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Table of Contents

Articles

Abstracts

Online Health Care Communication in Denmark: Changing the Playing Field?

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Abstract

This paper brings forward five propositions on the use of online communication in health care, its potential impacts on efficiency and effectiveness in health care, and which role government should play in moving forward the use of online communication. In the paper, each of the five propositions is illustrated with point of departure in the Danish health sector.

Keywords: IT in health care, social media, online consultations, health care costs, digital divide

Introduction

With the uptake of online communication and social media in particular, the belief in information and communication technology (ICT) being a potent vehicle for a transformation of health care has gain a worldwide revival. With social media and the associated user driven content and synchronous voice, video and text communication, the technological utopist are claiming that patients are being empowered and ability to retrieve extended health care in locations and at time where physical point-of-contact are not able to meet the demand due to lack of financial and man power resources. Contrasting this positive view of ICT-based transformation, the medical literature is showing less favorable impacts [1] [2].

While many studies have examined how the use of technology transforms activities within hospitals [3] [4] [5], less attention has been directed to the changes technology brings for the communication between the patients and the primary and secondary health care sector. This paper explores the changes brought about in the communication between the health care professionals and patients by the use of online health care ICT.

With social media and the associated user driven content and synchronous voice, video and text communication, patients are being empowered and provided the ability to retrieve extended health care in locations and at time where physical point-of-contact are not able to meet the demand due to lack of financial and man power resources.

A prominent example of this transformative view is the US Secretary of Health and Human Services that oversees a budget of approximately $700 billion and approximately 65,000 employees. With the policy ambitions to provide more inclusive and accessible health care, the Obama administration stimulates "..the use of non-traditional ways to access healthcare through the use of trusted sources, community based interventions, telemedicine, mobile medicine and social media" [6]. The Affordable Care Act includes technological platforms as healthcare.gov to disseminate information and engage citizen in sharing their health stories and help others. Governments are becoming placemakers [7] using ICT to win new territory and potentially save costs.

Protein internet technologies and among these social media in particular, hold the promises to help reduce the overall costs through less and more flexible communication channels. Citizens may use technologies to book time with general practitioners, find health related information at the internet, and join health forums in a magnitude and with a frequency that will ease the lines at the hospital clinics and waiting rooms at the general practitioners. Also, social media offers new ways of monitoring chronic diseases, spread of viruses, and post-operation treatment. Our aim is to ground the knowledge on this new playing field that so far has been studied relative fragmented [8] [9] [10] [11].

Materials and Method

The paper is part of larger, international effort to study the transformation of how patients and the health care professionals communicate online. We have not included clinical and electronic patient records technologies in our research scope. We have reported the details and the grounding of the framework in another forthcoming paper. This paper can be received by contacting the corresponding author of this SHI-paper.

In the present paper we have not detailed the literature grounding of the propositions on the magnitude of the use of online communication in health care, the potential impacts on consequences on efficiency and effectiveness, and which role government should play in moving forward the use of online communication.

In the following sections of this paper we put forward five propositions on online communication in the Danish health care sector. We have conducted interviews with health care administrators, logging and analysis of data at Netdoctor and Sundhed, analysis of data base from Eurostat and Statistics Denmark, and secondary data of previous analysis of online communication in the Danish health care sector. We have focused on bringing forward stimulating propositions for discussing where to focus research efforts. Clearly, the style of presentation of the propositions is not to advocate for strong data validity or solid research design. Our work on the online communication is at this point at a too early stage to apply these.

Propositions

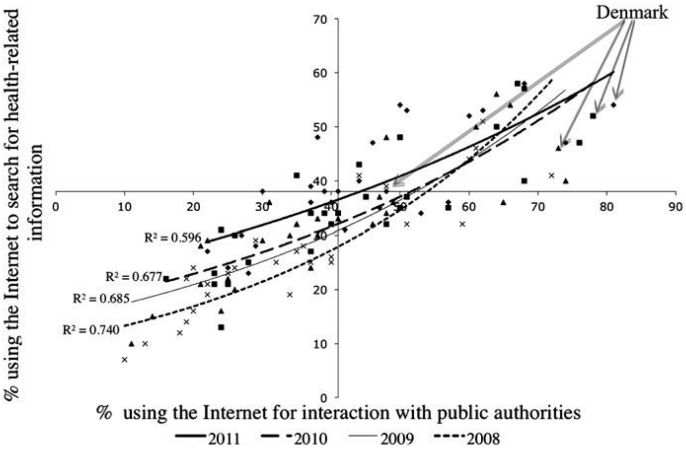
Proposition 1: Rapid Uptake of Internet Search for Information

Our first proposition is stating that citizens are increasingly using the internet to search for health related information.

In 2005, 24% of the Danes aged 16 to 74% were using the internet to search for health related information. By 2011, this had escalated to 54%. On average, the EU had jumped from 16% in 2005 to 41% in 2011. National and local government in Denmark can demonstrate a very high uptake of online services. With more than 80% of the population using the internet for interacting with public authorities, Denmark is at the very top level in international benchmark studies from UN and OECD.

Using data from Eurostat, we have analyzed the percentage of the population in European countries, and among these Denmark, that are using the internet for interacting with the public sector (horizontal axis) and searching for health related information (vertical axis) for 2008-2011.

The analysis shows a growing trend for communication with the public sector and health care information retrieval, with the search for health care information growing more rapidly. For the four years combined, there is an average of 41% of the Europeans interacting with the public sector through the internet and an average annual growth rate of 5%. On average for the four years, 37% were searching for health related information but an annual growth rate of 20%. Denmark is in the North-East corner of the diagram giving them a comfortable lead in both general public sector interaction (81% in 2011) and health related internet use (54% in 2011).



Source. [8]

Figure 1 - Use of internet to search for health related information and for interacting with public authorities, 2008-2011

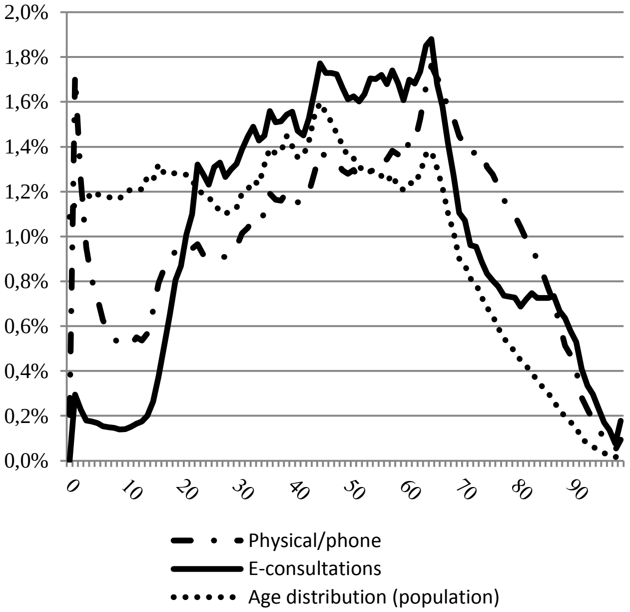
Proposition 2: Reinforcement of socio-economic gaps, shriveling age-divide

The second proposition is stating that the uptake of technology in health care communication between patients and doctors will reinforce gender and socio-economic gaps (income, education, urban-rural), but will reduce the age-divide gap. In proposition 1 we have described a rapid uptake of online communication. In this second proposition we bring the analysis one step forward and have analyzed whether the uptake is reinforcing already existing age- and socioeconomic gaps in the use of the health care sector.

Our analysis shows that the uptake of e-consultation is primarily an urban phenomena, primarily used by people with higher income, the well-educated and women. This uptake-pattern is consistent with the socio-economic gap in health care.

The uptake of online communication distributed on age groups has a significant different distribution than physical/phone based consultations distributed on age groups. The age group 50-65 years has less frequency of online communication as compared to physical consultation. Whereas it expected that that citizens in the age group 20-49 years are relative more frequent users of online communication than physical communication, the Danish data show surprisingly that the age group older than 65 years has a relative high use of online communication.

In Figure 2 we have visualized the age distribution along the horizontal axis age in years and along the vertical axis age the use of online communication between the patient and the general practitioner (e-consultation) and physical/ phone consultations. The Figure shows that whereas the 45 year old has a share of 1.8% of the online consultations, the 45 year old only has 1.4% share of the physical consultations. This age group has 1.6% of the total population. Thus, for the age group of 25-65 years old there is an uptake of online consultations that is higher than physical consultations and more than their age group has as population share.



Source. [9]

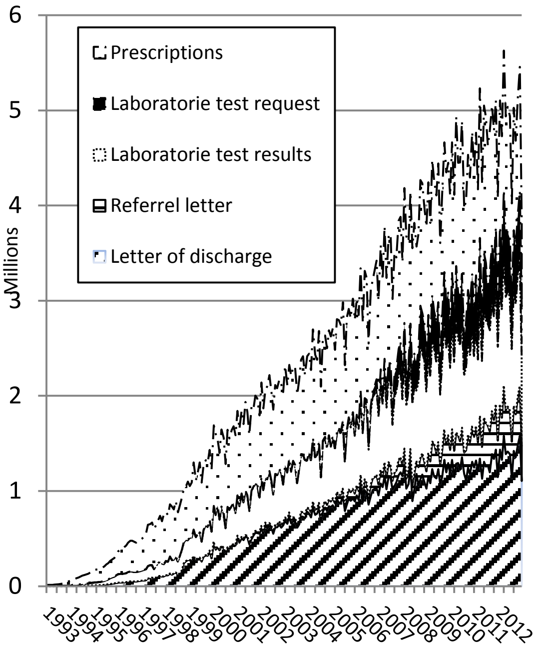
Figure 2 - Visits to GPs distributed on age (Percent). Age distribution and Online and Physical Consultations, 2011

Proposition 3: Positive impacts on quality and efficiency

Our third proposition is that technology use in health care communication brings forward new forms of communication and improvement of quality and efficiency.

A prominent indicator of these impacts is the rapid technical induced communication changes in the number of messages exchanged through the Danish national MedCom data infrastructure. MedCom facilitates transmission of letter of discharge, prescription letters, laboratory test requests, laboratory test results, and referral letters. The communication regarding these issues between 1) the 2,100 private general practitioners clinics and 330 pharmacies, 2) the public sector hospitals, and 3) the patients are now close to 100% of the total communication.

In Figure 3 we have displayed the number of messages per month exchanged in the MedCom network for a twenty year span (1992-2012). Prescription letters from the general practitioners to the pharmacies started being electronic transmitted (EDI) in 1992 and has, along with letter of discharge and laboratory test results, escalated. The national communication network enables for examples pharmacies and patients to access the prescription letters at online document repositories and in pick-up medicine at a pharmacy of the patients choice. Also, the MedCom network has resulted in improvement in data reliability and reduction of data redundancy.



Source. [10]

Figure 3 - MedCom Messages 1992-2012

The rapid growth of MedCom has virtualized the transmission of messages and has connected the health actors in a by international standard unique setting. Close to all messages are digitalized enabling trace-and-track options and more smoothly interactions.

Proposition 4. Reduction in marginal costs, increase in total costs

Our fourth proposition is that the uptake of communication through the internet and social media will reduce marginal communication costs but paradoxically lead to increase in total health care costs. The overall uptake of social media in Denmark is following the trend in most other First World countries with an increasing use and a strong bias of the younger generating posting messages to social media sites and instant messaging. Only 11% of the 65-74 year age group were active social media users in 2012, whereas the 53% of the 25-54 years and 86% of the 16-24 years used social media in Denmark (Eurostat 2013).

The introduction of online consultation in Denmark has led to quite extensive public debate whether or not the number of online consultations will increase due to time savings, a simpler service, reduced transport demand, and increased availability.

In January 2009 a ministerial order made it mandatory for the private general practitioners to offer online consultations with the patients. Also, government launched online health forums and digital communication to cope with areas of health care where supply of medicare was limited and in areas where sensitive issues but prevent citizens from seeking medicare. Citizens have taken onboard the new channels, but the overall numbers of consultations have increased. Hence, the total costs are escalating.

In Table 1 we have displayed the number and costs of general practitioner consultations for year 2008 and 2012. These data has been computed through access to health care statistics. The distributions on three channels (physical, phone, and e-mail consultations) show an increase in the number of e-mail consultations of more than 100% during the period 2008-2012. There has been a minor reduction on phone based consultations but also an increase in daytime physical consultations.

Table 1. Consultations by General Practitioners: Proximity, Number of Consultations, and Costs (1,000 USD) of Consultations, 2008, 2012

Proximity	**2008**		**2012**	
	N	Cost	N	Cost
Physical (day)	19,151,421	313,731	20,280,154	351,567
Physical (night)	938,069	24,524	916,470	24,431
Phone (day)	14,840,136	49,715	13,479,966	45,582
Phone (night)	1,645,846	21,405	1,626,629	21,575
Online	1,284,336	8,607	2,860,303	16,681
∑	40,727,703	909,906	41,588,137	1,017,268

Source. [9]

Proposition 5: Government involvement in open social media

Our fifth proposition is addressing what role government can play in use of social media in health care. Our daring proposition is that government fails when it attempt to create and manage open, online social media based health care forums. Government is much more successful when it focuses on social media use where the access to the groups and communication is restricted.

At Aalborg University Hospital, an online patient book was implemented in 2009 for male patients with prostate cancer undergoing radical prostatectomy surgery. The ambition with the online patient book was to meet the patients need for information, support, and dialogue with other patients and with healthcare professionals [11]. Since 2009, 400 patients have used the online consultation forum.

The number of men diagnosed with prostate cancer increased significantly from 2000 to 2009. Previously, these men (typically in their fifties or older) were hospitalized up till twenty days including the surgery. Today they are hospitalized less than three days, and the time still decreases towards planned discharge the day after surgery. One of the reasons for the short stay at the hospital is the use of robots to undertake the surgery. In addition, the men have to visit the outpatient clinic numerous times both before and after the surgery.

The use of Online Patient Book© has transformed the place of communication between the patient and the health professional to a closed virtual space with six members (patients) where the pre-assigned group members can see the questions and answers from others in their group. The patients can ask questions to health professionals that will answer the questions within 24 hours. The communication is done in native language (Danish) and with local health professionals.

According to the administrative manager of the online patient book, Anette Højer Mikkelsen, the main reasons for why the patients use the online forum are that the patient fell comforted by the ability to ask questions to health professionals they have been physical introduced to and the use of native language in the communication. The communication includes general and individualized information and support empowering the men, as it assists the patients in being active participants in their own care with the freedom to use the tool. The patients experience an increased ability to stay in control, which reduces the dependence on the healthcare professionals.

Also, the national health care portal (sundhed.dk) is trying to use new media for interaction. Building a national health portal with access to electronic patient records, letter of discharge, prescriptions, etc. is far more extensive than what is being offered at the US war veteran online communication site and Keizer Permanente. This Danish national health portal is linking all the actors and institutions into one virtual territory. The health communication has moved to a virtual place.

The portal aims at ensuring consistent patient treatment and improving patients' ability to take care of their health. As of January 2008, the portal had about 300,000 registered users. By January 2013, the number of registered users had grown to 850,000. However, the impact of Sundhed.dk on citizens should not be measured only by the number of visitors to the portal, but also by the extent to which patients are more informed, know where to go for the health services, and by the amount of time freed for those working daily in the health sector. With the exception of debate on recurrent miscarriages and cervical cancer, the open communication forum is not used much of the citizens. By contrast, online communication, postings, and re-tweets at the private run social network as Netdoktor.dk and various Facebook and Linkedin groups are growing rapidly in numbers.

Sundhed.dk increasingly faces the competition from the privately funded and operated fora, and from patient-driven fora. These health fora do not aim at minimizing online traffic and interaction, but at maximizing them. The underlying business logic of Web 2.0 applications and that of the majority of private health fora is to reach a high volume of traffic and a high turnover ratio. For example, the netdoktor.dk's business model is that it sells marketing relevant data collected at the health communication oriented website to online marketing companies. Thus, more users generate more data that can be sold. By contrast, the government operated health care communication platform has assigned health care professionals to intervene in case the communication result in dialogue and advises that are against national health care rules. Thus, the costs of adding more users are not approaching zero for the government operated sites since the number of postings will increase with more users.

Table 2. Postings at the Online Patient Network at Sundhed.dk, July 2011-February 2013. Accumulated Number of Postings and Number of Users (N)

Patient Network	July 2011		November 2011		June 2012		February 2013	
	P	U	P	U	P	U	P	U
Miscar-riages[1]	935	388	1081	430	1159	477	1239	543
Cervical cancer[1]	266	362	292	380	332	412	352	458
Inconti-nence	32	83	48	127	70	182	81	225
Rape	29	65	39	105	67	152	95	196
Lym-phoede-ma	6	22	8	32	16	42	22	66
Modic changes	32	44	50	87	74	146	84	206
Over-weight	4	12	6	24	6	31	6	55

Note. P is the number of postings, U equals the number of users.

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Why Continuing Education in eHealth

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Abstract

Continuing Education in health informatics is suggested as a necessary part of achieving suitable IS in the health sector in order to address the long term needs of the health professions, the providers and those who design and maintain the ICTs. Our approach is to include both healthcare workers and those working with health ICT in our educational program so that they may to learn together. The aim is to harness relevant experiences through reflection and learning both during their studies and in their future work practices.

Keywords[1]:

Continuing Education, Health Informatics, Multidisciplinary

Introduction

At any level, Information and Communication Technologies (ICTs) figure prominently in current strategies for improving the provision of health care. Governments aim for a healthcare system that addresses the public's expectation of timely and fair assistance for each and every citizen. Both the private and public health care providers seek to produce efficient and competent services. A number of businesses seek markets for their ICT services and products in the health care context. And, citizens want timely and correct treatment for themselves and their close ones. The potential benefit of using ICT to leverage all these aims and more seems obvious.

On the other hand, reports of the utility previous investments in IT for health care provision vary greatly. In Norwegian media the past years, optimistic stories of newly acquired state of the art mingle with more shaming tales of system updates and reports being sent on minidisc by postal mail, patient data in the municipalities sent on by newly acquired fax machines [1] and examples of patients dying because their referrals for urgent treatment went missing somewhere in paper-cyber space. So, while ICTs by the hundreds are in use throughout the sector for various purposes, the desired benefits seem elusive and the systems in use often come with downsides as well as added value. A case in point being the fate of the British NHS' attempts at establishing a common IS [2].

Research on the adoption and use of information systems (IS) over the last decades has reported on the challenges of introducing new technologies into existing work practices. The difficulties increase with scope and scale, and are not unique to the health sector. However, the health sector with its traditional sense of organizing activity, numerous and continuously evolving knowledge bases and circumstances, along with a variety of professions presents itself as extremely complex and intricate to support with IS. Reported problems range from the basic and local to the kind of functionality that supports coherence across time, space and organizations. On the one hand that of impractical functionality, outdated technology/legacy systems with poor fit to present organizational needs, and poor usability. On the other hand the difficulty of achieving up to date practices and fluent collaboration relates to for instance poor compatibility/integration, lack of supportive functionality or simply to the fact that the IS for some reason fails to be adopted by relevant users in a way that supports other than some actors' individual short term needs of getting a local task done [2].

One approach to understanding and thus dealing with the establishment and uptake of large scale information systems is to see them as socio-technical ecologies that need ongoing nurturing [3] and sustainable conditions [4] as circumstances and ambitions are in continuous drift [5]. This implies not only designing usable and suitable technology that actually affords the practices they are meant to support, but also supplying the professionals who are meant to use the systems with the abilities to do so also in the long run by supporting the revision and evolution of their disciplinary knowledge base [6]. We venture that the eHealth integrated health care system will do no better than its weakest links – including both the people that design and maintain them and those who use them. Beyond the immediate challenges of working systems there are long term issues to address in order to support the evolution of both the health care practices and the technical systems and their use. How may IS support trust for collaborating across interests and domains [7], support learning for the individual practitioner as well as improve the knowledge bases of the professions and the organizations they belong to?

2 Continuing Education in Health Informatics as Strategy

In order to design and use IS for leveraging knowledge based services and practices we venture that the practitioners themselves must be involved in their creation and introduction.

Continuing education is a means to bring this about. Harnessing the expertise of those already in the sector is vital to secure relevant solutions and ownership in introduction, reorganization and maintenance. Research based teaching combined with language and experience allow for new insights and learning. Adding methodology for cross disciplinary collaboration allows for future technical and organizational innovation [8]. The following description is based on [9].

2.1 NTNU's Continuing Education Master Program in Health Care Informatics

NTNUs Continuing Education Master Program in Health Care Informatics may be entered by both those with a bachelor or equivalent in a health care profession or with an ICT profession. Also a minimum of 2 years working experience is mandatory. As part time students they receive a few courses aimed at giving them a basic knowledge of their counterparts' discipline, but mostly they have a common curriculum where they study together in multidisciplinary groups. Being confronted with the realities and experiences of fellow students and insights from research is central to establishing cross disciplinary communication and collaboration both in their studies and for their working life. The first year of the four year program aims for establishing some mutual language and common ground. The second year teaches through practical projects methodologies that allow for bridging the gaps of differing perspectives and objectives. Finally a two year master project allows the students to put into practice and internalize insights from some of that which they have learned in theory. The list of courses is shown below in Table 1.

Our aim is that our students may make informed choices with realistic ambitions and strategies for systems design and their implementation and revision. Our starting point being innovation grounded in working practices and a usability focus for all relevant users or roles.

Table 1. *Courses given in the 4-year program. A student with a health education background will do the topics in the first two columns. Those with an ICT background will do topics in the middle and right columns.*

Topics for health personnel	Topics for both groups	Topics for ICT personnel
	Master's thesis	
	Pilot study	
	Chosen theory (two topics)	
	Research Methods	
	Human-Computer Interaction	
	Epidemiology and Community Medicine	
System Development	Clinical Information Systems	Clinical Decision-Support Systems
Programming	IT, Organization and Collaboration in Healthcare	Medicine and Healthcare Services
Databases	Introduction to Health informatics	Introduction to Biology and Disease

2.2 Experiences So Far

Five years into the running, the program has students, ages thirty to fifty, from all over Norway. They form a balanced mix across gender and private or public occupation. While a third has a technical background, the others include nurses, doctors, radiographers, pharmacists and bioengineers. Pedagogically it is a challenge to cater for the variety of backgrounds. On the other hand they are highly motivated and inspired by new found language and understanding. "Finally, there is someone to talk to about my experiences." Discussion runs high both in class and group projects. Several state that they feel more self-assured: "I plan differently now as I can support my opinions", or "Suppliers answer when I ask questions instead of moving on to another issue." But also they want hear of more success stories, rather than all the potential difficulties and problems. For our teaching staff these students present an opportunity for direct contact with real organizational and technical life issues through the case material these students often have access to.

However there also challenges to teaching these students, most of who are in full time employment. Activities need to have flexible time frames, and they often need more coaching time than ordinary students who stay on campus in the thick of student activity. In terms of teaching outcome this is amply made up for by the level of understanding many reach given their relevant experiences.

3 Conclusion

In striving for eHealth – not only do we need to acknowledge the legacy technologies when new systems are to be designed and put to use. We also need to attend to the objectives and requirements of those working to achieve innovation – both those with a technical perspective and those with a health background. In supporting the harnessing of experience from both these groups, more comprehensive innovation involving ICTs may take place within the health sector.

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Telementoring as a Service

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Abstract

Increasing number of ubiquitous mobile devices in daily routine encourages software design adaptations. Hardware/software independence, minimized end user efforts to maintain the compatibility of their preferred devices with the software systems are very important properties in the rapidly updating technological world. As a support for this claim, a concept of service based surgical telementoring system is presented and illustrated by a prototypical implementation. It proves the fact that technological progress is reaching the level allowing the redesign of telementoring systems to be provided as a service in a hospital's network, using only web browser as a client.

***Keywords:* telementoring, SOA, telestration, service, WebRTC**

Introduction

Recent global focus and increasing numbers of publications on telementoring shows a growing interest of the researchers on poorly explored remote surgical mentoring techniques [1], [2], [3]. Rising level of life dynamics, advancing ICT, aging society and predicted shortage of surgical work force [4] make us rethink the concepts of education, mentoring, medicine. Tele-education, telementoring and telemedicine are the concepts, spinning in the heads of many researchers nowadays. The optimistically-minded have no doubt about the benefits "tele" feature brings; publications prove the cost and time gains of telementoring techniques in comparison with traditional mentoring [5], Doarn describes them as "a natural fit" in surgery [6]. However, telemedical research is still in its infancy and the benefits need a proper knowledge base to support the sound claims.

This paper explores the concept of telementoring in a wider scope, proposing a novel outlook to the implementations of telementoring systems. Our goal is to push the technology towards being available as a service in a global health network.

The paper is structured as follows: after overviewing the state of the art of developing telementoring solutions, we highlight the drawbacks which could be resolved by changing the software architecture design pattern. Conceptual architecture together with the details regarding the prototypical implementation is presented. The limitations of current solution are emphasized.

Telementoring as a Service

This section is an attempt to draw the high level of abstraction guidelines for delivering telementoring as a service.

Service Oriented Architecture

The concept of software as a service is not a new one. Service Oriented Architecture (SOA) is a well-established software architecture design pattern, based on the idea of developing platform-agnostic computational elements accessed by a lightweight client. Due to uniform data exchange protocol between the service and the client (usually web browser) cross platform, browser and hardware compatibility is highly increased [7].

State of the art of telementoring systems

Notwithstanding the global trend towards the use of mobile devices, telementoring systems remain conservative. Stationary mentoring posts, restricted hardware and software platforms are still common features of nowadays remote guidance systems [8]. A lack of research in employing mobile environments and devices as a medium for enabling ubiquitous support service was identified [9]. Hypotheses of the potential, brought by the introduction of the mobility to the domain are to be supported.

Telementoring systems are based on video conferencing (VC) solutions as a foundation. They are developed having client-server architecture in mind. Providing video channel between the two parties is a fundamental feature of VC. Client software is mandatory to make the system run. However, the variety of software platforms, versions of client application, the need to install extra software and constantly update it results in a headache for IT administrators as well as the end users.

Looking from the technological perspective, the choices for delivering video content to the remote client are limited. Table 1 represents a comparison of most popular current video streaming technologies with respect to 3 main aspects: necessity to install third party software on client side, variety of supported platforms and compatibility with HTML5 video specification. Web Real-Time Communications (WebRTC) gets the highest score based on our comparison as the technology for the novel concept – telementoring as a service.

Service-based mentoring

The main idea behind the attempt to push the mentoring systems to the service layer is to increase the availability of the system and minimize the burden experienced on the remote client side. The goal is to enable telementoring on any device mentors use in their daily routine without the need to install and update any third-party software to maintain the device's compatibility with the mentoring system. Software normally supplied with the machine should be sufficient for the purpose of telementoring. In other words, we propose a browser-based telementoring system prototype.

The main advantages, service based mentoring provides in comparison to the traditional approach are:

- No hardware/software dependencies;
- No extra software install/update on the client side (Flash player, Silverlight, plugins, etc…);
- No network customizations and dedicated networks;
- Centralized control of the mentored procedures (automatic recording, scheduling, participant management, etc.)

Adapting the advantages of SOA to enhance telementoring is a way to eliminate the drawbacks introduced by current state-of-art of developing remote guidance solutions.

Table 1 - Comparison of video streaming technologies

Technology	Software on the client side required	Platform support	Supported as an input for HTML video tag
Real Time Messaging Protocol (RTMP)	Yes	Multiplatform	No
Real Time Streaming Protocol (RTSP)	Yes	Multiplatform	No
Microsoft Smooth Streaming	Yes	Multiplatform	No
HTTP Live Streaming (HLS)	No	iPhone, iPad and iPod	Yes
Web Real-Time Communications (WebRTC)	No	Multiplatform	Yes

WebRTC based implementation

Web Real Time Communication (WebRTC) is an open source framework providing a set of Javascript APIs for real time peer-to-peer media interaction between browsers. Briefly speaking, it enables the development of video conferencing systems using only Javascript and HTML5 [10]. The systems runs inside a WebRTC enabled browser and introduces no additional burden to the user (installation, updates and customization).

To prove the concept of telementoring as a service an open source WebRTC implementation (easyRTC, developed by Priologic) was customized to meet the requirements of the end users. The prototype consists of:

- One way (Operating Room -> remote expert) video link;
- Two ways (Operating Room <-> remote expert) audio link;
- One way (Operating Room <- remote expert) live video annotation link.

Architecture of WebRTC based telementoring system is represented in Figure 1. The mentoring session is initiated by OR client connecting to the WebRTC server. After remote client connects to the server, it is provided by shared session data and peer-to-peer connection between two clients is established. The remote expert is enabled to follow the live video from the operating room, interact with local surgeon verbally and telestrate on live video content.

Discussion

The conceptual and prototypical results presented in the paper are still in their infancy. The developed prototype is very dependent on relatively new and still evolving technologies, having limited support. Currently it is the main weakness of the implementation. Taking the perfect position for keeping up with technological progress as well as ensuring the quality of the service is a challenge. On the one hand, controlling the technological variables, we are dependent on, slows down the application of newest achievements in WebRTC and HTML5 technologies. On the other - adapting to the rapid progress interferes with the stability of current setup.

WebRTC promises fundamental changes in the way video conferencing is used. Minimized infrastructure maintaining burden for the end users, easy integration with current web-based systems is pushing VC technology to a higher level of availability [10]. Increased compatibility enables the inclusion of ubiquitous mobile computational devices as endpoints of the link. Looking from the telementoring perspective, especially in emergency cases, shortening the response time of the mentor is of critical importance. Easy accessible mentoring service, having no client side prerequisites is a step forward.

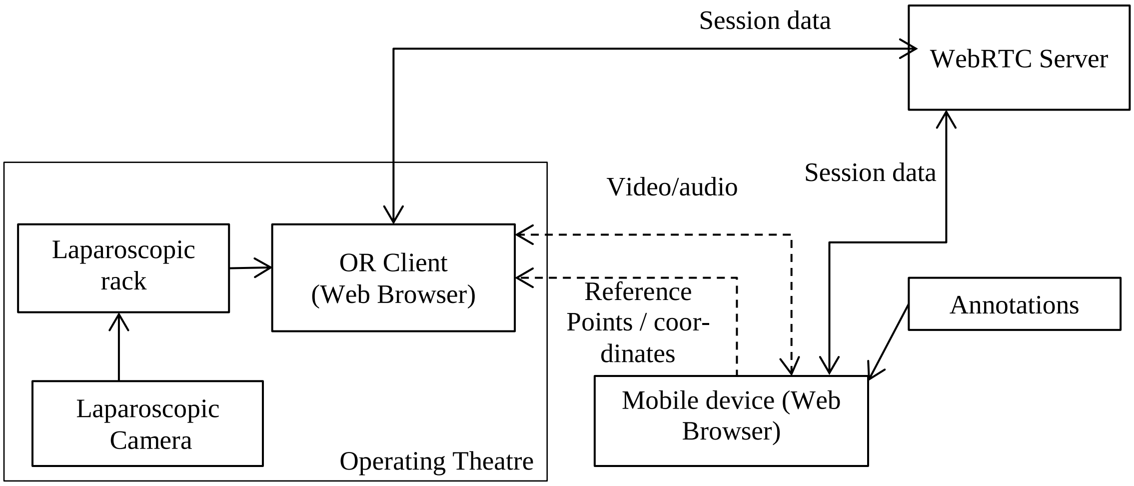

Figure 1 - Architecture of a WebRTC based telementoring system

In a more general perspective, the new winds, WebRTC brings to the VC arena, open the new ways for telemedicine to evolve. Simplified process of establishing an audio-video link between the patient and the clinician forms the premises for tele-emergency service. A similar 24/7 VC systems was developed by Trondsen et al. for emergency telepsychiatry consultations. Conventional VC software solutions were installed in predefined consultancy posts to ensure high availability of the service for the patients [11]. This and other similar research identify the possibility of establishing a VC based virtual emergency clinic [12]. If the patient is able to start the VC session with the clinical service provider as easy as entering the symptoms into an online form, patient side acceptance of this technique should increase.

The use of this service may be limited to non-critical emergency cases, for instance when only a consultation is sufficient. It should also minimize the workload of general practitioners (GPs) by "filtering" the cases and treating one part of them online, avoiding the visit to the hospital. The other part, who were suggested for a GP visit, could be diagnosed and treated faster, as the symptoms would have already been recorder by the virtual tele-emergency clinic, forwarding the patient to the clinician meeting his needs the best and scheduling the meeting according to the clinical condition. Assumptions regarding cost effectiveness, minimized work load of GPs and shorter duration between patient's decision to see a doctor and start of the treatment are just a few of many positive outcomes.

Application of the discussed technologies in telemedical domain has not been done before. However, telementoring approach has already found its supporters among the clinicians. Even though current state of the art of telementoring applications suffers from the technology-related drawbacks, the "clinical outcomes and educational benefits" have some proof already [1]. Technological changes in the established software architectures in VC and telementoring promise a "hassle-free one-click" service. The expected outcomes are exciting; however, a more detailed research is necessary for proving the sound claims.

WebRTC based telementoring software prototype testing results show that we still lag behind if compared with the well-established technologies (Table 1) from the performance perspective. Video encoding/decoding process should highly improve to ensure a wider range of supported resolutions, higher quality and lower latency. WebRTC employs a highly efficient VP8 video codec, however, not being a "de facto" standard it suffers from the absence of hardware acceleration, meaning that video processing is done on a software level. It is especially well noticeable on mobile platforms. However, it is only a matter of time until technological promises of WebRTC and HTML5 will be completely fulfilled making them strong competitors in the video conferencing and telementoring arena.

Conclusion and Future Work

The paper presented an out-of-the-box concept of surgical telementoring. The approach takes advantage of the newest achievements in reshaping the established state of the art of video conferencing. Following the latest VC trends enables telementoring research to stay on the cutting edge of technology. However, keeping up with the dynamics of the developing infrastructure is always a challenge.

Lab testing of the developed prototype is in progress. Results supporting the claims made in the paper are being collected.

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Educating Health Care Professionals
Master's Program in Health Informatics at Aalborg University

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Abstract

The program in Health Informatics at Aalborg University was started in 1994 as a part-time continuing education for health care professionals. The program is based on a problem based, project organized learning strategy and is structured in a mix-mode way with face-to-face seminars at the university combined with learning activities on a learning platform. Since 1994 both healthcare and the role of ICT in health has changed as ICT systems has matured and grow into being a natural part of everyday practice in all aspects of the health domain. Thus the focus and content of the education has been revised several times during the past almost twenty years in order to meet the changing needs and expectations to health care technology. At the moment we are going through such a revision and in this paper we present our program, the revision process that we are going through, and discuss major trends and challenges in health care, and how this should be reflected in continuing education of health care professionals within the area of health informatics.

