Proceedings of EHR2024 Workshop on

Implementing Electronic Health Records – Objectives, Obstacles, Outcomes

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Welcome

Welcome to the EHR2024 workshop on implementing electronic health records (EHRs).

EHRs support patient treatment by providing healthcare professionals with the means to order, document, and follow up on the steps taken to treat and care for each patient. EHRs are complex systems. Their implementation is a major undertaking, which has received sustained attention in computer-supported cooperative work (CSCW) and other research fields. While this research has provided important insights, they remain partial and somewhat disconnected. It is difficult to stay up to date.

This workshop aims to provide a forum for participants to get updated on current CSCW studies of EHR implementations and create connections with other researchers who study such implementations. More specifically, the workshop aims to stimulate:

- Cross-fertilization among the participants' questions, their frameworks, and their cases
- Reflection on what CSCW contributes to the study of EHR implementation
- Discussion of the interest in further networking initiatives regarding EHR implementation

These workshop proceedings contain the five papers presented at the workshop. The copyright to the papers remains with their authors.

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Implementing Electronic Health Records: Shifts and Obstacles in Machineries of Knowing

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Abstract. In this paper, we examine knowledge work among key actors involved in the implementation of an EHR in nursing homes. The EHR is an in-house development in one large Norwegian city, and its main objective is to ease patient handover. We use the perspective of machineries of knowing as our analytical framework, and draw on qualitative data (observations, interviews and document materials) from the local health agency and five different nursing homes. Our preliminary findings show how the EHR became an unfolding object of knowing in itself, which at the same time changed ways of approaching existing objects in larger machineries of knowing.

Introduction

The implementation of new technology like electronic health records (EHRs) requires knowledge work that unfold in several ways as EHRs can be knowledge generating tools, *and* tools that alter conditions for ways of knowing (Pachidi et al., 2020). Planned and unforeseen consequences may emerge as EHRs go live (Ellingsen & Monteiro, 2006), some that may emerge as obstacles to implementation, and others that may materialize as obstacles to knowledge work in larger machineries of knowing. Meaning, knowledge work within an institution may be continued or disrupted as new EHRs are introduced to already-existing machineries of knowing, for instance through obstacles of uncertainty (Monteiro, 2022). In this paper, we focus on the beginning stages of the local implementation of a novel EHR in Norwegian nursing homes, and the various obstacles that occurred when nurses and their leaders started engaging with the system in their daily practice. The platform we study is in continuous development. That is, users are encouraged to report needs and wishes to the local health agency responsible for the design and support of the system. This type of strategy can be said to follow a design-in-use process (Hertzum & Simonsen, 2019), where professionals are invited to make changes to the EHR according to their professional and organizational needs. There is no end-date to the development side, meaning continuous changes is a central part of its use, and the boundaries between design, development and implementation may be blurred (Sadorge et al., 2023). Consequently, working around obstacles in knowledge work may become a regular activity for the professionals engaging with the EHR.

Our aim with this paper is twofold. We are interested in exploring the EHR as a technology embedded in practices of knowledge work and knowing, and suggest that the practices enabled by the EHR constitute important, but fragile, machineries of knowing in the nursing homes (Monteiro, 2022). We are especially interested in the various obstacles that arise when the EHR disrupt existing ways of knowing. In an extension of this paper, we are also interested in exploring what obstacles mean in a project that is under continuous development and what that implies for changing ways of knowing.

Analytical Framework

We draw from Knorr-Cetina's (1999) work on epistemic machineries, or machineries of knowing, and further theorizations of her work (i.e. Monteiro, 2022). Epistemic cultures are cultures of knowledge production that are comprised of specific arrangements that 'make up how we know what we know' (Knorr-Cetina, 1999, p.1). They involve expert work in interactions with artifacts, and it is through these interactions that knowledge is produced. We take a sociomaterial understanding in that we view tools, technologies, and other materials to take an active part in the epistemic machineries of knowing. Meaning, we do not view the EHR as merely representational, but also as working to enforce and create particular ways of knowing together with the professionals. We understand the EHR (and elements within it, such as patient data) as an object of knowing (Monteiro, 2022), and at the same time as a mediator of other objects of knowing through the interactions between the EHR and professionals in nursing homes. Implementing EHRs therefore requires knowledge work in-between existing and emerging ways of working. How objects of knowing become through different means and methods of knowing patients (and the work surrounding patients) is a central tenet in our framework.

Examining the EHR as an object of knowing and the methods of knowing also implies that there may be some obstacles to knowledge work, especially because it often rests on a data-driven approach to knowledge where issues of legitimacy and credibility of the data is a challenge (Kitchin, 2014; Pachidi et al., 2020). When these processes are digitized, there are also a number of complex sociotechnical relationships that form and create other obstacles to knowing. For instance, the participants in this study reported that there were several data sources they would want to have in the EHR that is not there, meaning, they miss certain information about their patients. How the participants worked around this missing data, and other types of obstacles, is a central focus in our analysis.

Case Description

The EHR we study (our case) started as a joint initiative between four city districts in one large Norwegian city in 2018, and is an in-house development that expands according to users' needs. From 2020, the City's health agency took over the project and organized a bottom-up design approach with a core team comprising a project leader, a developer, and healthcare workers. The EHR is built on a low-code development platform that supports a continuous design approach in which the system is designed, tested and implemented in parallel. The EHR is used across health institutions in the city/municipality, and the aim is for it to be generic, rather than having extensive specializations embedded within it (see Sadorge et al, 2023 for more information about the EHR). From the outset of the initiative, the main objective has been to ease patient handover in the municipality.

For nursing homes, there are additional objectives for the EHR. In addition to easier patient handover, the EHR is also supposed to have better data privacy, easier transitions between shift changes in the nursing homes, easier access to patient information, better, faster, and more systematic overview of changes in the patients' health status, more structured management and distribution of daily tasks, and better support in work-processes. The EHR is generic, meaning it targets broad needs, which may be in contrast to the local needs of nursing homes (Ellingsen et al., 2022). The expectation is to digitalize some work processes, and to get rid of old work habits such as the use of whiteboards, "black books" (notebooks) and post-it notes.

The implementation process in the nursing homes has happened gradually. A multidisciplinary team in the local health agency are responsible coordinators for the implementation, and they have developed an implementation plan where the nursing homes were divided into different ‘pools’. In pool one, all rehabilitation centers and a few nursing homes were included, pool two consisted of four nursing homes, and pool three consisted of 15 nursing homes. There has thus been an upscaling in the implementation. The plan for implementation includes two training workshops provided by the health agency, and a plan for local implementation in the nursing homes with suggestions for a timeline. Each nursing home have had at least one ‘implementation coordinator’ responsible to coordinate the implementation in their own institution, and several ‘superusers’ responsible for local support and training.

