

## 6 DATA PANDEMIC

*April 17, 2020:* “The numbers speak for themselves!” Mathias exclaims, pausing briefly, as if he wants to let it sink in. Mathias, at eighty-three years old, has kindly offered himself for a telephone interview during Denmark’s first national lockdown in the face of the COVID-19 pandemic. With a group of epidemiologists, I have initiated a project to document how people understand and cope with the lockdown, and Mathias has been recruited for the interview, as he had responded to a questionnaire we had developed. Reflecting on the severity of the viral threat and the need for concerted governmental efforts, he then continues: “Just look at the US. It’s running totally wild over there!” Yet there is still something nagging him: “I can’t help thinking . . . they say COVID-19 causes this and that, but many people die also of cardiovascular diseases, diabetes and so on. . . . How can you know that they die *because* of corona? . . . If you count 100, then 60 percent of them might have died anyway?” While trusting the Danish authorities, Mathias, an ordinary man with no specialist background in medicine or statistics, cannot help reflecting on the data and what they mean. He cannot help pondering how to interpret the data now ruling his world.

During 2020, as a consequence of the COVID-19 pandemic, citizens all over the world, much like Mathias, were beginning to follow and discuss health data on a daily basis. In some countries, people were flooded with daily numbers, graphs, and heat maps. In other countries, debates focused on missing data or data gaps. Some citizens used government sources; others began building networks for disseminating alternative information. In supermarkets and public squares, you could hear people discussing epidemiological

questions relating to the reliability and validity of testing numbers, as if they had always had an opinion about these matters. People with no epidemiological training would casually use expressions such as “the R number” and consider how to interpret aggregate test results with an interest usually only granted to their favorite sports. COVID-19 brought citizens into the scientific conversation about health data in an altogether new way.

The historian of science Lorraine Daston comments on the pandemic that it is as if “we are back in the seventeenth century, the age of ground-zero empiricism, and observing as if our lives depended on it” (Daston 2020: 57). Ground-zero empiricism is when a community seeks to know about the world without a “settled script for how to go about knowing” (56). Another historian, my colleague Adam Bencard, said during a seminar that thanks to the pandemic, the wider public could suddenly “witness the scientific sausage as it was being made.” I immediately liked the analogy. Sausage-making can be a pretty messy process, and yet sausages are consumed in large numbers by people who usually seem to agree on the benefits of ignoring what went into making them. Now they all had their hands in the filling.

COVID-19 is a *data pandemic*. I mean this term in a double sense. The disease and its prevalence can be understood and reacted upon only based on data, *and* it has provided the impetus for a tsunami—a pandemic—of data. While illness and death are experienced as individual tragedies, the particular virus cannot be seen by the affected patients and their relatives: it takes data to establish cause and effect. Furthermore, individual tragedies do not constitute a pandemic: it is their sum—the documentation of their global reach—that establishes the phenomenon as a pandemic. As the pandemic started a tsunami of data, it accelerated the existing dynamics of intensified data sourcing: even more people now wanted more data on more people—and yet other actors wanted to reuse the data for additional purposes (see also Felt, Öchsner, and Rae 2020). It generated a lot of conflict and tension.

These observations are in line with what I had already found, as well as what I have presented in the previous chapters. Indeed, I am not the only observer who saw a reason in the crisis for reiterating points they had made before, however different the particular points are. The philosopher Giorgio Agamben (2020), for example, quickly stated that the pandemic was an excuse for installing what he had theorized as a proclaimed state of exception: “It would seem that, terrorism having been exhausted as the cause of measures of exception, the invention of an epidemic could offer

the ideal pretext for extending them beyond all limits” (1). The anthropologist Carlo Caduff, who had studied pandemic overpreparedness (2015), now wrote: “The response to the disease is driven by a fantasy of control that overestimates and overreacts. This fantasy has caused and is causing enormous harm” (Caduff 2020:10). The sociologist Slavoj Žižek (2020) commented that the pandemic was as much caused by the global political and economic systems as by any virus, adding that “the coronavirus epidemic has also triggered a vast epidemic of ideological viruses which were lying dormant in our societies: fake news, paranoid conspiracy theories, explosions of racism” (39). In a sense, we might add, the pandemic also seemed to reinvigorate dormant analytical dispositions.

While confirming some of my own observations, the pandemic also challenged some of the analyses presented in the previous chapters. In chapters 1 and 2, I criticized the prophecies of disruption as being unrealistic, but now swift and drastic changes suddenly did look much more feasible. It was not disruption in the sense suggested by the dominant data promises, but an abrupt and sudden reorganization of healthcare still seemed at least partially achievable. Also, my description in chapter 2 of pervasive but invisible data infrastructures might have given the impression of a docile and trustful Danish population, but during the pandemic, there suddenly were people protesting and demonstrating in the streets about government interpretations and uses of health data. People were also protesting against reuse, in future research, of test tubes from coronavirus testing.

With people taking to the streets contesting government interpretations—and uses—of data, I realized that I had hitherto primarily described political uses of data as a way of preempting opposition and turning politics into technicalities (cf. Espeland and Stevens 2008; Merry 2016). This, as if data politics were what Ferguson (1994) once called an “anti-politics machine.” Now I had to acknowledge that data also open up politics. Citizens such as Mathias were openly questioning governmental data analyses. In short, the pandemic made me aware of a new paradox of two competing but coexisting truths: *data close down debate and conceal political choices—and yet data also open up and unsettle political choices.*

I should not have been so surprised. Debates about various types of vaccination (Rose and Blume 2003; Halpern 2004; Decoteau and Underman 2015), as well as populationwide screening programs (Timmermans and Buchbinder 2013; Raz 2004; Sjönell and Brodersen 2009) have been

important precursors to the forces released by the pandemic. The climate crisis can be seen as another example where conflicting interpretations of data generate divisive political struggles (Edwards 2010; Roeser 2012; O'Reilly, Isenhour, McElwee, and Orlove 2020). Still, the COVID-19 pandemic took contestations of data interpretations—and of the government's approach to data reuse—to new levels.

The Danish government took a strong and determined approach to slow the spread of the disease. The country was among the first in Europe to go into lockdown at a time when there appeared to be few carriers of the virus in the country. The lockdown was based on a data prediction. It was announced at a press conference one Wednesday evening, March 10, 2020, when Prime Minister Mette Frederiksen explained, "We have a very significant obligation to protect in particular the weakest in our society, the most vulnerable, people with chronic illnesses, cancer patients, older people. For their sake, the virus must not spread." She continued with what became a mantra, repeated again and again, politically as well as at dinner tables: "Now it is time to stand together, by keeping a distance" (Redaktionen 2020). At the press conference, the Minister of Health showed what was to become a famous graph, with a red curve and a green curve, which appeared in slightly different versions around the globe. The curves symbolized two possible scenarios: the red curve represented no intervention and many people in need of hospital admittance at the same time, while the green curve represented interventions that "flattened the curve" to spread out hospital admittances over time and ensure that the pressure on hospitals remained within capacity limits (see figure 6.1).

The lockdown literally emptied the usually busy streets of the city overnight. I live in central Copenhagen, and the morning after the press conference, a homeless young man who often hangs around my neighborhood stood confused in the empty street, shouting: "It's because of 4G. It's because of 5G. It's the immigrants!" The image of the man, vulnerable and distraught, trying to make sense of the silent city, came to serve as a premonition of the search for causes and meaning that was to erupt, as well as the blame games that would unfold next. Going back to my apartment, I also had to acknowledge that even though the prime minister emphasized solidarity, this crisis would also fuel existing inequalities and introduce new ones (Wahlberg, Burke, and Manderson 2021).



FIGURE 6.1

The red and green curves. Here, Minister of Health Magnus Heunicke is handing over the famous red and green curves used at the press conference to my colleagues at the Medical Museion, who have included it in their collections (credit: Julie Wouwenaar Tovgaard, Medical Museion).

Mickey Vallee (2020) comments on the pandemic that “strangeness and indeterminacy call for more data” (6). However, data cannot create certainty. They can be interpreted in many ways. In the mud of uncertainty, several types of doubt have found fertile soil. A way to cope with doubt is to turn to morality and politics. Data doubts, therefore, provide ample space for political tensions. In this chapter, I reflect on the ongoing pandemic as a data-political moment where data both conceal political choices and yet also open up new forms of political contestation. I return to the themes from the previous chapters and illustrate how promises, living, work, experience, and wisdom play out under COVID-19 and sustain, deepen, and sometimes challenge the points from the preceding chapters. First, however, I present a few

reflections on why the pandemic gave rise to such an interest in data—and on the data that it made me and others generate with a rare sense of urgency.

