Context Sensitive Health Informatics: Sustainability in Dynamic Ecosystems

Romaric Marcilly, Craig E Kuziemsky, Christian Nøhr, Sylvia Pelayo

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Context Sensitive Health Informatics: Sustainability in Dynamic Ecosystems

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The digital transformation of healthcare delivery remains a work in progress, and contextual variation continues to be one of the barriers to the development of sustainable health information technology. Context-sensitive health informatics concerns health information technologies and their environments, which may be people such as patients, users, designers and evaluators, but also non-human constructs such as organizations, work practices, guidelines and protocols, or buildings and markets.

This book presents papers from CSHI 2019, the international conference on Context Sensitive Health Informatics, held in Lille, France, on 23 and 24 August 2019. The subtitle of the conference was Sustainability in Dynamic Ecosystems, and the thirty papers included here are divided into six sections: understanding organizational contexts; towards sustainable EHR; different contexts for medication errors and patient safety; methods and models to study contexts for health information systems; citizens in health contexts; and designing and evaluating in contexts. Two keynote speeches from the conference are also included.

With its focus on context sensitivity and sustainability in digital healthcare, the book will be of interest to all those working in the field of health informatics.

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CONTEXT SENSITIVE HEALTH INFORMATICS: SUSTAINABILITY IN DYNAMIC ECOSYSTEMS

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Preface

This volume presents the papers of the International Conference on "Context Sensitive Health Informatics" held at Lille University in August 2019.

Context Sensitive Health Informatics is about health information technologies and their environments. Environments may be people in different roles such as citizens, patients, users, designers, and evaluators, but also non-human constructs such as organizations, work practices, guidelines and protocols, buildings and markets.

The conference is endorsed by and organized/supported by the International Medical Informatics Association (IMIA) working groups "Human Factors Engineering for Healthcare Informatics" and "Organizational and Social Issues", and by the European Federation for Medical Informatics (EFMI), especially the working group "Human and Organizational Factors in Medical Informatics".

The CSHI 2019 conference is sponsored by Lille University, Lille Academic Hospital, the Federative Research Structure for Health Technology" (SFR-TS), the research team 2694, I-site ULNE, and Inserm.

The editors want to thank the sponsors and the local organizing committee for making it possible to have the conference in Lille.

We would also like to thank Pierre-François Gautier for setting up the conference web site and Linda Peute for designing the logo of the conference. Finally, we want to thank the Scientific Program Committee for their efforts to establish the content of the conference and all the reviewers for providing constructive feedback to the authors. Their excellent work has significantly improved the quality of many papers.

Romaric Marcilly
Christian Nøhr
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May 2019

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Sustainable Health Informatics: Health Informaticians as Alchemists

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Abstract. The digital transformation of health care delivery remains an elusive work in progress. Contextual variation continues to be a significant barrier to the development of sustainable health information systems. In this paper we characterize health informaticians as modern alchemists and use this characterization to describe informatics progress in addressing four key healthcare challenges. We highlight the need for informaticians to be diligent and loyal to basic methodological principles while also appreciating the role that contextual variation plays in informatics research. We also emphasize that meaningful health systems transformation takes time. The insight presented in this paper helps informaticians in our quest to develop sustainable health information systems.

Keywords. Sustainability, Health informatics, Decision support, Ontologies, standards, Work practice, Usability, Context

1. Introduction

In the middle ages Alchemists used mixture of science, philosophy and mysticism to find the philosopher's stone that would enable them to develop:

(1) A formula for the elixir of immortality – a mythical portion that would cure all diseases and grants the drinker with eternal life
(2) A universal alkahest which is a solvent having the power to dissolve every other substance including gold
(3) An elusive substance that was believed to make the transmutation of common substances into gold.

To find the elixir of immortality became more of a theological religious task and the trials to prove the effect has probably taken the lives of more alchemists that it has cured. The search for the universal alkahest faced the fundamental problem that, if it dissolves everything, then it cannot be placed into a container because it would dissolve the container.

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The English alchemist James Price had demonstrated to lay audiences that he could turn mercury into silver or gold by mixing borax, potassium nitrate, and a red or white powder – the white powder produced silver while the red produced gold. Challenged by other members of the Royal Society he reluctantly accepted to demonstrate his capability, but when they turned up to watch his transmutation, he in their presence drank a flask of Laurel water (contained hydrocyanic acid) and promptly died before the audience could do anything. Price was supposedly terrified by peer review [1].

The original alchemists can be divided into two categories, tricksters who fooled thousands of gullible people to obtain gold and jewels, and obsessed, but enthusiastic men who spent all their lives occupied by the science of alchemy. The latter were the early chemist pioneers who discovered numerous substances and chemical elements, which eventually led to the drawing up of the periodic table.

Health informaticians can be characterized as the present-day alchemists. We have all seen examples of well-hyped health information technology (HIT) systems that fail to live up to the promised functionalities when implemented in complex clinical work settings. However, many informaticians are also diligent scientists who have been striving for years to achieve useful and sustainable solutions for healthcare's most pressing issues. This paper describes informatics progress in addressing four key healthcare challenges. We focus on the contextual aspects of these contributions in keeping with the theme of the Context Sensitive Healthcare Informatics Conference.

2. Areas in focus

In the following sections, we will describe the state of science of four specific areas where health informaticians have developed meaningful solutions to key healthcare challenges including interoperable health systems, redesigning clinical work practices, the development of algorithms to enable safe and efficient decision making, and the design of interfaces to support the entire user experience continuum.

2.1. Ontologies and standards

Interoperable data interchange needs the backbone of clinical data exchange and the substrate for all large-scale big data analytics and predictive modeling [2]. We have made considerable progress over the last thirty years in advancing interoperability [3]. We have come from looking at basic science informatics questions regarding the quality of standards (terminological, messaging and transport), NLP [4], Health Information Exchange [5] and data warehousing [6] to studies of the impact of these implementations on clinical outcomes and business measures of health and healthcare [7, 8].

To define the problem more clearly, we need to define interoperability. Here Robert Heinlien's concept of "Grocking" can be instructive [9]. This is described as where one person or in our case healthcare organization when receiving information understands it exactly as the person who sent the information understands the information exchanged. To break this down further we need to define syntactic interoperability where the way that the information is structured is well defined. Semantic Interoperability implies that one has syntactic interoperability and in addition has defined in a computable fashion the information in the content of the information being exchanged or stored for reuse [10].

We have made great progress on defining standards to support all the layers of the model that define true semantic interoperability. However, there is still work to be done.

To date, we have transport standards and great examples of syntactic interoperability such as HL7 v2.X for many use cases including admission, discharge and transfer messages used in many and perhaps most hospitals and NCPDP Script [11] for prescription information which has empowered ePrescribing and is one of the few parts of the EHR that has improved the safely of healthcare. For semantic interoperability we have strong upper level ontologies such as the Basic Formal Ontology (BFO) [12], we have domain ontologies such as HL7 FHIR [13] and the Ontology of General Medical Sciences [14] and we have large scale clinical ontologies for naming such as SNOMED CT for diagnoses and findings, LOINC for laboratory Test Results, RxNorm and ATC for drug codes. There is a new effort by the US Department of Veterans Affairs to create a merged ontology of SNOMED CT, LOINC and RxNorm, named SOLOR, which is focused on greater interoperability among and between these individual standards. There is ongoing work to make the terminological standards conformant with the domain models and the domain models conformant with the upper level ontologies. Good work has already been accomplished which encapsulates terminological standards into messages and then the transport layers [15].

Some studies have already been published showing the importance of these methods and that their use leads to important clinical outcomes [16, 17]. This can improve the quality of data for input into predictive analytics to improve both the efficacy of healthcare and the safety of the care that we provide [18, 19]. More work is needed to use these integrated pipelines to represent large portions of our healthcare data which will improve our clinical decision support, our biosurveillance and help to move healthcare from a cottage industry into a systematized practice of health and healthcare [2, 20–22].

2.2. Redesigning work practices in healthcare

When we think about how technology will change work practices it is not a matter of if it will happen but rather how it will happen. Technology such as electronic medical record (EMR) systems enables new connections across patients, providers and settings and we need to understand the nature of these connections to enable better redesign of work practices [23]. One on hand, technology can enhance existing processes. Healthcare practitioners spend a substantial amount of time documenting and doing information retrieval tasks. Artificial intelligence (AI), Natural Language Processing or speech recognition-based tools such as digital scribes can automate some of these documentation tasks, allowing providers to spend more time delivering true patient centered care [24].

Technology can also support new or evolving processes. Collaborative care delivery is a fundamental part of healthcare transformation initiatives worldwide but collaboration is still not well operationalized in front line care delivery. We need to better understand the transition from macro level collaborative processes to front line micro level collaborative work practices. However, this transition is challenging because collaborative care delivery takes place within a complex and dynamic system of people, processes, care delivery settings and technologies. Further, we cannot understand collaboration by focusing on individual aspects of care deliver. Redesigning work practices to support collaboration requires the development of collaborative competencies that enable the transition between individual and collaborative work practices [25]. One such competency is common ground, which is essential to ensure that all agents engaging in collaboration have shared knowledge of the processes,

technologies and terminologies that will operationalize collaborative care delivery [23, 25]. Another evolving process enabled by connected health technologies is patient engagement. Patients can play active roles not only in the planning and delivery of their care, but also in informatics tasks such as the development and implementation of HIT [26].

Regardless of whether we are redesigning work practices for existing or evolving processes, we must understand that technology alone will not transform healthcare delivery into a collaborative patient centered system. Rather we need to ensure that redesigned work practices are contextually grounded in the needs of all users (e.g. patients, practitioners and providers) in the sociotechnical ecosystem where HIT will be used.

2.3. Decision support

Expert systems use heuristics that employ methods of reasoning with only partial evidence. This requires experts in the field to encode knowledge about how they reason and put it into a computable format. This is accomplished by specifying weightings such as Evoking Strength which is defined as given the manifestation (finding, test result, etc.) how strongly should you think of the diagnosis. The other method used frequently is feature selection in a machine learning algorithm. Bayesian approaches employ conditional probabilities in the form of sensitivity and specificity to define and combine probabilities of for example a diagnosis being present. For many years, leaders in medicine have felt that there was something special about the heuristics doctors use to create a differential diagnosis.

In 1959, Ledley and Lusted reported that computers could help doctors in the diagnostic process [27]. Many papers have been published demonstrating the accuracy of computational medical diagnosis, generally in a very limited field such as thyroid disease or congenital heart disease. Only a few of these early systems were used outside the environment of their developers' institutions due to their specific coding against their local databases, limited knowledge bases, poor user interfaces and the many obstacles to sharing computer systems developed in the early 1960's. In the current environment of the Internet and widespread availability of personal computers and smartphones, the potential for routine use of decision-support systems to assist health professionals in the diagnostic process has become a reality.

Tim de Dombal at the University of Leeds created the first abdominal pain diagnosis program using Bayesian probability theory. The system helped users differentiate between appendicitis, diverticulitis, perforated ulcers, cholecystitis small-bowel obstruction, pancreatitis and non-specific abdominal pain using data acquired from thousands of patient presentations [28]. Ted Shortliffe at Stanford University developed a program MYCIN, that provided decision support regarding the empiric antibiotic management of infectious diseases [29]. MYCIN used production rules consisting of conditional statements [30]. This is one methodology that falls under the general category of artificial intelligence [31].

Homer Warner at the University of Utah developed the HELP system which was integrated with the hospital information system (HIS) and provided clinicians with clinical decision support [32, 33]. The HELP system incorporated a complete electronic medical record within an HIS. The rules in the HELP system were written in the Arden Syntax [34]. Each complete rule set is a medical logic module and each such module has

its own conclusions [35]. Homer Warner also built the Iliad system that used a pure Bayesian approach calculating the post-test odds for each disorder.

Randy Miller and Jack Myers created the quick medical reference (QMR) system, that was developed as a diagnostic decision support system in support of all of general medicine [36]. QMR was employed at the University of Pittsburgh for use on a consult service which functioned under the model that a physician with a computerized clinical diagnostic decision support system was more effective at making diagnoses than the physician alone [37]. In QMR, manifestations are associated with diagnoses and the positive association of these manifestations are graded by their frequency of occurrence and by their evoking strength (i.e. how often should a clinician think of this diagnosis if one has a particular manifestation). Manifestations and diagnoses are both graded by their importance and this information is used as part of the weightings to provide a ranked list of the differential diagnoses for a given set of manifestations [38].

DXplain, a computer-based decision support system, was developed in the early 1980's by Octo Barnett, MD from the Laboratory of Computer Science (LCS) at Massachusetts General Hospital (MGH) [39, 40]. DXplain has been employed as an electronic medical textbook, a medical reference system and a decision support tool. In the role of a medical textbook, DXplain can provide a comprehensive description with selected references for over 2,300 diseases. Descriptions include the etiology, the pathology, and the prognosis for the diagnosis. As a clinical decision support tool, DXplain uses its knowledge base of probabilities of approximately 6,000 clinical manifestations (History, PE findings, Lab data, X-ray data and elements of the past medical history) and generates a differential diagnosis [41]. The system uses an interactive format to collect clinical information and makes use of a modified form of Bayesian logic to produce a ranked differential diagnose list. The system also provides references and disease descriptions for each of the diagnoses in its database [42].

Over the past nineteen years, DXplain has been used by thousands of physicians and medical students. Eleven years ago, LCS began to make DXplain available over the Internet to hospitals, medical schools, and medical organizations [43]. Elkin, et al compared the predictive accuracy if using Evoking Strength as compared with Sensitivity in arriving at the correct diagnosis computationally [2].

Zhou et al, developed machine learning algorithms for disease phenotypes for primary care using electronic health records which she tested in Rheumatoid Arthritis [44]. Qureshi et al, reported a hierarchical machine learning method for distinguishing types of Attention Deficit disorder from structural MRI data [45]. Ye et al, used support vector machines to predict cancer type from full text articles from the biomedical literature [46].

CDS has had variable uptake in the practice of medicine and override rates continue to be quite high. Vendors and healthcare institutions continue to work to find a balance between efficiencies in the practice and patient safety.

We are working toward a learning health system organized with the infrastructure to facilitate continuous practice improvement by incorporating data from our practice and our clinical outcomes to improve our next day's clinical practice [47]. This data driven continuous quality improvement employing a human-computer partnership can lead us to a future of safer and more effective health and healthcare.

2.4. From usability to user experience

Problems in usability of health information technology (HIT) systems are well acknowledged in research [48]. The vast investments in the adoption of HIT in the United States as well as in Europe have been driven by expectations reflecting key usability goals, particularly increased effectiveness and efficiency in health care [49]. Usability is defined by the International Organization for Standardization (ISO) as "the extent to which a user can use a product to achieve specific goals with effectiveness, efficiency and satisfaction in a specified context" [50]. The term human factors is described by the American National Standards Institute and the Association for the Advancement of Medical Instrumentation as "the application of knowledge about human capabilities (physical, sensory, emotional, and intellectual) and limitations to the design and development of tools, devices, systems, environments and organizations" [51]. In the US, the Food and Drug Administration (FDA) and the Agency for Healthcare Research and Quality, and in Europe, the European Commission have called for usability and human factors evaluation of HIT systems and medical devices during the design process, requiring evidence of end user involvement during the design process.

User-centered design (UCD) is a design philosophy that seeks to place the end user at the center of the design process. The term was coined in the 1980s by Donald Norman [52] who put forward guidelines that designers could follow in order for their interfaces to achieve good usability outcomes. From that point on, many designers, researchers, and policy makers have proposed various methodologies and techniques that seek to involve the end user in the design process. In their 2010 standard ISO 9241-210 [53], the ISO extended the definition of UCD to "address impacts on a number of stakeholders, not just those typically considered as users," referring to the design approach as human-centered design (HCD) and defining human-centered design as "an approach to systems design and development that aims to make interactive systems more usable by focusing on the use of the system and applying human factors/ergonomics and usability knowledge and techniques." The main goal of HCD is to increase the usability of the product in order to create maximum user satisfaction and increase the safety performance of the device. There are six requirements that a process must meet if it is to be considered an HCD process: (1) The design is based upon an explicit understanding of users, tasks, and environments; (2) Users are involved throughout design and development; (3) The design is driven and refined by user-centered evaluation; (4) The process is iterative; (5) The design team includes multidisciplinary skills and perspectives; (6) The design addresses the whole user experience (UX).

UX is an intriguing phenomenon that has been widely disseminated and speedily accepted in the Human-Computer Interaction (HCI) community. The immense interest in UX in academia and industry can be attributed to the fact that HCI researchers and practitioners have become well aware of the limitations of the traditional usability framework, which focuses primarily on user cognition and user performance in human-technology interactions. In contrast, UX highlights non-utilitarian aspects of such interactions, shifting the focus to user affect, sensation, and the meaning as well as value of such interactions in everyday life. UX is defined as the perceptions and responses of users that result from their experience of using a product or service [53]. It reflects the overall experience related to usability, usefulness, function, credibility, and satisfaction with the technology [54]. To show evidence of significant quality and productivity gains with technology, appropriate measures need to be used integrating long term usability and user experience collection [55].

3. Discussion and Conclusion

The vision of HIT being a key player in health care delivery has existed for a long time and has consumed many individuals and organizations. However, this grand vision remains elusive and HIT implementation continues to be a struggle with very few systems proving to be sustainable solutions when implemented in complex health care contexts. In looking at our field, we see a clear parallel to the alchemists where viability over time can be attributed to a set of basic methodological principles. Health informatics involves basic knowledge about the empirical world as well as specific knowledge on the plethora of evolving and constant contextual issues that influence human health. This knowledge must be acquired in a systematic way using transparent logic so that others can replicate an experiment or observation. True alchemists also highlight that finding the right mix of chemicals that lead to real scientific discoveries and societal benefit takes time. Similarly, health system transformation will not happen overnight but rather is an ongoing process and we must continue to be diligent and methodological in our approaches while also being patient in our quest for meaningful outcomes. Formative evaluation and concepts from learning health systems [47] must be an integral part of health informatics research.

Health informaticians can become modern day alchemists by:

- Turning leaden software into usable, responsive and efficient software;
- Weaving golden and usable threads out of the vast number of chaotic data formats and contexts;
- Using HIT to improve work processes that were/are often inchoate or informally arranged - usually formed by history, past privilege, old technologies, legacy systems, etc.
- Making decision support systems more responsive and available to the right user at the right processes at the right time. This requires incorporating AI and machine learning approaches for the benefit of all concerned - patients, providers, administrators and research and science.

Our work as informatics alchemists is frequently influenced by the political and economic contexts of where health care is being delivered. In societies with a liberal market-controlled economy, the criteria of full transparency and replicability can be difficult to satisfy because vendors want to protect their proprietary product to maintain their market share. Political policy can also impact how health care is designed and governed, including the role that informatics will play in health care delivery. Despite these challenges we implore health informaticians to strive to honor basic methodological principles in our overall quest to develop and evaluate innovative and sustainable health information systems.

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Human Factors and Ergonomics for a Safe Transition to Digital Health

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Abstract. In this paper we elaborate a preliminary framework to fill this gap and describe the potential contributions of HFE to improve digital health interventions, at the macro, meso and micro level of a health system. Researchers present a practical approach, integrated with some limited reflections on methodological aspects, recently covered in a position paper [8], while previously in conference series and handbooks. This paper presents a HFES perspective on digital health - from the macro, meso and micro level to improve patient safety and delivery of quality care. Experts in HFE can play a key role in creating evidence for an ethical and effective design of digital health intervention and providing support to their implementation and evaluation at the macro, meso and micro level. This framework may help to integrate HFE at the different levels of the system and following the tracks of organization, technology and human factors.

Keywords. Digital health, human factors and ergonomics, patient safety

1. Introduction

"Health care delivery systems are complex by design and prone to errors. Human factors are a core element in most cases of harm, operating in systems where procedures and practices are poorly designed. Punitive cultures of blaming individuals prevent reporting of safety-related incidents and impede learning. Certain patient groups are more vulnerable to safety incidents, including the elderly, children, migrant populations, patients with chronic conditions and those in palliative care" [1].

The "Global action on patient safety", approved at the World Health Assembly in 2019, clearly recognizes the role of human factors in affecting the delivery of care, by stating that a poor design of procedures and practices is a core element of most cases of harm. We would have preferred to read the same sentence in positive terms, but to date research in human factors and ergonomics (HFE) in healthcare has been more effective to show the dark side of patient safety rather than the wide opportunities for improvement at all levels of the system.

Digital health is one of the areas where we accumulated evidence of failures and few examples of effective interventions.

As previously argued [2], programs for the development and implementation of digital healthcare, have sometimes failed miserably despite the investments and

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commitment of key stakeholders [3], due to inconsistencies generated on the clinical, organizational and institutional level or to open confrontation between professionals, managers and policy makers for decision-making power on technological innovation [4]. Also, the intrinsic quality of IT products for health care is sometimes lacking, both in terms of functionality, and above all of ergonomics and systems integration [5]. Consequently, the transition to digital systems to manage internal and external communications have been much slower in health services than in other industrial sectors, even in high income countries.

Not surprisingly, while WHO recognizes the relevance of human factors in negative terms as a key risk for patient safety, no reference is made to the potential contribution of HFE in the development and implementation of digital health interventions, neither in the WHA resolution [6] nor in the most recent guideline just released [7].

In this paper we elaborate a preliminary framework to fill this gap and describe the potential contributions of HFE to improve digital health interventions, at the macro, meso and micro level of a health system. We present a practical approach, integrated with some limited reflections on methodological aspects, recently covered in a position paper [8], while previously in conference series and handbooks.

Therefore the goal of this paper is to present a HFES perspective on digital health - from the macro, meso and micro level to improve patient safety and delivery of quality care.

2. Framework for HFE in digital health

From the point of view of HFE, the transition to digital health is a complex process with multiple interactions between policies, systems and practices, generated through decisions and actions of a relevant quantity of qualified and non-qualified actors, using a huge number of applications and devices accumulated over time in busy and highly variable working environments. In order to clarify and classify the potential interventions to support and improve the transition, a functional distinction between a macro, meso and micro level is proposed, taking the perspectives of users and the goal of safety and efficiency that are the basic principles of HFE. For each level, we address 3 critical interactions to improve the transition to digital health, related to organization (O), technology (T) and human factors (H). Therefore, our framework can be applied either following a horizontal (O-T-H) or a vertical sequence (macro-meso-micro).

2.1. Macro level

At the macro level we recognize and report the following critical interactions: national and international policies, systems features and infrastructure, stakeholder's profiles and power.

At the macro level we can affirm that digital health interventions are not a substitute for functioning health systems and should complement and enhance health system functions.

So it is important understanding the ecosystem and its ability to absorb digital interventions, understanding in the local context, the contributing factors related to ergonomics and human factors which are fundamental for a successful implementation of the technology, such as the health domain area and associated content; the available

software and communication channels; the ICT infrastructure, with a special attention to the understanding of the *work as done vs the work as imagined.*

In the next paragraphs we report current problems and discuss potential opportunities for HFE interventions.

2.1.1. National and international policies - O

Taking into account the current policies of WHO and EU to the transition to digital health, we observe first of all a late recognition of the digital revolution that has been occurring in the past few years. On one side, we observe the spread of computer supported clinical and administrative procedures in health services, on the other side, we see the rise of the web as an enormous knowledge base and relational context for health problems. The WHO issued guidelines for the use of digital technologies based mainly on identifying digital health interventions, primarily available via mobile devices, able to address health system challenges in order to support the promotion of UHC. The understanding of ergonomics and human factors for improving its use and the impact on patient safety it is actually not a main focus of the elaborated recommendations from WHO. Nevertheless, it is emphasized how it is important to address some enabling layers in order to have success in the implementation of the digital interventions. Especially, at the system level, a country should consider to establish a clear leadership and powerful governance based on the development of a common strategy and adequate investments. This should be the basis for creating a national infrastructure, or at least interoperable systems based on common standards and shared services and applications to use in all the different parts of the healthcare system. These prerequisites bring in immediately the issue of HFE, which are key factors in order to create a robust enabling environment, without this kind of environment, there is the risk of a proliferation of unconnected systems and a severe impact on the effectiveness and sustainability of the health intervention.

The European Commission, in a recent document (November 2018) related to an expert panel on effective ways of investing in health underlined how governments could be more active in optimizing the decision making process and the related outcomes [9]. In this document the EU emphasizes the need to find a balance in the development of the digitalization between promoting centralized and decentralized activities. It is also important to deal with all the aspects that can prepare the health sector to accept the transition to the digitalization like education of the main stakeholders, the introduction of specific regulatory conditions, the implementation of monitoring systems to monitor its effects on health system performance. All this aspects are interconnected and need a systemic approach, typical of the human factors discipline, in order to be developed synergically and to guide the transition to digitalization successfully. It is also important to build a European repository. Further investment in developing and sharing methods and evidence on evaluations of digital health are also considered as a recommended actions from the EU, and we argue that in this sense the adoption of the HFE approach can help in introducing consolidated methods of evaluation for understanding the impact of an innovation into a specific context.

2.1.2. Systems features and infrastructure - T

Digital technologies are introducing a powerful group of innovations that can support healthcare in the realization of some important purposes, such as:

- Bridging gaps in care delivery systems (through the use of mobile applications that can reach everyone in the most remote places) and supporting the UHC to ensure the quality, accessibility and affordability of health services;
- Facilitating communications to individuals in order to generate demand and broaden contact coverage;
- To give to healthcare workers more immediate access to clinical protocols and telemedicine consultations with other health workers.

But, at the moment, these innovations are a big challenge to realize as the current situation represents some relevant limits to their diffusion. First of all, the adopted applications are isolated one from the other and not integrated with the main clinical documentation, in primis with the clinical record. In the development of these applications, as well as for the development of digitalized clinical documentation, there are no established standards, both at the international and national/regional level. Usually the usability of a digital solution, is considered only when healthcare workers, while using it, face a practical problem that affect their performance. Then the approach to the evaluation of such solutions is usually a reaction to a bad events or a bad user-experience. The reactive mode is dominant comparing to a proactive way to design and develop technology by embedding the principles of HFE into this process. There is also a lack of competencies on this field inside the healthcare systems, which facilitate the lack of attention to this aspect while designing information systems. The presence of experts in HFE among the professionalities involved in the project team for the transition to digitalization and the consideration in a proactive way of these aspects during the analysis and design of a clinical care process into an informative system, are essential elements for avoiding primarily adverse events and secondly underqualified performances and inefficiencies.

2.1.3. Stakeholder's profiles and power - H

At the macro level, the strategic functions we discussed in the previous paragraph, especially the establishment of a strong leadership, an effective governance, some transparent regulator mechanisms, are dependent from the key stakeholders at the international and national level. The challenge here for the national institutions and regulators is to overcome a consolidated technology and administrative driven approach, where the main skills involved in the design for transition to digitalization are usually engineeristic and normative/administrative. These skills are more addressed to satisfy the organization's needs in terms of having a reliable infrastructure and a legal protection instead of looking also at the users' needs (both healthcare workers and patients) in terms of transparency, usability, effectiveness of the clinical performance. HFE approach helps stakeholders to consider the system with a wider perspective and introduces methodologies that can favor the design of the informative system according to the real world of the daily practices rather than according to the organization as imagined.

Another critical point concerning the stakeholders' role at the national level is the difficulty in setting up a clear agenda for the transition to the digital era for the healthcare system. Usually national programs are too generic and fail in including specific goals and controls over their use.

There is also a lack of awareness about safety and security of personal data, and how to manage it with a potential clash between data protection and patient safety.
These criticalities can be overcome only if the transition to digitalization is seen as an occasion for triggering a deep innovation process.

2.2. Meso level

At the meso level of the system, that is the context where health organizations are set up to manage important amount of public and private resources to deliver care services, we recognize three main themes: development, selection and purchase of systems; management and integration of information systems and devices; fitness with strategies and goals to deliver safe and quality care.

At this level, the transition to digital health is generally an incremental process, where new software or digital devices are added to current clinical practices and pre-existing tools without a clear and integrated vision about opportunities and threats related to the presumed innovation.

2.2.1. Development, selection and purchase of systems - O

HFE principles may help decision makers within health organizations to develop, select and purchase systems. If we take the example of electronic patient record, a significant amount of literature is already available to suggest some basic principles that can be applied to integrate HFE at this level:

- Co-development
- Continuous evaluation and iterative design
- Service dominant logic

First of all, the digital solutions, where considered an integrated part of the care process, can be co-developed between providers and health organizations by performing basic and applied research before and after the release of any digital solutions. As it is common with medications or surgical techniques, the cooperation between producers, researchers and users is fundamental to guarantee safety, effectiveness and hopefully sustainability of any intervention. A well-known systematic review of electronic patient records conducted in the United States has promoted only a very limited number of products, highlighting how the few co-developed products between computer scientists and clinicians within healthcare facilities were superior to commercial products [4]. This is HFE in practice, given that the participatory approach to design of any artifact, especially to address complex problems, is the standard strategy included in the national and international norms on principle of HFE, such as ISO 6385:2016 Ergonomics principles in the design of work systems.

Secondly, while selecting any digital intervention, a continuous evaluation must be considered in order to support dynamic interactions with the new technology and a contribution to a recurrent design at least of the digital interfaces. End-user products are routinely selected according to their recognized capacity to adapt to different situations and be updated according to user experience and feedback. Health organizations need to be prepared to have pro-active facilitators who can collect, analyze and report data about user-experience so to systematically evaluate the digital intervention and pretend a human centered iterative design of each tool, well summarized in the manifesto for an ethical design [10].

A service dominant logic [11] should substitute any remaining traditional way of contracting the purchase of products between health organizations and providers of digital solutions. A “one size for all” product seldom exists for interventions where the capacity of the health organization to succeed and survive strongly depends to its connections with macro-level strategies on one side and with local practices on the

micro-level. Therefore, in a service dominant logic a digital intervention is at the same time compliant within a highly regulated institutional environment and flexible to respond to emerging needs of fast changing communities and personalization of care [12].

2.2.2. Management and integration of information systems and devices - T

Despite the density of information systems and devices in health organization, we still see relevant problems of integration and lack of coordination between software and devices. An extensive evaluation program of the digitization process of health information systems conducted in the UK has shown all the limitations of existing products and even the new risks that may result in clinical activities (eg errors of prescription of medications induced by automatisms in the data entry) and managerial (eg prolonged waits for exam results due to difficulties in finding relevant information), as well as the ways that operators and managers use to override software limitations, through routine violations of procedures and good working practices (eg transcription of operational notes on paper notes to prepare the letter of discharge, use of commercial applications for internal communications such as handover or consultancies) [4].

On the other hand we have very good examples of a strong integration of systems and practices in the development of chronic care models, where health organization have established care plans for people affected by chronic conditions, such as diabetes or hypertension, that are based on the growing use of wearable or implantable devices, connected to a patient record, integrated in a network of interactions between professionals and services capable of providing effective and timely response to the needs of an empowered patient [13].

2.2.3. Fitness with strategies and goals to deliver safe and quality care - H

Measuring quality and safety is a fundamental duty for health organizations. Nowadays, the collection and analysis of data on health processes and outcomes are included in authorization and accreditation schemes all around the world, in order to guarantee patient safety and value of health services. These activities are often based on extensive review of paper-based records or on the production of data for the unique goal of measurement. Many human and technical resources are spent for data processing, even the time of clinicians is absorbed more by documentation than by direct patient care. Besides, both the impact of accreditation systems the publication of data on strategies and goals of health organization on performances are still debated [14].

In any case, from an HFE perspective, we consider measurement as a basic requirement to understand the fitness between strategies, goals and the delivery of care. The problem is more about how and what to measure and who is involved in doing measurement. New technologies provide new opportunities to look at measurement as part of the managerial and clinical work, rather than as an additional duty to be performed for accreditation purposes. The intrinsic characteristic of digital technologies allow them to support workflows and at the same time to produce data about process performance, as it is well known in manufacturing. So any software or device, co-developed with the health organization and contracted in a service dominant logic, can also automatically produce useful data on performance just if it fits with strategies and goals of quality and safety improvement. Technology driven approaches cannot help because they are not necessarily aligned with the responsibilities of a health organization to deliver safe and

quality care, according to its institutional context and resources, communities needs and demands [15].

2.3. Micro level

The Micro level is where real people interact and health eventually flourishes thanks to individual decisions and behaviors, organizational capacities to address and act against accidents and diseases, institutional and communal resources to sustain people needs and desires.

When we look at our three themes about HFE for digital health at the micro level we see: users and designers interactions; flexibility of workflows; availability and characteristics of hardware and infrastructures. The transition is very fast at this level and often outside of the deliberate control of an institution or an organization, especially as a consequence of the development of mobile technologies and internet connections.

2.3.1. Flexibility of workflows - O

Patient pathways are spread throughout home care, community services and hospitals. The fragmentation of information systems and accountability for care interventions negatively affects workflow and patient experiences. In high income countries, the hyper-specialization of medical treatments has contributed to the success of life saving procedures, sometimes at the expenses of an holistic approach to care and cure, that integrates illness as the personal experience along with the classification, diagnosis and eventual resolution of a disease. In low and middle income countries, as well as in poor and deprived sector of HIC, contacts with providers are less systematic and often patients and their families take the clinical and social burden of a disease on their shoulder, in an attempt to compensate limited availability of specialized services with traditional remedies based on cultural heritage that are difficult to connect with western medicine. In this scenario, dissemination of mobile devices and access to the internet give an opportunity to connect people in needs and health providers in new ways, yet to be explored in their full potential along with their risks. Knowledge about health promotion and disease prevention can be designed and delivered through the web, from accountable health organizations and providers to fit with user needs, old and new habits about personal care and life styles. Moreover, for diagnosis, treatments and rehabilitation, HFE can contribute to the design of health plans with flexible workflows for health professionals, built around health profiles of selected populations, mixing traditional with digital consultations and integrating patients activation in performing tasks and reporting data about their health and care experiences.

2.3.2. Availability and characteristics of hardware and infrastructures - T

Hardware and infrastructure to support the transition to digital health has been developing much slower in health systems than in other industrial sectors, where user experience pushed systems to change such as in banking, commerce or travel services. More and more health professionals report to use their personal devices to help decision making, to communicate with peers and patients, to record relevant information about a treatment, in place of official tools provided by the health organizations. Investment in health information technologies is still very low, compared to the budget for medications or biomedical devices, despite the evidence related to how communication may negatively affect patient care [16] and efficient workflows [17]. Provided enough

security in terms of data protection and continuity of services at the macro and meso level, a distributed decision making process about hardware and infrastructures can help to hardwire the provision of digital health within the local microsystem, by creating lean and adaptable infrastructures open to low cost hardware solutions that can host software and devices aligned with user habits and needs (users = patients and professionals), fully integrated within flexible workflows.

2.3.3. Users and designers interactions - H

Traditionally, digital interventions, especially based on software to support and manage information flows, have generated a tension on the clinical level between standardization and personalization of care, as well as some preoccupations about organizational control over the autonomy of health professionals to take decisions about diagnosis and treatments. Medicine is still considered an art and the doctor a special kind of human with the capacity to integrate intuition rooted in experience with complex reasoning related to a wide knowledge base. Certainly, medicine has got an artistic component in the creative processes of decision-making and actions in practice that help to solve complex problems with limited information and tools, and doctors are probably the professionals who dedicate more time to education and training than any other to be prepared to face daily tens of patients with multiple and highly variable conditions. Anyway, from our perspective, acceptability and usability of digital interventions in healthcare can be addressed by improving the interactions between users and designers. Therefore, the macro level principle to consider organization as it is rather than organization as imagined, it may unfold in daily practices as the users become designers of the systems and designers walk in the shoes of the users through the application of classical HFE techniques such as cognitive walkthrough or scenario based design [18]. To close the gap between users and designers, both professionals and patients have to spend time to express their needs about effective interactions with software and devices. On the other hand designers have to access actionable knowledge about those interactions. The contribution of expert in HFE is critical to analyze real context and represent user needs.

3. Potential application and limits of the framework

The "health system" in Western countries has an urgent need to implement innovative organizational models and reallocate resources optimally between the various care settings.

Digital technology can be an enabling tool to respond to these needs with a profound structural change in care and assistance models, starting with the strengthening of interactions and the integration between the health world and the social world at the micro-level of the system.

The evolution of IT tools provides solutions of proven efficacy to address the core functions of care, that is to assist professionals and patients in their daily work, using accessible digital technologies within flexible workflows, fitted to institutional and organizational strategies and goals.

However, the change will take time; it is necessary to set a multi-year implementation plan, in which a strategic regional and national vision is combined with the priorities of the local contexts, with the involvement of all the stakeholders: policy

regional makers, doctors and health professions, technologists, citizen associations, suppliers. Experts in HFE can play a key role in creating evidence for an ethical and effective design of digital health intervention and providing support to their implementation and evaluation at the macro, meso and micro level. Our framework, summarized in table 1, may help to integrate HFE at the different level of the system and following the tracks of organization, technology and human factors.

Table 1. The HFE contribution to the transition to digital health.

Areas of interventions	Macro-level	Meso-level	Micro-level
Organization	*National and international policies* • creating a national infrastructure, or at least interoperable systems based on common standards and shared services and applications to use in all the different parts of the healthcare system. • create a robust enabling environment, for avoiding the risk of proliferation of unconnected systems and a severe impact on the effectiveness and sustainability of the health intervention	*Development, selection and purchase of systems* Three principles to integrate HFE in the development: • Co-development • Continuous evaluation and iterative design • Service dominant logic	*Flexibility of workflows* • contribute to the design of health plans with flexible workflows for health professionals, built around health profiles of selected populations • mixing traditional with digital consultations and integrating patients activation in performing tasks and reporting data on their health experiences
Technology	*Systems features and infrastructure* • promoting a proactive way to design and develop technology by embedding the principles of HFE into this process. • including experts in HFE among the professionals involved in the project team for the transition to digitalization	*Management and integration of information systems and device* • strong integration of systems and practices in the development of chronic care models, • connection of wearable or implantable devices, with a patient record, integrated in a network of interactions between professionals and services capable of providing effective and timely response to the needs of an empowered patient	*Availability and characteristics of hardware and infrastructures* • creating lean and adaptable infrastructures open to low cost hardware solutions • software and devices aligned with user habits and needs (users = patients and professionals), fully integrated within flexible workflow
Human Factors	*Stakeholder's profiles and power* • overcoming a consolidated technology and administrative driven approach, and introduce a systemic approach • value digitalization as an occasion for triggering a deep innovation process	*Fitness with strategies and goals to deliver safe and quality care* • adopting measurement as a basic requirement to understand the fitness between strategies, goals and the delivery of care • align data produced with software or device on performance to strategies and goals of quality and safety improvement	*Users and designers interactions* • Application of classical HFE techniques such as cognitive walkthrough or scenario based design • Analyze real context and represent user needs

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Context Sensitive Health Informatics: Sustainability in Dynamic Ecosystems
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Human Factors in Health(care) Informatics: Toward Continuous Sociotechnical System Design

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Abstract. Developing structures and processes for continuous sociotechnical system design is key to sustaining human factors (HF) knowledge in the context of rapid health care changes and technological innovations. Two research studies illustrate how to embed HF in organizational learning processes and structures. We need to develop innovative HF methods for continuous sociotechnical system design.

Keywords. Sociotechnical systems, organizational learning, human factors and systems engineering, continuous implementation, usability of health IT

1. Introduction

There is increasing evidence of the benefits of human factors (HF)-based health IT design for patient safety [1]. We also see how HF-based health IT design can support clinicians' work and improve clinician outcomes, such as reduced workload [2]. The application of HF methods and design principles to health IT can make a difference for both patients and clinicians. However, we continue to see poorly designed health IT and negative impact on patients (e.g. health IT-related errors with harmful consequences for patients [3]) and clinicians (e.g. burnout [4]). Clearly, our extensive compendium of HF knowledge is not sufficiently applied. Are we providing usable HF knowledge that can be systematically applied to health IT design? Are we addressing emerging problems with health IT (e.g. health IT to support team-based care of chronically ill patients)? Are we developing HF knowledge relevant for evolving health care needs and constraints? In this paper, I focus on challenges posed to our HF community by the constantly evolving world of health care and technological innovations. I will address *sustainability of HF knowledge in the context of health IT design, implementation and use*.

Given rapid changes in health care and technologies, it may not be judicious to focus on sustainability of specific health IT-based interventions. Instead, we should address how our HF knowledge can be sustained and embedded in organizational learning processes and structures. This approach fits with the concept of *continuous technology implementation* [5]. The continuous cycle of technology design, implementation and use involves both formal and informal activities where technology users adapt to the technology and adapt the technology [6, 7]. I first review various conceptual approaches

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of continuous sociotechnical system design, drawing on literature in human factors and ergonomics, organizational psychology and technology adaptation. I then present two research studies that address various aspects of continuous sociotechnical system design. Finally, I compare the two studies and highlight the need for innovative HF methods of continuous sociotechnical system design.

2. Continuous Sociotechnical System Design

Sociotechnical (work) systems are dynamic systems that continuously adapt, evolve and change [6]. In the SEIPS model of work system and patient safety [8, 9], the feedback loops exemplify the dynamic nature of sociotechnical systems as they represent (1) continuous improvement and learning (e.g. data on patient safety outcomes used as input to redesign work system), and (2) adaptation to the work system or adaptation of the work system (e.g. workers learn the new work system and/or adapt system elements over time). This has major implications for sociotechnical system design, including the need to go beyond technology design and initial implementation and consider *emergent properties of technology-in-use*.

2.1. Sociotechnical system design as a longitudinal extended process

In 2000, Clegg [10] wrote: *"Design is an extended social process"*. Designing a technology and the rest of the sociotechnical (work) system is not clearly temporally bounded: it does not have a clear beginning or end. Technology design occurs over an extended period of time: before, during, immediately after and long after the technology is in use. Clegg emphasized the HF implications of this sociotechnical principle: "Different people will interpret systems in different ways, and there need to be structures and mechanisms through which views can be aired, recognized and understood".

Participation of end users and more broadly of stakeholders is key in developing structures and processes for organizational learning that extends over time. Initially, HF experts may accompany end users and other stakeholders in their individual learning, e.g. skills in usability evaluation. Over time, organizational learning and integration of HF in organizational structures and processes will move from external regulation (e.g. HF experts) to internal regulation (e.g. "just-in-case" HF consultants) [11].

2.2. Continuous change and emergent technology-in-use

As proposed by Weick and Quinn [12], episodic change is infrequent, discontinuous and intentional. Effective approaches for managing episodic changes, such as implementation of health IT, include planning for the change, change management and use of change agents or champions. In contrast to episodic change, Weick and Quinn propose continuous change, i.e., a series of ongoing, evolving, cumulative, and often uncertain and less predictable activities. Individual and organizational learning are key concepts in effective continuous change. As ongoing changes occur, individuals need to develop new skills and knowledge, and organizations need to develop new modes of functioning. Individual and organizational learning contribute to system adaptation, i.e. feedback loops in SEIPS model [8, 9]. In line with the idea of continuous change, Orlikowski and her colleagues emphasize the need to go beyond the transition phase of technology implementation and to understand *technology-in-use* and different ways that

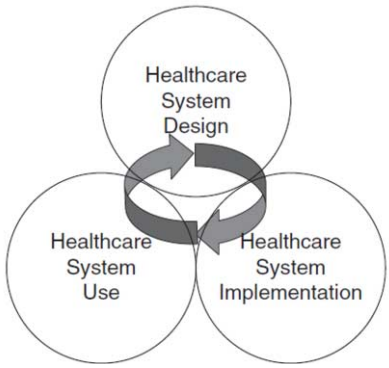

Figure 1. Continuous adaptation and improvement of healthcare sociotechnical systems [7].

users adapt to and adapt the technologies [13]. In systems thinking, emergence plays a key role as system elements (including technology) interact and produce outcomes that may not have been anticipated at the stages of design or implementation. Therefore, systems evolve through continuous phases of design, implementation and use, and adapt as users interact with technologies [7] (see Figure 1).

3. Example 1: Continuous Implementation of Smart Infusion Pump Technology

Smart infusion pump technology has helped to reduce medication administration errors, but has not completely eliminated them [14]. In addition, the technology has had multiple usability challenges, e.g. alert fatigue. Whereas HF methods such as proactive risk assessment can identify and mitigate design vulnerabilities [15], these methods are not full-proof and, as suggested above, technology-in-use may bring up emergent issues that were not anticipated at the design stage. In a study on the implementation of smart IV pump technology in an academic hospital, we described what we call *"continuous technology implementation"* [5]. Using Weick and Quinn's [12] framework, we identified activities and processes related to both episodic and continuous changes.

Before the smart IV pump technology was implemented, the hospital convened a committee to evaluate various IV pump technologies, conducted an ROI analysis of IV pump technology, performed an FMEA of the IV administration process [15], executed a pilot test of the new IV pump technology on one hospital unit, and conducted extensive just-in-time training for all pump users (e.g. nurses and anesthesiologists). These activities aimed at managing the episodic change, i.e., the implementation of smart IV pump technology in the entire hospital. A few weeks after the IV pump technology was in use, a major safety event occurred; fortunately the event did not produce long-term patient harm [16]. The safety event was followed by multiple activities that fit the concept of continuous change. The hospital had developed capabilities to react quickly to the safety event, as well as an open organizational culture for error detection and correction. The FMEA team was reconstituted as a multidisciplinary (e.g. nursing, anesthesia, medicine, pharmacy, human factors engineering) implementation team, which led the investigation of the pump-related safety event. A small interdisciplinary group was rapidly organized to conduct usability evaluation of the various IV pump technology versions produced by the manufacturer [17]. Both individual and organizational learning occurred in this phase of continuous technology implementation.

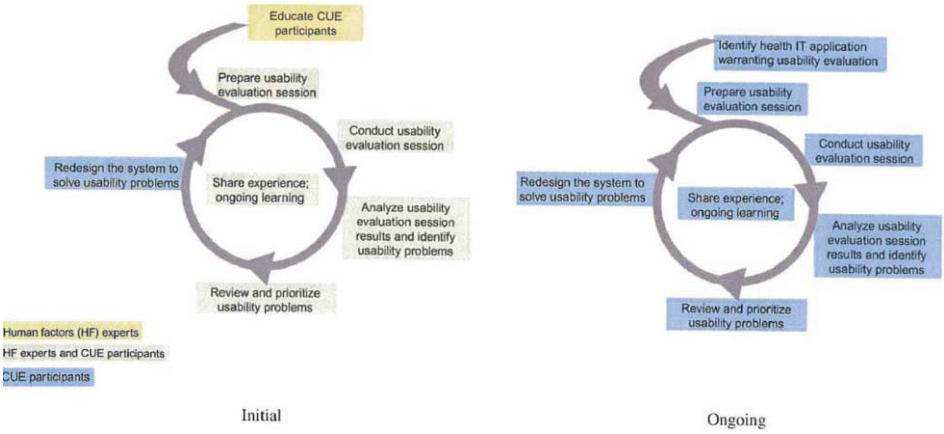

Figure 2. Collaborative Usability Evaluation (CUE) model [20]

4. Example 2: Collaborative Usability Evaluation (CUE) Model for Inpatient EHR Implementation

Usability of EHR technology remains a major concern with responsibilities shared by EHR manufacturers, vendors and implementers [18]. In particular, technology design decisions made by health care organizations contribute to (lack of) usability of EHR technology [19]. A challenge is then *how to institutionalize usability skills and processes in health care organizations*. In collaboration with a large health care organization, we developed a participatory ergonomics model aimed at building a network of individuals trained and proficient at usability evaluation [20]. As shown in Figure 2, the Collaborative Usability Evaluation (CUE) model consists of two phases: an initial phase where HF experts play a significant role in setting up the network and providing training, and an ongoing phase where health IT analysts conduct usability evaluations, implement technology redesigns, and share their experience and learnings. Individual and organizational learning are key to move the CUE program from external regulation (initial phase) to internal regulation (ongoing phase) [11].

In the initial phase, 28 people, including IT analysts and IT leaders from the health care organization and analysts from the EHR vendor, learned and applied usability methods (e.g. heuristic evaluation, user testing, scenario-based evaluation). Over time, the collaborative network of internal usability specialists deepened their impact as they participated in ongoing discussion and application of what they learned in the initial training. In addition, usability evaluations were formally incorporated in the health care organization's implementation timeline for all new EHR functionality and vendor upgrades.

5. Discussion and Conclusion

The two research studies provide examples of continuous sociotechnical system design and illustrate methods for embedding HF in organizational learning processes and structures. The first study shows how a health care organization reacted to a safety event

after the implementation of smart IV pump technology. The second study describes an organizational approach for embedding HF in technology implementation. Table 1 compares the two examples on multiple characteristics of continuous sociotechnical system design, and emphasizes the *developmental or constructive perspective to HF*, i.e., an approach that focuses on both individual and organizational learning [21]. Participation of end users and stakeholders from various disciplines, units and organizational levels is key to developing and sustaining learning.

The two studies provide examples of HF methods for continuous sociotechnical system design (i.e., continuous technology implementation and collaborative usability model), and demonstrate that sustaining HF knowledge cannot be considered as a "one shot" activity. Designing usable health IT is important, but it needs to be embedded in a broader organizational framework to be sustained and have continued impact. In 2004, Bentzi Karsh wrote an important article on "Beyond usability: Designing effective technology implementation systems to promote patient safety" [22]. He argued that we need to not only consider HF technology design (e.g. usability), but also consider HF and organizational methods for implementation and change management. I am proposing *to go "beyond-beyond" usability* and to not only consider technology design and implementation but also technology-in-use (see Figure 1). Effort should be dedicated to the development of HF methods to support the extended sociotechnical system design process described by Clegg [10]. Because health IT users often collaborate to provide team-based care, we need to develop HF methods through which multiple (team members') perspectives can be shared and understood. This may, for instance, rely on visual methods such as cognitive mapping [23] or collaborative design approaches [24]. For HF to make deep, sustained impact on health IT and both patient and clinician outcomes, we need to support the continuous process of sociotechnical system design.