Methods

This paper is based on a qualitative case study where we followed the training – and implementation steps of the EHR. The data set consists of observations of training workshops and information meetings held at the health agency where implementation coordinators, superusers and institutional leaders across the city’s nursing homes participated (ranging from 16 to 32 participants in each). Interviews were held with the head of the project in the health agency, and with implementation coordinators and superusers in five nursing homes. Document materials from the training workshops and the nursing homes have also been included in the data set (PowerPoint-presentations, training materials developed by the nursing homes, fact sheets etc.). All observations and interviews have been done in-person, and the observations and interviews at the health agency were held prior to the ones in the nursing homes. The nursing homes who participated in the study were in pool number three, meaning they were the last of the nursing homes to implement the new EHR. The implementation started in December-January 2023/2024, and interviews were held in March and April ’24.

From an initial analysis of the data from the health agency we focused on the types of questions and concerns that were brought up by the participants from the nursing homes and found that the participants had a number of concerns and suggestions for improvement, such as other types of information about their patients like behavior patterns. Based on these findings we designed the interviews with the implementation coordinators/superusers to focus on their role in the implementation, changing work routines and challenges they may have had so far in the implementation.

The data analysis of the interviews in the nursing homes is currently on-going. We have so far had a conventional content analysis (Hsieh & Shannon, 2005) where we have focused on specific/detailed examples of how the EHR is used in daily practice (which we have found to be in parallel with other objects of knowing), and specific obstacles that emerged in these situations.

Preliminary Findings

The findings we present here are preliminary and describe some of the obstacles in knowledge work produced through interactions with the EHR and the professionals engaging with it (nurses and leaders in nursing homes). We begin by describing obstacles in the training phase, and then move on to obstacles that have emerged after implementation.

Obstacles during the training phase.

The implementation coordinators in the nursing homes we did field work in reported that they used a course model developed by the health agency, including a demo-version of the EHR and YouTube videos to train and prepare their staff. At that stage, they only had access to the demo version. The implementation coordinators explained that the demo-version looked different from the real version, with pseudonyms and fictive wards that were unfamiliar to the staff, and which ultimately resulted in much confusion. In other words, there were no real knowledge sources and many uncertainties about the data on it. In three of the nursing homes, the implementation coordinators made their own training modules in a Word document, and that was later printed out and made into a booklet. This is an example from one of the nursing homes:

> In general, there is no written user manual, and it is a huge challenge, because when you make everything on video, you have to have two screens. Because you have to have one screen where you watch the video, and then you have to pause it, and then you have to try it on the real thing [the EHR]. But our employees do not have two screens, they do not sit in an office, they are out with the patients, and they have pads, one pad each, and we only have one single PC. They do not have the opportunity to sit with two screens and stop and test, so I had to create my own templates then, on a Word document. Printed it out, and it had screenshots and pictures taken, I took a bit from here and there.

In other nursing homes, they have developed similar booklets with templates on how to log in, information about the EHR and its purpose, contact information for help and improvements, as well as copy-pasting a Q&A that was made by the health agency. All these materials are available in digital form (either in video or written format), however, the implementation coordinators saw it necessary to print it and make it into an analog format. These materials also act as objects of knowing, and the amount of work that the coordinators had to do in order for their staff to be able to retrieve the necessary information *about* and *through* the EHR.

Obstacles after taking the EHR into use.

The nursing homes have experienced a number of obstacles after introducing the new HER in the services, such as whole days when the EHR and the local wi-fi has been down. In these cases, they report that they have had to go back to using notebooks and post-it notes as a temporary solution. They also describe situations where nurse's check-in with each other across wards and roles to make sure that they are up to date on all information about their patients. But the obstacles are not restricted to times where the sociotechnical constellations break down, there are also continuous obstacles because of the way the EHR is designed in terms of data privacy. To secure data privacy, one has to log-in each time one uses it, and spending too much time inactive will automatically log you out. One nurse, a superuser in one of the nursing homes, describes how she works to avoid logging in to the system throughout the day:

> When we started using the platform, we were told that we don't have to use notebooks anymore, and that we don't have to carry notes in our pockets and all that. But yes, here we are…Yes, I am retrieving all these notes from my pocket as you see. I still have my notes. I write up my tasks for the day on these notes, which I retrieve from the EHR, write them up, and put them in my pocket. Because during the day I don't have time to log-in again and again to check.

In this example, the nurses' notes became an object of knowing created to tackle time-consuming activities. The notes emerged as a consequence of the lack of interaction between the nurse and the EHR, and as a way for her to remember her daily tasks. This is an example of a continuous obstacle that happens each day and is now part of the nurses' daily routine. Problems with log-in have been a wide-spread problem for the nursing homes, to the point where some have paused the implementation. The health agency is currently developing other log-in options. Nevertheless, the very act of having to log in each time you use it, will still be very much applicable.

Concluding Remarks

In this paper, we have focused on two empirical examples from nursing homes, as they prepare and implement an EHR in their daily practices. From the preliminary analysis, we have found that the EHR can be understood as an object of knowing in itself, but also as a technology that can become a productive tool to mediate other and already existing objects of knowing, such as Word documents and personal notes. The empirical examples in this paper are illustrative and will be presented in the workshop as a way to discuss further possibilities for interpretation. For instance, we are interested in working further with the notion of obstacles in machineries of knowing, what obstacles mean when one of the objects of knowing (the EHR) is under continuous development, and how that affects knowledge work.

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Challenges of configuring and implementing a large-scale generic electronic health record (EHR) in Central Norway

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Abstract. Considerable research has been conducted on EHRs within the field of CSCW, primarily focusing on workplace studies. However, limited attention has been given to the challenges of configuring large-scale generic EHR systems to meet local needs through user participation. Additionally, there's a gap in understanding how these systems impact collaborative work practices among healthcare professionals when implemented. Therefore, there is a pressing need to further investigate this phenomenon within the healthcare context, which is characterized by its diverse and multiple stakeholders. In Central Norway, a large-scale generic EHR system has recently been configured and implemented, providing an excellent opportunity to study these challenges, and contributing valuable insights to the broader CSCW research field.

Introduction

The field of Computer-Supported Cooperative Work (CSCW) has long been concerned with healthcare and how information and communication technology (ICT) influences collaborative work practices among healthcare professionals. Most contributions in this area can be categorized as workplace studies (Fitzpatrick and Ellingsen, 2013). However, these studies often concentrate on healthcare provided within a single setting, such as a hospital department, rather than examining collaborative practices across multiple settings (e.g., Ellingsen and Røed, 2010; Bossen and Jensen, 2014; Bansler et al., 2016). With the implementation of the national e-health strategy *One Citizen – One Health Record* (Helse- og omsorgsdepartementet, 2012), which aims to enhance healthcare services through a unified electronic health record system (EHR) across primary and secondary care, the ability of EHR systems to facilitate collaboration across different levels of healthcare has become a pressing issue in Norwegian healthcare.

Aligned with the national e-health strategy, health authorities and municipalities in Central Norway are in the process of implementing a new Electronic Health Record (EHR) system across all hospitals and municipal healthcare services in Central Norway. This local system implementation, known as *Helseplattformen* (English: the Health Platform), was recently introduced in Trondheim (in autumn 2022). The establishment of *Helseplattformen* marks a significant service innovation project wherein all healthcare services and residents of Central Norway will transition to a unified EHR system (Helseplattformen, 2022). This position paper advocates for a research agenda focusing on a case study of the configuration and implementation of *Helseplattformen*, aimed at providing insights for the field of CSCW.

