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Building a Learning Healthcare System in North Norway

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Abstract

The Learning Healthcare System paradigm promises fast progression of knowledge extracted from health data into clinical practice for improving health for populations, personalizing care and minimizing costs (the Triple Aim). It is, however, less clear how these ideas should be adopted to address the challenges of healthcare worldwide. While challenges are global, the healthcare systems and their organization are highly country-dependent, thus requiring a customized development approach and tailored impact measures. This paper sketches high-level ideas of demonstrating the potential benefits of the learning healthcare in North Norway. The implementation serves as a pilot project for measuring the impact of the paradigm on healthcare delivery, patient outcome and estimating the consumption of resources for a large-scale (national) deployment.

Keywords: *fragmented care, triple aim, data reuse, patient experience*

Introduction

Observing the increasing pace of innovation in technology, industry and research, one may wonder, why and how healthcare remains so inertic and resistant to changes. Reports suggests a 17 years long timespan for implementing positive research results into clinical practice [1,2]. It is a surprisingly long time to take advantage of scientifically proven practices and interventions for improving patient care. Many changes are likely to occur during this time, which may affect the methods under adoption, minimize or even void the need of them in a rapidly changing context. Such considerations triggered a series of workshops organized by the Institute of Medicine (IOM) on reengineering the delivery of healthcare services to make them more efficient, adaptable and agile.

The Learning Healthcare System (LHS) concept was one of the formal products defined in the workshops to address the challenges in the current healthcare delivery [3]. The proposed paradigm describes processes within healthcare as a continuous cycle of clinical practice generating data for condensing and extracting knowledge, which, with minimal delays, are fed back to healthcare services to produce new data (Figure 1). The iterations of the cycle enable the healthcare to react rapidly to new knowledge, increase the adaptability to individual needs and establish more accurate quality assurance procedures.

The promises of the LHS map well into the items of the triple aim for healthcare: "improving the individual experience of care; improving the health of populations; and reducing the per capita costs of care for populations" [4]. However, it is not clear how all three interdependent characteristics could be improved without compromising any of them. For instance, it may be easy to improve care and patient experience by investing in technology and human resources on the service provider side. However, managing costs in this scenario depends on the increased efficiency caused by the acquisitions. Finding an appropriate balance is not always possible.

The LHS concept has already been interpreted in several different ways aiming to achieve adaptable, patient centered and preventive healthcare services worldwide. The different approaches to the LHS often occur while deciding upon what data should be included (Figure 1). In a straightforward translation, data are referred to as information accumulated in the electronic health records (EHRs), reflecting the clinical side of patient health and treatment strategies. Regardless of the selected data collection and processing approach (centralized [5] or distributed [6]) it provides an information rich representation of "patient data shadow" [7].

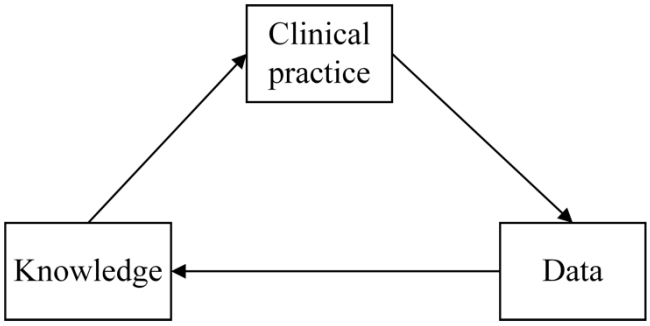

Figure 1- LHS cycle

Another approach to data within LHS is patient reported goals, outcomes and experiences. Such information provides an alternative view to the patient health and gives feedback on healthcare interventions [8]. It also helps identifying the gap between the medical and patient perspectives to health out-

comes, which is often overlooked by the current healthcare services [9].

This paper presents a vision to adopt the LHS practices in Norwegian healthcare context and demonstrate its feasibility and potential benefits in North Norway.

Materials and Methods

To demonstrate the potential of the LHS paradigm within the Norwegian healthcare system an infrastructure visualizing the different perspectives of health will be developed. It contrasts three representations of patient/population health status defined by:

1. Health data documented in EHRs across service providers (holistic view of treatment)
2. Patient reported health outcomes (patient profiles)
3. Clinical guidelines (Figure 2)

Health data

The fragmentation of healthcare data is one of the challenges in the project. It will be tackled through the Model, Extract, Transform and Load (METL) methodology for clinical data reuse [10]. The Model will be constructed from the archetypes defined in the Norwegian Clinical Knowledge Manager (CKM) in coordination with the openEHR international CKM. Extraction will be performed using distributed data processing and aggregation infrastructure provided by the SNOW project [11] enhanced by the techniques for privacy preserving computations [12]. SNOW platform is earning its momentum in Norway for health data extraction. It is already deployed at several healthcare institutions (general practices, microbiology laboratories) throughout Norway and expanding.

Transformation techniques will be applied to make the extracted data compliant with the archetypes defined in the Model stage [13]. The transformed data will be loaded into an openEHR database that facilitates queries in the Archetype Query Language (AQL) [14]. These queries are executed over the archetypes and detach data from the original proprietary schemas. Information retrieved through AQL will be afterwards merged with the patient reported outcomes.

Patient outcomes

The available reference models and ontologies will be considered to determine the most appropriate structure for patient profiles. The usability of visualized and tailored parameters will be evaluated by the healthcare professionals from primary, secondary and homecare to maximize their knowledge about a certain case.

Patient perspectives will be collected through manual feedback mechanisms adapted to the medical condition. Patterns and trends discovered by the visualization tool will be qualitatively evaluated by the stakeholders before they are made available to the healthcare professionals outside the project. A quantitative evaluation will follow every iteration of the LHS (Figure 1) to assess the impact of the paradigm on patient outcomes and health services delivery. Results will form estimates for adoption of the LHS in a national scale.

Clinical guidelines

Computerized clinical guidelines will represent a formal perspective of the treatment. Applicable guidelines will be visualized together with health data and patient outcomes (Figure 2).

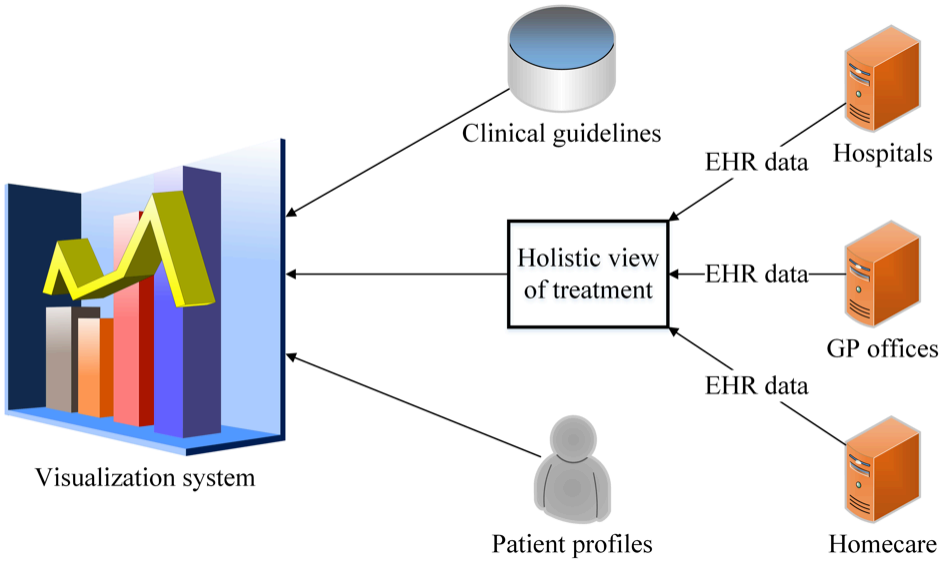

Figure 2- Data sources

Results

This paper demonstrates an interpretation of IOM's ideas on transforming the healthcare services into patient-centered and adaptable LHS. We aim to develop a tool for healthcare professionals enabling them to observe a holistic view of patient treatment for better coordination of care. Instead of introducing changes to healthcare delivery top-to-bottom, an opposite approach of healthcare specialists triggering changes based on provided information is prioritized.

While keeping the transition between clinical practice, data and knowledge (Figure 1) in mind, major attention is paid to data collection, making sure the fragmented patient information is as complete as possible. Such information is often distributed among service providers within the healthcare system. If we take a complex elderly patient, having multiple long-term conditions as an example, he/she is likely to be continuously treated by GP, hospital doctors and homecare (Figure 2). Data sharing between these service providers is often limited to discharge letters, summarizing the intervention. However, a complete overview of care the patient is receiving is not available at any institution.

To create a comprehensive representation of clinical patient care, three data sources are linked into a holistic view of the treatment (Figure 2). Properly visualized this view alone could potentially contribute to better care coordination between the providers by delivering a detailed insight into patient pathway, treatment history throughout the evolving long-term condition.

In addition to the clinical representation of health, patient-reported health profiles are established and continuously updated by the patients themselves. They reveal how clinical treatment corresponds to the health-related goals and expectations. These two perspectives of health (clinical and patient-reported), supplemented by the applicable clinical guidelines are visualized and contrasted, providing healthcare professionals with a comprehensive view of care process. Such representation is a starting point for finding a compromise between the three perspectives to tailor the care plans according to the expectations of the patient (Figure 3). The complexity of such visualization in real life may limit its usability, the number of dimensions describing health status of a complex patient over time may become difficult to administer. A balance between too simplistic (missing important indicators of healthcare status changes) and too complex (hindering the usability) needs to be found.

Clinical guidelines represent control measures in the visualization with regards to the provided (holistic view of treatment) and perceived (patient profiles) care (Figure 3). They define standard path for a patient profile and enables deviation detection. From patient point of view they work as control mechanisms ensuring the compliance of the delivered treatment and recommendations, while from a society scale, they reveal population specific trends.

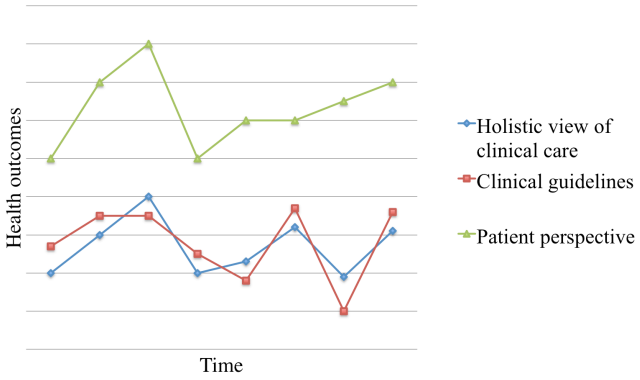

Figure 3- Simplistic visualization of health perspectives

Discussion

Minimizing the fragmentation of healthcare services is a hot research topic worldwide. It is defined as a major research and development direction by the Norwegian government in a long-term strategy for healthcare "one citizen – one electronic health record" (norw. "En innbygger – en journal") [16]. This initiative addresses numerous challenges related to insufficiency of the current IT infrastructure to support seamless data sharing between healthcare services in a national scale, patient inclusion into clinical decision making process, increasing the development of e-health technologies and establishing quality assurance procedures [17].

The LHS paradigm aligns well with the aforementioned strategies. It is, however, less clear how the aims of the discussed initiatives could be reached. An optimal recipe does not seem to exist and much research is required to define it. Looking at the future, additional challenges regarding the compatibility of national LHS instances in an international context are likely to occur. However, it may be too early to speak about international scale, considering that reports on much smaller LHS are only appearing in the literature and their impact on healthcare service delivery and patient outcome is still explored in a limited manner.

A national LHS is a big goal from both technological and social perspectives. It will take time and effort until such system is in place. It involves numerous decisions in selecting sufficient technologies to support the evolving LHS. The initiative to demonstrate the capabilities and impact of the paradigm in North Norway contributes to the overall understanding of how LHS ideas could be implemented in practice and how they are perceived by the healthcare professionals. It serves as a demonstrator project evaluating the impact of adopting LHS paradigm in a national scale and providing initial estimates on the required resources.

From a pragmatic perspective, Norwegian healthcare provides an advanced context for adopting the LHS. Many bits of the system are already in place: the coverage and active use of EHRs exceeded 90% of healthcare service providers in 2010 [16], making the majority of health data available in electronic form. Automated clinical guidelines and their impact on the process of care has already been investigated in numerous research initiatives that demonstrate positive achievements [18,19]. Comprehensive patient profiles for collecting patient

reported measures have so far been researched in a limited manner, making them the least explored part of the proposed LHS.

Evaluation of impact on healthcare services delivery, patient outcome and experience is a complex matter, raising philosophical questions. How can a perfect care be defined? Is it adherence to clinical guidelines? Improved vital signals? Or a satisfied patient? These three goals are sometimes located in different planes and cannot be maximized at the same time, complicating the impact measures. Considering that healthcare is supposed to serve the patient, self-reported measures could be fundamental for assessing the impact of the LHS.

Threats to success

Operationalizing the ideas of the LHS is not only a technological but also an organizational challenge. It requires a wide scale deployment of data processing infrastructure across the providers of healthcare services to achieve its goals. Limiting the scope to North Norway isolates the deployment in a single health region, however still remains challenging due to the organization of the providers. For instance, GP offices function as private entities, coordinating technology-related decisions, such as selection of EHR platforms, themselves. Despite the technological incompatibilities, organizational barriers need to be crossed to recruit the offices into the research activities. The payback for the GP is often insufficient for attracting their attention and, therefore, is slowing down the deployment.

Recruiting patients with complex conditions is another challenge. Elderly individuals circling in health services are the targets for demonstrating the validity of the LHS concept. Their input shapes the self-reported perspective of health – one of the data sources of the LHS. Technological literacy may become a bottleneck in this patient group, limiting the collection of data. Long-lasting inclusion in the LHS may also become challenging if direct payback for the patient is not visible.

Conclusion

It is not easy to estimate the impact of making the healthcare services fully aware of the interventions they are providing with regards to the clinical guidelines and patient perspective. However, it is an incentive to trigger changes in service delivery and learning from practice in a more rapid manner than it is done now. Moreover, it is also an attempt to personalize healthcare services paying more attention to the preferences and goals of the patients.

The LHS is an iterative process; its impact is not easy to measure. This paper presented high-level plans for establishing a LHS demonstrator in North Norway to estimate the adoption of the paradigm in a national scale.

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Communicating to employees the implementation of patient online access to their EHR. The case of adult psychiatry in Southern Sweden.

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Abstract

In 2015 Region Skåne was the first county council in Sweden to add adult psychiatry patients to the civic service of patient online access to their EHR (electronic health records). The initial implementation of the service in somatic care had previously raised both questions and resistance amongst the healthcare professionals. It was thus considered important to inform the professionals involved about the planned introduction in psychiatry well in advance. This paper presents and discusses how well the management was able to do this. The material presented derives from a survey that was distributed to employees in adult psychiatry in Region Skåne just before the introduction of the service. Overall, the results show that different professions receive information through different channels. This indicates that it is important for an employer to use many information and communication channels to reach employees. It is also important to use both interpersonal and mediated communication channels as they serve different purposes.

Keywords: eHealth, EHR, psychiatric care, patient online access, employees, communication channels

Introduction

Government and public agencies in Sweden have promoted the expansion of eHealth in the past decade. In 2006, key organisers in Swedish healthcare, monitored by the Ministry of Health and Social Affairs [1], jointly formulated a national IT strategy. The planned enhancement of development and deployment of eHealth services was later described as a paradigm shift in Swedish healthcare [2]. In its 2013 action plan, the National Board of IT in Healthcare (Cehis, now a part of Inera) described online patient access to their electronic health record (EHR) as one of the most important civic services and anticipated that by 2017, all patients in Sweden would be able to access their EHR through the Internet [3]. The main arguments behind the drive for eHealth as a civic service is to increase patient empowerment and patient participation in their own health. eHealth is also seen as a way of responding to increased demands for healthcare in the future. The Swedish Association of Local Authorities and Regions (SKL) claims that civic services will increase the accessibility, efficiency and quality for patients, inhabitants and families [4].

In November 2012, Uppsala County Council became the first county council in Sweden to introduce online patient access to the EHR service and was followed by Region Skåne in March 2014. In both county councils, some medical specialties were exempt in cases where patient digital access was considered sensitive. One of the exemptions was psychiatry. However, in 2015 Region Skåne became the first county council in Sweden to add adult psychiatry to the service. This development is in line with the reasoning of the Open Notes Project in the US: that patients in psychiatric care should not be treated differently than other groups of patients in terms of their online access to EHR [5]. Patient online digital access to their medical records had raised both questions and resistance amongst healthcare professionals, primarily in Uppsala [6]. Because of this, it was considered important to inform the professionals in Region Skåne well in advance about the planned introduction of EHR in psychiatry.

Communication between the change management and the employees is an important part of any planned change. However, the view of what information should be shared and how it should be distributed may differ between management and employees. The greater the distance between management and employees, the less direct is the information they receive. Employees will have to rely on the different levels of management to distribute information to them. Still, the engagement and cooperation of employees is key for the success of the implementation process [7].

This paper presents and discusses how well the management in this case was able to inform the professionals beforehand. The material presented is derived from a survey that was distributed to the employees in adult psychiatry in Region Skåne two and a half weeks before the introduction of the service. The survey study is a sub-study in a research project (the EPSA project, financed by AFA insurance in Sweden) on how healthcare professionals' work and work environment are affected by eHealth services, such as patient digital access to their EHR.

Description of the case

The Division of Psychiatric Care in Region Skåne consists of three subdivisions: adult psychiatry, children and youth psychiatry, and forensic psychiatry. It was decided that only patients in adult psychiatry should have online access to their EHR, at least to begin with. The adult psychiatry subdivision employs roughly 3000 people divided into four geographic areas. A multi-professional management board including representatives from patient organizations was established in the autumn of 2013. The management board held regular meetings to discuss and decide on the introduction and implementation of online patient access to their EHR in adult psychiatry. The date for introduction was set to the 28th of September 2015.

One of the tasks of the management board was to carry out a risk analysis. One of the main risks identified was the failure to inform the employees or the professionals in the adult psychiatry subdivision. It was thus considered very important to find suitable communication channels to let the employees know about the planned implementation. Ambassadors for the service were engaged in each of the four geographical areas in Region Skåne and were included in the management board. A communication plan, aimed at the employees, was formulated by the management board. The plan consisted of:

- Education, given in form of two identical 1½ hour slots (one in the morning and one in the afternoon) in each geographic area during the spring of 2015
- Information on the Region Skåne's intranet
- Information at workplace meetings
- Information at professional staff meetings
- Information sent by managers to employees by email

The management board considered the education events to be the most important information channel because they gave the participants an opportunity to pose questions and to participate at their workplace.

Somewhat delayed, the online patient access to the EHR service opened on the 5th of October. Through the service, patients in adult psychiatric care in Region Skåne were able to access entries in their EHR from then on. Inpatients (ca 5% of the patients) are exempted from immediate access to the service, but are able to access their EHR four weeks after hospitalisation. Outpatients can choose to read entries in real time or with a delay of two weeks.

Methods

The researchers gathered information about the formulation and execution of the communication plan from observations they made of the management board meetings, the education events, and from focus group interviews. Thereafter, an online survey concerning online patient access to their EHR, and the work environment of the professionals was distributed to all health professionals in adult psychiatry in Region Skåne.

Subject selection

The survey was a full population study encompassing all individuals employed in adult psychiatry in Region Skåne (*n* = 3017). Previous surveys on the implementation of online patient access to their EHR in Sweden have either been directed to doctors or nurses [8].

Study design

The baseline survey used in this study is based on an electronic survey used in the Open Notes Project in the US [9]. The survey was adjusted to fit the Swedish context. It consists of 30 fixed-choice questions and three open-ended questions. The survey was programmed so that the person taking it could choose not to answer individual questions. A pre-test of the survey was carried out involving two members of the management board. For the purpose of this study, only the answers to one of the fixed-choice questions is reported. The results from the rest are planned to be published in future papers.

The 3017 email addresses were provided by the Communication Department at the Division of Psychiatric Care in Region Skåne. The web survey tool, *Sunet Survey*, was used and Lund University was the sender of the emails.

On the 17th of September, a pre-notification email was sent to the study population and on the 18th of September, the survey was sent electronically to the institutional email addresses with a cover letter and a link to the survey. Both the pre-notification email and cover letter informed the recipients that participation was voluntary, that the computer files with the results were confidential, that the respondent could terminate their participation at any time and that it will not be possible to track the individuals' responses. Reminders were sent the 22th, 24th, 28th of September and the 1st of October. The survey closed on the 2th of October, three days before patients could get online access to their EHR. All the material in the baseline study was thus collected before the implementation.

The three research questions are:

- From which communication channels did employees in adult psychiatric care in Region Skåne get information about the implementation of online patient access to their EHR?
- Does the main communication channel differ between different professions?
- Comparing the answers in the questions in the survey to the communication strategy of the management board, how well did the strategy work?

Material and statistical analysis

The response rate to the survey was 29% (n = 871). The survey data reported in this paper include demographic data of the participants' professions, and the results from one of the survey question, posed as a statement:

I have received information about the online patient access to their EHR in adult psychiatry through (you can choose several answers to this question):

- Intranet
- Work place meeting
- Education during the spring of 2015
- Meeting for a specific profession, such as meeting for doctors
- Email
- Informal conversation with colleagues
- Social media
- Mass media

- I did not receive any information

Results

The demographic characteristics of the respondents' professions are presented in Table 1. The results from the above question are presented for all the respondents in Table 2, and for all the respondents according to professional groups in Table 3. The statistical analyses were made in IBM SPSS Statistics 23.

Table 1 - Demographic characteristics of the respondents in percentage and number (n).

Profession*	
Occupational Therapist	2% (17)
Doctor	15.6% (133)
Medical secretary	8.9% (76)
Psychologist	10.7% (91)
Physiotherapist	1.9% (16)
Nurse	26.7% (228)
Assistant nurse	21.3% (182)
Social worker	6.7% (57)
Other	6.2% (53)

** 853 of the 871 respondents answered the question about their professional affiliation.*

As the survey is a population study, it is important to investigate if the 871 individuals who answered the survey are representative of the full population. The survey population was thus compared with demographic information about all the employees at the adult psychiatry subdivision in Region Skåne. The comparison showed that the response rate is consistent for medical secretaries, is a few percentage points lower for nurses and assistant nurses, and slightly higher for the other professional groups. All deviations are less than 10%.

Table 2 - Responses to the statement, "I have received information about the online patient access to their EHR in adult psychiatry through (you can choose several possible answers to this question)", given in percentage and number (n).

Communication channel	
Workplace meeting	48.9% (414)
Intranet	40.4% (342)
Email	37.8% (320)
Informal conversation with colleges'	24.9% (211)
Mass media	15.8% (134)
Education during spring 2015	14.4% (122)
Meeting for a specific profession	13.0% (110)
I didn't get any information	7.3% (62)
Social media	4.1% (35)

The results presented in Table 2 show that the respondents received information from a variety of channels. It is important to note that respondents could choose multiple answers to this question. The total percentage is therefore higher than 100% and there were a total of 1750 responses to this question. 48.9% of the respondents stated that they received information at a workplace meeting. 14.4% of the respondents received information at one of the education meetings held in the spring of 2015. Slightly more respondents (15.8%) stated that they had been informed through the mass media. It is also noteworthy that 7.3% of respondents claimed they had not received any information at all.

Table 3 shows that the different professionals groups received information through a variety of communication sources and that the results differ between the professions. 34.1% of the physicians received the information via the intranet, while the result for medical secretaries was 52.1%. The results also show the most common channel of information for each profession.

Table 3 - The different professions responses to the statement "I have received information about the online patient access to their EHR in adult psychiatry through (you can choose several answers to this question)" in percentage.

	Occupational Therapist	Doctor	Medical secretary	Psychologist	Physiotherapist	Nurse	Assistant nurse	Social worker	Other
Workplace meeting	70.6%	28.8%	49.3%	65.9%	53.3%	53.6%	44.4%	64.9%	36.5%
Intranet	52.9%	34.1%	52.1%	38.5%	33.3%	39.7%	35.0%	49.1%	55.8%
Email	35.3%	44.7%	39.7%	29.7%	33.3%	34.4%	46.7%	21.1%	38.5%
Informal conversation	5.9%	35.6%	26.0%	35.2%	33.3%	24.1%	17.8%	21.1%	17.3%
Mass media	5.9%	22.0%	8.2%	14.3%	13.3%	19.6%	15.6%	8.8%	11.5%
Education	35.3%	12.9%	21.9%	13.2%	26.7%	11.2%	8.3%	21.1%	26.9%
Meeting profession	0%	50.0%	6.8%	7.7%	0%	4.5%	1.7%	1.8%	30.8%
No information	0%	6.1%	6.8%	7.7%	6.7%	8.0%	10.6%	1.8%	1.9%
Social media	0%	3.0%	5.5%	1.1%	0%	4.9%	5.0%	3.5%	7.7%

For occupational therapists, psychologists, nurses, physiotherapists and social workers, workplace meetings were the most common information channel; for the doctors, it was in meetings for their specific profession; and for the assistant nurses, email was the most common channel of information.

Discussion

This paper presents and discusses how well management was able to inform the professionals in adult psychiatry in Region Skåne beforehand about patient online access to their EHR. In Sweden, the rhetoric put forth by key actors is that patient online access to EHR is a civic service and a technical solution aimed at the patient [4]. It is thus not considered to have any significant impact on the healthcare professionals' work or work environment. However, through experiences from other implementation cases of similar services, there was an awareness of the necessity to inform all the professionals in adult psychiatry in Region Skåne about the implementation.

Communication channels can be interpersonal, primarily face to face communication, or they can be mediated, implying the use of either mass media or some form of technical mediator. The interpersonal channels are preferable when complex changes, or changes involving risks are implemented. The strength of the mediated channels, however, are that they are efficient mediators of general information, such as facts about the change [7] [10].

The results of the survey show that the employees received information from a variety of channels. Interpersonal channels such as workplace meetings are the most common. Almost half of the respondents (48.9%) got information at these meetings. In workplace meetings, managers are able to inform employees who have the opportunity to ask questions and different issues can be discussed. As workplace meetings are common for different types of professionals, they also reach many categories of employees at the same time.

On the contrary, meetings for specific professions are internal and limited to a single profession. In total, these meetings are not considered by the entire group of respondents to be a large channel of information (13.0%). But they are the main information channel for doctors (50.0%). This may indicate that doctors prefer receiving and giving information amongst their professional peers, or that they simply do not participate in the workplace meetings as frequently as employees in other professions. Email is also an important information resource for doctors (44.9%), and the largest one for assistant nurses (46.7%). Generally, email is one of the most frequently used channels of information.

