Chapter Eight: Not as Good as Gold? Genomics, Data and Dignity

Bruce Baer Arnold and Wendy Elizabeth Bonython

# Abstract

Genomics enables us to read individuals and populations as abstractions – repositories of genetic data rather than persons. Through that lens it is tempting to regard ‘good data’ as a matter of what is big (comprehensive) and better (more accurate), rather than considering whether it is beneficial to or respectful of its human contributors. As nations move swiftly to whole-of-population data collection, analysis and sharing, this chapter suggests that construing bigger and better data as necessarily beneficial to people is contrary to the dignity that is central to personhood. From both a bioethics and legal perspective we are often asking the wrong questions about ‘good data’. The chapter critiques contemporary genomic initiatives such as the Genographic Project, Ancestry.com, deCODE and 23andMe in arguing it is imperative to consider meaningful consent regarding data collection and use, alongside establishment of a genomic commons that addresses problems inherent in propertization of the genome through patent law. Public and private goods can be fostered through regulation that ensures data quality and an information framework centred on public education about genomic data, encouraging responsible use of data within and across national borders. If the genome is ‘the book of life’ we must ensure that ‘good’ data is available to all and is understood rather than monopolized, mishandled or misread.

# Introduction

The genomics revolution – opening, understanding and manipulating ‘the book of life’ – results in fruitful questions about ‘good data’, dignity, ethics and law.[[1]](#footnote-1)

They are fruitful because they require engagement with issues that extend beyond diagnostics, therapeutic practice and the interaction of life-sciences research with business.[[2]](#footnote-2) They are also fruitful because they can be addressed through reference to past philosophical inquiries by figures such as Kant and Locke and to instances such the exploitation of vulnerable people in Nazi Germany and Jim Crow America where scientific ends were deemed to justify outrageous means.

We live in a world where there is excitement about genomic tools such as CRISPR,[[3]](#footnote-3) where governments are endorsing the establishment of population-scale health databases to facilitate advances in public health while strengthening national champions in an emerging global bioeconomy,[[4]](#footnote-4) where corporations such as Myriad are exploiting genomic patents,[[5]](#footnote-5) and where consumers are unwarily gifting familial data to private sector initiatives such as 23andMe[[6]](#footnote-6) or Ancestry.com.[[7]](#footnote-7)

In that world it is pertinent to examine assumptions about the nature, derivation and use of genomic data. Such an examination offers an opportunity for thinking about ways in which potential harms can be minimized, so that data functions as a social good rather than as a commodity subject to data strip-mining.[[8]](#footnote-8) It also offers an opportunity to think about personhood. Most saliently, in an age of Big Data and algorithmic governance are individuals: people who must be respected, or commodities that can be mined by the artificial persons that we characterize as corporations and governments, creations that exist to foster our flourishing?[[9]](#footnote-9)

This chapter accordingly considers ‘good data’ – and good data practice – through a lens of genomics. The chapter initially discusses genomics as a way of seeing that enables us to read individuals and populations as abstractions: repositories of genetic data (and hence potential susceptibilities, disorders and even behavioural traits) rather than persons. Through that lens it is tempting for the researcher to regard ‘good data’ as a matter of what is big (comprehensive) and better (more accurate) and commodifiable through law that provides patent holders with exclusive rights. As nations move swiftly to whole-of-population data collection, analysis and sharing, the chapter suggests that construing bigger and better as necessarily beneficial to people is contrary to the dignity that is central to personhood.[[10]](#footnote-10) From both a bioethics and legal perspective, typically centred on property rights, we are often asking the wrong questions about ‘good data’. ‘Bigger’ and ‘better’ may be beneficial from a data perspective; without an adequate ethical and legal framework, however, those benefits will not necessarily be extended to its human contributors.

The chapter accordingly critiques contemporary genomic initiatives such as Ancestry.com, National Geographic’s Genographic Project,[[11]](#footnote-11) deCODE[[12]](#footnote-12) and 23andMe in arguing it is imperative to consider meaningful consent regarding data collection and use, alongside establishment of a genomic commons that addresses problems inherent in propertization of the genome through patent law. Public and private goods can be fostered through regulation that ensures data quality and an information framework centred on public education about genomic data, encouraging responsible use of data within and across national borders.

