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Routledge Handbook of Genomics, Health and Society

Edited by Sahra Gibbon, Barbara Prainsack, Stephen Hilgartner and Janelle Lamoreaux

Handbook of Genomics, Health and Society

The *Handbook* provides an essential resource at the interface of Genomics, Health and Society, and forms a crucial research tool for both new students and established scholars across biomedicine and social sciences. Building from and extending the first *Routledge Handbook of Genetics and Society*, the book offers a comprehensive introduction to pivotal themes within the field, an overview of the current state of the art knowledge on genomics, science and society, and an outline of emerging areas of research.

Key themes addressed include the way genomic based DNA technologies have become incorporated into diverse arenas of clinical practice and research whilst also extending beyond the clinic; the role of genomics in contemporary 'bioeconomies'; how challenges in the governance of medical genomics can both reconfigure and stabilise regulatory processes and jurisdictional boundaries; how questions of diversity and justice are situated across different national and transnational terrains of genomic research; and how genomics informs – and is shaped by – developments in fields such as epigenetics, synthetic biology, stem cell, microbial and animal model research.

Presenting cutting edge research from leading social science scholars, the *Handbook* provides a unique and important contribution to the field. It brings a rich and varied cross disciplinary social science perspective that engages with both the history and contemporary context of genomics and 'post-genomics', and considers the now global and transnational terrain in which these developments are unfolding.

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Handbook of Genomics, Health and Society

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Edited by Sahra Gibbon, Barbara Prainsack, Stephen Hilgartner and Janelle Lamoreaux

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1

Introduction to *Handbook of Genomics, Health and Society*

Sahra Gibbon, Barbara Prainsack, Stephen Hilgartner and Janelle Lamoreaux

As we reflect on the period between the publication of the first edition of this *Handbook* in 2009 and the second edition, a great deal seems to have changed. In terms of scope, scale and speed, genomic technologies have become increasingly embedded within different health care and research arenas. In the process, the 'new genetics' seems to have seamlessly segued into genomics, even post-genomics including epigenetics. At the same time, while some of the core themes raised in the first edition, including questions of ethics, regulation and commercialisation, remain vital to current social science engagements with the evolving terrain of genomic science and medicine, these are increasingly seen through the lenses of justice, governance and the bioeconomy. Such shifts are in part reflected in the thematic focus (and renamed title) of the current Handbook that places Genomics, Health and Society centre stage. Whilst recognising that what constitutes 'health' in an era of genomics remains contested, inequitably distributed and not always easily defined, the renamed title reflects how 'health', broadly construed, has been and continues to be a vital resource, a site of transformation and a tool in the reshaping of genomics and society. In this sense, the new title points to the focus of the volume on genomics in human health-related contexts, and not, for example, forensics or environmental genomics. While the discussions in this volume do touch upon many areas beyond health, given the expansion and growth of genomic technologies in fields outside of health, we have had nevertheless to limit the area which we can claim to cover systematically.

We argue that the 'novelty' of the present moment in genomic research related to 'Health and Society' might be characterised in terms of a series of tensions, contradictions and paradoxes. Whilst these can propel different fields of research and medical care at particular intersections, they can also at times pull against each other. Some of these dynamics reflect themes that have long been entangled with historical and contemporary change in genetic science and medicine, such as individual rights versus societal obligations. Yet there are new dimensions at stake also, particularly when as Sabina Leonelli succinctly highlights, genomic practices are 'caught in a web of technical acceleration, societal changes and logistical chaos' (this volume). We identify four cross-cutting themes in the *Handbook* that reveal the porous and fluid boundaries of topics and themes related to Genomics, Health and Society.