Informal discussions with colleagues are on average an information channel for 24.9% of the respondents. This could imply that some of the employees that got information through planned information channels spread it to their peers. But as many of the respondents received information through more than one communication channels, it can also be interpreted as employees discussing the implementation and further informing each other. On the other hand, as information sometimes is misinterpreted or misunderstood, even misinterpretations or misunderstandings may have been passed on.

One of the most interesting findings is that only 14.4% claim that they were informed through the education events. This is noteworthy as the management board considered the education events to be the most important activity in the communication plan. It is also interesting in light of that 15.8% of the respondents were informed through mass media, a communication channel that Region Skåne did not use consciously and thus had little or no control over. Since there were only a limited number of articles in the local press and reports in the local radio about the implementation of patient online access to their EHR, some of the professionals may have got information through their trade press where the implementation was discussed.

The organization's intranet was considered to be one of the most important source of information by management and was thus expected in this case to be an effective information channel to reach all empoyees since the intranet is available to everyone and employees can access the information when it suits them. Despite this, only 40.4% of the respondents stated that they received information through the intranet. This is in line with earlier research that shows that management often believes in and relies on technical channels such as intranet, whilst it is often less appreciated information source of the employees [11]. Actually, some of the employees who participated in the focus group interviews referred to the Region Skåne's Intranet as "a black hole". Their opinion was that it is impossible to find anything on the Intranet and as a result they never sought information there.

Despite all the different communication channels used in the information campaign, it became clear during the focus group interviews that all employees had not been reached by the information or, at least, had not got all the information they needed. Participants in the focus group interviews had several unanswered questions, especially about practical and technical details. Amongst others, they wondered what type of information the patients will be able to see; how to make entries that patients cannot see; when entries become visible to the patient; what happens if a patient is upset about the information in their EHR and contacts the healthcare professionals to complain and how these situations should be handled. It is also noteworthy that 7.3% of the respondents of the survey stated that they had not received any information at all despite all the efforts made by management.

Conclusion

Overall the results show that different professions receive information by different channels. This implies that it is important for an employer to use many information and communication channels to reach employees. It is also important to use both interpersonal and mediated communication channels as they serve different purposes. Mediated channels, such as email, can give exact and correct information whereas interpersonal channels, such as workplace meetings and education

events, provide employees with an opportunity to pose questions and discuss the implementation.

The education events do not seem to have had the expected impact, but may well have had a symbolic value as they signal that the management was prepared to invest resources in the information campaign and make the effort to disseminate information amongst all four geographic areas. The mass media may have been an underestimated information channel and could probably have made an even greater impact than it did. Still, that requires a conscious usage of the media and a wish to reach out to the public as well, which may not have been one of the management's aims.

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Interoperability Mechanisms of Clinical Decision Support Systems: A Systematic Review

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Abstract

The interoperability of Clinical Decision Support (CDS) systems is an important obstacle for their adoption. The lack of appropriate mechanisms to specify the semantics of their interfaces is a common barrier in their implementation. In this systematic review we aim to provide a clear insight into current approaches for the integration and semantic interoperability of CDS systems. Published conference papers, book chapters and journal papers from Pubmed, IEEE Xplore and Science Direct databases were searched from January 2007 until January 2016. Inclusion criteria was based on the approaches to enhance semantic interoperability of CDS systems. We selected 41 papers to include in the systematic review. Five main complementary mechanisms to enable CDS systems interoperability were found. 22% of the studies covered the application of medical logic and guidelines representation formalisms; 63% presented the use of clinical information standards; 32% made use of semantic web technologies such as ontologies; 46% covered the use of standard terminologies; and 32% proposed the use of web services for CDS encapsulation or new techniques for the discovery of systems. Information model standards, terminologies, ontologies, medical logic specification formalisms and web services are the main areas of work for semantic interoperability in CDS. Main barriers in the interoperability of CDS systems are related to the effort of standardization, the variety of terminologies available, vagueness of concepts in clinical guidelines, terminological expressions computation and definitions of reusable models.

Keywords:

Clinical Decision Support Systems; Semantic Interoperability; Terminologies; Clinical Models; Ontologies.

Introduction

Clinical Decision Support (CDS) systems are applications to assist users in health care decision making. They contribute to improve health care and reduce costs [1]. Current initiatives to power the adoption of health information standards are setting the basis for the general use of CDS systems. However interoperability to enable CDS systems smooth integration into clinical workflows and reuse across health care providers are considered as main barriers hindering CDS systems broad adoption [2–4]. New CDS specific standards such as the HL7 Virtual Medical Record (VMR) [5] are improving their modularity and interoperability. Nevertheless, the specification of precise semantics for the concepts used in CDS modules are hampering their successful adoption [3]. This has unveiled that advances in clinical information architecture standards are necessary but do not suffice to grant semantic interoperability (SIOp). Also, advances in other aspects of SIOp such as web services architectures that link information models, terminologies and knowledge models of CDS systems are needed [6].

This paper presents a systematic literature review of SIOp in CDS Systems that extends and includes the studies published since our previous work [7]. We have extended the publication period (adding the period from November 2014 to January 2016). We have modified the keywords in the search from our previous work in order to focus the discussion on the standards available to implement CDS systems attempting to provide a comparative overview of them. We answer the following research questions: which are the approaches and mechanisms currently available to enable SIOp of CDS Systems?; and, what is the coverage of each approach in the literature?

Materials and Methods

Three major research databases were searched for studies about SIOp in CDS. Pubmed, IEEE Xplore and Science Direct databases were queried using keywords ("clinical decision support" and "semantic interoperability"). Additionally studies from other sources considered relevant by the authors were included. Journal papers, book chapters and conference papers written in English since January 2007 to January 2016 were included for the first screening.

Inclusion criteria of papers were based on the following characteristics: (a) The study described a CDS with some degree of SIOp with other systems; (b) the paper described mechanisms for the reuse of the CDS functionality across systems. Most papers included were related to medical use of decision support but papers from other areas such as decision support interoperability in industry were also considered if they provided new insights and directions for CDS SIOp.

Eligibility assessment was performed by a single reviewer mapping the identified publications into the aforementioned criteria. Titles and abstracts were first screened rejecting irrelevant papers. A second revision reviewed the studies in full-text selecting those compliant with the eligibility criteria.

No specific data collection form was used. Instead, for each included publication we extracted aspects related to mechanisms used to enable syntactic and semantic interoperability; and how these mechanisms (syntactic and semantic) are combined to grant SIOp. Special attention was paid in identifying barriers and advantages linked to the use of every approach.

Results

Study Selection

The search of the three databases provided a total of 117 records after removing duplicates. Also 11 studies from other sources were considered for review. After screening by title and abstract 75 were discarded for not accomplishing criteria, 53 were selected as relevant for full text review. Of the 53 selected for full-text examination 41 remained to be included in the synthesis and 12 were discarded as they did not comply with the eligibility criteria. Figure 1 contains the workflow followed in the studies selection.

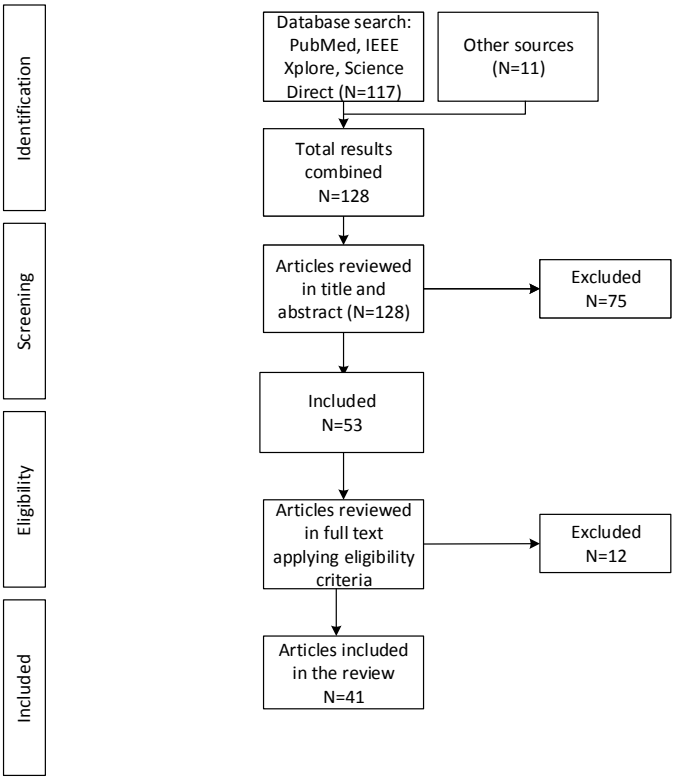

Figure 1 – Workflow followed in the review

Study Characteristics

Among the papers reviewed we identified five main mechanisms used to enable CDSS interoperability. Some provided features to enable syntactic interoperability while others enhanced those features to share information at a semantic level.

Of the 41 papers reviewed 22% (n=9) described the application of medical logic and guidelines representation standards (e.g. GLIF, Arden Syntax etc.); 63% (n=26) described the use of clinical information standards such as HL7 CDA, HL7 RIM, OpenEHR or HL7 VMR; 32% (n=13) employed semantic web technologies such as ontologies; 46% (n=19) outlined the use of standard terminologies; and 32% (n=13) reported the use of web services to offer CDS functionalities. Table 1 presents the mechanisms used to enable interoperability in the studies reviewed. It is important to notice that those categories are not disjoint but complementary. Thus a particular study may pertain to several of them.

Table 1 - Mechanisms used to enable SIOp

Category	Studies		
	Database search	Other resources	%
Use of Clinical Information Standards and Integration with the EHR	[8–27]	[4,28–32]	63 % (n=26)
Use of Terminologies	[3,8,33,12,13,6,16,17,19–21,24–27]	[28,31,34,35]	46 % (n=19)
Use of Semantic Web	[33,13,6,14,16,17,36,27]	[4,29,34,37,38]	32 % (n=13)
Use of Medical Logic Specification Standards	[13,20–22,39–41]	[4,32]	22 % (n=9)
Use of Web Services	[42,8,10,12,43,44,15,19,21,24,26,45]	[32]	32 % (n=13)
Others		[2]	2% (n=1)

Use of Clinical Information Standards and Integration with the EHR

Currently, several information architecture standards exist for the documentation and exchange of EHR extracts. Several works propose their use to specify the interface to interact with the CDS system. Thus, the logic references a standard information model rather than a proprietary data schema. This alleviates the 'curly braces' problem (queries to the EHR proprietary data schema from the MLM logic preventing decoupling

and reuse). Some of the reviewed works [4,12–14,24,25,32,45] propose the use of the HL7 RIM to create a VMR to feed the CDS system. This approach is followed by formalisms such as SAGE or the Arden Syntax [25,39].

Other clinical information standard used as data model for CDS systems is the HL7 Clinical Document Architecture (CDA). CDA is earning momentum as standard for clinical documents consumed by CDS systems as a consequence of the Meaningful Use initiatives [8–11,15,21,22,26,46]. An example of the use of CDA was found in Bouhaddou et al. [46]. They shared messages of patient information between the Department of Veterans and the Department of Defense to enable decision support for alerts and reminders such as drug-drug interactions, allergies or duplicative therapies.

Preparing the data specified in standards such as CDA or RIM to be used by the decision logic is challenging as a consequence of the impedance mismatch between the information model and the inference model. Works to map the RIM VMR to the guideline specification can be found in Peleg et al. [4]. Specifically, they use a mapping ontology (KDOM) to create the abstract concepts required by the logic from the fine grained information contained in the RIM-based VMR. To solve this problem in CDA-based VMRs, Saez et al. [22] proposed to use a wrapper in order to link CDA documents to the CDS rules. Although both RIM and CDA can be used as information models to build a VMR, they are complex and too detailed for the requirements of a CDS data schema. Kawamoto et al. studied the requirements to create a CDS specific information standard to build VMRs based on a simplification of RIM [30]. That work evolved into the current HL7 vMR CDS standard [11,19].

In the archetype-based standards milieu, Marcos et al. [20] and Fernandez-Breis et al. [29] proposed the use of openEHR archetypes. They relied on a VMR created reusing archetypes from the openEHR Clinical Knowledge Manager. As it occurred in the study of Peleg et al.[4], they needed to raise the level of abstraction of clinical concepts. This was accomplished by defining additional layers of archetypes over the VMR to finally provide the CDS with the high abstract concepts required. These layers are linked defining mappings between archetypes with LinkEHR [47].

Weather it is performed with ontologies or archetypes, the process of abstracting concepts from the VMR with mappings is complex and error-prone. In order to simplify it, Marco-Ruiz et al. presented an archetype data warehouse (DW) to execute queries in the Archetype Query Language to generate the concepts with the requested level of abstraction [18].

The choice of a particular information standard when developing CDS systems is not straightforward and has major implications for developers. Only one study was found comparing some of the available standards for implementing the CDS VMR. González-Ferrer and Peleg implemented several use cases to compare HL7 CDA, HL7 vMR and openEHR archetypes [11]. They concluded that HL7 vMR has the best learning curve and ease of implementation; whereas openEHR/ISO13606 archetypes are more powerful for extending and constraining the information model of the CDS system.

Table 2 presents the coverage of each standard in the studies reviewed. Among the 63% (n=26) of the studies covering the use of information model standards, HL7 CDA is the most spread, covered in 35% of the studies; it is followed by HL7 RIM-based VMR appearing in a 31%; and openEHR in 27% of the studies. 12% of the papers covered HL7 CDS VMR.

Table 2. Clinical information standards coverage

Information standard	Coverage in reviewed studies
HL7 CDA	35% (n=9)
HL7 RIM	31% (n=8)
openEHR	27% (n=7)
HL7 vMR	12% (n=3)

Use of Terminologies

The reviewed studies covered the need to adopt standard vocabularies to enable: (a) logic expressions to reference standard terms, (b) the mediation among systems, and (c) the annotation of the information model entities.

The most common use of terminologies in CDS is to provide a standard vocabulary for medical logic specification. This use has been studied by Ahmadian et al. [35] to identify the main barriers in specifying the concepts used in pre-operative assessment guidelines with SNOMED-CT. Although they successfully represented 71% of the 133 terms extracted from 6 guidelines, they found that 2 issues hampered the mapping of several concepts. First, 27 out of 39 non-matched concepts were terms specified in the guideline vaguely which violated the submission rules of those; i.e. they are not contained in SNOMED-CT and they cannot be considered for submission to it. Second, 12 of the non-matched concepts were valid and must be added to the terminology. In another review about use of terminologies in CDS systems [3] they point out that recent implementations of CDS systems are more likely to adopt international terminologies. They also report that the percentage of positive clinical performance is higher in systems using standard data (79% vs. 50%). That study identifies several barriers hindering the adoption and SIOp related to the use of terminologies: (a) the lack of standardized data is mentioned as a major obstacle by implementers of CDS systems (92% of the problems in CDS systems adoption are related to a lack of standardization); (b) despite the adoption of terminologies, their diversity is an obstacle for the interoperability of CDS systems; (c) despite the advances in international terminologies adoption, 42% of the systems still use local terminologies. To alleviate the problems derived from the diversity of terminologies they propose to adopt UMLS as integrator of different terminologies. In fact, The National Cancer Institute, provider of the UMLS, documents in their architecture caCore

[31] the improvement of their NCI Thesaurus terminology service to facilitate its use in CDS.

Terminologies are also found to play a role in mediation among systems. This is well documented by Bouhaddou et al. [46]. They present the use of several terminologies (RxNorm, UMLS and SNOMED-CT) to build a mediator providing SIOp between the Department of Veterans Affairs and the Department of Defense. Among other objectives, they aim to share patient summary information to apply CDS on allergies, drug-drug interactions and duplicative therapies. Their approach is to provide mediation terminologies and map the institutional terminologies to them. In specific, they used SNOMED-CT for allergy reactions, UMLS for drug allergies and RxNorm for medications. They report 92% successful mappings to terminologies. The mapping to pharmacology terms is reported as one of the main challenges.

Terminologies are also used to support knowledge modelling. Marco-Ruiz et al. [17] used SNOMED-CT to model respiratory symptoms and signs using archetypes and a ontology annotated with SNOMED-CT.

Overall 46% (n=19) of the studies covered use of terminologies. Table 3 shows how the most commonly used was SNOMED-CT reported in 63% of the studies; LOINC was used in 53% of the studies; RxNorm in 21% and ICD in 16%. Also the terminology integrator UMLS was used in 21% of the studies that covered terminologies.

Table 3. Terminologies coverage

Terminology	Coverage in reviewed studies
SNOMED-CT	63% (n=12)
LOINC	53% (n=10)
RxNorm	21% (n=4)
UMLS	21% (n=4)
ICD	16% (n=3)

Use of the Semantic Web

Ontologies have been extensively used in decision support due to their capabilities for knowledge representation and reasoning. Several works have been found in the review documenting their use for different purposes that cover from interoperability and knowledge representation to reasoning.

In knowledge representation we found studies such as the presented by Iqbal et al. [14]. They built an ontology extending the W3C Computer-based Patient Record (CPR) with the Western Health Infostructure Canada (WHIC) for chronic disease management. Of particular interest is the replacement of the CPR vocabulary with SNOMED-CT standard terms. They also map each of the concepts of the ontology to HL7 RIM classes to ensure that HL7 messages can be integrated with the ontology. For the HL7 RIM mapping a 100% successful mappings are reported; for properties, they report 8 out of 80 partial mappings and 10 out of 80 not possible mappings respectively. Another example is the aforementioned use of ontologies to represent symptoms and signs of respiratory diseases [17].

Ye et al. [38] present a pure semantic web-based approach. They defined the Clinical Pathway Ontology (CPO) for the specification of clinical pathways. The ontology is implemented as a combination of a new defined model, the process ontology specified in OWL-S and an entry ontology of time. They rely on their CPO rather than other formalisms as they consider: (a) CPO to be more accurate to specify pathways were multidisciplinary teams interact; (b) CPO to be more adequate to manage knowledge documentation and evolution. For temporal rules specification they used the Semantic Web Rule Language (SWRL) which guarantees a seamless integration with the OWL-based model. In their case study they use their framework to specify Cesarean guidelines. Another example of semantic web technologies used for CDS implementation is presented by Zhang et al. [27]. They implemented a CDS for diabetes management over a RIM-based information model using OWL for knowledge specification, SPARQL for queries definition and Jena rules for specifying decision logic.

Ontologies have also been used for integration of heterogeneous data models in several studies. For example, the project Advancing Clinico-genomic Trials on Cancer – Open Grid Services for Improving Medical Knowledge Discovery (ACGT) describes a complete framework where the ACGT master ontology is used to integrate heterogeneous distributed databases and clinical genomic data [34]. The project defines the model and the integration mechanisms to map ontology elements to data access service schemas. Next version is expected to exploit the model for decision support in assessment and management of clinical trials. Already mentioned, is the use by Peleg et al. [4] of the mapping ontology KDOM to map the HL7 RIM VMR to the clinical guideline by mapping ontology concepts from more basic (and close to the EHR) to more abstract (and close to the guideline).

Also, ontologies have been used for inferences. Fernández-Breis et al. [29] used OWL DL reasoning for clinical trials eligibility. They used archetype layers to raise the level of abstraction from the EHR to populate their ontology. The ontology was used to classify cohorts of colorectal cancer patients.

The combination of ontologies and archetypes is of special interest as enables reasoning over clinical data stored as archetype instances. Lezcano et al. [16] transformed archetypes into OWL and enabled decision support defining SWRL rules over the OWL representation. The work of Lezcano et al. annotates the ontology concepts with SNOMED-CT allowing the application of SWRL over standard terms.

The use of semantic web technologies appeared in 32% of the studies (n=13). Table 4 shows the field of application of semantic web technologies. 69% (n=9) of studies used ontologies to represent the conceptual models of the knowledge base; 38% (n=5) used ontologies to integrate different conceptual models or to overcome the impedance mismatch between the EHR and the CDS logic. Regarding inferences, OWL reasoning or SWRL were used in 31% of the studies (n=4).

Table 4. Areas of aplication of Semantic Web

Type of use of semantic web technologies	Coverage in reviewed studies
Knowledge representation	69% (n=9)
Integration and mapping	38% (n=5)
Rules specification	31% (n=4)

Use of Medical Logic Specification Standards

Several works used medical logic specification standards. One of them was the Arden syntax. It was one of the first formalisms designed to specify medical logic. Its main innovation was the capability to encapsulate CDS in sets related to one decision support functionality called Medical Logic Modules (MLM) which gradually evolved into HL7 standard. Samwald et al. [39] present the use of the Arden syntax to implement diverse MLMs in hepatology, rheumatology, oncology and Intensive Care Unit monitoring among others. They found that the reusability of the MLM was compromised by the well-known 'curly braces' problem. To overcome this issue they propose the integration of Arden with GELLO to take advantage of GELLO's object-based expression language and rely on the VMR as standard interface for data access. GELLO is currently another HL7 standard which data model is a simplified view of HL7 RIM [48].

Other publications focus on guidelines and workflow specification. Peleg and Gonzalez-Ferrer [32] reviewed several guideline specification languages based in Task-Network Models. The most prominent are EON, GLIF, GELLO, New Guide, PROforma, GLARE and GASTON. A full evaluation of them is out of the scope of this paper but examples of PROforma and GLIF-3 use can be found in Marcos et al. [20] and Peleg et al. [4] respectively. A relevant work which evolved many of the features presented in those formalisms and deployed them in a standards oriented environment is the Standard-Based Active Guideline Environment (SAGE). Tu et al. [25] presented a SAGE overview describing the use of different standards for CDS in the project. It relies both in standard information models and terminologies as, for example, SNOMED-CT. It evolves concepts as the VMR of EON or the GLIF decision models. It also uses previously defined languages to specify data access and computation such as GELLO. A difference of SAGE with respect to other guideline formalisms is that it relies in an event-driven architecture so as not to interfere with the host system's workflow. Other example of the SAGE architecture applied to CDS for immunization is described by Hrabak et al. [13].

More oriented to knowledge management of CDS modules, Sordo and Boxwala [23] present the Grouped Knowledge Elements (GKE). The GKEs are artifacts which contain: (a) structured templates to specify the patient data to feed the CDS and (b) an order set which contains the set of actions to be applied under certain circumstances. This way a GKE links the specification that the patient data should comply with and the medical logic to process it. HL7 has published the HL7 CDS Knowledge Artifacts (KA) [49] for the specification of GKEs using Event-Condition-Action (ECA) rules and an harmonized data set of several existing CDS data schemas. We found that 22% (n=9) of the studies covered medical logic specification formalisms. Table 5 shows the coverage of each logic formalism. SAGE was covered in 33% (n=3) of studies; the Arden Syntax, GLIF, PROforma, were covered in a 22% (n=2) of the studies each. Other standards for logic specification and knowledge management were mentioned less commonly, Jess and the HL7 KA 11% (n=1) each.

Table 5. Logic specification formalisms coverage

Logic specification formalism	Coverage in reviewed studies
SAGE	33% (n=3)
Arden syntax	22% (n=2)
GLIF	22% (n=2)
PROforma	22% (n=2)
Others (e.g. Jess, KA)	11% (n=1)

Use of Web Services

With regards to Web Services, 32% (n=13) of the studies covered their use to interoperate with CDS systems. Web services can play an important role in the modularization and interoperability of CDS systems. One of the pioneer works that proposed to take advantage of the Service Oriented Architecture (SOA) for CDS is the presented by Kawamoto et al. [43]. Recently, Dixon et al. [8] and Wright et al. [26] performed a pilot to study the challenges in offering a CDS system in the cloud to several independent health organizations. Among the lessons learned they reported that the main challenges were the difficulties in the negotiation of the legal framework, concerns of clinicians about lack of control over the CDS rules hosted in other organization and the high cost in implementing SIOp. Regarding the cost of SIOp the following are pointed out as main barriers: (a) mapping of local terminologies to SNOMED-CT; and (b) use different terms of the same vocabularies for same entities in each of the organizations.

Discussion

The reviewed publications show that five main fields of work are opened in SIOp for CDS systems: information standards, terminologies, medical logic specification formalisms, semantic web and web services. Most studies covered the use of some information model standard to provide the information interface to represent data. Standard terminologies are used to annotate data instances and integrate different vocabularies. The review shows that they are being increasingly adopted. Ontologies are suggested to provide knowledge domains specification, conceptual models integration and reasoning. Medical logic formalisms are proposed to specify the reasoning logic and allow the reuse of medical procedural knowledge. Web

services are proposed as a tool to offer CDS across organization boundaries.

Different information standards are used to define the VMR data schema. These standards allow decision logic to reference standard information entities of the VMR instead of the EHR avoiding dependencies on proprietary DB schemas. HL7 CDA is the most spread information standard. HL7 CDA is not only used to define the VMR but also to define messages that travel across organizations as SOA payloads [8,46]. Although HL7 CDA is the most adopted standard, HL7 RIM is still significantly used to define VMRs [4,13,14,24,25,39,45]. Regarding openEHR, the studies covering it exploit its archetype model as a scalable method to define the VMR with several layers that gradually increase the level of abstraction of the concepts in the VMR to define aggregations that feed decision logic [20,29]. Also the use of AQL to abstract information using queries over archetypes has been proposed to reduce the amount of mappings needed [18]. Less spread is the use CDS specific information standard HL7 VMR. Nevertheless some evaluations have recognized HL7 vMR as the standard with the best learning curve for developers [11].

Terminologies provide standard vocabularies that are used to identify the concepts referenced from the CDS logic, integrate disparate systems using the terminology as a concept mediator and annotate information models. The use of standard terminologies is becoming more common in new implementations of CDS systems [3]. However, the lack of standardized data and the high diversity in existing terminologies is still a barrier for CDS SIOp [3]. Terminologies also play an important role when systems from different organizations need to be integrated. They provide the common vocabulary that the different organizations will need to map their concepts to [8,46]. Main challenges found in the adoption of terminologies are: (a) the effort of standardization [3]; (b) the linkage of local terms to standard terminologies [35,46]; (c) the diversity of available terminologies; (d) the need to transform iso-semantic models [3,6]; (e) the annotation of information model entities [6]; and (f) the limitation to process pre- and post-coordinated expressions [6,20].

Semantic web technologies acquire a transversal role in CDS implementations. They have been used to cover areas where information standards, terminologies or logic specification do not suffice; or areas where advanced semantic interoperability features such as reasoning are desired [14,38,45]. The most relevant use of Semantic Web technologies is the definition of ontologies for knowledge specification. Some studies use semantic rules systems for logic specification [16,38,45]. Semantic web technologies also play a role in heterogeneous data models integration by defining a common ontology as mediator [34]. Other use as integrator is the use of mapping ontologies to overcome the impedance mismatch between the EHR/VMR and the CDS logic [4].

