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Published in:
Nordicom Review

DOI:
10.2478/nor-2021-0040

Publication date:
2021

Document Version
Publisher's PDF, also known as Version of record

Citation for published version (APA):
Mahnke, M. S., & Nielsen, M. (2021). EHealth platforms as user-data communication: Examining patients' struggles with digital health data. *Nordicom Review*, *42*(s4), 45-58. https://doi.org/10.2478/nor-2021-0040

eHealth platforms as user–data communication

Examining patients' struggles with digital health data

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Abstract

Sundhed.dk is Denmark's national eHealth platform allowing citizens to access their personal health data. Based on 16 qualitative interviews with patients, our aim in this article is to examine how patients engage with their health data. First, we illustrate how patients struggle in different ways to make sense of numerical measurements and written notes. Second, we examine the platform as a communicative space and suggest that a new "medical-domestic" space arises in which medical data is interpreted and negotiated at home. Third, we investigate how health data affects patients' experiences of being involved as equal partners and how access to data potentially enhances patient empowerment, but also how expectations are sometimes unfulfilled. In conclusion, we argue for a broader public dialogue in order to make sure that the data provided actually creates an optimal starting point and does not foster insecurity or self-doubt on the patient's side.

Keywords: eHealth, health data, sense-making, communication, struggles

Introduction

For many patients, access to their health data offers hope of gaining a better understanding of personal health issues and deeper insights into treatment plans and decisions. Involving patients in decision-making processes is also a strong political desire aimed at making patients active, engaged, and well-informed partners in the health care system. eHealth platforms, which provide the possibility of transmitting, storing, and retrieving health data, challenge the current way of thinking (Eysenbach, 2001). Through the application of information and communication technology, it has become possible to make health data instantly accessible. eHealth platforms have thus started to blur traditional doctor–patient relationships and changed the role of the patient (Brown et al., 2015). Patients' ability to access their health data has become the new norm in Western democracies and is generally regarded as a positive development; however, in the context of patients' everyday life, it comes with many challenges. Petersen (2018)

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has pointed out that access to data alone does not necessarily lead to better and more informed decisions, and that a variety of competences are needed to be able to translate accessible data into meaningful information.

In 2003, the Danish Regions, the Ministry of Health, and local authorities launched Denmark's first national eHealth platform called *sundhed.dk*. Today, the platform is not only web- and mobile-based but has become a national supplier of IT-related health solutions. According to the platform's own information, they have 46 million site visits[1] per year and an average of 386,000 monthly users. 66 per cent of the Danish population over 15 years old is aware of the platform. *Sundhed.dk* provides a variety of services for its users, including, among others an overview of doctor visits, access to health journals, access to laboratory results, and administrative possibilities such as giving consent for organ donation or preventing life-prolonging treatments. The strategic goal of *sundhed.dk* is to create a digital health universe that is shared by both citizens and health professionals (Sundhed.dk, 2019–2022). The platform's vision is to help citizens "master their health"; in other words, *sundhed.dk* wishes to create an optimal starting point for citizens to become coresponsible in the treatment process.

Taking the strategic goal of *sundhed.dk* as a starting point and adopting a patient's perspective, we pose the following questions: How do patients interpret and relate to data on *sundhed.dk*? And what are the implications of having access to digital health data on patients' experiences of being active participants in the treatment process? The aim of this research is hence threefold: First, we explore how patients understand and engage with their health data and illustrate how patients struggle, in different ways, to make sense of both numerical measurements and written notes. Second, we examine the platform as a communicative space and suggest that a new "medical-domestic" space arises in which medical data is interpreted and negotiated at home. Third, we look at how the data provided affects patients' experiences of being involved as equal partners and demonstrate how access to data potentially enhances patient empowerment, but also how expectations are sometimes unfulfilled. In conclusion, we argue for a broader dialogue to ensure the data provided does not foster insecurity on the patient's side.

