnosis & medication (prescription) & pathways (developing a personalized treatment) & prevention	Patient clinical notes & clinical practice guidelines & clinician knowledge	Knowledge-based system (ontology based) & international standards/desktop application (linked to electronic health record)	—	Generalist doctor/home care in long-term conditions (eg, obesity, diabetes, cardiovascular diseases, chronic respiratory diseases, chronic kidney disease, neurological conditions, mental health disorders, chronic musculoskeletal diseases)	Controlled comparison-survey (positively judged)
Riaño et al [86]	Medication (prescription)	Patient clinical notes & clinician knowledge	Knowledge-based system (rule based)/—	—	Generalist doctor/cardiovascular diseases & diabetes	Controlled comparison-expert panel (results validated by a generalist doctor)
Suojanen et al [87]	Diagnosis	Patient clinical notes & clinician knowledge	Machine learning/—	—	Specialist doctor/chronic neurological diseases	Controlled comparison-simulation (out of 30 cases: false positive rate=19%; false negative rate=23%)
Vallverdú et al [88]	Medication (prescription)	Patient clinical notes & clinician knowledge	Knowledge-based system (rule based)/desktop application	—	Generalist doctor/cardiovascular diseases & diabetes	Controlled comparison-expert panel (agreement with output from the system 100%-20/20)
Wicht et al [89]	Diagnosis (comorbidities)	Patient clinical notes & clinician knowledge	Knowledge-based system + data visualization techniques/Web platform	Interactivity	Specialist doctor/other (cancer)	Controlled comparison-expert panel (agreement with output from the system 84%-26/31)

Authors	Decision support target	Contextual information	Decision support methods/delivery	User interface considerations	Decision maker/diseases	Evaluation
Wilk et al [90]	Pathways (merging clinical practice guidelines for different diseases into 1 personalized guideline)	Patient clinical notes & clinical practice guidelines & clinician knowledge	Knowledge-based system (rule-based constraint logic programming)/—	Workflow graphs	Generalist doctor/other (duodenal ulcer, transient ischemic attack)	—
Wilk et al [91]	Pathways (alerting physicians about possible adverse interactions between 2 concurrent clinical practice guidelines)	Patient clinical notes & clinical practice guidelines	Knowledge-based system (rule-based constraint logic programming [92])/—	—	Specialist doctor & generalist doctor/chronic neurological & gastrointestinal diseases	—

Results of Individual Studies

Table 2 shows the frequency distribution of the categories of aspects of CDS reported.

Most articles reviewed focused on 1 of 3 clinical tasks: medication (n=10), clinical guidance (n=8), and diagnosis (n=6). From a methodological point of view, knowledge-based systems were the most frequently used (n=17). To further illustrate this, Riaño et al [85] described a CDS system that targets 3 decisions and uses knowledge-based systems. The authors developed a system that (1) provided patient-centered recommendations to better manage chronic diseases in the home setting and (2) used EHRs to refine an ontology, which described relevant concepts from clinical practice guidelines and the literature for 19 chronic diseases. The goal of this study was a patient-tailored ontology that contained patient-specific concepts that could be used to verify the diagnosis entered into the system. Starting from the personalized ontology, general treatment plans and patient management instructions could be combined into an individual plan. For multimorbid patients, a semiautomatic procedure was applied that involved the system's end-user. The system was able also to identify preventive opportunities by looking for anomalous circumstances, such as diagnosis inconsistent with other information or information missing which should always be presented alongside other information.

Abidi et al [73] presented a system that helped doctors in diagnosis and management of patients (2 decision support targets) and used an ontology (knowledge centric) that was able to align clinical pathways for the multimorbid patient.

In the articles reviewed, medication was the main theme by far. This clinical task had the most contextualized input data and appeared as prescription (n=7) and medication review (n=3). Michel et al [83] developed a system that aimed to guide the generalist doctor through a summary of comprehensive relevant information (patient information, patient medication, patient laboratory results, and patient comorbidities) and suggested the optimal opioid treat for chronic pain. Dassen et al [75] developed a system, along the lines of Michel at al [68], considering comprehensive relevant information (patient information, patient medication, patient laboratory results, and patient comorbidities) and used an ontology to support cardiologists' prescriptions according to clinical practice guidelines. The articles by de Wit et al [76] focused on medication review and their system was intended to support safer care for the elderly. The system was capable of processing extracts of clinical data from electronic prescribing systems and EHRs (containing patient medication, patient conditions, and patient laboratory results) and alerted nurses about potentially harmful situations.

Another prevalent theme was the possible interaction between concurrent clinical practice guidelines for multimorbid patients. For example, Abidi et al [73] and Jafarpour et al [81] used ontologies to develop systems to merge 2 concurrent clinical practice guidelines into a comorbid personalized guideline. Jafarpour et al [81] carried out this task by creating an ontology that collected merging criteria obtained from clinical experts. Wilk et al [90,91] used constraint logic programming to identify and mitigate possible adverse interactions between clinical practice guidelines. One system alerted doctors about possible hazards and suggested how to mitigate them [91]. Martinez-Garcia et al [82] developed a system that improved clinical guidance by providing health care professionals with relevant information from clinical practice guidelines and also supported communication between health care professionals. Their system (1) was directly linked to the EHR through HL7, an international standard for interoperability in health care and (2) adopted social networking techniques to enhance the continuity of care through a Web platform—it provided relevant patient information and performed safety checks according to clinical practice guidelines.

Some studies addressed the diagnosis of comorbidities for patients affected by an index condition/disease. For example, Farkas et al [78] used natural language processing applied to clinical notes to diagnose comorbidities in obese patients. Suojanen et al [87] used machine learning (causal Bayesian networks) for diagnosis of multiple concurrent neuropathies.

Table 2. Synthesis of occurrences' numbers and references for collected data items.

Theme and category	Frequency	References
Decision support task		
Prevention	1	[85]
Diagnosis	6	[73,78,84,85,87,89]
Pathway	8	[72,73,81,82,84,85,90,91]
Medication	10	[74-77,79,80,83,85,86,88]
Patient education	1	[73]
Continuity of care	1	[82]
Self-management	0	—
Decision support technology		
Data visualization techniques	4	[77,83,84,89]
Social network techniques	1	[82]
International standards	5	[73,75,82,83,85]
Machine learning	1	[87]
Natural language processing	2	[77,78]
Knowledge-based system	17	[72-77,79-81,83-86,88-91]
Mobile technologies	0	—
Contextual information		
Patient clinical notes	19	[72-76,78-91]
Laboratory results	4	[74-76,83]
Comorbidities	2	[75,83]
Medications	4	[74,75,77,83]
Clinician knowledge	11	[76,77,81-83,85-90]
Clinical practice guidelines	13	[72,73,75,76,79-85,90,91]
Decision maker(s)		
Nurse	2	[76,82]
Specialist doctor	6	[75,77,82,87,89,91]
Generalist doctor	13	[73,77,79-86,88,90,91]
Pharmacist	1	[74]
Patient	0	—
Not specified	2	[72,78]
Diseases		
Obesity	3	[78,84,85]
Diabetes	5	[80,84-86,88]
Cardiovascular diseases	9	[73,75,79-81,84-86,88]
Chronic respiratory diseases	2	[80,85]
Chronic kidney diseases	2	[84,85]
Chronic neurological conditions	3	[85,87,91]
Mental health disorders	1	[85]
Chronic musculoskeletal diseases	2	[80,85]
Other	8	[76,80,83-85,89,90]
Not specified	4	[72,74,77,82]

Theme and category	Frequency	References
User interface considerations		
Interactivity	4	[73,75,77,89]
User-centered design	1	[84]
Summarization	3	[73,77,83]
Workflow graphs	2	[75,90]
Not specified	13	[73,74,76,78-82,85-88,91]
Evaluation		
Impact evaluation (service performance metrics)	1	[84]
Impact evaluation (survey)	1	[84]
Controlled comparison (expert panel)	4	[72,86,88,89]
Controlled comparison (survey)	2	[82,85]
Controlled comparison (simulation)	2	[78,87]
Controlled comparison (human vs system)	1	[74]
Controlled comparison (new vs old system)	1	[77]
No evaluation	2	[76,81]
Not specified	7	[72,75,79,80,83,90,91]

For the decision makers, generalist doctors were the most cited users of the CDS systems (n=13) followed by specialist doctors (n=6). No articles reported the patient as the decision maker. The system that appeared to involve the largest number of decision makers was described by Martinez-Garcia et al [82], in which nurses, specialist doctors, and generalist doctors were end users.

For disease, many articles considered multiple diseases (eg, [80,84-86,91]), with Riano et al [85] reporting 19 chronic conditions.

For user interface considerations, most articles (n=13) did not provide details about the user interface. Where this information was provided, interactivity (n=4) [73,75,77,89] and summarization (n=3) [73,77,83] were the most cited features, whereas workflow graphs [75,90] were seldom mentioned. Only Naureckas et al [84] presented a CDS system that adopted a user-centered design with prompts and forms that helped generalist doctors to develop more effective behaviors for supporting diagnosis, management, and screening of comorbidities for children with obesity.

Regarding type of evaluation, some articles reported effectiveness objectively, including controlled comparisons (n=9) or impact evaluations (n=1). The articles that conducted surveys about their systems achieved positive judgments about the outcome provided [82,85]. In terms of accuracy, many studies reported good performance [87-89]. Duke et al [77] compared UpToDate [93] with a new system that had the same accuracy, but improved (by 60%) timeliness of decision. Bindoff et al [74] compared a CDS system with expert pharmacists when performing a medication review; overall, the system identified more potential problems than the human experts did.

Discussion

Summary of Evidence

Overview

This literature review found a modest number of articles addressing CDS and multimorbidity—an evidence base disproportionately small in comparison to the need for decision support.

The Lack of Patient-Centered Approaches

Most articles dealt with CDS targets that (1) were narrowly defined in terms of comorbidities around an index condition or (2) considered patient comorbidities only during prescription for a specific condition. Thereby, only a few of the studies reviewed referred to multimorbidity using a patient-centered approach, which is the ideal [5]. Riano et al [85] adopted a comprehensive approach to integrated care; however, user intervention is necessary to personalize treatments when multimorbidity is present.

Combination of Clinical Practice Guidelines

An important challenge of multimorbidity in CDS is the combination of clinical practice guidelines in a nonharmful way [39]. We found some studies that addressed this explicitly. An interesting solution was introduced by Jafarpour et al [81], which created an ontology with merging criteria provided by experts. Although rigorous evidence is lacking, to exploit physicians' "clinical mind-lines," such as "tacit guidelines that are internalized and collectively reinforced from the experience and discussion with colleagues and patients to embody the complex and flexible knowledge needed in practice" [94], seems the only solution. However, all systems described in the articles reviewed tended to simplify the analysis by referring to only 2 concurrent clinical practice guidelines. This scenario is too simplistic for the current reality because multimorbid patients often face more than 2 simultaneous pathologies [29].

Continuity of Care

Discontinuity of care between different health professionals is an important source of safety problems, which is highly relevant to multimorbidity considering the large numbers of professionals involved. Yet only 1 article [82] considered this aspect. Prevalent technologies such as social media may foster communication across different clinical settings. There is a notable gap in the evidence base here.

No Self-Management Interventions

Self-management is key in multimorbidity [21]. In the articles reviewed, no CDS interventions for multimorbid patient self-management were found. Similarly, we noticed the absence of mobile technologies for CDS in multimorbidity.

Methodological Considerations

From a methodological point of view, knowledge-based systems were most commonly reported. Data-driven methods, such as machine-learning techniques, were barely used in the reviewed studies, with just 1 study adopting them [87].

The Technological Interoperability Shortfalls

Multimorbidity is composed of interacting variables; therefore, systems need to be aware of as many contextual factors as possible to deliver relevant support and information [95]. Emerging international standards, such as HL7, are supposed to enable interoperability in health care; however, only 1 article reviewed used HL7, the system developed by Martinez-Garcia et al [82].

The Need for More Rigorous Evaluations

Evaluations of usability and effectiveness of systems are key to avoiding patient harm and waste in health care systems [96]. The so called "e-iatrogenesis" [97] arising from information systems has more potential pitfalls when there are multiple conditions. Rigorous evaluations are needed to test systems before and after their deployment to guarantee patient safety [98,99]. We found a lack of rigorous evaluations of effectiveness and usability here, which is consistent with the overall state of CDS [36] research. Patient safety needs to be assured by rigorous evaluation, not only of the underlying software/technologies but also of their real-world interaction with users [100]. The expected approaches to evaluating human-computer interaction [101,102] were not found in the articles we examined.

Limitations

This review has several limitations. First, only Scopus and PubMed sources were searched—other relevant material may exist in the grey literature. Second, the titles and abstracts of the articles selected are anchored to the terms included in the 3 thesauri—some articles may have been missed if other synonyms were used. Third, it was not possible to find studies covering all aspects of CDS we considered—some aspects, such as the evaluation of the effectiveness and usability, were quite sparsely covered, but this is a general weakness of the CDS literature [36]. Finally, we did not follow the traditional systematic review process for all searches. However, we are confident that our strategy guaranteed the inclusion of all relevant articles about the topic. There is an ongoing discussion of what should and should not be automated in systematic reviews, particularly to strike the right balance between depth and timeliness [103]. Here we took the middle ground, using computational methods to make a more "concept-complete" search tractable. Therefore, this review may contribute to the ongoing discussion about semiautomated prescreening of medical literature while preserving rigorous methods of evidence synthesis.

Implications for Future Research and Conclusions

This review shows how multimorbidity is understudied in CDS, yet this is an area of public health and clinical importance that should be a prime target for CDS research.

There are already many technologies in health care and industry relevant to dealing with the complexity of multimorbid decision support. Kawamoto et al [104] argue that wider adoption of international terminologies (eg, SNOMED CT) and electronic health record standards can lead to better CDS, tapping into the vast amount of data produced in routine clinical practice for multimorbid patients. Moreover, technical frameworks [105] were already proposed for a "shared and informed decision making" in industry that with appropriate adjustments could be used to enhance continuity of care in multimorbidity. In addition, the absence of any substantial articles dealing with self-care for people affected by multiple conditions was remarkable given the rapid growth in connected/consumer health and its inevitable influence on CDS in the future.

Multimorbidity is a relatively new field of clinical research and more evidence is needed to support CDS in this area. This underpinning knowledge is, however, challenging. For example, patients with multiple conditions or on multiple medications are often excluded from clinical trials [106]. However, EHRs afford the possibility of observational studies important for understanding multimorbid disease risks, care processes, and care outcomes. Such observational data have established value in decreasing the prescribing cascade and other iatrogenesis [107]. Automation of care pathways/processes that are poorly understood, such as merging guidelines [30], may lead to unhelpful or harmful clinical actions. The informatics challenge herein is to build the evidence base about multimorbid care while engineering more supportive/directive clinical information systems incrementally. The clinical epidemiology and health services research must be interwoven with the systems development. Gathering more clinical evidence and getting more involvement from patients and health professionals is central to finding a technological approach to managing multimorbidity and enhancing patient safety. At the same time, rigorous evaluation of all sociotechnical and human-computer interaction aspects of produced CDS interventions is certainly a priority for the future.

Patients with multiple conditions are one of the most important groups for health care systems to understand and evolve to serve [33]. There are multiple dynamics in which CDS and health informatics can contribute in meeting this challenge: (1) using EHR data to understand multimorbidity and plug a relatively sparse evidence base, (2) coproducing care decisions between patients and practitioners in the face of complexity and uncertainty, and (3) blending n-of-1 patient experiments/experience with evidence about the “average patient like Mrs X...” It is hard to conceive of such complexity being tamed by today’s EHR interfaces, punctuated by blizzards of alerts and dashboards. Future CDS may be part of an integrated health avatar [108]: “the electronic representation of an individual’s health as directly measured or inferred by statistical models or clinicians.” To achieve such integration, however, there is a pressing need for more realistically complex CDS research, particularly in multimorbidity.

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Conflicts of Interest

None declared.

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Abbreviations

EHR: electronic health record
CDS: clinical decision support
NICE: National Institute for Health and Care Excellence

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Original Paper

On-Admission Pressure Ulcer Prediction Using the Nursing Needs Score

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Abstract

Background: Pressure ulcers (PUs) are considered a serious problem in nursing care and require preventive measures. Many risk assessment methods are currently being used, but most require the collection of data not available on admission. Although nurses assess the Nursing Needs Score (NNS) on a daily basis in Japanese acute care hospitals, these data are primarily used to standardize the cost of nursing care in the public insurance system for appropriate nurse staffing, and have never been used for PU risk assessment.

Objective: The objective of this study was to predict the risk of PU development using only data available on admission, including the on-admission NNS score.

Methods: Logistic regression was used to generate a prediction model for the risk of developing PUs after admission. A random undersampling procedure was used to overcome the problem of imbalanced data.

Results: A combination of gender, age, surgical duration, and on-admission total NNS score (NNS group B; NNS-B) was the best predictor with an average sensitivity, specificity, and area under receiver operating characteristic curve (AUC) of 69.2% (6920/100), 82.8% (8280/100), and 84.0% (8400/100), respectively. The model with the median AUC achieved 80% (4/5) sensitivity, 81.3% (669/823) specificity, and 84.3% AUC.

Conclusions: We developed a model for predicting PU development using gender, age, surgical duration, and on-admission total NNS-B score. These results can be used to improve the efficiency of nurses and reduce the number of PU cases by identifying patients who require further examination.

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KEYWORDS

pressure ulcer; nursing needs score; prediction; logistic regression; imbalanced data

Introduction

Pressure Ulcers

The National Pressure Ulcer Advisory Panel (NPUAP)/*European Pressure Ulcer Advisory Panel*, 2009 defines a pressure ulcer (PU) as a “localized injury to the skin and/or underlying tissue usually over a bony prominence, as a result of pressure, or pressure in combination with shear” [1]. PUs are also known as pressure sores, decubitus ulcers, and bedsores.

PUs result in excessive hospital lengths of stay [2] and increase treatment costs [3]. Some PUs can be prevented, thereby reducing costs considerably. Bennett et al showed that PU treatment costs would likely increase as the population ages and the incidence of pressure damage increases [4]. Particularly since Japan is an aging society (the Ministry of Health, Labour, and Welfare expects that Japan will have a globally unprecedented super-aging population by 2025) [5], this will greatly influence national medical care expenditures, thus leading to an escalating financial burden. PU prevalence is much lower in Japan than in other countries, and the Ministry of Health, Labour, and Welfare implemented PU reduction measures in all hospitals covered by the National Medical Insurance System [6]. The latest advances in data mining techniques will help predict the risk of PU development and further reduce the number of PU cases.

The Japanese Society of Pressure Ulcers considers shock, surgical duration of more than six hours, and peripheral circulatory insufficiency among the factors that contribute to a high risk of developing PUs [7]. However, no single factor explains PU risk, but rather a complex interaction of factors increases the probability of PU development [8]. Surgical intervention itself is a risk factor [9], and surgical duration is significantly positively associated with PU development [10]. Some studies have shown that PU development is negatively correlated with mobility and activity [8]; neurological, motor impairment and activity level [11]; mobility, activity, and sensory perception [12]; functional abilities such as getting out of bed, walking, and feeding [13]; and laboratory values such as albumin [14]. Yet, other studies have shown that PU development is positively correlated with length of bedfast period [15]; Nursing Needs Scores (NNS) [16]; comorbidities (eg, diabetes, chronic renal failure, congestive heart failure, and metastatic cancer) [8,14], and longer hospital stay [17]. Gender, on the other hand, is rather controversial. Some studies have reported that males are more prone to develop PUs than females [8,15], while others have reported a higher tendency among females [9]. Yet, other studies have concluded that gender is not a risk factor for PU development [17,18]. A number of studies have reported that increasing age is a risk factor [9,17,18].

Nurses usually use a risk assessment scale, such as the Waterlow or Braden scale, to identify high-risk patients, reviewed in [11]. According to a systematic review, some studies have shown that a low total Braden score is significantly positively associated with the development of PUs [8]. However, Anthony et al argued that there is no evidence that the use of risk assessment scales reduces PU incidence [19].

Tokushima University Hospital established a team of PU specialists in 2007 to detect early PU cases and prevent their advancement. An interdisciplinary team composed of plastic and reconstructive surgeons; wound, ostomy, and continence nurses; a medical informatics engineer; a physical therapist; and others have been designated for this purpose. They investigate data of PU patients and discuss countermeasures on a weekly basis. All inpatients in Tokushima University Hospital are assessed for their PU risk using a nonstandard procedure requiring the collection of additional items. High-risk inpatients are followed up according to our hospital PU risk assessment protocol with the Braden scale. A method that can easily and accurately identify high-risk patients for further inspection using only data available on admission would be highly beneficial.

Table 1. NNS items in general wards.

NNS-A[a]	Monitoring and treatment	Score			NNS-B[b]	Patient condition	Score		
		0	1	2			0	1	2
1	Wound treatment	No	Yes		10	Turn over	Able	Partially able	Unable
2	Blood pressure measurement	0-4 times	More than 5 times		11	Sit up	Able	Unable	
3	Urine volume measurement	No	Yes		12	Keep a sitting position	Able	Partially able	Unable
4	Respiratory care	No	Yes		13	Transfer activity	Able	Partially able	Unable
5	≥3 Intravenous lines	No	Yes		14	Oral care	Able	Unable	
6	Electrocardiogram monitor	No	Yes		15	Feed self	No assistance	Partial assistance	Full assistance
7	Syringe pump	No	Yes		16	Change clothes	No assistance	Partial assistance	Full assistance
8	Blood transfusion or blood derivative	No	Yes						
9	Specialized treatment[c]	No		Yes					

[a] NNS-A=Nursing Needs Score-A

[b] NNS-B=Nursing Needs Score-B

[c] 1, antineoplastic agent; 2, narcotic injection; 3, radiation therapy; 4, immunosuppressive agent; 5, vasopressor agent; 6, antiarrhythmic agent; and 7, drainage management

Nursing Needs Score

Many methods have been implemented for standardizing medical cost calculations to comply with the Japanese medical insurance system that includes all residents in Japan. In acute care hospitals, one method used to evaluate nursing costs is the NNS that was introduced first to intensive care units in 2003, then to high-care units in 2004, and finally to general wards in 2008 (Table 1) [20]. The NNS provides a score of 0, 1, or 2 for each nursing task. Nursing tasks are divided into two groups: (1) group A (NNS-A) includes tasks performed during patient monitoring and treatment, and (2) group B (NNS-B) includes tasks related to patient condition. The total NNS-A score ranges from 0 to 10, while the total NNS-B score ranges from 0 to 12. Table 1 shows examples of NNS-A and NNS-B tasks used in general wards. Our hospital finished implementing NNS in its hospital information system (HIS) for all divisions in 2008, and staff NNS training has been performed regularly according to Ministry of Health, Labour, and Welfare guidelines.

Objective

Nurses are the principal specialists for risk assessment of in-hospital acquired PU. We aimed to develop a quick and simple PU prediction tool that uses only data documented by nurses on patient admission to estimate the risk of PU development. Patients identified as being at high risk can be further investigated. With this tool, there would be no need for nurses to assess factors such as a patient's moisture, friction, or shear state using the Braden scale, or skin type, weight loss, or continence using the Waterlow scale. Rather, early predictions can be made using the data available on admission with regard to the patient's risk of developing PUs. Those identified as being at high risk could then be identified and followed more closely.

Methods

Data Description

The institutional review board of Tokushima University approved the study protocol, and opt-out consent was obtained. This was a retrospective study with respect to PU prediction for all inpatients that had their NNS recorded on admission in Tokushima University Hospital (696 beds), an acute care hospital, from January 1 to December 31, 2012. This study assessed data pertaining to demographic characteristics, surgical duration, and NNS data collected from the HIS, and PU data recorded by PU specialists. The total number of PUs per patient and PU stages were categorized from "depth unknown" to Stage IV (full thickness tissue loss), as defined by NPUAP staging guidelines [1]. There were 51 patients with in-hospital PUs and 8235 control patients without in-hospital PUs. Table 2 shows the average age, average NNS-A, average NNS-B, and average surgical duration with or without PUs. Patients who did not undergo surgery were assigned 0 hours for surgery duration. Figure 1 shows the distribution of NNS-A and NNS-B scores for patients who developed PUs. NNS-B scores in particular show a broad distribution.

The data we collected suffer, as do many other medical data, from class imbalance. In an imbalanced dataset, the number of one class is much higher than the other. This occurs primarily because of a high prior probability of one class and a low prior probability of the other class. The dataset used has 8235 patients without in-hospital PU and 51 cases with in-hospital PU, resulting in a high imbalance with a positive to negative ratio of 1 to 162.

Table 2. Descriptive statistics of patient age.

Gender	PU-positive		PU-negative	
	n	Age mean (SD)	n	Age mean (SD)
Male	35	62.1 (14.1)	4566	62.6 (15.6)
Female	16	67.2 (14.7)	3669	59.4 (18.0)

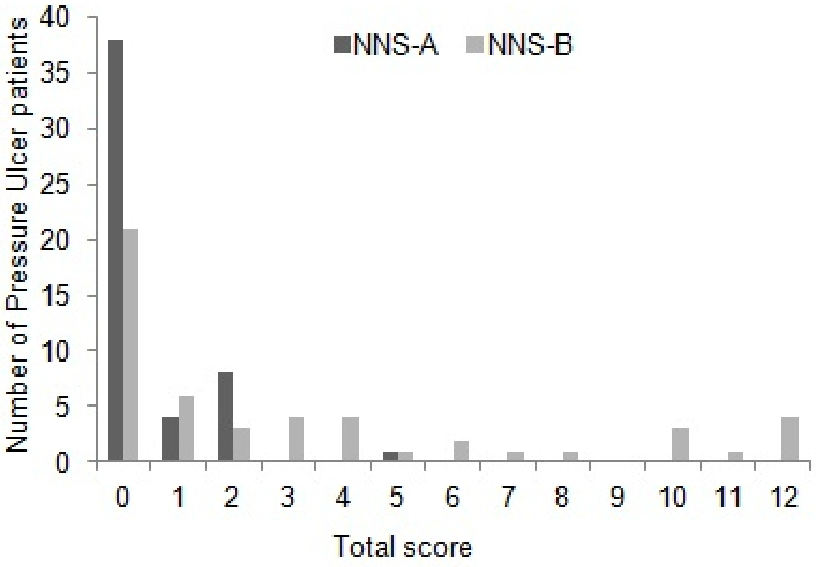
Table 3. Descriptive statistics of patient surgical duration.

Surgery	PU-positive		PU-negative	
	n	Duration (hours) mean (SD)	n	Duration (hours) mean (SD)
Yes	28	6.5 (4.4)	3158	2.7 (2.2)
No	23	-	5077	-

Table 4. Descriptive statistics of patient NNS.

PU-positive	PU-negative
NNS-A mean (SD)	NNS-B mean (SD)
0.5 (1.0)	0.3 (0.8)
3.2 (4.0)	1.1 (2.3)

Figure 1. Distribution of total Nursing Needs Score group A =NNS-A, and Nursing Needs Score group B = NNS-B scores for pressure ulcers patients.



Method

Logistic regression analysis is commonly used to determine the relationship between different qualitative and quantitative independent variables and a qualitative dependent variable. In this study, the dependent variable was whether the patient developed an in-hospital PU or not. The logistic regression model was generated using the Weka logistic regression component in RapidMiner version 5.3, Community version (RapidMiner, Inc, USA).

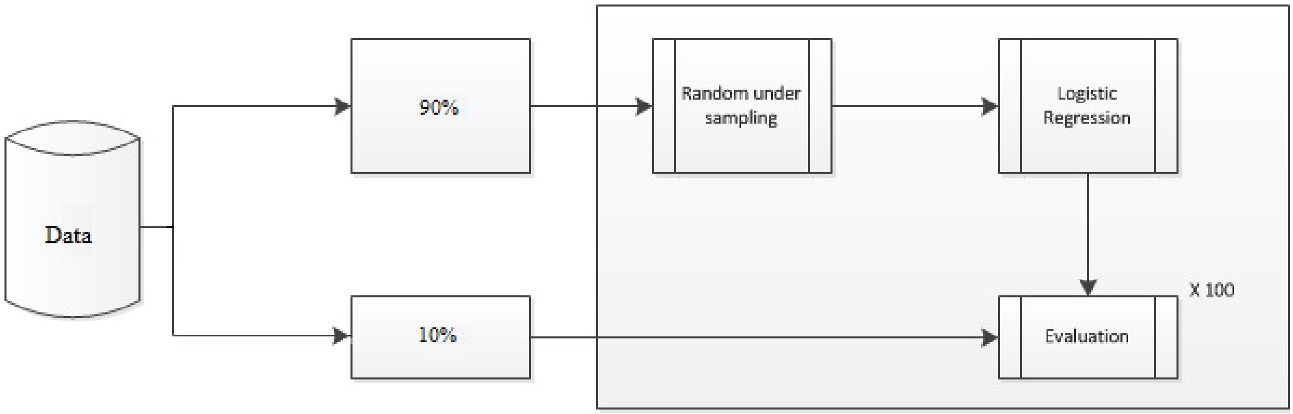
Standard data analysis procedures do not apply to imbalanced datasets [21], and the process of model generation and evaluation must take data imbalance into consideration. A common method for dealing with imbalanced data is to artificially balance the data during model generation (training) by either undersampling the majority class or oversampling the minority one [22]. Studies have shown that undersampling performs better than oversampling on large domains [23], and although many undersampling methods exist, the simple procedure of randomly selecting a reduced set from the majority class provides competitive results compared with other undersampling methods [24]. In this study, we used a random undersampling method during model generation to overcome the problem of class imbalance.

Data were randomly divided into two sets. The first set (training dataset) includes 90.00% (7412/8235 patients without in-hospital PU) and 90% (46/51 cases with in-hospital PU) of each class and was used for model generation, and the second set (test dataset) consists of the remaining 9.99% (823/8235 patients without in-hospital PU) and 9% (5/51 cases with in-hospital PU) of each class and was used to evaluate the generated model (Figure 2 shows this). This was necessary for validating the generated model on an imbalanced dataset. From the training set, we randomly sampled a smaller set of the negative class (ie, patients who did not develop in-hospital PU) and combined it with the positive class (ie, patients who developed in-hospital PU), thereby obtaining a balanced dataset. A logistic regression model was generated using the balanced dataset, and evaluated using the imbalanced dataset. This was repeated 100 times in order to cancel the effects of chance.

Using the above-described method, the following three sets of factors were examined to determine the most predictive dataset.

1. The ΣA set of factors were gender, age, surgical duration, and total NNS-A score
2. The ΣB set of factors were gender, age, surgical duration, and total NNS-B score
3. The ΣAB set of factors were gender, age, surgical duration, total NNS-A score, and total NNS-B score.

Figure 2. Model generation and evaluation process.



Model Evaluation

Our aim was to use the generated logistic regression model for classification, so the classification table is the most appropriate evaluation method [21]. In classification, the generated model is usually evaluated using its prediction accuracy; however, with such an imbalanced dataset, a model that simply classifies all inputs as negatives will achieve 99.38% (8235/8286) accuracy. Such a model is useless because it cannot classify the more important positive class. Therefore, other evaluation measurements are required. Common measurements used in such situations are model sensitivity (1) and specificity (2), which are defined in Figure 3.

It is important to have a model with both high sensitivity and high specificity, since a low sensitivity means the model will not efficiently predict the more important positive class, while having a low specificity means the model will have many false positives. A measurement that combines both sensitivity and specificity is the area under receiver operating characteristic curve (AUC). A high AUC indicates the model has both high sensitivity and specificity. In this study, we used AUC to identify models with high sensitivity and specificity.

Figure 3. Sensitivity and specificity.

$$\text{Sensitivity} = \frac{\text{True positives}}{\text{True positives} + \text{False negatives}} \quad (1)$$

$$\text{Specificity} = \frac{\text{True negatives}}{\text{True negatives} + \text{False positives}} \quad (2)$$

Results

The Datasets

Table 5 shows the average accuracy, sensitivity, specificity, and AUC for each factor group over the 100 balanced datasets. The ΣA dataset gave a high average accuracy, but the average sensitivity of the generated model was very low. In contrast, the other two factor sets (ΣAB and ΣB) provided similar results with high average accuracy, sensitivity, specificity, and AUC. Given that ΣB has fewer factors, it is preferable to use ΣAB.

Table 5. Mean performance of different factor sets.

Factor set	Accuracy mean (SD)	Sensitivity mean (SD)	Specificity mean (SD)	AUC mean (SD)
ΣA	82.2 (2.8)	47.6 (10.5)	82.4 (2.8)	71.4 (4.5)
ΣB	82.7 (2.0)	69.2 (11.5)	82.8 (2.1)	84.0 (3.3)
ΣAB	82.1 (2.3)	70.6 (10.8)	82.2 (2.3)	84.3 (3.9)

Models

The model that provided the closest results to average was the model with the median AUC (3) (Figure 4). This model achieved 80% (4/5) sensitivity, 81.3% (669/823) specificity, and 84.3% AUC. Odds ratios and 95% confidence intervals for gender, age, surgical duration, and total NNS-B score were 3.3 (1.2-10.2), 1.0 (1.0-1.1), 1.5 (1.3-1.9), and 1.5 (1.2-2.0), respectively.

Figure 4. Logistic regression model of the median AUC.

$$1.19 \cdot Gender(Male = 1) + 0.02 \cdot Age + 0.42 \cdot Surgical\ duration + 0.42 \cdot NNS\text{-}B - 3.86 \quad (3)$$

It is worth mentioning that only four of the 100 models gave minimum sensitivity using the ΣB factor set, which indicates that the random undersampling procedure was effective in overcoming class imbalance and will provide a good prediction model in most cases.

Discussion

Predicting Pressure Ulcers at Patient Admission

We examined the possibility of predicting PU development from data typically recorded by nurses on patient admission, such as gender, age, surgical duration, and total NNS scores. Being able to achieve this would make efficient use of the existing HIS system and be of great benefit to nurses. An argument can be made that using other hospitalization data (eg, skin and support surface status, special mattresses, laboratory test results, malnutrition, etc) might improve prediction accuracy; however, our aim is to provide a system that can predict PU risk on admission without the need to collect additional data. An experienced nurse can observe changes in a patient’s status and provide an effective assessment, while a novice nurse may not be able to. With PU assessment on admission, a novice nurse can identify patients likely to develop PUs during hospitalization. Studies have shown that education [25] and use of a risk assessment scale [26] can independently influence PU prevalence.

Follow-up procedures will be needed for patients identified as being at high risk of developing PUs based on admission data. Our hospital uses the Braden scale to follow high-risk patients, which includes assessment subscales for mobility/activity risk factors [8]. To take the proper measurements, we defined PU incidence according to NPUAP and national guidelines.

Notably, gender requires further consideration. We found that, consistent with other reports [8,15], males are more prone to develop PUs than females. However, the Waterlow scoring system suggests that females are at a higher risk of PU development, and yet other studies have reported that gender does not affect the risk of developing PUs [17,18]. A potential reason for our finding that males are more prone to developing PUs is that they have less subcutaneous fat than females. In Japanese adults, a significant gender difference between males and females was found with respect to the amount of subcutaneous fat at all sites except for the side chest and lower back [27]. Given the above, the gender factor may require further investigation.

Surgical method and duration are considered important risk factors in PU development [9,10]. Our results also showed a high odds ratio for surgical duration. More than half of the inpatients that developed PUs had surgery, and most surgeries lasted more than three hours. Our results also show that the total NNS-B score is an important factor for predicting inpatient PU, while previous studies investigated the effects of individual NNS items [11-13,16].

This study showed that with highly imbalanced medical data, random undersampling could provide good results in some cases despite its simplicity. In fact, only four models generated using random undersubsampling had low sensitivity.

It is worth mentioning that no special data collection was required for this work. Collection of the data used is required at all Japanese acute care hospitals under the Japanese medical insurance system for purposes of medical fee reimbursement. Notably, this work allowed for the use of existing HIS data.

In this study, we investigated the possibility of predicting PU development in hospitalized patients from data collected by nurses on admission. Identifying the probability of developing PUs on patient admission enables nurses to take precautionary measures, and thus reduce the total number of in-hospital PU cases. The model uses the total NNS score combined with patient age, gender, and estimated surgical duration as predictive factors. Data were highly imbalanced, and the random undersampling method was used to overcome this problem. The logistic regression model achieved an average of 69.2% (6920/100) sensitivity and 82.8% (8280/100) specificity, demonstrating that random undersampling was effective for balancing the training dataset.

Limitations

This study has a number of limitations worth noting. First, we used retrospective data with class imbalance. We are planning to investigate the results on new data. Second, the retrospective analysis was conducted in an acute care hospital setting, and thus cannot be generalized to long-term care hospitals. The current NNS does not reflect other important medical care tasks such as patient education, admission, and discharge instructions, coping with a dementia patient, fall prevention, and medication management. These are expected in a future NNS revision, and are required for further data mining of PU risk factors.

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Conflicts of Interest

None declared.

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Abbreviations

AUC: area under receiver operating characteristic curve
HIS: hospital information system
NNS: Nursing Needs Score
NPUAP: National Pressure Ulcer Advisory Panel
PU: pressure ulcers

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Original Paper

From Data to Optimal Decision Making: A Data-Driven, Probabilistic Machine Learning Approach to Decision Support for Patients With Sepsis

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Abstract

Background: A tantalizing question in medical informatics is how to construct knowledge from heterogeneous datasets, and as an extension, inform clinical decisions. The emergence of large-scale data integration in electronic health records (EHR) presents tremendous opportunities. However, our ability to efficiently extract informed decision support is limited due to the complexity of the clinical states and decision process, missing data and lack of analytical tools to advice based on statistical relationships.

Objective: Development and assessment of a data-driven method that infers the probability distribution of the current state of patients with sepsis, likely trajectories, optimal actions related to antibiotic administration, prediction of mortality and length-of-stay.

Methods: We present a data-driven, probabilistic framework for clinical decision support in sepsis-related cases. We first define states, actions, observations and rewards based on clinical practice, expert knowledge and data representations in an EHR dataset of 1492 patients. We then use Partially Observable Markov Decision Process (POMDP) model to derive the optimal policy based on individual patient trajectories and we evaluate the performance of the model-derived policies in a separate test set. Policy decisions were focused on the type of antibiotic combinations to administer. Multi-class and discriminative classifiers were used to predict mortality and length of stay.

Results: Data-derived antibiotic administration policies led to a favorable patient outcome in 49% of the cases, versus 37% when the alternative policies were followed (P=1.3e-13). Sensitivity analysis on the model parameters and missing data argue for a highly robust decision support tool that withstands parameter variation and data uncertainty. When the optimal policy was followed, 387 patients (25.9%) have 90% of their transitions to better states and 503 patients (33.7%) patients had 90% of their transitions to worse states (P=4.0e-06), while in the non-policy cases, these numbers are 192 (12.9%) and 764 (51.2%) patients (P=4.6e-117), respectively. Furthermore, the percentage of transitions within a trajectory that lead to a better or better/same state are significantly higher by following the policy than for non-policy cases (605 vs 344 patients, P=8.6e-25). Mortality was predicted with an AUC of 0.7 and 0.82 accuracy in the general case and similar performance was obtained for the inference of the length-of-stay (AUC of 0.69 to 0.73 with accuracies from 0.69 to 0.82).

Conclusions: A data-driven model was able to suggest favorable actions, predict mortality and length of stay with high accuracy. This work provides a solid basis for a scalable probabilistic clinical decision support framework for sepsis treatment that can be expanded to other clinically relevant states and actions, as well as a data-driven model that can be adopted in other clinical areas with sufficient training data.

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KEYWORDS

sepsis; clinical decision support tool; probabilistic modeling; Partially Observable Markov Decision Processes; POMDP; CDSS

Introduction

Over the past few decades, our society has transitioned to a state where bottlenecks have shifted from a lack of data, to limitations in extracting meaningful knowledge and subsequently use that knowledge to drive decisions. This data-rich, knowledge-poor oxymoron is particularly true in computationally-driven Clinical Decision Support Systems (CDSS), where advances in automated high-throughput data acquisition and electronic health records have yet to be translated into knowledge extraction and probabilistic decision guidance. This is true even in the cases of dangerous and ubiquitous threats to human health, one of which is sepsis. Sepsis is an overwhelming systemic immune response to infection, which results in damage to the patients' own tissues and organs. This process can happen at any age, regardless of the underlying health condition and from seemingly benign incidents. Severe sepsis strikes about 18 million people annually (750,000 cases in the United States) and has a very high short-term mortality risk (28% to 50%) [1] Severe sepsis is the leading cause of Intensive Care Unit (ICU) deaths (60-80% of ICU deaths in developing countries) and it kills more than 6 million children world-wide every year [2].

Surprisingly, while sepsis is one of the most common diseases (more deaths than prostate cancer, breast cancer, and HIV/AIDS combined [3]), it has the lowest state-funding rates for research. This is in contrast to its severity, occurrence in our society (sepsis hospitalizations have more than doubled over the last 10 years [2]) and money spent to battle it (US $14.6 billion in 2008, an increase by an average of 11.9% each year). The diagnosis of sepsis is often delayed because it is difficult to differentiate from other high-risk conditions and this delay can lead to the rapid deterioration of the patient. One potentially transformative approach to this problem would be to exploit the vast amount of information that is hidden in the Electronic Health Records (EHR) of patients to derive a CDSS.

Adoption of EHR's by health care systems was predicted to vastly improve the efficiency and quality of patient care [4]. Unfortunately, despite explosive EHR adoption, and enormous associated capital expenditures, these gains have yet to be realized [5,6]. One reason for this failure is that our capacity to utilize complex, large-scale data to generate knowledge and inform clinical decisions remains limited. For example, while CDSS have existed for decades, they are mostly limited to alert systems and (data-oblivious) agent-based suggestions that rely on hard-coded criteria. Although in certain systems patient cases are used for probabilistic training, these efforts focus on feature correlations and final clinical outcomes [7-10] rather than actionable policy (see [11,12] for a review). Our previous work on the associations among EHR observations for lactic acid prediction work falls also in this category (11).

Some of the most powerful methods for modeling decision making in clinical decision support are those that treat the learning problem as a Markov Decision Process (MDPs) [13]. A MDP is a discrete-time stochastic control process, where the next state depends only on the current state and the action that the decision maker performs, while it is conditionally independent of all other states and actions. An extension to MDPs are the Partially Observable MDPs, (POMDPs), where the states themselves are hidden and only observations are available. In that case, a belief regarding the current system state is formed based on the observations and their state-based likelihoods [14]. There are many methods to solve MDPs/POMDPs, including dynamic programming, linear programming and reinforcement learning [13-17]. When the problem becomes intractable, reinforcing learning methods are preferred as they do not require knowledge of the underlying MDP model.

Surprisingly, although the use of MDP methods in clinical settings is well established, there are only a few notable examples where POMDP has been explored for disease-specific decision support with probabilistic outcomes. MDP has been used for decision support in determining liver acceptance for liver transplants [18-20], HIV therapy initiation [21], breast cancer screening [22], treatment of hepatitis C [23], statin therapy timing [24], among others [25]. However, in most cases the pathology is complex, the underlying state of the patient is latent and we can only observe emitted signals (observations) with some uncertainty. A notable example of POMDP adoption in medical decision support is that of Hauskrecht and Fraser [26,27] who modeled Ischemic Heart Disease with a POMDP model that included both treatment and test actions. This work used an impressive hierarchical model for state variables and performed reasonably well in predicting optimal policies in that given scenario. Similarly, Turgay et al [28] used a POMDP model to support personalized mammography screening decisions in a model that used six states, three of which were fully observable. Kreke et al created a 2-state POMDP model for pneumonia-related sepsis patients that included only a Cytokine test as an investigative action and incorporated the Sequential Organ Failure Assessment (SOFA) score for the MDP state space definition [29,30]. In all these cases, both the state model and policy were course-grained, the parameter space limited and the training sets were a few dozen patients.

Here, we use a point-based POMDP solver together with a dataset of 1492 patients that is complete with time-stamped blood tests, vitals, and other relevant records for sepsis. We model patient trajectories and treatment by defining data-driven states, observations, probabilistic beliefs, actions, and rewards. We then evaluate the potential of this method to inform on optimal administration of antibiotic combinations, defined as antibiotic "policy". In addition, we assess the predictive ability of applying machine learning methods to predict patient mortality and length of stay, in order to drive clinical decision support.

Methods

Data Collection

An EHR database containing 1492 adult patients (≥18 years of age; ICU cases) with personal health information removed and meeting at least two Systemic Inflammatory Response Syndrome (SIRS) criteria [31] admitted to the University of California Davis Health System (UCDHS), was used for all the analyses, Figure 1 (a). Informed consent was obtained for all human subjects and the analysis was approved by the institutional review board of the University of California, Davis (IRB # 254575). Of the 1492 patients, 45.0% were female, the mean length of stay was 17.0 (SD 36.7) days, and 38.0% were admitted from the emergency department. Table 1 summarizes the dataset used; Figure 2 provides a histogram of the total/ICU length of stay). UCDHS is a tertiary care, academic medical center that did not have an active EHR alert system for the diagnosis or treatment of sepsis during the study period. All data were abstracted retrospectively from the EHR via structured query language interrogation of a de-identified relational database. Patients were included in the database if they were hospitalized and discharged between 1 January 2010 and 31 December 2010. The following six variables were used as *observation variables* in our model Figure 1 (a): temperature, respiratory rate (RR), white blood count (WBC), mean arterial pressure (MAP), systolic blood pressure (SBP), and blood culture results, with explicit mention of the bacterial species that were present in the culture. The first five variables are measurements of a patient's condition recorded over time; temperature, RR, WBC, and MAP are part of the SIRS criteria.

Table 1. Database characteristics.

States and state transition distribution in the dataset		
State	Transitions (4200 total)	Patients (1492 total)
No SIRS	1300 (30.85%)	915 (61.33%)
SIRS	294 (6.98%)	264 (17.70%)
Sepsis	41 (0.97%)	38 (2.54%)
Septic Shock	17 (0.40%)	17 (1.14%)
PS (Probable SIRS)	1929 (45.79%)	939 (62.94%)
Bacteremia	157 (3.73%)	121 (8.11%)
BPS (Bacteremia Probable Sepsis)	323 (7.67%)	179 (11.99%)
PSS (Probable Septic Shock)	139 (3.30%)	135 (9.05%)
Demographics and Final Diagnosis		
Characteristic	Value	
Female Gender	677 (45.37%)	
Male Gender	815 (54.63%)	
Mortality Rate	376 (25.2%)	
Length of Stay (days)	Mean: 17 Median: 8	
Intensive Care Unit Stay (days)	Mean: 6.5 Median: 1	
Sepsis Diagnosis	188 (12.60%)	
Septic shock Diagnosis	21 (1.41%)	
Severe Sepsis Diagnosis	8 (0.53%)	

Figure 1. Development and evaluation of a clinical decision support system (CDSS) for Sepsis. (A) Synopsis of the EHR database, distribution of vitals, states, actions. Likelihood functions were used to calculate state-specific transition and observation probabilities. (B) The state-action diagram describes underlying patient states, possible transitions and beliefs based on the values of the observed variables. There are two absorbing states, "Death" and "Dismissal". The training of the POMDP model that is applied on the state-action space performs value iteration updates on a sample set of beliefs, effectively using a Monte Carlo approach for sampling together with dynamic programming for the calculation of the value iteration. (C) Belief (ie, probability distribution of the patient states) is updated based on the action taken and the new observations. At each time step patient vitals are observed and the action that corresponds to the optimal policy is taken. A new set of observations (vitals, tests) will lead to an updated belief that may lead to a new action to be undertaken. The update is asynchronous, as it is calculated on-the-fly as new information arrives. (D) Evaluation of the CDSS framework was performed through 5-fold cross validation and data size sensitivity analysis.

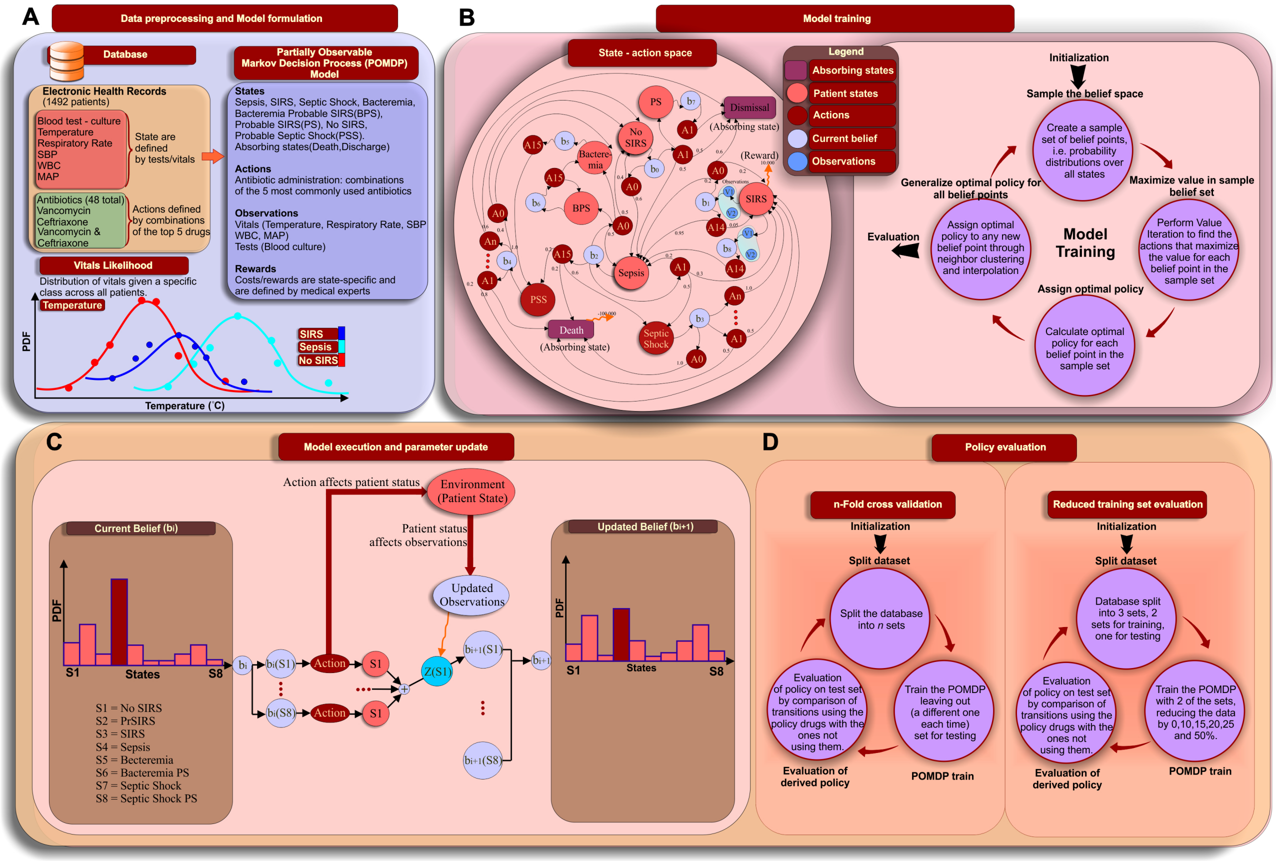
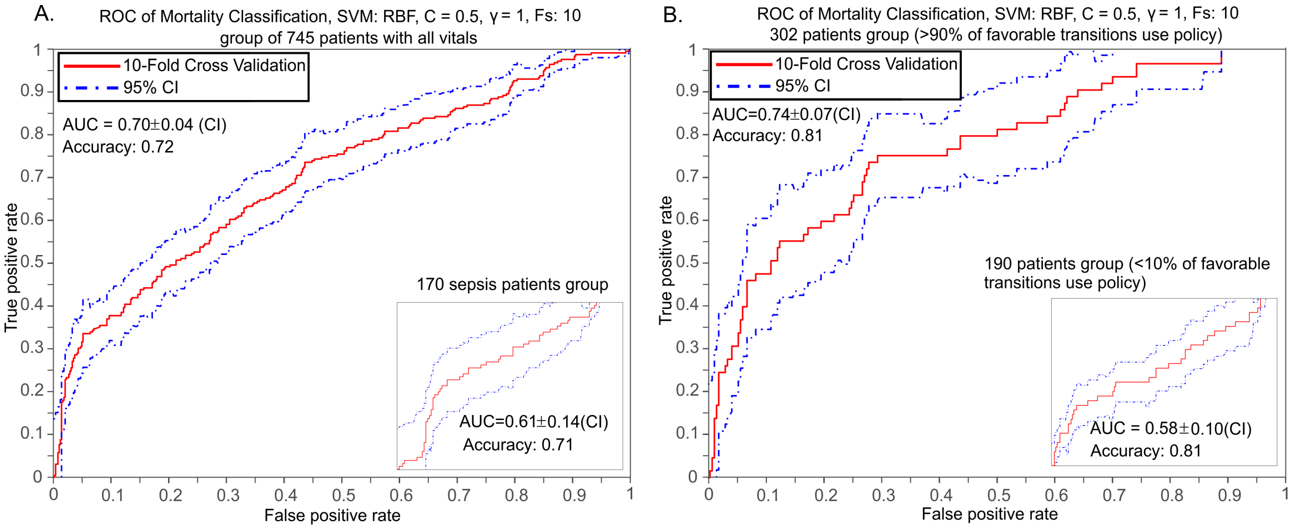


Figure 2. ROC curves of mortality classification/prediction. Support Vector Machine training results, given the provided vitals and mortality model, in a 10-fold cross validation scheme. The features used for the classification are temperature, respiratory rate, WBC, MAP and lactate levels and 745 patients for whom all seven variables were available were considered out of the 1492 of the DB. Radial Basis Function (RBF) kernel was used for the SVM training. The five measurement variables were summarized by their mean and standard deviation (STD) across the trajectory of each patient. Principal Component Analysis (PCA) was also used to assess whether linear transformation of the feature space and dimensionality reduction can be achieved in this case. A filter method was applied using the Area Under the Curve (AUC) of the Receiver Operating Characteristic (ROC) curves as a ranking criterion. The positive/negative classes for mortality prediction are defined as alive/deceased respectively. (A) Classification using the patients that have all features available. The maximum prediction accuracy when all patients with available all vitals are used, is 0.72 (72%) and the AUC is 0.70. (Inset) Classification using the 170 patients that have a diagnosis related to Sepsis. The maximum prediction accuracy is 0.71 (71%) and the AUC is 0.61. (B) SVM classification performance when the patient group that have ratio of transitions to better states with policy drugs vs all transitions to better states > 0.9 (302 patients out of 745) is used. (Inset) SVM classification performance for the patient group that have ratio of transition to better states with policy drugs vs all transitions to better states less or equal to 0.1 (190 patients out of 745).



Sepsis Model

State Definition

The states that we include in our formulation were selected based on the existence of well-defined criteria and expert opinion, Figure 1 (a). Each of these states is defined by a number of features as illustrated in Table 2. The SIRS criteria that define the respective state are HR >90 beats per minute, RR >20 breaths per minute (or partial pressure of arterial $CO_2 < 32$mm Hg), temperature either >38°C or <36°C, and WBC either >12,000 or <4000 cells/mm3 (or > 10% bands). For a patient to be diagnosed with sepsis, at least two of the SIRS criteria need to be present and a suspected infection should be present (eg, evident through blood test results). Septic shock occurs when there is sepsis-induced hypotension (where either SBP is below 90 mm Hg, < 40 mm Hg below baseline, or MAP is below 70 mm Hg) that persists despite adequate fluid resuscitation. Additionally, we included states that cannot be fully determined during the training phase because of missing database information, such as missing vitals measurements and time stamps. These states are “Probable Septic Shock” (PSS: Hypotention, positive blood test and no adequate vitals to determine SIRS and/or Sepsis), “Probable SIRS” (PS: no infection and no vitals to determine SIRS), “Bacteremia Probable SIRS” (BPS: infection but no vitals to determine SIRS and/or Sepsis). We have not included the “Severe Sepsis” state in this work, as the current dataset does not offer enough information required to incorporate the organ failure into the patient state definition.

Table 2. States and their definition based on vitals and blood tests.

State	Features
No SIRS	
SIRS	heart rate (HR) >90 beats per minute
	respiratory rate (RR) >20 breaths per minute (or partial pressure of arterial CO2 < 32)
	temperature either >38°C or <36°C
	white blood cell count (WBC) either >12,000 or <4000 cells/mm3 (or > 10% bands)
Sepsis	SIRS and Infection (blood test result)
Severe Sepsis	Sepsis and Organ failure (shown in ICL code)
Septic Shock	Sepsis and Hypotension (systolic blood pressure (SBP) is below 90 mm Hg, < 40 mm Hg below baseline, or the mean arterial pressure (MAP) is below 70 mm Hg)
PS	No infection– no vitals to determine SIRS
Bacteremia	Infection (blood test result) & No SIRS
BPS	Infection – no vitals to determine SIRS (thus Sepsis)
PSS	Hypotension, positive blood test and no vitals to determine SIRS (thus Sepsis)

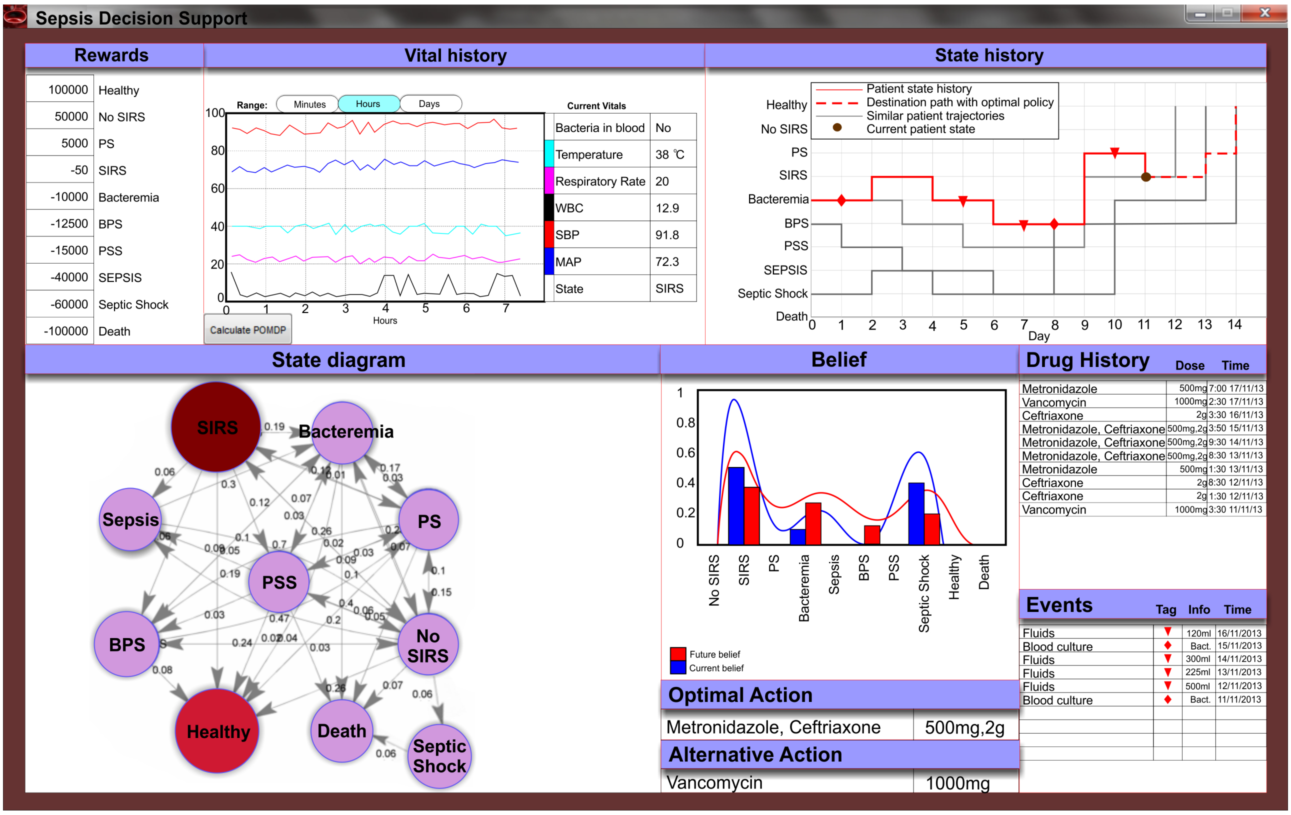
Actions

A policy is one or more actions that are followed. Each antibiotic combination is considered a possible action. A total of 48 antibiotics have been included in the patients' EHR that we analyzed. Here we consider the top five more frequently used antibiotics (Vancomycin, Cefepime, Metronidazole, Ceftriaxone, and Meropenem) and all their possible combinations, plus one more combination that encapsulates all other antibiotics that may have been used. This results in 32 possible combinations, each one defining a different action of the five most frequently used antibiotics. Vancomycin is a glycopeptide antibiotic that inhibits the cell wall synthesis of gram-positive bacteria, although it is avoided due to its nephrotoxicity and ototoxicity. Both Cefepime and Ceftiaxone are cephalosporin antibiotics that have activity against both Gram-negative and Gram-positive bacteria and they are especially used to treat moderate-severe pneumonia. Cefepime is also used to treat infections caused by multi-drug resistant microbial strains. Metronidazole is a nitroimidazole antibiotic that is used particularly for anaerobic bacteria and some protozoa. Meropenem is an ultra-broad spectrum antibiotic and beta-lactam that inhibits bacterial wall synthesis. Combinations of all states with all possible actions comprise the state-action space for our sepsis model, Figure 1 (b, left side).

