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"We can still talk to the patient!" - Negotiating the narrative power of patient reported data

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Abstract. Patient Reported Outcome data (PRO data) are standardized questionnaire data on patients' own experience of their health and quality of life increasingly collected on digital platforms as part of treatment trajectories. In Denmark, national efforts are being put into developing questionnaires tools for meaningful clinical use of such data in cross-sectorial clinical pathways. PRO data is among other things seen as a way to enhance patient involvement by focusing the clinical encounter on "what matters to patients". With increased datafication of healthcare, some see the power of the irreducible patient narrative set aside for quantified, standardized and thus reductive representations of the patient – PRO data potentially being a case in point. Rather than assuming such reductionism, in this paper I will explore empirically how health professionals engaged in developing PRO-tools enact the relationship between PRO data and more complex, narrative representations of the patient. Based on fieldwork in the national Danish initiative engaged in choosing and developing PRO-tools for heart-rehabilitation, I will suggest that PRO data is both enacted as an illumination of the patient narrative, a substitution for the narrative and an inhibitor of the narrative. The tensions between different enactments call for further reflections on the role of PRO in emergent digital health infrastructures.

In recent years, great efforts have been put into making patient involvement more systematic and clinically relevant and the concept of Patient Reported Outcome data (PRO data) has gain significant success as useful both in and beyond the clinical encounter. PRO data is data registered by the patient in (online) standardized questionnaires and in the Danish context defined as: "data on the patients' health status, physical and mental health, symptoms, health-related quality of life and functional level" (PRO-danmark.dk – my translation). Health policy makers, clinicians, and patient advocates increasingly see access to patients' individual assessments of their health and the effects of treatment as a necessary source of knowledge about the individual patient case as well as about the overall outcome of healthcare system (Black 2013). Research has shown that clinicians rarely ask patients about all the issues that they might find to be problems (Sprangers & Aaronson 1992) and asking more systematically for patients' own assessments and needs with standardized questionnaires has been shown to be positively correlated with clinical outcomes (Basch et al. 2017). Coupling such arguments for more clinical patient-involvement through data with a parallel promotion of more organizational involvement of patients experiences of outcomes as a better steering mechanism for healthcare systems, has made PRO data an extremely popular field of exploration when pursuing more patient-centered and efficient health system configurations.

However, the hype around PRO data should be seen in relation to a broader datafication of healthcare (Hoeyer 2016) in which the patient increasingly is datafied including the more subjective, intimate and everyday aspects of disease. However, with increased datafication of healthcare some see the power of the irreducible patient narrative set aside for quantified, standardized and thus reductive representations of the patient (Lyon 2007; Lupton 2012). In their paper entitled "Electronic Health Records and the Disappearing Patient" Hunt et al. (2017) describe, how the increased influence of the electronic health record in the everyday clinical encounters demands evermore standardized data points on the patient for documentation, billing and quality monitoring purposes. This, they argue, has pushed aside the clinical conversation and attention to the patient's individual narrative: "[EHR] seems to be obstructing clinicians' authority to direct consultations based on their knowledge, and is all but erasing patients as individual persons from the clinical encounter, replacing them with a digital representation as the object of care" (ibid; p. 404). The concept of "the data double" has also been put forward by scholars as a way to suggest that the real, embodied patient is being separated out from and made secondary to an artificial and de-humanized representation in data (Haggerty and Ericson, 2000; Lyon, 2007). However, as Grew and Svendsen has shown in their exploration of the increased datafication of heart patients, the experiences of knowing the patient and knowing oneself with data in healthcare arrangements may be more ambivalent, as the "real" patient and the patient-with-data cannot be easily separated to begin with (Grew & Svendsen 2016). Still, they also call into attention the frictions between data and personal story that may arise in the clinical encounters: "In many situations, there is no discrepancy between data and the embodied patient, and the use of data goes smoothly. In some situations, however, data become dominant and patient testimonies are marginalized, generating experiences of being secondary to data and not belonging in the clinic." (ibid; p. 84). However, might PRO data be different, taking into consideration that they concern subjective aspects of having and living with disease? Prainsack argues, that we should still be critical in assessing their ability in supporting, what Prainsack has called a "deep" patient-centeredness (Prainsack 2018): "Meaning cannot be ascertained by handing out questionnaires to patients about what matters to them and what they believe in. Knowing what is important to patients, and supporting them in making decisions that are meaningful to them and their significant others, requires that patients are treated by people and in institutions that know them, see them and listen to them." (Ibid, p. 156). The use of data does not by definition stand in opposition to knowing, seeing and listing to patients. Rather the specific configurations of tools, infrastructures and practices may or may not afford a sensitivity toward "what matters to patients". Therefore I am in this research interested in exploring, how health professionals negotiate data vis a vis the patient narrative while being engaged in developing what is presented as patient-centered PRO tools.

PRO in Denmark: PRO for cross-sectorial heart-rehabilitation

Under the auspices of the Ministry of Health and managed by the Danish Health Data Authorities a national PRO initiative has since 2017 been seeking to initiate and support widespread and cross-sectorial use of PRO in Denmark. A central task for the PRO office is to select and/or develop nationally certified PRO-tools for a still undecided number of clinical areas to be made accessible to health professionals and health managers through a central 'PRO bank'. Central to its task is also to ensure a functional national it-infrastructure for sharing PRO tools and PRO data across sectors. The work is highly collaborative, where questionnaires are selected and developed with the involvement of patients, health professionals, patient associations and those responsible for national clinical quality databases. The work of selecting and developing PRO tools for cross-sectorial heart rehabilitation was planned in the beginning of 2018 and in August approximately 40 participants – mainly physicians and nurses from hospitals and municipalities across the country – participated in the first of 4 clinical coordination groups aimed at selecting and developing a national PRO tool to support the rehabilitative care given to heart patients. Parallel with these meetings a group of patients also meet in four workshops to discuss their perspectives on PRO and specifically to inform and reflect the decisions made by the group of primarily health professionals in the clinical coordination group. In this paper, I have limited myself to mainly analyzing the observations made in the clinical coordination group. The participants in these workshops had very diverse experiences with PRO data - from not having worked with such tools and data at all to already having extensive experiences with specific tools for research or quality monitoring purposes. Also, they came from a number of different sectorial, organizational, professional and regional contexts with – which became evident in the workshops – very different practices and experiences. Nevertheless, the workshops can be regarded as an important space for the initial negotiation and scripting of the national PRO tool – a standard which will have implications for clinical encounters in future cross-sectorial heart rehabilitation.

Methods

During the fall of 2018, I did participant observations in eight workshops arranged by the Danish Health Data Authorities: Four half-day workshops for heart-patients and four whole-day workshops for clinicians. In addition I had informal conversations with the chair and project manager and consultants from the health data authorities and included written material such as mail correspondence and power point shows. The fieldwork is part of a larger assemblage ethnography (Wahlberg, 2018) studying the emergent PRO data assemblage in the Danish context (see also Langstrup 2018). I wrote extensive field notes during and shortly after the workshops and analyzed the material thematically.

Results

PRO data as illumination

“PRO is the patient’s own illumination of his/her condition and situation – without the health professionals’ interpretation” (my translation). This quote is taken from a slide with the caption “Why PRO is a good idea”, which was presented by a consultant from the health data authorities to the participants at three of the four clinical coordination meetings on heart rehabilitation. The slide also shows a human figure illuminated by four sources of light each with a caption: “the record”; “test results”; “the consultation”, and “PRO”. The slide also says PRO as a source of information should be added to “give the patient more insight into and influence on his or her treatment” and “to complement the knowledge the health professionals have about the situation and condition of the patient [...]”. Throughout the four clinical coordination workshops, PRO is promoted as data, which can illuminate the perspective of the patient. A doctor, in a small promotional movie shown to participants, says “PRO is openness” and describes how PRO data has helped him get to talk with patients about issues like depression and anxiety – issues he would not normally have the time – or the nerve – to get around to talk about. Here and elsewhere, the traditional consultation is depicted as a limited space with very limited time – and PRO as a way to expand this space and the conversation between the clinician and the patient by asking the patient to consider “what is important to me” in advance with the questionnaires. The clinicians at the meetings are very positive toward this version of PRO: “Patients feel that these tools can help them get better at verbalizing how they are feeling”, one physician with PRO experience argues.

However, illumination and extended dialogue may not be without its problems. Getting to know more about the patient’s emotion and everyday life can be “heavy”, and not all the participants found every patient narrative set in motion in a clinical encounter equally relevant: “Patients want to talk about a lot of things. We cannot talk about everything!” (Physician). Another physician says: “Not all patients are equally clever. If the patient controls everything [that is talked about, ed.], then we lose our justification for taking up their time” (Heart surgeon), suggesting that it is the clinician, who has the expertise to know what is relevant and irrelevant to address in the clinical encounter. Moreover, some of the participants fear that more rich accounts of patients’ lives, concerns and needs produce new demands for clinical action that in reality are not actionable or not a medical concern to begin with. In a discussion about whether to add an item in the questionnaire tool about sleep, a cardiologist reflects: “Sleep! But what the hell am I to do about that with my cardiology expertise? […] We should not ask about things that we just leave unattended, then patients will be very disappointed”. The possibility of referring the patient to someone with expertise in sleep is suggested as the obvious solution by other participants. Regarding issues that might be brought up, but are seen as irrelevant for treatment – in this case their relationship status, which statistically may be predicative for their outcome – a physician jokingly asks: “Maybe we should find them a partner? Refer them to a dating app?”.

PRO data as substitute

However, PRO is not just introduced by the health authorities as a tool for starting and enhancing a dialogue – it can also be a tool for focusing the dialogue or substituting it altogether. PRO data is produced by patients answering questions at home in advance of a clinical encounter, and it is standardized and can be presented to the clinician in advance as a color-coded overview of the patient’s concerns (issues encoded as red, yellow or green when rated on severity). However, the calculability of the data also makes it possible to sort patients and prioritize services accordingly. In the clinical coordination workshop, this usage of PRO data is referred to as “visitation”. Here PRO data could be a substitute for a clinical encounter and thus for the patient narrative. The issue of automation, substitution and prioritization is a delicate matter throughout the workshops. On the one hand, using the data to substitute redundant or time-consuming dialogues is supported by some physicians: “PRO is smart. We can use it to sort our patients. It is more rational! The resources can be allocated to where I need them” a physician argues. “We are getting more and more patients! We need to prioritize […] Who should be seen by us, and who shouldn’t. Some patients drive a very long way!” (physician). Here the possible substitution of a clinical encounter with screening through PRO data is seen as a way to curb raising demands and avoid wasteful care – also for the sake of the patients. On the other hand, the wish to engage more with patients and their individual concerns is by most participants seen as the main purpose – not to rationalize visits. The ambivalence toward the use of PRO data becomes particular evident in discussions about a paper-based dialogue-tool promoted by a participating nurse. This tool does not record any data, but as the nurse argues: “It signals, “We are interest in you as a patient!”. It helps us get away from the biomedical model! It is important to be met very openly and not as a category in a questionnaire”. However, in the workshops PRO is differentiated from such more unsystematic and ‘analogue’ approaches which are deemed inappropriate with reference to their incalculability: “The dialogue-tool might be important for conversations, but it isn’t an instrument that can measure anything” (chair of the workshop, physician). This indicates that even if dialogue is the central purpose, data should be produced for several purposes, not just supporting the patient recounting their narrative.

However, using the data algorithmically for deciding who should be seen and how shouldn’t is opposed by the majority of participants and also by powerful stakeholders in the cardiology arena beyond the meetings: “We are skeptical because it has been linked to cost-reductions, wanting to cut some consultations”. “We are not ready to use it as visitation support, deciding whether to see the patient or not. We still want to see the patient” (Cardiologist referencing conversations she has had with the Cardiological society between workshops). The hesitation toward substitution of clinical conversations with patient also surface in other discussions: “There shouldn’t have to be a PRO questionnaire before every meeting – it doesn’t make sense! It is still a clinical task talking to patients! We have to be very critical when considering what we are committing ourselves to. People and trajectories are different.” (Physician). At a different occasion, the same physician forcefully exclaims: “We can still talk to the patient!”. The issue whether PRO data is supplementing or substituting the clinical conversation is professionally touchy as many of the participants see “talking to the patient” and getting to know their problems and concerns as their core task and competence as clinicians. When asked about his thoughts on PRO at the first workshop a physician laconically answers to the amusement of the participants, “Sounds like a good idea. Asking patients questions and acting on their answers”. He obviously felt, that this was at the core of what he already did.

PRO data as inhibitor

Getting better, more patient-centered, systematic and more clinically relevant knowledge about the patient is the main argument for PRO data in the workshops. However, the risk that PRO will become an inhibitor for the clinical conversation and for allowing the patient to recount their illness narrative is also considered during the workshops. The standardization of the questions is seen as one challenge:

“During a break a couple of nurses discuss if PRO could imply new inequalities in access to treatment. Even if people get the same questions they will understand them differently. Nurse: “If a man from North Jutland answers, “I feel fine” it means something totally different from a man from Aarhus [big city] answering the same”. The other nurses agree – this is something they can handle when they talk to people, but if they only get the data, they might not consider it.” (Fieldnotes). This concern of inequality also related to language, as not all PRO tools are translated into all the languages spoken by patients: “We are so excluding toward patients who don’t read Danish. […] We risk pushing them even further away.” (Nurse). At another meeting, participants are again discussing if PRO could worsen inequality: “Answering a questionnaire, it is demanding. “Well, all in all I am doing okay”. Then we get them into some it-system where it is registered that they are doing well. Then they will be referred to “no appointment”.” The consultant comments, that the answers should not stand alone, but other participants are equally concerned: “A number of people will not answer because they feel that answering is an additional burden.” (Physician).

At the very first meeting, the introduction of PRO is argued as the anti-dote to inattention to the patient: The chair of the workshops quotes a patient saying “Ten years ago you listened to us. Today you do not. You are too occupied with registration work”. However, some participants are worried that this inattention will worsen with more PRO data to attend to: “I think it will be much worse with clinicians looking at their screens!” (nurse). Generally participants are worried about increasing data work in an already stressful clinical reality, looking more at screens and it-systems not working: “We will have to use time looking at it and doing something. We don’t want to drown in data”. The organizational and technological reality is thus seen as something that might corrupt the otherwise positive aspects of PRO inhibiting a more patient-centered dialogue with the patient.

Final reflections

The workshops ended with participants deciding on a 77 item questionnaire on a large range of issues ranging from symptoms over sexuality to mental health to given to patients at 3 to 5 different times during their treatment and rehabilitation trajectory. The questionnaire is to be tested during 2019 in a pilot study in a number of clinical practices across sectors. The participants also decided that the data collected should not be used to substitute any visits. The overall consensus was that PRO should be used to support the clinical dialogue. How this particular PRO tool will be used in practice is still an open question as is its actual implications for clinical encounters.

However, the analysis above does show that clinicians are actively trying to navigate between the different implications of datafication of the patient encounter. The participants in the four workshops actively engaged in discussing the purpose and use of PRO in cross-sectorial heart rehabilitation enacted PRO data as an illumination, a substitute and a potential inhibitor of the narrative of the patient. They generally supported the idea that data may enhance patient-centeredness by allowing for more nuanced accounts about what patients experience and need while dealing with severe heart problems. PRO data was here seen as a way to extend the clinical dialogue beyond the confines of the clinical encounter, supporting reflection and verbalization on the patient's part and giving legitimacy to talking about subjects otherwise easily neglected on the clinician's part. However, this primary enactment of PRO as a way to illuminate the patient's narrative rubbed up against the other enactments of PRO. These tensions concerned trade-offs between PRO data and clinical expertise; Trade-offs between the data-work implied with PRO data and having time to talk to and see the patient (Langstrup 2018); and finally, trade-offs between illuminating the narrative and raising demands (unrealistically or wastefully) for more care.

In one sense the analysis shows the seductive power of quantification (Merry 2016) of patient's intimate and everyday experiences of health problems. Participants were overall supportive of the ambition of using PRO as a way to ensure more systematic patient-centeredness in clinical practice and discarded the paper-based reflection tool for its inability to quantify and make calculable patients' reflections – even if dialogue was their stated primary goal. At the same time participants were also very cautious of the possible negative implications of increased reliance on a "data double" rather than the real patient in the clinical encounter. Knowing *about* patient through data rather than knowing *the* patient through "seeing them, and listening to them" (Prainsack 2018, p. 156) was something the participants were aware might be at stake and with this their professional expertise as interpreters of patient's narratives.

References

Black, N. (2013). Patient reported outcome measures could help transform healthcare. *Bmj*, *346*, f167.

Basch, E., Deal, A. M., Dueck, A. C., Scher, H. I., Kris, M. G., Hudis, C., & Schrag, D. (2017). Overall survival results of a trial assessing patient-reported outcomes for symptom monitoring during routine cancer treatment. *Jama*, *318*(2), 197-198.

Grew, J. C., & Svendsen, M. N. (2017). Wireless heart patients and the quantified self. *Body & Society*, *23*(1), 64-90.

Haggerty KD and Ericson RV (2000) The surveillant assemblage. British Journal of Sociology 51(4): 605–622.

Hoeyer, K. (2016). Denmark at a crossroad? Intensified data sourcing in a research radical country. In *The ethics of biomedical big data* (pp. 73-93). Springer, Cham.

Hunt, L. M., Bell, H. S., Baker, A. M., & Howard, H. A. (2017). Electronic health records and the disappearing patient. *Medical anthropology quarterly*, *31*(3), 403-421.

Langstrup, H. (2018). Patient-reported data and the politics of meaningful data work. *Health informatics journal*, 1460458218820188.

Lupton, D. (2012). M-health and health promotion: The digital cyborg and surveillance society. *Social Theory & Health*, *10*(3), 229-244.

Lyon D (2007) Surveillance Studies: An Overview. Cambridge: Polity Press.

Merry, S. E. (2016). *The seductions of quantification: Measuring human rights, gender violence, and sex trafficking*. University of Chicago Press.

Prainsack, B. (2017). *Personalized medicine: empowered patients in the 21st century?*. NYU Press.

Sprangers MAG & Aaronson NK. The role of health care providers and significant others in evaluating the quality of life of patients with chronic disease: a review. *J Clin Epidemiol* 1992: **45**: 743-760.

Wahlberg, A. (2018). *Good Quality: The Routinization of Sperm Banking in China*. Univ of California Press.

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Keeping the loop going: representations and data practices in remote care

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Abstract. Data-driven remote care involves more than just monitoring patients' health values through digital means. It requires a two ways interaction between health professionals and patients where reciprocal trust and personalized care develop over time. For this to happen, continuity in interaction is crucial. In this study, we focus on the work of nurses to achieve continuity in data-driven remote care. Specifically, we focus on how nurses work on digital representations. This paper examines this issue through a case study of nurses work in a remote care center in primary care for patients with chronic conditions. We found that nurses work by enriching, tailoring and improving digital representations, and through these practices they support continuous interactions. Our findings show that the work on digital representations is highly iterative and show how the nurses work to keep the iterations going.

Introduction

In remote care health providers and patients interact at a distance. This form of care has increasingly become data-driven as digital personal devices and apps on mobile devices for measuring various vital signs are developed and adopted (Lupton, 2017). Data-driven remote care is, however, more than a monitoring activity for health providers. The use of digital personal devices in healthcare has shown to create health benefits when patients are motivated and involved. Benefits depend on patient compliance and on behavioral changes that take place on a daily basis outside of the formal care system (Brennan and Casper, 2015). This is not easily achieved as it requires, for instance, patients to develop analytical skills (Grisot et al, 2018), and health providers to interpret data with 'absent' patients (Andersen et al. 2010).

In this paper, we examine this issue from the perspective of health professionals, and their work through data in remote care. Data work in healthcare has recently been defined as that portion of work whose execution, articulation and appraisal deeply and intensively rely on data (Bossen et al 2019). The datafication of healthcare is changing the required competences, tasks, and functions of existing occupations and professions. In our study we specifically focus on the work of nurses with digital representations resulting from combining patients' data, and on how they are created and used and what is their role in the interactions between nurses and patients. Research on telecare workers has foregrounded the complexity of their tasks (Procter et al 2016) and the additional 'emotional labour' carried out (Roberts et al. 2012). Also, it has pointed out that telecare often is not used in situations requiring immediate medical help, but it is rather part of long-term care services (Farshchian et al, 2017). Farshchian et al, argue that support to continuous care processes is crucial. However, they also point out that we lack understanding of how continuous long-term care processes should be supported both in relation to tools, documentation and practices (Farshchian et al, 2017).

In our study we are interested in understanding the role of digital representations for continuity in interaction between health professionals and patients in remote care. We study this in the context of a pilot for a novel remote care service in chronic care. The service is designed to support a continuous and personalized relation between nurses and patients. The work practices of the nurses are focused on the data and framed by their constituting digital representations of patients. While this might be considered an extreme case, as it is designed as a pilot for data-driven remote care, it provides an occasion to study in detail the work of nurses with digital representations. In this setting, patients remotely (at home) generate data by using personal digital devices. The development of this type of service is still in its early stages and there is a limited understanding of how patients' health data shape how digital representations are formed and used, and how they affect remote care practices. In particular we are interested in understanding what is the role of digital representation in 'keeping the loop going' by which we mean the work of supporting the iterative and continuous nurse-patient interaction the service requires for care delivery.

As argued by Burton-Jones and Grange representations are fundamental to understand the use of digital technology (Burton-Jones and Grange, 2012). Thus, attention should be directed towards understanding how data are collected, processed, and structured into representations, and how these representations are used and manipulated. In addition, research has shown that these processes are not smooth and technology-driven but require tuned configurations of practices and technologies to be carried out (Jones, 2018; Monteiro and Parmiggiani, 2019). Thus, we focus on how digital representations used in remote care to support continuity of interaction. Our findings show three practices by which nurses engage with digital representations: enriching, tailoring and improving. We describe each practice and show how they support continuity in interaction. We contribute to the understanding of data work in remote care.

Methodology

The research reported in this paper is based on an empirical case study of nurses' remote care practices at Digicare. Digicare is a Norwegian company that has developed ProAct, a system supporting the collection and analysis of personal device data and supporting patient-nurse communication through messages and personalized questionnaires. Between 2016 and 2018, Digicare has run in-house a remote care center staffed with four nurses and a medical doctor. As part of a government funded pilot, the center provided remote care to a group of chronic patients in a small municipality. The patients were selected by the municipal care services and had chronic conditions such as diabetes, COPD and heart diseases. The pilot aimed to try out a new service model for remote care in Norway where the remote care service is outsourced by the municipality to a private company. In addition, the pilot tested a data-driven mode of remote care. In this mode, patients generate data by using a set of measuring devices in their homes and the data are then sent to a remote care system (ProAct) accessed by nurses. Previously, patients with chronic conditions were monitored at a distance by use of alarms (e.g. fall alarms, GPS tracking, door alarms). Thus, the new mode introduces a focus on data-driven care.

In this study we have focused on the practices of the nurses working at the center. We primarily used three methods to collect data: interviews, observations, and document analysis (Yin 2017). We conducted a total of 23 semi-interviews with the nurses, other staff at Digicare, as well as municipal, regional and national stakeholders involved in the pilots. Interviews were recorded and later transcribed verbatim. We conducted 47 hours of observation of the work practices of the nurses. We observed the nurses during their daily tasks: while using the system, informally discussing among them, during the lunch breaks and during their weekly internal meetings, and other meetings (for instance in discussions of how to improve their care plan). In the center there was one head nurse and three operational nurses sharing the same office on three separate pc desks. We sat next to them, looking at their screen to observe their use of the system. To grasp what the nurses were doing we asked questions and listened to their conversations. We also participated in informal conversations with both nurses, developers, management and technical staff. During each visit, we took extensive field notes to document how the staff interacted in the office. Following the observation sessions, we immediately (on the way back, ca 1 hour on train) spent time to reflect on our observations, to write analytical memos, and to note down questions for later clarification. We also analysed various document including project reports, Digicare documentation, the care plan, and strategic documents.

Case background

Remote care at Digicare's center is organized as follows. When patients are assigned to the remote center by the municipal care coordinator, nurses are informed about the patients' diagnosis, health conditions, treatment plan and other details (e.g. to what extent the patient is expected to self-manage, what type of support s/he has from family and from municipal home services). Once enrolled, the patient receives a home visit from Digicare, where a nurse collects additional information about behavior, autonomy, cognitive capability, and more generally about the home environment, and the patient is provided with a set of digital devices (e.g. digital thermometer, digital scale) according to their needs and including a tablet with the ProAct application. The nurse instructs about how to use the devices and the app on the tablet.

The care plan structures the interaction between nurses and patients for the first year. In the first weeks, patients are followed up closely to make sure they learn how to use the devices properly, and acceptable ranges are set for each type of measurement (e.g. the range that is considered normal for each patient). Overall, patients are expected to use the devices to take regular measurements (e.g. temperature, weight, blood pressure), heed to directions given by the nurses via messages, on a daily basis answer personalized questions, and reply to messages in the ProAct application at least once a week. Following the enrollment period, there are a number of check-points. Both nurses and patients have access to the patient record including graphical visualizations of the measurements from each device (also listed with time of measurement), the message log between nurses and patients, and the personalized questionnaire. Nurses have additional access to each patient profile (e.g. personal information, diagnosis, medicines, comments) and to individual alert settings for each type of measurement.

Nurses attend to each patient at least once a week examining measurements, messages, and questionnaire answers received in ProAct. Based on these data, nurses compose a text message comprising an analysis of the weekly trend, responses to questions from patients, and general advices. Nurses communicate with patients mainly with text messages, less frequently with phone calls and via SMS, but the style of communication varies with patient preferences.

Findings

Our analysis focuses on how the nurses work with digital representations in their interactions with patients. In ProAct various type of data are collected from the personal measuring devices, from the messages, and the answers to the questionnaires. The data are displayed in form of chronological lists of events (e.g. measurements, text messages), of graphs (based on the measurements), of scores (according to the answers to the questionnaire). The various ways data are displayed, and their combination form digital representations. Data about the patient are at first based on information nurses receive from the municipal care coordinator, and on information collected during the home visit. These are about the medical history, diagnosis, and overall health status, as well as family and housing situation. This baseline is over time enriched by data from devices, answers and messages generated by patients. Digital representations are updated many times per day as patients take measurements, reply to messages and answer the questionnaire.

In the following text we highlight the work of nurses to achieve continuity through digital representations, specifically we describe the practices of *enriching*, *tailoring* and *improving* digital representations as core practices to 'keep the loop going'.

Enriching digital representations. Digital representations are not fixed representations of the patient's health status. They are sensemaking device that work as long as they are updated to the current health status. When nurses attend to patients, they consider and triangulate the various data received in ProAct to assess the patient's condition. For instance, they observe the values from the devices and the trend that is forming in the graph. They check if the new values are below or above the set threshold, and how they relate to the values of the previous week or weeks. They do this by zooming in an out of the graphs. Also, they read the text messages from the patient, and they check if the patient has answered to specific questions they have formulated in a previous message, or if they have taken measurements regularly. If they have not, nurses follow up and remind patients to do so. For instance in the case of a patient with diabetes who has not measured as expected, the nurse comments: "I am sure here it was in the evening and she had eaten and had been without insulin because you maybe have chosen the wrong food to eat, and so she has not checked her glucose level afterwards, which is not good because we have reminded her to do that, because when you have a so high value then we tell that you should try to correct it and then take another measurement, but she has taken it until the day after in the morning and then the value was 5,5 which is ok". Nurses follow up on a missing data by reminding patient to take measurements. It is important that the flow of data does not stop. Nurses work with digital representations by enriching them by developing and building up a narrative over time, making sense of the new data in relation to the past data.

Tailoring digital representations. Digital representations can be manipulated and tailored to the needs of each patient. ProAct is a flexible technology where the different features can be tailored to the characteristics and needs of each patient. For instance, the text messages between nurses and patients are not standardized in terms of length, content or frequency of interaction. This supports nurses to develop a personalized interaction with patients. Personalization is important, because each chronic patient experiences his/her illness differently and has specific illness trajectories. In addition, as patients' own behaviors and habits affect their health conditions, nurses need to understand their overall life style and situation. For instance, some patients not very comfortable with reading and writing text messages and prefer short messages, while others are very active. The nurse says: "here you have access to health personnel so you can ask any question, so depends on the person, some are very interested and ask a lot of questions, other are not, and you have to repeat and repeat." The questionnaire is also flexible and can be personalized in content, formulation and scoring. For instance, in a case a patient with COPD has questions that track his use of painkillers. The notes from the observation report the following: "the nurse looks at the answers from the questionnaire: the patient has answered that 'yes' she has taken some extra painkillers this week. She had answered 'yes' also the previous week. The nurse comments on this in the text by saying that she sees from the answers that she 'is struggling with pain everyday' because she says that she takes pills every day". Nurses work with digital representations by tailoring them to each patient as over time they get to know the patient preferences and adapt their interaction accordingly.

Improving digital representations. Digital representations guide nurses' interpretation of the health status of patients. By combining various data, nurses, in a continuous interaction with patients, reflect on how well the collected data and the digital representations they form actually represent the patient health status. For instance, they often revise and reformulate the questions in the questionnaire to match the changing needs and concerns of patients. In addition, nurses also reflect on the use of digital representation. For instance, one concern they have is that if a patient has all her measurements within the appropriate value range, the system would not display any alert. This would risk the patient to go 'unnoticed'. As one nurse commented: "we started by saying ok I think they should have a feedback once a week, what we were afraid of in the beginning is that some of the patients that were doing well, they will slip through our fingers and we wouldn't see them, you know, they are not alerted". Thus, they decided to interact with patients every week with a feedback text message, in addition to replying to messages patients sent. As the nurse explains: "we are doing both, and we still do it, if one of (nurse)'s patient is having an alarm on Monday and she gives him a feedback on that one, she gives him also a weekly feedback the next day as a weekly message, and that was not the thought when we started". Thus, working with digital representation means also to understand if the way they are formed and used is in line with the purpose of the care activities. In this case, a patient that has good routines 'slips through the fingers,' showing that the use of alerts can also contribute to unreliable digital representations.

Conclusion

In this paper we have examined a case of data-driven remote care which requires a continuous flow of information between health practitioners and patients. While chronic care has traditionally been delivered episodically, digital tools enable novel forms of remote patient care that support continuity of care (Lupton and Maslen 2016). Continuity is critical in remote care, yet we lack understanding of how it should be supported (Farshchian et al, 2017). In this paper we have approached this issue from the perspective of the health professionals providing remote care, and we have focused on the data work of nurses with digital representations. Specifically, we have examined the work of supporting continuity as work of 'keeping the loop going', thus proposing to understand continuity of care as an interaction loop between health providers and patients which needs 'to keep going'. We have identified three ways nurses work with digital representations, which we have called enriching, tailoring and improving. By doing so, we have foregrounded the data work of nurses in keeping continuity in their interactions with patients and in care.

A crucial aspect of chronic care is that it takes time and work to cope with a chronic disease. Through the care process we have described, the aim is that patients become partners in a continuous conversation that iteratively builds up their knowledge of their disease and how to manage it. Patients learn how their habits affect their condition (e.g. how alcohol affects glucose), how medicines work (e.g. should insulin be taken before or after a meal?), how their condition can be acted upon (e.g. what a headache or insomnia may mean and what to do). For both nurses and patients this is a continuous learning process, as chronic conditions can develop and interact in unexpected ways over time. The nurses need to learn which methods are most effective in providing remote care for chronic conditions, what works in some cases (e.g. to a depressed patient they would write bold statements), and what does not work (e.g.an overweight patient that stops using the digital scale because her weight is increasing).

Responding to the call for research by Farshchian et al (2017), our findings show that the interaction between nurses and patients, needs to be iterative and continuous to support continuity of care. We propose to understand the challenge of supporting continuity as a challenge of keeping digital representations as active working tools for both nurses and patients. Our findings are relevant for the design of systems supporting patient-health provider interactions in remote care, and our future research will contribute to the definition of design principles for supporting iterations in remote care.

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References

Andersen, T., Bjørn, P., Kensing, F., & Moll, J., 2011. Designing for collaborative interpretation in telemonitoring: Re-introducing patients as diagnostic agents. International journal of medical informatics, 80(8), e112-e126

Andreassen, H.K., Dyb, K., May, C.R., Pope, C.J., Warth, L.L., 2018. Digitized patient–provider interaction: How does it matter? A qualitative meta-synthesis. Social Science & Medicine 215, 36–44.

Bossen, C., Cabitza, F., Ellingsen, G., Pine, K., Piras, E., 2019. Data work in healthcare. Special issue of Health Informatics Journal.

Brennan, P.F. and Casper, G., 2015. Observing health in everyday living: ODLs and thecare-between-the-care. Personal and Ubiquitous Computing, 19(1), pp.3-8.

Burton-Jones, A., Grange, C., 2012. From Use to Effective Use: A Representation Theory Perspective. Information Systems Research 24, 632–658.

Farshchian, B.A., Vilarinho, T. and Mikalsen, M., 2017. From episodes to continuity of care: A study of a call center for supporting independent living. Computer Supported Cooperative Work (CSCW), 26(3), pp.309-343.

Grisot, M., Moltubakk, A. K., Hagen, L., & Aanestad, M., 2018. Supporting Patient Self-Care: Examining Nurses' Practices in a Remote Care Setting. Studies in health technology and informatics, 247, 601-605.

Jones, M., 2018. What we talk about when we talk about (big) data. The Journal of Strategic Information Systems.

Jonsson, K., Mathiassen, L., Holmström, J., 2018. Representation and mediation in digitalized work: evidence from maintenance of mining machinery. J Inf Technol 33, 216–232.

Lupton, D., 2017. Digital health: critical and cross-disciplinary perspectives. Routledge.

Lupton, D., & Maslen, S., 2017. Telemedicine and the senses: a review. Sociology of health & illness, 39(8), 1557-1571.

Monteiro, E., & Parmiggiani, E., 2019. Synthetic Knowing: The Politics Of The Internet Of Things. MIS Quarterly, 43(1).

Procter, R., Wherton, J., Greenhalgh, T., Sugarhood, P., Rouncefield, M. and Hinder, S., 2016. Telecare call centre work and ageing in place. Computer Supported Cooperative Work (CSCW), 25(1), pp.79-105.

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User participation in the implementation of large-scale suite systems in healthcare

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Abstract. Currently, much software in healthcare is introduced as large-scale suite systems that aim at covering needed functionality for different institutions, wards, and professionals. With these systems, the software is already in place and development is largely replaced with the activity of configuration. Configurable suite systems create new conditions for user participation in healthcare software projects. We want to explore these conditions further, and we ask the following research question: What is the users' role in the implementation of large healthcare suite systems? In this study, we discuss four ways in which user participation in implementing large-scale suite systems are different from smaller-scale software projects.

Introduction

The importance of engaging users in the development of information systems is well-recognized (Johannessen & Ellingsen, 2012; Markus & Mao, 2004). Users are expected to provide designers with valuable insights into the users' work practice and they also need to get an understanding of the technical possibilities and limitations of the new system. This may be achieved through agile methods (Cockburn, 2007; Silsand & Ellingsen, 2014), such as Scrum, which emphasize short iterations to make the design receptive to changes in the environment. An agile approach implies that the developer gives high priority to satisfying the users' needs through early and continuous delivery of valuable software, where changes of requirements are welcomed. In these processes, the users have a direct role in decisions about the development of new systems. Such bottom-up processes are supposed to ensure “empowered” and satisfied users, on the basis of a general belief that user participation leads to better systems (Howard, 2004, p. 41). It also aligns well with design strategies in the information infrastructure field where the aim is to make simple IT capabilities that are initially useful (Hanseth & Lyytinen, 2010).