Conceptualising the eHealth platform *sundhed.dk* as user–data communication

eHealth platforms have been increasing in popularity since the early 2000s and have typically been user-driven solutions. Therefore, it has not been primarily medical professionals demanding such applications, but politicians, patients, and other, often technical, professionals. Denmark actively embraced digital technologies in the health sector early on, and the creation of the *sundhed.dk* platform was closely connected to the idea that access to health data creates a momentum for patient engagement and improved communication. In public discourse, eHealth platforms are typically promoted for their potential to empower by providing access to various kinds of health data. In academic literature, however, the empowerment of being well-informed as a patient also brings with it an increased responsibility on the user's side (Lupton, 2012), and eHealth platforms have been critically discussed for supporting neoliberal ideas of self-management and self-optimisation (Ouellet et al., 2015).

eHealth platforms and the health data available have been subject to a variety of studies in the medical field. Earlier academic studies on the digitisation of health data pointed toward doctors being sceptical of patients receiving access to health data (Fisher & Britten, 1993). More recent studies, however, are positive in this regard. A qualitative study (Fisher et al., 2009) examining the electronic records provided by the United Kingdom National Health Service (NHS) states that patients use electronic records to update themselves on previous consultations and for clarification when they feel that patient–doctor communication has been insufficient. Another qualitative study conducted at the Portland Veterans Administration Medical Center in Oregon, USA, concludes that access to personal health records empowers patients and enhances their role in contributing to healthcare decisions (Woods et al., 2013).

While there is general agreement in the medical field that access to data is beneficial to patients, there is a lack of research that looks deeper into how patients experience themselves through digital health data, in other words, how people *relate* to eHealth platforms and digital health data. This study sets out to close this gap by examining *sundhed.dk* as user–data communication and by engaging in literature on the Quantified Self and entanglements of human use and technical structure. In the following theoretical section, we discuss the concept of digital health data and how it relates to the user, and, finally, conceptualise *sundhed.dk* as user–data communication. The conceptual perspective developed in the following theoretical section provides a unique lens when investigating digital health data on eHealth platforms, thereby offering a valuable contribution to the field.

Questions of data

The primary question that accompanied the introduction of eHealth platforms is related to the very access to data. As stated above, actors involved in creating *sundhed.dk* generally agreed on the importance of providing access, but initial discussions focused on *when* patients should get access to their health data. In 2013, Danish citizens still only had access to their medical records with a two-week delay. In 2015, it was then decided that citizens should be granted immediate access to their data.

The debate about access led us to question the very concept of data: what are we talking about when we talk of digital health data? At first glance, *sundhed.dk* provides two types of data: laboratory results in the form of numbers and quantitative data, and medical notes in the form of keywords and short written sentences. When patients' access to data was discussed academically, it was mostly in relation to the question of empowerment, focusing on *how* access to data supports citizens undergoing medical treatment. In the following, we will discuss the issue from a data perspective, asking *which* data empowers citizens. As a backdrop to this discussion, we will draw on literature on the topic of Quantified Self (QS) and the concept of data sense-making (Lupton, 2017).

The exponential growth in smartphones and the subsequent emergence of self-tracking applications, from counting steps to following sleep cycles, spawned a QS movement aimed at creating "self-knowledge through numbers" (QS, 2020). While new technological possibilities were initially celebrated and welcomed by a broad community interested in a healthy lifestyle, over time those practices have been criticised for morphing into forms of surveillance, routine behaviour, and performance of the self (Lupton, 2016; Williamson, 2015). De Moya and Pallud (2017) note three central issues that characterise QS data: 1) digital technology as a means to capture data; 2) cognitive aspects of working toward self-knowledge or self-reflection; and 3) related behavioural adjustments. Lupton (2018: 2) takes this conceptual approach a step further, writing that "digital monitoring practices tend to position the body as a data repository". Tracking devices dissect the body into a series of numbers and measurements that call for new forms of interpretation and sense-making processes. However, QS data is not self-explanatory and self-knowledge does not arise by itself. Lupton (2018: 3) therefore proposes the concept of data sense-making to raise awareness of the "co-constitution of human and non-human sense-making". Typically, sense-making processes are related to cognitive or behavioural processes, as described above; however, Lupton argues that the hybrid entanglement of humans with data must be emphasised.

