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Lost and Found: Relocating the Individual in the Age of Intensified Data Sourcing in European Healthcare

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Abstract:

Both inside and outside the health services, patients and healthy citizens give rise to increasing amounts of health data. They are created, collected, curated, stored and used for multiple purposes in a process I characterise as intensified data sourcing. This data intensification changes how we deal with health issues. In this chapter I reflect on similarities and differences between data flows mediated by public and private institutions, using Denmark as my primary example. Denmark in interesting ways prescribes a form of solidarity that might be associated with We Medicine: people deliver data in the process of receiving, or in exchange for, publicly financed healthcare; and the data can be used for research for the common good. The solidarity of the model is currently being challenged in various ways, however, as authorities circumvent the voluntariness of participation and begin seeing health data as business opportunities. Simultaneously, a private market in health data is emerging mediated by privately owned platforms. The chapter compares the public and commercial forms of data sourcing to explore what is at stake for individuals and society in those processes.

Introduction

Places with intense human traffic, such as train stations and airports, often have an office for the lost and found. Ideally, a lost and found office reconnects people with the objects they might lose in the course of their journey. To achieve the purpose somebody has to find the lost object – it must be handed in at the office, catalogued, and thus be made available for retrieval. Lost and found offices can be fascinating places. Like Simmel's famous figure of 'the stranger'[1], they are products of modernity's complex forms of social organisation and mobility. Simmel notes that a 'stranger' unites what is far away in a social sense with that which is near in a physical sense, and that the 'stranger' is both an outsider to a social group, while concomitantly being granted a social position,

[1] G. Simmel, The Stranger. In K. Wolff, ed., *The Sociology of Georg Simmel*(New York: Free Press, 1950), pp. 402-408.

that of *stranger* that is, thanks to the group. In lost and found offices, things act as strangers, and strange things happen. Sometimes what is 'lost' was never meant to be retrieved, it was lost on purpose, and sometimes it is retrieved by others than the original owner. The passage from being lost to being found can redefine an object; make it into something else for somebody else[2]. Even when returned to the original owner, an object can acquire new meaning and significance after having been lost.

This chapter is about being lost and found in new places of intense traffic: the digital infrastructure for health data. It is about the passage from individual data to population data, where the interests of individuals are lost, as it were, and how these data can be used to create personalised advice which is applied to individuals. A new 'owner' is found. Health data can operate as 'strangers' in the sense that users of data can experience physical nearness to data subjects despite social distance. Sometimes a researcher will know things about an individual that not even close relatives would know; but still not know the individual as an actual person. As data change hands, they potentially change meaning and function, much like the stuff in the lost and found office. Health data always relate in some way to individuals and, in the end, the various uses of this data are supposed to benefit individuals, one way or another. Benefits are never guaranteed, however, and the routes to potential benefit are many and not always easily understood. As data uses multiply, data come to live more promiscuous lives.

As laid out in the introduction to this book, Dickenson suggests a distinction between We Medicine and Me Medicine to interrogate contemporary developments in healthcare[3]. With We Medicine, Dickenson refers to the publicly organised delivery of healthcare that takes solidarity as its primary starting point, while Me Medicine begins in the individual and transforms collective challenges to individual opportunities and risks. Using this distinction, this chapter explores how the on-going data intensification relates to this spectrum of Me Medicine and We Medicine. How do public and commercial forms of data sourcing operate? What counts as collective and individual risk and benefit? How do the public and the private forms of data sourcing compare? What are the

[2] K. Hetherington, 'Secondhandedness: consumption, disposal, and absent presence', (2004), *Environment and Planning D: Society and Spaces* 22, 157-173.

[3] D. Dickenson, A reality check for personalized medicine. In D. Dickenson, *Me medicine vs. We medicine: Reclaiming Biotechnology for the Common Good*(New York: Columbia University Press, 2013), pp.1-6.

stakes for individuals in those processes? What are the interests of society? How do the two relate? Who are lost and what is found? What is lost, and who are found?

Data sourcing and use in Denmark

Health data are collected, stored and exchanged all over the world, but the ways in which this happens differ according to place and the political, economic and social norms and material infrastructures of different healthcare systems. The Nordic healthcare systems deliver universal access and they are primarily financed through taxes. In the following discussion of infrastructures for data, I will take most of my examples from one Nordic country, Denmark, where public collection and use of health data is pervasive[4]. Thanks to the use of personal identity numbers in all encounters with public services, Danish health data can be combined with data on socio-economic and educational status from employers and tax authorities[5] [6]. The other Nordic countries have similar elaborate register infrastructures[7], but Denmark has taken what can be seen as a more radical

[4] M.K Saunders, 'In Denmark, Big Data Goes To Work', (2014), *Health Affairs* 33(7), 1245.

[5] L. C. Thygesen and A.K. Ersbøll, 'Danish population-based registers for public health and health-related welfare research: Introduction to the supplement', (2011), *Scandinavian Journal of Public Health*, 39(Suppl 7), 8-10; L. C Thygesen and A.K. Ersbøll, 'When the entire population is the sample: strengths and limitations in register-based epidemiology', (2014), *European Journal of Epidemiology* 29(8), 551-558

[6] The registers are regularly validated (M. Schmidt, SA. Schmidt, JL. Sandegaard et.al., 'The Danish National Patient Registry: a review of content, data quality, and research potential', (2015), *Clinical Epidemology* 7, 449-489) and they are primarily used for epidemiological research designs where the ability to control how the diseased compare to a background population implies that many of the criticisms raised against new Big Data methodologies (e.g. D. Boyd and K. Crawford, 'Critical questions for big data: Provocations for a cultural, technological, and scholarly phenomenon', (2012), *Information, Communication & Society*, 15(5), 662-679) and poor administrative and clinical data systems in other countries are not particularly relevant (e.g. M. S. Lauer, E.H. Blackstone, J.B. Young and E.J. Topol, 'Cause of Death in Clinical Research', (1999), *Journal of the American College of Cardiology*, 34(3), 618-620; L. Li and P.M. Rothwell, 'Biases in detection of apparent "weekend effect" on outcome with administrative coding data: population based study of stroke', (2016), *BMJ*, 353 1-9; D.M. Maslove, J.A. Dubin, A. Shrivats and J. Lee, 'Erros, Omissions, and Outliers in Hourly Vital Signs Measurements in Intensive Care', (2016), *Critical Care Medicine*, 44, e1021-e1030). The special status of the Nordic health data can be illustrated for example with the fact that when the (public) American Food and Drug Administration approved the (private) company Merck's vaccine for Human Papillomavirus, it was on the condition that they would use the (publically sanctioned but privately run) Nordic registers to follow up on long-term vaccine outcomes (Food and Drug Administration. *June 8, 2006 Approval Letter - Human Papillomavirus Quadrivalent (Types 6, 11, 16, 18) Vaccine, Recombinant*. Rockville, USA: Department of Health and Human Services, 2006).