### PAN(DEM)IC: A TSUNAMI OF DATA

If the coronavirus pandemic has become a data pandemic, it is partly because of certain biological properties of the specific virus strain, SARS-CoV-2, which is causing the disease Corona Virus Disease 2019 (abbreviated as COVID-19). For example, it has an incubation period where carriers can infect others even if they themselves show no signs of the disease. Also, COVID-19 develops very differently in different individuals. Some hardly notice it, or they feel as if they have a light (or perhaps severe) flu, while others suffer a violent and painful death. Some patients, who first see themselves as only lightly affected, later experience strange and uncomfortable side effects such as loss of memory or sense of smell or taste. It is almost as if the same virus causes very different diseases in different people. As the virus mutates, these uncertainties multiply. Such biological properties mean that individuals cannot know their own risk, nor the risk they might pose to others. People cannot necessarily feel whether they are contagious or safe—so if they want to act, they need data. COVID-19 is not the only such disease, but it is rare for people around the entire globe to face this type of uncertainty at the same time. The pandemic created a sense of panic, partly as a result of this uncertainty operating at a new, much greater scale.

In response, a tsunami of new studies was hitting the shores of academia, news media, and governmental institutions. The burst of quickly produced data created the public spectacle of “watching the scientific sausage being made.” In Denmark as well as many other countries, a public crash course in data analysis unfolded around figuring out ostensibly simple matters, such as how many citizens were carrying the virus. Newspaper articles, radio hosts, and blog posts explained how these statistics depended on, for example, test capacity and test strategy. Many of the people we interviewed would remind us that “one cannot compare test data from the spring of 2020 with those from the autumn, because many more people were being tested in autumn.” They had learned not to compare figures produced under different circumstances. Similarly, many people realized that death tolls and delineations of risk groups were anything but straightforward. Mathias was right: it is difficult to determine how many die *with* or *of* COVID-19.<sup>1</sup> The most basic

question about whether one's life was at risk could get no simple answer from the data, and yet there was no answer without data either. Everybody seemed to request more data.

I joined the data rush. I felt an urge to understand what was going on, and to do so, I turned to documentation. What did I do? In my general sense of bafflement, I first took pictures, recorded press meetings, collected policy papers, and took field notes on all types of experiences. However, my main commitment ended up being the collaboration mentioned in the introduction of this chapter, with two eminent epidemiologists in another section of my department, Naja Hulvej Rod and Katrine Strandberg-Larsen. They also introduced me to an ethnologist working with them, Amy Clotworthy, as well as other epidemiologists working in their respective groups. Within the first weeks of the lockdown, we constructed the Copenhagen Corona-Related Mental Health (CCMH) questionnaire to document some of the effects of the pandemic. It came to focus mainly on mental health because of Naja's and Katrine's expertise in this area, but it covered behavioral changes and people's sources of information about the pandemic as well. Later, we added attitudes to vaccinations to the studied topics.

It was when answering this questionnaire that respondents like Mathias were invited to volunteer for a phone interview as well. Amy and I were coordinating this qualitative element. Many researchers volunteered, and the project group grew. The CCMH questionnaire was translated into Dutch, English, and French by other groups. Many of the questionnaire elements were already being used in a large cohort study managed by Katrine, and we distributed the CCMH questionnaire to the cohort, as well as to the wider population through a time-series study administered by a survey company and through our project website. In this way, we hoped to be able to evaluate effects both diachronically in Denmark and synchronically among countries. The survey methodology and material have been described in separate papers (Clotworthy, Skovlund Dissing, Nguyen et al. 2020; Varga, Bu, Dissing et al. 2021). In the qualitative part, we ended up interviewing forty-eight individuals in Denmark, some of them several times.

In our interviews, most people expressed great support for the governmental approach, something also found in other studies.<sup>2</sup> Indeed, according to the Pew Institute, Denmark was at the top of the list of public satisfaction with the government's strategy compared to fourteen other countries (Devlin and Connaughton 2020). Even in the midst of a global crisis, there

are people who have time for fabricating rankings. According to political scientist Michael Bang Petersen (2021), who did the most extensive studies of public attitudes in Denmark and served as an advisor to the government, the widespread popular support in Denmark was related to the way in which the governmental communication embraced uncertainty and stated up front that they would inevitably commit mistakes.

Petersen's studies, as well as our survey, furthermore suggested that people really did change their behavior radically (Clotworthy et al. 2020). According to our data, however, it came with a mental health price: increased loneliness, isolation, lower quality of life, and more anxiety and worry. Other studies around the world found a similar negative impact on mental health (Vindegaard and Benros 2020). We had distributed the survey in the general population and in Katrine's existing cohort study, but the numbers differed in the two "populations." In the general population, the young in particular seemed to be negatively affected, while data from the cohort study (where people had long been answering the same questions) did not fluctuate enough to suggest extraordinary pressure on the young. With different results in the two populations, Naja had to exert judgment. She decided to advise the authorities to do more to prevent mental health problems among the young. Eventually, restrictions on schooling were lifted before other restrictions in order to help the young cope with the pandemic.

My engagement in this project gave me hands-on experience with the challenges that civil servants like Torben and Flemming described in chapter 5. We had to acknowledge doubts and uncertainties and yet use data to help inform our decisions. We had to speak on behalf of the data we had, although we were aware that we were missing data on many other potentially important factors. For example, there might very well be more vulnerable people than those responding to our questionnaire (e.g., in eldercare, among unregistered migrants, and the homeless). Another resemblance to the challenges of civil servants was the ambition of isolating effects. Torben and Flemming were tasked with isolating healthcare performance, and we had wanted to isolate the effects of the lockdown strategies in different countries. However, data from the four countries did not suggest clear differences in mental health effects despite very different political strategies (Varga et al. 2021). If the questionnaire did measure the chosen mental health aspects in a valid way, it appeared that the type of lockdown was less significant than we had anticipated (and had we found a clear variation



between the countries, it might have been caused by a parameter other than the lockdown strategy).

The questionnaire was made carefully, but under great time pressure. Some questions were not conceptualized and tested as we would normally do because getting started as soon as possible was a main priority. When we asked respondents which precautions they took to avoid infection, the reply options included, for example, “Increased handwashing and use of sanitizer.” As the crisis continued, the term “increased” became dubious, but we could not change the wording because it would be difficult to publish in epidemiological journals if questions changed along the way. Although questions on loneliness were previously validated questionnaire items, they were not validated for this particular use. Maybe they were understood differently in the context of a shared societal lockdown, where loneliness might have become a more legitimate feeling to express? Still, if we were to create data in the midst of the crisis, we could not wait until the perfect solution materialized. In the end, we had to accept, as argued in chapter 5, that even though data can give rise to invalid conclusions, the situation can be worse without data.

COVID-19 also became a data pandemic by accelerating the datafication of my own research. We interviewed forty-eight people, but *I* did not interview them. It was a group endeavor. Three assistants were employed, Sofie Amalie Olsen, Sif Vange, and Nikoline Nygaard, to help with the “data collection” (a term I otherwise rarely use to refer to interviews). Sofie, for example, interviewed Mathias, whom I previously quoted, and Sif conducted a follow-up interview with him in September 2020. Later, Sofie á Rogvi joined to explore the growing opposition to the government strategy. Through the work of these talented assistants, interviews and ethnographic observations were turned into shareable *data*—decontextualized, digital, and transferable (Poirier, Fortun, Costelloe-Kuehn, and Fortun 2020). We obtained funding from the Velux Foundation, which also emphasized data sharing. Data sharing disentangles narratives from the intimate relation between interviewer and interviewee. It was new for me to, at least in this way, draw information from interviews I did not conduct myself. Amy and others were using the same interviews for other analyses. Even interview data in this way become multiple: serving many purposes at once.

“It feels strange that people who have confided in me, should see their thoughts used by others,” Sofie á Rogvi said at one point when we spoke

about placing interview transcripts in sharable folders. “It feels like *my* informants,” she continued, holding her hands up like a hug or holding a baby. Sofie is not a “data hoarder” (Tupasela 2021a). She was expressing care. Although we all want to understand and represent our interviewees well, datafication can exert a sort of violence on the relations through which the data emerge. I do not wish to ignore or downplay the role that ethnographic encounters have had in extractive colonial practices (Clifford 1986), but I do wish to suggest that face-to-face encounters provoke ethical reflections in ways computer screens and data in columns do not. It is a relational care that we as a research community must consciously work to preserve if all our data are to be offered in machine-readable formats for secondary analyses as part of the open data movement. Data sharing facilitates some new and intriguing forms of analysis, but it comes with a price.

