Genetic Research and

Aboriginal and Torres Strait Islander Australians

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Abstract

While human genetic research promises to deliver a range of health benefits to the population, genetic research that takes place in Indigenous communities has proven controversial. Indigenous peoples have raised concerns, including a lack of benefit to their communities, a diversion of attention and resources from non-genetic causes of health disparities and racism in health care, a reinforcement of “victim-blaming” approaches to health inequalities, and possible misuse of blood and tissue samples.

Drawing on the international literature, this article reviews the ethical issues relevant to genetic research in Indigenous populations and considers how some of these have been negotiated in a genomic research project currently under way in a remote Aboriginal community. We consider how the different levels of Indigenous research governance operating in Australia impacted on the research project and discuss whether specific guidelines for the conduct of genetic research in Aboriginal and Torres Strait Islander communities are warranted.

Keywords Genetic research · Ethical issues · Indigenous · Aboriginal Torres Strait Islander · Research governance

Introduction

Human genetic research is a rapidly developing field that promises to deliver a range of health benefits to the population in general. However, genetic research that takes place with minority groups raises many sensitive issues and has generated much debate in both scientific journals and the media (Juengst 1994; Wade 2005; Hausman 2008). Attempts to carry out genetic research in Indigenous communities have proven particularly controversial (Foster and Sharp 2000; Scott et al. 2005). There is a growing international literature showing that genetic research can have a detrimental effect on minority groups, including Indigenous people (Lone Dog 1999; Reardon 2005; Marks 2003). Indigenous peoples have raised concerns about a lack of benefit to their communities, a diversion of attention and resources from non-genetic causes of health disparities and racism in health care, a reinforcement of “victim-blaming” approaches to health inequalities, and possible misuse of blood and tissue samples (Dodson and Williamson 1999; Pearce et al. 2004). The philosophical and cultural implications of genetic research can fundamentally change the ways we think about our bodies, disease, human variation, and what it means to be human (Rose 2001). For Indigenous peoples, these can also challenge one’s sense of identity and cultural beliefs (Greely 1998).

This article reviews the issues Indigenous people have raised with reference to genetic research projects, DNA banks, and other population genetic initiatives, and points to a way forward for resolving these issues. Although the article focuses on Aboriginal and Torres Strait Islander populations in the Australian context, it also considers other

Indigenous populations within settler states, particularly Canada and Aotearoa/New Zealand. While Indigenous communities differ dramatically both between and within these countries, their common experience of British settler-colonisation and resulting nation-states means it is useful to compare their respective strategies for asserting their rights to self-determination, including control over health research (Cunningham and Stanley 2003). After discussing these issues in general, we then consider how they have been negotiated in one genomic research project in a remote Aboriginal community.¹

This represents the first attempt to review ethical issues pertaining to genetic/genomic health research in an Indigenous Australian context. We consider the issue of consent to genetic research and the specific concerns that should be taken into account as part of a culturally appropriate consent process. We then outline the existing “layered” governance arrangements in place for Indigenous health research and how they facilitate Indigenous control of health research. Following that, a description of the processes of community consultation and obtaining ethical approval for the pseudonymous Remote Aboriginal Project (RAP) is provided. We seek to share our experiences of genetic research in order to open up discussion on how genetic research should be conducted in Aboriginal and Torres Strait Islander communities. We argue that while, in the case of the RAP, the multiple layers of Indigenous governance were successful in protecting research participants, a better solution would be to develop clear guidelines for Indigenous genetic research.

Background

Concerns about lack of benefits or detrimental outcomes for individuals or collectives have been found to affect the participation of members of minority groups in genetic research (Sanner and Frazier 2007; Bowen and Penchaszadeh 2008). In Australia, such concerns may have acted as a barrier to conducting genetic research in Indigenous communities. A recent review of public health genomics in Australia

¹ The authors have an interest in this topic from a variety of positions: as non-Indigenous genetic health researchers working in Indigenous communities (JB, SJ), as an Indigenous researcher engaged in health research projects (GP), and as a non-Indigenous cultural anthropologist of genomics and Indigeneity (EK). Author contributions were as follows: EK led the overall research and writing of the article and drafted the article. GP advised on the major Indigenous genetic research project discussed in the article and contributed to the article. CP conducted the PubMed literature review of past genetic research projects and commented on the article. JB and SJ conducted the major Indigenous genetic research project discussed in the article and commented on the article.

commented that “very little is known about the specific genetic issues relevant to Indigenous Australians” (Metcalf et al. 2009, 127). Our review of the literature found only 56 research papers on some aspect of Indigenous Australians and genetics (including both genetic research on population history such as the distribution of mitochondrial DNA haplogroups and genetic health research such as genetic associations with a disease), with the earliest published in 1979.² To give a sense of the contrast with other Indigenous populations, a search for keywords “Native Americans” and “genetics” using the U.S. National Library of Medicine search engine PubMed yields 1,999 articles published since 1963. Concurrent with scientific research, Indigenous communities in Canada, the United States, and Aotearoa/New Zealand have been considering the use of genetic technologies in both research and clinical contexts for some time.³ This literature is only beginning to emerge in Australia.⁴