Keywords:

Health informatics education, continuing education, future challenges

Introduction

The conception that Information and Communication Technologies (ICT) could and should play an important role in the delivery of better and more efficient health care is far from new, nor is the acknowledgment that education is needed in order to fulfill the expectations. International Medical Informatics Association (established in 1979) has during the years initiated various activities in order to promote health informatics education and a special working group, the IMIA working group on Health and Medical Informatics Education, is especially dedicated to this work. The aim of this working group is to raise the scope and quality of education by dissemination and exchange of information on Health and Medical program and courses. This has been done by e.g. organizing conferences on health and medical education, by special issues of the international Journal of Medical Informatics on education, and by establishing and promoting the IMIA database on programs and courses [1, 2]. The focus on educational issues also led to the development of recommendations on educations in health informatics, the first version of these came in 2000, and a revised version was available in 2010 [3]. Recently a procedure for accreditation of health informatics programs is developed and tested [4].

Thus the emphasis on education as a way of promoting health informatics has a long history, but the focus and the content has obviously changes over the years as ICT systems in health has matured and grown into being a natural part of everyday practice in all aspects of the health domain. In the early days there was a high focus on computer literacy and health care specialists. The focus of today is also including applications that are more directly utilized by patients and citizen, and on health care professionals as IT users. This s also reflected in the IMIA Strategic plan – Towards IMIA 2015 [5] where several target groups are mentioned as relevant health informatics education e.g. health informaticians, implementers, health professionals and people. Taken to the extreme, one could say that the early expectations were that IT in itself could change the healthcare system and make it more efficient and cohesive. It has appeared that this it not the case and this has led to more focus on contextual issues, and the need for an deeper understanding on how IT mediates remediate different health practices.

The Master's program at Aalborg University

The program in Health Informatics is a continuing education program for health care professionals based on a problem based, project organized approach. The program was initiated in 1994 and has run ever since. Approximately 380 persons have successfully completed the education since we started. It is an inter disciplinary program run in a collaboration between Department of Health & Technology (host of the education), Department of Development & Planning, and Department of Communication & Psychology at Aalborg University. Around 15-20 students primarily from Denmark, but also from Scandinavia are admitted every year, the admission criteria being a bachelor or master degree in health sciences (e.g. doctors and nurses) and at least two years of professional experience. The program is a 2 years part time study, corresponding to 60 ECTS, and provides the students with knowledge, skills, and competencies to work theoretical and methodological with health informatics problems from different angles, e.g. management, health care professionals, and patient/citizens perspectives. The aim is to provide the students with capabilities that enable the to bridge the gap between health professionals and IT professionals, thus being able and to cooperate with e.g. suppliers, regions and municipalities. Furthermore the students should be able to handle both development- and implementationprocesses in a professional way, and to cooperate with patient an citizens on speciffic IT solutions. The program is organized as a mix-mode study combining face-to-face seminars at the university and work on a learning platform between the seminars. The face-to-face seminars takes place at the university 4 times a year and include intensive lectures, laboratory exercises and perhaps most importantly dialog and discussions between the students and the teachers and the students.

The students work with two main types of activities: project work and courses. A course is a systematic presentation of a discipline and the purpose is to provide the student with sufficient disciplinary knowledge to cope with inter disciplinary problems. There are 6 courses, three each year, and three project, two on the first year, and one master thesis at the last year. Table 1 provides a list of study activities. To complete a course the students have to pass a test. These test are normally conducted through the learning platform; at a specific date and time an assignment is made available for the student at the system, and the students then have one or two hours to work with the assignment.

The project works offer the students the possibility of working with problems of their own choice and usually student work with problems relevant for their professional background. The project of the first year has to be stated within the frame of "Health Informatics from an analytical perspective" whereas the master projects of the second year are within the frame "Health informatics from a design and/or implementation perspective". To identify and work with problems in collaboration with other students is an important part of the education. Examples of project from this year are "Design of a consent register", "Standards in communication between home care and hospitals", "The role of paper in digital information environments", "Challenges in implementation of new technologies in home care", and "User perspectives on apps for self-monitoring and control in diabetes care". Work with the project is discussed in "project seminars" at the weekend gatherings at the university. At these seminars the student present their work and discuss the challenges with other students and supervisors. The result of the project work, the project report, forms the basis for an examination that takes place at the university as an oral presentation and discussion between the students, the teachers, and the external examiner.

	1. Year	ECTS
	Introduction to problem-based learning	5
	Health informatics from an analytical perspective	10
Courses	Data flow and quality	5
	Implementation and usability	5
	Technological and organizational changes	5
	2. Year	
	Health Informatics from a design and/or implementation perspective	15
Courses	Clinical databases and decision support	5
	User driven innovation and patient empowerment	5
	Management, quality improvement and evaluation	5

Table 1: study activities at the master program in Health Informatics at Aalborg University

More information on the master's program in Health Informatics at Aalborg University can be found on: **http://www.sundhedsinformatik.aau.dk/**

Ongoing revision

The educations have, as mentioned, been revised several times since 1994 both in size, content and organization. Thus the size has varied from 60 ECTS, to 90 and back to 60 ECTS again. The course content has changed from being based at a data cycle perspective to include the contextual perspectives of management, organization, implementation, and use practices. Some of the features in the development of the education have been described in [6 and 7]. The problem based, project organized learning approach is still a very important feature of the education. Development in how to frame and enacts this pedagogical model is an ongoing process for all of Aalborg University and to strengthens this process a PBL academy have been established in 2010 [8].

The ongoing revision was initiated in spring 2013 and addresses primarily the content of the courses. We conducted a series of interviews with important stakeholders in the health informatics area that is decisions makers from municipalities and regions, clinical experts, representatives from doctors and nurse's trade union, patient organizations etc. We gathered information on these people's conceptions of health informatics, and what kind of knowledge, skills and competencies students should poses. We interviewed 12 people and on this background we identified at list of keywords that could be used for revising the course content. The list of keywords included: Implementation, usability, quality assurance, patient empowerment, data quality and clinical information systems. As for now we have made a revision of the course content taking into account the ideas and opinions of the stakeholders. In the coming year we are going to teach and test the courses with the students. We also are considering developing the program into a more module-based structure making room for individual needs and a flexible cooperation with other programs. Furthermore the use practices of the learning platform need to be developed.

Future trends and challenges

In a discussion paper from 2010 Rainhold Haux reflects on medical informatics as a discipline and suggests and discusses future research directions within the field [5]. He presents two different ways of thinking in identifying important future research fields within medical informatics, the first one called the evolutionary approach, and the other one called the revolutionary approach. The evolutionary approach is based on former discussions and papers and Haux makes 10 statements that sum up the discussion of future research directions. He then sums up the evolutionary approach in 4 statements, which he uses as an outset for 16 statements hen denotes the revolutionary approach. The four central statement reads as: (a) Health has to be considered more and more as an integral and continuous part of life (not as health care within in a limited time frame of a disease episode), (b) medical informatics is addressing both health care professionals (plus their professional environment) and individual/consumers (plus their social environment), (c) the individual, the human being, is being at the center of research, even though medical though medical informatics research can range from molecules to populations, (d) research, education and practice may shift more and more from local, to global activities. [4, p. 606]

These statements, along with the idea that typical individual health problems (e.g. diabetes and COPD) that require prevention and health promotion strategies should be addressed in communities of practices, will be used as an inspiration in the further revision of the Master in Health informatics at Aalborg University.

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Aspects of Standardisation for Point-of-Care Solutions and Remote Home Monitoring Services

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Abstract

The health care services are focusing on seamless healthcare and defining typical patient flow conditions, where a close follow-up from the patient's home after hospital treatment can be important in order to avoid readmissions. In several international projects different technological solutions have been developed with the aim of obtaining an international standardized solution from end-to-end perspective in the information chain, where vital signs data are measured in the patient's home and transmitted to the hospital specialist. This is; however, a complex task without any clear recommendations, which leads to local variations in the implementations and to island solutions. The consequence will be no or limited interoperability of systems across organizations and local boundaries of services.

In this paper we will highlight different levels of standards and give some recommendations for future research, based on a typical scenario for a remote home monitoring situation.

Keywords:

Remote home monitoring, Interoperability, Standardization, Data exchange, Mobile health, Seamless healthcare.

Introduction

Remote home monitoring is a rapidly growing area, where the patient is supported to live in his own home and with daily use of necessary equipment for vital signs recording [1]. For the technical solutions to be used, this is a quite complex situation where a focus on standardization is needed in order to incorporate different medical recording devices from different vendors. This has been put into focus in several European projects with the aim of obtaining standardization both at the semantic level and at the technical levels [2].

In general, the existing solutions are mostly based on proprietary data formats and centralized servers with a typical "silo" setup for the technical solutions [9]. That means both the patient and the remote medical supervisor (e.g. at a hospital) will need to use the specific components from the same vendor. This limits the flexibility to incorporate new monitoring devices also from other vendors in cases where this can be a need based on the patient's condition.

In this paper, we will highlight the encountered problems by describing a typical user scenario. The particular challenge is that not only daily values of a single medical parameter are transmitted from the patient's home, but also Electro CardioGraphy (ECG) recordings should be transmitted on-line. In this focus, we will analyze applicable standards and explain the framework of standards for reference systems and solutions that allow realizing typical use case scenarios like the one described in this paper. As a result from that analysis we will give some recommendations for future research on deployments of point-of-care solutions and cloud-based system integration into electronic health records (EHR), .and on related standardization.

Materials and Methods

Description of a typical user scenario

In order to give recommendations for an end-to-end system design, we will focus on a typical home care scenario involving different use of vital signs monitoring solutions. As the first step, a patient suffering from cardiac heart failure (CHF) is recommended to perform a daily recording of the pulse and oxygen saturation in blood, using a standard pulse oximetry device. If the recorded pulse rate is above a defined threshold, the patient should put on electrodes connected to a device for performing an ECG recording. All data measured by the patient at home will be transmitted to a secured database containing a Personal Electronic Health Record (PEHR). From this database the doctor will have secured access to retrieve the recorded information, in order to be displayed on his computer for diagnostic purposes. Such a system can be implemented according to the overview shown in Figure 1.

The tablet device carries out different essential functionalities which are required for the remote monitoring user scenario:

- Different types of medical devices (as the pulse oximetry device and the ECG device in the described scenario) are connected through a wireless nearfield connection (as e.g. Bluetooth) with the tablet. The data carrying the information about the measured vital signs are transmitted through this link, and are stored in a local storage on the tablet devices.
- The tablet device establishes a communication link with the secured PEHR storage system, where the personal vital signs data is stored and made available to medical service providers. This can be e.g. general practitioners or specialized doctors at hospitals. The communication link can either utilize the inbuilt Wireless LAN capabilities, or cellular communication capabilities. The data transfer shall not be restricted to a single, proprietary

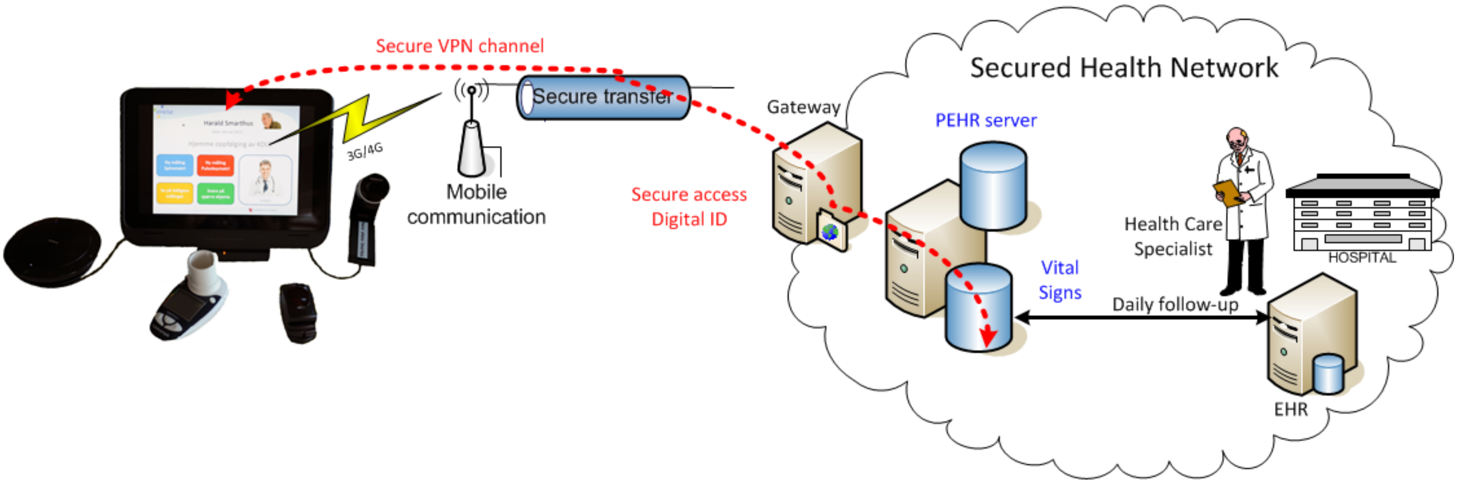

Figure 1- Overview of an end-to-end remote monitoring solution, where the monitoring devices are connected to a patient's tablet for secure upload into a PEHR from where the health care specialist can retrieve the actual data.

PEHR system from a specific vendor. In order to protect the privacy concerns of the patient, the remote monitoring data shall be encrypted prior to transmission, and corresponding access control mechanisms shall allow only the intended doctor to get access to the data through his remote diagnosis appliances. This has to be implemented according to the legal constrains for access, storage and distribution of sensitive medical information, which might differ from country to country.

- A user interface (UI) is presented in order to support all required interactions of the system with the user during the measurement and monitoring session. Part of those interactions is the identification and secured authentication of the user, in order to confirm the relation of the measured data and the individual patient.

In a nutshell, the tablet device takes data from connected local devices and transmits those data together with the authenticated identity of the patient over an encrypted link to a remote storage system. As such it carries out the role of a personal communication gateway between the local devices and the remote PEHR storage system.

All these functionalities are realized as software running on the tablet device. From an interoperability perspective it shall be possible to run the software also on other tablet PCs or even desktop PC hardware without restriction to a single specific device model or vendor.

Interoperability and Standardization

In order to connect a plurality of medical devices from different vendors, there will be a need of standardization, both at the patient's side and at the doctor's side. At the same time, the transportation layer with necessary security precautions will have a need for standardization, and the stored measurements in a PEHR should be according to standardized formats.

Interoperability of complex systems requires standardization on different levels. Braa and Sundeep ([12], based on [13]) have described three levels of interoperability and standardization, spanning from an "organizational / political / pragmatic" perspective of interoperability via a "semantic level" down to a "syntactic / technical level". The EU-project HITCH [14] describes a similar four-level model of interoperability, covering:

- Organizational/political level, addressing the continuity and quality of the exchange of medical information,
- Application/software level, addressing the interoperability between patients and clinics/doctors with regards to software functionality and presentation of information,
- Logical level, addressing the semantic interoperability in terms of medical content and terminology,
- Technical level, looking at data formats and transmission protocols.

We do not address organizational and political aspects of interoperability in this paper.

Subsequently a selection of standards on the logical level is listed that are relevant for the discussed use case scenario. Then it will be explained how existing standards on technical level are utilized, and finally a number of interoperability challenges on application and software level will be discussed.

Pulse oximetry data formats

For a pulse oximetry recording scenario (Figure 1), the patient will put his recording device on to a finger, and automatically the device will start recording both the value of pulse rate, given as an ASCII value, and the measured level of oxygen concentration in blood given by another ASCII value. This device can be connected to an Android based tablet device by a Bluetooth connection, in order to wirelessly transfer the measured values to a typical portable device.

A dedicated application on the tablet device will receive the measured values together with a time stamp and an ID-code identifying the device. The international standard IEEE 11073-10404 is specifying the data exchange between the personal health device, i.e. the pulse oximetry device, and the hosting device, which is the actual tablet device enhanced with dedicated software.

ECG recordings and formats

From a wearable device ECG signals can be sampled for each of the leads used (normally 3-12 leads), and stored as a file containing a sequence of ECG data sampled for a certain duration of time. In order to later on interpret the actual recordings, the presentation software on the receiving device will need to know the parameters used by the recording device. This would be the sampling speed (normally 250 Hz or more), the signal resolution given by µV/bit, the number of leads used etc.

Those parameters will normally be stored in the file, so that the viewer application can correctly read the file content and display the ECG data as waveform time series signal.

There are several international standards describing ECG formats [3]-[5], and also for remote home monitoring purposes. This can give challenges as there exist today only few solutions for converting ECG recordings between the different formats.

SCP-ECG is based on a European initiative from the Open ECG project[1], and is adopted by the international standard ISO/DIS 11073-91064:2009 which describes the interchange format and messaging procedures. This standard describes binary files for storing the actual samples, and in order to obtain a compact file structure, a data compression method based on Huffman encoding is used. This requires some processing capacity of the mobile devices; however, this format is very suitable to be used for mobile solutions and remote monitoring purposes.

Medical Waveform Format (MFER) is accepted as an international standard, ISO/TS 11073-92001:2007 [6]. This standard is based on a Japanese initiative in the MFER committee, where the aim was to develop a universal standard description format for medical waveforms in general. This format is also using a binary file format, without any compression methods, but with a compact file header structure. Also this standard is suitable to be used for wireless solutions and remote monitoring purposes.

HL7 Annotated ECG (aECG) is an XML-based format for storing and retrieving of ECG recordings [7]. This format was developed based on the FDA´s digital initiative from 2001, and is published as ANSI/HL7 V3 ECG, R1-2004[2]. Based on the nature of XML-files, this ECG recording format is quite complex and contains huge amount of descriptive data compared to the amount of sampled ECG data. For wireless and mobile purposes, this format will hardly be used.

Digital Imaging and Communications in Medicine (DICOM) is a standard defined for storing, printing and transmission of information [8] related to medical imaging. Thus DICOM files can be exchanged between two entities and the supplement 30 was introduced to store medical waveforms together with images. DICOM was published in 1993, and accepted as a standard in 1995 (MEDICOM, ENV 12052)[3]. Because of the relationship to DICOM SOP-classes, the file structure is quite complex, and is difficult to use in a wireless mobile service. Thus it seems natural to store ECG recordings in the DICOM format only if the recordings are obtained in connections with medical images.

Information Integration Platform

To avoid "silo" integration and to promote reusability of information gathered/measured from medical devices by different applications/services, a broker between the two entities is needed. Publish/subscribe messaging pattern is suitable for such a broker which enables different applications/services to be notified of new information without having to repeatedly request updates from the information source.

The publish/subscribe messaging pattern was introduced more than a decade ago. It is still considered to be one of the most important communications mechanisms as it is well adapted for the loosely coupled nature of distributed interactions in large-scale applications. Subscribers have the ability to express their interest in an event or information update, and are subsequently notified of any event which is generated by a publisher and matches their registered interest [10]. This complies with an event-driven architecture where an event is asynchronously propagated to all subscribers. Different applications/services can make use of the information being sent from medical devices to the broker. This type of broker acts as an information integration platform [15]. Such platforms commonly use a store-and-forward approach underneath their publish/subscribe implementation, where the platform will also store information from medical devices and forwards them to subscribed applications/services. Figure 2 shows the general concept of an information integration platform.

From standardization standpoint, at least two aspects should be considered related to the interfaces between the platform and information providers (e.g. devices), as well as between the platform and information consumers (e.g. applications/services).

Firstly, the communications protocol is very important as the platform is intended to become a "relay" between two communicating entities. Existing mature standards should be utilized as it will make the platform easier to be adopted by different applications/services. One proposed application layer protocol for communication is HTTP/HTTPS, as it is widely used by a myriad of services on the Internet. Combined with REST architectural style [11], the HTTP/HTTPS protocol can become the prime choice for disseminating information in healthcare services.

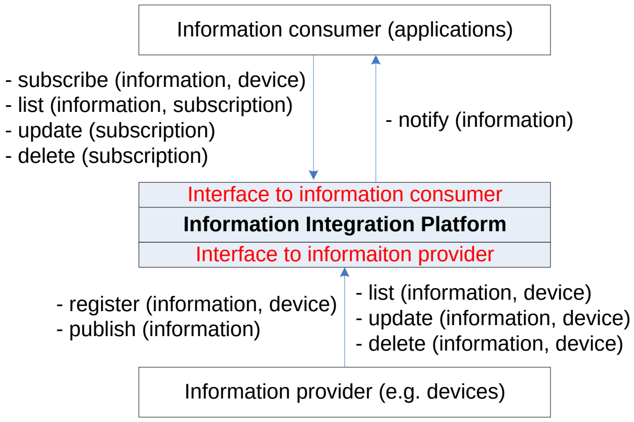

Figure 2- Information integration platform architecture

Secondly, the format and content of the messages being exchanged should also follow well-known standards. Within the healthcare domain, HL7 v3 messaging has a strong position to be adopted as it is implemented by many healthcare providers, utilizing XML encoding. However, this standard is specifically designed for health-related information. Thus, if the platform is aimed to handle information beyond health, a separate HL7 adapter is a good option to be considered. This is of particular importance when novel services are about to be developed and integrated that require more information (e.g. ambient information) than the ones supported by HL7.

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[1] http://www.openecg.net/

[2] http://www.hl7.org/documentcenter/public_temp_1179111A-1C23-BA17-0C3C1DA290147323/wg/rcrim/annecg/aECG%20Implementation%20Guide%202005-03-21%20final%203.pdf

[3] http://dicom.offis.de/dcmintro.php.en

When focusing on publishing/subscribing of vital signs recordings, there are developed methods for using HL7 v3 exchange of messages (based on XML), where both the MFER [16] and SCP-ECG binary formats [17] can be used.

The IIP is a typical example for a cloud-based solution, with the information broker together with the EHR/PHR storage being deployed in the Internet service cloud. Commercial solutions as Telenor Shepherd [18], Microsoft HealthVault [19], and the Caradigm Intelligence Platform [20] (formerly Amalga) also follow the cloud-based solution approach,

Presentation of vital signs information

The remote diagnosis appliance at the doctor shall be able to present the measured vital signs data of the patient as illustrated in Figure 3.

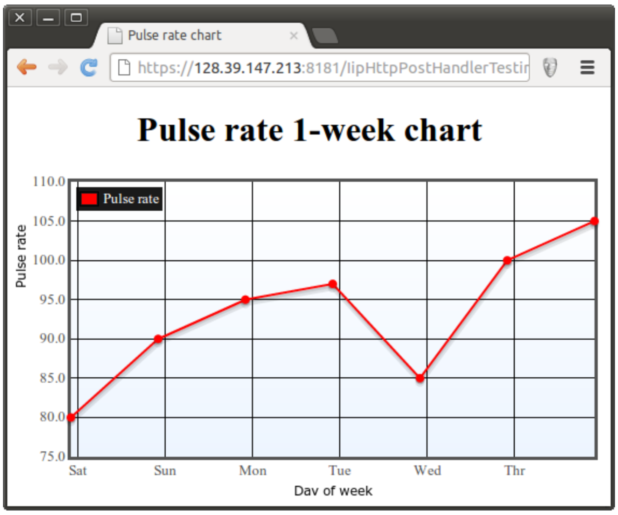


Figure 3- Pulse rate histogram (sample from prototype appliance)

In order to do so, the software must support the same protocols for authentication and encryption as the PEHR storage system. Further on it must support the same syntactic as the PEHR system for the data exchange, and the same semantics as the medical devices in order to be able to interpret and display the measured data correctly.

Similar to the display of the patient's pulse rate, the prototype of a Web based renderer of the remotely measured vital signs will also render ECG data.

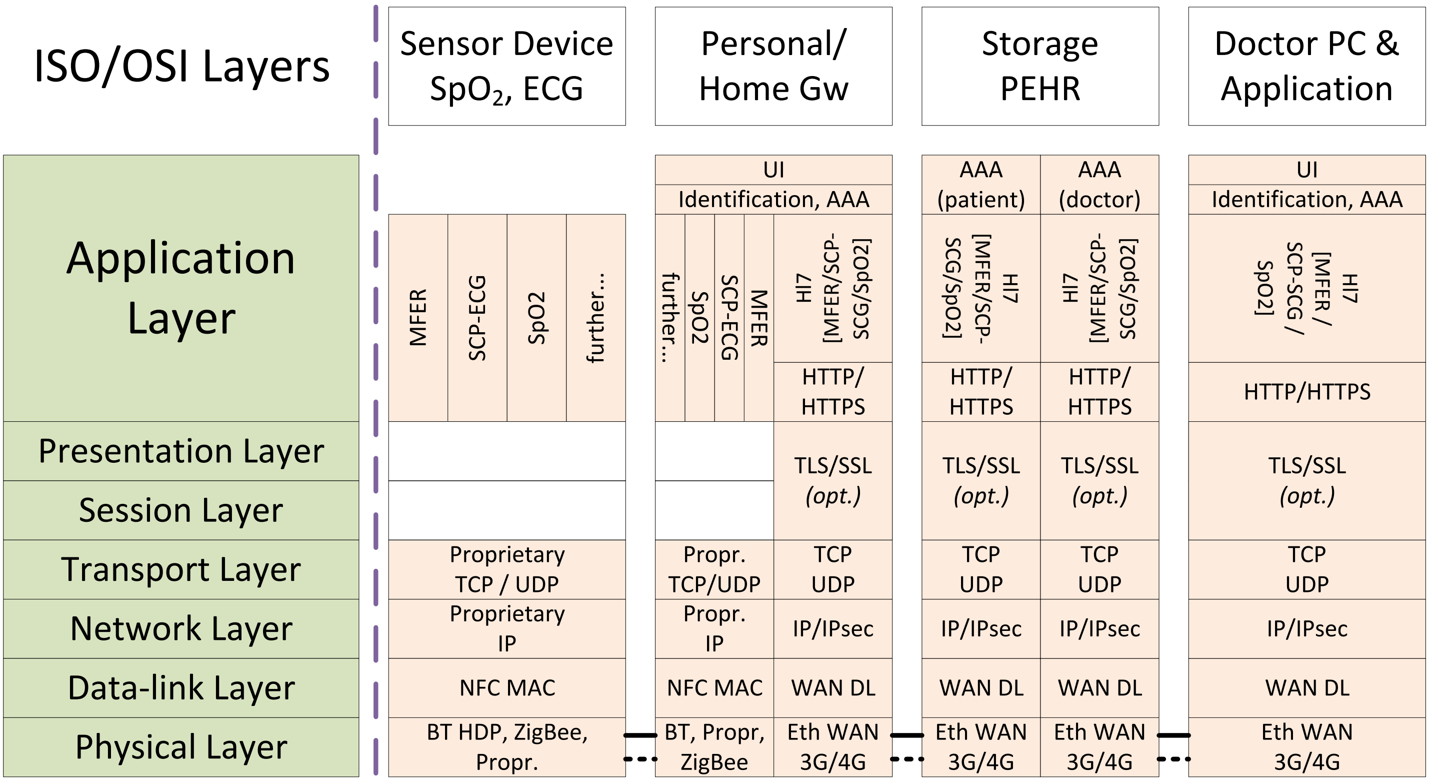
End-to-end perspective

The transmission of arbitrary data containers through a communication infrastructure is covered by standardized protocols corresponding to the ISO/OSI model. This includes protocols for the secure authentication and for the encryption/decryption of the data. The logical sequence of functionalities for a specific use case scenario takes place on the *Application Layer*. A simplified view on the end-to-end protocol stack for the remote diagnosis scenario as described above is presented in Figure 4. Focus is put on the main devices and the main functionalities involved in the described scenario (i.e. SpO_2 and ECG devices, personal gateway, PEHR storage system, remote diagnosis appliance at doctor).

Integration into existing EHR systems

If the existing EHR system is a proprietary closed system, there's no straight-forward possibility for the integration of the solution for the remote diagnosis scenario. If the existing EHR system otherwise provides an interface supporting any standard on semantic or syntactic level, the integration with the remote diagnosis system is possible by utilizing transformation of content and protocols between the different source and destination standards. This can be carried out by a broker as the IIP, as explained above.

Proof-of-Concept prototype



ISO/OSI Layers	Sensor Device SpO_2, ECG	Personal/ Home Gw		Storage PEHR		Doctor PC & Application
Application Layer	MFER SCP-ECG SpO2 further...	UI Identification, AAA further... SpO2 SCP-ECG MFER	Hl7 [MFER/SCP-SCG/SpO2] HTTP/ HTTPS	AAA (patient) Hl7 [MFER/SCP-SCG/SpO2] HTTP/ HTTPS	AAA (doctor) Hl7 [MFER/SCP-SCG/SpO2] HTTP/ HTTPS	UI Identification, AAA Hl7 [MFER / SCP-SCG / SpO2] HTTP/HTTPS
Presentation Layer			TLS/SSL (opt.)	TLS/SSL (opt.)	TLS/SSL (opt.)	TLS/SSL (opt.)
Session Layer						
Transport Layer	Proprietary TCP / UDP	Propr. TCP/UDP	TCP UDP	TCP UDP	TCP UDP	TCP UDP
Network Layer	Proprietary IP	Propr. IP	IP/IPsec	IP/IPsec	IP/IPsec	IP/IPsec
Data-link Layer	NFC MAC	NFC MAC	WAN DL	WAN DL	WAN DL	WAN DL
Physical Layer	BT HDP, ZigBee, Propr.	BT, Propr, ZigBee	Eth WAN 3G/4G	Eth WAN 3G/4G	Eth WAN 3G/4G	Eth WAN 3G/4G

Figure 4- Overview of protocol stacks

An end-to-end prototype system has been implemented covering the described use scenario and following the overview illustrated in Figure 1. It integrates off-the-shelf medical devices from different vendors, an Information Integration Platform (IIP) based on open standards (covering also the functionality of a PEHR system), and a Web based demonstration client for the access to and display of remote diagnostics data for e.g. a doctor. It proofs that a system with data access, transmission and storage based on open and flexible standards allows addressing the requirements of specific end-to-end use scenarios. Different interoperability requirements along corresponding interoperability levels can be addressed by flexible adaptation of data structures and interfaces, in particular looking at the semantics of the specific medical data, syntactic and data formats for the data exchange and storage, as well as protocols for the exchange of arbitrary data structures through a multitude of communication networks involved in the end-to-end scenario.

Results

Overview of eHealth related standards

Looking at the ISO/OSI model, the exchange of medical data utilizes known communication standards on layers 1-4 (see Figure 4), so no eHealth specific standardization is required for the transmission of medical data through an Internet-based network infrastructure. However, various standardization bodies specify different aspects of the communication of medical information, which all find their implementation in the *Application Layer* according to the ISO/OSI model. Due to the tight relation between device hardware, medical content and communication technology, a few standardization bodies (as e.g. the Continua Alliance) specify Personal Medical Devices (PMD) or Personal Health Devices (PHD), covering aspects of the communication with the personal gateway on all ISO/OSI layers in a vertical manner.

Table 1- Overview of eHealth standards

Logical level Semantics, Terminology	ICD-10	Snomed CT (IHTSDO)	DICOM	LOINC
Technical level Messaging	HL7 v2.x	CEN EN 13606 (CEN TC251 Health informatics)	HL7 v3 /w CDA incl. MFER	OpenEHR Foundation
	IHE-XDS (Cross Document Sharing)	IHE-RID (Retrieve Information for Display)	DICOM-SR (Structured Reporting)	OpenMRS Community
Protocols	ITU-T/SG 16 (Multimedia Systems)	ASTM F2761 –ICE (Integrating the Clinical Environment)	ISO/IEEE 11073 PHD / POC - SCP-ECG, SpO2 BT HD Profile USB PHD Class Serial, IrDA, LAN, PAN	Health Care and Life Sciences
Devices, Systems, Platforms	ISO TC215 (Health Informatics)	IEC/TC 62 (Medical Devices)		IHE-PCD (Patient Care Device)

A (non-complete) overview of eHealth related standards and standardization bodies is shown in Table 1.

Evaluation of standards

Communication protocols will take care for the transport of arbitrary medical and health care related data by means of containers that are encapsulated in messages, which are carried then to the destination equipment. This includes specific protocols for encrypted transmission, as e.g. IPsec and TLS/SSL. Other security related issues like identification, authentication and access control are supported by corresponding application layer protocols (as e.g. HTTPS), and have not to be covered in eHealth standards (Table 1).

eHealth specific application layer standards will include the actual vital signs recordings. For wireless mobile recording purposes, there are two actual ECG formats defined as international standards that can be used; SCP-ECG and MFER. In order to combine several recording devices as in this case both pulseoxymetry and ECG recordings, the MFER format can be used in both cases as this is a general encoding format for medical waveforms. In the header specifications, the actual recordings will be specified; thus by specifying a simple one-time measurement containing two parameters each with a single value will be possible. This opens for defining a common standard recommended for remote monitoring purposes. If future patient set-ups will require more devices for measurements of other vital signs parameters, this can be combined by a proper software application at the patient’s personal tablet solution.

For the receiving partner, as in this case the doctor, such a set-up will only require that he has available suitable vital signs viewer solutions. Already there are free available open source viewers that can be used for both of the formats SCP-ECG[4] and MFER[5,6]. However, there exist today no free viewer that can be able to open and display both of the formats, and this will be a challenge for future development.

Future direction and recommendations

Most required standardization aspects for the described scenarios (remote diagnosis of SpO2 and ECG measurements) are addressed on different standardization levels by corresponding standardization bodies. They span from platform aspects of EHR systems and

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[4] https://play.google.com/store/apps/details?id=org.sribog.ecg

[5] http://ecg.heart.or.jp/En/DownLoad.htm

[6] http://cardiocurves.sourceforge.net/index.html

medical devices, via protocols and message contents and formats for the communication between the involved eHealth parties, up to the semantics of the medical and care related data to be communicated, stored and presented.

Also dedicated standards exist for various security aspects of the data communication in general, which are also applicable for the communication of eHealth data in particular, covering different technologies for encryption and access control.

What is missing are clear interoperability guidelines for the development and compliancy testing of complete end-to-end scenarios, in order to facilitate that medical devices from different vendors can work smoothly together with EHR storage systems from different vendors and also with devices and software solutions for the medical service providers as doctors and hospitals.

