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Datafying the patient voice
The making of pervasive infrastructures as processes of promise, ruination and repair

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Denmark is a classic Nordic welfare state. It builds on models of collaborative governance, provides universal access to healthcare to Danish citizens, and it operates a particular form of data-intensive service delivery said to be citizen-centric. For years, Denmark has pioneered public digitalization and participatory methods such as user-driven innovation and citizen-involvement in medical technology assessments. However, welfare services should never be taken for granted, not in any state. They emanate from a long history of power struggles. The rights and duties embedded within the welfare edifice serve as reminders of earlier activism and solidified forms of collaboration. This chapter discusses the temporality and moral ambiguity of healthcare activism and state-sanctioned empowerment by providing examples from the infrastructuring of Danish healthcare, giving rise to both lauded achievements as well as unintended and contested consequences. We explore how patients are engaged in new forms of health data production and how various forms of activism attempt to affect public digital data infrastructures – and we emphasize the involved moral and epistemological ambiguity of these attempts to affect data flows. Welfare infrastructures, we suggest, evolve through such processes of promise, ruination and repair.

Keywords: Activism, collaborative governance, Denmark, data, infrastructures, welfare
Introduction

Data have become objects of power struggles in multiple ways. It is increasingly through data that priorities are made, rankings established, and privileges granted or revoked (Adams, 2016; Bigo, Isin & Ruppert, 2019; Erikson, 2012; Kitchin, 2014; Merry, 2016). Data are tools of governance. Concurrently, new forms of activism are emerging around datafication where multiple parties try to influence what is datafied, by whom, for which purposes and for whose sake. Rabeharisoa and colleagues identify in some of these data struggles a form of evidence-based activism, arguing that it involves a shift in positions. In contrast to classic notions of activism, it is done from within or in close collaboration with institutions rather than in opposition to them (Rabeharisoa, Moreira and Akrich, 2014). In evidence-based activism, data are mobilized as resources for collective action. It may involve datafication of patient voices: patient experiences are standardized and accumulated to allow organizations to speak on behalf of – or through the numbers of – populations, rather than through the narratives voiced by individuals. Who is seeking to datafy the patient voice, in which ways and with which consequences? What do we learn about healthcare activism in an age of ‘intensified data sourcing’ (Hoeyer, 2016) from following the development of data infrastructures over time? These are bigger questions than what can be answered in one chapter, but here we begin exploring them based on studies of infrastructural developments in Denmark.

Denmark is an interesting place to explore health data infrastructures and their intended and unintended consequences. The country is both a dedicated digital frontrunner and a pioneer in participatory methods, user-driven innovation, and citizen-involvement in health technology assessments. In many ways, the country already has what many other countries only recently have begun to develop (Sheikh, Sood and Bates, 2015): nation-wide IT infrastructures for health, decades of work with standard specification for exchange of health data, and a data infrastructure that since 1968 has ascribed traceable identity numbers to all individuals. Denmark is
also a classic welfare state. Welfare states did not emerge out of nowhere: they are the result of enduring power struggles and contestation of rights and entitlements. Denmark has taken a route of what we call collaborative governance, by which we mean that the government generally seek to contain and transform opposition rather than plainly suppress it. Whereas Mountford and Geiger (2018) intriguingly describe specific strategies in collaborative governance that governments can adopt in relation to specific problems, we use the term here in a more general sense of governance that mostly seek to establish consensus when dealing with contestations. Contestations thereby solidify into webs of legal frameworks as well as in various infrastructures aimed at creating opportunities for care as well as control.

Following Star and Ruhleder, we think of infrastructures as fundamentally relational: they are never finished and they have no clear boundaries (Star and Ruhleder, 1996). Data infrastructures instantiate multiple historical layers of activism and means of governance. Gupta emphasizes the temporality of infrastructures: notwithstanding their accomplishments, they always carry the weight of failed promises of the past (Gupta, 2018). In a sense, action in the present takes place in the ruins of infrastructures emanating out of promises made in the past. Jackson suggests considering this temporality as processes of breakdown, maintenance and repair (2017). Promises, however, precede the breakdown, and may survive in various ways without ever materializing as intended (Larkin, 2013). The temporality is not linear. We think of ruination, not as total sojourn of function, but as processes where failures give rise to new forms of life and unintended uses (Tsing, 2015). These spaces gradually emerge over time. With this inspiration, we approach infrastructuring as processes of promise, ruination and repair. This understanding points to the need to understand the unfinished nature of activism. It also indicates an impossibility of delineating what and who are inside or outside a given infrastructure. Finally, it suggests a moral as well as epistemological ambiguity of the effect of power struggles.
In this chapter, we thus explore the multiple layers, unfinished nature and unintended consequences of Danish data infrastructures for healthcare as intertwined processes of promise, ruination and repair. We illustrate how government attempts at empowerment also involve examples of unintended dis-empowerment and unwarranted vulnerabilities. Similarly, even the most well-intended and capable government attempts at empowerment can disappoint. Data integration is not without risk (O’Doherty et al, 2016). We also point to the way in which emerging data activism in the area of healthcare tend to give special voice to elitist groups. Our message is not pessimistic, however, as we wish to highlight all these attempts of repair as central to the continuous power struggles through which healthcare infrastructures take form and meet the needs of people confronted with illness and suffering.