'Genetics for the world?';[1] globalising genomics, national histories and inequities

One of the novel themes illuminated in this edition of the *Handbook* is the global terrain on which genomic research, technologies and medical interventions are unfolding and the way that this process constitutes dense and complex intersections between the so-called global 'north' and 'south'. National governments throughout the world, multinational corporations that operate throughout it, and transnational scientific communities are all engaged in building genomic medicine. Interest and investment in genetics by international organisations such as the WHO has a long history. But the increased use of genomic tools and techniques in low income countries for addressing health care challenges and the widening global market for genomic information delineates a current moment of transnational expansion.[2] In this expansion, compliance of practices and tools with international standards is an important consideration. Yet standardisation is not the only outcome with national or local regional contexts, practices and concerns continuing to shape developments in genomic science and medicine. This is the case within as well as between North America and Europe and also in and at the interface with other regions of the world (Sleeboom-Faulkner, 2011, Fullwiley, 2011, Wade et al., 2014). Consider how differently prenatal testing is configured in, say, North America than in China, where an emphasis on 'population quality' and 'good births' informs how 'choice' is configured in the context of prenatal testing (Zhu, this volume). Or consider the diversity of stem cell research, which is simultaneously a 'global biological' (Franklin, 2005) and a locally shaped practice (Thompson, 2010, Bharadwaj, 2013). As Jennifer Liu puts it, the often used label of 'Asian Tiger' belies a resistance to standardisation when it comes to stem cell research in certain national and international contexts (this volume).

The increased transnational expansion of genomic research and technologies is often rhetorically and practically tied to 'humanitarian' efforts to widen inclusion, access and participation (within) and far beyond the 'global north'. However, this very process can at the same time also reveal the stark inequities that have and continue to shape these developments (Prainsack; Fullwiley and Gibbon, this volume). This therefore constitutes another central tension that cuts across the chapters in this *Handbook*. We see how both colonial and postcolonial histories of scientific research and entrenched 'power asymmetries' continue to have a central place in the way genomic research and medicine is being extended, even if improving the health of the poor is often the laudable, if still somewhat elusive, aim of such actions.

In this sense, the comparative and transnational perspectives offered by many chapters in the *Handbook* reveal the 'frictions' and 'zones of awkward engagement' (Tsing, 2005) that characterise genomics as a global enterprise and which remain a key and ongoing focus of concern and analysis for social science research.

Stability and instability in 'post-genomics'

Another particularly striking theme in the new edition of this volume is the frequency with which stability and instability now enter into conversations of (post-) genomic research. Social scientists of science who previously challenged scientific black boxing, reductionism, and determinism, now often find themselves studying biological fields that embrace theories of complex systems, multifactorial causalities, and intricate interaction between genes and what stands outside them. While there is widespread acknowledgement that the genetic inheritance of disease is, with few single-gene exceptions, a process involving multiple factors, biomedical professionals, patients and other users of genetic data often seek stability in messy genetic

information. (Post-) genomic instability, then, does not replace genetic stability, but conscripts a history of presumptive solidity into the assumed variability of the present.

Contributions in this volume point to a variety of sites where tensions between new and old, stability and instability, impact scientific practices in genomic research and treatment settings. Martyn Pickersgill's contribution, for instance, discusses the way epigenetic research in brain science does not necessarily move health policy in new directions; instead 'novel articulations of the imagined biological potentially reify policy paths already mapped or trod' (this volume). Other examples include the ways that the growing field of genetic counseling (Löwy, this volume) and the increase in personal genetic testing (Kelly, Harris and Wyatt, this volume) raise complicated issues about how genetic instability is potentially translated into what is often interpreted as stable information when shared with patients and consumers. Genetic instability, and the increased orientation of the social and natural sciences toward complexity, interaction and temporal change, leaves those striving to improve health outcomes with a multiplicity of paths forward.

Today instability comes not only in the form of new genomic theories, where genes exist and express only in relation to a variety of environments across time and space. Instability also comes in the ways that disciplinary boundaries, and lines between the social and biological sciences, are being transgressed. While such genomic and disciplinary instabilities do not replace stable genetic theories or institutional mechanisms, the flux characterising the contemporary moment does create a propensity for many social scientists to experiment with what have been called 'biosocial', 'biocultural' or 'bioethnographic' approaches (Ingold and Palsson, 2013; Roberts, 2015; Callard and Fitzgerald, 2015). Such interdisciplinary research often attempts to bring experts from the social and natural sciences together, resulting in collaborations with mixed degrees of success (see Scott, Berry, and Calvert, this volume). Bringing genomic and social scientists together potentially creates concomitant research (see Benezra, this volume) or para-ethnography (Nading, 2016) that hopes to improve health outcomes across geographic and species boundaries – a multispecies co-flourishing (Haraway, 2008). But some fear that the disciplinary instability on which such theories of health rest also risks the loss of distance necessary to enable critical perspectives (Helmreich, 2015). As with the present moment of (post) genomic instability, disciplinary flux inspires both optimistic and pessimistic forecasting of futures.