In short, COVID-19 is a phenomenon known through data, and it instigated a call for even more data, as well as deepened datafication. In the wake of this data tsunami, I began reflecting on my previous points about promises, living, experience and wisdom.

#### PROMISES: CHATBOTS, APPS, AND DIGITALIZATION

As the anthropologist Adriana Petryna (2002, 2005) has shown, any good crisis involves opportunities for those who seize them. The pandemic was no different. It was not just producers of masks, sanitizers, and vaccines who made a fortune, along with online shopping companies like Amazon and delivery services of various sorts. The pandemic also fueled the data promises that already had a strong grip on decision makers. Lockdowns instigated an immediate need for digital tools for communication, and the authorities instantly began working with ‘data-driven’ software to monitor and prevent COVID.

Some of these tools proved effective, such as the construction of data pathways that allowed the authorities to identify the long-term effects of the disease, side effects of vaccines, and pressures on healthcare resources. In other cases, however, investments seemed motivated by data promises that were able to overrule any call for evidence. Chatbots, for example, were almost instantly set up as online symptom checkers in many countries (Greenhalgh, Koh, and Ca 2020). In Denmark, one chatbot was supposed to serve as a digital replacement for GPs and thereby relieve the health services

(Danske Regioner 2021). One of the key data promises, that automated data processing could replace doctors, finally seemed to be materializing—and to be doing so overnight. Indeed, several hundred thousand Danes were now communicating with a computer rather than with a person. Christoffer Bjerre Haase, a PhD student of mine who is also a medical doctor, invited me and a couple of other colleagues to analyze the chatbot. It turned out to be a relatively simple algorithm. It focused only on capturing COVID-19 symptoms, which meant that if a patient had symptoms of another illness such as meningitis, the chatbot would not suggest any urgency. Still, the algorithm was disposed toward “better safe than sorry,” and therefore almost every other symptom led to the same chatbot response: “You should see a doctor.” How would this relieve the healthcare system? And how would its degree of success be evaluated? There was no way of capturing its potential mistakes, no way of figuring out whether it served its purpose. It was an evidence-free invention, and yet it was heralded as a great digital triumph (Haase, Bearman, Brodersen et al. 2020).

In the space of urgency, politics and science were mingling with ease, and in many ways that ease was not all that different from the general embrace of the new digital options described in chapter 1. Digital contact tracing apps were developed at great speed in many countries. The Danish authorities moved a little slower than most other countries on the implementation of these apps. There was no doubt that the government wanted a contact-tracing app, but numerous complaints from many sides about data security delayed the process (Mirzaei-Fard 2020). When a mobility tracker app aimed at identifying risk of exposure was introduced in Denmark in June 2020, it was basically the same as an earlier Norwegian version. Ironically, Norway had dropped this app for lack of proven effects just a week before it was implemented in Denmark (Datatilsynet 2020).

Yet the lack of evidence of effects did not disturb the Danish plan. The Danish delay was explained as a matter of ensuring a *safe* version (apparently more than an evidence-based one). It made it somewhat peculiar that while the population was told that this special Danish version did not constitute any digital risk, employees in the Ministry of Foreign Affairs were told not to download the app due to increased risks of hacking (Krogh 2020). Such double standards, along with more or less dubious attempts at using data collected for the combat of disease for security purposes, mushroomed in various versions in countries all around the globe (Harari 2020; Powers

2020), including China (Mozur, Zhong, and Krolik 2020), Singapore (Illmer 2021), and even Germany (Privacy International 2020), a country otherwise known for being cautious with data being repurposed for surveillance.

In June 2021, Lisbeth Nielsen, the director for the Danish Health Data Authority, was interviewed by a political magazine about the impact of the pandemic on the work with digital health data in Denmark. She emphasized the importance of the strong data infrastructures in place in Denmark already before the pandemic struck. She added that “nobody notices infrastructure when things work as they should” (in Lehmann 2021). Policymakers and the public have long been accustomed to think that “somebody” knows exactly how many patients have a particular diagnosis, for example, but the pandemic made the work going into producing such numbers more visible as the demand for real-time data became more urgent than ever before. The director explained:

We are now on steroids in this data production. These days we make sizable reports daily [with] very detailed data on who is vaccinated, where, and which parishes have high infection rates. . . . Suddenly, it’s the Prime Minister’s office reading health data. I don’t think they’ve done that before (in Lehmann 2021).

With the pandemic, the demand for health data exploded! Nielsen was also thrilled to see how the pandemic had pushed the agenda of digitalization and “data-driven decision making” (Ibid.). It took less than a week to introduce video consultations into general practice using the existing infrastructure (Danske Regioner 2020). Then, only two weeks after initiation of the first lockdown, it was also possible for psychologists to offer online therapy options on safe connections (Dansk Psykolog Forening 2020). In a book about the government’s multi-level response to the pandemic, a group of retired top civil servants and academics observed, with a hint of envy, that “changes that would usually take years were implemented in weeks” (Østrup, Jørgensen, and Zwisler 2020: 261). Within a year, a whole range of new so-called self-service options were introduced to ensure physical distance between patients and staff, and citizens were invited to book their own tests and vaccinations, download their own proof of infection status, and so on.

Nielsen also saw in the pandemic response a confirmation of the legitimacy of previous political choices: “A couple of years ago, we were still discussing whether it was reasonable for people to see their own laboratory results—without a delay. . . . We will never return to a situation where we have to discuss whether people can bear seeing their own data.” Interestingly,

she seemed to reach this conclusion because of a renewed digital conviction, not because of any new evidence (and more likely *despite* the emerging evidence—see chapter 5). Thereby, the pandemic response in Denmark has accelerated the transition toward wired medicine and self-care, which characterizes data living.

#### LIVING: RISK, TESTING, AND SOCIAL DISTANCING

With my mention of tracking apps that do not capture what they are supposed to, and yet which open up possibilities for surveillance in new ways, I have exemplified how the pandemic revived some of the common paradoxes of everyday data living: data both reveal *and* conceal; they both empower *and* disempower. These paradoxes have played out differently in different countries, depending on the preexisting (but largely invisible) infrastructures and healthcare options already in place. Infrastructures, and not just political leadership, have shaped the pandemic response—and determined who were left with which opportunities for obtaining help in a time of crisis (Bal, de Graaff, van de Bovenkamp, and Wallenburg 2020; Caduff 2020). In Denmark, a publicly funded healthcare system has ensured broad coverage, and existing data infrastructures have ensured an overview of developments. Test figures, hospital capacity numbers, daily numbers of hospital admissions, intensive care admissions, people on ventilators, and other forms of real-time monitoring not only were shared with the prime minister's office, but also were turned into direct updates and graphs shared online and with media outlets. Data were used for planning, but they also were publicly released so that news agencies could produce automated heat maps such as those in figure 6.2 (from the National Broadcasting Company), indicating the geographical distribution of positive tests and high-risk groups (based on age, comorbidity, and overweight). A real-time cohort was set up for research on safe servers to follow all those infected (and later, all the vaccinated) across all subsequent uses of healthcare (Pottegård, Bruun Kristensen, Reilev et al. 2020). It has been used to monitor the long-term effects of having had COVID-19 (Lund, Hallas, Nielsen et al. 2021), as well as the side effects of treatments and vaccinations. When reports appeared internationally about deadly side effects of the AstraZeneca vaccine, such as the so-called vaccine-induced thrombotic thrombocytopenia (VITT), it took a week to identify all healthcare contacts from everyone who

