

**Proceedings from
The 15th Scandinavian Conference on Health
Informatics**

2017

**Kristiansand,
Norway
August 29–30, 2017**

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Linköping Electronic Conference Proceedings, No. 145

ISBN: 978-91-7685-364-1

ISSN: 1650-3686

eISSN: 1650-3740

URL: <http://www.ep.liu.se/ecp/contents.asp?issue=145>

Linköping University Electronic Press

Linköping, Sweden,

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New Technology in Norwegian Municipalities' Health Care Services: Experiences in Small Rural Municipalities

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Abstract

New assistive technology appears as part of the solution for a coming 'crisis' in health care services. This paper analyses experiences with introducing welfare technology in small municipalities in the region of Sogn and Fjordane. The empirical material is based on nine interviews with project groups and health care leaders in municipalities working with welfare technology. While many of the national advice and recommendations about assistive technology are good guidelines, the findings suggest that certain challenges are increased by the small size of the municipalities. This points to the importance of recognising different needs created by a variation among municipalities.

Keywords

Welfare technology, Assistive technology, Municipality health care services

1 INTRODUCTION

There is a widespread agreement that we will need to deliver health care services in new ways in the future due to an increasing gap between a growing population in need of health care services and the number of 'warm hands' working within municipal health care. It is projected by Statistics Norway that the 'care burden' in Norway will double within the next 25 years. A lack of resources for supporting institutional care means that more people will have to be supported in their own homes. The Norwegian report Innovation in Care (NOU 2011:11) suggests that assistive technology, or 'welfare technology' which it is often called in Scandinavia, will help to make more people able to remain and live safely in their own home until an older age. At the same time, welfare technology will increase quality of health care services for users and relatives and, according to the report (NOU 2011:11), it will reduce or postpone the need for institution based care. Welfare technology is further defined in the report as technological assistance that contribute to increased safety, social participation and mobility, as well as physical and cultural activity. It enables the individual to manage everyday life despite of sickness, old age or mental and/or physical disability.

The goal is that technology will provide an early warning about accidents or unwanted episodes. This can increase quality of care, as well as save time for health care personnel. Seen from the perspective of the users or relatives, such technology might increase personal freedom. For instance, using a GPS or a digital system for localising a person can have significant positive effects for persons with a cognitive disability that like to go for a walk. With a GPS relatives or health care personnel can be notified and the wandering user can be found if she

cannot find her way back on her own (Øderud, 2015). We will not go into the discussion of whether 'cold technology' or 'warm hands' are better for health care services or the users. However, we recognize that there is a strong political pressure for municipalities to introduce welfare technology in Norway (Melting, 2017; Melting, 2015; Helsedirektoratet, 2012). Similar trends concerning assistive technology in health care services can be seen in many western countries. Although this invites to exchange of knowledge and experiences across national borders, some challenges in this work are national. In Norway, there is a national programme for welfare technology run by the Norwegian Directorate for Health in collaboration with the Norwegian Association of Local and Regional Authorities (KS), providing advice and guidelines for introducing welfare technology in municipalities' health care services. In this paper, we analyse and discuss experiences from a project aiming to implement welfare technology in a selection of municipalities in the rural region of Sogn and Fjordane.

The municipalities in the region Sogn and Fjordane are mainly small regarding population, but with relatively large areas and long distances. The geography is challenging and many of the municipalities have scarce financial as well as human resources. As we will show in the analysis, some of the challenges that the municipalities meet can be found also in other regions. However, some of our findings suggest that the size of the municipalities also produce some of their challenges – some of which have not been thoroughly investigated and clarified by the national programme.

1.1 Welfare technology in municipalities in Sogn and Fjordane

This study analyses experiences from the project Welfare Technology in the Municipalities in Sogn and Fjordane,

Paper from the 15th Scandinavian Conference on Health Informatics SHI2017, Kristiansand, Norway, 29 - 30 August.

Conference Proceedings published by [Linköping University Electronic Press](http://www.ln.se/Linkoping_University_Electronic_Press).

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which started in 2014. The project has since then been run by a cross-sectoral working group, including several municipalities, county council, representatives from research and education and regional health authorities. The County Governor funded the project with 50%, while the municipalities have provided the remaining 50%.

In 2014, none of the 26 municipalities in the region had started implementing welfare technology. Consequently, the first phase of this project focused on inviting all municipalities to participate and encouraged them to start the process of placing welfare technology on their agenda.

The second phase of the project was running through 2015. At that time, the Norwegian Directorate for Health had set a dead-line for implementing welfare technology in municipal health services by 2018 and there was apparently no time to lose. This deadline has later been postponed several times. Project phase 2 focused on establishing practical experience and knowledge by testing specific welfare technological solutions in pilot municipalities. This included safety systems for sheltered housing and private homes, with various sensors and alarms that warn health care services or relatives when unforeseen and unwanted events happen. Such unwanted events could be a person falling (fall-detection technology), leaving her home (GPS or motion-detection sensors) or leaving bed at night without returning (sensor in bed). Other technological solutions that were tested included digital medicine dispensers that reminds the user with an alarm when it is time for her medicine. Also, if the medicine is not taken, an alarm can warn relatives or health care personnel. One municipality introduced activity technology in their pilot, represented by an exercise bike coupled with a video showing recordings from local village roads to increase motivation for indoor exercise.

At the time of the third project phase, in 2016, the national welfare technology programme had started to publish results and nationwide advice for municipalities. Thus, when the pilots continued, national advice was more directly involved through the introduction of a framework, created by the national programme, for realising cost and quality benefits from using technology. The pilot municipalities continued their activities while receiving training in this cost and quality benefit tool. The municipalities were then encouraged to use this method in their own work, and the work was evaluated through interviews five months later.

The aim of the regional project was not only to gain experience in single municipalities. The experiences and knowledge gathered through these pilots would become the basis of advice for municipalities in the region and simultaneously create local and regional spearhead municipalities. The technological solutions that were piloted were not new technology, but they were unfamiliar to the municipalities of this region. Many other projects across Norway, as well as other countries, have documented positive effects of such technologies

(Melting, 2017; Melting, 2015). The aim of this article is however not to evaluate the technology, but to analyse the processes of introducing technology within the municipalities.

2 LITERATURE

There are several studies analysing the challenges of implementation of welfare technology in Norwegian municipalities (Ørjasæter, 2016; Dugstad et al., 2015; Nordtug et al., 2015; Disch et al., 2015; Grut et al., 2013). These mostly focus on the effects of the technologies, as well as the experiences of health care workers regarding implementation. Dugstad et al. (2015) identify several barriers regarding implementation of welfare technology in various municipalities in eastern and southern Norway (Dugstad et al., 2015). Some of these are presented as universal challenges, that probably could be found in most municipalities. Examples of such barriers are knowledge of technology in general as well as the specific welfare technological solutions and communication between technologists and health professionals.

Nordtug et al. (2015) studies three districts in mid-Norway implementing sensor technology in their health care services. They found high motivation among the health professionals, as well as a need for extra resources to focus on cross-sectional cooperation. Grut et al. (2013) found that 'to be successful, the adoption of welfare technology needs to be anchored at several different levels within the municipal organization' and that communication between all parties is crucial in such processes.

One of the early welfare technology projects concluded that welfare technology could be perceived as a threat to the existing corporate culture, structures and values of municipal health care (Det Midnorske velferdsteknologiprojektet 2014). This project also provided a list of advice for municipalities that were interested in welfare technology, which became part of the inspiration for the work in the region of Sogn and Fjordane.

Small municipalities in somewhat rural areas are included in some of the studies mentioned above. However, none have cases from the region of Sogn and Fjordane, and none are identifying specific challenges connected to size of the municipality. In this article, we will point to experiences from Sogn and Fjordane that suggest that also size of municipalities is important in the process of implementing welfare technology.

3 METHODS AND THEORETICAL FRAME

The empirical material includes a total of nine interviews with welfare technology project groups or representatives from different municipalities' health care services in the region. Eight of the interviews were with single municipalities, while one was a group conversation with several municipalities. The interviews lasted

between 30 and 90 minutes, and had between one and nine participants. These were mainly the leader of health care services in the municipality and people from the project group, often including middle leaders with responsibility for home care services. Other participants present in one or two interviews, were representatives of IT services, representatives of user organisations and, in one case, a politician. The interviews were completed during 2016 and 2017.

The researchers responsible for the interviews were part of the cross-sectoral working group that met and discussed the local projects several times in the project period. The researchers were not involved in the municipalities' local project groups. At the end of phase 2 and phase 3 the researchers visited the municipalities or met the project groups in video meetings, to interview them about their experiences in the work of introducing welfare technological solutions as well as their experience with using the cost and quality benefit tool.

Two different interview guides were used, both designed to evaluate the process of implementing welfare technology, however one also focusing on the cost benefit tool. The interview guides built on findings from similar analysis in other projects in Norwegian municipalities, thus aiming to capture experiences related to aspects that had been found important in other projects. The interview guides also reflected the theoretical framework from technology studies, seeing technology not only as a physical object, but also including knowledge, skills, symbols and routines. The theory of domestication emphasises that when technology is implemented in a new context, this context already has its own routines, norms and values that the new technology has to adjust to, simultaneously as introduction of new technology changes the context (Silverstone et al., 1997). Thus, technology has an 'interpretative flexibility' for different user groups (Bijker et al., 1993). Our aim was to explore how the process of implementing welfare technology was perceived and experienced by those who were close to this process in the municipalities, while recognising the complexity and negotiations going on in such processes.

We were two researchers present during the interviews, with one asking questions and the other in charge of making extensive interview notes to capture the dialogues in the interviews. The extensive notes were later analysed with Grounded Theory Method, meaning that we coded the text to discover patterns in the material (Charmaz, 2006).

Below we will go through some of the experiences that stand out as particularly noteworthy for the municipalities we interviewed in this region.

4 RESULTS

4.1 Abundance of will and lack of knowledge

We found that introducing welfare technology was welcomed both by political and administrative leadership

in the municipalities that acted as pilots in the project. This was not surprising. In fact, they had been recruited as pilots exactly because they had already put technology on the agenda, making them ready, or nearly ready, to implement technological solutions. Simultaneously as we found political will to support welfare technology initiatives, we also found an equally large lack of knowledge about the same. In one of the municipalities, the message from politicians was that they supported welfare technology regardless of what kind. In another municipality, acquiring and installing welfare technology had been part of a public procurement in which the technology was not specified, thus placing the choice of technology outside the health care department of the municipality. For a third municipality, a political decision to close shielded housing for persons with dementia was followed by a requirement that technology should solve the situation, with no further specification.

The political will was not only accompanied by a lack of knowledge, but also a lack of practical support. To one of the project groups, it felt as if the support from politicians and administration was 'almost too big' – they were 'cheered on', but did not receive adequate resources, time or funding to see projects through. This caused frustration among those who had been appointed as responsible for driving the local project forward. It was difficult for them to achieve their goals and they had to do project work, like preparing reports, in their leisure time.

4.2 Project leadership and project groups

All the municipalities in this study had established a clear project leadership – in most of them this was the head of health care services, occasionally delegated to middle leaders. They had also established project groups, although it had been a challenge for some of the municipalities to find participants for the project, thus the size of the project group varied between municipalities. Project leaders together with project groups were the vital driving forces in the work of implementing welfare technology in all the municipalities.

One of the largest challenges that the project leaders reported, was the new competence requirements they met when starting to work with welfare technology. Most of these leaders had a professional background in health care, thus, technology represented a new competence for them: 'Now I have to learn things I shouldn't really know', one of them said. Another project leader explained how she had to act as a 'Jack of all trades', doing things she 'does not know', and when people asked, she could not give satisfying answers.

Another challenge for leaders and the project groups was to build motivation among other employees. Motivating health care workers to start handling new technology was not a simple task. Only one of the municipalities had reserved time for involving employees. In the other municipalities, the new tasks had to be integrated in an

already fully packed work day schedule, making the smallest challenges difficult to overcome.

We found that in some of the municipalities with a leader-driven process, the employees were not involved from the start of the project. The result was a weak motivation and a lack of 'ownership' among the employees. This in turn made the leaders even more important to keep the project going. Thus, increasing the leader-driven character of the project, in one municipality even resulting in the technology not being used according to the plan.

4.3 Technology competence

Challenges to put together a project group was partly referred to as a lack of people, and partly as a lack of the right people. Lack of people referred to the size of the municipalities: being small also meant few hands to share the work. The lack of right people had to do with the new competence required to deal with technology. We saw that even technology that is apparently simple to handle requires basic technological competence, such as plugging the right cable into the right socket. Lack of technology competence among employees who were responsible for the daily contact with the technology was a challenge in several municipalities. Some of them claimed that employees were hesitant or did not feel safe being introduced to new technology. Rhetorically, the challenge of finding health care personnel with a satisfactory ability to handle technology was several times referred to as a challenge tied to gender and age, and in some municipalities they left the handling of technology to the younger personnel. Some also suggested that scepticism towards new technology had to do with gender: the 'woman syndrome', or the 'what if everything goes wrong syndrome'.

This lack of technology competence among health care professionals was further complicated in some of the municipalities that also had a lack of general technological competence in the municipalities – a lack of IT people. This was a result of inter-municipal companies and agreements about collaboration around ICT support for the small municipalities in the region. In addition, several of the municipalities emphasised that they needed a person who could 'translate' between health care and technology: a 'healthcare-ICT person' who knew enough about technology but at the same time understood the needs within health care services.

4.4 Finding technology for users, or users for technology

Other studies have found that municipalities have had different pathways into their work with welfare technology, from starting with a technology, a user need, or a service in need of innovation (Grut et al., 2013). A similar variation is found among municipalities in Sogn and Fjordane. One municipality was approached by a producer; one was forced to solve a user need; one chose a technological solution that one of the involved health care personnel had learnt about it; and finally, one municipality had left the choice of technology to the

entrepreneur building their health care institution and new sheltered homes.

What all these cases have in common is the difficulties in establishing sufficient knowledge about different technological solutions due to limited personnel resources and limited technological competence among the health care leaders. We saw that one result of this was reluctance to make any choices, but rather to wait for more concrete advice from health authorities. This way the municipalities would not have to do all the explorative groundwork themselves. Another result we found, was a tendency to feel 'stuck with' the technological solutions they had already chosen, or to the technology that appeared to be within reach of their practical and economical resources. Thus, when a municipality already had acquired a technological artefact, their next challenge was to find a user for that technology, turning the health care authorities' advice to 'start with the users' upside down.

4.5 When size is a challenge

The municipalities did not only experience challenges in establishing adequate knowledge about the technological landscape, but also about the technological solutions they had chosen. One municipality experienced this when testing digital medicine dispensers. The dispensers notified the user when it was time to take their medicine, and could send a text message to relatives or health care services if the user did not respond to this notification. However, they soon discovered that the digital platform that sends messages from the dispenser required a larger number of dispensers in use than the two this municipality had acquired.

The small-scale operations represented a challenge for the municipalities also in another way. Having a limited set of technological artefacts or solutions in use, also meant that it took longer time to build experience among employees responsible for using the technology, particularly when this was not part of their everyday routine. Lack of knowledge about how to operate the technological solutions could result in the technology not being used: 'Standing there and fumbling with something technical that we can't make work is difficult – then we'd rather do it the old way', one of the home care workers explained.

Although most of these technology solutions are not new, it is still a challenge to make different technological systems communicate with each other. Three different digital health care systems are in use in the municipalities, and some of the welfare technology solutions communicate with one of these, but rarely with all. The pilot municipalities saw themselves as 'too small' to negotiate with the producers to make them develop the technology to fit the municipality's needs. The municipalities found it particularly frustrating when it appeared that technological solutions recommended by the national programme were not fully developed and ready to be implemented, like one of them illustrated by saying:

'it represents large costs for a small municipality budget and it's perceived as a risk with municipal money when the solution that is recommended is not properly tested or communicating with established professional programs. We are not certain that these really are the future of good solutions.'

4.6 Identifying benefits from using technology

The pilot municipalities did not only test technology, they were also invited to a course to learn and later test a cost and quality benefit tool developed by the national programme. At the course, large sheets of paper with tables to fill in were presented for the participants. Some wrote directly on the paper, others used post-it notes. They started with the user's needs and explored how these could be (better) met with technological solutions, and further, which changes that had to be made to achieve the identified benefits.

The municipalities agreed that this was a good method. They suggested that it increases consciousness of the pre- and post-technology scenarios, making it possible to see benefits. Thus, they saw this as a tool for documenting progress for politicians and to demonstrate for sceptical colleagues that using technology could benefit users by increasing service quality as well.

However, we also found a unanimous agreement that the tool was too complex for their needs and resources, and none of the municipalities used the method in a systematic way. 'It is too cumbersome with all those sheets of paper. That was a bit deterrent', representatives from one municipality explained. In one of the other municipalities they were planning to use the method, however they also perceived it as too complex and time consuming compared to the size of their welfare technology project. Using a complex method like that is probably fine in large projects involving large sums of money and many users, they suggested. However, they could not justify using the same complex method involving many employees for their limited use of technology for a handful of users. Only one of the municipalities we interviewed claimed to use the method, however, they had also adjusted it and simplified the tool to the resources and competences found within the municipality. On the other side of the scale we found that one of the municipalities had more or less given up their welfare technology project, explained by the insecurity it represented for them as a small municipality with limited resources, to invest in technology that was still not fully developed and adjusted for the municipalities' needs. A better strategy for a small municipality would be to wait, they suggested, and let the larger municipalities do the work with adjusting and adaptation of welfare technology.

5 DISCUSSION

Summarizing the findings, we saw a high level of will (or wish) to use technology, but also a lack of knowledge and a lack of practical support in the pilot municipalities

resulting in limited funding and personnel resources. We saw leader-driven processes, with a lack of technology competence resulting in health care leaders doing things they 'shouldn't really know', further complicated by IT personnel posted in inter-municipal ICT companies rather than in the municipality organisation.

The importance of getting these factors right have been pointed out in other projects (Dugstad et al., 2015; Disch and Johnsen, 2015; Grut et al., 2013; Det Midtnorske velferdsteknologiprojektet, 2014). A good project structure, dedicated time, funding, a combination of health care and technology competence etc., are as important for large as for small municipalities. However, our findings suggest that, firstly, the effects of these challenges are sometimes escalated in small municipalities – the extreme version seen in one municipality that decided to put on hold all their activity with welfare technology. Secondly, finding solutions are also complicated by size, like the challenge of including personnel with technology competence in a small municipality that relies on the inter-municipal collaboration rather than internal IT personnel. While other projects have reported on challenges of communication between technologists and health care personnel (Dugstad et al., 2015) the challenge in this case was rather a lack of technologists to communicate with in the first place.

Even though the municipalities operated in small scales and experiences with technology were limited in these projects, the new experiences increased their knowledge about technology, and more importantly, also their attitude towards technology. The municipalities expressed an increased will to use technology and all pilot municipalities engaged in discussions of how to further develop this. 'Don't test, just start', was the advice given by the health care authorities when they visited one of the regional conferences about welfare technology in Sogn and Fjordane. Our findings do however suggest that small-scale testing and trying out technological solutions, including the organisational aspects, in their own speed and scope, was important for the small municipalities. Even though the technology itself is not new anymore, it is still not a natural part of the general competence in the municipality-based health care sector. Like findings in other municipalities (Moe and Nilsen, 2015) also in this region we found staff that were reluctant or sceptical of including technology as a part of the health care solution. However, staff with the ability to use the technological solutions that are being introduced is crucial to achieve benefits from the technology. The challenges of technology competence seem to be more critical in smaller municipalities due to the reasons mentioned above, where access to technology competence appears to be one of the weakest points for some of the small pilot municipalities. This suggests the importance of small-scale pilot activity, as that provided them with a possibility to establish experience and to build knowledge that they need in the further process of implementing welfare technology.

Other challenges related to municipality size are found in the technology. Some of the technological solutions on the market require operations on a larger scale than the small municipalities in this region needed. Learning from larger municipalities (Bjørkquist, 2015) as well as advice from the national welfare technology programme (Melting, 2015; Melting, 2017) had not prepared them for their small-scale operation being a problem.

The small municipalities with limited resources also appeared to react negatively to what they perceived as technological solutions that were not ready for implementation, in particular when 'authorised' through advice from the national programme for welfare technology (Melting, 2015; Melting, 2017). Investing in technology that is not the 'right' solution represents a high risk for them. A recurring question from the health care managers was: 'How can we know that the technology we choose and spend our financial resources on, are not outdated in a year or two?'

The advice and tools coming out of the national programme are indeed important resources for municipalities in their work with welfare technology. Many of the challenges we found appear to reflect municipality size. However, the national programme has not fully recognised that the prerequisites for introducing welfare technology in the health care services in small and rural municipalities might be different from the prerequisites in larger city-based units. Municipalities in Sogn and Fjordane are motivated to work with welfare technology, but they also need to scale and organise the work to fit within their own limited resources and abilities.

6 CONCLUSION

Our study illustrates that size matters for the municipalities' experiences, attitudes and possibilities in the first phase of implementing welfare technology. On the negative side, the most critical factor appears to be lack of technology competence, not only among health care workers, but in general in the municipalities. A recurring theme in the Norwegian discourse is the complexity of welfare technology and the need to focus on human factors rather than the technological object (NOU 2011:11; Helsedirektoratet, 2012; Corneliussen and Dyb, 2017). There is no doubt that implementing welfare technology involves many other aspects than the physical artefact itself. Still, the pilot municipalities illustrate that the technology itself creates prerequisites and challenges that cannot be measured in percentages. Although not knowing which cable to connect is perhaps not the most intricate challenge to solve, such small issues can also prevent the use of technology in practice. On the positive side, however, being small is not only a disadvantage. The small municipalities have a rather large degree of flexibility when they can work at their own speed and within the scope that is achievable within their limited resources.

Although we should not generalise from the interviews in this project, they illustrate that municipalities are different and have different access to economic resources, as well as people with necessary motivation and competences. Some of these differences are not trivial, and size appears to be one factor that needs to be recognized as making a difference in municipalities' efforts to implement welfare technology. More research is needed in this field, to learn more about the situation, and to produce advice about implementation of welfare technology that can reflect the differences between municipalities.

7 ACKNOWLEDGMENTS

We want to thank collaborators in the project Welfare Technology in the Municipalities of Sogn and Fjordane. The project was funded by the County Governor of S&Fj.

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Mapping FHIR Resources to Ontology for DDI reasoning

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Abstract

Fast Healthcare Interoperability Resources (FHIR) specifications are used to exchange clinical and health related information between different systems. There is unfinished on-going work to represent FHIR resources using Semantic Web technology to support semantic interoperability. This same technology would then also fit applications doing reasoning. We utilize and customize the FHIR unofficial draft ontology for doing drug-drug interactions reasoning. We give one use case of such reasoning based on family history; this kind of reasoning may extend the capabilities given by Forskrivnings- og ekspedisjonsstøtte (FEST) alone. We achieve this by setting up a FHIR server and making a FHIR client that store drug and patient information to the server; we then later retrieve some of this information, translated it into Web Ontology Language (OWL) based ontology, do drug-drug interaction (DDI) reasoning exposing potential health risks.

Keywords

FHIR Ontology, DDI reasoning, Semantic Web, SPARQL

1 INTRODUCTION

Electronic health records (EHR) capture health information about patients and their medication; standards and protocols allow such records to be shared between different stakeholders such as hospitals, labs, pharmaceutical companies, etc. One of these standards is the FHIR specifications, built on Health Level 7 (HL7) which is a widely accepted set of protocols and standards used to exchange clinical and health related information between different systems (Benson, 2016).

Some consider HL7 V2 and V3 the most relevant exchange standards in healthcare (Oemig and Snelick, 2017). Our purpose is to do reasoning about Drug-Drug Interactions (DDI) based on patient information together with available information about drugs utilizing FHIR. The reasoning can help doctors making decisions, and pharmaceutical companies in manufacturing drugs. OWL (Bechhofer, 2009) being based on description logic supports reasoning and is our chosen ontology language. Many of the existing medical ontologies are expressed in OWL, e.g., Systematized Nomenclature of Medicine - Clinical Terms (SNOMED CT) (Whetzel et al., 2011), this supports our choice.

Combining data from different sources may allow enhanced reasoning to derive useful information, e.g., detect drug-drug interactions and potential health problems, which again enables early beneficial interventions. To achieve this various medical information systems, implemented on different platforms, need to exchange healthcare data in a standardized way.

This paper describes an important step towards reaching our goal. In short, we demonstrate how a FHIR client can store drug and patient information on a FHIR server; how to retrieve this information and translated it into an OWL based ontology. How to perform drug-drug reasoning on this ontology and transfer the results of the reasoning back to the FHIR server. The ontology we use for reasoning is the FHIR unofficial draft ontology (Anthony, 2016); we customize and extend this ontology for our needs. The contribution of this paper is the demonstration of how system components (EHR, Drug information, ontology for reasoning) may be tied together with help of the FHIR standard to support DDI.

Rest of the paper is organized by different sections as follows: Section II describes the background, and literature review of related concepts and work. Section III describes the solution architecture and a detailed description of solution methods and results. In Section IV, we discuss the usability of this work and provide some options for future work.

2 MATERIALS AND METHODS

2.1 Background and State of the Art

When a patient takes two or more drugs at the same time, DDI's can occur. This interaction may create unexpected side effects. The situation becomes even more complex when the side effects of two drugs together results in new symptoms falsely indicating some potentially new disease (leading to the introduction of new drugs). In some cases, the medical history of the family of a patient may contain information that helps reasoning. One of the approaches for representing the domain of Drug-Drug Interactions (DDI) is medical ontologies which provide a vital

integration of knowledge base and drugs data. Medical ontologies are often defined in OWL whereas reasoners such as Fact++ and Hermit (Glimm et al., 2014) can be used to infer Drug-Drug interactions. SNOMED CT is an example of a medical ontology defined in OWL where medical concepts like "organism" and "substances" are represented as classes in a hierarchical structure. Another class like "chemical" has a subclass "Inorganic chemical". Properties such as "has active ingredient" representing the relations and rules between individuals which are created under each class. Reasoners apply the rules against the knowledge base and determine the action that should be carried out in case a DDI is inferred.

Another form of reasoning on OWL ontologies may be performed with help of rule languages like the Semantic Web Rule Language (SWRL) (Horrocks et al., 2004).

OWL statements may be serialized by using the Resource Description Framework (RDF) where the statements are represented as triples forming RDF graphs (W3C, 2014).

Another key technology of the Semantic Web is the SPARQL Protocol and RDF Query Language (SPARQL) (W3C, 2013), which allows complex queries to retrieve data from an OWL ontology.

The Drug-Drug Interactions Ontology (DINTO) defined in OWL describes and categorizes DDIs and all the possible mechanisms that can lead to them; it demonstrates that the combination of drug-related facts in DINTO and SWRL rules can be used to infer DDIs and their different mechanisms on a large scale (Herrero Zazo et al., 2014) (Herrero-Zazo et al., 2015). Yoshikawa et al. (2004) developed Drug Interaction Ontology (DIO) with a focus of inferencing a possible drug-drug interaction based on the molecules of the drugs. It checks all possible biomolecular interactions between drugs that may lead to unexpected side effect(s). It infers not only drug-drug interaction, but also checks the individual differences in drug response or genetic susceptibility of drugs, and optimization of balance of efficacy and safety of new drugs.

"Founded in 1987, Health Level Seven International (HL7) is a not-for-profit, ANSI-accredited standards developing organization dedicated to providing a comprehensive framework and related standards for the exchange, integration, sharing, and retrieval of electronic health information that supports clinical practice and the management, delivery and evaluation of health services." (HL7, 2017).

HL7 has affiliates in all continents. European HL7 affiliates comprises 21 countries including Norway. FHIR (Benson, 2016) is a set of HL7 standards introduced by HL7 as Draft Standard for Trial Use (DSTU) which includes various features from different versions of HL7 such as HL7 v2, HL7 v3 and CDA.

FHIR resources are modular components that can be combined to build a solution for many problems existing in the real world of clinics and can be used to solve administrative problems as well. According to FHIR

standards, resources are the common building blocks for exchanging documents and information related to healthcare information (Benson, 2016). Figure 1 shows an example of a FHIR resource in the form of a UML Diagram; the Medication resource is primarily used for the identification and definition of a medication (FHIR-HL7, 2017). As shown in the figure 1, it includes the ingredients and the packaging for a medication; communicating a medication would come as a bundle containing an instance of this pattern in one of the supported serialization formats (e.g., JSON).

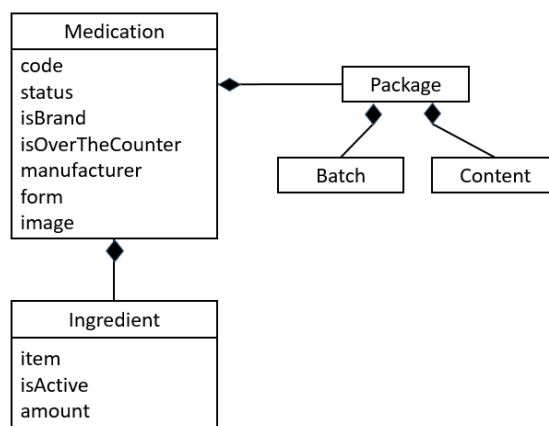


Figure 1. FHIR Medication resource (FHIR-HL7, 2017)

The main challenge for healthcare standards is the continuous need to add more fields and options to the specification which increases the cost and complexity of implementations. FHIR has defined a framework in such a way that it becomes easy enough to extend the current resources and add custom definition (Kasthurirathne et al., 2015). As FHIR mainly focuses on implementation, there are many libraries available for development with no restrictions on specification (Kasthurirathne et al., 2015).

There are also research efforts in the direction of representing FHIR data types in terms of OWL constructs which enhances semantic interoperability of FHIR resources. One key change of HL7 FHIR Release 3 is the definition of an RDF format, and how FHIR relates to Linked Data (Grieve, 2017).

An unofficial HL7 FHIR ontology draft was presented on 11th October 2016 by the ITS group (Anthony, 2016). This unofficial draft is a result of the ongoing work and its effort towards describing all the FHIR resources using OWL format. They used the same name of FHIR resources for their OWL class. Content that describe a resource is given as OWL object properties. And, some of the content is represented using OWL data properties. An OWL object property describes links going from one individual to another, e.g., the description of a specific patient (instance of class *Patient*) linked by an object property called *prescribed* to a specific drug (instance of class *Drug*). OWL data properties describe links from individuals to data values like text strings and numbers, e.g., representing name and year of birth.

There are several HAPI-FHIR FHIR RESTful servers available; HAPI FHIR is developed by the University Health Network (UHN) group. It is a Java implementation of FHIR resources, and it is an open source RESTful server which gives opportunities for researchers and academicians to use it freely and provides java libraries for all resources (UHN, 2017). HAPI-FHIR test server has implemented all the FHIR resources and is built from numerous modules of the HAPI FHIR project. The server has uploaded sample data for all resources. It is possible to read, edit, create, update, delete and validate these resources. The output of the read operation is either in JSON or XML formats. RDF is still not defined for accessing a RESTful server.

There are several tools available for working with OWL. Protégé is an open-source ontology editor used for creating and editing OWL ontologies; it also supports reasoning. It has a plug-in architecture with a rich set of plug-ins, e.g., SPARQL, SWRL and reasoners like Fact++ and Hermit (Musen, 2015). Jena is a collection of Java libraries used for creating Semantic web and Linked data applications (McBride, 2002). It provides a framework for inferencing, storage, querying (SPARQL) and it provides a database solution, called Fuseki (Apache, 2011), for handling ontologies, e.g., through a web interface.

3 SOLUTION OVERVIEW

Figure 2 shows the architecture of our solution. We developed a customized FHIR ontology, comprised of the resources which are relevant to our drug-drug reasoning example. The part of our ontology concerning the FHIR resources coincides with ideas presented by Beredimas et al. (2015); the part concerning DDI reasoning is partly inspired by (Herrero-Zazo et al., 2015) all together with our own contribution.

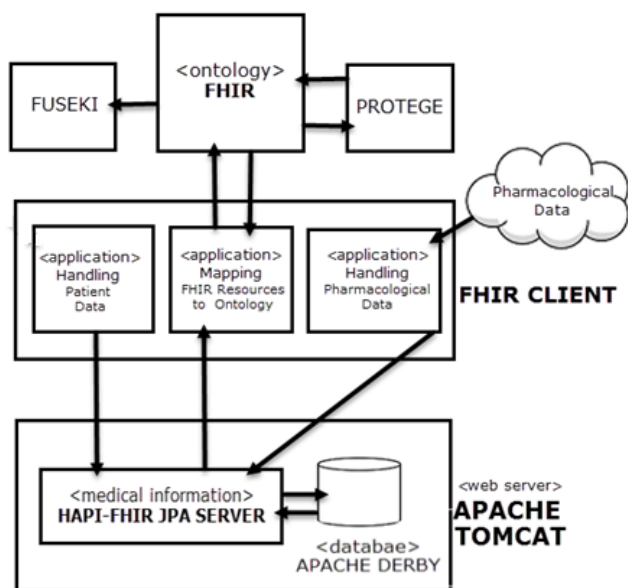


Figure 2. Architecture overview

In the ontology, we need to represent the information given by FHIR resources, and we do this in a one-to-one style. We do not represent all the FHIR resources in detail, but using a similar approach, we can extend the ontology

for all the resources. We built a FHIR client consisting of three Java modules, which can easily be made as three separate applications:

- one for inserting pharmacological data into the FHIR server.
- one for inserting patient data into the FHIR server.
- one for retrieving pharmacological and patient data; mapping of these FHIR resource instances to the corresponding FHIR ontology classes.

The server is locally hosted HAPI-FHIR server. We then used Protégé for reasoning and display of the results; to do this in the Java application is also straight forward. Also a SPARQL endpoint, e.g., Fuseki, as shown in the figure, can be used for storing the ontology.

3.1 FEST to FHIR

FEST is a database used for prescription in Norway, and have a huge collection of drug descriptions. Pharmaceutical data that we have used for the representation of drug-drug interactions is taken from FEST (i.e., from the distributed FEST xml file). For the purpose of demonstrating a drug-drug reasoning, the FEST data is handled manually by identifying relevant drugs and importing them to the FHIR server (Legemiddelvek, 2016). A different project, in the form of master thesis with title "Ontological modelling of FEST with support for DDI reasoning" (Abbas, 2017).

3.2 FHIR server

Of the FHIR resources, we mainly used Medication, Patient, Practitioner, DetectedIssues, and MedicationStatement re-sources. In the FHIR server, drugs are represented using the Medication resource. We identified 10 different medicines from FEST database where some may have potential drug interaction with each other, and created FHIR resource in-stances. Patient and Practitioner instances were created using the corresponding FHIR resources. When it comes to the identification of a medicine, two different coding systems were used: Anatomical Therapeutic Chemical (ATC) Classification System and SNOMED CT.

```
<code>
  <coding>
    <system value="http://snomed.info/sct"/>
    <code value="116078005"/>
    <display value="Efavirenz (product)"/>
  </coding>
  <coding>
    <system value="https://www.whocc.no"/>
    <code value="J05AG03"/>
    <display value="efavirenz"/>
  </coding>
</code>
```

Figure 3. SNOMED CT and ATC codes example

Above is an example of a medicine, which is stored in FHIR server, identified by both using SNOMED CT and Anatomical Therapeutic Chemical (ATC) codes.

In figure 3 above, *system* value specifies the coding system that is being used and corresponding *code* displays the actual code that is used to describe the particular medicine. While *display* value describes the name of the medicine which is also specified by the coding system being used. *DetectedIssue* resource, for our use case, is used only to represent drug-drug interactions. Similar to the resource instances of *Medication*, in the FHIR server, we stored resource instances of *Practitioner*, *DetectedIssues*, *FamilyMemberHistory*. In addition, *MedicationStatement* that is used to record the drugs being used by a patient.

3.3 From FHIR to OWL

Pharmaceutical and patient data that was stored in the local FHIR server were retrieved and mapped to the FHIR ontology using JENA libraries. A part of the customized FHIR ontology has the class structure shown in figure 4.

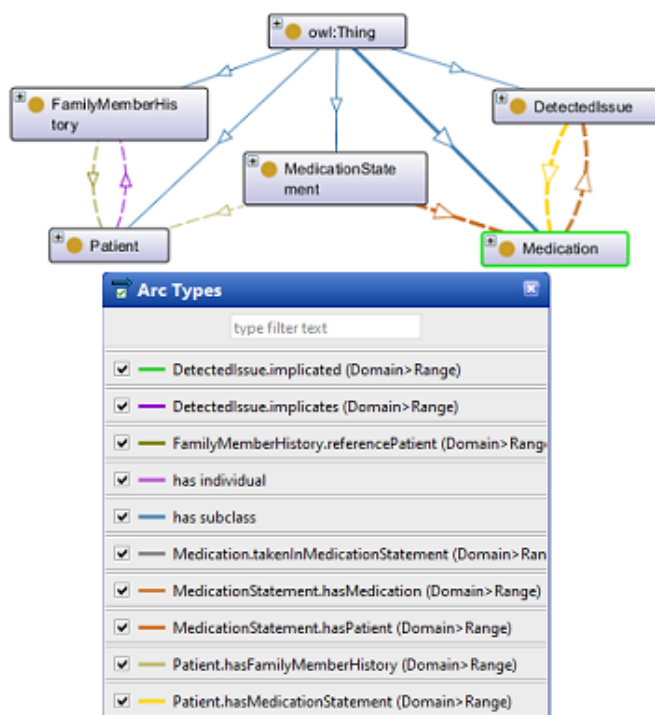


Figure 4. UML diagram of the FHIR resource Medication

We choose the approach to represent the FHIR resources (or more specifically FHIR resource types) as classes (e.g., Figure 4 shows FHIR resource Medication in a UML diagram) using same naming scheme, e.g., Medication is called Medication. The contents that describe a particular resource are represented as OWL object properties. Some of the contents are also represented using OWL data properties. Figure 5 below shows some of the data properties used to describe the details of the Medication resource.

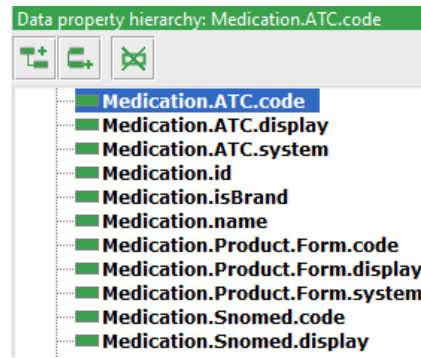


Figure 5. Data properties of the FHIR resource Medication

In this way, we mapped the details of all the selected resources from FHIR server to our ontology. Figure 6 shows a detailed description of the object properties along with their purpose.

When it comes to the mapping of FHIR resource instances (e.g., description of an actual drug), we accessed the resource instances from the FHIR server, and added it to the ontology. E.g., a specific drug is then seen as an individual of class Medication and inserted as such an individual into the ontology. Figure 7 shows the example of mapping instance of Medication resource named "Efavirenz".