Rewards

Reward/cost values have been provided empirically by physicians, based on the severity of each state. These are, from best to worse: Healthy (100,000), No SIRS (50,000), Probable Sepsis (PS, 5000), SIRS (-50), Bacteremia (-10,000), Bacteremia Possible Sepsis (BPS, -12,500), Possible Septic Shock (PSS, -15,000), Sepsis (-40,000), Septic Shock (-60,000), Death (-100,000). This information is also depicted in Figure 3, first panel.

Figure 3. A graphical user interface (GUI) for the clinical decision support system. Physicians have access to real-time and historical vital history (upper left), as well as state history (upper right) for a given patient. The state history displays events, most likely path if optimal policy is to be adopted and the past trajectories of the top three patients that had similar profiles (ie, past states and vitals) to the current patient. The state diagram (bottom left) depicts the state transition probabilities and its updates based on the current state. The GUI also displays the belief distribution, optimal action given the current belief and the second best alternative action. Drug history and significant events are displayed (bottom right). The tool updates values automatically with new data, although the user has the flexibility to revise the desired reward values (upper left) and then manually trigger a recalculation of the optimal policy.



Rewards

100000	Healthy
50000	No SIRS
5000	PS
-50	SIRS
-10000	Bacteremia
-12500	BPS
-15000	PSS
-40000	SEPSIS
-60000	Septic Shock
-100000	Death

Current Vitals

Bacteria in blood	No
Temperature	38 ℃
Respiratory Rate	20
WBC	12.9
SBP	91.8
MAP	72.3
State	SIRS

Drug History	Dose	Time
Metronidazole	500mg	7:00 17/11/13
Vancomycin	1000mg	2:30 17/11/13
Ceftriaxone	2g	3:30 16/11/13
Metronidazole, Ceftriaxone	500mg,2g	3:50 15/11/13
Metronidazole, Ceftriaxone	500mg,2g	9:30 14/11/13
Metronidazole, Ceftriaxone	500mg,2g	8:30 13/11/13
Metronidazole	500mg	1:30 13/11/13
Ceftriaxone	2g	8:30 12/11/13
Ceftriaxone	2g	1:30 12/11/13
Vancomycin	1000mg	3:30 11/11/13

Events	Tag	Info	Time
Fluids	▼	120ml	16/11/2013
Blood culture	◆	Bact.	15/11/2013
Fluids	▼	300ml	14/11/2013
Fluids	▼	225ml	13/11/2013
Fluids	▼	500ml	12/11/2013
Blood culture	◆	Bact.	11/11/2013

Optimal Action

Metronidazole, Ceftriaxone	500mg,2g

Alternative Action

Vancomycin	1000mg

Calculation of Transition and Observation Probabilities

Transition probabilities are calculated as the frequency of State-Action-Next State patterns in each State-Action combination. Similarly, observation probabilities are calculated based on the frequency of observing vital value (in bins) combinations in any given state. In order to extract the probability of the observation combinations, we fit the distribution that best describes the data for each vital and state and then divide it in five non-overlapping, equally-sized bins. The number of bin was selected such that sufficient data (>10 samples) will be present in each bin. For each state, the distributions of the five vitals are divided in five equal parts across their min-max range (each assigned a probability from the distribution) with blood test being modeled with a binary variable (presence/absence of bacteria). This leads to 6250 combinations ($2 \cdot 5^5$).

POMDP Formulation

A POMDP is defined as a 8-tuple ($S, A, Z, T, O, R, b_0, \gamma$), where S is a finite set of states, A is a finite set of actions, $T:S \times A \times S \rightarrow P(S)$is the state transition function, $T(s, a, s')$ denotes the probability $P(s'| s, a)$ of reaching state s' from state by taking action a, $R: S \times A \rightarrow \Re$ is the reward function, $P(s's, a)$ denotes the immediate reward of executing action a in state s, $\gamma \in [0, 1]$ is the discount factor, Z is the finite set of observations, $O:S \times A \rightarrow P(S)$ is the observation function, $O(s, a, z)$ denotes the probability $P(z|s, a)$ of perceiving observation z when taking action a and arriving in state s, b_0 is the initial state probability distribution, b is the state probability distribution and $b_0(s)$ denotes the probability of starting in state s. A policy π for a POMDP problem is defined as $\pi(b) \rightarrow a$ and its value is the expected cumulative discounted reward that we will receive if we perform actions a when we have belief b. The policy that maximizes this cumulative value is called the *optimal policy*. We used a POMDP model training methodology that is based on a Monte Carlo approximation for solving the Value Iteration method over a sampling belief space, Figure 1 (b, right side). Value iteration calculates the value of each state by solving the Bellman equations (Figure 4).

If we have belief b(s) of being in state s, perform action a and we observe z, the updated belief for being in state $b(s')$ is shown in Figure 1 (c) and Figure 5.

Figure 4. Value iteration calculates the value of each state by solving the Bellman equations.

$$V_{k+1}(b) = \max_{a \in A}\left[\sum_{s \in S} b(s)\,R(s,a) + \gamma \sum_{z \in Z} P(z|b,a)V(\tau(b,a,z))\right]$$

$$\pi_{k+1}(b) = \operatorname*{argmax}_{a \in A}\left[\sum_{s \in S} b(s)\,R(s,a) + \gamma \sum_{z \in Z} P(z|b,a)V_k(\tau(b,a,z))\right]$$

Figure 5. Belief b(s) of being in state.

$$b(s') = \tau(b(s),a,z) = P(s'|b,a,z) = \frac{O(s',a,z)\sum_s T(s,a,s')b(s)}{P(z|b,a)}$$

POMDP Statistical Evaluation

We use *Perseus* [32], a randomized point-based value iteration algorithm to extract the optimal policy with default settings. We use 5-fold cross-validation to evaluate the generalization error of the policy, Figure 1 (d). For a specific transition, a CDSS-derived policy is deemed as followed if one or more of the antibiotics in the policy have been administered to the patient. Comparison is performed between treatments that are in agreement with the CDSS-derived policy for each transition and those that are not (non CDSS-derived policies), measuring the percentage of transitions that lead to a better/same/worse state in both cases. At a trajectory level, we compare what percentage of trajectories move to a better state on average with and without the CDSS-derived policy. The robustness of the algorithm to perform in the context of reduced data is tested by splitting the patient data into 3 parts, where only the 2 out of the 3 parts are used for training. The algorithm is trained on randomly selected subsets of the 2/3 training data that correspond to the desired percentage of the total training set. The performance is always evaluated in the same testing set (ie 1/3 of the total dataset) and the whole process is repeated 10 times to reduce bias, Figure 1 (d). All *P* values are calculated using hypergeometric distribution with multiple hypothesis correction (Benjamini-Hochberg).

Length-of-Stay and Mortality Inference

For the length of stay (LOS) prediction, we first split the patients in equally-sized bins, based on their LOS distribution, thus maximizing entropy and to avoid bias on the training data. Then we used Support Vector Machines (SVM) with different kernel functions [33,34]. In SVM classification, the training feature vectors are mapped to a higher dimension space, in which the SVM determines a linearly separating hyperplane given by a maximal margin [35]. In order to predict survivability results given a patient's vital signs, an SVM classification method was used, taking into account five features (temperature, respiratory rate, WBC, MAP, and lactate levels) and the mortality state of each patient, for both binary and multi-class classification. For the latter, we consider both combinatorial pairwise and one-versus-all schemes [36], where we observed no significant difference in our results. We evaluated the performance of the classifier by performing cross-validation (CV) and calculating the Receiver-Operator-characteristic (ROC) curves, confidence intervals (CI), and the area-under-the-curve (AUC).

Results

Optimal Policy Prediction by Data-driven Machine Learning Approaches

We performed 5-fold cross validation (CV) to evaluate the generalization error of our approach, with similar results across all folds, Figure 6 (a) and Tables 2 and 3. The CDSS-derived optimal policies in each transition led in significantly more occurrences to better states than when the treatment that was followed by the physicians was not in agreement with the CDSS-derived policy (49% of transitions to better states when the CDSS-derived policy was followed vs 37% otherwise; *P*=1.3e-13). Interestingly, when non-CDSS policies were used, patients tend to stay in the same condition (35% in non-CDSS policies vs 25% in CDSS policies, *P*=5.1e-13) while the difference between CDSS-derived policies and non-CDSS policies is not statistically significant for transitions to a worse condition (28% in non-CDSS policies vs 26% in CDSS policies, *P*=4.2e-1). We then analyzed each patient trajectory independently, to estimate the number of transitions within a trajectory that lead to better states, with and without following the policy. Results show that when the optimal policy prediction (ie, the policy that maximizes the expected cumulated reward, as defined in the methods section) is followed, there exists a significant shift to trajectories that have more than 90% of their transitions leading to a better state, Figure 6 (b). When the policy was followed, 387 patients (25.9%) have 90% of their transitions to better states and 503 patients (33.7%) patients had 90% of their transitions to worse states (*P*=4.0e-06), while in the non-policy cases, these numbers are 192 (12.9%) and 764 (51.2%) patients (*P*=4.6e-117), respectively. Furthermore, the percentage of transitions within a trajectory that lead to a better or better/same state are significantly higher by following the policy than for non-policy cases. Indeed, 605 versus 344 patients (*P*=8.6e-25) have 90% of their transitions to a better state with versus without following a CDSS-derived policy, Figure 1 (a).

This result was observed in all five runs of the 5-fold CV and on the full dataset, hence it holds for different data distributions.

Next, we evaluated the robustness of the POMDP framework to decreasing sets of training data. To perform this analysis, we iteratively reduced the training set and we evaluated in the same testing data set (see Methods). Results demonstrate the method is robust to decreasing amount of data in the set, Figure 6 (c) as well as Figures 3 and 7, mainly due to the significant overlap of the various antibiotics in each combination proposed by the optimal policy. To gain more insight on how the policy changes by decreasing the training set we constructed a comprehensive map of the optimal policy for each state, Figure 6 (d). The resulting map provides the CDSS-derived drug combination that led to more favorable outcomes in each state, Table 3. It is important to note, that these policies correspond to a definite knowledge that the patient is that specific state (belief/probability of 1), which is almost never the case as his/her prior history (previous states, clinical information, etc) shapes the belief distribution across all states at any given time. Additionally, the depicted drug combinations are associated with a better outcome overall, and not that are necessarily the optimal combination under any condition when a patient is in that specific state, since potent drug combinations are used to more severe cases, which have a higher probability to transition to a worse state. The optimal decision for any state will ultimately be a function of all observations (vitals, blood results, etc). Their associations will depend on the structure of the data that were used for the CDSS training.

Table 3. Optimal Policy based on from the POMDP CDSS tool. Note that this result assumes that current state is known and given in the state column (Belief/Probability of 1).

State	Drugs
SIRS	CEFEPIME,METRONIDAZOLE,CEFTRIAXONE
PS	METRONIDAZOLE,CEFTRIAXONE,MEROPENEM
Bacteremia	CEFEPIME,CEFTRIAXONE
Sepsis	CEFTRIAXONE
BPS	VANCOMYCIN,CEFEPIME,CEFTRIAXONE
PSS	METRONIDAZOLE,CEFTRIAXONE
Septic Shock	CEFTRIAXONE

Figure 6. Performance and Robustness of the POMDP Clinical Decision Support System for Sepsis. (A) 5-fold cross-validation results depict the performance of each fold with (left, blue) and without (right, brown) using the policy-proposed antibiotic combination. Each cell contains the number of transitions (4225 total transitions; 843 transitions per test fold) that lead to worse, equal or better states in each case. A state-specific percentage across all folds allows for comparison between the different policy strategies. (B) Number of patient trajectories vs. the percentage of their transitions that lead to a better state. (C) Dependency of CDSS performance on data size based on stratified reduction of the dataset. Outcome is shown for policy-proposed antibiotic combinations (left) and all other combinations (right) for different states (D) Changes in antibiotic combinations proposed in calculated optimal policy as a function of data-size reduction. Each row is a state and each column represents a drug-training set combination. The two tables depict which drug combinations were found to lead to better outcomes when in the perspective state, in the general case. States are as defined in the Methods sections, with three states denoting uncertainty due to missing data (PS: probable sepsis; BPS: bacteremia, probable sepsis; PSS: probable septic shock).

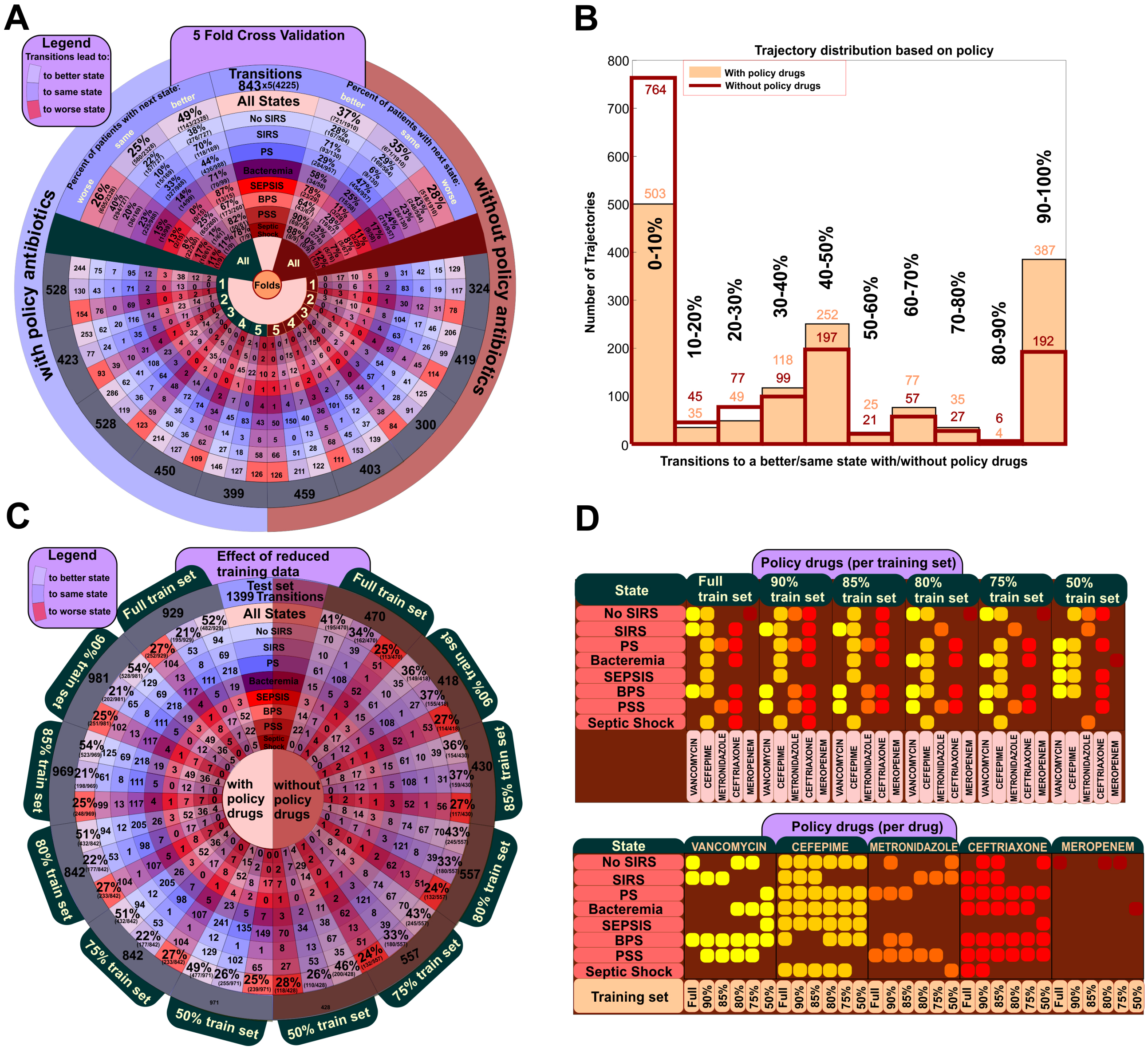
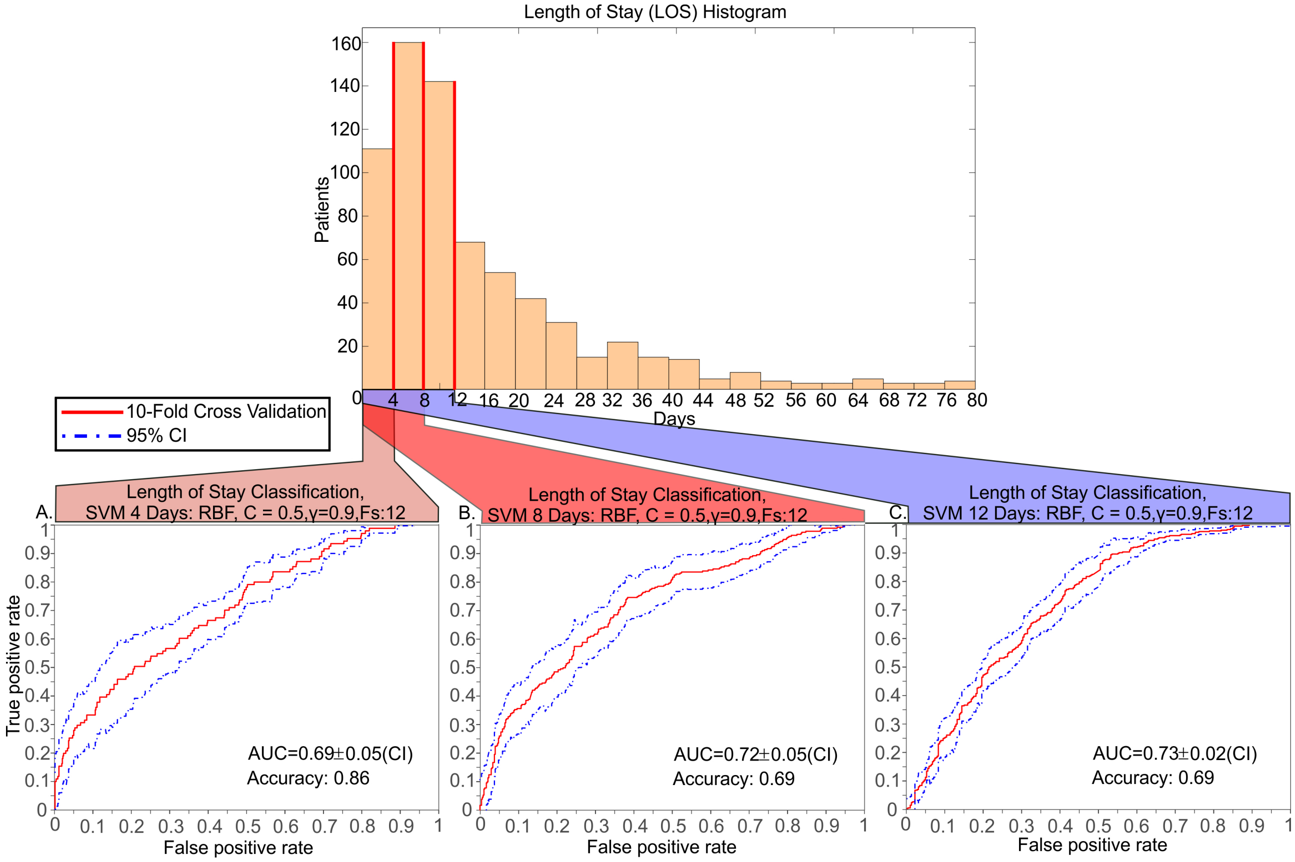


Figure 7. Predicting a patient's Length of Stay (LOS). Histogram of the LOS for the 745 patients in the database that have a complete record (median length of stay is 10.4 days). ROC curves for binary classifiers when 4, 8 or 12 days was used as the boundary between the two classes.



Mortality Prediction

Clinical outcome was found to be accurately classified by using Support Vector Machines (see Methods). In order to predict patient mortality, we used the five features (temperature, respiratory rate, WBC, MAP, and lactate levels) as well as the final outcome for each patient. This led to a dataset of 745 patients out of the 1492 total for whom all six variables were available. The five measurement variables were summarized by their mean and standard deviation (STD) across the trajectory of each patient [37]. Principal Component Analysis (PCA) was also used to assess whether linear transformation of the feature space and dimensionality reduction can be achieved in this case [38]. A filter method was applied using the Area-Under-the-Curve (AUC) of the Receiver Operating Characteristic (ROC) curves as a ranking criterion [39]. Radial Basis Function (RBF) kernel was used for the SVM training in a 10-fold cross validation scheme. The positive/negative classes for mortality prediction are defined as alive/deceased, respectively. Mortality classification of 745 patients has an AUC of 0.70 (SD 0.04; 95% CI) and accuracy of 0.72, Figure 2 (a). When the test set focuses on the 170 patients with sepsis group, it achieves an AUC of 0.61(SD 0.14) and accuracy of 0.71, Figure 2 (a). For the group of patients with a better-to-all transition ratio larger than 0.9 (302 patients out of 745) the AUC is higher at 0.74 (SD 0.07) and the accuracy is 0.81, Figure 2 (b), while AUC drops to 0.58 (SD 0.10) for patients with a ratio of better-to-all smaller than 0.1. Comparison of these results argue that the trained classifier performs better and is more accurate in cases where the proposed policy has been used and its discrimination power is higher when these policies lead to a favorable outcome.

Length of Stay Prediction

To predict the length-of-stay (LOS), we trained SVM classifiers with two extra features that were found to be informative: the occurrences of a positive blood culture and the number of policy drug administration during a patient's stay. We then defined and classified the patients in two classes, based on the length of stay. The threshold for that discrimination was driven by the median length of stay in the hospital (10.4 days) and hence we selected thresholds of 4, 8 and 12 days. A 10-fold cross validation scheme was used for the evaluation of the classifier. The AUC of the classifiers were 0.69 to 0.73 with small deviations in the CI (0.02-0.05) and accuracies from 0.69 to 0.82, Figure 7. Multi-class classification for multiple length-of-stay bins (0-3, 3-6, 6-12, 12+ days) had similar results, although the AUC drops to 0.53 when predicting the two intermediate (3-6 and 6-12) classes, Figure 6.

Discussion

In this work, we used the EHR of 1492 patients to build a decision support tool and predictive classifiers for patients with sepsis. Despite the fact that the dataset was limited in both number of patients and features available, the CDSS methodology resulted in data-driven policies that led to significantly improved patient outcomes. Similarly, we demonstrated that time-stamped EHR observational data, such as patient vitals and blood results, can be used to predict mortality and length of stay intervals, with increased accuracy and discriminative performance.

Given the vast combinatorial space of treatments and outcomes, one of the main challenges in the development of a statistical decision support tool is the definition of states and actions in a way that is both clinically relevant and computationally feasible. To create a framework that balances these trade-offs, we used expert knowledge and statistical methods to efficiently represent clinical cases within the POMDP framework, while at the same time making sure that each state-action combination has sufficient data for model training and testing. As the size of clinical databases scales up, an automated state and action definition technique can be applied, which might lead to interesting insights on what is medically relevant in each case. Our robustness analysis argues that a POMDP-based tool is quite robust even for small sample sizes and it remains to be seen the generalization boundaries of such approach for larger, integrative datasets, more sophisticated state-action spaces with additional features, and complex clinical histories. As with any data-driven predictive approaches, the generalization error and applicability of the results is dependent on the extend a model can capture the real state and action space, as well as the various biases that arise due to limited sample sizes, data quality and precision. For instance, differences in patient populations, microbiological resistance patterns of the wards, anti-infective pre-treatment of patients, administration of drugs (eg, vasopressors) or treatments (e,g, ventilator support) that are currently not captured limit the applicability of this study as they can substantially change the proposed policies and actions. To address these issues, the methods that are proposed here can be applied in larger datasets that can support a more extensive modeling for states, actions and observables, while correcting for possible biases across different attributes.

This initial study paves the way for several interesting directions towards a predictive CDSS for sepsis treatment. In addition to the SIRS criteria and the indication of an infection, it would be useful to take into account possible dysfunctional organs, a set of information that was not present in the database that we used here. As such, we can define nine states for organ dysfunction: absent, Respiratory, Coagulation, Liver, CNS, Renal, Metabolic, Cardiovascular, Multi-organ dysfunction (the latter defined as two or more organ failures). The Sequential Organ Failure Assessment (SOFA) criteria and score [40] can be used for this purpose. The action space can similarly be expanded to include several other actions that are important for sepsis treatment, such as the administration and dosage of IV fluids, vasoactive medications, initiation of mechanical ventilation, oxygen therapy, hemodialysis, the use of sepsis order set, and other admission and/or transfer decisions. To this end, a more extensive dataset, both in terms of features and patients is crucial so that the state/action combinatorial space will have adequate training samples. Furthermore, it is important to extend the number of composite features that one will investigate for complex traits, as in this study we only considered up to seven features. Such extension would likely lead to more accurate predictions regarding mortality and patient’s length-of-stay. From a technical perspective, it would be important to work towards an algorithmic framework that can distinguish patients that have reached a state from different trajectories, as the optimal treatment in each of these scenarios can be substantially different. Although this would violate the Markov property in the general case, one can investigate finite-memory models that can accommodate such setting.

Finally, an important aspect of any CDSS tool is an intuitive and interactive visualization of the patient status, past history and decision space. For this work, we have developed an interactive graphical user interface (GUI) that is connected with the POMDP solver and the database and can display the vitals, drug and state history, state belief, state diagram with all possible transitions and their probabilities, as well as the optimal/near-optimal actions given the current belief for the patient’s state, Figure 3. The user can also define the rewards for each state and re-calculate the POMDP-derived optimal policy. In addition, the patient’s trajectory is compared on-the-fly with other patient’s trajectories in the database for comparison and visualization of potential outcomes. Novel visualization methods and interactive tools, such as head-mounted displays that are non-obtrusive are promising candidates to pair with the proposed CDSS, both as display and acquisition devices. The ultimate goal should be to use real time learning and analysis obtained from readily available EMR data, to warn the clinician of important changes in patient “states” and the need for new “actions” to improve the outcome of severe sepsis patients. As such, the integration of “big data” analytics with ubiquitous computing has the potential to revolutionize emergency and intensive care medicine as we know it.

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Authors' Contributions

AT performed all experiments and analyzed the data. TA advised on the clinical approach and relevance of the study. IT advised on all computational aspects and supervised the data analysis of the study. AT, TA, and IT wrote the manuscript.

Conflicts of Interest

None declared.

Multimedia Appendix 1

Supplementary Tables and Figures.

[PDF File (Adobe PDF File), 453KB - medinform_v3i1e11_app1.pdf]

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Abbreviations

AUC: area under the curve
BPS: bacteremia probable SIRS
CDSS: clinical decision support system
CI: confidence interval
CV: cross-validation
EHR: electronic health records
ICU: intensive care unit
LOS: length of stay
MAP: mean arterial pressure
MDP: Markov Decision Process
PCA: principal component analysis
POMDP: Partially Observable Markov Decision Process
PS: probable SIRS
PSS: probable septic shock
RBF: radial basis function
ROC: receiver-operator-characteristic
RR: respiratory rate
SBP: systolic blood pressure
SIRS: Systemic Inflammatory Response Syndrome
SOFA: sequential organ failure assessment
SVM: support vector machines
UCDHS: University of California Davis Health System
WBC: white blood count

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Original Paper

CIMIDx: Prototype for a Cloud-Based System to Support Intelligent Medical Image Diagnosis With Efficiency

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Abstract

Background: The Internet has greatly enhanced health care, helping patients stay up-to-date on medical issues and general knowledge. Many cancer patients use the Internet for cancer diagnosis and related information. Recently, cloud computing has emerged as a new way of delivering health services but currently, there is no generic and fully automated cloud-based self-management intervention for breast cancer patients, as practical guidelines are lacking.

Objective: We investigated the prevalence and predictors of cloud use for medical diagnosis among women with breast cancer to gain insight into meaningful usage parameters to evaluate the use of generic, fully automated cloud-based self-intervention, by assessing how breast cancer survivors use a generic self-management model. The goal of this study was implemented and evaluated with a new prototype called "CIMIDx", based on representative association rules that support the diagnosis of medical images (mammograms).

Methods: The proposed Cloud-Based System Support Intelligent Medical Image Diagnosis (CIMIDx) prototype includes two modules. The first is the design and development of the CIMIDx training and test cloud services. Deployed in the cloud, the prototype can be used for diagnosis and screening mammography by assessing the cancers detected, tumor sizes, histology, and stage of classification accuracy. To analyze the prototype's classification accuracy, we conducted an experiment with data provided by clients. Second, by monitoring cloud server requests, the CIMIDx usage statistics were recorded for the cloud-based self-intervention groups. We conducted an evaluation of the CIMIDx cloud service usage, in which browsing functionalities were evaluated from the end-user's perspective.

Results: We performed several experiments to validate the CIMIDx prototype for breast health issues. The first set of experiments evaluated the diagnostic performance of the CIMIDx framework. We collected medical information from 150 breast cancer survivors from hospitals and health centers. The CIMIDx prototype achieved high sensitivity of up to 99.29%, and accuracy of up to 98%. The second set of experiments evaluated CIMIDx use for breast health issues, using *t* tests and Pearson chi-square tests to assess differences, and binary logistic regression to estimate the odds ratio (OR) for the predictors' use of CIMIDx. For the prototype usage statistics for the same 150 breast cancer survivors, we interviewed 114 (76.0%), through self-report questionnaires from CIMIDx blogs. The frequency of log-ins/person ranged from 0 to 30, total duration/person from 0 to 1500 minutes (25 hours). The 114 participants continued logging in to all phases, resulting in an intervention adherence rate of 44.3% (95% CI 33.2-55.9). The overall performance of the prototype for the good category, reported usefulness of the prototype (*P*=.77), overall satisfaction of the prototype (*P*=.31), ease of navigation (*P*=.89), user friendliness evaluation (*P*=.31), and overall satisfaction (*P*=.31). Positive evaluations given by 100 participants via a Web-based questionnaire supported our hypothesis.

Conclusions: The present study shows that women felt favorably about the use of a generic fully automated cloud-based self-management prototype. The study also demonstrated that the CIMIDx prototype resulted in the detection of more cancers in screening and diagnosing patients, with an increased accuracy rate.

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KEYWORDS

association rules; cloud computing; breast cancer; pre-processing; segmentation; feature extraction; intelligent system; UDDI; SOAP; Web-based intervention; medical diagnosis

Introduction

The past few decades have seen major advancements in medical science and technology, which have transformed the medical field, and the implications are apparent [1]. However, millions of people across the world do not have the opportunity to access optimum Web-based medical health care services, and are limited by their cost and accessibility [2]. Information communication technology (ICT) has revolutionized an operating model that presents an opportunity for universal access to medical information at very low cost [3]. However, the existing models or systems face many barriers such as capacity building, accuracy, integration of prevailing health systems, promotion of inter-operability using universal standards, cost, eHealth observatory, and security, and do not provide free health services [4]. To overcome these barriers, cloud computing is emerging as a new way of delivering computing resources and health services.

Medical experts believe that cloud computing can improve health care services, benefit health care research, and change the face of health information technology [5]. Cloud computing refers to an on-demand, self-service in the cloud Internet infrastructure, that enables the user to access computing resources anytime, from anywhere in the world, with the help of the Internet [6]. The cloud is a new model of delivering computing resources to health care service provider industries, for the development of medical applications, which includes Microsoft HealthVault and Google Health platform [7]. Compared with conventional computing, the cloud model provides three advantages: (1) massive computing resources available on demand, (2) elimination of an upfront commitment by users, and (3) payment for use on a short-term basis as needed [8]. Health care, as with any other service operation, requires continuous and systematic innovation in order to remain cost effective, efficient, timely, and provide high-quality services [5]. The biomedical informatics community, especially consortiums that share data and applications, can take advantage of the new computing paradigm [9]. Anderson et al [10] indicated that data-handling problems, complexity, and expensive or unavailable computational solutions to research problems are major issues in biomedical research data management and analysis.

Some of the commercially available cloud platforms include Amazon Elastic Compute Cloud (EC2) [11], Google App Engine [12], and Microsoft Windows Azure [13]. The cloud model is composed of three main services depending on the capability and availability to support Web-based health services, such as (1) Infrastructure as a Service, (2) Platform as a Service, and (3) Software as a Service. In addition, cloud computing has special features for clients (radiologists, physicians, researchers, and patients), aiming to reduce the burden of heavy investments and to utilize resource outsourcing, software, hardware, automated resource management, parallel computing, virtualization, and utility computing [9].

The medical image datasets are usually large scale and distributed in different hospitals and, at the same time, the physicians who are skilled in special diseases are spread across the globe [14-16]. In the past, the medical experts collected the images that the hospital provided, analyzed the images, and obtained results, which was time-consuming. They could not get better analytic results as the asynchronous collaboration could not give the physicians real-time feedback [15]. Synchronous collaboration among physicians should be a more effective way to share knowledge and experience during the process of analysis. It is a challenge to provide a medical image collaborative analysis system (MICAS), which can enable physicians to do synchronous collaborative analysis on medical images over geographic distances [16]. Web services are platform independent and provide the facility for experts and patients to access medical services in the cloud environment [14,16]. Medical Web services are important applications running on the cloud server and these services can be accessed by clients through computers from remote places anywhere in the world [14-16]. A medical Web service can provide guidance to clients and offers services through the Internet in real time. The client can access the Web service with minimum software or even none, since many of these applications are accessible using a Web browser.

Breast cancer is by far the most common cancer diagnosed in women worldwide [17-20]. An estimated 1.38 million women across the world were diagnosed with breast cancer in 2008, accounting for nearly a quarter (23%) of all cancers diagnosed in women (11% of the total in men and women). The incidence is generally high in developed countries and markedly lower in developing countries, though the difference in population sizes means that an approximately equal number of cases were diagnosed in the developed and developing regions in 2008 (around 690,00 cases each). Breast cancer incidence has increased in most countries worldwide in recent decades, with the most rapid increase occurring in many of the developing countries [18,20]. Breast cancer is the second-most common and leading cause of cancer death in women in the world.

Women with breast cancer in their family are more susceptible to developing breast cancer. The risk also increases by age. It has become a major health issue in the world over the past 50 years and its incidence has increased in recent years [17]. Early detection is an effective way to diagnose and manage breast cancer. Mammograms can help early detection or diagnosis of breast cancer and increase patient survival rates. A vast number of medical images are generated daily in hospitals and medical centers. Consequently, radiologists have to analyze more and more images manually. After analyzing a small number of images, the process of diagnosing becomes more complicated and leads to susceptible errors. The computerized analysis of medical images has evolved from automated computer-aided detection (CADe) or computer-aided diagnosis (CADx) systems, where radiologists use computer output as a "second opinion" to assist them, speeding up the diagnosing task and bringing more confidence to it [21-26]. CADe or CADx systems have been successfully introduced in many hospitals and specialized clinics, to provide quick access to screening. The CADe or CADx system can play an important role in the early detection or diagnosis of breast cancer, and reduce the death rate among women due to breast cancer. The CADe system in detection work-up usually involves having the computer extract the margin of the lesion from the surrounding parenchyma, extract characteristics (features) of the lesions, merge these computer-extracted features into an estimate of the probability of the mammogram abnormalities [21]. The primary goal of CADe is to increase detection of the disease by reducing the false negative rate, which could be due to observational oversight [22]. The CADx systems in diagnostic work-up involve the computer identifying the region of interest (ROI) in the lesion, extract the visual contents (features) of the lesions, and merge these computer-extracted features with diagnostic keywords. The merged features are given to the feature selection and discretization method to identify the consistent features and further estimate the probability of mammogram abnormalities [23-26]. In the medical domain, the objective of a CADx system is to aid the specialist in the medical diagnosis process [23-26], retrieving relevant [26] past cases with images revealing proven pathology, along with the corresponding associated clinical diagnoses and other information. Recently, the CADx system has begun supporting experts and patients in analyzing digital images to identify possible diseases, via the cloud environment [27]. Thus, building a CADx system in health care is becoming highly important and a priority for research in hospitals and medical centers [21-27].

CADx is a complex procedure that requires several processing phases in breast cancer images, such as pre-processing, segmentation [28-31], feature extraction [32-36], feature dimensional reduction [37-40], association rule mining [41-44], and classification [25,26]. To provide these functionalities in a separate way in the cloud environment is very difficult. Web services that enable users to access heterogeneous, distributed resources provide easier integration and interoperability between data and applications in the cloud environment [45]. The cloud provides the functionality to access computational resources for image processing [46], image retrieval [48], and mining biomedical data [48]. Web services are accessed through the HTTP/HTTPS protocols, and utilize Extensible Mark-up Language (XML) for data exchange [49]. The interaction among the Web service components exploits the Universal Description, Discovery and Integration (UDDI) registry. The service provider defines a reference to its Web service, using the Web service description language (WSDL). The WSDL document is published in the UDDI registry; the service consumer can search the registry and retrieve the WSDL reference to the Web services. The service consumer, using the information stored inside the WSDL document, contacts the Web service and issues a service request in the cloud environment. Figure 1 shows the cloud-based medical images sharing and diagnosis framework.

In this research, new intelligent medical image diagnostic Web services were developed and deployed in the cloud, called "CIMIDx" (Cloud-Based System Support Intelligent Medical Image Diagnosis). The proposed CIMIDx prototype provides the facility for clients to support the diagnosis of a medical image in the heterogeneous environment. It consists of two main service models, namely training and test service models. These service models are deployed in the UDDI cloud server, by which patients, radiologists, physicians, and researchers (both engineering and medical) make use of the CIMIDx prototype. The proposed framework facilitates cross-platform application and makes access to the CIMIDx prototype easy for the diagnosis of the medical image. This proposed approach was applied to 150 client images, and the result shows high sensitivity (up to 99.29%) and accuracy (up to 98%).

Figure 1. Intelligent Internet Medical Research Group.

Cloud based Medical Images Sharing and Diagnosis

Cloud is synonymous with the Internet in most of the ways. However, new images diagnosis and retrieves through cloud based medical images sharing and diagnosis system can be viewed freely and publicly over the internet.

"Cloud based image diagnosis and sharing is a very cost-effective solution because it doesn't require monetary investment in a lot of hardware". Saint-Clair said that the cloud solution has about 350 hospital customers and it is an excellent way to go for groups or hospitals towards cloud environment that doesn't want to solely own an image sharing and diagnosis solution which is very expensive.

Cloud based sharing and diagnosis is a one-step process for hospitals or clinics that are part of the same cloud network. For unaffiliated hospitals, it's almost easy to access information from the cloud. After confirming the identities of each provider, cloud image sharing system can proceed over a virtual private network (VPN). As part of this connection, user receives the authorized information from the service provider via an email to invoke into the

Cloud image sharing solutions are really the custodian of images that are shared between providers. It's quickly becoming an accepted way to handle data. Physicians, radiologists, researchers and patients benefit from cloud based image diagnosis and sharing. Many times, patients don't always see their diagnostic studies, but loading images to a cloud based intelligent medical image diagnosis (CIMIDx) system gives them diagnosis result in an easy manner.

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Methods

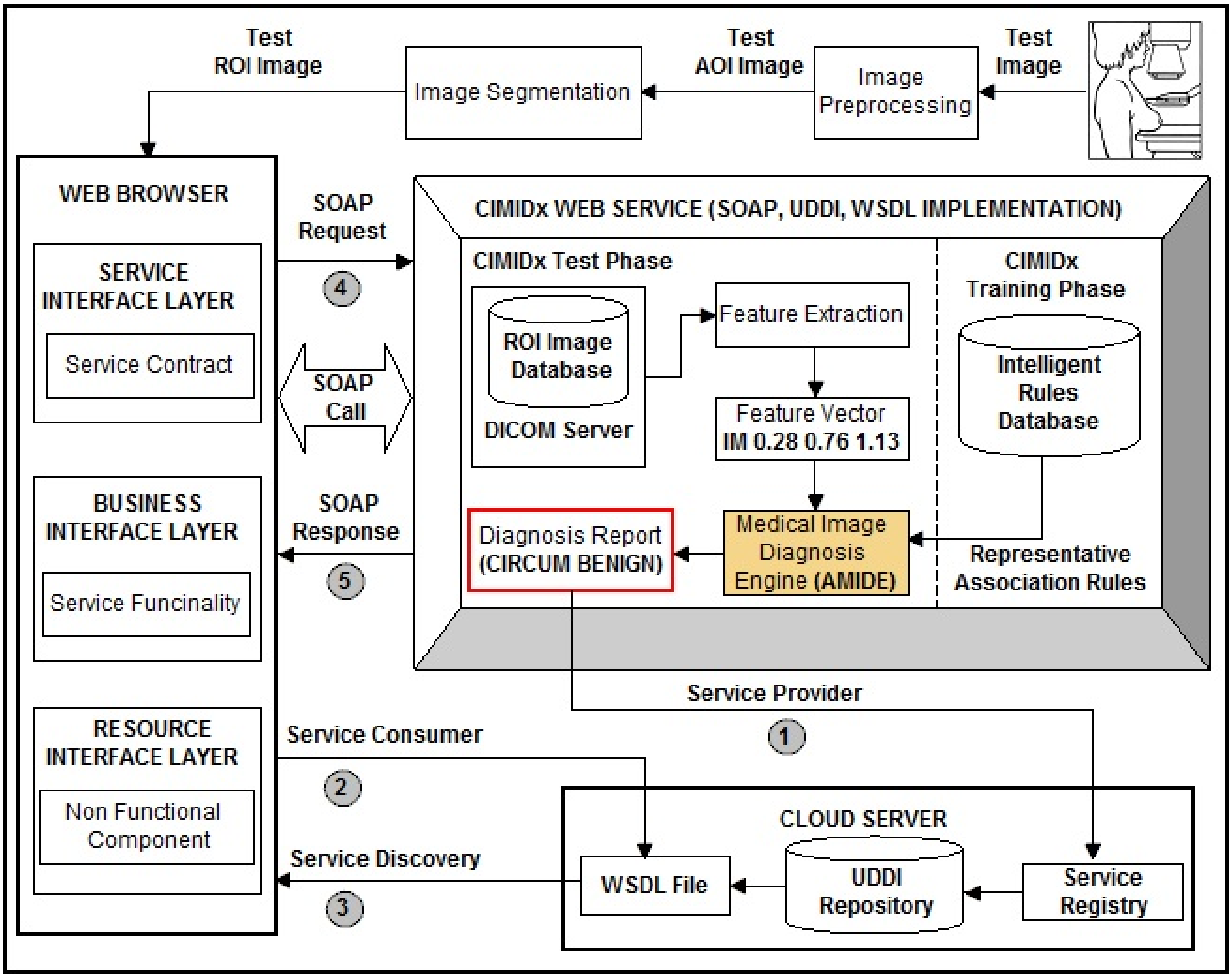
Research Design

The proposed study was conducted in May 2013 in three phases. In the first phase, researchers focused on general breast cancer image diagnosis, treatment experiences, and the reactions of the medical image diagnosis participants. The second phase of the study was a usability test of the site that focused on participant reactions about the CIMIDx prototype. The third phase of this study was based on the user reactions about the general idea for the CIMIDx prototype, and further refinement with the new technologies. Based on user reactions, the introductory site content and approach were revised. In this research, we conducted two different sets of experiments for the proposed CIMIDx prototype. The first set of experiments aimed at evaluating the classification performance of the client's use of the CIMIDx framework. The second set of experiments aimed at validating the usability of the CIMIDx for breast health issues. We used *t* tests and Pearson chi-square tests to assess the differences and binary logistic regression to estimate the odds ratio (OR) for the predictors of CIMIDx for breast health issues.

CIMIDx Architecture

The proposed CIMIDx framework combines visual features, automatically extracted from the medical image, with the high-level knowledge given by the specialist about the training images, to search for patterns. The CIMIDx prototype consists of two main service models, namely, training and test models. Each training image is associated with a set of keywords or classes (keywords are representative words given by a specialist to use in the diagnosis of a medical image). Figure 2 shows the proposed CIMIDx architecture.

Figure 2. The proposed CIMIDx architecture.



CIMIDx Web Service Model

Overview

The CIMIDx Web service framework is cloud-based, so that the client side contains diagnostic Web pages shown to the user to test the new medical image, without intervention anywhere in the world. The developer has the ability to train and test the medical image in the cloud environment. The client has the ability to test a new image on his/her computer and receive the diagnosis result from the CIMIDx prototype running on the cloud server. In this research, an integrated approach based CIMIDx training and test Web services framework, which supports the distributed medical image diagnosis, is presented. In the training service model, the CIMIDx prototype has derived new knowledge as representative association rules (intelligent rules) by invoking the following five Web service models, namely, image pre-processing, segmentation, visual feature extraction, feature selection and discretization, and representative association rule mining. In the test service model, the clients are invoked by the CIMIDx test Web services with a new diagnosis image, by using the following four test Web service models viz, image pre-processing, image segmentation, visual feature extraction, and medical image diagnosis engine.

The proposed method facilitates the sharing of resources and infrastructure in the cloud environment. These resources can be located at different nodes that may be accessed through Web services published in the cloud platform. The philosophy of the platform is to minimize the time of the CIMIDx application development, and provide this facility to the client without any intervention. The communication established between the CIMIDx service providers' application and the cloud server (where the CIMIDx prototype deployment is accomplished) is done using the Simple Object Access Protocol (SOAP) protocol. Hence, the implemented CIMIDx training and test Web service applications are able to publish using Web services. The CIMIDx Web service framework includes four different methods as follows.

1. Central Controller: The Central controller (CC) is responsible for the execution of the CIMIDx method in the task of medical image diagnosis in a cloud environment. It is also responsible for publishing the CIMIDx training and test Web service model, and making the services available to the developer and the clients.

2. Web Browsers: The Web browser is responsible for invoking the CIMIDx prototype through the SOAP call from any computer connected to the Internet. It contains three layers: the service interface layer, business interface layer, and resource interface layer. The components of the service interface layer include the service contract and the service adapter. The service contract defines what operations the CIMIDx service can

perform but it does not include any behavior, such as how the operation is actually implemented. This requires defining interfaces, which are groups of operations defined in terms of message exchange patterns. For each operation, the developer defines the message type used in the exchange, and defines each message type in terms of the composable data type. The service adapter implements the service contract that is exposed on an endpoint (commonly referred to as the service host) and is responsible for adapting the endpoint to the underlying business layer.

The business layer consists of three components: business entities, business logic, and business workflows. Business entities are classes that model real-world, domain-specific objects. They are different from the data types used in the service contract because they include behavior and perhaps state. The business layer encapsulates the business entities so that they are not exposed across a service boundary. This ensures more flexibility within each layer. It also gives the opportunity to format the data in different ways, catering to specific integration scenarios. However, this also means that entity translation is necessary for moving between the layers.

The business logic implements the actual business behavior. These classes operate on the business entities to perform a desired action. Some business entities are quite simple while others take advantage of more complex logic.

Business workflows handle long-running processes that require sophisticated message correlation and state management. They are typically implemented with a business process management product. The business layer operates on the underlying resource access layer.

The resource interface layer provides access to both data access logic and service agents. The data access logic provides the opportunity for interacting with the underlying data store while the service agents provide the facility for the developer and client to interact with external Web services.

3. Web services: A set of Web services (training and test) implements the CIMIDx framework, by invoking the developer and client for an effective diagnosis of the medical image in the cloud environment.

4. CIMIDx Web services: CIMIDx Web services are deployed in the cloud. The developer and the client are able to access the CIMIDx prototype remotely, for diagnosis of the medical image provided by the shared databases within or outside the cloud network.

The CIMIDx framework contains a Web application and uses the interface, which allows accessing the proposed system from any computer connected to the Internet and a Web browser. CIMIDx also includes an application server, which is in charge of the processing methods and the communications with the remote applications that offer them. Communications between user interface and remote CIMIDx services are accomplished through Web languages. The communication between the client and remote CIMIDx services is performed using SOAP messages. Together with Web capabilities, the CIMIDx Web service architecture offers the possibility of integrating algorithms developed in different computer languages, enabling the integration and linkage of already developed libraries. The detailed workflows for the processing of the medical image diagnostic methods, integrated using the CIMIDx Web service, are described below.

Service Discovery

The Service Discovery (SD) creates the new service directory in the service agent that acts as a proxy between the service consumer and the service provider. The service agent provides the list of services to the CIMIDx developers and clients, which are retrieved from the repository of the regulating authority. The administrator and the client select the set of services that are needed to refine and diagnose a new image. Based on the selected service, the service agent will send the requested service and its respective method name to the service scheduler. The service discovery acts as an intermediary between the service providers and service requesters. The following steps are involved to create a service directory in the cloud server: (1) service discovery accepts requests from service providers to publish and advertise Web service descriptions, ie, the WSDL file format, and (2) it allows the new service requesters to search the collection of service descriptions contained within the service registry.

The main role of the service registry in the service directory is the matchmaking between service providers and service requesters. Once the match has been found, the interactive processes are carried out directly between the service requester and the service provider.

Service Provider

The Service Provider (SP) defines the reference in its Web service, using the WSDL. Once the WSDL document has been published in the UDDI registry, the service consumer can search the registry, and then retrieve the WSDL reference from the Web service in the cloud. The following steps are necessary for creating the training and test service description in the cloud: (1) the service provider develops a new training and test service description for the proposed CIMIDx prototype, such as image pre-processing, segmentation, feature extraction, feature selection and discretization, representative association rule mining, and medical image diagnosis engine, (2) once the CIMIDx training and test services are created and deployed in the cloud (runtime) environment, the developer and client can access the respected services through the Internet, (3) SP publishes the training and test services description into one or more service registries in the cloud, and (4) SP receives the invoking service messages from the service requesters.

Service Consumer

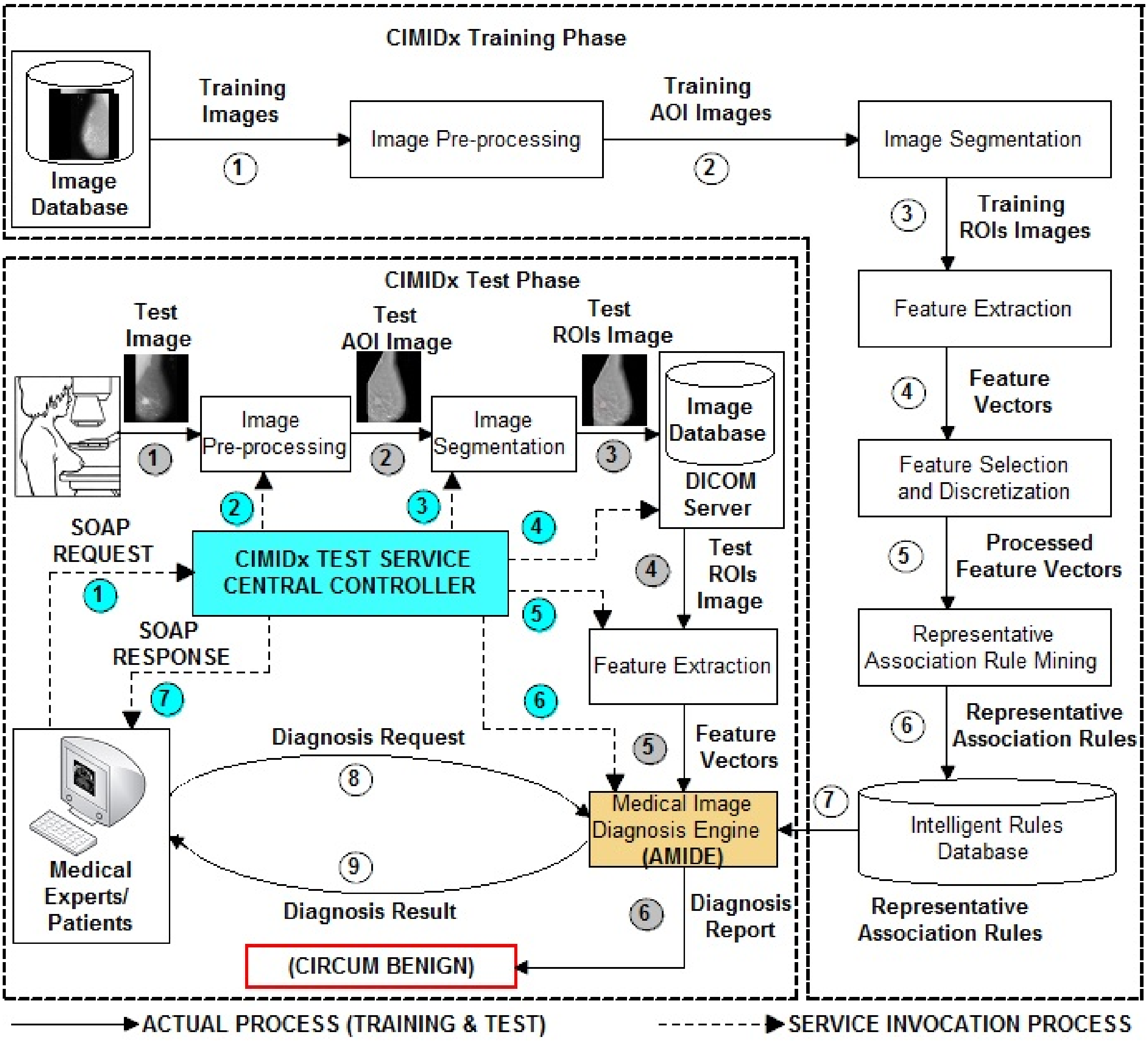
The Service Consumer (SC) is a client that invokes the test Web services for the diagnosis of the medical image through the Web browser. Using WSDL, the client issues an XML SOAP request to the developed CIMIDx Web service method and the diagnosis result is obtained as an XML SOAP response. The following steps are involved to develop the service consumer details in the cloud environment: (1) the service consumer (client) of the CIMIDx prototype searches for the WSDL file from the UDDI registry, (2) once the SC finds the WSDL file in the UDDI, it issues an XML SOAP request to the created CIMIDx test Web services method, (3) then the SC invokes the CIMIDx test services sequentially, and performs the medical image diagnosis automatically in the cloud environment, and (4) finally, the XML SOAP response as diagnosis result (keyword) is given to the service consumer.

CIMIDx Training and Test Web Services

Overview

Once the service provider and client receive the WSDL file from the UDDI, the central controller issues the XML SOAP request to assess the CIMIDx prototype, and the XML SOAP response as the diagnosis result. The central controller passes the control between the CIMIDx training and test service model and the client, as shown in Figure 3.

Figure 3. Pipeline of the proposed CIMIDx prototype.



CIMIDx Training Web Services

The central controller invokes the CIMIDx training Web services method, which extracts new knowledge as representative association rules to support the diagnosis of the medical image in the cloud environment. The CIMIDx training Web services invoking procedure is as follows.

First, the CC passes the training images to the CIMIDx training Web service, by invoking the image pre-processing Web service model. The fundamental step of an intelligent medical image analysis is image pre-processing, which identifies the area of interest (AOI) in the medical images. The presence of the pectoral muscle in mammograms biases the detection procedure and recommends removing the pectoral muscle during mammogram pre-processing. The proposed image pre-processing method contains two phases, namely breast contour identification and pectoral muscle removal. In the first phase, the proposed method identifies the breast contour (breast profile orientation) with region-based active contour model, with the level set formulation method [31]. The region-based level set method deals with intensity inhomogeneity for the identification of the breast profile orientation in the mammogram image. In the pectoral muscle removal phase, we define an accurate AOI containing the pectoral muscle, after obtaining the breast border in the breast contour identification phase. The proposed method initially defines four control points x_1, x_2, y_1, and y_2, which are used to describe the pectoral muscle region. The control point x_1 is the top-left corner pixel of the breast contour, x_2 is the top-right corner pixel of the breast contour, y_1 lowest pixel on the left edge of the boundary, and y_2 lowest pixel on the right edge of the boundary. Next, the proposed method segments the pectoral muscle region with the Seeded Region Growing (SRG) technique [50]. The proposed method defines two new control points x_3 and y_3 in addition to the four control points x_1, x_2, y_1, and y_2.The control point x_3 is the immediate variations of intensity between x_1 and x_2. The control point y_3 is the immediate variation of intensity between x_1 and y_1. Then the proposed method defines the straight line between the control points x_3 and y_3, using the straight line equation $y=mx+c$. This method removes the rough edges present in the three control points x_1, x_3, and y_3 in the pectoral muscle boundary. Finally, the proposed image pre-processing method identifies the accurate AOI in the mammogram image. This procedure makes use of these techniques [32-36,56].

Second, the CC passes the training images to the CIMIDx training Web service by invoking the image segmentation Web service model. The image segmentation is achieved in two phases, namely, edge detection and edge refinement. In the edge detection phase, we identified the accurate region edges based on the orthogonal polynomials [28]. The edge detection method performs two different tasks in a single step, such as orthogonal feature components extraction and edge detection. In the orthogonal feature components extraction stage, a class of orthogonal polynomials obtained from the point-spread operators for different sizes of the image window is proposed. A simple computational procedure for constructing a complete set of difference operators from these point-spread operators is employed in the edge detection method. Based on the polynomials' operator, the edge detection method extracted a set of orthogonal feature components with DC (direct current) energy feature coefficients, AC (alternating component) edge, and texture feature coefficients from the medical image. Then, the extracted orthogonal feature components are utilized to identify the region edges in the medical image. In the edge detection stage, we conducted the Nair test [51] and the *F* test [52] to separate the responses to the edge and noise in the orthogonal feature components, due to the polynomials' operator. Finally, the image edges are detected by maximizing the signal-to-noise ratio (SNR). The extracted edges are submitted to the edge refinement phase for further identifying the accurate ROI in the image. This procedure makes use of these techniques [28,51-55].

In the edge refinement phase, the edge-based active contour model is devised with a level set formulation method, based on the orthogonal polynomials [28] and level set method (LSM) [54]. The extracted region edges in the edge detection phase are further refined, using a variational level set formulation method [55]. The edge refinement method is a variational level set formulation, in which the regularity of the level set function (LSF) is intrinsically maintained during the level set evolution. The level set evolution is derived as the gradient flow that minimizes the energy functional with a distance regularization term, and an external energy (edge information) that drives the motion of the zero level set toward desired locations. The distance regularization term is defined with a potential function, such that the derived level set evolution has a unique forward-and-backward (FAB) diffusion effect, which is able to maintain the desired shape of the LSF, particularly a signed distance profile near the zero level set. This method yields a new type of level set evolution called edge-based active contour model with level set formulation. The distance regularization effect eliminates the need for reinitialization, and thereby avoids its induced numerical errors. The edge refinement method also allows the use of more general and efficient initialization of the LSF. In its numerical implementation, relatively large time steps can be used in the finite difference scheme to reduce the number of iterations, while ensuring sufficient numerical accuracy. Based on this procedure, the edge-based active contour model with the level set formulation method identifies the accurate ROI in the image. This procedure makes use of these techniques [54,55]. The image segmentation Web services model responds as the ROI image, to the central controller for further visual feature extraction.

Third, the CC passes the ROI image to the visual feature extraction service model. The CIMIDx method extracted 1037-dimensional visual sub-band statistical and spectral orthogonal polynomials based texture features from each image. It includes features generated by the orthogonal polynomials based texture feature (113 features), sub-band statistical and spectral orthogonal polynomials based texture feature (448 features), bivariate discrete orthogonal polynomials based texture feature (336 features), and the gradient gray level co-occurrence probabilities based texture feature (140 features). The visual feature extraction Web service model responses the 1037 texture features to the central controller for further feature selection and discretization. This procedure makes use of these techniques [32-37,56].