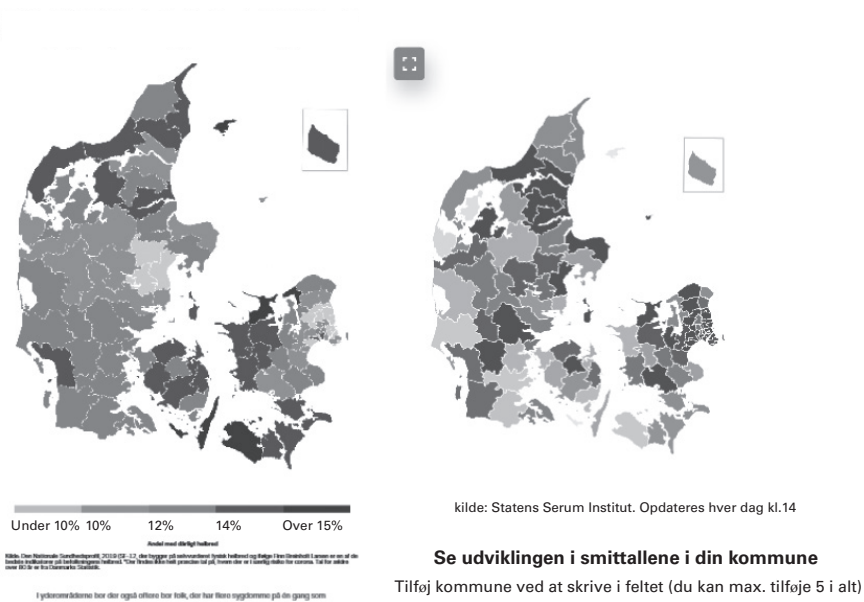


FIGURE 6.2

Heat maps of viral risk. On the left, a map entitled “How many are at special risk of coronavirus infection,” showing the concentration of high-risk groups (age, overweight, comorbidity) published at the beginning of the pandemic. On the right, an interactive map entitled “Check infection rates of the past week in your municipality,” showing the concentration of positive test figures per 100,000 inhabitants (from June 1, 2021). This map was updated throughout the pandemic. In contrast to the one on the left, it contains no legend linking the color coding with specific numbers: coloring continuously changed to show maximum difference between municipalities (credit: data analyst Nis Kielgast and graphics Simone Cecilie Møller, National Broadcasting Company).

had received the vaccine in Denmark and analyze their disease patterns.<sup>3</sup> Based on such calculations, first the AstraZeneca vaccine, and later the Johnson & Johnson vaccine, were left out of the Danish mass vaccination program.<sup>4</sup> The data infrastructures were operating “on steroids,” as the director of the Danish Authority of Health Data put it.

These experiences with digital data infrastructures were mostly continuations of forms of data living that I already described in chapter 2, such as being connected to digital monitoring and communication devices. There was, however, a new way in which the pandemic inscribed itself in data living. It was the mass experience of living in the shadow of data predictions. With COVID-19, society as a whole had become an extended healthcare

sector: work to fight disease was no longer confined to certain institutions or practices. “Morbid living” (Wahlberg 2018b) permeated the everyday behaviors of even those who had never been touched by disease.

In our interviews and in the survey, we learned about how people experienced the social changes brought about by the pandemic. We could observe some dramatic shifts in behavior. According to the survey, more than 95 percent of respondents reported increased use of handwashing and sanitizers and practicing physical distance with strangers. This was “thin data,” ethnographically, but the information sent a clear signal. In our interviews, we learned more about what such a response meant to people and how they practiced these precautions. The interviews also indicated that sometimes we might not be measuring exactly what we thought we were with the CCMH questionnaire. For example, we could see that Pernille, in her response to the survey, stated that she did *not* practice increased handwashing and use of sanitizers. We assumed that that meant that she had decided not to follow the public guidelines, but when we interviewed her, she explained, “We already were doing that [before the pandemic], sanitizing our grocery shopping and all that. So we kind of had a head start on all of that.” Such deviations in measurement are probably not a big deal when numbers are large enough, but it was amusing to see our own assumptions challenged.

What the numbers could not convey was what behavioral change *meant* to people. First and foremost, the sudden shift in behavior in the early months of the pandemic generated social conflict, both between strangers and in intimate relations: What was the adequate level of precaution? Most people felt that they were being too strict in the eyes of some and too lax in the eyes of others. They complained about others, but also about others complaining about them. In April 2020, Lise (age 81) remarked: “There are many young people who are out running . . . and some of them are ruthless; they only think of themselves while running.” I read this and similar remarks about runners and began practicing a lot of distance when passing people on my own runs, only to have an older couple shouting aggressively after me: “We are not carrying the plague, you know!” Also, in April 2020, Chunhua (age 31), a woman of Chinese descent, said she had been wearing a mask long before it became official policy in Denmark. She reflected on feeling “weird”: “We were a little concerned, . . . if we would make other people panic if they saw the mask.” Others, indeed, commented on those

using masks, and later, when that became mandatory, they would comment on those *not* wearing a mask. Even before the pandemic, masks were embedded in dense scientific symbolism. Writing on the history of masks, Lynteris (2018) says that they provide an “essentially atropaic promise of scientific control,” where the mask assigns the wearer to particular communities (442; see also Lupton, Southerton, Clark, and Watson 2021, for a fine analysis of the social dynamics of mask wearing during the pandemic).

The sense of social anxiety wrote itself into intimate relations (Schiermer 2020). Interpretations of data predictions influenced who could spend time with whom, how, and where, and with every cycle of lockdown, reopening, and renewed lockdown, people had to renegotiate risk levels with family and friends. The interviews are permeated with examples of inconsistent personal choices aimed at balancing differing perceptions. Johan (age 64), for example, admitted that he saw his girlfriend’s children in a very casual way, but he avoided his own children and grandchildren or saw them at a marked distance: “Last time I saw my daughter, son-in-law, and the grandchildren, the children stayed inside in the living room, and then we opened the door to the terrace and I could stand out there talking to them.” Johan explained that his daughter and son-in-law were nurses and “knew much more about COVID” than his girlfriend’s children, so he had to accept their rules when he was with them. He did not doubt their expertise, but when they were not around, he had decided to focus on other priorities.

People with chronic diseases would talk about the disempowering feeling of having to communicate about diseases that they usually tried hard to make sure did not determine how they lived their lives (see also Grabowski, Meldgaard, and Rod 2020; Clotworthy and Westendorp 2020; Lau, Kofod Svensson, Kingod, and Wahlberg 2021). Davis and Lohm (2020) noticed similar reactions in the wake of the swine flu outbreak in 2009 in the United Kingdom and Australia. On top of this, social distancing generated a common sense of *loss*. The people we interviewed spoke about not being able to attend funerals and of people who lost contact with their close relatives in their final year of life. Such tragic experiences have been recounted all over the world (Nagesh 2020; Videbæk 2020). When Sif Vange spoke to Mathias again in September 2020, he also commented on a sense of loss, but of a more mundane type:

We can talk on the phone, we can talk on Skype, but it’s just not the same as face-to-face cozy intermingling where you can read their bodily gestures and



their facial expressions. Body language is as important as what the mouth says, almost.

For most people, connections are not just informational. When society as a whole structures people's interactions on the premise of preventing disease, people will tend to experience their loss of social life in a much more direct manner than the preservation of biological life that the preventative measure serves.

#### WORK: LAY EPIDEMIOLOGISTS, CONTROL, AND OPPOSITION

Similar to the way that the pandemic affected how I thought about data living, it influenced my understanding of data work. Intensified data sourcing continues to create both more and less data work by moving it around among groups of people. I had already noticed the data work undertaken by patients (chapter 2), but my main focus had been on the work carried out by health professionals (chapter 3). Now all citizens faced much more data work, not least because the pandemic accelerated the ongoing transition toward digital self-service options, as observed by Lisbeth Nielsen. To avoid physical contact, patients increasingly had to (and to date still must) enter information from home (or through sanitized iPads or data entry stations in the clinic), rather than speaking to a nurse or secretary. It has had the consequence that citizens now do more of the data-work-of-production. Many citizens have also embraced data-work-of-analysis, mostly just in the form of comparing and interpreting numbers as Mathias did, but some citizens have kept Microsoft Excel spreadsheets of their own, with which they have been monitoring the veracity and consistency of official statistics. Citizens have also faced more data-work-of-instruction in the form of having to present health data to access social gatherings, cafés, and educational institutions. This is data-work-of-instruction because they might have been in line to get test results not to know their infection status, but to comply with rules. Some families have installed rules of their own that generate a form of data-work-of-instruction, such as to provide a digital certificate proving negative infection status when children move between divorced parents or as a ticket to enter a birthday party. Most important, however, the pandemic has generated much more data-work-of-use. Keeping up to date with the latest numbers became a daily occupation for practically every person I have encountered since March 2020. It is, therefore, data-work-of-use that I focus on in this chapter.

