

NOTES

INTRODUCTION

1. Many will recognize the voices of people like Eric Topol (a cardiologist and scientists known for his bestselling books about the future of healthcare) or Leroy Hood (a biologist and scientists known for his ambitions for a type of medicine, which is predictive, preventive, personalized and participatory) filtering through these promises (Hood and Flores 2012; Hood et al 2015; Topol 2010, 2015). I nevertheless leave them without references here because this is how they typically appear: as facts in no need of a reference.

2. Interestingly, the Danish word for “computer science” is *datalogi* (the study of data). The word *datalogi* was invented in 1966 by Peter Nauer and is today used in the Nordic languages, whereas Anglophone speakers say “computer science.” The term “computer science” puts semantic emphasis on the hardware, whereas the French *informatique* and the German *Informatik* slither toward software, though they do not focus on data in the same way, as a basic unit of computation.

3. The image of the Internet as a global arena for free speech is becoming increasingly difficult to uphold as online communication is increasingly subjected to censorship and an increasing number of Internet lockdowns (Freedom House 2021). There is no longer *one* Internet (if there ever even was such a thing), but multiple Internets subject to different types of control and censorship. Furthermore, concomitantly with the rise of promises of a “data-driven” future, venture capitalists very far from Barlow’s old counterculture have become deeply entangled in the economic structures of Silicon Valley. Some of them are affiliated with the most conservative political forces in the United States. They also subscribe to a future beyond the grip of the state, but for them, it means beyond taxation and beyond democratic control (Chafkin 2021).

4. Since Mol’s important work has been subject to diverse receptions, it is probably better to clarify the nature of my argument. I suggest that multiple uses of the

same data turn these data into particular types of semantico-material actors: they do different things in different organizational practices (simultaneously or over time). Unlike the reception of Mol that emphasizes multiplicity as a basic ontological condition relevant for basically all phenomena, I thus point to a shift in the work that data come to do in healthcare organizations. My intention is not to criticize the more general reflections on ontological multiplicity. Indeed, you could say data have always been multiple, just as any other phenomenon can be claimed to be so. However, as a consequence of current political and organizational processes in healthcare, we see a shift in the agential properties of data whereby the ontological multiplicity acquires a different political salience in need of our attention.

5. I draw on a range of very different materials, including personal experiences as citizen and patient, informal professional encounters, interviews, and participant observation, as well as media and policy representations. These materials call for different ethical and methodological reflections. When I refer to named persons in media stories, I use the name occurring in the story or report for the sake of transparency (full names for people in official roles and first names only for citizens and patients). I provide pseudonyms for people whom I interviewed. For some, anonymity has been paramount, and they have asked to appear under a different gender, have no name given, or both, so that it is harder to combine different quotes and potentially reidentify them. I have translated Danish into English from both written and oral sources, discussing difficult passages with colleagues and the language editor Julie Dyson.

CHAPTER 1

1. Promises also shape the business opportunities for health tech companies outside the governmental sector (Fiore-Gartland and Neff 2016). In a particularly conspicuous scandal, a woman named Elizabeth Holmes managed to raise nine billion US dollars for a company called Theranos by promising to deliver omnipotent diagnostics with new data-intensive technology—but it turned out that there was no such technology (Hartmans and Leskin 2020). It was just a promise. Other companies have raised venture capital by claiming to develop sophisticated artificial intelligence (AI) but actually employing poorly paid people in India to do the work more or less manually (Statt 2019). This type of politics operates in a realm of potentiality (Taussig, Hoeyer, and Helmreich 2013). Companies and policymakers imbue data with potential; a potential for future certainty. They do not, however, impose the criteria of evidence on the quest of data per se.