Fourth, the CC passes the texture feature vectors to the feature selection and discretization service model. The CIMIDx method uses the NANO algorithm [57] and produces consistent features in the feature database. The NANO algorithm combines feature selection and discretization in a single step, and reduces the mining complexity. This algorithm is employed to solve two problems: feature discretization and selection in a single step. An important contribution is the reduction of irrelevant items to be mined, and the same is achieved with the proposed NANO algorithm. The algorithm NANO selects the relevant features based on the average global inconsistency and average global cut point measures, speeding up the CIMIDx framework. The feature selection and discretization Web service model responses as 135 consistent features to the central controller, for further mining the representative association rules. This procedure makes use of these techniques [57].

Finally, the central controller passes the consistent features to the representative association rule mining service model. The CIMIDx method mines the representative association rules, based on the bounded portion of the density frequency pattern tree and density frequency pattern growth methods. The proposed mining method produces representative association rules to support the diagnosis of the medical image. This model produces representative association rules to the central controller. This procedure makes use of these techniques [58,59].

All of the above processes are executed in a sequential manner. The CC passes the representative association rules as a SOAP response to the developer**.** The extracted representative association rules are then hosted in the cloud server to support the intelligent medical image diagnosis in an efficient manner.

CIMIDx Test Web Services

In the test model, the administrator and clients invoked the CIMIDx test Web services with the new image. The CIMIDx test Web services method diagnoses the new image (without the biopsy details) by invoking the following four Web services.

First, the CC passes the test image to the CIMIDx test Web service, by invoking the image pre-processing Web service model for the identification of AOI. The proposed method contains two phases, namely, breast contour identification, and pectoral muscle removal. In the first phase, the proposed method identifies the breast contour (breast profile orientation) based on the LSM [31]. Second, the method segments the pectoral muscle with the breast profile orientation image, using the seeded region growing technique [50]. Finally, the proposed pre-processing method identifies the accurate AOI in the mammogram image. This procedure makes use of these techniques [31,50].

Second, the CC passes a test image to the image segmentation Web service model. The proposed image segmentation method identifies the accurate ROI, based on the orthogonal polynomials and LSM. The proposed image segmentation Web services model responds and passes the ROIs image to the central controller. This procedure makes use of these techniques [28,51-55].

Third, the segmentation method passes the region of interest image to the visual feature extraction method. The ROI image is used for the extraction of visual features automatically. A total of 1037-dimensional visual sub-band statistical and spectral orthogonal polynomials based texture features were computed for each image. It includes features generated by the orthogonal polynomials based texture feature (113 features), sub-band statistical and spectral orthogonal polynomials based texture feature (448 features), bivariate discrete orthogonal polynomials based texture feature (280 features), and the gradient gray level co-occurrence probabilities based texture feature (140 features). This procedure makes use of these techniques detailed in [32-36,56]. These texture features are given to the feature selection and discretization method. The detail of the visual feature extraction process is discussed in visual feature extraction service model.

Finally, the central controller passes the representative association rules with the feature vectors from the test image to the medical image diagnosis Web service model. The CIMIDx model uses the Associative Medical Image Diagnosis Engine (AMIDE) algorithm to classify a new image. The diagnosis result (keyword) is passed to the central controller. All the above processes are executed in a sequential manner. The central controller passes the diagnosis keyword as a SOAP response to the developer and the client**.**

Associative Medical Image Diagnosis Engine (AMIDE) Algorithm

Overview

In this research, a new medical image diagnosis algorithm, called “AMIDE” is presented. In the AMIDE algorithm, it is necessary to clarify some terms. We say that an image matches the set of representative association rules, if the image features satisfy the whole body of the representative association rules (decision rules). An image partially matches a rule, if the image features only satisfy part of the decision rules body. An image does not match a rule, if the image features do not satisfy any part of the decision rules body. AMIDE is a new special classifier that can return multiple keywords (classes) when processing a test image.

Condition 1

The AMIDE algorithm stores all itemsets (set of keywords) h belonging to the head of the decision rules in a data structure. An itemset h is returned by AMIDE in the suggested diagnosis if the condition stated in (1) Figure 4 is satisfied, where $nM(h)$ is the number of matches of the itemset h, and $nN(h)$ is the number of non matches. The weight of the itemset is w_1 indicates the strength that an itemset belongs to the diagnosis. The higher the value of the weight, the higher is the confidence that h belongs to the diagnosis of the image. A threshold α of minimum weight $0<\alpha\leq 1$ is employed to limit the weight of an itemset in the suggested diagnosis. If $\alpha=0$, all itemsets in that test image do not have even one match in the training representative association rules. Figure 5 shows the working principle of an AMIDE algorithm in condition 1. In this example, the values of (1) are: $nM(h)=2$ and $nN(h)=1$ for the itemset $h=\{Circum\ Benign\}$. Therefore, if $w_1=(2/3)\geq\ \alpha$, the itemset $h=\{Circum\ Benign\}$ is returned by the algorithm.

Condition 2

An itemset h is returned by AMIDE in the suggested diagnosis, if the condition stated in (2) Figure 4 is satisfied, where $nP(h)$ is the number of partial matches of the itemset h. The weight of the itemset w_2 indicates the strength that an itemset belongs to the diagnosis. A threshold $\delta(0<\delta\leq 1)$ is employed to limit the minimal number of matches required to return an itemset in the suggested diagnosis. If $\delta=0$, all itemsets in that test image do not have even one match in the training representative association rules. Figure 6 shows the working principle of an AMIDE algorithm in condition 2. In this example, the values of (2) are: $nM(h)=1$, $nP(h)=1$, and $nN(h)=1$ for the itemset $h=\{Circum\ Benign\}$. Therefore, if $w_2=(2/3)\geq\delta$, the itemset $h=\{Circum\ Benign\}$ is returned by the algorithm, otherwise it is discarded.

If Condition 1 is satisfied with the threshold weight of w_1, then the algorithm adds the diagnosis keyword K into h. If Condition 1 is not satisfied, then the algorithm AMIDE executes Condition

2 (see Figure 6). If it is satisfied with the threshold weight of w_2, then the algorithm adds the diagnosis keyword *K* into *h*. Otherwise, the algorithm AMIDE does not add the diagnosis keyword *K* into *h*.

Figure 7 summarizes the proposed AMIDE algorithm. As we show in the section on experiments, AMIDE is well-suited to generating suggestions for diagnoses. Although the approach presented here is applied to breast images, we describe the problem in a general way, in order to provide a common approach for other related fields. As we will show in the section on experiments, the proposed method is well-suited for medical images analysis, enhancing and bringing more confidence to the diagnosing process.

Figure 4. Equations (1) and (2).

$$w_1 = \frac{nM(h)}{nM(h)+nN(h)} \geq \alpha \qquad (1)$$

$$w_2 = \frac{nM(h)+nP(h)}{nM(h)+nP(h)+nN(h)} \qquad (2)$$

Figure 5. Example to show the calculation of Associative Medical Image Diagnosis Engine (AMIDE) in Condition 1.

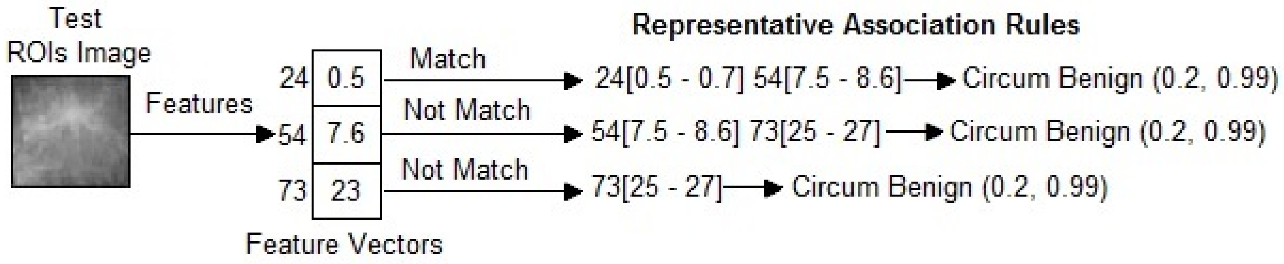


Figure 6. Example to show the calculation of Associative Medical Image Diagnosis Engine (AMIDE) in Condition 2.

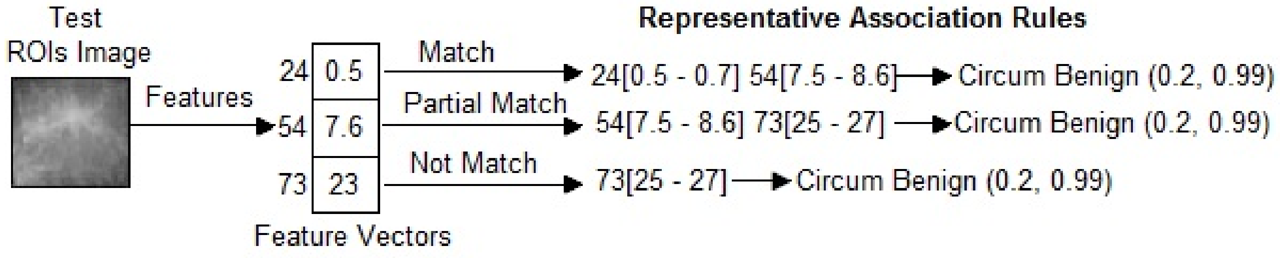
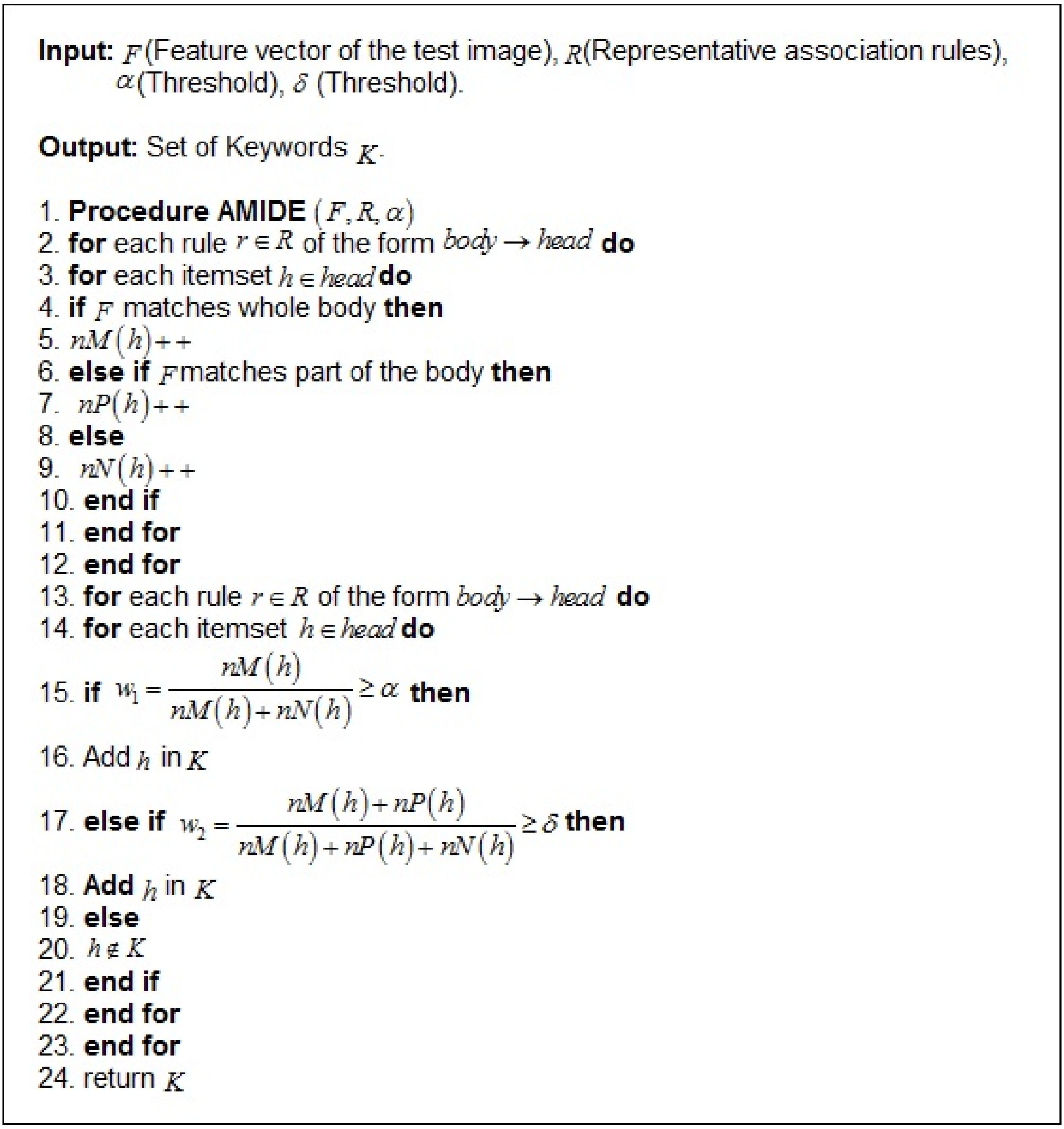


Figure 7. The AMIDE Algorithm.



```
Input: $F$(Feature vector of the test image), $R$(Representative association rules),
       $\alpha$(Threshold), $\delta$ (Threshold).

Output: Set of Keywords $K$.

Procedure AMIDE ($F, R, \alpha$)
  for each rule $r \in R$ of the form $body \rightarrow head$ do
    for each itemset $h \in head$ do
      if $F$ matches whole body then
        $nM(h)++$
      else if $F$ matches part of the body then
        $nP(h)++$
      else
        $nN(h)++$
      end if
    end for
  end for
  for each rule $r \in R$ of the form $body \rightarrow head$ do
    for each itemset $h \in head$ do
      if $w_1 = \frac{nM(h)}{nM(h)+nN(h)} \geq \alpha$ then
        Add $h$ in $K$
      else if $w_2 = \frac{nM(h)+nP(h)}{nM(h)+nP(h)+nN(h)} \geq \delta$ then
        Add $h$ in $K$
      else
        $h \notin K$
      end if
    end for
  end for
  return $K$
```

Experimental Results

The dataset BI-RADS [60] consists of 446 abnormal images and 26 normal images taken from mammograms, collected from the Breast Imaging Reporting and Data System (BI-RADS) of the Department of Radiology, University of Vienna. Each image in BI-RADS has a diagnosis composed of three main parts.

- Morphology: Mass (circumscribed, indistinct, speculated); Arch. Dist.; Asym. Dens.; Calcifications (Amorph, Pleomorph, Linear, Benign).
- BI-RADS: Six levels (0-5).
- Histology: Benign lesions (breast tissue, cyst, calcifications, ductal hyperplasia, fibrosis, fibroadenoma, fatty tissue, hematoma, harmartomo, lymphangioma, lymphatic node, mastitis, mastopathia, papilloma, sclerosing adenosis and scar); high-risk lesions (atypical ductal hyperplasia, lobular carcinoma in situ, phyllodestumor and radial scar); and malignant lesions (ductal carcinoma in situ, invasive ductal cancer, invasive lobular cancer, invasive tubular cancer and muc. cancer).

The BI-RADS categorization was developed by the American College of Radiology to standardize mammogram reports and procedures. The BI-RADS categorization is summarized in Table 1.

The dataset mini-MIAS [61] used in our experiments is taken from the mini-Mammographic Image Analysis Society (mini-MIAS). It consists of 322 images and belongs to three big categories: normal, benign and malignant. There are 208 normal images, 63 benign, and 51 malignant, which are considered abnormal. In addition, the abnormal cases are further divided in six categories: micro calcification, circumscribed masses, speculated masses, ill-defined masses, architectural distortion, and asymmetry. All the images also include the locations of any abnormalities that may be present. The existing data in the collection consists of the location of the abnormality (like the center of a circle surrounding the tumor), its radius, breast position (right or left), type of breast tissues (fatty, fatty-glandular, and dense) and tumor type if it exists (benign or malign). All the mammograms show a medio-lateral oblique view.

For training purposes, we took 560 abnormal and 52 normal cases from both BI-RADS and mini-MIAS datasets. During the test phase, the developer and client invoked CIMIDx test cloud services model with the new images.

Table 1. BI-RADS[a] assessment categorization.

Category	Description
0	Need additional imaging evaluation.
1	Negative.
2	Benign finding.
3	Probably benign finding. (Less than 2% malignant.) Short interval follow-up suggested.
4	Suspicious abnormality. (2-95% malignant.) Biopsy should be considered.
5	Highly suggestive of malignancy. (Greater than 2% malignant.) Appropriate action should be taken.

[a] Breast Imaging Reporting and Data System

Results

Table 2 describes the classification accuracy of the proposed CIMIDx cloud services model for the diagnosis of the medical image. The diagnoses suggested by the CIMIDx method with the client test image were compared with the real diagnoses (biopsy results) of the training images (BI-RADS and mini-MIAS) given by specialists. To validate the CIMIDx prototype, we compared the CIMIDx (considering the diagnosis of calcifications (benign and malignant), masses (benign and malignant), and normal cases) with two well-known classifiers (Naïve Bayes and C4.5) and the IDEA [26] method. First, with Naive Bayes [62], the classifier is a probabilistic approach based on the Bayes' theorem to predict the class labels. Second, with C4.5 [63], the classifier constructs a decision tree in the training phase, to derive the decision rules for testing a new mammogram image. Finally, with the IDEA method [26], a medical image diagnosis uses the representative association rules to predict the class label. The proposed CIMIDx framework leads to higher values of sensitivity, specificity, and accuracy, and it also presents the smallest error rates: false positive and false negative rates. During the training phase, the developer invoked the CIMIDx training cloud service model with BI-RADS [60] and mini-MIAS [61] datasets. Note that the training process was performed internally and produced representative association rules, that is, intelligent rules and deployed in the cloud for the diagnosis of new image.

The proposed CIMIDx method shows results of high sensitivity (up to 99.29%) and high accuracy (up to 98%). It is evident that the CIMIDx prototype is highly suitable for cloud-based self-management intervention for remote users. Figure 8 shows the implementation details of the cloud-based intelligent medial image diagnosis of the mammogram image.

Table 3 describes the characteristics of clients (patients and experts) in the use of CIMIDx for breast health. The CIMIDx is prompted by the detection of larger tumors, intermediate stage, low-grade DCIS, benign and normal cases. However, the proposed CIMIDx prototype-based breast cancer diagnosis can still be refined, using a greater number of samples (user images), and the results of this study show that its use can lead to the diagnosis of more cancers. This study was conducted by an experienced mammography interpreter (expert) during the developing stage of the CIMIDx prototype, and it is possible that the CIMIDx might contribute a higher percentage of increased cancer detection rates without biopsy information.

In our sample data collected from various hospitals and medical colleges, we found that the mean age of the CIMIDx users (patients) was 47.5 years (SD 33.2) and that of experts was 26 years (SD 18.3). The average length of time since the diagnosis was found to be more significant than the age. In the CIMIDx usage analysis for patients and experts for the diagnosis of breast cancer, the users were more educated, more likely to be younger, middle-aged group, and it differed neither in the breast cancer stages nor in the length of time since their cancer diagnosis. The annual household income and education levels are not reflected in the expert use of CIMIDx in the diagnosis of medical images. The stages of cancer diagnosis are broadly classified as normal, benign and malignant. The percentages of the subcategories of benign stages for CIMIDx users (patients) are given as normal breast issue 8% (8/97), fibrocystic disease 3% (3/97), fibroadenoma 6% (6/97), a typical ductal hyperplasia 3% (3/97), benign lesion, and others 1% (1/97). The percentages of the subcategories of malignant stages for CIMIDx users (patients) were given as DCIS grade I 9% (9/97), DCIS grade II and III 27% (26/97), IDC 25% (24/97), ILC 12% (12/97), ILC & IDC 3% (3/97), and malignant lesion, others 2% (2/97).

The cloud-based self-intervention system's use is popular among breast cancer patients. Over 99% of our samples used it for breast health issues. The proposed CIMIDx results are consistent with those in prior literature, suggesting that a higher income and education are associated with patients' information seeking [4,5]. We observe that the income and educational level were significant predictors for patients, of the use of CIMIDx for medical image diagnosis. However, the income and education level may not influence experts with the use of CIMIDx. Individuals with these characteristics may have been exposed to the new technologies, and may have the comfort level to experiment with the use of the CIMIDx prototype. In the CIMIDx study, the age, length of diagnosis time, and breast cancer stage were not significant predictors of cloud based self-intervention.

Table 4 shows the results of the logistic regression analysis for patients and experts in the diagnosis of medical images, using the CIMIDx prototype. From our test samples obtained from clients at various hospitals, health centers, and medical colleges, we found that the age and time since diagnosis were significant by .89. The annual household income (INR) for the category >2,70,000 was significant by .89, compared with the other income level categories. In education, grade 13-15 was significant by .96. In the benign stage, the category fibroadenoma was significant by .78, and in the malignant stage, the category ILC was significant by .86. The overall significance value *P* is obtained from the odds ratio (OR) and confidence interval (CI).

Table 5 shows the study between the two user groups based on the comparison of the intended versus observed frequency and activity: 44 low users and 53 high users. User feedback about the CIMIDx regarding ease of navigation was received as an input from the active users. The proportion of elements obtained as useful was higher in high users for the good category, 96% (51/53) compared to low users 88% (39/44) with a significance of *P*=.89.

The self-report by the users in the organization of information for the CIMIDx was gathered as input from the active CIMIDx users. The ratio of ingredients perceived was higher among the high users for the good category, 92% (49/53) compared to low users 93% (41/44) with a significance of *P*=.77.

Questionnaires about the CIMIDx's usefulness were collected as active input from the users. The percentage of ingredients collected as useful was higher among the high users for the good category, 96% (51/53), compared to low users 95% (42/44), with a significance of *P*=.77.

The statistics about CIMIDx prototype's user friendliness was received as active input from the users. The fraction of ingredients perceived as useful was higher among the high users 98% (52/53) compared to low users 98% (43/44) with a significance of *P*=.31.

Finally, the overall satisfaction of the prototype was gathered as input from the users. It was higher among the high users 98% (52/53) compared to low users 95% (42/44) with a significance of *P*=.31. The overall significance value *P* is based on the *t* tests and the Pearson chi-square tests.

Table 2. The classification accuracy of the proposed CIMIDx cloud services model with 150 client test images during the development of CIMIDx, and compared with the Naïve Bayes and C4.5 classification algorithms and IDEA method (n=150).[a]

Stages	Naïve Bayes		C4.5		IDEA Method		CIMIDx Method	
	Diagnosed	Missed	Diagnosed	Missed	Diagnosed	Missed	Diagnosed	Missed
	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)	n (%)
Normal breast issue	6 (4.0)	3 (2.0)	7 (4.7)	2 (1.3)	7 (4.7)	2 (1.3)	8 (5.3)	1 (0.7)
Fibrocystic disease	4 (2.7)	1 (0.7)	4 (2.7)	1 (0.7)	4 (2.7)	1 (0.7)	5 (3.3)	0
Fibro adenoma	7 (4.7)	3 (2.0)	8 (5.3)	2 (1.3)	9 (6.0)	1 (0.7)	9 (6.0)	1 (0.7)
Atypical ductal hyperplasia	4 (2.7)	1 (0.7)	4 (2.7)	1 (0.7)	5 (3.3)	0	5 (3.3)	0
Benign lesion, other	3 (2.0)	0	3 (2.0)	0	3 (2.0)	0	3 (2.0)	0
DCIS[b],								
grade I	8 (5.3)	7 (4.7)	11 (7.3)	4 (2.7)	13 (8.7)	2 (1.3)	14 (9.3)	1 (0.7)
DCIS grade II & III	23 (15.3)	9 (6.0)	26 (17.3)	6 (4.0)	31 (20.7)	1 (0.7)	32 (21.3)	0
IDC[c]	42 (28.0)	3 (2.0)	42 (28.0)	3 (2.0)	44 (29.3)	0	44 (29.3)	0
ILC[d]	16 (10.7)	2 (1.3)	16 (10.7)	2 (1.3)	18 (12.0)	1 (0.7)	19 (12.7)	0
ILC & IDC	4 (2.7)	1 (0.7)	5 (3.3)	0	5 (3.3)	0	5 (3.3)	0
Malignant lesion, other	3 (2.0)	0	3 (2.0)	0	3 (2.0)	0	3 (2.0)	0
Total	120 (80.0)	30 (20.0)	129 (86.0)	21 (14.0)	142 (94.7)	8 (5.3)	147 (98.0)	3(2.0)

[a] At interviews with various medical colleges and hospitals in Chennai, Tamil Nadu, India, May 2013 to April 2014, the cloud-based system support intelligent medical image diagnosis prototype was used for breast health issues. The accuracy, sensitivity, specificity, false positive rate, and false negative rate results in percentage were calculated, with the true positive, true negative, false positive, and false negative measures.

[b] DCIS: ductal carcinoma in situ

[c] IDC: invasive ductal cancer

[d] ILC: invasive lobular cancer

Table 3. Characteristics of 150 women with breast cancer.

Demographic variable		Category	Use of CIMIDx by patients (n=97) mean (SD) or n (%)	Use of CIMIDx by radiologist (n=53) mean (SD) or n (%)	Significance (*P*)[a]
Age (years)			47.5 (33.2)	26 (18.4)	.53
Time since diagnosis (years)			47.5 (40.3)	26 (21.2)	.59
Annual household income (INR)					
		<1,00,000	12 (12.4%)		
		1,00,000-2,70,000	36 (37.1%)		
		>2,70,000	49 (50.5%)		
Education					
		Grades <12	13 (13.4%)		
		Grades 13-15	48 (49.5%)		
		Grades >15	36 (37.1%)		
Stage					
	Normal	Normal breast issue	8 (8.3%)	1 (1.9%)	.57
	Benign				
		Fibrocystic disease	3 (3.1%)	2 (3.8%)	
		Fibroadenoma	6 (6.2%)	4 (7.6%)	
		Atypical ductal hyperplasia	3 (3.1%)	2 (3.8%)	
		Benign lesion, other	1 (1.0%)	2 (3.8%)	
	Malignant				
		DCIS[b], grade I	9 (9.3%)	6 (11.3%)	>.99
		DCIS grade II and III	26 (26.8%)	6 (11.3%)	
		IDC[c]	24 (24.7%)	20 (37.7%)	
		ILC[d]	12 (12.4%)	7 (13.2%)	
		ILC and IDC	3 (3.1%)	2 (3.8%)	
		Malignant lesion, others	2 (2.1%)	1 (1.9%)	

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[a] At interviews with different medical colleges and hospitals in Chennai, Tamil Nadu, India, May 2013 to April 2014, the cloud-based system support intelligent medical image diagnosis prototype was used for breast health issues. The *P* values were calculated with *t* tests for the means, and the Pearson chi-Square tests for the percentages.

[b] DCIS: ductal carcinoma in situ

[c] IDC: invasive ductal cancer

[d] ILC: invasive lobular cancer

Table 4. Predictors of CIMIDx use of 150 women with breast cancer.

Stages		Category	Odds ratio	95% confidence interval	Significance (*P*)[a]
Age (years)			1.93	0.51-7.34	.89
Time since diagnosis (years)			0.19	0.07-0.53	.89
Annual household income (INR)					
		<1,00,000	1.00		
		1,00,000-2,70,000	2.44	0.19-31.53	.48
		>2,70,000	0.89	0.18-4.36	.89
Education					
		Grades <12	1.00		
		Grades 13-15	1.05	0.16-6.92	.96
		Grades >15	0.92	0.34-2.45	.86
Stage					
	Normal	Normal breast issue	1.00		
	Benign				
		Fibrocystic disease	0.5	0.01-19.56	.71
		Fibroadenoma	1.5	0.09-25.39	.78
		Atypical ductal hyperplasia	0.5	0.01-19.56	.71
		Benign lesion, other	-	-	.39
	Malignant				
		DCIS[b], grade I	1.00		
		DCIS grade II and III	0.48	0.07-3.37	.45
		IDC[c]	1.33	0.32-5.59	.69
		ILC[d]	0.88	0.10-6.78	.86
		ILC and IDC	0.5	0.01-19.56	.71
		Malignant lesion, other	-	-	.39

[a] From interviews at various medical colleges and hospitals in Chennai, Tamil Nadu, India, May 2013 to April 2014, regarding the cloud-based system support intelligent medical image diagnosis prototype used for breast health issues, the *P* values were calculated with *t* tests for the means, and the Pearson chi-Square tests for the percentages.

[b] DCIS: ductal carcinoma in situ

[c] IDC: invasive ductal cancer

[d] ILC: invasive lobular cancer

Table 5. Group characteristics (social, economic, and the usefulness of the CIMIDx prototype for the two user groups).

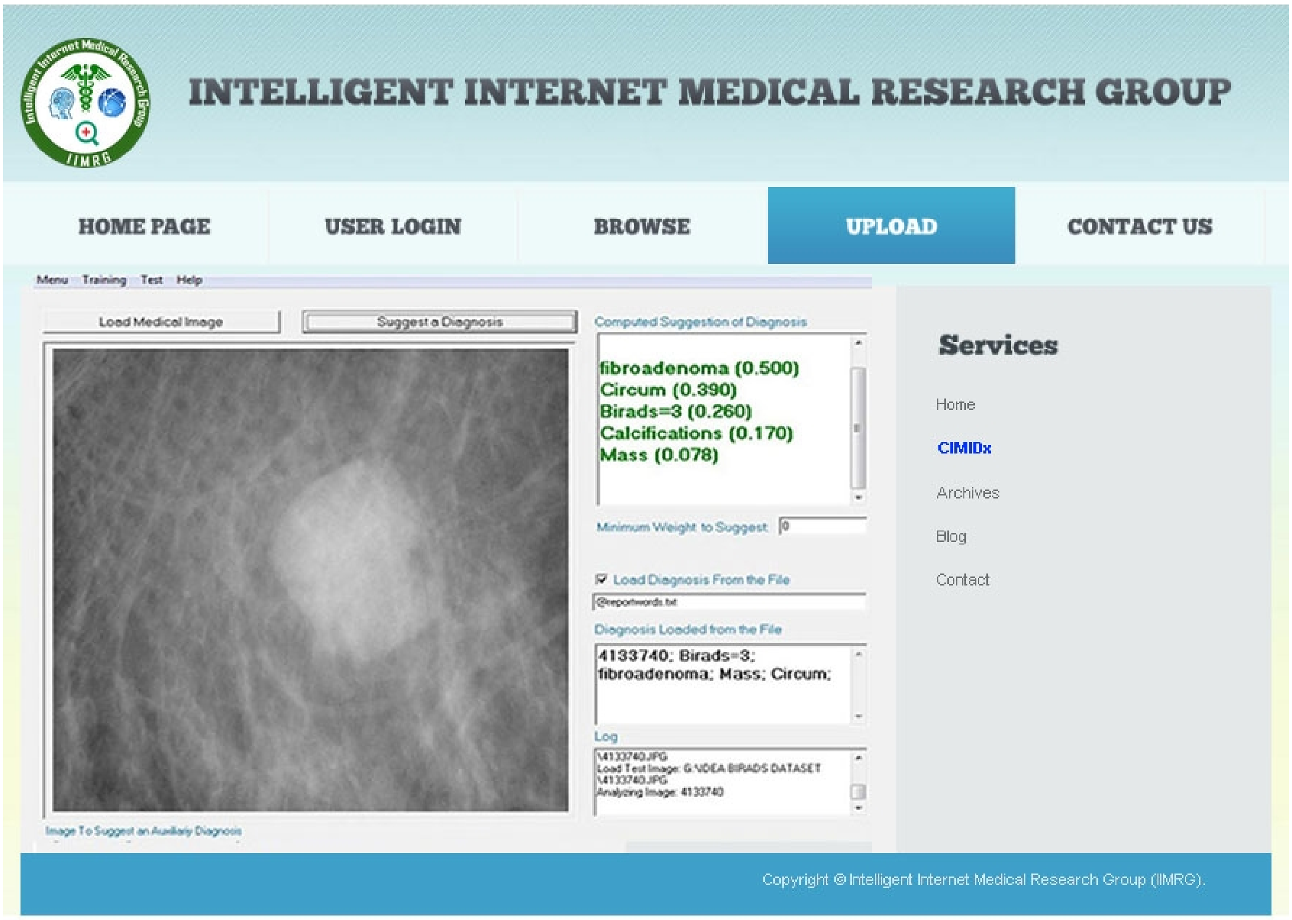
		Users (n=97)		
		Use of CIMIDx by low user (n=44)	Use of CIMIDx by high user (n=53)	
Characteristics	Category	mean (SD) or n (%)	mean (SD) or n (%)	Significance (*P*)[c]
Age (years)		22 (22.6)	26.5 (31.8)	.89[a]
Time since diagnosis (years)		22 (24.0)	26.5 (33.2)	.89[a]
Annual household income (INR)				
	<1,00,000	4 (9.1)	6 (11.3)	.78[b]
	1,00,000-2,70,000	11 (25.0)	12 (22.6)	.48[b]
	>2,70,000	29 (66.0)	35 (66.0)	.89[b]
Education				
	Grades <12	5 (11.4)	8 (15.1)	.93[b]
	Grades 13-15	8 (18.2)	11 (20.7)	.96[b]
	Grades >15	31 (70.5)	34 (64.2)	.86[b]
Ease of navigation				
	Good	39 (88.6)	51 (96.2)	.89[b]
	Average	5 (11.4)	2 (3.7)	.81[b]
Organization of information				
	Good	41 (93.2)	49 (92.5)	.77[b]
	Average	3 (6.8)	4 (7.5)	.81[b]
Usefulness				
	Good	42 (95.5)	51 (96.2)	.77[b]
	Average	1 (2.3)	2 (3.7)	.39[b]
User friendliness				
	Good	43 (97.7)	52 (98.1)	.31[b]
	Average	1 (2.3)	1 (1.9)	.99[b]
Overall satisfaction				
	Good	42 (95.5)	52 (98.1)	.31[b]
	Average	2 (4.5)	1 (1.9)	.39[b]

[a] *t* test

[b] Pearson chi-square test

[c] From the interviews at various medical colleges and hospitals in Chennai, Tamil Nadu, India, May 2013 to April 2014, regarding the cloud-based system support intelligent medical image diagnosis prototype used for breast health issues, the *P* values were calculated with *t* tests for the means, and the Pearson chi-Square tests for the percentages.

Figure 8. Implementation details of the CIMIDx framework.



Computed Suggestion of Diagnosis:

fibroadenoma (0.500)
Circum (0.390)
Birads=3 (0.260)
Calcifications (0.170)
Mass (0.078)

Minimum Weight to Suggest: 0

☑ Load Diagnosis From the File: @reportwords.txt

Diagnosis Loaded from the File:

4133740; Birads=3;
fibroadenoma; Mass; Circum;

Log:

```
\4133740.JPG
Load Test Image: G:\IDEA BIRADS DATASET
\4133740.JPG
Analyzing Image: 4133740
```

Discussion

Principal Findings

In this paper, we introduced the CIMIDx prototype that follows a new approach to a systematically developed and well-organized diagnosis of mammogram images for authorized patients and experts. We performed several experiments to validate the proposed CIMIDx method and the results show the quantitative evaluation that users positively assessed and searched the functionalities in an efficient manner.

The objective of the CIMIDx technology is to provide the facility for experts and low-income patients, anywhere in the world at any time to use the CIMIDx prototype-based mammogram image diagnosis. The results show a high sensitivity of up to 99.3% (139/140) and accuracy of up to 98% (147/150) (the classification accuracy up to 99.1% (117/118), in the malignant mass; up to 96% (22/23), in the benign; and up to 89% (8/9), in the normal category).

The CIMIDx prototype increased the cancer diagnosis rate for the benign (mass and calcification) stages by 96% (22/23), compared with the other methods (from 91% (21/23), of IDEA method; 83% (19/23), by C4.5; and 78% (18/23), by Naïve Bayes). Similarly, it increased the diagnosis rate of malignant (mass and calcification) stages by 99.2% (117/118) (from 96.6%, 114/118, of the IDEA method; 87.3% (103/118) by the C4.5; and 81.4% (96/118), by the Naïve Bayes).

The CIMIDx alone diagnosed 98.0% (147/150) of benign and malignant stages, whereas the IDEA method diagnosed 94.7% (142/150), the C4.5 86.0% (129/150), and the Naïve Bayes 79.3% (119/150). In total, 2.0% (3/150) were dismissed by the CIMIDx whereas the IDEA method dismissed 5.3% (8/150), the C4.5 14.0% (21/150), and the Naïve Bayes 20.7% (31/150), which is clear from Table 2.

The characteristics of patients and experts have been discussed in the use of the CIMIDx prototype for breast health. In our samples, 64.7% (97/150) of patients and 35.3% (53/150) of experts used the CIMIDx for cloud-based diagnosis of the breast cancer image. Of the 150 women screened during the study period, 23 were diagnosed under the category of benign stage, 118 were diagnosed under malignant category, and 9 were diagnosed under normal category. Out of the 150 test images 15.3% (23/150) (benign stages, the patients diagnosed by the CIMIDx prototype were 100%, 13/13) and those by experts were 90% (9/10). Out of 150 test samples, 78.7% (118/150) malignant stages, the patients diagnosed by the CIMIDx prototype were 99% (75/76), and those by experts diagnosed were 100% (42/42). Out of 9/150 (6.0%) normal stage cases, the patients diagnosed by the CIMIDx prototype were 88% (7/8), and those by experts were 100% (1/1). It is evident from Table 3 that the malignant stage of diagnosis was significant by >.99 than the benign stage.

The predictors of the CIMIDx used 150 women with breast cancer, and obtained the results based on the logistic regression analysis. As can be seen, the income and education levels remained significantly related in the diagnosis of the medical image with the CIMIDx prototype. Those with an income level (INR) >2,70,000 have higher significance than people with incomes between 1,00,000-2,70,000 and <1,00,000. Patients with post graduate education (ie, grades >15) have higher significance than those with undergraduate education (ie, grades 13-15) and high school level (ie, grades <12). The use of the CIMIDx prototype is unrelated to the patients' age, duration of the diagnosis, and breast cancer stages. It is evident from Table 4 that the model was significant with $\chi^2_{0.90}$=0.0164 and *P*=.89.

In this study, the user (low and high) groups differed only in the usage statistics, which is how they were classified. With regard to how the intervention was used, high users provided the self-help information more often and reported more consistently on the social and economic and the usefulness of ingredients compared to low users. In addition, no specific sociodemographic, medical, or personal characteristics were found that distinguished the user groups, supporting our hypothesis that the present generic, fully automated intervention could be acceptable for patients' use of the CIMIDx prototype. It is evident from Table 5 that the CIMIDx prototype was highly useful with the significance of *P*=.77.

Strengths and Limitations

The strengths of our study include the high participation rate and the inclusion of those with different stages of cancer. However, we relied on self-reports, and this information may require further refining of the CIMIDx prototype in a better manner. The use of the CIMIDx prototype provided the results of the test image with biopsy relevant information. In [49], the author discussed that 70% of the physicians refer their cancer patients to various online support services for their cancer diagnosis. Breast cancer patients' use of the CAD services is quite low in the earlier stages, from 2% to 8%. Of those patients aware of cloud-based cancer information services, which they found to be 7%, only one-half (7%) used it. The diagnosis is limited to those with early-stage breast cancer, women <60 years, and those with a diagnosis of almost 6 months' period. It is possible that many of these late-stage patients died during the time interval from diagnosis to the study completion or refused to participate. For those recently diagnosed, improved mammography screening rates allow many to be diagnosed with an early-stage rather than a late-stage cancer. Furthermore, the participants were from anywhere in the world. Many patients may find it more comfortable to seek information over the cloud-based medical image diagnosis (self-evaluation), than to use traditional cancer support services. The research should evaluate whether patients and/or experts feel that there are potential clinical benefits for this CIMIDx use. The refinement of the CIMIDx is based on the patient information from the questionnaire in Multimedia Appendix 1.

Conclusions

This study shows that women felt favorably about the use of the cloud-based self- management website for breast cancer survivors to meet their expectations for credibility, accuracy, privacy, and sensitivity to their situation. The present study mainly focuses on the implementation and usage evaluations of the generic, fully automated cloud-based self-intervention for breast health issues. The proposed CIMIDx prototype is an efficient and useful tool for the medical and scientific communities, in order to manage mammographic images including their associated diagnosis, featuring the advantages and functionalities of a cloud service. This study demonstrated that applying the CIMIDx prototype to experts, resulted in the detection of more cancers in screening and diagnosing patients, with an increased sensitivity of up to 99.3% and accuracy rate of up to 98%. This study focuses on the evaluations of the usage statistics for the CIMIDx prototype in the realistic estimation of exposure to the intervention of clients.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

CIMIDx questionnaire.

[PDF File (Adobe PDF File), 117KB - medinform_v3i1e12_app1.pdf]

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Abbreviations

AMIDE: Associative Medical Image Diagnosis Engine
AOI: area of interest
BI-RADS: Breast Imaging-Reporting and Data System
CADe: computer-aided detection
CADx: computer-aided diagnosis
CC: central controller
CIMIDx: Cloud-Based System Support Intelligent Medical Image Diagnosis
DCIS: ductal carcinoma in situ
EC2: Amazon Elastic Compute Cloud
FAB: forward-and-backward
HTTP: Hypertext Transfer Protocol
HTTPS: Hypertext Transfer Protocol Secure
ICT: information communication technology
IDC: invasive ductal cancer
ILC: invasive lobular cancer
LSF: level set function
LSM: level set method
MICAS: Medical Image Collaborative Analysis System
mini-MIAS: mini-Mammographic Image Analysis Society
ROI: region of interest
SC: service consumer
SD: service discovery
SNR: signal-to-noise ratio
SOAP: Simple Object Access Protocol
SP: service provider
SRG: seeded region growing
UDDI: Universal Description, Discovery and Integration
WSDL: Web Services Description Language
XML: Extensible Markup Language

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Original Paper

The Role of Health Care Experience and Consumer Information Efficacy in Shaping Privacy and Security Perceptions of Medical Records: National Consumer Survey Results

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Abstract

Background: Providers’ adoption of electronic health records (EHRs) is increasing and consumers have expressed concerns about the potential effects of EHRs on privacy and security. Yet, we lack a comprehensive understanding regarding factors that affect individuals’ perceptions regarding the privacy and security of their medical information.

Objective: The aim of this study was to describe national perceptions regarding the privacy and security of medical records and identify a comprehensive set of factors associated with these perceptions.

Methods: Using a nationally representative 2011-2012 survey, we reported on adults’ perceptions regarding privacy and security of medical records and sharing of health information between providers, and whether adults withheld information from a health care provider due to privacy or security concerns. We used multivariable models to examine the association between these outcomes and sociodemographic characteristics, health and health care experience, information efficacy, and technology-related variables.

Results: Approximately one-quarter of American adults (weighted n=235,217,323; unweighted n=3959) indicated they were very confident (n=989) and approximately half indicated they were somewhat confident (n=1597) in the privacy of their medical records; we found similar results regarding adults’ confidence in the security of medical records (very confident: n=828; somewhat confident: n=1742). In all, 12.33% (520/3904) withheld information from a health care provider and 59.06% (2100/3459) expressed concerns about the security of both faxed and electronic health information. Adjusting for other characteristics, adults who reported higher quality of care had significantly greater confidence in the privacy and security of their medical records and were less likely to withhold information from their health care provider due to privacy or security concerns. Adults with higher information efficacy had significantly greater confidence in the privacy and security of medical records and less concern about sharing of health information by both fax and electronic means. Individuals’ perceptions of whether their providers use an EHR was not associated with any privacy or security outcomes.

Conclusions: Although most adults are confident in the privacy and security of their medical records, many express concerns regarding sharing of information between providers; a minority report withholding information from their providers due to privacy and security concerns. Whether individuals thought their provider was using an EHR was not associated with negative privacy/security perceptions or withholding, suggesting the transition to EHRs is not associated with negative perceptions regarding the privacy and security of medical information. However, monitoring to see how this evolves will be important. Given that positive health care experiences and higher information efficacy were associated with more favorable perceptions of privacy and security, efforts should continue to encourage providers to secure medical records, provide patients with a “meaningful choice” in how their data are shared, and enable individuals to access information they need to manage their care.

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KEYWORDS

electronic health records; privacy confidentiality; health information exchange; health surveys; health knowledge; attitudes; practice

Introduction

The Health Information Technology (HITECH) Act of 2009 put a number of federally funded initiatives in place to support the adoption and “meaningful use” of electronic health records (EHRs) by eligible providers, including physicians and hospitals [1,2]. These included financial incentives, initiatives to develop standards to exchange information electronically, and technical support for providers to adopt and use EHRs. A key and important element, which the HITECH Act also emphasized, was the importance of ensuring patient and provider trust in EHRs and the electronic exchange of health information [3].

The evolution of both technology and policy to address privacy and security needs is critical as providers’ use of EHRs has grown rapidly since HITECH [4,5]. As of 2012, almost three-quarters of physicians reported adopting an EHR [6]. As EHRs become the norm, a majority of patients’ medical records will become digitized, enabling providers to share health information electronically with other providers to better coordinate care.

As we transition from a paper-based to an electronic system of storing and sharing medical records and we make advancements to ensure the privacy and security of electronic health information, it is critically important to understand how consumers perceive these developments. Consumers represent important stakeholders in this process because it is their health information that is being digitized and shared electronically.

Consumers have expressed a desire for greater transparency and control over their health information, which many see as a key aspect of ensuring privacy [7]. Ensuring safeguards are in place to protect medical records so the information remains confidential is also an important concern and is considered a fundamental component of security [7]. A number of studies have suggested that consumer perspectives regarding the privacy and security of electronic health information are complex and varied. National surveys have shown that there is widespread concern about the privacy and security of EHRs and electronic health information exchange (HIE), with about half of individuals reporting in a recent survey that they expect EHRs to worsen privacy and security [7,8]. However, other findings indicate that many view EHRs as enhancing certain elements of privacy such as providing patients with greater control over their information and transparency regarding who accesses their information [9]. Findings across several surveys also suggest that a majority of individuals understand the potential benefits of EHRs and HIE [7-9], and consider these benefits to outweigh the potential privacy risks [7,10,11].

Evidence is still emerging regarding how these complex perspectives and growing adoption of EHRs may affect consumers’ perceptions regarding the privacy and security of their own medical records, including the sharing of their data among providers and patient-provider communication. Few studies have examined the association between consumer privacy and security concerns with provider EHR adoption [8].

With the increasing adoption of health information technology (IT), the Office of the National Coordinator for Health IT seeks to monitor general trends as well as identify key factors associated with individuals’ perceptions of privacy and security of medical information. Using data from a nationally representative survey of adults conducted by the National Cancer Institute (NCI) in 2011-2012, we sought to answer the following questions:

1. How confident are adults in the privacy and security of their medical records? What technology-related care experience and patient engagement–related factors are associated with consumer confidence in privacy and security?
2. What proportion of adults have withheld information from their provider due to privacy or security concerns? What technology-related care experience and information efficacy–related factors are associated with withholding information?
3. What are adults’ levels of concern regarding sending health medical information from one provider to another? Does this vary by whether it is sent by fax or electronically, and what differentiates adults who express concerns about these different modes of sharing electronic health information?

Methods

Data Collection and Response Rates

The data presented here are from the 2011-2012 administration of the NCI Health Information National Trends Survey (HINTS). HINTS is a nationally representative survey of the US noninstitutionalized adult population (≥18 years) that tracks attitudes, knowledge, and behavior related to health and cancer communication and health outcomes, with an emphasis on the evolution of health information technology in health care [12,13]. Data collection for the fourth iteration of HINTS (HINTS 4 Cycle 1) began in October 2011 and concluded in February of 2012 (N=3959), and included new items related to privacy and security of medical information. There are 3 more cycles of data collection planned through 2014. Data were collected via a self-administered mailed questionnaire using a comprehensive national listing of household addresses available from the United States Postal Service using a 2-stage, stratified sample. Within households, respondents were chosen using a randomized selection process. The final response rate for the postal survey was 36.7%, which is congruent with norms for federally funded population surveys. Full-sample and replicate weights were computed and are available to obtain population-level estimates and correct variance estimates, respectively. These weights correct for nonresponse and noncoverage to the extent possible. In creating these weights, sampling errors are reduced through the use of calibration variables from the American Community Survey (ACS) of the US Census Bureau based on the following demographic variables: age, gender, education, marital status, race, ethnicity, and census region. In addition, 2 other calibration variables from the National Health Interview Survey (NHIS) were used; namely, health insurance status and cancer status. Thus, weighted estimates of these calibration variables using the HINTS data will agree with those from the source data. Full details on the survey design and sampling strategies for the HINTS program have been published elsewhere [12,14].

Outcome Measures

The NCI and the ONC worked collaboratively to create new HINTS items to assess perceptions about privacy and security of medical information. These questions underwent multiple rounds of cognitive testing to assess their validity using respondents who represented a range of levels of education, age, and health status.

The definitions for the items related to security and privacy were developed from the National Committee on Vital and Health Statistics (NCVHS) [15]. According to NCVHS, health information privacy is an individual’s right to control the acquisition, uses, or disclosures of his or her identifiable health data. Security refers to physical, technological, or administrative safeguards or tools used to protect identifiable health data from unwarranted access or disclosure.

Security concerns were assessed with the question “How confident are you that safeguards (including the use of technology) are in place to protect your medical records from being seen by people who aren’t permitted to see them?” Response options included very confident, somewhat confident, and not confident.

Privacy concerns were assessed with the question “How confident are you that you have some say in who is allowed to collect, use, and share your medical information?” Response options included very confident, somewhat confident, and not at all confident.

Withholding of information was assessed by asking: “Have you ever kept information from your health care provider because you were concerned about the privacy or security of your medical record?” (yes/no).

Finally, concerns regarding sending medical information to providers were assessed through 2 questions. The first was in regards to sending information by fax and asked respondents: “If your medical information is sent by fax from one health care provider to another, how concerned are you that an unauthorized person would see it?” (very concerned, somewhat concerned, not at all concerned). The second question focused on medical information “sent electronically from one health care provider to another” with the same response options.

Independent Variables and Measures

Overview

The complex perspectives regarding privacy and security of medical and health information suggest a variety of factors may be involved that go beyond sociodemographic and health-related factors, which have been the focus of some studies [7,16]. Experience with technology, including their providers’ use of an EHR, may affect how individuals perceive privacy and security of their medical information. Additionally, individuals’ experiences with their health care provider may affect their level of confidence in the ability of the provider to maintain the privacy and security of their medical records and their subsequent withholding of information from their health care provider. How individuals seek out and obtain health information may affect their perceptions related to privacy and security of their medical information. Individuals with greater health information efficacy are more likely to seek out health information and make health care decisions on their own, and have higher levels of health literacy and numeracy [17-19]. Individuals in poor health may also perceive privacy and security of their medical records differently than those who are healthy and have fewer encounters with the health care system. Thus, in addition to sociodemographic characteristics (age, education, race/ethnicity, and gender) and health status, we also included the following variables in multivariate analyses.

Health Care Experience-Related Variables

Respondents reported on the quality of care received in the past 12 months from their health care provider (excellent, very good, good, fair/poor, no health care visits in the past 12 months) and their trust in information provided by a health care provider (a lot, some, a little/not at all).

Technology-Related Variables

An index of Internet activity was created to assess the degree to which respondents were engaged in online behaviors. This index considered use of the Internet, use of a personal health record (PHR), use of email to communicate with a health care provider, and having downloaded health information from the Internet. Respondents were given a score of “0″ if they did not use the Internet, “1″ if they used the Internet but did not engage in any of the 3 specific activities included in the index, “2″ if they used the Internet and had engaged in 1 of the 3 activities, and “3″ if they used the Internet and had engaged in 2 or 3 of the 3 activities. Participants were also asked “As far as you know, do your health care providers maintain your medical records in a computerized system?” (we use the term electronic “health” record although the survey items use the term “medical records”). The survey sought to ask about perceptions neutral of whether it was a paper-based system or electronic system.

Information Efficacy

Information efficacy was assessed with the question “Overall, how confident are you that you could get advice or information about health or medical topics if you needed it?” (completely confident, very confident, somewhat/a little/not at all confident).

Data Analyses

We used SUDAAN version 10.01 [20] to account for the complex sampling procedure used by HINTS and to incorporate the final sample and jackknife replicate weights needed to produce nationally representative point estimates and correct standard errors, respectively. Descriptive statistics were used to provide population-level estimates for American adults' (1) perceptions of privacy and security of medical records, (2) choice to withhold medication information from health care providers because of privacy or security concerns, and (3) relative concerns about the transmission of medical information via electronic means or via fax. Bivariate analyses estimated the degree to which privacy and security concerns were related, and how each of these was associated with choosing to withhold medical information. Finally, multinomial generalized logit models were used to estimate the relative odds of having concerns about security, privacy, or unauthorized access to faxed versus electronically transmitted health information. Multivariable logistic regression was used to estimate the odds of withholding information from a health care provider due to concerns about privacy and/or security. Predicted probabilities were also computed.

Results

Respondent Characteristics

Table 1 shows the sociodemographic characteristics of the nationally representative sample. In all, 58.58% (2443/3924) of adults reported that over the past 12 months they had received either excellent (28.73%, 1190/3924) or very good quality of care (29.85%, 1253/3924). A quarter of adults reported they were completely confident in their ability to obtain health-related advice or information they needed (25.53%, 1002/3931), whereas more than one-third (38.81%, 1531/3931) reported they were only somewhat, a little, or not at all confident in their abilities to do so. With regards to technology exposure and uptake, approximately one-quarter (26.26%, 957/3621) of adults engaged in some health-related activity online. The majority (83.99%, 3332/3855) reported their providers kept their medical records in a computerized format.

Table 1. Respondent characteristics (N=3959).

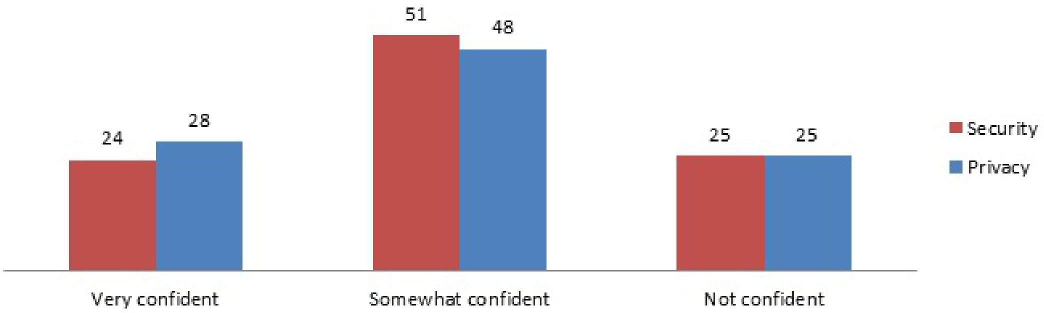
Variable	Unweighted sample size, n	Respondents, %
Age (years), weighted mean (SD)	3891	46.47 (0.09)
Education		
Less than high school	391	12.9
High school	785	23.1
Some college	1167	31.1
College grad or more	1531	32.9
Race/ethnicity		
Hispanic	461	14.5
Non-Hispanic white	2431	66.8
Non-Hispanic African American	576	11.4
Non-Hispanic Asian	168	5.0
Other/multiple	103	2.4
Gender		
Female	2304	51.5
Health status		
Excellent	496	13.6
Very good	1398	37.1
Good	1397	34.2
Fair/poor	632	15.1
Overall quality of care in the past 12 months		
Excellent	1190	28.7
Very good	1253	29.9
Good	590	13.7
Fair/poor	254	6.6
No visits in the last 12 months	637	21.1
How much do you trust information from a health care provider?		
A lot	2685	71.0
Some	1001	23.1
A little/not at all	230	6.0
Internet activity index		
Not online	1043	24.7
Online, but does not use a PHR, email providers, or download health information	1621	49.1
Online and does 1 of the 3 activities	588	16.3
Online and does 2 or 3 of the 3 activities	369	10.0
How confident are you that you could get health-related advice or information if you needed it?, n (%)		
Completely	1002	25.5
Very	1398	35.7
Somewhat/a little/not at all	1531	38.8
As far as you know, does your health care provider keep your medical records in a computerized format?		
Yes	3332	84.0

Confidence Regarding Privacy and Security of Medical Information

Overall, three-quarters of adults reported they were very or somewhat confident in the security of their medical records (75.45%, 2570/3461). Three-quarters of adults also reported they were either very or somewhat confident in the privacy of their medical records (75.41%, 2586/3469).

The distribution of adults' level of confidence regarding the privacy and security of their medical records was fairly similar (Figure 1). Concerns about security and privacy were related: among those who were very confident in the security of their medical records, 75.1% (644/826) were also very confident in the privacy of their medical records (χ^2_4=99.9, *P*<.001).

Figure 1. National perceptions regarding confidence in the privacy and security of medical records (data source: HINTS 4 Cycle 1, 2011-2012).



Factors Associated With Confidence in Privacy and Security

In multivariate analyses, reported quality of care and information efficacy were significantly associated with perceptions of privacy and security (Figure 2). Specifically, adjusting for other characteristics, predicted probabilities estimated from the model indicated that more than twice as many adults receiving high quality of care reported being very confident in the privacy of their medical information as compared to those who received fair or poor quality of care (38.11% vs 15.69%, *P*<.001). Similarly, twice as many adults who received high-quality care reported they were very confident in the security of their medical records (33.19% vs 14.51%, *P*<.001). Approximately one-third of adults with higher levels of information efficacy reported they were very confident in the privacy of their medical information (35.92%) or the security of their medical information (31.79%) compared to approximately one-fifth of adults with low levels of efficacy (both *P*<.001).

Additionally, Hispanics, African-Americans (*P*=.03 for privacy, *P*<.001 for security), and women had significantly (both *P*<.001) higher odds of reporting greater confidence in the privacy and security of their medical information (Table 2). Provider EHR use was not associated with confidence in privacy or security of medical records.

Figure 2. Perceptions regarding privacy and security of medical records by quality of care received and information efficacy (data source: HINTS 4 Cycle 1, 2011-2012).

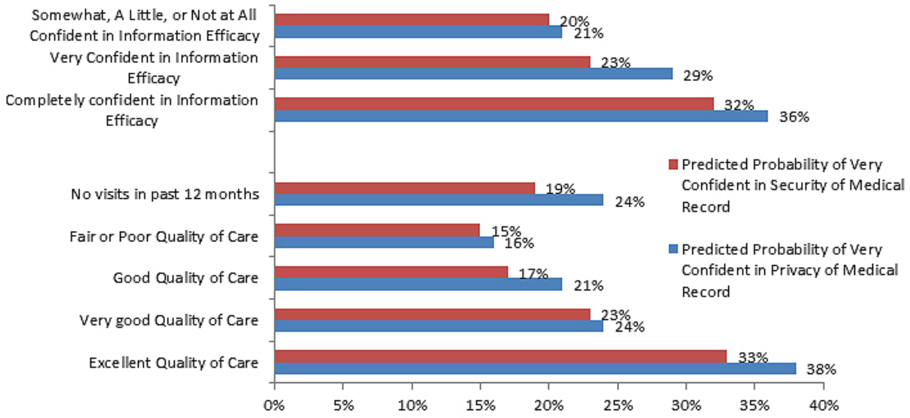


Table 2. Multivariate models of concerns about security and privacy.