As a result, the potential for genetic research to contribute to improving the health of Indigenous Australians has not yet been explored. There is a large gap between Indigenous and non-Indigenous health outcomes. In Australia, the life expectancy at birth for Aboriginal and Torres Strait Islander people⁵ is 12 years less than non-Indigenous Australians for men and 9.5 years less for women, largely due to higher rates of chronic disease and injury (Australian Institute of Health and Welfare and Australian Bureau of Statistics 2008). Indigenous health disparities in other comparable nations also exist to a lesser degree. In Canada and the United States, for examples the life expectancy at birth for Indigenous people is six years less than non-Indigenous people, while in New Zealand there is an eight-year difference (Cooke et al. 2007).

The question of whether genetic research has anything to offer Indigenous populations has been debated. Given the large socioeconomic inequalities that exist between Indigenous and non-Indigenous populations, some argue that social factors rather than genetic factors are solely responsible for Indigenous ill-health (Pearce et

² Search conducted using PubMed on February 29, 2012, using the following search terms: Australia* AND Aborigin* AND polymorphism (Limits = Title/abstract); Australia* AND Aborigin* AND genetic (Limits = Title/abstract); Australia* AND Aborigin* AND SNP (Limits = Title/abstract).

³ For examples of models for Indigenous genetic research and service provision, see Foster, Bernsten, and Carter 1998; Canadian Institutes of Health Research and Institute for Aboriginal Peoples Health 2001; Dukepoo 1998; Glass and Kaufert 2002; Duster 2003.

⁴ See Kowal 2012; Kowal and Anderson 2012; Kowal, Rouhani, and Anderson 2011.

⁵ The terms “Indigenous Australians” and “Aboriginal and Torres Strait Islander people” are used interchangeably in this paper.

al. 2004; Paradies, Montoya, and Fullerton 2007). However, others argue that while the poor health of Indigenous people is largely due to social factors, it is likely that the interaction of genetic factors with the environment also plays a role (Durie 2003). The potential for genomic research to both benefit and harm Indigenous communities is illustrated by the case of a recent research project in a Maori community. Maori and non-Maori health researchers at New Zealand's Environmental Science Research Institute collaborated with Te Iwi o Rakaipaaka (the organisation representing members of the Rakaipaaka community) on the Rakaipaaka Health and Ancestry Study, based predominantly in Nuhaka (Hawke's Bay). It aimed to recruit 3,000 Maori to participate in a longitudinal "envirogenomics" project to investigate common diseases affecting families such as diabetes, gout, heart disease, and cancer. The research team was composed of Maori and Pakeha (non-Maori) researchers, led by Rod Lea and Marino Lea, the latter of whom is a member of the Rakaipaaka iwi. The design and governance of the project responded to many of the concerns that are discussed in this article. An incorporated community organisation had control of the project and retained ownership of the genetic information. They also formed a "Maori *kaitiaki* [guardianship] group" to oversee research that uses Maori genetic information and to develop policy regarding secondary use of samples.⁶ The research team also expressed concern about possible stereotyping in the media if their study findings are interpreted as proof of "Maori genetic susceptibility" to certain diseases. They proposed to manage this by taking care not to extrapolate their findings beyond the community they studied (Hudson et al. 2007).

However, the lead researcher Rod Lea generated worldwide controversy in 2006 when he presented findings from a separate research project that found that Maori were twice as likely as non-Maori to carry a gene associated with alcohol and tobacco use (Lea 2006). The particular polymorphism of the gene that encodes the enzyme monoamine oxidase (MOA) has also been associated with risk-taking and aggression and is consequently known as the "warrior gene" (Stoke 2006). This episode was widely reported in the international media as proving that Maori were genetically predetermined to be violent, a depiction that the researchers argued was a misrepresentation of their research (Lea, Rod, and Chambers 2007). A recent critique

⁶ One example of such an arrangement for culturally appropriate procedures for the storage of blood and other samples comes from the New Zealand cancer tissue bank, which since 2004 has offered all donors the option of having their sample disposed of with a Maori blessing or *karakia* (Morrin et al. 2005).

by a Maori academic argued that linking the MOA allele with high levels of violence among Maori is scientifically unsound, effectively makes being Maori a “disease,” and may lead to genetic and racial discrimination by insurance companies. Further, “contributions to racial stereotyping by trained scientists are unethical and scandalous” (Hook 2009, 6).

This leaves us with a dilemma: Are we to perceive Rod Lea as the culturally appropriate lead co-researcher of the Rakaipaaka Health and Ancestry Study or as the proponent of the potentially damaging “warrior gene” hypothesis? Rather than a split personality, this apparent contradiction may reflect the dangers of conducting Indigenous genetic research in an environment where both long-held racial stereotypes and health inequalities are widespread.

