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THE INDIGNITY OF ABSTRACTION: DATAMINING AND AUTONOMY IN THE AGE OF DIRECT-TO-CONSUMER GENOMICS

BRUCE BAER ARNOLD* AND WENDY BONYTHON**

Direct-to-consumer genomics services such as 23AndMe and Ancestry.com promise to foster medical research and deepen personal connections through sharing information about the human genome. This article contextualises those promises by asking questions about dignity, the services, and the legal frameworks in which they operate — which are predicated on abstracting people as sets of genetic data. The commonality of that data among biological relatives means that individuals who gift a service with data about themselves are disregarding the autonomy of relatives who might not want to be genetically datamined. Law about such genomics should acknowledge Kant’s wariness about abstracting people as a means to an end.

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I INTRODUCTION

What is the nature of dignity in the era of recreational genomics, where individuals contribute data about themselves and biological relatives to global enterprises engaged in genomic data-mining? Does Australian and international law provide an adequate framework for affirmation of that dignity through protection of human rights? This article offers a perspective on the significance of dignity for recreational genomics and other population-scale genomic data-mining initiatives that elide autonomy and, in abstracting people as genomic profiles, improperly treat their data subjects as a lucrative means to an end.¹

The article begins by providing an introduction to the recreational genomics sector. This sector is diverse but unevenly monitored. It features well-known global enterprises such as 23AndMe and Ancestry.com alongside an increasing number of less prominent businesses, many of which will exist only fleetingly, leaving unresolved issues about the disposal and custodianship of their data assets following the demise of the business. Some operate in ways that might be deemed fraudulent or unconscionable. The following paragraphs then discuss concerns regarding autonomy, reward, and abstraction. The article draws on Kant to critique claims about the benefit and potential harms of profit-centred genomic data mining. It concludes by discussing Australian privacy, health law, and consumer protection law in relation to recreational genomics marketing and practice, suggesting that a more equitable and respectful global regime is achievable.

II READING THE 'BOOK OF LIFE'

The past sixty years have brought growing recognition regarding the significance of genomics, particularly in the identification and understanding of the genetic code that is the basis of life in human animals, non-human animals, and other life forms. Governments, businesses, and not-for-profit entities are seeking to map, analyse and

¹ Bruce Baer Arnold and Wendy Bonython, 'Not As Good as Gold: Genomics, Data and Dignity' in Monique Mann, Kate Devitt and Angela Daly (eds), *Good Data* (Institute of Network Culture, 2019) 135; Kazimierz Krzysztofek, 'The Algorithmic Society: Digitarians of the World Unite', in Paul Kidd (ed), *European Visions for the Knowledge Age. A Quest for New Horizons in the Information Society* (Cheshire Henbury, 2007) 57.

(increasingly) manipulate what journalists have dubbed the ‘book of life’.² That endeavour is based on awareness that some ailments or disabilities such as Down Syndrome, Haemophilia, or Huntington’s Disease are predetermined by the genetics of the individual, while other conditions, such as predisposition to certain cancers, may have a more complex, multifactorial causal basis involving genetic variations and exposure to environmental or lifestyle factors. One consequence is that researchers and investors see a potential role for genomics in the early identification and treatment of illnesses, alongside visions of a highly-personalised and effective ‘precision medicine’ that tailors diagnostics and therapeutics to each individual in ways that bring together lifestyle guidance, pharmaceuticals and testing.³

Making sense of the book of life is facilitated by the accumulation and analysis of population-scale data about the genome, ailments, treatments, and behaviours. Understanding requires associating a map of an individual’s genes and a population’s genes with information about their health, occupations, consumption patterns, and so forth. Scale and association are thus profoundly important, raising questions about privacy, confidentiality, consent, discrimination, rent-seeking by patent holders, and other issues.

The genomics ‘new frontier’ has the potential for profound community benefit. It also has the potential, akin to other frontiers, to be an opportunistic and egregiously exploitative wild west. Such a market space is one in which human rights are disregarded and regulatory incapacity fails to address profit-seeking by corporations that exploit consumer naivety and new technologies across jurisdictional borders.

III RECREATIONAL GENOMICS

Decreasing costs in genomic analysis and popular excitement about genetic medicine, alongside a yearning for ‘connectedness’ through internet-based family history services,

² Elizabeth Pennisi, ‘Finally, The Book of Life and Instructions for Navigating It’ (2000) 288(5475) *Science* 2304; and Kean Birch, ‘The Neoliberal Underpinnings of the Bioeconomy: The Ideological Discourses and Practices of Economic Competitiveness’ (2006) 2(3) *Genomics, Society and Policy* 1.

