

3 DATA WORK

November 2016: “It was a big step for *me*, I thought, but I had never expected that type of public reaction,” the chief gynecologist Morten Hedegaard¹ writes in a diary note about his resignation from his position as chief physician at the most prominent birth ward in Denmark. The resignation caused a big media stir, and the note was later printed in a magazine for doctors (Boysen 2016). For fourteen years, he had acted as a flagship of authority on matters of gynecology. He had been medically responsible for births in the royal family, and therefore also had experienced a certain amount of public interest before, but nothing like this. Every national newspaper covered the resignation. There were television interviews and massive social media reactions. It is rare to have the career choices of a doctor covered with such intensity, but the story was not so much *that* he resigned; it was *why* he resigned.

Hedegaard resigned, he said, because the ward had become too busy to ensure the safety and attentiveness that parents and newborns deserve. The working conditions had become intolerable. In the midst of the media hullabaloo around his resignation, the politician responsible, Head of the Capital Region Sophie Hæstorp Andersen, responded. Interestingly, she dismissed Hedegaard’s professional concerns and stated as a matter of fact: “It is safe [to give birth at the hospital]!” She said so even though she was not a doctor and did not work on the ward. To support her claim, she argued: “No data indicate that we have more complications in relation to births taking place here. It is probably more a question of staff experiencing that they are running faster and faster, and many burn out. It is actually a serious problem, because we lack staff” (quoted in Maach 2016). In this

way, she acknowledged a problem of human resources, which could be supported by data, but dismissed the doctor's concerns about the implications of this problem for safety. Her disregard of this senior clinician's disquiet was, ironically, based on data produced by the very doctors and nurses raising these concerns.

I followed this story with interest. At the time, I had already interviewed two data analysts servicing politicians and administrative management, who had proudly explained to me how, typically, they could document that levels of activity were absolutely normal when clinicians said they were too busy. I kept wondering: Who is right? What counts as knowledge about work? My sense of curiosity was stimulated further by the debate taking place in the ensuing months. In response to Hedegaard's exit, the political management defended itself by stating that the ward had received an extraordinary budget expansion of four million DKK. The staff had no reason to complain. However, the so-called reprioritization contribution, mentioned in chapter 1 (where operational expenses on hospital budgets have been reduced based on an expectation of 2 percent increased efficiency every year), happens to imply reductions of, yes, also four million DKK. Hedegaard explained to the media that the annual 2 percent reduction was, for him, the straw that broke the camel's back (Redaktionen 2016). In the following months, the picture became even muddier. When the minister of health, Ellen Nørby, was asked by political opponents to do something for prospective parents, she presented new data: from 2001 to 2015, the number of doctors and nurses had gone up 44 percent and 20 percent, respectively. In 2001, a midwife assisted delivery of sixty-five children on average, and in 2015, that number had fallen to thirty-eight. Nørby firmly stated: "There have been no cutbacks. Resources have been added" (quoted in Dørge 2017). Did Hedegaard then resign for no reason? Are healthcare professionals not busy at all? Or are they busy doing something else instead of taking care of babies and their parents? What counts as knowledge about clinical work?

Subsequently, numerous other stories have appeared in the media about doctors resigning in protest. Initially, these stories all referred back to Hedegaard. Then these accounts almost created a subgenre with its own narrative arc, with a new, increasingly prominent antagonist: *data work*. Many doctors now explicitly point to the time spent producing data when explaining their decision to leave the health services. Further, the digital tools offered for data

work attract unprecedented public attention. In particular, in two of the five administrative Regions in Denmark, clinicians complain about a new information technology (IT) system (mentioned in chapter 1). Launched in 2016, it is delivered by the American company Epic and in Denmark it is known under the name *Sundhedsplatformen* (The Health Platform).² While the digital record systems used in the other Regions live relatively dull and unremarkable social lives, the Health Platform begins being featured heavily in news headlines with stories about clinical staff “who break down and cry” when having to work in the new system and who ask for (and receive) “psychological crisis assistance” (Heick 2016). One physician published a book in which he blamed his resignation from the post of chief physician on the current “yoke of Kafkaesque idiocy, grotesque over-administration, Health Platforms, crazy demands of documentation, [and] marginalization of medical competence and care” (Jacobsen 2018: 31). Another physician claims that as the health services are now “drowning in data work,” health professionals are losing the motivation that used to be essential for them. He adds: “You have to survive, and you can cope only by letting a sense of indifference take over” (Olesen 2018: 84).

Also, in interviews with my colleagues and me, clinicians speak matter-of-factly about “meaningless work” as an integral part of clinical work. It is a startling observation. A recent Danish bestseller even describes meaningless “pseudo work” as a characteristic of modern organizations across all sectors in Denmark (Nørmark and Jensen 2019). Pseudo work can be considered a Danish version of what anthropologist David Graeber made internationally famous as “bullshit jobs”—jobs that make no difference and are meaningless even for those making a substantial income from them (Graeber 2018). According to Graeber, such work constitutes a form of “spiritual violence” that crunches the soul of the employee (67). When clinicians speak to me about the tasks that they think of as “meaningless,” they often refer to something they also call “data massage” or “data fiddling.” Data massage is typically related to what in organizational theory is known as “gaming”—to produce data in order to appear in a particular manner rather than simply as a procedure of clinical documentation. Their comments about data massage are typically followed by ironic gestures, jeers, and raised eyebrows. One general practitioner, Bente, who I interviewed together with my colleague Sarah Wadmann, used the phrase “it makes no sense” no less than forty-six

times in the course of an interview, during which she said that the data tasks required by the regional authorities were “just plain idiocy, gosh, it’s these kinds of absolutely foolish things (. . .) it’s without meaning or purpose.”

What is going on? Healthcare workers resigning. Complaints about meaningless work. Dull administrative matters such as IT systems suddenly making it to the news headlines. And politicians and administrators confidently asserting that there is no reason to worry. If Denmark really is at the forefront of digital healthcare, as the rankings presented in chapter 2 suggest, then it appears that there are some worrisome elements associated with this data-intensive mode of working. The pursuit of data promises seems to involve some unintended consequences. Once translated into everyday work, data-intensive healthcare is apparently not progressing as smoothly as the high-flying gospel from Silicon Valley would suggest.

In this chapter, I focus on *data work*. Data work is a key battleground for data politics. Again, I will suggest that the politics of intensified data sourcing involves paradoxes: apparently contradictory claims, yet both sides of the contradiction carry elements of truth. Data create less work *and* more work. Datafication both tightens organizational control *and* facilitates organizational disintegration. Data work involves tasks experienced by some as meaningless, and yet at the same time, data have become a prime source of meaning. Different versions of truth are presented on the one hand by clinicians and on the other by administrators (and politicians). Doctors and policymakers seem to live in separate realities, although they refer to similar data and ostensibly talk about the same clinical and organizational phenomena. Instead of opting for one or the other version as the “real” truth, the point is to approach these opposing stories as paradoxes and see what the coexistence of multiple truths allows people to do.

