Real Person, Digital Patient: Representations and Reflective Practices in Remote Care

Completed Research

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Abstract

Digital representations are critical in the context of remote care, where nurses and patients interact at a distance through digital means. Based on an empirical study of nurses' work in remote care, we propose a model to depict how nurses and patients collaboratively form and interact through digital representations, and we show that when knowledge is gained through patient-generated digital data, novel reflective loops are introduced. We identify a multiloop dynamic of understanding through and reflecting on digital representations. We show how nurses work to generate and understand representations of patients and reflectively improve these processes. At the same time, we show how patients take active parts in forming and using representations, guided by the nurses who coach them. By discussing our findings in light of existent literature, we offer the notion of representational configurations, point to the crucial role of reflective loops, and extend Information Systems' theorizing on representationality.

Keywords

Remote care, datafication, digital representations, performativity.

Introduction

Digital sensors and systems are increasingly used in healthcare to generate, collect and transmit data. This trend, called datafication (Jones 2018) is changing the way healthcare practices, as well as other types of knowledge work, are performed. Large and real-time streams of data lead to new ways for healthcare practitioners to make sense of e.g. symptoms and vital signs of patients. Their work is increasingly based on interpreting and acting upon digital representations of a patient's body (Grisot et al. 2019). This is a critical aspect in remote care where digital representations are crucial for service delivery. In remote care, the provider and the patient are spatially separated, and service provision is dependent on a technological medium (Andreassen et al. 2018). Differently from early forms of phone or video-based remote care, contemporary services are based on the digital transmission of quantitative and qualitative data from patients to health providers. In this setting, patients remotely (at home) generate data by using sensors, personal digital devices, and smartphone apps. The development of this type of service is still in its early stages, and there is a limited understanding of how patient-generated health data shape how digital representations are formed and used, and how they affect remote care practices.

Representations are fundamental to understand the use of digital technology (Burton-Jones and Grange 2012). Studying digital technology's representational capacity "draws attention to how human and material agency afford opportunities to leverage representations of real-world phenomena (e.g., a patient or a machine) in particular tasks" (Jonsson et al. 2018, p. 218). This includes how data are collected, processed, and structured into representations, and how these representations are used and manipulated. However, these processes are not smooth and technology-determined, but require fine-tuned configurations of practices and technologies to be carried out (Jones 2018; Monteiro and Parmiggiani 2019). In this paper, we focus on digital representations and their *representational configurations*. By introducing this term

(derived from Jonsson et al., 2018), we want to draw attention to the technologies and practices generating and making use of digital representations. Specifically, we investigate a case where the object of representation (the patient) takes an active part in the configuration practices (through patient-generated health data). While earlier research primarily has studied configurations that produce representations of physical objects (Bailey et al. 2011; Monteiro and Parmiggiani 2019; Zuboff 1989), we find that patient-generated data introduces novel dynamics. We are interested in understanding how this plays out and which dynamics emerge.

We formulate the following research question: *How are representational configurations in healthcare shaped by the participation of patients through patient-generated health data?* To address this research question, we have conducted a study of remote care in Norway and examined how nurses and patient interact through the digital representation they collaboratively form. Specifically, we focus on the reflective loops between nurses and patients as they form and use digital representations in their care and self-care practices. Remote care has characteristics that make it especially relevant for theorizing on representational configurations in knowledge work. In this type of service, a variety of data from different sources need to be combined into meaningful representations. This requires work from both nurses and patients: representations need to refer to a measurable symptom or vital sign; at the same time, not all data are relevant, and they need to be sorted out. In addition, patients' conditions change over time, meaning that different data may be relevant at different points in time. Finally, remote care is often carried out with the intent of supporting the healthy behaviors of patients, an aim that entails that representations must be generated or used in a way that induces this type of change.

Our findings show that when knowledge is gained through patient-generated data, novel reflective loops are introduced. Both nurses and patients engage in a multiloop dynamic where they not only know the state of the patients' health and wellbeing through representations but also reflect on the processes that create them. Based on our findings, we contribute to the ongoing discussions in Information Systems on digital technology's representational capacity, as well as on the performativity of digital representations.

