A Holistic Approach of how to handle Patient Information to support Seamless and Secure care

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Abstract

Healthcare, like society in general, is facing great changes and challenges. Rapid development and uptake of digital technologies bring about the need to change. With the COVID-19 pandemic, the amount of healthcare meetings taking place online has surged. This means, among other things, that there are more healthcare actors involved in a patient's care, and that information relating to a patient needs to be shared across borders now more than ever need to be improved. However, this is currently not done seamlessly, and there are many hinders and obstacles to overcome. This research aims at enabling a holistic approach on how to handle patient information in order to support seamless and secure care along the whole patient process. In doing so, drivers and hinders need to be identified, and a socio-technical framework with concrete guidelines will be developed. These results will be a first step towards filling this research gap, and will connect several perspectives in order to make the results truly actionable and holistic.

Keywords

patient information, seamless patient process, information security, socio-technical framework

1. Introduction

In healthcare, the patient process should be the primary focus. However, responsibilities are unclear throughout the complete patient process and with the current healthcare structure, no one has the responsibility to specifically keep the patient in focus [1, 2]. Commonly, each healthcare unit is responsible for its own process, but when the patient's process extends over several units, who is responsible for coordinating the care and the efficient flow of information? A holistic perspective on the patient process is lacking and leads to a number of issues: Who takes responsibility for the patient's process through the care system? Who should be responsible for quality being balanced against finances from a holistic perspective for the patient? Who should do what at different levels of healthcare and what requirements can the levels of healthcare place on each other? What information should be available at each care level? Who owns the information generated in the patient's process through the care system? There are many hinders and obstacles to overcome to achieve seamless information management in the patient process given the current healthcare organisational structure. Digitalization has been seen as a major technical driver to seamless patient information management [3]. A major issue with digitalization of healthcare systems, however, is that they can obscure responsibilities in the process and actually hinder seamless patient information management rather than drive it [4].

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The *aim* of this research is to enable a holistic approach on how to handle patient information in order to support seamless and secure care along the whole patient process. In order to achieve this, *two objectives* are identified: 1) *to identify drivers and hinders for healthcare organisation management concerning requirements for achieving process-oriented care where patients are prominent and active partners*; and 2) *to develop a socio-technical framework with concrete and actionable guidelines for how to drive the innovation of seamless and secure process-oriented patient centric information and avoid the hinders to applying them in an organizational and inter-organizational processes*. The first objective is hence descriptive in nature, while the second one is prescriptive. Practical implications of the research include a hands-on approach that will enable healthcare providers to change towards the desired holistic situation. Scientific contributions include a first version of a holistic framework for success factors for achieving holistic, process-oriented care where patients are in focus. The framework will benefit from being studied, developed, extended and tested in future research projects. For clarification, "seamless care" refers to care where information follows the patient throughout his/her healthcare process regardless of healthcare provider, ward or system involved. "Secure care" refers to protecting information from unauthorized persons, as well as the information being available and correct. Additionally, patients and healthcare professionals must have access to their relevant and correct information when they need to, and it must be kept up to date. Structured security also requires fully implemented standards and regulations.

2. Background

Current healthcare systems are based on the need for information from separate and delimited care interventions. Healthcare providers are differentiated, and suffer from "siloed data" [5]", as they focus on their own situation and not the complete patient process". This makes it difficult to exchange information: there is redundancy of information and thus potentially conflicting information and, perhaps most seriously,is not effort not focused on the patient's needs. A number of local, regional and national structures have been created that should secure patient safety across transitions in care (the seamlessness) [6]. However, information is not shared, updated, available, sufficiently protected, accessible when needed, nor communicated in a consistent manner with the patient and between the health care professionals.

A holistic approach requires regard to multiple perspectives: management, public and private healthcare providers, and individuals both from a patient and healthcare professional. Management and public should be viewed from national, regional and municipal levels, as well as from private and public organisation views. The individual view caters for both patients and healthcare professionals. In fact, achieving functionality in systems that meet the needs of both patients and healthcare professionals is a major challenge [7]. The way information is managed during communication must also be consistently approached, in particular when considering the varying ways communication of information takes place (for example one way, request - response, or interactive).

