



# COMMUNICATION AS ONGOING CARE PATIENTS AS ACTIVE PARTNERS IN CARE WORK WITH MYCHART

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# KEYWORDS

CARE INFRASTRUCTURES, SELF-CARE, COMMUNICATION, INFORMATION, PARTICIPATION, CHRONIC DISEASES, MYCHART.

# ABSTRACT

THIS ARTICLE INVESTIGATES HOW THE PATIENT PORTAL MYCHART IS CURRENTLY EMBEDDED IN THE INFRASTRUCTURE FOR THE COLLABORATIVE CARE FOR PEOPLE IN REHABILITATION OR LIVING WITH CHRONIC DISEASE. WE AIM TO SENSITIZE DISCUSSIONS ABOUT LOGICS OF CARE (MOL, 2008), CARE INFRASTRUCTURES (DANHOLT & LANGSTRUP, 2012) AND THE PUSH FOR SELF-CARE TO THE ROLE OF INFORMATION, MEDIATED COMMUNICATION AND PARTICIPATION IN ACHIEVING GOOD CARE. WE BASE OUR ARGUMENT ON FINDINGS FROM FIELDWORK AMONG PATIENTS AND CLINICIANS AT TWO HOSPITAL UNITS FOR GASTROENTEROLOGY AND CARDIOVASCULAR DISEASES IN COPENHAGEN AROUND THE IMPLEMENTATION AND USE OF MYCHART FOR INFORMATION, COMMUNICATION AND PARTICIPATION IN SELF-CARE. OUR FIELDWORK INDICATES THAT PATIENTS HAVE CLEAR – BUT VERY DIFFERENT – PREFERENCES FOR ACCESSING AND ENGAGING WITH INFORMATION AND COMMUNICATION THROUGH MYCHART. WE LINK THESE MODES TO EXPERIENCES OF AUTHORITY, ROLE-EXPECTATIONS AND THE PROSPECT FOR JOINT DECISION-MAKING IN HEALTHCARE. WE SUGGEST THAT THE INTRODUCTION OF MORE COMMUNICATIVE FLEXIBILITY FOR SOME PATIENTS SPEAKS TO AN IMPORTANT ELEMENT IN CONTEMPORARY CARE INFRASTRUCTURES, REGARDING MEDIA CHOICE. THIS CHOICE, WHILE SEEMINGLY TRIVIAL, GRANTS THE PATIENT COMMUNICATION AGENCY AT A POINT WHERE THE PATIENT CAN ACTUALLY MASTER THE ROLE OF ACTIVE PARTNER IN CARE. WE FURTHER SUGGEST THAT ATTENDING TO OFTEN OVERLOOKED RITUAL ASPECTS OF COMMUNICATION MAY HELP QUALIFY ANALYSES OF CARE IN PURSUIT OF A GOOD LIFE.

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## Introduction

In 2016–17 the hospitals in the Capital and Zealand regions in Denmark implemented the new patient portal, MyChart (in Danish: Min Sundhedsplatform), as part of a broader IT-infrastructure for healthcare, The Health Platform (in Danish: Sundhedsplatformen). It is a portal meant for patients who for example take part in a rehabilitation program after hospitalization, and for people with chronic diseases, making them able to better manage their disease and chronic living in collaboration with their professional healthcare provider. Parents are able to do the same on behalf of their children, and so are spouses to e.g. frail people, who have given consent. Ultimately, the goal of the platform is to provide better and more efficient care, but it is also foreseen to offer patient empowerment and collaborative care by promoting the notion of the patient as an active partner in their own care (Sundhedsdatastyrelsen, 2019). Citizens, patients and spouses 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 have been tasks and responsibilities of clinicians. Patients’ work in this regard may be described using the vocabulary of self-care and self-tracking. In the self-tracking literature, new forms of patient-driven monitoring of health issues through the use of IT have been celebrated in and cast to revolutionize the medical system (Hansen, 2012; Swan, 2009), even if empirical studies have modified and challenged such claims (e.g. Lomborg, Langstrup & Andersen, 2020; Weiner & Will, 2019). MyChart is not designed and marketed as a tool for patients’ self-tracking, but it allows for some of the same kinds of information processing and communication that is typically implied in such healthcare apps and services.

One version of MyChart is meant for hospitalized patients, while another is meant for out-patients. Further, not all hospitals offer both versions, and the functionality may vary among both implementations of the portals, which makes comparisons difficult. On a general level, studies of MyChart and similar platforms have pointed to their potential to enhance e.g. patients’ engagement, improve their understanding of the illness, and increase self-efficacy for self-management (Ramsay et al., 2018; Redelmeier & Kraus, 2018). In order to increase the low number of uptake and usage of MyChart for a group of outpatients (minority, urban adolescents) Ramsay et al. (2018) offered help to sign-up when patients came to see their provider at the hospital. Over a nine-month period only 28% of those who were helped to sign-up had actually used the portal, even though in an on-line survey offered after the sign-up session, the patients had reported that they would be especially interested in appointment reminders (92%), lab results (75%) and general health messages (64%). A study of the other version, MyChart Bedside, showed that 78% found it easy to use, that it improved communication with nurses (74%) and physicians (53%), and helped them understand their medication (90%) (Winstanley et al., 2017). Additionally, 32% reported that they needed help to learn to use the platform, while patients in the other study only received help to sign-up. It is worth noting that both studies relied solely on a web-based self-reported survey, which did not allow the researchers to dig deeper into the backgrounds and reasons for the answers. To mitigate for this methodological limitation, we have conducted two longitudinal field studies using interviews and observations as our primary data collection techniques. In addition, we contend there is a need for grounding empirical studies of MyChart in a long history of theorizing both in care and communication.