Standardization bodies to be addressed

About 10 years ago the entertainment industry has founded the Digital Living Network Alliance (DLNA), which standardizes guidelines focusing on the interoperability between networked entertainment and media devices that involve digital content in form of images, audio and video. Analog to that, clear interoperability guidelines should be developed and specified for the interoperability of networked eHealth devices, appliances, and software components. For that a standardization body or dedicated interoperability organization with a holistic view on end-to-end scenarios involving eHealth devices and appliances is required.

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Ten Lessons for Successful Implementation of Telemedicine Services in North Norway

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Abstract

North Norway has been a world-leading area in the use of telemedicine services. Since the first telemedicine services were established in the late 1980ies, telemedicine and e-health services have been established in many areas of specialist health care. The goal has been to provide specialist health care to people living in rural and very remote areas. Success factors for this development are summarized in ten lessons learned: (1) Strong governmental involvement through National plans; (2) Access to a secure communication infrastructure; (3) Mandatory use of standards; (4) Implementation of Electronic Health Record (EHR); (5) Laws adapted to the modern way of working; (6) Reimbursement must be in place for telemedicine services; (7) Videoconference is often the best solution; (8) Management and support is essential; (9) KISS - Keep it simple, stupid; and, (10) Electronic messages for high volumes.

Keywords:

Telemedicine, telehealth, e-health.

Introduction

North Norway has been a pioneer region for the use of telemedicine in rural areas. With a scattered population, severe weather conditions in the wintertime, and specialist health care service in two regional centres only; telemedicine services have been an important part of health care in this area. The first telemedicine services were established in the late 1980ies. These included teledermatology, telepathology, teleotorhinolaryngology and teleradiology. These were soon followed by teleophthalmology, telecardiology, teledialysis, teleobstetrics, teleemergency service, teleoncology, eleodontology, telegeriatric, teleendocrinology, telepsychiatry, maritime telemedicine, teleeducation and telecare. In the beginning, only videoconference systems were used. Gradually store and forwards solutions became the preferred communication channel. However, in recent years we have experienced an increased use of videoconferences. Electronic messages became the preferred format for referrals and discharge letters, lab reports and lab answers, and for communication between health care professionals.

Fifteen years after the first services were initiated, the Norwegian Centre for Telemedicine (NST) at University Hospital of North Norway (UNN), had become the world largest centre for telemedicine and had established telemedicine services within the most suitable areas for telemedicine. In 2002, NST was appointed as WHO collaboration centre for telemedicine. Since the majority of NST publications were published in Norwegian only, telemedicine experiences from North Norway were only available for the Scandinavian population. Thus, twenty years of knowledge of telemedicine service in rural, and often resource poor, areas, are not widely known. This paper introduces some of the large quantities of knowledge about telemedicine services in North Norway that has not been accessible to a non-Norwegian reading audience. We present the ten most important lessons learned for successful establishment of telemedicine services in rural, and often resource poor, areas.

Materials and Methods

The guidelines presented in this paper are the results of studies of papers and reports on implementation of telemedicine services in North Norway during the last 20-25 years [1-12].

Compared to the number of reports and publications published by the Norwegian Centre for Integrated Care and Telemedicine at University Hospital of North Norway, only a small number of publications have been written in English. The majority are published in Norwegian. A list of papers and reports can be found at www.telemed.no

Studies of the use of telemedicine in North Norway

A limited number of attempts to present the experiences from telemedicine services in North Norway have been published, including [1-12].

In June 2005, Northern Norway Regional Health Authority (Helse Nord RHF) established a working group of senior doctors and health executives that performed a systematic evaluation of which of the tested and suitable telemedicine services in North Norway should be selected for large-scale implementation [10]. After an examination of the different telemedicine projects, the group organised its recommendation into four groups in accordance with priority [10]: (1) *Must be implemented:* Teleradiology (incl. solutions for neurosurgery, orthopaedic, different kinds of surgery, nuclear medicine, acute traumatic and oncology, digital communication and integration of patient data, and distant education; (2) *Should be implemented:* Teledialysis, pre-hospital thrombolysis, telepsychiatry, and teledermatology; (3) *May be implemented:* Paediatrics, district medical centre (DMC), teleophthalmology and teleotorhinolaryngology; and, (4) *Not recommended.*

Johnsen et al. [7] describe and systemize documented benefits for Norwegian health services of telemedical services and projects. The authors reviewed all relevant projects and services and available documentation of both economic and qualitative benefits. The authors identified 29 studies that described qualitative profits. They divide the qualitative profits in three main categories: (1) Electronic health records (EHR) and electronic messages, (2) discipline-specific solutions and (3) patient-oriented solutions.

In the first group, electronic patient records (EPR) and electronic messages, the authors found improved integration between EPRs and electronic information exchanged between primary and specialist health services. In this way, institutions avoid duplicating tasks and there are fewer errors made in recording patient information. The authors report that: "In general practitioners offices (GP-offices), EPRs have contributed to the re-deployment of resources – among other things, medical secretaries have been delegated more interesting duties. In the nursing and care services, mobile EPRs for nursing and care documentation have contributed to simpler routines and fully up- dated records and to faster communication with the outside world."

In the second group, discipline-specific services, the authors identified improved knowledge for health personnel, which improved patient treatment, e.g., in teledermatology. In addition, the selection process for dermatology patients requiring hospital treatment was improved. For teledialysis, a higher level of care quality was experienced. By the use of teleradiology, patient travels were reduced. For emergency medicine, the authors report that the solution for acute heart problems saves time and the benefits increase in step with the travelling time to hospital.

In the third group, patient-oriented solutions, telemedicine resulted in increased patient empowerment. [12] Johnsen et al. [7] that: "The benefits show as greater openness regarding illness and in some cases it is easier to discuss sensitive issues "online" than face-to-face. E-mail between patients and GPs seem to lead to a relationship of trust between the patient and health service personnel, as well as replacing a number of consultations and telephone enquiries."

In the following, the most important lessons learned from the publications and reports from NST are discussed.

Ten lessons for successful implementation of telemedicine services

Implementation of telemedicine services in North Norway has been a process of trial and error. Some errors have been inevitable; others could have been prevented had proper knowledge been available. Based on the experience of more than twenty years of telemedicine services, we have proposed ten advises anyone planning to implement telemedicine services should consider. These are presented below.

Lesson 1: Strong governmental involvement through national plans.

Since 1997 there have been several national plans that have had an impacted on the development of telemedicine and e-health in Norway, including "More health for each bIT" (1997), "*Say @h!*" (2001), and "Te@mwork 2007" (2004). The strategy documents communicate the expectations of positive effects of the technology, both in regard to efficiency and quality. Normann et al. [12] recommend to initiate a national effort to develop a methodology for the implementation of telemedicine.

Lesson 2: Access to a secure communication infrastructure.

Norway has a well-functioning and well-structured public health service with a strong infrastructure and a high level of competence. The backbone of telemedicine and e-health in Norway is the Norwegian Healthnet. This computer network is, together with the electronic health record (EHR), prerequisites for telemedicine and other e-health services.

Lesson 3: Mandatory use of standards.

One of the problems with introduction of teleradiology was the lack of use of the DICOM standard. The radiology department at UNN had to convince the vendors of PACS systems to support most part of the DICOM standards in order to achieve interoperability. A lesson learned is that it is necessary to change the governmental messages on the implementation of standards from "ought to" to "must".

Lesson 4: Implementation of Electronic Health Record (EHR).

The implementation of Electronic Health Record (EHR) is very good, but there is still some work to do on interoperability. For many years, almost 100 % of the GPs have used EHR for their documentation of patient's information. At the hospital side, 100 % of the hospitals are using an EHR from two different vendors. Both the hospitals and the GPs have been busy thinking of their in house need for documentation of their own work than the possibility of sharing the same information electronically between them when patients are refereed from the GP to the hospital or when the patients are refereed between hospitals. For many telemedicine services, EHR integration is a key success factor.

Lesson 5: Laws adapted to the modern way of working.

When legal issues are concerned, privacy, confidentiality and data security stand out as some of the most important in the whole area of telemedicine and e-health. Nohr et al. [13] argue that most of the large amount of heterogeneous information generated in health care is considered sensitive. All relationships in health care are based on trust and at the basic principle is confidentiality. All health care personnel are dependent on the information provided by the patient and the patient must trust that the health care personnel treat the information given as confidential. Normann et al. [12] argue that prioritization and implementation of telemedicine services require thorough analysis and assessment of legal and security aspects.

Lesson 6: Reimbursement must be in place for telemedicine services.

The issue of reimbursement of telemedicine and e-health services has, for many years, been high up on the international agenda, so also in Norway. The issue of reimbursement is closely linked to the notions of cost effectiveness, return of investment (ROI) and cost benefit. Another aspect of this discussion has been to discuss quality of services instead of ROI. Without reimbursement, no sustainable telemedicine services. The first telemedicine fees in Norway were introduced in August 1996. This made Norway become the first country to implement an official telemedicine fee schedule making all telemedicine services reimbursable by the national health insurer.

Lesson 7: Videoconference is often the best solution.

Most of the videoconference (VC) activity is in North Norway. Helse Finnmark alone uses 1/3 of the traffic in the Norwegian Healthnet (1,5% of the population). All hospitals in North Norway use VC. The biggest users are the clinics. The success factor is that VC has become a natural part of the work to doctors, psychologists, nurses, etc. The use of VC in education has been very important for the development health services in North Norway. It is expected that PC-based VC solutions will improve the use of VC even more.

In recent years there have been several successful research attempts to bring video conferencing solutions in emergency situations in order provide expertise where the acute hospital is located. Smaller hospitals and health institutions often have limited emergency medical skills. In order to make emergency medical expertise available in emergency situations started the NST, with Acute Unit at University Hospital and Longyearbyen hospital project based videoconferencing acute medical conference (VAKe) [14]. The project had as purpose to make emergency medical expertise available at the local hospital.

Normann et al. [12] argue that we should increase the use of videoconferencing for clinical, educational and administrative purposes: "Videoconferencing can be used as a collaborative tool for outpatient consultations, before admission to treatment, ensuring quicker discharge from hospital, as well as teaching and supervision of primary health care."

Lesson 8: Management and support is essential.

Many enthusiastic supporters of telemedicine and e-health solutions experience difficulties in moving from the initial project phase onto the implementation and operation phase. NST has suggested the following "get started list" to motivate the users [10, 12]: (1) Establish support team / super users; (2) The responsibility for the equipment must be clearly identified; (3) Establish proper facilities for training, client participation, and codetermination; (4) Provide up-to-date equipment; (5) The system must be customer-oriented; and, (6) Continuous operation must be ensured.

Lesson 9: KISS - Keep it simple, stupid.

The design principle from the U.S. Navy is valid for telemedicine, as well. This regards both the use of simple technology and simple user interface. An example of the first is the teledermatology services for eczema and ulcer treatment in which low-cost digital cameras are used [15]. An example of simple user interface can be found in the VAKe system for acute medical videoconference. The system makes emergency medical expertise available at the local hospital. A major design goal was to establish the connection by pushing only one button [14]. For teledialysis, one of the basic recommendations for implementation of the service is to "establish a service which is simple as possible, both technically and in relation to costs (depending on what you want to achieve)" [16].

Lesson 10: Electronic messages for high volumes.

Electronic messages are sent through the Norwegian Healthnet. Together with the EHR providers, a number of standardized messages that can be sent between health care personnel in the health net have been developed. The messages have been formed in a way such that they can be sent from one patient journal to another journal. The goal is to provide faster and more secure communication within the health care sector, while improving the documentation quality. In January 2013, more that 9 million messages were sent through the Norwegian Healthnet each month. Normann et al. [12] recommend to strengthen the national initiative on electronic messages.

Concluding remarks

North Norway has established a suitable infrastructure for the use of telemedicine services: All primary care physicians, all municipal nursing and care services, and all health authorities are using EHR; Referrals, discharge letters, requisitions, laboratory and X-ray responses are sent electronically between GPs, hospitals and care facilities; and, All health authorities, hospitals, an many health institutions, are involved.

UNN has figured out that around 7,000 consultations each year can be replaced by videoconferences. UNN's vision is that it must be as natural to get into the consulting room through the PC or videoconferencing (VC) equipment than through the door. To do this, VC equipment must be in place in all outpatient clinics' rooms. In addition, the VC equipment will be used for educational purposes and meetings.

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International Master's Program in Telemedicine and E-health at University of Tromsø

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Abstract

In autumn 2005, the University of Tromsø started a 2-year master of science in telemedicine and e-health. Students can choose between technology and health, and the program starts each fall. The program is developed and run in close collaboration between the University of Tromsø and the Norwegian Centre for Integrated Care and Telemedicine (NST). The idea behind the development and implementation of telemedicine is to move information instead of patients and reduce the growing burden on health care. Master's degree in Telemedicine and e-health provides a thorough introduction to medical technology, how health care is organized and how best to introduce telemedicine to provide better services to patients. The teaching language is English. Teaching is a mixture of lectures and group work. All students write a final thesis.

Keywords:

International master's program, telemedicine, e-health

Introduction

The development of telemedicine in North Norway started with the foundation of an office to the Norwegian Telecommunication Administration's research department in Tromsø in 1988. The task was among others to improve access to specialist healthcare to rural areas in North Norway through the use of telecommunication. The activity was done in close collaboration with among others medical doctors at the University Hospital of North Norway (UNN). Gradually, the activity grew into a separate department at UNN, which today is known as the Norwegian Centre for Integrated Care and Telemedicine (NST).

In 1997, the Department of Computer Science, University of Tromsø, established a research group in medical informatics and telemedicine. The Department has in this time initiated and / or been involved in several research projects in this area. Most of the projects have been carried out in collaboration with researchers at NST and UNN. Since 1997, more than 40 MSc students have worked on issues in medical informatics and telemedicine.

In 1999, a committee was appointed at the Faculty of Medicine. The committee was asked to answer whether it was doable and desired to establish a master's program in telemedicine at the university. The committee, chaired by professor Toralf Hasvold, answered "yes" to both questions. In 2005, the first international students were accepted in the International master's program in telemedicine and e-health. This paper presents the study program and discusses problems and challenges related to this program.

Materials and Methods

Among the background documents for the curriculum work was an earlier version of IMIA's "Recommendations of the International Medical Informatics Association (IMIA) on Education in Biomedical and Health Informatics" [1]. This document also provides an overview of major publications on competencies in biomedical and health informatics.

The MSc program in telemedicine and e-health

The Master's program in Telemedicine and e-health offers two different track – in technology and health [2]. The Faculty of Science and Technology is responsibility for the "Technology" track and the Faculty of Health Sciences is responsible for the "Health" track. The study program is monitored and administrated by an inter-faculty program board. The master's program is administrated by The Faculty of Health Sciences.

Objectives

The master's program's main objective is to provide healthcare professionals and technologists with further training in telemedicine and e-health, i.e., medical practice at a distance using communication technology [2]. In addition, the program deals with "Information and Communications Technology (ICT) processes and systems that support various health services, including those that patients can use directly." [2]. The "Health" track addresses "methodological and technological prerequisites and the associated social and organizational processes". In the "Technology" track, the students work with "various aspects in the construction of telemedicine and e-health systems".

Student profile

The "Health" track accepts "students with a bachelor's degree or the equivalent in medical/health sciences, for instance, medical doctors who have completed their education or graduates with other health-related degrees such as physiotherapy, nursing, pharmacy and radiography" [2]. The "Technology" track accepts "graduates with bachelor's degrees in computer sciences or the equivalent". Both Norwegian and international graduates in health-related disciplines and computer sciences are important target groups for the two study tracks [2].

Professional and occupational prospects

The public health service is a large and complex cooperative enterprise with increasing "need for collaboration, coordination and communication". We believe that candidates who understand both the healthcare and how technology can be used strategically to create new ways of working together will be attractive in a growing labor market that promotes technology in integrated healthcare [2]. The advantage of having the knowledge of the public health service also applies to graduates who will be responsible for design and development of telemedicine and e-health systems [2].

The master's program will qualify its graduates to [2]:

- "Promote and introduce telemedicine and e-health systems and services.

- Participate in the development of telemedicine and e-health systems and services.
- Apply telemedicine and e-health services in professional health work.
- Qualify graduates for researcher education and Ph.D. studies."

Learning Outcomes

The candidates should be able to [2]:

- "Describe the main types of telemedical applications in current use in the Norwegian health system as well as identify the primary actors.
- Understand how technology and e-health services can be exploited strategically to create new ways of working together.
- Contribute in the design, implementation and use of telemedicine and e-health systems.
- Promote and introduce telemedicine and e-health services and programs."
- Identify the conditions for successful implementation of telemedicine and e-health systems and services.
- "Apply telemedicine and e-health services in professional health work.
- The master's program will also qualify graduates for researcher education in telemedicine and e-health."

The health track

The candidates should be able to [2]:

- "Share first-hand experience regarding some telemedical applications.
- Identify potential gains, challenges and barriers related to the implementation of telemedicine and e-health in clinical practice through scientific-founded empirical work.
- Critically appraise scientific work on telemedicine and e-health.
- Design, carry through and write up a study relating to a topic within the field of telemedicine and e-health."

The technology track

The candidates should be able to [2]:

- "Contribute in the design, development and implementation of telemedicine and e-health systems and applications.
- Contribute in adaptation and maintenance of telemedicine and e-health systems and applications.
- Solve advanced problems in telemedicine and e-health experimentally through applying an engineering approach to problem solving.
- Evaluate the robustness of telemedicine and e-health services and projects."

Teaching methods

The master's program employs different teaching methods. Theories and science topics are investigated in lectures while the students are required to participate actively in group work and seminars. Teamwork includes practical problem solving, discussion of course materials and presentation of their findings in seminars [2].

The courses comprise a mixture of regular lectures and 1-2 days seminars where students must be present on campus. In addition, the students can solve online tasks via Fronter LMS (Learning Management System). Students are required to attend and participate in practical exercises, group presentations, demonstrations and laboratory exercises [2]. "In addition to lectures and seminars, visits and excursions are organized" in order to let the students see how telemedicine and e-health systems are used in real settings [2].

Forms of evaluation

Different forms of evaluation are used. Some courses end with a final written and/or oral exam [2]. Other courses require a take-home exam where students must write an essay or solving problems at home [2]. These tasks include reviewing articles and essay writing. Most of the written tasks require electronic submission in Fronter.

Course plan

The 2-year master's program starts with one year of regular courses and ends with a one-year (60 ECTS) master thesis. Based on feedback from students and faculty members, the thesis in the technology track was extended from 30 ECTS to 60 ECTS. The argumentation was to allow more interaction with physicians and other health professionals. The figures 1 and 2 present the courses in the health and technology tracks, respectively.

1 A	TLM-3010 Telemedicine Applications	TLM-3040 Electronic Patient Records – theories, concepts and practice	INF-3792 Medical Informatics
1 S	HEL-3030 International and Environmental Health	TLM-3060 Patients and the public	TLM-3070 Quantitative methodology TLM-3080
2 A	TLM-3902 Master's Thesis in Telemedicine and E-health (60 ECTS)		
2 S			

Figure 1 - List of course related to teaching semester (1st and 2nd year autumn/spring) for the health track [2].

1 A	INF-3791 Telemedicine and e-health systems	INF-3792 Medical Informatics	INF-3200 Distributed systems fundamentals
1 S	Elective subject	HEL-3030 International and Environmental Health	INF-3795 Advanced telemedicine and e-health systems
2 A	INF-3997 Master's Thesis in Telemedicine and E-health (60 ECTS)		
2 S			

Figure 2 - List of course related to teaching semester (1st and 2nd year autumn/spring) for the health track [2].

Challenges

Starting a master's program in any field is not easy. The two most important elements are faculty members and students. Today, there are two full-time faculty members in each of the tracks, which is a very low number.

The program accepts up to 10 students each year in each of the two tracks. So far, there have been vacant seats every year. This despite of the fact that we have received more than 5 times as many applicants than places in recent years. Unfortunately, most of them are not qualified to enter the program or they do not have sufficient funds to enter the country.

As for the majority of study programs in Norway, there is no tuition to be paid for the two years master's program. (All students, both national and international, receive a tuition scholarship.) The main obstacle for those who come from countries outside the European Union is that they need a bank guarantee of approximately 25.000 EURO to be allowed to enter the country. (This is a guarantee for Norwegian immigration authorities that the student is self-supported during the stay in Norway.) Every year, 1-2 students have received a scholarship from the university. The scholarship is approximately 25.000 EURO, which is sufficient to be able to stay two years in Norway.

The telemedicine and e-health program can be classified as an inter-professional education (IPE) program. IPE has been defined as "occasions when two or more professions learn from and about each other to improve collaboration and the quality of care" [3]. As a multi-disciplinary program, the telemedicine and e-health program aims at teaching the students of the two fields to collaborate on developing future health services for the benefit of future patients. The increasing use of communication technology within the health service underpins the need for the education program. Also, the need for improved collaborations between the two fields is necessary as recent reports of a general tendency of dis-satisfaction among health personnel with the IT systems [4]. This tendency raises the need to improve both the IT tools and the collaborations skills of the professions. This tendency may also be met by including medical informatics, telemedicine and e-health topics in the education program of the health professions, as recommended by IMIA [1]. As other IPE programs, we face the traditional challenges, identified by others [5,6]. In particular building the capacity to offer new courses, use up-to-date education methods and tools and cover relevant and needed research areas.

Results

In 2005 the University of Tromsø started a two-year international Master's program in telemedicine and e-health. The program has two specializations within, respectively, technology and health. Every year, up to 20 students are accepted. Students come from all over the world. The motivation for starting this program was the tremendous efforts at the Norwegian Centre for Integrated Care and Telemedicine to spread telemedicine in Northern Norway, and later also internationally. With this in mind, University of Tromsø decided to help develop the subject in a more academic direction, while retaining the close links to the telemedicine community at NST and the rest of the University Hospital of North Norway.

Students attending the technology track work both experimentally and theoretically with systems in telemedicine and e-health. In addition to studying existing solutions, the students get experimental experience in designing what we think will be tomorrow's telemedicine and e-health systems. Many of the students contribute to the ongoing research in the field. Some of them also write scholarly articles. In April 2013, for example, a second-year student traveled to Paris to present what she was doing in mobile games for children and adolescents with type 1 diabetes. During the summer of 2011, two of our students spent 3 months in Nice in France where they participated in IBM eXtreme Blue program together with three students from France. They developed an application for electronic disease surveillance, modeled after one of our research projects. The student group was among the best groups of students in the international competition.

Many of the student projects carried out in collaboration with researchers and developers at NST. Students sit in the locality of NST during the study. Most students also spend the last year of the NST premises where they are working on their thesis.

IT in healthcare is one of the fastest growing areas internationally. This is an independent economic sector. The need for expertise in this area is universal, as is knowledge. If an approach works in Norway, it also works in most other countries where the infrastructure is in place. In addition, it is a very exciting area. Most of our graduates are working in Norway. They are working with consulting, development and operation of health-related IT systems. Several have continued with doctoral studies in telemedicine and e-health. Some of our international students are working as advisors for their respective health authorities.

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Constructive Technology Assessment for HIT development: Learning, feedback and user involvement

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Abstract

Experience and time has shown a need for new evaluation methods for evaluating Health Information Technology (HIT), as summative evaluation methods fail to accommodate the rapid and constant changes in HIT over time and to involve end-users, which has been recognized as an important success factor in HIT development. A new evaluation methodology, including an analytical framework, has been developed specifically for HIT development: Constructive Technology Assessment (CTA) for HIT. It offers solutions to both the problems associated with summative technology evaluation and a way to involve end-users. The CTA methodology is based on a Socio-technical understanding of technological development as an open ended, emergent process. The CTA was used during the EHR development process in the Region of North Jutland where it proved successful in providing learning and feedback between all relevant groups during all the phases in the process. Thereby a number of problems were prevented to occur later on. Thus, the CTA method and its framework are useful for evaluators and project-management in order to facilitate and support successful HIT development.

Keywords: Constructive Technology Evaluation, Evaluation, Health IT, User involvement, Systems development

Background

Traditionally, summative evaluation methods have been the preferred methods for assessing health technology during the past decades, and still is[1,2] . However, in the case of assessing health information technologies (HIT), summative evaluation methods, as the often-used traditional Health Technology Assessment (HTA) method, pose more challenges [3] . HTA is meant to provide decision support for management for choosing between comparable fully developed technologies based on an evaluation of organizational, social, economic and ethical aspects [4,5] . One major challenge for using HTA for the evaluation of HIT is that many HIT systems are being tailor made for specific purposes. This means that the development process extends over a longer period of time, which again means that the technology might have changed more times before the evaluation is completed. Also, because traditional HTA is conducted when the technology is fully developed, major changes can only be made with great difficulty and at great expenses. This often results in only minor changes being implemented [6] . Last but not least, traditional HTA fails to accommodate the vast complexity of the health care sector: the departments and the wards have their own work practices, the clinical specialities have different needs, contemporary healthcare comprises different professional groups, and the end-users have different individual work practices. Therefore, the rapid and constant changes in HIT over time pose specific needs for the evaluation methods used in HIT evaluation [7-9] .

Already in the 1980s, researchers within the early science-technology-society (STS) movements in the Netherlands, Scandinavia, the UK and USA respectively, set a new research agenda aiming at challenging the limitations to summative technology evaluation methods. The outcome was the development of a formative technology evaluation methodology: Constructive Technology Assessment (CTA) [6,9,10] . With CTA the focus shifted from only assessing the various impacts of fully developed technologies to also paying attention to the technological process as a learning and feedback process, when new technologies are developed and implemented [6] .

During the late 1980s researchers at Aalborg University further developed the CTA for the evaluation of HIT specifically [6,11] . The objective was to deliver a constructive evaluation of both intended and unintended consequences of HIT implementation. Besides, it was to involve the end-users at an early stage in the process, as they were seen as the most important knowledge capacity with respect to the work practices into which the technology should be integrated [12] . However, the CTA methodology did not gain ground in HIT development at that time. According to Müller this was due to management's and staffs view on researchers as foreign intruders and of past experiences on technology evaluations without any significant effect on technological development [10,12] .

During the past decades, experiences have shown the need for new methods to improve HIT development [13-15] . At the same time, the importance of end-user involvement in HIT has been increasingly recognised [16-18] . Thus in the newly published eHealth Task Force Report: “Redesigning Health in Europe in 2020” by the European Union, end-user involvement is mentioned as a key recommendation [19] .

Within systems development methodologies agile development methods have been shown to be a successful approach with a focus on iterative processes and user involvement. These methods emphasize the need to integrate product developer perspectives with management, user and evaluation perspectives. This has not only to do with changing processes but also changing the way management, end-users, and evaluators view the HIT development process [20] .

Based on these insights, we argue that time is now mature for reintroducing CTA in HIT evaluations, as the CTA methodology offers solutions to both the problems associated with summative technology evaluation (e.g. traditional HTA) and a way to involve the end-users throughout the technological life cycle. The Danish Centre for Health Informatics (DaCHI) at the Department of Development and Planning at Aalborg University, Denmark, has over the past 30 years studied HIT development, and in recent years with a focus on further developing the CTA methodology for HIT specifically. The outcome of this work is the methodology: "CTA for HIT". The CTA for HIT comprises an analytical framework for both process- and outcome evaluation. The process evaluation part is conceived as a learning process based on continuously feedback throughout the technological lifecycle thereby making it possibly to change directions during the process. The objective of this paper is to present the "CTA for HIT" methodology and to offer an analytical framework for a combined process- and outcome evaluation in order to facilitate and support successful HIT development. It is also to present a case in which the method has been successfully used.

Methods

Theoretical approach

The CTA for HIT methodology is based on Socio-technical theory with a focus on user participation. Socio technical theory is characterized by a view on technological innovation as an adaptation process, during which both the technology and the user's work practice are changed through mutual and lasting impacts. However, if social balance in the work is to be attained when implementing new technology, both social and technological needs must be met [21] . In Scandinavia, a broad concept of technology was introduced in Socio-technical theory in the 1980'ies, focusing on the micro-level and the user as opposed to the macro-level and the technology. According to this, technology embraces: technique, knowledge, organization and product. These four constituents are inseparable components of any technology. However, active users within each of these, is a prerequisite for a technology being considered as such [6,22] . HIT-research in DaCHI is based on this concept and on a strong focus on the user perspective. The CTA for HIT methodology and its associated analytical framework is developed from previous research in DaCHI, hence the focus on user participation [23,24] .

Design and data-collection methods

The "CTA for HIT" methodology was applied in a case study aiming at assessing the EHR system: Clinical Suite, in the Region of North Jutland (RNJ) in Denmark (the RNJ case). Evaluators from DaCHI conducted the evaluation from phase1 to 4 (se below). The evaluation took place at different locations at four hospitals in the region 2006 – 2010. Data were collected by questionnaires, interviews (personal and focus-group), observations and insight into documents [25-27] . The final evaluation (phase 5) remains to be done once the implementation process is completed.

Analytical framework

Based on our studies within the healthcare sector, we have developed the following analytical framework for CTA for HIT development[1] divided into five phases:

1. Research and planning phase
2. Design phase
3. Development phase
4. Implementation and diffusion phase
5. Summative evaluation and reporting phase

It is important to notice that in practice, the phases are not distinct, but overlap.

Results and Discussion

In this section, the "evaluator" is referred to in each phase. The evaluator is the person responsible for the evaluation (summative as well as formative) during the HIT development process. He/she can be hired from outside as a consultant or be part of the development team or the project management. This depends on the system being assessed, the method of systems development used and on the decisions taken by the executive board. The main responsibility of the evaluator, besides conducting the outcome evaluation at the end of the implementation phase, is to facilitate learning and feedback between the different groups involved during the entire process.

Based on our experiences, more preconditions have to be met to conduct CTA for HIT. Firstly: Throughout the process, good practice for evaluation studies has to be followed carefully [7,28] . Secondly: both the contracting authorities and management at all levels have to support it and have to have a full understanding of its implications with respect to both advantages and disadvantage. Thirdly: the evaluator has to be involved during the entire process, in contrast to in e.g. HTA, where the evaluator is first involved at the end of the implementation phase. This has to be fully understood and agreed upon by both the contracting authorities and management at all levels.

This section is structured in the following way: for each of the phases in the analytical framework provided with the CTA, general recommendations for using the framework is first presented. Then the evaluator's role in the respective phases is described, followed by a description on how the framework was used during the RNJ case study. Finally, the results of using the method in the RNJ case are discussed.

1. Research and planning phase - Identifying and assembling the relevant actor groups

The identification of the relevant groups of actors to be involved in the different HIT development phases can be conducted by using e.g. partner analysis [29,30] . Obvious groups in HIT development are: groups of professionals at ward level (the end-users), the executive board, the management, vendors and it-professionals. The evaluator's role is to ensure that when steering committees and HIT-working groups are assembled, all identified relevant actor groups are represented – and that focus is on the end-users. Besides, it is to ensure that the representatives from each user-group are appointed by members of the respective groups themselves - and not handpicked by management. Experience show that this is important with respect to achieving ownership to the decisions taken during the process [17,31] . At regional and hospital level the most natural way to find representatives is asking the respective professional associations representing the different groups to identify their own representatives. At ward level a useful method is the "Participatory method" [32] . However, in the RNJ case, the outlined approach was not followed.

In the RNJ case, the members of the project management group were handpicked by the executive board. This resulted in protests from the end-users at ward level, which led to a decision in the executive board to expand the group. However, this was done half way through the design phase, resulting in

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[1] The concept: " development" is being used both to designate the entire HIT development process and the third phase in the development process. The meaning will appear from the written context.

the newcomers not having the necessary knowledge to make informed decisions. As a consequence not feeling any ownership to the decisions made through this phase [26] .

2. The design phase – needs and problem analysis
During the design phase, need- and problem analyses have to be implemented in order to clarify, which needs and functions the new technology must fulfil. In 2005 the EU announced a new way to implement tender processes aimed at particularly complex contracts, where the provider (the HIT project management) is not able to define technical, legal or financial matters related to the project: *The Competitive Dialogue Process* (CDP) [33] (fig.1). The field of application of the CDP applies to the development of most new HIT systems, when no off-the-shelf items meet the provider's needs and requirements. This way of conducting a HIT development process is fully in line with the CTA for HIT methodology. During this phase, the evaluator's role is to facilitate learning between all groups involved. This must be done in close collaboration with the project management.

In the RNJ case, the CDP comprised (fig.1): a) *The prequalification phase*: the provider (the project management) developed a tender notice inviting vendors to apply for the development of a new EHR system for RNJ. Among all the applying vendors, the provider - based on criteria's decided on beforehand - choose four vendors for further dialogue. b) *The dialogue phase*: Based on experiences and knowledge from both existing technologies and work practices in RNJ and other regions, the provider devised a document describing provisional requirement specifications. This document constituted the basis for the initial dialogue between the provider and the four respective vendors – one at a time. c) *The quotation phase*: At some time during the process, the vendors were all asked to present provisional solutions/quotations for the new EHR. These were based on the knowledge of the provider's needs gained during the initial dialogue. These provisional solutions/quotations then constituted the basis for further dialogue. During this dialogue with one vendor at a time, the provider gained further knowledge and insight into the possibilities for new technical solutions and work practices. The dialogue process continued until the provider had the gained enough knowledge to work out the final requirement specifications. d) *The decision phase*: Based on the final requirement specifications, the vendors forwarded their final quotation, and - based on certain criteria's – one vendor (CSC) was chosen to develop the EHR for RNJ (Clinical Suite).

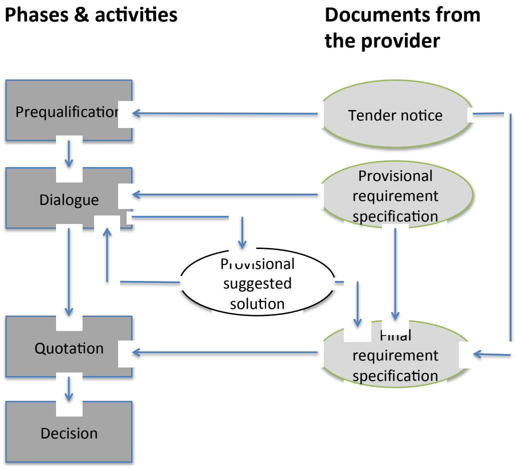

Figure 1- shows the different phases in the Competitive Dialogue Process method, which was used in the Region of North Jutland [33]

The greatest advantage of the competitive dialogue is that it allows the single members of the project management to gain a deeper insight into – for most members in the RNJ case - unknown technological areas by means of dialogue with the different vendors. This allows them greater influence on decision-making. The disadvantage is that it requires many resources (time- and personnel wise) to organize the process and to hold dialogue meetings with each vendor at a time. However, the provider in the RNJ case had a very positive attitude to the CDP and recommended the EU to allow the use of the CDP in a broader context and not only for complex projects [33] .