The chapter concludes by arguing that if the genome is ‘the book of life’ we must ensure that ‘good’ data is available to all and is understood rather than monopolized, mishandled or misread. Goodness may be fostered by respectful clinical protocols, best practice on the part of research funders/regulators and enhanced awareness on the part of consumers rather than merely by exclusions under intellectual property law or an international agreement regarding genetic privacy and genomic rights.[[13]](#footnote-13)

# You are Data

Valorization of humans as entities deserving respect, a status often characterized as dignity and differentiated from other life forms, is a feature of Western philosophy and debate about political economy.[[14]](#footnote-14) Kant saliently articulated a categorical imperative that condemned treatment of people as means to a political or other end.[[15]](#footnote-15) After World War Two and the Nuremberg trials, the value of the personhood has been formally recognized through development of binding codes of ethical research and practice entrenching respect for the dignity and autonomy of people as patients and research participants, for example.[[16]](#footnote-16) Movements in psychosocial medicine, for example, reflect the ideal of treating patients as a whole, rather than as an embodiment of discrete conditions that happen to be stored in a common vessel.[[17]](#footnote-17)

Conversely, nation states have long read individuals and communities in terms of gender, social status, military capability, religious affiliation, age, ethnicity, lineage, tax liability, criminality and nationality.[[18]](#footnote-18) Some of those attributes are innate. Some are mutable. Many can be subverted or evaded. Information tools such as the population census, initially often crude head counts mapped to specific locations, have been supplemented through technologies that collect biometric data in forms such as fingerprints and mugshots.[[19]](#footnote-19)

The aggregation, rapid sorting and interpretation of such data will be increasingly pervasive as public and private sector entities across the globe deploy sophisticated algorithms for biometric data analysis (for example at international airports and other transport nodes),[[20]](#footnote-20) and leverage communication networks that foster the sharing of data between diverse government agencies and private sector proxies.[[21]](#footnote-21)

A rich scholarly literature over the past forty years has identified privacy and other dignitarian concerns regarding the identification of citizens and non-citizens – the latter being potentially especially vulnerable as people situated outside the law that protects their citizen peers – as data subjects. Those subjects are entities that are administered as and because they are manifestations of specific attributes rather than as individuals who are more than a social security number, a tax file number, an affirmative action tag or an entry on a national security watch list. In essence they are depersonalized, made subordinate to their embodiment of a particular type of data.

Such abstraction is inherent in ‘seeing like a state’,[[22]](#footnote-22) a practice that embodies inescapable tensions about data and data subjects. Abstraction fosters the bureaucratic rationality, discussed below, that is a salient feature of the modern state and more broadly of modernity.[[23]](#footnote-23) Like is treated alike. Decisions are made on the basis of facts (that is, what are deemed to be value-free data). Entitlements and disabilities are addressed on the basis of shared identity with other members of a cohort, rather than on the basis of an administrator’s whim or personal values. Increasingly, decisions may be made by algorithms without any direct human intervention.[[24]](#footnote-24)

An inflection point in our identification and potential understanding of human animals and other life forms came in the 1950s with discoveries regarding DNA, notably publication by Watson and Crick regarding the ‘double helix’, the code found in all people and characterized by some scholars as the ‘book of life’.[[25]](#footnote-25) It is a book that contrary to tabloid enthusiasm about genetics still contains many secrets: we can see the letters but still struggle to read the syntax and the meaning.[[26]](#footnote-26)

An implication of genomics is that we can abstractly construe people as genetic files. Using a genomic lens you are, for example, a set of genomic data. You are a file that came into being at conception and that will be relatively stable throughout your life, reflected in comments that although you can change your name, nationality and gender you cannot change your genes.[[27]](#footnote-27) Your genomic data represents genes that may determine your life-span, susceptibility to specific medical disorders and potential as a champion athlete rather than merely your hair color, gender and skin pigmentation.[[28]](#footnote-28)

As a file your data can be primarily be isolated from a blood or other biological sample. It can be expressed in a way that enable analysis and facilitate the transmission of data across jurisdictions and between discrete databases or users. It also facilitates comparison with data relating to other people. That identification is something that is increasingly automated. It is a practice that is routinized in applications such as paternity testing or forensic analysis regarding homicides and sexual assaults, with DNA testing for example replacing fingerprint testing as a trope in popular culture.[[29]](#footnote-29) Such identification seeks to differentiate one person from another or to confirm a questioned identity through reference to data embodied in a crime scene sample or a law enforcement register of offenders/suspects.[[30]](#footnote-30)