Departing from the concept of “care infrastructures” (Danholt & Langstrup, 2012) this article investigates how MyChart is currently embedded in collaborative care for patients in Denmark. Chronic illness implies the need to manage and treat a disease for long periods, and for some patients being chronically ill is a lifetime project. It involves daily work distributed between patients, informal carers such as spouses and health professionals; and it is situated in and between the home and hospitals or clinics. For Danholt & Langstrup (2012), the concept of care infrastructures sheds light on self-care as a decentred practice, enacted everyday along several tracks that all take part in care. As Langstrup (2013, p. 1010) argues, the concept of care infrastructures provides a lens through which we can see and map the socio-material arrangements that make this work spatially distributed. MyChart is, as part of a care infrastructure, envisioned to become a mediating technology to facilitate ongoing communication between patient and clinic, thus adding a temporal flexibility to self-care and collaborative care work.

In general, the platform introduces a new media choice in the patients’ ongoing communication with the clinic. While patients can still call the clinic during opening hours, MyChart enables patients to receive information and communicate in writing with their physician about their treatment at a time and place convenient to them, for instance on the bus on the way home from work or when they experience symptoms at night. MyChart also facilitates patients’ monitoring of their disease through access to test results and clinicians’ notes. Indeed, having access to one’s medical trajectory is often seen to enable self-care and

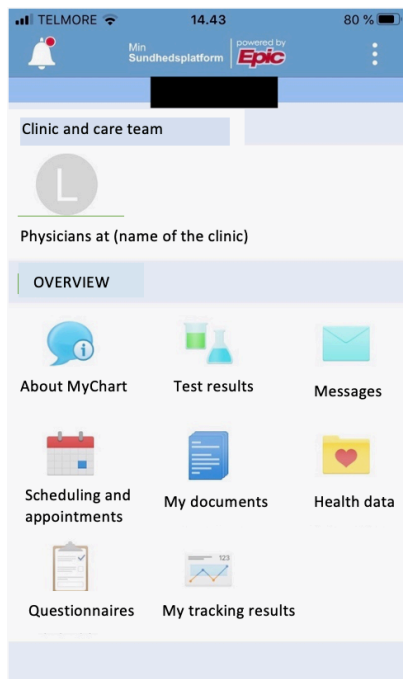
engage the self-managing and self-monitoring individual in para-clinical practices (Greenfield, 2016). However, the idea of self-care also potentially shifts the responsibility for the patient's health, diagnosis and treatment from the medical professionals and the system to the individual patient (Lupton, 2013; Wang et al., 2014). This holds the potential to destabilize the institutional arrangements and expert regimes in the medical sector as well as reconfigure the relations between patients and healthcare professionals in care infrastructures (Winthereik & Langstrup, 2010).

Zooming in on the patient's position in the care infrastructure, the aim of the article is to develop an understanding of the experiences, opportunities and challenges MyChart presents to patients in rehabilitation and/or with chronic diseases. This is done with a specific focus on how the platform provides information and facilitates communication that enable patients to engage as active partners in their own treatment. We draw on empirical data from two case studies: one of heart patients' experience and practice of using MyChart as part of their medical treatment and rehabilitation, and another among patients diagnosed with chronic inflammatory bowel disease. The empirical studies were conducted at two hospital units for Gastroenterology and Cardiovascular diseases in Copenhagen, Denmark, around the implementation and initial use of MyChart from 2016 to 2018.

In the following, we first present MyChart and its main functionalities. We then offer a communication-based theoretical framing of the idea of the patient as an active partner in care, unpacking the relation between communication and care, before introducing the two case studies and presenting our key findings. We focus our analysis on how patients experience MyChart and specifically, we study what information is sought and exchanged through the platform, what is communicated, and to what extent the communication facilitates patient participation in terms of self-care and collaborative decision-making with clinicians through MyChart. Finally, we use our findings to discuss the possible renegotiation of medical authority and responsibility in care that MyChart in principle enables, and to point to the potentials and drawbacks of patient participation in digital care infrastructures.

