



Interpretation as luxury

Heart patients living with data doubt, hope and anxiety

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Interpretation as luxury: Heart patients living with data doubt, hope, and anxiety

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Abstract

Personal health technologies such as apps and wearables that generate health and behavior data close to the individual patient are envisioned to enable personalized healthcare - and self-care. And yet, they are consumer devices. Proponents of these devices presuppose that measuring will be helpful, and that data will be meaningful. However, a growing body of research suggests that self-tracking data does not necessarily make sense to users. Drawing together data studies and digital health research, we aim to further research on data ambivalence, a term we use to refer to the ambiguities and uncertainties people experience when interpreting their own data, as well as the critical obligation towards cultivating ethically sound uses and responses to such data in context. We develop the relationship between data, interpretation, and context as a central theoretical and practical problem in the datafication of healthcare. We then show how interpretation and context matter for data ambivalence through an empirical study of heart patients with an implanted advanced pacemaker who were offered a Fitbit wristband for self-tracking as part of a research project. We argue that the hope, anxiety, and doubt connected to the promise and accuracy of data are tempered by the context and purpose of self-tracking, and by individual circumstances. Finally, we link the findings on context-sensitivity in data interpretation to questions about response-ability in cloud-based care infrastructures. We discuss the ethical dilemmas associated with the use of commercial wellness-technologies in healthcare, and with researching such emerging practices.

Keywords

Self-tracking, Fitbit, care infrastructures, chronic patients, interpretation, ethic of response-ability

Care in the cloud? Expectations about personal health technology

Health policy advocates, politicians, and tech business leaders have high expectations for the role that personal health technologies such as apps and wearables may play in moving healthcare from the ground and up into the “cloud” in the near future (Garge et al., 2017; Rosenbloom, 2016; Steinhubl et al., 2015). It is envisioned that such technologies, which generate health and behavior data close to the individual patient or citizen, will allow more personalized healthcare—and enable algorithmically supported self-care, potentially cutting the human healthcare professional out of the loop (Fitbit Health Solutions, 2019). And yet, these devices are aimed primarily at the consumer. Fitbit and similar activity trackers were originally designed to be used for leisure and wellness activities. But as

they are being commercialized, these devices are finding their way into other domains, including work (e.g., corporate wellness programs) and disease management in public and private healthcare, thereby feeding into broader processes of datafication (Hoeyer, 2016; Hogle, 2016; Petersen et al., 2019).

The commercial market for wellness and health technology, along with movements such as the Quantified Self (QS) movement (Wolf, 2010), works on the dataist assumption that the data generated

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from using self-tracking apps and devices will enable empowerment through self-knowledge (of bodily reactions, mood, etc.); knowledge that everyone is assumed to want and use for self-optimization. Proponents presuppose that measuring and the data-based feedback it produces will be helpful, that data will be meaningful. Yet, a growing body of research suggests that self-tracking data does not necessarily make sense to users (e.g., Lomborg et al., 2018; Pink et al., 2016). These data come with a certain degree of uncertainty leading to questions such as: Are the logs accurate and complete? How do the captured data map onto an actual course of events or sensory experience? What can others use these data for? Therefore, we cannot assume that the emergent uses of self-tracking devices and data in healthcare are inherently unproblematic. This article explores what happens at the patient's end, and what the stakes are, when fitness-tracking devices meant for personal, leisure, voluntary self-measurement are appropriated and "pushed" (Lupton, 2014b) into day-to-day self-care and management of serious health issues.

The aim is twofold. First, drawing together two distinct scholarly fields, data studies and science and technology studies (STS) and other sociologically informed digital health research, we aim to further research on data ambivalence, a term we use to refer to the ambiguities and uncertainties people experience when interpreting their own data, as well as the critical obligation towards cultivating ethically sound uses and responses to such data in context. We develop the relationship between data, interpretation, and context as a central theoretical and practical problem in the datafication of healthcare and beyond (Ruckenstein and Schüll, 2017). Second, we show how interpretation and context matter for data ambivalence through an empirical study of heart patients with an implanted advanced pacemaker (ICD) who were offered a Fitbit wristband for self-tracking as part of a research project investigating how they navigate and cope with a severe health condition. We analyze patients' experiences with Fitbit data and the ambiguity inherent in such data, thus moving beyond the focus on leisure users that dominates existing work in data studies of self-tracking. Based on in-depth interviews with these "high risk" self-tracking patients in Denmark, we argue that the hope, anxiety, and doubt resulting from the promise of obtaining accurate data are tempered by the context and purpose of self-tracking as well as by individual circumstances. For heart patients who experience severe illness, self-tracking data is loaded with more emotional significance than is usually seen in empirical studies of leisure-driven self-trackers. Chronic heart patients cannot "afford" to disregard any abnormalities in heart rate, or sleep, even when data patterns

seem biased or measurements are flawed. Rather, abnormalities urge a sense of action to alleviate possible critical incidents and perform self-care, reflecting strategies of coping through hope and trust in the data. However, just as privacy has been cast as a luxury for the wealthy and educated elite (Papacharissi, 2010), the interpretation of healthcare data, including data from consumer apps and wearables, may also be perceived as a luxury, rather than a given, and thus something that must be cultivated contextually in the healthcare sector for the benefit of all.

Finally, we link the discussion on how different personal capabilities and social and professional support structures affect the interpretation of data to questions about response-ability in cloud-based care infrastructures (Prainsack, 2017; Schwennesen, 2019). We also link this discussion to the ethical dilemmas associated both with the use of commercial wellness-technologies in healthcare, and with researching such emerging practices. Our study exposes certain ethical dilemmas and calls for developing concrete practices to promote what Schwennesen (2019) has dubbed an "ethic of response-ability" when using activity data in the context of care. If we are indeed all living with data (Kennedy, 2018), and if we are moving towards a situation where patients become health data prosumers (Lupton, 2014a), how and when can data meaningfully inform people's health and wellbeing practices? We need a better understanding of the work that we are expected to do ourselves in interpreting data, in order to qualify the future role of personal health data in broader infrastructures of care (Langstrup, 2013, Weiner and Will, 2018).

