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Indigenous Australians, genomics, and the law

Buddy Tait[1] and Belinda Carpenter[2]

Abstract

This article utilises three key characteristics of human genetic information—namely, its ubiquitous nature, its familial relationships and its predictive capacity—to explore how such research continues to exacerbate existing health inequalities for Indigenous Australians. By utilising substantive equality as its theoretical framework, this article explores key regulatory issues as follows: first, and regarding genetic information's ubiquity, the article discusses how property laws in Australia fail to adequately protect Indigenous Australians from unauthorised usage of historical DNA samples; second, the familial nature of genetic information can leave Indigenous Australian's liable to hyper-precise genetic definitions of Aboriginality, leading to a potentially adverse impact on claims of Native Title, due to the application of a biological definition to something which has always been more contextual and flexible; finally, the predictive element of genetic information is explored, and it is suggested that without proper regulation, could lead to increased genetic discrimination.

Keywords

equality, genetics, genomics, Indigenous Australians, regulation

Introduction

Twenty years ago, the Australian Law Reform Commission (ALRC) and the Australian Health Ethics Committee of the National Health and Medical Research Council (NHMRC) produced a report entitled *Essentially Yours: The Protection of Human Genetic Information in Australia (ALRC Report 96)* (*Essentially Yours*) (Law Reform Commission, 2003). This report recognised the increasing medical importance of genetic research, and sought to provide industry-wide recommendations (Law Reform Commission, 2003). Despite the significant advances since that report was released, it is still the only Australian Government report on the topic of genetics. The subsequent regulations that flowed from its release have been strongly criticised for failing to adequately consider the profound cultural meaning of current and historical genetic information for Aboriginal and Torres Strait Islander peoples, hereafter Indigenous Australians; for not providing sufficient legal structures to ensure appropriate protocols and protections for these groups; and for exacerbating health inequalities for Indigenous Australians (McWhirter et al., 2015). This article explores these concerns through a focus on Australia's extensive legal and regulatory framework, alongside the procedures adopted by researchers in undertaking genomic research, and protections imposed by policymakers. It seeks to determine whether Indigenous Australians' legal and cultural rights are adequately safeguarded by existing regulations, and the potential impact on existing health disparities if they are not.

Utilising equality as a lens, and employing the framework from *Essentially Yours*, which suggests that the three distinctive characteristics of genomic research are that it is "ubiquitous, familial and often predictive," this paper will make three central points about potential regulatory shortcomings that may impact on Indigenous Australians (Law Reform Commission, 2003, p. 132). First, regarding the idea that genetic information is *ubiquitous*, property laws will serve as an example of the way in which regulation can fail to appropriately endorse Indigenous ideas of ownership and control over historical genetic samples. Second, with respect to the *familial* element of genomic information, claims to Native Title will serve as an example of the ways in which the need for precise definitions of Aboriginality could adversely affect Indigenous claims. Third, and based on the knowledge that genetic data can be *predictive*, this article will use the example of insurance policy to demonstrate that there must be stronger regulatory protections of such prognostic information to prevent the disadvantage of Indigenous Australians. Finally, this article will compare Australia's approach to that of other jurisdictions to both contextualise the current approach in

[1]London School of Economics and Political Science, UK
[2]Queensland University of Technology, Australia

Corresponding author:
Belinda Carpenter, Queensland University of Technology, Victoria Park Road, Kelvin Grove, Brisbane, QLD 4059, Australia.
Email: b.carpenter@qut.edu.au

Australia and to offer relevant solutions and best practices that have been successfully utilised in comparable situations. However, prior to engaging with these issues, the following section places genetic research in its historical and social context alongside the competing concerns of equality and utilitarianism in guiding genetic research.