While QS data is not Big Data in the traditional understanding of large datasets, users may experience it as "big" in the context of their own lives (Lupton, 2018), and it is hence subject to individual interpretation processes. In contrast to this subjective and interpretative view of data, Hartzband (2020: 15) claims that health data is factual and verifiable and that medical professionals "establish facts either by direct measurement or by the analysis of direct measurements" and that they "need to have facts that can be verified to establish the truth or credibility of the statement".

Questions of data are strongly bound up with epistemological and ontological questions. Although health data provided on eHealth platforms follows medical standards and is not subject to personal collection processes as QS data is, it is still strongly bound to users' interpretation processes. Digital health data has left doctors' offices and entered private homes. Digital health data is accessible anytime, anywhere, and, in the light of these new practices and new contexts, it is important to understand digital health data as more than factual information provided by the medical field. It is data, as Lupton (2018: 2) puts it, that *confronts* users with "making sense of the information, deciding how valid or valuable it is" and *calls* users "to know their bodies better and more intensively, and to work to interpret these novel forms of information about themselves". As an extension to these thoughts, we understand the digital health data provided on *sundhed.dk* as data that is inevitably bound to the patient's body, *calling* and *confronting* its owners to understand and know themselves.

eHealth platforms and their users

Ever since information and communication technologies became an integral part of society, questions have arisen as to the extent to which digital technologies empower their users. While, in the beginning, access to information was viewed as being of unique and substantial value, critical studies raised awareness of the affordances of technological infrastructures. Krantzberg's (1986: 545) first law of technology proclaims that "technology is neither good nor bad; nor is it neutral". By this, he means that the introduction of technology is always subject to greater consequences than the immediate, intended purpose of the device. While *sundhed.dk* was created with the ambitious purpose of patient empowerment and improved communication, the greater consequence is that it affects patients' experiences in many different ways.

Digital media use has been studied extensively in this respect, especially with regard to sense-making processes and how habitual practices revolving around digital media inform individual life choices (Couldry, 2012; de Certeau, 1984). Digital media use from an everyday perspective is often understood as routinised and less reflexive; however, digital media studies have also emphasised that user agency should not be underestimated. While digital media use may appear as a seldom-questioned routine, several studies show that users are aware of their behaviour and often highly critical of digital platforms (Schwartz & Mahnke, 2020). Positioning the user in the context of everyday life is hence of special importance. Typically, digital media technologies are black-boxed to their users, and underlying values are therefore hard to grasp. As mentioned above, affordance is often used as a term to describe the entanglement of human use with technical structure. Dourish (2017) criticises the wide use of the term affordances and points to the fact that digital technologies are made by humans and that digital media platforms are material objects, albeit constantly evolving because of their human users.

Regardless of how the term affordances is used, it reminds us how important it is to acknowledge the user–data relationship. Even though critical studies emphasise the power aspects engrained in digital technology (Peacock, 2014), users are not without agency. With regard to digital health data, in particular, users are not passive consumers of data but must actively engage with and, as noted above, make sense of the data. eHealth platforms thus do not broadcast information like traditional media but are part of creating an active, personal relationship with the user. This emphasises the relational aspect that connects users to their health data. Checking one's health data is a highly personal endeavour that requires an active user. Digital health data is therefore not just about reading and understanding, but about building a user–data relationship in which eHealth platforms create the *context* for this relationship.

Sundhed.dk through a communicative lens

In the previous two sections, we shed light on questions related to digital health data and eHealth platforms as a context for user–data relationships. In the following, we elaborate on the concept of communication as the defining element of the user–data relationship. Traditionally, digital technologies are understood as mediators, for example, as mediators of the doctor–patient relationship. However, as we have argued, eHealth platforms do not simply mediate the experience but create a new kind of context for a new kind of relationship between patients and their health data. Following the considerations on human–machine communication (Guzman, 2018), we argue that this relationship is a communicative one.