One aspect of this is the need to raise the skills and competence levels for all stakeholders (here: care providers, patients, and others), as many currently lack sufficient knowledge of how to use and draw benefits from digital technology in healthcare. Furthermore, digital and social inclusion go hand in hand. Social inclusion is activities that aim at equality of access to goods and services and to assist all individuals to participate in their community and society. Social exclusion does not happen overnight, but involves change over time [8]. This can lead to gradual withdrawal from community networks and decrease access to social resources. These days, with the pandemic still raging over the world, the use of digital technology has been rapidly increasing. Along with it comes the risk of digitally excluding those who 1) have no access to digital technology [9]; 2) lack skills to use it [10]; and 3) do not know how to use it to empower themselves [11]. Digital skills have become crucial for accessing healthcare and information, as well as for participating socially [12].

3. Research Methodology

The research project will collect data in field studies with structured interviews and workshops to capture the experiences and opinions of the health care professionals and patents and document the

work process. The semi-structured interviews and workshops will be based on socio-technical frameworks of Sittig and Singh [13], Østby, Kowalski and Katt [14] and adapted with the Non-Invasive socio-technical interview techniques developed by Nohlberg, Kowalski, and Karlson [15]. A holistic approach is difficult to achieve, for example as it is difficult to determine when exactly the holistic part has been fulfilled. The socio-technical approach is the methodological path most suitable to ensure that a holistic view will be achieved. These multi-dimensional frameworks identify the many dimensions of socio-technical systems in healthcare to be considered in both development and evaluation of complex, adaptive healthcare systems. This makes it suitable for the project, as it has a multifaceted perspective which is required in order to achieve a holistic perspective. The Sittig and Singh [13] framework and other frameworks will be studied in two phases: 1) an analysis of the framework for its applicability and adaptation needs to the current situation with digital healthcare and management of patient information in focus; and 2) use the adapted framework as an analysis tool for identifying success factors. Previous research has utilised this framework to identify where issues arise, regardless of these issues being e.g. technical, policy- or implementation-related [16].

The project will have three phases: 1) Literature and document review of existing research and practical development and implementation of relevant projects. The purpose is to identify drivers and hinders contributing to the project aim and make a first draft of a framework; 2) A longitudinal study of the implementation of the Millennium system and the future holistic healthcare environment around it; and 3) Interviews and workshops in two stages to firstly identify drive and hinders and secondly to evaluate and enhance the socio-technical framework.

Millennium is a digitisation initiative aimed to develop patient information to provide a sustainable, all-encompassing and modern healthcare information environment. It will replace all current systems, and make information seamless and available for healthcare providers, patients and individuals. The goals are new information management in the patient process, working methods that simplify the work in healthcare, reducing administration and freeing up professionals time. Knowledge management and informatics will be standardized, and it will be easier to introduce new treatment guidelines with standardised processes, terms and concepts. While Millennium is the name of the system to be implemented, it will be used to encompass the entire initiative

The first phase includes developing a state-of-the-art using literature and document review of both research publications and other relevant reports and works. Selection criteria will be developed to allow for a systematic approach. The result of phase one will be a description of drivers and hinders to be used as a basis for a first draft of the framework. New searches for updated works will be conducted to ensure quality and relevance. In phase two, the longitudinal Millennium initiative study will be conducted in several steps from capturing the current situation, perceived drivers and hinders, to revisiting interviewees for updates and new discussions, as well as for jointly evolving the framework using for example workshops. The researchers have established channels on various levels with healthcare that will constitute the basis of the study. In the last phase of the project, the framework will be refined and revisited based on acquired data and experiences, as well as quality assured using the interview and workshop participants

4. Impact and expected results

According to the World Health Care Organization the digitalization of health systems requires the establishment of certain basic elements in a health care infrastructure which meet the challenges of integrating multiple existing systems and projects and developing legal and regulatory frameworks. The 20th-century vision of privacy may be incompatible with the need to make information accessible in order to improve health outcomes, and with the need for truly interconnected, interoperable health systems [5]. These needs are also present when discussing the sustainable development goals. Good health is a basic condition for people's opportunities to reach their full potential and contribute to societal development, not least the Covid 19 pandemic has shown that. People's health is affected by financial, ecological and social factors, and the global sustainable goal 3 includes all dimensions and people of all ages. When people fall ill, their ability to participate and influence their own care is essential for their recovery. However, this requires a holistic perspective and handling of patient

information. Furthermore, growing cities can create new opportunities for economic growth, but can also lead to increased social differentiation, as expressed in the global goal 11: sustainable cities and societies. Healthcare faces scalability challenges, and the need for technological systems that support the ways of working instead of hinders them. Ensuring that involved stakeholders such as healthcare staff and patients alike have the skills and competences needed to utilise technology to enhance the care is essential.