Property	Domain	Range	Explanation
<i>DetectedIssue.author</i>	DetectedIssue	Practitioner	Used to describe a practitioner who worked with the particular detected issue.
<i>DetectedIssue.detects</i>	Practitioner	DetectedIssue	Inverse of <i>DetectedIssue.author</i>
<i>MedicationStatement.medicationReference</i>	MedicationStatement	Medication	Used to describe a referenced medicine.
<i>Medication.medicationStatementReference</i>	Medication	MedicationStatement	Inverse of <i>MedicationStatement.medicationReference</i>
<i>MedicationStatement.patient</i>	MedicationStatement	Patient	Used to describe referenced patient.
<i>Patient.medicationStatement</i>	Patient	MedicationStatement	Inverse of <i>MedicationStatement.patient</i>
<i>DetectedIssue.implicated</i>	DetectedIssue	Medication	Used to reference a medication which leads to an issue.
<i>DetectedIssue.implicates</i>	Medication	DetectedIssue	Inverse of <i>DetectedIssue.implicated</i>
<i>FamilyMemberHistory.patientReference</i>	FamilyMemberHistory	Patient	Used to refer to the relative patient
<i>FamilyMemberHistory.relationship</i>	Patient	FamilyMemberHistory	Inverse of <i>FamilyMemberHistory.patientReference</i>

Figure 6. Object properties

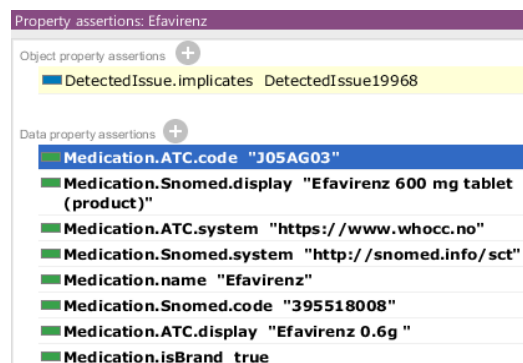


Figure 7. Medication instance mapping

As the medication is identified using two coding schemes, Display value of corresponding drug is mapped to Medica-

tion.Snomed.display property in the ontology and takes the value as "Efavirenz 600 mg tablet". Similarly, code value from the FHIR server, in case of SNOMED, is mapped to Medication.Snomed.code in the ontology. The same mapping procedure is used for ATC code mapping.

3.4 DDI Reasoning

SPARQL queries are used to retrieve and manipulate data from the ontology, e.g., we can check whether two drugs have an interaction by the following SPARQL query:

```
SELECT ?X
WHERE { ?X :DetectedIssue.implicated :Fluvoxamine.
        ?X :DetectedIssue.implicated :Rabeprazole. }
```

X
DetectedIssue19969

Figure 8. SPARQL query result

The result shown in Figure 8 above can also be verified by running reasoner in the Protégé. Similarly, if we have a complete database from the FHIR server, we can use SPARQL queries on that existing data to generate specific results. Explicit as well as implicit results can be generated using SPARQL queries on the FHIR data, which was the purpose of this paper. One example of generating implicit results from the data is presented below.

We used the SPARQL CONSTRUCT query to generate implicit triples about unknown DDI's by examining the existing data. For example, suppose that father of Ole Nordmann, having a heart disease, was prescribed a combination of drugs A and B; and his brother, having similar disease, was also prescribed same combination of drugs. Their statement history exhibit that both of them suffered from some side effects, possibly a DDI. But this DDI is not explicitly stated in the database nor the drugs A and B were supposed to exhibit a reaction. A hypothetical diagnose can be linked to such a situation that genes of the concerned persons may have a problem with this combination of Drugs. We can check this whole scenario by constructing a SPARQL query, and in response, Ole Nordmann can be prevented from taking the same combination as he is potentially inheriting the same genes. A possible warning can be generated for the practitioner responsible for treating Ole.

```
CONSTRUCT {
?X :hypotheticalDiagnose :UnknownDDI }
WHERE {
?X :Patient.hasFamilyMemberHistory ?a.
?a :FamilyMemberHistory.relationshipCodingCode
    "father";

    :prescribed :DrugA;
    :prescribed :DrugB;
    :sideEffects :UnknownDDI.
?X :Patient.hasFamilyMemberHistory ?b;
```

```
?b :FamilyMemberHistory.relationshipCodingCode
    "brother";

    :prescribed :DrugA;
    :prescribed :DrugB;
    :sideEffects :UnknownDDI.
}
```

Subject	Predicate	Object
Patient9952	owl:hypotheticalDiagnose	UnknownDDI

Figure 9. CONSTRUCT query result

The implicit triple generated by the query above, can be inserted and stored in the ontology. The result says that Patient9952 individual, which is Ole Nordmann, may possibly suffer from the same DDI as his family members, thus the practitioner should make further observations regarding prescription.

4 DISCUSSION AND CONCLUSION

Several clinical tools provide comprehensive lists of DDIs, often they lack the supporting scientific evidences and different tools may not give consistent results (Tari et al., 2010). One of our goals is to find out the implicit drug-drug interactions that are not explicitly stated or that are inconsistent in the currently available drug catalogs. Such reasoning would typically involve several ontologies and data sources; in this context standard protocols needs to be applied and our work success-fully demonstrate one way of doing this with help of FHIR.

We have also demonstrated some beneficial DDI reasoning based on family history. However, the reasoning potential seems huge and should be further investigated.

Our task may be simplified in the future since using RDF with the REST API is on the TODO list of HL7 (Anthony, 2016). They have already specified how each resource can be represented as a set of RDF triples represented using the Turtle syntax. Our work fits well with this format. When FHIR servers give the REST API support we can easily directly insert the RDF Graphs into our ontology that we use for reasoning.

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EDMON - A Wireless Communication Platform for a Real-Time Infectious Disease Outbreak Detection System Using Self-Recorded Data from People with Type 1 Diabetes

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Abstract

The relation between an infection incident and elevated blood glucose (BG) levels has been known for long time. People with diabetes often experience variable episodes of elevated BG levels up on infections incident. Hence, we proposed an Electronic Disease Surveillance Monitoring Network (EDMON) that uses BG pattern and other relevant parameters to detect infected diabetes individuals during the incubation period. The project is an extension of the results achieved in the mobile diabetes (mDiabetes) field within our research team for the last 15 years. The proposed EDMON system is a kind of public health surveillance, which uses events analysis at individual levels (called micro events) to reach on a conclusion for uncovering events on the general populations (called macro events) based on spatio-temporal cluster detection. It incorporates self-management mobile apps, sensors, wearables, and point of care (POC) devices to collect real-time health information from individuals with Type 1 diabetes. In this paper, we will present the proposed EDMON system architecture along with the design requirements, system components, communication protocols and challenges involved herein.

Keywords

Type 1 Diabetes, Wireless Communication, BG Pattern Detection, Infection Detection.

1 INTRODUCTION

Diabetes mellitus is a chronic metabolic disorder, which is mostly caused by either failure of pancreas β -beta cells to produce insulin secretion (Type 1) or lack of body response to insulin action (Type 2)(IDF, 2015). According to recent reports, there are approximately 450 million adults with diabetes worldwide and is projected to raise to 642 million by 2040 (IDF, 2015). Currently, there is no cure for diabetes; however, it can be prevented from creating further complication with one's proper self-management of the disease. The advent of information and communication technology (ICT) has much revolutionized self-management and made treatment of the disease a lot easier than before, which is mostly connected with the introduction of mobile apps (mHealth), wearables and sensors, and POC devices that can provide individually tailored information for a better informed decision making (patient empowerment) (Walseth et al., 2005; Li et al., 2017; Issom et al., 2015; Botsis et al., 2009). These advancements in turn have also created huge accumulation of the individual patient health data gathered on a daily basis, which creates opportunities for further analysis of these data to capture relevant information for better self-management and treatments (Béranger et al., 2016; Mohammadi, 2015). The introduction of big data, data mining and advanced analytic concepts have made the detection of aberrant pattern, an outbreak signal, a way more relevant and easier than before (Vayena et al., 2015). In this regard, use of patient self-gathered data for public health surveillance purpose has now become more

apparent than ever; given the ubiquitous nature and widespread use of mHealth apps, wearables and sensors for self-management purpose (Walseth et al., 2005; Issom et al., 2015).

Likewise, the introduction of cloud computing technologies since the millennium has brought a significant improvement in various healthcare delivery settings, of which public health surveillance is not an exception (Swan et al., 2013; Council 2017).

Currently, most of the existing electronic disease surveillance systems rely on data sources (surveillance indicators and events) that span from the incident of the first symptoms till physicians or laboratory confirmation, such as web based (i.e. google search engine) (Choi et al., 2016), Over-the-counter (OTC) pharmacy drugs sell (Pivette et al., 2014), school absenteeism (Lawpoolsri, et al., 2014) or work absenteeism (Paterson, Caddis, and Durrheim, 2011), and others leaving the incubation period out of their systems. According to the Centres for Disease Control and Prevention report (Holt et al., 2013) on indicators for chronic disease surveillance, more than 20 individual diabetes indicator measures are given while the use of BG patterns as surveillance indicators are not indicated, which shows the complexity and uniqueness of the proposed approach. Botsis et al. (Botsis et al., 2012) presented the most notable proof of concept study that empirically supports the use of blood glucose pattern of diabetes individuals as surveillance event indicator. Moreover, blood glucose pattern has also been described as event indicators for surveillance purpose in other related literatures (Botsis et al., 2012; Botsis et al., 2010; Lauritzen et al., 2011).

The proposed EDMON system is a real-time early disease outbreak detection system that uses self-recorded health data from people with Type 1 diabetes. It is a kind of public health surveillance, which uses micro events analysis (detecting infection induced elevated BG pattern on an individual level) to reach on a conclusion for uncovering macro events on the general populations based on spatio-temporal cluster detection. The system will analyse the individual's blood glucose levels in real time, an online context, to look for aberrant patterns; variable episode of elevated blood glucose levels as a result of metabolic instability due to infection incident (Woldaregay et al., 2016; Årsand et al., 2005; Rayfield et al., 1982). Therefore, the surveillance case definition encompasses the infection induced deviated pattern of the individual's BG dynamics. In addition, patterns of other supporting parameters such as insulin injections, physical activity, and dietary information along with physiological parameters like body temperature, blood pressure, and others will also be included. Of course, it is not only infections that could cause variable episode of elevated blood glucose levels, and factors such as stress could also result in somehow similar pattern. As a result, the plan is to incorporate all contributing variables known to the patients in the surveillance case definition and analysis so as to suppress the effects of these confronting variables. Moreover, the spatio-temporal nature of the EDMON's system is supposed to alleviate these challenges; given that the probability of having sufficient number of people to be stressed at a specific location and specific time interval is probably low to trigger the necessary threshold as compared to an infection incident. This characteristic is highly dependent on the contagious nature and its progressive prevalence of an infection after any initial incident. EDMON will use techniques from big data analytics, social media, mobile computing and a novel health monitoring systems. If successful, EDMON will pave the way for the next generation disease surveillance approaches. In this paper, we will present the proposed EDMON's system architecture along with the design requirements, system components, communication protocols and the challenge involved herein.

2 BACKGROUND AND RELATED WORKS

2.1 Wireless communication platforms

Currently, the rapid development of information communication and technology (ICT) and Internet of Things (IoT) have created opportunities for a quantified-self, which aims to empower patient's decision making based on documenting their own health condition. This in turn has created a rapid pace on the integration, communication and use of wearables, sensors, POC devices and other body area network for physiological monitoring and other health related purposes (Swan, 2013; Béranger, 2016). Diabetes is not an exception in this case, experiencing a rapid advancement in its field. In this regard, different communication systems, protocols and standards for various purpose such as intelligent diabetes monitoring, remote diabetes surveillance, remote diabetes

management, tele-management and tele-monitoring, follow-up systems, data analysis, personalized and customized feedback and decision making have increasingly been studied and presented in the literatures, e.g. (Huzooree, Khedo, and Joonas, 2017; Liao et al., 2004; Mougiakakou et al., 2010; Mougiakakou et al., 2005; Martinez et al., 2011; Al-Taei et al., 2015; Chang et al., 2016), but none of the recent studies have considered detection of infection incidents in diabetes people as the underlying purposes.

For example, Huzooree et al. (Huzooree, Khedo, and Joonas, 2017) developed a communication platform for a wireless body area network for remote diabetes patient monitoring and analysis. The system integrates physiological data from the body area network into a standalone mobile app, which sends these data into a remote server for further analysis and monitoring (Huzooree, Khedo, and Joonas, 2017). Moreover, Mougiakakou et al. (Mougiakakou et al., 2010) developed a communication platform for an intelligent remote diabetes monitoring, management, follow up and treatments for Type 1 diabetes patients. The system uses state of the art technologies and standards and consisted of two units; a patient unit and patient management unit (Mougiakakou et al., 2010). Mougiakakou et al. (Mougiakakou et al., 2005) also developed a telemedicine system that provides tele-monitoring and tele-management services for type 1 diabetes individuals. Besides, Liao et al. (Liao et al., 2004) developed a communication platform for remote diabetes surveillance, where the diabetes individual is monitored from home by remote healthcare givers. The system promotes the individual with diabetes to measure and update his/her status at home, which is communicated to their healthcare givers. In addition, Martinez et al. (Martinez et al., 2011) developed a system that provides a remote monitoring of the individual diabetes patient's metabolic profiles through Application Hosting Device (AHD), which manages the sensor platform and allows sending IHE-PDC messages compliant with Continua Health Alliance at a WAN level along with a mobile application. The system incorporates three modules;1073 adaptation, Data Access API and Sensor Management module. The patient is able to register physical activity, food intake (menu and CHO quantities), blood pressure, weight and glycaemia measurement manually, medication intake (i.e. insulin and other drugs), and special events (i.e. stress at work, holiday and birthday party), which are integrated into a diary application (Martinez et al., 2011). Furthermore, Al-Taei et al. (Al-Taei et al., 2015) presented a platform to support self-management through remote collection and monitoring of self-gathered data and provision of personalized feedback on the smartphone based on Internet of Things (IoT). Based on the current and historical self-gathered data, the system enables real-time clinical interaction and tailored feedback to the individual needs (Al-Taei et al., 2015). Likewise, Chang et al. (Chang et al., 2016) developed a context aware, interactive cloud based mHealth system that can provide a real time, two way communication between

diabetes patients and caregivers by using Internet of Things technology.

2.2 State of the art

For the past 15 years, our research team has been working on the patient unit and created and developed the Diabetes Diary, which is now available in both google play (Android) and app store (Apple) (Nse, 2017). Currently, our team is working towards a tailored version of the diabetes diary with more data integration, patterns analysis and monitoring options. The tailored version will include measurements like blood pressure, heart rate, body weight and temperature in addition to blood glucose, carbs intake, physical activity, and insulin injection. Moreover, a feasibility study towards the use of POC devices has been conducted (Botsis et al., 2009). The study concluded that devices like white blood cell count (XBC analyser) seems to be problematic due to usability issues and the cost is regarded as the main bottleneck (Botsis et al., 2009). Therefore, the plan is to request measurements from these POC devices only when it is necessary and appropriate.

There have been some research activities regarding the infection detection system using blood glucose levels as a potential indicator. For example, Årsand et al. (Årsand et al., 2005) presented an approach for developing an epidemic disease detection using blood glucose (EDDG) system based on blood glucose measurements. The paper describes the system components including the necessary equipment, data structures and data repository along with the proposed detection mechanisms. Furthermore, a number of studies regarding the outbreak detection computing algorithm have been conducted. For example, Woldaregay et al. (Woldaregay et al., 2016) have developed an infection detection algorithm based on the continuous glucose monitoring (CGM) readings. However, the study has considered only blood glucose patterns as the input to the system. Moreover, other similar studies like (Granberg et al., 2007) have tried to detect infection induced blood glucose deviation. Even though these studies have shown the proof of concept, they have certain limitations, i.e. the number of input parameters, real infection BG data and sample size. Therefore, the plan is to include more input parameters, a real infection BG data and larger sample size to develop a more robust approach for the computing algorithm.

3 EDMON DESIGN REQUIREMENTS

Diabetes self-management mobile applications (mHealth apps), sensors and wearables, including both invasive and non-invasive, and other POC devices should collect the patient's blood glucose level, insulin therapy, dietary intake (carbs), physical activity, and physiological information such as body temperature and blood pressure. Some other ideal and optional physiological parameters like white blood cell count, CRP test, heart rate, respiration, oxygen saturation, and stress level should be recorded and sent upon request from EDMON system. The measured parameters should be integrated into a standalone mobile app, i.e. personal health record application, which acts as a

gateway for the data to be transferred to a private cloud (remote server) in a real-time scenario. Therefore, data quality is the determinant factor for successful processing, computation and interpretation of those health data (Huzooree, Khedo, and Joonas, 2017). As a result, all the recorded key diabetes and physiological parameters should be transferred securely and appropriately through either a mobile infrastructure or a private network and should be safely stored in the cloud (remote server) in a real-time environment. Any possible failure that may arise due to network coverage, sensors and wearables failure, lack of signal strength, transmission reliability, and delay, could lead to an unpredictable effect on the accuracy of the detection system, and also on the quality and reliability of patient tracking (Huzooree, Khedo, and Joonas, 2017; Sachidananda et al., 2010). Hence, ensuring the quality of information (QoI) attributes such as accuracy, timeliness, completeness, relevancy, and reliability (Sachidananda et al., 2010; Zahedi et al., 2008), along with system usability (ease of use) are key design requirements for the acceptance of the proposed EDMON system.

4 EDMON ARCHITECTURE

The EDMON architecture consists of a patient unit, computing unit, and end users, as shown in Figure 1 (Mougiakakou et al., 2010). The patient unit is responsible for collecting the necessary parameters into the user's smartphone. The computing unit will analyse the incoming data for aberrant patterns on the individual as well as on the cluster level. The end users (desktop, laptop or smartphone version of EDMON's application) could be physicians, patients, family and relatives, or the general public or any concerned hospitals or public health authority that should have access to the outbreak information from the system.

4.1 Communication architecture and protocols

EDMON is a three-tier architecture that incorporates; sensor and wearable tier, mobile computing tier, remote server (cloud) tier, as shown in Figure 2. This kind of architecture might be prone to a degraded data accuracy due to remote site computations as a result of transmission and other errors. However, we prefer to minimize the power consumption, and save the memory storage issues incurred in the participants' smartphones.

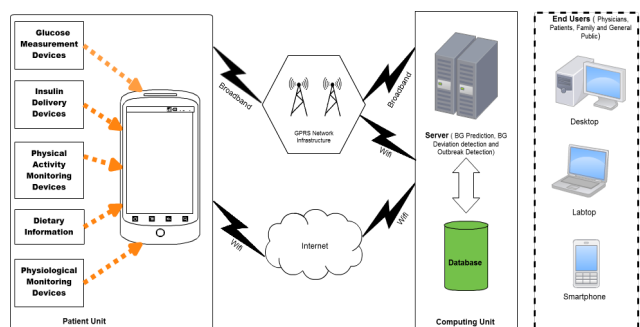


Figure 1. EDMON architecture.

In EDMON, the invasive and non-invasive sensors and wearables, and POC devices, record the data automatically

and send these readings to the smartphone app (Diabetes Diary) using existing communication protocols that ensure security, robustness and privacy, i.e. Bluetooth and ZigBee (Huzooree, Khedo, and Joonas, 2017). In some cases, when there is no such automatic facility the user might be asked to record the data manually. The smartphone app acts as a gateway node, which integrates the data from the sensors and wearables nodes and forwards it to the access point. Secure communication protocols such as IEEE 802.11/Wi-Fi/GPRS could be used as a communication medium with the access point (Huzooree, Khedo, and Joonas, 2017; Rafe and Hajvali, 2014). The communication between the access point and the remote (server) could be implemented via a Protected Network, connected via an independent secure IP-network, i.e. the Norwegian Health Network, to enable secure electronic communication between the access points and the remote computing centre.

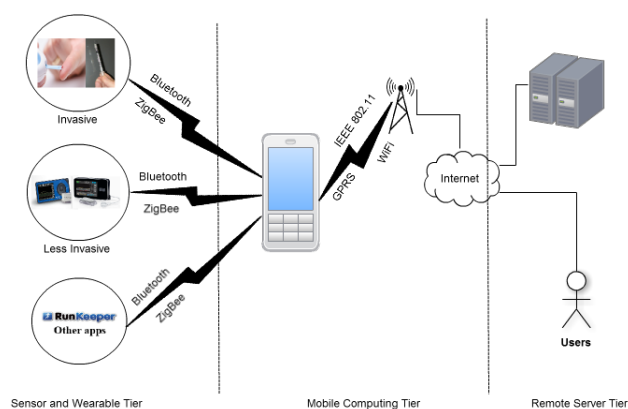


Figure 2. The three tiers of EDMON Architecture.

4.2 Sensor and wearable tier

The first tier is a sensor and wearable tier that incorporates self-management apps, POC devices, wearables and sensors for collecting the diabetes key parameters and other necessary physiological parameters of the individual diabetes patients, as shown in Figure 2, where the data entry is either automatic or manual. The automatic data entry will use the device API, i.e. Bluetooth, whereas the manual data entry requires users to manually input like dietary information, i.e. menu and amount of CHO quantities and others. This node includes circadian cycle measurements of the individual's physiological parameters, diabetes key parameters and other point of care test devices. The diabetes key parameters include dietary intake, insulin injections, CGM readings, physical activity and other measurements. The physiological parameters group includes body temperature, blood pressure, oxygen saturation, respiration rate and stress level measurements. The POC measurements incorporate white blood cell count, CRP test and other necessary quantities. However, the frequency of these readings, physiological parameters and POC measurements, are determined by the EDMON system upon necessity except the key diabetes parameters, which are the default input to the system.

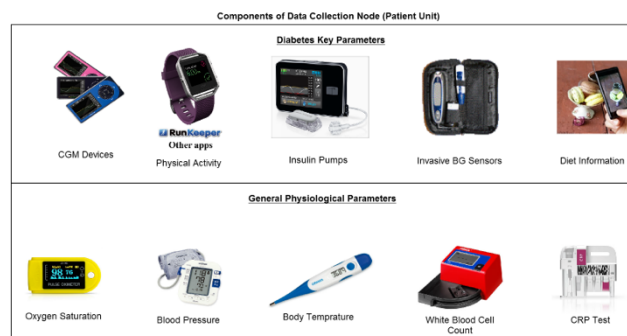


Figure 3. Components of EDMON data collector's node.

4.3 Mobile computing tier (Gateway Node)

The second tier is a mobile computing tier, which is a standalone mobile app that integrates the reading of the individual's key diabetes and physiological parameters. The mobile app acts as a sink for measurements that come from the diabetes individual's sensors, wearables and POC devices. It is built on the top of the existing diabetes mobile App-Diabetes Diary, which is developed by Norwegian scientists at the Norwegian Centre for E-health Research (NSE), as shown in Figure 4 (both English and Norwegian version). This tier also acts as a gateway that forwards the recorded parameters to the access point, as shown in Figure 2. Currently, the tailored version of the diabetes diary supports measurements like blood glucose, insulin, physical activity, carbohydrate, calories, weight and medications (Årsand et al., 2016). Therefore, the plan is to add more monitoring options including more physiological parameters to enhance the accuracy of the infection detection capability based on the self-recorded data.

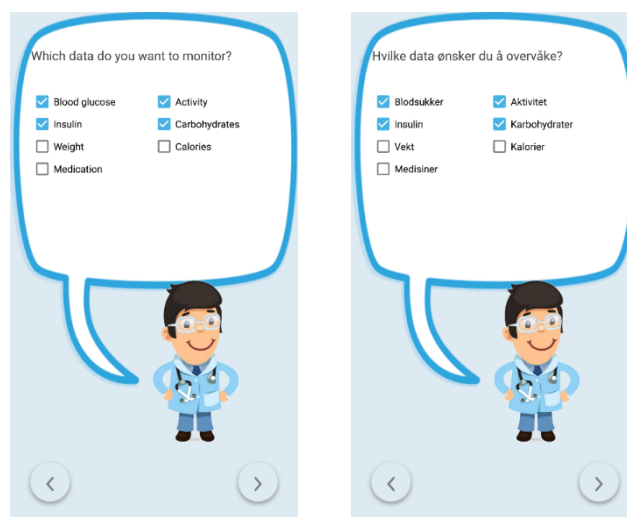


Figure 4. Diabetes Diary-Tailored Version.

4.4 Remote server (Cloud computing) tier

The third tier is a remote server (cloud computing) tier, which incorporates a repository and computing centres that will carry out the data storage and computation tasks respectively. This tier also fetches and provides the outbreak detection results for the responsible bodies, i.e., public health officials, physicians, patients, relatives and general public audiences.

Data Repository

The repository is used to store the incoming data from the participating Type 1 diabetes individuals. The user's data are stored in a data structure stamped with a user ID, time and geographical location containing the key diabetes and physiological parameters (Årsand et al., 2005). The size of the data repository will depend on the size of the area the system covers.

Computational Service

The computational server is the most crucial part (heart) of the EDMON system. The server carries out an intelligent data mining and advanced data analytics concepts to uncover both the micro and macro events. It performs various computation at individual and cluster levels including BG profiling, analysing, reporting and disseminating information. BG profiling involves modelling a personalized health model, which keeps track of the individual's blood glucose dynamics and predicts the upcoming blood glucose values depending on a set of input parameters, such as previous BG values, dietary intake, amount of physical activity, amount of insulin injection, and others. The analysis will carry out a comparison of the individual predicted BG and actual BG values so to look for any statistically significant aberrant patterns. Moreover, the aggregational analysis will look for a maximum number of micro events based on spatio-temporal cluster detection. The reporting and dissemination part of the computation respectively will organize the information in a user-friendly format (tables, graphs, and maps) and distribute this information, such as the spatial and temporal distribution of the disease outbreak on a map of the region, the degree of severity and others, to the audience via EDMON webpage or application.

5 DISCUSSION

Advanced systems and functionalities like EDMON could be a breakthrough in digital disease detection (DDD), and public health surveillance and might also have a significant improvement for diabetes self-management. The proposed wireless communication platform will use the state of the art communication standards and protocols, database and server technologies. However, given the sensitivity of health data there are challenges that need special attentions such as user privacy/security, quality of information and standardization issues, geographical location estimation and user mobility, and user acceptance.

Health related personal data are very sensitive and need to be treated confidentially throughout the system's data flow. In this regard, in addition to the recommended three tier architecture, it is necessary to look for robust approaches to ensure the user privacy and security during data collection and transmission as this is highly critical for successful design and acceptance of the proposed EDMON system. For example, privacy preserving mechanisms such as de-identification (Office for Civil Rights, 2012; Uzuner, Luo, and Szolovits, 2007), which involves removal of user direct identifier, could be one possible options. For accurate data analysis, quality of data is the most

determinant factor since corrupted, heterogeneous (due to multiple sensors, wearables and POC devices), missing, and delayed data could result in unpredictable performance degradation. Therefore, it is necessary to look for an advanced data quality control and pre-processing algorithm, which might pre-process the incurred heterogeneity, and check and request a retransmission upon corruption, delay, and missing data (Huzooree, Khedo, and Joonas, 2017). User acceptance is also an important factor that should be considered and tackled since people might not be willing to adopt a new system for multiple reasons such as lack of trust, lack of motivation, if the system hinders mobility, and lack of perceived usefulness and ease of use (Huzooree, Khedo, and Joonas, 2017). Therefore, it is necessary to look for approaches to buy users trust and enhance their motivation and perception. User mobility also could create challenges in terms of geographical location estimation and transmission power. However, a real time geographical location estimation techniques relying on the signal sent from the user through GPS or Wi-Fi positioning data and energy aware communication protocols could be an option (Niewiadomska-Szynkiewicz, 2013; Gautam and Gautam, 2009).

6 CONCLUSION

EDMON is a real-time early disease outbreak detection system that uses self-recorded health data from people with type 1 diabetes. It mainly exploits the presence of an elevated BG levels upon infection incidents. Therefore, the surveillance case definition will be formulated entirely based the individual's pattern of BG dynamics. However, patterns of other supporting parameters such as insulin, physical activity, and diet along with physiological parameters like body temperature, blood pressure and others will also be included. If successful, EDMON will pave the way for the next generation disease surveillance approaches. We presented the proposed EDMON architectures along with its persistent challenges that needs to be solved. We believe such kind of system might benefit other similar systems, i.e. diabetes patient monitoring, decision support and other patient empowerment system, and most importantly provoke further thought in the challenging field of real time electronic disease surveillance systems.

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Complex Medication Reconciliation in the Danish Medication System: Shared Medication Record for patients in transition of care across sectors

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Abstract

The purpose of Shared Medication (SMR) is to ensure medication reconciliation and thereby reduce the medication errors, thus increasing patient safety. However, medication errors concerning high-risk drugs as Warfarin remain a well-known issue in transitions of care. We examine if different ways of prescribing Warfarin in SMR affect patient safety in regard to transitions of care. We conducted a literature research and semi-structured interviews to investigate the objective. Data were analyzed based on the three analytical questions, and findings were synthesized. The findings indicate that implementing SMR has resulted in new errors. The medical order entry system allows for different manners to prescribe Warfarin which complicates reuse of information in primary sector. This can potentially jeopardize patient safety. Challenges using SMR in relation to the prescription of Warfarin creates workarounds which prevents a number of potential medication errors. But workarounds induce the risk of new undiscovered medication errors, which is why we argue for a higher degree of standardization in medication reconciliation of high risk drugs as Warfarin.

Keywords

Patient Safety, Medication Reconciliation, Medication Systems, Hospital, Medication Systems, Medication Errors, Medical Order Entry Systems, Shared Medication Record.

1 INTRODUCTION

Medication errors are a well-known problem internationally. In the Danish health service the most frequent form of adverse events reported by the Danish Patient Safety Database (DPSD) is medication errors. There are several causes of medication errors, and data from adverse events show that the errors occur in the entire medication process from prescription, dosage and administration to monitoring (Patientombudet, 2012).

High-risk medicine including the anticoagulant drug warfarin constitute a particularly increased risk of patient safety in case of errors in the medication process (Sundhedsstyrelsen, 2005, 2007). A medication error involving warfarin can cause serious consequences (Lægemiddelstyrelsen, 2011), e.g. haemorrhages and blood clots (Dansk Patientsikkerhedsdatabase, 2015). Due to the fact that the warfarin dosage often varies on a day to day basis and depends on effect monitoring, the prescription can be complex to administer (NSI, 2016), which particularly is seen during transitions of care between the secondary and the primary sector (Dansk patientsikkerhedsdatabase, 2016). The errors are often related to insufficient communication concerning the dosage, lack of control of International Normalised Ratio (INR), delivery of treatment responsibility during sector transition and mix-ups between dosage and number of tablets (Sundhedsstyrelsen, 2003). In the study, (Enheden for Brugerundersøgelser, 2006), *"The Patients Experiences in the Transitions Between the Primary and the Secondary*

Sector" from 2006, the patients express concern regarding the exchange of information between the hospital and the general practitioner as well as the co-operation between the hospital and the district nursing. This is stated as the reason for complications regarding medication (Enheden for Brugerundersøgelser, 2006). Doubt and uncertainty concerning medication in sector transitions can, according to McLeod (2013), result in medication error, delay, need of repetition, increased use of resources and it can reduce patient safety (McLeod, 2013). Since 2010 it has been possible to analyse the patient safety in Denmark in relation to adverse events across the health sector, and the number of reported incidents has been on the rise in recent years. Health care professionals at secondary sector have reported 262 incidents in 2015, where the incident occurred in the primary sector. Conversely the municipalities have reported 2.529 incidents, where the incident originated in secondary sector (Styrelsen for Patientsikkerhed, 2015). This indicates the occurrence of many errors in the sector transitions.

In Denmark, the Shared Medication Records (SMR) is developed to ensure a safe and trustworthy medication reconciliation by giving an overall picture of the individual patient's actual and current prescriptions. The solution is supposed to rectify medication errors resulting from sector transitions (National Sundheds-it and MedCom, 2011), and thereby contribute to a better coherence in patient courses across the health service, making the transitions between sectors on schedule, faster and safer (Statens Serum Institut and National sundheds it, 2014).

Paper from the 15th Scandinavian Conference on Health Informatics SHI2017, Kristiansand, Norway, 29 - 30 August.

Conference Proceedings published by [Linköping University Electronic Press](http://www.lnku.se/Linkoping_University_Electronic_Press).

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The Audit Department, (In Danish: Rigsrevisionen) (2014), has pointed out some challenges concerning the SMR. In sector transitions where the medication responsibility changes, doctors and nurses find it difficult to get a clear picture of the patients' relevant medication, which can lead to medication errors. This indicates that the SMR does not ease medication procedures at sector transitions but instead create frustrations for both professionals as well as patients. The cross-sectorial cooperation is challenged and the job assignments have increased instead of decreased (Rigsrevisionen, 2014). A recent report by the Audit Department from 2016 shows that many patients continue to be discharged from hospitals without correct information on the relevant medication in the SMR (Rigsrevisionen, 2016).

While SMR seems to solve some of the current problems concerning accumulation, sharing and reconciliation, the SMR creates new problems as well.

The objective of this study is to explore if and how different ways of prescribing high-risk drugs as Warfarin in SMR affect patient safety in regards to transitions of care across sectors.

Materials and Methods

To investigate the objective we identified three relevant research themes with each having a specific research question:

1. **Patient Safety:** How is the patient safety affected by SMR?
2. **Medication Reconciliation:** How does primary sector use and reuse medication orders?
3. **Medication Errors:** Why is medication errors still present in the transitions of care when SMR is implemented in both primary and secondary sector, and how can they be prevented?

2 METHODS

In figure 1 the overview of the method is presented.

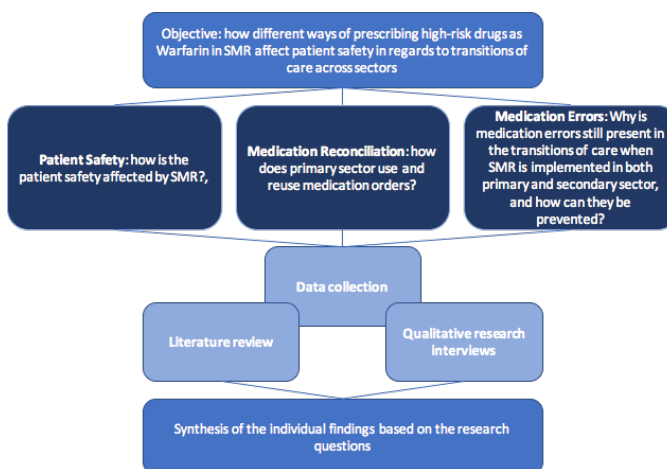


Figure 1 The method used to investigate the objective.

To answer the objective, we have been inspired in Hevner et al's (20) Information System Research Framework illustrated in figure 3. The framework is used to ensure a just evaluation of the developed SMR (the artifact).

According to Hevner et al. (2004) design science consists of factors from two different paradigms: design science and behavioural science. In the framework, there is given a premise for conducting evaluation in the area design of information system.

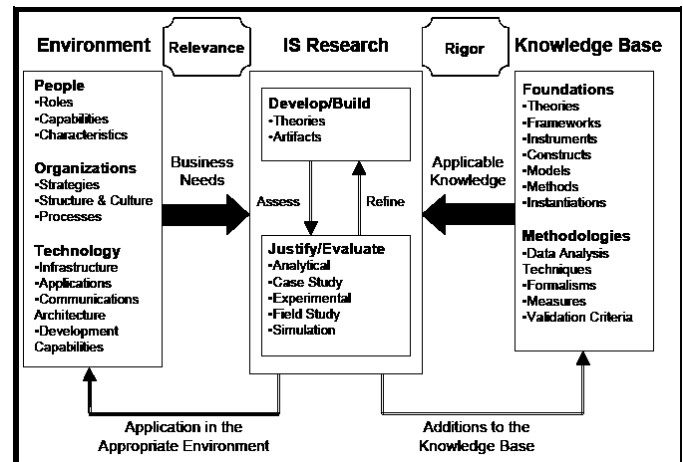


Figure 2 Hevner et al's Information System Research Framework (Hevner *et al.*, 2004).

If the artifact (SMR) is to be useful, there is a need for relevance between the artifact and the environment in which the artifact is to function. In order for the information technology to benefit the environment, it must be adapted to the real world (Hevner *et al.*, 2004). Therefore, we used the environment to structure our understanding of the clinical domain e.g. organization, the patients, district nurses, treatment and the ideal and actual medication process. In the knowledge base, we applied our data collection e.g. literature review and interviews. Both the environment base and the knowledge base are relevant to answer research questions One and two. Finally, to answer research question three, we evaluated the existing designed and developed SMR through an extreme case (warfarin treatment) with use of both knowledge base and environment base. This evaluation can lead to a suggestion on how to prevent medication errors across borders through re-design considerations relevant for preventing medication errors.

2.1 Literature review

The review of the research covered the period from 2000 to 2016. This period was considered adequate to cover most accurate elements in the literature in regards of the datafication of medication reconciliation. Research papers were sourced in three different ways. First, the most adequate electronic databases as PubMed and Embase were searched. Second, relevant cross-references from published literature were followed up and included if they met inclusion criteria. Third, additional 'gray' literature not identified in electronic searches were sourced. This third step included reports for government bodies. In table 1 our structured search is documented. To ensure that we have all relevant studies, we have created our search queries using PubMed's and Embase's underlying thesaurus (MeSH and Emtree) in collaboration with free text searches.

We found 627 articles. We excluded 605 articles based on their title, abstract or because they were doublets. Six of the authors reviewed the remaining articles and excluded an additional 15 articles due to exclusion criteria as focus on side-effects, focus on decision support system or focus on solemnly warfarin treatment. The included seven articles were checked for quality using CASP-UK 2016.

AND				
Informationssystemer	Medicinering	Sektorovergang	Patientsikkerhed	
"Medical Order Entry Systems" (MeSH + fri)	"Medication Reconciliation" (fri)	"Patient Transfer" (MeSH + fri)	"Patient Safety" (MeSH)	
"Computerized Physician Order Entry" (Fri)	"Medication Reconciliation" (MeSH + Fri)	"Sector Transition" (Fri)	"Patient Safe*" (fri)	
"Computerized Medical Record System" (MeSH + fri)	"Medication Prescribing" (fritekst)	"Health Care Transfer" (fri)	"Patient Security" (fri)	

Table 1 illustrates an extract of highly relevant search queries.

2.2 Qualitative research interview

We conducted three qualitative research interviews following a semi-structured interview guide. Our informants were all district nurses and met the following inclusion criteria:

- Employed in a locale municipality
- Using SMR on a day-to-day basis
- Minimum six months of experience working with SMR
- Experience on administrating warfarin medication orders

The data from the interviews were transcribed and coded in different themes.

3 FINDINGS

When analyzing the objective, it was found that in connection with the use of SMR the patient safety was at risk and new medication errors occurred, challenges arose around the medication reconciliation and the medication errors showed a need for standardized guidelines on complex prescriptions.