Background and context

Genomics, genetics, and Indigenous Australians

An important distinction at the heart of this issue is the difference between genomics and genetics. Genomics is the study of all the genetic material present in an organism (Archibald, 2018; National Human Genome Research Institute, 2024; World Health Organization, 2002). This allows for examination and discovery of variations that have implications for health, disease, and drug efficacy (NHMRC, 2011). Often confused with genetic research, genomics differs due to its study breadth. While genetics examines individual genes as associated disorders, known as Mendelian diseases, genomics focuses on entire genomes (NHMRC, 2011). For example, most sickle cell anaemia cases are due to the mutation of a single gene—the HBB gene—whereas type II diabetes can be the result of up to 38 gene mutations (Ali, 2013; Carlice-dos-Reis et al., 2017). Since the *Essentially Yours* report, genomic research has come to the forefront of medical advancements (Jowett et al., 2020). As a result, this article will principally use the term "genomics" in line with the majority of the academic literature in this area. However, please note that these issues span across genomics and genetics.

The 2003 publishing of the *Human Genome Project*, an international collaborative research programme of the late nineties, marked the commencement of the genetic age (Jurecic, 2014; National Human Genome Research Institute, 2022). This era promised a therapeutic revolution of personalised medical treatment, but it has also brought with it a plethora of complex ethical and legal considerations. In response to the *Human Genome Project*, and following two years of research and consultation, the *Essentially Yours Report* provided 144 recommendations for reform, focused on the protection of privacy, unfair discrimination, and the promotion of high standards in practice and research (Law Reform Commission, 2003). As noted in Part 1, this report considered material collected in genetic research to be distinct due to three characteristics: its ubiquitous nature, its familial characteristics, and its predictive qualities.

Genomics and the resultant capacity for personalised medicine are the future of medical treatment (Vicente et al., 2020). Their application and capability in clinical settings is becoming increasingly effective and it holds promise of advanced disease treatment and prevention. Currently, genomics and personalised medicine remain an emerging technology, but as the technology advances, this article maintains that legal protections are needed to ensure that minority groups, such as Indigenous Australians, also benefit from this new era of medicine (Fröhlich et al., 2018). This is because genomics has a diversity problem (Guglielmi, 2019; Popejoy & Fullerton, 2016).

Internationally, European descendants account for close to 80% of participants in genomic research, despite only making up around 18% of the global population (Popejoy & Fullerton, 2016). Furthermore, estimates indicate that Indigenous people contribute to only 0.02% of this research, decreasing from 0.06% in 2009 (Claw et al., 2018; Garrison et al., 2019; Mills & Rahal, 2019). This underrepresentation is likely due to historical, logical, and systemic issues (Fatumo et al., 2022; Popejoy & Fullerton, 2016). Common explanations include ease of research by active reduction of variables, and funding focus in wealthy geographical locations (Popejoy & Fullerton, 2016). However, for Indigenous populations, the rationale for underrepresentation is the result of a more complex and problematic history (Caron et al., 2020). For centuries, Indigenous Australians have been the object of western and colonial science and research, and these practices have been plagued by unethical treatment and disregard for cultural and social beliefs (Caron et al., 2020; Cheng et al., 2021). In addition, centuries of exploitation of patentable material, theft, misuse of samples and years of study with little community benefit have resulted in extreme mistrust by Indigenous Australians, resulting in a hesitancy to participate in scientific research (Garrison et al., 2019). Negative dealings in the genomics and broader research context among global Indigenous populations also negatively impact confidence and trust (Garrison et al., 2019).

There is also a large disparity between Indigenous and non-Indigenous health outcomes. This is most clearly displayed within life expectancy data. On average, life expectancy at birth for an Indigenous Australian is 8.2 years less than a non-Indigenous Australian (The National Indigenous Australians Agency, 2020). This disparity is largely due to higher rates of chronic disease (Al-Yaman, 2017; The National Indigenous Australians Agency, 2020). As mentioned, genomics brings with it the promise of personalised medicine, but with reduced levels of research conducted with Indigenous Australians, there is potential for them to be left behind. By failing to appropriately engage Indigenous Australians in genomic research, diseases disproportionately impacting Indigenous Australians may be left under-researched, drugs based on broad genetic code can be rendered ineffective, and individualised clinical care capabilities could be reduced (Bentley et al., 2017).

