

PERSONALISED
MEDICINE, INDIVIDUAL
CHOICE AND THE
COMMON GOOD

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Introduction

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1.1 What Is Personalised Medicine?

Hippocrates famously advised physicians that it is more important to know *what person the disease has* than *what disease the person has*. So it might well be thought that all good medical practice is personalised, and that there is nothing new about that. But the phenomenon that has been widely presented as a paradigm shift in medicine – and which is our concern in this volume – is both more specific and more general.

In the specific sense, *personalised* or *precision medicine* builds on the achievements of genomic science, aiming to offer doctors and patients more sophisticated tools of molecular profiling to identify and treat genetic variants implicated in disease risk and treatment. Pharmacogenetics, probably the most advanced arm of personalised medicine, aims to minimise adverse drug reactions and produce better responses by tailoring pharmaceutical regimes in cancer care and other branches of medicine to the patient's individual genome. For example, the application of whole-genome sequencing to the care of a patient with early onset breast and ovarian cancer but no significant family history revealed unsuspected genetic defects, enabling clinicians to change her treatment plan from bone marrow transplantation to successful targeted chemotherapy.¹ Outside oncology, treatment for the liver disease hepatitis has been successfully personalised to avoid the worst side effects for patients whose genetic variation makes them more responsive to a lower drug dosage.² The discovery of a 'Goldilocks' gene affecting patients' inflammatory

¹ Daniel C. Link et al., 'Identification of a novel PT3 cancer susceptibility mutation through whole-genome sequencing of a patient with therapy-related AML' (2011) 305 *Journal of the American Medical Association* 1568–76.

² Amy Maxmen, 'Pharmacogenetics: playing the odds' (2011) 474 *Nature* S9–S10.

response to tuberculosis could be crucial, particularly in the Third World, in determining who will contract the disease and who would benefit from steroids.³

Such is the sense captured in the following description:

Precision medicine is an approach to disease treatment and prevention that seeks to maximize effectiveness by taking into account variability in genes, environment and lifestyle. Precision medicine seeks to redefine our understanding of disease onset and progression, treatment response, and health outcomes through the more precise measurement of molecular, environmental, and behavioral factors that contribute to health and disease. This understanding will lead to more accurate diagnoses, more rational disease prevention strategies, better treatment selection, and the development of novel therapies. Coincident with advancing the science of medicine is a changing culture of medical practice and medical research that engages individuals as active partners—not just as patients or research subjects.⁴

This is the goal underpinning the announcement made by President Obama in January 2015 of a \$215 million Precision Medicine Initiative (PMI), coupled with plans to recruit a million participants into the accompanying ‘PMI-Cohort’ programme. As a junior senator, Obama had already championed the bill that was to become the Genomics and Personalized Medicine Act 2007, remarking: ‘We are in a new era of the life sciences, but in no area of research is the promise greater than in personalized medicine.’ In these initiatives the language of *individualisation* was powerfully dominant, despite the ‘rhetorical reform’ implicit in the change of nomenclature from ‘personalised’ to ‘precision’ between the 2007 statute and the 2015 initiative.⁵ In the words of the White House statement accompanying the PMI announcement:

Until now most medical treatments have been designed for the ‘average patient’. As a result of this ‘one-size-fits-all’ approach, treatments can

³ Linda Wijlaars, “‘Goldilocks’ gene response to TB suggests best treatment’ (6 February 2012) *Bionews*.

⁴ Precision Medicine Initiative (PMI) Working Group Report to the Advisory Committee to the Director, NIH, *The Precision Medicine Initiative Cohort Program – Building a Research Foundation for 21st Century Medicine* (2015), September 17, p. 1. See also Maya Sabatello and Paul S. Appelbaum, ‘The precision medicine nation’ (2017) 47(4) *Hastings Center Report* 19–29.

