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The Quantified Doctor/Nurse: How Quantification Infrastructures 'redo' Care

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Abstract. This paper explores how accountability metrics are enacted in unfolding healthcare practices. We examine the socio-technical infrastructures that underpin and enable quantification of care, and how users of quantified data not only react to quantitative practices and underlying infrastructures, but also actively give shape to them through practices of gamification. In the paper, we elucidate three ways of gamification: adjusting to quantification infrastructures, ignoring quantification infrastructures, and playing with quantification infrastructures. Such games, we show, are played within the context of, and give shape to emerging infrastructures of measuring healthcare. This opens up to a diversity of ontological practices in relation to quantification infrastructures, as well as to unfolding identities of the professional quantified self.

Introduction

In the past few years, healthcare organizations, particularly hospitals, have grown into 'big data houses'. Driven by 'outside' wishes for transparency and accountability, and 'inside' needs to governing care processes and improving outcomes, all types of data are collected and processed, ranging from complications after surgery to malnutrition among elderly, and from physicians' scores on their training of medical residents to nurses' level of caring competences. Furthermore, data is generated by 'others': patients, for example, are encouraged to write reviews and score their healthcare providers on rating sites (Adams 2011).

These measuring practices prompt the creation of a wide range of instruments and technological infrastructures: electronic patient files are adapted to enable and standardize the registration of patients' measurements (e.g., pain scores, fall risk, malnutrition) and facilitate the coding of treatments to enable billing and reimbursement, electronic forms are introduced to measure and compare practitioners' competences, and registries are used to collect data on patient outcomes for different medical specialties (to name a few) (Wallenburg, Quartz, and Bal 2016). The use of metrics to display (and improve) performance is part of a much wider phenomenon of attention for indicators, performance and accountability, of what Michael Power has called 'the audit society' (Power 1997). A growing body of critical accounting literature discusses this desire for accountability metrics, pointing at their patina of objectivity and envisioned commensurability: numbers would not only reveal 'what's really going on' but also render practices comparable (i.e. rankings), distinguishing the 'good' from the 'bad'. In practice, however, numbers are often heterogeneous, plural, and contradictory (e.g. de Rijcke et al. 2016). Furthermore, indicators and rankings (as a way of valuing numbers) have constitutive effects; organizations may become overly focused on metrics rather than on the qualities the metrics are intended to assess. Similarly, attention might be diminished for what is not measured (Dahler Larsen 2012). Hence, metrics are 'reactive' (Espeland and Sauder 2016), exerting a form of disciplinary power; through processes of surveillance and normalization, metrics change how internal and external constituencies think about a certain field and about themselves.

Although we are attentive to this disciplinary view, we like to take the analysis one step further by examining how users of data not only react to quantitative practices, but also actively give shape to them through practices of gamification. In public administration literatures, gaming is often described as an unwanted effect such as 'hitting the target and missing the point' or reducing performance when targets do not apply (Bevan 2006). Gamification, in turn, as a rather new concept in the accounting literature, pinpoints the enabling and more 'playful' practices of quantification. Drawing on the emerging literature on the 'quantified self' – that is, people gathering quantitative data about themselves, using mobile apps and always-on gadgets[1] (Lupton 2016) – scholars highlight the entrepreneurial and gaming features of quantification, elucidating the liberating and empowering capacities of the emerging algorithmic professional identity (Hammerfelt, Rushforth, and de Rijcke 2016, Bal 2017).

To gain a better understanding of how quantifying effects are generated in the healthcare setting, and how metrics are purposed and repurposed in the attempt to govern care, we need to gain insight in how numbers are actually done, shared and get meaning in everyday practices of healthcare governance. In this

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[1] These are also termed 'lifelogging techniques'; the use of sensors is a pivotal feature of self-tracking technologies, using mobile apps and always-on gadgets to track and analyze one's body, mood, diet and spending—just about everything in daily life you can measure. We see a connection here with the professional world of medicine and science in which increasingly performances (whether the distribution of drugs, the amount of hospital patients with a pressure ulcers or the reference scores of a scientific paper) are being collected, thus quantifying individual professional performance on all kind

paper, we examine the infrastructures that underpin and enable quantification of care, and how they are played with.

Research approach

The paper builds on three distinct yet related ethnographic research projects we have conducted on the quantification of care in the past few years. These projects all concerned the use of indicators and performance measurement in hospital in the Netherlands (2011-present). Relying on our theoretical background in Science & Technology Studies (STS), the projects share an interest in how accountability metrics are enacted ('how they are done') in the socio-technical practices of care provision and care regulation.

The concept of infrastructure is key here; numbers do not move freely in outer space, but are actively created, completed, and translated in and between settings. Infrastructures are commonly depicted as substrate: something upon which something else "runs" or "operates" (Star and Ruhleder 1996). STS literature, however, underscores the relational and emergent nature of infrastructures. Key to any infrastructure is its ability to permit the distribution of action over space and time. Rather than an accomplishment, infrastructures require continuous and active engagement, mediating exchange over distance, and bringing different people, objects and spaces into interaction (Larkin 2013). Through the infrastructures that make numbers move, numbers are complemented, sliced, and diced in new ways at other sites, giving rise to a continuous stream of new quantifications.[2] It is this relationality and heterogeneous character of infrastructures that we build on in this paper, focussing on how this gives occasion to new professional identities through practices of gamification.

Findings

Form our research, three ways of gamification emerge: adjusting to the quantification infrastructures, ignoring the quantification infrastructures and playing with the quantification infrastructures (Cf. Bal 2017). These three ways of doing often intermingle, elucidating the rather playful and, we argue, experimental ways of dealing with and giving shape to accountability metrics.

First ***adjusting***. Hospitals (managers, quality staff and practitioners alike) feel overwhelmed with accountability metrics. Each day, they are busy measuring

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of aspects, see http://blogs.lse.ac.uk/impactofsocialsciences/2017/05/15/advancing-to-the-next-level-the-quantified-self-and-the-gamification-of-academic-research-through-social-networks/

[2] Thanks to Anna Essén for pointing this out.

care, building and adjusting technical infrastructures to facilitate data collection and train practitioner in ‘correct coding’, and monitoring whether measurements are actually being done.

> During a meeting of nurse managers in a university hospital, one of the oncology managers displays a long list of performance indicators on a screen. She states that the department faces a long list of items on which they have to account for their performances, as the oncology registry and some large studies on cancer treatment require a lot of measuring from the nurses, which comes on top of the obliged hospital quality indicators. Each performance indicator is indicated with a coloured ball, reflecting how the department is doing on the specific indicator. The chair congratulates the nurse manager on this achievement; she has succeeded in bringing all requirements in one ‘handy’ schedule, creating a good overview of the things that need to be done. The nurse manager nods vaguely, and shies: ‘it’s a hell of a job.’ (Field notes, 17 January 2017)

In our research, we encountered many of these examples: accountability metrics are here to stay and you better make them ‘doable’. Although practitioners complain about the amount of administrative work, they also stress the importance of quantification quality work: “Thanks to the numbers we know what we are doing, and how to improve care in here” (Interview, 25 August 2016).

Second is ***ignoring***. Practitioners sometimes deliberately ignore accountability metrics, often with support of hospital administrators. For instance, when an indicator doesn’t make sense (e.g. ‘measuring fall risk for elderly at a paediatric ward’) or when it doesn’t add to quality of care, they are not filled out. A urologist, for example, pointed out how he was ‘just box ticking’ a list of quality scores requested by the insurance company, as, he argued, *‘these questions don’t embark on real quality issues’* (interview, 2 December 2012). Likewise, on a nursing ward for infectious diseases, towels were temporarily removed from the sink cupboards during an external audit to obtain the anxiously wanted JIC accreditation,[3] and restored immediately afterwards: *‘We’re keeping them in for good reasons; we have seriously ill patients in here, who are incontinent, we don’t have any other convenient place to store towels and diapers.”* (Interview, January 2017)

These quotes demonstrate a rather playful way of ignoring; practitioners do not fall out on the indicators, but only cosmetically comply with them, sticking to their own quality routines. Hence, ignoring doesn’t necessarily mean ‘doing nothing’, but may also encapsulate box ticking or ‘cosmetic compliance’. Practitioners and managers seek to balance ignoring and adjusting: doing away

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[3] Joint Commission International, a prestigious international accreditation system for hospitals.

with all or too many required measurements would harm the hospital tremendously as accreditation would probably be lost or never obtained, and hospitals fear the risk of shaming and reputation damage. Furthermore, ignoring *some* metrics allows professionals to focus on those that they *do* find important for quality work, as becomes clear in the next theme.

A third practice is ***playing the quantitative game***, which is particularly exerted at the work floor level. Here, practitioners strategically deal with numbers to enhance performance. During our field work, we encountered a ward manager who checked each morning whether the nurses had done the obligatory scores, and filled in the missing ones. He distinguished the important from the unimportant ones, and confronted the nurses if they had failed to do the scores that are important for patient health: *"you should score an elder patient's mental stage, so you can signal if they develop a delirium, you should anticipate this.*" (Interview, January 2017). Yet, he didn't mind the nurses not scoring pain or malnutrition when this was not applicable to a patient (yet) although it was required by hospital management.

On a different mode, physicians experimented with social media to provide new types of care, and to display themselves as 'good doctors'. They explained how they translated medical scientific knowledge for patients and put it on Facebook, informing patients about clinical developments and new medical insights. Next to informing, using social media is 'fun' and enables to be followed and be 'liked' by patients – represented through the cloud score. One of the physicians explained how he prepared his tweets early in the morning, automatically posting them in the course of the day: *"If I post 3 tweets at 7.30 AM, they're gone in the afternoon. So I prepare them; I get up at 6.30 AM and leave at 7.30 AM and the tweets are ready by then. I make sure they are posted at 8, 12 and 5 o'clock; those are the moments people get to work and have time to check their phones"* (Interview, May 2017). Physicians using social media (particularly twitter and Facebook) stressed the importance of being seen and read, for their own careers (the cloud score, getting recognition among colleagues and patients), but also to help (more) patients and provide care in a new and accessible manner, for instance by being a member of a Facebook webpage for patients. In similar vein, communication departments worked on the hospitals' website and cared for the hospital twitter account, displaying successes on academic output and care innovation. Hence, hospitals (and physicians alike) experiment with numbers; managers step in to fulfil the quantification duty but expect (and teach) nurses to know when measurements *do* matter. Furthermore, social media is used to display performance, and to be credited for that.

Conclusion & Discussion

Gamification 'redoes' care through ignoring, changing and playing quantification practices. Such games are played within the context of, and as such give shape to emerging infrastructures of measurement in healthcare practices. This short paper has briefly (and maybe a bit fragmentally) shown how quantitative infrastructures are created and experimented with in a hospital setting. What is considered 'good care' is shaped and reshaped through quantification practices; good care encapsulates ignoring scores, making up scores, carefully scoring a patient's status, and caring for your twitter account. The scoring forms in the electronic patient file, the patient Facebook webpage and the twitter account make up the emerging socio-technical infrastructure of healthcare governance; connecting, valuing, counting and experimenting with organizing care. Rather than 'gaming', which is usually considered something negative and to forestall change, gamification is a way of *working with* and enacting the quantification paradigm – thus actively constituting it. Furthermore, the concept of gamification helped us to escape the rather deterministic language of 'disciplinary' discourses, and to open up for a diversity of ontological practices in relation to measurement infrastructures—as well as the identities of the professional self.

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Evolving relations between the practices of nurses and patients and a new patient portal

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Abstract. The paper offers preliminary reflections on a patient portal that is part of a glocal digital infrastructure – an EHR - currently being implemented at 18 hospitals in two of the five Danish regions covering more than half of the population. We focus on the evolving relations between the technology and the practices of nurses and patients in a rehabilitation program after a blood cloth, with a specific interest in how the rehabilitation infrastructure promotes clinical governance and patient empowerment. Our analytical lens is that of patient empowerment, understood broadly as the patient's capacity for and experience of self-care within the infrastructure. This, we contend, may be seen as a specific and increasingly important aspect of clinical governance.

Introduction

Infrastructures in healthcare have traditionally served the double purpose of 1) supporting clinicians in their daily practices and 2) being the basis for the practices of managers and researchers through primary or secondary use of data generated in the former practices.

This secondary use of data supports governance in the health sector. In recent years clinical governance has grown in importance due to the rapid changes in the economic, legal and technological developments around healthcare organisations. The fundamental assumptions behind clinical governance originate from the field of corporate governance, with an explicit interest in securing cost-effectiveness, efficiency, quality and safety in healthcare services, but there are also differences in their focus as clinical governance is associated more closely with the ward, unit, department, health centre and clinic (Braithwaite & Travaglia, 2008). Bodolica and Spraggon (2014) states that clinical governance is a top-down approach to develop and improve the system of healthcare delivery. It can be defined as macro-level governance and refers to the creation of "appropriate infrastructures for integrated clinical governance initiative aiming at elimination medical failures, minimizing costs, and boosting the efficacy of service delivery" (Bodolica and Spraggon, 2014, p. 187). However, Bodolica and Spraggon claim the need for including micro-level processes in order to enhance the effectiveness of the macro-level initiatives. Micro-level are the processes "...related to different tools monitoring the relationship between the medical staff and the consumer of care..." and are labelled as "relational governance" (ibid, p. 192, 194). The micro-level therefore includes the work done by patients in relation to the clinician, but also in relation to the technological infrastructure as such. Citizens, patients and relatives are to an increasing degree included as new types of users and stakeholders of such infrastructural arrangements for the purpose of improved patient experience and outcome, or for "out-sourcing" to them what for a long time has been tasks and responsibilities of clinicians.

Patients' infrastructuring work may be described using the vocabulary of self-tracking. In the self-tracking literature, new forms of patient-driven monitoring of health issues through the use of IT have been celebrated for empowering the patient in the medical system (Hansen, 2012; Swan, 2009). Indeed, having access to one's medical trajectory is seen to enable 'self-care' and engaging the self-monitoring individual in para-clinical practices (Greenfield, 2016). This has the potential to destabilise the institutional arrangements and expert regimes in the medical sector. But the idea of self-care also potentially shifts the responsibility for the patient's health, diagnosis and treatment from the medical professionals and the system to the individual patient (Lupton, 2013; Wang et al., 2014). This shift, in turn, ties in with questions about governance and governmentality. Subsuming the individual patient to the logic of self-care, patient treatment costs are allegedly lowered, thereby ensuring a more efficient and lean health care system.

In this paper, we present a case study of Danish heart patients' experience and practice of using MY HEALTH PLATFORM (MHP) as part of their medical treatment and rehabilitation for e.g. communication and self-tracking purposes. Our overall research questions include: In what ways do patients feel empowered and experience MHP as involving a shift in responsibility towards self-care? What are the possibilities and pitfalls for patient empowerment that may be taken into account in the future development of the infrastructure?

MHP is part of a larger infrastructural arrangement, THE HEALTH PLATFORM, the main parts of which are the usual EHR modules for clinicians' notes, lab tests, ordering, and medication. We see it as a *glocal* digital infrastructure as it is developed for *global* usage, and as it has to be adapted to the *local* technical and organizational infrastructures in each of the healthcare provider organizations that buy it. It is intended to serve local, clinical interests while simultaneously enabling regional integration and management of the health care system in The Capital Region of Denmark and Region Zealand.

In turn THE HEALTH PLATFORM is part of yet a larger infrastructural arrangement including e.g. clinical databases, nationwide registers and sundhed.dk. The latter "is the official portal for the public Danish Healthcare Services and enables citizens and healthcare professionals to find information and communicate. The portal facilitates patient-centred digital services that provide access to and information about the Danish healthcare services." (sundhed.dk, 2017). Hence, there is some overlap between sundhed.dk and MHP.

Part of the political vision for MHP is to digitally include and engage patients in their own treatment and care processes. From a governance perspective, the digital infrastructure is seen as a way of enhancing patient involvement and participation. It is envisioned to facilitate *patient empowerment* through access to parts of the clinicians' notes and tests results, communication with clinicians, managing appointments at the local hospital etc. It is not designed and marketed as a tool for patients' self-management or self-tracking, but it allows for some of the same kinds of information processing and communication that is typically implied in such health care apps and services.

Yet, vision and practice often fail to connect, as witnessed by decades of scholarship into the potentials and actual realizations of IT across domains. We analyse the experienced potentials and barriers as gleaned from current uses of MHP from the patient's viewpoint at this very early stage in the implementation of this glocal digital infrastructure in Danish healthcare practice.

Research setting and method

In this paper, we focus on rehabilitation as it is practiced at one clinic at the first hospital to implement and adapt the new system. Patients, who have been recently discharged after being treated for a blood cloth, are offered consultations with a rehabilitation nurse. Every 6 weeks during a 3 months period a patients sees the nurse for ½ to 1 hour. An overall guide for the rehabilitation sessions stresses the importance of patient involvement throughout and beyond the rehabilitation period.

This preliminary study involved 5 patients and 3 nurses over a period of 9 months. Data was gathered through artifact and document analysis, and recorded and transcribed interviews and observations in patients' homes and in nurses' offices before, during and after these consultations.

We approach the data through our main analytical concept, patient empowerment, which is a broad term for the processes, structures and relationships that can strengthen a patient's agency and improve quality of life (e.g. Piper, 2010). However, if empowerment is both a process and an outcome we mainly focus our analysis on the process, meaning the ways in which patients are engaged in the infrastructural arrangement around rehabilitation. Specifically, we study the consultation between the nurse and the patient and the patients' information practices in-between the consultations, asking: 1) What *information* is sought for and exchanged in the situation, 2) how it is *communicated*, and 3) to what extent does it equip the patient to *act* in terms of self-care and self-management through MHP throughout the rehabilitation process, see e.g. Jensen (2010).

Preliminary findings

In the following, we briefly present our preliminary findings on how the platform is actually used as an infrastructure for information, communication and action by the rehabilitation patients, in order to elicit its potentials and pitfalls for enabling self-care and thus, empowerment and governance of the patient.

Information

The nurse mainly lets the patient decide the themes for the consultation. However, she sees to that the patient get an orientation about the rehabilitation program, learns about the heart, blood cloth, and what might be done about it. Furthermore, she asks for information that she has to type into The Health Platform, for her own use and for other involved personnel at the hospital and in the municipality that may take over when she is done with the patient.

The main part however, takes the form of counseling - emphatic listening to the patient' concerns while zooming in on what might be relevant for this patient. Issues dealt with include: Mental reactions, job and family situation, medication and helpful changes in lifestyle. Also the nurses taking part in this study make sure that the patient is informed about MHP, and how that may be used.

Yet, while the rehabilitation meeting covers a variety of aspects and aims to provide clarity about the patient's treatment, progress, feelings and further activities, there may be gaps between the experience of clarity *in* and *after* the meeting. As one patient notes on the experience of leaving a rehabilitation meeting: "…you think you have thought things through, but then this insecurity comes" The same patient envisions MHP as a possible relief of this insecurity: "It would be great if I could look up my treatment plan. In the clinicians notes I can read what they consider my treatment plan, but it needs to be presented differently for me to understand."

The preliminary results indicate that patients have certain expectations about being informed by the hospital, doctors or nurses on issues of relevance regarding their illness and/or treatment. Especially they request that information regarding their treatment e.g. treatment plans or overviews of medication, are *pushed* in their direction through the MHP. The patients express an interest in accessing information about their physical state e.g. some patients would like access to x-ray pictures, while all the patients looked up results from blood samples or other clinical tests. But they are also aware that this information is disseminated to the patient as the end-user, and that it often requires medical knowledge to interpret.

Communication

Our data suggest that MHP plays a very marginal role in the infrastructuring of the process of rehabilitation, at least for the patients. Although this is likely a result of the research taking place in the platform's early implementation phase, where this part of the system has not been given much attention from management and implementers, it is somewhat surprising. The rehabilitation process implies very episodic, though systematic, contact between the patient and the health care system/the clinician (once, every six weeks), and MHP has the potential to compensate for the low frequency of ongoing monitoring by facilitating mediated, asynchronous contact at times of the day suitable for the patient and clinician in the form of registration of symptoms and wellbeing, progress, consultation about medication etc.

While the patients value the conversations with the nurse, these meetings are fixed in time and space. A patient expresses that he would like the infrastructure to support a more 'ongoing' communication, e.g., the opportunity to pose questions on-line to nurses or doctors about diagnoses or medical treatment when they occur in the patient's daily rehabilitation work. While the nurses do inform patients about this feature in MHP, few patients make use of it so far.

Action

Patients may request various information as well as show interest in different ways of communicating about their rehabilitation. Yet, it does not necessarily mean that they to a greater extent want to be actively engaged and given responsibility for their own treatment. We found that the "drive" for empowerment through self-care is contradicted by most patients being comfortable by leaving decision making and management of their disease to the health care professionals, as also noted in Piper (2010, p. 174).

However, an important part of the rehabilitation program is that nurses make patients aware of the actions they need to do themselves e.g. in relation to diet, exercise, alcohol, and smoking. Some patients are starting to see the system as an enabler for monitoring the effects of such self-care activities. E.g. monitoring the relations between diet changes and results from blood tests.

Discussion

So far patients have limited knowledge about the system's information and communicative options. It may not in its present form support answers to their questions and reduce their insecurity about their illness and its treatment. Therefore it does not offer them a real point of departure for actively engaging themselves in the rehabilitation process.

In terms of governance, the infrastructure thus appears mainly directed towards the clinicians – enabling, supporting but also monitoring their work practices.

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Complex integrations in health care

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Abstract. Integrations in health care are hard to manage in practice due to their complex organizational realities. To categorise the integrations as syntactic, semantic or pragmatic may help to better plan the process in developing them, and deciding how to manage them in a good way and hence obtain well-functioning integrations.

Introduction

Integration of information systems in hospitals is considered a foundation for efficient treatment and care as well as for functional cross-departmental patient pathways. Key systems involved are amongst many others: Electronic Patient Records (EPRs) and Electronic Medication Management Systems (EMMS). Unfortunately, healthcare is still a late adopter of integrated systems. Overall, a key problem appears to be related to the practical issues of integrating the vast number of systems where the technical problems become messed up with complex organizational realities. A key lesson learned from these – and other socio technical - studies is that one needs a thorough understanding of the practices involved when implementing new technology (Fitzpatrick and Ellingsen 2012). A principal aim of our paper is therefore to contribute to a socio-technical understanding of integration in health care. Particularly the paper aims to develop a framework that describes integrations and hence recognize and contributes to resolve challenges when constructing integrations. Theoretically, we draw on the concept of information infrastructures (Bowker and Star 1999). We extend this perspective to Carlile's (2004) integrative framework for managing knowledge across boundaries to narrow down on specific and different integration challenges. Based on this perspective, we categorize integrations into syntactic integrations where information is transferred between systems, semantic integrations where information has to be translated between the systems, and pragmatic integrations where information has a transformative effect on the organization. Based on an interpretive research method (Walsham 1995), we have studied the formative stages of a large-scale EMMS project in the Northern Norway Regional Health Authority that was initiated in 2012.

The EMMS project and the anticipated use scenario

In January 2012, the Northern Norway Regional Health Authority decided to start a bid for tender process for a common EMMS for the health region. The cost of the procurement, the implementation and 15 years of use is estimated at EUR 114 million. The EMMS needs to be tightly integrated with other key systems in clinical practice, most notably the Electronic Patient Record (EPR) from the vendor DIPS ASA. One of the overall aim of the EMMS project was that all information, documentation and decision support regarding medications should be gathered in one system to ensure complete overview for the clinicians. The original plan was that patient information at admittance like name, birth date and address should be registered in DIPS EPR, but an integration should ensure that this information could be used in the EMMS as well. Furthermore, the process of deciding what medication the patient is using including a reconciliation of the medication list, should happen in the EMMS.

Analysis

At the *syntactic* level, there is a common understanding of the differences and dependencies between data that are crossing the boundaries between two systems (Carlile 2004). This makes the integration a simple transfer of data from one system to another. In our case, patient information, like name, birth date and address are examples of data that easily could be transferred and used from the EPR to the EMMS and thereby can be classified as a syntactic integration. The same goes for the integration between the EMMS and the lab system. The results from lab tests are interpreted the same way in the two systems and transferring the answers are sufficient to make a well-functioning integration.

At the *semantic* level of integration, the differences and dependencies between data that is crossing the boundaries are somehow unclear or the meanings of the data are ambiguous (Carlile 2004). This leads to different interpretations. To develop a successful semantic integration, it is crucial to establish shared meanings and find a meaningful way to share and manage data that are crossing the borders between systems. At this level, is it not adequate to transfer data from A to B, the data have to be translated to give meaning. An example from our case, is when the clinicians using the EMMS request the medication-in-use list for a specific patient from DIPS EPR. In the EPR the drugs are denoted by their brand name while the EMMS uses the international non-proprietary name of the active substance(s). For the latter, it means that each international non-proprietary name (active substance) could match more than one brand name. This is a problem when a medication list is transferred between the EPR and the EMMS because there is no one-to-one relationship between the brand name and the international non-proprietary name. For instance, ibuprofen is the non-proprietary name of the active substance, while some of the different brand names are Advil, Ibux, Bufen, Ibumax and Motrin. This came as a surprise for the EMMS project members. One of the members said: “I was surprised that the relationship between international non-proprietary name and brand name lacked uniqueness, i.e. when patient had been admitted to the hospital and had a medication list that contained some brand products, the lists could not be translated uniquely to international non-proprietary name without a human touch. Everybody was very disappointed by this”. The effect of this is that there must be a translation between the brand name in the EPR and the international non-proprietary name in the EMMS. Therefore, the physician must carefully examine each translation of medication between the systems. The integration will suggest a mapping, but the physician using the EMMS must check whether this mapping looks correct and potentially make changes before the process is considered complete. When this is done, the medication list is ready for use in the EMMS.