Big data as 'biofuel'

An important new actor that has entered the stage since the first edition of the *Handbook* is 'big data'. There are various definitions of the concept, ranging from references to work with very large datasets, to new epistemologies that focus hypothesis-free data mining, to the view that only comprehensive datasets (N=all) deserve this name. But like DNA, the concept of big data has also developed a mystique, becoming a new cultural icon (Nelkin and Lindee, 1995). One might say that big data are the genes of the twenty-first century: they fuel imaginations about what genomics can and should do, they determine the status and power of research groups, shaping access to funding and other resources. *The Economist* called data the new fuel of our economies (N.A., 2017). Data have certainly already become the fuel of bioeconomies – the system of processing, selling and consuming biological resources, as discussed below.

Social scientists have criticised aspects of these trends. Media studies scholar Gina Neff famously warned of the temptation to invest more money merely in collecting more data; to create benefits for patients we need to do more than collect and integrate data. We need to understand what they mean. We need to enhance not only the technical but also the social interoperability of our systems. In Neff's words, 'big data won't cure us' (Neff, 2013). We also

need to avoid the danger of treating unstructured information such as patients' stories, values, and practices – information that is meaning-full – as worth-less in this context. If the focus on information that is easily quantifiable and/or readily available in digital formats comes at the cost of what is meaningful for patients, then this would also have a negative effect on current efforts to personalise medicine. What kind of person would this type of medicine serve? (Reardon, 2011; Prainsack, 2017)

The trend toward personalised medicine also highlights another concern, namely control over data use. The data used to tailor prevention, diagnosis and treatment more closely to the individual characteristics of patients have 'escaped the clinic' (Leonelli, this volume; Nettleton 2004); they are coming from a range of contexts including people's digital devices, their homes, and public archives (Weber, 2014). This means that what is at stake here is no longer merely individual privacy as we know it; it is the ability of people – both personally and as a collective of citizens – to have a say over what information about them is collected, used, shared, and for what purpose.

Innovation and value

Another cross-cutting theme in the collection is the increasing prominence of imaginaries of genomics and post-genomics as a source of innovation and value. Since the Human Genome Project (HGP), visions of high-throughput analysis of biological data leading to dramatic improvements in health and significant economic opportunities have inspired many actors, stimulating investments of money, talent, and hope in the possibilities of the 'bioeconomy'. The emergence of this term as prominent policy buzzword in the latter half of the 2000s was not merely a matter of attaching a new label to the biotechnology industry. It also marked the growing salience of new visions of the *value* of genome-based knowledge and technology, expressed by authorities in government, finance, and biomedicine, as well as by patient advocacy groups and many others. The bioeconomic futures that they promoted were not always neatly aligned, but contradictions and slippages did not prevent the formation of a 'discourse coalition' (Hajer, 2009) that made the bioeconomy into an object for policymakers, investors, and others to care about and seek to nurture.

A macro-level conception of 'the' bioeconomy as a policy object cannot be taken at face value, however. For one thing, as genomic technologies have grown increasingly entrenched in biomedical research and practices, the transformation of medicine and health care has proceeded more slowly than anticipated, and investment has been sustained more by the perpetual renewal of its future promise than by actual delivery of new cures or spectacular profits (Martin, this volume). For another, specific bioeconomies – implicating particular materials, forms of knowledge, actors, and social relations – are taking shape, as new patterns of circulation (often global ones) are transforming political economies of health (Sunder Rajan, 2017). Contributors to this volume raise pressing questions about emerging bioeconomies and the political economies (Birch, this volume) and gender politics (Lamoreaux, this volume) that they instantiate and reflect.