A key challenge in healthcare is that much software is introduced as large-scale suite systems that aim at covering needed functionality for different institutions, wards, and professionals. Examples of such systems include the US-based systems Cerner, Epic, and InterSystems, which all have been implemented in several European countries. With these systems, the software is already in place and development is largely replaced with the activity of configuration (Pollock & Williams, 2008). While configuration makes some functionalities easy to set up, it also restricts the space of possible functionalities to those envisioned by the designers of the configuration facility. In addition, configuration facilities make it possible to shift some design work from the vendor to the users because it is less complicated to configure systems than develop them from scratch (Hertzum & Simonsen, 2019). While the process will not be bottom-up, the configuration facilities may present opportunities that stimulate the users in thinking in new ways about what it could be like to work with the system. This way, configurable suite systems create new conditions for user participation in healthcare software projects. We want to explore these conditions further, and we ask the following research question: *What is the users’ role in the implementation of large healthcare suite systems?*

Empirically, we investigate the ongoing preparations for the implementation of the EPR from the vendor Epic in the whole region of Central Norway, including all its hospitals, general practitioners, home-care services, and nursing homes. Epic is promoted as a platform with infrastructural capabilities, such as being able to connect a wide range of heterogenous users and enable new functionality (Star & Ruhleder, 1996).

Method

The study adheres to an interpretive research approach (Klein & Myers, 1999; Walsham, 1995). Data were gathered in the autumn of 2018 and consist of interviews and publicly available documents. We have conducted six interviews with top management in the Health Platform program, which is responsible for the Epic implementation in Central Norway. The interviews include two interviews of the Director of the program. The interviews were audio-recorded and transcribed for analysis. Media coverage provided supplementary input. In quotes, the interviewed directors are denoted Director-1, Director-2 etc. where the numbers indicate the order in which they are quoted in the text for the first time.

Case

The EPR implementation is run by the Health Platform program, which is owned by the Central Norway Regional Health Authority and Trondheim municipality. The cost of the program amounts to NOK 2.7 billion (EUR 270 million). Out of eleven prequalified EPR vendors in 2016, Epic, in 2019, is the only contender.

Project background

Epic is an integrated suite of software that originally was developed for the US market, but is now also in use in Europe. Its functionality ranges from patient administration, through systems for physicians, nurses, pharmacists, radiologists, lab technologist, and other care providers, to billing systems, integration to the primary health sector, and a facility for granting patients access to their own data. The Epic system offers extensive configuration possibilities to fit the system to existing work practices or to facilitate new and optimized ways of working. Configurations may be made during the initial setup of the system as well as after the system has entered into operational use.

Negotiations are currently underway concerning the content of the Norwegian solution and the plan for its implementation. The signing of the contract is planned for 2019 and the first implementation for 2021. Trondheim municipality will be in the first implementation, while the rest of the 84 municipalities in Central Norway have the option to opt in after that. In total, the Central Norway region has a population of approximately 720,000 citizens, including 44,000 healthcare professionals.

The vision that mobilizes the users

A major motivation for implementing the Epic system in the entire health service in Central Norway is to provide complete and up-to-date information about the patients' condition and their prescriptions and use of medication. This information would make it possible for the municipal health service to take more responsibility in the treatment and care of patients in their homes or in nursing homes. It would also ensure that clinical specialist teams have access to the EPR information when they visit outpatients. Overall, it is envisioned that fewer patients will need to be hospitalised. Sometimes it is believed to be safer to monitor patients in their homes than admitting them to hospital. For the clinicians in the specialist health service, this is a central motivation for participating in this project. One of the directors put it like this:

> *"If this program had only been aiming for the hospital sector, it would have been really demotivating (...) but since the aim is to procure a system for the whole healthcare service in Central Norway with its future potential, it warrants taking a risk like this" (Director-1).*

An argument for the municipalities to participate and, thus, get the system is that it will automate several of the existing work processes. Once a solution for automating a work process has been devised in one municipality it will also be deployed in the other municipalities, thereby increasing the returns on devising such solutions:

> *"We must do a sales effort and show them what they get. We have already uncovered many areas we can simplify (...) Through the new solution, we will have much more automated actions instead of punching everything yourself. So, there will be less pressure and less time spent. In Trondheim municipality, I believe that there is now an agreement on four service-oriented standardized pathways related to homecare and institutions. This will also be deployed in the other municipalities" (Director-2).*

For the GPs, it may be a bit more difficult to find the key argument for participating in the program given that they already have quite good GP systems, but the Health Platform management has argued that there will be fewer phone calls from other employees in the municipal health service to get updates on the patients' status, such as their diagnoses, last visit, regular medication and so forth. At present, it is not entirely clear whether this will be sufficient to persuade the bulk of the GPs:

> *"Today there is a high workload among the GPs and, therefore, they are terrified of implementing something new that makes things worse, but they lean toward being positive. I tell them: 'we cannot force you, we will have to tempt you. This solution must be better than what you have and the economy must not worsen" (Director-3)*

A diverse user community

From early on, extensive user participation and top management anchoring in the line organizations have been identified as crucial to the success of the program. They are necessary to create ownership of Epic as well as to ensure a well-working functionality. This point was underscored by one of the managers who pointed out that they had involved 400 clinicians from the entire healthcare service in Central Norway, including small and large municipalities as well as hospitals. Through 101 workshops these clinicians described what was good about the current ICT systems, their current challenges and what was missing. The outcome of these workshops became the basis for the requirements specification, which included 4000 specific requirements. In addition to clarifying the functional requirements, user participation is also intended to ensure the legitimacy of the new system:

> *"We need to have a plan for the implementation in such a way that all categories of personnel experience that they own the solution" (Director-4).*

Achieving buy-in from all categories of personnel is a challenge because several of the stakeholder groups have quite different needs in relation to the system. For instance, the required functionality for the municipalities is just a fraction of the total functionality. For this reason, the user representatives from the municipalities are aware that it will take some effort to ensure that their perspective is maintained:

> *“Even though Trondheim municipality owns part of the program, the main work is to procure an EPR for Central Norway [meaning the hospitals]. We, therefore, feel that we must ensure that the municipalities are taken into account” (Director-2).*
>
> *“As a municipality representative, I feel that the hospitals are dependent on our participation and they must give us ’space’ for this. On our part, we must establish legitimacy in the municipal sector for the program” (Director-2).*

Users as configurators

According to Epic policy, key users (and not the vendor) will be responsible for configuring the system. One of the managers put it this way:

> *"You are actually building this system yourself. Its configurability enables you to set up and decide a lot of things" (Director-5)*

If successful, this approach is an efficient way of achieving working functionality as well as reducing dependence on the vendor. One of the managers remarked that this approach was very different from the systems development processes they had previously been involved in:

> *"This represents a completely different division of responsibility between us and the vendor [than what is traditionally the case]. Until now, we have produced a requirements specification and sent it to a vendor who has developed it. This will occur to a much smaller extent because this is a very configurable system" (Director-5)*

To be able to do the configuration themselves a group of key users will have to be formed and trained. In Epic terminology, these clinicians are called “physician builders” and "clinical builders". They will become responsible for configuring the layout of the system, its information flows, and its support of workflows. During the configuration of the initial Epic setup the physician builders will work together with Epic personnel. In a subsequent regional organization the physician builders will continue to work on optimizing and streamlining work processes. To prepare for this task, the physician builders will attend a six-week training course in the US and will subsequently work full-time as physician builders in Central Norway. They will constitute the core team with respect to effecting changes in the system in the foreseeable future. In a recent implementation of Epic at twelve hospitals in Denmark in 2016-2017, there is now around 70 physician builders. The other group, the so-called clinical builders, will have this as a part-time job in combination with their full-time work as clinicians in their respective healthcare practices. The role of clinical builder is to ensure effective communication between the clinical line organization and those who configure the system.

A user-led decision process with tight deadlines

After signing the contract in March 2019, there will be a 2-year preparation phase including development, recruitment and training of physician builders and some configuration. In 2021, the actual implementation will be initiated and will according to the Epic implementation strategy be accomplished in a period of 2 months. This makes it a tightly run project as argued by one of the managers:

> *"They have a very rigid and tight project plan. They have the philosophy of: let's just get the solution up and running and let's build the capability in the organization to understand the solution and its possibilities" (Director-5)*

It is imperative that the customer has allocated resources for participating in this process and that the allocated clinicians have the competences and decision-making power to make decisions about what the configured system shall look like. The compressed time schedule necessitates a formal decision-making structure. According to the Epic implementation strategy, decisions must typically be made within a 10-day deadline. If the customer fails to meet one of these deadlines, Epic will set up the system with a default functionality for the area in question (so-called foundation functionality):

> *"Now we are in the process of establishing a decision structure (...) that is, involve people from the line organizations who can contribute to responding to all the questions that need to be responded to on a very short notice [10 days]. Epic will probably raise something like 8000-12000 questions when they start the implementation" (Director-1).*

The regional strategy for establishing this decision structure involves relying on (and extending) existing regional networks within different clinical specialties. For instance, within the area of cardiology there is a network of 40-60 experts. Each network will constitute the formal decision structure for its disciplinary field. The networks will be led by a clinical authority from St. Olavs hospital.

The formal decision structure also reflects that it will be impossible to involve all the future users of the system in the implementation process, partly due to the sheer number of people but also because the day-to-day operation of the healthcare services must be sustained. Thus, the management has to strike a balance between participation and decision capability:

> *"[we] need to ensure sufficient participation of health personnel of all categories without turning it into a general assembly, because we will not achieve consensus among the 44000 healthcare workers in Central Norway" (Director-4).*

Responsibility for the final product

The implementation strategy entails that the system is to a large extent configured by its users. As a consequence, the current draft version of the contract stipulates that it is the customer who is responsible for major parts of the resulting product. This issue is a cause of concern among the interviewed Health Platform managers:

> *"I am very skeptical that Epic transfers all the responsibility for delayed delivery or non-delivery to us as customer, while they have very little responsibility" (Director-1).*

It is a key point for the Health Platform program to negotiate the division of responsibility for the product between the customer Health Platform and the vendor Epic and to stipulate this issue clearly in the contract. Particularly, it is important for the Health Platform program to have the option of terminating the contract if the solution is not deemed acceptable.

Concluding discussion

Large-scale suite systems such as Epic require considerable configuration before they are ready for use in any specific healthcare setting. This makes user participation essential but at the same time quite different from user participation in bottom-up, and normally smaller-scale, software projects. In this study we focus on differences in the preparations for EPR implementation; the post-preparation stages of the process will see further differences in the conditions for user participation. We point to four differences in particular.

First, the vision of a complete solution for the whole healthcare service in Central Norway serves as a means to mobilize users and resources (Borup, Brown, Konrad, & Lente, 2006; Swanson & Ramiller, 1997). User representatives and future users are attracted to the Health Platform program because they want to take part in the process of changing healthcare services in Central Norway at a grand scale. This is well illustrated when Director-1 argues that it is the potential for a transformed healthcare service that really is the motivating factor for participating in the program. The overall vision also allows for flexibility in the interpretation of the end result in order to attract stakeholders with different needs (Swanson & Ramiller, 1997). The vision may then serve to mobilize user groups for whom participation is optional (e.g. the municipalities) or the immediate benefit is not always obvious (e.g. the GPs).

Second, the users' involvement consists to a larger extent of responding to opportunities provided by the vendor. In bottom-up development the users have a primary role in specifying requirements to the vendor; in the Norwegian preparations for implementing Epic a central user task will be to respond to queries from Epic. Otherwise the system will be delivered with preexisting default functionality. We are not claiming that requirements specification is no longer important but that its main role is in vendor selection. After the vendor has been selected the preparations for implementing the system are strongly shaped by the product already available from the vendor, including its configuration possibilities. In this process the requirements specification may face considerable competition and initial requirements may be revised on the basis of descriptions and demonstrations of the vendor's suite system (Finkelstein, Spanoudakis, & Ryan, 1996, p. 1). Consequently, it is not only the resulting system that is being shaped by the product, but also the user base that increasingly is being homogenized within the boundary of what the system can offer (Pollock, Williams, & Adderio, 2007).

Third, the customer needs a decision structure that can withstand the pressure from a vendor that already has default functionality available. The presence of default functionality means that the vendor is ready to deliver quickly; the temporal pressure is consistently on the customer. The vendor may even see an interest in keeping the customer under a temporal pressure that makes it difficult to formulate coherent requests that deviate substantially from the default. At the same time, the customer organization needs to obtain buy-in from its users, who will likely be concerned about a plethora of local particulars and have little patience for default functionality that does not meet their needs. While the Health Platform program is well-aware of this tension, there is no easy fix (Fleron, Rasmussen, Simonsen, & Hertzum, 2012).

Fourth, many configuration tasks are, fully or partly, shifted onto the physician builders. An important upside of this shift is that the customer gets improved possibilities for evolving the system after go-live. Such possibilities are central to large-scale EPR systems, which have a long operational lifetime (Pollock & Williams, 2008, p. 83). However, the physician builders' considerable involvement in configuring the system is also the basis for the vendor's stipulation that the customer should be contractually responsible for major parts of the resulting system. This stipulation is a very clear indication that the users' role in the process has changed compared to traditional software projects.

At present, it is too early to say anything about how user participation will play out in the long run, for instance how the expert networks will manage their formal decision power in between the vendor and the users they represent, whether the configuration facilities will enable the physician builders to make robust functionality, and to what extent the users will be satisfied with their role in the implementation process and with the system that results from it. It is, however, predictable that the scope and speed of the Health Platform program will necessitate extensive mutual negotiations among the various user groups and other stakeholders, for example to clarify functionality for supporting standardized patient pathways that span multiple clinical practices.

References

Borup, M., Brown, N., Konrad, K., & Lente, H. Van. (2006). Technology Analysis & Strategic Management The sociology of expectations in science and technology. *Technology Analysis & Strategic Management*, *18*(April 2012), 37–41.

Cockburn, A. (2007). *Agile software development: The cooperative game* (2nd ed). Upper Saddle River, NJ: Addison-Wesley.

Finkelstein, A., Spanoudakis, G., & Ryan, M. (1996). Software package requirements and procurement. In *Proceedings of the 8th International Workshop on Software Specification and Design* (pp. 1–7). Schloss Velen, Germany, London: IEEE Computer Society Press.

Fleron, B., Rasmussen, R., Simonsen, J., & Hertzum, M. (2012). User participation in implementation. In K. Halskov, O. S. Iversen, M. Büscher, J. Simonsen, & K. Bødker (Eds.), *PDC2012: Proceedings of the Twelfth Conference on Participatory Design (Vol. 2, pp. 61-64)* (p. 61). New York: ACM Press.

Hanseth, O., & Lyytinen, K. (2010). Design theory for dynamic complexity in information infrastructures: the case of building internet. *Journal of Information Technology*, *25*(1), 1–19.

Hertzum, M., & Simonsen, J. (2019). Configuring information systems and work practices for each other: What competences are needed locally? *International Journal of Human Computer Studies*, *122*(September 2018), 242–255.

Howard, J. (2004). Toward Participatory Ecological Design of Technological Systems. *Design Issues*, *20*(3), 40–53.

Johannessen, L. K., & Ellingsen, G. (2012). Lightweight Design Methods in Integrated Practices Liv Karen Johannessen ,. *Design Issues*, *28*(3), 22–33.

Klein, H. K., & Myers, M. D. (1999). A Set of Principles for Conducting and Evaluating Interpretive Field Studies in Information Systems. *MIS Quarterly*, *23*(1), 67–94.

Markus, L. M., & Mao, J.-Y. (2004). Participation in Development and Implementation — Updating An Old , Tired Concept for Today ' s IS. *Journal of the Association for Information Systems*, *5*(11–12), 514–544.

Pollock, N., & Williams, R. (2008). *Software and Organisations* (Vol. 20085774). Routledge.

Pollock, N., Williams, R., & Adderio, L. D. (2007). Global Software and its Provenance : Generification Work in the Production of Organizational Software Packages. *Social Studies Of Science*, *2*(April), 254–280.

Silsand, L., & Ellingsen, G. (2014). Generification by Translation : Designing Generic Systems in Context of the Local. *Journal of the Association for Information Systems*, *15*(April 2014), 177–196.

Star, S. L., & Ruhleder, K. (1996). Steps Toward an Ecology of Infrastructure : Design and Access for Large Information Spaces. *Information Systems Research*, *7*(1).

Swanson, B. E., & Ramiller, N. C. (1997). The Organizing Vision in Information Systems Innovation. *Organization Science*, *8*(5), 458–474.

Walsham, G. (1995). Interpretive case studies in IS research: nature and method. *European Journal of Information Systems*, *4*(2), 74–81.

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Adaptation of Clinical Information Infrastructures by and for Users

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Abstract. This paper reports work-in-progress, investigating user-driven adaptation of a large complex EHR system in two Danish regions. It focuses on the experiences of so-called 'physician builders,' tasked with adapting the system, and identifies five issues and challenges that are of particular concern to the builders. Finally, it discusses how working as a builder can be seen as 'voluntary work'.

Introduction

Electronic Health Record (EHR) systems are commonly considered the backbone of hospital IT infrastructure (Bansler et al, 2016). While early adopters of EHR systems developed their own software in-house, medical centers and hospital systems today usually prefer to rely on generic software packages from large software vendors such as EPIC and Cerner. These packages are produced to meet the perceived needs of a particular sector, e.g. large hospitals, and will, of course, not always meet the specific needs of the individual customer. They have, so to speak, a 'one size fits all' set of generic features. However, they are usually also highly configurable and thus able to provide flexible and adaptable solutions to a wide range of organizational needs (Bansler & Havn, 1994).

Their organizational implementation and use will, therefore, necessarily entail a mutual adaption of technology and organization. It is important to emphasize that this is not a onetime activity, but an ongoing process of technological innovation and organizational transformation. New versions of the software package will be issued at regular intervals and the needs of users will develop over time, both as a result of organizational learning and because the context of the organization evolves.

Despite the importance of this mutual adaptation process, it has so far not received the attention it merits. This paper aims to begin remedying this situation by reporting on an ongoing case study of user-driven adaptation of a large EHR system. The study focuses on the post-implementation phase and seeks to understand the role and experience of end users, e.g. physicians and nurses, who have been trained to configure the software to local needs.

The case presented here concerns the ongoing user-driven adaptation of a large, complex EHR system (referred to as the *Health Platform*) from the American vendor Epic in two large hospital systems in Denmark. The system serves 17 hospitals with a total of about 44.000 users (e.g., physicians, nurses, radiologists, and medical secretaries).

The main takeaway from the study is that user-driven adaptation is not simply a technical issue, but a site of organizational and professional politics.

The Study

This section briefly describes the Health Platform, the organization of the user-driven adaptation program, and the methods used for data collection in the research project.

The Health Platform

Denmark has a single payer tax supported health care system. The country is divided into five regions, each governed by a council with popularly elected members. The regions' main responsibility is health care and they own and operate the public hospitals within their respective geographical areas (Danish Regions, 2012; Kierkegaard, 2013).

In 2013, the Capital Region and the Zealand Region jointly decided to replace their existing portfolio of health information systems with an integrated EHR system from Epic. The system was configured to meet the requirements of the Danish health care system and rolled out across all 17 hospitals in the two regions from May 2016 to December 2017. The roll-out was fraught with technical and organizational difficulties and it drew heavy criticism from physicians as well as independent health IT experts and the Danish Public Accounts Committee (Rigsrevisionen, 2017). At the time of writing, there is still widespread dissatisfaction with the new system among physicians and other health professionals. According to a recent user satisfaction survey from the Capital Region, 61% of the physicians disagree or strongly disagree with the statement that "the Health Platform supports my work" while only 14% agree or strongly agree with the statement (Capital Region, 2018).

Epic's software package can be configured at three levels: system-wide (global), local, and individual. System-wide configuration requires considerable experience and expertise and is carried out by specialists in the Capital Region's IT department, often in close collaboration with Epic. At the local level, the scope of configuration is more limited and it can be carried out by so-called 'physician builders', i.e., physicians (or other healthcare professionals) who have attended Epic classes on how to create and configure various documentation and ordering tools, templates and reports (*builds* as they are called in the jargon of Epic) so that they better match the needs and workflows of a specific medical specialty or hospital department. Finally, individual users can 'personalize' the set-up of their user interface and create templates, macros and short-cuts.

The current paper focuses solely on the local configuration carried out by physician builders.

The Physician Builder Program

The two regions have established a common physician builder program. At the end of 2018 the program comprised approximately 50 trained and certified builders. Most of the builders are physicians, but there are also some nurses in the program. Builders are affiliated with a hospital department and they typically spend between 10% and 50% of their time on tasks related to the local configuration of the EHR system. The rest of their time is spent on their normal duties as a physician or a nurse in the department.

Depending on its size, each medical specialty, e.g. cardiology, oncology, and psychiatry, has been allocated one or two builders responsible for configuring the EHR to the specialties' specific needs and requirements. Instead of configuring the system at the level of the individual hospital department, the intention is to reconfigure the system at the level of the specialty. This means, for instance, that all cardiology departments in the two regions should, in principle, use identical system configurations. The decision to carry out adaptations at the specialty level instead of the department level is motivated by top management's longtime desire to standardize clinical processes and documentation practices across departments, hospitals and even regions.

Responsibility for providing technical assistance to the builders lies with the Capital Region's IT department (the hospitals do not have their own IT departments). To assist the builders, a new role as *mentor* was created in the IT department. A mentor is a health professional, typically a nurse, who has been trained and certified by Epic. Each mentor specializes in specific system areas and tools, which means that builders often have to interact with several different mentors.

Furthermore, each specialty has appointed a so-called *leading medical expert* who is responsible for reviewing proposed new builds as well as changes to existing builds.

Overall responsibility for the builder program lies with a board of deputy directors from each of the 17 hospitals.

Data Collection

Data collection began in September 2018 and will continue at least until the end of 2019. It is based on both primary and secondary methods. Primary data collection involves meetings and interviews with physician builders, chief physicians, information architects, IT specialists, IT managers, and senior managers. So far, I have interviewed 13 builders (12 physicians and 1 nurse), an information architect, 2 support staff and a middle manager in the IT department, and a senior manager. In addition, I have had formal and informal meetings with numerous physicians, chief physicians, senior managers, and administrators.

In terms of secondary data, I have collected and analyzed a multitude of documents including, e.g., policy documents, minutes from council meetings, organizational charts, and user satisfaction surveys from the two regions as well as Epic's teaching material.

The builders' experience

This section presents and discusses five issues and challenges that are of particular concern to the builders. Before doing so, I will briefly consider the question of why they became builders in the first place.

Reasons for joining the builder program

There are many different and often quite personal reasons for becoming a builder. About half of the interviewees joined the program because their superiors asked them or talked them into doing it. As one of them humorously put it, "I was forced to volunteer." The other half applied for the position as builder on their own initiative, for different positive or negative reasons: an interest in IT; a "love of systems;" an interest in "making things work" and helping colleagues; a desire to participate and influence the process; and a wish to spend less time on patient care.

Thus, the builders interviewed are a diverse group with quite different motivations for joining the program. Regardless, they all find their role as builders more or less frustrating.

Uncertain career prospects

Some of the younger builders are particularly worried that being a builder could be detrimental to their career, because it does not count towards career advancement in the same way as, for instance, research and clinical experience: "It is like throwing your career in the deep freezer" as one of them expressed her concern. She further speculated that this has led, or could lead, to a situation where it is impossible to attract first-rate physicians to be builders.

Time pressure

The original idea was that about 50% of the builders' time should be allocated to their duties as a builder, but in reality, it varies enormously how much time the builders actually have. Some have just a few days per month while others have 20%, 50% or, in a single case, even 100% of their time. There are two common reasons why many builders have less time for the task than planned: The host departments are struggling to manage their clinical workload with the available staff and have difficulty doing so when physicians serve as builders. Also, the builders do not want to spend too much time on this task, because they are afraid this could hurt their career (see previous section). Not surprisingly, the builders who have less than half of their time officially allocated to their duties as builder complain about lack of time to do the job.

Unclear role expectations

Several builders complain that role expectations are unclear or contradictory and that there are no clear lines of authority. As mentioned above, each builder is affiliated with and paid by a particular hospital department, but at the same time s/he is supposed to serve the needs and requirements of all departments within the specialty. This, of course, begs the question for whom is the builder working. Is it the host department, the hospital, the region, the IT department, or the Health Platform? As one of the builders remarks:

> "But, in principle, one could ask, why should one department pay for work done for another department?"

There is no consensus on this and the lack of clarity creates tensions and confusion amongst the builders and within the program as a whole. In some cases, builders work for an entire specialty, but in other cases, they have been told to solely work for their own department:

> "And this is primarily because either the hospital directors or the particular department managers have monopolized the physician builder and told them, we want you to only build for us. This is completely… At best, they have misunderstood the whole concept, or they have deliberately chosen to ignore the decision about how things should be done. Because there is only *one* physician builder, or in some cases two, for each specialty. That is, you actually

> have the responsibility for contributing to the whole specialty and not just to your own hospital."

Strained relationship with the IT department

Almost all of the builders are very dissatisfied with the way the IT department treats them. The builders' dissatisfaction is rooted in what they perceive as the IT department's lack of responsiveness, competency, and mutual respect.

Firstly, virtually all builders complain that it is extremely difficult to get in contact with the mentors in the IT department. One builder, for instance, describes the situation as a communicative "Berlin wall" between the builders and the mentors. It is not possible to call or email the mentors directly. Instead, the builders have to write to a generic email-address without knowing who will read their message or when they will get a response:

> "[You can] send a mail to an anonymous email address (…) and then you might get an answer after a couple of days perhaps. And it might be from someone named Marianne, but Marianne's surname and telephone number is not listed. And this is *infuriating*. It feels as if I'm being treated as a preschooler, who doesn't know how to behave herself."

Secondly, builders generally find that they get little help or support from the mentors, because their technical skills and competencies are too limited. As one of the more experienced builders explains:

> "If I have some problems or there is something I can't figure out [how to do], then they [the mentors] can't figure it out either. They know as little as I do. That's how it is. They are not stupid or incompetent or recalcitrant, they just don't know more than I do."

Thirdly, many builders often feel that the mentors treat them as adversaries rather than collaborators, and that the IT department wants to control them and keep them in a subordinate position:

> "But I think they fear that we'll become too proficient out here. (…) So, if we overtake them, because we are becoming more and more sophisticated and competent, then they are afraid that they can't control it. And this is why we are being held back."

It is important to note that the builders' criticism is not directed personally at the mentors, who they generally find friendly and helpful, but at the way the IT department manages the builder program.

Overly bureaucratic approval procedures

Before a new or revised build can go into production, it must be described in detail in an elaborate Excel sheet, reviewed by the relevant leading medical experts and, finally, approved by a mentor. The builders readily accept the need for some level of quality assurance, but find the approval procedure to be overly bureaucratic, lengthy and time consuming. As one builder puts it:

> "It is a process so cumbersome, you can't imagine. It is super easy to do [the technical part], but the bureaucracy we have to go through, it is… and it is so undynamic."

Another builder jokingly compared the process to that of obtaining permission to build within a conservation area (which is virtually impossible in Denmark):

> "It is easier to get permission to build a garage on a protected plot of land than it is to get approval to go on with a new build."

Some builders implied that the strict approval procedures are rooted in a general distrust in the builders' intentions and abilities:

> "They [the mentors] are supposed to keep an eye on us physician builders. (…) It is as if they are afraid that we're trying to cut corners when it comes to standardization."

Standardization versus local adaptation

As for the feasibility of making adaptations at the specialty level, instead of the department level, opinions are divided. A few of the builders find this to be quite straightforward, but most think it is impractical, because there are, often small, but essential variations in clinical processes across departments and hospitals, even though they belong to the same specialty. The variations are, for instance, due to differences in hospital organization, staff composition and competencies, building layout and facilities, and available medical technology.

One of the builders explained why he believes it is a huge mistake to target the specialty level instead of the department level:

> "I think one of the biggest mistakes they [the managers of the Health Platform] have done in relation to get this building program up and running is that they have said we want… The politicians have said, we want patients to get the same treatment at the surgical department in Hillerød, as they get in Herlev and Hvidovre and Bispebjerg and so on. And the underlying idea is good enough. (…) [But in practice,] the geography is different, things are not done in exactly the same order – even if the end result is the same. And this means that you have to build it [i.e., configure the system] in slightly different ways at the different hospitals."

Another builder argues that experience has repeatedly shown that this kind of IT-driven standardization is futile:

> "you can't come with an IT system and – we've seen it a hundred of times – and standardize [the clinical processes]. You can't do it."

According to a third builder: "this is simply… this is just *so* stupid."

Further, it is worth mentioning that many builders are disappointed with what they have been able to achieve so far, despite their best intentions and efforts. They feel constrained by the red tape and bureaucracy imposed on them and by the lack of support from the IT department. They want more autonomy and control over what they do and how they do it, and they believe this would be much more productive.

Discussion and conclusion

In trying to understand the significance of the builders' experiences, it might be useful to view the physician builder program as a kind of 'volunteer organization' (Wilderom & Miner, 1991), in the sense that the success of the program hangs on attracting, engaging and retaining a sufficient number of experienced and dedicated physicians as builders. In this perspective, the builders are viewed as 'volunteers,' that is, as someone who voluntarily undertakes a service or duty, but can also easily opt-out if they want to.

The builders act as 'technology-use mediators' (Bansler & Havn, 2006; Orlikowski et al, 1995) and 'bridge-builders' between the IT specialists on the one hand and the physicians, nurses and other healthcare professionals on the other hand. This requires that they not only have intimate knowledge of clinical work processes and requirements, but also that they are highly respected by their colleagues. In other words, it is essential to attract the right people to join the program and to maintain their interest in serving as mediators.

Seen in this light, it is quite alarming that the builders are so frustrated with the way the program is designed and run. Consequently, it is imperative to understand their motivations to volunteer, develop suitable incentives to foster participation, and finally tackle the identified issues and challenges.

Physicians' motivations for joining the program are multifaceted and complex, as indicated above. There is not space to go into detail here, but it should be noted that there is an extensive literature on motivations for volunteering and that it is important to recognize that volunteer work is undertaken not just for the pursuit of self-interest, such as career advancement, but also for altruistic and relational motives (Lopes, 2011; Prouteau & Wolff, 2008). Hence, it is not a simple and straightforward task to design appropriate measures and incentives to attract and retain experienced builders.

It is, however, obvious that management must address the three (interrelated) issues about uncertain career prospects, time pressure, and unclear role expectations. Although these issues can, in principle, be resolved through a revision of task and incentive structures, it requires paying attention to the builders' concerns.

Moreover, the findings also raise some more difficult and thorny issues rooted in basic organizational tensions that must be resolved, or at least managed, if the program is going to succeed. At least three such tensions can be identified: (1) the tension between the builders and the IT department, (2) the tension between the perceived organizational need for coordination and control and the builders' wish for autonomy and empowerment, and (3) the tension between the perceived need for system-wide standardization and the perceived need for adaptation to local needs and requirements.

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References

Bansler, J. P., & Havn, E. C. (1994). Information systems development with generic systems. In *Proceedings of the European Conference on Information Systems* (*ECIS),* May 30-31, Nijenrode, The Netherlands, 707-718.

Bansler, J.P. & Havn, E. (2006). Sensemaking in technology-use mediation: Adapting groupware technology in organizations. *Computer Supported Cooperative Work (CSCW)*, *15*(1), 55-91.

Bansler, J. P., Havn, E. C., Schmidt, K., Mønsted, T., Petersen, H. H., & Svendsen, J. H. (2016). Cooperative epistemic work in medical practice: An analysis of physicians' clinical notes. *Computer Supported Cooperative Work (CSCW)*, *25*(6), 503-546.

Capital Region (2018). *Stadig blandet tilfredshed med Sundhedsplatformen* (in Danish). https://www.regionh.dk/presse-og-nyt/pressemeddelelser-og-nyheder/Sider/Stadig-blandet-tilfredshed-med-Sundhedsplatformen.aspx (accessed January 9, 2019).

Danish Regions (2012). *The Danish Regions in Brief,* Copenhagen, Denmark.

Kierkegaard, P. (2013). eHealth in Denmark: a case study. *Journal of medical systems*, *37*(6), 9991.

Lopes, H. (2011). Why do people work? Individual wants versus common goods. *Journal of Economic Issues*, *45*(1), 57-74.

Orlikowski, W.J., J. Yates, K. Okamura and M. Fujimoto (1995): Shaping Electronic Communication: The Metastructuring of Technology in the Context of Use. Organization Science, vol. 6, no. 4, 423–444.

Rigsrevisionen (2017). *Beretning om Sundhedsplatformen* (in Danish). Folketinget, Copenhagen, Denmark.

Prouteau, L., & Wolff, F. C. (2008). On the relational motive for volunteer work. *Journal of Economic Psychology*, *29*(3), 314-335.

Wilderom, C. P., & Miner, J. B. (1991). Defining voluntary groups and agencies within organization science. *Organization Science*, *2*(4), 366-378.

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IT Infrastructure for Workplace Health Promotion: Between self-management and organisational coaching rhetorics

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Abstract. As Workplace Health Promotion (WHP) initiatives are gaining relevance in welfare programmes, employers are becoming more interested in ensuring that workers, particularly those at risk, can benefit from guidance in following lifestyle intervention that can reduce extra costs for the companies who employ them. This opens new possibilities for dedicated health infrastructures in the workplace enabling health information sharing and connecting various stakeholders, such as doctors, employees, employers, data protection officers, designers. In this paper we describe DMCoach+, a platform aimed at supporting healthy lifestyles at work- Overall a group of 120 users are followed by a physician as coach for six months assisting them getting aware of their basic parameters (heart rate, BMI, waistline, activity time) and, through a gamified experience, improve their condition. The aim of this paper is to provide a preliminary discussion to understand how stakeholders and users across three pilots (two in Italy and one in the Netherlands) have planned the use of the app DMCoach+, which was provided by their work organisations as part of a more widespread health welfare infrastructure. The paper features a preliminary discussion about the main findings about the stakeholder's workaround to shape the infrastructure designed for people and organisations that have voluntarily participated in a pilot to prevent illness in the workplace.

Keywords: *organisation studies, workplace health promotion, case study, organisational welfare, safety*

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Introduction

In recent years several labels – such as Workplace Wellness, Wellbeing and Welfare – have been coined to describe new challenges for organisations to play a key role in health promotion. While all these labels all refer to wellbeing in organisations, Workplace Promotion Program (WHP) has become to most used label. A general accepted definition about this label is: “A healthy workplace is one in which workers and managers collaborate to use a continual improvement process to protect and promote the health, safety and well-being of all workers and the sustainability of the workplace” (WHO 1995).

Several campaigns have been addressed at employees avoiding unhealthy behaviour, to reduce unproductive time and to follow personal objectives in training and physical activities (Goetzel 2019) also employing self-monitoring devices to take care of one’s health condition. There is growing concern about the consequences of unhealthy behaviour. Smoking, alcohol, dietary habits, and sedentary life, associated with some medical parameters (e.g. cholesterol, BMI, blood pressure) are becoming part of the social competences to define an unhealthy lifestyle and are represented as part of a predictive framework of future illness. On the one hand we can consider a situation where laypeople are become more competent in healthy habits, and on the other hand organisations are dealing with the structural changes arising from such a workforce.

Some characteristics of the workforce in Western societies show that working life is being prolonged by at least ten years compared with the recent baby boomer generation of workers. As a consequence, workplaces are facing an increase in the average age of employees. Several studies have shown that the aging workforce and prolonged careers pose a significant challenge to employers when it comes to maintaining a healthy workforce (Mooney 2012; WHO 1995). Employees’ wellbeing has become especially important in those people who experience various parameters (such as body mass index) out of the healthy range provided by national and international guidelines (Abarca-Gómez et al. 2017).

Such transformations of the workforce have caused two other main problems. From one side, Western countries are facing strong restrictions in health budgeting. Economic crises and the increasing costs of health systems are pushing governments to find other strategies to keep their populations healthy and reducing access to health structures. On the other side, Western populations are increasing awareness of key information regarding health conditions. The long history of personal health management shows that people want to be aware of their health conditions and are asking for increased involvement in health decisions. While this does not mean that people's health conditions are getting better, it demonstrates that there is great potential in sustaining programmes aimed towards prevention of health problems (Arena et al. 2013).