We structure the paper as follows: we first describe how configurations of practices and technologies producing digital representations can be characterized as reflective. We then present our case and methodology. In the section on findings, we show how the configuration of nurses' practices and digital technologies produce digital representations, and how these are understood and reflected upon. Finally, we discuss our findings in light of existent literature and present our contribution.

Reflective Loops in Representational Configurations

The capacity to decouple information from physical forms is fundamental to digital technology (Normann 2001). Consequently, how this capacity can be utilized in knowledge work has been a long-lasting issue in information systems research. Zuboff termed the capacity informating, as it enables processes where "activities, events and objects are translated into and made visible by information" (Zuboff 1989, pp. 10–11). For informating to be useful in organizations, however, workers needed to transform the way they "acquired and exercised knowledge" (Burton-Jones 2014, p. 14), meaning that their knowledge practices had to go from engaging with physical phenomena to their representations. The workers in a paper mill would no longer know the state of the paper pulp by smell and touch, but by the structures of data in a control system (Zuboff, 1989), requiring a re-constitution of their understandings and competencies.

Since Zuboff wrote her book in the late 1980s, there has been an exponential growth in work mediated by digital representations. Unlike the workers in the paper mill, most of us take for granted that we can understand and act in the world through the digital. The savvy user turns the lights on in her house through an app on her phone and trust that the digital representation of these lights corresponds to the actual state of the physical lightbulb. Moreover, developments in sensors and algorithms mean that almost all measurable aspects of the physical world can be made into digital representations (Monteiro and Parmiggiani, 2019). This is utilized in new types of services, for example in industrial settings, where machinery is instrumented and represented as so-called "digital twins" (Barata and Rupino Cunha 2018), reducing risks for expensive downtime and allowing new forms of optimization (Jonsson et al., 2018).

Effective knowledge work has been characterized as having dynamics of double learning loops, where practitioners interact with and learn about objects in the first loop and reflect on the processes that govern the first loop in the second loop (Argyris 1977; Seidel et al. 2018). We interpret previous research on digital

representations to show that representational configurations display similar dynamics. Our model in figure 1 illustrates this interpretation. In loop 1, human agents act on representations and get their understandings of real-world objects through these. In loop 2, they reflect on the technologies and processes that create these representations and change them to become more accurate and fit-for-purpose.

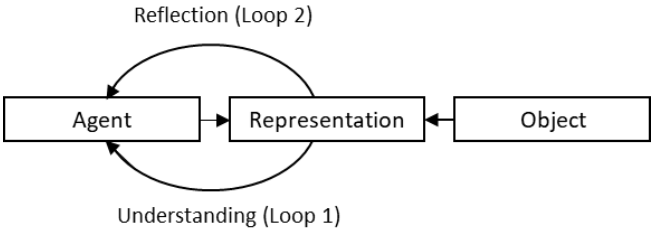

Figure 1. A double-loop representational configuration

Following this dynamic, the paper mill workers described in Zuboff's work got new insight in the operations of the mill through structures of data, while reflecting on whether they could trust these representations to be faithful or not (1989). Kallinikos, in his study of the early digitalization of a dairy production plant, shows how the plant needed to use what we conceptualize as a loop 2 dynamic to reorganize the symbols of their control system to represent the physical layout of their machinery, for a loop 1 dynamic to function for the dairy production workers (Kallinikos 2011). Bailey et al. studied both loops in their work on simulations in car design (Bailey et al. 2011). The engineers and designers in their study worked to make car design by 3D simulations reliable, enabling a loop 1 dynamic where designers would be able to test out their designs without having to interact with physical models. But even though the simulations became well developed, the designers still depended on empirically validating their simulations on physical parts to be able to work efficiently.