⁵ Eric Juengst, Michelle L. McGowan, Jennifer R. Fishman et al., ‘From “personalized” to “precision” medicine: the ethical and social implications of rhetorical reform in genomic medicine’ (2016) 46 *Hastings Center Report* 21–33.

be very successful for some patients but not for others. Precision Medicine, on the other hand, is an innovative approach that takes into account individual differences in people's genes, environments, and lifestyles.⁶

1.2 The Personalisation of Medicine and the Common Good

However, this emphasis on individualisation – ‘Me Medicine’, as one of us has termed it⁷ – is controversial, despite Hippocrates’ dictum. To begin with, it is extremely unlikely that completely individualised treatments are ever going to be feasible. Many commentators and clinicians acknowledge that the best aspiration is to deliver diagnoses and treatments stratified into patient groups by genomic science:

I don't think that we can ever, ever become truly personal and truly individualized . . . [T]he way I look at personalized medicine is whereby we can stratify patient groups respective of ancestry, ethnicity, into individuals who are more likely to respond using novel technologies . . . So I see a way of being able to subphenotype individuals in the way they're going to respond to drugs, and that's what I see as personalized medicine. So I don't see it as individual.⁸

The term ‘stratified’ medicine, however, lacks the powerful appeal of ‘personalised’ medicine, with its promises of greater *individual choice* and patient empowerment. These claims have been made most explicitly by the direct-to-consumer (DTC) genetic testing sector, in which firms offer customers whole- or partial-genome sequencing analyses of their risks for particular diseases. As one firm put it, ‘We use the latest science and technology to give you a view into your DNA, revealing your genetic predisposition for important health conditions and empowering you with knowledge to help you take control of your health future.’⁹ Direct-to-consumer genetic testing is the self-proclaimed vanguard of the personalised medicine movement, with leading proponents advocating a proactive approach

⁶ Quoted in J. Patrick Woolley, Michelle L. McGowan, Harriet J. A. Teare et al., ‘Citizen science or scientific citizenship? Disentangling the uses of public engagement rhetoric in national research initiatives’ (2016) 17(33) *BMC Medical Ethics*, pp. 7–8.

⁷ Donna Dickenson, *Me Medicine vs We Medicine: Reclaiming Biotechnology for the Common Good* (New York, NY: Columbia University Press, 2013).

⁸ A senior editor of a genomics journal, interviewed in Juengst et al., ‘From “personalized” to “precision” medicine’, p. 23.

⁹ Navigenics advertising, quoted in Dickenson, *Me Medicine vs We Medicine*, p. 32.

to individual health that stresses the importance and validity of DTC tests in taking control of one's own health.¹⁰

But are these promises of empowerment illusory? 'The weakness of "personalized genomic medicine", as a promissory label for what genomics might bring to health care, is that it promises more than genomics can actually deliver – both in terms of increased patient empowerment and in terms of the individualization of care.'¹¹ Perhaps personalised medicine might even *diminish* patient choice by denying patients treatments which they would like to have but to which they are unlikely to respond. Or it might leave that decision more firmly in the hands of physicians and genetic counsellors, operating on the pharmacogenetic ethos of 'the right treatment for the right patient at the right time'. But the inevitable corollary is 'the wrong treatment for the wrong patient at the wrong time', conceivably meaning 'no treatment' for patients whose genomic profiles make them less likely to respond.¹²

Rationing decisions such as these are only the start of the ethical and social issues arising from personalised medicine. Interpreted broadly, personalised medicine can encompass a whole gamut of new biotechnologies, united mainly by their common emphasis on patient choice and empowerment. As a prominent example, 'enhancement technologies', such as neurocognitive stimulation techniques, brain-computer interfaces, drugs to improve mental functioning, and, most controversially, germline genetic modification, can be seen as a form of personalised medicine. They are typically predicated on the individualistic ethos of 'being the best Me I can possibly be'.¹³

Yet the original ideals behind the rise of genomic medicine were communitarian, not individualistic: they symbolise 'We' rather than 'Me' Medicine. This 'We' may refer to a variety of concerns: our genetic relatedness, ideals of solidarity and distributive justice, or global public goods such as the genetic commons. The ideal of the genome as the common heritage of humanity permeates the international scientific community's 1996 'Bermuda statement', which declares: 'All human genome sequence information from a publicly funded project should be freely available in the public

¹⁰ E.g. Francis Collins, *The Language of Life: DNA and the Revolution in Personalized Medicine* (New York, NY: Harper Collins, 2010).

¹¹ Juengst et al., 'From "personalized" to "precision" medicine', p. 30.

¹² Dickenson, *Me Medicine vs We Medicine*, p. 72.