Making meaning with ambiguous data

As research on the uses and experiences of digital self-tracking devices and apps becomes more consolidated, a central finding is that there are ambiguities associated with the data produced through self-tracking. This critique of data and measurement is in line with critical data studies (Iliadis and Russo, 2016; Kitchin and Lauriault, 2014), while also assuming a very empirically based form in the studies into self-tracking. Self-trackers—ranging from participants of the QS community to casual self-trackers—question the quantified measurement of their activities, its accuracy and validity as a benchmark for future performance (Didžiokaitė et al., 2018; Kristensen and Ruckenstein, 2018; Sharon and Zandbergen, 2017): the data we see may differ from what we have sensed when carrying out a particular activity (Ruckenstein, 2017) or users may manipulate their data to avoid negative feedback (Lomborg et al., 2018). Using the conceptual metaphor

of “broken data”, Pink et al.(2016) alert us to the situatedness and temporality of data, suggesting that repair work and maintenance are part and parcel of our mundane living with data. Moreover, people’s encounters with data are not just a matter of cognitive “knowing”, but equally involve sensory and affective dimensions. As Lupton et al. (2018) contend, data do not just record and represent something about our bodies, “they can also contribute to or mediate such experiences” (Lupton et al., 2018: 649). As many social scientists have noted, “data” are not solid facts to read off a device (Gitelman, 2013); it requires work on the user’s part to meaningfully appropriate and act upon the data. Expanding on such ideas, we propose that data *communicate* (Lomborg and Frandsen, 2016), that is, they offer semiotic cues to the self-tracker, who must attend to these cues by mobilizing her personal and socio-culturally constituted resources to interpret them vis-à-vis the context they are embedded in. That is, the communicative meaning of data is grounded, made, and validated in the specific context of use. The affective dimension is central to understand how data communicate and become meaningful: engaging with data about our bodies and selves can be experienced as fun, motivating, pleasurable, but equally as nagging, frustrating, and troubling (Figueiredo et al., 2018; Fotopoulou and O’Riordan, 2017; Ruckenstein and Schüll, 2017). These emotional responses are not independent of the tools and data nor of the embedded lives of the users—rather they relate in different ways to normative dimensions of what is considered “good” or “bad”, “normal” or “sick”, “better” or “worse”.

Pink et al. (2018) have accounted for the mundane experience and management of uncertain data with the notion of “data anxiety”: “Living with and having to take responsibility for data manifests itself in the form of mundane and often small but relevant anxieties, which might be experienced as more explicit worries, niggles and sometimes feelings of confusion”. Data anxiety is handled through anticipatory strategies and improvisatory work on data to repress uncertainty or make data feedback fit into existing habits and values associated with everyday life. For Pink and her colleagues, data anxiety is balanced with choosing to place trust and hope in the data—we manage our relationships with data by negotiating when and how to act on it, or by simply deciding to ignore it and move on. In alignment with our communicative perspective on self-tracking, users make data meaningful by interpreting them, thereby striving to achieve a sense of control, despite the inherent uncertainties in communicating data. We build on Pink et al.’s (2018) vocabulary of data anxiety, hope, and trust to explore how *data as a communicating entity* may make a difference for people

living with chronic illness. If data anxiety for Pink and her colleagues is a mundane, and perhaps general, experience in self-tracking, it may take on a different role in the context of healthcare. We suggest that focusing on context, and on the way it shapes meaning-making, remains a very important element in understanding and assessing the effects of individual and collective interpretation and management of self-tracking data.

In the context of patients using self-monitoring technologies for self-care, STS and other sociological digital health research has shown that self-care poses a range of challenges (Chapple and Rogers, 1999; Danholt and Langstrup, 2012), and that how patients actively engage in making sense of data in relation to self-care is far from straight-forward. For patients with diabetes, using a glucose meter can be essential to the daily management of their disease and for their long-term health. Echoing self-tracking research, interacting with personal biometric data in relation to health is not just a matter of reading off a set of facts and figures about your body; on the contrary, data is “lived”: For many people with health challenges “data become the medium and means of living with an unpredictable body” (Kaziunas et al., 2017: 85). Patients’ interactions with self-monitoring devices involve a shift away from physical sensations and towards purely numerical measurements—which then may result in new bodily sensations (Mol, 2000; Willems, 2000). Furthermore, in chronic disease management, the interpretation of data and the actions taken always involve more than the individual self—they are situated in a care infrastructure (Langstrup, 2013). They involve sharing and negotiating interpretations with clinicians and relatives: comparing results with previous measurements, forecasting outcomes, and weighing up different trade-offs when deciding what action to take (Kaziunas et al., 2017; Marent et al., 2018; Mol, 2008; Nunes and Fitzpatrick, 2015). In these cases where patients with chronic illnesses self-monitor, the measuring devices analyzed have mainly been clinical tools prescribed by health professionals to patients and as such have been part of a formal treatment arrangement. Here patients are invited to participate in their own treatment (Nielsen and Langstrup, 2018) and may become engaged as “diagnostic agents” (Oudshoorn, 2008). Fitbits and similar consumer tracking devices are in most cases not formally part of such arrangements. One of the reasons for this is that their measurements are much more generic: they are not aimed at registering clinical data about a sick body, but at collecting data that can be used by anybody. So while the STS literature alerts us to the wider personal and clinical context in which data is interpreted, we find that data studies, conceptualizing how people make sense of

more generic biometric data in self-tracking, are helpful for informing meaning-making in the case of Fitbit use for healthcare.

In sum, if data from self-tracking devices communicate, they do so by offering semiotic cues that guide the user toward possible interpretations of the meaning in the data, and by extension, indicate the healthiness of the self, which as a result may require further action. While the interpretation of self-tracking data may be validated against other data (bodily or, in the case of chronically ill patients, data provided by medical devices or health experts), it is a fundamental feature of communication and its interpretation that it is never certain; this inherent ambiguity affects both patients' knowledge production and their affective engagement with data (Prainsack, 2017). As we shall demonstrate in our analysis, the uncertainty of interpretation, and the hope, doubt or outright anxiety it generates, impacts quite differently on different individuals, in this case chronically ill people, who find themselves in very different contexts and with different capacities to act, even within such a strong welfare system as the Danish one. This, in turn, raises critical questions, and considerable caution should be exercised when chronically ill patients engage with consumer wellness devices for self-tracking and self-care (Schwennesen, 2019), and when researchers venture into this domain.