Variable	Privacy, AOR (95% CI)			Security, AOR (95% CI)		
	Very confident vs not confident	Somewhat confident vs not confident	*P*	Very confident vs not confident	Somewhat confident vs not confident	*P*
Age	0.99 (0.97, 1.00)	0.99 (0.98, 1.00)	.64	0.99 (0.98, 1.01)	1.00 (0.98, 1.01)	.06
Education						
Less than high school	4.90 (2.17, 11.06)	1.67 (0.89, 3.11)		2.37 (0.98, 5.71)	1.14 (0.45, 2.86)	
High school	2.41 (1.45, 3.98)	1.24 (0.83, 1.83)		1.61 (0.96, 2.69	1.31 (0.82, 2.09)	
Some college	1.44 (0.96, 2.15)	1.28 (0.90, 1.81)		1.27 (0.79, 2.02)	1.22 (0.78, 1.91)	
College grad or more	Reference	Reference	.39	Reference	Reference	.01
Race/ethnicity						
Hispanic	3.06 (1.60, 5.87)	1.66 (0.89, 3.13)		1.91 (1.10, 3.30)	1.28 (0.71, 2.31)	
Non-Hispanic white	Reference	Reference	.03	Reference	Reference	<.001
African American	2.78 (1.83, 4.23)	2.40 (1.45, 3.99)		2.55 (1.44, 4.52)	1.51 (0.80, 2.84)	
Asian	1.72 (0.75, 3.95)	1.16 (0.52, 2.61)		1.05 (0.52, 2.11)	0.82 (0.32, 2.12)	
Other/multiple	1.92 (0.79, 4.70)	1.53 (0.79, 2.97)		1.66 (0.62, 4.38)	1.77 (0.86, 3.64)	
Gender						
Female	1.70 (1.30, 2.21)	1.23 (0.95, 1.60)	<.001	2.22 (1.68, 2.95)	1.27 (0.95, 1.68)	<.001
Health status						
Excellent	Reference	Reference	.13	Reference	Reference	.01
Very good	0.92 (0.59, 1.42)	0.99 (0.60, 1.65)		1.27 (0.63, 2.57)	1.40 (0.71, 2.79)	
Good	1.14 (0.70, 1.86)	0.99 (0.61, 1.62)		1.63 (0.90, 2.94)	1.58 (0.84, 2.98)	
Fair/Poor	0.47 (0.26, 0.86)	0.71 (0.40, 1.27)		0.88 (0.44, 1.76)	1.31 (0.63, 2.71)	
Overall quality of care						
Excellent	Reference	Reference	<.001	Reference	Reference	<.001
Very good	0.57 (0.37, 0.89)	0.99 (0.65, 1.52)		0.36 (0.17, 0.78)	0.65 (0.34, 1.23)	
Good	0.31 (0.16, 0.58)	0.72 (0.44, 1.19)		0.25 (0.13, 0.51)	0.55 (0.33, 0.92)	
Fair/poor	0.17 (0.06, 0.43)	0.39 (0.19, 0.79)		0.16 (0.06, 0.43)	0.48 (0.24, 0.94)	
No visits last 12 mo	0.28 (0.17, 0.47)	0.53 (0.32, 0.89)		0.32 (0.18, 0.58)	0.57 (0.33, 0.99)	
Trust in HCP						
A lot	Reference	Reference	.23	Reference	Reference	<.001
Some	0.42 (0.27, 0.67)	0.54 (0.40, 0.73)		0.58 (0.36, 0.95)	0.77 (0.53, 1.12)	
A little/Not at all	0.61 (0.29, 1.27)	0.50 (0.25, 1.00)		0.71 (0.36, 1.40)	0.82 (0.45, 1.49)	
Internet activity index						
Not online	1.03 (0.61, 1.75)	1.03 (0.67, 1.57)		1.47 (0.82, 2.61)	0.89 (0.52, 1.52)	
Online but no health activity online	Reference	Reference	.08	Reference	Reference	.87
Online and does 1 of 3 health activities (PHR, email doctor, download health information)	0.88 (0.58, 1.32)	0.76 (0.51, 1.14)		1.19 (0.75, 1.89)	0.75 (0.51, 1.12)	
Online and does 2 or 3 health activities online	0.93 (0.54, 1.60)	0.95 (0.65, 1.38)		1.02 (0.52, 1.99)	0.86 (0.52, 1.43)	
Information efficacy						
Completely	Reference	Reference	<.001	Reference	Reference	<.001
Very	0.67 (0.49, 0.92)	1.10 (0.72, 1.68)		0.83 (0.51, 1.33)	1.27 (0.79, 2.06)	

Variable	Privacy, AOR (95% CI)			Security, AOR (95% CI)		
	Very confident vs not confident	Somewhat confident vs not confident	*P*	Very confident vs not confident	Somewhat confident vs not confident	*P*
Somewhat/a little/not at all	0.52 (0.36, 0.74)	1.08 (0.78, 1.49)		0.36 (0.21, 0.62)	0.78 (0.51, 1.18)	
Provider EHR use						
Yes	Reference	Reference	.99	Reference	Reference	.59
No	0.80 (0.49, 1.32)	0.84 (0.56, 1.28)		1.00 (0.55, 1.81)	1.03 (0.61, 1.73)	

Withholding of Information Because of Privacy or Security Concerns

A total of 12.33% (520/3904) of adults reported they had kept information from their health care provider because of concerns about the privacy and security of their medical information (Figure 3).

Factors Related to Withholding Information From a Health Care Provider

As shown in Figure 3, adjusting for other characteristics, individuals who rated the quality of care they received as lower (fair or poor) had 3 times the predicted probability of withholding information compared to those who received excellent care (23.93% vs 8.39%, *P*=.02). Asian-Americans had 2 times higher predicted probability of withholding information from their health care provider due to privacy or security concerns compared to white non-Hispanics (22.39% vs 9.90%, *P*=.01). Provider EHR use was not associated with withholding due to privacy or security concerns (Table 3).

Figure 3. Predicted probability of withholding of information from health care providers due to privacy or security concerns (data source: HINTS 4 Cycle 1, 2011-2012).

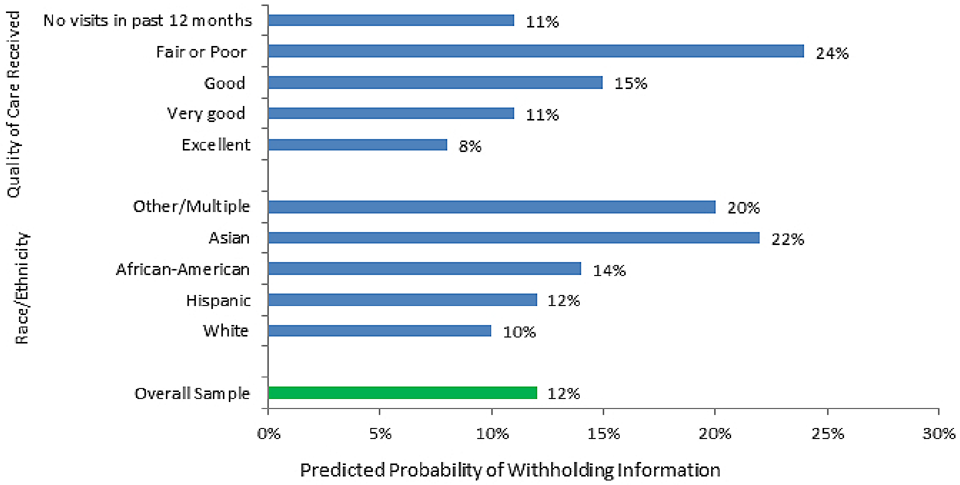


Table 3. Multivariate model regarding withholding of health information from health care provider due to privacy or security concerns.

Variable	Ever withheld health information (yes vs no), AOR (95% CI)	*P*
Age	1.00 (0.99, 1.01)	.70
Education		
Less than high school	0.87 (0.39, 1.96)	
High school	0.67 (0.36, 1.23)	
Some college	1.19 (0.82, 1.72)	
College grad or more	Reference	.24
Race/ethnicity		
Hispanic	1.31 (0.78, 2.21)	
Non-Hispanic white	Reference	.01
African American	1.56 (0.84, 2.90)	
Asian	2.73 (1.43, 5.22)	
Other/multiple	2.29 (0.82, 6.41)	
Gender		
Female	1.30 (0.90, 1.87)	.15
Health status		
Excellent	Reference	.80
Very good	1.22 (0.77, 1.93)	
Good	1.06 (0.67, 1.70)	
Fair/poor	1.18 (0.51, 2.72)	
Overall quality of care		
Excellent	Reference	.02
Very good	1.40 (0.90, 2.16)	
Good	1.96 (1.13, 3.42)	
Fair/poor	3.57 (1.64, 7.75)	
No visits last 12 mo	1.33 (0.72, 2.47)	
Trust in HCP		
A lot	Reference	.23
Some	1.35 (0.87, 2.10)	
A little/not at all	0.74 (0.36, 1.52)	
Internet activity index		
Not online	0.91 (0.45, 1.84)	
Online but no health activity online	Reference	.06
Online and does 1 of 3 health activities (PHR, email doctor, download health information)	0.79 (0.49, 1.28)	
Online and does 2 or 3 health activities online	1.57 (0.98, 2.51)	
Information efficacy		
Completely	Reference	.92
Very	1.08 (0.71, 1.66)	
Somewhat/a little/not at all	1.09 (0.69, 1.71)	
Provider EHR use		
Yes	Reference	.78
No	0.93 (0.55, 1.56)	

Concerns Regarding Sending Medical Information Between Providers

A majority of individuals expressed they were either very or somewhat concerned about unauthorized individuals viewing their data when it is sent between health care providers, whether by fax or electronic means (data not shown). A quarter of adults were “very concerned” (24.89%, 892/3474) about unauthorized persons gaining access to faxed health information compared to 18.75% (724/3462) if the information was sent electronically. Similar proportions of individuals expressed they were “somewhat concerned” about fax (42.12%, 1476/3474) or electronically (45.77%, 1566/3462) sending of information. Approximately one-third of individuals expressed they were not concerned about fax (32.99%, 1106/3474) or electronic (35.47%, 1172/3462) means of transmitting their health information between providers.

When responses to these questions were combined to understand the percentage of adults who were concerned about both methods of transmission, neither or only 1 or the other, a majority of adults (59.06%, 2100/3459) indicated they were either very or somewhat concerned about both electronically sending or faxing their health information, whereas approximately one-quarter (27.55%, 914/3459) were not concerned about either method. Very small proportions of adults were concerned about electronically exchanging data only (5.44%, 188/3459) or faxing data only (7.94%, 257/3459) (Figure 4).

Factors Associated with Concerns Regarding Methods of Sharing Data Between Providers

As shown in Figure 4, adults with higher levels of information efficacy had a significantly lower predicted probability of being concerned about both fax and electronic means of sending information between providers compared to adults with lower levels of information efficacy (49.61% vs 60.28%-61.15%, *P*=.02). Provider EHR use was not associated with concerns regarding methods of sharing data between providers (Table 4).

Figure 4. National concerns about exchanging medical information between providers by methods of exchange and information efficacy (data source: HINTS 4 Cycle 1, 2011-2012).

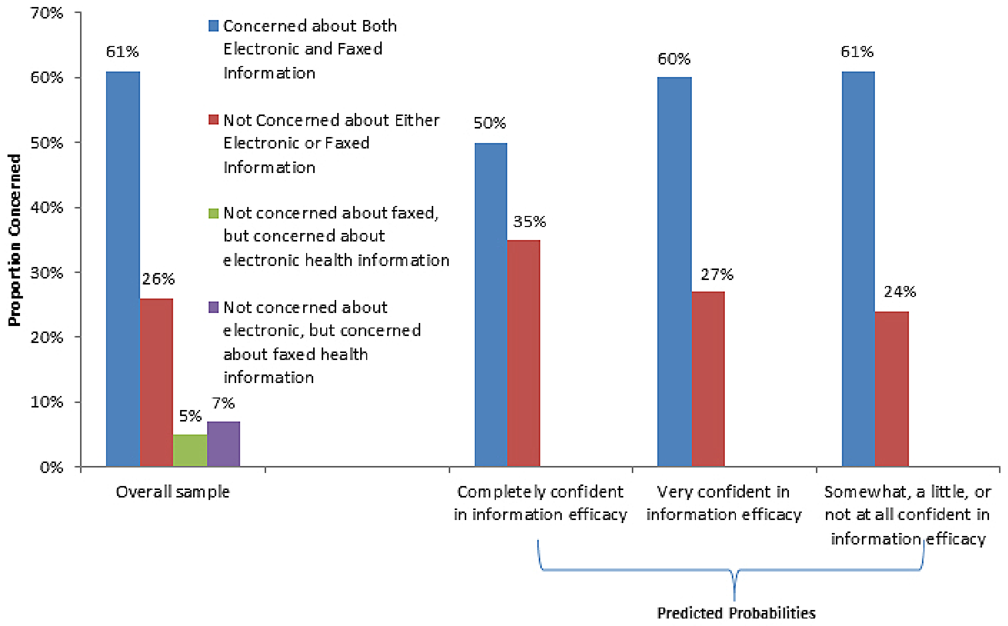


Table 4. Multivariate models of concerns about faxed versus electronic health information.

Variable	Concerned about both vs not concerned about either, OR (95% CI)	Concerned about fax vs not concerned about either, OR (95% CI)	Concerned about electronic vs not concerned about either, OR (95% CI)	*P*
Age	1.00 (0.99, 1.01)	0.99 (0.98, 1.01)	1.00 (0.98, 1.02)	.68
Education				
Less than high school	0.75 (0.37, 1.53)	0.97 (0.27, 3.47)	1.55 (0.22, 11.04)	
High school	1.05 (0.71, 1.55)	1.22 (0.53, 2.81)	0.51 (0.23, 1.13)	
Some college	1.26 (0.93, 1.70)	0.85 (0.53, 1.35)	0.85 (0.48, 1.50)	
College grad or more	Reference	Reference	Reference	.16
Race/ethnicity				
Hispanic	1.29 (0.75, 2.23)	1.07 (0.36, 3.21)	0.82 (0.25, 2.71)	
Non-Hispanic white	Reference	Reference	Reference	.06
African American	2.49 (1.46, 4.25)	1.50 (0.56, 4.04)	2.04 (0.27, 15.57)	
Asian	2.86 (1.38, 5.95)	4.72 (1.20, 18.54)	2.59 (0.71, 9.43)	
Other/multiple	0.99 (0.46, 2.13)	0.59 (0.14, 2.58)	0.63 (0.13, 3.15)	
Gender				
Female	1.24 (0.94, 1.62)	1.36 (0.72, 2.57)	0.98 (0.59, 1.63)	.41
Health status				
Excellent	Reference	Reference	Reference	.31
Very good	1.23 (0.71, 2.13)	0.63 (0.31, 1.28)	1.07 (0.40, 2.86)	
Good	1.08 (0.65, 1.77)	0.78 (0.43, 1.41)	0.69 (0.25, 1.85)	
Fair/poor	1.26 (0.69, 2.29)	0.93 (0.32, 2.67)	0.99 (0.31, 3.16)	
Overall quality of care				
Excellent	Reference	Reference	Reference	.09
Very good	1.29 (0.80, 2.06)	1.00 (0.49, 2.05)	0.79 (0.41, 1.51)	
Good	1.07 (0.68, 1.69)	0.36 (0.15, 0.84)	1.11 (0.51, 2.42)	
Fair/poor	2.13 (0.96, 4.74)	2.58 (0.67, 9.93)	3.27 (0.49, 21.66)	
No visits last 12 mo	1.19 (0.76, 1.85)	1.03 (0.45, 2.33)	1.80 (0.67, 4.86)	
Trust in HCP				
A lot	Reference	Reference	Reference	.20
Some	1.46 (0.96, 2.23)	1.02 (0.47, 2.20)	1.12 (0.51, 2.45)	
A little/not at all	0.57 (0.25, 1.27)	0.24 (0.06, 0.90)	0.41 (0.13, 1.32)	
Internet activity index				
Not online	1.51 (0.84, 2.73)	0.58 (0.22, 1.52)	1.25 (0.40, 3.92)	
Online but no health activity online	Reference	Reference	Reference	.16
Online and does 1 of 3 health activities (PHR, email doctor, download health information)	0.93 (0.64, 1.34)	1.50 (0.74, 3.07)	1.02 (0.45, 2.33)	
Online and does 2 or 3 health activities online	1.44 (0.90, 2.30)	1.44 (0.82, 2.51)	1.16 (0.51, 2.64)	
Information efficacy				
Completely	Reference	Reference	Reference	.05
Very	1.61 (1.08, 2.40)	1.27 (0.66, 2.48)	0.86 (0.33, 2.23)	
Somewhat/a little/not at all	1.82 (2.26, 2.63)	1.66 (0.88, 3.12)	1.08 (0.44, 2.67)	

Variable	Concerned about both vs not concerned about either, OR (95% CI)	Concerned about fax vs not concerned about either, OR (95% CI)	Concerned about electronic vs not concerned about either, OR (95% CI)	*P*
Provider EHR use				
Yes	Reference	Reference	Reference	.71
No	1.26 (0.73, 2.17)	0.90 (0.41, 1.97)	0.93 (0.33, 2.60)	

Discussion

As EHR adoption has increased dramatically, a majority of individuals report they are confident in the privacy and security of their medical records. Three-quarters of adults reported they were either very or somewhat confident in the security of their medical records; similarly, three-quarters of adults reported they were very or somewhat confident in the privacy of their medical records. However, we found evidence suggesting that concerns regarding privacy and security may have a negative influence on provider-patient interactions. In all, 12.33% of adults reported they have withheld information from their health care provider due to concerns about the privacy and security of their medical record. Additionally, a majority of adults (59.06%, 2100/3459) reported being very or somewhat concerned that an unauthorized person might view their medical information when it is sent between health care providers, regardless of whether the information was sent by fax or electronically.

Our findings suggest that, thus far, the transition from paper to electronic health records is not associated with negative perceptions regarding the privacy and security of individuals' medical information. Individuals who believed their providers were using electronic modes of storing or sharing health information did not report lower levels of confidence or greater concerns. Our findings regarding the lack of association between perceptions of provider EHR adoption and privacy and security concerns are consistent with other national survey results, which also found a lack of association between whether an individuals' doctor used an EHR and perceptions regarding the privacy of HIE [8]. Our findings also suggest that there is room for improvement because half of adults reported they were less than very confident in the privacy and security of their medical records; this is consistent with prior studies that have indicated a majority of individuals are concerned about the impact of EHRs on privacy and security [7,8]. Thus, monitoring this over time will be critical because these perceptions may evolve as exposure to providers' use of health IT increases.

A majority of adults did express concerns about the sharing of information between health care providers, whether by fax or electronic means. Similar levels of individuals (between 64.52% and 67.01%) expressed being very or somewhat concerned about either fax or electronic means of sharing their data. Our findings suggest that safeguards and policies should focus on building trust in the exchange of health information between providers, regardless of method of exchange. Although relatively few had concerns specific to electronically sharing information only, ONC is leading several efforts to ensure that entities facilitating exchange implement appropriate privacy and security policies to protect the information as it flows electronically across organizations while also enabling patients to have a "meaningful choice" in how their information is exchanged [3]. For example, in order for providers to receive incentive payments, they must transmit health information using secure technology.

Lack of confidence in privacy and security of medical records seems to negatively affect patient-provider communication. Although a minority of individuals (12%) reported withholding information due to privacy and security concerns, the impact on their health care may be significant. A prior survey found that 4% of individuals reported they had avoided requesting medical care or filling a prescription due to concerns about privacy [21]. Another survey found that 15% of individuals reported they would withhold sensitive information if their providers could exchange health information electronically [22]. A recent study found that smokers were more likely to withhold information from their health care provider due to privacy and security concerns, suggesting that individuals with potentially stigmatizing health conditions may be more likely to withhold sensitive information [16]. Together, these findings suggest that greater privacy and security concerns may be associated with negative patient-provider interactions and that withholding may be specific to certain types of sensitive health information. There are federal initiatives underway that seek to segment or separate sensitive information from other types of electronically transmitted information to alleviate potential concerns [23]. Five pilot projects are underway to demonstrate the technical capability for exchanging sensitive health information so that a patient's privacy preferences are honored.

We did find racial and ethnic differences in privacy and security perceptions as well as potential cultural differences affecting withholding of information due to privacy and security concerns. Our findings that African-Americans and Hispanic Americans had a higher likelihood of expressing they were "very confident" in the privacy and security of their medical records compared to white non-Hispanics does run counter to prior studies which have found individuals from racial/ethnic minorities expressing greater privacy and security concerns [7]. However, other studies also show high interest in health IT use and support for HIE among most minorities [24,25]. Thus, monitoring these perceptions over time to see if these patterns are anomalies or new patterns will be important to assess as future rounds of the HINTS survey are conducted. We also found that Asian-Americans were more likely to withhold health information. This finding is consistent with a smaller, community-based study that found a high proportion of Asian-Americans expressed lower levels of support for HIE and PHRs which may have been related to privacy or security concerns [24]. There will be an opportunity to monitor and validate our initial finding as a national survey on privacy and security funded by ONC in 2014 will be oversampling Asian-Americans. Other converging evidence is slated to be published from special emphasis studies using HINTS items in Guam and the People's Republic of China [26].

Our findings also suggest that confidence in the security and privacy of medical records may be associated with perceptions of quality and a sense of engagement with the health care system. Adults who reported more positive appraisals of the quality of their health care tended to be the same ones who reported greater confidence in the privacy and security of their medical information and were less likely to withhold information from their health care provider due to privacy or security concerns. These findings underscore the important role that individuals perceive that providers play in maintaining privacy and security of medical records. Adults' general confidence in the privacy and security of their medical records may be linked to high levels of trust in their health care provider to protect the privacy and confidentiality of their health information [9]. High-quality health care providers may also be perceived to be more rigorous in their maintenance of medical records. Future research should examine the adoption of privacy and security safeguards by providers.

Adults who reported a greater sense of information efficacy—that is, a sense of confidence in their ability to find and control the information they need for their own health and health care—also reported a greater sense of confidence in the privacy and security of their medical records and less concern about data transmitted between providers. Our findings suggest that if health information technology serves to empower individuals to successfully gain greater access and control over their health information, their positive perceptions regarding the privacy and security of their health information may increase. Providing individuals with greater access to their own health information and the ability to use that information to manage their health and health care of their loved ones is a central cornerstone of ONC's strategy to advance the use of health IT to improve care [27]. Federal initiatives are trying to make this vision into a reality by increasing consumers' access to their own health information through the incentive program requirements and through the Blue Button download initiative [28,29].

Our study assesses individuals' perceptions using general definitions of privacy and security, but both these concepts consist of a variety of specific areas. For example, privacy includes openness, access, and use limitations, whereas security encompasses issues such as availability and integrity of information. This survey did not cover these individual domains and they warrant further investigation. Additionally, although these survey items were cognitively tested to ensure respondents' understanding, it is possible that respondents had difficulty assessing the differences between privacy and security. These are self-reported data that cannot be verified. For example, respondent-reported rates of EHR adoption (86%) are higher than physician-reported rates (72%), suggesting that some individuals may have mistakenly thought their health care provider was using an EHR when they were using a practice management system. Although these individuals may have erroneously believed their provider was using an EHR, this study's examination of the association between perceptions regarding individuals' privacy and security of their medical records and their providers' use of health information technology is valid given that the focus of this study on individuals' perceptions. The response rate for the postal frame tended to be low, although it exceeds random digit dial surveys and is comparable to other federal surveillance mechanisms [30,31]. Efforts were made to address potential sources of error (eg, nonresponse) through poststratification weighting techniques [32].

This nationally representative survey provides timely data on individuals' perceptions regarding privacy and security of their medical records and its association with health IT and care experiences. Although EHR adoption rates have increased, a majority of adults report they are very or somewhat confident in the privacy and security of their medical records. However, many individuals do express concerns regarding the sharing of medical information between providers. Furthermore, privacy and security concerns have led a small but significant minority of individuals to withhold information from their health care providers. Yet, we did not find an association between these concerns and negative impacts with EHR adoption or electronic HIE. Our findings suggest it will be important to continue monitoring the effects of EHR adoption and HIE on privacy and security attitudes and behaviors. Additionally, efforts should continue to encourage providers to secure medical records, provide patients with a meaningful choice in how their data are shared, and enable consumers to access information they need to manage their care.

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Conflicts of Interest

None declared.

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Abbreviations

ACS: American Community Survey
EHR: electronic health records
HIE: health information exchange
HINTS: Health Information National Trends Survey
HITECH: Health Information Technology
NCI: National Cancer Institute
NCVHS: National Committee on Vital and Health Statistics
NHIS: National Health Interview Survey
PHR: personal health record

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Original Paper

Identification of Relationships Between Patients Through Elements in a Data Warehouse Using the Familial, Associational, and Incidental Relationship (FAIR) Initiative: A Pilot Study

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Abstract

Background: Over the last several years there has been widespread development of medical data warehouses. Current data warehouses focus on individual cases, but lack the ability to identify family members that could be used for dyadic or familial research. Currently, the patient's family history in the medical record is the only documentation we have to understand the health status and social habits of their family members. Identifying familial linkages in a phenotypic data warehouse can be valuable in cohort identification and in beginning to understand the interactions of diseases among families.

Objective: The goal of the Familial, Associational, & Incidental Relationships (FAIR) initiative is to identify an index set of patients' relationships through elements in a data warehouse.

Methods: Using a test set of 500 children, we measured the sensitivity and specificity of available linkage algorithm identifiers (eg, insurance identification numbers and phone numbers) and validated this tool/algorithm through a manual chart audit.

Results: Of all the children, 52.4% (262/500) were male, and the mean age of the cohort was 8 years old (SD 5). Of the children, 51.6% (258/500) were identified as white in race. The identifiers used for FAIR were available for the majority of patients: insurance number (483/500, 96.6%), phone number (500/500, 100%), and address (497/500, 99.4%). When utilizing the FAIR tool and various combinations of identifiers, sensitivity ranged from 15.5% (62/401) to 83.8% (336/401), and specificity from 72% (71/99) to 100% (99/99). The preferred method was matching patients using insurance or phone number, which had a sensitivity of 72.1% (289/401) and a specificity of 94% (93/99). Using the Informatics for Integrating Biology and the Bedside (i2b2) warehouse infrastructure, we have now developed a Web app that facilitates FAIR for any index population.

Conclusions: FAIR is a valuable research and clinical resource that extends the capabilities of existing data warehouses and lays the groundwork for family-based research. FAIR will expedite studies that would otherwise require registry or manual chart abstraction data sources.

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KEYWORDS

Informatics for Integrating Biology and the Bedside (i2b2); data warehouse; familial relationship

Introduction

Overview

Over the last several years there has been widespread development of medical data warehouses. The National Institutes of Health (NIH) funded the development and adoption of Informatics for Integrating Biology and the Bedside (i2b2). The i2b2 scalable informatics framework enables researchers to use existing clinical data for discovery research that may be combined with genomic data. This framework can be extended for new and unanticipated data types, as well as for functionality [1-3]. Unlike disease registries, the i2b2 architecture is not limited by project-specific designs, implementation, and policies for data use. Thus, the potential to extract high-quality data for cohort identification, surveillance, and predictive clinical tools has never been greater [4].

Current data warehouses focus on individual cases, but lack the ability to identify family members who could be of interest for dyadic or familial research. Currently, the patient's family history in the medical record is the only documentation that we have to understand the health status and social habits of family members. Recent projects have attempted to gain a better view of family history using natural language processing, but these studies have not linked individual records to each other [5]. Recent literature has demonstrated the capability of linking children with their parents through electronic health records (EHRs) using guarantor and emergency contact information [6].

Many research projects have an interest in families or multiple members of the same familial unit, but study recruitment can often be difficult due to the clinical system's lack of efficiency in documenting biological ties. Consider the clinical research informatics study described below and the benefit of using the Familial, Associational, & Incidental Relationships (FAIR) tool, which is integrated in the clinical data warehouse.

Case Study Using the FAIR Initiative

A research project required the identification of a cohort of children with autism. The research team was able to identify a cohort of children using diagnostic codes in the clinical data warehouse. In the warehouse, there was also an identifier for children who had a specimen in the institutional biorepository. However, the project required information about the autistic children's mothers. The investigators sought consultation with the leaders of the biomedical informatics component of their institution's NIH-funded Clinical and Translational Sciences Award. The challenge was to use the data warehouse to identify how many mothers of the identified cohort of children had also received care in the clinical system. Once identified, both phenotypic and biorepository data would be available on this cohort of mothers for the study.

Finding the mothers of children is often not possible because family members are not linked in the underlying databases. FAIR could aid researchers in the identification of eligible children and also identify which individuals have a mother with a biospecimen stored in our biorepository.

Study Overview and Goal

In response to this research challenge, this paper describes the methodology we developed, the preliminary testing of the method, and the implementation of FAIR, based within the i2b2 framework, for linking data on children and their mothers. We focused our initial testing on the capability of FAIR to accurately find mothers of a randomly selected group of children. The FAIR initiative i2b2 plugin will identify and extract data into cohorts and aid in the understanding of disease by examining the demographic, clinical, and genetic variations of risk through families and generational cohorts. The goal of this study is to develop an algorithm that uses data commonly available in EHRs to find mothers of a group of 500 children. We hope that this algorithm will be able to link children to their mothers accurately enough to enable recruitment for future research studies.

Methods

Study Design

The FAIR initiative had two phases. In Phase I, we conducted a manual chart abstraction to evaluate the test characteristics (eg, sensitivity, specificity) of potential linkage variables selected to link an index population of 500 children and their mothers. In Phase 2, we developed an i2b2 Web app designed to construct linkages and present the results through the Web interface. FAIR was reviewed and approved by the University of Massachusetts Medical School Institutional Review Board.

Phase I: Evaluating the Test Characteristics of Potential Linkage Variables

In Phase I of FAIR, we measured the test characteristics of three potential linkage variables in a sample of 500 children.

Setting and Sample

We included patients (children and their mothers) who had received care in the University of Massachusetts Memorial Health Care (UMMHC) system. We limited the population to patients in the 774 area code, which covers a large portion of the catchment area for the UMMHC system. The initial index population consisted of 13,090 children who were 17 years of age or younger. We randomly selected 500 of those children as our test cohort. For this pilot study, we decided to focus exclusively on finding mothers, versus fathers, because the maternal-child relationship was the focus of several of our colleagues' research, including the investigation of medications used during pregnancy and possible outcomes for the child.

Data Elements

We identified a set of three variables that could potentially link children and their mothers: insurance number, phone number, and address. These variables were chosen because they are available for the majority of patients in our data warehouse and have face validity to support linkage between child and mother. While we considered other identification variables, such as name and race, this data is not often specific to single or small groups of families, therefore, this data was excluded as part of this query.

The Comparison Reference Standard: Manual Chart Abstraction

In order to evaluate the accuracy of our automated match process, we conducted a manual chart audit to validate the findings. During the manual chart audit, we were able to discretely explore numerous documents and data points that were not available for extraction. We started the process by reviewing the child’s chart to look for references to other people who might be related. We used search functions native to our EHR to determine if individuals had the same phone or insurance number and checked those charts to find a match, similar to what was done with the automated match process. In addition, we reviewed documents that were scanned into charts to look for relatives. In many cases, we found that signed consent forms in the child’s chart listed a parent’s name and their relationship. We also found more detailed insurance information, including guarantor, which often led to mothers who were not found using phone or insurance number.

The Familial, Associational, & Incidental Relationships Automated Linkage Algorithm

The automated linkage algorithm occurred in two steps. The first step was to find patients that had the same insurance number, phone number, or address as a child in our study cohort. In the second step, once the linkages were made, the system was designed to differentiate the relationship. For this study, we designed the algorithm to identify potential child-mother linkages only. In cases where multiple automated linkages were identified for a single child, the system selected the oldest linked female to enhance the linkage accuracy and avoid sibling identification. If that person was 15 to 50 years older than the child, the system classified the relationship as a child-mother link.

Analyses

We compared the use of the individual identifiers, as well as identifier combinations, to the reference standard results to determine the sensitivity (ie, finding mothers that are in the system) and specificity (ie, not finding mothers that are not in the system) of the process. This helped determine the positive predictive value (PPV) and negative predictive value (NPV) of the FAIR automated linkage algorithm. In addition, we reviewed the false positive and false negative linkages and compared them to true positive linkages to identify characteristics of the child that might modify the success of the automated linkage algorithm. It is important to note that NPV can be misleading because our manual linkage method allows for the possibility of missing some mothers who do exist in the database.

Phase II: Developing and Testing an i2b2 Web App

In Phase II, we developed a set of i2b2 plugins that can be used to view the diagnoses of a patient’s relatives. The “FAIR-correlated” patients are available through the Massachusetts Integrated Clinical Academic Research Database (MICARD), the University of Massachusetts’ implementation of the i2b2 informatics platform for clinical research.

This software was built first in our development server and then integrated in the production environment. We tested the system in a number of ways to make sure that the software worked as intended. Software inspection (SI) was used to find errors, omissions, and anomalies in the source code. The SI was conducted using a peer-review process of developers in our academic division along with the primary developer for this study. We also conducted unit testing to verify whether independent units of code were working correctly [7]. Moreover, integration testing was used to verify the accuracy of the software [8]. Mock test cases with input and predicted output datasets were then developed to conduct the unit and integration testing.

Results

Overview

The average age of the children in this study sample was 8 years of age (SD 5). The cohort was 52.4% (262/500) male. Of all the children, 51.6% (258/500) were identified as white in race (see Table 1).

Table 1. Characteristics of index patients (children) in the test sample (n=500).

Patient characteristic		n (%)
Age		
	Less than 1 year	12 (2.4)
	1 to 5 years	180 (36.0)
	6 to 10 years	138 (27.6)
	11 to 15 years	124 (24.8)
	16 years and over	46 (9.2)
Gender		
	Male	262 (52.4)
	Female	238 (47.6)
Race/ethnicity		
	White	258 (51.6)
	African American	39 (7.8)
	Hispanic	71 (14.2)
	Other	66 (13.2)
	Unknown	66 (13.2)

Phase I: Evaluating the Test Characteristics of Potential Linkage Variables

Overview

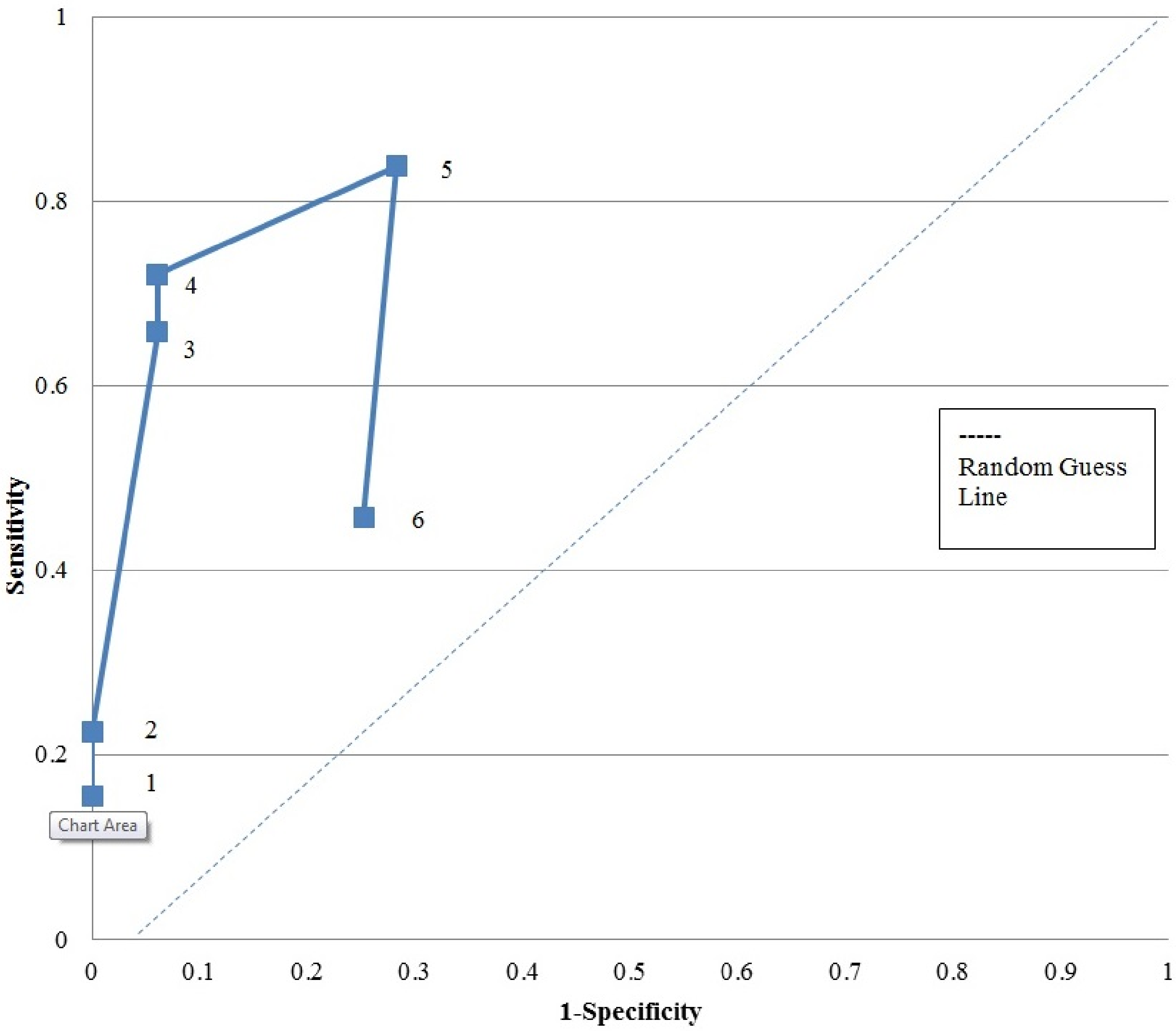
The identifiers used for FAIR were available for the majority of patients: insurance number (483/500, 96.6%), phone number (500/500, 100%), and address (497/500, 99.4%). Using the manual review process, we determined that the prevalence of having an identifiable mother in the system was 80.2% (401/500). Initially, we considered each identifier alone. Subsequently, we used these results to also test combinations of the identifiers.

The sensitivity and specificity for each identifier and combination is presented in Table 2. The corresponding receiver operating characteristics (ROC) curve is shown in Figure 1. Each initial identifier produced differing results for sensitivity, specificity, PPV, and NPV in this analysis.

Table 2. Test characteristics of individual identifiers and combinations compared with verification of child-mother linkage by manual chart abstraction.

Identifier(s)	Sensitivity (n=401), n (%)	Specificity (n=99), n (%)	Positive predictive value, n/n (%)	Negative predictive value, n/n (%)
Insurance identification number	90 (22.4)	99 (100)	90/90 (100)	99/410 (24.1)
Phone number	264 (65.8)	93 (94)	264/270 (97.8)	93/230 (40.4)
Address	182 (45.4)	74 (75)	182/207 (87.9)	74/293 (25.3)
Insurance *or* phone	289 (72.1)	93 (94)	289/295 (98.0)	93/205 (45.4)
Insurance, phone, *or* address	336 (83.8)	71 (72)	336/364 (92.3)	71/136 (52.2)
Insurance *and* phone	62 (15.5)	99 (100)	62/62 (100)	99/437 (22.7)

Figure 1. Receiver operating characteristics (ROC) curve of matching methods (1=insurance and phone, 2=insurance only, 3=phone only, 4=insurance or phone, 5=insurance, phone, or address, 6= address only).



Data Elements

Insurance Number

Matching children to their mothers based on insurance number alone resulted in low sensitivity (90/401, 22.4%) but perfect specificity (99/99, 100%). The insurance number was the only identifier that did not contribute to any false positives with PPV (90/90, 100%). The NPV for insurance number alone was also quite low (99/410, 24.1%). A major issue was that family insurance numbers are not assigned by many companies. In particular, most safety net insurers use individual numbers. Thus, querying by insurance number alone will exclude families of lower socioeconomic status. Additionally, working with insurance numbers requires restructuring the data due to the length of the numbers, which often vary by provider. Typically, the insurance numbers contain two sets of digits: the first number specifies the account, and the second number specifies the individual. Hence, prior to matching, the digits specifying the individual need to be removed.

Phone Number

Unlike insurance, phone number was far more sensitive (264/401, 65.8%) in identifying true relationships with only a small drop in specificity (93/99, 94%). The PPV (264/270, 97.8%) was high, yet the NPV (92/230, 40.4%) was still quite low, though better than when only insurance was used. Since phone numbers were available for all of the patients, it was the only consistent way to find family members of patients who were uninsured or had insurance from a company that assigned unique numbers rather than family numbers.

Address

Address had sensitivity of 45.4% (182/401) for identifying relationships, a specificity of 75% (74/99), a PPV of 87.9% (182/207), and an NPV of 25.3% (74/293). Variation in how patients' addresses were entered into the system was a major issue. In particular, it was common to find addresses for an apartment building that were lacking unit numbers. This inaccurate data resulted in a large number of false positives.

Insurance or Phone Number

The algorithm we used for the primary comparison required either insurance number or phone number. Since the primary application of FAIR is cohort discovery to enable recruiting, we placed a high value on the PPV. This method resulted in the highest combined sensitivity (289/401, 72.1%) and specificity (93/99, 94%) of all of our tests. The PPV (289/295, 98.0%) was high, but the NPV (93/205, 45.4%) was low.

Insurance Number, Phone Number, or Address

As anticipated, using any of the three identifiers would result in the most sensitive method (336/401, 83.8%), but with a lower specificity (71/99, 72%). It provided a high PPV (336/364, 92.3%), but a low NPV (71/136, 52.2%).

Insurance and Phone Numbers

Requiring both insurance and phone numbers in the query was the most restrictive combination tested, but the utility was dominated by the use of insurance alone. Requiring multiple variables to match patients limited the sensitivity (62/401, 15.5%), but the specificity (99/99, 100%) was perfect. The PPV was 100% (62/62) because matching was based partially on insurance. The NPV (99/437, 22.7%) for this method was the lowest of all the matching methods tested.

Based on the performance of the individual variables, we decided to drop the address identifier from our final algorithm and use only phone number or insurance number. Once initial matches were made, we had to differentiate the relationships of the patients and determine the one to be selected if multiple potential mothers were found. We limited the group to females who were 15 to 50 years of age older than the child in the cohort. If we found multiple matches, we considered phone and insurance numbers first, then insurance number, and then phone number. If, at that point, we still had multiple matches, we chose the oldest female from the group.

The algorithm is run outside of i2b2 and loaded into the schema. This allows institutions to use whatever matching algorithm works best. Flexibility is crucial since the data available for matching differs by institution.

The Comparison Reference Standard Versus the Automated Linkage Algorithm

In our comparison of the manual and FAIR automated linkage study, we uncovered some situations where FAIR was less successful. One challenge was the inability to differentiate biological and nonbiological parent cases. A second set of challenges was related to socioeconomic status.

The system is not able to differentiate between parents and stepparents. In some instances, we found that the stepparent had more variables in common with a child than a biological parent. Thus, any use of FAIR will require an additional manual review to confirm the biological connection of the identified relationship.

Unfortunately, populations of lower socioeconomic class had a lower chance of matching for several reasons. First, most safety net insurance plans (eg, Medicaid) have unique numbers for individuals, but do not use family numbers. This is an important linkage variable because, although specific, it was not sensitive as it missed all patients with these insurance plans. In addition, if a family frequently changed phone numbers, the chances of making a positive match decreased. Lower income households are more likely to have unstable phone service, potentially changing plans frequently as finances require, thus making it difficult to identify a familial linkage based on phone number. Finally, we found that individuals of lower socioeconomic class often resided in multi-unit dwellings, so these locations would have the same street address. Because address data often lacked unit numbers, false positives were identified in the lower socioeconomic strata, reducing the specificity for this important variable.

Phase II: Developing and Testing an i2b2 Web App

As part of this initiative, a set of i2b2 Web Client plugins were engineered to enable researchers to utilize relationship information in their studies. The plugin displays the FAIR members of each patient in an i2b2 patient set, and then allows the user to select the relevant groups of patients and their corresponding FAIR members on which to tabulate their concepts. In other words, it enables a researcher to quickly trace the occurrences of certain concepts in various FAIR groups.

The i2b2 Web Client is a Web-based interface to the i2b2 Hive, which enables a user to access the i2b2 data through a Web browser. The primary advantage of the Web Client is that the software does not have to be specifically installed on the user's computer or device. In addition, because the Web Client is Web browser based, researchers using non-Windows computers or devices (eg, tablets) may also access the i2b2 data, which aids greatly in the enterprise-wide rollout of the i2b2 across an institution [9].

The architecture of the i2b2 Web Client also facilitates the addition of plugins supporting new, specific analytic functions. The FAIR Concept Tracer is such a plugin that facilitates the access of any available FAIR data for rendering. In general, adding a new plugin to the i2b2 Web Client is rather straightforward and does not require any stoppage of an institution's i2b2 installation. The FAIR Concept Tracer is packaged with a detailed installation guide and a user document, along with the source code [10]. So far, there have not been any problems reported by other institutions concerning the incorporation of the plugin. We estimate that all the software required for FAIR could be installed in less than half an hour.

The i2b2 framework allows the storage and access of patient data for research purposes. We introduced an additional provision to expedite the capture and storing of any such FAIR information in self-defined—by each institute—simple eXtensible Markup Language (XML) forms. A set of tools has been developed to facilitate the storing and rendering of these FAIR data.

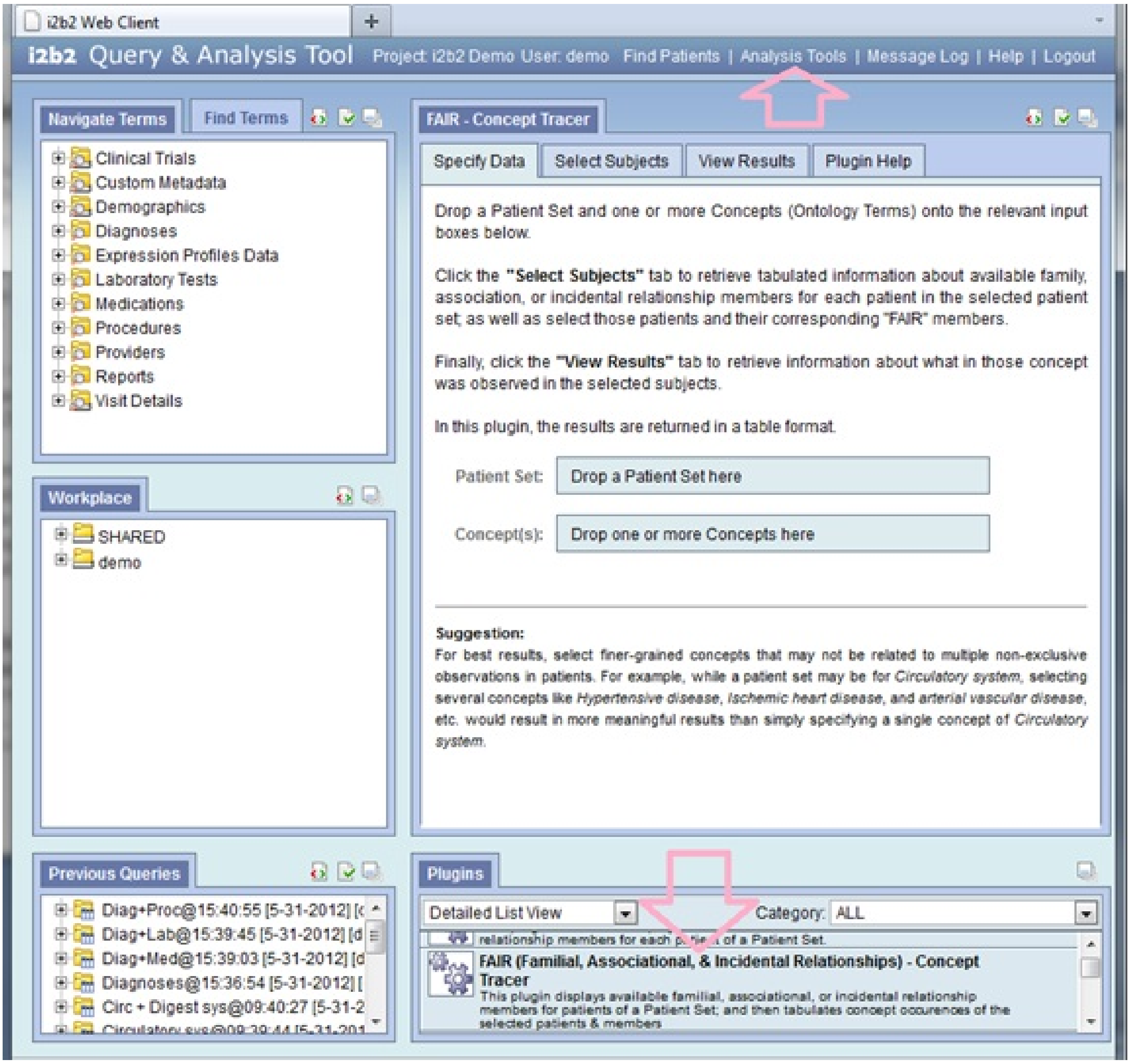
Using our FAIR schema, the incorporation of the FAIR data does not require any schematic and/or hive-cell code changes. The FAIR database administrator toolset (DBA Toolset) was developed to enable the incorporation of the new FAIR data into the existing i2b2 database while observing such constraint.

The FAIR output can be extracted into an Excel spreadsheet (XLS) or a comma-separated-values (CSV) file.

We conducted some initial FAIR usability testing with users in the i2b2 community and the feedback has been positive. Users felt that the way the data were presented, as well as the flexibility of the system to modify the FAIR data structure, was excellent. The approach and methodology will be made available to all academic institutions that are part of the i2b2 community.

Figure 2 shows the *Specify Data* window from the FAIR Concept Tracker. This window allows the user to load the desired *Patient Set*—from either the *Workplace* or the *Previous Queries* panel—and one or more *Concepts* and drop them into the appropriate drop-in boxes. Figure 3 shows the *Select Subjects* window from the FAIR Concept Tracker, which allows the user to select appropriate subjects for tracing the selected *Concepts* in the "related" individuals. Figure 4 shows the *View Results* window from the FAIR Concept Tracker. This window displays a group of patients that match, the identification number of each patient, the relationship of each group member, and the circulatory diagnoses of each patient. This example shows a view of how a fully functional system would look once all relationships, beyond that of the child and mother, have been defined.

Figure 2. Specify Data window for the FAIR Concept Tracker.



Drop a Patient Set and one or more Concepts (Ontology Terms) onto the relevant input boxes below.

Click the **"Select Subjects"** tab to retrieve tabulated information about available family, association, or incidental relationship members for each patient in the selected patient set; as well as select those patients and their corresponding "FAIR" members.

Finally, click the **"View Results"** tab to retrieve information about what in those concept was observed in the selected subjects.

In this plugin, the results are returned in a table format.

Patient Set: Drop a Patient Set here

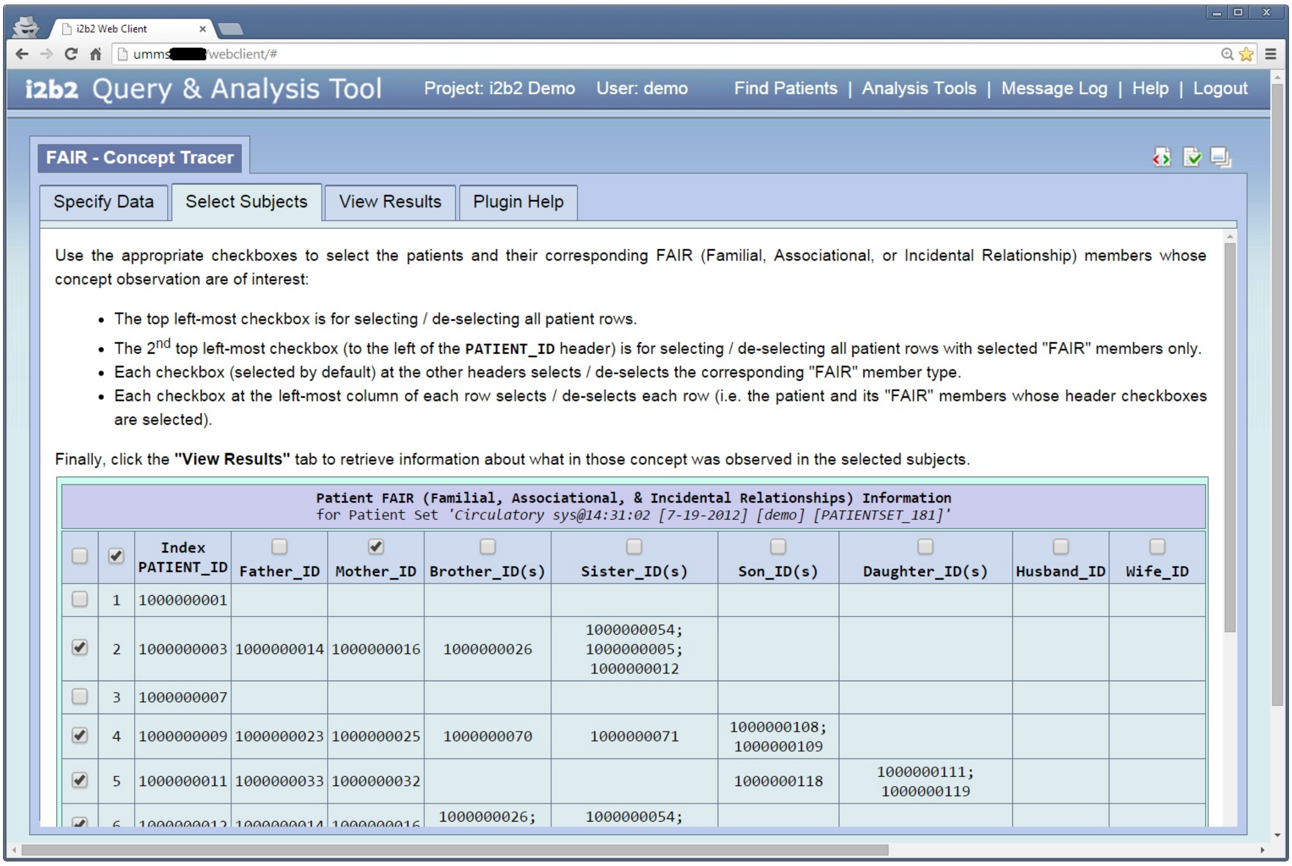
Concept(s): Drop one or more Concepts here

Suggestion:
For best results, select finer-grained concepts that may not be related to multiple non-exclusive observations in patients. For example, while a patient set may be for *Circulatory system*, selecting several concepts like *Hypertensive disease, Ischemic heart disease, and arterial vascular disease,* etc. would result in more meaningful results than simply specifying a single concept of *Circulatory system.*

relationship members for each patient of a Patient Set.

FAIR (Familial, Associational, & Incidental Relationships) - Concept Tracer
This plugin displays available familial, associational, or incidental relationship members for patients of a Patient Set; and then tabulates concept occurences of the selected patients & members

Figure 3. Select Subjects window for the FAIR Concept Tracker.



Use the appropriate checkboxes to select the patients and their corresponding FAIR (Familial, Associational, or Incidental Relationship) members whose concept observation are of interest:

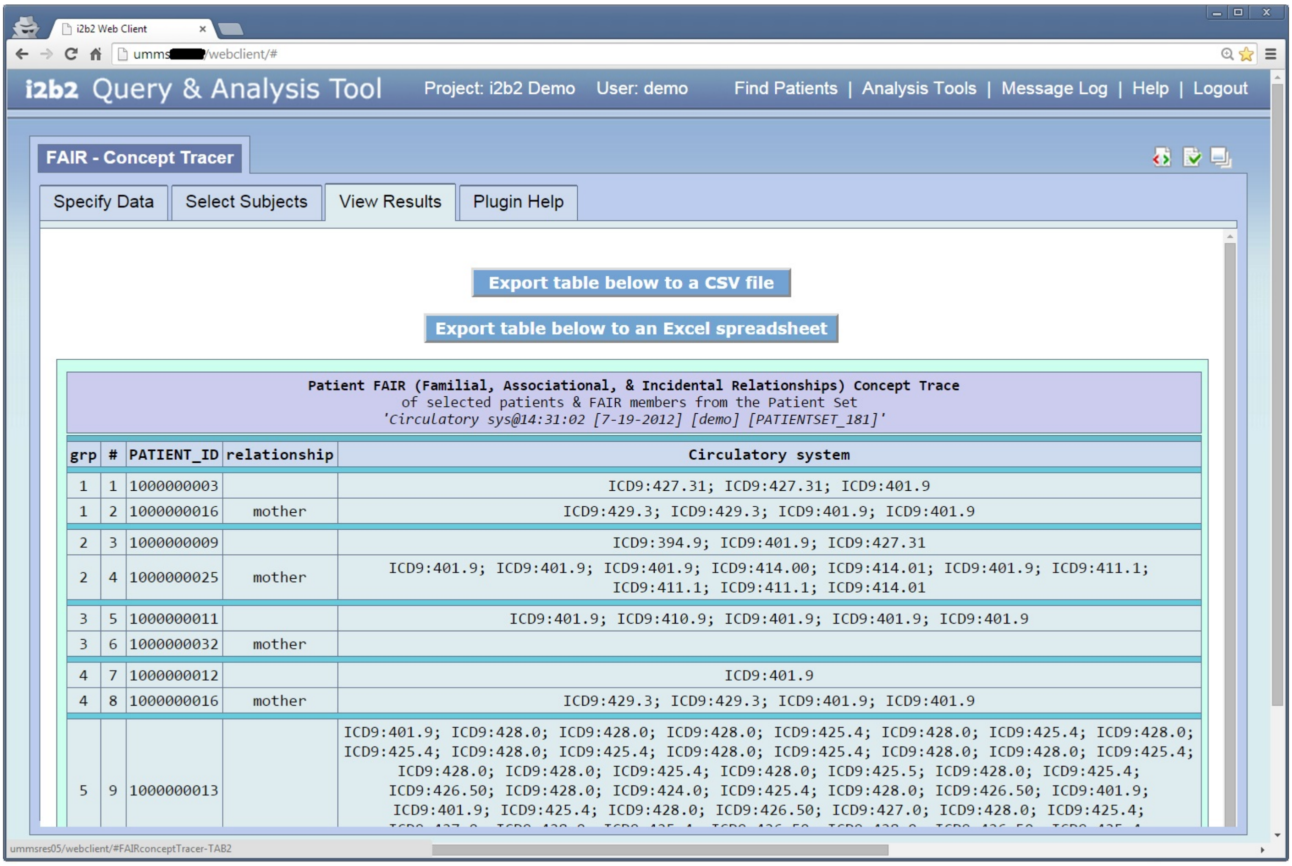
- The top left-most checkbox is for selecting / de-selecting all patient rows.
- The 2nd top left-most checkbox (to the left of the **PATIENT_ID** header) is for selecting / de-selecting all patient rows with selected "FAIR" members only.
- Each checkbox (selected by default) at the other headers selects / de-selects the corresponding "FAIR" member type.
- Each checkbox at the left-most column of each row selects / de-selects each row (i.e. the patient and its "FAIR" members whose header checkboxes are selected).

Finally, click the **"View Results"** tab to retrieve information about what in those concept was observed in the selected subjects.

Patient FAIR (Familial, Associational, & Incidental Relationships) Information
for Patient Set *'Circulatory sys@14:31:02 [7-19-2012] [demo] [PATIENTSET_181]'*

☐	☑	Index PATIENT_ID	☐ Father_ID	☑ Mother_ID	☐ Brother_ID(s)	☐ Sister_ID(s)	☐ Son_ID(s)	☐ Daughter_ID(s)	☐ Husband_ID	☐ Wife_ID
☐	1	1000000001								
☑	2	1000000003	1000000014	1000000016	1000000026	1000000054; 1000000005; 1000000012				
☐	3	1000000007								
☑	4	1000000009	1000000023	1000000025	1000000070	1000000071	1000000108; 1000000109			
☑	5	1000000011	1000000033	1000000032			1000000118	1000000111; 1000000119		
☑	6	[illegible]	[illegible]	[illegible]	1000000026;	1000000054;				

Figure 4. View Results window for the FAIR Concept Tracker.



Patient FAIR (Familial, Associational, & Incidental Relationships) Concept Trace
of selected patients & FAIR members from the Patient Set
'Circulatory sys@14:31:02 [7-19-2012] [demo] [PATIENTSET_181]'

grp	#	PATIENT_ID	relationship	Circulatory system
1	1	1000000003		ICD9:427.31; ICD9:427.31; ICD9:401.9
1	2	1000000016	mother	ICD9:429.3; ICD9:429.3; ICD9:401.9; ICD9:401.9
2	3	1000000009		ICD9:394.9; ICD9:401.9; ICD9:427.31
2	4	1000000025	mother	ICD9:401.9; ICD9:401.9; ICD9:401.9; ICD9:414.00; ICD9:414.01; ICD9:401.9; ICD9:411.1; ICD9:411.1; ICD9:411.1; ICD9:414.01
3	5	1000000011		ICD9:401.9; ICD9:410.9; ICD9:401.9; ICD9:401.9; ICD9:401.9
3	6	1000000032	mother	
4	7	1000000012		ICD9:401.9
4	8	1000000016	mother	ICD9:429.3; ICD9:429.3; ICD9:401.9; ICD9:401.9
5	9	1000000013		ICD9:401.9; ICD9:428.0; ICD9:428.0; ICD9:428.0; ICD9:425.4; ICD9:428.0; ICD9:425.4; ICD9:428.0; ICD9:425.4; ICD9:428.0; ICD9:425.4; ICD9:428.0; ICD9:425.4; ICD9:428.0; ICD9:428.0; ICD9:425.4; ICD9:428.0; ICD9:428.0; ICD9:425.4; ICD9:428.0; ICD9:425.5; ICD9:428.0; ICD9:425.4; ICD9:426.50; ICD9:428.0; ICD9:424.0; ICD9:425.4; ICD9:428.0; ICD9:426.50; ICD9:401.9; ICD9:401.9; ICD9:425.4; ICD9:428.0; ICD9:426.50; ICD9:427.0; ICD9:428.0; ICD9:425.4;

Discussion

Principal Findings

The FAIR method is useful for finding potential dyadic cohorts. Identifying familial linkages in the phenotypic data warehouse can be valuable in cohort identification and in beginning to understand the interactions of diseases among families [11-13]. The optimal combination of variables was to find a match either using the insurance or phone number. However, that is assuming that sensitivity, specificity, positive predictive value, and negative predictive value are of equal importance for a given project. As noted, the automated matching algorithm was imperfect and was less successful for matching family members at lower socioeconomic levels.