¹³ Dickenson, *Me Medicine vs We Medicine*, p. 113.

domain.¹⁴ Likewise, article 1 of the 1997 UNESCO Universal Declaration on the Human Genome and Human Rights stipulates: ‘In a symbolic sense, the human genome is the common heritage of humanity.’

Does personalised medicine undermine and threaten this conception of the ‘common good’? If more resources are dedicated to precision medicine, for example, will less attention be paid to public health?¹⁵ That could be counterproductive in overall population terms, bearing in mind that it was public health initiatives such as improved sanitation and screening that radically improved lifespan figures in the twentieth-century Western world by lessening the incidence of contagious disease.

This phenomenon is not ‘merely’ historic; nor is it limited to infectious disease. ‘Most of the recent successes in cancer care have resulted from the traditional public health measures of screening, early detection and smoking reduction as well as some immunologic therapies.’¹⁶ Even two of the most prominent ‘poster children’ for genomic medicine, the BRCA1/2 genes implicated in some breast and ovarian cancers and the discovery of specific cystic fibrosis mutations responsive to recently developed drugs, have arguably had less effect than ‘We Medicine’. ‘Although well-deserved recognition has accompanied these genetic discoveries, neither has been a significant factor in the substantial reduction in mortality from the two target diseases during the past 25 years. The commitment to screening technology and adherence to best practices has proven far more important to the lives of affected patients.’¹⁷ More broadly, it has been argued that a solidarity-based ‘We Medicine perspective’ could allow us to formulate better policies in areas ranging from palliative care to organ donation.¹⁸

¹⁴ HUGO (Human Genome Organization), *Summary of Principles Agreed at the International Strategy Meeting on Human Genome Sequencing* (‘Bermuda Statement’) (London: Wellcome Trust, 1996).

¹⁵ W. Burke et al., ‘Extending the range of public health genomics: what should be the agenda for public health in an era of genome-based and “personalized” medicine?’ (2010) 12 *Genetics in Medicine* 785–91.

¹⁶ Michael J. Joyner and Nigel Paneth, ‘Seven questions for personalized medicine’ (2015) 314(10) *JAMA* 999–1000, p. 999.

¹⁷ *Ibid.*

¹⁸ Barbara Prainsack, ‘The “We” in the “Me”: solidarity and health care in the era of personalized medicine’ (2018) 43(1) *Science, Technology and Human Values* 21–44.

1.3 Digital Health and Personalised Medicine

All these developments regarding personalised medicine need to be seen in connection with the digital health (or e-health) revolution. In 2017 the digital health industry was already worth US\$25 billion globally.¹⁹ Digital health includes diverse technologies, e.g. automated algorithm-based decisional support systems, mobile health apps (m-health) monitoring health-related behaviours, remote consultations (or ‘telemedicine’) and Electronic Health Records (EHRs). Staggeringly, 153,000 m-health apps have been released since 2015, bringing the worldwide total to 320,000.²⁰ For most of these technologies, robust governance is lacking.²¹

These technologies also result in an increasing ‘pile’ of Big Data. Increasingly, as in other contexts (not only businesses but also election campaigns, for example), in healthcare, too, attempts are made to link disparate data sets at the individual person level. New kinds of data collection, linkage and analysis are expected to profoundly transform clinical medicine, public health and epidemiology.

In her hugely impressive article in *The Lancet* on ‘The art of medicine’, Immaculada de Melo-Martin analyses the impact on current-day medicine of the Cartesian concept of the human body as a machine. Although this model has resulted in unquestionable benefits from the biomedical sciences, she adds this caveat:

[I]t also underlies the belief that the goal of medicine is to somehow eliminate human vulnerability. Because contemporary biomedical sciences ask questions oriented to that end, it is not surprising that their responses tend to sustain medical practices that are directed to produce cures. Of course, we cannot emphasise enough the importance of curing human diseases. But excessive emphasis on this goal runs the risk of disregarding those things that cannot be cured, such as disabilities and chronic illnesses. This goal also underscores the emphasis on individual solutions to problems that might best be addressed by attending to social and economic aspects, and hence the common lack of attention given to public health solutions.²²

¹⁹ ‘Does mobile health matter?’ (2017) 390 *The Lancet* 2216. doi:10.1016/S0140-6736(17)32899-4.

