Preface and Acknowledgements

For many years my work has focused on the governance of DNA technologies. From this perspective saw personalized medicine mostly as a new buzzword, a way of labeling old practices in a different way to open new doors for funding. It was during the European Science Foundation’s Forward Look on Personalised Medicine for the European Citizen (ESF 2012), a two-year long scoping and consultation exercise that I had the privilege of helping to lead, that I was convinced of the deeper significance of personalization. Many practitioners, scientists and policy makers that I spoke to in those years and the years that followed, from Europe, North America, the Middle East and other parts of the world, saw personalization as a way to use technological advance to make medicine more “precise”. But many of the same people also saw it as an attempt to address the challenges posed by rising healthcare costs and aging societies. They regarded it as a cost-saving strategy with patients in the driver seat. And the role envisaged for patients went far beyond having to manage individual risks: One of the key tenets of personalized medicine is its data-driven nature, including wider ranges of data than clinical or medical ones. Many of its proponents are very open about the fact that patients need to play a key role also in collecting and “sharing” these data.

At the same time as the work required from patients expands, their influence over what data and information will be used, how they will be used, and for whose benefit, is waning. The “tapestries of health data” that are envisaged to underpin medical practice and research are prescriptive in what they can include and what they cannot. Narrative, unstructured information and “subjective” meaning have little room in them, and data and information from marginalized
populations are often not included at all. This all stands in a clear tension with the pronounced rhetoric of patient empowerment and patient participation. The mission of this book is to address this seeming paradox. Why is it that the work required from patients is becoming more expansive and less self-directed at the same time as the flag of patient empowerment and participation is raised over ever wider territories in medicine and healthcare?

A lot of people and institutions have supported this book project. I am deeply grateful to the Rockefeller Foundation for inviting me to spend a month at their Bellagio Center in the summer of 2016. I had planned to use that month to try to forget about personalized medicine and start a new project. I ended up doing the opposite: I forgot about my new project and started rewriting the book. The final manuscript has benefitted greatly from numerous conversations with my fellow residents, including Isher and Montek Ahluwalia, David Autor, Kate Bredeson, Edith Brown Weiss, Medora Dutton Ebersole, Alec Freund, Matthew Goulish, Ann Hamilton, Ben Hecht, Lin Hinxson, Lynn Leibovitz, Michael Mercil, Pam and Jim Murray, Eric Nordstrom, Auma Obama, Kate O’Regan, Tania and Antonio Patriota, Sanchita and Somitra Saxena, Stephen Rapp, Donatha Tibuhwa, Charles Weiss, and Karl Zimmerer. I am particularly grateful also to the Center’s managing director, Pilar Palacia, and everybody else at the Foundation and the Bellagio Center who has made our time there so special.

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Technical Terms and Acronyms

ALS: *Amyotrophic Lateral Sclerosis*, a rapidly progressive neurological disease that is also called Lour Gehrig’s disease, or motor neurone disease.

Amygdala (pl. amygdalae): Two almond-shaped parts of the brain that play an important role in decision making, memory, and emotional reactions.

BOP consumers: “Bottom of Pyramid” consumers—the largest but poorest people in the world.

Care.data: A program that would have allowed the English NHS to share patient data with healthcare organizations and commercial companies in the UK and beyond. It led to public resistance due to an alleged lack of transparency about the goals of the program and the plan to have patients opt-out instead of opt-in.

Crowdsourcing: A composite of the words “crowd” and “outsourcing”, i.e. the enlisting of large numbers of people (crowds) in a task, often online.

CSR: *Corporate Social Responsibility* refers to programs and strategies that combine profit-maximization with the creation of social benefits.

CT: *Computed tomography*, a technology in medical imaging

Deep phenotyping: A person’s phenotype comprises her actual physical, personal and behavioral characteristics (to be contrasted with genotype). Deep phenotyping refers to the description of (often disease-related) phenotypes using a data-rich approach.

DTC: *direct-to-consumer*

Epigenetics: The study of changes in organisms stemming from modifications of gene regulation or expression rather than changes in the DNA-sequence.
ESF: The *European Science Foundation* is a non-governmental non-profit association of research organizations in Europe and beyond.

EU: *European Union*

FDA: The *Food and Drug Administration* is the U.S. government agency responsible for approving medical products, including pharmaceutical drugs and medical devices.

FTC: The *Federal Trade Commission* is an independent agency of the U.S. government, tasked with consumer protection and anticompetitive business practices.

GBM: *Glioblastoma multiforme*, one of the most aggressive and most common brain tumors.

High-throughput technologies: The computational tools and methods that enable the simultaneous and rapid examination of large amounts of genes, proteins, and other substances.

HIPAA: The *Health Insurance Portability and Accountability Act* was passed by the U.S. Congress in 1996 and established a set of national standards for the protection of certain types of health information.

Hippocampus (pl. hippocampi), parts of the brain that play important roles e.g. in memory and special processing.

IOM: *The Institute of Medicine* is a division of the National Academies of Science, Engineering and Medicine (NAS).

IoT: The term *Internet of Things* refers to connected computing devices (such as sensors) without requiring human-to-human or human-to-computer interaction. Some people expect that our entire physical environment will start to wirelessly “talk to” one another in this way.

IP address: *Internet Protocol address*, a numeric label assigned to a device participating in a computer network.
MRI: *Magnetic resonance imaging*

MS: *Multiple sclerosis*

NAS: U.S. *National Academies of Science, Engineering and Medicine* are private non-profit institutions providing expert advice to policy makers, funders, etc.

NHS: *National Health Service*, the public health services of England, Scotland, and Wales

NIH: The *National Institutes of Health* in the United States is a research agency within the U.S. Department of Health and Human Services

ODL metrics: Metrics for *observations of daily living*. ODL metrics can be very personal sensory and behavioral indicators for the purpose of health monitoring (and often also for behavior modification)

Privacy-by-Design: An approach committed to designing privacy-enhancing measures into hardware and software. It was originally developed by Ontario’s Information and Privacy Commissioner Ann Cavoukian and is now enshrined in laws and regulations including the General Data Protection Regulation in Europe.

Privacy-by-Default: An approach that prescribes that only the minimum set of personal data necessary for a purpose should be processed, and that service providers need to offer customers the strictest possible privacy setting by default. It is enshrined in the General Data Protection Regulation in Europe.

PROM: *Patient-reported outcome measures*

Prosuming: A composite of the words “producing” and “consuming”, referring to the practice of users or consumers creating value for corporations by producing some of the content or products that they then consume (e.g. social media)
Redlining: The discrimination of specific of people on the basis of socio-economic, behavioral, or other profiling. Redlining is often used to refer to practices that are not illegal (such as not offering certain discounts in specific ZIP-codes, or not offering shipment to some regions)

Smart glasses: Eye glasses that are wearable computers

Social biomarkers: information reflecting non-somatic characteristics of patients that matter to them in connection with their healthcare

STS: *Science and Technology Studies*, an interdisciplinary field of studying how scientific knowledge and technologies are produced in conjunction with social and political order.

Theranostics: A composite of the terms “therapeutics” and “diagnostics”. It refers to strategies to combine diagnostic and therapeutic capabilities in one single agent or process to tailor both more closely to individual characteristics and needs of patients.