3. The development phase – user involvement and agile development
During this phase, the project management in close collaboration with the end-users and the vendor/it professionals, outline possible technical configurations thought into different clinical contexts. A useful method for this process is the "User Innovation Management" (UIM) method, where the focus is on involving the end-users in designing the functionalities of the new technology [34] . The outcome of this process is the development of a prototype of the HIT system. This might first be tested in a usability laboratory or in clinical set-ups in order to assess e.g. user-friendliness and the consequences on clinical word practices. Jacob Nielsen has developed ten heuristics to follow for usability studies [35] . When the laboratory testing is completed, the next step is to text the prototype in real clinical settings. Experience show that no matter how realistic a usability study has been performed, unforeseen disruptions and communication challenges can be hard to imitate [36] . The role of the evaluator in this phase is to ensure that the end-users are involved throughout the phase, and that they are working closely together with the vendor/it-professionals.

In the RNJ case the project management group (which included end-users) and the vendor conducted this phase together in close collaboration. Initially, they designed parts of the EHR (e.g. the user-interface) using different games and muck-ups, and as a result the involved actors developed a strong sense of ownership to the different decisions and solutions. Based on the result of this process, the vendor developed a pre-prototype of the EHR, which were pre-pilot tested at one ward. This test went on for several months, during which the pre-prototype was redesigned more times based on feedback from the end-users. During this phase, the evaluators from DaCHI facilitated feedback between the different groups. Besides, a number of meetings were held, and more reports were delivered to the project management, thereby proving them the necessary information's for changing direction during the process, if necessary [27] .

4. The implementation and diffusion phase – pilot testing and redesign
During this phase, prototypes of the new HIT system are implemented at selected wards for pilot testing. At this point of time, working-groups at ward level is set up to give feedback on the system's functionalities and user friendliness. The evaluator's role in this phase is to: a) make sure that all relevant groups are represented in the new groups. It is especially important to ensure that the vendor/ it-professionals are an integrated part of the groups set up during this phase, as they must work closely together with the end-user in order to ensure that the new system meets the requirements, e.g. on clinical benefits. b) to provide feedback from observations and interviews at ward level between groups to share experiences and knowledge, and to management for learning and management reasons.

During the pilot testing of the EHR in the RNJ case, which took place at four hospital wards, the evaluators from DaCHI gave feedback to the project management on a number of occasions. A few examples are given in the following: a) At the Gynaecological ward, we found that the project management had forgotten to include the midwifes, when the working group at ward level was set up. The most important work document for the midwifes is the so-called “Partogram” which is a graphical record of key data recorded during labour. Because of the midwifes not being part of the working group from the start, this record was initially not part of the EHR, which meant that the EHR did not provide any clinical benefits for this professional group. Because of our feedback to the project management, the midwifes were included in the working group, and the EHR was expanded to include the Partogram. b) At the Emergency ward we encountered complains of a too long upstart time of the new EHR system in the different emergency rooms, resulting in the system not being used. It turned out that a certain procedure beforehand handled by the night duty staff, here re-starting all the computers during night shifts, had been closed down by mistake when reorganizing work procedures. This meant that when the staff entered the emergency room with patients in the morning, they had to wait for the computers to start up in order to enter the EHR. This was very time consuming and meant that they did not use the system. When this was reported to the project management, the previously used work procedure was reintroduced c) A pocket size EHR system guide was available for all staff. However, only a few found them useful. At one pilot ward, staff members had encountered a number of errors in the guide and therefore, they had lost fait in using the guide to solve problems. On all these occasions, and all others encountered, we provided feedback to all relevant actors, thereby preventing a number of problems to occur later on in the process.

During this phase we had regularly meetings with the project management, on which we provided feedback on our observations. Our final recommendations based on observations and interviews with the end-users, were to await full implantation/diffusion until more of the functionalities were able to met the end-users needs. The Region of North Jutland did adjust these functionalities and did wait another year before starting the implementation of the system to all hospital wards in the region, thereby presumably preventing a number of problems later on in the process [25] .

5. Summative evaluation and reporting phase – reflections on outcome and process:
The outcome evaluation in CTA for HIT is different from traditional outcome evaluations with outcomes decided on very early in the process and rigidly assessed up upon at the end of the process. In CTA for HIT the formulation of outcomes is seen as an on going process, and the outcomes are reconsidered and changed during the process based on the new insights gained during the process.

The final outcome evaluation had not yet been conducted in the RNJ case.

Conclusion

The CTA for HIT is an agile development methodology, requiring a new view on HIT development and evaluation as integrated and not as separate activities and with a focus on the end-user as a knowledge capacity with respect to the work practices into which the technology is going to be integrated. The CTA for HIT comprises both process- and outcome evaluation. The process evaluation is conceived as a learning process based on continuously feedback throughout the technological lifecycle thereby making it possibly to change directions during the process. The CTA for HIT offers solutions to the well-known limitations of summative evaluation methods. Besides, it meets the increasingly recognized need for involving the end-users throughout the HIT development process. Thus, it focuses on iterative processes and user involvement.

The CTA for HIT method was used during the EHR development process in the Region of North Jutland. Despite the fact that not all recommendations in the CTA analytical framework were followed, the method proved successful in providing learning and feedback between all involved groups during the different phases in the process. Thereby a number of problems were prevented. Thus, the CTA method is useful for evaluators and project-management in order to facilitate and support successful HIT development.

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Is there a connection between telehomecare technology and health literacy?

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Abstract

Chronic obstructive pulmonary disease (COPD) is a chronic disease characterised by a graduate decline of pulmonary function and it constitutes a provable burden on both society and patients. Patient empowerment is recognised as an essential part in the management of COPD, as there is a strong connection between this concept and a reduction in the utilisation of various healthcare services. Telehomecare technology has been shown to enhance the level of empowerment among COPD patients. Patient empowerment is strongly associated with health literacy, so if telehomecare technologies are used to improve the level of health literacy among COPD patients it may be possible to provide a better and more individual care for COPD patients and at the same time reducing healthcare costs. Both health literacy and telehomecare technologies have shown great potential in terms of reducing healthcare costs and improving quality of life for COPD patients, so the aim of this paper is actually to raise awareness regarding the potential of using telehomecare technology to improve the level of health literacy among COPD patients.

Keywords: Health literacy, patient empowerment, education, patient-centered care, COPD, quality of life.

Introduction

During the last decade, there has been an increase in the transition from acute to chronic health problems in the society - thereby producing a need for new skills in the healthcare system. The chronic patient is a complex case due to progressive functional decline, a high risk of hospitalisations, multiple co morbidities and difficult individualised diagnoses and prognoses. This raises a need for making existing treatment more individual and preventive - urging the healthcare system to try and meet the needs of chronic patients (1).

Chronic obstructive pulmonary disease (COPD) is a chronic disease characterised by a graduate decline of pulmonary function and it constitutes a provable burden on healthcare professionals and healthcare systems (2) (3). The Global Burden of Disease study, conducted under the auspices of the World Health Organisation (WHO) and the World Bank, states that COPD was the fourth leading cause of death in the world in 2007 with almost 2.8 million deaths worldwide (3). In 2004, WHO estimated that 64 million people suffered from COPD and 3 million people died of the disease. In their estimations from 2004, WHO also predicts that COPD will become the third leading cause of death worldwide by 2030 (4).

In Denmark approximately 400.000 people suffer from COPD, and COPD patients account for about 20% of acute admissions to medical wards. The readmissions rate for COPD patients within the first month is 24% (5). COPD is primarily seen in the elder part of the population, and due to development and improvement in science and technology and enhancement of social conditions in general, the life expectancy is increasing around the world (6). This leads to an ageing population all over the world, which in turn contributes to an increase in the prevalence of COPD. The changing age structure combined with an increasing use of cigarettes has lead to the estimation that the global burden of COPD will increase over the coming years (7), which is in accordance with prior predictions made by WHO in 2004.

It is because of frequent and lengthy hospital admissions that COPD comprise such a serious increasing burden on society and healthcare resources. Lengthy hospital admissions increase the risk of acquiring a secondary hospital infection, and hence the possibility of escalating treatment costs (2). An investigation from 2002 estimated the costs related to COPD to get a picture of how heavily COPD weights on the Danish healthcare budget. These costs were estimated to be approximately 3 billion Danish kroner corresponding to about 10 % of the total hospital and national health insurance costs when treating persons at 40 years or above in Denmark – so COPD weights heavily on the healthcare resources (8).

COPD does not only place a burden on society and healthcare resources, but also on the COPD patients. COPD patients experience a gradual deterioration in their health, resulting in a limitation of activity of daily living and decrease in their health-related quality of life (HRQoL) – especially due to exacerbations (9). The increasing burden and massive costs, COPD places on society, provide a strong motivation to develop less costly and more effective ways to care for COPD patients (6).

A variety of guidelines have been developed with the purpose of improving the management of COPD – but have we succeeded in finding a possible solution that can lift the burden of COPD – both from a societal and patient point of view?

Patient empowerment concerns the ability of patients’ to be an active part of their own health care process, and thus be well informed about all aspects of their health (29). Currently, there is a focus on patient empowerment and giving the patients’ somewhat more control over their own disease. Patient education with the purpose of enhancing the level of empowerment is recognised as an essential part of the management of COPD, as it is recommended in various articles as well as both national and international guidelines (5, 7, 15).

It is beneficial to focus on enhancing the level of empowerment among COPD patients, since there is a strong connection between this concept and a reduction in the utilisation of various healthcare services (3, 10, 11). Furthermore, there is a connection between enhanced patient empowerment and improved HRQoL (11, 12).

Disease knowledge is often an overused outcome when evaluating self-management education programmes for COPD patients. Disease knowledge is a weak less effective outcome measure compared to comprehensive patient empowerment interventions addressing patient education, health literacy, motivation and behavioural changes (10).

Telehomecare technology is a field of research that is kind of unexplored, but it has shown some potential with regards to enhancing the level of empowerment among COPD patients (6, 17).

Health literacy is a concept closely connected to empowerment and it is defined as following by WHO: "*Health literacy represents the cognitive and social skills which determine the motivation and ability of individuals to gain access to, understand, and use information in ways which promote and maintain good health. Health literacy implies the achievement of a level of knowledge, personal skills and confidence to take action to improve personal and community health by changing personal lifestyles and living conditions. Health literacy means more than being able to read pamphlets and successfully make appointments. By improving people's access to health information and their capacity to use it effectively, health literacy is critical to empowerment. Health literacy is itself dependent upon more general levels of literacy. Poor literacy can affect people's health directly by limiting their personal, social and cultural development, as well as hindering the development of health literacy.*" (23).

This knowledge has given rise to the purpose of this paper: to increase awareness about the importance of focusing more on the level of health literacy among COPD patients, as this may hold some potential in terms of reducing utilisation of healthcare services. The use of telehomecare technologies has been shown to improve the level of empowerment among COPD patients, leading to the hypothesis: ***If telehomecare technologies are able to enhance the level of patient empowerment, it could have the potential to improve the level of health literacy among COPD patients as well.***

Materials and Methods

Systematic literature search

A literature search was conducted in two electronic medical databases: PubMed (Medline) and the Cochrane Library (only reviews).

The references, identified by the search strategy, were screened by title and abstract. In order for the articles to be selected for further reading, their abstracts had to clearly identify the study design, an appropriate population and relevant components of the intervention as described above. Clearly irrelevant references were excluded.

The full-text reports of all remaining trials obtained and assessed independently for eligibility. The literature search was centred on three fields:

Search 1: ***COPD and patient empowerment (health literacy)***
PubMed: 82, selected 6; Cochrane: 15, selected 1; other: 5.

Search 2: ***Telehomecare technologies and patient empowerment***
PubMed: 16 selected 5; Cochrane 1, selected 0.

Search 3: ***Telehomecare technologies and health outcomes***
PubMed: 6 selected 4; Cochrane 3, selected 0; other: 4.

Criteria for selected articles and reviews in all three searches

- Literature published from 2002-2012
- COPD patients as target group
- Language: English, Scandinavian
- Meta-analysis, reviews, RCT studies or original research

Search 1: COPD and patient empowerment (health literacy)

The purpose of the search

To get a picture of the tendency in the literature with regards to the importance of enhancing empowerment among COPD patients. How does current literature evaluate the importance of patient empowerment in the management of COPD? The clinical guidelines concerning the management of COPD were investigated to see how empowerment is incorporated in these. As patient empowerment is associated with the concept of health literacy, this search also explored the relationship between COPD and health literacy with the purpose of determining if COPD patients has some characteristics that influences their level of health literacy.

The use of telehomecare technologies is said to enhance the level of empowerment among COPD patients, but it is relevant to get a sense of how important empowerment actually is in the management of COPD according to the literature.

The search was based on the following words

["Chronic obstructive pulmonary disease" or "chronic obstructive lung disease" or COPD] and ["health literacy" or "literacy" or "patient education" or "self-management" or "patient empowerment"]

Criteria for selected articles and reviews

The studies had to include a patient education with the purpose of enhancing the level of empowerment among COPD patients.

Studies that assessed how the level of health literacy affects the course and management of disease among COPD patients were also selected for inclusion.

Search 2: The use of telehomecare technologies and patient empowerment

The purpose of the search

The purpose was to explore the literature with regards to the effect of telehomecare technologies in terms of enhancing the level of patient empowerment. Patient empowerment was found to be important in the management of COPD in the previous search (**Search 1**), so now it is relevant to investigate if the use of telehomecare technologies has the potential to enhance the level of patient empowerment among COPD patients.

The search was based on the following words

[telemedicine or telehomecare or "home telehealth" or telemonito? or "home healthcare"] and ["chronic obstructive lung" or "chronic obstructive pulmonary" or COPD"] and ["patient education" or "self-management" or "empowerment"]

Criteria for selected articles and reviews

The intervention had to fall in the landscape of telehomecare technologies. There is no sharp defined differentiation between patient empowerment and self-management in the literature, so both concepts are included in the search. **Outcomes of interest** in this line of studies:

- Patient education programmes with the purpose of enhancing the level of empowerment among COPD patients.

Search 3: The use of telehomecare technologies among and health outcomes

The purpose of the search

To identify articles and reviews that assessed how telehomecare technologies affect health outcomes among COPD patients. This line of investigation was relevant due to the hypothesis that there is a connection between the use of telehomecare technologies and health outcomes in terms of reduced utilisation of healthcare services and improved quality of life among COPD patients.

The search was based on the following words

[telemedicine or telehomecare or "home telehealth" or telemonito? or "home healthcare"] and ["chronic obstructive pulmonary" or "chronic obstructive lung" or COPD] and ["economic evaluation" or "economic assessment" or "cost minimization analysis" or "cost effectiveness analysis" or "cost utility analysis" or "cost benefit analysis"].

Criteria for selected articles and reviews

Articles and reviews that included an economic evaluation with following **outcomes of interest**:

- Hospital admissions
- Visits to the emergency room
- Health-related quality of life (HRQoL)

Results

The result section is based on an analysis of selected articles and reviews identified through the three literature searches:

1. *COPD and patient empowerment (health literacy).*
2. *The use of telehomecare technologies and patient empowerment.*
3. *The use of telehomecare technologies and health outcomes.*

COPD and patient empowerment (health literacy)

Health literacy is shown to be strongly associated with healthcare outcomes. The overall tendency in the literature is that a low level of health literacy is associated with poorer health outcomes and poorer use of healthcare services (25).

Additionally, as implied in the definition, patient empowerment is a key component when discussing health literacy, as there is a strong connection between these concepts - health literacy is crucial to empower COPD patients in the management of their own disease and course of rehabilitation. COPD patients experience great impairment in their everyday life in terms of deterioration in cognitive function, increasing isolation, difficulties with walking and performing everyday activities resulting in a decrease in their quality of life (24). Therefore, patient empowerment has become an important term when discussing management of COPD. Over time, patient education, with the purpose of enhancing patient empowerment, has been incorporated into various clinical guidelines describing the management of COPD (9).
WHO recognises patient education as an essential part in the management of COPD; they state that both COPD patients and healthcare professionals need to learn more about the disease (15).
The Global Initiative for Chronic Obstructive Lung Disease (GOLD), established in the 1990'ies with the purpose of raising awareness of COPD and encouraging renewed research interest in this very prevalent disease, also emphasises patient education as a part of their global strategy for the diagnosis, management, and prevention of COPD (7).
On the national level, The Danish National Board of Health published a report in 2007 that also recommends patient education with regards to early detection, treatment and rehabilitation of COPD (5). Hence, consensus exists between international and national guidelines and recommendations.
The guidelines and recommendations concerning patient education as a part of the management of COPD from the three abovementioned organisations are of course based on documentation from the literature, as the benefits and importance of patient education is widely accepted in relation to COPD (16).
Based on the review of the literature it can be said that patient empowerment is recognised as an important factor in the management of COPD. Additionally, there is a connection between patient empowerment and health literacy.

As stated by Richard Wootton: "*Telehomecare technologies have a primary function of providing education to patients*" (14) – the interesting questions are then:

- **Can telehomecare technologies affect the level of patient empowerment COPD patients?**
- **Can the use of telehomecare technologies influence the utilisation of healthcare services among COPD patients?**

The use of telehomecare technologies and patient empowerment

Richard Wootton states that one of the main functions of telehomecare technologies is to provide education to the patients, and thereby enhancing their level of empowerment (14). Furthermore, telehomecare technologies have in general been known to hold a great deal of potential when it comes to dealing with the burden of COPD. Telehomecare technologies include various aspects: a remote exchange of data between a patient and healthcare professionals – enabling easy information transfer – as a part of the COPD patient's healthcare management. The rapid information transfer is referred to as telemonitoring in the landscape of telemedicine (13, 14). As the field of telehomecare is relatively new field of research, only a limited amount of literature exists on the subject of how it affects the level of empowerment among COPD patients. Although, no final conclusions can be made and a solid evidence base is lacking then telehomecare technologies still shows a tendency towards positive results in the literature.

The overall tendency, in the existing literature regarding telehomecare technologies and patient empowerment, is that the COPD patients benefit from using the telehomecare technology in various ways. For instance, COPD patients feel empowered in the management of their own disease due to the direct involvement in their own care process. The direct involvement improves the knowledge about their disease and contributes to the feeling of empowerment among the COPD patients (6, 17). The COPD patients' experience that the telehomecare technologies provide them with a sense of control over their disease, and at the same time inspires them to take charge and do something about their symptoms, in terms of self-monitoring, gaining better access to information about their disease and understand the level of benefit associated with being in charge (18). Another advantage by using the telehomecare technologies is a sense of improved compliance with treatment among COPD patients (19). A recent study from 2012 states that telehomecare technologies can assist the COPD patients' in a better management of their condition, resulting in a decrease in the incidence of acute exacerbations that need emergency admissions (13). An important component in the management of COPD is to provoke some behavioural changes among the COPD patients; they need to be ready to make a change in their lifestyle in order for the treatment and rehabilitation to work properly. A connection between telehomecare technologies and altered patient behaviour has been found (13, 20).

The review of the literature implied a strong association between the use of telehomecare technologies and an enhanced level of empowerment among COPD patients

The use of telehomecare technologies and health outcomes

In order for COPD patients to benefit from their treatment and rehabilitation as much as possible, they need to understand the extent and severity of their disease. Hence, understanding the information given from the healthcare sectors constitutes an important element. However, the role of health literacy in the management of COPD has not received much attention; especially how health literacy could influence health status and health outcomes among COPD patients has not been well elucidated (28).

A review with focus on chronic diseases, including COPD, finds that health literacy can influence health outcomes considerably and that improvement can be made by paying attention to the problem (26). The centre for Health Care Strategies states that patients diagnosed with a chronic disease, including COPD, are at higher risk of having a low level of health literacy and less likely to receive the needed health care (27).

It is known that telehomecare technologies do not only affect the level of empowerment among COPD patients, but they have also been shown to reduce healthcare costs. In addition, it seems that telehomecare technologies improve or do not affect quality of life among COPD patients (19, 21, 22).

The review of the literature indicates that the use of telehomecare technologies is associated with a reduction in the consumption of health utilities among COPD patients.

Discussion

Patient education is an essential component in the management of COPD in terms of enhancing the level of empowerment among COPD patients. Existing literature implies that the use of telehomecare technologies have the potential to empower and enhance the level of empowerment among COPD patients, with regards to being more in control of their own disease, behavioural changes, compliance etc. These are important findings in relation to reducing the massive burden COPD poses on both society and the patients. On the basis of these findings it can be said that it is essential to focus on initiatives that enhances the level of empowerment among COPD patients. The definition of health literacy includes components of empowerment; therefore it could be beneficial both from a societal and patient point of view to focus more on the concept of health literacy in relation to COPD patients, as both the concept itself and enhanced patient empowerment have been shown to have a positive effect on the utilisation of healthcare resources. The use of various telehomecare technologies have been shown to reduce the healthcare costs and increase quality of life among COPD patients, and since telehomecare technologies also have shown to enhance the level of patient empowerment among COPD patients maybe connecting all of this to the concept of health literacy could be very beneficial.

It can be said that as the use of telehomecare technologies enhance the level of empowerment among COPD patients, they may also hold a great potential in terms of enhancing the level of health literary among COPD patients. Health literacy has been shown to be strongly associated with health outcomes in the existing literature, just as telehomecare technologies. So by combining these two concepts – meaning if telehomecare technologies is used to improve the level of health literacy among COPD patients it may be possible to provide a better more individual care for the COPD patients and at the same time reducing the healthcare costs. Both health literacy and telehomecare technologies has shown great potential in terms of reducing healthcare costs and improving quality of life for COPD patients, so the objective of this paper is actually to raise awareness regarding the potential a combination of the two could hold.

Conclusion

Patient empowerment is recognised as a key component in the management of COPD. There is a strong association between telehomecare technology and an enhanced level of empowerment among COPD patients. Telehomecare technology has been shown to reduce healthcare costs. A poor level of health literacy leads to poor health outcomes. Hence, if telehomecare technology is used to improve the level of health literacy among COPD patients it could increase their quality of life and reduce healthcare costs for society

Implications for future research

Currently no studies have investigated the connection between health literacy and telehomecare technologies, but the findings regarding the two concepts separately indicates that it may be beneficial to investigate this connection.

Conducting research about the connection between health literacy and telehomecare technologies could comprise an important key point in solving the puzzle of managing COPD in a less costly and patient satisfactory way.

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Developing and testing a novel study design for improving hypoglycaemia detection and prediction with continuous glucose monitoring data

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Abstract

Persons with Type 1 diabetes need continuous exogenous insulin supply throughout their life. Determining the optimal insulin treatment in relation to diet and physical activity is one of the main goals of diabetes management, but is difficult, especially for vulnerable populations, such as adolescents. Erroneous treatment may result in both repeated and severe low blood glucose events. Continuous glucose monitoring (CGM) may help in avoiding these events, but is inaccurate compared to traditional glucose monitoring. Models have been developed to significantly improve CGM's detection of insulin-induced events by using information from the CGM signal itself. Additional temporal data on insulin doses, diet and physical activity may improve hypoglycaemia prediction models. In this research, we present and pilot test a study in which a smartphone was used to obtain these data. Data from one female was obtained over a period of two days. CGM and continuous physical activity accelerometry data were collected with minimum and no dropouts, respectively. The collection of diet, insulin and blood glucose data, also, proceeded without problems. These results indicate that it is possible to collect glucose, diet, insulin and physical activity data of high quality. These data will facilitate further development of models for the detection and prediction of low blood glucose.

Keywords: *Hypoglycaemia, detection, prediction, continuous glucose monitoring, study design.*

Introduction

Persons with Type 1 diabetes (T1D) lack the ability to produce the glucose-regulating hormone insulin due to a partly unknown autoimmune destruction of the pancreatic beta-cells. The result is an abnormal high blood glucose that typically leads to severe late-diabetic complications, such as neuropathy, nephropathy, retinopathy, micro- and macroangiopathy. Late-diabetic complications are not only very disabling for the patient, but they also place a significant economical burden on society: the annual estimated cost of late-diabetic complications in the USA is $58 billion. [1]

Abnormally high blood glucose is most often treated with an individually-tailored regimen of either exogenous insulin as boluses or continuous insulin from a pump. The Diabetes Control and Complication Trial demonstrated that intensive insulin therapy delays the onset and slows the progression of late-diabetic complications in people with T1D. [2] This finding was subsequently confirmed by the UK Prospective Diabetes Study Group. [3] Unfortunately, the intensive insulin therapy results in a 2-3-fold increase in the prevalence of hypoglycaemia. Hypoglycaemia (plasma glucose $\leq$ 70 mg/dl [4]) is potentially fatal and is a constant concern for those with T1D and their care providers. [5]

Adolescents with T1D, previously thought to be protected from early development of microvascular complications, are at significant risk of these complications, [6] making optimal glycemic control an important goal in their diabetes management. However, the metabolic demands combined with an unpredictable lifestyle make adolescents vulnerable to both repeated and severe hypoglycaemia. Consequently, detection of imminent hypoglycaemic events followed by recommendations to prevent further hypoglycaemic development may help adolescents identify a personally optimal diabetes therapy. Continuous glucose monitoring (CGM), which measures interstitial glucose and produces a reading typically every 5 minutes, offers a much higher temporal resolution than conventional glucose monitoring and is, therefore, a promising technology for hypoglycaemia detection in adolescents. Unfortunately, CGM is inaccurate, especially in the hypoglycaemic range primarily due to an interstitial-blood glucose delay and a filter delay. [7] On 71 adults with T1D, Bode et al. [8] demonstrated a significant reduction in hypoglycaemia by using hypoglycaemic threshold alerts, but they also revealed 67% sensitivity, 90% specificity, and 47% false alerts. Although, the study of Bode et al. provides some insight into the the potential for CGM devices in diabetes managment, the evidence of hypoglycaemia detection is sparse. [9] A study by Jensen et al. [10] has shown that it is possible to develop a model that processes CGM and insulin data and improves the retrospective detection of insulin-induced hypoglycaemic events. Another study by Jensen et al. [11] showed that with similar information and processing, it was possible to improve real-time detection of these events. However, during the process from retrospective to real-time, it was evident that the detection rate decreased. Apparently, this was due to the reduced amount of information to discriminate between hypoglycaemia and non-hypoglycaemia periods for the real-time algorithm. Plausible, spontaneous hypoglycaemic events occurring in real-life data from people with T1D will cause an even lower detection rate because they do not exhibit such pronounced characteristics as insulin-induced events. Moreover, ideally *predicting*, as opposed to only detecting these events, places further demands for real-time data. Information that may help in discriminating between hypoglycaemia and non-hypoglycaemia periods besides the CGM signal itself are the three primary glucose-regulating factors, insulin, diet and physical activity. Studies have dealt with collection of these data but the reliability of especially diet and physical activity data has been an ongoing problem, which hampers the results. [12] [13]

The aim of this research was to present and pilot test a study design for collecting accurate data on insulin, diet, physical activity and glucose using modern smartphone technologies that are already prevalent and are increasingly used amongst adolescent populations. We present data from one of our pilot test subjects with the goal of illustrating the qualities of information from integrated monitoring, and furthermore, to present our intended data analysis methodology.

Protocol presentation

Population

The population of interest for our study met the following criteria.

Inclusion:

- $10 \leq$ Age ≤ 18 years.
- Type 1 diabetes.
- Diabetes duration ≥ 6 months (to avoid subjects with honey moon periods)
- $6.5\% \leq$ HbA1c $\leq 11\%$.
- Insulin pump users.
- CGM device users.
- Blood glucose meter with memory function and connection to CGM.
- English proficiency of 3rd grade or above.

Exclusion:

- Non-English speaking.
- Pregnancy.

The adolescents should already be CGM and insulin pump users to ensure elimination of user-related measuring errors. Furthermore, an inclusion requirement is the use of a blood glucose meter, which can wirelessly transmit self-monitoring of blood glucose (SMBG) measurements to the CGM. Hereby, human errors occurring on typing in data are reduced. The remaining criteria represent accepted typical standard for diabetes studies.

Information recorded

The subjects should as part of their diabetes-related routines measure interstitial glucose, blood glucose, physical activity and register insulin injections and carbohydrate intake.

Glucose and insulin recording

The interstitial glucose, blood glucose and insulin injections were recorded with the Paradigm® REAL-Time Revel™ System (MiniMed Inc., USA) or similar, which together with a blood glucose meter like the CONTOUR® LINK (Bayer, USA) is capable of transmitting data to the MiniMed system wirelessly, eliminating most user interaction and, thus, reducing the probability of human errors. Furthermore, the transferred blood glucose values were automatically used to calibrate the CGM.

Diet recording

Carbohydrate intake has previously been estimated based on patient self-reporting. But this approach has been linked to both inter- and intrapatient variability, [12] [14] which makes the use of the unreliable data in detection/prediction models difficult. Because most subjects in the age group already have smartphones, carbohydrate intake was recorded by capturing a photo of each carbohydrate-containing intake. This simple photo-taking approach, as opposed to completing detailed food diaries, reduced the burden on patients. Thereafter, three blinded dieticians estimated the carbohydrate content of each picture and the median of the three estimates was used. This ensured homogeneous estimates, reducing inter- and intra-patient variability.

Physical activity recording

Also, recording of physical activity has been performed manually in the past but with varying reliability due to many reasons, one of which may be that subjects do not want to appear sedentary. [13] To ensure increased reliability, physical activity was estimated with CalFit. [15] CalFit is a non-commercial application developed for Android smartphones. Continuously, it records the subject's time-location patterns and energy expenditure associated with physical activity using the phone's integrated GPS and accelerometer, respectively. Since the application works on the smartphone, which the subjects already use for diet photo recording, they just have to carry the smartphone around in their pocket or purse to monitor physical activity.

Number of subjects

To train models of pattern classification, both glucose readings in hypoglycaemia and otherwise are necessary. With at least 100 paired PCGM-SMBG readings in hypoglycaemia, it is possible to train a model. People with T1D are in hypoglycaemia 10% of the time, [16] and the total number is, thus, 1000 paired PCGM-SMBG readings Assuming that T1D people are capable of measuring SMBG 3 times per day and the monitoring period is 7 days, the number of subjects needs to be at least

$$N = \frac{1000 \text{ PCGM-SMBG readings}}{7 \text{ days } x \text{ } 3 \text{ SMBG pr. day}} \approx 50$$

A monitoring period of 7 days is deemed acceptable in light of the inconvenience of the diet registration

Data analysis and model development

The obtained data are in a sense, raw. For example, the carbohydrate intake of the diet recording does not directly specify the absorbed amounts from the gut. However, several models for this purpose exist. For example, the absorption from the gut can be found as a non-linear function of the carbohydrate in the content in the gastrointestinal tract. [17] Data on insulin injections also need post-processing. One way is estimating insulin-on-board, which can be derived from the model of Berger and Rodbard [18] that via superposition also works for multiple injections. With these post-processing approaches, there will exist continuous data for diet, insulin, physical activity and CGM. Systematic feature extraction and reduction methods previously demonstrated in Jensen et al. [10] [11] can be performed on these data and discriminative features iden-

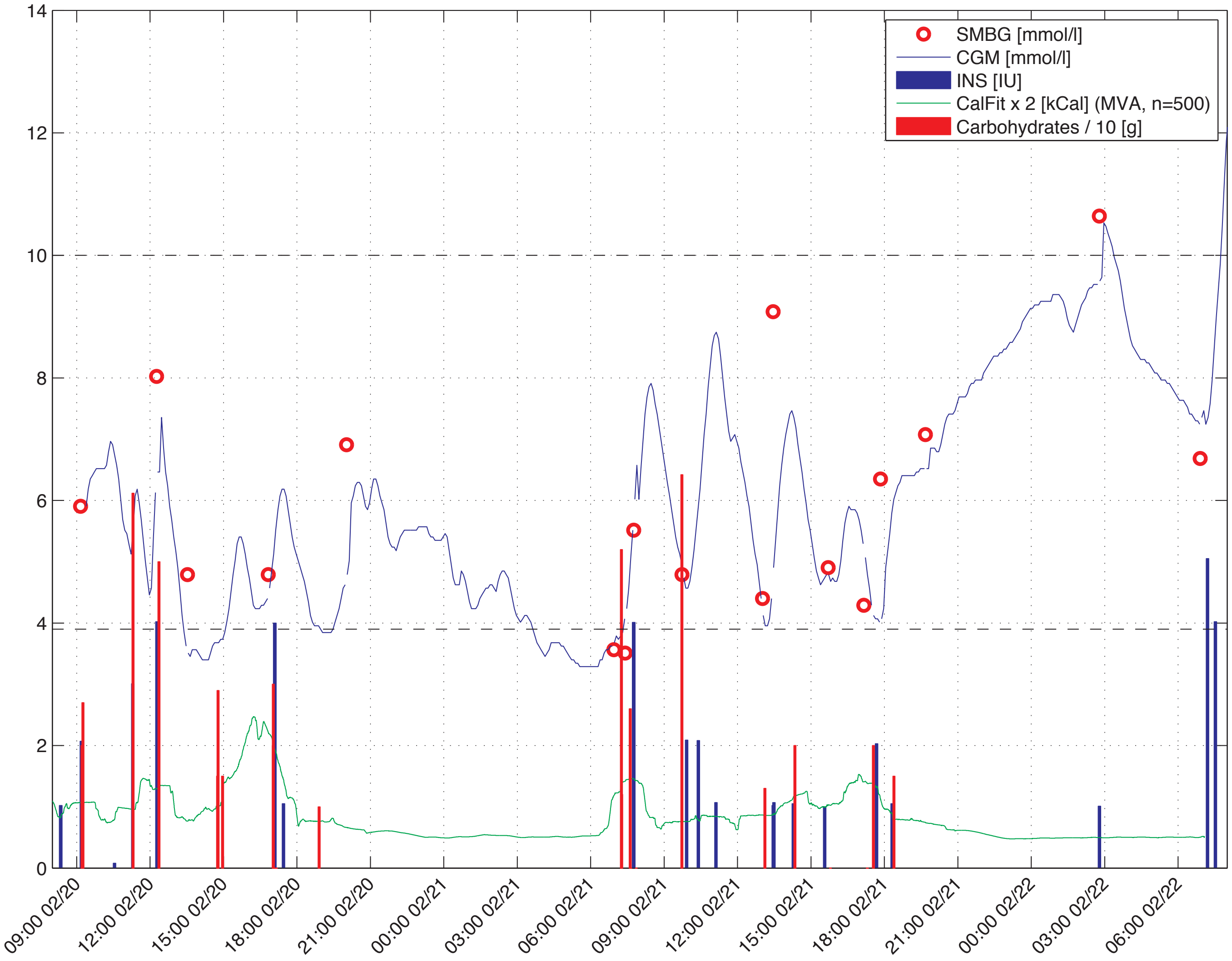

Figure 1 – Obtained data from the pilot study. The subject was monitored from 9 AM 20th Feb 2013 to 6 AM 22th Feb. 2013. The CalFit signal was filtered with a moving average filter (MVA) using a delay of 500 readings. For visual aid, carbohydrate readings were divided by 10 and CalFit readings were multiplied by 2.

tified. Applying models, such as, Support Vector Machines on the remaining features can determine how well the different glucose-regulating parameters classify CGM readings in hypoglycaemia and in non-hypoglycaemia as defined by the SMBG readings.