²⁰ IQVIA, ‘The growing value of digital health in the United Kingdom: evidence and impact on human health and the healthcare system’ (7 November 2017). www.iqvia.com/institute/reports/the-growing-value-of-digital-health (Accessed 11 February 2018).

²¹ Rishi Duggal, Ingrid Brindle and Jessamy Bagenal, ‘Editorial: Digital healthcare: regulating the revolution’ (2018) *British Medical Journal* 360:k6. doi:10.1136/bmj.k6.

²² Immaculada de Melo-Martin, ‘The art of medicine – Vulnerability and ethics: considering our Cartesian hangover’ (2009) 373 *The Lancet* 1244–45.

Promises of ever more cures where none were previously available can be found throughout the ‘personalised medicine’ rhetoric, to an increasingly embarrassing extent, as explained powerfully by Stanford epidemiologist John Ioannidis:

I have had great excitement about the prospects of omics, big data, personalized medicine, precision medicine, and all. Much of my effort has been to put together these efforts with rigorous statistical methods and EBM (Evidence-Based Medicine) tools. But I am tired of seeing the same overrated promises recast again and again. For example, several years ago I gave an invited lecture at a leading institution on the danger of making inflated promises in personalized medicine. Right after my talk, everybody rushed to hear the launch of a new campaign, where the leader of the institution singled out this unique historic moment: that institution would single-handedly eliminate most major types of cancer within a few years. Several years have passed, and none of these cancer types have disappeared. I recently tried to find the name of that campaign online but realized that this institution has launched many similar campaigns. Which among many was the unique historic moment that I happened to be at? Multiply this by thousands of institutions, and there are already millions of unique historic moments where cancer was eliminated. The same applies to neurologic diseases and more. I do not understand why academic leaders and politicians need to make such self-embarrassing announcements now and then.²³

1.4 Me Medicine vs We Medicine

To examine these wide-ranging and global questions, this volume brings together an international array of scholars from various disciplines, including law, bioethics, anthropology and sociology, to exchange ideas on the tensions between Me Medicine and We Medicine.

One of the recurring questions in the contributions to this book is what *Me* and *We* exactly mean in this context. As various authors argue, personalised medicine gives rise to new conceptions of the self and the communal. What kind of concept of the person is implied by the notion of personalised medicine: a geneticised self, quantified self, potential self, fictional self, consumer self? And what is the nature of community and the common good implicit in We Medicine: collective morality, social solidarity or rather new types of commons, such as ‘genome-commons’ (e.g. the human genome as common heritage of mankind), ‘bio-

²³ John Ioannidis, ‘Evidence-based medicine has been hijacked: a report to David Sackett’ (2016) 73 *Journal of Clinical Epidemiology* 82–6.

commons' (e.g. sharing DNA samples) and 'data-commons' (e.g. promotion of early data disclosure and release)?²⁴

Moreover, many of the chapters offer reflection on the causes of the spectacular rise of the rhetoric of personalised medicine. One of us has argued²⁵ that four possible explanations can be distinguished, with some emerging from further analysis as more plausible than others. These four explanations also resurface in most of the chapters and can be characterised as follows.

A first possibility is that the personalisation of healthcare is rooted in a more general sense of threat and contamination in society. For example, the fear of contamination can be recognised in the growing lack of confidence in public health resources. Second, the popularity of products and services in the field of Me Medicine, such as DTC tests, could be understood against the background of a broader trend towards narcissism and a fixation on the self. Third, it seems likely that corporate interests also fuel the fascination for personalised medicine. The highly lucrative and still expanding market in products and services based on personalised medicine suggests a correlation between the emergence of personalised medicine on the one hand, and the rise of neoliberal politics and the privatisation of most domains of life on the other. Last, the rhetoric surrounding personalised medicine alludes to a celebration of personal choice, personal empowerment and personal autonomy. From this perspective, the belief in personalised medicine as the new panacea is intimately connected to modern society's belief in the 'sacredness of personal choice and individualism'.²⁶

These four hypotheses have engaged the attention of many of our contributors, allowing a more sophisticated and multi-disciplinary analysis of the phenomenon of personalised medicine to be united under a shared framework. In the next section we summarise each of their contributions separately.