## Setting the scene: MyChart and the push towards collaborative care

MyChart is a patient portal linked to The Health Platform, the main parts of which are electronic health record (EHR) modules for clinicians' notes, lab tests, ordering, and medication. The Capital Region of Denmark and the Region Zealand joined forces in a call for tender and the subsequent procurement of a new EHR system. The winner was the American EPIC system, which has widespread use in the US, e.g. at Kaiser Permanente, and which has been implemented in the UK, Australia and The Netherlands, and since 2016 also in Denmark.



**Figure 1** The MyChart app homepage  
(Danish version, translated)

The Health Platform and MyChart are part of a larger and complex digital communication infrastructure that links health care professionals, citizens and government agencies in Denmark. It includes other public portals such as sundhed.dk (sundhed.dk, 2020) and borger.dk (borger.dk, 2020), eBoks (eBoks, 2020), as well as the day-to-day communication between healthcare centres, clinicians and patients through SMS (e.g. consultation reminders), e-consultation, phone calls and face-to-face communication. In addition to the connections between healthcare professionals and external stakeholders and citizens, the healthcare sector in Denmark operates through a vast number of sparsely inter-connected information and communication systems (e.g. electronic patient records, clinical databases, and cooperation software). In this article, we home in on MyChart, the new 'patient entry point' for the healthcare infrastructure, to explore how it might facilitate patient-clinician collaboration and self-care. MyChart comes as both an app and desktop application and includes a range of functionalities that are expected to promote self-care and patient empowerment, enhancing patients' capabilities for acting on their own treatment and well-being. Figure 1 presents a screenshot of the homepage of the MyChart app after login. We walk through the most important functionalities in the following.

MyChart facilitates one-way information from the clinic to the individual

patient. Upon personal login, the patient can access test-results, general personal health information, and clinical notes from their treatment at a time and place convenient to them. Such information may also be gleaned from e.g. sundhed.dk, and MyChart is thus not unique in pushing information from the healthcare providers to the patient.

MyChart also enables *reciprocal message-exchange between healthcare professionals and patients*. This may take the form of short standard exchanges such as patients requesting prescriptions that the healthcare professional then prescribes, or more ongoing communication regarding the patient's worries, experiences and possible actions in relation to their disease, treatment and rehabilitation. This possibility for continuous communication is a unique new option made available to patients seeking continuous guidance, coaching and support in managing their disease. It is akin to email consultations (Grønning & Assing Hvidt, 2018), but arguably offers a more informal, open-ended exchange.

MyChart furthermore functions as an *appointment booking system*. This allows the patient to look for available time slots for visiting the clinic, granting an overview of the available options that is seldom obtainable if calling the clinic to make a booking – which may also involve waiting in a queue. Arguably, then, this feature places more initiative in planning of treatment on the patient.

Lastly, MyChart enables *ongoing monitoring of the patient's disease and overall health*, by way of customized questionnaires (PRO), and measurements of relevant health indicators to detect, for instance, flares of chronic diseases, as indicated in test-results over time. By way of these features, MyChart in a sense becomes a self-tracking device, allowing patients to monitor their health over time. It is important to stress, however, that MyChart is not currently designed and marketed as a tool for patients' self-tracking, even if it allows for some of the same kinds of information processing and communication that is typically implied in such commercial healthcare apps and services.

In sum, MyChart is envisioned to facilitate patient self-care in collaboration with healthcare professionals through a rich set of functionalities. While these technological functionalities are not necessarily new to the care infrastructure, the combination of them on one single platform is intriguing. In a sense then, MyChart constitutes a highly relevant and timely case for examining how well the political winds and technologically enabled invitation to participate in patient–doctor collaboration and self-care match the practical realities of using the platform to manage rehabilitation processes or live with chronic conditions.

## Theoretical framework

What does the notion of the patient as an active partner in collaborative care mean in this context? We borrow inspiration from audience researcher Nico Carpentier's (2016) theoretical work on degrees of user activity and involvement in media production and reception. Developed to qualify what is labelled the participatory turn in audience research, Carpentier introduces a continuum from *access* (to technology, content and relevant others), over *interaction* (i.e. using technology to co-produce and interpret content, receiving feedback from relevant others) to *participation* (defined as the ability to co-decide on technological preferences, content etc).

The political vision of MyChart is to *digitally* include and engage patients in their own treatment and care processes, through offering more information as well as new opportunities for communication and participation. Hence, if we transfer Carpentier's categories to MyChart, we find it is envisioned to facilitate patient self-care through *access to information*, i.e. parts of the clinicians' notes and tests results, *communication* with clinicians, managing appointments at the local hospital etc., and thereby ultimately *participate* in their own care through shared decision-making and self-care. Contributing to the achievement of value-based, efficient healthcare, MyChart specifically envisions patient self-care to grow from its provision of technological affordances for the patients to track and share additional contextual information that may be relevant for evaluating their health and recovery status. Thus, – at least in principle – the patient using MyChart is invited to participate in negotiating what data may be relevant to their treatment. The patient-as-data-provider communicates directly with the system, rather than through the medical professional intermediary.

