PAHI 2015
Practical Aspects of Health Informatics

Proceedings of the 3rd European Workshop on Practical Aspects of Health Informatics (PAHI 2015)

Elgin, Scotland, UK, October 27, 2015.

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Table of Contents

Session 1: Service Design

Session 2: Tele-mediated Health Communication

Session 3: Health Information and eHealth Literacy

Abstracts of Keynotes and Additional Presentations

PAHI 2015 Preface:
Transforming Patient Experience using Digital Technologies

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1 Introduction

The third European workshop on Practical Aspects of Health Informatics (PAHI 2015) took place at the Alexander Graham Bell Centre, Moray College, UHI in Elgin, Scotland between Oct 27th and 28th, 2015, with participants from Scotland, Norway, Germany, Portugal and England.

The Norwegian University of Science and Technology (NTNU) organised this year¹s workshop in collaboration with the Institute of Design Innovation (InDI), the Norwegian Research Network for Women in Health Informatics, the University of Highlands and Islands, the University of Aberdeen and NHS Grampian. (The InDI leads the Experience Labs, which are a core element of the Digital Health Institute, a Scottish Funding Council Innovation Centre.) The workshop reception was supported by Highlands and Islands Enterprise (HIE).

This year's workshop focused on transforming patient experience using digital technologies. The Western paradigm of health care has favoured medical solutions rather than public health and cultural solutions. While this paradigm has been effective in delivering health care in the past, it is not positioned to handle complex new societal challenges. New approaches are needed to solve the problems facing health care delivery caused by ageing populations, globalisation and long-term chronic conditions. Ensuring future effectiveness of medicine increasingly requires innovation through preventative, participatory, personalized, and predictive modes. Changes must involve movement from a reactive model to a preventative patient-centric model. Information and communication technologies will play an increasing role in this process at all stages of life leading to an approach which can simultaneously maximize health and minimize or prevent illness (creating preferable

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
Proceedings of the 3rd European Workshop on Practical Aspects of Health Informatics
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health outcomes). However, the patient must buy into using these technologies for these goals to be realised.

1.1 The objective and aims of PAHI 2015

The objective of PAHI 2015 was to explore how patient experience can be transformed through digital technologies. The specific aims were fivefold: 1) a platform for academics to present research within this field, 2) the opportunity for clinicians and civic organisations to discuss key challenges requiring digital solutions in health and social care, 3) the opportunity for businesses to understand this emerging landscape, 4) the opportunity for government to present the overview of health and social care innovation in Scotland and Norway, 5) to provide a platform enabling the exchange of ideas between Scotland and Norway resulting in new collaborations and partnerships for future European funding.

1.2 The review process

The call for papers to the workshop included, but was not limited to, the following topics:

- eHealth communication,
- eHealth literacy,
- Professional and lay communication in citizen-centred records,
- Quality and risk management in eHealth,
- eHealth ethics,
- The increasing mobility and communication in citizen-centred records,
- Lessons learned in relation to failure projects,
- Patient-centred ICT,
- The impact of ICT for professional healthcare practice,
- Translating HI research into clinical practice,
- Methodological development of healthcare ICT relevant for practice,
- Usability of health informatics,
- Policies and strategies for ICT in healthcare,
- Bridging the gap between health informatics research and clinical practice,
- Health informatics on new computing platforms,
- Health informatics for home use,
- Coordination aspects in use of health informatics,
- Design aspects of health informatics and Health Web Science.

Papers and abstracts from researchers from many fields of health informatics were received. Each of the submissions underwent a minimum three reviews (some had five reviews) from anonymous reviewers, and was rated according to predefined criteria. The accepted submissions were categorised thematically under *service design*, *tele-mediated health communication*, *health information and ehealth literacy*.

In addition to the peer-reviewed submissions, the program included *abstract presentations* and *poster pitches* (the posters are described in the following booklet: http://sislab.no/pahi/2015/PAHI_posters_booklet.pdf). Full papers are eligible for Cristin points in the Norwegian system. The accepted submissions and abstracts can be found in the proceedings.

2 The Workshop

Prof Grant Cumming welcomed the delegates and opened the workshop. He gave a brief overview of why the venue was named after Alexander Graham Bell and an overview of the programme within the context of transforming patient experience using digital technologies (see http://sislab.no/pahi/2015/DHI_programme_03.pdf). The workshop also hosted a real time demonstration of QUBE. QUBE is a fully immersive virtual platform (http://www.qube.cc) which provides a collaborative virtual office/workshop environment and has been driving innovation in Scotland. QUBE has over 400 tools to support agile Projects, innovation and leadership and helps change behaviours and ways of working in a positive way to better enable sustained change across geographies and organisations.

QUBE has shown a reduction in project lifecycle of around 50%, reduced costs by around 50% (staff time saved, travel time and costs, cost of external workshops). 100% of users surveyed said QUBE significantly increase effectiveness in collaborating with stakeholders and that the embedded tools significantly improve better project outcomes. Over 80% of users surveyed felt that QUBE offered a safe and open space for collaborative working that is difficult to achieve in the real world.

NO Delays was used as an example of using the QUBE platform for collaboration with participation from colleagues in Norway, Scotland, Ireland and Brazil.

2.1 Invited keynotes

Eddie Turnbull is currently the Head of eHealth for The Scottish Government. Eddie has worked for Scottish central government for 36 years, always with ICT leadership as a career anchor. Over the years he has directed a number of large national programmes with ICT as the major enabler. His current role is to ensure that eHealth activity across NHS Scotland is coordinated and supports the aims of the NHS Scotland Quality Strategy, delivers joined-up provision of healthcare in pursuit of Scotland's 2020 Vision of health and care, and ties in with the change and improvement agendas set out by The Scottish Government. He is actively involved is shaping and delivering a number of Scotland's wider strategic digital initiatives. He gave an overview of ehealth strategies in Scotland.

Justene Ewing is the CEO of the Digital Health & Care Institute (DHI) and is charged with establishing and delivering the DHI objectives. The DHI is one of a family of innovation centres in Scotland funded by the Scottish Founding Council and aims to utilise Scottish universities infrastructures, human resources and research excellence capability to create an exciting platform for collaborations across Scotland.

As part of her keynote, Justene outlined the structure and work of the DHI, highlighting that “person-centred innovation” is at the core of its activities

Gabriel Kiss, PhD is senior engineer/researcher at the Operating room of the future (FOR), and a researcher at MI-Lab, ISB, NTNU. At FOR his main responsibility is to maintain the technology platform provided by the Norwegian Centre for Minimally Invasive Image Guided Therapy and Medical Technologies, NorMIT as well as research in the field of medical imaging. He presented the evolution of the FOR at NTNU from conception to present and then proposed a direction of travel for the foreseeable future.

2.2 Chairs

General Chair: Grant Cumming (UHI, UoA, NHS Grampian)
Program Chairs: Tara French (Glasgow School of Arts), Heidi Gilstad (NTNU)
Publication Chairs: Ellen Jaatun (NTNU), Martin Gilje Jaatun (SINTEF ICT)

Acknowledgments. We wish to thank NTNU, HIE, InDI and the DHI for their support of the workshop.

Moving towards a Comprehensive Medication Dispensing Service for Patients in Transition from Hospital to Primary Care

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Abstract. In primary health care it is often challenging to obtain a supply of drugs when a patient is discharged to their home or to a nursing institution. Both access to updated information about the (new) medication, and the practical organization per se, present obstacles. The need for early information in the receiving units is in conflict with the hospitals` need to make decisions regarding treatment up until the point of discharge. The practical handling is affected by e.g. distance to the local pharmacy and the accessibility of certified health care workers. We aim to design and implement a medication dispensing service to ensure that the patients who are discharged to primary health care (home care services or nursing homes) are supplied with medication in the transition period, until regular supply is (re)established. In this paper we describe the complexity of the area, impacting factors to be considered and outline a stepwise approach to design a comprehensive service for enhanced patient safety.

Keywords: Medication dispensing service, care transition, multidose drug dispensing, unit dose drug dispensing, clinical pharmacy, medication reconciliation, patient safety.

1 Introduction

Ensuring the supply of drugs for a patient in transit between hospital and primary health care is a challenging task, in particular when medication treatment regimens are changed. The challenge consists of two subsequent and interdependent main parts; information transmission with regards to the (changed) medication and the process for acquiring and dispensing the drugs.

The availability of drugs is affected by distance and accessibility of health services, e.g. 168 (39%) of the Norwegian municipalities do not have a local pharmacy [1], which consequently impacts how fast it is possible to acquire drugs. The administration of drugs is a task undertaken by the nurses in public health care services. Other health care professionals may also assist, but in internal protocols the dispensing of drugs is most often described as being a nurse’s responsibility to safeguard. Thus, when a nurse is unavailable at the time the patient arrives, a practical

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problem arises. Furthermore, introduction of the multidose drug dispensing system (MDD) has been shown to represent a lack of flexibility within the system [2].

Along with an ageing population and a shift towards increasingly advanced medical treatments outside hospitals, new approaches to ensure patient safety are called for. When elderly patients are transferred between care settings, an average of two drug errors occurs [3]. Errors often occur due to poor communication about the drug use.

The University Hospital in Trondheim, St. Olav's Hospital, has a written cooperation agreement with local municipalities, describing e.g. interaction with regards to the transition of patients between care settings. There are often conflicting interests between the care providers at the time of discharge, affecting the practical handling of the transition and consequently the transit time: The hospital wants the flexibility to alter care regimens and therefore medication lists close to the time of discharge. Whilst the receiving units, on the other hand, need time to prepare, preferably during opening hours, and therefore require early discharge information.

Today these challenges are solved more or less ad hoc, e.g. the patient is given a few tablets “in hand” at discharge, but the lack of standardized procedures leads to poor predictability for the receiving units. To reduce the issue, we aim to design a medication dispensing service ensuring patients in transit between hospital and home care are provided with some days’ supply of drugs. The targeted patient group is typically dependent on care support to be able to return home, and represent approximately 200 of the weekly discharges from St. Olav`s Hospital.

Complex interventions – consisting of multiple behavioral, technological, and organizational components – are common and important features of health care practice and research [4]. Designing a medication dispensing service within the hospital for patients in the discharge phase falls within the definition of complex interventions. As an example, the financing of medicines in Norway is complex in itself; covered in part by the patient itself and in part by the Government, split between hospital-, municipality- and insurance budgets [5].

This paper presents an approach for developing a service and discusses different conditions that need to be met. Since the project is in a very early phase, no results are reported in this current paper.

2 Dispensing of drugs

In primary care, dispensing of drugs is primarily done by using two different approaches; conventional, manual dispensing from tablet boxes undertaken by a nurse or an assistant, or multidose drug dispensing (MDD). MDD (Figure 1) are drugs that are machine-packed into dose unit bags for each time of administration [6].

At St. Olav's Hospital unit dose drugs (UDD) (Figure 2) dispensed at the local Hospital Pharmacy are used. UDD is more flexible than MDD since the single dose unit bags are labeled with drug content data only, and not with patient data and time for intake. In primary care the changes in medicines are less frequent than in hospitals, and most often multidose drugs are dispensed for a period of two week for patients in home care services, and one week for patients in nursing homes.

Figure 1: Multidose dispensed drugs packed for two weeks' use for a patient in home care services

Figure 2: One tablet unit dose dispensed drug packed for a patient in hospital

2.1 Obstacles within the multidose drug dispensing system

When an intervention presents practical obstacles, or elements of the intervention are considered unnecessary, or not meaningful, in order to complete the work, stakeholders will redesign the work process to minimize the obstacles [7, 8]. It has been reported that a lack of flexibility in prescriptions of drugs when implementing the MDD system, e.g. a temporary change in dosage, was considered problematic in the MDD system [2]. For most patients, some drugs (such as eye drops and inhalers, as well as drugs taken irregularly) have to be maintained manually in parallel with the multidose dispensed drugs, and for other drugs only manual dispensing is suitable. This is an indication that the MDD system is not adequate by itself, and manual dispensing has to be maintained together with the MDD to ensure medications are dispensed. Thus, additional use of manual dispensing is a way to work around an imperfect MDD system.

Although MDD systems have been called an automation of the medicines management chain, there are manual processes within the chain. The patient's medication list is recorded several times during the process, and all the manual work causes a risk of errors during the different steps of the process. In addition, there will always be a risk of adverse drug events because of errors in the communications between professionals involved in the MDD, i.e. when patients are transferred between various health care settings [9, 10]. Therefore, automation in the processes for updating information between relevant care providers has been called for [11]. On the other hand, it has been emphasized that automated processes in the handling of drugs may threaten the quality of many (hidden) manual work processes [12].

The patients in primary care are primarily elderly and sick people that move between health care providers. Thus, health care providers outside primary care must also act in accordance with the MDD system. There are few studies that look at how health professionals in secondary care experience the MDD system. However, a published paper concluded that when elderly patients are transferred from hospital to community/primary care, the main risk factor seems to be the MDD, or rather the process for using it [10]. More research is needed to learn how best to handle the MDD patient when moving between different care settings.

3 Information transfer

To ensure safe, efficient and seamless patient care, it is essential to have access to correct information regarding patient medication. Reported in one study, only 61% of patients admitted to an emergency ward had updated medicines lists [13]. Furthermore, errors in medication prescription histories at hospital admissions are found in up to 70% of the lists [14].

3.1 Information and communication technology solutions

Several information and communication technology solutions aim to reduce these problems. However, introduction of new systems are not entirely unproblematic, as new obstacles and new sources of errors may occur [15-17]. In general it could be sensible to handle information transfer electronically with some caution as it could be assumed that a more structural presentation of information could lead to a false sense of security.

Since early 2013, the system for electronic prescribing has gradually been introduced in Norway, and has later been introduced in Norwegian hospitals. Electronic prescribing for the MDD-system is currently under development. In addition, the national core health record is introduced and gathers selected and important information about the patients' health, included medications. This is particularly useful during urgent medical assistance.

Electronic messaging (e-messaging) is commonly used for information transfer between different parts of the health care system, e.g. between primary and specialist care, and between primary care and general practitioners. An evaluation of the integration of e-messaging has been conducted, and both desirable and undesirable effects as well as large variations in the routines for using it, have been found [18].

The Central Norwegian Regional Health Authority is currently, in collaboration with the regional municipalities, evaluating the need and possibility for a new, joint electronic patient health record. This ICT solution will provide care providers across different settings with real time patient information.

3.2 Quality assurance of information about medicines

Clinical pharmacist in Norway most commonly use the method of Integrated Medicines Management (IMM) when involved in patient care [19]. The method follows the patient care through three main phases: medication reconciliation at admission, medications review during the stay, and medication reconciliation at discharge [20]. The method is described as systematic and seamless, the latter referring to the exchange of information across different care settings.

During the period 2014-2015 there has been a considerable increase from 11 to 25 clinical pharmacists in hospital wards within the Central Norwegian Regional Health Authority. The clinical pharmacists are integrated in multidisciplinary teams, and are advisors to the responsible doctors. Hopefully this initiative will drive quality improvements in our hospitals as seen in Sweden, where systems supported by clinical pharmacists resulted in a reduction in the frequency of errors when patients were transferred from hospital to primary care [10].

Still, quality assurance may be done by different measures and by different health workers. Thus, it is essential that the responsibility is clearly assigned to ensure a systematical approach. Regardless, to ensure a medication dispensing service that enhances patient safety, it is a prerequisite that the basis for the dispensing is a correct medication list. Together with the dispensed medications, the drug information following the patient at discharge should be good and coherent [21].

4 Practical approach for designing a medication dispensing service

Complex interventions might need complex solutions, and therefore it is of importance that the process leading to a proposed solution for medication supply is carried out in several steps, as depicted in Figure 3: First, a thorough mapping of factors influencing the design of the service will be done. The complexity of the area and the questions needed to be addressed are outlined in further detail in section 4.1 and Table 1. A thorough identification of the needs of the different users, i.e. health care workers in both care settings, the hospital pharmacy and last but not least the patients, form the basis for an initial design of the service. A small pilot study is then conducted with patient discharged from one hospital ward. Finally, the service will be evaluated for further adjustment (redesign) and implementation in more wards, which then again needs to be tested and evaluated in a circle of continuous improvement.

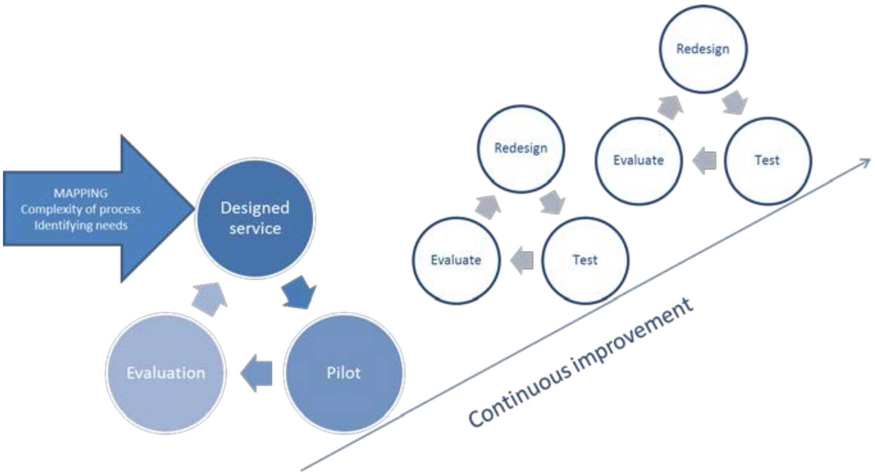

Figure 3: Stepwise approach and continuous improvement for design and implementation of the medication dispensing service

A new service must safeguard different considerations for the service to fulfil quite some critical needs, and it can be assumed that "one size fits all" will not apply. Nevertheless, the service must be of such uniformity that predictability is ensured, which in turn will allow the receiving units to plan and restructure how they handle patient flow. Thus, it is of critical importance to collaborate closely with the municipalities when designing the service, to ensure commitment and beneficial outcome for all parties. This collaboration will start by identifying needs through work-shops and interviews with central persons from one or two included municipalities.

The timing of the dispensing in the discharge process should be as late as possible in order to avoid errors in the dispensing caused by changes made at a late stage of the hospital stay. Likewise, the prescription source for the dispensing must be defined. This depends on the location of the dispensing; at the hospital ward or in the hospital pharmacy, and by whom the work is undertaken; by nurses or pharmacists.

As previously pointed out, thorough consideration of the differences between the receiving units in primary care is important. The service may also be differentiated due to patient characteristics (e.g. multidose drug user) and by the different medications used (providing all medication or just the ones changed? etc.). These and other considerations are listed in Table 1.

Table 1: Needs and impacting factors to be considered in the mapping process

Setting/Actor	Need	Questions
Hospital	Right timing of the dispensing	• How much time is needed to dispense the drugs? • How close to the point of discharge are changes made in the prescribing?
Pharmacy/Hospital Hospital/Pharmacy/ Municipality	Detailed and accurate prescription information for dispensing and labeling of the dispensed medication	• What source of information is used for dispensing? • How should the dispensed drug be labelled, controlled and delivered to the ward/patient
	Information transfer to patient and/or primary care providers	• How is information about administration given to the patients along with the dispensed drugs? E.g. labeling of the unit dose bags or on a separate information note. • Should the service include a complete updated medicines list along with the drugs?
Hospital/ Municipality	Categorization of patients included in the service	• What kind of service is the patient discharged to? • Does the patient administer the drug him/herself or with assistance from the health care service? • Is the patient a MDD patient or a patient with ordinary prescribing? • Has there been made (major) changes in the medication list during the hospitalization?
Pharmacy/Hospital/ Municipality	Categorization of medications included in the service	• Are the drugs available as unit dose drugs in the hospital? • Medication by formulation (e.g. tablets, eye drops, and inhalers) or • Medication by dosage (only medication taken regularly, or drugs to be used as required, as well)? • Is the cost of the medication (low-high) a factor to take into account

Table 1 (cont.)

Setting/Actor	**Need**	**Questions**
Municipalities	Optimal period of time (days) with dispensed drugs from the hospital before regular dispensing is reestablished	• Are there differences in needs in terms of the length of the dispensing period between municipalities, depending on distance to local pharmacy? • Does the need vary depending on type of health service (nursing home, home care services or rehabilitation institution)? • Does the need vary depending on whether the patient is a MDD user or not?
Hospital/Pharmacy/ Municipality	Clarification of roles and responsibilities	• What are the responsibilities and tasks of the different participants in the medicines management chain? These may be the prescribers at the hospital, the nurse at the hospital, discharge coordinator, the clinical pharmacist, the pharmacist at the hospital pharmacy, the patients GP, the nurse in the municipality and others. • What are the jurisdictional frames regulating these responsibilities?
Hospital/ Municipality/the patients	Addressing the medication costs	• In the phase of moving between care settings; who bears the cost of medicines? And for the associated dispensing?

5 Conclusion

Changing between health care settings presents several challenges. Two of the main obstacles with regards to medications have been discussed; information transfer and medication acquiring. To enhance patient safety, a service for medication dispensing for patients in transit between hospital and primary care is being planned. When designing a new service it is important to understand the needs and how the problems are solved within current conditions. Hence, the complexity of the area and all impacting factors will be mapped out and piloted at a small scale before further implementation. The final aim is a service that is beneficial for all involved parties.

Acknowledgments We would like to thank our colleagues for the input during the work with this topic, and the commitment for establishing a service for drug dispensing in interest of the patient moving between different care settings. Thanks also to our leaders for having granted us the work time spent writing this paper, and to Kirsty Holter for proofreading the manuscript.

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MediTake, a Medication App to Improve Adherence – a Service Design Evaluation

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Abstract. Medication is one of the most important factors for preventing, treating, or revealing the impact of illness and disease. Medication non-adherence is a challenge because it reduces the effectiveness of treatment and imposes significant resources on the healthcare system and society as a whole. Studies show that up to 50% of people with chronic illnesses do not take their medications as prescribed. MediTake application was developed to support people in their medication management, as a means to increase self-management and medication adherence. The aim of this study was to implement and evaluate a suggested pharmaceutical service, where the MediTake app had a central role, to support patients' medication adherence and self-management. We here report on the professionals' perspectives from the service design evaluation.

1 Introduction

Medication is one of the most important factors for preventing, treating and revealing the impact of illness and disease. The management of medications depends on several factors such as correct diagnosis, correct treatment, implementation of measures, and on the patients' adherence to medications prescribed. Many people do not take their medications as prescribed; this is particularly prevalent among people suffering from chronic diseases and among people that use multiple concomitant medications[1-3]. Studies show that up to 50% of all people suffering from chronic diseases do not take their medications as prescribed [1, 2].

Adherence is by the International Society for Pharmacoeconomics and Outcome Research defined as "the extent to which a patient acts in accordance with the prescribed interval, and dose of a dosing regimen" [4]. The cause of medication non-adherence is broadly categorized as intentional or unintentional [5, 6]. The latter involves that the patient intents to take a medication as instructed but fail doing so because of reasons such as forgetfulness, carelessness, misunderstandings etc. Patient characteristics, treatment factors, and patient-provider issues influence such non-adherence. Intended non-adherence involves that the patient stops taking a medication as instructed due to perceptions, feelings, or beliefs. Such non-adherence reflects a rational decision-making process where the treatment benefits are weighed against any adverse treatment effects [5]. Successful management of chronic disease is highly

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dependent on the individual patients abilities to take responsibility for own care and treatment. The integration of mobile phones into our lives creates new opportunities to enhance self-management activities through features such as reminders, informational and motivational messaging, and, provides possibilities for self-monitoring of symptoms and behaviors (e.g. adherence to medications) [7].