Counter arguments: utilitarianism and equality

This article suggests that substantive equality offers the most appropriate approach to the problem, which is in contrast to the majority of research on genomics, which takes a utilitarian, consequentialist approach. Examples of utilitarian arguments include the primary right to science and the dangers of overregulation in medical research, but these can be countered through an equality lens with concerns of infringement on the rights of minority groups. This can serve to clarify a different approach that positions Indigenous concerns as central to the debate.

Equality is a relatively contemporary concept, yet it is a foundation of the rule of law and Australian society

(Allsop, 2018). The two most commonly accepted forms of equality are formal and substantive equality (Fredman, 2011). The aim of formal equality is to ensure identical treatment for all members of society (Fredman, 2011). In a genomics research context, this would require the identical use, collection, sharing and storage of all genomic data without consideration of the individual. Substantive equality extends past identical treatment and necessitates equal outcomes (Fredman, 2011). It concerns the imposition of positive obligations that seek to promote uniform results, especially among the disadvantaged (Fredman, 2016; Gaze & Smith, 2016). Utilising substantive equality as a frame would expand genomic research requirements to ensure that the broader social, cultural, and ethical impact is measured.

Ironically, the strongest argument against an approach based on substantive equality—that would require specific regulation for genomic research conducted on Indigenous Australians—is one based in formal equality (Jacobsson, 2016), suggesting that all members of society who contribute to research should be treated equally. Any attempts to protect Indigenous rights are positioned as a deterrent for research, adding time and complexity to the research approval process (Eckstein et al., 2018). It is also suggested that substantive equality and differential protections and treatment of Indigenous Australians in genomic research support the idea that the state knows best when it comes to Indigenous affairs. It is argued that such an approach reinforces persisting power imbalances and requires the Australian Government to play the role of guardian, as opposed to partner (Jeffes, 2020).

The second argument is based on consequentialist reasoning and requires Indigenous Australians to participate in genomic research for the greater good of global health. Given that genomic research, which fails to account for ethnic diversity, has been compared to completing research without any variables (Hindorff et al., 2017), genomic research in Indigenous populations not only benefits Indigenous Australians, but also the global population (Smart & Williams, 1973). This is supported by a recent genomic study of Greenlandic Inuit populations which revealed a common genetic mutation that had consequences for European descendants in whom it appeared with far less frequency (Popejoy & Fullerton, 2016). Consequentialist reasoning thus argues that despite current practices infringing upon Indigenous Australians' cultural and legal rights, the potential benefit to public health outweighs any negative impact this may incur.

This article disputes these arguments and instead argues that that the regulations that ought to be implemented for the protection of Indigenous Australians in genomic research are not paternalistic, but rather provide increased autonomy. It is also the case that substantive equality is a far more empathetic and reasonable approach than formal equality, and that consequentialist arguments for the promotion of public health are not sufficient justification for the disruption of Indigenous Australians' rights.

Moreover, arguments that promote formal equality and describe substantive equality as paternalistic fail to recognise the lasting and ongoing impacts of colonialism on Indigenous Australian communities (Kowal, 2015). Formal equality disregards the notion that equal treatment does not result in equal outcomes (Fredman, 2011). In the genomics context, formal equality would exacerbate the existing diversity problem by inadequately endorsing Indigenous Australian rights. Reducing existing health disparities to actively improve Indigenous Australian outcomes, requires favourable legislation and regulation that promotes autonomy without being paternalistic (Baynam et al., 2017). It is possible that the red tape acts as a deterrent for researchers in the area, but the protections are a necessity for the promotion of Indigenous representation in genomic research and the path to equal outcomes.