There is a high diversity of formalisms to specify decision logic. The Arden Syntax was the first presented to encapsulate CDS artifacts and it is still broadly used. Nowadays its 'curly braces' problem can be alleviated using a VMR and languages to define restrictions and mappings such as GELLO [39]. Some of these logic definition formalisms are ontology based running over reasoners providing a good integration between terminologies, ontology concepts and decision algorithms [25]. Other formalisms lack of mechanisms to manage the data model and mappings. Archetypes [20] or ontology [4] mapping frameworks can be a good complement for them.

With regards to Web Services, the definition of SOA principles is a constant. CDS web services are proposed as a solution to encapsulate the CDS into a web service decoupling it from the EHR. Also, SOAs are proposed to create national frameworks to share CDS systems to allow their broad adoption [43]. UDDI registers to enable their discovery can be useful for this as proposed by Nee et al. [21]. Specific projects to study CDS services (HSSP) architectures have led to the HL7 DSS Implementation Guideline that leverages the use of CDS web services with the HL7 vMR and terminologies [50].

Finally, knowledge management of CDS modules is a topic only covered in one study. Rocha et al. covered this topic and presented the HL7 standard for Knowledge Assets specification [23]. It defines a complete set of metadata for knowledge management and a new information model harmonizing other existing information schemas such as GELLO or the HL7 CDS VMR.

Conclusion

Five main complementary mechanisms are currently used to grant SIOp of CDSS. Clinical information standards are used to define standard data models to interoperate at a syntactic level. Semantic Web technologies are used to define conceptual models of knowledge bases, integrate them, and, in some cases, specify procedural knowledge (decision rules). Logic specification formalisms aim to define shareable algorithms among systems. Terminologies provide a standard language to attach accurate terms descriptions to data and conceptual models. SOA is used as architectural paradigm to encapsulate the CDS and allow several clients to reuse its functionality. The mechanisms presented have effectively helped to decouple CDSS from the EHR and advanced in their interoperability capabilities. Nevertheless, challenges implementing SIOp to share CDS across organizational boundaries are still present [8,26].

Acknowledgments

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Electronic Disease Surveillance System Based on Inputs from People with Diabetes: An Early Outbreak Detection Mechanism

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Abstract

Pandemics or epidemics are serious concerns for any public health authority and mandate for proper monitoring and early detection strategies. In this study, we focus on people with diabetes and propose the use of continuous blood glucose, insulin, and dietary data, to develop an algorithm for the early detection of infections during the incubation period (i.e. before the onset of the first symptoms).

We present a system that consists of three modules: the blood glucose prediction, the outbreak detection, and the information dissemination and reporting module. The novel approach incorporated in the system is an interval prediction mechanism that is based on a set of autoregressive models and predicts the blood glucose values for an individual with diabetes. The actual blood glucose value is compared against the predicted interval, which is generated using autoregressive (AR) and Autoregressive moving average (ARMA) methods. The system was trained and validated based on continuous blood glucose measurements (CGM) from two individuals with type 1 diabetes. The single step point prediction was found to be accurate with a Root Mean Square Error (RMSE) of 0.2121 mmol/l. Moreover, we accurately monitored the blood glucose fluctuations for an individual with a significance level of $\alpha = 0.01$. The model was also tested against an artificially simulated dataset, which resembles blood glucose evolution of an infected individual with diabetes, and successfully detected statistically significant deviations from the normal blood glucose values. Our prototype system is still under development and has not been fully tested yet. Our initial findings though are promising and we plan to further test and validate our approach.

***Keywords**:*

Diabetes Mellitus, Continuous blood glucose measurement, Self-management system, Blood glucose prediction, Outbreak detection, Electronic disease surveillance.

Introduction

Most of the existing self-management applications for people with diabetes include modules for continuous monitoring of the blood glucose measurements (CGM) to assist individuals in better controlling their blood glucose (BG) levels. Mobile devices and smart phones offer considerable advantages towards the development of sophisticated apps [2, 9, 11, 14]. Recently, mobile self-management applications for people with diabetes have been integrated with Electronic Health Records [4, 13, 15]. If this integration is coupled with timely CGM data from people having diabetes, it can further enhance the establishment of efficient and effective disease surveillance systems.

Previous findings indicated that BG levels are elevated due to any exposure to pathogens [10]. Årsand et al. demonstrated an elevation in BG levels for both type 1 and type 2 diabetes individuals after the infection by Influenza, Cholera, Plague, Ebola, Anthrax, or SARS viruses [3]. Botsis et al. also described the positive correlation between BG elevation and infections in people with type 1 diabetes [7]. These findings suggest the potential use of the BG parameter for the early detection of disease outbreaks in the general population [3, 7]. Other parameters (such as body temperature, white blood cell count and blood pressure) are directly associated with the presence of infections in the body [6, 12]. Multiple incidents with abnormal values for the above parameters in the population may indicate the presence of an outbreak [1, 10]. We therefore argue that the incorporation of all these parameters into advanced modeling solutions can potentially support the early detection of outbreaks. The objective of our research is the development of a reliable electronic disease surveillance system for the analysis of diabetes data at both the individual and the population level. In this paper, we describe our initial exploration and our first-hand results.

Materials and Methods

Datasets

This research was conducted using data from two individuals with type 1 diabetes. The Dexcom CGM and the diabetes diary[1] that have been developed by Norwegian Center for E-health Research (previously known as NST) were used for the data collection. These modules are part of a mobile applica-

tion designed for diabetes management. The collected data included continuous BG measurements from the Dexcom CGM (in 5 minutes intervals) for one month and BG, insulin, diet and physical activity data from the diabetes diary for one year[1]. We used these datasets to train and validate the developed system for its goodness of fit to the BG dynamics of the two subjects in their non-infection status. We subsequently tested our system with a simulated dataset that included consecutive patterns of high BG values; this resembled the CGM during the infection period. Various increments per minutes ($\frac{\Delta BG}{minutes(t)}$) and various time intervals of elevated BG were considered.

Methods

The system can predict the BG values with a confidence interval and assess this prediction against the actual BG values. It can further analyze the measured and predicted BG values for the presence of any aberrant pattern. If there is a detection of any abnormality, the system will generate and send a notification signal to the concerned bodies or authorities and support the investigation by displaying this on the map of the interest. The system consists of a BG prediction module, an outbreak detection module, and an information dissemination and reporting module.

Blood glucose prediction module

This module includes a personalized health model that monitors the BG fluctuations of the individual with diabetes. It predicts the single step BG value using the previous BG, insulin, diet and physical activity records. This module also calculates the confidence interval of the predicted values based on the recent empirical distribution of errors between the actual value and the predicted value. The prediction module utilizes a black box approach using an autoregressive model that incorporates Autoregressive (AR), Autoregressive with Exogenous input (ARX), Autoregressive Moving Average (ARMA), and Autoregressive Moving Average with Exogenous input (ARMAX) methods. Autoregressive models were selected because they rely on the most recent information to forecast the future values. In our approach, it is very important to follow the persons' cyclical habit on a weekly or longer-period basis. The model simplicity and reproducibility were the factors that were considered in our selection. The well-defined procedure for calculating the intervals of the forecasts is definitely important as well. We evaluated and compared the performance of these models using the Root Mean Square Error (RMSE) function.

Outbreak detection module

The outbreak detection module is necessary for comparing the actual BG values with the predicted intervals. This module is built on mathematical models that can compare and detect any statistically significant deviations between the measured and the predicted BG values. This outbreak detection mechanism evaluates whether the actual BG values are outside of the predicted interval for the individual. Moreover, moving window z-score are used for better detection accuracy. The purpose of this moving window z-score is the detection of any significant deviations (anomalies in the data) based on the moving mean and standard deviation. Given a window size w, the mean and standard deviations are used to check the agreement of the actual BG measurement with the previous trend in w. This module also performs an aggregation analysis, which counts the maximum number of events on a spatio-temporal basis. In other words, it detects a disease outbreak in both space and time using a specified threshold that is defined based on the region it covers (space) and occurrence of statistically deviated BG values (time) for a number of individuals. If the number of people in the cluster exceeds the threshold, an alarm will be sent to public health authorities or hospitals. The performance of this module is evaluated based on the accuracy of detecting the cluster in a timely manner. A Receiver Operating Characteristic (ROC) curve is used to determine the best operating threshold of the system.

Information dissemination and reporting module

A principal function of the disease surveillance system is the generation of reports containing information about the detected disease outbreak. The related information is presented in tables, graphs and maps. The corresponding module submits the reports to the authorities and other interested parties via SMS and Email. Initially, an SMS is sent followed by an email to the responsible persons with the adequate information regarding the outbreak. The email contains information about the spatial and temporal distribution of the disease outbreak on a map of the region, the degree of severity and other critical data.

Design and Implementation

Prediction Model and Interval Prediction

The prediction of the BG values is based on an Autoregressive model including autoregressive with Yule Walker Algorithm, Autoregression using ratio of consecutive data points and Autoregressive Moving Average using Yule Walker Algorithm.

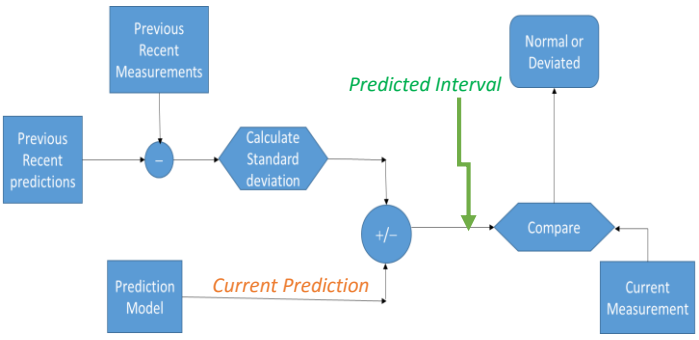

Figure 1: The Proposed Algorithm

Based on the point prediction and the empirical error distribution between the measured and the predicted value, a prediction interval is calculated with a certain confidence interval (1-α)*100%, where α is the level of significance [8].

[1] www.diabetesdagboka.no

As shown in Figure 1, the proposed algorithm computes the predicted intervals based on the previous recent predictions and measurements along with the current point predictions. The empirical distributions of errors between the previous predictions and measurements are the basis for the current interval prediction. This is clearly shown in Figure 1, where the predicted intervals are compared with the current measurements.

The system was developed in MATLAB version R2015b. A system identification toolbox along with the partial autocorrelation function (PACF) was used to identify the optimal model order. The autoregressive (AR) and autoregressive moving average (ARMA) were developed based on the CGMs that are shown in the Figure 2.

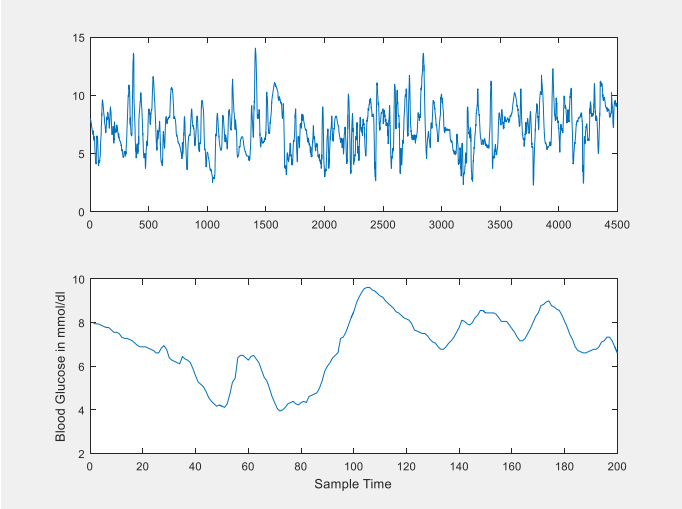

Figure 2: Plot of the entire sets and the first 200 data elements of the continuous blood glucose data.

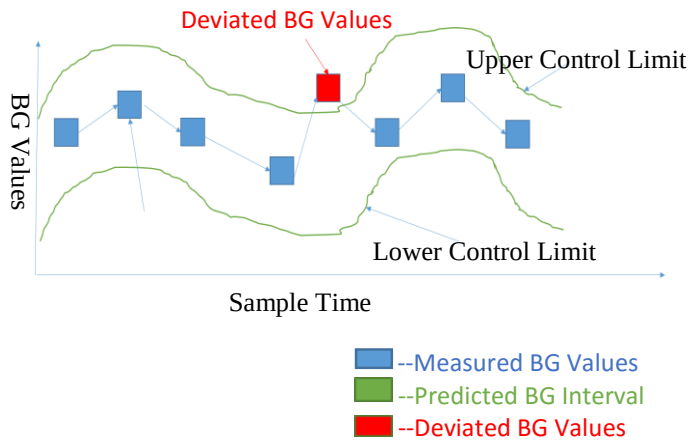

Figure 3: The proposed solution for the detection of the blood glucose deviation for an individual patient.

Outbreak Detection/Surveillance

The proposed solution is similar to a control chart/statistical process control algorithm, where the controls are determined by the intervals predicted from the individual blood concentration profiles defined by the AR models. As shown in Figure 3, the next BG value can be effectively controlled by the predicted upper and lower control limits with a reasonable accuracy. Moreover, as described in the above section (see outbreak detection module), the output results from the moving window z-score and the output results from the predicted intervals mechanism are augmented for better accuracy.

Results

We used the autoregressive models to predict the BG values using CGMs in 5-minute intervals. Autoregressive model using Yule-Walker algorithm, autoregressive model using ratio of the consecutive data points and autoregressive moving average with Yule-Walker algorithm were implemented and tested for 8495 data points. The RMSEs were calculated for 4495 testing data points. The first model, a fifth order autoregressive (AR), efficiently predicted the single step BG values with a RMSE equal to 0.9727 *mmol/l*. The second model, a fifth order autoregressive, is also capable of predicting the single step BG values. The prediction produced interesting results with a RMSE equal to 0.3413 *mmol/l*. Furthermore, the third model, an autoregressive moving average with a third order autoregressive terms and a second order moving average terms, is also capable of predicting the single step BG values. The prediction generated promising results with a RMSE equal to 0.2121 *mmol/l*. The prediction interval calculated from these models was constructed with a significance level of $\alpha = 0.01$, which means that one is 99% confident that the future values fall within the predicted intervals. Both the first and the second models produced intervals with reasonable sizes. However, the third model had a shortcoming in producing a good prediction interval, which is too narrow.

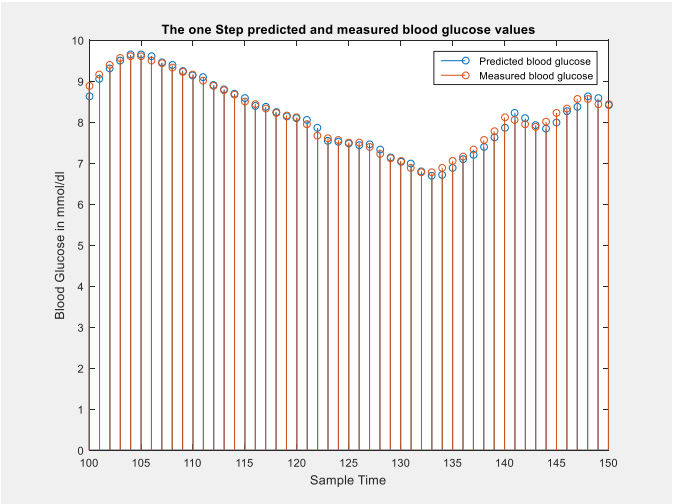

Figure 4: The predicted and measured blood glucose.

The point prediction and its interval prediction for the single diabetes subject are given in the Figure 4 and 5. These results were generated from the first model, the Autoregressive model using Yule-Walker algorithm.

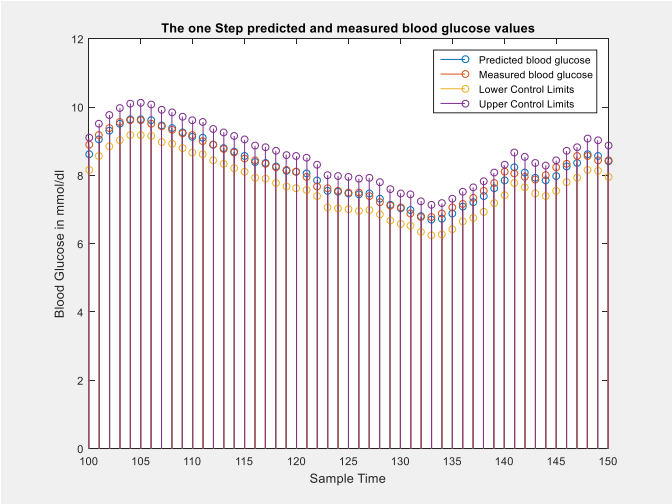

Figure 5: The predicted interval, predicted and measured blood glucose.

The moving window z-score process is also capable of detecting high BG values based on trends for various periods and rates of growth. For example, as shown in Figure 6, it can detect BG values over a long period of time. Therefore, an outlier can be detected by setting threshold values of three and more standard deviations from the mean value.

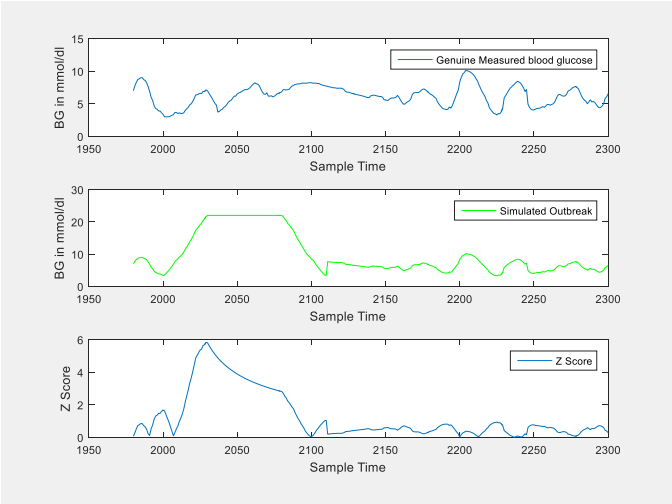

Figure 6: Measured blood glucose, simulated outbreak and the moving window z-score.

Assumptions, Biases and Limitations

The major limitation of this project is the sample size. We based our experiments and simulation on two individuals with type 1 diabetes, and more data is needed to further validate our approach. Moreover, the "holiday effect" has not been considered in this study. The "*Holiday effect*" is the bad eating style of people with diabetes in the holiday season [10] and usually leads to high BG values. In such cases our system may generate false alarms, especially given the absence of frequent measurements for other supporting parameters, such as the white blood cell counts and temperature readings from these individuals [5, 6].

Conclusion

With the advent of information technology, the transition from paper- into electronic-based reporting has revolutionized the disease surveillance systems. Our system should be grouped under the syndromic surveillance systems that also use certain data (absenteeism, Internet search volume, over the counter pharmacy sells and so forth) prior to the confirmation of infections through diagnosis. However, this information is generated after the onset of the first symptoms and syndromic surveillance systems that focus on the incubation period have not been developed yet. This is the novel and unique characteristic of our work. Our system incorporates a BG prediction mechanism that can both predict the BG values for an individual and efficiently detect an infection during the incubation period. Even though we have not fully tested and evaluated our approach, we believe that our initial findings are very promising to support our next steps. The systematic evaluation and validation of our system is among our future plans. We also hope to pave the way for the next generation disease surveillance systems.

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Approaches to Learning openEHR: a Qualitative Survey, Observations, and Suggestions

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Abstract

Approaches such as ISO 13606 and openEHR aim to address reusability by defining clinical data structures called archetypes and templates, based on a reference model. A problem with these approaches is that parts of them currently are rather difficult to learn. It can be hard to imagine what an archetype-based clinical system combined with modern terminology systems will look like and what consequences different modeling choices have, without seeing and experimenting with an operational system.

This paper reports findings from a survey among openEHR learners and educators combined with observations of related openEHR mailing list discussions. The paper ends with an opinion piece, where we discuss potentially fruitful ways to learn, explore, and extend archetype-based EHR systems using visualization and examples.

The findings highlight potential stumble blocks and solutions and should be of interest for both educators and self-learners.

Keywords: Electronic Health Records; Software; Learning; Standards; openEHR; archetypes

Introduction

Electronic health record interoperability approaches such as ISO 13606 and openEHR aim to address reusability by defining small clinical data structures called *archetypes* and *templates*, based on a *reference model* that can be used as building blocks in different clinical systems. With openEHR being used in domains as diverse as methadone treatment in general practice [1], biobank information management [2], and geriatric home care [3], a growing number of learners have invested time to learn—at variable depth—how archetype-based systems work. Future development and maintenance of such systems at a large scale will require many clinicians and developers familiar with various aspects of these frameworks. The aim of this paper is to explore approaches to teaching and learning openEHR and to suggest ways to make it easier for new-coming system developers and clinical content developers to become productive.

A crucial feature in openEHR is the two-level modeling approach, which separates technical infrastructure concerns and clinical concerns [4]. The technical **Reference Model (RM)** provides the foundational, general building blocks that are then combined, named and used in tree-like data structures according to rules and constraints defined in archetypes and templates. The aim of the RM is to provide common structures for general data that are useful in many clinical settings: configurable data fields, units, time-points, user participations, versioning, etc.

An **archetype** in openEHR and ISO 13606 contains a set of names, rules and constraints describing how to use the RM building blocks to create a data structure that tries to cover all possible aspects (maximal dataset) of a specific well-bounded clinical concept, such as the recording of blood glucose measurements or body weight (including details of measurement method, amount of clothing etc) [4]. These archetypes, expressed using the **Archetype Model (AM)**, can then, for example when used for data entry, be combined into larger structures.

An archetype can also contain language translations so that structured data entered using labels from the archetype in one language can be displayed in another language. (The content of unstructured free-text fields will not be automatically translated by this.)

A **template** in the openEHR sense of the word is used to combine several archetypes into a larger structure intended for a specific use case, for example to be used as the basis for a data entry form in a certain EHR system [4]. A template can also constrain, hide, or set default values in the archetypes and the reference model it builds upon. Templates do not "add" new clinical concepts; they use and constrain concepts defined by existing archetypes.

Every part (node) of an archetype-based data structure in an EHR is addressable and thus retrievable by a **path** containing, among other things, a concatenation of the used archetype IDs

and subsequent node-IDs. Combinations of paths and values can be used in queries to extract and display data in the EHR system [5].

The split between archetypes and templates is primarily for practical and pedagogical reasons; they have different purposes. Archetypes, due to their maximal dataset nature, are supposed to be reusable and created for example nationally or internationally [6]. Templates are intended for more specific and local use cases, for example reflecting local terminology usage, and don't add data with any other paths than the ones available in the archetypes [4]. Thus, data originating from systems using different templates but the same archetype can be retrieved using the same query.

Advanced terminology systems like SNOMED CT and many other biomedical ontologies also aim to address reusability, for example by providing internally cross-linked structures that allow data entry at fine granularity that can be re-represented and interpreted also by other users later using a coarser granularity. This allows shifts of perspective between entry and retrieval [7]. Archetype and template nodes, including fields and field values, can optionally be bound to external terminologies [4], thus adding another level of possibilities but at the same time complex relationships that need thoughtful design and maintenance.

If you by now feel a bit puzzled and confused about the role and usage of RM, archetypes, templates, paths, queries, terminology systems and what difference they all make in practice, then you sense a bit of the commonly occurring learning difficulties that meet people trying to understand and get started with these systems.

Before diving further it's important to realize that the average EHR user does not need to understand more of the system "under the hood" than for current "classical" systems. The RM, archetypes, templates and terminology systems don't need to be shown in user interfaces. Those who need to understand more about the underlying possibilities and constraints of the different system levels are for example software developers, interaction designers, and clinical "super-users" wanting to develop and modify the system and the clinical models used. Policy makers may also need to understand the options and implications of design decisions.

Materials and Methods

This study was conducted as an international qualitative survey via email. One set of questions was sent to eight well-known educators who were actively involved in technical and clinical openEHR development and were all teaching a mixture of audiences from technical, academic, and clinical background. Four educators responded. Another set of questions was sent to the two main openEHR mailing lists (for technical and clinical discussions, respectively), where another four people responded. The learners that responded were from both clinical and technical background but all had some software development experience.

The discussion section combines the survey results with observations from actively following openEHR mailing lists discussions since 2006 and being involved in education, research, and development of related systems.

Results

The **bold** texts below show the questions, and the bullet lists show (spell-checked and shortened) reply samples. Queries to learners are *in italics* and marked with (L). Related questions to educators and learners follow each other when possible.

When teaching, how do you describe the structure and semantics of openEHR?

- I usually start by dividing the specs into RM and AM. Then drill down into different parts of RM and AM, but I think for non-developers it will be too much information in the beginning. A graphic overview of all specs would be very useful with zooming possibility to look at details etc.
- I describe it as a 3 layer model: reference model, archetypes, templates.
- Describe the 2 level model—clinical vs. technical domains; clinicians driving the clinical domain. Classes described, with practical examples.

What activities did you do to learn the structure and semantics of openEHR? (L)

- Looked at example program code
- Partially read/browse the docs on the website, lurk on mailing lists. Engaged in software implementation.
- Read openEHR specs, was involved in producing views of openEHR sample data and that familiarized me with the most common openEHR RM classes.
- Studied the reference documents and existing presentations

If you are using metaphors to describe the structure and semantics of openEHR, describe the metaphors.

- Lego bricks!! I also talk about the need to 'evolve interoperability' whilst maintaining 'bio-diversity' of local practice and content.
- Composition Class aligning with a piece of paper in a paper record. Section aligning with headings on a Word document. Entry Classes of archetype aligning with the clinical tasks done by the clinician. Templates aggregate archetypes and allow them to be constrained to be 'fit for use'.
- We have used the following metaphors to describe archetypes. **Language**: the reference model is like a dictionary of words—not meaningful on its own; archetypes are like meaningful sentences. **Lego**: the reference model is like Lego bricks; archetypes are like Lego model designs (which you see on the paper that comes with the Lego)
- Lego bricks, for example. I also compare to existing EHR systems.

What metaphors and/or examples were used to explain the structure and semantics of openEHR (also describe the metaphors)? (L)

- None, I invented a few myself, for example, a car-dealer/repair keeping track of his sold cars.
- Lego bricks for putting together archetypes into a template, the Lego round thingies being the openEHR archetype slots, (but I don't like this metaphor for more than a very basic understanding of what an archetype is and what it's for). In describing archetypes, I personally like the metaphor of a sculptor with a block of marble taking parts of the maximal dataset (original marble block) away to make a domain concept (sculpture of person).
- **1:** Archetypes as models of USE, needing their own models, next to models of Documentation/Archiving (EN13606-1/openEHR) and models of Knowledge. **2:** The patient system and types of ENTRY classes.