As this case illustrates, a combination of factors means that genetic research in Indigenous populations presents particular challenges. First, Indigenous scholars from the United States, Canada, New Zealand, and Australia have argued that there are specific cultural issues relating to DNA (and the collection, use, and storage of blood products in general) that need to be considered in ethical guidelines (Dodson and Williamson 1999; Hudson et al. 2007; Dukepoo 1998; CIHR 2007). Second, Indigenous people often have a mistrust of research because of negative past experiences with researchers and other institutional structures within the dominant society (Smith 1999). Third, and related to this, there is an array of separate institutional processes and ethical norms relating to research in Indigenous contexts in countries such as the United States, Canada, New Zealand, and Australia (see the section on “governance” below). As argued above, genetic research has been similarly targeted as an area offering specific ethical challenges that require a specialised approach. The combination of two areas of ethical complexity—Indigeneity and genetics—has a compound effect. The vulnerability and cultural difference of Indigenous people collide with the potential for “geneticisation” (the belief that traits, and in this case group traits, are wholly determined by genes) such that a seemingly beneficial genetic research project can too easily spiral out of control, as occurred with the warrior gene example. Due to this combination of factors, we argue that, at least in Australia, Indigenous research issues are not adequately covered by guidelines for genetic research and, equally, genetic research concerns are not adequately addressed within Indigenous health research guidelines.

The warrior gene controversy is by no means the only research scandal related to genetic research in Indigenous communities. The Havasupai case involved a small tribe who live in the base of the Grand Canyon in the United States and who provided samples for genetic study into diabetes in the early 1990s. Over the following decade, their samples were used for a number of studies without their knowledge, including population genetics studies, which, they felt, threatened their sovereignty. The case was widely publicised in 2010 when the tribe settled with Arizona State University, which held the samples, and tribal members reclaimed the remaining samples from the freezer in an emotionally moving ceremony (Mello and Wolf 2010).

A similar scandal concerned the Canadian First Nations Nuuchahnulth community, who initially participated in a project on the genetics of arthritis, and the researcher involved subsequently used their samples for population genetics without their specific consent (Wiwchar 2004). Another prominent case that preceded all of these concerned a Hagahai man from Papua New Guinea and U.S. researchers who attempted unsuccessfully to patent a cell line derived from DNA extracted from a sample of his blood (Cunningham 1998). That no such scandals have yet occurred in Australia is likely to reflect the dearth of genetic research, rather than the superior cultural sensitivity of Australian researchers.

Indigenous Responses to Genetic Research

Indigenous and minority communities around the world have expressed concern about research—and health research, in particular—that takes place in their communities (Smith 1999; Freimuth et al. 2001; Humphery 2001). As mentioned above, genetic research has been the focus of specific attention. Research in New Zealand reported that some Maori perceived genetic research in the context of past research practices that had exploited Maori communities. They worried that genetic researchers did not have their best interests at heart and that poor access to health care would mean they might not benefit from any breakthroughs that resulted from genetic research (Du Plessis et al. 2004). The Indigenous People's Council on Biocolonialism in the United States argues that much genetic research on Indigenous people is “genetic theft” or “biopiracy” (Indigenous Peoples Council on Biocolonialism 2000). In contrast, Maori health researcher Mason Durie argues that genetic vulnerability is a key cause of Indigenous ill-health, along with socioeconomic disadvantage, resource alienation, and political oppression (Durie 2003). In Australia, recent consultations with

Indigenous people to identify health research priorities, facilitated by Australia's National Health and Medical Research Council (NHMRC), have identified genetic research for the first time as an area requiring more attention (NHMRC 2010). Many different kinds of genetic research projects have been conducted in Indigenous communities, only some of which have been contentious. For the purpose of this discussion, genetic research can be considered in three categories: research on rare genetic disorders; population genetics; and the study of common, complex diseases. Generally, genetic research into rare diseases affecting some families within Indigenous communities has not been controversial. For example, Canadian researchers began researching primary biliary cirrhosis (an autoimmune disease that causes liver failure) in a First Nations community in northern Canada after local doctors noted the high rates of this disease (Arbour, Yoshida, and Field 2004). Research into a rare neurological disease on Groote Eylandt in the Northern Territory of Australia was similarly welcomed by the community (Burt, Currie, and Kilburn 1996).

The bulk of Indigenous opposition to genetic research relates to population genetics. Population genetics is the study of the genetic composition of human populations and how this genetic composition changes in response to evolutionary processes. Population genetics in Indigenous populations has generally focused on using genetic information to determine the history of these groups and their relation to other populations. Some Indigenous groups believe that genetic research into human population history threatens their cultural beliefs. For example, an upheaval was caused when evolutionary accounts of history stated that Native Americans migrated to North America through the Bering Strait 15,000 to 45,000 years ago; many in the Native American community believed their ancestors had always been in North America and did not "arrive" from somewhere else (Foster and Sharp 2000). Native Americans have also resisted DNA research on ancestral remains found on their lands (TallBear 2003).