It is estimated that 10% of all hospital admissions are because of reduced adherence, in worst case leading to illness and death [3]. The impacts of poor adherence to medication regimens are severe, both for the individual as in worsening of disease and death, and for the society as a whole because of health care costs and societal expenses. Physicians' ability to recognize patients' non-adherence has been poor, and interventions to improve adherence have been substantially complex, costly, and with mixed results [2]. In short-term drug treatments, studies show that counseling, written information and personal phone calls help [8]. For long-term treatments, no simple intervention lead to improvements in health outcomes, and only some of the more complex interventions are shown to have impact [8]. Therefore, the need to explore approaches for improved service delivery and creating support tools for those with long-term treatments are therefore still important. The two main objectives of the hospital pharmacy enterprise in Norway are: (1) to provide pharmaceutical services to ensure the correct use of medicine, and, (2) to ensure the reliable and cost efficient distribution of medicine [9].

As part of this research study, a proposed pharmaceutical service model "app @ the pharmacy" was implemented into the hospital pharmacies in Central Norway. The service involved that pharmacist promoted correct use of medication by introducing a medication app, as a means that the patients could use in their daily life to improve self-management and medication adherence. The objective of the current study was to evaluate the suggested pharmaceutical service. We here report on the pharmacists' perspective. The patients' experiences are reported elsewhere.

2 Methods

The study was conducted 2014 – 2015. Norwegian Social Service Data Services (NSD) approved the project. All participants provided informed consent when participating in the study.

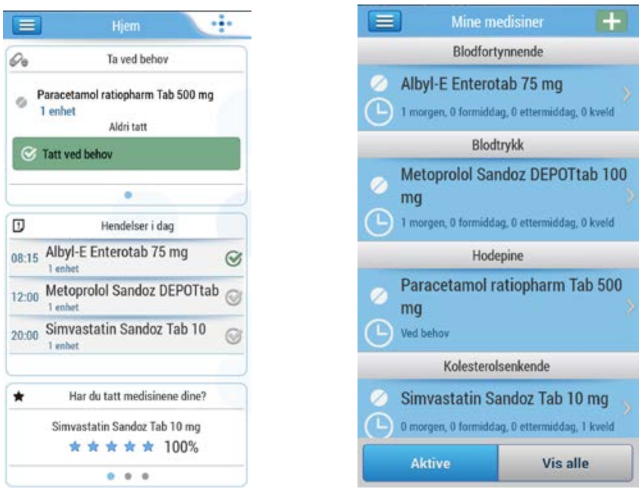
2.1 MediTake Medication App

The MediTake app was developed by Pierre Major in cooperation with the hospital pharmacy trust and NTNU Technology Transfer. The app was programmed in Android Native Development Kit, and was available for Android phones through Google play at the time of the study.

The features of the app included:

- The patient's medication list (had to be registered manually)
- Reminders (about when to take the medication: pop-ups with sound)
- Self-monitoring (statistics adherence rate: medications taken)

- Information about medications (hyperlink to felleskatalogen which delivers patient information about medications)



Hjem

Ta ved behov

Paracetamol ratiopharm Tab 500 mg
1 enhet
Aldri tatt

Tatt ved behov

Hendelser i dag

08:15 Albyl-E Enterotab 75 mg
1 enhet

12:00 Metoprolol Sandoz DEPOTtab
1 enhet

20:00 Simvastatin Sandoz Tab 10
1 enhet

Har du tatt medisinene dine?

Simvastatin Sandoz Tab 10 mg
★ ★ ★ ★ ★ 100%

Mine medisiner

Blodfortynnende

Albyl-E Enterotab 75 mg
1 morgen, 0 formiddag, 0 ettermiddag, 0 kveld

Blodtrykk

Metoprolol Sandoz DEPOTtab 100 mg
1 morgen, 0 formiddag, 0 ettermiddag, 0 kveld

Hodepine

Paracetamol ratiopharm Tab 500 mg
Ved behov

Kolesterolsenkende

Simvastatin Sandoz Tab 10 mg
0 morgen, 0 formiddag, 0 ettermiddag, 1 kveld

Aktive

Vis alle

Fig. 1: Two Screen Captions from MediTake Medication App

2.2 The Pharmaceutical Service

The pharmaceutical service, “App @ the pharmacy”, was implemented at the 6 hospital pharmacies in the Mid-Region of Norway. The service was implemented into the regular daily work at the pharmacies without extra incentives, and involved that pharmacists requested and offered the service to patients. Patients’ inclusion criteria to receive the service were: (1) age above 16 years, (2) have an Android smartphone, (3) manage own medications, (4) use medications for more than three weeks (long-term use), and (5) provide an informed consent.

The service involved that the pharmacists taught the customer about the app and provided patient information about the customers’ medications. To get access the app, it had to be downloaded from Google play to the patients’ phone. The pharmacists were instructed to facilitate the customer and provide a short introduction about the app, before registering some of the patients’ medication so that the patients’ could complete the list by their own, and, thereafter use the app in their home environment. The pharmacists were instructed to call the patients’ by phone after a couple of weeks, to follow-up the patients and provide support if necessary.

2.3 Data collection

Throughout the project period, 18 pharmacists provided the service. Data collection involved 4 semi-structured group interviews with 13 (9 women & 4 men) of the pharmacists who had provided the service. Both authors conducted most of the group interviews together, except from the last interview, which was conducted by the first author alone due to practical reasons. In each interview, 3-4 professionals attended, and the participants represented 4 of the 6 involved pharmacies where the service was implemented.

During the group interviews, participatory design methods were applied, such as brainstorming sessions, storyboarding activities, presentation rounds, and plenary discussion. Each interview lasted 2-2,5 hours, was tape-recorded, transcribed verbatim, and analyzed inductively.

Fig. 2: Participant in group-interview creating a storyboard

3 Results

The participants reported on barriers and benefits of conducting the pharmaceutical service. Four major themes were identified: (1) user groups, (2) workflow integration, (3) usability, and (4) usefulness.

3.1 User groups

During the study period, the pharmacists provided the service to 77 patients but reported to have offered the service to significantly more people than included. The main reasons for customer rejection to the service were because of lack of experience or competence to enable the technology, that they did not have the required smartphone, or the time required to acquire the service. The fact that some customers had limited experience in using a smartphone became a challenge for the professionals, who used considerable recourses in teaching some customers basic features of using a smartphones, a task they considered to be beyond their responsibility:

> *"Well, I don't think the challenge is merely the app. We are to access Google-play. Okay! It is all the other stuff. Not all patients are qualified, even though they have an Android phone, they aren't there. We partly used lots of resources in teaching them how to use a smartphone. And that isn't, I don't think that is our… then we could have let it be. I don't think it will be successful either" (male, pharmacist).*

The pharmacists acted deliberate in whom they offered the service, and whom they avoided to request. Several reported that customers non-verbal language influenced whether they would introduce the service: "*it's something with their body language,* *they are like "can't I just get my pills and leave?" (male, pharmacists).* Thus, some reported that it was easier to offer the service to the elderly, who they found to have time. In other instances, the pharmacists would purposely avoid to suggest the service to certain user groups whom they considered the service would to be an extra burden: *"I don't remember all the reasons, but for instance a couple with a chronic ill child, and those kind of customers, don't bear to consider asking them"(female, pharmacist).* The pharmacists reported that they had avoided customer groups whom they perceived to be vulnerable, such as cancer patients and patients in palliative care:

> *"I think it is so… I have avoided cancer patients, because I have felt that they have enough. Even though they use complex medications" (male, pharmacist).*
>
> *"Another group are those in palliative care. Come and get their last dose with strong opioids, then you don't start talking about this service… No, so there were actually quite many, I experienced, who were like that"(female, pharmacist).*

Another said that she wanted to protect the customer from an information overload: *"for those patients that already are frequently in the hospital and get a lot of information, it is something with not overloading them totally" (female, pharmacist).* On the other hand, the pharmacists reported that the inclusion criteria for receiving the service were too restricted because they considered that other user groups, in addition to those with long-term medication treatment, would benefit of getting the pharmaceutical service:

> *"User groups that would benefit of using the app would for instance be parents of small children, or customers that are to use antibiotics for a week, or ten days or so… [] I feel that some user groups are excluded. And some who I really would like to get hold of, like the orthopedic patients, would probably have been very positive, some of those who go for rehabilitation, right? […] They use anticoagulant drugs and they use painkillers. It would be very practical to get a summary of how much painkillers they have been using."(male, pharmacist)*

Among other potential user groups they mentioned: (1) relatives that managed the medication for their children or parents, (2) users that needed to establish new dosing schedules, (3) users that needed time critical dosages (e.g. Parkinson's disease, people using painkillers), (4) for complex dosing schedules, (5) for people using time limited medication (antibiotics) – and particularly if several times a day, and, (6) for those who needed cognitive support/reminders to take medications.

3.2 Workflow integration

Most of the pharmacists in this study worked at the front desk in the public department of the pharmacy, while a few also worked in the hospital wards, conducting medication reconciliation and reviews. The success of the workflow integration depended on where the service had been carried out. Those who conducted it during their work in the hospital ward reported that the service became an integrated part of their already established work:

> *“And when I was in the ward, I didn’t ask everyone, but I asked those who I during the interview identified had a problem, who didn’t remember to take their medication […] So when you start talking to them, you find that they don’t have a regular intake, or that they don’t take it, that they forget it in the evening, or that they… so you reveal many of those kind of things during the conversation, and then I have asked if they would like this […] When I have been in the ward, I think it has been easier to introduce it in a way, when you have a conversation about their medications anyway” (female, pharmacist).*

Providing the service in the public department involved more challenges with limited workflow integration. The service often fell behind due to other work tasks, resulting in that the pharmacists forgot to offer the service to their customers, as a female pharmacist explained: *“yes, I have just forgotten it”*. Another pharmacist reported: *“And it is to remember to offer the service, in general. I feel that I have to [prioritize] to have it in my head somewhere: That day, yes, okay, that day I will really do it.”* Another expressed that he found it challenging to introduce the service to the customers: *“Sometimes I think it has been difficult to introduce MediTake in a good and informative way. But then, I have become better for each time I have done it.”* This was a shared experience by several. Self-confidence about providing the service was connected with experience:

> *“Yes, I have asked everyone. Had to force myself to ask, though. Because, then I felt, it became a routine, yes, to get used to it. But in the beginning it was like “oh, no, don’t want to get rejected”(female, pharmacist).*

The main difficulties of conducting the service were related to limited time, resources, and infrastructures. Short of staff, heavy workload and limited time at the front desk and influenced if the pharmacists could prioritize conducting the service. Some reported that they preferred requesting the customer about the service, and making an appointment for the customer to come back to receive the service. Among the infrastructural challenges, Internet access was reported to be cumbersome and inconvenient, which made it a barrier because installing the app required Internet access to download it from Google play.

3.3 Usability

A structured usability evaluation was not within the scope of the current study, but usability issues concerning the app were identified as part of the project. The main usability issue that influenced the service delivery was the required time to register medications in the app, a task the pharmacists assisted the customers with. The participants reported that time to conduct this task depended on the customers’ experience with smartphone and the number of medications prescribed:

> *“It takes enormous amount of time before they can register the one medication. And it is not intuitive, that you are supposed to go there, and there, and then I have to help them. It is not as integrated as for us younger… if it is a person with less technological experience and who has many medications, then it takes very long time. So it is a challenge (male, pharmacist).*

This resulted in that the pharmacists tried to plan to have sufficient time to carry out the service, which again influenced the (dis) integration with their workflow.

3.4 Usefulness

The pharmacists reported about the usefulness of the service and app. They considered the app to be a good support tool that they could offer to their customers. Some experienced that the service involved increased direct patient contact that facilitated promotion of correct use of medication:

> *"They, I have taken them [patients] with me to the information room, right? And then they share more about their medications and their experience. And I became kind of surprised, because when we are at the front desk, then, I don't think people are that sharing. So, then I have like…there was this guy who said that he had impotence problems, and questioned the medications. And then I asked about when he had started to take his beta-blockers. And I said that he absolutely needed to discuss this with his doctors, and he was a bit…I felt that I was useful there. Those kind of things."(male, pharmacist)*

The participants talked about the convenience of providing the app to certain users, particularly younger users who needed a support tool to manage their medications:

> *"[…] in the conversation you discover that there are too many [medications to handle], and that they need help to remember to take their medication. And I feel that they get good help when you can offer them a support tool. And in the hospital ward… you have more time and you can offer something to those who feel too young to use a pillbox. Because, many are. You like, when you ask them: "do you use a pillbox?" many answer "no, no, no, no! I am not that old"" (female, pharmacist)*

The pharmacists reported that pillboxes could be perceived as stigmatizing. The app was not connected with stigma in the same way and was therefore considered to be a great benefit:

> *"First of all, I think it is very good, a good support tool, if you get hold of the right customers to recommend it to. And then I think, I feel that some customers become so offended if you offer them a pillbox. Because then I indirectly say that they are developing dementia. But you don't get the same problem when you start talking about the app. Then no one feels old and forgetful […] so here you can say the same, but a bit, in a more youthful way to say it. You don't get this, or, it is actually opposite." (female, pharmacist)*

4 Discussion

In this study we have identified benefits and barriers of conducting a pharmaceutical service concerning patient counseling involving introduction to a smartphone application to long-term medication users. The results show that such a service model has potential for various patient groups. From a professional point of view the application offers an entry to a more profound conversation with the patients about their medications, and an approach to promote correct use of medications and self-management activities.

The pharmacists expressed that the application could be a support tool for patients in need of reminder aid, as well as to those that needed to establish new dosing schedules, and to patients that had complex dosing schedules. In this way the service model supports patients in the acquisition of skills and techniques to learn to manage a chronic disease. Such interventions might be effective as one of the foremost challenges in chronic disease management is the engagement in self-management activities of patients in their daily routines [7]. Depending on the type of non-adherence and patient characteristics, using a combination of tailored interventions such as patient education, patient self-monitoring and stimuli to take medications have the greatest potential for improving adherence [8, 10-12]. However, a number of barriers such as usability issues, lack of workflow integration and challenges with including users according to the inclusion criteria, influenced on how the service was carried out. Another hazard in the front-desk pharmacy setting was the fact that other customers were waiting for turn, and thus the pharmacist would not always prioritize the counseling service because it would lead to additional waiting time for the customers.

As part of this study the pharmacists collected patient questionnaires for quantitative data collection. This involved paperwork that had to be done together with the customer, but that would not have been part of a real service. This required additional time and might explain some of the challenges considering time to conduct the whole service. The situation in the hospital ward was different, and the pharmacist found it easier to carry out the service there, as demands about time-efficacy was not as prevalent there as at the front-desk. Conducting such patient education and counseling is in line with the hospitals' intention to conduct patient education and medication reconciliation at discharge.

4.1 Limitations and Implications

This study was limited to patients with long-term medication treatments. However, others such as relatives managing the medication for their children or parents, or people on short-time medication treatment (antibiotics), were mentioned as possible user groups. Of various reasons, the pharmacist found it difficult to implement the service as part of their normal workflow at the pharmacy. The introduction to the MediTake application was sometimes complicated and time-consuming due to limited technological knowledge among the users. This might certainly be a problem today, but considering the increasing number of people using smartphones and the technological development in this area, one can expect that such problems might diminish with time. The results of this study are limited to its qualitative approach, and the results can therefore not be generalized. The results might have been different if other participants, another setting, or other technology was studied. However, the findings show a number of implications relevant to similar service design projects. The usability issues, infrastructural, and workflow challenges identified in this study are aspects that need to be addressed for increased workflow integration in potential future projects.

5 Conclusion

The need to explore approaches to facilitate self-management and improved adherence is an important issue that becomes increasingly prevalent with the number of people suffering from chronic diseases and thus, who require medication treatment. The findings of this study show that a pharmaceutical service model involving patient counseling including introduction to a smartphone application has potential. However, there are a number of considerations that need to be undertaken when implementing such services in real life. The pharmacists reported a number of benefits of providing the service tool to their customers, but factors such as workflow integration, usability issues and user groups, influenced on how the service was carried out. Despite the limitations, adherence apps such as MediTake, represent a low-cost strategy that can be incorporated into a variety of healthcare services as means to promote self-care management and medication adherence.

Acknowledgments This study was funded by the Central Norway Health Authority. We acknowledge the work of Liv Tran who conducted her master’s project in pharmacy in connection to this study. We thank the patients and professionals that participated in this study.

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“IPLOS” - Countable Care? Use of Care Mapping for Statistical Purposes in Norwegian Municipalities – What are the Challenges for Nurses?

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Abstract. Introduction: “IPLOS” is a central health register providing the basis for mandatory national statistics on care in Norwegian municipalities. Data are entered in IPLOS under 16 variables, for example “dressing” or “social behavior”. A score reflecting the care level is assigned for each variable. The aim of this study was to explore knowledge, skills and needs for increased competence in IPLOS mapping among care providers and to pilot a collaborative “World Café” training intervention. Methods: A three-step sequential approach starting with a questionnaire, followed by field observation of an intervention using the “World Café” method. The third step was a follow–up questionnaire. Results: The first questionnaire showed that four IPLOS variables were challenging to map and score. The World Café activated the participants through discussions and reflections. The second questionnaire showed no general improvement in mapping skills. Discussion and conclusion: The nurses obtained an insight into their own IPLOS competence and lack of competence, and their motivation for mapping. There seems to be a need for more experience-based learning during everyday practice.

Keywords. Nursing assessment, municipal care, statistics, electronic patient records, World Café method.

1 Introduction

In Norway, IPLOS is a tool for documenting and reporting care needs in municipalities [1]. The system type and amount statistics of care required to meet all individual patients' needs, and is used for organizing healthcare. Health care personnel in Norwegian municipalities carry out the care mapping for planning and statistical purposes. This study explored care providers’ perceptions on IPLOS mapping challenges, and their experiences of learning additional mapping skills by attending a World Café intervention.

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
Proceedings of the 3rd European Workshop on Practical Aspects of Health Informatics
(PAHI 2015), Elgin, Scotland, UK, 27-OCT-2015, published at http://ceur-ws.org

Individual-based statistics for nursing and care services (IPLOS) is a Norwegian system of care mapping. The name "IPLOS" is an acronym for "Individbasert pleie- og omsorgsstatistikk", in English: "Statistics linked to individual needs for care". IPLOS was introduced in 2006 as a basis for mandatory national statistics for municipal care. IPLOS information is collected about each individual patient or care service recipient in care planning and care practice. (see Table 1 for an overview of the variables and score levels). IPLOS mapping is carried out as soon as care needs occur or change, unless the change is temporary. It is then followed up regularly. National authorities collect municipal IPLOS statistics twice a year. The objectives are to gain systematic knowledge of care in Norwegian municipalities, to develop quality of care and to utilize resources optimally. IPLOS information is also used for improving equality of care between municipalities, or even among care recipients individually [1].

Table 1 IPLOS variable and score levels

Variables:	**Score levels:**
Daily housework Food and goods supply Personal hygiene Dressing/undressing Toilet routines Eating Walk around in house Walk around outside Take care of own health Memory Communication Daily life decisions Social activities Control own behaviour	Score 1: No problems or challenges Score 2: No need for help/assistance Score 3: Some need for help/assistance Score 4: Great need for help/assistance Score 5: Total need for help/assistance Score 9: Not applicable
Vision Hearing	Score 1: Normal vision/hearing Score 2: Slight visual/hearing impairment Score 3: Moderate visual/hearing impairment Score 4: Severe visual/hearing impairment Score 5: Blind or deaf Score 9: Not applicable

Municipal care providers in Norway document healthcare in electronic health records (EHRs) [2]. The three main EPR systems used in Norwegian municipalities all include domains for IPLOS registration. System functionality varies from full integration between daily care documentation and IPLOS registration to separate domains for daily care documentation and IPLOS registration.

Implementing IPLOS, municipalities experienced discrepancies in IPLOS mapping and documentation practices in different care districts. Therefore, one municipality in mid-Norway conducted an internal survey on nurses' practice and knowledge about IPLOS mapping [3]. Nurses in the municipality expressed a need for more training in IPLOS documentation. Our study was a follow-up. Were all the IPLOS variables and criteria well understood? Could a collaborative learning intervention lead to more knowledge and shared understanding of the IPLOS mapping among the care providers?

Aim of the study:

- To gain insight into which variables were hard to map and score correctly according to the criteria for the IPLOS variables.
- To find out whether care providers experienced any IPLOS variables as challenging to understand.
- To explore whether the World Café method could stimulate collaborative learning and increase competence in IPLOS mapping and scoring among care providers.

2 Methods

In this study, we applied a multi-method, three-step sequential approach:

1: An initial questionnaire with questions on the 16 IPLOS variables as well as some questions on the ICT system used.
2: Field observation of an intervention using the "World Café" method.
3: A follow-up questionnaire with identical questions to the initial questionnaire to evaluate the result of the intervention.

This study was carried out in a medium-sized municipality in mid-Norway (14000-15000 inhabitants in 2011).

2.1 Sample and sampling

The sample was information-rich and homogeneous [4] in that the respondents were nurses and nursing assistants in health care services in the municipality who worked with IPLOS mapping. Nurses and nurse assistants at one ward in a nursing home and in one care district of the municipality were included. The 29 registered nurses (bachelor's degree level) and the 17 nursing assistants (technical college level) working part-time or in fulltime positions at these two sites were asked to participate in the study. An information note from the researchers requesting participation was distributed in advance of the study. This study started in January 2011. The World Café seminars took place during two weeks in April/May, and the last questionnaire was distributed 20 weeks after the intervention period.

The objectives of the World Café meetings were 1) to learn from university college teachers, 2) to engage in meaningful conversations about the four IPLOS variables that were experienced as difficult to score, and 3) to promote future IPLOS scoring competence experiences among the World Café participants. The World Café format [5] created a dialog in order to explore questions in small group discussions and co-create a learning culture aimed at raising the nurses' competence in future scoring practice. "The World Café is a simple yet powerful conversational process that helps people engage in constructive dialogue, build personal relationships, foster collaborative learning, and discover new possibilities for action". The World Café method is useful for creating dialogs and stimulating learning through reflection [6, 7]. The World Café method emphasizes an informal style and atmosphere, without a focus on the performance of the participants [7]. The philosophy behind World Café education is that each person has his or her interpretations and mental models of the world, and individuals can broaden their understanding only by sharing viewpoints and learning about alternative interpretations and understanding of various alternatives for action [8].

2.2 The questionnaires

The questionnaires were developed especially for this study, because no representative and validated questionnaire was found. We arranged a pilot test of the initial questionnaire among 11 nurses who were using IPLOS mapping in a neighboring municipality. After receiving their responses, we modified two questions linguistically.

The questionnaires focused on two main areas:

- Understanding of IPLOS as a system for mapping nursing interventions and care needs.
- Understanding of IPLOS registration challenges finding the correct level for scoring care needs.

A third, minor area of the questionnaire focused on ICT system challenges in mapping and scoring IPLOS variables.

The initial and follow-up questionnaires had identical questions about IPLOS registration. There were four alternatives for answers in a Likert scale: Totally agree, agree somewhat, disagree somewhat and totally disagree. Some parts of the questionnaires included open areas for complementary comments. Questionnaires were analyzed using SPSS 19, frequency analyses.

We used the results from questionnaire 1 for the following intervention, the World Café. In a World Café process, each table has its own host. Groups of five to seven participants circulate between the "café tables", discussing the theme in focus at each table. We arranged three café sessions each covering one or two of the four themes identified in the responses to questionnaire one. To involve the participants working shift hours, each café session was repeated once. Each session lasted for two hours.