Table 1. Characteristics of continuous sociotechnical system design.

Characteristics	Continuous implementation of smart IV pump technology	CUE model for organizational health IT usability
Initial structures & processes	IV pump committee; FMEA team; pilot test; training on new IV pump	Two phases of in-house usability training for 28 CUE participants; shared experience and learning
Ongoing structures & processes	Implementation team; multidisciplinary safety investigation; multiple usability evaluation cycles	Usability evaluation embedded in health IT implementation timeline; shared experience and learning
User & stakeholder participation	IV pump nurse as liaison; participants in usability evaluation; multidisciplinary teams (FMEA, implementation, event investigation)	28 CUE participants (including 2 analysts from EHR vendor); participants in usability evaluation; involvement of hospital IT leaders
HF methods	FMEA, usability evaluation, safety investigation	Usability evaluation (heuristics, scenario-based)
Individual learning	Skills and knowledge in usability evaluation and safety investigation	Skills and knowledge in usability evaluation
Organizational learning	Multidisciplinary structures and processes; open organizational culture for error detection and correction	Incorporation of scenario-based usability evaluation in health IT implementation timeline for all new EHR functionality and vendor releases/upgrades

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Understanding Organizational Contexts

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Researching Collective Mindfulness and Health IT: A Framework and Translation to Context-Specific Questions

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Abstract. To improve patient safety, hospital organisations are encouraged to run their operations in line with high reliability organisations' collective mindfulness principles and practices. For the same safety goals, they also implement health information technology (IT). However, little is known about whether, or how, health IT can impact organisational mindfulness, and thereby safety. We propose that research in this area can be approached through a simple framework of overarching, umbrella questions, then carefully translated into nuanced context-specific questions and study designs. The framework and approach we propose provides a structure for comparing results from studies of collective mindfulness and health IT, across different clinical contexts and IT applications.

Keywords. Patient safety, collective mindfulness, health IT, research methods

1. Introduction

Hospital organisations are encouraged to become high reliability organisations (HROs) to improve patient safety [1, 2]. The HRO approach to reliability and safety takes a resilience perspective, relying on an organisational capacity to detect and recover from errors or near misses [3]. In particular, five dimensions have been identified at collective (organisational or group) level in HROs contributing to reliability and safety, in aggregate known as 'collective mindfulness': *preoccupation with failure*, *reluctance to simplify*, *sensitivity to operations*, *commitment to resilience*, and *underspecification of hierarchical structure* [4]. Through 'mindful organizing' – such as enhancing staff alertness to risks and resourcefulness – organisations can enhance their resilience. Research suggests, for example, that higher mortality after surgery is associated with some hospitals acting less resiliently, or 'failing to rescue' [5]. Collective mindfulness[2]

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[2] Collective mindfulness [4] is not equivalent to an aggregate of individuals' mindfulness [6] but more akin to processes of organisational learning. However, for the purpose of our research, and the improvement of patient safety, both individual and collective mindfulness are important. For brevity, in this paper with collective mindfulness we refer to both individual and group level mindfulness.

builds on individuals' mindfulness – i.e. awareness of interdependency of actions and capacity for interpretations beyond familiar categories [6]. Both individuals' and collective mindfulness are critical, since the "locus of resilience" is across individuals, groups and systems [7].

Health information technology (IT) is introduced in hospitals worldwide with the aim of improving safety [8]. Health IT can fundamentally change work practices, and it is reasonable to ask whether this can affect an organisation's capacity for collective mindfulness. For example, IT can facilitate information flows, thus potentially enhancing organisational mindfulness [9]. However, it can also disrupt existing (e.g. face to face) communication processes, and/or increase opacity over organisational interdependencies, thus potentially hindering mindfulness. Research on mindfulness with IT in the workplace is limited and fragmented [10], and very little is known of the consequences of *health IT* for collective mindfulness in healthcare settings.

Over the past year we have launched a program of research to study the impact of health IT on collective mindfulness in hospitals. The initial focus of this work is medication safety. In this research in progress we have been exploring the impact of electronic medication management systems of different kinds – including electronic prescribing and administration systems (EPMA; also known as computerized provider order entry – CPOE) and ward-based automated dispensing cabinets (ADCs) on collective mindfulness in its various dimensions. Our current study sites are children's hospitals in Sydney (Australia), implementing a range of IT applications for medications. In this paper we describe the development of a framework of research questions and methods, and how we adapted these to specific clinical settings in these children's hospitals (paediatric ICU, paediatric oncology).

2. Methods

The aims of our research are to improve patient safety in hospital inpatients by: 1. developing theory and methods for evaluation of individual and collective mindfulness associated with health IT; 2. investigating whether and how technology can support organisational resilience; 3. providing (locally/nationally-adjusted) guidance for technology implementation aimed at achieving and sustaining resilience.

To address these aims we pose six overarching questions (Table 1), underpinned by sociotechnical assumptions and human factors understanding of technology in the workplace [11, 12]. These questions constitute a framework to plan collective mindfulness studies of the implementation of different health IT applications in different clinical contexts. Q1 and Q2 are about understanding current practices, with Q2 focused on the role of information systems in use before health IT implementation. Q3 focuses on the changes introduced with the health IT implementation, and the role of the new technology. Q4 reminds us to expand the unit of analysis to patients and their families, as they have an important role in maintaining patient safety. Q5 is about future improvements. And since improvement interventions are difficult to implement beyond national borders - as countries differ in structures, processes, technology and legislation, Q6 addresses generalizability of research findings across nations.

The questions call for qualitative methods in data collection and analysis, including interviews, ethnographic observations, analysis of hospital patient safety incident reports, and review of documentation of medication use.

Table 1. A framework to study the impact of health information technology on collective mindfulness.

Understanding current practices
Q1. *How does mindfulness manifest in healthcare work practices?*
Q2. *Does the current sociotechnical system support mindfulness? What role do existing tools (e.g. paper-based systems) have on staff 'rescuing' potential patient safety near misses?*
Understanding the change
Q3. *How do practices change with the implementation of heath IT? What role has the new technology on maintaining mindfulness?*
Understanding patients' role in the sociotechnical system
Q4. *What is the role of patients in processes of collective mindfulness and 'rescuing' patient safety near misses in hospital? Does the role change with the introduction of new technology?*
Exploring improvements
Q5. *How can we improve system design and implementation strategies in order to support mindfulness in hospital inpatients for better and safer patient outcomes?*
Identifying potential for generalizability
Q6. *Are there specific factors that may affect processes and outcomes of mindfulness in different contexts?*

In planning for our current studies (research in progress), we applied these questions to the challenges of medication safety, and in particular to two different clinical contexts (paediatric oncology and ICU) and different types of medications (e.g. chemotherapy and 'drugs of dependence' such as opioids) and to IT applications implemented in these settings to improve medication safety. We adapted the framework to each of these settings by first identifying which medication safety incidents are specific/typical to each of these settings (which the IT may be aimed at preventing) and then drawing hypotheses on which of the five dimensions of collective mindfulness are likely to be most relevant to prevent or rescue such medication safety incidents (with or without the IT) (Figure 1).

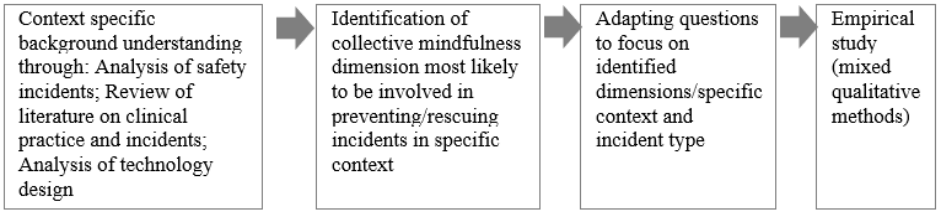

Figure 1. Methods to adapt framework of questions to collective mindfulness dimensions.

3. Results

In this section we explain the context-specific medication safety challenges and the questions we ask for each of the two settings.

3.1. Oncology and a chemotherapy electronic prescribing/administration system

Oncology medications are a particularly risky area of medicine management [13], and especially complex in pediatrics. Prescriptions are set in terms of cycles, repeated a number of times on the basis of prescriptive protocols. Medications must be sequenced and timed correctly, upon clinical monitoring of patient response, to contain side effects [14]. The treatment can last for months or years. The medicine management work is distributed in time and place (inpatient and outpatient settings, home care), with a number

of people and roles involved. Thus, oncology medications present a high degree of interdependencies. Research has shown how EPMA systems can reduce oncology medication errors [14-16] although limited work has focused on their impact on 'errors linked to interdependencies' (e.g. erroneous scheduling of cycles) – which, we hypothesize, could be associated with problems in collective mindfulness, and in particular *sensitivity to operations*. Thus, we have adapted our questions (Table 2) with this collective mindfulness dimension in focus.

Table 2. The framework applied to medication safety and medication management systems, adapted to two different technologies, types of medications and clinical contexts.

Overarching questions applied to medication safety and IT systems for medications	**EPMA in oncology setting – questions refined to this context**	**ADC in ICU setting - questions refined to this context**
Q1. How does mindfulness manifest in *medicines management practices, including their prescribing, dispensing and administration?*	**Q1.** How does mindfulness manifest in managing the *interdependencies inherent in children patients' chemotherapy treatments*?	**Q1**. How does mindfulness manifest *in DD management practices, including supplying, controlling, administration and documentation*?
Q2. Does the current sociotechnical system support mindfulness *in medicines supply and use*? What role do existing tools (e.g. paper-based systems) *have on 'rescuing' potential risks in the medicines use process*?	**Q2**. Does the current sociotechnical system support mindfulness *in chemotherapy supply and use*? What role do existing tools *(e.g. paper-based chemotherapy protocols) have on maintaining awareness of the treatment process*?	**Q2**. Does the current sociotechnical system support mindfulness *in DD supply and use*? What role do existing tools *have on 'rescuing' potential risks in the DD use process, such as those posed by unaccounted use*?
Q3. How does the practice *of medicines use* change with the implementation of IT? What role has the new technology on maintaining mindfulness in *medicines use*?	**Q3**. How does the practice change with the implementation of *EPMA* systems? What role has the new technology on maintaining *awareness of the treatment process, and in particular in consideration of its potential for adding opacity or transparency over interdependencies*?	**Q3**. How does the practice of *DD use* change with the implementation of *ADCs*? What role has the new technology on maintaining mindfulness *in DD use*?
Q4. What is the role of patients in processes of 'rescuing' in *using medicines* in hospital? Does the role change with the introduction of new technology?	**Q4**. What is the role of *patients' families in hospitals maintaining awareness of interdependencies*? Does the role change with the introduction of new technology?	**Q4**. What is the role of *patients' families achieving safety/security of DD*? Does it change with the introduction of new technology?
Q5. How can we improve system design and implementation strategies in order to support mindfulness *and medication safety* in hospital inpatients for better and safer patient outcomes?	**Q5**. How can we improve system design and implementation strategies in order to support mindfulness *and awareness of interdependencies in the treatment process* for better and safer patient outcomes?	**Q5**. How can we improve system design and implementation strategies in order *to reduce the potential risks to mindfulness associated with the introduction of automation*?
Q6. Are there specific factors that may affect processes and outcomes of mindfulness and rescuing *in medicines use* in different nations?	[to be explored with future studies in Europe in 2020]	[to be explored with future studies in Europe in 2020]

Note: *italics* indicates adaptation of generic framework to specific setting. Abbreviations - ADC: automated dispensing cabinets; DD: drugs of dependence, e.g. opioids; EPMA: electronic prescribing and administration system; ICU: intensive care unit.

3.2. Intensive care and an automated dispensing cabinet for drugs of dependence

'Drugs of dependence' (DD) can be dangerous. In hospitals, DD misuse can lead to harm to staff and patients, and legal and financial consequences for the organisation [17]. Documentation of DD use in paper registries, for control and legal purposes, is very time consuming, especially in wards where DD are used frequently, such as intensive care units (ICU). Automated dispensing cabinet (ADCs) are introduced in hospital pharmacies and/or in clinical wards to improve control of medications [18, 19] and reduce the burden of documentation. However, as most health IT, they may generate unwanted effects on workflows and introduce new mechanisms for errors, such as the nurse not recognizing a wrong drug in the ADC drawer, assuming it to be as expected – a phenomenon known as automation bias [20]. It is necessary that healthcare professionals maintain awareness of risks to prevent harm occurring. Thus in this context, we adapted our questions (Table 2) to investigate specific technology-related mechanisms for errors (automation [21, 22], 'equivocality' [23]) and collective mindfulness dimension essential to counter these (*reluctance to simplify* [4]).

4. Discussion and conclusion

With our research we are proposing a framework of questions to structure the study of the impact of health IT on collective mindfulness in hospitals. The questions must be translated to the specific clinical contexts and IT applications, as each can be expected to have specific patient safety risks and different potential impacts of the technology on the varied dimensions of collective mindfulness. For example, a workflow management system, such as an EPMA system, implemented in paediatric oncology, is expected to support (and semi-automate) the distributed work of the different clinicians involved in a patient's treatment, and to affect the management of the many interdependencies that characterize oncology care. This clinical context invites a study focus on *sensitivity of operations*, and the potential for increased opacity (or transparency) over interdependencies. Instead, a technology such as automated dispensing cabinets (ADCs), implemented in an ICU, where there is high use of dangerous drugs of dependence, is expected to change specific tasks (e.g. retrieving medications at the time of administration). New risks brought by ADCs are associated with automation effects such as individuals' premature cognitive commitment ('mindlessness'). Thus, it invites a focus on collective mindfulness strategies put in place to counter these effects, such as '*reluctance to simplify*'. By the process of translation, we hope to be able to drill into the many varied ways that health IT may affect collective mindfulness in different organisational settings. We will use the framework of overarching questions to then 'reassemble' the distinct findings into a larger picture of whether and how health IT affects collective mindfulness in healthcare. As our studies progress, and with them our understanding of collective mindfulness with health IT, we may refine our original questions. We invite others wishing to investigate this territory to position their findings in this framework, to 'test' it and contribute to our collective understanding.

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Impact of Work Organization on Technology Use: The Case of Hydration Process with a Smart Drinking Glass

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Abstract. This paper presents preliminary results from a larger project led with the French company Auxivia. The latter offers a smart drinking glass (SDG), supporting monitoring daily water intakes of elderly people and helping identify residents to encourage. Contexts and work organizations can deeply differ from a nursing home to another and can impact the use of the SDG. Based on a comparison between two nursing homes, we unveil the impact of both work organizations on the integration of technology requirements. We discuss the results by providing recommendations to improve the integration of SDGs in various work organizations.

Keywords. Smart drinking glass, Work organization, Technology requirements, Acceptability, Adapted design, Nursing homes

1. Introduction

Scientific literature has highlighted the risks related to the dehydration of elderly people [1-7]. It has been shown that the thirst sensation is blunted in this population [7-8]. Hence it is essential for elderly people, as for their formal or informal caregivers, to know if the daily water intake is sufficient or not.

In order to prevent dehydration, a few companies have developed tools which allow to track the water intake over a given period of time [9]. The French company called Auxivia is one of them, which offers a smart drinking glass (SDG) specifically for elderly people. Thanks to its connection to a personal tag, the glass allows to monitor the volumes drunk by each person. In nursing homes, especially if the elderly is not autonomous, those data can be used by the staff to judge whether the person needs more or less liquid intakes. The process of hydration monitoring through SDGs involves four requirements (R1, R2, R3, R4):

- R1: the SDG must be charged. The caregivers have to put the glass on a charger and meet the time charge before using it anew. Only a few hours of charging enable to use the SDG for one week.
- R2: ensure the pairing between the glass (which is not assigned to a specific resident) and a personal tag (assigned to a resident). The tag must be kept close

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to the person. With this aim in mind, several solutions can be considered: worn tag (necklace or wristband) or installed on furniture (table or coaster).

- R3: the glass detects and records water intakes. To be exploitable, the data must be transferred to a computer platform. A pairing between the glass and a data collector is needed. To ensure the data are properly collected, the glass must remain less than five meters from the data collector for 30-45 minutes.
- R4: a resident who is monitored must *always* drink in a SDG. If (s)he drinks in regular glasses, the water intake will not be measured. Therefore, the collected data will not reflect the overall water intake.

The SDGs logistics is the same as for regular glasses: distribution, dishwashing (they can be washed by the dishwasher) and storing.

The aforementioned SDG requirements may be sometimes difficult to meet in certain nursing homes because of the various existing work organizations (WOs). As with any technology, the implementation initial WO impacts the SDGs logistics and vice versa [10]. Thus, this paper explores how two initial WOs impact the acceptability of the tool by the staff and the integration of the SDG requirements. With this goal in mind, we performed work system analyses of two nursing homes' WOs.

2. Material and method

The present study is part of an Auxivia company project aiming to improve the implementation of their SDG in nursing homes. Auxivia SDGs are implemented in fifteen nursing homes, all located in France. Our observations were carried out in three of them, selected according to WO criteria that may impact the hydration process (nursing home size, fixed or random seat at the restaurant, formal hydration process or not). This article relates preliminary results from two nursing homes, representing two very different WOs.

Nine hours of observation were spent in each nursing home, by the same observer and with the same observation table. The observed items concerned both the hydration process (i.e. regardless of the SDG: distribution, collection and washing of the glasses, staff involved, division of tasks) and the use of the SDG (including constraints for the staff depending on their role, and usability or use problems).

Lastly, interviews were conducted with the staff. They complemented our observations and were based on the same items. Six interviews were conducted in the nursing home A (the nurse coordinator, the housekeeper, a psychomotor therapist, a hospitality aide, two caregivers) and six in the nursing home B (the assistant director at the care unit, the general practitioner, a nurse coordinator, a nurse, two caregivers).

The collected data were used to compare nursing homes item by item.

3. Results

3.1. Nursing home A

3.1.1. Context and initial WO

The 63 rooms (representing 63 residents) are distributed over four floors. The ground

floor provides a central restaurant, where most of the residents eat, and a smaller restaurant dedicated to a specific unit for people with memory or behavior disorders (12 residents). The two restaurants are about 50 meters apart from each other. Cooking, setting the tables and dishwashing are outsourced to a hospitality aide from an external company. Cooking and dishwashing are performed in the basement.

The glasses (connected or not) are brought and distributed by the caregivers at several places: residents' rooms, common spaces on the four floors, central restaurant, and small restaurant. To bring the glasses at each floor, caregivers use two lifts (often overused leading to long waiting times). Then glasses are brought back to the ground floor by the caregivers, to be washed by the hospitality aides in a dishwasher for communities. Lastly, hospitality aides store them in a cabinet at the central restaurant.

Despite the rather small size of the nursing home A, the circulation of the glasses is large and complex because: (1) the glass can be used at many places; (2) distances (and time) between places are significant, and (3) the process involves both caregivers and hospitality aides.

3.1.2. Use of the SDG

Ten residents are monitored by the means of SDGs. Thirty glasses have been initially put into circulation for these ten residents to guarantee there is always a glass available for each resident.

SDGs are distributed, washed and stored as the regular glasses. In comparison to regular glasses, hospitality aides have an additional task: to put the glasses on the charger after they have been washed, and to wait for the green light before using them anew. The charger and the data collector are close: therefore, when charging the glasses, hospitality aides meet both requirements R1 and R3 at the same time.

However, some difficulties to stick to the requirements have been noticed, especially R4 (always drink in a SDG). The difficulties are often related to the spatial configuration or to the diversity of staffs involved in the hydration process, or both. Table 1 details the impact of those characteristics on the adherence to these requirements.

The care staff asserts that SDG are not always available. Hence, they use regular glasses, so that the technology requirements are not met, and the measure of the daily water intake is distorted. Accordingly, the long and complex circulation of the glasses impacts the integration of technology requirements in the WO.

3.2. Nursing home B

3.2.1. Context and initial WO

Unlike nursing home A, each floor ("living unit") accommodates 17 to 20 residents. Each one has its own restaurant, and a kitchen equipped with a standard dishwasher and cupboards to store the glasses.

Glasses can be used in the residents' rooms, in common spaces (including the restaurant) located at the same floor, and they are washed and stored in the floor kitchen. As a consequence, all glasses (connected or not) always remain on the same floor, in places not further than a few dozen meters apart from each other.

In this WO, only the caregivers are in charge of distributing the glasses, bringing them back to the kitchen, putting them in the dishwasher and storing them. Thus, the circulation of the glasses is short and simple because: (1) there is only one place for the meals, (2) distances are reduced, and (3) only the care staff takes action in the process.

Table 1. Impact of the nursing home A's characteristics on the use of the SDG.

Characteristics of the organization	Observations in nursing home A
Diversity of places	Some glasses have been broken or lost, others remain a long time in the rooms or in common spaces at the floors. As a consequence, glasses are rarely available in the storage cabinet. Because glasses are not dedicated to a particular place, the caregivers often take more than needed to prevent running out. As a result, SDGs are missing on other floors. The personal tags are glued to a necklace; sometimes, they are not worn because the care staff forget them or because the resident refuses them. Then the water intakes are not recorded.
Diversity of operators	Because of a lack of information or training and due to turnover, caregivers do not really know the SDG requirements, or they do not know which residents are monitored. They frequently give a regular glass to the monitored residents, causing the water intake not to be recorded.
Both diversity of places and diversity of operators	Meal trays are provided to the small restaurant. According to caregivers, the SDGs should be provided with the trays by the hospitality aides; but according to the latter, the caregivers must fetch them at the central restaurant. Then there is a misunderstanding about the rules related to the circuit of the SDG. As a consequence, SDGs are often missing at the small restaurant.

3.2.2. Use of the SDG

Most of the residents (about 50) of three living units are monitored by the means of the SDG. As in nursing home A, three glasses per resident have been initially provided by Auxivia. The distribution, washing and storage processes are the same as for regular glasses.

Nevertheless, the use in nursing home B differs from nursing home A. Table 2 shows the impact of the characteristics of the glass circulation on the adherence to the technology requirements.

Caregivers access a SDG more easily than in nursing home A. In this situation, technology requirements are more often met. In this WO, the short and simple circulation of the glasses impacts the use of the technology, by facilitating the compliance with the requirements.

Table 2. Impact of the nursing home B's characteristics on the use of the SDG.

Characteristics of the organization	Observations in nursing home B
Proximity of various places	The charger and the data collector are both installed in the kitchen, as well as the dishwasher and the storage cupboard. These elements are not further than three meters from each other. As a result, the SDGs always remain within a limited area. When the caregivers look after a SDG, either they see it right away or they have a relatively short distance to walk and fetch one at the residents' rooms. The personal tags are glued under the restaurant table and tables in the residents' rooms as one resident always eat at the same place. But the caregivers have difficulties to ensure that the monitored residents are always close to their personal tags when they drink. As a consequence, water intakes can be recorded for another resident.
Only the caregivers are involved in the process	All caregivers have the same rules in mind. The newcomers arrive in a small team, so that they soon reproduce their colleagues' activity. The communications are fast, the technology requirements are rapidly learned by the operators.

4. Discussion

For the care staff, the integration of the Auxivia technology requirements appears to be more difficult in case A than in case B. The two WOs impact differently the use of the SDG and the integration of the technology requirements. The acceptability of the SDGs depends partly on the matching between their requirements and the actual WO: in the present study, nursing home B's organization suits better the SDGs' requirements than nursing home A's.

A thorough analysis of the WO upstream of the implementation is therefore crucial to ensure a more efficient integration of the technology.

Yet, manufacturers cannot design a tailor-made tool for each WO. To ensure that the technology is adapted to various organizations, one approach could be to set different profiles of WOs, and to define the needed adaptations of the technology to these profiles. For instance, when the technology is implemented in a long and complex glass circuit, as in case A, three solutions can be considered in order to help the staff better understand and adhere to all the steps: (1) provide more glasses, knowing that it would increase the costs to nursing homes; (2) emphasize support, information and training towards the care staff; (3) introduce the tasks related to the SDG in the job descriptions.

Despite the differences we observed in the meeting of technology requirements between A and B, results do not mean that the use of the technology is better in one nursing home than in the other, as it depends on a wide range of requirements and tasks. In this article, we focused on the acceptability of a few ones by the staff. A forthcoming paper will further develop the overall efficiency of the SDG.

Competing interests

The authors declare that they have no competing interests in conducting and in reporting this study.

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Lost in Translation? Care Coordination Across Contexts in Swedish Homecare Nursing

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Abstract. The responsibilities for delivery of care in Sweden is divided between the regions and the municipalities. The regions run the hospitals and the primary care centres (PCCs) whereas the municipalities are responsible for homecare nursing and nursing homes. The homecare nurses and the doctors they need to seek advice from, thus belong to different organizations/contexts. As more patients with multi- and long-term illnesses are taken care of in their homes the workload of the homecare nurses has increased. A new healthcare agreement has thus been signed between a region in South Sweden and its municipalities. The healthcare agreement states that doctors from the PCCs are to form mobile teams together with the homecare nurses. This paper reports from a pre-study investigating how the agreement, in terms of translation sociology, is interpreted in four of the municipalities. The aim of the research project as a whole is to develop digital support systems for the mobile teams.

Keywords. Care coordination, homecare, nursing, teams, sociology of translation

1. Introduction

In Sweden, there is an increasing trend of patients, especially the elderly, being cared for in their home, even during multi- and long-term illnesses [1, 2]. This means that the care moves from the hospitals to the patients' homes. This, in turn, increases the workload of the homecare nurses [3]. Another aggravating circumstance is that the organization and responsibility of healthcare in Sweden is divided between two organizational levels, the regions and the municipalities included in the regions. The regions run the hospitals and the primary care centres (PCCs) whereas the municipalities are responsible for homecare nursing and nursing homes. The homecare nurses and the doctors they need to seek advice from, thus belong to different organizations. In response to this, a new *healthcare agreement* was signed in 2016 between a Region in Southern Sweden and the region's municipalities. The healthcare agreement states that the homecare nurses should be able to call a doctor from the PPC when needed. When called upon, a doctor is to reside in the patient's home within two hours, around the clock, to team up with the homecare nurse. A PPC doctor and a homecare nurse are thus the core of the new team but can, when needed, request other care professionals as an assistant nurse, a physiotherapist or

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an occupational therapist to join the team. This will potentially imply increased support for the homecare nursing staff, as they will get a team to turn to.

Besides the apparent organizational challenges with a transition to a new work form including several organizations, the interpretation of the core concept, the *team*, can constitute another obstacle. Previous research indicates that different understandings of how the team is supposed to work together lead to poor team functionality and communication failures [4-6]. Furthermore, we know that the concepts of a *team* and *teamwork*, sometimes are interpreted differently [7, 8]. Thus, it is of interest to investigate how a team based organizational change initiative, implemented broadly in several different municipalities, is interpreted and translated into organizational practice.

In this paper, we present findings from a pre-study of how the new healthcare agreement has been interpreted in the local context in four different municipalities. The pre-study is the first step in a larger project intended to develop digital support systems for the mobile teams. In the paper we will consider; 1) how the interpretation of the agreement and multi-professional team varies between the different municipalities, 2) to what degree the multi-professional teams have materialized in the four municipalities so far, 3) how (and by whom) the cooperation between the region and the municipalities has been organized, and 4) what possible indications this may have for the future development of digital support systems.

2. Theory: Sociology of translation

To catch and analyse the variations in interpretation of the agreement and multi-professional teams between the different municipalities we use *sociology of translation* i.e. the notion that ideas are translated when they move in/through the field [9, 10]. Latour [9] and Callon [10] define *translation* in a wide sense, including all possible variations in a process of interpretation. Thus, here translation goes beyond mere translation word for word, and also refers to, for instance, that an abstract language can be translated into a concrete one, or that words can be translated into action. This implies that it is difficult to control the process of implementation. Latour [9] writes of tokens, which implies anything that can be spread. Latour's intention with the concept of translation is to give an alternative to the "usual" diffusion models [11]. Latour [9] rather sees each and every encounter between the token being spread and the people it meets as an "happening" to which the outcome cannot be predicted. This in turn has implications for the power of the ideas. There is an important difference between Latour's and Callon's translation models as they focus on or highlight different parts of the translation process. Latour's translation model highlights the translation itself, while Callon's model of translation highlights the translators and how they become translated through the process. Callon uses the concept of the *obligatory passage* to explain how different translators (actors) are linked to each other through the mutual "problem".

3. Methodology

The design of the pre-study was qualitative and the data was obtained through: 1) document studies related to the *healthcare agreement* and its implementation and 2) semi-structured interviews with representatives from the four municipalities' home care nursing units. The interview questions were concerned with; *the current organization of*

home care nursing in the municipality, *how the mobile teams are interpreted and organized*, *plans to develop their organization with regards to the mobile teams, power and influence over the organization of the mobile teams, how the patients were selected and enrolled in the program, and perceived effects on the patient care and the work environment of the nurses.* All interviews were recorded and transcribed. In total, 13 persons were interviewed, from the four municipalities (see table 1).

Table 1. Number of interviewed personnel in relation to municipality and profession/occupation.

Municipality	Section manager	Home health-care nurse	Medically responsible nurse	Social service manager
A	2	1	0	0
B	0	1	1	0
C	2	3	0	1
D	1	1	0	0

4. Results: The agreement and interpretation of the agreement in four municipalities

In the agreement, the region and the municipalities commit to a common development of the organization and work-routines of the mobile teams, their healthcare quality and a better resource allocation. Enrolment of patients into a mobile team is to be a common activity and decision between the region and the municipalities (i.e. a doctor from a PPC and a nurse from the homecare organization). In order to be enrolled, the patient has to fulfil four out of six predefined inclusion criteria. If the patient accepts enrolment, a joint coordinated individual plan for the patient's care is established. Before the agreement, the municipalities have been able to call a *mobile doctor service*, an emergency service procured by the Region when the PPCs are closed (ca 16.30-8.00). The mobile doctor service provides a doctor on call that comes directly to the patients' home. Patients are normally listed on a specific doctor at a PCC of their own choice.

4.1. The state of affairs in the municipalities

The four municipalities were chosen to represent different types of municipalities in the Region: two small towns, one by the sea including small satellite villages A (a total of 20 000 inhabitants); one in the country side including rural habitation B (a total of 15 000 inhabitants); and two larger towns, one with concentrated town habitation C (a total of 33 000 inhabitants) and one including rural habitation D (a total of 33 000 habitation).

4.1.1. Municipality A

In municipality A, the respondents from the homecare organisation did not know which patients were enrolled and listed on the mobile team. They had vague perception of the mobile team and seemed to have the opinion that the mobile teams are the PCCs responsibility. The homecare nurses were not informed of the list of patients that had been enrolled in the mobile teams and they have to phone the PCC to be informed on the matter. During the day the PCC sends a doctor to team up with the homecare nurse or decides what other actions to take (as calling the mobile doctor service or arranging for an ambulance transport to the hospital). In municipality A they claim that they mostly work in the same way as they did before, daytime they call for a doctor from the PCC and other hours they call the mobile doctor service. They have not made any changes in

their organization or the composition of their staff on behalf of the agreement. Still they feel that the PCC doctors make more visits to the patients than before but they also point out that the intention was even more enhanced cooperation with the PCC and that it is difficult to share information between the homecare and the PCCs as they belong to two different healthcare organizations. They communicate with the PCC through a weekly meeting about patients (planning), fax and telephone. They also told us that they are interested in becoming more mobile, amongst other with support of e-health technology, but they did not connect this to the agreement or the mobile team. The respondents also commented that the mobile doctor service was intended to become superfluous but that this has not happened yet.

4.1.2. Municipality B

The respondents in municipality B referred to another type of a mobile team – regional mobile teams that have been put together by and depart from the regional hospital and serve the municipalities in the area. These teams are better equipped than the local mobile team and the mobile doctor service and can provide more advanced care on site. The routine is that when needed the homecare nurses call the PCC for a doctor and the PCC decides whether to send one of their own doctors, the mobile doctor service or the regional mobile team to the patient. According to the respondents, the PCC doctors rarely come themselves though. The homecare nurses are involved, together with the PCC, in the enrolment of patients into the local mobile teams. Planning is done through a monthly meeting between the operational managers from the PCCs and the municipality together with the medically responsible nurse. They do not work differently from before but say that now the PCC takes larger responsibility to call for the mobile doctor service or the regional mobile team. The respondents also made a comment about not really understanding why there is an enrolment of patients for the mobile team because all patients seem to have the right to be visited by the regional mobile team. The bottom line is that the respondents from municipality B do not feel that they work with the PCC in mobile teams but they do meet up with the regional mobile team at the patient's home.

4.1.3. Municipality C

In municipality C, they have decided that the mobile team coincides with their "ordinary teams". They have thus not created any new organizational forms or teams for the mobile team but have extended their teams with competence in rehabilitation. The respondents also doubt that the PCCs are well enough equipped to work with the mobile teams i.e. to fulfil their part of the agreement. Still, they have good communication with the different PCCs amongst others through already existing collaboration groups. The local hospital is also involved in the communication. The municipality has chosen to work with one particular PCC to form the mobile teams. The other PCCs are included in the information loop but are not involved in setting the guidelines for the cooperation. The respondents note that on a higher level in the organizations everyone agrees on what the agreement means, but that when it comes to the shop-floor in a particular PCC the interpretation can be more problematic. The PCCs work as they have always done and individual doctors can be more or less informed about the agreement. The result is, according to the respondents, that the doctors are not always involved and engaged in the enrolment of patients and the writing of the joint coordinated individual plans. They perceive the lack of doctors as the main cause of this. As the PCC does not live up to their part of the agreement, the region has come up with the idea of a regional mobile team as a support

(the same sort of team as in municipality B). However, in the homecare organization they have done what they can but are dependent on the PCC to develop their part of the mobile teams further and come into action.

4.1.4. Municipality D

In municipality D the respondents claim that the homecare nurses have worked in mobile teams with doctors from the PCCs for quite a while before the agreement (daytime). Therefore, the agreement has not changed much for their organization. Normally, the particular doctor that the patient is assigned to will team up with the homecare nurse. Thus, more or less all doctors at a PCC can be involved in a team with the same homecare nurse. One of the PCCs is testing a system where one doctor takes all team calls and teams up with the same homecare nurse (forming a stable team). However, some nurses work with as many as three different PCCs and with several doctors at each PCC. If the patient changes PCC or doctor the homecare nurses will follow the patient and work with a new PCC and doctor. The respondents claim that sometimes the PCCs try to get the homecare nurses to contact the specialists in the hospital but the nurses refuse, as this is the responsibility of the PCCs. Still, they say that they have had a good cooperation and communication with the PCCs since before and sometimes the doctors manage to team up with the homecare nurse and sometimes the PCC calls the mobile doctor service or the regional mobile team instead. None of the PCCs provide doctors during the nightshift yet (the same is true for the other municipalities). The respondents also claim that the number of patients that are sent to the emergency at the hospital have not been reduced even if that was one of the aims of the implementation of the mobile teams. They also comment the fact that the regional mobile team is called the same as the local mobile team (both are called "the mobile team") which they think is confusing and a pity. The respondents also state that they need to reorganize some of the homecare nurses' work so that they cover up for the nurse that teams up with the doctor (implicitly meaning that the nurse that teams up with the doctor misses out on her/his round of patients). They will thus hire an assistant nurse that can support the homecare nurses. The enrolment of the patients is done in cooperation between the homecare nurses and the PCCs and the homecare nurses have weekly planning meetings with the PCCs. The respondents do not feel that there is a need for the PCCs to provide a doctor outside daytime as they have a good cooperation and communication with the mobile doctor service.

5. Discussion

The brief accounts from the interviews in the municipalities above, show that the agreement has been interpreted or translated, in Latour's [9] and Callon's [10] meaning, in different ways in the different contexts/municipalities. The interpretations also seem to be dependent on the local routines and the contact and communication channels between the homecare and PCCs'. Where there is an established communication and cooperation between the homecare and the PCCs, as in municipalities C and D, the translation of the agreement into practice seems to be simpler than in municipalities A and B where the communication and planning is not so elaborated or happens on a level above the homecare nurses and the PCC doctors. In addition, there is a difference between the different PCCs understanding of the agreement and the degree to which they translate it into practice. Several of the respondents describe a disbelief in the PCCs

capacity to fulfil their part of the agreement. The fact that the PCCs often prefer to call the mobile doctor service or the regional mobile team instead of sending their own doctors also indicates that they have problems realizing the agreement in practice.

The common enrolment of patients could have been an obligatory passage [10] for both the homecare nurses and the doctors, as they become linked to the patient and the mobile team. However, the doctors do not seem to be totally translated into team members (even though the degree of commitment varies between the different municipalities) as they pass on the task to the mobile doctor service or the regional mobile team. This shows that an obligatory passage only works as long as there are enough available resources, in this case doctors, to materialize the engagement in practice or as long as the problem is not recognized as mutual and the linkage of the obligatory passage is not made as in municipality A where the homecare nurses were not even invited to participate in the enrolment of the patients.

All the municipalities have, to different degrees, translated the agreement to become a part of "business as usual", adjusting their work only to a small extent, or not at all. In some cases (C and D) because the existing routines already resembled the agreement and the mobile teams or because there was a confusion about what the agreement and the mobile team really meant (as in municipality A and B). An idea, in this case the agreement, that allows for this type of adjustment to the existing contexts has to be vague or abstract enough for the different actors to translate it in different ways [12]. However, a digital system is per definition more concrete and does not allow the same type of local interpretation. The task to develop a uniform digital support system for the mobile teams will thus be challenging as long as the participating organisations do not align their interpretation of how to translate the agreement into practice.

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Adapting mHealth to Workflow – A Case Study in South Africa

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Abstract. Community Health Workers (CHW) perform important healthcare and health promotion in many low and middle income countries. They are increasingly supported in their work by the use of mHealth. This study aims to explore how mHealth services can support the everyday work for CHWs when delivering home care in rural areas in South Africa. A single case study was performed, mapping CHWs workflow and investigating where and when CHW can be supported by mHealth services. Despite the very positive feedback from the CHWs and the fact that the studied mHealth solutions appears to support the majority of the important activities in the CHWs work process, the application is no longer in use. Financial and strategic decisions are behind the discontinuation of the project, further stressing the importance of taking all socio-technical dimensions into account when evaluating success or failure of implementation projects.

Keywords. mHealth, Socio-Technical Systems, Community Health Workers

1. Introduction

Globally, healthcare systems are facing similar challenges and a pressure to perform alongside limited budgets and shortage of staff. eHealth has the potential to facilitate the work for healthcare professionals, however problems with low usability and poor interoperability continue to cause problems [1]. Low- and middle-income countries (LMICs) suffer from several health care challenges, one of the major ones being lack of workforce. This leads to understaffed hospitals, patients not having access to care, and a communication-gap between patients and physicians, especially in rural areas. South Africa is a middle-income country with a private and a public healthcare sector. Healthcare is funded by a mixture of taxes, private medical schemes and out-of-pocket payments [2]. The private healthcare sector has larger funding, since it comprises private out-of-pocket payments and medical schemes. This leads to an unequal distribution of healthcare, since most health care professionals decide to work within the private sector, which the poor cannot afford [2].

To bridge this gap, community health workers (CHWs) play a vital role [3]. CHWs are a group of health workers who have a formal but limited training for certain health-related tasks [4]. Their tasks include providing health education, referrals and follow ups,

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home visits to specific communities, and basic preventive health care. They support individuals and families to access the health and social services system [5]. CHWs work outside of health care facilities, visiting people in their homes, neighborhoods, communities or other nonclinical spaces [3]. The individuals and families they visit often do not have the means to go to the health care facility themselves, therefore the CHWs often work in rural areas. Mobile technology support community health workers in collecting health data, facilitate health education sessions, receive alerts and reminders, and to communicate [6]. The concept mHealth has emerged as a sub-category of eHealth and can be defined as medical and public health practice supported by mobile devices [7]. By using mHealth tools, CHWs might be able to improve the quality and range of the services they provide.

To improve design and implementation of mHealth to support homecare in rural areas in the future, we need an in-depth understanding of the factors that impact the success or failure of mHealth interventions. Today, there is a lack of empirical evidence of effectiveness when implementing mHealth services in rural homecare [8]. mHealth interventions can be classified as complex socio-technical systems [9], and therefore it is important to address more than only technical aspects when studying success and failures of mHealth implementations.

This study aims to explore how mHealth services can support the everyday work for CHWs when delivering home care in rural areas in South Africa.

2. Methods

A single case study was performed, focusing on how mHealth services can support CHWs in South Africa when delivering home care to patients in rural areas. The focus is on mapping their workflow and investigating where and when they can be supported by mHealth services.

2.1. Setting and participants

Data collection was done in two different sub-districts in the North-West province, South Africa. The municipality has a population of around 82 000 people. It is a farming community where the main economic sector is agriculture. There are eight clinics in the area. The clinics are either primary health care clinics or community health centers. Mobenzi is a mobile application for smartphones that had been used in the studied context. It was specifically developed for CHWs in South Africa. Mobenzi allows the CHWs to register patients, collect data and keep records of them. The mHealth solution also allows screening different diseases, sending referrals and intervention-specific functionality according to program guidelines and requirements [10]. Real-time notifications and screening provide real-time decision support. The automatic report makes it possible for management, the outreach team leaders (OTLs), to monitor key indicators. The mHealth application can be used offline, meaning data synchronization will happen automatically in the background, which makes it possible to use in remote areas without network connection [10]. It is possible for the users to communicate with each other through the application.

Since the study is limited to the pilot of a specific mobile health application, the number of users is small. Due to the small group of participants, convenience sampling was chosen as sampling technique [11]. Three focus group interviews were conducted,

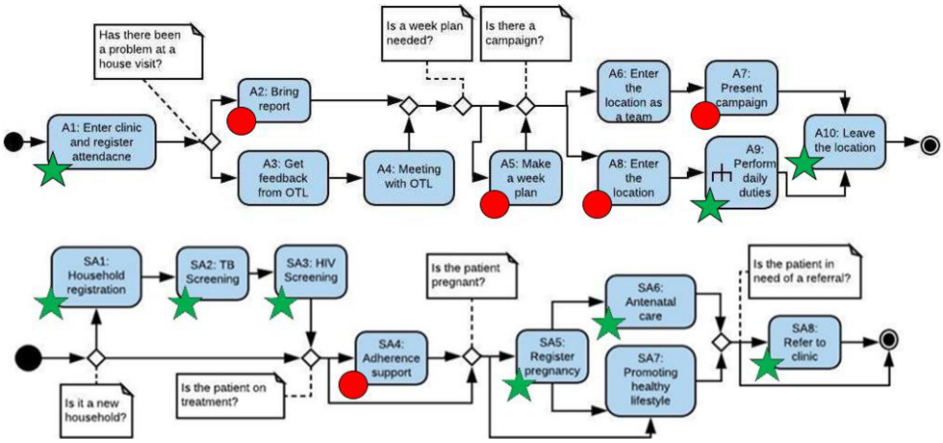

Figure 1. CHWs workflow in the South African context.

one with OTLs and two with CHWs. A total of four OTLs and 23 CHWs participated in the focus group interviews.

2.2. Data collection and analysis

The focus group interviews were mainly held in English, but with support of local researchers indigenous languages were also used when necessary. Interview guides focused on understanding the workflow and activities undertaken by OTLs and CHWs and how the mHealth application supported them in their work. The interviews were transcribed and where necessary translated to English. Activity diagrams were used for visualizing the CHW's workflow (Figure 1). Based on the analysis of the focus group interviews, activities that could be supported through mHealth was identified, and a mapping with the functionality of Mobenzi was performed to further understand how well it supports the current workflow.Qualitative content analysis was used for analyzing the interviews [12]. In this study, we took our starting point in the socio-technical framework proposed by Sittig & Singh [13] focusing on two of the eight dimensions; workflow and clinical content.

3. Results

The analysis of the case study is presented in the form of activity diagrams (Figure 1) with accompanying descriptions of activities that could be supported through mHealth (marked by a symbol in the diagrams). A green star indicates that the studied mHealth solution provides support for this activity, whereas a red circle indicates that it does not. A further description of the marked activities is presented in Table 1.

The activity diagram for CHWs in South Africa was broken down into two parts, where A9 is broken down into sub-activities SA1-SA8.

3.1. Qualitative analysis of the focus group interviews

The South African CHWs were very positive towards the Mobenzi application and said it was very useful to them. They experienced an increase in efficiency, data collection

and entry was faster, and they could do more patient visits when they used it. The application had reminders of which patient to visit and when, which also supported them. According to the CHWs, the application also made their work more tangible and possible to track. They thought Mobenzi helped them feel motivated to do a better job, because they could see their improvements, *"it motivates you to do better and to do more, go an extra mile"*. Mobenzi would also help organizing and structuring the data; *"clients are being categorized in Mobenzi. For the pregnant woman, you found that there is a category for that one with this code, because of Mobenzi, if the woman has already delivered, it will automatically change, there was no need to scroll on the phone and change it"*.

Table 1. Description of CHW's workflow with potential for mHealth support.

Activity	Description	Possible mHealth support	Supported?
A1	The CHW is entering the clinic and registers their attendance	The attendance could be registered in the application which in turn could be integrated with the OTLs' application	Yes
A2	Brings report from previous workday	The report could have been written in the application	
A5	Sometime the OTL and CHW are planning for the CHW to follow during the upcoming week	The week plan could be integrated in the application for the CHW to follow	
A7	Presents campaign for the household. The campaign can have themes such as the usage of condom, encourage to be tested and other health promotions	Instructions for the campaign could be integrated in the application before the presentation	
A8	If there is no campaign, the CHW enters the household on their own	In order for the CHW to be prepared for the visit he/she could read about the household in the application	
A10	Depending if it's a campaign the OTL and CHW leave the household as a team, if not the CHW leaves the household. The CHW can either end their day or enter a new household	Instead of documenting on paper on site or back at the clinic, changes could be edited in the application on site	Yes
SA1	If the household is not registered, the CHW registers it, who lives there, their work, age and other demographic details	This activity is possible to do in the application instead of writing on paper	Yes
SA2	If the household is registered the daily duties is followed by TB screening	The screening could be registered in the application	Yes
SA3	TB screening is followed by HIV screening if there is a new patient	The screening could be registered in the application	Yes
SA4	If the patient has an ongoing treatment adherence support is given. The CHW instructs on how to take treatment and dosage	If the treatment was registered in the application, the CHW could check it and make sure the patient is following the instructions	
SA5	If there is a pregnant patient in the household, she will be registered and educated about healthy eating and the importance of booking visits at the clinic	The pregnancy could be registered in the application and book appointments at the clinic for the patient	Yes
SA6	Antenatal care is encouraged, and post-natal care is provided after the child is born.	The changes in pregnancy and check-ups could be registered in the application	Yes
SA8	If the patient is in need of a referral, the CHW can refer the patient to the right clinic and department	When entering patient data in the application, it will provide a form with yes/no questions	Yes

The CHWs also appreciated the improved confidentiality when using mHealth rather than paper-based documentation; *"sometimes when you let the patient fill out a form, it will be as if the other household members see what this patient is saying in the form. So, if it was captured in the phone, it was much easier to keep the confidentiality"* because, *"each one of us was having a code to get into Mobenzi. I was not able to touch anyone else's Mobenzi. That's how it was confidential"*.

In table 2 below, findings from the focus group with the South African participants regarding the clinical content and human computer interface are presented. Three categories could be identified in this theme; missing functions, user satisfaction, and usability.

Table 2. Findings of clinical content of Mobenzi.

Category	Description	Quote
Missing functions	Referrals to other departments is not supported	*"More icons for the paper referrals, more icons that would include other departments, because we are delivering an integrated service, so we need to have this integration in the Mobenzi as well".*
User satisfactio	The participants are satisfied with the application.	**"***Mobenzi was making our work easy because it was faster than the papers***"**
Usabilit	The participants think the application is making their work more efficient.	*"Mobenzi can you show you your performance" and "for me, Mobenzi was like my additional colleague. In the sense that, it kept me on track with my visit plan. I just follow the guidance. So, it was like my guide, like my adviser, it led me in performing".*

When the participants were asked about what specific functions they miss, they only mentioned one; that they would like to be able to send electronic referrals of patients to not only health clinics, but also other departments, e.g. social services.

4. Discussion and Conclusion

According to the CHWs, they felt their work was more efficient when using Mobenzi. A systematic review about CHWs and mobile technology shows similar results [6]. The CHWs said that they were able to collect data faster, and that they could visit more households during a day when they had Mobenzi. They would also be more effective since Mobenzi reminded them who to visit and when. According to the systematic review [6], there would be less data loss when using mHealth. In this study however, we found that data loss could be one of the issues with Mobenzi. The collected data would sometimes disappear for no reason. We were not able to investigate why this happened, but it is a challenge for the developers to solve. An advantage with mHealth, that the review does not mention but was discussed during the focus group, was that the integrity of patients improved as data was not as easily accessed by non-authorized users in the mHealth tool as it was on paper. Although our results come from one case study, the workflow analysis and suggestions for functions to support the workflow are likely relevant in similar settings. The method of visualizing the workflow and mapping it to functions of the mHealth tool may also be useful to others.

Despite the very positive feedback from the CHWs and the fact that the studied mHealth solution appears to support the majority of the important activities in the CHWs work process, the pilot project was terminated and the mHealth is no longer in use. In the larger research project, further information regarding the implementation and use of the application has been gathered, indicating that financial and strategic decisions led to

the discontinuation of the project. This is a common problem for mHealth and eHealth projects globally, and further stresses the importance of taking all socio-technical dimensions into account when evaluating success or failure of implementation projects.

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Exploring mHealths Fit to Workflow in Homecare – A Case Study in Sweden

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Abstract. With an ageing population and limited resources in healthcare, many high-income countries such as Sweden see an increase in homecare and mobile work for healthcare professionals. In this case study, we explore how mHealth services can support the everyday work for healthcare professionals when delivering home care in rural areas in Sweden. The studied mHealth application had failed to be adopted among district nurses, despite a great expressed need for mobile tools. The results indicate that the mHealth solution did not live up the healthcare professionals' expectations in terms of providing the same functions as the regular electronic health record systems, and with poor integration into the existing eco-system of eHealth applications. In conclusion, in order for a mHealth application to be successfully implemented in a context where many digital services are already in use, it is not enough to support important activities in the current workflow. The mHealth application will need to be carefully integrated into the existing eco-system of healthcare applications to increase the chances of adoption.