Medical regulation and law exist in the "intersection between consequentialist and deontological reasoning" (Savulescu & Wilkinson, 2019, p. 68). In theory, the goal of medicine is consequentialist in nature, in that it is interested in maximising health outcomes (Smart & Williams, 1973). Modern medicine seeks to balance maximum health results while also promoting patient autonomy. Echoing Bernard Williams' seminal objection to consequentialist ethics, the issue with an exclusive consequentialist model, such as requiring participation in genomic research for the greater benefit of global public health, is that it benefits the majority at the expense of the minority (Williams, 1972). This fails to recognise individual rights and health outcomes, and while this would promote public health and assist in increasing medical standards, it does so to the disadvantage of Indigenous Australians. For the reasons to be outlined in this paper, Indigenous sovereignty and autonomy are vital in the genomics context. Sacrificing the cultural and legal rights for the benefit of greater global health does not align with the principles of substantive equality that genomic research should seek to embody.

To continue the path to closing the gap between Indigenous and non-Indigenous Australians' health outcomes, this paper will argue that appropriate legal measures and protections that consider the special characteristics of genetic information must be employed. Indigenous Australians should not be disproportionately victimised by the age of personalised medicine and genomics, without reaping its benefits. Genetic information's identified special characteristics of being ubiquitous, familial, and predictive each present legal and ethical challenges for Indigenous Australians.

Genomics as ubiquitous

Information that is gathered through genomic research is ubiquitous in the sense that it is perpetual and that every cell—excluding sex cells and mature blood cells—contains all the genetic code of an individual (Law Reform Commission, 2003). This genetic code can be sequenced from a hair left behind at a café, dropped at a crime scene, or discovered in an archaeological dig site. While all three contexts are potentially useful to identify a body, solve a crime, or source a contagion, and all three bring with them a range of legal and ethical concerns, such as privacy, theft, and discrimination, this section is most interested in the genomic sequencing of historical genomic material. This is

because while such sequencing—specifically that of Indigenous populations—has become more common as technology has advanced, generating significant discoveries in human lineage, it also raises substantial ethical and legal questions at the intersection of property law and consent. By providing insight into institutions that have exemplary approaches to the issue and comparing the Australian experience with the current position of the USA, it will be argued that the sequencing of historical biological material requires uniform legislative recommendations on ownership and ongoing usage, to ensure the adequate protections of Indigenous cultural and legal rights.

Ownership and usage of historical biological samples

In 2011, the first full genomic sequence of an Aboriginal Australian was produced (Rasmussen et al., 2011). This full sequence was acquired from a hair sample gathered in 1920 by British ethnologist Alfred Cort Haddon (Callaway, 2011; Rasmussen et al., 2011). Identified by the authors as the model research approach to sequencing historical biological material, it was also considered "unchartered ethical territory" (Callaway, 2011, p. 522). While determined to be donated to Haddon "freely," it provoked criticism from Indigenous activists who maintained that the research had failed ethical standards due to inadequate cognizance of the broader cultural, social and historical context (Callaway, 2011, p. 522; Kowal, 2012). Despite 11 years passing since this research, concepts of ownership and usage of Indigenous historical biological samples remain unclear.

In fact, complex and convoluted is the most accurate description of the laws and regulations that govern ownership of historical collections of Indigenous Australians' blood and hair samples (Prictor et al., 2020). Current regulation fails to appropriately define and attribute ownership of historical biological materials, and impedes the promotion of Indigenous Australians' research autonomy and participation (Elsum et al., 2019). Authority in common law could grant proprietary rights to the institutions that hold considerable material, as long as the collection was lawful and authorised (Prictor et al., 2020). However, there was no legislative definition of lawful collection of biological material prior to 1970, and consent has since had an evolving definition (Prictor et al., 2020; Transplantation and Anatomy Act, 1979). In addition, there are both Commonwealth and State-based legislation that provide some regulation, but they are ultimately silent on future use, storage, and access (Aboriginal and Torres Strait Islander Heritage Protection Act, 1984; Prictor et al., 2020; Queensland Heritage Act, 1992). Even if property rights are established, it is unlikely that this would result in outright ownership, rather it would likely only constitute the permission to remain in possession (Prictor et al., 2020). The guidelines that govern the usage of genetic information are similarly convoluted. The Privacy Act 1988 (Cth) provides the central rules of usage regulation. This legislation ensures adequate protection of genetic information on an individual level, but, at this point in time, fails to take into account group interests (Dallaston et al., 2021).