In order to achieve a holistic perspective on healthcare, which is necessary regarding the National Health strategy [17], a multifaceted perspective is needed. Socio-technical approach frameworks related to Sittig and Sing [13] as well as Østby et al., [14] with many dimensions of social-technical systems in healthcare, gives that kind of holistic perspective considering development and evaluation of complex, adaptive healthcare systems.

With a socio-technical approach where the purpose is to capture the whole in a more adequate way, success factors can be identified. These success factors can then contribute to the health care's management and leadership to achieve the healthcare's set goals both on a national [17] and global level [18]. For example, the Swedish e-Health Agency [17] expresses a vision for Swedish e-health that raises how it will be easier for people to achieve good and equal health and welfare. This research will enable the individual to be in focus, that the right information is provided in a seamless manner when needed to those authorised, and that development and digital transformation goes hand in hand. In this way, this research serves as a bridge, integrating research and practice, and will enable healthcare to learn and evolve from past failures and successes. In doing so, both the social and the technological (or digital) perspectives will be taken into account. In order to improve the way people think about, and the knowledge they have in using digital technology, one perspective cannot exist without the other. By enhancing digital skills and competences with those who need it, being it patients or healthcare professionals, a more engaged and empowered healthcare situation can emerge. This research aims to contribute to resolving this complex situation, by for example identifying the challenges and developing concrete guidelines for how to address them.

In patient-centered care, the value of healthcare activities depends on the patient's perception of these activities [19]. Standardizing of the care activities shifts the practitioners' focus toward the knowledge required for successful practice [20]. Patient information must be handled securely and safely, in particular when the activities are shared between different caregivers. This requires a holistic approach and development of proper information security processes around patient information. The highly complex organization in healthcare, characterized by professional groups and regulatory systems, complicates the application of information techniques developed in the involved organizations [21]. The core philosophy to handle patient information securely and safely, is to continually improve the standardized care chain in the patient process by waste reduction through the removal of non-value steps in these processes [22], and also by continuously improving quality in every-repeating activities [23]). To identify drivers and hinders for healthcare organisation management concerning requirements for achieving process-oriented care where patients are prominent and active partners, it is necessary to map the activities in patient processes related to patient information in an added value stream mapping process. It is important to focus on the patients' perception and remove unwarranted variation to achieve efficiency and quality care.

5. Concluding remarks

The aim of this research is to enable a holistic approach on how to handle patient information in order to support seamless and secure care along the whole patient process. The holistic approach needs to be considered from different perspectives: 1) national - regional - local; 2) socio and technical/digital; and 3) Patient - healthcare professionals, the individual actors' perspective. The first perspective concerns collaboration and identification of drivers and hinders at different organisational levels, as in organisations focused on healthcare from a national, regional, and local perspective. The interplay and dependencies between these levels are also of importance to cover. What kind of forces from the national level influence how the other two operate? In what way do events on the "lower" levels influence the upper ones? What kind of information and decisions need to be communicated within and across levels? These are only a few of the questions at hand to investigate. The second

item highlights the need to intertwine drivers and hinders from both the socio and the technical or digital perspective. As already has been discussed in this paper, the two are inevitably linked and need to be considered together if sustainable effects and results are to be achieved. Finally, the third item concerns the individual perspective in terms of viewing drivers and hinders for the people involved, mainly patients and healthcare professionals. What do patients need in order to be able to participate in healthcare in general and digitally? What training do healthcare professionals need in order to use the new technology as intended? The need for training and education for people and groups who lack sufficient digital skills is often highlighted [24], but very little concrete action has been taken thus far. The second objective in this research aims to develop a sociotechnical framework with concrete actionable guidelines for how to drive the innovation of seamless and secure process-oriented patient-centric information, and avoid hinders along the way.

The need for a holistic perspective has been highlighted many times [25, 26, 27], but research often stops at that - pointing to the need for it. Actionable guidelines that take the whole picture into account for how to actually achieve it are needed, but still missing. This is the gap this research intends to bridge. Because of this, the project will adopt a broad entry to the research, meaning staying clear of as many assumptions as possible. Throughout the project phases, the research and results will take shape.

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