Research design

In 2018, we carried out an empirical study of how patients with an implanted cardioverter defibrillator (ICD) experienced wearing a Fitbit device and using the data it produced over a six-month period. The study was part of a broader research and development project, Self-, Collaborative- and AUto-detection of signs and symptoms of deterioration (SCAUT), comprising a consortium of medical professionals, computer scientists, and a medical software company. The project functions as a living lab to improve the treatment of cardiac device patients (Andersen, 2019), and has previously developed an online patient record system, supporting distance-monitoring through patient involvement and two-way communication between clinicians and patients (Andersen et al., 2019). The consortium wanted to explore predictive analytics—collecting and combining the data from the ICD with activity data from wearable devices to find out whether this could improve clinical decision-making and avoid dangerous heart arrhythmias. The device chosen for the project was the Fitbit Alta HR. It enables tracking of heart rate, sleep and number of steps walked, and supports visualization of data on the wearable device, in a smartphone app and online on a webpage. One of the authors was directly involved

with the SCAUT project, and two of us were invited onboard as collaborators to enhance SCAUT's understanding of what it means for patients already in treatment for a chronic health condition to make sense of and live with Fitbit data. As such, we positioned ourselves as “outsiders” to the overall project of SCAUT and contributed to framing the study towards the patients as an intervention that was external to their treatment and exploratory in nature. The project was offered to prospective patients as an opportunity to be assisted by a social science research team to develop their ability to think critically about self-collected data providing information about their chronic condition as embedded in daily life.

From the SCAUT living lab, 65 heart patients with a secondary prevention ICD were invited by e-mail to take part in the study. Twenty-seven patients volunteered to receive and wear a Fitbit Alta HR device for six months and to be interviewed three times about their experiences with Fitbit activity data. The majority of informants were males aged over 50 (with an age range from 28 to 74). The sample largely reflects the demographic composition of ICD patients in Denmark. In 2017, 82% of ICD patients in the Capital Region of Denmark were male (Hjerteforeningen, 2020).

Patients were assisted in connecting the wristband with the Fitbit App and informed that our research team would be able to access their data throughout the study period. Patients were also told that the study was not part of their formal care at the remote monitoring clinic. However, we did inform the remote monitoring care team about the study and involved nurses and bio analysts in exploring the use of the Fitbit data as part of remote follow-ups and encouraged the patient participants to talk to the care team about their data, if necessary.

We conducted 66 semi-structured interviews in total. Patients were interviewed individually, sometimes with relatives, in their homes or in convenient locations like their workplace or at the hospital. While ethically committed to listening and responding to the stories that patients wanted to share, we sought to carefully direct the conversation towards the role of the Fitbit and their interpretation of the data. Whenever accounts of symptoms or worries related to their condition came up, we recommended patients to seek advice from their healthcare professionals, emphasizing that as researchers, we were not directly involved in their formal treatment. However, as we shall see, because the Fitbit was applied in existing and already complex chronic care infrastructures and daily lives, this had a number of implications for the care process, and it was difficult for many patients to disentangle Fitbit from their status as cardiac patients.

The interviews were transcribed and analyzed jointly through five workshops. The strategy of analysis was thus to work iteratively from the empirical data and initial theoretical ideas toward a common coding scheme detailing participants' data experiences in terms of knowledge production, affective encounters and evaluation of the Fitbit data that was then applied to all patients. This coding scheme was then applied to all patients and was used to loosely group patients according to their experiences with and orientations to data. We found two overall groups: group one, consisting of 11 patients, did not really see any relation between their illness and the Fitbit data, and therefore mostly used the device for motivational purposes related to exercising, out of curiosity or for supporting leisure activities. Some patients in this group live quite happily without worrying very much about their chronic condition and do not really perceive themselves as ill.

The remaining 16 patients, group two, did connect Fitbit data with their illness in various ways. Some appeared vulnerable and struggled to manage their condition, and many experienced different symptoms such as dizziness, shortness of breath, and palpitations. They found that the Fitbit activity data sometimes supported their own reflections on their illness and provided emotional comfort, while at other times the data raised doubts and caused worries. Against this background, we developed narrative vignettes through which to analyze the specific personal hopes, doubts, and anxieties (Pink et al., 2018) provoked by the Fitbit data. Vignettes are a typical analysis strategy in healthcare and nursing research, but have also recently been used in data studies (Maslen and Lupton, 2019) as an interpretivist strategy to fully explore the depth of single cases, and to exploit the interview methodology as a process of joint production of meaning (Langer, 2016). The vignettes serve to tie data experiences and meanings to more fully fledged accounts of the embodied conditions and the embedded contexts of each of the patients in the study (Marent et al., 2018). They also serve to present developments in participants' meaning-making with the data as they evolved over time. The following analysis is based around three vignettes from typical patients selected from each "group" of patients. The three vignettes illustrate the quite different ways respondents interpret the ambiguities of data and integrate Fitbit data into their daily lives. While the vignettes cover the breadth of communicative meanings from the Fitbit data in our material, they also illustrate the types of patients, and strategies for self-care that we encountered in the study.

Ethical concerns surface to some extent in clinical studies that explore commercial activity trackers in healthcare. For example, Rosenberg et al. (2016) found that men with prostate cancer endorsed the

Fitbit Zip as they found it motivational and supportive, thereby justifying the use of fitness trackers in clinical care for high risk populations. Ancker et al. (2015), on the other hand, found that patients associated several negative experiences with self-tracking because data can be emotionally charged. As we shall see, the contextual sensitivity of the vignette method alerts us to individual variations within patient groups in interpreting data, and by extension, helps us to reveal the complexity of ethical dilemmas that may arise from introducing activity trackers into chronic care contexts.

Analysis

Data doubt: Wellness tracking and self-nudging with ambiguous data companions

Finn is a 49-year-old public-sector employee. He is married and has two adult children. Finn leads a very active life. He is an enthusiastic amateur road cyclist, cycling long distances to and from work almost every day, and he does CrossFit three to five times a week. He had a cardiac arrest in 2017, underwent bypass surgery, and got an ICD to prevent future events. The whole idea of an ICD is that the device should be able to respond—with a shock to the heart—if the patient develops arrhythmia that could be fatal. Capacity for care is distributed to the device, but the device and the patient are also part of a care infrastructure that includes remote ICD monitoring by clinicians of the patient's heart and health, communication through a digital platform and regular follow-up meetings at the public hospital.

Finn does not perceive himself as ill, and does not experience any symptoms apart from a low heart rate which he knows is caused by the beta blockers that are prescribed to him by his doctor. Indeed, he is keen to continue the active, healthy lifestyle he had before he got the ICD: because "wise men say it is perfectly safe to do high-intensity exercise". He wants to explore if the Fitbit can help motivate him further to achieve this goal, although he has a slight reservation: Finn has for a long time used other activity tracking devices, including an advanced cycling computer and a heart rate monitor worn around the chest connected to a training watch. He finds Fitbit rather basic and "low key" in comparison. As such, Finn is typical of a number of the patients we talked to, who mainly regarded the Fitbit data feedback as "a kick in the butt"—something that might help them become more physically active during the daily grind. These participants did not link the data to their illness.