Nurse education professors or assistant professors at the University College of Nord-Trøndelag introduced each theme. After the introductions, the discussions at each table started. For each group, the discussion at the table lasted for 15 minutes. The groups then moved to the following two tables for 15 minutes each. At each table, the host had prepared relevant questions to reflect upon within the theme, served coffee and cakes, and stimulated discussion without interfering with the results of the discussion. The participating groups documented their IPLOS challenges, reflections, discussions and ideas for improvements. They sketched on paper at each table in a way that was not focused on performance. The results from all participating groups were collected and discussed in a plenary summary at the end of each seminar [3].

The second questionnaire was distributed to participants 20 weeks after the intervention. The period was chosen in order to allow time for IPLOS mapping experiences and collaboration.

2.3 Ethics

The research project was approved by the Norwegian Social Science Data Services (NSD). Participation in the study was voluntary. Department heads provided verbal information to their employees before the questionnaires were distributed to respondents. Written information and a consent form accompanied the distributed questionnaires and the World Café intervention part of the study. All information was kept confidential.

3 Results

3.1 The initial questionnaire

We received 19 answers for the first questionnaire, a response rate of 41.3 % of the nurses and nurse assistants asked to participate in the study. The results showed that four variables were more challenging than others to map correctly and document in a proper nursing professional style; results are presented in the next paragraph, and in Table 2. The results also showed that scoring “Some need for help/assistance” was less challenging than other levels and that scoring “Great need for help/assistance” was more challenging than other scoring levels.

3.2 The field study of the “World Café” intervention

In total, 46 health care personnel (29 nurses and 17 nursing assistants) participated in the seminars. Based on the results from the initial questionnaire, three themes that refer to the four ‘difficult’ variables were introduced, and thereafter discussed in the seminars:

1. To control one’s own behavior.
2. To take care of one’s own health, AND to make daily life decisions (two variables in one seminar).
3. To participate in social activities.

The results from these seminars showed that participants reflected upon each of the challenging IPLOS variables in a professional way. They discussed which data and which identification of patient needs by nurses would be relevant to include in IPLOS mapping, and how to score variables at correct levels.

1. “To control one’s own behavior” was regarded as referring to both verbal and physical behavior related to each individual health situation, illness and emotional balance. The seminar participant’s interpretations of behavior and causal connections then influenced criteria for score levels. Challenges in understanding of the “behavior” variable were the staff’s acceptance level for “uncontrolled” behavior, and variations for each patient during a day, e.g. in connection with patients with dementia.

2. “To take care of one’s own health and to make daily life decisions”: The participants showed little confidence in scoring these variables. They discussed the patients’ scope and capability for decision-making and the difference between scoring these variables in a home-care situation and in an institutional situation.

3. “To participate in social activities”: Motivation for and confidence in the situation were elements highlighted in the discussion about the patient’s social life. Challenges were factors such as scoring the possibility of active living and needs for activity for the patients. Individual mapping including available background information about individual patients was regarded as essential.

Summarizing comments from seminar participants were: “It is necessary to implement IPLOS mapping routines”, and “All my colleagues should have participated here”. Participants suggested changes in mapping practice, scoring more frequently and pairs of two nurses mapping IPLOS.

3.3 The follow–up questionnaire

The second questionnaire was distributed to 15 nurses who had participated in two or three seminars. Fourteen nurses answered (93.3 %). Comparing results from questionnaire 1 and 2, we found minor, but no clear changes in understanding the meaning of each IPLOS variables. See Table 2.

Table 2, "I know what these IPLOS variables mean", responses from questionnaires before and after intervention.

IPLOS Variable	**Survey number, and sample size**	**Response alternatives**		
		Totally agree	Somewhat agree	Somewhat or totally disagree
Social Activities	1st questionnaire, *n* 19	7 (36.8%)	8 (42.1%)	4 (21.1%)
	2nd questionnaire, *n* 14	4 (28.6%)	7 (50.0%)	3 (21.4%)
Take care of own health	1st questionnaire, *n* 19	8 (42.1%)	7 (36.8%)	4 (21.1%)
	2nd questionnaire, *n* 14	6 (42.9%)	6 (42.9%)	2 (14.3%)
Daily life decisions	1st questionnaire, *n* 19	5 (26.3%)	9 (47.4%)	5 (26.3%)
	2nd questionnaire, *n* 14	7 (50.0%)	4 (28.6%)	3 (21.4%)
Control own Behaviour	1st questionnaire, *n* 19	6 (31.6%)	8 (42.1%)	5 (26.3%)
	2nd questionnaire, *n* 14	5 (35.7%)	8 (57.1%)	1 (7.1%)

Was there a difference in knowledge about how to score each IPLOS variable from the first to the second survey? Comparing the results, we found changes from questionnaire 1 to questionnaire 2. The majority of answers showed increased understanding for the “somewhat agree” statement. Fewer nurses totally disagreed with the statement on knowing how to score all IPLOS variables after the intervention. For those who totally agreed that they knew how to score some of the variables in the first questionnaire, the results varied from no change to both higher and lower agreement with the statement in the second questionnaire.

Table 3, "I know how to score each IPLOS variable", answers from questionnaires before and after intervention.

Score levels:	**Survey number, ¨ and sample size**	**Response alternatives**		
		Totally agree	Somewhat agree	Somewhat or totally disagree
Score no 1: No problems or challenges	1st questionnaire, n 19	4 (21.1%)	5 (26.3%)	9 (47.4%)
	2nd questionnaire, n 14	1 (7.1%)	10 (71.4%)	3 (21.4%)
Score no 2: No need for assistance	1st questionnaire, n 19	5 (26.3%)	4 (21.1%)	7 (36.8%)
	2nd questionnaire, n 14	10 (71.4%)	3 (21.4%)	1 (7.1%)
Score no 3: Some need for assistance	1st questionnaire, n 19	3 (15.8%)	7 (36.8%)	6 (31.6%)
	2nd questionnaire, n 14	3 (21.4 %)	11 (78.6%)	0
Score no 4: Great need for assistance	1st questionnaire, n 19	6 (31.6%)	1 (5.3%)	9 (47.4%)
	2nd questionnaire, n 14	1 (7.1%)	9 (64.3%)	3 (21.4%)
Score no 5: Need for full assistance	1st questionnaire, n 19	4 (21.1%)	3 (15.8%)	9 (47.4%)
	2nd questionnaire, n 14	2 (14.3%)	8 (57.1%)	4 (28.6%)
Score no 9: Not applicable	1st questionnaire, n 19	7 (36.8%)	1 (5.3%)	7 (36.8%)
	2nd questionnaire, n 14	5 (35.7%)	3 (21.4%)	6 (42.9%)

The responses to the initial questionnaire did not highlight ICT as one of the major challenges in mapping practice, thus this subject was not specifically addressed in the World Café seminars. The answers in the second questionnaire nevertheless showed that fewer nurses answered ‘totally agree’ when asked whether they had had suitable ICT training after the intervention period than in questionnaire 1, before the intervention.

Asked if they thought the EHR system was difficult to use for mapping and scoring IPLOS variables, more nurses totally agreed with that statement *after* than *before* the intervention, and vice versa: more nurses totally disagreed to the statement *before* than *after* the intervention.

Table 4, ICT training and documenting challenges in the EPR system. Answers from questionnaires before and after intervention.

Survey questions	**Survey number, and sample size**	**Response alternatives**		
		Totally agree	Somewhat Agree	Somewhat or totally disagree
Suitable ICT system training for IPLOS mapping	1st questionnaire, n 19	13 (68.4%)	1 (5,3%)	5 (26.4%)
	2nd questionnaire, n 14	3 (21.4%)	8 (57.1%)	3 (21.4%)
Difficult to use the EHR system for IPLOS mapping	1st questionnaire, n 19	1 (5.3%)	10 (52.6%)	7 (36.8%)
	2nd questionnaire, n 14	5 (35.7%)	7 (50.0%)	2 (14.2%)

4 Discussion

The first survey identified challenging areas of IPLOS mapping. The World Café activated the participants by discussions and reflections, but the second questionnaire did not indicate an improvement in their understanding of the 'difficult' IPLOS variables. There seems to be some change in their knowledge about how to score each IPLOS variable.

- Understanding IPLOS as a system for mapping needs for nursing care seems to be changing among the participants. Motivation for IPLOS mapping was expressed during the intervention. The results from the second survey did not reflect change in understanding and mapping practices.
- Understanding IPLOS registration challenges due to scoring the intervention needs at a correct level still seemed problematic several weeks after the intervention.

It is uncertain whether the World Café participants had any learning outcome from lectures given by the teachers of the University College. On the other hand, the findings showed that the participants in the World Café seminars discussed both relevant professional matters and technical mapping problems. The occurrence of open discussions is consistent with World Café method theory [7, 8]. We found that participants showed interest in increasing their competence, but results from questionnaire 2 showed no clear indication of increased mapping or scoring competence.

The World Café method is considered to be a suitable methodology for educating groups of people [6, 7]. In this project, the World Café method seem to be useful for creating dialogs and to stimulate learning through reflection, in line with other research findings [6, 7]. The participants were also motivated for collaborative learning by suggesting mapping IPLOS variables together in pairs. This is also in accordance with World Café method theory [5, 7]. In line with the philosophy of the World Café method [8], participants expressed their own perspectives, collaborated, and extended their knowledge.

The data from the questionnaires and the seminars showed a change in understanding of the content of IPLOS variables. The results from the World Café method may indicate learning as described in the theory of group-based experiential learning through reflection on experience from practical professional work [9]. On the other hand, the results of this study do not indicate that use of a World Café method improved the care staff's confidence in their own IPLOS mapping and scoring competence, and therefore they were motivated for more collaborative learning and mapping practice. This corresponds with results regarding needs for ICT training and learning about how to overcome EHR documentation challenges regarding IPLOS mapping.

The intervention in this study, and use of the World Café method, relied on the nurse's experience-based knowledge. During the World Café discussions, they could support each other in learning about the four mapping variables they all seem to feel uncertain about. By collaborating, they could gain knowledge from the "zone of proximal development" [10]; the zone of what was difficult was about the same for all participants. This could lead to a feeling of equality that supported the collaborative discussions underlined as a philosophy of the World Café method [8]. This may have led to an increase in collaborative learning confidence as well as a stronger focus on participants' own mapping and scoring challenges seen in the results of the second questionnaire. We consider this to be relevant learning in the sense that nurses obtained an insight in their own IPLOS competence and even more important; insights into areas where they did not have enough knowledge.

During everyday nursing practice, IPLOS mapping should be learned gradually, like learning other complex skills. Ways of working that include organizational changes and ICT systems have been found to take 17 years to implement [11, 12]. People learn from remembering something and may then analyse and evaluate knowledge, and in the end learn to use the knowledge in a situation-based way [13]. In the learning process during the World Café seminars, the participants stated that they had increased their understanding of IPLOS mapping and scoring as such. Understanding the challenge in utilizing this knowledge also seemed to increase. In line with theory and research underlining that learning about new mapping systems and change of practice may last several years, our results underline a need for more time for learning activities [14]. The World Café created an opportunity for reflections, although these were not necessarily followed up in daily mapping practices. From the World Café experiences, we learned that nurses wanted to sit down together in pairs to discuss, map and document the IPLOS variables and scores before entering the results in the patient EHRs. This collaboration during mapping practice may support learning in a situation-based way [13]. On the other hand, there seemed to be a need for development of methods and tools to support nurses in their learning and mapping of countable care. After completion of this study, the Norwegian Directorate of Health has identified training needs [15, 16], and generated an e-learning platform to support nurses in learning IPLOS mapping practice [17].

4.1 Study limitations

No validated questionnaires regarding content, criteria and knowledge about IPLOS variable scoring were found. Another limitation was the low number of participants in the study. To obtain statistically significant results, there is a need for larger samples in future research. Respondents from only two care entities of one municipality also represented a limitation that may make the results of the study less representative.

5 Conclusion

Charting experiences of challenging IPLOS variables and scoring levels, followed by three World Café seminars, seemed to support the participants in obtaining an insight into their own IPLOS competence and lack of competence, and to heighten their motivation for mapping. The results indicate that collaborative learning and reflection during World Café sessions may provide more insight into each participant's knowledge level. There seemed to be a need for more training to achieve relevant competence and a need for more experience-based learning during daily practice.

Acknowledgments We want to thank the nurses who answered our questionnaires and participated in the World Café seminars. We also want to thank Gunn Wolden, Aud Moe and Bente Northug for being lectures in the World Café seminars. Finally, thanks to Margaret Forbes for her contribution in improving the language of the article.

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Improving Nurses' Hand Hygiene Compliance using Gamification

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Abstract. Healthcare acquired infections are one of the biggest problems healthcare field is facing, which can end up in an increasing quantity of deaths, extra-days of hospital stay and costs for both the hospital and the patient. Performing hand hygiene is a simple and inexpensive prevention measure, but healthcare workers compliance with it is still far from desired. Recognized hurdles are lack of time, forgetfulness, wrong technique and motivation. Besides, nurses' perception about their compliance is disturbed by a busy schedule. This study aims at exploring the use of gamification to promote nurses' HH compliance self-awareness and action. Real-time collected from an indoor location system will provide feedback information to a group of nurses working in an ICU ward. In this paper we present our research's motivation and methods, along with the collected results and its discussion.

1 Introduction

Healthcare acquired infections (HAI) are infections that are neither present nor incubating when a patient is admitted to hospital [1][2]. HAIs' increasing number is one of the biggest problems healthcare field is facing, leading directly to around 37 000 deaths, 16 million extra-days of hospital stay and €7 billion financial losses of direct costs, only in the Europe [3]. They are a risk that hospitals must control to manage healthcare economically and safely for patients, whom can became disable at long-term or even die. Although preventable, by means of hand hygiene (HH) compliance, these infections are the most adverse event a patient can experience during care delivery, and cause more deaths than AIDS, breast cancer and auto accidents together [4].

Nonetheless, leading busy healthcare workers (HCW) to comply with HH remains puzzling. Recognized hurdles are lack of time, forgetfulness, wrong technique and motivation. Besides, nurses' perception about their compliance is disturbed by a busy schedule.

As HCW's HH compliance rate decreases, the number of patients affected by HAI increases [5], so it becomes crucial to understand this problem's root and try to cope with it.

Having this, it becomes crucial to monitor nurses' compliance with existing guidelines and provide them with feedback regarding their performance. Direct observation, the observation of HCW's HH practice by professional observers, is the

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
Proceedings of the 3rd European Workshop on Practical Aspects of Health Informatics
(PAHI 2015), Elgin, Scotland, UK, 27-OCT-2015, published at http://ceur-ws.org

standard approach to fulfil this task, but it is costly and time-consuming. Hospitals need to come up with innovative ways of doing this.

Automated monitoring systems have emerged during the last few years, and can electronically identify when an HCW uses a sink or a handrub dispenser. It provides exact quantitative results, which can be used to examine trends regarding the value of HH compliance over time.

Some studies are attempting to prove that these solutions can effectively lead to a better HH compliance, and so far they appear to be be promising in improving monitoring performance and improve HH compliance among HCW. Levchenko et al [10] provided eleven nurses working on a nursing unit with personal wearable electronic monitors which monitored, recorded and prompted reminding signals regarding their HH practices. Despite this study's short duration, they were able to demonstrate the feasibility of using such technology to improve HH performance, since the HH compliance rate during the trial was higher than the rate generated by the baseline observational study. Swoboda et al [11] conducted a three-phased study in an intermediate care unit. During phase I HH compliance was measured both by means of direct observation and electronic monitoring. Phase II included both electronic monitoring and computerized voice prompts for failure when HH was not performed on room exit. Finally, phase III was only electronically monitored. Considering electronic monitoring system's data, HH compliance improved 37% in phase II and 41% in phase II, comparing with results from phase I. They concluded that the electronic monitoring system provided effective feedback regarding HCWs HH compliance and improved HH performance.

Gamification is a recent but popular approach which can be defined as "the use of game elements and game-design in non-game contexts" [6] to "engage and motivate people to achieve their goals" [7], providing a whole different user experience. It aims at stimulating people's intrinsic motivation in doing an activity by trying to make it rewarding for itself.

Game elements are the "toolkit" for building a game [6] and they must be chosen in the end of the process of designing a game, after some variables are analyzed and defined (goals, behaviors we want to stimulate, our target players, etc.). Werbach and Hunter provide a list of game elements divided into three categories with different levels of abstraction: dynamics (at the top), mechanics and components (at the bottom) [6].

In the last few years, gamification has started to emerge in health related contexts. The majority and most well-known solutions relate to personal wellness improvement, helping people adopting healthier life habits (eating better, exercise more, etc.). Others are more directed towards medical education and practice, where gamification can have an important role in improving processes typically repetitive, tedious and boring by creating engagement among HCWs and improve their performance [16]. Nike+ [8] is an example of a successful gamification application, and it is perhaps the most mentioned one. It gamifies personal fitness by measuring the number of miles run and providing feedback using game elements like points, badges, progression bars, etc.

Pereira et al [16] presented some state-of-art regarding the usage of gamification in healthcare contexts. Presented and analyzed examples lead them to conclude that gamification can be successfully used in promoting healthcare and healthy habits.

However, this process is not simple and can be subject to some major concerns and bad practices that we must be aware of. Some people believe that gamification is just a “marketing hype” used to lead people to engage into tasks that do not fit their better interests [12] (this phenomenon is called “exploitationware” [12]). Others find it hard to believe that that this is nothing more than playing games and that will act as a distraction at work [16], very inappropriate to a serious context. Another huge barrier is applying and receiving ethical recognition to conduct trials that are typically designed for drugs and new equipment that have a long-term development [17], which contrasts with the iterative process for implementing gamification solutions. When collecting data, we must be sure to meet all the consents from the players, by means of terms of service agreement and/or a privacy policy, stating what data and why we’re collecting it, what we are going to use it for and other related practices [12]. If HCWs are to experience a gamification solution, this must be designed such that the additional workload is as negligible as possible, because this can represent a very impeditive barrier to the effectiveness of the project [17]. To finish, players might be tempted to play around the system’s rules and to create their own rules – what we call “gaming the game”. This represents a problem because players can lose sight of the solution’s main purpose(s) (for example, eating better) or can interfere with data collection for researching purposes (for example, when trying to educate HCWs).

There is one last concern, more directly connected to the design of a gamification solution, which is called “pointsification”, and corresponds to focus deeply on giving rewards and neglecting the players’ experience. As the name suggests, it happens when a designer creates what he believes is a gamification solution just by adding points to a process, and expecting that this can create engagement, which is much rarely true. People play to be better, to overcome obstacles and socialize with other players. This is one main reason why so many gamification solutions fail.

This study aims at exploring the use of gamification to promote self-awareness and action regarding nurses’ HH compliance. An automated monitoring system was used to collect data in real time, and a gamification application provided feedback information to a group of nurses working in an ICU ward, in a fun and engaging way. As we have already mentioned, there is evidence to support that automated monitoring systems can be successfully used to improve HH compliance. By applying a gamification layer, we aim at creating a fun environment in the ICU and to engage nurses even more in complying with HH moments.

We start this paper by defining the methods we used to conduct our research. The already collected results will be presented, followed by their discussion. We end with future work statements and a conclusion.

2 Methods

In this section we present the methods used in our study. We chose to adopt a design science research methodology since it is based on an iterative process, which allowed us to incrementally design, develop, test and evaluate a solution that is align with the organization and our end users' needs [9]. Our solution consists on an automated monitoring system combined with a gamification layer to promote nurses’ engagement. It was already presented to its target users (the nurses) and its usage was simulated in both non-real environment (by non-real users) and real environment (by a real user).

2.1 Design and implementation of the solution

The first component of our solution is an automated monitoring system built with innovative smart beacons and smart tags, which use both Bluetooth and a proprietary protocol (also operating on the 2.4GHz frequency band) to communicate, and a proximity based technique.

Smart beacons are the passive devices to be positioned at specific locations in the hospital (near beds, sinks, etc.). Smart tags, which are physically identical to smart beacons, are the active devices in this system, which was built using a proximity based technique. More specifically, the smart tags (which are carried by the nurses) receive information from smart beacons and they send a message to the server (communicating its position, the smart beacon detected and the current time) whenever they are approaching a smart beacon or walking away from it. Analyzing the messages stored in the server, we are able to detect nurses' position over time.

The next step is for the system to detect and validate HH moments. To achieve this, we built an algorithm based on the the World Health Organization (WHO)'s "My five moments for hand hygiene" framework [10], which links specific moments to HH opportunities (Table 1).

Table 1: WHO's "My five moments for hand hygiene" framework (adapted from [10])

Moment	Period where HH must take place	
	After…	Before…
1 – Before touching a patient	…the last contact with a surface in the health-care area	…the first contact with a surface in the patient zone
2 – Before clean/aseptic procedure	…the last exposure with a surface	…access to a critical site with infectious risk for the patient or critical site with combined infection for patient care.
3 – After body fluid exposure risk	…a care task associated with a critical site with body fluid exposure risk for the patient or critical site with combined infection	…the first contact with any other surface
4 – After touching a patient	… the last contact with a surface in the patient zone, with touching the patient	…the first contact to any surface in the health-care area
5 - After touching patient surroundings	…the last contact with a surface in the patient zone, without touching the patient	…the first contact to any surface in the health-care area

With this framework, we are able to create and implement business rules in our system (for example, if a nurse is approaching a bed, he/she must have approached an alcohol hand rub dispenser or a sink previously).

After data is collected from the ward and processed, we have information regarding each nurse's HH compliance.

Here is where our second component of the solution, the gamification application, comes into action. This application is partitioned in two parts. The first one is a one-page dashboard, which is presented in a screen located at the nurses' room. It displays nurses' HH compliance in real-time, in an anonymous way. A screenshot of this dashboard is presented in Fig. 1. A nurse can only be identified by its smart tag name, which corresponds to a color, represented in the avatar' cap.

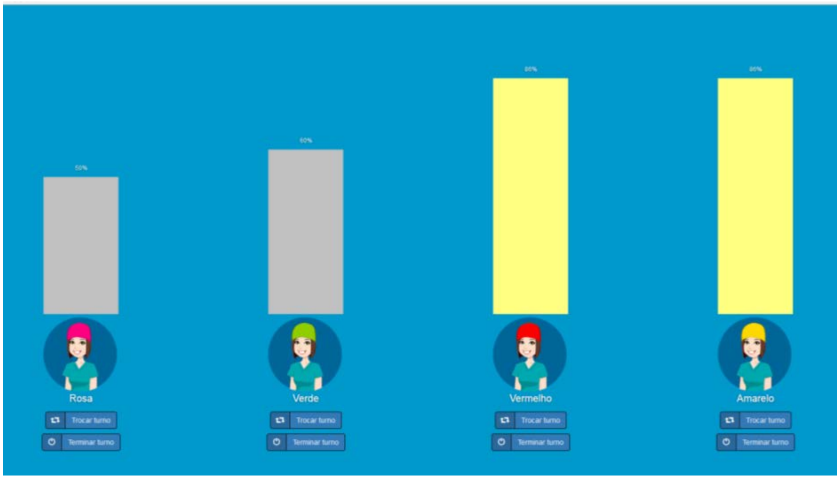


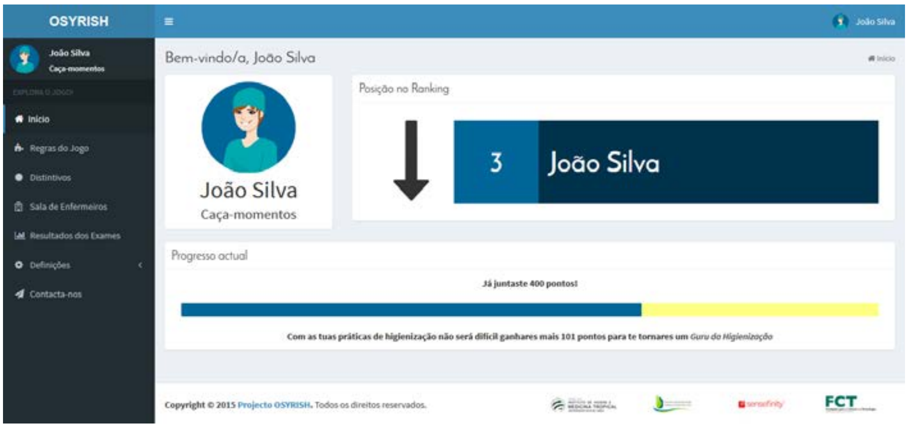
Fig. 1: First part of the gamification solution: a dashboard screen that provides feedback in real-time to the nurses working on a shift. This is always presented in a screen in the nurses' room

Nurses indicate when they start or end a shift using this application. After the end of their shift, they receive a simple e-mail, which provides feedback regarding their HH compliance rate and has a link to the second part of the gamification application, for further information. This part of the application is to be used outside their labor hours and provide a wider range of game elements for nurses to interact with.