The challenges of governing innovation in genomics has been a salient concern of science policymakers and social analysts alike. Since its earliest days, genomics has been a site where new forms of knowledge and new regimes of control have been co-produced (Hilgartner, 2017). The contributors to this volume explore how governance of medical genomics has become a complex, distributed process involving a variety of regulatory mechanisms, both formal and informal, that are often contested (Cambrosio et al. this volume; Hogarth, this volume). Extant formal regulatory frameworks and concepts are often challenged by developments, and jurisdictional boundaries, both formal and informal, are being reconfigured (Dove,

this volume). At the same time, at a deep, quasi-constitutional level, sociotechnical imaginaries (Jasanoff and Kim, 2015) help to stabilise allocations of authority grounded in the (intellectually indefensible) ontology of the linear model of innovation (Hurlbut, this volume).

With these overarching themes in mind we have organised the *Handbook* in relation to five key areas of cross disciplinary social science inquiry and investigation. The first section, edited by Sabina Leonelli, entitled 'Genomic Based DNA Technologies in the Clinic and Beyond', presents a series of chapters which explore how (both historically and in the contemporary moment) genomic knowledge, technologies, and medicine have become central to certain fields of clinical practice, whilst also exceeding and extending beyond the confines of the clinic. Chapters in this section reflect on the ongoing scope and limits of biomedicalisation in the context of a shifting terrain of genomic medicine (Bliss); the consequences of 'scaling' up technologies and incorporating 'big data' in the clinical arena (Leonelli and Tempini); and the way personal genetic testing is being uneasily and unevenly 'mainstreamed' into health care practices (Kelly, Wyatt and Harris). The final two chapters, each using a somewhat different lens, focus on one area of medical intervention, reproductive genetics, which has been profoundly changed by developments in genomics. These two chapters provide a complementary perspective focusing on the historical evolution of genetic testing and counseling (Löwy) and an in-depth examination of prenatal genetic testing in contemporary urban China (Zhu and Dong).

Our second section, edited by Claire Marris, addresses 'Genomic Technologies in the Bioeconomy'. As Marris points out in her introduction to the section, what a social science perspective brings to the table here starts with a different take on the notion of bioeconomy. While in the life science community, economics, and policy, the bioeconomy is typically seen as the system of production, exchange and consumption of renewable biomaterials such as fish, wood, or human materials, critical social science work has challenged some of the assumptions and expectations underpinning dominant discourses on the bioeconomy. It has in fact scrutinised the productive (in the literal sense of the word) role of expectations in the bioeconomy as such. Contributions to this section show – from different perspectives – how the bioeconomy is not just about getting value from biological things, but is also about transforming the organisation and conduct of science and innovation (Martin; Chiapetta and Birch). An example of this is the rise of public-private partnerships as a template for innovation due to the alleged 'productivity crisis' in drug development (Nik-Khah), which is accompanied by a de-politicisation of science and research governance (Felt). Because the biological is seen as mutable, interventions into the biological seem a particularly promising form of investment (Pickersgill); value cannot only be extracted from the processing, selling and other uses of biomaterials but also from intervening into the renewal of these materials. Expectations from, and interventions into, the 'renewal' of biomaterials in turn has tangible social dimensions. Not only because these expectations and interventions are shaped by ideas about what purpose materials should serve, but also because in the human domain, biological materials are always also racialised and gendered (Lamoreaux).

Our third section, edited by Stephen Hilgartner, addresses the 'Governance of Medical Genomics'. As the chapters in this section show, governance of genomics is a contested domain in a variety of sites. The first chapter reviews the history and legacy of the Human Genome Project's ethics programmes (ELSI and ELSA), arguing that the institutionalisation of such programmes – a novel mode of governing emerging technologies – is a significant development in contemporary politics (Hilgartner). The next chapter (Parthasarathy) uses comparative analysis to reveal and explain differences in how patent offices in the United States and the European Union managed the politics of biotechnology patents on human genes and life forms. Turning