Pilot study

Materials and methods

To illustrate how an integrated set of monitoring data may be useful for modelling, we present data from one female subject aged 18 years with Type 1 diabetes who participated in the pilot study, which preceded our main study. During a period of two days she was monitored with the Paradigm® REAL-Time Revel™ System (MiniMed Inc., USA) and a CONTOUR® LINK (Bayer, USA) blood glucose meter. Furthermore, she used a Galaxy Y (Samung, USA) for diet and activity recording. A Registered Dietician performed estimation of carbohydrates from the diet pictures. To assess the quality of the study design, the pilot study is presented with a plot of raw data and with a table of daily sum of insulin injection, calorie burn and carbohydrate consumption. Furthermore, a Clarke Error Grid Analysis (EGA) is presented. The EGA is presented to elaborate on the CGM accuracy in the pilot study. Presentations of the obtained pilot study data were created in MATLAB® (version R2011b; MathWorks, Natick, MA, USA).

Results

The obtained two-days monitoring pilot test data from the one female can be seen in Figure 1. In Table 1, daily sum of injected insulin, burned kilocalories and consumed carbohydrates is seen.

There was a CGM dropout of 3.3% with a maximum gap of 15 minutes (2 readings). A Clarke Error Grid analysis of the CGM can be seen in figure 2. 62.5% CGM readings fall in zone A and 37.5% in zone B. It took two hours for the dietician to decode the pictures and estimate carbohydrate contents.

Table 1 – Average of daily insulin injections, calorie burn and carbohydrate intake for the pilot study subject.

Parameter	Average daily sum
Insulin (U)	21
Physical activity (kCal)	3405
Carbohydrates (g)	250

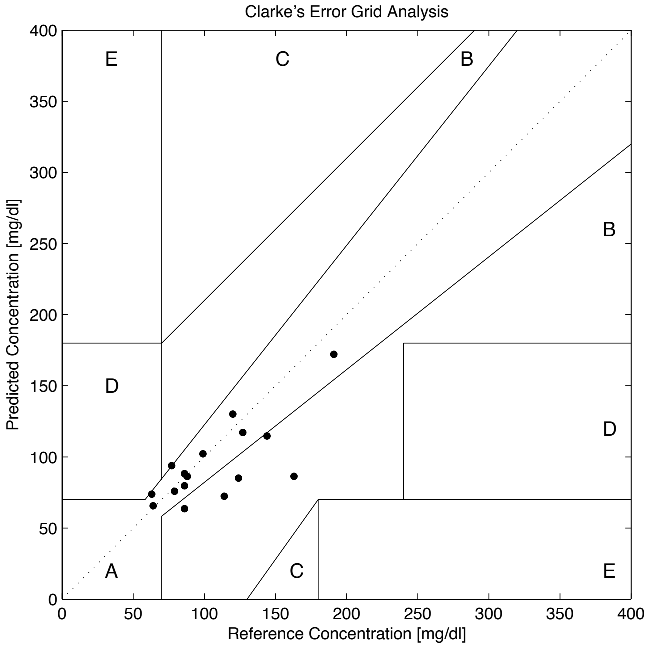

Figure 2 – Clarke Error Grid analysis of obtained pilot data

Discussion

In this study, we have presented and pilot tested a study design that can be used to optimize the CGM detection/prediction of hypoglycaemia in adolescents with Type 1 diabetes.

To our knowledge, no prior study has investigated optimization of CGM hypoglycaemia detection/prediction with such rich information about glucose-regulating factors using novel smartphone physical activity and photo-based diet assessments. In a study by Pappada et al., [19] Neural Network combined information from CGM, SMBG, insulin, diet, lifestyle and emotional factors were used to predict hypoglycaemic events. In the study, they used CGM to characterize hypoglycaemia and non-hypoglycaemia periods, which is misleading due to the significant inaccuracy especially in hypoglycaemia. In the study by Jensen et al., [11] only 71% of the hypoglycaemic events were confirmed by CGM. Training a prediction model to not produce alerts during these 29% events will result in an erroneous model. Other researchers only use CGM as input in their models to optimize the CGM prediction of hypoglycaemia but the varying results might suggest that this is not enough. [20] [21] [22]

Our pilot study has shown that it is possible to continuously collect these rich data of very high quality in community daily living situation. From Figure 1 it is possible to see that there is very few data gaps. Only the CGM has dropouts. But they do not exceed 15 minutes, and are acceptable in relation to other observed dropouts. [20] [23] It is impossible to know if the pilot subject took pictures of every carbohydrate intake, but from the density of the recordings only a few could have been missed and the amount of consumed carbohydrates is consistent with the literature. [12] Also, it is difficult to know whether the subject wore the smartphone, and thereby whether CalFit recorded accurate accelerometry. However, from the signal, it can be concluded that the smartphone was in motion all the time except at night-time.

The Registered Dietician's estimation of carbohydrates is naturally linked to some degree of inaccuracy and the use of only one dietician is dangerous. However, in our main study we will use three blinded dieticians. From a detection/prediction model's point-of-view inaccuracy is acceptable because features from the carbohydrate intake will only be used to discriminate between hypoglycaemia and non-hypoglycaemia periods and the absolute carbohydrate values are therefore less important.

From the EGA, it appears that the CGM-SMBG consistency is clinically acceptable (Zone A and B). Zone D represent dangerous failure to detect either hypoglycaemia (left D zone) or hyperglycaemia (right D zone). [24] Typically, left D zone would contain a lot of readings due to the CGM hypoglycaemia inaccuracy. However, from Figure 1 it can be observed that the pilot subject only measured hypoglycaemic blood glucose two times during the pilot study. Both are measured during a spontaneous hypoglycaemic event developed during the first night. Due to the slow development of this event the interstitial-blood delay and filter delay do not have significant influence on the interstitial measurement and the CGM readings are, thus, accurate. Furthermore, this subject did measure blood glucose more than usual. The typical regimen is 3-4 times per Day. An increased regimen results in a more accurate CGM model.

In conclusion, our pilot study indicates that it is possible to obtain CGM data from adolescents with Type 1 diabetes, as well as quality information about insulin, diet and physical activity. With such data, and appropriate modelling it may be possible to determine the added value of these additional behavioural data in the processing of CGM to obtain clinical acceptable hypoglycaemia detection and prediction rates.

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Heart Patients' Experiences and Use of Social Media in Their Rehabilitation: A Qualitative Study

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Abstract

In the Teledi@log project, an interactive portal, ActiveHeart has been developed. The portal contains information for patients on how to make lifestyle changes presented in text, speech and video. The aim is to explore how heart patients experience and use social media as a part of their rehabilitation. The patients had access to the portal for three months. Qualitative interviews (n=7) were conducted and participant-observation was performed (n= 3.5 hours). A theoretical framework based upon eHealth Literacy, crisis psychology theory and learning theory has been used. The computer programme NVivo 10.0 was used to analyse the collected data. The results show that the patients were used to finding health related information on the Internet. The patients were affected emotionally to different degrees after having had a heart attack/ surgery. The patients had different competences in using new technology, and their skills in eHealth Literacy varied. The study concludes that the patients' emotional state may influence their ability to learn and reflect upon new information and social media can support the patients' eHealth Literacy.

Keywords: *Heart patients; telerehabilitation; social media; eHealth Literacy*

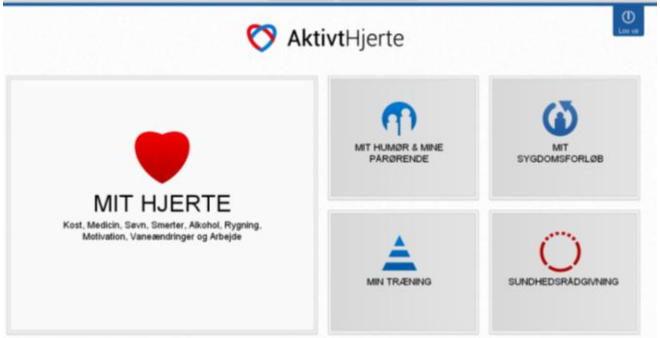
Introduction

Heart patients often experience loss of memory, increased fatigue, depression, anxiety and reduced quality of life following a heart attack or heart operation. Two international meta-analyses conclude that hearth rehabilitation is effective in lowering mortality and improving quality of life [1,2]. Today most health information is available on the Internet. The use of the Internet can improve patients' understanding of chronic disease, the treatment offered or help them understand other symptoms related to their disease [3]. To use the Internet as a health information resource, it is necessary to possess certain skills. These skills may be defined by the concept of eHealth Literacy. An individual's level of eHealth Literacy depends on whether they are used to using the Internet to seek and find information, and if they are capable of understanding the information obtained [4]. The literature shows [5] a focus on using the internet as a mean to manage rehabilitation. The purpose is to help patients make behavioural changes and to reduce symptoms. Simultaneously, using the internet to make interventions do help reduce several traditional barriers, such as shortage of qualified working capacity, prolonged communication waiting time, difficulties with treatment or unwillingness to seek treatment [5]. Using web portals enables the patient to receive care from the healthcare professionals because the patient is able to give and receive social support, acquire new knowledge and information, and feel they are a part of a community [6]. Therefore, the current study examines how heart patients experience and use the interactive portal, ActiveHeart as a part of their rehabilitation.

Teledi@log – a telerehabilitation program

Teledi@log, a Danish research project, has developed a telerehabilitation program for patients with the following diagnosis: patients suffering from angina or who have suffered from a cardiac attack, heart failure, or patients who have had bypass surgery or who have received a new heart valve. Heart patients participating in the telerehabilitation programme receive telehealth equipment so that they can monitor their weight, pulse, blood pressure and steps. The data are transmitted to an online patient record, to which both patient and healthcare professionals have access. The patients can view the data on a tablet device or on their personal computer. A part of the telerehabilitation programme is an interactive portal, named ActiveHeart, where heart patients can find information on how to make lifestyle changes. Information is presented in the form of text, speech and video. The hypothesis of the research is that using social media as part of the heart rehabilitation of the patient may help the patient to seek out, locate, understand and evaluate health information from electronic sources and apply the knowledge gained to addressing or solving their personal health problems. The information on the portal covers topics relevant to a heart patient, such as how to talk about one's condition in the workplace or how to be intimate with one's partner. The portal operates at three learning levels. In the short videos, heart patients and their relatives tell their story about living with heart disease. The portal also has a forum for heart patients so that they may share their experience with other heart patients, ask and exchange advice. The portal has a nurse and a psychologist connected to it, enabling heart patients to obtain professional guidance. The ActiveHeart is developed using user driven innovation. Figure 1 shows a screen dump from ActiveHeart.

Figure 1 - Screen dump of patient's options after logging on to ActiveHeart. The five categories are: 'My Heart', 'My mood & my relatives', 'My disease course', 'My workout' and 'Health Advice' (call centre).



Methods

The Teledi@logs project has been approved by the local ethical committee (N-20120051) and was carried out according to the Helsinki Declaration. A qualitative study has been performed. The participants in this study were selected from the pilot phase of the Teledi@log project. The heart patients included in this study have used the ActiveHeart portal for 3 months. Semi-structured interviews were conducted with seven patients (5 men and 2 women) in their homes, and participant-observation was also performed (n= 3.5 hours). The aim of the observation was to clarify the patients' ability to navigate on the portal. Table 1 describes the characteristic of the participants in this study.

A theoretical framework, eHealth Literacy theory [4], has been used for analysing the data. eHealth Literacy theory provides a framework for accessing the patients skills in locating, understanding and using health information on the Internet.
Crisis psychology theory [7] was chosen in order to focus on the emotional situation of a patient following a heart attack or heart operation. Learning theory [8] was as applied in order to understand how patients learn and reflect upon using social media in a rehabilitation process. The theories support each other in understanding the mental situation of heart patients after eg a heart attack. Data from the interviews and notes from the participant-observation were audio recorded and transcribed. QSR NVivo 10 software was used to code the collected data. The analysis was done in collaboration with a research colleague.

Table 1 - Participant characteristics

Identification	Sex	Age	Diagnosis	Work	Computer/use of tablet
Patient A	Male	89	Heart attack	Retired engineer. Working as a freelance photographer and journalist	Experienced computer user – both at work and in spare time
Patient B	Male	51	Heart attack	Excavator driver	Experienced computer user in spare time
Patient C	Male	65	Bypass and new heart valve	Excavator driver	Not familiar with using a computer
Patient D	Male	66	Bypass	Early retirement. Active in different associations	Experienced computer user in spare time
Patient E	Female	68	Heart attack	Retired home helper	Experienced computer user – spare time
Patient F	Female	67	New heart valve	Retired librarian	Experienced computer and tablet user – work and spare time
Patient G	Male	56	New heart valve	Fisherman – unemployed	Experienced computer user – spare time

Results

The patients have used the ActiveHeart portal differently over the period. One patient had used it approximately once a week, five patients had used it during the first six weeks, and one had not used ActiveHeart at all. The following table shows themes and sub-themes found in the data analysis.

Table 2 - Results of patients' experiences and use of ActiveHeart

Themes	**Sub-themes**	**Quotes**
Emotional status	• Patients do not recognise their disease • Patients are moving on with their life • Patients are able to reflect on their progress in life	"I want to keep it in a completely different place. It's not me that it has happened to" (Patient C). "Yes it is properly because I have felt, 'What can I say, the development goes in a different direction where I have more and more energy'" (Patient F). "Well, there are so many aspects to it, I think, because in a sense you could say, 'I have at least got my life back'" (Patient D).
Competences to use the Internet for locating health information	• Poor at reading and writing • Competent in searching and using health information	I cannot get it down in writing. And I have never been able to" (Patient E). "I can use the computer to find different things" (Patient E).
Internet as a source for health information	• Patients are used to finding information on health issues on the Internet	"Well I do it on the Internet. I have used the Internet quite diligently (…) Actually, I have searched mostly on the Internet" (Patient F).
Use of social media	• Patients are used to commenting on pictures posted on Facebook • Patients are passive on Facebook	"But I like to comment and 'like' the photos they put in, it is kind of fun to follow them, too" (Patient E). "I use Facebook, but it's to see what others are doing" (Patient G).

Discussion

The purpose of this study was to examine how heart patients experienced and used social media in their rehabilitation. The sample of participants was limited due to the fact that they were participating in the pilot phase of the Teledi@log project. Even though the sample was limited, however, they still managed to provide a useful picture of how they experienced using the ActiveHeart portal.

The patients had different psychological reactions to their disease. Two patients stated that they had trouble recognizing that they had been sick; they did not want to be remembered by others as having had a disease. Analysis of data showed that they distanced themselves from the disease and their surroundings. Five of the patients found they were able to move on with their lives, returning to work, if they were still on the labour market, and participating in their everyday lives as they had done before.

The patients explained that when searching the Internet, they looked for information that was easy to read. The analysis point out the importance of having credible sources of health information on the Internet. If the patients automatically search for information that is easy to read, they might choose information of low quality because they find it easier to understand. This may lead to the patients making decisions that may have a negative influence on their health or quality of life. Ghaddar et al. found that it is important for patients to have access to a credible online source of health information, and that it could be beneficial to introduce this source in a school health education curriculum to promote Health Literacy [9]. Two patients with poor reading and writing skills experienced trouble reading and sometimes understanding the health information they found on the internet. Reading and writing skills are essential for achieving Health Literacy and eHealth Literacy. In eHealth Literacy, the ability to read, write and speak a language is called 'traditional literacy' [4]. If a person does not possess these skills, they can experience problems with everyday tasks and have difficulties utilizing the health information they find. More than 65 percent of the health information available on the Internet is in English [4], which makes it even more important for these patients to know where to find a reliable source of health information.

Six of the seven patients all believe, that they are able to use the information they find on the ActiveHeart portal to obtain a lifestyle change. The patients showed two learning styles in assimilating new information. One group preferred to read it themselves, since they achieved a better understanding of the text and had the opportunity of absorption. The second group preferred to hear the information from someone else. One informant explained that it was good to be able to ask questions, when given oral information. This correlates with the existing knowledge that everyone has different learning styles. This testifies to the importance of presenting information in several different ways so as to ensure that everyone has an equal opportunity to learn new information. If the information is presented in only a single way, some people will have difficulty assimilating it.

The analysis showed that the patients were aware that the Internet may be used as a source of new health information. Six patients were used to finding health information on the Internet. They preferred using the Internet when having to find new information on disease and health. In the USA, the proportion of people using the Internet to find health-related information has increased significantly, from 53 percent in 2005 to 71 percent in 2008 [10]. The number and proportion of online health information users is expected to increase as more people obtain Internet access. Among the most searched topics on the Internet, are the leading causes of death: cancer and heart disease [6].

Five of the patients were familiar with the use of social media (Facebook) in their everyday life. They described the ability to keep in contact with especially children and grandchildren as their largest motivation. Three of them had posted information about themselves on their 'wall', but most used it to comment on others pictures and status updates. They did not believe themselves to be experts in using social media, describing themselves largely as beginners, even though more than one had used Facebook for a period of over three years. These comments resembled those made about the forum on ActiveHeart; forum members liked the idea of following what others wrote but did not want to take an active role.

Conclusion

Evaluation of the pilot phase in the Teledi@log project shows that emotional states of the patients may influence their ability to learn and reflect upon gaining new information on how to change their lifestyle. The results indicate that the interactive portal, ActiveHeart may support the patients' eHealth Literacy. Further studies are needed.

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Professional Language in Swedish Radiology Reports – Characterization for Patient-Adapted Text Simplification

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Abstract

In health care, there is a need for patient adaption of clinical text, so that patients can understand their own health records. As a base for construction of automated text simplification tools, characterization of the clinical language is needed.
We describe a corpus of 0.43 mill. radiology reports from a University Hospital, characterize it quantitatively and perform a qualitative content analysis. The results show that a limited set of words and phrases are recurrent in the reports and can be used for exchange to more easy-to-read vocabulary. Semantic categories such as body parts, findings, procedures, and administrative information can be used in the simplification process.
This study investigates the potentials and the pitfalls for text simplification of medical Swedish into general Swedish for laymen.

***Keywords:* clinical text, health records, text simplification, natural language processing, patient empowerment**

Introduction

Health records are accessible to read for patients in several countries via patient portals on the Internet, for example North America [1, 2] and the Scandinavian countries Denmark[1] and Norway[2]. Today, making record information available to the citizens via e-services is a highly prioritized goal also for Sweden [3, 4]. The roll-out of the e-service *Min journal* (My health record) is planned at the end of this year [5], using the patient portal *Mina Vårdkontakter*[3] (My Health Care Contacts) as presently used in Uppsala county. However, there are a number of issues being discussed involving technology, security, legal and ethical questions, but there are also language issues. The content of the health records will not be available to the patients just because the records are accessible on-line; it needs to be comprehensible for laymen readers. Many studies report problems for patients to understand health records [6, 7, 8, 9, 10]. There is a need for explicatory tools to decipher the content.

Clinical text

Patient records have a high content of medical terminology, necessary for exactness and medical safety. In health care, a precise language is needed to describe findings and events. The medical professional language is fact dense and also contains many abbreviations, neologisms and jargon, and is laced with words of foreign origin [7, 11, 12]. In Swedish medical records, foreign words are of Latin, Greek and English origin. The style is ungrammatical, telegraphic and informal, but also characterized by the fact that health records are legal documents, for example containing many passive verbs typical for official documents [12].

The text is not addressed to the patient, and this is a problem for patients who want to follow their own health care-process. Studies from several countries have shown that patients find it especially difficult to understand test results, radiology reports, and medication lists, and in all of these the main issue is medical terminology and abbreviations [6, 7, 8, 9, 13, 14].

Text simplification

Text simplification of medical records will require various, and probably simultaneous, approaches; e.g. lexical exchange for terminology, abbreviation expansion, compound splitting, and syntactic simplification. The level of simplification depends on the intended audience and the purpose.

There have been several efforts for making medical information more consumer friendly [15]. Kandula et al [16] developed a tool that addresses semantic difficulty by substituting difficult terms with easier synonyms, or hierarchically or semantically related terms, and syntactic complexity by splitting long sentences. Leroy et al [17] developed an algorithm for semi-automated simplification of medical text, using a measurement of term familiarity based on lexical and grammatical corpus analysis, to help estimate text difficulty.

Project: Automated text simplification of radiology reports

On-line health records can widen social gaps of health care usage if not taking into consideration the diverse language abilities of patient groups, as well as varying health literacy [15, 18]. If possible, the health records should be written in a language that is understandable for many patients. However, this is not always feasible. In radiologic reports, which convey communication from the radiologist to the treating physician, there is a need for precise descriptions, and it is not possible to compromise with words from layman terminology that can be less distinct. Thus they are not written with the aim of making the text comprehensible for the patient. Several studies have shown that radiology reports are among the most difficult form of clinical text to understand [e.g. 6].

To address the ongoing efforts in Sweden for making records available online, a pilot project on making medical records more readable for patients has been initiated. The long-term goal of this project is to construct a “translator” that can pro-

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[1] www.sundhed.dk
[2] www.minjournal.no
[3] www.minavardkontakter.se

duce a simplified parallel text to the original medical text, thus respecting the needs of both the patients and the professionals.

The aim of this study is to describe a large corpus of Swedish radiology reports, made available for research by ethical approval. Our goals are to quantitatively analyze the content of these records, and qualitatively characterize the most frequent terms and sentences. The purpose is to understand the content of the radiology reports and to be able to use this corpus in the future development of a text simplification tool enabling patients to better comprehend medical text.

Materials and Methods

A corpus of Swedish radiology reports was characterized quantitatively in aspects of frequencies of words, bi- and trigrams, and sentences. A qualitative content analysis was performed for each of these aspects.

Materials

The radiology reports are part of the Stockholm EPR Corpus[4], a large corpus of health records containing more than 600 000 unique patients from the greater Stockholm area during the years 2006-2010 [19]. The records are de-identified with anonymized serial numbers for individual patients.

To create the Stockholm EPR X-ray corpus, we used radiology reports for examinations performed during the years 2009-2010 at Karolinska University Hospital. The size of the corpus is 434 427 reports, containing both the text of the referral as well as the result of the radiologic examination (i.e. questions and answers). Radiologic examinations were performed on in-house patients and patients referred from outpatient clinics to the radiology departments: general radiology as well as thoracic, neurologic and pediatric radiology. The reports are examinations of all patients for this period, i.e. both genders (50.34% females) and all ages from premature babies to a 108 year-old. Due to missing values in the database (1.6%), gender and birth year information is not available for all 152 170 unique patients. 19.41% are under the age of 18, and the majority of the patients are born 1931 - 1970 (51.97%). On average, there are 2.85 reports per patient (min = 1, max = 142), with 50% of the patients having 4 or less reports and 75% of the patients having 10 or less reports.

In this study, we examined only the texts originating from the radiology departments and not the text comprising the referrals.

Methods

For the quantitative corpus statistics analysis, we extracted a number of different corpus categories: all words, bi- and trigrams (sequences of two (bi-) and three (tri-) adjacent words in the corpus) and sentences. Moreover, we extracted all nouns, verbs and adjectives. For each category, we counted frequency information for types (unique occurrences) and tokens (all actual items). The Natural Language Toolkit (NLTK) [20] was used for extracting words, bi- and trigrams, and sentences. For nouns, verbs and adjectives, a Part-of-Speech (POS) tagger trained for general Swedish was used: Stagger [21]. To account for inflected forms of words, Stagger was also used to create lists of lemmatized words (inflections conflated to base form).

A qualitative content analysis was performed on the 100 most frequent items for each category (words, bi- and trigrams, sentences, nouns, verbs and adjectives). The method included a step of modification: the top 100-lists were edited in regard to names for de-identification and POS-tagging errors by simply removing these posts and replacing with next posts. The content analysis included classifying the content into new semantic categories. Verbs were also analyzed with regards to active and passive voice. The qualitative investigation was performed by a senior physician and a computer linguist.

Results

Corpus statistics

The statistics for words, bi-/trigrams and sentences in the Stockholm EPR X-ray corpus as well as the three word classes are shown in Tables 1 and 2.

Table 1 – Number of words, bigrams, trigrams and sentences in the Stockholm EPR X-ray corpus

	All words	bigram	trigram	sentences
types	200703	2534969	5357542	1874464
tokens	20290064	17728463	15276077	2567035
top100				
tokens	7150511	2759515	1403104	201074
%	35%	16%	9,2%	7,8%

The sum of the top 100 sentences represents 7.8 % of the total number of sentences in the corpus. However, the vocabulary is recurrent; the sum of the top 100 words represents 35 % of the total number of words used in the corpus, and 16 % of all bigrams are found among the top 100 most frequently occurring bigrams. When conflated to the base forms (lemmatized) in the three word classes, the proportions are higher (Table 2). More than half of the nouns are found among the top 100, as well as an astounding 79% and 74%, respectively of all the verbs and adjectives. This is in part due to the very frequent use of a few words (figure 2). Removing the 5 most common nouns, verbs and adjectives, shows that the top 100 still make up a sizable part of the total token (39 %, 35 % and 47 % respectively).

Table 2 – Number of nouns, verbs and adjectives in the Stockholm EPR X-ray corpus, lemmatized

	Noun	Verb	Adjective
types	111468	20351	25278
tokens	8254868	2079040	2951736
top100:			
tokens	4389486	1640789	2189288
%	53%	79%	74%

On average, a radiology report consisted of five sentences (min = 1, max = 66). The average length of the sentences (with word frequencies between 1 – 40) was 12 words (Figure 1). Many sentences were not full sentences; among the top 100 sentences only 23 contained both subject and predicate. Also, 7 of the top 100 sentences were composed of a single word, and 30 were composed of only two words. Among the

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[4] This research was approved by the Regional Ethical Review Board in Stockholm (Etikprövningsnämnden i Stockholm), permission number 2012/2028-31/5

longest sentences of the 100 most frequent were standard phrases of administrative character.

A small number of words and expressions were found to be very frequent (Figure 2), which can be explained by the structure of the radiology reports. Headings and administrative phrases such as information about dates, names of radiologists, pagers and telephone numbers are included in the free text section of the reports. The peak at 22 words per sentence (Figure 1) reflects an example of this; these sentences contained a recurring administrative phrase.

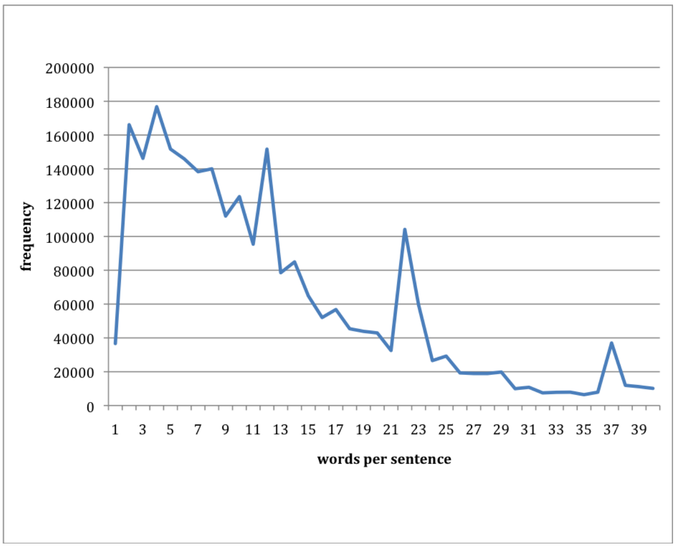

Figure 1 – Frequency curve for number of words per sentence, Stockholm EPR X-ray corpus

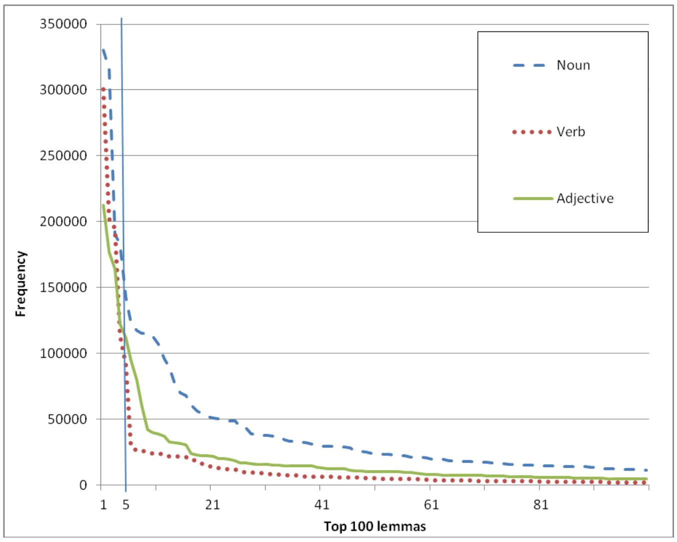

Figure 2- Frequency curves for the top 100 nouns, verbs and adjectives in the Stockholm EPR X-ray corpus

Content analysis

The structure of the radiology reports was usually coherent, providing a better orientation for the reader [22]: first a heading or first sentence describing the procedure and method used, and which body part was examined, thereafter a description of what is seen in the radiologic pictures produced during the examination, followed by an interpretation of the findings and their importance, with diagnostic reasoning. Administrative information, such as dates and names of physician(s) in charge would usually be at the end of the report.

The 100 most frequent sentences mainly contained information about findings, body parts, procedures and administration (Table 3). A vast majority of the mentioned findings were negated. In fact, the most common sentence in the corpus was *Ingen stas* (No stasis), from pulmonary X-rays. Negated findings were commonly expressed with simple negation cues: *ingen*, *inga*, *inget* (“no” in different inflections). Also, the most common sentences reporting on findings were about normal status, e.g. confirming normality of size for the ventricles of the brain.

Table 3- All words, sentences, bi-/trigrams; semantic categories from content analysis of top 100-lists. (nd= not determined)

	All words	**sentences**	**bigram**	**trigram**
abbrev.	18	12	38	29
admin.	**20**	16	**24**	**67**
definition	nd	4	1	4
method/ procedure	11	**25**	13	7
body part	8	**49**	**22**	10
position	7	0	11	1
finding	**18**	10	**21**	13
negated finding	nd	**61**	8	5
time	3	2	0	0
size	13	1	12	5

The top 100 bi- and trigrams were found to convey information about administrative phrases, body parts, findings, and procedures (Table 3). As all radiology reports contain the name of the examining radiologist as well as the senior radiologist contra-signing and taking the responsibility for the report, many bi- and trigrams contained person names (38 % and 70 % respectively). These were removed before the content analysis presented in Table 3.

Administrative words and phrases were common, present in 20 of top 100 words and 16 of top 100 sentences, and dominated the trigrams (67 of 100). Body parts were mentioned in about half of the top 100 sentences, and in 22 and 10 of the top 100 bigrams and trigrams, respectively.

Foreign words were of Latin, Greek and English origin. They were most commonly words for body parts, positions and procedures. Generally, words originating from Latin were used for body parts while English words were used for the names of methods and for radiologic equipment.

Miscellaneous information such as administrative routines, definitions of various grading scales, or technical descriptions of examinations or procedures, was present in 45 sentences of the top 100 most common.

Abbreviations were common, 18 of the top 100 words were abbreviated. Of these, 7 were common abbreviations (e.g. *tel* = telephone, *cm* =centimeter*)*, 10 were domain specific (e.g. *iv* = intravenous) and one ambiguous (*ca* for cancer or circa).

In Figure 3, the semantic categories are shown for different word classes. Most commonly, nouns were words for findings (*pleuravätska*, *fraktur*; pleural effusion, fracture), body parts (*hjärna*, *mjälte*; brain, spleen) and administrative words (*dokumentdatum*, *preliminärsvar*; date of document, preliminary report). The adjectives most often concerned descriptions about findings, such as positions (*vänster*, *dorsal*; left, dorsal) and size (*liten*, *lång*; small, long). Verbs belonged to different semantic categories, with verbs about findings (e.g. *bukta*, *påvisa*; bulge, detect) dominating. Of the top 100 verbs, 70 were found to be in active and 30 in passive voice.

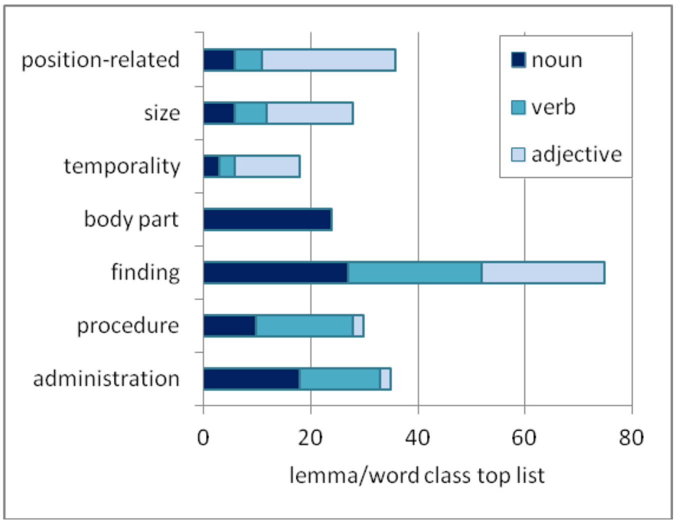

Figure 3 – Number of nouns, verbs, and adjectives in top 100-lists, according to semantic categories.

Discussion

We describe a large corpus of Swedish radiology reports. This corpus can be used to develop a text simplification tool for Swedish clinical text.

Historically, medical terminology origins from both Latin and Greek. The Latin terms generally denote body parts while Greek, the language of pathology, give rise to diagnostic terms as well as names for different medical specialties [12]. Nowadays, English expressions are gaining influence on Swedish health records since this is the vocabulary used in textbooks and medical journals. Many foreign words have been assimilated to the Swedish medical language by the addition of Swedish inflections, but will seem “Latin” to the layman reader and hence incomprehensible. Previous studies have shown differences in professional and layman vocabulary in the Swedish medical domain [23]. Also, the close resemblance of expressions in different languages, combined with Swedish inflections, results in diverging spellings which complicates automatic processing of clinical text.