[7] A. Cool, 'Detaching data from the state: Biobanking and building Big Data in Sweden', (2015), *BioSocieties* 11(3), 277-295.

approach to research facilitation than the other Nordic countries by allowing data to be used without consent[8] [9].

The remarkable opportunities for population-based research in Denmark have regularly been discussed in, for example, the journal *Science*, describing the whole country as a 'cohort study'[10]. To retain this position, the Danish parliament in 2014 deleted an opt-out register in which 16% of the population featured[11]. People could not opt out of register-based research[12], but with the registration they could avoid being contacted by researchers wanting further information from them. It will come as a surprise to many outside observers that nothing about the abolition of the opt-out register was communicated to the people who were now again eligible for invitation to active participation in research, but in Denmark the abolition gave rise to little public comment. Lately, the government has proposed the use of the publicly gathered health data to attract international investment in the Danish pharmaceutical industry. In the 'national lost and found office' of health data, data can not only change custodianship, but also purpose and beneficiary.

Taking the metaphor of the lost and found office and Donna Dickenson's notion of We versus Me Medicine[13] as the points of departure for my analysis, this chapter presents some reflections on changing meanings and uses of health data in an ever more data-intensive healthcare system. I first clarify my conceptual approach to data intensification and then outline some trends in, and outcomes of, data sourcing practices in the public sector followed by some examples from private-sector initiatives. Though using 'public' and 'private' casually as descriptive concepts, it

[8] K. Hoeyer, 'Denmark at a Crossroad? Intensified Data Sourcing in a Research Radical Country', (2016), *The Ethics of Biomedical Big Data* 29, 73-93

[9] Cohort studies and other research initiated data collections typically use informed consent, and some databases do too, not least if they are sponsored by or work closely with industry – but for public registers and clinical databases consent is not legally required.

[10] J. Couzin-Frankel, 'Science gold mine, ethical minefield, (2009), *Science* 324, 166-168; L. Frank, 'When an Entire Country Is a Cohort', (2000), *Science*, 287(5462), 2398-2399; L. Frank, 'The Epidemiologist's Dream: Denmark', (2003), *Science*, 301(5630), 163.

[11] F. Nordfalk and K. Hoeyer, 'The Rise and Fall of an Opt Out System', (2017), *Scandinavian Journal of Public Health*, In press.

[12] It is still the case that register data can be used for research without consent. Denmark and a few other countries lobbied hard to ensure exemption for the general consent rules of the EU Data Protection Regulation and succeeded in ensuring opportunities for continuation of the old system. This is also discussed in Chapter 9 of this volume.

[13] D. Dickenson, *Me medicine vs. We medicine: Reclaiming Biotechnology for the Common Good*(New York: Columbia University Press, 2013).

will be clear that the public-private distinction is itself in need of critical scrutiny[14], but it is beyond the scope of this chapter to discuss this. Subsequently, I discuss how We and Me Medicine as a conceptual pair work in relation to an assessment of what is lost and what is gained through intensified data sourcing in its various manifestations.

The data circle and intensified data sourcing

During the past decade, health services have undergone significant changes as they have sought to take advantage of new information and communication technologies in an intense process of digitalisation and integration of information platforms[15]. Everyday healthcare activities also generate numerous tissue samples taken for diagnostic purposes. Such samples, when stored, can be retrieved for quality assurance and research purposes[16]. A blood sample can be used for whole genome or exome sequencing or be used to identify new biomarkers. As a result, patients today give rise to increasing amounts of traceable healthcare data every time they use health services.

Accelerated data intensiveness has paved the way for a much hyped 'revolution' in science towards what is often framed as Big Data mining[17]. However, healthcare data are typically produced in conjunction with routine *care*, hence data intensification is not just a matter of facilitating *research*. Therefore, I have suggested supplementing the focus on Big Data with an interest in what I call *intensified data sourcing*[18], by which I mean attempts to get more data, of better quality, on more people in a dynamic process of creating, collecting, curating, and storing data while simultaneously making it available for multiple purposes. Big Data debates are strongly focused on research[19], but scientific research is only one of many purposes for which health data are

[14] S. Gal, 'A Semiotics of the Public/Private Distinction, (2002), *A Journal of Feminist Cultural Studies*, 13(1), 77-95.
[15] L. Olsen, D. Aisner and J.M McGinnis, *The learning healthcare system: Workshop summary*(Washington, D.C.: The National Academies Press, 2007).

[16] M. Richards, R. Anderson, S. Hinde *et al.*, *The collection, linking and use of data in biomedical research and health care: Ethical issues*(London: Nuffield Council on Bioethics, 2015).

[17] V. Mayer-Schönberger and K. Cukier, *Big Data: A revolution that will transform how we live, work and think*(London: John Murray, 2013).

[18] K. Hoeyer, 'Denmark at a Crossroad? Intensified Data Sourcing in a Research Radical Country', (2016), *The Ethics of Biomedical Big Data* 29, p. 74.

[19] D. Boyd and K. Crawford, 'Critical questions for big data: Provocations for a cultural, technological, and scholarly phenomenon', (2012), *Information, Communication & Society*, 15(5), 662-679; M. Hildebrandt, 'Who Needs Stories if You Can Get the Data? ISPs in the Era of Big Number Crunching', (2011), *Philosophy & Technology* 24(4), 371-390; J.P Ioannidis, 'Informed Consent, Big Data, and the Oxymoron of Research That Is Not Research, (2013), *The*

used. Also, I think 'sourcing' is a better concept than 'data mining' because 'mining' suggests that data are found, extracted, and consumed. Yet data are not 'found', but *made* to exist, and unlike raw metals and other mining products, there is no such thing as 'raw data'[20]. Furthermore, metals are finite resources, while data can be sold again and again, re-used and retained while forwarded[21]. Finally, metal retains essential material properties irrespective of its users, while data as semiotic products modulate when entering new networks with new users: data are epistemologically and ontologically unstable[22].

Partly, the new data opportunities reflect rapidly lowering cost of genetic sequencing technologies and electronic data storage[23], partly new real-time processing opportunities facilitating ever more uses[24]. Scientific research is only one of many drivers of data production. Data are produced to increase accountability, to ensure proper remuneration, to feed into performance measurement, quality development, and because of changed clinical needs[25]. In consequence, the health services are likely to increase their data intensity irrespective of research uses. Interestingly, this emphasis on reuse of data often leads policymakers and data users to ignore well-established

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American Journal of Bioethics 13(4), 40-42; B. D. Mittelstadt and L. Floridi, 'The ethics of Big Data: Current and foreseeable issues in biomedical contexts', (2015), *Science and Engineering Ethics* 1-39.