In Fig. 2 the home page of the nurses' profile is presented. It shows the player's avatar, a partial leaderboard (to promote competition), points and levels (that means, their progression). There are other functionalities, like a platform for players to see each other's progression and communicate and a list of badges to achieve.

With the gamification application, we aim at solving the compliance problem by engaging and motivating people to achieve specific goals [11], using several and distinct game elements (feedback, competition, points, levels, badges, etc.).

The presented solution is the result of several iterations of the DSRM process. In each of them, we met the end users (the nurses), developed a prototype and tested it in a chosen environment (real or unreal). This method will be further explained in the following subsections.



Bem-vindo/a, João Silva

Já juntaste 400 pontos!

Com as tuas práticas de higienização não será difícil ganhares mais 101 pontos para te tornares um *Guru do Higienização*

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Fig. 2: Second part of the gamification solution: an application to be used outside nurses' labor hours, providing a wider range of game options

Nurses' feedback was taken into consideration during the whole process, and several functionalities derived from their thoughts. For example, because they were a little skeptical in using some game elements that required them to access the system outside their work time, we decided to include the e-mail functionality in the system. This way, all of them are able to receive the feedback they are interested in with little additional workload (they only have to indicate they are starting and finishing a shift, and to consult their compliance rate during the shift) – which was one of our main concerns through the whole design and development phase. However, if they want to, they can follow the provided link and explore the application outside their labor hours. Our goal with this is to induce some curiosity and see whether or not they are moved into using the solution.

2.2 Meeting with the users

Nurses were involved in the project since the beginning, and we have met with them several times during the development of the solution, more specifically before system's development and each time we performed significant changes. Although we were not able to meet with all of them in the preliminary meetings, we got all the consents to participate in the study by means of a consent form, stating the data we were collecting, why we were collecting it and what we were going to use it for.

In these meeting sessions we presented the information system (IS) to the four nurses working on that shift, aiming at gathering feedback regarding their feelings about it. Their thoughts were not recorded, but the main conclusions were written down.

2.3 Simulation

In order to validate if the solution was technologically working correctly, it was tested in a simulation in a non-real environment by non-real users, more specifically the research members. A protocol was written and executed, and after that we looked at the HH compliance rate computed, which was compared with the expected rate.

After this, the IS was installed in the ward. We placed one screen in the nurses' room and 26 beacons in specific positions: in the rooms' doors, in each alcohol-based hand rub container, in each sink and in each bed. This way, the system would be able to trace a nurse's position along time based on the proximity to each beacon.

To analyze both the impact of the IS's usage by a real user and whether the solution worked correctly in the hospital environment or not, we asked one nurse from the ICU ward to carry a smart tag during a workday. During this period, her thoughts were written down, and in the end one small and informal interview was performed in order to understand how the gamification solution impacted her work. Data collected by the automated monitoring system was compared to a previously established baseline (built with respect to an observational study performed during a workday, where she was one of the professionals observed by two trained researchers, regarding whether or not the necessary HH took place) to measure the changes in behavior.

3 Results

We collected results from the already completed work, which are presented in this section.

3.2 Feedback from the nurses

The group of nurses to whom the IS was presented to enjoy the concept and think it is a unique and good opportunity to receive feedback regarding their performance (although they are sometimes subject to audits, they said that this would give them a totally different experience). Although worried with the accuracy of the location system, they found the avatars experience funny. In the first meeting, when we presented the concept, they showed little interest in components like badges, virtual goods and content unlocking because it would require them to use the system outside their labor hours. They, however, liked the concept of leaderboards.

To finish, we asked them if they prefer to maintain their privacy (that is, information presented by sensor and not by HCW) or if they wanted their name (or a chosen nickname) to appear on the screen. They said that this was indifferent for them, since they had no problem in having their identity exposed in the screen.

3.3 Simulation

The simulation in a non-real environment by the authors of this paper presented good results. The system worked accordingly to our expectations, returning a HH compliance rate of 100% regarding the moments simulated. However, when testing it at the hospital, we noticed that these results were a false positive and that the system needed some refinements.

Regarding the simulation performed by the nurse from the ICU ward during one 12-hour shift, little data was collected for us to make assumptions regarding changes in behavior, in comparison to the baseline. Plus, as we already mentioned, the system still had some flaws in terms of accuracy. Nevertheless, the feedback received was that the nurse got happier as she progressed in the game, and whenever she noticed that the rate had decreased (even if only a little), she felt the urge for being more aware of the HH moments. The participant nurse approved the measure as an opportunity to improve her performance. This nurse realized that she ended up consulting the webpage, even though she said she wouldn't in a first instance.

4 Discussion

Based on the results presented in the previous section, we can settle that the IS was conceptually validated, since we were able to detect the nurse's movements using proximity and to quantify the compliance with a good precision, which was only possible due to the indoor location system's capability of providing the nurses' position with great accuracy and in a real-time basis, despite using a radio-frequency based technology. After the refinements currently being performed, we believe that the system will be able to collect data with even better accuracy.

Nurses' feedback was taken into consideration during the whole process, and several functionalities derived from their thoughts. A good example is the e-mail functionality already presented and justified.

The results from the initial meeting with the focus group were confirmed, since the participant nurse approved the measure and believes, in long term, it can really improve her performance. Also, we verified the results we aimed at achieving with the e-mail functionality, since the nurse consulted the webpage. However, one huge limitation must be highlighted: our goal with this small simulation was to validate the concept and one nurse's opinion, and not to test the overall impact of the gamification solution in a ward. Thus, we were not able to analyze the impact of the interactions between colleagues and the nurse was not able to experience the cooperation and competition mechanics of it, which is of greatest importance in this study. This study's small duration (one work day) is also another relevant limitation.

Our gamification solution will be facing the barriers we previously mentioned, and it was built not only to fit HCWs needs but also to fight these barriers. Our main concern since the design phase was to keep the workload induced by the IS as low as possible, mainly during the shift. We believe that we achieved it, since nurses seem to accept the tasks of starting and finishing the shift in the applications as something that does not impose much effort. The nurse participating in the small simulation stated that her motivation in performing HH had augmented, thus we believe that the IS will increase motivation even more when nurses start to compete and interact with each other. Forgetfulness was fought since system's presence acts as a reminder for the nurses to perform HH.

Of course, players are different and will react differently to the system. In further tests we will try to understand the different type of players we have and refine the IS to please as many players as possible.

It is also important to highlight that the gamification application will not be used for monitoring purposes. Its goal is to create a fun environment and turn the process of cleaning hands not only as an obligation, but also as a thing that can make them progress in the game. Gamification tries to erase one of automated monitoring system's drawback of HCWs being afraid of being "watched" and "monitored".

Since, as we have seen, there is a direct relation between HH compliance rate value and the number of patients affected by HAIs, we believe that if we are able to improve HH performance we will also be decreasing the number of patients affected by HAI.

This system suffers from some of the typical limitations associated with automated monitoring systems. It is only able to detect compliance with moments 1, 4 and 5 of WHO's "My five moments for hand hygiene" framework. According to several studies, this means that we were able to detect 80% of the total HH opportunities [12]. There is some potential to observation bias: although there is no presence of a physical observer, nurses may have the sense of being observed, which can lead to higher (thus, unreal) HH compliance rates.

Results achieved were collected in an ICU, where the majority of the patients require full care for all daily activities like eating, bathing, dressing, etc. The same system deployed on units following different care models might present different results. Also, we only monitored nurses' HH performance, but it would be of importance to include physicians in further trials.

5 Conclusion

The impact of gamification on HH compliance is still under evaluation. Even though we only performed small validation tests to check whether or not the concept would work, so far the results show that the IS is promising in improving nurses' awareness.

A demonstration in the ICU ward is already planned. During a 5-day trial, 24 nurses will be using the gamification solution and will be provided with feedback regarding their HH compliance rate. Simultaneously, we will be observing their behaviors and reactions, trying to understand if they are comfortable with it and if they trust the presented results. We will also be focused on spotting technical issues that might be leading to undesired side effects of the system. In the end, we will analyze the gathered results and refine our tool, both in terms of improving our gamification solution and fixing problems that may emerge during the demonstration.

After this, our goal is to implement the solution in a unit of another hospital during a larger number of days. As we mentioned in section 4, the system might present different results depending on the care model the unit follows. This also applies to deploying it in different hospitals. It would be of interest to analyze the impact of these variables in our system's results.

To conclude, we believe that the IS is aligned with nurses' needs and that it will have a positive impact on their daily routine. Although we note some resistance to some ideas we discussed with the nurses regarding game elements, the nurse who participated in our initial test agreed that she ended up checking the system. We want to check if nurses' become curious about the IS and start exploring it (instead of just seeing and trying it on the meetings). From here, maybe they start using it on a daily basis.

It must be highlighted that by involving the nurses in the project since the beginning, a higher sense of ownership in the process was enabled and we were able to better understand their requirements.

Acknowledgments OSYRISH project is funded by Fundação para a Ciência e Tecnologia (PTDC/IVC-COM/5016/2012) and GTHM/FCT (UID/Multi/04413/2013). This support and the individual grants to R. Marques and J. Gregório are gratefully acknowledged.

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Planning for Post-hospital Care – Local Challenges to General Benefits of E-messages: Hospital Staff's Perspectives

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Abstract. An e-message system is one of the promising communication tools for fostering better collaboration between hospitals and municipal-based homecare services. However, hospital care is often confronted with patients that need a myriad of services after discharge, of which municipal homecare is only one. We conducted a qualitative interview study to examine hospital health professionals' experiences with an e-message system and the role of such a system. While e-messages are a helpful tool for communicating with homecare services, the findings highlight important policy, organizational and patient-related issues that the health professionals felt constrained their ability to fully exploit the benefits of the e-message system.

1 Introduction

Communication and collaboration are important when patients move between providers at different care levels. There is an emphasis in public policy on the use of information technology to support such collaboration. ICT-supported collaboration in particular is seen as a way to deal with weak lines of communication, failures in health information exchange, and delayed hospital discharges [1].

Norwegian health IT policy initiatives have broadened their focus from the use of EPRs (Electronic Patient Records) in hospitals to electronic collaboration across health, social, and welfare sectors [2, 3]. Although EPRs have been proven to facilitate the provision of care and to increase insight into care processes, as well as communication among health professionals, they do little to support communication in collaborative care settings that involve multiple services outside the hospital environment [4]. To overcome this shortcoming, electronic messaging (e-messages) between health providers has been introduced in Norwegian healthcare. While the EPR documents treatment and care that already have been provided [5, 6], the e-message system functions as a supplement to the EPR: oriented towards future actions, extending the providers' communication and planning possibilities [1, 7]. Norwegian policy expects the benefits to include improved quality of collaborative care with more timely communication and more streamlined flow of information [1]. At the turn of 2015, 99% of all Norwegian municipal health and care services utilized e-messages in collaboration with hospitals about patient transfers, and 95% of the

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
Proceedings of the 3rd European Workshop on Practical Aspects of Health Informatics (PAHI 2015), Elgin, Scotland, UK, 27-OCT-2015, published at http://ceur-ws.org

municipalities used e-messages in their collaboration with GPs [8]. The results so far demonstrate that use of e-messages enhances the quality of information exchanged between collaborating providers and leads to faster problem solving [9].

However, recent studies on e-messaging practice among nurses [10-12] have revealed that we know little about how the use of e-messages functions in settings where patients require multiple post-hospital services with involvement of various health, social and welfare units. In this paper we investigate a typical example of such a setting – a psychiatric department in which health professionals have to communicate and collaborate with different types of service providers outside the hospital in order to develop a discharge plan that covers the patient’s need for multiple post-hospital services. To the best of our knowledge, no studies have investigated the role of e-messages in such a complex working situation. The aim of this study is to explore the ways in which the use of e-messages may assist collaborative care planning for post-hospital services as perceived by health professionals working in inpatient psychiatric care.

2 Material and method

2.1 Brief description of the e-messaging system

The e-messaging system includes a portfolio of messages, of which some are specifically developed to support information exchange and communication among collaborating health professionals when dealing with patient transfers between hospital and municipal-based homecare services. Table 1 details the content of the various e-message elements and the relationship between them, as well as how each of them connects to different treatment phases of hospitalization during the course of a patient’s illness: the admission phase, the treatment phase and the discharge phase. As a communication tool, e-messages intend to replace traditional phone calls, faxes, and papers [13].

2.2 Health care setting

The psychiatric department of a Norwegian university hospital was used as setting for the data collection. The department has 72 beds and holds one emergency unit and several inpatient care units. As for the information infrastructure, the e-message system is integrated with EPRs. The staff started to use the e-message system progressively over the period 2011–2013. The following briefly describes certain features of the patient group: 1) the hospitalized patients covered a broad range of psychiatric diagnoses and represented all ages above 18, 2) the average length of hospital stay was 2–4 days, with stays ranging from less than 24 hours to several days. In the emergency unit, most patients stayed less than 24 hours, and 3) about half of the patients had municipal home care services at the time of hospital admission and even more patients needed such services after discharge.

Table 1: E-messages and descriptions (table from [12])

Descriptions
Patient is admitted. A patient who receives community healthcare services is admitted to a hospital. The hospital starts the chain of communication and information exchange by sending a ‘patient is admitted' message to inform the community healthcare service of the patient’s admittance. According to the guidelines, the admittance messages should be sent within 24 hours of admittance. The admittance message replaces the previously used method of faxing a paper form.
Admission report. Receiving the 'patient is admitted' message from the hospital prompts the community healthcare service to reply with health information about the patient and the type and amount of care provided by the municipality to provide the hospital with a better overview of the patient's resources (e.g. ability to take care of him/herself) and problems, and to enable the hospital to adjust the treatment accordingly.
Patient health information. After the patient has spent some time in the hospital, the hospital sends a more detailed, up-to-date, overview of the patient's status and needs, in addition to an indication of when the patient will be discharged. This message marks the starting point for patients who did not receive community healthcare services prior to entering the hospital, but whom the hospital considers will need such services after their discharge. Community healthcare can also use this message to inform the hospital about the patient's health status. The message is based on a template and contains e.g. the patient's contact information, next of kin, community care needs, allergies, medical diagnoses, and nursing information – including nursing assessment of the patient and diagnoses.
Patient is ready for discharge. This message is sent by the hospital to the community healthcare service to inform them that the patient is ready to be discharged in 24 hours' time. Twenty-four hours after the discharge message has been sent, the community healthcare service becomes financially responsible for the patient and the message thus signifies an important transfer of responsibility.
Withdrawal: patient is *not* ready for discharge. If the patient's condition changes, and s/he needs continued treatment in the hospital, this message must be sent to community healthcare as soon as possible to inform that the patient is no longer ready for discharge.
Patient is discharged. On the day of discharge, the hospital sends this message to inform the community healthcare service that the patient has been discharged. The plan is that a discharge report containing more comprehensive information will accompany this message, but this has not yet been implemented.

2.3 Study design

We performed a qualitative study including semi-structured interviews with six nurses, three social workers and one milieu therapist, for which data were collected before and after the implementation of the e-messages system: November 2011 and March/April 2014, respectively. The sample was spread among three units/wards and the participants were selected by their managers. Participant *inclusion criteria* were at least *six months'* e-message experience. The interview guide focused on the health professionals' views on communication and the role of e-messages in offering collaborative services and on the challenges and opportunities they faced. Each interview lasted 45–60 minutes and was tape-recorded and later transcribed for analysis. The transcripts were read repeatedly to become familiar with the text and identify emerging themes. Drawing on the initial themes, the interviews were coded and categorized. Once categorized, relevant information was examined more closely and thereafter merged into a few broad, overarching issues that guide the structure of the result section.

Ethical issues: Approval was granted by the Norwegian Social Science Data Services. Additional permissions to conduct interviews with health professionals in selected wards and hospitals were obtained from the hospitals and the departments. Written informed consent was obtained from all the participants.

3 Results

In general health professionals were satisfied with the newly implemented e-messaging system. The interviewees reported that when communicating with collaborating municipal home care staff, they saved time by using e-messages instead of phone and fax. Clearly, the use of e-messages made it easier for them to arrange for collaborative meetings about post-hospital homecare services for in-house patients. Despite the positive attitude towards the e-message system, the interviewees expressed that they experienced tensions between the practical use of e-messages and care and discharge planning for in-patients. Moreover, they highlighted some issues that can be described as *policy, organizational, and patient-related* factors that they felt constrained their ability to fully exploit the benefits of the e-message system.

3.1 Policy-related issues: weak links between hospital and other care services

Specific agreements have been developed to ensure timely flow of information in transitions between different levels of care. For instance, in Norway there is a 24-hour window for the municipal homecare service to respond with the e-message termed ′Admission report′ (see Table 1) after the emergency unit has sent an admission message for a patient with homecare services. However, the emergency unit considered this window to be too long as most of their patients were either directed to other care units or discharged well before the deadline. This was unfortunate as the ′Admission report′ had the potential to assist hospital staff with planning of care and unit assignment for the patient.

The e-message system was designed for messaging between hospitals and homecare service. In most cases, however, the interviewees regarded this to be insufficient as the homecare workers were only one out of several service providers that hospital staff had to arrange meetings with in order to make in-house care and discharge planning work (see Figure 1). For example, the hospital staff had to reach and make contact with providers from psychiatric outpatient and municipal-based services such as psychiatric nurses, physiotherapists/occupational therapists and others from the social and welfare services (NAV[1]). The lack of communication support from information systems highlighted other challenges: using the phone to get hold of the various providers proved to be ineffective, sometimes impossible, and time-consuming. For example, one professional reported she often had to be on the phone for 3–4 hours to reach the right person at NAV.

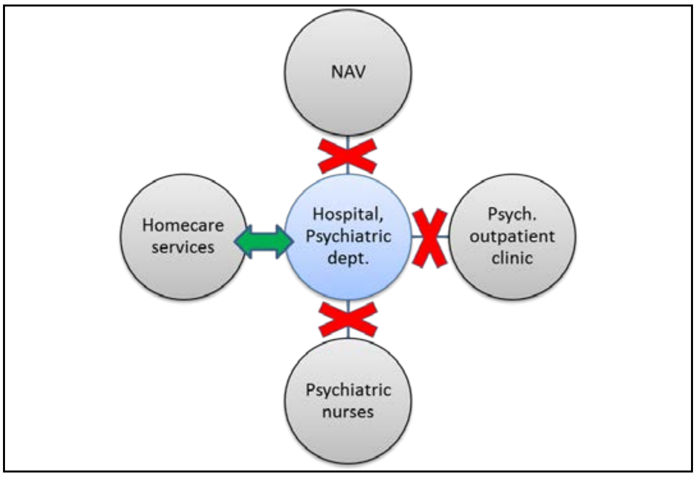

Fig. 1: The e-message system only supports communication between the hospital and homecare services

3.2 Organizational issues: hospital's internal routines

While the hospital staff was well aware of the e-message type 'Patient health information' and used this message on a regular basis, the admission report message was not often used. Nurses in inpatient wards therefore did not utilize the information provided by homecare services (if the patient had any homecare services before being admitted to hospital). Instead, the professionals stuck to a practice of oral handovers for patient transfers from the emergency unit to the ward units. These patient handovers included oral information with assessment of the patient's situation and

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[1] A short name for Norwegian Labour and Welfare Administration, ref https://www.nav.no/en/Home/About+NAV/What+is+NAV

health condition without directly using the ′Admission report′. Interestingly, during the interviews a few participants began to talk about how they could use the ′Admission report′ message from homecare as an approach to earlier and more streamlined planning of care:

[Concerning patient transfers from emergency unit to bed units:]
Well, this [patient] handover includes oral communication in which we describe what has been done [to the patient i.e. treatment]. Possibly, the routines could have been better with respect to… as this could involve us getting more information about the fact that e-messages have been sent [the admission note and report] and their content. Yeah, you know – during this interview I have been putting a lot of thought into it… our focus on [the e-messages] does not integrate naturally into our daily routines. They [the e-messages] must be implemented [in the daily routines] from the beginning and throughout the whole trajectory (Professional-06).

Also, the hospital staff described the practical patient shift to homecare as challenging and indicated that these patient transfers did not always take place in a timely manner. Even if the hospital routinely notified the homecare service by sending the e-message ‘Patient NN is ready for discharge’, the homecare staff did not always prepare for their admission within the same day. Presumably, a major reason was that the home care services did not have to pay for the extended stay, as is the case for extended *somatic* patients. Another possible explanation may be that these two organizations differ in terms of resources, resource allocation and time.

The municipal [homecare service] thinks we deliver the discharge note [the – e-message ‘Patient is ready for discharge’] too late [after 3 pm], and at that time, they [the homecare staff] have gone home and we cannot discharge the patient… but it does not work like this here: we do not stop providing care at 3 pm. This is a 24/7 unit and things happen all the time […]. Our conditions [routines] do not match those of the municipality (Professional-07).

3.3 Patient-related issues: the patient’s role as a co-decider

Furthermore, another challenging situation was associated with the balance between patient’s rights and the e-message practice, namely that the e-messages should not be initiated automatically without explicit permission from the patient. Interview accounts revealed details that made it quite clear that some patients opposed the use of e-messages between the hospital and municipal-based homecare services. A presumed reason was that the patients felt ashamed about their mental illness and did not want to tell anyone outside hospitals about their hospitalization.

Then we do not send any [e-messages]. One challenge is, however, that they [the homecare staff] know that this patient is here [at the hospital], but they do not receive any e-messages related to this patient. We haven’t got the permission from the patient

> *to do so… It might be that the homecare staff often expects that e-messages should be sent automatically [routinely] without thinking about the fact that many of our patients do not allow us to send [e-messages]. Some patients are designated by the term ‘red writing’- as we call it, meaning that confidentiality prohibits [sic], because they do not want anyone to know about their acute psychiatric boarding* (Professional-07).

4 Discussion

This study presents the experiences and perceptions of ten hospital health professionals from a mix of units within a psychiatric department related to a newly implemented e-message system.

There was a clear recognition amongst the interviewees that the e-message system filled a gap in the collaboration on post-hospital care for in-house patients. Despite their general satisfaction and a positive attitude towards the e-message system, the hospital staff also highlighted some constraints and difficulties, including that the homecare services’ 24-hour response time was too long to assist care planning for admitted patients at the emergency unit; the need for expanding the system to ease collaboration between the hospital and outside-hospital services (i.e. social/welfare services); and the difficulty of managing lack of patient consent to use the system.