³ Wendy Bonython and Bruce Baer Arnold, ‘Privacy, Personhood, and Property in the Age of Genomics’ (2015) 4(3) *Laws* 377. See generally Reza Mirnezami, Jeremy Nicholson and Ara Darzi, ‘Preparing for Precision Medicine’ (2012) 366(6) *New England Journal of Medicine* 489; Robert Williamson et al, *The Future of Precision Medicine in Australia: Report for the Australian Council of Learned Academies* (Australian Council of Learned Academies, 2018).

has fostered the emergence in the past decade of what have variously been dubbed direct-to-consumer genomics services, recreational genomics, personal genomics, or commercial genomics services.⁴ Those services are based in a specific jurisdiction, typically the United States, but use the internet to market globally. They operate on a for-profit basis, alongside government initiatives that seek to map the human genome.⁵ Examples of commercial enterprises include 23andMe,⁶ FamilyTreeDNA,⁷ and Ancestry.com.⁸ Some originated as traditional genealogical services, bringing together information from consumers to build large-scale family histories.⁹ Others were established expressly to gather genomic data for clinical or research purposes rather than to link an enthusiast with a distant uncle, Queen Elizabeth II, or Abraham Lincoln. Low regulatory thresholds (discussed below) and declining costs mean that the sector is vibrant, with the departure or takeover of numerous businesses over the past decade, and competition among enterprises that,¹⁰ in contrast to the examples above, have not gained global brand recognition among consumers. Some services emphasise ancestral connection (including indicia of ethnicity);¹¹ others claim to provide predictive guidance

⁴ International Human Genome Sequencing Consortium, 'Initial Sequencing and Analysis of the Human Genome' (2001) 409 *Nature* 860; Kevin Davies, *The \$1,000 Genome: The Revolution in DNA Sequencing and the New Era of Personalized Medicine* (Simon and Schuster, 2010).

⁵ James P Evans, 'Recreational Genomics; What's in it for You?' (2008) 10(10) *Genetics in Medicine* 709; Arnold and Bonython (n 1).

⁶ '23andMe' 23andMe (Web Page, 2019) <<http://www.23andme.com>>; Henri-Corto Stoeklé et al, '23andMe: A New Two-Sided Data-Banking Market Model' (2016) 17(1) *BMC Medical Ethics* 19.

⁷ 'Family Tree DNA', *Family Tree DNA* (Web Page, 2019) <<https://familytreedna.com>>.

⁸ 'DNA', *Ancestry* (Web Page, 2019) <<https://www.ancestry.com/dna/>>.

⁹ Spencer Wells, *Deep Ancestry: Inside the Genographic Project* (National Geographic Books, 2006); Jennifer Wagner et al, 'Tilting at Windmills No Longer: A Data-Driven Discussion of DTC DNA Ancestry Tests' (2012) 14(6) *Genetics in Medicine* 586; Ugo Perego et al, 'The Science of Molecular Genealogy' (2005) 93(1) *National Genealogical Society Quarterly* 245.

¹⁰ Examples are the takeover of Navigenics and DeCODE/DeCODEme (now part of WuXi NextCODE), which, as discussed in Michael Fortun, *Promising Genomics: Iceland and deCODE Genetics in a World of Speculation* (University of California Press, 2008), attracted attention for activity in Iceland. See Andelka M Phillips, 'Think Before You Click' (2015) 11(2) *The SciTech Lawyer* 1, for estimates of the number of enterprises.

¹¹ For an Australian perspective on 'ethnicity services' see Elizabeth Watts, Emma Kowal and Shaun Lehman, 'A DNA Test Says You've Got Indigenous Australian Ancestry. Now What?', *The Conversation* (online, 3 May 2018) <<https://theconversation.com/a-dna-test-says-youve-got-indigenous-australian-ancestry-now-what-95785>>; A US perspective is offered in Eric Beckenhauer, 'Redefining Race: Can Genetic Testing Provide Biological Proof of Indian Ethnicity?' (2003) 56(1) *Stanford Law Review* 161; Troy Duster, 'Ancestry Testing and DNA: Uses, Limits—and Caveat Emptor' in Barbara Prainsack, Silke Schicktanz and Gabriele Werner-Felmayer (eds), *Genetics as Social Practice* (Routledge, 2016) 75.