2. This means that the international ICD-10 manual specifies a taxonomy of disease that is adopted into a national classification system, making it possible to use a code to describe a hospital visit. In ICD-10, for example, there is a broad range of codes (M00–M99) for diseases of the musculoskeletal system and connective tissue, and under them, M15–M19 is used for “arthrosis,” M13 for “other arthritis,” and M15–M19 for “osteoarthritis.” In Danish coding, there will be a “D” in front of the code

to signal that the code refers to “diagnostics.” There are other overarching coding letters referring to different types of codes, signaling either administrative information (A), type of treatment (B, E, K, N, U, W), or pharmaceutical information (M). A code can have a maximum of ten digits. It nevertheless creates a complex coding language with many thousands of codes. The code DM138A, for example, means that it is a disease (D) and arthritis (M13) and a subcategory of “other arthritis” related to allergy (8A). Other codes describe which services has been delivered and where. It has become a specialist competence to read such codes, not least since they change over time.

3. The fact that digitalization enhances traceability, and thereby interacts with litigation practices, has been part of the history of digital communication practices from very early on. A US white paper from 1997 says about e-mail: “In contrast with telephone conversations, e-mail is self-documenting: Copies of e-mail can be printed or attached to the patient’s electronic record. Finally, since many malpractice claims can be traced to faulty communication, good communication is part of good insurance” (Kane and Sands 1997: 105).

4. The only person I have encountered who has considered whether data are worth the investment was Jens, a strategy developer. He had wanted to measure whether his data governance tools had any effect, but his boss responded that measurements were for documenting the achievement of political goals, not to evaluate administrative tools. The Deloitte report mentioned in this chapter is another exception. It states, however, that it cannot determine the cost of data production because there is no written agreement on data standards (a so-called service-level agreement) on which to base the calculation.

5. Danish GPs were using a piece of software that was generally seen as very helpful for generating an overview of patients, but it relied on pooling, and after a conflict about how the data began being reused for purposes that many GPs disagreed with, it was discovered that the pooling was unlawful. The database—which was, in an uncanny premonitory way, entitled DAMD—turned out to be damned. It had to be deleted. This case illustrates the need for engaging the political, legal, and social dynamics of data integration, not just the technical facilitation of data (Langhoff, Amstrup, Mørck, and Bjørn 2018; Wadmann and Hoeyer 2018).

CHAPTER 2

1. Henriette Langstrup has kindly agreed to let me reuse elements of this conversation and our shared work, which has previously appeared in a coauthored chapter in a book on patient activism edited by Susi Geiger (Hoeyer and Langstrup 2021).

2. The investigative journalist Adam Tanner refers to something he terms the “data paradox” in American medicine: “Our health-care system gives us little of what we want and need—easy access to our comprehensive medical records to help professionals with our treatment. But it has also given us much of what we fear—others

trafficking our records” (Tanner 2017: 37). It may sound similar, but as will become clear, I do not claim that the same is taking place in Denmark. Instead, data are pooled primarily to facilitate governance, and this takes place within the remits of the public healthcare system, not through commercial data sales. The ambition of turning health data into assets that can fuel the economy remains a policy “promise” more than an actual motor explaining who or what accesses Lone’s data.

3. Besides high-tech practices such as genomic medicine, P4 medicine translates into more mundane invitations to self-care. One example is a 2014 government health policy program called “The Sooner the Better” (*Da; Jo før, jo bedre*) (Regeringen 2014) with an “investment” of 5 billion DKK in the period 2015–2018. This suggested that GPs should be given data tools so they can profile their patients and discuss lifestyle issues with high-risk individuals. Most researchers working with prevention consider preventive consultations to have only limited effect (Jørgensen and Brunak 2014; Hollands et al., 2016). The majority of citizens targeted in this manner suffer from complex combinations of social inequalities rather than a lack of medical advice on what to eat or how to exercise (Marmot et al., 2010). Still, data-intensive care can make some patients visible in new ways while covering up the problems that these patients are actually dealing with. Data uncover and cover up.

4. I leave aside the usual arena for debates about data trouble—the commercial platforms. Again, my interests revolve around intensified data sourcing in healthcare systems and welfare services. On commercial platforms, the price for a seamless user experience is your data (van Dijck, Poell, and De Wall 2018). Those data are occasionally used against your interests, and sometimes you are cornered by harmful and misguided profiling (Pasquale 2015; Ebeling 2016; Goriunova 2019; O’Neil 2016). In that sense, they represent a parallel paradox: seamlessness empowers the user experience and disempowers citizen rights.