Different post-phenomenological traditions have inquired into the issue of how humans relate to technology. One famous and often-used example is Ihde's (1990) distinctions of human–technology relationships. He describes situations whereby technology is not explicitly noted as an embodiment relationship and provides representations of reality while not being related to the actual experience as a hermeneutic relationship. What he calls the alterity relation refers to humans interacting with technology, and in his understanding that means background relations create the context of an experience.

Several writers have taken his thoughts further to look at technology as something active rather than a form of mediator. This does not mean that technology must be actively experienced (it can still be in the background), but that it is active such that it *communicates* with its users. Gunkel (2012) was one of the first to point to the fact that, because of their highly complex technological operating mode, computers are no longer instruments that must be animated but have turned into machines that *call* for an appropriate response from their users. These thoughts are in line with Lupton's (2017) ideas of data sense-making, stating that data *calls* for user responses.

In our research, we follow Lupton's (2017) and Gunkel's (2012) ideas of digital technology and, more specifically, data calling for user responses, and define this as a communicative practice. This means that communication is not just about transmitting information but refers to complex processes of negotiating meaning. Meaning is crucial, as it is the basis for patient engagement and of the desire for patients to be coresponsible. To summarise, the conceptual lens we propose in this article is to understand eHealth platforms and, more specifically, *sundhed.dk* as user–data communication. The relatedness of users to their data and the process of negotiating meaning as communicative practice are crucial elements. The perspective developed hence sheds light on the relational aspects and the entangled communicative processes that account for the complex process of patients *responding* to their data.

Method

The study is based on 16 semistructured, in-depth interviews aimed at gaining a nuanced understanding (Jensen, 2012) of the multiple layers of patient experiences. The informants were sampled purposefully (Cresswell, 1998), according to criteria of user experience, age, health history, and gender to ensure a sufficient breadth of response. The criterion "user experience" was divided into "non-users", "moderate users", and "super users". Non-user refers to patients who knew of the platform but had never or only once logged in before the interview; moderate user refers to patients who had used the platform several times for longer periods and were familiar with their health data; and super user refers to patients who had used the platform extensively on several occasions in relation to their therapeutic treatments. The criterion "health history" distinguishes patients with regard to their treatment history. We differentiated between longer and shorter treatments, either somatic or psychological.

In all we interviewed ten women and six men between the age of 24 and 74 years over a period of six months in 2018. The interviewees were recruited through the university website, via our personal Facebook profiles, and through a special interest group on LinkedIn. All respondents are Danish citizens, and Danes are generally considered very open to the use and adaptation of digital technology. According to a European Commission report, Denmark is one of the most digital countries with regard to dissemination of digital infrastructure, overall usage, and level of engagement (European Commission, 2018). It can therefore be assumed that users are able to manage basic functionalities such as the login process and platform navigation. Finding the correct information was thus not a concern for us; we were more interested in the sense-making processes and the overall thoughts our informants had with regard to their health data.

The interviews vary in length from between 20 minutes and 1.5 hours, and are fully transcribed and anonymised. Citations have been translated from Danish to English and the names of our informants are pseudonyms, albeit indicating gender. Each interview has been coded thematically (Kvale & Brinkmann, 2009), primarily based on a data-driven principle (Gibbs, 2007). Our initial readings have, however, guided our interest and formed the basis of our interview guide and, similarly, we have moved backwards and forwards between our conceptual inspirations and interview transcripts during the coding process, in line with an abductive approach (Alvesson & Kärreman, 2007; Brinkmann, 2014).

Analysis

In the following analysis, we explore the patients' experiences of their health data. Throughout the analysis, we adopt the term "patient" rather than "user" to account for our sample and avoid confusion, as our sample does not include medical professionals as users. Based on our initial coding, we structured our analysis into three themes, each covering a related group of codes. The three themes define and structure the analysis. During the interviews, we quickly learned that patients were struggling with their data, that is, the advantage of having access to data comes with a number of challenges. It is these struggles that we focus on in our analysis.