regarding athletic or scholastic aptitudes,¹² and some function as overt/covert paternity test providers.¹³

The services are direct-to-consumer because data collection (provision of a swab from the individual's cheek) and analysis is not intermediated by a hospital, pathology service provider, medical practitioner, or other clinical/diagnostic body. Reference to 'recreational' reflects the marketing and, more subtly, the legal status of the services. Consumers pay a small fee to the service provider for a report on the genetic sample that they have provided, with the service using data from analysis of the sample to link the consumer to other people, or to provide guidance about supposed traits. In essence, the services are marketed as entertainment rather than as advice for which an Australian clinician would be legally liable.

IV WHAT'S YOURS IS MINE?

Dignitarian philosophers such as Kant, Nussbaum, Gewirth, and Foster have argued that we are individuals — to be respected in our own right regardless of our social status and familial relationships.¹⁴ An under-recognised aspect of recreational genomics is that there is substantial commonality between the genetic makeup of an individual and that person's biological relatives. Access to genetic data about an individual, for example, allows inferences of varying accuracy about the data of their siblings.

Recreational genomics is founded on depth and breadth: collecting highly-detailed genomic data from as many people as possible. Marketing encourages people to contribute data on the basis that provision will be fun, provide connection, assist self-management and, altruistically, benefit science. This type of marketing elides questions about commonality and thereby erodes dignity. It does so because few people who contribute data to 23andMe or other services appear to recognise that they are implicitly

¹² *Ancestry* (Web Page, 2019) <<https://www.ancestry.com>>.

¹³ 'Paternity Tests', *EasyDNA* (Webpage, 2019) <<https://easydna.com.au/paternity-tests/>>.

¹⁴ See, eg, George Kateb, *Human Dignity* (Harvard University Press, 2011); Martha Nussbaum, *Frontiers of Justice: Disability, Nationality, Species Membership* (Harvard University Press, 2006); Jürgen Habermas, 'The Concept of Human Dignity and the Realistic Utopia of Human Rights' (2010) 44(4) *Metaphilosophy* 444; Susan Shell, 'Kant on Human Dignity', in Robert Kraynak and Glenn Tinder (eds), *In Defense of Human Dignity: Essays for Our Times* (University of Notre Dame Press, 2003) 53; Charles Foster, *Human Dignity in Bioethics and Law* (Bloomsbury, 2011).

contributing data about their relatives. It appears to be rare for a contributor to seek the consent of siblings, parents, offspring or other relatives.

Such disregard of the autonomy of relatives is a denial of agency and dignity.¹⁵ It is, however, unsurprising given the low levels of understanding about genetics among many people, and the silence of service providers regarding consent on the part of relatives. It is also unsurprising given the paucity of law within and across jurisdictions about proprietary rights in genomic data and body parts.¹⁶ Recreational genomics service providers rely on traditional contract law, which has not been substantially challenged in Australia or elsewhere. It covers payment by the consumer for access to information that the service provider has generated, through processing the swab provided by the consumer. The service provider discards the biological sample embodied in that swab, thus stepping outside restrictions on biobanks (repositories of blood, organs, and other material), and adds the data derived from the sample to its genomic database.

The database as a whole, or sets of its component data, can be sold outright or licensed to a range of users such as pharmaceutical companies and insurers. What is entertainment for the contributor of a genomic sample is a treasure trove of data for life-sciences and associated businesses; data that can be mined on an ongoing, rather than one-off basis, to answer an indefinite number of questions. It is data that few fully-informed people would volunteer directly to an insurer, drug company, medical device developer, or similar entity, particularly in the absence of a meaningful regulatory framework that provides remedies for deception, unjust enrichment, and subversion of procedure relating to law enforcement. Gifting, as scholars such as Richard Titmuss have noted,¹⁷ is ethically valuable and conducive to social solidarity, but altruism or

¹⁵ Gerald Dworkin, *The Theory and Practice of Autonomy* (Cambridge University Press, 1988); Jerome Schneewind, *The Invention of Autonomy: A History of Modern Moral Philosophy* (Cambridge University Press, 1998).