Our findings indicate that the policy context in which the e-message system functions has to be considered because it provides the basis for how health professionals react in terms of their ability to fully exploit the benefits of this system. The findings further illustrate that some constraints related to the structure and organization of the health system, such as lack of formal links between the hospital and multiple providers outside the hospital; such links could assist hospital staff’s communication work when planning for post-hospital services. More specifically, the e-message system’s design limits its use to electronic communication between the hospital and municipal homecare services. However, for our group of psychiatric patients, the staff oriented care planning towards a continuum of services outside the hospital that went beyond the homecare setting. They had to have knowledge of, and be familiar with, a broad range of municipal-based facilities, services, and resources to be able to assist in arranging post-hospital care and services for their in-house patients. Examples from existing literature confirm that this is also the case for many other patient groups, such as cancer patients and heart patients [14–16]. It was suggested that the e-message system’s major value for the future could be its connection to a broader range of municipal-based services.

While helpful, the use of e-messages without changes to internal routines fails to realize complete communication support. Our impression is that the traditional oral handover carried out between professionals, with face-to-face communication when patients moved from emergency to wards, had the potential to be complemented by information from e-messages: in this case the ‘Admission report‘ made by the municipal homecare staff. By adapting technology that improve the links between the e-message system at hand and the manual handover routine, the ‘Admission report‘ could assist the staff with the discharge planning work so as to better facilitate the continuity of care. However, one should be aware that such a change in routine might pose unintended complications for professionals. For example, a recent study has shown that some care providers do not fully trust information mediated by electronic tools in a clinical handover situation [17].

There was a concern that some patients were unwilling to consent to the use of e-messages. This is interesting since the lack of consent threatens the care providers' communication across organizations and their ability to provide comprehensive care. However, patients have a basic right to consent to treatment and to choose whether or not to disclose information to other health care providers who will be involved in their care [18]. This is a typical dilemma that many health professionals face from time to time, with or without technology – but the technology makes it more visible. From an information technology perspective, it is therefore important to see both the patient's role as an important co-decider and the care providers' need for patient information. This raises the question of how patients, in general, learn about the e-message system – its content, use, and purpose – as well as how they comprehend the information given to them.

4.1 Limitations of the study

This study has some limitations. First, the applied research method gives only self-reported data on views and reflections of hospital health professionals and does not present a complete picture of the nature of the actual communication and collaboration practice. It is, however, a valuable method to further insight into and understanding of the hospital staff's early experiences with the e-message system, including which factors are likely to influence – as well as how they influence – communication in collaborative care that includes a myriad of providers and disciplines. Next, we caution against generalization of the findings because of the small sample size, specifically the small number of interviewees and departments, and the single-hospital design. The complex collaboration patterns that we observe among health professionals in the planning of post-hospital care for psychiatric patients can also be observed in the coordination of care for other patient groups i.e cancer patients.

5 Conclusion

The e-message system has proven to be useful for communication between hospital and municipal-based homecare services when patients transfer/move between the two sectors: E-messaging clearly supports planning and collaboration between providers. However, in work situations that require collaboration on post-hospital care with multiple providers across organizations and care levels, our findings point to organizational, policy- and patient-related challenges to better support from the e-message system. Taking these challenges into account may be informative and helpful for policy makers and managers in the process of further improving and implementing e-messages.

Acknowledgments We wish to thank the health professionals who were willing to participate in this study. We would like to thank research assistant Linda Aasvangen and Geir Andre Pedersen for transcribing the interviews, as well as Andreas Landmark for technical assistance. The research is funded by The Research Council of Norway Project 196365/V50 and Project 229623/H10.

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Remotely Supported Prehospital Ultrasound: Real-time Communication for Diagnosis in Remote and Rural Communities

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Abstract. We have created a system that aims to facilitate prehospital assessment of remote and rural patients using remotely supported ultrasound (US) and a novel communications device. Paramedics can function as remotely supported US operators, guided and advised by hospital-based specialists regarding diagnosis and treatment options. Novel communication technology can link these users in areas with low communications coverage by connecting to multiple cellular networks and/or satellites to stream live US and video images, plus two-way audio. A demonstrator system was used in locations around the Scottish Highlands to stream images to remote reviewers for image interpretation, as well as sending audio and video to allow mobile telestroke assessments while in transit. Connections with live US and audio-visual transmission were successful, with appropriate views provided in 94% scans. All telestroke assessments were completed successfully. This prehospital support US system could facilitate early diagnosis and streamlining of treatment pathways for remote and emergency patients. It could be particularly applicable and useful in rural areas worldwide with poor communications infrastructure and extensive transport times.

1 Introduction

Prehospital diagnosis can save time on arrival at hospital, streamlining patient care, and if early treatment can be given, it can potentially save lives and help improve patient outcomes. This is particularly true for patients who live a considerable distance from major centres of care, such as in the remote Scottish Highlands. Ambulances are currently limited in their diagnostic imaging capacity; however, providing imaging facilities is not enough: users would have to be trained in the use of the technology and image interpretation. One solution would be to send experts out as part of the ambulance team, and this option is used in some countries, particularly in major cities where ambulances are extremely busy and distances to hospital are relatively short. However, in remote and rural areas it is not feasible to staff ambulances with specialists and so diagnosis often must wait until the patient has travelled the distance to the nearest hospital, often being passed from smaller hospitals to larger ones that can provide the required level of care.

We are proposing a remotely supported diagnostic system, where experts in ultrasonography support novice scanners in the prehospital situation using robust communication links. Ultrasound users in the field can receive guidance on the

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recording of images and their interpretation from hospital-based experts through the use of cellular and satellite networks to transmit live images and data, even in areas with variable bandwidth availability. This means that remote ultrasound users need only basic training in how to use the equipment, and diagnosis can be performed by the same people who would be consulted upon the patient's arrival at hospital. This could potentially save time and help streamline the patient's care pathway, because even if treatment cannot be given in the ambulance, the hospital can be alerted to the patient's needs and prepare for their arrival.

Ultrasound (US) is routinely used to assess emergency trauma patients, where it can help locate bleeding within the body using the Focussed Assessment using Sonography for Trauma (FAST) scans, and we think it could also be useful in less routine scans, such as transcranial imaging to look for bleeding in the brain in stroke or traumatic brain injury. In stroke in particular it is vital to diagnose the aetiology (blood vessel blockage versus bleeding) because early intervention with 'clot-busting' (thrombolytic) treatment can significantly reduce disability and lower mortality [1]. However, thrombolysis must not be given to patients with a haemorrhagic stroke because it can worsen outcomes.

We suggest that US could be used to gather early diagnostic information in stroke and other conditions in situations where access to computed tomography is limited and/or delayed through remoteness. There is already a modest evidence for the use of portable ultrasound in the prehospital assessment of stroke patients [2]. The International Pre-hospital Stroke Project has demonstrated that Transcranial Colour-Coded Sonography can be used to identify occlusion in the middle cerebral arteries [3,4]. There is also limited evidence that b-mode (2D greyscale) transcranial ultrasound can be used to identify and rule out haemorrhagic stroke. Mäurer et al demonstrated that ultrasound detected 94.3% of haemorrhages detected by CT, and correctly confirmed the absence of haemorrhage in 95% of cases (n=133) where brain could be visualised [5]. More recently, Kukulska-Pawluczuk et al showed transcranial ultrasound successfully identified brain haemorrhage in 34/39 cases up to 12 hours after CT [6].

Attempts have been made to use a portable CT scanner for prehospital diagnosis of stroke: the PHANTOM-S study trialed a stroke emergency ambulance in urban Berlin (restricted to an area up to 16 minutes from base), which contained a CT scanner, a point-of-care laboratory, telemedicine link, neurologist, radiology technician and paramedic [7]. The study showed that this service could reduce time to thrombolysis by 25 minutes; however, this is likely only to be beneficial in a small-radius, urban area with a large number of potential patients: it would not be cost-effective in rural locations.

We have created a remotely supported prehospital US imaging system, transmitting ultrasound video, plus standard audio/video (AV) in real time, and this paper reports on the initial field testing. Telestroke, the remote assessment of potential stroke patients over a telephone or video link, has been successfully employed in many places worldwide, eg [8]. However, it is usually performed from a static base such as a primary care facility or patient's home. We also used our remote support system to attempt telestroke assessments while on the move, as this would save time and could help provide a more efficient patient pathway.

2 Methods

2.1 US scanning

Ten healthy volunteers without previous US experience received approximately 30 minutes of basic training with the US machine and 2-5 MHz probe (Sonix Tablet, Analogic Corporation, USA) focused on the operation of the machine and techniques to perform the required scans. They were asked to perform three scans that form part of a routine trauma assessment: Morison’s pouch to visualise free fluid around the liver and kidneys; the aorta, looking for any enlargement indicative of an aneurysm; and the lung, looking for signs of pneumothorax. Volunteers also attempted to image the brain, looking for the third ventricle which represented the midline of the brain, following the procedure described in Stolz et al. [9]. These scans were repeated in the ambulance with a clinical expert using the US machine to provide comparison data.

All US scanning was performed in an ambulance parked at 16 different sites around the Highlands. Live US video streams, plus AV from a fixed camera, were transmitted via an Omni-Hub™ communications system and bandwidth management device (Tactical Wireless, UK) using bandwidth from a combination of 2G and 3G cellular networks. Two trials were transmitted via satellite. Images were transmitted to one of four participating clinical assessors in Inverness for review and were given a rating for their quality and diagnostic utility on a five-point scale from 1 = poor to 5 = good. Data transfer rates and any equipment or connectivity problems were also recorded.

2.2 Telestroke assessments

The second part of the study involved performing remote stroke assessments in transit in a moving vehicle [10]. A telestroke checklist for clinical use has been created by NHS Highland stroke specialists, incorporating the ROSIER (Recognition of Stroke in the Emergency Room) Score, exclusion criteria for thrombolysis, Modified Rankin Scale, and National Institutes of Health Stroke Scale (NIHSS). This is used to decide whether a patient is a candidate for thrombolysis. In this study, volunteers used a ‘script’ providing details about a suspected stroke patient’s condition to allow them to play the role of a patient and/or responding paramedic for this assessment. There was a pool of scripts describing symptoms of thrombolysable stroke, those with contraindications to thrombolysis, and those with a non-stroke condition (e.g., epilepsy, risk of non-compressible hemorrhage).

The assessments were performed by hospital experts based on details provided by the volunteers using the AV transmission while the vehicle moved between the static test sites used for US scanning. Some assessments were performed while the vehicle was parked, for comparison purposes.

Ethical approval for the study was provided by the North of Scotland National Research Ethics Service committee (ref: 14/NS/0087).

3 Results

3.1 US scanning

Of the 16 sites where static transmission was attempted (see Fig. 1), at only one was there was not enough signal and the attempt was abandoned. At all other sites US and AV were successfully transmitted.

Reviewers' ratings of the images are summarized in Table 1, and show that they found the transmitted images suitable for diagnosis in the majority of cases when cellular networks were used, although the communications quality (e.g., stability, reliability) was not always good. Overall, 94% of the thoracic images were recorded and transmitted successfully, as were 67% of the brain midline images.

Table 1: reviewer ratings of the transmitted ultrasound images

Median rating (range) (Scale: 1 = worst; 5 = best)	**Cellular network (n=21)**	**Satellite network (n=2)**
Communications adequacy for diagnosis	4 (2–5)	3 (3–3)
Communications quality	2 (1–5)	3.5 (3–4)

Novice scanners did take slightly longer than experts to complete the scans: 3.5 minutes versus 1 minute for experts for the thorax scans and 5.7 minutes versus 3 minutes for the brain midline scan.

3.2 Telestroke assessments

Nineteen mobile and four stationary telestroke assessments were performed; none were abandoned due to connectivity problems and all were correctly categorized in their thrombolysable status. The mean time to complete an assessment was 11 minutes while mobile (range 1–31 minutes) and 10 minutes while stationary (range 4–16 minutes), which was not a statistically significant difference. (It should be noted that assessments of non-thrombolysable patient cases often took much less time to complete because as soon as a contraindication to thrombolysis was revealed, the assessment would stop; this helps account for the wide range of assessment times). The quality of the communications was rated lower by the experts during mobile assessments (at 3 out of a maximum score of 5) compared with during the stationary trials (at 5 out of 5). Both types of assessment received high ratings (at 5 out of 5) from experts asked whether the AV system allowed adequate diagnosis.

Occasional breaks in transmission were experienced in 47% of the tests, but connection was re-established quickly and only minor delays were reported: for example, several tests reported total delays of 2–3 minutes during the assessment.

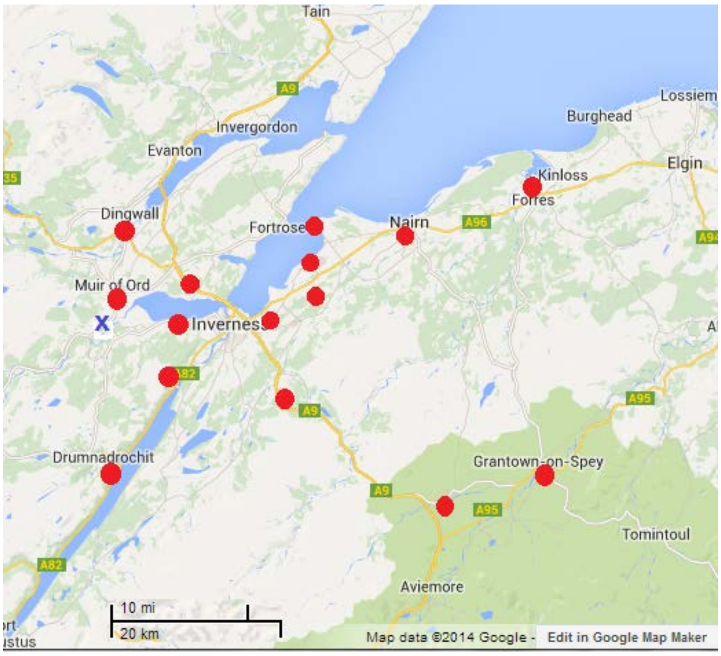

Fig. 1: Locations of the field test scans and transmissions. The blue cross indicates the unsuccessful transmission site

3.3 Transmission details

Transmission rates ranged from 22–1900 Kbps, with a mean of approximately 1250 Kbps. Higher rated AV quality (rated 4 out of 5, or 5 out of 5) was associated with a higher mean upload rate (1021 Kbps, range: 336–839), compared with AV rated 1 out of 5, or 2 out of 5 (553 Kbps, range: 447–1657).

The mean transmission latency or delay was 300 ms (114 ms with cellular networks and 2072 ms with satellite), which was not considered to be a limitation by participants at either end of the test.

4 Conclusion

This study shows that remotely supported prehospital US is possible even in the variable connectivity that is characteristic of the Scottish Highlands, and has the potential to be used in rural emergency care. The value of ultrasound is being able to deliver repeated imaging swiftly and without ionizing radiation. Our tests have also shown that it is feasible to perform telestroke assessments while mobile in rural locations – even when moving between signal areas – and this could be undertaken while a patient is in transit to a hospital, requiring no additional delays to perform and saving time on arrival. Using such a checklist assessment with US imaging results, it could potentially be possible to treat suitable patients with thrombolytic drugs in the ambulance.

Our results come from tests with healthy volunteers rather than patients and so it is difficult to compare them with those found in the existing literature on US for diagnosis of stroke, but we believe our image recording and transmission rate demonstrates the feasibility of remotely supported prehospital US. It should be noted that most previous studies using US to investigate haemorrhage were conducted some time ago with older ultrasound equipment. It is possible that with improved modern scanners, plus software and potentially probe optimisation, that prehospital US scanning for haemorrhage could be both viable and worthwhile.

Our study showed that despite relatively poor quality of communications, evidenced by the low ratings received for the cellular network transmission, images thought to be of diagnostic relevance did arrive with the hospital-based clinical reviewers in a high percentage of cases. This could offer hope for rural and remote areas where communications availability is known to be substandard.

The success of our mobile telestroke testing is also encouraging. There is already a body of evidence supporting telestroke assessment and thrombolysis rates achieved via such systems have been shown to match rates achieved via on-site expert assessment with comparable patient outcomes [8]. In Yperzeele et al.’s review of prehospital stroke care three generations of telestroke technology were described [11]: utilising communication over fixed landline; then the internet but only for patients who had already arrived at hospital; the third generation moves telestroke into the prehospital situation, but only a very limited amount of research has so far been conducted in this arena and the American Stroke Association advocates further research be performed [12].

The information transmitted in both of these initial tests could help accelerate patients’ path to appropriate treatment on their arrival at a centre of care and could be simply incorporated into patient care pathways in both rural and urban areas, saving time and potentially improving outcomes by reducing the time to treatment.

This sort of technology does bring with it many areas of contention, just one of which is the legal implications: does the paramedic located with the patient have legal responsibility for their care, or does the advising remote expert? What if something goes wrong and a connection to the experts cannot be made or breaks down mid-assessment? Does the addition of remote support empower prehospital care staff, or take away from their status? How will it affect the staffing required in hospital to ensure support is available? These and many other questions must be considered.

System optimization is ongoing and the whole process should be tested with real patients, and this will be the next step for the project. This will require considerable discussion and negotiation with the hospital and ambulance service to put appropriate protocols in place to cover various eventualities and ensure patients are not harmed or disadvantaged in any way. It should also be noted that this feasibility study was not powered for statistical analysis, so the results are at increased risk of incurring a type 1 error and being overly positive.

In conclusion, we believe that this remotely supported imaging and assessment system could facilitate early diagnosis and streamline care pathways for patients, particularly in areas worldwide which have poor communications infrastructure and extensive transport times to centres of care.

Acknowledgments The research team would like to thank all of our volunteers and reviewers for their time and efforts during this study. The research was funded by Highlands & Islands Enterprise, UK Technology Strategy Board's Space and Life Sciences Catapult, University of Aberdeen's dot.rural Digital Economy Hub and TAQA Bratani.

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Hearing Impairment:
An Initial Exploration of Information Sharing Practices

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Abstract. Hearing impairment is becoming increasingly prevalent. Even though hearing aids can contribute to increased quality of life, actual usage has proven to be problematic and limited. This preliminary explorative study has been carried out in order to get an initial understanding about sharing of hearing-loss-related information, both in terms of how information is shared as well as what kind of information is shared. We conducted four sub-studies with peer members of an interest group and people visiting relevant online resources, and combined the use of questionnaire, semi-structured interview, online observation and short survey. While our results are preliminary, they suggest that current information sharing practices are fragmented regarding both the content that is shared as well as which actors and media are involved, and the Internet as a multifunctional arena is underutilized. Finally, some possible directions for further research are outlined.

1 Introduction

Very many of the cues we are surrounded by in our daily lives are auditory signs. Being unable to perceive these sounds has a significant impact on how we are able to navigate and how we interact with tools, products, services, and each other. The number of people with hearing impairment is increasing [1]. For elderly people, degeneration of hair cells in the cochlea is a normal physiological process. Thus, in a population with a growing number of elderly people, hearing impairment is common. In addition to the physiology of aging, noise, trauma, medical side effects and genetic disposition may all contribute to increase the problem.

Much equipment and many tools have been developed for bridging the problem of hearing impairment. There is widespread work on improving hearing aids and speech processing [2]; courseware for various disabilities [3-5]; approaches for improving websites for special needs [6, 7]; as well as the use of the web for cooperative

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
Proceedings of the 3rd European Workshop on Practical Aspects of Health Informatics
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learning [8]. Additionally, there are mandatory (but poorly adhered-to) international rules for Universal Design, which allow technology-assisted transformation of web-page information for the disabled.

When used successfully, hearing aids have been proven effective in providing increased quality of life [1]. However, many international studies show that actual use of hearing aids is problematic. Many hearing impaired do not, for various reasons, acquire a hearing aid. Among those who have acquired hearing aid have problems using it in the intended way or have stopped using it [9]. One attempt to contribute to this issue is the development of a service that supports patients' participation in the tuning and fitting of their own hearing aid through the use of an interactive tabletop [10].

The support for individuals with hearing impairment has been criticized for being fragmented and not well adapted or scaled to address patients' needs [11]. The cost and appropriate balancing of service levels within this group will be further challenged since the number of adults suffering from hearing impairment is estimated to increase from 15 % up to 25 % in the year 2020 [1, 12]. In order to meet this challenge, different measures need to be considered to make sure that the delivery of both services and products can be tailored to the patients' needs, and at the same time provide effective management of the hearing loss.

Based on a previous study on internet use by hearing impaired people, the Internet seems to be more intensively used for personal and group communication than by those with normal hearing [13]. In addition, research in the domain of Web accessibility guidelines for hearing impaired people suggests tailoring to improve the interaction and accessibility of the webpage [6]. These two findings suggest that using the Internet is potentially a good strategy for providing information to this group of people. Designing websites that ease access to information as well as accommodating hearing impaired users' needs can improve interaction between people as well as their use of devices.

In order to learn more about the information needs of this group of people, we would like to explore how and where the hearing impaired, their next of kin, and health care personnel share information outside the clinical setting. We would also like to explore which information the hearing impaired are most interested in.

2 Methods

Without a predetermined notion of how hearing impaired people in Norway currently gather information relevant for their life situation, we decided on an explorative, largely qualitative approach. This was implemented as four sub-studies with different methods. We allowed ourselves to pursue ideas as they emerged, rather than follow a predetermined protocol. This approach was expected to lead to a comprehensive view of the study topic. The methods we used together with the related sub-studies are described in the following.

2.1 Questionnaire

First, we contacted Hørselshemmedes Landsforbund (HLF), the patient organization for hearing impaired in Norway. They have local chapters in most municipalities, and each chapter has a group of specially trained members who assist local members with information. In this context we have called them peer members.

We identified ten peer members on the official HLF website who we requested by email to fill out a questionnaire. We asked about which communication channels patients would mostly use to contact them, frequent topics and questions they were being asked, and which sources of information they would typically suggest to members. The peer members are responsible for different age groups and selected topics.

2.2 Semi-structured Interview

Secondly, we conducted an in-person semi-structured interview with one of the peer member who responded to our questionnaire. Three researchers were present for this recorded interview. We aimed to get a more in depth understanding of their experiences from advising about hearing loss. What do HLF members ask about, and what kind of information or understanding do they seek, and need?

Guided by some predefined topics, the interview can be characterized as a semi-structured and open-ended conversation which lasted for 90 minutes. Our questions covered the existing services and community networks related to hearing loss, the type of communication channels that people use to reach the peer members, what kinds of information people were typically seeking and the challenges faced in providing this information.

We did a rough content analysis of the transcribed interview to identify important themes.

2.3 Observation and analysis of web forums

We wanted to observe some of the hearing loss-related community networks suggested to us in order to analyse posts and identify, first hand, the types of information members were seeking. We asked the administrators for permission to participate as invited observers in two closed Norwegian Facebook groups aimed for people with hearing impairment. Facebook Group 1 (FBG1) targeted people associated with hearing impairment. Facebook Group 2 (FBG2) targeted people having a hearing impairment.

FGB1 was not clearly defined but the pinned introduction emphasized that the group was a closed group for the deaf, people with hearing impairment, or of normal hearing. The postings might contain personal issues and good conduct toward members of the group was to be expected.

While FBG1 had no details in its description, FBG2 was meant for hearing impaired in employment, and wanting to remain working despite their hearing impairment.

Unfortunately, due to privacy concerns on behalf of the members, we were denied access as observers in both Facebook groups, but we did get permission to post a survey on FBG1, as described in the next section.

To broaden our perspective we also observed and analysed a public US discussion room webpage in English (MyHearingloss.org). We looked at what kinds of questions were asked and how these were responded to both in terms of content and style.

2.4 Survey

The final study is the survey distributed via FBG1. The survey was Internet-based and anonymous, using surveymonkey.org. The survey had two main parts with 5 questions in total.

The first section addressed our main research objective with pre-selected answers on a scale from 1-5 (1 = low agreement / 5 = high agreement). In the second section, to be answered in free text, we asked the participants to state how they valued the feedback from fellow members in the Facebook group compared with the feedback from the peer members representing the patient organization HLF. Privacy was ensured by not identifying the IP address of respondents. The sampling method can be characterized as purposive and based on members' own interest to participate.