A key part of the problem is that the *consent* provided by Indigenous Australians when blood and samples were taken in the mid to late twentieth century was likely closer to *implied consent* due to the unequal relationship between Indigenous Australians and colonial researchers (Garrison et al., 2020; Prictor et al., 2020). As science and ethical research standards have developed, so too have the requirements for conducting research on humans. As government legislation and regulations are largely silent on this topic, the *National Statement on Ethical Conduct in Human Research* (*National Statement*), sets out the general requirements for consent (NHMRC, 2018). While this statement provides guidelines for researchers, punishment for breaches does not extend beyond reduced funding and potential employment misconduct proceedings (Jowett et al., 2020). It is argued that the lack of legislative clarification places unnecessary strain on, and vests excessive power in, the *National Statement*, thus failing to provide appropriate protections over the ongoing use of historical biological material.

International perspective

Internationally, there is no regulatory best practice, despite many countries—like Australia—being subject to extensive international obligations that govern the ownership and usage of historical biological material (Prictor et al., 2020). Most notably, Article 31(1) of *The United Nations Declaration on the Rights of Indigenous Peoples* states that Indigenous people have the right to "maintain, control, protect and develop their . . . human and genetic resources" (United Nations, 2006, p. 22). However, these international obligations have failed to influence substantive domestic legislative protections. Much like Australia, the USA's genomic research of its Indigenous people has been controversial. In the late 1990s, genomic research conducted in relation to diabetes in an Indigenous community was subsequently used in numerous secondary studies (Kowal, 2015). This resulted in successful legal action by the Havasupai (an Indigenous American tribe located in the Grand Canyon, Arizona, USA), but continues to provoke ongoing mistrust, and is argued to be a factor in the decreased Indigenous representation in genomic research in the USA (Kowal, 2015).

Globally, it is institutions rather than nation states that are ensuring the protection of Indigenous legal and cultural rights, with pockets of best practice in research centres around the world. The National Centre for Indigenous Genomics (NCIG) at the Australian National University (ANU) is considered an institution of example and holds a large amount of blood samples of Indigenous Australians collected between the years 1960 and 1990 (Prictor et al., 2020). In 2012, to promote and recognise their cultural, historical, and scientific significance, NCIG placed the samples under Indigenous Custodianship (NCIG, 2018; Prictor et al., 2020). This decision was motivated by recognition of the importance of Indigenous research sovereignty and designed to increase trust in genomic research within Indigenous Australian communities (NCIG, 2018). Recently, NCIG returned over 200 historical blood

samples to the Galiwin'ku (an Indigenous Australian community of Elcho Island, north coast of the Northern Territory, Australia) in line with their cultural beliefs (Lewis, 2020). The centre then worked with the community to engage in genomic research by taking new blood samples (Lewis, 2020). This considered and informed approach employed by the NCIG removes the debate over legal ownership and allows for Indigenous Australians to determine the role that historical biological samples play in future research. This empowerment ensures ownership and usage control is returned to Indigenous communities. The USA, like Australia, does have some legislation to guide repatriation of historical biological samples, and institutions that hold large amounts of these samples, such as the Alaskan Area Specimen Bank, have employed similar practices to the NCIG at ANU (Kowal, 2015).