I begin the chapter with a discussion of the term *data work* and situate this discussion in wider, and indeed classic, discussions of organizational work and the role of technology. I then turn to the scandal surrounding The Health Platform as an interesting example of what happens when dreams of superior American IT tools meet everyday life in an e-health context, which is arguably more advanced in terms of data integration than the American healthcare system. Building on the purposes outlined in chapter 1, I then give examples of the data work that is supposed to underpin the goals of research, clinical performance, administration, and governance. Based on these examples, I suggest a rethink about why the data mill keeps grinding

and what the implications might be for patients and health professionals alike.³

WORK: PRODUCTION, ANALYSIS, INSTRUCTION, AND USE

“Nice work if you can get it,” Frank Sinatra sang about love. Data work does not seem to carry the same appeal. Still, in recent years, scholars have begun paying more attention to data work and to the clinicians, patients, or documentary specialists who deliver it (Morrison, Jones, Jones, and Vuylsteke 2013; Bossen, Chen, and Pine 2019; Bossen, Pine, Cabitza, et al. 2019; Pine 2019; Pine, Wolf, and Mazmanian 2016; Møller, Holten, Bossen et al. 2020; Fiske, Prainsack, and Buyx 2019; Pinel, Prainsack, and McKeivitt 2020; Walford 2021; Petersson and Backman 2021). I described in the previous chapter how patients are doing increasing amounts of data work as a result of the shift in medical paradigms and organizational structures (Langstrup 2018; Torenholt, Saltbæk, and Langstrup 2020). In this chapter, I explore the data work undertaken by people employed in health services. So, what does data work involve, who does it, and why does it proliferate?

In the introduction, I referenced Berg and Goorman’s *law of medical information*, which famously states, “The further information has to be able to circulate (. . .) the more work is required to disentangle the information from the context of its production.” Berg and Goorman (1999) specifically pointed to a key question: “Who has to do this work and who reaps the benefits?” (52). They focused on the kind of work going into *producing* data: namely, clinical documentation. I think that intensified data sourcing generates other types of data work that also need consideration. Data work is carried out by people with a wide range of job titles and professional backgrounds situated in different parts of the healthcare system.

Consider again table 1.1 in chapter 1 and the many stakeholders interested in data. They all do some kind of data work. Just in the clinic, there are, in addition to doctors, nurses, and other clinicians, secretaries and information specialists working with data. Many people who work with healthcare data full time rarely visit the clinic. Some of them prepare data for quality databases. Some produce reports to management. Others assist politicians as described previously. Yet others work with how data can be used to intervene in and optimize work at all levels of the healthcare system, such as local “lean” consultants who work with management to optimize the efficiency

of clinical work by means of data analysis. There are also software programmers who work with data to design interfaces aimed at nudging clinical staff into following particular guidelines or adhere to certain standards. There are also all the public and private researchers who work with data derived from the clinic to produce new insights or products aimed at goals such as prevention. Finally, data-intensive organizations impose an obligation on employees to know about the data analyses produced. Even when not producing, analyzing, or managing data, most people have to spend time reading and discussing reports and findings. While Berg and Goorman (1999) rightfully asked who does the work, they focused only on the work associated with producing data. I believe that to understand the dynamics of intensified data sourcing, it is necessary to consider the other types of data work—and thereby data workers other than those working in the clinic—as well. When taking them into account, it is easier to understand how different groups come to hold such divergent conceptions of the impact of data intensification on everyday work.

I suggest thinking of data work as four types of activity that partly overlap and feed into each other: production, analysis, instruction, and use (see table 3.1). The distinction between these four types revolves around how the worker is positioned in relation to the purpose of the data work. When *producing* data, you are delivering data but do not necessarily enjoy the thrill of doing the analysis. When *analyzing* data, you are engaged in deciding what the data mean. When *instructing* people with, or being *instructed* by, data work, the epistemological purpose gives precedence to the political purpose: the meaning-making process is reduced to the effect

Table 3.1

The four main types of work associated with data-intensive healthcare

Data production	The work going into making data through actual documentation (e.g., application of a diagnostic code)
Data analysis	The work that transforms data sets into messages about what they mean (e.g., the making of a table, graph, dashboard or a narrative)
Data instruction	The work involved in governing others with, or being governed by, data
Data use	The work associated with understanding data or data analyses produced by others

on what people do and how they view each other. It subordinates validity to recognition and thereby positions people differently, as subjects of governance. All these three types of data work, of course, involve some form of use, but when I point to *use* as a distinct category, it is because data-intensive organizations circulate so many data and so many analyses that the use of data has become a precondition for retaining a right to voice one's opinion. When *using* data and data analyses, the work revolves around what it takes to make sense of the data analyses produced by others. You do not produce the data, you have not done the analysis, and the data practices are not aimed at controlling your work: you are just a user. It is a residual category aimed at capturing the fact that in data-intensive environments, it can take a particular kind of data work to create legitimacy around your person. When everybody refers to data, the right to speak one's opinion can depend on the ability to cite relevant analyses and to use analyses to make sense of the problems in front of you. It can be time-consuming to find the right data and to locate the analyses that you think you can trust. It takes work to disseminate what you have found. As I could see people in the clinic spending time looking into all sort of data analyses, reports, and rankings, I included it as a category of data work. It struck me as one of those types of work that is not counted and is not featured in the data sets that administrators and politicians use when claiming that health professionals are not busy. Clearly, in practical situations, all four can overlap, just as one type of data work can stimulate people to engage another.

Intensified data sourcing affects what counts as knowledge about the organization and intervenes in negotiations between professional groups about who needs to know what. Questions about what counts as knowledge about work (and who needs to know what) have invigorated sociology and organization theory for more than a century. In the current situation, where data promises sweep across healthcare systems around the globe, these questions are more relevant than ever. I now turn to these questions and show how they can inform our understanding of the implications of the four types of data work.

Historically, questions about work have stimulated controversies between positivist approaches, such as Frederick Taylor's scientific management school (Taylor 1998), and hermeneutic approaches, such as Elton Mayo's human

relations movement (Mayo 2003 [1933]). Arguably, Mayo used more numbers than Taylor in the actual writing, but he argued that workers need *meaning*. Mayo thereby developed Max Weber's hermeneutic approach to organizations and underlined the importance of Weber's warning against experiences of disenchantment and alienation in rational organizations—what Weber famously termed an “iron cage” (Weber 1947a).

At the time when Weber wrote about the rise of a legal-rational bureaucracy, records were kept on paper, in closed filing cabinets and archives. While professionals were expected to exert professional judgment and base decisions on their orientation toward organizational goals, they were also to be partly protected against political involvement when dealing with individual cases: “Every bureaucracy seeks to increase the superiority of the professionally informed by keeping their knowledge and intentions secret” (Weber, 1947a: 233). Max Weber identified a persistent longing for archival work in bureaucracies (Weber 1947a, 2003b). Professional data work (a term not used at the time) was aimed at supporting a professional role, much like clinical records used to serve primarily clinical goals (Bossen 2014). Today, however, there are many actors eager to use clinical documentation (again see table 1.1), and digitization has opened up many secret archives for inspection.

Management has long desired to “know” what employees are doing, as well as to optimize and control their performance. This urge was not born with digitization; digitization just provides additional tools. In 1911, when Taylor wrote his famous introduction to scientific management (laying out the seeds from which also Deloitte's mantra about “data and knowledge about what works” would later grow), he had already made it clear that he did not trust workers to understand or improve their own performance. He asserted that “the workman who is best suited to actually doing the work is incapable of fully understanding this science, without the guidance and help of those who are working with him or over him, either through lack of education or through insufficient mental capacity” (Taylor 1998: 9–10). An effective analysis of work, he asserted, should be based on numerical evidence and informed by statistics, not by the experience or opinion of the worker himself or herself. Today, digital technologies have propelled the pursuit of data-mediated optimization far beyond the factory floor and into professions that were previously more autonomous, including medicine (Moore 2018; Zuboff 1989; Rahman 2021).