Struggling differently with numbers and notes

Sundhed.dk is used for various reasons and in different ways. All of our informants had used the platform for its medical encyclopaedia, and more than half had used the platform's catalogue of medical specialists and their personal list of prescriptions. These general functions are valued and known by most of the users we interviewed. When it comes to specific medical data concerning the individual's health and treatment process, however, the picture is somewhat ambiguous. Checking numerical values from laboratory tests, and written notes, evaluations, and hypotheses proposed by the doctors in the individual's personal health record, produces different responses and reflections. While the consequences of the numbers and statistics may be difficult to fully understand, the numbers are perceived as facts and as a system one can learn to master. Written evaluations and hypotheses may be written in a medical language that can be difficult to understand, but, unlike numerical measurements, the interpretative quality of the written word tends to produce insecurity and confusion.

Peter, a 26-year-old man with no medical conditions, used *sundhed.dk* for updates on his laboratory results when he was occasionally tested. He was generally content with the information provided on the platform, but he found some of the data confusing and the medical language difficult to understand. Although the platform creates more transparency, which he found reassuring, it could be difficult for him to assess whether the data presented painted a good or bad picture. While Peter struggled to understand his laboratory tests, Marianne learned to interpret the results of her blood tests in terms of good and bad. Marianne is 70 years old and has undergone a severe case of cancer, and she was clear from the start that she wanted to know the details of her treatment process. For her, access to the laboratory tests was pivotal in coping with the disease and giving her a sense of agency. The following excerpt from the interview illustrates the importance of being able to monitor the laboratory test results during the treatment process:

> It's a bit like having… even though you don't have any control over how a cancer develops, it's still about having a bit of control over "now, that is how it is". […] I think right from the start, in a way, even though I was in shock, I somehow took

> the disease on. And, “we must do something about it – all the stuff I got injected into me”, and of course I also got curious about “what does it mean when one number is such and such”. […] I think it’s valuable. It gives me peace of mind – or turmoil at times [laughs].

Peter and Marianne both appreciated having access to their data, and the two examples demonstrate how transparency potentially has a great impact on the patient’s experience of involvement. Data from laboratory tests requires a level of medical literacy in order to feel in control. Unlike laboratory tests, however, reading doctors’ assessments, evaluations, and diagnostic hypotheses can be easier to understand to begin with but, later in the process, fosters new kinds of concerns. Anne, 50 years old, had never logged in to *sundhed.dk* and just used the public pages with general health information. During the interview, she signed in and started reading what appeared to be the doctor’s description of one of her pregnancies and subsequent weight gain. As we discussed the different details of the text, Anne commented: “It says so in black-and-white, right? ‘Obesity without specification’. It’s not nice, after all. But there it is”. At the time of her pregnancy, doctors had recommended she keep an eye on her weight, Anne recollected, but she didn’t realise they had perceived her weight as a particular problem. “It’s a special type of information, isn’t it? …which you don’t necessarily want”, she continued.

Being able to access data on *sundhed.dk* offers the opportunity to see the health professionals’ assessments of you as a patient and “to look over their shoulder”, as an informant put it, for better or worse. Anne’s health data tells a story of the past and a pregnancy she has come to terms with. But how is data interpreted when you are in the middle of a treatment process? And what if data involves vulnerable and highly personal information about you? Three of our informants had been through psychiatric treatment, and they all emphasised the difference between being described on the basis of somatic and psychiatric examinations. The language is different, for a start, but more existential elements are also at play when being assessed by a psychiatrist or a psychologist. Tina’s case exemplifies some of the dilemmas and ambiguities that follow when you have access to the professionals’ evaluations of you. 27-year-old Tina went through psychiatric treatment. She rarely checked what she calls her somatic data, since she considered this kind of data as correct; however, the accuracy of the psychiatric data worried her at times. She sometimes felt that the professionals’ descriptions of her misrepresented her and her challenges, and, for that reason, she occasionally checked her health records. Tina explained:

> I’m interested in knowing what they’ve written about me [laughs]. I’m very interested in the text being accurate, right? Because when it’s not only somatic but they are also describing your mental state, it’s important to agree with what it says, right? […] I get sad sometimes. When I think, “well, that’s not me”. Or it creates some frustration. And then at other times, it’s just fine, right? But there have been several times when I got upset because I couldn’t recognise myself in the text, you know?

