

5 DATA WISDOM

May 2019: “We make trends in data visible,” Torben says when I ask him what he does. Torben is a civil servant working at the national level figuring out how to use data to optimize clinical performance. He spends a good deal of his time facilitating informed debates among politicians on which areas of concern to prioritize. To do so, he works with finding ways of turning data into something visual, such as graphs, maps, or color-coded tables: “It’s so that you can say, ‘Oh, there was something interesting here. It’s going down, and it’s been going downwards for years. Why is it doing that? Why is this Region red?’”

A curve or a color coding inspires change, Torben says. He first mentions problematic areas, the “red” ones, as examples, but later he talks about using measurements to celebrate achievements and learn from best practice. All his examples revolve around learning through comparisons: over time, as curves are going up or down, or geographically and organizationally, through revelation of differences between Regions and Municipalities, or units. The graphic visualizations build on data from clinical reporting systems, administrative systems, or both. For Torben, the key point is that interventions should be “based on facts rather than opinion.” Considering how I have shown throughout the preceding chapters that people in paradoxical ways produce very different facts with similar data, it is time to examine in more depth such claims about factuality. It is time to explore the relationship between data and wise decisions.

Torben wants to be clear about the nature of the governmental aim: the point is *not* to set standards derived from evidence-based medicine (EBM).

“What is the right level?” he asks rhetorically, “Really, often we don’t know.” The point is to set a *direction*. He mentions the use of physical force in psychiatry as an example. Everybody agrees that use of physical force should be avoided when treating psychiatric patients, but despite doctors’ best efforts, force cannot be completely ruled out. There is no “right level,” but less force is most preferred. The politicians, therefore, want data to document that the use of physical force in psychiatry really is going down.

In my interview with Torben, he speaks mostly about a form of quality monitoring called “National Goals” (Sundheds-og Ældreministeriet, KL, and Danske Regioner 2018). This has replaced earlier forms of quality assurance such as accreditation, which included experiments with standards from the American Joint Commission. The Danish Ministry of Health works with the ninety-eight municipalities and the five administrative Regions to compile data on performance according to eight overall goals, and the performance measurement in relation to each depends on hundreds of indicators, each drawing on multiple data sources.¹ Examples of some of the data representations can be found in figure 5.1. Currently, the monitoring mostly uses data already collected in the health services. Torben imagines a near-future, however, where the effect of the health services can be measured directly by measuring the well-being of patients: “Hopefully, sometime soon, data will be generated automatically, I mean, something like citizens wearing watches with in-built sensors.” It sounds like a grand vision. Still, I have some nagging doubts, and they are not just related to privacy issues. I wonder: Is it really possible? How would data from wearables become useful for healthcare governance, remuneration models, and monitoring of the quality of service delivery?

Torben is not naive in any way. He knows how difficult it is to make sense of data. He provides several examples of inaccurate data analyses featured in the governmental report on National Goals. For example, it annoys Torben when comparisons between years are sometimes said to illustrate a trend even though they are made with indicators where the sources have changed the data formats during the period measured. A couple of weeks later, on Torben’s recommendation, I am interviewing Flemming, who has constructed a number of the indicators for the National Goals measurements. Like Torben, he is aware of trends documented in National Goals that do not reflect the actual organizational performance. In some instances, Flemming remarks that this is just because clinicians have changed their

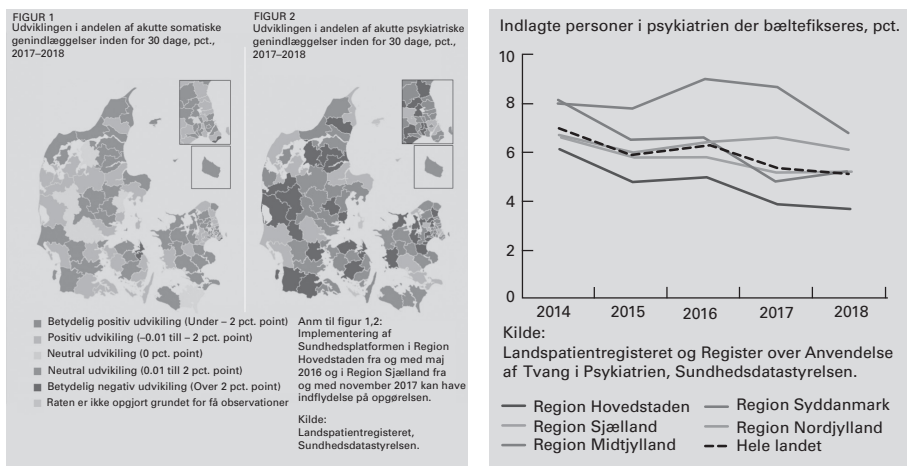


FIGURE 5.1

Examples of visualizations from National Goals, 2019. To the left there are two maps of Denmark where unplanned readmissions to hospitals for somatic (left) and psychiatric (right) disorders are indicated in different municipalities as degrees of positive and negative developments (percentages compared to the previous year). To the right there is an example of a graph that illustrates the number of persons who have been restrained with belts in psychiatric care over time and in the five administrative Regions (shaded lines) and the country as a whole (broken line). (Credit: The Danish Ministry of Health).

registration practices, akin to what I described in chapter 3 as “data massage” and “gaming.” Also, Flemming explains, there are in some units significant data gaps and missing values, not least after the introduction of the Epic system described in chapter 3. He mentions how people at his section at one point realized that for a particular indicator, they had data on the same thing from three different sources showing three different results.² At least two of the data sources had to be wrong (and perhaps all three were), but they could not know which was most accurate. The central authorities decided to use data from just one of the sources, not because it was definitely right but because they needed to have just one value for the report. In short, the data visualizations in the report do not correspond in any straightforward way to a particular “reality” outside the data. They are not so “factual” after all.

I keep having this feeling that there is something I do not understand—that there is a link or an argument that I have missed. In the course of the

interview with Flemming, I hear myself asking again and again in different ways: Do the numbers and visualizations in National Goals convey the performance that they are said to measure? Do they give an accurate impression of the quality of the service delivered by the respective units in each area? At one point, Flemming looks at me with the forbearing gaze of an indulgent father ready to explain the most elementary stuff a hundred times to a slightly dimwitted child. He takes a deep breath and then carefully explains that (1) the reports are no better than the data on which they are built; (2) it is not possible from these data to determine who reaches the “right level” of whatever they measure, whether it is use of force or unplanned readmissions (see figure 5.1); and (3) based on data of this type, one cannot conclude whether measured differences reflect the performance of the respective health services in those areas, divergent registration practices, or differences in background population. When Flemming mentions background populations, it is because the ninety-eight municipalities are composed of citizens with varying health profiles and socioeconomic backgrounds, as well as differing levels of exposure to environmental risks. Such variations—rather than the performance of the healthcare offered—could be the cause of any measured variation.

I already know this. What confuses me is why people working with the governance of the health services—who also know this—nevertheless insist on acting on data as if this uncertainty did not exist. Why do National Goals not draw on any of the established research methods for investigating the data and see whether it might be, for example, variances in the background population that give rise to differences? Case-mix is one such method for controlling for differences in background population.³ Why suggest adding wearable data—something so complicated—when *existing* research standards are not being implemented? Why suggest massive data tracking on the well-being of all citizens when we already know that it will not reveal what the authorities need to know about organizational performance? Reflecting on the current practice with National Goals, Flemming admits that “from a strictly disciplinary perspective, these analyses make no sense. It’s more like a political maneuver.” Still, he maintains that they are useful. They help to create that sense of *direction* also highlighted by Torben. They are tools for governance, not research. Still, I keep asking: Is the epistemic difference between governance and research not supposed to relate to novelty rather than accuracy and validity? Flemming and Torben then both explain that

there are so many users of the data presented in the National Goal dashboards that it simply does not make sense to talk about what constitutes the right, the accurate, the valid analysis. The different users want to know different things. I cannot help thinking: But is it *knowing*? What do they “know” in this way?

Torben and Flemming point to an interesting paradox: data gain power by appearing as tools of knowledge in a positivistic sense (“fact, not opinion”), and yet organizational actors find them useful even when fully aware that these data are not especially representative of the world these actors wish to govern. People readily admit that data can give rise to erroneous and invalid claims, and yet they maintain that having no data, or too few data, makes things even worse. Contemplation of this paradox, I suggest, adds again to our understanding of data politics because it invites us to understand the appeal of data even when those data do not deliver the insights that data promises announce.