3 Results

We present the results in accordance to the four sub-studies as delineated above.

3.1 Questionnaire results answered by peer members

We got two responses. According to these two respondents, members use different communication channels to get in touch such as e-mail, cell phone and face-to-face meetings during seminars or other arrangements. Frequent topics and questions concern case handling for acquiring hearing aids, communication with audiologist and labour rights. The respondents' suggested sources of information were grounded in personal experiences, dedicated websites and social media, leaflets and centres of expertise.

3.2 Semi-structured Interview with peer member

The results from the interview are structured around two categories: 1) Information connected to patient networks and 2) Information connected to understanding the consequences of one's own diagnosis. These categories were discussed and constructed in consultation with the informant during the interview. In the following we present the main points of each category.

Information connected to patient networks:

- Information is scattered and there seems to be a lack of coordinating responsibility.
- The treatment pathway appears unclear for patients and professionals.
- The interest group(s) do(es) not actively address GPs and specialists.
- There is a lack of prepared information procedures; it is unclear who has responsibility for providing information. Therefore, access to information from public health services is random - depends on attitude, available time, and knowledge of GP and specialist (consequences, rights, practical arrangements etc.).
- The interest group does not appear to be visible enough, much because they operate on voluntary basis.
- Peer members from patient organizations get few direct inquiries.
- Internet and social media are important for information and networking among peers. However, many of the hearing impaired are probably rarely (if ever) on Facebook.

Information connected to understanding the consequences of one's own diagnosis:

- Hearing loss often occurs gradually, and it is an invisible handicap. This makes it challenging to understand and acknowledge for the patients as well as for the people around them.
- Energy loss, stigma and embarrassment is commonly experienced, but information about how to deal with this is not readily available.
- It takes a long time to get used to hearing aids, information about how to deal with this is often not clear from a user perspective.
- The grieving process that comes with sensory loss, and how to deal with it is not an emphasized topic.

In addition, different Internet sources on information about hearing impairment were identified. Two resources for information frequently mentioned by the interviewed peer were HLF and Sansetap. Both websites are open and accessible to everyone. There are also others primarily addressing the deaf community.

The interest group HLF [14] has 58.000 members and is the largest patient organization in Norway. HLF had more than 600.000 hits a year on their website. The website provides general information on hearing and hearing impairment, announcements, items for sale, options for asking questions and information on what the organization generally does. Sansetap [15] is a public webpage with information about eyesight, hearing impairment and combined loss of senses. The focus of this webpage is on how to cope with the impairment.

3.3 Observation results

Observation was conducted on the US discussion room webpage (MyHearingloss.org), which is an open group for asking questions and reading archived questions about hearing loss. The website is founded by the Hearing loss association of America and uses moderators and administrators to moderate the content and appearance of the posted messages. The questions posted on the forum were categorized into the following groups:

- Technical hearing aid questions
- Is treatment X effective?
- Tinnitus
- Seeking technical aids and/or assistive devices
- Seeking peers with similar experience
- Techniques for coping with hearing loss

Moreover, through further analysis we found that:

- This is a forum where most people have or are experiencing hearing loss and are sharing their experiences with each other. They do not know each other, but they have their hearing loss in common.
- The majority of questions asked are extensive and many users include their personal hearing history in their questions.
- The forum users are friendly and supportive and the responses are mostly positive.
- Most questions are related to how you can cope with hearing loss, and the forum members are posting personal experiences with different treatments and aids.
- Some questions are left unanswered, but there is no clear pattern of which questions are answered and which are not.

3.4 Survey distributed through FBG1

The survey results are presented below, according to the two sections.

3.4.1 Survey section 1

The total number of members in Facebook group 1 was 3175. The group had no formal connection with the patient organization. Forty people completed the survey.

The participants responded a medium high engagement in social media for hearing impaired (mean score 3,6). Details of the respondents' answers to our survey regarding their reason for engaging in social media are presented in Table 1.

Reasons for engagement in social media for hearing impaired patients	
Category	Mean score (1-5)
Objective engagement	
Post questions related to technical issues about settings	3,6
Aid for hearing impaired	2,6
Medical questions	2.3
What they perceived to be the most important reason (personal motivation)	
Asking questions and get good answers	4
To get information about new things (being informed)	2,1
Find people like me	1.7
Actively engaged in giving response	
Response on aid for hearing impaired	3.3
Medical questions	2,7
Technical questions about settings	2,6

Table 1: Survey results – Respondents' engagement in social media

Category of questions they were seeking	
"Questions about any kind of aid for hearing impaired"	60%
Seeking answer for their medical questions	49%
Searching for answer about "technical settings"	45%

Table 2: Classification of respondents' questions

3.4.2 Survey section 2

In section 2 of the survey, the participants were asked to compare the usefulness of the Facebook group “peers” with the trained peer members from HLF.

Some of the participants commented that responses should be carefully considered since the members of the Facebook group might not have the ability to make a qualified response to the problems posted. A few responded that they did not take part in the discussions but used Facebook for getting information and tips and regarded themselves as observers in the group. This comment was also made by a professional using the Facebook group for information about the current “trends” among the people with hearing impairment.

Conformity requirements was commented by some of the participants who explained that posting their opinion could be difficult as they felt it was not accepted “by the group” to post something that was different than the perceived opinion of the group.

Quick access and effective spreading of news and information were considered the most important benefit of Facebook, but some also regarded this a disadvantage since disinformation might be spread just as fast.

4 Discussion

Our study suggests a lack of coordination and support for providing information to people with hearing impairment. Living with or becoming hearing impaired is a situation that affects both the individual and the person's surroundings. Based on the survey results completed by 40 participants, high engagement in social media (mean score 3.6) indicates that the format is perceived useful for people associated with hearing impairment. A platform which displays the functionalities patients appreciate in this format could represent a benefit for healthcare organizations for sharing information. As participants stated in their response, “asking questions and get good answers” (mean score 4) is one of the most important reasons to use social media. This is considered to be an important finding.

During this study we did not get a clear overview as to how one should proceed and where one should turn to for questions regarding experiencing hearing loss, as patient or as non-patient. Social media is apparently, and not surprisingly, an important source for receiving and sharing information. Therefore, if social media is to be used as official source of information it is necessary that the answers provided are easily accessible and correct.

As respondents stated in their answers, another reason they are involved in social media is networking with people like themselves. Thus, it is important to find out how hearing impaired patients are socially supported, and investigate their difficulties in finding new people/friends to socialize with, and how being in contact with people who have similar problems affects their quality of life.

According to our results, Internet and social media are important sources for different kinds of information about hearing impairment and for networking. For members of HLF and others (hearing impaired or not) seeking information about hearing impairment, Facebook was recognized as an important arena in Norway. Still, the interviewed peer member pointed out that part of the patient group is probably not using social media. Moreover, the respondent’s impression was that peer members from HLF received few direct inquiries in general. Seminars and courses are important arenas for knowledge transfer and social interaction. However, if people are difficult to reach via social media or even email, there is a chance that people miss out on such gatherings and especially if they are not familiar with the organization. For instance, we could not find any page listing up the various Internet-based resources and communities that are relevant in connection to hearing impairment, such as existing web pages and Facebook groups.

We have not been able to identify which basic information is currently being provided to patients, and if there is any kind of procedure to verify how the patients have actually perceived information given. This is nevertheless important in order to facilitate that patients start on the same page, so to speak, after initial consultation with GP and specialist.

A recent European health literacy survey concluded that 47 % of patients do not understand the information given by healthcare providers [16]. It may be reasonable to assume that members of this group might find perceiving information from a verbal source (e.g., from a physician) as even more difficult than in the general population. However, Internet-based information about this seems to be scattered around. Considering that stigma and grief that often accompanies sensory loss, the opportunities for lifting such important and sensitive topics through dedicated Web-based services such as the US discussion room webpage are expected to be highly valuable for both patients and professionals as well as relatives and colleagues.

Regarding different ways of sharing information on the Internet, our comparison between the functionalities offered by Facebook and the US discussion room support shows that:

- Users in the discussion room can log in by anonymous credentials whereas users on Facebook generally use their original Facebook profile.
- The discussion room supports classifying of information on different subjects (i.e., hearing aids, technology tips, families, friends, and parents of children with hearing loss) while in the Facebook groups there are no such categories.
- In the US discussion room, users are able to view the number of posts and topics for each category, when the last post was added to a category and who is the forum moderator. In the Facebook groups however, it is not possible to have such a comprehensive overview on the posts and topics, hence users have to scroll down to see all the posts and the most recent posted topics.
- In the US discussion room, users are able to subscribe to certain forums that they are interested in for receiving a notification email if someone adds comments to the forum, while in the Facebook groups users are not able to do follow up and receive notification emails without commenting on special posts.

Based on these differences between the Facebook groups and the US discussion room, we can emphasize that:

- Users on Facebook may be hesitant to comment or contribute as they are using their real user profile rather than an anonymous user account. This implies that there is a risk of revealing sensitive information or being judged by someone who knows them.
- Tracking of the posts in Facebook on different subjects requires more effort as posts are not classified.
- The person who posts a question on Facebook is the owner of the post, hence she/he is able to delete the post as there is no moderator involved in tracking of the posts and confirming the contents.
- There is a risk of spreading wrong information quickly by the users as a Facebook group does not necessarily have moderator who reviews comments and answers.

5 Concluding Remarks and Further work

Given the rapid technological and medical advances of recent years, along with the prevalence of hearing difficulties within society, we propose that there is a great potential for improvement of services regarding providing efficient information about hearing impairment, service and tools to address the problems.

While our results are preliminary, they suggest that current information sharing practices connected to hearing impairment are fragmented both regarding content as well as across a variety of actors and media, and the Internet as a multifunctional arena is underutilized. The issue of information sharing needs to be addressed more closely.

First, we have to investigate different practices for providing information during the first consultation: What kind of information is given by the GP, specialist and the audiologist, how is information provided and how do the patients and relatives perceive this information? To investigate this, studies at different clinics and among different practitioners in audiology should be conducted.

Secondly, we need to explore the basic knowledge about hearing loss that healthcare professionals have and how this knowledge best can be shared between various actors. This includes exploring how different media can be utilized. We also need to investigate why “asking questions and getting good answers” has such a high mean score. We will investigate who people can turn to in order to ask questions, and who are responsible for replying, and within which timeframe one can expect this to happen.

Acknowledgments We thank all the respondents who participated in the study and NFR for financial support via the NTNU Network for Health Informatics Research.

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Exploring Online Health Information Seeking in Scotland

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Abstract. Online Health Information Seeking (OHIS) has become an area of increasing interest over the last decade. The Internet has enabled the democratisation of health information as knowledge which was previously exclusive to health professionals has now become open access for all. The activity of OHIS has also revealed a digital divide in terms of those who access the Internet for health information. The prevalence of OHIS and the impact it has on patient outcomes and the relationship between health professional and patient is the focus of an on-going body of research outlined in this paper.

1 Introduction

Health information which is available online is changing how patients interact with health professionals. Much research focuses on the minefield of unregulated information and the impact this has on patient outcomes, positive and negative. However, it is vital to consider the impact on the health professional as this information has the potential to alter the relationship between patient and health professional as the patient becomes more empowered through OHIS. Recruitment of health professionals is in crisis. Short consultations and the changing landscape of healthcare have reduced the attractiveness of frontline healthcare [1].

In a recently published National Framework, The Scottish Government [2] encourages digital participation at a local level in the hope that the Scottish people are presented with the opportunity to benefit from the wide range of information, goods, and services accessed via the Internet. The particular focus is on improving digital participation among groups who are less likely to access the Internet, the elderly and low-income households [3]. These groups stand to benefit most from reduced-price goods and other benefits, which the Internet can provide. Internet use at home has been steadily increasing in Scotland. From 2007 to 2013 the percentage of adults accessing the Internet for personal use has risen 17.1 points (62.7% in 2007 to 79.8% in 2013) [3]. This compares with a 15-point increase of Internet use among adults in the United States for the same period (71% in 2007 to 86% in 2013) [4]. The increase in internet use at home results in people being able to engage in a range of online activities, potentially impacting on people’s lives. Information available which relates

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
Proceedings of the 3rd European Workshop on Practical Aspects of Health Informatics
(PAHI 2015), Elgin, Scotland, UK, 27-OCT-2015, published at http://ceur-ws.org

to health and well-being is one area in which the Internet is becoming increasingly important.

Scotland has a health service that is free at the point of need. As the population increases, the health of the nation continues to be an area of concern for the Scottish Government and the National Health Service (NHS) in Scotland. Internet use has enabled patients to access search engines, online symptom checkers, and health information sites to contribute to positive health outcomes for themselves or a loved one. This digitally literate population is described as "health seekers" [5].

Patient OHIS is not intended to replace physician care but to support it as health professionals also seek information online during a consultation as they include patients in the diagnostic process [6]. However, OHIS and user contributed health information is encouraging patients not to adhere to physician advice [7], to which health care professionals must adapt [8]. The online health seeker expects convenience, to be a partner in decision-making, and almost instant service in all aspects of their health care [9]. However, the health seeker must pass through a series of complex processes in order to access and utilise health information [10]. Barriers in language, information and communication technologies (ICTs) knowledge, or the ability to weigh up sources and formulate a reasoned perspective can all limit the positive outcomes of health seeking online. Trust has also been identified as a key barrier to improving the online health information-seeking experience [11].

Online Health seekers differ from offline health seekers by age, income and education [12]. Those accessing health information online are affluent, well-educated adults [13]. These differences are known as the digital divide [14-16]. Therefore issues surrounding the digital divide, focusing on eHealth literacy, are also important.

By identifying patient OHIS activities, the needs of the patient can be further understood. Technology has provided access to previously exclusive information and therefore it is important that the health professional be aware of how this information could potentially influence patient decisions. Knowledge of patient OHIS must be based on empirical data that is specific to the time and cultural context.

2 The Prevalence of Online Health Information Seeking in Scotland

Generating a baseline of the prevalence of OHIS among Scottish patients provides an important starting point in understanding how OHIS impacts healthcare. It is not necessarily appropriate to rely on data from secondary sources, other cultures or general Internet use surveys. To investigate this, an exploratory study of online health seeking behaviour in Scotland identified the number of patients who were influenced to seek further medical advice offline as a result of online health information seeking [19]. The attitudes patients have towards this information were also identified.

The study involved a convenience sample of 571 patients who responded to a self-completed questionnaire based on the Pew Internet and American Life Project [4]. Responses were predominantly on a nominal scale. Data were analysed using Statistical Package for the Social Sciences (SPSS). Findings revealed a total of 68.4% (379/554) of patients had previously used the Internet to acquire health information. A total of 25.4% (136/536) of patients consulted the Internet for health information regarding their current appointment on the day surveyed; 34.6% (47/136) of these patients were influenced to attend their appointment as a result of that online health information. With reference to the impact of the information on their health 43.2% (207/479) of patients stated the health information helped improve their health and 67.1% (290/432) indicated that they had learned something new. A total of 34.0% (146/430) of patients talked to a health professional about the information they had found and 90.0% (376/418) reported that the information was useful. In total, 70.4% (145/206) of patients were concerned about obtaining health information online from reliable sources. A total of 67.1% (139/207) of patients were concerned that a health site may sell their personal information, yet only 6.7% (36/535) checked the privacy policy of the site visited. However, 27.9% (55/197) of patients were not concerned about their employer finding out what health sites they visited, whereas 37.5% (78/208) were concerned that others would find out. The full study can be accessed online [19].

3 The Power Exchange Between Health Professional and Patient

It is argued that OHIS has the potential to impact the interaction between patients and health professionals [12, 19]. Specifically how, and to what degree this occurs is unknown. Patients are engaging in OHIS to meet their personal health needs, but they do not necessarily discuss this with a health professional [17-20]. In order to explore this impact a pilot study, the second stage of this programme of research, was developed in an attempt to identify how the democratisation of medical knowledge through the Internet creates new levels of empowerment and agency for patients as well as breaking down traditional barriers by shifting the balance of power from health professional to patient. The health professional/patient relationship is persistently asymmetrical [25]. The focus during this phase of the research is on the health professional’s experience of OHIS.

Following ethical approval from NHS Grampian, a series of unstructured qualitative interviews were conducted among health professionals (n=13). The focus of these interviews was to identify issues encountered during a typical patient consultation in relation to patient OHIS and the impact this has on the health professional. This was an exploratory study seeking to identify themes that will inform subsequent research. Therefore unstructured interviews were most appropriate as this method allows the interviewee to direct the conversation [22] and results in less arbitrary interviewing allowing the interviewee to tell their story [23, 24]. In this context this approach is particularly apt as the health professionals were sharing privileged information about their experiences with patients.

After an initial briefing and question the health professionals were given the opportunity to elaborate with minimal contribution from the interviewer. No confidential information was disclosed, however, this is a topic that some health professionals may not be comfortable with. The question asked was ‘In the context of a typical consultation, what is your experience of patient online health information seeking?’

Interviews lasted approximately 20 minutes and were recorded using a dictaphone. The recordings were later transcribed and imported into Nvivo as word documents. A conceptual framework analysis, as proposed by Miles and Huberman [23], was conducted using Nvivo in order to identify themes of power and efficacy in relation to patient and health professional interaction around OHIS. Miles and Huberman [ibid] recommend reducing the data, displaying the data and then drawing conclusions. This process was followed and the data were reduced by extracting relevant sentences and pasting them into a new document [26]. Themes were identified relating to; time spent discussing online health information; tension experienced during this process; trust in the health professional over the information; terminology as patients lacked digital or health literacy; and finally trouble when confrontation can occur.

3.1 Preliminary Findings

Preliminary analysis of the interview data indicated that most health professionals see the merits of increased patient OHIS. They largely accepted this as a part of their consultation process. Respondent 2 stated:
"Doctors attune themselves wherever they are to their circumstances and I am sure that people working in that environment are good at dealing with that" (R2)

However, some health professionals felt undermined by patients who present information during consultations that they found on the Internet. Trust was a key concept here:
"...quite a few times there have been minor symptoms which patients interpret online. Quite difficult for me to shake off as it often feels like patients think we are contradicting online information. Sometimes there is a lack of trust" (R5)

"People have extraordinary faith in the information they find on the Internet" (R6)

"…frustrated with patients who are difficult to convince." (R5)

"…frustrating…can lead to conflict in the consultation. No trust or respect" (R3)

On the other hand respondent 1 stated the following:
"I have been here quite some time so I have quite a good relationship with some of the patients so it may be that they are trustworthy of your opinion and so if I say 'I don't think it is that and here is why', then that is fine" (R1)

Although OHIS is seen as a largely positive activity, it is clear from the interview data that most health professionals spend some portion of a consultation discussing online health information. Existing research indicates that information presented during consultations as a result of patient OHIS can result in longer consultations [17]. In addition health professionals are often presented with information that they do not know themselves [17]. Health professionals indicated that they often search

for appropriate sources of information with a patient during a consultation. The following extracts highlight this:
“Sometimes patients bring data that you have no idea about…I have just been honest about that and tried to educate myself about that” (R5)

“Patient needs are diverse and therefore treatments equally so. In this sense a snapshot of [OHI] is not particularly helpful and it serves to confuse rather than help. Therefore time is spent fixing this during a consultation” (R6)

“…appointments are longer than 10 years ago as information giving is now built into consultation” (R6)

“…spend a long time persuading someone that they do not have something” (R3)

“…in a large % of consultations I will go online with the patient and point out a website that might be useful to them and ask them to go away and look at it and then come back” (R1)

Some respondents indicated a concern for the type of information patients were accessing and highlighted this as a potential cause of conflict in the consultation:
“The other kind of internet behaviour I would be very cautious about is the patient forum. It tends to be people with undiagnosed medical problems and they get onto forums and convince themselves they have something and they want a label for it and some of these things can be a bit toxic really and can cause difficulty ” (R2)

“…they [patients] come armed...” (R6)

Further to this, concern was expressed about patient ability to interpret appropriate information and actually possess the relevant level of literacy to understand it:
“…multi-disciplinary input for a patient...they come to you with almost an information overload. When problems are so complex the Internet stops being helpful at that point” (R1)

“The question usually is do I have this thing rather than what is thing. Pointing out reliable sources – forums are a problem and patients can think they have a side effect and join with collective in thinking they have it” (R5)

These preliminary findings support current discussion in the field of health communication and highlights the need for improvements in how health professionals mediate patient OHIS [17, 18, 20, 21].

4 eHealth Literacy: A Comparative Approach

Preliminary findings from the exploratory study outlined above indicate that digital health literacy is a concern for health professionals and patients alike [18, 20]. In general digital literacy is an issue that presents access issues for general Internet users across various socio-economic groups. This digital divide highlights certain characteristics that predispose affluent groups to enhanced digital literacy skills. When complex medical terminology is added to this in an OHIS context, the problem of access to health information via the Internet is further compounded [16].

Finland and Scotland are often identified as sharing certain social and health characteristics. With populations of similar size, comparison between the two in regards to digital health literacy is an interesting prospect. The authors and a partner in the University of Oulu, Finland, are to investigate levels of digital health literacy among patient populations, in a comparative study.

5 Conclusion

The impact of OHIS on health professionals and patients is a multi-dimensional issue that needs to be understood at the macro and micro level. Patient experience appears to be held above the plight of the health professional as the digital culture brings Dr Google further into the consultation space. The findings at this stage of this programme of work suggest that online health information-seeking behaviour influences offline health-related behaviour among the population surveyed.

The first study in the series provides support for the growing phenomenon of an empowered, computer-literate, health information consumer, and the impact of this phenomenon must be considered in the context of the patient-health professional dynamic. Patient attitudes to online health information seeking were focused on issues relating to trust, reliability, privacy, and confidentiality. This study provided a baseline of the prevalence of online health information seeking in the Grampian region of Scotland.

Preliminary findings from the second study, which focuses on the experience of health professionals in relation to patient OHIS, has shown that health professionals are adjusting their consultation style and spending time justifying diagnoses and treatment options as a result of patient OHIS.

Patient experience is not to be overlooked in this context, however, this particular topic has received much attention within the field across cultural, social and economic divides. It is important to conduct a Scotland specific study as assumptions of a universal experience should not be made. Therefore a further qualitative study will be conducted identifying the patient experience of presenting information found online during a consultation. By continuing this programme of work the authors strive to contribute to the overall understanding of the impact of OHIS on healthcare.

Acknowledgments We would like to acknowledge the support of Moray College UHI and NHS Grampian in this programme of work.

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Information Given to Patients Undergoing Nuclear Medicine Procedures

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Abstract. In this study, we have examined the information given to patients whom are undergoing nuclear medicine procedures – and in particular the information on radiation and exposure. We collected the written information provided prior and during the examination and conducted a small survey amongst patients on the information given. The main findings show that as these patients are sources of radiation to their surroundings, information about this should be made available for the patients in order to make the necessary precautions.

1 Introduction

Patients have a basic right to information about their illnesses, treatments and management [1]. This also includes information about possible risks and side effects. Advances in technology for both diagnosis and treatment combined with increased specialization, may challenge the balance in informed and shared decision-making, and the balance of rights and responsibility between the medical professional and the patient.

At the same time, the role of the patient is evolving. The availability of information and information technology has created new possibilities and relations between the health service and its users [2]. Patients are now also used to finding information in source and voices outside the regulated realm of the health service. As such, it is meaningful to discuss a "shift in the role of the patient from passive recipient to active consumer of health information" [3]. Patients search out information about their *specific* medical conditions for several reasons, including "*for reassurance or because of dissatisfaction with the amount of detailed information provided by the health professional during the encounter"* [ibid].