Helseplattformen as an opportunity for CSCW research

Helseplattformen is a large-scale EHR system, catering to a region encompassing over 44,000 healthcare professionals and serving the needs of 720,000 citizens. The implementation project ranks among the largest e-health endeavors in Norway, distinguished by extensive user involvement across all project phases. Over 400 subject matter experts (SMEs) have actively contributed to configuring the new EHR system to align with regional and local requirements (Helseplattformen, 2020). The primary objective behind the implementation of *Helseplattformen* is to enhance the efficiency of healthcare professionals, foster collaboration within and across primary and secondary care settings, and ultimately elevate the quality of patient care (Helseplattformen, 2022).

With the implementation of *Helseplattformen* in Trondheim, a unique opportunity arises to explore the challenges and opportunities presented by the new EHR system in terms of collaboration within and between primary and secondary care. It is crucial to leverage insights gained from similar implementation systems by the same vendor organization in various countries and settings. By sharing experiences, including challenges encountered and lessons learned, we can better understand the implications of the new EHR system (e.g., Hertzum and Ellingsen, 2019; Ellingsen and Hertzum, 2020; Ellingsen, Hertzum and Melby, 2022; Hertzum, Ellingsen and Cajander, 2022).

Completed and Current Work

In my research project, I am investigating the configuration and implementation of *Helseplattformen* in Central Norway. While there has been a considerable amount of CSCW research on electronic health records within healthcare, there has been less focus on the unique challenges that arise when configuring large-scale generic EHR systems to meet local needs, and subsequently the impact of implementing them on healthcare professionals' work practices. So far in my research project, I have examined the challenges of user participation that have emerged during the configuration of *Helseplattformen* to suit local requirements, in the aim of understanding how healthcare professionals involved in the process have perceived their level of involvement. To address these objectives, I conducted nine semi-structured interviews with healthcare professionals engaged in the configuration process. A paper detailing the findings has been submitted for publication and is currently under review, with an expected publication date in the latter half of 2024. The interviews revealed several challenges related to user participation throughout the configuration process. The results emphasize the significant role of respondents' initial expectations, both towards the system and the configuration process, in shaping their negative assessment of their participation, the process itself, and their personal influence on the resulting system. The paper concludes by offering key insights into managing expectations, the differences between configuration and design processes, and emphasizing the importance of flexibility in the configuration process.

The upcoming phase of the research project will involve the development of two papers. The first paper will focus on examining the impact of implementing *Helseplattformen* on collaborative work practices among healthcare professionals within primary care settings. Meanwhile, the second paper, currently in progress, will be a systematic literature review (SLR) assessing the existing state of CSCW research on EHR systems, as published in distinguished CSCW venues. The primary research question will explore the key insights and lessons derived from this body of literature. Both papers will undergo further refinement in subsequent phases of the research project.

Objectives, research questions, and methods

The overall objective of the current research project is to provide an in-depth qualitative understanding of the challenges and possibilities that *Helseplattformen* presents regarding configuration prior to the implementation, and with respect to collaborative work practices within and between primary and secondary after implementation. Specifically, the project aims to investigate whether the implementation of *Helseplattformen* results in a more integrated and comprehensive healthcare service, as perceived by healthcare professionals, and to identify any associated challenges that may arise. The current research project will seek to achieve its overall aim by being guided by three research questions (RQs):

- RQ1: How do future users involved in configuring a large-scale generic IT system to local needs experience the configuration process, their participation, and their influence on the result?
- RQ2: How does the implementation of a new EHR system affect healthcare workers' collaborative work practices within primary care?
- RQ3: How does the implementation of a new EHR system affect collaboration between primary and secondary care?

The research questions will be addressed through a comprehensive qualitative case study, incorporating interviews, observations, document analysis, and surveys. While the primary focus will be on qualitative data collection, supplementary quantitative data will also be gathered through the use of surveys.

Expectations and Desires for Workshop

I would appreciate the opportunity to participate in the *Implementing Electronic Health Records – Objectives, Obstacles, Outcomes* CSCW workshop, as it aligns closely with my ongoing research project. I believe that my work will make a significant contribution to the discussion surrounding the following theme within the workshop:

1) *Case analyses of empirical projects at different stages of completion – from preparations, through go-live, to continued use and design-in-use.* I am convinced that my research findings on the configuration process of *Helseplattformen* will hold great relevance for fellow researchers and

practitioners in the field. Specifically, the findings of various challenges related to user participation throughout the configuration process provides valuable insights into the substantial usability issues *Helseplattformen* has encountered post-implementation.

My primary aims and desires for the workshop is as follows:

1) Gather valuable feedback on the proposed case study with the aim of increasing its relevance for CSCW.
2) Share my experiences from doing research on *Helseplattformen* with fellow workshop participants.

Through this workshop, I hope to make connections with other researchers and designers whose work can also influence me. I would like the opportunity to share the knowledge I have gained from my research approache and my personal experiences in the field with other workshop attendees. Therefore, I believe that the CSCW workshop *Implementing Electronic Health Records – Objectives, Obstacles, Outcomes* will be an excellent venue to (1) discuss my work and have it critiqued, and (2) learn how to better approach my research project moving forward.

Biography

Adrian Sand is currently pursuing a Ph.D. in Computer Science at the Norwegian University of Science and Technology (NTNU), under the guidance of Principal Supervisor Yngve Dahl. His research interests lie at the intersection of Human-Computer Interaction (HCI) and Computer-Supported Cooperative Work (CSCW). His recent work has focused on investigating the challenges of user participation in configuring large-scale generic EHR systems to meet local requirements in healthcare settings. He is currently exploring the impact of implementing said systems on healthcare professionals' collaborative work-practices.

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The users’ role in configuring large healthcare suite systems

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Abstract. The main objective of comprehensive electronic health record suites is to meet the needs of various users across healthcare institutions. These EHR suites offer extensive configurability, allowing customization to accommodate diverse professional practices and user requirements. This customization process demands careful preparation, involving close collaboration between expert configurators and end-users to design the necessary functionality. We explore this collaboration across different phases of the project. Empirically, we investigate the preparation and implementation of the Epic EHR system by the vendor Epic in the Central Norway region.

Introduction

The main objective of comprehensive electronic health record (EHR) suites is to meet the needs of various users across healthcare institutions. These EHR suites, including Epic, Cerner, and InterSystems, offer extensive configurability, allowing customization to accommodate diverse professional practices and user requirements [1]. This customization process demands careful preparation, involving close collaboration between expert configurators (builders) and end-users to design the necessary functionality. We want to explore this collaboration, not as a snapshot in time, but across different phases of the project. Therefore, we pose the following research question: What are the opportunities for users to influence configuration processes before, during, and after the go-live of large healthcare suite systems?

Empirically, we investigate the preparation and implementation of the Epic EHR system by the vendor Epic in the Central Norway region, encompassing all its hospitals, general practitioners, home-care services, and nursing homes. In this position paper, our focus is on the hospital context. Conceptually, we draw on the CSCW field, which has a long tradition of attending to the users' perspective in local practice (Fitzpatrick and Ellingsen, 2013).