**How we approach the power struggles of datafication**

As healthcare systems strive to become ‘data-driven’ and ‘learning healthcare systems’ (Olsen, Aisner and McGinnis, 2007; Pollitt et al., 2010), power struggles and resource allocation issues increasingly unfold in relation to arguments based on available numbers (Hogle, 2019; Wadmann, Holm-Petersen and Levay, 2018). This datafication of health (Ruckenstein and Schüll, 2017) also affects activism. The STS literature from the beginning of the 21st century on patient activism and health social movements (Epstein, 1996; Brown et al, 2011; Wehling, Viehöver and Koenen, 2014) drew to a large degree on a notion of activism as “spectacular political protest and opposition” against existing institutions and their “inadequate results and […] unjust effects for certain groups of people and patients” (Wehling and Viehöver, 2014: 240). In accordance with the popular image of the internet at the time as democratizing in its own right, patients’ mobilization of digital means were often seen as instances of such authentic “voicing” and democratic empowerment (Slack, 1997; Eysenbach, 2002). In this paper, we add to work exploring the shift to evidence-based patient
activism by illustrating how the voicing of patients’ concerns and perspectives by digital means need not take the form of claimed spaces of protest but increasingly mean being part of invited spaces of participation. According to Petersen and colleagues, datafication in itself can be said to have changed the nature of patient activism by enabling activist groups to use “the insights, expertise and financial support of science and corporations to achieve their goals” (Petersen, Schermuly and Anderson, 2019: 23). Patient groups thus become more aligned with other mainstream actors, whether public or commercial (ibid.), and more collaborative configurations or “hybrid forums” (Callon, Méadel and Rabeharisoa, 2002) emerge that may organize around shared concerns, which can challenge but also contribute to existing ways of knowing and governing. In a participation-oriented healthcare system like Denmark’s, patient associations are valued collaborators – and “governing through participation” (Newman et al., 2004; Kjær and Pedersen, 2010) has become the default also in relation to digitalization (Vikkelsø 2010).

In systems governed in such a collaborative manner, there is a need to remain skeptical toward equations of patient groups and activists. Opposition to mainstream versions of datafication of health often comes from quarters other than those organized around disease categories. This point is also supported in the emerging literature on “data activism”, for which Lehtiniemi and Ruckenstein (2019) provide a number of recent examples in the context of health: in more and more instances, datafication is becoming an issue of political and civic action in its own right (ibid). Kennedy (2018) calls for more attention to “everyday data experience of datafication” – as opposed to spectacular protests and “elitist” activism – as a relevant knowledgebase for discussion of more fair data arrangements. In a similar vein, we suggest investigating power struggles surrounding data infrastructures without predefined dichotomies and ideas about strong and weak partners, power and resistance, and clear-cut categories of patients and experts. Instead, we wish to
draw attention to their interweaving ambiguities and temporal shifts as multiple actors build on the infrastructures set in motion by others to meet new goals.

Our own work with these topics and the material on which we build this chapter stems from years of following the evolution of data infrastructures in Danish healthcare (Hoeyer) and user involvement in digital technologies (Langstrup). To understand how patients’ participation shape and is shaped by digital health innovation, Langstrup has followed the work of governmental agencies, healthcare practitioners and patients working to develop digital questionnaires and infrastructures for cross-sectoral and national collection of Patient Reported Outcome data (PRO data). Langstrup has participated in meetings, workshops and public events related to the initiative, specifically focusing on initiatives on cancer and heart disease. She has interviewed key actors involved in the initiative. Alongside this, she is also following with collaborators the so-called ‘looping-community’ of diabetes patients who, supported by online peer-communities, alter technical features of their insulin treatment with unregulated technology and without formal clinical oversight. To understand the implications of governmental attempts of empowering citizens through increased data access, Hoeyer has traced the legal history, analyzed policy documents for data initiatives, and interviewed key actors working with the decision-making processes, the practical implementation of the policies and with health professionals using the data infrastructures in their daily life. Together we have interviewed representatives for two patient organizations taking an active involvement in development of new questionnaires to account for patient experiences, one for chronic diseases and one for cancer. In total, we have interviewed more than 100 individuals, and here present selected informants under pseudonym and in our own translation. Our point is not to account for a particular distribution of views or experiences in what remains a non-representative sample. We detail instead the processes of infrastructuring Danish healthcare as a way of
illustrating how attempts to do the right thing tend to bring about new fractures and reasons to repair.

We present the analysis in five steps, each illustrating the intertwinement of promise, ruination and repair, and each representing a historical layer of patient positions that are built into the infrastructure: first, the historical making of a right to healthcare. Second, governmental initiatives to establish a patient right to access the data produced through care. Third, governmental ambition of empowering patients by obliging them to produce data to evaluate healthcare. Fourth, patient activism aimed at increasing self-determination with respect to the mode of care. Fifth, activism the aimed at criticizing the data infrastructures in place.