The likely result of such patient communication with the system is messy information: the patient will deliver structured data in the form of patient-reported outcomes (PRO). But on top of these data are – possibly – reports on subjective judgments of wellbeing or insecurities regarding the patient's condition, as well as a vast array of metadata indicating the patient's physical

context at the time of communicating, e.g. timestamps, GPS location etc. These data are derived from the personal media (laptops, smartphones) that the patient uses for communication and which enable anytime-anywhere access and communication to the clinic. In a longer time-span, such data may prove important for patient monitoring, screening and analysis, and for patient self-tracking, but they also present kinds of personal data that the healthcare system may be less accustomed to deal with (for instance, they are not sensitive and critical in the same manner as clinical test results). Nonetheless, these data require measures and practices for personal data protection and raise ethical questions for the healthcare system.

With MyChart, the patient is given a new array of choices in the hope that these will enable patient empowerment and self-care. Yet, such ideas have been forcefully critiqued, for instance, for responsabilizing individual patients who are not always well equipped to interpret the symptoms and responses to their disease, let alone to make decisions about treatment and health (e.g. Prainsack, 2017). A seminal critique comes from Mol (2008) whose work on contrasting logics of choice and logics of care has demonstrated that good care often clashes with logics of choice. This is in part because the logic of choice positions patients as autonomous consumers and risks leaving each patient to their own (commercial) devices for disease monitoring, and to doing the work of care on a day to day basis more or less alone. Mol contrasts the logic of choice with a logic of care that is more flexibly appropriated to the situated and personal conditions of patienthood, and also speaks to the agentic capabilities of individual patients. Writing in favour of the much more complex logic of care, Mol argues that even if not consciously selecting between various options to deal with their condition, patients are active subjects doing stuff without which care would be impossible. For instance, they provide information to physicians about symptoms, and they decide on whether to follow the doctor's orders. Indeed, care, and associated care infrastructures (Langstrup, 2013) must be understood as a complex entanglement of institutional resources, professional caregivers, relatives, patients and the medication and technological devices used in treatment for better health (see also Weiner & Will, 2018). At the same time this points at care as relational and distributed across multiple agencies and materials (Bellacasa, 2012, 2017). It also raises questions about how to balance the collaboration between clinicians and patients, manage the distributed responsibility for treatment and care, and foreground choice for patients in a constructive way.

Patients, after all, live their lives with conditions, while managing their daily business, catering to personal and social needs as well as to the structural demands of everyday life. They may, as Weiner and Will (2018) suggest, find relief in having their health problems put out of sight, which may be difficult if responsabilized more profoundly for monitoring and managing their own care.

We posit that qualifying a care-centred distribution of responsibility may fruitfully start with understanding communication as a form of care. Without further developing this idea, Mol (2008, pp. 87-88) in fact notes that good communication is itself a form of care. We pick up Mol's idea to explore communication as a form of care. We identify relevant situations of choice and assess the experienced possibilities and challenges of using MyChart for patient participation in care through access to information and ongoing communication. For this, we revisit the basic features of communication, which are independent from technological media that channel communication.

Firstly, communication is fundamentally uncertain; it is made up of gaps, writes communication philosopher John Durham Peters (1994), to sensitize us to the fact that we can never be certain we really understand one another, although we must act as if we do to achieve a sense of meaningfulness in the process of communication. Communication can be compared to dancing: it requires careful ongoing coordination and adjustments of movements, utterances, mimic and posture to achieve a sense of mutual understanding. That mutual adjustment, trying to take each other's perspective and respond accordingly, we contend, may be seen as a very basic element in an understanding of care as relational. Secondly, when we think of communication, we typically think of information transfer, but as communication scholar James Carey (1992 (1989)) reminds us, there is also a ritual dimension to communication. Communication is not merely a process of information transfer, but a ritual practice, which is constitutive of social roles, frames of relevance and norms in specific situations, and ultimately, a foundational resource for acting in and on the day-to-day realities of individuals and societies (Carey, 1992 (1989); Craig, 1999). Such ritual aspects come into play as responsibility in care is (re)negotiated in the communication between patient and clinician. Synthesizing Carey's pragmatic communication theory and Carpentier's (2016) degrees of user participation, we understand patient self-care as a form of participation centred on the patient's own actions towards managing a chronic condition. These actions are, in turn, enabled by access to information and ongoing communication with healthcare professionals in care infrastructures.

## Research design

In the early stages of the implementation of The Health platform and MyChart, we conducted two case studies at two hospital units in Copenhagen, one for Cardiovascular diseases and another for Gastroenterology. The first study focused on patients who have been recently discharged after being treated for a blood clot and were offered rehabilitation at a clinic at the very first hospital in The Capital Region of Denmark to implement and adapt to the new system. We studied the consultations between patients and nurses that each patient was offered as part of their rehabilitation plan. These consultations lasted for ½ to 1 hour, and typically, 5 consultations were found to be enough by both patients and nurses. Our study ran for 13 months in 2016–2017. A research nurse from the clinic recruited 5 patients and 3 nurses. The nurses were all trained and experienced in rehabilitation. Patients were included if they were about to be discharged after treatment of a blood clot, if they were fluent in written and spoken Danish, and if they were regular users of computers for health purposes (e.g. mail with GP and searching the internet).