¹⁶ Wendy Bonython and Bruce Baer Arnold, 'Privacy, Personhood, and Property in the Age of Genomics' (2015) 4(3) *Laws* 377; Maureen Dorney, 'Moore v. The Regents of the University of California: Balancing the Need for Biotechnology Innovation Against the Right of Informed Consent' (1989) 5(2) *High Technology Law Journal* 333; Jasper Bovenberg, 'Inalienably Yours? The New Case for an Inalienable Property Right in Human Biological Material: Empowerment of Sample Donors or a Recipe for a Tragic Anti-Commons' (2004) 1 *SCRIPT-ed* 545.

¹⁷ Richard Titmuss, *The Gift Relationship, From Human Blood to Social Policy* (Allen & Unwin, 1971); Iain McLean and Jo Poulton, 'Good Blood, Bad Blood, and the Market: The Gift Relationship Revisited' (1986) 6(4) *Journal of Public Policy* 431.

unawareness of intergenerational impacts does not erase concerns about susceptibility to exploitation.

Substantively informed consent in online transactions is increasingly seen by regulators, consumer advocates, and scholars as a foundation of trust in electronic commerce and regulatory legitimacy enshrined, for example, in the European Union's consumer protection framework and in the General Data Protection Regulation ('GDPR').¹⁸ A salient concern regarding the marketing of recreational genomics, particularly across borders, is whether consumers are aware of what is being agreed to, in particular what a service provider — or the provider's unidentified partners — might do with data in the future. Terms and conditions for recreational genomics services do not allow contributors to revoke consent, and privity does not provide for intervention by a familial member who wishes to restrict a sibling or other relative from sharing data with a local or overseas service provider. There is increasing recognition that consumers may have difficulty exercising autonomy due to poor website design and maintenance.¹⁹ Boilerplate, a text that is reused for separate applications and which does not require substantial alterations, may be unreadable by non-expert consumers.²⁰ Privacy statements may provide inadequate disclosure,²¹ and, in the absence of effective action by regulators or a cause of action through a tort of privacy or confidentiality, may preclude meaningful remedies.

¹⁸ Among case studies see Marco Botta and Klaus Wiedemann, 'The Interaction of EU Competition, Consumer, and Data Protection Law in the Digital Economy: The Regulatory Dilemma in the Facebook Odyssey' (2019) 64(3) *The Antitrust Bulletin* 428; Iris van Ooijen and Helena Vrabec, 'Does the GDPR Enhance Consumers' Control Over Personal Data? An Analysis from a Behavioural Perspective' (2019) 42(1) *Journal of Consumer Policy* 91. Note also expressions of concern by the Australian Competition & Consumer Commission in its 2019 *Digital Platforms* inquiry report and Anelka M Phillips, 'All Your Data Will Be Held Against You: Secondary Use of Data from Personal Genomics and Wearable' in (ed) Susan Sterett and Lee Walker, *Research Handbook on Law and Courts* (Elgar, 2019) 404.

¹⁹ See, eg, Brett Frischmann and Evan Selinger, 'Engineering Humans with Contracts' (Cardozo Legal Studies Research Paper No 493, 2016).

²⁰ Anelka M Phillips, 'Reading the Fine Print When Buying Your Genetic Self Online: Direct-to-Consumer Genetic Testing Terms and Conditions' (2017) 36(3) *New Genetics and Society* 273; Uri Benoliel and Sschmuel Becher, 'The Duty to Read the Unreadable' (2019) 60 *Boston College Law Review* 2255. See generally Margaret Radin, *Boilerplate: Fine Print, Vanishing Rights and the Rule of Law* (Princeton University Press, 2013).

²¹ James W Hazel and Christopher Slobogin, 'Who Knows What, and When? A Survey of the Privacy Policies Proffered by US Direct-to-Consumer Genetic Testing Companies' (2018) 28(35) *Cornell Journal of Law and Public Policy* 35; Anelka M Phillips, *Buying Your Self on the Internet: Wrap Contracts and Personal Genomics* (Edinburgh University Press, 2019).

Those inadequacies may have a utilitarian benefit for investors in services but, in eliding consent and disregarding autonomy, they disrespect individuals and thereby deny dignity in favour of data exploitation.

V PEOPLE ARE NOT JUST GENOMIC ARTEFACTS

Kant famously and persuasively argued that people are not merely means to an end.²² The recreational genomics business model is predicated on abstracting people as sets of genetic data.²³ Compilations of such abstractions may benefit society as a whole through, for example, sustained profitability of pharmaceutical enterprises that have drawn on genomic data to develop novel diagnostics and therapeutics, or through lower public/private health costs and greater individual flourishing through the use of such products. In using a dignitarian lens we should, however, be wary about assuming that what is good for 23andMe, DNATribes and Pfizer is necessarily good for society.