1.5 Overview

In their chapter, 'Personalised Medicine and the Politics of Human Nuclear Genome Transfer', philosopher and bioethicist Françoise

²⁴ Bartha M. Knoppers and Vural Özdemir, 'The concept of humanity and biogenetics' in Britta van Beers, Luigi Corrias and Wouter Werner (eds.), *Humanity across International Law and Biomedicine* (Cambridge: Cambridge University Press, 2014).

²⁵ Dickenson, *Me Medicine vs We Medicine*, pp. 10–29.

²⁶ Dickenson, *Me Medicine vs We Medicine*, p. 24.

Baylis and feminist political scientist Alana Cattapan offer an important contribution to the debate on the governance of human nuclear genome transfer, commonly (but incorrectly) known as ‘mitochondrial replacement’. This emerging reproductive technology aims to provide women who are genetic carriers of certain mitochondrial diseases with the possibility of reproducing without passing on their mitochondrial DNA to their offspring. The result would be the creation of ‘three-parent babies’, with genetic material from two women and one man. In their thought-provoking analysis Baylis and Cattapan argue that the rise of human nuclear genome transfer should be understood as part of the current movement towards the personalisation of healthcare; as such, they claim, it deserves a critical examination. They subsequently argue against the implementation of this technology by fruitfully engaging with Dickenson’s aforementioned four possible explanations for the rise of personalised medicine. According to Baylis and Cattapan, Dickenson’s first explanation resurfaces in the context of human nuclear genome in the shape of a fear of genetic contamination of one’s familial DNA, against which this technology would offer protection. They then engage with Dickenson’s second hypothesis – narcissism and bowling alone – by highlighting how an important part of this technology’s appeal rests on a short-sighted prioritisation of genetic relatedness above all other interests. As to Dickenson’s third explanation, Baylis and Cattapan describe how the fertility industry’s huge commercial interests are steering the development and marketing of this reproductive technology. Finally, they argue that ‘the sacredness of personal choice’ has also clearly affected the reception of human nuclear genome transfer. The rhetoric surrounding this technology emphasises the right to have genetically related children who are free of mitochondrial disease, and obfuscates the risks that are at stake, such as the intergenerational effects of altering the genome.

Extending the scope of personalised medicine beyond genomic science into an unexpected and novel area, bioethicist Heidi Mertes applies the concept to ‘Stem Cell-Derived Gametes and Uterus Transplants’. Although both of these experimental techniques are far from being mainstream, they implicitly rely for their justification on the conventional view of ‘reproductive autonomy’ as a personal right. The sacredness of personal choice and the importance attached to genetic parenthood chime with this view. Likewise, the hypothesis that ‘Me Medicine’ derives its popularity from a fear of threat and contamination also seems to be supported by fear of third-party involvement in the

formation of a family, Mertes suggests. However, she concludes that 'it is far from obvious that the desire for genetic or gestational parenthood can trump considerations for the welfare of the future child and for the safety of the other parties involved (in the case of uterus transplantation), or that it can justify resource allocation to these new reproductive technologies.' She ends her analysis by exploring what measures a less individualistic approach to infertility might entail: one rooted in the 'We Medicine' concept of the common good.

Reproductive ethics is also the concern of Jyotsna Agnihotri Gupta, a sociologist who works on reproductive and genetic technologies from a gender perspective, in her original and important study combining media analysis, interviews and participant observation: 'Personalising Future Health Risk through "Biological Insurance": Proliferation of Private Umbilical Cord Blood Banking in India'. Private cord blood banking epitomises 'Me Medicine' in its ostensible concentration on the individual's future well-being, rather than the collective's health, which is better served by public banks. In India, however, public banks are few and far between, whereas private banking is very much on the rise. Gupta provides extensive detail on the Indian private cord blood industry – potentially the largest supplier in the world – along with interview results from patients and doctors alike. Locating the private cord blood phenomenon not only within the 'Me Medicine' framework but also in the literature on risk theory, Gupta documents the construction of a new kind of patient: the 'at-risk' individual who needs a form of personalised medicine from birth: the moment when cord blood is taken.