The question of how data relate to knowledge has been running as an undercurrent to the previous chapters. When do data give rise to knowledge? What type(s) of knowledge? What further types of knowledge might the health services need when caring for patients? It is, however, difficult to contemplate “knowledge”: for consciousness to understand itself is like asking a man or a woman to carry himself or herself. Ideas about what counts as knowledge have thousands of years of philosophical baggage, and those suitcases can hardly be lifted by a single chapter of a single book. Still, it is also dangerous to avoid the topic altogether because data promises thrive on fuzzy ideas about knowledge—a fuzziness that opens up a space for powerful commercial and political actors. Remember how, in the introduction, I cited civil servants and industrial lobbyists who conflated data and knowledge. When claims about data *as* knowledge become more and more authoritative and aimed at control (Cheney-Lippold 2017; Poster 1990; Zuboff 2019), it is time to discuss knowledge claims in a candid and direct manner.

Nevertheless, I will go light on the classic epistemological canon. I am avoiding established dichotomies such as idealism and realism, constructivism and positivism, as I have nothing much to add to those debates. By talking about data as *ontologically* multiple objects, I have already shifted the focus from what data mean to what they do. As a consequence of integration and reuse, the same data are involved in very different practices,

engaged by different networks, and have effects in several different places. They have become like cogs operating in several machines at once. Still, it is too easy to simply replace the epistemic question about knowledge with an ontological claim about data being multiple, when data in all the various practices in which they operate continue to be thought of in an epistemic register. If I wish to claim that data do *not* equal knowledge, I must be able to say something about what *does* constitute knowledge—in what sense, for which purposes—in each of the many practices where data operate.

In this chapter, I am proposing the concept of data wisdom as a form of practical ability to use data well. The use of the term “well” begs consideration of the questions “Well for whom?” “Well according to which criteria?” Normativity is built into the ambition of knowing. The pragmatist John Dewey famously evaded what he called the “problem of truth” by focusing on what knowledge claims do for people in the pursuit of something. He spoke about how knowledge claims take the form of an “inquiry for it” (Dewey 1998). For Dewey, knowledge was always inherently normative and guided by aspirations. The anthropologist Fredrik Barth (2002) similarly emphasizes the link between understanding and motivated action and even defines knowledge as “what a person employs to interpret and act upon the world” (1).

Analyses always bring norms with them (Callon and Law 2005). With *data wisdom*, I wish to integrate the analysis of knowledge claims with the ability to think about whose interests they serve. It is necessary because the same data serve so many purposes. With additional data reuse comes an increased risk of misunderstanding what the data signified and were meant to do when they were first produced. With data reuse come new forms of data error. I long thought about calling this chapter “Data Error” rather than “Data Wisdom.” This was because I was struck by the many obviously erroneous claims that are made with data. I became almost obsessed by error and compiled an archive full of examples. I even tried to categorize these examples into error types before I gradually realized how fruitless that was. There can be no exhaustive list of errors (Thylstryp 2021), not least because errors have as many dimensions as the people they affect. In the following discussion, I therefore cover examples of error without setting them up as if they could have had an imaginary twin of “Data Truth.”

To reflect on how data can be used wisely, I first address the relationships among data, knowledge, and wisdom. I then reflect on data challenges in medical research and clinical practice before I turn to how new algorithmic

inventions interfere with those established ideas about knowledge. After that, I consider citizen and patient experiences of data errors. My point is that to care for patients, both scholars and policymakers need to reflect on how to use data wisely, and I end the chapter on that note.

WISDOM: HOW TO USE DATA WELL

Data wisdom, as I suggest, is the ability to produce and apply “robust knowledge” with beneficial outcomes for those affected. It also implies consideration of how the reuse of data can interfere with several practices at once, thereby having both positive and negative implications for different people, or for the same people over time. Data wisdom means understanding both *how* and *when* to use data—and also when *not* to use them. In addition, it involves the willingness to consider what data do for those patients (and staff) who fit neatly into established norms, as well as those who deviate from them. In chapter 4, I highlighted the tension between endless human variation and data-imposed standardization. Prompted by my observations of people evading standards, I agree with the anthropologist Tim Ingold (2018) when he suggests thinking of wisdom as a willingness to embrace the unexpected: “Knowledge fixes and puts our minds at rest; wisdom unfixes and unsettles. Knowledge arms and controls; wisdom disarms and surrenders” (9). Data promises propagate the power of prediction, but healthcare systems must be able to care for those with unexpected problems as well. Unfortunately, as Ingold (2018) dryly observes: “At no previous time in history . . . has so much knowledge been married to so little wisdom” (10).

Knowledge, particularly the sort of knowledge that is generated with data, is increasingly treated as an asset that can be traded (Pinel 2021; Geiger and Gross 2019; Sadowski 2019a). Wisdom, in contrast, is a gift passed from generation to generation. It stems from processes of maturation. It is relational, created at the moment of gifting, not an object of barter. Wisdom is nurtured by strong institutions. In these institutions, wisdom is reinvented by each expert, but no expert can arrive at it by “mining” knowledge alone. It stems from socially sustained nurture and care. It takes wisdom to produce useful knowledge.

Kitchin (2014) suggests, in his acclaimed book *The Data Revolution*, that we should think of data as presenting aspects of the world that can be turned into information, which can then be used to produce knowledge

that might (but only *might*) be used wisely. He uses a triangular figure to illustrate his point—building on similar figures from Ackoff and other esteemed scholars (see Beaulieu and Leonelli 2022: 60). Figure 5.2 shows an adaptation of Kitchin’s version of the figure (though it leaves out “information” because this word is so often used interchangeably with both data and knowledge and therefore tends to create more confusion).

The figure is helpful because it reminds readers that not all aspects of the world can become data, not all data become knowledge, and not all knowledge is used wisely. However, I do have some reservations. It conveys an impression of higher levels being subsets of lower levels. In figure 5.2, all types of knowledge seem to build on data, and all wisdom seems to build on knowledge. I, conversely, think that there are types of knowledge needed in healthcare that do not derive from data. Furthermore, what might be right for one purpose can be wrong, or unsuitable, for another. The triangle also gives a temporally unidirectional impression—a path upward from world to data to knowledge to wisdom. This unidirectionality is also problematic. Leonelli (2012a) has reminded us that it takes knowledge to create good data, just as I suggest that it takes wisdom to create useful knowledge.

If I am complicating what counts as knowledge, why even use the word “knowledge”? Would it not be easier just to depart from this word altogether and simply focus on what people do with data and whether they like the results? It might, but I believe that it is important to hold on to “knowledge”—not only because policymakers insist on using this term, but

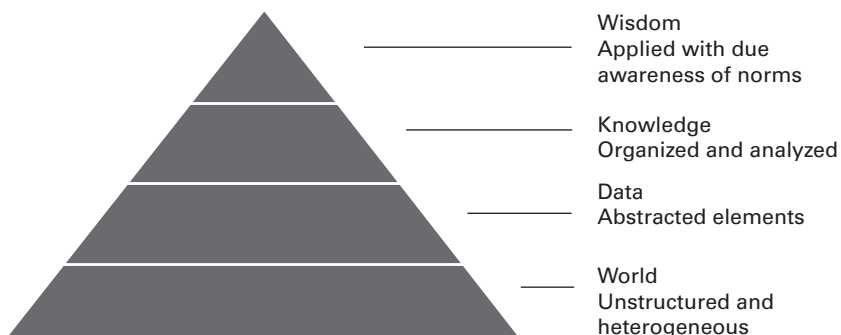


FIGURE 5.2

Data, knowledge, wisdom. Adaptation of the model of the path from world to wisdom presented by Kitchin, Ackoff, and others.

also because it speaks to something important and motivating for people, not least the ones working with data. Most of us have a phenomenological experience of knowledge as a moment of understanding something: the beauty, the contentment, and sometimes the dread and fear that arise when realizing something and comprehending a situation in a new way. I would like to keep an awareness of this experience of “getting to know” as part of our thinking about data. “Understanding,” or “knowledge,” is one of very few phenomena carrying intrinsic value. That places it in the company of, for example, “love” and “beauty.” The sense of understanding can make a person feel at home in the world. To be without it can be disempowering (as described in chapter 2), lead to feelings of meaninglessness (as described in chapter 3), and evoke disorientation and exhaustion (as described in chapter 4). Its value is instantiated right at the moment of comprehension. It is a practice, not a thing. This experience lies at the heart of what many researchers love. When Weber (1947b) spoke of science as a vocation, he articulated such love. The word “philosophy” is derived the Greek words for “love” (*philo*) and “knowledge” (*sophia*), which also suggests a deep devotion to insight among the earliest scholars in Western history. Learning something new is also at the heart of debates about confidentiality (Grossman 1977; Fainzang 2002), and very important for the politics of data: who gets to know what about whom? For these reasons, I am not willing to give up on “knowledge.”