5. The Danish healthcare sector is not simply “tax-financed.” Officially, approximately 80 percent of the health expenses are paid by taxes, although it can be debated what counts as “total expenses.” Intricate systems of partial out-of-pocket payment operate for dentists, pharmacy bills, psychologists, and other items and services. The welfare state ambition implies that systems are put in place to adjust for social inequality in relation to out-of-pocket payments (e.g., subsidies to low-income households), and these systems add to data demands to ensure that the right citizens get the right subsidies. Around 35 percent of citizens also have employer-paid health insurance giving access to various forms of private health promotion and/or private hospitals ahead of the public waiting list. Another 40 percent have a form of private insurance to cover part of the out-of-pocket payment simply called *danmark* (the country name, but noncapitalized), which is a membership association aimed at equaling out peaks in expenditure for the individual (Clausen 2020). Many have both types of insurance. Of course, each of these numbers could be questioned. Still, the type of health promotion allowed by insurance companies, where activity trackers become mandatory—a system that is becoming more prominent in countries

like the United States and Switzerland—remains rare in Denmark (Martani, Shaw, and Elger 2019).

6. GPs, as well as many specialists (such as neurologists or ophthalmologists), are typically run as private businesses, although citizens seldom realize this because their bills are paid by the regions and municipalities they live in. Their prices and terms of services are negotiated between the Regions and the unions of the specialists in collective agreements. It is also through these agreements that GPs and specialists become obliged to use electronic patient records and convey information for national registries and other data infrastructures.

7. Statistics Denmark (similar to Statistics Sweden, Statistics Norway, and Statistics Finland) provides platforms for researchers and administrators to combine data sets across sectors and explore correlations in a logged and controlled environment.

8. As of October 30, 2020, 6,680 people were registered not to have their blood and tissue samples used for research purposes, and 3,062 registered that they did not want their genome information used. Following debates about the storage of COVID-19 samples, the number of those opting out increased so that by June 2022, 12,022 had registered to avoid having their blood and tissue reused, and 7,773 to avoid having genomic data used for research (see chapter 6).

9. The private sector is thoroughly digitized too, building on the public data infrastructure. In the 1960s, the Nordic banks were already collaborating with public authorities on the digitization of the financial sector. A computerized billing method was introduced in 1968 in Denmark, and in updated formats today, it ensures an almost fully digitized billing system. In 1983, a national credit card (Dankort) introduced digital payments, and Denmark quickly had the highest number of digital payments in the world. It operates with no fee, in contrast to VISA and Mastercard. In 2000, a national digital postal service system called E-Boks was invented. It operates as a company, but on a public legal mandate: in 2005, state authorities decided to use E-Boks to correspond with all public employees, and in 2012, a law made it the default means of communication between the state and all citizens. As a consequence, surface mail is such a rarity that hospitals and GPs can no longer rely on it for sending tissue samples as they once did. In a further move toward pervasive digitalization, in 2010, a national secure access and multifactor identity system called EasyID (*Da; NemID*) was developed by a consortium of companies in response to a public tender request. It is currently replaced by an updated version called MyId (*MitID*). Today, it is used by both authorities and commercial service providers. It is yet another setup that the European Union is considering implementing across the whole union in modified forms (European Commission 2020b).

10. I asked my gym why, and though the man at the counter was at first a little annoyed by the folly of such a stupid question, he kindly asked around. He found out that it was because “their systems were set up in that way.” As I probed further, I was told that it was easier for them to always update people’s addresses from the Civil

Registration System (known simply as CPR) than maintaining their own registrations manually. In consequence, those without a CPR number cannot go to the gym.