Genomic good data, for some law enforcement personnel, is accordingly a comprehensive digital biobank that is parsed in order to point to a suspected offender, providing a basis for specific investigation and potentially offering what courts regard as conclusive evidence. It is good because it enables law enforcement and facilitates justice.[[31]](#footnote-31)

Genomics is not, however, restricted to authoritative differentiation between yourself, your neighbor and any other reader of this chapter. If we think of you as a living file of genetic data, a physical embodiment or expression of instructions, potentials and disabilities in your genetic code, we should be unsurprised that insurers, developers of diagnostic tools and pharmaceuticals, public policymakers, behavioral scientists, epidemiologists and other medical researchers are interested in what the genome can tell us about health and what opportunities it provides for medicine, personalized or otherwise. Governments are endorsing population-scale genomic initiatives alongside private ventures such as 23andMe that are marketed as recreational genomics.[[32]](#footnote-32) Such activity is complemented by public and private sector plans, notably in the United Kingdom and Israel, to share population-scale health records – for example data about everyone who has attended a hospital or general practitioner in England under the National Health Service. Recent studies have also identified health data and health institutions as key targets for cyberattack.[[33]](#footnote-33)

Using the files of individuals, communities and national populations offers potentials for breakthroughs in medical research. It also offers investors potential rewards that dwarf those reaped by figures such as Bill Gates, George Soros, Mark Zuckerberg and Larry Ellison.

We are thus seeing disputes about claims to own genes, most prominently in litigation about molecular diagnostic patents gained by Myriad Genetics Inc. regarding breast cancer diagnosis. Those disputes follow litigation regarding the highly lucrative exploitation of body samples from people such as Henrietta Lacks.[[34]](#footnote-34) They pose questions about privacy,[[35]](#footnote-35) ethics,[[36]](#footnote-36) trade secrets,[[37]](#footnote-37) treating data as property,[[38]](#footnote-38) and about the appropriateness of exclusive ownership of genomic data that is not unique to a particular individual but is instead common to that person’s siblings.[[39]](#footnote-39) They involve conundrums about the balance between public benefit and the private interests of people who have knowingly or otherwise shared their genomic data, not necessarily addressed through promises regarding de-identification to make data good.[[40]](#footnote-40) The effectiveness of de-identification mechanisms remains contentious, [[41]](#footnote-41) given the scope for associating individual/familial genomic data with other identifiers in the public and private realms – a manifestation of the ‘big data’ explored elsewhere in this book. The disputes require thought about incentives for innovation and about regulatory incapacity in a global economy where data may be readily harvested in one jurisdiction, analyzed in another jurisdiction and used or misused in other jurisdictions. They require thought about the balance between public and private goods, with an absolute de-identification for example vitiating much research.

As such they encourage thought about the nature of ‘good data’, explored in the following part of this chapter, and what might be done to minimize harms without forgoing the advancement of research in the life-sciences or disregarding perceptions that data gathered through the public health system is one of the few major assets that might be privatized by neoliberal governments in an era of budget stringency.

# Goodness

The goodness of data is a founding value of modernity.[[42]](#footnote-42) Data legitimizes public policy in the contemporary liberal democratic state. Data is perceived as freeing us from superstition and alleviating fear of what is unknown or misunderstood. Data is a matter of disenchantment, truth rather than fantasy. It enables bureaucratic rationality that is a marker of efficient public administration and commerce. Data allows a coherent evaluation of the past, management of the present and prediction of the future. Data is a prerequisite of fact-based medicine and public health initiatives, evident in for example disquiet about homeopathy and much ‘new age’ therapy. Data’s perceived innate goodness is implicit in catchphrases such as ‘the facts speak for themselves’, ‘statistics show’, ‘facts are power’, ‘the facts, just the facts’ and ‘the evidence proves’. It is implicit in the primacy of national statistical agencies (and the mandatory status of much census activity), the culture of risk-management on the basis of population-scale data resources that influence the provision of financial services,[[43]](#footnote-43) and the valorization of epidemiological studies since at least the time of John Snow’s mapping of cholera in Georgian London.[[44]](#footnote-44)

Reality is, of course, somewhat more complicated. Rob Kitchin, in referring to a ‘knowledge pyramid’, contextualized ‘data’ by commenting that ‘data precedes information, which precedes knowledge, which precedes understanding and wisdom’.[[45]](#footnote-45) In considering what genomic ‘good data’ is through a lens of community benefit and individual dignity, we might accordingly conceptualize data as a tool, rather than an outcome. On that basis goodness might be assessed through reference to how the tool is devised and used rather than merely whether the products of its use – the understanding, diagnostics, therapies and revenue – are beneficent.