The *pragmatic* level of integration arises when the actors and stakeholders have different interests that have to be resolved. The different interests impede the ability to share and manage the data that is crossing the borders between systems. The decision on how an integration is to be managed could lead to negative consequences for some stakeholders or actors when interests are in conflict. Hence a pragmatic integration is not just a matter of translating different meanings, but of negotiating interests and making trade-offs between stakeholders, potentially transforming a practice. This developing of common meanings is consequently a political process of defining common interests. Carlile defines this as transforming knowledge (Carlile 2004).

The Northern Norway Regional Health Authority has decided that the EMMS should be the master for medication data during the patient hospital stay. An overview and information about the medication - including drug name, dosage, frequency, route, and missed doses - will only exist in the EMMS during the stay. Currently the EPR has no access to this data prior to the discharge. The reason for this has been to clarify roles and responsibilities between the systems. However, this is problematic as there are several instances where EMMS data may be very useful to also have in the EPR during the patient stay. ”For instance, a good visualization of the patients’ trajectory- his status, what is done and what is to be done in the EPR – would help us to optimize in house resources and plan for discharge early on, hence reduce length of stay. Actually, the visualization in itself would be a kind of decision support” (physician in workshop).

This plan in the EPR represent the overall plan for the patient. Data on vital parameters coming from bedside devices and the EMMS is needed in the treatment plan (i.e. operation theater), because it provides information critical to deciding on actions, for instance deviations from the plan, but also in documenting actions and effects of actions. If a rising temperature indicates that an infection is progressing, steps need to be taken. In contrast, in configuring the EMMS, personnel working in the operational theater want to register procedures in the EMMS instead of the EPR, so that procedures can be connected to the recorded actions during the continual monitoring of the patient during surgery. To be able to combine and aggregate data of this kind is important to them for quality assurance, and for documenting effects. This shows that the two systems have overlapping functionality and the boundaries between them are are disputed. Different stakeholders have different opinions, potentially leading to rising tension between various user groups on what to do when and where.

Concluding discussion

Integrations are not solely a technical task. An organisational and socio-technical approach is necessary for managing integrations in health care. In this paper, we have used Carliles framework that describe boundaries and processes when managing knowledge across boundaries, on integrations. The categories syntactic, semantic and pragmatic is used to highlight the social and organisational issues regarding integrations.

A framework that categorise integrations as syntactic, semantic or pragmatic may help to better plan the process in developing them, and deciding how to manage them in a good way.

In syntactic integrations, the data can simply be transferred between the systems. It is a common understanding of the data, and the integration is mainly a technical task. There is few socio or organisational challenges related to the integration.

Semantic integrations need translation, the data may be interpreted differently in the different systems. In managing such integrations, processes that create shared meanings (Dougherty 1992) or mechanisms to reconcile discrepancies in meaning (Nonaka and Takeuchi 1995) are important to obtain well-functioning integrations. The data has to be translated to make the integrations work. This requires additional work, and social and organisational factors play an important role to make such integrations work. Compared to syntactic integrations, semantic integrations are more complex to manage.

Pragmatic integrations are highly complex, because actors and stakeholders involved have conflicting interests in how the integrations should be managed. And when an integration is categorized as pragmatic, translation is not sufficient. Translation do not deal with different interests. Such integrations requires a political approach with negotiation and the ability to find common interests among the stakeholders and actors involved. The data in the integration has to undergo a transformation before transferring between systems. Some stakeholders have strong voices and will not necessarily agree on the decisions made. This may lead to rematches that cause additional challenges in managing the integrations. What is required is a process in which actors and stakeholders negotiate and are willing to change their meanings and interests (Carlile 2004). By learning about other actors` interests and understanding the consequences of different integrations, their interests and meanings should transform to solutions that are for the best for the totality of the work practices.

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Developing Rural Healthcare Services: How to Create Efficient Services Using Service Design Methods

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Abstract. This paper presents a workshop model that can be used to develop digital healthcare services in rural communities. The workshop model is based on a case study done in South Africa in the context of health-related information and communication services. Participants in this case study were semi-trained home-based health caregivers working in rural communities. The research was structured around design methods drawn mainly from the service design field that enable user participation in the development process and that create a common understanding and mission through increased empathy among participants as well as co-creative flows while working together. The primary outcome from the case study was a workshop model, which focused on investigating and developing solutions to address the most important caregiver needs during a typical working day. This leads to interactions, which increases empathy among the participants. The goal of the case study was to design a mobile application that makes the caregivers' services more efficient. This research is part of the Critical Communication, Safety and Human-centered Services of the Future (CRICS) project, which runs from 2016–2017, and which is funded by Tekes, the Finnish Funding Agency for Technology and Innovation. It was conducted in cooperation with Cape Peninsula University of Technology (CPUT), Cape Town, South Africa.

Introduction

This case study was conducted in two communities, Genadendal/Greyton and Grabouw in South Africa. Both communities are poor rural villages located roughly 70–140 kilometers from the city of Cape Town. It focused on the healthcare work of semi-trained caregivers who provide basic healthcare services to people in their own homes and who support people suffering from tuberculosis (TB), human immunodeficiency virus infection and acquired immune deficiency syndrome (HIV/AIDS), and other chronic conditions. The main challenges in these rural communities are poor communication and information sharing among caregivers who encounter difficult cases and patients. Health-related information in rural communities is still recorded in paper-based systems because there is no access to computers (de la Harpe et al. 2013). Additional challenges include long distances, weather conditions, and language barriers. Moreover, the caregivers walk from house to house, which makes their working day physically exhausting. This was recognized during the observations and interviews that were conducted for this study. There is a need to develop more efficient healthcare services that can provide better knowledge and quality to caregivers whose skills might be limited, but who often face very difficult challenges in healthcare situations in rural communities. The workshop focused on how to create efficient healthcare services using service design methods. Using the information obtained from the workshops conducted in this case study, the paper will answer the following research question: is the use of the service design method valuable in workshops conducted in rural communities?

The intended outcome of this study was to develop a workshop model for collecting relevant data from stakeholders without disturbing their everyday work flow. The paper does not present the created service concepts; rather, it uses some of them as examples to clarify the outcomes and findings generated by the workshop model. The workshop model was divided into four main phases: 1) fieldwork to better understand the healthcare work being done in these communities; 2) an understanding session, which focused on gaining a more in-depth understanding of the work and the communication and information needs of the caregivers; 3) a service prototyping session to concretize the service needs as an application, and 4) a testing session, where users (caregivers) tried the application demos. More details about these phases will be provided in this paper. As a result of the case study, important and interesting aspects between interaction and empathy were found. The workshop model as a healthcare services development tool also provided a platform for generating conversations, enhancing learning, deepening understanding, and creating empathy.

Methods

The study involved qualitative research with design methods that are mainly used in the service design field. Service design provides tools and methods for human-centered and participatory approaches, and it is used to either improve existing services or create new ones for clients and service providers (Miettinen, 2016;

Polaine. Løvlie, & Reason, 2013; Oosterom et al., 2010). Involving users in design processes is a way to influence the development of services, increase equality during the design process, and increase empathy among the participants through a common understanding. Service design and its participatory approaches (especially prototyping) have an impact on the possibility for transformation and common learning (Kuure, Miettinen, & Alhonsuo, 2014). Mager (2009) noted that the service design method uses co-creation in two ways. First, it integrates users into the design process and adds their expertise to the project; and, second, it adds value to the service delivery process because users play an active role in it.

The case study data were gathered by observing the daily working routines of the participants (caregivers in rural communities), by interviewing them, and by involving them in co-designing sessions. In addition, one researcher kept her own notes in a research diary. Furthermore, a group interview with the participants was held after the all workshops.

The Case Study

The case study involved three separate cases (n=18; n=11; n=14) in different communities, and the workshop model was implemented in all of them. It should be noted that some divergence existed between the approaches used, and the session structures and methods used in the workshop model reflect the different resources and time limits of each of these cases.

Workshop Model

The workshop model was divided into four main components: 1) fieldwork, 2) an understanding session, 3) a prototyping session, and 4) a testing session (Figure 1). It follows a service design research process model (Oosterom, 2009; Mager, 2004; Moritz, 2005), but it has been modified for the needs of the healthcare sector, which usually involves time limits, multi-level services, and processes that use different systems and communication tools.

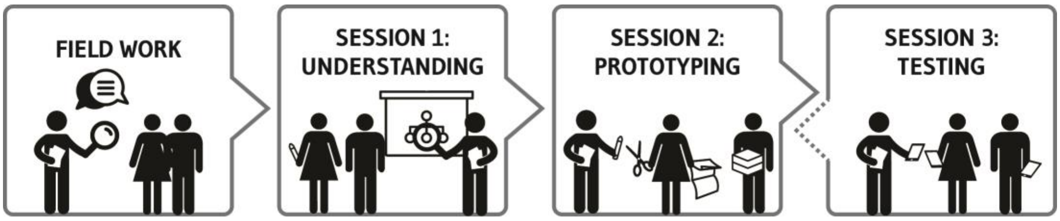

Figure 1. The workshop model

The fieldwork session consisted of observations and interviews to help the researchers (who were also service designers) understand the normal workdays of the caregivers. The aim was to identify the five main phases of the workday, starting from the morning and ending in the evening. It is obvious that the needs related to specific tasks/actions (also known as jobs to be done) diverged during the day. Thus, these five phases enabled us to identify the main needs in more depth in the understanding session.

The understanding session focused on visualizing the big picture of the healthcare professionals' working day. In this session, a template was used to make it easier to effectively facilitate the process of understanding. The five main phases of the working day were used as the core of the template. For each of the five phases, the participants visualized their existing communication links. The aim was to clarify the person or people they are calling, mailing, and/or talking to during each phase. After this, the participants used sticky notes to write their comments about tasks/actions, touchpoints, communication and information needs, existing cooperation or applications that work well, and pain points, as well as their ideas and aspirations related to each of the five working phases. The last step of this session was to define the emotions that each of the participants felt in each of the five phases. This was found to be a strong tool for gaining a common understanding about their needs and empathy for their experiences because the participants realized how similar their feelings were (mainly sadness and anger). They started to discuss more about how they felt; through that interaction they somehow empowered each other. After this, the main design challenges of the working process were identified. These design challenges were solved in the subsequent prototyping session (session 2). The visualization also helped provide a deeper understanding of the features and actions that were needed to support the caregivers' everyday work life, such as a smartphone and digital applications.

The third phase, the prototyping session, involved more hands-on work. In that session, the participants built and concretized a prototype of a digital application with minimum viable features based on the visual process picture and the main needs that were previously identified. Prototypes, also called probes, should be as simple as possible, and they should have a single, main function. Basically, the participants created five different application layouts suitable for each of the five work day phases. As an example, in one case the first phase was waking up, and the caregivers often felt very stressed about home visits and weather forecasts. Based on those needs, they created a layout of an application designing how it would look when they opened the phone and what they would first see when they viewed it. Consequently, the application home page showed symbols of existing weather forecasts and a list of patients, so the caregivers could prepare themselves beforehand for home visits, and in doing that, they could provide the best possible healthcare services to their patients.

The primary aim of the final phase, the testing session, was to test the usability of the concepts developed and to obtain feedback from real users. In this case study, information technology (IT) students from Cape Peninsula University of Technology (CPUT) developed application demos based on the concepts obtained from the prototyping sessions. The students coded applications with more functions, which enabled better feedback for the digital services. The feedback helped the students further evaluate the effectiveness of the applications.

Findings and Conclusion

The fieldwork done for the case study helped the researchers get to know the participating caregivers in the two rural communities that were the focus of this project. This made it easier to work with them in the co-sessions. It also played a crucial role in enabling the researchers to perceive details about the five phases of the caregivers' typical working day. The understanding session showed that, through visualizing the process and mapping emotions, it was easier for the caregivers to identify and discuss their personal challenges, ideas, and aspirations. That discussion led to an intensive group conversation where the participants learned that others were facing the same challenges. That was a good starting point for the co-creative flow, where everyone was motivated to develop their processes and services with greater efficiency and better quality. According to the researcher's notes, the sessions increased the level of empathy and empowerment among the caregivers. This strengthened these communities and the relationships within them. This is the value of service design in the workshops done in rural communities in South Africa. It is important to note that, after every workshop, the participants asked if they could apply the template used in the understanding session to other health-related challenges.

Based on the feedback collected through interviews after each of the cases, the participants were satisfied with how they could influence the service concepts from beginning to end. The understanding sessions increased the caregivers' empathy and empowered them in their work. The prototyping session was difficult for them because they felt that it was hard to create visual layouts based on design challenges. However, they were very surprised at how the IT students created the application demos for the test sessions.

The workshop model provides tools for improving the efficiency and effectiveness of healthcare services, which can improve quality of care whether the services are provided in cities or in rural communities. The values of this model are its service design and its co-creation and visualization tools, which were used in the understanding session. By first dividing the working day into five phases, and then focusing on identifying the main challenges and determining the most important information and communication needs for each of the phases, it was possible to conduct effective sessions and create applications for efficient ways to communicate and obtain and share health-related information.

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Emerging versions of patient involvement with Patient Reported Outcomes

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Abstract. It is a central argument in the growing Danish PRO-arena, that a large-scale collection of PRO from patients in the Danish Healthcare system will pave the way for more genuine patient involvement in clinical decision-making, quality management and governance of the health services. In this paper I discuss how patient involvement is being (re)configured when increasingly connected to national visions of participatory healthcare. A central discussion centers on 'meaningful use' of patient-generated data promoting patients' expectations and experiences as a criterion for how to proceed with the national use of PRO. But how do assumptions of what constitutes meaning for patients interact with the kinds of roles that patients are expected to take on with PRO-tools? What forms of participation are assumed to be meaningful and thus good and which are not? In sketching emerging versions of patient involvement with PRO, I want to point to the need for further empirical exploration of how patients and professionals engage with PRO in specific daily practices and to stimulate a general discussion of all too simple normativities of the so-called 'participatory turn' in healthcare. I draw on empirical insights from an ongoing study of establishment of a national initiative for systematic collection of PROs in Denmark.

Introduction: The emergent Danish PRO-arena

”The patient is the new hype in the health services” a Danish newspaper heading (Information, 2016) professed with reference to the interview with leading national expert on Patient Rated Outcome Measures (PRO/PROM) Professor Mogens Grønvold. Professor Grønvold argues that patient generated data from questionnaires are changing status among health professionals and policy makers from 'too subjective' accounts of individual experiences to reliable and timely data on patients' needs and outcome of clinical interventions (ibid). PROs are validated questionnaires collecting data on individual patients' own rating of their health and quality of life and the widespread interest in a systematic use of these tools in a Danish public health context is evident in the number of projects, agreements and institutional initiatives taken during the last few years: 159 PRO-projects were mapped as planned or taking place across the Danish regions (Danish Regions, May 2016), evaluation rapports published, public financing ensured in the national budget and new institutional frameworks established (eg. the office for PRO in the National Health Data Board Jan. 2017). Themes of patient involvement and participation are central to this accelerating development and Danish Patients (representing a all major patient associations) and the related Knowledge Center for User-involvement in the Healthcare sector, VIBIS, has had a central role in promoting increased use of PRO.

Analyzing Technologies of Participation

I see the spread of PROs as a reconfiguration of sociotechnical infrastructures of care that may have implications for what it means to be a patient and what constitutes care in practice (Langstrup 2013). As new tools, knowledge forms, organizational arrangements and accountability structures that are to be weaved into existing healthcare arrangements, PROs – together with other patient-involving technologies and initiatives – will have widespread implications for the daily lives of patients and health professionals. I draw on perspectives from Science and Technology Studies and in particular discussions of the interrelation between infrastructures, technologies and identities (Star 1999) and the politics and practices of care (Martin et al. 2015). The centrality of digital technologies in making patient and public participation in healthcare possible, calls for studies that explore how participation is discursively articulated and materially inscribed and "the normative variations among enactments of material participation" (Marres 2012: 2). Here I will sketch some of the emerging articulations of patient participation I have found in an ongoing study of PRO-tools that follows the national roll-out of PRO-tools. The empirical material consists of interviews with experts, policy-makers and other stakeholders engaged in the Danish PRO-arena (to date 8 interviews with 10 informants), participant observation at public meetings and conferences on PRO and written material. The preliminary insights give raise to a number of questions and concerns for research on participatory infrastructures of care.

Versions of patient involvement in PRO

By definition PROs demand the involvement of patients, in that patients are to answer a number of questions presented to them in the form of standardized and validated questionnaires. With these answers, it is expected, the health professionals and the healthcare system more broadly can better monitor the effects of treatment and ensure that interventions take into account what is important to and has positive effect for the patient. A more "needs-based" healthcare system. Still, it is stressed again and again by the proponents of these tools, that the use of PRO has to be implemented in a way that is valuable, relevant and meaningful for patients. In the report "Program PRO", where 26 experts made recommendations for the use of PRO tools on a national level in Denmark (VIBIS 2016), the concept of 'meaning' features 35 times in just 68 pages. Also in interviews with and meetings involving different stakeholders the concept of meaning features prominently. A high-ranking health official ends a public presentation on the national PRO initiative with a slide showing the face of an older man, with the heading "It has to make sense to Karl Anton!" and she urge the attending policy makers and clinicians to make this sentence their credo in the continued work with PRO. In the following I will sketch the ways in which patients are expected to be involved in and with PRO and how these versions of involvement relates to certain normative understandings of what are meaningful forms of participation.

Patient as data provider: A central activity for patients in relation to PRO is to provide data by answering questionnaires. PRO questionnaires may be provided in conjunction to a clinical encounter, to be completed in the waiting room, on paper or on a lab top. The patient may also receive the questionnaire at home via email, an online record or in paper form. Patients' role here is well known from the kinds of health-related quality of life research for which PRO-tools were originally developed. But the patient as being a 'mere' data-provider is problematized in relation to PRO. Proponents of PRO stress, that for PROs to be meaningful for patients, they need to be "active PROs", rather than passive ones. As a policy maker states, it is important "that you as a patient have the experience, that the answers that you have provided are used actively" (interview with policymaker, Sundhedsdatastyrelsen). "Passive PRO" in contrast would be data provided by patients and compiled for research or quality monitoring, but where the patient gets no individual feedback. Or "PRO for PRO's own sake" as a PRO-developer expresses it (interview). Passivity thus relates to the lack of response to the individual patient and is seen as problematic and something that might make PRO and the role as data provider meaningless for patients: "And then you have patients to answer and some clinicians who don't even bother to open [the PRO] on their screens. And it is exactly here, where they have been sitting answering ‘yes, I have sexual problems’ and ‘yes, I am sad’ and then nobody sees it!” (Interview with PRO-developer). As PROs are framed as types of data that transport information to the clinic on what is important for the individual patient these data comes with a normative expectation of clinical action. The health professional must see and act on these data. But how is it experienced to be producer of data via questionnaires? Do patients distinguish between this and other instances in which they provide data? And how may health professionals in practice respond to these data?

Patient as data-user: The public visions of PRO position the patient as a partner with the clinician. The answers in the PROs are envisioned to be put to immediate clinical use in shared decision-making. Here the meaningfulness of answering PRO is achieved when the patient and the clinician in collaboration uses the data actively in the consultation – that it also makes sense to the clinician: “It has to make sense for both the clinician and the patient, otherwise nobody will answer or look at the data” (interview with policy-maker, Sundhedsdatastyrelsen). A researcher involved in promotion of PRO argues at a public event, that patients themselves talk about the data as “their data” and that it is the patient that uses the data to “involve the healthcare system in *their* life” – not the other way around. In the practical use of PROs the patient may also get direct feedback on entries and some suggest that these can be used for patient education or as part of self-care activities. PROs can be used to screen which patients in out-patient treatment have a need for a face-to-face consultation and who are well enough to be cancelled or given a phone consultation. This use of PRO is promoted as a more rational use of resources, as more convenient for patients and as a way to promote selfcare and empowerment. An algorithm generally automates the feedback the patient may receive upon their entries – i.e. a mail telling them, that they are doing well and do not need to see a doctor, or a visual representation such as a green indicator showing, that all is well. It is rarely transparent to the patient what in the questionnaire caused a particular response. Here PROs converge with other digital self-monitoring tools known from telemedicine. But will patients in practice experience themselves as active data-users when answering questionnaires or mainly direct their answers at the clinician, in the same way as giving a blood sample? Research on telemedicine has suggested that visions of empowering patients with technology are often inflated (Langstrup et al. 2013). And to the extent that patients do use data in the context of self-care and everyday life, in what – also unexpected – ways will they do so (Mol et al. 2010)? How will the specific configuration of digital care infrastructures with PRO enable “respons-able” care (Martin et al. 2015)?

Patient as co-creator of PRO: It is increasingly argued that for PRO tools to be truly participatory, patients need to be involved at every step in development and use – as co-creators of the questionnaires, technologies and the interpretations of results (Staniszewska et al. 2012). In the context of the Danish development the Program PRO initiative was taken by a coalition of Danish patient associations putting patients institutionally at the center. Patient representatives are also in the clinical groups that are to select "national" questionnaires. Methodologically, in the construction and validation of PROs, patients are systematically involved. However, it is discussed if this is enough to qualify as "co-creation" (Ibid). The involvement of patients in the selection and validation of questionnaires may be said to have a "technocratic" or instrumental view of participation rather than a democratic aim if the primary goal is to increase answer rates (Martin 2008): "Patient need to contribute on what is relevant. Is this relevant to ask? If you don't feel that it is relevant, you wont bother answering. So if you want to have a high answer rate, it needs to make sense to patients" (interview with policymaker, Sundhedsdatastyrelsen). In practice intensifying patient involvement in design is not without challenges. VIBIS is one of the main sources of patient representatives and they increasingly have difficulties in supplying "good" patients for such "organizational patient involvement" (personal communication). Also, the balancing between patients' preferences, "the public good" and the wish among some experts to have standardized tools, which may allow for secondary use in research and quality monitoring, may prove difficult.

Discussion

In a Danish context PRO activities are increasingly framed as the road to genuine patient involvement in healthcare. Data provided directly from patients on their quality of life, functionality or symptoms is seen as a resource for more rational, patient-centered care and – potentially – value-based governance. The different versions of patient involvement articulated in relation to the promotion of PROs may in practice be deeply intertwined, but the analytical differentiation provided here may shed some light on normative assumptions involved. The concern for "meaningfulness" and the insistence that PROs need to be "active" point to an overall concern for the individual motivation of the patient. "Passive PRO" – PROs collected with no feedback to the individual patient – are articulated as problematic as the patient will not be motivated answering if the answers are not used for their own care. The version of participation that only gives the patient the role of data-provider is thus rendered practically and normatively problematic. Lack of individual motivation may cause low answer rates, disappointment and as well as defying the purpose of letting the concern of the patient set the agenda in the clinical encounter. One researcher also compared passive PRO to data collected for research purpose among indigenous people in Greenland, who ended up protesting when researchers "left with their data". Patients 'own' their data and the health system should be 'respons-able' for taking these data into account.

It is thus also obvious that the meaningful use of PRO for the individual patient to a large degree depends on the normative obligations of the health professionals.

When it comes to the extent to which patients should 'co-create' the tools that transform their knowledge into data, the question of 'meaning' mainly seems to relate to the formulation and selection of questions, rather than the overall design and purpose of the tools. Also here there is a focus on the sensemaking of the individual patient, rather than negotiations of what might make sense for collectives of patients or society at large.

Rather than defining meaningful patient involvement with reference to conceptual framework and normative scales my interest here has been to explore, how such framings emerge as part of new sociotechnical infrastructures of care. The three emerging forms of patient involvement sketched here should thus not be seen as steps toward a more comprehensive and thus better form of patient involvement. Rather, each version may in different ways help us explore and question the implications of this widespread commitment to PRO as devices of participation. What happens with forms of patient knowledge, that cannot translate into (PRO)data (Pols 2014)? What if there are projects in healthcare that cannot be participatory or where participation comes as at a high cost for other valuable aims?

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Care coordination with a patient centred plan

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Abstract. In Finland, a standardized data structure for continuous health and care planning is implemented as a Health and Care Plan (HCP) module in all electronic health record systems (EHR). The structure was initially published in 2011 and gradually implemented in the various EHR systems. In this study, the focus is on comparing the specifications of the data structure and the responses to a spring 2016 survey. We analyse the HCP as a representation that is interpreted in different contexts and for different purposes by those involved. The interactionist theory by Strauss (1993) is used as the lens to discern dualistic dimensions of interpretations. We found these dimensions: consensus vs. dissent, old vs. new, single vs. multiple, clearly imagined vs. unclear, and unchanging vs. changing. The implications of these for HCP use and development are discussed.

Background

In Finland, a standardized data structure for continuous health and care planning is implemented as a Health and Care Plan (HCP) module in all electronic health record systems (EHR). The standardized data format as the basis for the HCP provides a platform for uniform documenting, and primary and secondary use of patient information. The data structure for HCP was developed at the national level and it is part of the national e-health information services (Figure 1). A first version of HCP specification was published in 2011, after which several hospital districts have been using the HCP and developing documenting practices related to the continuous care planning. Its use became mandatory 1.1.2017. From the start, HCP aimed to facilitate better care planning and coordination for patients with chronic disorders and those with multiple problems or risks. HCP provides also means for regional and inter-organizational data exchange as its content is stored in the national central archive for patient information (Kanta), accessible for all care providers. HCP ties together information generated together with the patient and the health care professionals. As such, HCP means a break from previous documenting practices where only health care professionals produce and manage patient information. In this paper, we inspect diverse interpretations and implications of HCP.