Findings reported among the top 100 sentences in the Stockholm EPR X-ray corpus were dominated by reports of normal conditions and exclusions. Many negations were probably due to mandatory reporting of certain aspects, e.g., for X-ray of lungs to negate pulmonary infiltrates, for CT of brain to negate tumors or bleeding. This reflects something important: if the report conveys a new finding, this is not written in a standardized way. Instead, for each such situation, it is described in more varied ways. This has implications for a future text simplification system, as these more varied formulations probably convey more details that affect the patient directly.

Observations in this study confirm earlier findings that different medical terms can be used for the same pathology when excluding and reporting normality, or reporting specific findings [24]. For example, the word *fraktur* (fracture) was used to describe a pathological finding, but the more general term *skelettskada* (skeletal injury) was used when negating a fracture.

The content of the radiologic reports could to a large extent be classified into semantic categories, similarly to what has been found in other studies on clinical text [11]. There are several studies on automated tools for entity recognition for some of these categories, e.g. findings and body parts [25, 26]. Such tools could be used in conjunction with lexical exchange for text simplification.

Only 23 of the 100 most frequent sentences were complete, containing both a subject and a predicate. However, the majority of the short sentences contain an implicit subject and predicate, e.g. *Ingen stas* (No stasis) could be rewritten as a sentence such as “The radiology image (*subject*) shows (*predicate*) no stasis”.

Abbreviations were found to be of two kinds; abbreviations from general language and abbreviated medical terminology. The expansion of clinical abbreviations is not a trivial task and will require domain-adapted Natural Language Processing (NLP) tools, preferable context aware for disambiguation.

An important part of the radiology report is the concluding remarks with diagnostic speculation and reasoning, often intertwined with expressions for hedging and uncertainty. For text simplification, these parts need to be considered with great care since this poses special problems for layman comprehension [27].

Current state-of-the-art NLP tools are not tailored for this type of fragmented and information dense language that requires a lot of implicit knowledge. However, as has been shown in this study, the majority of the words convey a limited vocabulary and a large amount of recurrence, e.g. a small set of frequent adjectives. This has important implications: if the most frequent words, phrases and sentences are converted to more easy-to-read variants, a large proportion of the content is captured. Previous approaches for this problem include use of related expressions from hierarchical terminologies [16] or hyperlinked explanations from dictionaries [28]. The aim of the present project is to approach this not by introducing distracting fact boxes or choice of multiple lexical suggestions, but instead to produce a complementary simplified and coherent text adjacent to the original text.

We have limited this study to a description of the Stockholm EPR X-ray corpus. To deepen the understanding of these texts, we will conduct comparison studies with other text types. Furthermore, we are not reporting any conclusions on readability. This, and the level of required simplification, should be investigated with user studies.

Conclusion

We present a large resource of Swedish radiology reports. The qualitative analysis reveals that the most common words and expressions are about body parts, procedures, and findings, but also administrative issues. The study disclosed a set of recurring sentences and expressions, making up a considerate part of the corpus, implying that standard phrases can be identified and exchanged as part of a text simplification process.

Less easy to automatically process are the more varied descriptions of unique pathological findings.

The Stockholm EPR X-ray corpus can be used for development of text simplification and other NLP tools for health informatics purposes.

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Ambient Assisted Living Ecosystems of Personal Healthcare Systems, Applications, and Devices

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Abstract

Personal health monitoring aims to empower citizens' for their healthcare and wellness. The healthcare devices, connected with healthcare applications, clinical information systems, tele-medicine services, and national medical record systems are evolving into ambient assisted living (AAL) personal healthcare ecosystems. Accordingly, the research and development is gaining significant momentum and expanding multidisciplinarily, addressing functional, quality-of-service and quality-of-experience aspects. However, most of the current research in AAL focuses on specific aspects of AAL in isolation, lacking overall system design, integration and quality perspectives. Consequently, the evolving solutions fail to achieve one or more essential requirements such as interoperability, integration, usability, security, and dependability. To bridge the gap between requirements and technical services, this paper presents a conceptual framework providing a holistic view of AAL ecosystems. Besides, the system architectures and technology standards are discussed for the proposed CareStore platform for seamless deployment of AAL applications and devices.

Keywords: Ambient-assisted living, personal health monitoring, healthcare systems integration and interoperability

1 Introduction

Ambient-assisted living (AAL) offer personalized healthcare and wellness services supported by medical sensors/actuators, personal health monitoring applications, tele-medicine systems, communication networks, and health information systems. Current research in AAL addresses one or more aspects in isolation lacking a holistic AAL ecosystem perspective, which should consider business, organizational, technological, user-experience and quality-of-service aspects all together. Besides, there is a lack of conceptual frameworks, providing a complete view of AAL ecosystems. Some of the frameworks such as universAAL [1], SOPRANO [2], MonAMI [3], and ecosystems such as Continua [4] address various aspects of AAL systems. However, those focus mainly on resolving technological differences among medical sensors and healthcare systems through standards, i.e., IEEE 11073, HL7, EN13606, and ASTM F2761. The objective of this paper is to present the *OpenCare Conceptual Framework* for AAL ecosystems of personalized healthcare systems, applications and devices. The proposed framework is an extension to our previous research related to *OpenCare Project* [5]. In this contribution, we will extend the *OpenCare Platform* as an *OpenCare Conceptual Framework* providing a holistic view of AAL ecosystems, to bridge the gap between AAL services and technological platforms. We will also discuss the high-level system architectures of the proposed *CareStore Platform* [6]., which is our ongoing work realizing the *OpenCare framework.* The paper is organized as follows. Section 2 briefly presents the related research in AAL systems and solutions. Section 3 presents the proposed conceptual *OpenCare framework*. The framework is realized by the *CareStore Platform,* which is discussed in Section 4. This section further elaborates the internal architecture of different subsystems of the *CareStore Platform*.

2 Related Work

The scientific and business ventures are joining hands to reduce healthcare expenses by empowering the citizens in their personal healthcare. The consortia, conceptual frameworks and technical platforms are striving to bridge the wide gap between AAL services and technologies [1-3]. Technology standards i.e., IEEE 11073, HL7, EN13606 are struggling to resolve interoperability and integration issues among AAL medical devices, applications and systems. Whereas, the regulations i.e., HIPAA, IHE, EU-Directive are devoted for providing guidelines to achieve integration without compromising security, privacy, compliance, and usability. The AAL solutions ensuring QoS attributes i.e., usability, data accuracy [7], security/privacy [8], and availability [9] are leading the rest. Besides, the QoE (Quality of Experience) evaluation significantly contributes in identifying the concerns of potential AAL users to evolve better usable systems [10]. Other research also closely related to our work is [11, 12]. [11] has mainly focused on sensor, middleware, and interface layers, whereas [12] considers the high-level business services in AAL4ALL framework. In comparison, our proposed *OpenCare framework* identifies more conceptual levels, i.e., device and application marketplace, quality attributes, technology standards and external systems.

3 Material and Methods

We investigated ambient assisted living domain through academic research and practical experience. We conducted an extensive survey of existing AAL system and platform to evaluate the existing solutions and identify the major aspects of AAL solutions. Besides, we have been working with local industry and caring homes in Denmark and Germany to elicit the business and non-functional requirements of AAL systems through user-centered and participatory research. For user participation, initially we developed small-scale prototypes to connect the personal healthcare devices such as glucose meter and weight scale with the homecare platform. The users of different age, background and education level were selected to evaluate to prototypes. Based on the rigorous investigation and analysis of existing AAL platforms, and evaluation/feedback gathered through user experience, we propose a conceptual *OpenCare Framework*, which identifies the major aspects of AAL systems. Moreover, the high-level system architecture of proposed CareStore platform and detailed architectures of its subsystems are also elaborated.

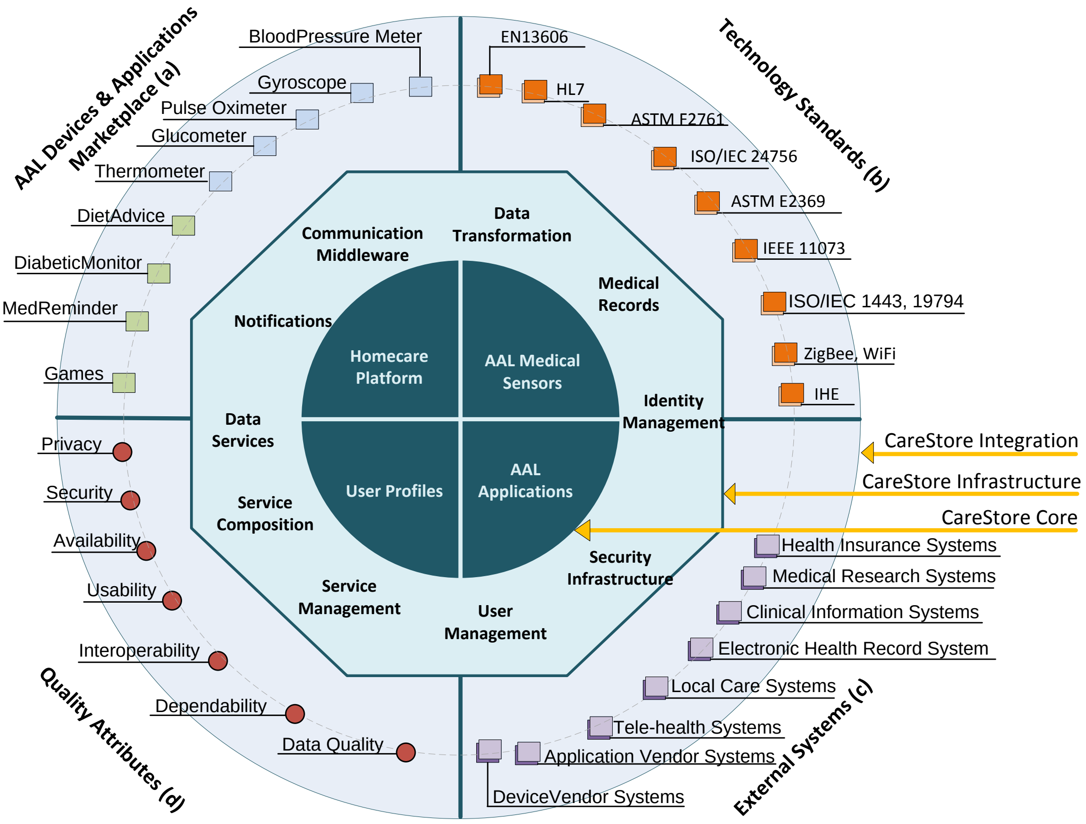

Figure 1: *OpenCare Framework* for AAL Ecosystems of personalized healthcare systems, applications and devices

4 OpenCare Framework for AAL Ecosystems

AAL ecosystems are complex, multidisciplinary, and personalized in nature. Therefore, it is important to understand different aspects of the AAL systems considering business services, quality attributes, usability/accessibility concerns, integration requirements, and technology standards required for implementation. The proposed *OpenCare* framework defines various aspects of AAL ecosystems to meet its complex requirements. *OpenCare* framework is divided into three conceptual levels including *OpenCare Core*, *OpenCare Infrastructure* and *Open Care Integration*, as shown in Figure 1 and discussed subsequently.

4.1 OpenCare Core:

OpenCare Core identifies very essential components of AAL ecosystems consisting of the *homecare platform, AAL medical sensors, AAL applications* and *user profiles*. The homecare platform is user's personal computer, which connects with AAL medical sensors and deploys AAL applications. The user profiles are created at the homecare platform, so that access to AAL applications and remote healthcare services is granted based on the user profile attributes. User profiles store personal, identity and healthcare data which includes social, credential, device/application information of citizens at a local or remote computer depending upon the system architecture.

4.2 OpenCare Infrastructure:

OpenCare Infrastructure represents infrastructural subsystems and components of AAL ecosystems. It consists of the applications, subsystems, communication middleware and data stores required for AAL ecosystems. The *Data Services* is the set of business services offered by an AAL system such as add new device, add new application, view blood pressure report and download device driver services.

The data services can be atomic services offered by a single organization or composed services from two or more services involving more organizations. For instance, configure homecare platform service will invoke the services to authenticate the user, download updated version of homecare platform, and install updated homecare platform before configuring it for a particular user. The composition will be performed by the *Service Composition component*.

The *Service Management* component will be used by a system administrator to manage business services. The service management activity includes service packaging, deployment, updation and monitoring. Moreover, the administrator uses the *User Management* component to add and manage users in the AAL system including citizens, caregivers, device vendors, application vendors, and system administrators. *Notifications* are used to send and receive messages among systems and subsystems for the subscribed events. AAL ecosystems are composed of the internal and external systems subscribing for events of interested topics. For example, the homecare platform will be interested to receive an update notification, when a new version of the platform is available at the central repository. Similarly, the homecare platform can subscribe for notifications from vendor systems to receive updates for AAL device drivers and applications.

The *Middleware* infrastructure provides many services to integrate technologically diverse applications and systems using protocol transformation, message exchange (i.e., mediation, filtering and routing), and monitoring and management of business services. AAL systems rely on a middleware to provide message-based communication to integrate and interoperate AAL devices, applications and systems. The *Data Transformation* component is responsible for receiving data from a source system or device, and transforming into the required format/protocol of the destination system or device to achieve interoperability. For example, the vital signs data created by IEEE 11073-compatible devices can be transformed to HL7-CDA format to store medical records in a central database. The *Medical Records* is an important healthcare IT concept in today's globally connected healthcare databases. There are voluminous standards and specification spotlighting several aspects of medical record systems. An *Identity Management* component deals with user identities, which are created as digital certificates, user name passwords, and biometric features. Whereas, the *Security Infrastructure* consists of security mechanisms, architectures, databases, and protocols to ensure data confidentiality and integrity.

4.3 OpenCare Integration:

The external fold of the OpenCare framework diagram in Figure 1 shows the integration perspective of AAL ecosystems. Integration is concerned with connecting the devices, applications, databases, subsystems and systems to accomplish an AAL ecosystem. The four quadrants in the figure show the major aspects of the integration perspective, which are discussed below.

a) *AAL Devices and Applications Marketplace***:** There is a growing trend of purchasing AAL products and services from online stores or marketplaces of medial sensors/actuators, mobile health apps, and health monitoring apps. Medical sensors/actuators are used for the measurement of physiological health parameters of the citizens such as temperature, pulse rate, blood pressure, motion, and glucose levels. The medical devices i.e., gyroscope, pulse oximeter, glucometer and others are used for collecting vital signs. The health and wellness applications such as Diet Advice, Medicine Reminder, Diabetic Monitor, Sleep Cycle, and Stress Check are installed on the homecare platform.

b) Technology Standards: The AAL ecosystems rely on technological standards in different system lifecycle phases. The IEEE 11073 standard defines a common framework for personal health medical devices data in a transport-independent manner to achieve interoperability. The ASTM F2761 standard focuses on safety requirements in using medical devices in integrated clinical environment. The HL7, EN13606, and IHE standard also address interoperability, integration and security requirements but at a broader level of healthcare systems.

c) External Systems: AAL system business workflows span across the boundaries of AAL subsystems for integration with external systems. AAL systems integrate with *application* and *device vendor* systems to download the device drivers and applications from the vendors' online marketplace. *Tele-health systems* will interact with AAL systems to provide home-based services through tele-medicine applications. *Electronic Health Record Systems* are the centralized medical record databases at regional or national levels. *Clinical Information Systems* receive citizens' medical data and enable physicians or specialists to access it for diagnosis and medication. *Medical Research Systems* collect the citizens' medical data from AAL systems to conduct research on specific diseases or medicine. Finally, *Health Insurance* organizations would be involved in health data to validate health insurance claims.

d) Quality Attributes: Quality attributes including quality-of-service and quality-of-experience are crucial factors in AAL. *Interoperability* is a key requirement to bridge the semantic and technical gap among personal healthcare devices, applications, networks and systems. *Usability* is critical as AAL systems are also used by elderly users or users with health impairments. User-centered development methodologies involving fast prototyping and interactive feedback from user space helps extensively to achieve better and more usable systems. *Availability* is concerned with many parameters including availability of devices (and their drivers), applications, network resources (network hardware and bandwidth), technical expertise and trainings in the AAL domain. Availability is increasing with growing global marketplaces (i.e., online stores) and technical infrastructure (i.e., web, grid and cloud solutions) ensuring high availability of resources. *Security* and *Privacy* are major concerns to protect the medical data against unauthorized access by eavesdroppers and misuse of personal data for commercial or criminal causes. *Dependability* is attributed to reliability, which encompasses system availability, performance, safety and integrity. Equally important is *Data Quality*, because inaccurate and erroneous data mishandled by the systems may result in severe and unfavorable consequences to the health and life.

Having discussed the conceptual *OpenCare* framework; we will present the *CareStore* platform, which realizes the concepts defined in the framework.

5 The CareStore Platform

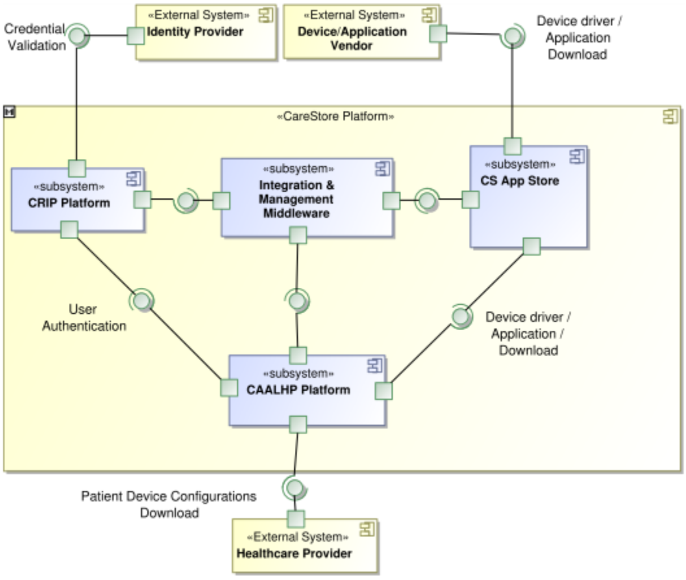

Figure 2: The System Architecture of the *CareStore Platform*

The CareStore platform is developed with the objectives to develop an open platform for seamless deployment and installation of medical devices and applications, and create a marketplace for downloading device drivers and applications. Besides, integration of the homecare platform with the external vendor systems is one of the major targets to be achieved. Security is provided by an integrated subsystem of the platform for user identification (through biometry and RFID) and device recognization (through RFID) [6].

Figure 2 shows the high-level system architecture of CareStore platform as a UML component diagram, which shows the internal subsystems of the platform i.e., *Common Ambient-assisted Living Homecare Platform* (CAALHP), *Common Recognition and Identification Platform* (CRIP), *Integration and Management Middleware* (IMM) and *CareStore AppStore*. The CAALHP subsystem provides the core AAL services to the end user; CRIP subsystem is responsible to authenticate the user; IMM subsystem is the infrastructural and communication middleware and CS AppStore subsystem is the repository of device drivers and AAL applications. The subsystems and external systems of CareStore system architecture are integrated with each other in a service-oriented way through services offered and services required by the subsystems and external systems, which are shown in system architecture using UML notations of circle (for service offered) and semi-circle (for service required). The CAALHP subsystem depends upon the services offered by other subsystems. For example, when a user interacts with CAALHP, it invokes the security services offered by CRIP to authenticate the user. The CRIP on the other hand depends upon the credential validation service offered by an Identity Provider.

Similarly, CAALHP invokes the device driver/application downloading services of the CS AppStore for deployment at the homecare platform. The *PatientDeviceConfigurations* are downloaded by CAALHP through the services offered by (external) Healthcare Provider. The *patientDeviceConfigurations* are the configurations of a particular medical device for a particular citizen created by a healthcare service provider i.e., therapist/physician/specialist using *Healthcare Provider System*. The idea is that a therapist creates (and uploads) a prescription for a particular citizen (or patient) to use a particular medical device with prescribed settings (e.g., ergometer load control settings, infusion pump settings for remote health monitoring. As soon as new configurations are uploaded, those are pushed to the homecare platform resulting in seamless configuration of remote health monitoring devices. Accordingly, the IMM subsystem, which is the communication and infrastructural backbone of CareStore platform offers services to CAALHP, CRIP, CS AppStore subsystems and external organizations, so that those can exchange business, security, notification and updation messages to each other in a loosely coupled component-based architecture. We will present more detailed internal architectures of different CareStore subsystems in the subsequent part of this section.

5.1 CareStore AppStore:

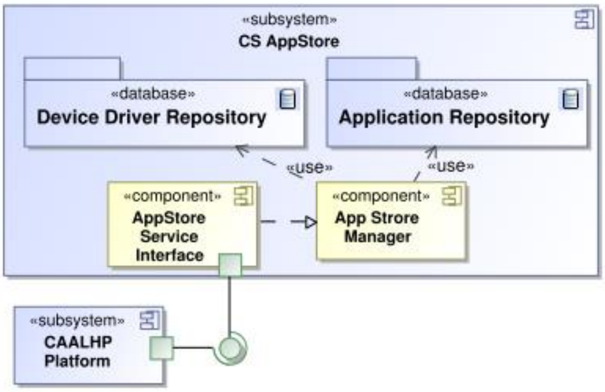

Figure 3: *CareStore AppStore* Subsystem

The registered device and application vendors will upload their products at the online CareStore AppStore subsystem, so that the same can be downloaded automatically by the CAALHP subsystem when a particular device is recognized by the homecare platform or an application is requested by the end-user. The technical design of the CareStore AppStore is shown in Figure 3. The AppStore services to download drivers and applications are offered by an *AppStore Service Interface*, which connects to the *AppStore Manager* component to retrieve the required artifacts from corresponding repositories.

5.2 CAALHP: The homecare platform represents the homecare subsystem of the *CareStore* platform. It consists of the core part of the platform called i.e., CAALHP, which offers AAL services to the end-users and platform administrators. CAALHP offers services to (seamlessly) add new devices, install health monitoring applications, send vital signs, update platform and register users.

The internal design of the CAALHP subsystem shown in Figure 4 consists of the CAALHP Interfaces i.e., *User Interface* and *Admin Interface*. The user interface offers AAL services to the end-user, whereas, the admin interface is used by the platform administrator to register new users, add/remove vendors, and update the platform. The *CAALHP Interfaces* are connected to the *CAALHP Services* component, which deploys the business logic of AAL services. We have separated the service interfaces from service implementation to provide integration of technologically diverse components for scalable and extensible systems architectures.

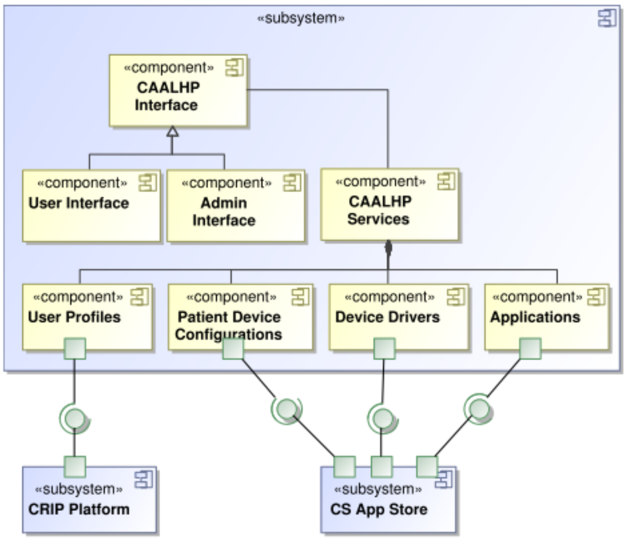

Figure 4: The homecare platform CAALHP

The *Applications* and *Device Drivers* components maintain the repositories and configuration information of different devices and applications installed at the homecare platform. The *Patient Device Configurations* component stores device configurations prescribed by a physician or doctor for a particular patient. The *User Profiles* component stores the profiles and identity details of users. The identity information is maintained with the help of CRIP platform, which is responsible to authenticate the users.

5.3 CRIP: The CRIP platform offers a set of security services required by the CareStore platform. The internal design of the CRIP subsystem is shown in Figure 5. CRIP stores the RFID data of medical devices, so that those can be recognized when added to CAALHP subsystem. The *Device Validation* component uses RFID data for device recognition. The *Encryption* and *Digital Signature* components provide functionality to use data protection algorithms (i.e., AES, DES, DSS, MD5) to ensure data confidentiality and integrity. The *Authentication* component validates user credentials, whereas, the *Authorization* component validates user roles and authorization policies. The authentication component relies on a local *Identity Store*. The user identities are verified by an external system i.e., Identity Provider, whereas, the access rights are verified through access control policies database. The *Non-repudiation* component ensures auditing and stores evidences of communication with internal and external systems.

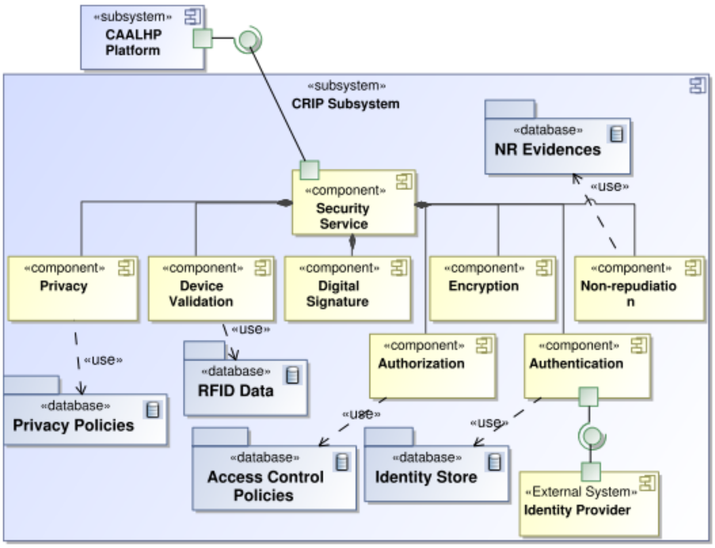

Figure 5: The CRIP Subsystem of CareStore AAL platform

The evidences are stored in *NR Evidence* database. Finally, the Privacy component evaluates the dissemination of data from CAALHP to external system. The privacy preferences of citizens are stored in the privacy policies database so that the same should be forwarded along with data when medical data is sent to the external systems.

Conclusion

Our theoretical analysis and real-world experience led us to the results that most of the current platforms and solutions are not easy to use in personal health monitoring and telemedicine scenarios. The conceptual frameworks are more ideal than practical, whereas the available solutions are still facing plenty of challenges such as interoperability, usability, dependability/availability, and security. In current status, the end-users still require significant technical support and continuous supervision from skilled IT and medical staff, which on one hand hinders their ‘independent-living’ and on other increase the cost for the (elderly) citizens with limited budget. Besides, it puts lot of economic pressure on the government and health insurance providers to meet the expenses. More validation and user experience studies are necessary to improve the systems with user feedback and participatory development. Based on the requirements identified through analysis of contemporary AAL systems and user experience evaluation the proposed CareStore platform aims to provide a technical solution for seamless deployment of medical sensors/actuators and AAL applications. CareStore is an ongoing project; currently we have preliminary prototype implementation to connect blood pressure and weight-scale devices with the homecare platform. We are extending the platform and it services to evolve as an open AAL platform for connecting devices and applications in a vendor-neutral way and integrate the AAL subsystems with tele-health and medical record systems.

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Scandinavian Approach to Assisted Living: Navigating the European Research Agenda

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Abstract

Scandinavian and European states alike are faced with a growing elderly population. Health factors leading to sensory loss, dementia and increasing physical frailty can pose barriers to independent living for this population. Research initiatives and implementation projects have cropped up at many levels of government with similar goals of seeking ways of addressing the diverse needs of the elderly citizen segment. Often projects find it difficult to gain a holistic understanding and may not succeed in obtaining the benefits of the larger European research agenda. This paper develops a "roadmap" or clarification of the larger European research agenda. It is our aim that local initiatives may be better able to apply the lessons learned from other research and be made aware of the knowledge resources available through the international European research community at large.

Keywords:

Assisted living, elderly, European Commission, Scandinavia.

Introduction

Active and healthy ageing has been on the research agenda in Europe for the past decade. With low birth rates, and a longer lived population, the future need for care workers for the growing elderly population has been recognized as a future challenge for society. Assisted living for longer independent living and application of assisted living technologies is recognized by many as an approach for addressing this current challenge. This paper addresses the two-part question: what is the European research agenda on independent living and how can local Scandinavia initiatives make use of the European agenda to further their own goals. We introduce some international trends and the Scandinavian policy for active and healthy ageing, and then present the European research agenda, describing how it arrived at its current state and where it is going. In the discussion section we suggest a research agenda for Scandinavia that aligns with the European agenda, with the goal to obtain the greatest value from larger initiatives. In conclusion, we forecast the future of Scandinavian policies for society's support of independent living, and highlight the ongoing challenges.

The remarkable growth in the elderly populations presents challenges to the welfare services. One challenge in particular, is that the relative amount of health care workers is decreasing compared to numbers of elderly. Among the approaches to address this challenge are: to change the services to incorporate more voluntary help; and use of information communication technology (ICT) technology such as sensor- and smart-home technologies to assist the elderly and make them able to carry out daily living activities in a safe and secure manner, and with necessary alarm systems implemented. The approach of incorporating ICT may have great potential value, and many authorities think such approaches warrant further investigation.

Elderly Independent Living as Assisted with ICT

One of the barriers to adoption of ICT solutions have been the technology readiness of the stakeholder group. However, trends show that in the home, use of computers and Internet access in the home, have achieved high rate of acceptance among the elderly in the Western world, including Scandinavia. Over the last 6 years the proportion of people in Norway in the age group 65-74 that has used a PC and Internet on an almost daily basis, has more than doubled. In this age group, 45% use a PC and 39% use Internet daily or nearly every day [1]. We expect this group will continue to be PC and Internet users as they get older, hence we expect a high increase in net users among the elderly. Mobile devices with new and easy to use interfaces have also successfully penetrated the market of senior citizens [2]. Hence we can expect that senior citizens will be ready to adopt technology for assisted living to an increasing degree.

The challenges faced by elderly vary considerably [3], although a public report for the Norwegian Health ministry [4] suggests focusing on three issues; fall prevention and detection, communication technology and wander management systems (GPS). There are also other challenges that senior citizens living at home may face such as lack of nutrition, difficulties in managing opening doors, heating, communication with medical staff and family etc. A SINTEF project on assistive technologies lists a number of possibilities [5]. Both this report and the NOU 2011:11 [4] base their division on the Center for Aging Services Technologies´ work [6].

One of the challenges is to select a portfolio of equipment that elderly can get access to as the need for assistive technology occurs and possibly gradually increases. This will require solutions which are easy to tailor to the patients' specific needs, and adjust according to decline in physical and mental conditions. Challenges also include issues concerning financing, standardization and integration, implementation in a health care setting, operations and maintenance, and keeping track of technologies and their application. There is very little prior research on effects of assistive technology for elderly in need of care, while living alone. However Van Malden et. al. [7] provides a systematic review of studies of interventions to enhance the Quality of Life (QoL) of older people in residential long-term care. In this paper, 35 articles were assessed on issues such as study design, quality of the studies, measures of

QoL and effects on QoL. The study finds that most of the papers are low on methodological quality. The instruments used to measure QoL were diverse and interventions were often rather limited.

QoL is an umbrella conceptualization that refers to well-being across multiple domains. It has both subjective and objective components, is based on individual needs and is composed of multidimensional constructs influenced by relationship and environmental factors. However no consensus exists on how it should be defined [8]. Perhaps the best known QoL instrument is the SF-36, a questionnaire which originally had 100 items, but now has 36. This has been criticized for having limited accountancy of social functioning, and for completely missing of items addressing the environment [9]. In [10] two of us have adapted and extended the QoL framework based on the core domains of Schalock and Alonso [8] to the challenges of the elderly. We also recommend subjective measures in defining the success of assistive devices, and that the assessment framework focuses on the subjective views of the elderly to avoid source biases of powerful stakeholders, such as ICT vendors [10].

In the next section we will take a look at some international trends and the policies and initiatives in the three Scandinavian countries Denmark, Sweden and Norway, before presenting the emerging European research agenda on assisted living.

International Trends and Scandinavian Policies

The Continua Health Alliance (www.continuaalliance.org) has established a system of interoperable personal health care devices and solutions, to give recommendations for interoperability and to promote use of international standards. The alliance is a non-profit, open industry organization of healthcare and technology companies. However not many products and manufactures follow this standard, and there is a lack of standards from sensors on the patient's body and at the patients home to the other endpoint at the health care services. The consequence is several "silo" products with proprietary solutions, which currently are impossible to combine into a common framework.

In the Scandinavian countries, the term "welfare technologies" is widely used, addressing technologies and solutions to be used by patients and elderly people in their everyday life in order to be independent, to have tools to improve living in original homes with necessary support by family and friends, and to have voluntary services and the health care services (public and private). These efforts have a goal of reducing hospitalization and use of caring homes.

The social welfare services in the Scandinavian countries have several similarities; it is therefore reasonable to suppose that by learning from each other, the welfare and health care services can exchange experience and bring forward good examples and typical use-cases. This will also be important at the local municipality level, where currently multiple local projects are initiated on the same issues, but without coordinated actions. Thus there is motivation to make a coordinated effort to learn from each other, to establish a close Nordic cooperation within this field, including the municipality health care services. The Nordic Centre for Welfare and Social Issues (http://www.nordicwelfare.org) was established in 2009 in order to facilitate inter-Nordic exchange of experience and knowledge [11].

In Denmark, funds have been made available for project within welfare technology (The Danish PWT Foundation, The Prevention Fund), and there are a lot of ongoing R&D activities and national networks (Carenet, CareWare, Center for Sundhedsteknologi, HanDiaTek, IntelliCare, RoboCluster). The National Board of Social Services aims to promote new development and initiatives in social services, to follow up initiatives from the Danish Parliament. An important initiative due to the "Quality Reform" was to invest three billions DKR in new technology which could reduce manual work and lead to changes in the organizations. Most of the projects have been within welfare technology.