Data for this study were gathered through artefact and document analysis, and through recorded and partly transcribed interviews and observations in patients' homes and in nurses' offices. Initially, a tape-recorded interview was conducted with one of the nurses to get an introduction to the rehabilitation program, the written material involved and the parts of The Health Platform that she uses before, during and after the consultations. A tape-recorded interview was conducted with each of the patients in their homes, or at another site chosen by them. The main part of the data was gathered through a 5-10 minute interview with patients before and after each consultation, and during observations of the ½-1-hour consultations. In total, 23 such tape-recorded processes took place. A guide was drawn up for the interviews, while not for the observations, which were explorative in aim.

The second case study focused more narrowly on patients' use of MyChart, specifically patients who recently had been diagnosed with inflammatory bowel disease, and as part of their treatment were monitored and regularly in contact with the Gastroenterology unit at a local hospital in Copenhagen. The study ran from May to August 2018 and included interviews with 5 patients. The patients were recruited by help of the clinician who was the main responsible for their treatment. The interviews lasted from ½-1 hour and were conducted at the clinic or in patients' homes, or at another site chosen by them. Each interview was tape-recorded and partly transcribed afterwards. In May 2018, we also created a video-recorded three-hour workshop at the unit to test and qualify the functionality of the messaging system in MyChart. Three doctors, six nurses and one patient attended the workshop. The workshop resulted in a flow chart of the communication process illustrating how The Health Platform mediates communication when a patient contacts the clinician through the system.

In both projects, the patients and health professionals involved were given an information sheet about the study, and patients were asked to sign a consent form, which they all did. Data were stored according to our university's procedures for data security. In Denmark, this type of study does not require approval from an ethics committee. We analyzed the two datasets through a focused coding of practices of information and communication that inform the patient's ability and willingness to participate in collaborative care with MyChart. All informants have been anonymized.

## Analysis: Information and communication for care with MyChart

In the following, we present our findings on how MyChart is actually used as an infrastructure for information and communication to discuss its potentials and pitfalls for enabling action through patient participation in self-care, and to explore in what ways communication via MyChart may be understood to facilitate forms of care.

### Information

As indicated in the theoretical framework, access to information about personal health is to be considered a basic condition for involving patients in shared decision-making and enabling their self-care. In both case studies, patients were initially informed when they began their treatment or rehabilitation programme about MyChart and how it may be used. This was done

to make sure that all patients registered themselves to the platform. If patients are registered on MyChart, the hospital unit can provide information and communicate with them through the system. However, although all respondents did sign up, some of them ended up never using the system or just using it very briefly, as was also found in other case studies about MyChart (e.g. Ramsey et al., 2018). One barrier for accessing information through MyChart seems to be these patients' ability to navigate the system. Some of the patients reported not being able to locate the information they were looking for while others lacked the competences needed to interpret the information presented to them by the system. One patient directly refrained from checking out the system, despite repeated encouraging efforts from his nurse during the eight months of his rehabilitation programme. He seemed confident that he was able to manage his condition well-enough without MyChart.

For clinicians, the consultations with patients have standard elements, which pertain to the disease and treatment, and the role of MyChart. Hence, they make sure that patients get oral or written information about their illness, different options for treatment, medication and/or relevant rehabilitation programmes. Furthermore, they collect information from the patient to type into The Health Platform, for their own use and for other personnel involved at the hospital and in the municipality, who are responsible for treatment or parallel rehabilitation activities on exercise and dietary programmes, for example. During consultations, clinicians take notes and after the consultation they write a summary that is made available for patients through MyChart.

Yet, while consultations normally cover a variety of aspects and aim 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 of the rehabilitation patients, Stewart, notes on the experience of leaving a meeting with the clinician: "...you think you have thought things through, but then this insecurity comes". The same patient envisions MyChart 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". This quote points to issues of information needs, availability and responsibility for the patient, which are generally perceived as somewhat problematic by this particular patient. A wish for being informed and engaged that is not supported by the system.

Several of the patients envision MyChart to gather and provide all the information relevant to them and their specific situation in one place rather than being dispersed on different media including e.g. brochures, sundhed.dk, eBoks.dk and MyChart. Sara who underwent surgery after a blood clot asks: "For instance, why is there no information about known side effects of the medication they prescribe. I looked up the side effects of beta blockers on the net. But why is it not in MyChart? Or a link? Likewise, with the leaflets I received today on diet and physical training?" Other patients emphasize that it would be beneficial if MyChart could work as an entry point or personalized information portal, and it could also work as a useful reference point for informing spouses. Interestingly, implicit in such assertions is a sense that, at the current stage, MyChart does not in fact comprise all the relevant information, with consequences for the patients' motivations for engaging with the platform.