The failed Human Genome Diversity Project (HGDP) that began in the 1990s was the largest population genetics project and the one that has generated the greatest opposition. It sought to collect DNA from Indigenous groups in order to understand the diversity of the human species. It created much controversy both in Australia and internationally by calling Indigenous groups "Isolates of Historical Interest" that had to be sampled before they "vanished" (Dodson and Williamson 1999; Reardon 2005;

Marks 2003). Indigenous advocates have stressed the links between researchers' desire for Indigenous DNA and the rush to exploit Indigenous lands in the colonial era (Mead 1996; Indigenous Peoples Council on Biocolonialism 2000; Marks 2005). When the Human Genome Diversity Project came to Australia in 1994 in an attempt to collect samples in central Australia, Indigenous representatives spoke out against the "Vampire Project" (Indigenous Peoples Council on Biocolonialism 2000; Anonymous 1994). John Liddle, at that time the director of the Central Australian Aboriginal Congress, expressed concern about the lack of consultation with Indigenous organisations and the lack of control "over how these samples are to be used and what research is to be performed on them" (Anonymous 1994, ¶3). In particular, he was concerned about "the possibility of patenting of Aboriginal genetic samples and any drugs developed from them" and, more generally, the possibility "that some company or government could legally own the genetic information present in our people's bodies" (Anonymous 1994, ¶4). He continued: "Our people do not want to stand in the way of research which will genuinely help people. At the same time, we are not going to allow our rights to be trampled on" (Anonymous 1994, ¶5).⁷ As a result of such comments, one genetic health research project based in an Indigenous community had its ethics approval revoked by an Aboriginal ethics committee (Kowal, Rouhani, and Anderson 2011). The current Genographic project, an international effort led by National Geographic and IBM to collect samples from groups around the world for population genetic research, has also been resisted by some Indigenous groups, who see it as a continuation of the HGDP (UNESCO 2006). A third type of genetic research focuses on common diseases such as diabetes, heart disease, and infectious diseases that occur at higher rates in Indigenous populations than in the general community. Researchers hope that by looking at the DNA of these groups, they may be more likely to find specific variants in genes that are relevant for understanding these diseases. Finding these genetic variants may lead to the development of new treatments or vaccines that will help the whole population. It may also allow people at higher risk of these diseases to be identified as targets for prevention and health promotion (Davey-Smith 2007; Khoury 2009).

⁷ Note that all the existing Australian literature that comments on Indigenous genetic research concerns population genetics. See Dodson and Williamson 1999; Dodson 2000; van Holst Pellekaan 2000; Rimmer 2007.

Although this type of research is less controversial than research into population genetics, it still attracts criticism. As mentioned previously, Indigenous people have argued that Indigenous health inequalities are not due to genetics but to social and environmental factors, including colonisation and racism (Pearce et al. 2004; Paradies, Montoya, and Fullerton 2007). Seen from this perspective, genetic research diverts attention from other potentially more important influences on health. By encouraging the idea that health inequalities are due to genetics and not social factors—an effect called genetic determinism—some argue that genetic research could even worsen health inequalities (Council for Responsible Genetics 2006). In turn, some geneticists argue that genomics can contribute to the elimination of health disparities (Ramos and Rotimi 2009). Contemporary genetic research generates much new information about disease development and progression as well as possible new ways to combat diseases. Geneticists argue that the dearth of genetic research in Indigenous communities means that Indigenous people may be excluded from biomedical innovations that result from genetic research, such as new pharmaceuticals and advances in pharmacogenomics. More generally, researchers have tried to counter genetic determinism by stressing that genes interact with the environment to cause disease and only rarely cause disease on their own. Therefore, using genetic research to explore a health problem need not be interpreted as saying that a disease is “genetic” and that social and environmental interventions are not relevant. Indeed, because we sample our environment through our genes, genetic research can often help us identify environmental variables (e.g., micronutrients or vitamins) that contribute to disease susceptibility (Ebrahim and Davey Smith 2008).

Ethical Issues Relating to Indigenous Genetic Research

While Indigenous people are likely to share the concerns of those in the general population about genetic research (such as the risk of genetic discrimination in employment or in obtaining insurance), in this section we briefly highlight the ethical issues specific to genetic research in Indigenous contexts, before considering how these issues were dealt with in the Remote Aboriginal Project (RAP) discussed below.

Consent to Genetic Research

Depending on the pre-existing knowledge of genetics and DNA within the community, informed consent may require the use of culturally appropriate tools for

promoting genetic literacy. Where English is not the first language of Indigenous people, an interpreter should be used (NHMRC 2010). In an Indigenous context, in addition to individual consent, group-level consent must be obtained from a collective organisation such as a community council (in the case of a discrete Indigenous community) or a community-controlled Indigenous health service (MacIntosh 2005).

Privacy and Storage of Genetic Samples

Indigenous people may be particularly concerned about the maintenance of privacy and the storage of and access to DNA samples. Some have expressed concerns about the potential use of DNA to exclude Aboriginal and Torres Strait Islander people from Native Title claims or from government assistance. Moreover, there are concerns that the police could access DNA for forensic purposes or that agencies dealing with child maintenance could access DNA for paternity testing (Australian Law Reform Commission 2003; Sutton 2005). In an Indigenous context, privacy issues may relate to the community as a whole as well as to individuals. Thus, Indigenous community representatives may not want the community to be named in research publications to prevent any harm arising from potentially negative portrayals in the media.