3.1 Research theme 1: Patient Safety

Both earlier studies and interviews from the present study point out problems regarding patient safety when implementing medical information systems as the SMR.

Studies by Turchin et al. (2011) and Steichen & Gregg (2015) indicates that information systems can facilitate new types of medication errors (Turchin, Shubina and Goldberg, 2011; Steichen and Gregg, 2015). Garrett & McCormack (2014) found fewer errors after the implementation of an information system, however the mistakes that did occur were judged to have severe consequences for patients (Garrett and McCormack, 2014). Interviews in this study indicate that medication information appears in several places, both electronically and in print, and it causes more complex workflows and potential risk situations in the medication process. The ideal medication process with warfarin is according to the

informants not consistent with the actual medication process. The ideal medication process involves three steps in communication perspective (Figure 3). The process is as following: First the hospital doctor updates the SMR (illustrated as database in the middle of figure 3) and a nurse announces discharge. Second the district nurse updates the patient's medication record in the local EHR-system with data from the SMR, and plans the first visit. Thirdly, the district nurse dispenses medication for the patient from the medication record in the SMR containing the patient's total, current medication information, including dosage and time of medication intake.

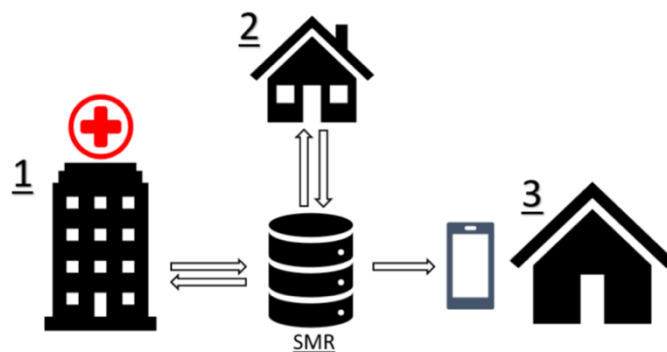


Figure 3 The ideal medication process.

The actual medication process at the time of discharge is contributing to several ambiguities and inconsistencies in the administration of the individual patient's medicine.

The actual medication process involves three steps in communication perspective (Figure 4). The process is as following: First the hospital doctor updates the SMR, and a nurse announces discharge. A printout of the patient's medication form from either the local EHR-system at the hospital or the SMR is given to the patient. Secondly, the district nurse reads discharge announcement where the dose and timing of intake of warfarin can be noted. The nurse updates the patient's medication form in the EHR-system using the current prescriptions of the SMR, and checks the dose and timing of warfarin, which is often omitted. Instead it says for example "see scheme", "after the written instruction", "0001" or "X". Thirdly, the district nurse compares the printed medication form to the current ordinations in the SMR, which often show inconsistencies and therefore the nurse has to obtain further information by contacting the prescribing department or the patient's doctor before dispensing the medication.

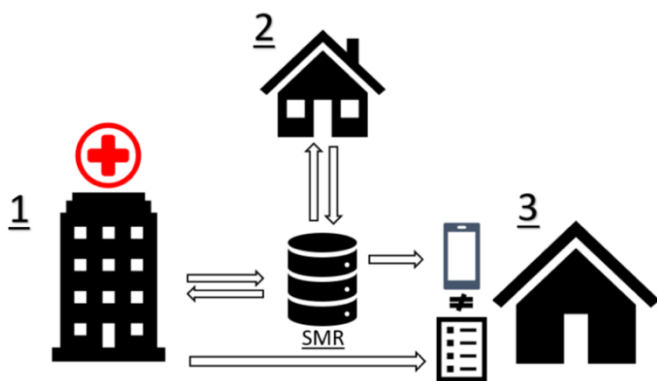


Figure 4 The actual medication process.

A study of Ash et al. (2007) finds that a failure between the information system and the clinician's workflow creates a number of problems that may be generated by the IT system's user interface not matching the clinician's workflow (Ash *et al.*, 2007). This is supported by the informants, who says that monitoring of the effect of warfarin can be overlooked after discharge, and cause either too high or too low a dose exposing the patient to serious complications.

"... and if people have been receiving warfarin before, then it is the old dose that is used. And if you don't think it through, you'll look at that [the former prescription]."

When a patient is discharged from the hospital with a prescription of warfarin, it requires special attention from the district nurses as they can be the intermediate link that discovers the errors or missing information in SMR.

3.2 Research theme 2: Medication Reconciliation

In transitions of care the use and reuse of data are dependent on how the local systems are utilized.

Warfarin is prescribed in different ways in the local medicine records at the hospital and there are indications that this affects the transfer of data when updating the SMR, where the district nurses get the medicine information. Both the local medicine records at the hospital and the SMR make it possible to store data in different ways, which complicates the reuse of data. If reuse of data is to be possible, it is a prerequisite that the it-system contains adequate XML-elements. Thus, XML-elements in the systems are crucial in determining whether district nurses can receive the information that is necessary to ensure correct administration of warfarin. In addition to this it is also a prerequisite that each local EHR-system is able to relocate and clearly present the information that is shared through XML-documents. If they cannot, information will be lost in the exchange of data with the SMR (NSI, 2016).

This is exemplified in the following, where one of the informants has found that in the prescription field in SMR times of dispensing are missing and instead it says "dosage according to written instructions", "as noted in the written instruction" or "see form":

"Then it says "dosage according to written instructions," and times of dispensing aren't noted. It may then be noted in the admission papers at start-up. Then we must put in

the dispensing times. Or we must call the ward and get them."

3.3 Research theme 3: Medication Errors

It seems medication errors are still present in the transitions of care because of the complexity involving human factors when developing information systems like the SMR.

The informants are not experiencing that SMR is contributing positively to their workflow as inadequate information causes prolonging of work processes and increases the risk of medication errors.

"... there are still errors, but as I said you can then write to the doctor or call the hospital like before and say: 'You know what? On the medication form she came home with, it says that she is to get two of it, but in SMR it only says one. What should we do?'"

According to Hevner, the different ways to prescribe warfarin may be related to a fault in the relevance between artifact (SMR) and the environment (the organization and the people using SMR) (Hevner *et al.*, 2004). It is well known that warfarin causes challenges to patient safety, and that technology, organizations and people affect each other, which begs the question why this was not taken into account in the development of the SMR. The different prescription procedures regarding warfarin also points to lack of standardization that has previously been identified as a contributing factor to errors and frustrations in the cross-sectorial communication (Sygehusapoteket Region Nordjylland, 2015). The district nurses, who administer warfarin to discharged patients, support the need for increased standardization.

"But that's why I think, that when it is so specific, there really should be only one way. There shouldn't be several different forms they can put it into (...) one big source of error!"

To prevent medication errors in information systems and increase patient safety Magrabi et al. (2013) suggests standardization and shared guidelines. It is described how initiatives in information systems in health services primarily focus on the software part of the information system (Magrabi *et al.*, 2013). This is problematic as technological science has a simplified view of the people and organizational contexts that information systems are to function in and this lowers the chance of success for the information systems (Hevner *et al.*, 2004).

4 DISCUSSION

It is well-known in national and international literature that there are challenges associated with the implementation of information systems such as the SMR (Turchin, Shubina and Goldberg, 2011; Steichen and Gregg, 2015). To better understand these challenges, a broader perspective is needed. Hevner et al. (2014) points out that there is an overriding focus on the importance of design science in the development and implementation of

information systems, and less so on behavioral science (Hevner *et al.*, 2004).

Berg (2001) describes the necessity of a sociotechnical approach, and points to the same challenges in regard to information systems as Hevner *et al.* (2004), i.e. technology and organizations inevitably change each other through an implementation process. Berg further emphasizes that, when planning the implementation of information system, account should be taken of the challenges that may arise in relation to the people who will use it and the organization to which the information system is to be implemented (Berg, 2001; Hevner *et al.*, 2004).

The findings in this study imply that managing the issues after implementing the SMR has not been successfully anticipated. This can be linked to a predominantly technical approach for the development and implementation of SMR. When implementing a new information system it is imperative that users accept it, and this requires coordination across organizations (Steichen and Gregg, 2015). An example is described in by Zwaanswijk *et al.* (2011), where health professionals resisted the implementation of a national information system. To address this, user-friendly guidelines should be developed so that application in daily practice can be ensured, and so fewer errors occur (Zwaanswijk *et al.*, 2011).

The district nurses point out that the SMR has the potential to facilitate their work and improve patient safety if used correctly and alike. The information in SMR is found to be inadequate, however, and the district nurse must disclose information from other sources than SMR. This practice can be described as a workaround.

Friedman (2014) describes workarounds as the result of a user's perceived limitations of an information system. This leads the user to explore ways to work around the perceived limitations. Friedman proposes a typology for different kinds of workarounds. Temporary workarounds are solutions to issues that occur when replacing one it-system with another. However, the temporary solutions may eventually develop into routine workarounds if they are accepted as a fixed part of the workflow (Friedman *et al.*, 2014). Obtaining missing information regarding warfarin ordination has evolved into a being part of the district nurses' workflow and can be considered a routine workaround that compensates for the lack of information exchange between the sectors. The district nurse has no alternative to retrieving the information, and the workaround is thus unavoidable. Whether this is a result of the system or the application of the system cannot be concluded.

It is possible to obtain knowledge about how complex prescriptions are managed in SMR and which effects the different prescription procedures have on the working procedures by conducting interviews of district nurses. This means that there is a risk of medication error, but a more exact description of how the patient safety is influenced require another study design. Consequently, it

indicates that the district nurses' critical approach to data in SMR prevents potential errors, that otherwise could reach the patient. The risks of this working procedure can be that the patient safety depends on the professional competences and vigilance of the individual district nurse.

The challenges of the documentation of warfarin at sector transition, is pointed out in a study by Day *et al.* (2016). The same challenges concerning sector transitions regarding the medication process with warfarin is identified in this study. Day *et al.* describes prescription errors, reduced compliance and insufficient monitoring as main reasons for medication errors and reduced patient safety. Furthermore, they find that there is a potential for implementing a decision support system for anticoagulants with five key elements, because it facilitates the cross-sectorial communication, forcing the responsible for the patient's medication from both sectors, to consider the patient's warfarin treatment at discharge. At the same time Day *et al.* have found that there are challenges in storing information, so they are available for both the discharging and receiving unit (Day *et al.*, 2016).

In addition, the study by Day *et al.* supports the findings in this study, where the standardization with the course of warfarin treatment at sector transitions could contribute with a positive effect on patient safety. Since SMR gives the possibility for healthcare professionals from both sectors to reach the same information, it is possible that a similar decision support system for anticoagulants could improve the communication, transmission of responsibility and in that way, ensure that the patient continuously receive the right treatment. Furthermore, the study by Day *et al.* can contribute with inspiration to some general guidelines to a decision support system with integration to the SMR (Day *et al.*, 2016). A decision support system and some general guidelines for prescription of warfarin can contribute to a correct and uniform use of SMR across the health sector, and according to Hevner *et al.* (2004) hereby contribute to be of relevance for the organization (Hevner *et al.*, 2004).

4.1 Conclusion

The findings of this study indicate that there are problems when dealing with complex prescriptions in SMR following current practice. It creates complicated working procedures and potentially risky situations when the ideal medication process with warfarin does not correspond to the actual medication process. Several of the utilized prescription procedures of warfarin in SMR does not allow for adequate reuse of data which causes the evolution of workarounds in working procedures of the district nurses. The managing of complex prescriptions thus depends upon the individual district nurse's ability to identify and compensate for the flaws of SMR, which leads to a need for a standardization that considers the reuse of data.

Future work: It can be relevant to research whether standardization of warfarin prescription or an individual decision support system for anticoagulants integrated into the SMR can ease the handling of complex prescriptions.

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6 ACKNOWLEDGEMENT

This work has been done as a part of the Master programme in Master of Science in Clinical Science and Technology at Aalborg University, Denmark. We would like to thank our informants for participating in the study and our peers for participating in the pilot-interview.

Using Mobile Sensors to Expand Recording of Physical Activity and Increase Motivation for Prolonged Data Sharing in a Population-based Study

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Abstract

Regularly conducted population cohort studies contribute important new knowledge to medical research. A high participation rate is required in these types of studies in order to claim representativeness and validity of study results. Participation rates are declining worldwide, and re-searchers are challenged to develop new data collection strategies and tools to motivate people to participate.

The last years of advances in sensor and mobile technology, and the widespread use of activity trackers and smart watches, have made it possible to privately collect physical activity data, in a cheap, easy and prolonged way. The unstructured way of collecting this data can have other applications than just showing users their activity trends.

In this paper, we describe our plans for how to use these pervasive sensors as new tools for collecting data on physical activity, in a way that can motivate participants to share more information, for a longer time period and with a renewed motivation to participate in a population study.

Keywords

Cohort studies, Motor Activity, Fitness Trackers, Heart Rate, Photoplethysmography

1 INTRODUCTION

The Tromsø Study is the longest running population-based study in Norway. Inhabitants in the municipality of Tromsø have participated for the last 40 years. The first survey took place in 1974, where the aim was to understand and develop strategies to prevent the high incidence of cardiovascular disease in Norway (Jacobsen et al., 2012, Njølstad et al., 2016). Altogether seven surveys have been conducted to date. The data collection has gradually expanded with more comprehensive questionnaires, additional measurements and clinical examinations as well as extended biological sampling. The multiple surveys over a long period of time comprises a unique collection of health data and repeated measurements. In total, 45,150 participants have attended at least once and 18,420 participants have attended three or more times.

An additional strength has historically been the high attendance rate, which for the first five studies was between 72 and 79%. The last two studies however, have only achieved an attendance rate of 65%. Figure 1 shows the attendance rate for all seven surveys in the Tromsø Study, as well as the declining tendency of participation. This tendency is not unique to the Tromsø Study. Participation rates for population studies have declined for decades worldwide (Hartge, 2006).

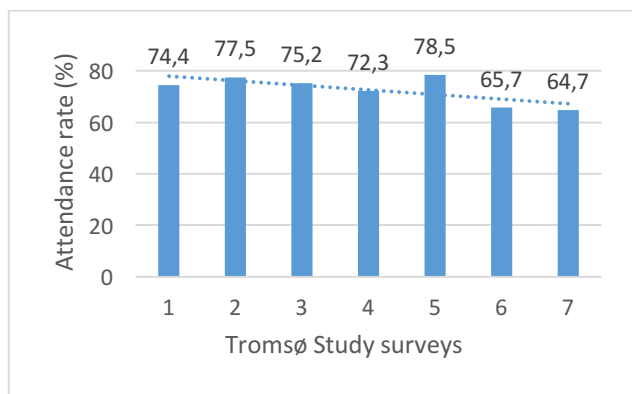


Figure 1. Attendance rates, Tromsø Study surveys.

In addition, lower participation rates are observed in the youngest and oldest age groups respectively. Younger people are less motivated to participate in health surveys and old people participate less, not only due to disease and frailty, but also because of increased intrusiveness and time demands. Figure 2 shows the attendance rate of the different age groups in the last four surveys. The first two age groups only have three pillars because only people above 40 were invited in the last survey.

Paper from the 15th Scandinavian Conference on Health Informatics SHI2017, Kristiansand, Norway, 29 - 30 August.

Conference Proceedings published by [Linköping University Electronic Press](http://www.linkopinguniversity.se/electronicpress/).

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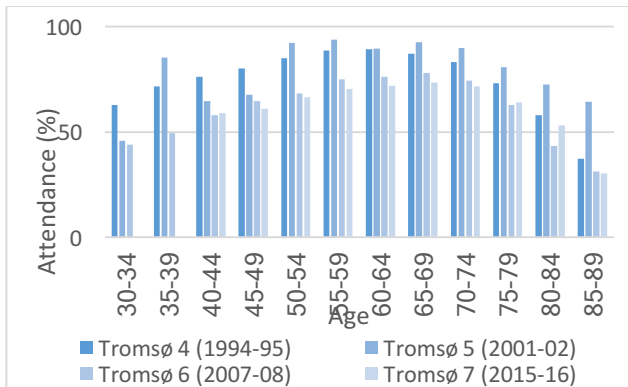


Figure 1. Attendance rate, survey 4 to 7, grouped by age.

The declining tendency in participation rate and the low attendance rate in the younger age groups emphasizes the need for new data collection tools and strategies.

In the last two surveys, self-reported data on physical activity (PA) were collected using questionnaires. Accelerometers were used to collect accurate objective data on PA. Heart rate (HR) data was collected from standard electrocardiography (ECG), combined ECG- and accelerometers, and via blood pressure measurements.

In the latest survey (Tromsø 7), 6,300 participants carried the ActiGraph wGT3XBT accelerometer for one week. A subsample of 700 participants carried the CamNtech Actiwave Cardio for one day, to collect accurate data on HR and heart rhythm, using a single lead ECG. Six questions related to PA (sedentary behavior, leisure-time and occupational PA, and PA frequency, intensity and duration) were included in the questionnaire. Data from Tromsø 6 show that self-reported moderate-intensity leisure activity was over-reported compared to objectively measured data (Emaus et al., 2010). Results from Tromsø 7 are not yet available, but similar conclusions are expected.

PA is an important health indicator and is used as a predictor, endpoint and adjustment variable. It is of interest to investigate new approaches for collecting PA and HR data, over a longer period of time.

For the next population study, we plan a new approach for collecting PA and HR data. In 2016, a total of 102 million wearable fitness trackers were sold worldwide (International Data Corporation (IDC), 2017). These devices use the same technology as accelerometers used for PA measurements in research studies. Wearable fitness trackers are cheaper, often have additional sensors, are less intrusive, and many study participants use them already. ActiGraph, Actiwave Cardio and similar devices are validated tools for measuring PA and HR. However, some studies indicates that wrist worn fitness trackers (Dooley et al., 2017, Evenson et al., 2015, Reid et al., 2016) and HR monitors (Stahl et al., 2016, Wallen et al., 2016) are accurate as well. In these studies, various wrist worn devices were compared using different tools for validation,

including pedometers (Yamax CW-700) and accelerometers (ActiGraph GT1M/GT3X/GT3X+, Actical) for PA, and ECG or HR chest straps (Polar T31, Polar RS400 HR) for HR.

Most wearable fitness trackers use a 3-axis accelerometer to calculate PA; including step counts, energy expenditure and energy intensity. This is the same technology used in accelerometers-based research instruments (e.g. ActiGraph product line). For HR monitoring a different technology is used, compared to ECG waveform recorders (e.g. Actiwave cardio). Photoplethysmography (PPG) is an optical technique used to detect HR by monitoring changes in blood volume beneath the skin (Allen, 2007), and is the most common solution for tracking accurate HR (Stahl et al., 2016) in wrist worn wearables. In addition, more and more modern wearables have a built in gyroscope, GPS, magnetometers, barometers, light sensors and others. These additional sensors can further improve data quality.

In 2016, the top five brands sold about 57% of all fitness trackers (International Data Corporation (IDC), 2017). Fitbit (22%), Xiaomi (15.4%), Apple (10.5%), Garmin (6.1%), Samsung (4.4%) and many of the smaller brands, collects and stores fitness data in online cloud based health repositories. Many of these repositories have a publicly available Application Programming Inter-face (API) we can use to access this data, if given permission by the user. Many brands can also synchronize with Apple Health Kit and/or Google Fit, two of the biggest online cloud repositories for health data. When connecting a wearable sensor to a smart phone, mobile applications can access these sensors, either directly or indirectly through affiliated cloud services. This also makes it possible to collect both historical and live fitness data.

One important limitation with most wearable devices, e.g. fitness trackers, is that they will not expose raw sensor data directly. Instead, they use custom brand and/or device specific algorithms to calculate common metrics, e.g. step count. These derived metrics are in most cases the only data available through device APIs.

In this paper, we will describe our plans for how to collect historical and live PA and HR data from participants in past and future studies, using mobile pervasive sensors. In addition, we will discuss issues regarding participant motivation.

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2 METHOD

The goals of this project are to 1) investigate how we can motivate participants to share data over a longer period,

and 2) whether this solution can be used as an additional source of health data and as a potential new tool for collecting this type of data in population-based studies.

Our plan for how to collect historical data using wrist worn fitness trackers, was thoroughly described in a previous paper (Henriksen et al., in press). In this paper, we will expand on our initial plan, describe alternative approaches, and focus on system architecture and requirements.

2.1 Approaches

We are considering several approaches for data collection. We can collect *historical data* from brand-specific or open cloud based health repositories, like Google Fit or Apple HealthKit. We can collect *live data* from the same repositories, retrospectively, or in some cases, by accessing the sensors data directly and extracting derived metrics. We can collect *raw sensor data* from a limited number of devices, and create custom algorithms for measuring various types of activity. We can create a *custom device*, and create custom algorithms for activity detection. A final approach is to use *third party aggregators*. These approaches have different benefits and drawbacks, and combinations of approaches are possible.

The main benefit of accessing data collected by this type of wrist worn wearables is the long period of which it can be collected. The common drawbacks for all these approaches are the unstructured nature of this data and the not well-known validity of the various devices used by participants for collecting this data.

Historical data

In ongoing projects where PA and HR have already been collected using ActiGraphs/Actiwave Cardios or similar devices, some participants may have worn a personal fitness tracker, by coincidence, during the data collection period, and synchronized this data to their phones. Depending on which device they wore and where their data was eventually stored, it may be possible to download this data in order to complement existing data for those participants.

The main benefits of this solution is that the data is already collected. Except ethical approval, recruitment issues and similar matters, the only additional *technical* requirement is to have the participants install an application on their phone and agree to share their data. This data can then be shared with the research project, retrospectively and automatically. The main drawbacks are that only some participants will have this data, and some will not agree to share the data they have. In addition, for some participants it may be difficult to install this application and set it up correctly.

Live data

In future studies, we can improve on the limitations described earlier. Participants who already have a fitness tracker will be asked to install the same application, but because it is done at the beginning of the project, it may be easier to have them accept this. In addition, they can be provided with assistance to set it up properly. Participants,

who does not own a fitness tracker, can be equipped with a suitable device for the duration of the study. An additional benefit with this approach is that for some systems, it is possible to access derived sensor data directly, i.e. without connecting to the cloud repositories. This makes it possible to continuously collect and transfer data for individuals who does not want to upload this data to brand specific or open health repositories, but are willing to share their data for research purposes.

Raw sensor data

In the two previous described methods, data retrieved from clouds and sensors are derived from raw sensor data. This raw data is processed through proprietary algorithms, written by device vendors. These algorithms change over time in an effort to improve them. However, when and how they change these algorithms are generally not reported. An alternative to relying on unknown algorithms is to create our own. The benefit of using this approach is that we have full control of how sensor data is interpreted. The drawbacks are that it will be a more complex solution, and few devices currently support this approach.

Custom device

Because there is a limited number of devices that supports direct access to raw sensors signals, another option is to make our own custom device. The benefits are that we can include only the sensors we need, and we will get full access to sensor signals. Drawbacks include, having to create our own algorithm for all activity types we want to measure, and working with hardware requires additional time and efforts and will be more expensive as a final solution. More expensive because of the need to produce enough devices for *all* participants. We may avoid some of these drawbacks by cooperating with existing device vendors.

Third party aggregators

Another way of improving on the limitations with the various vendor algorithms is to use third party aggregators, that can help standardize metrics received from different vendor APIs. Validic and HumanAPI are two examples of such services. These services can be expensive, but they make it possible to collect data from many different devices and normalize this data into comparable values. Not all devices and brands are currently supported.

2.2 Motivation

It does not matter how good the solution is if participants are unwilling to use it. We foresee two motivational challenges with this system. The first challenge is to motivate participants to install an application on their private phones. Because smart phone often contains a large part of a person's digital life, it is natural and smart to be conscious about which applications to install. The second challenge, and the area we will work with the most, is to motivate participants to keep sharing their personal health data over several months and even years. It is necessary to find the motivational factors that maximizes

usage. These factors will be defined through the system requirements. As part of the requirement process, we are planning to conduct a study where we will investigate what could motivate potential participants to use this system. As in many modern software projects where the end goal is clear, but how to get to that goal is unclear, we are planning an agile and iterative approach during implementation. Pilot participants will test each iteration and give feedback on what they think does and does not work.

Because of the declining participation rates in population-based studies, an additional challenge will be to motivate people to participate in the study in the first place. By including attractive features in this system, we believe that potential participants will want to contribute in order to get access to this system. Exactly what these features may be is something we will try to find out in the aforementioned study.

2.3 System architecture

The architecture is comprised of several existing systems, two new systems and an upgrade to one existing system. **Error! Reference source not found.** shows an overview of the architecture of the proposed solution. White elements represent existing systems we will integrate with in our solution. Grey elements are our contribution to the architecture. Partly grey/white elements are existing systems that must be upgraded to support our solution. Round edged boxes represent mobile phone systems. Regular boxes represent backend/server solutions. Boxes with dashed lines are hardware sensors internal or external to the phone. The figure also shows how each system is connected using arrows. Dashed arrows illustrates new communication lines we must implement.

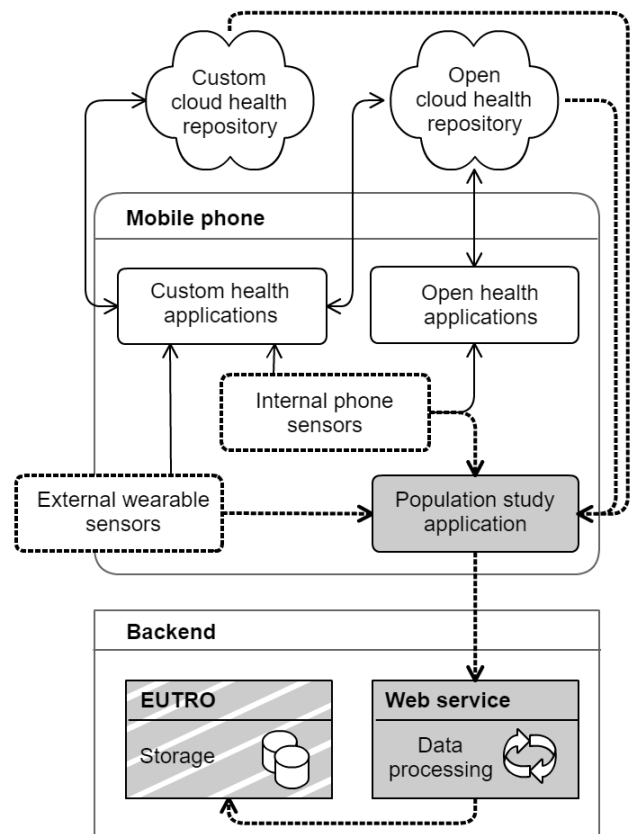


Figure 1. System architecture.

2.4 Existing systems

We have divided existing systems into three categories: 1) cloud repositories, 2) sensor systems and 3) mobile applications. Information travels between these systems differently for iOS-based (iPhone) devices and Android-based devices. In both systems, internal sensors are accessible by installed applications. On Android devices, this is also the case for externally connected sensors running Google's Android Wear. Sensors in the Apple Watch, running watchOS, can only be accessed by the affiliated Apple Health application. This is important because 10% of all fitness trackers are Apple Watches, and the only way to access these sensors are therefore indirectly through the Apple HealthKit cloud repository.

Cloud repositories

Open cloud repositories are services that can be used by any application, service or system to store health and fitness data online. We are only considering Google Fit and Apple HealthKit in our solution, because they are by far the most used systems. There are others, e.g. Microsoft HealthVault, which may be relevant down the line. Our first implementation will target open services.

Custom cloud repositories are online services that are mostly tailored for specific brands. There are several available custom cloud repositories. Depending on brand popularity, we may also have to implement support for some of these services.

Sensor systems

Different smart phones have different sensors. Most modern smart phones have several internal sensors that is relevant when measuring PA. When collecting historical data, we do not access these sensors directly, but rather download data from a cloud repository. When collecting live data, we may, in some cases, access these sensors directly and interpret the data in a custom way. Accelerometers, gyroscopes and magnetometers, often packed together into an inertial measurement unit (IMU), are the most important and widespread sensors for detecting PA.

External wearable sensors have the added benefit of giving results that are more accurate because these are generally carried throughout the day. In addition, with PPG-enabled wrist worn wearables, we will also be able to access HR.

Although it is possible to only use internal sensors in this solution, our plan is to focus on wearable external sensors, because they provide data more continuously. However, only a few fitness trackers support GPS, so in most cases this particular type of data must be collected from the phone.

Mobile applications

In our architecture, Google Fit and Apple Health are the only two open health applications considered. These applications will automatically collect data from internal sensors and store it as health information (e.g. step counts, activity intensity, energy expenditure, distance walked, floors, etc.). This information is then uploaded to affiliated cloud health repositories. Users can also view historic data and trends in these applications.

The difference between an open health application and a custom health application is that the first is meant to be used by any device, and the second is meant to be used by a specific brand of devices. Sensor data from externally connected sensors are not automatically stored in open health applications, but it is possible for the affiliated custom health applications to also forward sensor data to the open health application, and ultimately to the cloud.

2.5 New systems

We have defined two new systems, and identified one existing system that must be upgraded. The new systems includes 1) a mobile application (population study application) and a backend web service (WS). The existing system is a backend data storage (EUTRO) solution. We will pre-sent a high-level list of the core functional requirements and non-functional requirements related to motivation. Only the major must have requirements are included, as defined in the MoSCoW method (Agile Business Consortium, 2014), a technique used in agile development for task prioritizing.

Population study application

Participant must install the population study application on their smart phone, and allow it to connect to the cloud repository they use. We plan to support Android and iOS devices.

The main purpose of this application is to download health data from relevant sources and forward this data to a backend WS. In order to allow participants full autonomy over their data, they can specify what types of data they want to share and from which period they want to share it.

For Android phones, it is possible to write a background service that regularly uploads new data to the WS. For iPhones, this is not possible. An alternative approach is to use notifications to ask participants to regularly start the application and actively share new data. This limitation requires participants to engage with the application several times during the collection period. It is therefore essential that the application is easy to use and helps trigger participant motivation to keep sharing their data.

Functional requirement

- The mobile application must be able to correctly identify the user as a participant in the Tromsø Study.
- The mobile application must be able to connect to and download data from relevant cloud repositories using appropriate APIs
- The mobile application must be able to access available internal phone sensors and external connected sensors, and record live PA and HR data.
- The mobile application must be able to transfer collected data and sensor meta data to the online WS.
- The users must be able to decide which type of data they want to share.
- The user must be able to decide what period they want to share data from, including historic and future data.
- The user must be able to see an overview of the data they have shared.
- The users must be able to withdraw their consent for the use of specific data.

Non-functional requirements

- The mobile application must be easy to install, set up and use.
- The mobile application must include design elements that maximizes the period a user is willing to use the application and share data.
- The mobile application must include features that maximize the likelihood of motivating potential users to participate and use the system

Web service

Health data collected from mobile phones cannot be directly transferred to the final data storage for at least two reasons. Firstly, EUTRO contains sensitive data, and opening for direct access by mobile solutions, will be a great security risk. Secondly, some level of processing of the received data is necessary before storing it in a normalized and comparable way. The WS will solve both these issues, placing itself between the several thousand mobile phones and the final storage of the data receive from these phones.

Functional requirements

- The web service must be able to receive data from the mobile application
- The web service must be able to send data and sensor meta-data to a data storage system (EUTRO)
- The web service must be able to process and clean received data before sending it to the data storage system (EUTRO)

Backend data storage - EUTRO

EUTRO is “an IT solution designed to protect and manage biologic material, metadata, data and projects for major health surveys” (UiT - Department of Community Medicine, 2011). EUTRO is a standalone service, created, owned and operated by our own department, i.e. Department of Community Medicine. It is therefore possible to make changes to this system without involving external resources. It is however a complex system that is used by many research projects. Any proposed changes must be well defined and relevant to warrant inclusion. The Tromsø Study uses EUTRO, but other similar data storages can be used, as long as they have an interface for receiving continuous data from the WS.

Functional requirements

- EUTRO must be able to receive health data and sensor meta-data from the WS, and connect it to the correct research project and participant.
- EUTRO must be able to delete data collected from participants using the mobile application, who have withdrawn their consent.

2.6 Ethics

Participating and sharing health data requires informed consent from study participants. We will apply for approval from The Regional Committee for Medical and Health Research Ethics, as well as get approval from the Norwegian Data Protection Authority.

3 RESULTS

Some preliminary results show that in order to get access to data from as many different devices as possible, we will have to make the mobile solution capable of connecting to several APIs.

3.1 Cloud based health repositories

In our previous paper (Henriksen et al., in press) we only described Google Fit and Apple HealthKit, because these are the two largest online repositories for health data used by smart watches and fitness trackers. According to the Vandrico wearable database (Vandrico Inc., 2016), fitness trackers and smart watches are produced by more than 50 companies, several of which has more than one device on the market. In addition, this database does not contain all devices, and several less known brands exists.

Error! Reference source not found. shows an overview of what level of integration is possible for the top five brands. The second column shows if devices will automatically synchronize to Google Fit and/or Apple HealthKit. The third column shows if devices supports a developer API, that makes is possible to achieve this synchronization by 15th Scandinavian Conference on Health Informatics SHI2017, Kristiansand, Norway, 29 - 30 August.

implementing a custom solution, and transferring the data manually.

Brand	Google/Apple automatic integration	Google/Apple manual integration
Fitbit	No	Yes
Xiaomi	Yes	No
Apple	Yes (Apple only)	No
Garmin	No	Yes
Samsung	No	Yes

Table 2: Top five brands Google/Apple integration

Additional brands that supports direct integration with Google Fit or Apple HealthKit includes, *Fossil, Huawei, LG, Michael Kors, Mio, Misfit, Moto, Mushroom Labs, Nevo, Nixon, Sony, Tag Heuer* and *Withings*. Brands that only supports manual integration includes, *Huawei, Jawbone, Suunto, Timex Wellograph*. Some brands appear in both lists because they have multiple devices with different level of support. In addition, several brands do not support either solutions. This list is likely to change as new brands and devices appear on the market. It is also worth mentioning that the list in **Error! Reference source not found.** is a list of the most sold brands worldwide. If this list were for Norway only, it would probably be different. For instance, Xiaomi is a Chinese brand and does not have the same market share in Norway.

As these findings indicate, we will have to implement support for a range of brands using different APIs. In order to make sure we support most devices, we will at least have to implement support for Google Fit, Apple HealthKit, Fitbit, Garmin and Samsung. Implementing support for these five services will make it possible to import data from 19 brands.

4 DISCUSSION

Participation in population studies are declining worldwide and the Tromsø Study is no exception. This is especially true for the younger age groups. Because population studies are important for monitoring and understanding the health status of a population, we must find new ways to motivate the population to participate. There are many reasons for not attending. The number of questions, examinations and test have increased in every Tromsø Study survey, and the amount of time required to attend has increased accordingly. This may affect willingness to participate.

Physical inactivity is an important risk factor for disease, and collecting more data on PA in a population, can help to improve knowledge and understanding of the effects of this behavior. With plans to add additional tools for collecting more data, it is important to do it in a way that does not make it more inconvenient for participants.

A new way of collecting this data has been discussed in the context of already existing mobile sensors, and continuous data collection from these sensors. Several approaches

were discussed, highlighting benefits and drawbacks of the different options. Some of these options requires very little extra efforts from participants, and may therefore prove to be a value addition to the data collection regime, without affecting participation rates negatively. In fact, we hope that by introducing these new tools, we can help motivate participants to contribute more data over a longer period, while at the same time make them feel that they benefit from participating. We hope this will drive motivation, to both participate in the study and to participate longer.

We have discussed several ways to collect health data over several months and years, but all include using mobile sensors to measure PA and HR. These sensors could be used for other purposes as well, for instance measuring sleep patterns. For the most part, we are limited to the metrics supported by the various devices, but in future solutions this could be improved and open up new possibilities.

5 CONCLUSION

In order to collect PA and HR from all participants successfully over a period of several months and years, we have identified three possible options.

1. Access historical and live fitness data, using privately owned fitness trackers already worn by participants.
2. Access live fitness data, using one specific fitness tracker available on the consumer market, paid for by the Tromsø Study.
3. Access live fitness data, using a custom fitness tracker, built by and paid for by the Tromsø Study.

The first option requires the least resources and is most likely to result in longer recording periods, because participants wear private devices that they would use even if they did not participate in a study. However, received data will be from different devices with different level of accuracy, and there will be a greater need to implement access for multiple cloud services. The second option is more resource demanding and less likely to result in a very long recording period, because participants will have to wear a new unfamiliar device and recharge it regularly. However, it is easier to handle the data and we only have to implement cloud access for one type of device. A combination of option one and two is also possible, i.e. buy one type of device and ask participants who does not own a fitness tracker to wear this device. The third option is more complex, but allows us to have full access to sensor signals. This option is also less likely to result in a long recording period, for the same reason as in option two.

A combination of option one and two seams, at this point, to be the most viable option. By implementing support for five APIs, we will support at least 19 brands, including the five most popular brands. More brands, future and existing, may also implement support for Google Fit or Apple HealthKit APIs later, increasing availability even more.

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Collective action in national e-health initiatives

Findings from a cross-analysis of the Norwegian and Greek e-prescription initiatives

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Abstract

In this study, we examine the introduction of e-prescription in Norway and Greece as a process towards achieving embeddedness within the existing information systems' landscape of healthcare. This requires action taking by public sector actors at different government levels and also, by private actors. We used the lens of collective action for informing our investigation. Our analysis brings to focus the mechanisms of making initiatives happen when participants have the freedom to make individual decisions on their contributions, structuring their work in the best way they consider fit. Specifically, we identified how the solutions evolved through voluntary cooperation, strategic interaction and selective incentives. Our findings contribute to the extant literature on national e-health solutions shifting the focus from the important technical issues of standardisation and integration to the equally important issue of creating the conditions for collective action.

Keywords

Electronic prescribing, digitalisation, collective action

1 INTRODUCTION

E-prescription solutions capture and circulate prescription information between prescribing doctors, pharmacies and insurers that handle related payments. The digitalisation of information flows eliminates practical legibility issues (frequently faced when using handwritten prescriptions) while significantly improving auditability. Overall, such solutions contribute to cost containment, enhancement of patient safety, visibility over doctors' prescription patterns and process quality assurance. In this respect, e-prescription has a dual role: it is a tool introduced to everyday work to improve healthcare delivery and also, a mechanism for regulating, controlling and monitoring a large array of dispersed temporally and geographically professional tasks related to prescriptions' issuing, dispensing and reimbursing (Vassilakopoulou et al., 2012). Overall, putting e-prescription in place entails working with multiple and diverse sociotechnical components, finding ways to link and organise them (Rodon and Silva, 2015). During the past decade, most European countries had to address increasing healthcare costs and this fuelled the interest for e-prescription systems across Europe (Aanestad et al., 2017). According to the World Health Organization, pharmaceutical costs account for three of the most common causes of health systems' inefficiency: reducing unnecessary expenditure on medicines, using them more appropriately, and improving quality control, can contribute to significant health expenditure

reductions for most countries (World Health Organization, 2010).