Similarly, Jonsson et al. show a double loop dynamic in their case on industrial instrumentation. They argue that there must be *high cohesion* between representations and physical objects for work to be carried out (Jonsson et al., 2018). This describes the requirements for loop 1; the empirical understanding one gets from working with the representation must correspond to the empirical understanding one gets from working with the physical object it represents. However, "although digital representations may be enabled by a portfolio of digital technologies the involved actors must engage to make the information about the physical world as up-to-date, valid and useful as possible" (Jonsson et al., 2018, p. 228). To attain high cohesion, "remote analysts collected machine supplier information to make sure sensor data were analyzed according to the specification of the installed components (e.g., bearings); they decided on which interval to collect data and whether to use microloggers or sensors; they communicated with onsite workers to check the validity of measure and to collect complementary information about the condition of each machine" (Jonsson et al. 2018, p. 228). In other words, loop 2 is necessary for loop 1.

In our study we are interested in understanding how these loops play out when the represented object is a person who partakes in generating the representations and gains an understanding through them.

Methods and Case Description

To understand representational configurations that include patient-generated data, we have conducted an interpretive case study of remote care practices at Digicare. This Norwegian company delivers technology for remote care, and it is involved in various ongoing implementations in Norwegian municipalities. Since it was founded in 2012, the company has developed ProAct, which is a platform for collection and analysis of patient-generated data and communication with patients. Digicare has also run (2016-2018) an in-house remote care center staffed with nurses for a small municipality. The center was funded by a national welfare technology program (2014-2017), which intended to investigate the use of technology to assist people with chronic diseases within primary care. In this period, the company had about 15 employees including a technical team of developers and IT support, and a medical team comprising a GP, an experienced head nurse, and three nurses employed at the center. Since its opening, the center was assigned a varied number of chronic patients with a maximum of 150 patients.

We sampled Digicare as a paradigmatic case, i.e. a case that "highlights more general characteristics" of a larger phenomenon (Flyvbjerg 2006, p. 13). We find it paradigmatic of a representational configuration with patient-generated data for three reasons: first, a guiding principle in what Digicare term their "care methodology" is that the patient should be an active participant in generating data and should have access to the same data as nurses; second, in the context of the national welfare technology program Digicare was relatively free to carry out this care methodology in their service; and third, Digitare developed the ProAct system parallel to running their service, thus developing the technology to fit with their care methodology.

Data Collection and Analysis

We primarily used three methods to collect data: interviews, observations, and document analysis (Yin 2017). We conducted a total of 23 interviews and did 47 hours of observation. In addition to Digicare staff, we interviewed municipal, regional and national stakeholders. Interviews were recorded and later transcribed verbatim. During field work, we followed the nurses' routines while attending to patients, we sat next to them, looked at their screen and observed their use of the system. To grasp what the nurses were doing, we asked questions and listened to their conversations. We also participated in informal conversations with nurses, developers, management, and technical staff. During each visit, we took extensive field notes to document how the staff interacted in the office. Following the observation sessions, we immediately spent time to reflect on our observations, to write analytical memos, and to note down questions for later clarification. Document analysis included various reports, documentation, flows, and strategic documents that provided context to the study. Data collection continued until data saturation.

Following the principles of interpretive research, we conducted data analysis iteratively and in tandem with data collection. We hermeneutically went back and forth between pieces of data and a more holistic understanding shared between the authors (Klein and Myers 1999). This analytical work can broadly be divided into two phases. The first phase of analysis was primarily inductive and exploratory, where we aimed at understanding the practices of the nurses, what role patient-generated data played in their digital systems, and how patient representations were formed and used. In the second phase, we worked abductively, where we alternated between data and literature to discover and understand patterns in the data (Alvesson and Sköldberg 2017). Considering the practices and digital technologies in the case in light of the literature on digital representations (e.g. Bailey et al. 2011) and reflective practices in knowledge work (Argyris 1977; Seidel et al. 2018), we understood how the case relates to other types of representational configurations, and how it displays a type of reflective dynamic that has not been well researched before.