In the aforementioned case study, we discussed finding mothers of autistic children. The investigators desired a tool that was able to comprehensively identify as many child-mother linkages as possible. Thus, if a linkage was not found, the case was “ruled out” as valuable for the study with some degree of certainty. The investigators wanted a highly sensitive linkage algorithm, which minimized false negatives. The most sensitive linkage was a combination of all variables with *or* logic (ie, if any of the variables matched, a linkage was identified). However, the investigators were aware that many of the potential linkages were false positives, and additional manual review would be required.

Other studies could be considered where the task is not to be comprehensive, but rather to have an algorithm that identifies only true child-parent linkages, or maximizes specificity. For these studies, the insurance identification number is the single most effective linkage variable. However, investigators must recognize that many potential linkages will be missed. Maximizing specificity has repercussions, including drastically reducing sensitivity. This is especially problematic as the insurance identification number linkage variable was much less successful in lower socioeconomic groups.

Challenges for the Familial, Associational, & Incidental Relationships Tool

As noted, none of the linkage variables were perfect. There are certainly caveats to using data collected for clinical purposes for research [14-16]. In our validation, we found several challenges, including the inability to differentiate biological versus nonbiological parents. This problem is not likely to be solved easily with structured data elements and will likely require natural language processing of clinical notes to improve the algorithm. Also, the system was less successful with families at lower socioeconomic levels due to differences in insurance numbers, phone numbers, and street addresses.

The concept of FAIR poses new and important challenges to patient privacy in the context of clinical data being used for research purposes. FAIR facilitates linkage of information from one patient to another. Use of this identified data would require consent from both subjects to proceed. The University of Massachusetts Medical School has approved the implementation of the FAIR plugin for our de-identified i2b2 data warehouse, as the linkage is made before all identifiers that link back to patient charts are removed. However, different institutions may have different policies about relational linkage studies.

Limitations

Our initial evaluation of FAIR was limited to a single cohort of 500 children. We did not limit our selection of children to a specific diagnosis, as some diagnoses (eg, those that vary with socioeconomic status) may have influenced the test characteristics analyses. We purposely chose the children at random, enhancing the potential generalizability across diagnoses. However, this also means that our results may not be representative of targeted disease cohorts, and future validations of FAIR in specific projects are needed. In addition, we have only tested the indicator linkages in a single clinical data warehouse at a single institution. This data warehouse is representative of one institution, therefore, this study may not be generalizable to other institutions or hospitals that house EHRs with differing data points or levels of completeness. Further experimentation through the informatics community—taking advantage of the NIH-funded Clinical and Translational Sciences Awards network and the widespread availability of the i2b2 platform—is warranted.

Conclusions

FAIR is a valuable research and clinical resource that extends the capabilities of existing data warehouses and lays the groundwork for family-based research. FAIR will expedite studies that would otherwise require registry or manual chart abstraction data sources. Moreover, the knowledge that can be gained through biological ties is essential to the future prevention and management of complex diseases, such as asthma, depression, and specific childhood conditions. The potential for FAIR goes beyond child-parent relations. It could be used to identify geographically related cohorts of patients in a clinical data warehouse (eg, those living close to an environmental hazard or those living in an underserved area). Thus, the flexibility of FAIR should enable a wide variety of research. Our hope is that FAIR will be an innovative tool that will aid future researchers in their first steps towards predictive, personalized, and preemptive medicine.

The FAIR plugin is now available to all users of i2b2 [17]. Our matching algorithm is simple enough that it could be adapted to most clinical data warehouses with basic demographic, geographic, and insurance data available. Further research is needed to demonstrate the value of FAIR in concrete clinical research informatics projects.

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Conflicts of Interest

None declared.

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Abbreviations

CSV: comma-separated-values
DBA Toolset: database administrator toolset
EHR: electronic health record
FAIR: Familial, Associational, & Incidental Relationships

i2b2: Informatics for Integrating Biology and the Bedside
MICARD: Massachusetts Integrated Clinical Academic Research Database
NIH: National Institutes of Health
NPV: negative predictive value
PPV: positive predictive value
ROC: receiver operating characteristics
SI: software inspection
UMMHC: University of Massachusetts Memorial Health Care
XLS: Excel spreadsheet
XML: eXtensible Markup Language

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Original Paper

Information Persistence Services Designed to Support Home Care

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Abstract

Background: Due to the challenges faced by health and social care systems, in particular those related to actual demographic trends, home care emerges as a potentially cost-effective solution to answer the needs of citizens, and to allow the reallocation of resources to alternatives to hospitalization or institutionalization.

Objective: Home care services require cooperation between different actors, including health and social caregivers, care receivers, and their informal caregivers (eg, relatives or friends), across time, space, and organizational boundaries. Therefore, it is foreseeable that eHealth services can contribute to their improvement. The aim of this study is to evaluate information persistence services based on the Reference Information Model (RIM) of the Health Level Seven (HL7) version 3 to support formal caregivers, both health and social care providers, and informal caregivers in the context of home care services.

Methods: A pilot study was set up involving two Portuguese institutions that provide home care services for the elderly. Defining of information requirements was performed according to a comprehensive process. This included a review of the literature, observations of work activities, interviews with caregivers, care receivers and their relatives, analysis of paper documentation related to care receivers' histories, health conditions and care plans, and brainstorming groups involving specialized professionals. Following this, information objects were implemented and validated.

Results: The methodological approach, as well as the information persistence services, proved to be robust and adequate to specify, implement, and validate different types of information objects related to home care services for the elderly. This study also reinforces the application of the RIM of the HL7 version 3 beyond the strict scope of health care, allowing the persistence of not only health care information, but also information related to social assistance activities.

Conclusions: This study contributes to the ongoing efforts related to the development of eHealth applications to improve the cooperation among formal health care and social caregivers, as well as care receivers and their informal caregivers.

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KEYWORDS

long-term care; home help services; personal health record; electronic health record; information management; interoperability

Introduction

Background

Health and social care systems need to face challenges due to actual demographic trends, particularly the shift in the burden of illness from acute to chronic conditions. Home care emerges as a potentially cost-effective solution to meet the needs of citizens and to allow the reallocation of resources to alternatives to hospitalization or institutionalization [1]. Home care services can be defined as home-based health care and social care services provided by formal and informal caregivers. This care is not solely focused on clinical purposes, but also on a range of essential activities for the maintenance of the individual's quality of life and that are part of the normal everyday life of every citizen, with the use of technology when appropriate [1-3].

Various interacting organizational structures may coexist within home care services: formal care networks, including both health and social caregivers, and a diversity of informal care providers, such as relatives, friends, voluntary groups, or nongovernmental organizations [1,4]. The introduction of eHealth [5] services can mobilize synergies between the various stakeholders [4].

In order to contribute to solutions to integrate information objects, including the ones commonly associated with the provision of health care, as well as the ones associated with social assistance or that result from the proactive participation of the care receivers or their informal caregivers, the authors developed the We.Can platform [6]. This platform aims to support care in the community and comprises a set of eHealth applications, development tools, and technological services. In particular, these include security mechanisms (eg, authentication, authorization, or confidentiality) and information persistence services (ie, technological services able to retrieve, manage, and deliver information related to care receivers and to guarantee its internal and external semantic interoperability) based on the Reference Information Model (RIM) of the Health Level Seven (HL7) version 3 [7].

This paper deals specifically with the specification, implementation, and validation of information objects using the aforementioned persistence services in a pilot study involving two Portuguese institutions that provide home care services for the elderly. The introductory part of this paper justifies the need for new information objects for this application domain and compares existing solutions to retrieve, manage, and deliver information related to care receivers, for instance, electronic health records (EHRs), personal health records (PHRs), and electronic social records (ESRs). Additionally, this paper describes a pilot study where an implementation of the RIM of the HL7 version 3, together with the dual-model approach of the openEHR [8], was used to support home care services. Results from the pilot study show that the information services that were developed, based on the RIM, can contribute to the persistence of information usually distributed among EHR, PHR, ESR, and special purpose systems, thereby minimizing integration and interoperability issues. We hope this study can contribute to ongoing efforts to develop eHealth applications to support formal and informal caregivers who do not have access to structured information regarding their care receivers.

Related Work

Since health and social care systems need to adequately meet new demand patterns, eHealth services can contribute to better allocation and management of the available resources, in accordance with the needs of citizens and of the organizations providing care services. However, most existing eHealth services have been developed with the prevalent paradigm of the discrete specialization of clinical activities and, therefore, there is the need to overcome their fragmentation [9]. Concepts such as Medicine 2.0 [10], connected health [11], or holistic health [12,13] promote citizen-oriented and holistic solutions to manage mutual awareness and shared objectives among care receivers and formal and informal caregivers [12]. This requires an effective cooperation not only among health care and social care providers, but also among formal and informal caregivers, which is complex due to the lack of unified models, concepts, and terminologies. Therefore, the challenge exists to develop transversal information objects (ie, information objects to comply with wellness issues and to accommodate information generated by the care receivers or their informal caregivers, including information resulting from innovative monitoring devices [12]) with meanings that must be the same regardless of the organizational, logistical, or cultural differences of the actors involved. Consequently, the information persistence services should be able to contribute to the systematization of models, concepts, and terminologies and to combine new and existing types of information objects to allow coherent information support for each care receiver [12].

Nowadays, the need for retrieving, managing, and delivering large amounts of health care information is being met by EHRs [14]. EHRs, in their simplest form, consist of electronic files containing clinical information about individuals and can help to personalize care, prevent medical errors, promote the consistency of care, refer the correct service providers, control costs, and promote clinical research [15].

However, health conditions are influenced by factors distributed across different levels of impact that interact with each other continuously and in subtle ways [16]. These include behavioral (eg, medication adherence), social (eg, activities and participation), or environmental factors [17]. Nowadays, these factors can be monitored by ambient assisted living (AAL) and mobile health solutions [18-20], which produce a considerable amount of data.

Additionally, PHRs include information related to the individual's lifetime and the record of care maintained by the individuals [8]. This stands in contrast with EHRs, which are operated by organizations and contain information entered by formal caregivers.

The definition and implementation of ESRs have been considered during the last few years [21,22]. ESRs should be composed of various types of information, namely forms (eg, assessment forms used locally or nationally), coded information (mainly for management and statistical reporting purposes), or unstructured information (eg, letters or notes of meetings). Since the service models employed by health and social caregivers are different, there are important differences between EHRs and ESRs [21]. Health care records focus on a single patient, often in considerable detail and depth. On the other hand, social care records place the individuals in their daily living context of family and other informal caregivers, and include their attitudes and the effects on each [21].

Within the eHealth sphere [10,23], the use of technological solutions to provide information services to mediate among different actors that build functional care around the care receiver has been proposed by various authors [12,24-27]. This has been based on different technologies [28-32], including the management of chronic diseases [32-34]. Furthermore, there is a considerable effort to develop suitable services to manage psychosocial information [21,22,35,36], information generated by the care receivers and their informal caregivers, and information resulting from automatic data collection about individuals and their environments, through innovative monitoring devices [19,20,37]. However, the aggregation of data from different sources, and both the coherence and interoperability of the resulting information, require further research [12,38].

Methods

Overview

In Portugal, public services represent only a small part of the support that is given to the elderly. Social solidarity institutions (SSIs) (eg, church-sponsored charity institutions called Misericórdias or private social solidarity institutions), as they are in closer proximity to society, take on a very important role in filling the gaps left by public services [39]. SSIs provide a wide range of services, not only with respect to social assistance, but also to health care, and have differentiated employees, including health care personnel and social workers. Part of SSI financial support is regulated by collaboration contracts or agreements with the National Health Care System and, as their importance to long-term care has been increasing, they have become essential to the provision of health and social care.

SSI interventions are grouped by social responses, which are organized according to the needs of the potential care receivers. In Portugal, nearly half of all the social responses of the SSIs are focused on the elderly population and are classified into the following types: (1) social center (to support sociocultural and recreational activities), (2) day care (to help the elderly to stay in their environments), (3) retirement home (to provide social assistance activities, including temporary or permanent accommodation and provision of food, comfort, and hygiene), (4) residence (to provide common apartments to be used by the elderly with partial or total autonomy), (5) foster care (to temporarily or permanently integrate elderly people with technically-qualified families), (6) temporary reception center (to support social emergency situations), (7) night center (to support elderly with autonomy who carry out their activities of daily living at home, but during the night may need some support due to reasons of isolation), and (8) home care services. In evolutionary terms, home care services have been considered as an alternative to more traditional responses, such as retirement homes, and their availability has substantially increased during recent years.

This study deals with the definition of information objects related to home care services for the elderly. A pilot study was set up involving two SSIs that provide home care services, and a comprehensive process was performed to determine the information requirements. This process was based on the Contextual Design methodology [40] and included the following: a review of the literature, observations of work activities, interviews with caregivers, care receivers and their relatives, analysis of paper documentation related to care receivers' histories, health conditions and care plans, and brainstorming groups involving specialized professionals. Following this, the We.Can platform, which is briefly described in the next section, was used as a tool to implement and validate the information objects that were identified.

The Technology Used

Since the main goal of the We.Can platform is to provide eHealth applications related to health and social care in the community, it offers flexible structures to ensure the persistence of the information related to care receivers. In order to achieve this, it follows the dual-model approach that has been considerably developed by openEHR promoters [8]. In terms of the information model, the RIM [7], defined by HL7 version 3, was adopted to facilitate interoperability with external information repositories.

The current implementation of the information model follows the Representational State Transfer architectural style to promote greater scalability and is supported by PostgreSQL technology, which was selected based on performance criteria. The current implementation provides comprehensive operations to access the database of the information repository (ie, create, read, and update operations). Note that the delete operation was not considered because the persistence services should not support the deletion of previously existing records, due to the need to guarantee auditing procedures. Therefore, the operations include versioning mechanisms.

From the point of view of information persistence operations, a specific eHealth application should not have to know the structure of the RIM or the structures of the underlying database, but only the high-level structures of the information objects being used. This means that the create, read, and update operations include mechanisms to map each information object instantiation to the structures of the RIM and of the underlying database. These mechanisms ensure consistency with the RIM while avoiding poor optimized records (eg, a large number of empty fields). Additionally, a syntax specifically designed to allow for the formulation of flexible queries was implemented.

A high-level view of the implemented architecture is presented in Figure 1. Briefly, the Persistence layer implements the information model according to the RIM while the Data layer includes the underlying database. The Business layer provides services to ensure the use of the information repository with security and reliability (eg, data transport or security functions, such as authentication, authorization, or confidentiality, among others). This layer also provides the necessary mechanisms for the conversion of messages, to ensure interoperability in terms of the information that is imported from or exported to external information repositories. The Application layer includes specific eHealth applications and the Knowledge layer comprises the functions required to map these applications to the information repository. Finally, development applications are part of the Support services.

Two different development applications have an important role in the context of this study: the Generic Entity configures how the instances of the information objects are accessed and presented, and the Archetypes Manager supports the archetypes implementation (eg, searching, editing, publishing, authentication, versioning, or ownership).

The Generic Entity is intended to help with the development of high-level interaction modules—to be incorporated into the eHealth applications of the Application layer—by using mechanisms to create, access, or modify instances of information objects without the need to know the details of the Persistence layer, namely the structures of the underlying database. Additionally, based on the structures of the information objects, the Generic Entity can implement the visual representations of these objects, as well as the business rules that govern them. The following features provided by the Generic Entity should be highlighted: (1) abstraction of data access and business rules, (2) customization of fields (eg, data type or validation constraints), (3) automatic update whenever there is a definition of new components, (4) automatic generation of custom forms for viewing, entering, or editing data, (5) automatic generation of programming code to be included in the eHealth applications of the Application layer, and (6) versioning management.

For the implementation of the Archetypes Manager, aimed at the optimization of available resources and tools, it was decided to use the openEHR public domain resources. Obviously, this approach has the advantage of substantially reducing development efforts, particularly the ones related to a broad range of constraints that needed to be implemented. Therefore, archetypes and terminologies that were developed by the openEHR community are available, as well as the possibility to edit existing archetypes or create new ones by using openEHR tools, such as LiU Archetype Editor or Ocean Informatics.

However, this approach has a drawback due to the inevitable fact that the archetypes resulting from the openEHR tools, described according to Archetype Definition Language (ADL), do not consider the RIM to be the underlying information model. Consequently, bearing in mind the need to map the archetypes' structures resulting from the openEHR tools, it was necessary to integrate an ADL parser into the Archetypes Manager (Figure 2), this parser then being responsible for all of the necessary mapping procedures.

The formal structures that result from the ADL parser are eXtensible Markup Language (XML) Schema Definition (XSD) files. Within the We.Can platform, these XSD files are used in two different ways: (1) by the Generic Entity to automatically generate programming code related to the high-level interaction modules, including the visual representations and the business rules that govern the respective information objects, and (2) by the applications to invoke the Persistence layer services, and to guarantee the conformity of the instances of the information objects being persisted.

Figure 1. Architecture of the We.Can platform.

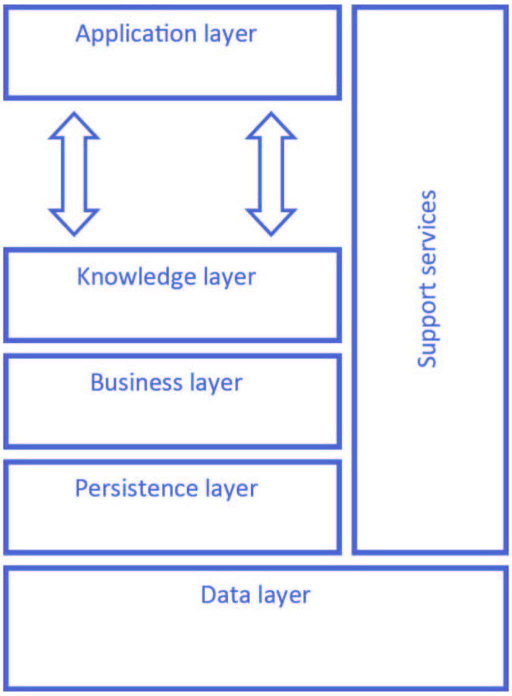


Figure 2. Archetypes Manager.

Results

Home Care Services

A pilot study was set up involving two Portuguese SSIs that provide home care services for the elderly. These services include the provision of individualized care in the home to individuals when, because of illness, disability, or other impediment, they cannot provide, either temporarily or permanently, the satisfaction of their basic needs or daily living activities [39] (eg, basic health care services, such as rehabilitative, supportive or technical nursing care, and social assistance, such as preparing meals, dressing, hygiene, comfort, home activities, communication, mobility, or transportation).

When potential care receivers, or their relatives, apply for home care services, the applications are evaluated by a committee. For each approved application, an assessment is performed to establish a care plan. This is a key component of home care services and it is based on professional judgments about health conditions and daily living issues.

In organizational terms, there is usually a social worker responsible for home care services who, therefore, takes on the coordination of team leaders and assistants, and interacts with other caregivers (eg, physicians, nurses, psychologists, or therapists).

The team leaders are experienced caregivers and they are responsible for the supervision of the assistants that, in general, do not have differentiated qualifications. The supervision of the assistants during home visits is frequent (ie, at least once a week). The teams can be organized in different ways, depending on the policy of the respective SSI, but they usually work in shifts, with guidelines to ensure that each assistant knows the maximum number of care receivers possible, and to guarantee that house calls are always carried out by two caregivers.

Whenever assistants consider that specific information is relevant, they communicate this to the respective team leader or home care service coordinator, so that appropriate measures can be taken (eg, making an appointment with a general practitioner or asking a specialized technician to give advice on specific assistive technology).

There are formal interactions between the formal caregivers involved, such as briefings about the activities or paper documentation related to care receivers' histories, health conditions, and care plans. However, the majority of interactions (eg, asking for or sharing information) are informal, face-to-face meetings or phone calls.

Specification, Implementation, and Validation of Information Objects

After a review of the literature related to home care services, eHealth services and applications, health and social care information, and interoperability standards, a comprehensive process was conducted to specify, implement, and validate the information objects required to support home care services (Figure 3).

Initial meetings were held at the two SSIs to explain the study to all the potential participants. Following these meetings, extensive analyses of work activities and elicitations of user needs were performed based on the Contextual Design methodology [40]. These started with observational studies (ie, observation of the work context and of the activities performed by a number of selected team leaders and assistants during their work shifts). Based on consolidated data of the observational studies, the Unified Modeling Language (UML) was used to model the work activities and the details of the working environment. Additionally, in order to understand the cooperation mechanisms and to include nonobservable aspects of the daily work practices, semistructured interviews focusing on specific objectives, rules, and obligations of the home care services were conducted with various professionals and care receivers and their relatives. Whenever possible, the participants were encouraged to include their personal views and to discuss issues that they thought to be important.

At the same time, an analysis of existing documentation related to care receivers' histories, health conditions, and care plans was performed. The different documents were studied and categorized according to the type of information they contained (eg, administrative, or health- and social care-related information), to complement the insights from observations and interviews. Different individual files were reviewed until new data could not be extracted from the documents.

The resulting materials were examined repeatedly by members of the research team in order to categorize them, and preliminary empirical results were presented to brainstorming groups. These groups were composed of experienced caregivers who were challenged to develop ideas about information that would be useful to promote person-centered care within home care services (eg, problematic issues, work activities, cooperative activities, information needs, and tools). Additionally, the moderator was instructed to direct discussions, not only toward current work processes, but also to visions of future work practices (eg, AAL or mobile health solutions).

The feedback from the groups composed of experienced caregivers supported the development of a set of archetypes by a team of experts in medical informatics. The resulting archetypes (ie, their formal structure and graphical representation using mind maps) were evaluated by interdisciplinary groups consisting of experienced specialists with different backgrounds (eg, elderly care or medical informatics), aiming as much as possible to encompass a broad perspective of home care services.

To complete the implementation of the information objects, there was the need to map the defined archetypes with the information repository using the ADL parser of the We.Can platform. Following this, the Generic Entity was used, together with the XSD files resulting from the ADL parser, to iteratively refine computerized prototypes. These were validated by the members of the interdisciplinary groups, considering usage scenarios with reasonably detailed descriptions. Finally, experts in medical informatics validated the consistency of the information being persisted.

Most of the qualified caregivers involved in the sequence of procedures being described recognized that it contributed to the following: (1) increasing the mutual understanding of the entire care process and the roles of the various professionals, (2) improving the services being provided and the internal communication, and (3) answering to the political pressure resulting from the modernization of the public administration.

Nevertheless, we should highlight some difficulties, including the following: (1) the natural resistance to the uncertainty and anxiety inherent to transitions, (2) the perception of a high-level of complexity associated with technological solutions, (3) some lack of recognition of the importance of technological solutions and difficulty in evaluating their qualitative benefits, (4) existence of actors that detain key information of critical processes, (5) low ability to contribute to the design of innovative solutions, (6) expertise directed toward the necessity of dealing with daily problems, and not available for planning and realizing advanced organizational and technological innovations, (7) poor formalization of work activities, with most of them in constant mutation, which is subtle at times, (8) lack of standardized procedures, (9) lack of unified models, which results in the use of different concepts and terminologies between different institutions, and even between care providers within the same institution, and (10) existence of rules, jurisdictions, and regulations that are, at times, contradictory, in addition to different institutional and professional cultures.

Last but not least, although there are a significant number of young professionals with a high digital literacy level and who are receptive to the introduction of new services, a low digital literacy level is common to the majority of the older care providers, particularly the assistants. This is also common to most care receivers, which is foreseen to hinder the design, development, and introduction of eHealth services.

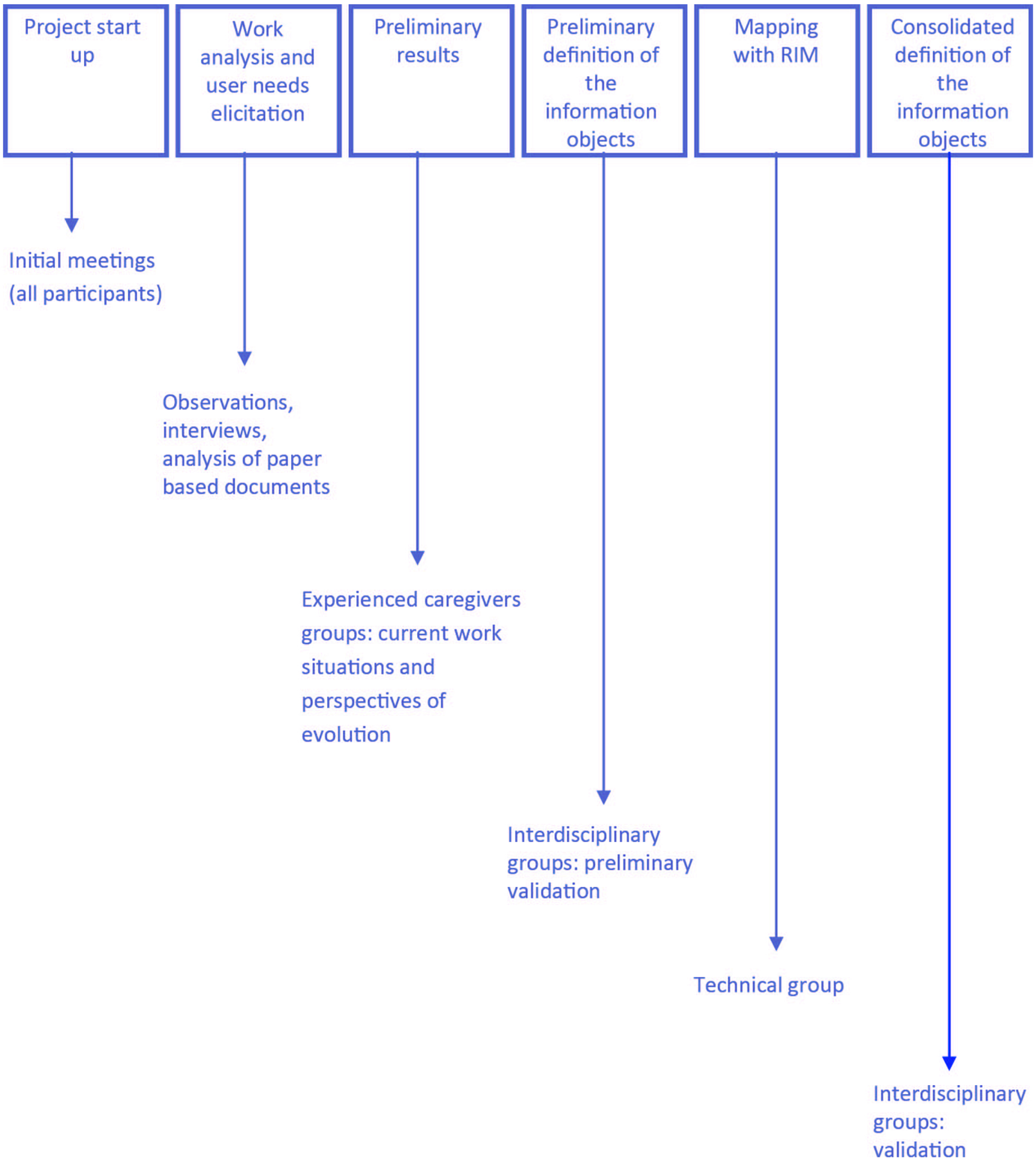
The methodological approach—particularly, the brainstorming groups together with the use of computerized prototypes—proved to be robust and reduced the impact of the above-mentioned difficulties in the definition of the different types of information objects related to home care services.

These objects were divided into the following different classes: (1) administrative (eg, account management, claiming, billing, or authorization), (2) demographic (eg, personal and contact information), (3) personal (eg, PHR objects), (4) current health condition (eg, objects for the description of the care receivers' current health conditions), (5) activity—to group information related to autonomy (eg, the daily activities that the care receivers are able to handle personally and those which they need help with, such as preparing meals, dressing, hygiene, comfort, home activities, communication, mobility, or transportation), habits (eg, eating or sleeping), or social participation, (6) context (eg, issues such as support networks or housing conditions), (7) care delivery—objects to support the ongoing care needs of an individual (eg, information about medication and prescriptions or risk factors), and (8) documentation, including objects for appointments, scheduling, daily notes, care plans (ie, description of the scheduled interventions during the day), performed activities, data from monitoring devices, guidelines, and irregular events (ie, events that, when occurring, imply the need of nonplanned, collaborative interventions).

The implementation of a set of objects with rather different characteristics, as the ones mentioned above, shows that the persistence services of the We.Can platform are able to retrieve, manage, and deliver information required to support home care services. Nevertheless, the integration of data from monitoring devices, such as the ones related to AAL, requires further development. The current implementation does not support the persistence of information related to sensors that provide continuous data streams.

The next section illustrates the implementation of an information object associated with the 9-item Patient Health Questionnaire (PHQ-9) [41], an assessment instrument identified during the definition of the information requirements. Other possibilities could be considered as examples, but since this particular assessment instrument is used internationally, it facilitates the understanding of the procedures related to the implementation of the information objects.

Figure 3. Process to specify, implement, and validate information objects.



The 9-Item Patient Health Questionnaire Information Object

The PHQ-9 has been studied as a useful screening tool for depression and is a clinical instrument of public domain. It is suitable for making criteria-based diagnoses of depressive disorders, as well as being reliable and valid in measuring depression severity and in determining the treatment response [41].

In order to determine a score of depression state, the PHQ-9 instrument comprises nine questions that evaluate how often over the last 2 weeks the patient has been bothered by a set of problems. In addition, there is a question to check if there are any problems that impact the way the person works, takes care of things at home, or gets along with other people. Therefore, the PHQ-9 information object is composed of 11 groups (ie, one group for each question and another one for the score).

Figure 4 represents a mind map related to the specification of the first question that evaluates if the patient has little interest or pleasure in doing things. Since possible answers are *not at all*, *several days*, *more than half the days*, or *nearly every day*, their possible values can be defined using a 4-point Likert scale, with a range from 0 to 3.

By using an editor provided by the openEHR framework (eg, the LiU Archetype Editor), the information expressed on the mind map can support the specification of the respective archetype. Given the extension of the ADL file resulting from this operation, just a small part (ie, the part related to the first question) is presented in Figure 5.

As previously mentioned, an ADL parser was developed. This can be used to create the XSD file required by the applications to guarantee, when invoking the persistence services, conformity with the RIM of all the instances of the PHQ-9 information object. Figure 6 presents part of the XML code resulting from this operation. This figure only focuses on the default value (ie,

-1) of the answer to the first question of the PHQ-9. Furthermore, Figure 7 shows a schematic representation of mapping a value of the PHQ-9 archetype with an observation value of the RIM structure.

Finally, the Generic Entity of the We.Can platform and the XSD file were used to generate a high-level interaction module (Figure 8), which was used as a prototype to validate the PHQ-9 information object.

Figure 4. PHQ-9 mind map representation.

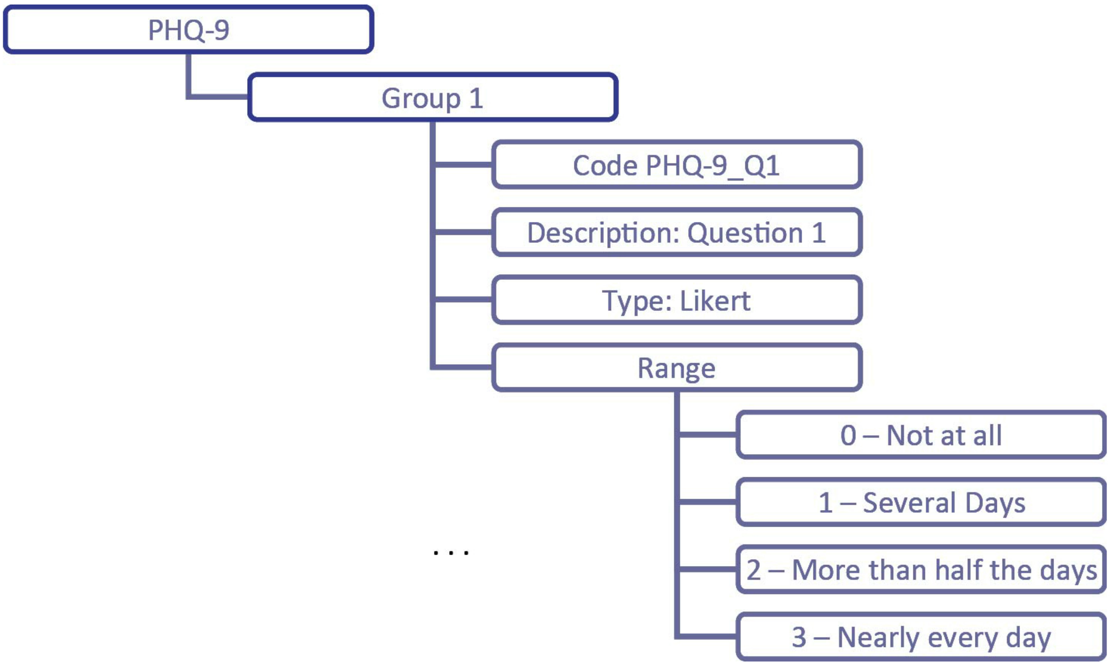
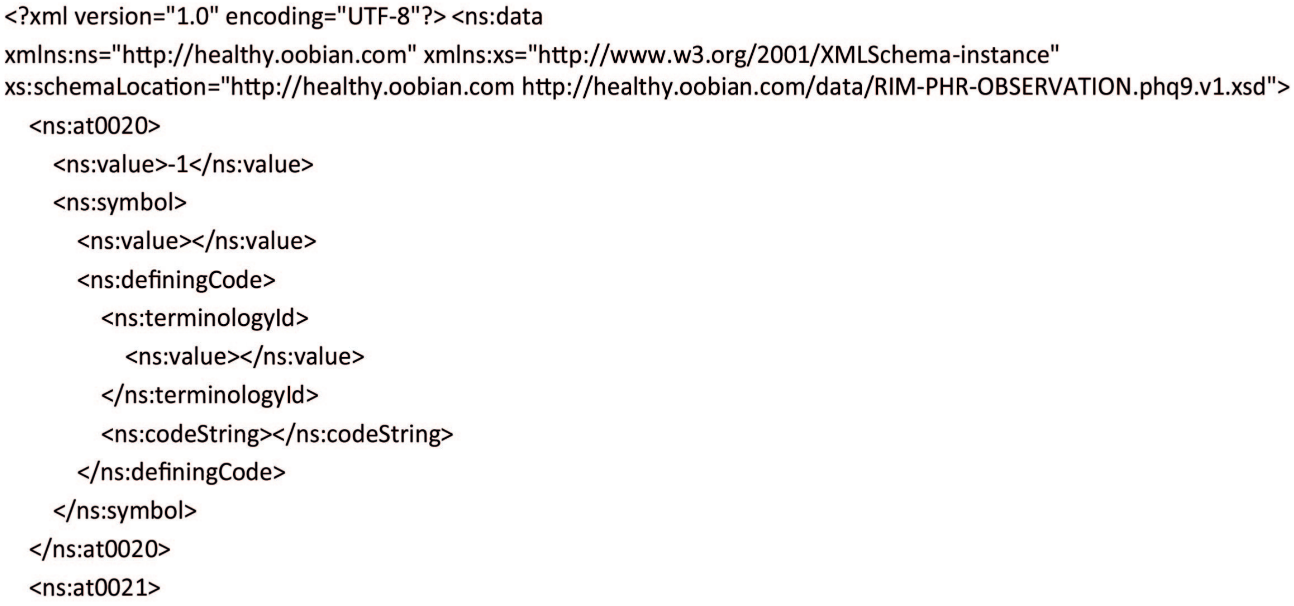


Figure 5. ADL file of the PHQ-9 archetype.

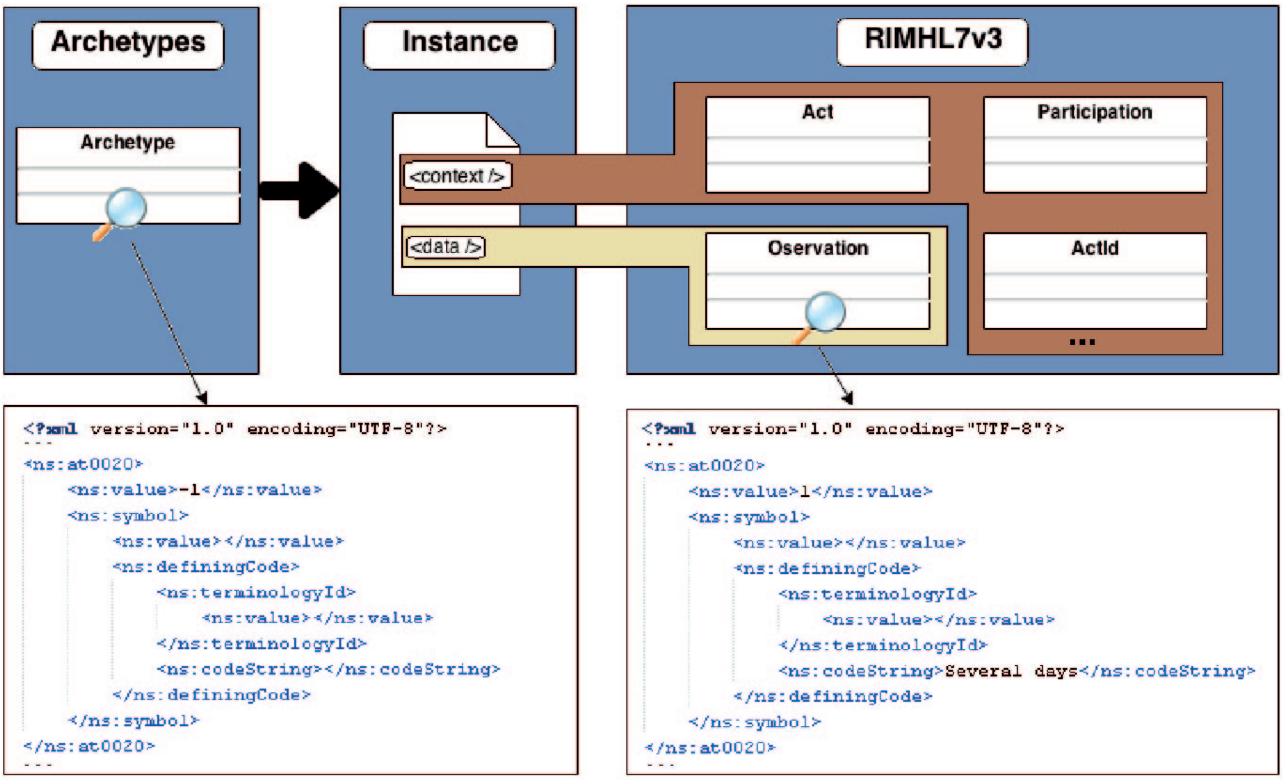
```
archetype (adl_version=1.4)
    RIM-PHR-OBSERVATION.phq9.v1
concept
       ...
language
       ...
description
       ...
definition
    OBSERVATION[at0000] matches {   -- Phq9
        data matches {
                     ...
            ELEMENT[at0020] matches {  -- question_1
                value matches {
                    0|[local::at0042],  -- not at all
                    1|[local::at0043],  -- several days
                    2|[local::at0044],  -- more than half the days
                    3|[local::at0045]   -- nearly every day
                }
            }
            ...
        >
      ...
    >
...
```

Figure 6. Part of the XML code of the PHQ-9 object.



```
<?xml version="1.0" encoding="UTF-8"?> <ns:data
xmlns:ns="http://healthy.oobian.com" xmlns:xs="http://www.w3.org/2001/XMLSchema-instance"
xs:schemaLocation="http://healthy.oobian.com http://healthy.oobian.com/data/RIM-PHR-OBSERVATION.phq9.v1.xsd">
  <ns:at0020>
    <ns:value>-1</ns:value>
    <ns:symbol>
      <ns:value></ns:value>
      <ns:definingCode>
        <ns:terminologyId>
          <ns:value></ns:value>
        </ns:terminologyId>
        <ns:codeString></ns:codeString>
      </ns:definingCode>
    </ns:symbol>
  </ns:at0020>
  <ns:at0021>
```

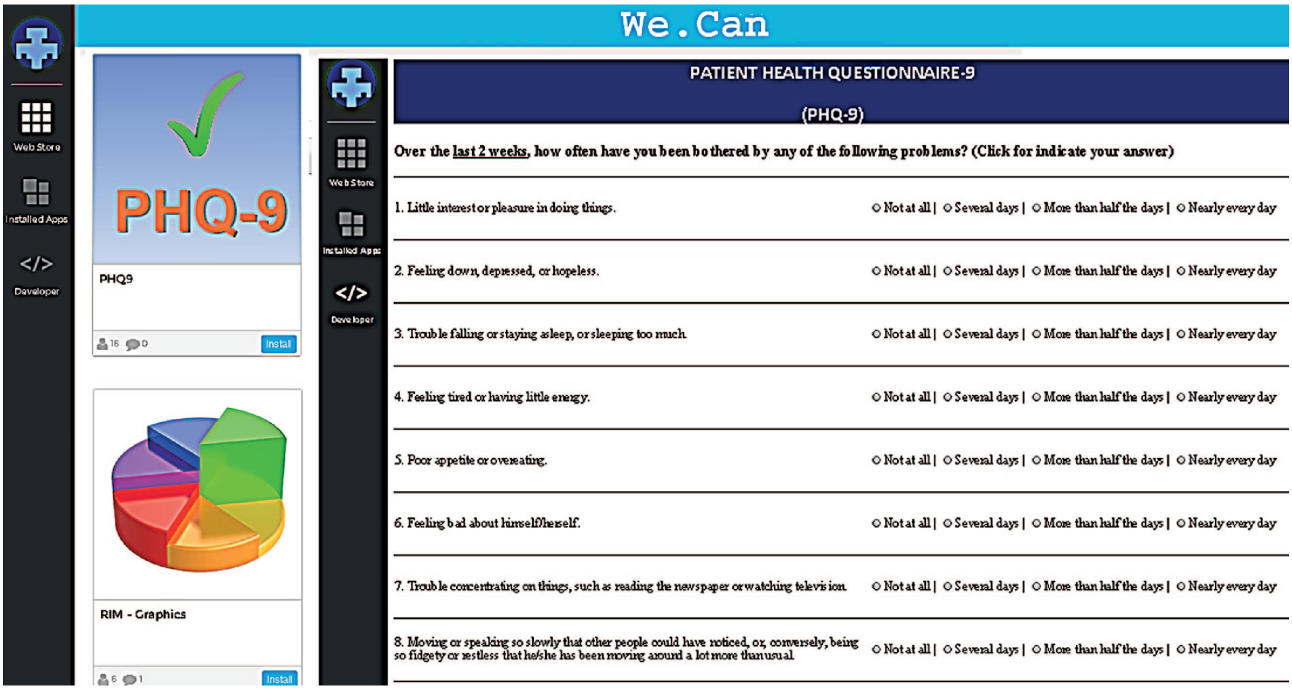
Figure 7. Mapping of a value of the PHQ-9 archetype with an observation value of the RIM structure.



```
<?xml version="1.0" encoding="UTF-8"?>
---
<ns:at0020>
    <ns:value>-1</ns:value>
    <ns:symbol>
        <ns:value></ns:value>
        <ns:definingCode>
            <ns:terminologyId>
                <ns:value></ns:value>
            </ns:terminologyId>
            <ns:codeString></ns:codeString>
        </ns:definingCode>
    </ns:symbol>
</ns:at0020>
---
```

```
<?xml version="1.0" encoding="UTF-8"?>
...
<ns:at0020>
    <ns:value>1</ns:value>
    <ns:symbol>
        <ns:value></ns:value>
        <ns:definingCode>
            <ns:terminologyId>
                <ns:value></ns:value>
            </ns:terminologyId>
            <ns:codeString>Several days</ns:codeString>
        </ns:definingCode>
    </ns:symbol>
</ns:at0020>
---
```

Figure 8. Screen capture of an application prototype to manage the PHQ-9 object.



PATIENT HEALTH QUESTIONNAIRE-9

(PHQ-9)

Over the last 2 weeks, how often have you been bothered by any of the following problems? (Click for indicate your answer)

1. Little interest or pleasure in doing things. ○ Not at all | ○ Several days | ○ More than half the days | ○ Nearly every day
2. Feeling down, depressed, or hopeless. ○ Not at all | ○ Several days | ○ More than half the days | ○ Nearly every day
3. Trouble falling or staying asleep, or sleeping too much. ○ Not at all | ○ Several days | ○ More than half the days | ○ Nearly every day
4. Feeling tired or having little energy. ○ Not at all | ○ Several days | ○ More than half the days | ○ Nearly every day
5. Poor appetite or overeating. ○ Not at all | ○ Several days | ○ More than half the days | ○ Nearly every day
6. Feeling bad about himself/herself. ○ Not at all | ○ Several days | ○ More than half the days | ○ Nearly every day
7. Trouble concentrating on things, such as reading the newspaper or watching television. ○ Not at all | ○ Several days | ○ More than half the days | ○ Nearly every day
8. Moving or speaking so slowly that other people could have noticed, or, conversely, being so fidgety or restless that he/she has been moving around a lot more than usual. ○ Not at all | ○ Several days | ○ More than half the days | ○ Nearly every day

Discussion

Principal Findings

Home care services are inevitably complex considering that the provision of care is carried out in the environment of the care receivers, which cannot be easily changed, and that it requires coordination between different actors across time, space, and organizational boundaries [42]. The analysis of work activities related to the home care services of the two SSIs involved in the pilot study shows that most of the information-sharing processes are informal, the institutions tightly control the information related to their care receivers, and the care providers have limited expectations of the information availability.

One of the major findings was the evidence of significant gaps in information availability. Most of the formal caregivers involved in home care services, as well as care receivers and relatives, lacked an overview of the complete care process. For instance, they considered it difficult to access care plans and, therefore, to analyze the interventions performed or being planned.

Despite the complexity of the home care services of the two SSIs involved in the pilot study, the methodological approach that has been followed, as well as the We.Can platform and respective information persistence services based on RIM, proved to be robust and adequate to specify, implement, and validate different types of information objects related to home care services.

Comparison to Previous Work

Most of the available eHealth solutions to support home care [19,28,32,33] do not present comprehensive approaches for integrating the information related to the care receivers in EHR systems. Frequently, dedicated database solutions are being used for persistence of this information, without considering the available standards for semantic interoperability. However, standards related to interoperability have been considered by the Old@Home project [26,27]. This project has developed tools to support home care services, specifically virtual health records to provide integrated views of information stored in different health information systems [26], and shared care plans to support nurses and social workers in home care services [27]. These shared care plans conform to the European Standard EN 13940-1 for continuity of care, and the Old@Home promoters expressed an interest in evaluating the HL7 standards as a possible alternative [27].

Therefore, this study, by using persistence services based on the RIM to guarantee internal and external semantic interoperability, can contribute to the adequacy of eHealth applications for home care services. This study also shows the application of standards related to health information interoperability beyond the strict scope of health care, allowing the persistence of not only health care information, but also information related to social assistance activities. Particularly in terms of social assistance activities, it would seem that ESRs can be foreseen as future natural extensions of EHRs and PHRs [43], which may contribute to continuous quality improvement [44].

Limitations

The results of this study, including the methodological approach, should be applied to additional domains. In fact, since the typologies of the care services can be quite different from institution to institution, the results of this study can be enhanced by the experience and knowledge gained from the participation of caregivers and care receivers from institutions offering other types of care services. In particular, integrated care services [9,45] should be considered.

There is a limitation related to the fact that the evaluation of eHealth applications provided by the We.Can platform is still at an early stage. The results presented in this paper are fundamental components for the next phase of the pilot study. This will consist of the evaluation of eHealth applications and a set of information objects to support home care services. Concerning the information objects, further research is required to integrate the broad range of monitoring devices that are available.

Future Work

The analysis of work activities and the elicitation of user needs—part of the processes related to the specification, implementation, and validation of the information objects—were also used to specify the eHealth applications of the We.Can platform for the pilot study. This specification was based on a detailed description of the different processes of the home care services, such as data collection, initial assessment, care plan definition, preparation of interventions, provision of care, or overall assessment and quality assurance. Given the heterogeneity of the SSIs, these processes are similar up to a certain level, but when details are incorporated they are inevitably different, partly due to organizational, logistical, and cultural differences. The existence of coherent models, such as the one supporting the information persistence services presented in this paper, is important to reduce the impact of these differences and to enable a common view of the processes, procedures, and concepts.

During the period of writing this paper (July 2014), the authors completed the implementation of the eHealth applications. After several working sessions to contextualize how to use these eHealth applications, formal caregivers will be asked to use them, as much as possible, to support their daily work practices. Safeguarding ethical and regulatory issues, information will be taken from volunteer care receivers, including information resulting from monitoring devices, such as the ones able to monitor physiological parameters. Observations and questionnaires will be used to evaluate the usability and perceived usefulness of the developed eHealth applications, their adherence to the needs and duties related to home care, and their capability of being used in everyday activities to manage the information related to care receivers. The evaluation is planned to take place over several months in order to assess the impact of the eHealth applications and the underlying We.Can platform on the efficiency and effectiveness of home care services.

Following this, the objective of the last phase of the pilot study will be to allow information access not only to formal caregivers, but also to care receivers and their informal caregivers. In terms of research, this will be an opportunity to further develop individualized health and social care services delivery. This includes mechanisms to integrate information provided by formal and informal caregivers, reasonable accommodation of individual choice, efficient teamwork involving formal and informal caregivers, and mechanisms to surpass the difficulties resulting from low levels of digital literacy, which is a major problem considering the target users. In parallel, the technical capabilities of the We.Can platform will be evaluated in terms of conformity, performance, and scalability.

Conclusions

This study contributes, with integrated solutions, to the persistence of care receivers' information required to support home care services. This is relevant because the research efforts related to the use of technological services to support individuals in their natural environment should not just consider new ways of collecting information. It should also consider the development of new models and tools that improve information access and interoperability in order to facilitate cooperation among formal health and social caregivers, care receivers, and their informal caregivers, both in technological and organizational terms.

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Authors' Contributions

NPR, AQ, FA, and JQ were responsible for the conception of this work. NPR and AQ were both responsible for the pilot study. NPR, FA, and JQ coordinated the conception of the We.Can platform. YLR, CC, and JMG implemented the platform services. All of the authors were involved in the preparation of the manuscript. The final manuscript was read and approved by all the authors.

Conflicts of Interest

None declared.

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Abbreviations

AAL: ambient assisted living
ADL: Archetype Definition Language
EHR: electronic health record
ESR: electronic social record
HL7: Health Level Seven
PHQ-9: 9-item Patient Health Questionnaire
PHR: personal health record
QREN: Quadro de Referência Estratégico Nacional
RIM: Reference Information Model
SSI: social solidarity institution
UML: Unified Modeling Language
XML: eXtensible Markup Language

XSD: XML Schema Definition

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Original Paper

Veteran, Primary Care Provider, and Specialist Satisfaction With Electronic Consultation

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Abstract

Background: Access to specialty care is challenging for veterans in rural locations. To address this challenge, in December 2009, the Veterans Affairs (VA) Pittsburgh Healthcare System (VAPHS) implemented an electronic consultation (e-consult) program to provide primary care providers (PCPs) and patients with enhanced specialty care access.

Objective: The aim of this quality improvement (QI) project evaluation was to: (1) assess satisfaction with the e-consult process, and (2) identify perceived facilitators and barriers to using the e-consult program.

Methods: We conducted semistructured telephone interviews with veteran patients (N=15), Community Based Outpatient Clinic (CBOC) PCPs (N=15), and VA Pittsburgh specialty physicians (N=4) who used the e-consult program between December 2009 to August 2010. Participants answered questions regarding satisfaction in eight domains and identified factors contributing to their responses.

Results: Most participants were white (patients=87%; PCPs=80%; specialists=75%) and male (patients=93%; PCPs=67%; specialists=75%). On average, patients had one e-consult (SD 0), PCPs initiated 6 e-consults (SD 6), and VAPHS specialists performed 17 e-consults (SD 11). Patients, PCPs, and specialty physicians were satisfied with e-consults median (range) of 5.0 (4-5) on 1-5 Likert-scale, 4.0 (3-5), and 3.5 (3-5) respectively. The most common reason why patients and specialists reported increased overall satisfaction with e-consults was improved communication, whereas improved timeliness of care was the most common reason for PCPs. Communication was the most reported perceived barrier and facilitator to e-consult use.

Conclusions: Veterans and VA health care providers were satisfied with the e-consult process. Our findings suggest that while the reasons for satisfaction with e-consult differ somewhat for patients and physicians, e-consult may be a useful tool to improve VA health care system access for rural patients.

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KEYWORDS

access; rural health; referral and consultation; patient satisfaction; veterans

Introduction

The Department of Veterans Affairs (VA) operates the largest integrated health care delivery system in the United States [1]. Many of the veterans served by the VA live in rural areas [2]. For example, within the VA system approximately 36% of the total enrolled veteran population and 15% of those seen for at least one service-connected disability are from rural or highly rural areas [2]. Rural areas present challenges to providing care to veterans from specialists that are almost exclusively based in a smaller number of large medical centers in urban areas [1].

One method to improve access to specialty care for rural veterans is through electronic consultations or e-consults, a telehealth modality. The VA's Office of Specialty Care Services/Office of Specialty Care Transformation launched an e-consult initiative to improve access to and delivery of specialty care that are veteran-centered, efficient, and evidence- and team-based [3]. In December 2009, the VA Pittsburgh Healthcare System (VAPHS) implemented an e-consult program designed to provide primary care providers (PCPs) access to specialists to enhance communication about short-term diagnostic and therapeutic management issues [3]. These e-consults, requested by the veteran's PCPs and completed by specialists at the affiliated VA medical center, provide an opportunity for PCPs who manage patients at remote Community Based Outpatient Clinics (CBOCs) or medical centers to obtain a consultation from a specialty care provider without requiring their patients to have a face-to-face encounter with the specialist.

PCPs in the western Pennsylvania region (associated with VA Pittsburgh) were sent a letter by the chief medical officer of the Veterans Integrated Service Network (VISN) 4 introducing a new program called "E consults" with a subset of medical (ie, cardiology, diabetes/endocrinology, renal, women's health) and surgical (ie, neurosurgery, orthopedics) specialty areas. They were informed that e-consults are specialty consultations you can receive without the patient needing to travel for a face-to-face visit with the specialist and that they offer your patients and you more convenient access to selected specialists. They were also notified that e-consults are best suited for questions about short-term diagnostic and therapeutic issues, but that they can also be used for specialist advice on what tests are needed in advance of a face-to-face specialist visit or for ongoing advice on how best to manage a chronic condition, such as a chronic kidney disease. PCPs were also provided the following e-consult information: (1) a script to use when speaking to veterans; (2) an informational brochure to give veterans; and (3) operational guidelines for e-consults developed by a group of PCPs and specialists. The operational guidelines instructed PCPs to select the "E consult" option from the Computerized Patient Record System (CPRS) consult tab and complete the template for veterans for whom the e-consult option appeared to be appropriate. For example, screenshots of the CPRS template for a cardiology e-consult are presented in Appendix A. The appropriate specialist at the VA medical center would then review the patient's VA electronic medical records in the Computerized Patient Record System (CPRS), a fully integrated electronic health record that allows a VA provider nationwide, including a referring provider and specialist, to access and view a veteran's entire medical record; all clinical information including progress notes, laboratory tests, radiology results, discharge summaries, other consultant reports, pathology results, and surgery reports are available [4]. The specialist would then "complete" the consult by providing an assessment via a progress note entered in the medical record, requesting additional diagnostic testing, scheduling a face-to-face visit with the veteran at the medical center, or other appropriate follow-up care. Veterans who alternatively requested face-to-face specialist care had their request honored.

The goals of this quality improvement project evaluation were to: (1) assess satisfaction with this e-consult program, and (2) identify perceived facilitators of and barriers to e-consult utilization.

Methods

Setting and Participants

Between August-October 2010, we conducted individual semistructured telephone interviews with veteran patients, CBOC or rural medical center PCPs, and VAPHS medical center specialty physicians who had used the e-consult process. To minimize recall bias, only veterans who participated in an e-consult during June-August 2010 were eligible to participate. We also interviewed providers who participated in one or more e-consults between December 2009 to August 2010. We attempted to contact all eligible patients (n=30) and PCPs (n=22); we stopped data collection when we reached our target sample size (n=15 patients and PCPs). Due to the limited number of eligible specialty physicians, we attempted to interview all 6 eligible specialty physicians and were unable to reach 2 during our data collection period. Our sample size was guided by the qualitative principle of "saturation," a process by which researchers collect and analyze data until no new themes are generated. It has been suggested that saturation can be reached with 12-15 participants within each group [5].

This quality improvement evaluation project was approved with a waiver of informed consent by the Institutional Review Board at the VAPHS.

Interview Content

Initially, all participants were asked to describe their e-consult experience in their own words (see Appendix B). Then, using additional open-ended questions, participants were asked to describe perceived barriers and facilitators to participating in the e-consult process. Next, respondents were asked to rate their satisfaction with e-consultation across eight domains: overall satisfaction, quality, time, access, safety, expectations, confidence, and intention to use e-consult in the future, using a 5-point Likert-type scale ranging from "completely agree" to "completely disagree". Participants first rated their satisfaction in each domain and then answered the open-ended question: "What are the important things that made you respond in this way about your satisfaction with the e-consult process?" Finally, participants were asked, "Given all of the things we have just talked about, which one thing is the most important to your satisfaction with the e-consult process?"

Data Coding and Analysis

We created descriptive summaries of the characteristics of project participants and their use of e-consults, as well as the quantitative Likert-type items regarding satisfaction with the e-consult process for each of the eight specific domains. We then identified key themes from the qualitative data for each of the eight individual satisfaction domains, as well as perceived barriers and facilitators to participating in the e-consult process.

Qualitative analysis began with codebook construction using a modified grounded theory methodology to provide rich information about veteran, PCP, and specialty physician satisfaction with the e-consult process [6,7]. The primary coder started the process by reading the transcripts from interviews with patients, PCPs, and specialists for emerging themes. The codes were recorded in a master file, which then became the basis for the final analysis. The resulting codebook was finalized and applied to all interviews by the primary coder and a co-coder per established standards in qualitative analysis [8]. During this coding process, the coders also tabulated any new or emerging themes that appeared during the course of reviewing the transcripts. This process of coding enabled the project team to maintain narrative coherence in the qualitative coding.

When there were no further changes to the coding scheme, we tested its reliability by coding all of the transcripts independently, comparing the results, and calculating an inter-rater reliability coefficient [9]. For each code, the kappa values, obtained from a statistical method of inter-rater agreement [9], ranged in value from .79 to .95. The kappa values for each code were as follows: overall satisfaction (.95), quality (.90), time (.79), access (.85), safety (.83), expectations (.83), confidence (.80), intent to use e-consult in the future (.92), most important domain (.91), barriers (.86), and facilitators (.86). We achieved a kappa value of .80 or greater, or "almost perfect" [9] on all but one code (time=.79).

Results

Participant Characteristics

Semistructured interviews were completed by 15 patients, 15 CBOC or rural medical center PCPs, and 4 VAPHS physician specialists. Veteran patients were primarily white (87%), male (93%), and had a mean age of 63 (SD 12). On average, veteran patients rated their health as fair (2+1 on 1-5 Likert-scale), and reported receiving care from the VA for a mean year of 10 (SD 10) (Table 1).