On the two occasions we visit him, he tells us that he keeps a close watch on the activity data—he checks his Fitbit app several times a day to monitor his

activity level. Patients can set their activity goals as they please, but most—including Finn—go with the default setting of 10,000 steps a day. Like many other participants, Finn laughs as he describes himself as being “nudged” by the Fitbit’s prompts and preset goals: “*I think it is fun. I check it often, many times a day, because it is fun, and if I sit at work and it buzzes then I go for a walk up and down the hall to get a red dot* [a mark, a semiotic cue on the app display to indicate that he has walked the 250 steps per hour that is Fitbit’s default setting]. *I would not have done that before*”. He is surprised to see his sleep-data—which suggest he consistently sleeps quite well, even if he does not feel this is the case. “I choose to interpret this pattern positively”, he says. By *consciously choosing* a specific positive interpretation, Finn can use Fitbit to enforce a positive feedback loop (Lomborg et al., 2018), where the validity of the data does not really matter: it is more playful than serious. What is important is the patient’s wellbeing and the sense of accomplishment they feel through getting positive feedback.

At the same time, Finn does not take the Fitbit data very seriously—he says he knows that Fitbit is only indicative, and he consults his other activity tracking devices for more precise measures when he needs to. His doubts about the data relate to physical exercise, sleep, and heart rate, but it is how poorly the Fitbit measures his main training activities, cycling, and CrossFit, that bothers him most. When we look at his data during the final interview, he discovers that Fitbit has classified his CrossFit as aerobics and his cycling as walking. This leads him to question whether Fitbit is useful at all, even if he maintains that the daily, visual status updates are still helpful and motivating as overall benchmarks, especially regarding the number of steps taken and his sleep patterns.

In sum, Finn is one of a couple of ICD patients in our study who engage very actively with the Fitbit as a wellness tool—as a leisure gadget. How he uses it and his reflections on it closely mirror findings from the self-tracking literature (e.g., Choe et al., 2014; Kristensen and Ruckenstein, 2018; Sharon and Zandbergen, 2017), suggesting that self-trackers use data selectively and purposefully to further their own goals, engage critically with data and thereby take on agency and gain a sense of control in dealing with data doubt. In our interviews, patients in some instances choose to disregard specific data as being totally irrelevant or untrustworthy, but apparently do not regard this as a big problem. For them, there is no connection between the data and their ICD or their diagnosis. In many ways, Finn’s critical meaning-making corresponds to performing the role of the healthy, responsible and autonomous citizen groomed by political

visions of personalized, choice-based healthcare (Sharon, 2016) and the vision of user empowerment pushed by commercially based consumer healthcare devices. For Finn, his health problems are dealt with through an effective course of treatment and prevention; the infrastructure of care is thus relegated to the background in his daily life.

Hope in data: On the road to better (self-)care

Sune is a 57-year-old IT professional living alone except every other weekend when his teenage son stays with him. After a heart attack, Sune got an ICD in 2001. Nevertheless, Sune continues to have unexplainable symptoms such as dizzy spells which sometimes make him faint. The dizziness may partly be related to his medication, but he has been told by health professionals that he will have to be on medication for the rest of his life—a notion that he resents and wants to challenge. “I am the type who says: You can forget about that! What can I do to get off the drugs? But then you are kind of out of the loop. Then you only have yourself and you can come up with some suggestions. But if everybody did that, the doctors wouldn’t have time for anything. So, there is kind of a vacuum of getting help.” Sune feels that he himself is very limited in the choices he has available to respond to his bodily discomfort in the care infrastructure in which he finds himself. He also feels that the health professionals have very limited resources to respond to his concerns, to help him explore his options, or even to improvise, as Pink et al. (2018) would say. He recognizes why they might not be able to respond—it costs the public health system a lot of time. He indicates that he feels he has a responsibility to self-ration his needs so that others can get proper care. When he was introduced to the Fitbit, Sune was already a participant in a project on designing and testing digital patient health records, and he sees the device as an opportunity to get into the loop of trying to make his care better by searching for a pattern in his own discomfort, and then being able to act on it. The second time we interview Sune, he is in the process of changing his diet and his physical activity program to see if it helps. He thinks he has noticed a relationship between his exercising and average heart rate: “During the twenty days I have been wearing the Fitbit, I have seen a drop in my heart rate of ten heartbeats per minute. I think that’s wild. I have been more active and I have been walking more. I have set exercise goals, right.” He interprets this heart rate drop as a positive thing, since his heart does not have to work as hard. He feels he has learned something new and, trusting the data, he feels a “sense of control in a space of uncertainty” (Pink et al., 2018: 3). Based on this experience, Sune has high expectations to how the

data might help in a longer perspective. “I have had regular follow-ups for my heart since 2001. If I had had the [Fitbit] data and been able to see when I did something which was bad and when I had done something which was good in relation to my medicine, then you’d have a baseline and would be able to say: You need to stop doing this.”

Sune thus invests a lot of hope in the accumulation of data and its relevance in making sense of his symptoms and monitoring his self-care and its effects. However, his investment is based on a fragile premise: he is assigning factual value to the data to allow him to gain “knowledge through numbers” (Wolf, 2010). In his frustration with a life sentence of medication, together with the failure to find any kind of pattern or improvement, the Fitbit promises a possible solution where he himself can do something to get better. The Fitbit gives him some new capacities and at the same time responsabilizes him. Sune does not share his ideas concerning the data with his physicians or with other patients—he shares it only with the researchers. But it does give him an opportunity to respond to his own body in a new way. It provides him with hope that he might be able to improve his health.

Data anxiety proper: Relying on data in precarious care arrangements

Allan is 66 years old, lives with his wife and—as well as having a heart condition, suffers from type 2-diabetes and other conditions—including depression and anxiety brought on by an ICD event, when he received 11 shocks from the device following too much fluid around his heart. The ICD does not always respond appropriately, and depending on a device which is unpredictable and sometimes causes unnecessary pain may have severe side effects. Depression and anxiety are very common comorbidities to ICD treatment. After the ICD events, Allan says he senses everything that goes on in his heart region. He easily gets afraid and anxious that he might get the very painful shocks from the ICD or in the event of a sudden cardiac arrest that the ICD might not work, and he will die. The physicians and technicians who monitor him remotely say that everything looks fine, yet he sleeps very poorly as he worries about his health. In addition, he experiences pain when he walks and has therefore become very inactive. The heart specialists to whom he has confided his anxieties have referred him to his general practitioner to get a referral to a psychiatrist.