Data on work still depends on data work. Management's knowledge typically builds on data that employees themselves produce. It is then not the same people doing the data work of production and the data work of analysis. Furthermore, digital tools are typically designed not only to *document* what people do, but also to shape *what* they do and *how* they do it (Amoore and Piotukh 2015; Moore 2018; Petersen 2019). Herein lies data work of instruction. The interfaces of electronic health records are designed to make them do the work in a particular order, but also to demand the documentation of particular tasks (Felt, Öchsner, and Rae 2020). Thereby, values and priorities become "inscribed" into the very tools offered for carrying out the clinical work (cf. Akrich 1992; Jensen 2021). Accordingly, Bovens and Zouridis (2022) claim that digitization has tightened the political control over public employees. The public servant used to have more room for professional discretion when meeting the citizen. There was what Lipsky (1980) called a street-level bureaucracy softening up the effect of new rules by being at liberty to exert judgment.

Bovens and Zouridis (2022) argue that it is now more appropriate to talk about screen- or system-level bureaucracy because frontline staff have to work in interfaces (screens) that steer and monitor their decisions. They cannot do their work without documenting it in data formats facilitating surveillance of compliance with organizational goals. They are under instruction. In some cases, performance management relies on criteria of measurement that remain opaque to the knowledge workers who increasingly find themselves under surveillance through their very tools of daily work (Rahman 2021). They sometimes need to hide what they are actually doing (Petersson and Backman 2021). Breit, Egeland, and Loberg (2019) suggest using the term "cyborg bureaucracy" to refer to a form of governance that is a mix of human and nonhuman forces. Cyborg-bureaucracy has coemerged with the new forms of "wired medicine" that patients meet when seeking care, as described in chapter 2.

Some forms of data work of production are aimed directly at facilitating the analysis of other actors or at tightening organizational control (in line with what I call instruction). Frontline staff, for example, are increasingly asked to "measure" the needs of citizens before attending to their care (Hoeyer and Bødker 2020; Lyneborg 2019). I gave an example in chapter 1 having to do with eldercare, but this trend cuts across areas and sectors, from education to social services and disability (Høybye-Mortensen 2015;

Fernandez and Lutz 2019; Shaw, Bell, Sinclair et al. 2009; Langstrup and Moreira 2021). In wired medicine, the problem has to be datafied before it can be solved. Parton (2008) has described how such documentation tools interact with and change the professional ethos and sense of purpose also among social workers. Parton points to datafication as one of the dynamics fueling this transformation: when asking for *data* on *what* citizens do, say, or want, rather than asking for a *narrative* about *why* they want it, professionals no longer provide an interpretation of the individual citizen. Through data points, citizens are monitored as a population. Datafication brings about a transformative process where interpretation is increasingly something that people can do elsewhere, based not on interactions *with* the citizen but on information *about* the citizen. It involves a separation of data-work-of-production and data-work-of-analysis, and it shifts decision making about individual patients toward seeing them as they are positioned in a population rather than as having a unique trajectory (Nordfalk, Olejaz, and Hoeyer 2022).

Work on instruction also goes into designing, implementing, and monitoring digital tools that can shape what people do. It can be with pop-up windows or interfaces that allow only certain options. In healthcare, it can take the shape of decision trees or alerts on risks, such as rare disorders, or polypharmacy (Wachter 2017).⁴ I interviewed one data analyst who had designed a data tool reducing general practitioner (GP) prescriptions of dangerous drugs by 20 percent simply by giving the GPs automated feedback benchmarking their prescriptions against those of colleagues. What was interesting about this form of instruction was that it did not add data-work-of-production to GPs but stimulated data-work-of-analysis among the GPs: they now wanted to understand their own prescription patterns.

However, not all tools of instruction operate as subtly as this. Some attempts to affect clinical decisions focus on achieving particular political goals, such as reducing the use of physical force in psychiatry, shorter waiting lists, and the shift from eldercare to rehabilitation training discussed in chapter 1. In these cases, data work aimed at *instruction* can encroach on the professional sense of judgment and, in some cases, make health professionals feel that their work becomes less meaningful. To lose influence can give rise to feelings of meaninglessness, whether understood as alienation (Blocker 1974), moral disorientation (Oakley 2010) or powerlessness (Seeman 1975).

Before I turn to more examples of the data work aimed at supporting the clinical, research, administrative, and political purposes laid out in chapter 1, I will tell the story of the very expensive medical record system known as The Health Platform, which two of the five Danish administrative regions purchased from the American supplier Epic. This software exemplifies the type of reactions that an interference in data work can spur. It also illustrates how some of the high-flying data promises that fascinate administrators and politicians can crash when they hit the ground.

OPTIMAL DIGITAL TOOLS FOR DATA WORK: BUYING AN AMERICAN LIMOUSINE

Despite the Nordic countries' long tradition for integrated digital e-health, it should come as no surprise in the current climate of admiration for US IT that the biggest IT investment in Danish healthcare history had to be an American system. The medical record system called The Health Platform was implemented in 2016. As should be obvious by now, no other health IT system has received similar media attention. Unfortunately, the attention has been almost exclusively negative (Røhl and Nielsen 2019). I initially tried to interview people in key positions about The Health Platform, but I quickly realized that I had to rely mostly on media reports. People still in office would agree to an interview only if I promised not to ask about this purchase. It was "too political," I was told. Though key actors declined, I could hardly meet any clinician working in one of the two Regions—whether by chance on commuter trains or at dinner parties or in more professional settings at seminars or conferences—without hearing them talk about the system. Still, anonymity remained important. It is a system that raises emotions and strong opinions.

One of the doctors to resign while blaming this system, the surgeon Ulf Helgstrand states:

The Health Platform steals your time. I am no longer in a position to provide the guidance and treatment that I believe patients deserve. (. . .) I am constantly sitting with my back to the patients because I have to look at the screen. (Baun 2017)

Another chief surgeon, Michael Halder, explains his resignation like this:

It is a terrible system. It has drained all joy from work and from caring for patients and their relatives. (. . .) I will never work again in a hospital using The Health Platform. (Mortensen and Dencher 2018)

Like many of the people confiding in me off the record, Halder says that he very often had to stay behind after work to do his documentation. Apparently, Epic has not managed to fulfill the hopes nurtured by health professionals of a seamless, efficient, and safe e-health system. Instead the system has increased their data-work-of-production.

When Danish politicians and civil servants decided to buy the e-health record, they said that it would replace “thirty systems with one.” Clinicians were working in a patchwork of systems, arguably not thirty for each individual doctor (more like six or seven), but there were around thirty systems from which some administrative workers needed to retrieve data. Better integration would be welcome, not least from the perspective of those doing the data-work-of-analysis: one tool rather than many. Epic was, at conferences, spoken about as an American limousine. “Limos” are rare in Denmark and associated with extravagant luxury. In line with this sense of indulgence, I remember the optimistic atmosphere before the launch, and how clinicians would talk about their hopes for more seamless interfaces facilitating their clinical work.