Keywords. mHealth, Socio-Technical Systems, Evaluation, Homecare, Workflow

1. Introduction

Globally, healthcare systems are facing similar challenges and a great pressure to perform alongside limited budgets and shortage of staff. eHealth has an enormous potential to facilitate the work for healthcare professionals. The increased use of tablets and smartphones improve opportunities for mobile technologies, also in healthcare. Despite all these opportunities, the everyday life of healthcare professionals in Sweden is filled with outdated systems that are more frustrating than supportive [1]. New mobile technologies are developed and implemented to support clinicians in their daily workflow, yet the failure rate is still high.

To improve design and implementation of mHealth to support homecare in rural areas in the future, we need an in-depth understanding of the factors that impact the success or failure of mHealth interventions. Today, there is a lack of empirical evidence of effectiveness when implementing mHealth services in rural homecare [2]. Often, the focus of evaluation of mHealth is on technical aspects of the systems. As mHealth

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interventions can be classified as complex socio-technical systems [3], it is important to consider also other aspects when evaluating mHealth.

Healthcare is to a large extent computerized in Sweden today, and information and communication technology, such as medical records, is used in everyday care. Most of the county councils and regions use one medical record system throughout hospitals, primary care and psychiatric care, which means the patient records are available in the entire county council. Private healthcare providers may use different systems which means the information access is limited, even though many county councils have an agreement with private actors, which allows information exchange [4]. The use of smartphones and tablets in healthcare is increasing and has the potential to improve workflow and access to information. Currently, seven (out of 20) county councils have strategies for the use of tablets, and they also use tablets in care-providing activities (e.g. to provide mobile access to medical records). The extent of implementation of mHealth solutions in homecare within these seven regions is however not known. Five county councils have strategies for the use of smartphones [4]. The use of mobile devices in homecare has increased in the municipalities as well. In 17 % of the municipalities, the health care staff have the possibility to read and write information using mobile device, compared to 5 % in 2015 and 11 % in 2016 [5].

This study aims to explore how mHealth services can support the everyday work for healthcare professionals when delivering home care in rural areas in Sweden. This study is part of the research project MobEval, a collaboration between Karolinska Institutet and Uppsala University, Sweden, and University of South Africa in Pretoria. The purpose of the project is to study different mHealth tools used in both countries, and try to exchange experiences, possible challenges and lessons from each other, to evaluate and possibly improve mHealth tools, and how they contribute to health care delivery.

2. Methods

A case study was performed, focusing on the implementation of a specific mHealth service intended to support district nurses in Sweden when delivering home care for patients in rural areas. The focus was on mapping their current workflow and investigate where and when healthcare professionals can be supported by mHealth services, and how well the implemented solution provided this support.

2.1. Setting and participants

"Hälsa På Plats" (HäPP) is a mobile application for tablets and is not tied to a specific medical record or supplier, but is built on established standards for information management within healthcare in Sweden [6]. The application is based on the "national service platform for information exchange", which is an online, virtual service and allows for information exchange between different systems used in health care [7]. The purpose of the service is interoperability, and for different systems to communicate with each other, regardless of which developer or technical solution they have [7]. The application was developed for clinicians working in primary care and homecare. Today, the mobile application HäPP is implemented in a municipality north of Stockholm. The area is partly located in the archipelago and countryside, which means the Internet/4G/5G network connection cannot be trusted. The functions of HäPP include access to the patients' medical records, which means reading and documenting in the records. The

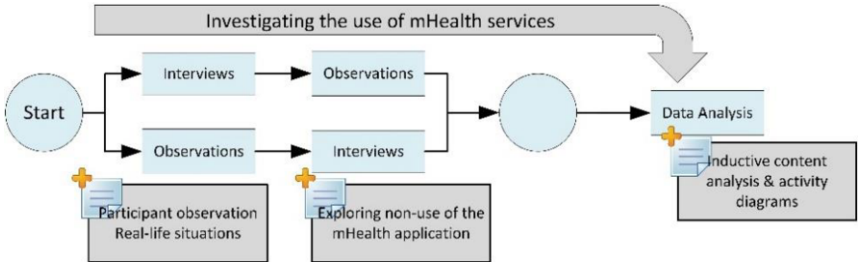

Figure 1. Study design.

patients' list of diagnoses is available, as well as certain lab results. The user can also create their own lists of patients, including the patient name unique identifier. There is a map function where the user can see where they and their co-workers are.

Participants in the case study were recruited using a convenience sampling strategy [8]. A total of seven healthcare professionals participated in the study. Five healthcare professionals were both observed and interviewed. To keep the anonymity, age, gender and workplace are not disclosed. More information about the participants can be found in Table 1.

Table 1. Overview over all participants.

Participant	Observation	Interview
1 district nurse	3 accommodations	One
2 district nurses, 1 physician	3 home visits	One
2 district nurses	-	One with both
1 district nurse	2 accommodations	One

2.2. Data collection and analysis

Two different qualitative data collection methods were used; observations and interviews. The participants were observed in their natural working environment. The aim of the observations was to obtain a clear understanding of the workflow. Interviews were also held with all participants in Sweden, in connection with the observations (Figure 1). The aim was to get in-depth knowledge of why the mobile service is not used. Ideally, interviews were to be held after the observations but for practical reasons the interview was sometimes held before the observation. The interview questions were developed by a team of researchers with both medical and technical background. The interviews were held face-to-face with the participants.

Activity diagrams were used for visualizing the healthcare professionals' workflow (Figure 2). Based on the analysis of observations and interviews, activities that could be supported through mHealth were identified, and a mapping with the functionality of HäPP was performed to further understand how well it supported the current workflow.

Qualitative content analysis was used for analyzing the interviews [9]. The first step of qualitative content analysis is to divide the text into meaning units; words, sentences or paragraphs that relate through their content and context. The meaning units are categorized into groups of common content. In this study, we took our starting point in the socio-technical framework proposed by Sittig & Singh [10] focusing on two of the eight dimensions they propose; workflow and clinical content.

The study has an ethical approval in Sweden by the Stockholm Ethical Review Board (2015/1457-31/5).

3. Results

The analysis of the case study is presented in the form of an activity diagram (Figure 2) with accompanying descriptions of activities that could be supported through mHealth. In the diagrams, a green star indicates that the studied mHealth solution provides support for this activity, whereas a red circle indicates that it does not. Further descriptions of the marked activities are presented in Table 2.

Table 2. Description of workflow with potential for mHealth support.

	Description of the activity	Possible mHealth support
A2	Print a to-do list of all patient visits during the day from ordinary medical record system	The list of patient visit does not necessarily need to be printed. The list can be provided in an electronic format through a mHealth service.
A4	A daily activity is to make calls to different persons to co-ordinate work and activities.	An asynchronous chat function provided in the mHealth service could make the communication more efficient. However, the purpose is not to replace phone calls
A6	If a physician is participating during the home visit, the district nurse will print the patient's measurement values for the physician, since the measurements are in the district nurse's system	This is an interoperability problem, because the district nurse's and physician's systems are not integrated. The measurements do not necessarily need to be printed, but could be accessible in a mHealth service
A7	All printed materials are put in a folder. The rest of the materials are put in a nurse bag	The printed materials could be supported by a mHealth service
A8	The patient is notified in advanced that the healthcare professionals are coming	It is possible that this activity can be supported by a mHealth service, although it must be integrated to a mHealth service for the patient.
A10	A GPS can be used to navigate.	The GPS is provided in the mHealth device
A11	The healthcare professional registers their visit by scanning through the IntraPhone	This is already supported by a mHealth service called IntraPhone, which is however not integrated with HäPP
A13	If it is a sheltered housing, the district nurse enters all apartments to check the signatures made when medications are administered, to ensure adherence to the treatments	The list of signatures could be provided in electronic format
A14	Notes are made on the papers that were printed at the hospital	The medical records could be accessed through a mHealth service
A17	All patient visits must be documented in the medical record system. The administrative work is scheduled to take approximately one hour	Function is provided in HäPP, but due to technical issues it has not been used. A mHealth service could make it possible to document on-site.

A district nurse working with the sheltered housing/nursing home for special needs patients makes approximately 1-4 visits a day. These visits are usually routine, and the same tasks are carried out. A district nurse usually works from 8 am to 5pm.

3.1. Qualitative analysis related to workflow and clinical content

During the observations, it was noted that the Swedish health care workers did not use the HäPP application. During the interviews, they were asked if they had used the HäPP application or not. All of them said that they had tested it, but that they do not use it. When they were asked about the reason why, they said that the application is not adapted

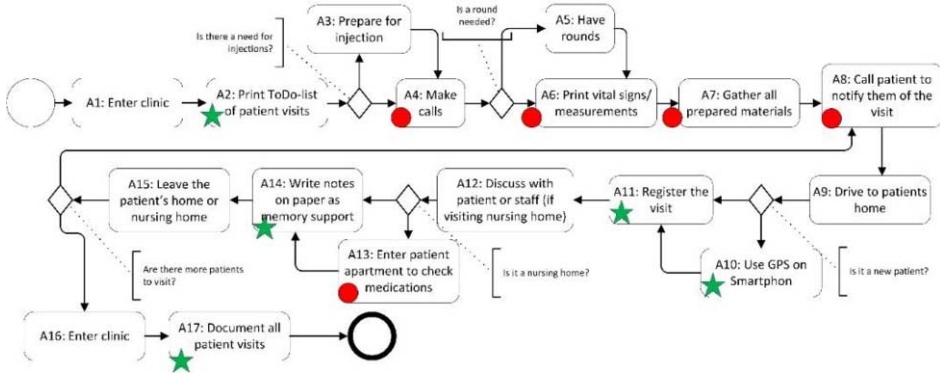

Figure 2. Workflow of healthcare professionals in rural homecare.

to their workflow. All participants mentioned this as the major reason. In table 3 below, findings from the interviews regarding the clinical content are presented.

Table 3. Findings related to clinical content of HäPP.

Category	Description	Quote
User satisfaction	The participants are not satisfied with the application.	*"Isn't adapted to the way we work"*
Interface	The participants are positive towards the application, and think it is easy to use.	*"Easy to use and simplified compared to the medical record system".*
Missing functions	The application lacks main functions from the ordinary medical record system that the health care workers need.	*"The most important functions are not there"*
Usability	The participants mentioned that the application is not adapted to their workflow.	*"Very few things were usable to us, unfortunately".*

4. Discussion and Conclusion

Without a mHealth service, paper and pen were used as the most common tool. The healthcare professionals find it insufficient; much of the work is spent on paperwork related tasks, it can be lost, missing or destroyed. The information stays local and takes longer to transfer. Despite a well-developed infrastructure, Sweden faces challenges of bad network connection in rural areas such as in the case study presented here. The healthcare professionals were handed the mHealth services with limited user-involvement or plan that reached further than the pilot-phase. The mHealth solution failed to support the most important activities in the homecare workflow, which was described as one of the most important reasons for the low adoption among the healthcare professionals. An improved communication tool was also described as important. As a district nurse within home care in Sweden, one is quite alone and in need of communication with other healthcare providers. Also, because of the healthcare system's structure in Sweden, several healthcare providers need to share information about a patient, for example change of medication [11]. This is an interoperability issue that is well-known in healthcare. When introducing a new mHealth service in a context such as the Swedish, where many digital tools, such as medical record systems, are already in use, it is essential that the application is integrated with the systems currently in use. Therefore, the national health information exchange platform was used, however in this

case not all relevant systems were able to share information. In such a context, the new application risks being yet another system – increasing the risk for non-adoption.

In conclusion, for a mHealth application to be successfully implemented in a context where many digital services are already in use, it is not enough to support important activities in the current workflow. The mHealth application will need to be carefully integrated into the existing eco-system of healthcare applications to increase the chances of adoption.

Acknowledgement

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Towards Sustainable EHR

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Context Sensitive Health Informatics: Sustainability in Dynamic Ecosystems
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Sustainable Information Infrastructures: Insights from a Realist Synthesis

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Abstract. Policy makers and health system managers in many countries are advocating the deployment of inter-operable health information technology systems, spanning organisations in a health economy, believing that they will be clinically effective. The case for investments has not, however, been made to date. This paper presents early results from a systematic review of the effects of inter-operable systems on patient safety. The review uses the realist synthesis method, which focuses on evidence about the decisions and actions that link interventions and outcomes, as well as the evidence about those outcomes. The evidence base is sufficient to identify plausible arguments for investments in inter-operable systems. This said, there is limited empirical evidence about each of the steps in the sequences of events. We comment on implications for the design of sustainable socio-technical solutions. We suggest that current gaps in the evidence base are in areas where informatics field methods can make a valuable contribution to our understanding of the role of inter-operable systems in patient safety.

Keywords. Interoperable, health information technology, patient safety, realist synthesis

1. Introduction

Governments and health system managers in many countries are funding inter-operable health information technology (HIT) systems [1, 2]. They believe that clinicians need access to the whole of a patient's record, particularly when that patient has complex needs and is supported by several professionals. It is therefore necessary, they reason, to deploy inter-operable systems across all organisations in a health economy. While the argument is intuitively reasonable, though, the case for inter-operable HIT systems has not yet been made. This paper seeks to establish whether a case can be made, and if it can, what evidence is available to support it.

If everyone agreed on the way forward, and was convinced of the value of inter-operable HITs, this might not matter. In practice, though, influential clinicians have recently drawn attention to the practical difficulties that they face in the course of their work [3, 4]. The case does, therefore, need to be made.

The need, then, is for a review method that 'opens the black box', and reveals on the sequences of decisions and actions that lie between the use of an inter-operable HIT and substantive outcomes, as well as establishing the nature and value of those outcomes. We present the early findings of a systematic literature review, using the realist synthesis

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method, which focuses on the effects of inter-operable HIT systems on patient safety. The IEEE defines inter-operability as the ability of two or more systems or components to exchange information and to use the information that has been exchanged [5]. In this review we focused on foundational and structural deployments that are more common in practice: more evidence is available about them, and findings will be relevant to the majority of current practitioners [6].

2. Methods

Realist synthesis involves, first, identifying programme theories [7]. These are sequences of decisions and actions that link an intervention to an outcome, and thus capture the *intended* effects of the intervention. Attention is also paid to policy makers, researchers and others' theories about the intervention. The review team use their theories to develop their own accounts both of how *and why* the intervention might work in a particular way. Literature searches are then designed, and empirical evidence identified, assessed and synthesised, to evaluate the extent of evidence for *actual* sequences of decisions and actions. The evidence might lead to a particular programme theory being supported, rejected, or to being refined. Realist syntheses therefore address both components of a business case, empirical evidence and closely reasoned argument.

The five stage of a realist synthesis is described in detail by Pawson in *Evidence-based Policy* [7]. Stage 1 of the review involves developing programme theories (see Figure 1). There were two elements to the research in this Stage. Three literature searches were undertaken, using Medline, Embase and other electronic resources:

(1) Systematic reviews that included insights into the relationships between inter-operable HIT systems and patient safety;
(2) Search for policy documents, opinion pieces (e.g. editorials) and reports describing leading theories about the relationships between HIT systems and patient safety;
(3) Author searches for articles by David Bates, the most cited author in the health informatics literature, and Robert Wachter, the author of an influential 2016 report on IT in the NHS in England.

The search findings were used to develop initial programme theories.

2.1. Nominal Group Meetings

The second element of Stage 1 comprised nominal group meetings with each of two groups of stakeholders, namely senior health and care service IT managers and policy makers. The nominal group technique involves an initial meeting, where initial agreement on a topic of interest is reached. This is followed by one or two rounds of email consultation, to allow participants to reflect on the initial agreement, and if necessary refine it [8]. In this review participants were invited to comment critically on the initial programme theories, on the basis of their knowledge and experience. They were also asked to prioritise theories, and/or particular sequences of events within theories, for further study. Following these meetings, and consultation with the study patient and public involvement group, decisions were made about the focus of the evidence searches in subsequent Stages.

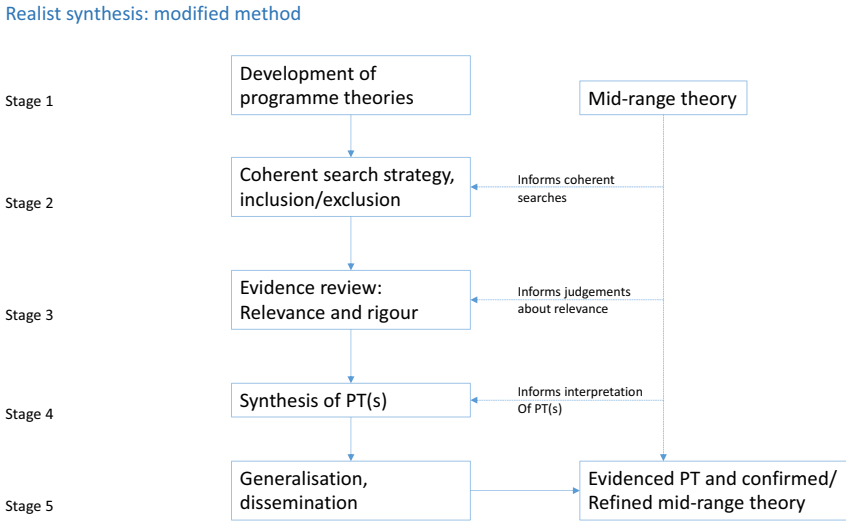

Figure 1. Stages of the realist synthesis (PT = programme theory).

2.2. Mid-Range Theory

Mid-range theories are more general forms of programme theories, which typically capture the way in which an intervention works across a number of settings, e.g. how a telehealth application works in a range of specialties, for different groups of patients, and in different countries [9]. They perform an integrating function in the course of a realist synthesis. As Figure 1 shows, they provide an explicit basis for methodological judgements in Stages 2-4. By their nature, realist syntheses deal mainly with observational evidence, typically drawn from studies undertaken in a number of different academic traditions (e.g. ethnography, cognitive psychology, organization studies). A mid-range theory was identified, which provided a broad theoretical framework for interpretation of evidence from the traditions covered in the review.

2.3. Evidence Search, Selection and Synthesis

Stages 2, 3 and 4 are designed to establish the sequence of events that lead to *actual* effects of inter-operable HIT systems: evidence is identified in literature searches, and used to evaluate the intended effects. Stage 2 comprises the main literature searches. Search PICOS – populations, interventions, comparators, outcomes and settings – were determined. Inclusion and exclusion criteria were agreed within the team, the searches undertaken, and included papers identified on the basis of titles and abstracts. Stage 3 involved close reading of the included papers, which were assessed for rigour and relevance. Papers were excluded at this Stage if it became clear that they were not relevant. In Stage 4 the findings from the included/relevant papers were synthesised, drawing on the mid-range theory as the theoretical basis for interpretation. The syntheses led to refinement of the initial programme theory.

Two sets of searches were undertaken, one focusing on the co-ordination of health and care services in general, and the other on a specific co-ordination challenge, medicine

reconciliation, where a patient is prescribed by more than one professional. Each set involved a number of literature searches, which together were designed to evaluate key steps in the programme theory, and reveal both how and why inter-operable HIT systems were effective (or ineffective). For care co-ordination, reported here, the searches were designed to address three questions:

(1) What is the nature of the care co-ordination problem? Are the problems of a kind that inter-operable HIT systems can help to solve – or not?
(2) What are the experiences of health and care professionals searching for information about patients in one anothers' systems?
(3) What are the effects of inter-operable HIT systems on patients' clinical risks?

3. Results

In Stage 1, we did not find any published, plausible, sequence of events linking the use of inter-operable HITs to patient outcomes. The searches did, though, yield a number of theory fragments, and we used these to construct three initial programme theories. Consultation with the nominal groups led us to focus on a specific domain, namely the treatment and care for frail older people living in their own homes. The consultation also prompted us to focus on evidence about functional HIT systems. The argument was two-fold. First, we should find relevant evidence about current systems, but relatively little about semantically inter-operable systems. Second, policy makers' and practitioners' immediate need was to identify convincing business cases for their current systems. The battle for hearts and minds in the broader health and care system was not yet won.

We also settled on a mid-range theory, which located the synthesis in the literature on information infrastructures [10]. The first statement of the mid-range theory was:

> *Older people with complex needs are supported by care professionals who have different backgrounds and training, and who often work in different organisations. Networked IT systems in health and care settings are embryonic information infrastructures, which over time are likely to become more inter-operable (in the sense that an engineer would use that term). Information infrastructures span a number of professionals and organisations. The long-run intention is that professionals will integrate the use of the IT systems into their work, so that they effectively become invisible. When infrastructures become invisible, they contribute to overcoming co-ordination challenges that naturally arise in these institutional arrangements. The resulting improvements in the effectiveness of co-ordination will, in turn, lead to reductions in patients' risks.*

At the time of writing we have completed three searches on each of two topics, care co-ordination and medication reconciliation, for older people living at home. The full search results, and synthesis, will be presented at CSHI 2019.

We comment here on the three care co-ordination searches. In the first search we found substantive evidence about the nature and extent of care co-ordination problems. Most of the problems were essentially social or cultural in nature. For example, there were several evidenced-based reports of difficulties due to different healthcare professionals having incompatible working assumptions about the kinds of support that older people needed. There was no obvious role for any HIT solution in most of these problems [11].

One problem, though, might be addressed using inter-operable HIT systems. This concerned difficulties associated with information seeking and retrieval, and the second set of searches focused on this question. A number of observational studies were identified, which reported a range of problems with information search and retrieval. The problems were attributed to inter-professional issues – not directly related to technology – as well characteristics of the technologies (such as multiple log-ons) and locating patient information held on other organisations' servers. We did not find any countervailing studies, which reported 'seamless' use of inter-operable HITs [12].

The third search focused on evidence of effectiveness – in this study, in measurable changes in risks to patient safety. We found very limited evidence relating to services for older people, and little more for services for adults more generally [13,14].

4. Discussion

The findings of the first Stage of the review indicate that no complete sequences of events have been published, that might plausibly represent the link between the use of inter-operable HIT systems and effects on patient safety. It is always difficult to 'prove a negative', but we conducted a number of different searches, using different databases, search themes and methods.

This said, we believe that it is possible to identify the outline structure of cases for inter-operable systems in health economies. Our main finding is that, currently, there is limited empirical evidence to support programme theories, particularly in relation to the effects of using HITs on patient level changes in risks. We suggest that this opens up a significant research and development agenda.

The early findings enable us to identify three broad strategic outcomes of current policies. One is the ideal sustainable outcome, where inter-operable systems are deeply embedded in everyday working practices. We have not found evidence for this outcome. The second might be termed 'sustainable but ineffective', or 'frustration with technology': systems fit poorly with working practices, but clinicians have little choice but to use them. There is empirical support for this outcome. A third outcome is failure to deploy, which we have not investigated in this review, but which other studies remind us is a possibility.

The question that follows is: can we explain the current evidence? Wachter, Gawande and others argue that current technology solutions are simply not very good. Our findings offer indirect support for this position. We favour a slightly different explanation, though, which has two related components. The first concerns the design and deployment of systems. Inter-operable systems are, by definition, developed on the basis that can help to solve a systemic co-ordination – or collective action – problem. If the ways in which HITs will help to solve these problems are not addressed in the course of the design and deployment, the scope for an inter-operable system to contribute to safer care must be limited. If experiences in England are at all representative, information technology policy making tends to focus on defining data and communication standards, and on the broad direction of IT developments. They do not consider, in any detail, the ways in which those technologies might produce safer care (or any other desirable outcome).

The second component concerns the need to address social and cultural issues in parallel with design and deployment. If, for example, responsibilities for the reconciliation of medication lists, and of medication lists with patients' symptoms, are

not clear in the first place, the extent to which any inter-operable solution can – by itself - lead to safer care will again be limited.

Finally, we suggest that the gaps in the evidence base are in areas where informatics methods can make a valuable contribution. The most obvious need is to understand the roles and responsibilities of health and care professionals, and the information flows involved. A research programme could draw on responsibility modelling, ethnographic studies of information flows and other methods to characterize these important socio-technical challenges.

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Context Sensitive Health Informatics: Sustainability in Dynamic Ecosystems
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Context and Meaning in EHR Displays

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Abstract. Many Electronic Health Record (EHRs) data displays are insensitive to their settings, contexts, and to clinicians' needs. Yet, the contexts in which the data are displayed critically affect EHR usability and patient safety. Medication prescribing is a complex task; especially sensitive to contextual variation in EHR displays as vast variations in formats and logic are often unnecessarily confusing, leading to unwanted cognitive burdens and medical errors. With examples of EHR screenshots, we illustrate contextual variations in medication and allergy displays across different EHR systems and implementations—noting often seemingly haphazard differences that can lead to misunderstandings and misinterpretations.

Keywords. Electronic health records, Data display, Medical errors, Context

1. Introduction

Context affects users' perceptions and understandings of data in health information technology (HIT) [1]. Among the models of relationships between context and HIT are the Context Implementation Model (CIM) that looks at the fit of HIT within individual, clinical and organizational contexts [2]. Other models have looked at specific contexts of HIT usage, i.e., primary care or pediatrics [3]. While these models help understand the relationship between context and HIT, we seek to examine contextual variability *across* different HITs and HIT implementations. Modern healthcare delivery requires connectivity across settings and clinicians, often requiring providers access to multiple systems. [4]. This multiplicity and variation create a contextual diversity that generate usability and other human computer interaction (HCI) issues because of differences in how data in different systems are accessed or displayed [5]. Unfortunately, the contextual aspects of EHR implementations have received insufficient attention.

Medication prescribing errors are a major cause of medical errors [6]. Although HIT has mitigated some errors it has also led to new categories of errors called Technology Induced Errors (TIE) [7]. We suggest that differences in EHR displays across different systems can lead to TIEs because of contextual variations in information presentations.

To date, contextual variations across different EHR systems have not been studied. In this paper, we address that issue by examining contextual variations across EHRs, offering differing systems' examples of medication displays. We indicate how these differences may lead to misunderstandings and misinterpretations that could be

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precursors to medication errors. We also provide guidance for how system designers can better account for cross-setting EHR variation in the design and implementation of HIT.

2. Methods

Drawing on previous studies, we examined the contexts within which different EHRs display: 1. drug names, dosages, formulations, routes and schedules; 2. problem lists; and 3. allergy lists. We analyzed the different ways EHRs display these data, and how patient safety dangers are linked to the widely disparate EHR visualizations across and within vendors, versions, implementations, and local information technology (IT) teams.

3. Results

The screenshots reflect the variations in EHR displays--revealing ways of providing information that are sensitive (or insensitive) to clinical contexts.

Problem Lists: The three problem lists in Figure 1 illustrate contextual issues in EHRs that can generate different perceptions and prompt clinicians to ignore or misunderstand critical information. The list in Figure 1a is in strict alphabetical order, while the list in Figure 1b appears to differentiate chronic and acute conditions, and also provides a date stamp. Figure 1c (right) is separated by actively managed problems vs. inactive ones, i.e., clinical priorities are on top. It also adds time stamps, diagnostic and prognostic notes, laboratory metadata, and counts for allergies and medications (both inpatient and home).

Medication Lists: Figure 2 illustrates differences in how drugs are displayed in simple medication lists vs. in the medication administration record (MAR). Figure 2a (top left), is in reverse chronological order and includes dosage, schedule and route of administration. Figure 2b (top right) is the MAR in alphabetical order and extends horizontally to allow documenting time and date of administration. It is unclear if this list includes medications for the entire admission or just for the timeframe shown in the MAR. Within the MAR, nursing administration instructions are included. Figure 2b also reflects duplicate medications (see both chewable and tablet 81 mg aspirin), with the comforting display that the patient was not double dosed (i.e., only received one of the aspirins). Figure 2c (bottom image) is also alphabetical but does not reflect which of the several duplicate medications was (or, were) administered to the patient. The formats of these medications lists – within and outside of the MAR - are correspondingly different, but some of the differences lead to confusion, e.g., the MAR presents duplicates without any visual cue that one is viewing the same medication and whether it were ordered at a different time from its counterpart. The bottom image combines inpatient and ambulatory medications. In fact, this EHR varies significantly in how medications are displayed: some show medications from all encounters, while some show only the current encounter. In many instances (unlike this bottom view) one cannot tell that they are from different encounters. Worse, when these lists are transferred to other systems, it includes all encounters without clearly identifiable information about which encounter each medication is from. This can result in display errors in the receiving system. Note also that the medication list shows medication names including the concentration data or dispensed dosage form, however these can often differ from the actual dose ordered. This

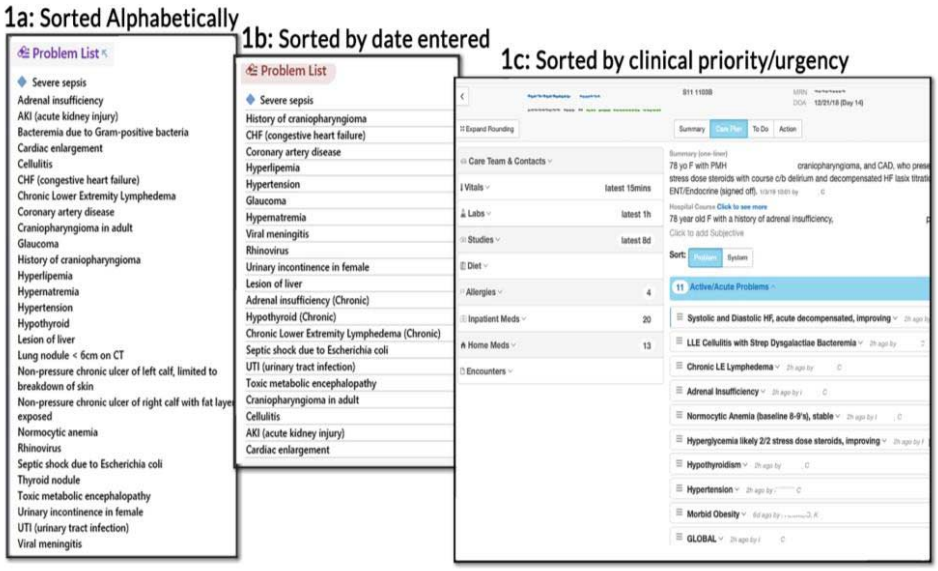

Figure 1 (a-c). Variation in problem lists displays.

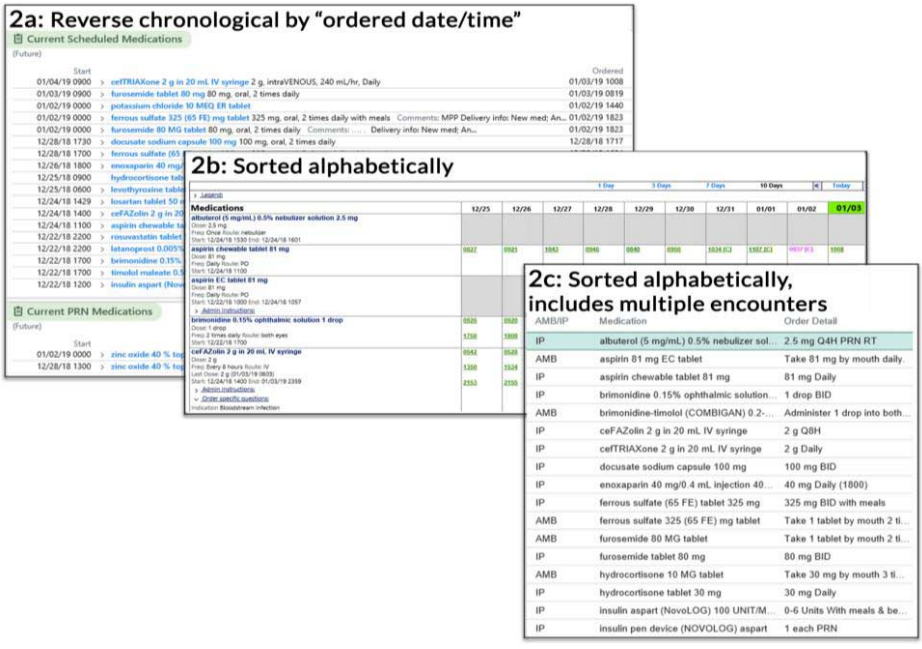

Figure 2 (a-c). Formatting differences in medication lists.

can be very confusing to providers, as some views do not show how the ordered dose is different from the strength reflected in the medication's name.

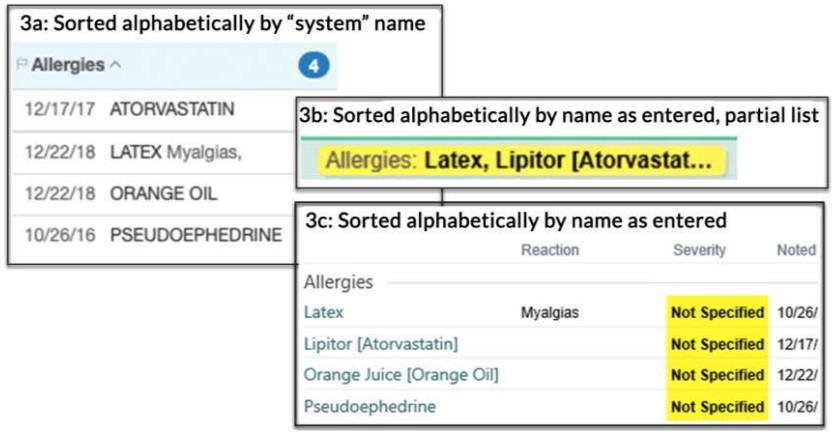

Figure 3 (a-c). Display differences for allergies.

Allergy Lists: Figure 3 displays allergy lists. Figure 3a (top left) lists allergies by the date they were entered into the EHR. Here, drugs are listed by their generic names. Figure 3b shows the first two items with the second followed by a "…" to indicate there are more allergies. If clinicians miss this ellipsis they may not realize there are many more allergies. Note also that Atorvastatin includes its brand name, which may be helpful if the list is also accessed by lay users. But this is not consistent for all medications. Figure 3c (bottom image) lists drugs in inconsistent formats, e.g., sometimes both brand and generic names are included. For example, none of Pseudoephedrine's many brand names (e.g., Sudafed) are displayed. In contrast, the allergy to "orange oil" is also listed as orange juice, which is probably how lay audiences understand it, and perhaps how it was entered into the EHR. Figure 3a also shows the option for listing allergy severity reactions, which is unpopulated in this example.

4. Discussion

We illustrate how differing EHR display contexts can affect clinicians' understanding and actions—often exacerbating patient safety dangers generated by the vastly different digital systems across the continuum of care. Undoubtedly, each format was created to address specific needs, even if the formats, and sometimes their juxtapositions, are vestigial remains that make little sense now. However, the plethora of data display configurations causes cognitive overload requiring each provider to mentally reconfigure different displays. Nevertheless, imposing a single display format or standard would be counter-productive and probably lead to more technology induced errors and other unintended consequences. Instead, we urge a context sensitive solution where HIT vendors, implementers, and users are obliged to systematically investigate the hundreds of ways information is presented in each of the relevant settings. They should seek common ground on EHR displays to reduce cognitive burdens, eliminate arbitrary surprises, and simplify visualization choices.

Designers should also consider the contextual reality of *why* information is being displayed and the significance behind the choices. Such a plan is straightforward: develop a matrix of users and settings, and then investigate the relevant display needs of

each combination. In this way, the solution to context insensitive EHRs is to examine the needs of the users in each context. This paper also emphasizes the need to consider both the semantics and the structure of how data fields are designed. While formal terminologies (e.g., SNOMED) can help with semantics, our findings suggest that we also need to pay attention to the way data fields are structured, (e.g., ordered alphabetically or by disease condition). Terminology and structure can both impact EHR usability.

The next step would be to develop responsive and coherent formats for each user that encourages intuitive comprehension appropriate to each setting and set of clinicians. Variations will still be pandemic, but we would be able to proactively identify the worst offenders to better design HIT displays to be contextually responsive. Mapping our findings to existing patient safety frameworks is also a next step.

5. Conclusion

Often the same data in EHRs are presented in vastly different arrangements, formats, linkages and sequences. Undoubtedly, there were once logical choices associated with each presentation, but with the multiplicity of screens, users and settings, it appears many displays are no longer logically connected to their relevant contexts-leading to significant confusion and misinterpretation. Such context-free arrangements should be reconfigured to reduce medical errors, and foster patient safety.

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Educational Electronic Health Records at the University of Victoria: Challenges, Recommendations and Lessons Learned

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Abstract. There has been an acknowledged need for the integration of health technologies such as the electronic health record system (EHR) into health professional education. At the University of Victoria we have been experimenting with different models, architectures and applications of educational EHRs in the context of training health informatics, medical, and nursing students who will ultimately use this technology in their daily practice upon graduation. Our initial work involved the development of a Web-based portal that contained a number of open source EHRs and is described in this paper. In addition to the technical side, considerations around pedagogy and how best to integrate such technology into the classroom and educational experience are discussed. Finally, challenges and lessons learned from our decade of work in this area are discussed.

Keywords. Electronic health record, education, physicians, nurses, health informatics

1. Introduction

Electronic health records (EHRs) are a ubiquitous technology in a modern health care system. From clinic offices, to hospitals, to a patient's home, EHRs are used to document patient data and support health care processes and health professionals' decision making. Yet, even as this technology has become available in most health care settings around the world, more work is needed to fully develop robust educational EHRs to support the development of digital competencies in a modern health care system. Educational EHRs are electronic records that are designed to support educators and students in their learning about how to manage a patient's health and disease. Educational EHRs also help students to learn about entering patient data, alerts, reminders and clinical decision support systems that can include links to the latest evidence based research. Such systems are designed to educate students in the technologies they will be using upon graduation in real health care settings by allowing students to access and work with the technology in an educational context [1]. In this paper, the authors outline their experiences over the past 10 years in the design, development, implementation and pilot testing of educational EHRs accessible via an EHR portal on the WWW with physician, nurse and health informatics students.

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2. Overall Architecture

Our initial work in deploying EHRs for education involved setting up a web portal that would allow for remote access to several different EHRs housed on computer servers at the University of Victoria [1, 2]. This involved three layers, including: a remote access layer, a middle firewall layer and EHR network layers, which hosted several systems and databases on our servers. Users of the initial system logged in on a remote desktop (using either PC or Mac computers). They could then select from several EHRs that are currently being used in hospital and community settings (including Open Vista, OpenMRS and POND4Kids) that run on a range of operating systems using virtual machine technology. The approach allowed for up to several hundred users (e.g. students and instructors) to simultaneously access hosted EHRs and related software from virtually any location in Canada or internationally [1, 2]. Since our initial deployment, we have been working on a new architecture to scale up to more EHRs and to lead to a sustainable platform (as will be discussed in a subsequent section of this paper). It was found that the approach to hosting educational EHRs on a centralized server mitigates the need for multiple sites or institutions to have to set up their own servers, removing complexity and cost for hosting and managing educational EHRs [1-3].

3. Development of a Portal and Access to Specific Electronic Health Records

Over the course of a lifetime, health professionals and health information technology professionals will work with many different EHRs and differing versions of the same EHR [1]. For these reasons, our work initially focused on identifying both open source and commercial EHRs that are typical in terms of the features and functions of those encountered in everyday work in differing health care settings [1]. This work began with identifying EHRs found to be the gold standard in design, function and ability to effect improved patient outcomes such as the Veteran's Affairs Vista system [1,5]. The Veteran's Affairs Vista system was identified as a core candidate EHR system for its user interface and fully functional decision support tools (e.g. drug-drug interaction checking) [1, 2, 5]. Followed by EHRs that have been developed for specific purposes such as a Pediatric EHR, a personal health record and a commonly utilized, and easily extensible, EHR – OpenMRS. Our choice of records was based on pedagogical reasons so that students would have the opportunity to engage with fully functional records [1]. Some students have limited exposure to EHRs in their training due to a lack of availability of an EHR in a classroom setting and/or the local regional health authority. Other students have access to a hybrid paper-electronic health record in their local health authority setting [3-6]. Here, the record may only provide access to specific components of a patient's record; for example, laboratory results, diagnostic imaging results, clinical documentation and medication information [6]. Some components of the EHR may be in the process of being implemented and may not be readily available such as ePrescribing and/or other decision support tools [6, 7]. For this reason, there is a need to provide students with the opportunity to access a fully operational EHR that has been successfully used and implemented [1]. In one pilot of this work, we provided access to OpenVista to nursing students as part of a classroom exercise. The students were provided access to OpenVista via the portal. Students were asked to interact with the record (that included artificial, simulated patient cases) and complete readings. Artificial patient cases (i.e. dummy data) were used so issues around patient privacy and

confidentiality did not arise. In class, a presentation was provided to students about the EHR and its use in a modern healthcare system. During a classroom exercise a case study approach involving student group work and faculty facilitation enabled students' to identify the benefits and challenges of using an EHR. Students' described the interaction between the technology's design, nurse's work and its influences on patient communication and care. Students adapted to the use of the EHR, identifying the need to be able to use the technology in the classroom and then the workplace setting [1, 4].

4. Development of an Educational EHR Simulator

In an extension of this work, we developed an EHR simulator. The simulator is a fully robust EHR that provides access to a real-world EHR with all the features, functions and decision support tools present in a typical EHR. Unlike a traditional EHR, the EHR simulator, afforded faculty the opportunity to incorporate simulated educational cases into the EHR that could be used to stimulate critical thinking and problem solving, much as would be done when a health professional was presented with information about a patient over time as laboratory and diagnostic test results are completed. Rather than reading a case, as was historically done in the context of a problem based medical curriculum, medical students were presented with an initial lecture and access to an EHR, where patient information was presented as would be typically provided during a typical hospital stay. During the course of a week, students were provided with additional information about the patient's condition in the form of diagnostic and laboratory test information as well as information provided through consult reports (much as information would be made available over time as tests are completed and results are provided). The information provided via the EHR was integrated with standard lectures about chronic illness and disease. Each day the instructor was able to discuss the patient case and information made available via the EHR with the students face to face in a classroom setting. Students were able to interact with the patient case via the EHR. Students were also able to prescribe medications, order laboratory and diagnostic tests, document patient information and interact with decision support tools to support medical decision making. The EHR afforded students and faculty the opportunity to interact via an EHR and to review students' decisions in the context of hypothetical patients' whose medical conditions evolve over the course of a week. Medical students participated in medical lectures and engaged with the EHR and a patient case – the EHR added a dynamic element to the medical decision-making component [8]. Students identified that the EHR could support physician work, and there was a need to test out several differing types of EHRs to determine their ability to fully interface with their own clinic workflows. The students' positively evaluated the technology's use in the classroom. The students rated the educational sessions highly and suggested that more classroom work be done on EHR integration into a medical office as well as critiquing the technology. Lastly, students wanted exposure to more than one EHR over the course of a 4-year medical curriculum to familiarize themselves with EHRs used provincially [9].

5. Loose versus Tight Coupling of EHRs in a Health Professional Curriculum

In the above two pilots, the authors discovered that introducing EHRs into a health professional curriculum, can be done on a continuum from "loose coupling" to "tight

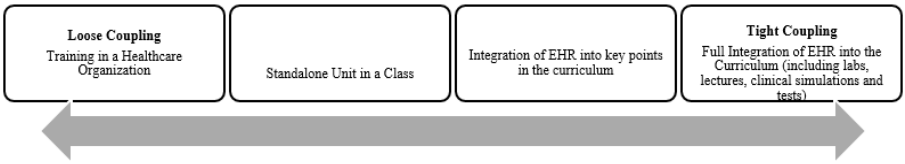

Figure 1. From loose to tight coupling.

coupling" (see Figure 1 below). In loose coupling curricular approaches, the EHR is introduced as a stand-alone artifact at differing points in time in a typical four year medical or nursing curriculum. The technology is used as an example of how the EHR can be used to support patient care. In a tight coupling curricular approach, the EHR is used to present materials in the context of a curriculum and becomes the dominant technology (much as the EHR is the primary tool used to support critical aspects of patient care). All patient teaching cases and links to educational materials and resources can be found in the EHR. The EHR becomes part of teaching in the classroom [10].

Both approaches have their advantages and disadvantages. The loosely coupled approach allows for student and faculty exploration of a technology or the integration of several differing technologies. Work must be done by instructors to determine how the technology can be used to illustrate concepts and content taught in the classroom. In a tight coupling approach the technology is a tool that the instructor and student use to educate and to acquire knowledge respectively; for example, the EHR becomes an educational tool and a tool that is used to support work [10].

6. Beyond the Electronic Health Record: Design, Development and Implementation

To date we have integrated EHRs into medical and nursing curricula using a tight and a loose coupling approach. Initially, our work focused on exposing students to the technology [10]. Then we focused on the technology as an educational tool that supports acquisition of medical and nursing knowledge as well as knowledge of the EHR [1]. We then turned our focus to the designers, implementers and innovators of health information technology tools.

Extending beyond this work, health informatics and health information technology students need to learn how to design, develop, implement and maintain health care technologies that are used by health professionals and by patients. Research was conducted at the School of Health Information Science that focused on training health information technology and health informatics professionals. Study results suggested that teaching students how to use an EHR in the classroom improved health informatics competency development and lead to the acquisition of competencies necessary for professional certification. Here, our work involving the portal went on to include the design, development and implementation of EHRs and those technologies that interface with EHRs. To illustrate, health informatics students may need to learn how to use an EHR in the first year of their studies, with their knowledge extending to an in-depth conceptual and technical understanding of the technology and how it can be designed, developed, implemented and integrated with other technologies to provide context sensitive patient care. Here, a student will learn about creating the databases that collect patient data, develop strategies for new innovations to interface with the EHR, learn how to extract data from EHRs, design new interfaces for new types of devices, and innovate

new technologies that go beyond the EHR (e.g. sensors) to support individuals in the community. The authors have also developed a model and approach based on this work at a curriculum level that can be used to inform decision-making regarding training of health informatics and health information technology professionals [11, 12].

7. Challenges, Recommendations and Lessons Learned for Educators

There are a number of challenges and needs for future work in this area. One of the key challenges is the development of a plan for sustaining the upkeep of the portal over time, as we have found this requires a fair amount of technical expertise. From our experience this requires educating decision makers in the educational and governmental hierarchies about the need to provide resources to support educational EHR initiatives over time, so they can continue into the future. From a technical perspective, modification of open source software to adapt to educational needs can be a challenge and the ease of doing this depends on the specific software. From a pedagogical perspective, unlike single vendor educational EHR products, which provide access to one type of system, portals provide access to varying types of EHRs so that students become familiar with varying systems and their use in clinical settings (which is important to address). As well, we had initially hoped that EHR vendors would donate their software to be hosted on our portal, but we have only recently begun to get commercial systems running for students.

There are challenges in the area of curriculum integration and how and when it is best to bring EHR education into medical, nursing and health informatics professional education. We have found a "training wheels" approach, where more advanced EHR features are hidden from students, may be useful during early parts of health professional education (as students' progress through their training on more advanced features can be made available). A further need is the development of authoring tools and interfaces to help educators both create cases for simulations (e.g. allowing simulated patient data to be easily input into the EHR by instructors) and to allow for adding comments, tips and quizzes embedded within key points in the educational EHR that support the development of discipline specific competencies. One approach we have experimented with is the inclusion of "info-buttons" that can be easily added to the user interface and that students can click on to receive context-sensitive advice and educational information as they work through cases using different EHRs. This may take the form of access to search tools such as PubMed [see 14] and there would be a need to extend this work to include lecture notes, videos and/or context specific information.

There is need to conduct further work regarding the level of access and integration of EHRs in medical, nursing and health informatics professional educational curricula that is necessary for health professionals to acquire EHR competencies. For example, physicians and nurses may only need to learn how to effectively use an EHR, reviewing only discipline specific information as individuals with differing disciplinary backgrounds attend to varying types of information to support their decision making [15]. In contrast health informatics and health information technology students will need to learn how to use an EHR, have exposures to differing types of EHRs, understand the underlying programming, develop EHR architectures, design user interfaces, develop interoperability structures, design databases and innovate new analytic methods for effectively extending and managing this technology (see [11]).

8. Discussion and Conclusions

Our work represents 10 years of research in the area of educational EHRs and their integration into medical, nursing and health informatics curricula. Technological and educational advancements have made it possible to provide hundreds of medical, nursing and health informatics students with access to an EHR portal that acts as a gateway to multiple differing open source electronic health records (including records developed to support the care of specific patient populations (e.g. children) and groups (patients who use personal health records) [1-4]. Yet, even as access to varying EHRs for health professionals is needed in a classroom setting, few health professional educational programs provide such access to EHRs and even fewer integrate the technology effectively into teaching using a tight coupling approach. Our work has shown that a portal approach where students can remotely access EHRs is ideal.

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Development of a Video Coding Scheme for Understanding Human-Computer Interaction and Clinical Decision Making

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Abstract. The usability of healthcare information technology has become a major issue in health informatics. There have been many reports of systems that have been deemed unusable by end users such as clinicians and a growing body of usability studies have been reported in the literature. The issue of how to fruitfully analyze and code usability study data in a meaningful way that can lead to optimized and more efficient systems has remained to be fully detailed. In this paper we describe our work in developing and organizing a principled video coding scheme that builds from our previous work in a couple of areas. We include video coding categories we have developed for understanding problems and issues with human-computer interaction. In addition, we integrate this coding scheme with categories we have used to characterize human cognition, such as clinical reasoning and decision making, in isolation of technology use. The resultant new scheme thus incorporates coding categories that can used to evaluate both usability issues (applying categories from human-computer interaction) and human cognition, in order to assess the impact of technology on clinical reasoning and decision making.