Mathias, for example, conveyed how he kept spending more time simply following data when he spoke to Sif in September 2020:

I often check this homepage, I can't remember its name. There you can really see the curves, how it looks right now. . . . And "how many on respirators," "so many on intensive care, but not in need of respirator." Yes. And then there are the age groups, I care a lot about them . . . and the geography, of course. Obviously, we're somewhat egocentric: How is my part of Jutland doing compared to the other regions? . . . I didn't care that much in the beginning. It's something that was awoken in me during the past couple of months. 'Cause you're bombarded [with data] . . . and now I can't help checking them (*giggling*).

Mathias, like many others, has become a data consumer. The direct feeds from hospital systems to central databases were released every day at 2 p.m., and some people used them for informal betting. A morbid pastime, fit for morbid living, but also a new form of work: recreational data-work-of-use.

Just like the other types of data work, the work associated with data use is unevenly distributed. Those individuals, who do not agree with the tacit priorities of the government's strategy, spend countless hours looking for sources supporting their hunch. Apparently, they need data to justify their position. In Denmark, as in Canada and several other countries (Lupton et al. 2021), the opposition to restrictions came from both the right- and left-wing sides of the political spectrum. It has not been a bipartisan issue of party politics to the same extent as in the United States, though in Parliament, it has mostly been a particular right-wing party that gradually began formulating criticism of restrictions. At demonstrations, a common battle cry has been "Fuck the left wing, fuck the right wing, fuck the centrists. We are the people, and we have had enough!" The antielitist stance is often articulated on the homepages of the opponents (e.g., *danmarkforst.dk*, which informs readers that the so-called elite has planned the pandemic to carry out genocide on the populace using vaccination as the weapon). Regardless of their political position, however, the Danish opponents of restrictions have found themselves steeped in data use. It is as if the only legitimate opposition to policies building on data predictions was alternative uses of data.

I stumbled across this type of data work aimed at challenging governmental choices among opponents more or less by chance when I, in April 2020, came across a demonstration against the government strategy. It was so strange seeing some 50 to 100 people gathering at a time when the city was otherwise empty. I stood listening a while, at a distance. The speakers

were presented as “experts,” and the main theme was that the authorities were lying—a point made by citing statistics. In the months to come, and in particular from September onward, the opposition mounted. A group convened in front of Parliament every day with saucepan lids and spoons, banging and making noise. I decided to pass there on my running route and stop for brief chats with some of the demonstrators. I have sometimes seen as few as two or six people, and sometimes what I guessed amounted to several thousands. They appeared to be an unusual mix: left-wing herbalists and right-wing pro-Israel supporters, yoga trainers and thoroughly tattooed bodybuilders, young and old, but they were all talking to each other, and all were very interested in explaining themselves to a passerby like me. Often, when I have asked, “How did you get involved with this?” they have responded something like, “Oh, I’ve been involved for years!” Apparently, many of them see themselves as engaged in various forms of opposition, with long histories. Others described themselves as “awoken” by the pandemic—for the first time, aware of the politics shaping their daily lives.

I expected to see something about the continued demonstrations in the news, but the media remained remarkably silent. Several new political parties emerged in this period, again without getting much media attention. By mid-2021, no fewer than 121 new parties had begun collecting signatures to begin the process of featuring on the next parliamentary ballot (Krogh, Lehmann, and Lønstrup 2021)—in a country of just 5.8 million inhabitants. One opposition party which had been around for some years before the pandemic, but which now attracted much larger crowds, is called Earth, Freedom, Knowledge. It has for years been warning voters against an evil elite. In their party manifesto, they suggest “treating herbalism and conventional medicine equally” and “banning 5G from entering Denmark, because it is extremely dangerous to health” (JFK21 2021). However, now their main cause is “to bring an end to the illegal restrictions in conjunction with COVID-19, to work for herd immunity like in Sweden, and to remove the Act on Epidemics.” In line with most of the other new parties, Earth, Freedom, Knowledge accused a proposed Act on Epidemics for installing mass surveillance. The final law was modified before being enacted, but it was not modified enough to satisfy many of those who have begun questioning the motives of the government. The pandemic has generated a burst of activism (Milan, Tréré, and Masiero 2021; Callison and Slobodian 2021), but in the latest election (which was for municipality and regional representation),

there was no increase in active voters. On the contrary, there was a slight decrease (Frost 2021). Mostly, this type of data activism challenges the basic legitimacy of existing political institutions.

When I first began hanging out at the margins of some of these demonstrations, I simply sought to understand their concerns. Gradually, it also became a micropolitical act. I wanted to maintain a dialogue with people whom I quickly realized feel silenced, ignored, and treated as outcasts (Tønder 2020). Dialogue came to feel like a necessity in an increasingly divided political atmosphere. One day in November 2020, I am speaking with two women, both retired, who offer me a leaflet. It is full of data derived from the Danish Health Authority, and it compares death statistics from smoking and COVID-19. I would have interpreted these data differently, but one of the women gives me a telling smile, saying: “Why don’t they [pointing to the Parliament building] do anything about smoking? Perhaps because they smoke themselves?” I ask whether they doubt the published data on COVID-19, and like many other opponents, they are pretty confident that the disease exists and that the official Danish data are correct. However, they maintain that the data are “manipulated to scare you.” I ask whether they think there is nothing to fear, and they respond as one voice: “No, we hug and shake hands and we’re all right.” Then much to my surprise, one of them adds: “It’s just the old and weak ones who die,” while her friend nods.

Statistically, these two women must belong to that very category. It then turns out they too have lost friends to COVID-19. They do not deny the deaths. One of them then takes a deep breath and explains that the real danger is “not to lose your life, but to stop having a life.” She had seen friends isolated in their final year of life, and others dying of diseases other than COVID, but isolated and alone because of the lockdown measures. She accepts the statistics of COVID-19 but opposes valuing biological life over social life. She then adds that herbal tea is probably the best prevention. It later struck me as strange that she initiated the conversation by handing me a list of numbers from the Danish Health Authority if she believes that herbal tea delivers a cure. Would she have used data to argue her affinity for herbal tea before 2020? Is it the pandemic that has forced her to use official health data to argue her case? At the given point, however, a young man comes over and begins advising me on how to find the “real data” on [www.bitcute.com](http://www.bitcute.com), explaining that the site is also where I will see the truth about “the Muslim invasion.” At that point, I decide to take off.

Attending these gatherings was like going down a rabbit hole and entering an alternative world, where everything takes on different colors and different meanings, gets filtered through different interpretations. If, in chapter 3, I observed how policymakers and clinicians could sometimes appear to live in separate worlds, now it was as if divergent segments of the population occupied different planets. Sofie á Rogvi and I decided to begin interviewing some of the opponents of the government's strategy, beginning with participants at these gatherings. Each mode of sampling creates its own public: data always reflect how they came into being. When we compared the interviews with our survey respondents (who, like the general population, were mostly supportive of the government strategy) to interviews with some of these opponents of the government, on the one hand, there was an interesting contrast in attitudes toward the government, while on the other hand, supporters and opponents were remarkably similar in other respects: both groups expressed doubt about official data analyses, they questioned the logic of specific restrictions, and both were looking for meaning and explanations using data. People on both sides had similar doubts, such as whether too much sanitizer could be harmful to health, granted that some bacteria are beneficial to human health (Hamblin 2020). As also found in a study from the United States, however, *opponents* often get to know much more about data analysis than supporters of the government's strategy (Lee et al. 2021). They needed to invest more in the data discourses to acquire a position from which to speak.