A salient concern is that people are not merely genomic artefacts; individual profiles in a population-scale database of profiles are collected for data-mining from people who may not understand the consequences of participation, and who may not preempt any decision by relatives through unilateral contribution of a sample.

Another concern, consistent with controversy over the worldwide commercial exploitation of cells extracted from Henrietta Lacks, is the fairness of reward for recreation service participants and third parties such as relatives.²⁴ Those relatives are not necessarily given access to data derived from the service providers' analysis of the sample provided without their knowledge and/or express consent by a family member.²⁵ They have no legal standing to prevent that member from gifting the service provider with, what will be turned into, data about the family. Along with everyone who provides a sample for analysis, they will not receive remuneration from the service provider when

²² Immanuel Kant, 'Groundwork of the Metaphysics of Morals' in Mary Gregor (ed and trans), *Practical Philosophy: The Cambridge Edition of the Works of Immanuel Kant* (Cambridge University Press, 1996) 82, 92.

²³ Bruce Baer Arnold and Wendy Bonython, 'Not As Good as Gold: Genomics, Data and Dignity' in Monique Mann, Kate Devitt and Angela Daly (eds), *Good Data* (Institute of Network Culture, 2019) 135, 135.

²⁴ Rebecca Skloot, *The Immortal Life of Henrietta Lacks* (Crown, 2010).

²⁵ Wendy Bonython and Bruce Baer Arnold, 'Direct to Consumer Genetic Testing and the Libertarian Right to Test' (2018) 44(11) *Journal of Medical Ethics* 787, 788.

that enterprise sells a data set outright, or licences it for several hundred million dollars to a pharmaceutical corporation.²⁶

Recreational genomics accordingly disregards self-determination and remuneration, with the reward for an individual's gifting of data that is common to that person, and the individual's relatives, being enjoyed by the investor in the service. There has been little discussion of those issues, in contrast to controversy in popular and specialist media about privacy aspects of recreational genomics. Privacy, conceptualised as freedom from inappropriate interference (including illicit or disproportionate observation), is a human right and a basis for individual and collective flourishing.²⁷ Recreational genomics services assemble data that relates to individuals. Such data is immutable, unlike a name, credit card number, nationality or gender (all of which can be changed). The services analyse some data themselves and, as noted above, provide data to other parties such as pharmaceutical companies. Subject to a participant's agreement, of which a family member might be unaware and which a family member cannot prevent, law does not prevent such commercial access.

That is potentially of concern, given the growing body of authoritative studies questioning assumptions about the effectiveness of 'deidentification' or 'anonymisation' — mechanisms conventionally perceived as protecting the privacy of individuals whose attributes have been abstracted through genomic or other profiling.²⁸ Non-commercial access is also of potential concern, evident in the controversy over claimed identification of the so-called Golden State serial killer through the warrantless use, by law enforcement officials, of genomic data on a 'family tree' site.²⁹ It is axiomatic that a private genomics

²⁶ Megan Molteni, '23andMe's Pharma Deals Have Been the Plan All Along', *Wired* (online, 2018) <<https://www.wired.com/story/23andme-glaxosmithkline-pharma-deal/>>.

²⁷ See, eg, *Universal Declaration of Human Rights*, GA Res 217A (III), UN GAOR, 3rd Sess, 183rd Plen Mtg, UN Doc A/810 (10 December 1948) art 12.

²⁸ Khaled El Emam et al, 'A Systematic Review of Re-Identification Attacks on Health Data' (2011) 6(12) *PloS one* e28071; Liangyuan Na et al, 'Feasibility of Reidentifying Individuals in Large National Physical Activity Data Sets From Which Protected Health Information Has Been Removed With Use of Machine Learning' (2018) 1(8) *JAMA Network Open* e186040; Luc Rocher, Julien M Hendrickx and Yves-Alexandre de Montjoye, 'Estimating the Success of Re-Identifications in Incomplete Datasets Using Generative Models' (2019) 10 *Nature Communications* 3069; Chris Culnane, Benjamin IP Rubinstein and Vanessa Teague, 'Health Data in an Open World', *Cornell University* (Web Page, 2017) <<https://arxiv.org/abs/1712.05627>>.