In Norway, the government initiated e-prescription back in 2003 with the aim to solve problems in payments' settlement for pharmacists and bandagists related to the circulation and processing of paper prescriptions (Pesaljevic, 2016). It was important for the authorities to monitor and control prescriptions not only for ensuring healthcare quality but also for reasons of cost control. The introduction of e-prescription in Norway has been a lengthy and challenging process entailing concerted action from multiple actors that developed extensions for a multitude of existing systems (Hanseth and Bygstad, 2017). Although it was initiated in 2003, it took almost a decade to reach full deployment.

The Norwegian e-prescription solution supports the registration, circulation and storage of information about patients (including their unique national identification number), prescribers, prescribed medicines and dispensing pharmacies. The registration of information is performed via the Electronic Patient Record (EPR) systems and Pharmacy Management systems in doctors' offices and pharmacies. The Patients can go to any pharmacy to fill their prescription and there is also the possibility to use e-pharmacies. Furthermore, the information on filled prescriptions is shared with NAV (the Norwegian Labour and Welfare Administration) for control and refunding. E-prescription is used both in primary care and in hospitals.

In Greece, the overall aim for e-prescription was to enhance control over pharmaceutical expenditure, to improve doctor-pharmacy collaboration and patient safety and to capture data required to support policy development (Law 3892/2010). The year when the e-prescription law passed (year 2010) the Greek economy was facing a severe public debt crisis which captured global attention. The strong financial motivation behind the e-prescription initiative is demonstrated by its inclusion in May's 3rd 2010 "Memorandum of Economic and Financial Policies" between Greece and the International Monetary Fund and subsequently in the "Hellenic National Reform Programme 2011-2014" (Vassilakopoulou and Marmaras, 2013; Vassilakopoulou and Marmaras, 2015). Differently to Norway, the deployment of e-prescription in Greece was swift: development started in 2010 and by 2013, reached almost full coverage (Papanikolaou, 2013).

The Greek e-prescription solution supports the registration of information about both the patient and the prescriber, the diagnosis, the medication specifications (type, quantity) and directions for the patient to follow. Prescribing doctors register the patient's name and social security number, the diagnosis encoded according to ICD-10, and the medications prescribed and then, print a summary page which is handed to the patient. Patients can visit any pharmacy to fill prescriptions. Before delivering medications, pharmacists scan the medication packages' barcodes which are then matched to prescription details. The information on filled prescriptions is sent to reimbursement authorities. Several rules related to reimbursement are inscribed in the e-prescription solution (e.g. different percentages for patients' share of costs). The rules inscribed are not only related to reimbursement. Therapeutic prescribing protocols for a series of conditions (i.e. diagnosis-based prescribing guidelines) have also been electronically implemented. The protocols include medication of "first choice", secondary medications, alternative therapies and rare cases. E-prescription is used in primary care and in hospitals.

Both e-prescription initiatives entailed introducing new technologies not as standalone objects, but as elements in larger infrastructural arrangements. Working within healthcare is especially challenging today because novelty has to link to historically built conventions of practice and to technologically congested landscapes that are the outcome of intensive digitalization efforts undertaken during the last decades (Grisot and Vassilakopoulou, 2017; Grisot and Vassilakopoulou, 2015). This makes the introduction of new electronic systems more challenging than it was a couple of decades ago when e-gov initiatives were starting in other public-sector domains (e.g. tax authorities). Earlier initiatives encountered less populated and less diverse technological landscapes than the ones found today. Nowadays, national-level digital initiatives rely on synergizing with many actors to achieve embeddedness (Bietz et al., 2010; Monteiro et al., 2013).

We examine the introduction of e-prescription in Norway and Greece as a process towards achieving embeddedness within the existing information systems' landscape of healthcare. This requires action taking by public sector actors at different government levels and also, by private actors. By focusing on the embeddedness concern, we can use the lens of collective action (Fulk and DeSanctis, 1995) for informing our investigation. The literature on collective action grapples "with the age-old problem of how to induce collaborative problem solving and other forms of collective action among self-interested individuals, groups, or organizations, assuming, of course, that they share at least some common goals" (idem, p. 60). This lens fits a situation where heterogeneous actors must develop or extend complementary resources through a dynamic process of collaboration. Heckathorn analysed collective action based on three underlying mechanisms: voluntary cooperation, strategic interaction, and selective incentives (Heckathorn, 1996). As collective action is a multifaceted phenomenon, all three mechanisms are important. In voluntary cooperation, actors choose between two strategies (cooperate or not) forgoing any attempts to influence others. In strategic interaction, actors make their choices conditional on others' choices according to principles of reciprocity. In the case of selective incentives, laws or social norms that punish defectors or reward co-operators are employed to facilitate collective action.

The remainder of the paper is structured as follows: first, we present the method used for collecting and analysing our empirical material, then, we present the results of our investigation, finally, we discuss and conclude by pointing to the contribution of this research and further research directions.

2 METHOD

The research reported in this paper is based on a multiple case study research design (Eisenhardt, 1989; Eisenhardt and Graebner, 2007). Multiple case studies allow for comparison across cases, resulting to more robust conclusions (Yin, 2014). Being focused to a single case could result to naturalising many of their aspects or making them look too singular. This combined view allowed us to be sufficiently attentive to details without losing sight of the overall picture.

Data were collected from on-line sources, documents, observations and interviews with key actors (Table 1). As a first step, we performed "within-case analysis" which led to the development of timelines for the two cases and preliminary narratives on their evolution. In the second step, we applied a cross-case analysis in order to look for patterns across the cases. At this step, we turned to the literature on collective action for dimensions around which we could cluster episodes identified during the first step of our analysis. Specifically, we looked for voluntary cooperation, strategic interaction, and selective incentives following Heckathorn (1996). This analysis helped us explore how e-prescription solutions were made possible through collective action.

Case	Data source	Description
Norway	Interviews	Semi-structured interviews with professionals involved in the development of e-prescription and professionals with domain specific knowledge (21 in total).
	Observations	Attendance of project meetings and workshops (50 meetings, 10 workshops).
	Document analysis	Norwegian Healthcare Strategic Documents; Policy, Regulation and Standards Documents; Project Documents.
Greece	Interviews	Semi-structured interviews with professionals in the domain (7 in total).
	Observations	On-site observations of e-prescription use in pharmacies for three full days.
	Document analysis	Legislation and guidelines, policy documents and strategic plans, press releases, public consultation documents, presentation documents, posts in professional electronic forums, press and articles.

Table 1. Data Collection

3 RESULTS

3.1 Overview of the two cases

E-prescription was introduced in both Norway and Greece with the aim to be all-inclusive (covering primary and secondary care), for the whole country and allowing patients free choice of pharmacy for prescription dispensing. This makes the two cases comparable. The Greek and Norwegian cases covered similar functionalities and were pursued to a great extent through centrally decided and implemented development plans (in Norway led by the Directorate for Health, in Greece led by the Greek e-Government Centre for Social Security). These similarities are important because, within Europe there is a great variety among e-prescription initiatives (Aanestad et al., 2017). For example, in England, a specialized e-prescription service only for primary care was introduced. In Spain and Italy, initiatives were taken at the region level. In Sweden, there was a decision to transmit electronic prescriptions to selected pharmacies, so patients could not walk-in to any pharmacy.

Regarding motivations, the cases have a lot in common. Firstly, they both aimed for cost containment, partly through automating parts of the overall process, but also through enhanced monitoring of drugs' expenditures and

physicians' prescribing practices; also, they aimed for improving patient safety and for improving the overall quality of the service delivered to patients. In Greece, the economic situation of the country played a role in pushing the project forward. The project was run during a difficult period for the Greek economy, and this accelerated the introduction of new electronic tools to reform the healthcare sector. In Norway, the project was initially triggered by the Office of the Auditor General's critique of inadequate monitoring and control of costs related to drug use. However, in order to ensure physicians' buy-in, the focus of the project changed early on from monitoring, control, and cost containment, towards improving patient safety. Table 2 provides an overview of the temporal evolution for the two cases.

Period	Description
Norwegian e-prescription	
2003-2004	Decision to initiate e-Prescription
2005-2006	Starting e-Prescription program
2007-2008	Tender First Pilot (stopped after significant problems)
2009-2012	Re-planning Successful pilot and rollout Prescribing Module developed
2013-2016	Extensions including: multidose dispensing, online-pharmacies and new projects for further extensions
Greek e-prescription	
2010	Decision to initiate e-Prescription
2011	Pilot and rollout
2013	Coverage 98%
2013-2015	Extensions including: therapeutic protocols, caps for prescribing doctors, diagnostic test ordering

Table 2. Temporal evolution of the e-prescription cases

Both e-prescription initiatives started with a focus on paper prescriptions and aimed at first to digitize the paper-based prescribing processes. They started with the (implicit) strategy of replicating existing paper-based practices and then, to a varying degree, enriching these with additional functions for detection of medication errors and decision support that would improve patient safety. However, both projects, while trying to stay close to the existing practices, had to find appropriate strategies for addressing challenges.

The Norwegian and Greek projects employed almost opposite strategies for dealing with the existing technological solutions. In the Norwegian case, the strategy chosen was to integrate tightly the e-prescription modules implementing new functionality within existing systems, in particular Electronic Patient Record (EPR) and Pharmacy Management systems. Due to the comprehensive functionality specified, the project

required extensive work from the vendors' side. The vendors had to develop new and quite complex software components, modify their existing solutions, and integrate them to the national e-prescription solution. This resulted in a situation where the overall project became dependent not only to the activities of the vendors directly involved in the e-prescription project, but also to the overall situation within the vendor organizations. For instance, the project was slowed down by one vendor's delayed development of a new product.

Differently from the Norwegian project, the Greek one developed first a simple solution based on easily available and straightforward web technologies without pursuing integration with the Electronic Patient Record and Pharmacy Management systems that were already in place. These integrations were made possible at a later stage, after the initial launch of the simple standalone solution. Due to economic and political commitments, the initial solution was developed within a very tight timeline and was launched within less than a year from the moment that development started. This is in contrast to the Norwegian solution in terms of both complexity and time. The actual "rollout" of the solution in Norway started eight years after the project was initiated.

The Greek solution was first extended by developing and providing Application Programming Interfaces (APIs) that the vendors of Pharmacy Management and Electronic Patient Record systems could use to integrate their solutions with the infrastructure. Then, various new functions were added such as the electronic implementation of therapeutic prescribing protocols, and diagnostic tests' ordering. These extensions were implemented swiftly. This was possible because the e-prescription solution was based on an expandable component-based architecture (Vassilakopoulou and Grisot, 2013). In addition, the initiative was run and maintained by a small centralized organization that had flexibility in modifying the solution. Overall, multiple changes have taken place as a sequence of small steps.

The Norwegian e-prescription solution is significantly more complex than the Greek one. Furthermore, the Norwegian solution was expanded beyond the traditional prescription areas. Specifically, it expanded into medication management of polypharmacy patients at home and in nursing homes through the development of new functionalities for supporting Multi-Dose Dispensing. Also, an extension was developed to support ordering of prescription medications through online pharmacies. Recently, additional initiatives were launched. A comprehensive and updated overview of patient's medications at a given time is being developed. This new development is practically signalling the phasing out of the document logic of prescriptions (which was the starting point in the e-prescription journey). A generic, semi-independent component for electronic patient record systems (named FM or prescribing module) was pivotal for the successful deployment and evolution of e-prescription. FM was initially used to secure deployment

of e-Prescription nationwide, making it much easier for EPR vendors to add e-prescribing functionality when their in-house development efforts were not advanced (the estimated cost of linking an existing EPR to FM is 1/100 of the cost required for developing all the functionality that the FM module covers). FM was built having in mind some of the EPR vendors that were lagging behind in development and also smaller vendors that develop systems for health practitioners with low prescribing volumes (e.g. dentists, ophthalmologists) but, eventually it was used also for adding e-prescribing functionality to hospital systems and to the systems used in community care (Pleie- og omsorgstjenesten). The introduction of FM facilitated significantly the large scale deployment of e-prescription which started in 2011. By 2013 e-prescription was in use by Doctors and Pharmacies throughout the country. The central project organization used this module to develop the new functionalities in an experimental fashion being able to test prototypes and launch pilots without involving application vendors.

3.2 Collective action for the introduction of e-prescription

Starting from the three Hackathon's fundamentals we look how the solutions evolved through voluntary cooperation, strategic interaction and selective incentives in the two cases.

Voluntary cooperation

The Norwegian e-prescription is based on voluntary initiatives (Norwegian: dugnadstiltak). Each party in the e-prescription value chain is responsible not only for the system(s) owned and controlled but also for the overall e-prescription function. The electronic prescription program is anchored on national policies and action plans but relies on the contributions of multiple parties and without their participation it would have not been possible. Although the idea was to base everything on the voluntary cooperation of key actors, the overall architecture of the solution is such that there is full dependency on developments performed by each involved party. A Cooperation Agreement for developing e-prescription (Samhandlingsprotokoll) was signed between the Norwegian Ministry of Health and all involved parties at the end of 2006. Nevertheless, the agreement was not enough for securing actual participation. One of the initial steps was the launching of a call for vendors to extend existing EPR systems with prescribing functionality. In this initial call, only one EPR vendor responded. This company was developing at that time a new EPR product. An agreement was made and a pilot was planned for the beginning of 2007. This plan proved to be overoptimistic and was later revised. Eventually, e-prescription was piloted in May 2008 but it was not satisfactory and was eventually stopped mainly due to the overall immaturity of the new EPR product. This created the need for re-planning the initiative.

In Greece, the initial versions of e-prescription in the 2010-2011 period were only accessible via web browsers. There was no connectivity to the EPRs used by doctors or to

pharmacy information systems. The idea was that EPR vendors and vendors of pharmacy information systems would be able to develop at their own pace prescription modules for their systems at a second stage. This was made possible with the publishing of Application Programming Interfaces (APIs) that allowed connectivity with doctors' and pharmacists' systems. The APIs for pharmacy systems were launched in 2012 and were subsequently used by multiple system providers connecting the majority of pharmacies (by the end of 2012). In 2015 the APIs for doctors' EPRs were launched. The introduction of the APIs and their exploitation by third party system providers allowed e-prescription to get embedded to the health IT landscape gradually.

In Norway, there is a relatively limited number of vendors providing EPRs and pharmacy systems (eight different EPR systems from six vendors used by hospitals and GPs, also, at that time all pharmacies were using the same solution which was developed by a software company owned by the pharmacists' association; as of 2017 there are three pharmacy systems). Differently to this, in Greece there is a multitude of EPR and pharmacy system providers. It was virtually impossible to expect all parties to cooperate within the limited timeframe. Hence, a browser-based solution was launched first and subsequently APIs were published for voluntary use by system providers. Furthermore, the Greek health IT landscape was not only characterised by the diversity of pharmacy and doctor systems but also by the high fragmentation of social security. There were many different social security funds in place with their own registries and systems in place. In January 2011, the service was officially launched in 4 social security funds. In 2012 four more additional funds were included. Each addition necessitated collaborating with the different funds to establish information exchange.

Strategic interaction

When collective action is organized through strategic interaction, some actors make their choices conditional on others' choices. This is different to pure voluntary cooperation where participants take action irrespectively of the choices of others. In 2010, in Norway the development of FM started. FM was conceptualized as a generic, semi-independent component of existing EPRs; all information exchanges with e-prescription actors would be taken care of by this module but it would not be functional in a standalone basis (i.e. not possible to run without an EPR). FM could be used in the case of further delays in EPR vendor deliveries. FM was initially used to secure deployment of e-prescription nationwide, making it much easier for EPR vendors to add e-prescribing functionality when their in-house development efforts were not advanced. Actually, it was an adjustment to the strategy of the Health Directorate based on the experience they had with the vendors in the earlier stage. FM was built having in mind some of the EPR vendors that were lagging behind in development and also smaller vendors that develop systems for health practitioners with low prescribing volumes (e.g. dentists, ophthalmologists) but,

eventually it was used also for adding e-prescribing functionality to hospital systems and to the systems used in community care (Pleie- og omsorgstjenesten). The FM module was offered to all EPR vendors without charge for its use. For its implementation, vendors had to develop connections to their own systems and to handle user support.

In the Greek case, the main challenges encountered related to ensuring information flows with the social security funds. When e-prescription was first introduced the funds were maintaining multiple electronic registries for their members and several of those registries were incomplete. In an initiative parallel to e-prescription, a new system named ATLAS that includes a new national registry for all healthcare beneficiaries was developed and launched by Greek e-Government Centre for Social Security in 2014. ATLAS links multiple registries and supports the flow and storage of information on insurance status and social insurance contributions. This new system was linked to e-prescription in the summer of 2014.

Selective incentives

Collective action among large groups can also be achieved with the use of selective incentives, such as laws or social norms, penalties for defectors or rewards for co-operators. In both the Norwegian and the Greek case, special laws were introduced for electronic prescription. Furthermore, the aim was to achieve universal coverage, i.e. electronic prescription to become the norm. In Norway, vendors were reimbursed for their expenses while in Greece, it was the vendors themselves that had to cover the costs (possibly transferring the cost to the end-users or incurring it themselves with the expectation to expand their user base). Furthermore, in Norway, at the pharmacy side, e-prescription was based on a newly developed pharmacy solution. As the new pharmacy system had to be deployed in multiple pharmacies, the software company developed a middleware named migration-factory to speedily deploy the new system across Norway. Practically, the migration-factory was a demand from the Health Ministry as it was critical to ensure the possibility of dispensing electronic prescriptions from all pharmacies and not only from selected few.

4 DISCUSSION

The development and implementation of e-prescription solutions required attention to the distinct capabilities and interests of various actors while leveraging voluntary cooperation, strategic interaction, and selective incentives. As the analysis of the two cases shows, there are many different alternatives for the development and implementation of e-prescription and the configuration for each setting depends on the particularities of the actors, their capabilities and interests. By applying the lens of collective action (Fulk and DeSanctis, 1995; Heckathorn, 1996), we provided an overview of the creation of fully functional solutions that depend on contributions from multiple actors.

The findings from the study have implications for both research and practice. Regarding research, this study contributes to the extant literature on national e-health solutions shifting the focus from the important technical issues of standardisation and integration to the equally important issue of creating the conditions for collective action taking. By analysing the development of e-prescription as collective action we illuminate how novel technical capabilities can become embedded to the technologically congested landscapes that characterize healthcare today. Regarding practice, findings from our study can inform both public and private actors involved in large scale e-health initiatives. Since our research only investigated a specific type of e-health solutions (e-prescription) which supports both healthcare related and administrative needs our findings might not be generalizable to all types of e-health solutions (for instance, the voluntary cooperation mechanism might not be applicable in some cases). Therefore, further research in large scale e-health initiatives with the lens of collective action is needed.

5 CONCLUSION

The e-prescription solutions are signalling a new era of digital initiatives shifting the focus from building novel functionalities per-se to the introduction of technological capabilities that incorporate and inter-operate with a wide range of existing systems. This kind of situation calls for collective action among diverse public and private actors that need to interact in complex ways to implement and upkeep e-health solutions. Furthermore, technologies are changing today very rapidly, and strategies for effectively managing future evolution are needed.

In this study, we examine the introduction of e-prescription in Norway and Greece as a process towards achieving embeddedness within the existing information systems' landscape of healthcare. This requires action taking by public sector actors at different government levels and also, by private actors. We used the lens of collective action for informing our investigation. Our analysis brings to focus the mechanisms of making initiatives happen when participants have the freedom to make individual decisions on their contributions structuring their work in the best way they consider fit.

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Systems integrating self-collected health data by patients into EHRs and medical systems: a State-of-the-art review

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Abstract

This template may be used for articles in journals or conference articles. Differences may occur, of course, and this template is only a guide how it may appear. Patients are being more and more autonomous in their disease management by collecting, viewing and analyzing health data themselves with the support of sensors, wearables and smartphone apps. Self-collected health data can be used by the medical environment to provide more tailored and efficient therapies. This paper presents a state-of-the-art review (per April 2017) on systems integrating self-collected health data by patients into Electronic Health Record (EHR) systems and other medical systems assessable for the clinicians at the point of care.

Keywords

Self-collected data, Wearable, Sensor, EHR, Integration

1 INTRODUCTION

Patients are increasingly using m-health services and applications for storing, viewing and analyzing their self-collected data, as an answer to geographical, temporal and organizational barriers in healthcare (Tachakra et al., 2003). Studies have showed that self-collected data and self-management is beneficial and effective for managing chronic diseases, especially in diabetes (Norris et al., 2001). Moreover, wearable devices and sensors become more and more important for long-term self-management (Haghi et al., 2017) by allowing automatic data collection without the intervention of patients. Also, systems permitting cooperation between empowered patients, collecting their own health data, and medical workers, have been proved to have a positive effect on their satisfaction managing patients' chronic diseases (Peleg et al., 2017) by providing patients mentoring and knowledge they will not be able to gain on their own. However, these studies are limited to specific cases and relies on custom cloud systems and on specific sensors to deliver their services. Therefore, these studies do not present a standard integration between patients' and EHR systems, i.e. enabling only exchange of some kind of data in separate systems. This is curbing cooperation between patients and medical workers, leading to security, transparency and privacy issues. Also, needing to relate to vendor-specific systems implies that patients cannot choose freely among systems or sensors that suit them the most, according to their experiences or preferences.

This paper presents a comprehensive review of the state of the art of systems that directly integrate patients' self-collected data into EHRs and similar medical systems, and the implications on security and privacy of such systems.

The results will be used as a basic set for the design and the development of a system allowing self-collected health data transmission between diabetes patients and healthcare institutions systems in Norway.

2 METHODS

2.1 Scientific literature search

The scientific literature search followed the Preferred Reporting Items for Systematic Reviews and Meta-Analyses (PRISMA) methodology. Keywords and the search query were selected through brainstorming sessions with the authors. Terms including "Fast Healthcare Interoperability Resources (FHIR)" or "OpenEHR" were omitted because they represent solutions for solving interoperability issues and usually do not include specific systems as was the target of this review. Considering the novelty of sharing patient-collected data, only peer reviewed articles published after 2012 were considered. The following online databases were searched: Pubmed, ACM Digital Library, IEEE Xplore and Scopus. The search query has been adapted for each online database considering their operational functions and restrictions and was run using the metadata fields: title, abstract and keywords.

All scientific papers resulting from the database searches were imported into Rayyan (Ouzzani et al., 2016), a web

service allowing a structured review of titles and abstracts, which was used by the authors for improving collaboration and quality assurance of the process.

(EHR or "Electronic Health Record" or "Health System" or "Medical System" or "Health Information System" or CDS or "Clinical System" or "Clinical Decision Support" or "Clinical Decision Support System" or EMR or "Medical Records" or EJS or "Electronic Journal System")
and
(interoperability or communication or exchange or integration or collect* or transfer* or shar* or stor* or gather* or record*)
and
(wearable or mhealth or phone or apps or "Mobile health" or sensor)

Figure 1: Search query and keywords used for the scientific literature review

Two of the coauthors identified irrelevant articles using metadata fields while considering inclusion and exclusion criteria. The first author then reviewed the remaining articles for inclusion based on relevance of the full texts.

Inclusion and exclusion criteria

To be included in the review, the paper should describe a solution that facilitate a direct integration of patients' self-collected data into the healthcare system, pre- or at the point-of-care, or in real-time.

Studies are included only if they describe an evaluation, an implementation, a review, a working solution or prototype transferring patient self-collected data into medical systems, or are related to the security or privacy for accessing and managing the medical data self-collected by the patient by such system.

Studies that required healthcare workers to log onto a service outside their healthcare institution's EHR system in order to consult the data (e.g. a cloud-based data consultation service such as a Personal Health Record System (PHR) on Internet) were excluded. Several reasons justify this exclusion:

1. Healthcare workers are not willing to spend time to use separate Internet tools (Bradway et al., 2017).
2. The healthcare workers do not have knowledge of all relevant cloud-based or Internet-based solutions available, and how to use them (Bradway et al., 2017), and.
3. The data from such systems is usually not directly transmitted to the healthcare system (often the healthcare workers must take screenshots or copy the data into their EHR system manually).

However, studies including PHRs directly integrated within EHRs, were included, being part of the healthcare institution system.

In addition, the papers must describe data that is collected by the patient themselves using their own system, e.g. apps or sensor systems, which could be obtained from a

healthcare or a research institute. Studies relying on "collector agents", typically medical workers visiting patients at home for collecting data, were also excluded.

Data categorization and data collection

The information mined from the papers was organized into categories, defined by the authors through brainstorming sessions, and were used to present an aggregated overview of the current situation:

1. *Patient data sources:* systems, e.g. sensors, apps or aggregators, that allow patients to collect data themselves.
2. *Data collection:* whether data sharing required automatic or manual interaction from the patients or the medical workers.
3. *Patient data type:* whether the data collected from the patient is structured (e.g. measurements values with units) or un-structured (e.g. videos or general notes).
4. *Interoperability:* which standards the system is using for data transfer, representing clinical documents, and/or terminologies (e.g. SNOMED-CT). Note, again, that for this review, we focused only on interoperability between the patient system and the medical system.
5. *Security:* which security protocols or approaches have been followed for either collecting, sharing, storing or analyzing the data; for authenticating patients; or for ensuring privacy.
6. *System services:* the types of services, applications or state of development of the project (e.g. proof of concept, prototype, or commercial).

The evaluation and analysis were based on these categories and each paper is expected to fulfil at least one of them to be included.

2.2 Grey literature search

The search query (**Error! Reference source not found.**) was also applied to both the Google and Bing search engines. The same inclusion and exclusion criteria were applied, but was extended to different type of results, including webpages and business documents. The data categorization, data collection and literature evaluation followed the same procedure.

3 RESULTS

3.1 Combined reviews on literature

As shown in **Error! Reference source not found.**, 811 articles were identified from the scientific literature and 4 from reviews of commercial product and business reports. Eighty-three duplicates were identified and removed in Rayyan after importing the articles. Two of the co-authors reviewed the resulting articles' titles and abstracts independently based on the inclusion and exclusion criteria. Discrepancies (i.e. when articles were included by one author but excluded by the other) were resolved through discussion. In total, 682 articles were excluded, leaving 50 articles for full-text assessment. The first author

then identified n=40 articles for exclusion based upon the following reasons:

- Out-of-scope study or review (e.g. focus only on reducing latency between mobile phone and healthcare systems) (34).
- Inaccessibility of the full-text article (3).
- Inappropriate study objectives and methods: description or testing of a model for integrating self-collected patient data that does not have either a working prototype or any low-level description of such system for replication (2).
- Inappropriate technology usage, e.g. use of Short Message Service (SMS). This technology for chronic disease management restricts the patient regarding how they enter and exchange data (1).

At the end, 10 articles were included for final data collection.

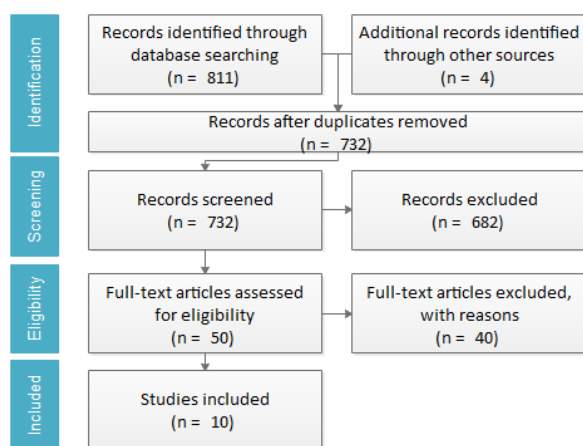


Figure 2: PRISMA flow diagram

3.2 Data Extraction from included articles

The evaluation and analysis of the included articles (Table 1) is based on the categorizations described previously in the methods section.

Functional solution

To the best of our knowledge, there were no standard and stable end-to-end systems permitting patients to share their own-collected data with EHR systems when this review was completed (April 2017). Eight of the papers presented a functional solution that described the design and usage of custom interfaces, Application programming interfaces (APIs), apps and/or restricted sensors in order to provide their services. Only three described an end-to-end system.

The closest solution to a fully operational system is the pilot described by Kumar et al. (2016), in which glucometer measurements were collected automatically by a specific IOS application, Share2, from the Dexcom G4 glucometer sensor worn by the patient. The data is then transmitted to HealthKit, then transmitted to the EPIC EHR system through MyChart app, a patient portal integrated with EPIC, to display data. This system requires explicit consent of the patient before allowing data transfer between the

HealthKit and MyChart. Unfortunately, this system includes some limitations:

- Time consuming: the one time setup requires to spend between 45 to 60 minutes in addition to the clinic visit;
- Performance issue: with up to 288 glucose readings per day, MyChart standard flowsheet was unable to visualize the patient trends over weeks to months and the MyChart app displayed errors and froze due to the high volume of data communication. These errors were fixed by limiting the import of data only from the preceding 24 hours and developing a custom web-service in the EHR system.

The second end-to-end system was a proof of concept (POC), described by Marceglia et al. (2015), where data was collected from an IOS app and sent to OpenMRS EHR through the Clinical Document Architecture standard (CDA), and using data related to heart failure. The opposite flow (from EHR to mobile app) was implemented as well. Unfortunately, this POC was validated using a simulated environment only.

The third end-to-end system, presented by Pfiffner et al. (2016), focused on gathering self-collected patient data for research purposes. To do so, the system relies on CTracker, an IOS created by this project, in combination with ResearchKit and Healthkit. On the medical side, the solution relies on the Informatics for Integrating Biology and The Bedside (i2b2), which is a research framework aiming to facilitate the design or tailoring of therapies and integrated in academic health centers. While i2b2 is not an EHR system, it is part of medical systems and therefore fulfills our inclusion criteria. Surveys and HealthKit data are collected. FHIR is used to manage the data exchange between all of these components.

Five articles dealt with systems that do not provide an end-to-end solution, but instead describe interfaces to missing components. For instance, the self-managed mobile personal health record system (SmPHR) described by Park et al. (2016) relies on the personal area network (PAN) and the wide area network (WAN) interfaces defined by the Continua standards to collect data from sensors and transmit them to health systems. Blood pressure, body weight, blood glucose and oxygen saturation are collected from sensors paired to the SmPHR and transmitted into a PHR. Other studies (Leijdekkers and Gay, 2015, Gay and Leijdekkers, 2015) describe the same smartphone application, MyFitnessCompanion, which aggregates fitness data from different online services (e.g. FitBit), Bluetooth Low Energy (BLE) and Universal Serial Bus (USB) devices and rely on other online services like HealthVault for *potentially* sharing data with EHR systems, using Health Level Seven (HL7) standard family for ensuring interoperability. The learning health system PORTAL (Young et al., 2014) relies directly on the EHR systems part of their network for gathering patient data which *could* be self-collected. The personal mobile health record system (PmHR) proposed by Song and Qiu (2016) relies on a PHR cloud solution for sharing data, using CDA documents in

combination with Snomed and Logical Observations Identifiers, Names, Codes (Loinc). Blood glucose, blood pressure, heart rate and heart rate variability, electrocardiography (ECG), weight, height and temperature are measurements used by the app.

On the 8 studies, 7 mention using apps as a source for data gathering, 6 reference using managers or aggregators, 5 declare using sensors. An EHR and a Cloud system are also mentioned 1 time each. The data collecting process is automatic in 7 cases, and none but one describes a required manual setup to access the services. The data collected is structured in 6 cases, unstructured in 1 and both in 1.

Security and privacy

Concerning the privacy, Hordern (2016) proposes an analysis of the protection of health data. According to this study, Health data is defined as personal data including *medical aspect of a person such as test results, doctors' notes, medical research* but as well as data collected by self-management sensors. However, a legal framework is lacking for Health data due to its diversity of services (e.g. smartphone apps, cloud, big data, and sensors). However, in a general approach, there are three requirements:

- Explicit consent from the patient to process health data, except if this data is necessary for carrying out obligations or in case of emergencies or medical diagnosis;
- A transparency notice informing the patient which, how and why the health data has been collected, and how it will be used;
- Full access to the health data collected, for allowing patients to consult and move data between providers.

The study also highlights the need to have controllers and processors. A controller is an entity which collects data for its own purposes (e.g. hospital) and is responsible for legacy compliance. A processor is a third party entity that uses personal information on behalf of the controller. This should comply with the controller instructions regarding health data storage and process, which requires a contract. This adds complexity: if the data is collected by a hospital directly from a patient, the hospital is a controller, in which case, it is straightforward to comply with the laws. However, in a situation where a sensor, an app, a cloud solution and an EHR are required to mutually share self-collected patient data (example described in the previous section), there are several unanswered questions: is the EHR, the app or the cloud service the controller and provider? Should all of these entities have a contract with the patient or merely between each-other? Should the end service (EHR) validate the whole exchange?

Concerning the security, Rubio et al. (2016) propose an analysis of and possible improvements for the security of the European standards regarding communications between medical, health care and wellness devices, sensors or systems (CEN ISO/IEEE 11073), especially involving personal health data (X73PHD). In our case, the highest level security described in this study corresponds

to our criteria: level annotated layer 2.5 and it describes solution *'intended for applications which may require integration with EHR systems [...] intended for patient remote monitoring, follow-up and laboratory-test'*. The study by Rubio et al. (2016) proposes the use of improved Integrating Healthcare Enterprise (IHE) profiles in 4 security-related categories: user identification, device identification and authentication, time coordination and encryption and proposes solutions and algorithms for doing so such as Twofish, RSA2048 or ECDSA256.

Considering that patient data could be stored on servers outside of the European Union (e.g. Healthvault or FitBit servers) and the huge amount of services/apps available, implementing a service for sharing self-collected patient data with EHR systems compliant with European privacy and security rules is extremely challenging.

Semantic interoperability

The semantic interoperability ensures that different systems are able to exchange, understand and analyze the data correctly by using standards for communication, medical representation (documents) and terminologies (Mead, 2006).

Among the previous 8 studies, 6 of them are describing the use of the HL7 family to ensure interoperability (4: CDA/ Continuity of Care Document (CCD)), 1: FHIR, 1: Continua WAN). Snomed-CT is described in 3 of them, 2 mentioned using the International Classification of Diseases (ICD), 1 Digital Imaging and Communications in Medicine (DICOM) and 1 LOINC. Surprisingly, there is no implementation of archetypes or the OpenEHR approach in these studies, even if there are mentioned (Marceglia et al., 2015).

However, using the same standard family is not enough for insuring interoperability, but the discussion is outside of the scope of this paper. None of the solutions described in the previous studies provide interoperability with each other's, and relies upon a custom approach as described in the previous section.

4 DISCUSSION

The focus on Decision Support Systems extracting data from patient self-collected health data systems and EHRs could explain the limited number of relevant papers identified in the scientific literature review (10 of 732), on top of the reasons cited in the results section.

Also, the trend of patients managing their diseases in the palm of their hands with health applications, e.g. PHRs, sensors and hacking commercial systems, which collect data without using proprietary solution, for privacy reason (Gay and Leijdekkers, 2015), is growing (Muzny, 2017). New sensors are developed and launched on the market at a more rapid pace than ever before, and more types of data can be used directly by patients. One example is Tytocare (<http://www.tytocare.com>), which is providing new sensors for examining the ears, throat, heart, lungs, abdomen, skin, and capturing heart rate and temperature. New open source operating systems for wearables and sensors such as Google Wear will also help standardize the

ecosystem and improve the semantic interoperability between components in the future. Even if there is no standard exchange between patients' self-collected data system and EHRs today, the authors believe this situation will evolve quickly. Businesses and researchers are more frequently acknowledging the new trend where patients are the center and key decision makers of their health services. This will lead to the design of new medical protocols and procedures in which patients are more empowered (Mantwill et al., 2015, Lamprinos et al., 2016). Additionally, businesses will increasingly shape their communication around the patients themselves (e.g. "With the Patient at the heart" catchphrase of EPIC Systems, <http://www.epic.com>). Even legal authorities are aware of these evolutions, but have not yet been able to provide an operational legal framework for the security and privacy for protecting patients and health institutions. It is also necessary to protect such systems against data forging (Hordern, 2016), which could lead to medical errors, and hacking of wearables, and subsequent risks to patients including death in certain circumstances (Halperin et al., 2008).

5 CONCLUSION

Our findings indicate that there are no standard and stable end-to-end system permitting the sharing of patient-collected data with EHR systems when this review was completed (April 2017). We suggest that this may be due to:

- Business models that currently only describe closed, proprietary and custom applications, interfaces and protocols;
- A lack of legal framework concerning the security, privacy and transparency of systems dealing with self-collected health data. The European General Data Protection Regulation (GDPR) can provide partial answers to the questions cited in the results section, but will not be enforced before next year;
- The complexity of integrating international and external aggregators or applications in such system, and the complexity of assuring a semantic interoperability between all actors;
- The large amount of patient-collected data that require more coordinated and efficient ways of analyzing and following up this new type of information.

However, the variety of data collected from sensors and wearable is expected to be important, from fitness activity to more advanced medical data such as ECG and blood values (glucose, lipids, etc.). Patients can now buy more and more sensors, which are not just limited to activities trackers and smartwatches anymore, but include a wide range of exotic solution like e-clothes (e.g. smart-bras, smart-socks, smart-caps) and medical sensors such as HRMs or CGMs. Unfortunately, most of the businesses manufacturing these sensors close their solutions using private protocols and standards forcing patients to use their in-house developed applications to consult the data. This has led to a situation where patients are not waiting

for the businesses to open-up anymore, and hack the protocols to extract, share and use the data the way they find to be the best for their health challenges.

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Acknowledgement

This work is supported by the Research Council of Norway (through the project "Full Flow of Health Data Between Patients and Health Care Systems", project number 247974/O70) and the Norwegian Centre for E-health Research through the Data Exchange project, a collaborative project with The Norwegian Directorate of eHealth .

Ref.	Data Sou. *	Data Coll. **	Data Type ***	Interoperability	Security Privacy	System
(Song and Qiu, 2016)	App	Aut.	S U	CDA, SNOMED, ICD-10, DICOM		Personal Mobile Health Record (PMHR)
(Rubio et al., 2016)	App, Man			ISO11073, X73PHD, HL7	Twofish, RSA2048, SHA512, RIPEMD256, ECDSA256	
(Pfiffner et al., 2016)	App, Man	Aut.	S	FHIR	OAuth2, AES 256, PKCS7, UUID, Explicit consent	End-to-End Research (ResearchKit, HealthKit i2b2)
(Park et al., 2016)	App, Man, Sen	Aut.	S	Continua-based	Continua-based	Self-management Mobile Personal Health Record
(Kumar et al., 2016)	App, Man, Sen	Aut. Man.	S	CCD-HealthKit	Explicit consent	End-to-End (Epic HER, HealthKit, Share2)
(Horder n, 2016)	App, Man, Sen, Cl				Transparency disclosure, Explicit consent, data access	
(Marceglia et al., 2015)	App	Man.	S	CDA2, SNOMED, LOINC	De-identified data, XPHR	End-to-End POC (OpenMRS, IOS app)
(Leijdekkers and Gay, 2015)	App, Man, Sen	Aut.	S	HL7 (CDD-HealthVault)	OAuth2	Android App (Healthvault, Google fit, Fitbit, Jawbone, Withings)
(Gay and Leijdekkers, 2015)	App, Man, Sen	Aut.	S	HL7 (CCD-HealthVault)	OAuth2	Android App (Healthvault, Google fit, Fitbit, Jawbone, Withings)
(Young et al., 2014)	Ehr	Aut.	U	CESR CDM, SNOMED, ICD		Portal network member

Table 1. Papers included in the review ordered by date.