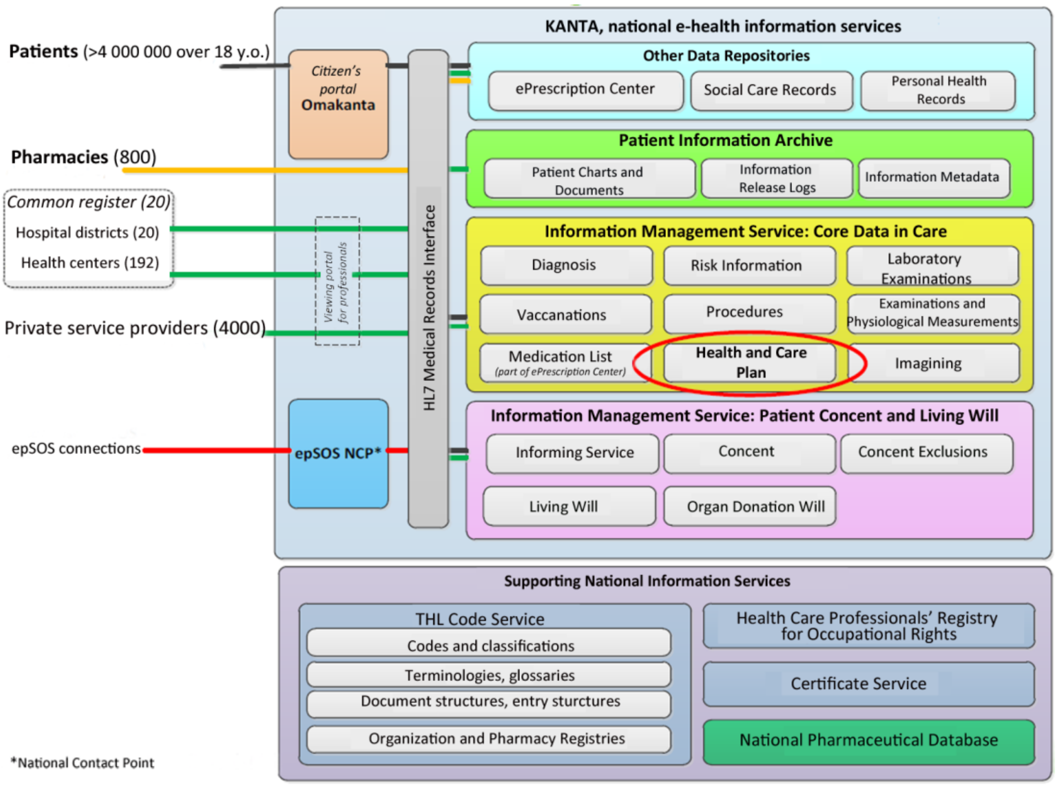

Figure 1. Health and Care Plan (HCP) as part of the national e-health infrastructure.

With the Health and Care Plan, patient interventions and plans for procedures are made visible to all service providers in the multidisciplinary care team. This in turn was expected to decrease the number of patient visits and overlapping examinations and, in this way, overall care costs. Even the initial phases of HCP in use have given evidence of these goals being achieved, especially when care needs of the patient are assessed during triage. The main aim of HCP is to bind the patient to the long-term care goals that have been tailored together with the patient and care giver to achieve a level of wellbeing that is realistic in relation to the patient's everyday functioning and commitment to care. Development of the structure for HCP facilitated new forms of care planning, following the current trend of involving patients in their own care (Agarwal et al, 2010; Klecun 2016). Another main aim of HCP was to decrease redundant work, such as copying text from one care document to another or jumping from patient chart view to a separate laboratory order application that might require separate logging in, work that consumes any health care professional's time (MacMillan et al, 2016).

The HCP consists of seven data modules: 1) patient demographics, 2) triage, 3) care goals, 4) realization of goals, 5) follow-up and assessment, 6) care team, and 7) additional information such as diagnosis or medication. Only nationally approved codes and classifications are used in these modules.

Representations and misinterpretations

Our data consists of the specification documents for HCP and results of a survey conducted in spring 2016. The questionnaire received 168 answers of which 77 % are by health care professionals and the rest by other stakeholders such as hospital administrators, technical personnel, representatives of system providers, and service providers in social care or in the third sector.

Our analysis of the data is enriched by Strauss's (1993) interactionist theory of action. We utilize concepts that are related to representation; its interpretations and intentional or unintentional misinterpretations. We analyse the HCP as a representation that is interpreted in different contexts and for different purposes. According to Strauss (1993), interpretation is dependent on the multiple capacities or roles of a person: the same person can act as a health care professional, a patient, or a patient's family member or as an expert participating in an HCP implementation project. In each of the roles, the person can use different strategies based on the interpretation of the valid action or representation at that point. In case of HCP, differing interpretations contribute to unconsolidated use of the structured format of the plan. Strauss considers that interpreting a representation is more temporal than just a performance at a specific time (cf. Goffman, 1959). Representation "has a past and present and, often is aimed at the future" (Strauss 1993, p. 173). Thus representations change over time as they are interpreted anew with different roles or capacities. This is apparent especially in lengthy development and implementation projects.

Findings

At the time of our data gathering, some had already been using HCP for three to five years and some were just starting its implementation. Our data illustrates how the HCP and its goals were interpreted differently by professional user groups. Strauss (1993) describes how goals change within dualistic dimensions. We found several such dimensions: consensus vs. dissent, old vs. new, single vs. multiple, clearly imagined vs. unclear, and unchanging vs. changing. This means that there can be parallel, differing interpretations and, as a consequence, original goals are likely to change. Next, we give examples of different interpretations and their implications for HCP use.

Our first example illustrates **consensus vs. dissent** on patient commitment and empowerment with HCP: *"HCP supports visibility of patient information regardless of the service provider, e.g. as well in specialized care and in home care."* However, the goal was not to increase information visibility only for professionals giving care but to support also that patients can access their own information. For example, for a physician it might be self-evident why a patient's liver tests should give results within normal range when treating a heavily drinking patient. However, for the patient commitment to care would not be realized as series of tests planned in HCP but as a goal to drink less.

In HCP, planned series of tests or other clinical examinations would be part of support provided by health care provider when the patients set their own wellbeing goals. This is closely linked to **new vs. old**; as in the patient's role and capacity to contribute to care planning. An end user conclusion that *"HCP supports multi-professional team work practices"* is good and valid but set in the old documenting practices where care planning is done only by care professionals. The new practices should include the patient. It may be not sufficient only to set realistic goals for care, but also to select appropriate interventions and to offer a selection of support functions available to the patient. HCP can cover self-care guidelines and other support for the patient to manage the situation. Often, the HCP is printed for the patient to support continuous commitment to the set goals of care. The HCP is also accessible in the national citizen portal, Omakanta. For example, if the patient suffers from chronic persistent hepatitis, their HCP could include references to the planned vaccination schedule and reasoning why vaccine administrations would be crucial in their long term wellbeing. However, if HCP and its documenting guidelines are misinterpreted in a sense that the practices cover only clinical information needs, it is likely that the planned benefits of HCP are not met.

Single vs. multiple interpretations are illustrated most clearly in the respondents' understanding of "plan" and "continuous plan." 25 different types of plans were called HCP plans even though 57 % of the respondents had the standardized HCP template already implemented in their EHR system. If health care professionals continue to use whole variety of documenting templates available in their EHR systems, this will result in unreliable HCP data in the national central archive. It also means that care guidelines or best practices might not be utilized as included in the original HCP development goals. If local documenting templates and storages are allowed, patient information will become less easy to search and review. In our study, 43 % of the respondents used the nationally standardized HCP data format, 23 % documented HCP content using free text notes and 30 % used alternative local data structures. When asked to evaluate documenting in the HCP, a respondent's interpretation that *"HCP is a patient centred plan for continuous care planning and coordinating"* would be more guiding than *"HCP structure must be flexible enough so that we can document individual plans; the structure must answer to different, individual needs."* In this context, flexibility of HCP does not mean that the template should be used for different types of plans but that it allows flexible documenting of patient specific care and support needs as not all modules or data fields would be required entries at every encounter. However, HCP is not intended to replace planning of specific encounters or interventions. That a variety of plans interpreted to be the same as the HCP indicates that the HCP concept of continuous care planning still needs more clarification and its structured documenting practices more training.

Intended goals for care coordination were realized partially with HCP at the time of our study: when using HCP, roughly two thirds of care professionals document triage, care goals and planned treatments or services. Follow-up and care outcome assessment is used by less than half of the professionals. Care guidelines or best practices were not necessarily linked to HCP as intended, due to missing decision support. Documenting needs expressed were **clearly imagined vs. unclear**. For example, a respondent detailed quite clearly what kind of system support they would require: *"System functions should support the user documenting a HCP so that the system provides, for example, default values or medication information with automated functions instead of cut and paste by an end user."* The structured content in a HCP allows for re-use of patient information instead of copying or entering same information into several places. Ultimately, the EHR system provider interprets the data structures intended use. This, in turn, influences the usability and use practices of the actual HCP. Some of the responses included vague wishes instead of detailed requirements, for example: *"The HCP should be a simple, clear document; not too much text to read."* This would still leave room for individual interpretations during requirements analysis and system implementation.

It is evident that different user groups interpret HCP in divergent ways. Each group seems to come up with different ideas for future improvements of the care plan as interpretations of the HCP are **unchanging vs. changing**. In line with the original HCP implementation goals, respondents had partly unchanging interpretations: *"Patient centred HCP has a communication focus; both patient and all staff know what is happening and when. This enhances care, makes it right care at the right time – resulting in better care quality and better resourcing of care."* Consequently, some of the respondents were already a step ahead and had further development goals for content they would want to access in the HCP: *"This should include a care summary by different professional groups as a HCP should provide a place to entry notes specific to one professional group."* This example cannot be a valid development goal, as care summaries are already available. The purpose of using HCP is not only to provide an inter-professional communication tool. The data in a HCP could provide a way to evaluate impact of various care approaches and best practices with a longer time frame for evidence building. In the long run, there is clinical interest for evidence based care; as the HCP provides new possibilities to gather data about health care outcomes: *"HCP data could be used for benchmarking, in quality registers and as basis for evidence based care."* In this regard, one challenge would be developing a more structured assessment and follow-up module for the HCP to support reliable and efficient data gathering.

Concluding thoughts

Intended goals of care coordination are currently partially realized with the HCP although feedback from the users is positive. The use practices of HCP are not yet established and would require further work to achieve more uniform interpretations of the HCP as a concept and as a tool. One voice has been largely lacking in the HCP development and that is patients. Various health monitoring applications and sensors produce much data that can be collected, for example, in personal health records. If the patients then would feed this data into the HCP, it could be one way to make personal health data visible for service providers. This would further change roles and responsibilities of patients and health care professionals; who produces what data and who interprets it.

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Maneuvering a Pilot Implementation to Align Agendas Across Sectors

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Abstract. A prerequisite for pilot implementations in complex organizational settings is that the agendas of the stakeholders of the system are maneuvered into alignment. In this paper we present a study of the pilot implementation of the IT-supported, preventive intervention TOF (Tidlig Opsporing og Forebyggelse). A core element of TOF is an IT system that stratifies citizens into risk groups on the basis of self-reported lifestyle information and data retrieved from the medical records of the general practitioners (GPs). In addition, the system facilitates cross-sectoral coordination between preventive offers at the GP and at municipal health centers. We find that TOF succeeded in maneuvering the agendas of the involved stakeholders by gaining the foothold, legitimacy, and GP motivation required to carry out the pilot implementation.

Introduction

In systems development, pilot implementations aim to improve system quality and reduce implementation risk through field trials of properly engineered, yet unfinished, systems (Hertzum et al., 2012). When the organizational settings are complex, pilot implementations must maneuver and obtain alignment among the various groups with a stake in the system. This is laborious, but highly important.

In this paper we investigate the pilot implementation of an IT-supported intervention developed by the project TOF (Tidlig Opsporing og Forebyggelse, Danish for ‘early detection and prevention’). The purpose of TOF is to enable local healthcare authorities in the Region of Southern Denmark to detect citizens at risk of developing a lifestyle-related disease and to initiate preventive activities. A core element of the intervention is an IT system that *automatically stratifies* citizens into risk groups on the basis of self-reported data about their health and lifestyle combined with data retrieved from the medical records of the general practitioners (GPs). Depending on their health profile, citizens are then offered preventive care either by their GP or in a municipal health center. Hereby, the system facilitates *cross-sectoral coordination*. With automatic stratification and cross-sectoral coordination as two of its features the system assumes infrastructural characteristics (Monteiro et al., 2013), which pose a challenge for pilot implementations. Collaborative systems in healthcare tend to bring out organizational politics and institutional logics (Egger & Wagner, 1992; Pine and Mazmanian, 2015), which are a potential source of tension and disagreement. Therefore, information infrastructures must maneuver in a web of diverse relations and succeed in bringing them into some sort of local alignment. Williams (2016) argues that success in such efforts is endangered by a weak learning economy in the healthcare sector when it comes to the design and implementation of IT systems.

In the case of TOF, a pilot implementation was launched with the specific purpose of learning about the end-user training, practical usefulness, organizational consequences, and scalability of the intervention, prior to full-scale implementation in the region. The purpose of this study is to analyze how the pilot implementation maneuvered among the agendas of the involved actors and to give examples of challenging issues that emerged in the process.

Pilot implementations

A pilot implementation is not just the period during which a system is in pilot use. Hertzum et al. (2012) propose that pilot implementations consist of five activities: planning and design, technical configuration, organizational adaptation, pilot use, and learning. The three first activities are preparations. During the preparations the focus and scope of the pilot implementation are defined, the system is configured for the pilot site, operational data are migrated to the system, interfaces to other systems are established, work procedures at the pilot site are aligned with the system, users receive training, safeguards against breakdowns are set up, and so forth. The preparations may consume more time than the period of pilot use, during which the staff at the pilot site uses the system for real work. Finally, learning about the system, its implementation, and use occurs during the preparations as well as during the period of pilot use.

Pilot implementations are conducted to learn prior to system finalization and full-scale implementation. However, previous research shows that the learning objective is often difficult to fulfil. For example, Hertzum et al. (forthcoming) find that learning from pilot implementations is situated and messy. Pilot implementations assign key importance to subjecting the system to the real conditions of the pilot site. This situated view of change is at odds with the premise that the learning from a pilot implementation will be valid beyond the pilot site. Difficulty in telling the particulars of the pilot implementation from generic insights about the system creates uncertainty and, possibly, confusion about what can be learned from the pilot implementation. Winthereik (2010) extends this argument by showing that the actors in the pilot implementation of an electronic maternity care record perceived the opportunities for learning quite differently. The organization that steered the pilot implementation tried to keep things stable – like in a controlled experiment – to avoid confounding the learning from the pilot implementation. The nurses who had to adjust their practices in order to use the maternity care record felt peripheral to the learning objective; to them the pilot implementation was largely a ritual. Lastly, the clinicians who were involved in designing the maternity care record saw it as a malleable object that could, and should, be changed on the basis of the learning from the pilot implementation.

Hertzum et al. (2012) point out that because a pilot implementation involves using the system for real work, the learning objective may also become secondary to concerns about getting the daily work done. The temporary nature of pilot implementations likely adds to this secondariness.

The TOF system

The TOF intervention was developed in a research-and-development collaboration headed by the Research Unit of General Practice, University of Southern Denmark. In TOF the targeted citizens received an electronic invitation to take part, and those who accepted filled in a questionnaire about their lifestyle and gave permission for the TOF system to retrieve specific information from their GP's medical records. On the basis of this information, the stratification model divided the citizens into four risk groups: (1) Citizens with a pre-existing diagnosis and/or in current treatment for a lifestyle-related disease. (2) Citizens at high risk of developing a lifestyle-related disease, who were offered a targeted intervention at their GP. (3) Citizens engaging in health-risk behavior, who were offered a targeted intervention at their municipality. (4) Citizens with a healthy lifestyle. The intervention was supported by a web-based system that was used by citizens to enter their health information and by GPs and municipal health workers to access citizens' health profiles.

After several years of preparations, the TOF system was in pilot use for three months in 2016. During the period of pilot use the TOF system was used by 47 GPs and by municipal health workers from two municipalities. In addition, 3587 citizens gave consent to participate and 2661 used the system to create a health profile. We investigated the pilot implementation of the TOF system through 31 interviews with stakeholders at the project level (e.g., the project leader and several project participants), practice level (e.g., GPs, municipal health workers, and citizens), and regional/national level (e.g., the Danish Medical Association and several patient associations). Our study protocol and interview guide were presented to the TOF research steering group. Informed consent was obtained from each interviewee, including permission to audio-record the interviews.

Analysis

> *The pilot has definitely contributed to breaking the ice by showing what makes sense. There are no one among my colleagues [i.e., GPs] who are not happy to do things that make sense.*
>
> Member of the TOF research steering group

The pilot implementation demonstrated the ability of TOF to maneuver the agendas of the involved parties and bring about a functioning alignment between the activities related to preventive care in general practice and in the municipality. However, achieving this alignment involved a substantial amount of work during the preparation phase. We found the following events particularly decisive for the establishment of the TOF pilot implementation.

First, TOF *gained foothold* both among GPs and municipal health workers by framing the outcome as a cross-sectoral intervention rather than a stratification model. This framing emphasized coordination across sectors and deemphasized automation. In recent years the provision of better offers for disease prevention has received considerable attention – including economic resources – in general practice and in the municipalities. Currently, the municipal health offers are however underutilized, partially because many GPs do not refer citizens to them. TOF addressed this issue by developing procedures for this cross-sectoral collaboration through a participatory process. Two work groups were established to define how the collaboration could be organized and accomplished. The result was the cross-sectoral concept of the TOF intervention, supported by both the GPs and the municipalities.

Second, TOF *gained legitimacy* among GPs by finding an alternative to the original data extraction model based on Sentinel (an IT system already in widespread use for other purposes). In TOF, Sentinel was to extract data about citizens from the GPs' medical records for use in the stratification. However, in late 2014 a database created through one of the other uses of Sentinel was ruled not approvable and consequently deleted, which increased skepticism among GPs toward data extraction through Sentinel. Instead of awaiting a full evaluation of the future of Sentinel, the TOF steering group decided to develop an alternative data extraction model, in which the GPs were directly involved in defining the extraction criteria. The increased transparency of the alternative data extraction model helped rebuild legitimacy with the GPs.

Third, TOF *fostered motivation* among GPs by changing from mandatory to voluntary participation. Originally, it was agreed in the steering group that participation was mandatory for GPs in the participating municipalities. This decision became a source of discontent because a general shortage of practitioners meant that many GPs found themselves unable to free up the time required to participate. To accommodate to this situation, the steering group decided to make participation voluntary in spite of the risk that this could cause GPs to desert. However, in the end, the result was a level of GP participation that fully enabled the project consortium to assess and learn about the TOF intervention. As much as 47 GPs participated in the pilot implementation out of a total of 68 GPs in the two municipalities (the project consortium had set 35 participating GPs as the critical threshold).

Discussion

At an abstract level a pilot implementation is successful if it provides valuable input to decisions about the technical finalization and full-scale implementation of the system (Hertzum et al., 2012). That is, success is determined by whether important learning ensues, not by whether the system performs well during the pilot implementation. It may be an important learning that the system does not perform well. In this perspective, the TOF pilot implementation can be described as successful because it gave, at least, three answers of importance to the wider implementation of the TOF system. First, the stakeholders were brought into alignment. This alignment was probably the main achievement of the pilot implementation, and it was achieved during the yearlong preparations for the period of pilot use. In this relation the period of pilot use merely provided the practical proof that a functioning alignment was in place. Second, a large number of citizens, GPs, and municipal health workers participated in the pilot use. Apart from serving as evidence of the functioning alignment, the volume of users from the different stakeholder groups also provided the basis necessary for assessing the stratification model. The aim of providing such a basis made the pilot implementation substantially larger than most other pilot implementations of IT systems (e.g., Hertzum et al., forthcoming; Winthereik, 2010). Third, the stratification model did not work to the GPs' satisfaction. About half of the GPs found that they had consultations with citizens who should not have been offered a consultation. In the evaluation that completed the pilot implementation this finding led to the realization that the task of motivating citizens to change their lifestyle was new to many GPs. Instead of a requirement for revising the stratification model prior to the wider implementation of the TOF system, the finding led to a requirement for offering the GPs courses on how to motivate citizens to change their lifestyle in order to prevent chronic disease. The finding also led the municipalities to clarify that their continued support of the TOF intervention would depend on broad support from the GPs, thereby showing that the obtained alignment might be temporary.

With this study we illustrate how a pilot implementation in a complex and cross-sectoral setting needs to maneuver among the agendas of the involved stakeholders. By doing this, the pilot implementation of the TOF intervention gained the foothold, legitimacy, and GP motivation required to go forward with the wider implementation of the TOF system. However, the pilot implementation also provided data for more concrete discussions of the performance of the stratification model. These discussions resulted in important learnings that must be resolved prior to wider implementation.

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Challenges and Opportunities of Health and Care Co-production with Social Media: a Qualitative Study

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Abstract. Future of health in EU faces the triple challenges of ageing, fiscal restriction and inclusion. Co-production offers ways to manage informal care resources to help them cater for the growing needs of elderly people. We investigate the opportunities and the challenges in use of Social Media (SM) as an enabler of co-production in healthcare. In order to do this, we conducted a qualitative study using interviews and online observations of activities of professional carers, voluntary organisations and informal carer. We found that particular types of SM are currently used to enable co-production through coordination and communication across boundaries. However, there are still many other types of SM, which are rarely used in this sector due to their limitations. Nevertheless, carers showed interest in using systems which help them to engage people in shaping of services, sharing of experiences and encouraging care activities.

Introduction

Informal carers, which consists of 10% of the UK population, play a very important role in caring for the increasing population of elderly in the UK. Their value is approximately equal to the total annual cost of UK health spending (Buckner and Yeandle, 2015). As a result the UK government is reshaping service delivery, which needs to consider how to utilize existing resources, including formal and informal carers (Boyle and Harris, 2009). The government announces the need for better coordination and integration (Christie, 2011). In order to do this, the concept of co-production is used by the government to better manage the existing resources. The full participation of informal carers in the co-production of healthcare has the potential to play a significant role in the sustainability of healthcare delivery. A key question for co-production of healthcare is how can the informal care resources be coordinated and co-deliver care along with the formal healthcare system. This massive resource is wide spread and uncoordinated in responding to pupils needs. SM is seen as a key enabler to overcoming these challenges as it enables co-production (Lin and Lu, 2011). Communications is a key element in co-production that enables coordinating across various boundaries. SM helps to communicate across boundaries. However, its effect on healthcare co-production for elderly care is poorly understood.

Therefore, this paper, which focuses on organisations that provide/support care service, explores how SM enables this co-ordination.

Objective and Methodology

Our study investigates the SM as an enabler of co-production in healthcare. Two main sets of questions are asked: what are the current uses of SM in health and social care? How can SM be reshaped to enable (and reshape) health and care co-production?

Material and methodology: This is part of wider qualitative study which investigates the sociotechnical aspects of the current and possible future uses of SM by different organisations and groups of health and social care as an enabler of co-production in UK. Our appraisal adopts a socio-technical technique, (May and Finch, 2009) using a mixed methods framework including multiple methods.

Theoretical framework: Normal Process Theory (NPT) has been used as our theoretical framework to enables us to obtain meaningful understanding of the complex socio-technical processes involved in use SM tools and service within healthcare co-production. NPT, us in better conceptualization of analysis in complex adaptive systems.

Data collection: We conducted 18 interviews with employees of private professional care companies, voluntarily organisations, which support carers or support patients in the UK, and informal carers. The interview guide (developed from NPT framework) focused on the services offered, the types of online applications (SM) used, their challenges and future possibilities. Additionally, we followed the online activities of the organisations and individuals (interviewees) and their uses of SM for health purposes.

Data analysis: Data were coded in NVivo and thematically analysed for each type of SM. We inductively identified emerging themes surrounding the benefits and challenges of SM in enabling co-production in healthcare. Those, that did not fit within the narrative, were explored in most detail. We categorised our results based on the type of care organisation.

Findings

In this study, we focused on three types of care systems, which used SM for carer purpose: Carers (informal), charity and voluntarily organisations, and professional organisations which provide care services. We discuss the findings in terms of these three groups.

Professional carers: Professional carers rarely use SM for their work. Our observations showed that the main purpose of use of SM in these companies is for advertisements or sharing of information. We also found that some line manager in organisations appreciated the work of carers through SM (Facebook), which was a way to have an informal relationship between carers and the care organisation. However, carers were not keen to engage in SM activities of the organisations they work for. The organisations too did not want to be connected to their professional carers through their SM sites because professional carers worked for them for a limited time.

"Company has a Facebook page but we are not interested in this because they don't want to be connected with carers again on the professional level."

Literature shows that SM reduces isolation of patient or carers (Mittal et al., 2012); whilst we agree with this, our findings also show that the SM connection between people is not the solution to all the patients needs, in particular physical needs.

"It's about relation... They need to see a human being, they need word of mouth"

The privacy of data is one of the biggest controversial issues of online activities (Norval, 2012). In SM applications, patients information sharing and safety and privacy of data are two important challenges. Professional carers, explained that they cannot discuss their patient stories with others due to privacy issues, leading to reduced online activities.

"I think there is a risk, personal data issues."

The population of elderly, who use SM has been increasing more than other age groups (Brenner and Smith, 2013). This shows a change of communication: one of the aspect of co-production. However, the professional carers believed that there is still a big gap between the two generations in use and familiarity with these kinds of technologies. This means despite the growth, there are still many people who cannot benefit from using SM.

"There are still the generation who are not so much convinced.".

Finally, some professional carers were very interested in use this application for their work.

"my boss is not so keen to push this direction, but this is for my own sake. I was desperate to find application for using on iPhone and iPad so it can help me everywhere I go."

Charity and voluntarily organisations: In most cases, we observed that in charities and voluntarily organisations SM is used for some specific collaboration with other organisations through sharing of information or advertisement of events, campaign or fund raising. We observed some professional health-related SM, such as healthunlocked.com, which were used by organisations to share information or help other organisations to broadcast various information. Despite the general belief that use of SM can reduce some costs and resources (Chou et al., 2013), charity and voluntarily organisations did not use SM widely in their daily activates. For instance, they did not make private groups for discussion with their users. The main reason was said to be the lack of resource, clear approach or budget for managing and maintaining. For example, an organisation which uses blog for their daily work consider that managing of some SM need a lot resource.