[20] L. Gitelman and V. Jackson, Introduction. In L. Gitelman,ed., *"Raw Data" Is an Oxymoron(*Cambridge & London: The MIT Press, 2013), pp.1-14.

[21] M. Th. Mayrhofer, 'About the new significance and the contingent meaning of biological material and data in biobanks', (2013), *History and Philosophy of the Life Sciences* 35(3), 449-467.

[22] J. van Dijck, 'Datafication, dataism and dataveillance: Big Data between scientific paradigm and ideology', (2014), *Surveillance and Society*, 12(2), 197-208.

[23] M. Richards, R. Anderson, S. Hinde *et al.*, *The collection, linking and use of data in biomedical research and health care: Ethical issues*(London: Nuffield Council on Bioethics, 2015); The Expert Group on Dealing with Ethical and Regulatory Challenges of International Biobank Research. *Biobanks for Europe: A Challenge for Governance*. Brussels: European Comission, 2012.

[24] J. Roski, G.W. Bo-Linn and T.A. Andrews, 'Creating Value In Health Care Through Big Data: Opportunities And Policy Implications', (2014), *Health Affairs* 33(7), 1115-1122.

[25] T. Hey, S. Tansley and K. Tolle *The fourth paradigm*(Redmond, WA:Microsoft Research, 2009); P. C. Smith, 'Reflecting on 'Analytical perspectives on performance-based management: an outline of theoretical assumptions in the existing literature', (2015), *Health Economics, Policy and Law*, 1-5.

social science insights into how secondary uses impede data validity[26]. Data are conceptualised as if immune to the social processes bringing them about[27].

One of the medical research areas thriving on (and stimulating) the data surge is personalised medicine[28]. Though it is termed 'personalised medicine', it is of course still a matter of creating sub-populations with particular characteristics and directing health guidance based on population characteristics to individual members of that population[29]. Therefore, personalised medicine necessitates a flow of data that can be described as following a classic public-health data circle (see Figure 1).

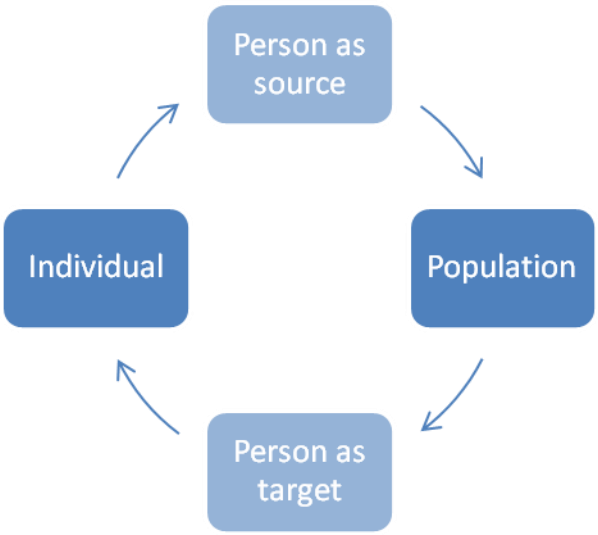

Figure 1: The Data Circle

With the data circle I mean the way in which individuals, named and known, serve as sources of data in the construction of population data. As data become accumulated at a group level in a smaller or larger 'population', the individual is *lost*, so to speak (in the sense of information being

[26] M. L Markus, 'Toward a Theory of Knowledge Reuse: Types of Knowledge Reuse Situations and Factors in Reuse Success', (2001), *Journal of Management Information Systems*, 18(1), 57-93.

[27] O. Halpern, *Beautiful Data: A History of Vision and Reason since 1945* (Durham and London: Duke University Press, 2014).

[28] L. Hood and M. Flores, 'A personal view on systems medicine and the emergence of proactive P4 medicine: predictive, preventive, personalized and participatory', (2012), *New Biotechnology* 29(6), 613-624.

[29] C. Holmberg, C. Bischof and S. Bauer, 'Making Predictions: Computing Populations, (2013), *Science, Technology, & Human Values* 38(3), 398-420.

disentangled and anonymised). But when knowledge from population data is put to use, it is again applied to named and known persons, who are *found* and targeted with preventive advice or treatment options expected to suit their case.

The image of a data circle might simplify the data journeys involved a little too much when we consider some of the intricate features of intensified data sourcing. Data travel in many directions, and some of the data uses influence the data values and thereby affect the goals of the idealised public health data circle. For example, some of the administrative uses of data, such as remuneration, are known to influence data quality[30]. When diagnostic codes are used to differentiate between prices for services, it is well known that more 'expensive' diagnoses become more prevalent, irrespective of the distribution of the disease burden in society[31]. The diagnostic coding system is used differently depending on the uses to which the codes are put, and in this way administrative uses of medical data can influence the clinical utility of the same data. In fact, there is a long list of such data problems associated with performance-based management[32]. As a consequence of increasing uses of data, they come to feed into many different circles whereby their valences potentially change.

With the current multiplication of purposes the classic public health data circle seems to be exploding into open-ended networks. Competing uses of data influence data values and in the process the information might lose its worth for some of the original purposes. If uses of diagnostic codes for remuneration purposes erode their clinical accuracy, the information loses both clinical and scientific value. As a lost-and-found office, data infrastructures can make simple pieces of information such as diagnostic codes change meaning and value as they are put to use by new 'owners' for new purposes. Even when publicly financed, collected and used, data might work through mechanisms that contain elements of both solidarity (We Medicine) and individualised gain (Me Medicine). To understand the value tensions in data sourcing better, I now discuss in a bit more detail how data is created, collected, curated, stored and used for multiple purposes, first in public and then private settings. Today, digital data dependency is engrained in most clinical work

[30] See also M. L Markus, 'Toward a Theory of Knowledge Reuse: Types of Knowledge Reuse Situations and Factors in Reuse Success', (2001), *Journal of Management Information Systems* 18(1), 57-93.

[31] E. Silverman and J. Skinner, 'Medicare Upcoding and Hospital Ownership', (2004), *Journal of Health Economics* 23, 369-389.