After reading the note, Tina reached out to the health professional who wrote it, asking if the data she disagreed with could be deleted. The response was that it could not, but a supplementary note referencing Tina’s comments could be added. “So that note follows you”, Tina said, “if someone bothers to read it, right?” Tina’s reflections on the consequences of having access to data illustrate how patient–doctor relationships potentially change, as patients not only educate themselves to understand data but also challenge and oppose what is documented. The technical materiality of the platform alters boundaries between doctors' and patients' knowledge; new questions arise and new conversations are necessary, as patients' interpretations of data becomes central to consultations. Digital health data, as Lupton (2017) reminds us, confronts users with information to make sense of, and patients are called to either take on the disease, as Marianne puts it, or evaluate themselves according to data on *sundhed.dk*, as Tina's case illustrates. Patients may struggle differently with qualitative and quantitative data (Nielsen & Grøn, 2013), and data may be subject to different kinds of interpretations and negotiations, but immediate access to health data undoubtedly fosters both new opportunities for self-reflection as well as patient empowerment and new concerns and struggles.

Struggling in a new medical-domestic space

Data on *sundhed.dk* is easily accessed from home – either on a computer or smartphone – and the immediate access to data enables users to read and interpret the medical data without guidance from a health professional. This may produce insecurity and concerns on the patient's side, along with a set of unanswered questions, but it may also give a sense of control, as Marianne commented. George, a 74-year-old man who had just been through an angioplasty,[2] welcomed the opportunity to check his health data online. George declared that he is "one of those people who wants to know everything. Even if the message is shit, to put it straight, I want to know. And even if I'm sitting at home, reading it on my computer". Similarly, Susan, who is 55 years old and has been through cancer treatment twice, was pleased she had immediate access to her data from home:

> Interviewer: I guess you've checked your lab test during the process?
>
> Susan: Exactly. And I have considered when I wanted to know what.
>
> Interviewer: What does it mean to receive that type of answer at home? Where there's not necessarily someone to ask?
>
> Susan: Well, that's it. Somehow, I have a blind faith that everything will be fine. I'm not on the brink of death. And of course, that idea can be shaken. But since that's how I feel, I dare to look. I don't know if I would have dared… in fact, if *sundhed.dk* had been there the first time I had breast cancer, I don't know if I would have dared.

According to Susan, her prior experience of treatment, reading about her condition elsewhere, and surviving cancer all enhances her faith in surviving a second time as well. Her experience emboldens her, so to speak, and only in that particular situation is she determined to check her data:

> Susan: So, when would I want to know? I obviously wanted to. I wanted to make sure I didn't miss anything. But that's a risk. I'm absolutely aware of that. What if I got a test for bowel cancer or some other kind of cancer? Would I be just as bold? I'm not sure because I wouldn't know about that cancer. I think it's about how confident I feel in what I'm facing. So that's why I think it must come down to something concrete, you know, in the specific case: would I dare?

> Interviewer: Yes, and would you be able to…
>
> Susan: …face the consequences…?
>
> Interviewer: Face the consequences, but also resist the temptation… the curiosity versus the fear of what you're reading?
>
> Susan: I would probably find it hard to resist, I think.