From the perspective of the health professional, providing information is also an act of balancing between a reasonably informed patient and not wishing to cause unnecessary fright or concern about upcoming treatment or prospective outcome. However, studies show that *"Patients very satisfied with their information had received the largest amount of information"[4]*. At the same time, an American study of 8 major sources of patient education material on radiation safety show that we fail to appropriately exploit these modern information channels. Their literature review

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
Proceedings of the 3rd European Workshop on Practical Aspects of Health Informatics
(PAHI 2015), Elgin, Scotland, UK, 27-OCT-2015, published at http://ceur-ws.org

showed that all of the 45 identified articles failed to meet the recommended level of readability for patient information [5].

Patients undergoing Nuclear Medicine (NM) procedures require specific and tailored information [4]. More specifically, they require information about their condition, information about the diagnostic or therapeutic procedure they are about to undergo, and lastly information about the fact that the patient can act as a radioactive source and constitute a dose and contamination hazard to their surrounding for some time after their procedure. The information must be provided in a format that is easily understood by the patient and is appropriate to the hazard presented. Hospital nuclear medicine departments are known to produce very varied instructions to patients[6]. The understanding of radiation and nuclear medicine procedures is not described in detail in research – and there is a need for further research into these concepts both for patient information, but for appropriate information to staff and professionals that come into contact with NM patients in other parts of the hospital. We have previously investigated the radiation from NM patients to their surroundings [8], and found that while the amount of radiation is small, current practices are not necessarily based on evidence-based evaluations. Better information and education of both patients and staff seems beneficial.

In Norway, the official recommendations from the Norwegian Radiation Protection Authority on nuclear medicine[7], clearly states that at the beginning of the treatment plan a whole range of questions concerning exposure to the surroundings should be covered. Individual counseling both oral and written of the patient and their kin should cover daily activities and how to reduce the risk of exposure to others where appropriate. The aim of this study is therefore to capture patient perspectives on the received information about radiation as well as to investigate current hospital practice on this issue.

2 Material and Method

Health care setting: The nuclear medicine center located at a university hospital owned by one of the four Norwegian Regional Health Authorities. The hospital’s catchment area is approximately 700 000 people.

Study design: A mixed-method approach with use of a quantitative questionnaire accompanied by a qualitative review of practice documents.

Data collection: The questionnaire was handed over to 40 patients undergoing a nuclear medicine examination in the period February – March 2013 and recorded data on 1) how and what information the patient received from the hospital before the actual examination, and 2) patient satisfaction with received information as well as their perspective on how such information may be mediated. In addition, the patient information leaflets about nuclear radiation precautions (i.e. the information intended to be distributed to patients) were collected from 7 hospitals, of which one hospital was Danish.

Data analysis: Simple descriptive statistic was applied to describe the features of the questionnaire dataset. This was accompanied by a qualitative content review of the collected leaflet, for which the focus was on information about radiation precaution related to pregnancy, children/next of kin and other people. Authors 1 and 2 did the analysis and the interpretation of the data.

Ethical aspects: Informed consent was obtained from the participants, and they were assured that questionnaire and document data would be treated confidentially and were guaranteed anonymity in the presentation of findings. No personnel or health information data were collected. The study was approved by the hospital's research board, and the ward manager.

3 Results

37 out of 40 patients (93%) completed and returned the survey within the given deadline. Figure 1 shows that 14 of the 37 patients (38%) were informed orally by the nuclear medicine department about radiation. 15 of the patients had not received any information in advance. 6 Patients say they have received information in advance by an information letter sent from the nuclear medicine department.

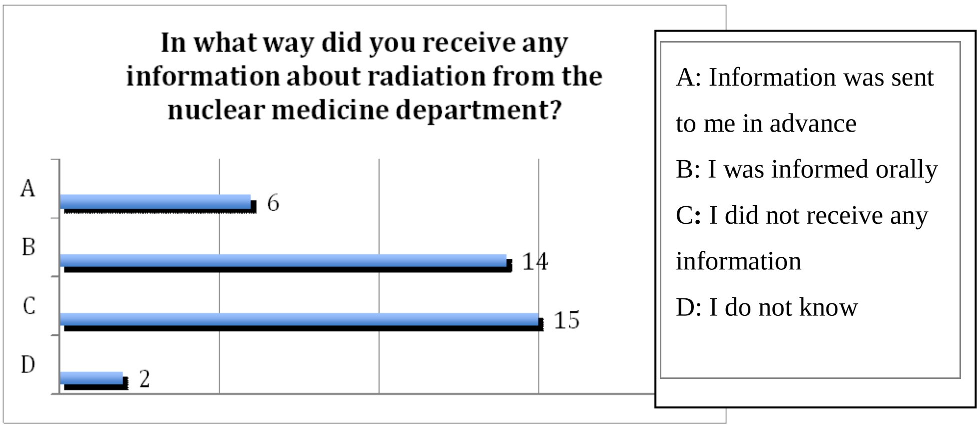
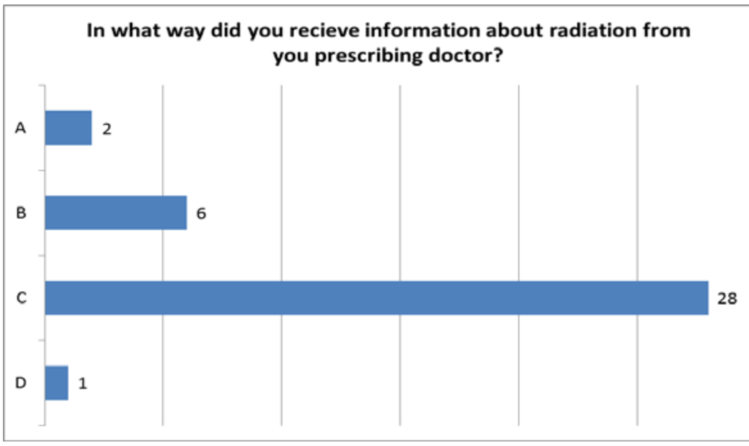


Figure 1. Information given from the nuclear medicine department to the patient.

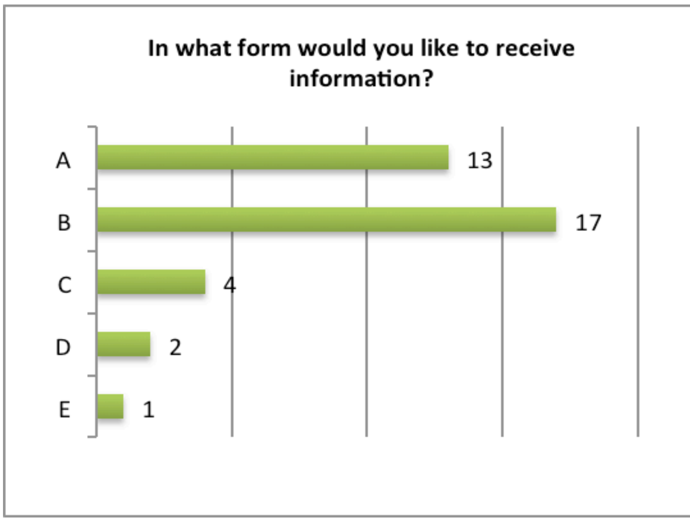
Figure 2 shows that 28 of 37 patients (76%) had not been informed by the doctor who referred the patient to the nuclear medicine examination. 6 patients have been informed verbally by the physician.



A: Information was sent to me in advance
B: I was informed orally
C: I did not receive any information
D: I do not know

Figure 2. Information from the prescribing physician regarding radiation.

Figure 3 shows that when it comes to the desired way to get information, 17 (46%) answer that they want to get information in the notice letter, while 13 (35%) will prefer the information given orally. Only two of the subjects want the information via the Internet.



A: Orally
B: Information should be placed in the summons letter
C: I prefer to read information at the department upon arrival
D: I prefer to read information on the Internet
E: I do not know

Figure 3. In what form the patient would like to receive information.

Figure 4 shows that 20 (54%) of those surveyed believe they have received enough information about the survey, while 11 (30%) think they have not got enough information. 6 (16%) do not know.

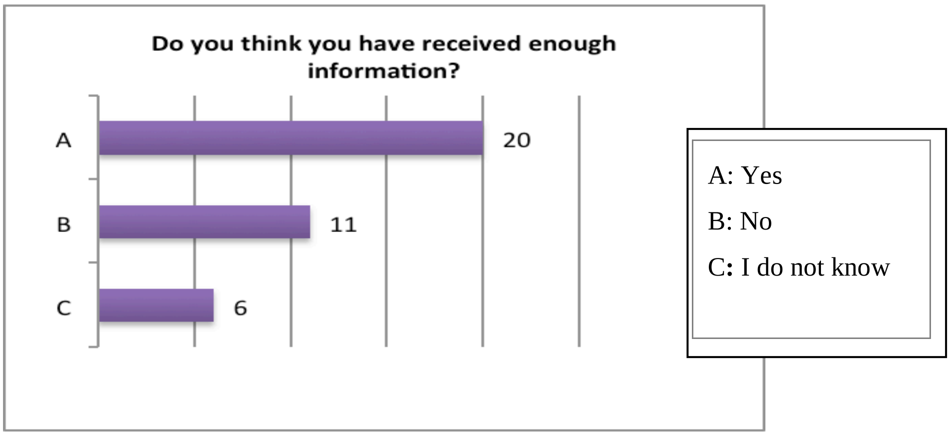


Figure 4. The answers to the question: "do you think you have received enough information?

As for the information hospitals give to this patient group by letter, all seven hospitals (Six Norwegian and one Danish hospital) send out general information as well as specific information related to the particular procedure. This includes information about radiation as well as which precautions the patient should undertake on a general basis.

However, concerning patient precaution when it comes to how they should keep clear of pregnant woman/children/others, Table 1 shows that there is only one hospital that lists such precautions in their information leaflet related to the three common NM examinations; skeletal scintigraphy, octreotide scintigraphy and MUGA.

Table 1. Whether or not the hospitals give their patient information regarding radiation comparing three common nuclear medicine examinations. One hospital give specific information about how far away the patient should keep clear of pregnant woman and children, and for how long.

Examination / Hospital	**1**	**2**	**3**	**4**	**5**	**6**	**7**
Sceletalscint.	NO	NO	NO	Yes	NO	NO	NO
Octreotidscint.	NO	NO	NO	Yes	NO	NO	NO
MUGA	NO	NO	NO	NO	NO	NO	NO

4 Discussion

As shown in the results (Table 1), only 1 hospital out of 7 hospitals (= a Norwegian one) provided information about restricting contact with children and pregnant women (even though this is explicitly mentioned in the recommendations from the Norwegian Radiation Protection Agency).

As we saw, many patients indicate that they did not receive any written information prior to the day of the examination. However, according to our survey the hospitals do provide general information. In this general information there are sections on radiation safety and precautions. We speculate that this indicate that half of our study population does not read everything they receive. If so, this raises several questions around the form of communication: the readability of the content and whether or not the information is at an appropriate level for the patient's comprehension.

Similarly, Figure 2 shows that most patients did not receive any information about radiation precautions from the referring physician. This was expected as it is the hospital's job to distribute this type of information, Still 2 of 37 respondents replied that they did receive information about radiation precautions. This raises some doubt with respect to the comprehensibility of the posed question. Respondents were divided in their view between preferring information to be distributed in the letter from the hospital and whether or not they would prefer oral information at the department. This may reflect that information provided on the day of the injection is better remembered than the information received potentially some time prior to the examination day. During our period of data collection, we observed that some patients brought their information letters to the hospital at the day of their examination, which in turn created an opportunity to provide all the necessary information written as well as repeating the key parts verbally on the day. Based on observations, our impression is that the written communication has potential to contain *more* information, but again tailored to the specific needs of the patients. This ranges from practical issues such as where and when, but also to more information about radiation, restrictions and precautions that should be observed after the injection of radioactive material. We also noticed that our informants did not seem to be afraid of more information, but rather saw it as important and necessary.

Comparing this with the literature on information to patients, especially for patients undergoing nuclear medicine procedures, our survey is inline with what similar studies have shown elsewhere[4-6]. Research has shown that the radiation from these patients to the surroundings are close to negligible [8]. It is therefore close to a paradox that the information – and knowledge of – about radiation and exposure both for staff, patients and their kin is thin. One could argue that this is unimportant given the context and the relatively harmless dose of radiation, but at the same time there is a basic right to information to be observed as well as a general need for reinforcing the ALARA ("as low as reasonably achievable") principle in a time where the average patient is exposed to an increasing amount of radiation through diagnostics and therapy.

Further research could involve bigger patient groups, other types of nuclear medicine examinations, other types of radiopharmaceuticals and a larger amount of patients/hospitals.

As well, one hospital changed their information practice resulting from our research findings. They now inform collaborating departments about the patient radiation as a way to assure them that it is not harmful. One might argue that more general knowledge about radiation inside the hospital walls could break down some of the undue anxiety and wrong assumptions toward nuclear medicine examinations.

One of the authors of this paper has now focused her master's degree towards patient information related to radiography.

4.1 Strengths and weaknesses

The biggest challenge in this study was to ascertain how much information the patients received without biasing them through at the same time informing them. The premise for our investigations was measurement of the radiation from the patients that made it necessary to inform them about the study and through that also the fact that they did act as a radiation source. For some, this came as news to them – which indicate that this was not something they had been informed of or had not comprehended from the information given to them. This means that it is not possible to reliably distinguish between the information given to them outside the scope of our study and the informed consent obtained in the study (which contained necessary information).

Concerning question 4 (Figure 4), 20 (54%) patients respond that they have received good enough information, and 11 (30%) that they did not. It is possible that their interpretation confuses the details about the procedure and radiation protection in general. This of course impedes the interpretation of our results.

There is also a potential confounder in that patients may receive different information based on whether they were referred from their general practitioner or as in-patients from a different ward. We have chosen to focus on their subjective experience and how and through which channels they would prefer to receive information. As such not a test of the information they have understood, but their subjective experiences. This could of course be biased by the respondents wish to provide "socially acceptable answers", i.e. a social desirability bias to appear favorable to the surveyor. Additionally, the "power of questions" is an inherent confounder, the questions posed to the informants also influences how they respond. Due to the size of the study, there were only a limited pilot of the survey. So there is an underlying challenge in interpretation of the responses.

5 Conclusion

Patients have a fundamental right to information about their own illness, examinations and, treatment; including side effects and risk factors. As this study has shown, the nuclear medicine patients do not receive the information they are entitled to. This is a balancing act between providing information enough information, but at the same time not overwhelming or causing unnecessary worries in the patient population.

In order to truly provide patient-centered care, attention to supporting activities such as patient information is important in order to change the patient experience. Today, information is available everywhere, on the internet or in more traditional channels, but it differs to which extent patients seek out information – as well as it varies how much of the given information is comprehended by the individual patient.

Acknowledgments We wish to thank the health professionals and the patients who were willing to participate in the study. We would like to thank Professor Hans Olav Myhre and Jan Gunnar Skogås at Operating Room of the Future, St. Olavs Hospital, who provided all-round good advice during this research as well as feedback on this manuscript. We would also like to thank Marianne L. Stokkan and Jeanett Hoff Antonsen at the Nuclear medicine dept. at St. Olavs Hospital for invaluable professional help.

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Contemporary eHealth Literacy Research – An Overview with Focus on Germany

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Abstract. eHealth Literacy is a crucial topic in regarding the acceptance of consumers towards eHealth services. There are several measurement methods, nevertheless they all lack interactive aspects of trending technologies such as mobile health apps or self-tracking services. Furthermore none of them acknowledges cultural and social backgrounds. Although the topic is of great importance it seems to be underrepresented in Germany.

1 Introduction

In today’s society electronic health services (eHealth) play an increasing role and generally in the western societies there is a great willingness to use them [1-3]. EHealth services are able to offer a variety of advantages to the user [4-6]. Eland-de Kok et al. found in a systematic review that eHealth interventions for chronically ill persons can lead to positive effects on primary health outcomes [7]. Santana and colleagues measured that almost 27% of European citizens who had searched for health information online also have made active suggestions on diagnosis or treatment to their physician and thus took a more active role in medical decision making [6]. In a meta-analysis of randomized controlled trials on the effects of consumer health information technologies for diabetes patients, Or and Tao found that the usage of eHealth technologies reveal positive effects on clinical parameters such as blood pressure or cholesterol levels [8].

Nevertheless the literature shows that eHealth services often are not accepted by the intended users (e.g. Google Health) [9] at all or that the interest is flagging over time [10]. If health services on the Internet are not used properly it might lead to emotional harm of the user or, in one reported case to the death of a patient [11]. Numerous factors contributing to an appropriate use of eHealth services include different facets: There might be different contexts of use (e.g. support from other persons) [12], different personalities (e.g. high intrinsic motivation, anxiety) [12, 13], and characteristics of the intended users (e.g. gender, age) [12] or diverse competencies of the users to use eHealth services [14, 15].

In addition, it is vital to know potential end-users’ obstacles to use such services. Due to the technological development and the increasing importance of modern

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
Proceedings of the 3rd European Workshop on Practical Aspects of Health Informatics
(PAHI 2015), Elgin, Scotland, UK, 27-OCT-2015, published at http://ceur-ws.org

information technology eHealth literacy research is the key part in health literacy research.

Due to ubiquitous accessible health information and interactive functions eHealth services are expected to help overcome unequal access to health care and thus help decrease social inequalities in health care. Nevertheless, we face the risk that individuals will not use them in the most efficient way simply because they are not able to. Thus, it is essential to understand what skills are needed to use eHealth services efficiently. Nevertheless, the contemporary understanding of eHealth literacy seems to lack several important aspects regarding further eHealth barriers such as other personality factors like anxiety or trust. Although in other nations like the United States or Scandinavian countries there is a vivid eHealth literacy research it appears that Germany is mostly lacking those research efforts. The objective of this article therefore is twofold: First it shows how the contemporary research regards eHealth Literacy and what aspects might be missing. A new approach is presented to integrate technology acceptance models into the eHealth literacy concept. Second it focuses especially on Germany and provides insights into German eHealth literacy research by presenting an overview on the research state and introducing several research projects.

2 Methods

To work on the first focus of this paper – the contemporary eHealth literacy research and the promotion of a possible model extension – we conducted a literature research in MEDLINE searching for terms like “technology acceptance AND ehealth”, “eHealth” AND “literacy” AND factors OR “barriers”. Furthermore a workshop was conducted during the 2014 MIE in Madrid to discuss possible eHealth barriers with experts.

To answer the second question regarding the state of eHealth literacy research in Germany Internet researches were conducted; also article alerts from MEDLINE providing regular updates on articles with the topic of eHealth literacy were used.

3 Results

3.1 eHealth Literacy research – state of the art and model extension

Health Literacy is a term that was first introduced over 30 years ago [16]. Ratzan and Parker created the mostly used definition; according to them Health Literacy is “the degree to which individuals have the capacity to obtain, process, and understand basic health information and services needed to make appropriate health decisions” [17].

Since the 1970s the concept of Health Literacy has been used widely in research and can be measured by a large variety of tools (e.g. TOFHLA, HALS, REALM, MART, FHLM, ELF…) [18]. One problem with these tools is that although they offer gold-standard for the measurement of Health Literacy (like TOFHLA and REALM), it is not possible to apply them for computer-based use [19].

Due to this background an extension of the Health Literacy concept to include e-health related competencies was performed. Cameron Norman and Harvey Skinner were pioneering in the concept of eHealth Literacy: They defined it as “the ability to seek, find, understand, appraise health information from electronic sources and apply the gained knowledge to addressing or solving a health problem” [20].

Whereas Health Literacy measures competencies in the context of paper-based resources in the healthcare environment, eHealth Literacy is much more complex: Persons who are intended to use electronic sources for health purposes need a variety of skills – basic literacy (reading and writing of texts) is as well necessary as knowing how to use computers and understand and evaluate science and media [20]. So Norman and Skinner defined eHealth Literacy not just as a combination out of the capability to use computers and Health Literacy but as a meta-literacy out of different facets of literacy.

Thus eHealth Literacy consists of six domain-specific facets:

- Health literacy: Health knowledge comprehension
- Computer literacy: Skills to use hard- and software to solve problems
- Science literacy: Understanding science processes and outcomes

These three competencies are the context-specific components of the e-health literacy model as they describe abilities needed to use electronic sources for health purposes. As one can see, health literacy is a part of it. Those components are supplemented by three analytic components describing more general competencies. Here constructs like traditional literacy are included:

- Traditional literacy: Reading, writing, and numeracy, which is important as electronic sources of health information are still text dominant.
- Media literacy: Thinking critically about media content
- Information literacy: Seeking and understanding information to make decisions

eHealth Literacy takes up the idea of health literacy but makes an addition to it by including more competencies. All the competencies are grouped in the so-called Lily model which is shown in Fig. 1. Important for the understanding of eHealth Literacy is as well that the competencies are not stable but might increase over the time [20] thus enabling the training of said literacy [21].

The aim of measuring eHealth Literacy is to prevent the creation of tools to promote health and deliver health care service that are inaccessible to the users they are intended for. By measuring an individual’s eHealth Literacy it is possible to get an overview of his or her competencies. Furthermore the functionality of e-health application software can be evaluated by measuring the changing of competencies over the time this software is used.

Until now eHEALS (eHealth Literacy Scale), [22] is the widest used measurement tool for assessing e-health literacy of individuals [19], consisting of 8-10 items. Norman and Skinner developed it in English using a sample of Canadian adolescents [14, 22]. Koo et al., van der Vaart et al., and Mitsutake et al translated eHEALS into Chinese, Dutch, respectively Japanese [23-25]. Soellner et al. provided a German translation of the eHEALS [26].

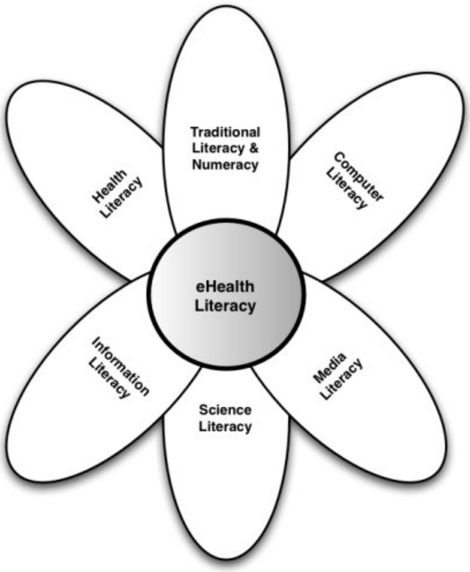

Fig. 1: eHealth Literacy: The Lily Model

Cameron Norman who, together with Harvey Skinner, created the Lily Model in 2006 wrote five years later that he sees some problems with it, for example that it does not fit to the Web 2.0 solutions [27]. Others stated that eHealth literacy was heavily depending on social structures [24] or the individual motivation to use a system [13] which is not included in the original Lily Model. Thus the original Lily Model is lacking several aspects of eHealth usage such as the contexts of use, further user characteristics like anxiety or motivation, and different personalities of the intended users including age, gender and socioeconomic status.

In her article “Toward a Comprehensive Model of eHealth Literacy” for the PAHI workshop 2014 [28]Heidi Gilstad describes how she included other literacies like cultural, contextual, and communicative competencies into the Lily Model. Furthermore she emphasized that it was important to distinguish between propositional (knowledge generated from theoretical sources such as books or research articles) and procedural knowledge (gained from practical experiences).

This is a very interesting approach to enrich the Lily Model. In our research we regarded numerous models dealing with technology acceptance factors besides the eHealth literacy concept.