Remote Care at Digicare and the ProAct Platform

Remote care at Digicare's center is organized as follows: When patients are assigned to the remote center by the municipality, the nurses are informed about diagnosis, health conditions, treatment plan and other pertinent details. Once enrolled, the patient receives a home visit from Digicare, where a nurse collects additional information, and the patient is provided with a set of digital devices (e.g. digital thermometer, digital scale), including a tablet with the ProAct mobile application. Following this, a yearlong care plan structures the interaction between nurses and patients. In the first weeks, patients are followed up closely to make sure they learn how to use the devices properly, and acceptable ranges are set for each type of measurement (e.g. the range that is considered normal for each patient). Patients are expected to use their devices to take regular measurements (e.g. temperature, weight, blood pressure), heed to directions given by the nurses via messages, on a daily basis answer personalized questions, and reply to messages in the ProAct application. Following the enrollment period, there are a number of check-points e.g. 24 and 36 weeks into the care plan, where the personalized questions are revised and the thresholds are recalibrated based on the nurse assessing the patient's health and trajectory. The care plan is managed by ProAct and nurses receive reminders about the various phases and corresponding tasks. Both nurses and patients have access to the patient record including graphical visualizations of the measurements from each device, the message log between nurses and patients, and the personalized questionnaire. Nurses have additional access to each patient profile (e.g. personal information, diagnosis, medicines, comments) and to individual alert settings for each type of measurement.

Nurses attend to each patient at least once a week, where they examine measurements, communication, and questionnaire answers received in ProAct. Questionnaires are based on standard themes, but questions are formulated ad hoc by the nurses for each patient. Based on these data, nurses compose a text message

comprising an analysis of the weekly trend, responses to questions from patients, and general advices. Nurses communicate with patients mainly with text messages, less frequently with phone calls and via SMS, dependent on patient preferences. Each nurse attends to around 10 patients each day. The distribution of patients among nurses is flexible and patients may be handed over from one nurse to another. Each patient takes up a variable amount of time, and fixed time slots are not assigned to each patient.

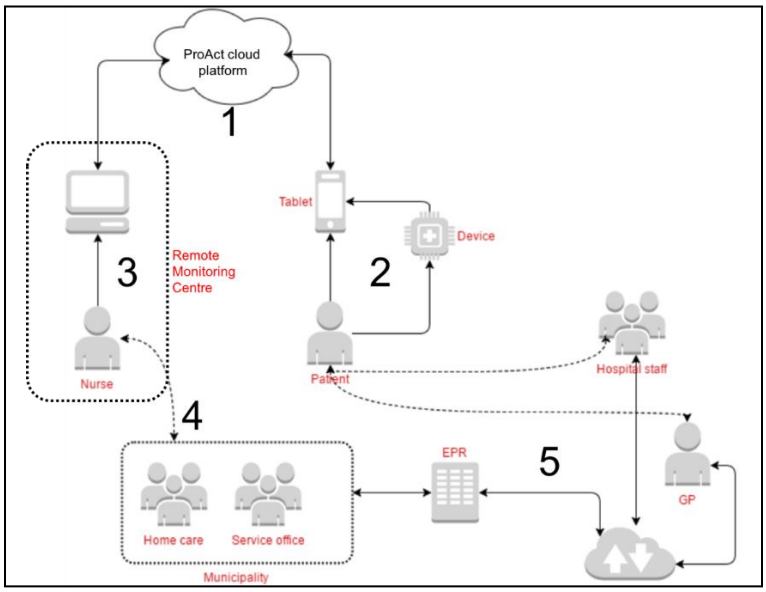

Figure 2. Setup for remote monitoring using ProAct.

Figure 2 illustrates how the service is set up to enable remote care. The ProAct system runs on a cloud-based platform (1) which collects measurement data from the personal digital devices that patients have in their homes and that are connected to the ProAct platform through an application installed on their tablet (2). ProAct is accessed by the patient through the tablet application and by the nurses via a web view on their computers in the center (3). Depending on their condition, patients are equipped with a range of digital devices (e.g. spirometer, pulsometer, thermometer). The nurses in the center coordinate with the municipal care services (4) but they cannot access the municipality's electronic patient record system (5). The data from ProAct can be shared with the municipality on request but this is unusual. On occasion, nurses will, therefore, ask patients to take their tablets with them when visiting their GP or other healthcare providers.