Tighter health budgets and a public willingness to be informed about personal health supports the idea of promoting health and wellbeing in a setting wherein people spend the bigger part of their time: their workplaces. Many researches have evaluated several companies' prevention programmes that have been promoted in recent years to discover how to maintain a healthy population. Goetzel and colleagues (2019) have analysed the stock performance of such programmes, and despite a correlation between the company dimension and the presence of WHP programmes, many aspects need further investigation to understand the effective impact on individual health. Cultural and organisational contexts can affect results and there is presently little data from longitudinal studies. However, on closer examination of individuals' habits, the topic assumes increasing complexity. One of the complexities is represented by the voluntary nature of participation in the programmes and the sensitive impact of biometric information being shared with employers. To tackle these problems, companies are turning to the mobile technologies, and programmes often use self-tracking apps, wearables, and dashboards to encourage personal adhesion to a suggested programme. However, such programmes are dependent on different characteristic, such as mood, self-identification, citizenship, biopolitics, data practices and assemblages (Lupton 2014). Workers are not completely free in their workplaces, therefore involving them in WHP requires special attention to avoid misuse, discrimination and any labelling.

With this complexity in mind, we can consider the WHP programmes and the technologies used as a mediators between the employer and the employees in preventing health problems in the workplace (Piras et al. 2017).

The IT infrastructure in 'the middle' becomes a boundary object for the interpretative flexibility of the object itself and for all the arrangements that a similar technology needs to face (Star 2010). It is thus relevant to explore how the infrastructure is actually used by all actors involved. Furthermore, despite the best intentions of the employers, this kind of infrastructure is complex and multi-layered, connected to many organisational components like employees, designers, occupational physicians, HR offices, and other institutional actors (Dunkl 2017).

Our questions in response to the issues described above are: how can an organisation use its infrastructure to encourage employees to assume healthier behaviours in their lifestyle? What happens to the infrastructure if the effort must be supported by health parameters and continuous contact between employer and employee through the infrastructure?

DMCoach+ in the middle: the object, the boundaries, and the people

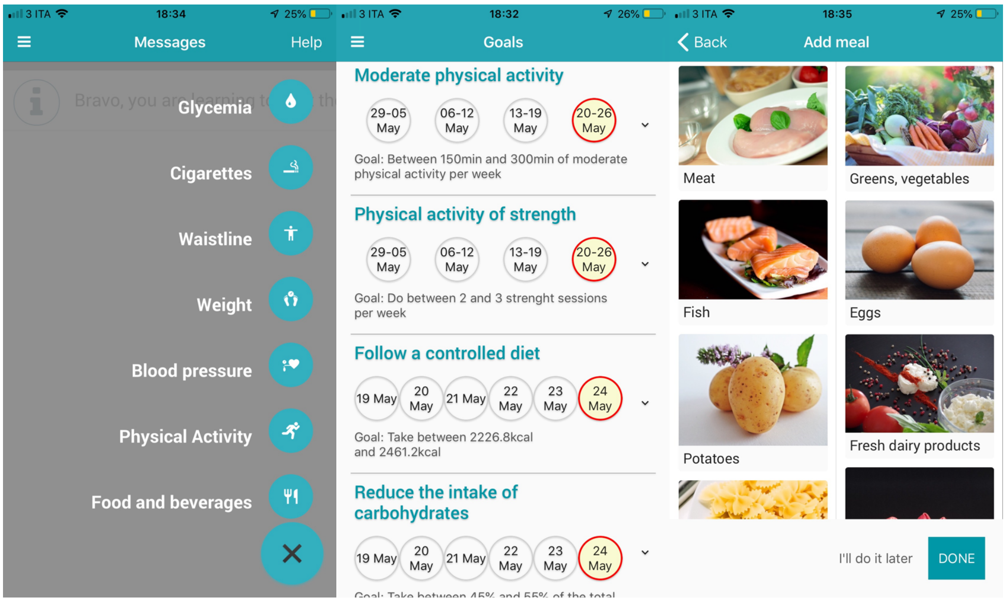
The study explores this topic following the trajectory of an app named DMCoach+ that was developed to help people with type-2 diabetes (T2DM), including those at risk of developing the condition. The app was supports mainly healthy nutrition, physical activity and weight loss as key factors to manage T2DM patients and reduce the risks of developing the condition in clinical settings. Literature suggests that technology-mediated interventions can be used as effective tools to improve adherence to prescribed treatment and to support patients in the self-management of their lifestyles, while disseminating diabetes prevention programmes (Lupton 2014, Kamar 2015, Goetzel et al. 2019). The app was evaluated through a one-year clinical trial in Italy (Ferron and Zancanaro 2018). More recently, the application was modified to be adapted to become a prevention tool to be used in a non-clinical setting, namely the workplace.

DMCoach+ is a platform to help to promote healthy lifestyles in the workplace driven by the occupational physicians. Physician cad remotely coach and monitor the employees and define a set of lifestyle and data tracking (self-monitoring) objectives for each employee/user. Employees are encouraged to adopt healthy habits also through motivational and personalised feedback in line with their attitudes and behaviour. DMCoach+ provides users with coaching that is automatic and contextualised to the personal profile (habits and lifestyles). Occupational physicians have the possibility of taking measures when necessary; they can change current goals or suggest others, and directly communicate with the employee about inappropriate behaviour that they have detected through the data collected by the app.

DMCoach+ includes a smartphone application for employee use and a web dashboard. The app gives the opportunity to track daily personal behaviors about nutrition, fitness and basic parameters. As in other apps for wellbeing , the interface has been designed to help user to have clear understanding of their vital parameters and a strong support in their goals behavior in changing life style.

The app includes some "games" to improve the performance in getting better about the physical control of the body through a virtual coach. Lifestyle objectives can take the following form: “Do at least <N> minutes of moderate physical activity every <i.e. week>”. Data tracking objectives can take the form: “Log your data related to <i.e. blood glucose> <N> times per <i.e. day>”. Ideally, these objectives will be discussed and agreed together with the employee during a medical appointment. Through the smartphone app, users can track some biometric data, such as weight and waistline measurements. Furthermore, employees are kept active through several specific data requests, reminders, motivational prompts and educational pills as appropriate to the situation.

Fig. 1 Three screen shot about the app



Goal: Between 150min and 300min of moderate physical activity per week

Goal: Do between 2 and 3 strenght sessions per week

Goal: Take between 2226.8kcal and 2461.2kcal

Goal: Take between 45% and 55% of the total

Users are profiled following the Transtheoretical Model of Behaviour Change (TTM) that suggests five different levels of motivation to change personal unhealthy habits – Centis et al. (2014) have reduced these levels to two groups: Not Ready to Change (NRC) and Ready to Change (RC).

Not Ready to Change:

- Pre-contemplation: the individual is not aware or interested in the consequences of her/his own behaviour and has no intention of changing it;
- Contemplation: the individual is aware of the consequences of her/his own harmful behaviour and is planning to change it in the near future.

Ready to Change

- Preparation: the individual is going to change her/his own behaviour and has made some efforts to do so;
- Action: the individual successfully changed her/his own behaviour for a short time;
- Maintenance: the individual has maintained the new healthy behaviour for at least six months.

The experimentation phase provided a six months program. Empoyees are assessed by team of health professionals such as physicians, psychologists, nurses to meet at the beginning of the experimentation. Based on some vital parameters, they give a complete evaluation about the objectives for each employee. The encounters lasted 20’ after an open meeting devoted to the recruiting. People at the meeting have to sign the Research Information Sheet, download the app and get all the help useful to get ready for the experimentation. During the experimentation employees are in contact with the physician who set month by month goals and games. At the end of the experimentation, not yet concluded, there will be an evaluation phase to analyze how the whole experimentation worked.

Preliminary findings

After one year of a preliminary clinical trial, now the experimentation phase is ongoing. In these two years of monitoring the app and the collection of the experiences about its use conducted through interviews, observation of meetings, and discussion with developers and stakeholders, about such subjects as user interface and design, health parameters, the doctor's duty, we can share the preliminary findings.

A first effect regards the health as "object". The stakeholders discussing details about the experimentation, have to deal with something that become a new topic in the relation with workers. This opened two different reaction. From one side health become a new field of negotiation between employees and the employer. This affect the idea that someone is at risk, and that this risk can affect the individual performance. An indirect effect of this regards the idea that many workers are doing something "dangerous" at the workplaces so the infrastructure shed light upon the life quality inside the company.

A second effect highlighted from the field is that the workers got a new vision of their heath, not just as individuals, but also as employees. Common practices about personal behavior like measuring vital parameters and keeping healthy habits, through the experimentation became part of the work experience. People, now, are allowed to give a look to the app during job time, chatting a little about goals and games with colleagues, asking for short answers from the health professionals.

A third effect is about the infrastructure itself. People consider it more than a simple "app" because it has been shared with the company which assure the support of a professional coaching. Yet, it seems that putting in the middle an infrastructure and some humans connected professionally to health domain, it become a trustworthy infrastructure, despite the real satisfaction about the requirements (Piras, Rossi and Miele 2018). Many times the app didn't match the expectation of people, but this doesn't affect the satisfaction of users. The infrastructure give the opportunity to the employees to be "seen" by someone relevant to the company.

These findings confirm others of several previous studies. The WHP infrastructures are promoted in a complex environment, usually through big companies, that provide programmes for prevention offered to the workforce (Roman and Blum 1988, Farnsworth 2004). Observations confirm how the infrastructure deals with complex 'translations' through a long process between HR offices, designers, occupational physicians and, less often, the employees or their representatives.

In this case the complexities relate to the sensitive information necessary to run the app and the 'coaching' functionality provided by the infrastructure. The word 'coach' is probably the most important wildcard of the infrastructure. To be a 'coach' is not a defined role in a technological setting, and general practitioners are not usually asked to act as coaches. However, this infrastructure allows emplyees/users and healthcare practitioners to be involved in a new way, and the companies using the app are supporting a new moral suasion strategy for their workforces. At the same time, employees/users are expected to be part of a complex process where they are expected to do a new 'job' for the benefit of the company and wider society.

Conclusions

This app project is pushing forward the common relationship between doctors and employees, organisations and workers, and, in some way eventually, their relatives. Qualitative research with users facing a lower level of illness – such as T2DM patients who therefore need constant control – confirms that both infrastructures and human presence play key roles in perception of the app.
When people face with health issues, they want to be a central net of their relationship network, even if this mean a new understanding of the relation with the company.

Some projects highlighted user preference for human interaction, despite the availability of the app (Mathiasen et al. 2017), while studies suggest paying closer attention to users' habits and providers' needs (Årsand et al. 2012, El-Gayar et al. 2013). The design of apps such as DMCoach+ need to consider that people want tools that provide an opportunity to become more knowledge-driven in their self-management when it comes to their personal health. Moreover, people are interested in increasing their visibility to health professionals to assume the 'value' of their individual stories. Unfortunately, as the DMCoach+ illustrates, such infrastructure is changing the network of relationships between actors. The apps are reconfiguring the network, transforming roles, expectations, belonging, and compliance. Following Hanseth and Monteiro (1997), from a sociological point of view – suggested for example by the actor-network approach – we can affirm that “granted that technological artefacts never fully determine patterns of use, the issue is really to what extent a specific artefact in a given context inscribes a certain behaviour. Analytically viewed, the strength of an inscription relies on three aspects: the size and complexity of the surrounding actor-network which is linked to the inscription, the degree to which it is aligned with this surrounding actor-network and the strength of the inscription on its own” (p.200). Apps for self-management, more than others, are pushing forward a new scenario among networks for health. They show how people are accepting an increasing diffusion of health networks made by both humans and non-humans, but employees still want a dominant position in this series of networks: they still want counsellors, health professionals, and personal goals, as our experimentation has shown. The coaching provided by several objects towards the people throughout all their life is accepted if it is seen as a way of being closer to the professional.

Creating the infrastructure for peoples’ health needs requires roles for people, for practices and for representation. Including the organisations and their workforce in such infrastructure reduces some complexities, as suggested by Hanseth and Monteiro, but will build something wholly new in which the ‘political fight’ prescribed by inscriptions of objects will continue.

References

Abarca-Gómez, L., Abdeen, Z. A., Hamid, Z. A., Abu-Rmeileh, N. M., Acosta-Cazares, B., Acuin, C., … Ezzati, M. (2017). Worldwide trends in body-mass index, underweight, overweight, and obesity from 1975 to 2016: a pooled analysis of 2416 population-based measurement studies in 128·9 million children, adolescents, and adults. *The Lancet*, *390*(10113), 2627–2642. https://doi.org/10.1016/S0140-6736(17)32129-3

Arena, R., Guazzi, M., Briggs, P. D., Cahalin, L. P., Myers, J., et. al. (2013). Promoting health and wellness in the workplace: a unique opportunity to establish primary and extended secondary cardiovascular risk reduction program’, in Mayo Clinic Proceedings, vol. 88, no. 6, pp. 605-617, Elsevier.

Dunkl, A., & Jiménez, P. (2017). Using smartphone-based applications (apps) in workplace health promotion: The opinion of German and Austrian leaders. *Health Informatics Journal*, *23*(1), 44–55. https://doi.org/10.1177/1460458215623077

Ferron, M & Zancanaro, M (2018). Technical evaluation of DMCoach solution. DMCoach: UX and acceptance evaluation of a mobile application for patients with diabetes mellitus type 2. FBK. Trento.

Goetzel, R. Z., Fabius, R., Roemer, E. C., Kent, K. B., Berko, J., Head, M. A., & Henke, R. M. (2019). The Stock Performance of American Companies Investing in a Culture of Health. *American Journal of Health Promotion*, 089011711882481 8. https://doi.org/10.1177/0890117118824818

Hanseth, O., & Monteiro, E. (1997). Inscribing behaviour in information infrastructure standards. *Accounting, Management and Information Technologies*, *7*(4), 183–211.

Kamar, M. (2015). Smartphone Application for Self Blood Glucose Monitoring & Disease Management-A Case Report. Paper presented at the Proceedings of the 5th EAI International Conference on Wireless Mobile Communication and Healthcare.

Leigh Star S (2010) This is Not a Boundary Object: Reflections on the Origin of a Concept. *Science, Technology, & Human Values* 35(5): 601–617. DOI: 10.1177/0162243910377624.

Lupton, D. (2014). *Self-Tracking Modes: Reflexive Self-Monitoring and Data Practices* (SSRN Scholarly Paper No. ID 2483549). Retrieved from Social Science Research Network website: https://papers.ssrn.com/abstract=2483549

Mooney G. (2012). Neoliberalism is bad for our health. International Journal of Health Services, 42, 3: 383-401).

Piras, E. M., Rossi, P., & Miele, F. (2018). La promozione della salute come forma di welfare aziendale: la co-costruzione di un'iniziativa di WHP tra prevenzione primaria e processi di simbolizzazione. *Sociologia del lavoro* 150: 202-217.

Piras, E.M., Miele, F., Fornasini, S. (2017). Infrastructuring primary prevention outside healthcare institutions: the governance of a workplace Health Promotion program. 6th International Workshop on Infrastructures for Healthcare: Infrastructures for governance, quality improvement and service efficiency.

World Health Organization (1995). Global strategy on occupational health for all: the way to health at work, recommendation of the Second Meeting of the WHO Collaborating Centres in Occupational Health, 11-14 October 1994, Beijing, China.

Malm-Nicolaisen, Kristian, and Ellingsen, Gunnar (2019): The role of clinical leadership in the implementation of large-scale Electronic Health Records in hospitals. 7th International Conference on Infrastructures in Healthcare, DOI: 10.18420/ihc2019_003

The role of clinical leadership in the implementation of large-scale Electronic Health Records in hospitals

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Abstract. Background: Many Information and Communication Technology (ICT) implementations fail to deliver described effects and organizational goals. Empirical evidence suggests that organizational and socio-technical challenges are frequently overlooked. Objective: The proposed PhD research project aims to develop theoretically informed guidelines and strategies for how clinical managers should be positioned and engaged in ICT implementation, change management and work practice adaptation. Methods: This qualitative study will employ an interpretive approach with data capturing at three different organizational levels: Top management, mid-level clinical management, clinicians. Empiracally we will use the implementation of a structured Electronic Health Record in Norwegian hospitals as case. Conclusion: A better understanding of how ICT portfolios can be governed, and how and too what degree clinical managers should be involved in an accusation and implementation process can improve outcomes and organizational effects of clinical ICT implementations. The proposed research project will study the implementation of large-scale clinical ICT, with the aim of identifying and describing strategies for what role and involvement clinical managers should have in both development, implementation and governance in order to facilitate the needed change management within own organization.

Introduction

Healthcare is a sector represented by great complexity, while it at the same time requires efficient coordination and communication for both patient and provider benefits (Moreno-Conde et al., 2015). Digitalization of work processes and the use of Information and Communication Technology (ICT) such as the Electronic Health Record (EHR) is expected to deal with some of these challenges (The Norwegian Directorate for e-health, 2018). In addition, the implementation of structured data formats and use of clinical standards for information modelling in clinical information systems (IS), is considered a key means towards organisational goals such as standardised patient pathways (Christensen & Ellingsen, 2013), clinical decision support (Silsand & Ellingsen, 2016), information interoperability and data exchange, standardisation of routines and practices, as well as safe treatment and care of patients (Fitzpatrick & Ellingsen, 2013). However, many large-scale ICT projects never live up to its ambitions, and the potential for increased quality and productivity remains largely unrealized, resulting in that many projects end up as outright failures (Øvretveit, Scott, Rundall, Shortell, & Brommels, 2007).

The many failures and problems suggest that organisational and socio-technical challenges are often overlooked (Boulus & Bjorn, 2010; Pollock & Williams, 2008). Frequently, new technology results in intended and unintended organisational consequences, which increases as both the number and complexity of the ICT portfolio is scaled up. The increasing scale of these projects also brings up another set of issues and concerns – that is, less focus on technical design issues and more focus on broader socio-technical complexity. Different user groups might have different and sometimes conflicting expectations for ICT, highlighting political tension about implementing new technology (Ulriksen, Pedersen, & Ellingsen, 2017).

Dealing with these challenges requires a thorough understanding of the organisation, a strategy for changing the organisation and not at least, a strategy for governing the ICT portfolio. These are crucial managerial tasks, also for clinical managers. They have to involve different types of users and have to provide necessary resources for the ICT projects. Still, without being able to govern the ICT portfolio effectively, it is very hard to achieve desired organisational effects. Traditionally many of the decisions related to ICT and implementation has been in the realm of ICT departments and the executive managerial level, while outside the comfort zone of most clinical managers (Øvretveit et al., 2007). Unfortunately, this has left managers in a largely passive role where they have been confined to approving the budget and endorsing major systems acquisitions. Only a handful take responsibility for driving ICT decisions within their organisation (Rosenmöller, 2013). This is also reflected in the ICT management research literature, which lacks conceptualisations of ICT; it is just referred to in very general terms such as "the ICT" (Orlikowski & Iacono, 2001). At the same time, it makes no sense to expect clinical managers to adapt a "direct" management style on the ICT portfolio, both because managers have many other priorities and because large-scale portfolios are nearly impossible to fully control (Silsand & Ellingsen, 2014). Hence, the goal of good governance of an ICT portfolio for management must not be to direct it, but rather to shape and influence it (Tiwana, 2013; Williamson & De Meyer, 2012). However, it is not obvious what constitutes the optimal extent or the best means to shape and influence such systems. Furthermore, it is not clear how a robust engagement from the clinical managerial level can be achieved.

As a result, there is a need for a method for clinical managers to conceptualise the interconnections between both the ICT systems and the work practice and routines. Without a method or knowledge on how to address the associated socio-technical challenges related to developing and implementing a structured EHR, it will be difficult to realize the expected benefits described in this chapter.

In this research project, we will develop theoretically informed guidelines and strategies for how managers in hospital departments should govern ICT portfolios to achieve organisational goals, specifically how clinical managers are positioned and engaged in change management and work practice adaptation in the process of development and implementation of structured EHRs. Empirically, we will study the ICT portfolio consisting of three ambitious interrelated systems in the NORTHERN NORWAY REGIONAL HEALTH AUTHORITY (NNRHA). Our main objective is therefore to *identify a strategy for what role clinical management can play in the process of changing from an unstructured to a structured EHR.*

Theoretical framework

Given the focus on large-scale ICT portfolios, there is a need for a theoretical approach that can assist in conceptualise the findings. In this regard, the notion of Information Infrastructure (II) is promising. This framework has been used to study the design, implementation and use of large-scale information systems (Aanestad & Jensen, 2011; Hanseth & Lyytinen, 2010; Star & Ruhleder, 1996). These systems are not recognized as standalone components, but to be integrated with other information systems and communication technologies, as well as with non-technical elements. Analyses of IIs therefore need to take into account a broad range of socio-technical issues shaping the implementation process. A basic principle of an II is that it is never built from scratch; rather, it evolves from the installed base-the existing information system (IS) portfolio in specific contextual practices (Pedersen, Meum, & Ellingsen, 2012). As a part of this, the infrastructure shapes, and is shaped by, the work practice, in an ongoing co-construction process between technical and social elements (Bossen, 2011; Ellingsen, Monteiro, & Munkvold, 2007). During the progression of an II in any given context, the installed base may become very large, increasingly shaping its environment. Similarly, the size and complexity of the installed base makes it difficult to replace or change. Therefore, newer versions are carefully introduced or adjusted, to replace previous versions, in order to maintain backward compatibility (Bowker & Star, 2000). This is a process of continuous negotiation and compromises for achieving stability or alignment between actors with different interests, competing agendas and related technologies.

In addition to II theory, Computer Supported Cooperative Work (CSCW) will serve as a valuable concept when investigating coordination and workflow design when implementing new technology in clinical setting. As CSCW seeks to look beyond the purely technological aspects of implementation, it is well suited for the investigation of how clinicians works in team within the hospital, and how the new ICT portfolio impacts these processes.

Empirical field

In 2011, the NNRHA initiated a large-scale clinical ICT project, intending to acquire and implement a shared ICT solution for all 11 hospitals in the health trust. The program, titled FIKS *(**F**elles **I**nnføring i **K**liniske **S**ystemer; Implementation of common clinical ICT systems*), was initiated to facilitated the implementation of the EHR DIPS CLASSIC, as well as shared clinical ICT solutions for laboratory, radiology, pathology and electronic requisition for microbiological tests from General Practitioners. DIPS AS won the bid for delivering the EHR in the project, partly based on a detailed transition plan from DIPS CLASSIC to their new structured EHR DIPS ARENA within 2016 (Helse Nord RHF, Helse Sør-Øst RHF, & Helse Vest RHF, 2017). However, DIPS AS failed to deliver ARENA on time, resulting in major delays in FIKS. All the other goals in the project were reached within time and cost (Direktoratet for e-helse, 2017; Helse Nord RHF et al., 2017). The FIKS-program was officially terminated in 2017, and the consecutive program 'FRESK' (***Fre**mtidens **S**ystemer i **K**linikken; Tomorrows systems in the clinic*) was initiated to continue the processes from FIKS. In this research project, the FRESK-program and the implementation of large-scale clinical ICT systems will act as the study object.

FRESK is a highly prioritized program for the NNRHA, funded with 450 million Norwegian Kroner from 2017-2022. FRESK aims to use ICT strategically for achieving regional, clinical and organisational goals related to standardised patient pathways, clinical decision support, standardisation of practice, interoperability and quality improvement of medication management processes.

The core technology enabling these goals is DIPS ARENA. DIPS ARENA'S core data structure is based on a national initiative using the OPENEHR architecture (Thomas Beale & Heard, 2008). This approach is aimed at enabling standardising and structuring of the EHR content through OPENEHR archetypes, promoting interoperability between different systems, reuse of data for clinical decision support and local tailoring of the EHR technology. The OPENEHR approach enables users (physicians and nurses) to design structured content suitable to their own needs. On the national level, the National Administration Office of Archetypes coordinates and organises the process related to recruiting and committing clinical users from each of the health regions.

Several related ICT projects meant to complement DIPS ARENA have also been initiated through FRESK. These are illustrated in Table I. One if the most central project is the acquisition and integration of an Electronic Medication Management System (EMMS) delivered by international vendors IMDSOFT and EVRY. The EMMS shall replace the traditional paper-based medication charts that is currently in use. This is expected to decrease the risk of medication errors and increase the overall efficiency of the medication cycle. The EMMS shall also provide decision support regarding medication management in patient pathways.

DIPS ARENA, OPENEHR and the EMMS are interdependent; The EMMS needs to be tightly integrated with DIPS ARENA and vice versa. Similarly, DIPS ARENA depends on developed structured content from the OPENEHR project. Therefore, in 2015, the management in the EMMS project ordered several integrations between the EMMS METAVISION and the DIPS ARENA EHR from the vendors.

Table I. Large-scale ICT projects in the Northern Norway Regional Health Authority

Project	**Start**	**Stop**	**Technology**	**Vendor**	**Key goal**
DIPS ARENA	2011	Extended from 2016 to 2022	DIPS ARENA EHR	DIPS AS	Implementing DIPS ARENA across all hospitals in the region; clinical decision and process support
Structured EHR	2012	No stated end date	OPENEHR, ISO 13606	OCEAN INFORMATICS	Structuring EHR content, making it available for querying and secondary purposes i.e. registers
EMMS	2012	2022	METAVISION	IMDSOFT, EVRY	Documentation of patient vital parameters and medication, including drug interactions, dosages, adverse effects and administration

Unfortunately, so far the progress of these projects is far below expectations. DIPS ARENA is still not implemented and the end date is now delayed from 2016 to 2022. In addition, the EMMS project has been postponed and put on hold multiple times, and the planned implementation is now set to begin at the end of 2019. The OPENEHR approach suffers from a lack of involved and committed users as well as a failure to fulfil the original ambition of user-controlled local tailoring (Ulriksen et al., 2017). The EMMS project is also delayed and faces major integration challenges with the current EHR. The preliminary tests of intertwined use of DIPS ARENA and the EMMS in clinical practice show several unexpected coordination problems for users (Bjørnstad, Christensen, & Ellingsen, 2017).

Overall, this raises several crucial questions related to ICT governance and architecture on how this has been established, how it has been carried out and what lessons one might learn from this about how to manage large-scale ICT portfolios and subsequently to obtain organisational goals.

In sum, these three technologies are perfect illustrations of architectural components in an ICT portfolio. Overall organisational success requires that each of the three projects succeed. Failure of one of them will mean that the high-end goals of support of patient's pathway (for instance surgery planning) and clinical decision support will not be realised. In addition, the implementation of such a large ICT portfolio require effective change management to be successful, as they inevitably will result in "*(...)* changes to the daily work routines for healthcare professionals in the hospitals" ('Rigger for én journal', 2019) (Styret Universitetssykehuset Nord-Norge HF, 2015). These challenges are increasingly recognised at the top Governmental level in Norway, as well as in the regional health authorities, but the strategies on how to deal with them are, however, not clear.

Method

This is a formative research project focused on the implementation of three interdependent ICT systems in the FRESK-program in the NNRHA as case. In order to address the objective stated, we will apply a mixed method approach where we endeavour to see things from different viewpoints to gain an increased understanding of the ICT portfolio as an emerging information infrastructure phenomenon, and get a complete picture of what is going on (Klein & Myers, 1999; Walsham, 1995).

In order to explore how new technologies and work practices co-develop, the study will aim to track the emerging ICT processes on three different healthcare levels that in various ways have been (and will be) involved in the three projects: I) On the top level, data collection will be targeted towards the regional health authority and the UNIVERSITY HOSPITAL OF NORTHERN NORWAY (UNN) at the director level through four open-ended semi structured interviews. The executive management level is included in order to investigate the strategic decisions and organizational motivation behind the ICT projects in the NNRHA, as well as strategies for development, change management and ICT governance; II) On the middle level, data collection will be targeted on departmental managers at the Department of Anaesthesia and Surgical Services, and the Department of Intensive

Care at UNN through 10 open-ended semi structured interviews. These departments have been selected for the initial implementation of the EMMS and DIPS ARENA and therefore it makes good sense to conduct our data collection here. Department managers are included in order to investigate how they are involved in strategic decisions and processes related to development and implementation of the ICT portfolio, and how they address the challenges of change management to motivate users in their own departments; III) On the ground level, data collection will target clinical users in these departments through five open-ended semi structured interviews in each department. Clinicians are involved in the study in order to investigate how they experience the implementation processes and changes in work practice. The analysis and topics revealed in the interviews will guide a subsequent round of observation among clinical system users in the departments. The aim of the observation is to investigate actual system use by clinicians.

In addition to the interviews and observations described above, extensive data collection will be conducted with participants and project members in FRESK. We plan to conduct five interviews with project participants from each of the projects in FRESK. Participatory observation will also be conducted within the Structured EHR project in order to investigate how the strategies and development process actually is operationalized, but also to identitfy and track emerging challenges throughout the implementation. In addition, extensive document analysis will be included. Interviews will be recorded in audio and transcribed verbatim. Analysis of qualitative data will be conducted according to the method of systematic text condensation as proposed by Malterud (Malterud, 2012).

The importance of social issues related to computer-based information systems has been increasingly recognized in IS, which has led researchers to adopt empirical approaches that focus particularly on human interpretation and meaning (Walsham, 1995). In practice, the movement of healthcare work activities is frequently much less linear than it is in other arenas, as it has flexibly defined roles. Interpretive research can help the IS researcher to understand human thought and action in a social and organizational context (Klein & Myers, 1999). Further, interpretive studies assume that people create and associate their own subjective and inter-subjective meanings as they interact with the world around them. The interpretive researcher thus attempts to understand through accessing the meanings participants assign to them (Orlikowski & Baroudi, 1991). Our study adheres to an interpretive research tradition of this nature. In general, qualitative research methods, such as interviews and observations, are optimally suited to understand a phenomenon from the participants' point of view, and in particular the social and institutional context. Qualitative research techniques can provide deep insight, identify problems and answer the "why" and the "how" questions that quantitative studies alone cannot answer (Ash, Berg, & Coiera, 2004).

Concluding discussion

Clinicians are dependent on effective, intuitive and adapted ICT systems for delivering quality care and treatment for patients. Not insignificant resources are used on designing and implementing ICT tools and systems that are essential to healthcare professionals in their day-to-day work. However, evidence shows that ICT implementations in healthcare often fail in delivering described organizational goals and effects. IT decisions and ICT governance is by and large in the realm of IT departments and top management. However, prior research indicates that involvement of mid-level management and clinical leaders are necessary for facilitating effective change management in ICT implementation.

The NNRHA has over the last decade put considerable efforts on developing and implementing shared and structured clinical ICT systems- a process that will require substantial changes in workflow and work organization for clinical staff. A lacking of change manage competency in managers is in FRESK project documentation recognized as a major risk factor for the success of the ICT implementation and level of goal realization.

A better understanding of how ICT portfolios can be governed, and how and too what degree clinical managers should be involved in an acquisition and implementation process can improve outcomes in this respect. The described research project addresses challenges central for realizing the potential in large-scale EHRs by investigating both the prerequisites and strategies at the executive level; the expectations and implementation feasibility at the department managerial level; and the motivation and perceived usability at the end-user level. By focusing on these three levels, we argue that the perspective gained from the different data points will be well suited to address the proposed objectives of identifying and describing strategies for what role and involvement clinical managers should have in these processes in order to facilitate the needed change management within own organization. Although findings will be context-sensitive, the proposed interpretive methodology and theoretical framework could prove valuable in providing transferable results. Change management in health ICT implementation and governing is a growing field of interest for decision makers and healthcare management. This implies a high degree of topicality, and the research project can be an important contribution in delivering sought-after insight and understanding into this topic.

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References

Aanestad, M., & Jensen, T. B. (2011). Building nation-wide information infrastructures in healthcare through modular implementation strategies. *The Journal of Strategic Information Systems, 20*(2), 161-176.

Ash, J. S., Berg, M., & Coiera, E. (2004). Some unintended consequences of information technology in health care: the nature of patient care information system-related errors. *Journal of the American medical informatics association, 11*(2), 104-112.

Bjørnstad, C., Christensen, B., & Ellingsen, G. (2017). *Medication, integration and practice.* Paper presented at the Proceedings of 15th European Conference on Computer-Supported Cooperative Work-Exploratory Papers.

Bossen, C. (2011). Accounting and co-constructing: the development of a standard for electronic health records. *Computer Supported Cooperative Work (CSCW), 20*(6), 473.

Boulus, N., & Bjorn, P. (2010). A cross-case analysis of technology-in-use practices: EPR-adaptation in Canada and Norway. *International journal of medical informatics, 79*(6), e97-e108.

Bowker, G. C., & Star, S. L. (2000). *Sorting things out: Classification and its consequences*: MIT press.

Christensen, B., & Ellingsen, G. (2013). Standardizing Clinical Pathways for Surgery Patients through ICT. *Edinburgh, Scotland, 9*.

Direktoratet for e-helse. (2017). *Komparativ analyse av de regionale helseforetakene på IKT-området*. Retrieved from

Ellingsen, G., Monteiro, E., & Munkvold, G. (2007). Standardization of work: co-constructed practice. *The Information Society, 23*(5), 309-326.

Fitzpatrick, G., & Ellingsen, G. (2013). A review of 25 years of CSCW research in healthcare: contributions, challenges and future agendas. *Computer Supported Cooperative Work (CSCW), 22*(4-6), 609-665.

Hanseth, O., & Lyytinen, K. (2010). Design theory for dynamic complexity in information infrastructures: the case of building internet. *Journal of information technology, 25*(1), 1-19.

Helse Nord FRESK. (2019). Rigger for én journal. Retrieved from https://helse-nord.no/fresk/rigger-for-n-journal

Helse Nord RHF, Helse Sør-Øst RHF, & Helse Vest RHF. (2017). *Felles plan - Neste generasjon PAS/EPJ*. Retrieved from

Klein, H. K., & Myers, M. D. (1999). A set of principles for conducting and evaluating interpretive field studies in information systems. *MIS quarterly, 23*(1), 67-94.

Malterud, K. (2012). Systematic text condensation: a strategy for qualitative analysis. *Scandinavian journal of public health, 40*(8), 795-805.

Moreno-Conde, A., Moner, D., Da Cruz, W. D., Santos, M. R., Maldonado, J. A., Robles, M., & Kalra, D. (2015). Clinical information modeling processes for semantic interoperability of electronic health records: systematic review and inductive analysis. *Journal of the American medical informatics association*, ocv008.

Orlikowski, W. J., & Baroudi, J. J. (1991). Studying information technology in organizations: Research approaches and assumptions. *Information systems research, 2*(1), 1-28.

Orlikowski, W. J., & Iacono, C. S. (2001). Research commentary: Desperately seeking the "IT" in IT research—A call to theorizing the IT artifact. *Information systems research, 12*(2), 121-134.

Pedersen, R., Meum, T., & Ellingsen, G. (2012). Nursing Terminologies as Evolving Large-Scale Information Infrastructures. *Scandinavian Journal of Information Systems, 24*(1).

Pollock, N., & Williams, R. (2008). Software and organisations. *The biography of the enterprise-wide system or how SAP conquered the world. London and New York, University of Teeside, UK.*

Rosenmöller, M. (2013). IT governance in healthcare institutions *eHealth: Legal, Ethical and Governance Challenges* (pp. 329-348): Springer.

Silsand, L., & Ellingsen, G. (2014). Generification by translation: designing generic systems in context of the local.

Silsand, L., & Ellingsen, G. (2016). *Complex decision-making in clinical practice.* Paper presented at the Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing.

Star, S. L., & Ruhleder, K. (1996). Steps toward an ecology of infrastructure: Design and access for large information spaces. *Information systems research, 7*(1), 111-134.