The interviews with patients as well as the observed consultations indicate that patients have certain expectations about being informed by the hospital, physicians or nurses on issues of relevance regarding their illness and/or treatment. They consider the hospital and the clinicians as being overall responsible for their treatment and request that information regarding their treatment, e.g. treatment plans or overviews of medication, is *pushed* in their direction. However, several of the patients also express an interest in accessing information about their physical state 'on demand', and to use information provided by the system to monitor their disease. Hence, they like to *pull* information, e.g. x-ray pictures, blood tests, or medication lists, from MyChart at their convenience. Liam, who is diagnosed with inflammatory bowel disease, uses the MyChart App to monitor his test results and to keep track of the clinician's notes. He feels a certain responsibility for taking care of his own health, and states that having access to his own data supports him in the ongoing dialogue with the clinician: "When you have access to the same data, the same facts as the clinician, then you become more equal. Then you can communicate on the same level. Not in medical terms but based on the same facts". Another patient, Sara, was at first very impressed by the type and form (oral, text and drawings) of the information she received from the clinicians before, during and after her treatment for a blood clot at the hospital. When she was sent home, she accessed MyChart, but realized that she did not find it very helpful: "I did find the lab test results and parts of the physician's notes. But I want to read all the physician's notes. And as to the blood tests, they were not well arranged. It would have been easier to see them all in one picture. Instead, I had to click on each test to see the value. Also, I missed seeing the normal values. I can't recall what they are."

As in Sara's example, some of the patients realize that the organization of information in the system and the ways in which



the information is disseminated to the patient (as the end-user) are tricky to interpret, because very often medical knowledge is required (as also documented by e.g., Deering & Baur, 2015; Prainsack, 2017), and most patients lack the competences to decode the information. Besides this, many of the patients get confused by the way information is presented to them across the different systems available, e.g. they can find the results from blood tests in both MyChart and at sundhed.dk, but the same information is visualized differently in the two systems. For instance, the patient Barry wanted to monitor the development in his blood test results over time during his rehabilitation for a blood clot, but he gave up and concluded; "... [that] the presentation of the information is unhelpful. For each category you have to click, and then go back to look at the next one, click again etc. At my own GP, I can see it all simultaneously, the values and also a graphical presentation".

Finally, in the early implementation phase, patients experienced breaches in the reliability of the system, e.g. in the form of not receiving notifications about future consultations at the clinic, not receiving test results etc., even though they had signed up for receiving online notifications. In the second case study these implications do not appear in the same way, although patients are still confused and often mix up the different systems as they receive notifications from both MyChart and eBoks by email.

## Communication

For outpatients in our study with blood clot rehabilitation, MyChart played a very marginal role in the communicative infrastructuring of the processes of rehabilitation and disease management. Although this is possibly 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. For the blood clot outpatients, the rehabilitation process implies very episodic, although systematic, contact between the patient and the healthcare system (once every six weeks). For the patients struggling with inflammatory bowel disease, communication via MyChart is more frequent, perhaps in part suggestive to the maturing of the use of MyChart by 2018 when we did the study, but also to the general characteristics of their disease. For them, visits to the clinic depend on e.g. flares in their disease, their status in the physician's screening and elucidation of their condition, etc., and consultations are thus not preplanned with the same regularity but agreed on ad hoc. In both cases, MyChart 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 and consultation about medication.

While all patients value the conversations with the nurse and physician, these meetings are fixed in time and space. In terms of communication, the relative advantage of MyChart vis-à-vis sundhed.dk and other parts of the healthcare infrastructure is that it embeds a direct channel to clinical professionals for advice, clarification of test results, booking of appointments etc. While this communication is screened by a secretary before being directed to the patient's responsible nurse and physician, MyChart thus offers a new and asynchronous communication line not found in any great measure elsewhere (indeed, the most similar facility is e-consultations with one's own GP) (cf. Grønning & Assing Hvidt, 2018). Asynchronous communication may be desirable, because it provides flexibility and allows the patient to contact the clinic when a question arises or when they have time, which may not correspond to the daily opening hours of the telephone line. Surely, the patient may have to wait for a response, which is similarly given at a time convenient for the nurse or physician.

As has also been shown in public debate over The Health Platform, the open communication line seems to create worry at the clinicians' end. Some healthcare professionals are worried that communication with patients outside of the formal consultations will be time consuming and keep them from doing their "real job" at the clinic. Old (job) roles are potentially being redefined by the intervention of technology. Our data suggest that clinicians have very little reason to be concerned about a communication overload at present. Even though some of the patients studied express that they would like the infrastructure to support a more 'ongoing' communication, i.e. the opportunity to pose questions online to nurses or physicians about a diagnosis or medical treatment when they occur in the patient's daily rehabilitation work, only a few of the patients regularly use the possibility of posing a question. One of the nurses responsible for blood clot rehabilitation recalls that since its implementation, only two patients have contacted her directly through the mail-function in MyChart, both to rearrange appointments and to pose brief questions that are probably perceived as too minor to justify an extra consultation with her. In the case of

inflammatory bowel disease, the communicative care work may be more time-consuming, but the healthcare professionals did not report in any measure that this disrupted their work.