When we meet Allan, he has received a referral and some antidepressants, but he is still waiting to get an appointment with a psychiatrist. In the meantime, his wife hopes the Fitbit can help him, because “he is very down”. Over the months that Allan uses the Fitbit and

we talk to him, he uses the Fitbit to try to make sense of the sensations in his body that are upsetting him. He is particularly interested in the heart rate data and looks at the display whenever he feels anything unusual, which is quite often. “It makes a difference when I get these [fast heart beats]. Then, when I look at the Fitbit, it is normal. Well, then okay, it is just you there is something wrong with. Then I’ll sit myself down and take a deep breath and it is okay. You can say that it has helped me like that. Physically, nothing is wrong – it is in my head that something’s wrong. It shows me that everything is alright.” Instead of panicking, he looks at the numbers on his Fitbit and calms down. Similarly, the data on his sleep patterns challenge his perception of not being able to sleep. As is also the case with Finn, the Fitbit data will often suggest (marked with stars) that he has slept even if he feels it has been a terrible night. His wife, obviously very worried about his anxiety and lack of sleep, recounts after the first month’s use: “His sleep rhythm has changed a lot. I don’t know, but wearing it maybe gives him some kind of peace of mind.” Interviewer: “How has it changed?” Wife: “He sleeps!! He isn’t up for 3–4 hours every night – doing crosswords because he feels anxious.” In the initial encounter with the Fitbit, Allan is provided with data that enable him to shake off the worst anxieties associated with his condition, and helps him to improve his day-to-day life. However, when we come back a few months later to re-interview Allan and his wife, the trust in the sleep-monitoring has decreased. His wife tells us: “It [the Fitbit] affects him. If it says something negative. For example, we looked at the sleep data, and it didn’t match, because he had been awake a lot. It was wrong, what it said. And we don’t know how it works.” Allan’s wife has started to worry about whether the Fitbit is trustworthy at all, and not knowing how it works makes her feel insecure. But Allan still finds some reassurance in looking at his heart rate, despite recognizing the doubts raised by his wife. When we meet for a third interview a couple of months later, Allan has still not seen a psychiatrist. He has not talked with any of the health professionals on his case about his Fitbit data and how he interprets it—and he is still feeling some ambivalence towards the data.

Allan is obviously not getting the care he needs. The ICD device that is supposed to help and care for him has actually introduced new anxieties and health problems into his life. Allan tries to utilize the Fitbit as a self-care tool to get immediate reassurance for want of any other solution; and to some extent, it does seem to reassure him. However, the Fitbit data on his heart rate might not really say that much about what constitutes acute danger—something which we also discuss with

Allan in the interviews. In contrast to Sune, Allan does not want to self-experiment to see if he can get better—he simply wants to avoid pain and get reassurance that he is not about to die. Apart from us, the researchers, who urge him not to read too much into the numbers and to seek professional help, Allan and his wife are alone in interpreting his anxieties, and now the Fitbit data is merely exacerbating a highly precarious situation. The new worry that he has—can he even trust these numbers—is added to all his other worries. Arguably, the pseudo reassurance that Allan gets from the Fitbit actually deepens a problematic division between the somatic condition of his heart—which the professionals are able to respond to—and his mental and emotional condition, which to a large extent he has to deal with himself. He thought he might be able—like Sune—to respond in a positive way to his problems. But he cannot. And the Fitbit can definitely not respond in a caring way: it does not change its readings and output in response to his misery. Allan's case offers an empirical echo of Lehoux (2008), who argues that while new developments in health technology enable us to do more, know more, these possibilities come with new worries and uncertainties, in line with the concept of data anxiety, that raise severe ethical concerns and require us to develop context-sensitive ethical responses to data ambivalence. We will return to this theme in the discussion below.

Our three vignettes testify to the fact that patients engage differently with the Fitbit, depending on their experience of living with an ICD, their perceived need for care, and their ability to integrate the Fitbit data meaningfully in managing their condition. While they all experience and reflect on the ambiguity of data, their interpretations of them and their resulting coping strategies vary considerably. One patient casts his doubts about the data aside, and playfully selects which data are useful and when in pursuit of his own pet project to live more healthily through caring for the body and the self; another expresses the hope that the data will *make him well*; the third patient has the rather precarious experience of tempering his daily anxieties with data that only serve to create new anxieties. In the process of making sense of the data, they draw on technical expertise (e.g. knowledge of devices and measurement biases), bodily knowledge (e.g. comparing displayed data to bodily sensations), and the affective experience of living with chronic illness. Introducing self-tracking systems, including the interpretation and selective use of data so often found in self-tracking studies, into the lives of people living and dealing with a serious condition, is a luxury that not everybody can manage or risk. On the contrary, for some being stuck with one's own data and not knowing what to do with them can be something of a burden. This burden

of data may—as in the case of Allan—result in deep anxiety. But other, more resourceful, patients in our study also feel stuck with their data. Some deal with it simply by taking the Fitbit off to escape the sense that they need to think about activity and disease all the time, and to avoid the confusion that arises from uncertain data. This corresponds to a strategy, also documented in other studies (Danholt and Langstrup, 2012), which reflects a need to define niches in daily life that are not all about being a patient. The hopes, doubts, and anxieties connected to heart patients' use of self-tracking data have serious implications for how we should think about embedding cloud-based, consumer-oriented devices, and data-trails in infrastructures of care. It also leaves us as researchers with a number of serious ethical challenges, as we pursue empirical studies to understand these emergent practices.

Response-ability, context-sensitivity, and data for care?

With our vignette-based analysis, we corroborate recurrent observations of data ambivalence in data studies, and advance theoretical conceptualizations of these observations by exploring the relationship between data, interpretation, and context. In contrast to most of the existing work in this area, which focuses on the highly specialized quantified self-community or on leisure self-tracking, the healthcare context is one where life may literally be at stake and where data ambivalence, and the hopes, doubts and new anxieties it fuels, is arguably more consequential. Understanding the multiple faces of data ambivalence is crucial as healthcare and the pursuit of personal wellbeing increasingly involve self-care.