Rather than abandoning knowledge, it is more useful to think about it as coming in many forms. I therefore wish to suggest a vocabulary that can foster reflections on the various types of knowledge already used in health-care. As I shied away from the philosophical canon and contemplated how people *experience* knowledge, I was drawn to psychology and found a vocabulary in the work of the American pragmatist and psychologist William James. In his seminal book *Principles of Psychology*, which came to form a foundation for modern psychology, he approached “truth” as those beliefs that are useful for the believer (James 1950 [1890]). Not surprisingly, he here aligns with Dewey. But James did something more. He spoke of a human capacity for different types of knowledge. He conceived of these forms of knowing in a developmental and hierarchical way, but when the hierarchy is disregarded, elements of his thinking can be useful even today—at least if you accept twisting and tweaking it a bit.

James claimed that human babies, as with nonhuman animals, begin in pure *sensation*. Humans only gradually develop the ability of *perception*. Sensation is a bodily engagement with the world. The baby does not see light; it *is* light, as it were (James 1950 [1890]: 4). The world is sensed in its totality. Perception, in contrast, is a conceptually mediated experience of the world, where categories of thinking shape objects of experience and make light into an object that can be recorded (76ff). In growing up, James suggested, humans lose the ability of pure sensation, but not sensation altogether. What they retain comes across as something that James terms “associative thinking.” Associative thinking is what happens when people sense a situation as a whole and compare it with previous experience. Associative thinking can imply an empathic understanding of the pain, anger, and fear that others feel, but it is first and foremost about drawing upon experience with “wholes”—similar situations—rather than delineated objects.

For me, associative thinking resonates with phenomena that others have spoken about as, for example, experience-based knowledge, bodily knowledge, and action skills (Zuboff 1989; Mauss 2007; Connerton 1989). I am grouping together vastly different traditions here, but my point is to say that a lot of work has identified bodily ways of knowing that do *not* stem from analysis of data and yet remain key to clinical work (Goodwin 2010; Gardner and Williams 2015; Moreira 2004; Friis 2021). These forms of knowledge shape what is known as clinical judgment, as well as the tactile skills needed for good clinical care. Experienced nurses do not analyze data when holding the suffering body of a patient, nor should they. Surgeons do not depend on analysis alone to become skilled. They draw on a range of tactile types of knowing. In her seminal work on the digitization of the workplace in the 1980s, Zuboff (1989) described tacit bodily knowledge as a form of “action skill” where hands “know” how to treat materials in ways that are not easily turned into data: “Some forms of meaning are comprehensible only as a whole and can be destroyed when objectified and analyzed,” she observed (186). Even though I am perhaps a little “hard-handed” with the term “associative thinking”—adapting the term to suit my own purposes—I hope James would forgive me for borrowing it to describe a type of knowing that does not stem from analysis of parts, but rather from experience with similar wholes.

James maintained that to identify causal factors, there was a need for “reasoning” instead of associative thinking. Reasoning, he said, builds on

perception rather than sensation. By taming perception, particular *aspects* of a situation are turned into data and related to other similar aspects of comparable situations. Each situation, however, remains unique (Verran 2021). Any situation can give rise to infinite aspects, including smell, visual impressions, humidity, and others. James (1950 [1890]) writes:

Every reality has an infinity of aspects or properties. Even so simple a fact as a line which you trace in the air may be considered in respect to its form, its length, its distinction, and its location. When we reach more complex facts, the number of ways in which we may regard them is literally endless. Vermilion is not only a mercury-compound, it is vividly red, heavy, and expensive, it comes from China, and so on, *in infinitum*. All objects are well-springs of properties, which are only little by little developed to our knowledge, and it is truly said that to know one thing thoroughly would be to know the whole universe. (332; italics in original)

In order to reason on something, in James's sense of the word, it is necessary to choose an aspect of the unique and momentary whole and focus on that to build an abstract phenomenon. As a product of his time, James believed that women, children, and the uneducated classes were more disposed toward associative thinking, while well-educated men like himself were better at rational reasoning. This dichotomous hierarchy between these groups appears ludicrous today. For people working in the health services, the point is to find the right places for different types of knowledge.

James was writing at a time when respect for *numbers*—and the authority they represented—was mounting. Science was aspiring to fulfill a new role in society. His British contemporary, Lord Kelvin, famously asserted (just one year after James published *The Principles of Psychology*):

I often say that when you can measure what you are speaking about and express it in numbers you know something about it; but when you cannot measure it, when you cannot express it in numbers, your knowledge is of a meagre and unsatisfactory kind: it may be the beginning of knowledge, but you have scarcely, in your thoughts, advanced to the stage of *science*, whatever the matter may be. (Thompson (Lord Kelvin) 1891: 73, italics in original)

It is a bold claim, “whatever the matter may be,” but the strident and slightly pompous tone may reflect how Lord Kelvin, along with others, saw themselves as engaged in an important struggle. They were building secular alternatives to the authority associated with religion and class (Hecht 2003). Today, however, this valuation of “reasoning” and its association with numbers is no longer in *opposition* to regimes of power. It is integral to how modern organizations work.

The type of numbers that Lord Kelvin was longing for depends on datafication, and this datafication involves categorization. Categorization has long occupied anthropology and science and technology studies (STS), but it was Immanuel Kant who several hundred years earlier had turned categories into central issues for modern philosophy. It was at the height of the Enlightenment period. He asserted that it is necessary to reflect on the relationship between one's categories of thought and the phenomena in the world which one is contemplating. In *Critique of Pure Reason*, Kant (2017 [1787]) stipulated that things cannot be perceived as they are, in and of themselves. He thereby thoroughly established how analytical knowledge (of the type that James would later relate to reasoning) must build on a reflective engagement with the involved categories of thought. The world does not just magically turn into data. My critique of the unidirectional assumptions conveyed by the triangle in figure 5.2 stems from this long tradition of work demonstrating that data do not precede knowledge. As stated previously, the converse is true: it takes knowledge to create good data.

A reflective engagement with categories also is the basis for counting. Counting may sound simple. It is not. It takes thorough disciplinary training to learn to delineate objects of counting (Martin and Lynch 2009; Deville, Guggenheim, and Hrdlicková 2016). In laboratory science, counting also involves relatively practical tasks, such as how to document what happens in a test tube. Latour (2014) talks about this as “inscriptions” where aspects of the world are “flattened” and turned into “immutable mobiles.” Inscriptions generate a form of flat ontology, where data regardless of provenance and type can be used in the same analysis (Stark 2018; Andrejevic, Hearn, and Kennedy 2015).

In her work on data practices, Borgman (2015) observes: “Every category, and name of category, is the result of decisions about criteria and naming. Even the most concrete metrics, such as temperature, height, and geo-spatial location, are human inventions” (26). Data wisdom involves investigating these inventions. It means looking *at* data and not only *with* or *through* data. In her important book about data-intensive research, *Data-Centric Biology*, the philosopher Sabina Leonelli (2016) similarly encourages

philosophers, historians, and science scholars to take data seriously as research outputs and think of them not as inert objects with intrinsic representational powers but as entities who acquire evidential value through mobilization, and may undergo significant changes as they travel (198).

In a similar way, the data analyst and media scholar Yanni Loukissas (2019) urges practitioners and scholars to pay attention to data as objects of knowledge in their own right, not just as means for acquiring knowledge: “You must learn to look *at data*, to investigate how they are made and embedded in the world, before you can look *through data*” (xv–xvi; emphasis in original). For Loukissas, it involves investigating what data mean in local contexts: “Do not mistake availability of data as permission to remain at a distance” (196). Still, this is exactly how data are often used politically: to govern at a distance. Chapters 1 and 3 are full of examples of this phenomenon, and the international rankings discussed in chapter 2 often exhibit a similar lack of care for the local meaning of data.