Keywords. Usability, human factors, cognition, reasoning, decision making, health information technology

1. Introduction

The usability of healthcare information systems has become a focus of considerable attention in the field of health informatics. There have been and continue to be numerous reports of systems that have been deemed to be unusable and even unsafe, and in some cases having a potential detrimental impact on clinical reasoning and decision making. In response to this, the authors have been involved in developing and applying a range of methods for evaluating the usability of healthcare information technology (IT) and pinpointing specific usability problems and issues. An important part of this work has been the development and use of video-coding schemes that are applied by analysts and researchers to glean essential information about usability problems and potential remedies from analysis of collected usability data [1]. This data is typically in the form of digital video recordings of user interactions (e.g. video of screen recordings) along with audio recordings of user verbalizations that can be analyzed using protocol analysis

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[2]. Although there have been many articles published describing the collection of usability data in healthcare, along with the results of studies, there have been far fewer publications about principled approaches to actually coding and analyzing video-based usability data. In this paper we report on our efforts to create a continually evolving and extensible video coding scheme that builds on previous work in the area of developing models for characterizing cognitive processes [3-5] and characterizing human-computer interaction in healthcare [1, 6]. The issue of how to characterize the impact of healthcare IT on clinical reasoning and decision making has emerged and continues to remain to be more fully explored. As a result, in the work described in this paper our objective was to create a framework that can be used to better understand the relationship between usability issues and their impact on clinical reasoning and decision making. The authors have been developing and applying classification schemes that can be used to guide the analysis of video and audio data from a wide range of usability studies. In this paper, we describe our new work in bridging our current work on coding and classifying usability problems with our previous work in characterizing and analyzing clinical decision making and reasoning. The objective of the combined coding approach described in this paper is develop an open ended, flexible and extensible classification scheme that can be used to better understand and characterize the impact of usability on key aspects of clinical reasoning and decision making in healthcare.

2. Methodological Approach

The authors have previously described a framework for describing human-computer interaction and identifying usability problems in healthcare that is based on three levels of complexity: Level 1 – the level of the individual user interacting with healthcare IT in isolation (the level of basic usability); Level 2 – the level of using a system or technology to carry out a basic work task (the level of workflow); Level 3 – the level of interaction involving multiple players and goals in interacting with a system in the larger organizational or societal context [6]. Since developing this approach to characterizing usability problems, the authors have been involved in creating and applying a range of video-based coding schemes for analyzing data from usability studies.

In a parallel line of work in cognitive research, the authors have also developed principled coding schemes for characterizing key aspects of clinical decision making and reasoning [4-5]. This work emerged from qualitative research in medical cognition. In previous work analyzing complex decision making in surgical intensive care, a coding scheme was initially developed that incorporated key aspects of decision processes with clinical reasoning. Although the scheme was successfully used for characterizing medical expertise at different levels in solving cases of varying difficulty in surgical intensive care [5], it had yet to be applied in the context of medical reasoning and decision making involving the use of health information technologies (e.g. electronic health record systems and clinical decision support systems). The process of video coding has been described by the authors in detail elsewhere and involves several phases including an initial transcription, an annotation phase (where the user actions are annotated) and a coding phase [1].

The process of developing the scheme described in this paper involved initially combining coding categories from a number of sources. The initial scheme was then reviewed by three human factors experts and iteratively refined. The scheme contains:

- Categories that include usability heuristics, such as Nielsen's heuristics [7] (which were initially designed to be used to guide usability inspection)
- Categories derived from published design and evaluation guidelines, typically focused on providing guidance to designers of new IT solutions
- Categories that have emerged inductively from numerous studies conducted by the authors and other researchers from a wide range of usability studies.
- Categories from medical cognition, focused on characterizing reasoning and decision-making processes from verbal and observational data

To develop and refine the coding scheme described in this paper, initial categories from the above sources were first merged, presented to the expert panel and then codes were classified as belonging to either Cognitive codes or Usability codes. Figure 1 illustrates the combined coding scheme that was arrived at through an iterative process of review by the panel of three human factors experts.

3. Results and Example of Application

As can be seen from Figure 1, at the top level the scheme includes **Cognitive Codes** and **Usability Codes**. Cognitive codes refer either to codes identifying key aspects of *Decision Making* and with codes dealing with *Reasoning*. The Usability Codes can be sub-classified as belonging to Level 1 (level of an individual user interacting with a system in isolation), Level 2 (the level of work activities), or Level 3 (the level of socio-cognitive interactions). The actual codes are given on the right-hand side of Figure 1 and are defined in a coding dictionary (that provides instructions to analysts for when to use that code when analyzing video and audio transcripts).

3.1. Cognitive Codes

Cognitive Codes consist of *Decision Making* and *Reasoning* codes, as illustrated in Figure 1. For example, under the *Decision Making* portion of the coding scheme, the code "Information Required" is coded if information is requested or required in making a decision (e.g. a doctor requesting information from a patient during a doctor-patient interaction). Other Decision Making codes include "Comparison of Alternatives" (coded if options are compared during decision making), "Investigation Choice" (coded if a medical investigation is chosen), "Other Action Chosen" or "Choice Reconsidered". Likewise, a set of codes for analyzing *Reasoning* (from the medical cognition literature [3-5]) are also shown in Figure 1.

3.2. Usability Codes

Usability Codes, as noted above these are organized in Figure 1 according to the three levels of human-computer interaction described by Borycki and Kushniruk [6]. For example, at the level of basic human computer interaction (Level 1) the coding categories include: "Speed" (coded if speed of user interaction is an issue), "Font Issues" (coded if there are problems regarding fonts, e.g. font is too small), "Layout and Organization" (e.g. coded if there problems with the screen's layout), "Content Issues/Usefulness Issues"

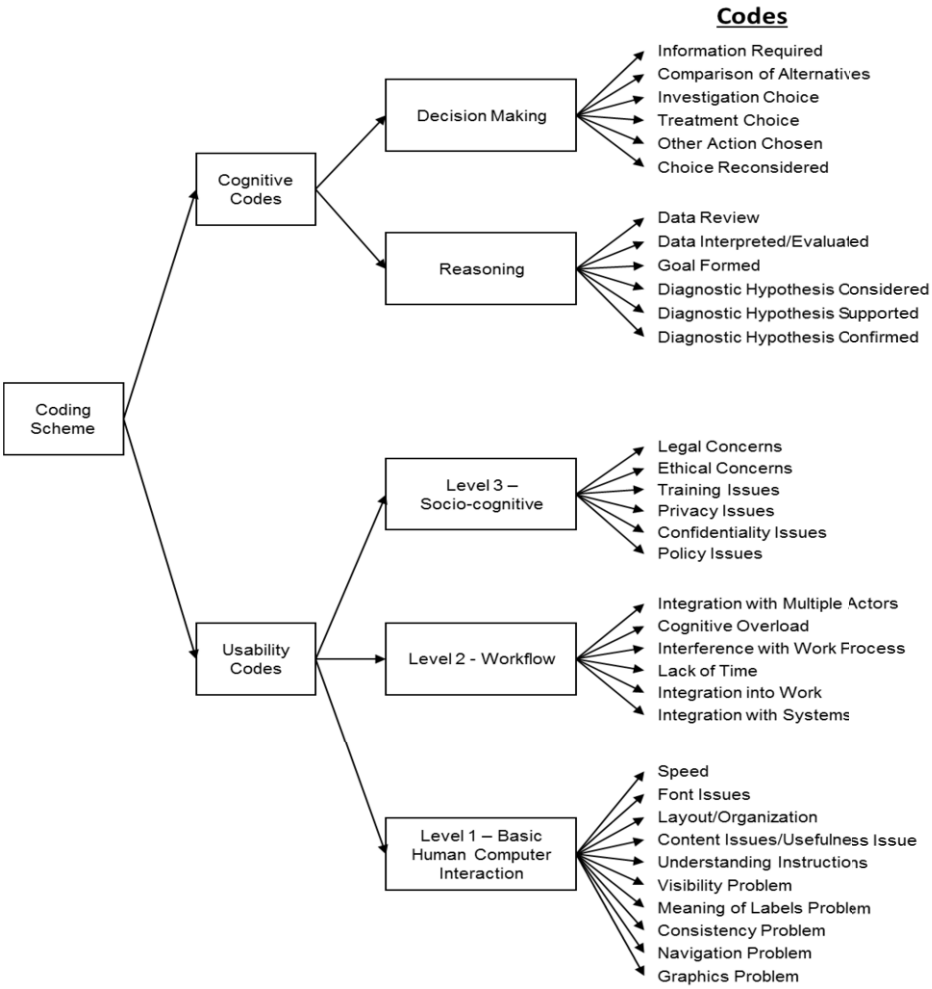

Figure 1. An integrated coding scheme for investigating the relation between cognition and usability in healthcare informatics.

(coded if the user indicates issues regarding content or usefulness of information provided by a system) and "Understanding Instructions" (coded when the user has problems understanding how to carry out tasks. Other categories include "Visibility Problem", "Meaning of Labels Problem", "Consistency Problem", and "Navigation Problem".

3.3. Example Application of the Scheme

To illustrate use of the scheme presented in this paper, the following is an excerpt from a study investigating the impact of the electronic health record (EHR) on clinical decision making and reasoning. In this study eight physicians participated in usability testing of a new EHR. The physician participants were instructed to "think aloud and verbalize their thoughts" while interacting with the system to arrive at a clinical diagnosis. They were

encouraged to think aloud about whatever came to mind, including verbalizing their thoughts about the user interface, the medical problem they were solving or any other thoughts as they worked through the clinical case using the EHR. In the excerpt below annotations are given in italics and the codes are shown in capitals in square brackets (directly beneath the relevant section of the transcript which they characterize).

00:01:25 Subject open up the category "family history" in the electronic health record
"I am opening up the information about the past medical history for this patient and I am looking to see if there is a family history of cancer"
[COGNITIVE - **DATA REVIEW** (EHR) - family history of cancer]
"I see that the patient's mother and uncle died of pancreatic cancer so I am wondering if the patient might have cancer or some genetic predisposition"
[COGNITIVE - **DIAGNOSTIC HYPOTHESIS CONSIDERED** – cancer, cause genetic]
"I would like to know if the patient has symptoms consistent with this particular type of cancer"
[COGNITIVE - **INFORMATION REQUIRED** – symptoms of patient]

00:02:25 Subject scrolls up and down current screen
"But I don't know how to get to the screen with the lab results"
[USABILITY - **NAVIGATION PROBLEM** – can't find lab results tab]

00:02:45 Subject notices an alert at top of the screen but does not know what it means
"I just noticed a yellow pop up at the top of the screen with BPA written on it, but I don't know what BPA means"
[USABILITY – **MEANING OF LABELS PROBLEM** – does not know what the label "BPA" on the alert means]
"I find this distracting as it has interfered with my train of thought about what I was looking up"
[USABILITY – **INTERFERENCE WITH WORK PROCESS** – alert distracting]
"I just clicked on the button with BPA written on it and it is telling me there is a risk the patient has high blood pressure. I would now like to know if this has anything to do with the patient's current chief complaint"
[COGNITIVE – **GOAL FORMED** – determine if information in the alert is related to the chief complaint for the current visit]
"Now I'll now go to look up those values"
[COGNITIVE - **INFORMATION REQUIRED** – lookup blood pressure]

The example excerpt above illustrates how codes for both cognitive aspects as well as usability issues are used in data analysis. The coding of the excerpt illustrates codes related to usability can be interleaved and coded throughout the transcript (as they arise in the transcript), as the subject moves back and forth between dealing with usability issues (e.g. navigation problems) and consideration of diagnostic hypotheses (e.g. consideration of cancer). From such coding we can elucidate the impact of system design (in terms of screen layout, organization and even details such as labelling of alerts) on clinical reasoning, decision making and workflow activities. For example, the above coded transcript indicated that the user had trouble finding key information in the EHR to support basic reasoning, and that the alert distracted their decision and work activities. Furthermore, from such analysis we are also able to quantify and statistically relate key aspects of reasoning and decision making to specific usability features (e.g. such as screen design and specific interface features such as labelling on alerts).

4. Discussion

The approach to coding described in this paper is unique in that it blends or incorporates within one integrated coding scheme categories that come from two separate literatures and domains, namely medical cognition and human factors. The need for this work arose from carrying out studies aimed at elucidating the relationship between human factors (and in particular usability problems) and impact on medical reasoning and decision making. To date, applying the type of approach to coding described in this paper has led to several key findings about the impact of technologies such as EHRs on medical cognition. For example, some of our work has indicated that some interfaces to systems such as EHRs may lead a physician user to become "screen driven" or limited to following the order imposed by the system during their diagnostic process. When this happens the clinicians may end up following the categories on the screen during the decision making process about a patient case thus profoundly impacting the physician's cognitive processes (by inadvertently guiding their information requests which form the basis for decision making processes) [8]. The overall approach for analysis of usability issues can also be extended to also explore areas related to usability and training, as well as for examining the relationship between cognition and human factors in general [9]. In addition, the approach can also be used to evaluate the impact of health information technology on clinician's interactions with patients while using technology such as the EHR. We are currently carrying out validation studies of the resultant classification employing a panel of experts who are reviewing the results of our work (i.e. the coding scheme presented in this paper).

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From Free-Text to Structure in Electronic Patient Records

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Abstract. We report from the initial steps of a collaboration project between two post-doctoral projects, both using a qualitative action research approach to address challenges related to shifting from a free text to a structured EPR system constituting important preconditions for establishing advanced decision support and reuse of healthcare data. We have started to explore three areas that may influence this process related to: 1) Legislative challenges of getting access to all relevant healthcare data. 2) Challenges of exchanging data between silo systems and open platform systems. 3) Replacing a free text silo EPR with an open platform system - and the practical challenges of defining the content of the context sensitive structured EPR. Hence, we ask the following research questions: How to address challenges related to the shift from free text to structured EPR systems? How will the need for semantic interoperability between different EPRs influence the goal of advanced clinical decision support? Empirically, we draw on the regional FRESK program (2017-2022), in the North Norwegian Health Region, which includes implementing both a new regional open platform based EPR system, and a proprietary medical chart system.

Keywords. Interoperability, open platform, silo systems, reuse, Electronic patient record, Clinical decision support

1. Introduction

The expectations for advanced ICT solutions in healthcare increases rapidly. Electronic Patient Records (EPRs) are considered to be crucial tools for supporting clinical processes across institutional boundaries, foundations for clinical research, as well as tools for informing managers and policy makers [1-3]. Particularly, advanced clinical decision support (CDS)[2] capabilities are in high demand, but yet not widely accessible. There has been a great effort to understand the reasons for limited availability due to this being an important demand for structuring the clinical information within the EPR is one of the absolute prerequisites to enable advanced CDS. Another reason is the lack of integrations between EPRs since healthcare organizations tend to use a plethora of specialized, non-standard electronic patient records (EPRs), defined as silo-systems [4], often developed to support specialized departments' internal processes. The silo system

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[2] Clinical decision support is an ICT tool that combines evidence-based knowledge, guidelines, procedures and treatment protocols with individual patient information to support decisions of the treatment and care to a specific patient.

approach gives access to only a single unified database for instance related to radiology, medical charts or EPR, which complicates exchanging clinical information between these systems. Information exchange between systems is of high importance for healthcare personnel to access all relevant clinical information and support patient pathways across organizational boarders. Consequently, the expected improvements of quality, as well as cost-effectiveness of treatment and care promoted through the use of advanced EPRs is at risk when clinical information during a patient pathway resides in more than one EPR. Based on the complexities described in previous research, there is a need to explore these intricacies related to the transition from today's silo systems to the deployment of structured EPRs enabling clinical process- and decision support [5-6].

This is a research in progress, were we have started to explore three environmental topics that may influence the process of shifting from free text to structured EPR system constituting important preconditions for establishing advanced decision support and reuse of healthcare data. Making such shift has not been done to the same extend as in Norwegian healthcare before, and structuring an EPR system is usually only done by system vendors today. Empirically, we will draw on the regional FRESK (Future systems in the clinic) program (2017-2022), in the North Norwegian Health Region, which includes implementing both a new regional open platform based EPR system, and a proprietary electronic medical chart system. Important aims of the program include structuring the clinical information within the new EPR system through the openEHR approach using archetypes as clinical standards 3 [9, 10], and defining how to integrate and share clinical information between the EPR and other healthcare systems, particularly the medical chart system. The empirical project is now facing the complex challenges related to the transition from silo systems to structured EPRs as an important precondition to enable advanced CDS. Hence, we ask the following overall research questions: How to address challenges related to the shift from free text to structured EPR systems? How will the need for semantic interoperability between different EPRs influence the goal of advanced clinical decision support? Responding to this, we have identified three important topics that need to be further explored: 1) Legislative challenges of getting access to all relevant healthcare data. 2) Challenges of exchanging data between silo systems and open platform systems. 3) Replacing a free text silo EPR with an open platform system - and the practical challenges of defining the content of the structured EPR. The research will be carried out as a collaboration between two post-doctoral projects both addressing the work with structuring the EPR, and establishing advanced clinical decision support.

2. Method

This study adheres to a qualitative action research approach. The purpose of an action research approach is to contribute to a co-constructive learning process based on feedback from healthcare personnel, developers, and stakeholders participating in the empirical field. The research will be carried out in the regional program FRESK. The

[3] The openEHR architecture based on archetypes designed to manage, store and retrieve structured health data in an EPR system [11], through an open platform where the data are completely shareable and independent of programming language, human language and database technology. Archetypes are the information models set to standardize clinical concepts in openEHR systems. This includes facilitating reuse of information, evidence-based practice and semantic interoperability. Archetypes are clinical standards including the context they are used for, established in a socio technical consensus process [12].

researchers' will through action research bring back scientific knowledge and relevant findings to FRESK and successively evaluate the ongoing processes [9].

The data will be collected through interviews (we have already conducted four), knowledge summaries, participatory observations, discussions and document studies. The interviews will be audio recorded, transcribed, and analyzed in relation to the context. The objective of analyzing collected data is to organize and structure the gathered material to generate an understanding of how the socio-technical interdependencies influence the evolving empirical process [10].

3. Case

In the North Norwegian Health Region, the goal is to shift from a free text EPR system combined with a paper based medical chart, to an open platform EPR system based on the openEHR architecture and a proprietary medical chart system. In relation to the work with structuring the EPR system, to reach the goal of CDS, we have started to explore three important areas of the existing socio-technical context influencing the implementation of the new EPR, with a particular focus on legislation, integration and practical design

3.1. Legislative challenges of getting access to all relevant healthcare data

The National eHealth Strategy (2017-2022) [13], addresses that EPR systems must be able to provide CDS functionalities where evidence-based knowledge is used directly to support patient treatment and care. However, important preconditions to enable CDS are structured clinical information, and access to all relevant patient specific clinical information, independent of where or in which system the information is stored [14]. In addition, exchange and reuse of clinical information still implies that confidentiality, legal regulations and restrictions of sharing personal information ("*GDPR Personal Information Act")* need to be taken care of. Today's situation in the North Norwegian Health Region does not comply with these preconditions.

First, even if clinical patient specific information is stored in one common database, this database is separated into four units belonging to each of the regional health trusts. Second, the present EPR system is built in such way that clinical information is written in free-text, and stored in document-files belonging to different journal groups within the EPR. Healthcare personnel get access to the documents through a very strict and complex hierarchy of access control aimed to ensure the confidentiality legislation. However, patient pathways often cross organizational borders and healthcare trusts, which means that patient data is recorded and stored in more than one health trust's database. According to the patient record legislation the health trusts are responsible for the healthcare information within their trust, and they decide if they want to partially or fully share the healthcare information. *"There are no legal restrictions against reuse of data or extracting data for decision support. However, in which format (sharing document, read-only document, sharing specific clinical information) this information is presented may be an issue to discuss (Legal professional)."*

Using a structured EPR seemingly provides more possibilities than limitations, and makes it easier for healthcare personnel to access significant and necessary information like blood pressure or weight without accessing an entire free text document. Still, it is important to explore how to enable CDS meanwhile ensuring confidentiality, legal

regulations and restrictions of sharing personal information according to GDPR. Hence, it may be necessary to reevaluate the existing hierarchical access control system to facilitate the goal of CDS with the need for exchanging and reusing clinical information in new ways. "The laws regarding healthcare information is designed first of all to ensure that healthcare personnel get access to necessary information related to a patient. (legal professional)." It is important to discuss:

(1) The balance between confidentiality, and protection of privacy in relation to the overview of relevant healthcare data within and across EPR system and potentially reuse in relation to accessing all relevant healthcare data.
(2) The need to change today's journal structure and access control system.

3.2. Challenges of exchanging data between silo systems and open platform systems

Implementing a structured EPR system demands for reevaluating the silo system structure in Norwegian healthcare, since one of the main prerequisite for advanced CDS is the possibility to extract and reuse relevant information about a patient regardless of in which healthcare system the information is stored. This is not possible with today's silo systems and potentially generates a risk of missing relevant information when treating a patient. The ideal data exchange includes converting all data into the same standards, preferably an open standard, to seamlessly exchanging healthcare data. However, the present systems in the North Norwegian Health Region are built on differing standards, demanding complex integrations to enable data exchange. Systems like the EPR, and the medical chart, which both includes numerous overlapping patient data, and demand for close integrations to provide a seamless information flow in between. Integrations between similar systems were conducted in the Southern and Eastern Norway Regional Health Region some years ago, including patient administrative terms, allergy import and FEST (medication). There was also provided a CCOW - real time synchronization of information as a HL7 standard, to provide seamless integration for users of both systems. These integrations have been adopted to the North Norwegian Health Region, due to close collaboration between the two programs. In FRESK, they now work with integrations of vital parameters, where to store master data, and what secondary systems/software to integrate towards to avoid double registration.

One way of integrating systems using different standards are profiling, using a common language for messaging between systems, e.g. HL7`s FHIR (Fast Healthcare Interoperability Resources). FHIR is designed to exchange healthcare information through resources, reflecting clinical and administrative information [15]. It is necessary to include a great deal of clinical work in forming consensus around how detailed clinical information should be captured and shared in FHIR resources since they have no defined structure [15]. Another challenge is that there is no established repository of FHIR resources available in Norway even if some FHIR resources, like observation, are already defined. Observation is useable for exchanging information on all vital parameters "the observation FHIR Resource is generic to integrate any vital parameter, or all observation archetypes (integration specialist)."

Accordingly, it is crucial to discuss how to establish high quality integrations and messaging language to provides seamless integrations and semantic interoperability between healthcare systems. Three important challenges need to be explored:

(1) The importance of agreeing on a format for message exchange and code to use, to enable CDS system to extract and understand information from all systems involved.
(2) If FHIR is to be used, there is a need for designing regional resources as soon as possible, and preferably within the next six months according to the implementation plan for the new EPR and medication systems.
(3) How to include metadata for information to be reusable from one system to another, to enable clinicians to know for instance when a blood pressure has been registered and how to evaluate the value before reusing it. Archetypes are information models that includes the context the data was registered in.

3.3. Replacing a free text silo EPR with an open platform system - and the practical challenges of defining the content of the structured EPR

Shifting from a free text based EPR system to a structured EPR demands for changing the way healthcare data are registered and presented. Based on previous experiences with converting clinical forms/schemas from unstructured to structured forms [16]. These processes often turn out to be more complex than initially expected. Hence, important challenges have been recognized for instance in the work with designing a structured registration form based on the free text schema in the existing EPR system described by Ulriksen and Pedersen [16]. The work resulted in a very long and complex schema including 58 standards, resulting in endless variables and boxes to check. The conclusion was that it is very important to define the reusable data necessary to structure, the rest should remain as free text. Other important lessons learned from this work, correlates well with the challenges recognized in the work with structuring forms in the FRESK program, these issues need to be further explored:

(1) The importance of include clinicians in designing forms used in the structured EPR to define values to reuse to end up with forms useful for clinical practice [16].
(2) The possibility for reuse of data depend on the granulation level of the standards. If one scheme is designed as one standard, the whole form has to be reused. If each variable is connected to a specific standard, all the elements are separately reusable.
(3) How to establish a socio technical network of different actors, in addition to clinicians including regional and national archetype specialist to identify the right structured elements to use and design new archetypes if needed, IT personnel with programming competence to design, queries, dependencies and so on to for instance make calculations like BMI is also needed. This includes the need for close collaboration with the system vendor since they are the only ones that are familiar with the form building tools and archetype design for the structured EPR system today.

4. Preliminary discussion

Shifting from free text to a structured based EPR is a socio-technical process, were it is not sufficient to focus only on the technical part of the process, hence including organizational issues, legal considerations, clinical practice and system users are just as

important to succeed. As a consequence, we have selected three important focus areas for our project related to accessibility, integration and registration of patient data in a EPR 1) Legislative challenges of getting access to all relevant healthcare data, 2) Challenges of exchanging data between different healthcare systems, 3) Transferring healthcare data when shifting from a free text-based EPR to an a structured-based EPR and registering data in a structured EPR.

Altogether, the focus areas enable receiving all relevant healthcare data necessary for treating a patient regardless of where the data is registered and stored. Advanced CDS demands for establishing close collaboration between necessary actors including a network of clinicians to gain high quality standards. Further to decide what information to structure, and how to reuse information during patient pathways. In addition, it is necessary to collaborate about how standards used for structuring information must be designed and governed. Accordingly, how these focus areas best are to be solved, will be given attention during the FRESK program. It is however important to consider also what information that has to be structured since registering structured data makes clinicians spend more time in front of the computer, which again makes for less time face to face with the patient.

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Different Contexts for Medication Errors and Patient Safety

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Mandatory Medication Indications in Electronic Systems – The Prescriber Perspective

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Abstract. As hospitals transition from paper to electronic medication charts, an opportunity exists to 'nudge' prescribers to document medication indications by making this data-entry field mandatory. The aim of this study was to explore hospital doctors' perceptions of mandatory documentation of indications in an electronic medication management (EMM) system. Ten junior doctors took part in brief semi-structured interviews. Participants identified improved communication among staff as a key benefit of indication documentation. Recording indications was also seen to act as a prompt for medication review. Despite these benefits, indication documentation for all medications would be challenging to implement in practice. Users of the EMM system (i.e. junior doctors) explained that they are time poor and are often tasked with transcribing medication orders into the electronic system with limited knowledge of why medications are being prescribed. Determining the indication for use would require additional time and effort, and prescribers reported a high risk of working around the system if indication documentation was made mandatory.

Keywords. Electronic medication management, medication indication, mandatory documentation

1. Introduction

Documenting the indication or purpose for a medication is considered best practice when prescribing [1]. It has been suggested that in addition to the five rights of safe medication use (the right patient, right drug, right dose, right route and right time), a sixth right be added – *the right indication* [2]. Australia's paper-based National Inpatient Medication Chart (NIMC), used in all Australian hospitals yet to implement electronic medication management, includes a field for medical staff to document each medication's indication [3]. Its purpose is to allow the medication order to be reviewed in the context of why the medication was prescribed, reducing the risk of an order being misinterpreted or misread

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[3]. Despite its inclusion, the field is not often used, with audits revealing that indications are typically documented less than 10% of the time [4].

As hospitals transition from paper to electronic medication charts, an opportunity now exists to 'nudge' prescribers to document medication indications by making this data-entry field mandatory. Anecdotally, some Australian hospitals have configured systems so that indication documentation is mandatory, while others have made this field optional. But what are the opportunity costs associated with making this data-entry field mandatory? And what are the benefits and risks of mandatory indication documentation? The aim of this study was to explore hospital doctors' perceptions of mandatory documentation of medication indications in an electronic medication management (EMM) system.

2. Method

2.1. Study site, medication management system and participants

The study was conducted at a 320-bed teaching hospital in Sydney, Australia. All hospital wards, expect for the emergency department, used the EMM system, MedChart®, for electronic prescribing, pharmacy review and medication administration. During prescribing, no specific data-entry fields were available for recording indications.

Prescribers at the hospital were opportunistically recruited via direct approach (i.e. directly approached while working on wards) and invited to participate in a brief semi-structured interview. Junior doctors were targeted for recruitment, as previous research indicated that junior doctors were more likely to use the system [5]. Ten prescribers were invited and all agreed to take part. These included two interns, six residents and two registrars.

2.2. Procedure

This study formed part of a larger project investigating antimicrobial prescribing at the study hospital. Interview questions focused on the current process for documenting indications and gaining approval for use of antimicrobials. At the end of the interview, prescribers were asked two questions about documenting indications for medications more broadly:

- What do you think about documenting indications more generally? That is, having to document an indication for every order?
- What impact do you think documenting the indication will have?

All interviews were audiotaped and transcribed verbatim. Responses to these two questions were de-identified and independently analyzed by two researchers. A general inductive approach [6] was used, where no a-priori framework was used to guide analysis. The two researchers came together to reach a consensus on positive and negative perceptions of recording medication indications in the electronic system.

3. Results

Table 1 summarizes the main themes that emerged from interviews with respect to recording medication indications in the EMM system. Most doctors held the view that recording indications was good practice, and theoretically should be done for all medications. For example, a doctor said: *"I think that's very rational."* (D2) However many doctors were not sure whether the benefits of having an indication available outweighed the added burden this would create for doctors.

Table 1. Prescriber perceptions of recording indications for all medications in the electronic medication management system.

Main benefits	Practical difficulties	Risks
Improved communication between hospital staff	Not all indications are known	Workarounds
Prompts prescriber to review medications	Extra time and effort for prescribers	Poor information quality

3.1. Main benefits of recording medication indications

The primary benefit of recording indications in the EMM system was reported to be improved communication among hospital staff. For example, participants said: *"I'm in cardiology at the moment and it's really helpful to know why people are on certain types of medications over other ones. And it makes it very clear for everyone subsequently."* (D2)

And: *"I think it is great, it's what you need, especially from the dispensing point of view, to know why you are dispensing this. And it is good, you know the other medical teams to come in say hey they are on this for this reason".* (D5)

Another benefit was viewed to be the medication review that typically accompanies determining an indication for a medication. A doctor explained: *"I think there's a couple of times when patients would come in on things and you would have no bloody idea why it's been prescribed…That can be difficult but I often think it's a good time to review that medication…So I think it's quite good when you have to think about the indications because if you've got someone on 6 tablets for one thing and you realize that they could be on 3 tablets for one thing, it's a good time that you can actually make changes"*. (D10)

3.2. Practical difficulties associated with recording medication indications

Almost all participants reported the main difficulty associated with recording indications to be the extra work this would create for prescribers. A doctor said: *"It seems like it could be a lot of work, especially, for patients on say the transplant team who are on 30 or 40 medicines. To scroll through every single one and pick out an indication…"* (D5) Doctors also described situations where it would be particularly difficult to find the time to document indications (e.g. after-hours, when a patient has just been admitted).

Another key barrier to documenting medication indications was reported to be the fact that not all medication indications are known. *"Some of the indications are difficult to ascertain, especially if some of the patients have been on these medications for quite a long time from the GP. And as a JMO (junior medical officer), if you don't know the indication, you can't write down anything, so then what's going to stop people from not writing down anything in the first place?"* (D7) This was particularly a problem for

junior doctors, who were often charged with 'transcribing' medication orders into the EMM system, rather than making prescribing decisions:

> *"I think that [recording indications] would be really beneficial only if the person doing it knew what they were doing. I can just remember as an intern, you know, you just copy whatever they are usually on, and sometimes you don't know why they are on this rather than something else."* (D1)

3.3. Risks associated with recording medication indications in the EMM system

As a consequence of the practical difficulties associated with recording indications, doctors expected that users would find ways to workaround the EMM system and either document non-indications (e.g. full stops and commas) or document inaccurate indications. A doctor explained: *"If you force people to write down the indication, they might write down garbage."* (D7)

And another: *"Time poor people having to do extra steps often cause people to cut corners where they don't see it of use. If there isn't good compliance or if it isn't used well that it might actually confuse people more…because if you have people using the system haphazardly and sort of putting in the standard indication without thinking about it and then someone comes along and says "look they're on frusemide for heart failure" when they're really on frusemide for some other indication."* (D9)

4. Discussion

This interview study revealed that although viewed to be best practice by prescribers, recording of indications for all medications would be challenging to implement in practice. Users of the EMM system (i.e. junior doctors) are time poor and are often tasked with transcribing medication orders into the electronic system with limited knowledge of why medications are being prescribed. Determining the indication for use would require additional time and effort, and prescribers reported a high risk of working around the system if data entry was made mandatory.

Participants identified a core benefit of recording indications to be improved communication among hospital staff. It is interesting to note that when asked to reflect on the impacts of documenting indications, prescribers focused on the immediate consequences of this practice on their work and on the work of others. No participants discussed impact more broadly, that is, to patients and to health professionals post-discharge (e.g. general practitioners, pharmacists). This likely reflects the *observability* [7] of these consequences. That is, increased workload is highly visible to prescribers, while the flow-on effects to external healthcare providers and to patients are less so.

Evidence of the positive impact of indication information on patients' medication management and on other healthcare providers is growing. For example, in a recent qualitative study, Australian consumers reported that having the indication on medication labels would make managing medications less confusing, especially when starting a new medication or when an alternative brand was dispensed [8]. Most consumers reported that they would be more likely to take their medication if they knew what it was for.[8] Research has also shown that pharmacists are more likely to identify prescribing errors when a prescription is accompanied by an indication, as this information facilitates a more comprehensive assessment of the medication order [9].

Another key benefit identified by prescribers in our study was that mandatory indication documentation could prompt prescribers to review a patient's medications. Potentially inappropriate polypharmacy occurs in approximately half of older hospitalized patients and is rarely addressed during routine hospital care [10, 11]. Thus, mandatory indication documentation should be implemented if this practice encourages medication review and subsequent deprescribing (i.e. the cessation of inappropriate medications). However, given that the prescribers entering medication orders into the EMM system are typically not the ones making the prescribing decisions, [5] further research is needed to determine how and in what contexts adding indications is beneficial, for example, in prompting medication review.

Workarounds are common when information technology does not align well with user workflow or when systems create additional work for users [12]. Data recorded into a system should be complete, but also accurate. In a previous study that assessed accuracy of indications documented for antimicrobials in an EMM system, doctors frequently entered inaccurate indications into the data-entry field in order to bypass the antimicrobial approval process and save time [13]. The data-entry field was mandatory, but in many cases, doctors entered nonsensical text (e.g. gduhb) to move past the perceived 'block' in prescribing [13]. As mentioned by a participant in our study, workarounds may also create additional risks, as inaccurate indications could be relied upon for subsequent decision making. Thus, minimizing, and if possible, streamlining any additional work for prescribers is recommended.

5. Conclusion

There are multiple benefits associated with having indication information available for all medication orders, however prescribers identified a number of practical difficulties and risks associated with mandatory indication documentation in EMM. Indication-based prescribing (i.e. selecting an indication, then medication) is gaining momentum internationally [9, 2]. The practical difficulties outlined here add to the raft of challenges already identified with indication-based prescribing, an ambitious attempt to shift prescribing work practices and thinking in order to improve patient safety.

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Data Quality Assessment of Narrative Medication Error Reports

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Abstract. Medication errors are preventable adverse events or unsafe conditions caused by inappropriate uses of medication. To collect data of patient safety events (PSE) and to analyze the root causes of PSE, reporting systems have been implemented in healthcare settings and patient safety organizations (PSO). However, the poor data quality of reports impedes the reporting and root cause analysis (RCA) of PSE. Incomplete or missing data is the most prevalent problem in event reports. To assess the data quality of PSE reports, we used an adapted taxonomy as the data evaluation model to evaluate the quality of narrative reports collected by a PSO. Sample reports were extracted based on eight error types and scored by experts. Most structured fields in the reports were ignored by reporters. In contrast, the narrative parts of the reports contain rich and valuable information. The evaluation results show that the adapted taxonomy is a promising tool for report quality assessment and improvement.

Keywords. Patient safety, Data quality, Medication error, Reporting system

1. Introduction

Patient safety events (PSE), such as adverse drug events, medication errors, patient falls, pressure injuries, health information technology (HIT) events, and surgical events, threaten the health of patients and lead to economic losses. Medication errors are preventable adverse events or unsafe conditions caused by inappropriate use of medication. To collect PSE data and to analyze root causes of PSE, reporting systems have been implemented in healthcare settings and patient safety organizations (PSO). However, the low data quality of reports impedes the reporting and root cause analysis (RCA) of PSE. Incompleteness or missing of data, is the most prevalent problem in PSE reports. Compared with data quality of PSE reports, dimensions and standards in data quality of electronic health record (EHR) are well discussed, which include completeness, correctness, concordance, plausibility, currency, etc. [1, 2]

Taxonomies and ontologies have been developed to standardize PSE reports, which hold promise to improving data quality and facilitating data sharing among healthcare facilities and PSOs. The National Coordinating Council for Medication Error Reporting and Prevention (NCC MERP) developed the Taxonomy of Medication Errors which defined standardized concepts, terms and relationships to improve medication error reporting, communicating and shared learning. In 2008, the World Health Organization (WHO) initiated a program for development and implementation of a generalizable

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framework, the Conceptual Framework for the International Classification for Patient Safety (ICPS), and furthermore released a Minimal Information Model for Patient Safety (MIM PS) based on the framework [3].

The purpose of this study is to understand the prevailing PSE taxonomies and ontologies to establish a strategy of data quality assessment for medication error reports. We examined the data quality, especially the completeness of the narrative part of medication error reports and discussed ontology-based solutions for the data quality issues.

2. Methods

2.1. Taxonomy for Narrative Medication Error Reports

We developed a taxonomy that was adapted from the MIM PS and other taxonomies in our previous work [4]. The taxonomy depicted the key elements involved in medication errors, including "Medication", "Indication", "Error Type", "Stage – Error Originating", "Personnel – Error Made By", "Stage – Error Caught", "Personnel – Error Caught", "Outcome", "Intervention", "Causes", and "Contributing Factors".

2.2. Dataset and Sampling

The dataset containing one-year, 3143 medication events was provided by our collaborator PSO. The reports were classified into 20 categories, based on a classification of error type adapted from the NCC MERP [5]. To reduce the human labor, we randomly extracted 63 reports (2%) from each category for further review and annotation.

2.3. Expert Review and Annotation

To assess the data completeness, three domain experts who are familiar with patient safety data and reporting process reviewed and annotated the medication error reports using the previously developed taxonomy [5]. The frequencies of presence (represented by "1") and absence (represented by "0") of the data elements were calculated and illustrated by error types. We summed the numbers to present the scores that reflect the data completeness. Discrepancies were fixed through group discussion.

3. Results

Two groups of taxonomies and classifications for patient safety are identified (Figure 1). In the International Classifications of Diseases (ICD), including ICD-9, ICD-10 and ICD-11, though not specifically developed for patient safety terms, the ICD terms focus on outcomes, for example, the adverse drug reactions (ADR). MedDRA, a taxonomy for adverse events of drugs and other medical productions, was developed based on ICD-9, ICD-9-CM, WHO-ART and FDA COSTART. Another group of the taxonomies focus on the attributes rather than the outcomes. For example, the NCC MERP Taxonomy of Medication Error is the first taxonomy exclusively designed for medication errors, which defines the terms and concepts in medication errors. Based on the JACHO patient safety

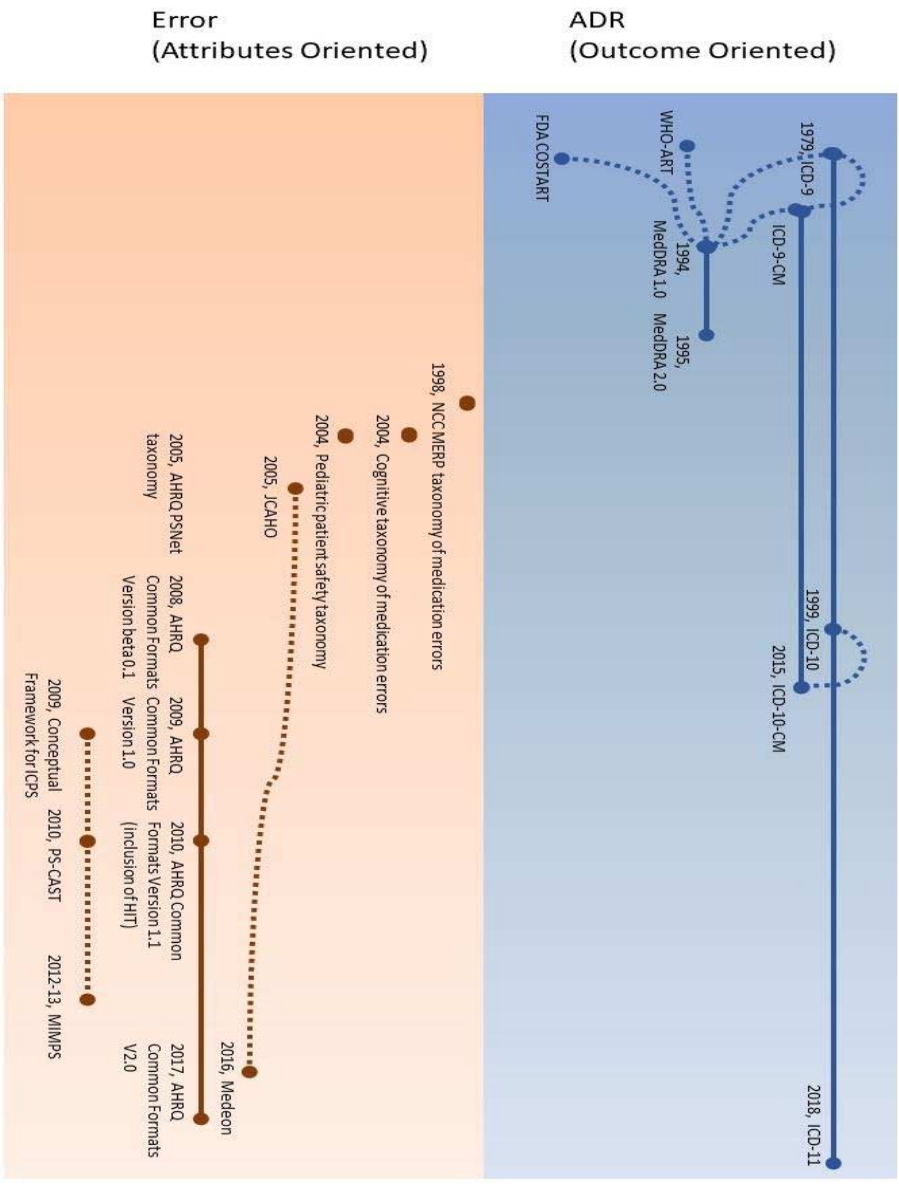

Figure 1. Evolution of taxonomies for patient safety. Solid lines: updates of the same taxonomy; Dotted lines: new taxonomies developed based on existing taxonomies.

event taxonomy, Medeon was developed for both human-understandable use and computer-compatible applications to present patient safety data including medication errors.

The data elements in the taxonomies were extracted and compared in Table 1. The elements shared by most taxonomies are drug information, type of event/error, outcome, cause and intervention. Causes and interventions are categorized in patient level and system level, according to the Instrument to characterize unintentional medication discrepancy (ICUMD) [6].

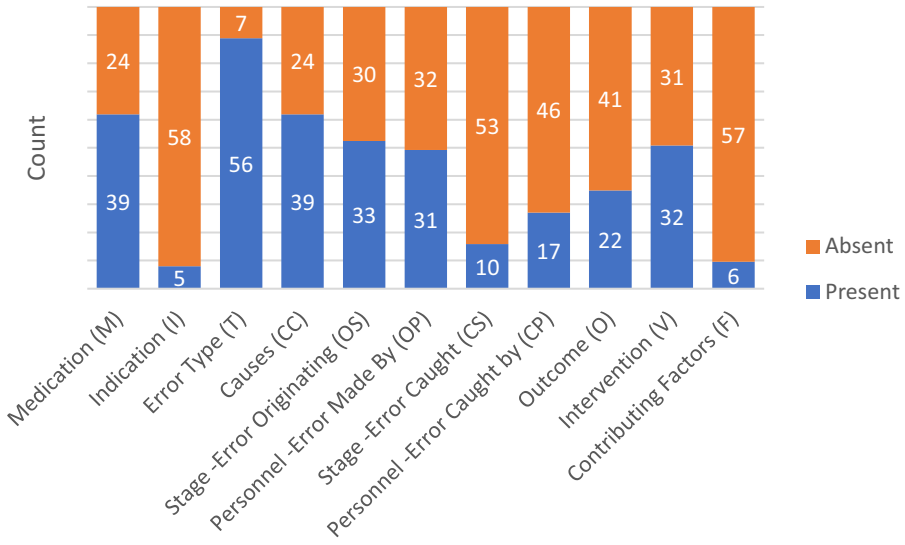

Figure 2. Absence and presence of data element in medication error reports (63 sample reports in the year 2016).

We reviewed and annotated the absence and presence of data elements on 63 (2%) sample reports. As shown in Figure 2, 56 reports contain the information of error types, while only 5 contain the information of indication and 6 contain the information of contributing factors. Meanwhile, information such as error originating stages and personnel is usually implicit, which makes it difficult to perform RCA.

Table 1. Categories and count of items of taxonomies for medication errors.

Notes: APS-Doc: A classification system for drug-related problems in the hospital setting; ICUMD: Instrument to characterize unintentional medication discrepancy; MDT: Medication Discrepancy Tool; NCC MERP: The National Coordinating Council for Medication Error Reporting and Prevention; PCNE: Pharmaceutical Care Network Europe; PI-Doc: Coding system for drug-related problems-interventions document.

Taxonomy, Author and Year	Categories/Domains and Count of Subcategories/Items (number of items in the brackets)
APS-Doc, Hohmann C, et al., 2012	Drug (13), Dosage form/drug strength (4), Dosage (7), Indication (3), Contraindication (1), Drug-drug interaction (3), Adverse drug reaction (2), Administration/Compliance (6), Application (7), Other (2)
ICUMD, Claeys C, et al., 2012	Type (11), Cause – Patient level (7)/System level (11), Interventions – Healthcare professional level (4)/Patient level (4)/Medication level (10)/Other
MDT, Smith JD, Coleman EA, & Min SJ, 2004	Medication discrepancy event description (Unstructured), Causes and contributing factors (19), Resolution (7)
NCC MERP Taxonomy of Medication Errors	The event (5), Patient outcome (4), Product information (5), Type (14), Causes (5), Contributing factors (14)
The PCNE Classification V7.0, PCNE, 2016	Problems (3), Causes (8), Planed interventions (5), Interventions acceptance (2), Status of the DRP (Outcome) (4)
PI-Doc, Schaefer M, 2000	Drug-related problems, Drug related interventions

4. Discussion

Despite the over-average presence rate of "Causes", the information is limited to direct triggers of errors such as choosing wrong medication name or dose in the system when prescribing or drawing incorrect dose of fluids, which are merely root causes. Compared to other data elements, the presence rate of contributing factors in the narrative reports seems quite low, because contributing factors are often not clear to the reporters upon the time of reporting. In many cases of medication errors, contributing factors are not immediately discovered and reported, which leads to the absence of invaluable information in the reports. Another challenge in medication error reporting is the balance between reporting efficiency and data completeness. Despite the information such as medications, indications and patient information that already exists in the EHR, reporters still have to manually fill the information in the reporting systems because the current reporting systems are stand-alone and do not have access to collect data from EHR.

Medication event reporting is a promising and important way of reducing the medication error occurrence and developing the error prevention strategies, especially for the high-alert medications. The Joint Commission in the USA has been collecting and analyzing error reports from accredited hospitals, and issuing alerts and recommendations based on the results of integrated data analysis. Reporting medication events remains a challenging task in clinical settings. medication events have one of the highest rates among all patient safety events. However, reporting medication errors can be time-consuming and labor-intensive. Medication errors may happen at any stage of the medication distribution process in hospitals, starting when a clinician prescribes a medication and ending when the patient takes the medication. Among all the medication error reports, those describing medication errors and near misses, are of high learning value for healthcare facilities to identify error causes and create processes to reduce the risk of errors.

Moreover, multiple personnel are likely to be involved in medication events, such as physicians, pharmacists, nurses, which could make event reporting complicated. The various types of medication event also increase the difficulty of reporting. Since a patient need to receive the right drug, in the right dose, at the right time and in a right way, any compromise during the procedure will lead to different types of errors. The cause of errors varies as well, for example, if a patient receives a wrong dose of drug, it may be due to a wrong prescription by physician, or a wrong administration by nurse. Thus, during medication error reporting, the events may need more elaborated narratives to restore the key information in the events.

To systematically study medication errors, guide the medication error reporting and promote the safe use of medications, it is important to build a taxonomy of medication error reporting. The effectiveness of medication error reporting and analysis of the error reports are highly dependent on quantity and quality of the data collected by medication error reports. NCC MERP Taxonomy of Medication Errors aims to record, track, categorize and analyze the medication errors is regarded as the most adequate medication error taxonomy. To reflect the complexity of medication error and the information need for its reporting, NCC MERP taxonomy has great potential in improving the efficiency and efficacy of medication error reporting if it is integrated in the error reporting system. The annotations on the taxonomy could help establish a knowledge base of medication errors. The knowledge base could make connection among various reports, unveil the healthcare professionals' blindfolds by providing them an integrated view of the events and showing similar cases and potential solutions to the cases under investigation.

Taxonomies such as NCC MERP taxonomy contain terms in high granularity that are useful for collecting rich information. However, clinicians, due to competing priorities, may be reluctant to complete a report with too many details, especially in narrative reports. It remains challenging for researchers to balance the efficiency and quality of reporting when considering the trade-off between richness of information and limited time and labor. Using our minimal information model for data quality assessment of the reports is a promising study for meeting the challenge and finding a solution.

5. Limitations

The sample size was limited. We explored the data quality of medication error reports, which may not necessarily reflect the facts of other PSE subtypes such as patient falls, surgical events, etc.

6. Conclusion

Despite the low data quality, narrative reports contain rich and valuable information. The taxonomy proposed in this study is a promising tool for report quality assessment and improvement, which facilitates the reporting and RCA of PSE.