²⁹ Felix Ralph, 'Convictions Through Kith and Kin: Legal, Policy and Ethical Issues in DNA Familial Matching and Genetic Metadata' (2018) 29(3) *Current Issues in Criminal Justice* 243, 244; George M. Dery III, 'Can a Distant Relative Allow the Government Access to Your DNA? The Fourth Amendment Implications of Law Enforcement's Genealogical Search for the Golden State Killer and Other Genetic Genealogy Investigations' (2019) 10(2) *Hastings Science and Technology Law Journal* 103, 121

database does not have the legal basis of official criminal forensics databases, generated through the collection of DNA under authority of law from criminal offenders or suspects.³⁰

One response to such concerns is that they are simply misplaced, with questions on how people are harmed when genomic data is used to catch serial killers, or when they do not receive income from commercial exploitation of genomic data provided through recreational genomics services? A salient answer is that use of genomic databases for law enforcement, alongside any other databases, must take place within a coherent and transparent legal framework: process and procedure is important, as is evident from the evolution of procedures such as warrants, which exist to protect citizens against abuse of civil liberties. In a liberal democratic state, just because a search is administratively convenient does not make it appropriate and legitimate. As discussed above, dignitarian theorists have encouraged gifting. However, principles underlying individual efforts to better society are that giving is both voluntary and informed (a potential problem where one family member silently gifts genomic data that is common to siblings and other biological relatives),³¹ and not unconscionably exploited.

Consumers of course exercise their autonomy by providing data through loyalty programs involving supermarkets and utilities, without a direct reward when the program operator bundles data for on-sale to other entities. That practice is traditional but it raises questions, akin to those in recreational genomics, about informed choice, a bad bargain sufficient for regulatory intervention, and even deception.³²

VI INADEQUATE UNDERSTANDING, INEFFECTIVE LAW

Regulators have been slow to address concerns regarding consumer protection aspects of recreational genomics. This is primarily because of uncertainties about responsibility and the inadequate resourcing of agencies such as the US Food and Drug Administration

³⁰ Sheldon Krinsky and Tania Simoncelli, *Genetic Justice: DNA Data Banks, Criminal Investigations, and Civil Liberties* (Columbia University Press, 2013); David Lazer (ed), *DNA and the Criminal Justice System: The Technology of Justice* (The MIT Press, 2004).

³¹ This issue was discussed in Arnold and Bonython (n 1); Wendy Bonython and Bruce Baer Arnold, 'Direct to Consumer Genetic Testing and the Libertarian Right to Test' (2018) 44(11) *Journal of Medical Ethics* 787.

³² One point of reference is the Australian Competition & Consumer Commission, *Customer Loyalty Schemes* (Draft Report, September 2019).

(‘FDA’), Australia’s Therapeutic Goods Administration (‘TGA’) and the Australian Competition and Consumer Commission (‘ACCC’).³³

The services do not neatly fall into traditional categories of pharmaceuticals and medical devices. Given the claimed recreational status, unmediated by a health practitioner and often marketed online across national boundaries (exacerbating regulatory incapacity given that gatekeepers concentrate on entities based in their own jurisdictions), consumers have been expected to engage in self-help in interpreting claims by service providers. This relates to the accuracy of data provided to an individual participant, or about the consequences of that data. Variation in data on an individual from competing service providers should result in caution. There have also been indications that data analysis from some of the less prominent services was bogus — a fraud addressable under consumer protection law.³⁴ In-house ethics frameworks regarding data analysis and sale are problematic,³⁵ largely because, in the absence of statutory requirements and effective monitoring by regulators with sufficient expertise, there is the potential for enterprises to obfuscate accountability and place corporate interests ahead of those of DNA contributors and third parties such as the biological relatives of those contributors

VII BUILDING A DIGNITARIAN FRAMEWORK

There are benefits from the development and extension of biobanks and of genomics databases on a population scale. Although precision medicine is often over-sold because it is misunderstood, or because of institutional imperatives in a competition for investment and research funding, there are potentially significant benefits from deepening our understanding of the ‘book of life’ and its interaction with factors like

³³ In Australia the TGA can draw on power under the *Therapeutic Goods Act 1989* (Cth) and *Customs Act 1901* (Cth) but in contrast to the FDA (which issued a ‘desist’ letter to 23andMe in 2013) has relied on a hands-off strategy. The ACCC, which has adopted a more activist and effective strategy in addressing claims regarding health goods and services, has scope under the *Competition & Consumer Act 2010* (Cth). For a view of resourcing, institutional culture, and prioritisation in the regulation of health products see Daniel Carpenter, *Reputation and Power: Organizational Image and Pharmaceutical Regulation at the FDA* (Princeton University Press, 2014); Editorial Board, ‘80,000 Deaths. 2 Million Injuries. It’s Time for a Reckoning on Medical Devices’ *The New York Times* (New York, 4 May 2019).