**Denmark, data, and the historical layers of power struggles**

As in the other Nordic countries, the Danish welfare state emerged gradually out of the people’s movements of the 19th century. The workers’ movement gained strength in tandem with new collaborative economic models – the so-called ‘andels’ movement, which encouraged shared ownership of, for example, abattoirs and dairies, as well as cooperative shops. This period was also characterized by religious awakening and a strong temperance movement. As pointed out by Swedish ethnologists, the call for greater influence of the poor was accompanied with a strong emphasis on self-control (Frykman & Löfgren, 1987; Qvarsell, 1986). The new movements were not welcomed by established power structures. In Denmark, however, during the recession in the 1930s, a consensus gradually emerged around a more social-democratic system and the establishment of state welfare provisions – as well as a collaborative system for negotiations between unions and employers that became known as the Danish Model (Marcussen, 2010). The totalitarian regimes south (Nazi Germany) and east (Soviet Union) of Denmark contributed to an evolving consensus around the benefits of more collaborative forms of governance. Many years of
violent and fierce activism thus preceded the establishment of rights that today are taken for granted by both right and left wing politicians, such as universal access to healthcare (Lundberg et al., 2008).

Rights rarely emerge without duties: the financing of the welfare state was a problem from its inception. In 1968, a new system was introduced to ensure comprehensive taxation. Three registries for identification purposes were established to trace each individual, all dwellings and all enterprises. As the three registries gave everyone and everything numbers and facilitated easier tracking, they quickly proved themselves useful also for purposes other than taxation. The identification numbers became the entry point for all public services, including social services, education, employment and health. The welfare state in this way came to involve a particular instantiation of the well-known double meaning of surveillance: to scrutinize and to watch over. In Danish the word for surveillance (overvågning) is a conjunction of the word for watching over someone (våge over), which has clear connotations to care.

The data accumulated using the identifying numbers quickly became too ubiquitous to be manageable as paper records. Denmark embarked on a digital adventure that came to lay the foundation for contemporary data infrastructures. Already in 1976, Denmark switched from the old census model to using the digitalized central person registry (Lange, 2014). From the 1980s, public sector digitalization became a main priority and Denmark turned into a digital frontrunner in a number of arenas. The registries grew in number as well as purposes. Though administrative in nature, they began to be used for research (Bauer, 2014). As a consequence, patients came to be spoken for in new ways as population numbers. The international journal Science celebrated the opportunities for research generated through the Danish registries system, describing Denmark’s population as one big cohort study and “the epidemiologist’s dream” (Frank, 2000; Frank, 2003). Several registries were hosted originally by patient organizations, or initiated by independent
clinicians. They were not part of a national plan. Only later were they transferred to governmental agencies in processes illustrating institutional responses to locally perceived data needs.

With the surge in data volumes and new data economies emerging during the 2010s, both industry and governmental agencies began to think about the data resources also as opportunities for economic growth. The old source of income – registries for taxation purposes – gradually became inscribed in new economic imaginaries: data as assets that should be exploited (see also Vezyrdis and Timmons, 2017; Tarkkala, Helén and Snell, 2018). The dominant trope during these years characterized health data as a ‘gold mine’ (Hoeyer, 2016), the argument being that new forms of income were needed if welfare were to be sustained and developed. The obligation to deliver data that should give rise to commercial gain signals a new form of social contract between citizen and state (Prainsack, 2017). The social sustainability of this contract is yet to be tested. Infrastructures from the past continue to facilitate unexpected opportunities; they never cease to redefine their purposes and give rise to unexpected benefits as well as dangers.

**Establishing a right to data: promise, ruination and repair**

The accumulation of data has been accompanied with increasing governmental awareness of patient interests in these resources. Interest groups such as patient associations, the Danish Consumer Council and the DanAge association (fighting against age barriers) have contributed to such awareness. Based on data from public consultations, these groups have contributed to the governmental discourses articulating promises of empowerment through enhanced data access. In 1987, patients acquired a legal right to request access to their own hospital records, and in 1988 also electronic records from their general practitioner. In 1998, a law was passed to gather and clarify patient rights. It had the stated purpose of ensuring patients’ dignity and self-determination. It is one
thing to have a right, however, and quite another to have the technical options for using it. In 2003, an internet homepage was established through which citizens could access their hospital records. The name was Sundhed.dk (sundhed is Danish for health), and it quickly became the main access point for patients to their data. Extensive work went into developing standards to make data from different systems available through just one interface. Over the years, sundhed.dk has expanded from computer access only to other platforms, including tablets and phones. Sundhed.dk is a form of national-health-services online. Besides personal health records, it is also a portal providing curated information about, for example, diseases, treatment options and waiting times at various units. From the very beginning, the platform, which is operated in collaboration between the Danish Regions, the municipalities and the state, has worked closely with patient associations on various projects to develop and incorporate tools for patient engagement and empowerment into the platform. Furthermore, Sundhed.dk (as is common throughout the Danish health services and governmental agencies) conduct user tests and to explore citizen interests relying heavily on anthropological methods for including “the patient” or “citizen voice” into their digital services.