Which are the internal components and processes in the structure and semantics of openEHR that are important to know for understanding how openEHR functions?

- The main process behind the Entries—observation, evaluation, instruction, and action.
- From a clinical perspective, the separation of technical infrastructure and clinical content in archetypes and templates. The way that terminology is used within openEHR.
- Classes of archetypes and how to differentiate between their uses. Features of each class and how they are expressed in the tooling; how they express the clinical content in various example scenarios

Which are the tools you use today to teach the structure and semantics of openEHR? What was the reason that you choose those tools?

- Right now very limited. Design specs in PDFs, a few archetypes in editors, and UML diagrams/PPT slides.
- PowerPoint, practical demos using an archetype editor, template editor
- Tools from Ocean Informatics: Archetype Editor, Template Designer, Terminology Service, Clinical Knowledge Manager (CKM).
- As much visualization of difficult concepts as possible.

What tools and/or resources did you make use of when you learned about the structure and semantics of openEHR? (L)

- Archetype-editor, archetype workbench, example code, and documents
- An archetype editor, now the CKM. Docs/specs on the openEHR.org website
- OpenEHR specs, sample archetypes, even mails on openEHR tech/implementers mailing list to some extent
- Tools by openEHR, Ocean Informatics and LINK-EHR

Which parts of the structure and semantics of openEHR do you think are easy to teach, and which do you think are hard to teach?

- Data types and structures are quite easy to grasp since they are common in other computing platforms. The distributed versioning and participation model is much harder since it's a difficult topic.
- From a clinical perspective, the relationship between archetypes and templates is easy to teach. It is difficult to teach about some aspects of the technical reference model that they do need to understand, e.g., the time attribute in the ACTION class. The difference between state, protocol and data can be difficult, especially when complex timings are involved. The relationship between INSTRUCTION, ACTIVITY and ACTION is complex and difficult to teach. The use of PARTICIPATIONS is also difficult to understand. Overall, understanding exactly how the data are finally recorded is difficult to teach, especially in complex cases as above.
- It is all hard to teach—it is very abstract for non-technical clinicians to grasp, especially archetype development. Templates are easier as taking a 'concrete' archetype and aggregating/modifying is an easier concept and the outcome is related to their clinical experience.

Which parts of the structure and semantics of openEHR do you think are easy to learn, and which are hard to learn for the learners?

- It mirrors the teaching difficulties.
- Observation and Evaluation are hard to learn and still very difficult to apply in real-life examples.
- Difficult: showing how archetypes work in real systems (we have used animated slides to explain it)

What parts of openEHR were difficult to learn? (L)

- Initially, to grasp properly the two levels of modeling. Then to realize that domain models are modeled by constraints rather than by adding data points. Hard for me to put this into words still!
- I found it hard to switch **from** an object-oriented approach where a simple base class is extended more and more to obtain resulting classes that are used in concrete programs, **to** a 2-model approach where one starts with a giant all-encompassing model (archetype) and cut away unneeded properties resulting in concrete classes that can be used in programs.
- I found the openEHR architecture overview document very hard to read; sometimes it wants to explain too much all at the same time, and sometimes terms are used without having been introduced properly (if I recall correctly, things like ENTRY, COMPOSITION, CONTRIBUTION) or without a concrete example. Referring to other documents (which does not work nicely in PDF). Often it is quite abstract and or too mathematical: e.g., as a relative outsider, I hate the use of the word ontology: it does not ring a bell to me at all.
- When to use what type of ENTRY archetype. How to deal with Instruction/Action? How to use the same documentation patterns as much as possible modeling archetypes

What were your strategies to learn the difficult parts of openEHR? (L)

- Never give up
- Ignore them; wait until they become clearer via discussions on mailing lists. It would be so much nicer to have one or two use cases (or patient's travels as they are called for the connect-a-thon) described on various detailed levels and introduce the openEHR concepts while discussing them. Using way more pictures/diagrams.
- Just a lot of work reading. I can't recall specific strategies. The RM class diagrams in the openEHR specs are certainly great to print out while still learning.
- Produced a 130-page document with all lessons learned and thoughts about improvements

Which properties in the structure and semantics of openEHR do you think are the most important to teach (e.g. if time is limited)?

- The process of obs/eval/instruc/action is important to communicate.
- 1) Two-level modelling with archetypes. 2) The documentation process.
- For a clinical audience, an understanding of the relationships between archetypes and templates, and the importance of the 'maximal dataset' approach.
- The two-level model—clinical vs. technical domains; clinicians driving the clinical domain.

If you could design your own tool to teach the structures and semantics of openEHR, what would it do and how would it look?

- The assistance from the tool should be context-specific depending on what in the model you are working with. Some examples from current archetypes would be good to have.
- Be able to show clinically relevant reference model attributes, interaction between archetypes and templates, relationship of INSTRUCTIONS and ACTIONS, and to be able to show how data are actually committed in a clinician-friendly way.
- A tool for engineers (who like the X-ray view of things) would just be a fancier version of the ADL Workbench, or the Valencia teams' tool. For clinical people and teaching, it would be something that visualizes each main Entry type in an intuitive way. Apart from EVALUATION, the other types have a time concept that needs to be visualized (the current Archetype Editor does this in a very simple way—by at least separating it from the structure data part).

Which properties of the structure and semantics of the openEHR would you wish that you could describe with the help of a graphical tool?

- Selecting appropriate RM classes and AM constraints, and a quick overview of the complexity of the models. If the tool can indicate the density of used RM classes by archetypes in a public repository, it will be useful information.
- Participations, Instruction, Actions, History class.
- The instruction state machine could obviously be visualized much more effectively. Also, the data/state/protocol pattern could be visualized. E.g., think of a picture of a human body and an instrument measuring a datum, and then you can imagine how to guide the user to correctly classify the various bits of information. E.g., in OGTT, the glucose value comes from the machine, the fact '1hr post glucose challenge' relates to the subject's body and the brand and other details of the machine are part of the protocol.

Comments

- "I'm not sure if you realize how hard your questions are to answer ;-) The scope of openEHR is huge and complex. The training has to be designed to reflect the audience as I'm sure you'll agree. These answers are brief as it is all I have time for but I hope will help a little—it is not easy to distill the essence of openEHR into even a couple of pages. The real answer is probably much, much longer than that."

Comments (L)

- "I hope you succeed in cutting the vast amount of concepts to learn into sizeable chunks, e.g. via a series of tutorials containing lots of visualizations!"

Discussion

The openEHR platform is a complex framework of design specifications, tools, and clinical models. Not surprisingly, responses indicate that there are easier as well as tougher parts to teach and learn. Tools designed for experienced users are also employed in the learning environment. This may work in some cases, but there is also need for more tailored learning tools.

Approaching openEHR as a beginner

Based on the survey responses and experiences gained in educational and research development projects, we have made some observations of recurring issues and learner reactions and questions.

It is hard and takes time to understand and learn!

It does take time to learn the inner workings of any big EHR system. A system designed to deal with the semantics at the scale of a nationally interconnected system of EHR systems may take even more time [8]. Survey participants indicated that they needed considerable time to learn the openEHR approach. For Swedish technical students doing their Masters thesis, it often takes around 10 weeks to properly get into openEHR fundamentals and then into the subparts of openEHR they need for the thesis using currently available specifications and teaching materials. The amount of time needed for a clinician to get productive in archetype authoring is shorter in most projects, and is usually shortened by the help of being closely guided by an informatician knowing the system very well. Guided training has evolved over the years, but the need for self-study materials and tools does not yet seem to

be adequately met regarding openEHR. This makes the hard task of learning on your own even harder.

Do archetypes allow me to model anything any way I like?

A common beginner misconception is that you safely can model anything you like anyway you like using archetypes. It is true that technically parts of the archetype formalism allow you to build arbitrarily big and complex clusters (tree structures) using building blocks from the RM with nodes that you can name any way you like. However, this does not mean you necessarily should do that.

If you need total freedom, then for example unrestricted object-oriented programming would allow users to model anything any way they want. The drawback is that there is a risk that many users will model similar things in very different ways and thus get incompatible systems. In openEHR, the RM is aimed to capture commonly occurring things in standardized ways in order to minimize unnecessary variation leading to incompatible systems.

Another issue we have seen on openEHR mailing lists (see Appendix) and in projects (including national eHealth activities) is that things such as certain time-points and agent participations that already have well-defined places in the RM have been re-modeled a second time in yet another place as free-form clusters in archetypes. One reason, which was also confirmed by the survey, seems to be that a common entry point for openEHR beginners is to look at archetypes and archetype editing software. It is then easy to think that what you see in an archetype editor corresponds directly to what an entry form in the EHR system will contain.

Archetypes only contain rules and constraints for exactly the part of the RM they are modifying. Every other part of the RM is invisible in an archetype, and in many archetype editor programs. If the archetype is "silent" about something in the RM, only the RM specification "speaks" the rules for that part. Since the RM specifications are technical, detailed, and long, it is not surprising that many parts of them are unknown to novice archetype authors. As a result, users build their mental models of the systems and their possibilities primarily based on example archetypes and oversimplified archetype editors. It is easy to fall into the trap of believing that the structure that you view or create in an archetype should contain every field you will have in a user interface form.

Providing users with tools that support and not mislead is of utmost importance for the openEHR community. For example, such tools would help beginners see archetypes in proper contexts, for instance with traceable RM parts included—parts that in the perspective of a plain archetype would have been hidden and thereby at risk of being remodeled.

Is It Unnecessarily Complicated?

Some consider the modular multilayered approach overly complicated, and if the purpose is to build a fairly static system for a specific setting where data reuse in other contexts is a non-issue, they are most likely right [8]. If, on the other hand, the purpose is to design a national eHealth platform for cooperation, they are likely to need something of considerable complexity [9]. The openEHR approach is developed to be suitable for example

- in a setting where data is reused and possibly aggregated in other contexts than the entry context
- in a system of systems where independent systems need to use and update shared information
- when clinical models change regularly and the system needs to update accordingly. (An archetype-based system can require considerably fewer man-hours to update than traditionally built purely object-oriented systems [10].)

The reusability problem and the benefits of maximal dataset approach with well-defined semantics and paths may not be obvious until one tries to reuse data or use software operating on that data. Writing algorithms to safely convert between different entry formats with mismatched semantics can be very complicated, if at all possible.

This does not mean that openEHR is at a minimal necessary complexity level for its purpose yet, and there are likely still parts that can be simplified without sacrificing functionality. For example, the model behind templates has been simplified and shrunk over time and integrated into the archetype model [11]. There are discussions regarding simplifications of other structures.

Suggestions for Learning Environments and Prototyping Approaches

Technical specifications and UML diagrams are the cornerstones of an archetype-based system, but they easily become obstacles for the novice. To make learning and experimenting with archetype-based systems easier, we need to find alternative ways for those who do not find them a useful, fast, or simple enough way to get started with openEHR and ISO 13606.

Using XML Representations of EHR Instance Data

In the survey, some participants asked for clear clinical examples like some complete "patient journeys". One related learning strategy that has worked rather well for master students and in tutorials for people with XML knowledge is to look at XML structures with openEHR-based EHR content. These show serialized instances of hierarchies of RM objects including references to used archetypes, and show all RM parts used in that particular example. Names of the archetypes and their nodes used for naming and constraints also show up in the XML EHR data. However, RM parts that are not used in that particular clinical example are not visible, which make UML diagrams or specifications needed as a complement. All the alternative constraints and possibilities of the used archetypes are not seen in that XML EHR data either, so access to the archetypes used are needed as a complement.

Graphical Representations of EHR Instance Data

Some openEHR specification documents such as the EHR Information Model [12] contain graphical EHR data instance examples like the one in Figure 1. While these diagrams lower the entry barrier by removing the need to read and understand XML, the same issues of just showing the parts of the RM and archetypes used remain. The available illustrations are useful

tools, but people risk missing these gems in lengthy specification documents.

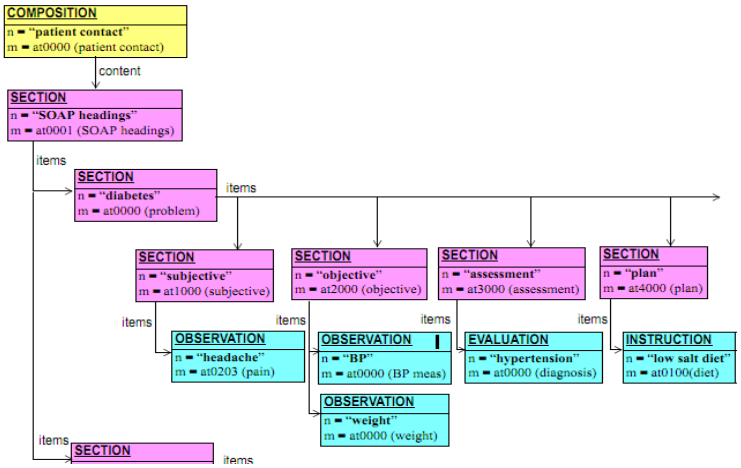

Figure 1- Parts of an explaining diagram from the openEHR specifications (part of figure 15 in the EHR Information Model [12]) © Copyright openEHR Foundation 2001-2016. All rights reserved. www.openEHR.org Reproduced by kind permission of the openEHR Foundation

Interactive Graphical Representations of EHR Instance Data, Allowing Browsing and Manipulation

In order to keep the official openEHR XML serialization (mentioned above) more compact, for example for messaging purposes, unused RM parts are—and should be—omitted and archetype information kept to a minimum. Graphical representations like the one in Figure 1 are also appropriately simplified and show selected parts of the chosen RM pieces. There are several reasons to simplify things, for example to fit models on available paper and to avoid information overload caused by details irrelevant to what one wants to illustrate at the moment.

Showing the entire RM together with archetypes and templates with equal emphasis for an entire example patient's EHR all at the same time risks overloading the user with information and is not likely to be useful. Instead, the visual information-seeking mantra [13] shortened as "overview first, zoom and filter, then details-on-demand" (with five out of seven main steps in bold below) could be applied to browsing archetyped EHR data examples in an interactive learning environment:

- **Overview**: Gain an overview of the contents of an EHR
- **Zoom**: Allow several steps of zooming into the EHR, for example drilling down via Folders to Compositions to Sections to entries like Observations.
- **Filter and details-on-demand**: Allow selection of perspective to filter out or de-emphasize some information. An RM perspective could put emphasis on RM class names (like "OBSERVATION") and also show unused optional RM attributes in the hierarchy. An archetype perspective on the other hand could put emphasis on names derived from the archetypes used (like "headache") and also illustrate unused options available in the archetypes and templates. The hierarchical nature of the EHR data provides for details-on-demand, for example via collapsing and expanding sub-trees.
- **Relate**: There are many relationships in EHR data that may be interactively explored. EHR data is created in relation to certain archetypes and templates which in turn may be related to other archetypes and templates via compositional or specialization relations. Objects can be related via several folders. Different versions of objects are of course related to each other. All this cannot be easily shown at the same time, but could be interactively explored a few at a time.

We have begun (but not published) design of such an interactive browsing environment to be combined with our Educational EHR Environment LiU EEE [14].

Understand Paths, Queries, and Reuse in Model Construction and Data Retrieval

A learning environment should encourage learning about different kinds of reuse enabled by an archetype-based approach.

Capturing clinical requirements for EHR systems can be daunting also in traditional systems not based on archetypes. Constructing maximal datasets like archetypes is even more demanding since it involves collaboration (often international) between different kinds of users in different contexts in order to catch different requirements. As of this writing, the Clinical Knowledge Manager (CKM), the major international collaboration system for archetype development, contains about 300 archetypes in different stages of maturity. A learning environment should encourage the user to reuse as much as possible from existing archetypes as a basis when creating local use-case specific templates (and only create new archetypes for missing things). This kind of reuse can reduce the total work needed to create a usable system—the requirements gathering work is broader than when focusing on a specialized system, but more people are involved to share that load. Reuse is also valuable in the emerging perspective of quality assurance [15].

An archetype-based approach also creates reusable paths that can be used to retrieve data for GUI construction, decision support rule engines, statistical queries, etc. A learning environment should encourage the user to explore and use path-based retrieval, for example via modifying and extending example queries and overviews. UML diagrams of the RM (and the technical specifications to a large extent) are useful when developers are building systems—basing learning in queries and paths instead puts the focus on how to use the system, including extending and modifying it for clinical needs.

Understand the Loose but Necessary Coupling between Interaction Design, User Interface, and the Underlying Semantics

When defining archetypes, focus should primarily be on use and reuse of clinical information, with reuse possibly in another context than that of data entry. However, it is not always necessary to manually fill out all things defined by the archetypes at the point of care, for example things that are obvious from the context of use. Such things could be set as default in templates or as sets of common presets by the system.

In an archetype-based system, the entry form in the user interface is not necessarily equivalent to the underlying semantic model, so it is important to prevent establishment of the false mental model "archetype equals entry form". The semantics of the underlying models will indeed affect data entry, and a change in one is likely to affect the other. Such dependencies have been explored and used by Kashfi [16] in the combination of a user-centered design (UCD) process and the process of archetype-based concept design.

Limitations

This study is limited in several ways. First, the number of respondents is small, and especially a higher number of responding learners could have made the picture more complete. Second, the study is based on spontaneous responses, and we do not know if participants are representative of the community. Third, the questionnaires were sent in January 2010, so answers may not reflect the current situation for example regarding available tools.

Conclusion

The learner and educator experiences reported in the survey can guide newcomers and those who develop supporting software in what to spend extra energy on and some learning traps to avoid. Further effort is needed from the openEHR community to reduce recurring learning issues.

If archetype editors–that often hide parts off the model–continue to be the most accessible tools available to learners then they will likely continue to be a common entry point. Risks associated with that approach include remodelling of existing structures–thus "re-inventing the wheel".

As the number of freely accessible examples of openEHR systems keeps increasing some learning issues are likely to be reduced. Showing the relations between archetypes, templates, queries, user interfaces and patient data instances using examples seems like a promising approach.

An even more streamlined start of the learning process may come from future visualization based learning tools that conveniently allow perspective shifts between for example RM focus, archetype focus and patient data instance focus.

Acknowledgments

We thank all survey responders. We also want to thank the named email list contributors for allowing publication of the excerpts in the Appendix.

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Appendix

Example snippets from mailing lists indicating the value of not hiding too much in archetype editing tools etc. Quoted with permission. The complete conversations are available in the list archives at:

http://www.openehr.org/community/mailinglists

Shortened text is indicated with [...]

From: Peter Gummer
Date: Tue, Jan 18, 2011 at 12:55
Subject: Re: Use of Identifiers in archetypes
To: openEHR technical discussions

[...]

Each LOCATABLE has an attribute called 'feeder_audit', of type FEEDER_AUDIT. Within the FEEDER_AUDIT class, there are lists of DV_IDENTIFIER where systems can store ids generated by the originating system and other systems. The FEEDER_AUDIT also has an attribute called 'original_content', where an image or a reference to the image would be stored.

Because COMPOSITION inherits from LOCATABLE, an obvious place to set the 'feeder_audit' attribute might be on the composition. You could of course prefer to set it on, say, the imaging exam OBSERVATION.

This is an excellent example of something that is already catered for in the reference model, and so it probably shouldn't be modelled in archetypes. Unfortunately, current tools don't make the feeder_audit attribute visible visible to modellers, so they are likely to "reinvent the wheel", unaware that it's already available. (They're designing "wheels" for the "car", but the car already has wheels.)
This is a problem to modellers: an important part of the model that they are designing is to all intents and purposes invisible to them in the archetype.
[...]

From: Peter Gummer
Date: Tue, Jan 18, 2011 at 23:12
Subject: Re: Use of Identifiers in archetypes
To: openEHR technical discussions

> Generally, about FEEDER_AUDIT, it's something I had missed, so
> I'll go and review it, but how does it manifest in the archetype editor?

FEEDER_AUDIT isn't shown in the Archetype Editor at all. It's one of many parts of the reference model invisible within the tools, and so easily overlooked by modellers. As Ian said, there's growing recognition that future tools need to rectify this.
- Peter

From: Heath Frankel
Date: Fri, Feb 22, 2008 at 00:05
Subject: RE: Understanding XML archetypes..
To: openEHR technical discussions

> - The fact that the current tools do not expose or use these
> attributes, is a design decision made by the people writing
> the tools.

Well probably often a "decision" in lack of time/resources or (less likely) lacking ideas of good/useful ways to present them. A tool exposing the RM has to deal with both RM and AM in detail and thus takes more time building than dealing with AM only.

Actually I think it was more to try to keep the task of archetyping simple as it is a task targeted at Domain Experts (Clinicians) without them requiring to know about the RM (well so we thought). Unfortantly, hiding some attributes that are commonly required by the clinician forces them to put it in the archetype so they can see it. We are also finding more and more RM attributes that we want to archetype other than just data structures such as participations.

The challange is to find a visualisation of the archetype that is still simple but can also expand out to include relevant RM attributes.

In Ocean's next generation of tools, mainly inspired by the requirements of the Archetype Query Builder where criteria on RM attributes is common, we will have a configurable tree view of templates where individual RM attributes can be turned on or off, right down to the data type attributes if needed. We are also looking at alternate visualisation of archetypes for the next iteration of the Ocean Archetype Editor.

From: "Erik Sundvall"
Date: Tue, 22 May 2007 09:24:15 +0200
Subject: Re: Point in time 2
To: openEHR clinical discussions

Hi!

On 2007-05-22, Heather Leslie wrote:
Perhaps the apparently 'hidden' reference model stuff should perhaps even be displayed, in an uneditable format, in the Archetype Editor and Template Designer - to make this design process more transparent and help bridge the clinical/technical divide just a little.

This very much matches my point of view. Ideally archetype editors etc should be delivered with a built in mini-EHR system for simple testing purposes (security, scalability etc would not be in focus then). I think such a solution will come from somewhere eventually.
[...]

Included for more context; On 2007-05-22, Heather Leslie wrote:
From my clinician point of view, the average clinical archetyper can only imagine that what they see in the archetype will be what can possibly be displayed on their User Interface. It would be ideal if we can work to make the 'unseen' magic that comes from the reference model clearer, as the UML diagram is (almost) totally unintelligible to others, like me, and even if it can be understood, they may not neccessarily be able to make the leap from the diagram to how it will work in practice (ie a UI).

End of appendix.

UXtract – Extraction of Usability Test Results for Scoring Healthcare IT Systems in Procurement

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Abstract

"In healthcare IT system procurement we always need to choose the cheapest one." Do we? In this paper we present a method and a procedure for effective extraction of usability test results for public procurement. Successful procurement necessitates the alternative products to be compared considering their realistic utility. We can significantly contribute to this comparison by measuring usability in a practical way. Our UXtract method enables the extraction of detailed, traceable and commensurate findings for objective evidence. The method extracts structured data straight from the test. Our case in large scale healthcare settings shows that this method is efficient for scoring usability in procurement. We elaborate the results and discuss about the impact and challenges of comparison testing when using it for decision making of multimillion investments in information technology.

Keywords:

Healthcare information system; usability testing; summative evaluation; comparison; public procurement.

Introduction

Usability testing [7] is traditionally conducted in a qualitative manner. Despite it being an effective method in formative settings (possibilities to change the system under evaluation), its applicability in summative settings (comparing large-scale systems in a selection process) is challenging [9]. The challenges relate especially to demanding and laborious analysis of the qualitative data which constrain the scalability of the method. Nielsen [7] presents that the amount of users in a usability test does not have to exceed 6 persons. With decent amount of tasks in the test, the amount of data to be analyzed remains reasonable. However, in situations that require and would benefit from several user groups or broad variety of tasks, the applicability of the method decreases: How to increase the number of usability tests from 5 to 50 without increasing the effort and resources for analyzing the results? These types of situations appear in the procurement of large IT systems that affect large numbers of people in multiple tasks. For example Denmark, Finland and Canada have initiated some healthcare information system related projects in large regional scales to facilitate the improvement of the service quality and keep the costs of service at affordable levels [4].

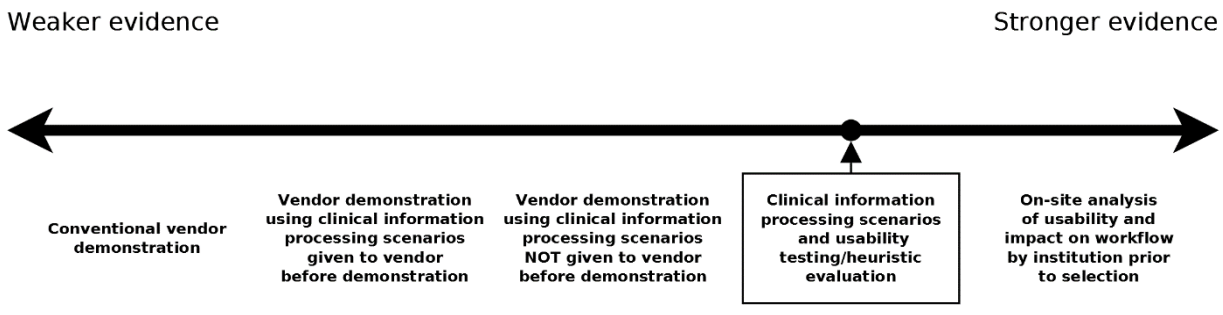

Figure 1 - Strength of evidence associated with usability testing and heuristic evaluation when applied by using realistic clinical information processing scenarios. Continuum of evidence, as introduced by Kushniruk et. al. [4], considers other possible methods to support system selection and their relative strength ranging from the weakest to the strongest one.

Government and public systems suffer from poor usability [3]. In EU public contracts are awarded to the lowest bidder or to the bidder with the economically most advantageous offer; the latter requiring that a scoring rule must be specified. A weighing of price and quality may be a good choice when there is uncertainty regarding what combinations of price and quality are achievable, while quality is not too difficult to measure and verify [1].

Despite these constraints, it is desirable to ensure high usability in advance. Sauro & Kindlund [11] present an attempt to create a single, standardized and summated usability metric for each task by averaging together the four standardized values based on the equal weighting of the coefficients from the Principal Components Analysis. Riihiaho & al. [10] have evaluated the economic value of choosing the better system in procurement by measuring efficiency (i.e. task completion) and comparing these percentages between the prospective systems. Kushniruk & al. [4] have presented a strength-of-evidence-on-usability continuum for healthcare settings (Figure 1). Clinical information processing scenarios can be used to test systems to determine whether they respond appropriately to the situations/scenarios described. In order to get stronger evidence on usability, the evaluation should be done in a way that positions at the right end of the continuum.