to the governance of clinical research, Cambrosio et al. argue that genomic platforms are sites where new technologies, new conceptualisations of the goals of clinical trials, new organisational routines, and new regulatory landscapes are taking shape and being brought into alignment. The subsequent chapter focuses on how regulatory agencies have addressed the challenges of evaluating genomic diagnostics in Europe and the United States (Hogarth), illustrating the complexity of this domain and outlining areas for future research. Control over personal genomic information in European Union law is the subject of the chapter by Edward Dove, who argues that traditional regulatory approaches, such as 'consent or anonymise', have serious limitations in the new environment in which genomic and other medical information circulates. The final chapter (Hurlbut) addresses the politics of governing technologies for editing the human germ line, such as CRISPR. Taken together, these chapters offer a picture of the dynamic changes in modes of governance now underway, while at the same time pointing out some continuities (e.g., in allocations of epistemic authority) that have contributed a degree of stability to this area of transformational change.

The fourth section edited by Sahra Gibbon and Barbara Prainsack revisits the theme of 'Diversity and Justice', which has both endured and diversified in the time between the first Handbook and the current edition. Chapters in this section examine how questions of equity, ethics and rights interweave and are folded into a range of genomic developments. Two chapters show how the complex inter-relationships between disability, eugenics and enhancement have been and should continue to be of central and ongoing relevance and concern for social scientists examining genomic technologies and medical interventions (Scully; Cavaliere and Camporesi). Other chapters provide perspectives on the framing of genetic discrimination by the insurance industry (van Hoyweghen) and the new form of participation in genomic research created by state and corporate interests (Prainsack). Both these chapters illuminate the inherent politics and power asymmetries that are entailed in foregrounding issues of 'solidarity' and a wider collective inclusion across an evolving terrain of genomics. Unpicking the complex issues and challenges that endure at the interface between race, genomics and health disparities is also the central concern in one of the chapters in this section (Lee). Our final chapter in this section comparatively examines how different histories of medical and population genetic research in Brazil and across the African region shape contemporary engagement with genomic research. This not only informs questions of 'diversity' but how wider concerns with ethics, social justice and inclusion are central to engagement with genomics in emerging and developing economies (Fullwiley and Gibbon).

Our final section, edited by Janelle Lamoreaux, brings together a collection of chapters through the new theme of 'Crossing Boundaries'. Each chapter in this section investigates emergent areas of genomic research – from epigenetics to microbiomes to synthetic biology – and discusses the ways in which such areas (claim to) cross a variety of boundaries – from disciplinary limits to species borders. The first two chapters discuss epigenetic research. The first provides a history of epigenetics and thinks through how Waddington's epigenetic landscape remains relevant in contemporary behavioural genetic research (Lock). The second introduces a critical perspective on epigenetics through the idea of scale, concentrating specifically on studies of suicide risk (Lloyd and Raikhel). The next chapter discusses the global and local characteristics of stem cells, emphasising ethnographic findings from research in Taiwan (Liu). We then turn to a conversation on the increasingly complex considerations of environments in genomic research utilising animal models (Friese), which is followed by a chapter on the natural and social sciences of the microbiome (Benezra). The next chapter provides a discussion of the historical importance of studying how epistemic cultures are both protected and crossed through the example of behaviour genetics (Nelson and Panofsky). The section ends with a

critical analysis of a field that once epitomised boundary-crossing, but that authors provocatively now suggest might be best left behind: synthetic biology (Scott, Berry and Calvert). Collectively these chapters suggest that while emergent genomic research often crosses epistemological and ontological boundaries in unexpected ways, some categorical and empirical limits are more obdurate.

Notes

1 This heading is taken from the title for an article in *Nature* by Bustamante et al. (2011).
2 See work being undertaken by Gaudilliere, J.P and Beaudevin, C. et al. as part of the ERC Advanced Grant 'GLOBHEALTH; From international public health to global health', ERC advanced grant 2014–2019, http://globalhealth.vjf.cnrs.fr.