[32] S. Wadmann,S. Johansen, A. Lind, H.O. Birk and K. Hoeyer, 'Analytical perspectives on performancebased management: an outline of theoretical assumptions in the existing literature', (2013), *Health Economics, Policy and Law*, 1-17.

practices, including record keeping, communication between units, and the construction of treatment plans: it is not an option to return to an analogue mode of narrative record keeping in a closed closet. But does it bring more Me or more We Medicine to the table (or the bedside)? Both, I think, as I shall seek to illustrate below.

Public data intensification

To assess the collective and individual values of public data sourcing and use, I present some trends and examples – but for obvious reasons I cannot claim that these provide a comprehensive picture. Nevertheless, in Denmark, data intensification in public healthcare institutions can be said to revolve around, and contribute to: 1) governance; 2) clinical care; and 3) research.

I have already described the multiple purposes of public *governance* above. Data are seen as essential in the creation of transparency, accountability, and predictability[33]. Without data there are fewer options for financial control, quality control, and planning – at least that is a common perception among policymakers[34]. This can be seen as a matter of We Medicine, because it is about the efficiency of a shared public system. Ironically, however, data are used to model tax-financed services on market ideals, for example by enhancing competition between the different units in the healthcare sector (reflecting methods of governance emphasising self-interest more in line with Me Medicine). Also, data intensification gives rise to new initiatives to facilitate cross-sector data sharing with potentially detrimental effects for distributive justice and access to care[35], as for example when health data is increasingly becoming part of decisions concerning the allocation of benefits in the social sector. The Director of the Danish National Board of Health, Søren Brostrøm, has suggested that the social sector puts such pressure on the health sector for diagnostic codes, that the meaning of the diagnostic codes is gradually changing[36]. When health data are used to allocate social benefits it also means that the notion of 'sharing information' changes, because of the differences between the interests of the individuals and the systems involved in the sharing.

[33] L. Olsen, D. Aisner and J.M McGinnis, *The learning healthcare system: Workshop summary*(Washington, D.C.: The National Academies Press, 2007).

[34] P. C. Smith, 'Reflecting on 'Analytical perspectives on performance-based management: an outline of theoretical assumptions in the existing literature', (2015), *Health Economics, Policy and Law*, 1-5.

[35] D. Dickenson, *Me medicine vs. We medicine: Reclaiming Biotechnology for the Common Good*(New York: Columbia University Press, 2013), pp.72-77

[36] Rasmussen,L.I. (2016). Danmark er et diagnosesamfund. *Politiken, March 27*, (pp.4-6)

When it comes to data intensification in the *clinical* setting, it is important to notice that it is co-produced with technologies of care that necessitate large datasets to find the right treatment for individuals[37]. Clinical guidelines and other support tools are now part of everyday care, and interaction with them depends on support software that guides both diagnosis and follow-up care. This type of software depends on translation of narratives about symptoms into data and diagnostic codes. A new data trend is to also facilitate patient-generated data[38]. It adds to the number of expectations, stakeholders and data types, as well as the potential uses: physicians might need to contemplate data in new formats produced by new data suppliers, and patients might acquire new responsibilities they had not foreseen[39].

It is often the *research* uses of public health data that are most hotly debated at the expense of the *governance* and *clinical* implications of data intensification[40]. This emphasis easily creates the impression that data intensification calls for well-known measures from medical ethics, such as informed consent, irrespective of whether it speaks to the collective (We) or individual (Me) challenges that come along with data intensification[41]. In the international perspective, Denmark has taken a radical route to promote research uses of health data by insisting on consent exemption rules and by deleting the opt-out register. In Denmark, everyone is included and this is defended with reference to public interest[42]. While this is not what Dickenson means by We Medicine, it is indeed

[37] A. Hedgecoe, *The Politics of Personalised Medicine: Pharmacogenetics in the Clinic*(Cambridge: Cambridge University Press, 2004); R. Tutton, 'Personalizing medicine: Futures present and past', (2012), *Social Science & Medicine* 75(10), 1721-1728; R. Tutton,R, *Genomics and the reimagining of personalized medicine*(Farnham: Ashgate Publishing, 2014).

[38] P. J. van der Wees, M.W.G. Nijhuis-Van der Sanden, J.Z. Ayanian *et al.*, 'Integrating the Use of Patient–Reported Outcomes for Both Clinical Practice and Performance Measurement: Views of Experts from 3 Countries', (2014), *The Milbank Quarterly 92*(4), 754-775.

[39] C. Dedding, R. van Doorn, L. Winkler and R Reis, 'How will e-health affect patient participation in the clinic? A review of e-health studies and the current evidence for changes in the relationship between medical professionals and patients', (2011), *Social Science & Medicine* 72(1), 49-53. See also Huijer and Detweiler, Chapter 11 in this volume.

[40] L. F. Hogle, The Ethics and Politics of Infrastructures: Creasing the Conditions of Possibility for Big Data in Medicine. In L. Floridi, & B. Mittelstadt, eds., *The Ethics of Biomedical Big Data*(Switzerland: Springer,2016), pp.1-32

[41] B. D. Mittelstadt and L. Floridi, 'The ethics of Big Data: Current and foreseeable issues in biomedical contexts', (2015), *Science and Engineering Ethics,* 1-39.

[42] Danske Regioner, *Handleplan for bedre brug af sundhedsdata i regionerne*. Copenhagen: Danske Regioner, 2015, pp.1-19; Danske Regioner, *Sundhedsdata i spil*. Copenhagen: Danske Regioner, 2015; Ministeriet for Sundhed og Forebyggelse, *National Strategi for Adgang til Sundhedsdata*. Copenhagen: Ministeriet for Sundhed og Forebyggelse, 2014, pp.1-2.

a route providing little emphasis on the rights of the individual in order to protect what the state defines as the interests of the collective. In the Danish context, researchers, policy workers and politicians use arguments of solidarity and the common good when justifying the system, though in the international literature it has been argued that solidarity presupposes awareness (e.g. through informed consent) of the purposes to which you as a citizen contribute[43]. This is not the case with respect to register-based research for the wider Danish population.

What type of research has been used to justify the consent exemption? What are the public registers used for? The best way of addressing these questions is to look at the examples that the official committee coordinating register-based research itself brings forward – that is, how it justifies register-based research. These justifications have been gathered in a document summarising key research results achieved using Danish health data[44], and I use that document as a reference for the examples below.

The document presents 29 examples of research with international impact. Thousands of studies use the registers, but these examples were selected to show how data representative of a whole population can give rise to many different types of knowledge that probably could not be gained in any other way[45]. Through comprehensive registers, the healthcare system becomes an *in vivo* experiment with long-term follow up. I convey the results as the researchers present them though some readers might doubt their validity. Indeed, what counts as true today can always be questioned tomorrow, but the examples have been chosen by the committee because of their high current standing in the scientific establishment. Civic groups, social scientists and ethicists typically continue to oppose medical findings, e.g. when it is stated that a treatment is 'safe'[46], but here I merely present the findings used by the medical establishment to justify national register-based research.