"It does take time. Somebody does need to be keeping an eye on this every day... there have occasionally been problems where people haven't always been respectful of each other."

This organisations mainly used general SM for broadcasting or advertisement of their own activities as well as others. SM was also used for fund raising or campaigning in these organisations. In some cases, it was used to coordinate between activities of different organisations. These kind of collaborations, can be consider as co-delivery of resources.

"We use SM to broadcast information to people so every day we get something on Facebook, and twitter. We might share information from other organisation..."

The observation of websites of the voluntary or charity organisation showed that they used mostly web 1.0 and the users had limited contribution on their online site. In some organisations, there were limited use of blogs in their website for sharing stories of their patients or carers. This was an effective way of sharing user experience and making motivation to be more active in this space. However, there were concerns that some stories had problems such as giving medical advice which may not be correct. So, organisations had to introduce policies with regard to what can and cannot be shared on the blog.

"...forum is going to be a difficult one because it's people posting their own experiences and that might not be medically right. Their experience might not match up with what a healthcare professional says, but I suppose our way of mitigating that is that we have a clear policy about what we allow on the web community [...] and it tends to self-managed."

So, to avoid sharing bad information, charities had to adopt various strategies. Some charities avoided their users to put their stories directly on the blog. Instead, they filtered the inputs to their blogs by checking them before they were shared. Other charities allowed information to be published, but monitored them later for breach of policies.

A set of problems faced by many organisations could be categorised as the "problem of access". The foremost challenge highlighted by charity and volunteer organisations, in terms of access, was that access to the internet was not available for some of their patients and carers. This was due to a large number of socio-economic factors such as educational level, income level or geographical situation. Although, carers use online information. Some also referred to reasons for not accessing internet as artificial barriers. These reasons include lack of desire or sufficient encouragement from the younger generations.

"I think there are people who [...] don't want to engage."

A second challenge in terms of access was finding the right groups.

"So, we'd like to be able to easily search and find what groups there are on Facebook and what groups are going on. Because that's been really difficult at the moment."

SM can increase the knowledge of patients and carers on how to cope with the disease and how to communicate with health professionals like GPs (Daneshvar et all, 2017). However, it can also lead to too much reliance and trust on the information provided online. This could lead to confusion or reduction of contact with professionals that may be risky.

"I think it's becoming over-reliant on one source of support rather than what I see as a network of support including your healthcare professional, any carers, family, etc."

Carers (informal): Carers use SM for a wide range of activates. Carers were interested to use SM to reduce isolation caused by care activities. Through SM they connected with other carers or patients with similar. One common kind of SM used by carers, was blog, on which they shared experience and care stories.

"*... the blog is base of story centre and you can always reflect back at it ..."*

In this situation, we can see SM as tool for making co-delivery of service to share knowledge and experience and receive feedback from other people with same condition. They used blogs to share stories, ask for support, and to receive emotional support.

"*I was scared and I was lonely, the blog was my only way of reaching out to people"*

In other words, SM is enabling co-service as carers can share their feeling or circumstances and get confidence without intervention of government or other organisations.

"*when my mum was to go to bed I would write about how I felt that day, how did we fear? ...from the confines of my own house, so it opened up a different world to me."*

Different kind of SM could be helpful in different situations. Involvement of carers in blogs was seen as a long-term investment. However, they also used SM for short-term and quick responses. For instance, to ask questions they used micro-belonging (twitter). It was seen as a quick platform with a lot of professional individuals being online.

"I think Twitter is about more what's happening right now [...] Twitter is more than the blog, I think Twitter is more a faster engagement whereas the blog is slow"

Despite its benefits, carers and patients also faced challenges in using SM. The main barriers for carers in use of SM was confidence to contribute and knowledge of setting up.

"I think that was my main challenge at first was really my self-confidence in myself..."

A different type of challenge was about conflict of feelings, lack of understanding or dispute on the stories shared on SM, which could make carers and patients disappointed.

"some people might not understand how you feel... My own blog is more of how I feel. [...] it's how I feel about my love for my mum when I was caring for her. It's how I feel about how I felt when I was doing it, so reactions to that can be quite a challenge."

Discussion and Conclusion

We can conclude that existing SM (in particular Twitter, FB, and blogs) are currently used to enable co-production. We discus three main actors playing an important role in healthcare system in UK. These groups have different extent of use of SM: 1) Professional carers did not use SM widely compared to other groups; 2) Voluntary organisations such as charities used SM for certain activities such as fundraising, campaigning, and information dissemination; 3) Informal carers used SM more than others in their daily healthcare activities. However, they are used for particular purposes such as advertisement and information diffusion for charity and volunteer organisations, and connection and emotional support between carers. We also argue that there are a wide range of opportunities in broadening the use of SM for organising and individuals who provide care for elderly populations. There are current challenges in use of SM such as low skills, awareness, and literacy, high setup and control, accessing to online resources, and security and confidentiality concerns. Moreover, current SM does not cater for all the needs of elderly people and their carers. Most user of SM are young people and the gap between the carers and patients who use SM is wide. Also, we identified a set of barriers we called "problem of access", which refers to carers or patients having problem to access the internet, access the appropriate group, or the suitable information. Therefore, new functionalities aimed at this particular group needs to be designed to better coproduce healthcare and manage the needs of elderly people.

Further work is needed to find out the new services (e.g. workforce co-ordination and cooperative organisations) which can be offered with existing SM. Then we will be exploring the possibilities of designing a new SM to cater for the existing need and new services required.

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A Methodology to Assess Changes in Healthcare Infrastructure in Stockholm

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Abstract. Designing major shifts in complex systems such as healthcare requires a combination of approaches and perspectives. A considerable change in healthcare infrastructure is due to occur in Stockholm with a major emergency department being closed. As this change impacts operations as well as governance, multiple methods are needed to assess it. In this paper, we present an approach combining simulations and data mining of healthcare data to assess the changes to healthcare system in Stockholm; and discuss the opportunities and challenges of doing so.

Introduction

The opening of the New Karolinska hospital (NKS), a super specialty hospital has raised many questions regarding the distribution of care in region of Stockholm county. The access rules to the emergency care will be changed in order to conserve resources for specialized care for those required. Patients who used to choose the Emergency Department (ED) of NKS will need to adjust to other alternatives within Stockholm County (SLL), unless they need special care.

This complex shift affects the overall healthcare system of Stockholm. Healthcare system, being a complex adaptive system contains self-organizing layers of people and processes, from people directly involved in patient care to management and administration. The healthcare system in a city is even more complex as authorities and politicians are also involved and are stakeholders in this system.

This shift raises many questions at various levels of the healthcare system. Apart from changes in capacities at the operational level at individual hospitals in the region, there is also a need for development of new governance strategies for the entire health care system. An investigation of the same problem was undertaken by SLL(Martling 2016). The report identifies technical aids to sort patients into the right level of care, process for developing governance strategies, common electronic health records to make clear communication possible and guidance to redistribute patients as main topics to be investigated. This sets the context for the research questions to be addressed.

While there are various theories that address socio-technical complexity of the health care system, no individual method can sufficiently address all the questions raised in such a case study(Raghothama and Meijer 2015) . An economical or physiological model of the system might be fundamentally correct, but that does not depict the behavior of the patients themselves. Patient behavior and preferences can be mined from healthcare data, but that does not depict how patients could behave after a relatively radical change in the system.

In this paper we introduce the combination of approaches. Simulation models and data mining can depict more thoroughly the change in system and patient behavior, so that more of the complexity of the health care system is captured, thus generating more knowledge of the system for the design process.

Background

Healthcare systems have evolved from a collection of components to Complex Adaptive Systems (Rouse 2008). The approach to study of healthcare as a hierarchical system of systems has facilitated in tracing the flows of patients, information and economy through the healthcare system(Kopach-Konrad et al. 2007). This has aided development of processes and efficient utilization of resources by providing insights into design of hospitals, special departments or services, looking into patient waiting-times, occupancy rates or scheduling issues (Comas et al. 2008; Giesen, Ketter, and Zuidwijk 2015; Mutlu et al. 2015).

Conceptual modeling of healthcare using Systems Dynamics (SD) models has also aided in focusing on aspects under study and figuring out causes and feedback loops in the processes and to hence make better decisions(Brailsford et al. 2004; Koelling and Schwandt 2005; Lane and Husemann 2008). Approaches that combine different simulation paradigms have also been successful at addressing process and workflow aspects with the that of patient behavior (Djanatliev and German 2013; Kittipittayakorn and Ying 2016).

Data in healthcare sector is being generated on a large spectrum, from genetics data to patient record data, all amounting to big data in healthcare (Schneeweiss 2014; Zhang et al. 2015). While much of the data in healthcare is used extensively for diagnostic purposes (Yoo et al. 2012), it has also been used study performance of healthcare infrastructure (Barnes et al. 2015; Peck et al. 2013). There are also examples of data being used for gathering insights and patterns within clinical processes, to identify patient groups and predicting readmissions and discharges (Barnes et al. 2015; Bates et al. 2014)

Simulation approaches have been successful in characterizing processes in the healthcare system and aided in design and management. However, translating these insights from simulations to actual hospital has been hard (Peck et al. 2014). Data driven approaches have been accurate at predictions and capturing needs. A change in the structure of a system that generates the data, changes its meaning and problem description itself. It is therefore beneficial to combine these approaches to capture needs and then study the structural changes to healthcare infrastructure in Stockholm.

Approach

The nature of healthcare provision in SLL makes it a unique case of a highly connected network of hospitals and primary care centers communicating flows of patients and information across the region.

The decision to close the ED in NKS will have an effect on demand to EDs in other major hospitals in the region. As the demand for different hospitals in Stockholm will change, the capacities and flows of the healthcare system in Stockholm will need to adapt.

In order to evaluate the changes over the whole system, there are three major questions that need answering.

- Which factors are affecting the choice of patients to choose a kind of care?
- Provided those factors, what effects are expected on the capacities of SLL major hospitals?
- How can this knowledge be further utilized to design processes to handle this change?

30 million anonymized records of patient visits over eight years are accessible to this study. The records consist of codes (nominal data) for departments and hospitals visited, symptoms and diagnosis. Using these features, profiles for hospitals as well as patients can be constructed. This could be achieved through data science approaches, by framing the hypothesis as a supervised machine learning problem, by using classification or recommender system algorithms. Through this, relevance of various features of the hospitals - such as staff, size, location, distance – to care choice can be discovered. Thus, by creating a space for exploration through data it could be possible to further understand patient behavior, through his/her visits to different hospitals.

Scenario based simulation taking into account the majors factors influencing healthcare in Stockholm can then explore further the healthcare system behavior after it undergoes the changes. Simulation can provide a tool to test the capacities and services of hospitals to different level of demands resulting for the transition to NKS. Potential solutions for problematic scenarios can be tested or even emerge from the use of the simulation.

Simulations allow particularly visualizing and understanding simple effects of some factors in isolation. In fact, simulation through simple models such as agent-based models can provide insight to decision-makers on the effect of possible behavioral changes of the population facing the new healthcare system. Agent based models, being best at describing emergence of behaviors from simple interactions between the population simulated and their environment, are used to investigate how interaction between patients and the new environment provided by the opening of NKS affects the whole system. At this point, two agent based models are already under development.

The first model tests the capacities of emergency departments in other hospitals in SLL against an increase of flow due to NKS being a super specialty hospital only. This model allows testing for different capacities and demands. It assumes that patients seeking an ED will choose the hospital that is closest to their residence. If the condition of the patient cannot be treated at that hospital, the patient moves on to the next closest hospital. This assumption, as well as the data used to run the model, can be modified depending on further data analysis.

Another agent based model being developed provides insight into the effect of having information systems for patients to know the length of queues as well as travel-times to different ED before choosing the hospital to go to. This model will provide decision-makers a space to explore the possibilities such an information system can provide.

The simplicity of these models allows particularly understanding in isolation effects of factors such as capacities or information. The hybrid approach of this work will enable simulations to rely on data to pick up scenarios of interest and provide tools of to verify models and increase their realism. The outcomes of the data-mining exploration can also identify other areas or factors into which theory driven-models can provide complementary of different insight.

Conclusion

The assessment of changes in healthcare infrastructure in Stockholm asks for a hybrid approach due to the behavioral and structural component of the issue at hand. This paper presented an approach to combine simulation and data mining that addresses the uncertainty of behavioral change and the volume of care data available. By combining the outcomes of both methods a richer assessment on design of new processes can be obtained. The main challenge for this work is validation of the hybrid approach, as validity will have to be ascertained at level of simulation, data mining and the combination itself. Future work will also validate the hybrid approach by following up the actual closure of the ED at NKS.

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Simulation Sessions as Engines of Improved Hospital Care Quality

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Abstract. With increasingly complex practices, improving the quality of hospital care must include infrastructures to support communities of practice. We argue simulation sessions are ideal opportunities, if managed well, to create successful communities of practice.

Medical Knowledge Generation and Simulation

Infrastructures in support of healthcare quality are either systems dedicated to governance or re-purposed systems, such as electronic health records, designed to support clinical care but also serving managerial objectives of increased efficiency and patient throughput. In this paper we will examine quality from the perspective of the medical knowledge as used ‘in practice’, and examine how medical simulation settings, increasingly used for training, can naturally become a quality tool for hospitals, supporting virtuous cycles of continuous knowledge creation and sharing from the (simulated) field to the daily medical practice. Our reasoning is grounded in the existing literature and two own user studies: first a set of four interviews of practitioners, secondly a field study of a medical simulation setting in a hospital (Boulard Masson et al., 2016).

The healthcare domain is transforming rapidly, with patient centric approaches and precision medicine. In this paper we will examine the aspects linked to medical knowledge. Medical science has greatly progressed and continues at a steady peace. Atul Gawande, reports that there are today around 4000 medical and surgical procedures, with around 6000 drugs that doctors are authorized to prescribe (Gawande, 2011). Other sources confirm this, for example (Vincent & Amalberti, 2016) state that in five years, half of the knowledge in a medical speciality has changed. This fast generation and update of knowledge has several important implications. Firstly it is increasingly harder to master this progress and we are getting to a turning point where no single practitioner can master it all. Secondly, there is an increasing complexity of the hospital care: Gawande mentions the evolution of how many clinicians it takes to care for a hospitalized patient: in the 1970s, two and an half full-time equivalents of clinicians (a nurse and a doctor), and by the end of the 90s more than 15 clinicians (specialists, physical therapists, nurses). This increasing knowledge complexity has therefore two impacts: on the capability of doctors and paramedical staff to master it and on the capability to accomplish care through the enactment of large coordinated teams with many different profiles.

Facing this increasing complexity, we have noticed, in a number of practitioners interviews we carried out, that participation in Communities of Practice (CoP) (Wenger, 1998) is mentioned as an effective support of the required continuous learning. This is aligned with a meta study (Ranmuthugala & al., 2011) showing a growing interest to understand what shapes effective CoPs in the medical sector, even if it still "requires a greater understanding of how to establish and support CoPs to maximise their potential to improve healthcare". In particular, there is a lack of understanding of what setting and communication medium may best support them. Starting from the core characterization of them as constituted by a joint practice (what is shared by the community) and sustained by interactions involving a mutual engagement, we observed that simulation sessions in hospitals, and especially the debriefing element of them (Boulard Masson et al., 2016; Horcik & Durand, 2011), can facilitate CoPs systematic creation and adoption, towards a continuous knowledge creation cycle. This result is based on the analysis of our field study debriefings, that indicates they provide an excellent opportunity to gather feedback on the reality of work and produces new knowledge to improve it. In (Boulard Masson, 2016) we provided several examples of the type of knowledge that would benefit real practice if taken into account. We highlight here three main forms of it: firstly the refinement of existing medical knowledge on the base of the practice, secondly, the sharing of good practices and teamwork dysfunction and thirdly the improvements of the teamwork organization.

Refining Medical Knowledge

Drawing examples from our field study, below is a discussion from a simulation debriefing, about the rate of norepinephrine that should be given to a patient recovering from an anaphylactic shock. The anaesthesia nurse chose to put 0.05 mg/h norepinephrine where normally the prescription is 0.1 mg/h or 0.2 mg/h. During the debriefing the trainer came back on that decision.

Trainer: "*Maybe in another context you would have chosen 0.2 or 0.1?"*

Nurse: *"No, not necessarily, a patient without any medical history, on a minor surgery, I feel comfortable to start with 0.05... Then if I have to hand off to a colleague I will carefully explain the situation [as it differs from the prescribed rules]."*

A following discussion with the trainer allows us to understand that this anaesthesia nurse is working in the cardiac surgical service and that, in that specific service, they are used to have patients who strongly react to norepinephrine. In that case, it is interesting to see that some anaesthesia nurses choose different dilutions from the prescribed ones, potentially for good reasons, such as the specificities of a service. To go further, the trainer, if supported by the organization to do so, could during future debriefings with other practitioners raise this practice to inform them that, in some specific context, it is possible to use another dilution or to recall the importance of communication on dilutions as sometimes practitioners do not strictly follow the prescriptions.

Sharing of Good Practices and Teamwork Dysfunction

During debriefings, we were able to observe the sharing of good practices where practitioners, in reference to the situation they just experienced in the simulator, describe also what their resources in real situations are. Here, the trainer tries to understand how the trainee identifies the worsening of the situation.

Trainer: *"It seems that the first signal that alerted you was the desaturation."*

Nurse: "*I really pay attention to this sound since a supervisor made me aware of this little sound to which I was not attentive, and brings so much information*".

This beeping sound is therefore identified as a core element for the anaesthesia nurse in order to perform safely. This comment also shows that this sound is not necessarily widely used: "*to which I was not attentive*". As a follow up, the anaesthesia nurse adds "*I often find myself in rooms where the beep has been cut off, but you're on the job, [...] so after a while you give up, after you've been asked to turn it off once, twice, three times*". In this debriefing, we see an opportunity to share good practices, which are not necessarily the prescribed ones but more the work-arounds that allow the practitioners to perform better. The idea is not to motivate all practitioners to follow this specific work-around, but more to share the opportunity of such good practices and leave it to the practitioners to decide when and whether he/she can use it. A second level is addressed here according to the use of the beeper and targets the teamwork. The trainee mentioned that sometimes surgeons said they were disturbed by the beep. This type of feedback could lead to discussions between anaesthesia practitioners and surgeons on the ways they can achieve together safer surgical operations.

Discovering Improvements of the Teamwork Organization

The last example we want to raise is a situation where a critical care resident, who is reaching the end of her training to become an anaesthesia and intensive care doctor, is discussing her position in the simulation compared to the position she usually holds in real situations.

Intensive care resident: *"I had the feeling to be in the position of the leader doctor that is new to me. During my three months residency at the 'déchoc' [where trauma patients are admitted when arriving in the hospital], I only held the position of the follower [main role is to perform technical tasks such as catheter insertion]. I never really made any decision on critical patients."*

Following this first statement, the trainers and trainees discuss as peers about possible changes they may initiate in order to improve the global training supported by the "buddy" experience.

Trainer (Intensive care doctor): "*Actually, we should reposition ourselves, when we can be several intensive care doctors, and let you [the residents] hold the position of leader. We can't really be the follower*."

Intensive care resident: "*Otherwise it could imply bringing in two intensive care residents, one with the senior doctor saying "you manage the situation, I stay behind", and the other one to equip the patient"*

Trainer (Intensive care doctor): *"Yes indeed when it's possible, we should maybe do it that way"*.

At the end of their discussion, trainers and trainees have agreed on an improved way to get things done, yet without taking risks and allowing residents to face situations they will face as doctors without really practicing them.

Besides the several examples described above, other useful information for CoPs and for organizations are shared during debriefings. It can be very concrete and target equipment dysfunction, obsolete procedures, or incomplete protocols (Boulard Masson et al., 2016). Through the data collected in our fieldwork, we demonstrate that discussions occurring during post-simulation debriefings reveal a high potential for understanding actual practices performed in the field, where improvements are possible and propositions for improvements are formulated.

Toward an Infrastructure in Support of Quality

We believe some well-designed technology can help preserving and systematizing benefits of simulation sessions in the longer term to sustain organizational learning, beyond individual training.

Central aspects of such infrastructure need to be around knowledge modelling and knowledge governance, to support effective sharing amongst stakeholders, both of which need to be sustained by additional specific research insight, in order to inform technology design. But we can already pinpoint that a major issue in this reflection is about how to move from verbal discussions that are mostly informal and confidential to written information that can easily be more formal and less confidential. With this in mind, we can already provide some elements of reflection related to the IT infrastructure.

Today we envisage two different types of infrastructures that could support simulation sessions while also putting them at the service of organizational learning. However, although similar, we believe they offer a different approach to governance: in the first case the system is encoding strict validation procedures to assure an *a priori* verification of insights coming from simulation sessions and ensuring that appropriate validation steps occur before any new knowledge comes to the surface, while in the second approach the system is much more open and it is only *a posteriori* that the knowledge governance is put in place.

The first type follows the spirit of an ecosystem of interconnected web applications targeted at different stakeholders with for instance two main modules: 1) A practitioner's module, with a personal area, for practitioners to: keep track of simulation sessions, of real practice noticeable events they would log in, and receive propositions for further training. This module should include also a CoP area, allowing them to provide feedback on training and simulation sessions, to submit real practice noticeable experiences, and to argue opinions on new guidelines; 2) A hospital module would provide each hospital management team with a dashboard to manage quality improvement of their practice by monitoring training requirements and identifying risks and need for personal and organizational evolutions. This module would be a tool to examine new insights and decide if and how to turn them into explicit and consensual new practices.

Another type of infrastructure could take the form of a bottom-up collaborative system such as a wiki. This format became famous from its usage as the base for the Wikipedia encyclopedia, but it is also used in private environments (Brichni et al., 2014 and Grasso and Convertino, 2012) as an infrastructure for knowledge management.

What we propose here is that the simulation sessions and their associated debriefings serve as a way to extract and create knowledge that can be capitalized through more informal knowledge sharing in a wiki and utilized towards quality improvement. In (Brichni et al., 2014), different axes have been identified to evaluate the appropriateness of this tool as an infrastructure for quality improvement, which was the goal of the wiki described in the study. These dimensions can serve as a relevant guide for a wiki infrastructure to be assessed and designed for quality improvement in healthcare.

Additionally in (Brichni et al., 2014), more commonalities can be found with our proposition. Firstly we both aim at sharing and connecting practical knowledge (*know-how*) in the field with listed procedures: these two aspects are often opposed although they were here seen in synergy in the industrial case. The web base structure of the wiki allowed the use of hyperlinks to easily create seamless navigation between know-how and procedures. Secondly, the existence of several different groups of users is a common feature: the groups were members of the IT Service on one side, and members of the manufacturing operations on the other side, differentiated through the use of login procedures and customized tools. The two groups had both common and differing interests. In our case, we could use the same strategy to offer different ways for practitioners, simulation professionals or hospital management staff to leverage the information.

Beyond the set-up and maintenance of the infrastructure itself, which is fairly light, the effectiveness of the self-regulation and *a posteriori* approach needs to be validated, firstly in relation to the validity of the information. In most wiki systems, communities manage to more or less self-regulate the validity of the content. How appropriate these self-regulated dynamics are in a hospital environment should be assessed, even if champions were distributed through the organization to constantly monitor what new knowledge comes to the surface though simulation sessions. Secondly, validation is needed in relation to confidentiality: here the risk is that curation would come into action after the 'damage is done', for example after the names of colleagues are mentioned and seen by readers.

Despite these needed verifications, we believe such types of infrastructures should be considered as necessary tools to be put in place so that simulation programs can become an effective mechanism towards the enhancement of care quality.

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Building an evaluation infrastructure: capturing feedback at the right time and place

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Abstract. Infrastructuring does not happen by itself; it must be supported. In this paper, we present a feedback mechanism implemented as a smartphone-based application, inspired by the concept of infrastructure probes, which supports the in situ elicitation of feedback. This is incorporated within an evaluation infrastructure which enables clinicians to collaboratively evaluate IT system usage and related work practices. Access to the collected feedback is given through a central online repository presenting the feedback and analysed collaboratively. We describe this through a case where nurses collaborate by the means of electronic whiteboards on the infrastructuring of a procedure of patient transfer from an intensive care unit to a general ward.

The need for an evaluation infrastructure

Obtaining usage feedback from healthcare production systems from the systems themselves can be difficult, not only because of technical limitations in existing systems' ability to export data but also due to bureaucratic and organisational barriers which enforce the legal conditions under which data can be accessed.

In order to facilitate the collection of feedback to feed into an infrastructuring process we describe a feedback mechanism based on the idea of infrastructure probes (IPs) that enables users to self-document IT systems usage and usage problems and conduct a local collaborative analysis of the collected feedback.

Within secondary healthcare the collection of feedback about issues concerning the use of IT systems is typically organized through a central helpdesk service. Clinicians may either call for immediate help or fill out an online formula to report a problem, which is then processed at the helpdesk asynchronously. While calling helpdesk may (or may not) solve an immediate problem for the individual clinician in a given situation the underlying problem may not be limited to the technical part of the IT system, but related to the work procedure that the clinician is carrying out through the system and the problem is therefore likely to surface again. The alternative of filling out an online formula to report a problem is related to a number of challenges one of them being that it takes too much time and does not solve the immediate problem of the clinician, thus resulting in workarounds. While we do not solve the latter challenge within the framework of an evaluation infrastructure, we aim at making it easier for the clinician to provide feedback and point to ways of how to analyse it.

The same challenge for attaining feedback accounts for research initiatives. According to (Davis 1995), the traditional way of collecting feedback during a naturalistic evaluation of a prototype is either paper-based forms or the location of a human observer to act as a mediator for the feedback. While the former is cumbersome for the user, the latter is expensive. We suggest a solution for attaining feedback in-between written feedback and a human observer where clinicians are able to document their observations (articulations) of problems as they occur in an easy manner and do so in a dedicated and separate platform-agnostic system that the clinicians have access to and set up locally, to avoid the practical problems of obtaining feedback through an existing system.