PCPs were primarily white (80%), male (67%) physicians (73%), with a mean age of 46(SD 10) who were practicing medicine for a mean year of 15 (SD 8), and 7 (SD 5) years practicing within the VA (Table 2).

Specialists were primarily white (75%), male (75%) physicians (100%), with a mean age of 55 (SD 13), and an average of 25 (SD 14) years practicing medicine and 18 (SD 16) years practicing within the VA. The four specialists interviewed were in the fields of cardiology, diabetes/endocrinology, nephrology/renal care, and orthopedics (Table 2).

Patients (Table 1) and PCPs (Table 2) were from a wide range of CBOCs or rural medical centers in the western region of Pennsylvania, with patients coming from 9 unique facilities and PCPs from 14 unique facilities.

Table 1. Patient characteristics.

Patient characteristics	Patient (N=15) n (%)
Age	
Mean (SD)	63 (12)
Gender	
Male	14 (93)
Female	1 (7)
Race	
White	13 (87)
Black/African American	2 (13)
Years receiving care at VA	
Mean (SD)	10 (10)
CBOC/Medical Center (western region)	
Cranberry Township	1 (7)
Crawford (Meadville)	4 (27)
DuBois (Clearfield County)	1 (7)
Erie	2 (13)
Mercer County (Hermitage)	1 (7)
Monongalia County	2 (13)
Tucker County (Parsons)	2 (13)
Venango County	1 (7)
Wood County (Parkersburg)	1 (7)
Self-rated general health	
Excellent (5)	0 (0)
Very good (4)	1 (7)
Good (3)	6 (40)
Fair (2)	3 (20)
Poor (1)	5 (33)
Self-rated health compared to 1 year ago	
Much better now (5)	2 (13)
Somewhat better now (4)	3 (20)
About the same (3)	8 (53)
Somewhat worse now (2)	0 (0)
Much worse now (1)	2 (13)
Marital status	
Never married	1 (7)
Married or living as married	12 (80)
Widowed	2 (13)
Education	
Less than 9th grade	1 (7)
9th-12th grade, no diploma	0 (0)
High school graduate/GED	10 (67)
Trade/vocational school	1 (7)

Patient characteristics	Patient (N=15) n (%)
Some college, no degree	0 (0)
Associate’s degree	0 (0)
Bachelor’s degree	3 (20)
Employment status	
Employed part-time	3 (20)
Not currently employed	2 (13)
Retired	10 (67)
Residence	
Own	12 (80)
Rent	1 (7)
Live with others, rent free	2 (13)
Household income	
Less than $10,000 per year	1 (7)
$10,000-$19,999 per year	6 (40)
$20,000-$34,999 per year	2 (13)
$35,000-$49,999 per year	1 (7)
$50,000 or greater per year	3 (20)
Refused	2 (13)

Table 2. Primary Care Provider (PCP) and Specialty Physician Characteristics.[a]

Characteristics	PCP (N=15) n (%)	Specialist (N=4) n (%)
Age		
Mean (SD)	46 (10)	55 (13)
Gender		
Male	10 (67)	3 (75)
Female	5 (33)	1 (25)
Race		
White	12 (80)	3 (75)
Black/African American	0 (0)	0 (0)
Asian	3 (20)	1 (25)
Years in practice (overall)		
Mean (SD)	15 (8)	25 (14)
Years in practice at VA		
Mean (SD)	7 (5.0)	18 (16)
Primary care provider type		
Physician (MD, DO)	11 (73)	–
Nurse practitioner (NP)	3 (20)	–
Physician assistant (PA)	1 (7)	–
Specialty area		
Cardiology	–	1 (25)
Diabetes/endocrinology	–	1 (25)
Nephrology/renal care	–	1 (25)
Orthopedics	–	1 (25)

[a] Note: Percentages may total over 100 as PCPs may provide Primary Care services at multiple CBOCs/Medical Centers

e-Consult Characteristics

Fourteen patients each participated in a single consult, while one patient had two separate e-consults with cardiology and diabetes/endocrinology. Patients had e-consults with diabetes/endocrinology (n=6; 40%), cardiology (n=5; 33%), nephrology/renal care, (n=4; 27%) or neurosurgery (n=1; 7%). On average, PCPs requested 6 (SD 6) e-consults, and VAPHS specialists completed 17 (SD 11) e-consults. PCPs requested e-consults for nephrology/renal care (n=11; 73%), diabetes/endocrinology (n=8; 53%), cardiology (n=7; 47%), neurosurgery (n=6; 40%), and orthopedics (n=3; 20%) (data not shown in tables).

Satisfaction With the e-Consult Program by Domain

We present descriptive summaries of the *Likert-type satisfaction items* regarding the e-consult process. We also include thematic summaries from our *qualitative* exploration of participant satisfaction with the e-consult process (Table 3). Finally, we present summaries of themes from our exploration of participant perceptions regarding *perceived barriers and facilitators* to the e-consult process. Salient themes will generally reflect the experience of multiple individuals, while views that are expressed by fewer individuals occasionally represent insightful perspectives. We provide examples of participant quotations to further elucidate their responses.

Table 3. Codes and frequencies for e-consult satisfaction domains identified during interviews with 15 patients, 15 PCPs, and 4 specialty physicians who utilized the e-consult process.[a]

Codes	# of Patients conveying theme	# of PCPs conveying theme	# of Specialists conveying theme	Total # of participants conveying theme
Overall satisfaction				
1. Communication	8	3	3	14
2. Timeliness of care	1	7	2	10
3. Quality of care	4	4	0	8
4. Travel to VA Pittsburgh Medical Center	1	5	1	7
5. Experience with e-consults	2	3	1	6
6. Access to specialist care	0	4	1	5
7. Electronic medical records system	0	2	1	3
8. Health-related outcomes	2	0	0	2
9. Option of face-to-face or e-consult	0	1	0	1
10. Preferring face-to-face visit	0	0	1	1
11. Coordination of e-consults	0	1	0	1
12. e-Consult is easy to use	0	1	0	1
13. Missing	0	1	0	1
Quality				
1. Quality of care	4	4	0	8
2. Access to specialist care	0	5	1	6
3. Timeliness of care	0	5	1	6
4. Communication	4	1	0	5
5. Travel to VA Pittsburgh Medical Center	1	2	1	4
6. Patient satisfaction with care	2	2	0	4
7. Health-related outcomes	1	1	0	2
8. Ensure recommendation implementation	0	1	1	2
9. Experience with e-consults	0	2	0	2
10. Coordination of e-consults	0	0	1	1
11. Patient compliance	0	1	0	1
12. Time required for e-consult	0	0	1	1
13. Appropriateness of case for e-consult	0	1	0	1
14. Option of face-to-face or e-consult	0	1	0	1
15. No answer	3	0	0	3
Time				
1. Time required for e-consult	4	9	4	17
2. Travel to VA Pittsburgh Medical Center	7	2	0	9
3. Timeliness of care	2	4	1	7
4. Communication	1	2	0	3
5. Electronic medical records system	0	3	0	3
6. Health-related outcomes	0	1	0	1
7. Coordination of e-consults	0	0	1	1
8. No answer	0	1	0	1
9. Missing	0	1	0	1

Codes	# of Patients conveying theme	# of PCPs conveying theme	# of Specialists conveying theme	Total # of participants conveying theme
Access				
1. Timeliness of care	0	6	2	8
2. Travel to VA Pittsburgh Medical Center	0	6	2	8
3. Access to specialist care	4	1	1	6
4. Communication	5	0	0	5
5. Clinic time available	1	0	2	3
6. Appropriateness of case for e-consult	0	1	0	1
7. Electronic medical records system	1	0	0	1
8. Add more specialists	0	1	0	1
9. Option of face-to-face or e-consult	0	1	0	1
10. No answer	6	2	0	8
Safety				
1. Appropriateness of case for e-consult	0	5	3	8
2. Quality of care	2	4	1	7
3. Experience with e-consults	4	2	1	7
4. Communication	2	3	1	6
5. Option of face-to-face or e-consult	1	2	1	4
6. Travel to VA Pittsburgh Medical Center	1	2	0	3
7. Ensure recommendation implementation	0	0	2	2
8. Access to specialist care	0	1	0	1
9. Electronic medical records system	0	1	0	1
10. No Answer	6	2	0	8
Expectations				
1. No expectations	8	2	1	11
2. Timeliness of care	3	6	2	11
3. Quality of care	1	8	0	9
4. Communication	5	1	1	7
5. Travel to VA Pittsburgh Medical Center	1	3	0	4
6. Access to specialist care	2	1	1	4
7. Improve face-to-face consults	0	0	1	1
8. e-Consult is easy to use	0	1	0	1
9. Appropriateness of case for e-consult	0	0	1	1
10. Somewhat skeptical	1	0	0	1
11. Experience with e-consults	0	2	0	2
Confidence				
1. Quality of care	7	6	1	14
2. Experience with e-consults	2	8	0	10
3. Communication	5	3	1	9
4. Appropriateness of case for e-consult	1	4	1	6
5. Timeliness of care	1	2	0	3
6. Health-related outcomes	1	0	1	2

Codes	# of Patients conveying theme	# of PCPs conveying theme	# of Specialists conveying theme	Total # of participants conveying theme
7. Travel to VA Pittsburgh Medical Center	0	0	1	1
8. No answer	0	1	0	1
Intent to use e-consult in the future				
1. Experience with e-consults	0	5	1	6
2. Quality of care	0	3	2	5
3. Availability of e-consults	4	0	0	4
4. Travel to VA Pittsburgh Medical Center	0	3	0	3
5. Communication	0	1	1	2
6. Appropriateness of case for e-consult	0	2	0	2
7. If specialist is asked by PCP	0	0	2	2
8. Timeliness of care	1	1	0	2
9. Option of face-to-face or e-consult	0	2	0	2
10. Electronic medical records system	0	0	1	1
11. Awareness of e-consults	0	1	0	1
12. If enough specialist personnel	0	0	1	1
13. No answer	10	1	0	11

[a] A given segment of conversation could include one or more codes from each category.

Overall Satisfaction

Overall, veterans and PCPs were satisfied with the e-consult program, with median (range) Likert ratings of 5.0 (4-5) and 4.0 (3-5) respectively. Specialty physicians reported slightly less overall satisfaction (3.5 [3-5]).

Qualitatively, the most common reason participants from all three groups reported for their overall satisfaction with the e-consults was improved communication (n=14), including effective information transfer, decision making processes, and a patient-centered approach to care (Table 3). Both patients (n=8) and specialists (n=3) identified communication as the domain that was most important regarding their overall satisfaction with the e-consult process. Patient ratings were often related to effective communication with PCPs or providers in general, while specialists largely focused on their effective communication with PCPs. For example, when asked why they were satisfied overall with e-consults, one patient stated, “Well, [my PCP] informed me with answers to my questions,” while a typical specialist quote regarding communication was:

> *It offers us a chance to talk to the referring physician...and then be certain we have the information that’s required to make the decision.*

For PCPs the most common reason for overall satisfaction was timeliness of care (n=7), which included general timeliness of the e-consult process, timeliness of the PCP receiving specialist recommendations, and timeliness of the implementation of specialist recommendations. For example, one PCP stated, “It was prompt, and the patient got the attention they needed in a very reasonable timeline.” Two specialists and only one patient reported timeliness as a reason for overall satisfaction.

Quality

In general, all participants (veterans, PCPs, and specialty providers) were satisfied with the quality of care provided through the e-consult program (4.0 [3-5], 4.0 [2-5], and 4.0 [3-5] respectively).

The most common reason patients and PCPs reported for their satisfaction with the quality of e-consults was the general quality of care provided (n=8) (Table 3). For example, as one patient stated, “I would get down to the bottom of my problems.” Specialists identified a number of reasons for their rating regarding quality of care, but no domain was mentioned more than once across the specialists.

Time

Overall, veterans were satisfied with time regarding e-consult (4.0 [3-5]), whereas PCPs and specialty physicians were somewhat less satisfied with time saved with e-consult (4.0 [2-5] and 3.0 [2-5] respectively).

Overall, the discussion was mostly focused on the time required for e-consults (n=17) (Table 3). PCP and specialists’ discussions focused on how e-consults do not save time for health care providers or patients, and sometimes created additional work. For PCPs, the focus was on e-consults creating more work for them:

> *The preparation…depending on the specialty, what kinds of tests have to be done.*

For specialists, discussions focused on:

> *We didn’t have any set consult time you know at my end to do this…Now there’s an extended figure and*

> *it's intended to go even bigger…I'm planning to increase my hours.*

The second most common reason why participants stated that time for e-consults was a reason they were satisfied with e-consults was based on savings on travel to VA Pittsburgh Medical Center (n=9). For example, one veteran stated:

> *Yeah, I take my pills not only at 7:30 in the morning along with a shot and at 11:30 and then at 3:30 along with a shot there, and then at 11:30, I mean at 10:30. But traveling, it throws you off…and a lot of times you even totally forget it.*

Access

In general, all participants (veterans, PCPs, and specialty providers) were satisfied with improved access to specialty care provided through e-consult (4.0 [3-5], 5.0 [3-5], and 5.0 [4-5] respectively) (data not shown in tables).

The most common reasons for patient satisfaction with access to care were communication (n=5) and access (n=4). The most common reasons for PCP and specialist reported satisfaction regarding access with e-consults was the timeliness of care (n=8, n=2 respectively) and avoiding travel to VA Pittsburgh Medical Center for patients (n=8, n=2 respectively) (Table 3). Regarding timeliness of care, one PCP noted:

> *Because of the structure and how the e-consult is set up and turn-around time being quicker, it allows us to essentially have an expert opinion in a timely fashion as opposed to a patient being delayed waiting for a traditional consult.*

Regarding travel to VA Pittsburgh Medical Center, one specialist noted:

> *We know that many patients were reluctant to come to Pittsburgh to the specialty clinic because they live two to four hours away…We're able to provide care to these patients without burdening them with the trip…to Pittsburgh.*

Specialists also mentioned that e-consults allows for increased availability of clinic time (n=2). As one specialist stated, "It frees up time for other patients to be seen."

Safety

In general, veterans (4.0 [3-5]), PCPs (4.0 [2-5]), and specialty providers (4.0 [3-5]) were satisfied with the safety of the care provided by the e-consult program (data not shown in tables).

Most patients (n=6) reported they were satisfied with the safety of e-consults based on their previous experience with e-consults. The most common reason PCPs (n=5) and specialists (n=3) reported was due to appropriateness of cases for e-consult (Table 3). One specialist noted that "If we have any reservations or the patient has any reservations, we see them [face-to face]."

Expectations

Overall, veterans (5.0 [3-5]) and PCPs (5.0 [2-5]) were satisfied with their expectations being met with e-consult, whereas specialty physicians were somewhat less satisfied (3.5 [3-5]) (data not shown in tables).

Timeliness of care was the primary expectation mentioned by PCPs (n=6) and specialists (n=2) (Table 3). For example, one specialist stated, "Primary care physicians would know [how] to identify the patients in a timely fashion and then for them to [consult us]."

Most patients did not have any expectations regarding the e-consult (n=8). For example, one patient stated, "I really didn't know what to expect."

Confidence

In general, all participants, including veterans (5.0 [2-5]), PCPs (4.0 [2-5]), and specialty providers (4.5 [3-5]), were confident about care management using e-consult (data not shown in tables).

For patients, the most common reason reported as to why they were confident with e-consults was quality of care (n=7). For example, one patient stated:

> *Everybody I've seen so far, they, they take good care of you and, and if they take a test on me, they've given me calls at home to let me know about things.*

For PCPs, they largely focused on their previous experience with e-consults (n=8). For example, one PCP stated, "Because I haven't had any problems so far." One PCP stated that it was too early in the implementation of the e-consults process to know if he or she was confident about the management of patient care using e-consults.

Specialists did not focus on any one reason in particular; they reported that they were confident with e-consults due to quality of care, communication, appropriateness of case for e-consult, health-related outcomes, and travel to VA Pittsburgh Medical Center.

Intent to Use e-Consult in the Future

The majority of patients (100%), PCPs (93%), and specialists (100%) indicated that they intended to use e-consults in the future (data not shown in tables).

For patients, the intent to use e-consults in the future focused primarily on quality of care (n=4) and timeliness of care (n=1). As one patient stated regarding e-consults and quality of care, "Well, cause it's excellent and will lead to better care."

For PCPs, their intent to use e-consults in the future was largely based on their previous experience with e-consults (n=5). For example, as one PCP stated:

> *Based on the experiences that I have had so far and the confidence that I have gotten from that, I have no qualms about trying it in the future.*

As with patients, specialists also noted that they would use e-consults in the future based on the quality of care (n=2). Specialists also discussed the importance of PCPs referring patients to them (n=2). Therefore, their intention to use e-consults was based on whether PCPs continue to request e-consults.

Perceptions Regarding Barriers and Facilitators to the e-Consult Process

Below we include brief summaries of themes from our exploration of participant perceptions regarding barriers and facilitators to the e-consult process (Table 4).

Table 4. Codes and frequencies for perceived barriers and facilitators to e-consultation utilization identified during interviews with 15 patients, 15 PCPs, and 4 specialty physicians who utilized the e-consult process.[a]

Codes	# of Patients conveying theme	# of PCPs conveying theme	# of Specialists conveying theme	Total # of participants conveying theme
Barriers				
1. Communication	2	6	2	10
2. Electronic medical records system	0	3	2	5
3. Time required for e-consults	2	0	1	3
4. Awareness of e-consults	0	2	1	3
5. Appropriateness of case for e-consult	0	2	1	3
6. Specialist credentialing	0	0	2	2
7. Healthcare provider workload credit	0	0	1	1
8. Patient confidence in e-consults	0	1	0	1
9. Coordination of e-consults	0	0	1	1
10. No answer	11	5	0	16
Facilitators				
1. Communication	8	4	4	16
2. Quality of care	3	6	0	9
3. Travel to VA Pittsburgh Medical Center	3	5	0	8
4. Timeliness of care	2	5	0	7
5. Electronic medical records system	0	1	4	5
6. Coordination of e-consults	1	0	2	3
7. Patient confidence in e-consults	2	0	0	2
8. No answer	1	3	0	4

[a] A given segment of conversation could include one or more codes from each category.

Perceived Barriers

When asked about the things that were not helpful or were barriers to their use of e-consults, most patients did not have an answer (n=11). PCPs (n=8), and specialists (n=2), on the other hand, mentioned communication between PCPs and specialists, as well as between PCPs and patients, as a barrier to e-consult utilization. An equal number of specialists mentioned communication, the electronic medical records system, and specialist credentialing as barriers to the e-consult process (n=2 for each). One PCP stated in reference to patients:

> *One of our big issues is getting a hold of any of the patients. Their phone numbers have been changed or disconnected or they screen their calls and won't answer because it comes up unknown name/unknown number.*

Other noted perceived barriers for participants included time required for e-consults (n=3), awareness of e-consults (n=3), appropriateness of case for e-consult (n=3), health care provider workload credit (n=1), patient confidence in e-consults (n=1), and coordination of e-consults (n=1).

Perceived Facilitators

When asked what were some of the facilitators or factors that were helpful regarding the e-consult program, most patients mentioned communication (n=8). As one patient stated, "I got a lot of information for myself, like things that I didn't really realize that was going on." Specialists also indicated communication (n=4) and the electronic medical record system (n=4) as facilitators of the use of e-consult. As one specialist stated in regards to the electronic medical record system, "Records are available for [inside] our system, or records from outside of the…VA." PCPs on the other hand mentioned quality of care (n=6) and travel to VA medical center (ie, saving the patient travel time and money) (n=4) as the main facilitators to the use of e-consult.

Other perceived facilitators included timeliness of care (n=7), the electronic medical records system (n=5), coordination of e-consults (n=3), and patient confidence in e-consults (n=2).

Addition of Specialty Areas: An Unanticipated Finding

One unanticipated finding was that, without prompting during the interview, 7 PCPs suggested specialty areas to add or that were not appropriate for e-consults. Specialty areas that were suggested included: endocrinology (n=5), rheumatology (n=2), nephrology/renal care (n=2), hematology (n=1), neurology (n=1), urology (n=1), and orthopedics (n=1). It is important to note that, of the aforementioned specialty areas, endocrinology, nephrology/renal care, and neurosurgery were already participating in e-consults. Three of these 7 PCPs also noted areas that they did not think e-consult was appropriate for, including neurosurgery (n=2) and cardiology (n=1). Patients and specialists did not convey such information.

Discussion

Principal Findings

This quality improvement evaluation project involved single semistructured telephone interviews conducted with veteran patients, CBOC or rural medical center PCPs, and VAPHS medical center specialty physicians who had used the e-consult process. The project was designed to assess satisfaction with the e-consult process and to identify perceived facilitators of and barriers to e-consult utilization. Our Likert-scale findings showed that, on average, veterans, CBOC and rural medical center PCPs, and VAPHS medical center specialty physicians were satisfied with the e-consult program. Patients were equally satisfied with the areas of quality, time, access, and safety. Both PCPs and VAPHS specialists were most satisfied with access and least satisfied with time. The majority of patients, PCPs, and VAPHS specialists agreed that they intend to use e-consults in the future.

The semistructured interview data revealed that the most common reason patients and specialists reported for their overall satisfaction with e-consults was communication; while timeliness of care was the most common reason for PCPs. The most commonly reported domains (as important to satisfaction with e-consults) included timeliness of care and quality of care for patients, timeliness of care and quality of care for PCPs, and communication and the electronic medical records system for specialists. Overall, communication was the most reported perceived barrier and facilitator to use of e-consults.

Limitations

Our project has several limitations. The project used convenience sampling, a nonprobability sampling technique. The sample was relatively homogeneous in terms of age, gender, race/ethnicity, and treatment site at a veterans' facility. Due to the timing of the evaluation and the qualitative nature of the project the sample size is small, with participants engaging in a small number of e-consults on which to base their feedback. Therefore, the results may not be representative of or generalizable to all veteran patients, CBOC or rural medical center PCPs, and particularly physician specialists who have completed e-consults. However, the data provide novel information about veteran, CBOC and rural medical center PCP, and VAPHS medical center specialty physician satisfaction with the e-consult process.

Comparison With Prior Work

While the *Veterans Health Administration* (VHA) has improved access to primary care by establishing CBOCs, access to specialty care continues to be lacking, with upwards of 35%of veterans experiencing issues with access that are directly related to distance and transportation needs [10-12]. Rural veterans have been shown to encounter significant barriers to receiving needed specialty services, particularly routine outpatient specialty services including but not limited to optometry, podiatry, audiology, gynecology, and physical therapy [13]. Over the years, VHA has surveyed the status of veterans and found that distance to VA facilities was one of the reasons veterans cited most frequently for not using VA services such as specialty care [13,14].

It has been argued that technology-based tools and services such as e-consultations with specialty care providers may enable more efficient organization of resources and care provision [10], greater utilization of services [10,15], and improved access to secondary care [16]. According to a recent survey of 440 health care organizations, more than 80% deliver some form of ehealth to patients [13]. Indeed, within the VA, e-consults are just one example of a number of telehealth initiatives implemented across facilities [4]. VHA rapidly adopted this approach nationally, with over half a million e-consults completed in the past few years [17]. On the other hand, e-consult penetration into the private sector and fee-for-service systems has been somewhat limited, perhaps related to billing or payment issues [17].

Similar findings have been reported in other published studies [18-24]; reported levels of patient satisfaction with telemedicine are consistently greater than 80% and frequently at 100% [23], often above the rates of expected satisfaction for traditional forms of health delivery [22]. Primary care providers and specialists have also generally reported quite positive results regarding satisfaction with telemedicine [3,4,18,22]. Overall, patient and provider satisfaction studies indicate optimism for this delivery modality [4,21,23]. Our investigation adds credence to the value of e-consults as it demonstrates that all parties, including veterans, referring PCPs, and VAPHS specialists, are satisfied with e-consults.

Conclusions

In summary, this quality improvement initiative provides critical veteran and health care provider insights regarding satisfaction with and use of the e-consult program, an innovative approach to specialty care. Our findings suggest that while the reasons for using e-consult may differ, it may be a useful and well-accepted tool to supplement face-to-face specialist visits and to improve health care to patients in rural areas. This information allows us to begin to identify strategies to improve implementation of, and participant satisfaction with the e-consult program.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Screenshots of CPRS template for a cardiology e-consult.

[PDF File (Adobe PDF File), 612KB - medinform_v3i1e5_app1.pdf]

Multimedia Appendix 2

Interview guide.

[PDF File (Adobe PDF File), 44KB - medinform_v3i1e5_app2.pdf]

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Abbreviations

CBOC: Community Based Outpatient Clinic
CPRS: Computerized Patient Record System
VA: Veterans Affairs
VAPHS: Veterans Affairs Pittsburgh Healthcare System
VHA: Veterans Health Administration
VISN: Veterans Integrated Service Network

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Original Paper

Real-Time Patient Survey Data During Routine Clinical Activities for Rapid-Cycle Quality Improvement

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Abstract

Background: Surveying patients is increasingly important for evaluating and improving health care delivery, but practical survey strategies during routine care activities have not been available.

Objective: We examined the feasibility of conducting routine patient surveys in a primary care clinic using commercially available technology (Web-based survey creation, deployment on tablet computers, cloud-based management of survey data) to expedite and enhance several steps in data collection and management for rapid quality improvement cycles.

Methods: We used a Web-based data management tool (survey creation, deployment on tablet computers, real-time data accumulation and display of survey results) to conduct four patient surveys during routine clinic sessions over a one-month period. Each survey consisted of three questions and focused on a specific patient care domain (dental care, waiting room experience, care access/continuity, Internet connectivity).

Results: Of the 727 available patients during clinic survey days, 316 patients (43.4%) attempted the survey, and 293 (40.3%) completed the survey. For the four 3-question surveys, the average time per survey was overall 40.4 seconds, with a range of 5.4 to 20.3 seconds for individual questions. Yes/No questions took less time than multiple choice questions (average 9.6 seconds versus 14.0). Average response time showed no clear pattern by order of questions or by proctor strategy, but monotonically increased with number of words in the question (<20 words, 21-30 words, >30 words)—8.0, 11.8, 16.8, seconds, respectively.

Conclusions: This technology-enabled data management system helped capture patient opinions, accelerate turnaround of survey data, with minimal impact on a busy primary care clinic. This new model of patient survey data management is feasible and sustainable in a busy office setting, supports and engages clinicians in the quality improvement process, and harmonizes with the vision of a learning health care system.

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KEYWORDS

quality improvement; patient-centered care; information management/informatics; office practice issues/practice reengineering

Introduction

Soliciting and using patients' ideas about how to improve health care delivery is an essential part of a patient-centered health care system [1-3]. Collecting patient's ideas can be as simple as a waiting room suggestion box or a focus group of active patients. The patient survey is another easy tool for obtaining input from a larger population of health care users. However, patient surveys have increased in length and complexity to the point that many institutions have outsourced the survey conduct and data management to third party vendors or governments. Disadvantages of outsourcing the patient survey include recall bias for the patient, delay in data turnaround, and inadequate number of patient responses. Most important among these disadvantages perhaps is the disengagement of clinicians and staff from the quality improvement process [4].

The Plan-Do-Study-Act (PDSA) method is a rapid-cycle quality improvement process borrowed from other industries that suits the rapid pace of the clinical setting and the need for rapid turnaround of quality data [5-7]. The ground-up strategy of the PDSA cycle requires clinicians and staff to be more involved in quality improvement, but time is at a premium in a busy clinical setting, especially for clinicians. In order to garner support from busy clinicians, rapid cycle improvements need to be more efficient and take full advantage of established and emerging technologies for data management.

This report showcases four patient surveys that we conducted in a primary care clinic over a one-month period using commercially available technology (Web-based survey creation, deployment on tablet computers, cloud-based management of survey data, and real-time Web-based accumulation and display of survey results) to expedite and enhance several steps in data collection and management for rapid improvement cycles. The four patient surveys targeted diverse yet specific areas for quality improvement and used a variety of personnel and deployment strategies. This approach of technology-enabled, rapid cycle improvement offers promise to clinics faced with limited budgets and time, and finally suggests a strategy of patient survey data management that is sustainable and accommodates the rapid pace of contemporary health care delivery.

Methods

Setting

Located in Winston-Salem, North Carolina, USA, the Downtown Health Plaza Adult Medicine Clinic is staffed by physicians and mid-level practitioners from Wake Forest University Baptist Health. The clinic typically logs more than 60,000 clinic visits each year and serves a large number of Medicaid and uninsured patients. Approximately 10% of patients are Spanish-speaking only. Four physician assistants have half-day clinic sessions every day, and 8 faculty and 40 resident physicians have clinic sessions 1-3 times a week. The EPIC electronic medical record serves as the data repository for all clinical information. Approval for this project was not initially sought from the local ethics review board as this is part of the clinic's standard and mandated quality improvement process, and no patient identifiers were collected. Still, institutional review board approval was sought, and this project has been declared exempt.

Clinic staff have long been interested in quality improvement and population-based approaches to improving clinical care. Earlier efforts at rapid data collection of patient survey data during routine clinical activities made use of pre-printed index cards with 3-4 multiple choice questions that were completed by staff and providers [8]. The availability of multiple handheld and tablet computers, and the expertise at developing applications for those devices set the stage for piloting a new patient survey strategy using the tablet computers.

Technology

CareToTell (Cupertino, CA, USA) is a commercially available Web-based suite of integrated data management tools that allows easy Web-based creation of survey forms, deployment and data collection using tablet computers, and real-time data accumulation and display on the company-hosted webpage. Sequential offerings of the survey on a single tablet computer is possible after an 8 second automatic reset, and survey deployment/conduct can occur on multiple tablets simultaneously. The data display on the website offers statistics on the average amount of time for the user to complete the entire survey and for each individual question; specific times for each respondent are only available for the entire survey, not for individual questions. Whether the survey was aborted, and which questions were skipped by the respondent is also available at the report webpage.

Survey Deployment

Over the one month period, we conducted a total of four surveys. Nurses and secretaries serving as survey proctors were trained simply by taking the survey once, and then discussing the positioning of the tablets in the clinic and protocol for offering the survey to the patient. The nurses proctored 2 of the 4 surveys, and two surveys were proctored by checkout personnel as the patient obtained their follow-up appointment before exiting the clinic. Anecdotally, patients needed help from the proctor in a minority of cases; however, patients who were clearly unable to complete the survey because of language, literacy, or disability were often not offered the survey. This judgment was made by the proctoring staff member. Family members were allowed to complete the survey for patients who were unable, and the nurse occasionally helped patients with the survey.

Survey Design

Each survey consisted of a maximum of 3 questions to minimize the burden that data collection would impose on the patient and on clinic workflow. Because of the limited number of questions and our decision to avoid patient identifiers, we chose not to solicit information on demographics or other patient characteristics that might affect patient confidentiality. We used only yes/no and multiple choice questions, and allowed survey questions to be skipped. For questions about continuity of health care, we drew from the CAHPS survey tool that is used in many health care settings to judge patient satisfaction [9]. We estimated that 1 to 2 days of data collection would be sufficient to accumulate enough responses to be credible and actionable.

Data Analysis

We estimated the denominator for possible respondents by comparing the number of responses with the number of patients who attended clinic appointments on survey days. We characterized surveys by the percentage of the surveys that were aborted or contained skipped questions, and by the amount of time spent with each survey (mean, standard deviation, range). Average times were calculated after elimination of unrealistically short survey times. We characterized the average amount of time spent on each question by question type, order of question, proctor strategy, and number of words in the question. As this was a feasibility study, we did not attempt to establish an *a priori* sample size calculations and specific hypotheses to be tested.

Results

Setting

Of the 727 patients who attended office visits when one of the four surveys was deployed, 316 patients (43.4%) attempted the survey, and 293/727 (40.3%) ultimately successfully completed one of the four surveys.

Data Analysis

Table 1 shows question formats, proctor strategy, completion rates, and the average times per survey.

For the 4 three-question surveys the average time per survey was overall 40.4 seconds, with the range of average answer times for individual questions of 5.4 to 20.3 seconds (Table 2). Yes/No questions took less time then multiple choice questions (average 9.6 seconds versus 14.0). Average response time showed no clear pattern by order of questions or by proctor strategy, but a trend was apparent for number of words in the question (>30 words - 16.8 seconds, 21-30 words - 11.8, <20 words - 8.0).

Figure 1 shows the findings of the four surveys that were presented to the clinic staff meeting for discussion, disseminated to the rest of the clinic, and policy making.

Table 1. Summary of the four patient surveys.[a]

Survey domain	Question formats	Proctor strategy	Patients completing survey, n (%)	Completions/ patients with clinic visit	Survey time, mean (SD)
Dental care	• 1 Yes/No • 2 multiple choice (4 responses)	Secretary at clinic checkout and exit	54/56 (96.4)	54/110 (49.1)	42.2 (19.4)
Waiting room experience	• 1 Yes/No • 1 multiple choice (3 responses) • 1 multiple choice (4 responses)	Nurse in exam room	74/81 (91.3)	74/193 (38.3)	43.9 (31.0)
Continuity	• 1 Yes/No • 1 multiple choice (4 responses) • 1 multiple choice (5 responses)	Secretary at clinic checkout and exit	79/86 (91.8)	79/23 (33.9)	38.7 (24.8)
Internet access	• 2 Yes/No • 1 multiple choice (4 responses)	Nurse in exam room	86/93 (92.3)	86/201 (42.8)	37.9 (21.8)

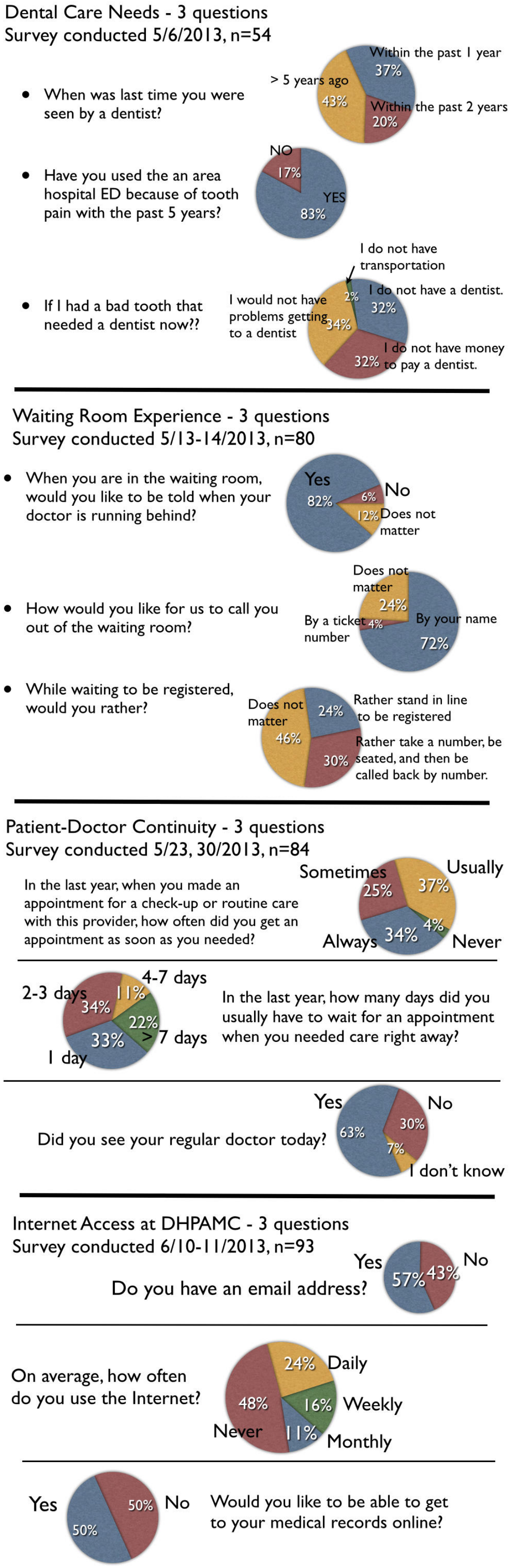
[a] surveys with no skipped answers or aborted attempts

Table 2. Average respondent time by individual question.

Survey domain	Question	Question types[a]	Word number (stem + responses)	Average question time
Dental care	1. When was last time you were seen by a dentist?	MC4	10+15= 25	12.2
	2. Have you used the Emergency Room at area hospitals because of tooth pain with the past five years?	Y/N	20+2= 22	8.6
	3. If I had a bad tooth that needed a dentist now	MC4	11+29=40	19.5
Waiting room	1. When you are in the waiting room, would you like to be told when your doctor is running behind?	Y/N	19+5=24	16.2
	2. How would you like for us to call you out of the waiting room?	MC4	14+10=24	10.2
	3. While waiting to be registered?	MC3	5+26=31	14.8
Continuity	1. In the last year, when you made an appointment for a check-up or routine care with this provider, how often did you get an appointment as soon as you needed?	MC4	30+4=34	20.3
	2. In the last year, how many days did you usually have to wait for an appointment when you needed care right away?	MC5	22+14=36	12.5
	3. Did you see your regular doctor today?	Y/N	7+5=12	5.4
Internet access	1. Do you have an email address?	Y/N	6+2=8	9.5
	2. On average, how often do you use the Internet?	MC4	9+4=13	8.7
	3. Would you like to be able to get to your medical records online?	Y/N	13+2=15	8.5

[a] MC=multiple choice; Y/N=yes/no

Figure 1. Survey findings from four patient surveys.



Discussion

Implementation Strategy and Impact

Our four patient surveys, conducted weekly over a one-month period, with different question types and deployment strategies, provided responses to important quality questions quickly enough to make the findings relevant and actionable. In the case of the dental care project, our findings were instrumental in justifying establishment of a community wide dental clinic for patients with poor dental access. With regard to the survey on waiting room experience, the findings led to revision of our current waiting room policies. The third survey on continuity between primary care physician and patient provoked important discussions about policies related to patient access and continuity, and also established a baseline for subsequent serial measurements that are increasingly required by accrediting organizations [10-12]. The last of the four surveys on Internet access repeated questions from our previous paper-based survey of Internet access [13], and addressed the increasingly important issue of patient willingness and ability to access online medical records. With all four surveys, the time from identification of the quality challenge and conception of survey questions to the time that results were disseminated to clinicians and administrators was less than one week, a time frame that encouraged rapid cycles of change in policy and health service delivery.

Underpinning our success with the four surveys was the overall response time per three-question survey of approximately 40 seconds. This rapid survey completion and turnaround time of the survey devices allowed the clinic to approach more patients in a busy clinic and yield a high response rate of 43%, a rate that rivals more sophisticated survey strategies [14-16]. The growing familiarity of patients/consumers with tablet computers along with supporting software should make this a preferred strategy for data demands in time pressed clinical settings [17].

Limitations

Several caveats with this innovative approach to patient survey data and quality management deserve mention. The first concern of generalizability has several dimensions. First, not every patient could complete the survey. Low literacy is well known in our clinic, an issue we have documented many times [13]. Surveys were not attempted in Spanish, despite the ability of the software to provide translations. Furthermore, staff who were proctoring the survey process used judgment in offering the surveys to Spanish-speaking patients or patients with communication or cognitive disorders. Still, we were able to accumulate a sizable number of responses without fatiguing clinical staff and patients with ongoing surveys that can be disruptive to clinic flow. Our response rate of approximately 43% is a dramatic difference from the meager monthly offering of a handful of respondents who are often misattributed to our clinic by the third party patient surveyor. Even with our efforts to estimate a denominator for generalizability within our clinic, we instead depended on the large number of actually collected surveys to counter concerns of statistical significance and sample size. A comparison of survey respondents with nonrespondents might have been useful but would have hampered the survey administration and made the survey process less practical in a busy clinic. Generalizability beyond our clinic setting is a reasonable question. This clinic has long used tablet computers routinely in patient care activities for years, our wireless system is near flawless, and our faculty and staff have active interest in computer-assisted patient education and quality improvement.

A second caution relates to technical aspects of the software. The software performed well with regard to survey creation and deployment on the tablet computers, cloud capture of responses, and accumulation/display of data. Despite a usability and execution that was surprisingly good for a relatively new software product, the current version of the software does not allow the use of the graphics or video, which could enhance the accuracy and acceptability to low literacy patients. For analytics, the current version does not report user-specific, question-specific user times, a feature that impeded our ability to examine individual user question-specific interactions. However, this may be less important to clinics that simply want a tool to facilitate data gathering and reporting.

Easier Data Collection and Management

The novelty presented here is not in the commitment of a community health care center aggressively pursuing quality improvement with rapid cycle projects. This rapid pace of practice improvement is evident in many health care settings where much time, energy, and manpower is being devoted to quality improvement, to the point of displacing regular clinical duties and wearying clinicians with change fatigue [18,19]. Rather, the novelty is the ease of the survey launch, the rapid data turnaround, and the time savings that more simple and practice-friendly data management brings to clinicians and administrators on the front line.

Making clinic operations patient-centered is a routinely stated goal of a modern health care delivery system and is important in settings as diverse as primary care and surgical theaters [12,20,21]. Data collection is a fundamental step in soliciting the patient’s opinion about how to improve health care delivery. If obtrusive, expensive, unrealistic, or inaccurate, the process of data collection can undermine enthusiasm for assessing and improving practice quality. Patients are already fatigued of requests for satisfaction surveys in health care and in daily life. Data collection must be quick, focused and part of routine care in order to encourage participation from patients and clinicians, and to be sustainable in a busy practice. Likewise, data entry and analysis are steps that can slow turnaround of quality improvement projects [17,22]. The commercially available technology suite (tablet computer, wireless environment, up-to-the-second, Web-based analytics) we used to conduct these four patient surveys is a major improvement over scannable paper survey forms, dedicated desktop computers for capturing patient survey data, and bulky, expensive waiting room kiosks from just a decade ago [16,23-25].

A Learning Clinic

In order for clinicians to participate fully in quality improvement activities, practical, real-time strategies for reliable and more efficient data capture and management are needed [1]. Having good technology is only part of the answer. A strategy that focuses on specific patient care issues and timeliness of data collection enhances the accuracy of data capture [16]. Standardized, and well-tested questions are available for examining specific patient care domains [9]. Leadership and teamwork are still necessary in championing a new strategy that promotes the value of the quality improvement and data collection process, and creates an environment where rapid-cycle quality improvement becomes routine.

Improvements in technology and redesign of patient survey strategy make the goal of the learning health care system (or clinic) realizable [7]. Whether or not patient opinions have a legitimate role in quality assessment of a practice or health system is still being debated [26,27]. However, having a system of collecting patient opinions and ideas about improving health care delivery shows patients the interest and abilities of the practice clinicians in improving health care delivery, and facilitates engagement of clinicians in designing the quality improvement process. Regular patient surveys, now becoming routine in our practice, point to a sustainability that was simply not possible before the availability of this technology. Especially with mandates from accreditation agencies that clinical practices routinely monitor patient satisfaction in specific care domains, repeat questions from sequential surveys to track improvement is finally realistic [28].

Conclusions

In a busy urban primary care clinic, the use of tablet computers and integrated data management software accelerated the usually burdensome task of surveying patients for quality improvement, and accomplished it during routine clinical activities. This practical implementation of technology-enabled, rapid-cycle quality improvement demonstrated a rapid turnaround time in the surveying process and in project completion, and showed a high response rate compared with other survey methodologies. Rapid-cycle quality improvement requires such a nimble data collection and management strategy in order to make the busy clinical setting a “learning” health care system.

Conflicts of Interest

No author (James L Wofford, Claudia R Campos, Sheila R Stevens, nor Robert E Jones) has a financial link or associated benefit with the software company being used including financial interests, activities, relationships, and affiliations.

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Original Paper

Effects of Individual Health Topic Familiarity on Activity Patterns During Health Information Searches

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Abstract

Background: Non-medical professionals (consumers) are increasingly using the Internet to support their health information needs. However, the cognitive effort required to perform health information searches is affected by the consumer's familiarity with health topics. Consumers may have different levels of familiarity with individual health topics. This variation in familiarity may cause misunderstandings because the information presented by search engines may not be understood correctly by the consumers.

Objective: As a first step toward the improvement of the health information search process, we aimed to examine the effects of health topic familiarity on health information search behaviors by identifying the common search activity patterns exhibited by groups of consumers with different levels of familiarity.

Methods: Each participant completed a health terminology familiarity questionnaire and health information search tasks. The responses to the familiarity questionnaire were used to grade the familiarity of participants with predefined health topics. The search task data were transcribed into a sequence of search activities using a coding scheme. A computational model was constructed from the sequence data using a Markov chain model to identify the common search patterns in each familiarity group.

Results: Forty participants were classified into L1 (not familiar), L2 (somewhat familiar), and L3 (familiar) groups based on their questionnaire responses. They had different levels of familiarity with four health topics. The video data obtained from all of the participants were transcribed into 4595 search activities (mean 28.7, SD 23.27 per session). The most frequent search activities and transitions in all the familiarity groups were related to evaluations of the relevancy of selected web pages in the retrieval results. However, the next most frequent transitions differed in each group and a chi-squared test confirmed this finding ($P<.001$). Next, according to the results of a perplexity evaluation, the health information search patterns were best represented as a 5-gram sequence pattern. The most common patterns in group L1 were frequent query modifications, with relatively low search efficiency, and accessing and evaluating selected results from a health website. Group L2 performed frequent query modifications, but with better search efficiency, and accessed and evaluated selected results from a health website. Finally, the members of group L3 successfully discovered relevant results from the first query submission, performed verification by accessing several health websites after they discovered relevant results, and directly accessed consumer health information websites.

Conclusions: Familiarity with health topics affects health information search behaviors. Our analysis of state transitions in search activities detected unique behaviors and common search activity patterns in each familiarity group during health information searches.

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KEYWORDS

health information search; health search activity pattern; health topic familiarity; sequence of search activities

Introduction

The emergence of the e-patient has encouraged non-medical professionals (consumers) to be more proactive regarding health care education and health decision making. More consumers are using the Internet to support health information needs [1-5]. A number of support systems have been developed to provide access to consumer-friendly health information. However, searching for understandable health information on the Internet is difficult for most consumers because they are not familiar with the standard health and medical terminology used in health care publications [6-9]. Thus, difficulties arise when formulating queries and when trying to understand documents. Researchers and health care providers are working on consumer-based initiatives to resolve the communication gap problem. In particular, Soergel et al [9] proposed an "interpretive layer" design to assist consumers when formulating effective queries, finding and interpreting relevant health information, and applying the information in an appropriate manner. This interpretive layer design concept has been implemented in several consumer health systems, such as Health Information Query Assistant (HIQuA) system [10], MedSearch [11], MedicoPort [12], and Interactive Online Health Information Systems [13].

To further reduce the communication gap between consumers and health care professionals/health materials, several researchers have studied the familiarity and recognition rate of health terminologies among consumers [6,7]. For example, Zeng et al developed the Consumer Health Vocabularies (CHV) initiative project, which links the vocabulary of consumers to the terminology used by health care professionals and in health care materials [6]. By building on the CHV project, several studies have proposed predictive models for measuring the average familiarity of various consumer health vocabularies based on term occurrence in text corpora [14], demographics factors [15], and contextual features [16,17]. In attempts to provide more consumer-friendly health materials, other researchers have developed automated tools for assessing the readability of health texts by substituting difficult terms with easier synonyms and simplifying long sentences [18] or by comparing the terms appeared in a document and terms known by the user [19]. Another study to improve the availability of consumer-friendly information is the consumer health educational project by European Patients' Academy on Therapeutic Innovation (EUPATI) [20].

Previous studies in the information search area have demonstrated the impact of topic familiarity on search behaviors [21-25]. Seekers who have greater familiarity with the search topic use more varied and specific vocabulary [21], perform specific search strategies [21,22], and have better search efficacy [23]. One approach for examining search behaviors is to analyze the search activities performed by seekers [22,23]. Several studies have addressed the activities involved in search tactics [26] and search strategies [27,28]. To obtain a more comprehensive understanding, researchers have also studied the transitions among states during search activities [29-31] and analyzed the sequence of search activity transitions using state transition network [23] and Markov chains [30,32,33].

Most studies of health information search by consumers have focused on improving the health search experience of consumers by providing intelligent assistance and utilizing more consumer-friendly terminology. Several studies have also examined the perceived familiarity of health terminology among groups of consumers [14-17]. However, there is a lack of research on *individual* health topic familiarity and how this familiarity influences health information search behaviors in *specific* consumers. These research topics are important because every consumer has different health topic familiarities. For example, a consumer may be well informed about "skin allergy" but uninformed about "cardiovascular disease", whereas another consumer may have the opposite health topic familiarities. The term "gastroesophageal reflux disease" may be well understood by some consumers, but completely unfamiliar to other consumers. This diversity may lead to misunderstandings because the information presented during health information searches may not suit the consumer's level of familiarity.

Given the challenges of health search, a personalization approach based on the consumer's familiarity is required to improve the search process. We consider that the familiarity has a larger impact on the search process (eg, the chosen search strategy/tactics, the performed search activity pattern) than on the search outcome (ie, the final information found). Searchers can find the correct information from many sources on the Internet that fits their needs. However, the process of finding the correct information is different among the searchers because it reflects their understanding about the health topic. It is expected that the unfamiliar searchers who had never heard of the search topic before would take a longer route and time to find the correct information and would face difficulty in the search process. These searchers need to build their understanding with the search topic first before they can locate relevant information. On the other hand, the familiar searchers would use advanced strategies and take a shorter route to find the correct information.

Thus, the purpose of this paper is to examine the effects of health topic familiarity on health information search behaviors by identifying the common search activity patterns exhibited by different groups of consumers with different levels of familiarity, which ranged from unfamiliar to familiar. The outcomes of this study will contribute to the improvement of the health information search process by providing suitable support for each searcher and by facilitating the development of a more advanced personalized health information search system.

Methods

Participants

In this study, the participants were observed in an experimental setting. A controllable environment and standardized health information search tasks are required to examine the effects of different parameters on the behaviors of participants. A convenience sample of 40 participants was recruited from several departments of a university in this study (Table 1). The participants were undergraduate students, exchange students, graduate students, and researchers from the Engineering, Material Physics, Applied Physics, Biotechnology, Information and Physical Sciences, and Computer Science departments. The criteria required for the recruitment of participants were non-medical professionals, the ability to read and write in English, and age ≥18 years. All participants had experience in health information searches on the Internet before the study was conducted.

Table 1. Demographic profiles of the participants.

Demographic profile	Categories	n	%
Gender			
	Male	24	60
	Female	16	40
Age			
	18–25 years	28	70
	26–35 years	12	30
	36–45 years	0	0
	> 45 years	0	0
Native language			
	English	15	38
	Non-English	25	62
Education			
	High school	0	0
	Bachelor’s degree	22	55
	Graduate degree	18	45
Health information seeking experience			
	Frequently on daily / weekly basis	8	20
	Occasionally on monthly basis	7	17
	Yearly or less than five times ever	5	12
	As the need arises	20	50
	Never	0	0

Instruments

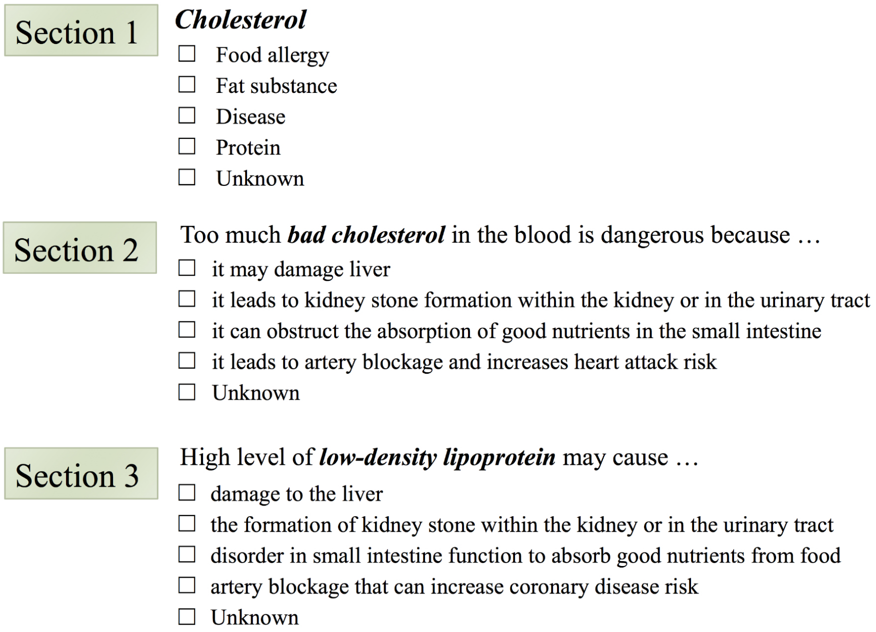
Overview

The instruments used for data collection comprised a health terminology familiarity questionnaire and a health information search task. The terminology questionnaire facilitated the rapid estimation of the familiarity of participants with predefined health topics, and the search task aimed to determine their search behaviors. Both instruments considered similar health topics, that is, skin allergy and its main treatments, cardiovascular disease, a common medical test (urinalysis), and cholesterol problems. The health topics selected for this study were based on the common health topics discussed on Yahoo Health [34] to ensure that the experiment reflected real-life health information searches. The answers for the entire health questions in this search task can be found in general consumer health informatics websites, health community/medical association websites, and medical journals listed in PubMed. We expected that the participants would be able to answer the questions easily. The participants can choose the correct answer from any sources according to their preference (familiarity).

Health Terminology Familiarity Questionnaire

The terminology questionnaire was modeled on the basis of the Familiarity of Sample Terms Questionnaire [14], the CHV Health Vocabulary Questionnaire [15], and the Test of Functional Health Literacy in Adults (TOFHLA) [35]. The questionnaire comprised three sections, each of which addressed the same four health topics. There were eight questions in each section. The questions with the same number in each section were equivalent (see Figure 1). The entire questionnaire is available in Multimedia Appendix 1. Section 1 estimated recognition at the surface level, while Sections 2 and 3 estimated the conceptual understandings of consumer-friendly terminology and the conceptual understandings of advanced health terminology, respectively. Each correct answer in the questionnaire was awarded 0.15 points for Section 1 and 0.175 points for Sections 2 and 3. The familiarity label was assigned to each health topic for each participant based on the total points awarded for the health topic (six questions). The labeling method employed in this study modified and extended previously described familiarity types [15], as follows: (1) Label L1 (unfamiliar) was assigned to a participant with total points ≤0.3 and label estimated that a participant had never heard of the terminology before or recognized it only at the surface level, (2) Label L2 (somewhat familiar) was assigned to a participant with total points >0.3 and ≤0.65, and estimated that a participant had some familiarity to associate the consumer-friendly health terminology with the basic phrase defining the terminology, and (3) Label L3 (familiar) was assigned to a participant with totals points >0.65 and estimated that a participant had good familiarity to associate the consumer-friendly terminology and its corresponding advanced terminology with the basic phrase defining the terminology.

Figure 1. Examples of the questions included in the health terminology familiarity questionnaire.



Section 1

Cholesterol

☐ Food allergy
☐ Fat substance
☐ Disease
☐ Protein
☐ Unknown

Section 2

Too much ***bad cholesterol*** in the blood is dangerous because …

☐ it may damage liver
☐ it leads to kidney stone formation within the kidney or in the urinary tract
☐ it can obstruct the absorption of good nutrients in the small intestine
☐ it leads to artery blockage and increases heart attack risk
☐ Unknown

Section 3

High level of ***low-density lipoprotein*** may cause …

☐ damage to the liver
☐ the formation of kidney stone within the kidney or in the urinary tract
☐ disorder in small intestine function to absorb good nutrients from food
☐ artery blockage that can increase coronary disease risk
☐ Unknown

Health Information Search Tasks

In this study, the health information search task comprised four separate tasks, each of which simulated one of the predefined health topics found in the questionnaire. A short scenario was added to each task to provide context (see Table 2).

Table 2. Health search tasks.

Task ID	Task description
Task 1	During the past six days, your skin has been very itchy and dry, particularly on your arm, wrist, and leg areas. You also noticed the appearance of rashes and redness on your itchy skin. You want to find out what might happen to your skin and how to treat it.
Task 2	In a first aid training course, your instructor emphasizes that lay people need to understand sudden cardiac arrest (SCA). SCA is often equated incorrectly with a heart attack, but SCA victims can survive if they receive treatment within 3-5 min after they collapse. You want to know (1) the difference between a heart attack and an SCA, and (2) how a lay person can help a victim when a suspected SCA incident happens in a public area.
Task 3	Every year your institution holds a mandatory general medical check-up. One of the medical tests is urinalysis. You usually receive the results about 3 weeks after the test. You want to know the purpose of each parameter (why each parameter is tested) in the sample below and the meaning of the results (normal or abnormal). Specific gravity: 1.030 (reference interval: 1.002-1.030) pH: 4.9 (reference interval: 4.6-7.5) Protein: Negative (reference interval: negative) Glucose: 100 mg/dL (reference interval: negative)
Task 4	Your doctor prescribed simvastatin and instructed you not to consume the medicine with grapefruit juice. You want to know the purpose of simvastatin and why it should not be consumed with grapefruit juice.

Data Collection Procedure

The data were collected in a private laboratory. On arrival, the participant was welcomed and given a brief introduction to the purpose of this study, instructions on how to complete the questionnaire, and the procedure of the search tasks. The participants were also asked to review a consent form. Each participant performed the data collection process in the following order.

1. Demographic profile survey: The participant provided demographic information and details of their experiences with health information search on the Internet.

2. Health terminology familiarity questionnaire: The participant completed the questionnaire from Sections 1 to 3 in chronological order. If the participant had never heard of the term used in the question, the participant was requested not to guess the answer and instead they were asked to select the option “Unknown”.
3. Health information search task session: The participant was asked to complete the search tasks one by one. The participant was free to use any search engines or health information retrieval systems, to access any relevant websites, and to search at their own speed. Videos of all the search sessions were recorded using Camstudio screen and audio recording software [36].

After completing each task, the participant provided comments about the search topic and the search session.

Data Analysis

Overview

The data collected from the participants comprised demographic data, responses to the familiarity questionnaire, and video recordings of the health information search sessions. Each participant produced four data instances, that is, one for each health topic. The demographic data were used to capture the general characteristics of the participants. The responses to the familiarity questionnaire were used to label the familiarity of participants with the predefined health topics. The participants were categorized into three familiarity groups (L1, L2, and L3). The search outcome (participant’s answer) from health information search task session was measured as relevant (correct) or not relevant to the question. Because this paper focused on the search process, we analyzed further only the search session from the Health Search Task that contained the finding of the relevant answer. Subsequently, the qualified video data were transcribed and analyzed.

Modeling Search Activities

This study used a search activity as the unit of analysis. A search activity comprised an action, which included an operational move and a conceptual strategy that the participants used to achieve their goal during the health information search process. A coding scheme was developed to transcribe the video data into a sequence of search activities. The overall coding scheme comprised 18 types of search activity, which were employed in the querying, evaluating, accessing, using, and discarding stages (see Table 3). Five types were modified from the study reported by Xie and Joo [30]: “Examining the retrieval result (E:ExamSR)”, “Evaluating the selected item (webpage) (E:EvalI)”, “Exploring link forward (A:XplorF)”, “Accessing link backward (A:AccB)”, and “Using the information (Use)”.

Table 3. Coding scheme for search activities.

Stage	Search activity code	Description
Querying		
	Q:AccSE	Access a general search engine/information retrieval system as the starting point during a health information search session.
	Q:AccHW	Access a consumer health informatics website as the starting point during a health information search session.
	Q:NewQ	Issue a new query, which is usually the first query in the search session.
	Q:ModQ	Reformulate the previous query to obtain more general/specific retrieval results.
Accessing		
	A:SelHI	Select and access a retrieved item from a health/medical website.
	A:SelGI	Select and access a retrieved item from a general/non-health-specific website.
	A:XplorF	In the retrieved item selected, access a link to another webpage that has not been visited before.
	A:AccB	Access a previously visited webpage using the browser's back button, by following hyperlinks, or by tracking the history.
Evaluating		
	E:ExamSR	Examine the results retrieved to identify items (webpages) that contain potentially relevant health information.
	E:DisSR	Discard the results retrieved with or without examining their relevance.
	E:EvalI	Evaluate the selected item from the retrieved results or visit a webpage to determine its relevance.
	E:FindQ	Search for a specific keyword on a visited webpage.
Using		
	U:UseHI	Assess the visited health/medical webpage as a relevant source and use the information it contains to answer the questions in the search task.
	U:UseGI	Assess the visited general/non–health-specific webpage as a relevant source and use the information it contains to answer the questions in the search task.
Discarding		
	D:DisHI	Assess the visited health/medical webpage as an irrelevant source.
	D:DisGI	Assess the visited general/non-health-specific webpage as an irrelevant source.
	D:UnchkHI	Discard the selected health/medical webpage without visiting and evaluating its relevance.
	D:UnchkGI	Discard the selected general/non–health-specific webpage without visiting and evaluating its relevance.