It is striking that the examples chosen demonstrate how registers have been used to document side-effects of drugs that could not be identified in short-term trials (e.g. risks associated

[43] B. Prainsack and A. Buyx, *Solidarity in Biomedicine and Beyond*(Cambridge: Cambridge University Press, 2017).
[44] Strategisk Alliance for Register- og Sundhedsdata, *Eksempelsamling. Brug af sundhedsdata i forskning til gavn for patient og borger*. Copenhagen: Strategisk Alliance for Register- og Sundhedsdata, 2016, pp. 1-55

[45] The document itself groups the examples somewhat arbitrarily, seemingly according to the research groups producing them: 'quality of treatment', 'biological data', 'children', 'pregnancy', 'cancer', 'medicine', 'vaccine', and 'prevention'.

[46] See also C.L Decoteau and K. Underman, 'Adjudicating non-knowledge in the Omnibus Autism Proceedings', (2015), *Social Studies of Science* 45(4), 471-500.

with new types of contraceptive pills), but also erased doubts about potential side-effects and dangers associated with particular treatments. They thereby serve to create a better understanding of safety, at least from a medical perspective. For example, for years it was assumed that heavy use of pain relief medication increased the risk of recurrence among breast cancer patients. The comprehensive Danish registers allowed researchers to compare the medication schemes and cancer prevalence in the whole population and thereby debunk the hypothesis and facilitate more effective pain relief without fears of negative impact on cancer risk. In another example, American researchers claimed that abortion was associated with a higher risk of developing breast cancer, while the Danish registers were used to debunk this claim, because all abortions in Denmark can be linked to all registered cancers in the whole population and show there was absolutely no correlation. Another example of suggested dangers that comprehensive registers suggest are non-existent, is the idea that it would be dangerous to live close to high-voltage lines. For many years it was assumed it could be dangerous, but Danish registers made it possible to combine data of residence and workplace (and their proximity to high-voltage lines) with rates of mortality, morbidity and use of medication, and found no such correlation. One day the medical consensus might change again, of course, but for now this is regarded the best available evidence. Similarly, expecting parents have for years feared the effects on babies of particular diseases during pregnancy, and the registers suggest that many of these fears were unfounded. The Danish registers were also used to investigate the effects of some vaccines accused of having serious side-effects, showing that there was no reason to assume they could cause, for example, autism, as some researchers had hypothesised. Registers have also been used to debunk claims with potentially stigmatising effects, such as the one that cancer patients commit suicide more often. Furthermore, the registers have been used to document inequality in health (here examples are numerous because inequality in health has been a key interest of Nordic epidemiologists – see, for example, the life-time contributions of Finn Diderichsen which inform WHO work in this area). Note that many of these research results constitute knowledge that can underpin new guidelines or policies. They do not need to be translated into commercially sold products to have an impact on public health. In this sense, they form part of We Medicine.

The research value of Danish registers depends on the full inclusion of an unbiased population (through universal access to healthcare) and the absence of opt-out opportunities. While Dickenson emphasises a right to informed consent even in We Medicine, I suggest that this Danish model could be seen as We Medicine in a double sense; the benefits of research are shared with the

public and depend on shared access to services and shared obligations to deliver data. There are, however, trends that undermine this 'mandatory-solidarity' approach. The World Medical Association, the European Union and the National Council of Ethics have all discussed the introduction of informed consent in register-based research. Probably many women who have had an abortion would opt out of research on abortion, not because they do not like the results described above, but because they would consider the past event sensitive and, given the option, that it is more appealing to ask for less attention, rather than more. Few of the Danish women who have had an abortion, however, will know that they have contributed to the research results mentioned above, or even think about it when reading about the results in the newspaper. They have been connected with a stranger, the data analyst, in the lost-and-found office, but never experienced any consequences. Their intimate knowledge of an abortion has been able to travel as data without returning to them as individuals. Informed consent, however, operates in a different way. It creates an emotional and personalised relation to data, it becomes 'My Data', even when researchers only work on population statistics, 'Our Data'. Informed consent makes the individual feel 'found', and thereby some of the opportunities for the population are lost. Furthermore, opt out registers literally are registers and thereby a new source of knowledge about people and the research types from which they wish to opt out. As long as people feature as part of a population only, their identities can be better protected than when singled out as autonomous decision makers. The data are gathered irrespective of research uses, so opting out of data-intensive medicine is never an option.

Another trend toward Me Medicine that affects the uses of population data for research is the recent rise in private healthcare delivery. Private hospitals are supposed by law to deliver data to the national registers, but here well-known problems from the USA pop up: there is a lack of incentives for proper reporting and no effective sanctions when data are not sent as agreed. It causes problems not only for the utility of population data, but also in some cases for the patients opting for private health care because they still depend on public health care in other instances, but now their medical records have gaps and omissions. Hence, Me Medicine also involves risks for the individual who cannot be found in the data jungle when having left the collective grid.

Finally, the We Medicine approach in data use is under pressure as a result of public authorities seeking to attract private investments into the Danish pharmaceutical industry by making the publicly collected data available for commercial partners[47]. There are similarities here to the

[47] See e.g. Danske Regioner, *Handleplan for bedre brug af sundhedsdata i regionerne*. Copenhagen: Danske Regioner, 2015, pp.1-19; Danske Regioner, *Handlingsplan for personlig medicin.* Copenhagen: Danske Regioner, 2015b; Danske

care.data case in the UK[48] and the collaboration between Google's DeepMind project and the National Health Service in the UK[49]. As noted by Cool[50] in a discussion of big data practices in Sweden, the state-centered notion of 'sharing' in relation to health issues is under pressure in an increasingly globalised world economy[51].

Private data intensification

Data are created, collected, curated, stored and made available for multiple purposes also – and perhaps chiefly – outside the public sector. Commercial data intensification is less transparent, however, and because data here equals competitive edge and monetary potential, it is difficult to gain any clear understanding of who accumulates which types of data, and how they do it. Huge amounts of data are gathered passively as people accept terms of use for their phone or cookies on homepages, and thereby allow companies to gather and sell data about their mobility patterns or interests[52]. Data is also gathered from people who opt for so-called 'free services' (apps or Internet searches such as the Google, Gmail, or other presumably 'free' platforms). As Andrew Lewis has put it: "If you're not paying for something, you're not the customer; you're the product being sold"[53]. Data can also be acquired as people purchase direct-to-consumer health services, such as various tests[54]. Here they might opt for a discount by way of giving the company access to their data (this is typically presented as a matter or allowing 'research' on it). In principle, private data sourcing is mediated by some form of contractual acceptance as people have to accept cookies and agree to

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Regioner, *Sundhedsdata i spil*. Copenhagen: Danske Regioner, 2015; Ministeriet for Sundhed og Forebyggelse, *National Strategi for Adgang til Sundhedsdata*. Copenhagen: Ministeriet for Sundhed og Forebyggelse, 2014, pp.1-2.