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Medication Errors and Safety Culture in a Norwegian Hospital

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Abstract. Medication errors are associated with adverse health outcomes and may prolong hospital stays and increase societal costs. Safety initiatives to reduce adverse health outcomes should be based on reliable information of current shortcomings. The aim of this study was to identify barriers to medication error reporting in a hospital and to describe heath personnel's views of the safety culture. Seven interviews with health personnel (two doctors, four nurses and one pharmacist) were conducted November 2016 - January 2017 at the University Hospital of North Norway. Nurses, more frequently than doctors, reported medication errors and discussed reported errors at staff meetings. Doctors preferred to solve the problem directly, for example writing a new medication order, rather than writing a report when a medication error had been identified. There was variation between the wards regarding the perception of support, confidence in and focus on error reporting, which indicates different safety cultures within the hospital. Identified barriers to medication error reporting included lack of time, and the impression that the reporting system is complicated and not user-friendly. Staff also reported inadequate training using the system, which could contribute to the perception that the system is inaccessible. Hospital management should take actions to improve the safety culture throughtout the hospital based on the barriers identified in this study. This could include stronger focus on the importance of reporting medication errors, a transparent review process and clearly communicated actions.

Keywords. Medication error reporting, hospital, error reporting system, electronic error reporting, safety culture

1. Introduction

Medication errors are associated with prolonged hospitalizations at higher health costs and represent increased burdens for patients and public healthcare services [1, 2]. The cost of unwanted medication incidents in the US has been estimated to $3.5 billion annually [3]. Norwegian health institutions are obliged to report unwanted incidents where such incident has resulted, or might have resulted, in considerable personal injury [4]. During 2017, 10 126 incidents were reported in Norway. Among these were 1 676 incidents concerning medication management, of which 14 resulted in death [2]. Health institutions are also obliged by law to continuously work on quality improvement and patient safety [4]. This includes establishing and maintaining systems for reporting errors

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and incidents, and to incorporate a safety culture characterized by openness, which is a prerequisite to uncover and prevent errors [5]. Systematic evaluation of error reports is needed to further develop health services and increase patient safety. Error reports can be used to identify areas where there is potential to improve, and can indicate what actions should be taken to avoid repeated incidents and errors [6]. The University Hospital of North Norway (UNN) uses a web-based system for management and quality assurance procedures and appurtenant documentation.

The aim of our study was to identify barriers to medication error reporting and to describe health personnel's views of the hospital's safety culture.

2. Method

2.1. Recruitment and Setting

Semi-structured interviews were performed from November 2016 to January 2017 at UNN. The strategic selection of informants was based on purposeful sampling and included two doctors and four nurses from one psychiatric and five somatic wards, and one pharmacist from the hospital pharmacy. The number of informants from each occupational group was determined in advance to cover multiple occupational groups with distinct authorities and duties. There was no relation between the interviewer and informants. There were no inclusion or exclusion criteria for the selection of informants based on gender, work experience or employment status, since health personnel in general should know and have experience with medication error reporting.

2.2. Interviews

Two relatively similar structured interview guides were made, one for the pharmacist and one for the other health professions. The questions for the pharmacist was directed towards experiences from hospital departments and not the pharmacy. Examples of prompts from the interview guide: "*Please tell me how medication errors are reported"*, "*What would you say are some of the positive/negative aspects of error reporting?*", "*What happened the last time you identified a medication error?*", "*What happens after a medication error has been reported?*" *What stops you from reporting errors?*".

The participants were interviewed once by AA. Interview transcripts were not returned to participants for further comments or corrections. The interviews, which lasted on average 30 minutes, were recorded and transcribed. Field notes were taken during the interviews.

2.3. Data Process and Analysis

The audio recordings were transcribed and edited using a slightly modified verbatim mode. The data material was de-identified during transcription. All data obtained from the interviews were analyzed by AA and later discussed with MW and ECL to compare personal interpretations. We performed systematic text condensation (STC) inspired by Giorgi's phenomenological analysis, modified by Malterud [7, 8].

2.4. Ethical Considerations

This study was conducted according to the guidelines laid down in the Declaration of Helsinki. The study was approved by the data protection officer at the University Hospital of North Norway. Written informed consent was obtained from all informants.

3. Results

A total of five themes, Table 1, were derived from the text condensation.

Table 1. Simplified version of the analysis matrix describing the themes and selected informant quotes on which the themes are based.

Themes	Quotes
Defining a medication error	*"I think it may be unclear what is conceived as an error"* *"[…]we are supposed to report errors even if it didn't reach the patient and caused no patient harm"* *"It happens several times that the wrong dose is prepared but is discovered during double check. This is never reported as an error."*
Leadership/management	*"[…] we prioritize the clinical work"* *"There need to be a decree from the management that this is something we are supposed to do, or prioritize to do"* *"[…] show that reporting errors makes a difference. There also need to be emphasized that reporting errors are ok, and that we actually need to take the time to do it, because it is part of the daily improvement work."* *"The report is sent to the department manager, and then you might not hear anymore, you just hope that someone takes care of it. […] in my experience, the only way to have something done about an error, is to do it yourself."*
Safety culture/under-reporting	*"Yes, errors are reported, but I think far too few are reported, and I do not think there is a good environment for error reporting"* *"I think employees in the departments know that they should report errors, but I think there is under-reporting of errors"* *"I feel it [the culture] is good among the nurses, but not so good among the doctors"* *"We have a good culture for talking about the reported errors […]"* *"It is the nurses who report errors, at least in our department"* *"I have never received an error report from a doctor"*
Barriers* to error reporting	*"Lack of time, and that you don't understand Docmap"* *"[…] I think there is a lot of potential for improvement when it comes to training and focus on errors, at least among the doctors"* *"[reporting] errors sounds like you are starting to report and denounce, it sounds like something which implies punishment, more than focus on quality improvement"*
Electronic error report system	*"I actually started to report an error, but it was so cumbersome and I understood so little of the report form that I discontinued"* *"I do not think it is intuitive and it is too difficult to use"* *"I think Docmap has a poor reputation when it comes to finding procedures"*

* Specifically mentioned as barriers by the informants

3.1. Barriers to Medication Error Reporting

The informants described several factors that represent plausible barriers to medication error reporting. They can be summed up in four main points: 1) the electronic reporting system (access, training and interface), 2) time, 3) culture, particularly among doctors (whistle-blowing, no doctors' discussions), and 4) management (communication, support, transparent review process after reporting).

(1) The electronic reporting system was mentioned by all informants as a barrier to reporting errors. Several nurses and students do not have access to the electronic report system because their employment is not linked to a specific ward. Accessing the form and other specific files/procedures regarding medication errors was described as cumbersome, with little "expert knowledge" even among word management. Nurses expressed a need for more systematic training in using the electronic report system. Although training sessions for interns are held a few times each year, the system is used so infrequently that staff forget how to use it. informants report error rarely, and when the training is rare too, they forget how to use the system. The system was described as non-intuitive and difficult to use. Several believed that a more user-friendly reporting system could make it easier to report errors, be less time-consuming, and thus increase reporting.
(2) The informants talked about hectic times during the shifts where there is no time for reporting errors. Some had been told by their management to report the error in quiet periods during the day and, if necessary, report the error during their next shift. The error was therefore often forgotten and not reported.
(3) The opinions varied regarding how informants experienced the safety culture on different wards. However, there was a clear agreement that the safety culture among nurses is better than among doctors. Doctors do not see the learning potential in reporting errors. The few errors reported by doctors are rarely discussed and the potential to learn from, and prevent future errors, is therefore lost. For example, should the wrong drug be given to a patient, the doctors will solve this situation by prescribing treatment to reduce potential discomfort/side effects, and not report this as an error. Doctors feel in control of such situations, and they do not view this as something they should share and learn from. Doctors, and a few nurses, stated that reporting errors sounded like whistle-blowing and something that could result in punishment. They were anxious about reporting and thereby upsetting colleagues.
(4) The informants expressed uncertainty about what should be reported as an error in medication management. Medication errors that, for some reason, do not reach or affect patients are generally not reported. Neither are medication errors that are resolved within a short period of time. The doctors, and some of the nurses, thought there was a lack of commitment to error reporting at the management level. Some of the informants experienced a lack of incentive to report errors and lack of support from management when incidents occurred. Some of those who had reported an error, claimed they rarely received feedback, thus did not bother to file new reports. Others voiced concern about the quality and the tone of feedback when provided by management.

4. Discussion

"To err is human" [9] and the aim of medication error reporting is to learn from our mistakes, thereby continuously improving treatment and ultimately treatment outcome. To establish a good reporting culture it is necessary to develop and achieve a good patient

safety culture [10]. Previous research have shown that reporting medication errors improves the safety of future patients [11]. There is positive correlation between high error report rates and positive patient safety culture [12]. Still, not all errors and incidents are reported [13]. The reporting culture should be characterized by openness and reassurance. It should aim for safety, learning and improvement [4, 5], and it needs to be underpinned by management policies, and work environment [5]. The organization need to build collective trust, system perspective and aim to learn from mistakes rather than blame those who make mistakes [10].

Our study suggests poor reporting culture and under-reporting of medication errors throughout the hospital, with variation between wards. From the interviews, we identified several barriers that can be grouped into four main challenges; the un-intuitive reporting system, lack of time, poor safety culture and unsupportive management. Of these, the reporting system might be the easiest challenge to address. To find time to report medication errors might be difficult within staff budgets and changing the safety culture will need constant work over time. Management and leadership is important in itself, but also heavily underpins the other three areas [5]. A study at UNN in 2010 about error reporting in general found that the most important barrier to error reporting was lack of time, followed by the poorly designed electronic reporting system [14]. Measures were taken to improve the situation, but apparently not sufficiently to avoid the same findings in our study.

To correct the situation, a number of measures need to be addressed. *Firstly,* staff need to know what incidents and errors are, and what should be reported. Clear guidelines effectively communicated by management could resolve this. *Secondly*, reporting errors should be considered worthwhile or staff will not prioritize this task. Discussions about what has been reported, and what measures have been taken to prevent similar errors in the future, should be discussed with, and communicated to, all staff. This seems to be in place for nurses, but not for doctors. Doctors carry the main responsibility for the treatment, and are supposed to be "in control". A doctor making a mistake probably feel a heavier burden than a nurse, increasing the threshold for reporting the error and for discussing it with colleagues [15]. An appropriate action to improve the safety culture among doctors, therefore, might be to facilitate regular meeting points for such discussions, as suggested by one of our doctor informants. *Thirdly*, the system used for reporting errors should be simple, accessible and intuitive. This could be achieved by intensified training in using the system, or substituting the software.

5. Methodological Limitations

The seven informants were all women. Health professions, particularly nurses, are predominately female, and the topics discussed are fairly gender neutral. Still, the results must be interpreted in light of the lack of male voices.

Due to the time frame for data collection (Master's thesis), the number of informants were set in advance while the recommended procedure is to continuing until data saturation [16]. As the last interview provided little new information, it seems that seven informants were sufficient.

6. Conclusion

Hospital management should take actions to improve the safety culture based on the barriers identified in this study. This could include a stronger focus on the importance of reporting medication errors, a transparent review process and clearly communicated actions. Of specific actions we would recommend improved communication, to establish a discussion forum for doctors and to manage the practical challenges represented by the electronic reporting system.

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Classification Scheme for Incident Reports of Medication Errors

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Abstract. This study aimed to develop a classification scheme for retrieving information from incident reports of medication errors. This 15-category classification scheme captures minimal medication-incident related information from incident reports and thus serves as an information model for automatic information retrieval solution. The automatic solution uses recent advances in artificial intelligence methods to learn from incident report resources and is promising to the prevention of adverse drug events and promotion of safety in medical care.

Keywords. Incident report, patient safety, annotation guideline, International Classification for Patient Safety (ICPS)

1. Introduction

The World Health Organization (WHO), Institute of Healthcare Improvement (IHI), European Medicines Agency and National Institute of Health (NIH) have all developed reference guidelines for hospital incident reporting systems intended to promote an understanding of the causes and contributing factors of near misses and adverse events. Given the need for incident learning, many national and hospital-level incident reporting systems, such as the England and Wales National Reporting and Learning System in the UK, the Advanced Incident Management System (AIMS) in Australia [1], the Advanced Incident Reporting System (AIRS) in Hong Kong [2] and the Project to Collect Medical Near-Miss/Adverse Event Information in Japan [3], have long been used to collect incident reports.

Medication errors are among the most frequently occurring medical incidents and can potentially cause life-threatening harm to patients [4]. In this article, we report a newly developed medication error classification scheme. We aimed to evaluate the explicit properties of medication errors associated with incident reporting and to organise complex concepts into meaningful entities. The resulting classification scheme comprises both the essential concepts of medication errors and the corresponding methods of annotation used to extract practical information from incident reports. Our study provides a framework for information retrieval from medication incident reports that is suitable for the automatic extraction of essential medication errors based on recent advances in natural language processing (NLP) and artificial intelligence (AI) methods [5]. We envision that this type of incident reporting classification scheme could revolutionise the collection, usage, and retrieval of information from incident reports.

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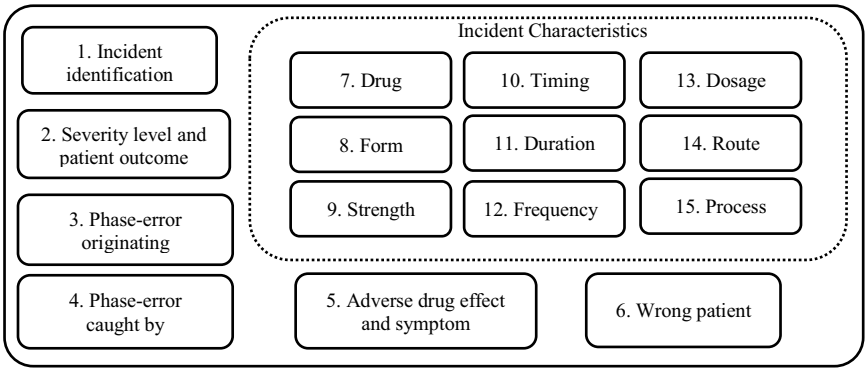

Figure 1. Proposed 15-category classification scheme.

2. Materials and Methods

This proposed classification scheme was developed to extract the minimal necessary information from incident reports of medication errors. We conducted a narrative review using the state-of-science incident reporting guidelines and existing literature on medication errors and classifications schemes and annotation. Literature from the WHO International Classification of Patient Safety [6], WHO Minimal Information Model for Patient Safety (MIMPS) [7], National Coordinating Council for Medication Error Reporting and Prevention (NCC MERP) [8], Agency for Health Research and Quality (AHRQ) Common Formats Version 2.0 [9] and European Medicines Agency Good Practice Guide [10], as well as other relevant studies [8, 9, 11-14], were carefully reviewed, referenced, and synthesised. We also referred to guidelines for the development of a classification scheme suitable for information extraction in general [15, 16] and clinical contexts [17, 18].

The occurrence and prevention of medication errors can be understood by considering their classification as contextual, modal, or psychological [11, 19]. In this research, we focused on a contextual approach to register the specifics of medication-related incidents. A contextual classification explains the event and why it occurred. The organisation and definitions of this classification scheme are presented in the Results section. Sample incident reports are used to illustrate the in-text annotation method for concepts that are likely to be found in the narrative text of an incident report.

3. Results

The classification scheme for medication errors is shown in Figure 1, and the synthesised categories are presented below. We proposed a scheme with 15 different categories based on the contexts of medication incidents.

(1) Incident identification. The MIMPS [7] defines patient information as data related to a patient who has been subject to a safety incident [7]. We therefore created an incident identification category that included both patient and incident information, including age, sex, time, location, people involved and reason for taking the drug. Age is defined as the length of the patient's life at

the time of the incident [7]. Sex is defined according to the patient's biological and physiological characteristics [7]. Time includes the date and time of day when the incident occurred. The time attribute also indicates seasonal/monthly changes, weekday and work shift, which may be essential hidden contributing factors [6, 7, 19]. Location refers to the physical environment in which a patient safety incident occurs. Environment includes inpatient (e.g., hospital, nursing home and care home) and outpatient settings (e.g., pharmacy, drug store and private home) [6, 7, 19]. People involved refers to those involved directly or indirectly in the patient safety incident [6]. Reason for taking the drug is defined as the medical cause for the prescription of the involved drug. This cause may be related to a disease, trauma, condition, procedure or any other issue. For example, a paediatric patient may require sedation for an examination. Here, we provide a sample incident report that addresses this section and its annotation method. (Incident report example: …the patient had hypoglycaemia due to viral enteritis. Doctor ordered 50% glucose without mentioning infusion or mixing in a bottle…).

(2) Severity level and patient outcome. Most mainstream literature on incident reporting identified a severity level component, such as the ICPS, NCC MERP and AHRQ [6, 7, 10]. In this category, we adapted the classification level developed by the National University Hospital Medical Safety Management Council in Japan [20] and mapped this with other state-of-the-art definitions.

(3) Phase-error originating. This category describes the phase of medication delivery wherein the error originated [9], including prescription, dispensation, preparation for administration and administration. A medication error may trigger a series of events, and multiple phases throughout the drug treatment process may be affected by an error.

(4) Phase-error caught by. This category describes the phase wherein the error was discovered or caught [9]. Errors may be detected during prescription, dispensation, preparation for administration and administration. As with phase-error originating, it is important to capture this category because an incident must be discovered before it can be stopped from reaching the patient. This information would provide an indication of any error-detection mechanisms in the medication process.

(5) Adverse drug effect and symptom. This category refers to any actual symptoms and reactions experienced by the patient. It is important to identify any irregularities in a patient's condition and to consider whether these might be related to an inappropriate medication [21]. (Incident report example: …acyclovir was extravasated on the patient's left forearm. The patient experienced pain and a hot sensation. The line used was old and caused difficulties during infusion…).

(6) Wrong patient. This category includes both an unordered-drug error affecting the patient who received the dose and an omission error affecting the patient for whom the dose was intended. The incident report should indicate both the event and progression of the affected patient [22]. (Incident report example: proton-pump inhibitor (PPI) was mistakenly administrated to patient A instead of patient B…)

(7) Drug. This refers to either the agent intended for delivery to the patient [6, 10] or the actual drug delivered to the patient. Blood products, illicit drugs and

alcohol should not be included. (Incident report example: …doctor prescribed diltiazem instead of diazepam…).

(8) Form. Form includes the prescription of a different form of the drug or different mode of action. (Incident report examples: …doctor ordered a stop of oral furosemide but the nurse mistakenly stopped intravenous furosemide…) (…sodium valproate was prescribed, but sodium valproate ER [extended release] was dispensed by the pharmacist…).

(9) Strength. Strength includes the amount, concentration or rate of medication. (Incident report examples: …pharmacist dispensed a 5-mg prednisone tablet instead of a 1-mg prednisone tablet...) (…doctor ordered vancomycin 500 mg diluted in 100 ml normal saline but the nurse used vancomycin 500 mg diluted in 10 ml normal saline) (…doctor ordered a change in the rate of fentanyl to 0.5 ml/hr but the nurse missed the order…).

(10) Timing. Timing-related errors include too-early or too-late administration relative to the designated time. (Incident report example: …nurse forgot to give oxycodone to patient at 8am. After discovery, the nurse administrated oxycodone at 11am...).

(11) Duration. Duration is defined as period during which a drug is administered to the patient [23]. A duration-related error may refer to a longer or shorter period than intended. (Incident report example: …doctor ordered the administration of 100 units/kg intravenous heparin sodium injection for the treatment of deep vein thrombosis for 7 days...).

(12) Frequency. Frequency is defined as how many times a drug is given per unit of time [23]. Frequency-related error may refer to a larger or smaller number than the planned number. (Incident report example: …doctor ordered heparin calcium 3 times/day for the prevention of deep thrombosis after myoma operation. Nurse administered it 1 time/day….).

(13) Dosage. Dosage is defined as the number of units (e.g., tables, bottles and ampules) given to the patient as a single dose [23]. Patients may use excessive or insufficient amounts of drugs. (Incident report example: …doctor ordered 3*100 mg aspirin tablets 1 time/day, but the nurse gave 1*100 mg aspirin tablet...).

(14) Route. Route is defined as the route of drug administration to the patient, which may include the infusion sites, routes and pumps. (Incident report example: …acyclovir was extravasated on the patient's left forearm…).

(15) Process. Process includes violations of the standard operating procedures (e.g., expiration, storage method and technique), violations of indication (e.g., off-label use), drug-drug interactions and monitoring errors. The latter refers to drug-food/nutrient interactions, documented allergies, drug-disease interactions and clinical factors [8]. Information technology-related errors are also included in this category [13, 24]. (Incident report ex.: …nurse did not check the expiration date, and an expired medication was given to the patient...).

4. Discussion

Figure 2 demonstrates the annotation of incident reports using multiple concepts from the classification scheme. The combined use of multiple concepts could provide

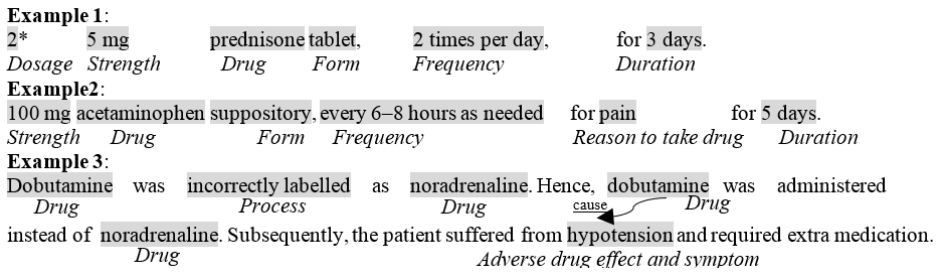

Figure 2. Example of annotations.

important insights regarding the nature and progression of incidents. For example, the drug category can be used to identify look-alike and sound-alike drug errors. The combination of age, drug and strength would allow us to identify hidden age-specific problems related to drug-taking errors. Furthermore, this schematic can also flexibly capture the relationships between concepts (Figure 2, example 3, arrow). This flexible framework thus provides possibilities for the exploration of new mechanisms involving medication errors and adverse drug events. We further plan to develop and verify this classification scheme using other entity attributes (e.g., introducing the dimensions of intended and actual events in the incident characteristic categories) and large volumes of hospital medication incident reports. The definitions of some categories, such as process, may require further investigation to enable the accurate extraction of information. We plan to validate this scheme internally and externally together with experts in patient safety and annotation guideline development. An externally validated classification scheme will allow patient safety researchers to compare incident reports among different institutions and countries.

We note that the interpretation of an incident may be subject to the reporters' explanation and the annotators' knowledge, as demonstrated by a case regarding the extravasation of vancomycin. This drug has a strong ability to cause tissue damage and is thus prone to inducing extravasation. One may record or interpret such an event as a strength-related error because of the high concentration of diluted vancomycin. However, this incident could also be classified as a process-related error because the clinical manual for vancomycin usage recommends dilution of this drug before usage. Any healthcare workers required to handle vancomycin should know this standard procedure. However, other workers may not be familiar with this procedure.

5. Conclusion

We developed a classification scheme for the extraction of information from medical incident reports. This scheme allows us to understand the systematic causes of medication errors, to compare information between institutions and countries, and possibly to detect hidden incidents by combining entities. Next, we plan to validate this scheme using hospital incident reports, perform internal/external validation and develop an effective information retrieval solution for incident reports based on AI-assisted clinical decision support.

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Methods and Models to Study Contexts for Health Information Systems

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Supporting Safety in Health Care Transformations

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Abstract. Health care is in dramatic transformation due to the rapid development and massive implementation of (high- and low-tech) technologies. But not all transformations are as intended. Research in health transformation has disclosed new sources of risk and unpredictability, which require more research and organizational adjustment, i.e. learning. However, unintended consequences and effects occur at different levels of interaction and collaboration, requiring corresponding adjustment and learning strategies. – On the background of an ethnographic study of support-work in surgery in different Danish hospitals, this paper analyses cognitive-socio-technical health care practices as learning ecologies, giving special attention to the intentional and unintentional roles of technologies herein and their context dependency. The paper argues for an increased awareness of support at different contextual levels of use, presenting three examples from the study as learning cases. The three cases exemplify instances of disruption of the workflow and the collaboration among clinicians. They display how these instances are taken as challenges requiring learning at different levels in order to live up to the overall purpose, which is to reestablish safety – in the team and for the patient.

Keywords. Transformation, HIT, patient safety, unintended consequences, infrastructure, learning, support, ecology

1. Introduction

Technologies play a decisive role in health care transformation, but not always as intended by developers and implementers, or wished for by users. This has led to a new research agenda for patient safety, as hospital information technologies (HIT) have induced new kinds of errors, and unintended consequences [1-4]. These hazards to clinical work have subsequently been studied as human factors in system design, with an emphasis on cognitive user aspects of interacting directly with the system, or as socio-technical challenges from a poor 'fit' between system and the work process of the organization. A more holistic view is advocated within a three-level framework, integrating both cognitive usability tests with social-technical analysis of communication and interaction in simulation studies in order to improve the design of the system prior to implementation [5]. Trends in HIT show, though, that the literature focusing on technology-induced errors continues to grow. More research is recommended to better understand and mitigate these types of errors [6]. There is a wide acceptance among researcher and policy makers that errors have many sources, and that research in software engineering, human factors, sociotechnical and organizational perspectives all are important to ensure safety in HIT [6]. One important approach is to see "errors as opportunities to learn from with the focus of improving HIT across the system

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development life cycle" [6:72]. One might also see errors as a source for organizational learning in order to improve workflow and to develop educational competencies that ultimately prevent errors and ensure quality in the long-term. Educating health and HIT professionals thus becomes important to fully disclosure and understand technology-induced errors [6]. Future directions of research are to "create organizations where there is a culture of HIT safety" [4]. This paper takes an organizational learning perspective, seeking to support HIT and health professionals' understanding of the contextual and cognitive, socio-technical nature of safety, and health care infrastructure [1,5]. An ethnographic study of support-work in surgery is chosen [6,12,13] to demonstrate the challenges of safety and learning in technology-dense health environments were predictability and team-collaboration is mandatory to patient safety.

2. Learning ecology

The three level framework of studying technology-induced errors in health care can be explained within the cultural-historical tradition of Activity theory, which discerns between three contextual levels of interacting with technology as an activity system, and the learning ecology of Gregory Bateson [7-11].

Human activity is object- and goal-oriented, conditioned by operational skills, embedded into existing practices, mediated by tools, and motivated by collective rules, values and division of labour. Interruptions or breakdown of activities fx from technology implementation can be identified as different levels of learning in the ecology. The 1-level of learning relates to the subject's operating skill and direct interaction with the tool, i.e. cognition and usability. The 2-level learning relates to contextual awareness and utility, when collaboration is mediated by artifacts, then adjusting and integrating different contextual understandings in the system and between users becomes essential. The 3-level learning is provoked from the experiences of double bind between divergent contextual understandings. If they contradict, and mutually exclude each other, then radical learning and creativity are demanded in order to establish a new organizational order. Accordingly, 0-level learning denotes the true ideal state, which is sought, not because of organizational laziness, but as an expression of harmony, the concordance between tasks, competences, motives and resources; the seamless fit between users, systems and activities. 0-level learning expresses the equilibrium of the ecology, and thus the safety and stability of the activity system as such.

3. Case-study of Support Work in Surgery

The case is developed from ethnographic field work with document analysis, 90 hours of observation, and twenty-six interviews [14,15]. It was conducted in three different hospitals located in the Capital Region of Denmark, two of which are university hospitals, with research as part of their practices. All of the hospitals have 24-hour emergency surgery and elective day surgery from 7:30 a.m. to 3:00 p.m. The study was undertaken at four surgery centers, covering the specialties of obstetrics, gynecology, gynecological oncology, orthopedic surgery, urology, abdominal surgery, pediatric surgery, pediatric oncology, and vascular surgery. The elective day programs in nine operation rooms (ORs) were observed, with a special focus on programs of action [16] in operational support work. The support work of nurses, social health care workers, and technical

assistance was observed in the ORs, documented through photographs and detailed notes on type of operation, action sequences, relations to humans and nonhumans, and modes of communication. Field notes and interviews were analyzed according to the theoretical frameworks of human–computer interaction and expansive learning in activity theory [11,17,18].

4. Intentional activities in surgery

The many sequences of action, interactions, and communication in the ethnographic study can be summed up as two programs of action (16) that explain the meaning and motives of operation support work in the activity system of surgery: first, and foremost, ensuring safety and second, efficiency. The following presents the first program of action.

4.1. The Program of Action: Ensuring Safety

The first program of action is concerned with ensuring safety in the care pathway for individual patients entering and leaving the OR. Ensuring safety is paramount to surgical support work, as it is not only concerned with the patient, but also with the surgeon's need to feel safe to concentrate on the operation itself and the general safety in the team as a group, with its interdependencies and shared responsibilities. There is a wide range of techniques, guidelines and rituals to ensure smooth and safe collaboration in the OR.

The room is divided into two zones; a sterile zone and a non-sterile zone to manage the continuous risk of infection. The sterile zone in the OR is constantly encroached by various kinds of disturbances that challenge safety in different ways: for example, by increasing the risk of the patient's wound being infected or breaking the surgeon's concentration. A chief surgeon sums up:

> *There is always a risk. We are in a sterile environment. Everything takes place in a sterile environment. This means that I can't just go to a cupboard and get what I need. Everything has to be in place from the beginning. We can plan 90 per cent, but something will always happen that wasn't planned for […]. It's a balance that means that you have to send people (non-sterile) in and out of the OR/room to fetch the things you need. Or you find out that it's really another type of operation the patient needs, and you have to re-saddle. Doing emergency surgery also amplifies this. These are the terms.*

Operation support work is thus concerned with ensuring maximum safety, knowing that absolute predictability is impossible to attain. There will always be a small amount of risk to learn from, chance to be aware of, and adjustments to make [19].

The "90 percent" predictability of an operation is achieved by the team in a process with three phases: the preoperative, intraoperative, and postoperative phases. These are elaborated in [12], and point to team collaboration in the OR as non-verbal "ping pong" in coordinated movements in and out of sterile and non-sterile, zones to be an ideal.

5. Unintentional transformations from disruptions of interaction, flow and safety

The unanticipated "10 percent" that is impossible to predict and plan for in advance, is always a threat to safety in the OR. Below are examples of disturbances at different levels

of interaction, leading to different kinds of breakdowns that challenge the role of the surgery support in the team, its resilience, and the safety of the patient.

5.1. Disruption Caused by a "Burner with No More Lives"

This example comes from gastrointestinal surgery. In many cases, open "low-tech" surgery using a scalpel and suture is replaced by endoscopic, high-tech surgery (i.e., laparoscopy, also called keyhole surgery), where operations are performed through small incisions in the body. A burner is used instead of a scalpel inside the abdominal working space to burn, instead of cutting out, affected tissue. The burning prevents the tissue from bleeding. In this example, the burner stopped working during the operation and, thus, interrupted the flow. The nonsterile supporter had to send for a new burner from the storage room. The surgeon became annoyed with the support workers because the "knife time" of the operation was prolonged by the wait for the new burner.

5.1.1. New task and guideline to keep count of use of burner

In the future, support staff members are expected to keep count of the burners' limited lifetime of twenty operations. This is a new task for the support workers, and they would have to agree on the development of a new "tool," a guideline to control it. Keeping systematic track of burners' lives through a guideline becomes an attempt to handle the high-vulnerability context in which surgery takes place, in a way that attempts to prevent any disruption to safety and efficiency. The technology must work according to plan.

5.2. Change of Direction in Mid Operation

The second example is also from abdominal surgery, on a patient with a gastrointestinal stromal tumor. Lack of access to the digital information system (with the patient's radiology scans) forces the surgeon to switch from the planned endoscopic operation to open surgery. In endoscopic surgery, the working and viewing space is provided by a laparoscope, a long, fiber-optic cable system, and carbon dioxide gas, which inflates the abdomen and thus makes it possible for the surgeon to see inside the patient's body. The image from the laparoscope is displayed on monitors placed above the surgery bed for the surgeons to look at and navigate by. However, they need additional information from the radiology scans to get a better overview to predict the location of the tumor and to navigate between the organs of the abdomen. However, as the information system remains inaccessible on this occasion, the surgeon was forced to change plans, and, thus, the whole operation was converted to traditional, open surgery, where the team members rely on their senses to observe and navigate directly inside the patient's body using their eyes and hands. This conversion of operational procedure increased safety because the nonworking HIT had made the planned procedure unsafe, but it also increased the operation time, the time the patient spent in anesthesia, and the size of the patient's operation scar.

5.2.1. Destabilization of Teamwork Because of an Inaccessible Information System

After the shift to open surgery, the team's spirits were low. There was no "ping-pong" between the team members, just a hostile atmosphere in the OR that was made worse by the knowledge that the patient would have a large operation scar, which in light of the events, became unavoidable—sixteen stitches for an incision of 14 cm. In the end, the

surgeon, clearly dissatisfied with the support workers, stated that they were "not a team." The support workers, on the other hand, had neither the skills nor the administrative user rights to solve HIT barriers. Therefore, the resilience of the teamwork, as well as the sustainability and efficiency of the operation program of the OR, depends on HIT infrastructures, and the organizational support of these.

5.3. Risk in Technology-Driven Research

Image technologies have also opened up new research possibilities between radiology and vascular surgery. Interventional radiology in vascular surgery makes minimally invasive image-guided diagnosis and treatment of disease possible. In this example, a young woman with leg pain from poor blood circulation is diagnosed with narrow veins, using image-guided diagnosis, and is offered treatment via the insertion of a stent to increase the diameter of the troublesome vein. She received only a local anesthetic and expected to participate in the image-guided surgery, holding her breath to improve the quality of the X-ray images, and so on. The stent was inserted after 2 hours of surgery, but after that, a blood clot (vein thrombosis) developed in the leg being operated on. The surgeon monitored developments continuously, viewing new images, and, in consultation with a radiologist, decided to continue with the operation, to prevent paralysis in the patient's foot. The stent was to be removed, after which, the blood clot would be sucked out to allow the blood to flow through the vein again. This prolonged the interoperational phase by several hours.

5.3.1. Ethical Patient Dilemma: "Hold Your Breath"

The patient is awake, holding her breath every time the accelerator takes an image. The X-ray radiation alarm—which monitors the amount of radiation the patient is being exposed to—goes off several times and is repeatedly turned off manually by the supporting nurse. At the same time, a team of four works intensely on finding and removing the clot by drawing out blood with a tube, called a venous access catheter. The surgeon needs total silence to concentrate. The work of the team requires fine motor skills and many coordinated movements, which are repeated in successive steps: patient holds her breath, X-ray, adjusting tube, drawing blood out, examining it for clots, cleaning instruments, and then again, holding of breath, tube adjustment, and so on, for more than 2 hours. The patient gradually becomes uncomfortable, cries quietly, starts shaking and sweating, and asks when this will be over. In the meantime, the personal assistant of the surgeon is called in, and two extra nurses come in to calm the patient. The patient complains that this was not what she was informed of and consented to. She wants to go home! A senior surgeon tells her that she has to spend the night in hospital.

6. Conclusion: Unintended Transformations in Surgery

Technologies are transforming health care and patient safety, also unintentionally. Technology-induces errors continues to rise [6]. The errors have many multiple sources and demand research into a range of knowledge areas from improvement of technology design to organizational learning [6]. This research draws on ethnographic methods and meta-theory to explicate and draw attention to different levels of interaction [4-6] and learning in health care organization in order identify risk and secure safety [4,9]. The

three examples point to interruptions of use that effects the safety in the OR. They transform the activity system at *different levels of interaction*: i.The broken burner at *the direct level of interaction, ii.* The inaccessible Information System at *the mediated level*, as the operation plan gets subverted to knife surgery, disturbing team collaboration, and iii. The role of the patient at *the infrastructural level*, as patient safety which is the core value and motive of surgery is jeopardized, and transformed, when the patient becomes co-responsible for her own safety during the operation. An awareness of these different, contextual levels of interaction is essential to a safer HIT culture. Support of usability and utility problems in cognitive-socio-technical practices are thus sources towards learning ecologies [10] that secure intentional transformation of health care.

7. Discussion: Intentional Transformation in a Socio-technical Learning Ecology

Following the learning ecology [1,2,7-11], errors and interruptions can be addressed as different levels of learning, that the organization can attend to in order to adjust and prevent unintended transformations of its health care practices.

7.1. Supporting Safety from different levels of learning

The overall purpose of the surgery as an activity system is patient safety and efficiency, which is achieved by planning, "ping-pong" and flow in teamwork. This corresponds to the 0.level of the learning ecology; it is a system in equilibrium with optimal use of its resources. This is experienced in the OR as harmony, because everybody knows his or her place and how to fulfill his or her role. It is the team as a predictable and stable "clock-work" with adequate competences and mutual trust, and thus safety.
When the broken burner occurs, the harmony and flow is disturbed, and a 1.level learning situation arises. The obstacle is solved by the non-sterile support worker, who leaves the OR for the storage to replace the burner. Future problems are prevented by creating a guideline for keeping account of the number of times the burner has been used.

The inaccessible information system is a more complex, 2.level learning situation, as the collaboration of the team is not mediated, neither the endoscopic operation, nor the collaboration of the team, as the support workers fail to solve the it-problem. This learning situation is not only an information problem, like in case of the broken burner in the 1.level learning. It is a contextual knowledge problem of understanding how the information system works, and for the support workers to be given administrative user-rights to the system, so that they can support the surgeons in getting access to the radiology scans. This kind of user support in relation to information technologies, that the safety and efficiency of operations depends on, is absent to the team, and outside the competences and jurisdiction of the support workers (all nurses by training). Lack of it-competences and/or it-support becomes a risk to efficiency (from prolonged operation time and anesthesia) and to safety. It also puts the support workers in a double bind, and thus 3.level learning position as the angry surgeon, who leads the team, see it as their task to solve the it-problem.

The third examples points to an ethical dilemma in technology-driven research as the understanding of patient safety in surgery transforms when the patient becomes part of the team, its efficiency and safety. The patient is in a double bind situation of becoming a risk to herself. She wants to leave the operation table while she is undergoing a prolonged operation (from the unexpected blood clot) she has not consented too. The

awake patient herself becomes part of the unpredictability, and puts the safety of the team and herself at risk. She has to stay on the table and keep her breath when signaled in order for the operation to be carried though successfully. Her leg is saved, but her patient right is violated, as well as the relationship of trust between patient and health care system, which leave both, patient and the team, in a borderline position.

This 3.level learning situation is not solved by information, like the 1.level, nor by new contextual understanding, the 2.level, but transcends established understandings. It is therefore an unpleasant, stressful position, only to be solved creatively, by thinking out-of-the-box, so to speak. In this case, there is no right answer, but seems to be the backside of research: unpredictability and thereby risk, rises for the patient and for the team, when developing new forms of surgery from new technological possibilities. The 3.level learning opens up to the ethical, and thus the bio-political nature of social-technical ecologies, including research agendas and motives hereof.

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Context Sensitive Health Informatics: Sustainability in Dynamic Ecosystems
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Shared Decision-Making in Emergency Departments: Context Sensitivity Through Divergent Discourses

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Abstract. Patient-centred care and the empowerment of patients through shared clinical decision-making is a key goal of healthcare systems internationally. The Emergency Department is one of the first opportunities for shared decision-making to occur, with information exchanged between patient and clinician, between clinical disciplines, across the continuum of care, and between clinicians and ancillary departments including radiology and pathology laboratories. The successful development and implementation of sustainable health information technology (HIT) to support shared decision-making in Emergency care requires an understanding of the factors affecting this context. From a purposive, maximum variation sample of clinicians and a convenience sample of patients across three metropolitan and regional Emergency Departments in Australia, we identified three divergent discourses from an in-depth qualitative exploration of issues around shared decision-making. This allowed us to identify unanticipated factors affecting patient-centred care to inform context-sensitive implementation of HIT in the Emergency Department.

Keywords. Patient-Centred Care, Emergency Care, Health Information Technology, Shared decision-making, Pathology, Medical Imaging

1. Introduction

In the Australian healthcare setting, patient-centred care is enshrined in the ethical principles of informed patient consent, the professional standards outlined in the Australian National Safety and Quality Health Service Standard 2: Partnering with Consumers (Second edition) [1], and The Australian Charter of Healthcare Rights [2]. Patient-centred care improves patient outcomes and satisfaction by enabling patients to become partners in their own healthcare through shared clinical decision-making that respects and responds to their preferences, needs and values [3]. On the continuum of care, the Emergency Department (ED) is one of the first opportunities for this shared decision-making to take place, where health information technology (HIT) systems, particularly concerning tests and test results, are used to exchange health information between patients and clinicians, between clinical disciplines, across the continuum of

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care, and between clinicians and ancillary departments including radiology and pathology laboratories.

The Institute of Medicine describes patient-centredness as a core healthcare service deliverable, and identifies empowering patients to manage and execute healthcare decisions as a key competency in 21st century healthcare [4]. Healthcare is a complex, adaptive sociotechnical environment in which even well-designed technology can fail due to contextual issues [5]. Developing HIT that supports patient-centred practices in healthcare requires a sociotechnical approach that considers both people and technology [6]. The failure to be context-sensitive when implementing HIT can lead to adverse effects on workflow, communication and safety [7]. Therefore successful and sustainable HIT development and implementation requires in-depth research that expands our understanding of the broader range of contextual factors [8] within particular healthcare settings. This enables us to anticipate rather than remediate issues post-implementation, and thus ensure the sustainability of HIT that supports patient-centred care [8].

A sociotechnical approach to HIT places an emphasis on the inclusion of qualitative [9] and sociotechnical methods such as participatory design [8], seeking the perspectives of clinicians and patients to identify these contextual factors. Additionally, seeking deviant cases [10, 11] and divergent discourses in qualitative data [12] enables researchers to discover potentially unanticipated factors. Therefore, by identifying divergent cases from an in-depth, qualitative study of the perspectives of a diverse sample of clinicians and patients in ED, this study aimed to identify factors potentially affecting the implementation of HIT supporting patient-centred care.

2. Methods

2.1. Study Design, Setting and Participants

This study included one regional (Site 2) and two metropolitan (Site 1 and 3) hospital EDs in New South Wales (NSW), Australia (see Table 1). MD and JL conducted 58 semi-structured face-to-face interviews between December 2016 and May 2018. A purposive, maximum variation sample of clinicians across the three sites (n=26) spanned Nursing, Medical and Management/Executive positions, various levels of experience from interns to senior specialists, and both male and female participants (Table 1). A convenience sample of patients (n=32) were eligible to participate if they presented to the ED of one of the three sites and received pathology or medical imaging testing. The sample featured a wide variety of clinical presentations and both male and female participants who ranged from 25-34 to 75-84 year age brackets (Table 1).

Table 1. Hospital and patient demographic information across sites

Site	Hospital Demographic	Average quarterly ED presentations in 2018*	ED Clinicians, n (% Female)	ED Patients, n (% Female)	Site Total
1	Major Metropolitan	17,245	14 (28.6%)	13 (61.5%)	27
2	Large Regional	10,022	7 (57.1%)	10 (60.0%)	17
3	Medium Metropolitan	7,691	5 (20.0%)	9 (55.6%)	14
		TOTAL	26 (34.6%)	32 (59.4%)	58

* Calculated using Bureau of Health Information ED presentation data for 2018 [13]

Ethical approval was obtained from the Human Research Ethics Committee of the relevant Local Health District and ratified by Macquarie University. All participants provided written consent to participate.

2.2. Data Collection

Clinicians were asked to describe current test management and communication processes, including: i) whether patients/family were informed about the types and purposes of tests; ii) how it is ensured that information is conveyed to patients/family in a way that is easy to understand and iii) if there had been any staff communication training.

Patients were asked about: i) their awareness of the types and purposes of tests ordered; ii) the results of tests and their understanding of the meaning of their test results; iii) their ability to access their results; iv) who communicated the results to them; v) how they felt about the result reporting process and vi) their opinion of potential electronic access to test results.

All interview data was audio-recorded and transcribed verbatim. All transcripts and recordings were de-identified and demographic information reported only as an aggregate (Table 1) to preserve participant anonymity.

2.3. Qualitative Analyses

In addition to being a highly important strategy for testing the internal validity of qualitative findings [10], seeking deviant cases [11] and divergent discourses [12] is valuable for studies which aim to discover unknown factors and capture the breadth and complexity of an issue. As we sought to inform the sustainable implementation of HIT in the ED context by identifying potentially unanticipated aspects of shared decision-making in ED, we analysed the whole dataset from all 58 participants to identify and examine discourses that were divergent from the remainder of the dataset [12].

Firstly, as data collection was part of a broader study of test result management, communication and follow-up [14], for the purposes of this study, MD and JT systematically excluded data describing test management processes to obtain data across all 58 participants which pertained specifically to the communication of diagnostic test information between patients and clinicians in ED. MM and MD then completed an iterative analytical process involving (1) immersion, (2) description, (3) coding and categorisation, and (4) interpretation of the dataset from 58 participants using both thematic [15] and qualitative content analysis [16] methods, after which MM and MD reached consensus on discourses that were defined as meeting all three of the following criteria: (1) represented a diverse or divergent view not seen elsewhere in the dataset from the 58 participants, (2) explored an aspect of shared decision-making in ED and (3) described the issue directly and in sufficient detail.

3. Results

As a result of our iterative analyses, three discourses met all inclusion criteria. These related to 1) the value of case and family history in preventing diagnostic error; 2) providing health information to facilitate self-management of chronic conditions and 3) clinician barriers to supporting patient health literacy of tests and results. We supply

below verbatim excerpts from each identified discourse, with indication of how each diverged from the whole dataset of 58 participants.

3.1. The value of case and family history in preventing diagnostic error

One patient reflected on an incident in their own life in which "I always felt that if that doctor had been able to – or given me advice to seek a second doctor's opinion, I would have been saved from a stroke which would have rescued my life and changed my life quite dramatically". This patient was the only interviewee across the whole dataset who described case and family history as a factor leading to an adverse outcome. The patient's conclusion from this experience was that:

> *"…you should be given your medical records in any form that you can take from GP [General Practitioner] to GP and it should be available to every GP. I had a long family history of stroke; both my mother and her sisters and my grandmother, all died from stroke, and yet nowhere was that information requested of me or did we know. It was only after I'd had a stroke we began to ask in my family and found out that my whole family had virtually died of stroke, whereas it would have been really handy to have had that information and been able to pass it to any doctor that I was seeing, and they have at least a starting point."*

3.2. Providing health information to facilitate self-management of chronic conditions

While most clinicians noted that providing health information enables a patient to take ownership of follow-up from ED with their own GP, one doctor described this information as "part of the reassurance" and the empowerment of patients to self-manage chronic conditions through adequate information and support;

> *"…if a patient comes in with, for example, headache, chronic headache and the first two presentation[s] of headache for each and every person - it will be like, you know, [a] nightmare because you will think about all the wrong, you know, very unusual things. But if - for example, migraine headache; most of the patients can manage at home and they have [a] weekly or bi-weekly or once a month attack, but they manage at home. They stop managing at home when they be[come] aware about the red flags, if we can call it [that], and what they need to- when exactly they need to come in [to ED]."*

This case was also distinct because an emphasis on efficiency in ED was a commonly cited reason among clinicians elsewhere in the dataset for not prioritising communication with patients, yet this exemplar advocated for greater triage efficiency in ED through increased communication and shared decision-making.

3.3. Clinician barriers to supporting patient health literacy of tests and results

While most clinicians across the dataset voiced the aspiration to inform patients despite describing shortfalls in doing so, one participant in the clinician sample provided a distinctly different tone from the remainder of the clinician sample and maintained this divergent discourse in the presence of a peer in the interview. This clinician countered the patient communication efforts described by their colleague by reasoning:

> *"…given that most junior doctors don't understand what the tests are anyway, it's a bit silly to try and explain to the patient. And the words that we use are a bit funny".*

This participant was unique in identifying this knowledge gap as a barrier for clinicians:

"But sometimes I don't actually know what test I'm doing when I'm talking to them. And that's the problem with the juniors: they don't know what test they need done".

4. Discussion and Conclusion

The aim of this study was to identify and examine divergent discourses from a diverse sample of 58 patients and clinicians in ED. Our findings support the value of this methodology to discover factors that may not otherwise be investigated and so capture the breadth and complexity [11, 12] of shared decision-making processes in ED.

The first exemplar depicting a diagnostic error is consistent with recent estimates that most people will likely experience a diagnostic error in their lifetime [17], and represents the individual experience of such an incident. The adverse outcome points to the potential impact of diagnostic error upon an individual's life, and the patient right and need [2] to be engaged in the diagnostic process [18]. It captured the importance of integrating a person's case and family history with their clinical presentation and test results, the value of partnering with patients as the only party in the shared decision who can "ask in my family" for this crucial data [18] and the frequent absence of this practice in primary care [19]. This finding supports current research exploring the potential to link electronic health records with a patient-reported health history tool [20] or to develop computerised family history systems and decision support tools [19].

The second exemplar depicted shared decision-making around a management plan and agreed "red flags", in which the patient had a more active role than merely re-presenting in ED or to their GP. This example was consistent with the literature in highlighting the potential for person-centred approaches to reduce the burden of care in ED by empowering patients to understand and self-manage chronic conditions for improved outcomes, greater reassurance, and reduced repeat presentations [3]. To this end, it supports the potential value of HIT to enable patients to monitor and manage their health beyond ED. For instance, the electronic health record in Australia, MyHealthRecord, includes a private personal notes section [21], and the Danish National eHealth Portal allows patients to monitor their own drug compliance [21].

The third divergent discourse uniquely explored the potential to facilitate the health literacy of patients by increasing support for the clinical decision-making of clinicians, highlighting the two-way nature of a shared decision. Usable HIT may therefore include electronic decision support tools to optimise the appropriateness and timeliness of diagnostic tests ordered for patients presenting to ED [22], or provide clinicians and patients with a shared taxonomy to bridge the gap between jargon and plain language. This diverse exemplar identifies potential issues and solutions that may need to be further investigated and addressed in ED.