I first suspected in 2015 that some clinicians would be disappointed. It was when I heard a talk by a woman in a leading position in the implementation of the Epic system. She stated that codes were to completely replace narrative elements (free text) in the patient record because codes are easier to search and compute. They can be used for more purposes. I feared I had misheard her presentation and wrote her an e-mail. She kindly replied:

It is correct that narrative elements shall be minimized and gradually be superseded. Epic facilitates monitoring of data fields so that a decision on when to terminate narrative elements will be based on actual data analysis. The first version of the Health Platform is not complete, hence this postponement.

It seemed that data codes indeed really were to replace narratives! The administration was inspired by the consultancy group Gartner talking about a five-step model of electronic health records, going from perceiving the health record as The Collector, The Documenter, The Helper, The Colleague, to, finally, The Mentor (Krogh 2016: 99). They thought it was time for the clinicians to get a mentor. The administration apparently felt confident that with enough data, they would be able to optimize clinical work—in line with Taylor’s attitude.

To act as a mentor, the record system really had to be good. Being good, however, always begs the question: good for whom, and according to which

criteria? Epic is constructed for American healthcare. It is built to support particular workflows, cultures, and purposes that are very different from those characterizing Danish healthcare (Allen 2019; Koopman, Jones, Simon et al. 2021). In American healthcare, each patient sees fewer doctors than in Denmark. When Danish doctors build a narrative, they write a short history, which is meant to help other doctors who are treating the same patient understand that patient's situation. Traditionally, Danish nurses have had more leeway to exert clinical judgment than do nurses working in American healthcare. Danish doctors and nurses also share tasks, but Epic is not built for that. Epic is excellent for billing purposes. Yet Danish healthcare is tax-financed: the economy of each hospital depends on sending data to national registries rather than on billing. In a number of major ways, therefore, the Epic system did not translate well into Danish practices (Bansler 2021).

There were also other elements lost in translation—and not only metaphorically. The builders of the system had relied partly on automated language translation with results that would have been laughable had they not been, potentially, so deeply serious (Allen 2019). “Right,” for example, as in the *right* leg in contrast to the *left* leg, would sometimes appear as the “correct” leg, and “left” was occasionally translated into the Danish word for “abandoned,” as in “left behind.” The Latin word *cave*, meaning “watch out,” which is used for highlighting drugs that risk giving a patient an allergic reaction, had been translated as “grotto” (Bentzon and Rosenberg 2021). Examples proliferated as health professionals agitatedly collected proof of their disappointment with the American limousine (Gadsbøll 2017). Doctors found themselves using interfaces that were described to me as “a dinosaur,” “from the darkness of the past century,” or “something you’d have expected to encounter in the 1970s, not in 2020.” Also, American clinicians complain about counterintuitive and cumbersome data work when working in Epic systems (Schulte and Fortune 2019). A Danish doctor remarked to me once: “If this is a limo, I think a family car would have been a better match.” In a sense, he acknowledged that the Epic system might provide new opportunities, but they were just not particularly relevant for the clinical tasks at hand. Some optimistic managers, in contrast, have shown me fascinating examples of what the system allows them to monitor, and they hope that their own enthusiasm eventually spreads to the clinical staff.

The integration element fared even worse than the initial translation problems. “Everything in one system” turned out to be a misnomer. Most

clinicians continue to work in several systems. Doctors have to communicate with health professionals outside the hospital, but The Health Platform is a closed system, designed for the American healthcare system where data are proprietary assets. As the platform was not set up for integration with outside systems, there were now gaps in the data sent to the national quality databases, as well as to the otherwise famously complete registries. As I discussed this with two consultants servicing the system, they winced, and one said: "I basically think Epic had no clue what a national registry is or why central reporting would be important." Indeed, Epic has been criticized for lacking commitment to data sharing in other contexts too, including in the United States (Sheikh, Sood, and Bates 2015; Jones, Laurie, Stevens et al. 2017). In Denmark, however, the problems stretched beyond the clinic because Epic lacked the ability to integrate with existing infrastructures. After fifty years with outstanding registries known for their completeness, frustrated researchers spoke informally and at conferences about "data gaps." Considering that the biggest IT investment in Danish healthcare history was supposed to deliver more data, with better quality and in a more integrated manner, such breaches are astounding. A healthcare system known as having one of the most integrated data infrastructures in the world was now disintegrating. The American limousine was not made for public transportation.

The price was exorbitant. The two regions paid 2.8 billion DKK for the system. It was the same amount that the biggest health insurance company in Denmark paid in subsidies to all of its 2.3 million members the same year. On top of that, productivity went down considerably (Højer 2016). Or, at least, the registered productivity went down. Data gaps make it difficult to verify the exact drop. Data gaps partly reflect the problems of integration described previously, but probably also changed registration practices. With the arrival of The Health Platform, secretaries were fired and doctors told to document their own work. It was said to increase patient involvement with doctors by including patients in the record keeping. Laying off the secretaries also featured in budgets as a cost-saving measure. As data work turned out to be more demanding than expected, many secretaries had to be hired again (Ritzau 2017). Paper also saw a renaissance, as nurses and doctors began taking notes on paper, sticky notes, and napkins (Hecklen 2017). In short, it turned out to be surprisingly difficult to get data *into* the system (the data-work-of-production) as well as *out* of it (the data-work-of-analysis).

On top of the economic setback and the sense of burnout, health professionals have complained about the safety of the system. The dispensing of pharmaceuticals, for example, continues to be an area of concern (Sørensen 2016; Mirzaei-Fard and Baun 2019). Clinicians must choose from predefined options for prescriptions, which do not always fit their plans. Furthermore, the system has not always integrated well with the otherwise acclaimed national system of pharmaceutical dispensing. When outpatients and people in eldercare visited a hospital, their prescriptions in the centralized system were not always up to date. Overall, the number and range of clinical complaints have been massive, but some clinicians are tired of all the grumbling—they do not see the reason for all the fuss. One nurse said to me: “The old systems were bad. The new system is bad. Why complain?” Furthermore, there are people who enjoy playing around with the new features (see chapter 4). Even difficult systems can be fun, if you are so attuned. One civil servant, who actually had asked not to be interviewed about The Health Platform, decided, unprompted, to convey her impression to me while leaning in over the table, confiding “I think the clinicians have just forgotten how much they hated the old systems. The problem is they were told they would get a limousine, and they were disappointed.”

She might be right. Clinicians thought they would get a system aimed at their own clinical objectives. What they got was a system helping the data work of the administrators. With its smart text and codes, it seems to be designed for easing the data-work-of-analysis, not the data-work-of-production. When the system was to be updated, clinicians again expressed hopes of more seamless interfaces. They were disappointed (Kristensen 2019). A representative for the management, Pia Kopke, responded to their disappointment as follows:

It seems like we have not aligned the expectations properly at all levels of the organization (. . .). The primary reason for updating [The Health Platform] was to prepare it for integration with The National Patient Register. (Mirzaei-Fard and Korsgaard 2019)

The updates were not aimed at dealing with the problems faced by the clinical staff. They were aimed at servicing the data needs of administrators and researchers.⁵

In short, the Epic system redistributed work rather than eliminating it. It was said to deliver optimal integration, but this ambition relied on the idea of having “everything in one system.” No single system can do the job

when data are to flow between many actors, performing very diverse tasks. Denmark's colonial heritage, for example, entails that the main hospital in Copenhagen also provides specialized care to citizens from the Faroe Islands and Greenland—that is, from different countries, outside the European Union, and with their own record systems. Having one system as an ideal for integration is, perhaps, just silly.