At a point when 95 percent of the respondents to our survey said "Yes" to wanting a vaccine (see figure 6.3), the majority of the people gathering at demonstrations seemed to be convinced that the vaccines were harmful tools of surveillance, or that the pandemic was manufactured to sell vaccines.<sup>5</sup> Personally, I am convinced that most opponents have misunderstood the science and the risks associated with the disease and the vaccinations, but in many ways, it is impossible to simply dismiss their analysis of the politics: most of them are convinced that big tech thrives on extractive practices, governments carry out mass surveillance, and a preposterously wealthy elite gladly uses any crisis as an opportunity to make money. Even if their concrete assumptions about COVID-19 cannot be backed empirically, these are relatively valid political assertions and legitimate viewpoints (see also Jackson 2002a; Wynne 1992). Vaccine hesitancy, Goldenberg (2021) argues, should not be understood as the result of

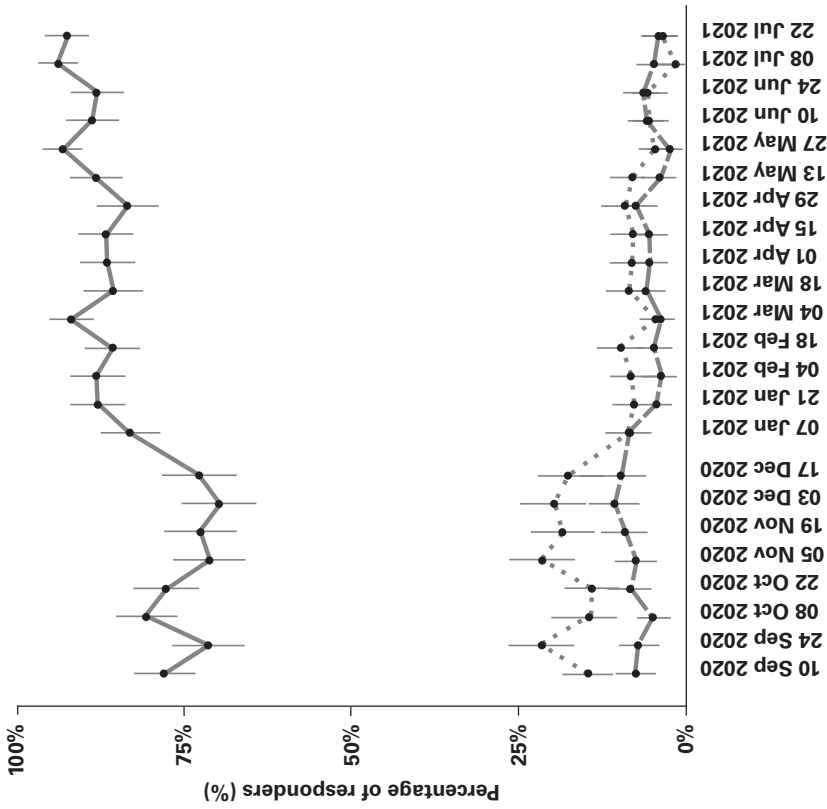


FIGURE 6.3

Graph of vaccination attitudes. Results from the survey after questions about interest in getting vaccinated were added: solid line means “yes,” dashed line “no,” and dotted line “not sure.” Willingness rose after the authorities decided to withdraw two vaccinations from the program due to risk of blood clots—that is, the VITT syndrome. (Credit: Tibor Varga.)

a knowledge deficit. Rather, it “is the result of unsuccessful science-public relations. The success of those relationships, like all relationships, hinges on trust” (17). Unlike me, many opponents have had experiences that dispose them toward mistrust of the government and the authorities. Now, to make space for themselves, people in this marginal position have to use data to justify their opposition.

Gradually, the sauceman demonstrations were replaced by more aggressive demonstrations led by an organization called Men in Black (Olsen 2021). An element of violence erupted from these events, which was moderate by international standards but it finally caused mainstream media to begin reporting on the opposition. While there were some at these events who claimed that the virus does not exist, others simply opposed the implicit values written into the data politics ruling their lives. Speakers at these events also opposed how mouth swab samples are stored and offered to researchers. They talk about how Denmark is on a route to becoming a surveillance state and a dictatorship. In this period, my husband, who is a schoolteacher, also observed how ordinary parents began opposing the testing of their children at schools because of its implied data sourcing.

When Sofie á Rogvi and I decided to interview some of the people producing the most popular data representations for the media, Piet from the National Broadcasting Company explained how the pandemic had given rise to reactions from readers like no previous topic ever had. He had had to respond to more than a thousand complaints and was surprised by the detail with which people argued their points. Line and Noah from TV2, the media corporation in Denmark that has had the most traffic on news about the pandemic, similarly told us about an unprecedented response from the public. Line and Noah were also the ones telling about people who monitor and comment on any deviance in official numbers based on their own Microsoft Excel spreadsheets (as I mentioned previously). Members of the public were also telling Line and Noah how important the daily figures had become for them. Piet compared these massive public reactions to the absence of response to news about a controversial impeachment trial of a former minister. The impeachment trial was big news politically and revolved around the illegal separation of refugee families. This is a very controversial topic indeed, but according to Piet there was virtually no public reaction to their news reporting:

It's difficult to get upset about [our reporting on] that [trial] because we say "some say this" and "others say that." But if we write "There were 1700 new cases of infection yesterday," then it opens up a discussion, because somebody can say, "Well, this American professor says that you can't measure it in this way" . . . It is quite simply easier to disagree with [data]. And everything has been on speed during coronavirus, also people's . . . misinformation. And there is some really, really thorough misinformation out there. . . . They provide so many numbers and they cross-reference each other.

It is indeed an interesting observation: controversial political topics are less controversial from a news perspective than a simple test figure based on the latest available health data.

The pandemic certainly gave rise to an explosion of "alternative facts" (Gruzd and Mai 2020; Islam, Sarkar, Hossain Khan et al. 2020), where those eager to find alternative analyses did so on international platforms. These platforms are designed to track people's interests and feed them what they want (Pariser 2011; van Dijck 2013). During the pandemic (as well as during the US presidential election in 2020), most platforms claimed to combat misinformation, but their very business model was to keep people connected to harvest their data (Crawford 2021; Zuboff 2019; Sadowski 2019b). It also implies that every time citizens *look* for information, they have to *provide* information about themselves and their interests. In this way, the data work goes full circle: when wanting to *use* data analyses, citizens *produce* data for big tech. Big tech then uses these data to feed people similar stories (Pariser 2011). As people, confused and distraught, are trying to make sense of the crisis, they are fueling the platform data economy.

The pandemic turned every citizen into a lay epidemiologist, but rather than establishing scientific authority, it opened up this authority for scrutiny. While the official data governance has sought to tighten societal control, it has simultaneously facilitated societal disintegration; and when official data interpretations are deemed meaningless, people have construed alternative stories using data. In this way, the paradoxes of data work have proliferated anew, no longer just in hospital wards, but in everyday life and among ordinary citizens.

## EXPERIENCE: CURVES, HEAT MAPS, AND THE PURSUIT OF MEANING

With all the new data-work-of-use, data experiences became a daily pastime. How did people experience the data? In his pre-COVID analysis of pandemic



preparedness, Caduff (2015) analyzes the many times a pandemic has been announced without materializing, noting that it takes a lot of work to create “the perception of an event as already in the process of happening even though it is yet to come” (62). Predictions convey probabilities. They can be wrong. For people to build their actions on scientific predictions of risk in a way that makes the suggested precautions meaningful, they have to trust the data used to make the argument—or, at least, the people presenting the data. As I just showed, not everybody did that. People are not like computers, which can be wired to use particular sources. Human beings make embodied, emotional decisions.

Homepages with virological visualizations have mushroomed,<sup>6</sup> and as citizens were bombarded with data, many began adding their own (Bowe, Simmons, and Mattern 2020). Data solidified their position as aesthetic objects expressing both danger and beauty (Carusi 2020). Throughout the pandemic, the paradox of dematerialization and rematerialization has played out, as the pandemic as an abstract phenomenon with no immediate presence or frame of experience has rematerialized through visualizations pored over on tablets, computers, and phones in people’s living rooms. Later, with a variant called omicron, many people experienced a light version of the disease that for some made the scare of the numbers appear alien and detached from their own experience. In 2020, when official numbers were still released each day at 2 p.m., Noah explained how they could see people began logging in from around 1:30 p.m., to get ready. TV2’s data on daily “views,” Noah said, reveal that “we have created a habit in people’s lives.” Line elaborated: “It’s without precedent . . . [Our COVID figures] have been viewed 190 million times. And we’re five million Danes. It is insane how many people there are who log on again and again and again and again . . . This number, it’s outrageous! You’ll find no parallels anywhere [in news history].” Noah adds: “Before coronavirus, the single story getting the most clicks had 1.3 million.” And those numbers were just website clicks (news can also be accessed through the app and other outlets).