[48] S. Sterckx, V.Rakic, J.Cockbain and P. Borry, '"You hoped we would sleep walk into accepting the collection of our data": controversies surrounding the UK care.data scheme and their wider relevance for biomedical research', (2015), *Medicine, Health Care and Philosophy*, 1-14; P. Vezyridis and S. Timmons, 'Understanding the care.data conondrum: New information flows for economic growth', (2017), *Big Data & Society*, 1-12

[49] J. Wakefield. Google Deepmind: Should patients trust the company with their data? BBC September 2016.

[50] A. Cool, 'Detaching data from the state: Biobanking and building Big Data in Sweden', (2015), *BioSocieties* 11(3), 277-295.

[51] See also Sterckx, Dheensa and Cockbain, Chapter 9 in this volume.

[52] See for example Huijer and Detweiler, Chapter 11 in this volume.

[53] E. Pariser, *The Filter Bubble*(London: Penguin, 2011), p. 21

[54] See for example S. Sterckx, J. Cockbain, H. Howard, I. Huys and P. Borry, '"Trust is not something you can reclaim easily" - Patenting in the field of direct to consumer genetic testing', (2013), *Genetics in Medicine* 15(5), 382-387

data policies to use the services through which their data are being sourced. It might look very much like Me Medicine with its praise of individual choice, but companies like 23andMe actively promote themselves as working for the common good. In this realm 'informed consent' serves to establish commercial rights for those who accumulate the data, and some participants were horrified when 23andMe took out a patent on a gene for Parkinson's Disease though the consent form mentioned that "intellectual property" would belong to the company[55]. Still, the notion of autonomous choice often lacks substance; in fact, the practices of accepting 'cookies', 'terms of conditions', etc., seem no less constricted than the public data sourcing initiatives described above because the terms of agreement often change, the agreements are obscure, or people are forced by other factors to use the services and thereby accept (even unreasonable) agreements.

If public data sourcing contributes to the development of public governance, clinical care, and research; what are privately created and collected health data used for? Basically, commercially gathered data are sold to those who can afford it. Uses of data therefore develop continuously and cannot be predicted. There is limited knowledge about the concrete data market flows because this type of information (data about data) constitutes a commodity in its own right, beyond the reach of academic research. Ethical analysis in this way becomes restricted through the new modes of organising health data markets. Commercial competition thus redirects the ethical analysis away from commercial data sourcing and back to national tax-financed initiatives, at least those that are (hopefully accurately) disclosed to the public, simply because this is what ethicists can analyse. Still, it seems safe to say that privately organised data collections contribute to, or are at least expected to contribute to three areas: 1) development of new health products; 2) 'personalised' pricing structures; and 3) personalised marketing.

Big Pharma has always used commercially gathered data to develop *new health products*, but some of the Big Data methodologies involved today are new. New types of products include also the devices and software used for data collection and handling. Furthermore, software with algorithms that allow development of personalised risk profiles, life-style guidance, and clinical decision-support tools also constitute important product innovations with a potentially big impact on healthcare[56]. Most of these products are sold direct-to-the-consumer as tools for self-

[55] E.C Hayden, 'A broken contract', (2012), *Nature* 486, 312-314.

[56] L. F. Hogle, The Ethics and Politics of Infrastructures: Creasing the Conditions of Possibility for Big Data in Medicine. In L. Floridi, & B. Mittelstadt, eds., *The Ethics of Biomedical Big Data*(Switzerland: Springer, 2016), pp.1-32.

improvement[57]. Some of these new self-monitoring apps are installed on people's mobile phones and thereby deliver the data circle – full circle – right in peoples' pockets: it is possible to generate data and to measure yourself against others and get your feedback right away[58]. You are never lost, so to speak; but a new question emerges: how many companies and other actors may find you?[59] The Veteran's Administration (VA) in the USA, that Dickenson[60] mentions as an example of classic We Medicine, has tested tools for the identification of people at risk of suicide based on changes in their typing speed and the vocabulary they use on social media[61]. Keeping track of the data gathered

[57] M. Bode & D.B Kristensen, The digital doppelgänger within. A study on self-tracking and the quantified self movement. In D. Bajde and R. Canniford, eds., *Assembling Consumption*(Oxford/ New York: Routledge, 2015), pp.119-134.

[58] T. Sharon and D. Zandbergen, 'From data fetishism to quantifying selves: Self-tracking practices and the other values of data', (2016), *New Media & Society*, online first (DOI: 10.1177/1461444816636090). See also Huijer and Detweiler in this volume.

[59] According to some observers, it is a general feature of the self-monitoring device industry that the start-ups begin selling devices and then acquire their real value based on the data they gather: the data becomes a selling point for the companies (H.K. Holst, Forsikringsselskaber vil tjekke dig døgnet rundt med smartwatch og skridttæller. Berlingske Business September 2016). Another, more publicised example, is FaceBook's takeover of the message service app WhatsApp. FaceBook wanted to data source although WhatsApp had promised not to do so. Nevertheless, WhatsApp had gained value through accumulation of the enormous amounts of data on people who had opted out of more easily accessible data (e.g. from Gmail-accounts), and FaceBook did not consider itself bounded by the previous owners' assurances. FaceBook's intentions were questioned by authorities in the USA (Federal Trade Commission, FTC Notifies Facebook, WhatsApp of Privacy Obligations in Light of Proposed Acquisition. Federal Trade Comission, April 2014), and in the UK the Information Officer is also looking into the legality (E. Denham. *Statement on changes to WhatsApp and Facebook's handling of personal data*. United Kingdom: Information Comissioner's Office, 2016), though revelations of terrorists using WhatsApp have stimulated the British Government also to pursue access to the data for investigative purposes. Most recently the Hamburg commissioner for data protection has started proceedings to stop the data sourcing (Hamburg Commissioner for Data Protection and Freedom of Information. *Administrative Order Against the Mass Synchronization of Data Between FaceBook and WhatsApp.* Hamburg, Germany, Hamburg: Commissioner for Data Protection and Freedom of Information, 2016), which comes as a continuation of the attempts the German *Bundeskartellamt* to prevent FaceBook from using its privileged market position to impose 'unreasonable' terms of agreement on its costumers (Bundeskartellamt. *Bundeskartellamt initiates proceeding against Facebook on suspicion of having abused its market power by infringing data protection rules*. Bonn, Germany: Bundeskartellamt, 2016). Furthermore, data live promiscuous lives also due to problems with data security. Basically everything can be hacked, and many of the new self-monitoring technologies (especially those dependent on blue tooth technology) have serious security flaws according to some studies (R. Goyal, N. Dragoni and A. Spognardi, 'Mind The Tracker You Wear: A Security Analysis of Wearable Health Trackers', (2016), *31st ACM Symposium on Applied Computing (SAC'16),* 131-136).