Ownership, Use, and Commercialisation

Many Indigenous communities consider that their natural and cultural resources are collectively owned by elders or the whole community. Some Indigenous groups extend this belief to DNA and consider the DNA of an Indigenous person the property of the Indigenous nation as well as the property of the individual (Mead 1996; Dodson and Williamson 1999). This is particularly the case where the DNA sample is wanted because it is “representative” of the DNA of the group, as is the case in population genetic studies (Indigenous Peoples Council on Biocolonialism 2000).

Research with Maori people found that their concerns about ownership relate to the potential for third parties to access their DNA for commercial purposes such as drug development (Du Plessis et al. 2004). Native American communities have similarly expressed concern about their DNA being used for research to which they did not actively and specifically consent (Foster and Sharp 2000). Indigenous communities and genetic researchers need to negotiate both the ownership and nature of the research conducted on the DNA samples. Canadian ethical guidelines suggest that

samples should be considered “on loan” to researchers, a concept developed by genetic researcher Laura Arbour and Indigenous researcher Doris Cook. Some genetic research has led to the discovery of new drugs that have generated profits for drug companies, raising concerns about the sharing of benefits between the researchers and the community that participated in the research (Knoppers 2000). Profit deriving from the genetic modification of organisms and from the patenting of DNA has created particular controversy among Indigenous people (Cunningham 1998; Indigenous Peoples Council on Biocolonialism 2000; Du Plessis et al. 2004). Therefore, inclusion of the issue of commercialisation in any research agreement between Indigenous communities and genetic researchers is desirable.

Benefits and Risks to the Community

All health research in Indigenous communities must benefit those communities in a meaningful way. As with many types of health research, there is likely to be a significant delay before the research findings translate into any health benefits. In many cases, these benefits will be provided to the whole population and not Indigenous people in particular. Maori people have expressed concern that they may even miss out on any health benefits of research because of their poorer access to health care, leading to a “double oppression” (Du Plessis et al. 2004). Researchers and community members should agree on what benefits the research will aim to offer the community, both short-term and long-term.⁸

The corollary of group benefits is group risks. Commentators have argued that Indigenous (and other socially identifiable) groups face culturally specific risks of genetic research *as a group*, in addition to their individual risks (Foster and Sharp 2000; TallBear 2001; Brodwin 2002). For example, the portrayal of an Indigenous group as “genetically susceptible” to particular diseases can affect the way Indigenous people are treated in society (as in the “warrior gene” example above) and even the way they experience their Indigeneity (American Academy of Pediatrics 2004). This is another aspect of the problem of “genetic determinism,” where problems that have complex causes are attributed solely to genetics and, thus, to the individual, rather than their social context. Accordingly, New Zealand’s ethical guidelines stipulate that

⁸ Depending on the project, short-term benefits might include education, training, and/or employment for community members or increased access to health care. Note that it is important that benefits cannot be inducements to participate in research. For example, it is not appropriate that basic health care is offered in return for participating in research (NHMRC 2003).

findings of genetic research projects with particular Maori groups should not be generalised to the Maori population at large (HRCNZ 2008).

Indigenous Research Governance and Genetic Research

An overarching theme of ethical guidelines for research in Indigenous communities is the need for Indigenous participation (Kowal, Anderson, and Bailie 2005).

Particularly given the social implications of genetic research, it is desirable that Indigenous people are in control of any genetic research that takes place in their communities. Ideally, Indigenous geneticists and genetic epidemiologists would lead genetic research initiatives (Dukepoo 1998). As this is not yet feasible, at least in the Australian context,⁹ non-Indigenous researchers should collaborate with Indigenous researchers on every part of the research process, from planning and data collection to publication and research dissemination (NHMRC 2010).

While the possibility of full Indigenous control over genetic research projects is some way from being realised, accepted research governance practices in Australia facilitate Indigenous participation at multiple levels. First, the major funder of health research in Australia, the National Health and Medical Research Council, requires all project applications concerning Indigenous people to explain how their project meets six criteria. These are: (1) community engagement, (2) benefit, (3) sustainability and transferability, (4) building capability (of both Indigenous communities and Indigenous researchers), and demonstrating that the research addresses an issue of (5) priority and (6) significance to Indigenous people (NHMRC n.d.). These criteria require researchers to take local priorities and needs seriously. The NHMRC has also taken steps to incorporate Indigenous perspectives into its structure, establishing the Aboriginal and Torres Strait Islander Health Research Advisory Committee, including at least one Indigenous person on all other committees and convening Indigenous-specific grant review panels with significant Indigenous membership to assess all project applications concerning Indigenous populations.