To begin the health information search session, a participant accessed a general search engine (Q:AccSE) or visited a known consumer health website (Q:AccHW). Their familiarity with health topics may have influenced the starting points they selected. Next, the coding scheme included submitting a new query (Q:NewQ) and reformulating a query (Q:ModQ) because the query keywords and the type of query (new or modify) may have reflected the searcher's information base, such as background knowledge and their familiarity with the search topic. During the evaluation stage, the participants exhibited different behaviors in terms of examining the search results (E:ExamSR) and evaluating an individual item (E:EvalI); thus both evaluation types were included in the coding scheme. When examining the search result, the searchers could not select a specific item/document from the results retrieved (E:DisSR). The evaluation stage also involved finding the query keyword (E:FindQ) because it may have indicated an advanced evaluation strategy or difficulty understanding the content. In the accessing stage, selecting an item from the results retrieved was included because it reflected the searcher's ability to locate a potentially relevant source. The item selection was divided into two codes: selecting a result from a health/medical specific website (A:SelHI) and selecting a result from a general website (A:SelGI), considering that the familiarity with the search topic may influence the domain type selected. The next codes, that is, exploring forward (A:XplorF) and accessing backward (A:AccB), were treated as different codes because the direction of accessing has different meanings in the search process [30]. The next stages, that is, using and discarding, were included to study the participant's behavior when assessing the webpages they visited, and to determine the efficiency and the success/failure rate of the overall search process.

After processing all qualified video data, each search session was encoded as a sequence of search activities. For example, a search session from a participant in a health search task exhibited nine search activities, as follows: the participant started the search session by accessing a general search engine, submitting the first query, and examining the results retrieved (Q:AccSE–Q:NewQ–E:ExamSR); the participant selected an item from a health website and an item from a non-health-specific website (A:SelHI–A:SelGI); the participant evaluated the first item selected and assessed whether it was a relevant source (E:EvalI–U:UseHI); and next, the participant evaluated the second item selected and assessed whether it was relevant (E:EvalI–D:DisGI).

Descriptive statistics were obtained to further examine the search activities performed by the participants in all of the familiarity groups.

Calculating the Transition Frequency Between Search Activity Types

To examine how the participants progressed during their search process, the next step involved calculating the transition frequencies and the probabilities between the states of all possible search activity types. Given a collection of mutually exclusive states (such as the search activity types in this study), the first-order transition probability in a Markov model gives the probability of moving from one state to another [32]. In this study, the transition probabilities were calculated on the basis of a first order Markov model.

After calculating the transition frequency and probability for each familiarity group, the chi-square test was performed at a significance level of alpha=.01 to verify the differences in the search activity transitions between familiarity groups. The null hypothesis was that there was no difference in the first order state transition probability matrices between familiarity groups. The test followed the procedure reported by Chen and Cooper [32], as follows:

1. Let A and B be the two samples that need to be compared. A transition frequency matrix for sample A is defined as *f_ij^A (i,j=1, 2, …, K)*, where *f_ij^A* is the number of transitions from state *i* to state *j*, and *K* is the number of states in the state space.
2. If sample B is similar to sample A, then *f_ij^B* should be close to the expected number of transitions from state *i* to state *j* in B, as shown in Equation (1) of Figure 2.
3. In this case, the value *C* obtained from Equation (2) of Figure 2 will approximate a chi-square distribution with degrees of freedom: $K^2 - N_1 - N_2$, where N_1 is the number of actual states in B and N_2 is the number of impossible transitions in B. The null hypothesis that there is no difference between transition probability matrices A and B is accepted if C is less than the critical value of C_a^(K^2-N_1-N_2) at a significance level of alpha=.01.

Figure 2. Equation (1) calculates the expected number of transitions from state i to state j in sample B. Equation (2) calculates the chi square score.

$$E\left(f_{ij}^{B}\right) = \sum_{l=1}^{K} f_{il}^{B} * \frac{f_{ij}^{A}}{\sum_{l=1}^{K} f_{il}^{A}} \qquad (1)$$

$$C = \sum_{i=1}^{K}\sum_{j=1}^{K} \frac{\left[f_{ij}^{B} - E\left(f_{ij}^{B}\right)\right]^2}{E\left(f_{ij}^{B}\right)} \qquad (2)$$

Identifying Search Activity Patterns

To better understand and characterize the search behaviors of different familiarity groups, the next step in the data analysis process was to discover common search activity patterns using the following method:

1. Building an n-gram language model of the sequence of search activities performed by participants based on the dataset. An n-gram model is a probabilistic language model, which is used to predict the next word from a sequence of word [37]. When estimating an n-gram model, it is normally assumed that the sequence histories of words depend only on the local prior context (Markov model assumption) because of the large number of parameters involved [33]. To build an n-gram language model, we utilized the SRI Language Modeling toolkit [38] and four datasets (L1, L2, L3, and the data for all participants) with the Witten-Bell discounting strategy [39]. Each dataset was divided into 80% training data and 20% test data. The n-gram language models were built using the training data with various sequences: 2-grams to 7-grams.
2. Evaluating the perplexity of the computed language models to specify the number of search activities in a sequence that best represented the search activity pattern. The perplexity of a language model represents the geometric average branching factor of the language according to the model and is used widely to measure the quality of a model (lower perplexity tend to have lower word-error rates) [40]. The perplexity $PP(p_M)$ of a language model p_M (next word w|history h) on a test set $T=\{w_1, \ldots, w_t\}$ is computed using the equation in Figure 3. This metric was used because the computed language models contained similar vocabularies (ie, the search activity types). The number of search activities in a sequence was represented by the n-gram sequence with the lowest perplexity.
3. Applying the selected n-gram model to the sequence of search activities in the datasets to identify common search activity patterns.

Figure 3. Perplexity equation.

$$PP_T(p_M) = \frac{1}{\left(\prod_{i=1}^{t} p_M(w_i|w_1 \ldots w_{i-1})\right)^{\frac{1}{t}}} \qquad (3)$$

Results

Health Topic Familiarity of the Participants

Table 4 shows the result of familiarity labeling for each health topic based on the responses to the familiarity questionnaire. According to this result, each participant in this study could have different familiarity labels for different health topics. For example, a participant could be highly familiar with topics 2 and 4, but unfamiliar with topics 1 and 3.

Table 4. Results of familiarity labeling for each health topic.

No.	Health topic	L1	L2	L3	Participants, n
1	Skin allergy and main medications	14	9	17	40
2	Cardiovascular disease	12	19	9	40
3	Common medical test (urinalysis)	17	11	12	40
4	Cholesterol problems	18	12	10	40
	Total	61	51	48	160

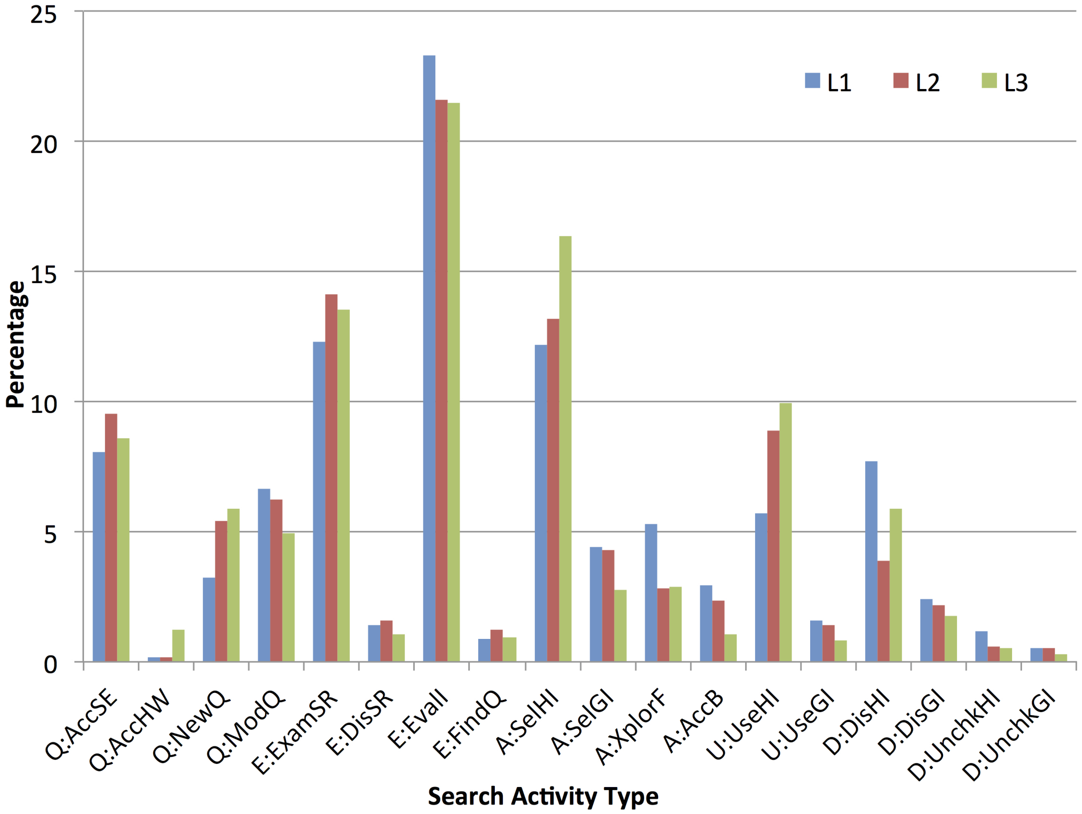
Frequency of Search Activities

All of the search sessions performed by the 40 participants contained finding the correct answer to the questions in a Health Search Task. Thus, all of the video data were transcribed and produced 4595 search activities (Figure 4 and Multimedia Appendix 2). The number of search activities in a health information search session varied from 6 to 221. On average, a participant performed 28.7 search activities during one health information search session (SD 23.27).

The most frequent search activity in all the familiarity groups was evaluating a selected item from the results retrieved (E:EvalI). This search activity accounted for 562 out of 2424 (23.31%) activities in group L1, 260 out of 1204 (21.59%) in group L2, and 208 out of 967 (21.51%) in group L3. The second, third, and fourth most frequent search activities in groups L1 and L2 were examining the results retrieved (E:ExamSR), selecting a health-related item from the results retrieved (A:SelHI), and accessing a general search engine (Q:AccSE), which together comprised 32.55% (789/2424) of the activities by group L1 and 36.88% (444/1204) by group L2. In contrast to these groups, A:SelHI, E:ExamSR, and U:UseHI were the second, third, and fourth most frequent search activities among participants in group L3, which together represented 39.81% (385/967) of the total. The fifth most frequent search activities were discarding the selected health-related website (D:DisHI), U:UseHI, and Q:AccSE for groups L1, L2, and L3, respectively.

All of the groups exhibited the same pattern when accessing the results retrieved. Participants were more likely to access health/medical websites than general domain websites. Group L3 accessed health websites more frequently than others, 85.42% (158/185) compared with 73.4% (159/211) and 75.36% (295/402). In contrast, group L1 accessed more general domain websites (26.60%, 107/402) than group L2 (24.64%, 52/211) and group L3 (14.58%, 27/185). In terms of locating the relevant health information, the participants in all groups tended to engage in a considerable number of search activities before reaching U:UseHI or U:UseGI. The combinations of U:UseHI and U:UseGI in groups L1, L2, and L3 were 7.30% (177/2424), 10.30% (124/1024), and 10.75% (104/967), respectively.

Figure 4. Percentage of the search activity types in all familiarity groups.



Transition Between Search Activity Types

Table 5 provides most frequent transitions between search activities. The calculations yielded a total of 4435 transitions, that is, 2363 transitions, 1153 transitions, and 919 transitions in groups L1, L2, and L3 respectively. The average numbers of transition between two search activities were 19.86 (SD 24.70) in group L1, 14.06 (SD 13.26) in group L2, and 11.78 (SD 11.38) in group L3. The most frequent transitions in all groups were related to accessing a health website from the results retrieved and evaluating its relevancy. The corresponding transitions were from E:ExamSR to A:SelHI (L1=7.96%, L2=9.80%, L3=11.1%) and from A:SelHI to E:EvalI (L1=7.66%, L2=8.76%, L3=11.0%).

The third most frequent transition in the unfamiliar group (L1) was different from that in the other more familiar groups (L2 and L3). The transition in group L1 from E:EvalI to D:DisHI showed that the participants assessed the selected item as irrelevant. In contrast, the third most frequent transition in groups L2 and L3 was from E:EvalI to U:UseHI. This finding indicates that the participants in L2 and L3 were probably more successful than those in L1 at identifying potentially relevant items from the results retrieved.

During the querying stage, group L3 had different search activities compared with the other less familiar groups (L1 and L2). The most frequent transition related to the querying stage was from Q:NewQ to E:ExamSR in group L3 and from Q:ModQ to E:ExamSR in groups L1 and L2. This shows that the L3 participants probably relied on their first query to discover relevant results. Group L3 also performed fewer query modifications than the other groups.

Table 5. Top 10 frequent first order transitions for each familiarity group.

No.	L1			L2			L3		
	Transition	Frequency		Transition	Frequency		Transition	Frequency	
		n	%		n	%		n	%
1	E:ExamSR–A:SelHI	188	7.96	E:ExamSR–A:SelHI	113	9.80	E:ExamSR–A:SelHI	102	11.1
2	A:SelHI–E:EvalI	181	7.66	A:SelHI–E:EvalI	101	8.76	A:SelHI–E:EvalI	101	11.0
3	E:EvalI– D:DisHI	160	6.77	E:EvalI–U:UseHI	94	8.15	E:EvalI–U:UseHI	81	8.8
4	Q:ModQ–E:ExamSR	158	6.69	Q:ModQ–E:ExamSR	75	6.50	Q:NewQ–E:ExamSR	56	6.1
5	Q:AccSE–Q:ModQ	121	5.12	Q:NewQ–E:ExamSR	64	5.55	E:EvalI–D:DisHI	51	5.6
6	E:EvalI–U:UseHI	120	5.08	Q:AccSE–Q:NewQ	63	5.46	Q:AccSE–Q:NewQ	48	5.2
7	A:XplorF–E:EvalI	91	3.85	Q:AccSE–Q:ModQ	52	4.51	A:SelHI–A:SelHI	44	4.8
8	E:EvalI–A:XplorF	88	3.72	A:SelHI–A:SelHI	40	3.47	Q:ModQ–E:ExamSR	44	4.8
9	Q:AccSE–Q:NewQ	75	3.17	A:SelGI–E:EvalI	39	3.38	Q:AccSE–Q:ModQ	35	3.8
10	Q:NewQ–E:ExamSR	75	3.17	E:EvalI–D:DisHI	36	3.12	A:XplorF–E:EvalI	24	2.6
Total		1257	53.20		677	58.72		586	63.8

Testing the Differences in Search Activities Between Familiarity Groups

Table 6 shows the result of the chi-square test described above. According to the results, the null hypothesis was rejected in all cases; hence, the three familiarity groups exhibited distinct search activity patterns.

Table 6. Results obtained after testing the differences between the familiarity groups (*P*<.001).

Familiarity group	L2	L3
L1	K^2=324[a] N_1=18[b] N_2=242[c] df=64 (χ^2=104.716)[d] C=5084.883[e]	K^2=324 N_1=18 N_2=246 df=60 (χ^2=99.607) C=6021.407
L2	—	K^2=324 N_1=18 N_2=246 df=60 (χ^2=99.607) C=2809.463

[a] K is the number of states in the state spaces.

[b] N_1 is the number of actual states.

[c] N_2 is the number of impossible transitions.

[d] df is obtained from K^2-N_1-N_2.

[e] C is the chi-square score obtained from Equation (2) of Figure 2.

Most Frequent Patterns in Search Activity Sequences for Each Familiarity Group

According to the perplexity evaluations of all the language models for all the datasets (Figure 5), 5-gram language models had the lowest perplexity values for the four test datasets. Thus, we used 5-gram sequences to identify common search activity patterns in each familiarity group. The numbers of observed 5-gram sequences in groups L1, L2, and L3 were 940, 444, and 359, respectively. There were large numbers of 5-gram sequences in each group, so only the 20 most frequent sequences were examined (for details, see Multimedia Appendix 3). Above this level, the frequencies of the sequences were too low to represent the search activity patterns in a familiarity group.

To compare the search behavior between familiarity groups, we used four activity categories from the health information search process based on the top 20 most frequent patterns, as follows: (1) the first category comprised accessing a search engine (general search engine or consumer health website), issuing a new or modified query, and accessing and evaluating an item from a health website (see Figure 6), (2) the second comprised accessing a search engine, issuing a query, and accessing multiple items from health websites (see Figure 7), (3) the third category was related to the assessment of the relevancy of the item selected from a health website (see Figure 8), and (4) the fourth category involved continuing the search process after finding a relevant item (see Figure 9).

Group L1 comprised participants who were not familiar with the health topic search task. The most frequent pattern in group L1 was submitting a modified query to a general search engine, followed by accessing a health-related website from the search results, and immediately evaluating the relevancy of the selected result (Q:AccSE–Q:ModQ–E:ExamSR–A:SelHI–E:EvalI), which accounted for 5.85% of all the 5-gram patterns. In locating the potentially relevant search results, this group accessed more non-relevant results than relevant results.

As shown in Figure 8, the proportion of D:DisHI assessments was larger than that of U:UseHI assessments. In total, 10/20 of the most frequent patterns contained D:DisHI (see Multimedia Appendix 3), which accounted for 23.3% of all the 5-gram patterns in group L1. In contrast, only 5/20 of the most frequent patterns included U:UseHI assessments, which comprised 11.5% of all the 5-gram patterns.

In group L2, all of the queries in the top 20 most common patterns were submitted to a general search engine. The proportion that issued a modified query was higher than that issuing a new query. The identification of the potentially relevant search results showed that participants in this group were likely to be more successful than those in group L1, as demonstrated by the higher proportion of U:UseHI assessments than D:DisHI assessments. The participants in group 2 created a new search after finding a relevant information source.

The final group, L3, had the most knowledgeable searchers. The proportion that issued a new query was higher than that issuing a modified query. Unlike the other groups, the participants in group L3 also accessed consumer health websites to search for health information. Two strategies were performed by group L3 when accessing the search results: accessing a single item from a health website and evaluating it immediately, or accessing multiple items from health websites and evaluating the items one by one. When identifying potentially relevant search results, group L3 found more relevant items in the results retrieved from the first query compared with the results retrieved using the modified query. The participants also continued their search process by creating a new search and reexamining the previous results retrieved.

Figure 5. Perplexity values for L1, L2, L3, and all the test data using different n-gram models.

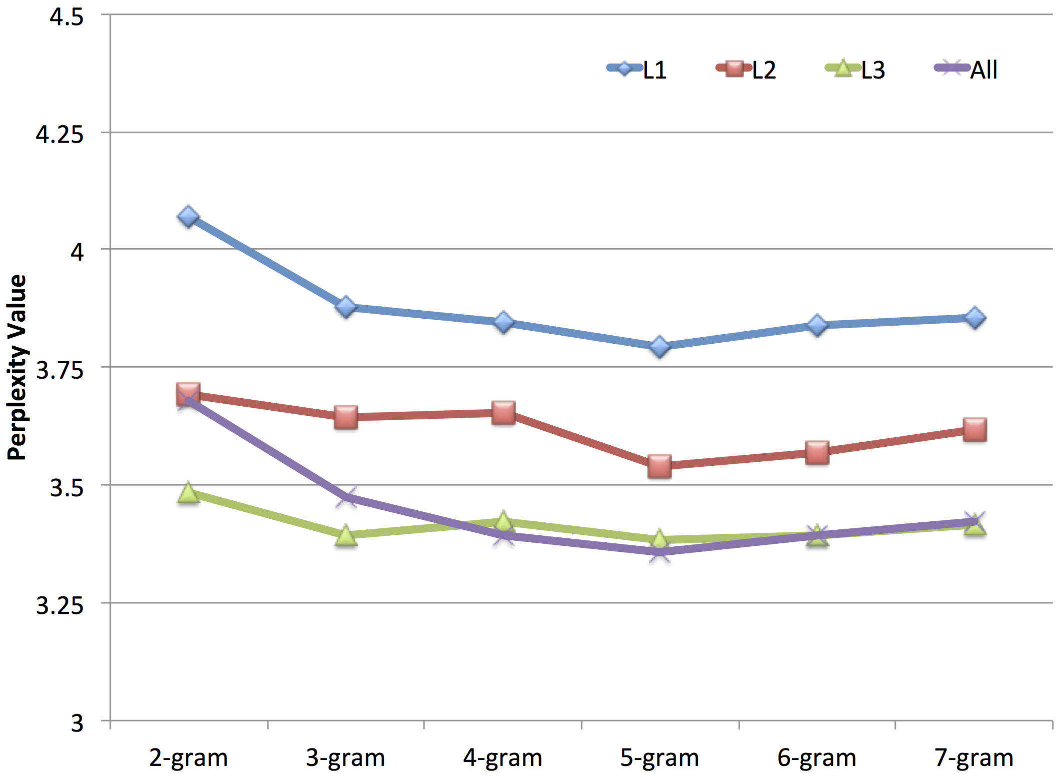


Figure 6. Comparison of frequent activity patterns in Category 1.

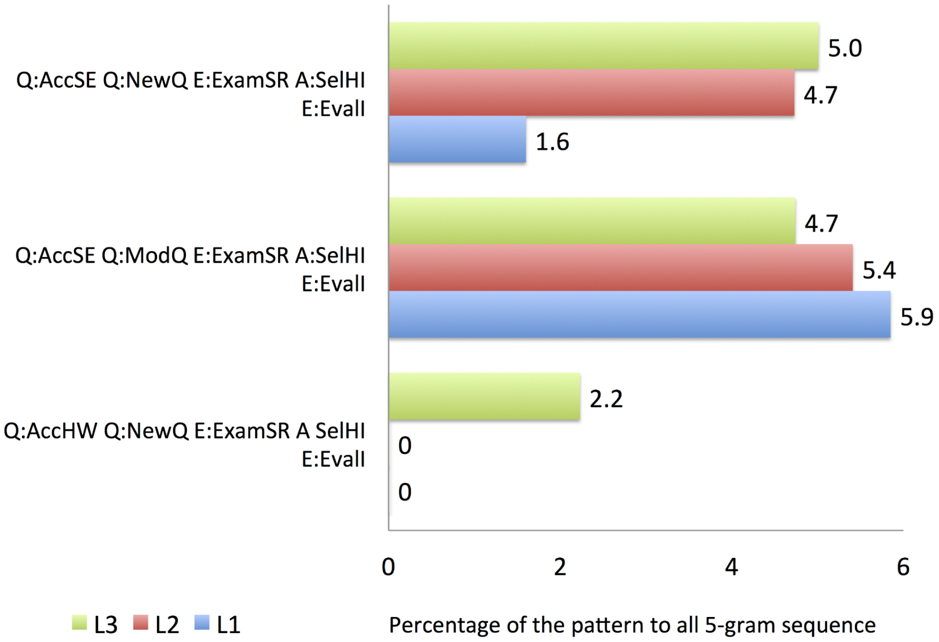


Figure 7. Comparison of frequent activity patterns in Category 2.

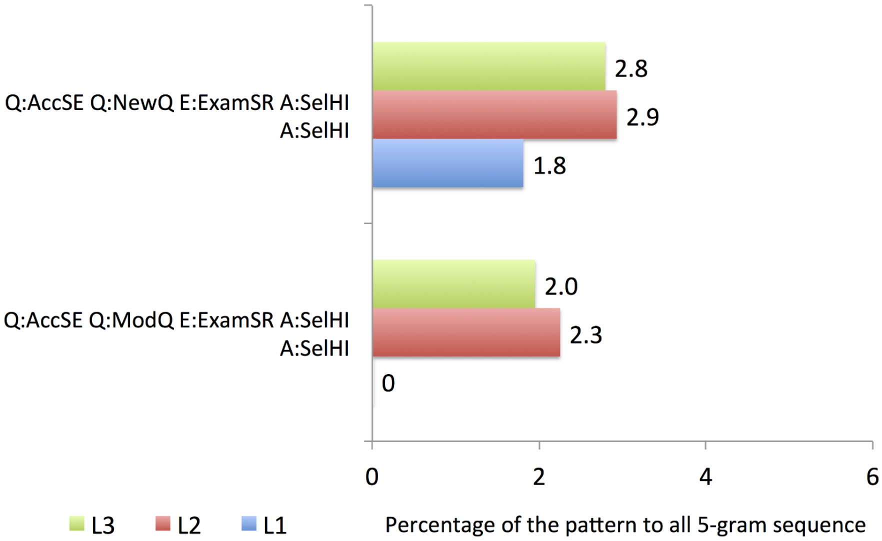


Figure 8. Comparison of frequent activity patterns in Category 3.

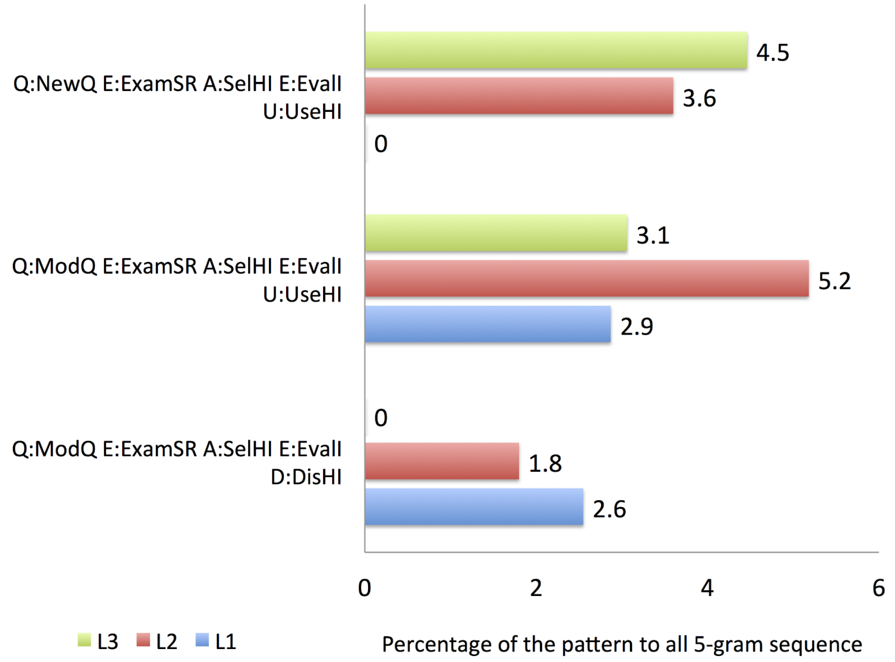
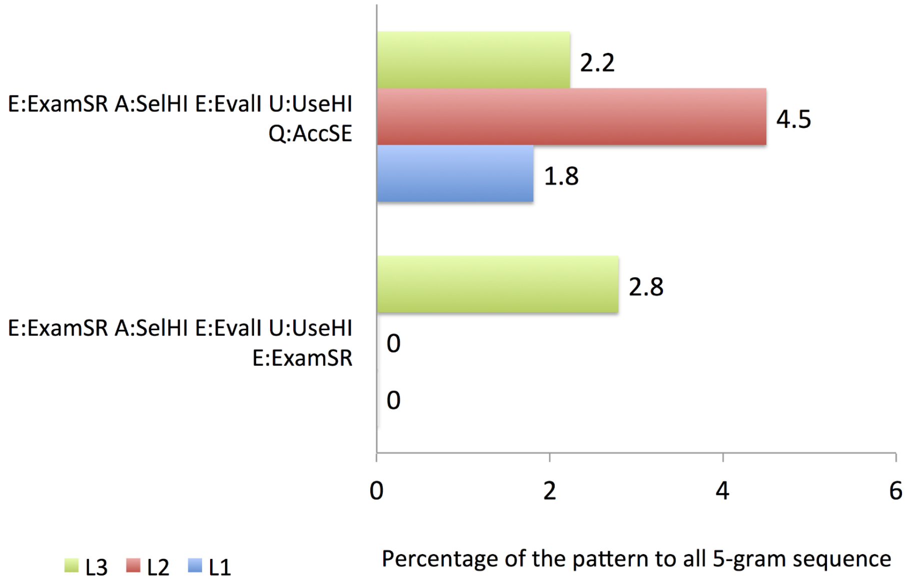


Figure 9. Comparison of frequent activity patterns in Category 4.



Discussion

Summary

This study considered the concept of individual health topic familiarity, where we examined its effects on health information search behaviors. In previous studies, the effects of familiarity during health information searches were investigated mainly in the context of the health terminology recognition rate by *all* consumers. In this study, we shifted the concept of familiarity from the health terminology perspective to the consumer perspective. To the best of our knowledge, this study is among the first to examine the effects of health topic familiarity on the activity pattern during health information searches. Results and findings from this study show that familiarity with health topics affects search activity patterns exhibited during health information searches.

This discussion section is organized around two themes: (1) effects of the familiarity level of consumers on their health information search behaviors, and (2) the implications for health search systems of better support for individual familiarity with health topics.

Effects of Level of Familiarity on Health Information Search Behaviors of Consumers

We characterized health information search behaviors as a sequence of search activities in this study. The frequencies of the search activities showed that the participants devoted substantial efforts during the evaluating stage, where they examined the results retrieved and evaluated the relevancy of the item selected. The participants also performed frequent search activities during the accessing and querying stages. Although the use of selected information (U:UseHI and U:UseGI) is the main goal of information search, the total proportions of these search activities were smaller than the search activities performed in the evaluating, accessing, or querying stages. These findings indicate that health information search remains difficult for most consumers.

In this study, the participants with different levels of familiarity performed a unique search behavior (see the summary in Table 7). The first effect of health topic familiarity was observed in the querying stage. The participants in the lower familiarity groups submitted more queries than the participants in the higher familiarity group. The average numbers of query submissions during a health search session were 7.2, 5.0, and 4.2 in groups L1, L2, and L3, respectively. The series of query submissions reflected the searcher's progress in understanding the searched topic. The participants with less familiarity submitted more queries because they needed to increase their understanding of the search topic before they could locate relevant information. A number of participants in group L1 started the search process by searching for definitions of the health terms that appeared in the searching task. Examples of this type of query are "what is rash", "urinalysis definition", "what is SCA", "special gravity in urine?", and "what is simvastatin". This finding is different from other studies in general Web-based search processes [41,42]. Liu et al in their study reported that no differences in the number of queries issued were found between users with different levels of topic knowledge [41], while Zhang et al stated in their study that the high-level domain knowledge group issued more queries than the low-level group [42]. In term of the average query length, there was no distinguishable pattern between less familiar and more familiar groups. This finding is also different from previous studies in [21,43] that suggested expert users issued longer and more complex queries than novice users.

Another interesting finding is how the familiarity affected the selection of the relevant source (webpages). Less familiar participants were likely to choose easier content, while more familiar participants tended to use more difficult content. We measured the difficulty of the source by its readability score using the Simple Measure of Gobbledygook (SMOG) formula [44]. We selected this formula because SMOG was the preferred measure of readability when evaluating consumer-oriented health care material [45].

The next effect was detected when locating relevant health information, which was estimated on the basis of the search efficiency. The search efficiency compared the proportion that used the information (U:UseHI and U:UseGI) against the number of items accessed (A:SelHI, A:SelGI, A:XplorF, and A:AccB). Group L3 achieved the best performance with a search efficiency of 46.6%, compared with 45.5% and 29.4% for groups L2 and L1, respectively. This result agreed with the frequencies of search activities in each familiarity group. Group L1 accessed more irrelevant items than relevant ones, whereas groups L2 and L3 did the opposite. This finding is in contrast to a previous study that reported that the search effectiveness remained the same for all participants in high and low levels of domain knowledge [42].

The patterns exhibited in each group also illustrated the effect of the level of health topic familiarity on search behaviors. The frequent patterns in group L1 showed that these participants were likely to experience difficulties during their health information search sessions, as demonstrated in the much higher percentage of issuing modified queries than issuing new queries and in identifying the potentially relevant search results. The participants found relevant information more often using the results retrieved with the modified query than the first query. The common strategies employed when the participants encountered search problems were querying followed by single accessing and evaluating (… D:DisHI–Q:AccSE–Q:ModQ …), or iterative accessing and evaluating (… D:DisHI–E:ExamSR–A:SelHI …).

In group L2, the most frequent pattern was issuing a modified query, accessing a health website, and evaluating the selected item immediately. Group L2 also discovered relevant items more often using the results retrieved with the modified query rather than the first query, but they exhibited greater search efficiency compared with group L1. When examining the results retrieved, group L2 performed single accessing and the evaluation of selected items, or multiple accessing followed by evaluating the selected items one by one. Another frequent pattern in group L2 was the transition from U:UseHI to Q:AccSE. This pattern indicates that the participants attempted to continue health information searches after they found relevant health information. The aim of these further searches was either to verify the accuracy of the health information they discovered, or to search for another related health topic during the search task.

The most common patterns in group L3 were related to query submission and single selection, and the evaluation of a health webpage. The participants in group L3 employed more varied keywords in their queries than the other groups. A frequent pattern in this group was accessing a known consumer health information website directly to start a health search session and search for health information (known item strategy). Several participants also referred to PubMed articles to answer the questions in the search tasks, for example, in Task 4 (the interaction between simvastatin and grapefruit juice). Another highly frequent pattern in group L3 was Q:AccSE–Q:NewQ–E:ExamSR–E:EvalI–U:UseHI, which represents a successful search when locating the relevant health information at the first attempt (first query submission and first item selection). A number of participants in group L3 continued the search process after they discovered relevant health information by issuing a modified query, or by reexamining the previous results retrieved.

Table 7. Summary of the findings.

Familiarity group	Characteristic frequent patterns
L1	More likely to reformulate the query: the proportion of frequent patterns that contained a modified query (Q:ModQ) was higher than that containing the first query (Q:NewQ).
	More likely to encounter difficulty during the search process, eg, they frequently accessed irrelevant websites and had a low search efficiency.
	Discovery of relevant webpages (information source) more frequently in the results were retrieved with the modified query than the first query.
L2	More likely to reformulate the query: the proportion of frequent patterns that contained a modified query (Q:ModQ) was higher than that containing the first query (Q:NewQ).
	Discovery of relevant webpages (information source) more frequently in the results were retrieved with the modified query than the first query.
	Achievement of better search efficiency than group L1.
	Continuation of the search process after discovering relevant webpages by issuing another query.
L3	Access of consumer health information websites directly to start the search session.
	Discovery of relevant webpages (information source) more frequently in the results were retrieved with the first query than the modified query.
	Continuation of the search process by issuing another query or by reexamining the results retrieved.

Implications for Health Information Search Systems

The main finding of this study is the identification of unique search patterns between different familiarity groups (unfamiliar, somewhat familiar, and familiar). Health information search systems can use this knowledge to identify the term familiarity by analyzing consumer's search behaviors. For example, multiple query reformulations pattern without any activities on the retrieved results may indicate unfamiliarity with the search topic. Addressing individual familiarity in health information search systems is necessary to provide better support for the consumers and to improve the overall search process.

To support unfamiliar consumers, these systems should implement assistive features during the construction of health queries and select understandable health information. These systems could help consumers build queries using predefined diagnosis questionnaires and/or human anatomy diagrams. To support unfamiliar searchers with the identification of potentially relevant results, these systems should automatically extract a consumer-friendly definition of the submitted health query, adjust the rankings of the items retrieved, and suggest a related term using CHV. For more familiar searchers, these systems could be of assistance by locating additional relevant results. Based on the patterns exhibited in this study, groups L2 and L3 were likely to continue the search process after they discovered relevant information. Systems could assist this process by clustering similar items into topic clusters in the page showing the results retrieved, by adjusting the ranking of retrieval items, and by providing a summary of health topic keywords.

Limitations and Future Studies

Most of the results obtained in this study correspond to our goals, but a more comprehensive user study is required for further validation. First, the participants involved in this study shared several common demographic characteristics, that is, higher education and a high level of experience in using the Internet. Therefore, the generalizability of the results is limited. A future user study should investigate further the background of the participants. Second, the time spent examining the results retrieved and evaluating the selected webpages were not considered in the search activities model. The time variable may characterize the search behaviors of different familiarity groups, and it needs to be considered in future studies.

The findings of this study may facilitate the development of a more advanced personalized health information search system based on the individual's health topic familiarity. This type of system could identify the consumer's familiarity with health topics by analyzing their usage behavior to provide suitable support. Because health information search remains challenging for most consumers, this approach would be a major improvement in health information search systems.

Conclusion

This study addressed the concept of individual familiarity with health topics and investigated its effects on health information search behaviors. The results of this study support two main conclusions. First, the analysis of state transitions in search activities can detect the unique behaviors of consumers in each familiarity group during health information searches. Second, we identified common health search patterns in unfamiliar and familiar groups. These patterns characterized the familiarity groups during all stages in health information searches.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

Health terminology familiarity survey.

[PDF File (Adobe PDF File), 82KB - medinform_v3i1e16_app1.pdf]

Multimedia Appendix 2

Frequency and proportion of search activity type.

[PDF File (Adobe PDF File), 3KB - medinform_v3i1e16_app2.pdf]

Multimedia Appendix 3

Most frequent 5-gram sequence patterns.

[PDF File (Adobe PDF File), 10KB - medinform_v3i1e16_app3.pdf]

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Abbreviations

CHV:	Consumer Health Vocabularies
TOFHLA:	Test of Functional Health Literacy in Adults

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Original Paper

Impact of Early Electronic Prescribing on Pharmacists' Clarification Calls in Four Community Pharmacies Located in St John's, Newfoundland

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Abstract

Background: Electronic prescribing (e-prescribing) can potentially help prevent medication errors. As the use of e-prescribing increases across Canada, understanding the benefits and gaps of early e-prescribing can help inform deployment of future e-prescribing systems.

Objective: The purpose of this exploratory study was to determine the prevalence of, reasons for, and average time taken for pharmacist clarification calls to prescribers for electronic medical record (EMR)-generated and handwritten prescriptions.

Methods: Four community pharmacies in St John's, Newfoundland, Canada prospectively collected information on clarification calls to prescribers for new prescriptions over a period of 17 to 19 weeks. Four semistructured interviews were conducted following the data collection period to gain further insight.

Results: An estimated 1.33% of handwritten prescriptions required clarification compared with 0.66% of EMR-generated prescriptions. Overall, 1.11% of prescriptions required clarification with the prescriber. While illegibility was eliminated with EMR-generated prescriptions, clarification was still required for missing information (24%) and appropriateness (51%). Key themes, including errors unique to EMR-generated prescriptions, emerged from the qualitative interviews.

Conclusions: Advanced e-prescribing functionality will enable secure transmission of prescriptions from prescribers to a patient's pharmacy of choice through a provincial electronic Drug Information System (DIS)/Pharmacy Network, which will lessen the need for clarification calls, especially in the domains of missing information and appropriateness of the prescription. This exploratory study provides valuable insight into the benefits and gaps of early e-prescribing. Advanced e-prescribing systems will provide an opportunity for further realization of quality and safety benefits related to medication prescribing.

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KEYWORDS

electronic prescribing; pharmacy; pharmacists; Clinical Pharmacy Information Systems

Introduction

The National Coordinating Council for Medication Error Reporting and Prevention (NCC MERP) defines medication error as any preventable event that may cause, or lead to, inappropriate medication use or patient harm while the medication is in the control of the health care professional, patient, or consumer, and states that such events may be related to prescribing [1]. The link between medication error and prescribing was further emphasized in 2000, when the Institute for Safe Medication Practices (ISMP) issued a call to action to eliminate the use of handwritten prescriptions, citing this as a source of medication errors. Although only part of a solution to a complex problem, ISMP identified electronic prescribing (e-prescribing) technology to be potentially useful in preventing medication errors [2]. In 2006, the Institute of Medicine recommended that all physicians and pharmacies use electronic prescribing by 2010 [3]. More recently in 2012, the Canadian Medical Association (CMA) and Canadian Pharmacists Association (CPhA) released a joint position that e-prescribing will improve patient care and safety, and committed to a vision that sees e-prescribing in place for Canadians by 2015 [4].

Despite this, there continues to be debate about the impact of e-prescribing technology on patient safety outcomes [5,6]. Previous research has largely focused on the benefits of computerized provider order entry (CPOE) in inpatient hospital environments, while studies of outpatient electronic prescribing have yielded mixed results [7]. Basic computerized prescribing systems with some clinical decision support functionality have been shown to decrease medication error rates in community-based practices [8,9]. However, a study in two US chain grocery stores found no significant difference in the number of pharmacist interventions required when comparing new handwritten prescriptions and electronic prescriptions [10]. It is important to consider the degree of sophistication and system integration of the e-prescribing technology when measuring the value of such systems, as these likely have a substantial impact on the benefits realized [11-14]. In particular, a recent study found that electronic transmission of prescriptions from physicians' offices to a pharmacy significantly decreased the risk of dispensing errors compared with outpatient CPOE alone [15].

The national landscape of health information technology deployment and adoption are important considerations when contemplating e-prescribing. In Canada, the electronic health record (EHR) is a secure and private lifetime record of a person's health and health care history, deployed using a series of repository systems. This approach is similar to that used in the United Kingdom, Norway, and the US Department of Veterans Affairs, as well as Kaiser Permanente, a large American health care organization. These repositories collect and store health information in jurisdictionally coordinated repositories. The provincial Drug Information System (DIS) is one component of the EHR. The EHR is then accessed by authorized health care providers using point-of-care systems, such as electronic medical records (EMRs) and pharmacy management systems [16].

E-prescribing is defined as the secure electronic creation and transmission of a prescription between an authorized prescriber and a patient's pharmacy of choice, using the clinical EMR and pharmacy management software [4]. In Canada, based on the hub-and-spoke model, the DIS component of the EHR serves as a central repository for electronic prescriptions. E-prescriptions would first be transmitted from EMRs to the DIS and then to the pharmacy management system. This is in contrast to the decentralized model traditionally deployed in Scandinavian countries known to be early adopters of e-prescribing, such as Denmark [16,17].

In 2010, Canada Health Infoway commissioned a Pan-Canadian Drug Information Systems study, which included an evaluation of early e-prescribing. At that time, fully evolved e-prescribing was not yet implemented in Canada. Early e-prescribing refers to the use of a stand-alone EMR in a clinician's office to generate prescriptions (EMR generated) that are printed on paper and then either provided to the patient as they leave, or faxed directly to the pharmacy. Pharmacists surveyed in the study estimated that 40% of prescriptions they received were EMR generated and that these prescriptions required less clarification calls than handwritten scripts [18]. The 2012 Commonwealth Fund survey found that 43% of primary care physicians surveyed used electronic systems for prescribing and, although this increased from 11% in 2006, Canada was still lagging behind other countries in e-prescribing adoption [19]. Results of a recent 2014 national survey of pharmacists reflects similar rates of e-prescribing adoption [20].

Based on this landscape, understanding the attributes of early e-prescribing in Canada will be valuable as fully evolved e-prescribing begins to be deployed across the country. Clarification calls occur when a pharmacist contacts a prescriber to seek clarity on various elements of the prescription and/or to discuss the appropriateness of a medication with the implicit purpose of preventing medication error. Therefore, although clarification calls may only represent one aspect of medication error avoidance, learning more about the frequency and nature of these interventions will help characterize benefits and gaps of early e-prescribing.

The purpose of this study was to explore the prevalence of pharmacist clarification calls to prescribers, the average time taken to perform these clarifications, and how the reasons for clarification calls differ between handwritten and EMR-generated prescriptions at four community pharmacies in St. John's, Newfoundland and Labrador. At the time of the study, a provincial DIS was being deployed across Newfoundland and Labrador [21].

Methods

Recruitment

The research team approached the Pharmacy Network Project Team at the Newfoundland and Labrador Centre for Health Information (the Centre). The Centre is the province's primary custodian of electronic health data, and is responsible for the development and implementation of the confidential and secure provincial electronic health record, including the provincial

Pharmacy Network. The Centre maintains key health databases, prepares and distributes health reports, supports and carries out health analytics and applied health research activities, and undertakes benefits-evaluation projects. Additionally, the Centre provides quality information to health professionals, the public, researchers, and health system decision makers. Given the Pharmacy Network Project Team's relationship with community pharmacies, they were chosen as a means for recruiting community pharmacies to participate in this study. Four of the five pharmacies identified agreed to participate, while the fifth declined due to work commitments.

Quantitative Data Collection

Data were collected at the four study pharmacies between July 20 and December 3, 2011, over a period of 17 to 19 weeks, depending on the pharmacy, using a one-page standardized data collection sheet. This data collection sheet was pilot-tested and refined prior to initiation of the study to ensure validity of the tool. Using this tool, pharmacists were asked to document the prescription type received (handwritten or EMR generated), how the prescription arrived at the pharmacy (brought in by the patient or faxed), name of drug(s) prescribed, which drug(s) required clarification, reason for clarification (illegible handwriting, missing information, dose discrepancy from previous prescription, possible drug interaction, allergy, cost contraindication, insurance issue, or other), and time taken for clarification calls to prescribers. Three pharmacies collected data Monday through Saturday. However, to minimize disruption in workflow, the fourth only collected data on alternating days of the week. Only the total number of new prescriptions (no refills) on designated data collection days was recorded. Data were analyzed using SPSS version 17.0.

Qualitative Data Collection

Four semistructured interviews were completed with participating pharmacists between December 22, 2011 and January 10, 2012. During these interviews, pharmacists were asked about the reasons that prescriptions require intervention, the time spent and methods used for resolving issues, and specific errors frequently associated with handwritten and EMR-generated prescriptions. They were also asked to estimate the percentage of EMR-generated prescriptions received at their practice site. Sessions were audiotaped and transcribed. Interview transcripts underwent thematic/content analysis with the aid of NVivo 9 software. This study was approved by the Health Research Ethics Authority of Memorial University of Newfoundland and Labrador on June 29, 2011 (REB Ref #11.112).

Results

Quantitative Data

Overall, for 18,042 new prescriptions filled during the study period, there were 200 (1.11%) clarification calls made. The mean length of time to make a clarification call was 9.1 minutes (SD 5.6). Table 1 provides the characteristics of the study pharmacies, while Table 2 shows the number and percentages of new prescriptions requiring clarification.

An estimated 1.33% (161/12,089) of handwritten prescriptions required a clarification call, compared to 0.66% (39/5953) of EMR-generated prescriptions. For three out of four study pharmacies, the estimated proportion of clarification calls for handwritten prescriptions was higher than that of EMR-generated prescriptions, whereas the fourth pharmacy required clarification for a higher proportion of EMR-generated versus handwritten prescriptions. Across all pharmacies, handwritten prescriptions resulted in the majority of clarification calls to prescribers (161/200, 80.5%).

Table 1. Characteristics of study pharmacies.

Pharmacy characteristics	Pharmacy[a]				
	A	B[b]	C	D	Total
Length of data collection time in weeks	18	19	18	17	72
Total number of new prescriptions in study period[c], n	2539	1980	11,473	2050	18,042
Estimated number[d] of handwritten prescriptions, n (%)	2412 (95.00)	990 (50.00)	7457 (65.00)	1230 (60.00)	12,089 (67.00)
Estimated number[d] of EMR-generated prescriptions, n (%)	127 (5.00)	990 (50.00)	4016 (35.00)	820 (40.00)	5953 (33.00)

[a] The four pharmacies are referred to as A, B, C, and D.

[b] Data for pharmacy B were collected 2-3 days per week over a period of 19 weeks, versus 6 days per week for the other pharmacies.

[c] Verbal (n=2) and missing (n=2) prescriptions were excluded.

[d] Estimates obtained during qualitative interviews with pharmacists.

Table 2. Prevalence of clarification calls by prescription type.

Prescription type	Pharmacy[a]				
	A	B[b]	C	D	Total
All new [c]					
Total, n	2539	1980	11,473	2050	18,042
Requiring clarification, n (%)	62 (2.44)	61 (3.08)	64 (0.56)	13 (0.63)	200 (1.11)
Handwritten					
Estimated total[d], n	2412	990	7457	1230	12,089
Requiring clarification, n (%)	55 (2.28)	43 (4.3)	54 (0.72)	9 (0.73)	161 (1.33)
EMR generated					
Estimated total[d], n	127	990	4016	820	5953
Requiring clarification, n (%)	7 (5.5)	18 (1.8)	10 (0.25)	4 (0.5)	39 (0.66)

[a] The four pharmacies are referred to as A, B, C, and D.

[b] Data for pharmacy B were collected 2-3 days per week over a period of 19 weeks, versus 6 days per week for the other pharmacies.

[c] Verbal (n=2) and missing (n=2) prescriptions were excluded.

[d] Estimates obtained during qualitative interviews with pharmacists.

The mean duration of clarification calls for pharmacies A, B, C, and D were 7.2 (SD 4.8), 13.2 (SD 3.1), 7.2 (SD 6.3), and 8.5 (SD 4.6) minutes, respectively. The mean duration of clarification calls for all pharmacies combined was 9.1 (SD 5.6) minutes.

Table 3 shows the reported reasons for clarification calls grouped across four themes: illegibility, missing information (ie, dose, drug, duration, and frequency), appropriateness of the prescription for the patient (ie, dose discrepancy, confirm dosage, known allergy to drug, possible drug interaction, previous adverse reaction, verify directions, and drug), and other (eg, medication not available, insurance, and cost of drug). Some prescriptions had multiple causes for initiation of a clarification call resulting in a total of 236 reported reasons for clarification.

Overall, the most common reason for clarification was to verify the appropriateness of the prescription for the patient (92/236, 39.0%), followed by illegibility (48/236, 20.3%). Dose discrepancy, a reason within the appropriateness category, made up 22.0% (52/236) of all reasons for clarification calls—40 out of 195 (20.5%) for handwritten and 12 out of 41 (29%) for EMR-generated prescriptions. Missing information was the reason for 19.9% (47/236) of calls. In the Other category, the most common reasons were that the medication was not available (15/236, 6.4%)—12 out of 39 (31%) for handwritten and 3 out of 10 (30%) for EMR-generated prescriptions—and insurance issues (12/236, 5.1%)—11 out of 39 (28%) for handwritten and 1 out of 10 (10%) for EMR-generated prescriptions.

Table 3. Reasons for clarification calls.

Reason for clarification call	Prescription type requiring clarification call		
	Handwritten (n=195)	EMR generated (n=41)	Total (n=236)
Illegibility, n (%)	48 (24.6)	0 (0)	48 (20.3)
Missing information, n (%)	37 (19.0)	10 (24)	47 (19.9)
Appropriateness of prescription, n (%)	71 (36.4)	21 (51)	92 (39.0)
Other, n (%)	39 (20.0)	10 (24)	49 (20.8)
Total, n	195	41	236

Qualitative Interviews

Several important themes emerged from the qualitative interviews, with respect to prescriptions requiring intervention and specific errors associated with prescription type. Four themes are reviewed in Textbox 1, including (1) reduction in clarification calls, (2) elimination of illegibility, (3) unique errors with EMR-generated prescriptions, and (4) errors with reprinting prescriptions. When asked about issue resolution, interview subjects cited engaging the patient, using medication profiles, and contacting the prescriber as common interventions. The two pharmacists that were connected to Pharmacy Network noted that while there are limitations due to partial adoption, the Pharmacy Network was beneficial in identifying potential drug abuse and for accessing the patient's profile. In addition, the medication management program was cited as an enabler for pharmacists to resolve prescription issues independently. Under this standard of practice, pharmacists in Newfoundland

and Labrador are authorized to change the form and/or regimen of dosage, change the quantity of medication, complete any missing information, and make nonformulary generic substitutions under specific circumstances, such as having historical information available from a patient's medication profile [22].

Although illegibility was eliminated, all participants agreed that certain issues with EMR-generated prescriptions still necessitate contacting the prescriber from time to time. For example, participants noted that certain computer-generated defaults, such as quantity calculations and drug catalogs, sometimes lead to error. Interestingly, one pharmacist alluded to incomplete medication reconciliation as a source of missing information: "The doctor will write out a list of medications for somebody and they omit one…and you have to call to get the prescription." Perpetuation of errors can also be a problem when discrepancies are resolved by the pharmacist at the point of dispensing, but are not documented in the prescriber's EMR.

Textbox 1. Themes and illustrative quotes from qualitative interviews, with respect to interventions needed and specific errors associated with prescription type.

Themes with illustrative quotes

1. Pharmacists perceived a reduction in clarification calls with EMR-generated prescriptions compared with handwritten prescriptions.

- "I think the computer-generated ones reduce the amount of calls. There are still calls there but I think there is a reduction."
- "…if they're typing it in they might be looking right at their chart because their charts are probably automated as well so that might help…"

2. Illegibility was eliminated with EMR-generated prescriptions.

- "Things that you cannot read are eliminated with computer-generated scripts."
- "…most times I can't make out a doctor's signature, but with computer generated it generates right on the bottom."

3. EMR-generated prescriptions have errors unique to EMR systems.

- "I find with computer-generated stuff is that they use defaults…little odd things like quantities. I had someone prescribed .6134 of a tablet before because the computer generated something odd."
- "The computer calculated quantities and a lot of the time the quantities come up as 12.3522…(the clinic next door) is set up for American drugs, too, and we don't have these here."

4. Some errors with EMR-generated prescriptions are due to prescribers' reprinting of prescriptions.

- "I get the same mistakes over and over again with computer-generated slips because they just print them off again every three months…I get errors, the same ones."

Discussion

Principal Results

In this study, the overall prevalence of new prescriptions requiring clarification was 1.11% (200/18,042). At three sites, the estimated proportion of clarification calls for handwritten prescriptions was higher than for EMR-generated prescriptions. The fourth site required clarification for a higher proportion of EMR-generated versus handwritten prescriptions, however, it also had the lowest estimated percentage of EMR-generated prescriptions. Consistent with the literature, an important benefit of EMR-generated prescriptions was elimination of illegibility, however, EMR-generated prescriptions still required pharmacist intervention, mostly due to omission of information and dosing [9,13,14,23]. While clarification calls to prescribers will continue to be required, the need to do so for missing information and dose discrepancies present important opportunities for future benefits possible with advanced e-prescribing.

Whereas missing information and dose discrepancy accounted for 41.9% (99/236) of all reasons for clarification in this study, these actually accounted for 54% (22/41) of reasons for clarifications for EMR-generated prescriptions. Errors unique to EMR-generated prescriptions, such as incorrect rounding or default quantities, were also highlighted by interview subjects. With the average time for a clarification call being 9.1 minutes in this study, a reduction in the need for clarification calls could have a considerable impact on the day-to-day activities of pharmacists. This may also translate to productivity benefits for both prescribers and pharmacists, as previously articulated in a Pan-Canadian DIS study [18].

Comparison With Prior Work

In the Canadian context, fully evolved e-prescribing will enable secure electronic transmission of prescriptions from prescribers to a patient's pharmacy via a provincial DIS which may further decrease prescription issues [15]. Connecting EMRs and pharmacy management systems to a DIS necessitates implementation of interoperability standards which may help mitigate issues frequently encountered for EMR-generated prescriptions in this study. For instance, defining mandatory information for successful transmission of a prescription to the DIS may reduce missing information, thereby reducing the need for clarification at the point of dispensing. This is analogous to a "forcing function" designed to prevent omitted information as described by Nanji et al [14]. Similarly, the use of specific terminology for drugs to create alignment between EMR drug catalogs and drug identifiers defined at the DIS level may help reduce prescriptions for products that are not available in

Canada. As part of implementation, jurisdictions may also impose business rules that could reduce the likelihood of incorrect default quantities being prescribed, for example, requiring the EMR to display the final prescription to the prescriber for review and validation prior to signing off.

In this study and others, consulting patient medication profiles was a frequent pharmacist intervention for resolving problems with prescriptions [10]. As noted in the interviews, once adoption of the provincial DIS in Newfoundland and Labrador (ie, Pharmacy Network) is complete, a more comprehensive medication profile will become available. This tool may further support pharmacists in assessing the appropriateness of prescriptions by providing relevant context such as titration of dosages over time. Advanced e-prescribing functionality will also enable prescribers to have access to the same medication profile, potentially mitigating issues like unintentional dose discrepancies at the time of prescribing.

Finally, despite issues being resolved at the point of dispensing, it was observed in this study that with EMR-generated prescriptions, errors tend to be repeated upon reprinting. With advanced e-prescribing functionality, information about the final prescription would be recorded in the DIS, not just the local pharmacy management system, decreasing the chance that the identical error could be perpetuated in the future.

Limitations

This study used an exploratory prospective research design focusing on a small convenience sample of community-based pharmacies in a small Canadian city. The small number of qualitative interviews conducted may also limit generalizability. In addition to a limited sample size, another constraint of this study is that for the purposes of reducing respondent burden, the total number of EMR-generated and handwritten prescriptions was based on pharmacists' estimates rather than collected prospectively. That said, insights from this small study are important from a lessons-learned perspective. Finally, this study did not quantitatively capture data about pharmacist interventions other than clarification calls, such as discrepancies resolved by the pharmacist using available medication management resources or in collaboration with the patient themselves. Including these may have been useful in understanding how advanced e-prescribing might offer additional benefit in either augmenting or making these types of interventions more efficient.

Conclusions

This study provides valuable insight around the impact of early e-prescribing on pharmacists' clarification calls in four community pharmacies located in St. John's, Newfoundland. While illegibility has been eliminated by computer-generated prescriptions, advanced e-prescribing functionality with connectivity to an electronic provincial DIS provides an opportunity for further realization of benefits related to medication prescribing.

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Conflicts of Interest

Valerie Leung is an employee of Canada Health Infoway Inc.

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Abbreviations

CMA: Canadian Medical Association
CPhA: Canadian Pharmacists Association
CPOE: computerized provider order entry
DIS: Drug Information System
EHR: electronic health record
EMR: electronic medical record
ISMP: Institute for Safe Medication Practices
NCC MERP: National Coordinating Council for Medication Error Reporting and Prevention

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Viewpoint

Dynamic Consent: A Possible Solution to Improve Patient Confidence and Trust in How Electronic Patient Records Are Used in Medical Research

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Abstract

With one million people treated every 36 hours, routinely collected UK National Health Service (NHS) health data has huge potential for medical research. Advances in data acquisition from electronic patient records (EPRs) means such data are increasingly digital and can be anonymised for research purposes. NHS England’s care.data initiative recently sought to increase the amount and availability of such data. However, controversy and uncertainty following the care.data public awareness campaign led to a delay in rollout, indicating that the success of EPR data for medical research may be threatened by a loss of patient and public trust. The sharing of sensitive health care data can only be done through maintaining such trust in a constantly evolving ethicolegal and political landscape. We propose that a dynamic consent model, whereby patients can electronically control consent through time and receive information about the uses of their data, provides a transparent, flexible, and user-friendly means to maintain public trust. This could leverage the huge potential of the EPR for medical research and, ultimately, patient and societal benefit.

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KEYWORDS

dynamic consent; electronic patient record (EPR); medical research; confidentiality; privacy; governance; NHS; data linkage; care.data

The United Kingdom National Health Service

The UK National Health Service (NHS) provides health care for over sixty million citizens throughout their lives. Around one million people are treated every 36 hours [1], with vast amounts of information about patients’ treatment and outcomes collected in their medical records. These “cradle to grave” records are increasingly captured within electronic patient record (EPR) systems rather than on paper. The United Kingdom has national EPR coverage in primary care, and coverage in secondary care (hospital) is increasing. While these records are primarily for health care delivery, such data have huge potential for medical research as well.

The reuse of NHS health care data, such as is routinely stored in these EPRs, has enabled medical research for decades. It has led to a huge expansion in our knowledge, with associated important public health impact, through observational research in areas such as epidemiology, drug safety, outcomes research, vaccines, and health services research. Examples of positive benefit range from how, in the 1940s and 50s, national statistics played a major part in identifying the rising incidence of lung cancer mortality and discovery of its link with smoking, more recently, disproving a suggested link between the measles, mumps, and rubella vaccine and autism [2].

Much research has been possible in England through initiatives such as the Clinical Practice Research Datalink (CPRD), The Health Improvement Network, and QResearch, whereby researchers can access anonymized primary care EPR datasets [3]. Linkage of patient data to national cancer and mortality registers, and to Hospital Episode Statistics, has been available for researchers more recently [4]. As an indication of volume, there are now over 900 peer-reviewed publications from CPRD alone. Linked datasets have also been made available for research in the devolved nations, drawing on the strengths of a unique, widely used Community Health Index number in Scotland [5], and on linkage between health care and social care data in Wales [6].