Method

We adopted an interpretive research approach, which considers a phenomenon from different perspectives (Klein and Myers, 1999; Walsham, 1995). Our data covered the period 2018–2024 and were based on various information sources: interviews, public and internal reports, and national policy documents. We conducted 30 interviews with various personnel (top management, physicians, nurses, and secretaries) involved in the Health Platform program. The interviews were open-ended but mostly focused on the expectations and experiences of Epic. All interviews were transcribed for analysis.

Background on the Health Platform project

The Health Platform is a regional program jointly owned by the Central Norway Regional Health Authority and Trondheim Municipality (Ellingsen et al., 2022). In 2019, the program signed a NOK 2.7 billion (EUR 270 million) contract with Epic Systems Corporation to implement the Epic EHR suite in Central Norway, including all hospitals, general practitioner clinics, nursing homes, and home care services. As a suite, Epic is relatively self-contained and is supposed to provide most of the functionality needed by health personnel, either in ready-to-use form or through configuration by expert configurators or so-called builders to meet the various health professionals' needs - before, during, and after implementation. In the preparation phase, the users were invited to take part in customizing the system, adding content, and setting up workflows and information flows. As a part of this, a hierarchy of formal decision fora of subject matter experts were set up to facilitate a negotiated solution. In addition, the role as subject matter coordinators were established to coordinate the activities of the subject matter experts.

Trondheim Municipality implemented it on 1 May 2022, while the large St Olav’s Hospital implemented it on 12 November 2022.

Results

The initial phase

In preparation for the configuration process, the Health Platform analysts and builders presented the configuration tool to the users as various workflows requiring IT support. They explained how the tool worked and said the users could decide for themselves how they should use it, and they promised the users that they would accommodate their needs in all relevant aspects.

At this stage the Health Platform (and Epic) didn’t have any working software to present to users to illustrate how things might work. What they could show were some bits and pieces of video snippets and PowerPoint slides depicting how things could look in the future. Thus, this initial phase came as a surprise for the users, as it was difficult for them to envision what a configured system would look like.

During the first workshops, the Health Platform builders attempted to understand the various practices by presenting terms and questions in Excel sheets. They also had to respond to questions about unknown terms such as ‘types of visits’, which later proved to be essential in workflows. The same ‘types of visits’ mentioned in the quote above turned out to be a recurring problematic issue over several years. Neither the Health Platform analysts nor the end-users were aware of the significance of these visit types for the rest of the system and how everything should function and fit together. For the users, it was a completely new concept, and in their feedback to the builders, they connected it to what they were familiar with from their practice. It turned out that it had a different meaning and impact on the new system.

Some users reflect on that it could have been beneficial to have some form of basic training in the fundamental principles of the Health Platform for those who were tasked with answering the builders' questions. However, this was also problematic, as one of them reflects as an afterthought, “because the system was not yet built”. The preliminary status of the software also became an issue during the initial training courses for the users. Since the system wasn’t configured yet, the users were informed that it wouldn't function as presented until the configuration was complete. This made the training sessions partly useless, and some participants argued that these courses should rather have been informational meetings where the developers could present the progress made in the building process.

Along the way

When the project started in 2019, the Health Platform stated that the subject matter experts should take all user-related decisions. Whenever these experts disagreed, the level above, comprising professional leaders, should take the decisions. Later, during 2021, the decision structure was radically changed. The Health Platform established several taskforce-group related areas that needed especial attention, namely workflows and NPR reporting. The task force got an independent role and was thus disconnected from the existing decision hierarchies. This made the decision tree difficult to understand because if there was disagreement between the subject matter experts who were in the task force and those who were not, it was unclear who had the authority to address matters. Accordingly, the level of formality was seen as a challenge due to fighting over what was most important as well as the lack of possibility to be creative together.

In addition, the lack of overview was worsened by the silo-based organization of the configuration process as Health Platform builders and subject matter experts typically focused on delimited parts of workflows. It wasn't until each group had completed their work and the workflows were integrated for end-to-end testing that they could assess whether they functioned properly.

Another issue where technical limitations in the software. When secretaries at clinics are grappling with the challenge of managing lengthy waiting lists. It's crucial for them to assign codes to different patient groups for efficient searchability of those scheduled for various examinations, but his was not possible. Epic's work lists only allow sorting one column at a time, limiting usability, especially given the multitude of waiting lists at each clinic. In response, secretaries got a new field on the waiting list called "waiting list subgroup," enabling entry of numerical codes, with each unit defining their meanings. Secretaries considered this to be a very simple solution, but the configurators said to them, “This was what we are able to do; this is what you will get.”

Gradually, it became apparent that builders made decisions without involving users. This stood in glaring contrast to how the configuration process of Epic was envisioned: Builders at the Health Platform should present solution alternatives to the subject matter experts who then should decide the best alternative. However, as the builders progressed to this point, they had been working on this for quite some time and taken many crucial decisions without consulting the users. As a result, for many decisions, there were only minor ones to be made, such as fine-tuning what had already been configured.

In use

A key “sales promise” with the Epic suite is that (expert) users can run continuous optimization processes (that is, configuration) of the software after implementation. Actually, such optimization has been much needed, not at least because of misplaced decisions made in earlier phases due to a lack of understanding among Health Platform builders and subject matter experts of what they were dealing with. Accordingly, new insights in recent years should prompt some corrections and redesign of the software, but many users are hesitant to raise the issue because so many resources and efforts have been invested in making it work in the first place, and “then it is stupid not to use it, you know” as some put it ironically.

However, direct errors in the software must be dealt with in any case, for example if a physician adds a patient to a waiting list, and no one monitors it, this may have grave consequences for patients. A secretary explained that last week (in 2024) she found two patients on an unmonitored waiting list who should have been admitted to the hospital in 2022, and this is not unusual. Unfortunately, there is no warnings in the system that tell the users that something is wrong.

While some upgrades (optimizations) of the system are for the better, users experience that rollouts of new versions come with a lot of unintended consequences in other parts of the system, and “that is where the newspaper headlines start” as a secretary explained. Solving these new issues may also be problematic because it may be hard to find the person at the Health Platform support service who has sufficient insight into the domain and the specific issue in question.

Lately, the users have got the impression that the builders rather than fixing real errors, focus on making layout changes, such as moving the search field from the right side to the left side of the screen, moving a line, color changes, and changing the icon “turning wheel” on the screen to a beating heart, etc.

Possible discussion points

Possible theoretical framework?

What kind of additional empirical data could add insight to the case?

Challenges of formal users participating in the configuration of large healthcare suite systems?

Any role for creativity?

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Data work in the design of EHR infrastructure

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Abstract. In this paper, we aim to analyze the design activities in an EHR infrastructure design and development initiative in primary healthcare aimed to improve the data flow in patient handovers. This paper is based on a longitudinal case study and observation data of design meetings in the Health Agency of a municipality in Norway responsible for the primary health services. The aim of the paper is to develop an understanding of data work from a design perspective.