To use data wisely, it is important to care about knowledge, but also to remain aware that data can be involved in several knowledge projects at once and have different implications in each. What appears to be a solution for one problem may carry the seeds of a new problem. Foucault (1997) once said: “My point is not that everything is bad, but that everything is dangerous, which is not exactly the same as bad” (231). I take this as an invitation to look into the interconnection between problems and solutions and to explore how “solutions” build on forms of knowing that are coproduced with specific forms of blindness or “unknowing” (Proctor 2008; Geissler 2013; Gross 2010; Michael 2015). It makes it possible to consider whether the most exciting forms of “new” knowledge might sometimes lie in recovering lost knowledge, a form of reknowing, where silenced voice are rearticulated (Hoeyer and Winthereik 2022). There is no perfect way to use data that works for all, but conversely, we should not think that no data or no attempt to generate knowledge would be a viable solution.

MEDICAL EVIDENCE AND CLINICAL JUDGMENT: TACTILE SKILL AND INFERENCE ERRORS

When, after World War II, Archie Cochrane and other founding figures of what later became known as evidence-based medicine (EBM) began developing new ways of testing the effect of treatments, they were also solving one problem while inadvertently sowing the seeds of the next. They wanted statistical treatment of data to take precedence over clinical experience, or—in James’s terms—to let perception and reasoning replace sensation and associative thinking. EBM continues to be a “malleable range

of techniques and practices” (Ecks 2008: 2639) and its exact definition remains subject to contestation (Kemmm 2006; Stegenga 2018). Still, it is fair to say that EBM seeks to isolate aspects of complex wholes to determine their “independent” effect, and also that this approach has been central for the development of regulatory efforts aimed at ensuring the safety and efficacy of pharmaceutical treatments (Daemmmrich 2004; Faulkner 2009).

A key feature of EBM has been the randomized clinical trial (RCT) (Bohlin 2011; Lambert 2006) and development of evaluation standards such as the GRADE (Grading of Assessment, Recommendations, Development, and Evaluations) guidelines. As the RCT seeks to isolate effects, it necessitates limiting the factors that can influence the result. Herein lies the potential for what I would call “inference errors”: trials are based on narrow groups, and inferences are made about a lot of other people who have not been studied (Langstrup and Winthereik 2010; Kaufman 2015; Stegenga 2018). Drug testing is carried out on particular groups, typically white adult men, so the results from the trial might not be representative for people of color, women, and children (Epstein 2007). As Armstrong (2007) observes, EBM cannot erase uncertainty. Still, the use of drugs without any testing is not particularly appealing either. In short, RCTs can give rise to error as a result of the simplifications built into the method, but it can be worse for patients if the alternative is no testing of drugs at all. To mitigate inference error, medical researchers typically request more data. If this is how medical research typically works, at least ideally, then how do the probabilities of medical science translate into clinical practice?

What might be true on average—for the population—might not be true for the individual (Henderson and Keiding 2005). EBM is a study of the generalized body, but a generalized body is a data invention. In real life, all bodies vary on an infinite number of parameters, like James’s line in the air. Epidemiologists talk about an “ecological fallacy” when doctors mistake knowledge about generalized bodies with predictions for individuals (Piantadosi, Byar, and Green 1988). Nevertheless, clinicians must treat individuals, not “generalized bodies.” They must find ways to translate EBM into practice. How do they do that? Clinicians employ a range of strategies, and data play a role in many—but not all—of them. I even wish to make a daring suggestion: clinicians sometimes use forms of associative thinking when trying to fit EBM guidelines to individual patients.

I first came to think about this as I interviewed Lars, a very experienced anesthesiology nurse also mentioned in chapter 4. When I asked Lars about his data needs in clinical care, he responded in this way:

Lars: Most of the data I get stems from the moment I walk up to the patient and do this [*he grabbed my hand, gave me a firm handshake, and looked me right in the eye*]

Klaus [*affected by the handshake and the intensity of the gaze*]: A firm handshake?

Lars: A firm handshake, yes, but more than that . . . how is the physiological tone [*Da: tonus*], is he warm, dry, cold, humid, and what kind of contact do I get? Physically as well as intellectually. I've worked with this for so many years, so I have learned to take in so many data in that moment.

Klaus: Do these data have any clinical implications?

Lars: Definitely! Absolutely! And I really make a point of this when I am teaching younger nurses . . . but I don't write it down. It just contributes to my *sense of the situation as a whole* [*Da: helhedsforneemmelse*, my emphasis]: what needs to be done in this specific case.

He later explained that although he was calling it “data” here, he did not regard this information as “real” data. To become that, his impressions would have to be entered into the electronic record, which he would not do. Lars tries to teach young nurses how the state of the patient—including fear and exhaustion—affects the metabolism, and it is necessary to adjust the dose of the anesthetic accordingly. He thereby seems to combine sensation with reasoning, if we use James's terms as I have suggested.

Lars in this way points to a fundamental clinical skill: the ability to “read” a patient's body. This is what I wanted to capture with my use of James's term “associative thinking”—the ability to draw on experience with other persons (“I've worked with this for so many years”). Lars uses a wide range of impressions, and with the handshake he actively engages his own body in collecting them (Gardner and Williams 2015; Goodwin 2010). In recent years, it has become common for older doctors and nurses to complain about the younger generation having lost the “clinical gaze” (Olesen 2018). A loss of clinical competence is also widely criticized in the international literature, which, in chapter 3, I discussed in relation to the datafication of clinical work (Nettleton, Burrows, and Watt 2008; Adams 2016a; Hunt, Bell, Baker, and Howard 2017; Hutchinson, Nayiga, Nabirye et al. 2018; Prainsack 2017; Taylor-Alexander 2016). Perhaps more

emphasis on associative thinking in clinical training, in line with Lars's approach, could address the problem and reintroduce the ability to read patients' bodies.

All the same, clinical work today *also* does involve reading data. With increased outpatient monitoring, many clinicians spend several days a week in office buildings looking at data rather than patients (Torenholt, Saltbæk, and Langstrup 2020). Clinical work depends on both associative thinking and data skills. Looking only at data is dangerous, but in a data-intensive healthcare system, the clinicians who cannot look at data at all are just as alarming. It can be incredibly difficult to make sense of data in clinical work. Thanks to the highly integrated data infrastructures, Danish clinicians have access to an abundance of data, but they often struggle to find and discern data, even on relatively simple matters.

Several clinicians have told me about their challenges. Take cholesterol levels, for example. It is not just difficult to find all the necessary measurements in a patient history: just figuring out where to look can be a challenge. Even when clinicians do know where to find all the relevant test results, reporting standards can change. Historically, some laboratories have reported cholesterol levels as above or below a threshold, and in these cases, clinicians must remember that clinical guidelines have changed over time. This could mean that although a value might first appear as “green” and later as “red,” the patient might have had the same value throughout (Green, Carusi, and Hoeyer 2022). A medication's coding number also can change, and some patients buy medicine abroad, whereby it is not registered in the Danish databases (Frandsen 2019). How would the physician know about this? There are also plain data gaps, such as the ones from The Health Platform described in chapter 3.

In short, even with the best intentions, and even in relation to simple issues such as cholesterol levels and prescriptions, it can be difficult for clinicians to find the answers they require just by having access to data. Giving clinicians access to more data on their patients is not the same as giving them more knowledge—and certainly not the same as training them to use data wisely. Conversely, denying clinicians access to data is not very helpful either.

ALGORITHMS, MACHINE LEARNING, AND AI: AUTOMATION AND PREEMPTION ERRORS

As it is time- and labor-consuming to produce valid claims with data, it is not surprising that many people hope to find a digital shortcut through computer automation. What do terms such as “algorithm,” “machine learning,” and “artificial intelligence (AI)” mean? In policy documents (Regeringen, Finansministeriet, Erhvervsministeriet 2019; Digital Vækstpanel 2017), they are often used interchangeably. For computer scientists, conversely, they can connote a range of significantly dissimilar approaches. There is no agreement on exact definitions, but for those doing the programming, there are profound differences between, for example, an algorithm treating data in specified ways and forms of machine learning where computers search for patterns in unstructured data. Alan Turing defined a classic measure of AI—namely, that humans experience an interaction with the computer as no different from an interaction with a person, what has become known as the Turing test. In principle, this definition of AI could both cover simple algorithmic chatbots and advanced machine learning products—at least if the test person interacting with the computer is gullible enough. Here, I will not seek to settle definitions. Instead, I wonder: how do such technologies of automation affect the points I have made about data, knowledge, and wisdom?