When moving beyond the specific Epic system, how do people engaged in data work aimed at promoting clinical, research, and political-administrative purposes make sense of their tasks? How does data work interact with the way that priorities are decided? In pursuit of answers, Sarah Wadmann and I interviewed a wide range of clinicians, researchers, and administrators about data work. One could easily have imagined that the data-work-of-production would be carried out by clinicians, the data-work-of-analysis by researchers, the data-work-of-instruction was initiated by administrators, and the data-work-of-use by politicians. It is not the case. Clinicians, researchers, and administrators do all four types of data work—but in various degrees, in different forms and sequences, and with different senses of purpose and pleasure. I will not discuss politicians and industry, even though they are featured in table 1.1, because I have not been close enough to their actual practices. When data are used for multiple purposes, it can be difficult to discern which type of work goes into achieving what. This floating nature of data work is important, I suggest, because it gives rise to silent shifts in prioritization (see also Pine and Bossen 2020).

DATA WORK FOR RESEARCH, CLINICAL, ADMINISTRATIVE, AND POLITICAL PURPOSES

Data can be used to reach many laudable objectives. The list in table 1.1 is long but not exhaustive. Most of the data must be produced in the clinic. In general, in our interviews, clinicians are positive about data work when they are convinced that it serves the interests of the patient. They accept data-work-of-production when data serve a clinical purpose and the work takes as little time as possible. It is important for them to work in digital interfaces fitted to their tasks. It should be obvious from the description of The Health Platform that it is not always seen as an optimal tool, but there are other excellent digital tools—tools that are intuitive and easy to use, and therefore make data-work-of-production manageable.

Clinicians do not only *produce* data. Many clinicians do data-work-of-analysis to gain an overview of patients and patient flows, as well as to plan and optimize their work. Sometimes they get assistance from “lean” consultants and administrative data specialists. It is also part of the clinical routine to instruct each other with data. In a healthcare system communicating through data, there is no way to avoid data-work-of-instruction. The national pharmaceutical platform that I have mentioned is, in a sense, a data tool for instruction. It helps the doctor responsible to assign tasks to other health professionals. The tools for data-work-of-instruction for clinical purposes must first and foremost be stable and safe. Finally, clinicians are also users of the analyses produced by others. Data-work-of-use, therefore, also consumes their time. In short, data are essential for clinical work, and clinicians engage in all four types of data work. Yet many complain about drowning in data work. Clinicians are, of course, as varied a population as any other, and what some dislike, others enjoy. It is also possible to dislike producing data on a particular topic and still appreciate the analytical results arising from those data—just as many of us appreciate a clean home without enjoying the act of cleaning as such. Still, clinical complaints seem to be increasing. Why?

Clinicians do a lot of data work serving purposes defined outside the clinic. As also described by Winthereik, van der Ploeg, and Berg (2007), some types of data work are aimed at *both* clinical *and* political-administrative purposes. The National Quality Databases provide an example. Clinicians want to ensure—and document—high clinical quality, but the quality databases and their particular formats are partly an administrative invention aimed at governing performance. While the old-fashioned registries build on singular pieces of information about patients, such as a diagnostic code, the quality databases monitor entire stays in hospitals. There can be hundreds of data points a day on a patient, ranging from blood pressure and temperature to patient-rated outcome measures. The quality databases necessitate a lot of data-work-of-production. The systems that clinicians work in, such as The Health Platform, are set up in a manner ensuring that the everyday clinical documentation gathers these data in predefined formats. The data are then automatically transferred to the central quality databases (it was this feature that partly failed in The Health Platform). Although data collection operates through the interface that clinicians meet, clinicians are not always aware of why certain data have to be collected or where the data go. I have spoken to nurses who did not know that they were producing

data for the quality databases. With the quality databases, information specialists analyze the data and send reports to local and central management through the management information system. The data-work-of-analysis is then no longer done by the clinical staff. Many clinical managers use these data in their daily running of the clinics. In such cases, the same nurse who produced some of the data may then come under instruction through the decisions made or become a user of the analysis when presented with comparisons among the local performance and that of other wards. Data work can act as a boomerang when you work at the front lines, as memories that you cannot control.

Many clinicians are also researchers. Doctors at specialized hospitals are expected to do at least some research. As researchers, they do data-work-of-analysis and depend on clinical data for this research. Several quality monitors pointed out to me that when the quality databases ask for so many data, this partly reflects research interests. The doctors on the database reference panels, who define which data to collect, are clinicians, yes, but their careers depend on the research they publish. By defining which data must be collected for quality assurance (an ostensibly clinical purpose), they can make nurses and junior doctors produce data for their own research. Both the documentation and the research take place in the clinic. It is, however, not necessarily the same people who do the data-work-of-production who then reap the benefits through data-work-of-analysis.

University researchers also benefit from massive amounts of data. Integrated digital infrastructures and intensified data sourcing have made doing research—especially epidemiological studies—easier. An experienced epidemiologist, who is a colleague of mine, once described to me how back in the 1970s, epidemiologists had to do a lot of manual work to prepare data for analysis. Data came in formats that were not interoperable. Today, complex data sets can be accessed on a virtual private network connection through Statistics Denmark. Although clinicians have ended up with more data-work-of-production, researchers have reaped some of the benefits. They can, whether for academic or commercial purposes, access data much more easily (though rarely easily enough, some maintain).

When more time goes into data-work-of-production to facilitate research, this indicates a shift between how the purposes in table 1.1 are prioritized. Francisca Nordfalk, a PhD student of mine, did some research with the

statistician Claus Ekstrøm documenting a shift in the use of blood samples in the Danish Neonatal Screening Biobank, a part of the Danish National Biobank. All newborn babies participate in a screening program where dried blood spot samples are collected. Since 1982, the samples have been stored in the biobank after screening. To see when and for what purposes the samples were reused, the two identified all published articles listing the neonatal biobank as a source (a total of 104 articles). Based on this, they were able to document a clear increase in use of the screening samples for research purposes over time. They also found a shift from use in research projects close to the clinical screening purpose to more general research questions, such as genetic disposition for psychiatric disease. An estimated total of 794,157 individual newborn samples had been used for research purposes, and an estimated 91,162 of them were used to study mental illness—though psychiatric disease is not part of the screening program (Nordfalk and Ekstrøm 2018). In the clinic, however, Nordfalk could also observe how health professionals used the resources allocated to collection of samples from newborns to pursue clinical goals. They used the task of sample collection to actively make time for parents and discuss issues that do not figure in evaluations of quality in official databases, but still matter for many clinicians and patients (Nordfalk 2021a, 2021b).

If research affects data work, how does data work aimed at administrative and political purposes affect priorities in healthcare? In many ways, the purchase of The Health Platform can be seen as a story about prioritizing data for administration and governance over clinical utility. Ironically, however, because of the lack of integration with the central registries, the investment ended up introducing data gaps that *undermined* the governance objectives. It is a more general experience, indeed, that strong governance is not always the effect of intensified data sourcing. When some years ago, the former head of the Danish Health Authority, Else Smith, stepped down to take a job at a hospital, she realized that she had been working “decoupled from reality.” In a published interview, she said: “In the Danish Health Authority we (. . .) had not realized how far the ideals were from practice. (. . .) Seen from where I am now, it was too easy to “just” write instructions and pass them on” (quoted in Steen-Andersen 2017: 4).