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Part 1

Genomics and DNA-based technologies in the clinic and beyond

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2
Introduction

Sabina Leonelli

The role of genomics in society has become ever more entrenched within the last decade. This is partly due to advances in technologies and particularly sequencing tools, which have transformed the act of obtaining an individual's genetic pedigree from an esoteric, labour-intensive, costly exercise to a largely automated, relatively affordable and mundane practice. It is also a result of the increasing globalisation of DNA-based technologies, which have been picked up by health systems, governments, insurance companies and data analysts all over the world, thus becoming more and more of a platform for international dialogue around understandings of health and disease. Given these developments, it is tempting to think of this historical moment as a "postgenomic" one in the sense that DNA-based tools – and related ideas about human nature and wellbeing – have irrevocably and fully established themselves across cultures and social customs, thus creating a uniform reference point for biomedical practice. And yet, talk of postgenomics can be interpreted very differently. It can indicate the increasing awareness by the public at large (including biomedical researchers and physicians) of how difficult and complex it is to interpret genetic results, and thus to create any generalised understanding of biological process and therapeutic intervention (Richardson and Stevens 2015) or ways to exploit advances in genomic understanding to effectively target the unique characteristics of individuals and groups (Green and Voigt 2016). Postgenomics can also be taken to mark the increasingly hegemonic institutional, corporate and regulatory landscapes in which DNA-based technologies are taking root (Peterson 2014, Sunder Rajan 2017, Murphy 2017), and the myriad questions surrounding their prominent status within and beyond biomedical and clinical environments around the globe (Bliss 2017, Reardon 2017). In short, postgenomics can and arguably should be viewed as marking the tension between the growing entrenchment of genomic practices within medical practices and markets, and the enormous logistical, scientific and moral challenges posed by enacting genomic knowledge and tools across very different medical regimes, skillsets and patients.

It is becoming ever more apparent that while technology may help enormously in making genomic sequencing and related tests increasingly affordable and available, the challenges involved in managing and interpreting the resulting data have in no way lessened. If anything, the hard problems confronted when attempting to decide who should have access to genetic data, and to do what, have acquired a new degree of severity due to the overarching shift in

discourse, practices and commercial interests around big and open data (Ebeling 2016, Leonelli 2016). Calls to view, handle and value data – and particularly personal health-related data – as sources of economic and political power are proving increasingly convincing, in the face of systems of data gathering and dissemination that exclude large parts of the population, are subject to very few restrictions concerning potential misuse and misinterpretation of the data at hand, and function as systems of citizen surveillance, protection and service provision all at the same time. Furthermore, some types of data are systematically favoured over others for technical and commercial reasons, again calling for an assessment of what such selective gaze implies for different social groups and activities. Genomic data in particular are often prioritised, thanks to their digital, portable format, their embedding in well-entrenched and highly marketable medical technologies and ways of knowing, and their continuing privileged status as quantitative documents of people's biological inheritance.

What at the turn of the century was mostly a worry for technical experts is now becoming acknowledged in public discourse: creating data may be relatively easy, but preserving them, protecting them and analysing them is difficult and expensive. Even more difficult is deciding who has the expertise and power to take care of such data and use them to extract biomedical insights, ground political and economic decisions, and shape perspectives on the future – and what responsibilities and accountabilities are involved in this process. This is particularly true in a world where internet communication and related technologies are ubiquitous, and yet the capacities to exploit those technologies are very unevenly distributed, and the ways in which they manifest themselves in specific situations, across geographical locations and cultural norms, continues to vary enormously. Contemporary information and computing technologies may make it easier for people to communicate, but who is communicating what to whom around the use of genetics in society, and with which results, interpretations and purposes? And how does such communication unfold in the contemporary political context, where nationalism and populism are on the rise in several high-income countries, and attitudes to national borders, cultural diversity, the threat posed by movements of people and related biological materials, and the legitimacy of scientific expertise are shifting?