If we look beyond the ‘data is good’ rhetoric noted above we might for example recognize that some data collection is egregiously wrong, fundamentally tainting knowledge that results from the tool. Provenance matters. We might also recognize that although the tool was devised with care for human dignity and used without any intention to harm some outcomes of its use may be subjectively or objectively bad. Recognition acknowledges differentials in who gets to collect data, who defines data, who analyses data, who acts upon it and who disseminates (or chooses not to disseminate) data.

Good data is thus more than a matter of accuracy, an accuracy that is often reflective of care to identify and thence reduce error in data collection and analysis. Accuracy may be a function of the scale of data collection, with a survey of a large number of people for example producing data that is ‘good’ because it is representative rather than being skewed to a specific cohort. That emphasis on comprehensiveness has driven the large-scale genomic initiatives discussed later in this chapter, with researchers and investors aspiring to population-scale mapping of the human genome and health.

‘Goodness’ might also be construed in terms of efficiency, with data collection being assessed in terms of the cost of data collection/analysis and more broadly in terms of the knowledge that results from the collection, knowledge that is valuable for investors or public administrators. In the age of the neoliberal enterprise university, where funders are wary of disinterested research, it is axiomatic that institutions deal with data to generate financially tangible outcomes: there is no collection for data’s sake.[[46]](#footnote-46)

In the life sciences several data collection projects over the past seventy years provide a framework for conceptualizing data goodness in considering genomic initiatives.

One project, in Nazi Germany, involved the collection by medical researchers of data about the resilience of the human body under extreme stress, with the expectation that the resultant knowledge would enable life-saving practices. The collection involved researchers placing concentration camp inmates in freezing water, in high pressure chambers, or depriving them of air. Those data objects – people – were not provided with painkillers. They were not in a position to consent, and were denied dignity.[[47]](#footnote-47) Many died during the data collection. The data collected during what we now characterize in law as a crime against humanity might have been accurate and useful but is fundamentally tainted.[[48]](#footnote-48)

The same can be said for the Pernkopf anatomical atlas, a masterly depiction of the human body and accordingly acclaimed over several editions for its accuracy and usefulness for medical students.[[49]](#footnote-49) From that perspective it is an artefact of good data. It is however a work that draws on the bodies of concentration camp inmates, some of whom may have been ‘killed to order’ for the anatomists. It prompts disquieting questions about goodness.

We can see other egregious denials of dignity in data collection and use closer to our own time. Recall for example, the Tuskagee Syphilis Study in the United States, where researchers tracked the health of communities containing residents infected with syphilis. Similar studies involved prisoners and people in Guatemala.[[50]](#footnote-50) Saliently, the people were not offered therapies, were not alerted to the nature of any symptoms (meaning that they did not gain treatment from other clinicians) and were in a subordinate position. National security was invoked to justify research for the US Central Intelligence Agency into the effects of LSD.[[51]](#footnote-51) Staff at the Alder Hey hospital, and other institutions in the UK, harvested organs for research purposes without family consent.[[52]](#footnote-52) Those organs are embodiments of genomic data and potentially beneficial for teaching; the practice means however that the data was not ‘good’. US surgeons famously commodified Henrietta Lacks; no consent was obtained from Ms Lacks or her family for culturing and marketing of a cell line cultured from her cancer biopsy (now used in laboratories across the globe), there was no acknowledgement and no compensation was provided for appropriation of her genetic material.[[53]](#footnote-53)

In construing the goodness of data we might accordingly be alert to questions about whether the tool is ethical rather than merely accurate and efficient. Does it for example respect dignity? Is the knowledge that results from the data fair?