[60] D. Dickenson, *Me medicine vs. We medicine: Reclaiming Biotechnology for the Common Good*(New York: Columbia University Press, 2013), p. vii.

[61] L. F. Hogle, The Ethics and Politics of Infrastructures: Creasing the Conditions of Possibility for Big Data in Medicine. In L. Floridi, & B. Mittelstadt, eds., *The Ethics of Biomedical Big Data*(Switzerland: Springer, 2016), pp.1-32.

on the many new devices can be extremely difficult. Some of the new data products can become engrained in classic We Medicine healthcare systems, while others circumvent ideas about shared responsibility and allocate benefits and risks to individuals.

Another avenue opened by private data collection and use of health data is *personalisation of prices*. In countries with private insurance coverage, data profiles of potentially expensive health service users (e.g. those at risk of low compliance) can be a valuable commodity for insurance companies[62]. According to Hogle[63], the data market in the USA is now taking over the insurance market. In Denmark, it was recently proposed to make it illegal to use genetic information to differentiate insurance prices (the insurance industry does not agree with this proposal)[64], yet at the same time insurance companies experiment with pricing models where those who are willing to provide access to apps and mobile devices that demonstrate high levels of physical activity can get discounts on their insurance[65]. It might look like a matter of free choice (Me Medicine), but it does remove other choices; e.g. not to share your data without paying extra, or to enjoy a run in the forest without bringing your devices along to prove your good health. Moreover, those who for various reasons cannot comply with the standards of healthy behaviour will have to pay a higher price if those who can comply get cheaper insurance.

According to some observers, this whole personalisation of the pricing structure is still only in its infancy, at least when compared to the personalisation taking place through the use of data intensive methodologies in other sectors[66]. In the area of Internet-based commodity trade, differentiated pricing furthermore goes hand-in-hand with *personalised marketing*. Algorithms and models are constructed in order to adequately describe and predict patterns of behaviour and interest. Based on predictions, individuals are targeted with offers using customised price-setting and other features aimed at optimising the chances of a deal with maximum profit. Amazon

[62] See also examples mentioned by Sterckx, Dheensa and Cockbain, Chapter 9 in this volume.

[63] L.F. Hogle, 'Data-intensive resourcing in healthcare', (2016), *BioSocieties* 11(3), 372-393.

[64] Lov (L 157) om ændring af lov om forsikringsaftaler og lov om tilsyn med firmapensioner (www.retsinfo.dk).

[65] H.K. Holst, Forsikringsselskaber vil tjekke dig døgnet rundt med smartwatch og skridttæller. Berlingske Business September 2016.

[66] H. M. Krumholz, 'Big Data And New Knowledge In Medicine: The Thinking, Training, And Tools Needed For A Learning Health System', (2014), *Health Affairs* 33(7), 1163-1170; J. Roski, G.W. Bo-Linn and T.A. Andrews, 'Creating Value In Health Care Through Big Data: Opportunities And Policy Implications', (2014), *Health Affairs* 33(7), 1115-1122.

pioneered this mode of personalisation, but today this type of data market is converging with health, as insurance companies and health care suppliers learn about the value of 'knowing their customer', as noted also by investigative journalist Eli Pariser[67]. This constitutes an arena of Me Medicine, and some costumers are bound to love the effects of an on-line sphere that knows them so well that they 'coincidentally' come across the very health products they are most likely to buy.

There is, however, a darker side to the personalised modes of marketing. According to researcher and data analyst Henrik Legind Larsen[68], the market in health data is intertwined with illegal trade in sensitive information, which gains its value because the people with the most desperate health needs can be targeted with offers of treatment with little or no evidence of efficacy at very high costs[69]. Marketing here typically interacts with medical tourism, although tourism is a flawed metaphor when we consider the nature of the travel undertaken by people desperately seeking a cure when there are no medically sanctioned opportunities left[70]. Others can be targeted for their potential interest in treatments that are either illegal or extremely expensive in their home countries. Still others can be targeted with treatments that involve materials in short supply within medical systems dependent on free donations of organs, gametes and tissues[71]. Here again, Me Medicine takes over from We Medicine, but it is not simply a matter of granting new opportunities to wealthy individuals who can purchase treatment – it can easily put the wealthy at risk too, as they chase treatment options with no guarantees and little legal (and scientific) backing.

Just as we saw with public data sourcing, data sourcing is ubiquitous in the private sector. It cuts across sectors and even if the research uses of data were to be more legally restricted, the data practices are not likely to become less intense or more aimed at the common good. Though

[67] E. Pariser, *The Filter Bubble*(London: Penguin, 2011).

[68] Personal communication, September 5, 2016.

[69] A recent episode revealed that IT criminals do target emails from Danish health authorities to harvest health data (O.N.M Toft, Blixt kræver samråds-svar i data-sag. Altinget September 2016).

[70] A. Wahlberg and T. Streitfellner, Stem cell tourism, desperation and the governing of new therapies. In A. Leibing, & V. Tournay , eds., *Technologies de l'espoir. Les débats publics autour de l'innovation médicale* (Montreal: Université de Montréal, 2009).

[71] D. A. Budiani-Saberi and F.L. Delmonico, 'Organ Trafficking and Transplant Tourism: A Commentary on the Global Realities', (2008), *American Journal of Transplantation* 8(5), 925-929; J.P. Pirnay, E. Baudoux, C. Olivier *et al*., 'Access to human tissues for research and product development: From EU regulation to alarming legal developments in Belgium', (2015), *EMBO reports* 16(5), 557-62.

primarily operating in the realm of Me Medicine, many of the privately mediated data practices are in practice no less inescapable than the ones in the Danish public sector.