A different dimension of the tensions between We Medicine and Me Medicine is explored in the chapter, 'Combating the Trade in Organs: Why We Should Preserve the Communal Nature of Organ Transplantation' by Kristof Van Assche. Van Assche, who is a legal expert on organ donation and transplantation, offers a powerful and highly critical examination of recent proposals to introduce elements of free market economics into systems of organ donation. Even if organ selling is still banned in most legal systems, 'as altruistic kidney donation symbolizes We Medicine at its noblest',²⁷ the call for a regulated market in organs is becoming louder in reaction to the continuing shortage in organs. Van Assche's ardent defence of the existing altruistic system rests on two lines of argumentation. His first argument is that a regulated organ market is likely to lead to the exact opposite of what proponents

²⁷ Dickenson, *Me Medicine vs We Medicine*, p. 72.

hope to achieve. As a result of the inability to control all market transactions, such a system cannot prevent organ patients from accessing black markets for organs, either in their own country or abroad. Moreover, a regulated market may crowd out altruistic organ donation. Finally, he stresses the problematic account of autonomy that underlies proposals to allow individuals to sell their organs. In the second part of his chapter, Van Assche expands his critical analysis of regulated markets in organs by connecting the issue with the debate on the commodification of the human body and by engaging with different theories of property. He argues that both utilitarian and Lockean theories of property fail to properly justify property rights in organs. Conversely, according to Van Assche, only personhood theories of property are able to recognise the grave immaterial harms at stake in organ vending.

In her chapter on one of the greatest global challenges in the twenty-first century, Alzheimer's disease – an untreatable disease whose prevalence and financial and social consequences are reaching epidemic proportions – legal scholar Robin Pierce addresses the *We/Me Medicine* aspects of research and development of diagnostic tests and therapeutic treatments. It may well be that Alzheimer's disease is in fact an umbrella term covering a range of separate diseases, some of which have a genetic cause while others do not. Until the cause of and possible treatments for the disease are discovered, research and development clearly falls into the *We Medicine* category, even though some of the diagnostic tests being developed are so complicated and expensive that their widespread deployment could currently only be considered to belong to the realms of research and *Me Medicine*. However, as Pierce powerfully explains, there is a danger that any cures which are developed would be applicable to and affordable by only a small minority. Thus, the development of such cures by commercial entities risks being *Me Medicine* only. Indeed, 'When There Is No Cure: Challenges for Collective Approaches to Alzheimer's Disease' shows that public pressure may be necessary to ensure that cures are developed for more than just a 'favoured few': without deliberate consideration throughout the R&D and translational process, collective approaches to the Alzheimer's crisis may lose ground to commercially more profitable individualised approaches.

In his chapter, 'Lost and Found: Relocating the Individual in the Age of Intensified Data Sourcing in European Healthcare', Klaus Hoeyer, who specialises in anthropology and medical science and technology studies, investigates the implications of 'data sourcing'. To an increasing extent, health data are created, collected, curated, stored and used for diverse

purposes. Denmark is the primary example described in this chapter because the Danish government prescribes a form of solidarity that Hoeyer associates 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 that promotes the common good. 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. Denmark takes a more radical approach to the facilitation of research than the other Nordic countries: since 2014, Danish citizens can no longer opt out from being contacted by researchers wanting further information from them. Hoeyer considers the rights and wrongs of establishing such comprehensive national public health and social information databases, based on what boils down to ‘conscription’ of personal data. Moreover, these data registries are increasingly used by the government to attract international investment in the Danish pharmaceutical industry. Hoeyer argues that the Danish registries hold great promise for the development of new therapeutic treatments and the improvement of current ones, for example, by allowing the identification of unknown side-effects of drugs. Although identifying some Me Medicine aspects in the Danish approach, he concludes that its We Medicine associated benefits outweigh the drawbacks. Nonetheless, a key task is to ensure that the collective goods do not become redirected into private pockets and that collectives help each other to counter individual risks.

In their chapter, ‘Presuming the Promotion of the Common Good by Large-Scale Health Research: The Cases of care.data 2.0 and the 100,000 Genomes Project in the UK’, philosopher and bioethicist Sigrid Sterckx, social scientist Sandi Dheensa and patent attorney Julian Cockbain offer an analysis of recent efforts by the UK government to expand the possibilities for collecting health-related data from UK citizens. The first part of their chapter consists of an examination of the political statements, official reports and legal documents used by the government to introduce both care.data and the 100,000 Genomes Project. In the second part, they build on this analysis to identify several ethically highly problematic aspects of these recent initiatives, such as their underlying consent model. One of the most striking findings of the authors’ ethical analysis is that the UK government tries to promote its policy by appealing to what are essentially We Medicine values. However, as the authors argue, upon closer inspection it emerges that behind this thin

layer of obfuscatory language hides a Me Medicine approach to health data, rooted in what, essentially, is a neoliberal political agenda.