In 2011 the Agency for Digitalisation was established to speed up the digitization processes required for modernization of the Danish Welfare society [12]. Results from a study in 2012 on strategies for welfare technology and solutions, showed that economic benefits can be obtained and at the same time as quality in public services could be increased [13]. Local Government Denmark (an interest group of Danish municipalities) has evaluated efficiency in Danish municipalities in 2012 and 2013, and shows that 500 Mil DKR was saved due to use of welfare technology [14]. In 2010 MedCom published a status report on use of Telemedicine [15], this led to a National Action Plan for Dissemination of Telemedicine in 2012 [16], where home monitoring services was suggested implemented in large scale trials.

In Sweden, The Ministry of Health and Social Affairs have established the project LEV (Long-Term Demand for Welfare Services: Health Care and Care of the Elderly up to 2050) as an important instrument. Through this project, two reports focus on options better health and more efficient services [17]. Based on simulation models they expect the level of cost to increase. A new report focuses on how the relationship between patients/clients and healthcare professionals must change, and presents many examples from the real world [18]. A review of Swedish municipalities use of welfare technology in 2012 [19] showed a positive attitude, however the economic situations for the municipalities was a barrier to continued efforts for implementing new solutions. Lack of adequate competence, lack of information, need of infrastructure and lack of clear strategies were also shown to be possible barriers for future work. There are interesting ongoing projects in Gothenburg, Norrköping and Västerås, where technologies for elderly people are evaluated [20].

In Norway, several governmental reports address the impact of ICT in future health care services [21]. In addition the NOU 2011:11 focuses on innovation in technologies and innovative use of technology in the health care sector [4]. Based on [4] the Directorate of Health recently launched a report [22] and a set of recommendations on welfare technology, proposing 19 actions. The governmental report (Stortingsmelding 10 (2012-2013)) [23] sets the future policy for developing health care services with improved quality and patient safety. The report focus on actions, access to information is said to be crucial, and efforts to develop comprehensive ICT solution are suggested. Another governmental report (Stortingsmelding 9 (2012-2013)) [24] focuses on the ICT services in the health care sector, and sets a goal of only one electronic health record per inhabitant.

In Norway, the ongoing activities within welfare technology are quite fragmented, although a lot of projects have been initiated. There are several competence centers as the University of Agder, University College in Bergen, University College in Gjøvik, University of Trondheim/SINTEF, and University of

Tromsø/Norwegian Centre for Integrated Care and Telemedicine. In addition, there are business clusters such as Oslo Medtech, Borg Innovation, Arena Helseinnovasjon and IKT Grenland. There is a Nordic Medtech cluster with industrial partners from Norway and Sweden, where Welfare technology is one on the activities in addition to medical devices, eHealth, Bioinformation and solutions for diagnostics and surveillance.

Emerging European Research Agenda

The European Commission (EC) research agenda will no doubt influence the research agenda, trial programs and also indirectly the policy development in the Scandinavia countries. An understanding of the EC initiatives may therefore be essential to a better development of ageing well programs in Scandinavia. The following section creates a roadmap for understanding the EC research agenda.

European i2010 Initiative on e-Inclusion is the European Commission research agenda on ageing well. The actions of this initiative were outlined and adopted in June 2007, in the Ageing Well in the Information Society Action Plan [25]. The EU backed research in the FP7 framework under the CORDIS Programme for fostering independent living and inclusion using ICT [26]. The i2010 agenda was active in the period of 2005-2009. The i2010 introduced a policy framework for promoting the contribution that information and communication technologies (ICT) can make to the economy, society and quality of life. The research agenda of this framework focused on public inclusion and access to information.

The Digital Agenda, created in 2011 (for 2013-2014) focuses on actions to create growth and jobs in Europe. The meaning for this is enhancing skills through use of ICT and digital technologies. This agenda was described as a short term "To Do" list [27]. The list named 7 new priorities, all were very technology focused. This was followed by the **Digital Agenda for Europe (DAE)** – A Europe 2020 Initiative that contains 7 pillars of goals [28]. These are: 1- Digital single market; 2- Interoperability & standards; 3- Trust & security; 4- Fast & ultra-fast Internet access; 5- Research and innovation; 6- Enhancing digital literacy, skills and inclusion; and 7- ICT-enabled benefits for EU society. While the overreaching goal of DAE has been to help European citizens and businesses get the most out of ICT, the 7th pillar – ICT enabled benefits for EU society, mentions the support of ageing citizen lives.

The eHealth Action Plan 2012-2020 [29] was revised in 2012 from the earlier plan of 2004. The goal of the action plan is to clarify the policy domain and outline a vision for eHealth in Europe aligned with the objective strategies of the DAE. In particular, the eHealth Action Plan focuses on the innovative healthcare for the 21st century. The vision is to improve management of chronic disease and multimorbidity, increase sustainability and efficiency of health systems, foster cross-border healthcare and improve legal and market conditions for developing eHealth products and services. The **Competitiveness and Innovation framework Programme (CIP)** that runs for the years 2007-2013 is organized around three multi-annual specific programs: The Entrepreneurship and Innovation Programme; The Information and Communication Technologies Policy Support Programme (ICT PSP)[30]; and The Intelligent Energy Europe Programme.

The **ICT Policy Support Programme** is aligned with and supports the policies of the Digital Agenda for Europe (DAE). Within the ICT PSP programme Theme 3 is of relevance for ageing wellness. The objectives proposed under this theme are ICT for health, ageing well and inclusion. These are inspired by extensive consultation with stakeholders, in particular via the **European Innovation Partnership on Active and Healthy Ageing (EIP AHA)** and the eHealth Action Plan.

The EIP AHA was introduced as a "pilot partnership" with the intention to be a key driver in the Horizon 2020 Programme (to be described in the next sub-section). The EIP AHA has stated the goals "a triple win for Europe: 1- enabling EU citizens healthy, active and independent lives while ageing; 2- improving the sustainability and efficiency of social and health care systems; and 3- boosting and improving the competitiveness of the markets for innovative products and services, responding to the ageing challenge at both EU and global level, thus creating new opportunities for businesses" [31].

The pilot Partnership will aim to achieve this by bringing together key stakeholders (end users, public authorities, industry); all actors in the innovation cycle, from research to adoption (adaptation), along with those engaged in standardization and regulation." [31][32]. The action plan is based on a report from more than 500 contributors from private sector, private individuals and public authorities. Overall respondents criticized existing financial mechanism as "fragmented and insufficiently coordinated", further stating that they expect the EIP AHA partnership to provide a detailed mapping of all available funding opportunities in the field of active and healthy ageing [32, p.4]. One of the programs referred to is the Ambient Assisted Living (AAL) Joint Programme. Impacts of the Call 6 programs are expected to be "contributing to the aim of the EIP AHA to increase by 2 the average number of healthy life years in the EU by 2020" [33].

Table 1 - Research Calls "aligned" with the EIP AHA

AAL JP Call 5 - Ambient Assisted Living (AAL) Joint Programme – ICT for ageing well is aimed at the development of ICT-based solutions which enable and sustain older adults to continue managing their daily activities in their home. This Call is closed [34].
AAL JP Call 6 - Progamme aims at the development of ICT-based solutions which enable older adults to continue managing and supporting their occupation, while preserving health and motivation to remain active [31]. This Call is opened (2/2013) [33].
EC ICT PSP /WP FP7- Part of the ICT PSP. This is listed as a programme serving as a bridge to activities in Horizon 2020. The ICT Work Programme in FP7 contains Challenge 5: ICT for Health, Ageing Well, Inclusion and Governance. The 2013 WP for FP7 is described in WP2013 [35]. This call is open through 2013.

Table 1 lists some of the calls for research proposals that are intended to be aligned with the EIP AHA. The WP2013 also makes preparations for the next framework, Horizon2020. It states, "WP2013 will support the EIP AHA by addressing relevant actions of its strategic implementation plan.

The most recent research agenda is called **Horizon 2020**, the EU framework programme for Research and Innovation. Horizon 2020 is intended to bring together all existing EU research and innovation funding currently provided through the Framework Programme for Research and Technological Development (e.g. FP7), the Competitiveness and Innovation

Framework Programme (CIP) and the European Institute of Innovation and Technology (EIT). Horizon 2020 is an initiative for Europe's global competitiveness (2014-2020) that aims to strengthen EU's position in science and industrial leadership. While competitiveness is the primary focus, the initiative recognizes the rest of society's challenges. Horizon 2020 will therefore also address societal challenges "such as climate change, developing sustainable transport and mobility, making renewable energy more affordable, ensuring food safety and security, or coping with the challenge of an ageing population" [36]. A steering group designed the Implementation Plan for Horizon 2020 in November 2011. The plan outlines a structure of Action Plans that are being mobilized by Action Groups [37]. The groups of interest to Active and Healthy Ageing (AHA) are

- C1: Assisted daily living for older people with cognitive impairment,
- C2: Extending active and independent living through Open and Personalized solutions, and
- C3: Innovation improving social inclusion of older people [37, p.7].

The Horizon2020 action plans in the area of EIP AHA are still being established in 2013.

Discussion of Implications

We have given a brief overview of the current situation and strategies in the Scandinavian countries and in EU regarding ambient assisted living and welfare technologies. Although there are several similarities between Denmark, Norway and Sweden regarding the social welfare services, we found that these countries actually have quite different approaches to patient oriented services and implementing welfare technologies, to assistance of the patients at home and to effective delivery of public services.

Denmark has invested monetarily through different funds; this has led to several projects and initiatives where new technology solutions are deployed and being evaluated. In addition, use of welfare technology is integrated into the national effort for digitizing the public sector in Denmark.

In Sweden there has been a project focusing on prognosis for future health care services, and some initiatives have looked into use of welfare technology. Ministry of Health and Social Affairs is responsible for policy issues related to disability and assistive technology, and the Swedish Institute of Assistive Technology is responsible for sharing knowledge, initiate pilot projects and assist companies in developing new ideas for international markets.

In Norway, the new Collaboration Reform will influence how the future home care services will be modernized. The Norwegian Directorate of Health has a dedicated division for eHealth and IT, with dedicated departments working on health portal, on core electronic health records and on standardization issues. Based on local initiatives, there is a plurality of ongoing projects and trials using new welfare technologies, even if those activities lack some coordination and common infrastructure for standardization.

When we study how the EC at a strategic level is organizing all the different efforts within eHealth and welfare technologies, we see some important points that can benefit the Scandinavian programs. First of all, the actual calls for strategic projects have been based on a defined problem statement and visions for the future. Such calls have not been used in the same manner in Scandinavia. This can give some explanation of why the initiated activities are not synchronized and coordinated. In the EIP AHA initiative, a main goal is that competence milieus and partners develop meeting arenas to share experiences and influence future research and projects. This multidisciplinary collaboration across organizational borders could be useful, also in a Nordic setting. Within each country, this model might also give opportunities to structure national and local initiatives, thus we will propose to introduce this model of organizational initiatives for gathering actual competence milieu's and to obtain a common interest for future development and projects.

Based on this overview we see a number of implications. One of the main goals of Horizon 2020 is competitiveness, stimulating research and development in industry and bringing together key stakeholders. A means for achieving this is innovative procurement or pre-procurement, opening up for cooperation between public sector and industry prior to announcing tenders. By doing this, industry can learn about the needs of public sector and the transparency in competition can still be maintained. Three areas are highlighted under EIP action group for active aging [37]:1- assisted living for elderly with cognitive impairment, 2- open and personalized solutions and 3- innovations improving social inclusion of older people.

Horizon 2020 is expected to start from 2014, and to carry more funding for research than previous frame programs. We will be seeing a number of calls for research proposals over the next few years, and it would be smart for the research community in Scandinavia to prepare for this. The government in the different countries and the numerous local pilot projects could benefit from aligning with the European research agenda, while at the same time keeping national policies and local contexts in mind. It is still only possible to "read between the lines" to identify some of the "big" research directions coming out of the Horizon 2020 program and the EIP Action groups. We call for more research and for more pilot projects on the following themes: 1- innovative procurement involving key stakeholders prior to announcing call for tenders; 2- open solutions / standardization / interoperability; 3- personalized solutions; 4- solutions for elderly with cognitive impairment; and 5- solutions for social inclusion.

Conclusion

In summary, we have in this paper shown the importance of meeting the challenge of the growing elderly population in Scandinavia, and that assistive technology can be one way of addressing this issue. We have further given an overview of the Scandinavian policies on active ageing and independent living, and shown some of the focus on the coming EU research agenda, and we suggest aligning the research community and the many local projects to priorities in the upcoming Horizon 2020 program and the EIP Action group on Active and Healthy Ageing (AHA). Finally, we recommend addressing the ethical problems of welfare technology with an open mind and that society needs to adjust the law in order to make the new possibilities useful for the users.

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Exploring barriers for health visitors' adaption of the Danish Children's Database through an empirical study

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Abstract

Denmark has unique health informatics databases such as "The Children's Database" (CDB), which since 2009 has held data on all Danish children from birth until 17 years of age. In the current set-up a number of potential sources of error exist - both technical and human - which means that the data is flawed. The objective of this paper is both to clarify errors in the database and to enlighten the underlying mechanisms causing these errors. This is done through an ethnographic study using participant observations, interviews and workshops. Additionally, errors are documented through statistical analysis. The data show redundant records. This redundancy can be explained by multiple transmissions conducted by end users or systems, or a lack of validation methods in the National CDB. In our results three types of cases are presented: from health visitors at school, from health visitors visiting families and from health visitors at central health offices. Results are discussed from a socio-technical perspective using Schein's cultural theory to understand the interaction between the health visitors and the information technology used for collecting data. Cultural theory is used to explain the underlying socially constructed mechanisms that cause errors when using the information technology.

Keywords: *Public Health informatics, Organizational Culture, Community health nursing, Point of care systems.*

Introduction

In spring 2009 a new public health informatics (PHI) database was established by the Danish National Board of Health (NBH): "The Children's Database" (CDB). The objective of the CDB is to monitor the health of all Danish children in order to detect infants at risk at an early stage [1,2], illustrated in fig. 1.

The CDB holds specific information on all Danish children and adolescents aged 0-17 years.

For the current pilot version of the database, only data about height, weight, passive smoking and breastfeeding are collected. This database is unique both internationally and nationally as it represents a national database holding health related information on a *complete* population. However, spot checks performed by the NBH show that the data are flawed. Therefore, they are not used for either primary (e.g. monitoring) or secondary purposes (e.g. research).

Experience shows that besides technical causes for invalid data in health information technology (HIT) databases – including PHI databases – data validity is closely related to the way data are entered as well as the time between data collection and data entry [3]. Experience also shows that when clinicians find HIT systems inappropriate to their work practice, they develop workarounds, including workarounds related to data entry [4].

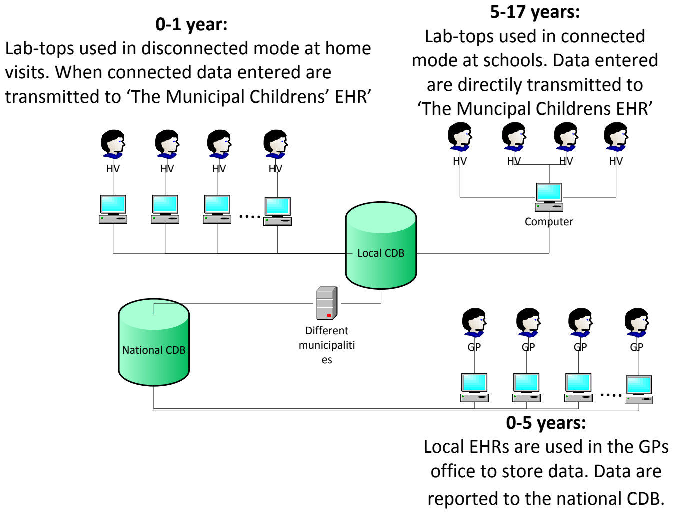

Figure 1 illustrates the setup of the CDB. There are multiple health visitors (HV) communicating information to the CDB in different 'modes'. [1]

During the past decades researchers from the Danish Centre for Health Informatics (DaCHI) at Aalborg University have been studying socio-technical interactions between users and HIT systems in order to develop new methods for studying, developing and evaluating HIT. Research both within and outside DaCHI shows that in contemporary clinical work practice, clinical work and health information technology are so closely integrated that user involvement during the development process is a precondition for the development of HIT systems providing clinical benefits, and hence for minimizing the clinicians' need for workarounds [5-8]. However, even though user involvement is known to be a very important success factor when developing HIT systems, no empirical studies of user involvement in the development of PHI systems for the primary sector seems to have been conducted. In response, DaCHI researchers in collaboration with researchers from University College North Jutland (UCN) have carried out a research study with a primary focus on the interactions between health visitors and the Children's Database system in two Danish municipalities during 2012. The objective was to gain a deeper insight into the health visitors' work practice, including any workarounds. In addition, a data study was carried out in order to study potential technical causes for invalid data.

The objective of this paper is both to clarify errors in the database and to explore the underlying mechanisms causing these errors, thereby providing the insights gained on end user interaction with PHI systems to management and developers. This will allow for the exploration of new avenues in PHI systems development in order to support, facilitate and improve real end-user participation, and hence minimize workarounds.

Materials and Methods

The NBH requires data from the 98 Danish municipalities to be entered into the national CDB in three different ways: 1) Up to one year of age, data collected at either home visits or at the central health office by health visitors are entered into decentralized, municipal, local CDB systems (4 heterogeneous systems in Denmark); 2) Between one and five years, data are entered into primary care electronic health record systems during visits to primary care physicians (11 heterogeneous systems in Denmark); and 3) In primary school, data are entered into decentralized, municipal, local CDB systems during visits by the health visitor or physician to the schools (4 heterogeneous systems in Denmark). Data from the decentralized, municipal, local CDB systems and the primary care electronic health record systems in each municipality are transferred to the national, central database CDB once a day.

During 2012, an ethnographic study on the interactions between health visitors and the municipal, local Children's Database was conducted at home visits, at school clinics and at the central health office in the County of Aalborg (Aalborg municipal CDB system) and the County of Hedensted (Novax municipal CDB system). A study of data from the two municipal, local CDB systems in Aalborg and Hedensted and from the national, central CDB database was also conducted. Data extracts from the two local databases and the national database were in both SPSS format and Excel format. We created a MySQL database to handle and manage our data, and used SQL queries to find redundant records. We used SPSS as a back up to determine whether the results from our database were correct, using the SPSS 'Duplicated cases' function; in MySQL we generated our own SELECT statements. All data were collected and analysed as presented in Table 1.

Table 1 illustrates data collection and analysis

Data collection	Techniques used for this study	Data analysis
THE ETHNOGRAFIC STUDY		
Observation	Non-participant observation of health visitors at home visits 8 days, health visitors at school clinics 7 days and health visitors at a consultant office 4 days. In average 5 children were examined pr. day.	Analytical coding, categorizing and condensation of observation data with a focus on the interactions between users and technology – and an "open mind" towards other themes
Informal interviews	Informal interviews with the 19 observed health visitors	As above
Workshop	Activity-based workshop, parted into two levels (validation-level and creativity).	As above
THE DATA STUDY		
Technical analysis	Data about CPR (central personal registration number), height and weight for all children from the municipality of Aalborg and Hedensted, aged 0-17 years, during the period of 1. April 2009 to 1. June 2011, were studied (~130000 records). Document analyze of system and database description.	Simple SQL-query for identification of redundant records. Analytic work on infrastructure, database and system design of the identified redundant records.

Trustworthiness with respect to the ethnographic study was sought through presenting our interpretations to the involved health visitors at the workshop, and through thoroughly describing all activities throughout the process (transparency).

With respect to the data study, permission to access person-level data was obtained from the Data Protection Agency, The National Board of Health, municipality of Hedensted and the municipality of Aalborg.

Theory

The views presented in this paper are based on the combination of the following two theories:

- The socio-technical theory
- Schein's Organizational culture theory

These theories will briefly be introduced.

Socio-technical theory

Socio technical theory is characterized by a view of technological innovation as an adaptation process, during which both the technology and the user's work practice are changed through mutual and lasting impacts [8]. However, if social balance in the work is to be attained when implementing new technology, both social and technological needs must be met, and users have to be involved in the development process. A broad concept of technology is introduced in Socio technical theory, focusing on the micro-level and the actor as opposed to the macro-level. According to this concept, technology embraces: technique, knowledge, organization and product. These four constituents are inseparable components of any technology. A qualitative change in any one of the components will eventually result in supplementary, compensatory, and/or retaliatory change in the others. In the present study, socio-technical theory was used as a framework to shed light on *the interactions* that occurred between the health visitors and the Children's Database system.

Schein's Organizational culture theory

Edgar H Schein defines organizational culture as: "A pattern of shared basic assumptions that the group learned as it solved its problems that has worked well enough to be considered valid and is passed on to new members as the correct way to perceive, think, and feel in relation to those problems" [9]. Schein has developed a model aiming at emphasizing how culture works and how it can be understood (fig. 2).

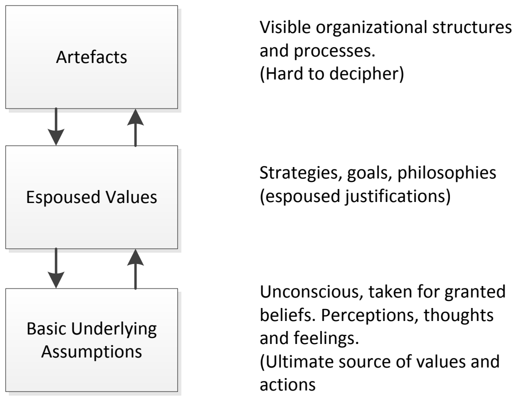

Figure 2 illustrates Schein's model of culture [9]

Schein identifies three distinct levels according to which culture can be analyzed: firstly the visible *artifacts* and behaviors, secondly the espoused values and thirdly the basic assumptions. According to Schein, in order to understand culture and values, it is imperative to delve below the organizational surface and uncover the basic underlying assumptions. These basic assumptions are the deeply embedded, taken-for-granted behavior, which is usually unconscious, but constitutes the essence of culture. Besides, they are typically so well integrated in the office dynamic that they are hard to recognize even from within. Thus, taken for granted assumptions are so powerful because they are not debatable.

The cultural model described by Schein is used in the present paper to understand the mechanisms within the organization that leads the health visitors to act in the manner they do.

The Socio-Technical- and Schein's Organizational culture theory are both well known. What is new is the act of combining them and employing them within the healthcare sector, which has not been done previously.

Findings

The ethnographic study shows that workarounds are developed by health visitors both at home visits, at school clinics, and at the central health offices. The workarounds are primarily related to data entry, where the health visitors are observed not to use the CDB for primary registration of data, but instead use sheets of paper, notebooks or post-it-notes. Empirically, this work practice involves a risk of registration errors, thus it affects the data validity [3]. The analysis of the observation data has revealed several possible reasons for these workarounds:

The interior of the health visitors' work place

The study shows that the interior of the health visitors' work place plays an important role with respect to data not being entered directly into the CDB: a) For toddlers' examinations carried out in the citizen's home, the health visitors bring an ordinary laptop with a screen size of approx. 14 inches. It is typically placed on a table, while the examination of the child typically takes place in the kitchen, bathroom or on the floor in the living room - never at the place where the computer is located. The measured weight and height are noted on a piece of paper and entered into the computer later on - either in the home when the examination is completed, or when the health visitor is back at the office; and b) When toddler's examination is carried out at the central health office, the location of the computer depends on the distance to, e.g. the power outlet and the internet connector. The computer is typically located at a distance from the examination table, the scales, and the measuring tape. The measured weight and height is noted on a piece of paper at the examination table and then later on entered into the CDB. c) Schoolchildren's examinations typically taking place in a special room for health examination at the schools, and the computer is placed on a desk. The initial interview with the schoolchild takes place at the desk, while the measurement of height and weight takes place somewhere else in the room. Data is noted on a piece of paper and either entered directly into the CDB after each single examination, or at the end of the day when all examinations are completed.

Overall, the observations show that the placing of the computer does not support the health visitors' work practice. It does not allow health visitors to enter data directly into the CDB, but forces them to write data on a piece of paper and then later enter them into the CDB. Experience shows that if technology does not support the work practice which it is supposed to be part of, there is a risk that users will develop workarounds in order to be able to carry out their daily work, which poses a risk to data validity [3;4]. Experience also shows that workarounds, as described above, increase the risk of typing errors and errors of understanding, and that the risk of errors increases with the time between data collection and data entering - e.g. if data are collected and first entered for more children at the end of the day or the following day. Besides these types of errors, there is also a risk that data will be entered into the wrong record [10].

Data discipline - health visitors entering data into the CDB

The study shows, moreover, that health visitors' data discipline is important with respect to data validity. Health visitors often enter data on weight and height into the CDB based on information provided by the children's parents by telephone. These data are initially measured by the primary care physician at a children's examination and communicated to the parents. Thus, the data have passed through several links before they are entered by the health visitor into the CDB, thereby posing a risk for transmission errors, hence to data validity [10].

Changing data in CDB

Data from the interviews shows that if the health visitors discover that they have entered data incorrectly into the CDB, they modify the data later on. This also poses a risk of error. This is also seen in the data study where numerous redundant and flawed records are observed.

Data analysis

Taking both municipalities, we find that in the National CDB there are 13.5% redundant records, with an individual difference between redundancies in the systems. Data analysis from the different systems are illustrated in tab. 2

Table 2 illustrates the frequency of redundant data in the national CDB

System A		**Frequency**	**Percent**	**Cumulative Percent**
Valid	*Duplicate Case*	7669	14	14
	Primary Case	47116	86	100
	Total	54785	100	
System B				
Valid	*Duplicate Case*	319	7,9	7,9
	Primary	3726	92,1	100

	Case			
	Total	4045	100	

Looking at the records from both municipalities and comparing these to the data in the National CDB we see that there are more records in the local databases than in the National CDB, i.e. the transfer of records is only partial. But the number of redundant records is identical to what has been identified in the National CDB. Our analysis assumes that data observed on the same day on the same child is redundant. What is troublesome is that data has been reported on several different days –up to 14 different times. This is troublesome because we cannot identify the exact reason for these incidences. Is it because the HV is reporting the data several times? Is it simply because of a poorly designed validator or an unintended repetition of data? How can this data be re-used when it is filled with flawed data?

Another disturbing observation in the data is that in approx. 5% of the records include corrupt data i.e. different observations on same date on the same child regarding weight or height. Table 3 is an example of this.

Table 3 illustrates an example from data on corrupt data

Primary key	DateOBS	DateRep	Height	Weight
#a#	10/12/17	11/01/04	72	8800
#a#	10/12/17	11/01/04	72	9800
#a#	10/12/17	11/01/04	71	8800

Apparently, erroneous data has been reported, but not deleted even though this is possible with one of the methods in the reporting Webservice. The method for this is `DeleteChildMeasurementReport()` or `ModifyChildMeasurementReport()`. These calls are valid for deleting and modifying a record.

Infrastructure and communicating method as possible reason for data errors

The communication between local and national CDB is a web service-based communication. This indicates that communication is applied to the SOA-oriented web service model, described in [11].

The infrastructure is deemed to be secure and shields the transmitted data because the sensitive nature of patient data. [12] The IT-architecture supports the use of web services as a method for sharing sensitive data.

An IT-architecture has to be reliant on stable and secure infrastructure, which can handle requirements as valid data and seamless co-operatively between users (i.e. health visitors to local CDB to national CDB).

The current architecture in Danish eHealth has been heavily influenced by the Danish health care organizational factors. Heterogeneous EHRs [13] are the results of autonomy in selecting EHR systems in different regions.

We found that the web service used for reporting data to the national CDB includes several methods for both generating records and deleting records. So the question is whether these calls for methods in the web service have been implemented in the decentralized heterogeneous systems.

Database designs as possible reason for data redundancy

The process of designing databases is often divided into two levels; a level with domain experts and a level with database developers. Domain experts specify the purpose and the end-user requirements for the database. Database developers transform the end-user requirements to a database through an entity relationship (ER) model.

According to Wang [14] a preliminary conceptual framework must be met if a requirement to the database design is useful data with quality and validity. The framework consists of four basic elements; 1) accessible, 2) interpretable, 3) relevant, 4) accurate.

The national CDB is designed according to this framework. However, it seems that accurate data is only implemented as in a single tuple and not with a possibility to avoid inconsistent data across tuples, which is why several tuples on the same observation date with different values. Apparently, the national CDB is also complying to be relevant, but again this is considered on a tuple level and not on a record level why redundant data is found.

Interactions between health visitors and technology

The focus in this section is to understand the interactions between health visitors and technology. The study show that most health visitors feel that the computer interferes with their attention and their relationship with the family and the child, and that the technology interferes with the contact and intimacy to the family. This has an important impact on whether they use technology or not. In one of the observational studies, it was observed that the health visitor chose to write data on a sheet of paper, even though the computer was located right next to her. Afterwards, the health visitor was asked whether she saw the computer as a barrier. She replied that she had no problems using the computer and electronic equipment in general, but thought that it took her attention, if she was sitting and looking at the computer while she was talking to the child.

During the observation study, workarounds could at first glance be conceived as a tangible and clear pattern of behavior. But through the analytical study of health visitor's historic and learning background, the more invisible levels of values and basic assumptions are exposed, yielding insight into the root causes of the development of workarounds. Thus, health visitors have a fundamental assumption that presence, contact and attention are important phenomena in working with children and families, and hence data entry carries a hegemonic meaning. [15] As an example, a health visitor said during an interview: "You have to understand that I must first and foremost focus on the contact with the family".

According to the National Health Service, nurses (including health visitors) must provide an individual supportive guidance[12, 16], where values such as trust, respect and intimacy are emphasized[17]. Besides, in the mind of the nurses, home visits are perceived as a form of feast or gift exchange [17]. These values underlie the common basic assumptions, developed by the health visitors as a professional group, about how work is to be performed, how the families are best supported, and how presence and awareness are best created. These basic assumptions will subconsciously affect how health visitors use the CDB. The technology is not perceived as neutral but as value-laden or value active and challenging, thus jeopardizing the trust-based contact with the child and the parents – a contact, which is crucial for the health visitors' work [10]. The way the health visitors interact with the technology therefore plays an important role with respect to transforming and organizing the visit in different contexts.

Cultural Analysis - when the basic assumption is that the computer intervenes in contact, relationship and intimacy with the family and child

It is interesting and perplexing that health visitors perceive data entry as a distraction, while it is not experienced as attention deficit to write down the same data on paper. Schein emphasizes that the concept of culture can be very useful to explain some of these seemingly perplexing and irrational aspects of behavior and attitudes. According to Schein, any group with a stable membership and a common history has developed a culture. Embedded in this culture are common basic assumptions, which are taken for granted and maintained by members of the group through external adaptation and internal integration. These values and assumptions are passed on to new members as the correct way to perceive, think and feel in relation to specific issues. Schein argues that culture is manifested at different levels, depending on the degree to which cultural phenomena are visible to the observer. These levels range from the tangible and distinct manifested artefacts that can be seen, to the deeply embedded and unconscious basic assumptions, defined as the core of culture.[9]

Basic values and assumptions are difficult to challenge or debate because of their deeply embedded and unconscious nature, meaning that they are difficult to change[18]. Thus, they are important factors contributing to the health visitors' development of workarounds instead of entering data directly into the CDB. To question basic assumptions often triggers insecurity. According to Schein, the responsibility for changing culture primarily rests with management, as organizational culture is partly created by management, and because one of the most important tasks for management is to create, manage and - sometimes - to break down culture[18].

Conclusion

The objective of this paper is both to clarify errors in the database and to explore the underlying mechanisms causing these errors.

We have identified the kind of redundancy occurring in the national CDB. There exist both corrupted redundancy, i.e. flawed data and duplicated redundancy, i.e. repeated record transmitted multiple times (a max of 14 times on the same record). We have clarified that the methods in the web service provide the possibility for the decentralized CDBs to delete or modify faulted records and that the basic database design framework is fulfilled. We have enlightened the underlying mechanisms causing these record errors by analyzing our finding in a STS-perspective and explained the culture in health visitors' organization.

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Eliciting requirements for a tablet-based data entry and reporting system for use in clinical microbiology laboratories to facilitate blood culture analysis: a case study

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Abstract

Sepsis is a large health care burden on a global scale with 1.8 million documented cases yearly. Furthermore, sepsis is associated with a high mortality rate. However, an early initiation of the correct antimicrobial treatment improves the survival rate.

A new molecular based diagnostic test named MultiplexBCT is currently under development. Furthermore, a tablet-based data entry and reporting system is being developed to facilitate the workflow of the MultiplexBCT test.

This study identified system requirements for the tablet-based data entry and reporting system through an observational study conducted at two clinical microbiology laboratories in the US. Three system requirements were elicited; communication of data with the laboratory information system, communication of test results to the treating staff, and the support of barcodes.

The three system requirements form the foundation for further development of the tablet-based data entry and reporting system.

Keywords:

Medical Informatics, Sepsis, Handheld Computer.

Introduction

In many patients, bloodstream infection is commonly associated with sepsis. Sepsis is a large health care burden on a global scale, and is associated with a high mortality for patients that are severely affected [1]. A yearly incidence of 1.8 million cases of sepsis has been documented. However sepsis is difficult to diagnose, and it has been estimated that the actual incidence rate is at 18 million cases yearly, which makes sepsis a leading cause of death [2]. Furthermore, the incidence of sepsis is increasing [1]. Depending on the state of disease, sepsis is classified into three categories: sepsis, severe sepsis (sepsis leading to organ dysfunction), and septic shock (severe sepsis, and hypotension despite attempted fluid resuscitation) [3].

A study estimated that for the US in 1995 there were 751,000 cases of severe sepsis, causing 215,000 deaths, corresponding to a mortality of about 30% [4]. Further, this study estimated that the average cost for treatment was $22,100 for each severe sepsis case, leading to an annual expense of $16.7 billion in the US. This implies that sepsis is a large economic burden on a global scale.

International guidelines recommend that a treatment based on broad-spectrum antibiotics be initiated within 1 hour after a patient is diagnosed with severe sepsis or septic shock [3]. A study has shown that for patients in septic shock each hour of delay in initiation of an effective antimicrobial treatment leads to an increased risk of mortality [5]. Furthermore, another study analyzed the treatment of patients with septic shock and found that about 20% of the patients initially received an inappropriate antimicrobial therapy [6]. In these patients, the survival rate was 10.3% compared to 52% in patients who initially received an appropriate antimicrobial therapy[6]. Similar considerations apply to patients with bloodstream infections generally.