# ‘Good’ Data, Bad Practice?

Those questions underpin a consideration of contemporary genomic initiatives, particularly those that are marketed as ‘recreational genomics’, and gene patents such as those held by Myriad Inc. More broadly they underpin thought about population-scale health data initiatives such as the UK care.data program that, as discussed below, encountered fundamental difficulties because bureaucratic indifference to consent eroded its perceived legitimacy.[[54]](#footnote-54) Data in public and private collections, for research or other purposes, may be good because accurate but was its generation respectful and is its use fair? In essence, ‘goodness’ as a matter of legitimacy may be a function of provenance rather than accuracy.

Excitement over the wonders of genomics, evident in characterisations such as reading ‘the book of life’, and fundamental reductions in the cost of genomic data processing have resulted in the emergence of recreational genomics. Put simply, consumers provide a genomic service such as 23andMe and Ancestry.com with a body sample, typically in the form of a painless swab from the mouth. That provision might be as a gift, with the consumer neither paying a fee nor receiving a payment. It might instead be on a consumer pays fee for service basis. In return, consumers receive reports that relate them to contemporary/historic cohorts (for example under the Genographic Project indicate that x percent of your ancestors were Vikings or came from Africa) or point to specific genetic traits, such as a dislike of certain vegetables, or phenotypic (physical) phenomena.[[55]](#footnote-55) The data that appears in those reports is the property of the service provider.

The marketing of those services has emphasized recreation, for example as part of a genealogical hobby, rather than therapy. They appeal to novelty and a popular desire for social connectedness. Although they use the language of science and rely on popular faith in the liberating effects of medical data they are typically situated outside health regulation frameworks. They do not require prescription or guidance by a clinician. They might be dourly viewed as akin to genomic fortune telling: an entertainment service that is correspondingly weakly regulated because outside the health realm.[[56]](#footnote-56)

Recreational genomics poses several issues. Consumers and some regulators may not appreciate the implications of the data that can emerge from the sequencing. From the perspective of privacy scholars the initiatives are problematic because individuals are not genetically unique. Some of our genes are common to biological relatives, especially siblings. Inferences of varying accuracy can be drawn about the genomic characteristics of close and distant relatives. If we conceptualize a person as a genomic file, an embodiment of genomic data, we can see that participants in recreational genomics are unilaterally offering service providers data about other people rather than just about themselves. Some people with concerns about potential genetic discrimination – the genomic redlining by insurers, employers and others that has featured in legal literature over the past twenty years – may choose not to participate in recreational genomics and be disquieted that others are tacitly co-opting them through undisclosed provision of swabs.[[57]](#footnote-57) The authors of this chapter have highlighted concerns about a ‘right not to know’ (freedom from an unwanted disclosure within a family circle of a health condition identified in a genomic report gained by a relative),[[58]](#footnote-58) and about the accuracy of reports from service providers and their potential misinterpretation by consumers.[[59]](#footnote-59)

Those concerns co-exist with weakness of national and international regulation of the services, which typically operate globally and are inadequately constrained by national privacy law that is often based on the principle that protections are waived if consumers consent to data collection, processing and sharing. Genomic data collection for aggregation and sale is likely to be the unstated or even express business model of recreational genomic services, given the value of large-scale genomic and other health repositories. That value was a driver of the contentious UK care.data initiative, with the British government proposing to sell several decades of National Health Service records (i.e. from hospitals and general practitioners) about all English patients, without patient consent on the basis that the data would be de-identified.[[60]](#footnote-60)

It is arguable that there is insufficiently informed consent on the part of many recreational genomics consumers, who are unaware of (or indifferent to) whether the data they provide is being sold to or otherwise shared with third parties such as pharmaceutical companies.[[61]](#footnote-61) Some presumably trust that the services will rigorously protect what in time will amount to global genomic databases that, like financial databases, are susceptible to unauthorized disclosure by insiders and hacking by outsiders. Few consumers will have much sense of the scope for law enforcement and national security agencies to override the often vague undertakings made by the services and access the data without disclosure to the affected individuals.