*Patient-data source: App=mobile applications, Man=Managers/aggregators, Sen=Sensors, Ehr=EHR, Cl=Cloud. **Data collection: Aut=Automatic, Man=Manual. ***Patient data type: U=Unstructured, S=Structured. Empty field means the subject was not described in the paper.

Infrastructure for the Learning Healthcare System: Centralized or Distributed?

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Abstract

The learning healthcare system ideas brought novel approaches to knowledge generation and adoption in healthcare. High focus on data created in routine practice highlighted the underexplored potential for quality improvement, cost reduction and personalized care. While the high-level goals promise major improvement in healthcare delivery worldwide, it is less clear how such practices should be implemented and maintained. Technical infrastructure to ensure data access and processing capabilities is the initial building block enabling agile learning from practice. Selection between distributed data processing network and centralized repository as a fundament for the learning healthcare system has implications to further development of the system and its utility. This paper contrasts two architectural patterns and highlights their advantages and limitation to serve data access and processing needs in the learning healthcare. It provides comparative insights in decision making and assists in selecting an approach for implementation.

Keywords

Learning healthcare systems, centralized, distributed, architecture, data reuse, infrastructure, primary care.

1 INTRODUCTION

Evidence based medicine (EBM) has left its footprint in modern healthcare by developing new research methodologies, building novel knowledge bases to be implemented in clinical care and increasing scientific publication standards. However, overwhelming amount of evidence in a form of scientific papers and slow adoption of knowledge in practice were identified as major limitations of EBM (Greenhalgh et al., 2014). It is shocking that the average duration of implementing research knowledge in clinical practice may span to 17 years (Morris et al., 2011). This finding gave an impetus for a novel approach to knowledge creation and adoption in healthcare – the Learning Healthcare System (LHS) (Institute of Medicine (US) Roundtable on Evidence-Based Medicine, 2007).

Since the first time mentioned in 2007, LHS attracted major attention in academia worldwide. The conceptual ideas were further developed with increasing expectations that the continuous loop of data-knowledge-clinical practice will change knowledge generation in medicine as we know it. Faster progression of research knowledge into practice, improved adaptation to individual patient needs, delivering personalized care, better balance in resource and costs utilization are major promises making LHS a preferred future direction for healthcare (Institute of Medicine (US) Roundtable on Evidence-Based Medicine, 2007). However, after ten years of global effort, we are not

much further compared to where we started. Even though the limitations in healthcare delivery are often clear, implementing changes still takes long. A recent review on LHS implementations confirmed it by identifying a relatively low number of attempts to implement LHS in practice. While the expectations in LHS are high, little is done to actually adopt LHS practices in reality (Budrionis and Bellika, 2016).

Lacking guidance on the infrastructure development was identified in the review. It is not yet clear whether LHS infrastructure should work as a distributed computation network (Figure 1A), analyzing health data close to real-time or a centralized repository (Figure 1B) accumulating data from various sources and making it ready for statistical analyses. The reviewed LHS instances divided almost equally when selecting their approach to the technical architecture (6 – distributed, 7 – centralized) (Budrionis and Bellika, 2016). Since both approaches have their strengths and weaknesses, this paper aims to compare them providing comprehensive argumentation for future development to enable an informed decision when choosing between the centralized and distributed LHS architectures. This paper looks into fundamental factors differentiating both approaches and present a comparative analysis based on predefined metrics.

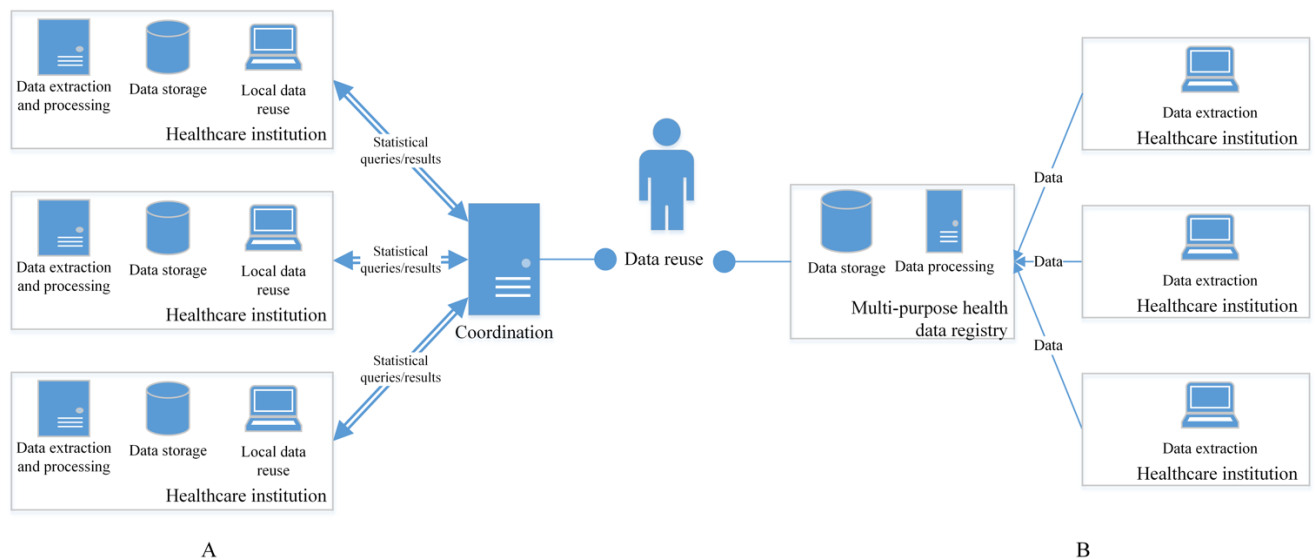


Figure 1 infrastructure for the LHS. A - distributed, B - centralized

2 MATERIALS AND METHODS

To compare the distributed and centralized LHS infrastructures an analysis framework was established. It originates from personal experience in building a distributed LHS infrastructure in Norway and combines characteristics, which were identified as important in this process. Centralized infrastructure refers to clinical data repository or registry, accumulating large amounts of data from various sources (Figure 1B). For the purpose of comparability, we assume that centralized system has the same data refresh rate as distributed one and does not store patient identifiable information. Moreover, unlike the national health registries¹, centralized LHS infrastructure is assumed to accumulate broad spectra primary care data without focusing on a certain use case (for instance, cause of death registry).

Distributed architecture functions as a network of computational nodes processing patient data locally in healthcare institutions and only sharing final results (Figure 1A).

Seven comparison areas were analyzed, giving a deeper insight in both architectural patterns. Data access and timeliness (1) was regarded as the fundamental piece of functionality fulfilling the main requirements for the LHS infrastructure. Capacity of statistical analyses (2) defines the potential of data reuse and ability to provide proof for behavior change in healthcare, while having sufficient measures to ensure patient privacy and data security (4). Having control over data (3) is of high importance,

especially in primary care, where clinicians have an ownership relation to patient information they are

collecting. Quality of data and its utility (5) in knowledge generation needs to be maximized together with the availability (6) to ensure sufficient feedback to the parties contributing to the overall system. Ability to integrate knowledge bases across borders (7) needs to be evaluated with regards to the legal frameworks and architectures for supporting the evolvement of the LHS. The aforementioned criteria define the comparison framework, which is explored in the remainder of this paper.

3 RESULTS

3.1 Data access and timeliness

Access to data is the main prerequisite enabling continuous LHS loop. Routine data is the source of knowledge for quality improvement and performance monitoring, therefore accessing it in a timely manner is a natural starting point when adopting LHS in practice. A traditional data access approach leveraging the long lasting experience is a centralized data storage. Clinical data is transferred and stored in a centralized repository at predefined time intervals, often as seldom as once every few years. Referring to the assumption made in Method section, data refresh rate is expected to be the

¹ <https://www.fhi.no/en/hn/health-registries/cause-of-death-registry/about-the-national-health-registries/>

same on both centralized and distributed architectures, therefore it is not highlighted as disadvantage.

On contrary to centralized data storage, distributed access to data implies no movement of data from the location it is collected. Data processing capacity is moved instead, implying access to close to real-time data. In other words, the infrastructure is a network of computational nodes, performing statistical computations on local data and aggregating the results. In this hypothetical case of equivalent data refresh rate, data access properties are comparable on both approaches. However, requirements for availability and reliability of the overall system are higher for distributed architecture to ensure sufficient coverage of data sources (discussed in section Data availability).

3.2 Capacity of statistical analyses

LHS is built on the idea of extracting knowledge from data. Therefore, the capacity of available statistical analyses is of high importance for achieving the goals of the LHS. Centralized data storage, in this case, does not have limitations with regards to methods, techniques and algorithms. Established data processing and analysis tools could be chosen based on personal preferences and results of the calculations can be reproduced at any time.

Distributed data analysis counts on distributed statistical processing algorithms, which are often referred to as research initiatives rather than established data processors (Asfaw Hailemichael et al., 2015; Bellika et al., 2015; Yigzaw et al., 2013). The availability of supported statistical functions is currently limited, however, it is improving and more off-the-shelf tools will likely become available in the future. Major limitation of distributed data processing is the lacking ability to explore data and verify the correctness of computations. Moreover, reproducing results from previous computations may be complicated due to changes in data and availability of the processing nodes.

3.3 Control over data

Care providers have the responsibility of ensuring secure management of patient data. Norwegian primary care consists of a large number of relatively small GP offices, running their EHR systems locally or hosted by municipality. Therefore, GPs often have a special ownership relationship to the data they are collecting. Having all data locked up in a server room gives a feeling of control over sensitive information and helps implementing security measures. Regardless of the aforementioned attitude, patients are data owners, currently having limited or no control over their personal information accumulated by healthcare services.

Getting access to such data for research is often a difficult process highly dependent on the willingness of GPs to collaborate. Moving data from EHR to a research repository (registry) for a GP means losing control over patient information, which could later be used for various purposes (for instance, monitoring the performance of a certain GP). On the other hand, distributed data

processing infrastructure ensures that patient data does not leave the institution it was generated and is only used in computations. Only the final product is then shared across institutions, protecting the privacy of both patient and GP. In this case GPs maintain the ownership of the data while enabling research and quality improvement activities. Moreover, distributed infrastructure ensures the ability to opt out of the network at the same time revoking access to data without involving infrastructure administrator or leaving any data trace.

3.4 Patient privacy and data security

Health data breaches are becoming a major threat to patient data security. Number of incidents and severity is increasing as reported in the American Health Information Breach Portal (U.S. Department of Health and Human Services, Office for Civil Rights, n.d.). Sixteen percent of reported incidents are caused by hacking or related to security of IT systems, however, they are responsible for health data losses of 79% of the population affected by incidents of handling health data from 2010 to 2016 (U.S. Department of Health and Human Services, Office for Civil Rights, n.d.). Similar trends are likely in other developed countries, highlighting that data security in healthcare sector is not managed well enough. This fact needs to be kept in mind when selecting the design approach for the LHS.

The level of sensitivity of health data needs to be assessed when deciding what data should be available for the LHS. Direct patient identifiers (personal number, phone number, etc.) can be replaced or hashed, however, reidentification risk still remains, especially in cases of rare diagnosis/symptoms and small patient communities.

Selection of data access and processing infrastructure plays a role in ensuring the security of patient data. If we define the risk as a product of likelihood and consequences, it is clear that centralized data storage, accumulating all data has higher security risk profile than distributed infrastructure. The consequences of a data breach in an infrastructure containing data for the entire population are catastrophic. An equivalent data breach in a distributed infrastructure implies getting access to every node in the system, containing a small fragment of the entire dataset stored centrally. The likelihood of compromising all nodes in the network is very small.

3.5 Data quality and utility

To preserve patient privacy, compromises on data quality and completeness need to be made. This process is more evident in a centralized architecture where access to the extracted data is available to the users. Data exploration step raises major security threats and may require information, which does not identify the patient directly, but could be used to find out the identity, to be excluded (for instance, zip code could be sufficient to identify a person having a rare condition). Relations between data variables could provide insights into the identity of the patient. Excluding all data, which potentially identifies the

patient (directly and indirectly) threatens the utility of the dataset.

The lacking direct access to raw data in a distributed architecture for data processing could be seen as an advantage from patient privacy and data quality point of view. Relatively few patient identifiers need to be excluded, maximizing the utility and maintaining higher quality of the available data.

3.6 Data availability

Referring to the assumption made in the Method section, data refresh rate is kept equivalent on both data processing approaches. Regardless of the selected infrastructure, data availability comprises of two steps: data supply from EHRs and availability of extracts to statistical analyses. Ensuring reliable data collection from EHRs may be challenging due to varying network infrastructure, power outages and human factors. However, this step is equally challenging in both approaches, while the complexity of the next one depends on the selected architecture. Many techniques and tools exist for delivering high availability of a centralized system populated with data. It is, however, often complicated to reach high availability in a distributed infrastructure where data extracts are also distributed and every node needs to be highly available for data processing. On the other hand, in many cases data processing does not need to be performed at the exact moment, when the query is created. Tasks targeting certain nodes could be pooled until expected coverage is reached and results for the available network is computed. It could minimize data availability concerns in the distributed architecture scenario.

3.7 Cross-border coverage

Expanding the scope of the LHS across region/country borders or linking several national LHS is an important functionality in a long-term development of the health data reuse infrastructure. It may be more relevant for systems covering relatively small populations to maximize the number of cases, especially for rare conditions. Legal obstacles often arise when trying to create such knowledge bases.

It could be rather complicated or in some cases impossible to reach international coverage of the LHS using centralized data reuse infrastructure. Varying legal regulations regarding privacy preservation in patient data need to be addressed and finding a compromise could easily become a long and cumbersome process requiring changes in legal requirements in all participating countries. Storage of such information outside the country of origin is a known restriction without a clear solution.

Distributed LHS infrastructure may be seen as a solution addressing the aforementioned challenges. It assures, that patient data does not leave the country of origin, voiding many of the legal barriers. Regardless of the easier adaptation to the existing legal frameworks, many problems related to data interoperability, management of

the infrastructure, sustainable funding and other aspects need to be addressed.

4 DISCUSSION

The comparative analysis summarized strong and weak points of choosing distributed or centralized architecture for implementing the LHS. A brief list of summary points is represented in Table 1.

Table 1 provides argumentation why making a choice between the two approaches is a complex task, as it was indicated in a recent review on the implementations of the LHS (Budrionis and Bellika, 2016). Both approaches have their advantages and limitations, which could have different weights depending on the legal framework the system is implemented in, experiences with health data reuse and other factors. Even though ensuring the privacy of patient data should be the highest priority, it also minimizes the utility of data and could even lead to misleading results (Tucker et al., 2016). It calls for research and development of novel techniques for privacy preserving data processing.

Criteria	Distributed	Centralized
1. Data access and timeliness	+	+*
2. Capacity of statistical analyses, trust in results	-	+
3. Control of data	+	-
4. Patient privacy/data security	+	-
5. Data quality and utility	+	-
6. Data availability	-	+
7. Cross-border coverage	+	-
Sum:	5+, 2-	3+, 4-

Table 1 Comparison of distributed and centralized data processing architectures for LHS (+ indicates that the infrastructure is sufficient for addressing the needs of the LHS, - lacks support to meet the requirements of LHS, * marks cases dependent on assumption of equivalent data refresh rate made in the Method section)

Assumptions made in Method section ensured that narrow purpose health registries were not included in the comparison due to their different function, which does not fit into the agile nature of the LHS. Instead, a multipurpose data storage was used in the comparison, meeting the requirements for establishing the LHS and highlighting the implications of centralized and distributed data processing. A term multipurpose in this context represents the potential utility of data to deliver benefits to various stakeholders. Such benefits should not be solely focused on clinicians in return to their data contribution or governmental bodies financing the initiative. The aforementioned assumptions made a centralized data storage a comparable counterparty, however, it is not yet clear how such information resource should be built and

maintained. There are many unanswered questions in large-scale distributed architecture as well, however, in a long run it has the potential to address all anticipated data reuse needs and overcome the bottlenecks of the centralized systems (Brown et al., 2010).

This paper has not looked into the potential of “hybrid approaches” combining the strengths of both distributed and centralized architectures. Centralization could be performed at various levels (for instance, commune), while keeping the advantages of distributed architectures in higher levels. Such choice would potentially increase the complexity of the overall system, but could contribute to addressing the weaknesses of both architecture choices summarized in Table 1. This approach calls for more research evaluating its feasibility and potential benefits.

5 CONCLUSIONS

This paper looked into the advantages and limitations of distributed and centralized health data processing infrastructures to support the development of the LHS. It provided argumentation for making the decision between the two architectures. The conclusions of the comparison were consistent with the findings of a recent literature review (Budrionis and Bellika, 2016) and global development in the field. A straightforward clear-cut answer to the question “distributed or centralized?” does not seem to exist and many important aspects need to be considered in the decision process.

Several discussed criteria were in favor of the distributed data access and processing architecture as a fundament for the LHS. Capacity of the available statistical methods, trust in the results and data availability were regarded as major limitations (Table 1), however, even more weak points were identified in the centralized approach. It calls for research to address the deficiencies of both approaches to meet the requirements of the LHS infrastructure better.

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7 ACKNOWLEDGEMENT

This research was funded by a grant from the Research Council of Norway to the Norwegian Centre for E-health Research, University Hospital of North Norway. Grant number 248150/O7

A Significant Increase in The Risk for Exposure Of Health Information In The United States. Result from Analysing the US Data Breach Registry

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Abstract

The study surveys the probability and consequences of protected health information (PHI) data breaches. We analysed the development of data breaches in the US data breach registry available online in 2010-2016 by focusing on two PHI breach categories: theft and loss, and hacking and unauthorised use. 79% of all analysed PHI breaches was the result of hacking or unauthorised use versus 19% caused by loss or theft. Totally over 171 million persons were affected by PHI breaches during the analysed period, which corresponds to 54% of the US population. On average, 4.6 million persons are annually affected by theft or loss of PHI versus 19.4 million affected by hacking and unauthorised use of PHI. The number of hacking attacks increased by 15 times from 2010 to 2016. The largest single loss of PHI so far is 78.8 million records. The analysis has shown the risk of PHI breaches in the US is high and significantly increasing. In Scandinavian settings, such a risk would imply measures to reduce both probability and consequence of breaches.

Keywords

Computer Security, Cybersecurity, Risk Assessment

1 INTRODUCTION

Risk is a measure that combines the probability and impact of an undesired event ("ISO/IEC 27005 risk management standard," n.d.). In risk analysis, risk can be estimated by computing the product of the probability that the event will occur and the consequence of the event: $\text{risk} (x) = \text{probability} (x) \cdot \text{consequence} (x)$. In addition, in risk analysis, consequence and probability are normally divided into specific categories, which provides the basis for graduation of risk levels. Estimates of risk levels form the basis for the evaluation of measures to reduce the risk.

One way of estimating the consequence of an event, is to look at the number of persons affected by the event. Normally, the more people affected by an undesired event, the more severe the consequence of the event will be, given that other aspects of the unwanted event are kept constant. Another approach could be to take into consideration the degree of sensitivity and amount of information exposed. For instance, the risk matrix used by Sykehuspartner, one of the regional health authority information technology support institutions in Norway, grade consequence from catastrophic to small consequence (HSØ RHF, 2017). Similarly, the frequency of an event is a way of classifying the probability of an event. If an event occurs every fifth year, it is less likely than events occurring weekly or daily. According to ("ISO/IEC 27005 risk management standard," n.d.), likelihood must be classified into distinct categories, for instance ranging

likelihood from very unlikely through very high or frequent.

The combination of probability and impact can be expressed in a risk matrix as shown in Figure 1.

		Likelihood of incident scenario				
		Very Low (Very Unlikely)	Low (Unlikely)	Medium (Possible)	High (Likely)	Very High (Frequent)
Business Impact	Very Low	0	1	2	3	4
	Low	1	2	3	4	5
	Medium	2	3	4	5	6
	High	3	4	5	6	7
	Very High	4	5	6	7	8

Figure 1. Example of risk matrix from ("ISO/IEC 27005 risk management standard," n.d.).

Risk could then for example be classified into the levels of low (0-2), medium (3-5) or high (6-8) risk.

The combination of a frequent event with very high consequences would imply maximum risk (8 in the example above). No health IT system should pass a risk analysis stage that involves maximum risk. Such a system should never make its way into production and usage by health personnel or patients.

In the United States, breaches of privacy in the health sector, which are regulated by the Health Insurance Portability and Accountability Act (HIPAA) ("Privacy | HHS.gov," n.d.), are reported to the U.S. Department of Health and Human Services, Office for Civil Rights. Events that represent a breach of this Act and involve more than 500 persons, are published in a breach registry on the

Department's Breach Portal ("U.S. Department of Health & Human Services - Office for Civil Rights," n.d.).

Liu et al. analysed the US Department of Health and Human Services data breach registry for the years 2010 to 2013 (Liu, Musen, & Chou, 2015). Liu et al. identified 949 breaches affecting 29 million records. Six of the events involved more than 1 million records. Lui et al. expressed concern for the increasing number of data breaches involving cloud based systems.

While the National Institute of Health in the US allows the use of cloud computing services for storage and analysis of genomics data sharing ("NOT-OD-15-086: Notice for Use of Cloud Computing Services for Storage and Analysis of Controlled-Access Data Subject to the NIH Genomic Data Sharing (GDS) Policy," n.d.), Filkins et al. provides a long list of advices on how a medical researcher can ensure that the cloud service provider is able to provide the necessary information security measures. At the same time, the authors note that "cloud computing represent significant unknowns, such as lack of direct control over hardware and software, lack of visibility into audit/system activities, physical location of data, and impact of different jurisdictions where the data may be held" (Filkins et al., 2016).

In May 2017, an incident occurred in Norway when a major health trust had to revoke privileges granted to employees of an international company. The employees of the international company should not have been granted access to patient data on 2.3 million Norwegian citizens, as the data was accessible to the employees globally [6]. Whether similar incidents have occurred in the past is unknown, since Norway does not currently have a publicly available data breach registry accessible to researchers.

As we do not have a breach registry available in Norway, one possibility to assess the risk for health-related data is to make estimations of probability and consequence based on data breaches registered in the publicly available US data breach registry. However, the remaining unresolved question then is whether the information security situation in Norway is comparable to the situation in the US.

2 MATERIALS AND METHODS

To survey the probability and consequence of the breaches to information security, we analysed the data from the US Department of Health and Human Services Breach Portal ("U.S. Department of Health & Human Services - Office for Civil Rights," n.d.). As stated on the Breach Portal site, "as required by section 13402(e)(4) of the HITECH Act, the Secretary must post a list of breaches of unsecured protected health information affecting 500 or more individuals". First PHI breaches on this portal were registered in October 2009.

To have comparable periods with full years of available data, we downloaded and analysed the reported breach events in the US health sector for the period 1st of January 2010 to 31st of December 2016 amounting to 1780 registered events. According to the Breach Portal, all

attacks on protected health information can be roughly divided into several categories, such as 1) hacking/IT incident, 2) unauthorised access/disclosure, 3) loss, 4) theft, and 5) improper disposal. We grouped the identified breaches into two higher-level event categories: 1) physical theft and loss of PHI, and 2) hacking and unauthorised use of PHI. We compared breach events frequency for the years 2010 to 2016. Further, for the analysed period, we compared cyber theft (hacking and unauthorised use of PHI) and physical theft (physical theft and loss of PHI) in terms of 1) number of PHI breaches annually, 2) shares of breach events of both categories in percentage of total number PHI breaches annually, and 3) number of individuals affected by PHI breach events annually.

However, the information about the types of the health information affected by each breach event was not provided on the US Breach Portal, which could influence the conclusions about the PHI breach risk consequences. Also, the breach registry do not contain a systematic grading of the sensitivity of the information exposed, which could have been used as input to estimation of consequence of the breaches.

3 RESULTS

According to data reported to the Breach Portal between 1st of January 2010 and 31st of December 2016, protected health information for 171,074,016 persons was exposed. Although some may have had their health information exposed more than once or have health information in several health care institutions (Liu et al., 2015), this indicates that approximately 54% of the United States population of 318.9 million have had their protected health information exposed.

This number includes 135,775,362 persons who have been affected by hacking or unauthorised use of protected health information, and 31,908,209 persons affected by theft or loss of PHI during this period. On average, protected health information for 19,396,480 persons has been affected by hacking or unauthorised use annually. However, this number is heavily affected by a single event where 78.8 million health records were exposed in a single event. Excluding this event, the average yearly expose was 8,139,337 persons affected by hacking or unauthorised use of PHI.

As a comparison, 4,558,316 persons were affected by theft or loss of protected health information. This means that in the period from 2010 until the end of 2016, the probability of being exposed by cyber theft was 4.26 times larger compared to physical theft.

The distribution of observed breaches presented in Figure 2 shows that 52% of the events were classified as hacking or unauthorised use. Theft and loss of data accounted for 42% of the data breach events.

The number of events in the category hacking or unauthorised use of PHI increased from 16 cases in 2010 to 240 cases in 2016. During the same period, the number of cases of thefts or losses decreased from 154 to 78, as

shown in Figure 4. As Figure 3 shows, the average number of protected health data breaches per day in the United States in 2016 was 0.89. This means that on average a breach of privacy regulations occurred more often than every second day.

The graph in Figure 5 shows the relative frequency of theft/loss and hacking/unauthorised use incidents as a percentage of all attacks on protected health information annually in the period 2010-2016. There is a steadily increasing trend for hacking and unauthorised use, and a decreasing trend for theft/loss incidents. In 2016, for instance, 10.3 times as many persons were involved in hacking/unauthorised use of health information compared to theft/loss.

Figure 6 shows the development of number of individuals affected by PHI breach incidents. From 2013, we see a rapidly increasing trend (dotted blue line) in number of individuals affected by hacking and unauthorised use of their health information. The historical development in number of this type of breach events (shown in Figure 4) is also increasing.

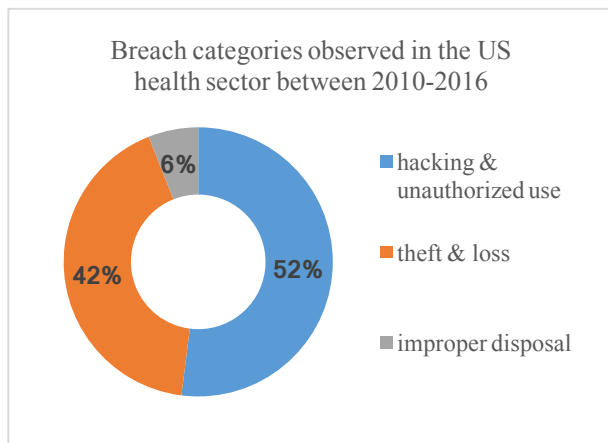


Figure 2. Observed health data breach categories.

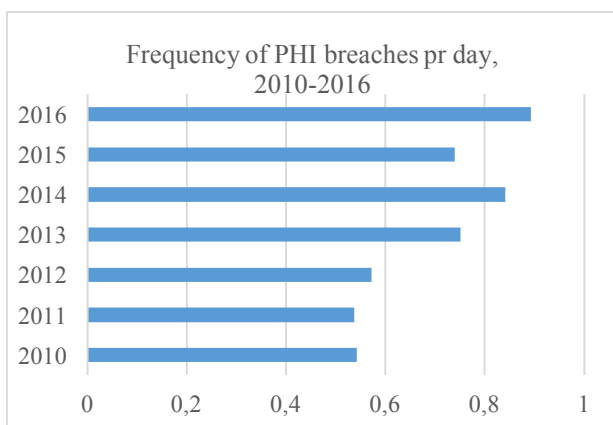


Figure 3. Frequency of PHI breaches per day for the years 2010 to 2016.

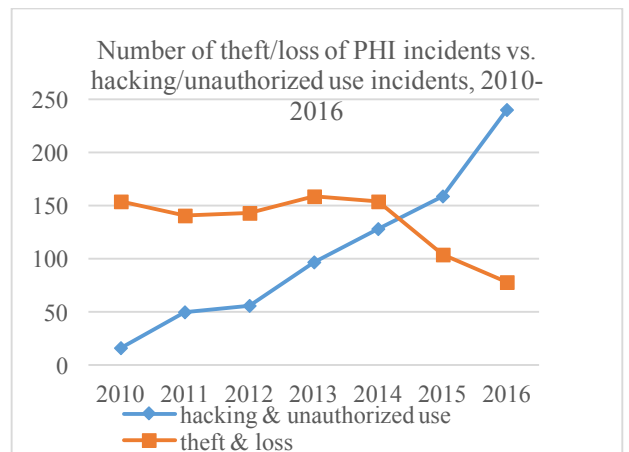


Figure 4. Historical development in number of PHI breaches for the years 2010 to 2016.

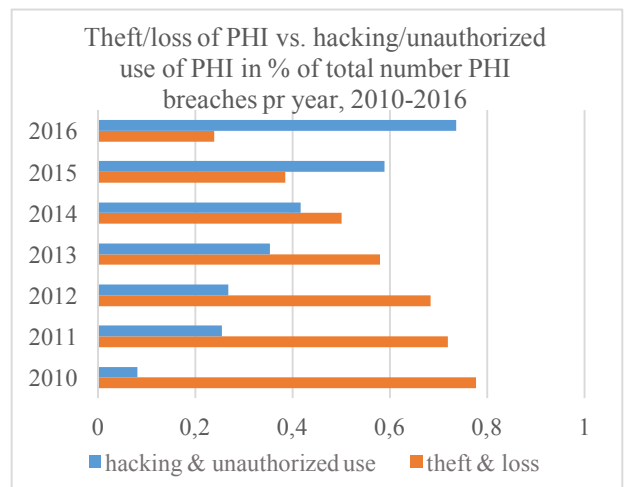


Figure 5. Historical development of the distribution of PHI breach categories for the years 2010 to 2016.

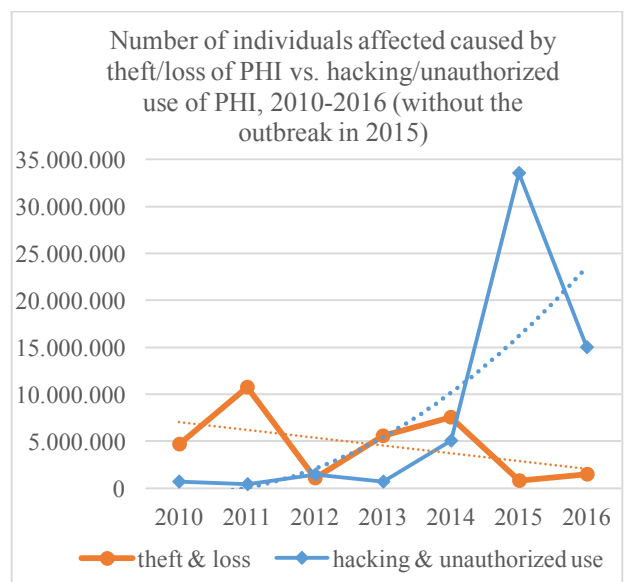


Figure 6. Historical development of number of people affected by PHI breach events for the years 2010 to 2016, excluding the event involving 78.8 million records affected in a single breach in 2015.

This trend corresponds to the increasing use of electronic health record systems in the US, as predicted by Lui et al.

At the same time, the trend for theft and data loss (dotted orange line in Figure 6) is decreasing. Based on the data reported to the US Breach Portal, hacking or unauthorised use of protected health data have to be defined as highly likely events. For the consequence measure, the annual average number of individuals affected is more than 12 million citizens, which is, using a conservative estimate, more than twice the size of the population in Norway, every year. And, the trend for number of persons affected by hacking or unauthorised use of protected health data (shown in Figure 6) is increasing.

4 DISCUSSION

Lessons learned by analysing the US data breach registry are twofold. First, a data breach registry is a very good tool to uncover and follow the development of PHI breaches across time. It provides a resource available to both patients, researchers, media and health IT managers to uncover the true probability and consequence of data breaches. Without a systematic approach to handle the reality of cyber security and failing to implement prevention measures, more data breaches may occur. Therefore, Norway should as soon as possible establish a publicly available data breach registry following the model established in the US.

The second lesson learned by analysing the data in the US data breach registry is the estimation of risk for PHI breaches we currently experience. In the United States, it is currently high, and it is increasing. If the situation in Norway is comparable, it is alarming, and measures should be implemented to protect the privacy of Norwegian citizens.

While the true risk for data breaches in Norway is currently unknown, Norwegian national health authorities are making health data about every citizen in Norway available through national web portals. A single data breach of these systems may expose sensitive health information about the majority of the Norwegian population. The decision on exposing the Norwegian population to this data breach risk has been taken without asking each individual whether they want or need to have their health records available online.

If we hypothetically assume that the risk for data breaches in Norway is high, what risk treatment can be taken to reduce the risk for data breaches to Norwegian citizens' health records? According to ("ISO/IEC 27005 risk management standard," n.d.), we can do risk modification, risk retention and risk avoidance. First, we can try to build security barriers that prevent breaches from happening. Secondly, we can do risk avoidance by reducing the consequences of data breaches. This can be done by decreasing the number of persons affected, if a data breach should occur. Alternatively, we can do risk retention by making the population to accept the risk of data breaches. This can be done by asking everyone to consent to have their data exposed to the risk of data breaches or switch to an opt-in solution where the citizen must actively ask for data to be available. As is, the current risk for data breaches may very well have consequences

for the relation between patients and health workers by patients withholding sensitive health information, as noted by Blumenthal et al. (Blumenthal & McGraw, 2015) and many others. If a data breach to Norwegian national health data portals should occur, the consequences for the trust relation between the patient and health workers on one side and Norwegian national health authorities on the other will be severely negatively affected.

However, a longer historical perspective of analysed data from the US Breach Portal, together with the available types of accessed protected health information could influence the inferred conclusions about breaches of unsecured protected health information in the United States.

5 CONCLUSION

The review of the United States Breach Portal shows that the probability of PHI breaches is increasing, and is close to becoming a daily event. The extent or consequence of breaches also shows an increasing trend. In sum, this means that the risk of breaches to the privacy legislation for protected health information in the United States is very high and increasing. In Scandinavian setting, such a risk would require measures to reduce both the probability and consequence of breaches. The extent of breaches of privacy legislation causes concern among health professionals that patients will withhold health related information from health workers, and, thereby, undermine opportunities to improve their health, as well as health services (Blumenthal & McGraw, 2015).

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7 ACKNOWLEDGEMENT

We thank the Norwegian centre for e-health research for funding this study.

Innovative Simulation of Health Care Services in the Usability Laboratory

Experiences from the Model for Telecare Alarm Services-project

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Abstract

In Norway, a recent health reform urged municipalities to prepare for telecare alarm services to handle alarms associated to welfare technology and telecare technology in citizens' homes. That requires a re-organisation of health and social services in many municipalities and several are preparing to establish new telecare alarm services operated in inter-municipal response centres. In this context, the research project "Model for Telecare Alarm Services" aims to study how existing telecare alarm services in Norwegian municipalities are organised and operated, and identify critical factors when designing new models for future services. This paper presents how an innovative simulation of health care services was used in the research project, when key informants from several municipalities, research partners and industry tested different models of telecare alarm services in a usability laboratory. The lessons learned by the research group showed that laboratory simulation was an efficient way of testing different scenarios of new telecare service models, together with key informants from heterogenous end-user groups.

Keywords

Clinical Simulation, Usability Laboratory, Telecare Alarm Services, Health Informatics.

1 INTRODUCTION

Telecare technology has the aim to facilitate and support communication between citizens at their homes and services of health care [1]. Demographic changes, with growing number of elderly people in society, make telecare technology a potential aid to respond to this challenge addressing interdisciplinary cooperation across health care services [2]. The goal is to meet the special needs of older people and their families with an integrated and comprehensive approach, facilitating self-dependent living in own home as long as possible [3][4]. In Norway, the Coordination reform was adopted in 2012 [5], with the aim to improve continuity of care, coordination and collaboration across the traditional health services. Services that were traditionally provided by hospitals and specialized health care services, were transferred to primary care services. Because of the reform, municipal health- and social care services are now responsible for a 24/7 service in emergency health care (in Norwegian Kommunal øyeblikkelig hjelp), including a dedicated phone line service (116117). With the municipal focus on facilitation of self-dependent living, there is an increasing number of telecare- and welfare technologies dedicated to citizens' home. Due to this development, many municipalities are exploring how to establish a service for the management of alarms. More than half of the

Norwegian municipalities are categorised as small size (less than 5000 inhabitants), making it challenging allocating resources to run a 24/7 service. To optimise resources, many small and medium sized municipalities have established inter-municipal cooperation (IMC) to provide new services, which in many cases requires re-organisation of the health and care services.

In this context, the research project Model for Telecare Alarm Services aimed to evaluate and propose models for telecare alarm services in Norway. Two research institutions, 18 Norwegian municipalities together with a company were partners in the research project. The project lasted three years, from (2015 until 2017), with the purpose of studying the management and operation of existing telecare alarm services in Norwegian municipalities. Workshops were organised early in the project including health care professionals, administrators and operators from existing telecare alarm service with focus on challenges in the existing services. The workshops identified user needs and critical factors that are important to take into account when proposing and designing new models for the telecare services of the future [6][7][8][9]. In a later project phase, the industrial partner (Imatis) developed a prototype solution consisting of a smartphone application and an information system for management of a telecare alarms. During the process

Paper from the 15th Scandinavian Conference on Health Informatics SHI2017, Kristiansand, Norway, 29 - 30 August.

Conference Proceedings published by [Linköping University Electronic Press](#).

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of technology development, three clinical simulations together with project participants were performed in a usability laboratory. The scenarios simulated a home-based alarm and tested how the new technology could be integrated in different models for handling alarms by operators of telecare alarm services and municipal health care services.

Based on the conducted simulations in the usability laboratory, the research team reflected on lessons learned from the procedures. This paper reports the simulation procedures that were used in the Model for Telecare Alarm Service project. The following three research questions (RQs) were addressed:

RQ1: *What steps are relevant in the simulation of health care services for new telecare alarm service models in Norwegian municipalities?*

RQ2: *What procedures can facilitate the active contribution of end-user groups in health care service simulations?*

RQ3: *What methodological approaches and lessons were learned from the laboratory simulation procedures that can be applicable in other contexts?*

Following this introduction, an overview of related research is presented. In the consecutive section, the method and materials are explained, followed by descriptions of the laboratory simulation procedures. Later, the discussion reflects on lessons learned from carrying out the simulations during the project. Finally, the last section includes the conclusions and future work.