Styret Universitetssykehuset Nord-Norge HF. (2015). *Møteinnkalling*. Retrieved from https://unn.no/Documents/Styrem%C3%B8ter%20dokumenter/2015/160915/innkalling_styremote_160915.pdf

The Norwegian Directorate for e-health. (2018). Key ICT standards for Norwegian health and care services. Retrieved from https://ehelse.no/key-ict-standards-for-norwegian-health-and-care-services

Thomas Beale, & Heard, S. (2008). *openEHR release 1.0.2. Architecture Overview*. Retrieved from

Tiwana, A. (2013). *Platform ecosystems: Aligning architecture, governance, and strategy*: Newnes.

Ulriksen, G.-H., Pedersen, R., & Ellingsen, G. (2017). Infrastructuring in healthcare through the openEHR architecture. *Computer Supported Cooperative Work (CSCW), 26*(1-2), 33-69.

Walsham, G. (1995). Interpretive case studies in IS research: nature and method. *European Journal of information systems, 4*(2), 74-81.

Williamson, P. J., & De Meyer, A. (2012). Ecosystem advantage: How to successfully harness the power of partners. *California management review, 55*(1), 24-46.

Øvretveit, J., Scott, T., Rundall, T. G., Shortell, S. M., & Brommels, M. (2007). Improving quality through effective implementation of information technology in healthcare. *International Journal for Quality in Health Care, 19*(5), 259-266.

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"MIPRES grew like a snowball and took us with it": Evolution of a health information infrastructure.

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Abstract. This paper explores how the Colombian MIPRES system emerged as a nationwide ePrescription solution and, how it evolved into a backbone for the country's Information Infrastructure. Our empirical qualitative study is based on the analysis of interviews conducted in the Ministry of Health, hospitals, insurance companies and patients' organizations. In addition, documents and notes from ethnographic observations were analyzed. Information Infrastructure theoretical insights were employed to analyze the contextual conditions that shaped this evolution. Initially, MIPRES was conceived as a simple reporting system. Through its non-threatening strategy and alliances, it gained momentum like a snowball and, grew to become a central component of the Colombian health information infrastructure. Considered a "successful" implementation, MIPRES triggered a new network of relationships that exists in the background, it is invisible, and frequently taken for granted; thus we conclude that MIPRES wove around it the health information infrastructure of Colombia.

Introduction

Due to the epidemiological and demographic challenges in contemporary societies, national governments are struggling with the increasing demands for biomedical technologies (Bloom et al, 2015; Fan & Savedoff, 2014). These technologies, such as medicines, devices and special treatments are crucial components of health systems and essential requirements to guarantee the right to health (World Health Organization, 2013). However, because of their innovative nature they are often very expensive, forcing governments to struggle to control health expenditure without sacrificing population needs. (Rumbold et al., 2017; Rovira, De Barcelona, & De Catalunya, 2001) To face this pressure, governments are looking for strategies to control the prescription of expensive biomedical technologies while protecting the public interest and guaranteeing the sustainability of health systems. To this end, they usually deploy information systems to monitor and quantify what happens with these technologies (Oortwijn, Mathijssen, & Banta, 2010).

In the global south, the landscape is not very different (Gaviria, 2014). A Latin American country has been a pioneer in introducing information technology for addressing these challenges (Prada et al, 2018; Gaviria, Vaca, Gómez, & Morales, 2016). In this paper, we present the case of the MIPRES system (Colombia, Ministry of Health and Social Protection, 2016) which is a web application created by the Colombian Government as a centralized ePrescription system for high-cost and high-tech medicines. Its purpose is to guarantee patients' access to medicines while controlling health expenditure (Congress of the Republic of Colombia, 2015). Before MIPRES, health insurers granted access to high-cost and high-tech medicines via cumbersome processes based on paper prescriptions and authorizations (Mejía et al, 2002). These processes frequently resulted to delays and/or medicine refusals while at the same time allowed space for system abuse through unnecessary prescriptions. Overall, before the introduction of MIPRES it was very difficult to control the costs related to special medicines (Abadia & Oviedo, 2009; Bernal & Barbosa, 2015). Addressing this problem required a solution that respects the different actors' interests (Congress of the Republic of Colombia, 2015). Thereby, through a process that included disputes and consultations the MIPRES web application emerged as a viable solution to fulfil all the expectations (Colombia, Ministry of Health and Social Protection, 2016). After a rapid design and implementation process, MIPRES began to operate compulsorily on April 2017 throughout the country. According to the Ministry of Health, MIPRES was a straightforward case of successfully adopting a web application. In this context, all the informational and institutional changes stimulated by it were downplayed, giving to the artefact and its role in the health system a marginal relevance.

These characteristics make MIPRES a relevant case for studying the emergence and evolution of information infrastructures, which are usually populated by examples of failure and implementation challenges (Greenhalgh, 2018). Because MIPRES appeared to be implemented in a straightforward way, this case can be interesting to discuss and compare with others which have been less fortunate. Meanwhile, MIPRES is there, as part of an infrastructure that exists in the background, invisible and, frequently taken for granted (Star & Ruhleder, 1996). Besides, "in such a marginalized state its consequences become difficult to trace and politics are easily buried in technical encodings" (Hanseth, Monteiro, & Hatling, 1996; Monteiro & Hanseth, 1997). Based on this background, we aim to answer the following research question: What contextual conditions make possible the evolution of an information technology towards acquiring a central role in an information infrastructure?

We explore the emergence of a health digital artefact, MIPRES, and its evolution into an Information Infrastructure (Hanseth, Monteiro, & Hatling, 1996; Monteiro & Hanseth, 1996) by shedding light on the contextual conditions of this process. We aim to contribute to the literature in Information Infrastructures (II) evolution in highly politicized contexts, such as those of the current Colombian health system and analyse the contextual conditions that allowed the success of this implementation and the emergence of this specific II backbone.

Research approach

Between January 2017 and January 2019, a qualitative case study was conducted to follow the introduction of MIPRES in Colombia's health system across different organizations. To examine how contextual conditions, make possible the evolution of an information technology as a central component of an II in the Colombian context, we draw on three sources. First, 40 semi-structured interviews about MIPRES design and implementation were carried out. The interviewees included government officials (managers and engineers), hospital staff (technicians, doctors and managers of hospitals) and insurers (managers and technicians) as well as patients. All interviews, which lasted two hours on average using individual interview guides, were recorded and transcribed verbatim after permission from the participants. Second, 110 MIPRES related documents were consulted (policy regulations, technical reports and media news). Third, we draw on a secondary analysis of data collected in an earlier ethnographic work. We conducted 63 hours of clinical and managerial MIPRES related information processes through non-participatory observations. The analysis of data provides an account of infrastructural emergence and interaction, rather than individual agents' accounts.

The analysis of empirical material was performed via an iterative approach facilitated by NVivo 12. The project was approved by the Research Ethics Committee at the University of the first researcher and the Research Committee of the hospital where the observation was conducted.

Findings

Emergence and evolution of MIPRES

In early 2016, MIPRES was born as an idea in the office of the Minister of Health of Colombia, where it was envisioned as a reporting system on the supply of high-cost medicines. Until that moment, the reports in flat files from hospitals and insurers to the Government were the main sources used to build the health information infrastructure in the country. However, in subsequent meetings, the initial idea began to change. Motivated by discussions with advisers and officials about the possible scope of this tool, the Minister of Health said: "Let's make of this a social experiment" (Interview, Ministry staff, Physician, 2018).

The Ministry wanted to develop the reporting system, and the Minister' office invited the IT Department to be part of this development. Several actors involved agreed that this was a special moment because "before, technology did not allow us to do some things, political will was not there, but, all the stars lined up for this to happen" (Interview, Ministry staff, Physician, 2018). The IT Department strengthened its capacity to develop applications and created several digital citizen-centred services such as miseguridadsocial.com.co or MiVox-pópuli in previous years. Based on these experiences, the IT department began to develop an online report of high-cost medications and named it Miprescription, i.e. MIPRES. The initial development was based on agile methodologies and soon the scope of the system began to change during the presentations to the Ministry officials.

> "So, let's say. At the beginning, the scope of this was only as a reporting system where doctors were going to enter the medical prescriptions of high-cost technologies not included in the health benefit plan, and that's how it started. But, suddenly, this began to evolve and evolve..." (Interview, Ministry staff, Engineer, 2018).

IT strategy in the making

The negotiation process between the different units of the Ministry was complex, because many needs and opportunities were expressed. In turn, the IT department identified that MIPRES was different from previous developments, because it responded to real clinical and pharmacological practice. So, the requirements elicitation could not be conducted only based on the administrative knowledge of the Ministry officials, they also needed clinical doctors and medical knowledge. The Ministry started to convene with medical societies as guilds of recognized knowledge and scientific authority among doctors.

The Ministry identified that "it was always an advantage to have scientific societies in our side. In fact, this was publicly presented as an initiative by them, as a scientific society solution for medical autonomy." (Interview, Ministry staff, Physician, 2018). Patients also participated, although initially not by invitation from the Ministry, but because they heard about the development in progress and demanded inclusion in the process. The leaders of the national patients' association said:

> "We realized that there was a first draft of MIPRES that was ready to be signed by the Minister, and the Ministry had not consulted us. Then, we presented a right of petition, with a copy to the attorney general's office, requesting to stop the process until the proper consultation with us was done". (Interview, Spokesman, National Association of Patients, 2018).

The Ministry responded to these requests by including the patients in the discussion meetings of MIPRES and making some modifications as a result of the negotiations with their representatives. This gave legitimacy to the Ministry because now leaders of patients and doctors associations had been part of the technology development. Of course, other interest groups also presented their complaints and concerns. The pharmaceutical industry, for example, was one of the most interested actors in this technological artefact and used different forms of relationship with the Ministry (political pressure, supporting medical training sessions and didactical materials).

Thus, technological development was negotiated among diverse interest groups, resistances and concessions, producing a technology that embedded multiple purposes. The Ministry itself was surprised by what MIPRES has allowed: "one of the things that seemed most interesting, is that MIPRES became the excuse, for the Ministry to do many things that for a long time we didn't." (Interview, Ministry staff -Physician, 2018). MIPRES was launched to serve a multiplicity of purposes implicit in its design and code: guarantee medical autonomy with self-regulation; protect right to health for citizens and, have access to transparent and real-time information (Colombia, Ministry of Health and Social Protection, 2016). Nevertheless, Ministry officials and engineers made the decision to not emphasize MIPRES potential capacities and uses: "We do not call it an information system but a tool, just an application" (Interview, Ministry staff -Engineer, 2018).

Introducing MIPRES in all the hospitals took less than a year, this happened mainly during 2017. Limited resources were invested, but the initiative had significant political backing. The Colombian health system has historically been fragmented due to its free market logic being based on competition among multiple organizations. Traditionally, health care actors and organizations viewed information as a strategic asset, making it difficult to access. For the first time, MIPRES triggered the connection of multiple interests, organizations and data sources that were previously separated. Unintentionally, MIPRES acquired a central role and became Colombia's most influential health information artefact. Within less than two years of its introduction, it attained the role of the backbone in Colombia's health information infrastructure.

After two years of operation and with more than 11 million prescriptions of high cost technologies through it, MIPRES use is established among professionals and institutions, although resistance and some unintentional uses persist. MIPRES in the official discourse remains just an application. But, MIPRES is far from being just another app in the Colombian health information landscape. In fact, Ministry officials recognized that “MIPRES has been growing like a big snowball, it grew like this and it took us” (Interview, Ministry Executive commanding MIPRES ideation and implementation).

The snowball phenomenon metaphor reflects the significance of the application for the healthcare system. The MIPRES introduction stimulated a cascade phenomenon (a snowball effect) in the previously fragmented Information Infrastructure (II). By enabling real-time connections between institutions, MIPRES led to the creation of new data registers and data flows. Because it got linked to and required data from, the introduction of MIPRES triggered the reordering of existing sources (Figure 1. MIPRES connections) such as the National Register of all the Hospitals and Health Providers and the Colombian National Register for Rare Diseases. Also, the Colombian Register of Victims and the National Register of People living with Disabilities, both were connected to MIPRES. All these registers previously existed only on paper or were outdated and fragmented throughout many institutions. Additionally, the insurance companies also got access to rich data contained in MIPRES flat files that are available for them to download daily. Also, a new mandatory web register was created for all the health professionals: RETHUS (Register of Human Talent).

Furthermore, MIPRES introduction required updating all databases containing catalogues of health products (medicines, devices, nutritional products, etc.) with prices, international denominations, registers of sanitary authorization about safety and efficacy and standardized codification. In that sense, MIPRES reassembled and connected all these various systems and reports into a new Information Infrastructure in the country, becoming the Colombian healthcare system´s II backbone (Figure 1. MIPRES connections). Most of these sources had been created many years ago but due to low response and low data from health sector institutions, the databases were almost empty or not useable. Also, there was no mechanism or incentive to update these systems. However, MIPRES triggered a comprehensive upgrading and revitalization of the Colombian health information infrastructure.

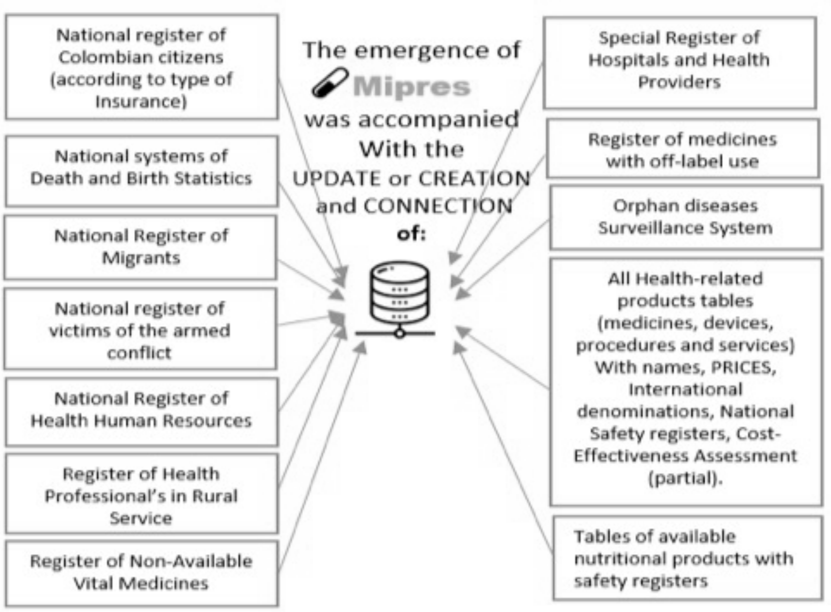

Figure 1. MIPRES connecting multiple pre-existing and new data sources and triggering updates.

Conclusion & Discussion

This paper explores the contextual conditions that allowed an information technology to expand in a way that transformed the entire information infrastructure of a country, turning it into an informational backbone. In the MIPRES case, the application was born humbly, but with the particular political and historical conditions given, it became more complex than the initial scope indicated. MIPRES also triggered a cascade effect of upgrading the rest of the II.

We identified three main elements in the MIPRES expansion strategy that can be analysed and serve as a reference to other national initiatives:

- MIPRES was born as a simple artefact, "just an app". Although it has been growing and becoming more complex, its low profile has been continually maintained, avoiding producing more resistance.
- MIPRES achieved legitimacy through consultative and deliberative processes with key actors (doctors and patients) for its production and use.
- MIPRES became important for others in the healthcare system since it began to connect multiple data sources. Thus, different actors and processes started updating information to or for MIPRES use. MIPRES awakened an interest

for increasing information quantity and quality, which led to an information reengineering exercise across information processes of the Ministry and many other organizations in the health system.

Although the particular trajectory of MIPRES is context-dependent and historically situated, the strategic elements that have been identified have a universal character and can shape technological developments in different contexts. We suggest that the insights from the MIPRES case analysis are relevant for making sense of the dynamics of infrastructural expansion, stabilization and use contributing to the literature on II in highly politicized contexts.

Prior II literature has pointed to the role of tactics for introducing new infrastructural component including the tactic of staying under the radar (Grisot, Thorseng, & Hanseth, 2013), furthermore prior literature has identified the importance of legitimisation (Vassilakopoulou & Marmaras, 2015). Additionally, with the MIPRES case, we gain insights about the catalytic role of creating real-time connections. MIPRES created links with multiple other systems and data sources that were previously stand alone. This way, the addition of a single component to the existing infrastructure, radically changed the overall infrastructure topology. Despite being in a marginalized state, MIPRES became a central node in the overall network of systems. Our study aims to go beyond the static focus on technology itself investigating infrastructural dynamics. The findings of the MIPRES case study remind us that infrastructures are complex adaptive systems and the creation of new connections significantly affects their overall behaviour and also the various newly connected components.

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References

Abadia, C. and Oviedo, D. (2009). Bureaucratic itineraries in Colombia. A theoretical and methodological tool to assess managed-care health care systems. Social Science & Medicine, vol. 68, no.6, pp.1153-1160.

Bernal, O. and Barbosa, S. (2015). La nueva reforma a la salud en Colombia: el derecho, el aseguramiento y el sistema de salud. Salud Pública de México, 57, pp. 433-440.

Bloom, D., Chatterji, S., Kowal, P., Lloyd-Sherlock, P., McKee, M., Rechel, B. and Smith, J. (2015). Macroeconomic implications of population ageing and selected policy responses. The Lancet, vol. 385, no. 9968, pp. 649-657.

Colombia, Ministry of Health and Social Protection. (2016). Resolution 003951de 2016. Por la cual se establece el procedimiento de acceso, reporte de prescripción, suministro, verificación, control, pago y análisis de la información de servicios y tecnologías en salud. Bogotá D.C: The Ministry.

Congreso de la República de Colombia. (2015). Ley Estatutaria 1751 del 16 de febrero de 2015. Por medio de la cual se regula el derecho fundamental a la salud y se dictan otras disposiciones. Bogotá, D.C: El Congreso.

Fan, V. and Savedoff, W. (2014). The health financing transition: a conceptual framework and empirical evidence. Social science & medicine, vol. 105, pp. 112-121.

Gaviria, A. (2014). Cost of progress prices of new medicines threaten Colombia' s health reform. Finance and Development, vol. 5, no. 4.

Gaviria, A., Vaca, C., Gomez, C. and Morales, A. (2016). The debate on regulating biotechnology drugs: Colombia in the international context. Revista Panamericana de Salud Publica, vol. 40, no. 1, pp. 40-48.

Greenhalgh, P. (2018). How to improve success of technology projects in health and social care. Public Health Research and Practice, vol. 28, no.3.

Grisot, M., Thorseng, A. and Hanseth, O. (2013). Staying Under the Radar: Innovation Strategy In Information Infrastructures For Health. ECIS 2013 Completed Research, vol 149.

Hanseth, O., Monteiro, E. and Hatling, M. (1996). Developing information infrastructure: The tension between standardization and flexibility. Science, Technology, & Human Values, vol. 21, no.4, pp. 407-426.

Mejía, S., Vélez, A., Buriticá, O., Arango, M. and del Río, J. (2002). National pharmaceutical policy and social security reform in Colombia: access and rational use of medicines. Cadernos de Saúde Pública, vol.18, no. 4, pp. 1025-1039.

Monteiro, E. and Hanseth, O. (1996). Social shaping of information infrastructure: on being specific about the technology. En W. Orlikowski, G. Walsham, M. Jones, J. DeGross(eds.):, Information technology and changes in organizational work, Springer, Boston, pp.. 325-343.

Monteiro, E. and Hanseth, O. (1997). Inscribing behaviour in information infrastructure standards. Science, Technology & Human Values, vol 21, no 4, pp. 407–426.

Oortwijn, W., Mathijssen, J. and Banta, D. (2010). The role of health technology assessment on pharmaceutical reimbursement in selected middle-income countries. Health Policy, vol. 95, no. 2-3, pp. 174-184.

Prada, S., Soto, V., Andia, T., Vaca, C., Morales, A., Márquez, S. and Gaviria, A. (2018). Higher pharmaceutical public expenditure after direct price control: improved access or induced demand? The Colombian case. Cost Effectiveness and Resource Allocation, vol. 16, no.1.

Rovira, J., De Barcelona, U. and De Catalunya, G. (2001). The role of prices in drug expenditure analysis. Eur J Health Econ, vol. 2, pp.142–9.

Rumbold, B., Baker, R., Ferraz, O., Hawkes, S., Krubiner, C. and Littlejohns, P. (2017). Universal health coverage, priority setting, and the human right to health. The Lancet, no. 390, pp. 712–14.

Star, S. and Ruhleder, K. (1996). Steps toward an ecology of infrastructure: Design and access for large information spaces. Information Systems Research, vol. 7, no. 1, pp. 111–134.

Vassilakopoulou, P. and Marmaras, N. (2015). Investigating technology-induced transitions in healthcare: work practice adaptations within their overall context. *Health Policy and Technology*, vol. 4, no. 3, pp. 277-285.

World Health Organization. (2013). Medical devices and eHealth solutions: Compendium of innovative health technologies for low-resource settings 2011-2012. Geneva, Switzerland: WHO.

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Instant messaging systems as grassroot healthcare infrastructures. The case of an expert opinion service for breast cancer via WhatsApp

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Abstract. 'Healthcare infrastructures' is often associated with large, complex and costly technical solutions made available by institutions. The widespread use of smart devices made possible the development of information exchange building on general purpose communication technologies. Through the analysis of an expert opinion service for breast cancer via WhatsApp, we illustrate the process of setting up the service, the challenges and the ramifications of health information exchange taking place through non-institutional channels. We introduce the concept of 'grassroot infrastructures' to indicate socio-technical systems created and managed by lower-ranked organizational actors, invisible to rationalized representations of work.

Instant messaging systems as grassroot health infrastructures

The notion of healthcare infrastructure, far from being a mere analytical construct, possesses a significant evocative power. The design, testing and implementation of information systems and infrastructures in the clinical practice has traditionally required the involvement of national or regional governments, standardization authorities, professional bodies, technology assessment experts, healthcare managers and the list could easily go on. The naïve enthusiasm of the early days of medical informatics has been soon flanked by the acknowledgement of the complexity in coordinating different professional visions, funding the implementation and maintenance of systems, coordinating different local practices, not to mention the increasing building on the installed base and taking into account legacy systems. Each system is, at least partially, an *ad hoc* technology tailored to fit the needs of a specific context.

Alongside the traditional information infrastructures and systems, however, the adoption of personal communication devices by the vast majority of the population has created the opportunity to develop new forms of information exchange building on freely available general purpose communication technologies. Mobile phones, SMS, e-mail have allowed providers to create new forms of minimal healthcare services delivery bypassing the formal communication systems provided by institutions (Brooks and Menachemi, 2006). The use of such communication systems in the clinical practice has been accompanied by the fear of work overload and difficulties to define reimbursement schemes.

Despite these issues, the rise of instant messaging system (such as Whatsapp or Telegram) has increased the possibility to set up grassroot services such as remote monitoring schemes (Petruzzi and De Benedittis, 2016), doctor-to-doctor communication (Gulacti et al., 2016) or in clinical practice in general (Mars and Scott, 2016). In the present paper we document one of such systems, namely an informal second opinion service for breast cancer activated in northern Italy based on short messaging communication via a WhatsApp group chat used by 24 clinical oncologists. Drawing on our research (still ongoing) we illustrate the process of setting up the service, the challenges and the ramifications of health information exchange taking place through non-institutional channels.

Theoretical framework

Here we propose to look at the process or creating such a grassroot infrastructure as a practice. Expert opinion is a practice, a set of specific patterned activities that are meaningful to those involved and as well as to researchers. Following Silvia Gherardi, we define a practice as “a mode, relatively stable in time and socially recognized, of ordering heterogeneous items into a coherent set” (Gherardi, 2006, p. 34). Seen through the conceptual lens of practice, organised activities are sustained by a shared understanding among practitioners that allows their replication in a more or less institutionalised way. Practitioners do not act according to a rigid script; rather, they share a “feel for the game”, the logic of practice (Bourdieu, 1990), which allows a “repetition without repetition” (Clot and Béguin, 2004). The recursiveness of the organised activities, their regularities and the (at least partially) shared meaning attributed to them both by those who practice and those who observe from the outside allow consideration of a given practice as an emic unit of analysis of a social phenomenon. In a socially informed perspective, there is no clear-cut distinction between knowing and practicing. Pre-existing knowledge (e.g. a guideline) is mobilised and put-in-practice, thus becoming a resource for collective action. Knowing is practicing and participating.

We consider the practice of ‘expert opinion’ as an ‘infrastructuring practice’. Drawing on Karasti and Baker we consider infrastructuring as “an ongoing design process that highlights participation and co-construction, as well as the complex relationships between the long-term, data, participants, collaborations, information systems, and infrastructures” (Karasti and Baker 2004). As we shall see in the next pages, practitioners create the new practice practicing it, learning and defining as they proceed how to become competent practitioners. In doing so, they shape the infrastructure that sustain their interaction, creating a set of relations among each other, the data shared and the technology.

Methodology

The process of setting up of the expert opinion on breast cancer has been studied analysing the messages exchanged in the WhatsApp chat exchanged between March 2017 and August 2018. The log file contains all the messages (texts and emoticons) plus information about actions performed on the group (e.g. new people invited).

The research was performed through a structured contend analysis of the messages with the objective to identify patterns of interaction, language style and rules regarding the use/misuse of the chat, content different from request/offering of expert opinion. Access to the field was negotiated having being invited to the first (and only) two-days face-to-face meeting held in 2019. In this occasion it was possible to perform a quick-and-dirty participant observation and to discuss with participants about their involvement in the project. In the next phases of the research we will interview a sample of the participant to investigate in depth the history of the service, the use in the daily practice, the rules of engagement, and the relation between this service and other information systems or infrastructures.

The case

Clinical oncology has evolved over the years into a highly formalized discipline (Band 2010) with several subspecialties (e.g. Albritton et al. 2009) each of them with a specific set of guidelines and protocols. The fast-paced innovation in pharmacology and the continuous clinical research has led to a significant standardization of each subdiscipline. As a consequence, however, the specialization of each subdiscipline has created a partial incommunicability among oncologists with different subspecialty. In most clinical setting it is rare for a physician to have an expert opinion since only large oncological department hire more than one oncologist for each subspecialty. While guidelines and protocol offer a clear pathway to follow in most cases, in some cases several therapeutic options are equally possible. According to doctors involved case described, undecidability affects the 20% of all cases of breast cancer. While this is more a rule of thumb rather than accurate figure, it suggest that in one case out of five oncologist dealing with breast cancer believe that guidelines and protocols would need to be complemented by a second opinion which is often impossible to have.

Donna Rosa (trans. Pink Lady, but in Italian it also can be considered as a proper noun) is an expert opinion service for breast cancer set up in March 2017 by two breast cancer specialist with "*the objective of sharing ideas, doubts, questions and therapeutic strategies on the most controversial breast cancer cases addressed in daily clinical practice*" (A.A.V.V. 2019, p.3). At present 24 breast cancer specialists have been admitted to the group and some more required to join.

The preliminary analysis reveals that some participants are very active in providing opinions while others tend to keep a lower profile. The style of communication is in line with the personal conversations taking place in instant messaging platforms: short sentences, little or no attention to form (punctuation, capitalization, spaces between words), use of emphatic tone (e.g. emoticons, exclamation marks), colloquial tone.

Expert opinion

The expert opinion is offered by peers in a WhatsApp group. All oncologists admitted to the network can post their clinical case and receive an opinion by a colleague. Each interaction follows a similar pattern. The doctor initiating the conversation presents a case in short sentence, providing only the information deemed necessary to describe it and she poses a question to the group. Data is anonymized and presented making use of the jargon well understood by specialist.

As a general rule, the question should not introduce a bias as in the following case.

> Hi! Women born in 1976, QIE to dcis (3mm) g1 E100%,P100%. What would you do?thanks (Doctor 1)

At times, however, the request is to confirm the correctness of a decision or to decide among given alternatives. The different ways to phrase the questions depend on what doctors require to the community, whether a suggestion or a reassurance.

> Women, 64 years, invasive ductal c., pT1a (4mm)N0M0, G1, ki 67 9%, ER 100, P2%, her 2 neg. how many of you would do Ot? Thanks (Doctor 2)

> 60 years. Pt1b 9mm er 95 PgR 60 ki 67 15 her 2 pos 3 pos. Antra yes or APT study? (Doctor 3)

Presenting their decision and asking for confirmation is consistent with one of the declared objectives of the service that is to provide reassurance about a difficult clinical decision. While the final responsibility is on the designated provider, "*having at disposal a service less fallible than one own's personal experience offer a significant professional comfort*" (A.A.V.V., 2019). For each case presented, there are five/six opinions on avereage. The responses are mostly very short to the point that when a simple confirmation is asked the usual reply is a series of dry 'yes' or 'no'.

Only in few cases there is a debate among different positions. In these cases, the short discussion offers not merely a range of opinions but also it allows to catch a glimpse of the clinical reasoning of colleagues, the different local practices in different settings or professional opinions about a still controversial study.

> I agree with Michael. Here [in our department] too we do test to manage follow ups not for platinum (Doctor 5)

> Yes, because here I have colleagues great at immunotherapy. (Doctor 6)

> There are huge controversies about this among radiotherapists! There is a random [randomized] study in Pat dcis small g1/2 that shows preferability of rt (Doctor 4)

Each conversation, while focused on an expert opinion regarding a specific clinical case, holds the potential to offer more information about how the profession is practiced in different contexts.

In some cases, the expert opinion can even open up to offer new therapeutic services to patient. Some doctors of the network may be aware of some ongoing or soon-to-start experimental protocols in which the patient could be enrolled. In such cases, all participants to the chat are informed about studies and may have privileged access to them.

> If you need, just let me know the name and I will enrol her. I only need her consent and the histologic material, the lady will still be cared for by the oncologist who send her to me, obviously. Contact me if you need!! (Doctor 2)

Beyond expert opinion

As noted above, the discussion of a clinical case can trigger the sharing of additional information. In some cases the WhatsApp chat is used to deliver information relevant to the community. We identified different contents that go beyond the expert opinion about a clinical case.

The first is what could be considered as an expert opinion not regarding a single case but a protocol or guideline. The discipline advances rapidly and new protocols may not be adopted at the same time in all clinical setting or there could be different approaches still under discussion. In these occasion the chat allows to have a quick idea about how new or contested protocols have been adopted.

> Sorry but I'm at Evento Era in Rome and they discuss about premenopause and ot! Here experts say that women intermediate-high risk should do lhrh and exe independently from their age. None starts with lhrh and tam but that is considered a shift only in case of collateral effect from lhrh and exe! Is that what you do?

Similarly, the chat can be used to share information regarding administrative requirements and regulations or other not strictly clinical matters.

> Has anyone already started to implement the new directives ("oncology visit with handing over of oral drugs"..) and if yes, did you understand the financial implications?

At times the chat is used to spread news or requiring collaboration in projects. In the period under analysis, several times participants provided information about clinical trial offering colleagues the possibility to join if interested. Enrolling patients can be a burdening task and collaboration with colleagues is of the only viable option to fulfil the requirements of the clinical protocol.

> Girls/boys I take the opportunity of this group to ask if someone is interested in a first line study of brca mutate triple negative patients that will be treated with carbo e pembrolizumab until PD. It's my study and I need to enrol 53 patients in two years: without networking I'll never make it… I'll share the feasibility form if interested. Bye

While the tone of the conversation is colloquial and some not strictly clinical information is shared among participants, the community has drawn a line between admissible and not-admissible content. In one significant case, for instance, one doctor share a joke on immigration and someone responded with emoticons. Later that day, one of the founding members of the chat contacted him/her privately to ask to stick to professional contents.

Discussion and conclusions

The case presented allows to reflect on the complexities and ramifications of what we have termed as 'grassroot infrastructures'. The label evokes the shop-floor level process stemming from the voluntary work of healthcare professional through the use of personal resources. The term also suggests the tinkering and bricoleur-like activities of using raw materials to create unique combination that fits a particular need (Barret 1998).

We refer to infrastructuring to describe the process of setting up the expert opinion service as it emerges from practicing it among participants. The process observed bears only partial resemblance to the most common processes usually observed in the healthcare domain. The main difference is that the technology is pre-existing an not modifiable by users, which do not have access to designer nor are furnished with tools to customize it. The relationships among participants cannot not inscribed in the artefact itself rather they are defined through the interaction. While interaction cannot be structured by design (e.g. imposing limits to text, defining undesirable contents), the repetition without repetition of conversations (Clot and Béguin 2004) allows participants to develop a shared understanding of the ‘correct’ way to perform the practice.

With no institutional involvement or any form of organizational rewards implied, the practice of expert opinion is sustained by the commitment of participants to the group. This reveals the fragile and ephemeral nature of grassroot infrastructures. However, analysis reveals how over time the group develops a sense of communality and a feeling of belonging to a professional community which creates the premises for the resiliency of the infrastructural arrangements and the continuation of the service. Under this light, what is shared besides the mere ‘expert opinion’ proves to be highly relevant to understand why participation to the group is appreciated. By creating connections among dispersed professionals with limited possibilities to have a significant discussion with peers in their daily routines, the expert opinion offers a solution to an unmet need of connectedness and sense of professionals of a subdiscipline. The information needs in complex clinical cases, reassurance and sense of belonging are inextricably intertwined and they are all to be taken into account.

On a separate note, it is worth noting how the ‘grassroot infrastructure’ identified as no connection, at least from a purely technical standpoint, to the existing infrastructures and systems in place and currently used by oncologist in their work routines (for example, systems described in Galligioni et al. 2015, Passsardi et al. 2017). While this may provide some flexibility and no dependency on legacy systems, further research is needed to explore if the lack of communication with systems that are obligatory passage points in key organizational processes may weaken and lead to the abandonment of grassroot infrastructures in the long run.

References

Albritton, K., Barr, R. and Bleyer, A., 2009. The adolescence of young adult oncology. In *Seminars in oncology* (Vol. 36, No. 5, pp. 478-488).

A.A.V.V., 2018, L'utilizzo della chat per il decision making negli scenari clinici complessi di carcinoma mammario (Trans. The use of chat for decision making in complex clinical scenarios of breast cancer). *Unpublished workshop report*.

Band, P.R., 2010. The birth of the subspecialty of medical oncology and examples of its early scientific foundations. *Journal of Clinical Oncology*, 28(22), pp.3653-3658.

Barrett, F.J., 1998. Coda—creativity and improvisation in jazz and organizations: Implications for organizational learning. *Organization science*, 9(5), pp.605-622.

Bourdieu, P., 1990). The logic of practice. *Stanford university press*.

Brooks, R.G. and Menachemi, N., 2006. Physicians' use of email with patients: factors influencing electronic communication and adherence to best practices. *Journal of Medical Internet Research*, 8(1), p.e2.

Béguin, P. and Clot, Y., 2016. L'action située dans le développement de l'activité. *Activités*, 1(1/2), pp.27-49.

Galligioni, E., Piras, E.M., Galvagni, M., Eccher, C., Caramatti, S., Zanolli, D., Santi, J., Berloffa, F., Dianti, M., Maines, F. and Sannicolò, M., 2015. Integrating mHealth in oncology: experience in the province of Trento. *Journal of medical Internet research*, 17(5), p.e114.

Gherardi, S., 2009. Organizational knowledge: The texture of workplace learning. *John Wiley & Sons*.

Gulacti, U., Lok, U., Hatipoglu, S. and Polat, H., 2016. An analysis of WhatsApp usage for communication between consulting and emergency physicians. *Journal of medical* systems, 40(6), p.130.

Karasti, H. and Baker, K.S., 2004, Infrastructuring for the long-term: Ecological information management. In *37th Annual Hawaii International Conference on System Sciences*.

Mars, M. and Scott, R.E., 2016. WhatsApp in clinical practice: A literature review. In *The Promise of New Technologies in an Age of New Health Challenges*, pp.82-89.