Services conceptualize genomic data as property, an asset that can be bounded by confidentiality and employment law and that can be assigned a value for sale or security. Entities outside the recreational genomics sector have also conceptualized genomic data in terms of exclusive rights that enable a substantial return on investment. A salient example is Myriad Inc., a United States corporation that has aggressively sought and asserted patent rights regarding the BRCA 1 gene, associated with breast cancer.[[62]](#footnote-62) The prevalence of breast cancer, the morbidity of its occurrence and perceptions that life-threatening illness can be predicted for pre-emptive surgery or other therapy means that Myriad’s patents are commercially very valuable. Unsurprisingly, Myriad has sought to exploit what is often misreported as ‘ownership’ of genes or more accurately as a tool with some diagnostic value, resulting in criticism across the globe that its pricing and asserted monopoly exclude the disadvantaged. Analysts have questioned whether gene patents as such should be recognized in law, either on grounds of public policy or because they involve discovery rather than invention. Others argue that much of the data at the heart of gene patents was gained through publicly-funded research, so any patent revenue should be shared with the state.

# A Genomic Commons?

One response to propertization of genomic data (i.e. characterising it as something over which a discoverer, collector or aggregator has exclusive rights that are legally enforceable and that can be commodified through sale, licence or gift) is to treat the human genome as a commons, something that is properly considered as requiring a public understanding that extends beyond debates about potential commodification of resources on the basis of exclusive rights.[[63]](#footnote-63)

Recognition of the genome as something that is a global resource that must be both socially understood and curated rather than strip-mined on an opportunistic basis will strike some readers as legally or politically naive. It would require change to national law and interpretation of international intellectual property agreements. It would not chill discovery, consistent with a history of research that was funded by government and philanthropic institutions that valorised the common good through an emphasis on what would now be characterized as ‘open data’, i.e. publication in readily accessible journals. (Such publication would prevent much patent activity, given that the ‘invention’ to be protected would not be novel.)

A commons would not resolve conundrums regarding genomic privacy. A solution to those conundrums lies outside patent law.

# Genomics and Data in a Good Society

Infolibertarian John Perry Barlow envisaged that in the imminent age of data – bits and bytes – the state would wither because neither relevant nor effective, with what he construed as the individualistic values underlying the US Constitution becoming universal. [[64]](#footnote-64) Regulation, seen as innately restrictive of creativity and thus of individual goods, would cease to be viable in a digital world without borders, a market integrated by the internet rather than by state agreements such as the Agreement on Trade-Related Aspects of Intellectual Property (TRIPS). Nicholas Negroponte more vividly pictured the irrelevant state evaporating like a mothball.[[65]](#footnote-65) A succinct response was provided by Bart Kosko: ‘we’ll have governments as long as we have atoms to protect’.[[66]](#footnote-66) The past two decades have shown that the lions are reluctant to lie down with the lambs. National borders (and national interests) remain powerful. The law of man – as distinct from Barlow and Lessig’s law of code – continues to shape both investment and consumption.[[67]](#footnote-67) In thinking about good data we need to think about the good society, one that John Rawls would consider to be fair,[[68]](#footnote-68) and that Martha Nussbaum would endorse as fostering the capabilities of all members of the state.[[69]](#footnote-69) Good data from that perspective is data and practice that underpins the good society. It is not solely or primarily a matter of property and of law regarding property.

It is unlikely that we will see an international reworking of international intellectual property law to specifically exclude the genome from patent protection. An inability to achieve such a reworking reflects the difficulties evident in global trade negotiations over the past five decades, with the slowing of economic growth and the mercantilism evident in statements by US President Trump, for example, exacerbating the recalcitrance of key actors about surrendering what they see as national advantages. Leading corporations appear unlikely to relinquish what they perceive as key competitive advantages in terms of exploiting genomic information, with public policymakers being influenced by a genomic data version of the axiom that what’s good for General Motors is good for the US.

There is perhaps more hope at the national level, especially in response to egregious rent-seeking of the type highlighted by Martin Shkreli.[[70]](#footnote-70) In the age of big data states remain relevant because they permit private actors to exercise power (something that is not inherently bad) and have scope to intervene through a range of policy levers when those actors fail to exhibit adequate internal restraints. Liberal democratic states have tended to acknowledge private property rights and offset market inefficiencies by respecting patents but subsidising the price of key pharmaceuticals for consumers. In essence, the taxpayer fills the gap so that disadvantaged consumers can flourish, and trade sanctions will not be instituted. We might act more boldly.

Such action would recognise genomic patents, such as those gained by Myriad, but cap the prices charged for products embodying those patents and attributable to genomic data. That restriction can be deemed as legitimate both in terms of rationales for intellectual property protection – patents are not an end in themselves – and because much genomic research is founded on discovery in the public domain by public institutions or funded by public agencies.