2 BACKGROUND

Laboratory simulation of new health care service models refers to testing of scenarios, workflows and technology in a simulated clinical environment [10]. Such simulation in real clinical environments is usually unsuitable for legal, ethical and privacy reasons [11]. In a laboratory setup for clinical simulation, participants are asked to perform a role-based scenario while being observed and/or recorded, commonly used in nursing education to allow students to learn and apply theoretical principles of nursing care in a safe environment [12][13]. This kind of simulations can be combined with a think aloud protocol [14] where the students are instructed to verbalise thoughts while completing tasks [15]. In the context of the development of health information technology, clinical simulation with end-users has the potential of providing an insight about how technology and alternative organisational models may impact on existing procedures and workflow in health care settings before final implementation and installation. Traditional usability testing is usually performed individually in a usability laboratory, often with a think aloud protocol with the aim of assessing the technology [16][17][18]. The approach of clinical simulation in the usability laboratory introduces the dynamics of clinical workflow, in addition to evaluating the technology. The combination of think aloud protocol and clinical simulation provides an assessment of how the technology and work processes would interact in a clinical

environment, allowing evaluation and redesign to augment clinical utilisation [19][20].

3 MATERIALS AND METHODS

The simulations of health care services in the *Model for Telecare Alarm Services* project were carried out as a realistic clinical situation in a usability laboratory together with project partners and end-users of the technology, applying a think aloud protocol. The scenarios were based on information gathered from previous workshops during the same project.

3.1 Test Environment Settings

The simulations were executed in the usability laboratory of the Centre for eHealth at the University of Agder, Norway. The usability laboratory consisted of four rooms, where three of them were used for the simulation: patients home, the telecare alarm service/response centre alarm operator room and the municipal nursing services, all with camera sources. A fourth room was the observation room where the observers could follow the simulation simultaneously on screens. Between one of the test rooms and the observation room, there was a one-way mirror that allowed the observers to closely follow the process and the technology interaction. The technical infrastructure for simulation has been further described in the research project [21].

3.2 The Research Team

The research team involved in the clinical simulation was composed of five people, see Table 1 for the participation in the different project phases. They had background from health informatics and human-computer interaction, all with working experience in health and technological environments. In addition, two senior researchers participated from the industry partner and research institute partner.

Researchers N=7	Sim 1	Sim2	Sim 3
Project leader and Professor	x	x	x
Associate Professor 1	x	x	
Associate Professor 2	x	x	x
Associate Professor 3	x		
Assistant Professor			x
Senior Researcher 1	x	x	x
Senior Researcher 2	x	x	x

Table 1 Participants in the Research Team

3.3 Participants

The participants in the clinical simulations were from the 18 Norwegian municipalities that were partners in the research project. The end-user groups were: nurses, assistant nurses, administrators, technicians, leaders and representatives from end-users. Simulation 1 had 25 participants, simulation 2 had 20 participants and simulation 3 had 16 participants.

3.4 Material

For replicability and information purposes, the technical material used during the simulations is presented grouped by rooms.

Test room 1 Patient's home

- GPS geolocation device for triggering alarm
- Fixed camera
- Boundary microphone

Test room 2 Telecare alarm service

- Laptop and desktops for the telecare alarm system
- Smart board display
- Portable camera
- Boundary microphone

Test room 3 Municipal nursing services

- Smartphone with the telecare alarm service application activated (and a tablet device)
- Fixed camera
- Boundary microphone

Test room 4 Observation room

- Desktop
- 4 monitors

Remote controller for fixed cameras

3.5 Data Collection

The simulations were audio-visually recorded. The recordings from the cameras were merged into one single video file using the software Wirecast v.4.3.1 0. Having all the camera perspectives merged in one file facilitated the data analysis, having one file with multiple video perspectives and one single audio channel.

3.6 Ethical Considerations

The Norwegian Centre for Research Data (NSD) 0 approved this study with the project number 44494. All participants received oral and written information about the project and they signed a consent form. Their participation was voluntary and they could withdraw at any time without any reason

4 THE SIMULATION PROCEDURE

Three simulations of health care were run in April, September and November of 2016. In each simulation, there were different role-based scenarios, each with a description of a context and a concrete situation to be handled. The roles were: a) patient at home triggering a



Figure 1. A group of four observers in the observation room

telecare alarm function, b) telecare alarm service operator, c) municipal home nurse on duty using a mobile device, d) observer in the observation room following the interactions. Each role was assigned a group of 2-4 participants/actors, and participants were distributed across the four test rooms together with a moderator from the research team.

In all the three simulations, the patient triggered an alarm at home that was sent as an electronic message with information to a receiver. Different models for receiving and handling alarms were tested with both a local telecare alarm service and regional response centre. In addition, automated routing with notification to municipal home nursing services was tested. Upon an alarm, a two-way voice or a video-voice channel was established with the patient. All sharing of information between telecare alarm service and home nurse was made electronically. The information flow and the interactions required between the participants' roles were specially taken into account for further analysis. Three test rooms were used simultaneously, with interactions through technology between the rooms, observed by a group in the observation room, see Figure 1.

4.1 Simulation 1

In the simulation 1, a prototype version of the telecare alarm service information system and the corresponding app were used, based on low-fidelity software such as mock-ups of an early prototype, that described predefined steps in the scenario, see Figure 2. During the scenario, the screen/UI was changed by instructions from the moderators, who used a chat-channel in order to synchronise the roleplay screenshots for each actor.

The context was a patient in the test room *Patient's home* fell on the floor, triggering an alarm with the GPS geolocation device. Three scenarios representing different models for handling the alarm were tested.

In the scenario 1, the alarm was registered at the *Municipal nursing services*, where the nurse on duty accepted the alarm and visited the patient's home. The patient's family was contacted to follow-up the situation.

In the scenario 2, the triggered alarm had automatic notification directly to the *Telecare alarm service* which was assumed to be co-located with emergency primary

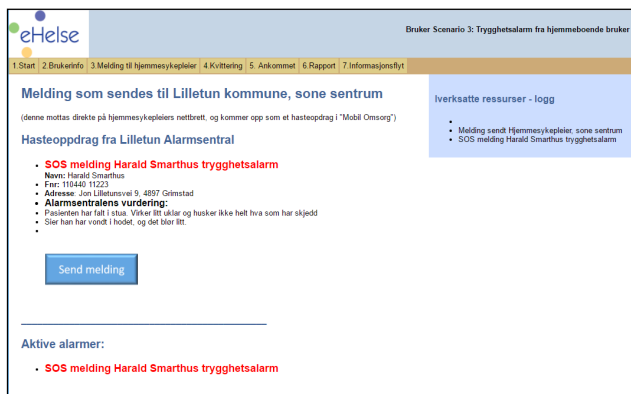


Figure 2. A screen shot from the prototype in simulation 1 (in Norwegian)

health care (in Norwegian *Kommunal øyeblikkelig hjelp* and *Legevakt*) with a responsible doctor on duty.

The operator established a voice contact with the patient and electronically sent an alarm message to the tablet device of the nurse in *Municipal nursing services*. The home nurse accepted the call out electronically and travelled to the patient's home, while the operator kept the contact with the patient. During the contact, the operator conferred with the doctor at duty that there was a need for assistance by an ambulance, which was also called out electronically, and updated notifications were sent to the home-nurse. At arrival, the home-nurse sent a message electronically to telecare alarm service by pressing the *Arrived* button in the tablet UI. In the tablet, the home nurse could fill in necessary documentation to the electronic health record, and by pressing the *Mission completed* button a notification was sent to the telecare alarm operator.

In the scenario 3, a regional telecare alarm service received the triggered alarm. The patient was called up, the operator evaluated the situation and called out the home-nurse by electronically sending a message. The home nurse accepted the alarm on the tablet device and travelled to the patient's home. On the way, the home-nurse initiated a voice-call to the patient. The need of assistance from an ambulance was acknowledged, and the home-nurse sent a message to the ambulance station. As the telecare alarm operator was not involved in the actions taken, no updated information or notifications were sent to the operator.

Between the scenarios and at the end of the day, there was a group debrief together with all the participants and research team to summarise the actions and related interactions.

4.2 Simulation 2

During the simulation 2, the smartphone app and the information system for telecare alarm service had been further developed and had additional functionality. Three models for handling alarms were tested. In the scenario 1, the alarm from the patient's home was automatically notified directly to the municipal home nurse, to the nurse on duty that had patient registered on a task list or was



Figure 3. The home nursing service at the patient's home geographically closest to the patient. A home visit followed, see Figure 3.

In the scenario 2, the telecare alarm service received the alarm and electronically called out home nurse services for home visit. In the last scenario, the telecare alarm service also received the alarm, but was organised in a model with an own local team to call out for home visits. At the end of the day, there was a group debrief to summarise the scenarios.

4.3 Simulation 3

In the simulation 3, the app was used in the smartphone device (see Figure 4), and the information system was shown on a large display in the telecare alarm service room. Two models for handling alarms were tested.

In the scenario 1, the alarm from the patient's home was received in the information system in the telecare alarm service. A two-way conversation was established with the patient and the home nurse was called out electronically through the system. The nurse received the call out from a message in the app. The nurse contacted a colleague via the app, and together they went to the patient's home, at arrival the *Arrived* button was activated in the app.

In the scenario 2, the alarm from the patient had automatic notification directly to the home nurse.

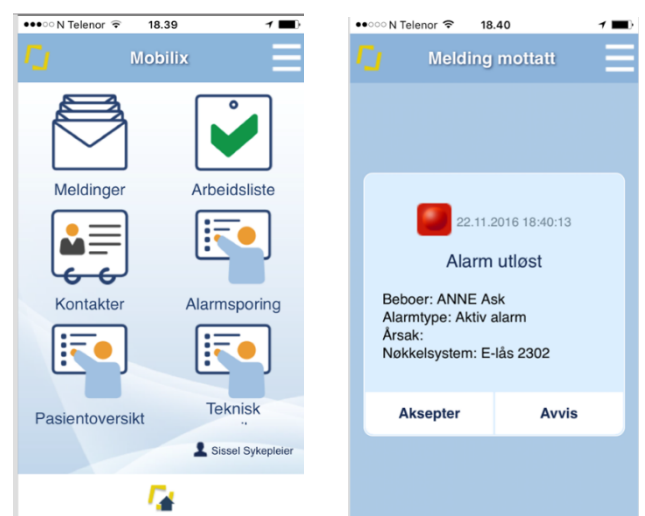


Figure 4. Screenshots from the smartphone app

The nurse had to touch the *Received Alarm* button, contact a colleague and establish a two-way communication with the patient during the travelling to the patient's home. At arrival, the *Arrived* button had to be touched.

Each scenario was repeated twice, and the participants changed groups between the scenarios, so each participant acted more than one role. Between the repetitions of the scenarios there was a group debrief, which was also held at the end of the day.

5 DISCUSSION

This paper has presented how to practically perform laboratory simulations of health care services, based on the experiences from the research project *Model for Telecare Alarm Services*. The lessons learned by the research team showed that this kind of simulation was an efficient way of testing different organisational models for telecare alarm services, together with key informants and end-user groups.

The three research questions (RQs) formulated at the beginning of this paper are answered below based on the results from the study.

About the RQ1, asking about which steps are relevant in a simulation. It is recommended to have a high level of realism in the context of a simulation [11][24]. Based on the experiences in the project, the initial workshops together with end-users provided an in-depth understanding of the context and important details to consider when preparing the simulations. Each day started with introduction to the technology and the scenarios, followed by signing of an informed consent form. The research team composed the groups, with a focus on the professions and experiences of the participants.

The RQ2 asked about what procedures can facilitate the active contribution of the end-user groups in simulations. As the focus was on actual work procedures and necessary information flow between the actors, the debrief session at the end of each scenario had an important role for the participants to discuss what had happened, in line with [18][25]. It was discussed how they had experienced the situation and whether anything in the workflow of corresponding information flow should have been changed to make the necessary functions more effectively or with improved quality. During the debrief, a process model of the workflow was presented and discussed, which gave all participants a good understanding of all details in the actual situation and the actions taken. Such visual representations are meaningful in workflow discussions, to show who did what and at what time, it became clear that the icons used should be standardised so the drawing can be used for documentation of workflow procedures and to make standardized treatment plans in the future.

About the RQ3 that asked about methodological procedures and lessons learned that are applicable in other contexts. The defined roles and with acting by the participants made the scenario realistic, also described in [20]. The group construction, with 2-4 participants

assigned to each role, can be recommended as that added the element of dynamics to the simulations. In addition, the role in the observation room, allowed the participants to actively follow the simulation process and making notes, which contributed at a detailed level to the group debrief.

This paper on simulation had some limitations such as a reduced number of actual roles included in the defined scenarios, and a limited number of simulations ($n=3$). However, the study had a number of participants with different professions that meaningfully represented the end-user groups of telecare alarm services. The empirical research data from user workshops and simulations regarding workflow and functionality of telecare alarm technology under development were not in the scope of this paper, as the main focus was the methodological procedures for simulation of health care services.

6 CONCLUSION

This study was framed within the research project *Model for Telecare Alarm Services*, in order to provide experiences on how to practically perform laboratory simulation of new and innovative organisation of health care services. The main contribution of this study lies on the descriptions of the procedures for simulation, how to facilitate the active contribution of the end-user groups and methodological approaches transferable to other telecare and development projects in health care services. The results presented are congruent with other studies of simulation in laboratory environments [10][11][19] and showed the importance of involving the different end-user groups when simulating the interactions. The role-play was useful and informative, in line with [20], even though it caused a complexity that required a large test team. The dynamic character of the post-test group debriefs, inspired by O[18], provided a platform for discussion for the participants and is recommended to other innovative simulation procedures. The usability laboratory provided a controlled environment, with audio-video recordings to retrospectively reflect the collected data. In terms of future work, a detailed analysis of the empirical data in the research project will be made for publication purposes.

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8 ACKNOWLEDGEMENT

The research team would like to thank all participants and informants for their contribution in the study. The Regional Research Fund of Agder in Norway provided financial support for the Model for Telecare Alarm Services project, with Grant number 247605. Work on the technical infrastructure of the laboratory settings was made with support from Aust-Agder Innovation- and Competence Fund, ref. 2012/42.

Fictional Narratives for Clinical App Development

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Abstract

This paper presents the use of fictional narratives in participatory design for health information technology (HIT). We used the case of an established occupational therapy assessment tool to investigate how fictional narratives can aid de-sign workshops and their outcomes in the health domain by means of participatory principles. The methodological findings show how a fictional narrative can be adopted in a di-verse manner across design workshops by practitioners and participants with a research background. Also, the importance of tailoring fictional narratives towards specific participants in the design process is emphasised.

Keywords

Fictional narratives, Participatory design, Health information technology, Occupational therapy

1 INTRODUCTION

The digitization of work procedures by means of health information technology (HIT) implies a number of benefits, such as safer health-care systems, reduced expenses, increased accessibility, improved quality and reduced medical errors (Abugabah and Alfarraj, 2015; Agarwal et al., 2010; Chiasson, 2007). However, at the same time, digitization has also proven to be challenging, presenting problems such as unreliability, lack of usability, difficulty in terms of integration into the workplace, and lack of involvement by future users in the decision process (Abugabah and Alfarraj, 2015; Karsh, 2010; Ventola, 2014).

A recent review study has shown that involving users in the design process increases the probability of the end product or technology becoming a success (Bano and Zowghi, 2015). This paper reports on parts of the development of a digital version of a current paper-based investigation tool for occupational therapists. The intention was to achieve some of the benefits of HIT mentioned above; and, at the same time, to reduce the challenges associated with digitization in the health domain. Specifically, we used a variation of fictional narratives (Brandt et al., 2013) in participatory design workshops to identify the novel potential of digitizing a tool well-known to the workshop participants. Fictional narratives have previously been used for technology design in the leisure domain (a marine centre) (Iversen and Dindler, 2008), in a museum context (Dindler, 2010), and in education (Brodersen et al., 2008). With the present paper, we chose to analyse the applicability of fictional narratives in the design of work-based health technology.

2 FICTIONAL NARRATIVES AND PARTICIPATION

Fictional narratives represent one technique among many in the participatory tool box. Brandt, Binder and Sanders (Brandt et al., 2013) applied the concepts of telling, making and enacting to organise participatory design techniques and elucidate their strengths in the design process. Telling concerns activities that support participants in telling about their experiences and imaginings with respect to everyday life and activities. The purpose is to identify problems and opportunities that can be considered, accounted for and incorporated into new designs. In regard to making, participation consists of participants creating physical artefacts as a kind of embodiment of their thoughts and ideas. In enacting, participants try out future scenarios by enacting their imaginations regarding future possibilities. Participatory design practice combines telling, making and enacting to capture the insights gained from the design process (Brandt et al., 2013).

Fictional narratives belong to telling techniques (Brandt et al., 2013). Fictional narratives are also an example of how fictional design spaces can be created in participatory design (Dindler, 2010). The idea behind fictional narratives is that by presenting participants with imaginative spaces in the design process, a more open and explorative design space can be created. This explorative space then allows participants to remove themselves from the current practice they might face concerning the design challenge at hand (Brodersen et al., 2008). Fictional narratives can take different forms, such as imagining the Olympic Games (Brodersen et al., 2008), a murder case (Brodersen et al., 2008) or a tale of Atlantis (Iversen and Dindler, 2008). With the present paper, we investigate the utility of this technique

amongst participants well acquainted with a professional tool that will be digitized in the near future. Our use of the technique is directed towards the form of the digitization, as the tool under revision should still be kept at a principal level. We will use the methodological outline and the documentation of the workshops to reflect on the usefulness of the fictional narrative developed for a specific, work-based case.

3 THE ETUQ CASE

The current design project concerns the specific design of a mobile application for data collection based on the principles of the established occupational therapy tool, the Everyday Technology Use Questionnaire (ETUQ). Everyday technology plays an increasing role in everyday activities and has in many ways changed how people participate in them. In many cases, technology has become a prerequisite for various activities; for instance, using a TV remote control, a coffee maker, or collecting a train ticket in a kiosk. Also, communication requires mobile phone, tablet or computer skills in order to contact family members and various social groups. Although, in general, technology is aimed at improving access and reducing effort, it can also be a barrier to accessing certain activities should one have limited technological skills or abilities. The ETUQ is a questionnaire that offers a systematic method for capturing clients' or groups' perceived difficulties in using everyday technologies alongside the relevance of such technologies in their everyday lives (Nygård et al., 2015; Rosenberg et al., 2009). The ETUQ was developed to target older adults, but can also be used with adults in general.

The ETUQ comprises a semi-structured conversation whereby the interviewer documents the respondent's answers on a paper-based questionnaire. The questionnaire contains background information about the client along with technologies grouped into seven topic areas: (1) home maintenance, (2) information and communication, (3) self-care, (4) maintenance and repair, (5) accessibility, (6) finances and purchasing and (7) travel. The ETUQ form, comprising 13 pages, includes a total of 90 technologies to rate and comment on. The ETUQ is used, administered and completed by occupational therapists, at either a hospital, a care home or a patient's home (Nygård et al., 2015; Rosenberg et al., 2009). The ETUQ is used in occupational therapy practice to characterise technology use by citizens and for research purposes.

In the present study, we used the development of a mobile app version of the ETUQ as our case. The purpose of the design process was to develop a digital version of the ETUQ to facilitate occupational therapists' data collection with greater ease, both while collecting the data *and* in subsequent data processing (transferral to desktop, exchange with colleagues and data analysis).

4 MATERIALS AND METHODS

Spinuzzi outlined three stages in participatory design processes: the initial exploration of the design use context (stage 1); the follow-up discovery process whereby goals are identified and design values are stated (stage 2); and, finally, the iterative development of the technology (stage 3) (Spinuzzi, 2005). In this design process, design workshops correspond to the second stage. Ahead of the design workshops, the authors of this paper followed a 1-day course along with a group of occupational therapists. The course introduced the background and principles of the ETUQ alongside instructions for correct use. The course also demonstrated an example of how a full ETUQ investigation is carried out. The course participation represented our initial exploration of the use context of the ETUQ, which is important in terms of communication with the workshop participants. The course also provided valuable inputs to the development and form of the design workshops. As the purpose of this paper is to present methodical perspectives on the design workshops, we will not elaborate further on stage 1 and 3 here.

4.1 Workshop participants

The segmentation of users represents a specific challenge in HIT due to conceptual and pragmatic barriers across user groups (Mønsted and Onarheim, 2010). In the present project, we identified two core user groups on the basis of both the nature of the ETUQ tool and the purpose of the technology to be designed: (1) users applying the ETUQ in clinical practice, and (2) users applying the tool for research purposes. We invited participants from both groups to the workshops in order to reflect both current and future users of the ETUQ. One workshop consisted of participants with a clinical perspective (three participants, workshop 1). The other workshop included participants with a research perspective on the ETUQ (six participants, workshop 2). All participants were women with a background in occupational therapy and practical experience using the ETUQ. The participants were recruited in different ways. The research participants were invited from the occupational therapy research environment at Karolinska Institute in Stockholm, which is responsible for researching and teaching the continuous development of the ETUQ. The clinical participants were recruited from a pool of former ETUQ course participants in Sweden. For practical reasons, we invited participants who lived within reasonable distance from Stockholm, where the workshops took place. Every participant filled out an informed consent form at the introduction of the workshops. The workshops were conducted at Karolinska Institute, Division of Occupational Therapy, in Stockholm, Sweden. All participants were Swedish, but the workshops were conducted in English to avoid any misunderstandings between the Swedish participants and the Danish workshop facilitators.

4.2 Developing the fictional narrative

One overall fictional narrative was developed for use throughout both workshops. The fictional narrative framed the workshops and acted as a bridge between the exercises carried out. Specifically, we used a sequence from the 2002 American science fiction movie, 'Minority Report'. The movie tells the story of a policeman who, in the near future, solves murder cases before they are even committed (Minority Report, 2016). In the sequence, the lead role involves investigating a murder by means of various ICT-based solutions and features of the future as detected in the present, including video conferencing, gesture-based user interfaces, grouping, ungrouping and comparing content. In this sense, the movie sequence represents a movement forwards and backwards in time. Backwards, because the movie is not entirely new; and forwards, because the sequence is presented in a science-fictional fashion, depicting what technology will allow humans to do in the future. We wanted the workshop participants to make the same movements by means of the narrative, going from somewhere well known to a new and unknown place with the existing tool. The fictional narrative was intended to support the participants in framing their current experiences with the tool alongside their future expectations for a digital version. We used the fictional narrative to illustrate this movement in time and space to the workshop participants.

The fictional narrative chosen for the workshops addressed the form rather than the content of the concepts developed within them. Developing the fictional narrative, we knew that the participants had experience in using the ETUQ. Generating a digital version of an existing tool as the goal of the design process also meant that the principles of the tool established some guidelines regarding how far the idea generation could go during the workshops. To compare, earlier examples of fictional narratives have addressed the King of Atlantis at a marine centre (Iversen and Dindler, 2008) and a story about the Egyptian pharaoh Tutankhamun at a prehistoric museum (Dindler, 2010). In these examples the idea generation carried out at the workshops concerned the content and themes of the design solutions identified. In the fictional narrative reported here, the form of the design is emphasised more, as the technology comprises the core of the narrative.

4.3 Workshop exercises

The workshops consisted of three exercises. To guide and connect the exercises, an overall challenge was presented to the participants. The challenge was defined as: 'Explore how we can create an app that protects the core values of the tool, leaves the biggest challenges behind, and develops the potential of the tool'. The three exercises were developed on the basis of the overall challenge. Due to differences in the participants' experiences in using the paper-based version of the

ETUQ, the first exercise served the purpose of identifying the core values of the tool.



Figure 1. Participants working in workshop 2.

The second exercise was concerned with identifying the challenges experienced using the tool. The last exercise revolved around the potential for a digital version of the ETUQ. Here the aim was to generate specific design ideas for the future mobile app.

As an introduction to the workshops, the participants watched the abovementioned sequence from 'Minority Report' on a TV screen. The first exercise was then introduced and the participants were given time to write down their thoughts on what they considered to be the core values of the ETUQ to keep in a digital version of the tool. The question had a broad scope and could encompass interactions with the client, details on the questionnaire form, and any other associations the participants might generate on the basis of the metaphor. Each association was written down on paper slips and the relative importance of each was then discussed by the participants with the purpose of rating which were more or less important in the development of the app. In cases where there were many notes, the participants grouped the paper slips before discussing the importance of the associated content (see Figure 1).



Figure 2. Inspiration cards for triggering associations in the workshops.

In cases of few associations and paper slips, a set of inspiration cards (Halskov and Dalsgaard, 2006) was used to trigger more associations with the participants (see Figure 2). The same procedure was followed in exercise 2 and 3. For each exercise, the workshop facilitators referred to the fictional narrative to help the participants explain their thoughts on the questions raised and to encourage them to think 'outside of the box' in generating inputs for the future design. The duration of both workshops was approximately three hours. Both authors served as workshop facilitators throughout the workshops.

4.4 Data collection and analysis

The workshops were documented in various ways. A video camera recorded the workshop activities taking place around the table. In addition, a dictaphone recorded the conversations and interactions. The dictaphone was used to document the workshops, but also to let the workshop facilitators focus on the interactions with participants instead of taking notes. The cards filled out by the participants were photographed concurrently. Subsequently, core passages of the sound files were transcribed by an external transcriber. Thus, introductory and closing parts were left out along with affirmative remarks from fellow participants. Further, as the purpose of the analysis was to investigate the suitability of the fictional narrative, the assignment of specific statements to specific participants was not considered important. Therefore, the transcription only distinguished between workshop facilitators, participants and specific workshops, not between specific participants. Below, we identify quotations according to the workshop they belong to, be it workshop 1 or workshop 2. Finally, the transcriptions were meaning-coded (Brinkmann and Kvale, 2014) to identify and characterise the function of the fictional narrative in the workshop exercises. Thus, in the coding process, inputs for the specific ETUQ were less important. Instead, we coded the workshop transcriptions according to different applications of the fictional narrative.

5 RESULTS

The workshops generated many inputs, ideas, comments and criticisms for a future mobile app version of the ETQU tool. We will not go further into these findings here, as our focus is methodical. However, the analysis of the workshop data has provided us with various findings regarding the methodical approach chosen for the workshops. We will report these below.

The workshop participants used the fictional narrative in various ways, as hoped for by the authors. We observed numerous examples of participants using the narrative as a referral in their own ideations, sometimes very explicitly:

'I had a suggestion that when you start the interview, you choose what its aim is. If I'm a clinician and I want the full map. And this is also for later when we have the option of

a measure or some kind of more sophisticated report. That you could sort of start by clicking the choice. And this is for the future. But Tom. I'm thinking about Tom' (workshop 2).

Here, the participant is using the narrative to keep herself on track in the discussion about the digitization possibilities.

'I think he was, he had already finished his data collection. I think that was more the data analysis part. I felt that could be me next time!' (workshop 2).

This participant applies the narrative to illustrate different stages of the process of using the ETUQ and to explain how she is using the tool at present and where the digitization could potentially take her work in the future. In the quote, 'he' refers to Tom in the narrative.

At other times, the referential use of the narrative had a more subtle character:

'Yeah in a hierarchy of difficulty. So that you don't need to ask about the easiest thing if the person is quite well-functioning' (workshop 1).

This quote exemplifies how the participant sees the technology as a way to minimise elements of the ETUQ if they are not relevant to the client in question.

'I was thinking maybe a bit ... thinking Tom on this one, then maybe we could have some function where you could, in conversation with the client, prioritise what are the most important things for you to get on with' (workshop 2).

This quote relates to the previous one, pointing to both possibilities of and needs for the digital version of the tool.

Another use of the fictional narrative is for comparison; for instance, when the development of the ETUQ is contrary to the fictional narrative. To exemplify:

'So I was thinking about Tom Cruise's role as very dominant; he did all these things, but in the ETUQ, the subjects, what the subjects tell us, is much more prominent. It's much stronger in the ETUQ' (workshop 2).

During the course of the workshops, it became clear that the fictional narrative had some positive side effects on the interactions in the group. Having the focus removed from the participants, when they went to watch the movie sequence, had a relaxing influence on them. Some laughed or giggled at the look of the main character of the movie (Tom Cruise), while others wanted to keep the cardboard cutout that had been made of the main character after the end of the workshop:

'Hey Tom, will you stay here afterwards or will you bring him back home?' (workshop 2).

What is evident from the analysis of the transcriptions is that the fictional narrative was used to a larger extent among the participants in workshop 2. Several issues may explain this difference. In workshop 2, the participants were direct colleagues and, therefore, perhaps also more familiar with each other. In addition, the majority of their

working focus concerned the ETUQ. To compare, the participants of workshop 1 were not well acquainted in advance, and the ETUQ was one among many other work tasks in their occupational therapy practice. We do not have data to explain the difference in the adoption of the fictional narrative empirically, so we will have to leave the answer to that question to a follow-up study.

6 DISCUSSION

As mentioned in the method section, the current fictional narrative differs from other examples in addressing the form rather than the content of the desired outcome of the workshops. One implication of the difference in focus is a more narrow and solution oriented outcome of the current workshops, when compared to the examples of (Iversen and Dindler, 2008; Dindler, 2010). Thus, both Iversen and Dindler (2008) and Dindler (2010) generate rich and creative design concepts on the basis of their fictional narratives, whereas the current workshops rather generate a discussion of the solution to specific challenges in using the paper based version of ETUQ. One could claim that the focus on the form and not content of the solution as aimed for here is provides a too narrow outcome of the workshops. However, as illustrated by the analysis above, we have seen how the fictional narrative can provide workshop participants with a way of explaining and framing their discussion on a tool, they are already very familiar with.

Further, the nature of the fictional narrative may be discussed. It was clear from the workshops that it came more natural to the participants of workshop 2 to engage with the fictional narrative. The two groups of participants differ as to number (more participants in workshop 2) and background. From our data collection and analysis, it is not possible to identify, whether the difference of engagement depends on the number of participants in the two workshops, the sci-fi nature of the fictional narrative, the different backgrounds of the participants or something different. Further studies are needed to understand how different users apply different fictional narratives in different workshop settings.

7 CONCLUDING REMARKS

To conclude, we have learned that when workshop participants apply a fictional narrative in a design process, it serves as a highly valuable tool for explaining thoughts, perspectives, ideas and the like. Also, a well-functioning fictional narrative can be supportive of social processes amongst the participants (and designers) of a participatory design process.

However, more importantly, we have learned how the same fictional narrative can be used differently by different types of stakeholders or participants in workshops. Despite many similarities between the participants in the two workshops, their uses of the fictional narrative differed. From conducting these two workshops, it has become clear that a fictional narrative

design, although concerning the same design process, must be adjusted to the specific stakeholders participating in the design process. Pilot testing is one way to help ensure the active use of the fictional narrative in participatory design. The current study is based on a rather small sample. Further studies are needed to gain a deeper understanding of workshop participants' engagement with and use of fictional narratives, and the resulting design concepts.

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9 ACKNOWLEDGEMENT

We would like to thank the Department of Occupational Therapy and the University College of Northern Denmark for funding the project.

Social Network Analysis and Tele Homecare

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Abstract

The use of tele homecare solutions in Denmark is increasing and moving from locally anchored pilot projects to large-scale or even nation-wide projects. TeleCare North has finished and evaluated a large-scale project for patients with chronic obstructive lung disease (COL). Some of the experiences show, that the cooperation between the healthcare professionals can be improved – or need to be adjusted more explicitly to the tele homecare solution.

This study is part of a larger Ph.D.-study, that will focus on the cooperation and communication between the healthcare professionals in the new TeleCare North Heart Failure project, and will study collaborative relationships between the actors before and after the implementation of the Heart Failure solution.

The result from two literature reviews indicates that the area is novel and unstudied, since no articles have been written about SNA and telemedicine/tele homecare, but a few (16 in the review) have been written about SNA and health informatics.

Keywords

Telemedicine, Medical Informatics, Organizations, Organizational Change, Social Network Analysis

1 INTRODUCTION

This paper describes the background to the PhD, the methodological approaches and preliminary results of a literature review.

The use of telemedicine and tele homecare solutions in Denmark is increasing. Over the last years, there have been an increased amount of locally anchored pilot projects, but only a few have gone into operation – and even fewer have gone into large-scale projects or nation-wide projects (MedCom, 2017). From 2012 to 2015 Region North and later TeleCare North¹ hosted a large-scale project for patients with chronic obstructive lung disease (COL). The experiences from this project is used in a nation-wide project for COL in Denmark, but also used in a new TeleCare North large scale tele homecare project for patients with Heart Failure.

Even with focus on the organizational issues in the implementation of the COL-project, the experiences call for even more focus on the organizational issues. Among the experiences from the COL-project is, that “...it is an intensive work to adjust and adapt services and procedures to get coherent and effective processes.”

(Region Nordjylland, 2015). Despite the focus on organizational issues, both the solution and the cooperation must be improved. The final report for the COL-project mentions the importance of “... a constructive and close cooperation across the core actors” (Region Nordjylland, 2015), and that the cooperation is not “... implemented to the bottom, and there must be continued focus on behavioural- and practice changes.” (Region Nordjylland, 2015). Another experience from the COL project is, that in some places implementation has been more successful (measured by actors activity) than elsewhere: This could raise the question of why it is going well in some places and less well elsewhere, when it is the same technology solution that has been implemented.

TeleCare North has now initiated a new large-scale tele homecare project for citizens with Heart Failure. The new project is not only for another disease, but also gives the possibility to focus on some of the organizational and implementation issues from the COL-project. The hope is to be able to optimize the organizational results of the Heart Failure project or to be more explicit in seeing the background for the results in terms of the organizational side of the implementation.

¹ Established in 2015 as a cooperation between 11 municipalities and Region North in Denmark. Supports tele homecare projects.

The focus of this Ph.D. study is the cooperation between the healthcare professionals before and after the tele homecare solution has been implemented, and the difference between the different organizations involved in the large-scale project.

The analysis of the relationship between the health care professionals will be based on Social Network Analysis (SNA), which is a structured approach to uncovering and describing networks (Waldstrøm and Engelbrecht, 2013; Provan and Milward, 2001; Pryke, 2017; Carrington and Scott, 2014).

The research objectives in the current study is, by using SNA, to give an insight to the difference between communication and relations between the actors in organizations, and to show whether there has been a change following the implementation of TeleCare North Heart Failure.

2 BACKGROUND

The purpose of the Ph.D. project is to carry out a descriptive/exploratory study (Andersen, 2013; de Vaus, 2002) to:

- Study collaborative relationships between the actors before and after the implementation of TeleCare North Heart Failure, to outline which degree of importance the implementation of TeleCare North Heart Failure has had on collaborative relationships
- Study whether there is a correlation between the co-operation relations and the outcome of the implementation, depending on which organization, the actors come from

The two purposes are chosen based on the evaluation of the COL-project and have been done in cooperation with TeleCare North. It is the intention that this PhD. project can help generate knowledge, that afterwards can help minimize the organizational challenges that emerged in the COL-project, in future tele homecare projects.

In this section, a brief description of the state-of-the art in the field of tele homecare in Denmark and SNA is given.

2.1 Tele Homecare

Telemedicine has been used by the Danish health service for many years for communication between health professionals, e.g. between Rigshospitalet in Copenhagen and Queen Ingrid Hospital in Nuuk, Greenland. Today, telemedicine has high priority in the Danish health service as a tool for optimizing treatment processes. Telemedicine allows patients to be discharged faster from hospitals, allows patients staying in their home to keep contact with health professionals from primary or secondary sectors, and health professionals can easily come into contact with colleagues in their own or other sector. Tele homecare or telemedicine for citizens has been tested through many (smaller) pilot projects in recent years.

The TeleCare North COL-project and the KIH Project (Clinical Integrated Home Monitoring) were the first two large-scale projects in the field of tele homecare in Denmark and form the basis for the nation-wide tele homecare project

15th Scandinavian Conference on Health Informatics SHI2017, Kristiansand, Norway, 29 - 30 August.

in Denmark to citizens with COL. The objective is: "... telemedicine must be an offer to all relevant citizens with COL across the country by the end of 2019." [9] and in the finance agreements of 2016, the Government, KL (Local Government Denmark) and Danish Regions agreed on a:

"... nationwide spread of telemedicine for citizens with COL by the end of 2019" (Finansministeriet 2015). Based on that, funds have now been allocated to ensure the first nation-wide tele homecare project in Denmark.

In "National Health Care Objectives" ("Nationale mål for sundhedsvæsenet") (Sundheds og Ældreministeriet, KL and Danske Regioner, 2016) telemedicine/tele homecare are not mentioned directly, but several of the goals set out could include the use of tele homecare. These could include the objectives: "Better coherent patient pathways", "Strengthened efforts for chronic and elderly patients", "Increased patient involvement" and "More healthy living years".

According to "The Telemedicine Map" (figure 1) all Danish municipalities and regions are involved in at least one telemedicine project and in total, 418 telemedicine initiatives in Denmark were registered by the end of 2016 (MedCom, 2017). 207 were reported to be in operation and 12 as being in the dissemination phase. The figure below shows the distribution of initiatives per region based on whether the initiatives are in operation (I drift), in dissemination (Udbredelse) or in the case of an ongoing project (Projekt).

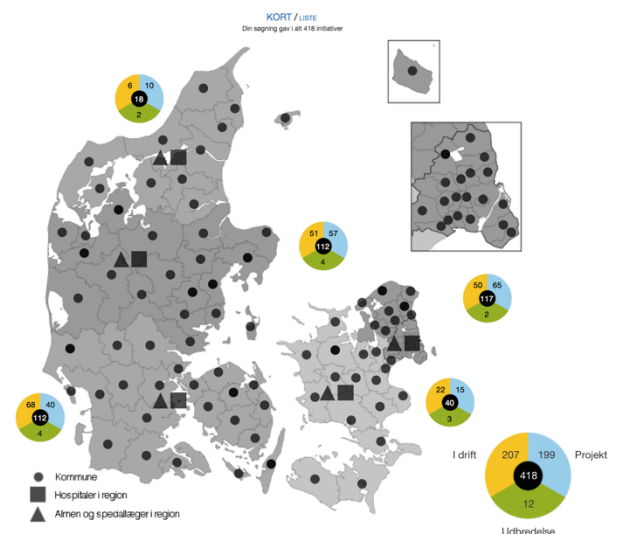


Figure 1 The Telemedicine Map of Denmark (MedCom, 2017).

2.2 Social Network Analysis

Social Network Analysis can be brought back to the 1930's, where an increasing number of anthropologists and sociologists began to look at social structures (Carrington and Scott, 2014; Scott, 2013). One of these was Radcliffe-Brown, who worked in the 1920's with the concept of "structuralist view of society" and mentioned "net-work of social relations" in a public lecture in 1937 (Carrington and Scott, 2014).