³⁴ See Jorge Barrera and Tiffany Foxcroft, ‘Heredity or Hoax?’ *CBC News* (Webpage, 13 June 2018) <<https://newsinteractives.cbc.ca/longform/dna-ancestry-test>> regarding a report that canine samples were misinterpreted or misrepresented as indicating First Nations ancestry.

³⁵ Rachel Kalf, Rachel Bakker, and Cecile Janssens, ‘Predictive Ability of Direct to Consumer Pharmacogenetic Testing: When is Lack of Evidence Really Lack of Evidence?’ (2013) 14(4) *Pharmacogenomics* 341; Michael Murray, ‘Why We Should Care About What You Get for ‘Only \$99’ from a Personal Genomic Service’ (2014) 160(7) *Annals of Internal Medicine* 507.

lifestyle.³⁶ Recreational genomics is not necessarily an evil and precluded by human rights law.

Law and public policy about such services should, however, clearly acknowledge Kant's wariness about abstracting people as a means to an end,³⁷ and more recent debate about the allocation of rewards. From those perspectives, dignity might be respected through law reform that addresses several concerns.

Dignity is a matter of self-respect and mutual respect. It is as much a matter of shared understanding as it is of values enforced by public/private law, such as the privacy tort most recently advocated by the Australian Competition and Consumer Commission.³⁸ Community education about genomics and its consequences is achievable, and may foster discussion within families about the legitimacy of an enthusiastic individual unilaterally sharing data about siblings or other relatives. That is a matter of self-determination.

Education might also foster understanding of data provided by the services to participants, with consumers having a sense that data needs to be interpreted, and that there is particular value in seeking guidance from expert clinicians.³⁹ In practice, law in Australia and other jurisdictions could go further in requiring service providers to expressly state that participants should seek guidance and that the data is not a medical service. Such express requirements would necessarily require further clarification of the law governing disclosure of the results of genetic testing, including for the purpose of obtaining insurance. Recognition of these services as medical services, with the authority such recognition entails, requires closer scrutiny by adequately resourced regulators and appropriate supervision by independent ethics bodies. Close involvement of clinicians in advising consumers about the status and interpretation of data from recreational genomics services will, of course, require effort by clinicians alongside a public education

³⁶ See, eg, Pekka Martikainen, Mel Bartley and Eero Lahelma, 'Psychosocial Determinants of Health in Social Epidemiology' (2002) 31(6) *International Journal of Epidemiology* 1091; Sheldon Cohen, 'Psychosocial Models of the Role of Social Support in the Etiology of Physical Disease' (1988) 7(3) *Health Psychology* 269.

³⁷ Immanuel Kant, 'Groundwork of the Metaphysics of Morals' in Mary Gregor (ed and trans), *Practical Philosophy: The Cambridge Edition of the Works of Immanuel Kant* (Cambridge University Press, 1997) 14, 31.

³⁸ Australian Competition and Consumer Commission, *Digital Platforms Inquiry* (Final Report, 26 July 2019).

³⁹ Michael G Artin, Deborah Stiles, Krzysztof Kiryluk and Wendy K Chung, 'Cases in Precision Medicine: When Patients Present with Direct-to-Consumer Genetic Test Results' (2019) 170(9) *Annals of internal medicine* 643.

campaign. However, that effort does not impose a disproportionate or unduly large burden on the public/private health systems and, apart from its general educative value, is consistent with the sort of engagement needed as Australians embrace the promises of precision medicine.⁴⁰

Law enforcement and other officials should be precluded from using community-based or other private genomic search tools and recreational genomics services as proxies for forensic databases are properly bounded by rules about access and authority. Bureaucratic convenience is not identical to legitimacy, a confusion evident in the controversy about unauthorised and creeping access to telecommunications metadata in Australia.⁴¹

Given the indelibility of genomic data, it is necessary to ensure best practice in relation to privacy both within and across borders. Earlier paragraphs have also noted the absence of a global monitoring regime regarding the performance of current and new entrants into the market for recreational genomics services. Australia's privacy framework is not systematic and regulators are under-resourced. More forward-looking law would address concerns regarding data breach, informed consent (a focus of development in the European Union) and use, or misuse, of data by third parties.