Findings: Generating, Using, and Reflecting on Digital Representations in Caring for Chronic Patients

In this section, we present the findings from our research. We focus on how the nurses work on digital representations in ProAct and how they use them in their care practices. These representations enable them to understand the health conditions and main concerns of the patient. Simultaneously, nurses use the representations in their interactions with patients to guide them into understanding and self-monitoring their health. Both nurses and patients participate in generating data: the patients by using the digital devices and answering to questions and messages, and the nurses by formulating questions, writing messages, and monitoring that the devices are used as expected. Based on clinical guidelines and experience, the nurses constantly probe for data and coach patients to proactively change habits to improve their health condition. We have identified three core practices where this is carried out: the nurses generating and using representations, the nurses reflecting on representations, and the nurses coaching the patients to understand and reflect on representations.

Generating and using representations

The primary focus of the nurses' work in the initial phase is to form representations that are 'personalized'. This is important, because each chronic patient experiences his/her illness differently and has specific illness trajectories. In addition, as patients' own behaviors and habits affect their health conditions, nurses

need to understand their patients' overall lifestyle and situation. Representations are at the start based on information nurses collect from the municipal care coordinator and from the initial home visit. Then, representations are enriched by data from sensors, as well as answers and messages generated by the patients.

The work to form these representations includes mapping and profiling. *Mapping* involves gathering data to understand what is specific about each patient. *Profiling* is about targeting patients on the basis of mapped characteristics. The task of mapping is primarily performed by using the questionnaire to know how the patients' conditions develop and to identify their major distresses. By default, the questionnaire covers a set of topics according to each diagnosis (e.g. patients with diabetes are asked about their eating and exercise habits, about thirst and dizziness). The questions are then revised by the nurse in agreement with the patient. For instance, some diabetic patients have a tendency to overeat sweets, and the consumption of sweets is then what should be represented and monitored. Others have multi-morbidities; a COPD patient with a BMI below 22 should be monitored for both COPD symptoms and eating habits. In addition, each patient might show different symptoms in case of an exacerbation, and it is critical to know which symptoms to expect. In the case of COPD, for example, different signs could indicate an infection: hard coughing, colored slime, rising fever. Thus, the nurse needs to single out these symptoms for each patient, to be able to catch them as early as possible. By posing and answering questions, nurses and patients co-generate the representations needed to provide care. Patients answer the questions daily, and both questions and their scales can be adapted by nurses over time.

The representations that are generated through mapping of specific conditions and habits enables the nurses to profile patients and understand what they (both nurses and patients) should pay attention to. By using profiles to direct their questions, the nurses can more accurately map those habits that the patient needs to improve. For instance, threshold settings are part of the patients' profile, and these can be calibrated to trigger alerts in ProAct. In the first weeks, nurses make patients take measurements frequently to understand what their typical values are and set an acceptable range. The range is then personalized as values considered high for a patient could be considered low for another patient.

Reflecting on representations

To understand the conditions of the patients, the nurses triangulate their different representations. For instance, measurements from the patients' devices, e.g., rising blood pressure values, have to be interpreted in the light of other pieces of information. In this way, the nurses analyze single representations from different perspectives, correlate them to other representations and to the accumulated values across different sensor readings. Triangulation is a reflective practice where nurses reflect on the relation between representations and patients. This includes what we term relating and probing. *Relating* involves correlating the received measured value to the broader contextual information about the patient, while *probing* involves corroborating hunches and falsifying interpretations. The use of alerts and text messages in ProAct are central in these activities. The alerts are automatically generated whenever an incoming value is outside of the acceptable range set for a patient. To understand the signification of an alert, nurses move between data displays in ProAct. There could be many reasons for why a value is out of range. They look at the graph of previous measurements, observe trends, zoom in on specific weeks or months, and look at how the average value e.g. blood pressure has changed from week to week. For instance, if the alert is of a high blood pressure value, the nurse needs to understand what may have caused it. Thus, she looks at when the measurement has been taken, whether it is in the morning or in the evening. She checks if the patient has a fever. She checks in the message history if the patient has mentioned that his medicines have been modified by the GP. She then checks the questionnaire to see if the patient is reporting not feeling well.