Usability testing appears at that part of the continuum making it the preferred method without a need to implement the prospective systems on site. Our UXtract method aims at solving the challenges on scalability and enabling usability testing in large IT procurement projects including scoring.

The UXtract Method and Technology

Our method constructs a practicable way of (i.) collecting structured data from a moderated usability test session and (ii.) extraction of usability test results aggregating the data from multiple test sessions into a single score of usability for each system under test.

The types or usability metrics associated with the method include effectiveness, errorlesness and satisfaction. Other types of usability aspects such as learnability and accessibility are not specifically in the scope of this testing method, but can be considered by other means of system evaluation to be included in scoring schemes for procurement ranking.

According to National Institute of Standards and Technology, at least two testers are needed to conduct the sessions. These two testers are: 1. An expert/test administrator who facilitates the testing and is in charge of interacting with the participant during the test session. 2. An assistant/data logger who is responsible for all aspects of data collection. The data logging role can be fulfilled with data capture software where appropriate; however, a two-person test team is the minimum recommendation [6].

The following details are possible to betraced during the test sessions:

- task duration (hh:mm:ss)
- task success (pass or fail)
- moderator marking of events
  - major negative issue (--)
  - minor negative issue (-)
  - generic positive issue (+)
  - issue for further analysis (?)
- feedback via user buttons
  - task satisfaction (good or bad)
  - emergent issue (good or bad)

The test moderator is provided with a tracing pad shown in figure 2, which allows making marks of specific types to keep track of task durations, success rate and marking of issues. Each user is provided with a user console shown in figure 2, which allows giving feedback with two buttons during test sessions.

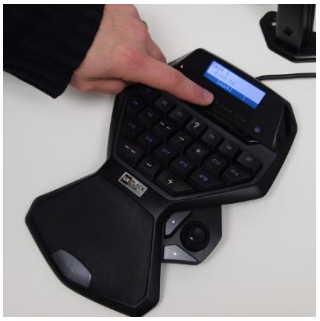

Figure 2 - Left: A commercial game control pad is used as the moderator pad, which is configured to keep track of test session status on display and to provide buttons for making marks during test sessions.

Figure 3 - Right: A wireless user console with two buttons is constructed for providing user feedback.

Human-computer interaction (HCI) and spoken communication is recorded during test sessions. For regular workstation environment this involves recording of display, keyboard and mouse activity for HCI, while a microphone is connected to the same recording system to capture speaking.

Extraction of Usability Test Results

Commensurate usability scores for evaluated systems are extracted from the structured data, which is produced by task tracing and satisfaction monitoring. Recordings from the test sessions provide a possibility to review any unclear events or judgements, which might remain after the testing. Otherwise the recordings are kept just for an objective evidence to make the tests traceable:

1. Task duration, success information, number of each type of issue and feedback collection is produced per task and test session.
2. Quantification of chosen measures.

3. Averaging the results over session repetitions per tested system.
4. Considering significance of difference per measure between tested systems (especially in case of discrete scales of quantification).
5. Calculating weighted sum of measures per system according to chosen scoring scheme and relative weightings to form an overall score for comparison.

Evaluation of the UXtract Method

In order to assess the performance of the UXtract method we conducted tests with seven representative scenarios of three domain areas (C=clinical, S=social and P=patient) and representative user groups (nurses, physicians, social workers and citizens) presented in table 1. Users for test participation were chosen from the actual user groups associated with each scenario: nurses and physicians as users for three scenarios in clinical work domain, social workers as users for two scenarios in social welfare domain, and citizens as users for one scenario in patient portal domain. Test users representing their profession as nurses, physicians and social workers were involved in test participation in pairs. Pair testing is known as the constructive interaction method, where two subjects are encouraged to experiment with the system under study [8]. Patient portal was a web based part of the system for self-service and thus expected to work for individual, first-time users.

Table 1 - Test scenarios addressed clinical work (C) and social work (S) related domain areas of the system with two users at a time (pair test), while patient portal (P) domain was tested in a traditional way with a single user. Each test scenario was repeated n times per system with different user(s).

Scenario	User Group	Users per Test	N per System
C1	nurses	2	3 tests
C2	nurses	2	3 tests
C3	physicians	2	3 tests
S1	social workers	2	3 tests
S2	social workers	2	3 tests
P	citizens	1	10 tests

Running 50 usability tests (table 2), which each included 10 to 19 tasks and take up to 90 minutes of active testing time, required two testing spots to be operated in parallel for the project to meet a given schedule. Two usability specialists (JK and MT) planned and moderated the testing, while test sessions were supported and data gathering maintained by a testing tool provider (JP and MP). The testing spots were located in two regular office rooms reserved for the purpose. Non-intrusive testing tools allowed the vendors to deliver their systems (combination of software and preferred computer hardware) for the tests as is. No additional software was needed to be installed for testing purposes to make sure not to compromise the overall performance of the systems in comparison.

Table 2 - Number of test sessions, task items per scenario and total number of tasks conducted within usability testing efforts. (Pilot tests not included.)

Scenario	Tests	Time [min]	Tasks Items	Task Totals
C1	6	90	14	84
C2	6	90	12	71
C3	6	90	19	114
S1	6	90	12	72
S2	6	90	10	60
P	20	90	13	260
Total	50	75 h	80	661

UXtract Results: Automatic Calculation of Usability

Extraction of test results is applied by summating chosen measures by reasonable weighting to represent overall usability for comparative purposes. This can be done with spreadsheet computation by importing the logged data from test sessions to a spreadsheet workbook, which is prepared to calculate the usability metric automatically.

Effectiveness is measured in all the test scenarios based on the percentage of successfully completed test tasks as follows:

$$\textbf{Effectiveness} = \frac{\text{Succesfully completed tasks}}{\text{Total amount of tasks}}$$

For each scenario and task, there is a predefined maximum time of execution. Test moderator marks each test task either as passed or failed upon completion of the task or when the maximum time is exceeded. In case of session time runs out, the remaining tasks are considered as failed.

Errorlessness is evaluated in all the test scenarios based on the number of errors during successfully executed test tasks. An error is defined here to be a deviation from a reasonable task execution path (non-productive activity considering the goal of the task, e.g. transition to wrong view, unintentional activity, mistake or ignorance of substantial information). The errors during test execution were classified as minor (½ pts.) and major (1 pts.) ones, which were marked up in real time on the tracing pad. The error points are averaged over test tasks and repeated scenarios for each system. A session with none of the tasks succeeded gives a default of 12 error points as an average. *Errorlessness* is quantified here based on these error points on a scale from 5 to 0 (*where the highest score is achieved with the least amounts of errors*) as presented in table 3.

Table 3 - Quantifying of errorlessness based on error point averages for each test scenario.

Errorlesness	5	4	3	2	1	0
Error points	[0,1]	]1,2]	]2,4]	]4,6]	]6,∞[	12

Satisfaction is evaluated in all the scenarios based on the users' positive and negative feedback collected upon completion of each test task. In addition to this, the test scenarios conducted in pairs involved feedback collection also during the test tasks with user initiated positive and negative experiences of use (e.g. subjectively positive event or personal satisfaction and negative struggle, inconvenience or dissatisfaction towards the behavior of the system along execution of a test task). Only successfully completed test tasks count for this.

Table 4 - Quantifying of satisfaction based on proportion of the tasks evaluated with more positive than negative feedback on average.

Satisfaction	5	4	3	2	1
Rate	p > 80%	80% ≥ p > 60%	60% ≥ p > 40%	40% ≥ p > 20%	p ≤ 20%

Assessment of the results

An IT system under usability testing was designed to support three different domain areas which can be considered being partly separated from each other in terms of functionalities and related subsystem implementations. Usability testing based evaluation produced a consistent differentiation between the compared systems for each domain area, since all the usability measures indicated the same order for each domain with good correlations presented in table 5. However, there were differences between the domain areas indicating that the system X was 45% better in clinical use and 32% better in social work (C and S domain areas), while the system Y was 21% better in the patient service portal (P domain).

Table 5 - Correlation (Corr.) of the effectiveness, errorlessness (Err∑) and satisfaction (Sat∑) measure comparison between the systems X and Y. Correlations calculated with zeros (0/0).

Domain	Effectiveness (X/Y)	Err∑ (X/Y)	Sat∑ (X/Y)	Corr.
C	46% / 75%	10 / 12	8 / 13	.9983
S	67% / 75%	5 / 7	6 / 9	.9996
P	97% / 85%	5 / 4	5 / 4	.9999

By default, there was no need to go through the recordings afterwards for extraction of these results. However, moderators checked and reviewed some situations from the recordings right after a test session, whether they felt that anything would have remained unclear. There was less than 10 situations in total, which needed review and/or correction (e.g. accidental wrong task marking or open issue related to interpretation of an error).

Discussion and Conclusions

Our experience in using the UXtract method demonstrated that it is an efficient way in public procurement for conducting comprehensive usability testing of a large IT system that is being used by large number of people in a large number of tasks.

The real-time recording of usability issues/markers appeared feasible for the test moderators. However, further development of observation guidelines for marking would even improve the task by automating the generation of structured and readily available results from the tests.

The results in table 5 show that the defined components of usability (effectiveness, errorlessness and satisfaction) correlate strongly. This suggests that weighing of the components in scoring appears not critical in this case, because all weighing combinations would result in similar ordering of the compared systems in each domain. A dedicated and pre-defined weighing scheme (including components of usability and domains) was used for the actual procurement scoring[1]. Usability testing contributed 74,4% of the usability comparison criteria, which further contributed 20% of the overall quality criteria for the procurement. In addition to these, price-to-quality consideration resulted to final scores of 89,76 vs. 92,23. A contract was awarded to the system Y vendor with a 65 million euros higher bid price (385M€) compared to system X (320M€).

Based on our promising experience, we will apply the method in similar procurement cases to gather more data for developing more elaborate models for procurement scoring.

Acknowledgments

The authors wish to thank the project office that provided the possibility to test the method in a representative case.

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Internet of Things Technology for Remote Healthcare – A Pilot Study

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Abstract

One of the latest trends in health informatics is Internet of Things (IoT). IoT consists of various types of technical objects connected to Internet and/or connected to each other, cooperating to reach a common goal. This pilot study explores how chronic patients, potential patients and healthcare personnel (n=100) perceive sensors and implanted sensors as two examples of IoT in remote healthcare. Data was collected through an acceptability questionnaire based on the Unified Theory of Acceptance and Use of Technology (UTAUT) framework using criteria as: performance expectancy; effort expectancy; attitude towards technology; and social influence. The pilot result indicated e.g. a strong acceptance of implants and that external sensors in a treatment requires further work. Differences between men and women were found: acceptance of sensors was preferred by women, and implants by men. In conclusion, IoT could be used to enhance person-centered healthcare, aiming to better engage patients in their treatment, rather than being a passive recipient of a medical intervention.

Keywords:

Biomedical/Health technology assessment, Patient Care Management, Patient Acceptance, Pilot study, Telemedicine, eHealth, Point of Care Technology, Internet of Things.

Introduction

With each passing day, technology takes a step forward and creates a reality of what could previously be thought of as being only a dream. Twenty years ago, it was unique to have a personal computer connected to internet and today 92 % of the Swedish population has access to internet on several devices [1]. Technology is developed together with other factors in society. Some effects are that life expectancy of people grows and higher demands are put on the healthcare system. Health and social care must become more effective as more and elderly people will seek and need care. Remote healthcare is one of the solutions that adapts technology to provide good care [2].

Within Swedish healthcare there is a trend to work more person-centred, similarly to concepts as patient-centred [3] or people-centred [4], in order to include the patient and the whole person in the care process [5, 6].

Patients are supposed to, together with their healthcare staff, come up with a plan that works for them. Rather than being a passive part of the treatment, the patient is included and a partnership is formed [7].

One of the latest trends in health informatics is Internet of Things (IoT). The principal idea with IoT is the presence of objects surrounding us, e.g. mobile phones, sensors and RFID-tags, which through wireless networks cooperates with each other to reach a common goal. A prominent strength with this technology is the effect it will have on the daily lives of people from several different aspects [8]. Technical solutions reach the market and an increasing number is developed with the intent to make healthcare more effective, but how do patients feel regarding these technical solutions? How do they feel about implanting a sensor in their body?

The purpose of this study was to examine the receptiveness of remote healthcare through IoT technology, such as external (or wearable) sensors and implants. Using the Unified Theory of Acceptance and Use of Technology (UTAUT) [9] this study measures the acceptance of current and potential patients regarding a few existing IoT solutions.

Research Questions

In terms of acceptance, which type of IoT technology for remote healthcare do patients and potential patients prefer?

By a set of sub-questions this study examined which of the presented IoT technologies that the respondents would prefer for daily use and if there are any differences in acceptability between different subgroups of the respondents:

- current patients and potential patients?
- healthcare professionals and non-healthcare professionals?
- men and women?

In relation to hypothetical acceptability, we also aimed to examine perceived usability of the presented IoT technology.

Theoretical and Technical Background

Examples of IoT Technology in Remote Healthcare

New technology provides the possibility to solve problems that previously seemed impossible to solve. This study exemplified this to its respondents by highlighting two new IoT solutions for healthcare, an implant and a wearable sensor, both applicable for treatments based on remote healthcare.

The first technology is the iDiab and zPhone technology [10]. The purpose of the solution is to facilitate the life of diabetic patients and to streamline the care process for professionals. In the iDiab article [10] we meet the fictional character Robert

who is suffering from diabetes. Robert has had an iDiab sensor implant that continually measures his blood sugar level and informs Robert should the level reach critical amounts advising him to inject insulin. The connected zPhone transmits data to Robert's physician for further evaluation and care planning.

The other technology uses external sensors to facilitate and streamline effectiveness of remote healthcare within an Ambient Assisted Living setting. Also here, two methods are combined: online measurement of blood pressure, pulse and other values of the patient and a Tele Monitoring Service Centre acts as an intermediary for the patient and the caregiver, sending and receiving data to both parts to help streamline the treatment of the patient [2]. Both solutions are currently in a prototype testing stage.

Previous Research

Current research within information systems is focused, amongst other things, towards identifying factors which are crucial for the use of new technologies [11]. Regarding acceptance of new technology this has led to several newly developed measurement models originating from informatics psychology and sociology, where e.g. Technology Acceptance Model (TAM) [12] is frequently used. To measure acceptance of new technology it is also possible to mix theories [9] or to use UTAUT which is an extension of TAM [9, 12, 13]. Also within the area of healthcare these methods are used, but the authors have not found many acceptance studies specifically concerning IoT technologies in healthcare.

In Thailand, a broad study using a UTAUT questionnaire was conducted to identify factors affecting IT systems within healthcare [14]. As one of the central results was facilitation of understanding of how the system could improve users' productivity [14], usability was considered also in this pilot study. Like our study, another Swedish UTAUT study also tries to capture the perceived usefulness of e-services in healthcare, although in an different area; the medical professionals' perceived advantage of an online care and rehabilitation planning tool for stroke patients [15]. Only one UTAUT study regarding acceptance of wearable technologies within healthcare was found [16]. A central finding to reuse in our study was that the user experienced a high value in the following UTAUT criteria: perceived expectancy; effort expectancy; self-efficacy & perceived severity during use [16].

Comparisons of UTAUT with other models for creating questions [9] conclude that UTAUT had a substantial improvement compared to the other models, e.g. TAM, regarding the users' variation in intentions towards the usage of the technology [9].

Methods and Materials

This study was based on the theory of UTAUT as a framework and more explicitly as the method to examine the acceptance of the two different IoT techniques in remote healthcare. Recent studies that apply UTAUT criteria were used as inspiration for the questionnaire [17, 18, 19, 20] We also aimed to examine perceived usability of the presented IoT technology, inspired by Davoody & Hägglund [15].

The questionnaire contained 18 questions, where seven of them regarded acceptance (table 1) and checkbox answers (table 2 and 3) based on four of the UTAUT criteria, interpreted in the following way:

- Performance Expectancy – Measures how the user expects that the technology affects the user's life.
- Effort Expectancy – Measures how hard the user believes the technology will be to use or understand.
- Social Influence – Measures if the user's surroundings affect the user's choices whether to use the technology.
- Attitude Towards Technology – Measures the user's attitude towards the technology.

It also contained eight questions (1-8) about the respondent: age, gender; if care professional; if chronic patient; if remote care recipient; contact frequency with healthcare; about remote care and how it was experienced and two open follow-up questions about the experience of remote care (9)and the preferred treatment (16). The last question (18) regarded the possibility to follow up the answers in an interview. The questionnaire was published 2015-11-29 in the Facebook groups "Dom Kallar Oss Studenter" and "Informatikgruppen Örebro Universitet" as well as on personal timelines to reach as many respondents as possible. It was closed 2015-12-02 when 100 responses were received.

Table 1 – The 18 questions, translated into English

	Questions related to acceptance in the web questionnaire
10	Imagine yourself in the following situation: You have diabetes. How do you think an implant according to the following scenario * would affect your healthcare experience? * Scenario description based on [10]..
11	What do you think of using implants in your body according to the scenario*?
12	What is your general attitude towards having an implant according to the scenario *?
13	Now imagine that you instead of the implant are using a bracelet or a plaster on your body to perform measurements **. How do you think a wearable sensor according to the scenario would affect your healthcare experience? ** Scenario description based on [2].
14	What do you think of using the bracelet or plaster in your treatment according to the scenario **?
15	What is your general attitude towards using external sensors in a treatment according to the scenario **
17	Would you as a patient mind getting treatment only through remote care, provided the treatment is of the same or better quality as the traditional one? Yes, of [timesaving], [improved quality], [less trips to caregiver] reasons. No, [no, prefer traditional healthcare visit]. No opinion. Other.

Respondents

The number of respondents in this pilot study was set to 100, distributed on 46 women and 54 men, with birth years ranging from 1962 to 1996. The average year of birth for respondents was 1989, i.e. the mean respondent was 26 years old. Ten respondents marked that they were suffering from a chronic disease and the respondents who worked within healthcare were 16 in total.

Due to the low number of respondents, the analysis should not be used as a statistical basis, but the results of this pilot study can be viewed as an indication that could lead further research.

Choice of IoT solutions to present as examples

Two examples of IoT technology were presented to the respondents in remote healthcare scenarios in order to make IoT technology easier to relate to. A number of criteria was developed in order to sift out those IoT solutions related to the purpose and field of this study:

- The solution should be based on IoT technology.
- The usage of the solution should be within healthcare.
- The purpose of the solution should be to facilitate the life of patients.
- The purpose of the solution should be to improve the treatment from the perspective of the patients.

We chose an implant technology called iDiab and its connected zPhone [10]. The target disease for the solution is diabetes, which was suitable as it is a widely known disease making the scenarios presented easier to relate to for the respondents. A wearable sensor technology was also chosen, used for measuring pulse, blood pressure, movement and other values, which are sent to healthcare professionals via a Telemonitoring Service Centre [2]. One practical example for each of the technologies was described as support for the survey questions.

Data analysis

Data was analysed using a frequency analysis, meaning that the frequency of how a specific question was answered was summarized in a table to display the share of the responses [21].

Data was separated based on different respondent groups, e.g. age and gender, patients or non-patients. Current health status was important in order to be able to compare the answers of a person with a chronic disease to a person who was not suffering from any chronic disease. People who expressed being experienced in using similar technology were grouped in one group as well as others with a theoretical knowledge of such technology, e.g. healthcare professionals.

In this study, non-patients, i.e. persons not currently engaged in active medical treatment, are called potential patients, as there is a hypothetical potential of becoming a patient in the future, and as such being able to use remote healthcare solutions or IoT technology such as implants or wearable sensors.

Results

In the analysis of this study, the results are connected to the four selected UTAUT criteria to assess the acceptability for the two IoT technologies presented in this study, external sensors and implants. Some important differences found in the results are visualized in six circle diagrams, which are explained below (figure 1-6) and the legends of the labels of the diagrams are presented in table 2 and 3.

Figure 1 – Women and the idea of using implants

As seen in figure 1, which shows the distributed answers for women regarding use of implants, the major part thought of the technology as a generally good idea. A quarter of the total answers leaned towards both that the technology was a good idea and that they would enjoy using it while 19 % answered that the technology was a good idea only. 11 % did not think any of the alternatives would fit their view on implants and chose to answer “none of the alternatives”.

Figure 2 – Men and the idea of using implants

Men, who responded towards using implants in their treatment thought the idea was good, represented 35 % of the distributed answers. Another 22 % thought of the technology as a good idea and would enjoy using it. 17 % of the male respondents thought that all the positive answers fit their view and answered A together with B and C. 14 % however answered none of the alternatives showing that at least a sixth of the respondents among men were unconvinced.

Table 2 – Legend to figure 1 and figure 2.

A	This would improve my treatment experience
B	This would make my life more like one without my illness
C	This would improve my treatment
D	None of the alternatives
E	A together with C
F	A together with B and C
G	B together with C

Figure 3 – Women and the use of wearable sensors.

A 33 % thought of wearable sensors as being a good idea while almost a fifth, 19 %, were unconvinced and chose none of the alternatives. Only 11 % chose a combination of multiple positive answers. 28 % were evenly distributed amongst the options stating that the technology is a good idea and that they would enjoy using the technology.

Figure 4 – Men and the use of wearable sensors

28 % of the men who responded regarding the use of a wearable sensor chose all the positive answers (A together with both B and C). 11 % chose none of the alternatives while 26 % stated they viewed the technology as being a good idea but nothing more.

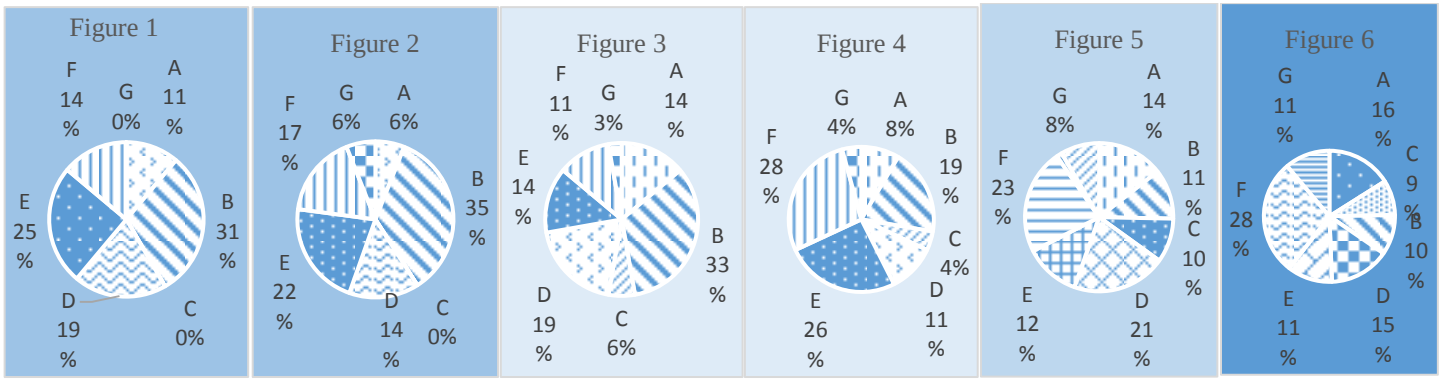

Figure 1-2: women/men & implants. Figure 3-4: women/men & sensors. Figure 5: Sensor treatment. Figure 6: Implant treatment.

Figure 5 – Sensor treatment experience amongst the patients that were not employed in healthcare

A 21 % did not see any of the alternatives fit their expected view of the effect from the IoT treatment. 23 % felt that all of the options reflected their experience with the treatment technology and 79 % felt that it had a positive effect in one way or another.

Figure 6 – Implant treatment experience amongst the patients that were not employed in healthcare

Only 15 % felt that none of the alternatives reflected their view of the effect the treatment hypothetically would have on them. 85 % felt that the technology would have one or another positive effect on their treatment. 28 % felt that all of the positive answers reflect their experience with the technology in use with a treatment.

Table 3 – Legend to figure 3, 4, 5 and 6.

A	I would enjoy using the technology
B	The technology is a good idea
C	People in my environment would like for me to use the technology
D	None of the alternatives
E	A together with B
F	A together with B and C
G	B together with C

Discussion

Data collection method and respondent groups

An open web questionnaire link was distributed in several channels. It provided in a short time 100 responses. The number and type of respondents could correlate to the amount of days the questionnaire was open as well as the forums in which it was published. We closed the questionnaire after reaching 100 responses and luckily the respondents belonged to varying groups which provided possibilities for comparison. There was a 50/50 ratio between female and male respondents as well as respondents who had received remote healthcare previously, healthcare professionals and patients with chronical illnesses albeit smaller groups. For following studies these specified respondent groups could be addressed directly and in larger amounts, rather than focussing solely on some respondent groups, such as e.g. chronically ill patients. Moreover, when using the indications of this pilot study for further research, complimentary interviews should be planned for, to get the possibility to go deeper into the reasons behind the responses, which also could be of interest.

Analysis method and interpretation of the results

The objective of this pilot study was to bring an indication on what type of new IoT technology the respondents would prefer, in terms of acceptance and potential use of the technology.

Some disadvantages with UTAUT are that the effective use of the technology which it examines cannot be visualized (in e.g. percentage), nor is it possible to draw concrete conclusions as UTAUT do not cover usage factors that may affect the user's life situation or work performance [21].

As the respondents never have had the chance to test the technology in person, an interpretation of the criterion performance expectancy was needed. In general, performance expectancy is about what the respondents could expect of the result of using the technology. In this study, the criterion is related to how respondents hypothetically expect that the technology would affect their care experience, treatment and quality of life.

Nevertheless, we consider the method useful when you need an indication of acceptance and potential use of a technology as in this study.

Here, some of the results are further discussed: the chronic patients were more positive towards implants compared to wearable sensors. This could possibly be the result of the wearable sensor being a constant reminder of their health, or the lack thereof, and therefore they preferred the implant. There is also a risk that the sensor could be damaged from daily use and thus the implant is a more viable option for the users who know how it is to live with a disease that requires daily treatment. Such responses, as well as potential differences between men and woman could be further analysed. In this study men and women differed in how they perceived the technologies would change their healthcare experience. Men seemed to favour the wearable sensors while women seemed to prefer the implanted sensor. This could possibly be due to women having experiences with other implants, such as e.g.

contraceptives for birth control, as mentioned in the questionnaire.

The vast part of the respondents expressed a positive view and stance towards using either implants or wearables to extend their current treatment plan. This could be an indication that the general public is ready to embrace a new form of healthcare treatment plan with more focus on enabling the patients to go about their lives in a normal fashion while still being under treatment.