Other levels of Indigenous governance and control are provided through the ethical review process. Researchers must demonstrate that the relevant Indigenous communities support the research proposal, usually in the form of an official letter from an Indigenous organisation. However, Indigenous communities may not have

⁹ At this time there are only three Indigenous Australians with a Ph.D. in any branch of epidemiology and one Indigenous Australian with a Ph.D. in lab science. None is working in genetic research.

trust in the oversight provided by mainstream ethics committees, underlining the importance of Aboriginal ethics committees (Humphery 2001; Castellano 2004). Although it is not mandatory, many research projects are reviewed by Indigenous ethics committees that operate in four out of eight Australian states and territories. These committees are made up of Indigenous people and are perceived by many as providing a higher standard of Indigenous-specific ethical review. For instance, Indigenous ethics committees are more likely to independently contact Indigenous organisations to assess the quality of the researchers' community consultation process and may also review draft publications to independently assess their likely impact on the researched community. In addition to the role of the Aboriginal ethics committees, many Indigenous health projects will have their own oversight committees, such as a Steering Committee or Reference Group, depending on the size and nature of the project.

It is likely that these multiple levels of Indigenous participation in the research process have contributed to the dearth of genetic research in Indigenous communities in Australia. Given the range of sensitive issues raised by genetic research and the many stakeholders who have the ability to comment on a research project (including Indigenous community members, ethics committee members, NHMRC committee members, peer reviewers of grants, and grant review panel members), it is not surprising that so few Indigenous genetic health projects have eventuated. Thus, up until the present time, the idea that "you can't do genetic research in Aboriginal communities" has been a self-fulfilling prophecy. Perhaps more importantly, the perception that "it can't be done" has hampered national discussion of how to meet the challenges of Indigenous genetic research and, consequently, this discussion lags far behind comparable nations such as Canada, the United States, and Aotearoa/New Zealand (Port et al. 2008; Burhansstipanov, Bemis, and Dignan 2002; Sharp and Foster 2002; Arbour and Cook 2006; Bowekaty and Davis 2003; Hudson et al. 2007; Tano 2006). However, as the technology and evidence base associated with genetic research tools rapidly advance and genetic methods are incorporated into many mainstream health research projects, the imperative to work through these issues grows stronger.

The relatively strong platform of Indigenous participation in research governance in Australia will hopefully provide a robust basis with which to engage the challenging ethical issues raised by Indigenous genetic research. This is illustrated in the case

study around which the remainder of this paper focuses. As will be demonstrated, although the research team developed a Memorandum of Understanding with the community, the intervention of the Aboriginal ethics committee reshaped the conduct of the project in critical ways.

The Case: The Remote Aboriginal Project

The Remote Aboriginal Project (RAP) set out to examine genetic risk factors for metabolic disease and paediatric ear infections using a family-based study design that would be inclusive of all members of the community. The research team was composed of non-Indigenous genetic researchers who had extensive experience working in developing countries but no experience working in Aboriginal and Torres Strait Islander communities. However, the research team was established within a Research Institute (RI) with a long history of working with Aboriginal communities. Members of the research team embarked on an extended phase of consultation over four years with Aboriginal researchers within and outside the RI before the specific research project was proposed.

To initiate the specific research project, researchers from the RI made presentations to the boards of the local community-owned Aboriginal health service (AHS) and of a regional, community-owned Aboriginal education community (AEC). These boards comprised, respectively, elders and leaders of local families serviced by the AHS and parents of children at the AEC. After consulting with their constituents, both boards decided to participate in the research and began negotiating the terms of the project with the RI. Several months after the initial presentations, Memoranda of Understanding (MOUs) were prepared and signed between the AHS, the AEC, and the RI participating in the project (see Box 1). The purpose of the MOUs was to clarify the relationship between the AHS, the AEC, and the RI and outline the responsibilities of each of the parties. It outlined the principles and guidelines that would guide the research, the collection and governance of phenotypic data from clinical records, the provision of culturally appropriate educational materials, and community review of publications arising from the research. A separate agreement was signed granting joint and equal ownership of intellectual property arising from the project (details available on request).

Following the signing of MOUs by all parties, letters of support from the two boards were provided that, with the MOUs, formed part of the formal submission to the

relevant Aboriginal Research Ethics Committee (AREC). Given the sensitivities surrounding genetic research, as discussed above and familiar to members of the AREC, formal presentations were also made to the AREC by the researchers participating in the study in addition to a standard written application. This was followed by multiple face-to-face discussions and correspondence between the researchers and the AREC in which the AREC's concerns were discussed. In these discussions, the involvement of a senior Aboriginal elder known to but independent of both the RI and the AREC, and who was also an experienced Aboriginal researcher, was crucial to finding common ground. Specific issues that were raised during this lengthy process of negotiation included the storage of samples for future studies. The storage arrangements for samples were originally called a "DNA Bank." The AREC found this wording unacceptable, as it was thought to imply that other researchers outside the research team could access the samples, and it was removed from the application and project documents.