The integration of data from multiple sources is of value also for health professionals who receive patients from other units and whose data are not available in internal systems. To ensure that no health professional uses the access to patient records for inappropriate reasons, a system of logging has followed the data integration, and through this service, patients can check who has viewed their files. On average every year, six health professionals are caught viewing health records without authorization, for example of ex-boyfriends, ex-wives or employees. Though built as an opportunity for urgency care – access to the records of patients in need of urgent help – the data integration also came to generate these relatively rare cases of abuse. The logging system, conversely, is a form of repair, where patients acquire tools to regain control. One patient shared her story with us of finding out that her boss had looked into her medical record to cast doubt on her
absence from work. She described feeling “appalled, angry, offended, nervous, and extremely psychologically affected”. The logging made it possible for her to document the unauthorized viewing of her medical data.

The logging of electronic data has had various other unintended consequences involving other types of risk. Patient record audits are well-established measures of quality assurance aimed at optimizing care, but partly as a consequence of logging, patients began complaining about health professionals having looked into their records without being their treating physician. In the course of dealing with these complaints, it was revealed that the audit practice had never been authorized in the law. In 2017, a law was passed to legalize the old practice (Hartlev & Wadman, 2018). The promise of patient empowerment backfired and necessitated legal repair work.

Attempts to minimize and control physician access to patient data through systems such as logging might also have worked against other, older practices aimed at ensuring adequate treatment for each patient. In 2019, it was reported that more than 11,000 physicians had shared patient stories through a closed Facebook group. According to media reports, they did so mostly to get feedback from colleagues in a system without governmental logs (Jyllands-Posten, 2019). Facebook extracts and logs information in its own way, but it is not easily accessible to patients. This case made clear that some attempts at empowering patients had contributed to the development of new patient risks – not because anybody wanted to harm patients, but because different professional groups held different ideas about how to serve patient interests. Even attempts at repair can produce new sources of ruination.

Health professionals are not the only potential source of data leakage. When patients have access, they too can decide – or be forced – to share data (Petersson, 2020). After having opened up for patients to access their own health data, Sundhed.dk learned that individuals where sharing their access codes with others. To address this and safeguard privacy, they then developed a system of
authorization to enable patients to grant others access to their records. This repair move aimed to make citizen access to records traceable in the same way as health professionals’ access. However, when in a short period all data from general practice were made available on the portal, general practitioners reported how some patients felt forced to share their access also with family members who wanted to assert control over their medical appointments. Young girls, for example, faced problems when using preventative services that their parents had not sanctioned. Insurance companies and employers also capitalized on the changes; where previously they had had to pay for statements from GPs in cases where they were entitled to information about a given health condition, now they simply asked the patient for a printout. It was clearly cheaper for the companies to do this, but crucially it also provided them with access to far more information than they otherwise would have had. Once again, patient empowerment became an unwarranted source of disempowerment. As yet another instance of repair, Sundhed.dk developed a system of ‘privacy marking’, where patients could choose to hide certain pieces of information not only from the view of health professionals, but also from themselves (and thereby those that might force them to grant them access to it). Infrastructures are never finished; they are continuously in processes of promissory development, ruination and repair.

Data access can also feel disempowering, even when used as intended by policy makers. Medical doctors had for long insisted on a temporal delay of laboratory results, so that patients would hear about a diagnosis from the doctors before reading it online. This was regarded as paternalistic by policy makers and by consumer activists. In the course of investigating these infrastructural changes, we met a civil servant who had been part of implementing the removal of the time delay. It transpired that she had also had personal experiences, following which she no longer saw merit in the instant sharing of the data. She had had a tissue sample sent to a pathology
laboratory, and she recalled how she began shivering as she looked up the result online before speaking to her doctor:

“I could see it was a very long test result, masses of text. That was the first thing that struck me, ‘there’s a lot here, that’s not good’. And then I read ‘malignant’ and I thought, ‘is that good or bad, is that good or bad, is that good or bad?’ (…) and then I thought ‘shit, I’ve got cancer. I’ve got cancer’ (…) I started trembling all over.”

She realized there was a lot in the lab results she did not understand and began contacting people she knew who might be able to translate the technical jargon. In spite of what she knew about data privacy from her work in the health services, she began to send images and printouts to people she did not personally know, asking for help with interpreting this data that she could access but not understand. She explained to Klaus how it provoked her thinking back on the small ‘disclaimer’ she had to click before accessing the results, which informed her that she might prefer to see a doctor before reading them:

“What the f… is that? Such political ‘cover-my-ass’ bullshit. (…) of course, it won’t stop me when I’m already logged on to Sundhed.dk. (…). This is not protecting my interests.”