Datafication is a technology of distance. Distances can be productive. They allow what I discussed in chapter 1 as “functional stupidity” in

organizations (Alvesson and Spicer 2012). It can be expedient for people with overall responsibility *not* to know certain things happening at lower levels (Geissler 2013)—especially when they do not know what to do about them.

Most doctors actually agree with many of the goals set by central authorities, at least in the abstract. They agree with politicians that waiting time is a problem in cancer treatment. They mostly agree with politicians that the use of physical force in psychiatry ought to be minimized. They worry about the side effects of polypharmacy and agree with politicians and administrators that tools are needed to monitor these goals (Mainz and Bartels 2014). When clinicians across specialties and localities need to report in the same centralized systems, however, they often find that they need to do the data-work-of-production and -instruction, while others do the data-work-of-analysis. This distance and disconnection—decoupling—mean that clinicians sometimes cannot recognize their local clinical reality in the data. The data work then feels meaningless.

This is far from news to healthcare managers. Clinical department managers are aware that many clinicians find many data tasks meaningless. It is a challenge for managers to retain authority among clinical staff when also having to ask for data that are not essential to clinical work. One clinical department manager explained to Sarah Wadmann: “Of course, it’s a little absurd. But it’s a consequence of being measured in a particular way. It makes it important to tick the right boxes.” I interviewed a quality coordinator who explained how she was spending a lot of time (data-work-of-instruction) making clinicians deliver “complete data” (data-work-of-production), not because it was clinically important but because “it did not count as quality” if there were gaps in data. What were considered meaningless data at the ward level made sense at the administrative level.

Jens, the strategy developer, gave an example of what he thought was a really successful use of data for governance: whiteboard meetings. There are now boards in all wards in the Capital Region where the staff are exposed to data on performance in relation to politically defined goals:

Every week, new data gush out on the boards, and then clinicians say, “I don’t agree with this; it must be a mistake.” They engage with the data in a totally different way than I’ve seen before. It is extremely valuable. It is splendid!

Note how Jens is fully aware that clinicians think that data misrepresent their reality. It is not particularly important to him, however, because they are at least discussing the goals set by administrators and politicians. Their

attention has been refocused: “It is splendid!” Jens disagrees with those saying that data need to be valid and correct: “God damn it, no! Data shall make people have a dialogue about how we can achieve the goal.” Not all clinicians find these dialogues as stimulating as Jens suggests.⁶ When questioning the validity of data representations, however, they sometimes feel inclined to begin collecting their own data to better represent the clinic as they know it (Wadmann, Holm-Petersen, and Levay 2018; Winthereik 2003). The grinding data mill accelerates.

THE GRINDING DATA MILL: WHY IS IT ACCELERATING?

There is indeed an odd thing about the complaints about data work: even clinical staff become hesitant when asked to name data tasks that they would like to see terminated. In interviews, I have several times heard full-time data analysts working in administration explain how they see themselves as the ones trying to reduce the “documentation burden” for the clinical staff. However, even when they set up meetings with clinicians on how to reduce registrations, they encounter requests for *more* data. One experienced quality monitor, Mona, gave this account of how such meetings typically proceed:

They say, “we want something evidence-based,” “we want to know what we are doing,” “we want to have some ammunition if anybody says, we are really under great pressure,” and really, it’s the way you build an argument. You can’t say “my gut feeling is that we are running very fast.” Well, it might be right, but over there on the other ward they can manage and that is how it is. [Data collection] is *the way we build arguments*; it’s the way we work (my emphasis).

Liselotte, the data analyst from the regional level, similarly said:

I don’t think anybody would sincerely say they saw a need for additional registrations. Absolutely no! Everybody thinks they produce data to the point of vomiting. It is crazy what needs to be registered. On the other hand, they also want the documentation. For instance, in cases of mistakes. What happened to the patient?

I think the point is that work needs to leave a data trace in order to *count as work* in the systems. Sarah Wadmann and I were struck by the way in which nearly all our interviewees presented themselves as merely responding to “meaningless” demands imposed by external actors or IT systems. In one of the hospital departments, the clinical staff complained that their ward management insisted they should document that they had examined and approved all prescriptions for all patients—even when no medication had

been administered, as in cases with healthy relatives registered as “patients” because they were staying in the hospital to accompany sick children. When Sarah mentioned the frustration among the clinicians to the ward manager, it turned out he was frustrated too. He said it made no sense to count patients who received no pharmaceuticals as “not monitored,” but unfortunately the IT systems had been set up to facilitate counting of how many who were “not monitored” because this was defined as deviations from the standard of good care, as “bad quality.” The ward manager had the ward generate its own supplementary statistics to prove the centralized monitoring system wrong. Nevertheless, the ward manager routinely had to present at the hospital management’s office and explain the supposed “quality breach.” The ward managers would then be asked to audit their clinical records on the following day to compensate for this “lack”—a procedure he described with irony and references to Kafka’s bureaucracy. When Sarah later asked one of the hospital managers about the standard that caused the clinicians’ frustration, he also agreed that it did not make sense to demand pharmaceutical monitoring of *all* patients and added: “Sometimes it is so bureaucratic that it is almost unbearable.” He proceeded to convey his frustrations with the officials at the regional administrative level who demanded explanations of deviation from the standard.

When I was trying to understand why the Regions would enforce these standards, several people at the regional level said that it was because the Regions needed to document their performance to the national authorities. Because cessation of regional self-rule has been on the political agenda for some years, the Regions have been under great political pressure. Moving a step up the hierarchy, I asked a representative from the state level about the pressures connected with data collection. She gave a really interesting insight into this sense of responding to data requests posed by others, even at the highest level of government:

My experience is that a lot of people want more data, [and] it’s also the clinical research staff that request more data. And a lot of patients cannot understand why they cannot get an answer on this or that, and there’s a whole parliament also asking, “Why can’t you tell us this or that?” And when we say, “No, we can’t because we don’t have the data,” they say, “Well, then you’ve got to get them.” So it’s kind of funny (. . .) I think (. . .) it’s not necessarily the ministry and the civil servants requesting more data. I experience it more as a response to needs articulated in various environments.

So even when we reach the highest administrative levels, staff see themselves as responding to demands raised elsewhere.

Data-intensive healthcare creates a form of bureaucracy-on-steroids where arguments only count when they are based on data. Administrators only seem to acknowledge the tasks that are documented. They have no data on the time spent on data work. The work related to data production remains invisible. It is not enough for doctors like Hedegaard to state that they are busy, when they do not have data to back their claim. To legitimately argue your case, you need backing by data. This is also what generates what I call data-work-of-use. It is by means of data that the staff pursue meaningful action even when this implies doing “meaningless work” in a strictly clinical sense. Here, we are seeing the accelerating motor of the data mill: an organizational environment creating interconnectedness through data—where being seen and recognized as doing important work of sufficient quality implies the use of standardized data that can travel across contexts. Well-known dilemmas of standardization (Brunsson 1999; Busch 2011; Hogle 1995; Timmermans and Berg 1998; Winthereik and Vikkelsø 2005) thereby generate the dual pressures of more locally initiated data collection (to be seen for what you do) and “meaningless work” in centralized systems (to respond to what the external parties want to see). While “building arguments” with data, clinicians still seek to produce patient-focused results. To some extent, the frustration they associate with meaninglessness might reflect their increased work pressure. Data work keeps them busy.