In their chapter, 'My Genome, My Right', sociologist Stuart Hogarth, patent attorney Julian Cockbain and bioethicist Sigrid Sterckx consider the claim that people have the right to *access* their genomic data, e.g. using direct-to-consumer genetic testing companies such as 23andMe, and that that right extends to the use (and publication) of such data in any desired way. In effect, the claim is to an *ownership* right that corresponds to the central libertarian claim to self-ownership of the body and all body material. The authors, however, argue that the libertarians conflate a right to ownership of material, a rivalrous good, with a right to *own* information, a non-rivalrous good to which others may also legitimately claim control rights since genetic information is shared with relatives, at least. Accordingly, while the authors propose a human right to access personal genetic information, subject to regulatory control to ensure counselling where appropriate, they argue that, to protect the rights of others, not least to privacy, the person has no right to publish their 'own' genetic data. The 'Me Medicine' of personal control is trumped by the 'We Medicine' of privacy.

"The Best Me I Can Possibly Be": Legal Subjectivity, Self-Authorship and Wrongful Life Actions in an Age of "Genomic Torts", written by legal scholar and philosopher Britta van Beers, demonstrates the necessity of a legal perspective on personalised medicine. This chapter demonstrates how the 'person' in personalised medicine is connected with the legal understanding of a 'person' as a bearer of legal rights and responsibilities. However, this emphasis is changing. In her analysis of new types of legal claims that affect the law's understanding of the 'person', van Beers focuses on the emerging area of 'genomic torts'. Who, if anyone, is liable to compensate the children or their parents if children are conceived and born with disabling conditions that could have been detected or predicted before birth, or sometimes even before conception? Should responsibility lie with the physician who fails to offer appropriate tests, the parents who, knowingly or not, allow pregnancy to go to term, or society in general? Recently, two forms of legal action have come into focus: wrongful birth (an action against the physicians by the parents) and wrongful life (an action against the parents by the children). Britta van Beers investigates two different interpretations of a wrongful life claim (a right not to be born or a right to be born in a different body) and explains why both are problematic. Interestingly, she also discusses the potential effects that recent developments in gene-editing, such as the

CRISPR-Cas9 technique, may have on wrongful life actions. Moreover, gene-editing and preimplantation diagnostics run the risk of enhancing parental antenatal and pre-conception obligations and of transforming the responsibility for ensuring the welfare of the handicapped child from being a societal responsibility into a personal one. The analysis undertaken by van Beers clearly shows why wrongful birth and wrongful life claims are emblematic of a Me Medicine approach to regulation, i.e. an approach that views the legal issues involved in reproductive medicine as disputes between *individuals* about *personal* rights and entitlements, and why we should be concerned about the radically individualistic model of self-authorship that underlies this approach.

In their innovative chapter, 'I Run, You Run, We Run: A Philosophical Approach to Health and Fitness Apps', philosopher Marli Huijer and design researcher and philosopher Christian Detweiler focus on self-tracking technologies as a new kind of Me Medicine. Also known as *Quantified Self* or *Personal Informatics*, these popular applications ostensibly reflect the individualistic enhancement ideal of 'becoming the best Me I can possibly be'.²⁸ However, Huijer and Detweiler question whether these technologies do actually empower individuals. A Foucauldian analysis, they argue, might instead suggest that 'there is concern that personal informatics technologies submit their users to disciplinary forces that seduce or force the individual to take responsibility for their own health' as a means of governing the self, a form of voluntary self-surveillance. By expanding the scope of what counts as personalised medicine and sceptically questioning its rhetoric of individual choice and empowerment, the authors offer an unexpected counter-analysis to the prevalent optimistic discourse on precision medicine.