Susan and George were both well aware of the risk they took when they accessed data from home. This new medical-domestic space, in which the patient is accessing highly specialised medical data at home, potentially gives insight into a professional domain of notes for documentation, evaluation, and assumptions about diagnoses. The platform produces a new borderland of healthcare at home (Mattingly et al., 2011) that generates new reflections and considerations. Marianne remembered the first time she signed in to *sundhed.dk*. It was Christmas morning, "to add to the drama", as she put it. This first visit was one that created more turmoil than peace of mind, Marianne recalled, as her medical record indicated that the doctors suspected her condition to be a particularly aggressive form of cancer and, in that case, the prognosis was bad. Marianne was shocked but had to wait until she could talk to her doctor to ask about the hypothetical diagnosis. The ambiguous answer she received from the doctor neither comforted her nor clarified the matter further, but the example demonstrates the dilemma of either accessing data at home – enabling you to prepare for and ask qualified questions at the next consultation but leaving you without immediate professional guidance – or waiting for the health professional's presentation and interpretation of data. Asked whether or not they preferred the current option, all our informants agreed that immediate access was a privilege as well as a prerequisite for qualifying the conversation between patient and health professional. Literature on eHealth technologies traditionally describes access to digital health records as part of medicine 1.0, referencing web 1.0, whereas medicine 2.0 refers to web 2.0 and patients' sharing of data online (Petersson, 2019). However, as our analysis demonstrates, *sundhed.dk* is far from being solely a mediator between doctors and patients or an external memory system (Själö, 2005), as the platform creates a space for a new relationship between the medical institution and the home as well as a new relationship between data and patients. From that perspective, "'empowerment' becomes a set of obligations" (Lupton, 2013: 261) that prompts the patient to reflect upon their health status, whether or not they feel qualified.

Struggling with expectations

As all Danes have access to their health data on *sundhed.dk*, people have certain expectations of the platform – some are met, others not. Our informants generally expected data on the platform to offer new insights into knowledge previously reserved for health professionals. What this knowledge entails, however, is rather uncertain. Half of the people we interviewed were satisfied with the platform's data and had educated themselves to understand that data; the other half questioned what value the data contributed. Susan, who survived cancer twice – first as a patient with no access to her data and the second time with immediate access to data – emphasised the significance of being involved in the treatment process through such access. She recollected the experience of not being perceived as an equal partner during her first cancer treatment. She elaborated:

> I actually wish I had access to my own data earlier. Because I simply felt that I was one step behind all the time. […] I felt talked down to and that they talked over my head sometimes, right? It was as if I was a standard patient. But I thought I was no standard patient, I wanted to know everything, right? But I just wasn't told. I felt like they wouldn't want to scare me.

Susan wanted to be prepared for her consultations, involved in considerations and decisions about her treatment, and taken seriously as an equal partner – and having access to data is a crucial element in this. As an example, Susan mentioned that access to her own data enabled her to remind doctors of examinations in other medical units, which, in her experience, was sometimes necessary. The element of control and shared responsibility was also noted by Peter as a central part of such immediate access to data. Even though Peter had never been treated for any medical conditions, he imagined that access to data increases patient involvement:

> Peter: It's a receipt, right? And maybe some kind of control. There hasn't been anything to note specifically. But it's nice to know that if anything happens, I can go check and see what has been written about me. That's a level of control that I as a patient value a lot.
>
> Interviewer: And why control? What does that entail?
>
> Peter: I don't mean mistrust. More that… as a patient I can share responsibility for my own treatment. But also make sure to follow up on things I wouldn't be able to if my medical record was difficult to access.

While access to data is perceived as the prerequisite for being involved as a patient and as a kind of control mechanism for some of our informants, others question what kind of knowledge is gained from such data. A 34-year-old woman, Louise, logged in to *sundhed.dk* after the birth of her first child, encouraged by her midwife. She remembered the disappointment she felt when reading the data: "It's not that you get an assessment, it's just facts. There are no conclusions like 'this was a very complicated birth', or 'normal birth' or something, right? […] All you get is a process description". Louise expected to find evaluations or conclusions in the data but only found descriptive notes of the birth. In a similar vein, one of our informants, John, a 64-year-old man, expressed his disappointment with the data. John had been through several medical examinations within the previous couple of years, and been referred back and forth between units. He found the data on the platform "banal" and lacking information about the doctors' reasons behind, for example, referring him to a certain specialist. He also wanted the doctors to "write down some general reflections, other than, everything is fine, right? I mean, they could at least comment on the red numbers [numbers outside of the normal scale], right?" These statements raise questions about how patients are expected to engage with data and how patient involvement is ensured. Moreover, they shed light on the complex quality of interpretation. A lack of doctors' reflections and conclusions may disappoint patients, whereas insight into doctors' notes and considerations paradoxically possibly creates insecurity and frustrations. The importance not only of granting patients access to data, but also of prioritising resources for explanations and shared interpretation becomes obvious if misinterpretations and uncertainty are to be limited.