When there is an inconsistency between data, the nurses turn to the patients to probe their understanding, e.g. by examining what a red alert in combination with normal values may mean. For instance, a patient with severe COPD triggered a yellow alarm in ProAct every day. However, his vital signs were within the acceptable range, and he seemed overall to be stable. The nurse said that she knows that this should not be considered a "real" alert, and she thinks that they need to re-formulate the question in a way that it makes better sense for the patient—the way it was formulated did not trigger a useful reflection for this patient, and he was unable to provide a meaningful answer. In other cases, triangulating representations generated from answers, measurements and messages show trends that need further explanation. For instance, a patient with high blood pressure seemed for some months to manage to keep it under control, but then the

value became high again. The nurse sent him a message to ask about his medication regime: "has your GP made changes to your medicines? Have you noticed yourself that the pressure is higher?" She wanted to check if the values increased because of the effect of medications, which probably signaled that these medications were not rightly dosed. However, ProAct does not contain medication data, so she had to ask the patient to probe if her interpretation was correct.

Coaching the patient to understand and reflect on representations

By integrating and forming digital representations, the nurses set the ground for supporting patients to learn to be proactive in their self-care practices. ProAct is also designed to be a tool for patients to manage their own disease. Thus, patients, similarly to nurses, need to understand what digital representations mean and how they can be used. To facilitate this, the nurses coach their patients. This involves motivating the patients, asking questions a certain way, and sending friendly reminders to guide patients into self-management. These tasks are aimed at enabling the patients to both understand what the representations are representing and to reflect on the relation between own behavior and the representations, i.e., which processes produce which types of representations. Nurses coach patients to reflect on the process of generating data (e.g., using sensors and app) and on how these data are structured into representations. They also guide patients to see correlations, for example how specific behaviors produce specific representations (for example how exercise and diet produces different types of data).

The digital text message in ProAct is a core tool in coaching. The messages support a continuous dialog between nurses and patients and help both parties keep a sense of direction. For instance, nurses will often remind patients of their tasks, even when measurements are showing improvements. One patient that managed to keep the blood pressure and glucose level lower than usual for a couple of weeks, got the following message: "this is good, you have good control on the blood glucose level." The nurse added: "be careful, however, that it does not go too low, do you manage to eat a little and frequently?" Thus, she tells him that he is doing well but also reminds him to keep his focus on eating habits because those influence the glucose level.

In the messages, nurses also ask patients to reflect on data and events, rather than providing ready-made interpretations and explanations. For instance, if a patient with diabetes had fluctuations in glucose level over a week, nurses would ask a question along the lines of "I see that your blood glucose level has changed, have you done something different this week?" This, according to the nurses, should trigger the patient into reflective thinking: have they for instance eaten differently, or not exercised, or had the flu? The average values calculated in ProAct is also often used to trigger reflections. For instance, by drawing attention to a decreasing average value over the last 4 weeks, the nurses would ask the patient to think of why this is the case. In one extreme case a patient with a heart condition tracks glucose because of a family history of diabetes. She has been asked to monitor her glucose level to catch any sign that indicates that she might be developing the disease. Thus, by tracking glucose, she is guided by the nurses into focusing on which habits affect her glucose level, and she learns the effects of e.g. food and physical activity. To help her, the nurses ask her to take measurements before and after exercising, to teach her how the mechanism of glucose regulation works in her body. This, in turn, is intended to help the patient to reflect on the choices of food and the extent of exercise and motivate her to change her behavior accordingly, e.g. by making healthier food choices. Nurses use messages to push patients to reflect on the correlation between what they do, how they feel, and what the measured values are. They worry that without an ongoing dialog, patients will "slip through their fingers". Relying only on the automatic alarms is thus not enough: a patient with acceptable values and answers would not generate any message. Without the messages, caring at a distance risks becoming meaningless for the patient.