Other well-known researchers who participated in the birth of SNA were Lévi-Strauss, Lewin, Moreno, Warner

and White (Carrington and Scott, 2014). The University of Michigan and Tavistock Institute in London therefore became central to the development of SNA (Carrington, and Scott, 2014). Today, SNA is a recognized approach to social network-ing with dedicated journals, such as "Social Network", "Journal of Social Structure" and "Connections", its own professional community (International Network for Social Network Analysis – <http://www.insna.org>) and dedicated computer programs for analysis and visualization of social networks (Carrington, and Scott, 2014).

Today SNA is widely used to describe social relations both within and between organizations, but also in areas as epidemiology, to describe infectious patterns and optimize efforts, fight against criminal gangs, terrorist networks and intelligence services (Waldstrøm and Engelbrecht, 2013). It is alleged, that it was using SNA, that the Americans found Saddam Hussein.

3 METHODS

The overall methodological approach is partly to compile a literature review to see how others have used SNA and to do an empirical study including the healthcare professionals involved in TeleCare North Heart Failure.

3.1 The literature review

The literature review will be based on Moher et al.'s (2009) PRISMA Model (Preferred Reporting Items for Systematic Reviews and Meta-Analysis), which consists of four phases and a 27-point overall checklist for the purpose of facilitating the preparation and reporting a protocol for a systematic literature review.

3.2 Method of empirical part of the study

Data collection to the SNA is based on an adapted "prospective panel longitudinal" study (de Vaus, 2001). Adapted, as the first data collection occurs after some of the respondents have begun to use or have been trained to use the TeleCare North Heart Failure solution. This could speak for calling the first data collection retrospectively, but since other respondents did not start to use or are trained to use the Heart Failure solution at the time of data collection, it is called "adapted". The "prospective panel longitudinal" is selected as the study follows the same population over time from before to after implementation (de Vaus, 2001; Bowling, 1997).

The empirical part of the research project is divided into two phases:

1. Prior to implementing TeleCare North Heart Failure
2. After implementation of TeleCare North Heart Failure

By the end of 2016, the prior-study had been performed. A questionnaire was sent to 11 municipalities, 4 hospitals, and 172 GP's using an electronic questionnaire in SurveyXact, where access was via mail sent to the respondents.

Due to a low response rate from the municipalities, the research design has been changed, and only eight municipalities will be part of the pre-/post-study based on questionnaires.

To increase the data for studying whether there is a correlation between the cooperation relations and the outcome of the implementation, depending on which organization the actors come from, the post-study will be based on interviews instead of questionnaires. Actors from all included organizations will be interviewed – even if they have been part of the pre-/post-study based on questionnaires. This also gives an opportunity to compare data retrieved by questionnaires and by interviews.

After the post data collection and analysis, it is planned to hold a focus group interview to discuss the result and possible explanations of these with selected respondents. The combination of quantitative and qualitative study will be done with inspiration from mix-methods (Curry et al., 2013; O'Cathain and Murphy, 2008) and successive triangulation (Hollensen, 1996) to seek an explanation of the results from the quantitative study.

The purpose of applying SNA in this study is to use a recognized approach to analyse the communication/relations between the healthcare professionals in the TeleCare North Heart Failure project. The aim is to explain and, if so, to what extent the relationship between health professionals' changes after the implementation of TeleCare North Heart Failure. The reason for looking only at the healthcare professionals is justified by the fact, that the experience from the COL-project does not include the citizens/patients, but points to organizational relationships among and between the healthcare professionals.

The networking approach is considered relevant, as the implementation of the TeleCare North Heart Failure project goes across organizational borders in and between the primary and secondary health sectors.

4 THE LITERATURE REVIEW

In this section two literature reviews seeking telemedicine and health informatics projects that had used SNA are mentioned.

4.1 Literature review: SNA and tele homecare

By the end of 2016 a literature study was performed. The intention was to analyse the use of SNA in tele homecare projects. Despite an extensive literature search using PRISMA (Moher, 2009), no papers were included.

Two search blocks were used – one with "tele home care" OR "tele homecare" OR "home telecare" OR "home tele care" OR "telemedicine" OR "telemedicine" OR "tele medicine" OR "tele medicine" – and one with "social network analysis", but later changed to "network analysis" to extended the search.

The searches were performed in: Cinahl, Cochrane, Embase/Emtree, Google Scholar, ProQuest, PubMed, Scopus, and Web of Science. The PRISMA model (figure 2) shows the amount of records identified before/after

removal of duplicates, records screened, and full-text articles accessed for eligibility – and that no articles are included.

The conclusion is that – at the moment – no researchers have published papers in scientific journals, to document the use of SNA in tele homecare projects.

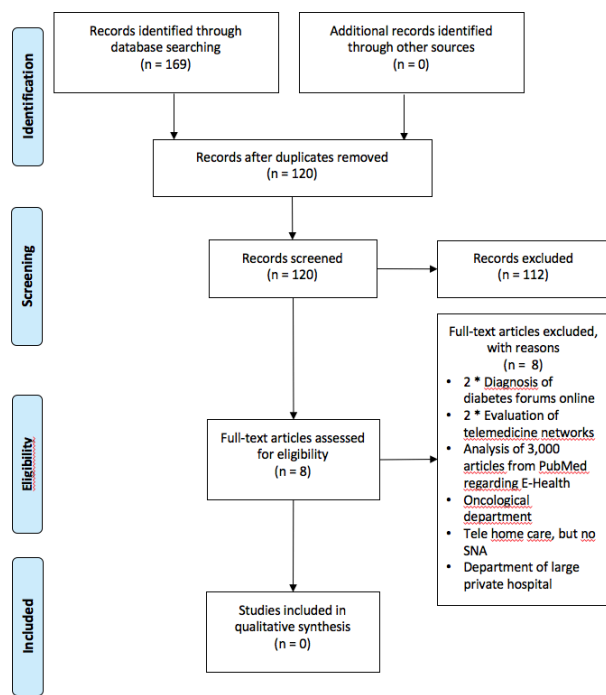


Figure 2 PRISMA for literature review: SNA and telemedicine/tele homecare.

4.2 Literature review: SNA and health informatics

To make the search wider, tele homecare was replaced with health informatics, and a new literature study was done in January 2017. PRISMA was still used and the two search blocks were "health information system" OR "health IT" OR "health information technology" OR "health informatics" OR "medical information technology" OR "medical informatics" and "social network analysis". The searches were performed in: Cinahl, Cochrane, Embase, ProQuest, PsycInfo, PubMed, Scopus, and Web of Science. 367 records were screened, and selected on title and abstract, 25 full-text articles were assessed for eligibility. After full-text reading, 16 articles were included in the qualitative analysis (see figure 3).

Two of the 16 articles were Ph.D. theses (Benham-Hutchins, 2008; Raman, 2009), three from conferences/symposiums, and 12 from scientific journals (Computers in Biology and Medicine, International Journal of Medical Informatics, Journal of Biomedical Informatics, Journal of Medical Internet Research, Journal of Organizational Computing & Electronic Commerce, Journal of the American Informatics Association, Studies in Health Technology and Informatics, and Technology Innovation Management Review). Most of the articles (11) are from

USA, one from Canada, one from Australia, and two from Europe.

4.3 Preliminary results of the literature review

A wide span of methodology approaches is used – from data mining in log-files, to survey and observational cross-sectional studies.

The analysis in the 16 articles have been performed using APL2/iGraph, ATLAS Ti, Clairlib, Cytoscape, Gephi, GUESS, MATLAB, NetMiner, Netdraw, ORA (Organizational Risk Analyzer), Pajek, SNA Package in R, SPSS, UCINET, and Visone. Most of the articles illustrate results in a combination of tables and network diagrams.

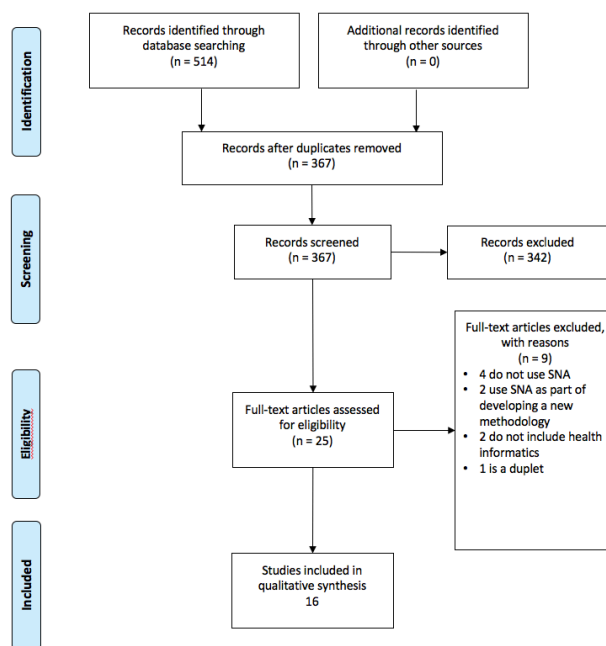


Figure 3 PRISMA for literature review: SNA and health informatics

To summarize the major findings from the literature review, we would like to site Anderson, Aydin (Andersen et al., 1994): "Social network analysis can be used to analyze relationships among health care providers, departments within health care organizations and other organizations...This methodology can also be used to better understand changes in communication patterns or other interactions over time."

5 EXPECTED RESULT

Before SHI 2017 in August, the literature review for SNA and health informatics will be finished, and the conclusions will be part of the oral presentation.

Later the result from the empiric study will be published, and the intention is to focus on the methodology experiences and to increase the knowledge of the organizational issues when implementing a tele homecare solution.

On the methodology side, the intention is to demonstrate that SNA is a useful tool for quantifying changes in

collaboration before/after implementation of a tele homecare solution.

On the empirical side, the intention is to give TeleCare North a quantitative insight into how relationships and collaboration change after implementation of a tele homecare solution. The intention also includes a qualitative analysis through a final discussion of the outcome of SNA, to chart why the cooperation has changed/not changed. Perhaps the conclusion also will propose what can be done to change the cooperation.

This is in an expectation of providing knowledge that can be used to address and possibly minimize the organizational challenges in the relationships and cooperation between the health professionals and across the sectoral border. In addition, if a difference can be seen among the involved organizational units.

6 DISCUSSION

Using PRISMA for the literature review gave a structural approach to the review. In the first review covering SNA and tele homecare, working with two search blocks gave the possibility to change each of them individually, to extend the search for articles covering SNA and tele homecare. A change of "social network analysis" to "network analysis" gave more articles in the search result, but none of these articles could be included in the review.

As the results from the literature reviews indicates, the area is novel and unstudied since no articles could be included in the review focussing on SNA and tele homecare. By using SNA in this study focussing on a tele homecare solution for Heart Failure, our intention is to contribute to more scientific knowledge regarding the use of SNA in relation to tele homecare.

The two-sided use of SNA will give knowledge in relation to a before/after study and a study focusing on the difference from implementing the same tele homecare solution in different organizations.

7 ACKNOWLEDGMENTS

Thanks to the people at TeleCare North for their support.

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Factors affecting elderly people's behaviour to technology

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Abstract

The elderly population is increasing, both relatively and in numbers, implying future challenges for the care services. Innovation and internet based well-fare technology have been proposed as part solutions. The new pensioners are supposed to be more positive to internet based technology but very few studies have explored this. In order to initiate innovation and long term planning a broader understanding of the attitudes in the elderly population is needed. On basis of Theory of planned behaviour, we developed a questionnaire to assess a broad variety of factors; socioeconomics, housing, health, social network, attitudes of the elderly population on giving and receiving care, and attitudes towards the use of internet based solutions. A 66 items questionnaire was sent to the population of new pensioners (age 67-70 years, n=1011) in the municipality of Grimstad with a response rate of 56.5%. The analyses indicated that the questionnaire was relevant and that socioeconomic factors were associated with attitudes towards the use of internet based solutions. Further validation of the questionnaire in a broader set of municipalities is needed

Keywords

Elderly, Welfare technology, Socioeconomic factors

1 INTRODUCTION

In 2040 the number of elderly (< 80 years) will double in Norway (Tønnesen, Leknes and Syse, 2016) compared with today. This has been a focus of concern amongst policy makers due to the presupposed increase in the need of publicly financed care, and implementation of welfare technology is a major strategy in meeting this challenge (Parliamentary report 29 (2012-13)).

Data from Norwegian and Swedish surveys among home-dwelling elderly people showed that self-reported health increased positively in the period 1998-2008 even though the incidence of illnesses has increased the last 20 to 30 years (Fors et al., 2013) (Mørk, 2011). According to the National Institute of Public Health, it is expected that more people will live with chronic diseases and cancer, while fewer will die of heart disease. Furthermore, it is pointed out that more people will have dementia and that the incidence of bone fractures is particularly high in Norway (Norwegian Institute of Public Health, 2017).

The next generation of elderly is expected to have higher education, be more resourceful and have better health than today's elderly. To a greater degree than today's elderly they will also be used to and expect to be able to decide on their own lives (Parliamentary report 25 (2005-2006)). There is however surprisingly little data on the elderly's beliefs and attitudes on services in the years to come, their own health, and life situation.

A Danish study showed a picture of increased polarization, where a smaller group of elderly people will be hanging

after the majority in terms of health, economics, technology and social conditions.

This group had an overweight of women and singles, and had otherwise high age, bad health, low household income and shorter education (Ældre Sagen, 2010). If the results from Denmark is applicable to Norway, special considerations should be done to meet the needs of this elderly group.

To plan the future, policy makers need to establish a knowledge base on beliefs and attitudes among the coming cohort of elderly people. Newly pensioners (67-70 years of age) will in 10-15 years be a part of the large cohort of elderly (> 80 years), and the expectations and attitudes of this group on future services is important to map.

The main aim of this study was to develop and preliminary test a questionnaire that measures socioeconomic factors, data on housing, health, social network and beliefs and attitudes towards giving and receiving help and care, and attitudes on the use of information technology. A secondary aim was to assess predictors for positive technology attitudes among new pensioners.

2 MATERIALS AND METHODS

We did not find suitable and validated instruments covering our questions. Some survey instruments focus on elderly groups (often > 80 years) or on specific behaviours among senior citizens (physical activity) and we found the need to develop a questionnaire tailored to the circumstances relevant for our target population.

Paper from the 15th Scandinavian Conference on Health Informatics SHI2017, Kristiansand, Norway, 29 - 30 August.

Conference Proceedings published by [Linköping University Electronic Press](http://linkoping.university.se/electronicpress/).

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As a starting point, we used theory of planned behaviour (Ajzen, 1985) which improves the predictive power of the theory of reasoned action by including perceived behavioural control. The theory focuses the relations between beliefs, attitudes, intentions and behaviours.

Based on this theory we developed a questionnaire focusing on beliefs and intentions toward welfare technology, housing, receiving (and giving) care and general expectations towards becoming elderly. The questionnaire was grouped into the following sections; Background/demographics, general housing conditions, health, to give and receive care and practical help, social network, use of technology, attitudes towards welfare technology, and expectations towards future needs. The SF-12 is a 12-item measure of general health related quality of life (Ware, Kosinski and Keller 1995) and were used to assess physical and mental health status. The SF-12 questionnaire consists of 8 items using a 3-7 points Likert scale, and 4 dichotomous questions (yes/no). Items are scored into 2 sum-scores (physical component summary, PCS and mental component summary, MCS). The scores range from 0 to 100, where higher score represents better health.

The questionnaire was pretested in a group of 7 volunteers in the age between 67-71 years, and some questions were altered or removed. The final questionnaire consisted of 66 questions. In order to elicit scales, questions were either scored on a 10-point Likert scale or were dichotomous.

The municipality of Grimstad (22692 inhabitants) cooperated in the study. All inhabitants between 67 and 70 years (n=1011) were included in the study. A total of 36 persons lived abroad or had no address, leaving a sample of 975 participants. Each participant was given a unique ID-number corresponding with a name and address list. The ID-number was printed on each questionnaire.

The survey was presented in the local newspaper. The questionnaire, together with an information letter, and a recommendation to respond signed by the mayor, together with a ready-made reply envelope were sent by mail to the participants. After 2 weeks, a reminder was sent to the non-responders. The returned questionnaires were scanned at University of Oslo.

2.1 Statistical methods

Using IBM SPSS v. 24.0 the SF-12 questions were scored in accordance with the instructions given by the authors (Ware, Kosinski and Keller 1995) resulting in 2 scales, physical and mental component score (PCS and MCS). Each scale is scored from 0-100, highest scores indicates best health. The population mean is set at 50, with standard deviations = 10.

A total of 11 questions measured attitudes towards technology. These questions are as follows: I'm following the technology front, I think it's fun to use technology, I would like to use technology that can help me to cope with everyday life, If I got sick I could think of using technology

to master my own health (e.g. blood pressure or blood glucose measurement, I would like to pay for technology that can help me in everyday life, I may install security technology (security alarm, door sensor, fall sensor etc.) in my home, I may be one of the recipients of alarms if one of my closest relatives has security alarms, Electronic communication with healthcare professionals can be a supplement to physical meetings, The elderly must be able to use computer technology to handle chronic diseases, The internet has useful information about health conditions. Each question was given with an 11-point response scale, ranging from 0 ("strongly disagree") to 10 ("strongly agree").

These 11 questions have acceptable internal consistency with Chronback's alpha coefficient = 0.89. Bartlett's test was statistically significant ($p < 0.001$) and the Kaiser-Meyer-Olkin test was not significant ($p = 0.895$) and data were therefore adequate for Principal Component Analysis (PCA). The 11 variables were analysed in a varimax rotation with selection criterion equal to eigenvalue > 1.0 giving 2 components. Component 1 had eigenvalue = 5.544 with explained variance = 50.4% and component 2 had eigenvalue = 1.116 with explained variance = 10.2%. Catell's scree-plot confirmed this, with a bend in the curve at component 2. At PCA, the selection of components is critical, and therefore Parallel Analysis (11 variables, $n = 507$, 100 iterations) was performed and component 2 had a lower eigenvalue (1,116) than the eigenvalue criterion in a randomly generated data matrix (1,174). Component 2 was therefore rejected. The 11 variables were additionally summed and converted to a scale of 0-100. In this Technology Attitude Scale (TAS) higher scores indicate positive attitudes towards internet based technology.

To describe any gender differences in the material, Mann-Whitney U tests and Student T tests were conducted on continuous skewed and normalized variables respectively, and chi-square tests and Fisher Exact Tests (2x2) on categorical variables. Furthermore, bivariate correlation analyses calculating Spearman and Pearson correlation coefficients for skewed and normally distributed continuous variables) on TAS. Categorical variables were analysed via Mann-Whitney U tests and Student T tests on TAS. Stepwise linear multiple regression analysis was performed on significantly associated independent variables ($n=28$) on TAS as dependent. A p value < 0.05 was set as a limit for statistical significance.

2.2 Data collection

A total of 36 persons lived abroad or had no address, leaving a sample of 975 participants. Each participant was given a unique ID-number corresponding with a name and address list. The ID-number was printed on each questionnaire.

The survey was presented in the local newspaper. The questionnaire, together with an information letter, and a recommendation to respond signed by the mayor, together with a ready-made reply envelope were sent by

mail to the participants by an administrative person at municipality of Grimstad.

After 2 weeks, a reminder was sent to the non-responders.

The returned questionnaires were scanned at University of Oslo and transformed into an SPSS datafile.

2.3 Ethical considerations

The Norwegian Centre for Research Data (NSD) approved this study with the project number 2017-50835. All participants received written information about the project and by returning the paper based questionnaire they accepted the consent form.

3 RESULTS

The sample consisted of 975 persons with registered address in the municipality of Grimstad. A total of 552 questionnaires were returned (56.5%), consisting of 279 males (50.5%) and 272 females (49.5%). Around 80% of the sample was married or cohabitant, and there was a greater proportion of widows (13.2%) than widowers (3.6%). There was also a larger proportion of males (48.1%) with higher education than females (33.5%). In terms of access to technology, nearly all had mobile phones, and 91% of respondents had access to a PC or tablet at home. There was no statistically significant gender difference in terms of access to technology, but females compared to males had mean score of 53 versus 58 points (of maximum 100). It is worth noting that a quarter of females and males scored less than 36 and 43 points respectively. Males had a yearly mean income of NOK 415,000 and females NOK 267,000. A quarter of the females had a yearly income of less than NOK 183,000 (minimum pension). We found no gender difference on health. When it came to receiving care from people other than family members, females reported to a greater extent than males that they thought this was okay. Males reported to a higher degree that they were willing to pay for services, whether it was upgrading housing, care assistance or practical assistance. The stepwise linear multivariate regression analysis revealed 8 of 28 variables significantly associated with TAS. These were grouped into three categories: personal background factors, demographic factors and environmental factors (Table1).

Table 1. Stepwise regression. Variables affecting TAS.

	Regression coefficients		p-value
	Unstandardized	Standardized	
<i>Personal attitudes</i>			
Willing to be a helper for the family ¹	1.542	.172	< .001
Intending to live at home even if sick ¹	1.056	.139	.001
Positive to receive help from others ¹	.745	.103	.017
<i>Demographical factors</i>			
Education ²	4.295	.186	< .001
Technology access ³	18.175	.217	< .001
Income: willing to pay for housing upgrade ¹	.984	.137	.004
Income: willing to pay for personal help ¹	1.459	.181	< .001
<i>External factors</i>			
Age of housing ⁴	.041	.106	.013

1 = Scale 0-10. 2 = scale 1-4. 3 = dichotomous 0-1. 4 = number of years.

4 DISCUSSION

The questionnaire seems to be relevant for assessing socioeconomic factors, data on housing, health, social

network, and beliefs and attitudes towards give and receive help and care, and also attitudes on the use of information technology in a population of newly pensioners.

The questionnaire was developed on basis of Theory of planned behaviour (Ajzen, 1985) which postulate that background, demographical and external factors affect attitudes. In our case TAS was significantly associated with factors that fitted into the theoretical model.

We found that personal attitudes like being there for other people, especially the family, and a positive attitude towards receiving care from others, together with an intention to live home as long as they could. Seen together these characteristics may be interpreted as an ability to reflect over the individual's life in a longer time span, and maybe as an intellectual sort of reflection pointing to a drive towards independence and a wish to be in control over one's life. We also found that level of education, technology access and income related variables were significantly positively associated with TAS. If you have a higher income, you have more positive attitudes to paying yourself, probably because you have better chance to do so. Higher income may be due to higher education. Our findings correspond to the findings made by Claes et al. (2015), which indicated that payment willingness may be related to factors such as education and income, which in turn were related to a positive attitude towards using technology. The last finding, age of house may also be coupled to a socioeconomic association. A newer, and thus more expensive, house is positively associated with an attitude towards using technology. Seen together, our findings support findings from Denmark drawing a picture of increased polarization, where a smaller group of elderly people will be hanging after the majority in terms use of technology (Ældre Sagen, 2010).

The study's main weakness is that the questionnaire is not fully validated. A further investigation on a larger sample is necessary to thoroughly validate the questionnaire for use in a broader set of municipalities. Our findings should be interpreted with care.

5 CONCLUSION

The questionnaire seemed relevant to explore attitudes towards the use of technology in a population of pensioners. We found that socioeconomic factors may be an important determinant on positivity towards the use of information technology.

Acknowledgments

The research team would like to thank all informants for their contribution in the study. Financial support was provided by University of Agder and Municipality of Grimstad.

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The Role of IT-department in Future Health Care, Can They be Ignored?

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Abstract

In traditional information systems literature, there is great focus on the need for top management involvement and involvement of the users, when considering implementation of technology in an organization. However, how the IT-department in an organization is involved has not received as much attention.

Through our research, we have interviewed the IT-department in five Norwegian municipalities, who have participated in an innovation project to implement welfare technology. Our findings show that this important function in the age of digitalization of public health care is not involved early enough in implementation projects and is still treated as a 8 am-4 pm service by Norwegian municipalities.

We argue that the IT-department needs to become an integrated part of the future health care services, and should no longer be considered a support function.

Keywords

Welfare technology, IT-department, implementation, eHealth

1 INTRODUCTION

In traditional information systems research we have learned that top management support is a crucial aspect of IT-projects and success of such projects (Sumner, 1999; Thong, Yap and Raman, 1996). In addition, the involvement of end users has been identified as another critical success factor when developing and implementing new information systems into an organization (Damodaran, 1996), including such projects in public sector (Følstad, Jørgensen and Krogstie, 2004).

However, the role of the IT-department has not been given much attention in the traditional information systems literature. Naturally, one might say, since the IT-department should be an integrated part of any IT-project, system development or implementation. Even in implementation of eHealth in hospitals there is no mention of the IT-department and their role in the implementation (Høstgaard, Bertelsen and Nøhr, 2017).

Although, the role of the IT-department has little focus in municipal context, it has been of interest in private sector (Guillemette and Paré, 2012). Guillemette and Paré (Guillemette and Paré, 2012) identified five ideal roles of the IT-function where if successful focus on a specific source of value. The five ideal roles identified were: Partner, Systems Provider, Architecture Builder, Technological Leader, Project Coordinator (Guillemette and Paré, 2012).

The motivation for this research is found within the notion of the IT-department's role within implementation of welfare technology in public sector. What is the role of the IT-department in a Norwegian municipality and how does it experience the process of digitalization that is pushed from central government?

The aim of this research is to identify the role of the IT-department at present and to answer the research question:

What is the future role of the IT-department when implementing welfare technology in municipal health care?

To answer this question we are presenting the experiences of the IT-department in five Norwegian municipalities. We aim to understand how the ongoing digitalization affects this group within the organization, which until now has been seen as a support for the core activities of an organization.

The remainder of this paper is structured as follows; first, we present the research method, second we present the findings from our research, then we discuss how the IT-department might have a more prominent role than it traditionally has had in municipal services, and lastly we conclude this research.

2 RESEARCH METHOD

The methodological approach in this study is qualitative and interpretive. A case study is applied because the issues

Paper from the 15th Scandinavian Conference on Health Informatics SHI2017, Kristiansand, Norway, 29 - 30 August.

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under study are processes very much linked to their contexts. Secondly, the complexity of the case makes the study unfit for a cross-sectional questionnaire; there are too many “variables” for the number of observations made (Hartley, 2004). The case we studied was purposely and theoretically sampled (Eisenhardt, 1989).

2.1 Case

Through the Digital Surveillance project, eight municipalities worked together as a network, cooperating with two technology supplier companies to develop and implement sensors and digital communication in local nursing homes and home nursing service.

The technology includes sensors on doors and electronic blankets for use in the beds during night. A web portal facilitates communication through computers and mobile units. Most of the participating municipalities had some former welfare technology installed, such as alarm systems. The new element was that the sensor technology was closely tied to a web portal that can support multiple technologies in various categories. Each patient/user can get personalized services, based on the individual need of the patient/user. Any changes in the service, based on time of day or changes in the diagnosis, happen through the web portal. When an incident happens, an alarm will show in the portal, and the system is programmed to send an alarm to mobile units or computers of the nursing staff. When the staff has checked the patient/user, they will sign for the alarm in the system.

The case in question, Digital Surveillance, was organized as parallel projects: Eight municipalities coordinate their own innovation projects, implement technology from participating suppliers and share knowledge among themselves.

Simultaneously, a research project followed the innovation projects organized by the eight municipalities and suppliers. One of the participating municipalities were the owner of the research project, on behalf of a consortium involving the eight municipalities, two supplier companies and the two research institutions. All parties were represented in the steering committee for the research project.

The research project, Digital Surveillance, was financed by three parts, The Research Council of Norway’s regional research funds; Oslofjordfondet, Fondsregion Hovedstaden and Fondsregion Agder, while VRI Buskerud financed some of the physical meetings for the project.

The research section of this project was a collaboration between University College of South-East Norway and University of Agder, Norway.

2.2 Data collection

Data were collected through observations and interviews. We observed the interaction between health personnel, technology suppliers and IT staff in meetings and other work-situations in the municipalities, as well as in five workshops for all the municipalities in the project, in the

period April 2014 – December 2016. One of the workshops was dedicated to information security and privacy, whereas topics related to IT (infrastructure, technological devices of choice, procurement, cooperation and communication, training and routines/service design) were included in every workshop. Table 1 presents the timing and topics of the workshops, as well as number of participants from different categories.

The interviews include three group interviews and two individual interviews, focusing on the role of the IT-department when implementing welfare technology in Norwegian municipalities.

Time and place	Topic	Participants				
		Healthcare	IT	Supplier	Research	Other
November 2014	Service innovation	23	3	5	7	7
February 2015	Communication	27	3	3	5	
May 2015	Service design	28	4	4	7	5
September 2015	Information security and privacy	10	4	2	7	2
November 2015	Routines, documentation and technology	24	2	4	5	
April 2016	Service innovation and ethics	17	2	3	6	
September 2016,	Implementation of digital surveillance technology	11	2	4	6	2

Table 1. List of workshops in the project

Ten individuals working in the IT-departments of five municipalities were interviewed. Due to privacy reasons we have anonymized the individuals interviewed. All interviews were conducted in the spring of 2016. They were recorded after informed consent was given, and later transcribed. Table 2 shows an overview over the interviews conducted.

Municipality	# of participants	Method
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Municipality 1	3 participants	Face-to-face
Municipality 2+3	4 participants	Face-to-face
Municipality 4	2 participants	Face-to-face
Municipality 5	1 participant	Face-to-face

Table 2. Overview over interviews

2.3 Data Analysis

The data has been analyzed using content analysis. Content analysis is a well known method for analyzing qualitative data. Patton (2002) stated: *“Content analysis is used to refer to any qualitative data reduction and sense-making effort that takes a volume of qualitative material and attempts to identify core consistencies and meanings”* (p. 453).

By reading all the interviews inductively to find the common topics, three topics were identified as important; Involvement of the IT-department, Resources, and 24/7 service.

3 FINDINGS

In this section, we present the findings from our data analysis. All the interviews were conducted in Norwegian, and the presented quotes are translated into English, aiming to best show their original meaning.

3.1 Involvement of IT-department

During the project, the IT-departments have been involved in various ways. However, in line with the observations, many of the informants point out that there is a lack of planned involvement in projects of implementation of welfare technology.

The decision to implement welfare technology was made by the politicians of the municipalities, following national recommendations (Meld. St. 29 (2012-2013), 2013). The health and care services have been involved from the very beginning in all the municipalities. The IT-departments, on the other hand, seem to not have been involved in the decision process at all.

“We [the municipality] were not good enough to involve the IT-department in the beginning. This was suddenly decided, or suddenly might be wrong, but it was a fast decision. We had a political decision, that we were going to be a part of this project, and we got started, before we even had checked into anything. We went out high and wanted ten sensors, or ten apartments equipped with this technology. We had an on-site inspection, and all of this went very fast. Nobody thought of the IT-department until we got the first requirements. The requirements were sent to the IT-manager, and the response was that this could not be serious, that we were suppose to implement all this. The first requirement plan was enough to maintain a small country.” (Municipality 1, Participant 2)

The IT-departments experience that there are decisions made on issues and parts of the operation, directly in their

path. When they are not involved in these decisions, the outcome can be barriers hard to overcome.

As reported in (Nilsen et al., 2016), the municipal top management failing to involve the IT-department from the beginning represented a risk both to the implementation and to the quality of the care service. As the IT-departments got involved during the course of the implementation, barriers arose and caused resistive behavior. The IT staff sometimes had rather aggressive and un-cooperative behavior when the project managers, health care management or the suppliers expressed their expectations, requiring the IT staff to solve problems that they might not have the authority, equipment, infrastructure or knowledge to do (Nilsen et al., 2016). The resistive behavior included not answering calls, e-mails and questions, postponing installations, failure to attend meetings, not preparing infrastructure and so on. Such incidents put the implementation on hold for shorter or longer periods (Nilsen et al., 2016).

“In this case we were not considered at all, until it was decided what should be implemented. Then all we could do was “et fait accompli”, considering what it was suppose to be. We had to act in accordance to what it was. We didn’t want to...Well, this did not fit with the platform, there was no... Well, they had not investigated the possibility for interaction with the existing systems, and then it is all over, really.” (Municipality 5). The same experience was reported from another municipality: “And we experienced internally that the project was not, well, they did involve the IT-department, but on paper we did not have a role in the project. We experienced that they called when they needed something installed or implemented, but didn’t have a plan, we got a server just sent in the mail.” (Municipality 4, Participant 1)

Municipality 2+3 have an inter-municipal IT-department, which supports 7 municipalities. In the case of “Digital Surveillance”, the IT-department was the initiator. However, they also indicate the lack of involvement of the IT-department as an issue when making the decision to implement welfare technology.

Especially when discussing health- and welfare technology this is an important topic, due to the many different suppliers in the field, which require knowledge about how these systems communicate and act. *“But, out there, like you said, there are so many different solutions. And something that has been useful for us is to say ‘We have to stop buying solutions all over the place, something for this little part and something else for this little part. Suddenly they all wanted different alarm systems; we cannot have that. Everything needs to fit together. That is why IT has to be involved.’* (Municipality 2+3, Participant 2)

The need to see the full technical picture throughout the organization is identified as important to being successful when implementing welfare technology in municipal context.

In Municipality 4, which also has an inter-municipal IT-department, this project was run without the involvement of IT at all. However, because the nursing staff is used to

contacting the IT-department when something is wrong, they still got a role in the project.

3.2 Resources

Further, the IT-department identifies the lack of resources as a barrier for successful implementation of welfare technology in municipal health care.

“I know we paid for equipment and projects within health... For the [implementation] project, there was nothing.. As far as I know, there was no funds for working with the project, which was in addition to all our other tasks, which makes it hard. When you don't get the resources to work with it.” (Municipality 1, Participant 2)

From the IT-departments' viewpoint, there is no understanding in the decision-making parts of the municipality about how these systems are intertwined and complex. Due to the complexity and importance of the systems being up and running, the IT-departments are in need for additional resources, both for participating in projects, but also to be able to administer the systems after implementation.

“They could not have done it, you know. The smallest municipalities, we could not have done this on our own.” (Municipality 2+3, Participant 1)

IT-departments pinpoint that the lack of resources is a risk factor for any welfare technology project, including the maintenance and support required by such systems:

“But the IT-department has asked the municipal administration and the politicians, do you really want to run this way? It is risky. Yes, we do not have the money, we cannot prioritize, it just has to... It is good if it works. The support and maintenance has been ad-hoc, a few phone calls over the weekend, does not matter where you are. Over the phone if you cannot show up. This is where the municipalities has not accepted their responsibility, they have implemented services in health care sector, that requires 24/7 IT-support, without the support” (Municipality 2+3, Participant 3)

Which leads us into the next issue identified by the IT-departments, 24/7 IT-service.

3.3 24/7 IT-Service

Implementation of welfare technology and digitalization of health care require a new way of thinking when it comes to the IT-service. In the workshops, the healthcare personnel reported that IT systems were not accessible during the night shifts, due to the back-up routines of the IT-departments. Back-up was taken when the IT-departments themselves were off duty and hence not interfering with their daily work. However, as the health care service is working 24/7, the routine was not convenient nor user-friendly.

The IT-departments identified the risk of not being available if the system goes down when it is outside office hours. In the worst case scenario, the implications of systems not being online is life or death.

“No, like I said earlier, we who are working here with IT are a support department, we are. So we deliver what we are

required to deliver. Like I said earlier... Sometimes you have all the claws out, we are afraid of the consequences we can experience, if we are unable to keep the system up and running 24/7.” (Municipality 1, Participant 1)

Other municipalities bring up examples of how the health care workers have created work-arounds to ensure possible system failures will interfere as little as possible in their day-to-day work, support this:

“Right, not all of the municipalities have managed to establish a 24/7 IT-service. So we have, yes, some nursing homes in our group... At Easter, they will print the critical journals, because they do not know when or if somebody will come to fix things if the system goes down.” (Municipality 2+3, Participant 3)

Due to the importance of this technology, the IT-departments are worried about both being accessible and having the competencies to give the support needed 24/7:

“It is hard to build the competencies to deliver services of good quality, when you speak about... After a while, life-and health systems. Right, that cost an arm and a leg. You need surveillance 24 hours a day; you have to be on every little sensor, right?” (Municipality 3)

All of these findings show there is great concern both in the healthcare service and in the IT-departments about the day-to-day operation of the IT-systems, and how they are expected to support a new digital era.

4 DISCUSSION

Then what are we to do when critical systems are supported by an IT-department which is under-staffed and has office hours between 8 am and 4 pm? Not only that, by a group of knowledge workers who are not involved when decisions are made in their domain. How do we expect the future of our health care to look, when digitalization is moving forward in a speed we cannot stop, but the ones responsible for decision-making do not include the very people they have hired to implement, maintain and support the systems they decide to use?

Previous literature have informed us that involvement of top management and end users are crucial to the success of technology implementation, both in public and private sector (Damodaran, 1996; Følstad, Jørgensen and Krogstie, 2004; Høstgaard, Bertelsen and Nøhr, 2017; Sumner, 1999; Thong, Yap and Raman, 1996). However, the lack of involvement of the IT-department has not been discussed. As presented in the findings in this study, the decision to implement technology in municipal health care is made politically, without involvement from the knowledge workers. Although, the nature of the IT-department has been studied (Guillemette and Paré, 2012), involving the IT-department too late into an IT-project have been demonstrated in this study. Existing IT infrastructure forms a barrier and IT staff exhibit substantial resistance to the implementation of welfare technology, when IT has not been involved from the very beginning of the implementation (Nilsen et al., 2016). Based on this knowledge it can be argued that the IT-

department should be seen as the Project Coordinator described by Guillemette and Paré (Guillemette and Paré, 2012). In this theoretical ideal the IT-department function aim to develop a sourcing strategy that will create business value (Guillemette and Paré, 2012).

Figure 1. shows the three different versions of organizing an IT-department in a municipality.

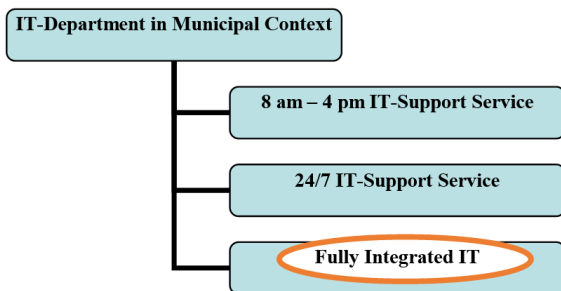


Figure 1 Organizations of IT-department

The IT-departments are arguing that they need the resources to be able to deliver a 24/7 IT-service to the municipalities. By being allocated the resources the IT-department see themselves as Systems Providers, Architecture Builder and Technological leaders (Guillemette and Paré, 2012). Through these roles, they can be a valued member of the municipality and be able to respond to issues as they appear. The typical IT-department in a municipality has office hours during the day, and need to be available on ad-hoc basis through phone or be able so show up on short notice to deal with issues outside working hours. This is not calculated in their core time, which means it is ideal-work to keep the wheels running. The IT-departments ask for resources to ensure systems staying operative and no down time. Through this work, the IT-department still will be a support, not part of the core activity.