With the introduction of consumer health monitoring through self-tracking, it is critical that we consider the *contextual sensitivity* in assessing the possible consequences of the blurring of healthcare and wellness. As we have seen in our analysis, in the case of ICD patients, their personal sense of living with or the prospect of dying from a particular disease matters to how they interpret their personal activity data and how they act on it. Self-tracking devices such as Fitbit are aimed at the consumer market and do not operate in a way that acknowledges the boundaries between healthy and sick people, nor do the devices offer interpretive aid (although Fitbit offers health coach services). Fitbit markets itself as eliminating the need for any interpretation beyond the authoritative standard measures inscribed in the technology: if you do your daily 10,000 steps and sleep 8 hours, you are presumed to be healthy or at least on the right track. It lacks

sensitivity to personal context. In fact, its indifference to context and a person's embodied condition casts interpretation as a luxury add-on. Yet, the ambiguous data generated by these consumer-oriented self-tracking devices in practice, compounded by the fact that users and patients' alike continually question "what it all means", suggest that interpretation is far from superfluous, on the contrary, it is at the heart of caring for the self. Moreover, as Prainsack (2017, 2019) has argued, not everyone benefits equally from generating personal health data: "as long as computers cannot separate between meaningful information and "noise", the interpretation of data cannot be fully automated. The time and effort of human experts is required to make data meaningful, and differences in access to this resource will be an important manifestation of inequity in the era of personalized medicine" (Prainsack, 2017: 176–177). The power differentials often critiqued in data studies, about access, data ownership and control over technical infrastructure, must also encompass resources and capacities for interpretation, and by extension, the ability to translate such interpretations into meaningful actions in pursuit of a happy and healthy life (see also Sharon and Lucivero, 2019).

As patients try to make sense of their Fitbit data, some might need the assistance of other actors in the care infrastructure in question, including spouses, friends, and healthcare professionals. Managing chronic illness and interpreting complex health data is never a solitary task—self-care is never done in isolation, but always relationally as "together-care" (Danholt and Langstrup, 2012; Pols, 2012). In practical terms, as consumer healthcare devices are increasingly adopted by the healthcare system, thus prompting patients to generate a mass of health and activity data, we need to understand how best to utilize these data, and how best to support interpreting them. We need to cultivate an ability to—critically—respond to commercial personal health technologies, and consider carefully how we establish interpretive authority over data and knowledge produced by these technologies. In the context of healthcare, one of the major challenges is that "the dynamics of lived data, however, no longer make it clear how and when clinical expertise is needed" (Kaziunas et al., 2017: 88).

With her work on new "geographies of responsibility" in cases where self-tracking is "pushed" (Lupton, 2014b) into care infrastructures, Schwennesen (2019) draws attention to the need for developing an "ethics of response-ability" to intervene and steer the actions and meanings of self-tracking data in healthcare towards desirable outcomes. The notion of response-ability prompts us to consider who or what is able and willing to respond to the needs of others

(Martin et al., 2015). The patients we have studied are using a cloud-based technology—Fitbit, but their care is not in the cloud. Data is not care. The care and self-care that Finn, Sune, and Allan experience are the more or less precarious results of a quite complex and distributed care infrastructure involving many actors and elements and spaces: ICDs, relatives, medication, online health records, public health services, and—potentially—self-monitoring data. Navigating the benefits and risks from such data is in itself a daunting task for people with severe health problems and their relatives, even before the introduction of Fitbit. Introducing a commercial health tracker like Fitbit can prove to be a valuable resource for some patients—like Finn and Sune—to help them self-care in a context where public health institutions have to prioritize their resources, thereby leaving it up to the patients themselves to improvise to a certain extent. For others—like Allan—who are in need of something or someone to respond with care, Fitbit may only seem to be better than nothing but could easily become the opposite: increasing uncertainty, fear, and anxiety by leaving patients stuck with meaningless data. We should recognize that care may be delivered using data, including data coming from commercial personal health technology like Fitbit, but as just *one* relational resource among many that are helping us—collectively—to respond to our human problems. What can make the difference between careful and careless data is the broader care infrastructure and the institutional and political context in which these commercial technologies and data are embedded. Like Schwennesen (2019), we find that more empirical work is needed on how healthcare actors engage with new types of data to make them meaningful and useful, like the study with patients that has informed this article. There is also a lack of studies looking at the healthcare professionals involved. Such work is needed to achieve a more nuanced understanding of the promise and perils of health data in existing and emerging care infrastructures. Such nuances are, in both practical and ethical terms, crucial for informing the public debate and research which will in turn feed into the technological and regulatory development of datafied healthcare.

Our study did not require ethical approval from the Danish authorities; and yet, the concept of ethics is not just black and white. Ethical research requires continuous reflection throughout the whole of the research process. Even though two of us were "outsiders" to SCAUT, our roles as researchers were in some cases blurred with those of "data interpreters" and caregivers, especially in the encounters with patients like Allan. When interviewing and discussing data ambiguities, we had a role in explaining the limitations of

consumer devices and their measurements to our participants. While we had originally framed the study as an exploration of activity trackers in healthcare, and made clear that we were in no way connected to their professional health care, for the patient-participants we were nonetheless perceived as being part of their care infrastructure. When we realized this, we sought to practice the ethics of response-ability: guiding their interpretation of the Fitbit data, assisting them in reflecting critically on the relationship between data and bodily cues. We also advised those patients that needed it to go back to their healthcare professionals, who would be better able to help them interpret the complex interaction of data, body and mind, or to seek out additional professional help for their heart condition. Our approach, then, to some extent counters the individually centered descriptions of mundane data anxieties and strategies to handle them (Pink et al., 2018), by addressing the response-ability of trying to moderate data anxiety, hope, and doubt in a concerted effort, a form of together-care, in which the researcher takes part.

There is currently a lot of interest in using these new devices to improve clinical trials, and applying wearable activity trackers in healthcare contexts (Shin et al., 2019). It is recognized that incorporating wearable trackers in study designs requires that issues of data security, accuracy and privacy, and other potential risks to the patient, are taken into account (Wood et al., 2015).