Discussion

A crucial aspect of chronic care is that coping with a chronic disease is a continuous long-term effort. The aim of the care process we have described, is that patients become partners in a continuous conversation that iteratively builds up their knowledge of their disease and of how to manage it. Over time, patients learn how their habits affect their condition (e.g. how alcohol affects glucose), how medicines work (e.g. should insulin be taken before or after a meal?), how their condition can be acted upon (e.g. what a headache or insomnia may mean and what to do). The nurses reflect on how digital representations not only give them insight into the patients' state but also can be used to motivate the patients to continue generating data and

self-manage their disease. For nurses, this is a continuous learning process, as chronic conditions can develop and interact in unexpected ways over time. The nurses need to learn which methods are most effective in providing remote care for chronic conditions, what works in some cases (e.g. to a depressed patient they would write bold statements), and what does not work (e.g. an overweight patient that stops using the digital scale because her weight is increasing).

Remote care is part of the current trend where the world is increasingly instrumented by digital sensors and devices. This development transforms how people know and work. Researchers have from the 1980s been interested in understanding how workers have gone from a physical to a digital workspace, asking what new skills are needed, what new opportunities for innovative and effective practices are enabled, and what mediation through digital representations imply for knowledge (Hanseth and Monteiro 1994; Zuboff 1989). Although these are old questions in the discipline, they must be continuously revisited as new technologies are taken into use, which radically alters the way knowledge, representations, physical reality, and work practices hang together. The ubiquity of digital systems in contemporary knowledge work creates a large variety of how digital technology's representational capacity plays out in practice. Thus, we need both to theorize about the general characteristics of digital technology's representational capacity and more specifically about the arrangements where they are generated and used (Jonsson et al. 2018; Monteiro and Parmiggiani 2019).

In this paper, we asked the following research question: *How are representational configurations in healthcare shaped by the participation of patients through patient-generated health data?* In the findings, we empirically accounted for how the capacity to represent active patients is produced in interactions between nurses, patients, and technologies. We found that the nurses interact with the ProAct system to generate digital representations, which they use to understand and care for their patients. They continuously reflect on the relation between the representations and what they represent, i.e., the patients, by triangulating different types of representations against each other. They also work to make their patients understand and reflect on the representations in relation to their own health and wellbeing. As illustrated in figure 3, the patient thus becomes both a represented object and an active agent in the representational configuration. Theoretically, we characterize the configuration as having a multiloop dynamic of reflection and understanding, where the loops feed into each other. The patients partake in generating representations, which in turn shapes their understandings. This understanding, together with reflection on how the representations are generated and how they relate to physical and psychological states of the body, in turn, shapes how both nurses and patients generate representations. This dynamic therefore becomes an underlying logic for how the different users and technologies interact.

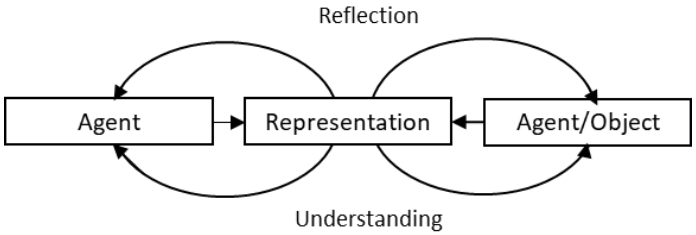

Figure 3. A multiloop representational configuration.