Introduction

Digitalisation has rapidly transformed the healthcare sector and the work of health professionals. The widespread use of digital technologies and the vast amounts of data generated have transformed the way healthcare is organized, delivered, and managed. The shift towards a more data-driven way of caring takes place at all levels, from home nursing and elderly care to specialised treatments in hospitals. This transformation has enabled healthcare providers to harness the power of health data to improve patient care, advance medical research, and enhance overall healthcare outcomes (Grossglauser and Saner, 2014). Data work is a recent line of research across the research field of IS, CSCW, HCI with an interest in examining how this shift towards data-drive care deeply affect the way health professionals relate to data, how are data used in practice, which novel comptences are required and how data are cared for (e.g. Bossen et al. 2016; 2019; Møller et al. 2020).

In this workshop contribution we address data work from a design perspective by investigating how a design team explores issues of data work while designing an information infrastructure for patient data in primary care. Data work is, in this paper, used in a broad sense to indicate the work required to deal with the exponential increase in the amount of digital data in healthcare work. Thus, rather than regarding data work as 'getting insight from data', we focus on data work related to the datafication of care (Ruckenstein and Schüll, 2017) and on the process of becoming data driven.

In this workshop contribution we address the following research question: *what are the concerns for data work in design for EHR infrastructures?* The paper is based on a longitudinal case study on the design activities for a novel information infrastructure for patient data in primary health services. The initiative is a complex multi-actors iterative participatory design, development and implementation processes. The case study has followed the initiative for almost 3 years, and in this paper we focus on the discussions and design activities related to the integration solution between the existing Electronic Patient Record (EPR) in use in primary care - simply called the EPR in this paper - and the novel information infrastructure named ELISE. Our empirical data consist of notes and transcriptions originated from observations of design meetings, and interviews with key participants. Based on the analysis of our data, we identify aspects of this work in the design activities, and specifically we identify how the concern make data meaningful is discussed in design activities.

Case context and description

This section presents first the background for the case, the ELISE initiative, and the process of integration between the EPR and ELISE.

Patient hand-over in the municipality

In primary care, patient handover is critical. The municipality in this study has recognized the significance and difficulties associated with patient handover in primary care, particularly concerning data sharing. Consequently, efforts have been made to establish a safe protocol for patient handover between various care services in the vast municipality of Oslo. These care services include emergency room, municipal acute dayhospital known as 'KAD', short and long term nursing homes, and homecare.

To tackle this issue, on a mandate form the Ministry, the municipality initiated a project named 'The Good Patient Journey' which was completed in 2018, and shed light on the limitations of the existing health information systems being used, particularly emphasizing the heterogeneity of these systems in terms of their types and versions. Recognizing this challenge, the municipality initiated the ELISE initiative with the objective of "taking back control over the data." During the early phase of ELISE, an IT team member provided insight and reflection on the initiative, and said:

"*We had a vision, and that was to have a safer patient transition, with each of those transitions, you forget everything, or it takes three days to receive a message, or you use a chat channel in (the EPR), where it is not allowed to provide health information or identifying elements, to chat about a patient, so the big problem we tried to work on first was transition*".

ELISE

ELISE is an abbreviation for "Electronic information sharing between interacting units in health" (in Norwegian: Elektronisk Informasjonsdeling mellom Samhandlende Enheter i helse) (Oslo municipality, 2019a). It is the name of an initiative and an application developed by and for the municipality of Oslo, specifically the Nursing Homes Agency – owner of the project - and the Heath Agency (Helseetaten, 2022a). ELISE is legally a treatment-oriented health register ("behandlingsrettet helseregister").

ELISE is developed based on the Pasinfo platform, which is a cloud-based platform hosted on Microsoft Azure and Power Platform and owned by the Health Agency of the Oslo municipality. Pasinfo serves as a data platform and ecosystem specifically designed to tackle the issue of fragmented health data systems (the silo systems problem) within the different healthcare organizations across the municipality. Pasinfo is a Low-Code data platform that collects and compiles relevant information to support various health and care services in the municipality. Low-code technologies like the Power Platform offer a set of ready-made components that can be quickly put together to deliver solutions. The platform collects, aggregates and makes available data from more than 25 actors and systems, and also has the role of ensuring the quality of data and data models across sources that are used for public statistics.

ELISE displays data from source systems such as the municipality EPR and the national registers for instance the register of the General Practitioners, and the Population register. Data can also be entered in ELISE, for example in structured forms for mapping (kartlegging) the conditions of a patient (Helseetaten, 2022a). ELISE is developed with interfaces for mobile phones (for the homecare teams), for whiteboards (for nursing and elderly homes), and for PC.

The ELISE initiative was initially launched as a small pilot in 2018 and subsequently established as a formal strategic area for the municipality. Development work commenced in 2019 but was temporarily paused during the pandemic due to limited resources being allocated to the development of contact tracing and vaccination solutions from February 2020 to ca February 2022. ELISE is designed and developed collaboratively by a team comprising a project leader from the central municipal Health Agency, development resources, and representatives from the city districts.

It is important to note that Oslo consists of 15 city districts, each functioning as independent administrative units with a certain level of coordination from the central municipality. To ensure the engagement and ownership of the city districts in ELISE, their representatives have been actively involved in the design process. Their involvement includes also coordinating the testing activities in the services and providing feedback to the development team. The representative are also implementation coordinators and responsible for the implementation in their own district. This inclusion of the districts facilitates the implementation and use of ELISE, and addresses the challenge of competing systems (some city districts already had an existing whiteboard solution for nursing homes that would potentially compete with ELISE). Additionally, the initiative has been organized as a scaling process, with two city districts initially involved and others gradually brought in through a structured approach known as 'pulje' (groups of 3-4 city districts working together in sequence) and 'fadder' (experienced city districts guiding and supporting novices). Using this approach, ELISE has been rolled out to all city districts during 2023. Most activities took place online in video meetings in Teams and some in person meetings have been organized (post-pandemia).

ELISE has been developed with the aim of providing process-oriented support throughout the patient journey. Thus, the data structure is task-oriented: the healthcare professionals in the municipal services work according to assigned tasks and related updated information in one place, rather than making them search for information across several systems in order to be able to conduct the task. In principle, ELISE is developed to be complementary to the existing EPR by incorporating additional functionalities that are not currently available in the EPR, but are critical for the needs of users within the healthcare services. This shift required a major effort to define the novel work procedures for ELISE in the various services. The work procedures are stored in the Extend Quality System (EQS) available from 2019 to all employees in the municipality.

ELISE is built upon a flexible technology platform that enables partial implementation rather than requiring a complete system implementation. This approach allows for adjustments and refinements to be made continuously, even to existing functionalities. The implementation process is carried out gradually, focusing on specific functionality within ELISE that undergoes testing and approval before being introduced. This iterative approach ensures that the implementation of ELISE is both controlled and adaptable, allowing for ongoing design and redesign to meet the needs of users.

Research methodology

The research followed a longitudinal case study design on ELISE, and it is part of a multidisciplinary research project on competence development in digitalization. Data collection was conducted from January 2020 to June 2023 and resulted in an extensive and rich set of empirical data. The main data collection technique is non participative observation of online meetings (in Microsoft Teams) which were sound recorded and partially transcribed. In addition we took detailed notes during the meetings. We observed the following meetings series:

- weekly 2-hours project meetings of the core design team.
- weekly 30 min status meeting of the supervisory team.
- weekly 30 min follow up reflection with the project leader.
- weekly 1 hour meeting wit new user groups for implementation.