While legislation and international law provide some relevant rules regarding historical biological samples, more well-defined guidelines for use and ownership of genomic research need to be established to ensure the empowerment of Indigenous communities in Australia and Internationally. This is required to ensure that the historical wrongs do not have a lasting impact in existing health disparities between Indigenous and non-Indigenous populations. Despite institutions appropriately handling the genetic information of Indigenous Australians, uncertainties and mistrust remain due to the familial nature of the information and its potential application.

Genomics as familial

An individual's genomic information is inherently unique (Law Reform Commission, 2003). However, it also has the potential to reveal information about family and community (Law Reform Commission, 2003). That is, analysis of a person's genome has the possibility to reveal information about—and therefore have implications for—the broader ethnic, Indigenous, or ethno-religious community to which they belong (Law Reform Commission, 2003). In an Indigenous context, the familial dimension raises three central concerns. First, the complexity of the community system within Indigenous society requires a more considered approach to independence and interdependence, as relational autonomy would govern Indigenous participation in genomic research (MacKay & Dawson, 2021). Second, Indigenous Australians' very low levels of trust in research due to past misuse, as discussed above, has negatively impacted vital broad data-sharing (Jowett et al., 2020). Finally, hyper-precise definitions of Aboriginality through genetics have both ethical issues in itself, and also have the potential for a profound negative impact on Native Title claims (Watt et al., 2020). The following discussion will focus on this final point and will seek to provide international context by discussing the use of genetic information in land claims in Peru.

Aboriginality, Native Title, and genetics

Aboriginal has been subject to 67 definition changes since colonisation (Weisbrot, 2014). Currently, Aboriginality is defined by a three-pronged working criteria that includes descent, identity and community acceptance (Gardiner-Garden, 2000). There are no phenotypic or genotypic requirements (Gardiner-Garden, 2000). With the rise of readily available, accessible, and accurate genomic sequencing, there are fears that the definition of being an Indigenous Australian could move away from the social and cultural to the biological. Utilising a biological definition for Aboriginality challenges the Indigenous conception of belonging and self, which has traditionally been contextual and flexible (Watt et al., 2020). Furthermore, concerns have been raised that the pursuit of hyper-precise definitions of ethnicities could contribute to the resurgence of race as a biological classification (Kent, 2013). While broadly rejected in Australia, it is not unprecedented and was discussed in political campaigning as recently as 2019 (Latimore, 2019). At present, Australia does not have a comparison to the *blood rules* that operate in parts of North America, and which seek to determine Indigenous rights based on an individual's percentage of *Indigenous blood* (Rodriguez-Lonebear, 2021). Therefore, the more likely result of a move towards genomically precise definitions of Aboriginality would be its potential impact on claims of Native Title.

Native title claims are founded upon the principles in the High Court's 1992 ruling on *Mabo v Queensland* (No 2) and are clarified in the Australian Federal legislation Native Title Act 1993 (Cth). For Native Title to be acknowledged, Indigenous communities must claim that their "laws and customs . . . have continued substantially uninterrupted since sovereignty" (Members of Yorta Yorta Indigenous Group v Victoria, 2002, p. 374). Indigenous Australians have been quoted as stating that "[before] all this Native Title business, no-one cared about which family you came from" (Babidge, 2016, p. 126). Representatives from Indigenous Australian communities tend to argue that kinship is not a biological, but rather a social phenomenon. As a consequence, genomic information has not been used in Native Title claims in Australia, and the use of this information in such claims currently remains widely criticised (Watt et al., 2020). While Native Title itself has impacted the very structure of Indigenous lineage, it has been argued that the incorporation of genomic testing as a requirement for future claims would further infringe upon Indigenous Australians' cultural rights and potentially act as a deterrent for communities to participate in genomic research, for fear of impact on Native Title (Cheng et al., 2021). Despite this, there is a growing shift in emphasis towards bloodlines in post-colonial Indigenous Australian communities (Watt et al., 2020). Ethnographers argue that this is due to overlapping Native Title claims that take place in an adversarial legal system and the requirement for *continuity*. In this context, some Indigenous Australians are shifting from "more fluid and contextual characterisations of group membership towards a reliance on linear descent rules" (Watt et al., 2020, p. 142). This demonstrates that the impact genetics may have on Native Title claims could extend beyond acting as a deterrent for participating in genomic research to accelerating disruptions to traditional

notions of kinship with the further imposition of western conceptions of lineage.