Collectively, the three exemplars above contributed unique insights not captured elsewhere in the dataset, consistent with literature yet also giving voice to the real experiences of patients and clinicians in ED that may not otherwise be investigated. Further research into such factors is warranted to broaden our current knowledge of how to implement sustainable HIT that supports patient-centred practices in ED. Increasing partnerships with patients and clinicians through such research is key to implementing translational, sustainable and impactful HIT solutions in the ED context.

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The Design of PE Dx, a CDS to Support Pulmonary Embolism Diagnosis in the ED

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Abstract. Designing and implementing clinical decision support (CDS) in health care has been challenging. Attempts have been made to design and implement CDS to support clinical procedures, but many of these CDSs have met user resistance. One possible explanation for the lack of acceptability can be the poor design of the CDS. In this study, we describe the design of PE Dx, a CDS built to support the diagnosis of pulmonary embolism (PE) in the emergency department (ED) using human factors methods.

Keywords. User-centered design, clinical decision support, pulmonary embolism, emergency department

1. Introduction

Estimates show that between 650,000 and 900,000 individuals are diagnosed with a pulmonary embolism (PE) each year in the US, 200,000 of which will be fatal [1]. A PE is the sudden blockage of an artery in the lung, usually by a blood clot. If the clot is large and stops blood flow to a substantial portion of the lung, it can result in sudden death [2]. It is difficult to correctly diagnose a PE. Individual signs and symptoms are often not accurate enough to rule in or rule out a PE [2]. No single test is enough to diagnose a PE. The literature shows that less than 50% of patients who die from a PE were correctly diagnosed [3]. Several tests are needed to either rule out a PE or make the PE diagnosis. To support the diagnostic pathway for PE, risk-scoring algorithms have been developed.

1.1. PE diagnosis and PE Risk scoring algorithms

The most reliable method to diagnose a PE is the computerized tomography pulmonary angiography (CTA) scan. However, CTA scans are expensive and expose the patient to potentially hazardous radiation and renal injury because of the administration of IV contrast [4, 5]. Therefore, CTA scans should be avoided when possible [5]. The D-dimer test is a diagnostic test that has significantly less risk and a high negative predictive value in low to moderate risk patients [6]. However, D-dimer is limited by a relatively poor positive predictive value [7]. As CTA scans have excellent positive and negative predictive value, many physicians order them when they suspect a PE, resulting in over-

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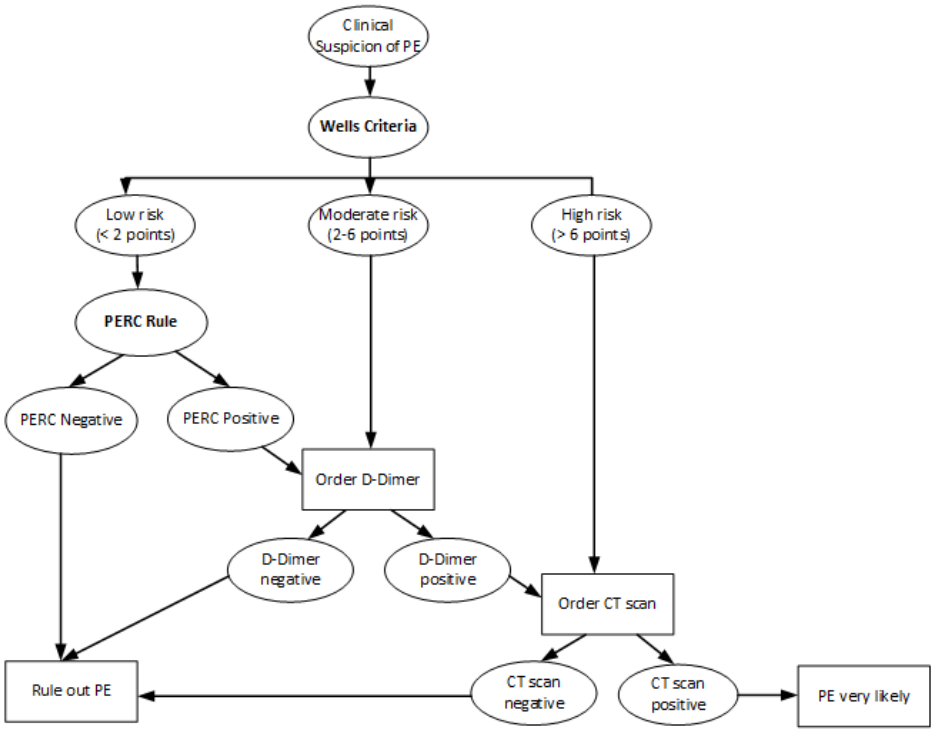

Figure 1. Best practices for the PE rule in/rule out process, American College of Physicians [8].

testing. The number of CTA scans for PEs has dramatically increased in the past decade without a decrease in mortality [8]. There are several clinical decision aids that help physicians choose the appropriate clinical pathway to rule out PE or confirm it with tests. The most often used aids are the Wells' criteria and the Pulmonary Embolism Rule-out Criteria (PERC) rule. Often these two decision aids are used together to rule out a PE diagnosis. The Wells' criteria consist of seven questions. On two of the questions, you can get 3 points: "clinical signs and symptoms of PE" and "PE is #1 diagnosis or equally likely". Three questions can result in 1.5 points (heart rate >100, immobilizations during last 3 days or surgery in previous 4 weeks, and previously, objectively diagnosed with PE or deep vein thrombosis (DVT)). Finally, two questions result in 1 point each: having been diagnosed with hemoptysis or malignancy with treatment in last 6 months. The answers to these seven questions result in a score that reflects the risk of a PE (see Figure 1). Depending on the risk, the clinician needs to either apply the PERC (low risk), proceed with D-dimer testing (moderate risk) or go directly to CTA (high risk). If a clinician responds affirmative on one of the 8 PERC questions, PERC is positive.

1.2. CDS for PE in the emergency department

The emergency department (ED) environment uses many clinical decision rules and is therefore an ideal environment to design and implement CDS. As a result, EDs have seen explosive growth in CDS implementation. However, although most studies (84%) in a recent review by Patterson et al. [9] showed an impact of CDS on processes and process measures, few studies have shown an impact on clinical outcomes, such as length of stay

(LOS) or readmissions. Several studies that have examined CDS to provide support for PE in the ED showed an impact of the CDS on the PE diagnostic process [5, 8, 10-12]. For example, studies by Raja [5, 8], Prevedello [12] and Jiminez [11] resulted in a significant reduction of CTA use. However, few ED clinicians use the CDS that were designed to improve the PE diagnostic process [10, 13]. In other words, results of studies on CDS for PE do show effectiveness but lack acceptance. Several authors suggest that poor CDS usability is the cause of low acceptance: "*The computerized decision support system, however, was poorly accepted by emergency physicians (partly because of increased computer time), leading to possibly selective use, reducing the effect on overall yield, and leading to removal of the computerized decision support system from the computer order entry."*[10] Our study uses a sociotechnical systems approach to the design of CDS to support diagnosis of PE. This way, we can address the range of sociotechnical system issues that have limited the acceptance of prior CDS designed for PE. Based on a user-centered design process (an iterative process in which designers focus on the end users and their needs in each phase of the design process) with the participation of both human factors engineers and clinicians, CDS design requirements were developed. Those design requirements were embedded in CDS mock-ups; and the CDS mock-ups have been evaluated through scenario-based usability evaluation and group debriefings.

2. Methods (CDS tool development)

To better understand the PE diagnostic processes in the ED, in the early stages of this research project, we interviewed several ED clinicians. We also conducted detailed workflow studies to better understand the Wells' and PE workflows. For the actual design of the CDS (so called PE Dx), we used design sessions, focus groups and usability evaluation. The study and associated data collection procedures were approved by the Institutional Review Board (IRB) of our university.

2.1. Design sessions

We conducted 9 design sessions in which the design team consisting of 6 human factors experts and 2 clinicians discussed advantages and disadvantages of several design solutions for PE Dx. Each design session lasted between 1 and 2 hours. In total, the 9 design sessions lasted 13.5 hours. During most of the design sessions, we used mock-ups of PE Dx created in MS PowerPoint. Based on the feedback received during a design session, we would make changes to the mock-up and discuss the redesign in the following design session.

2.2. Focus groups and interviews

We organized two focus groups and two interviews with clinicians to gather feedback on early designs of PE Dx and asked specific questions about particular parts of the design, such as which vital sign data to pull from the EHR, hover over/information buttons, error messages, and calculate buttons. Each focus group lasted about one hour. The interviews lasted about 30 minutes.

2.3. Survey

We conducted a survey for the design team to help make design decisions. The survey consisted of 20 questions. The first set of 4 questions was about possible triggers for the tool. The second set of 5 questions asked about the Wells' criteria and the third set of 7 questions asked about the PERC rule. The next question was about placing orders and the final set of 3 questions asked about documentation.

2.4. From designing to building the CDS

This iterative process, using different methods, resulted in a design of PE Dx that was agreed upon by the whole design team. We then asked an electronic health record (EHR) programmer to program PE Dx in an existing EHR. After the CDS had been programmed, we conducted a heuristic usability session with the programmer to make PE Dx more user-friendly.

3. Results

User-centered design is an iterative process, and the design of PE Dx went through different stages. During those stages, decisions needed to be made to be able to move forward. In this paper, we focus on three major design decisions because we believe they not only had a major impact on the design of PE Dx, but will affect the design of other CDS as well: (1) considering the whole process: designing from start to finish, (2) auto-populating vs. supporting clinical autonomy, and (3) (auto) calculating.

3.1. Designing for the whole process, not only for a specific task

If an ED physician suspects a PE based on observed physical symptoms, they have several tools to rule in or rule out a PE. The tools provide support for the next steps of the process, such as ordering a D-dimer or a CTA scan, and documenting these steps. We believe that a CDS should also support these next steps, and for example, depending on the test results, provide the physician with an easily accessible option to order a D-dimer or CTA scan. Further, test results should be "automatically" documented in the doctor's notes. We strongly believe that, if you add a task for a clinician, you should design your health information technology (IT) in such a way that other task(s) in the same process are eliminated.

3.2. Auto-populating vs. supporting clinical autonomy

To make the CDS as efficient as possible and prevent physicians entering data that are already available in the EHR, we tried to auto-populate as much as possible the CDS. The CDS is auto-populated with items that have numeric values, such as heart rate, blood pressure and oxygenation (SpO_2). However, although physicians like auto-population, they also like their autonomy. Especially in the ED, there is sometimes confusion about the reliability of some these values. For example, heart rate (HR) is measured by the triage nurse at intake, and then periodically rechecked during the ED stay. The number that is auto-populated in PE Dx from the EHR is the highest recorded HR, but this does

not always best reflect the observed medical condition of the patient. Therefore, physicians would like to be able to edit that (auto-populated) value, sometimes to see how that would impact the final risk score. Evidently, there is an interesting trade-off between automation and autonomy. In our CDS, both options are available: the PE Dx is auto-populated, but clinicians can edit the data and the edited value is used in (auto) calculating the score.

3.3. (Auto-) Calculating

ED physicians work with many clinical diagnostic decision rules to evaluate the probability of a medical condition (e.g. Ottawa rule for ankle fracture). Most rules require some combination of symptoms, physical exam findings, and laboratory results. The values assigned to each element produce a score that helps guide the next step in the diagnostic process. Often a diagnosis can be ruled out if none of the elements is present. For example, results of the Wells' criteria can vary from 0-1 (PERC Rule needed to rule out PE), 2-6 (Order D-dimer) and >6 (Order CT scan). One of the questions presented during design of PE Dx was whether to "simplify" execution of the different rules. For example, as soon as a certain score has been achieved (for example >6 points in the Wells' criteria), it is often not necessary for the diagnostic process to continue: there is no difference between 7, 8, 9 or 10 points, all are above the cut-off score. One way to speed up the work process is to provide the physician immediately with a score as s/he goes through the different items and as soon as she has reached a certain cut-off point, to provide her with decision support (e.g. recommendation to order CT scan). However, from a clinical perspective, there are advantages to obtain the responses to all questions, and to have all responses documented. Local hospital policy supports physicians responding to all questions before calculating the score. Further, data collected in this way can be used to further improve clinical decision rules.

4. Discussion

In this study, we designed a computer decision support tool (PE Dx) to support PE diagnosis in the ED, following user-centered design methods and principles. Preliminary results of a simulation study show that the CDS is well accepted by clinicians, more efficient and effective and results in higher end-user satisfaction compared to an online CDS [14]. PE Dx has been implemented and will be evaluated.

4.1. Lessons learned

The procedure to rule in/out a PE is challenging from a human factors design perspective. A two-step process is needed to rule out a PE. There is considerable overlap between the two tests (PERC, Wells'): 3 of the 12 questions are the same. Further, administration of PERC is dependent on the results of the other test (Wells'). In the early stages of PE Dx design, we focused on integrating the two tests as much as possible to avoid duplicate data entry, which can be frustrating and does not encourage clinicians to use the tool. However, apart from trying to deal with the similarities between the two tests, we should also have focused on the *differences* between them. The Wells' criteria need the responses to several questions to calculate a score, while the PERC only needs one single item to be positive. That makes integration of the two tests challenging; it took us a while

to realize that and to let go of our initial design approach. Further, only in certain situations (a Wells' score lower than 2) is the PERC needed. Therefore, we decided to gray out the PERC, and only make it active when the Wells' criteria indicated use of PERC (see Figure 1). The lesson is not to be narrowly focused on certain design features before the whole process is completely understood.

During the design of PE Dx, we were confronted with difficult decisions. A design decision from a human factors point of view would have been different from that from a clinical perspective. Evidently, a CDS is created for and used by clinicians and therefore, they make the ultimate decision. However, in some instances, the human factors experts could explain why certain (design) solutions would be better. The combined input of clinicians and human factors experts contributed to the design process. The human factors experts developed basic knowledge of the PE diagnostic process, and input from clinicians helped to understand why physicians made specific choices, and also to explain specific tasks and processes, such as the actual D-dimer test and its advantages and disadvantages.

Defining design requirements for a CDS for PE was the original goal of the study. However, we were able to actually design and program PE Dx, and to conduct a usability evaluation in a simulation experiment. In this experimental study, we evaluated the usability (effectiveness, efficiency and end-user satisfaction) by comparing PE Dx with an existing web-based CDS. Results of the experiment are promising, which underlines the central message of this paper, i.e. that it is possible to use human factors principles to design health IT that will be accepted by end-users. However, the ultimate test is whether clinicians actually use the tool.

4.2. Study limitations

In this study, we describe the design of a specific CDS (PE Dx) for a specific environment (ED). We realize that designing CDS is context dependent; designing a CDS for the ED is not the same as designing a CDS for the inpatient wards or for ambulatory care clinics, because the work system characteristics and workflow are very different in those clinical settings. Nevertheless, we think that the issues we described here can also inform the design of CDS in these other settings.

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Model for Evaluating the Implementation of a Third Generation EHR System

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Abstract. Most theoretical approaches to evaluate implementation of EHR systems origins from the time when EHR systems replaced paper records. When staff and management have many years' experience in use of EHR, the approaches to implementation is different. In this protocol paper we review the main implementation theories and discuss the adequacy for planning and evaluation of implementation of third generation EHR. Finally, we present a model to understand relations between leadership, the implementation of the EHR system in the individual clinical departments, the perception of the staff and the quality of care. The model is used to outline five hypothesis that can be tested in a specific evaluation project.

Keywords. Evaluation, Electronic Health Record, Implementation, Management

1. Introduction

The Region of Southern Denmark has decided to introduce a new Electronic Health Record (EHR) system at the hospitals in the Region in 2020 [1]. The hospitals in the region were among the very first hospitals to implement EHR systems to replace the paper record in the late 1980's. Different systems have been used, and the new system may be described as the third generation EHR system in the Region of Southern Denmark. The new system is intended to be characterized by a stronger collaborative model between vendors and users, improved semantic interoperability, and an increased emphasis on the problems, work tasks and needs of the users in a specific context [2]. It will be the primary IT tool for about 22,000 doctors, nurses, secretaries and other staff at the region's hospitals, consisting of the core elements:

- Clinical notes and record management
- Medication
- Requisition and answers from laboratory and imaging systems,
- Patient administration
- Booking.

Reviews about the impact of EHR systems have shown that good leadership and management, infrastructure support, staff training and focus on workflows and usability is important for the outcomes of implementing EHR [3].

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Hospitals consists of a large number of clinical departments each with its own management team. Often a department includes more than 200 employees and is an organizational unit with its own local management, even though all departments have a superior management in the directors of the hospital. Studies of the implementation of quality management systems and IT systems in Denmark and other countries have shown that the management of the individual departments are quite diverse and can make a huge difference to the implementation process in terms of variations in management skills, management goals, organizational tasks and responsibilities [3, 4]. A Danish case study of an EHR development process in the North Denmark Region also found differences between wards in the implementation and use of EHR systems [5].

Thus, the implementation of the EHR system in each of the clinical departments can be expected to vary with regard to the focus and importance that the management puts on the implementation and the amount of resources that is allocated during the process to make it a success. These differences between leadership styles in clinical departments in the same hospitals can be used to study the impact of management on the outcomes of implementation of a new EHR system.

In the hospital sector as well as in many other sectors, there have been massive challenges associated with the implementation of major information and communication technologies, ICT systems. It applies internationally in both the private and the public sectors and examples are abundant. Significant difficulties were encountered when large scale ICT systems were implemented in Massachusetts General Hospital in USA, Cambridge University Hospital in England, Copenhagen University Hospital in Denmark, and numerous other hospitals [4, 6].

There are many reasons why such implementation processes often go wrong, and the aim of this project is to develop scientifically sound knowledge of the different reasons for failures and to enable planning and actions that will increase chances of success.

2. Status of knowledge and theoretical approaches

The theoretical approaches to study implementation processes fall in three main research traditions:

- Change management literature
- Literature on diffusion and implementation of innovations
- Literature on the implementation of EHR systems

The first and oldest tradition has elaborated and tested general theories concerning how to lead change processes and took off with the work of Kurt Lewin in the late 1940s [7-9]. The second tradition is really a merger of the diffusion of innovations literature [10] and the implementation literature [11] which began in the 1960s and 1970s. This tradition has elaborated and tested theories concerning factors that generally tend to enhance or inhibit the adoption and implementation of innovations.

While the two first traditions have uncovered more or less general theories, the third and newest tradition took off in the 2000s and has focused on the implementation of EHR systems [3]. Thus, in the latter tradition the ambition is to uncover the drivers, enhancers and inhibiters of this specific type of change processes.

We have chosen to deliberately triangulate between the very specific research in EHR implementation and the more general theories of change management and the

diffusion and implementation of innovations. Combining and synthesizing these traditions, the research project can embrace the complex context of a hospital organization and thus develop important new insights. The three traditions represent decades of research and thousands of research projects and here we can only present the most conspicuous characteristics of the three traditions.

2.1. The change management literature

The change management literature is the oldest of the three research traditions. It has been characterized by a number of stage models more or less resembling and elaborating on Lewin's early unfreeze-transition-refreeze model [12]. The most influential has been Kotter's eight-stage model [13], which claims that successful change management follows eight steps: 1) Establish a sense of urgency; 2) Form a powerful guiding coalition; 3) Create a vision; 4) Communicate the vision; 5) Empower others to act on the vision; 6) Plan for and create short term wins; 7) Consolidate improvements and produce more change; 8) Institutionalize the new approaches. Very few studies have applied the change management perspective to EHR implementation processes. There is a review chapter relating this literature to health information systems [14] and two recent PhD dissertations based on qualitative interviews and using Kotter's and Lewin's framework [15, 16].

2.2. The innovation diffusion and implementation literature

While the change management literature focuses on leadership and management factors influencing processes of organizational change, the innovation diffusion and implementation literature has a broader focus on the factors that tend to influence the adoption and implementation of innovations across contexts [10, 17]. Thus, change management is seen as only one among many factors that influence successful implementation. In that respect, it resembles the EHR implementation literature presented below. Since this tradition is older than the EHR implementation literature and tries to generalize across the implementation of many different types of innovations, it has produced general theoretical frameworks, theories and concepts that are useful for the interpretation of the EHR implementation literature. The following list indicates the type of factors that hundreds of studies have found to be important to most implementation processes [17]: 1) Historical background of the intervention; 2) Design of the intervention; 3) Implementation actors; 4) Addressee response; 5) Other simultaneous interventions; 6) Issue networks and other environments.

2.3. The EHR implementation literature

The newest tradition is a specific EHR implementation research. Numerous studies have since the late 1990s examined factors related to success, failure and implications of EHR system implementations. This EHR implementation literature has been reviewed recently [3] and they organize their findings from 117 studies conducted between 1999 and 2017 in three categories: 1) Barriers to successful implementation; 2) Factors associated with successful implementation; and 3) Studies reporting on efficiency and productivity pre- and post-EHR implementation. The review reports empirical findings under these headings, but there are no or very little theoretical considerations and there are no attempts to relate the findings to the literatures on change management and adoption and

implementation of innovation presented above. However, among the studies in the three categories we have identified a number of areas that will be relevant to study.

2.3.1. Impact of EHR on productivity

Productivity is defined as the ratio between the output produced (e.g. number of admissions or surgical procedures) to the resources (e.g. number of medical doctors) used in production of health care [18]. Thus, productivity is equal to the number of outputs produced per input unit. EHR may have impact on the productivity of hospitals because EHR, on the one hand, may result in more accurate documentation, reduction in medical errors, improved quality of care and improved reimbursements [19]. On the other hand, there may be unintended consequences of implementation of new EHR systems that can have impact on the productivity, e.g. increased documentation time, interruption in clinical workflow and system errors in patient care [20].

2.3.2. Impact of EHR on clinical outcomes and safety

EHR may have impact on the clinical outcomes of the patients treated at the hospital and the safety of the patients. The review by Priestman et al. [3] describes a number of studies of the impact of EHR systems on clinical outcomes and point out that clinical impact depends on the setting. Whereas some studies have found positive improvements in clinical outcomes and safety others have found negative results. Similar to the effects on hospital productivity, studies have also found that impact on safety and clinical outcomes may return to baseline over 6-18 months.

2.3.3. Impact of EHR on patient satisfaction and perception

The introduction of the new EHR system in the Region of South Denmark will include a patient portal, where patients have online access to their own record. In addition, the patients will get the possibility to change their bookings for e.g. outpatient visits. Many of these features already exist in the national health portal "sundhed.dk" and if they replicate what already exist, it is relevant to evaluate the impact of the new system on the patients' perception of and satisfaction with the hospital services. A review by de Lusignan et al. [21] shows that the online access EHR services most utilised by patients are prescriptions, viewing the test results, messaging with their clinician, arranging referrals and rescheduling appointments. The review also describes that 16 studies have reported how patient experience and satisfaction with having online access to their EHR was high. The patients' perception of this service is mostly studied by use of interview or questionnaire to patients.

2.3.4. Impact of EHR usability on satisfaction and use

The Region of South Denmark envisions that clinical workflows are to be adapted to the solution to the largest extent possible in order to ensure most effective utilization of the new EHR, and to enable a fast implementation. This also emphasizes a streamlining of speciality specific workflows across hospital units. Such standardization offers long term benefits, but potentially amplifies the risk of alienating users by imposing changes to work and acceptance of a new information system simultaneously.

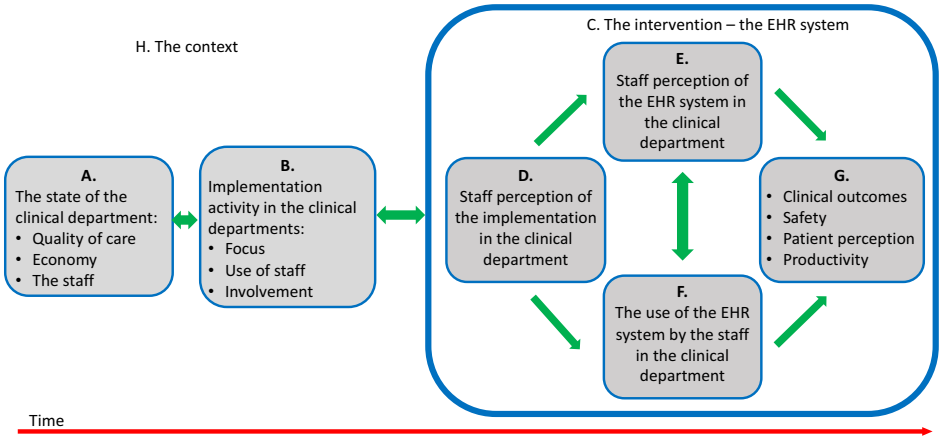

Figure 1. Relations between leadership, the implementation of the EHR system in the individual clinical departments, the perception of the staff and the quality of care examined in the study.

Several models for evaluation of the relationship between intention to use, and actual use are used in research today. DeLone and McLean's "Information Systems Success Model" [22] includes elements of systems quality, information quality, intention to use, satisfaction, actual use, individual and organizational impacts, and has been deployed to evaluate EHR implementations in multiple studies [23]. The Technology Acceptance Model (TAM) by Davis [24] has been widely used to evaluate acceptance and use of new technology with an analysis of how the users believe the new system would enhance job performance, and the degree to which it would be easy to use. However, like any other widely used explanatory model, TAM has received its share of critique. Consequently, several modified models have been proposed, most noteworthy are TAM2 by Venkatesh and Davis [25] and the Unified Theory of Acceptance and Use of Technology (UTAUT) [26], both of these seek to improve social influences and facilitation conditions in the model. Holden and Karsh reviewed the use of TAM in a number of studies and reported that although the model predicts a substantial part of use and acceptance of health IT, several aspects relating to the healthcare challenge the use of acceptance models [27]: e.g., essentially information system usability permeates all models as an abstract level construct, rather than focusing on tasks and challenges specific to clinicians. Consequently, a more implementation-oriented approach may yield better insight into specific issues of the EHR system in question.

3. Conceptual model for studying implementation of third generation EHR

Based on the three research traditions and the four identified impact areas, we have elaborated a conceptual model to guide research in implementation of third generation EHR systems (Figure 1). The implementation and change management activities at the level of the clinical departments (B) and its impact on the staff's perception of the EHR system (E) and, in the end, the impact on the quality of care, safety and productivity (G) is the central relation in our model. But the model also considers the impact of the state or point of departure within the clinical department with regard to the economic situation, quality of care and the state of the staff (A), the functionalities of the EHR system (C), the

perception of the implementation of the EHR (D), the use of the EHR among the members of the staff in the department (F), and the overall context of the health care system (H).

Based on the Hansen and Nørup approach [4], we will test five hypotheses:

(1) **Hypothesis 1**: There is a positive association between initial support for an ICT innovation before the implementation and the perceived performance of the ICT innovation after the implementation.
(2) **Hypothesis 2**: There is a positive association between higher levels of directive leadership of the employees during the implementation process and the perceived performance of the ICT innovation after the implementation.
(3) **Hypothesis 3**: There is a positive association between levels of participation in the implementation process and the perceived performance of the ICT innovation after the implementation.
(4) **Hypothesis 4**: There is a positive association between an implementation strategy that has been adapted to the specific department and the perceived performance of the ICT innovation after the implementation.
(5) **Hypothesis 5**: There is a positive association between clinicians' use and satisfaction with the current EHR system, and the perceived usefulness and usability of the replacement EHR system.

Based on the literature we know however that the process will be influenced by a number of other factors than the leadership styles of managers at the clinical departments. A number of structural factors at the departmental level such as their resources and their staff (B) will determine the point of departure. It is also evident that the overall context (F) is important, and rises questions such as: How is multilevel governance practiced? How much support is given and how? What are the temporal characteristics of the implementation (e.g. who implements first and who last?)? And, of course, all theoretical approaches emphasize basic characteristics of the intervention (the EHR system to be implemented (G)) as an important factor to be considered. We are not only interested in the perceived outcome according to the users of the new EHR system (C and D), but also in the quality of care and in the patient's satisfaction with the system (E).

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Lessons Learned from Implementing a Patient Prioritization Tool Designed with End-Users in a Pediatric Emergency Ward

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Abstract. Introduction. Overcrowding is a common problem in emergency departments. This is true for adult and pediatric emergency department (PED) and issues are potentially important (e.g. quality of care, financial, social, ethical). Optimum is one among several solutions implemented to fight this phenomenon. It is an electronic patient prioritization tool for PED devoted to non-vital emergencies. First usage assessments reported the tool was not used by the PED staffs despite their strong involvement during the development. Aim. This paper aims at understanding why the PED staff did not use the Optimum system that has been designed with them and for them, through a user-centered design process. Method. PED staffs answered answer a short survey about their usage of Optimum. Depending on their answer (user vs. non-user), they either underwent an individual semi-structured interview or an unstructured one. Interviews were audio-recorded and transcribed and, from each interview, meaningful semantic units representing the reasons for using/non-using Optimum were extracted and organized iteratively following a grounded approach by three ergonomics experts till a consensus was reached. Results. 12 interviews have been performed with 6 physicians, 5 nurses and 1 auxiliary nurse. Overall, the prioritization tool Optimum have received a mixed response from the PED staff: Optimum display is neither understood nor trusted by users. Moreover, it is mainly used to estimate the PED attendance rate and not to prioritize patients. Discussion. This study shows how much it is difficult to implement new tool in wards despite a user-centered development and without being included in the daily used patient management tool.

Keywords. Pediatric emergency, patient prioritization tool, usage assessment, human centered design process, overcrowding

1. Introduction

Overcrowding is a common problem worldwide in emergency departments (EDs) [1-2]. Although there is no consensual definition [1,2], crowding can be defined as a mismatch between the ED's human and material resources and the large, often unpredictable number of patients. In extreme cases, it may lead to overcrowding when the number of patients compels the EDs to operate beyond its capacity [3–5]. Usually, EDs are

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considered overcrowded when all of their rooms, chairs, stretchers and waiting rooms are full [1]; A more simple form of overcrowding "*exists when there is no space left to meet the timely needs of the next patient requiring emergency care*" [1].

Several solutions have been tested to prevent EDs from being overcrowded. Educational initiatives have been proposed to reduce the rate of low-acuity visits and flyer-patients, and more generally to reduce the pediatric ED (PED) use [6]. Organizational adjustments have also been studied: for instance by employing someone dedicated to managing beds' occupation [7], or by scheduling staff according to the busy and light times for patient arrivals [8], or by increasing the number of beds. Finally, other initiatives implemented electronic patient triage systems to help optimize patients' triage and prioritization [9]. However, data used by electronic patient triage systems must often be entered manually by the clinicians; this is not possible when the ED is overcrowded, and therefore limits the system's usage and potential impact [10]. To be fully efficient, those systems must display reliable information without requiring supplementary data entry: the Optimum tool has been developed with this goal in mind [11, 12].

2. Context of the study

Optimum is a homegrown electronic patient prioritization tool developed to help clinicians prioritize patients (except vital emergencies) and manage patient flow in real time by automatically retrieving and analyzing data available in the ED's electronic health record (EHR). Optimum is not incorporated into the EHR. It was developed in Lille academic hospital following a human-centered design (HCD) process involving the PED staffs at each step of the process to maximize its usability and acceptance [11, 12]. A work analysis through interviews and shadowing allowed identifying the prioritization rules and patient flow strategies applied by the healthcare professionals during busy periods. Results were turned into functional specifications in collaboration with the PED's head physician. Early mock-ups based on these specifications were presented to a focus group comprising three physicians, two nursing nurses, two human factors specialists and 2 software engineers. Based on healthcare professionals' feedback, a revised mock-up was designed and evaluated through user testing. Results highlighted that the Optimum triage is 98% identical for physicians and 86% for nurses and that users understand the icons and the arrangement of the graphical user interface (GUI) [11].

The GUI displays the distribution of patients in the various steps of the care process using columns and blocks arrangements and, for each patient, the level of delay in his/her care process along with a proposed prioritization to help the PED staff to manage patient flow. A preliminary study confirmed that the indicators mirrors the actual patient progress in the care process and its usefulness [12, 13].

Optimum was implemented in December 2016. Two meetings were organized respectively with medical and nursing staffs to present Optimum's aims, features and indicators. The implementation was fully supported by the PED head physician who incited the staffs to use the tool. In the PED, four monitors display Optimum: 2 in physicians' rooms (main office and residents' office) and 2 in the nursing rooms.

One month after the implementation, shadowing and interviews showed that Optimum was very seldom used. Clinicians expressed they lacked knowledge on the tool. Therefore, another meeting was organized to present Optimum again to the medical and nursing staffs, and explanatory posters were put up beside each Optimum screen. At month 6, a second round of observations showed no change in the usage.

The present study was performed 12 months after Optimum implementation on demand of the HF project owner and carried out by two independent HF experts. It aims at understanding why the PED staff does not use the Optimum system that has been designed with them and for them, through a HCD process.

3. Method

PED's physicians, nurses and nursing auxiliaries were contacted by email 12 months after the Optimum implementation to answer a short electronic survey about their usage of the tool. Depending on their answer, they were categorized as users or non-users. Then, all were interviewed individually: semi-structured interviews for users, unstructured ones for non-users.

Semi-structured interviews were inspired by the critical incident technique [14, 15]. Appointments with the users were made one month before the interviews; for the interview, clinicians were asked to note at least three examples of critical incidents they faced with Optimum, i.e. significant situations during which Optimum proved to be helpful, useless, or disturbing. An email reminded this instruction one week before the appointment. During the interview, the participants had first to relate the situations they identified. Then, 8 questions were asked dealing with: the type of situation, the information sought on Optimum, the impact of having the information and the outcome on the work process and the patient. Besides, participants were asked to explain how they were introduced to Optimum, whether they had been trained, by whom and when, and how they would qualify their usage of Optimum. For the non-user group, unstructured interviews aimed to explore the reasons for their non-usage.

All interviews were audio-recorded and transcribed. Meaningful semantic units representing reasons for using/non-using Optimum were extracted and organized following a grounded approach [16] by two HF experts till consensus arose.

4. Results

Nine persons out of 21 declined the interview invitation. Twelve interviews were performed including 6 physicians (including the head of the service), 5 nurses and 1 nursing auxiliary. Among them, 7 were users (6 physicians, 1 nurse) and 5 non-users (4 nurses, 1 nursing auxiliary). On the day of the interview, none of the interviewees had identified "incidents". They all reported generic situations. During the analysis of the themes tackles during the interviews, we reached saturation with physician users but not with other users and non-users.

4.1. Optimum usage

Overall, the PED staff expressed mixed attitudes towards Optimum. Three main profiles of users emerged: *i)* advanced user, *ii)* sporadic user and *iii)* non-user.

(1) **Advanced user** (n=1; physician head of the PED). He was a driven force for the development of Optimum; he took part to the design phase of the HCD process and to each evaluation session performed after the Optimum

implementation. He has a sound knowledge of the Optimum features and of the underlying prioritization algorithm. He reported using Optimum almost daily because it allows him having an overview of the PED crowding and estimating physicians' and nurses' workload. The delay indicator allows him identifying patients who have been waiting for too long and investigating the causes of those "extra-delays". He uses Optimum to detect the beginning of an overcrowding period in order to quickly and efficiently reorganize the PED staff, and, if need be, to ask other units for more human resources.

(2) **Sporadic users** (n = 6; 5 physicians, 1 nurse). One physician reported using sometimes Optimum to know which patient to call next and to manage residents during overcrowding situations. The others (5/6) do not use Optimum as a prioritization tool neither during overcrowding situations nor during quiet periods: they do not know the underlying prioritization algorithm and are therefore not confident in the system and in the information it provides. At best, they use Optimum to get a global picture of the department's crowding and to identify patients whose wait time is abnormally long. Interviewees explained they initially looked at Optimum's screens because they were placed beside the EHR they constantly used. They gradually noticed that Optimum provided a better overview of the PED situation than the EHR and supplied a very useful delay indicator whose color evolves: "*It is the only information not provided by [the EHR]*". Interviewees insisted on the "red" delay indicator: "*I watch Optimum only when I see the delay indicator is red. For me, this means we are late to care this patient*".

(3) **Non-users** (n = 5, 4 nurses, 1 nursing auxiliary). These healthcare professionals said they did not use Optimum. They considered Optimum as a useful tool for physicians' but not for nurses' work: "*There are no relevant information for us. We spend much more time with patients than physicians, we are always communicating with other nurses and nursing auxiliaries. We know which patient must be cared first*". Furthermore, all nurses criticized the stress issuing from the indicator displaying the patients who are waiting for hospitalization discharge: they related this information is completely unnecessary because they know they have to care these patients and discharge them to empty the PED.

In sum, Optimum is neither used as a prioritization tool nor understood by most of the users. Only two physicians (including the head of the department) perfectly knew Optimum's features. For example, whereas the delay indicator was the mainly used information, only two physicians and one nurse knew its actual meaning: 2 interviewees thought its color varied depending on whether an action or a visit to the patient was needed, 1 thought that it was related to the patient's emergency level; 5 ignored the calculation of the indicator.

4.2. Weaknesses and strengths of Optimum and its implementation

Several weaknesses were reported. Despite their involvement in the design process, nurses and auxiliaries pointed out their lack of training and consequently their lack of knowledge and misuse of Optimum. Besides, the staff highlighted that Optimum's logic and look-and-feel are too different from the EHR's (e.g. icons are different, patient data are more detailed in the EHR, information arranged in columns vs. in rows), which

requires an extra effort to understand and use Optimum. Even if they acknowledged how interesting Optimum may be for physicians, nurses and nursing auxiliaries pointed out Optimum is not designed for their work: to make it more useful, they suggested to add an alert to inform nurses when they have to take patients' vital signs.

Two main strengths were reported. The first one concerns the delay indicator: it allows them identifying and discharging patients who have been waiting for too long and so, avoiding patient's frustration and clear the PED by releasing beds. The second one concerns the patient's prioritization feature. Eight interviewees related an automatic triage feature could be very helpful for their patient management activity: they acknowledged Optimum's added value and agreed it provides a more relevantly patients' prioritization than the EHR.

5. Discussion

This study aimed to understand why, 12 months after its implementation, the PED staff do not use the electronic patient prioritization system that has been designed with them and for them. Only the PED's head and a physician use Optimum as a prioritization tool; others do not use Optimum at all or not as a prioritization tool. Interviews highlighted two main causes depending on the users' profile. From the medical staff's point of view, the lack of understanding of the prioritization rules led not to trust the provided information. From a nursing's point of view, two main issues were expressed: a lack of relevance of Optimum for their tasks probably due to a lack of involvement in the design process from what they said, and a lack training.

These results are surprising given the PED staffs' involvement during the tool design and evaluation process, and the several meetings and supports provided. Different lessons can be drawn based on these results. As regards the medical staff, we should have ensured the correct understanding of the underlying rules implemented in the system along with the data on which the system is based, i.e. their own prioritization rules, validated by themselves during a validation session, based on reliable data of their current EHR. It should be noted here, that, due to turn-over, part of the medical staff left the PED during the period of the study, but some of them were involved from the beginning. As regards the nursing staff, the feeling of not being involved in the process is more difficult to understand. Indeed, they attended less the meetings, but 2 to 3 representatives were there at each meeting and were involved in the design and evaluation sessions as the physicians were. Our hypotheses are that Optimum may be helpful for them only in some conditions that have not been correctly highlighted during the definition of the usage context, or the nurses' needs have evolved.

Results led us to suppose also that Optimum would be more used if it were integrated into the ED's EHR. Indeed, the differences in the display (e.g. icons and arrangement) between the EHR and Optimum bothered the interviewees. Integrating the patient prioritization tool (incl. the delay indicator) into the EHR would help improve its visibility, its understanding, and its perceived reliability and, consequently its usage.

From a methodological perspective, one may be surprised that, despite several reminders, interviewees did not note any incidents to prepare the interviews. This may question the reliability of the results, and the suitability of the critical incident technique to the emergency care context. Yet, all interviewees reported the same kinds of generic situations indicating that the latter were built on similar experiences with Optimum. It ensures a quite good reliability of the results. Nonetheless, the critical incident technique

may not be the method that suits the best the PED's constraints. Indeed, ED staffs' priority is to provide care to patients in a very fast dynamic context. Asking them to take notes of the context of their interaction with a tool increases their workload and may be detrimental to the care process: this may be the reason why interviewees were not able to note instance of their critical interaction with Optimum. Other methods should be tested to explore the interactions of the ED staffs with health informatic technology. An interesting and promising research area to train the clinicians would consist to use virtual reality technology to immerse PED staff in a virtual overcrowding PED environment in which they have to regulate the patient flow by using the Optimum tool.

Conflict of interest

Authors do not have conflict of interest to declare.

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Citizens in Health Contexts

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Managing Privacy and Data Sharing Through the Use of Health Care Information Fiduciaries

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Abstract. Policy and regulation seldom keep up with advances in technology. Although data de-identification is seen as a key to protecting one's data, re-identification is often possible. Whether one's data is to be used for care, research, or commercial purposes, individuals are concerned about the use of their information. The authors propose the concept of an information fiduciary for holders of data, describe how it might be applied in a health care context, and outline considerations to determine whether a holder of health care-related information should be regarded as an information fiduciary.

Keywords. Privacy, data sharing, health policy, de-identification, fiduciary

1. Introduction

An electronic health record (EHR) is the systemized collection of patient electronically-stored health information in digital format. Before EHRs came into wide use, when a patient visited a clinician, notes of that visit were generally kept in a paper record of some kind. The patient and the clinician were the key stakeholders in the encounter, the patient had an expectation of privacy and confidentiality in the relationship, and both patient and clinician expected the clinician to retain that privacy and confidentiality. De-identification of patient information was largely nonexistent because the information was not accessible without access to the paper record or the claim, and the form in which health information existed was not conducive to large-scale research. When a patient participated in a clinical trial, that person's data was used in the context of the trial, and recorded in some form, but generally the only information available was that which was accessed in the context of the clinical trial.

Today, protected health information (PHI) exists in multiple sources, including EHRs, and patient-generated health data (PGHD) that may be transmitted electronically to one's care team through fitness or other devices that can track additional information about an individual. Thus, the company hosting the EHR, the vendor of the data-creating devices, and third-party trackers are also stakeholders that have access to these data. In addition, individuals post information on social media, create health-related information (e.g., the number of steps taken per day, searching the Internet for flu remedies), and complete transactions that are not healthcare-related in nature (e.g., purchasing items at

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a supermarket). Entities playing a role in these transactions are additional stakeholders that hold information about an individual that can be accessed in some form.

Policymakers and regulators seek to preserve the integrity of the patient-clinician relationship by enacting laws and regulations that protect the confidentiality associated with clinical encounters. However, such groups also desire to facilitate research that might benefit the common or public good and public health. Such researchers and research organizations and their funders, whether nonprofit or for-profit, are stakeholders, and policymakers and regulators may prioritize their interests in data to avoid stymieing or impeding technological developments, even if data commercialization could occur.

2. Protection of PGHD through De-Identification

De-identification of PGHD is one aspect of health policy in which regulators have attempted to direct commercial activity. The General Data Protection Regulation (GDPR) [1], which replaced the Data Protection Directive [2], applies to European Economic Area (EEA) member states and to companies that offer goods or services to European Union (EU) data subjects or monitor behavior of EU data subjects. The GDPR defines personal data broadly compared to the Health Information Portability and Accountability Act (HIPAA) [3] in that it includes identifying information of EEA health care providers, including institutional staff and individuals who are not study participants or patients. It also includes personal data of a data subject, noting what those identifiers might be, and special categories of personal data. The GDPR covers the processing and/or operations performed on personal data, and applies to controllers who are persons or entities that determine the purposes and means of processing personal data on behalf of the controllers. Even US entities can be subject to the GDPR when they interact with data that is subject to the GDPR [4].

Similarly, American policymakers enacted HIPAA and the Health Information Technology and Economic and Clinical Health Act (HITECH) [5] to manage use of health data. HIPAA contains privacy and security rules that provide protection for PHI that may be used or disclosed by providers, health plans, or data clearinghouses (also known as covered entities). These covered entities and their business associates are regulated, but not the data itself. Of particular importance is the fact that data which can be de-identified consistent with HIPAA's parameters are not protected by HIPAA; it is in this context that data can be used or sold for research and/or commercial purposes. HITECH was created to promote meaningful use of health IT and reinforce HIPAA privacy and security measures related to transmission of health information [6]. In addition, some US states also seek to regulate data use. In 2018 California passed its own form of GDPR-type legislation, the California Consumer Privacy Act, which includes portions of the GDPR and the ballot initiative from which it emanated [7].

However, policy and regulation seldom keep up with the advances in technology, among them data de-identification [8]. In addition, different jurisdictions have different laws and regulations, which often overlap or are inconsistent. In the global economy, innovations rarely are put into use in just one jurisdiction. Thus, when policymakers and regulators promulgate law and regulations on how to de-identify data, as with HIPAA, such laws and regulations can become outdated. Though some stakeholders seek to de-identify data in accordance with applicable law and regulations or validate that they have done so correctly, others actively attempt to re-identify what was thought to be de-

identified data, and review of re-identification attacks indicates that approximately 25% were successful as of 2015 [9].

Clearly, a balance of the interests of patients, clinicians, hospitals, and payers with those of researchers and commercial entities must be achieved. It may be argued that if the de-identification of data might lead to advances for the public good, for example through improved public health measures that benefit society as a whole, there should be greater tolerance for data re-identification than if it would lead to the development of a commercial product. However, that commercial product might result in something that is more readily available to all (e.g., through investment in the company). In this regard, at the risk of adding another layer of regulation on the already numerous layers of regulations, one can expand the notion of "information fiduciary" from the setting of search engines and social media platforms to the above stakeholders, thereby holding them to a higher standard that currently exists.

3. Data Holder as Fiduciary

A fiduciary is an individual or an entity that holds another's information in trust. For example, financial advisors are fiduciaries. An information fiduciary, thus, is an entity that holds personal information in some protected way [10]. Given that the law does not seem to keep up with technological advances and following existing law (including de-identification requirements) and company privacy policies may be insufficient to protect personal data, the concept of "information fiduciaries" may offer a useful framework for analysis. Even if there is an opportunity to "consent" to what a company might do with one's data, one must consider whether the consent was truly volitional and whether the person really knew what he or she might be consenting to. One could argue that in the context of health care, one's consent to use one's data is even less volitional than with social media or search engines because one may be unable to live without medical care.

In determining whether one or an entity might be considered an information fiduciary, a number of questions should be considered. Initially, the kind of information should be identified (e.g., from an EHR, personal device that creates PGHD). It may be important to ascertain how the information was generated. Other considerations include who is/are the intended recipient(s) of such information, to whom the information was actually transmitted, and the purpose of the data transmittal. A more thorny issue might be who owns the data, given that there might be more than one owner, and one might own it as the initial data (e.g., a patient), but another in a different form (e.g., a patient record). The nature and extent of any consent processes and disclosure agreements completed for the use of the data also should be taken into account.

Whether one should be treated as an information fiduciary depends upon what benefits might be derived from the use of the data, and whether those benefits inure to the public good or if they are commercial in nature, where only the holder of the data benefits financially and otherwise. That could include a company developing an algorithm which uses artificial intelligence and machine learning for which the company obtains intellectual property protection, and makes millions of dollars. If a financial advisor makes more money by selling a client financial products rather than by managing the individual's overall financial situation, questions would be raised about whether the financial advisor is really a fiduciary. Similarly, if an individual or entity is to be considered as a potential information fiduciary, consideration must be given to whether they would benefit financially from an individual's information without the individual's

full knowledge and consent and without some benefit inuring to the individual, whether directly or indirectly.

Another important consideration should be to whom is the data transmitted. Individuals may have less of an expectation of privacy and confidentiality when information is placed on social media for others to see than when one conducts a search on Google. An individual would have even a greater expectation of privacy and confidentiality when their data are communicated to their medical care team.

At a broader level, also meriting consideration is the value of the data and whether the original patients whose data is used will receive some benefit. In this context, it will be important to analyze any legal considerations and whether the data is truly de-identified or has been subject to pseudomynization. Who made these determinations and the potential means of re-identifying the data and the possibility of doing so are other relevant concerns.

4. Ethical Considerations

It is important that those individuals and entities who would be within the ambit of an information fiduciary comply not only with all applicable laws and regulation, but also ethical considerations. In fact, given the special relationship that they are in, they should go beyond legal and ethical considerations. Given the special nature of an information fiduciary, this individual or organization should not merely determine whether data has been de-identified or subject to pseudomynization in accordance with applicable law and regulation, but should also try to anticipate whether the data might later be re-identified. Data sets are dynamic in nature and additional information might be added later that would increase the likelihood of re-identification. Advances in technology too might make reverse engineering the data de-identification process possible later.

Some guidelines to consider in determining whether a holder of health care-related data, including PGHD, should be regarded as a health care information fiduciary include the following:

- Does the individual whose data is generated have an expectation of privacy and confidentiality with respect to that data?
- How sensitive might the individual believe his or her data is?
- Was the form in which the data was transmitted such that an individual would reasonably expect that it would only be received and used by the party intended?
- Will the data be used to provide better care for the individual whose data it is, or be for the common or public good, or will it be commercialized for the good of the holder of the data?
- Would the individual whose data it is have consented to the eventual use, if it knew what that use was?
- What is the value of the data?
- Can the data truly be de-identified and not re-identified?

The answer to most of these questions typically will indicate whether an individual or entity holding health care-related data should be treated as a health care information fiduciary. As such, additional research is necessary to try to better define the parameters of healthcare information fiduciaries and provide guidance in this evolving area.

Having the holder of one's personal data be a fiduciary or at least have the relationship governed by some sense of responsibility and protection for the individual's data offers obvious advantages. Of course, defining what that sense of responsibility and protection might be can be quite difficult and depend upon the answers to the questions posed previously. One might look to traditional notions of privacy and confidentiality to explore what an individual's expectation might be for his or her data. Most likely, some data (e.g., whether a person has a communicable disease) will be much more sensitive than other data (e.g., one's height). An individual's expectations about privacy and confidentiality might also depend upon how the information is generated and transmitted. For example, one might have less of an expectation of privacy and confidentiality about the number of steps on one's fitness tracker than their genetic information.