Passardi, A., Rizzo, M., Maines, F., Tondini, C., Zambelli, A., Vespignani, R., Andreis, D., Massa, I., Dianti, M., Forti, S. and Piras, E.M., 2017. Optimisation and validation of a remote monitoring system (Onco-TreC) for home-based management of oral anticancer therapies: an Italian multicentre feasibility study. *BMJ open*, 7(5), p.e014617.

Petruzzi, M. and De Benedittis, M., 2016. WhatsApp: a telemedicine platform for facilitating remote oral medicine consultation and improving clinical examinations. *Oral surgery, oral medicine, oral pathology and oral radiology*, 121(3), pp.248-254.

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Structuring Electronic Patient Record Data, a Smart Way to Extract Registry Information?

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Abstract. The paper reports from one of the first efforts to generate data for a national register by automatically reusing data recorded in the clinical documentation process. Today, the process of reporting to national registries implies filling out a paper-based or electronic form as the final step of documenting patients' treatment. The registries' forms are hence not part of the patients' Electronic Patient Record (EPR). Therefore, the Norwegian Directorate for e-health has established a program for developing a shared infrastructure for 51 national registers, aiming to improve the utilization and quality of the reported health data. We argue that the quality of the registries' data rests heavily on an understanding of today's practice and how and when to capture the data. This paper describes the initial work of facilitating automatic reuse of standardized clinical data recorded from the EPR to the Norwegian registry for spine surgery. The empirical setting is the regional FRESK (Future systems in the clinic) program (2017-2022), in the North Norwegian Health Region.

Introduction

In Norway, the government is investing heavily in 3.-4. generation Electronic Patient Record systems (EPRs), offering process - and decision support, and reuse of data for the purposes of quality assurance, research, and management (Ministry of Health and Care Services, 2012; Pedersen et al., 2015). Related to this, different medical specialties have established quality registries to monitor the outcome of their treatments. There are for instance registries for hip replacements, coronary surgery, spine surgery etc. Overall, there are 51 different registries in Norway.

Today, clinical data is recorded in EPR systems, but there exist no automatic reuse of the data to national registries. The present way of reporting to the registries reflects a touted problem of todays' EPR systems, where the documentation of treatment and care is mainly free-text descriptions recorded retrospectively.

On this backdrop, the Norwegian Directorate for e-health has established a program for developing a shared infrastructure for the registers (NDE, 2018). The aim of the Health Data Program (not introduced) is to improve the quality and utilization of health data, simplify reporting to the national health registers and to make data management safer. So far, in establishing an infrastructure that facilitates the utilization of data from different registries, the primary focus has been on the platform and how the connected variables accompanying different registries should be standardized (NDE, 2018). However, we believe that the quality of the registries rests heavily on the input from the EPRs and knowledge of clinical work processes, i.e. when clinical information is recorded and how clinical information can be extracted for secondary purposes.

The research questions posed are therefore: a) How to design a registry form based on reuse of clinical information? b) How should the clinicians participate in the design process?

The case reports from one of the first efforts of automatically generate data for a register purpose by reusing clinical data recorded during the medical treatment and care processes. The overall goal of the project is to integrate primary and secondary data to eliminate double documentation work, to raise the contribution rate for the registry, and minimize data errors by automating the process. The aim of the first phase of the project is to design and integrate an electronic registry form within an openEHR based EPR system used in hospitals in the North Norwegian Health Region, in which clinical data is to be reused for a secondary registry.

We use the theoretical framework of information infrastructures (Bowker and Star 2000; Ulriksen et al, 2017; Silsand and Ellingsen 2016; Hanseth and Lundberg, 2001). This framework contribute with a specific perspective on how designers should 'build upon the existing installed base', in terms of the present clinical documentation process.

Method

The study adheres to a qualitative action research approach, with the objective of contributing to a co-constructive learning process for healthcare personnel, developers, and stakeholders, as well as for the researchers (Baskerville and Myers, 2004). The data was collected through close participation in the design processes related to developing archetypes and forms (see Table I), and will be complemented by interviews, discussions and document studies (Klein and Myers, 1999).

Table I. Data collection from November 2018 to March 2019

Participatory observation	**Meetings/workshops with:**
• Participated in the design process • Mapping variables to archetypes • Design archetypes • Designing templates (OET/OPT) and the form **In total 320 hour.**	• The vendor • Clinicians • Project management • Members of OpenQ-reg Registry • NRUA **In total 50 hours**

Empirically, we draw on the regional FRESK (Future systems in the clinic) program (2017-2022), in the North Norwegian Health Region. This program includes implementing a regional open platform based EPR system, and structuring the clinical information system through the openEHR approach, using archetypes as clinical standards (Christensen and Ellingsen, 2016; Atalag, 2016).

Case

The Norwegian registry for spine surgery (NORspine) aims at improving the quality of surgical treatment for degenerative disorders in the cervical and lumbar spine (Solberg and Olsen, 2017). In 2017, the coverage rate to the registry was only 70, 2 %. Accordingly, it is of great interest to raise this level, and include more data into the registry. Automatically extracting clinical data recorded as part of the EPR documentation process, and exporting the data to the registry is anticipated as a key means to improve the coverage rate and quality for the NORspine registry. Accordingly, the separation of reporting to registries from the clinical documentation process is pointed out as a main reason for the contribution rate lower than the ambition (Solberg and Olsen, 2017).

1) The clinical documentation process

Today, healthcare personnel in the health region mainly uses free-text in the EPR to document treatment and care given during the clinical processes. For clinical purposes, these free text documents are effective for internal knowledge sharing, and support of the daily work, but unsuitable for reusing information within and across EPR systems, to enable clinical decision support (CDS), quality improvement, health monitoring, management, and research.

In the current clinical documentation process, information is stored in several steps and connected documents, e.g. outpatient clinic notes, evaluation notes, surgery notes and discharge notes. In addition, the registry form is not part of the clinical documentation process in the EPR system. Therefore, reporting to national registries implied filling out a paper-based- or an electronic form as the final and separate step of documenting the patients' treatment. Either a physician, or a secretary, based on the physician's instructions, did this. Hence, the separation of the clinical documentation process and reporting to registries increased the clinicians' documentation work. Especially when work was hectic, or in weekends and vacations when fewer clinicians were at work, the reporting to registries was neglected. In addition, there was a risk that part of the information like the patients medication or thrombosis prophylaxis was recorded only in the registry form, and this could cause clinical complications for the patients (Solberg and Olsen, 2017).

2) Designing a structured electronic registry form and integrating it to an openEHR based EPR

In the North Norwegian Health Authority, the implementation of DIPS Arena was expected to enable reuse of EPR data. The system was developed in accordance to the openEHR architecture, using archetypes as flexible information models for structuring clinical data, to enable reuse of information within and between systems. The innovative aspect of the openEHR approach comes from separating the system's generic reference model from the clinical information layer, which implies that the archetypes are developed 'outside' the technical system (Atalag et al., 2016). Each archetype represents a description of a maximum dataset of one clinical concept (e.g. blood pressure), and the information is thoroughly described to be useful in every imaginable clinical use context.

OpenEHR based EPR systems are "empty" systems where the users need to determine and design up-front the archetypes representing the clinical information they expect to create and record during clinical processes. In accordance to the openEHR specification, transforming clinical concepts to archetypes implies an increased level of abstraction because the openEHR idea is aimed at producing an understanding of how information systems can support the creation of information during a generic care delivery process (Beale and Heard, 2007). The development of archetypes is given to clinical communities as a bottom-up standardization approach. To support clinical communities in developing archetypes, the openEHR community provided a web-based tool called the Clinical Knowledge Manager (CKM), whereby healthcare personnel and experienced clinical experts could develop, publish, use and govern the information models. In Norway, a national initiative was established in 2014 to lead this work. When developing the form for the NORspine registry, the first effort was to understand how archetypes could support the need for exchanging variables from the EPR system to the registry and simultaneously support the documentation of the clinical spinal surgery process.

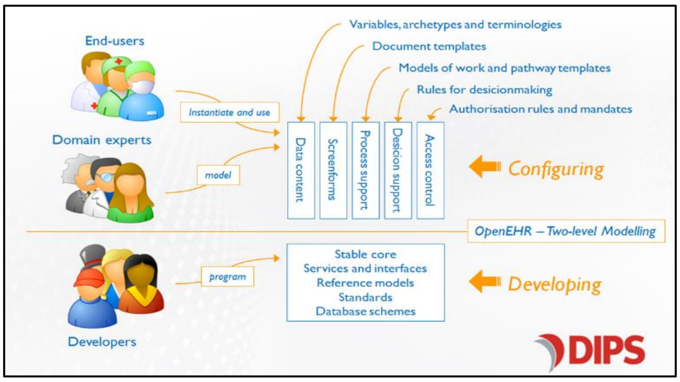

Figure 1. The openEHR platform approach

3) Capturing the variables from steps in the clinical process

In November 2018, the design team in the FRESK Program started to collaborate with NORspine to design a structured registration form to be implemented in the EPR system. The spinal surgeons “ordered” an electronic form that automatically extracted data from different parts of the clinical documentation process and reused the data in the registry form.

The case description is limited to the design process of structuring the registry form by using archetypes, and do not describe the work of transferring data from the EPR to the registry (not finalized). Structuring the registry form for spinal surgery was the first time that standardization work in this scale was done by domain experts (the design team in FRESK) (see Fig. 1), and the first effort in the health region of shifting from unstructured to structured documentation by using archetypes in the EPR system.

In the first phase of the standardization work, the most reasonable course of action was discussed. The point of departure was placing the variables of the existing form into an electronic mind map to have an overview of the relation between archetypes and the registry’s variables, and an overview of where in the clinical documentation process the different variables occurred. The information was categorized as preoperative-, per operative – and postoperative information, in addition to a general category of administrative information. The categorization gave directions for which archetypes to include in which documents corresponding to the different steps of the clinical documentation process. In doing so, the design team collaborated closely with the clinicians to understand their current use of the documents. For example, when and where do they record the clinical information, what are the logic relation between different variables in the registry form, and the relation between clinical needs of specific and unambiguous information compared to the use of more generic variables in the registry form.

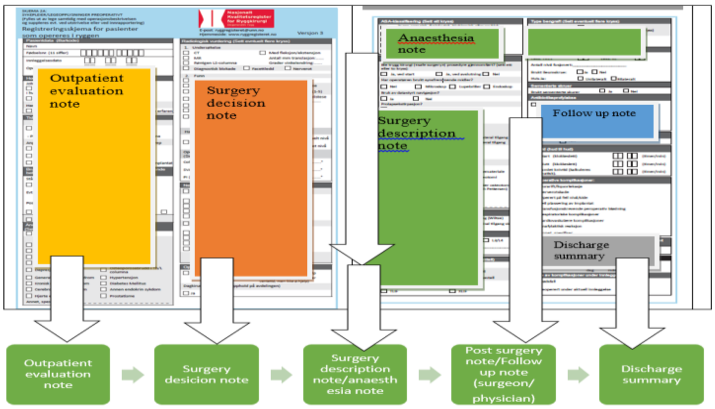

Figure 2. Clinical variables to be included in different clinical notes.

Even if this seemed to be to most appropriate way of starting the design process, the present use of free-text to record clinical information influenced the design process because there was no structured data represented as archetypes to reuse. In addition, the implementation of the new EPR system was in the initial phase, doing stepwise implementation of clinical functionality, but by the time no functionality supporting the surgery process necessary to underpin reuse of information to the registry form. Accordingly, the design process had to change course of action, and a next best decision was made in collaboration with the clinicians towards implementing an electronic registry form in the EPR. In this first version of the form, reuse of clinical information (variables) from the clinical documentation process was not possible as described above, and the clinicians still needed to fill in the form manually. The benefit of the first version was related to 1) including the form in the EPR, and 2) implementing a reminder in the EPR system giving the surgeons the decision to start creating the registry form when medical codes for spinal surgery was recorded. Hence, the vendor had to map the medical procedure codes for spinal surgery and the form. Even if the first version was far from the overall goal of automatically reuse of clinical information, the clinicians saw it as a leap forward compared to the existing form and registration process. With the new form, all documentation – both for clinical as well as registry purposes, is recorded in the EPR, which means that all information is available in the same system, addressing the before mentioned misunderstandings related to recording data in the registry form only.

4) Structuring clinical information for primary and secondary purposes

In parallel with designing the first version, the design team started to develop a more advanced version of the form using national reusable archetypes as an attempt to produce valuable data for both primary and secondary purposes. Balancing such needs raised some design challenges in relation to structuring clinical information. In example, clinical variables for the registry was often defined much more generic compared to variables defined to support clinical purposes. An example illustrated this: In the registry form, a variable is defined as “other endocrine diseases”, and it serves the registry’s need for information. However, this definition was too generic to support clinical needs, and the variable had to be defined and granulated to all the specific endocrine diseases to be useful for clinical purposes. Taking into account that the registry form was the end point of the clinical documentation process within the EPR, structuring clinical information had to be based on the primary purpose of supporting daily work and knowledge sharing. Accordingly, the categories containing more than one disease needed to be structured in several separated archetypes. Then it was necessary to do an underlying mapping of all the diseases related to different categories in the registry form, e.g. “other endocrine diseases”.

Concluding discussion

Designing structured registry forms as part of the EPR, where variables are automatically generated from the clinical documentation process, raised three issues to be discussed related to: 1) the tension between data for primary and secondary purposes, 2) adjust the progression of the design process to the installed base, 3) the clinicians’ expectations and participation in the design process.

1) The tension between data for primary and secondary purposes addresses a need for translation work required to produce valuable data for both purposes. On the one hand, the primarily purpose is to record the patient’s status in point of time, and on the other hand structured elements must also inherent capabilities for secondary use e.g. registry specific information or information important later in the process. This is a complex and time-consuming task that needs to be solved. As described in the case, clinical data is often defined in different terms and levels of granulation in the clinical documents vs registry variables. Even if the variables of the first version of the NORspine form was developed to support the registry purposes, it is of importance to take into account the primary purposes of clinical information when designing the variables, which is to support daily work and knowledge sharing. In accordance to developing an information infrastructure, the design process has to produce variables that technically and socially can support prospective needs of a growing II (Hanseth and Lundberg, 2001). Therefore, it is necessary to dig into the complex process of standardization, for example deciding

which clinical information is necessary to standardize, defining where in the clinical process the standardized information first occur, and where can the information be reused as it is or need an quality approval. There are several issues related to standardization. In addition, governance of the standards and of reuse of information is a complex topic in it selves.

2) In relation to the progression of the design process, it is important to balance the design process to the installed base, in this case represented by the present system, existing documentation practice and absence of structured clinical information. In addition, the stepwise implementation of the new EPR also set directions for the progress of designing the registry form. To comply with the premises from the installed base, the design process was tailored to be in sync with the implementation progress of DIPS Arena. The difficult question to answer is, what is possible to achieve when changing from using unstructured, free-text notes to a structured clinical documentation practice enabling reuse of information and exchange to secondary purposes? Because there is a balance between the prospective goal, and the progression and necessary changes of the socio-technical system, to reach the goal. Nevertheless, when developing an II, it is of importance to come up with a solution that persuade the clinicians to adopt, even if the solution (the registry form) is in its premature state (Hanseth and Lundberg, 2001). This bring the discussion over to the next issue, how to comply with the clinicians' expectations and participation in the design process.

3) In this case, the clinicians had initiated the cooperation of designing the new form, and they were informed about the stepwise progress towards automatically reuse of clinical information. More interesting is the upcoming work of designing the next version of the form, where information from the clinical documentation process is to be defined and developed. It is of importance that clinicians find the use of structures notes meaningful to prevent them for continuing using only the free-text field in the notes, accordingly, there has to be some instant profits. Reuse of already recorded information into other documents and forms is a "carrot" that the clinicians themselves long for, in addition to using the data for quality improvements on site, as well as generation of a future knowledge basis as part of advanced clinical decision support.

There are unsolved issues related to the implementation of the new form, which also point to the need for clinical participation. Based on previous research, implementation of new forms, tools etc. in clinical practice influence organisational - and workflow processes (Silsand and Ellingsen, 2016). Accordingly, there will be tensions related to the existent practice of using the paper-based form and the implementation of the new electronic form that need to be recognized and solved.

Finally, the quality of reliable and unambiguous data into national registries rests heavily on the input. Therefore, the focus to improve the utilization and quality of health data at a national level, needs to start with structuring the clinical documentations processes, and addresses the need for more research on the discussed issues.

References

Atalag, K., Beale, T., Chen, R., Gornik, T., Heard, S. and McNicoll, I. (2016): openEHR—a semantically enabled, vendor-independent health computing platform, URL: http://www.openehr.org/resources/white_paper_docs/openEHR_vendor_independent_platform.pdf.

Baskerville, R. and Myers, M. (2004): 'Special Issue on Action Research In Informaton Systems: Making IS Research relevant to practice foreword', *Manag Inf Syst Q*, vol.28, no.3.

Christensen, B. and Ellingsen, G. (2016): 'Evaluating Model-Driven Development for large-scale EHRs through the openEHR approach', *International Journal of Medical Informatics*, vol. 89, pp. 43-54.

Hanseth, O. and Lundberg N. (2001): 'Designing work oriented infrastructures', *Computer Supported Cooperative Work (CSCW),* vol. 10, no. 3-4, pp. 347-372.

Klein, H.K. and Myers, M. (1999): 'A Set of Principles for Conducting and Evaluating Interpretive Field Studies in Information Systems', *MIS Quarterly*, vol. 23, no.1, pp. 67-94.

Ministry of Health and Care Services, (2012): Whitepaper. no. 9 (2012 - 2013): "One citizen – one Health Record". Whitepaper. 9 https://www.regjeringen.no/no/dokumenter/meld-st-920122013/id708609/sec1.

The Norwegian directorate of eHealth (NDE) (2018): The healthdata program - masterpresentation**:** https://ehelse.no/Documents/Helsedataprogrammet/Masterpresentasjon%20Helsedataprogrammet%202019.pdf

Pedersen, R., Wynn, R. and Ellingsen, G. (2015): 'Semantic Interoperable Electronic Patient Records: The Unfolding of Consensus based Archetypes'. *Studies in Health Technology and Informatics*, vol. 210, pp. 170-174.

Silsand, L. and Ellingsen, G. (2016): Complex Decision-Making in Clinical Practice, *Computer Supported Cooperative Work (CSCW)*, San Fransisco.

Solberg, T. and Olsen L. R. (2017): National quality registry for spinal surgery (NKR) - Annual report for 2017, SKDE, University hospital North Norway**:** https://unn.no/Documents/Kvalitetsregistre/Nasjonalt%20kvalitetsregister%20for%20ryggkirurgi/%C3%85rsrapporter/%C3%85rsrapport_NKR_2017.pdf

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Infrastructuring knowledge in practice: designing self-experiments for type 2 Diabetes care

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Abstract. Healthcare institutions increasingly delegate the self-management of their condition to patients and their extended network: consequently, there is an increasing production of patient health data outside healthcare settings, also thanks to the increasing number of digital technologies able to assist in the collecting, interpretation and use of health data. This shift on the "personal" dimension of data has placed emphasis on self-knowledge practices supported by personal informatics systems. In the last years, studies on digital technologies supporting lifestyle-related diseases are becoming interested in the so-called "personal experiments", emphasizing self-interpretation of patient-generated health data through self-reflection. In this paper I will present some preliminary points concerning my PhD research project, in which I'm following the co-design and implementation of technology-supported personal experiments aiming to encourage type 2 diabetes patients to collect personal health data and increase their motivation and self-knowledge.

Introduction

In recent years in the healthcare sector there has been a growing emphasis on self-knowledge practices supported by personal informatics systems, shifting the attention on the "personal" dimension of health data (Gherardi et al. 2018). This is despite health care services sometimes obstruct rather than support self-care and learning (Cooper at al. 2003), because the ethics of individualism (i.e. blaming the individual patient), because the privileging of experts over lay people and because a one-way flow of information (Gravois Lee and Garvin 2003). The increasing production of patient health data outside healthcare settings is made easier by the growing number of digital technologies able to assist in the collecting, interpretation and use of health data (Piras 2016, 2018). In numerous clinical settings, patients are required to keep track of parameters for various purposes (e.g. management, diagnosis) and in some cases, the objective of the patient–provider encounter itself is the analysis of self-tracked data. This collection specifically denotes the monitoring of data that can only be collected by patients themselves, sometimes also referred to as 'observation of daily living' (Brennan & Casper, 2015). Recently, studies on personal informatics systems supporting lifestyle-related diseases are becoming interested in the so-called "personal experiments", a collection of data based on self-tracking but with a particular emphasis on self-interpretation of data through a structured self-reflection. In the next paragraphs I will present the background and motivation of my PhD project, aimed to investigate how personal experiments goes into the process of knowledge and management of type 2 Diabetes, affecting the daily care practices of patients and their relationship with providers.

From collection to reflection: self-experiments

The starting point of my PhD project has been to explore and try to give an order to literature about systems and methodologies that support the conduction of "self-experiments" aimed to collect health data for self-knowledge. These approaches has been explored especially by studies on Personal Informatics (PI), defined 'those that help people to collect personally relevant information for the purpose of self-reflection and gaining self-knowledge' (Li et al. 2010, 558). The advent of digital technologies has been vitally important in promoting the cause of PI. Mobile and wearable digital devices have facilitated the ever more detailed measurement and monitoring of the body and everyday life in real time and the analysis, presentation and sharing of these data (Lupton 2014). The conventional approach driving personal informatics systems in the field has been self-betterment through self-knowledge, potentially enabling the arising of self-discoveries, self-reflection, and triggering processes of behaviour change (Choe et al. 2014; Rapp et al. 2018). In recent years PI has been expanded to include the so-called "lifestyle related diseases," including metabolic syndrome, obesity, cardiovascular disease and type 2 diabetes (Heymsfield & Wadden 2017; Arsenault & Després 2017; Van Ommen et al. 2018). This shifting has led to a growing interest in production of personal health data outside healthcare settings. From this perspective, PI can be employed as an intervention technique for behavior recording and producing a change in behaviour itself (Consolvo et al. 2006, Matthews & Doherty 2011; Rapp et al. 2018). Following this stream, some studies have been shifted the focus on self-experimentations or personal experiments (Daskalova et al. 2016; Karkar et al. 2015; Lee et al. 2017; Kocielniket al. 2018). The "experiment" can take place independently or in collaboration with health providers and usually requires three standardized phases: formulating a hypothesis (es. "does physical activity impact my glycemic index?"), testing the hypothesis (measuring glycemic index before and after doing physical activity) and examining the results of the study through reflection (Karkar et al. 2015; Lee et al. 2017). The hypothesis is testing using "paired testing" (Parkin et al. 2009; Greenwood 2015), a process that includes defining independent variables (e.g., causes, triggers) and the dependent variables they may affect (e.g., symptoms, health outcomes). Technology for self-experimentation can be included in this process: traditional self-tracking methods, such as food journals or fitness trackers, may be adopted to collect data and tests hypotheses. Patients can then use findings to target the most appropriate health behavior change to address their needs.

A key-concept of personal experiments is that of “self-reflection”: patient is involved in both collection and reflection on the data at the end of the experiment. (Baumer 2015; Li et al. 2010; Greenwood 2016). Clinicians have a significant role in the final reflection: they can encourage the person’s problem-solving skills by asking questions (e.g.: “Review the comments you made during the week. What can you learn from these notes?”, or “What changes can you make next week? What would you like to learn?”) helping them to reflect on their week. According to literature, reflecting on their data patients can increase their self-knowledge and formulate realistic behavior change goals (Lee et al. 2015; Kocielnik et al. 2018). However, as for the reflection phase, a gap exists in understanding how the reflection process can be supported through technology (Slovak et al. 2017; Baumer 2015; Fleck and Fitzpatrick 2010; Baumer et al. 2014). Indeed, one first means of facilitating reflection in behavior change and personal informatics relies on visualizations of self-tracking data, assuming that reflection will occur naturally when data is presented (Kocielnik et al.2018). One second means is based on conversational systems that delivers a structured reflection prompts on 3 levels based on learning theory: Noticing, Understanding, and Future Actions (Fleck and Fitzpatrick 2010; Moon 2013). A third means could be to integrate a motivational interviewing approach that can help patients identify their strengths and challenges and what changes they can implement in an action plan (Greenwood 2015).

As illustrated in the previous paragraphs, although the emphasis of personal-experiments on the importance of self-experience, literature describes the process as strictly standardized and methodologically rigorous. Analysis on self-knowledge are limited to the “reflection” phase, conceived as a well-defined moment that follows a structured script. These approaches are especially focused on the development of persuasive systems and on the evaluation of behavioral and clinical outputs, but seeks to overshadow the broad processes and infrastructures through which, during the use of a technology, knowledge practices take place.

The case study: infrastructuring self-experiments for type 2 diabetes

My PhD research project is flanking a clinical trial conducted in north Italy and aimed at quantifying the effectiveness and the acceptability of a self-tracking/remote-monitoring platform for type 1 and 2 diabetes patients. The system includes a web interface for the doctor (medical dashboard) and a mobile interface for the patient (app). The web-based dashboard accessible by doctors was endowed with a system of rule-based alarms designed to send an alert to clinicians and/or patients in the presence of certain data or combinations of data, and permits to the doctor to activate or not activate the functions of the app, depending on patient’s needs. The app for the patient is prescribed by the doctor and supports the management of diabetes, partly through virtual coaching, and partly sharing data with the doctor. The virtual coaching intervention is preceded by a self-care profiling phase and a patient's lifestyles analysis. The main features of the app are patient's diary, on-demand educational modules, microlearnig activities, a virtual coach intervention to support lifestyle goals defined with clinician, a chat with other patients and a chat with clinicians. It is also expected the design and implementation of a digital support for the execution of personal experiments. The idea is that clinician could prescribe the experiment from his/her dashboard, "personal experiment" feature would support patients during the data collection -sending reminders and motivational messages- and at the end of the experiment provider would encourage patient's reflection on their data asking them focused questions. The more long-term goal of the implementation of this feature is to design and implement a chatbot-based conversation that would permit to patients to reflect independently on their data. The whole implementation process is shown in the figure below, that includes also a preliminary phase during which personal experiments will be conducted using a paper diary, according to a co-design approach. And that's where my doctoral project came in.

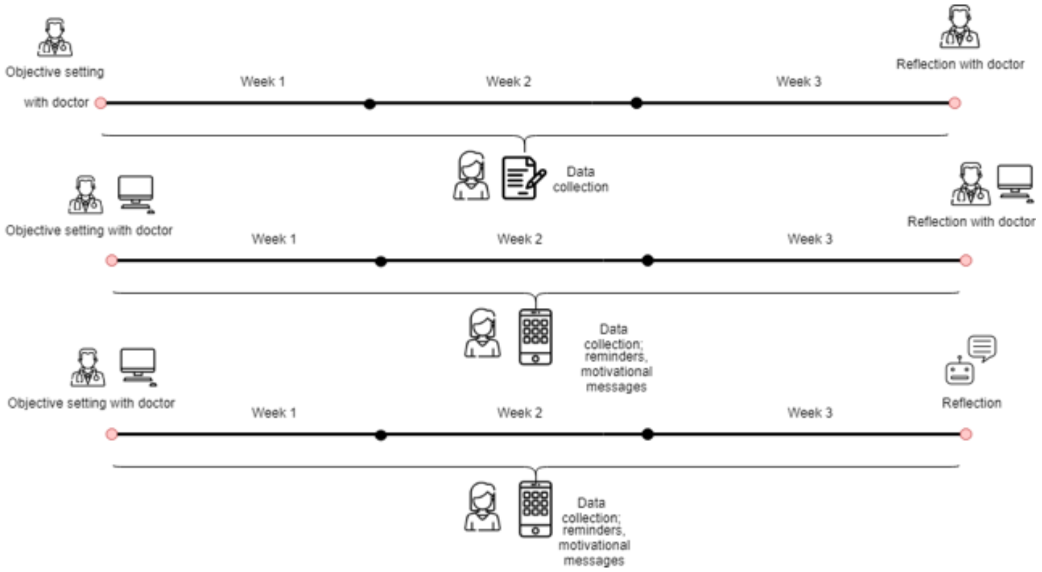

Figure 1. Implementation process

Type 2 Diabetes

The case study introduced in this paper is therefore part of this larger infrastructural arrangement and will explore type 2 diabetic patients' experience and practice of personal experiments as part of their medical treatment. Indeed, type 2 diabetes (T2D) seems to be an interesting setting to explore digitally-supported personal experiments. T2D is a "genotype-environment interaction disease", where the diabetic phenotype is expressed as a result of accumulated environmental pressures (wrong diet, too little physical exercise, disrupted sleep, and too much stress) in concert with genes that render individuals susceptible to the disease (Van Ommen et al. 2018). The chances of getting T2D increase with age and often occurs in combination with other symptoms and diseases such as overweight and cardiovascular diseases. T2D is quite mute and can remain unnoticed for several years without the diabetic experiencing the disease very concretely. Such as other chronic conditions, T2D need long-term approach to care, which imply a higher synergy and service integration outside of the institutional boundaries of hospitals. To be a type 2 diabetic thus entails that you learn to be diabetic, and that you must continue to be so for the rest of your life (Maunsbach 1999). Since it is mostly treated through a combination of medication and lifestyle changes, such as dieting and physical exercise, it must include the patient's active participation in both the treatment and the preventive actions against further development of the disease. Hence, patient empowerment is central to the diabetic condition in order to enable diabetics to participate actively and rationally in their treatment (Danholt et al. 2004). Studies explored the effectiveness of mHealth interventions in modifying type 2 diabetes patients lifestyles, especially those related to dietary behaviors and physical activity, by facilitating diabetes self-management processes outside the clinical setting (Cotter et al. 2013; Holts, Loring).

Personal experiments as sociotechnical infrastructure

Although contextual informations and personal knowledge provided by patients and caregivers are relevant, their contribution is often underestimated as an integral part of a work of articulation of care that remains invisible or underestimated (Unruh e Pratt 2008; Piras e Zanutto 2010; Gherardi et al. 2018). Therefore, my intention is to consider personal experiments as organizational arrangements and knowledge forms that are to be weaved into existing healthcare structures. On that basis, P.E. are sociotechnical infrastructures of care permeating the daily lives of patients and health professional and that may have implications for what it means to be a patient (and a health professional) and what constitutes care in practice (Langstrup 2013). In order to analyze P.E. from this point of view, I draw on perspectives from Science and Technology Studies and in particular on processes through which the diabetic patient learns to manage his/her illness (Mol, 2000; Mol e Law, 2004; Bruni e Rizzi, 2013; Miele, Piras 2016). The studies of Annemarie Mol, in particular, show how diabetes management is a situated and emerging activity that involves first of all the patient's body, technologies and therapies, leading the individual to develop their knowledge about the disease. Health data tracking has a situated meaning, and specific sense of clinical self-tracking must be considered in the context of the organisational practices of which it is part (Gherardi, 2010; Oudshoorn, 2012). The same self-tracking activities may be performed to delegate an active role to patients, to monitor their compliance, to educate newly diagnosed patients or to delegate most of the care to patients themselves. From this perspective, technologies allow patients to redefine their identity, renegotiate the power relationship with health professionals and become experts in their illness (Ballegaard et al. 2008). This is because management tools "do much more than passively record an act" (Mol 2000, 9), becoming an essential part of the process that leads the patient to become autonomous from the doctor and, at the same time, orienting him to assimilate part of the medical role, internalizing the practices and changing their gaze on data and measurements (Miele, Piras 2016). Observed through these lenses, P.E. are part of a context in which care practices are complex activities learned over time through continuous trials and errors, carefully studying your body and its reactions to various attempts to treat it and bring it to a state of well-being.

Conclusions and next steps

Starting from these considerations, my main research interest is to investigate how personal experiments fit into the daily care practices of persons with type 2 Diabetes, affecting the processes of knowledge and management of their illness.

Starting from this research interest, I am facing the following points of analysis:

- *The learning processes triggered by personal experiments,* observing the forms of appropriation and knowledge of personal experiments as sociotechnical infrastructures that involve the patient's body, objects, technologies, contexts and relations.
- *The ways in which in which personal experiments, and in particular the final reflection on personal data, affect the motivation* of persons with type 2 diabetes to maintain a correct lifestyle and, in the long term, affect their behavioral change.
- *The ways in which personal experiments fits in the doctor-patient relationship,* observing how technology becomes part of the doctor-patient relationship and affects existent educational and motivational practices.

Before starting the empirical study, I am planning to do two focus groups with clinicians and with diabetic patients, and a co-design workshop with diabetic patients to gather reactions to the self-experimentation process, to explore how self-experimentation fits with participant priorities and to design a first paper instrument.

During the empirical study, in order to explore educational and motivational efficacy of personal experiments, I am planning to do motivational interviews and questionnaires on self-efficacy and health literacy. In order to explore learning processes triggered by personal experiments, I set out to do semi-structured interviews with patients with diabetes after personal experiments.

In order to explore personal experiments inside the doctor-patient relationship, I propose to do semi-structured interviews with doctors before personal experiments and ethnographic observations of clinical encounters before and after the carrying out of personal experiments.

At the end of the empirical study, during which personal experiments will be conducted through a paper diary, the results will be delivered to the developers of the app, in order to implement a more efficient and user-centered instrument.

References

Arsenault, B. J., and Després, J. P. (2017): 'Cardiovascular disease prevention: lifestyle attenuation of genetic risk'. *Nature Reviews Cardiology*, *14*(4), 187.

Ballegaard, S. A., Hansen, T. R., and Kyng, M. (2008, April): 'Healthcare in everyday life: designing healthcare services for daily life'. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems* (pp. 1807-1816). ACM.

Baumer, E. P. (2015, April): 'Reflective informatics: conceptual dimensions for designing technologies of reflection'. In *Proceedings of the 33rd Annual ACM Conference on Human Factors in Computing Systems* (pp. 585-594). ACM.

Baumer, E. P., Khovanskaya, V., Matthews, M., Reynolds, L., Schwanda Sosik, V., and Gay, G. (2014, June): 'Reviewing reflection: on the use of reflection in interactive system design'. In *Proceedings of the 2014 conference on Designing interactive systems* (pp. 93-102). ACM.

Bruni, A., and Rizzi, C. (2013): 'Looking for Data in Diabetes Healthcare: Patient 2.0 and the Re-engineering of Clinical Encounters'. *Science & Technology Studies*.

Choe, E. K., Lee, N. B., Lee, B., Pratt, W., and Kientz, J. A. (2014, April): 'Understanding quantified-selfers' practices in collecting and exploring personal data'. In *Proceedings of the SIGCHI Conference on Human Factors in Computing Systems*(pp. 1143-1152). ACM.

Consolvo, S., Everitt, K., Smith, I., and Landay, J. A. (2006, April): 'Design requirements for technologies that encourage physical activity'. In *Proceedings of the SIGCHI conference on Human Factors in computing systems* (pp. 457-466). ACM.

Cooper, H., Boothe, K. & Gill, G. (2003) Using combined research methods for exploring patient education. *Patient Education and Counseling* 51(3), 45– 52.

Cotter, A. P., Durant, N., Agne, A. A., and Cherrington, A. L. (2014): 'Internet interventions to support lifestyle modification for diabetes management: a systematic review of the evidence'. *Journal of Diabetes and its Complications*, *28*(2), 243-251.

Daskalova, N., Metaxa-Kakavouli, D., Tran, A., Nugent, N., Boergers, J., McGeary, J., and Huang, J. (2016, October): 'SleepCoacher: A personalized automated self-experimentation system for sleep recommendations'. In *Proceedings of the 29th Annual Symposium on User Interface Software and Technology* (pp. 347-358). ACM.

Danholt, P., Bødker, K., Hertzum, M., and Simonsen, J. (2004, January): 'Healthcare IT and Patient Empowerment: The case of diabetes treatment'. In *Artful Integration: Interweaving Media, Materials and Practices. Proceedings of the eight Participatory Design Conference* (pp. 80-83).