Future work

To further investigate how current patients that undergo remote care treatments would like to use IoT, we recommend further studies to include associations for these persons such as e.g. diabetic associations. Further work could also be based on investigating challenges in deployment of the presented technologies on a broader and wider scale within the healthcare system.

Conclusion

In this pilot study chronically ill patients showed more positive attitudes towards the use of implanted sensors compared to external sensors. Respondents who had previously received remote healthcare also indicated that they could see an improvement with an implant in comparison to wearable sensors. Replies from the potential patient group demonstrated a similar tendency, although the wearable sensor also had a high number of positive replies. The same trend could be seen in the group of healthcare professionals: in general, implants had a positive response rate that was almost twice as high as the number of positive responses for wearable sensors. A majority also felt that the idea of implants was easier to understand and to use compared to the presented alternative. The analysis however showed a difference between men and women: the women indicated a 50 % larger distrust towards the external sensor.

Due to the low number of respondents (N=100) this study should be seen as a pilot study and its result should be viewed as an indication for further research. The results were however interesting and indicate that the respondents find that remote healthcare with presented technologies could be applied to improve person-centered care.

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Evaluation of a Context Specific Communication System Based on Smartphones: Nurses' Uses and Experiences

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Abstract

Nurses often have stressful work environments. This paper presents a study that investigates if and how the intelligent phone communication system CallMeSmart, which is designed for use in hospitals, affects and improves the communication and information flow among nurses. We collected the empirical material through a multi-method research approach using both quantitative and qualitative data. The data were from phone logs, six individual face-to-face interviews, a focus group interview and informal discussions. We categorised the empirical data into two main groups. One group was for the benefits the nurses experienced. The nurses liked the dedicated phone system, and they gave many examples of how the system could facilitate communication and information flow in their work practice. The second group was for the negative experiences, and it included problems the nurses experienced while using the technology. The phone log material showed the usage of the system. Our conclusion is that this dedicated phone system has great potential in facilitating hospital communication. However, the condition to realise this potential is that the problems that were registered should be resolved.

Keyword:

Hospital communication systems, context awareness, nursing, e-health, work practice, implementing ICT, smart phones in hospitals, work efficiency.

Introduction

Nurses' work environment has often been defined as stressful. A negative relationship between their stress and job satisfaction has been revealed [1]. Different research has been conducted to identify how the nurses' stress can be reduced, or how the nurses can cope with stress [1, 2]. Workload, leadership/management style, professional conflict and emotional costs of caring have been described as the main sources of distress for nurses [3]. Our study focuses on how new technology, a telephone system, can simplify the communication flow and the nurses' daily work practice.

The nurses, like other health care personnel, need effective communication and information flow to provide high quality care [4-6]. It might, however, be challenging in a clinical setting to gather and redistribute the right information at the right time. Hospital staff need to have easy access to and be able to redistribute data, such as patient status reports, lab test results and so on. The management of this information is challenging in a hospital setting where time is a scarce resource. Getting the 'whole picture' can require frequent conversations and discussions [7]. In addition, information and communication systems in hospitals have shown to suffer from poor practice and inefficiency caused by insufficient infrastructure. This is especially challenging when the need for information or communication is urgent [7-9]. Today, hospitals often rely on a mobile communication infrastructure with dedicated devices for each role, which may result in each health care provider carrying several mobile devises. Figure 1 shows a picture of all the communication devices that a nurse at a Norwegian hospital carries on every shift to reach and be available to other health care personnel.

Figure 1. All the devices an acute nurse at a Norwegian hospital carries on every shift

Currently, pagers are the most dominant mobile communication device in use, in addition to wired/wireless phones and Personal Digital Assistants (PDA) [10].

Studies have demonstrated that common mobile phones can overcome most of the limitations of pagers, and improve and facilitate the communication in a hospital setting [11]. Ordinary mobile phones can improve the accessibility and communication in healthcare [7, 9, 12]; for example, by offering two-way text and voice services. However, at the same time, as availability and accessibility increase, an overload of information and numerous number of interruptions on key personnel may occur [5, 11].

Today, mobile phones are not widely used in hospitals, even if they have the potential to reduce delays in communication and

improve patients care, as well as reduce the risk of medical errors [9]. In general, only a few staff members carry mobile phones due to the assumptions that a phone is more interruptive than a pager [5, 10].

To solve some of the challenges described above, an intelligent, efficient and context sensitive communication system called CallMeSmart has been developed. This phone system has been fully described elsewhere [13]. CallMeSmart is a mobile phone system designed for use in hospitals. The system aims to improve communication and information flow and to reduce unnecessary interruptions in clinical settings. A first version of the system has been tested by physicians and nurses in a lab setting. The feedback was primarily positive and has been used as input for the further development and improvement of the system, moving from prototype to production [14, 15].

The system supports voice services, text-messaging and paging services in an efficient and non-interruptive manner. It intends to avoid interruptions when health personnel is busy; for example, when nurses are involved in important conversations with patients or relatives. This kind of context information, whi ch affects the workers' availability, is normally extracted automatically from different sensors, calendar information, work schedule and so on. With this device, individual users can change their availability manually. If a user is busy, the call will be forwarded to another professional at the same level and with the same role, and the caller will be given feedback about the health care workers' availability.

Using these phones, the nurses need to carry only one device in total, instead of one device for personal use and one for each professional role they have. The role-based communication also enables other users to contact someone assigned on an 'on-call' duty at a specific department, even if they do not know the name of that person. The system enables acute calls and alarms to be forced through, balancing between availability and interruptions.

However, before introducing a health care sector tailored communication system like the phone system in question as standard hospital equipment, usability, user satisfaction and impact on work practices need to be investigated. As part of this, we have studied nurses' experiences from using the phone system in their daily work.

In a different paper, we have reported on the frequency of use and the nurses' expectations on the system [16].

The following research questions have been investigated:

1. Would the communication system in question designed for use in hospitals affect the nurses' work practice?
2. Would it aim to improve the communication and information flow among nurses?

Materials and Methods

In the following, we present the research setting, how to use the phone system and the methods used in this study.

The Research Setting

Testing took place at the Oncology Department (OD) of the University Hospital of North Norway (UNN).

The OD offers chemotherapy, radiation therapy, hormone therapy, other symptomatic treatment and care and palliative care guided by national guidelines. The ward includes 25 beds and around 120 employees as nurses, nurse assistances and medical doctors. The nurses work in three shifts: day shift including ten nurses, afternoon shifts with five or six nurses and night shifts with three nurses.

The OD ward has 33 rooms in total, including patient rooms (bathrooms included), storage, examination room and many other amenities. These rooms are distributed along two corridors. Furthermore, they have 26 offices, two meeting rooms and one technical room dispersed over two floors in a connected separate building. The nurses also accompany patients to the radiology department and to the patient hotel. This means that nurses can walk long distances and visit many different rooms during a typical working day.

The phone communication at the OD is currently by wired or wireless landline telephones. Staff on call also carry pagers, but the nurses have no mobile devises for efficient information exchange. This situation has led the management at the OD to invest in mobile communication devices and to test the phone system with the aim to save time and improve patient care.

The Phone System

A detailed technical description of the phone system can be found in Solvoll [13]. To log on to the phone system, users can use their ordinary username and password from the hospital information system. Users can make and receive calls in a one-to-one configuration, or in a one-to-many configuration for conference calls. Moreover, messages can be sent in a one-to-one or one-to-many configuration. The phone system may deliver and read the acknowledgement for each message silently. Whenever users are logged on, their messages will be available on the phones through their profile, since the messages are stored on the users' profiles. A user cannot receive or start another call without hanging up on the first one.

Each nurse was provided approximately five minutes introduction and training before they started using the phone system. The inventor of the phone system was at the ward the first two days after the first nurses started using the system for support if needed. The only support asked was to create new accounts for new users.

Methods

This study focuses on the experiences gained from the use of the phone system at the OD at UNN. Fifteen phone devices were in use during the day shift. The study utilised different methods to collect data, both quantitative and qualitative.

The study data has been reviewed in light of the results from the previous sub-study of the evaluation [16]. The previous study focused on nurses' expectations of the system, while this article focuses on nurses' experiences with the system.

Interviews

Qualitative approaches are used to explore and explain experiences and to achieve in-depth understanding of behaviour and

what reasons actors have for their behaviours [17]. Qualitative methods are also appropriate to investigate how the context affects the outcomes [18, 19]. It is critical to understand how systems are used, instead of only how systems are designed and intended to be used since 'plans and situated action' may differ [20].

Our approach was as follows. After the nurses on the ward and unions had been informed about the study, we showed up at the OD in periods we had been informed as usually not too hectic to get interviews. There, we asked at the nurses' station whether the nurses on duty were willing to be interviewed. We completed six individual interviews. Three of these were with participants who had used the phones through the entire trial period, while three were with nurses who had quickly put the phones away. The interviews were semi-structured. The interviewer was the first author of this article. The interviews were recorded and transcribed.

- How do you use the phone system? In which situations and for what purpose?
- Changes the phone the way you perform your daily work; is it improved or does it cause problems or troubles?
- Do you know whether the other nurses use it differently?
- Can you sum up the positive and negative changes that the phones make in your work?
- Can you describe the changes in information and communication flow?

Box 2. Main questions from the interview guide.

Furthermore, a focus group interview was conducted with the senior charge nurse and other nurses. The reason for the focus group was the feedback in the individual interviews about problems with the technology, and that the problems had led some of the nurses to stop using the phone system. At most, eight nurses were present, while some had to leave or they were 'to and from' because of work. The first and last author conducted and made notes during the group interview.

We explored the empirical data using a content analysis to break them down into categories relevant to this study [21]. The data were categorised in two main groups. One group included the benefits that the nurses experienced with the system. The other group included the different kinds of problems they experienced. Furthermore, we coded the empirical material in the following categories: savings of time, fewer interruptions and less messages to remember.

The results section presents quotes both from those who used the phone system through the entire period (quotes marked 1, 2 and 6) and from those who did not (quotes marked 3, 4 and 5).

Log Data

Log data on each user has been collected from the introduction of the phone system in December 2016. From these logs, we extracted the usage on every user between January 1st. and February 10th using Structured Query Language (SQL) for querying the log database.

The logs identified the usage of the system, such as how many messages and phone calls were performed at which date and at what time of day.

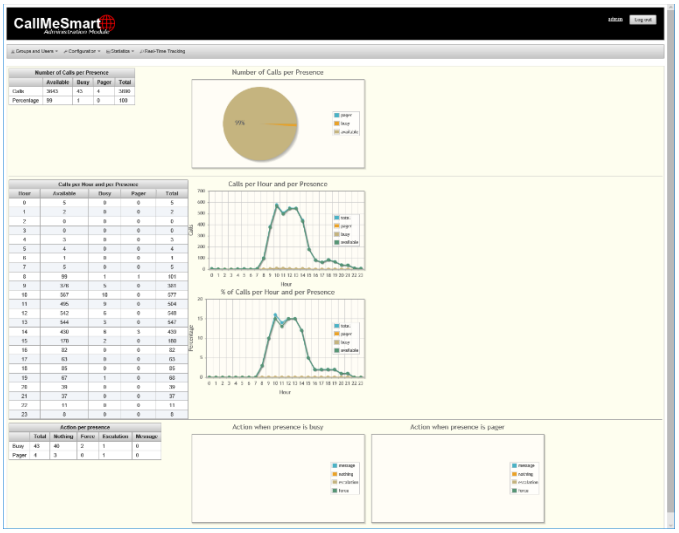

Figure 3. Screen dump from the administrator module of the phone system (Web-based), showing statistics from the usage—calls, messages, availability, missed calls and so on

Ethics

Our project does not cause any risk to patients and does not include any activity that requires approval from the Regional Committees for Medical and Health Research Ethics (REC). (helseforskning.etikkom.no/ikbViewer/page/reglerogrutiner/soknadsplikt/sokerek?p_dim=34998&_ikbLanguageCode=us) Neither is our project subject for notification to Data Protection Official for Research since it does not process personal data (www.nsd.uib.no/personvern/en/index.html).

Results

This section presents the results from the interviews about the nurses' experiences from their use of the phone system at the OD. Furthermore, it presents data from the phone logs regarding the use of both the message and call service.

The Nurses' Experiences on Using the Phone System

In this section, we present the benefits and problems that the nurses experienced while using the system. It also presents the nurses' wishes for improvement.

Benefits

When asked for the most important change that came with the phones, a nurse answered, 'I saved time because I didn't have to search for people - to convey messages - or to tell everybody in the group that the meeting starts at 11.15, not at 11.' (4) The informants emphasised that by using the phone system they can save ample amount of time since they do not have to search for the colleagues that they need to contact.

- You spend a lot unnecessary time searching to find someone, to deliver a simple message, only a number or a blood test result. Or maybe a patient has become suddenly ill, and you need to get the doctor, and so you need give a message to the nurse, that she's got to do something right away. (1)

- With the phones, you can give messages directly to people, just call and you do not have to go and look for them. Especially secretaries who [forward requests] - when patients should take a medical examination, when the home health care calls with questions [...] Every time they need to contact us. Without the phones, we must go to them to get the messages and then go back to our work - and probably have to do something in between. [...]. (2)

- The secretaries could easier reach us - when there was a call from the radiology department or the operating room or anywhere. They could send messages saying that we should fetch/bring back a patient, or to send a message immediately to inform us when a new patients has arrived. (3)

- I need the phone when I have four patients with possible lymphoma! Lymphoma reports progress at full speed ... lots of examinations the first few days, [...] and I need to know their examinations scheduled time and when they will be ready. (4)

One advantage with the phone system reported was that nurses could reach many colleagues at once. One example is that a group leader can easily reach those who made a pre-round and then redistribute messages to many people at once, or send a message to those who are scheduled to perform specific tasks.

With the phone system, nurses can easily receive and give messages and answer inquiries. They can also avoid unnecessary interruptions. They can request assistance without leaving the patient or the task they are about to do. For example, when the nurses were involved with a patient, the phone system made it possible for them to answer a call or to relay a message without leaving the room. Another difference from the pagers is that the phones show who is calling, and this provides the opportunity to assess whether the call is urgent or can wait.

- When I wanted help with a patient, it was helpful for me to find the phone number of one [...] in my group and to ask for assistance. (3)

- When I am with a patient and I have forgotten something, I can just call and say I have forgotten this and that, can you please help me get it. (6)

- For example when the secretaries had sent me a message, [...] I could answer [...]. Then the others knew that I was with a patient and unable to leave the room. (5)

- When using the pagers, you first go to the secretaries [... or to the landline phone]. I do not use the landline phone otherwise. Then I have to go to one of the offices to find a phone, and then dial the number that and that. Then I have to wait until those [... I want to contact] arrive. [With the phone system] you don't have to look for people [... and] you get in touch at once. (6)

- Another thing is that the phones show the name of the person who is calling in the display, allowing you to consider what the call is about. (2)

Using the phone system can make interruptions become less time consuming than using the pagers. The nurses could send messages and inquiries and receive and give responses immediately wherever they are. The nurses expressed that they avoided leaving the room while they were with a patient, and having the phones, they did not have to take off the sterile clothing and leave the room when working sterile. Instead, they could step away from the patient and use the phones to receive and send a message. Thus, they did not have to undress, leave the room, come back, put on sterile clothing once more and continue to help the patient.

- [Then I] had put on the [protection] again, and maybe even had to dispose it, and then go out to get the message. Sometimes I just had to let them call on me for a long time because I prioritized finishing. Now I can just move away from the patient bed and use the phone to let them know that I am busy and so and so. (6)

- Probably also the secretaries experience that the phones make their work easier. (3)

When asked where they used the phone system, one of the nurses replied, 'I could answer "everywhere", but I did not. I answered calls everywhere, but I avoided writing messages when I was in a patient room'. It was not always appropriate to use the phone by the patients' beds.

Searching perceived as unnecessary use of time creates discomfort and frustrations. It also steals energy.

- It offloads not having to search for others. It saves time and the nurses avoid the frustrations that come from experiencing time consuming unnecessary searching. (2)

- The time you spend walking around searching...are time you could have spent on other things. On patients. This cause frustration. It drains energy. (1)

Another source of stress being reduced was to remember to pass on messages. Particularly stressful was when the nurses had forgotten to pass on a message and only remembered when she or he met the person the message was intended for.

- Far fewer paper messages – a relief! (4)

- That is the good thing, that you can deliver the message when it should be delivered, and directly to the person it is intended for. And it does not take that long. When you deliver it directly, then it's less likely to get lost. . Especially if it is a hectic day, [...] and there are four other tasks that pop up, the message can be forgotten until you see the person again. (1)

Several nurses said that they rarely or never used the "busy" button available on the phones.

Problems

What kind of problems did the informants describe?

Sometimes they were not able to get in touch with a specific person even if this person was logged on to the system. Other times they were notified as not available even though they were. In addition, it happened that an English speaking voice answered a call.

Problems that could arise were that only (contact) numbers and not names came up when someone made a call, or the wrong name from the contact list came up when they received or made a call. They also had trouble when they tried to delete messages.

The problems in contacting colleagues made some of the nurses experience the phone system a nuisance. :

> - It is only a hassle [...] When you have to take with you [...] the on-call mobile and the pager and the glasses, the pocket gets very full. (5)
>
> - Now I don't take the phone with me. I will not carry it with me if it does not work. (4)
>
> - In addition, sometimes we have to be sterile. So we 'disinfect' a lot. (3)

Moreover, the phones have a smooth surface both on display and the back, and it can easily slip out of the pocket in some situations.

Early in the test phase, a loud alarm went off. One of the nurses stated that: "Just after we had started using the phone system again, a very loud alarm went off [... and] we were forced to turn the phones off that day." (6) The alarm caused some of the nurses not to use phones.

> - *Why did you stop using the phone?* All the alarms that went off for no reason made us tired of it. […] Before the alarm, we thought it was all fine. (3)

One of the nurses said she did not know if it was just a rumour, but 'there were some who said [...] it does not work anyway.' When some gave up using the phones, this caused those who actually did use the system to face a new problem: Others were offline.

> - It has been a fine tool. However, I think we still use it too little. [... To] few is logged on. (2)

Several mentioned that they would like to access the Physicians' Desk Reference on the phones. They use it several times daily, but the shortcut on the phones does not work.

Will they continue using the phones?

A final question in the individual interviews was whether the informants wanted to continue using the phone system. All responded affirmatively, even those who eventually had stopped using the phones. However, the premise was clear. The system must operate as they were envisioned.

> - I really hope we can continue to use the system. That it will work ... work the way it should. (1)
>
> - The system must be improved so we avoid [problems] ... so we can have confidence in it. Nevertheless, if it works, then I would use it. It is a good system! (5)

Improvement opportunities?

New means of electronic communication may require new social ways to communicate. Although the nurses had used the phones, it was not viewed to be okay to make personal phone calls by the patient's bed. One informant referred to yesterday's staff meeting where they argued the need for a cover to the phones that could signal to the patients that the phones are not private phones but work related. Such a phone cover can be an easy and useful innovation. The same applies to a solution that in a hassle-free way prevents the phones from slipping out of the pocket.

They described several requests for the further development and improvement of the phones. One request was to be able to call personnel in other parts of the hospital building in the same way they could call their colleagues in the oncology ward.

> - Perhaps, we can use it to call others on the house as well. Instead of searching for other phones, [...] pharmacy, physiotherapist, intensive care nurses and others, it could be very nice to [...] reach them with a short number, like we do here. (6)

Other wishes were to get medicine charts and internet access on the phones.

> - It may be even more positive if we get the medicine charts, access the electronic records and the Physicians' Desk Reference on the phones so you do not need to go and look for a computer if there is something you need to look up... Sometimes, we have to find things, and having access to the Internet, I think that would be useful. (2)

It was also emphasised that it would be very helpful if they could track the drug curves.

> - We spend a lot of time going around looking for drug curves. Because the nurses need the curves for the medications, to fill pill dispensers, and when patients say they have pain, the nurses must check what they can give. The doctors also needs these curves to look through and see that everything is correct, what you give the patient, maybe add some medicine or take away some medicine. They can also use it to retrieve information. (1)

Phone Logs

We also collected data from the phone logs on the use of both the message and phone service. Figure 3 and 4 show the total usage of the system between January 1st and February 10th. Both figures reveal that the system is used less in the weekends than during the week. We can also see that they use the message service more than the call service.

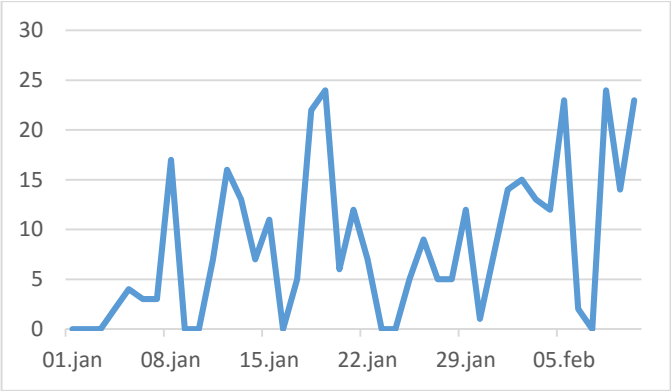

Figure 4. Number of calls between January 1st and February 10th

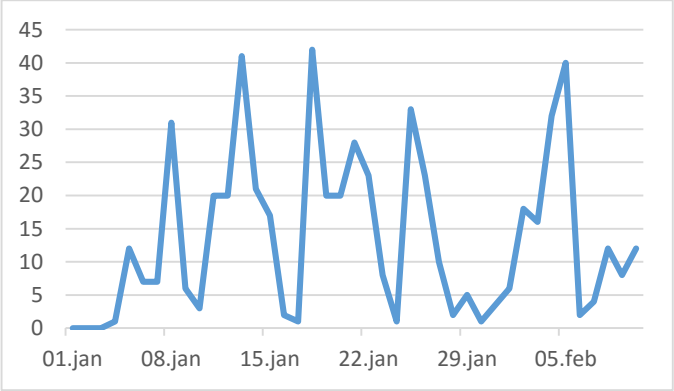

Figure 5. Number of messages between January 1st and February 10th

Discussion

This paper studies whether the phone system in question, which is designed for use in hospitals, affects the nurses' work, practice, and if it improves the communication and information flow between the nurses.

Using the phone system instead of pagers, imply changes at the OD. The nurses are more or less in continuous motion within and partly outside the OD. At the same time, a continuous stream of communication and information is taking place between the nurses and between the nurses and the department secretaries. The secretaries conveys messages and requests for contact from both personnel at the OD and from external bodies.

Without the phones, the nurses must look up the other nurses who they want to contact, and the secretaries must use the pagers to make contact with a nurse. When the secretary uses the pagers to call for a nurse, the nurse has to go to the secretary or has to find a landline phone to learn what the call is about. If the nurse is asked to call someone outside the OD, then it may involve waiting by the landline phone for contact.

Effects on work practice

An earlier study revealed that the nurses expected the phone system to save time because of less searching for others; especially for other nurses in their department, and that it would reduce disruption and interference during their daily work [16].

In our field trial less searching for others was something the nurses highlighted as positive by the phone system. They did not have to search for the other nurses at the department. Neither did they have to walk to the department secretary to receive or to give messages. Interruptions could be less disturbing. This is because using the actual phone system, the nurses could receive answers immediately, and they could receive and send messages, and answer inquiries "there and then", instead of walking to and from to get it done, or wait until they had time if they were busy with a patient.

Less disturbances meant less feeling of stress, and so do avoiding "unnecessary" use of time and energy searching for others or on giving or getting a message. In addition, it is a relief when you can deliver a message "here and now" and not risking forgetting it.

Nurses themselves expect that "time saved on unnecessary searching" will be spend on more useful patient work.

With the phones, the nurses can administer their availability more targeted. They can be reached "here and now", while they can protect themselves from interruptions, in their work practice by using the phones' "busy" button. No use or low use of the "busy" button may be because that the nurses are carrying the norm "being available" and that they have not experienced the buttons potential for less unnecessary bustle combined with accessibility.

Effects on communication and information flow

The nurses' communication at the OD, as in hospital in general, is complex with large numbers of messages and many participants communicating. The phone system in question have a potential to simplify the communication and information flow at the department and make it less energy demanding, by giving the opportunity to communicate 'here and know'. Furthermore, it can simplify the flow because of fewer participants. Finally, the flow can be safer, with less risk for information to disappear or be delayed. However, the potential of the phone system was not taken 'fully out' because of problems that arose during the trial.

What caused the problems?

Certain problem arose in the communication and information flow. Some of the participants gave up when the problems appeared. They became disappointed and insecure. Consequently, they put the phone system away. In turn, those who used the phones could not reach them. Others forgot to install the Physicians' Desk Reference. These factors can be attributed to the human factor. Lack of training can also be a reason, as discussed in Bergmo and colleagues [16].

Other contact problems are interpreted as caused by technical weaknesses in the hospital's wifi-network system, unforeseen difficulties that became visible when the use of the system were moved from the lab setting to the field setting.

Learnings from the logs

The phone logs collected between the 1st. of January and the 10th of February show that the nurses use the message service slightly more than the call service. This is probably because a significant amount of the information does not require immediate response. Since the messaging service acknowledges if and when a message has been delivered and read by the recipient, the sender knows if an important message has been received and read. If we compare the usage with our earlier study [16], we experienced in that study a low usage right after implementing the phone system at the department. However, after a couple of weeks, the usage increased, both for the message and call service. The latest logs (Figure 3 and 4) show that the usage and the number of messages and phone calls seem to have stabilised on this level. From Figures 3 and 4, we also see that during the weekends, there are less messages sent and less phone calls. This is because there is less nurses at work, and if we compare the numbers in the log, we see that the usage narrowed down to each user is approximately on the same level during the weekends. From Figures 3 and 4, we can also see some peaks in the usage, which looks like they used the system more in the beginning and in the end of the week, Mondays and Fridays, than during the other weekdays. We cannot claim that this is a pattern, since the figures show that we also have a peak in the middle of the week. We need more data to claim or discharge this idea. However, if this is a pattern, it can be because the department receives new patients in the beginning of the week; therefore, they need more information exchange than during the middle of the week. The same happens when the weekend gets closer; patients leave the department and/or information needs to be forwarded to the personnel on shift during the weekend.

We have also collected data regarding which time of the day they use the system. These data are not presented in this paper due to space limits. However, the logs revealed the same patterns that we presented in our earlier study [16]. The data emphasises that the nurses use the system's calling and messaging services more during the day shift than during the other shifts. There is also a peak in the usage during the beginning of the shift, right after they are done with reports and morning meetings. This is probably due to the patient rounds in the morning and all the following information that needs to be sent between nurses and physicians, such as updating patient records, medication and so on.