First we describe the concept of infrastructure probes as a theoretical base for the feedback mechanism followed by an example of how an evaluation infrastructure can be established, based on the sample case. Finally we briefly discus lessons learned.

Infrastructure probes as a feedback mechanism

We adopt the conceptualisation of work infrastructure of a worker or organisation as coined by Pipek and Wulf (2009) as ”the entirety of devices, tools, technologies, standards, conventions, and protocols on which the individual worker or the collective rely to carry out the tasks and achieve the goals assigned to them.” (Pipek and Wulf 2009 p.455). Following this definition the denominalization of infrastructure: *infrastructuring* is “all activities that contribute to a successful establishment of usages” (Pipek and Wulf 2009 p.450). The notion of “point of infrastructure” (POI) is specifically the notion of either a breakdown where the work infrastructure becomes visible to the user or a use innovation in which the user experiences an improvement toward achieving the work goal (Pipek and Wulf 2009). We acknowledge that design is both motivated and transformational as it seeks to induce change related to the work infrastructure, but infrastructuring puts emphasis on the users' role and less on the designer.

The problem is to support and organise infrastructuring because of the still existing separation between "design time" and "use time". At design time users rarely have time to do the additional task of designing and in use time designers may not be present to obtain feedback. To support the search for possible points of infrastructure is to support the capture of in situ reflections at an activity level. Our goal is to support what (Pipek and Wulf 2009) refer to as articulation support – that is to "support the technology-related articulations" (p.467) concerning usage and usage problems within the work context by providing them with a feedback mechanism. One way to support this is by means of infrastructure probes (Dörner, Heß, and Pipek 2008). IPs are tools that enable users to self-document and reflect on their usages of IT infrastructures the purpose being to find out which problems users are confronted with during use and the reasons for why the problems occur. Secondly IPs can give indications on how users solve their immediate problems. One practical methodological benefit is that the user can remain in his/her working context and that an observer does not have to be co-located.

In our case the use of smartphones as an entry point for clinicians to provide in situ feedback seems opportune. Previous studies (Hertzum and Simonsen 2011) indicate that formative ongoing feedback can enrich understanding in the pursuit of continuous appropriation and improvement of a healthcare infrastructure. We have applied the experience sampling method (Csikszentmihalyi and Larson 2014) in an earlier study in which coordinating nurses at an operating ward provided feedback on the occurrences of a general problem: interruptions from phone calls. One of the lessons was that elaborated descriptions of specific instances of interruptions was favourable for understanding the phenomenon and generate specific ideas for how to counteract some of the interruptions (Brandrup et al. 2017).

Our feedback mechanism is based on an IP tool that builds on the concept of a voice-memo. Practically the user provides explanations of points of infrastructure by the means of a smartphone application that implements an audio recording functionality and forthwith automatic uploading to a central repository, thus making it easy to use. Feedback captured in situ reduces the likelihood of recollection bias and hassle-free upload to a central repository is deemed important regarding ease of use.

The collaborative analysis of the collected feedback is then analysed by the clinicians using techniques like affinity diagramming (Brassard 1989) to create an overview of issues and diagnostic mapping (Lanzara and Mathiassen 1985) to transform issues to suggestions for interventions. See Simonsen and Friberg (2014) for an elaborated example.

Establishing an evaluation infrastructure

Within Region Zealand, Denmark, nurses work with a central shared information space in the form of an electronic whiteboard. In each ward, this provides them with a local overview of their patients, and it supports interdepartmental coordination within the hospital. The sample case is a participatory design project conducted at a medium-sized hospital in this region. The wards invited to join the project include a medical ward for pulmonary diseases, an orthopaedic ward, a surgical ward and the intensive care unit (ICU).

The overall concern is how an electronic whiteboard can support nurses in a patient transfer from an ICU to a general ward, with a specific focus on the initial 24-hour follow-up plan. The goals include sharing knowledge about the patients and establishing common ground with the ICU follow-up to improve care and eventually save lives (van Sluisveld et al. 2015). During twenty-four workshops (1 to 1½ h duration), engaging approximately 85 nurses, they investigate challenges related to patient transfers, the ICU follow-up procedure and possible solutions and suggestions on how to collaborate across wards. Discussions within the group of nurses result in lists pertaining to the needed information related to the former ICU patient (Brandrup and Østergaard 2015). Two nurses from each ward then participate in two design workshops (three hours' duration each) where the purpose is to collaborate on the design of the ICU follow-up plan and procedures in a manner which make sense both to the ICU and to the general ward nurses (Ostergaard, Karasti, and Simonsen 2016). The nurses' shared vision, as an extension of an existing production system, does not include considerations about the ability to provide feedback within the system or evaluation of the use of the follow-up plan. The need for evaluating the nurses' design is, however, still desired as input for the second design workshop.

Three out of four wards were represented at the design workshop when the smartphone application was presented as an alternative to hand writing comments about the use of the follow-up plan for each patient transfer. The nurses' initial reaction was to strongly resist the use of the smartphone and the recording application. They did not feel comfortable audio recording their answers and argued that it was too much to deal with the live testing of the design of the follow-up plan and using a smartphone with an unfamiliar application at the same time. The nurses tried the application at the workshop, and their behaviour was clearly uncomfortable. They did not know how to 'activate' the application, and as the application started to record they started to giggle, saying *No, no, no… If it is the same to you I'll just do my answers in hand writing.* Another nurse said *No one can argue that our colleagues will see the fun in recording their answers – I will do my answers in writing. When writing in hand…that will also make me reflect on things... This* [the smartphone] *will not make me do that. What if we say* *something that we want to correct? Then it is too late.*[1] They did agree to have a smartphone with the application available during the three week testing period though. The ward that was not represented at the presentation of the application was handed a smartphone as well along with the choice of audio recording the feedback or do it in hand writing. One nurse from this ward used the application for recording her feedback on the use of the follow-up plan. Her argument was contrary to the other nurses, that it was much *easier* than writing the answers in hand.

Lesson learned

Implementing ICT tools in a hospital setting can be challenging due to technical and organizational barriers. We implemented a feedback mechanism that took some of these into account by making it a standalone application easy to use. One critical challenge in this sample case, however, was the nurses' ambiguous stance toward the smartphone and its application. At the workshop it was perceived by the nurses as a complication of testing the follow-up plan and the notion of voice recording itself was seen as uncontrollable because it is uneditable. For the nurse not present at the workshop the application was in contrast ideal. One lesson learned is that a feedback mechanism has to acknowledge different personal preferences for providing feedback and it should not be the single point of entry for feedback in situations where users prefer writing in hand.

Conclusion

As in much other clinical work, the use of a follow-up plan is fragmented and distributed in time and place. Thus, in order to support an evaluation of the use of this particular system, the clinicians ideally need to provide feedback at the right time and in the right place. That is when they encounter a point of infrastructure.

We have described how a feedback mechanism implemented as a smartphone-based application based on the concept of infrastructure probes can be part of an evaluation infrastructure. The purpose is to support clinicians in the easy collection of feedback in order to share knowledge, evaluate design goals and eventually generate ideas for how to improve the existing healthcare work infrastructure. Through the sample case we have also hinted at some of the challenges of doing so. Our experiences from earlier projects are that smartphones are still not an integral part of the work infrastructure within secondary healthcare, but that it is to some extent feasible to conduct investigations as long as the

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[1] The quotes in this paper, which have been translated from the Danish, have been edited very slightly for clarity in English.

phones are separated from the internal hospital network and properly introduced to the users. From the sample case our experience was that the nurses simply had different personal preferences for providing feedback which suggest that a successful feedback mechanism allow for different types of open input.

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Translating value-based healthcare into practice

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Abstract. In this paper, we report from an experiment into healthcare governance called 'new governance in the patient's perspective' (NG) initiated by a Danish Region. The experiment was inspired by principles of value-based health care (VBHC), and initiated to transform governance from a productivity-regime, allegedly incentivizing clinical conduct in 'perverse' and counter-productive ways, towards a new regime focusing on value for the patient. Pursuing this ambition the Region exempted nine hospital departments from activity-based financing based on Diagnosis-Related Groups (DRG), and asked instead the departments to develop self-chosen indicators to measure and account for 'value for the patient'. Drawing on the notion of 'translation' (Latour, 1987) we analyse how NG was put into practice in the departments, and how their indicators were accounted for. Relating to literature on performance indicators, our case seemingly confirms a well-established distinction between indicators for internal improvement vs. external accountability. However, in pointing out the dialogues facilitated by the indicators between the Region and the departments, this distinction is challenged. Our analysis provides inspiration for healthcare governance to think of indicators as means, not for purely data-driven governance, but for dialogical practices in which concerns with accountability and local quality improvement conflate.

Productivity, value, and performance in healthcare

In this paper we report from a three-year governance-experiment initiated by Danish Region entitled 'New Governance in the Patient's Perspective' (NG). Inspired by value-based healthcare (VBHC) (Porter 2009) the Regions intention was to transform healthcare governance from a strictly productivity-oriented regime to a value-based regime. The Region in charge of the experiment had for several years criticised the national system of Diagnosis-Related Groups (DRG) because it held hospitals accountable based on their levels of activity, disregarding whether their activities were right, in terms of health-value for the patient and cost-efficiency. DRG works by associating patient's diagnoses with pre-calculated costs of treatment, making productivity measurement and reimbursement based on the costs of each patient possible. Allegedly the DRG-system entails 'perverse' and counter-productive incentives. For example, since only one DRG-rate can be generated per patient visit, hospitals are incentivised to perform pre-examinations on the same patient on different days. Other examples are 'over-treating' or 'cherry-picking' patients in order to maximize DRG-value.

In the NG-experiment, the Region exempted nine departments from DRG-based reimbursement. Instead the departments were asked to develop self-chosen indicators through which to be held accountable, hoping that this would lead to the discovery of new indicators that would be both meaningful to clinicians and in alignment with VBHC-principles.

The loose framework for choosing indicators diverges from VBHC-principles, in which indicators are specifically to measure outcome (Porter 2009). We see this divergence as a specific and interesting 'translation' (Latour 1987) of VBHC, as it can be taken as an unfolding in practice of what VBHC might look like when developed and practiced from the clinicians' perspectives.

More generally, the critique of DRG's 'perverse' incentives and the consequent 'setting free' of clinicians to develop indicators, relates to broader discussions regarding the uses and effects of indicators in healthcare (see fx Kerpershoek et al. 2014) One particular issue, which is interesting to the present case, is whether indicators for professionals' use for internal improvement are also suited external accountability. Sceptics argue that performance information for internal improvement is too specific for external reporting, and in so far as this was to be externally reported and rewarded, incentives to game the numbers immediately arise (for an overview see Freeman 2002).

The following analysis shows how the nine departments responded to NG and how indicators were developed and accounted for to the Region. Based on our analysis, we discuss how NG on the one hand seems unsuccessful and naïve in its ambitions to make locally developed indicators the basis for governance and accountability, consequently supporting the distinction between internal and external indicators. On the other hand we argue that the indicators did facilitate a fruitful interaction between the Region and the departments, which might inspire future governance schemes to: (1) engage with the idiosyncrasies of local practices; to (2) rethink the role of performance indicators; and (3) to develop formats in which concerns with accountability and professional values conflate in mutually engaging relations.

Our analysis is based on interviews with the heads of the nine departments, observations of meetings between Regional staff and the departments as well as access to documentation and evaluation reports of the NG-project.

Translations of New Governance at the departments

Generally the departments welcomed the delegation of responsibility and authority to define quality indicators in accordance with their specific medical practices and values. Also they found the focus of the project on quality and value instead of productivity meaningful.

Most evident, however, was the refusal that NG and the exemption the departments from DRG-based reimbursement would constitute such a dramatic and paradigmatic change, as the Region suggested. They rejected the implicit assumption, which motivated the NG-experiment in the first place, that they should have been driven by the 'perverse' DRG-incentives. This was evident from examples of how the departments prior to NG had initiated changes causing a decrease in DRG-value but an increase in organisational efficiency and value for the patient. For example transitioning to ambulatory treatment, or guiding patients to choose rehabilitation before high-cost and (high-risk) surgery. The resulting decrease in DRG-value was coped with for example by scaling up production in ambulatories, by balancing out DRG-deficits and -surplus between hospital departments in dialogue with hospital management, or by revising patient journals for errors in diagnostic entries that generated a lower DRG-rate than the actual treatment justified. Thus for the departments the NG-project was not considered a novelty that radically changed the basis of their conduct, but rather an initiative that provided more leeway for the quality and efficiency agendas they were already pursuing.

Accordingly the indicators were not developed from scratch with a sole consideration of a future governance paradigm, but rather in a pragmatic manner by tailoring existing practices and agendas to fit the NG indicator-framework. Another circumstantial factor was the relatively short timeframe (3 weeks) for the departments to suggest indicators. Indicators were decided upon exclusively by the heads of the departments, and overall the majority of the 55 resulting indicators represented improvement initiatives that were either planned or already taking place locally at the departments irrespective of NG.

Here is a short example of an existing practice turned into an indicator in NG: A few months prior to NG, a department started an initiative allowing patients from the primary sector who experienced painful joints, access twice a week to a brief examination and clarification of whether the pains were caused by arthritis or not. The purpose was to improve collaboration with the primary sector and internal procedures for treating arthritis. Here NG became a timely and obvious opportunity to evaluate the initiative via indicators measuring the number of patients clarified at first visit. Other examples of indicators are reducing the number cancellations, comparing work-times across clinical teams, monitoring the number of patients receiving immunoglobulin at home.

Accountability: Translating the indicators back to the Region

The examples above serve to illustrate how indicators were locally bound to the departments in terms of their purpose and meaning. This made indicator-data far from self-explanatory for the Region, and it left the Region perplexed of how the myriad of local and idiosyncratic indicators would be conducive to their new governance vision. Unfit for aggregation and comparability how would these local indicators serve as meaningful accounts to the upper levels of the hierarchy, from hospital management to the Regional council?

NG did not find any solutions to these challenges, but as a part monitoring the progress with the NG-experiment, the indicators were indeed reported and accounted for to the Region. This accounting practice was of a dialogical kind rather than a standardized, data-driven kind: Regional staff members visited the departments twice a year for a status meeting. During these meetings, the departments explained their indicators, how and why progress or regress was made. Based on these meetings Regional staff members collaborated with the departments in writing evaluation reports to the regional council. These reports included a listing of indicators and performance data as well as contextual, explanatory information for each indicator. The reports also included qualitative accounts about how the exemption from the DRG-system had mattered locally. Obviously in these meetings and evaluation reports a lot of account giving was performed, and Regional staff played an active part in constructing accounts. The indicators facilitated these accounting-practices, not by constituting a ‘front stage’ of performance information to be assessed by Regional staff, but by facilitating structured conversations about the department’s efforts to improve quality.

Discussion: dialogical or data-driven governance?

As mentioned the literature on indicators points out internal improvement and external accountability as two distinct and mutually exclusive functions of indicators (Freeman 2002). One the one hand our case confirms this distinction, as NG was not able to build a system in which local indicators could be meaningfully accounted for to upper levels of the hierarchy in a standardised manner. Thus NG might seem unsuccessful, and perhaps also quite naïve, in its ambition to develop indicators for a new governance paradigm from the bottom-up.

However, as a part of the Regions continuous evaluation of how the NG-experiment played out locally, the indicators were successful in facilitating dialogues with the departments which provided the Region with a detailed insight to the manifold and hitherto only locally known efforts to improve efficiency and quality at the departments. Compared to such an insights in the departments' work, the Region's initial critique of how the DRG-system incentivised the departments in perverse ways, arguably represents a far more simplified and distorted view of the conduct and quality-efforts at play here.

Thus, although NG did not succeed in developing a new standardised system of indicators, the dialogue facilitated by the indicators in the process of the NG-experiment can in itself be regarded as a fruitful result, as it engaged the Region and the departments in each other's practices. This observation is not so much about the representative (in)capabilities of indicators, but about the kind of interaction they make possible between different stakeholders.

Therefore, we will argue that NG might indeed inspire how mutually engaging accountability-relations in a value-based healthcare paradigm can be developed. Crucially, this seems to require new imaginations of how accountability-relations can be developed and sustained: Imaginations that are not tightly harnessed to ideals of data-driven governance and self-explanatory data-flows that connects different stakeholders, but consider indicators instead as the things around which healthcare professionals and their authorities meet in a dialogue on performance and goals, and where quality is a shared matter of concern rather than a contested issue torn between interests of external accountability and local, professional values.

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Socio-technical Infrastructures for Healthcare Automation in NHS Primary Care

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Abstract. Automation and computerisation technologies are poised to impact some 47 percent of the U.S. labour market. While automation is typically seen as a threat to workers in many economic sectors, it is an opportunity in the current state of NHS England primary care and general practice services. The early findings reported here are from a recently approved research program that employs ethnography to understand the socio-technical interactions of all primary care staff. With a keen eye on the occupational roles, the tasks those occupations perform, and the tasks technologies perform. The concept of junction work is used to discuss opportunities for automation across different task workflows and occupational roles connecting to the infrastructure at each primary care research site. The project aims to better understand questions surrounding the social dynamics of adopting new technologies, detail the existence of current infrastructures, and identify the key features that may resist automation or support the implementation of automative technologies into existing infrastructures. Early findings are from two health centres, one rural and one urban.

Introduction

Computerisation and automation are typically seen as a threat to workers in most industries because automation leads to reduced wages or layoffs. While automation may target vulnerable workers in many economic sectors, healthcare is one of the few areas in which automation is viewed as an opportunity; specifically, an opportunity in NHS England primary care system. Primary care faces numerous pressures including staff shortages, increased workloads, increased demand, reduced budget, skill shortages, and decreased time for patient consultations (Baird, Charles, Honeyman, Maguire, & Das, 2016; Hopson, 2016; Martin, Davies, & Gershlick, 2016). While automation may address these pressures in primary care, it will also reconfigure the work of all staff roles and change the patients' relationships with their general practitioners.

The pharmacist is one example of a health occupation reconfigured through decades of automation and computerisation technologies. Prior to 1970, the majority of a pharmacist's time was spent on distribution – counting and packaging pills. Between 1967 and 1970, the first portable, digital tablet counting device was developed by John and Frank Kirby in Manchester, England. Since 1970, the ability to automate pharmacists' tasks has expanded to measuring, mixing, handling, packaging, distributing, drug interaction alerts, and allergy warnings. This change has increased a pharmacist's scope of work to include more patient consultations, as well as consultations with primary care physicians, so that a pharmacist now requires greater technical skill. In fact, the Pharm. D. has become the required prerequisite for a career as a pharmacist (Angelo, Christensen, & Ferreri, 2005; "Pharmacist Scope of Practice," 2002). This example provides a clear perspective on the history of how a medical profession has responded to, and been shaped by, automation. The next important question is to identify how automation and additional digital technologies will reconfigure other professions in primary care and how automation will shape technical and social infrastructures within healthcare.

Using Junction Work to Understand Automation

Given the potential benefit automation technologies can bring to a troubled NHS England primary care service, I report on early fieldwork from a project that looks at opportunities and challenges to automation in primary care. The research design is organized into two phases. The first phase is collection of qualitative data by observation of all health centre employees – including during clinician and patient consultations – and assembly of these empirical data to richly describe general practice occupations, the tasks performed in these occupations, the skills required to accomplish occupation tasks, and the features of each task. The second phase of the project involves translational work to convert these qualitative data into quantitative expressions to ultimately understand the probability of automating each specific task. Both phases are intended to provide insights into the challenges and opportunities of automation in primary care, with a particular emphasis on the effect of automation on primary care staff work, and the potential changes to the patient-provider relationship.

I employ a socio-technical perspective in conducting ethnographic fieldwork to understand the work practices of staff and clinicians. Specifically, the objective is to identify tasks of work susceptible to automation and also the reconfiguration of staff work. Primary care health centres in England can choose to purchase one of four modern electronic medical records to help manage the overall practice and patient information. In addition to electronic medical records are a host of medical devices, sensors, and measurement tools to facilitate the diagnosis and treatment of patients. A better understanding of these technical infrastructures is key to effective automation support of primary care. To this end I employ the concept of junction work articulated by scholars Piras and Zanutto (2016). Junction work is the work that is performed to share data across systems that are not integrated or interoperable (Piras & Zanutto, 2016). The concept of junction work has been integral to understanding staff work because several occupational roles (receptionist, secretary) are almost entirely junction work related roles. Those two occupations consistently work across multiple systems moving data from one system to another. Another example of junction work in these occupational roles is using a clinical letter as a way to identify all the required information requested by a medical professional, and then assembling that information from multiple sources into a new letter. Many challenges remain in how these systems can or cannot be interoperable, what staff members use what technologies, and how the installed base of the primary care system may hinder new automation technologies (Star, 1999).

Preliminary results are reported from two research sites. The first site is a larger health centre in an urban setting with a catchment (surrounding area the clinic serves) of about 10,000 people. The second site is smaller with a rural setting and a catchment of about 4,000 people. As a data check, when the field researcher had a complete list of tasks for an occupation, that occupation was presented with the task list to confirm the data is an accurate representation of that occupations work tasks. Both sites use the same brand of electronic medical record (EMR) and many other systems that are required by NHS England for primary care clinics to use for reporting data and viewing contracts. These systems enable data sharing between the individual health clinics and various NHS institutions, and systems such as the Calculating Quality Reporting Service (CQRS) web portal. This CQRS system is one of several that practice managers use to share data about their patient population and services rendered for financial reimbursement. Overall, the specific tasks and workflows of each occupation remain remarkably similar between the urban and rural sites. The most notable difference is that GPs at the rural location type many of their own letters rather than dictate. Because of this, one of the major differences is that the rural health centre did not have a secretary. The secretary at the urban location was responsible for transcribing letters dictated by the doctors.

Early findings from both research sites indicate an overwhelming amount of, what I refer to as, letter work performed by receptionists. I focus on letter work because it is an example of a widespread practice performed throughout the primary care setting and is observed at both research sites. This letter work includes both writing letters to and receiving letters from other practices, secondary care, private parties, consultants, and other entities. The work to respond to and generate these letters is piecemeal, as it requires receptionists to scan in letters, import them into the document management system, and then assign tasks to different staff members based on the content of the letter. They also locate information across a variety of platforms including multiple locations in the electronic medical record, paper records, practice website, or intranet, and then place this information into a letter template. Receptionists are primarily responsible for letter work, but certain tasks may be delegated to other staff contingent on the actions requested in a letter.

The instances of junction work observed at both research sites are too many to describe here in detail. However, the most prominent example of junction work occurred at the urban practice where the workflow for digital letter management was the following: receive an email with a digital letter attached, print the letter out on paper, scan the letter into the digital document management system, and finally assign tasks and make the letter actionable across the EMR. In this event the receptionist is moving data (the letter PDF) from one system, to a physical format, back to digital, and then into a different information management system that would finally allow the letter to be acted upon.

Although junction work can be both disruptive to a practice or integral to specialized practices, in the case of this research the junction work observed is highly automatable from a technical perspective. The ability to automate the junction work from each field site is primarily an interoperability problem. It usually requires a staff member to exchange or share data from one system to the next. When the staff member was queried about why the letter process involved printing, scanning, and importing back into a digital format, the staff member did not know. The reason for the process was simply that the workflow had always been that way and it was how that type of work is completed. However, though the work can be automated through solving technical interoperability issues, changing the junction work will have ramifications for the occupations that once performed that work.

It is anticipated that automation technologies will reconfigure much of this junction work. One approach to automation of some of this junction work is through the use of a digital infrastructure that supports key characteristics of interoperability and integration of multiple types of heterogeneous work that occurs in the primary care setting (Ribes & Lee, 2010). It is important to note that every occupational role at both research sites used a desktop computer. While specialized technologies were used, they were only used by clinical staff. The greater the experience of the clinical occupation, the more technologies that occupation was qualified to use. The role of these technologies in a digital infrastructure is to reduce the junction work that is required to share data generated by the medical technology and back into the clinical record system. This preliminary work shows that certain infrastructural configurations lead to greater amounts of junction work performed by primary care staff and therefore present additional opportunities for automation. Although it is not always possible or desirable to eliminate each instance of junction work, this early research establishes that the concept of junction work may be useful in the identification and separation of task workflows that may be automated from those that may not.

Discussion

I want to end with a few discussion questions in regard to the empirical cases presented here. Clearly the many challenges and constraints that NHS England faces point to the fact that something needs to change. Aside from sweeping organizational and funding changes, the ability to "work smarter not harder" is change that can be implemented and potentially have a meaningful impact. How can, or should, letter work be automated? Communication across the health system is based on receptionists and GPs writing letters to each other. The reason for this is one part to communicate results and another part to create a paper trail of treatments, therapies, exams, and the documentation of the practice of medicine. So how can work be automated when the purpose of the work being automated is to coordinate different social actors and to create an audit trail?

Clearly, some junction work is inefficient: the previous case of printing digital documents and scanning them in to get those documents into a different digital document management system. Other junction work is either impossible to automate or is useful to help staff members understand aspects of their health centres function. Case in point is the practice manager moving data from the EMR databases to the NHS CQRS system. This task requires junction work, but through this junction work the manager can discover errors in payments, changes in the centres scope of work, and other critical details that amount to financial outcomes for the health centre. Theoretically this work could be automated since it is an interoperability problem. However, doing so would remove the social actor from error checking and learning about the direction of the health centre as a business. Given these two examples, how can we identify junction work that is wasteful and junction work that serves critical functions for the health centre?

Some junction work can be institutionally inherited and the person performing the work can be doing that work the way it has been conducted for years without considering how technology and other practices have changed. Given this, how can junction work that is institutionally ingrained be revised either when that work is automated or partially performed by social actors?