For the patients, health communication by way of the MyChart app is woven into the general flow of everyday communication and coordination with the smartphone as the central medium. Being partly app-based, MyChart thus comes to carry a range of conventions and expectations from mobile communication in general into the management of and collaboration in healthcare, for instance, regarding the availability and flexibility in communication. In addition, the app arguably remediates already known communication situations, namely those of exchanging brief messages with peers (e.g. SMS or messaging apps) and of “calling the doctor” – which is now in writing. For some, the “new” medium presents a challenge. Harold, 80 years old and living with inflammatory bowel disease, does not feel comfortable using the computer, let alone the MyChart app. He relies on his wife to check for messages from the clinic. Harold and his wife prefer good old face-to-face or telephone dialogue when communicating with the physician. Harold states that with oral communication he feels competent, included, and heard when *“I receive comprehensive answers from the doctor if I ask a question”*. Arguably, MyChart may be perceived as an extra care burden by patients like Harold, who defend pre-existing arrangements of communication to get care. For others such as 34-year-old Matthew, the new opportunities for written message exchange with the physician is a relief: *“I prefer getting things in writing, because if I forget something, I can reread what was agreed”*, he asserts. Matthew has set up MyChart to provide instant notifications when he receives a message from his physician. In the interview, he further recounts how the written guidance in MyChart has made him stop looking for information about his disease elsewhere on the internet. He just uses MyChart for communication whenever something comes up. And he then follows the physician’s instructions 100% percent because he perceives the physician as the “expert”. Matthew, in this manner, constitutes an exemplary case of how MyChart might simplify the care work of the patient.

From the perspective of care, we suggest MyChart enables specific situations of communication as care. It is driven by the push for patient convenient communication where patients and healthcare professionals jointly practice care through a medium that many patients already master in daily life as such. In that sense, a seemingly trivial, but often overlooked element of care is the granting of *niches of communicative agency* to the patient, who can choose between writing and talking to the physician, depending on their preferred mode of communication. Furthermore, as a result of the possibility of exchanging written messages with the physician, the temporal flexibility of care work is enhanced. Media choice, we contend, is valuable in itself for patients, because this choice is about something on which the patient is as much an expert as the healthcare professionals. With Mol (2008), we might say that the logic of choice, in this specific situation, plays a meaningful part of the care infrastructure, as long as at least two conditions are met: One, that the element of choice is restricted to selecting preferred media for ongoing communication about day-to-day aspects of chronic disease management that do not require physical consultation; Two, that MyChart is offered as one among several modes of communication in the care infrastructure and not as a replacement of face-to-face contact for all patients. Importantly, our data do not indicate that particular socio-demographic or diagnosis-related characteristics of patients correspond to specific communication preferences.

## Discussion: authority and patient participation in digital care work

Focusing on communication as a basic form of care reveals the ongoing (re)negotiations of responsibility between health professionals and patients in the care infrastructure. Patients require various types of information and cherish ongoing communication with healthcare professionals, but they do not equally want to be empowered, engaged in, and responsabilized for their own treatment. We found that the envisioned “drive” for self-care is contradicted by most patients being comfortable by leaving decision-making and overall management of their disease to the healthcare professionals, as also noted in Piper (2010, p. 174). Many patients have limited knowledge about or make limited use of MyChart’s information and communicative options and have difficulties translating the information fed to them to meaningful points of action and participation in self-care. They need the professionals’ help and support in answering their questions and reducing their insecurity about their illness and treatment. Hence the responsibility for care and treatment cannot just be “out-sourced” to patients (see also Prainsack, 2017).

The professional caregiver function is also facilitated in new ways with MyChart, by ongoing communicative exchanges, which is not embraced by all clinicians. As a case of contemporary IT-based healthcare, MyChart underscores the relationality of care: the usefulness of the app is contingent on the communicating parties' active participation in ongoing communication and translating information to meaningful points of action.

Our analysis of information and communication as resources for participation within MyChart thus has implications for the political vision of the IT infrastructure as an enabler of better and more efficient self-care, ultimately transforming the governance of public healthcare. Our case studies suggest that present patients are not included as relevant partners for making decisions about themselves, but still addressed as recipients of "the doctor's orders". The patients, too, comfortably conceive of themselves as the ones at the receiving end of the information and communication flow. This is not surprising given historically institutionalized roles of the patient and clinician in the context of healthcare: Clinicians are seen as professional experts with interpretive authority, to be trusted, and to whom we safely delegate responsibility for cure and care. In our study, such role-division is performed and reified in the observed encounters between patients and clinicians, and in their communication on MyChart, thus speaking to ritual aspects of communication. In that sense, MyChart is at this stage not being used in a way that fulfils the vision of collaboration between patients and clinicians, even if some patients see the possibilities of monitoring the effects of treatment and self-care activities through data provided on the platform. Patients are called upon as subjects of treatment, not as partners capable of taking decisive part in the next steps in their rehabilitation process or management of chronic disease. In the context of MyChart, we are far from a scenario that fundamentally challenges epistemic and professional regimes of medical authority and puts the patient in the driver's seat.