Concluding reflections

In the current age of intensified data sourcing, data creation, collection, storage and use have become ubiquitous. Collective and individual interest in the new data practices can be difficult to pinpoint. Data can serve individuals and collectives, but can also expose them to potential harm. Public data intensification is intertwined with attempts to ensure key values of public administration – transparency, efficiency, evidence – but it also feeds into new forms of obscuration, increased expenditure and initiatives based on unfounded promises of prediction. In practice, data gathered in the public and the private sector may cross-over and be used for new purposes irrespective of their mode of production. Unless carefully regulated, data infrastructures easily acquire traits of the lost-and-found office. Like Simmel's 'stranger', they can give people who are far away from data sources in a social sense a physical presence to information that is highly intimate. Moreover, data infrastructures can – by way of the outside position of the data analyst (the stranger) – create new social groupings, ideas about disease, and notions of the self.

Because ethicists typically have access to more information about data flows in the *public* sector, and because medical ethics has a long tradition of discussing the terms of *research* participation, there is a tendency to focus criticism of data intensive methods on *public* data used for *research* purposes. In particular, critique tends to focus on study methods that violate norms from clinical ethics associated with the right to give an informed consent[72]. It is problematic, however, to nail the analysis to the notion of informed consent as a 'solution' developed to address a different set of problems[73]. The private sector thrives on forms of data sourcing that are no less inescapable

[72] K. Hoeyer and N. Lynöe, 'Is Informed Consent a Solution to Contractual Problems? A Comment on the Article ""Icelandic Inc."? On the Ethics of Commercial Population Genomics" by Jon F. Merz, Glen E. McGee, and Pamala Sankar', (2004), *Social Science and Medicine* 58(6), 1211-1213; J. F. Merz, G.E. McGee and P. Sankar, '"Iceland Inc."?: On the Ethics of Commercial Population Genomics', (2004), *Social Science & Medicine* 58(6), 1201-1209.

[73] D. Grande, N. Mitra, A. Shah, F. Wan and D.A. Asch, 'The Importance of Purpose: Moving Beyond Consent in the Societal Use of Personal Health Information' (2014), *Annals of Internal Medicine* 161(12), 855-862; L. F. Hogle, The Ethics and Politics of Infrastructures: Creasing the Conditions of Possibility for Big Data in Medicine. In L. Floridi, & B. Mittelstadt, eds., *The Ethics of Biomedical Big Data*(Switzerland: Springer, 2016), pp.1-32; B. D. Mittelstadt and L. Floridi, 'The ethics of Big Data: Current and foreseeable issues in biomedical contexts', (2015), *Science and Engineering Ethics,* 1-39.

than those of register-based public research, though in principle relying on 'consent', and commercial data practices are furthermore combined with less transparency. 'Acceptance of cookies' and similar clicks do little to care for consumer rights and interests. Do we expect that quick 'click' options would do much good in the public health sector? Also, informed consent for data usage for *research* purposes leaves all the other uses of data unexamined, and might in fact expose the individual more (not less) because it involves creating a tighter connection between the individual and the data which will gathered anyway. If individuals are to access and administer research access to their personal data then the digital networks will need to have more entry points and become easier to hack. It will not necessarily protect individuals better.

So are Danish health data practices part of We Medicine or Me Medicine? I think there are elements of both. When publicly sourced data are used to attract commercial investments and generate profit, it looks more like Me Medicine thriving on the illusion of We Medicine. When data are used for identifying individuals based on algorithmic profiling and this identification individualises risks and benefits it similarly comes across more like Me Medicine using We Medicine as a veil. Nevertheless, if we believe at all in the value of medical consensus, the common goods derived from research uses can also be significant. Without the Nordic registers and consent exemption rules, there are fewer options for checking and challenging the claims made by the pharmaceutical companies based on short-term randomised controlled trials (RCTs). The registers have been used to identify unknown side-effects, to stimulate a better understanding of poly-pharmacy effects, and have also shown that certain fears were probably unfounded. Many of these research results arising from public Danish health registers are now freely available and implementable in a nonrivalrous manner and to the benefit of the people delivering the data in the first place. In this sense, the data circle works and it works as We Medicine. If research uses were to be restricted through the use of informed consent, the risks would be differently distributed and the benefits of unbiased information disappear.

Rather than insisting on informed consent, would it not be more adequate to focus on the responsibilities that authorities and companies incur through mandatory data sourcing? Responsibilities for insuring safety, communal purposes, and fair use? For compensating those harmed by data leaks or hacking? For ensuring that secondary purposes with data sourcing do not overrule primary purposes so that clinical utility is hampered in the pursuit of administrative or research utility? Responsibilities to think through carefully how data usage can avoid undermining the entitlement to healthcare for vulnerable individuals? Furthermore, there is a need to complement

the current focus on the privacy and autonomy interests of those from whom data derive and to take into account also the group privacy interests of those at the receiving end of the new data tools developed with the big datasets to ensure they are put to use for the common good and not just as profiling tools that individualise risks and benefits[74]. Will it be possible to be lost and stay lost? Is there a right to be forgotten as well as a right not to be tagged as a particular profile? There is a need to find ways of countering the risks associated in particular with private data sourcing, and to help individuals manoeuvre the landscapes of personalised pricing, marketing and services that might make the user into the product. Data intensification involves many challenges, but they are hardly solved with rules about informed consent. They demand communal approaches setting rules for collectives rather than distributing responsibilities to individuals. Those scholars who continue to insist on informed consent as an obligatory passage point for data sourcing will have to address these challenges too; lest they simply aim at individualising responsibilities in a complex data intensive age.

Intensified data sourcing changes medicine as we know it. It reflects and affects epistemological issues (what we can know), issues of citizenship (the rights and duties of individuals), economic issues (costs of healthcare and accumulation of capital), as well as issues of societal morality (public values and the distribution of goods and risks). In many ways, it looks as if data intensification tends to take healthcare in the direction of Me Medicine. Still, if we think of the common good not as 'accumulated goods' (akin to accumulated data), but as goods that derive from the collective[75], intensified data sourcing could also be a prime example of We Medicine when only directed towards common good goals. It is, however, a key task to ensure that the collective goods do not become redirected into private pockets – and that collectives help each other to counter individual risks. I believe it is possible to bring some of the old values of We Medicine to the table of a data intensive healthcare system and work for communal use, shared risk, and collective benefits. It is well-worth the try considering that there is little reason to assume that healthcare will become any less data intensive in the future.

[74] L Taylor, 'Safety in Numbers? Group Privacy and Big Data Analytics in the Developing World'. In L Taylor et al (eds.) *Group Privacy. New Challenges of Data Technologies.* (Dordrecht: Springer, 2017).

[75] H. Widdows and S. Cordell, 'Why communities and their goods matter: Illustrated with the example of Biobanks', (2011), *Public Health Ethics* 4(1), 14-25.

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