Theorizing multiloop representational configurations allow us to complement earlier discussions on representational configurations. The representations produced in the configuration are *both referential and performative*. With referential, we mean that a representation "point[s] to something definite in the world, a physical entity" (Bailey et al. 2011, p. 1486). In the case, digital sensors are used to record various measurable states of the patient. All parties are aware of errors and mis-calibrations that can make a measurement inaccurate. And all measurements, for example of a pulse, are mediated by the technologies' methods for capturing and calculating data. Nevertheless, the generated representations point to something physical. This means that the representational configuration under study can, at least to an extent, be evaluated by how *faithful* the representations are to their physical referents (Burton-Jones and Grange 2012). This does not entail a direct physical relation between the representation and the represented; links between symbols and referents are always established by convention (Oshri et al. 2018). A representation consisting of the label "Pulse" and the number 90 does not have a direct relation to a person's heart-beat;

instead, the person derives meaning from this based on a background of conventions and technological configurations (Mingers and Willcocks 2014). Because there is no direct link, it has been argued that the key issue in working on, with and through digital representations is related to trust (Bailey et al. 2011): how do people working with a physical objected mediated by a representation know that the representation actually represents the object faithfully? The reflective loops in representational configurations are therefore crucial; they enable conventions to be established and re-established and trust in the referentiality of the representations to be developed.

In addition to being referential, the representations in our case are also performative. With performative, we mean that the representations partake in forming what they portray. The nurses work to structure the data into representations that nudge the patients to think and act in specific ways. By combining quantitative data pointing to a physical or psychological state with a qualitative interpretation of this data, the nurses perform the digital patient as well as represent the real person. Bailey et al. discerned between manipulating objects and communicating with people through representations (Bailey et al. 2011). In our case, the nurses are not manipulating their patients as objects, as one would manipulate machinery in a digital control room. Neither are they using representations merely to communicate, as in text messages representing someone's utterances. Rather, they are manipulating digital representations to enable their patients to understand and reflect on the same representations.

Most literature on digital representations takes either a referential or a performative stance to digital representations and the configurations that produce them. Klein and Hirscheim argue that studying digital technology's capacity for representing "real" phenomena is a "dead end", justified by the flux of reality (Klein and Hirschheim 2006, p. 313). Orlikowski and Scott have argued for a theoretical move from representational to performative accounts of digital technologies (Orlikowski and Scott 2015). Quoting Barad, they write that the "the move toward performative alternatives to representationalism shifts the focus from questions of correspondence between descriptions and reality (e.g., do they mirror nature or culture?) to matters of practices/doings/actions" (Barad 2003, p. 802; Orlikowski and Scott 2015, p. 700). In other words, we should not ask about the fidelity of the representations based on patient-generated data, but how patient-generated data "create what they purport to describe" (Orlikowski and Scott 2015, p. 700), e.g. the boundaries, identities, and actions of the "good patient". As the nurses work to make patients understand and behave in new ways, the representations created in this practice are performative. What the multiloop model of representational configurations introduces is an understanding of how this performativity works. Patients are performed in the multiloop dynamics of understanding and reflecting on digital representations, at the same time as referentiality exists between the representation and the represented.

Building on Monteiro and Parmiggiani's work on digital technology and knowledge, we argue that digital representations can be both referential and performative because digital technology's representational capacity is both scoped and open-ended (Monteiro and Parmiggiani 2019). Digital technology is open-ended because digital artifacts can be combined and recombined in a variety of ways and thus represent the same physical phenomenon in multiple ways. Relatedly, digital representations are scoped, in that "what you know is intractably connected with how you know it" (Monteiro and Parmiggiani 2019, p. 14). As in all representational phenomena, a configuration of technologies and practices can generate representations that have high fidelity, while at the same time scope out parts of the phenomena it represents, allowing it to be performed in specific ways.

Conclusion

In this paper, we have discussed digital representations in the context of remote care. Humans have for millennia handled aspects of the world through the representational means of writing. Knowing and working through digital representations is nevertheless one of the most profound changes brought on by digitalization (Kallinikos 2011). Scholars have dealt with this change by analyzing referentiality, the link between representation and reality, and how work practices shape and are shaped by representational configurations. Some scholars have also argued that representations are not representational but performative, in that they shape what they claim to portray. Our contribution to literature is to show how the inclusion of active patients in representational configurations can lead to multiloop dynamics of understanding and reflecting. In turn, these dynamics lead to representations that are both referential and performative.

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