She emphasizes that for data to make sense, they must be exchanged between people who know how to understand and use them. Unlike other pieces of information she had accessed in conjunction with childbirth and infant care, she said the laboratory data “were not written for me.” Following the incident, she stopped trying to discern what data she could and could not use: “I have not logged on to Sundhed.dk since.” This experience shows that while the promise of empowerment through data access can be fulfilled sometimes, the new opportunities it yields can also generate a sense of ruin beyond repair.
It is not only patients who face new dangers as a result of new data infrastructures. In many hospitals, health professionals have begun wearing nametags with only their first name to protect their identities. Patients can occasionally become threatening and angry, and it is important that they cannot locate the home address of the health professionals by using online tools. Despite this, the log system on *Sundhed.dk* provide patients with a new means of identifying the people who have treated them – and this has had unforeseen consequences. In a particularly tragic case in 2019, a doctor was killed by a former patient. The police found a printout from *Sundhed.dk* where the patient had used the log to identify the doctor and six other treating health professionals (Dalsgaard, 2019). Patient empowerment policies rest on the assumption that patients are in need of leverage and pursue legitimate interests aimed at improving their own health. Sometimes, however, it might be the health professionals who are in need of protection. If infrastructures solidify previous power struggles, they also create the foundation for new forms of power abuse. Every promise of empowerment risks ruination and new calls for repair.

**Making patients active: datafying patient voices**

While the aforementioned modifications of data infrastructures revolve around data *access*, a number of recent national initiatives are aiming more explicitly at providing a national data infrastructure that supports patients to become active and continuous *contributors of data* about themselves to public health services. One initiative concerns the collection of data on patients’ experiences of the effects of the treatments they receive as they engage in cross-sectoral treatment trajectories. These data are termed Patient Reported Outcome (PRO) data and they are increasingly collected through digital questionnaires to inform clinical decision-making, enable data-driven screening and provide aggregate data for management and research. The national PRO initiative, which started in 2016, has already been praised by the OECD as an exemplary move toward a
health system that learns from “what matters to patients” (OECD Health Ministerial Meeting, 2017). While other countries are also implementing PRO data as a means for more patient-centered clinical decision-making and value-based management, apparently only Denmark has a national, cross-sectoral initiative, which involves both clinicians and patients throughout the process of designing the questionnaire tools and digitally supported pathways for a number of selected treatment areas (Langstrup 2018). The PRO data initiative is just one of many aimed at “patient-centeredness” and participation through technology, but it stands out for its scale and scope; the realization of the initiative’s vision would mean the continuous production, collection, use and re-use of PRO data from a large proportion of the total patient population. Major patient associations have continuously supported the initiative by helping recruit patients. Patients participate in elaborate workshops exploring how to design the questionnaires and data pathways for specific treatment areas. For these associations, an infrastructure for PRO data is a major step towards more systematic inclusion of the (individual) patient voice in clinical as well as management matters. However, for the patients who were recruited to participate in, for example, four workshops on heart rehabilitation, the very concept of PRO data was at first unclear. Furthermore, while the participating patients generally liked the idea of being asked more about their experiences and quality of life, and engaged enthusiastically in the testing of possible questionnaires, they expressed concerns regarding their own representativeness of the whole population of heart patients. They feared that the “data work” in the form of continuous registration required by patients less resourceful than themselves would exclude some from being heard and seen. Similar concerns for new inequalities produced through these participatory data infrastructures were raised among clinicians, who in parallel workshops were responsible for ensuring the clinical quality and organizational viability of the PRO infrastructure. Still the framing – individual data collected with a questionnaire and used and shared along a patient trajectory – was given. This became clear, for
instance, when a patient was rebuffed as she expressed a need to get more answers from the clinicians she meets, rather than questions. The workshop coordinators responded that PRO is about the patient providing answers, not posing questions.

The Danish health services are also working to establish a solution that allows patients to upload their self-tracking and wearable data to the national systems, including Sundhed.dk. The commercial tech-giants’ success in encouraging people to use devices 24/7 and self-track their health is both in line with public promises of datafying patient experience and – in the case of the emergent commercial health data infrastructures of Google, Fitbit and Apple – a potential threat to public infrastructures. Whether data from patients’ personal devices should be uploaded onto the established public data infrastructures – and in the end health record systems – is not without contestation. The general practitioners’ association has issued a policy in which it argues against a default “data-in” model for patient reported data (Dansk Selskab for Almen Medicine,’ 2017).

Whether it is PRO data generated through the national PRO data infrastructures or data from patients’ own tracking devices, the general practitioners’ association oppose the sourcing of data that they have not “ordered”, and which could “contaminate” the patient record (ibid). It is for these reasons that general practitioners have not been represented at most of the participatory activities involved in the national PRO data initiative. What counts as a promise of voice for some may be seen as a risk of ruination for others.