In terms of shaping political choices, however, the most prominent data visualization was probably the graph with the red and green curves shown in figure 6.1. The two curves build on interpretations of different interventions in two states in the United States during the Spanish flu pandemic in 1918 (Wilson 2020; Strochlic and Champine 2020). The evidence behind the two curves has been questioned (Markel, Lipman, Navarro et al. 2007);

it is difficult to isolate intervention and effect, as discussed in chapter 5 and earlier in this chapter. However, the point is that rather than analyzing the evidential status of the curves, most people used them to *make sense* of the restrictions. How people experience data informs their path of action. When we interviewed Pernille the second time in October 2020, she reflected on the red-and-green curves, saying: “I found it really overwhelming. I thought ‘My God! Will so many people be infected?’ And I thought, we’d better act a little more carefully.” Pernille, who sanitized her groceries even before the pandemic, already was very careful. For her, the curves spoke to a sense of danger already present in her life. In January 2021, Jeppe (age 24) similarly mentioned the curves as being powerful, but in a less emotional register: “I thought it made really good sense. Really, I’m a math teacher, so I guess it was the math in it that made me think, ‘it is logical.’ There are these two options: it can look all wrong or all good. From a mathematical perspective.” In this quote, Jeppe does not analyze the underlying data, and he does not question the normative assumptions. For him, the curves seem to make the lockdown meaningful by conveying a sense of mathematical precision.

Sebastian (age 34) who was interviewed in October 2020, said: “I thought some really bright people must have made these graphs somewhere. And therefore I think that you have to trust them.” He did not find comfort in the mathematical simplicity of the curves as Jeppe did. Instead, he saw them as symbols of sophisticated work by clever people. For Sebastian, the curves were “signs” of science as much as science communication. He added that it was images from Italy of overburdened hospitals and rows of military vans with coffins that made the danger feel real: “When you see these scenes from Italy, then you think, okay, it probably makes sense to do something to stop this virus.” The same data representation, including the red-and-green curves, comes to make sense to people through different pathways of sense-making.

As I was reading the interview transcripts, I began realizing how I also read the daily COVID numbers in an emotional register. I could get worried looking at curves that take a bend regardless of the levels of infection, sometimes even ignoring my own analytical precautions about numbers that should not be compared. Apparently, I am no different than Torben and Flemming from chapter 5. Similar disregard for careful data analysis has unfolded when I have been communicating with friends in other

countries. In June 2021, for example, Sydney went into lockdown at the same time as Denmark was lifting restrictions—although the infection rates were higher per capita in Denmark than in Sydney. I could simultaneously sympathize with my friends in Sydney who worried about rising numbers and feel relieved about the much-higher Danish numbers that had at least stabilized. Even when we train ourselves to use data with analytical care, they work on many of us through an emotional register.

Data do not contain any clear message about what is the “right level” of risk. They gain power through human interpretation. Similarly, data cannot create trust on their own. As one data analyst remarked with a hint of humor, alluding to the data that he worked hard to communicate as truthfully as possible: “I only trust the numbers I myself have manipulated!” During the pandemic, I have noticed how people rarely lean on data alone when explaining their choices. They describe themselves as part of a community, using expressions such as “being in this together” and “we are all in the same boat” and speaking about their local communities or Denmark as a whole as “managing this pretty well.” Anders (age 54) said in November 2020 that he was proud of his local community, and he then confirmed his trust in the authorities and in particular the director of the Danish Health Authority, Søren Brostrøm, in this way:

If the health services and Søren Brostrøm says, “Just do it, God damn it,” then I do it. No doubt. He doesn’t tell me to do anything for his own sake. He’s telling me for my own sake. That’s how naïve I am (laughing) . . . When anybody says “Jump!” I just ask, “How high?” It has worked before for me.

Anders is not naïve, but he is convinced that he is better off following advice than trying to figure out for himself what to do. Beate (age 24), conversely, did not find any reason to trust the authorities. Sofie á Rogvi interviewed Beate because of her stated opposition to the government approach. Beate is one of the few who are convinced that it is all a conspiracy: “I believe 100 percent that coronavirus is planned. It is to, well, in a way, to decimate the weak, because they are too expensive for the rest of society. They are doing that.” Who “they” are is not clear in this quote, but that is partly her point: the people pulling the strings are hiding from view. Beate was also convinced that vaccines are introduced to “control people.” Just as Anders seemed to trust the authorities based on past experience, Beate did *not* trust them, also based on past experience. They both depended on communities of interpretation to make sense of the data. Both the opponents

and the supporters of governmental policies glean information from their communities of belonging—it is just different communities—and they do so based on their experiences of whom they trust to be on their side. People learn from people, not just data.

Governments are no different. A study of government responses to the pandemic showed that shifting policies did not build on data or new evidence, but rather on mimicking the responses of other governments: “In times of severe crisis, governments follow the lead of others and base their decisions on what other countries do” (Sebhatu, Wennberg, Arora-Jonsson, and Lindberg et al. 2020: 21201). When the Danish government decided to adopt a mask policy, it came just weeks after the authorities had released an analysis stating that there was no evidence of effect. As the government decided to follow the World Health Organization (WHO) and surrounding countries and impose masks, the authorities then released a new report based on practically the same studies as their previous report, but now saying that public masking might have a positive effect. Just like citizens, governments listen to people they respect, not to data alone.

I remarked previously that supporters and opponents were questioning the logic of government interpretations and restrictions in similar ways, though they differed in their willingness to obey the rules. Both sides articulated similar reflections when trying to make sense of the pandemic. Citizens use numbers to produce meaning, and they seek to make numbers meaningful. They do not only analyze death tolls and infections rates—they try to make sense of them in a normative way. This was obvious, for example, when we asked people in the interviews to reflect on “Why do you think we are in this situation?” Among the responses, several supporters of the government approach said things that were not that different from Beate, who saw coronavirus as a tool for decimating the weak. While Beate was just twenty-four and thought with horror about the decimation of the weak, the seventy-six-year-old Hanne, who supported the government’s approach, said:

There are . . . these people saying that we all need to be vaccinated, we should do this and that, because “people are not allowed to die.” But we’re all going to die at some point, God damn it, if the old ones—yes, I know I sound a bit cynical, but that’s my way of expressing myself—if the old ones are not allowed to die, where will you make space for the newborns? . . . We have had yellow fever, and the plague, and we have had—well, it’s not like I’m religious, but the Earth might need to clean out and make space once in a while.

For Beate, the pandemic was somebody's plan; for Hanne, it was nature's response. Similar to Hanne, Edith, at seventy-nine-years-old, said that the pandemic might be a way of ending meaningless life:

You can't help getting a little philosophical and ask, "Is it worth it?" It is this cynical assessment that pops up once in a while . . . I mean, I can't in good conscience say that anybody should purposefully be killed, but I could sometimes say that we should hold back on the preservation of life.

For Edith, the pandemic made sense as a way of making lives end in a society that kept old people alive at any price but offered them only biological life, not a life worth living. Other supporters of the government's approach saw in the pandemic a reason to question overpopulation, globalization, hygiene standards, and a wide range of political priorities. They do not understand the pandemic as just a matter of data analysis: they are trying to make sense of the changes around them in morally and politically embedded ways, and through the communities in which they see themselves as belonging. In line with the esteemed scholars with whom I began this chapter, they saw in the pandemic crisis a reason for rearticulating their opinions and used these opinions to make sense of the crisis. Žižek (2020) suggests that such longing for meaning is a mistake:

We should resist the temptation to treat the ongoing epidemic as something that has a deeper meaning: the cruel but just punishment of humanity for the ruthless exploitation of other forms of life on earth. If we search for such a hidden message, we remain premodern: we treat our universe as a partner in communication (14).

Still, human beings tend to search for meaning, and how they orient themselves in the world shapes the kind of spaces they come to inhabit. Just as we have never been modern, to paraphrase Latour (1993), we have never stopped being premodern, if premodern means longing for meaning. People are not computers; they are embodied and emotional beings trying to make sense of the world around them.

## WISDOM: PRIORITIES, PROTECTION, AND CAUTION

The pandemic also reinvigorated the key paradox of data as sources of knowledge: data clearly were used for drawing invalid conclusions, while the whole pandemic situation simultaneously appeared worse in countries with limited available data and no respect for data predictions. It takes competence and care to use data well. What, then, was the wise way to respond

to the viral threat? What was a wise use of data? Which countries took the right approach? Which losses, tragedies, and lives—or ways of life—count in such a calculation?