Fleck, R., and Fitzpatrick, G. (2010, November): 'Reflecting on reflection: framing a design landscape'. In *Proceedings of the 22nd Conference of the Computer-Human Interaction Special Interest Group of Australia on Computer-Human Interaction*(pp. 216-223). ACM.

Gherardi, S., Piras, E. M., and Zanutto, A. (2018): 'Quanto è «personal» il «Personal Health Record»? Tecnologia ed empowerment del paziente diabetico'. *Social Policies*, (2), 179-200.

Gravois Lee, R., Garvin, T. (2003): 'Moving from information transfer to information exchange in health and health care'. *Social Science and Medicine* 56, 449– 464.

Greenwood, D. (2015): 'Better type 2 diabetes self-management using paired testing and remote monitoring'. *AJN The American Journal of Nursing*, *115*(2), 58-65.

Heymsfield, S. B., and Wadden, T. A. (2017): 'Mechanisms, pathophysiology, and management of obesity'. *New England Journal of Medicine*, *376*(3), 254-266.

Karkar, R., Zia, J., Vilardaga, R., Mishra, S. R., Fogarty, J., Munson, S. A., and Kientz, J. A. (2015): 'A framework for self-experimentation in personalized health'. *Journal of the American Medical Informatics Association*, *23*(3), 440-448.

Kocielnik, R., Xiao, L., Avrahami, D., and Hsieh, G. (2018): 'Reflection Companion: A Conversational System for Engaging Users in Reflection on Physical Activity'. *Proceedings of the ACM on Interactive, Mobile, Wearable and Ubiquitous Technologies*, *2*(2), 70.

Langstrup, H. (2013): 'Chronic care infrastructures and the home'. *Sociology of health & illness*, *35*(7), 1008-1022.

Lee, M. K., Kim, J., Forlizzi, J., and Kiesler, S. (2015, September): 'Personalization revisited: a reflective approach helps people better personalize health services and motivates them to increase physical activity'. In *Proceedings of the 2015 ACM International Joint Conference on Pervasive and Ubiquitous Computing* (pp. 743-754). ACM.

Lee, J., Walker, E., Burleson, W., Kay, M., Buman, M., and Hekler, E. B. (2017, May): 'Self-experimentation for behavior change: Design and formative evaluation of two approaches' In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (pp. 6837-6849). ACM.

Li, I., Dey, A., and Forlizzi, J. (2010, April): 'A stage-based model of personal informatics systems'. In *Proceedings of the SIGCHI conference on human factors in computing systems*(pp. 557-566). ACM.

Lupton, D. (2014, December): 'Self-tracking cultures: towards a sociology of personal informatics'. In *Proceedings of the 26th Australian computer-human interaction conference on designing futures: The future of design* (pp. 77-86). ACM.

Miele, F., and Piras, E. M. (2016): 'Learning How to Cure Oneself, Inside and Outside School: Diabetes Selfmanagement as Socio-material Practice'. *Scuola democratica*, *7*(1), 139-158.

Mol, A. (2000): 'What diagnostic devices do: the case of blood sugar measurement'. *Theoretical medicine and bioethics*, *21*(1), 9-22.

Mol, A., and Law, J. (2004): 'Embodied action, enacted bodies: The example of hypoglycaemia'. *Body & society*, *10*(2-3), 43-62.

Moon, J. A. (2013). *Reflection in learning and professional development: Theory and practice*. Routledge.

Parkin, C. G., Hinnen, D., Campbell, R. K., Geil, P., Tetrick, D. L., and Polonsky, W. H. (2009): 'Effective use of paired testing in type 2 diabetes'. *The Diabetes Educator*, *35*(6), 915-927.

Piras, E. M. (2016): 'The Changing Locus of Health Data Production and Use: Patient-Generated Health Data, Observations of Daily Living, and Personal Health Information Management'. *arXiv preprint arXiv:1606.09589*.

Piras, E. M. (2018): 'Kairotic and chronological knowing: diabetes logbooks in-and-out of the hospital'. *Data Technologies and Applications*, *52*(1), 148-162.

Piras, E. M., and Zanutto, A. (2010): 'Prescriptions, x-rays and grocery lists. Designing a Personal Health Record to support (the invisible work of) health information management in the household'. *Computer Supported Cooperative Work (CSCW)*, *19*(6), 585-613.

Rapp, A., Marcengo, A., Buriano, L., Ruffo, G., Lai, M., and Cena, F. (2018): 'Designing a personal informatics system for users without experience in self-tracking: a case study'. *Behaviour & Information Technology*, *37*(4), 335-366.

Slovak, P., Frauenberger, C., and Fitzpatrick, G. (2017, May): 'Reflective practicum: A framework of sensitising concepts to design for transformative reflection'. In *Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems* (pp. 2696-2707). ACM.

Unruh, K. T., and Pratt, W. (2008, November): 'The Invisible Work of Being a Patient and Implications for Health Care:"[the doctor is] my business partner in the most important business in my life, staying alive."'. In *Ethnographic Praxis in Industry Conference Proceedings* (Vol. 2008, No. 1, pp. 40-50). Wiley/Blackwell (10.1111).

Van Ommen, B., Wopereis, S., van Empelen, P., van Keulen, H. M., Otten, W., Kasteleyn, M., ... and Evers, A. W. (2018): 'From Diabetes Care to Diabetes Cure—The integration of Systems Biology, eHealth, and Behavioral Change'. *Frontiers in endocrinology*, *8*, 381.

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Expanding hospital infrastructures: boundary resources for peripheral actors

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Abstract. Fostering innovation while maintaining a traditional IT infrastructure is challenging. We have conducted a qualitative study in the health sector, following three ICT-related innovation initiatives in a hospital. The innovators sought to connect the new solutions with the complex hospital digital infrastructure but the governance regime was not conducive to experimental development. We describe the challenges of relating to the existing information infrastructure and thereby identify the requirements for innovative projects to be sustained. In our analysis we zoom-in on the problematic "meeting points" between the innovation initiatives and the pre-existing infrastructure, as these reveal which capabilities and resources are required for the existing infrastructure to accomodate novelty. Conceptually, we frame these as boundary resources. Our study contributes a concrete description of the resources that are required if large, entrenched infrastructures shall be able to harness innovation.

Introduction

Digital health infrastructures provide support to multiple different activities catering for a range of potential users and types of use currently and in the future (Pollock & Williams, 2010). Due to the inherent capabilities of new digital technologies (for instance, recombination and extensibility), digital infrastructures can be the basis for making healthcare smarter enabling the introduction of novel digital solutions to address problems and improve performance. Neverthless, even though innovations in medical devices and clinical procedures are revolutionising medical practice, everyday "information work" within hospitals is not characterized by “smartness” as digital capabilities are not sufficiently exploited. Information work includes exchanging information and documenting information exchanges between healthcare practitioners within and across health organisations. It also includes the work entailed in exchanges between practitioners and patients related to the provision of care. Overall, hospital digital infrastrucures are slow in supporting novelty and are known to be lagging behind in terms of providing support for information exchanges (Afferni et al., 2018). This paper is researching the problem of extending hospital infrastructures to support information work by connecting novel peripheral solutions.

Our research is empirically grounded on the analysis of innovation initiatives within a Norwegian hospital that offers multidisciplinary rehabilitation to patients with complex functional impairment following illness or injury, and has a strong emphasis on research and innovation. We analysed three different initiatives to introduce new solutions related to information sharing. Following the trajectories of these initiatives, we traced challenges of relating to the existing digital infrastructure and identified the requirements for enabling innovative extensions of complex and heavily regulated hospital infrastructures. In our analysis we zoom in on the problematic “meeting points” between the innovation initiatives and the pre-existing infrastructure.

Theoretically, we leverage the concept of boundary resources which we draw from the research literature on platforms and ecosystems (Ghazawneh & Henfridsson, 2013). Platform architectures include a core and several peripheral modules (often developed by third parties) that interact through standardized interfaces. Boundary resources are the key means for exposing and extending the core and can be both technical and social in nature. For instance, application programming interfaces (APIs) are the most common type of technical boundary resources, while regulations, incentives and guidelines are examples of social boundary resources.

Our findings show the critical role of boundary resources for the introduction of novel digital services and their embedding to the pre-existing information infrastructure. Boundary resources serve as the interface between the core systems that are part of hospital infrastructures (e.g. Electronic Patient Record Systems) and new external applications that need to connect and build upon the capabilities of core systems. They are the key means for exposing the infrastructure core facilitating innovative development from the periphery.

Method

We performed a revelatory case study (Yin, 1994; Sarker et al., 2012) to reveal the needs and requirements for infrastructural embedding of novel digital capabilities. Thus, we selected initiatives where there was a challenging relation to the pre-existing information infrastructure. Data collection for this research includes formal interviews with staff in the hospital's IT department, project managers, project participants, clinical staff (users) and less formal updates on project progress through conversations with project managers. Important data sources were the status reports, project documents and presentations that were reviewed for factual information. In summary, the research reported is based on data collected using a combination of fieldwork and documents' analysis.

The analysis of empirical material was performed from an infrastructure perspective informed by the concept of boundary resources (Ghazawneh & Henfridsson, 2013; Hanseth et al., 1996; Ribes & Finholt, 2009). Our concern has been to let empirical detail guide the development of insights. Thus, we followed closely the the trajectories of the initiatives studied. We analysed our material to understand how the initiatives met with the existing infrastructure and how they grappled with the related challenges.

Overview of Empirical Cases and Key Findings

Three initiatives related to the introduction of new digital solutions for information sharing were analysed. An overview of the three iniatives is provided in Table I.

Table I. Overview of the three hospital initiatives studied

Initiative	Key aim	Brief trajectory
Scheduler	Information sharing for patient schedules for e.g. tests, physical exercise, or speech therapy. The schedules were earlier printed in multiple copies and distributed across the hospital. A digital version would be more easily updated and shared.	The vendor of a University Scheduling solution offered a test of the (web-based) solution. A pilot (without integration to EPR system) was successfully conducted and a scaling strategy planned. Gaining access to core infrastructure (for data exchange) proved challenging. The solution remained "stand alone".
Mobile Movement	Information transfer from patients to clinicians through a clinician devised solution for distributed harvesting of sensor data (for movement analysis). Enabling remote patient training and interaction with therapists.	The project successfully secured funding and a prototype for sensor data harvesting and analysis was developed. For the next step of testing there was a need for secure data storage and ideally integration with EPR to enter data. The project is on hold.
Bedside Data Harvester	Information registration by clinical personnel on a mobile tool for clinical documentation and communication. Enabling data entry on the move to improve work efficiency during documentation.	A prototype (based on extensive observations of clinical work) was tried out, first in a mockup version. Technical integration with the hospital infrastructure is pursued for pilot implementation (ongoing).

The trajectories of the three initiatives show that in the hospital under study it was possible to conceptualise and to develop proof of concept solutions for novel digital services. Nevertheless, taking a step further and making the new solutions an integral part of the existing infrastructure was very challenging. Specifically, it was not possible to implement two-way communications and data exchanges with the core systems. Furthermore, it was not possible for the peripheral applications to use the secure storage facilities that serve the core systems of the hospital. Additionally, the further development and testing of the new peripheral applications was impeded as it was not possible to get access to realistic data or to test and experiment wiithin a comprehensive sandbox environment fully mirroring the production environment. In other words, it was not possible to use resources that would allow peripheral actors to gain *insight* into the infrastructural core through actual probing and experimentation. Furthermore, we found that the novel solutions could not benefit from the infrastructural dynamics because the peripheral actors were not *vested* with rights for leveraging existing infrastructural components or for deploying their solutions for other users within other hospitals currently sharing the same overall infrastructure.

Ghazawneh and Henfridsson, used the concept of boundary resources to theorise on the evolution of platforms and their ecosystems and found that the development of such resources was driven by: a) the aim of platform owners to secure control b) their aim for enhancing scope and diversity through third party resourcing (Ghazawneh & Henfridsson, 2013). For our research, we use this platform-related concept to look at infrastructural arrangements beyond platforms studying the interplay between the infrastructure core and new applications in the periphery. Ghazawneh and Henfridsson identified two types of boundary resources: securing resources (i.e. resources to increase control) and resourcing (i.e. resources to enhance scope and diversity). Drawing from our findings, we supplement the two types of resources identified by Ghazawneh and Henfridsson adding two more that relate to the needs of peripheral actors. Specifically, we named these additional types: discovery resources and vesting resources. Figure 1 provides an overview of the different types of boundary resources.

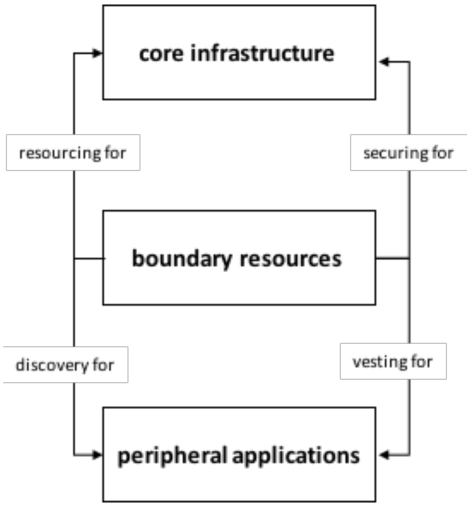

Figure 1. Overview of the four types of boundary resources

Discovery resources allow peripheral actors to gain insight into the infrastructural core through actual probing and experimentation. Periphery actors need to make sense of the possibilities and limitations of the core, ensuring some level of visibility into it. Vesting resources relate to arrangements for the appropriation of benefits, e.g. related to rights for exploiting the existing infrastructure or the new data streams. The two additional types of boundary resources reflect the needs of peripheral actors and complement the types of resources that reflect the concerns of those that control the core hospital infrastructure. In table II we provide examples of the concerns that relate to the four different types of resources.

Table II. Boundary Resources for the three initiatives

		Scheduler	**Mobile Movement**	**Bedside Data Harvester**
Perspective from the core	**Securing**	Need to protect sensitive data (in EPRs) from access by third-party cloud solution. Requiring the application to run within the secure environment. Limited resources offered relying on regulation.	Need for generic data storage facilities (not only for core systems' data). No such resources available (only development environment).	Need for adherence to IAM solution (Identity and Access Management) and MDM (Mobile Device Management).
	Resourcing	Limited interest to expand based on third parties. Lack of relevant resourcing boundary resources.	Boundary resource was planned but not provided (because regional resources prioritized core systems).	Available APIs for access to EPR data. APIs to feed data but not to receive.
Perspective from the periphery	**Discovery**	Need to use the EPR possibilities regarding demographic and logistics´ information. Not having access implied double work of manually copying information and also limited generativity of new types of functions.	Need to make sense of capabilities for secure storage of measurements now and in the near future. Also, visibility into analysis capabilities required for further development.	Need to be able to test/operate against the concrete production configuration (not a test instance). No test data available to third parties. Services for real life testing needed.
	Vesting	The vendor expands in healthcare but not clear if it would be possible to appropriate benefits beyond a single hospital to compensate for costs.	Potential data ownership and management issues. Requires related decisions.	Reuse data (based on employee consent) for analysis and learning. Decisions needed for data ownership and management.

Discussion

Focusing to the interface between the infrastructural core and the periphery, our study complements prior research which addresses mostly the concerns of keystone players (Dal Bianco et al., 2014; Eaton et al., 2015; Ghazawneh & Henfridsson, 2013). We add the perspective of actors that aim to link new peripheral components to an infrastructure core. Specifically, we extend the concept of boundary resources to include also types of resources relate to the needs of peripheral actors (discovery and vesting) going beyond the concerns for securing and resourcing.

As shown in the initiatives studied, novel services may emerge out of problem-solving activities in practice. This may also be facilitated by repurposing and transferring solutions and services used in other contexts and settings as in the case of the Scheduler (Garud et al, 2016). However, the introduction of novelty in everyday practice entails moving beyond successful solution demonstrations and ensuring that new technological solutions are not standalone objects, but elements in larger infrastructural arrangements (Hanseth and Lyytinen 2010). The inherent capabilities of new digital technologies make it possible to leverage existing arrangements for new services creating a wealth of possibilities for supporting healthcare operations and information exchange but this is far from straightforward. Healthcare organizations have now the opportunity to introduce novel technologies built around a core within an ecosystem of complementors (Cusumano, 2010; Tiwana et al., 2010). Nevertheless, the introduction of novelty is challenging, as it involves an immense number of localized and cross-cutting dependencies (Bygstad & Hanseth, 2016) in an environment where there are entrenched roles related to the management of the historically built infrastructural landscapes (Grisot & Vassilakopoulou, 2015). Analysing the interface between the infrastructural core and the periphery from both the keystone player´s perspective (governing the core) and the complementor´s perspective (aiming to link peripheral components) allows us to provide a unified foundation for addressing the challenges of introducing novelty within hospitals extending their infrastructures.

References

Afferni, P., Merone, M. and Soda, P. (2018). *Hospital 4.0 and its innovation in methodologies and technologies*. 2018 IEEE 31st International Symposium on Computer-Based Medical Systems (CBMS).

Bygstad, B., & Hanseth, O. (2016). *Governing e-Health Infrastructures: Dealing with Tensions*. 2016 International Conference on Information Systems, Dublin, Ireland.

Cusumano, M. (2010). 'Cloud computing and SaaS as new computing platforms'. *Communications of the ACM,*vol. 53, no. 4, pp. 27-29.

Dal Bianco, V., Myllärniemi, V., Komssi, M. and Raatikainen, M. (2014). *The role of platform boundary resources in software ecosystems: A case study*. 2014 IEEE/IFIP Conference on Software Architecture.

Eaton, B., Elaluf-Calderwood, S., Sorensen, C. and Yoo, Y. (2015). 'Distributed tuning of boundary resources: the case of Apple's iOS service system'. *MIS Quarterly: Management Information Systems,*vol. 39, no. 1, pp. 217-243.

Ghazawneh, A. and Henfridsson, O. (2013). 'Balancing platform control and external contribution in third-party development: the boundary resources model'. *Information Systems Journal,*vol. 23, no. 2, pp. 173-192.

Grisot, M. and Vassilakopoulou, P. (2015). *The Work of Infrastructuring: A Study of a National eHealth Project*. ECSCW 2015: Proceedings of the 14th European Conference on Computer Supported Cooperative Work, 19-23 September 2015, Oslo, Norway.

Hanseth, O., Monteiro, E. and Hatling, M. (1996). 'Developing information infrastructure: The tension between standardization and flexibility'. *Science Technology & Human Values,*vol. 21, no. 4, pp. 407-426.

Pollock, N. and Williams, R. (2010). 'e-Infrastructures: How Do We Know and Understand Them? Strategic Ethnography and the Biography of Artefacts'. *Computer Supported Cooperative Work (CSCW),*vol. 19, no., pp. 521-556.

Ribes, D. and Finholt, T. A. (2009). 'The Long Now of Technology Infrastructure: Articulating Tensions in Development'. *Journal of the Association for Information Systems,*vol. 10, no. 5, pp. 375-398.

Tiwana, A., Konsynski, B. and Bush, A.-. (2010). 'Research commentary-Platform evolution: Coevolution of platform architecture, governance, and environmental dynamics'. *Information Systems Research,*vol. 21, no. 4, pp. 675-687.

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Infrastructural Artefacts in Community Health: A Case Study of Pregnancy Care Infrastructures in South India

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Abstract. The work of frontline health workers providing access to pregnancy care services to women in South India is highly distributed and often overlooked in the design of healthcare infrastructures. Unlike clinical and nonclinical personnel who engage in different care practices within and across hospital departments with clearly established work roles, the work of frontline workers is performed across different geographical areas beyond the boundaries of the hospital and with loosely defined roles and resources making the coordination of work more complex. Based on a case study investigating the work of frontline health workers, we report a number of material infrastructural arrangements (the Thayi Card, physical and digital registers, and mobile phones) that played a major role supporting community health practices. We conclude by discussing the opportunities that these artefacts offer for the design of healthcare infrastructures.

Introduction

In healthcare, infrastructures relate to all physical, relational, spatial and structural entities (human and nonhuman), their functional capacities and the arrangements and configurations of these elements that support and sustain healthcare practices at all levels (from community and home care to national and regional services) including facilities (e.g., health centres, operating rooms, laboratory), equipment, staff, information systems, management, financing, and etc. (Smith and Bryant 1988). Taking a socio-technical perspective, Star (1999) draws attention to the social and material arrangements of people, routines, artefacts, conventions and the visible and invisible work needed to sustain infrastructures. While Orlikowski (2007) highlights the relational role of materiality and how material artefacts should be treated as "relational products" in practice, Star and Ruhleder (1996) refers to infrastructure as a highly relational concept describing "something that emerges for people in practice, connected to activities and structures" rather than "sinking into the background". Aligned to this perspectives, Shove (2017) highlights how material artefacts can have an "infrastructural" relation to the practices they enable and how they shape each other over time. Thus, artefacts should not be understood only by their intrinsic material aspects but within the infrastructure in practice.

Previous HCI and CSCW research in healthcare have looked at the information and human infrastructure in place to support healthcare work practices in a complex and distributed environment such as hospitals (González et al. 2005; Bossen and Markussen 2010; Fitzpatrick and Ellingsen 2013; Bossen et al. 2014; Tang et al. 2015; Stisen et al. 2016; Stisen and Verdezoto 2017). While healthcare information infrastructures have been introduced as a way to mitigate the increasing demand of healthcare delivery aiming to reduce errors, support coordination and enhance the overall efficiency and quality of care of healthcare services through the use of Information and Communication Technologies (ICT) (Haux 2006; Pollock and Williams 2010; Piras and Zanutto 2016), the human infrastructure relates to the social system supporting the work done across healthcare settings including clinical and non-clinical personnel, patients, caregivers, etc. (Tang et al. 2015; Stisen and Verdezoto 2017; Gui and Chen 2019). However, healthcare infrastructures reach far beyond the boundaries of the hospital and accounts for the home (Aarhus et al. 2009; Chen et al. 2012; Nunes et al. 2015), municipality care settings (Bossen and Grönvall 2015), and community health settings (Pinelle and Gutwin 2003; Pinelle and Gutwin 2006). While there has been recent attention to investigate the social and material arrangements of care infrastructures at home (Danholt and Langstrup 2012; Langstrup 2013; Weiner and Will 2018), there is limited research investigating the role of these socio-material arrangements in community health infrastructures especially in developing countries (Fitzpatrick and Ellingsen 2013).

In developing countries, public health infrastructures are supported by multiple entities and organizations including a particular group of close-to-community health care service providers, often termed as 'frontline health workers' (Ismail et al. 2018). Frontline health workers are part of the human infrastructure that supports community health, including community health workers, volunteers, health extension workers and community social service providers, etc. (Collyer 2006; Mireku et al. 2014). Frontline health workers deliver counseling and health education programmes, support early identification and registration of new pregnancies and neonatal outcomes as well as making referrals (Mireku et al. 2014; Sharma et al. 2014). Although frontline health workers are being accepted and appreciated by healthcare professionals and the community (Mireku et al. 2014) and have shown potential to improve the uptake and access of healthcare services (Adam et al. 2014; Lunsford et al. 2015), their work is often unheard (Oliver et al. 2015) and overlooked within the overall healthcare infrastructures.

In India, frontline health workers are considered "intermediaries"

(Ramachandran et al. 2010; DeRenzi et al. 2017) and “infomediaries” (Ismail et al. 2018) of a wide range of community-based healthcare services. However, existing norms, community power structures, socio-cultural practices, lack of monetary incentives, limited knowledge, lack of resources and the fragmented and distributed nature of care services challenge the work of frontline health workers (Saprii et al. 2015; Ismail et al. 2018; Bagalkot et al. 2018). Although a number of IT support for community health exists (Ramachandran et al. 2010; DeRenzi et al. 2017; Vashistha et al. 2017), these have mostly focused in providing training and feedback on work performance (e.g., number of visits) for one group of frontline workers overlooking the collaborative work of different groups of frontline health workers. Based on a project investigating the challenges of pregnancy care practices (Bagalkot et al. 2018), we investigate the distributed and complex work of heterogeneous groups of frontline health workers in South India. The analysis presented in this paper focuses only on the existing material arrangements in community health that emerged from our diverse studies including six focus groups with 23 frontline health workers and a visit to the district hospital and 27 household interviews as secondary data. We identified material arrangements that have an infrastructural relation to community health practices.

Case Study: Pregnancy Care in South India

In India, public health care services are divided into three levels (Bagchi 2008). The primary level includes the primary health centres (PHC) that offer curative and preventive services, and the sub-centres (SC) as the first contact point for the community offering services for maternal health and disease control. At the second level, we find district hospitals and community health centres and at the third level medical colleges, specialized hospitals, etc. (Bagchi 2008). The first and second levels are complemented by ambulance services and community health (CH) services provided by frontline health workers (different from the community health centres), a web-based mother and child tracking system (MCTS), different government-supported schemes and incentives aiming to reduce maternal and infant mortality (Rate 2017), and private health services (Baru and Nundy 2008).

Table I. Focus Groups and Visit to the District Hospital

Session	Activities	Participant
S1	Focus group with AWs and JHAs at the PHC *Getting an overview of roles and responsibilities as well as primary health facilities, services and infrastructural arrangements they interact with.*	JH1-JH5 AW1-AW4
S2	Focus groups with Health Navigators *Getting insights about the community experiences and perceptions of different roles of frontline health workers, their counselling activities and additional challenges they face.*	HN1-HN6
S3	Focus groups with Health Navigators *Brainstorming potential interventions to tackle the challenges uncovered by the interviews with pregnant women*	HN1-HN6

S4	Focus group with ASHAs at the Taluka District Hospital *Getting insights into the everyday practices of ASHAs workers, recruitment criteria, responsibilities, motivation, and infrastructural arrangements they interact with.*	A1-A4
S5	Focus groups at the Urban Anganwadi Centre *Getting insights into the everyday practices of AWs, recruitment criteria, responsibilities, motivation, and infrastructural arrangements with particular focus on artifacts they interact with.*	JH6 AW5
S6	Focus groups at the Rural Anganwadi Centre *Getting insights into the everyday practices of AWWs, recruitment criteria, responsibilities, motivation, and infrastructural arrangements with particular focus on artifacts they interact with.*	AW6 A5 HN6
S7	Visit to the Taluka Hospital and Additional Interviews *Confirmation of insights and continuous exploration of practices, roles and perceptions at the THC.*	A1 A2

In this paper, we report our engagement with different frontline health workers in rural and semi-urban areas of Karnataka state, South India. Through the help of our local collaborator, MAYA Health[1], we conducted six focus groups with 23 frontline health workers: five Accredited Social Health Activists (ASHAs), six Health Navigators (HNs), six Junior Health Assistants (JHAs), and six Anganwadi workers (AWs), and 27 interviews with community households. The primary data comes from the focus groups in which frontline health workers were invited to discuss about their everyday work practices, roles and challenges in relation to the healthcare services they provide. Table I provides a summary of the focus groups sessions and the visit to the Taluk district hospital. The secondary data comes from the household interviews that mapped the pregnancy journey showing the challenges and interactions between diverse entities of the healthcare infrastructures. The initial analysis was guided by an open coded approach by the first four authors. The material artefacts and arrangements were identified as the main concept from the initial analysis and thereof represent the main concept for further exploration. The study received three institutional ethical approvals from the ethical review boards at the University of Leicester, Loughborough University and the Srishti Institute of Art, Design and Technology.

Infrastructural Artefacts in Community Health

The Thayi Card: Multiplicity of Uses within the Healthcare Infrastructure

The Thayi Card, according to Ministry of Health and Family Welfare Government of Karnataka, is a ‘comprehensive mother and child registration booklet’, and is used as a unique identification document enabling fair disbursal of public health services under the various schemes, including health counselling, tracking of

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[1] MAYA Health: http://mayahealth.net/

vaccination during and post pregnancy, institutional birth, distribution of supplements and nutritious food, and health insurance[2]. It was introduced as part of the Mother and Child Tracking System (MCTS) outlined in the National Rural Health Missions (NHRM) 2005-2012 (Rate 2017). It now continues to be used as a key document to track mothers and infants under the Reproductive and Child Health (RCH) policy initiative (Rate 2017). Apart from the initial intended use, we found multiple usages of the Thayi Card simultaneously figuring as a material element in several practices and how the infrastructural relation to them changes in practice.

Unique identification and tracking of pregnant women in rural areas

In our studies, we found that AWs or ASHA workers or both (based on who is active in a particular locality) conduct periodic surveys of households in their designated areas, and collect a set of basic information for various purposes. One of these is the survey termed as 'line-listing' of pregnant women with the purpose of registering them on the MCTS system and disburse the Thayi Card. An ASH worker mentioned, "We do *our own line-listing of pregnant women in our locality, and take the women to PHC to register them (on the MCTS) and get them the Thayi card.*" (S7A2). At the PHC, information about the pregnant woman is entered manually by a data operator into the MCTS system, which generates a unique numeric identifier for each pregnant woman. This numeric identifier is then printed on the Thayi Card, which is then handed over to the woman and her family. In the areas where ASHA workers are not present, the Anganwadi center becomes the site of registration as the designated JHA visits the Anganwadi center periodically for administering vaccines, counselling, and registering new pregnant women on the MCTS and issue the Thayi card and give it to the women. The unique identifier of the Thayi card is designed to enable access to the digital data from the MCTS system by both the frontline workers and the care- providers at the PHC & THC.

A portable "health record" during and post pregnancy in rural areas

The Thayi Card acted as a form of portable 'health record' of the pregnant women in the rural areas, where all the health information of the pregnant women is either recorded or attached to it. This includes all the information about height, weight, last date of menstruation, due date, etc., and all prescriptions by the doctors at the PHC and blood test reports gets attached (stapled) on the inside of the card. This is done so that the data is available for follow-up at the THC and across other tertiary settings. Although in the urban area an 'Out Patient Department' (OPD) book is used to enter and maintain prescriptions, an ASHA worker mentioned, "*that's* [OPD book] *not available here* [at the rural PHC]*, it's only in the urban THC. Here everything is entered directly into the Thayi Card. For medicines and tests they* [doctors] *write in slips and pin it to the card*" (S6A6). Thus, documentation practices are done differently between urban and rural areas. During our interview study, we found that most pregnant women moved to their mother's homes during the third trimester (eighth or ninth month). Here it is important to note that the institutional delivery of care did not get affected, due to the way the frontline health

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[2] Thayi Card: https://www.karnataka.gov.in/hfw/nhm/pages/mh_schemes_thayicard.aspx

workers worked with the portable and unique properties of the Thayi Card and the underlying MCTS system to enable a more or less 'seamless' tracking of pregnant women across the geographical shift.

Thayi Card as a gateway for follow-up and verification

Frontline health workers also used the Thayi Card to verify multiple entries across data-registers (see next section). In particular, the AWs in the rural areas of our study mentioned that they write down the basic data about pregnant women, namely, the last menstruation period, vaccination dates, due date, etc. from the Thayi Card to verify the information recorded during the surveys conducted in their communities and update their data. For example, an AW in the rural area mentioned, "*we refer to the Thayi Card and look up the last menstruation period and expected date of delivery and write down correct data* [in the Pregnant Women & New Mothers' Register]. *First the sister* [JHA] *would have already entered the date on the card. That data we enter into our registers*" (S6AW6). Information logged in the MCTS system through the Thayi Card is also supposed to be used as a means to follow up with women, to provide timely reminders about specific care services they need to access. One of the pregnant women (R1PW3) we interviewed mentioned, "*One day before my visit to the PHC, my husband got a call from the PHC reminding of the visit.*" However, several pregnant women we interviewed did not get either messages or calls reminding them about their upcoming visits either because they had lost their mobile phone (e.g. R4PW3) or changed the phone number registered in the MCTS system. In these cases, frontline health workers often took the initiative to follow-up on women and remind them of their periodic visits.

Acting as a health literacy artefact

The Thayi Card is also intended to be used as an Information, Education and Communication (IEC) material to enhance health literacy of the pregnant women, as it contains infographics explaining the various aspects of home-based pregnancy and infant care that the women and potentially other family members involved need to perform (see figure 1). This includes procedures about maintaining hygiene and cleanliness, suggestions about good nutrition, timely vaccinations, information about nominal height and weight of both the mother and the infant, symptoms to track in case of emergency, etc.

Both the urban and rural frontline health workers mentioned that they use the card infographics to counsel women and their families about pregnancy care at home, particularly about immunization. For instance, a rural ASHA worker mentioned, *"whenever I go for house visits I tell them to read it* [information on the Thayi card]. *I read it to them if they cannot read. We tell them to ask us anything if they cannot understand."* (S6A5). Although we found literacy issues understanding the Thayi card, we also found a multiplicity of uses beyond health education, figuring as material elements with additional roles and meanings in several practices.


a) b)

Figure 1: a) Illustrations of the Thayi Card regarding potential problems during pregnancy and health services available; b) Information of check-ups, injections, weight and additional details

Thayi Card as a "Ticket" for free care and monetary incentives

In our study, frontline health workers highlighted that the infographic and suggestions are not enough to engage pregnant women as intended by the design of the Thayi card. They discussed how the Thayi Card only represents a 'ticket' to get financial incentives (money varies from 600 to 1400 INR) as part of one of the world's largest conditional cash transfer scheme, Janani Suraksha Yojana, that promotes institutional deliveries (Lim et al. 2010). For example, an ASHA worker mentioned during the interview, "*They* [Pregnant women and their families] *use it only for money.*" (*S*7A2). The Thayi card acts as a 'ticket' to financial incentives in a direct way, as it has a voucher attached to it when issued, which the pregnant women can claim most of the payment after the institutional birth. A junior health assistant mentioned, *"if the Thayi Card is lost, they will not have the voucher and will not be able to get money back. But they can access other free services due to the unique number* [registered on the MCTS] on it*"* (S1JH5).

Maintaining Multiple Physical and Digital Data-registers

The household surveys carried out by the frontline health workers usually record details such as pregnant woman's name, age, husband's name, bank account number (for direct transfer of financial benefits), stage of pregnancy, and phone number of the pregnant woman (or her husband's) for sending follow-up information. This information is recorded by the ASHA worker and is also maintained by the AW worker in a physical book / register termed as 'Record of Services offered for Pregnant Women & Nursing Mothers' (see figure 2). In addition, AW workers also verify the distribution of nutrition and track vaccinations that take place at the Anganwadi centre and the ASHA workers keeps the record to keep track of the financial incentives during the postnatal period.

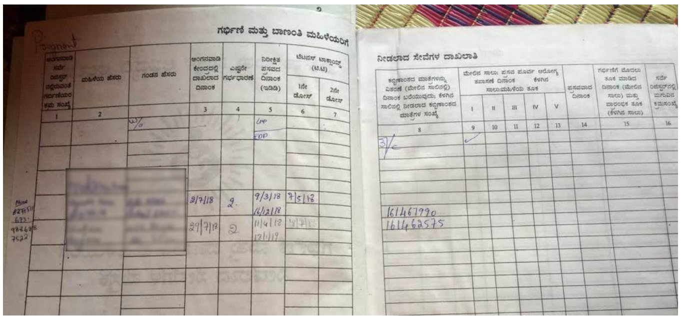

Figure 2. Physical records of pregnant women and nursing mothers at the Anganwadi center

Information collected through these surveys are entered onto the MCTS portal. However only the JHAs and ASHA workers operated the digital portals, and AW workers maintain records in physical form. The portal that came across in the focus groups (S1 and S2) was MCTS portal. However, a JHA informed us that, "*MCTS has been cancelled now but there's a new portal called RCH5*" (S5JH6). According to a JHA some differences exist: "*in MCTS there were 12-14 things to enter but now in RCH there are around 32 things to enter*" (S5JH6). She also discourage data entry in the portal for AWs, "*If data entry comes for everybody it will seem too heavy. For that we can't even sit anytime and enter. Even if we sit with it for 10 mins the head will feel heavy. I feel if data entry doesn't come for AW is best*".