International perspective

Genetics has been used internationally as a political strategy by Indigenous peoples in land title claims. The Uros (the Indigenous population that inhabits Lake Titicaca in Peru and Bolivia) have previously sought to prove descent from ancient Uros in territorial disputes with the Peruvian Government with some success (Kent, 2013). As identified in Indigenous Australian culture, it has been assessed that the use of genetics in territorial disputes, while potentially acting as conclusive evidence, requires Indigenous communities to create an essentialised ethnic identity (Kent, 2013). In attempts to apply a contemporary definition to ancient concepts of lineage, land claims around the world have resulted in the evolution of Indigenous ancestry. While this may be of some benefit politically, if genomic sequencing does not provide Indigenous populations with the answer that will grant them their land claim, it could potentially risk reducing trust in research (Kent, 2013). In addition, the potential threat of genetics playing a role in land claims, thus reducing ancient concepts of lineage to a genetic test and potentially negatively impacting future Indigenous land claims could act as a deterrent globally.

With advancements in technology and increased knowledge of historical groups and their locations, precise definitions of Indigeneity are becoming increasingly achievable. However, these definitions attempt to attach direct lineage to ancestry which has historically been more social and cultural. Internationally, genetics has been used as a political tool by Indigenous communities with mixed and controversial effect. It has been suggested here that Australia should not seek to employ hyper-precise definitions of Aboriginality with genetics, as this has potential to infringe upon cultural and legal rights. While these issues have potential to impact Indigenous Australians, under current legislation, the predictive nature of genomic research leaves Indigenous Australians susceptible to discrimination.

Genomics as predictive

Genomic information is predictive, in that it can reveal information about specific genetic mutations that increase the likelihood of developing health conditions in the future (Law Reform Commission, 2003). This aspect of genomic information is a double-edged sword: while it can inform lifestyle changes and provide early recognition and potential treatment, it can also inform patients of incurable and debilitating genetic disorders they are likely to suffer in the future. With increased awareness of an individual's health future, there is the potential for discrimination in employment and insurance, and increased stigmatisation of ethnic groups that possess specific genetic traits. While discrimination based on genetic information is broadly legislated against in Australia, there are flaws in this prohibition, and Indigenous Australians suffer disproportionately from these shortcomings. This section will discuss the current legislation that allows for genetic discrimination in insurance, how this unfairly targets Indigenous Australians, and will compare Australia's approach to that of New Zealand and Canada.

Genomic discrimination

The more that genomic research develops, the more it is discovered that genetic codes are linked to the risk of significant diseases. For example, while identifying *Cancer genes* such as BRCA1 gene and BRCA2 gene can increase survival rates (Cortés et al., 2019), early access to this information has potential harms. Australian Federal legislation—the Disability Discrimination Act 1992 (Cth)—prohibits discrimination based on genetic status, but an exception allows insurance to discriminate on actuarial grounds (Tiller et al., 2020). If it is deemed that the discrimination based on genetic information is reasonably justified, there is potential for insurers to use this in life and income protection, permanent disability, and travel insurance to increase premiums (Tiller et al., 2020). While this is a legal practice, it is ethically questionable (Rothstein, 2018). It has been reported that individuals were twice as likely to decline participation in genomic testing if they were informed that it could potentially have insurance implications (Keogh et al., 2009). A Parliamentary Joint Committee in 2018 made recommendations to the Australian Life Insurance Industry that endorsed an immediate ban on the use of predictive genetics. No ban was implemented; rather, the Financial Services Council introduced an industry-regulated moratorium that failed to reach the standards and recommendations set out by the Parliamentary Joint Committee (Tiller et al., 2020).