Answers to normative questions about who took the right approach cannot be data driven (Weible, Nohrstedt, Cairney et al. 2020). Data can, and in many cases should, inform assessments of relative merits, but they cannot settle questions about which goals that are worth pursuing. Furthermore, data are extremely difficult to interpret when making comparisons among different contexts. From the outset, the Danish governmental strategy focused on protecting the weak and vulnerable, at least rhetorically, but what type of weakness? Prime Minister Frederiksen focused on virological vulnerability when announcing the lockdown, but just weeks later, when commenting on how to open the country back up, she said that it was time to prioritize those harmed by the lockdown: people with mental illness, children in families with abuse, the homeless, and other vulnerable people (Outzen 2020). It was a different type of vulnerability—a different aspect of the pandemic. Even while talking about those negatively affected by the lockdown, she nevertheless insisted on prioritizing biological life more highly than social and economic life; in her words: “What is more important than anything else is to save as many lives as possible!” In a sense, it looks as if Agamben (1995, 2020) was right when seeing his thoughts about a reduction to “bare life” played out in relation to the pandemic. Still, I cannot see it as just an excuse for installing a state of exception. The prime minister had to choose priorities, and at least she was clear about them. Frederiksen furthermore complicated the notion of a reduction to “bare life” when she added that the real danger was actually not just the loss of lives, but the loss of faith in the institutions that we depend on to live our lives with a sense of basic security: “As a society, we simply cannot afford to let the institutions we otherwise trust break down” (quoted in Outzen 2020). Biological life here gives way to a form of collective life: trust in societal institutions as a common good. Whether she succeeded on that parameter remains difficult to ascertain (Petersen 2021).

As the pandemic has unfolded, however, it has become clear that collectives, in order to prioritize and care for some, exclude and ignore others. All around the world, governments have valued some lives more than others, as many refugees, sex workers, drug users, and others in marginal positions have come to realize (Outsideren 2020; Heissel 2020; WHO 2020; Faber and

Hansen 2020; Sørensen 2020). In the Global North, people in low-income jobs have been working throughout the pandemic in warehouses, delivery services, and as “self-employed” assistants in the platform economy, where they have had to face risks so that others could work safely from home. Meanwhile the platform owners have profited enormously from the boom in online trade (BBC News 2020). Measures to protect older people in privileged countries also involved the redistribution of risk globally. One report even suggested that as a consequence of changed economic conditions aimed at protecting older people in the Global North, the global child mortality rates would go up, in particular in the Global South (Robertson, Carter, Chou et al. 2020). In 2022, Oxfam released a report stating that, in the course of the pandemic,

the world’s 10 richest men have doubled their fortunes, while over 160 million people are projected to have been pushed into poverty. . . . The cost of the profound inequality we face is in human lives. As this paper shows, based on conservative estimates, inequality contributes to the deaths of at least 21,300 people each day (Ahmed 2022: 9)

It seems that at least some of the activists expressing mistrust of government restrictions got something right when sensing that the pandemic would benefit the elite at the expense of people like themselves. In Frank Snowden’s book about the history of epidemics, he succinctly observes that “every society produces its own specific vulnerabilities” (Snowden 2019b: 7), which any epidemic then exposes.

Measures to protect human life also implied a massive loss of animal life. Just in Denmark, a mass slaughter of mink took place in November 2020, when a mutation of SARS-CoV-2 became associated with mink farming (Hagemann-Nielsen 2020). Almost three times as many Danish minks as there are Danish citizens were culled and mostly buried in mass graves (admittedly, they were to be killed anyway, but not in this way). It brought an end to mink farming in Denmark, as the particular Danish Saga mink breed is now extinct, and it was carried out in such haste that no legal mandate was in place. In a world of viral entanglement, protection of human life also has implications for animals, and as Svendsen (2022) vividly argues: prioritization cuts across species and sacrifices some for the benefit of others. Data cannot tell you which dimensions to prioritize, nor can they delineate the collective that needs to choose priorities. It takes “Data Wisdom” to make such choices.

## PARADOXES OF PANDEMIC POLITICS

To sum up the lessons of COVID-19 for the politics of intensified data sourcing, it has stimulated a *data pandemic*, where data, just like the virus, have experienced exponential growth on a global scale. The pandemic fueled already-dominant data promises and put data integration, surveillance technologies, digitization, self-service, and home monitoring “on speed.” Again, data promises could claim benefits based on the hope of *future* evidence. In many cases, the pandemic implied abandoning even established norms of evidence without reflecting on what to put in its place (Hoffman 2020), as when several countries, including the United States, quickly decided to lower the evidence threshold for new treatments to speed up any mitigating options (Meyer 2020). Many researchers began to base conclusions on preprints rather than wait for peer-reviewed papers. Nevertheless, in Denmark the pandemic also illustrated the benefits of highly integrated data infrastructures (Pottegård, Bruun Kristensen, Reilev et al. 2020). The existing digital options for communication, furthermore, made the transition to healthcare at a distance much more seamless than in many other wealthy and technologically advanced countries. I think it is also evident, even though the global pandemic is not over as I am writing this, that data—and data predictions—have helped save lives.

The pandemic widened the scope of data living and instigated a boom in data work. Looking at data representations became a daily occupation for most citizens. Looking at data is an embodied act, not just an analytical achievement. Although examining more or less the same graphs, people had remarkably different data experiences. The pandemic also made many more citizens realize that their samples and health data *are* being reused, and it is now obvious that not everybody agrees with this reuse—not even in Denmark. Many citizens gained a new data literacy and suddenly understood terms such as “false positive tests” and “R-number,” but for many, this increased data literacy also provided more awareness of how difficult it is to interpret data. Data do not speak for themselves after all. It might have changed the future conditions for data politics: a more general awareness seems to be emerging around data as carriers of values and priorities.

In the previous chapters, building mostly on fieldwork conducted prior to the pandemic, I have emphasized how data can be used to close political conflicts or depoliticize decisions. Now, I have realized how the public data



spectacle also opened up political conflicts. Many supporters of the government would question the same issues as opponents and still see opposition as “irrational.” For those disagreeing with the moral and political values shaping the government approach, however, data became the hook on which to hang their complaints. In paradoxical ways, *data simultaneously close down and open up political contestation*. The undetermined space of data probability can end up being filled with moral certainty. The window of epistemic doubt is closed with political and moral stances as people decide who to trust, which community to join.

It is dangerous when societies fall into antagonistic camps of people unable to communicate because they subscribe to different “facts” or different communities of fact-making. If the authorities wish to establish a conversation with an increasingly hostile opposition, it is probably not useful to maintain that opponents *simply* misunderstand the data, even when they do. Policymakers and researchers must be willing to discuss the valuations shaping their own data analyses, as also suggested by Oreskes (2019) in relation to other data conflicts. Without honesty about values and political priorities, data can unleash violent and divisive forces. Here might rest a more general lesson for data politics. Bickerton and Accetti (2021) talk about *technopopulism* as a type of governance that presents itself as a simple technical solution to the management of state affairs. It is “populist” because it claims to govern for *the* people as a singular entity with one set of interests. In technopopulist regimes, those in office present themselves as the clever interpreters of data. Data, however, never serve all citizens equally well. Any data analysis involves priorities. To use data wisely, therefore, is also to dare to reflect on—and articulate—the priorities shaping the analyses and to open up these priorities for political debate. The political scientist Anna Durnová (2019) similarly suggests that for science to retain legitimacy in politics, scientists must refrain from claiming neutrality. We must all acknowledge the normative—and even emotional—aspects of various data analyses, exactly because “public debates on science mediate values and beliefs through emotional appeals” (Durnová 2019: 46). Human beings do not simply compute data messages; they engage them with a meaning-seeking and emotional intent. Their embrace of data also depends on their relationship to those who produce the data representations. Among those who reject certain data, we find many people with the experiences of not being heard, not being cared for, and not sharing a vision of the Good Life

with those in power. They do not feel respected. When, conversely, people experience institutions as embodying care and respect, they are more likely to accept the data that these institutions use to do their job (Taylor 2020).

My own work is also informed by norms, of course, and I should be honest about them. They revolve around solidarity, justice, and mutual recognition, as I will explain when I turn to the ethics of intensified data sourcing in the conclusion. Humans (and nonhuman forms of life) are so fully and utterly entangled that it is necessary to build communities in which we can live together, even when wanting to live different lives. A virus knows no borders. It does not acknowledge race, gender, or class. Some forms of virus even move between species. It is the ways in which we erect borders and differentiate—based on parameters such as race, gender, and class—that shape the forms of suffering that a virus eventually instigates. We need social institutions that are able to care for all if we are to respond to viral threats in ways in which everybody is willing to join the fight. This is a normative point, and as I sum up my overall argument next, I elucidate how I think that a more explicitly normative approach to data politics can help conserve the benefits of intensified data sourcing and reduce the risks.

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# Data Paradoxes

## The Politics of Intensified Data Sourcing in Contemporary Healthcare

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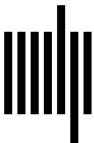
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