5. Conclusion

Protected health information exists in multiple sources, including as data generated by patients for their own health-related uses, and it can be transmitted and shared in numerous ways. Patients, citizens, clinicians, researchers, payers, health care administrators, policymakers, and others have variable expectations of privacy with respect to such data, though most can agree on the importance of protecting patients' privacy and managing access to PHI appropriately. Although de-identification of data prior to non-care-related uses is seen as important, the limitations of data de-identification have become apparent and other approaches to the maintenance of privacy are needed. The health care information fiduciary offers one such option.

Given the possibilities for data re-identification, for uses of it for purposes not intended by the original holder of the data, and for its commercialization without benefit to such individuals, there is potential for ultimate holders of protected health information to be considered as health care information fiduciaries with the responsibility of holding such information in trust. This article provides guidelines for determining whether a holder of health-related data should be regarded as a health care information fiduciary.

Initial steps to explore the potential use(s) of health care information fiduciaries should focus on what might be done to minimize health care information fiduciaries from using personal data in ways not intended by the individuals to whom data pertain. Structures that prevent health care information fiduciaries from benefiting from such data use unless it is for the common good or the public or unless there are other extenuating circumstances are needed. In addition, standards should be developed for information fiduciaries, including a code of conduct that would be dynamic in nature.

Beyond these efforts, further work should emphasize determination of practice standards and policy changes needed to establish and regulate fiduciaries, and to create mechanisms for enforcement, recognizing that standards and policies may need to change from time to time. Perhaps policymakers and legislatures should focus on what might happen to such individual data in the future, rather than considering only what has happened in the past as they create a regulatory infrastructure.

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The Evaluation of Decision Support Tools Needs to Be Preference Context-Sensitive

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Abstract. Individuals have different preferences in how they wish to relate to healthcare professionals such as doctors. Given choice, they also have preferences in relation to the type and location of support they want for their health and healthcare decisions. We argue that preference-based clusters within this heterogeneity constitute different contexts and that evaluations of decision aids should be context-sensitive in this respect. We draw attention to two distinct preference-based clusters: individuals with a preference for 'intermediative' decision support as a patient, implemented in a largely qualitative deliberative model, on the one hand, and for 'apomediative' decision support as a person, implemented in a largely quantitative multi-criteria decision analytic model, on the other. For convenience, we refer to the latter as Person Decision Support Tools (PDSTs), leaving Patient Decision Aids (PDAs) for its former, conventional use. Seeking to establish proof of method, we present an online PDST that can help individuals establish which of these two types of decision support they would find optimal. It is based on nine key attributes on which PDAs and PDSTs can be contrasted. Within population heterogeneity, preference clusters should be identified, and acknowledged and respected as contexts relevant to the evaluation of decision support tools.

Keywords. Patient decision aid, person decision support tool, decision quality, apomediation, intermediation, shared decision making, preferences

1. Introduction

In a much-needed reminder that shared decision making is a means to an end, not an end in itself, Barry and co-authors argue that the ultimate product of a shared decision making process - indeed of any decision making process - is the *decision* [1]. The primary outcome in the evaluation of any decision-making process, perhaps especially a decision-aided one, should therefore be the *quality* of that decision. It is somewhat surprising, then, that the latest systematic review concluded that, while patient decision aids used in clinical encounters significantly increased patients' knowledge, lowered decisional conflict, increased observation-based assessment of shared decision making, and satisfaction with the decision-making process, decision quality was not mentioned as an outcome anywhere in the research covered [2]. Among the possible explanations, we suggest here that it is because *decision quality*, as a formative construct, requires measurement which is both context- and preference-sensitive. It follows that both types of sensitivity are needed in evaluating any decision making process (including shared

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decision making), in evaluating any decision aids designed to support decision making (whether 'shared' or not), and in evaluating any instrument proposed to evaluate either.

The vast majority of health decisions taken by individuals are *preference-sensitive*. Multiple considerations – various benefits and harms - are relevant and decisions require the relative importance of each to be established, indicating the trade-offs they are willing to make among them. Any decision aid needs to recognise and reflect the multi-criterial and preference-sensitive nature of health decisions. In the context of person-centred health decisions the relevant preferences are those of the individual person (patient-as-person, not as patient) elicited at the point of care [3]. The individual's preferences cannot be treated as just further epidemiological characteristics, to be added to their age, sex, location, or literacy level [4]. This ontological transgression is committed in any clinical or clinical guideline context when the person's preferences are regarded as adequately captured by the dependent variable in a group-based regression equation which employs their epidemiological characteristics as the independent variables.

This offence can, however, only occur in the clinical setting. Elicitation and use of average group preferences is valid and necessary in policy development and decision making. Here the key issue becomes the appropriate level of aggregation and hence the appropriate context for analysis and evaluation. It is clear from clustering studies that preference-based sub-groups exist in most populations in relation to many, if not most, health-related conditions. As just one example, in the case of PSA screening for Prostate Cancer, preference-based sub-groups are constituted by the different relative importance attached to avoiding prostate cancer on the one hand and experiencing the impotence and incontinence side effects of treatment on the other [5]. In this paper we argue that a preference cluster constitutes a context and that evaluations of decision aids and decision quality should be sensitive to preference-defined contexts.

Preferences may relate to states, as in the PSA screening case, or to processes. Here we pursue the notion of preference-based contextualisation in the provision of decision support processes that can potentially enhance decision quality. If there is surprise that *cognition*-based *contexts* are being proposed, it is worth pointing out that contextualisation on the basis of cognitive *pathology* is well accepted in mental health. And, beyond health, segmentation on the basis of the preferences of consumers – in most cases assumed to be in 'normal' health – is the accepted basis of marketing success.

2. Preference-Based Contexts for Decision Support

As stated at the outset, a vital contribution made by the Barry piece is in pointing to the context-sensitivity of the definition and measurement of shared decision making. They note that the National Quality Forum definition does not specify how or where it might take place and that patients and clinicians interact in many ways - phone conversations, virtual visits, email, and web portals are all ways of communicating about a decision.

Furthermore, they acknowledge that personal preferences will affect not only the type and location of shared decision making, but whether it occurs. Crucially for this paper they draw attention to their earlier study [6] in which it was found that 38% of men given a decision aid on PSA screening for prostate cancer outside a visit wanted to make the decision themselves *before* viewing it. This figure rose to 43% *after* viewing the aid. 'In the face of such strong data, should we still require these men to come in for an additional face-to-face visit to say that shared decision-making happened?' ask the authors. Finally, they note that the Cochrane review showed that the use of patient

decision aids is linked to improvements in 'decision quality' in the domains we have discussed, including knowledge, involvement, and match between values and choices, without apparent harms [7]. 'These benefits were seen regardless of whether the patient decision aids were used within or outside of clinician visits.'

It is clear from this, and many other studies (including on internet searching), that individuals have heterogeneous preferences in relation to the way they wish to relate to health professionals (especially doctors); also, that given choice, they have preferences in relation to the type and location of support they prefer for their health decisions. At the moment they have limited choice, especially where only licenced practitioners can perform some actions (diagnose conditions, prescribe many medications). But the scope for autonomous choice is expanding rapidly as the digital paradigm envisaged by futurists such as Eric Topol [8], Robin Farmfarmanian [9], and Bertalan Mesko and Dave deBronkart [10], encroaches on the status quo. In the not too distant future *self-production* of health is supplemented by its *co-creation* undertaken in collaboration with a healthcare professional; a process akin to 'shared decision making' but only when the empowered person is the driver [11].

The mainstream orthodoxy in relation to decision support for individual's health decisions focuses on just one context, that of Shared Decision Making (SDM) between clinician (or clinical team) and patient. This SDM can be facilitated by Patient Decision Aids such as Option Grids [12], assessed normatively by IPDASi standards [13]. The extent to which the SDM occurs in deliberative consultations is to be measured by instruments such as OPTION [14]. Empirical implementations of the PDAs are to be evaluated by DQIs [15]. (We cite only Dartmouth-Boston examples; others exist.)

To make clear the existence of at least one other major context, we draw attention to two distinct preference-based clusters in the population: individuals with a preference for *intermediative* decision support as a patient, implemented in a largely qualitative *deliberative* model on the one hand, and for *apomediative* decision support as a person, implemented in a largely quantitative *multi-criteria decision analytic* model on the other. For convenience we will refer to the latter as *Person* Decision Support Tools (PDSTs), leaving *Patient* Decision Aids (PDAs) for its former, conventional, use.

Following Eysenbach [16] decision support is 'apomediative,' when the resources involved are produced independently of the provider of the good or service in question (apo = away from) and are delivered publicly accessible 'direct to *person'* in the community. Familiar examples of apomediative decision support resources, based on largely quantitative multi-criteria decision analytic models, are the proliferating product and service comparison websites, such as 'Which' in the UK, 'Consumer Reports' in the US, and 'Taenk' in Denmark. Apomediation is distinguished from 'intermediation,' where the provider develops a decision support resource on the basis of their perceptions and decisions as to what the *patient* can benefit from, as well as their in/ability to deliver options that could potentially be covered in the resource. Intermediation is not provider-independent and options present in an apomediative aid may be censored or filtered on the basis of the beliefs, values, and interests of providers – and any other stakeholders involved in intermediative aid development. Public access PDSTs which constitute the main type of apomediative resource, eschew such option censoring or filtering, seeking to supply high quality independent guidance without conflicts of interest of any sort.

Apomediation is to be distinguished from 'dis-intermediation,' where the individual (sometimes a dissatisfied patient) attempts to find what they want without help from healthcare providers, for example by doing anonymous internet searches. Apomediation can therefore be seen as acknowledging some of the motivations underlying dis-

intermediation but seeking to supply a better alternative to Dr Google - one which will be superior, or inferior, to intermediation *depending on the preferences of the person*.

If engagement with an apomediative aid results in a decision to contact a healthcare professional, we have the possibility of blended 'apo-intermediation'. However, in this case the clinician will engage with the person in a way that is different from that which characterises the pure intermediative mode. For example, they will need to be prepared to discuss options in the apomediative PDST that may not have appeared in an intermediative PDA for the same decision.

Even if an intermediative aid is made available online at home as preparation for an encounter - as in the Barry PSA study - it remains an intermediative PDA. It will be recalled that 43% of their participants decided to treat it as apomediative support, so the issue is whether those who prefer to decide for themselves would not be better served by a genuine apomediative aid, one which will have different characteristics and require different standards and evaluation.

3. Establishing Preference-Based Contexts

Information support is only a component of decision support. Decision support requires showing how any information can be incorporated into a decision framework that also introduces the preference component and makes the impact of each component observable and explorable. It is characteristic of intermediative decision aids that they are not based on any analytic model and aim to help the patient 'make up their mind' during shared encounter deliberation, without producing a preliminary opinion to be discussed. In contrast, to be effective in their community setting, apomediative resources must include decision support, not just information support.

Seeking to establish proof of method, we present an online PDST that can help individuals establish which of the two types of decision support they would find optimal, based on their preferences over the key distinguishing attributes. Nine attributes which distinguish PDAs from PDSTs (as defined) were derived from surveying a large number of the PDAs in the Ottawa Directory (https://decisionaid.ohri.ca/AZlist.html), as well as the IPDASi checklist for PDAs [13] and a tabular comparison of the latter with the contents of an MCDA-based PDST. [17] (Table 2, p.6). These attributes exclude those associated with development processes, or supplementary information presentation concerning condition or options, where both types are assumed to meet equally well. Full definitions are in the online tool at https://ale.rsyd.dk (enter 1498 as survey ID).

Shorthand versions of the nine criteria are:

- Home vs clinic engagement.
- No option filtering vs option filtering.
- Do nothing option included vs only action options.
- Numerical vs verbal chances.
- Absolute vs relative risks.
- Overall vs only condition-specific mortality/morbidity.
- Functional vs clinical outcomes.
- Numerical vs verbal preference weights.
- Calculated option scores vs no opinion.

Figure 1. Screen capture from online tool with purely illustrative responses.

Slight stereotyping of PDAs is involved as a few will not match all these characteristics.

Results from this survey will establish the number and strength of the emergent preference clusters, but their existence is not in serious doubt. Even a small number preferring PDSTs will justify their production and delivery, subject to cost-effectiveness considerations. In this respect, any relevant cost-effectiveness analysis must cover the production and delivery processes for both types, as well as their service consequences. In many cases, especially screening, PDSTs are likely to be cost-effective, possibly even cost saving, as a result of reducing preference-based over-diagnosis and over-treatment.

4. Conclusion

The preferences of individuals in relation to health and healthcare decision making processes are heterogeneous. Within this heterogeneity preference clusters should be identified and acknowledged and respected as contexts relevant to the evaluation of decision support tools. The task of developing normative and empirical evaluation tools for the full range of preference-based contexts, including apomediation, remains.

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Conflict of Interest

Jack Dowie has a financial interest in the Annalisa software when used commercially.

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Avoiding Sedentary Work: Exploring Motivational Issues

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Abstract. In this paper we present a qualitative study on motivations for avoiding sedentary work. Sedentary work has been recognized as a significant public health problem and many workplaces now invest in initiatives to support employees in avoiding it. The initiative in focus here include bikes, treadmills, step machines and adjustable workstations combined with a digital platform to keep track of activities and to make relevant information available. Experiences indicates that while employees are excited at the beginning, the use of exercise tools drop relatively fast. In order to understand motivation for use, clarify challenges and identify opportunities to support use of exercise tools through the digital platform we did interviews with employees and decision makers from four different companies. The overall challenge identified was pressure of busyness and reasons for use was due to individual objectives. Thus, in order to support employees in avoiding sedentary work the digital platform should provide facilities which allow for formulating and pursuing individual objective.

Keywords. Sedentary work, interventions, ecological approach

1. Introduction

Sedentary behavior (from Latin sedere – "to sit") is the term used to characterize behaviors that involves sitting and low energy expenditure (1.0-1.5 metabolic equivalents), such as computer use, driving, and television viewing. [1] Contemporary changes in work, transport, domestic activities, and leisure time in general have led to more time spent in sedentary behavior, and this behavior has been recognized to play a significant role in the development of chronic diseases such as type 2 diabetes, musculoskeletal symptoms, cardiovascular diseases, obesity and premature mortality. [2, 3] Furthermore, research also indicates that negative effects associated with sedentary behavior are independent of efforts to meet general recommendation of daily physical activity [4] which is typically 30 minutes a day, e.g. [5]. Reducing sedentary behavior at work is especially important as work take up a large part of the day's hours, and a study from US shows that over the last decades the proportion of sedentary occupations has increased [6].

Interventions strategies to avoid sedentary work have been categorized in slightly different ways. According to a review, based on 26 intervention studies, presented by Chu et.al. strategies can be divided in educational/behavioral strategies, environmental strategies and multi-component strategies [7]. Educational/behavioral strategies involve

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educational initiatives for adoption and maintenance of behavior change, and providing motivational signs like so called decisions points placed on or near stairwells, elevators, and escalators to encourage individuals to use stairs. The educational/behavioral strategies have been explicated in the CALO-RE taxonomy covering 40 items of behavioral change techniques [8]. Environmental strategies involve changes in environment like providing access to adjustable work stations, bikes, treadmills, step-machines and the like. Multi-component strategies are combining educational/behavioral and environmental strategies. All the mentioned strategies are found to have some effect, with the multi-component strategies evaluated as the most effective.

Other studies operate with the same categories but add an organizational or policy level to the strategies and designate this as an ecological approach [9, 10, 11, 12] to address the problem of sedentary behavior. Hutcheson et al in their review, based on 15 intervention studies, describe four core principles (based on [11]) that characterize an ecological framework [12, p. 42] (1) health behaviors are affected by more than just intrapersonal (knowledge or skill)-levels factors, (2) factors affecting health behavior interact across different levels (3) potential factors influencing health behavior should be identified at multiple levels, and (4) interventions focusing on multi levels of influence should be most effective in producing the desired change.

There seems to be an agreement that interventions of the mentioned types in general shows some effect and that multi-component strategies involving the organizational/political level are the most effective. However, a majority of intervention studies are short-term intervention, and the rather few longer- term interventions shows a decline in activity. This make the authors of [9, 12] to point to the need for long-term evaluations on the one hand, and to suggest, on the other hand, that some of the effects of the interventions might be due to novelty or excitement, whereas in the long run employees return to their ordinary (sedentary) habits.

In our study we address the question of employees' motivation for use, and thus add to the understanding of long-term effects of interventions directed at avoiding sedentary behavior at work. We focus on actual use-practice and the challenges experienced with the aim of identifying ideas and opportunities to support use of exercise tools mainly through the digital platform.

2. Case

The company that we cooperate with offer a multi-component strategy to combat sedentary behavior at work. The strategy consists of bikes, treadmills, step machines, adjustable desks and other exercise artefacts. This is combined with a digital platform where the users can register activities (biking, walking, stepping, standing or other exercises), participate in event and challenges, watching video instructions targeting specific problems e.g. back pain, getting general information, and participate in various forms of competitions. Furthermore, apart from the possibility of monitoring own performance the digital platform also provide access to data from own company, departments, section as well as data from other companies and institutions. Thus, you can set up an event, like reaching La Rambla in Barcelona, and compete with another section e.g. in your own company, on who is arriving first, deciding that the losers serve tapas and sangria for the winning team. Or participating in a four-week squat challenge starting with 10 squats the first Monday and ending with 105 squats the last Friday. The digital platform is web-based, but also available as an app.

Apart from exercise artefacts and the digital platform the implementation of this concept involves a kick-off meeting and the nomination of one or more health ambassadors. At the kick-off meeting all the employees at the specific site is informed on the importance of avoiding sedentary behavior and instructed in how to use the exercise artefacts and the digital platform. The overall message is that a small effort, like standing up 30 minutes a day, make a huge difference in the overall health status. The health ambassadors are nominated by their own company and their role is among other things to act as mediators between the costumer and the company selling the multi-component strategy.

The company is around 4-year-old and already have many costumers from private companies and public institutions, mainly in Denmark but also in Scandinavia and Germany. The concept is still under development and especially the design and use of the digital platform is in focus. The company receives continuous suggestions for improvement to the digital platform from the costumers. These suggestions concern both small improvements to the current functionality, such as a possibility to add more participants to an ongoing challenge or easier registration, and more general comments, such as improvement of the visual experience, the request of the app/web to work faster, or the need of functionality to motivate colleagues. The company's own idea on how to improve the digital platform concern adding more possibilities for various kinds of competition, and also the inclusion of nudging elements.

The overall experiences are as mentioned that while the employees are enthusiastic at the beginning, the use of exercise tools drop relatively fast at least for a god deal of the employees. In order to understand use practice, the challenges involved, and eventually point to functionalities and procedures that might support a more constant use of the concept we did an exploratory pilot study.

3. Methods

The study is based on qualitative interview. Staff from four different companies/institutions where interviewed, 9 persons in all. One interviewee came from a company who decided not to buy the concept after a 3-month testing period. The remaining came from companies that have had the concept installed for a period between 5 months and 2 years. The interviewees where all users or potentially users of the concept, but also had different roles. Thus, we did interviews with one decision maker, one health ambassador and one ordinary user at two of the companies, and one decisionmaker and one health ambassador from one company. We were both present at the interviews, which took place at the company site, also given us the opportunity to see how the exercise artefacts was placed in the environment.

In order to understand the use-practice and the challenges experienced by the employees we asked two types of questions. On the one hand we posed very specific questions on what, when, how, why and why not. E.g. we asked if and when they have used the exercise artefacts lately, if they have used them today, for how long, what triggered the activity, what where they working with while they were using it? What was the reason for not using the exercise artefacts. We posed similar specific questions concerning the use of the digital platform. This approach was inspired by contextual inquiry [13]. The other type of questions, inspired by the narrative interview form, addressed the meaning, significance, and value of the concept. E.g. we asked questions on if and how and with whom the interviewees talked about the concept, how would they

characterize the value of having access to the facilities, did they participate in competitions, did they feel any pressure from colleagues etc. These questions were asked to all participants.

Decision makers was further asked why they have chosen to implement the concept, if they did any kind of monitoring of the use, if sickness absence had gone down, and how they evaluated the success or failure of the concept. Additional questions to health ambassadors included, how they got the role (voluntary or appointed), task and responsibilities, contact with other health ambassadors, and so on.

Interviews had a duration of approximately 30 minutes, were audio recorded and data was manually coded by both authers seperately, in order to clarify the themes of reasons for use, role of health ambassadors, general use practice, challenges for use, and ideas and wishes for the digital platform.

4. Results

According to the decision makers, the choice of introducing the exercise concept was due to concerns for the overall working environment, and not just for health reasons. In one of the organizations there was a history of problems in the work setting with massive notifications of illness as a result and the exercise concept was one of several initiatives made to change this situation. Thus, the intention focused more on creating a sense of community among members of staff, than on the actual exercise. Other decision makers state the reason for adopting the exercise concept as an additional benefit for the staff in line with e.g. high-quality lunch and access to a physiotherapist. There was no specific monitoring of use in any of the organizations/companies.

The role of health ambassadors was to act as mediators between the company selling the exercise concept and the costumers. In general, the ambassadors were voluntary appointed, meaning that decisions makers appointed people they knew were interested. Some understood their role as those who had to set a good example for the others, e.g. raising the table or using the bike on a regular basis. Others conceived themselves more as facilitators, e.g. taking responsibility for providing a reservation system for the exercise artefacts and making sure they are repaired if broken. Some had a regular contact with one or more health ambassadors from the same organization/company and some had not. Overall there were some confusion on the role of the health ambassadors and the respondents said that this was something they had to discuss further.

It was mentioned in all three companies/institutions that after the first couple of months excitement the use of the exercise tools declined for a part of the employees. Several reasons for this were mentioned, some said that they never really got started after the summer holiday, others that it had been too hot, or it was difficult when wearing high heels or flip-flop shoes, but the main explanation was bustle. When very busy at work they tended to stop using the exercise tools. One explained that for example in order to bike when working, you must have everything you need within reach, and even getting something from the desk drawer is difficult while sitting at the bike. Once you have stopped it can be difficult to get started again.

As for the employees who continued to use the exercise tools regularly, the main explanation was found in individual circumstances. That is, exercise help you keep depression at a distance, or keeping your cholesterol down, or give less back pain and so on. It seemed as if the competition element (competing with other groups in the same company or with other companies) that played an important role in the beginning became

less important over time. This might also have something to do with the fact that registration of how far or for how long time you have biked, walked or stood had to be manually done. Generally, people were quite happy with the digital platform, but we learned that it was rather diverse what was recorded which also made it difficult to compare activity between departments and companies. The digital platform also provided different challenges, like wall sitting or squat challenges, but what was especially appreciated and motivating was specific information like "If you stand up at your desk every day for 2 hours in a year then it corresponds to running 6 marathons". Also, some of the decisions makers and health ambassadors asked for strategies that could help people to get started again.

This pilot study reveals that the main motivation for employees to continuously use the exercise tool are due to individual circumstances such as keeping e.g. depression or back pain at a distance. The more competitive element seems to be less important. However, this can also be due to the fact that registration of activities is experienced as difficult. In general, these indications from our pilot study, need to be explored on the basis of more data on user practice and challenges experienced by the users.

5. Conclusion

Based on this pilot study we can conclude that the exercise strategy is implemented to afford a sense of community and at the same time provide the employees with a possibility of doing exercise while working. The role of the health ambassadors could be clearer. Motivation for regular use is primarily due to individual reasons. The digital platform should allow for formulating individual objectives, provide functionalities for easier registration, and deliver timely and specific information on health issues.

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Narratives and Stories: Novel Approaches to Improving Patient-Facing Information Resources and Patient Engagement

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Abstract. Patient-centered healthcare requires development of materials for health consumers that increase health literacy, enrich the provider-patient dialog, empower shared decision-making, and improve downstream outcomes. Unfortunately, evidence suggests current methods of communication, including print and electronic media, are inadequate. The Narrative Theory of Learning is grounded in the premise that humans define their experiences and form cognitive structures (e.g., new learning, novel concepts) within the context of narratives. Simply put, humans remember stories better than fragmented bits of information. Therefore, we propose leveraging the power of narratives and stories to improve the efficacy and impact of consumer health applications. We describe several examples of future technologies that could incorporate narrative techniques and present a call to action for future research and development.

Keywords. Usability engineering, implementation science, consumer informatics, health information technology, quality improvement, health literacy

1. Background

High quality healthcare is contingent upon meaningful engagement of patients in all aspects of their care including information-seeking, clarification of goals, and shared decision-making [1]. Moving to patient-centered models of care frequently requires the implementation of evidence-based "bundles" – processes and tools that foster dialog, improve patient self-management, and downstream clinical outcomes [2]. Bundle elements may include (1) re-imagined workflows; (2) educational artifacts (e.g., drug handouts, illness management brochures, clinic visit summaries); and (3) consumer-facing health information technologies (HIT) [3].

2. Problem Statement

Traditional methods of communication intended to educate and engage patients are often inadequate [4]. Studies suggest that up to 80% of information provided to patients is

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immediately forgotten [5]. Further, in over 50% of encounters, patients or representatives do not understand the diagnosis or treatment plan, and only 12% of patients proficiently act upon health information [6, 7]. For example, materials accompanying prescription medications and intended to improve medication safety (e.g., paper package inserts, medication guides, consumer medication information) are often confusing to health consumers (e.g., patients, families, caregivers) [8]. Moreover, even when printed materials (e.g., tests, results, management recommendations, or side effects) are furnished in consumer-friendly language, patients may need additional context, such as prior experiences or examples, to make values-based decisions [9, 10].

Technologies intended to close these communication gaps and improve patient self-efficacy (e.g., patient portals, self-service kiosks, and mobile applications) can paradoxically increase cognitive overhead, particularly in patients with low health or information technology literacy [11, 12]. Hence, while there is a role for user experience (UX) research to inform the human factors of responsive designs, we also believe developers need to consider approaches that borrow from other industries such as education, business, and the social and psychological sciences [13]. In this monograph, we propose leveraging the power of narratives and storytelling to improve the impact of consumer health information systems.

3. Purpose and Audience

In the following sections, we (1) discuss key references supporting the value of multi-channel learning; (2) review an established model of learning that uses narrative techniques; (3) offer hypothetical examples of tools using stories and narratives; and (4) present suggestions for future research and development. This paper should be of interest to researchers in health informatics and the social sciences as well as health services researchers engaged in "boots-on-the-ground" implementation and dissemination work.

4. Key Literature

Mayer's Cognitive Theory of Multimedia Learning argues that presenting information using multiple channels (e.g., auditory and visual) can improve cognitive performance [14]. The theory describes several evidence-based principles to guide development of instructional content such as using photographs, graphs, timelines, and infographics to communicate information [14-17]. Unfortunately, clinical resources using these strategies have an unreliable effect upon patient recall, accuracy, and self-efficacy [5, 7, 18]. Rather than simply combining channels (e.g., audio and visual), instructional materials should mirror the way the human mind works by organizing information logically and sequentially. Studies suggest using interactive content can improve patient understanding of clinical material and clear narratives can foster insights to inform patient-centered and values-based decision making [10, 19-21].

UX researchers have also begun testing consumer health information systems that attempt to empower patients and enrich the clinical dialog [22, 23]. However, design strategies are still be lacking [12, 24]. For example, the inclusion of pharmaceutical images in an application for medication reconciliation neither improved patient accuracy, nor the ability to detect adherence discrepancies [25].

To summarize, currently there is no single most effective method to communicate

health information to consumers. Moreover, learning theories proven in other domains do not reliably translate to successful consumer informatics software. While these theories hold promise for the development of new applications, additional research is needed to understand how context mediates learning (e.g., mode of communication, types of information conveyed, and patient-specific characteristics). Moreover, we believe that the use of narratives and stories warrants exploration. It is possible that narratives can organize health information for patients to improve comprehension, recall, and application in values-based decision-making.

5. Theoretical Model for Narrative Learning

Cognitive scientists, psychologists, and anthropologists have long acknowledged the human tendency to draw associations of causation between observations [21, 26, 27]. Presumably, these heuristics conferred an evolutionary advantage, enabling individuals to adapt to unfamiliar environments and respond quickly in critical situations [28]. With regards to andragogy, constructivist theory and the related contextual model of learning argue that humans pragmatically encode information through lenses of personal history, socio-cultural environment, and physical space [29, 30]. Learning is deeply embedded in context and enriched through reflection that occurs over time [31].

Bruner's discovery learning theory, though constructivist by nature, goes further by arguing that narrative thinking is the "default mode" for constructing meaning [29, 32, 33]. Clark and others have built on this foundation and advanced the narrative theory of learning as an epistemological tool for engaging learners on a deeply emotional and personal level (Table 1) [30]. Stories are not only cognitive scaffolds to consolidate learning, but also recognizable paths to personal agency within a larger fabric of cultural norms and sociotechnical systems [30, 32, 34]. Learners that can link a concept to their own experiences can also construct a counter narrative to increase self-efficacy and influence social systems. For this reason, Avraamidou and colleagues describe the use of stories to teach sophisticated scientific concepts [29, 35].

Table 1. The essential components of a narrative, adapted from Avraamidou [35] with an example adapted from Dohan [10].

Component	Description	Example
Purpose	To help understand the natural and human world.	Why a patient with early stage breast cancer opted for bilateral mastectomy and reconstruction.
Events	A sequence of connected events.	An exchange with a breast cancer survivor influenced her decision.
Structure	An identifiable beginning, middle, and end.	She learned about treatments, listened to another patient's perspective, and saw an opportunity.
Time	Narratives concern the past.	A prior exchange created new insights beyond the recommendations from a surgeon.
Agency	Actors cause and experience events.	The story aligned with the patient's feelings about identity, sexuality, and empowerment.
Narrator	The teller can be a character or an observer.	A breast cancer survivor provided the account.
Reader	The listener must be able to recognize and interpret.	A patient weighing options used the narrative to consider alternative decisions and outcomes.

6. Practical Strategies Using Narratives and Emerging Technologies

We propose several approaches in which the narrative theory of learning may inform HIT development, health systems delivery, and patient-centered care. We categorize

these approaches into:

(a) **Interpersonal communication.** Practitioners should deliver important messages and educational content through established case stories (e.g., description of drug interactions, symptom manifestations) with an identifiable narrator and sequence of events [36]. Practical ways to scale stories for clinical settings include using standardized interview scripts during interviews and patient learning journals to track understanding over time [30]. Also, conducting group medical appointments where peers can recount personal experiences and insights has been shown to be an effective way to provide hope, support, and disease management strategies [37].

(b) **Distributed networks.** Peer-networks, on-line rating platforms, and social media are powerful channels for exchanging information, identifying solutions, and fostering supportive communities [12, 38]. For example, Henao and colleagues describe Alicanto (http://alicantocloud.com), a multi-function social community website dedicated to maternal and fetal health that includes educational materials, a discussion forum, and toolkits to improve self-management [39]. We envision virtual hubs providing a repository of searchable healthcare-related stories from patient narrators and aggregated patient-centered experiences [38].

(c) **Educational artifacts.** Content providers should organize educational materials using stories that describe an inpatient care-day or clinic encounter, as well as the purpose, key events, clinical reasoning, and potential health outcomes patients may anticipate. In the future, providers may forgo traditional print media such as after-clinic summaries, drug monographs, and disease brochures in favor of narrative media such as internet web logs (i.e., "blogs"), podcasts, and videos [19].

(d) **Human-computer interfaces.** Current consumer health interfaces are still in their relative infancy and often suffer from usability issues [12]. Future interfaces may draw heavily from the gaming industry–particularly role-playing and immersive formats – by using devices and affordances that place the user at the center of interactive or enhanced experiences. For example, augmented reality may help patients experience real-world scenarios such as advanced directives discussions, hospital navigation, and specialty consultation [40].

7. Implications for Future Research and Call to Action

In summary, we believe that the narrative theory of learning offers a new direction for health services research, informatics development, and implementation campaigns. Rather than being orthogonal to current development efforts, it offers a theoretical scaffolding to inform new concepts and a roadmap for interdisciplinary research. We propose three practical strategies to foster the inclusion of narrative theory into research protocols, user-centered design, and care delivery:

(a) **Intersectional research.** We believe the wellspring of innovation and research breakthroughs are dependent upon collaboration between disparate disciplines such as healthcare, information technology, business, and the social sciences.

Future initiatives should strive to include stakeholders that bring fresh perspectives to the design of human-centered products and contextually-sensitive research protocols. Specialists in UX, design, education, philosophy, anthropology, cognitive psychology, public health, business, and marketing have important roles to play in these initiatives.

(b) **UX methods.** The software and technology design lifecycle must include UX methods at every stage. We envision including UX techniques at the requirements definition, design prototyping, and implementation phases. At each step, researchers should seek to clarify user values, environmental constraints, and informational needs through ethnography, workflow mapping, journey mapping, and empathy mapping [41]. Design activities should include high-fidelity simulations to validate use-cases and surface practical user needs [42]. Data collected through these activities will help to inform more robust use-cases, educational environments, and responsive interface designs.

(c) **Implementation bundles.** We envision future implementation and dissemination campaigns that include story-driven patient artifacts and HIT-supported communities of practice. To properly design, deploy, and evaluate tool effectiveness, it is critical that protocols include theoretical frameworks informed by narrative learning theory. Also, measurement instruments should seek to quantify the relationship and impact of narratives upon consumer learning, health literacy demands, and disease self-management [7].

8. Conclusions

Consumer health information systems are becoming increasingly prevalent. However, at present these systems are failing to capitalize on what we know to be true about human cognition: we are better at remembering stories and narratives than discrete bits of disconnected information. Developers need research to understand and capitalize upon the potential benefits of integrating narratives into consumer health information.

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Patient Experiences and Digital Involvement in Patient-Centred Care Models

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Abstract. The provision of individualised treatment and care from health care services to patients with chronic conditions and multi-morbidities is under pressure because of an increasing elderly population. There is a need for services that are: 1) person-centred, 2) integrated and 3) proactive, and supported by digital technology. The research project 3P- Patients and Professionals in Productive Teams aims to study different patient-centred teamwork models in Norway and Denmark. This paper presents a study on patients' experiences and digital involvement in patient-centred care teams. Qualitative research methods were applied with interviews and demonstrations of technology use made at patient's homes. The results showed that the patients were satisfied with the patient-centred service models and had an increased feeling of safety. A constraint was information sharing between the patient-centred health care team and the patients. Most of them did not have access to read own medical information and mainly verbal information was shared between the patients and the health providers.

Keywords. Health technology, patient-centred care, telemedicine, patient safety

1. Introduction

There are demographic changes in society with an ageing population that is increasing, and prone to long-term conditions and multi-morbidities [1], [2] and this is threatening the sustainability of the health care systems [3]. Patients, health care professionals and authorities claim the need for re-organising the service model for people with long-term conditions and multi-morbidities. The patient's needs have to be in focus with development of service models that are patient-centred, integrated and proactive [4]. A patient-centred health care builds on a proactive stepped care plan with goals and supports self-management. Digital solutions for communication and collaboration between patients and health providers are a central element in integrated and patient-centred care models. This paper presents a qualitative study about patients' experiences and digital involvement in four health organisations in Norway and Denmark, that apply patient-centred service models. A special focus was made on the use of health technology in home settings. The research questions (RQs) stated were:

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(1) RQ1: What are the patient experiences with health technology for communication and information sharing with patient-centred health care teams?
(2) RQ2: What are the benefits and constraints of using health technology seen from a patient perspective?

2. Methodology

This paper was made within the research project *3P - Patients and Professionals in Productive Teams* that aims to study health care services models that are run with patient-centred teamwork approaches, but also focusing on digital support for communication and care of patients [5]. The 3P-project is 4-year long (2015-2019) and funded through Helseforsk, a cross-regional health research fund owned by the four Norwegian Regional Hospital Trusts [6]. The project consists of ten work packages that target different aspects of patient-centred teamwork, including patient experiences, patient safety and digital support. Four health care organisations that utilise patient-centred care models and located in different health regions of Norway and Denmark participate in the project. Three of the health organisations provided telemedicine services for chronic obstructive pulmonary disease (COPD) [7][9] and the fourth organisation provided services in the transition period from hospital to home for elderly patients with multimorbidity and chronic conditions [10].

A qualitative research approach was used in this study of patient experiences, with semi-structured interviews and observations of technology use made in the period from June 2017 and until October 2018 [11]. Visits were made to all the four health organisations and the selection and recruitment of informants was made in collaboration with key contact persons. A total of ten informants contributed in the study, whereof two patients from each health region, expect for one region where three patients participated. One separate interview was made with a close family member to gather experiences from a family perspective. The informants had the age from 56 to 83, with a mean of 74 years old. The aim of the interviews was to study patients' involvement and experiences from different patient-centred care models and how technology was used for communication and information sharing purposes. The goal was to map the experienced obstacles in the communication and outlining optimal digital support for the patient-centred care models of the future.

Seven of the patients had experience from using health technology at home and made a demonstration of the functions and shared their user experiences. The data collection consisted of audio- and/or video recordings and annotations that were thematically analysed and categorised into three main groups. A total of 7 hours was recorded, and the interviews had a mean duration of 42 minutes. The Norwegian Centre for Research Data approved the study, with project number 53771 [12]. All the informants participated voluntary and signed a consent form, also the family member.

3. Results

The results are presented in three sub-categories: 1) patient involvement, 2) information sharing and 3) patient safety.

3.1. Patient involvement

All patients had been or were included to services from patient-centred health care teams that were run with different service models. In two of the health organisations, the patients were enrolled for team services for a limited time. In the other two organisations there was no time limit for the services. In the interviews, patients enrolled in services from all the organisations expressed that they had experienced "increased safety" regarding their contact and medical follow-up from the patient-centred care teams.

Seven of the patients had used a tablet for remote monitoring of COPD and made measurements and questionnaire answers that were sent to telemedicine centres. They all had received a visit at home to be included to telemedicine service and connect the technology. The patients expressed that the service models for telemedicine were well-organised and with pre-defined topics to individually go through, such as inhalation- and breathing techniques. The patients expressed that the telemedicine sessions provided a good opportunity to ask questions and that they learned how to observe own symptoms and self-management. It was experienced as more personal to be able to see the face of the health provider compared to a telephone consultation. The patients used technology from three different vendors, and for all of them it was stated that it was easy to use the equipment and not additional workload in the daily life. It was expressed that the telemedicine nurses were specialised in COPD and could provide more targeted advices compared to the patients' GPs and the informants would recommend inclusion to such services to other patients.

Two of the patients had received services from a patient-centred team in the transition from hospital to home. They particularly received advices and support related to physical activity and targeted training and had no remote follow up except from telephone calls. They did also receive home nursing services, so they had more than one service provider. One of the patients expressed "*the team cares about me and they try to help me*".

3.2. Information sharing

In both Norway and Denmark there are national health portals for the citizens to access own medical information. In Denmark all the patients had used the national health portal to read own information, but in Norway the patients had neither heard about or used the portal. In two of the Norwegian health organisations, the patients could access their electronic health record at the hospital but not the municipal record. In the two other organisations, the patients had access to own measured telemedicine information in a tablet solution, but no access to information in electronic health records.

In all health organisations, the patients-centred teams had made an individual plan for each of the patients, but only two of the patients had a clear printed plan at home for daily management and how to handle treatment during deterioration.

In one of the health regions, the information about the patients was not shared with other health providers such as the GP or hospital specialist. The patients considered that as a limitation in the information sharing and one expressed: "*it is important that also the home nursing services know about the telemedicine information*".

3.3. Patient safety

The health information about the informants in this study was stored in at least three different information systems: 1) the hospital electronic health record, 2) the municipal electronic health record and 3) the General Practitioner's system. In addition, there were private specialists involved using their own digital system. The use of so many different systems have the constraint of limited interoperability and lack of information sharing, such as the updated medication list of the patient.

Three of the health organisations could not provide written feedback on verbal information given through telemedicine consultations or by use of telephone. One patient expressed "*I write down the instructions immediately*" and another stated that "*this is a limitation because for instance during high fever also elderly people can get confused and forget instructions*". The patients in one health organisation did have solution that facilitated a message function between the provider and the patient.

The patients in Denmark could use their telemedicine technology also abroad and highlighted the benefit of having a short response time for exacerbations or other acute medical conditions. They expressed that the telemedicine service was most important during exacerbations and did only send measurements in such situations. They also had a "medication kit" always available to reduce the start-up time for treatment.

Regarding information security, none of the patients sending telemedicine measurements were worried about privacy or confidentiality. But most of them had thought that all systems can be hacked, or information sent to wrong receiver. One of them expressed "*it is impossible to avoid sharing of personal information and I trust the system because I can see how useful it is*". However, one informant stated *"I do not like that companies abroad host and can access our patient data"*.

4. Discussion and Conclusion

This paper has presented a study of the experiences and digital involvement of patients enrolled in services from patient-centred health care teams. The research questions (RQs) are answered based on the results.

Regarding RQ1, that asked about the patient experiences with health technology for communication and information sharing purposes. The study showed that the patients expressed an increased feeling of safety and self-management during telemedicine intervention, also seen in [13], [14]. In general, they found the telemedicine equipment easy to use. However, In Denmark, the telemedicine technology shortened the response time and it was possible to use it abroad. Also, in Denmark, the patients were more familiar with using national health portals compared to Norway where none of the patients had logged in to read own information. Regarding the individual plan with goals and "What matters to you?", there should be digital access for patients and where registration of own activities or health-related goals might be a solution.

RQ2 addressed constraints and benefits. There was a lack of written confirmation on verbal information made in telemedicine consultations, a limitation that impacts on the patient safety for instance regarding changes in medication. The patients had limited access to their own information and it was stored in several different systems. When the patient is a "part of the team" s(he) owns the information and should be able to access it in a user-friendly way. Information systems and electronic health records are usually designed for health care professionals and to some degree collaborative work across

organisations, but patients have become a user group of the same systems and their needs must be taken into consideration. Patients that are equipped with tablets for monitoring purposes, should be able to use the same device to access and read all needed information such an individual treatment plan and medical information in electronic health records.

This study had some limitations such as including a limited number of informants. However, the informants meaningfully represented the patient group with diversity in age, gender and digital literacy, and they contributed with sharing their experiences regarding technology and interactions with patient-centred teams applying different care models. Future work would target a larger comparative study across countries on how to improve the digital involvement of elderly patients.

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Designing and Evaluating in Contexts

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We Built It, But They Are Not Coming: Exploring Deterrents to Consumer Medication Information Use

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Abstract. Given the prevalence of prescription medication use, it is important that consumers are aware of the benefits and risks of taking their prescribed medications. One approach to informing consumers in North America is to provide them with Consumer Medication Information (CMI), the paper leaflets given to consumers when they fill a prescription for the first time. Unfortunately, reported use rates of written medication information are quite low. As part of a broader study investigating memory, perceptions, preferences and information needs around CMI, this study specifically examined reported deterrents to CMI use. Findings from this study revealed three areas that appear to influence CMI use: 1) Documentation, how CMI is designed and what it contains; 2) Provision, how and when CMI is given to consumers; and 3) Context, what the individual's characteristics and experiences are. These three factors warrant further investigation to reveal more of their unique facets and their relative influences on CMI use. That is, some aspects may be more influential than others.

Keywords. Consumer Medication Information, Patient Medication Information, Prescription Drug Information Leaflets, Written Medication Information

1. Introduction

Many people take prescription medications. In Canada for example, approximately 4 in 10 Canadians aged 6-79 are using prescription medications, with the likelihood of use increasing with age [1]. Some medications are taken regularly for a prolonged period of time (e.g. blood pressure medication once a day), others only as needed (e.g., creams for skin conditions, nasal sprays for seasonal allergies), and some medications are for a limited duration (e.g., antibiotics multiple times a day for a week). Regardless of the regimen, it is important for consumers to be informed about the risks and benefits of medications to ensure the safest practice possible. There are several resources consumers can turn to for prescription medication such as prescribers (e.g., physicians, nurse practitioners), pharmacists, written material (e.g., paper package inserts, consumer medication information), and the internet.

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Consumer Medication Information (CMI) is the paper information provided to consumers when they receive a prescription for the first time. Providing CMI to consumers is common practice in Canada, but not necessarily in other countries (e.g., Denmark [2]). However, unlike paper package information (i.e., the paper information included within the prescription package) CMI is unregulated and, as a result, often varies between pharmacies. However, it is unclear whether consumers are even aware of this variability. Given this variability due to source, consumers may receive CMI that differs in length, design, and content, depending on the pharmacy source. Alarmingly, in one study, investigators observed discrepancies between reported side effects in CMI for the same medication sourced from two different pharmacies [3].

Consumers are given verbal and written medication information to inform them about the associated benefits and potential risks of taking a particular medication to increase the likelihood that consumers maximize its benefits and minimize its risks. Verbal information is readily forgotten [4]. Therefore, arguably the goal of written medication information (e.g., CMI, patient medication information, prescription drug information leaflets, medication guides, paper package inserts) is to reiterate and complement the verbal information that prescribers and pharmacists share with consumers.

The 1989 movie *Field of Dreams* popularized the quote "*if you build it, they will come"*, but this has not been the case for CMI. Recently reported reading rates of written prescription information show that a significant portion of consumers are not using it. For example, in the United States, many participants rarely (21%) or never (9%) read prescription drug information leaflets [5]. Thus, a significant portion of people taking medications may not be properly informed about the benefits and risks of the medications they are taking.

This qualitative study revealed some reasons consumers are deterred from reading CMI. This study was part of a broader exploration of CMI investigating consumers' memory, perceptions, preferences, and information needs.

2. Methods

The Human Research Ethics Board at the University of Victoria approved this study. Thirty-six adults participated in this study (M = 23.6 years old, SD = 3.8, range = 18 – 35) and each was compensated with a $20 gift card. Participants were recruited using on-campus advertisements and student listserv. Data for two participants were excluded, because they were older than three standard deviations above the mean. Thus, although there were 36 participants, numeric identifiers go up to 38. The investigator used semi-structured interviews to query participants about their previous experiences with CMI. Interviews were approximately 30-45 minutes long, during which participants were asked to discuss whether or not they read CMI when they received it and what they liked and disliked about CMI. Interviews were recorded. Interview recordings were subsequently transcribed and coded using directed and conventional content analysis. Directed content analysis is a deductive approach using an existing coding framework, whereas conventional content analysis is an inductive approach to identify emergent themes [6]. Specifically, this study used previously identified possible factors affecting CMI use [7,8] as a coding scheme for the directed content analysis. Additionally, the conventional content analysis facilitated the identification of emergent themes that were not captured by the coding framework.

3. Results

Although the investigator did not ask about factors influencing participants' use (i.e., read) of CMI, several participants discussed reasons guiding their behaviour. Reported deterrents in this study were captured in three themes:

(1) Documentation, how CMI is designed and what it contains
(2) Provision, how and when CMI is given to consumers
(3) Context, the individual's characteristics experiences while taking a prescription medication

Analysis of the interviews in this study revealed a variety of reasons consumers are dissuaded from using CMI (see Table 1 for explicit examples). Examples of reported deterrents to CMI use included: excessive length (documentation theme), lack of aesthetic appeal (documentation theme), and not being available when needed (provision theme). Interestingly, one participant described how a specific situation (context theme) impacted whether or not she used CMI. That is, participant 27 described that she used CMI only if she experienced symptoms that might be potential side effect (see Table 1).

Table 1. Participant quotes illustrating deterrents of CMI use.

Participant #	Theme	Subtheme	Quote
38	Provision	Ease of keeping CMI	*"It's just a bother to have to carry it around, especially if it's medication that you're taking for an extended period of time. You kind of feel like you need to have the paper with you in order to reference it if any future questions come up but, yeah, they just get lost and crumpled."*
32	Documentation	Utility	*"I feel like they're too lengthy. That's maybe part of the reason why I never read them [laughter]."*
37	Documentation	Design quality	*"That I didn't even look at. That it was so easy to not look at. That there was nothing that kind of, piqued my interest. If it had some kind of visual aid, or color, or something like that, it maybe would've been more likely that I would've looked at it."*
27	Context	Experience of possible side effect	*"The only time I'm actually ever really-- only thing I ever really read through is side effects. And normally, the only time I read side effects is if I'm having something weird going on, and I'm like, 'Oh, okay. Maybe this is coming from this sort of thing.' But even from my doctor, I don't think I've ever been told, 'These are the possible side effects,' or even from the pharmacist. I don't think."*

4. Discussion

Consistent with other studies of written medication information use, participants in this sample generally underutilized CMI. This preliminary exploration of deterrents to CMI use yielded results that warrant further investigation. Participants generated several explanations as to why they did not use CMI, only used it in a limited sense (e.g., skimming it, only reading the side effects), or would not use CMI.

Two important issues were revealed with respect to the current *design* of CMI. First, the excessive length of CMI deters consumers from using CMI. This supports other

research findings [e.g., 9] and the recommendation that CMI should have a concise summary [10]. Moreover, concisely written CMI has shown to bolster memory for the information [11]. Therefore, improving the utility by reducing the amount of information, might have at least two benefits: consumers might be more likely to read it and remember it better. Second, CMI is currently not visually appealing and often fails attract consumers' attention. This may also contribute to suboptimal use rates of CMI. In an era of constant competition for our attention and time, the design of health information is increasingly important. Thus, future studies should examine how making CMI more concise and visually appealing may bolster its usage.

In addition to design elements, CMI *provision* appeared to influence consumers' reported use rated. That is, CMI given to consumers as paper leaflets precludes its use in many instances. If CMI is lost, it cannot be used. Moreover, if a consumer experiences a possible side effect while away from home and the CMI is at home in the medicine cabinet, it cannot be used. Thus, alternate methods of providing consumers CMI should be investigated.

Many countries are moving towards digital and away from hardcopy CMI. Likely more Canadian pharmacies will follow this trend and begin offering digital CMI as well. However, we should be prudent during this transition about how digital CMI is *designed and provided* to consumers. Some of the findings from this study can be leveraged to improve the design of digital CMI. For example, a concise summary of content could be displayed initially, but allow users gradually reveal more details if necessary. Additionally, digital CMI could be aesthetically appealing and include some multimedia (e.g., images depicting directions for taking medications). However, many more opportunities exist for improving digital CMI above those recommendations that can be made for the paper medium. For example, digital CMI would allow the use of a search function to locate specific information quickly and have the content read aloud for consumers who have difficulty reading. Thus, digital CMI warrants its own investigation to ensure it is optimized for the medium. In addition to digital CMI design, there are several important considerations with respect to digital CMI provision.