The simpler algorithms typically depend on established theory building (or, as it is often called, “model building”) and validation of the categories in use. Some uses of machine learning, in contrast, depart from this type of analytical engagement with category formation and theory building. There are epidemiologists doing both types of research, but they typically remain engaged in a particular topic or area of health. Some data scientists, conversely, move relatively freely among subject areas and search for patterns in data without necessarily knowing existing theories of pathology, causation, and effect—and in some cases without caring about known validity problems with the data sources (if they subscribe to the belief that with enough data, bias and validity become irrelevant). In these cases, everything that Kant cared so much about and many of the methodological refinements from decades of medical research seem to be dissolving. Gone are careful conceptual reflections; what is left is a fascination with computational power attuned to pattern recognition. It was the perceived power

of pattern recognition that led the editor of *Wired*, Chris Anderson (2008), to famously declare, in an article titled “The End of Theory”: “Forget taxonomy, ontology, and psychology. Who knows why people do what they do? The point is they do it, and we can track and measure it with unprecedented fidelity. With enough data, the numbers speak for themselves” (2).

Researchers have challenged his assertion endlessly, but it is fair to say that Anderson did not propose it in a piece of serious research. Still, it continues to inspire developments associated with automated data processing. Whereas classic epidemiology tried to build models and make carefully balanced assessments to avoid jumping from mere correlation to assumptions about causation (Hill 1965; Rothman and Greenland 2005), the new, data-intensive technologies challenge these ideas about how to exert judgment. A review has shown that it is now increasingly common in the medical literature to present a mere association as a prediction (Varga, Bu, Dissing et al. 2020). Furthermore, some of the new technologies in effect black-box some of the steps of the analysis (Fedak, Bernal, Capshaw, and Gross 2015). Black-boxing can be augmented through a division of labor whereby programming is outsourced or delegated to others who do not discuss their choices with those knowing the substance area (Anthony 2021).

The potentials associated with algorithmic prediction and rapidly expanding computer power are at the heart of the powerful data promises with which I opened this book (Krumholz 2014), though they are, of course, also much older than the recent Silicon Valley iterations (Greene and Lea 2019). It is likely that some readers would have expected the whole book to be primarily about how machine learning is disrupting clinical practices. However, I have consciously downplayed the grand claims about doctors being replaced by Google’s DeepMind or IBM Watson. In the clinic, data intensification mostly comes about as a continuation of existing regimes, incrementally transforming, first, clinical work, and second, what counts as evidence (Gjødtsbøll, Winkel, and Bundgaard 2019; Torenholt and Langstrup 2021).

In a few cases, though, machine learning has changed clinical practice. A Danish example is an algorithm that was trained on recordings from Danish emergency call centers to identify signs of heart failure. It is now used as decision-support software to alert health professionals about the risk of heart failure while they are taking calls (Blomberg, Folke, Kjær Ersbøll et al. 2019). Computer scientists cannot say what the algorithm identifies, but they can prove a high predictive value, and it is claimed to help the human

operators. Such tools are sometimes embedded within decision-support software and can potentially help raise awareness of rare diseases and broaden the scope of clinical thinking (Wachter 2017). In Denmark, some radiologists use automated image analysis as a backup to alert them of potential pathologies (Friis 2020), and since 2021, some hospitals have replaced one of two radiologists looking at each mammography image with AI (Albinus 2021). These applications depend on thorough data cleaning and years of development—they have not magically popped out of a computer. Still, they do represent important innovations, and it is fair to expect other similar innovations to gradually bring about important changes in healthcare.

Sometimes machine learning can help generate new hypotheses that can be tested with classic means for building evidence. Machine learning has, for example, been used to suggest potential changes to antibiotics to help counter antimicrobial resistance (König, Sokkar, Pryk et al. 2021). The exact value of these findings can then be determined in more classic laboratory experiments or RCTs. Still, we are *not* witnessing a healthcare system where digital monitoring of all citizens using wearables are about to facilitate automated administration of prevention and treatment as well as automated remuneration schemes, as Torben suggested.

Novelty goes hand in hand with continuity. While the current appetite for data and automation feeds on the eschatological sense of being on the brink of a new era, I think that this appetite gains voracity from the well-established culture of metrics that already has such a strong grip on medicine and healthcare organizations. As Lord Kelvin's blunt assertion about the ability to measure as a prerequisite for knowing has become how many policymakers and clinicians think (Mau 2019), investments come to focus on making data available. These investments are informed by old, but persistent, dreams of having access to all information in all places at all times (Poster 1990). Today, these dreams circulate in Silicon Valley (Wiener 2020), as exemplified by the quotation from Domingos in chapter 1 (Domingos 2015), but they can be traced right back to Laplace in early-nineteenth-century France (Busch 2017), Lovelace and Babbage as they invented the first "computer" in nineteenth-century Britain (Plant 1998), and Tesla's and Well's early-twentieth-century hopes for a "World Brain" of all available information (Wells 1938).

The thought of having all available information at hand permeates the open data movement that is seeking to make public data sources accessible

in a machine-readable format, the work with the European Health Data Space, and the so-called FAIR data policies that seek to make research data “Findable, Accessible, Interoperable, and Reusable” (Jirotko, Lee, and Olson 2013). FAIR in reality means making it possible for *computers* to read the data! Open data policies downplay the problems that persist in finding the *right* data and *interpreting* what they mean (Denis and Goëta 2017; Gregory 2020; Gregory, Groth, Scharnhorst, and Wyatt 2020; Wyatt 2017). The trouble that a clinical doctor experiences when looking for information about a patient’s cholesterol levels could be a useful reminder to proponents of open data about the difference between having *access* to data and being able to *find* what you need and *understanding* what you find.

Many proponents of open data also ignore the previous concerns about categorization. With pattern recognition, data are about whatever the analyst aims to predict. Every type of data can be health data if somebody can find a correlation with a health outcome (Schneble, Elger, and Shaw 2020). If a person’s electricity use can be associated with heart attacks, then electricity data are also health data. Also the caution related to categorization and statistical probability, which I referred to as “ecological fallacy,” is evaporating, and big data scholars matter-of-factly talk about predictions that operate at the “single-patient level” (Jørgensen and Brunak 2021, 7). In the pursuit of data for the old positivist dream, the very conception of knowledge is thereby tacitly reconfigured.

When Auguste Comte (1830–1842) announced the birth of a positivist sociology in the middle of the nineteenth century, he proposed a clear distinction between premodern magical thinking and a new type of science to come. He was confident that through “reasoning and observation,” it would be possible to arrive at “the actual laws of phenomena” (2). Does machine learning finally deliver on that ambition, then? Do open data finally generate a digital “world brain.” I do not think so. In contrast to Comte, Claude Lévi-Strauss (1966 [1962]: 13) suggested that rather than “contrasting magic and science,” it is better “to compare them as two parallel modes of acquiring knowledge.” He pointed out that the “great arts of civilization—of pottery, weaving, agriculture and the domestication of animals” (13) could not be seen as “chance discoveries” (14); rather, they were the result of a determined search for meaning. Unlike in the trained scientific experiment, magical thinking takes everything available and tries it out until the solution is found. It is a dedicated process. The same may well apply to

big data enthusiasts. They construct trials without the dogma of established science. It is a material form of magical thinking, working with whatever is available in a computer-readable format. If driven by genuine curiosity (and combined with other modes of knowing), there is no doubt that this explorative approach can generate brilliant new ideas. It is, however, not a path to establishing “the actual laws of phenomena” in a positivist sense.

There is something striking about comparing Neolithic pottery making with the brute usage of ontologically flat data in contemporary computer science. Besides seeing data science as a meaning-making practice like any other human endeavor dependent on experience, skill, and imaginative capability (Franklin 2006), the comparison is compelling because it points to the way that certain uses of big data methodologies can be seen as “bracketing” scientific theory building. It also suggests that it is not necessarily (or not always) a bad idea: important innovation can arise from brute experiments. Still, the “savage mind” described by Lévi-Strauss would not limit itself to what a computer can process. The Neolithic pottery maker would take in all aspects of the world and work by analogies and comparisons, again akin to James’s associative thinking. She would insist on meaning. Indeed, the clever data scientists who produce the major breakthroughs in big data research probably do use associative thinking, bodily experience, and imaginative power. Perhaps greater awareness of this experimental “pottery mode” also could serve as an inspiration for computer scientists and big data proponents to broaden their argumentative style and repertoire when translating their findings to worlds inhabited by people.