The trend toward “defensive medicine” discussed in chapter 1 also accelerates the data mill. The multiplication of data uses then again involves a shift in the priorities in the clinic. In an attempt to explain how data work has created a change in the “work culture,” Mona (the quality monitor) laughed timidly as she said: “In the old days, we used to call it Cover My Ass [*Da; Dæk Din Røv*], DDR.” With DDR, the Danish abbreviation, she made a pun on the former East German regime Deutsche Demokratische Republik (known in English as the German Democratic Republic, or GDR). The GDR is also widely associated with its use of surveillance. She said, “in the old days,” but she also talked about a recent change, thereby illustrating how practices which used to be looked down upon have become normalized. Similarly, a leading quality program developer was recently cited in a medical newspaper for her warning against a changing hospital culture experienced as “an

inferno of documentation” that “risks creating a Cover My Ass culture, where the physician’s attention shifts from what is good for the patient to the physician’s own ass” (L. Lange 2017, pp. 13).⁷ Organizations eager to “punish” deviance stimulates peoples’ urge to defend themselves (Fassin 2018).

In an organization where data means visibility, it can be dangerous to rely on “invisible work” (Star 1991). To have efforts acknowledged by superiors, work needs to be visible in a format that the organization values. As Zuboff (1989) argued, in computer-saturated workplaces, many tasks come to revolve around the “manipulation of symbols” rather than physical execution (23). It is by becoming visible to others, as data, that tasks come to count as working with (and for) other humans. Visibility is part of making the work meaningful. However, when meaning becomes a matter of communication and recognition within and among organizations, data work can become detached from the clinical goal orientation.

Could technology solve the problem of “meaningless” data work? It is certainly possible to build systems with more intuitive interfaces and seamless integration than those in place, which would reduce the number of complaints. However, automation will not halt the data mill. Automation cannot settle which purposes to pursue. It shifts data work around, but in the health services, it does not eliminate it (Vikkelsø 2005). When automation creates less work, it is mostly for those requesting data (doing data-work-of-analysis). Those in the clinic who have to respond to the requests get more work because many forms of data entry remain manual (Boyce 2016; Morrison et al. 2013). With automation, requests for data become easy to execute, and the tasks of responding become invisible to those setting up the system. Furthermore, automation can make data collection continue in perpetuity. Automation in this way adds fuel to the motor of the grinding data mill, but it is the pursuit of meaning through data that keeps the mill grinding. If the data mill is grinding with growing intensity, what does it produce?

PATIENT FLOUR: THE EFFECT ON RESEARCH, CLINIC, AND GOVERNANCE

Data work is meant to serve a range of laudable goals. However, when the data mill grinds, some of the objectives work against each other. The friction generates heat (Edwards et al. 2011; Tsing 2015), but it does not stop the grinding. It accelerates it. While I have shown that the result can be a loss of

meaning, the motor of the mill also can ironically be located in the pursuit of meaning through data. In the examples discussed here, disagreement with data generates a longing for more, for better, data—data that can tell stories that people are eager to purport.

Datafication means that information about the patient is disentangled into small data elements. It is like wheat broken down into flour in a flour mill. My use of the term “patient flour” might seem to carry unnecessary violent connotations, but I refer here just to the informational representation of the patient. Datafication makes the small bits of information available for more users than the old clinical narrative. Flour, similarly, is a product with much higher utility than whole wheat. It can be used to make many things, from cake and bread to sauces. Information in the form of diagnostic codes, precoded “smart text” phrases, or searchable digital narratives can be employed for far more analyses than the old paper-based narratives in clinical records stored in closed archives. It can, however, be difficult to reassemble an understanding of the full situation of the patient from the flour produced by the data mill. A sense of the person does not always emerge from the individual data points just as the sense of wheat plants in the field is hard to generate from a package of flour. The patient as a person with a history can dissolve. This effect of datafication has been found in other contexts as well (Hunt, Bell, Baker, and Howard 2017; Hutchinson, Nayiga, Nabirye et al. 2018; Olesen 2018; Taylor-Alexander 2016; Vergheze 2008). This is, however, not the only implication of the pursuit of meaning through data. In the following discussion, I wish to suggest that intensified data sourcing makes people relate to and use data in new ways. Data can come to operate as symbols rather than as references to patients. This has ramifications beyond the care for the individual patient. It introduces a profound epistemic doubt—doubt about what is going on in healthcare. Like flour thrown up in the air, data can become a haze impairing visibility.

The epistemic doubt relates first and foremost to “data massage,” and then from an inability to understand data at a distance. The tendency to have more data-work-of-analysis carried out, detached from the data-work-of-production, leads to mistaken conclusions. When clinical data furthermore become the primary tools for governance, they gradually change in character for those who are simultaneously producing data and instructed by analyses made with the very same data. Some people are very frank about manipulation, as when a hospital manager said to Sarah Wadmann: “One

thing is certain: you become very creative. If you are pressured on something that you can't possibly deliver, you cheat." Margit, a quality coordinator I interviewed, preferred not to call it "cheating." Instead, she explained the ambiguous nature of data validity in the current system in this way:

Times are changing. People are getting more used to having everything out in the open, so if you haven't documented it, somebody will be chasing you down asking for it. I actually think you can hide as many things today as you used to be able to, because you can just produce bad data, invalid data, then the documentation is there. It's just as if a slippery slope has been opened somehow.

It is an interesting observation: "you can just produce bad data." Such data massaging is equally well known elsewhere. In the United States, one observer notes how Medicare "pressures hospitals to cheat, saps doctors' and nurses' intrinsic motivation to do good work even when no one is looking, and corrupts the data" (Himmelstein and Woolhandler 2015: 5).

Liselotte, the data analyst from the regional level, was very aware of data manipulation practices among clinicians, but she decided to use data anyway "as if" they were valid. She saw no alternative. She also admitted that data manipulation took place not only in relation to data production. Her own data work related to analysis was not all that different; she said, "You can manipulate data endlessly, and you can get practically any result that you'd like. You can clean the data so much that you get rid of anything that contradicts your point." She felt confident that she knew when to trust her own results, but she also admitted that she was under increasing pressure to get particular results desired by the administrative management or at the political level. The pharmaceutical industry has long been accused of manipulative data practices (McGoey 2010; Creager 2021), and it is worrisome to hear public data analysts articulating these pressures (Knudsen 2011). Jonna, a data analyst working in one of the big municipalities, explained that "you sometimes just have to do the dirty work." She referred to cases where top management needs "a particular number" for a purpose like legitimizing letting off particular people. It is always possible to find something in the data to support the story they want to tell, she explained. For some, validity problems represent opportunities.

Taken together, these reflections point to a very profound effect of intensified data sourcing: an experience of referentiality as an illusion that can be departed from. Data need not refer to—or pretend to refer to—something "real" to have effects. French postmodernists such as Lyotard and Baudrillard

awaited and embraced such a moment (Baudrillard 2021 [1994]; Lyotard 1984). Baudrillard spoke of a culture of signs operating as simulacrum: copies with no originals. Drawing on this tradition, Mark Poster (1990) argued that the “database” transforms data into a *self-referential* sign. Data serve as signs *without* any connection to an external “reality.” What is real to the organization is what is in the data—what can be found in the database.