For identifying the microorganism causing bloodstream infection, and thereby guiding the antimicrobial treatment, the use of blood cultures is considered the gold standard [7,8]. A limitation of blood cultures is that they are dependent on the bacterial growth rate. Blood cultures will typically be ready for analysis after a period of 6 to 48 hours [9]. Using conventional, culture-based methods, a period of 24 to 72 hours is required before the causative microorganism can be identified and its antimicrobial susceptibility can be tested [8]. As these results become available, they can be used for interim and final adjustment of the antibacterial treatment.

New diagnostic tools based on molecular techniques allow for a faster identification of the microorganisms causing bloodstream infections in comparison to the conventional use of blood cultures [7,8,9]. These molecular tests have the potential to improve the treatment of patients with bloodstream infection-associated sepsis by allowing a faster initiation of an effective antimicrobial therapy. The new diagnostic tools are limited in some aspects, as they are labor intensive, and can only be used to identify a limited range of bacteria [9]. Their use is therefore limited at the present time.

Fluorescence in situ hybridization (FISH) is a molecular technique that is used for identification of bacteria from blood cultures with bacterial and fungal growth. Compared to conventional blood culture analysis methods FISH based molecular tests allow for a faster identification of microorganisms [7].

Tests that allow for rapid detection of the causative microorganism from positive blood cultures, and thereby allow for a shorter time to notification, is an aspect that can shorten the length of hospital stay for patients with bloodstream infections [10]. However, other aspects such as blood culture transportation time, prioritization of doing the identification tests once a blood culture is positive with bacterial growth, and time for communicating a result to the treating physicians all play an important role in the time to notification [10]. Promptly communicating results from a FISH based test to clinicians has previously shown that it can lead to a reduction in mortality for patients with bloodstream infections [11].

A new FISH based test named MultiplexBCT (MBCT) is being developed, which aims to identify the most prevalent blood culture pathogens. While this test will still be dependent on the bacterial growth of blood cultures, it will be faster than conventional diagnostic methods, and this has the potential to enable a quicker adjustment of antimicrobial treatments.

A tablet-based data entry and reporting system will be developed to facilitate the clinical workflow of the MBCT test. The aim of the tablet-based system is to allow a rapid access for clinicians to the results of the MBCT test, and thereby allowing for a quicker adjustment of antimicrobial therapy if necessary. The focus of this paper will be on the tablet-based data entry and reporting system.

Mobility is an important aspect of clinical work in both wards and laboratories. The use of mobile technologies such as personal digital assistants has demonstrated that it can support the needs of mobility in health care work. Furthermore, such systems have been shown to bring benefits, where time is a crucial factor [12]. Therefore, we develop a tablet-based system.

It has been well documented, that the implementation of new IT systems can lead to large changes in workflow, which can be disruptive and lead to a decrease in efficiency [13]. For a successful implementation of IT systems in the health care sector, it is important to understand that new information systems often bring organizational changes [14]. As the tablet-based data entry and reporting system is not designed explicitly for one clinical microbiology laboratory, it must be flexible enough to meet the end users' different needs without restricting their workflow in a disruptive manner.

The objective of this study is to elicit system requirements for the tablet-based data entry and reporting system, which will ensure that the system supports the workflow of a blood culture analysis process in a clinical microbiology laboratory.

Materials and Methods

Data collection

All data was collected at two US clinical microbiology laboratories through an observational study. One of the microbiology laboratories processes approximately 90,000 blood cultures yearly and services four different hospitals. The other microbiology laboratory processes approximately 20,000 blood cultures yearly and services a single hospital.

Observational study

The goal of the observational study was to gain an understanding of the clinical workflow of blood culture analysis at US clinical microbiology laboratories.

At each laboratory, an experienced medical laboratory scientist (MLS) was observed, while conducting daily routines involved in blood culture analysis.

Before the observations began, the MLS was given a brief introduction to the purpose of the study, and how the observations would be carried out. Furthermore, the authors were given a tour of the laboratory so they were familiar with the physical location before the observations began.

The observation of the two MLS lasted for about 2 hours and 40 minutes, and 1 hour and 40 minutes respectively. Both observations took place in the morning, and started when the MLS began their work. The first two authors took part in the observational study and the data collection process.

An additional period of about 50 minutes at each clinical microbiology laboratory was used for semi-structured interviews, which aimed to clarify observed events, by building an understanding of the complete diagnostic circle. The questions were structured into the following sections: blood culture sample collection, blood culture analysis, and communication of blood culture analysis results.

During the observations, the activities of the subjects were recorded. This included a note of the physical location where the activity took place, and a timestamp for each activity. After the observations had been conducted, the field notes were reviewed and digitalized.

For organizing the observations a semi-structured observation guide was used, which focused the observations into two main categories:

1. Analysis of blood cultures.
2. Communication of results.

By using a semi-structured observation guide, the observations focused on important events in regards to the process of blood culture analysis, while still allowing other relevant events to be observed.

Informal interviews took place during the observations between the observers and the MLS. The informal interviews were used to clarify some of the observed events.

The observed data was coded by themes as part of the analysis process through meaning condensation [15]. The themes were structured around the analysis of blood cultures and the communication of results, which was also the focus for the semi-structured observation guide. The data was managed by hand.

Results

The observational study clarified how the results of blood culture analysis were communicated from the microbiology laboratory to the treating staff. Furthermore, the use of IT systems to support the blood culture analysis workflow and communication of results was explored.

Blood culture analysis workflow

Through the observational study, a generalization of the workflow for a MLS for the process of blood culture analysis was modeled, which is shown in Figure 1.

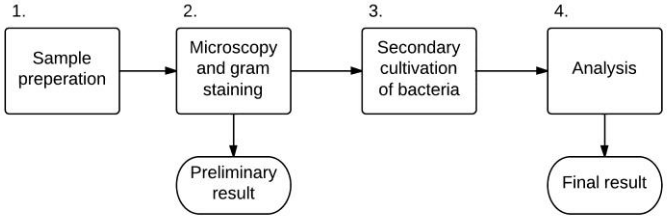

Figure 1 - Generalized model of the workflow, and the results produced during the blood culture analysis process.

The initial step of the blood culture analysis process was the preparation of microscopic slides with a sample from a blood culture bottle with bacterial growth.

In the second step of the workflow, the MLS conducted gram staining and microscopy of the positive blood culture sample, which produced a preliminary result. The preliminary result was initially entered into the laboratory information system (LIS), and in some cases, the result was also written onto a paper document. Thereafter, the MLS retrieved contact information for those who had to be informed of the preliminary result. The contact information was retrieved though other IT systems. The MLS would then call the treating staff and communicate the result. The treating staff was either a physician or nurse from the department that had requested the blood culture analysis. At one microbiology laboratory, the results were also communicated to a Pharm. D. if the patient was on a pharmacy department watch list. At the other microbiology laboratory, the results were communicated to a Pharm. D. if the results identified certain types of bacteria. The MLS then documented the call in the LIS. The process of communicating results from the clinical microbiology laboratory to the treating staff is shown in Figure 2.

In the third step of the blood culture analysis process, the MLS did a secondary cultivation of bacteria, which was then incubated.

The last step of the workflow is the analysis of blood culture plates, where the cultivated bacteria are examined. By analyzing the blood culture plate results, and comparing with the results from microscopy and gram staining, the causative microorganism is identified. The blood plate analysis could be an iterative process, where more plates would have to be produced and additional tests carried out, before the microorganism was determined. This produced the final result of the blood culture analysis process.

When the MLS began the examination of blood culture plates the barcode was scanned, which loaded the patients information in the LIS. The MLS used an overview of the patient's previous microbiology results, as an important element in determining the results of the blood culture plate being examined. The result from analyzing a blood culture plate was documented in the LIS. Furthermore, when a final result was produced by identifying the causative microorganism the result was documented both in the LIS and on a paper document. In one case, a final result was communicated to the treating staff as described for the preliminary result, which is shown in Figure 2.

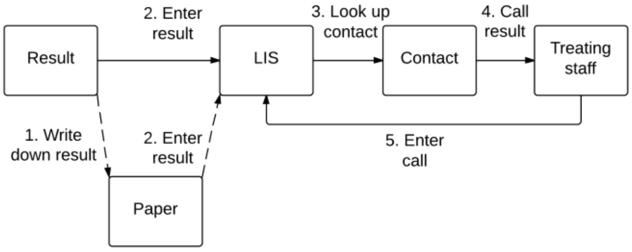

Figure 2 - Model representing the documentation and communication of results obtained during the blood culture analysis process. The numbering indicates the order of events. The dashed line indicates an optional event.

Analysis of workflow

Throughout the blood culture analysis process the use of various IT functions were an important part of the workflow. The IT systems were used for documentation of results, and to retrieve information about previous results, and to obtain information about whom the blood culture results should be communicated to. These functionalities can be used as a basis for system requirements, when designing a new system for data entry and communication of results for a clinical microbiology laboratory.

The LIS was accessed throughout the blood culture analysis process to provide an overview of information about the patient's previous microbiology results, and to document all new microbiology tests that were conducted throughout the process. It was observed that both preliminary and final results were documented in the LIS, but also on a paper document.

Information about whom results must be communicated to was available through the LIS, however for obtaining direct contact information another IT system had to be used. Paper was used to make temporary notes four times during the observations: to note down a result that was produced without a computer nearby, to make a note that a patient's result should not be communicated to a Pharm. D., to make a note of who accepted a result through a phone call, and to make a note of a patient's data in the LIS.

The use of barcodes was an integral part of the workflow, as barcodes representing the patient's ID were placed on both blood culture bottles, and on blood culture plates. This meant that barcodes were scanned as a means of data entry whenever a patient's data was accessed through the LIS.

In summary, the following system requirements for the tablet-based data entry and reporting system can be defined, if the system is to support the existing use of IT functionalities:

- Communication of data with the LIS. This includes sending blood culture analysis results to the LIS, and receiving microbiology results obtained through the LIS, which can then be displayed to the user.
- Communication of results to the treating staff, which requested the blood culture analysis. Furthermore, the ability to communicate results to other staff depending on the laboratories blood culture analysis routines, e.g. a Pharm. D.
- Support the use of barcodes to enter information into the system, e.g., the patient ID.

Discussion

The results of this study are based on data collected through a single observational study at two different clinical microbiology laboratories in the US. This is a limitation, which must be considered when analyzing the results. However, it can be expected that the overall workflow for conducting blood culture analysis is similar for most clinical microbiology laboratories. For clinical microbiology laboratories that handle larger or smaller numbers of blood cultures, or are organized differently, the communication of blood culture analysis results may be different. The observational study can be conducted at other clinical microbiology departments until data saturation is achieved. This would allow the results to be considered widely generalizable.

Through the conducted observational study at two different clinical microbiology laboratories, a total of three system requirements were identified. These requirements are vital to fulfill if the tablet-based data entry and reporting system is to be successful in supporting the clinical workflow for the blood culture analysis process.

The tablet-based data entry and reporting system must be able to both send and receive blood culture results to the LIS in order to support the user's needs of submitting and retrieving test results. The ability to look at a patient's microbiology test history is an important aspect in the blood culture analysis process.

Double documentation of results occurred commonly during the blood culture analysis process. Both preliminary and final results were documented on paper and in the LIS. Furthermore, in one case a microscopy result was temporarily written on paper before being entered into the LIS. This is due to the nature of a microbiology laboratory, where not all test equipment is near a PC. Double documentation of results brings a risk of error, when the results from a paper document must be entered into a PC. By using a tablet-based system for data entry, and thereby taking advantage of the mobility it offers, it is expected that double documentation can be reduced or possibly eliminated [16].

Barcodes were frequently used to enter a patient ID into an IT system throughout the blood culture analysis process. Barcode reading can be supported by utilizing the tablets built-in camera. However, the efficiency of tablet-based camera barcode scanning should be tested in clinical settings, as parameters such as lighting and barcode size may affect the scanning performance. Alternatively, an external barcode reader could be used, which connects to the tablet through Bluetooth or similar technology.

The tablet-based data entry and reporting system must be flexible enough to support changes in the clinical workflow, as exceptions to workflows often happen in the health care sector [17].

By letting the tablet-based data entry and reporting system communicate results directly to the treating staff, the notification time for blood culture results can be reduced. Additionally, the MBCT test will allow blood culture results to be available more quickly than conventional test methods, which in combination will lead to a reduced time to notification. This will pave the way for the antimicrobial treatment be optimized earlier, which can lead to an improved survival rate for sepsis patients [10,11].

Conclusion

The study identified three system requirements for a tablet-based data entry and reporting system, which must be fulfilled for a successful implementation of the system. The system requirements were identified through an observational study conducted at two clinical microbiology laboratories in the US. The generalizability of the results should be further explored. By implementing the system requirements, and letting the MBCT results be send directly to the treating staff through the tablet-based data entry and reporting system, the time for notification can likely be decreased. This can lead to faster optimization of the antimicrobial treatment, which in turn is likely to result in a higher survival rate for the sepsis patients. The system requirements presented in this study will build a foundation for further development of the tablet-based data entry and reporting system.

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Data warehousing in the Danish healthcare sector

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Introduction

In the Danish healthcare sector enormous amounts of data are stored as fragments in a large number of unintegrated IT-based information systems (IS). It is a very resource-intensive task, but it has been demonstrated that the existing data can be used to provide an information basis for strategic decisions and research. However, data are rarely used beyond individual patient care because of its contextual nature. Therefore, fragments of data are rarely meaningful. Without data integration it becomes problematic to interpret and use the data for secondary purposes. Consequently retrieval and aggregation are not fully realised which are some of the most prominent advantages of IS. The health care sector has begun to realize the potential of dimensional data warehousing (DDW) to query across several data sources, thus creating data sets for research. DDW's has been developed to extract and load data from many heterogeneous sources into a joint underlying model. The aim of this study was to expand the existing patient administrative data warehouse in the North Region of Denmark (RN) to demonstrate integration of two data sources creating a dataset with type 1 diabetic patients and their laboratory results.

Materials and Methods

RN's DDW embracing patient administrative data is in production. In this study a copy was expanded with a model embracing laboratory data. The copy is solely in an experimental state.

On the basis of laboratory processes and data extracted from LABKAII, a dimensional model was designed through three steps. 1. Determining the granularity. The highest level of detail in the laboratory data and the business process behind generation of the laboratory data was used to determine the models granularity. 2. Choosing and designing dimensions. Dimensions were designed to be highly denormalized tables containing all descriptive information fitting the granularity of data in the fact table. Dimensions in RN's DDW and LABKAII had overlapping information, why these were used as conformed (shared) dimensions. 3. Designing the fact table. The fact table was designed to only contain aggregable data and foreign keys to dimensions.

The dimensional model was implemented through *extract*, *transform* and *load* (ETL). A test dataset was extracted from LABKAII through a series of stored SQL procedures from a Microsoft SQL Server 2008. The raw extracted data from LABKAII were transformed to fit the dimensional model: Data types were changed, table columns were sorted, distinct values were extracted and data were filtered to remove redundant historic data. All descriptive information for dimensions was stored in Master Data Services (MDS) entities on a Microsoft SQL Sever 2012. After transformation the dimensional model was loaded into the DDW. The fact table has foreign keys to the dimensions; hence the dimensions were loaded before the fact-table by combining relevant MDS entities.

Results

The final dimensional model consisted of one fact table, two new dimensions and four conformed dimensions. The fact table contained approx. 95 million rows. The granularity in the fact table corresponds to one laboratory result per row. Descriptive data unique to LABKAII were loaded in two new dimensions. The first contained information related to analysis types, reference limits and instruments. The second contained descriptions of priority, status and archetypes related to each result in the fact table. The dimensional model also relied on four conformed dimensions encompassing information about date, time, citizens, and organization. A query combined laboratory results with patient administrative data belonging to patients with diabetes mellitus type 1. The query yielded 4.949 patients with 2.612.219 laboratory results from 1.539 types of analyses.

Discussion

The time is right for DDW's, because the Danish healthcare sector does a tremendous job classifying and structuring data in selected sources, making this DDW project manageable. It is important to realize that the DDW does not actually integrate data. It only loads the data into a joint model that can be queried across different sources easily. The secondary purpose decides the integration and it should be considered carefully with each new integrating query.

In conclusion the DDW can be used to retrieve large datasets for research and other secondary purposes. The more data sources it embraces the more secondary purposes it can support. However, concrete examples analysing datasets are needed to show the value and increase the acceptance.

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The Science Centre Health and Technology; a Case Study of a unique arena for progressive health care education, welfare technology and service innovation

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Introduction

Most higher education institutions have taken initiatives to meet the future needs of welfare technology implementation, service innovation and new educational initiatives in the health- and care services. However, many institutions struggle to move beyond pilot studies, to actively contribute in both welfare technology innovation and service innovation and thereby establish long lasting results. The Science Centre Health and Technology opened in 2012 in Drammen, Norway, constituting an arena where researchers, educators and students interact and cooperate with public and private working life as well as users and patient organizations. The Centre offers education ranging from presentations and work-shops to higher education programs within health and welfare technology, applying clinical- and simulation training and web-based learning facilities. The Centre develops and implements welfare technology, service innovation and social entrepreneurship. Research is conducted related to the activities in the Centre. This case study describes why and how Buskerud University College (BUC) has developed the Science Centre Health and Technology through a partnership with public sector and private companies. Research questions are: 1) why did BUC develop a Science Centre; 2) how did strategies and characteristics of BUC contribute, 3) how did national, regional and local political strategies and development contribute in this process ; 4) how has BUC contributed to regional development of new educational initiatives, development of welfare technology and service innovation through the preceding process and establishment of the Science Centre Health and Technology and 5) what are the success factors?

Materials and Methods

We use a mixed methods case study design and collect data through publicly available data, review of documentation and interviews. The main data sources are reports and minutes of meetings from 2004 until today. Key persons will be interviewed to validate the findings from the document analyses and elaborate on questions raised through the analyses. Meetings has been held with management of BUC, employees of the Faculty of health sciences, the partners such as regional authorities, municipality administration and health and care service, technological developers, regional health trust, regional welfare authorities, funding agencies and policy makers such as Innovation Norway, Norwegian Research Council, politicians and users such as students, health care professionals, user/patient organizations and visitors to the Science Centre.

Results

Preliminary document analysis reveal that BUC has had a strategic focus on health innovation, creating a new way of cooperating with regional partners in the Drammen region since 2004, in concordance with national and regional strategies. Data from the Database for Statistics on Higher Education shows that BUC has a good production of students, one of the highest academic levels among the employees and a high production of health and care research, a high number of master programs developed in regional partnerships and a high degree of innovation and entrepreneurial activities. BUCs initiative to and participation in the Arena Health Innovation Network has been of great importance both for the realization of the Science Centre and for regional development. The Science Centre Health and Technology was built as an entirely new entity housing a “mini health Norway” including hospital wards, x-ray lab, a mental health clinic and a (private) innovation apartment. BUC has initiated a number of research projects related to development and implementation of technology in municipalities and service innovation. Several new educational programs and learning activities have been introduced. And finally, a large number of municipalities and users have visited the Science Centre in order to learn more about welfare technology.

Discussion

After the opening in 2012, the Science Centre Health and Technology seems to be a unique arena connecting partners in a quadruple helix setting. Although obstacles have been reported, BUC is perceived as quite successful and effective to partners and students in the role as facilitator and co-producer of health- and care innovation and educational innovation, working through the Science Centre in concordance with national and regional needs and strategies.

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Master's Program in Health Informatics at University of Agder

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Introduction

University of Agder (UiA) offers a master's program in health informatics. This is a part-time interdisciplinary program with a problem-oriented approach. The master program was established in 2000 together with Aalborg University. The two first years (60 ECTS) was offered at UiA and the last year (30 ECTS) at Aalborg University. From 2010 the whole master program in health informatics has been offered at UiA.

Academically, the program benefits from the longstanding collaboration between Aalborg University and their overall problem-oriented approach [1]. The program has been developed and modified in a joint effort between the Faculties of Health and Sport Sciences, Engineering and Science and Economics and Social Sciences and builds on the academic traditions of the humanities, social sciences and technology.

The Master's Program

Approximately 30 students apply every year to the master program. To be qualified they need a bachelor degree in health or social care, and at least 2 years of professional experience in the field of their degree. They come with background as nurses, x-ray technicians, disability nurses, child welfare workers, bio-engineers, occupational therapists, physical therapists, or social workers. The program runs over 6 semesters. Teaching is supplied during two weeks on campus every semester by lecturers, as well as by guest speakers. The program offers a solid theoretical foundation for the study of health informatics and identity and develops students' practical skills through three project management courses. The last year the students conduct their master thesis. The master program contains 8 separate courses. The first two years the students do one course per semester, and in parallel they do a project which also counts towards the degree. These projects are problem based, and the students generally find projects related to their work.

The master thesis is usually undertaken individually or in a group of up to three students. The grade for the thesis is based on the submitted report and an oral presentation with a question and answer session.

The learning environment contains a learning platform used between the two seminar weeks in every semester. Supervision is given both in the two seminar week and in between. Due to the projects that run all through the study year, students meet regularly over Skype and supervision is to a large degree also done over Skype. Group work, project work and report writing are important pedagogical methods. The lectures are given in Norwegian but the literature is mainly in English. More information about the master program in health informatics is available from www.uia.no [2].

The program has been highly successful, due to the increase use and pressure on using technology in healthcare. High quality candidates with a master in health informatics are recruited to different positions in business, academia and practice.

Developing an E-Learning Course

Our further plans include developing a 5 ECTS online course in health informatics; this will be made available for students in the master program from January 2014. The course will be developed in collaboration with University of Nebraska (UNO), Omaha, USA. It will run as a joint course, available both for UiA students and UNO students in health informatics.

Stand-alone Course for Further Education

We have experienced a growing demand for shorter courses for larger groups of employees, especially in municipalities. As a response to this we will from Fall 2013 be offering a course on Assistive Technology over one semester. The course is 15 ECTS and will be offered as a combination of a seminar on campus over 2 days, and on-line teaching and supervision. For more information on this, see: http://www.uia.no/portaler/studietilbud/etter-_og_videreutdanning/innfoeringskurs_i_velferdsteknologi.

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Exploring technologies to foster wellbeing and vitality among older people

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Introduction

The interest in older people as technology users is increasing. A growing body of literature is concerned with the design of digital solutions for the ageing population, many aiming at facilitating active ageing. Maintaining social, physical and mental wellbeing may prevent functional decline and hence postpone the individual's needs for extensive, costly health care services.

Healthy eating and social participation are two core challenges among older people. Subtle small changes in nutrition and social contact can accumulate over time, often leading to vicious circles of lost vitality, which in turn may result in increased demand for extensive health care. A growing ageing population combined with a limited number of qualified health care personnel challenges the health care services.

Although older people use a mobile phone or have a PC, large cohorts are still laggards to adopt new technologies like smart phones or tablets. For this presentation we will report on experiences from exploring this technology's potential to foster participation and stimulate wellbeing seen as social engagement and healthy eating.

Materials and Methods

We collected data in from November 2012 to May 2013, first, as a focus group interview and secondly as three iterative technology workshops with six home dwelling care recipients. Three men and three women aged 76-95 (mean 88,5) participated. The focus group interview was undertaken to identify their challenges with regard to diet and healthy eating and social contact and participation in addition to their attitudes towards and experiences with technology. During the technology workshops the participants tried out tablets (iPad) and applications (apps) for social contact, such as video communication; and for facilitating healthy eating, for example acquisition of food, meal tips and recipes. The conversation evolved around their interest in using such applications in everyday life and the applications' perceived usefulness for them. Experiences from the first workshop informed the second and third workshop. The empirical data: field notes and transcripts from the focus group and workshops was subject to inductive qualitative content analysis with coding within and across the data sets. The codes formed three categories of technology experiences.

Results

The participants reported challenges to healthy eating due to health issues, functional decline or living alone. Their social network was reduced and some of the participants depended on help from their family. Attitudes towards technology varied from being generally sceptical to being enthusiastic.

Their experiences with technology varied from a feeling of exclusion to claiming increased life satisfaction. The hands-on try-outs of tablets showed that an iPad was relatively easy to use. However, significantly impaired vision created difficulties. Applications for social contact, such as video communication appealed to some participants. They showed less interest in applications facilitating acquisition and preparation of food.

Preliminary analysis of data from the focus group and the technology workshops points to three categories of technology experiences, influencing wellbeing and felt vitality; *the excluded*, *the entertained*, and *the networker*. The *excluded* was sceptical to the on-going digitalization, expressed mistrust towards the technology and feared necessary bank and health care services would be solely replaced by technology. The *entertained* used the tablet to find information on Internet, read digital newspapers, catch up on favourite TV-shows or music, or just reminisced by looking at pictures of family, from travels or past activities. The *networker* used the tablet to communicate with friends and family, some far away and others living nearby. For the latter two categories of experiences, enthusiasm, curiosity and willingness to embrace new technology were reported to positively affect their quality of life.

Discussion

The research reported here can help to understand the potential of an easy-to-use, available technology to facilitate active ageing. We will elaborate further on potential for using tablets in everyday activities to facilitate wellbeing by social contact and participation, and as encouragement for healthy eating. The older persons' varying experiences lead us to suggest individual considerations and tailoring before implementation if we are to fully exploit the potential in use of technology mindful of each user's choices, needs and interests. Our initial findings add to increasing insights into use of ambient assistive technology to compensate for functional declines that are part of the ageing process. We will share how common and easily available technology may support active and independent living, foster wellbeing and vitality, and postpone demands for extensive health care resources and costly services.

Acknowledgments

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Nurses' experiences with electronic medical records

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Introduction

Electronic medical records (EMR) have the potential to make healthcare better (Haux & Howe et al., 2008; Ayatollahi, Bath & Goodacre, 2009; Goldzweig & Towfigh, et.al., 2009; Chaudhry & Wang, et.al., 2006). Even so, there is a perceived dissatisfaction among nurses worldwide regarding the use of EMR, which indirectly affect patient care (Viitanen & Hyppönen, et. al.., 2011; Darbyshire 2004; Timmons 2003; Stevenson, Nilssons et. al., 2010; Top & Gider (2011). There is a lack of knowledge of how widespread this dissatisfaction is amongst Swedish nurses. Too few studies have been done on the subject. according to (Otieno, et. al., 2007; Clark, 2007; Stevensson, et. al.., 2010; Stevensson & Nilsson, 2011; Top & Gider, 2011; Holtz & Krein, 2011). This study looks at the dissatisfaction that Swedish nurses experience, in the use of EMR.

Materials and Methods

A survey was conducted with Swedish nurses. Respondents were identified and accessed during May 2013. Firstly 111 nurses were found using goal steered sampling. The second sampling was carried out by getting the nurses' union to send out the survey to 500 of their members. The result is represented by 167 Swedish nurses from a total of 611 nurses who received the survey which gives a response rate of about 27%. The survey questions were based on a framework developed by Otieno et. al 2007 for investigating Japanese nurses opinions in a similar study. Twelve questions were asked and correlations were looked for in terms of which particular system was being used, how long the respondent had worked as a nurse and if the respondent had received education in using the system. Answers were according a five grade likert scale.

Results

On average there was no large scale dissatisfaction with an average score of 3.0 for all respondents and all 12 questions. Dissatisfaction was greatest for the system's ability to; answer questions about normal medical knowledge (2.5) and simplify the collection of information for discharge notes (2.6). Satisfaction was highest for was greatest for the system's ability to; document the physical evaluations of patients (3.6) and acquire results from previous examinations and tests (3.4) .

When comparing different systems, nurses were not more dissatisfied with a particular system (2.9 -3.4) but dissatisfaction was present for different functions of all the systems. The largest variations between systems were for the systems' ability to acquire information about medicines (1.7). Looking at years of employment, there was no linear correlation between the length of employment and the responses to particular questions or on average for all the questions. When looking at the amount of education in the system, there was a correlation of responses to three of the questions; increasing education gave more satisfaction regarding the systems ability to provide an overview of the patient's medical condition (from 2.8 to 3.0 to 3.3) as well as the system's ability to simplify the collection of information for discharge notes (from 2.4 to 2.6 to 2.8). Increased education led though to more dissatisfaction regarding the systems ability to document daily care. There was no linear positive correlation between education and decreasing dissatisfaction

Discussion

This knowledge acquired from this study can be used to improve the experiences in the use of electronic medical records among Swedish nurses.. A limitation in this study was that no differentiation was made between the different types of nurses, with their different tasks and responsibilities.

The work can be a pilot study for further research with a larger sample that would provide reliability. In a larger study those issues that appeared to point to dissatisfaction could be delved into in greater depth. Differences between different groups of nurses could also be studied to give more refined results.

While there was no extensive dissatisfaction found, most of the responses varied narrowly from 3.0. Given the role that electronic medical records play for nurses and by extension the health of patients, it could be argued that a score of 3.0 is insufficient. It is somewhat surprising then that nurses are not "heard" from more. Even the nurses' union was initially reluctant to allow the researchers access to their members. Access to the limited number of 500 was eventually given.

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A Heuristic Evaluation of a Telehealth Solution from the Danish TeleCare North Large-Scale Randomized Trial

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Introduction

Chronic Obstructive Pulmonary Disease (COPD) is a progressive lung disease in which the airways are damaged making natural breathing challenging. Many COPD patients experience acute events, exacerbations, characterized by significant worsening of lung function and symptoms for more than one day. COPD has a significant effect on mortality, health care costs and quality of life. TeleCare North is a large-scale, cluster randomized trial that will be implemented in 2013-2015 in the North Denmark Region. The project consists of a cross-sectional design where the municipalities, general practitioners (GPs), the North Denmark Region and Aalborg University collaborate in the development of a telehealth solution (named Telekit) for COPD patients. The aim of this study was to usability test Telekit, so that COPD patients easily can access the solution and benefit from its functions.

Materials and Methods

In this study an evaluation method called heuristic evaluation for testing the usability of a telehealth solution was used. The objective was to capture and predict obvious problems with the solution by using knowledge from experts in the area of usability. Telekit is an internet-based monitoring and treatment system that consists of: a tablet (Samsung Galaxy TAB 2), a fingertip pulse oximeter (Nonin, onyx II % SpO_2), a blood pressure monitor (Model UA-767, plus BT-C) and a weight (not included in the heuristic evaluation). To ensure that all aspects of the Heuristic Evaluation served adequately the procedure was tested in a pilot test. Five experts (2 women, 3 men), including the expert from the pilot test had an educational background as engineers. The average age of the experts was 29 years (min 25, max 36). They evaluated the solution individually and judged its compliance with Jakob Nielsen's 10 general principles for interaction design, called "heuristics". The experts got an overview of Telekit and its capabilities from constructed scenarios. They continuously evaluated the various dialog elements of the solution and compared them with the heuristics. When usability problems were discovered, the experts had to categorize them into Rolf Molich's classification of problems.

Results

Based on the lists of usability problems, the experts identified a total of 152 problems in Telekit. Each expert identified between 22-40 problems. 86 (49%) out of the 152 problems were only identified once. 3% of the problems were found by all experts, 4% by four experts, 8% by three experts, 36% by two experts. The experts with most experience within usability identified the highest number of problems. Not all heuristics were applied by all experts - heuristics such as "*User control and freedom*", "*Recover from errors*" and "*Help and documentation*" were only applied by the three experts with most experience. However, in total all heuristics were used, but the three most frequently used were: *"Match between system and the real world"* (32%), *"Consistency and standards"* (13%), and *"Aesthetic and minimalist design"* (13%). The most widely used classifications were: "*Improvements*" (40%), and *"Minor problems"* (43%).

Discussion

The goal of a Heuristic Evaluation is to discover usability problems in an existing design (so these can be solved). The study lasted ten hours, two hours per expert, which indicates that the method produces results quickly. The findings indicate that Telekit needs an improvement. Especially the design of Telekit has to be improved or redesigned. It is important that the solution is user-friendly because otherwise people will not use it. It is also important to strive for good usability in order to ensure satisfactory clinical outcome. Therefore, close attention to users and the human issues involved are essential as well. In conclusion, usability testing approaches like the Heuristic Evaluation gives the opportunity to reveal severe usability issues, which in worst case could cause implementations to be unused.

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Functions for Personal Health Records in Sweden – Patient Perspectives

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Introduction

As part of the ongoing shift in health policy, with focus on patient empowerment, the Swedish government prioritizes the patients' access to their medical records. Different models for personal health records (PHR) are suggested.

Studies have shown difficulties for patients when navigating and understanding the information in their records. Electronic health record systems are physician-oriented and do not include patient-oriented functions. One problem with medical records is that they contain a lot of data which is usually kept as unstructured text in narrative form; this information overload needs to be structured and presented in a manner that patients understand. Furthermore, in order for the PHR to be a supporting tool for patients, there is a need to identify which key functions should be implemented to support patients. Usage of PHR is highly dependent on the information offered and that functions available meet patient needs. In Sweden, little research has been conducted regarding PHR functions preferred by patients. This study addresses the research question "Which PHR functions are preferred by patients living in Sweden?".

Materials and Methods

Structured interviews were conducted with five participants (ages 18 to 79) to capture how Swedish patients perceive medical records and the information obtained from healthcare. The thematic analysis of the interview data was used to design an online survey that was available for two months during the summer of 2012. A five-point Likert scale was used to perform a descriptive analysis of the respondents' attitude to 18 statements. Five patient organizations distributed the survey to their members, and the survey was also made available in an online article published by the newspaper Metro. 201 respondents participated in the survey.

Results

Five themes were identified through the interviews:

- overview of the content
- help to understand the content
- help to understand screening results
- communication/interaction with healthcare
- additional functions

Besides these themes, the participants confirmed issues regarding insufficiency and understandability of the information received by healthcare providers.

The typical survey respondent was a middle-aged female who suffered from some kind of illness and had good computer skills. The respondents wanted timelines for a better overview of their illness and medication, help to understand the content in everyday language, and text summaries. Further, they wanted explanations illustrated with pictures and videos, and access to a medical dictionary. Most of all, they would appreciate fact boxes and search engines as functions in the PHR. Also, they wanted the possibility to add information to the medical record. To communicate with caregivers apart from face-to-face meetings, e-mail was preferred. Video calls were deemed least important.

The respondents considered all categories important, almost all the answers were at the level of "strongly agree". However, the statements regarding the possibility to communicate with a chat bot and the possibility to view PHR content in another language had a low agreement level.

Discussion

In this study on preferred functions in PHRs, interview participants confirmed that medical records are hard to understand, due to structure and content, e.g. the extensive use of abbreviations and Latin terms. Existing techniques, such as Natural Language Processing for summarization, presentation in everyday language, usage of different visualization techniques for presenting screening results and different communication means, should be exploited for interactive and user centred PHR. Offering patients a tailored PHR can facilitate achieving high acceptance. This can further create active participation, which in turn may lead to patient empowerment.

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