Humans remain problematic to work with. They vary a lot. They are not consistent. They harbor prejudices. In a popular book about diagnostic uncertainty, Steven Hatch (2016) even calls his fellow physicians “error machines” (30). When humans rate each other, the rater often says as much about the rater as the rated (Scullen and Mount 2000). Deloitte also saw this in their own organization in relation to performance measurement: scores said more about the managers doing the scoring than the employees who were scored (Buckingham and Goodall 2015). Prejudice can generate a human form of what I call *preemption error*, where people preempt their own chances of realizing they were wrong because their decisions become self-affirmatory. A famous example is a group of research participants who had claimed to be mentally ill just to test the reliability of psychiatric assessment. Once inside the walls of the psychiatric institution, they could not

convince the doctors that they had only faked their illness and should be allowed to leave the ward (Rosenhan 1973). Once a person was labeled as ill, this preempted reassessment.

It is in many ways justified, therefore, when many policymakers look for solutions to the persistent challenges with human prejudice, lack of consistency, and inattention (Kahneman and Klein 2009). With new solutions, however, come also new sources of error. Algorithms can also carry prejudice, and they also involve the risk of preemption error. They may replicate societal prejudices engrained in datasets and perpetuate racism, sexism, and other injustices (Lee and Larsen 2019; O'Neil 2016; Achiumi 2020). They are no better than the data on which they are trained (Jaton 2017, 2020). When implemented in healthcare, Henriksen and Bechmann (2020) suggest that AI “may prompt a world that is fit to algorithms rather than a world to which algorithms are fit” (813). To make patients fit into the algorithmic tools offered to clinicians, medical decision-making risks becoming “a matter of classification rather than judgment of individual cases” (Peeters and Schuilenburg 2021: 2). The clinical work becomes a matter of fitting patients to risk scores, and then algorithmic scoring tools determine which measures patients are offered (Amelang and Bauer 2019; Holmberg, Bischof, and Bauer 2013). Algorithms then preempt judgment.

Faced with digital interfaces, patients and staff cannot argue their case: “Algorithms do not argue. They present an outcome without an argument or reasoning. They present a truth without revealing sources or assumptions” (Schuilenburg and Peeters 2021: 198). With automation, therefore, the key point is to figure out whether reality has a chance of kicking back: do automated decision-making practices preempt the chance of realizing that the assumptions built into the system were wrong? Computers cannot get an epiphany or suddenly feel concern. It is therefore important to ensure that their applications are designed so that somebody can detect potential errors. This caution is missing when some Danish municipalities want to use big data to assess, for example, “parental preparedness” (Mortensen 2018). Predictions of this type risk becoming “self-fulfilling prophesies” (Merton 1968), with very important implications for those who are algorithmically assessed, as suggested by Mertens, King, van Putten, and Boenink (2021).

When algorithmic decisions preempt the discovery of mistakes, it can turn the paradox around: it can be dangerous without data, but it gets worse when decisions are made based solely on data. Automation, therefore, does

not replace human folly with science; rather, it produces different sources of error in need of other tools of correction. In some cases, keeping “a human in the loop” can be source of error because of human inconsistency and prejudice, and yet in other cases a human in the loop will be the only way to detect error. Data wisdom therefore involves ensuring that different types of knowledge can complement each other and mitigate the risks involved (van der Niet and Bleakley 2020).

There is an ontological dimension of this argument that is rarely appreciated. AI builds on a unidimensional perception of phenomena—a flat ontology. Machines treat data as representative of wholes—a representational view. Data, however, represent only one dimension of situations and practices with many dimensions. When AI researchers such as Max Tegmark warns against a super-intelligent Master Algorithm that could potentially conquer the world (see chapter 1), he speaks of networks of machines optimizing everything toward a particular goal, such as economic value (Tegmark 2017). If powerful enough, such a network will dominate all other values thanks to its superior calculative ability. Associative thinking carries a form of intelligence that differs from calculation: because humans can experientially engage wholes rather than merely calculating datafied aspects of those wholes, they can balance different types of values against each other. This is a key reason for continuous training of associative thinking in clinical practice. Although human judgment often appears inconsistent, this inconsistency might partly reflect a key ontological resource for overcoming the preemption errors of automation: the ability to appreciate how every situation involves an infinite set of dimensions and a need to weigh them differently over time.

CITIZENS AND PATIENTS: EXPERIENCING DATA AND CODING ERRORS

How do citizens and patients experience the types of knowledge, and errors, that datafication produces? When posing this question, it is important to note first that for many patients, integrated data infrastructures do exactly what they are built to do: patients can expect healthcare professionals to have access to the information they need in order to deliver high-quality treatments. Still, as datafication implies that healthcare professionals communicate increasingly through codes, the potential for coding error—along with the failure to *decode*—perseveres. Coding errors can be when people like Steen are declared dead in the computer system even though he is very

much alive (as I described in chapter 2). In most cases, however, the veracity (and falsity) of data cannot be as easily ascertained. Doctors and patients sometimes disagree about diagnoses; and general practitioners (GPs) have told me how some patients oppose simple diagnostic labels because the corresponding codes poorly represent complex social and medical problems. Again, data can never fully capture the multidimensionality of individual experience (Middleton 2022).

Here, I wish to focus on types of coding error that are generated specifically by data *reuse*. They are particularly relevant for intensified data sourcing because they stem from actors wanting more data while disagreeing about how they should be used. A telling example came about when in 2016, Søren Brostrøm, the director for the Danish Health Authority, stated matter-of-factly in an interview that psychiatric diagnostic codes were no longer medically valid among the young (Rasmussen 2016). His point was that municipalities (and with them, schools) had begun demanding a diagnostic code, such as the one used for depression or attention deficit hyperactivity disorder (ADHD), before they would provide special pedagogical support to children. It had put pressure on GPs and psychiatrists to provide diagnoses and thereby help families to get extra resources for the child. The diagnostic labels were stretched, as it were.

It turns out, however, that what a doctor does to help a ten-year-old can have unintended consequences when the child reaches adulthood. When people apply for a driver's license, for example, the Danish Patient Safety Authority checks with the registries. Just as Lone was surprised to find her driver's license cancelled when she had not reported her diabetes measurements (see chapter 2), there has been an increase in young people who have to wait for months to get a license, simply because the registries contain old diagnostic codes that trigger a warning of having the would-be drivers' psychological reliability assessed (Guerdali and Nielsen 2018). Similarly, from 2009 to 2017, Danish military authorities noted an increase of 72 percent of young men under nineteen years old who were not allowed to join the military because of psychiatric diagnostic codes acquired during childhood (Forsvaret 2018). Data that open doors to pedagogical support in childhood can in this way close other doors later in life. A diagnostic code is not necessarily right or wrong—but it can do things for persons that over time feel right or wrong.

Diagnostic codes can raise even more kaleidoscopic questions about veracity and error. Next, I will recount in some detail the story of a young man, Sebastian, to illustrate how coding errors become a lens through which a patient must experience subsequent encounters with healthcare. In his case, it was a psychiatric diagnosis that caused him problems. Sebastian was referred to me by a colleague who knew about my interest in data. I met him in my colleague's apartment in a town a few hours' drive from the capital. It was a warm and sunny afternoon, and the three of us first sat outside getting to know each other. After a while, Sebastian and I moved inside and logged on to his electronic health record through the online portal *sundhed.dk*. During the next couple of hours, he used the data on the screen as prompts to tell his story. We both struggled to understand the data, where they came from, and what they meant. For him, however, it was more than a puzzle. He has to live in the shadows of these data as they convey a story that he cannot control.

Sebastian grew up in a family where things had not always been easy: "I guess I didn't have the best childhood. It could have been better, well yes, but it's what lots of people experience." A troubled childhood in a small town was, he assumed, part of the reason why he, as a very young man, reacted strongly to getting type 1 diabetes. He was out of balance. At the time, he was also accused of a crime that he himself found hideous, and though later acquitted, he found it very challenging to see his name in the local news in relation to this case. He felt isolated and ostracized, and he thought that he really needed to talk to someone, preferably a psychologist. At that time in Denmark, however, people had to pay psychologists out of their own pocket, and Sebastian could not afford that. Psychiatry, conversely, was tax-financed, but when psychiatrists take on a patient, they usually need a diagnosis.⁴ It is built into the remuneration system. Sebastian explains it like this:

I ended up in the psychiatric system because that is where you are sent if you can't afford a psychologist. Psychiatry is the answer from the public system, when you ask for help. In the course of this treatment, they added this diagnosis, paranoid schizophrenia, or first "schizophrenia," and then later "paranoid" was added.