**Discontented patients: patient activism aimed at increased self-determination**

Despite all these governmental attempts at engaging and empowering patients, there are people engaged in activism who believe there are better ways to do so in the age of data-intensive healthcare. As we now turn to the patients who mobilize to affect change in the healthcare services (rather than those who are mobilized by the health services), we also look towards the classic activist position of opposition. It is important to remember, however, that even for the most well-
known of these, such as HIV activism of the 1990s, patient mobilization has rarely focused on dismantling healthcare systems: many forms of oppositional patient activism still have increasing access to care as a central goal. Accordingly, the types of activism to which we now turn are strikingly similar to the invited participation and ‘empowerment’ initiatives of the welfare state: they too seek to develop and repair rather than break down or sidestep existing infrastructures. And, in most cases, they are welcomed by the authorities. One case in point which also epitomizes the particular Danish version of collaborative governance is the international patient movement known by its hashtag #wewillnotwait. This movement was formed after a number of diabetes patients and parents of children with diabetes in the international diabetes community began independently to change their treatment devices (sensors measuring blood glucose, CGMs and insulin pumps administering insulin intravenous). Their goal in doing so was to reduce the burden on quality of life that the strict treatment and data regime of diabetes self-care can have. In online spaces such as Twitter and Facebook, these patient innovators started organizing around what became termed DIY APS (do-it-yourself artificial pancreas system) and “looping” (creating a closed loop that administers insulin automatically). These patient innovators have stirred a lot of debate and some concern in diabetes communities internationally as their innovations involve unregulated alterations undertaken without formal clinical oversight and with unapproved equipment. Some authorities, such as the FDA in the US (FDA 2019), have issued public concern and critique of these activities, warning patients against experimenting, and anecdotal stories are shared about patients being asked to sign waivers by their treating clinician or being refused treatment equipment because they were using these methods. Most patients engaged in the movement are quite explicit about their desire to collaborate not only with clinicians but also regulators and device manufacturers. Collaborations are also starting to take place. In any case, our interlocutors state that Denmark is possibly the only country in the world where a public authority responsible for the treatment of diabetes – the Steno
Diabetes Center Copenhagen run by the Capital Region – has issued a treatment recommendation for clinicians on patients’ use of DIY management technologies. The recommendation states that while clinicians cannot endorse or directly be involved in the DIY treatment, patients “must continue to receive support and care from their diabetes healthcare providers at SDCC for all other aspects of their diabetes care” (Steno Diabetes Center Copenhagen, 2019). The so-called looping community has been very enthusiastic about this, viewing it as a bold move toward recognition and collaboration. Moreover, SDCC has invited central patient innovators to public meetings, where they have presented their solutions and results for an audience of patient advocates, clinicians and researchers. At two events that Henriette participated in, the organizers as well as participating clinicians publicly applauded the patients for their achievements, in contrast to the wider condemnation among clinicians internationally. Also, the SDCC recently offered to house “meet-ups” or “build-parties” where experienced DIY users guide newcomers in how to alter their devices – something which in most other countries has taken place only privately. The first event took place October 2019 and was shared on social media by clinicians and patients. The case aptly exemplifies how a participatory-minded and innovation-oriented health system seeks to enroll rather than expel activists in order to harness their efforts toward collaborative aims. While clinicians internationally have regarded this type of activism as instances of ruination, the Danish mode of collaborative governance facilitates alternative routes from promise over ruin to repair. The process involves multiple shifts in terrain as authorities acknowledge the ruination of their own treatment promises and patients become recognized as agents of repair.

There are other forms of patient activism serving as patient-initiated attempts of repair of what some patients consider governmental failure. In Denmark, two patient associations have been active in developing their own questionnaire tools aimed at data collection in research and daily care. These associations represent cancer and chronic disease patients respectively. We interviewed
two women participating in this work to understand better what they wanted to achieve. The chronic disease patient, who we call Lone, first highlighted that she really valued the online access options for patient data on Sundhed.dk: “I think one good thing about this is that I as a patient can log in and see (...) who’s been looking into my health record”. She was less enthusiastic about the various attempts of gathering patient experiences through standardized questionnaires, however, and said that –

“There is no great love of [the standardized patient satisfaction surveys] among patients – and it’s the same all over the country. It does not feel relevant. It’s the system celebrating itself”

Lone had decided to join some working groups to develop better questionnaires aimed at gathering patient experiences. Some of these groups were supported by the pharmaceutical industry. She wanted to ensure that doctors – or ‘the system’ – cared about what matters to patients. To achieve this, there was a need for more systematic methods:

“I’m particularly fond of Patient Rated Outcomes because of how systematic they are. We’re not learning anything new, but it is getting collected systematically (...) and thereby it is given greater attention. It’s usually been something the ‘nice nurse’ could deal with on the side because of her ‘big heart’.”

As instances of what Rabeharisoa and colleagues call evidence-based activism (Rabeharisoa, Moreira and Akrich, 2014), she wanted to present patient concerns in a manner that was convincing and scientific. A cancer representative, Hanne, similarly emphasized the need for data on patient concerns to be heard in a resource-pressured system: “The way things are now, we need data [on patient experiences] because data make people listen”. They were both tired of what they called ‘the case-story function’ of patient narratives used to generate sympathy and raise money, but not to influence the mode of care. They wanted to change the priorities in the everyday procedures of the
health services and in research. Lone saw data as essential to this end because: “We won’t be recognized anywhere if we can’t measure this in ways that are acknowledged as evidence. (...) We’ve all felt ignored when things don’t appear in a formalized questionnaire”. They have thus begun repairing the lack of attention to patient concerns by developing additional questionnaires. These questionnaires are supposed to make authorities and clinical listen.