Finally, law might grapple with questions about the proprietorial rights that underpin the business models of the recreational genomics sector.⁴² One response is to conceptualise the human genome as a data commons.⁴³ In practice, people might be encouraged to contribute samples to a not-for-profit repository that operates under independent

⁴⁰ See Michael Murray, 'Why We Should Care About What You Get for 'Only \$99' From a Personal Genomic Service' (2014) 160(7) *Annals of Internal Medicine* 507; Heidi Howard and Pascal Borry, 'Personal Genome Testing: Do You Know What You are Buying?' (2009) 9(6-7) *The American Journal of Bioethics* 11; Amy L McGuire and Wylie Burke, 'Health System Implications of Direct-to-Consumer Personal Genome Testing' (2011) 14(1) *Public Health Genomics* 53.

⁴¹ Rick Sarre, 'Metadata Retention as a Means of Combatting Terrorism and Organised Crime: A Perspective from Australia' (2017) 12(3) *Asian Journal of Criminology* 167; Nicolas P Suzor, Kylie M Pappalardo and Natalie McIntosh, 'The Passage of Australia's Data Retention Regime: National Security, Human Rights, and Media Scrutiny' (2017) 6(1) *Internet Policy Review* 1.

⁴² Richard Spinello, 'Property Rights in Genetic Information' (2004) 6(1) *Ethics and Information Technology* 29; Alexandra George, 'The Difficulty of Defining 'Property'' (2005) 25(4) *Oxford Journal of Legal Studies* 793; Wendy Bonython and Bruce Baer Arnold, 'Privacy, Personhood, and Property in the Age of Genomics' (2015) 4(3) *Laws* 377.

⁴³ Amy McGuire and Wylie Burke, 'An Unwelcome Side Effect of Direct to Consumer Personal Genome Testing: Raiding the Medical Commons' (2008) 300(22) *Journal of the American Medical Association* 2669; Wendy Bonython and Bruce Baer Arnold, 'Privacy, Personhood, and Property in the Age of Genomics' (2015) 4(3) *Laws* 377.

supervision with a strict ethical code and is not captured by a private sector partner, taking on board lessons from the United Kingdom's flawed care data initiative.⁴⁴ Such contribution might foster community goods and — in embodying choice — offer a competitor to the commercial services. In a neoliberal economy, it is politically impractical to nationalise or close enterprises such as 23andMe or GoogleHealth but, in exercising our agency, we do not need to feed them. As a good global citizen, Australia might correspondingly agitate for an international genomics framework that has more bite than aspirational declarations by UNESCO.⁴⁵

⁴⁴ Pam Carter, Graeme Laurie, and Mary Dixon-Woods, 'The Social Licence for Research: Why care.data Ran into Trouble' (2015) 41(5) *Journal of Medical Ethics* 404; Justin Keen et al, 'Big Data + Politics = Open Data: The Case of Health Care Data in England' (2013) 5(2) *Policy and Internet* 228; Jon Hoeksma, 'The NHS's Care.Data Scheme: What are the Risks to Privacy?' (2014) 348 *British Medical Journal* 1547; Paraskevas Vezyridis and Stephen Timmons, 'Understanding the Care.Data Conundrum: New Information Flows for Economic Growth' (2017) 4(1) *Big Data & Society* 1.

⁴⁵ Shawn Harmon, 'The Significance of UNESCO's Universal Declaration on the Human Genome and Human Rights' 2005) 2(1) *SCRIPT-ed* 20; David Winickoff and Larissa B Neumann, 'Towards a Social Contract for Genomics: Property and the Public in the "Biotrust" Model' (2005) 1(3) *Life Sciences Society and Policy* 8; Bastian Greshake Tzovaras and Athina Tzovara, 'The Personal Data is Political' in Jenny Krutzinna and Luciano Floridi (eds), *The Ethics of Medical Data Donation* (Springer, 2019) 133; Shawn Harmon, 'Ethical Rhetoric: Genomics and the Moral Content of UNESCO's 'Universal' Declarations' (2008) 34 *Journal of Medical Ethics* e24.

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