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PHR governance requirements leading to patient selection

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Abstract. Personal Health Record (PHR) projects have been supported in recent years by several health institutions. The aim has been to involve patients, the idea being that patients must become more significant in health infrastructure policy. The paper presents some results concerning a PHR system implemented in a region of North Italy. The system has been active since 2011, and more than 10% of the region's residents use it. The purpose of this paper is to highlight how an extensive PHR infrastructure planned for everybody has become an interesting "tool" for specific intensive health situations. Drawing on the results of 20 interviews with the most frequent users of the system, we have identified three categories of users: individual or family health controllers, therapy driven managers, and complex illness managers. These diverse ways to adopt the infrastructure only partially meet governance expectations.

Introduction

A PHR system is a web-based technology that allows all its users to manage, share, and access medical information. Originally it was conceived as a tool to keep a personal network of formal/informal caregivers active, but it was also considered an instrument to help create a new doctor/patient relation (Markle Foundation 2004). Despite this optimistic scenario, however, PHRs have developed a complex new scenario among health infrastructures. Healthcare managers and policymakers, the main sponsors of PHR systems, are convinced that a design for all patients should be the main aim. The economic crisis in Western societies has generated two opposite effects regarding eHealth investments. On the one hand, governments are investing in more efficient infrastructures for health systems, often supporting centralization and connections among many different systems. An opposite effect is the proposal of extensive infrastructure projects that unfortunately reduce the interest of citizens who use them (Greenhalgh *et al.* 2010). Recent studies exploring the evolution of these systems suggest that design has often failed to give a new functional infrastructure to basic and common services. It has more often happened that some functionalities have been adopted, but only a few patients have used them. Or people simply do not find the system useful for what the design was developed to achieve, and use it for other purposes. As Davidson and colleagues (2015) have shown, PHRs have shifted their objectives from a general and nationwide approach to single issues and single medical institutions. Similarly, PHRs have changed from being communication tools intended to enable close interactions between patients and doctors to more distant monitoring tools. As stated by Piras (2016), the patient side in data management displays a range of many different things like "Patient-Generated Health Data", "Observations of Daily Living", and "Personal Health Information Management". This is one of the reasons why, after the adoption of PHRs system, something in the field has changed and we can observe some unsuccessful targets and the affirmation of other aims (Davidson *et al.* 2015). The paper explores how the changes incurred from the design phase until deployment and thereafter have intercepted the patient's needs, and which kind of data use has been generated by the interaction between patients and systems.

Empirical studies show that patients want to exercise control on their condition, and this purpose induces them to manage decisions in the first person, sometimes without consulting doctors (Civan *et al.* 2006; Halamka *et al.* 2008; Moen and Brennan 2005).

Infrastructures play a strategic role in this relationship. On the one hand, they allow people to access more information; on the other, they seem to reproduce the 'physical' world. This means that the infrastructure design is driven by the physical display of buildings, services and organizational hierarchies. Hence patients have new opportunities to use their data as the system changes the materiality and the flow of some services. But, they are again pushed to the periphery of the system and not involved in the design and implementation phases (Davidson *et al.* 2015).

Research design

The system discussed by this paper is a web-based PHR that has been monitored with a long-term program (2011-2016). The PHR is owned by the regional administration, and it was designed and developed by a publicly-funded Health IT Research Centre. The basic purpose was to replace the existing paper-based diagnostic tests delivery system, which required patients to return to the hospital to obtain their medical results. The PHR collects electronic copies (usually PDF) provided by all public or private sources of diagnostic tests, laboratory tests, diagnostic services, hospital discharge letters, and results from almost all medical services belonging to the regional public health system. Hence, when a health problem arises and the GP sends the patient for a medical test or specialist examination, after the access, the system usually sends all the results in this repository within a few hours and, at the same time, an alert by email. These alerts sent simultaneously to similar alerts sent to the family GP patient repositories. This solution, adopted by design, despite being appreciated, also generate some minor troubles. Patients, after they have received an alert, expect that their GPs have immediately had a sigh of them.

When patients access the system, they access a wide range of applications. They can view their tests, but also the payments procedure, the appointment booking service, a procedure to change the family GP. The system also allows users manually to insert other personal health information (i.e. drugs, temperature, blood pressure, intolerances, and other measurements provided by personally owned instruments). From this perspective, the PHR is also an instrument, and perhaps a symbol, of the local healthcare system built around the citizen/patient (Halamka *et al.* 2008).

Among the population, after some institutional advertising campaigns which lasted over four years, the system was ‘opened and it has been used at least once by 60,000 people. For our research, we selected those who had used the system at least three times, assuming that theirs was not just ‘exploration’ but real use.

After a quantitative online questionnaire answered by 15,000 (50%) respondents, we decided to select 20 of the most frequent users for face-to-face interviews, for the most part in their homes. Ten most active users were selected considering the entire system activity period (from 2011); five were selected in the previous year and five in the previous six months. It was important to consider both long term users and recent users to avoid any bias due to an intense use determined solely by a specific problem.

In the interviews, we asked the respondents to describe: i) how they interacted with the system, how complicated it was to start, what ‘help’ was provided, what future developments should be adopted, and finally how they felt as citizens involved in this system. Adopting a qualitative research design, we wanted to investigate perceptions and use of the system. We used a contextual interview methodology. During the conversations, we collected information on diseases, everyday use, tricks and problems resolved to adapt the system to their expectations. The project’s stakeholders were also interested in monitoring how much they appreciated the functionalities, and what new functionalities were most expected. We recorded all the interviews, and the transcriptions were analyzed using the template coding method (King and Brooks 2015).

‘Personal’ challenge versus ‘public’ designed infrastructure

The first finding of the analysis was that, as the monitoring progressed, patients using the system did not precisely represent the population of the region. Indeed, most of them were well-educated or affluent persons of high social status. As regards the distribution of ages, the system’s users were overrepresented in ages around forty, underrepresented in youngest and oldest ages, and overrepresented in the central ones. After a general quantitative account, we started to code the transcriptions. Working with the excerpts from the interviews, we identified a typology of three non-exclusive styles of use.

1 *Individual or family controllers*. These users were interested in the system mainly in order to have constant access to diagnostic tests made available by professional providers through the infrastructure. This style was associated with the need to control bodily parameters on a regular basis, especially when patients had to be monitored and the burden was shared among several family members. For example, this was the case of elderly patients managed by sons and daughters responsible for conducting simple analyses to monitor the situation. Such users probably represent those who fitted the original purpose of the design. Once system access was established, it became an everyday service and a tool to organize health assistance. These users appreciated the functionalities and every new feature of the system. Moreover, it is significant that this enabled them to avoid intense relationship with health professionals.

2 *Therapy driven managers.* These users had severe but stabilized illnesses. The role, performed by these users, is to be continuously working on a specific therapy. Some used the system to check blood viscosity, for example after heart disease, to understand and establish a regime of medication to stabilize and improve their health. Usually these users considered the system to be a specific tool (like a thermometer). They were not interested in adding personal data to the system, since the functionality was well accepted and combined with new practices developed around the technology by health professionals and patients alike. There is evidence that patients, in this way, are happy to be in contact with professionals and can suggest drug management to doctors themselves. In addition, the system is often able to help geographically dispersed families to share information on relatives.

3 *Complex sickness managers*. This group of users comprised patients suffering from severe illnesses who required intensive treatment. These patients’ illness affect also family relatives. Quite often if someone was suffering from cancer, or a complex pathology, especially with ambiguous symptoms, the system became a ‘working-around platform’. Users collected diagnostic tests to ask for a second opinion, or to monitor the development of unexpected symptoms. What is quite clear is that these users were not at all satisfied with some of the system’s

functionalities. In fact, as a regional public infrastructure it is not connected with other regional health systems. Only recently has a national mandatory protocol required every regional infrastructure to provide specific parameters to help systems share information. This evidence from the field shows how systems are adopted and integrated into practices. On looking closely at these practices, objects seem to change their functionalities and relevance to patient trajectories between different infrastructures.

Discussion and conclusions.

Data management is related to infrastructures in the sense that the latter require peculiar work by the patients. Moreover, their presence and adoption by users change the perception of both health system performance and quality in therapy management. The infrastructure used changes knowledge of health practices and health systems. Although administrations are looking for the 'true' PHR with which to innovate the health system, it has been found that infrastructures are knowledge sensitive and require skills for autonomous data management (Fortin and Drazen 2012). This is the reason why selected users from the general population play the most active part (Halamka *et al.* 2008). Day-to-day requirements are easier and simpler if an infrastructure can simply reduce the waiting time for a diagnostic test. As Moen and Brennan (2005) have shown in this regard, specific treatments are considered as less important than data. A patient considers it much more important to stay in close contact with his/her health data after, for example, a medical test results than a specific access to a visit for a treatment.

As we have seen, the implementation of this regional patient-centered infrastructure engenders new patient practices, whilst offering different services - mainly to patients requiring intensive treatment. When interviewed, patients talk about a more positive sense of wellbeing, simply because they have a quicker access to their health data. This confirms the idea that general infrastructures are not the best representation of users. What Greenhalgh *et al.* (2010) have understood from the NHS, become here clearer. Patients consider data something personal, to use personally and to build a composite identity when a sickness incurs. The population should be divided into specific target-groups, to help everyone with specific functionalities (Butler *et al.* 2013). Some users are interested in "simple" services such as fast access to lab tests or general advices on wellbeing. More intensive user are interested in dedicated functions to monitor specific symptoms whilst realizing more effective progress in their diagnosis investigations. Specific design of these infrastructures should be addressed to open connections to players, enabling them to generate tools for auto monitoring or to analyse eligibility to screening programs (Davidson *et al.* 2015).

A final problem is one relevant missing actor in the scene. These infrastructures are putting aside the general practitioners. There is no strategy to share information between their medical programs and this public infrastructure. A sort of alliance has been developed with specialists, as they need fresh data always to set the therapies. It seems nothing like what GPs want to do with this infrastructure. And so far, Governance is still concentrated on specific ‘vertical’ performances (systems requirements) and specialist treatments.

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Taking care of sensitive milieus: a story about dialogical interviews

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Abstract. To be engaged in design processes in healthcare organizations often implies to deal with sensitive contexts, which, in turn, deal with a unique and delicate emotional setting. In this paper, we address reflections related to our research experience adopting dialogical interviews in sensitive design contexts. These reflections arise from a field work carried out within a network of nursing homes, within which we conducted 27 dialogical interviews with family members of patients in severe end-of-life conditions. With this contribution, we want to address the importance of taking care of the human relationships while working with sensitive participants, as a way to comprehend to which direction the design of a new technology should be driven.

Our fieldwork

The work presented in this paper represents only a part of a broader ongoing project financed by the Province of Trento, Italy (Di Fiore et al., 2017), which aimed to provide a picture of the relational issues that occur between the care professionals and the relatives of the residents of a network of six Nursing Homes (NHs) located in the province of Trento. The project was conceived to explore the potentials of ICT solutions in supporting communication between the professionals and family caregivers.

The initial idea was to comprehend how technologies could tear down the boundaries that often hinder the communication between family and professional caregivers. NHs, as healthcare contexts, where conceived as based on a mere exchange of medical information (Storni, 2010) and, therefore, the quality of the communication was considered correlated to the ability to deliver reliable and rapid medical information to relatives. Hence, the project believed that a better communication would have been allowed by an improved way of transmitting medical information to the relatives; this would have helped to improve the quality of the human relations between professionals and families. In addition, it was expected that a clearer understanding of the medical situation of a resident would have decreased the level of emotional distress that the relatives often experience (McFall & Miller, 1992). Conversely, a system that allows users to automatically deliver real-time medical information, was expected to help care professionals to better concentrate on their tasks and decrease their level of stress, while informing relatives on what is necessary to know (Hazelhof et al., 2016).

Despite the initial ideas - now fallacious - which drove to the design of the project, we structured the research to have first a "gaze" within the context of the NHs, in order to comprehend how to approach and enter the field. We aimed to explore the context we were about to study by comprehending how it was experienced by the families of the relatives. Therefore, we first conducted 27 dialogical interviews with family members of the network of the six NHs.

The dialogical interview is conceived as a dialogue based on reciprocity, a process where the interlocutors are *immersed in the relational flow*, finding a balance between staying focused on the outline, and open to interviewees' human needs (La Mendola, 2009). Our interviews aimed to explore the reality and the daily routine within the nursing homes, and also to comprehend the logistical and communication problems experienced by professional caregivers and family caregivers. The interviews also served to understand to which extents, if really needed, a technology could solve the relational issues within the NHs.

Our preliminary study led us to comprehend the nature of the issues that affect the relations between the care professionals and the relatives. Differently from what initially believed, the relatives lacked a "listening space", and this, in our design framework, shed light on different ICT potentials.

In this paper, we refer to how we took care of the relational settings, conducting the interviews. In particular, we stress the importance of our experience in helping us to better frame and understand the issues that emerged from the interviews.

Experiencing dialogical interviews in sensitive contexts

Working within delicate contexts like nursing homes, we encountered several difficulties that challenged our capabilities as researchers, as well as human beings. On the one hand, we faced a strong emotional attachment to many interlocutors and to their stories. On the other hand, we often questioned the possibility to gather concrete data that could inform our research and support our design process.

As mentioned above, we conducted 27 dialogical interviews as part of an exploratory study to evaluated the feasibility of the design process we aimed to accomplish. The interviews were built on a guideline that focused on investigating the communication and relational issues that the family caregivers experienced in relating with the staff members. In particular, the guideline considered how the family members approached and dealt with the transition from being the primary caregivers f their loved ones, to visit them in the nursing home, sharing the care activities with the staff members. Specifically, during the interviews we focused on the following topic: *i*) the history that led the family caregivers to draw on the NH; *ii*) what is their relation with the staff; *iii*) if they have any relation with family caregivers of other residents; i*v*) how they manage the medical information; *v*) their ICT literacy; *vi*) changes they would like to have within the NH.

We interviewed the relatives who agreed to participate to our invitation, and the interviews were conducted within the NHs where the relatives had their loved one hosted. Each interview was conducted in a private office by only one of the researchers who participate to the study. The interviews were recorded and transcribed. Each interview lasted approximately one hour.

From the interviews, we understood that the detachment from the loved-ones creates a deep distress (McFall & Miller, 1992) in the family caregivers, hindering also the possibilities to establish positive relations with the staff members.

During our research experience, we somehow let the context drag us into the overwhelming nature of feelings and sentiments that the family caregivers experience. Although the interview guideline focused on communication issues, most of the interviewees displayed a need to talk about the experience of detachment from their loved-one, talking with us about their sense of guilt and burden. Despite our research purposes, we experimented the willingness of the interviewees to open up to us, due to their need of personal space where to be listened. The interviewees approached the interview almost as a way to open themselves on matters they could not discuss elsewhere. Because of this, we had role issues, struggling to be researchers and empathetic humans at the same time. Sometimes we even felt inappropriate to extrapolate *cold data* from their stories. As researchers, we had to approach the "talk" as a way to gain new information, but as human beings we were reconsidering our "role". Hence, we needed to create a safe place within which we could safely interact; the relation between us and the interviewees was approached as a human-to-human dialogue, rather than a hierarchical perspective researcher-interviewee. The interviewees who participated welcomed us within their private lives and shared their experiences, their feelings, and fears with us; we received the privilege to be considered worthy and trustworthy listeners. Conversely, we had the responsibility to comprehend, accept and keep these information as our own, and we could not avoid to be shocked by the often-difficult experiences interviewees shared with us.

We *took the side* (Becker, 1966) of the interviewees having a dialogue with them, without passively receiving their information. We understood that to better comprehend what they were trying to share, we had to put ourselves in their position with a reciprocal sharing process. We delivered something back that could correspond, and shared our own care experiences in a way that they could perceive our being human before researchers.

However, this does not signify that we interpreted the role of the peer over our intrinsic nature of researchers. On the contrary, we freed ourselves from the mask of the researcher to reveal ourselves as human beings as the interviewees did. In this way, we had the opportunity to feel more attached to the stories of our participants and to the related data, perceiving them as *warm data*. Hence, we had to grasp the perspective of the interviewees embracing their narrations without imposing timespan within the interviews and conceiving the topics of our guideline as flexible, in order to give more space to our participants' stories. In this way, we have been in touch with their experiences as we experienced them ourselves, rather than consider them from a perspective immune from any sort of emotional involvement.

Taking care of sensitive milieus

With this paper we attempted to restructure, as researchers, what we experienced and comprehend as human beings. Previous works on using qualitative methods in sensitive contexts already cover a wide range of topics, such as managing emotions (Rager, 2005), and detachment from the field (Morrison, 2012). Yet, we tried to convey the necessity to reconsider healthcare contexts as rich of information that cannot be treated as source of *cold data*. Contrarily to what the rationalising trends are telling us (Traweek, 1992), as researchers and human being we have to keep in our minds how doing research, especially in sensitive healthcare contexts, is all about *taking care* of others' stories. In this scenario, in accordance with Light & Akama (2014) we understood our engagement in sensitive milieus as a form of *carework*. We distinguished the concept of care from a paternalistic sense of caring, conceiving it as a way to entangling our experiences with others, or using Puig de la Bellacasa's (2012) words, as a way to do sustainable actions by engaging "with the inescapable troubles of interdependent existences" (p. 199).

Researchers involved into healthcare milieus, are likely to deal with sensitive research settings. Since sensitive milieus are emotionally powerful, they can bring aftermaths that shake both the participants and the researchers themselves (Jones, 2013). Sensitive contexts can be hard to approach, especially in absence of previous experiences in such contexts. Indeed, Dickson-Swift (2007) highlight the need of care professionals to deal themselves with these sensitive contexts. The authors explain that, often, care professionals develop their own strategy to cope with the emotional distress that sensitive contexts may bring; care professionals protecting themselves by becoming insensitive to certain situations, perceiving them as *bizarrely ordinary*. On the opposite, as outsider in these contexts, we have been emotionally *thrown* into them, absorbing - sometimes too much - the distress and discomfort of the family caregivers.

In this work, we addressed our research experience in conducting dialogical interviews with relatives of critical end-of-life patients. We focused on taking care of human relationships by appreciating reciprocity when adopting qualitative interviews. This preliminary study highlights how important can be to open dialogical spaces, reflecting on the role that researchers should play within healthcare contexts. We discovered that approaching the interview guideline with flexibility helped us to focus on the stories of our interlocutors, giving space to the difficulties and the memories that for them were important to share. Thus, we had the opportunity to be more connected with their sense-making and understanding of the care settings in which they were involved. On the one hand, the interviewees approached the interviews as an opportunity to be listened and momentarily relieved of their burdens. On the other hand, by accepting our participants stories we had the opportunity to go deeper into their care experience, and reshape the initial design concept at the base of our project.

This approach allowed us to take care of this sensitive context by fulfilling the need of being listened of the interviewees, and by using their narrations to adjust the rationale of our project. In particular, throughout the interviews, we had the possibility to comprehend the hidden need of the family caregivers to establish better relations and more sensitive communications with the professional caregivers of the nursing homes.

Conclusion

Our reflections want to be memorabilia for both the novices that are facing such contexts, for those who are working there for some time and that need to remember the privilege of entering such unique others' lives, and also for us, the authors, grasping thoughts on our present experience and leaving a memento for our future ones. Indeed, "we are engaged in important, difficult research, but we must keep the purpose of our work in mind. What we do is significant and makes a difference for those who follow" (Morse, 2007, p. 1005).

Our experience in using dialogical interviews, shed a light on what was needed within the NHs context. The interviews made us comprehend that family caregivers lack a "listening space" rather than a better strategy to be kept aware on the health situation of their loved ones. What we learned is that to take care of sensitive milieus it is fundamental to create open dialogical spaces, providing a place where the participants can feel listened and accepted, and where we, as design researcher, can take care of their stories by shaping the design processing that will affect them. In our case study, this opened up to greater potentials for a new design. Indeed, we understood that a new technology should support the family caregivers in having better communication with the staff members through a dialogical experience, as the one we had experienced with them.

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eScience Insights to Inform Infrastructure for Accountability of Healthcare

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Abstract. Healthcare organizations and providers are being held accountable for the care they give and for their processes of improving care safety and quality to an unprecedented degree. In countries around the world, there is a pressing need to develop infrastructure for accountability of healthcare to support performance measurement and reporting activities. Yet, little research exists on the design, development, management, or governance of infrastructure for accountability in healthcare, nor on practices of data sharing and reuse that are central to healthcare performance measurement. This paper draws on literature on data sharing and cyberinfrastructure for eScience to identify key concepts from research on supporting collaborative scienctific practice to inform research on practices and infrastructure for healthcare accountability.

Introduction

Driven by flagging public trust, pressure to contain costs while increasing service quality, and re-organization of healthcare around industrial models, healthcare organizations and the individuals working within them are facing huge pressure to make healthcare practice transparent and accountable to an unprecedented degree (Wiener, 2000). Healthcare organizations and professionals have long been held accountable to acceptable standards for structure, process, and outcomes of their work (i.e. Donabedian, 1980). Yet, the particular form that accountability practices are taking is unprecedented in that they leverage digital information technology, including automated performance measurement algorithms and expanded capabilities for data storage, retrieval, and analytics (Dickersin & Manheimer, 1998).

The imperative for healthcare accountability has resulted in development of a massive ”machinery” (Wiener, 2000) to support the accountability endeavor. This includes regulatory agencies, processes for vetting and selecting performance measurements, third party vendors who collect and transmit performance data, new hospital personnel and new skill sets for existing personnel, a vast consulting industry, and so on.

A rich body of research has examined design, adoption, and use of electronic patient records (Fitzpatrick & Ellingsen, 2013). Although a major driver of electronic record system adoption is the promise of using data contained within these systems for second-order purposes including retrospective medical research and accountability functions, much of the research to date focuses on how electronic record systems impact clinical practice. Research on accountability functions of electronic records systems focuses on how such accountability functions impact in-the-moment clinical care (i.e. Bossen, 2011; Pine & Mazmanian, 2014). While other applied fields, such as education, have studied the development and unintended consequences of information infrastructure with an explicit focus on accountability functions (see Anagnostopoulos, Rutledge, & Jacobsen, 2013), little empirical or theoretical work focuses on the design, use, and unintended consequences of infrastructure for healthcare accountability and quality improvement.

In addition, at present there is a “problem of infrastructure” (i.e. Colombino et al., 2014) when it comes to healthcare accountability. Data is available—in a sense-- because it is increasingly collected, stored, and extractable via electronic record systems and other IT. Yet producing usable information from stores of potential data is still incredibly difficult. The situation is complicated by the fact that external accountability requirements are rapidly changing (Pine, Wolf, & Mazmanian, 2015) and healthcare systems around the world are implementing payment model reforms, specifically value-based reimbursement (Berenson & Kaye, 2013). European healthcare systems, despite largely providing healthcare through centralized and publicly funded delivery systems, are also struggling with the challenges of infrastructuring for accountability and experimenting with novel accountability practices (i.e. Bossen, Danholt, & Ubessen, 2015).

Insights from Research on eScience

As healthcare performance measurement and quality improvement theory and practice develop, researchers will benefit from drawing on existing research on supporting collaborative eScience. This rich body of work includes studies of ’cyberinfrastructure’ to facilitate the conduct of science: research on cyberinfrastructure for eScience is concerned with creation, deployment, and maintenance of tools for supporting scientific collaboration across distance. Another key line of research focuses on data sharing and reuse. As leading scholars argue, successfully engaging in data sharing and reuse is essential if science is to reap the rewards of the digital age (i.e. Borgman, 2015).

While there are some differences, the activities of assessing healthcare quality bear much in common with more traditional ”bench” science. Healthcare accountability tools and practices are vast and extend beyond the local, making an infrastructure perspective critical (Monteiro et al., 2013). Performance measurement, the basis of healthcare accountability practice at present, rests upon a supporting infrastructure that enables data to be “…acquired, collected, sorted, analyzed, interpreted, and disseminated” (Ratnayake, 2009, p. 158). While performance measurements for accountability require collaborative data collection, management, sharing, and reuse (Pine & Mazmanian, 2016), the nuanced complexities of these collaborative practices are largely overlooked in design of healthcare information systems and data analytic tools employed for healthcare accountability. Next, I outline some key concepts from the eScience literature on cyberinfrastructure and data sharing and describe how each concept is useful for research on healthcare accountability infrastructure and practice.

Key eScience concepts applied to healthcare accountability infrastructure and practice

Data provenance. Provenance refers to the chain of custody of data and the transformations that data undergo as they pass through different hands. Tracing custody and transformations makes datasets more useful (Borgman, 2015). Performance measuremens for healthcare typically utilize data elements drawn from administrative sources such as billing data or birth certificate data. Such data is often already a transformation of clinical data, and is not collected with performance measurement in mind. Billing data, for example, maximizes financial gain rather than clinical truth (Pine, Wolf, & Mazmanian, 2015). As accountability infrastructure develops, it should support custodians of healthcare data in recording and easily tracing the data’s lineage.

Background and foreground data use. In the process of doing research, researchers do a number of activities which may include calibrating instruments, assessing site conditions, or verifying measurements. Such activities often involve existing data from archives or repositories, but data reuse is often in the “background” of research (Borgman, 2015). Researchers of healthcare quality and accountability would benefit from paying explicit attention to background data reuses. At present the various sources of data that are reused in the process of calculating performance measurements are poorly understood, particularly by those that are being evaluated according to the measurements. Making the background data reuses part of the everyday discourse about performance measurement in healthcare organizaions and healthcare quality research would improve quality science and transparency of the accountabilty practices themselves.