There is an irony in this form of data work, however. Though both Lone and Hanne work to create questionnaires that can datafy their primary concerns and interests, the questionnaires they develop standardize patient concerns and consume the time of health professionals. Lone thus remarked:

“When I was diagnosed in the 1980s there was very limited data collection, but ample time for the clinical dialogue. There isn’t anymore because you prioritize talking about data today, and you collect so much data. There’s just 10 minutes for the consultation and you need to go through all the data. The clinician is obliged to focus on these things. (...) I sometimes refuse some tests, but I know it will cost the clinic because it counts as bad quality”

Hanne also recognized that in many ways she contributed to the making of a system that by way of datafying the patient voice gave the aggregate and the arithmetical mean priority over the individual and the personal. What she wanted was to “combine all these data with the lived life, the whole person, so that you get this back and forth. (...) I think it’s going to be fantastic! It’ll facilitate better treatments. I think it can give new hope.” Promises, activism and power struggles solidify in new infrastructures through which new struggles will be fought. As they are repairing the mishaps of the past, they entrench data practices that consume time and energy, and they are aware of this conundrum already at the point of system repair, but no solution is without its downsides.

Opposing data infrastructures: data activism against the digital infrastructures
There are also activist groups opposing the integration of health data altogether – those that do not simply wish to repair the infrastructure, but to replace or overcome the systems described above. Various activists and commercial operators are trying to build alternative infrastructures for health data storage, such as the organization Data For Good, or the many startups claiming to do a better job of empowerment than the government authorities. Ironically, it is a legal change brought forth with the European Union’s General Data Protection Regulation (GDPR) that opens up this space for action by establishing a ‘portability principle’ according to which citizens can demand a copy of data on them and transfer it to other stakeholders.

Some forms of activism also oppose datafication and data exchange. They are relatively few, but they exist. An association called the Patient Data Association (Patientdataforeningen) has been established on the initiative of general practitioners as a reaction to the political processes making data from General Practice available online, as described above (Wadmann and Hoeyer, 2018). They claim to be concerned for the privacy of their patients and argue that data sharing leaves the confidentiality of the doctor-patient relationship at risk. Paradoxically, they mobilize through Facebook, perhaps the digital economy actor most associated with intensive data sourcing. The nature of ruination and repair look very different depending on which actors the activists trust. The Patient Data Association is also a relatively elitist group. In this sense, it signals a return to the oldest forms of patient activism, in that it is mostly run by a small group of doctors, who claim to speak on behalf of patients. Members of the association are well-connected, and use their contacts to members of parliament to pose questions to ministers and influence the public agenda. Their promise might be to destabilize the infrastructure, rather than repairing it, but the extent to which it positions itself as within or outside the existing power structure is difficult to ascertain.
A quite different data activist initiative unfolding in the Danish context is *Techfestival*. Debuting in 2017 and funded by the successful Danish digital entrepreneur and millionaire Thomas Madsen-Mygdal, this three-day event is organized as an international gathering for technology innovators and entrepreneurs. The festival markets itself as being in opposition to the ideologies of Silicon Valley and big tech, aiming to promote “a new agenda that anchors technology progress in society” (Thomas Madsen-Mygdal in promotion material from the 2017 festival). The festival has attracted a large number of entrepreneurs, who have publicly lamented their own involvement in and contribution to what they now see as a digital economy turning against the initial visions of an open and democratic digital society (Berensen, 2019). The festival organizers have intended to mobilize the tech industry through the festival’s participatory processes. These have produced both The Copenhagen Letter ([https://copenhagenletter.org/](https://copenhagenletter.org/)) and later The Copenhagen Catalogue ([https://www.copenhagencatalog.org/](https://www.copenhagencatalog.org/)) as documents for transforming the tech industry. The Letter invites people in technology industries to sign a number of principles for more responsible technological innovation, including: “tech is not above us”, “progress is more than innovation”, “let’s build from trust”, “design open to scrutiny”, and “let’s move from human-centered design to humanity-centered design”. The Catalogue holds 150 principles “for a new direction in tech” that can be signed individually to express support. It is a form of activism aimed at challenging the digital infrastructures that Zuboff (2019) associates with surveillance capitalism. It does not only aim to repair the infrastructure; it wishes to recreate it and the principles on which it stands.

Whereas the Patient Data Association uses private data infrastructures to challenge the public system, *Techfestival* challenges the private infrastructures and the ways in which large multinational companies infiltrate and take over public infrastructures and service delivery. Both types of activism are nonetheless elitist. Both are in the business not of repair, but of pointing to ruins and articulating new promises. *Techfestival* is supported financially by a number of both large and small
technology companies as well as by the Copenhagen Municipality and the Danish Business Authorities. There are multiple positions in play within this grid, but no organization fully outside of some form of grid.