However, despite clear health care benefits from analysis of high quality data, the success of EPR data for research may be threatened by a loss of trust from patients. Sensitivities abound which need careful management, particularly with respect to the confidentiality of health data. Perception by the public that their personal health care data are being used inappropriately, either shared with organizations such as insurance companies or being sold for profit, leads to distrust. This loss has been exemplified by adverse public reaction to NHS England's care.data program [7].

Public Concern and Confidence

Public and patient views about the confidence and trust in the use of EPRs cannot be considered homogeneous. Research has highlighted that the public are often broadly supportive of the use of EPR data for research, while concomitantly having little knowledge of how data held in EPRs are shared, and also articulating concerns about privacy of their data. For example, in a recent study, 80% of UK people supported confidential access to their medical records for research [8]. Nicolson [9] and Kass et al [10] highlight that the public had little knowledge of how their EPR was accessed, used, and shared. Support for EPR data sharing is often grounded in safeguards to protect privacy [8-12]. Concerns expressed within studies [13] and surveys [14] mainly relate to the type of recipient, (ie, anxieties are greater with respect to access by the pharmaceutical industry compared with university academics) anonymity, and types of information shared, with patients less willing to share information as it takes on more of a personal nature [15]. The potential for privacy breaches and data misuse are of particular concern [16]. Privacy invasion concerns were found to be greater among Scottish people, black and minority ethnic groups [12], and among those with lower socioeconomic status or living in rented accommodations [11]. These trends are repeated globally. A recent survey [17] among adult social media users in the United States indicated a willingness to share health data (92% with a medical condition agreed with sharing their health data to help research) despite potential risks (76% worried that health data that they share may be used in detrimental ways).

These concerns about the potential misuse of health data in EPRs are examined in the next section, which focuses on the challenges faced by England's care.data initiative. The dynamic consent approach, which manages patients' consent preferences, is presented as a possible solution.

Concerns About Care.data

Much important UK population health research has successfully used anonymized primary care data. Although much progress has been made, the United Kingdom does not yet have national coverage of EPRs within secondary care. Research into medical conditions managed in hospitals has required bespoke research studies at significant cost and effort, for example, the establishment of national drug safety registers for medication prescribed only by hospital specialists [18]. Access to routinely collected data from emergent hospital EPR systems could solve this problem. Linkage of EPR data across primary and secondary care would enable examination of health problems managed in both settings. Indeed, NHS England's care.data program plans to collate general practitioner records and link to hospital records on a national scale, significantly increasing the volume and depth of data for research and other uses [19]. In time, wider linkage to other information such as social care, dental records, and biobanks will progress [20]. This paradigm shift in "big data" would expand research opportunities, but, as the public response to care.data revealed [21,22], it also raised important challenges in terms of patient confidence and trust in how EPRs are used in medical research. These challenges include anonymity and the role of consent. When more and more parts of an individual's information are pieced together, even if anonymized, the chances of reidentification increase [23]. As more datasets are linked and whole genome sequencing becomes part of standard clinical care, this problem will worsen [24], and risk loss of public trust.

Personal data are routinely collected in the NHS with patients' implicit consent, with data processing governed by the Data Protection Act (DPA). Access to personal health care data is permitted only for those directly involved in their care. Informed, explicit, and voluntary (opt-in) consent is required for access to identifiable patient-level data for research. However, consent is not required when anonymized data are used for research. Linkage of personal data from primary and secondary care by the care.data program does not require patient consent under the Health and Social Care Act (2012). This individual-level data is only subject to limited anonymization [22]. Nevertheless, a fair processing obligation under the DPA requires that data subjects know what happens to their data. NHS England's two main approaches to ensure fair processing are: (1) an opt-out process with the default assumption that routine NHS data can be used for approved research, and (2) a public awareness campaign to inform patients of data processing and use. There have been criticisms of both.

Opt-Out Versus Opt-In

Opt-out makes the moral assumption that people are content for their anonymized health data to be used to benefit public health. However, anyone who objects to sharing data outside the NHS, or to sharing certain types of data, will have to opt-out of sharing any information with anyone [25]. Mass opt-out, perhaps worsened by misunderstanding of the risks, could result in a marked reduction of potential participants and threaten research validity. It is worth noting that opt-in systems also have challenges of uptake and representativeness for population research. Furthermore, proposed amendments to the European Union Data Protection Directive (95/46/EC) may render opt-out unlawful [26]. Opt-in relies on active patient participation. Some evidence shows that this is what people expect, despite not being legally required [15,27]. It avoids problems arising through patients feeling lack of control over the fate and flow of their electronic data [28].

Knowledge of the Data Recipients

In early 2014, care.data ran a public awareness campaign including a national leaflet delivery, a patient telephone information line, and social media activities. These described how health data from primary and secondary care EPRs may be used, who might receive it, provided reassurance on the safeguards in place, and explained how to opt-out. The campaign received criticism for not adequately conveying its benefits and safeguards [29]. Although the campaign met the DPA fair processing requirements and Caldicott 2 review recommendations [30], the population-level approach lacked reassurance of individual patient data flow. Advocates believe studying deidentified data in safe havens does not threaten confidentiality, but the public understanding of data safe havens is questionable, and needs proper explanation. Access by "other approved organizations" remains a grey area, raising concerns for potential participants [31]. At the time of writing, care.data rollout had been deferred [32]. The observed discourse between patients' general support for reuse of routine data for research and concerns raised around care.data may be explained by the ambiguous nature of the information disseminated in its awareness campaign. Also, the positive attitudes revealed from research cannot be easily translated to the care.data campaign; caution should be heeded in doing so, and experience warrants independent research.

Dynamic Consent in Medical Research

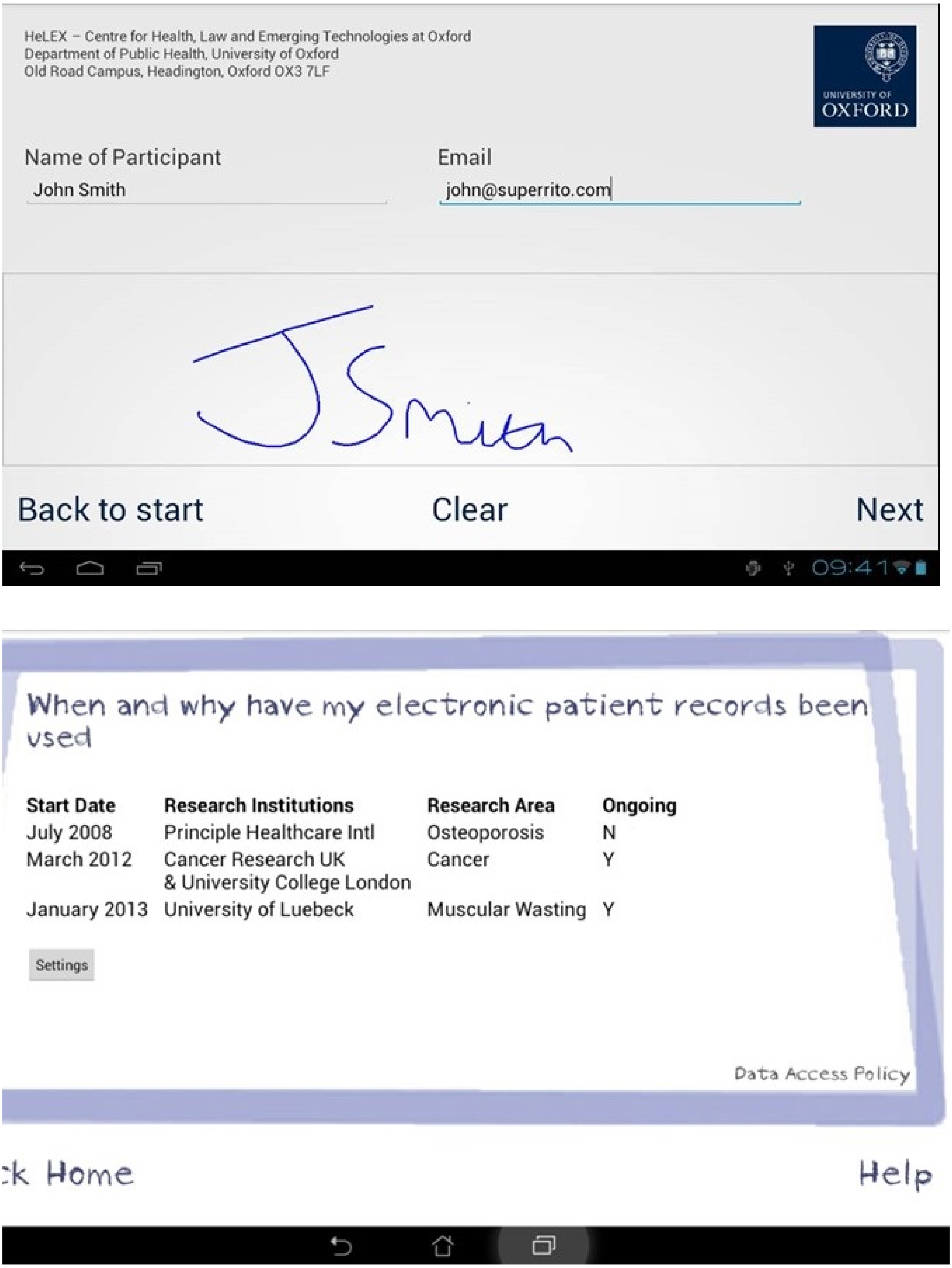
A solution to the challenges described above is to move to a more effective, on-going model of patient information and consent [33]. Using consent as the basis for sharing medical data stored in EPRs addresses the technological limitations associated with anonymization techniques, while also respecting the autonomy of patients. Making it dynamic could allow patients to more readily provide or withdraw their consent over time, while also providing information to patients about how their personal data are used. This could list data recipients, and demonstrate how EPR data sharing has contributed toward better health care by providing lay summaries of research results from the studies toward which their data have contributed.

The Dynamic Consent model [34] is one solution that provides a participant centered approach to consent (Figure 1). It provides additional functionality by exploiting technology to allow on-going engagement and maintenance of research participants' consent preferences ("expressions"). The UK Ensuring Consent and Revocation project [35] developed a prototype comprising privacy-enhancing technologies, such as policy-driven privacy-aware access control and obligation management, within an overall Web 2.0 compatible technical architecture. State of the art enterprise information technology and cryptographic techniques wrap and bind patient information with consent expressions and enterprise policies. Novel techniques such as attribute-based encryption [36], identity-based encryption [37], and functional encryption [38,39] each provide suitable techniques for the binding of different classes of metadata with information, and the control of access to that information. Information can flow throughout and between health care information systems, while assuring patient information is handled in accordance with regulations. Patients could also track and audit their information usage, change privacy settings, and choose how and when they are contacted [34]. It enhances confidence by passing control to patients, with data flow controlled at the level of consent, thereby avoiding the broad opt-out, which does not satisfy a patient's wish to allow access to some groups/projects, but not others (ie, academic researchers, but not the pharmaceutical industry). It also avoids problems arising through patients feeling they have no control over the fate of their EPR, and because of this, may avoid seeking treatment through fear of insurance refusal, loss of employment, or stigmatization [28]. The implementation of Dynamic Consent through a convenient computer-based interface allows for the possibility of using videos, animation, and other formats to increase the communication to the patients, including the presentation of lay summaries of research results.

A legitimate concern raised by Dynamic Consent is that it may present new ethical questions around user coresponsibility and social exclusion [13]. Representative uptake might be problematic, as groups with lower socioeconomic status may be less likely to engage with opt-in models [21,22,40].

At the institutional level, Dynamic Consent implies an e-infrastructure that is able to collect consent, to allow data permissions to direct the flow of data to recipients, to capture a complete audit trail of data recipients, and to receive comprehensive, up-to-date lay summaries of research findings to feed back to patients. Scalability is thus constrained by the provision, maintenance of such systems, and infrastructure. We are currently exploring hospital patients' perceptions of health information security, and the role of consent in health data use and EPR access, with positive early results.

Figure 1. Dynamic consent interface. The origin of the image is from HW Communications and the University of Oxford.



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When and why have my electronic patient records been used

Start Date	Research Institutions	Research Area	Ongoing
July 2008	Principle Healthcare Intl	Osteoporosis	N
March 2012	Cancer Research UK & University College London	Cancer	Y
January 2013	University of Luebeck	Muscular Wasting	Y

Conclusions

Dynamic Consent alone will not adequately provide a population of well informed, engaged, and e-Health literate research participants. However, it does provide a platform to develop the ethical and engagement framework to ensure respect for the rights, needs, and expectations of diverse participants. It may also play a role in widening participation in an age where health care is increasingly characterized by digital innovations. As the experience of care.data has shown, public trust is fundamental to the successful use of data held in EPRs. Dynamic Consent may provide a transparent, flexible, and user-friendly means to inform and maintain that trust.

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Authors' Contributions

HW, KS, and WD wrote the first draft, with EW, DL, JK, and CS providing technical and ethicolegal advice.

Conflicts of Interest

None declared.

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Abbreviations

CPRD: Clinical Practice Research Datalink

DPA: Data Protection Act
EPR: electronic patient record
NHS: National Health Service

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Original Paper

Impact of Information Technology on Information Gaps in Canadian Ambulatory Care Encounters

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Abstract

Background: Specialist physicians require clinical information for patient visits in ambulatory encounters, some of which they may access via digital health solutions.

Objective: This study explored the completeness of information for patient care and the consequences of gaps for ambulatory specialist services provided in ambulatory settings in Canada.

Methods: A sample of specialist physicians practising in outpatient clinics was recruited from a health care provider research panel. The study (n=1800 patient encounters) looked at the completeness of patient information experienced by physicians who work in environments with rich health information exchange (Connected) and a comparison cohort with less information available electronically (Unconnected).

Results: Unconnected physicians were significantly more likely to be missing information they needed for patient encounters (13% of encounters for Unconnected physicians vs 7% for Connected physicians). Unconnected physicians were also more likely to report that missing information had consequences (23% vs 13% of encounters). Lab results were the most common type of patient information missing for both Unconnected and Connected specialists (25% for Unconnected physicians vs 11% Connected physicians).

Conclusions: The results from this study indicate that Canadian physicians commonly experience information gaps in ambulatory encounters, and that many of these gaps are of consequence to themselves, their patients, and the healthcare system. Wasting physician and patient time, as well as being forced to proceed with incomplete information, were the most common consequences of information gaps reported.

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KEYWORDS
digital health; information gaps; ambulatory; outpatient

Introduction

Ambulatory care includes a wide range of health care services for patients who are not admitted overnight to a hospital. These services are performed at outpatient clinics, urgent care centers, ambulatory or same-day surgery centers, diagnostic and imaging centers, primary care centers, community health centers, occupational health centers, mental health clinics, and group practices. Canadian Institute for Health Information reported 34 million hospital ambulatory care service visits across all provinces (excluding Quebec) in 2011-2012 [1]. The vast majority of these patients would also receive care in other settings, such as from primary care providers, making continuity and coordination of care a priority.

Evidence suggests that information availability in ambulatory care settings is an important factor for productivity and quality of care [2-5]. Some research has looked at the impact of information technology and health information exchange on addressing ambulatory care information gaps in specific settings [6-9] with generally positive findings, but there is a need for further research in the Canadian context on the impacts of information technology in these diverse and complex settings.

Canadian hospitals, health authorities, and governments are making significant investments in both local digital health solutions and broader health information exchanges, with increased adoption resulting from these investments. In 2006, there were approximately 7600 users of electronic health records that share information across settings. By 2014, this had increased significantly to over 62,000 users across Canada [10]. Primary Care Physician use of electronic medical records in their practices increased from 24% in 2007 to 64% in 2013 [11].

This study explored the completeness of information for patient care and the consequences of gaps for ambulatory specialist services provided in ambulatory settings in Canada. The completeness of information is based on the extent of information available to physicians electronically from within their practice setting through their own electronic medical record and beyond through access to jurisdictional electronic health record services.

Methods

A sample of 18 specialist physicians practicing in outpatient clinics was recruited from a health care provider research panel. Physicians who do not see patients in an ambulatory setting, those who never require lab or diagnostic imaging results and those who were not from the nine target specialty groups were removed from the sample. Those that remained were segmented into three groups based upon their reported use of information technology in their main ambulatory setting:

1. “Connected” physicians (63% of qualifying physicians with n=9 recruited for this study) had access to and used comprehensive digital health solutions within their practice settings, such as electronic medical records or hospital information systems. For example, 8 of 9 physicians have entered encounter notes electronically and 9 of 9 could electronically view lab and diagnostic imaging reports that they had ordered. They also had access to patient information from outside their practice setting through health information exchanges (8 of 9 for lab results, 9 of 9 for diagnostic imaging reports, 9 of 9 for a full medication history, and 8 of 9 for referral notes).
2. “Unconnected” physicians (15% of qualifying physicians with n=9 recruited for this study) had similar access to internal digital health solutions (7 of 9 could access lab and diagnostic imaging reports for tests that they ordered), but only 1 of 9 entered clinical notes electronically. They had less external connectivity, with 1 of 9 able to access lab data from other providers or settings and 1 out of 9 with electronic access to referral notes.
3. “Partially connected” physicians (22% of qualifying physicians with none included in this study) had some use of digital health use within their practice setting.

This distribution is generally consistent with the variations in digital health use in Canadian ambulatory clinics. Access to internal hospital systems for laboratory and diagnostic imaging test results is now common across the country, with varying levels of progress in implementing health information exchanges in different regions [12]. For example, as shown in Table 1, while the 9 Connected physicians are from across the country, there is a heavier concentration in the western Canada. There was also a mix of specialist types across the two study groups.

Table 1. Specialty/region matrix for Connected and Unconnected physicians.

		IT Enabled				Non-IT Enabled			
Region		West	Ontario	Quebec/East	Total	West	Ontario	Quebec/East	Total
Specialty									
	Cardiology						1	2	3
	General Internal Medicine	1	1		2			1	1
	Endocrinology						2		2
	Nephrology								
	Oncology		1	1	2				
	Ophthalmology	1			1	1		1	2
	Orthopedics						1		1
	Surgery	1	2	1	4				
	Urology								
Total		3	4	2	9	1	4	4	9

The 18 physicians that participated in this study collected data about information needs, gaps, and impacts at each of 100 distinct patient visits randomly selected using Canada Health Infoway’s Patient Data Collection form for a total of n=1800 individual patient encounters. For each encounter, this form was used to capture the need for patient information such as lab results, diagnostic images and reports, medications and referral/clinical notes, the completeness of that information, and the consequences of any information gaps. Differences between the Connected and Unconnected groups were evaluated using a *t* test, *P*=.05, as calculated using Quantum 5.8.

Physicians collected data between July 17 and August 12, 2013. They were offered an incentive of around CAN $500 for 100 completed forms. Ethics approval was obtained from the Sudbury and District Health Unit Research Ethics Review Committee.

Results

Physicians reported that one or more types of patient information were required for almost all of the 1800 ambulatory clinic visits tracked in this study. As shown in Table 2, clinical/referral notes were most often needed (95% of encounters), followed by lab results and medications at 71% and 67% respectively. Immunization information was least often needed of the 8 types of information included in the Patient Data Collection Form (required in 3% of encounters).

Table 2. Proportion of all encounters for which a specific type of information was required.

Information Needed	Base	Proportion %
Clinical/Referral Notes	1715	95%
Lab Results	1280	71%
Medications	1211	67%
Diagnostic Imaging	1060	59%
Allergies	750	42%
Discharge/ED Reports	531	30%
Specialist Referral/Appointment Status	300	17%
Immunizations	62	3%
All Encounters Total	1800	100%

Connected physicians were more likely than Unconnected physicians to report having the patient information they needed during clinical encounters. This was true across all of the five types of information most often required (see Figure 1). The largest differential between the two groups was missing lab results (25% Unconnected vs 11% Connected) or diagnostic imaging test results (20% Unconnected vs 11% Connected).

In addition to analyzing results by Unconnected versus Connected, New Patient encounters versus Regular Patient encounters were also explored. At an overall level, information gaps of any type were more common for patients new to the physician (15% of such encounters), than patients the physicians have previously seen (7% of encounters).

Information gaps for Connected physicians were more likely to result in “no action required”, or there was no consequence to the missing information, compared to information gaps for Unconnected physicians (see Figure 2). Across the 900 encounters in the Connected group, 87% of the time, physicians either indicated “no action required” or identified no impacts related to information gaps. That compares to 77% of encounters for the Unconnected group.

There were statistically significant differences in the impacts of information gaps between the two groups for five of the six types of potential impacts investigated. It is also important to note that consequences of information gaps existed for both groups, Connected and Unconnected; however, Unconnected physicians were more likely to have to take action because of the missing information than Connected physicians.

Physician time was more likely to be wasted because of information gaps with Unconnected physicians (13%) compared to Connected physicians (10%). Likewise, as a result of missing information, patient time was more likely to be wasted for Unconnected physician encounters (9%) compared to Connected physician encounters (5%). While re-ordering of tests was less common for both groups, the Unconnected group was significantly more likely to report re-ordering a lab test or diagnostic imaging because of information gaps (5% and 3% of encounters respectively), compared to 2% and 1% of encounters with Connected physicians, respectively. With over 34 million ambulatory care encounters in Canada annually, even differences of 2-3% in test volumes are meaningful and substantive in terms of daily patient volume, costs, and impact on the patient. The largest differential between Connected versus Unconnected physicians is where physicians indicated they were forced to proceed with incomplete information, which impacted 4% of encounters for the Connected group and 13% for the Unconnected group.

Figure 1. Missing information by required patient information.

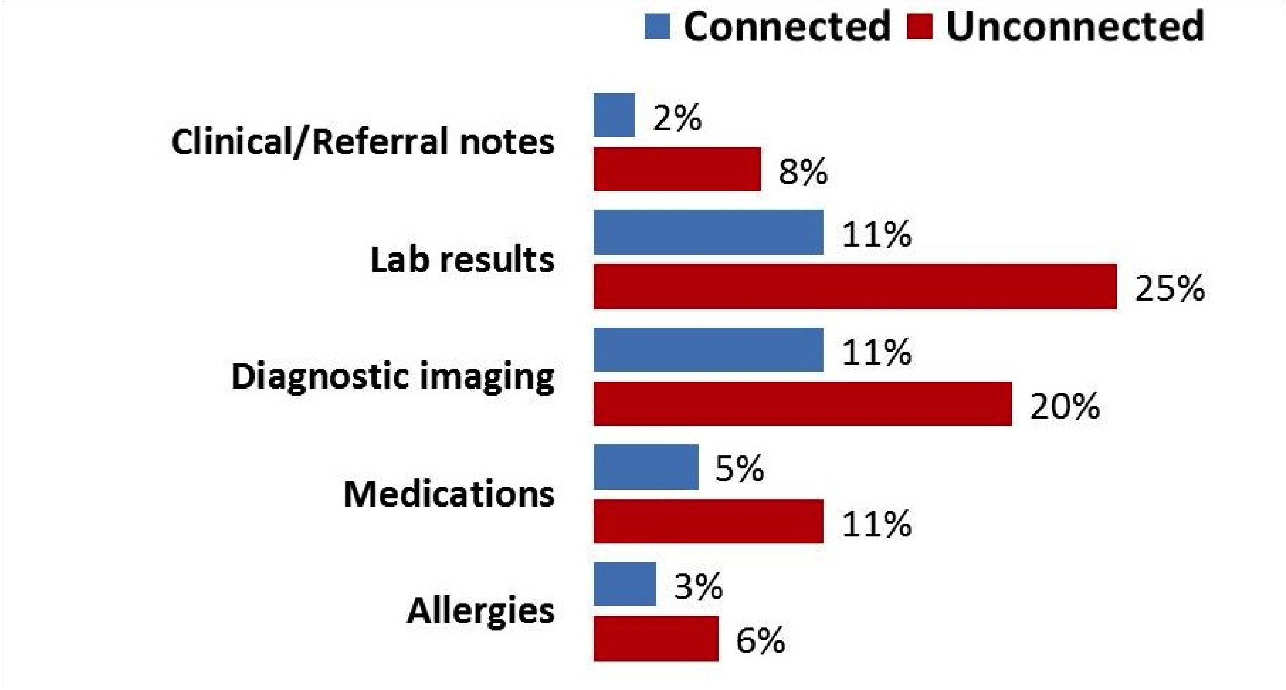
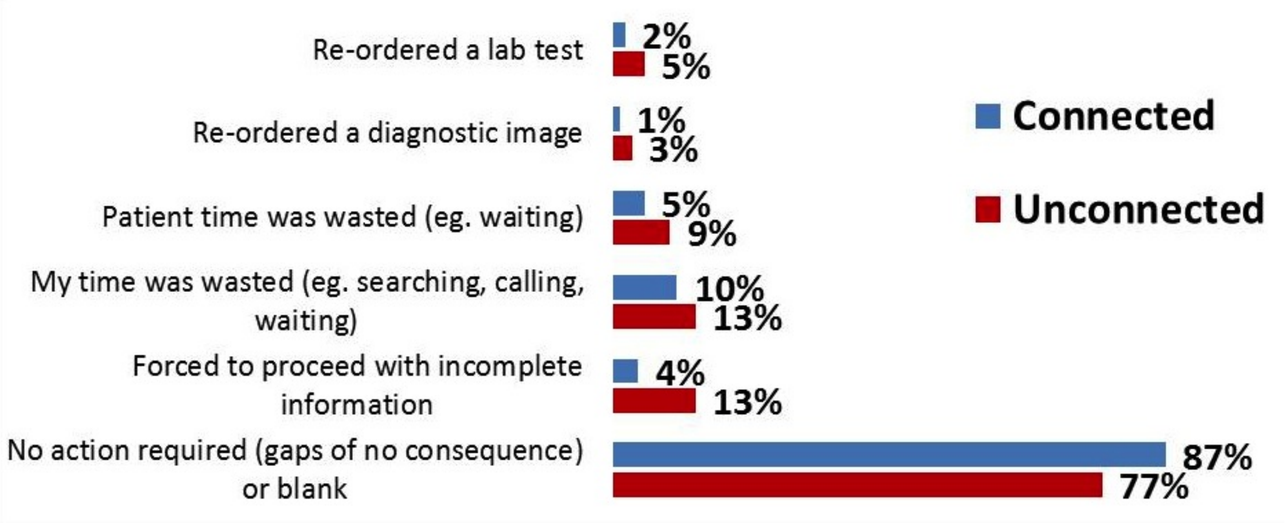


Figure 2. Impacts of missing information.



Limitations

While the sample size in terms of physicians (n=18) across a diverse group of specialties is a limitation of this study, the total number of encounters studied (n=1800) provides a robust basis for analysis. Due to the sample size, we were not able to match specialist types or geographic regions across the two groups. Potential diversity in information needs across specialty types is mitigated by focusing on gaps only for information types that physicians report being required in each encounter. It should also be noted that the existence of information gaps and the related impacts were subject to interpretation by the participating physicians.

Discussion

The number of patients being seen in ambulatory clinics is rising, both in Canada [13] and in other countries. These patients tend to be receiving care in multiple settings from a variety of providers, making care coordination important. Investments in local digital health solutions and broader health information exchange aim to help address this challenge.

The results from this study indicate that Canadian physicians commonly experience information gaps in ambulatory encounters, and that many of these gaps are of consequence to themselves, their patients, and the healthcare system. However, Connected physicians (those who indicate they have more robust internal and external electronic access to patient information) are much less likely to experience information gaps compared to Unconnected physicians. Information gaps experienced are also more likely to have a material impact for Unconnected physicians and their patients. The findings thus support the drive to increase availability and adoption of digital health solutions and health information exchange in order to provide authorized clinicians with more complete information to support patient encounters.

This study also generates some important questions for further research. While having access to electronic information from both inside and outside the organization reduce the incidence of information gaps and related impacts, there are still 13% of encounters in the Connected group where action was required or the gaps had other consequences. A better understanding of the source of these gaps will be important for continuing to improve health care quality, including coordination and continuity of care. Likewise, for both groups it would be helpful to understand the magnitudes of time wasted, implications of being forced to proceed with incomplete information, and consequences of having to re-order laboratory or diagnostic imaging tests.

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Conflicts of Interest

None declared.

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Original Paper

Teleophthalmology for First Nations Clients at Risk of Diabetic Retinopathy: A Mixed Methods Evaluation

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Abstract

Background: Access to health services is a particular challenge for First Nations (aboriginal Canadians) communities living in remote or underserviced areas. Teleophthalmology can provide them with the same level of retinal screening services provided to those in urban centers. This screening can lead to the identification of high-risk individuals who can then be monitored and receive treatment related to their diabetes or other health issues.

Objective: The intent was to develop, implement, and evaluate a service delivery model for teleophthalmology screening and follow-up for at-risk and diabetic First Nations clients on Vancouver Island, British Columbia, Canada.

Methods: A highly consultative, culturally appropriate, and collaborative approach was used to develop and deploy a teleophthalmology service delivery model to First Nations communities. This project was evaluated with regard to utilization and operational costs. Also, clinicians and team members involved in the teleophthalmology project provided assessments of the teleopthalmology quality, productivity, and access. Health providers in First Nations communities provided their perceptions of areas of improvement for the remote retinal screening services, areas where expansion of services could be offered, and opportunities to increase client education and health promotion.

Results: All 51 First Nations communities on Vancouver Island expressed interest in receiving teleopthalmology services. During the 1-year project, teleopthalmology clinics were held in 43 of 51 communities on Vancouver Island. During these clinics, 524 clients were screened and 140 of those clients were referred to a general ophthalmologist, family doctor, retinal specialist, optometrist, or other provider. Ratings of teleopthalmology system quality, information quality, service quality, and system usage were positive. Satisfaction with the teleopthalmology project was high among clinicians involved with the project. Satisfaction was also high among health providers in First Nations communities, with clinic scheduling identified as a potential area of improvement moving forward. The average cost savings per client, taking project costs into consideration, was calculated to be CAN $28.16, which was largely due to the elimination of client travel costs.

Conclusions: Teleophthalmology was a welcome addition to health services by the First Nations communities on Vancouver Island, as evidenced by the 100% rate of interest from those communities. There was no evidence of dissatisfaction by clinicians involved in the teleopthalmology project or by First Nations community health providers. The now-operational teleopthalmology program is a testament to the early success of the project.

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KEYWORDS

Ophthalmology; Diabetic Retinopathy; Telemedicine; Mobile Health; underserved populations

Introduction

Overview

Aboriginal peoples living in Canada are among the highest risk populations for diabetes and related complications [1].

For First Nations communities, which are most often remote and geographically isolated, availability of primary health care is often reduced, and access to secondary and tertiary care can be challenging or non-existent. This includes access to eye-related services such as ophthalmology and optometry, which are important for at-risk and diabetic individuals.

Teleophthalmology enables remote populations to access retinal screening services provided more readily in urban centers. This screening can lead to the identification of high-risk individuals who can then be monitored and receive treatment related to their diabetes or other health issues.

Mobile screening initiatives for First Nations and aboriginal populations have previously been conducted and evaluated in Canada. A retinopathy remote screening pilot project among Quebec First Nations populations found positive outcomes with respect to satisfaction among community members and users, and financial and societal costs [2]. In Alberta, a mobile screening program for diabetes complications in aboriginal communities was found to be effective with respect to clinical outcome measures [3]. Mobile diabetic retinopathy screening among isolated First Nations people in remote Ontario has been shown to be cost-effective [4]. Teleophthalmology screening for diabetic retinopathy through mobile imaging units in five Canadian provinces was shown to efficiently lower barriers to screening and create new screening opportunities for a large number of known diabetic individuals who would not have been screened in the traditional health system [5].

This Initiative

The teleopthalmology project began in November 2008 and was officially launched on May 14, 2010. The project was led by the Inter Tribal Health Authority (ITHA) in British Columbia (BC), in collaboration with the Vancouver Island Health Authority (VIHA). The project concluded in July 2011, at which time it became and still remains an operational program.

Objectives

The objectives of the teleophthalmology project were to develop and implement an effective teleophthalmology service model, which included an accessible and integrated mobile retinal screening and tracking service. This teleophthalmology service model would be implemented for high-risk populations (specifically, First Nations peoples and diabetics) in rural and remote populations at risk of retinopathies. A target of 600 people at risk of retinopathy was set for screening. It was anticipated that the service model developed and used for the teleophthalmology project would provide a basis for a broader provincial program.

The project focused on retinal health and eye disease, and was not intended to replace routine visits to optometrists. In fact, referrals resulting from teleophthalmology visits would include referrals to optometrists.

Methods

Framework

The Canada Health Infoway Benefits Evaluation Framework [6] provides a high-level evidence-based model to guide evaluations of health information systems. It includes six main dimensions of system quality, information quality, service quality, use, user satisfaction, and net benefits. The Benefits Evaluation Framework was referred to as a guide to determine the evaluation design and to identify measures.

Recruitment, Communication, and Community Engagement

Matters of communication and community engagement were particularly critical to ensure awareness of vision-related disease among diabetics in First Nations communities and acceptance of the teleophthalmology project. Adherence to, and respect of, First Nations' cultural values were considered to be the most important aspects and success factors of the project.

The first 5 months of the project were dedicated to implementing a community engagement strategy. The teleopthalmology project team sent letters to all 51 First Nations communities on Vancouver Island to determine the communities' interest in a short presentation about the project.

The communities were invited to attend project launch meetings. Representatives from all communities attended these meetings, which served as informational sessions that invited participation in the teleopthalmology project. Attendees included chiefs, band members, community nurses, and representatives from both VIHA and ITHA. These meetings adhered to cultural protocols, and were widely publicized by the media, sponsors, and ITHA. Key messages pertained to awareness about the project, the importance of retinal screening, and implications for those suffering from diabetes.

After the meetings, representatives from First Nations communities that were interested in participating in the project were welcome to contact the teleophthalmology project team. Clinic dates and times for communities were determined based on the communities' availability and preferences.

As well, a letter of intent was also sent to the British Columbia Association of Optometrists to its members of the teleophthalmology project. This letter provided details about the project, and also explained that the project was not intended to replace optometrist visits or discourage clients from making routine visits with optometrists.

Project Resources and Governance

Overview

The Inter Tribal Health Authority was responsible for overall management and direction of the project. Various ITHA team members developed materials, put together the community engagement strategy, developed and delivered communications with stakeholders, and addressed logistical and technical matters. A Telehealth Project Office was instituted within ITHA, and the provincial Telehealth officer oversaw the project.

A medical advisor and clinical advisory group were put in place for this project. They provided medical expertise, community engagement advisement, and acted as a sounding board to ensure that the project operated in a culturally appropriate manner with the First Nations communities. The clinical advisory group consisted of administrators, ophthalmologists, First Nations leaders, various health care providers, ITHA leaders, and teleophthalmology project team members. One key representative from each of the three language groups across Vancouver Island was invited to join the clinical advisory group to guide and protect their interests and convey information to and for their communities.

Identification of Target Clients

Potential clients were initially identified through a combination of activities and information sources, and in cooperation with the existing chronic disease management (CDM) program and health services providers. The participating First Nations communities provided ITHA with lists of individuals in their communities who were diabetic, individuals previously diagnosed and treated for type 1 or type 2 diabetes, individuals at risk of diabetes, or individuals with a family history of diabetes.

These individuals received phone calls from the ITHA team to schedule individual screening appointments during clinics to be held in their communities. Other individuals also learned about upcoming clinics in their communities through local health care providers and by word of mouth. The clinical advisory group recommended that an open door policy exist for the screening clinics, and individuals who self-referred to the clinics also received services.

Development of Teleophthalmology Service Delivery Model

Overview

The teleophthalmology project involved the implementation of a service delivery model, including the technology to deliver services. The service delivery model arose from a detailed workflow analysis directed by the clinical advisory group and the medical advisor. A comprehensive clinical procedure and protocol manual was developed by ITHA to define and standardize how the mobile teleophthalmology clinics would be conducted. It identified all processes, materials and equipment, and roles involved. The manual included the teleophthalmology service delivery model.

Description

Overview

This teleopthalmology service delivery model provided early retinopathy detection services to residents of rural and remote communities, and utilized a proven pathway for effective treatment of retinopathy that can reduce incidence, as well as social and economic impacts, of blindness and vision impairment [7].

The service delivery model provided the following set of services: retinal screening, triage, treatment, and tracking. A description of the activities and workflow are discussed below; following that is a description of the technology and equipment.

A team of two First Nations technicians and a trained teleopthalmology eye care nurse travelled to the remote First Nations communities within the geographic region of the VIHA. They travelled in a truck that was dedicated to the teleopthalmology project; the truck was fully outfitted with the equipment required to hold the clinics.

Wherever possible, clinics were held within existing health centers in the communities. In some cases, they were held in community centers or gymnasiums, with provisions made for client privacy during appointments. Clinics typically operated from 8am until 4pm, varying based on travel schedule and client volume.

Client Appointments

The nurse registered individuals upon their arrival to the clinics. In the waiting area, clients were given pamphlets that explained the importance of the teleopthalmology project. They were also given small MP3 players with which to listen to diabetes education content while awaiting their appointments.

The clients were then assessed for details of visual function, intraocular pressure, and three-dimensional digital photographs of the anterior and posterior segments of the eye. Alcaine drops were used for freezing prior to intraocular pressure testing and Tropicamide drops were used for dilation. Pilocarpine drops were kept in case of a close angle glaucoma reaction. Drops were administered by the nurse. Figure 1 shows a teleopthalmology screening appointment.

Client data collected for registration and screening included: demographics, an abbreviated medical history, tonometry, and visual acuity results.

Figure 1. Teleophthalmology screening appointment.

Medical Assessments

The technicians securely uploaded images to the ITHA Data Centre for subsequent assessment by either an ophthalmologist in Comox, BC or a retinal specialist in Victoria, BC. Their documentation and reports included recommendations for follow-up examinations or specific additional tertiary examination and treatment. Figure 2 shows how grading physicians viewed results.

Figure 2. Grading physician review of results.

Follow-Up

Follow-up communications and appointments proceeded based on the grading assessments and results. The teleopthalmology project at ITHA effectively operated as a satellite office for the ophthalmologist and retinal specialist by scheduling follow-up appointments with other eye specialists on Vancouver Island based on the type of referrals made during the grading of the retinal images.

All clients were contacted after their appointments regardless of the outcomes of their assessments. They were mailed a copy of the teleophthalmology report unless mailing addresses were unknown. In those cases, reports were sent via fax to the clients' local community health units. The clients' physicians also received a copy via mail.

ITHA produced a weekly summary for the clinical advisory group. It combined the standard reports used by the teleopthalmology project team (ie, Client Summary Report, the Follow-Up Report, the Diabetic Retinopathy Report, and the Referral Report).

Technology and Equipment

Mobile units contained program equipment and disposable clinic supplies. These included a retinal camera, peripheral devices, laptop, image capture software, and travel containers.

The camera was a Topcon NW6-S Retinal Camera, which weighed 89 lb including the case. A truck lift was required for the vehicle, and a two-person lift was required where planes, barges, and boats were involved. Setup time was 30 minutes for the camera, table, laptop, and chair.

The software used by mobile screening clinics was a combination of IMAGENet [8] and the Secure Diagnostic Imaging (SDI) application [9]. IMAGENet enabled the capture of images and the SDI application provided a standardized format for the grading physicians. Seven-field stereoscopic imagery was used as the standard to build complete image sets of each eye. This provided the grading physicians with a three-dimensional high-resolution perspective of the eye similar to a live exam. Figure 3 shows the user interface. The SDI application also produced a final report that was used as the basis for any subsequent referrals. Client data was then synchronized with the Intrahealth Profile Electronic Medical Records System for more detailed administrative and clinical management [10]. Intrahealth Profile was also used to capture client demographics upon registration, record measurements, document screening appointments, create client letters, and manage follow-up and referrals.

The retinal images that were captured during the clinics were securely uploaded, stored, and backed up on a daily basis. This was an important consideration for First Nations in BC, as autonomy and ownership of First Nations data is foremost in the adoption of new health information systems. The First Nations Principles of Ownership, Control, Access and Possession (OCAP) apply the concepts of self-determination and self-governance to research, statistics, and information involving First Nations communities. The Inter Tribal Health Authority ensured that the project strictly adhered to OCAP principles.

All data was stored at the ITHA data center, a First Nations operated data storage facility located in BC. The Inter Tribal Health Authority is a First Nations organization; it controls, stores, and owns the data collected in the project. It is on Snuneymuxw territory enabling the physical possession of the data on First Nations land consistent with the OCAP protocol.

Figure 3. Screenshot of grading system.

Implementing the Service Delivery Model

Training and capacity building for the teleopthalmology project include three unique aspects: specialized one-to-one training, job shadowing, and capacity building among First Nations youth. Detailed logs by clinic members were kept and reviewed to continually improve project operations.

Specialized one-on-one training for team members with an SDI and teleophthalmology expert addressed clinical processes and client care, retinal image photography, equipment maintenance, secure image transmission, mock clinics, and cultural protocols.

Job shadowing took place in the offices of the grading physicians—the ophthalmologist in Comox, BC and the retinal specialist in Victoria, BC. During these work experiences, the nurses and technicians were able to see how the clinics operate, how retinal scans were taken, and how clients were treated in busy urban practices.

One of the known deficiencies in the aboriginal health field is the markedly low level of First Nations people trained in health care professions. The teleopthalmology project provided a capacity building opportunity to three First Nations youth and supported their continued education and work experiences.

Each member of the teleopthalmology team maintained detailed logs of each clinic that was delivered. These logs were free-form, hand-written notes about team members' experiences and lessons learned from each clinic. They pertained to logistics of booking the clinics, equipment, perceived assessments of the clinics, and observations about cultural protocol. The hand-written notes were converted to electronic format by the technicians upon returning to ITHA offices. They were all incorporated into a Microsoft Word document that continued to be updated with information to assist in the continual improved provision of the clinics.

Evaluation Approach

Overview

The evaluation for the teleopthalmology project involved multiple data collection sources and activities. These were: utilization measurement, system and use measurement, community health provider feedback, and operational cost measurement.

The ITHA teleopthalmology team conducted analysis for the various data collection activities. The primary author of this paper worked with the second author (the ITHA teleopthalmology team leader) to synthesize this analysis, conduct additional analysis, and develop the paper.

Utilization Measurement

Individual client records from the SDI database were summarized and compiled for analysis. Reports from the SDI program were used to produce summaries from the retinal screening clinics. These included the number of clients screened, the number of clients referred, and the results of diagnoses by the grading physicians.

System and Use Measurement

The System and Use Survey (S&U Survey) was developed by Canada Health Infoway as a tool to assess quality and use of health information technology systems and also to flag obstacles to the adoption of systems and the realization of net benefits from them. The S&U Survey was customized to consist of 25 questions and was designed to determine initial reaction to the screening solution in relation to quality, productivity, and access. Multimedia Appendix 1 provides the S&U Survey used for the teleopthalmology project.

The S&U Survey was developed in a web-based format using SurveyMonkey and sent via email to clinicians involved in the teleophthalmology project. Clinicians were also given the option to request and submit a paper version of the survey.

Survey results were extracted and interpreted by the ITHA project team using simple univariate analyses.

Community Health Provider Feedback

The Community Health Provider Feedback Survey was developed by ITHA for this project. The survey, which was administered using SurveyMonkey, consisted of 10 questions. It was designed to solicit feedback on the retinal screening clinics from those who deliver health care in each of the communities. It asked respondents to identify areas where the retinal screening service could improve, to identify areas where expansion of services could be offered, and to identify opportunities to increase client education and health promotion. Multimedia Appendix 2 provides the Community Health Provider Feedback Survey.

The teleopthalmology project team sent a Web-based survey via email to 22 community health care providers from communities that had received retinal screening clinics during the past 11 months.

As with the S&U Survey, results from the Community Health Provider Feedback Survey were extracted and interpreted by the ITHA project team using simple univariate analyses.

Operational Cost Measurement

Operational costs to support the delivery of the retinal screening clinics were examined and compared to what could be identified as pre-teleopthalmology costs for retinal screening.

Travel costs for each of the First Nations communities were tabulated based on then-current Non-Insured Health Benefits (NIHB) Health Canada reimbursement schedules. Additionally, Medical Services Plan (MSP) base costs for Optical Coherence Tomography (OCT) scans, general practitioners, and specialist referrals were applied to the relevant points in the service delivery model.

A value for average client travel cost was provided by the NIHB program. Travel costs for each First Nation were based on the distance to the nearest ophthalmologist, calculating the cost of a return trip to and from that ophthalmologist for each client. An additional 15% of travel costs were added for those cases where an escort for the client was required. This 15% value was recommended by the NIHB team, based on historical travel records.

Results

Screening Communities and Participants

Teleophthalmology screening was conducted in 43 of the 51 First Nations communities on Vancouver Island in the first year of operation (the evaluation period). These First Nations communities are listed in Multimedia Appendix 3, including volumes for screening and referrals by community. Although all 51 First Nations communities expressed interest in the teleopthalmology project, resource and time constraints allowed for the deployment of clinics in 43 of these communities during the first year.

In these 43 communities, 524 diabetic and at-risk individuals were screened. Table 1 shows the breakdown of clients screened by age and gender. Of the 524 at-risk individuals who were screened in the first year, 140 were referred for additional treatment. This represents 26.7% of all clients screened; these screened clients were from 30 of the 42 First Nations where screening clinics were held. In communities where there were referrals, between 12% and 100% of clients who were screened were referred.

Table 2 shows the overall breakdown of the type of referrals that were made following the delivery of the retinal screening clinics. It shows that the majority of referrals were for general ophthalmologist services.

The retinal screening revealed a variety of eye disease and health problems apart from diabetic retinopathies. Other conditions that were diagnosed included cataracts, glaucoma, hypertension, macular degeneration, and other vascular diseases.

Table 1. Breakdown of teleopthalmology clients screened (n=524).

Teleophthalmology clients		n (%), mean or total years
Total female clients, n (%)		296 (56.5%)
Total male clients, n (%)		228 (43.5%)
Average age, years		55
	Female	54
	Male	57
Youngest client, years		9
Oldest client, years		93

Table 2. Number of teleopthalmology clients per referral type (n=140).

Type of referral	n (%)
General ophthalmologist	102 (72.9%)
Family doctor	14 (10.0%)
Retinal specialist	12 (8.6%)
Optometrist	10 (7.1%)
Other	2 (1.4%)

System and Use Measurement

Overview

Of the eight participants invited to take the S&U Survey, seven individuals responded. All seven used the electronic format of the survey. These participants were teleopthalmology team members, including the system administrator.

Overall User Satisfaction

Five of the seven respondents were highly satisfied with the system in terms of ease, functionality, quality of information given, and quality of services provided for the system. Two respondents were moderately satisfied.

Six out of seven respondents strongly or moderately agreed with the following statements: “the system improves my productivity”, “the system improves the quality of care I can provide”, “the system makes my job easier”, “the system enhances our ability to coordinate the continuity of care”, and “the system enhances the efficiency of ordering retinal screening referring clients for onward treatment client follow-up”. For all of these, one respondent (the system administrator) indicated that these were “not applicable”.

For the following two statements, five of the seven respondents indicated that they strongly or moderately agreed and one indicated that she/he moderately disagreed: “the system improves our sharing of client information amongst providers”, and “the alerts, reminders and order set features (ie, support tools, reporting) improve the quality of my decision-making”.

Three of the seven respondents answered an open-ended question about aspects of the system that they would change, and if so, what they would be. These included better integration of the SDI tool with other health systems, more flexible reporting, the addition of mobile units to increase speed and efficiency of screening, and additional information provided in reports.

Two of the seven respondents answered an open-ended question about describing experiences with the system where it had supported the provision of care. One of the respondents, the system administrator, described witnessing the expedited manner in which providers conveniently worked together to identify conditions requiring immediate attention and avoiding dire clinical consequences. The other respondent attested to the timely and effective manner in which specialist care was provided to clients.

System Quality

Of the seven respondents, five rated the system as being highly acceptable and two indicated that it was moderately acceptable.

All seven respondents strongly agreed with the statement: “the system is reliable in its performance”. All seven respondents moderately agreed with the statement: “the system is integrated with my workflow”.

For the following statements, six respondents strongly agreed and one moderately agreed: “the system is easy to use”, “the response time is acceptable”, and “overall, the quality of the system is excellent”.

Four respondents strongly agreed, and three respondents moderately agreed with the statement: “the system features enable me to perform my work well”.

For the statement “the system security is acceptable”, five respondents strongly agreed, one moderately agreed, and one did not answer.

Information Quality

Four respondents rated the quality of the information provided by the system as highly acceptable, and three rated it as moderately acceptable.

The distribution of responses to statements regarding information quality were varied. Table 3 presents the results.

Table 3. Information quality ratings (n=7).

	Strongly agree	Moderately agree	Moderately disagree	Strongly disagree	Not sure	Not answered
The information is complete	2	5	0	0	0	0
The information is quickly provided	5	1	1	0	0	0
The information is accurate	4	3	0	0	0	0
The information is relevant	7	0	0	0	0	0
The information is available when I need it	4	3	0	0	0	0
The format and layout of the information is acceptable	4	2	1	0	0	0

Service Quality

Three of the seven respondents indicated that the quality of the services (ie, technical support and training services) provided for the system were highly acceptable.

For the statement “the implementation process within the Vancouver Island Health Authority catchment area was acceptable”, one respondent strongly agreed, four moderately agreed, and two indicated that they were not sure.

For the statement “the current level of training is acceptable”, four respondents strongly agreed and three moderately agreed.

Three respondents strongly agreed with the statement “the level of on-going support provided is acceptable”, whereas three moderately agreed and one was not sure.

System Usage

Users were asked how many times they use the system in a typical day. Four respondents indicated that they used the system constantly throughout the day. The other three respondents indicated that they used the system two to three times per day, one time per day, and three or four times per day. One respondent indicated that they used the system only 1 day per week, and did not specify how many times they typically used the system on that 1 day a week.

One respondent indicated that they used the system three or four times a day. Three respondents indicated that they used the system 5 days a week. Another respondent indicated that they used the system 3 days in a week.

Respondents were asked to indicate the percentage of their clients for whom they used the system. Of the six respondents to this question, four indicated that they did not know. Of the two respondents, one indicated 100% of clients and the other respondent indicated 95%.

All seven respondents indicated that they would definitely recommend the system to health care providers at other hospitals or centers.

Four respondents indicated that they would, given a choice, moderately increase their future use of the system. Two indicated that they would significantly increase use, and one respondent indicated that they would remain with the same use.

Other Comments

Two respondents provided additional comments in the survey. The comments related to future desired and planned functionality. One respondent indicated that the new business intelligence system connected to the SDI system would provide more progressive reporting in the future. Connection with Electronic Medical Records (EMRs) or “health networks” was also indicated as desired future functionality.

Community Health Provider Feedback Survey

Of the 22 community health providers invited to take the survey, 11 individuals responded. Responses to questions that did not relate to the teleopthalmology screening clinics, but rather current staffing complements, care delivery models and service provisions, are not included in this paper. These questions were included to inform ongoing development and deployment of teleopthalmology services.

With regard to being satisfied with how the retinal screening clinics were conducted in their communities, four of the respondents strongly agreed and six agreed.

Satisfaction with various aspects of how the ITHA retinal screening clinics was measured. Most were very satisfied or satisfied with all aspects, with very few neutral responses. No respondents were dissatisfied or very dissatisfied with any of the aspects. Results from the eight respondents to this question are summarized in Table 4, expressed in the number of responses per rating and aspect.

The survey listed potential areas for improvement for the teleopthalmology screening clinics. Two respondents cited that clinic scheduling could be improved. Communication with ITHA, length of clinics, and sharing of client results were each identified by one respondent as potential areas of improvement.

Six of seven respondents to the question about whether ITHA retinal screening clinics helped to raise awareness of diabetes self-management among participating community members indicated that they neither agreed nor disagreed. One respondent agreed. Four respondents skipped this question.

No respondents indicated any problems occurring during retinal screening clinics.

Table 4. Satisfaction ratings for retinal screening clinics (n=11).

	Very satisfied	Satisfied	Neutral	Dissatisfied	Very dissatisfied
Communication with ITHA	1	8	0	0	0
Clinic scheduling	1	5	1	0	0
Clinic setup	2	5	0	0	0
Communication with clients	3	4	0	0	0
Professional conduct of team	4	3	0	0	0
Length of clinic	1	6	0	0	0
Clinic dismantling	2	3	2	0	0
Follow-up with client results	3	3	1	0	0

Operational Cost Measurement

Costs were calculated using the assumption that teleopthalmology removes the need to have referrals from a general practitioner (GP) or ophthalmologist.

Traditional versus Teleophthalmology Cost Comparisons

The average per client total cost for traditional ophthalmology screening, according to MSP fees is CAN $647.15 ($92.10 for the specialist exam fee, $160.17 for the GP referral, and $182.92 for the ophthalmologist referral). The average per client travel cost for those clients who would have had to travel to see a specialist for a retinal scan was estimated to be $211.96. This figure was provided by the NIHB program, which provides payment for client travel. This amounts to a total cost per client of $647.15 for the traditional ophthalmology model.

The average per-client cost of teleopthalmology was CAN $590.81. A cost of $553.15 was incurred per client, according to ITHA general ledger entries for teleopthalmology operations. This included the salaries of the teleopthalmology team, travel costs, and medical supplies. In addition, the cost for an ophthalmologist to grade a retinal screen for the teleopthalmology project was $37.66. (No MSP fee codes had yet been created for teleopthalmology grading. A fixed rate of $37.66 per scan was set at the outset of the project. The MSP fee code application was beyond the scope of the teleopthalmology project.)

The direct per-client cost of teleopthalmology was CAN $56.34 less than the direct per-client cost of traditional ophthalmology screening.

Discussion

Principal Findings

The teleopthalmology project nearly achieved its goal of screening 600 clients in the first year through the delivery of the clinics via a single mobile unit and limited resources. One of the practical benefits of the teleopthalmology project was the establishment of a rough baseline of those individuals who were either at risk of diabetes or suffer from type 1 or type 2 diabetes. ITHA will now be able to use this baseline to monitor these individuals and provide additional preventative services in an effort to minimize complications and long-term detrimental effects.

The 140 clients who were referred by grading physicians were diagnosed with conditions (ie, cataracts, glaucoma, hypertension, macular degeneration, and other vascular diseases) that may have gone undetected and untreated for long or indefinite periods of time. In addition to the direct cost savings measured for this project, the savings of various indirect costs of worsened and further-progressed conditions (which may also be associated with additional co-morbidities) are possible benefits of the project. Many of the clients screened (and referred) may not have otherwise received care if it had not been made accessible to them via the teleopthalmology project.

Overall user satisfaction with the teleopthalmology system was high. System quality, information quality, and service quality all received favorable ratings.

User experiences with the teleopthalmology system were positive. Respondents planned to use the system no less than before or at the time of the survey. All seven respondents indicated that they would definitely recommend the system to health care providers at other hospitals or centers.

Providers in the First Nations communities rated the setup and operations of the clinics favorably. No dissatisfaction with any aspects of the clinics was indicated. A higher rate of participation from these community health providers would have been desirable to obtain a representative and comprehensive assessment of the teleopthalmology clinics.

The direct average cost savings per client was calculated to be CAN $56.34. The figures used in this evaluation underestimate the cost savings that teleophthalmology offers on an ongoing basis. The main reason is that the capital costs of the teleopthalmology project were included in the analysis; these initial costs were not intended to result in a return on investment in monetary terms nor were they limited to the timeframe of the project and evaluation. The setup cost for relevant components of the traditional health care system was not feasible or included for comparison. As well, the project now operates as an ongoing program, which benefits from greater economies of scale and efficiencies identified throughout the project. Importantly, teleopthalmology was not intended to be a cost-saving project or program, but was intended to improve quality of and access to health care services for First Nations communities.

Although not assessed in this evaluation, there are additional intangible and health-related benefits to clients and caregivers associated with the elimination of travel costs and increased access to screening services (which may prevent the progression of eye-related and other conditions that have impacts in terms of cost, client health and wellness, and caregiver burden). Other potential and indirect benefits that were not assessed include savings in terms of environmental and ecological impacts associated with travel to access health care services. Although not measured in this project, non-monetary impacts on client and caregiver travel such as physical exertion and stress are potential benefits to teleopthalmology.

Demonstrating support for First Nations youth contributed to the successful acceptance of the retinal screening clinics in First Nations communities. The project has also supported capacity building among First Nations people. The two technicians were of First Nations descent; they have gone on to pursue formalized accredited training as ophthalmic assistants.

Limitations

The evaluation of the teleopthalmology project involved a limited focus on teleopthalmology operations, usage, and costs. Future study could explore the impact of teleopthalmology on local and regional health systems as well as health outcomes of First Nations clients.

A low survey response rate from community health providers yielded a limited understanding of communities' experiences with the teleopthalmology project.

Post-Evaluation and Current Activity

Following the initial year of operations, the teleopthalmology project became an official program.

At this time, the teleopthalmology program serves 50 of the 51 First Nations communities on Vancouver Island, with approximately 1300 active clients. The teleophthalmology program now focuses on serving diagnosed diabetics, based on a synthesis of evidence that did not find a clinical benefit of retinal screening for non-diabetic clients [11].

There are now two mobile clinics that provide teleopthalmology services across Vancouver Island. Currently, the referral rate is 19.64% (down from 26.7% in the evaluation period). This may result from a reduced need for treatment and stabilization of health outcome.

The teleopthalmology program receives ongoing funding by the Aboriginal Diabetes Initiative (this is now received through the recently established First Nations Health Authority (FNHA) in BC, which was previously First Nations Inuit Health). The FNHA was established in 2013 as the first Canadian provincial health authority responsible for the planning, designing, management, delivery, and funding of First Nations health programs on a provincial level.

With time, the actual cost savings for the teleopthalmology program have increased compared to the cost savings measured in the teleopthalmology project. Improvements in clinic scheduling have led to the increase in the number of clients that receive retinal screening per clinic. Related to this, improved planning of clinics have contributed to reduced travel costs as multiple clinics are delivered per trip.

Moving forward, additional program costs may decrease with the potential successful establishment of an MSP fee code for Telehealth services that would reimburse grading physicians for their services. Currently, the FNHA provides this funding for grading physicians. During the teleopthalmology project, before the FNHA was established, the federal government via First Nations and Inuit Health (FNIH) provided this funding.

Empowering First Nations youth, in particular those with a willingness to reconnect with their peoples, has been a major point of success with the teleopthalmology program and continues to be a goal of the program. First Nations youth are considered to be uniquely qualified to engage with communities, as they understand the cultural protocols and landscape. The teleopthalmology program ensures that job postings reach youth in First Nations communities. It targets First Nations youth training centers, community events such as health and career fairs, and university First Nations study programs.

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Conflicts of Interest

None declared.

Multimedia Appendix 1

System and use survey.

[PDF File (Adobe PDF File), 426KB - medinform_v3i1e10_app1.pdf]

Multimedia Appendix 2

Community health provider feedback survey.

[PDF File (Adobe PDF File), 158KB - medinform_v3i1e10_app2.pdf]

Multimedia Appendix 3

Patient screening and referral volumes by First Nations community.

[PDF File (Adobe PDF File), 6KB - medinform_v3i1e10_app3.pdf]

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Abbreviations

EMR: electronic medical record
FNHA: First Nations Health Authority
FNIH: First Nations Inuit Health
ITHA: Inter Tribal Health Authority

MSP: medical services plan
NIHB: non-insured health benefits
OCAP: Ownership Control Access Possession protocol
OCT: optical coherence tomography
VIHA: Vancouver Island Health Authority

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Corrigenda and Addenda

Metadata Correction: Making Big Data Useful for Health Care: A Summary of the Inaugural MIT Critical Data Conference

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The author Vipan Nikore, MD, MBA was inadvertently omitted from the list of authors during the submission process of the paper "Making Big Data Useful for Health Care: A Summary of the Inaugural MIT Critical Data Conference" (JMIR Med Inform 2014;2(2):e22). The author Vipan Nikore, MD MBA (MIT Critical Data Conference 2014 Organizing Committee, Institute for Medical Engineering & Science, Massachusetts Institute of Technology, Cambridge, MA, USA) should have been added after Tristan Naumann, MS in the original published manuscript. The missing author has been added to the original online paper with publishing this correction notice on January 21, 2015, and the correct full-text has been resubmitted to Pubmed Central and other full-text repositories.

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