Our study, while focusing on patients' data anxieties, hopes and doubts, has also exposed an ethical conundrum for doing research in this context. We introduced patients who were already part of a research and development project to the Fitbit device and talked to them about data; in doing so, we found ourselves raising hopes that patients can improve their condition using what is, after all, uncertain data. Indeed, we positioned ourselves more as distributors of personal health devices than we initially realized. If we as researchers end up being data brokers, we need to be quite sure that the benefits outweigh the drawbacks. After careful consideration, we believe that our study is justified for two main reasons: firstly, because of the need for empirically based knowledge about the issue, and secondly because the healthcare sector is already experimenting with commercial wellness devices, including activity trackers, in practice and massive resources are already being invested in developing technology for datafying healthcare. To qualify such experimentation and technological development and ensure they actually benefit patients and care infrastructures, we need to understand the possible implications of self-tracking for patients and clinicians. Our study has

enabled us to get deeper insights into the experiences of patients living with heart disease, something which would have been more difficult if we had simply recruited people who were already using Fitbit independently. Furthermore, the study was carried out within the confines of a living lab with real professional caretakers "in the loop". This meant there was an extra safety net for patients in precarious situations. The fact that the study took place in the welfare state of Denmark further corroborates this, as with a public healthcare system providing equal access for all, Denmark arguably offers a best-case scenario for experimenting ethically with activity tracking in healthcare.

Conclusion: Making meaning with fitbit data

As both public and commercial interests in collecting personal patient data for health purposes grows, and as clinical experiments using commercial activity trackers are carried out, researchers are urged to consider the practical applications, changes to healthcare and ethical-political implications of the datafication of health.

In this article, we have drawn together data studies on self-tracking and STS- and sociologically informed digital health research on data ambivalence. In the field of data studies, we have aimed to advance the notions of data anxiety, doubt, and hope by accounting for the interpretive efforts and communicative meanings of self-tracking data in a chronic care context. The uncertainty that is associated with making meaning of data, and the hopes, doubts and anxieties that the interpretation of data fuels are inextricably linked to contextual circumstances and to the individual physical, embodied condition which self-tracking is supposed to help. For example, for patients living with a chronic illness, such data anxieties, hopes, and doubts take on a different meaning and may sometimes create or exacerbate precarious situations. Unpacking the role of interpretation in our communicative relationship with self-tracking data, it is evident that the ability to interpret data must be enhanced not only at the personal level, but relationally and ethically, as a central element in response-able data-driven care.

Our 27 patients were very diverse in terms of how much they were affected by their illness. We did find some patients who used Fitbit to nudge themselves to do more exercise like a regular healthy leisure tracker. However, there were far more patients who had high hopes of the data improving their health, making meaning based on abnormalities in the data or unusual physical reactions. There were also patients for whom

data-tracking represented a desperate attempt to practice self-care to offset being neglected by a precarious care infrastructure. We have contributed to sensitizing the field of digital health research and practice to the need for nuanced, contextualized accounts of the communicative meanings and implications of patients' engagement with self-tracking devices and data. Measuring and tracking our bodies is not new, and it does not make sense to provide either a celebratory, dismissive or dystopian narrative about these tools and practices. However, which specific tools, bodies, and contexts we look at will make a difference, and our study of how heart patients interpret data makes it evident that the cost and burdens of data hope and data doubt are not evenly distributed and do not carry the same implications for everyone. Empirical, contextually sensitive studies of peoples' engagement and experience with specific personal health devices may significantly advance our understanding of the risks and benefits of activity data for care. Using self-tracking data in care infrastructures for the benefit of individual patients and for the overall care sector requires that we develop concrete ethical practices of response-ability, for instance by offering interpretive aid from within the care infrastructure to help patients make meaning with ambiguous data.

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References

Ancker JS, Witteman HO, Hafeez B, et al. (2015) "You get reminded you're a sick person": Personal data tracking

- and patients with multiple chronic conditions. *Journal of Medical Internet Research* 17: e202–12.
- Andersen TO (2019) Large-scale and long-term co-design of digital health. *Interactions* 26(5): 74–77.
- Andersen TO, Bansler JP, Kensing F, et al. (2019) Aligning concerns in telecare: Three concepts to guide the design of patient-centred e-health. *Computer Supported Cooperative Work* 28: 1039–1072.
- Chapple A and Rogers A (1999) 'Self-care' and its relevance to developing demand management strategies: A review of qualitative research. *Health & Social Care in the Community* 7: 445–454.
- Choe EK, Lee NB, Lee B, et al. (2014) Understanding quantified-selves' practices in collecting and exploring personal data. In: *Proceedings of the SIGCHI conference on human factors in computing systems (CHI '14)*, Association for Computing Machinery, 28, April–1, May 2014, New York, NY, USA, pp. 1143–1152.
- Danholt P and Langstrup H (2012) Medication as infrastructure: Decentring self-care. *Culture Unbound: Journal of Current Cultural Research* 4: 513–532.
- Didžiokaitė G, Saukko P and Greiffenhagen C (2018) The mundane experience of everyday calorie trackers: Beyond the metaphor of quantified self. *New Media & Society* 20: 1470–1487.
- Figueiredo MC, Caldeira C, Eikev EV, et al. (2018) Engaging with health data: The interplay between self-tracking activities and emotions in fertility struggles. *Proceedings of the ACM on Human-Computer Interaction* 2: 1–20.
- Fitbit Health Solutions (2019) <https://healthsolutions.fitbit.com/healthcoaching/> (accessed 30 January 2020).
- Fotopoulou A and O'Riordan K (2017) Training to self-care: Fitness tracking, biopedagogy and the healthy consumer. *Health Sociology Review* 26: 54–68.
- Garge GK, Balakrishna C and Datta SK (2017) Consumer health care: Current trends in consumer health monitoring. *IEEE Consumer Electronics Magazine* 7: 38–46.
- Gitelman L (2013) "Raw Data" is an Oxymoron. Cambridge, MA: MIT Press.
- Hjerteforeningen (2020) <https://hjerteforeningen.dk/alt-om-dit-hjerte/hjertetal/hjertetal.dk/> (accessed 30 January 2020).
- Hoeyer K (2016) Denmark at a crossroad? Intensified data sourcing in a research radical country. In: Mittelstadt B and Floridi L (eds) *The Ethics of Biomedical Big Data*. Cham: Springer.
- Hogle LF (2016) Data-intensive resourcing in healthcare. *BioSocieties* 11: 372–393.
- Iliadis A and Russo F (2016) Critical data studies: An introduction. *Big Data & Society* 3: 1–7.
- Kaziunas E, Lindtner S, Ackerman, et al. (2017) Lived data: Tinkering with bodies, code, and care work. *Human-Computer Interaction* 33: 49–92.
- Kennedy H (2018) Living with data: Aligning data studies and data activism through a focus on everyday experiences of datafication. *Krisis: Journal for Contemporary Philosophy* 1: 18–30.