**Conclusion: promise, ruination and repair**

In this paper, we have described how Danish health data infrastructures have evolved through processes of promise, ruination and repair. We have used this case to rethink activism as it evolves within a framework of collaborative governance. Infrastructures are never finished. They always deliver both more and less than promised, and it is in the ruins of failed promises that both patients and institutions mobilize to repair. In these moments of repair, new visions and promises emerge, and through them infrastructures evolve. Promises, ruination and repair operate in recursive circles where no step is definitely right for all stakeholders or forever. Even acts of repair will be part of creating the infrastructures through which future problems emerge. While this may sound pessimistic, we have wanted to use the Danish case to acknowledge these power struggles as embodying also forms of care. In the course of establishing a welfare state, earlier generations fought hard to turn promises of a better life into public obligations. Without a welfare state, there probably would be fewer public data mistakes – but also fewer services available to all. This does not legitimize every use of data; rather the gravity of the entitlements at stake should serve to install precaution and care when tinkering with the system. There is no perfect healthcare system, but there are systems that seek to react when unintended effects develop – or when realizing that some people experience intended effects as unfair or objectionable.

We have emphasized how promises as well as complaints about ruination and attempts of repair can come from all quarters and do not ‘belong’ to either activists or state institutions. On closer inspection, dichotomies are not stable: what count as inside and outside, weak and strong,
constructive and destructive, patient and expert, shifts over time. Similarly, the action going into the making of infrastructures always overflow: it is morally ambiguous in its intent as well as effect.

What type of questions does this raise for scholarly work on patient activism in an age of data-intensive healthcare? Perhaps we can begin to discern with greater clarity how scholars position themselves along lines similar to those described above for the forces at play. Some scholars seek to articulate (and realize) new promises as alternatives to the existing options; others give voice to dissatisfaction and complaints about ruination; while others, again, work alongside people in their attempts of repair. All three modes of scholarly work can take sides with governmental agencies, patient activists or other stakeholders. Some seek authenticity in their attempts to break down existing structures; others in their attempts to make them stronger, fairer, or better tuned to the needs that their research seeks to articulate. Each form of scholarly activism probably carries elements of the same inherent moral ambiguity that we described above as characterizing attempts to shape the everyday practices of the health services.

Situatedness is also geographical, social, and political. We have described a Danish case that is in some ways extreme. The Danish experience of collaborative governance provides a particular backdrop for discussions of data infrastructures. They differ in significant ways from, for example, the Chinese proclaimed communist ambition with minimal tolerance of civil activism, as well from as the deep mistrust of state initiatives in the US where a powerful form of right-wing activism mobilizes against what it designates as ‘Big State’. All socio-political assemblages are in a certain sense unique. While policy discourses often claim universality, scholarly work serves exactly to create awareness of this type of situatedness.

In our analysis above, we might have emphasized the care aspect of the welfare state too much. We can be said to have placed ourselves mainly among those opting for rights to care and thereby failed to give adequate attention to the ways in which citizens might stand to lose, for
example, rights of privacy. On October 17, 2019, special rapporteur on human rights for the United Nations, Philip Alston, warned welfare states against digital data integration of the type that Denmark has so radically pursued. He forcefully suggested that “as humankind moves, perhaps inexorably, towards the digital welfare future it needs to alter course significantly and rapidly to avoid stumbling zombie-like into a digital welfare dystopia” (UN Secretary General, 2019: 19). There is a risk that once an infrastructure is in place, it will be used by all the wrong people for the wrong things (O’Doherty et al, 2016). Tupasela and colleagues (2020) have pointed to contemporary attempts to exploit Danish data infrastructures commercially as one such deviation from original promises that can endanger trust. Danish philosopher Mads Vestergaard (2019) has warned the Danish public against the emergence of a form of ‘digital totalitarism’ eclipsing human dignity. By emphasizing totalitarism, Vestergaard differs from Shoshana Zuboff’s (2019) famous critique of surveillance capitalism in two respects: totalitarism aims for controlling the soul (whereas Zuboff suggests control is aimed just at behavior) and it is linked to the state (where Zuboff suggests that commercial surveillance is accepted in the US exactly because it is not state-centered).

Though the role of the state gives rise to concern, it could – perhaps – also become a source of hope. The hope of democratic control. The surveillance opportunities of digital infrastructures alter the conditions of possibility for mobilization against those that control the data flows; every act online today leaves a trace that can also be used against you. It is therefore critical how these opportunities are used, which interests they serve, and which checks and balances keep them under control. When and how data are used to watch over (våge over) and mobilize repair work, and when they are used to survey and control (overvåge) will remain empirical questions fraught with enduring moral ambiguity. Similar technologies can have very different social implications in different locales. Just as the people we study, we as scholars are caught in medias
res – in the processes of promise, ruination and repair. Consequently, as Foucault (1997: 232) famously suggested, “we always have something to do”.

References


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