We also conducted semi-structured interviews with participants from the design core team, the project leader, the participants in the supervisory team, and the IT team at the Health Agency of the municipality. The author participated in all the observation sessions together with two researchers (who attended some of the sessions) and a master student (who attended some of the session focused on the integration. The master student conducted additional interviews with the IT team, and the data are included in the dataset. The meetings were held online because the participants are geographically distributed in Oslo. We asked for consent via email.

In addition, we had access and analyzed some of the ELISE documentation (e.g. the slides used during the core design team meetings), and the national and municipal reports and document.

Our first approach to data analysis was to create a timeline for ELISE with the major events and decisions taken. For this paper the analysis has focused on data work, and – as mentioned - on the specific process of integrating the EPR and ELISE. The data about this topic concern the period autumn 2022 - spring 2023.

The integration solution

This paper focuses on the efforts aimed at integrating ELISE with the existing EPR system within the municipality. The EPR, which was established in 2002, is a comprehensive system designed and developed by an IT vendor. It can be regarded as a "heavyweight" IT system, as described by Bygstad (2017), and is regularly updated based on vendor releases and feedback from various user organizations. According to an IT team member, the decision to develop ELISE rather than further enhancing the EPR was influenced by the slow production process and prioritization of requirements within the EPR. An informant said: «*So it is a process then, that the product queue at (the vendor) is too long, we are not an important customer, they are not focused on our desires, this is the pillar in ELISE, we want to be able to shape the service as Oslo needs them, not as (the vendor) thinks it should be, in Finland or Sweden*".

The integration is needed because a significant portion of the data in ELISE is sourced from the EPR. Given that ELISE focuses on the same patient population as the EPR, it relies on the EPR to obtain data on all its patients. While this close relationship has been beneficial, it has also posed some challenges. Achieving a well-functioning solution for data retrieval from the EPR has been an incremental process, with progress evolving over time. Initially, the approach involved retrieving all the information from the EPR. However, they soon found out that any changes made in the EPR after the data retrieval posed a problem. In order to ensure that the information in ELISE aligns with that in the EPR, any update to the information in the EPR should trigger a corresponding update in ELISE. One of the informants noted that a possible solution would be to regularly retrieve all information from the EPR at specific intervals. However, due to the large patient volume and extensive information stored in the EPR, this approach was not deemed optimal. An informant said: "*You cannot, in a way, get all the information on all one hundred thousand inhabitants every five minutes, in the case that there has been a change in two of them*."

To address this issue, the team opted to modify their approach by no longer retrieving all information each time but focusing on retrieving information specifically where changes had been identified. To identify these changes, they began consulting the system log in the EPR to determine which elements had been modified. However, the informants expressed that this process proved to be more challenging than initially anticipated.

One specific challenge highlighted by the informants was related to the flexibility provided to healthcare personnel in the EPR, allowing them to complete a patient's record on a later date than when it was initially created. Unfortunately, the EPR did not updated the date of the entry in such cases. This discrepancy posed a problem during the retrieval process since not all changes were being properly logged. It was pointed out by one informant that this lack of comprehensive logging went against legal requirements. Despite these challenges, the team persisted in finding a viable solution for detecting changes in the EPR and extracting the relevant information for ELISE integration.

A new approach was devised to effectively capture all changes made in the EPR, addressing the previous challenge. Instead of relying on the system log, the team now accessed the EPR's database and can specifically check the database's change log. By leveraging the capabilities of the SQL database, which logs all modifications made to a table, ELISE can actively monitor and extract the relevant information from the EPR's database. This retrieval method is known as ‘change tracking’. The implementation of change tracking has proven successful in overcoming the earlier issues. However, it does mean that ELISE cannot utilize the EPR's existing APIs. Instead, ELISE relies on direct access to the EPR's database to ensure comprehensive data retrieval and synchronization. This custom approach allows ELISE to listen to changes happening in the EPR and extract the necessary data, enabling a more effective integration between the two systems.

To accommodate the framework of ELISE, certain APIs will be specifically tailored and adapted. These APIs, particularly in relation to ELISE, have undergone risk assessments to ensure secure access and determine the authorized individuals who should have access to the retrieved information. As the team delved into exploring the possibility of writing data to the EPR, they identified the need to establish a connection between the employee registering information in ELISE and the corresponding employee record in the EPR. To achieve this, they sought to obtain the employee's ID number. Initially, they attempted to utilize an existing API, but encountered an issue wherein this API provided more information than necessary for their requirements. This realization prompted the team to reconsider their approach. They recognized the need to utilize a solution that would retrieve only the specific information required, without returning extraneous or unnecessary data. Adjustments were made to the API or alternative methods were explored to obtain the employee's ID number accurately and efficiently.

Discussion

This paper attempts to develop an understanding of data work form a design perspective. We have addressed the following research question: *what are the concerns for data work in design for EHR infrastructures?* Based on a longitudinal case study on ELISE our findings show that data work is implicated in design in various way. First, data work is implicated in the motivation for designing novel systems. In the case of ELISE, the existing EPR did not facilitate data work for health personnel. It facilitated data enter and storage, but it did not allow for novel ways of using data for reporting or for craeting an overview on patient’s current situation and services. Second, data work is implicated in the design decisions of the novel system. Third, data work is implicated in the design of the architecture of the information infrastructure. The configuration of the architecture has consequences for data work, for instance lack of data synchronization and visualizations would require additional work of copying and pasting data from one system to another.

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Digital mental health as the future of data-driven decision-making

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Abstract. More than 30% of the estimated health-related burden accounts for mental health, yet the funding allocated to the area does not adequately reflect its scope. Therefore, the need for innovation and research in this field is clear in order to use technology to support and enhance the treatment of patients with mental disorders. In this study we are working with patients with bipolar disorder, patients with schizophrenia and their healthcare professionals. During the course of the study we have used a co-design approach to design and develop a digital mental health platform that collects and visualizes health data from different sources, i.e. from smartwatches and from a mobile app. The smartwatches bring metrics like hours of sleep per day, heartrate, and step count into the platform, whereas the mobile app brings answers from a daily wellbeing survey. These two data sources provide objective and subjective data to the study. Additionally, we have survey data and access to health records. So far, we have seen interesting patterns in the data, uncovered design principles and understood that there are both positive and negative sides to collecting health data.

Introduction

In this position paper, the feasibility of digital platforms for supporting people who are being treated for mental disorders is the focal point. Mental disorders have a profound impact on individuals and societies, and that health-related burden can be difficult to quantify. However, one way to estimate it is by counting years lived with disability. According to Vigo et al. (2016), the estimated mental health-related burden accounts for 32.4% of all years lived with disability in the world. This part of the healthcare system has been known to lack financial support, and hence, the waiting lists for mental healthcare tend to be long (WHO, 2022). Individuals suffering from mental disorders often require significant care and support. Therefore, there is a need for innovative digital solutions in order to enhance self-care and move towards increasingly data-driven monitoring, both for patients in self-care and for enhancing the work of healthcare professionals as support in treatment.