- Kitchin R and Lauriault T (2014) Towards critical data studies: Charting and unpacking data assemblages and their work. In: Eckert J, Shears A and Thatcher J (eds) *Geoweb and Big Data*. Lincoln: Nebraska University Press.
- Kristensen DB and Ruckenstein M (2018) Co-evolving with self-tracking technologies. *New Media & Society* 20(10): 3624–3640.
- Langer PC (2016) The research vignette: Reflexive writing as interpretative representation of qualitative inquiry – A methodological proposition. *Qualitative Inquiry* 22: 735–744.
- Langstrup H (2013) Chronic care infrastructures and the home. *Sociology of Health & Illness* 35: 1008–1022.
- Lehoux P (2008) The duality of health technology in chronic illness: How designers envision our future. *Chronic Illness* 4: 85–97.
- Lomborg S and Frandsen K (2016) Self-tracking as communication. *Information, Communication & Society* 9: 1015–1027.
- Lomborg S, Thylstrup NB and Schwartz J (2018) The temporal flows of self-tracking: Checking in, moving on, staying hooked. *New Media & Society* 20(12): 4590–4607.
- Lupton D (2014a) The commodification of patient opinion: The digital patient experience economy in the age of big data. *Sociology of Health & Illness* 36: 856–869.
- Lupton D (2014b) Self-tracking modes: Reflexive self-monitoring and data practices. *Imminent Citizenships: Personhood and Identity Politics in the Informatic Age workshop*. Canberra, Australia.
- Lupton D, Pink S, Heyes Labond C, et al. (2018) Digital traces in context: Personal data contexts, data sense, and self-tracking cycling. *International Journal of Communications Special Issue on Digital Traces in Context* 12: 647–665.
- Marent B, Henwood F, Darking M, et al. (2018) Ambivalence in digital health: Co-designing an mHealth platform for HIV care. *Social Science & Medicine (1982)* 215: 133–141.
- Martin A, Myers N and Viséu A (2015) The politics of care in technoscience. *Social Studies of Science* 45: 625–641.
- Maslen S and Lupton D (2019) Enacting chronic illness with and through digital media: A feminist new materialist approach. *Information, Communication & Society*. Available at: <https://doi.org/10.1080/1369118X.2019.1602665>
- Mol A (2000) What diagnostic devices do: The case of blood sugar measurement. *Theoretical Medicine and Bioethics* 21: 9–22.
- Mol A (2008) *The Logic of Care: Health and the Problem of Patient Choice*. London / New York, NY: Routledge.
- Nielsen KD and Langstrup H (2018) Tactics of material participation: How patients shape their engagement through e-health. *Social Studies of Science* 48: 259–282.
- Nunes F and Fitzpatrick G (2015) Self-care technologies and collaboration. *International Journal of Human-Computer Interaction* 31: 869–881.
- Oudshoorn N (2008) Diagnosis at a distance: The invisible work of patients and healthcare professionals in cardiac telemonitoring technology. *Sociology of Health & Illness* 30: 272–288.
- Papacharissi Z (2010) *A Private Sphere: Democracy in a Digital Age*. Cambridge: Polity Press.
- Petersen A, Tanner C and Munsie M (2019) Citizens' use of digital media to connect with health care: Socio-ethical and regulatory implications. *Health (London, England: 1997)* 23: 367–384.
- Pink S, Lanzeni D and Horst HA (2018) Data anxieties: Finding trust in everyday digital mess. *Big Data & Society*. Available at: <https://doi.org/10.1177/2053951718756685>
- Pink S, Ruckenstein M, Willim R, et al. (2016) *Broken Data*. Lund: Lund University Publications.
- Pols J (2012) *Care at a Distance. In on the Closeness of Technology*. Amsterdam: Amsterdam University Press.
- Prainsack B (2017) *Personalized Medicine: Empowered Patients in the 21st Century*. New York: New York University Press.
- Prainsack B (2019) Logged out: Ownership, exclusion and public value in the digital data and information commons. *Big Data & Society*. Available at: <https://doi.org/10.1177/2053951719829773>
- Rosenberg D, Kadokura EA, Bouldin ED, et al. (2016) Acceptability of Fitbit for physical activity tracking within clinical care among men with prostate cancer. In: *AMIA annual symposium*, American Medical Informatics Association, 12–16 November 2016, p. 1050.
- Rosenbloom ST (2016) Person-generated health and wellness data for health care. *Journal of the American Medical Informatics Association: Jamia* 23: 438–439.
- Ruckenstein M (2017) Keeping data alive: Talking DTC genetic testing. *Information, Communication & Society* 20: 1024–1039.
- Ruckenstein M and Schüll ND (2017) The datafication of health. *Annual Review of Anthropology* 46: 261–278.
- Schwennesen N (2019) Algorithmic assemblages of care: Imaginaries, epistemologies and repair work. *Sociology of Health & Illness* 41: 176–192.
- Sharon T (2016) The googlization of health research: From disruptive innovation to disruptive ethics. *Personalized Medicine* 13: 563–574.
- Sharon T and Lucivero F (2019) Introduction to the special theme: The expansion of the health data ecosystem – Rethinking data ethics and governance. *Big Data & Society*. Available at: <https://doi.org/10.1177/2053951719852969>
- Sharon T and Zandbergen D (2017) From data fetishism to quantifying selves: Self-tracking practices and the other values of data. *New Media & Society* 19(11): 1695–1709.
- Shin G, Jarrahi MH, Fei Y, et al. (2019) Wearable activity trackers, accuracy, adoption, acceptance and health impact: A systematic literature review. *Journal of Biomedical Informatics* 93: 103153.
- Steinhubl SR, Muse ED and Topol EJ (2015) The emerging field of mobile health. *Science Translational Medicine* 7: 1–7.

-
- Weiner K and Will C (2018) Thinking with care infrastructures: People, devices and the home in home blood pressure monitoring. *Sociology of Health & Illness* 40: 270–282.
- Willems D (2000) Managing one's body using self-management techniques: Practicing autonomy. *Theoretical Medicine and Bioethics* 21: 23–38.
- Wolf G (2010) The data-driven life. *The New York Times*. Available at: <https://www.nytimes.com/2010/05/02/magazine/02self-measurement-t.html> (accessed 12 April 2020).
- Wood WA, Bennett AV and Basch E (2015) Emerging uses of patient generated health data in clinical research. *Molecular Oncology* 9: 1018–1024.