Well-known and widely used is the Technology Acceptance Model (TAM) which was developed in the 1980’s in the light of the concern that workers were not using IT. Its originators reasoned that the key to increasing use was to first increase the acceptance towards IT, which could be assessed by asking individuals about their future intentions to use the IT. Knowing the factors that shaped one’s intention would allow organizations to manipulate those factors in order to promote acceptance and thus increase IT use. Early TAM research discovered that only two factors (perceived usefulness and perceived ease of use) were needed to explain, predict, and presumably control acceptance [29] (Fig. 2).

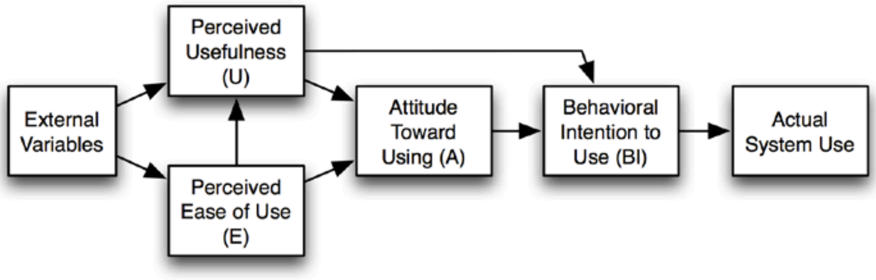

Fig. 2: Technology Acceptance Model (TAM)

Until today the original TAM model has gone through a number of changes (TAM2, TAM3, and UTAUT). An impressive effort to unify the IT acceptance resulted in the Unified Theory of Acceptance and Use of Technology (UTAUT), a [12] (Fig. 3).

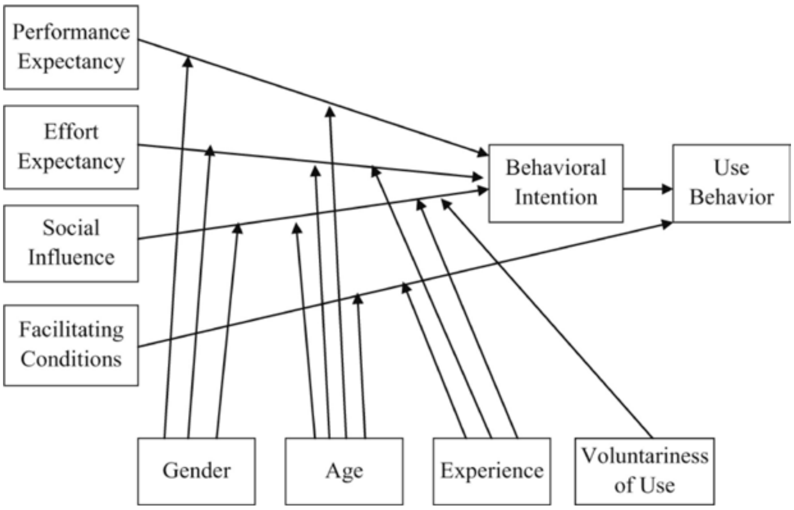

Fig. 3: Unified Theory of Acceptance and Use of Technology (UTAUT)

Nevertheless neither the eHealth Literacy model nor the technology acceptance models do include all relevant factors leading to the acceptance of eHealth services.

Regarding the research on eHealth usage among consumers it becomes clear that eHealth literacy is only one amongst other factors influencing the use behavior. During a workshop focusing on consumer-oriented eHealth barriers conducted at the Medical Informatics Europe (MIE) conference 2015 in Madrid, Spain with interdisciplinary experts (e.g. medical professionals, technicians, and social scientists) this finding was supported: eHealth Literacy is one important but by far not the only factor that needs to be taken into account when regarding and predicting the usage behavior towards eHealth solutions among consumers. Literacy is merely one of several cognitive barriers amongst barriers regarding the motivation of the user, the accessibility to Internet technologies, trust issues, environmental and organizational barriers and technical barriers such as the usability of the respective service [30].

This finding is supported by a literature research conducted in 2013 using Medline. The review showed that eHealth service acceptance was influenced by many factors including e.g. trust, anxiety of the user, or UTAUT factors such as the perceived usefulness of a service. EHealth Literacy was found to be directly connected with the intention to use eHealth services [31]. In a subsequently developed research model eHealth Literacy was thus a central explanation factor of the intention to use eHealth services. The research model which aims to provide an overview on eHealth acceptance factors is shown in Fig. 4.

For example if a person intents to use an eHealth service his or her acceptance directly depends on factors like the social influence (do other persons who are important for me think that I should use the system?), facilitating conditions (are there conditions that help me using the system?), performance expectancy (what benefit do I expect by using the system?), and effort expectancy (what efforts do I expect by using the system?). Those factors were derived from the UTAUT model. Besides those factors anxiety and trust were found to directly influence the intention to use eHealth services by analyzing the literature [32, 33]. Direct influence was also found for the user’s condition (the degree of well-being) [32, 34], the health specific knowledge (the users’ perception of how much knowledge they have regarding the own health condition) [35, 36], the Internet dependency (degree of habit or compulsion to use the Internet for information or self-management) [20], and the satisfaction with medical care (users’ beliefs concerning the medical services received or experienced) [32]. Attitude towards using describes the expected feeling about using an eHealth service and was as well found to have a direct influence on the usage intention [32] as the computer self-efficacy (individual judgement of the own capability to use computers or eHealth services) [37].

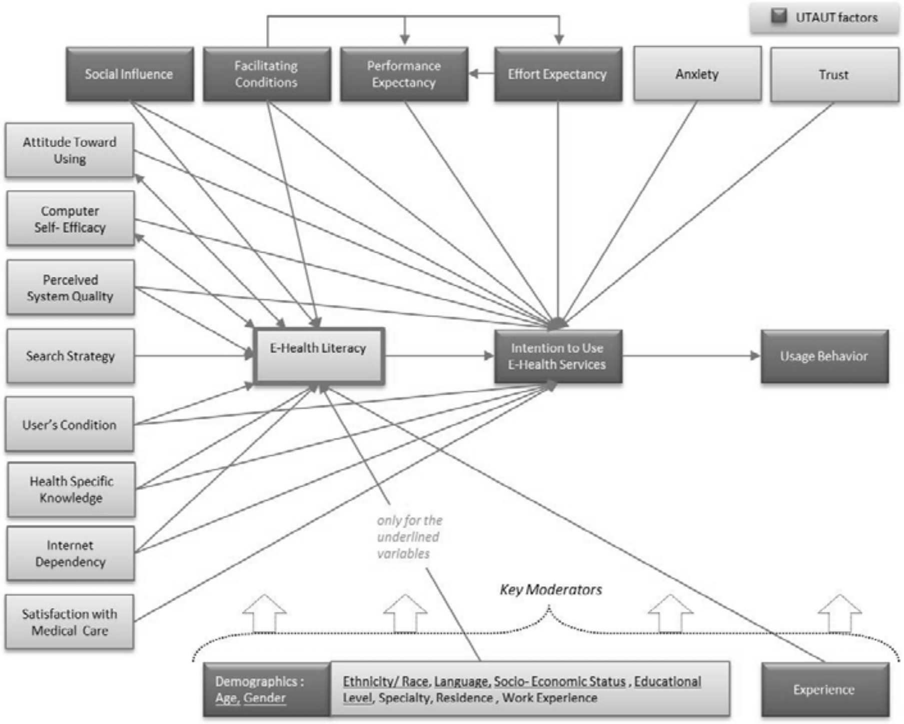

Fig. 4: eHealth Literacy and Technology Acceptance - a research model

3.2 eHealth Literacy Measurement – State of the Art

By measuring an individual's eHealth Literacy it is possible to get an overview of his or her competencies that are needed for using eHealth services and applications. Furthermore the functionality of e-health application software can be evaluated by measuring the changing of competencies over the time this software is used. Until now eHEALS (eHealth Literacy Scale), [22] is the widest used measurement tool for assessing e-health literacy of individuals [19], consisting of 8-10 items. Norman and Skinner developed it in English using a sample of Canadian adolescents [14, 22]. Koo et al., van der Vaart et al., and Mitsutake et al translated eHEALS into Chinese, Dutch, respectively Japanese [23-25]. Soellner et al. provided a German translation of the eHEALS [26].

After it has been developed by Norman and Skinner in 2006 the eHEALS has been used several times in the healthcare environment. Brown and Dickson measured healthcare student's e-health literacy skills [38].

Also Hove et al., Ghaddar et al., and Paek and Hove used eHEALS to measure eHealth Literacy of adolescents [39-41]. Neter et al. reduced the number of items to only six to measure eHealth Literacy in the average Israeli adult population [14]. Another broad approach of eHEALS to measure eHealth Literacy of a larger group of people is the work of Mitsutake et al. who measured an association of approximately 3000 Japanese adults with their knowledge about colorectal cancer [42]. Furthermore Ossebaard et al. measured the eHealth related literacy for patients with chronic diseases. This study is one of the few found papers that used eHEALS outside of the North American area (Netherlands) [43]. Also eHealth Literacy of low-income parents with chronically ill children or with children that are in a pediatric palliative care program, HIV patients and older adults has been measured using eHEALS [44-48].

Tennant and Stellefson found that baby boomers and older persons who used Health 2.0 technologies had higher levels of eHealth Literacy than persons who did not. For their study they as well used the eHEALS [49].

An alternative measurement of eHealth literacy was proposed by Chan et al. who developed a taxonomy to characterize the complexity of several eHealth tasks and therefore draw conclusions on the individual users' competencies to perform those tasks [50]. This approach nevertheless is very complex and time consuming as it implies the direct observation of individual persons during their usage of an eHealth system. In our approach including three spatially separated user sites with a large number of users it was not practicable to perform such an observational study. In 2014, Chew published a conference paper dealing with the development of a new scale to measure eHealth literacy [51].

In 2013 Jones developed the Patient eHealth Readiness Scale (PERQ) which includes items from the eHEALS as well as contextual factors like Internet use, support from other persons and demographics such as age and gender [52]. This approach has been used two times in published papers [53, 54]. Philipp Abbott-Garner from Plymouth University currently uses it in his PhD work [55].

The work of Chew has not been tested in the practice yet thus does not deliver starting points for its usage. To adequately address the finding that the eHealth Literacy concept does not include all relevant factors explaining the use of interactive eHealth solutions a broader range of factors should be included in a measurement tool to adequately assess eHealth Literacy.

There has been done some international research in measuring eHealth Literacy but still all tools lack the acknowledgement of different personal backgrounds that influence deeply the measured competencies: social and cultural factors need to be taken into account when discussing the level of eHealth Literacy.

3.3 eHealth Literacy in Germany

In Germany research on eHealth Literacy is practically still in its infancy. A group of researchers around Prof. Dr. Soellner at the University of Hildesheim translated the self-reported measurement tool eHeals in German [26]. It was presented for the first time at a conference in France in 2013.

The University of Bielefeld organized a Health Literacy conference in 2014 where eHealth Literacy as an independent field of research unfortunately was just a side note. Research on Health Literacy of children and adolescents is done by Ullrich

Bauer who situated at the Faculty of Education at the University of Bielefeld. He concentrates on health literacy and has no focus on eHealth Literacy.

Apart from these approaches the authors of this paper are working on the subject of eHealth Literacy. At the chair of Medical Informatics at the University of Erlangen-Nürnberg a project developed the eHealth Monitor. It provides a platform that generates a Personal eHealth Knowledge Space (PeKS) as an aggregation of several knowledge sources (e.g., ECG reports or information pages from the Internet) relevant for the provision of individualized personal eHealth services. This is realised by integrating service-oriented architecture, knowledge engineering, multiagent systems, and wearable/portable devices technologies.

The eHealthMonitor was evaluated in the light of acceptance factors including eHealth Literacy measurement of medical laypersons and medical professionals in three study sites (Germany, Poland, and Greece) using the eHEALS. It was found that the self-assessed eHealth Literacy of all user groups was medium to high whereas the biggest barriers towards the use of eHealthMonitor have been seen in data privacy aspects and usability issues [56].

At the Institute for eHealth and Management in Healthcare (IEMG) at Flensburg University of Applied Sciences two project applications dealing with eHealth Literacy of specific user groups are currently prepared. The research field is also part of the research done in the eHealth for Regions Network, which is coordinated at the IEMG in Flensburg.

Another German initiative in the field of eHealth Literacy is the national ePatient survey [23]. The users of online eHealth information websites are questioned concerning their user habits and the effects on their health and medical therapies and on their health behavior. The survey is conducted online and carried out annually since 2010. The outcomes are used to analyse the user habits of patients, their families and other groups depending on their diseases, risk factors, therapies and care pathways. It monitors the behaviour of individuals seeking for health information in the internet in the German speaking area. The survey asks the users about their usage habits and the effects of the web usage on their health behaviour, diseases and therapy. Studies have shown that the usage of internet for seeking health information has a significant impact on knowledge, attitude and health behaviour and internet based health and care services can help to optimize medical therapy. Until now the survey has not yet been scientifically evaluated. According to the findings some hypothesis can be formulated regarding future research on eHealth literacy, acceptance of eHealth services and patient empowerment.

4 Conclusion

To conclude, one can say that internationally there is a vivid research on eHealth Literacy and there are possibilities to measure it. Nevertheless there are four points that are open for future research:

1. How is eHealth Literacy connected with other acceptance factors? How important is it that consumers have a high eHealth Literacy from the beginning when it is possible that their competencies increase over time?

2. How can eHealth Literacy be measured and interpreted taken into account social and cultural backgrounds of people?
3. Does the eHealth Literacy construct needs a rebuilding in the light of trending interactive health technology solutions such as mobile health? There are services that use the Internet without the user having to handle browser etc. (e.g. smart watches).
4. What are the reasons that eHealth Literacy research is still so weak in Germany and how can it be fostered?

In the future research to answer all those questions is needed. Besides all possible further acceptance barriers that might be at least as important as eHealth Literacy, the ability to use eHealth services properly will always be a key to the success of all kind of electronic health services.

Due to this it is essential that Germany starts to take the user into account and focuses on his wishes and expectations. For this a large study is needed providing an overview on German laypersons competencies concerning eHealth services including mobile Health services and interactive health solutions.

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Operating Room of the Future (FOR)

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Abstract. The "Operating Room of the Future" (FOR) is a collaboration between St. Olavs Hospital, the University Hospital of Trondheim and the Norwegian University of Science and Technology (NTNU). The most important goal for FOR is research to obtain better and more safe patient care, more efficient logistics and better architecture of operating departments. Teaching is also an important task for FOR. FOR is an arena for research and development which includes six operating rooms, in various clinics. The operating rooms are unique "laboratories" made for the development, testing and clinical implementation of new technology and new treatment modalities.

Since it fosters multidisciplinary collaboration with close interactions between clinicians, technologists, scientists and industry, FOR is a research platform where new prototypes can be developed and tested under safe conditions. The most modern medical and visualization equipment will be available at FOR.

FOR is also an example of how various professional disciplines and medical specialties can utilize the same equipment, areas and competence. Both clinical and animal studies are offered to interested parties. At FOR there is a possibility to perform a broad spectrum of scientific work of multi-disciplinary character. Research can be carried out by PhD candidates, scientists, students and clinicians. In addition several bachelor and master degrees are performed at FOR.

FOR is also a partner in the Norwegian Centre for Minimally Invasive Image Guided Therapy and Medical Technologies (NorMIT). NorMIT offers a large infrastructure for image-guided minimally invasive therapy and medical technology. It focusses on research and development into areas such as logistics, workflow, communication, organization, and the transmission of high-resolution images. The NorMIT equipment is available for internal and external partners.

St. Olavs Hospital and the Norwegian University of Science and Technology, NTNU, are forerunners in developing an integrated university clinic by joining university and hospital. Research and teaching is a natural part of the integrated hospital activity. The students face patients from day one, and take part in an attractive and integrated learning environment. In the new buildings, researchers, students and health care providers work side by side. This provides for a close cooperation between clinical and basic research and makes the "Trondheim Model" unique both nationally and internationally.

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
Proceedings of the 3rd European Workshop on Practical Aspects of Health Informatics
(PAHI 2015), Elgin, Scotland, UK, 27-OCT-2015, published at http://ceur-ws.org

eHealth Literacies Required for Patient Involvement in Decision-making during Cancer Patient Pathways (CPP)

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Abstract. Elaborating on a definition of eHealth Literacy presented at PAHI 2014, this paper offers a discussion about the potential for actual patient involvement in decision-making on diagnosis, treatment and cure during cancer patient pathways (CPP). The hypothesis is that in order for actual decision-making to take place, the patient needs to be informed. In order to obtain relevant information, she needs several competencies and skills about eHealth since updated information about specific cancer patient pathways in Norway is mainly available on the Internet. This project examines the Information available online and discusses what eHealth Literacies are required to actually understand and operationalize the information and to make it relevant for decision-making about own health.

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
Proceedings of the 3rd European Workshop on Practical Aspects of Health Informatics
(PAHI 2015), Elgin, Scotland, UK, 27-OCT-2015, published at http://ceur-ws.org

The Introduction of Cancer Patient Pathways in Norway: Premises and Challenges

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Abstract. Standardized health trajectories, or patient pathways, are organizing principles in healthcare aiming to get an overview of administrative as well as logistical responsibilities. The aim of pathways is to achieve better quality of care, through a more efficient, equal and predictable process of diagnosis, treatment and cure. Inspired by Denmark, the Norwegian Directorate of Health has introduced 28 cancer patient pathways (CPP) during 2015. So far in Norway, no studies have looked into how the cancer patient pathways are practiced. In this presentation we discuss the promises cancer patient pathways in Norway holds, especially with regard to communication and coordination. The role of the pathway coordinator(s) is especially interesting, since there is both a coordinator employed at the municipal level, and one at each hospital. These are key players for coordination and communication between the various actors and their tasks along the pathway. In Norway, and also in Denmark, time has been portrayed as the most important indicator for success when realizing cancer patient pathways. However, there is currently less focus on other aspects such as quality, patient perception of safety and care, and finally, how do those not included in the cancer patient pathways experience their trajectories?

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
Proceedings of the 3rd European Workshop on Practical Aspects of Health Informatics
(PAHI 2015), Elgin, Scotland, UK, 27-OCT-2015, published at http://ceur-ws.org

Are Anaesthetists Still Living in the Past?

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Abstract. Changes have occurred in the doctor patient relationship over the last 20 years. However, it seems that guidance published by the Royal College of Anaesthetists (RCOA) is not in line with patients' wishes.

1 Extended Abstract

“Patient knows best", "patient triumphs over paternalistic doctors" and "doctors need to listen to what patients want, not dictate" are anecdotal straplines which give a flavour of the changes that have occurred in the doctor patient relationship in medicine over the last 20 years where the emphasis is now on the public to take a much more active role in their health utilising the shared model of the patient-doctor relationship and decision making [1].

The General Medical Council requires doctors to undergo revalidation every five years. This includes feedback from patients on the doctor’s politeness, listening skills, ability to explain conditions and treatments, honesty and ability to inspire confidence [2]. Guidance was published by the Royal College of Anaesthetists (RCOA) in 2014 regarding feedback [3]. Anecdotal evidence suggested that this advice was not what patients preferred in our unit. We therefore undertook a study aimed at gathering preliminary evidence to identify the time in a patient’s pathway that was considered as most appropriate from the patient perspective to provide such feedback and is in keeping with the ethos of having the patient voice at the centre of our healthcare services [4].

The results showed a contradiction between what the RCOA suggests and what patients want. In total, 106 patients responded, with 99% willing to give feedback. Most felt that providing feedback for the anaesthetist would be somewhat (39%, n=41) or very useful (59%, n=63). Fifty-nine percent of patients (n= 62) felt it was appropriate to be asked for feedback in the postoperative period, and 44% (n=46) felt this was the single best time, compared to after going home (21%, n=22), on the ward before the operation (18%, n=19) or after pre-assessment (15%, n=16). Patients were most likely to feel able to assess the doctor’s performance after the operation (67%, n=70) as opposed to after pre-assessment (29%, n=30). Only 15% (n=16) of patients felt that current guidelines matched their preference.

Current RCOA guidance recommends gathering feedback after pre-assessment. Contrary to this expert guidance the results from our case study suggest patient support for feedback to be collected later in the patient journey. This professional guidance may represent professional opinion rather than patient wishes and if true needs to be rectified. Guidelines must always be cognisant of what the patient wants- the so-called wisdom of the crowd [5]. Other guidelines including anaesthetics and other health related bodies should be reviewed with this approach in mind.

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
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(PAHI 2015), Elgin, Scotland, UK, 27-OCT-2015, published at http://ceur-ws.org

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Health Web Science: Formulating Healthcare for the 21st Century – A Health Web Metadata Curation Framework to Evolve a Behavioral Model for Preferable Health Outcomes

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Abstract. To address the complex societal challenges or solve the current problems facing health care delivery, whether caused by ageing populations, globalisation and long term/chronic conditions, a shift from the traditional reactive model to a proactive health care model has begun. Furthermore, as knowledge about individual variation, in particular genetic variation, epigenetics and drug response increases, there is an evolution from a one size fits all to personalised treatment protocols. In addition, "gender-specific medicine" and a "life course approach to health" are emerging areas of study, to further tailor treatment plans to the patient. Thus the future of medicine is shifting to a patient-centric model, that is: personalised, preventative, participatory and predictive. This new approach utilizes the Internet and is underpinned by the academic disciplines of Health Web Science and Medicine 2.0. where the utilization of digital interventions play a significant role. Health Care information therefore provided through the conduit of the Internet that employs an effective behavioural model may have a pivotal role in changing health behaviours. However current evaluation and impact of of healthcare on health outcomes via the Internet is limited in its scope in terms of feedback and throughput between the Web, healthcare providers and patients. The curation of metadata of and about the Health Web is a potential tool to be able to analyse health outcomes. Metadata curation from websites and Web data increases the utility of social networks, social machines, and documentation. Web Observatories work by the insertion of metadata into a web site and using a crawler to associate these sites. Health Web Observatories will be required to enable the triangulation of data to identify new integrated strategies for preferable health outcomes. This position paper presents an integrated behavioural model, the need for Health Web Observatories, the minimum necessary components for a Health Web Observatory, and a challenge to the community to develop the necessary software tools.

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
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(PAHI 2015), Elgin, Scotland, UK, 27-OCT-2015, published at http://ceur-ws.org

Service Improvement for Childhood Obesity Treatment through eHealth Cooperation and Communication

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Abstract. Childhood obesity is defined as one of the most serious health challenges of this century (WHO). From being a raising problem in western societies and US in particular, it has become a global challenge, often connected to social inequality. Children suffering from obesity are inclined at remaining obese as adults, facing the risk for developing non-communicable diseases such as diabetes and cardio vascular diseases at an early age. Obesity and its comorbidities are preventable, and the prevention of childhood obesity is therefore increasingly important. In Norway, the authorities have introduced a program for regular weight measurements among preschool and school children. This program has three main goals, 1) to conduct an early identification of children at risk of developing obesity, in order to offer services and treatment, 2) follow the development locally, regionally and nationally, and 3) increase the knowledge about reasons to growth deviations, and about what preventable measure, local and national, which are appropriate for different age groups. Currently there are no standardized guidelines, services or interventions following this weight measurement program.

With an interdisciplinary and multi-methods approach, this project will study the practices of this weight measurement program in Norway. The objective is to contribute to the development of improved services for the involved actors. In particular the project will focus on (eHealth) cooperation and communication before, during and after the weight measurements and practices at school, and addresses the needs of children, next of kins, health personnel, teachers and other relevant actors. Further we will explore whether and where eHealth technology can facilitate improved practices and outcomes.

In: G. Cumming, T. French, H. Gilstad, M.G. Jaatun, E.A A. Jaatun (eds.):
Proceedings of the 3rd European Workshop on Practical Aspects of Health Informatics
(PAHI 2015), Elgin, Scotland, UK, 27-OCT-2015, published at http://ceur-ws.org