It is arguable that these regulations, while having a potential negative impact on all members of Australian society, unfairly disadvantage Indigenous Australians. Previous research demonstrates that Indigenous Australians have a shorter life expectancy and are more susceptible to life-threatening diseases (The National Indigenous Australians Agency, 2020). Inadequate protections in the field of genomic research further impact the ongoing and historical mistrust that prevents Indigenous Australians from freely participating in genomic research, by compounding their fear of genetic discrimination in life insurance. This supports the importance of a ban on the use of genetic information in insurance policy, and greater government oversight, for the substantive equality of Indigenous Australians (Tiller et al., 2020).

International perspective

Like Australia, New Zealand has also failed to protect this information and as a result it is negatively impacting their Indigenous population (Shelling et al., 2022). However, a number of countries around the world have used legislation to ban the use of predictive individual genetic information in the context of insurance and employment (Otlowski et al., 2019). In Canada, for example, the use of genomic information in insurance is prohibited (Bombard &

Heim-Myers, 2018). In addition, this legislative ban was upheld on appeal (Canadian Coalition for Genetic Fairness v Attorney General of Canada, 2020). It would, therefore, seem that—in comparison to Canada—the Australian Government is failing its Indigenous people by declining to legislate against the use of genomic information in insurance. Not only does this disproportionately impact Indigenous Australians due to the existing health disparities, but it also acts as a deterrent for individuals to undergo potentially life-saving genomic sequencing for fear that it could impact future insurance claims.

Conclusion

Genomic research in its current state may exacerbate existing health disparities between Indigenous and non-Indigenous Australians. The ubiquitous nature of genomic data has displayed flaws in the ownership and usage of historical biological material. The familial characteristics that genomic research unveils have negative implications for definitions of Aboriginality; it has the potential to introduce genetics to Native Title claims founded on complex and sensitive cultural issues. The predictive role that this research will play in personalised medicine has the potential to result in legal discrimination in insurance policies that unfairly impact Indigenous Australians. The exploration of international perspectives—America, Canada, Peru and New Zealand—has clarified the globally systemic flaws that result in Indigenous underrepresentation in genomic research. Despite arguments that centre on the primary right to science for the benefit of both Indigenous Australians and broader society, these paternalistic and consequentialist approaches, respectively, would neglect rights and destroy trust. Australia has a commitment to ensuring that existing health disparities are not exacerbated. Legislative change must effectively account for genomic information's special characteristics and the legal and ethical problems these characteristics can cause for marginalised groups. Only then will we ensure that Indigenous Australians can enjoy the benefit of sciences' incoming era of personalised medicine.

Authors' note

Buddy Tait (MSc, LLB (Hons), BSc) recently completed a Masters of Global Health Policy at the London School of Economics and Political Science and is now commencing a career in public health, with a specific focus on health inequalities, the social determinants of health, and improvement of the outcomes of and conditions within prisons.

Belinda Carpenter (PhD, BHMS (Hons first class)) is a Professor in the School of Justice at Queensland University of Technology, Australia. She has more than 70 articles, books, and book chapters published on topics that maintain a social justice focus, including death investigation of vulnerable populations and sex crimes against women. Belinda has gained more than AU$500,000.00 in external grant money from the Australian Research Council and state government. She has had a number of Community Board appointments and University managerial positions including as a member of the Queensland Parole Board and as Associate Dean of Research in the Faculty of Law at QUT.

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ORCID iD

Belinda Carpenter https://orcid.org/0000-0002-5699-2155

Glossary

Galiwin'ku	an Indigenous Australian community of Elcho Island, north coast of the Northern Territory, Australia
Havasupaian	an Indigenous American tribe located in the Grand Canyon, Arizona, USA
Uros	the Indigenous population that inhabits Lake Titicaca in Peru and Bolivia

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