11. When a nongovernmental organization (NGO) started a clinic for people without a CPR number on the island of Funen, they were approached by approximately seventy unregistered migrants a year (DR Nyheder 2019b). This will seem to most people like a small number, and that is part of what causes the misery: it is indeed small, small enough for organizational interfaces to assume that *everybody* has a number. There are procedures for tourists and others passing through the country who can have an artificial number if visiting a hospital, but those rules do not apply to people who are not supposed to be in the country.

CHAPTER 3

1. As explained in the introduction, people from published sources are identified with their real names, interviewed persons with pseudonyms, and some, at their request, anonymously.

2. A similar name is used in Norway, Helseplattformen, and in Finland, Epic has sold an integrated social care and healthcare system and given it the name Apotti. The company also has customers in the Netherlands, but otherwise it mainly operates in the United States at the time of writing.

3. Part of this analysis has been published in an article coauthored by Sarah Wadmann (Hoeyer and Wadmann 2020). I am grateful for our discussions and her permission to allow me to reuse elements here. Besides analyzing policy documents, Sarah and I interviewed sixty-nine persons: five working on developing the frameworks for data collection at the state level; at the regional level, thirteen data analysts, along with five other people, working with data integration tasks; three hospital managers; four clinical department managers; four staff nurses at hospitals; one hospital-based quality manager; three nurses subspecializing as quality coordinators working in hospital departments; twenty-two physicians working in hospitals and general practice; eight hospital-employed nurses; three hospital secretaries; and three audit workers. Wadmann also undertook four days of observation on two different wards and one day of observation of a management seminar. See also (Wadmann et al. 2018; Holm-Petersen, Wadmann, and Andersen 2015).

4. For example, Google's DeepMind algorithms are touted to be able to warn physicians of acute kidney injury (Tomašev, Glorot, Rae et al. 2019). Danish emergency calls are monitored with artificial intelligence (AI) designed to alert doctors of the risk of cardiac arrest based on patterns in previous calls, including speech pace and judder (Blomberg, Folke, Ersbøll et al. 2019, see also chapter 5). Such tools use data from other patients to make predictions that operate in real time and react to data produced with new patients.

5. The management, at least, has remained positive and optimistic. Promises persevere. Despite problems with patient safety, staff burnout, lost efficiency, and

data that remain stuck in the system, the Capital Region announced in 2017 that the introduction had been “satisfactory” (Højer and Flach 2017). A national audit concluded that the administration had failed in its implementation, it had omitted necessary tests, and the system had caused a serious reduction in efficiency and productivity (Statsrevisorerne og Rigsrevisionen 2018). Still, the administration decided to grant a bonus of 100,000 DKK to the director for the implementation (Larsen and Nielsen 2018). The administration points to consultancy reports and surveys that they interpret as proof that the system is better than its rumor (Hildebrandt 2017c).

6. Some science and technology studies (STS) scholars have discussed this type of dialogue as a productive type of “data friction” where new hybrid insights are produced (Bonde, Bossen, and Danholt 2019; Edwards, Mayernik, Batcheller et al. 2011). My point here is primarily that the friction generates extra (but invisible) work for the clinicians (Boyce 2016).

7. A particular case has fueled these concerns. A doctor was taken to court for a prescription that was, according to the doctor, given verbally due to high work pressure. The medicine was never given to the patient, with fatal consequences. The doctor could not prove the verbal prescription, and it escalated the debate about the need to prioritize “covering one’s ass” over organizational solidarity when under pressure (Folkmann 2017; L. Lange 2017; Nathan 2017; Redaktionen 2018).

8. An edict often referred to as “Campbell’s Law” states: “The more any quantitative social indicator is used for social decision-making, the more subject it will be to corruption pressures and the more apt it will be to distort and corrupt the social processes it is intended to monitor” (Campbell, 1979: 85). In Donald Campbell’s framing, the power dynamics relate to people trying to optimize their own position and income. This is probably true, but it is only one element of the story, as my focus on the pursuit of meaning suggests.

CHAPTER 4

1. I looked up the legal framework at home and found a regulation of the business area from 1994 stating an obligation to keep records. It does not mention using the CPR number for record keeping (Sundheds-og Ældreministeriet 1994).