He could still have had the diagnosis even today had he not later been reassessed by the psychiatric system. The doctors wondered how he had acquired the previous diagnosis and declared it an "error." Paranoid schizophrenia

is not something that comes and goes. He seemed to have been misdiagnosed, he was told.

Sebastian wanted to delete this code. However, from a system perspective, data are never supposed to be deleted. It is only possible to add corrections. Deletion would open up the possibility of covering up malpractice, so the system is carefully designed to retain everything. Data are multiple in this sense as well: data might be erroneous as diagnostic statements and still true as statements about what doctors have entered into the record in the course of treatment.

Looking at Sebastian's file on the online portal for health records, I could see how his insulin and other medications came in as "health record notes" [*Da; journalnotat*] under the diagnosis "paranoid schizophrenia." It kept moving this particular diagnosis to the top of the list of what you would see when looking at his records. Algorithmic ordering is supposed to help create a relevant overview, but here, it had come to misrepresent his pharmaceutical and medical history. He was worried about the implications for how health professionals would view him if they thought he was a paranoid schizophrenic.

You can't help wondering whether it affects how people view you . . . For example, last year, I broke my wrist, and as I enter the emergency room I get this impression—I can't be sure that it's true—but the doctor [after having viewed the record] dismisses my case. The way I was treated, there was something, I couldn't work it out at the time, but it was as if I wasn't being treated objectively. . . . And there was this nurse, she was really rude. . . . I tried to get an X-ray, but the doctors just said [the wrist] wasn't broken and I was sent home. . . . It turned out it was broken, in two places actually, and it is a little annoying if they were somehow colored by the [psychiatric] diagnosis.

Sebastian does not know whether the health professionals were biased on account of the obsolete psychiatric diagnosis. He also admits that he is not even certain that the health professionals in question saw the diagnostic label. He did not see their screen. Still, he cannot help wondering whether they might have seen him through the lens of that label. It illustrates how coding errors are not limited to the pieces of information they pass on—whether correct or false. The errors also operate through the interpretations people make—and those that they in turn think other people make.

After spending the afternoon with Sebastian, I tried for a couple of months to figure out what had happened on the technical side: why were

insulin prescriptions featured under a psychiatric code so that the code kept moving up to the top of his record? I called several people whom I had interviewed on other occasions or knew as experts. Sebastian had already asked multiple doctors who did not know what to do, and now the experts did not know either. With intensified data sourcing come very complex forms of integration, which make it increasingly difficult to find a responsible human being capable of mitigation. In the end, the hospital that entered the original diagnostic code figured out how to close the erroneous health record. It had taken years for Sebastian to achieve this outcome. He had acquired a data label that haunted him, and for which nobody felt responsible.

Sebastian could see his own data online because of a political commitment to patient empowerment. Online patient access to data also constitutes a form of data reuse—another purpose with data. Still, access is not always empowering. Patients have online access to all the specialized medical data serving to document their hospital trajectories and use of laboratory services. If we define it as a coding (or decoding) error when patients who are given access to data do not understand what they see, then there are certainly many coding and decoding errors as a result of the Danish system that gives immediate online access to laboratory results and health records. Even with my background, I have felt worried, confused, and in need of help when I have looked up my own laboratory results, brain scans, and other examination data. There used to be a time delay placed on cancer results to avoid worry and confusion, but this delay has been removed.

To learn more about this, I interviewed Jenny, a civil servant who had been working on the task of removing the time delay. At the time I interviewed her, however, she had also experienced seeing her own cancer diagnosis on a test result from a pathology laboratory. She thereby came to tell me the story from the perspective of a patient, not a civil servant. She told me how she began trembling as she looked at *sundhed.dk*:

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.

Jenny explained how she found it provocative to think back on the small disclaimer she had 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."

Even a well-educated, competent woman with a great deal of knowledge about this area—and who, moreover, used to be inside the system—ended up feeling anxious when finding herself in the patient position. She emphasized that for data to make sense, they must be exchanged among people who understand what they mean. Today, however, data are not just conveyers of knowledge. They do many different things for different people and what they do can shift over time.

A different type of error comes about when some people use integrated data infrastructures to access information they should not see. Two interviewees have told me that on average, six health professionals are caught every year peeping into the medical records of lovers, ex-lovers, or others. In a few cases, medical secretaries have complained about their employer having looked at their data, as their labor union informed me. Patients can also be pressured into sharing their data once they have access. GPs have told me about young women who are forced by family members to share access to their medical records (which is used, for example, by parents to look into their daughters' means of contraception), and insurance companies that ask their client for a full printout instead of paying the physician for a statement, whereby the company also gains access to irrelevant—and private—pieces of information.

The authorities have tried to counter these pressures by offering citizens the opportunity of hiding data from view, including self-viewing, through something they call "privacy marking." It generates new sources of potential error when access to data might be selected in ways that the viewer does not realize. Conversely, patients have also used the log system on *sundhed.dk* to identify and threaten the doctors who have treated them. 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 health professionals involved in this patient's treatment (Dalsgaard 2019). The murder has generated anxiety, and some health professionals have mobilized to ensure their anonymity so they are featured only with numbers on the online portal and cannot be identified by patients (Clante and Allerslev Eriksen 2021). Such a solution, however, would make it difficult for patients to see whether somebody they

know have peeped into their record. More commonly, of course, patients simply complain about elements in their health records that they dislike. This has caused doctors to change their documentation practices, omitting information or writing it in ways that they believe patients will not understand (Kristensen, Brodersen, and Jønsson 2022)—something that was also observed in Sweden when their health records went online (Pettersson 2019; Pettersson and Backman 2021). Viewed from a doctor’s perspective, patients thereby instigate coding errors.

DATA ERROR REVISITED: QUALITY, MISCALCULATION, AND DEEPPFAKE

The examples of “errors” presented in this chapter do not constitute an exhaustive list. As stated at the outset of this chapter, I do not think it is possible to produce such a list. Unintended errors can arise in relation to each of the four types of data work (production, analysis, instruction, and use), and for each of the four groups of purposes (research, clinic, governance, and industry). Errors are not just epistemological. They can happen simultaneously in several dimensions, as it were, affecting different aspects of people’s lives, interacting with different interests and ambitions. Again, this is why I say that data are ontologically multiple—they are part of several practices at once.

There is a lot to learn from errors. I have highlighted inference error, preemption error, and coding error as types in need of more attention in organizations eager to become “data-driven,” but these terms only add to the existing literature. They are not meant to stand alone. In the literature, there already are well-developed vocabularies for many other types of error, including types of missing data (Hand 2020) and types of error occurring when data are used for governance (Wadmann, Johansen, Lind et al. 2013), or what I have called data-work-of-instruction.⁵ There are also terms for data quality and methods for assessing it,⁶ and for data cleaning and curation (Plantin 2019; Gabrielsen 2020). Despite all of these well-established insights and their associated terminology, Deloitte and other consultancies insist on a simplifying positivist vocabulary about “data and knowledge about what works,” without any serious acknowledgment of what it takes to produce knowledge out of data and how often error occurs. The European Union data strategy papers, the open data movement, and the Silicon Valley “gospel” make practically no mention of existing research into data

errors and how to mitigate them. What is in fact so striking, so utterly fascinating, but also scary is the way in which the powerful data promises announcing a new era of data-driven healthcare have swept away old concerns about data error.

I have participated in numerous committee meetings where computer scientists and industry representatives have argued for their need for direct and unmediated access to Danish registries, and where they have not even been aware that most registries have documents describing how variables have changed over time. Although they thereby reveal themselves to be unaware of the simplest ways to detect and avoid a principal type of data error, they maintain that they only need *easy access* to data. Trained epidemiologists, conversely, maintain that often it is not even enough to read the documented coding histories stored with the registries. For instance, Schmidt, Schmidt, Sandegaard, and colleagues (2015) suggest discussing coding practices with clinicians before using new data derived from the clinic. In one article guiding newcomers to registry-based research, they write, “Before engaging in extensive retrieval and analysis of data, it is . . . important to consult clinicians from the relevant specialty to learn about current and previous coding practices” (462).