Similar concerns are further developed from a psychoanalytical perspective by philosopher of science Hub Zwart in his chapter, 'The Molecularised Me: Psychoanalysing Personalised Medicine and Self-Tracking'. The emergence of wearable tracking devices can be seen as a 'second revolution', bringing together paradigm shifts in computer technology and genomic sequencing. A 'quantified self' has emerged: what Zwart calls 'a digital version of the superego'. Self-knowledge in this new context links to but transcends narcissism: as Zwart puts it, 'Self-tracking devices purport to provide access to our molecularised unconscious.' Supposedly, these developments transform us all into proactive and empowered bio-citizens, reducing physicians to mere assistants or

²⁸ Dickenson, *Me Medicine vs We Medicine*, p. 113.

managers and promoting the ideal of citizen health science. But do they actually represent a new form of surveillance like Jeremy Bentham's panopticon? – what Zwart calls 'a ubiquitous electronic panopticon, a molecularised version of the super-ego, the voice of conscience of the terabyte age'. Like Huijer and Detweiler, Zwart is concerned that this enhancement-orientated form of Me Medicine actually forces a powerful new form of discipline on its users, rather than increasing their autonomy.

Each chapter in this book in its own way offers a critical examination of the grand claims made by the 'evangelists' of personalised medicine. Does personalised medicine truly bring about a revolution in medicine by offering tailor-made medical treatment? Can this new approach indeed do justice to patients' biogenetic uniqueness and as such empower them to make better-informed choices about their health? Which values and interests are championed by Me Medicine's promissory discourse, and which are neglected? And how can the sudden rise and wide appeal of personalised medicine be explained?

As both the disciplinary richness of the chapters and the wide variety of themes with which they engage indicate, the increasing dominance of Me Medicine approaches over We Medicine approaches is also intimately connected to other developments, such as the hegemony in bioethics and biolaw of the principle of autonomy,²⁹ the dominance of rights discourse at the cost of attention for more collective interests,³⁰ the commodification of the human body³¹ and human reproduction,³² and

²⁹ For critical discussions of the primacy of autonomy in bioethics in the context of genomics, see, *inter alia*, Bartha M. Knoppers and Ruth Chadwick, 'Human genetic research: Emerging trends in ethics' (2005) 6 *Nature Reviews Genetics* 75–9; Michael J. Sandel, *The Case Against Perfection: Ethics in the Age of Engineering* (Cambridge, MA: Harvard University Press, 2007); Heather Widdows, *The Connected Self: The Ethics and Governance of the Genetic Individual* (Cambridge: Cambridge University Press, 2013).

³⁰ Mary A. Glendon, *Rights Talk: The Impoverishment of Political Discourse* (New York, NY: Free Press, 1991); Costas Douzinas, 'The paradoxes of human rights' (2013) 20(1) *Constellations* 51–67.

³¹ Margaret J. Radin, *Contested Commodities: The Trouble with Trade in Sex, Children, Body Parts, and Other Things* (Cambridge, MA: Harvard University Press, 1996); Donna Dickenson, *Body Shopping: The Economy Fuelled by Flesh and Blood* (Oxford: Newworld Publications, 2008).

³² Michele Goodwin (ed.), *Baby Markets: Money and the New Politics of Creating Families* (New York, NY: Cambridge University Press, 2010); Britta van Beers, 'Is Europe "giving in to baby markets?" Reproductive tourism in Europe and the gradual erosion of existing legal limits to reproductive markets' (2014) 23(1) *Medical Law Review* 103–34.

the datafication of healthcare.³³ One of the aspirations of this book is also to contribute to academic reflection on these important themes.

Moreover, although it is true that the chapters in this book generally focus on Me Medicine's more problematic aspects, it would be too easy to conclude that the book's central message is that personalised medicine is bad news and that efforts in this field should therefore be abandoned. Instead, it is our hope that, by exploring the frictions between Me Medicine and We Medicine, between *individual choice* and the *common good*, this book can fuel and stimulate the debate about personalised medicine and enable its participants to come to a more balanced understanding of the interests and values at stake.

³³ Jonathan H. Chen and Steven M. Asch, 'Machine learning and prediction in medicine – Beyond the peak of inflated expectations' (2017) 376 (26) *New England Journal of Medicine* 2507–9; K. A. Oye, G. Jain, M. Amador et al., 'The next Frontier: Fostering innovation by improving health data access and utilization' (2015) 98 (5) *Clinical Pharmacology & Therapeutics* 514–21.