At the same time, something is changing, namely the basic premises of communication, not least owing to the flexibility of the introduction of the app-based version of MyChart. For those who use it, MyChart in a sense offers comfort and a feeling of safety in having 'the clinic at hand' at all times – even if this is sometimes illusory. To be sure, patients are called upon, and call upon themselves as subjects of care with MyChart. But at the same time, with the communicative agency to choose their preferred modality of communication with the clinic, patients are offered a redefined role in the care infrastructure: as partners in communication – to reach a shared understanding of the situation by whatever communicative means they find suitable. By extension, this may help them in articulating a division of labor between the professional experts and themselves in their personal context of care. As long as this choice is meaningful for patients, and the healthcare system is equally responsive regardless of the medium in question, the invitation to participate in ongoing communication may signpost the initial steps of a development in which the ritualized practice of patient–doctor communication, and the social role division it enacts and sanctions, may foster more joint responsibility and collaborative care over time.

When asked to reflect on the future vision of MyChart as a resource for patients, one of our patient respondents, Stewart, stressed that for him, it is important that MyChart: "*[...] does not just reproduce the existing practices, but that it is pushed for changing and developing these*". One way to do this is by leaning more on the unstructured input generated by the patients themselves. Yet, if we consider care to be also about distributing labour and lifting away responsibility from being patient 24/7 as other work in this vein has suggested (Langstrup, 2013; Lehoux, 2008; Weiner & Will, 2018), going further down the road of patient initiative and engagement for self-care may not be desirable if we want better care. Moreover, the patients who never manage to master MyChart risk becoming disadvantaged in the care infrastructures. For them, the telephone or the face-to-face consultation remain the desirable, safe or only available communication options. If MyChart moves toward the centre of communication in care, this will, in a sense, leave them with less choice and more restricted access to the information and communication that is envisioned to support and care for them. In the context of a healthcare system like the Danish one, such a development risks undermining the welfare-based model of a free and equal healthcare system, and the care infrastructures that undergird it.

In terms of theoretical insight, pursuing a more detailed account of information and communication as resources for action and patient participation in the analysis of care might help us recognize the mundane choices that play a meaningful part in the patients' navigation of care infrastructures and the ongoing negotiation and balancing of roles in care, and qualify what is good care from the perspective of the individual patient. In a philosophical essay about the aesthetic values of care, Jeanette Pols argues that "*Attempts to achieve a good life could be supported by knowledge that attends to everyday practices of living with disease*" (Pols, 2019, p. 58). We suggest our framing of care in terms of communication as one fruitful analytical focus among others that could contribute to an agenda that puts the good life in all its variations at the centre of care infrastructures.

## Conclusion

In the coming years, the growth in data and the use of artificial intelligence will likely entail a significant transformation of the healthcare system. The development will create a basis for new ways of accessing the healthcare system and new workflows as the system becomes more digitally enhanced. It may also change the roles of clinicians and patients, the ways that they cooperate and communicate, and challenge existing regimes of competences and authority over time. Yet, the disruptive discourse of patients as active partners in joint decision-making and empowered self-care hardly matches the reality of the more incremental and subtle changes in roles and care work that our case studies indicate.

Our analysis has demonstrated that MyChart is used as yet another IT infrastructure for electronic patient records and as an information dissemination channel with patients at the receiving end. The platform is, however, to some extent being mobilized as part of a ritualized practice for creating new forms of collaboration between patient and clinician, for instance by altering the initiative in communication, and – in limited measure – the motivation structures for providing input in the system. Such developments could serve as a starting point for renegotiating expert knowledge and professional–patient roles at the consultation, but further and larger-scale empirical work is needed if we are to document and qualify such general developments.

Despite technological potential and political expectations, numerous IT-based healthcare projects around the world have struggled to fulfil their visions of efficiency and burden-relief for professionals as well as activating patients, let alone the capacity to support collaboration between clinicians and patients in diagnosing and treating conditions. We contend that this is largely a result of poor understanding of the various contexts in which IT infrastructures operate. Healthcare systems in general are organized around dealing with conditions, patients as subjects of these conditions, and treatment organized around expert knowledge and professional practices for cure and treatment of conditions. Such contextually grounded understanding requires systematic empirical effort to chart the practical engagement with IT solutions for healthcare. Our analyses indicate that patient experiences with MyChart, and perhaps in broader care infrastructures, are highly diverse, partly because patients come to this platform with very different motivation and capacity for engaging in information and ongoing communication for care, and partly simply because their health conditions vary, and some follow less predictable trajectories than others. As a consequence, the promise and prospect of care through ongoing communication to discuss insecurities, flares of chronic disease and so on may look quite different, depending on the lived experience of patients with chronic disease.

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