To consult with clinicians also can be considered a way of drawing on the resources associated with associative thinking and ontological multiplicity: it involves learning from the practices where clinicians code amid many values and interests. While many epidemiologists (including some of those who would also call themselves data scientists) continue to adhere to these norms, the effect of data promises has been that it has become legitimate in some communities of practice to sidestep this old care for understanding the data well.

Besides the mostly unintended errors that I have described, there are of course also *intentional* errors of various kinds. As I stated in chapter 1, some people want access to data to cover up, distort, manipulate, control, or misrepresent phenomena to suit their interests. Sometimes it can be difficult to tell the difference between intended and unintended errors. The clinicians doing “data massage,” for example, may think of these “errors” as attempts to get remuneration or quality indicators right. Still, not even intentional cheating with data is given much attention in policy discourses and consultancy reports. This is surprising, especially considering that fake data is nothing new. Discussions of data cheating have a long intellectual history. In a

famous essay, Charles Babbage (1830 [2018]) accuses his fellow English scientists of four “impositions”: hoaxing, forging, trimming, and cooking (108–110). They are all forms of what today might be called “data manipulation.”

Contemporary international research integrity manuals usually talk about falsification, fabrication, and plagiarism, where the former two again clearly revolve around data manipulation (Jensen, Whiteley, and Sandøe 2018). As already mentioned, commercial interests are also known to make companies sometimes pick data selectively or color their interpretations in conspicuous ways (Bekelman, Li, and Gross 2003; Barnes and Bero 1998; Sørensen 2013; Pisinger 2013). All of these examples of insights into intentional data error also seem to have been forgotten by the people now advising governments and authorities about how to become “data-driven.” Years of accumulated insights into data difficulties also seem to evaporate when decision-makers contemplate automated algorithmic tools. In the words of the epidemiologist David Grimes (2010): “In recent decades, the computer science concept of ‘GIGO’ (garbage in, garbage out) has somehow come to mean ‘garbage in, gospel out’” (1019). I do acknowledge that it is possible to combine suboptimal datasets carefully so they contain different types of error and thereby produce meaningful results even with somewhat problematic data—but still, if these technologies are to deliver the progress suggested by data promises, I maintain that care and caution need much more space in governmental and organizational practices than the current race for big data allows.

When approaching a future where AI is gaining increasing influence within healthcare systems, it is important to remember that it is not only a means of analyzing data. It has become a way of producing them (Peeters and Schuilenburg 2021). This point has gained new urgency with the rise of deepfake technology. Most people will know deepfakes from entertainment. They have, perhaps, seen a video with President Barack Obama saying things that are wildly out of character (Warzel 2019)—and learned that it was produced by AI. Or they have witnessed public debates about nude pictures and porn videos featuring people who never took part in those activities (Harwell 2018). The visual material was produced by a computer program. Deepfakes have moved into healthcare too. Pharmaceutical companies have been caught submitting protocols of RCTs that never took place (Hildebrandt 2017a). A computer generated the data. To combat deepfake technology in the pharmaceutical industry, authorities such as the US Food

and Drug Administration (FDA) and European Medicines Agency (EMA), as well as major companies, are inventing AI so it can detect AI-generated fraudulent protocols (Hildebrandt 2017b). Healthcare is entering a race on fake data.

Ironically, in the midst of this deepfake race, artificially produced data (also known as “synthetic datasets”) have also become an official way to circumvent privacy issues. Researchers and authorities produce virtual data sets generated by computers to facilitate *in silico* trials (Hogle 2018) and to create open-source data that do not reveal sensitive information derived from real patients (Carusi 2014, 2016). Such synthetic data can be used as “sandboxes” (see chapter 1), where companies can explore correlations without data protection violations. This blurs even further the notion of data as a reference to something outside the computer: data-derived knowledge can be produced in its own closed circuits.

PARADOXES OF KNOWLEDGE MAKING

Data are needed for generating robust knowledge about abstract phenomena. Many medical problems are knowable only through data. Research, therefore, depends on good data. Data is also of vital importance in clinical care when they help ensure consistency and symmetry where human judgment may suffer from inattention and prejudice. Furthermore, data can be important elements of ensuring accountability and transparent forms of governance. Data wisdom is therefore not to abandon data, but to use them with awareness of potential errors and to be able to assess whether the problem at hand can be solved with data or is in need of other types of knowledge. Big data methodologies are also potentially very useful. They can identify novel patterns that can inspire new theories, new questions, and new curiosities (Swierstra and Efstathiou 2020). They should, however, support—not replace—human judgment. Judgment presupposes training (Kahneman, Sibony, and Sunstein 2021), and I have suggested that judgment is helpfully guided by experience with other similar situations—that is, *associative thinking*. The five lessons summarized at the end of the previous chapter are also ways of sustaining judgment to support wise data use.

Not all decisions are necessarily improved by being based on reflection or data analysis. Mercier (2020) suggests that in relation to most of our daily tasks, experience-based habits provide a better protection against mistakes

than a quick analysis. Data analysis can generate reflections, which disturb good habits without having established a firm and valid alternative. It usually takes multiple experiments to overthrow an old insight, but in those organizations that aim to become “data-driven,” we see people suggesting that organizational changes should be based on a quick-and-dirty gaze at the latest data available in the organization. Quick-and-dirty analyses of data then risk becoming very dirty indeed. A decision does not become scientific by referring to data if scientific care has not informed the data analysis. If the available data are not sufficient for drawing any firm conclusions, or if they reflect a random variation or are used to transfer insights between incomparable organizational situations, decisions do not become better by being based on data. Furthermore, it is important to acknowledge that some problems do not even call for analysis as such. When caring for people who suffer, warm bodies can sometimes deliver more comfort than cool brains. The health services continue to need people who know how to meet other people with openness, dignity, and care. Human bodies learn to deliver comfort through guided experience and associative thinking, probably more than through analysis. It takes strong institutions to pass this type of experience from one generation to another.

In this chapter, I have pursued the paradox that though data might well be used for drawing invalid conclusions, the situation can be even worse without data. I have also suggested that this paradox occasionally has to be formulated in reverse: the problems faced are dangerous without data, but they are even worse if data take primacy. It all depends on who has what at stake in the given situation. Data are used to pursue very different goods—knowledge, health, governance, and wealth—and in some cases, they may be seen by some stakeholders as serving one goal perfectly well while working against the goals of other stakeholders. An example of this is when a child acquires a diagnostic code of ADHD as part of a data practice aimed at streamlining the allocation of resources in schools (a governance goal), but this use of diagnostic codes then undermines clinical communication (a health goal), as well as the validity of registries for research use (a knowledge goal). It can undermine even the opportunities for the child as a grown-up.

I believe that most of the people I have interviewed are working to improve healthcare. The errors they introduce emerge as they pursue solutions to earlier errors—and sometimes just from lack of experience. In most of the organizations I have visited, public *and* private, people complain about constant

reorganization. They talk about being moved around and constantly given new tasks, their sections being closed and later reopened elsewhere; and they talk about a tier of managers who try to prove their worth with yet another reorganization as a step to their next promotion. This modus of constant reorganization is not how you nurture wisdom. This is not how to sustain and train judgment. What is politically expedient, therefore, is not necessarily the path to good governance. Data *create* a reality that makes political interventions possible. Perhaps this is why Torben and Flemming insist that data do not have to convey a representative impression to be useful. Political utility does not always equal “good politics,” however, at least from the perspective of the affected staff, patients, and citizens.

The proper use of judgment presupposes the courage of delegation. Delegation of decisions implies giving up certain forms of political control. It takes judgment to figure out what to delegate, just as it takes judgment to determine which type of problem needs which type of knowledge. For democratically elected leaders to be able to govern, they need some form of data. Data are their primary means of control. However, I showed in chapter 3 that if data are overused for governance, they lose referentiality. Data become detached symbols of communication. Accountability, therefore, hinges on a balance between *delegation* of decisions to health professionals and *documentation* (in line with what I call data-work-of-instruction). A good place to begin when looking for that balance is to focus on using only data that are deemed clinically relevant for governance purposes—that is, to let clinicians design data practice and let administrators figure out how to carefully analyze the resulting data instead of asking health professionals to document what policymakers would like to see.

Data wisdom involves the willingness to ask questions such as: How can data inform judgment rather than replace it? Are data needed for tackling this problem? With COVID-19, such questions acquired an all-new sense of urgency—for politicians, researchers, clinicians, and citizens alike. It is to the data politics of the pandemic I turn in chapter 6.

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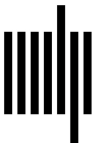
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