Interpretation & trust of data is a crucial component of assessing the potential of a data resource for reuse (Faniel & Jacobsen, 2010). Successfully reusing data is largely dependent on social relationships rarher than technical tools, as users need to understand what data is available, the curcumstances under which data were collected, and the trustworthiness of the data (Faniel & Jacobsen, 2010). In healthcare, breakdowns occur when social relationships do not exist between key players in the lifecycle of data. For example, low-paid clerks may not have mechanisms to query questionable medical chart data or opportunities to discuss documentation practices with clinicians even though the data they record based on medical records produces key data elements for performance measurement (Pine & Mazmanian, 2016). There is a need for research on the social relationships and organizational structures that would support data reuse for healthcare performance measurement.

Knowledge infrastructures. Knowledge infrastructures (i.e. archives, collections, data systems, databanks, information systems, repositories) are considered common pool resources by Borgman (2015). Common pool resources require governance relating to collection development policies, rules for contribution and access, classification standards and data structures, and plans/structures for sustaining the resource over time. Investments in governance are crucial; infrastructure for accountability for healthcare requires investments in human and technical governance structures. This will be particularly important as the stakes of healthcare accountability increase—a crucial question facing healthcare organizations is how good must data be in order for it to be used to sanction a healthcare provider?

Bridging communities of practice. A challenge of data sharing is imposed by the difficulty of communicating the meaning of data and understanding what is happening in another's dataset when data is being shared across different communities of practice. A ”community of practice” (CoP) is a group of practitioners who have a shared passion or engagement in something and engage regularly over time (Lave & Wenger, 1991); in the domain of work, communities of practice can refer to different occupational groups. Healthcare accountability infrastructure and practices must bridge multiple CoPs: clinicans, educators, administrators, regulators, etc. Cyberinfrastructure for eScience literature offers a number of useful concepts ripe for study in infrastructure for accountability of healthcare, such as boundary objects (objects that inhabit several communities of practice and satisfy the informational requirements of each of the communities they inhabit) (Bietz & Lee, 2009). Further, it is incumbent on researchers and other stakeholders to place explicit attention on CoPs to understand which of multiple

CoPs perspectives, interests, and values are prioritized in healthcare accountability infrastructure and what the potential consequences of these decisions will be.

While there is much to be gained from looking to the eScience literature, there are some aditional considerations that researchers must take into account. Since performance measurements are tied to systems of reward and sanction and embedded in organizational and national policy, the social and political stakes of healthcare accountability are quite high. Also, most stakeholders of healthcare accountability are engaged in clinical practice or support services as their primary activity—quality science is a shadow of this primary work and can all too easily interfere with it (Bossen, 2011; Pine & Mazmanian, 2015).

Conclusion

Healthcare organizations are facing huge pressure to make healthcare practice transparent and accountable to an unprecedented degree. Yet, little empirical or theoretical work focuses on carrying out data-intensive healthcare performance measurement on the ground. Existing literature on conducting large scale eScience, including data sharing and cyberinfrastructure for supporting scientific collaboration, offers valuable insights for healthcare accountability stakeholders (i.e. researchers, managers, designers). Specific concepts drawn from eScience literature that could be fruitfully applied to healthcare accountability and quality science include: data provenance, background and foreground data use, interpretation and trust, knowledge infrastructures, and bridging communities of practice.

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Infrastructuring primary prevention outside healthcare institutions: the governance of a Workplace Health Promotion program

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Abstract. Workplace Health Promotion (WHP) programs are undergoing significant changes mixing the healthy lifestyle promotion with the self-tracking opportunities offered by digital technologies. The shift to more pervasive (or intrusive) forms of primary prevention for chronic diseases requires to justify the existence of healthcare infrastructures in work settings and a redefinition of the role of employers and healthcare institutions. The paper describes and analyses a WHP initiative conducted in Italy to illustrate the infrastructuring of the governance of technologically-enhanced prevention in the workplace.

Introduction

“Workplace Health Promotion” (WHP) is an umbrella term used to designate programs whose aim is to improve lifestyle and consequently improve health, work ability, and work productivity. WHP complements “Occupational Safety and Health”, which aims at creating a safe work environment, and fosters primary prevention programs mostly focused on promoting healthy eating habits and physical activity. Several studies have shown that health and wellness programs in the workplace can reduce risk factor profiles both in apparently healthy individuals and in those at high risk of cardio vascular diseases (Arena *et al.* 2013). The underlying assumptions of WHP programs is the recognition of the underexploited potential of promoting a behaviour change in a confined space and the possibility to leverage on the resources offered by the organizational setting.

While WHP programs are not new and date back as far as 30 years (World Health Organization 1986) there is a growing interest in recent years in the light of two major changes. On the one hand, health care systems are facing budgetary restrictions for prevention programs and see employers and workplaces as potential allies. On the other hand, data gathered through mobile and wearable technologies allow to imagine new forms of health prevention. The combined effect of such changes has paved the way for WHP programs designed to address primary prevention and thus complement or even replace services which should be offered and managed by healthcare authorities. Several new WHP programs (see Masson *et al.* 2016) now do not merely act on vending machines, canteen, or physical activity promotion in general but combine these actions with forms of imposed self-tracking (Lupton 2014) which make use of digital technologies.

The involvement of employers in the field of primary prevention raises several issues regarding the legitimacy of organization to promote health, misuse of sensitive data, discrimination of vulnerable segments of population (e.g. unemployed) just to name a few. These issues are part of a broader redefinition of emerging forms of governance of health prevention and behaviour change promotion as new actors come into play, old actors play new roles and technologies are designed and integrated.

We argue that the analysis of technologically-enhanced WPH programs could furnish an interesting empirical field to scholars interested in healthcare infrastructures. Despite the IT components and the coordination needs are far from being as complex and multi-layered as the ones found in healthcare institutions, the installed base, which includes also the existing institutional and organizational components and arrangements (Chae and Lanzara 2006), creates a challenging environment to study the process of infrastructuring and the inter-institutional negotiation, collaborative practices and concerted action needed to create room for the IT infrastructure (Karasti *et al.* 2010).

The research question is thus, how do infrastructures designed for health or clinical purposes find a legitimate space in the work setting? How is primary prevention governance infrastructrured outside the healthcare institutions?

The case study: infrastructuring the governance of prevention

The paper reflects on the aforementioned issues through a case study regarding the process of design and implementation of an ongoing technologically-enhanced WHP program in a 500+ people research foundation based in Northern Italy. Authors have been involved, with different roles, in the design and management of the WHP program. The research has flanked each step of the process. The first two authors attended the project meetings with stakeholder (both internal and institutional) and the design team for 18 months and conducted 5 focus groups with employees to explore their representation and acceptability of the WHP program. Notes were taken during meetings and focus groups were transcribed. Data was coded through a content analysis; the segmentation of text had the primary purpose of breaking down the process and identify relevant stages.

The WHP program originated from the idea to push the boundaries of existing experiences in the field of health workplace initiatives targeting workers at risk of developing cardio-vascular diseases and/or type 2 diabetes, two chronic conditions whose onset is strongly correlated with lifestyle.

The WHP program was meant to test the applicability in a work setting of a remote monitoring platform used to manage several chronic conditions (e.g. type 1 diabetes, home chemotherapy) (Piras and Miele 2017; Galligioni *et al.* 2015). The platform, a web dashboard for clinicians and mobile apps for patient connected with activity trackers, is endowed a specific software component designed for the WHP program, a virtual coaching system to provide nutritional recommendations based on the Mediterranean diet principles (Bailoni *et al.* 2016).

In the next pages we shall describe the evolution, refinement and finalization of the outline of the program from its draft to its final version. We identified three phases, each requiring the involvement of new actors, new requirements and arrangements.

First phase: tech refining and the discovery of the institutional complexity. The first draft of the program was conceived by the research group and the occupational physician of the research foundation. Unlike other WHP programs, its target was not all the working population but only those at risk, to be identified administering a standardized questionnaire for risk assessment. Twenty workers would be enrolled in the program prioritizing those with higher risk score and on a strictly voluntary basis. The intervention was planned to last 6 months and consisted on a mix of virtual and human coaching provided by the mobile application and a counsellor. Physician was in charge of defining a set of parameters to be measured at baseline and at the end of the program to assess the efficacy of the intervention.

This program envisioned a slightly modification to the existing technical platform, mostly regarding the customizing of the mobile application for dietary recommendation and the integration with the IS of the canteen to feed the application with the menu of the day.

As the program started to get drafted, the need to involve stakeholders in the refinement was felt. The mapping of the potential stakeholders revealed that there were a significant number of organizational units and external institutions to be involved in the process so to strengthen it. It was thus decided to create two separate working groups running in parallel, one internal and the other inter-institutional, both coordinated by the research group.

Second phase /1: internal working group and the employees

The internal working group involved the Prevention and Safety department, the Communication department, Human Resources, the internal Recreation & Leisure Club, and the unions. From different perspectives each of the newly involved stakeholder pushed for a more inclusive and "universalistic" approach.

The need to extend the program was particularly felt by HR which considered the initiative as yet another form of occupational welfare to be offered to the largest number of employees. This vision was shared by employees involved through focus groups: in their representation the WHP program was to be put alongside other services offered to workers and available to anyone such as the parcel drop service, the summer camps for kids, the laundry and ironing service. Both employees and representatives of Recreation & Leisure Club noted how the first draft of the program targeted the individual worker and suggested it to be complemented with actions to leverage the informal social relations among workers by promoting group activities. Other stakeholders, namely unions and Prevention and Safety department, stressed the need to ensure rigorous policies regarding data collection and privacy.

The internal working group activities led to a significant change of the whole project. The clinically-oriented prevention program drafted in phase 1 (hard program) was flanked by a well-being program without clinical supervision, consisting on the use of the mobile application plus health cooking and low-impact exercise course organized (soft program).

Recommendation from internal stakeholders modified some technical requirements of the platform to anonymize data gathered through questionnaire and the application. This required some significant work since in the clinical trials the research group was allowed to access all data produced by patients.

Second phase /1: inter-institutional working group.

The inter-institutional working group involved representatives from the provincial government, the local healthcare authority and the public National Institute for Insurance Against Industrial Injuries. These partners were included to strengthen the initiatives leveraging on the credit they enjoyed in the field of primary prevention. These stakeholders considered the WHP program as an opportunity to test new partnerships to promote primary prevention and a pilot test of a larger scale application of the initiative. The aim of the working group became to create a 'model' to be subsequently applied to other working settings.

Stakeholders role changed over time as they co-financed the initiative both in monetary terms and in kind (e.g. the counselling service for the ‘hard’ program was provided by local healthcare authority). Moreover, representatives of stakeholders promoted the initiative within their professional networks and in their organization. As a result, a branch of the local government and the local healthcare authority expressed their interest in activating a similar program even before the pilot test started.

Third phase: technical adaptation

While the design of the technical platform started with the beginning of the project, the requirements emerged from the involved of the stakeholders required ongoing adaptations. The platform was integrated with the canteen IT but other integrations with the research centre IT systems, while technically feasible, were not performed. The introduction of a clinical infrastructure in a work setting required to find ways to avoid any unwanted access to sensitive information by any member of organization. For example, it was decided not to integrate the platform to the authentication system to preserve the anonymity of the data. This and similar issues were mainly solved creating workarounds to allow the research group to manage the platform without being able to associate data to the individual worker and providing access to the physician.

Discussion and conclusions

In this paper we have limited our analysis to the design of the WHP program, from its first ideation to the start. This time frame has allowed to observe the processes through which primary prevention comes be defined a legitimate organizational purpose in a non-clinical institution. This involved the co-construction of arrangements between all actors involved and the technical platform. Both the technologies and the actors involved are redefined in a process that modified their roles and their technical features.

Healthcare institutions and local government, with limited resources to do perform extensive primary prevention, find a new role as experts in support of programs run and managed by employers. In the process the pre-existing healthcare infrastructure had to be modified to accommodate to the specific setting and to ensure higher standards of data protection and privacy. However, the acceptability of such intervention depended on its symbolization as a part of a larger initiative of occupational welfare open to all the members of the organization. The preliminary findings suggest that a WHP program targeting only high risk workers could have insufficient legitimation and that it could be necessary to promote other, more inclusive, initiatives to foster the acceptability of the primary prevention initiative.

This paper offers a glimpse into a possible trend in the evolution of primary prevention as it becomes less a strictly healthcare issue and it is performed in unruly settings. As we have tried to show, primary prevention cannot be simply delegated to employers but it requires a change in how it is governed and a redefinition of roles in a broader network. The governance of prevention itself is not the result of a display of rationality but rather the emerging product of the local and contingent negotiations that builds of the inherited features and constraints of the sociotechnical installed base.

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Examining practices for remote care in in different infrastructural configurations

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Abstract. In this paper, we report from ongoing research on two cases on the use of telecare solutions for remote patient monitoring in Norway. Our analytical focus is on the practices of the nurses working in the remote care services and how the practices relate to the infrastructural configurations in which they are situated. By infrastructural configuration we refer to the organizational structure, service design, and technological solution. Specifically, we focus on three aspects emerging from the analysis of nurses' practices: the interrelation of care and coordination of work, the fragmentation of information and the constitution of patients.

Introduction

In the last decade, telecare systems - information and communications technologies linking people at home to health care services - have been promoted as a technological solution for problems of access to care and increasing health expenditures. Telecare solutions allow people with chronic illnesses to be remotely monitored at home, enabling the identification of early signs of health deterioration, and allowing the prevention of hospitalization. However, this approach to care has challenged traditional health services, which predominately target acute and episodic care, creating uncertainties in adoption and integration to existing care services, and leading to slow and uneven implementations (May et al. 2011). Moser and Tygesen (2014) argue that such processes are demanding and conditioned by dialogue, involvement and negotiation as well as flexible and adjustable solutions. They propose to understand them as a longitudinal, multilinear and learning processes. In addition, Pols and Willems (2011) point out that telecare technologies "cannot be regarded as a finite 'intervention'" and technologies should not be expected to work in a pre-defined way. Thus, this literature emphasizes the complex and open arrangements in which telecare solutions are situated. In this study we want to build on this line of research to examine the implementation of telecare technologies for remote care in relation to their *infrastructural configuration*. By infrastructural configuration we mean the relation between service design, organizational structure and technological solution in which telecare is situated. Previous research on telecare technologies for remote care has to a large extent focused on how specific interactions and relations have changed, for instance relations between patient and devices, patient and health personnel, and patient and service. These relations, however, do not exist in isolation, but are part of larger arrangements and nexuses of health-related practices.

In this study, we address the following research question: *how are remote care practices shaped by different infrastructural configurations*? We address this question based on the empirical study of two telecare projects. In Norway, telecare solutions in the homes are currently being implemented according to a new service model where remote monitoring centers are created in municipal care. We have examined the novel monitoring practices of nurses working in the remote monitoring centers. In the center, nurses monitor and analyze data and take follow up actions as appropriate. In this context, the use of remote care technologies proposes a proactive approach - a model where health professionals (i.e. nurses in the remote care centers) rather than being in control of the patient's situation and telling patients 'what to do', guide patients in understanding their own conditions and enabling them to take actions themselves. This model entails the need to develop practices and systems that support nurses in knowing when and how to guide patients. However, there are still many uncertainties and challenges related to the use of telecare technologies in proactive care and remote care, and our intention is to contribute to an improved understanding of these novel services.

In the following section we briefly present the case background and research methodology. We then describe the two cases (as city 1 and city 2) where we focus on the two different infrastructural configurations (organizational structure, service design and information technology). Our preliminary analysis is organized around three aspects that emerged from cross-analysing the nurses' practices in the two centers: the interrelation of care and coordination of work, the fragmentation of information and the constitution of patients. We conclude the paper by pointing to directions for further analysis and discussion of the cases.

Case background and method

In Norway, there are several ongoing governmentally sponsored pilot projects for remote care. In this research, we have conducted two case studies (Yin 2013) on two of the pilots in the national pilot program. Our research is designed as an interpretive in-depth case study because it is explorative and we aim to study an emerging phenomenon (Walsham 1995). The cases have been selected because they implemented the same information system for collecting and analyzing measurements from medical devices in the homes, and because they have a different organizational structure (public vs private center). The study started in September 2016 and is ongoing at the time of writing (May 2017). Data collection is based on interviews, observation and document analysis. Specifically, we have interviewed project leaders, nurses working in the remote care centers, and the management team of the vendor (HealthTech) of the information system. We have also conducted observation of work practices in the remote care centers, where nurses explained their work practices both in relation to the interaction with patients at home (via phone or using the remote care information system), and in relation to the coordination and cooperation in the center and across the other municipal care services.

Remote monitoring practices

Configuration 1. In city 1, remote care is organized in a new unit in municipal care, called remote care center, where two or three nurses work in shifts Monday to Friday. Patients are recruited to the program by the municipal care service, based on referrals from local hospital or municipal care assessments. When enrolled in the service, patients are usually visited in their homes by a nurse from the remote care center or by a member of a designated training team. During the visit, the patient is taught how to use the tablet and to take measurements with the devices by himself, and the devices are set up. While operating the center, the nurse sits at a desk in front of a computer and by the phone. To access and manage patient data, the nurse uses two systems: ProAct and the electronic patient record (EPR) system of the municipality. ProAct receives the data from the home devices of the patients in form of alerts, and the messages they send from their tablets. Each patient has a record in ProAct, and ProAct shows a dashboard where all recent measurements are displayed ordered chronology and by criticality (color coded according to personally set values). The second system is the EPR which is the medical record system used by all the health services in the municipality. It is a documentation system, but also a communication system. One of the functionalities offered is electronic messages (called PLO messages) between municipal care and GPs, and hospitals. For instance, when a patient is discharged from the hospital, a PLO message is sent to municipal care to inform about the patient's follow-up care. Most communication between nurse and patient happens per telephone.

Configuration 2. In City 2, remote care is offered as a private service by HealthTech to the municipality. The nurses employed by the company operate the response center from the company premises. They keep approximately the same opening hours as in City 1. Patients are selected and recruited to the program by the municipal care services. Once recruited, patients receive two home visits. The first is from a municipal care worker, who does an initial assessment of the patient health and informs him about what to expect from the service (for instance by explaining that it is not a service for emergency care). This initial assessment is reported in ProAct. The second visit is from a nurse from the remote care center, who sets up the devices in the home and teaches patients how the devices should be used for taking measurements, and how to use the tablet for reading measurements and reading and writing messages. After this initial phase, the HealthTech nurses and the municipal health services coordinate via weekly phone calls but not during the day to day care of each patient. As the service is operated privately by HealthTech, the nurses are not required to document patient information in the municipal EPR and do not have access to it. Consequently, they do not receive any PLO messages coming from doctors or hospitals. This decoupling from other health services means that they rely on the patient himself to convey relevant information to and from such parties. ProAct is central in the communication with patients, and most communication takes place in the form of textual messages (which patient receive and respond to by using the tablet).

Preliminary analysis

In our preliminary analysis we focus on the differences in the practices of remote care in the two centers. Specifically, we point to three aspects.

First, **interrelation of care and coordination work**. We have observed that in the first case the work of the nurses when monitoring and caring for patient is interrelated to the work of coordinating the novel services of remote monitoring with the existing care services in the municipality. This work has many aspects, for instance it includes 'finding' patients in existing services that may benefit from remote care, or checking if actions from other services have taken place (for instance a visit of the home nurses). A concrete example of this type of work, as explained by a nurses, is the monitoring of patients' weights. While a weight loss might be overlooked in the tight schedule of the home nurses, this type of measurement is coded automatically by the system and therefore made visible to the remote care nurse. She can use this information in her communication with the home care nurse and direct his attention to the potential problem. This type of coordination work does not have the same role in the second case, given their organizational and infrastructural decoupling from the home care nurses and other care services.

Second, **fragmentation of information**. The nurses in the two centers have different practices in order to make sense of how patient's conditions are developing. For instance, in the first case, the nurse deals with various pieces of information across a variety of artefacts: alerts, alert history, messages, patient record entries, calendar reminders, PLO messages. In the second case the nurse uses ProAct as the main information source. The nurses use ProAct for multiple purposes: to document their care interaction, to monitor the measurements from home devices, to communicate via messages with the patient, to set reminders and coordinate their work in the center and to plan the work in advance. They do not need to cross check information from other systems or services. As a consequence, the practices in the first case are less streamlined than in the second case. In the first, the nurses use substantial amounts of time – up to 1.5 hours a day – to manually copy data from one system into the other. In addition, in order to coordinate their work in the office and across services, they print out most data on paper (e.g. patient list) and keep track of patients manually on the office large whiteboard. These nurses, supported also by the project leaders, underscore the need for a technical integration between the systems as a necessary step to effectively coordinate with the other municipal services. Differently, in the second case, technical integration is not seen as an issue, and nurses' work is focused on monitoring incoming patient data and on exchanging messages with patients in ProAct.

Third, **constituting patients**. Patients have different roles in the two centers. While in the first one, the patient receives a care service that is integrated across the different health services, in the second case the patient is expected to work as service 'integrator' – this means for instance that he is expected to contact the GP in case of need. Another example is about hospitalizations. In case 1 when a patient is hospitalized, the remote care center receives a PLO messages from the hospital. Thus the nurse would know that the patient is in the hospital and that no measurements will be received for certain period of time. They receive another PLO message at discharge. In this PLO message the hospital would also specify the patient health condition and what kind of treatment and care the patient needs once at home. This differs from case 2, where the nurse does not receive PLO messages. Often, if a patient is hospitalized, the patient himself or a family member would send a message to the center.

Conclusion

We are at an early stage of data analysis and our data collection is still ongoing. However, we believe that our study on the practices in the remote care centers raises some important questions about the implementation and use of remote care services. The infrastructure configurations in which the nurses operate shape their practices in several ways. When the center is decoupled from the other services as in the second case, the nurses' work is focused on the interaction with patients via ProAct, while at the same time patients have to take an 'integrator role' while receiving care from different services (GP, hospital, home nurses). Differently, when the center is integrated in the existing municipal care services as in the first case, the nurses' work includes coordinating and communicating with the other actors and dealing with different systems and communication modes. We acknowledge that the use of remote care technology in our cases is still at the stage of 'domestication' both in the homes of patients and in the centers, and that nurses' practices of dealing with alerts and caring for patients are 'in the making'. However, we think that it is important to reflect further on the implications of the infrastructural configurations on both patients' and nurses' role and practices.

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The Complexity of Governing a Regional EPR System

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Abstract. This paper focus on the complexity of governing a regional EPR system. This is done directing the following research question: what is the role of the regional archetype governance organization, and how does it relate to the other actors in the ongoing infrastructuring process of establishing a regional EPR system? The paper builds on infrastructuring and boundary work theory. Empirically it follows the work of governing a new openEHR based EPR system, and the governance structures connected to the system. Some important issues are the interrelation between the governance organizations, the boundaries between them, and if the archetype governance organization can work as a bridge builder between technical and clinical governance.

Introduction

An emerging concern in Western healthcare is to establish Electronic Patient Record systems (EPR) able to collaborate on serving several hospitals, like in a health region, to enable managing and streamlining complete patient pathways and semantic interoperability, as well as monitoring and comparing the hospitals. However, implementing a regional EPR is not done over night. Involved hospitals typically have implemented different technologies diverging routines and policies, depending on the size of the hospital. It is therefore important to include the interconnection between technology and organization in this socio technical process.

One possible solution is to implement a openEHR based EPR system with archetypes as the storage for clinical information. Archetypes are clinical standars formed by clinicians to ensure structuring and reuse of data (Chen et al. 2009). However implementing such large scale EPR system requires a well functioning governance organization to work sufficiently across an health region. Hence the North Norwegian Health Authority decided to establish an regional archetype goverance organization. The health region was an II including two regional (technical and clinical) goverance organizations as well as four (one for each health trust) local goverance organizations. This was a complex and fragmented governance structure for governing parts of the same EPR system. Some important issues to define were the power balance between the different actors governing the same system, and how to define the responsibility areas among them as well as the boundaries between them. One challenge with fragmenting the EPR governance is the lack of total overview and an increased need for boundary spanners to define the boundaries and ensure collaboration between different actors (Gieryn, 1983). McGinnis (1999) states that it has been impossible to agree on such fragmented governance models in the past were several heterogeneous interests and resources are involved in the same large scale II. Therefore and important question is whether adding an extra actor to this fragmented regional governance only contributes to complicating the governance structure, or if it is possible for the archetype governance organizations to gain an interconnecting role between the existing governance organizations in the infrastructuring process of estabishing a regional EPR system. Therefore the research question is as following: what is the role of the regional archetype governance organization, and how does it relate to the other actors in the ongoing infrastructuring process of establishing a regional EPR system?

The paper builds on theory in relation to infrastructuring and boundary work. Empirically it follows the work of governing a new openEHR based EPR system, and the governance structures connected to the system.

Theory

ICT governance is widely believed to lead to more effective use of ICT systems in organizations and it addresses how to design and implement effective organizations through flexible information systems (IS) and processes (Patel, 2002).

Information infrastructure (II) is a framework fit to describe the interplay between the different actors connected to an EPR system like in this case different governance organizations, set to govern parts of the same EPR system. II is a way to study the design, implementation, and use of large-scale information systems (Aanestad and Jensen, 2011; Star and Ruhleder 1996). The infrastructuring process of establishing an II is defined by Karasti and Baker (2004), as a ongoing process highlighting a complex interrelation between e.g. co-construction, participants collaborations, information systems, and infrastructures.

Having a fragmented governance of the regional EPR provodes an increased need to define the boundaries and ensure collaboration between different actors (Gieryn, 1983). Boundary work is required to distinguish the responsibility areas of the different governance units (Ibid.). The boundaries are not permanent and frequently negotiation will be necessary. Boundary work is used to define niches including goals, methods, capabilities and functional expertise to separate the responsibility of the actors in the fragmented governance organization (Ibid.).

Method

This study is positioned within a qualitative interpretive paradigm. The focus is on evolving and improving the understanding of a studied phenomenon, by looking at it from different viewpoints, within a context (Klein and Myers, 1999; Walsham, 1995). The fieldwork draws on observations and participation both in the regional and national archetypes work in Norway. This includes 27 open-ended interviews with archetype reviewers and members of NRUA, including themes like why they chose to participate as reviewers, challenges with participating in this work and how the work is organized.