5 CONCLUSION

Our research reveals that there is clearly a need for a deeper understanding of the nature and needs of the health care service and for in-depth knowledge of all the new technology. In addition, knowledge about how welfare technology should be accommodated in the municipal IT infrastructure and integrated in the national e-health systems. When appropriate IT-services are designed for the new, digital era. We argue that a fully integrated IT-department is a better solution for the municipal health- and care service. The future of public sector, and especially health care, will experience an increasing need for digitalization (Vest, 2010). We argue that we cannot treat IT as a support function, but need to see this as an integrated part of the health care services provided to citizens from the municipality.

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Evaluation of a Telemedical-Based Care Pathway for Patients With COPD

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Abstract

This paper presents results from an evaluation of the care pathway for patients with COPD in the U4H project in Agder, Norway and may serve as a recommendation for future care pathways for COPD patients. Our evaluation was based on qualitative interviews and a review of key documents and research papers.

The care pathway included daily videoconference follow-ups for a period of 14 days, then a reduced follow-up for at least 16 more days. It contributed to increased accessibility, increased safety, and improved clinical insight for patients with COPD. However, we recommend a care pathway with room for more flexibility depending on individual needs, on the severity of COPD, and on what level of the services the patients already have. Patients should be able to be recruited from hospitals, home care services, and GPs. Video communication should be offered. Continuity in the follow-up is important for the sense of safety. The integration between specialist health care, home services, and GPs will become even more important in future telemedicine services as the number of patients increases.

Keywords

Care pathway, Telemedicine, COPD

1 INTRODUCTION

The proportion of elderly people in need of healthcare is increasing, and the prevalence of people suffering from chronic and long-term illnesses in different age-groups has been rising (Freid et al., 2012), and is likely to continue to rise with rising proportion of elderly. These trends will cause significantly increased pressure on society in terms of access to qualified health personnel (The Ministry of Health, 2009) and to financial resources (Nielsen et al., 2011). The planning and organization of health and social services must be rethought due to this challenge (Morris et al., 2006).

In Norway, better collaboration in the healthcare services, changes in the division of responsibilities between primary care and specialist health services, and innovation through utilizing technological solutions, such as ICT, telemedicine, and welfare technology, are suggested as measures for accessible, better, and more rational services (The Ministry of Health, 2011). This was the basis for the implementation of the Collaboration Reform in 2012 (The Ministry of Health, 2009), and based on this reform, major changes in the Norwegian healthcare services have been implemented. Patients are increasingly being followed up at a lower level of care than before and are transferred to the municipal health service more rapidly post treatment in the specialist health service, a change that requires well-functioning collaborative chains (The Ministry of Health, 2009). However, in line with increasing specialization, the healthcare services have become more and more

fragmented, resulting in a lack of continuity in the follow-up of older adults and of patients with chronic disorders (Coleman and Berenson, 2004; Stange, 2009). In addition, introducing clinical guidelines into routine daily practice often implies major difficulties, and as a result, many patients do not receive appropriate care (Paulsen et al., 2013). One potential tool to facilitate the implementation of evidence into practice is by implementing a care pathway. Care pathways are defined as “a complex intervention for the mutual decision making and organization of predictable care for a well-defined group of patients during a well-defined period” [9]. However, one of the major challenges associated with establishing care pathways is to ensure good interaction between the specialist health services and primary healthcare, for example in connection with patient discharge from hospitals (Paulsen et al., 2013). Therefore, in recent years, special attention has been focused on integrated care by developing care pathways involving both specialist healthcare and primary care (Smith et al., 2007; Sunde et al., 2014). Most of these care pathways are made for specific chronic diseases (Smith, 2012; Vanhaecht et al., 2016).

Chronic Obstructive Pulmonary Disease (COPD) is a chronic life-threatening disease, and patients with severe COPD typically need repeated hospital treatment (Vestbo et al. 2013). About 1 in 4 patients who are prone to COPD deterioration will be readmitted within the first 30 days after discharge (The ministry of Health, 2006). Hence, there is a need for further follow-up for many patients

Paper from the 15th Scandinavian Conference on Health Informatics SHI2017, Kristiansand, Norway, 29 - 30 August.

Conference Proceedings published by [Linköping University Electronic Press](http://www.lnupress.se/).

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when they are discharged from the hospital. In this regard, self-management strategies and care pathways have been developed for patients with COPD (Vanhaecht et al., 2016). In addition, to improve the efficiency of healthcare services, attempts have been made to provide follow-up for certain groups of patients with chronic disorders through telemedicine (Henderson et al., 2013), where especially many have focused on care pathways for patients with COPD (Pinnock et al., 2013).

Traditionally, both care pathways and telemedicine services have been offered by the specialist health service, but as municipalities have taken over much of the follow-up of patients with chronic disorders, it has become more relevant for municipalities to take these initiatives (Røsstad et al., 2013).

A care pathway for patients with COPD, which included telemedicine services and that would work across levels of management, was established in the Agder region in Southern Norway as part of the European project United4Health (U4H). (<http://www.united4health.no/>). The project started in 2012 and ended in 2015. The telemedicine service was established as a municipal service (Gallefoss et al., 2012), whereas in other regions in the project, this was a service organized under the hospitals (Kidholm, 2016). Three telemedicine centrals (TMCs) were established; each intended to cover a group of surrounding municipalities. The purpose with this paper is to present the results from an evaluation of the care pathway for patients with COPD established in Agder for the U4H project, which may serve as a recommendation for future care pathways for patients with COPD.

2 METHODS

2.1 Design

We used a qualitative research approach, which is well suited to study problems that cannot be explored in isolation from their human and social context (Creswell, 2013). Case studies facilitate the investigation of a phenomenon within its social context, in its natural setting (Yin, 2014). Because of the exploratory nature of the research, we used an exploratory approach with qualitative interviews and a review of key documents in our evaluation.

2.2 Setting of the case

The case was carried out as a project in a region in southern Norway and involved two TMCs. The centrals were open Monday to Saturday during the daytime, staffed with one nurse each, all the time. Some of the nurses had additional tasks for other departments, and in short periods some nurses from other departments would step in.

The staff at the two TMCs communicated with the patients, and hence needed to access medical information about them and to communicate with the specialist health service. Patients had at their disposal tablets with

measuring equipment (pulse oximeter) and an online self-reporting tool. The measuring equipment transmitted measurement values wirelessly to the tablet, before being transferred from the tablet to the TMC.

Description of the care pathway

Patients with COPD were included in the project as they were discharged from hospitalization due to exacerbations. With a few exceptions, they received equipment and training at the hospital.

From October 2015 and onwards, patients could also be recruited by the municipalities. Patients recruited and included from the municipalities were given equipment and received training from the staff at the TMC.

The new routines were intended to contribute to a comprehensive care pathway. The GP continued to have the main responsibility for patients while they received telemedicine services. The nurses could obtain advice from the GP and from the municipality's home care services, and they could send information back. The specialist health service could be consulted via a separate electronic health record (EHR) system, developed for this project, where both nurses at the TMC and at the hospital had access.

At the start of the telemedicine follow-up, an intake interview was conducted to establish contact with the patient. An e-message was then sent to the GP with information about the enrolment. From then onwards, daily talks were conducted for 14 days. During these talks, staff from the TMC went through a questionnaire based on a checklist and reviewed the patients' measurements and their self-registration of health status. The checklist contained topics like smoking cessation, nutrition, and physical activity. After 14 days, the nurses would generally suggest reduced monitoring, and a new e-message with information was sent to the GP. Reduced follow-up implied continuing daily measurements and self-registration of health status, which were transferred to the TMC and controlled by a nurse. If necessary, a nurse would call the patient. In addition, the patient could contact the TMC if they felt the need. The patients completed a more comprehensive form (CAT - COPD Assessment Test) twice; this served as a mapping of their quality of life. After 30 days, the nurses reassessed the patients' status after a talk with them. Another e-message was sent to the GPs to allow input from them, before deciding whether to end the already reduced monitoring. In some cases, patients wanted to continue, and some were allowed to continue with daily measurements and self-registration for several more days before handing in the tablets. After submitting the tablets, patients could call the TMC when needed.

In addition to sending e-messages to the GP, the routines indicated that an e-message should be sent to the Health and Care Service Office and to the Home Care Services in the patients' home municipality at start-up, after 14 days, and at the end of TM treatment. The care pathway indicated that a "security card" should be established in

the home municipality's EHR for service recipients who had not previously received municipal healthcare services. This was done to register the patients as a recipient of telemedicine services.

Technology support

The nurses at the TMCs had three computers with monitors: a screen with a web camera and a headset for video conferencing, a screen with access to the municipal EHR (only possible for patients from the host municipality), and a screen with access to the EHR system that was shared with the specialist healthcare service. Thus, the nurses had to log on to two different systems on two different screens for each patient, and they had to communicate with the patient via a third screen.

The nurses had a decision support tool in the form of a "triage system," which was based on patients' measurements and self-registration of their health status. The results of pulse and oxygen saturation and the self-assessment formed the basis for a color-coded score. A green score indicated no need for action, a yellow score indicated a need for follow-up of a nurse within one hour, and a red score implied immediate follow-up / ingestion, and possible contact with a physician. If a patient had a yellow score for two consecutive days, a red score was shown.

2.3 Data collection

Five interviews of stakeholders involved in the establishment and implementation of the new service were carried out. We interviewed a counselor responsible for communication with GPs in the municipality concerning the role of the GPs in U4H, a project manager/employee in one of the municipalities concerning the start of the project, a home nurse with special responsibility for following up with patients with COPD concerning the involvement of home nursing services, and two nurses about their work in the TMC. The interviews were all semi-structured, and the questions were tailored to the interviewees (e.g., asking about their experiences carrying out their specific tasks). We taped three of the interviews, and notes were taken for all. The interviews lasted from 30–40 minutes each.

In addition, we carried out a review of notes and reports describing the care pathway (Gallefoss et al, 2012; Dagsvik and Ås, 2016; Kidholm, 2016; Vassbø, 2016). The results from several master's theses (Gundersen et al., 2016; Bårdsen, 2015; Moløkken, 2015; Urving, 2015) and from two research papers were also included in the evaluation (Barken et al., 2017; Vatnøy et al., 2017).

The project was approved by the Regional Committee for Medical Research Ethics ref. 2013/2115, but was considered outside of REK's mandate according to the Health Research Act. It was approved by the Norwegian Social Science Data Services, ref. 41549.

3 RESULTS

Our assessment shows that the service and the telemedicine treatment process in the United4Health (U4H) project have had several positive effects.

Most patients were pleased with the follow-up and believed that it contributed to increased accessibility, increased safety, and improved clinical insight. Good accessibility to healthcare professionals was important in the periods when patients experienced deterioration, especially patients with anxiety.

At the start of this project, only the hospital recruited patients. However, both the municipalities and the doctors wanted to recruit patients. When recruiting, it was important to ensure that patients knew what they possibly said no to. The training had to be good, so the patients understood why and how they should participate. Many of the COPD patients were so fatigued that it required a great deal of energy to master modern technology.

Several of the informants noted in their interviews that the care pathway in our case study was not flexible enough. Not all patients needed follow-up every day and with the same intensity. Some only needed follow-up during periods when they were ill. By being followed-up every day, some experienced feeling pathologized through having too much focus on their health status. Too much of an emphasis on disease can reduce motivation and hope for recovery. Some patients expressed getting "too much" follow-up and having too many people to deal with. Flexibility in terms of the time of day was also important. Many patients with COPD have sleeping disturbance, and it may be difficult to have a daily video conference meeting early in the morning. This was, for some, a reason for refraining from participating in the project.

It was important for the staff at the TMC to help patients see and interpret their symptoms and to do what they could do to prevent deterioration. Our findings indicate that the checklists were a good starting point for the daily conversations. In addition, the triage system was useful to support their decisions, but not sufficient. The nurses had to search several sources to gain a more comprehensive picture of the patients' medical history and to make a final assessment of the situation in collaboration with the patients. However, a lack of integration between different IT systems was a key barrier for working effectively. The fact that some information was fragmented reinforced this.

Initially, good practices were established for information exchange between TMS, doctors, and service offices and the home care services; however, data from interviews indicate that routines were not followed in periods when temporary staff took over for permanent employees.

We found that information about telemedical monitoring should be repeated regularly to relevant partners as GPs, hospitals, and decision makers of healthcare services in municipalities. In addition, employees in the home care services that may be called to move out to patients who have an exacerbation must receive regular information

about when and how they can access the required patient information.

There are several conditions that should be present for the GPs to become engaged. There must be a large patient base, which makes it worthwhile to invest time and resources to establish new routines for follow-up. A combination of e-messages and video consultation will be a good basis for interactions between TMCs and general practitioners. Co-operation meetings between TMCs and general practitioners should also be possible through video conferencing.

Technical problems were a significant challenge in the project. Good support was perceived as critical, as one-stop support, without too many healthcare professionals involved and having too many phones, as this tired the patient. Using video provided greater opportunities for assessing the patient's condition, while some patients were satisfied with only telephone contact.

4 DISCUSSION

In this case study, we have evaluated the care pathway for patients with COPD.

Our findings imply need for flexibility both in terms of frequency and form, including the time of day, and are in line with findings from previous studies (Hendy et al., 2012; Sunde et al., 2014; May et al., 2011). According to Hendy et al. (2012), the development of a remote care service cannot occur in a contextual vacuum treated as a prewrapped generic implementation package to be adapted later. Locally sensitive levers and incentives must be factored in and co-designed, both from inception and along the way. Interventions are needed that ensure user-centered rather than biomedical/service-centered models of care (Sunde et al., 2014). Hendy et al. concluded that the implementation of a complex innovation such as telemedicine requires it to organically evolve, be responsive and adaptable to the local healthcare system, and driven by front-line staff and management (Hendy et al., 2012). Flexibility in care pathways must be prioritized; Røsstad et al. (2013) found that disease-based care pathways for older patients are neither feasible nor sustainable in primary care and recommended a patient-centered care pathway.

Our findings imply that it is important to adjust the follow-up to individual needs. Follow-up should be organized so that one can easily regulate the frequency and the approach to following-up. This confirms May et al.'s previous findings, concluding that understanding the fit between everyday routines of the users and technologies in the home is essential for the uptake and use of technology (May et al., 2011). A more personalized and individual supervision, possibly with individualized content, can help the service to fit more patients. In addition, one should consider developing more checklists, both to be able to serve more diverse patient groups and as a quality assurance by having a documentation of the dialogue with the patients. With an understanding of the

content of the conversations and of the service, it is easier to fully know what works. Further, our findings clearly indicate that video communication should be offered. Pols (Pols, 2016) found that telemedicine technology did not put care at a distance, but rather in close proximity.

Our results imply that the hospital should continue to recruit patients as they discharge them. We find that, in addition, it is important that patient recruitment is available from home care services, which may potentially free up resources for these services. GPs can also identify and recruit patients who would otherwise have no healthcare. Seemungal and Wedzicha (2006) referred to a number of different studies, some of which have applied different forms of recruitment, but they did not find any correlation between recruitment and readmission rates.

We further found that continuity in the follow-up, when the patients met with the same nurse regularly, was important for their sense of safety. Oudshoorn pointed out that to know the patient as a person, including having knowledge about the disease, can provide valuable information about the patient's health status (2016). The nurses in our study had all undergone specific training and had several supporting technologies (checklist, triage system, and self-reporting from the patients). Horton underlined that nursing management in a telemedicine context requires new and advanced knowledge (Horton, 2008). We will argue that the competence at the TMC must be maintained when new employees start. If the target audience for telemedicine is expanded, employees must have a good insight into all relevant diseases, and there must be nurses with special expertise.

Integration between host communities, home services, and GPs will become even more important in future telemedicine services as the number of patients increases. It is especially important to ensure useful information exchange from the host municipalities to other municipalities they are covering.

There is also a need to be careful in the level of the service offering. According to May et al. (2011), telecare services may offer a cost-effective and safe form of care for some people living with chronic illness, but not for all. Hence; there is a need to assess cost-effectiveness before deciding on what level of service to offer to a patient.

5 IMPLICATIONS AND CONCLUSION

The care pathway applied in the U4H project contributed to increased accessibility, increased safety, and improved clinical insight for most of the patients. These were patients who had just been discharged from the hospital after a severe exacerbation. They were all followed up and could talk to a nurse daily, most over videoconference, for a limited period. In addition, they registered measurements daily, and hence could be contacted by the nurse after the initial period with daily talks. This implies that there is a need for a care pathway for this group with daily follow up and with daily talks with a nurse for a limited period, and the possibility of getting in touch with

the nurse beyond this initial period. However, the needs of the patients differ, and there is a definite need for flexibility in the care pathways. Based on our findings, we will propose a somewhat adjusted care pathway than the one applied, with room for more flexibility for individual needs. We will also propose that recruitment can be done by both specialist healthcare and primary care, including both GPs and home care services. However, it is still necessary to have a comprehensive recruitment and training process, especially for patients whose health condition is poor and with low technology experience.

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7 ACKNOWLEDGEMENT

The acknowledgement can include reference to grants, colleagues, institutions etc. important for the support, research and writing the paper.

Sensor Technology for Night Surveillance: The Experiences of Next of Kin

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Abstract

In-depth interviews were conducted to gather information. The aim was to investigate next of kin experiences when healthcare professionals used sensor technology to take care of their relatives in elderly care. Findings show that next of kin experienced better sleep for both themselves and their relatives. Those who were offered the sensor technology services were few. We need more research to conclude how it will work on a larger scale. We know that implementing Information and Communication Technology changes work flow, but we don't know the effect of how these tools will make changes when implemented on a larger scale.

Keywords

Home healthcare services, Night shift, Sensor technology, Elderly care, Welfare technology

1 INTRODUCTION

Motivated by an increasing cohort of elderly people, the Norwegian Ministry of Health, the Norwegian Directorate of eHealth, Norwegian municipalities, and healthcare providers look to technological solutions for help in managing the upcoming challenges in elderly care. They expect that "Welfare technology and assistive technology, as in smart homes and telecare, improve healthcare quality at the same time as saving resources" (NOU2011:11) and (NOU2015:13) and (White Paper no:2, 2016). This paper explores next of kin experiences when healthcare professionals use sensor technology to take care of their relatives in elderly care. The sensors were bed sensors, front door sensors, and fall sensors used in bathrooms. None of these elderly patients were offered video recording. Bed sensors triggered an alarm when a patient went to the toilet and did not return to bed within a pre-set time. The research questions were as follows:

1. What was perceived as the main reason for using sensor technology?
2. What were the next of kin's experiences of using sensor technology, regarding safety and security?

The project has followed four municipalities in Southern Norway in their challenges and efforts when implementing welfare technology over a period of two years.

2 BACKGROUND

Most people want to take care of themselves. However, if you are in need of daily support, you might need healthcare services or to stay in a nursing home.

Healthcare professionals may use technology to enable patients to stay at home longer and take care of themselves. Application of sensor technology as part of nursing care to get the most out of limited human resources, should be discussed. Findings from Missouri, USA, show that patients who are using sensor technology in controlled areas, such as an independent living facility, live longer (Ranz, et al.2015). No similar study has been conducted in Norway. However, the healthcare system in the municipalities aims to improve quality of life for its healthcare receivers by using sensor technology; and living longer is not necessarily a measurement of better quality.

The project we followed in this study mainly intended to monitor elderly or disabled people with sensor technology. The sensors operated in a network or were individually connected to a centralized alarm center. Combining the individual needs of the users and trying to manage elderly care in a cost-effective way were some of the overall goals for the project we studied. Maslow's Hierarchy of Needs, a five-stage pyramid where the lower levels cover how humans seek to satisfy basic physiological needs and the desire to feel safe and secure, is well known in healthcare. However; Thielke et al. (2012) have suggested that this model is only slightly consistent with how Assisted Technology (AT) tends to solve human problems in elderly care. According to Maslow's model, human needs on the lower levels must be solved before progressing to higher level needs; in this project, the AT tries to cover the need to feel safe and secure by using sensor technology to look after patients at night. In Norway, there has been a policy to get patients back to their homes quicker (White Paper:2008-2009 no. 47). Patients end active treatment and are discharged to their homes even if they could benefit from a day or two more in hospital. Patients who need nursing

Paper from the 15th Scandinavian Conference on Health Informatics SHI2017, Kristiansand, Norway, 29 - 30 August.

Conference Proceedings published by by [Linköping University Electronic Press](#).

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services at night after being discharged; are offered these services through home healthcare or nursing homes in Norway.

The AT alarm system has been developed to monitor people who cannot reach a phone or push an alarm button. It is important to feel safe and secure and to sleep undisturbed; however, healthcare professionals checking overnight may disturb sleep. Sensor systems that include AT may prevent sleep disturbances. Many patients and next of kin request services characterized as “to be looked after” at night in case of an emergency, for instance a fall. There are narratives from healthcare professionals of how night visits disturb the patient without providing any guarantee that they will not fall as soon as the Registered Nurses (RN) has left their bedroom. Patients suffering from dementia, who tend to go out walking at night and cannot find their way home again, are in the target user group.

Innovation in care is a politically wanted change, as this may help in dealing with the increasing number of elderly people who will need care in the years to come (NOU2011:11). Nurses working overnight shifts in nursing homes have found innovative ways to manage looking after patients who tend to walk around overnight. The photo below illustrates how some used a plastic cup on the door. When patients went to the door to get out, the healthcare professionals would be warned by the sound of the cup falling, and therefore be able to catch up with them before they left the building.



Figure 1 - Photo from Østre Agder, Project: Digital Look at Patients

2.1 Prior Research

Earlier studies have shown how workflow is changed when Information and Communication Technology (ICT) is implemented (Li, 2010). The workflow in this study mainly concerns how the next of kin can change their way of interacting with their relatives when using sensor technology. Sensor technology has been introduced in smart homes as a part of AT, but the level at which it interacts with healthcare providers, with the inhabitants of the smart home, and with their relatives varies. Ding et al. (2011) argue that sensor technology seems to support independent living in smart homes; however, more evidence should be collected before widely deploying it in everyday life. Grant and Rockwood (2015) studied 14 home healthcare agencies and assisted living facilities across five states in the US by carrying out

interviews, and describing clients' satisfaction, health quality, and patient safety. They argued that clients living with telehealth services as AT would be more satisfied than those not implementing it. Chan et al. (2008) reviewed studies of smart homes. They presented challenges such as design difficulties with validating the alarm triggered, but stated that technological devices are designed to allow elderly people a more autonomous life even though they live in a secured and comfortable environment. It seems that using sensor technology in combination with services from health professionals can support fragile elderly, both in nursing homes and in their own homes. Regarding these prior studies, it is necessary to look at the use of sensor technology as a tool in the context of nursing care in the municipalities.

3 METHODS

3.1 Design

A qualitative design is well suited to catch lived experience (Polit & Beck, 2014). The findings reported in this paper are based on interviews of the patients' next of kin.

3.2 Setting and sample

The project was followed almost from the start of the planning phase to the implementation of sensor technology for monitoring of the patient during the nights. Special considerations have been made to protect individuals' anonymity in this project, as there were individuals participating from small municipalities where people know a lot about each other. Everybody included in the project was therefore invited to be interviewed and to give their opinions to the researchers. Information about this opportunity to tell about their experiences was communicated to all next of kin by the project leaders, both via oral communication individually and handing over written information and consent forms. A total of six next of kin returned signed consent forms. No additional request was made.

The interviews were planned to be conducted from the start of the project. One interview was not included in our data set because the experiences this next of kin had at the time were from only two nights of use, as the sensor had been moved to someone else who needed it more. Five individual interviews were included in this study. An open question technique was used to catch their experiences and all the interviews started with the question “Can you tell us about how and what you experienced when sensor technology was given as an opportunity to your relatives?” The interviews with next of kin gave rich information about how they regarded the use of technology and what they expected from the municipalities. The age of the patients is not recorded. The three who still lived in their own homes had all reached a point where it was a question of either installing sensor technology or applying for a full-time place in a nursing home. All the information given by the

next of kin concerning their needs is anonymized, since they all live in small municipalities. Neither the project group nor anyone else should be able to identify these persons, irrespective of whether they clearly welcomed the sensor technology or considered not implementing it. Three municipalities started implementing sensor technology in nursing homes and in-home healthcare at the same time. Both wired sensors and wireless sensors were installed. During the first stage of the project, which lasted six months, as many as 12 patients were using sensor technology during the night. By the end of the project in December 2016, a total of 75 users had been included. These users were all from three municipalities. The fourth municipality taking part in the project did not have the financial means to start implementation of the sensors, but decided to follow the process in order to be ready to install when they got funding. One of the municipalities had tried out the sensor technology in a previous pilot.

The project group contacted the researchers and participated in a discussion of design and methodology. In this paper, we present the lived experiences for patients seen from the view of the next of kin, regarding the feeling of being safe and secure overnight when sensor technology is applied in elderly care.

Both males and females were among the interviewees. Their mean age was early sixties. One of them worked full time and studied in addition. Three were retired or out of regular work in other ways. All of them also had other family members to take care of. The interviewees all decided where to conduct the interviews, these were carried out either in their homes, in the nursing home, in the researcher's office, or in an office in the public house of the municipality. There were no disturbances during the interviews; and the conversations were easy to carry out. None of the interviewees seemed embarrassed or distracted; they were all eager to share information, to express their thoughts, and to tell whether this technology was something they were able to rely on.

When there is such a close bond between the people receiving the service and the people interviewed, it is important to critically evaluate both the process and the end results. Therefore, the whole process needs to be as transparent as possible (Fog, 1994). In challenging the transparency of the research process, it is necessary to be well aware of the presuppositions of those involved. In this study, we experienced that the project group were convinced that the results were good even before we had started collecting data, and their presuppositions may have influenced some participants.

3.3 Data analysis

In hermeneutic thinking about interpretation and analysis, the whole and parts are inextricably linked to each other (Alvesen & Sköldberg, 2009). Once we had decided to examine the feeling of safety at night, it was essential to determine how and if those involved felt safe and secure. The hermeneutic approach argues a more

phenomenological approach to their experiences in this context (Alvesen & Sköldberg, 2009; Van Manen, 2006). Several field notes were taken as a supplement to capture the "whole" from meetings and situations where the researcher was present. Capturing the whole is limited by the preunderstanding, by what the respondents can describe, and by what the analyzing process discovers. Deep interviews have been used to investigate if relatives' experiences are connected to the technological equipment, and if so, whether it influences the feeling of being safe and secure at night. The project leaders in the municipalities recruited participants for interviews, and the scientists were not permitted to directly contact any participant before they had signed and returned their declaration of consent in a closed envelope. The project has been approved by the Norwegian Centre for Research Data (NSD) and is registered with the following number: 40832.

Deep qualitative interviews were done with the patients' closest relatives. The patients could bring their relatives with them for the interviews if they wished. All the interviews, the field notes, and other texts are interpreted and analyzed through a hermeneutic-phenomenological approach. The interviews were transcribed verbatim. When they were read through again, different colors were used to separate the meaning units, and the quotes were marked. After this process, a mind map was made to identify the most important statements, and these were analyzed in a hermeneutic-phenomenological understanding as described by Hammersley & Atkinson (2007) and Kvale and Brinkmann (2009). When analyzing the data, the first focus was on the words spoken: the content. Thereafter the researcher stressed keeping preconceptions aside, because of the close bond to the project group and the fact that they wanted to tell about the success factors and how well the sensor technology worked in every meeting. We wanted to get the next of kin's descriptions without any distortions (?) and find out how they regarded the patient's and their own experiences using the AT.

4 RESULTS

All the patients who were offered sensor technology had a previous history of either wandering out alone or accidentally falling during nights. One relative said: *"We were offered help with technology after he had been staying out in the evening; it was this Spring, and it was a cold night, and he was sent to the hospital, ... I thought it was the end. It seems he didn't manage to find his way back and get inside, and I realized this could have been a very sad ending; I could no longer take the responsibility.... [I was] arguing about him with my sister, if and how he should live at home alone any longer. We decided to apply for him and try to get a place to stay and be looked after, especially at night, in a nursing home."*

The municipalities offered to let them try the sensor technology. Permission to use sensor technology is often given by next of kin who find technology useful for looking after their relatives. Another example from a next of kin shows this quite clearly. He/she said: *"After her fall in the bathroom where she lay on the floor with a hip fracture for fourteen hours, she lost her belief in being able to manage at home, but with these sensors or the technology she's confident that she will manage again."* The next of kin interviewed seemed to believe in technological solutions as something naturally to use for both helping the patients to live longer in their homes and strengthening the feeling of being safe and secure in their homes. The next of kin seem to expect technological solutions to be useful all the time and regard them as wanted by the patients because of their physiological needs. Some next of kin regard technological solutions as the rule. One said: *"I think this should be the normal standard, everybody should have it... if or when needed."*

Next of kin to patients with dementia who tend to wander around, express feeling more safe and secure that their relatives will be taken care of if needed, after the sensors were implemented. One said: *"My number one fear her worst nightmare: lying on the floor or somewhere.... not being able to alarm anyone or get up; lying there in pain for hours. You know that would be awful."*

The next of kin described the patients using sensor technology as rarely being aware of the technology. In addition, the patients were often unable to commit voluntarily to the use themselves. A relative said: *"I don't think she even knows if it is there; she never asks me about it, about the sensor, or touches it. It's just standing there. I wouldn't mind myself if I was in this condition. I would be glad someone cared for me and to be safe, even though I might not know."* Some of the next of kin clearly stated they would have given permission for the use of sensor technology both day and night, but one argued for not wanting the technical solutions to be used in the daytime because of the patient's social needs for seeing other people.

Next of kin living in multi-generation homes reported having better sleep quality when their relatives were looked after by sensor technology. One next of kin said: *"One can more easily go to sleep, as well."*

Although one next of kin did not want the sensor technology to be used in the daytime, they had decided that using it at nighttime for security was an advantage. A next of kin who had his/her relative in the nursing home living alone in an apartment argued: *"I agreed to the use of sensor technology because it was to be used at night. By day I feel she needs to see people as much as possible rather than sitting alone."*

5 DISCUSSION AND IMPLICATIONS

Some next of kin expect technological solutions to be available for everyone. The technological solutions seem to give the opportunity to let next of kin fulfill the patient's wish to live in their home as long as possible. The more sensors we install, the more alarms we will have to answer. This will change the way next of kin communicate and look after their relatives. We have examples of people developing their own surveillance systems to monitor their parents or spouses when they get ill; they often argue that these systems help the monitored person to become more independent of other people or to live home longer. Use of technology might give the patients and the next of kin a higher level of self-care; as described by Barnard and Sandelowski (2001) technology can be an extender of care. Normally people are regarded as wanting to manage on their own. One can divide patients in need of nursing in two groups: those who can decide to buy and install technology to be able to live longer in their homes on their own, and those who need help to still be able to live at home or to stay independent. Nursing theory is described by Orem (2001) in different levels of self-care, with human potential and human limitations; nursing theory can regard applying technology as the patients' action to maintain a higher level of self-care and allowing them to stay at home longer. Technologies used in social media might change this situation totally. Just imagine taking part in a family Christmas dinner sitting in your own place, or in the nursing home, and having a real-time video communication; being able to see enjoying the feeling of being there. Using technology in healthcare solutions and knowing how reliable it is; is another interesting issue. Permission to install sensors is often given by relatives, who find technology useful for this purpose. When asking next of kin, the researcher needs to have a clear understanding of the technology's capabilities and rely on the information given. The next of kin seem to expect technological solutions and assume them to be useful all the time.

Implementing technology changes the workflow in more than one way. It is nearly always expected that one can work more effectively and get more done using technology, but research has also shown how ICT is reshaping organizations by simply affecting more and more tasks and thereby changing the way we work (Li, 2010). Is it in fact possible that the technology will identify more work to be done, and if so, how will the health professionals manage and deal with this extra workload? In this case, it is possible to program the sensors to alert relatives first if they live nearby or in the same house. If the alarms are activated precisely every time an acute situation occurs, everyone will be satisfied with these solutions. But if the alarm alerts the next of kin without being needed the technology will most certainly be considered useless. Ding et al. (2011) argue that sensor technology for smart homes should address actual needs. In our study, it seems that this

recommendation is taken care of, as all the next of kin described a change in the patients' health as the triggering reason to start using the sensor technology. But one must consider carefully whom this sensor will alert, and how often the relatives will be alerted at night. The situation will also differ between households; as everybody has individual needs. When family members are part of the caregiving team through being alerted, one should consider whether the situation is properly taken care of regarding all parts involved. First, is this a solution the patients would want if they could commit voluntarily? Zwijsen and Niemeijer (2011) point out that the debate regarding autonomy in ethics of using AT in elderly care seems inappropriate considering the situation of frail, elderly people. Some may regard this use of sensors as illegal surveillance. In some ways, this is quite close to our opinion, especially regarding those patients unable to commit to the use of sensors.

But we also need to discuss whether use of technology is what is needed and wanted for patients with dementia to live the way they would wish if they could decide for themselves. It ought to be possible to give an early statement regarding commitment to use before dementia develops too far.

Considering the case of relatives, often patient's closest contacts are his or her own children, friends, or neighbors living nearby. Hence, it is necessary to know the will of the patients. Who are to be involved as next of kin if a person with dementia falls on the way to the toilet and can't get up again without help? Family structure is changing fast in Norway; more and more families consist of few people. One- or two-person families are not rare. One can't expect everybody to take on the responsibility for elderly people living at home. If sensor alarms go off every night, this would be very much like having a baby to look after. Being able to sleep undisturbed through the night is crucial to most of us. Relatives in this study report sleeping better after the sensors were implemented. Relatives of patients with dementia who tend to wander around feel more safe and secure that their relatives will be taken care of if needed. This feeling also tends to improve their sleep: relatives living in multi-generation homes report having better sleep quality when they know the patients are looked after by sensor technology. In this case, the alarms tend to give better sleep quality because relatives can rest and let go of worries about whether the patients are wandering around and might fall. To this point, one can say the relatives are feeling safe and secure and get better sleep.

But do the patients with dementia feel safe and secure with the technology when they don't know they are monitored? Some of them will never feel safe and secure no matter what the technology can provide because their illness is at a stage where this is beyond their concern. In this case, the technology can help the healthcare giver to meet a patient's needs from the moment they occur and this may lead to the next of kin feeling safe and secure

that their relatives are taken care of in a proper way. But the patients themselves will hardly notice why they receive help in the moment they fall or rise to get out of bed. Another important question is whether they would want this solution if they knew of it.

So far, all technological solutions need power to work; if technological solutions don't have any backup power, they will be turned off after a storm or when someone accidentally destroys a cable. In healthcare, this needs to be paid proper attention to; one needs to know what to do when technology fails, because it will sooner or later.

Before jumping to the conclusion that both patient and next of kin feel more safe and secure, there is a need for a broad discussion about whether this is a solution that the patients wish for themselves and welcome for use in their own life. One must pay attention to the skepticism noticed among elderly people, who tend to respond that it might be useful for someone else but not for them Thielke et al. (2012). This might be a polite way of telling us that this is something they don't want to be used in their home. It is also important to discuss whether a longer life is necessarily a better life. Individuals seek to meet their needs differently; some want to be as healthy as possible and put safety and the feeling of being safe and secure above nearly everything else, while others tend to seek independence which implies insecure situations. The AT used in this study was introduced to frail, elderly people who had accidentally had a fall, got lost by wandering, or encountered other risky situations and this made their next of kin feel insecure on their behalf. This might present an easy argument for a decision to use sensor technology to monitor all patients so it won't happen again. We must recognize that AT can feel like a technological prison for people who usually do as they please in their own home. Thielke et al. (2012) have argued that AT in general does not yet meet what the patients seek; as it is described by elderly as not what they want for themselves, but something that may be useful to someone else. Some elderly who tend to be insecure and anxious might welcome this technology more than others who rarely get that feeling.

The same arguments can be made for people who have responsibility for someone else, whether they are healthcare providers or next of kin. Taking risk in one's own life is something one does all the time and is closely connected to the feeling of being independent as a human. The technological solutions must seek to still give this feeling of independence, even when using sensor technology. If the individual being taken care of can still manage and make real use of the technology to live more independently, that is a reasonable situation if one wants to live at home. Some elderly argue that living at home is the most important. However, being frail and old might be different from what we imagine; a lot of elderly seem to appreciate getting company, and tend to seek satisfaction of social needs by staying in nursing homes. Some even get more active because they are not alone. In Norway, these institutions are not being prioritized;

nursing homes tend to be inhabited by patients who are very sick and fragile and who often suffer from cognitive failure. This might make sensor technology useful for the healthcare providers in nursing homes.

More and more people in Norway tend to buy their own flats to manage better when growing older. This trend might open up for installing and using technologies in ways that have not yet occurred to the developers. Smartphones can take care of a lot of needs as long as you manage to program or install what you want on them. An example is controlling heat and blocking out the sun in a home; this is more common today and something many people manage on their own. Nearly everything can be regulated by sensors, and if this is how one can manage everyday life, why not use it in care when getting fragile and old? Sensor floors in flats may send a message if you stay there more than an hour and might not even feel intrusive if you install them yourself. Chan et al. (2008) stress the need to meet the individual needs of each person when installing assistive technology and they underline the need to consider the legal and ethical problems in this context. In Norway, the regulations were changed to allow use of sensor technology in elderly care. This change was made during the project period, and there is a need to follow this developing process further to be sure ethical challenges are properly solved. Digital security and the use of ICT for a simpler working day are intended to both streamline work processes and protect individuals White Paper no. 27 (2015 - 2016). We must also consider and discuss further whether loneliness is a private problem, or a healthcare problem to be taken care of. If we accept it as a healthcare problem, nursing may be able to discover if this is caused by sickness and if not, nursing might not be the right treatment.

6 CONCLUSIONS

Better sleep quality is a key reason for installing sensor technology in nursing homes and home healthcare services, according to the next of kin in this study. Sleep quality has an effect on a person's health conditions and everyday life. Our results need to be confirmed through further studies because the number of participants was low. The question of when and if a patient or next of kin is feeling safe and secure is one perspective. However, both earlier studies and this study implies that use of sensor technology lead to the next of kin's feeling of keeping their relatives safe and secure during night. Also, the importance of being able to sleep undisturbed is of utmost importance for the health of both patients and their next of kin. Regarding Maslow's pyramid these basic needs for sleep and feeling safe and secure can be met to a certain extent by using sensor technology to look after the elderly at night. This also seems to help some patients, and/or their next of kin, to maintain a higher level of self-care. The question of whether to apply digital surveillance to achieve healthcare quality and efficiency needs to be solved, especially when people who need AT

care can't commit voluntarily to its use. Technology is not the only challenge for dignity in elderly care; but if it used in a way that the patient or the next of kin finds suitable, it may actually protect dignity. In a few years, this might actually not be regarded as an ethical issue any more.

Author contributions

LIMH was responsible for the study's conception and design, performed the data collection and data analysis, and drafted the manuscript. MF and CEM participated in data analysis and made critical revisions of the paper.

Acknowledgement

We would like to thank all the participants involved who shared their experiences and knowledge. We would also like to thank the project group and the four municipalities for engaging the researchers from the University of Agder to follow their project. The study has partly and indirectly been financed by the Department of Health, which arranged meeting places to discuss and share knowledge from these nationally financed projects.

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