Discussion

Examining *sundhed.dk* from a patient perspective sheds light on the complex communicative practices of navigating, engaging with, and interpreting data as part of data sense-making processes. It also prompts us to ask: what can data tell us about ourselves as patients, and what is needed for patients to continuously engage with their data? The analysis shows that data on eHealth platforms represents an assemblage of various actors' descriptions of and ideas about the patient (Johnson, 2019); data is structured according to medical specialities' and units' examinations of the patient and according to the technical structure provided by the platform. Consequently, what the patient sees is not a coherent picture of themselves or their health data, but a fragmented representation of various kinds of medical data and the patient's, often crooked, path through the medical system, as noted by one of our informants:

> It's not produced based on who I am. I'm divided into appointments, pictures, medical records, laboratory tests, general practitioner, referrals between units, and vaccinations. I'm all those things, all of a sudden. I'm not seeing a coherent picture of myself. About my health, right?

Many patients experience health data more as a reflection of the medical institution than as a reflection of themselves as individuals. The patient's psyche and body are dissected into words and numbers and, when gaining access to health data, it is the patient's task to draw these fragments together. From that perspective, the platform discloses what is often criticised as a lack of coordination between medical units, but it also points more generally to the issue of whether the platform is the doctors' tool (enabling patients a small glimpse into their world) or an instrument for greater patient involvement and empowerment through knowledge. As the literature shows, health data can contribute to processes of self-knowledge and self-reflection (De Moya & Pallud, 2017), but these processes of gaining knowledge about one's health are also connected to increased individual responsibility (Lupton, 2012). Our analysis indicates that in order for patients to continuously engage with and make sense of their health data, new kinds of conversation are required in the clinical room, and responsibility for empowering the patient through data interpretation must be shared more strategically between doctor and patient. Since data *calls* and *confronts* its owners to understand and know themselves, doctors must be aware that whether the provided medical data supports a patient's empowerment or not depends heavily on the patient's response as a user, and it is therefore crucial that medical data does not stand alone but is understood and addressed in relation to this response.

Conclusions

eHealth platforms have become crucial to Western societies. The main idea behind such platforms is that access to health data will lead to patient engagement and improved communication. While the intention is noteworthy, not least from a political perspective, patients' everyday experiences of the medical system paint a different picture: they struggle. They struggle first and foremost with making sense of the data to which they have access. As the medical data presented is neither explained nor specified, it is up to the patient to take responsibility for either asking their doctor or finding other ways of working with the data; many turn to Google for explanations. They struggle further with the new spaces created by the platform. *Sundhed.dk* allows their users to access data anytime and, while many patients are aware of the impact the data may have on them, it is up to them to find an appropriate space and time. Last but not least, patients struggle with their expectations of the platform and thus the medical system. Many patients expect to learn something about their health and want the data to guide them, but this is not always the case. Notes and laboratory results do not come with general statements, which often leaves patients with more questions than answers.

In conclusion, we therefore argue for a broader medical and public dialogue about how to understand the data and what is expected from patients. This will help ensure that the data provided actually creates an optimal starting point for patients to take responsibility in the treatment process and does not, in contrast, foster insecurity or self-doubt on the patient's side.

Notes

1. The term "site visit" refers to a user who comes to the page for the first time or more than 30 minutes after their last visit.
2. A procedure to restore blood flow through the artery.

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