Table I. Details of the data collection.

	Number of persons	Duration	Period
Interviews			
Archetype reviewers	12	30-90 min	2014-2016
NRUA members	5	60-90 min	2014-2015
Persons involved in the EPR development	7	60-120 min	2013-2015
Observations			
NRUA/regional resource group		200 hours	2014-2016
Development of EPR system		80 hours	2012-2016
Archetype review and CKM use		5 hours	2014-2015
Discussions		100 hours	2012-2016
Document studies			
		240 hours	2015-2016

The purpose of using open-ended interviews is enabling informants to tell their story, without the author's pre-perceptions getting in the way. The interviews were transcribed and analyzed both separately, and as a part of a whole (Walsham, 1995). In addition, information about the reviewers and the nationally approved archetypes documents from the CKM were important parts of the data collection, also observations from several workshops and meetings were included.

Case

This case focus is on the complexity of governing a regional EPR system and how the existing governance II is extended by adding an additional governance organization.

The Infrastructing Process of Regionalizing the EPR System

In the North Norwegian health authority an infrastructuring process of regionalizing the ICT portfolio has been going on since 2011. Responisble for this process was the regionalization project (Felles innføring kliniske systemer - FIKS). The primary goals were to collaborate closely with system users, vendors and governance organizations on creating a foundation for regionally standardized patient pathways, decision support and interaction between clinical ICT systems.

An important part of the regionalization process was the ongoing development of a new openEHR based EPR system, collaborating closely with the system vendor. The new EPR was built on an openEHR architecture, with a goal to ensure interoperability and design flexibility for the users. The openEHR architecture consisted of a two-level modelling approach for EPRs separating technical design of the system from clinical concerns. This made it possible for clinicians to be in charge og defining the clinical content of the EPR system, the archetype standards. Archetypes are structured data elements of clinical concepts, envisioned to ensure technology-independent interoperability, easy reuse of information and efficient decision support (Chen et al. 2009).

The Existing EPR Governance Organizations

The existing technical regional governance organization including about 200 person had since 2005 been responsible for supporting and managing all technical and some clinical issues of the existing EPR system. In the new EPR system they would be in charge of governing mainly the technical part of the new two-layered openEHR. This demands for defining the boundaries towards the clinical EPR goverance It was not an alternative to merge the clinical and tecnical EPR goverance in this organization even if it was a a regional organization with both technical and clinical competence. "The distance between the clinics and the regional technical governance organization is too long. It takes to much time to solve a problem" (project leader). The director of the regional technical governance also said that they mainly wanted to focus on technical issues of the new regional EPR system in the future.

When the health region decided to regionalize their ICT portfolio included the EPR system in 2011 they started working on establishing a regional clinical governance organization. However it was very challenging to negotiate the nature, form, and location, of this organization. Several models were suggested and discussed, but the region was not able to decide on a final solution. "To carry on the regional work it is necessary to have a solid regional governance in place. If not all regional structure falls apart after the regionalization process finishes" (Project leader). One reason for this was that all health trusts had local clinical governance of their EPR. The bigger the health trust, the larger local governance organization. At the The University Hospital North Norway (UNN) the local governance organization had about 20 multidisciplinary experienced system users from hospitals. It took five years to find an agreement on how to organize the clinical goverance in the health region. In 2016 a regional clinical governance organization was established, this was located at UNN with employees from all over the health region. They focused on all types of clinical issues in relation to running the EPR system.

The Role of the Archetype Governance Organization

For the new EPR system it was necessary to establish archetype standards for defining the clincial content. This was a collaboration between a nationally established governance group described by Ulriksen et al (2017) and the health regions. This was a large task going on for years, including several hundred clinicans across Norway. These standards were the main building blocks of the new EPR system, and it was therefor decided to establish a separate archetype governance group in the health region as a part of the clinical governance It was very important to define the boundaries between the different governance organizations to establish a best possible total governance of a large scale II like the regional EPR system. The new EPR system and the two level model the openEHR architecture built on, generated a need for establishing a regional archetype governance, for this infrastructuring process to succeed. To illustrate the importance of this one of the members of the regionalization project described that early attempts to pilot parts of new EPR system had stopped due to the lack of a sufficient governance organization.

This organization had a secretary of three persons in with representatives three of the four health trusts in the region. The archetype governance group assist regional projects in archetype related matters and they are working with identifying all the regional and local archetype initiatives. They also worked in close collaboration with the national archetype governance contributing to establishing national archetype standards for the EPR system. Hence they are a link between the regional and the national archetype work described for instance by Ulriksen et al., as well as between clinical and technological governance of the new EPR system. There is a identified gap between the tecnical and clinical aspects of the EPR system, hence there is a need for intervening the clinical and technical resources to coordinate pure clinical knowledge and pure technical competence to form a total overview of the new EPR system. This is a new way of establishing an information infrastructure within healthcare to organizing ICT governance at a regional level and to establish a close collaboration between the clinical and the technical ICT goverance organizations, linking system developers and healthcare personnel. This enables the organizationally challenging work with clinical standardization. The health region currently dont have healthcare personnel with formal competence to coordinate these socio- technical processes and the role have to be defined and evaluated over time in an extencive infrastructuring process.

Concluding discussion

The success of developing and implementing an EPR system will always be influenced by the information infrastructure it is implemented into. Establishing a regional EPR system demanded for more clinical goverance at a regional level. The openEHR architecture build on a two level model (Chen et al. 2009), claiming the possibility of separating technical and clinical issues, enabling also separating the governance of such issues. However as described by for instance Ulriksen et al. (2017) there is a close interrrelation between the new EPR system and the clincial content of the system (Archetypes). It is not possible to finish the arhcetype standards without having a system to try them out in, to see how they work in clinical pratice. Also, it is impossible to complete the functionallity for the new EPR, without having the archetype standards for the clinical content. Hence having several organizations governing the same EPR system is very complex, requiring constant collaboration and negotiation. There are several borders between the different actors within such infrastructure that has to be clearly defined to avoid boundary disputes (Gieryn, 1983). Also, there are no one responsible for a total overview of the systems, and it is unclear how to solve disputes if some of the governance organizations disagree on how to handle a particular issue. This may be particularly challenging for a newly established information infrastructure as the on in the North Norwegian Health Authority. There were several concerns relating to having several governance organizations in charge og different parts of the same EPR system “If it was up to me technical and functional governance would be organized in the same unit to avoid the complications of defining all the necessary borders separating them creates, (leader of regionalization project).” Technical modifications often have potential effects on clinical issues as well as clinical adjustments may have effect on technical issues. The technical concerns of how to model archetypes, and how to connect it to for instance terminologies, will affect the clinical usefullness of these standards in relation to for instance how to reuse data and how to store the clinical information in the EPR system.

When it comes to achetype governance this organization is located under the regional clinical EPR governance, however the goal is for this to be an interconnecting link between technical and clinical governance of the EPR system. Establishing archetypes and archetype governance demands for a close collaboration between technical and clinical resources, since this is a new concept including both how to modell the archetypes, and how to use them for clinical practice. This requires educating information architects to aquire the necessary competence on the boarder between technical and clinical relations and provide a better understanding of both sides of the regional EPR governance. Having an organization linking the closely connected clincial and technical issues of the new EPR system will increase the chance of the infrastructuring process of establishing a regional EPR system becomming a success. Hopefully this will contribute to a future smooth and well-functioning governance of the regional EPR system in the health region.

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Generification in change: the complexity of modelling the healthcare domain.

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Abstract. In this paper we explore the concept of ”generification” through a Model-Driven Development (MDD) approach. We claim that the concept of generification is in change as the MDD approach, exemplified by the openEHR framework, gives a network of voluntary clinical users a prominent role in the generification process. The customization is no longer ”in the hands” of the vendor, and needs to be formalized for the public healthcare service to take the ownership of the generification process and the standarization of clinical information. Empirically, we have followed the development of a new EPR system adhering to MDD methodology from 2012 to 2016.

Introduction

At present, Electronic Patient Record (EPR) Systems have to a large extent replaced the paper-based patient record in Western healthcare services. Nevertheless, patient information is often spread over different systems and stored in unintegrated applications, which complicate realization of political ambitions like sharing and reuse of patient data to increase quality and patient safety (European Commission and Directorate-General for Health and Food Safety, 2015; National ICT - Action 48, 2014). Moreover, most of todays’ EPRs are built using “single-level” methodologies, in which both information and knowledge concepts are built into one level of object and data models, making them hard to change according to everchanging needs in the sector (Beale, 2002).

On this backdrop, a promising strategy for dealing with these challenges is to increase the level of abstraction in the development process through model-driven development (MDD) (Selic, 2003). In healthcare, the openEHR standard (Beale and Heard, 2007) is a promising MDD approach for electronic healthcare records (Martínez-Costa et al., 2009; Lopez and Blobel, 2009). It is a two-level modelling approach within a service-oriented architecture and it allows clinical personnel to be directly involved in defining the semantics of clinical information systems. In OpenEHR, a small and standardized reference model represents the first level while structured models of the use domain—the archetypes—represent the second level.

Archetypes are thus not part of the software or database of a system. An archetype is a re-usable, formal definition of domain level information. A fundamental aim of the archetype approachis to empower domain experts to create and change the knowledge inherent in archetypes, thus controlling the way EHRs are built up using designed structures to express the required clinical data The essence is that clinical personnel now become enrolled as the customizers of an EPR-system, responsible for defining certain data-objects (Blobel et al., 2014). Consequently, this approach gives a high degree of local configurability for users and domain experts (Garde et al., 2007: 336).

Pollock and Williams (2008) have described the vendors' strategy of customization as "generification", in terms of making a generic system work in several settings. The concept of generification gives valuable insight about how a vendor align user request to make generic ERP systems tailored to different organizations. Generification involves social processes of ordering, prioritizing, and persuading users in order to motivate them to use similar versions of the same system that is installed in different organizations (Pollock & Williams, 2008). In the MDD approch the customisation is handed to the users by the modeling the domain. Accordingly, the concept of "generification" is in change, and in this paper we explore the concept through a MDD apporach that gives a network of voluntary clinical users a prominent role in the generification process (Beale and Heard, 2007; Beale and Heard, 2008; Christensen and Ellingsen, 2016; Pollock and Williams, 2008) Based on this, we ask: ***How do the MDD apporach of EPR systems change the concept of generification?***

Empirically, we have followed the development of a new EPR system addering to the MDD methodology from 2012 to 2016 The project took place in the North Norwegian Health Region, in which The North Norwegian Health Authority decided in 2011 to invest in new clinical ICT systems for all the 11 hospitals in the region. The overall aim of the procurement was to replace an existing, largely free-text-based EPR with a semantic interoperable EPR enabling advanced process- and decision support within and between the hospitals in the region. DIPS ASA was chosen as the principal vendor of the new EPR.

The research is grounded in an ethnographic-inspired study (Klein and Myers, 1999), and the analysis was guided by a provisional understanding of the nexuses in which the artefact, attendant practices and knowledges were being created.

Case

The Vendor's need for a generification strategy

DIPS had since year 2000 grown from the smallest to the largest EPR vendor in Norway. Currently, they enjoys approximately 86 percent of the Norwegian hospital-based EPR market. Their system, DIPS Classic, contains 500 features/functions, 7,5 million lines of code and has approximately 82 000 users. However, in response to national strategies for ICT in health care, and to cope with increasingly requests for changes in their system, they decided in 2011 to use the openEHR architecture for its EPR for the future. This would also make it possible for DIPS to become a vendor on the International market.

> *"Very much of what we had developed in the period 2008-2011 - was good functionality, but all the screens and modules were hardcoded, and every tiny change to our software had to be done by our developers and that was an overwhelming task (...)"When the user interface can be [automatically] generated based on the archetypes, it will save the developers an enormous amount of work. It implies that domain experts can define the content, and the developers will not have to spend time on designing screen forms for data entry and workflow"*(system architect, DIPS).

While focusing heavily on development of the software, DIPS had expected the users—in accordance with the openEHR approach and the national strategy (National ICT - Action 41, 2012), to take charge of modelling archetypes. Hence, DIPS expected the North Norwegian Health Authority to organize relevant user forums for doing this:

> *"The process of modelling archetypes is something the FIKS project has not dealt with at all. They [the users] like the idea of archetypes—having structured data and eventually being able to exchange information that different systems can understand—but I don't think they realize what is their responsibility in the process" (*developer DIPS)

Hence, the first piloting showed that the new EHR would not be fully operative without the presence of a broad range of archetypes to represent the clinical content of different disciplines. Consequently it became difficult for the users to grasp the potential of the new technology and the users where not informed of their role in developing archetypes.

The management of the FIKS project realized that building a repository of archetypes would be a task too huge for Norway's smallest health region. This needed to be done on a national level. An increased understanding of the need for a broader national initiative on this work led to the establishmet of an editorial group for national governing of archetypes (NRUA) in January 2014. NRUA was part of the National ICT organization.

Handing the generification over to the user communities

Up and running, NRUA organized the process, aimed to govern the Norwegian archetype repository by the same principles as the international repository. Moreover, the repository was going to evolve thorugh a so-called "do-ocracy" for which clinicians, allied health workers, and other experts propose needs of clinical information defined as archetypes. This denotes that the clinicians had to map and detemine which clinical information needed to be modelled, e.g. mapping a patient pathway and the need for clinical information to support the pathway. However, for each and every clinical information concept, e.g. "smoking history" used in the admission note, the work with modelling archetypes started with a mind map where the different aspects of the proposed archetype were listed.

To start out, clinicians took the archetype for "smoking history" from the international CKM, and translated it into Norwegian. However, they discovered that some aspects were missing due to contextual differences: In Norway, use of snuff has been replacing cigarettes, and hence it is just as important to map use of snuff as the number of cigarettes smoked. Thus, the archetype had to be revised to take this into consideration. The clinicans worked in two different project groups, and it turned out they "mind-mapped" different aspects of the archetype on smoking history, resulting in two different suggestions. To alig the different suggestions a concensus process was initiated, which turned to be time consuming and cumbersome.

NRUA organized the important consensus process of the requested archetype, which included picking and recruiting relevant clinicians in terms of their specialist background – and issued the approved archetypes when consensus was obtained. The concencus processes were conducted through an online-tool – the openEHR clinical knowledge manager (CKM). Accordingly, the clinicians did not have to meet in person, but could take part in the consensus process from their private computers. However, the review process in the Norwegian CKM depended on the clinicians' willingness to contribute :

“It is not easy to recruit clinicians; we try to get a permanent staff of dedicated people who are willing to spend the time—it is actually volunteering in the first place. Some say no for this reason, they want to do it as part of their working hours. Once enrolled in the CKM, you have to train them in how the system is used, so it takes some time before you have a bunch of people who know what to do when the invitation to evaluate a new archetype pops into their mailbox”. (Member, editorial group)

Concluding discussion

There is a complex interplay between the vendor’s decsion of ”business strategy” to fit into the huge and evolving heathcare market, and the necesarry generification to make a system work in several different contexts. In this case, the vendor’s development strategy influenced the traditional generification because the new strategy changed the customization process. The processes of ordering, prioritizing, and persuading as described by Pollock and Williams (2008) is now moved from the vendor to the clinical communities. Even though the users are ”put in the drives’ seat” of the customization process, the complexity of customization through the MDD approach presuppose the process to be organized. This addresses a need to formalize the responsibilty of the generification process. First, there is a need for an overall decision, on a national and regional level, to allocate appropriate resources to take part in on all levels of this work, both the consensus process and the formalization of archetypes. Second, the must be an organization responsible for tailoring the archetypes into different organisational needs.

Accordingly, the MDD apporach of EPR systems change the concept of generification in terms of «handing over» the customization process to the user communitites’ and their willingness to contribute to the development and maintenance of archetypes. The generification process is no longer ”in the hands” of the vendor. The new aspects of the generification processes need to be further explored (Beale, 2000; Christensen and Ellingsen, 2016; Pollock and Williams, 2008).

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Infrastructures for Sense Making

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Abstract. This paper is about discussing infrastructures as enablers of users' sense making. Infrastructures facilitate process-oriented, interactive and socially sense making in case of complex problem settings like care giving. On an example of a platform that is used to support informal care givers, it expresses the importance of different channels in interaction mechanisms of infrastructures that are meant to support non-professional care givers in their daily activities, especially to deal with situations of uncertainty and mental overload.

Informal care

Care is a complex cooperative action involving several stakeholders. Informal care givers, who are in charge of caring of their partners or other family members, independent of their age, health condition or job situation, are often under high pressure for they have to: know how to take care of their care receivers; properly organise the care and the necessary treatments; be responsible for the care receivers' everyday activities; manage financial and legal issues concerning the care; and especially be 100% available and poised for care around the clock (Pinatti et al., 2016; Brouwer et al., 2004; Cranswick and Dosman, 2008). This situation requires their active involvement in seeking information. They are the first ones who are involved in deciding whether it is necessary to act based on certain symptoms or in case of unexpected change of care receivers' conditions. As *co-workers* of professional care givers, they are in charge of caring at times when professional care givers are not present – which is in most cases the most time of caring.

This big responsibility is difficult to carry and the most informal care givers are not trained for care. In case of an emergency or uncertainty in the health condition of the care receiver, the first thing that an over challenged care giver does is to access the Internet and search for information about the symptoms. They hope they can find instructions or clear descriptions about the situation they are facing. But they are mostly frustrated because of several reasons: they don't find any relevant information to their question; or the information they find is not understandable for them, it is addressed to professionals; or the forum entries they find are either not complete or not representing their own situation and that is why the advice given or the data presented there are not applicable for their own situation, etc. In such cases, sense making becomes almost impossible for informal care givers. This is what we try to discuss in this paper and suggest *infrastructures* to help solve it. On the example of the *TOPIC CarePortfolio* we show what we mean with infrastructures in the context of care giving that facilitate multi channels for users' sense making.[1]

Sense making for care giving

Sense making, as described by Lebiere et al., is a procedural activity involving a "[...] a meaningful and functional representation of some aspects of the world." (2013, p.1). At the core of this process are interactions – be it between one person and another person or between a person and an information source, such as a book, an article or an instructional video. Given the importance of interactions for this process, Dervin argued that any attempt at creating technological infrastructure such as knowledge management systems with the goal of supporting sense making activities must be "[...] responsive and iterative and open." (1998, p.44) This correlates with Klein et al.'s "Data/Frame Theory of sensemaking", which is based on a continuous cycle of framing, elaborating and reframing data (2006, p.88ff). Within this system, there is an inherent, two-way relationship between data and the way it is framed by an individual: "Frames shape and define the relevant data, and data mandate that frames change in nontrivial ways." (Klein et al, 2006, p.88).

In applying this argument to health infrastructure – in particular the ones aimed at informal, primary caregivers – these systems must not just allow, but encourage an iterative process of information-seeking and collaboration with colleagues, medical professionals and supplemental information sources alike. The act of questioning a particular frame of data is an integral part of the Data/Frame Theory's cycle; a corresponding action could be an informal care giver questioning their interpretation of a change of symptoms they observe in the person they care for.

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[1] TOPIC was a European research project funded by the AAL Joint Program that aimed to advance the understanding of elderly informal carers' needs and design ICT solutions to support their daily lives (Breskovic et al., 2013; Hensely-Schinkinger et al., 2015). It addressed the lack of an integrated social support platform and the lack of accessible ICT applications for elderly people involved within informal care. The project congregated nine partners located in Austria, Germany and France. For more information visit the TOPIC project (AAL-2012-5-169) website available at http://topic-aal.eu.

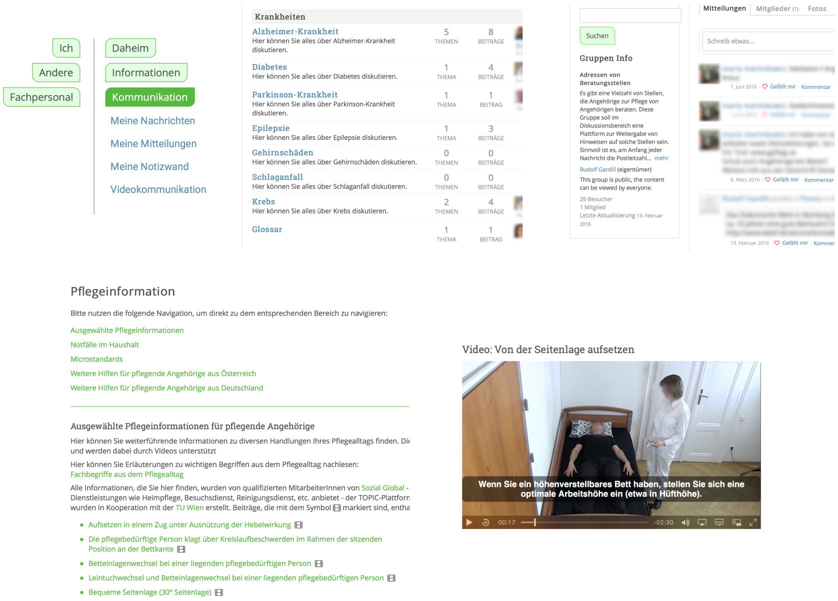
While medical professionals might be able to assess the situation based on a large amount of (framed) data, an informal care giver has only limited data to base the interpretation on. Thus, the process of questioning the interpretation will be less informed and more of a struggle, and both care givers and their care receiver could profit from health care infrastructure that encourages collaborative sense making.

An Example: The *TOPIC CarePortfolio*

The *TOPIC CarePortfolio* implements different modes of interaction to facilitate users' sense making. It provides care information in listed text (instruction mode) (Fig. 1, bottom left), care video with text and audio complemented (multimedia mode) that is configurable by the users (Fig. 1, bottom right), easy access to interact with peers or professionals like email, push notifications, video/audio communication, digital notes board (interaction mode) (Fig. 1, top left), search for different conditions posted by peers or other professionals in form of forums (search mode) (Fig.1, top middle), as well as provide and share relevant care data with peers and others in form of groups (share mode) (Fig.1, top right). The informal care givers can choose between different modes to select the most appropriate channel for exchange or search for information. This depends on the care situation they are in and data frames provided for them. Sometimes they jump between different areas, e.g., read a latest post in a group, then search for information to find out a legal issue, and then again ask a question in their peer group, sometimes about something they have read but not understood in the information area. Sometimes they contact one, per a message or an ad-hoc video chat. Through the notification centre, they are easily informed about others' activities and responses.

In case of unexpected changes or uncertainties in the health condition of the care receiver in the course of progress of the health condition of the care receiver, the first thing informal care givers need is to interact with someone who is able to help them in these situations of need or to find the right information in the given context. How can this interaction be supported by technologies that are available for the care givers in their ambient environment?

The answer is to provide such infrastructures that, on the one hand, host relevant trustful information in an easy-to-understand multimodal format with adaptable interactive (data) frames defined by individuals and, on the other hand, facilitate simple and clear interaction mechanisms to encourage users to ask questions, contact others, search for help, share their own knowledge and experience with others, etc. to make sense of the data provided – sometimes in order to apply it in their real context. Designers need to think about interaction mechanisms that support access to information and social infrastructures as a major but also delicate-to-design factor in helping users sense making of complex information in sensitive areas like caring for others.



Krankheiten

Alzheimer-Krankheit Hier können Sie alles über Alzheimer-Krankheit diskutieren.	5 THEMEN	8 BEITRÄGE
Diabetes Hier können Sie alles über Diabetes diskutieren.	1 THEMA	4 BEITRÄGE
Parkinson-Krankheit Hier können Sie alles über Parkinson-Krankheit diskutieren.	1 THEMA	1 BEITRAG
Epilepsie Hier können Sie alles über Epilepsie diskutieren.	1 THEMA	3 BEITRÄGE
Gehirnschäden Hier können Sie alles über Gehirnschäden diskutieren.	0 THEMEN	0 BEITRÄGE
Schlaganfall Hier können Sie alles über Schlaganfall diskutieren.	0 THEMEN	0 BEITRÄGE
Krebs Hier können Sie alles über Krebs diskutieren.	2 THEMEN	4 BEITRÄGE
Glossar	1 THEMA	1 BEITRAG

Gruppen Info

Adressen von Beratungsstellen

Es gibt eine Vielzahl von Stellen, die Angehörige zur Pflege von Angehörigen beraten. Diese Gruppe soll im Diskussionsbereich eine Plattform zur Weitergabe von Hinweisen auf solche Stellen sein. Sinnvoll ist es, am Anfang jeder Nachricht die Postleitzahl... mehr

Rudolf Gardill (eigentümer)

This group is public, the content can be viewed by everyone.

26 Besucher
1 Mitglied
Letzte Aktualisierung 13. Februar 2016

1. Juni 2016 - Gefällt mir - Kommentar

6. März 2016 - Gefällt mir - Kommentar

13. Februar 2016 - Gefällt mir - Kommer

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Bitte nutzen die folgende Navigation, um direkt zu dem entsprechenden Bereich zu navigieren:

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wurden in Kooperation mit der TU Wien erstellt. Beiträge, die mit dem Symbol 🎞 markiert sind, entha

- Aufsetzen in einem Zug unter Ausnützung der Hebelwirkung 🎞
- Die pflegebedürftige Person klagt über Kreislaufbeschwerden im Rahmen der sitzenden Position an der Bettkante 🎞
- Betteinlagenwechsel bei einer liegenden pflegebedürftigen Person 🎞
- Leintuchwechsel und Betteinlagenwechsel bei einer liegenden pflegebedürftigen Person 🎞
- Bequeme Seitenlage (30° Seitenlage) 🎞

Video: Von der Seitenlage aufsetzen

Wenn Sie ein höhenverstellbares Bett haben, stellen Sie sich eine optimale Arbeitshöhe ein (etwa in Hüfthöhe).

Figure 1. The *TOPIC CarePortfolio*: Example of an infrastructure providing different modes for interaction (from top left to bottom right): interaction, search, share, instruction, and multimedia.

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