This position paper is built on the foundations of a project that focuses on designing digital treatment support for treatment support in two of the more severe mental disorders, bipolar disorder, and schizophrenia, which are both chronic and pose various life challenges. For bipolar patients, the symptoms include extreme mood swings, activity fluctuations, and sleeping difficulties (Mansell et al., 2007), whereas schizophrenia patients typically experience symptoms like paranoia and delusions (McNiel et al., 2005), but both patient groups can experience similar symptoms. Research suggests that increased physical activity can improve wellbeing for patients with schizophrenia as well as bipolar disorder (Callaghan, 2004; Melo et al., 2016). Harnessing data on physical activity and documenting closely monitoring mental well-being has proven impactful for these two patient groups (Sigurðardóttir et al., 2022a). However, it is difficult to fit patient-generated health data into the existing scaffolding of healthcare and more specifically, into the electronic health records as they are designed in most countries. It is against that backdrop, that this position paper is written.

Research Approach

This position paper is based on a canonical action research project that features the two aforementioned patient groups (hereinafter simply referred to as patients) who are under constant medical care in an out-patient clinic. The digital platform co-designed, developed, and used in this study has been designed at Reykjavík University and is called DataWell, the name reflecting on ‘Data for Wellbeing’ and it is an extension of the electronic health record in Iceland, although it serves as a stand-alone digital platform, collecting patient-generated health data. DataWell is under further development with a co-design approach where both patients and healthcare professionals provide important feedback for its improvement. So far, 21 patients have been through a data collection phase of collecting data through wearable devices and smartphone application feeding data into DataWell, harnessing the data with the dual aim of enhancing decision-making of patients and healthcare professionals. More specifically, the patients that choose to partake carry a smartwatch for six weeks, continuously collecting data into DataWell. Additionally, they answer five daily wellbeing questions in a mobile application, a longer questionnaire three times over the interval, and at the end of the period, they attend a semi-structured interview. To supplement that data, we have access to patients’ electronic health record two weeks prior to data collection period, as well as two weeks after it ended, outlining a novel way of utilizing patient-generated health data and enhancing data-driven decision-making, which we see as one of the pivotal elements for the future of digital mental health.

For the overall project we decided to adapt an approach called canonical action research (Davison et al., 2004) to our needs (see Figure 1). We, in collaboration with Landspítali University Hospital (hereinafter called Landspitali) which is the nation's largest hospital, are using DataWell to study the feasibility of digital platforms supporting psychiatric care, in order to reach the overall goal of enhanced data-driven decision-making. The digital platform is under further development through a co-design approach, both with patients (P) and with the healthcare professionals (H) that have been treating the patients. We have obtained an ethical approval for a study with six week data collection per patient and so far we have been through a data collection phase with 21 patients.

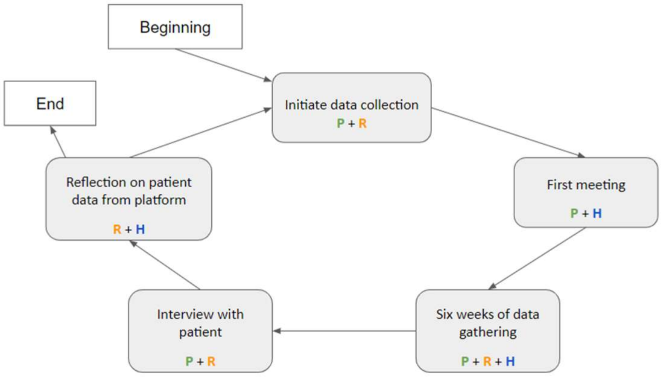


Figure 1: The process of this CAR research project. This figure illustrates the cyclical process of the project, where researcher (R) is the first author of this paper, patient (P) is any patient included in the study and healthcare professional (H) is any healthcare professional involved.

DataWell currently has three perspectives, the patients, the healthcare professionals, and the researchers (see Figure 2). These perspectives all have different features to them; for example, the healthcare professional is offered a focused list of patients, whereas the researcher's perspective offers a way to download data in a convenient way, to investigate further and the patient is merely able to view their own data through visualizations. Working with various stakeholders, i.e. the patients, their healthcare professionals, and researchers allows us to enhance the data-driven decision-making using DataWell and to acquire a powerful extension to the electronic health record. Hence, the aim of DataWell is slightly different than the traditional electronic health record but we would like to argue for the importance of examining the digital ecosystem as a whole, outlining both the traditional electronic health record as one pillar therein, but also recognizing the importance of other pillars, such as digital platforms harnessing patient-generated health data.

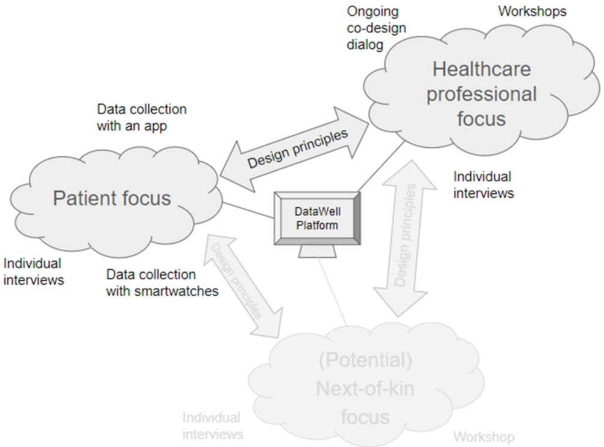


Figure 2: The figure shows how the different focuses of the project have various empirical data sources. It also shows a potential way of adding another perspective, where the focus would be the loved ones of a patient, or the next-of-kin as a future potential of enhancing the digital platform. The digital platform is situated in the middle, indicating that it has the serves as a bridge between the patients and healthcare professionals (alongside researchers), and the potential to add the fourth perspective for the next-of-kin.

For this project, we have also designed and developed a mobile app that collects answers to daily wellbeing questions, which are the following i) I was successful in achieving my goals, ii) My mental state was positive, iii) My physical condition was good, iv) I experienced little stress, v) Today's movement was good, vi) I slept well last night. Answering this survey allows patients to reflect on their day, and also results in a single number that can then be associated with how other metrics resulted for the day.

Towards Cohesive Digital Ecosystems of the Future

When discussing digital platforms and patient-generated health data, different aspects need to be considered. For example, the granularity of data is pertinent to consider (Perin et al., 2018), also when it comes to trends, they can be relational, hierarchical, or a combination of the two, which is important when choosing the data on the one hand and which types of graphs, visualizations, and tables to utilize on the other hand (Basole & Saupe, 2016). Additionally, suitable visualizations need to be carefully selected, both depending on the type of data and the type of user to enable that the data can be interpreted in a straightforward manner without precisely relating to other data points, e.g., some parts are less suited for creating specific visualizations. This is especially impactful for digital mental health, as the patients often need assistance with complex tasks and cognitive impairment is a common observation for individuals with schizophrenia (Bowie & Harvey, 2006) and bipolar disorder (Lima et al., 2018) which results in difficulties with written information. Moreover, the resources are scarce across healthcare in general and the healthcare professionals working with these patients certainly have limited time. This means that how the data is presented differs between what type of data is being represented as well as on the granularity and the intentions of data representation (Perin et al., 2018). With that in mind, designing a digital platform with a focus on visualizations is preferably done through collaborations with all stakeholders involved.