These are the questions that motivate the first section of this new handbook, where authors examine the most recent developments in genomic and DNA-based health technologies, and bring fresh perspective on their social and scientific role that takes account of the evolving political landscape. Catherine Bliss starts off the section with a comprehensive review of contemporary instantiations of *biomedicalisation*, which she proposes as the lens that 'helps us ascertain the major shifts in today's social order around the expansion of biomedicine'. Her discussion includes the role and goals of medical care and the pervasiveness of molecular conceptions of biomedicine in everyday life, with significant implications for conceptualisations of the body, personal identity and the pathological. Her chapter situates the development of DNA-based technologies within a rich social, cultural, economic and political context, thus providing a textured landscape for many of the themes that other *Handbook* contributors will address in some detail in what follows.

The chapter by Niccolo Tempini and Sabina Leonelli then zooms into the ways in which the emergence of big data discourse, infrastructures and practices has affected – and, arguably, boosted – the role of genomics in biomedical research and care. They emphasise the ways in which attention to data practices shifts the focus of STS researchers interested in biomedicine beyond the clinic, to embrace the vast variety and multiplicity of social environments (digital or physical) in which the production, dissemination and interpretation of data of medical relevance is happening, and in which data practices are valued in a variety of different ways by different actors. They conclude that whether and how the transformative promise of big data can be

delivered for biomedicine and health care depends on the tools and assumptions used when assembling, interlinking and integrating genomic data with other types of biomedical data – a task fraught with technical, ethical and social challenges.

Susan Kelly, Anna Harris and Sally Wyatt also place emphasis on the ways in which genomics is escaping the biomedical and clinical context, by examining in detail the rise and commercialisation of personal genetic testing. Drawing from studies of the dynamics and usage of the internet, as well as research on the enactment of direct-to-consumer testing by online providers such as *23andMe,* this chapter stresses the extent to which bringing genetics out of the clinic is impacting the identity of patients (who are at once consumers and contributors of a service with multiple goals and accountabilities), their relationship with health care professionals and their understanding of the value of data produced through medical interactions. In particular, Kelly, Harris and Wyatt emphasise the disruptive effect of this evolving landscape on the various relations of trust that underpin and facilitate biomedical knowledge and care.

What do these developments mean for clinical work? This question is tackled by Ilana Löwy's chapter, which builds on the history of genetics and its clinical applications to portray how genetic testing and counselling practices have evolved over the last fifty years, the relation between such developments and broader societal trends, and the effects of these shifts on contemporary clinical practice. Löwy focuses on the increasing diversity of tests and targets developed for clinical use, the strong link between test availability and patients' uptake, and the implications for understandings of risk, parenthood and parental responsibility. She also points to the challenges raised by unanticipated secondary findings, as for instance in the case of hereditary conditions that affect whole families, and the resulting climate of "managed fear" in which human reproduction is now planned and enacted.

The last chapter in the section moves away from the Global North and Anglo-American trends, and takes a close look at the historical development and contemporary social implications of the implementation of genomic technologies in China. Jianfeng Zhu, Shiyi Xiong and Dong Dong focus specifically on prenatal genetic testing, a particularly sensitive issue in China given its birth control policies as well as the Confucian approach to responsibility and bonds within the family. The chapter considers recent changes in governmental discourse around the regulation of maternal and infant care, and particularly the role played by genetic knowledge in the current shift from a policy centred on population 'quality control' to an opening towards personal choice around 'reproductive insurance'. As the authors point out, this intersects in complex ways with the expectations and preferences of the families affected by state policies, as well as the training and everyday practices of health care professionals tasked with delivering treatment and assistance. It also exemplifies the surprising speed with which a country can reposition its role as participant and contributor to global health discourse and practices, with China now rapidly moving to establish genomic collection facilities to capture data and samples from its population and make them visible and potentially accessible internationally.

Genomic practices continue to be caught in a web of technological acceleration, societal changes and logistical chaos, with financial resources and market forces driving both the direction and the location of innovation in medical care. As pointed out in all the chapters within this section, this has substantial and uneven effects on popular attitudes and discourse on reproductive technologies and genetic testing. In particular, the increasing alignment of service provision, commercialisation and medical care derives in confusion around who is responsible and trustworthy, for what and in which way – a confusion that affects not only prospective patients, but also health care professionals and regulators. In this moment of transition and change, it is critical for scholarship in the history, philosophy and social studies of genomics and