2. I have, of course, done many other things. The data infrastructures I set out to study are funded, regulated, and sustained by organizations that document their decisions and actions. Taking an ethnographic response to documents (as in Riles 2006), I therefore traced policy papers, budget agreements, legal documents, and guidelines. Hundreds of policy papers, copies of internal memos, distributed slides, and even video presentations on YouTube and elsewhere have made it into my archive. Along with analyzing documents, I have participated in conferences, meetings, workshops, and public hearings. Based on all of these sources, I have identified actors for interviews, and through these interviews, I found other papers and

additional actors with whom I needed to engage in order to understand the workings of Danish health data infrastructures.

3. A significant amount of work has been done on the topic of “numeracy” by scholars with a behavioral approach coming from, among other disciplines, psychology (Nelson, Reyna, Fagerlin et al. 2008). This is a strand of work with a lot of merit in explaining how difficult it is for some people to use numerical data when making decisions. Still, I have deliberately not drawn upon numeracy here because I do not share the ambition in this literature of finding an instrument with which to measure the size of the “deficit in understanding.” I wish to focus on what people *do* understand, and how they do it.

4. I have been inspired by the Chatham House Rules for meetings (www.chathamhouse.org), where participants in meetings can use the information provided, but they cannot reveal the identity of speakers and other participants. It has rarely been relevant—or possible—to go back and ask for informed consent to use concrete examples, but the point has not been to cite a particular colleague for anything, but rather to let everyday encounters inform my understanding of the link between what Mills (2000 [1959]) called personal trouble and societal issues (8). It would be against my sense of research integrity to ignore what I know as a person when writing up my analyses as a researcher. It does not matter how I came to know something. I therefore draw on every experience, including at meetings, but avoid conveying anything that could expose people who have not agreed to participate in my research.

CHAPTER 5

1. The eight goals are (1) integrated patient pathways, (2) better care for chronic patients and older people, (3) improved survival and safety, (4) high quality of treatment, (5) quick access to diagnosis and treatment, (6) improved patient empowerment, (7) more health-adjusted years of life, and (8) a more efficient healthcare system (Sundheds- og Ældreministeriet, KL, and Danske Regioner 2018).

2. Several times, I have heard researchers complain about receiving different data on the same phenomenon when requesting them from different sources. Data are no better than the infrastructures through which they are collected. If some systems do not report to certain databases, the data will have gaps, but people will not always know that because they see only the data that make it all the way through to the interface in which they work. See also Hjertholm, Flarup, Mahncke Guldbrandt, and Vedsted (2017).

3. Case-mix is developed in health economics and helps with adjusting for variance in the population compositions between various areas. It is time consuming to apply case-mix, and it makes the numbers less straightforward to understand because they are presented as weighted figures. When doctors once complained in a letter to the editor in a medical journal about naive data uses that ignore the importance of case-mix (Krasnik 2021), the regional quality agency replied that they did in fact produce

annual reports with case-mix figures (Jensen, Settnes, Lund Jensen et al. 2021). These annual reports, however, do not feed into everyday performance management. Speed and accuracy are not always compatible, and when data need to serve many competing purposes, and in “real time,” no standard will fit them all (Winthereik 2004).

4. The conditions for access to psychological therapy have been changed several times, and in 2020, depression and anxiety gave direct access to psychologists on the public purse. However, this again necessitated a commitment to a diagnosis. Apparently, there is no such thing as a free chat. Experiments with digital access to therapy is hoped by some to help solve this problem, as patients can approach the psychiatrist directly without referral.

5. Muller (2018) suggests the following types of error: measuring the most easily measurable; measuring the simple when the desired outcome is complex; measuring inputs rather than outcomes; degrading information quality through standardization; gaming through creaming; improving numbers by lowering standards; improving numbers through omission or distortion of data; and cheating (23–25).