The issue of consent for future research was also raised by the AREC. As discussed above, both collective and individual consent is required for Indigenous genetic research projects. The MOUs formed the basis of community consent for participation in the RAP. In addition to community consent, individual written consent was required both for participation in the study and for collection of DNA (see Box 2). The RI proposed that individuals could give consent for their sample to be used for future research subject to the approval of their representative community organisation (the AHS or the AEC). The outcome of these discussions was that the AREC agreed that the RI would securely store the samples for the purposes of continuing studies of other diseases in this community and that no other researchers outside the research team would have access to them. However, while the MOU with the community organisations allowed for the samples and clinical data to be used for research into health concerns of interest to the community beyond the two conditions currently under investigation, subject to the approval of the community organisation and the AREC, the AREC was not comfortable with providing this option for individuals to delegate the provision of consent for future research to their representative organisations. Instead, the ethics committee felt that individuals need to be re-consented for their DNA samples to be used to study a disease or clinical phenotype that was not part of the original study

(e.g., cancer or alcoholism). The researchers modified the consent form to comply with this request (cf. below and italicised in Box 2).

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[PRODUCTION NOTE: *Insert Box 2 about here*]

Discussion and Conclusions

In Australia, there are now excellent resources available to help Aboriginal and Torres Strait Islander communities and researchers ensure their research is valued by the community, is conducted ethically, and provides meaningful benefits to participants (NHMRC 2003, 2006). While these provide ethical guidance for all health researchers, issues specific to genetic research (or biospecimens in general) are not mentioned.¹⁰ In contrast, Canadian and Aotearoa/New Zealand Indigenous health research guidelines do provide guidance for genetic health researchers. Drawing on work by Arbour and Cook mentioned above, the Canadian guidelines argue that biosamples should be considered “on loan” to researchers, with researchers acting as “stewards” rather than owners and research participants retaining the right to access data about themselves (CIHR 2007; Arbour and Cook 2006). The New Zealand guidelines share this concept of ownership and state that genetic research must take place within the “paradigms of a Maori world view” (HRCNZ 2008, 19).

More research is needed to assess the impact of culturally specific guidelines on Indigenous genetic research practices and outcomes. However, given the importance of relationships and engagement to Indigenous health research (NHRMC 2003) and the high levels of national and local Indigenous community engagement required to develop guidelines, it is probable that the process of producing guidelines will have a beneficial impact on the Indigenous Australian community, in addition to any effect of the guidelines themselves. Embarking on this process would work to build a strong, respectful *research* culture within the Indigenous genetic research community and begin to heal the wounds inflicted by the “Vampire Project.”

As a step in this direction, this article has reviewed the political and cultural context of genetic research in Indigenous communities internationally and the ethical issues

¹⁰ Note that the NHMRC National Statement and the Values and Ethics document are designed to be used together. However, there is still a lack of specific guidance on the conduct of genetic research in Indigenous contexts, as is provided by the New Zealand and Canadian guidelines and in the academic literature cited in this article regarding Indigenous communities in the United States, Canada, New Zealand, and elsewhere.

associated with this kind of research. It has explored these issues through a case study of a genetic research project taking place in an Australian Aboriginal community—a setting where very few genetic research projects have taken place to date.

This case study has illustrated the impact of multiple layers of Indigenous research governance, particularly in the absence of clear ethical guidelines in this area. In this case, the AREC raised issues relating to the use and storage of samples and obtaining individual consent for future research that were not contained in the Memoranda of Understanding signed with the community organisations that directly represented the community involved in the study. As a result of this, researchers will need to contact individual donors to seek their informed consent to use samples for any further study, in addition to obtaining consent from the AREC and community representative organisations. While providing a higher level of protection for individual donors, this arrangement also necessitates additional research funds.

The issue of obtaining individual consent for further use of DNA samples is one that has generated discussion in the research ethics literature, much of it centred on the use of DNA samples in biobanks (see, for example, Caulfield et al. 2008; Elger 2010). Some argue that it is a cumbersome practice that can compromise the viability of future studies, both in a financial sense (as consent is expensive and difficult to obtain, a problem compounded when working in remote Indigenous communities) and because the representativeness of the sample population is threatened if those who do not consent systematically differ from those who do. Further, Wolf argues that “although people want to be asked whether their biological materials can be used in research, *most* people do not object to most research uses and would be satisfied with a one-time, blanket consent to research use. Requiring them to consent to each individual research protocol, for example, may be unduly burdensome to donors and could even create a disincentive to participation” (Wolf 2010, 147, *emphasis original*). In an Indigenous health context, the issue of research burdens on participants is particularly salient, as some Indigenous leaders argue that their people have been “researched to death” with little or no benefits flowing to them (Humphery 2001; Smith 1999).

The challenge is to find a balance between respecting the interests and preferences of research subjects while maintaining the viability of medical research. In light of the Havasupai case discussed above, Mello and Wolf (2010) argue that “tiered consent” provides the best balance. Tiered consent involves asking individual donors exactly

how they want their sample used as part of the informed consent process. Typically, they are asked whether their sample can be used for any studies (“general consent”); whether samples can be used for other directly related studies in the future (for instance, studies on the same health problem); whether they wish to be contacted by the researchers to ask about any future uses; or whether they wish their sample to be destroyed after the conclusion of the present study (all examples of “specific consent”).¹¹ In the Indigenous health context, it is common to offer the additional safeguard of ensuring that any possible future research will be approved by the relevant community organisation and/or Aboriginal ethics committee. In this way, the community organisation or ethics committee has a de facto role of sample or data custodian.