Generalisations

Hospital departments are different. We do not know the extent of the communication, and informing generally corresponds to other departments. However, we know that the need for effective communication is undoubtedly huge at hospital departments, generally speaking.

One factor that makes this technology valuable on OD is that the department has only red alert outside patient rooms. There is no green that shows when someone is by the patient. We do not know to what extent this applies to other hospital departments.

Further Work

The problems that the users experienced during this trial period, such as the minor bugs in the system, will be addressed immediately after this trial is over. We see that the system has real potential for solving many of the communication problems or challenges experienced by the nurses during their shifts at the hospital. One of our biggest challenges is that the system is not yet connected to the existing phone system, which means that nurses cannot call from the system's phone to a phone outside of the system. This go together with the fact that we are still waiting for the vendor of the alarm system (patient alarms) to deliver the connection module that sends the alarms to the phone system. This is ongoing work and will be ready during March this year. Another issue is that the department experienced a theft raid, and several of the phones were stolen. This has also been a frustration for the users since less phones are available for the nurses. An ideal situation would be that all the nurses and the physicians at the department use the phone system, along with the connection to the ordinary phone system and the alarm system. Subsequently, we believe that some of the frustrations from the users will decrease.

Future work in this evaluation is to study the use of the phone system after prolonged use. What are the experiences regarding advantages, problems and time spent? Future research questions will include whether the phone system influences the quality of patient care, safety of information flow and productivity at the hospital ward.

Conclusions

In this paper, we reported a pilot study evaluating the use of a hospital phone system at a hospital department. Our conclusion is that the phone system has great potential to improve the hospital communication and information flow. The condition for releasing this potential is that the problems that were registered are being resolved in a satisfactory manner.

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Towards Process Support in Information Technologies for the Healthcare Sector: The Context-Aware Methodology

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Abstract

Health Information Technology denotes an enormous potential to improve health care cost effectiveness and quality of care. However, health information technology has been failing to demonstrate its foreseen benefits, and its involvement in the care process is limited to specific fields. Several disadvantages of health information technologies have been reported. Partly due to the autonomy of most clinical departments, few health care processes have been modelled comprehensively enough to provide a basis for specifying software requirements to health information technology designers. Alternatively, health information technology designers have focused on supporting the work of individual care team members by taking existing paper-based tools, as their models. The result is that most health information technology does little for process support. Health information technology usability, and adoption in daily practice is closely related to the systems' semantic and technological interoperability. The trend in the health information technology field has been to push as much information as possible to the users, with a view to finding a solution. In this paper is discussed how the context-aware methodology can contribute as a solution to this problem, by enabling process support.

Keywords:

Context-awareness, healthcare, workflow, information technology, process support.

Introduction

The potential of Health Information Technology (IT) to improve health care cost effectiveness, and quality of care, has been acknowledged for decades [1, 2]. However, health IT has been failing to demonstrate its foreseen benefits, and its involvement in the care process is limited to specific fields. Several disadvantages of health IT have been reported [3-7]. Additionally to the factors that contributed to such results, another reason may be found on the focus of health IT on improving individual tasks rather than supporting value added care processes. By supporting individual tasks, IT is focusing on the provider. This is a significant contribution to a lower quality and high cost health care. On the other hand, process focused care is centred on the patient. It integrates the team work (e.g. patients, physicians, nurses, caregivers, managers, and administrative personnel) to provide high quality, and efficient care, throughout the full process. Value added care processes are the goal of the patient centred health care.

Health IT orientation to individual tasks reflects the focus of health care itself: The majority of clinical departments behave as discrete and independent sets of physicians, nurses, and other health personnel instead of a single team [8]. Partly due to the autonomy of most clinical departments, few health care processes have been modelled comprehensively enough to provide a basis for specifying software requirements to health IT designers. Alternatively, health IT designers have focused on supporting the work of individual care team members by taking existing paper-based tools, as their models. The result is that most health IT does little for process support [9]. By *process support* the authors refer to the support of interdisciplinary cooperation along with the patient pathway.

Hospitals are dependent on a wide and reliable communication infrastructure for exchanging different kinds of data, such as patient reports, lab tests and working shifts, together with text, voice and alarm services. The management of this information is difficult and requires considering a wide variety of problems that should be avoided in order to properly meet the needs of hospital professionals. In such scenario, context-aware systems present themselves as a promising approach for health IT designers.

This paper is divided in four section. In the first section, Introduction, is described how the lack of standardize process models is affecting health IT. In the Background section, is presented a brief literature review on evidence that some of the health IT, currently implemented in clinical practice, is unsuitable to its purpose, and is instigating a negative stigma in healthcare workers towards technology. In the third section, is presented the context-aware methodology, and, in the last section is discussed how this methodology can contribute to process support, and improvement of operational management.

Background

Several reports of unsuccessful implementations of health IT can be found in literature, such as [10-25]. Hereafter, the most relevant reports are briefly described.

Dünnebeil et al. [18] studied the physicians' resistance to adopt health IT as a barrier for the its diffusion, and explored the factors that influenced the physicians' attitude towards IT. The authors argue on the importance of standardization and process orientation as facilitators of health IT implementations [18]. Ash et al. [23, 24], also reported on unsuccessful health IT implementation due to resistance to change by the staff. This was identified to be a problem, especially when change was thrust upon them. Various predictable and unpredictable positive and negative behaviours were reported as a result [23, 24]. In this studies, the effort to establish standards and mandatory treatment processes are pointed as a major influence factor in the adoption of health IT.

The effects that EHR systems have on physicians' professional satisfaction was studied by Friedberg et al. [25]. It was reported that for many physicians, the current state of EHR technology significantly worsened professional satisfaction in multiple ways [25]. Poor EHR usability, time-consuming data entry, interference with face-to-face patient care, inefficient and less fulfilling work content, inability to exchange health information between EHR products, and degradation of clinical documentation were prominent sources of professional dissatisfaction [25].

The above described work identifies common signs that the implemented technology lacks process support. To complete care processes, health personnel work as a team, performing high risk tasks under uncertainty and time pressure. Therefore, processes that are not modelled and re-engineered consistently and without a careful analysis will replicate the existing inefficiencies and, ultimately, worsen them or create new ones which may lead to loss of patient safety [26]. Processes that are designed having a full understanding of: what they are meant to do, how resources act on it, e.g. their responsibilities and competences, how information is generated and required, and how they interact with other processes, provide the necessary knowledge for health IT to reduce inefficiencies and manage complexity.

Materials and Methods

Let us start by defining context. To define context, we had to investigate some of the definitions given by the research community [27-31] over the years, and concluded that the most suitable definition for our research is [32]:

"Context is any information that can be used to characterize the situation of an entity. An entity is a person, place, or object that is considered relevant for the interaction between a user and an application, including the user and applications themselves."

This definition shows the importance of which information is relevant or not in a context-sensitive system. A context-sensitive system could, therefore, be defined as a system allowing interactions between multiple entities using relevant information. In [32] they state that: "*A system is context-aware if it uses context to provide relevant information and/or services to the user, where relevancy depends on the user's task".* This definition shows that a context-sensitive system can change its behaviour and send some relevant information according to the context, which reflects our view.

The trend in the health IT field has been to push as much information as possible to the users, in order to provide more sophisticated and useful services while, at the same time, making users more available. During a preliminary research study on the Aware Media system [33], they suggested a classification that splits the above listed information along three main axes:

- Social awareness: `where a person is', `activity in which a person is engaged on', `self-reported status';
- Spatial awareness: 'what kind of operation is taking place in a ward', 'level of activity', 'status of operation and people present in the room';
- Temporal awareness: 'past activities', 'present and future activities' that is significant for a person.

A context-aware system, as shown in Figure 1, comprises two main modules:

- Context engine: This module interfaces with other information systems and devices to collect raw data. These are then fed to an analyser to classify raw data and generate context data.
- Rules engine: This module acts as filter between the data and the user. By applying a set of pre-defined conditions that define what, when, and to who the information must be presented. Such rules can be defined manual or automatically.

The adoption of context-aware systems based on these definitions is growing in a variety of domains such as, smart homes, airports, travel/entertainment/shopping, museum, and offices, as mentioned in [34].

Discussion and Conclusions

Health IT usability, and adoption in daily practice is closely related to the systems' semantic and technological interoperability. Such requires that the systems provide a comprehensive platform for process support. On the other hand, to provide this platform is required structured knowledge that is not currently available in the EHR systems in use in most Norwegian hospitals. The technological interoperability can achieved by describing clinical guidelines using standardize languages. The context-aware methodology described above, can support both the knowledge and technological interoperability required.

A context-aware system can collect data not only from the EHR, but also from the other IT existing at the hospital. Such data can be then made available in different patient settings, and processed, according to rules, to generate new knowledge. A context –aware system can also learn from the user interaction with the system to automatically improve his/her experience. In this manner, a context-aware system is able to provide process support by analysing process related data from two categories: (1) what is done; (2) how it is done.

The progression of a patient in a clinical process is determined by the completion of the tasks that compose the same process.

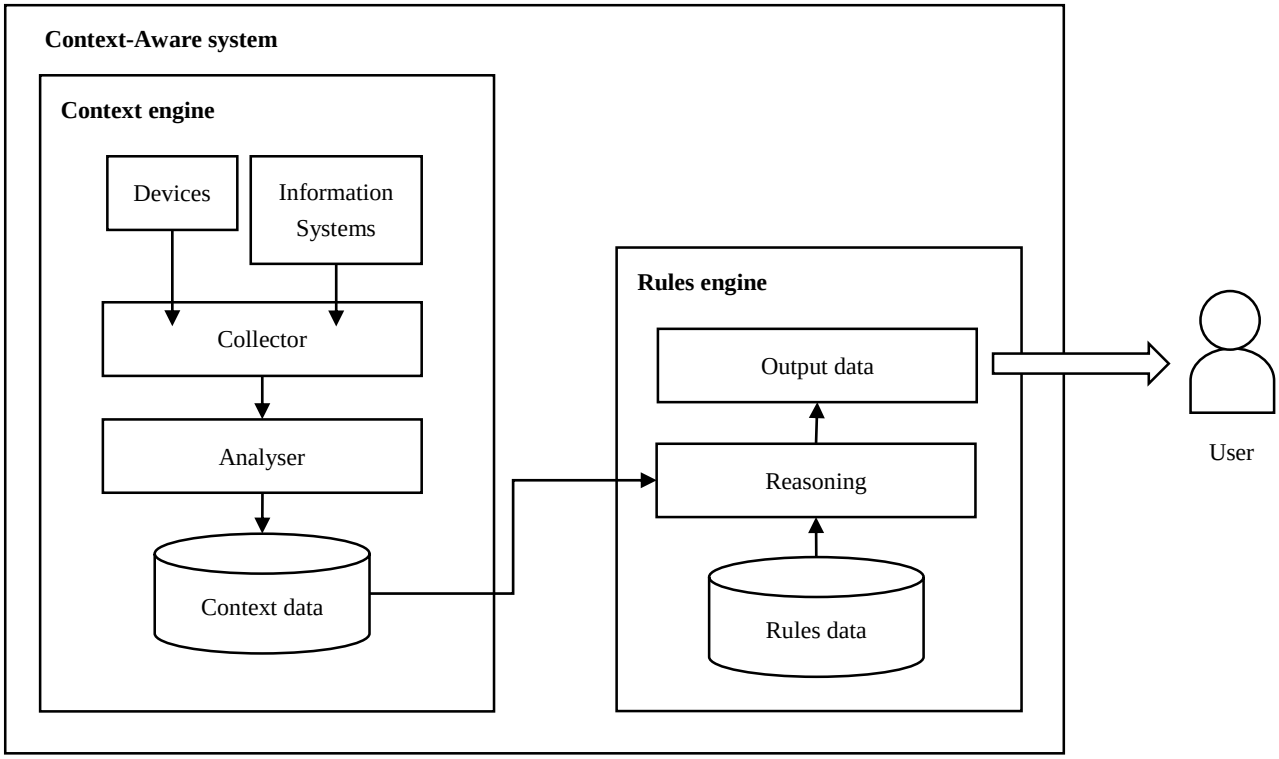

Figure 1 – Illustration of context-aware systems' basic architecture.

However, EHR systems are not always updated on the tasks' completion as different individuals evidence different work patterns. If technology is able to separate the process related data as described above, then it becomes possible to achieve adaptive workflows.

"What is done" can be described on the EHR, by translating clinical guidelines using a standardize language like OpenEHR archetypes. "How it is done" can be achieved by using machine learning techniques, fed with context data, to adjust the clinical guideline to the individual user work pattern. The semantic interoperability is achieve through the definition of the data required to support workflow on the individual level to bring both concepts together using OpenEHR archetypes. An illustration of the system architecture is presented in Figure 2.

Context-awareness allows health IT to provide process support by manging the complexity inherent to clinical processes while supplying the technology with the process standards required to ensure usability.

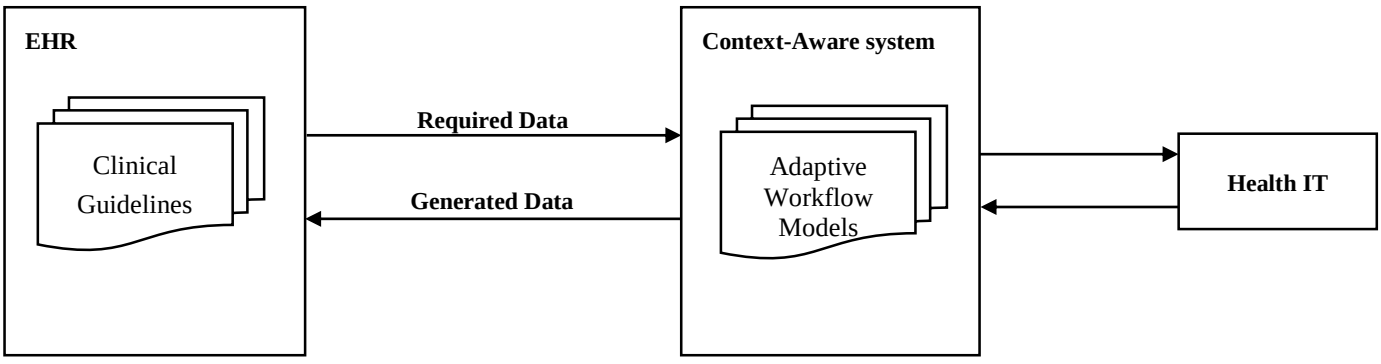

Figure 2 –Illustration of the proposed context-aware based health IT system architecture.

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Research Ethics in Health Informatics – Why Bother?

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Abstract

Research ethics is an obvious part of every researcher's life. For some areas like health informatics, the multi- and interdisciplinarity of the field make it necessary to pay attention to ethical guidelines, acts/laws, and principles from medicine, health science, science, technology, social sciences and humanities.

If you know where to look and what to look for, it is easy to find relevant information about research ethics. However, studies have indicated that we cannot take this knowledge for granted. If you do clinical trials in Norway, you have to apply to the Regional Committees for Medical and Health Research Ethics (REC) for approval. If you do studies with patients that do not imply any treatment or improvement of medical procedures, i.e., are not covered by the Health Research Act, you need to contact the "personvernombudet" (patient data protection ombudsman) to get approval for involving patients in your study. But for many research projects in health informatics, these kinds of approvals are not necessary. Some PhD students take part in large project with an existing approval by REC. This means that they probably have not been involved in writing the research protocol and applying for REC approval. As a consequence, the do not know this process very well nor the implications of this process.

For most researchers, ethical guidelines are not something they have good knowledge of. A small inquiry among PhD students in science and technology at the University of Tromsø – The Arctic University of Norway showed that ethical guidelines were vaguely known. This paper gives an overview of what kind of ethical guidelines, acts and ethical principles a researcher in a multi- and interdisciplinary field as health informatics needs to know and pay attention to. Norwegian laws and regulations ae used to illustrate what kind of information that is needed.

Keywords:

Ethical guidelines, research ethics, health informatics.

Introduction

Health Informatics is *"the interdisciplinary study of the design, development, adoption and application of IT-based innovations in healthcare services delivery, management and planning"* [1]. The multi- and interdisciplinarity of health informatics implies that a range of research methods and approaches might need to be applied in order to solve the research problems addressed, which again makes it necessary to pay attention to ethical guidelines, acts/laws, and principles from both medicine and health science, science and technology, and social sciences and humanities.

Researchers in health informatics often have their education and research training from one of these disciplines. E.g., researchers with a background in computer science often lack formal training in medicine, health science, social science and humanities, researchers in medicine are not familiar with experimental research in computer science and technology, etc. Compliance with ethical guidelines for research is an obvious part of doing research in a field. Also, for ethical guidelines, there are differences between the fields. And, as for research training, ethical guidelines vary a lot between different fields. If you do research in, e.g., computer science, it is sufficient to know the content of and follow ethical guidelines for science and technology. The same goes for other disciplines – researchers in that particular area have to adhere to the guidelines for that specific area. But, as indicated above, researchers in health informatics often have to deal with ethical guidelines and principles from many areas.

For many researchers, it is a challenge to know the ethical guidelines for a single area. A few years ago, Hartvigsen [2] conducted a survey among doctoral students at the Faculty of Science and Technology, University of Tromsø – The Arctic University of Norway (UiT). In this study, PhD students where asked whether they knew about ethical guidelines, and if they did, if they could name one of the guidelines. The result was rather discouraging; no one passed the test – the knowledge of research ethics was almost non-existing. The only positive result was that all respondents thought research ethics was important for their research.

But it is perhaps not surprising that Norwegian doctoral students fail to reproduce one of the guidelines: the document that presents the current ethical guidelines in science and technology spans nearly 20 pages [3]. Each of the 24 guidelines is presented with a detailed explanation. Similarly, ethical guidelines for social sciences, humanities, law and theology, consist of 47 different guidelines described in a 40-page document [4]. (Both sets of guidelines will be revised in 2016, but the length will be approximately the same.) These guidelines cover all relevant aspects of research ethics that a

researcher might touch upon during his/her career. Today's guidelines are consequently not designed in such a way that researchers should walk around and remember them, but designed to educate scientists in scientific practice and to be a useful tool for in-depth discussions about research ethics.

In addition to the ethical guidelines, we have a separate law in Norway, the Research Ethics Act [5], which shall, as stated in §1, *"contribute to research in public and private sector made in accordance with recognized ethical standards."* (It is strange that the law does not use the term "ethical norms". The law is also being revised in 2016.)

In medicine and health science, we have a separate law, the Health Research Act [6], which together with a regulation on the organization of medical and health research, regulate research in this area. §1 of the Health Research Act states that: *"The purpose of the Act is to promote good and ethically sound medical and health research."* The Act also regulates medical research involving human subjects related to the Helsinki Declaration [7] prepared by the World Medical Association.

Different research societies have their own ethical norms developed jointly. These can be defined as a research community's generally accepted standards of good research practices. (A discussion of research ethical norms is, e.g., given in [8].) We can say that the national research ethics guidelines represent a summary of ethical norms formed internally in the research community supplemented with norms that occurred in a broader societal context.

In addition to a fairly extensive selection of literature on research ethics available from The National Research Ethics Committees' (FEK) Research Ethics library (FBIB) [9], there is a lot of relevant literature available from other nations and supranational bodies, including the "European Textbook on Ethics in Research", which can be downloaded from the European Commission's Website [10].

As pointed out, for the researcher, there is actually no lack of relevant ethical guidelines. The problem is that ethical guidelines, regulations and acts, are unknown. Or, if the researcher knows about their existence, the knowledge is superfluous. For researchers in health informatics, the situation is even more complex since their research often covers several fields that are regulated with separate ethical guidelines. We cannot assume that we for this group, in particular for researchers in science and technology or social sciences and humanities, will find a much higher percentage of people that know all relevant ethical guidelines.

There are, in general, two different approaches to this problem: (1) Don't bother (we do our research as the rest of the crowd), and (2) please teach me (all what a researcher in health informatics should know about research ethics). (The first alternative cannot be chosen if the project is regulated by the Health Research Act.) For the second alternative, the main question is: *how can we teach our researchers about the existence of ethical guidelines and their content and meaning?*

This paper gives an overview of ethical guidelines, regulations and acts that regulate our research fields. In addition, the paper presents an example of a simple set of ethical guidelines, the ten commandments of research ethics, which can be used when discussing and teaching ethical guidelines in health informatics. The paper is based on the situation in Norway, but most of the paper is relevant for other countries as well. Except for ethical guidelines in medicine, which, by the way, is well regulated internationally and available in may different languages, all Norwegian guidelines and regulations are available in English.

Research Ethics Guidelines Used in Norway

As mentioned above, quite a few research ethics guidelines exist. They vary in length and contents, depending on purpose, field and research society. In this paper, the Norwegian rules and regulations are used to illustrate what is going on in research ethics guidelines.

In Norway, we have three National Research Ethics Committees in: (1) medicine and health science, (2) social science and the humanities, and, (3) science and technology. Below, we summarize the committees' most important guidelines and recommendations for research ethics.

Medical and Health Science Research

The Norwegian National Research Ethics Committee for medical and health research (NEM) deals with ethical questions related to medicine and health science research. Since medical research is concerned with human beings directly of indirectly, and treatment of humans, guidelines for research ethics in medicine and health science research is regulated by quite a few ethical guidelines, regulations and acts.

The primary ethical guidelines relevant to medical and health science research are:

- Declaration of Helsinki - Ethical Principles for Medical Research Involving Human Subjects [7]
- The Vancouver Protocol [11]
- Convention for the protection of Human Rights and Dignity of the Human Being with regard to the Application of Biology and Medicine: Convention on Human Rights and Biomedicine. CETS No. 164. Oviedo, 4.IV.1997. [12]

In addition, NEM has published the following relevant documents:

- Guidance for research ethics and scientific evaluation of qualitative research in medicine and health sciences. ("Veiledning for forskningsetisk og vitenskapelig vurdering av kvalitative forskningsprosjekt innen medisin og helsefag.") [13]
- Payment to participants in medical or health research. ("Betaling til deltakere i medisinsk eller helsefaglig forskning.") [14]
- Guidelines for the inclusion of women in medical research. ("Retningslinjer for inklusjon av kvinner i medisinsk forskning.") [15]

- Clinical trials of medicinal products. Guidelines for ethical evaluation of post-marketing studies. ("Klinisk utprøving av legemidler. Retningslinjer for vurdering av post-marketing studier.") [16]
- Guidelines for research on persons with impaired informed consent capacity. ("Redusert samtykkekompetanse i helsefaglig forskning. Retningslinjer for inklusjon av voksne personer med manglende eller redusert samtykkekompetanse i helsefaglig forskning.") [17]

All five reports are available in Norwegian only. (NEM has not developed its own ethical guidelines.)

Finally, we have the Norwegian Health Research Act:

- Lov om medisinsk og helsefaglig forskning. (ACT 2008-06-20 no. 44: Act on medical and health research (the Health Research Act)) [6]

In medicine, clinical trials are regulated by the Regional Committees for Medical and Health Research Ethics (REC) [18]. These "shall provide advance approval for: (1) Medical and health research projects, (2) General and thematic research biobanks, and (3) Dispensation from professional secrecy requirements for other types of research."

Clinical projects also have to register their clinical trials at ClinicalTrials.gov. *"ClinicalTrials.gov is a registry and results database of publicly and privately supported clinical studies of human participants conducted around the world."* [19]

Science and Technology

The National Committee for Research Ethics in Science and Technology (NENT) has its own guidelines:

- Guidelines for research ethics in science and technology [3]

Social Sciences and the Humanities

The National Committee for Research Ethics in the Social Sciences and the Humanities (NESH) has published two ethical guidelines:

- Guidelines for research ethics in the social sciences, law and the humanities [4]
- Ethical guidelines for Internet research. ("Etiske retningslinjer for forskning på Internett") [20]

How to Proceed with Research Ethics in Health Informatics

The National Research Ethics Committees deal with issues regarding research ethics in their respective fields. Several of the committees have made their own ethical guidelines that can be downloaded from their web-page [18].

Medical and health research projects are managed by The National Committee for Medical and Health Research Ethics (NEM) and The Regional Committees for Medical and Health Research Ethics (REC). The REC is contacted directly through their web-page [18]. General enquiries must be addressed to the REC in the researcher's own geographical region.

NEM is an advisory and coordinating body for the seven regional committees for medical and health research. NEM is also appellate body for research projects discussed in REC.

The National Committee for Research Ethics in Science and Technology (NENT) *"is an advisory body for research ethics in its subject areas and provides advice and recommendations for specific projects submitted to the committee. Obtaining advice prior to a research project is not mandatory, but researchers are encouraged to contact the committee if the project is considered to present challenges in terms of research ethics. You can also obtain assessments on matters of research ethics that go beyond the framework of a single research project."* [21]

The National Committee for Research Ethics in the Social Sciences and the Humanities (NESH) *"is an advisory body for research ethics in its subject areas and provides advice and recommendations for specific projects submitted to the committee."* As for NENT, it is not mandatory to get approval or obtain advice prior to a research project. Likewise, *"researchers are encouraged to contact the committee if the project is considered to present challenges in terms of research ethics."*

Discussion and Recommendations for Health Informatics

As indicated above, for a student in health informatics with a different background than health science, research ethics may appear as complex and comprehensive. To improve this situation, this section presents some possible starting points for discussion of ethical guidelines for research.

Ethical Guidelines in Short

There are no specific ethical guidelines for research in health informatics. As argued above, health informatics is both a multidisciplinary and interdisciplinary field, which might involve ethical guidelines, acts/laws, and principles from both medicine and health science, science and technology, and social sciences and humanities. This creates a dilemma for research groups in this area – should they allocate sufficient time to discuss all ethical guidelines in minute details or discuss major ethical principals and let each member study the details on their own? In accordance with this author's own experiences, a presentation of overall principles receives much more attention and initiate real discussions, while a presentation of ethical principles in full almost has the opposite effect – no one cares. This has led us to look for shorter and more general ethical principles that can be addressed during research group meetings and supervision of students.

Research ethical commandments

To be sure that doctoral students have a mature relationship to research ethics, we have made 10 research ethics

commandments in which we have tried to summarize what we believe for them (as doctoral students and researchers) are the most important research ethics guidelines. (We presuppose that a presentation of national research ethics guidelines is included as part of the compulsory courses that they must follow during the doctoral program.) Our 10 research ethics commandments are:

1. You shall conduct research in accordance with good research practice.
2. You shall always be honest.
3. You shall not copy other researchers' research.
4. You shall recognize contributions of other researchers.
5. You should make your results available to other researchers.
6. You shall act as a responsible citizen.
7. You shall comply with all laws, rules, regulations and guidelines that apply to your research.
8. You shall report serious breaches of ethics.
9. You shall be able both to explain and defend all publications where you are co-author.
10. You shall when you evaluate other researchers' research unasked declare all relationships, positive and negative, to he/she/them you evaluate.