There are obvious advantages to making CMI available online (e.g., it cannot be lost, it is environmentally friendly), yet the potential impact on usage rates of different distribution methods are unknown. In some cases, CMI is merely published online, not given directly to consumers. For example, Denmark uses a website (min.medicin.dk) for Danish citizens to access CMI. Relying on consumers to seek out CMI rather than giving it directly to them should be studied to determine if there is an impact on usage rates. That is, consumers may be less likely to use CMI if they need to seek it out of their own volition. Additionally, consumers may use alternate sources of information instead of credible CMI. Therefore, it may not be prudent to simply make CMI available online in lieu of current practice, yet a combination approach is feasible and would overcome this limitation. Specifically, in conjunction with having CMI available online, digital CMI could also be pushed (e.g., emailed, texted, printed upon request) directly to consumers with new prescriptions. The strengths and weaknesses with these different approaches should be carefully investigated to determine the best ways to bolster use rates.

How CMI is designed and provided to consumers appears to influence whether or not CMI is used. Additionally, there are contextual factors that also deserve investigation. Each consumer has a unique set of experiences that may influence whether they use CMI or not. For example, one participant in this study noted that she typically only consulted CMI to determine whether she was experiencing a side effect of the medication. This supports the findings of an exploratory study in Australia [7]. The authors proposed

several other contextual factors which could increase the likelihood that consumers used CMI (e.g., severe illness, previous negative experience with medication, acting in a caregiver role) [7]. Additionally, if a particular medication has serious possible side effects, it may motivate consumers to make themselves more informed and therefore more likely to use CMI. Indeed, one showed that intentions to use prescription drug information leaflets were higher when participants imagined they had a life-threatening illness and the medication had significant side effects [5]. Thus, aspects of CMI itself (e.g., length, appearance), how it is delivered, and the specifics of the scenario all appear to influence whether or not CMI is used.

One participant's quote illustrated why CMI is an important practice. Specifically, she described that she consulted her CMI to determine if a symptom she was having was attributable to taking a prescription medication (i.e., a side effect). However, she did not recall verbally receiving information from either her prescriber or pharmacists outlining possible side effects. This participant may have forgotten the discussion of this information or indeed it may not have occurred. Regardless, this account emphasizes the need for providing medication information as a supplemental source of information about prescription medications. However, as previously described, not all countries use this approach to providing consumers CMI with new prescriptions. Moreover, there are various sources of digital and hardcopy (e.g., paper package inserts, medication guides) medication information available to consumers, so the advantages of CMI over these other options are unclear. In an effort to combat the redundancy and ensure materials are more user-centred, the United States is to moving towards offering a single standardized document available digitally to health care providers, pharmacies, and consumers directly [12]. This streamlined approach is logical and may also benefit usage rates (whether digital, analog or a combination of both) by increasing consistency and accessibility.

This study was exploratory and deterrents to CMI use, to some extent, were inadvertent findings and thus limitations are important to note. First, this investigation was not conducted in the context of recently receiving CMI (e.g., recruiting participants right after receiving a new prescription). Therefore, participants were asked to reflect on their previous experiences which may have been subject to memory decay or self-report bias (e.g., participants reporting they had read CMI when in fact they had not). Second, the investigator in this study only asked participants to describe what they liked and disliked about CMI. However, this led to some participants discussing what deterred them from using CMI. Yet, because participants were not asked to describe the motivations behind using and not using CMI explicitly, there are likely more factors that contribute to use behaviours than were captured here. Moreover, it is not possible to tell how prevalent these opinions were amongst the sample as a whole. Thus, further investigation is warranted specifically examining this question and querying participants about reasons why they may or may not be using CMI.

5. Conclusion

This study provides some insight as to why consumers may underutilize CMI. Although this was not the intent a priori, some important deterrents to CMI use were identified that should be investigated in more detail. CMI is an important resource to support safe and beneficial medication practices and efforts. However, reasons why consumers are deterred from using CMI should be investigated so that they can be mitigated and bolster

CMI usage. Although some argue that contextual factors have the most influence over CMI use [8], by ignoring identified deterrents that we are capable of changing (e.g., document, provision), we are doing a disservice to consumers and CMI will continue being underutilized negatively impacting safe and effective medication use.

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"I feel like a nurse and my clients learn more": mHealth, Capacity Building and Empowerment in Community Based Care

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Abstract. Community health workers, led by trained nurses who are linked to a health facility are well positioned to play an important role in improving health of the communities in low and middle-income countries. The South African Department of Health has implemented various mobile health programmes to improve community-based services. This paper presents a component of a study that evaluates mHealth interventions in South Africa. The study was conducted in Pretoria urban and semi-urban areas, with the aim of understanding how community health workers experience mHealth technologies. Three focus group interviews were conducted and data analysis followed Thorne Interpretive Description framework. An overarching theme was that the mHealth application provided clinical content that empowered community health workers to develop confidence, higher efficacy, independent decisions making and experience higher social standing with their clients. This in turn, translated into informed clients. There is evidence of strengthened capacity in the use of mHealth technology and application of knowledge to provide an engaged client care. Functionalities in the application allowed timely exchange of information and decision support.

Keywords. Capacity building, mHealth application, self-efficacy, user satisfaction, psycho-social aspects

1. Introduction

South Africa introduced re-engineering of primary health care (PHC) in 2012, to improve communities' access to health services and the quality of health care provided [1]. One of the key features of this model is the establishment of ward based PHC outreach teams for each electoral ward (WBPHCOT). The team is made up of a trained nurse (team leader), responsible for supporting, supervising and leading the outreach teams and six to ten Community Health Workers (CHWs) [2]. In many situations, community members are serving as community health workers, who perform diverse functions related to health care delivery and social care. They receive basic healthcare training developed by the national department of health in collaboration with Non-Governmental Organisations (NGO) [3].

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CHWs are well positioned to play an important role in improving health of the communities in low and middle-income countries [4], improve access to basic health care services and act as interface between the health care system and the community [5].

2. Utilization of mHealth

Mobile technologies for health (mHealth) represent a growing range of tools being applied in diverse health care settings [4]. Like many other low and middle-income countries, the South African Department of Health has implemented various mobile health programmes to improve primary health care services [6]. This mHealth strategy focuses on using the existing mobile platforms amongst others, improve access of patients to healthcare, improve access to health services and real time data management to assist addressing the current inefficiencies in the Health System service delivery" [7].

WBPHCOTs in this district, utilise AitaHealth application to keep record, manage caseloads, profile households and enroll clients. Modules in the Aita Health are used to collect patient information; support treatment plans and schedule visits. Data are transmitted and aggregated into the cloud based data management system, where healthcare professionals and managers can access it. The development of this application was a joint collaboration between the government, local academic institution and private sector [8]. This paper reports a component of the main study on evaluation of mHealth in South Africa and Sweden.

3. Methodology

The study used the Sittig & Singh 8 dimensions socio-technical model [9], with emphasis on the people and clinical content dimensions, to understand the perceptions of CHWs regarding the use of mobile health technology in community based-care. A single exploratory, holistic case study using three focus group interviews was used. 46 participants were purposefully selected from three sub-districts, with diverse contexts. Written, informed consent was obtained. Interviews were semi-structured and focused on personal experiences with mHealth. All interviews were recorded with a digital audio recorder.

The audios were translated and transcribed by local research assistants to ensure accuracy, as respondents often used indigenous language. The audio recordings were coded and analysed using Thorne interpretive description [10]. The Interpretive description is an analytical, inductive approach used to understand the subjective experiences of mHealth [10]. During the analysis, there was rigorous engagement with data and constant questioning and reflecting upon data to ensure trustworthiness. Team leaders' input was used to confirm or validate data, especially, the clinical content. Throughout the analytic process, findings were shared with CHWs, for verification [10].

Thematic patterns and commonalities and individual variations that characterised empowerment benefits of mHealth were noted. Concepts were linked to arrive at interpretive explanations. The need to use approaches that elaborate understanding of situations that occur in natural settings, influenced the choice of methods.

4. Findings

An overarching theme was that the mHealth application provided clinical content that empowered CHWs to develop confidence, higher efficacy, independent decisions making and experience higher social standing with their clients. This in turn, translated into informed clients. There is evidence of strengthened capacity in the use of mHealth technology and application of knowledge to provide an engaged client care. Functionalities in the application allowed timely exchange of information and decision support. This was made possible through the interconnectedness of the application that involves CHWs and outreach team leaders.

Table 1. Themes, sub-themes and categories.

Themes	Subthemes	Categories
Sense of empowerment	Knowledge acquisition	Access and quality of health education content
		Improved care experience
		Remote monitoring
		Enhanced compliance with national guidelines
	Educational benefits to clients and communities	Self-management and enhanced compliance
		Learning about condition
Psycho-social aspects	Self-efficacy	Enhanced self confidence in data management
		Psychological gratification
		Mobile devices and social recognition (electronic consent)

4.1. Theme 1: Sense of empowerment

The clinical content dimension includes aspects of the data-information-knowledge continuum that is stored in the system [9]. In the South Africa context, this refers to content that allows CHWs to register households and vulnerable populations**,** pregnant women, postnatal visits within 48 hours of birth, immunization, as well as demographic data of registered households.

CHWs perceived the application useful for their performance; they were very satisfied with the clinical content and its presentation in the device. Through interacting with the content, they were able to learn new terminology, new ways of managing health data of clients presenting with different conditions. According to them, the information in the device was accessible and coherent. This is illustrated by the following: *"When I go to the field, I educate my clients about different diseases such as TB, HIV, diabetes, hypertension and importance of knowing their HIV status. This is possible because, in the device, there is health education module for every condition that we encounter, so we know what to say in each situation"*.

The clinical content was perceived as superior, and it appeared that the training they received supported their understanding of what needed to be done. They were content with the standard of training for the mHealth system. In particular, they appreciated the questions and content on risk factors that are embedded in the device. They could navigate and manipulate demographic data of their clients with ease, such as closing the case of a deceased or a family that relocated. They gained adequate experience from interacting with clients to a point where they could identify gaps in the content. That gave them a sense of knowing. Some said: "*When I register a client, I ask questions in a particular sequence, I already know the questions by heart, there is questions on danger*

signs, such as bleeding, vomiting, for pregnant women and questions on adherence. I also add follow up questions".

The majority of participants believed that the content in the device has enabled them to form new knowledge pathways, where they could make associations between a specific condition and client responses to construct their responses appropriately. "*Before the visit, I get reminders regarding priority cases, I know my follow up cases and activities related to that household or a particular client".*

They also felt that household registration, which is the core of community-based care, is completed smoothly on the mHealth tool. However, they lamented prolonged registration of a vulnerable individual. They explained that this was due to the type of additional questions that follow when the client answers in affirmative for a particular symptom and the time the device takes to synchronise. Despite the time the system took to complete the registration of a vulnerable individual, they acknowledged that the series of questioning increased their knowledge about health conditions. *"Some clients refer to us as their nurses, because we give them the right information, they can see that we know. They trust what we tell them because they can see that the information or questions are from the tablets".*

Participants demonstrated greater understanding of National Indicators, policies and guidelines. This reflects an alignment between the clinical content and national guidelines. The two-way communication between CHWs and their team leaders, in addition to group chat on the device, enabled them to make decisions at the point of care. They indicated that their increased knowledge translated to greater clients' self-management. They knew more about their conditions and complied better with medical regimen. Their clients were happy with their service. *"I feel like a nurse, clients tell us we have helped them a lot".* The other one added*: "The team leader is a text-message away, when I have an emergency, I tick on the device that there is an emergency and send a text".* They all pointed out that when there were updates, they got notifications and the weekly meetings with team leaders provided further training.

4.2. Theme 2: Psychosocial aspects

The people dimension according to Sittig & Singh, represents the humans involved in all aspects of the implementation and use of the mHealth application [9]. CHWs expressed increased level of confidence with data management processes, triage, scheduling, and performance management. *"It is time for technology, the gadget helps us produce quality data. We feel good that we can monitor our performance on the gadget*". They believed that the tool enabled them to capture all the information and provide client-specific care. They were also satisfied with the security features of the tool. "*There is a field for electronic signature, we learned about confidentiality and data security. Clients sign and give consent for us to collect information."*

One said: *"I did not know what triage was until I used the device, now I can triage my clients and categorise them accordingly. Category 3 means bedridden client. These are clients that we collect and administer medication for. Honestly, we are doing nurses' tasks".*

There was a sense that they have become agents of transformation in the delivery of healthcare. They could interpret and apply clinical care, document care in the application and write free text in the open field. This gratified them: *"The tool keeps important information, we can manipulate it easily".* Another one said: "*We make a difference in the lives of people, all because of technology".* A few expressed the need to include local

languages in the application, as they left the open field blank sometimes due to '*perceived lack of proficiency'* in English language. However, others indicated that the spellcheck functionality in the tool was helpful.

A few were not aware of the automated scheduling functionality because they were doing it manually. However, one of them explained to them that it was shifted to a different location. She illustrated: *"I love the gadget, it makes my work easier. Hence, I am always searching for new things on it".* This functionality makes scheduling easier, but they still need to meet once a week as a team to discuss plans for the week.

One aspect that came up strongly was the social recognition and acceptance they experienced from their clients because of the devices they were carrying. They believed people took them seriously and that gave them a sense of pride in their work. One said: *"The gadget gives you some status."*

5. Discussion

This study highlighted the impact of mHealth technology on performance and perceived capabilities of CHWs in community-based care. The focus of the study is based on the premise that technology is operated by people who have own perceptions of how the system should operate and its usefulness in supporting their activities. Baxter and Sommerville [11] support this stance and argue that socio-technical approaches are especially appropriate in health and social care "because the problems of developing technology for healthcare lie not with the complexity or novelty of the technology itself, but in the complex ways healthcare is practiced and organized".

CHWs appeared to have developed enhanced self-efficacy in performing their tasks supported by mHealth, including the decision support via real-time consultations with their team leaders. Braun et al agree that technologies need to be a better fit for CHWs tasks to optimize performance [12]. The increased exposure to core intervention messages in the tool, the use of information appears to have provided them the authority and job enrichment. Kane, Kok, Ormel et al, posit that access and exposure to medical knowledge is empowering for CHWs [13]. They reported efficiency in executing their tasks, such as decreased time in household registrations, the questions embedded in the tool that enhanced their understanding of the health conditions, the improved quality of data and lastly, the number of tasks they were able to execute. This study highlights evidence that AitaHealth was useful, and that it improved the activities of CHWs and health care delivery. Views regarding the need to pay attention to some areas in the programme, to maximize investment in mobile health technologies were articulated.

In addition, the educational benefits seemed to have translated to increased self-management on the part of their clients. Timely exchange of information through text messaging ensured they stayed up-to-date with relevant information. Thus, enabling them to disseminate appropriate health education messages, conduct counseling and accomplish targets set up by the national department of health. The personalised engagement with clients and households allowed CHWs to provide holistic care and respond to national indicators [14].

This study offered CHWs the opportunity to evaluate the WBPHCOT program and the related mobile technology tools. Their ability to identify the gaps in the clinical content and develop accurate follow up questions demonstrates the link between self-efficacy and generation of knowledge. South Africa recognises the contributions of CHWs and mHealth tool to primary health care. Hence, there are established policies,

protocols and formal training program in place. Currently, in this province, CHWs are acknowledged as a formal part of national health systems and work *in close cooperation with facility-based health practitioners, other government departments, non-governmental organisations, community structures and the private sector* [15]. The insights that emerged from this study are for a different context. However, there is a possibility of transferability in similar contexts.

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Application Programming Interfaces (APIs) in Health Care: Findings from a Current-State Assessment

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Abstract. Interest in application programming interfaces (APIs) as a means to increase health data access and exchange among patients, health care providers, and payers has become an important area for development. In an effort to better understand the various contexts in which APIs can be applied, we explored different use cases. While APIs and our collective understanding of the best ways to implement and use them continue to develop, in the coming years the use of proprietary and standards-based APIs could be key to the sustainability of applied clinical informatics research, as well as associated improvements in patient engagement, clinical decision making, efficiency, quality and safety of the healthcare delivery system.

Keywords. APIs, interoperability, standards, FHIR®, EHRs

1. Introduction

Application programming interfaces (APIs) serve as a go-between among data systems—using interoperable processes to exchange data and specific standards to ensure the data can be understood by receiving systems. APIs are well known in the smartphone realm for allowing multiple applications to interact (for example, when a customer review platform seamlessly integrates a map utility to show the location of a restaurant) [1]. APIs are frequently used to facilitate bank transactions and are integral to the way many companies conduct web-based business [2]. In health care, APIs can enable different health information technology (health IT) systems (regardless of vendor, region, health system, etc.) to share data of mutual interest. Moreover, they can allow virtually instant access to data (e.g., right place, right time for health care providers) [3]; and they create an opportunity for third-party developers to build interoperable solutions that supplement or complement the traditional vendor-led health IT offerings [4]. Given the public-sector and industry interest in APIs as a key feature of an interoperable health

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system, this paper elucidates the current state of the field with regard to technical and non-technical considerations associated with *API use for data access and exchange.*

2. Methods

We used an eight-dimension socio-technical model developed by Sittig and Singh to assess key dimensions of health IT [5]. The model gives consideration of technical aspects (e.g., hardware, software, and standards) and non-technical aspects (e.g., clinical workflows, internal policies, procedures, and work environment) involved in the design, development, implementation, use, and evaluation of safe and effective health IT [6]. We employed the following methods to conduct the current-state assessment and mapped key findings to the socio-technical mode dimensions.

Literature Review. Searches of the published literature were conducted in PubMed. Given that much of the innovative work in this area is emergent and has not necessarily been published in scientific journals, the peer-reviewed literature review was complemented by reviews of the grey and white literature. We identified 390 peer-reviewed articles and over 100 resources from the grey literature, the majority of which were then excluded based on a title and abstract review. We conducted full text reviews of 39 peer-reviewed articles and 90 articles and reports identified through a Google search. In total, we included 20 peer-reviewed articles and 41 articles from the grey literature (n=61).

Key Informant Interviews. We recruited 13 key informants who provided additional perspective and helped fill gaps we found in the literature. The informant group consisted of representatives from academic institutions and health care delivery organizations (n=5); EHR vendors with predominant U.S. market share (n=2); and app developers and third-party data sharing platform providers (n=6). We developed an outline of core themes to discuss, and then developed discussion guides that were tailored to the expertise of each type of informant. Key discussion themes included an exploration of current API use cases, the use of read and write capabilities, challenges related to advancing write capabilities, and the characteristics of "open" APIs. We reviewed the notes by theme, synthesizing the responses across interviews, and within informant types.

EHR Vendor App Gallery Review. To determine the types of apps available in the marketplace, we performed an environmental scan of three EHR vendor app galleries [7,8,9] and the SMART® app gallery [10] and identified 271 available applications. As a first step, we categorized the applications based on whether they were primarily provider-facing, patient-facing, or both. We then assigned each application to a category based on 'intended purpose,' which included patient education and engagement, population health analytics, clinical decision support and patient safety, care coordination, administration, and finance.

Technical Expert Panel. The TEP convened in December 2018 to discuss the present and future applications of APIs in health care. The meeting consisted of a review of findings from the literature review and key informant interviews, followed by in-depth discussion of four thematic areas in the field: 1) use cases and standards for APIs; 2) challenges, technical concerns, and facilitators for read and write capabilities; 3) outlook for future development of write capabilities; and 4) current costs associated with API development, implementation, and use.

3. Findings

While the use of APIs in health care delivery and research is increasing at an astonishing pace, broad use of APIs is still in the pilot stage. The promise of APIs liberating data and contributing to value-based care principles is much discussed in the popular press, with more limited representation in the peer-reviewed and grey literature.

3.1. API Use Cases

To explore the use of APIs to facilitate more efficient access to clinical documents and clinical data elements, we focused on the use of APIs in five distinct use cases: 1) to facilitate bidirectional exchange data between an EHR and external sources such as data repositories; 2) to allow external apps/devices to contribute data to an EHR system; 3) to aggregate clinical data from multiple EHRs into a single app; 4) to facilitate clinical decision-making (i.e., write or read/write); and 5) APIs for Bulk Data Access (i.e., read).

Use Case 1: APIs for Bi-Directional Exchange of Data (i.e., Write/Write). Data exchange among health care providers supports care coordination and downstream improvements in patient care and health outcomes. The focus of this use case is data exchange between two entities using an API to write data from an EHR or into an EHR. This exchange can occur between health care providers and/or between data repositories and EHRs, such as public health registries (e.g., state prescription drug monitoring program registry) and other external data warehouses (e.g., for research purposes).

Use Case 2: APIs to Contribute Data to EHRs (i.e., Write or Read/Write). APIs can enable outside entities (e.g., patients, external health care providers, or clinical laboratories) to push data into an EHR, either via an unstructured document that can be stored and viewed (e.g., a PDF) or as structured data that can be written into an EHR's structured database (e.g., via a Fast Healthcare Information Resource [FHIR®] interface or via a Clinical Document Architecture document). Examples of the types of data that a patient may want to write or store in an EHR include patient-generated health data (PGHD) from a wearable device or patient-reported outcomes from a health survey.

Use Case 3: APIs to Aggregate Patient Data (i.e., Read). This use case involves pulling or querying patient data from multiple EHRs to a single point, such as a smart phone application under control of the patient, where the data can be aggregated across the multiple sources, displayed to and used by the data requester. While personal health record (PHR) solutions and EHR "view, download, and transmit" (VDT) capabilities allow patients to access their health information, there are currently limited solutions available that support a consolidated view of a patient's health information across providers and across visits. Specifically, we were interested in market-based solutions using APIs to read data from multiple EHRs to create longitudinal patient records.

Use Case 4: APIs to Facilitate Clinical Decision-Making (i.e., Write or Read/Write). There are three instantiations of this use case. The first represents the emergence of specialty APIs, such as CDS Hooks, that enable an HCO to access information from outside data sources (e.g., servers, data warehouses/repositories) to initiate an app or decision support function within the EHR. TEP participants also described two new provider-facing use cases: business-to-business exchanges between HCOs, and surveillance and predictive modeling apps designed to assist providers with care delivery optimization, population health management and risk calculation. The former represents an example of an app with no user interface and/or apps that either do not use clinical data or do not have direct applications for patient care.

Use Case 5: APIs for Bulk Data Access (i.e., Read). Currently, most APIs are designed to access data for a single patient. However, to be useful for population health and other kinds of research, APIs must also facilitate bulk queries for data from multiple patients. The Da Vinci Project, an effort under way at HL7 with private industry partners, is attempting to use FHIR®-based APIs to address value-based purchasing needs such as population health management, which will necessarily involve bulk queries of multiple patient records [11].

3.2. Use of Read and Write APIs

Currently, read-only APIs predominate, particularly for patient-facing apps. There are comparatively limited examples of write APIs beginning to emerge for low risk, tightly constrained functions like scheduling. Some of these read and/or write APIs leverage the HL7 US Core Implementation Guide profiles and resources developed for the 2015 Edition Common Clinical Data Set. When a FHIR® API is being used to read or write data, mapping is needed between the native EHR database and FHIR®.

3.3. API Standards

Discussions with EHR vendors and TEP members indicate that many of them have made investments in proprietary APIs over many years, supporting both read and write capabilities. FHIR® R1 achieved DSTU status only 5 years ago and is now recognized as an important standard for representing and exchanging EHI. Given the EHR vendors' prior investments in proprietary APIs, and that the standard has multiple versions and is still maturing, FHIR® adoption is not widespread. Only an estimated 32 percent of EHR vendors are supporting the FHIR® version 2 Draft Standard for Trial Use (DSTU2) released in 2015 [12].

3.4. Current Challenges and Technical Concerns

Both the literature and interviews demonstrated the reluctance of health care providers, HCOs, and EHR vendors to allow external data, including PGHD, to be fully integrated (i.e., written) into an EHR. Concerns raised included the volume of data providers would need to review; liability issues if providers overlooked EHI that in retrospect had an arguable potential to improve clinical outcomes; potential for cyber-attacks; potential for information overload from the myriad false positives; and issues around maintenance and display of data provenance. In spite of the associated concerns, some leading HCOs report exploring use cases for write capabilities, in highly constrained environments.

In spite of the technical challenges and associated concerns, HCOs are venturing into API write capabilities and reported during interviews that they see tremendous value in doing so. Some leading HCOs are exploring a range of use cases for write capabilities, but are doing so within secure, highly controlled environments. Specifically, the HCOs are developing apps themselves and making them available to their providers on HCO-issued and -controlled devices, which can be quickly deactivated in case of loss or theft. These HCO apps use proprietary APIs by and large.

4. Discussion of Findings

The use of standards-based APIs to support exchange is still very much in its infancy. A multitude of app marketplaces are becoming available, offering numerous apps. The

majority of apps are targeted at providers, with far fewer supporting patient access to data. Where consensus technical standards are being used, they are largely FHIR®-based, which is a positive indication of the market's support for interoperable solutions. The current focus is on read APIs, with very limited use of write APIs. The following sections discuss lessons learned from our work.

4.1. Enhanced Support for Write Implementation

To advance write capabilities, FHIR® implementation guides need to be updated to include write access (currently, it is focused on read access). Some informants argued that, in developing write implementation guides through community stakeholder consensus process, a practical path would involve taking a use case driven approach—starting with less complicated write functions (e.g., scheduling) and gradually moving to more complicated functions (e.g., medication ordering). Informants suggested a number of potential simple use cases that would improve provider clinical decision making and patient contributions to the medical record:

- Posting Documents: Writing simple documents to the EHR from third-party apps that serve as an information filter
- Questionnaires: Writing questionnaire responses back into the HER.
- Defining FHIR® Resources: This would assist in using PGHD and PROs in the calculation of clinical risk scores.
- Innovating the User Interface with Machine Learning and Predictive Analytics: Presenting actionable information at point of care.
- Patient Data Corrections: Developing an app that allows patients to contact their providers and request edits to their record (e.g., medication lists).
- Leveraging specialized APIs: This includes CDS Hooks and other APIs that process data and provide clinical decision support.

When considering the future of write APIs, discussion of the utility of pursuing APIs within a given use case will help establish industry standards for write implementation incrementally and in high value areas.

4.2. Patient-Generated Health Data and Patient-Reported Outcomes

Interest in the incorporation of PGHD and PRO information to inform, enable, and recognize better care has grown, but questions remain as to how these data can be best captured and used. Concerns related to these data encompass not only their accuracy and reliability, but their clinical utility. TEP participants expressed concern about the preparedness of providers and HCOs to manage an influx of raw PGHD/PRO data, and a lack of mechanisms to incorporate these data into their clinical workflows in an efficient and meaningful way. One possibility noted was that apps be developed to filter and summarize raw PGHD/PRO data, before they are transmitted to the provider. For purposes of this assessment, it is important to note that these questions include whether such data should written into the EHR, especially in raw form, or if its potential would be more effectively realized by using alternative approaches to derive clinically meaningful, actionable information from these data and deliver that information in usable

forms at helpful points in care delivery processes.

4.3. Development of a Robust Normative Standard for FHIR®

While significant progress has been made in the evolution of the FHIR® standard, multiple FHIR® versions are being pursued by vendors and developers. The lack of a stable normative standard has been highly problematic for interoperability among those currently using different versions of the FHIR® standard. HL7's recent release of a new version of FHIR® as a normative standard will help ameliorate the challenges posed by variability in versioning across the market as new versions are implemented over time.

5. Conclusion

The literature review, key informant interviews, app gallery review, and TEP input provide a significant window into the current API landscape—including a market focus on provider-centric use cases; insight into the rationale behind the emphasis on read instead of write technology; the players involved; and complexities related to standards and security. There are numerous unmet needs with regard to patient-facing apps, including facilitating data access, aggregating data into a patient-controlled health record, and strategies for effective capture and use of PGHD and PROs. Many of the available apps use consensus technical standards, but many others remain proprietary. Where consensus technical standards are being used, they are largely FHIR®-based, which is a positive indication of the market's shift towards developing interoperable solutions. Most of the activity is focused on read APIs, however, with very limited use of write APIs. Thus, while APIs are being touted as a solution to the interoperability challenges within the health system, they remain an emerging technology that is likely to be one piece of a multi-pronged approach to data exchange, integration, and use.

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Open or Closed: A Project Proposal for Investigating Two Different EHR Platform Approaches

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Abstract. Technical platforms form the fundament on which IT systems and Electronic Health Records (EHRs) are implemented. The use of either open or proprietary standards and technologies for information modelling and interoperability have implications for how clinical and health data is handled and made available for the system users. In Norway, two different EHRs are procured in different health regions of the Specialist healthcare service. The two platforms are characterized as one being open platform-based and the other being closed platform-based. The study aims to identify and describe consequences and implications related to two different platform approaches for EHRs from an end-user perspective. The study will employ three methods of data capturing; scoping study, interviews, and questionnaires. Data will be systematically analyzed through proven methods. Interviews and questionnaire data will be gathered from European hospitals having implemented EHRs in recent years. Results will be compared to the Norwegian context. The technical platform used for health IT systems in general, and the EHR specifically, can have substantial consequences for clinicians and organization of work. Closed platform-based EHRs still constitutes the majority of the market, but open platform approaches are rapidly gaining popularity. An assessment of the consequences related to different platform designs can shed light on the implications the chosen technical approach will have on clinical and organizational practice.

Keywords. Electronic Health Record, Open Platform, Closed Platform, User Satisfaction, Adoption Rate, Implementation, System Evaluation, openEHR

1. Introduction

From the early developments and implementations of Electronic Health Records (EHRs) in clinical practice in the late 70s and 80s, healthcare has undergone an extensive process of digitalization and innovation. Initiatives to improve treatment, care, patient safety and effectiveness with Information Technology (IT) and digital tools are ever-increasing. Concurrently, both the number and complexity of healthcare IT systems that clinicians have to rely on in their day-to-day work increases. Clinicians are dependent on effective, intuitive and adapted IT systems to treat and care for patients; documenting, accessing and evaluating patient information is to a large degree done through digital formats. The

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technical platform used for health IT systems in general, and the EHR specifically, can have substantial consequences for clinicians and organization of work. The architecture of the platform, and in turn also the clinical applications that run on top of the platform, are built using either open standards, proprietary standards or a combination. In this study we will investigate two conceptually different architectural platform approaches.

2. Open platform-based EHRs vs Closed platform-based EHRs

For most healthcare provider organizations, the EHR contains the core functionality for documenting and accessing patient information and health data. The bedrock of any system application ecology is the platform, which provides a set of technical specifications and definitions for the interface and integration of separate applications implemented on the platform [1]. For the sake of argument, we will draw a conceptual line between the two different approaches for EHR platforms; on one side, are platforms based on open standard specifications for architecture and information modelling – from now on termed 'Open Platform EHRs'. For an EHR platform to be truly *open*, it arguably needs to conform to a set of principles. In 2016, Ewan Davis proposed that such principles should include the following; i) the use of freely available open standards; ii) the use of common information models; iii) that applications implemented to run on one instance of the platform easily can be implemented and ran on a different instance of the open platform; iv) the standards used in the platform should be technology and vendor neutral; v) the support for open data in a sharable and computable format; vi) the platform should provide open APIs [2].

On the other side are closed platforms, where the technical standards and information models used in the architecture are developed, maintained and controlled by the vendor using primarily proprietary technologies [1]. Traditionally, EHRs have to a large degree been based on closed platform architectures, often labeled 'megasuits' and 'monolithic systems' – termed 'Closed Platform EHRs'. From a business perspective, the idea behind megasuits have been to offer if not all, then most, needed software functionality in a single solution [3]. While this approach can yield great stability, it inevitably leads to 'vendor lock-in' and a situation where the vendor controls the data, and information interoperability and agility is impeded [4, 5]. On an open platform, it will be substantially easier to either replace applications or add new applications when new needs arise [6]. This dichotomous distinction between the two conceptual approaches is, however, a simplification; on a continuum ranging from open to closed, EHRs can be found on either side of a centre line, rather than on either periphery, depending on its characteristics.

3. Norwegian context

The Norwegian specialist healthcare system is organized in four separate geographic regions. Each Health region operates a number of hospitals and outpatient clinics, and governs their region with a large degree of autonomy in terms of IT decisions and procurements. Today, three of the health regions runs different implementations of the same EHR system from the Norwegian vendor DIPS AS, while the fourth is in the process of procuring a solution from the US vendor EPIC Systems.

The next version of the DIPS EHR (DIPS Arena) is based on the openEHR platform

specifications, and will be implemented in all three health regions currently running DIPS. With the new EHR, DIPS is moving from the proprietary, closed platform-based approach of their current EHR, to an open platform approach with DIPS Arena [7]. There are also cross-regional efforts to consolidate the databases between the three health regions [8]. In addition, through the public organization Nasjonal IKT, the Norwegian healthcare sector has a significant involvement in the development of the openEHR archetypes (ISO 13606) information standard [9]. Although EPIC Systems are, to some degree, starting to use open sourced standards and APIs through the Fast Interoperability Resources (FHIR) specification [10], the EHR is still considered a monolithic and proprietary, closed platform-based systems [4]. This places the fourth health region's EHR in stark contrast to the upcoming EHR in the three other regions, at least in terms of the chosen platform approach. Common for all of the health regions, are the fact that they are procuring EHR systems that architecturally are fundamentally different from what they currently are using.

Nationally, the Norwegian healthcare system operates toward a strategical aim of 'One citizen – one journal' [11]. This implies that a patient's health data should be available regardless of which hospital or health region s/he is admitted to. In practice extending the scope of the EHR from the institution level to a national integrated health and care community. A prerequisite for this, is that data needs to be fully interoperable between IT systems and organizational lines. The platform and information modelling used by their new EHRs will have implications also for how legacy data and systems are migrated and made available for clinicians post-implementation [12]. The consequences of using differing technical platform approaches to achieve this not fully understood. We wish to explore this in the present project.

4. Objective and research questions

In order to fully understand the consequences of EHR and platform choices, more knowledge is needed. The Norwegian context is unique; the specialist healthcare's IT systems are based on two arguably conceptually different approaches. We propose a study protocol to investigate and examine consequences of implementing either an open platform-based EHR or a closed platform-based EHR in general, and examine consequences for a future Norwegian system landscape.

The proposed subject is one that can be investigated from a number of perspectives; implementation process evaluation, technical implications, clinical outcome, workflow and organizational effects, financial consequences and patient care delivery and safety are all relevant variables when studying health IT innovation. The focus in the present study is on clinicians and their perceptions of usability in their EHR.

The main research question in this study is:

- Does the underlying technical EHR platform affect system adoption rate among clinicians?

Secondary research questions are:

- How does the underlying technical platform affect clinicians perceived system usability?
- How does clinician satisfaction with the EHR compare between the open platform approach and the closed platform approach?

5. Methods

The scope of the present project has to be sufficiently narrow to provide practical analysis for the Norwegian national context, yet wide enough to not miss important evidence from sources outside of traditional academia. For instance, a part of the evidence that are relevant for the subject at hand exists in non-peer reviewed literature, and the study will have to look into this so-called grey literature as well as the traditional research literature. Furthermore, because we aim to include sites that are similar to one of the two EHR systems that are in acquisition or implementation in Norway, a categorization is required in order to select hospital locations of interest. Therefore, the categorisations of different EHR systems in this study is a pragmatic attempt to relate to one of the two systems that are being implemented in Norway, and by no means a proposed global taxonomy. In order to achieve its goal, the project is designed to contain three phases: scoping review, interview with mid-level manager staff in hospitals and finally, a survey from clinical hospital staff.

5.1. Scoping study

The scoping study methodology is in most applications well suited for rapidly mapping key concepts, and flexible enough to include both research literature as well as other evidence that are relevant for a research question [13]. In the present project, the first step is to formulate the research question, then identify relevant studies and other evidence and make a selection. Finally, the evidence will be charted and summarized. The scoping procedure will resemble the stages proposed by Arksey and colleagues [14]. The review is designed to identify recurring themes and trends in the literature.

5.2. Interview with mid-level manager staff in hospitals

Interviews are conducted at minimum two, preferably four, hospitals in Europe. We aim to visit hospitals that adhere to different concepts of EHR-solutions- with respondents at the head of department level. The interview will be conducted in a semi-structured fashion. The questions will be open-ended and similar between hospitals, and the interviewees will be invited to elaborate on themes that they deem important. Qualitative data collected from the interviews will be analysed using the Framework Method [15]. Interviews will be recorded in audio and transcribed verbatim, and the transcripts independently read by each member of the research team. Interesting segments of text are then underlined and assigned to a label, to categorize which part of the research questions they are relevant to. Secondly, the research teams meet and present their suggested labels- and the following discussion results in a set of consensus-based codes. The resulting analytic framework is applied to all interviews, by assigning appropriate codes to each meaningful passage of text. Thirdly, the resulting data is summarized in a framework matrix using spreadsheets. Finally, the qualitative data in the framework matrix is reviewed to identify common themes [16].

5.3. Survey

A short questionnaire will be created to survey the clinical staff's perceptions of the EHR. It will be distributed in a digital format. In order for the questionnaire to have minimal interference with the schedules of the clinicians, the questionnaire will be designed to

take a maximum of five minutes to complete. The questionnaire will be based on the System Usability Scale [17], in addition to approximately three items based on recurring themes that were identified in the interviews, and a free text section. The quantitative data from the survey will be summarized and presented descriptively, while the qualitative data from the free-text sections is analysed with a framework theory-based procedure, similar to the interview data.

6. Discussion

6.1. Limitations of the chosen methodological approach.

The methodology of the present project does not control for the effects of differences in implementation timelines of the EHR systems in the studied hospitals. The length of time from implementation is likely to affect the variables of interest in the present study, such as user satisfaction and adoption. Any attempt to make comparisons between hospitals should consider this limitation.

6.2. Risk of bias in respondents and study population

The interview respondents in the present study are not randomly selected, but are volunteers suggested by hospital administration or EHR vendors. There is a risk that the respondents have attitudes that are more positive towards their EHR systems than the hospital staff population in general.

7. Preliminary suppositions and implications

One of the most fundamental tools available for healthcare professionals and clinicians are the functionality provided through the IT systems in the hospital. A prerequisite for high quality and efficient treatment and care delivery are IT systems that are context sensitive, scalable, and with a high degree of usability and data interoperability [18, 19].

This study could contribute with new insight and understanding of the implications of fundamental concepts of the health IT portfolio from the end-user perspective. The growing market trends indicate substantial movement from the traditional megasuite scenario, towards an open platform-based ecology consisting of a multi-vendor system portfolio [20, 21]. This implies that the subject of the study has a high degree of topicality, and can be an important contribution for decision makers and hospital CIOs considering IT procurements.

An assessment of the consequences related to different platform designs can shed light on the implications the chosen technical approach will have on clinical and organizational practice. In addition, this study can constitute a basis for further research, possibly by conducting a more focused investigation on one of the themes that emerges in the present study, expand the number of respondents, or study a different aspect of EHR implementation.

Contributors

KMN and AJF conceived and designed the study and performed the initial investigation on the subject. KMN and AJF have been the main contributors to the manuscript. RP

have critically revised the manuscript and contributed insight on the method and discussion. All authors approved the final manuscript before submission.

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Evaluating the Contextual Integrity of Australia's My Health Record

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Abstract. My Health Record (MyHR) is Australia's national personally-controlled electronic health record. Initially established in 2012, it moved from an opt-in to an opt-out system in 2018. This paper considers the privacy aspects of MyHR shared health summary. Drawing on Nissenbaum's theory of privacy as contextual integrity, we argue that the shift in the event-specific nature of information sharing leads to MyHR breaching contextual integrity. As per Nissenbaum's decision heuristic for contextual integrity, we evaluate this breach through a reflection on the changing nature of health care, including patient empowerment, and the greater complexity of care. It is evident that more needs to be known about the benefits of shared health summaries, as well as the actual use of MyHR by clinicians and patients. Though we focus on MyHR, this evaluation has broader applicability to other national electronic health records and electronic shared health summaries.

Keywords. Medical Records, Online Systems, Privacy, Ethics

1. Introduction

In Australia, My Health Record (MyHR) is a nationally established electronic health record that contains, among other things, a shareable summary of an individual's health information (www.myhealthrecord.gov.au). The transition of the MyHR system from opt-in to opt-out has fueled public concerns about privacy. To understand some of the privacy concerns we draw on the theory of Contextual Integrity. Contextual Integrity views privacy as the appropriate flow of information, which stems from the information norms in a specific context [1]. This contrasts with many definitions of privacy that are concerned with the control of information about oneself [1]. Nissenbaum [2] has proposed a decision heuristic to evaluate whether a new technology breaches contextual integrity, and further evaluation to see if this breach is warranted through a consideration of the moral and political implications of the new technology, as well as the values, goals and ends of the context. MyHR shared health summary which shifts the traditional 'push' method of information sharing to a 'pull' method of information sharing [3] may breach contextual integrity. One may question whether this breach of contextual integrity is justified by the changing nature of health care, as it evolves from a sole clinician model to a shared care participatory model.

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2. My Health Record

At the core of MyHR is a shared health summary (SHS); a summary of a person's health information, including critical information such as medical conditions, allergies and medications [4]. A patient's SHS is created by their regular provider; this may be a doctor, nurse or Aboriginal health worker [4]. Clinicians who are not the patient's regular provider (e.g. a doctor at an after-hours clinic) can upload an event summary detailing information that may be relevant for their regular clinician to know [4]. By 2022 the Australian Digital Health Agency plans for all health professionals to be able to contribute to and use MyHR [5]. Although clinicians are recommended to consult with patient's about what information is uploaded to MyHR, they are not legally bound to do this [6]. MyHR is the first Australia-wide example of a shared record that is set-up to allow a health care provider to view information about a patient that was created by other primary or tertiary care providers. Currently, the main users of MyHR are general practitioners (GPs) who access it through their practice based proprietary electronic patient record systems [7]. Unlike many international examples, MyHR is a way to exchange a summary record rather a way to exchange a full health record. The only comparable example would be the UK's National Health Service summary care record. Patients can access and view any documents uploaded to their own MyHR – and can upload some information themselves - through a national government portal (https://my.gov.au). Patients can also apply a number of privacy controls; however, these are not activated by default [8]. We are specifically interested in the privacy aspects of the SHS component of MyHR, as this is new in the context of primary health care [9].

3. Contextual Integrity

Contextual Integrity is a theory of privacy that views privacy as the appropriate flow of information, where what is appropriate stems from context specific information norms [2]. Privacy as contextual integrity shifts the focus of privacy from control over information to control over the flow of information that is appropriate to the context specific information norms [1]. Information norms that guide appropriate information flow can be mapped out using five parameters [2]. These parameters are the sender, receiver, and subject of the information, the type of information being shared and the constraints on information sharing, known as transmission principles. Transmission principles include constraints such as the need for consent before information is shared [1]. If any parameter is changed with the introduction of new technology, it is considered a breach of contextual information norms, and thus contextual integrity [2].

4. Method

The method for evaluating a potential breach of contextual integrity is outlined by Nissenbaum [2] as a nine-step decision heuristic. This heuristic first describes the new practice and the current context using the Contextual Integrity parameters. Information norms are determined, and any departures from these as a result of the new technology are identified. An initial assessment as to whether the technology breaches contextual integrity is made. It is acknowledged that contextual integrity can be conservative and that norms can change [1, 2]. Thus, if the new technology breaches contextual integrity,

it is recommended that the moral and political implications of new technology be considered, as well as whether it aligns with the goals, values and ends of the context [2]. The decision heuristic and its application to MyHR SHS is outlined below.

5. Results

5.1. Describe the Practice in Terms of Information Flow

The MyHR SHS envisages clinicians, mainly GPs, uploading a summary of their patient's information to a national electronic health record that other treating clinicians and the patient themselves can access. When a person attends a GP consultation, at the end of that consultation, their GP will upload a SHS - unless the patient specifically says that they do not want information uploaded. GPs are encouraged to discuss with each patient the information they are uploading to that person's MyHR.

5.2. Identify Prevailing Context

Hitherto, outside of referral and discharge letters written for particular purposes and exchanged by hand, mail or fax, clinicians have not provided a summary of information about a patient that other clinicians can access without notice, that is, without specific contact between the clinicians about the care of that patient [9]. Information exchange is usually done on an 'as required' basis, such as someone visiting their GP in need of a referral to a specialist. In such a case, only the most pertinent health information would be summarised in this exchange, but not a summary of the patient's full record.

5.3. Identify Information Actors

GPs act as gatekeepers in the Australian health care system, with access to specialist care requiring a referral from a GP [10]. Thus, in this context GPs in many cases act as the senders of information. Patients who visit a GP with a health problem, or for routine health care, are the main subjects in this context. Where the complexity begins is in considering the recipient, as there are a number of potential recipients of information from the GP. This could include a range of allied health professionals, medical specialists, or diagnostic services that provide tests such as x-rays or blood tests [10]. The type of recipient (i.e. where the patient needs to go next) will determine the type of information the GP needs to send.

5.4. Identify Transmission Principles

Currently, clinicians are guided both by confidentiality and acting in the patient's best interests [11, 12]. Under Australian privacy law, clinicians can share relevant information regarding a person's health with another treating clinician without that person's consent [13]. Patients tend to have limited knowledge of what information is shared between clinicians and how it is shared, though they appear to trust that clinicians will do what is in their best interest [14, 15].

5.5. Locate Applicable Entrenched Information Norms and Identify Significant Points of Difference

Current information norms are steeped in the trust placed in the clinician-patient relationship, and the values of patient benefit and confidentiality that clinicians balance when sharing information [11, 12]. Because of this, clinicians make decisions based on what they perceive as the patient's best interest when deciding to share information. Clinicians also record information differently depending on the recipient [16]. For example, clinician A pushes information to clinician B based on an event, such as the patient seeing clinician A for a health issue that requires further clinical involvement to address. Clinician A decides two things: what information is clinically relevant to clinician B, and what information should be shared with clinician B in the best interest of the patient. Thus, it could be said that the information is curated for the needs of the event (e.g. the patient's visit to clinician A), and the needs of the receiver (clinician B).

MyHR SHS is a new information practice. This type of record has been described as a shift from a 'push' method (a referral or discharge letter) to a 'pull' method, where a clinician can download information about a patient from that person's MyHR [3]. This information may not be curated, and thus may not be pertinent to the clinician 'pulling' it from MyHR; it may not even be up-to-date regarding the current health of the patient. One anonymous submission to a parliamentary enquiry described MyHR as [17, p. 1] "a glorified dropbox." This is in contrast to something like a management and care plan, which is designed to be used in team-based care of a particular type (e.g. aged care, chronic disease, mental health) and to include information relevant to those providing care.

5.6. Initial Assessment

An initial assessment of MyHR SHS points to a breach of contextual integrity due to the shift from a 'push' method of information sharing to a 'pull' method of information sharing. This is a change from the current curated and event-based nature of information sharing.

5.7. Evaluation I - Moral and Political

MyHR has been claimed to empower the individual by giving them control over their health record [5]. This aligns with a shift towards greater participation by patients, and the democratising of health care through ownership of one's health information [18]. This is seen in the patient's ability to access MyHR and apply security controls, but also in the recommendation that clinicians collaborate with their patients when writing that person's SHS. However, the benefits of this shift are not guaranteed to be experienced equally by all people. People may be marginalised due to issues such as low literacy or limited communication options [19, 20].

5.8. Evaluation II – Values, Goals, and Ends

When we consider the values, goals, and ends of health care, we are faced with a challenge due to the shift towards more complex models of care in the community [12]. Health care traditionally involved seeing a GP who provided treatment or referral on to a specialist with a referral letter; in this context, two clinicians balanced confidentiality

and the patient's best interest. The emergence of chronic and complex conditions has led to more collaborative care where several clinicians and services provide integrated aspects of care in parallel [21]. With this has come a shift in the importance of information sharing, and this has required new interpretations of the value of confidentiality [12, 21, 22]. Clinicians and patients may be willing for information to be shared more liberally if there is a benefit to a person's health [11, 15]. The trade-off between benefit to patient health and confidentiality when applied to MyHR is unclear, as we have little evidence to date about the benefits of the SHS. The SHS is supposed to improve the availability of "potentially lifesaving" information according to the Australian Digital Health Agency [5 p. 21]. However, there is a risk with summary records that this essential information will be lost because data are not curated [23].

5.9. Outcome

There is no definitive outcome from this evaluation of MyHR SHS, but it does raise issues for discussion in the shift to a more digital health system. There is a need to reflect on what confidentiality means in the age of complex and integrated care, and how this applies to an individual's electronic health record. Further, the benefit of promoting patient participation in care through their access to their MyHR needs to be considered within the context of power and privilege regarding who will be able to take up this opportunity to participate. Finally, the value of the SHS needs to be backed up with evidence.

6. Discussion and Conclusion

Initial assessment of MyHR SHS points to a breach in contextual integrity due to a shift from a 'push' to 'pull' method of information sharing. This disrupts the event-specific nature of current information sharing. Evaluating the contextual integrity of shared information in an electronic health record is complicated by the changing nature of health care. Team-based care requires greater sharing of information, which challenges traditional values related to confidentiality and privacy. In addition, clinicians' need for information to support individualised decision making is growing, and providing that information in an efficient and effective way is essential. If MyHR proves to have benefits to patients and clinicians, a breach of contextual integrity may be warranted. However, the evidence for summary records is still limited. There appears to be a risk that the promise of better care will be sunk by too much data with too little relevance at the point of care. New values related to patient empowerment pose opportunities for a shareable electronic health record that may justify breaches of contextual integrity. However, this rests on the assumption that patients have the resources to take control of their MyHR. Further evidence of MyHR SHS benefits, and of patients and clinicians actual use, is needed before we can conclusively determine whether MyHR breaches contextual integrity.

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