Mobile phones as Infrastructural Artefacts

Mobile phones were present in all our discussions with frontline health workers. The usage patterns varied depending on the role, responsibilities and digital literacy of frontline health workers, as well as perceived benefits versus costs. While some frontline health workers (e.g., S6A5, S5AW5) used feature phones, others (e.g., S5JH6, S4A1, S4A2, S4A3) used smartphones. The majority of the JHAs and urban ASHA workers have smartphones. Mobile phones were mostly used for calling and they served to share care information and coordinate household visits, hospital visits and camps/meetings, etc. We found that calling acted as a key communication channel to coordinate tasks and for quick resolution of issues in practice between women and frontline health workers. Calling was also used for counselling of women and their household members according to need and based on the familiarity with the patient, emergency of the situations and literacy. For example, an AW expressed "*for the people who don't know how to read or the ones who don't have time to read, I have given counselling over the phone and asked them to look for things on the mobile. I tell them there is a lot of information about healthcare on the phone itself so look it up*" (S6AW6). However, it can also have unintended consequences as described by a JHA (S1JH1) who has both a feature phone, used during community visits only for calls, and a smartphone used at home and for personal use. After couple of incidents of being disturbed late at night by pregnant women and their families who video-called her on WhatsApp, the JHA now only shares her feature phone number, as she considers this less intrusive.

Discussion and Conclusion

Our study shows a number of material arrangements that shape and are shaped by the community health infrastructures in South India. The social, cultural and political properties of the Thayi Card expressed through its multiple uses highlight the visible and invisible arrangements of care infrastructures (Langstrup 2013; Weiner and Will 2018) for community health that are inextricably related (Orlikowski 2007). When used as a portable record of the pregnancy journey including the contact points and use of public and private healthcare services, it also acted as a boundary object (Leigh Star 2010; Bossen et al. 2014) and coordination mechanism (Schmidt and Simonee 1996) (Schmidt and Simonee 1996) facilitating the exchange of information between different social worlds. When used to support health literacy, similar to the digital portals/registers, these artefacts can be seen as devices (Shove 2017) that are directly engaged with, and actively manipulated by women and/or frontline health workers during counseling or documentation practices respectively. The Thayi Card, similar to the physical registers, also have an infrastructural relation with documentation and verification practices that enable access and provision of healthcare services. Mobile phones emerged as an important infrastructural artefact that helped frontline health workers to actively call each other to share information, coordinate activities, and regain awareness while dealing with internally infrastructural misalignments and even nonalignment between frontline health workers practices. Mobile phones also acted as a medium to provide counselling to the pregnant women and families with some unintended consequences for the frontline health workers when receiving video calls.

Rather than focusing on the biopolitics of global health (Prince 2012; Storeng and Mishra 2014; Kenny 2015), our study shows the importance of understanding the multiple roles and usages of artefacts and the internal dynamics and local context of community health in practice before the design and introduction of digitally enabled infrastructures in developing countries (Schräpel 2010). Our future work seeks to further understand the invisible, infrastructural (Gui and Chen 2019) and emotional (Park 2017) work that frontline health workers do configuring, connecting, communicating, adapting and sustaining infrastructural arrangements within and across different healthcare settings to make them work for them and their communities. We are interested in further investigating the intended and unintended outcomes of infrastructural arrangements and misalignments and how these can be re-imagined, enhanced, or mediated through ICT to make them more visible (Calkins and Rottenburg 2017) to support a mutual reconfiguration (Tang et al. 2015) and negotiation of the multiple human and nonhuman entities in community health infrastructures. Our findings are most likely far from complete and we encourage HCI and CSCW researchers to continue investigating the socio-cultural practices and material arrangements that conform and influence pregnancy care infrastructures as well as the many intersecting infrastructures (Bjørn and Boulus-Rødje 2018) that can influence community health in developing countries.

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References

Aarhus R, Ballegaard SA, Hansen TR (2009) The eDiary: Bridging home and hospital through healthcare technology. pp 63–84

Adam MB, Dillmann M, Chen M, Mbugua S, Ndung'u J, Mumbi P, Waweru E, Meissner P (2014) Improving maternal and newborn health: effectiveness of a community health worker program in rural Kenya. PloS one 9:e104027

Bagalkot N, Verdezoto N, Lewis M, Griffiths P, Harrington D, Mackintosh N, Noronha JA (2018) Towards Enhancing Everyday Pregnancy Care: Reflections from Community Stakeholders in South India. ACM, Bangalore, India

Bagchi S (2008) Growth generates health care challenges in booming India. Can Med Assoc

Baru RV, Nundy M (2008) Blurring of boundaries: public-private partnerships in health services in India. Economic and Political Weekly 62–71

Bjørn P, Boulus-Rødje N (2018) Infrastructural inaccessibility: Tech entrepreneurs in occupied palestine. ACM Transactions on Computer-Human Interaction (TOCHI) 25:26

Bossen C, Grönvall E (2015) Collaboration in-between: The Care Hotel and Designing for Flexible Use. In: Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing. ACM, Vancouver, BC, Canada, pp 1289–1301

Bossen C, Jensen LG, Udsen FW (2014) Boundary-Object Trimming: On the Invisibility of Medical Secretaries' Care of Records in Healthcare Infrastructures. Computer Supported Cooperative Work (CSCW) 23:75–110 . doi: 10.1007/s10606-013-9195-5

Bossen C, Markussen R (2010) Infrastructuring and Ordering Devices in Health Care: Medication Plans and Practices on a Hospital Ward. Computer Supported Cooperative Work (CSCW) 19:615–637 . doi: 10.1007/s10606-010-9131-x

Calkins S, Rottenburg R (2017) Evidence, infrastructure and worth. In: Infrastructures and Social Complexity. ROUTLEDGE in association with GSE Research, pp 253–265

Chen Y, Tang C, Cheng K, Park SY (2012) Bridging clinical and non-clinical health practices: opportunities and challenges. In: CHI'12 Extended Abstracts on Human Factors in Computing Systems. ACM, pp 2723–2726

Collyer NE (2006) Training community health workers: Using technology and distance education

Danholt P, Langstrup H (2012) Medication as infrastructure: Decentring self-care. Culture Unbound: Journal of Current Cultural Research 4:513–532

DeRenzi B, Dell N, Wacksman J, Lee S, Lesh N (2017) Supporting community health workers in India through voice-and web-based feedback. In: Proceedings of the 2017 CHI Conference on Human Factors in Computing Systems. ACM, pp 2770–2781

Fitzpatrick G, Ellingsen G (2013) A review of 25 years of CSCW research in healthcare:

contributions, challenges and future agendas. Computer Supported Cooperative Work (CSCW) 22:609–665

González VM, Tentori ME, Morán EB, Favela J, Martínez AI (2005) Understanding mobile work in a distributed information space: implications for the design of ubicomp technology. In: Proceedings of the 2005 Latin American conference on Human-computer interaction. ACM, pp 52–63

Gui X, Chen Y (2019) Making Healthcare Infrastructure Work: Unpacking the Infrastructuring. In: In 2019 CHI Conference on Human Factors in Computing Systems Proceedings (CHI 2019). ACM, Glasgow, UK

Haux R (2006) Health information systems–past, present, future. International journal of medical informatics 75:268–281

Ismail A, Karusala N, Kumar N (2018) Bridging Disconnected Knowledges for Community Health. Proc ACM Hum-Comput Interact 2, Article 75:27 pages

Kenny KE (2015) The biopolitics of global health: Life and death in neoliberal time. Journal of Sociology 51:9–27

Langstrup H (2013) Chronic care infrastructures and the home. Sociology of health & illness 35:1008–1022

Leigh Star S (2010) This is not a boundary object: Reflections on the origin of a concept. Science, Technology, & Human Values 35:601–617

Lim SS, Dandona L, Hoisington JA, James SL, Hogan MC, Gakidou E (2010) India's Janani Suraksha Yojana, a conditional cash transfer programme to increase births in health facilities: an impact evaluation. The Lancet 375:2009–2023

Lunsford SS, Fatta K, Stover KE, Shrestha R (2015) Supporting close-to-community providers through a community health system approach: case examples from Ethiopia and Tanzania. Human resources for health 13:12

Mireku M, Kiruki M, McCollum R, Taegtmeyer M, De Koning K, Otiso L (2014) Context Analysis: close-to-community health services providers in Kenya. 2014. Nairobi: Reachout Consortium

Nunes F, Verdezoto N, Fitzpatrick G, Kyng M, Grönvall E, Storni C (2015) Self-care technologies in HCI: Trends, tensions, and opportunities. ACM Transactions on Computer-Human Interaction (TOCHI) 22:33

Oliver M, Geniets A, Winters N, Rega I, Mbae SM (2015) What do community health workers have to say about their work, and how can this inform improved programme design? A case study with CHWs within Kenya. Global health action 8:27168

Orlikowski WJ (2007) Sociomaterial practices: Exploring technology at work. Organization studies 28:1435–1448

Park S-J (2017) They overworked us. Medicine Anthropology Theory 4:75–94

Pinelle D, Gutwin C (2003) Designing for loose coupling in mobile groups. In: Proceedings of the 2003 international ACM SIGGROUP conference on Supporting group work. ACM, pp 75–84

Pinelle D, Gutwin C (2006) Loose Coupling and Healthcare Organizations: Deployment Strategies for Groupware. Computer Supported Cooperative Work (CSCW) 15:537–572 . doi: 10.1007/s10606-006-9031-2

Piras EM, Zanutto A (2016) Tinkering Around Healthcare Infrastructures: Nursing Practices and Junction Work. In: COOP 2016: Proceedings of the 12th International Conference on the Design of Cooperative Systems, 23-27 May 2016, Trento, Italy. Springer, pp 173–189

Pollock N, Williams R (2010) E-infrastructures: How do we know and understand them? Strategic ethnography and the biography of artefacts. Computer Supported Cooperative Work (CSCW) 19:521–556

Prince RJ (2012) The politics and anti-politics of HIV interventions in Kenya. In: Rethinking biomedicine and governance in Africa: contributions from anthropology. transcript, pp 97–116

Ramachandran D, Canny J, Das PD, Cutrell E (2010) Mobile-izing health workers in rural India. In: Proceedings of the SIGCHI Conference on Human Factors in Computing Systems. ACM, pp 1889–1898

Rate CD (2017) KARNATAKA INTEGRATED PUBLIC HEALTH POLICY 2017. population 19:21.4

Saprii L, Richards E, Kokho P, Theobald S (2015) Community health workers in rural India: analysing the opportunities and challenges Accredited Social Health Activists (ASHAs) face in realising their multiple roles. Human resources for health 13:95

Schmidt K, Simonee C (1996) Coordination mechanisms: Towards a conceptual foundation of CSCW systems design. Computer Supported Cooperative Work (CSCW) 5:155–200

Schräpel N (2010) Connecting Africa–African Connections Africa's engagement with information and communication technologies (ICTs) and their role for development–the case of telemedicine in South Africa. ICT and Development - Research Voices from Africa International Federation for Information Processing (IFIP), Technical Commission 9 – Relationship Between Computers and Society Workshop at Makerere University

Sharma R, Webster P, Bhattacharyya S (2014) Factors affecting the performance of community health workers in India: a multi-stakeholder perspective. Global health action 7:25352

Shove E (2017) Matters of practice. The nexus of practices: Connections, constellations, practitioners 155–168

Smith DL, Bryant JH (1988) Building the infrastructure for primary health care: an overview of vertical and integrated approaches. Social science & medicine 26:909–917

Star SL (1999) The ethnography of infrastructure. American behavioral scientist 43:377–391

Star SL, Ruhleder K (1996) Steps toward an ecology of infrastructure: Design and access for large information spaces. Information systems research 7:111–134

Stisen A, Verdezoto N (2017) Clinical and Non-Clinical Handovers: Designing for Critical Moments. In: Proceedings of the 2017 ACM Conference on Computer Supported Cooperative Work and Social Computing. ACM, Portland, Oregon, USA, pp 2166–2178

Stisen A, Verdezoto N, Blunck H, Kjærgaard MB, Grønbæk K (2016) Accounting for the invisible work of hospital orderlies: Designing for local and global coordination. In: Proceedings of the 19th ACM Conference on Computer-Supported Cooperative Work & Social Computing. ACM, pp 980–992

Storeng KT, Mishra A (2014) Politics and practices of global health: Critical ethnographies of health systems. Taylor & Francis

Tang C, Chen Y, Semaan BC, Roberson JA (2015) Restructuring Human Infrastructure: The Impact of EHR Deployment in a Volunteer-Dependent Clinic. In: Proceedings of the 18th ACM Conference on Computer Supported Cooperative Work & Social Computing. ACM, Vancouver, BC, Canada, pp 649–661

Vashistha A, Kumar N, Mishra A, Anderson R (2017) Examining Localization Approaches for Community Health. In: Proceedings of the 2017 Conference on Designing Interactive Systems. ACM, pp 357–368

Weiner K, Will C (2018) Thinking with care infrastructures: people, devices and the home in home blood pressure monitoring. Sociology of health & illness 40:270–282

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Information Infrastructures in healthcare and emergent data work occupations: The case of medical scribes and CDIS

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Abstract. The development of information infrastructures in healthcare is often described in abstract terms as datafication, the conversion of qualitative aspects of life into quantified data, which makes the people and actual work involved invisible. To make visible the actors and the efforts implied in the term 'datafication', in this paper, we describe two emergent data work occupations in healthcare: Medical scribes and clinical documentation improvement specialists (CDIS). These cases provide a starting point for understanding the impacts of digitization of healthcare and the emergence of new kinds of work and new occupations that health organizations adapted to accommodate such impacts. Making data work visible is important in order for these occupations to be acknowledged. If data work remains invisible, healthcare organizations and researchers alike will have an incomplete understanding of how data is actually produced in practice, hindering the organizational design, human resources, and organizational learning that are essential for healthcare organizations to become competent producers and users of data.

Introduction

Digitization of healthcare has been ongoing in Europe and Northern America over the last two decades, involving electronic health records (EHR) for hospitals, electronic care records for home care, and most recently patient generated health data via mobile and monitoring devices. Together with demands for increased accountability (Wiener 2000, Power 1997), and ambitions for healthcare to become more data-driven (Madsen 2014, Raghupathi et al. 2014, Mayer-Schönberger et al. 2018), data-centric technological development and implementation has become the norm in healthcare.

Concomitant with the widespread implementation of digital information infrastructures for healthcare and the expanded ability to collect, store, manage, analyze, and deploy data is the phenomena of "datafication." Datafication is defined as the conversion of qualitative aspects of life into quantified data (Ruckenstein & Dow Schüll, 2017). Discussions have emerged of implications of the datafication of healthcare in a wide range of areas. One the one hand, increased computing power for data collection and management coupled with increasingly complex data analytic tools promise earlier discovery and prevention of diseases; more precise diagnoses; discovery of new correlations between symptoms, treatments, and cures; and more effective management of healthcare (Raghupathi et al. 2014, Mayer-Schönberger et al. 2018). On the other hand, questions have been raised about the assumptions and critical implications of this development. Thus, one overall trend is the increased integration of clinical research and commercial domains. As Hogle (2016) describes: "The data curated from 'nonmedical' and conventional medical sources can be combined and repurposed from original contexts and uses, and made available to serve a variety of healthcare, marketing, and governance needs." (ibid, p387).

Critical scholars and concerned citizens alike point to privacy as an ongoing concern with data-intensive health research, particularly research that utilizes data that have previously not been used for health research, such as social media data. An oft cited example of the dangers of data intensive business intelligence tools for privacy is that of the USA-based Target Corporation identifying the pregnancy of a young woman via her purchasing behavior before her father knew, and disclosing her secret to him via targeted advertising (New York Times, Feb. 16, 2012 "How Companies Learn Your Secrets"). Another concern is the new kind of social sorting of populations into groups based on algorithmically created categories, which might reinforce old beliefs about social differences (Hogle, 2016, p388). Overall, datafication implies that healthcare organisations reorganize around data production and analysis in a process that can be labelled as 'data-intensive resourcing,' defined as: "… attempts at getting more data, of better quality, on more people. Sourcing is a dynamic process of creating, collecting, curating and storing data while simultaneously making them available for multiple purposes, including research, governance and economic growth'' (Hoeyer, 2016, p74).

The current discussions around datafication have been centered on the use and integration of various types of digital health data and the impacts of digitizing such data on both clinicians and patients, e.g. the research that focuses on the implications of EHR implementation for clinical practice and patient experience. Another line of scholarly work places a critical spotlight on datafication, attending to the political and ethical implications of measurements and algorithms and the potential downsides of valorizing data-intensive methods over other forms of seeking knowledge for organizational and institutional reflection and decision making. However, both lines of work fail to provide deep empirical accounts about the work of actually producing data. Scholarly attention to datafication thus far, in both healthcare and in other domains, tends to treat datafication as an abstract process without active subjects when describing the overall process. We find this reflected in phrases like ‘data is the new oil (or gold)’ and ‘datafication will (insert some effect) … ’, and while we acknowledge the need to summarize and describe overall processes, people as actors seem to fall into the background.

But, data does not come from air--nor is it simply a byproduct of other processes (e.g. clinical documentation in EHRs). In this paper, we take a broader approach to include active subjects in the process of digitizing data and focus on the people, occupations and actual work involved in producing data that populates data repositories and isfed into algorithms and complex data analytics. This is a way of making otherwise invisible work that underlies the phenomenon of datafication and the implications of the development information infrastructures in healthcare visible. To understand the dynamics of how the new ecology of healthcare information infrastructures transforms work, we focus on two occupations: medical scribes and clinical documentation improvement specialists (CDIS). Making this data work visible is important in order for these occupations to be acknowledged, and because neglecting it can have detrimental consequences for the achievement of the right skill-mix in healthcare organizations and thus their use of digital information infrastructures.

Surfacing data work in healthcare

Visions for Big Data herald high-skilled professions build of formal knowledge such statisticians or data scientists (Mayer-Schönberger and Cukier 2013, Madsen 2014), while far less attention is paid to the low-paid work behind, for example, Amazon Mechanical Turk (Irani 2015), or the moderators removing content in conflict with nudity policies of e.g. Facebook (Roberts 2016). Entrepreneurs and innovators like Bezos and Zuckerberg are highly visible, while the work behind these fronts remains in the background, almost invisible. Data work, however, encompasses a far wider range of present and future ‘data professionals’ (Foster 2016), and indeed a small number of emerging studies does exist that focus on the work of producing and making data meaningful (Foster 2016, Fischer et al. 2017, Kristiansen et al. 2018).

However, data work is often invisible. When infrastructures such as electricity or data-generating e-health systems are in place, they tend to disappear in the sense of being taken for granted and unnoticed (Bowker & Star, 1999). Invisibility of work derives from three main components: The division of social spaces into front- and backstage (e.g. sales counters vs storerooms) (Goffman, 2002); the social construction of what counts as ‘real work’ or not (e.g. paid work vs. domestic work); and how it represented or not (e.g. statistics abstracting away sweat and exertion) (Star & Strauss, 1999). Invisibility is often closely connected to low status and remuneration, but can also crucially influence the implementation of ICT systems and make them fail, when designers and other stakeholders fail to attend to and account for crucial work perceived as superfluous or routine in their design (Bowers, Button, & Sharrock, 1995; Suchman, 1995). Hence, ‘making work visible’ is important both for the data workers themselves as well as for the organisation in which they are employed.

The new data work occupations

In the following, we will focus on two emergent data work occupations: medical scribes and clinical documentation improvements specialists (CDIS). The purpose is to get a better understanding of what kinds of new work and occupations emerge in the wake of datafication of healthcare.

The descriptions are based on data from qualitative methods, and a literature review. In the case of medical scribes, we conducted 14 interviews with medical scribes and their manager amounting to approximately 13 hours of interviews (shortest 39 minutes; longest 68 minutes; mean 53 minutes), and 3 rounds of observations amounting to 9 hours of medical scribes working in an Emergency Room at a hospital in the Western region of the USA. In addition, we conducted a literature review on previous studies of medical scribes (Bossen, Chen & Pine 2019). For the case of CDIS we conducted 12 interviews with CDIS for approximately 4 hours of interviews in total (shortest 14 minutes; longest 29 minutes; average 24 minutes), and 9 rounds of observation of CDIS working on patient records (total of 27 hours). The present paper is based on preliminary analysis of the transcribed interviews and extended field notes.

Medical scribes

Medical scribes write down information from conversations between patients and doctors, and enter this information into EHRs on behalf of doctors in order to lessen doctors’ workload. One could call them a kind of doctor’s secretary.

Medical scribes have grown in number especially in the wake of digitization of healthcare in connection with the implementation of EHRs in the USA since the 2010, and are especially popular in Emergency Departments where the pressure for speed and seeing many patients is high. Medical scribes have no formal teaching or education and are typically trained for some weeks before starting to scribe for physicians. They are usually paid the minimum wage and generally leave the occupation after a year. Several companies have emerged to provide scribe services to healthcare organizations. These companies recruit, train, and contract with hospitals to provide scribes at a fee. In 2012, medical scribes were acknowledged by the non-profit USA based healthcare accreditation organisation Joint Commission as a job or an occupation within healthcare. In summary, one could say that medical scribes are low-skilled, low-paid, have a large turn-over and that the provision of scribes services has become occasions for businesses to grow (For an overview, see (Bossen, Chen, & Pine, 2019). We can also say that digitization of healthcare, the precondition of data-intensive research and data-driven decision making in healthcare, has led to the emergence of a new kind of data work. Medical scribes are contributing to the production of the data through providing the raw material for big data, because digitization in the form of EHRs entail more documentation and a higher workload for doctors.

A closer look at medical scribes provides a more nuanced narrative. Being a good medical scribe actually requires several skills. First, they need to be able to extract the relevant information from conversations between doctors and patients in the hectic, noisy, and sometimes intense context of emergency rooms, and enter this information into the proper fields in the EHR. To be able to do this, they learn medical terms and the structure of doctors' medical interviews with patients, including the following items: Reason for the visit; History of Present Illness (HPI); Past Medical History (PMH); Review of Systems (ROS); Social History (including recreational drug use); Family History (FH), Allergies, etc. They also learn the structure in which information is formatted in the EHR, and the idiosyncratic styles in which each particular doctor wants their notes to be written. Further, scribes must also be able to be the doctor's unobtrusive and silent shadow, who is unavoidably visible to the patient, but does not obstruct the conversation, and they must be able to move around with their computers on wheels in a tight, crowded space. Often, they look up medical terms online at idle moments, or when they come home, in order to learn more. Despite the demanding work and low pay most scribes find the work experience rewarding, and becoming a scribe is relatively competitive. One might wonder why?

Our interviews revealed that most medical scribes have a bachelor's degree – often in natural sciences – and use their medical scribe job to get experience within healthcare, and thus improve their chances of being admitted to medical school (See e.g. (Lowry, 2017)). Therefore, another narrative that emerges is that medical scribes are highly competent persons gaining relevant experiences as a step in their educational career.

Clinical Documentation Improvement Specialists

Another emergent data occupation is that of the Clinical Documentation Improvement Specialists (CDIS). Like the medical scribes, their occupation has emerged and grown along with the implementation of EHRs. Their job is to code medical records with the labels that form the basis for reimbursement from insurance companies for medical treatment and care. A job that requires solid and broad knowledge of medical terms.

Unlike the medical scribes that have recently finished their undergraduate degrees,, CDIS are typically nurses with 10 or more years of experience who for varying reasons want to make a change in their career. Also, while scribes work at the minimum pay, CDIS earn on average US$ 68,000 a year, approximately the same as the salary of registered nurses working in clinical practice, but significantly more than the approximately. US$ 29,000 a year for medical scribes. Indeed, more than 25% of all CDIS earn more than 100,000 a year (See: Association of Clinical Documentation Improvement Specialists (ACDIS) (2019 “2018. CDI Salary Survey). Thus, one CDIS we met found nursing work physically too hard, while another had worked with cancer patients for many years and found this to be too emotionally demanding. Also, unlike the medical scribes who work surrounded by patients, nurses and doctors, CDIS work in quiet offices away from patients on desktop computers through which they have access to two systems: One is the hospital’s EHR in which they look at particular patient’s medical notes, examinations, test results, etc, while another is a system based on Natural language processing combined with the classification codes embedded in Diagnosis-Related Groups (DRG) used as the basis for reimbursement of healthcare services in the USA, and many other countries, including Denmark (On computer aided coding, see for example systems such as 3M’s ‘3M 360 Encompass’ system; for DRG See: (Busse, Geissler, Quentin, & Wiley, 2011)).

The work for CDIS consists in making sure that clinical documentation by doctors is precise, correct and comprehensive. Seen from their perspectives, doctors are – for good reasons, CDIS acknowledge – more focused on keeping up with treating incoming patients than on producing complete and accurate records for post hoc purposes (e.g. billing and calculating quality measurements). However, “bad” records (form the perspective of these post hoc usages) mean that hospitals provide services for which they are not paid, resulting in economic deficits and hence potentially lower quality of treatment and care. For that reason, it is important for hospital administration that patient records are accurate and comprehensive, and it is the job of CDIS to read records and code them accurately in order for the hospital to be reimbursed. This job includes occasionally writing to doctors asking them to be more specific. When the patient was admitted, did he or she have ‘mild sepsis’ or ‘severe sepsis’? What kind of pneumonia did the patient have? These inquiries called ‘Clinical clarifications’ are conducted via special forms in which CDIS may ask for precision or reconsideration of a diagnosis. Particularly in these instances is it important CDIS to have and display medical knowledge, since doctors would otherwise disregard such clarifications Notably, clinical clarifications cannot point in any specific direction in order to ensure that CDIS do not pressure or lead doctors to choose diagnoses or terms that result in higher reimbursement.

Unlike medical scribes, CDIS often remain in their positions long term and consider being a CDIS a career choice, where scribe work is seen as short term, temporary employment on the road to a medical career. The data CDIS produce are those of DRG-codes and numbers indicating the severity of the diagnosis recorded as CCs (Complications and Comorbidities) and MCCs (Major Complications and Comorbidities). Their narratives are checked by another data occupation, Coders, who are experts on the legal specification and coding systems, and go through the claims report before it is sent to the insurance company. As in the case of medical scribes, CDIS work to make medical records more precise and accurate, but they do this in specific ways, since, for example only the medical records of patients admitted to the hospital and staying more than 2 days are reviewed by CDIs. The rationale for this being that return of investment of CDIS time is low, and records for outpatient patients or those staying for less than two days are simple, relatively low on reimbursement, and hence the opportunity for making high-dollar value improvements to clinical documentation is small.

Discussion

Medical scribes and CDIS are two examples of occupations that have emerged in connection with datafication of healthcare. Both are relatively new, which goes some way to explain why relatively little research has been conducted with and about them. We found 60 papers published over 43 years - most after then turn of the century - on medical scribes and most are concerned with return of investment on hiring these workers (Bossen, Chen and Pine 2019).research papers on CDIS are even more scarce. However, we also suspect that their relative invisibility is related to the mundane kind of data work that these occupational groups do. They do not head successful IT companies or digital platforms, nor do they have the lure of new high-skilled occupations such as ‘data scientists’. However, acknowledging their contributions to the achievement of datafied healthcare is vital for understanding what strategies data-driven healthcare require, and how this might change the existing skill-mix of occupations.

The dynamics of digitization and the changing tasks, emergency of new tasks, and ongoing negotiation of the scope of work of different professions and occupational groups is part of the dynamic interrelations between professions. Professions are seen as integral to the division of work in modern bureaucracies such as healthcare (Abbott, 1988; Bourgeault, Dent, Denis, & Kuhlmann, 2016; Freidson, 2001), and the boundaries between them change as part of power struggles, technological developments and emergence of new government policies (Dent, Bourgeault, Denis, & Kuhlmann, 2016). Within healthcare, new occupations emerge as routine tasks are delegated to new occupations (e.g. physician assistants), or when new technology is implemented (e.g. radiology technicians). The drivers of change to the overall skill-mix in healthcare can be attributed to technological innovation along with new expectations towards healthcare services, and changes in inter-professional and profession-state relations (Cooper, 2001; de Bont et al., 2016; Tsiachristas et al., 2015).

The dynamics of changes in professions’ roles and work tasks can be described as entailing four processes: 1) *diversification* (adding tasks to the existing portfolio. E.g. physicians taking ownership the technology of anesthetics); 2) *specialization* (acquiring increased level of expertise. E.g. anesthetics nurses), 3) *vertical substitution* (task adoption across hierarchical boundaries. E.g. nurses doing prescriptions); and 4) *horizontal substitution* (task adoption across same-level professions. E.g. ward secretaries taking over nurses’ tasks) (Nancarrow & Borthwick, 2005). A central factor in the change dynamics is the ability of high-ranking professions to delegate routine or unpleasant tasks to professions with lower rank.

Medical scribes and CDIS are two examples of how these dynamics can unfold. Both occupations work to produce advanced, structured, and precise narratives of healthcare data. The former at the point of entry to the hospital, the latter whenever admittance and more complex treatment and care is required. Both occupations have grown as an outcome of digitization of healthcare and the push for more documentation and data-intensive forms of management, accountability, and regulation of healthcare and. The emergence of the occupation of medical scribes can be characterised as the result of a process of vertical substitution, where doctors delegate the routine (but still skilled) task of documentation to people with (relatively) less formal education (a BA degree is an achievement). For medical scribes, working for a short time at a minimum pay is balanced out by the acquirement of knowledge and experience within the healthcare domain, and thus the improvement of the chance of getting admitted to medical school. It should be noted, however, that this balance is only temporary, since medical scribes usually stay for a year maximum after which they move on either to go into medical school, or pursue another career. As for the CDIS, the emergence of this occupation can be seen as a similar process of delegating the routine tasks of coding documentation that doctors otherwise would have to do, to persons with less formal education (and with lower pay). However, at the same time, this process can also from the perspective of nurses be characterised as a case of diversification, where the tasks of improving and coding clinical documentation becomes an addition to the portfolio of their occupation (though nurses do not have a monopoly on this task). For nurses (and related professions), working as a CDIS is physically and emotionally less stressful, and potentially offers the gain of a higher salary.

Based on the examples from these two occupations, datafication of healthcare entails both the delegation of routine tasks of creating data to less skilled people, as well as specialisation of nursing work with similar or higher salary prospects. In a wider perspective, the use of medical scribes is a way to lessen the increased documentation and work load that datafication of healthcare has entailed for doctors. CDIS are a result of that same process of increased documentation and data work for doctors, and both increase and decrease the pressure of more data work for doctors: They do the required coding work that doctors otherwise would have to do, but at the same time through for example ‘clinical clarification’ inquiries increase data work by requiring more specific and detailed information than doctors sometimes deem necessary.

Getting a full picture of the implications for data work in healthcare is challenging and there we have focused on only two emergent occupations. We suspect that several others can be found. However, one overall point is that datafication is a process that does not unfold by itself, but requires new kinds of tasks and work, and which we need to put into the equation when considering the overall gains and costs of the new era of datafied healthcare.

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References

Abbott, A. (1988). *The system of professions*. Chicago and London: The University of Chicago Press.

Bossen, C., Chen, Y., & Pine, K. H. (2019). The emergence of new data work occupations in healthcare: The case of medical scribes. *International Journal of Medical Informatics, 123,* 76-83. doi:https://doi.org/10.1016/j.ijmedinf.2019.01.001

Bourgeault, I. L., Dent, M., Denis, J.-L., & Kuhlmann, E. (2016). General introduction: The changing world of professions and professionalism. In *The Routledge Companion to the Professions and Professionalism* (pp. 19-28): Routledge.

Bowers, J., Button, G., & Sharrock, W. (1995). *Workflow from Within and Without: Technology and Cooperative Work on the Print Industry Shopfloor*. Paper presented at the Proceedings of the Fourth European Conference on Computer-Supported Cooperative Work, Dordrecht.

Bowker, G. C., & Star, S. L. (1999). *Sorting Things Out. Classification and Its Consequences*. Cambridge (Mass) & London: MIT Press.

Busse, R., Geissler, A., Quentin, W., & Wiley, M. (Eds.). (2011). *Diagnosis-related groups in Europe*. New York,: Open University Press.

Cooper, R. A. (2001). Health Care Workforce for the Twenty-First Century: The Impact of Nonphysician Clinicians. *Annual Review of Medicine, 52*(1), 51-61. doi:10.1146/annurev.med.52.1.51

de Bont, A., van Exel, J., Coretti, S., Ökem, Z. G., Janssen, M., Hope, K. L., . . . Wallenburg, I. (2016). Reconfiguring health workforce: a case-based comparative study explaining the increasingly diverse professional roles in Europe. *BMC Health Services Research, 16*(1), 637. doi:10.1186/s12913-016-1898-0

Dent, M., Bourgeault, I. L., Denis, J.-L., & Kuhlmann, E. (2016). *The Routledge companion to the professions and professionalism*: Routledge.

Freidson, E. (2001). *Professionalism, the Third Logic*. Chicago: Chicago University Press.

Goffman, E. (2002). The presentation of self in everyday life. 1959. *Garden City, NY.*

Hoeyer, K. (2016). Denmark at a Crossroad? Intensified Data Sourcing in a Research Radical Country. In B. D. Mittelstadt & L. Floridi (Eds.), *The Ethics of Biomedical Big Data* (pp. 73-93). Cham: Springer International Publishing.

Hogle, L. F. (2016). Data-intensive resourcing in healthcare. *BioSocieties*, *11*(3), 372-393. doi:10.1057/s41292-016-0004-5

Lowry, J. E. (2017). Medical Students' Perspectives on Their Experiences as Medical Scribes. *MA Thesis. Michigan State University*.

Nancarrow, S. A., & Borthwick, A. M. (2005). Dynamic professional boundaries in the healthcare workforce. *Sociology of Health and Illness, 27*. doi:10.1111/j.1467-9566.2005.00463.x

Star, S. L., & Strauss, A. (1999). Layers of Silence, Arenas of Voice: the Ecology of Visible and Invisible Work. *Computer Supported Cooperative Work, 8*, 9-30.

Suchman, L. (1995). Making Work Visible. *Communications of the ACM, 38*(9), 56-63.

Tsiachristas, A., Wallenburg, I., Bond, C. M., Elliot, R. F., Busse, R., van Exel, J., Rutten-van Mölken M.P., de Bont A., and MUNROS team.(2015). Costs and effects of new professional roles: Evidence from a literature review. *Health Policy, 119*(9), 1176-1187. doi:10.1016/j.healthpol.2015.04.001

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Usability and Utility of Head Mounted Displays in Care according to Caregivers

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Abstract. Nowadays, professional caregivers need to provide care in less and less time, while quality requirements are increasing. Therefore, access to information and guidance need to be improved. One solution to support caregivers is the Care Lenses which support caregivers during everyday care with Augmented Reality (AR). AR may provide additional information, guidance and remote support. While technology is not always the best solution for such a difficult and manifold problem, extensive evaluations are needed in order to investigate the potential of AR in everyday care context. In this Paper we summarize perceptions of 25 caregivers, who were participating in our study, using Care Lenses in a simulated everyday care situation. It shows AR is able to support caregiver during their work and what kind of problems might occur during the introduction into professional care.

Introduction

Care Lenses is a smart concept using augmented reality (AR) technology to support caregivers in their daily work. It is meant to ease the time and quality pressure in the care system by providing smart support such as access to information on the patient, workflow guidance and remote helper access during the provision of care. With the help of AR Head Mounted Displays (HMD), it is possible to provide people with additional information while they are able to interact with the real world freely (e.g., using their hands for work tasks instead of operating computing devices). Augmented Reality (AR) supplements the real world with digital information (Azuma, 1997). Typical use cases include expert-novice scenarios (e.g., Datcu, Lukosch, & Lukosch, 2016; Fakourfar, Ta, Tang, Bateman, & Tang, 2016) or workflow support for workers (e.g., Blattgerste, Strenge, Renner, Pfeiffer, & Essig, 2017).