One of the benefits of this short form is that it is suitable to be debated during supervision and in research group meetings. Several commandments have also been changed following discussions in our research group. For example, the commandment "You shall tell the truth" changed to "You shall always be honest" as a result of a discussion on truth versus honest ("truthful"). The discussion of what is the most important commandment led what is now commandment No. 1 to the top.

An important issue that is not explicitly pointed out in these short commandments is that the law comes first. If a research project is regulated by The Health Research Act, ethical guidelines come second.

The commandments directly address the responsibility of each individual researcher. Hopefully this will help to ensure that these guidelines both will be remembered and followed. They are also suitable for being published in social media. The review of the commandments may advantageously be followed up with examples, both real and constructed.

Other ethical guidelines for research in short form

The National Research Ethics Committees launched in 2014 "General guidelines on research ethics" [22]. These consist of 14 guidelines, which all fit on an A4 page. These are based on the four principles [22]:

- *"Respect.* People who participate in research, as informants or otherwise, shall be treated with respect.
- *Good consequences.* Researchers shall seek to ensure that their activities produce good consequences and that any adverse consequences are within the limits of acceptability.
- *Fairness.* All research projects shall be designed and implemented fairly.
- *Integrity.* Researchers shall comply with recognized norms and to behave responsibly, openly and honestly towards their colleagues and the public."

The board of the University of Oslo (UiO) passed in 2007 "UiOs 10 bud for for god forskningsetikk" / "Guidelines for ethical practice in research: UiO's 10 Commandments" [23]. UiO's commandments also include the use of research funding and responsibility to stay current in a research field. UiO's 10 commandments are substantially longer than the commandments that we have put together. UiO's commandments do not affect the researcher's responsibility or duty to report serious breaches of ethical guidelines. At the University of Bergen (UiB), the university board in 2006 acknowledged "10 Code of Ethics for the University of Bergen" [24]. Since each of the rules is elaborated and explained, UiB's ethical rules are somewhat more extensive than UiO's rules. (UiB's ethical rules are available in Norwegian only.)

There are numerous examples of "rules" or "principles of research ethics" available online. These are often tailored to specific disciplines. One of the more famous ethical guidelines for research in short form (10 rules), is the "Nuremberg Code" of 1947 [25], designed in conjunction with the trials of German doctors who had participated in cruel experiments on humans during WWII.

Relevant Ethical Guidelines

Every researcher in health informatics should know which ethical guidelines are relevant for their research. As argued in the above section about "Research Ethics Guidelines Used in Norway", Norwegian researchers in health informatics need to know about current ethics guidelines, principles, laws, regulations, etc. in several disciplines. The question is, however, to what extent these guidelines etc. should be discussed in research group meetings.

The Advisory and Management Responsibilities

Every supervisor should regularly discuss research ethical issues with his/her students. At UiT, we have since 2004 had ethical guidelines for supervision [26]. These are available both in Norwegian [27] and English [28]. The guidelines, presented over two pages, say nothing about whether the supervisor has the responsibility to inform the student about research ethical guidelines or to discuss these during supervision meetings. At the Department of Computer Science, no common methodology courses for master's degree students exist, despite the fact that students submit a research-based thesis. As a consequence, ethical guidelines remain unknown for many students.

But what about the ethical guidelines for supervision? This author believes that if we carry out the same exercise as the one referred to in the introduction to this article (and presented in [2]) with other faculty members, it would hardly be many

who would have been able to render one or more of the ethical guidelines for supervision at UiT.

Evolutionary Development of Ethical Guidelines

Ethical guidelines are not static or developed in a vacuum. On the contrary, such guidelines are a result of a specific field's characteristics and must be adjusted in accordance to the development of the field. In a guest editorial in Cambridge Quarterly of Healthcare Ethics (CQ), Goodman [29] argues that:

> *"The global bioethics community is, collectively and generally, a quick study. The literature rapidly incorporates, analyzes, and otherwise metabolizes the latest scientific developments as they relate to health-care and pose new ethical issues. Genetics and genomics shaped a new subspecialty in bioethics; neuroethics arose quickly as brain research evolved and matured; and nanoethics blossomed as nano-technology and nanoscience posed new challenges ranging from personal tracking to human enhancement.*
>
> *Strikingly, however, the community of bioethics scholars and educators has been comparatively slow to grasp, let alone analyze, the significant transfor-mations and challenges caused and elicited by the use of health information technology (or biomedical informatics, e-health, or information and communi-cation technology)." (p. 252)*

In order to meet the rapid development within this area, the CQ has introduced a special section on "Bioethics and Information Technology" that *"aims to address this short-coming and fill this lacuna"*. Goodman [29] illustrates his points by stating:

> *"Countries around the world are spending billions of dollars, euros, and pounds to promote the use of electronic health records, which are transforming the clinician-patient relationship. Intelligent machines render diagnoses and prognoses more accurately than human experts, challenging traditional notions of professional practice. The analysis of big (and not-so-big) data fosters and identifies conundrums about the limits of privacy and the scope of informed consent. Indeed, every aspect of clinical practice, hospital operations, and biomedical research is touched by the use of computers, by information technology." (p. 252)*

Even though not every research project in health informatics has to deal with similar problems, we have to make all researchers in our field aware of what is going on. These kind of problems should have a natural place on every health informatics research group's meeting agenda.

Violation of Ethical Guidelines

To this author's knowledge, there are none "famous" cases of scientific misconduct in health informatics / medical informatics. There are some blogs that mentions cases, e.g., the blog by Gunter Eysenbach, who, among others, discusses a case about plagiarism in a medical informatics journal [30]. The tools for detecting scientific misconduct are becoming better and better. Sox [31] argues that: *"Plagiarism in the digital age is easier to commit but much easier to detect. On balance, we're making progress."* Hartvigsen [32] claims that committing plagiarism probably is the stupidest thing you can do as a researcher.

Teaching Ethical Guidelines in Health Informatics Research Groups

Even though teaching of research ethics and ethical guidelines and principles is a mandatory part of research education (i.e., PhD program), ethical guidelines should also be on every health informatics research group's agenda. This paper argues that this kind of discussion should take place on both research group and individual (supervision) level. Topics that should be discussed include:

- Ethical guidelines in short
- Relevant ethical guidelines
- The advisory and management responsibilities
- Evolutionary development of ethical guidelines
- Violation of ethical guidelines

How much time that should be spent on each of these topics will vary in accordance with the group members' knowledge of these issues.

Final Remarks

This paper has presented "10 research ethics commandments" that have been established through discussions in a health informatics research group. The objective of preparing a digest of research ethical guidelines has been to be able to discuss the topic in research team meetings and supervision sessions. Researchers and students are also encouraged to go ahead and consult the website of The National Research Ethics Committees (FEK) (www.etikkom.no). Students are encouraged to download FEK's poster with "General guidelines for research ethics" ("Generelle forskningsetiske retningslinjer") [22] and make it visible in their workplace. For those who want to get started with teaching in ethics, FEK's "Short Guide to teaching" ("Miniguide til undervisningsopplegg") [33] and RREE (Resources for Research Ethics Education) [34] are good starting points.

International sources for research ethics can be found at UNESCO and its Global Ethics Observatory (GEObs) [35]. According to their web-page: "The observatory is a *system of databases with worldwide coverage* in bioethics and other areas of applied ethics in science and technology such as environmental ethics, science ethics, and technology ethics." GEObs contains among others comprehensive databases of "related legislations and guidelines" and of "codes of conduct". UNESCO has published several books and reports of ethics, including "Ethics of Science and Technology at UNESCO" [36].

CODEX, the Swedish Centre for Research Ethics & Bioethics presents a comprehensive list of "Rules and Guidelines" on

their web-page [37]. Their web-page is a very good starting point if you want to get overview of what is going on in research ethics in the world.

This paper has only scratched the surface of ethical guidelines. The goal has been to present the minimum knowledge needed in this field for researchers in health informatics. The paper has not addressed the value of the specific guidelines, e.g., as discussed by Eriksson et al. [38]. In their paper, they question *"the premise that laws and ethical guidelines are as useful for ethical decisionmaking as is often assumed."* (p. 15)

We have to suppose that perceptions about how many and whether it is possible to identify a range of key ethical guidelines vary between disciplines, research groups and individual researchers, and that this topic in itself is a good starting point for a debate. And perhaps it is precisely a debate which is the basis of commitment and compliance with ethical guidelines for research?

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How can European policy recommendations inform use of standardized terminologies in clinical information systems in Sweden and Denmark?

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Introduction

Semantic interoperability in health requires the use of standardized clinical terminologies and classifications. However, many such standards exist, and deciding on which terminologies to implement, and how to implement them has proven difficult [1-3]. These difficulties have been acknowledged on the European level. Consequently, the Horizon2020 research project ASSESS CT aims to investigate the fitness of the international clinical terminology SNOMED CT as a potential standard for large scale eHealth deployments in the EU. The investigation includes comparison of SNOMED CT to other standardized clinical terminologies and local terminologies. This comparison is done to be able to make fair recommendations to the European Commission about standardized terminology adoption in Europe. Representatives from both Sweden and Denmark participate in ASSESS CT, and data have been collected from Danish and Swedish stakeholders to represent current terminology experiences, opinions and expectations. One of these data collection methods have been two focus group interviews (one Swedish and one Danish) [4] plus a common follow-up session conducted in April 2015. The aim of the focus groups was to gather expert opinions, beliefs, and attitudes regarding the European views on current and future terminology use in the health care sector, with a special focus on the role of SNOMED CT.

The focus groups have been formed using inclusion criteria's that aimed to provide a broad range of perspectives from policy makers, vendors and implementers of clinical terminologies in Denmark and Sweden. In addition, participants were selected so that there would be a balanced view of the benefits and shortcomings of using SNOMED CT compared to other terminologies. Consequently, people involved in health terminology related work, but without using SNOMED CT, was selected as well as those working with SNOMED CT.

The results showed that Denmark and Sweden is in the same situation when it comes to terminology adoption. Both countries have extensive current use of international classifications, have translated SNOMED CT, and face the challenges associated with coordinating the first large implementations of SNOMED CT. Consequently, it makes sense in a future perspective to share experiences, discuss possible solutions and maybe even do cross-border projects.

One way of initiating such knowledge sharing is to keep the discussion alive among Danish and Swedish stakeholders, and continue to learn from the best European experiences.

Focus of the workshop

In this section, we present the focus of the workshop. First we present the preliminary finding from the Danish and Swedish focus groups conducted as a part of the ASSESS CT project, to give insight into health terminology challenges as perceived by Danish and Swedish stakeholders. Next, we present how these findings have helped form European policy recommendations.

In the workshop session, the aim is to evaluate whether the policy recommendations could actually help resolve terminological challenges as perceived by the focus group and the attending audience.

Key findings from Danish and Swedish focus groups

The focus group discussions showed that many of the perceived benefits and shortcomings of implementing and using standardised classifications and terminologies were true for all terminologies. For example, many terminologies aid in exchanging healthcare data, which have its meaning unambiguously defined. In other aspects, the discussed terminologies differed, in purpose, granulation level, coverage, perceived quality etc., making them fit for different purposes. The availability of many different terminologies with different characteristics makes it difficult to choose one terminology over another.

Even if there are perceived benefits of choosing one terminology over the other, shifting terminologies is a challenge. The existing classifications are in wide-spread use but there are gaps which are not easily filled while keeping to the existing terminology workflows.

Findings of the focus group also suggested that many of the perceived barriers relates to the gap between an international complex terminology and local needs. For example, focus group members mentioned: Stakeholders' preference for their own terms, lack of sufficient stakeholder involvement in terminology related projects and lack of synonyms in SNOMED CT are barriers of SNOMED CT adoption.

Focus group results showed that stakeholders are concerned about what human- and IT-resources are available and important when it comes to supporting terminology implementation. It was highlighted that such problem is more significant in

small countries compared to larger ones, because it is not feasible to have large terminology competence centres in small countries. In addition, they pointed out that efficient tooling e.g. with focus on getting different overviews of terminology in use, could improve implementation processes. In addition, they emphasised that when we decide to use SNOMED CT for a specific purpose, we should be aware of evaluating whether intended benefits are reached. This will help form realistic business cases, which are most important if stakeholders are to invest in both technical and organisational terminology implementation.

In conclusion, the challenges ranged from adoption related, to implementation and business related:

- **Adoption:** The challenge of choosing one terminology over another and migration challenges given the existing terminological workflow in the health sector
- **Implementation:** The challenge of using an international terminology in local settings and the challenge of lacking education and tooling, which is enlarged in smaller countries
- **Business:** The challenge of setting up positive business cases for terminology implementation

From European findings to policy recommendations

The results from the Danish and Swedish focus groups have been key findings in the ASSESS CT project as a whole because Denmark and Sweden are some of the first non-English speaking countries that have started adopting SNOMED CT. Together with other European implementation experiences and studies performed as a part of the ASSESS CT project, they will inform the policy recommendations which are the final deliverable of the ASSESS CT project. The final deliverable will not just be a list of recommendations, but some guidance on how those recommendations may be taken forward across Europe, including recommended actions for different stakeholders. At the time of the workshop, a first draft of this final deliverable will be finished.

Organization of workshop

The workshop will have two parts: First a summary of the focus group results will be presented, and we will facilitate a short discussion session with the audience to establish whether their views on terminology related challenges are in accordance with the findings of the focus group.

In the second part a selected subset of ASSESS CT policy recommendations will be presented one by one. For each recommendation, the audience will discuss and rate the importance in a Scandinavian context.

Intended audience

Stakeholders from national e-health bodies, health IT implementation organizations, vendors, and universities with interest in the use of classifications and terminologies in health IT.

Expected outcome

We intend to create an open dialog about terminology implementation, to build the ground for more collaboration between the Scandinavian countries. In addition, we will track the main points of the discussion and feed them back to the European ASSESS CT project, to ensure that a broad range of Scandinavian perspectives will continue to inform the project.

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E-services and Social media for Persons with Mild Acquired Cognitive Impairment.

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Introduction

Mild acquired cognitive impairment (MACI) is a term used to describe a sub-group of persons with mild cognitive impairment who are expected to reach a stable cognitive level over time. One strategy that can be considered for further developing treatment for this group is the use of information and communication technology and e-services. The purpose of this study is to investigate the current use of common e-services and social media by persons with mild cognitive impairment and to explore their opinions and experiences.

Materials and Methods

In collaboration with the Swedish Association of Brain Injury (Hjärnkraft), data were collected through a self-administered survey and analyzed using quantitative and qualitative methods. The questionnaire focused on the participants' use and experience with e-services. To estimate participants' degree and type of impairment, the Cognitive Failure Questionnaire (CFQ), measuring cognitive difficulties in performing everyday tasks, was added.

Results

In total, 282 persons with acquired brain injury participated in the survey. The participants' total CFQ scores showed that they were suffering from mild to moderate cognitive impairments, most often acquired from traumatic brain injuries (40%). The majority (89%) used e-services in different categories whereof the most popular and essential ones were communication services/social media (59%) and banking services (39%). The usage of electronic devices decreased by age with the exception of electronic tablets that were used by older participants almost as much as other age groups.

Discussion

Our survey study of persons with mild acquired cognitive impairment demonstrated that the majority are using personal computers and mobile devices mostly as communication and banking aides. The results showed that a large proportion of these persons use e-services and have a positive attitude towards using them. It also helps them to achieve a more self-regulating and independent life. To the best of our knowledge, this study is one of the first to show persons' with MACI usage of e-services.

In addition areas such as navigation, alarms, memory, video and music services, writing, banking, seeking health information and specifically social interaction services are the most important aspects of information and communication technology for this group. However, further studies are needed on utilizing these identified e-services to support this group with their chronic condition. Similarly, further efforts are needed to popularize persons with MACI among the research community as a group with special needs and necessities towards using e-services. It may be interesting to explore the relationship between cognitive function and the use of e-services, in addition to the usage of the Internet and social media, more on an individual level.

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The impact of e-Learning for the elderly on drug utilization – a randomized controlled trial

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Introduction

Prescription and use of medications by the elderly have to be improved.

The objective of this study was to investigate the effects of e-learning for the elderly on drug utilization concerning knowledge, self-confidence and beliefs about medicines.

Methods

The study was a randomized controlled trial in elderly people (aged ≥65 years). Participants (included n=248, analyzed n=194, drop-outs n=54) were recruited from patient and pensioners´ associations. Participants were randomized to either an intervention group (IG, n=95) that participated in the e-learning or to a control group (CG, n=99) that did not participate in the e-learning.

A web site including e-learning modules with informative films was used to distribute information in the field of drug utilization. The modules were adapted for the use of the elderly. Data were collected using questionnaires; the General Beliefs about Medicines Questionnaire (BMQ) were used as well as a questionnaire concerning the content in the e-learning modules (knowledge questions). The participants were asked to fill in and return the questionnaires within two weeks after agreeing to participate in the study.

The questionnaires were evaluated with quantitative analysis. A two-tailed unpaired t-test was performed to compare the scores of the knowledge questions between the groups.

Results

Results from a pilot study indicated that e-learning modules were a suitable tool for distributing information and education and that they could be managed by elderly individuals, allowing them to learn more about medication use.

The preliminary results from the present study showed that there was a statistical significant difference ($P<0.0001$) in knowledge scores (mean ± CI) between the IG (14.12 ± 0.75) and the CG (10.76 ± 0.66). The total number of knowledge questions in the questionnaire was 20.

The work is in progress and the analysis of all the results will be completed during the spring 2016.

Discussion

In the future, the proportion of elderly in the population will increase and each individual will probably take more responsibility for her own health. It is important to enhance patient participation and empowerment. Increased knowledge and self-confidence about medicines among patients might create better conditions for a good communication between the patient and health care, and enhance the participation.

The use of internet allowed flexible learning, i.e. participants were able to choose the time and place that suited them, and to repeat the lesson as required in their own pace. In general, a lack of experience with computers could prevent elderly patients from participating in e-learning.

The elderly people who agreed to participate in our study were probably those with an interest in drug and medical treatment and who wanted to learn more. This limits the generalizability of the results.

In the future, we will explore the attitudes of elderly people to e-learning in the field of drug utilization, with particular emphasis on layout, usability, relevance and level of knowledge.

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Assessment of the value of a national telemedical monitoring system for patients with diabetic foot ulcer and venous leg ulcers.

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Introduction

In 2012 a national implementation of telemedical monitoring of patients with diabetic foot ulcer or venous leg ulcers was initiated in Denmark. The intervention included improving the skills of the municipality wound nurses and improving the possibilities of the nurses to communicate with hospital physicians regarding the treatment of the specific patient. This was made possible by use of an IT-system called plejenet.dk in which municipality nurses could register the treatment of patients with diabetic foot ulcers and submit questions and pictures (by use of smart phones) of the ulcers to hospital physicians.

The purpose of the implementation was to improve the quality of care and reduce the number of outpatient visits and costs. In relation to this national implementation a health technology assessment of the value of the telemedicine intervention was also planned. The aim of this presentation is to describe the results from this Health Technology Assessment (HTA) of a new innovative health technology based on MAST (Model for ASsessment of Telemedicine).

Materials and Methods

MAST includes assessment of safety, clinical effectiveness, patient perception and economic and organizational aspects.

The assessment is based on a randomized controlled trial (RCT) including 374 patients, data from public registers, two studies on patient perception and interview and survey studies with a sample of 418 health professionals of the perception of clinical staff in hospitals and municipalities in the five regions in Denmark.

Results

The assessment has demonstrated the following outcomes of the telemedicine intervention:

Safety: The IT system plejenet.dk has demonstrated a high degree of technical reliability.

Clinical impact: The RCT shows that the telemedicine patients have a statistical significant reduced number of outpatient visits. No difference in the clinical outcomes wound healing and amputation rate was found. A potential increase in the risk of mortality was found, but the relation to the use of telemedicine is not clear and further studies are needed.

Patient perception: Two minor studies of patient perception demonstrate that the patients have a high level of satisfaction due to the improved collaboration between municipalities and hospitals and the time saved for transportation of the patients.

Economics: Based on the RCT the reduction in the costs per patients by use of telemedicine was identified.

Organization: Results from interviews and surveys indicate that the project has increased the skills of the municipality nurses. Communication between primary and secondary health care is also improved. Also, the project has resulted in improved documentation with respect to ulcers.

Discussion

The assessment of the national implementation of telemedical monitoring of patients with diabetic foot ulcers or venous leg ulcers demonstrates a number of benefits for patients, the clinical staff and the economy of the health care sector. Based on the findings of a potentially increased mortality, patients with severe comorbidity are no longer offered the telemedicine intervention in order to avoid the potential risk for the patients.

Even though the intervention is implemented in all regions, the assessment has also highlighted a number of differences in the implementation of the telemedicine intervention in the five regions in Denmark and not all regions are using all facilities of the intervention. Therefore, improvements are still possible by a more consistent implementation in all regions.

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Collecting evidence about eHealth implementation in the Nordic Countries

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Introduction

The Nordic eHealth Indicator Research Network (NeRN) is aiming at identifying similarities and differences in the Nordic national eHealth policies and surveys with the aim to develop, test and assess a common set of indicators for monitoring eHealth availability, use and impacts in the Nordic countries. Starting in 2012, the NeRN collaboration has resulted in two key reports [1-2]. The aim of this poster is to summarize the results achieved so far and to describe ongoing work.

Materials and Methods

The work has been based on an indicator methodology containing four phases: 1) Defining the context through eHealth policy analysis (key stakeholders and the relevant area or system), 2) Defining the goals with a combination of top–down and bottom–up approaches, 3) Defining methods for indicator selection and categorisation, and 4) Defining the data, reporting results and feedback.

Key systems were informed by taking the OECD –defined key functionalities for Electronic Health Records (EHR), Health Information Ex-change (HIE), Personal Health Records (PHR) and Patient Portals. The availability and use of these functionalities were selected as the first indicators. The national eHealth survey variables in different Nordic countries were compared with OECD definitions to find common availability- and use-measures for these functionalities.

Results

Availability rates for the different key functionalities were relatively high especially when it comes to HIE functionalities related to prescriptions as e.g. the *proportion of ePrescriptions of all prescriptions made* in 2014 exceeded 60% in all the Nordic countries. The availability of Patient Portal functionalities was also high. Its intensity of use was however low, except in Danmark. Many of the Patient Portals were still local, and data on intensity of use by patients were not available at a national level. Comparable usability benchmarking was only available from Finland and Iceland and in some cases from Sweden.

Currently ongoing work focuses on harmonizing existing indicators, collecting and defining new indicators related to citizen views and developing a common system for data collection and presentation.

Discussion

This work represents the first systematic analysis and comparison between Nordic countries regarding eHealth monitoring. It clearly highlights the challenges such as unclear and ambiguous indicator definitions, lack of monitoring data for a great amount of variables and associated challenges in data comparability.

Acknowledgments

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References

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Towards the Characterisation of Medical Apps from Their Descriptions

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Introduction

Mobile devices and apps have completely changed our lives, including the approach to healthcare. In fact, medical or health mobile applications (hereinafter referred to as 'medical apps') are more and more available on app's stores (e.g., Apple Store and Google Play), and downloaded by consumers, or patients. However, downloading the right apps is still a challenge.

To guide the consumer, the patient, or the doctor, in selecting the right apps some methods and strategies were developed by different research groups or national health organizations. First, our previous research aimed at developing and testing a Pictorial Identification Schema (PIS) for an extensive user-oriented identification of medical apps. Then, at the Peter L. Reichertz Institute for Medical Informatics, Hannover Medical School, Germany, researchers developed an App Synopsis (AS), i.e. a checklist, for assessing the trustfulness of an app. Finally, the UK National Health System (NHS) implemented the "Health Apps Library", a catalogue of apps tested, and evaluated by NHS experts. However, that initiative is now under revision for improvements.

The aim of this project is to develop a computer application to allow patients - without specific medical knowledge - to characterise medical apps by a lexicon analysis of the descriptions published on the app's stores. The system is also thought to allow the healthcare professionals to speed up the advanced search of apps to recommend them to their patients. The concept on which this work focuses is as follows: the app description - free text published by the app's developers in an app store - is the only information sources apps have in common. Our hypothesis is that the extent of the specialized medical language used in the descriptions can help the understanding of the helpfulness of an app.

Materials and Methods

According to the software development process, we developed a computer application by Microsoft Access 2010, to collect the descriptions of apps available in the app stores, and their reviews published on the iMedicalApps.com website. The application is based on a relational database that models the structure of the app descriptions and their reviews in terms of entity types and attributes (metadata). In addition, terms from the Consumer Health Vocabulary have been included to tag the medical terms of the app descriptions. By defining queries in Structured Query Language, we defined a characterisation index based on the percentage of the medical terms included. To compare the apps within a medical domain, we grouped them according to that percentage. To this end, we divided the range from the minimum percentage of medical terms to the maximum one into five classes. Consequently, the apps were assigned to those classes. Then, we tested the application by a number of app descriptions (60 descriptions of 48 apps) of the "pharma" domain from the Apple Store and the Google Play store. We choose that domain as we considered it for the development of the PIS. Descriptions and metadata were manually entered in the application and the data entry was checked.

Results

The application we developed consists of a database to collect and manage the apps descriptions and metadata, and a user interface to interact with the users. For the "pharma" apps, Class I (2,82-10,84%) holds the 13% of the descriptions, Class II (10,84-18,86%) the 43,3%; Class III (18,86-26,89%) the 33,3%; Class IV (26,89-34,91%) the 8,3%, and Class V (34,91-42,93%) the 1,6%. Summarizing, the 90% of the total apps includes less than 26.89% of medical terms (Classes I - III).

Discussion

In this project we proposed a characterisation of medical apps based on a lexicon analysis of their descriptions, automatically performed by the developed application. Other classification methods are based on subjective evaluation. The PIS provides a graphical view to represent the strengths and weaknesses of a single app, according to different user's types. Then, to express a judgment about app trustfulness, the AS requires the user to subjectively answer 11 questions. From the test results, it appears that the most of "pharma" apps has poor medical contents. Future work includes the tests of apps from other medical domains, an evaluation of the user interface, and the improvement of the algorithm for the index calculation.

Acknowledgments

Some preliminary results of this project were presented to the Conference Apps for Medicine Health and Home Care – Elements of Safety and Effectiveness, Politecnico di Milano, Italy, 8-9 May 2014. (http://www.ehealth.polimi.it/appqa.asp).

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