6. Data quality in registries, for example, is assessed in terms of “validity and completeness” (Schmidt, Schmidt, Sandegaard et al. 2019), “completeness, inaccuracy, ambiguity” (Laudon 1986: 137–138); “completeness, accuracy and comparability” (Chan, Fowles, and Weiner 2010); or “completeness, correctness, concordance, plausibility, and currency” (Weiskopf and Weng 2012). Quality is typically assessed by comparing data sources (White 1999)—data against data.

CHAPTER 6

1. Even when going into the individual death certificates, doubts only proliferate. In many cases, the “real” source of death cannot be known. Counting the dead is not as easy as it sounds (Kielgast, Hecklen, and Møller 2021).

2. See, for example, a project run by psychologists (<https://ku-corona-diary.netlify.app/2020/04/07/what-are-all-the-people-doing/>) and one run by political scientists (<https://hope-project.au.dk/>).

3. In Denmark, 600 people had received two doses of the vaccine and 150,000 the first dose at the time when the vaccinations were halted. The European Medicines Agency (EMA) acknowledged vaccine-induced thrombotic thrombocytopenia (VITT) syndrome, but it continued recommending vaccine use because it asserted that the overall death rates in society could be reduced with continued vaccinations. In Denmark, the authorities decided that people at risk for VITT would not face similar dangers to their own health from COVID-19, so they withdrew vaccines associated with VITT from the official program.

4. The Johnson & Johnson vaccine was later offered in a parallel program for voluntary use for people wishing to get a vaccination before it was their turn in the mass program.

5. As with the doubts articulated by Mathias, many people turned out to be less clear-cut in their stance on vaccines. The vaccination rate in December 2021, before children below twelve years could get the vaccine, was 77 percent, and in January 2022, when children above five years were included in the program, the rate was 82 percent. At the same time, however, only 60 percent of the population had opted for the third booster shot.

6. See, for example, COVID-19 Dashboard by the Center for Systems Science and Engineering at Johns Hopkins University, <https://gisanddata.maps.arcgis.com/apps/opsdashboard/index.html#/bda7594740fd40299423467b48e9ecf6>; <https://www.worldometers.info/coronavirus/>; <https://ncov2019.live/>; <https://nextstrain.org/>; and “Tracking Coronavirus COVID-19,” <https://app.developer.here.com/coronavirus/> (accessed July 10, 2021).

CONCLUSION

1. Data security is immensely important, and presumably something is still lacking in the case of Denmark. In 2022, a governmental report found that the Danish Health Data Authority met only fourteen of twenty defined security standards for public authorities (Statsrevisorerne 2022). While clearly more care is needed here, my point is that such standards do little to solve the social and ethical challenges with intensified data sourcing.

2. I do not mean to suggest that individuals hold *no* responsibility for their actions, or that responsibility is not important. New technologies typically interact with responsibility in important ways (Schicktanz and Raz 2012). The question is what responsibility implies. Schicktanz and Schweda (2012) point out that when carefully analyzed, relations of responsibility are much more defined and restricted. Responsibility typically has seven dimensions (or *relata*, as they put it): “Someone (*subject*) is in a particular time frame (*time*) retrospectively/prospectively (*temporal direction*) responsible for something/someone (*object*) against someone (norm-proofing *instance*) on the basis of certain normative standards (*standard*) with certain sanctions or rewards (*consequences*)” (133, italics in the original). This is altogether different from expecting individual citizens to behave wisely.

3. In this section I use the term informed consent to cover various concepts figuring in laws regulating research, healthcare and data protection, though GDPR for example only uses the term “consent”. There are important legal differences between the various regulations and remaining elements of confusion (Dove and Chen 2020; Gefenas, Lekstutiene, Lukaseviciene et al 2021). My argument is not a legal one, however, but aimed at the thinking around individual responsibility embedded in the concept.

4. When this book was submitted to the publisher the European Union had not yet adopted the Digital Service Market Act which takes timid steps in this direction.

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Data Paradoxes

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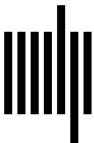
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