Liselotte, Mona, and the other people who do data analytical work in Danish healthcare would not agree with the postmodern interpretation. They insist that some analyses are better than others. They mostly dislike pressures, biases, registration errors, and corrupted practices. Still, they have come to accept working with data as signs that are desired as much for their performative effects as their epistemic veracity. Data lie at the heart of their meaning-making practices. They need data to feel that what they do is meaningful, even when the data act partly as self-referential signs.

In addition, a sense of epistemic doubt creeps into research uses of data. The epidemiological literature explicitly discusses data validity problems arising from reuse (Chan, Fowles, and Weiner 2010; Pedersen, Klarlund, Jacobsen et al. 2004; Severinsen, Kristensen, Overvad et al. 2010). From these quarters, the proposed solution is, like the response from politicians, to collect *more* data to make up for data omissions and errors. The result is a self-enforcing epistemological kaleidoscope relying on data that need verification by other forms of data, which are then in need of verification from yet other data in a potentially endless regression loop.

Industry researchers, or at least the lobbyists working to ensure access to data, seem a lot less worried about validity. I have pondered this point a lot. How come people like Bent, the lobbyist cited in the introduction, do not fear data validity problems? Is it because they do not know the registries well enough to have the data analytical skills needed to make sense of them? Or might it be that industrial research has gone further down the postmodern lane and acknowledged “dissolving referentiality” as an opportunity? Epistemic doubt creates space for the most powerful actors to promote the narratives they see fit (Oreskes 2019; McGoey 2010). It is well known that some industrial actors have used data access for years to debunk claims made by public researchers about topics such as risk stemming from tobacco use, environmental pollution, and climate change (Angell and Relman 2002; Sismondo 2008; Egilman 2005). While epistemic doubt can be favorable for certain interests, it is important not to overemphasize suspicion. I do

not even think of the embrace of data massaging as driven (primarily) by corruption or greed.⁸ It is not useful to give in to one's paranoia (Sedgwick 2003). Paranoia derails the understanding of intensified data sourcing. Instead, I see a key driver in the pursuit of meaning through data.

I opened this chapter by describing a particular conflict between clinical and administrative perceptions. When Hedegaard resigned in 2016, he claimed that patient safety was at risk because the staff were too busy, but the politicians said that no data supported his claim. Indeed, Hedegaard and colleagues had just published a research study about the falling risk of stillbirth as a consequence of a more proactive approach where all prolonged pregnancies were acted upon earlier than previously (Hedegaard, Lidegaard, Wessel Skovlund et al. 2014). In 2020, the hospital released new figures showing that stillbirths had doubled in the preceding five years (Lidegaard, Krebs, Petersen et al. 2020). The primary explanation was that due to high work pressure, births were no longer initiated in time in cases of prolonged pregnancy (Munk 2020; Knudsen 2020). Perhaps the staff were right when they said, back in 2016, that the work pressure had reached a level where it affected safety. At the time, however, data did not yet support their everyday experience. Instead, their experience was overruled by data.

PARADOXES OF DATA WORK

This chapter has shown how intensified data sourcing has changed the conditions for professional work—as well as what counts as valid knowledge about this work. The imposition of data work for objectives other than clinical purposes influences the moral landscape of the clinic by changing the work culture and priorities of clinical attention. Digital tools now structure work practices, and the documentation formerly kept in closed cabinets is made available for continued monitoring and reuse. In the course of that process, the epistemic status of data has changed. The attraction of data no longer hinges on the belief that data refer to an external “reality” or serve a “rational” clinical goal. What is real to the organization can be simply (and only) what is in the data. Data are multiple, and people in different places with different agendas may use the same data with very different interpretations, drawing conspicuously dissimilar conclusions. A radical implication of this is that the pursuit of meaning no longer is determined by clinical goal orientation. Health professionals, however, continue to see patients. They

care about patient outcomes. This is, perhaps, why they find themselves so busy. They encounter actual people and cannot work only with symbols.

With this in mind, the paradoxes outlined in the opening of the chapter are no longer logically inconsistent. Intensified data sourcing produces both less and more work. Work, however, is redistributed (see also Svenningsen 2004; Vikkelsø 2005). The very concrete experience of less work (for some) legitimizes more work for others. In this sense, the paradox is productive: it does something for some of the stakeholders. Ironically, the increasing amounts of data seem to legitimize new recruitments among the administrative data users who get easier access to data. There has been a consistent growth in administrative staff relative to frontline staff at least since the 1930s—and it does not seem to be about to stop (Østrup, Jørgensen, and Zwisler 2020; Vallgård 1992).

The second paradox is similarly productive. Data intensification tightens organizational control and facilitates organizational disintegration. With data, the political and administrative layers have better options for controlling the narratives that are told, as in the conflict between Hedegaard and the politicians, while being comfortably unaware of what is going on in the clinic. Organizational disintegration, however, can also be beneficial for clinicians and other frontline staff. Data can serve as shields deflecting further interest. But such data massage practices propagate a sense of epistemic doubt. Epistemic doubt informs the productivity of the third paradox. Data create meaningless tasks, and yet they still are used as meaning-making tools. As data purposes mingle in multiple ways, the same data can be seen as meaningless in one context and yet meaningful in another. Meaningful and meaningless are not two distinct classes of data. Epistemic doubt provides room for multiple stories. It allows them to coexist. Thereby, people can work alongside each other with an equal sense of conviction, though with different perceptions of the problems they confront. Still, they seem to agree that they need data to tell their stories.

The French postmodernists happily embraced the dissolving referentiality. They considered references to the “real” as tools of power. Lyotard (1984) associated claims of truth with totalitarian ambitions and said: “In the computer age, the question of knowledge is now more than ever a question of government” (pp. 8–9). His ambition was to open up access to data and “give the public free access to the memory and the data banks” (67). For him, open access to all data was the way to ensure a plurality of voices.

Baudrillard (2021 [1994]) similarly detested the longing for the real and concluded: “There is no hope for meaning. And without doubt this is a good thing: meaning is mortal” (164).

Be careful what you wish for, some might say. Opening up for the reuse of data indeed created a plurality of voices, but also a loss of meaning (Rahman 2021). Dissolving referentiality is a double-edged sword. In 2020, American voters were told by their president, Donald J. Trump, that they did not have to believe in election results if they did not agree with them. Today, after having seen the success of Trump at promoting “alternative facts” (Fuchs 2018), the postmodernist attraction has faded. There is reason instead to sustain and speak to the sense of integrity that makes clinicians and data analysts most proud.

For patients, dedication to “truth” has a particular and very personal urgency: What helps their fight against suffering? For their sake, there is a need to embrace the search for robust knowledge. Chapter 5 explores the role of data in generating robust knowledge. First, however, I believe that there is a point to paying much more serious attention to how data form part of meaning-making practices. I am thinking here of how people experience data. There is an experiential dimension to data that has not yet been explored adequately. I suggest paying attention to how people engage data work as sensing bodies, not just analytical beings. Chapter 4 is therefore about *data experiences*.

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Data Paradoxes

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