As a part of our co-design approach to the design of the digital platform, we hosted a workshop with 13 healthcare professionals. Our main conclusions from that were three design principles: First, for the the patient's side that clarity and information accessibility is important. Second, that efficiency and flexibility are vital when it comes to the healthcare professional's side, and third, that our mobile app design needed to include a notification function (Sigurðardóttir et al., 2024). We have used these results as our primary guidlines in our upgraded design. See Figure 3 for a glimps into the patient's perspective of the platform.

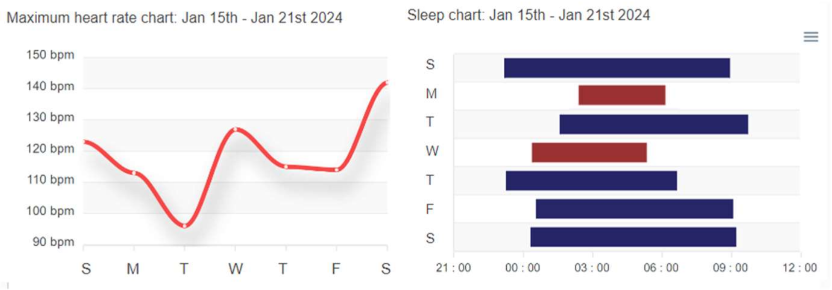
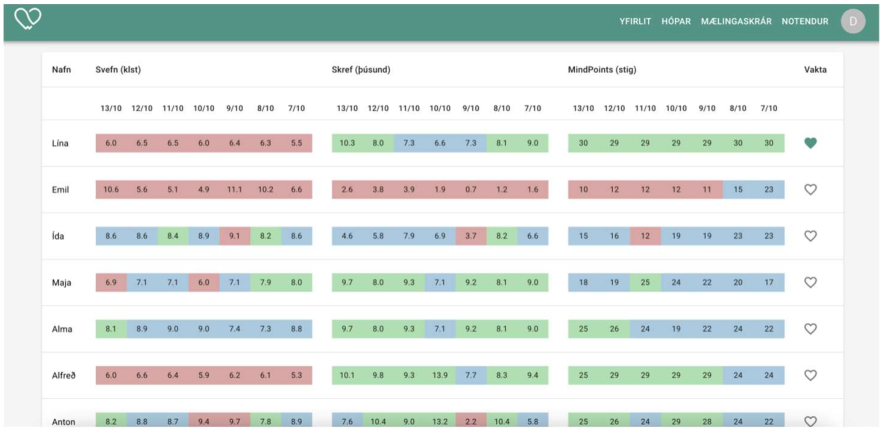


Figure 3: To the left we present a heart rate chart, showing the maxium heart rate per day over the course of one week. To the left we offer a sleep chart, displaying the hours of sleep for each day in the week, colorcoding red if the sleep is less than a certain limit.

Healthcare professionals are busy people, and the design principles we derived reflect that. Based on these principles, we created the view shown in Figure 4 to meet their primary need: the ability to access a large amount of information in a single display. Additionally, we learned that bringing the healthcare professional's participation in co-design brings a sense of inclusion that we believe will be supportive of the practical use of the platform.

Through our collaboration with patients and healthcare professionals, we have also learned that data work and somatic experience are not widely discussed as concepts when it comes to digital mental health interventions, but rather there has been a focus on the possible positive outcomes of data collection, or the lack thereof. Even though the positive sides of data collection can include healthier habits, enhancement of treatment and empowerment, the dark sides can entail surveillance feeling, attempts to 'serve to the data collection' and feeling overwhelmed, and in addition negative somatic experiences like constant adjustments of the wearable, rash or wounds. We would like to emphasize that researchers take that into account when designing studies, especially when it comes to vulnerable groups of patients.



Nafn	Svefn (klst)							Skref (þúsund)							MindPoints (stig)							Vakta
	13/10	12/10	11/10	10/10	9/10	8/10	7/10	13/10	12/10	11/10	10/10	9/10	8/10	7/10	13/10	12/10	11/10	10/10	9/10	8/10	7/10	
Lína	6.0	6.5	6.5	6.0	6.4	6.3	5.5	10.3	8.0	7.3	6.6	7.3	8.1	9.0	30	29	29	29	29	30	30	♥
Emil	10.6	5.6	5.1	4.9	11.1	10.2	6.6	2.6	3.8	3.9	1.9	0.7	1.2	1.6	10	12	12	12	11	15	23	♡
Ída	8.6	8.6	8.4	8.9	9.1	8.2	8.6	4.6	5.8	7.9	6.9	3.7	8.2	6.6	15	16	12	19	19	23	23	♡
Maja	6.9	7.1	7.1	6.0	7.1	7.9	8.0	9.7	8.0	9.3	7.1	9.2	8.1	9.0	18	19	25	24	22	20	17	♡
Alma	8.1	8.9	9.0	9.0	7.4	7.3	8.8	9.7	8.0	9.3	7.1	9.2	8.1	9.0	25	26	24	19	22	24	22	♡
Alfreð	6.0	6.6	6.4	5.9	6.2	6.1	5.3	10.1	9.8	9.3	13.9	7.7	8.3	9.4	25	29	29	29	29	24	24	♡
Anton	8.2	8.8	8.7	9.4	9.7	7.8	8.9	7.6	10.4	9.0	13.2	2.2	10.4	5.8	25	26	24	29	28	24	22	♡

Figure 4: From the healthcare professional's perspective, a featured list of patients (their names are pseudonames) showing hours of sleep, steps in thousands and mindpoints from the mobile app, all in one display. The variables are displayed with a red, blue or green background, depending on benchmarks specified in the platform. Patients that are evaluated by these metrics to require attention are arrange at the top of the list. Also, the heart on the right allows users that want to watch specific patients.

Research is paved with examples of failed implementations within healthcare due to usability issues or superficial understanding of the practices involved (Ellingsen and Monteiro, 2012; Fitzgerald and Russo, 2005; Press et al., 2013) leaving us with a healthcare sector that in some cases can be skeptical towards novel digitalization efforts. Moreover, altering the electronic health record can, in many countries be a herculean task as in many countries, the electronic health record is a sanctioned system which is difficult to add to. Consequently, it is critical to examine supplements to the digital ecosystem, for instance digital platforms, meant to serve as an extension to traditional electronic health records. Within the domain of healthcare, there is a growing interest in personalization in care for patients as well as data work of caregivers, which has potential to both increase self-care and self-management in everyday life, while also influencing the caregivers' work (Fitzpatrick and Ellingsen, 2013; Islind et al., 2018). The patients potentially have an increasingly important and empowered role in their own care, a role that they were unable to have without having a say in the digital platforms and the data-driven decision-making which impacts their lives, and the same goes for the healthcare professionals; their voices are vital for designing and developing the digital ecosystems where the electronic health record coexists with novel digital platforms.

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