The potential of AR support for caregivers has been recognized. Among relevant work in this area, AR has been investigated for remote support of caregivers (Mather et al., 2017), care procedure training (Azimi et al., 2018; Kobayashi, Zhang, Collins, Karim, & Merck, 2018) as well as image capture and documentation (Aldaz et al., 2015).

Despite this work, little is known about the application of AR support for care in practice. To close this gap, we conducted a study with our Care Lenses, a multi-functional AR support tool for care. In particular, we were interested in the applicability in care practice and the acceptance of the Care Lenses. We present results of interviews conducted with caregivers and insights stemming from this.

The Study

Care Lenses

Care Lenses provide caregivers with planed care guidance for care specific tasks such as pain management, wound management or endotracheal suction and provides data from patients, making health infrastructure accessible. In addition, caregivers can call remote experts via video calls and synchronize data from tasks done in digital documentation systems directly. Care Lenses are supposed to ease care practice, increase care quality and to unburden caregivers from effortful and time-consuming tasks like documentation or ordering material.

Figure I: Left: A caregiver while treating a patient in the study. Right: The AR Head Mounted Display used in the study (Epson Moverio BT 300).

Care Lenses Features Tested

In the study we used support for ordering everyday care material and a typical care workflow. The first supports ordering with Care Lenses' context recognition, which enables users, among other things, to order some recognized material by selecting one of a couple of preset amounts. This makes ordering material, which we were reported as lengthy and complicated, a ten second process directly feasible. The second feature provides support for pain management workflows at the patient. It consists of seven steps leading the user through the workflow during the treatment and providing helpful information about what to do, ensuring a high standard of care. The workflow holds short questions (for example "Can the patient answer to questions?") in order to adapt the workflow according to the needs of patients. It also allows caregivers to enter patients' assessments of their pain level, matches it with the maximum and minimum levels prescribed and provides advice how to proceed according to those levels. Finally, the Care Lenses document the pain level in the documentation backend. Both were chosen as they had been identified to be tasks that either were error-prone (pain management) or time-consuming and often forgotten (ordering material) in the design phase of the Care Lenses as they had been identified in our field work and from statements by care staff we interviewed. In our study we used a fully operational prototype, controllable via touchpad or head gestures (Prilla, Janßen, & Kunzendorff, 2019) and displaying static data instead of using a documentation backend. As HMD we used an Epson Moverio BT 300 (see Figure I), which is a lightweight model of and looks close to real glasses.

Table I: Research questions of our study and examples for questions in the interview.

Research Question	**Examples for Questions in Interview**
How is support for workflows in AR able to facilitate and relieve everyday care?	"Can you imagine using Care Lenses in everyday care? Justify please!"
	"What kind of benefits of Care Lenses do you notice for the executed task?"
	"What kind of limitations of Care Lenses do you notice for the executed task?"
How does AR influence the interaction of caregivers with patients?	"What do you think about how Care Lenses will change the interaction with patients?"

Methodology

The study was performed in simulated care situations: They took place in real patient rooms, and we used one of the researchers to act as a patient (see Figure I). For reasons of ethical approval collected for the project, we did not use Care Lenses prototypes with real patients. In the study, the care givers were asked to use the Care Lenses for the conduction of the two tasks described above. After that, they were interviewed. Besides questions about perceived usability and utility of Care Lenses in everyday care we were interested in general impressions of caregivers about the Care Lenses and their opinion about how Care Lenses could be used during the interaction with patients (see Table I). We audio-recorded the interview and transcribed them later for analysis.

Participants

The study was done at four different locations (care providers) and with 25 caregivers in total (see Table II). The participants were aged from younger than 25 to older than 50. 19 of them were female and 6 male. Their experience in care was on average 12.6 years (SD=8.6), and all of them had experience in pain management or were at least educated in it during their apprenticeship. In what follows, we will refer to participants as caregiver 1 to 25 (C1-25, see Table II).

Table II: Overview of caregivers participating in the study.

Care Provider	**Participants**	**Indices**
Elderly care ward	6	C1-C6
Intensive care shared apartments	6	C7-C12
Care laboratory, participants from different care providers	5	C13-C17
Intensive care stationary unit, participants from different providers	8	C18-C25

Data analysis

For data analysis, we transcribed and paraphrased the recorded interviews and sorted the paraphrases into categories mainly derived from the questions of the structured interview (see Table I). Within those categories we sorted positive and negative aspects of the feedback (e.g., what they liked and did not like regarding interaction with patients). In the following analysis, we used mainly inductive clustering. We clustered paraphrases according to their content within the negative and positive aspects of our categories in order to find underlying arguments for or against Care Lenses in practice. As an example, one resulting cluster contains all positive arguments about using Care Lenses in the near of patients and another holds negative arguments about using them during the whole day. From these, we created 32 clusters that represent topics mentioned in the interview through a second clustering. For example, clusters about working with Care Lenses at the patient and potential reactions of patients to it were summarized in the topic “Care Lenses at the patient”.

Below, we report on general topics dealing with the applicability and utility of Care Lenses in care. These include everyday use at the patient, familiarization and learning curve, ensuring quality in care, and communication.

Results

Use of Care Lenses in everyday care

In general, the caregivers were positive about the Care Lenses. One even told us: “Continue! I would wish that the Care Lenses will arrive in practice!” (C2).

The Caregivers appreciated different aspects of Care Lenses and none stated that they did not see benefits in using it. Availability of data from health infrastructure in situ was an aspect often mentioned: “For assessment I think it is great that I can directly access it (Author comment: Health infrastructure) at the patient. Without the need to write anything (Author comment: Documentation of assessment). So, I can talk to the patient and concentrate on him completely.” (C16).

The caregivers also stated they appreciated getting information from Care Lenses they would otherwise miss or need to lookup: “The information I get from it!” (C10 on the pros of Care Lenses in everyday care). Regarding helpful information to be displayed on Care Lenses, caregivers mentioned “vital parameters” (C3), “weight” (C23) and “diet” (C2). Furthermore, they asked for “information about care plans” (C10) and “reminders about specific care tasks” (C23).

Another aspect mentioned is the ease provided to otherwise effortful tasks. They particularly liked to order or document directly, which helped to avoid to forget documentation: “Very good! ...When you notice something must be reordered, you have it on the spot, can order and done!... Usually you will definitely forget it faster than with such glasses!“ (C2 on benefits of workflow support). Others mentioned advantages for coordination: “With four people in service you always have to talk about what they have to do and when… With glasses this is done in a few seconds.“ (C19 on benefits of Care Lenses)

Despite the positive feedback, caregivers also mentioned some problems. Some were concerned that (other) caregivers could rely on the Care Lenses too much without using their own experience or knowledge: “Perhaps someone relies too much on the device without rechecking.” (C17). Another issue mentioned was whether Care Lenses could be misused e.g. to enable unexperienced caregivers to do tasks they were not trained in – which is not the purpose of Care Lenses. In contrast, some caregivers even thought the Care Lenses could provide a chance to support less able colleagues (compared to letting them work without support): “But it is better to have bad staff with Care Lenses than bad staff without… or to work to much under the Care Lenses without to bring in own experience.” (C10).

A few caregivers were unsure how the Care Lenses would fit in everyday care practice because they “learned to treat patients differently” (C13) or they already have a routine in everyday care and therefore do not need Care Lenses. “Perhaps I am stuck in my everyday routine and I just know what I have to do … Actually I do not need the Care Lenses, but I did not have it before. Perhaps I cannot imagine being without it if I worked with it a little bit more.” (C25)

Perceived influence on interactions with patients

The caregivers discussed and were able to differentiate between which support provided by Care Lenses should be used at the patient and which not. A few caregivers stated they would avoid to wear Care Lenses in front of patients. For example, they suggested to use ordering support only outside the patient's room and to document care tasks while going from one patient room to another: "At the bed of the patient I would not like to use it (because Care Lenses distract from patient (interpreted from prior comments in this interview)). For documentation afterwards, it was fast and practical, or for ordering care materials it is useful." (C9). In contrast, many others stated they wanted to use Care Lenses in front of the patient because of the offered support like automatic documentation (C4, C5, C10, C16, C18).

Regarding the interaction with patients, some caregivers concern: "Care Lenses are not patient friendly" (C9). This was often explained by the distraction from the patient Care Lenses could possibly provide. Some mentioned they had the impression to talk less to the patient than usual. One caregiver mentioned that he did not "talk to the face of the patient" (C25) and another reported on missing eye contact to the patient (C23). Another caregiver stated he felt unpleasant if he does "look into the Care Lenses without focusing on the patient because in care patients expect caregivers to talk with them" (C19). In the same vein, a caregiver assumed colleagues could be more focused on Care Lenses and talk even less with patients if those patients are less talkative by themselves (C10). In contrast, some caregivers denied any influences of the Care Lenses on their interaction with patients, stating for example to "still talk with the patient as usual" (C22).

Keeping patients in focus

Care Lenses were also perceived as distraction by caregivers, with some mentioning difficulties to keep the patient in focus. They mentioned that "the focus goes away from the patient" (C20) while wearing Care Lenses and that the use of it requires concentration because caregivers "have to read the text" (C20) on it. Some Caregivers expressed their fear to "miss something important at the patient" (C9) while using Care Lenses or that a patient could notice their distraction and "could get the feeling he would not be taken seriously as a human" (C12). Some mentioned the impression they were not completely focused on the patient like they usually are ("I believe I was just to less there for Miss Smith[1]" (C21)). It needs to be mentioned that besides these few statements, most of the caregivers did not mention these fears. Many stated they would most likely get used to the Care Lenses over time (see below).

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[1] Name changed by the authors.

Estimated reactions of patients and experience with Care Lenses

Some caregivers mentioned the Care Lenses make them “look ridiculous (Author comment: for the patient)” (C20) or they “feel strange while wearing it” (C15). Some of them just stated they are not used “to wear glasses” (C12) or simply “to work with Care Lenses in front of patients” (C23). Others said they would feel uneasy during the patient contact. They also estimated patients would think caregivers would be “out of their mind” (C23) or “do not take them seriously” (C12) if they use Care Lenses in front of them without looking to them.

Some caregivers feared patients would not be able to understand Care Lenses and their purpose because they show information only to their wearer. One caregiver added that “patients suffering from dementia could be even more irritated by Care Lenses than they usually are, which is a big problem for them” (C1). Nevertheless, caregivers stated also that the current generation of patients is not used to technology in general. Some caregivers concluded that “later generations of patient will possibly not have this problem” (C23).

On the other side, most caregivers did not assume negative reactions of patients and some were even speaking of positive reactions. A lot of caregivers thought that patients would “accept the Care Lenses if they get a proper explanation” (C3) or that “many (Author comment: patients) will tolerate the Care Lenses and will find it great” (C6). Some even assumed that patients could be interested in Care Lenses by themselves: “The mentally healthy (patients), depending on how technophilic they are, (…) can be enthusiastic about the Care Lenses” (C12).

Familiarization and Learning Curve

Many caregivers recognized that some of the difficulties they had with the Care Lenses could stem from the fact that they were just not used to it and needed some more practice: “Had to be occupied with the Care Lenses, because I did not know it before” (C4). For example, one caregiver mentioned that wearing HMDs in general “is matter of habit” (C12). Other caregivers mentioned that distraction from patient could also be reduced if the Care Lenses become a known tool: “You have to get used to it (Care Lenses) first, (…) it is quite big, I think it is heavy, it is unfamiliar.” (C18). According to caregivers the focus on patients could be a question of getting used to the Care Lenses: “If you cope with the Care Lenses nicely at some time, the patient definitely is paramount. (…) Initially you focus more on the Care Lenses, but you get used to it.” (C22).

Another aspect caregivers estimated to get accustomed to is the handling of the Care Lenses in order to work faster than in the study and to get along with the Care Lenses while treating a patient: “As soon as I get used to it (Author comment: Care Lenses) I think I will become faster (Author comment: in using Care Lenses) and come along at the patient quite well” (C16).

Discussion and Conclusion

Our study shows that our concept of using AR for the support of caregivers has good potential to provide value and to become accepted. We did not find reasons that would prevent users from using Care Lenses in everyday care while treating patients, and no other reasons to exclude usage. Nonetheless, we found considerable concerns about using Care Lenses. Many of them arise from the study situation and brief confrontation with Care Lenses. The concept was new and unknown to the caregivers, and in many of their statements it became clear that this affected their perception of using Care Lenses. Caregivers also told us their impression could change if they had more time to get used to the concept. Moreover, some caregivers said they focused too much on the Care Lenses and had difficulties to focus on the patient or talk to them during care. As above, caregivers stated that they just need time to get used to and deal with Care Lenses in order to diminish this problem. We will explore this in long-term exposure studies and onboarding or tutorial strategies for the initial usage of Care Lenses.

Another issue that could have caused concerns is the HMD used in the study, which is a commercially available product and should be wearable by the general public. However, in practice it often did not fit perfectly or was too big and slipped. Current and future development will most certainly solve this with less weight and displays that can show information easier to read and less obtrusive.

Beyond the concerns mentioned above, most caregivers did not have additional concerns. We assume they understood Care Lenses as a tool supporting them, while others rather understood them as something new, they needed to explore first causing them to focus on the HMD.

One interesting aspect is that caregivers told us they might be embarrassed by wearing the Care Lenses in front of patients. These caregivers also had concerns about their own appearance with Care Lenses on, which reinforces their concerns about using them with patients. Therefore, they told us they would avoid using Care lenses near the patient. In practice, it may be the case that this feeling changes quickly when they recognize that patients accept or even welcome the support provided by the Care Lenses as assumed by other caregivers. Less obtrusive technology with more natural and inconspicuous controls can also help caregivers to overcome this. Moreover, it will also be easier for patient to get used to caregiver wearing it and even helps avoiding confusion of patients who are suffering from dementia.

While our insights suggest that Care Lenses can be accepted and helpful in care practice, this needs to be scrutinized in practice. It is not sure that Care Lenses work in real care practice where people are stressed, attending multiple patients, and where the potential for technical issues is much higher. The simulated care task was free of this and possibly ease to accept Care Lenses this way. Our future work will be devoted to investigate this any further.

References

Aldaz, G., Shluzas, L. A., Pickham, D., Eris, O., Sadler, J., Joshi, S., & Leifer, L. (2015). Hands-Free Image Capture, Data Tagging and Transfer Using Google Glass: A Pilot Study for Improved Wound Care Management. *PLOS ONE*, *10*(4), e0121179. https://doi.org/10.1371/journal.pone.0121179

Azimi, E., Winkler, A., Tucker, E., Qian, L., Sharma, M., Doswell, J., … Kazanzides, P. (2018). Evaluation of Optical See-Through Head-Mounted Displays in Training for Critical Care and Trauma. *2018 IEEE Conference on Virtual Reality and 3D User Interfaces (VR)*, *00*, 1–9. https://doi.org/10.1109/VR.2018.8446583

Azuma, R. T. (1997). A survey of augmented reality. *Presence*, *6*(4), 355–385.

Blattgerste, J., Strenge, B., Renner, P., Pfeiffer, T., & Essig, K. (2017). Comparing conventional and augmented reality instructions for manual assembly tasks. *Proceedings of the 10th International Conference on PErvasive Technologies Related to Assistive Environments*, 75–82. ACM.

Datcu, D., Lukosch, S. G., & Lukosch, H. K. (2016). Handheld Augmented Reality for Distributed Collaborative Crime Scene Investigation. *Proceedings of the 19th International Conference on Supporting Group Work*, 267–276. https://doi.org/10.1145/2957276.2957302

Fakourfar, O., Ta, K., Tang, R., Bateman, S., & Tang, A. (2016). Stabilized Annotations for Mobile Remote Assistance. *Proceedings of the 2016 CHI Conference on Human Factors in Computing Systems*, 1548–1560. https://doi.org/10.1145/2858036.2858171

Kobayashi, L., Zhang, X. C., Collins, S. A., Karim, N., & Merck, D. L. (2018). Exploratory Application of Augmented Reality/Mixed Reality Devices for Acute Care Procedure Training. *Western Journal of Emergency Medicine*, *19*(1), 158–164. https://doi.org/10.5811/westjem.2017.10.35026

Mather, C., Barnett, T., Broucek, V., Saunders, A., Grattidge, D., & Huang, W. (2017). Helping Hands: Using Augmented Reality to Provide Remote Guidance to Health Professionals. *Studies in health technology and informatics*, *241*, 57–62.

Prilla, M., Janßen, M., & Kunzendorff, T. (2019). *How to Interact with AR Head Mounted Devices in Care Work?* Gehalten auf der Twenty-Seventh European Conference on Information Systems (ECIS2019).

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Co-designing infrastructures

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Abstract The paper builds on an ongoing research project striving to reduce hospitalization of elderly citizens with dementia (ECwD). In the research project sensor technologies are used to gather large amounts of data to speak on behalf of the ECwD about change in their behaviour. But in order for the data to create value, network-building efforts made by the project researchers is needed, as the case illustrate. Inspired by the framework of participatory infrastructuring we illustrate how front-stage as well as back-stage activities leads to negotiations and translations of concerns and data in a process of network-building together with a multiplicity of users and other actors such as ECwD, their loved ones, caregivers, sensors, researchers, municipalities, companies and nursing homes.

Introduction

Big data is on everyone's lips these days. Especially within healthcare, big data is said to hold amazing potential in terms of population health management, clinical decision support to allow for better informed decisions, and prediction of disease progression (Lazarou et al., 2016; Raghupathi & Raghupathi, 2014). Thus, as Raghupathi and Raghupathi concludes: '*big data analytics has the potential to improve care, save lives and lower costs* '(2014, p. 1). Within the field of healthcare dementia is an interesting area where big data may be of particular use as assistive technologies such as sensors has the potential to speak on behalf of some of the elderly citizens with dementia (ECwD) which is no longer capable of expressing their own emotions and symptoms of a disease. For instance, sensors of varying kinds can measure biometrics such as pulse and heart rate, fall sensors can measure where citizens walk and whether ECwD suddenly fall, while GPS trackers measure their whereabouts so they can be found if they stray and get lost etc. The data from all these sensors can be seen as big data: '*a collection of data elements whose size, speed, type, and/or complexity require one to seek, adopt, and invent new hardware and software mechanisms in order to successfully store, analyze, and visualize the data*'(Belle et al., 2015, p. 1). Dementia is not only interesting as the people suffering from this condition require a lot of help but also because a vast increase in number of ECwD is expected in the future. Studies estimate that in 2030 around 75,6 million people worldwide will suffer from dementia – and the number even increases to 131 million people by 2050 ("Dementia Statistics," 2018). The majority of this group lives in nursing homes and is thus very dependent on having dedicated caregivers who knows them and can detect signs of illness. If the caregivers fail to do so, the disease might not get noticed and treated resulting in hospitalization and in worst case in the death of the ECwD.

This paper builds on preliminary work and findings from an ongoing Danish research project PACE (Proactive Care for Elderly People with Dementia) striving to reduce hospitalization of elderly citizens with dementia. Using PACE as a case study we draw upon participatory design and Actor-Network Theory (ANT) to illustrate how big data is only one of the actors in a larger network comprising a multiplicity of actors such as ECwD, their loved ones, caregivers, sensors, researchers, municipalities, companies, legislation, research institutions and nursing homes. Our argument is, that in order to reap the benefits of big data analysis the point is not only to build suitable algorithms but rather to co-design an infrastructure which according to ANT require network-building activities. Bødker, Dindler & Iversen (2017) from the participatory design tradition refer to such network-building activities as participatory infrastructuring. Building on their research, this paper describes and analyses the negotiations and translation currently taking place as part of the network-building in PACE.

PACE: Preventing hospitalisation of ECwD

Having dementia causes severe challenges both to the citizens themselves, their relatives but also to the healthcare system. For instance, studies show that a higher level of comorbidity is found among people with dementia (Bynum et al., 2005), which calls for extra coordination between the clinicians and the elderly citizens in order to report symptoms. If not reported, this may result in inadequate treatments and hospitalization. Thus, both from a citizen and a socio-economic perspective it is essential that hospitalizations must be avoided.

PACE wish to explore how the use of big data can contribute to detect changes in practices and behaviour among ECwD by combining already existing technologies such as different sensor technologies to speak on behalf of ECwD. Thus, PACE builds on the work of Lazarou et al. who advocates that '*Smart systems can improve the quality and variety of information monitored from specific measures of* *physiological signs and behavioral patterns and translate them into accurate predictors of health condition and disease progression*' (2016, p. 1562).

Similarly, to Lazarou et al. PACE explores the potentials of sensor technologies and big data. However, rather than mainly focusing on adopting and inventing new hardware and algorithms (which is often the case of project involving big data) the PACE project seeks to take a participatory design approach to co-designing an infrastructure of people, software, sensors, institutions and a new user interface that acknowledge the practices of the caregivers at nursing homes and provides valuable insights enabling them to take even better care of the ECwD. We argue that this entails staging spaces for negotiation between actors to allow for translation of the results generated by big data into something which is meaningful for the caregivers, the ECwD, their loved ones and at the same time creates value for the healthcare system.

Theoretical framework: Participatory design and infrastructuring

Involving users in the development of healthcare equipment is not new as private companies do recognize the importance of understanding their 'users' in order to design solutions which 'meet their needs' (Shah & Robinson, 2006). As several studies illustrate, engaging users will increase the success rate of the products, reduce the risk of failure and ensure long lasting products and services (Shah & Robinson, 2008).

Particularly the participatory design tradition stemming from Scandinavia provides methods for engaging users and other actors to actively contribute to the design process as they see 'users' of varying kinds *"…as the true experts in domains of experience such as living, learning, working, etc."* (Dubberly & Sanders, 2008, p. 13). The core values of this design tradition are democracy and change and participatory design promotes the idea that the people who are going to use the solutions should also have a say in their design and development (Bratteteig & Gregory, 2001).

Bødker et al suggest the notion of participatory infrastructuring, where infrastructuring work is linked to the sustainability of the design projects meaning continuous involvement over time. What is special about participatory infrastructuring is the analytical focus on how infrastructuring (interplay among people, organisations and levels of political authority) ties into existing networks, and how front stage *as well as* back-stage activities is used to obtain this anchoring and constant involvement (Bødker et al., 2017). Front stage activities refers to workshops and co-design settings while the back-stage activities refers to *'preparations, negotiations, and political work that fundamentally shapes the set-up and outcomes of the entire process'* (Bødker et al., 2017, p. 250). Both are equally important, as the back-stage activities are an essential part of staging what Pedersen and Clausen terms Negotiation Spaces (Pedersen & Clausen, 2017).

In the PACE project examples of actors from different political levels would be local ECwD, their loved ones, private companies, public municipalities. Whereas government legislation initiatives provide a way for the new network to anchor and thus sustain after the traditional design process ends. However, traditionally the participatory design literature does not occupy itself with networks, and sometimes neglects the central role of objects in negotiations. Thus, we turn to Actor-Network-Theory (ANT) for a vocabulary related to infrastructuring as network-building through translations.

Network-building

The combination of participatory design and ANT is not unexplored as for instance participatory design researchers like Björgvinsson et al. (2012) have drawn upon ANT to investigate and give a vocabulary to the processes of network-formation, translation, alignment of knowledge and diverse actors in design processes. ANT is a constructivist approach where the word actor refers to both human and non-human entities giving a voice to ECwD, doctors, caregivers, loved ones as well as prototypes, drawings, sensor technologies and algorithms. Thus, the design process is seen as a "*collective interweaving of people, objects and processes*" (Björgvinsson et al., 2012, p. 130). The formation of socio-technical assemblies is central in design as the goal of many design processes is to form a stabile network. But before the network or infrastructure become stabile, the actors go through a process of translation. Storni (2012) argue that such translation processes is often associated with numerous negotiations of the matters of concern of multiple actors. Matters of concerns are (as opposed to matters of fact) characterized by being rich, complex, surprising and constructed (Latour, 2004) which makes them political and open for discussion, negotiation, conflict and compromise (Björgvinsson et al., 2012; Latour, 2005). A key enabler in these negotiations are traditionally material objects such as mock-ups, prototypes, post'its, graphs etc. However, in our case also algorithms , sensor-technologies and user-interfaces are central objects as they together with the traditional prototypes and drawings have the potential ability to perform as intermediary objects (Boujut & Blanco, 2003; Vinck, 2012). These intermediary objects *represent* knowledge and *perform* as an important actor in the translation, production and negotiation of data and knowledge.

The PACE research approach

As previously mentioned, the primary aim of PACE is to prevent hospitalisation of ECwD. The primary nodes in the new network-in-the-making are two Danish nursing homes Skovhuset and Ryetbo, who sees a potential in allowing sensor technologies to help the caregivers in their efforts to identify early signs of a beginning disease such as urine infections or pneumonia among ECwD. PACE also involves researchers from Aalborg University (AAU) who are experts in participatory design activities and who's first task was to identify indicators of sickness. These indicators are used in a big data analysis, done by researchers from the Technical University of Denmark (DTU), who will be designing an algorithm based on these indicators. Further, PACE also includes a supplier of sensor-technologies. Alongside the human actors in the network, the PACE participants also automatically bring an assembly of other human actors and objects which forms the different institutions such as electronic patient record systems, the administrators of the systems, the legislation and rules of conduct from the municipalities and many other.

The research is based on a combination of qualitative and quantitative research. The qualitative research is carried out by the authors and include ethnographic interviews, desk research, workshops, observations and informal meetings with a variety of actors. The quantitative part of the research entails analysing data generated from sensor technologies and developing an algorithm that is comparable with the existing electronic patient system.

In present time, the project is 1,5 year into its 4 fours of running. The sensor technologies currently chosen for the purpose of data collection consists of existing products or products almost ready for market launch. Based on the initial identification of indicators the sensor technologies were selected based on their ability to measure these indicators. At this point in time, four technologies are included in the research: sensor floor, emergency system, radar and a biosensor padge. These four technologies can provide the project with unique data on the following parameters:

What is measured?	*Floor*	*Emergency System*	*Radar*	*Bio Sensors*
EKG				X
Heart frequency			X	X
Respiration				X
Position			X	X
Fall	X			X
Step counter				X
Temperature			X	X
Contact		X		

Figure 1: Overview of sensors and of what they measure

The next step after selecting the sensor technologies is to translate the indicators into something that can be measured. This step is crucial as it affects the results of the big data analysis. For instance, as apathy is one of the indicators, the DTU researchers will look for less walking around on the sensor floor. And similarly, with the other indicators.

Negotiating concerns

As already indicated, the participatory design researchers initiated their search for indicators of deterioration of health for the ECwD as these would provide the DTU researchers with a starting point in terms of building algorithms and searching for patters in the data. So, our first task in the research project was trying to understand and identify *what* to look for in the sensor data. Through desk research we identified a number of potential indicators of possible sicknesses such as frequent toilet visits, increased anger, apathy etc. We soon learned that the effects of dementia present itself in different ways, and also that no dementia expert or other expert could possibly give one fulfilling answer as to which indicators to look for. So, we expanded the network to include actors such as experts in dementia (doctors, nurses, dementia coordinators etc.), nursing home staff, and patient associations. Through roll-the-snowball techniques new actors were identified, and meetings where set up. These meetings can be seen as negotiation spaces (Pedersen & Clausen, 2017) that was staged to negotiate a number of potential indicators. A central actor in these negotiations was a set of game pieces with icons and wording representing an initial list of eleven indicators (see figure 2). These pieces acted as intermediary objects (Vinck, 2012) illustrating and representing indicators, mediating between the researchers and the dementia experts, and translating knowledge from one spaces to the next by introducing new game pieces based on feedback from the previous experts. While building a shared knowledge on indicators of sickness the negotiations also had the effect that the consulted experts also became translated to be part of the new network that the PACE project was about to build up.

Figure 2. Illustration of how indicator cards were used in engagement with a variety of actors

What became apparent from these negotiations (besides new indicators such as difficulty for the caregivers in performing personal care due to increased anger and discomfort) was that all engaged experts agreed, that each indicator is only relevant if there is a *change in behaviour*. For instance, frequent toilet visits do not indicate illness if the ECwD always has frequent toilet visits. Another important learning was, that such changes in behaviour is not necessarily a sign of illness, but might be an indication of e.g. over- or under-stimulation. Thus, during the negotiations under- and overstimulation of ECwD emerged as a new matter of concern to be explored. Our response to this was to engage a team of Bachelor's students, who further investigated this concern. They staged negotiation spaces with props such as design games, personas etc. and invited ECwD, caregivers from Skovhuset and relatives into negotiations around how to ensure a right level of stimulation of the ECwD and keep track of extraordinary activities such as physiotherapy, birthdays etc. so this information would feed into the big data collected by the sensor technologies. The students ended up developing an app, in which relatives and caregivers could upload pictures of these extraordinary activities and tag the ECwD so they were linked to specific activities. The app provided a transparent way for the relatives to see that the caregivers engaged the nursing home residents in fun activities, while at the same time providing the caregivers (and PACE researchers) with insights as to why there might be changes in the behaviour of the residents. After graduation, the students have continued their work, and are now a sub-partner in PACE.

In line with the previous work on participatory infrastructuring we also initiated the process of expanding the network by tying the PACE network-in-the-making to existing networks and infrastructures. In Hillerød municipality where the nursing home Skovhuset is located, they have an electronic patient record (EPR) system called Nexus where all information on the nursing home residents is documented. To ease the workload of the nursing home caregivers PACE strives to integrate the results of our algorithm with the local patient record system. Thus, we have initiated negotiations with the municipality as well as with the private company developing the EPR to provide us with an API. Even though it is still quite early in the project and we have not produced any algorithm and only gathered some initial data from 6 residents, it is a central part of the participatory infrastructuring activities to also enroll municipality representatives in the PACE network. We (the AAU researchers) have had several meetings with representatives from the municipality IT department in an effort to involve this key actor in the network. In these spaces the municipality representatives were introduced to illustrations of the project setup, and based on these encouraged to voice their own concerns and how they could see their own role in the project. Thankfully the municipality representatives were very supportive and thus an ongoing task in the project is to keep these actors in the loop and nurture the good relationship. Furthermore, the help from the municipality has proved central in designing the informed consent documents that are necessary for collecting the data. This has been an ongoing effort as it is important for the municipality who owns the nursing home to make sure that none of their citizens' rights are violated. Because many of the ECwD are not capable to sign these informed consents on their own, it is also an ongoing task to nurture the relationship with their relatives as they are the ones who can sign on behalf of the ECwD. Thus, we have arranged relatives-cafés at both nursing homes to tell about the project and answer any questions they might have.

Recently, we have also staged and facilitated workshops with nurses and caregivers at the nursing homes to initiate a second translation of the project. Thus, we need to translate the results from the big data analysis into something that provides value for the practices of the caregivers. In order to do so we have used what might be termed back-stage work (having project meetings, info-meetings, meetings with the municipalities) to stage these workshops.

As we are now 1,5 year into the research project we have tried to make every activity carried out (whether it be a back-stage or a front-stage activity) count as one step in the direction of participatory infrastructuring.

Conclusion

In this paper we conclude that one of the most important elements of design is to build relationships between actors that can forms a stabile network. This is obtained through staging spaces for negotiation which foster a translation process where each actor develops their own identities and roles in the network. In PACE we have initiated this process by inviting a multiplicity of actors to participate in negotiations about diverse matters of concerns. The first negotiations focused on identifying indicators. The next negotiation revolved around the translation of the indicators into something that can be measured with sensor-technologies. And when the big data analysis is conducted, the results will be translated into something that provides value for the caregivers. The essential thing here is, that the caregivers themselves are involved in this development process.

Despite the research project is still only 1,5 year into its activities, many front stage and back stage activities has already been conducted. Each of these represents one step towards building and expanding the network through participatory infrastructuring. Thus, even though the PACE project is designing an algorithm, we are indeed also (and perhaps more importantly) co-designing an infrastructure to support and sustain the use of the designed algorithm in a way that it provides value for all actors in the network.

Bibliography

Belle, A., Thiagarajan, R., Soroushmehr, S. M., Navidi, F., Beard, D. A., & Najarian, K. (2015). Big Data Analytics in Healthcare Review. *Biomed Research International*, *2015*, 1–16. https://doi.org/10.1155/2015/370194

Björgvinsson, E. B., Ehn, P., & Hillgren, P.-A. (2012). Agonistic participatory design: Working with marginalised social movements. *CoDesign*, *8*(2–3), 127–144. https://doi.org/10.1080/15710882.2012.672577

Bødker, S., Dindler, C., & Iversen, O. S. (2017). Tying Knots: Participatory Infrastructuring at Work. *Computer Supported Cooperative Work: CSCW: An International Journal*, *26*(1–2), 245–273. https://doi.org/10.1007/s10606-017-9268-y

Boujut, J.-F., & Blanco, E. (2003). Intermediary Objects as a mean to foster Co-operation. *Computer Supported Cooperative Work*, *12*, 205–219.

Bratteteig, T., & Gregory, J. (2001). Understanding Design. *Proceedings of the 24th Information Systems Research Seminar in Scandinavia (IRIS 24)*, *3*.

Bynum, J. P. W., Rabins, P. V., Weller, W., Niefeld, M., Anderson, G. F., & Wu, A. W. (2005). The relationship between a dementia diagnosis, chronic illness, medicare expenditures, and hospital use. *Research and Practice in Alzheimer's Disease*, *10*, 160–164.

Dementia Statistics. (2018). Retrieved May 12, 2019, from https://www.alz.co.uk/research/statistics

Dubberly, H., & Sanders, E. B.-N. (2008). *On modeling an evolving map of design practice and design research. Interactions* (Vol. 15). https://doi.org/10.1145/1409040.1409043

Latour, B. (2004). Why Has Critique Run out of Steam? From Matters of Fact to Matters of Concern. *Critical Inquiry*, *30*(2), 225–248. https://doi.org/10.1086/421123

Latour, B. (2005). From Realpolitik to Dingpolitik or How to Make Things Public. In P. Latour, B. and Weibel (Ed.), *Making Things Public: Atmospheres of Democracy* (pp. 14–41). Cambridge: MIT Press, ZKM, Center for Art and Media.

Lazarou, I., Karakostas, A., Stavropoulos, T. G., Tsompanidis, T., Meditskos, G., Kompatsiaris, I., & Tsolaki, M. (2016). A Novel and Intelligent Home Monitoring System for Care Support of Elders with Cognitive Impairment. *Journal of Alzheimer's Disease*, *54*(4), 1561–1591. https://doi.org/10.3233/JAD-160348

Pedersen, S., & Clausen, C. (2017). Staging Collaborative Innovation Processes. In *The XXVIII ISPIM Innovation Conference – Composing the Innovation Symphony*. Vienna, Austria.

Raghupathi, W., & Raghupathi, V. (2014). Big data analytics in healthcare: promise and potential. *Health Information Science and Systems*, *2*(3), 10. https://doi.org/10.1145/2347736.2347741

Shah, S. G. S., & Robinson, I. (2006). User involvement in healthcare technology development and assessment: Structured literature review. *International Journal of Health Care Quality Assurance*, *19*(6), 500–515. https://doi.org/10.1108/09526860610687619

Shah, S. G. S., & Robinson, I. (2008). Medical device technologies: who is the user? *International Journal of Healthcare Technology and Management*, *9*(2), 181–197. https://doi.org/10.1504/IJHTM.2008.017372

Storni, C. (2012). Unpacking Design Practices: The Notion of Thing in the Making of Artifacts. *Science, Technology & Human Values*, *37*, 88–123. https://doi.org/10.1177/0162243910392795

Vinck, D. (2012). Accessing Material Culture by Following Intermediary Objects. In L. Naidoo (Ed.), *An Ethnography of Global Landscapes and Corridors* (pp. 89–108). INTECH Open Access Publisher. Retrieved from http://www.intechopen.com/books/an-ethnography-of-global-landscapes-and-corridors