Lawyers and legal academics typically conceptualize problems and solutions in terms of law, with data, for example, being addressed in terms of jurisprudence regarding copyright, evidence, employment, computer and confidentiality law. Conceptualising good data in relation to a good society requires an acknowledgement that there is scope for regulation outside international agreements, national statutes and judgments. The preceding paragraphs imply that we might look to the behaviour of clinicians and researchers, bounded at an individual and institutional level by ethical codes regarding the exploitation of human subjects, the oversight of research (which often has an institutional or cross-institutional basis) and the allocation of funding. Can researchers refuse to partner with corporations deemed to be unduly exploitative, a refusal that is likely to be career limiting? Can research institutions more easily refuse to licence to those corporations or, despite government pressure to be self-sustaining through an aggressive patent-building strategy, emphasise placing genomic research in the public domain. Is ‘Good Data’ that which is available to all, across borders and without the tyranny of the quarterly return?

A contention in this chapter is that dignity is inextricably associated with agency, at its simplest the ability to make decisions, enjoy benefits (individual or social) and take responsibility. The genomic initiatives critiqued above typically deny agency.

That denial is a matter of obfuscation where providers of genetic material, for example participants in recreational genomics projects such as 23andMe, are not equipped with the information they need to make informed choices about the consequences for themselves and relatives of that participation. Respect for the capacity of consumers to make decisions, including what we might construe as foolish decisions, should be reflected in both fuller disclosure as part of the initiatives and more broadly by a public education program that informs people about public policy issues rather than merely about the wonders of gene sequencing and the likelihood of achieving fundamental medical breakthroughs from large-scale data capture. Education might reduce some privacy harms by alerting people of the potential consequences of unilaterally providing data about close/distant relatives, particularly if law changed to inhibit genomic discrimination.[[71]](#footnote-71)

Measures to foster that public understanding of what is ‘good’ data and good data practice would importantly serve to inform community debate about initiatives where people have been denied agency by having no choice about whether their data is mandatorily conscripted for national health databases such as Care. Data or by having little real choice because use of ‘opt out’ mechanisms is designed to be unduly onerous.

# Conclusion

This chapter began by referring to pre-genomic conceptions of what is good, with Kant for example addressing Aristotle’s questions about ‘the good’ by exhorting us not to treat people as a means to an end, abstractions without dignity that can be sacrificed for personal, institutional or political needs. In an era where investors, governments and researchers are awed by ‘big data’ – the bigger the better – it is useful to recall statements such as Stalin’s ‘the death of one person is a tragedy, the death of a million is a mere statistic’ and the fetishization of bigness in Mao’s China where the demise of millions was an acceptable price to pay for an industrial leap forward.[[72]](#footnote-72)

The collection, study and exploitation of genomic data does not have to be dystopian. Bigness is not inherently bad; nor is profit. A contention running through this chapter is that the ‘goodness’ of genomic data is a function of respect for human dignity, something that requires thinking beyond specific data collection mechanisms and applications.

Good genomic data is not a matter of bulk and breadth: the number of data subjects and their representativeness of a national or global population. It is not a matter of good title: recognized property rights under patent or other law. It is instead more usefully conceived in terms of a mindset, a response to questions that are best addressed through an ethic of responsibility rather than ownership.[[73]](#footnote-73) As we increasingly make sense of the book of life we might accordingly choose to exercise our own agency, and the agency of the governments that are accountable to us, and conceptualize good data as a matter of curation for the common good rather than property in which a fortunate few have exclusive rights. The potential agency of government has been disregarded or dismissed by proponents of neoliberalism, i.e. an ideology in which the invisible hand of the market solves all policy questions. In considering genomic data we suggest that agency may be construed in terms of intellectual property and other legal frameworks at both global and national levels, alongside state-sanctioned professional codes and decision-making by government funders of genomic research. Agency may also be construed in terms of action by public sector entities, a matter of formal authority to intervene in markets, of expertise to both understand and articulate questions about genomic data, and a culture in which regulators are willing to intervene. That intervention – what might be characterized as a reintroduction of state – should provide legitimacy for the state (a social good) and foster understanding by individuals about how we collectively and individually manage the genome. An ultimate function of the state is enabling discourse about what is good.

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