While the layers of Indigenous governance were arguably successful in protecting research participants in the study described in this paper, a better solution would be to develop clear guidelines for Indigenous genetic research. Among the many issues such guidelines could address are the use of tiered consent and enlisting Indigenous organisations to act as data custodians. The process of formulating guidelines would allow Indigenous peoples’ perspectives on the relevant issues to be heard, enabling them to realise the full benefits of this kind of research while avoiding the risks.

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¹¹ A critical question here, although one that cannot be answered, is whether the AREC would have insisted on re-consenting individual participants for each new use of the sample even if tiered consent was used by the researchers.

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Figures

Box 1: Outline of Content of the Memoranda of Understanding (MOUs)

- *Naming the parties*, including statement: whilst not binding on either party, this Memorandum of Understanding reflects an intent to form a partnership and to collaborate on certain projects for the benefit of local Aboriginal communities.
- *Short description of the AHS* and its role in the community
- *Short description of the RI* and its track record in Aboriginal research
- *Purpose of the MOU*: to undertake projects relevant to the needs of the local Aboriginal community that have the potential to benefit Aboriginal people, and are conducted in a way that respects Aboriginal values (with reference to the national guidelines).
- Outline of the *scientific background* of the proposed project and the track record of the RI in work leading up to the project.
- *Responsibilities of the AHS*
 1. To ensure that projects undertaken by the AHS in partnership with the RI have:
 - (a) The full support and written permission of the AHS Board, who must approve the study tools and methodology to be employed.
 - (b) The potential to benefit Aboriginal people in the community.
 - (c) Are undertaken within the framework of the NHMRC and other national guidelines.
 2. To provide access to clinical records for ascertainment of phenotypic information needed for the study in a manner that complies with strict guidelines on maintenance of patient confidentiality, restricted access to data, and anonymity of individuals and families at the time of publication of study results.
 3. To provide support for the proposed project, and to encourage the development of projects that generally promote improved health outcomes for Aboriginal people in the community.
 4. To review all study results and reports prior to publication.
 5. To encourage and ensure the participation of health care professionals and members of the community, as appropriate to the specific aims of projects undertaken jointly with the RI.
 6. To retain the right to stop specific projects at any time if the NHMRC and national guidelines, and/or cultural sensitivities of the local community, are not being met.
- *Responsibilities of the RI*
 1. Mirror of the responsibilities of the AHS.
 2. To be responsible for the preparation and dissemination of educational information about studies undertaken between the RI and the AHS in formats that are culturally appropriate to the local Aboriginal population.
 3. To support and encourage the participation of RI staff with expertise in specific areas appropriate to the aims of projects undertaken in partnership with NAHS.
 4. To ensure that any RI staff having access to clinical records for ascertainment of individuals and families comply with strict guidelines on maintenance of patient confidentiality, restricted access to data, and anonymity of individuals and families at the time of publication of study results.
 5. To ensure that the AHS has the opportunity to review all study results and reports prior to publication, and to present feedback to the local community in culturally appropriate formats.
 6. To encourage and support the participation of health care professionals and members of the community as appropriate to the specific aims of projects undertaken jointly between the RI and the AHS and, wherever possible, to provide specific training and support to build capacity at the AHS that will allow staff and community members to participate in community health projects.
 7. To retain the right to stop specific projects at any time should circumstances arise that prevent the RI from meeting its responsibilities, for example inadequate funding, the AHS can't meet its responsibilities or the NHMRC guidelines change.
- Partnership outcomes: outline of short-term outcomes and broader goals
- Intellectual property: the partners agree to the joint ownership between AHS and RI of any intellectual property arising from this research project, as outlined in a separate Statement of Agreement on Intellectual Property.
- Period of agreement: dated and signed by the parties

Box 2: Items on Individual Consent Form for Remote Aboriginal Project (RAP). Items added at request of Aboriginal Research Ethics Committee in italics.

- ◆ I have been given an explanation of this study and my questions have all been answered
- ◆ My participation is voluntary and I can withdraw from the study at any time, in which case my DNA will be destroyed
- ◆ Withdrawal from the study will not affect my medical or legal rights
- ◆ A sample of my saliva and/or cheek swab will be collected from which DNA will be isolated
- ◆ My DNA sample will be stored as explained to me and may be used for extended studies of other diseases in my family *only with my further consent*
- ◆ I will have to provide only one sample, and my DNA may be amplified to ensure this
- ◆ My DNA sample will be used initially for gene research into ear health and metabolic diseases including diabetes
- ◆ No diagnostic testing will be performed using my DNA sample
- ◆ No information derived from my DNA sample will be reported back to me
- ◆ The researchers may contact me again in relation to this research project
- ◆ Study samples (DNA) may be sent to members of the research team in other centres for the purposes of this study, or extended family studies, as approved by the Board of AHS
- ◆ *The DNA may be stored for use in studies of other diseases in my family and community*

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