
Genetic research in Indigenous health: significant progress, substantial challenges

TO THE EDITOR: Kowal's article resonates with our experience.¹ However, the National Health and Medical Research Council has supported genetic testing in Indigenous Australians for longer than she cites. Through a 1995–1997 project grant, a 1998 PhD scholarship,^{2,3} a 2006 program grant and an Australia Research Fellowship (2008–), the NHMRC has supported work on kidney and related chronic diseases, in protocols endorsed by two remote communities and approved by appropriate agencies. Information from family pedigrees, phenotyping and DNA profiling underpins validation studies underway in a currently funded project grant.

However, progress has been agonisingly slow, with much interference, as Kowal describes, which generates trepidation in conducting and publishing the work.⁴ The waste of precious research funds and obstruction of scientific progress by these impediments are very serious. In one community, which has engaged in dialogue on genetic testing for 20 years, which wants to participate and contribute on the global stage, and in which DNA has already been collected and stored, a very long delay was resolved only through a heated and explicit protest by the community itself.

Aboriginal people must marvel at the collaborative disarray among non-Indigenous agencies supposedly acting in their interests. We must question the probity of obstruction of projects, genetic and otherwise, that are requested by specific communities, and approved through orthodox channels, by intermediary bodies with whom those communities have no direct connection. Non-Indigenous people might not tolerate such interference. Aboriginal people should be alerted to these issues and invited into the dialogue through the news and social media, including *Imparja* Television and *Living Black*, email, Twitter and Facebook, and indeed,

within the pages of the Journal itself.

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Acknowledgements: I thank the Tiwi people for their longstanding engagement and support.

Competing interests: No relevant disclosures.

doi: 10.5694/mjal2.11046

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TO THE EDITOR: We read with interest the article by Kowal about genetic research in Indigenous health.¹ As stated, this topic is extremely sensitive, but it is one that we must now tackle. The article raises a related issue that has not received any attention: the provision of genetic health services to Aboriginal and Torres Strait Islander people.

We should not presume that Aboriginal and Torres Strait Islander people are not interested in genetics



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or finding out more about their illness or disease. In our research (unpublished) on the supportive care needs of 221 Indigenous cancer patients in Queensland, we found that Aboriginal and Torres Strait Islander people with cancer are very interested in knowing more. Preliminary results show that 55% of participants (122 patients) would like to speak to a specialist doctor about the risk of cancer in their family, and over 68% of participants (151 patients) are concerned about other family members getting cancer.

Indeed, in the area of cancer in Aboriginal and Torres Strait Islander people, much can be gained through genetic research; in particular, identifying an individual's genetic risk of cancer. Given that the standardised mortality rate for all cancers combined is around 1.5 times higher for Indigenous Australians than that for non-Indigenous Australians,² identifying patients' genetic predisposition to cancer may help them and their doctors in making decisions about treatment.³

We need to move forward cautiously and ensure that appropriate guidelines are in place, but most importantly, we need to embrace these powerful research tools for the benefit of improving

the health and wellbeing of Indigenous Australians.

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Competing interests: No relevant disclosures.

doi: 10.5694/mja12.11075

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IN REPLY: I thank Hoy, and Garvey and Bernardes, for their responses. Hoy highlights the difficulties her group has experienced in conducting genetic research in an Aboriginal community over two decades. Indeed, this was the project I referred to as losing its ethics approval as a direct result of the Human Genome Diversity Project.¹ She attributes the difficulties she has faced to conflicting views between the community, which has consistently supported her research, and “intermediary bodies” who have sought to delay or curtail her activities. Without knowing the details of the “intermediary bodies” of which she speaks, I can only reiterate that the sensitivity of genetic research in Indigenous contexts provokes extreme caution among those who need to make decisions about research projects. Developing clear guidelines for Indigenous genetic research will give all the parties involved in research governance confidence that researchers and communities can negotiate appropriate research processes. Further, if guidelines are developed using a collaborative process, the process itself will enhance the capacity of Indigenous communities, ethics committees and researchers to confidently engage in discussions about genetic research.

Garvey and Bernardes discuss the provision of clinical genetic services to Aboriginal and Torres Strait

Islander people. This is another neglected issue that will need to be tackled as genomics becomes more integrated into clinical care over the coming years. There has been recent attention to Indigenous Australians’ lack of access to allied health, dental and specialist medical care.^{2,3} Genetic health services may be another area that needs consideration.

Garvey and Bernardes’ finding that over half of their study participants were interested in accessing clinical genetic services shows that there is likely to be unmet need for these services, and further, that thought should be given to making genetic health services appropriate and accessible to Aboriginal and Torres Strait Islander people. For my own part, I am currently working with colleagues and student researchers from the Master of Genetic Counselling program at the University of Melbourne to record the experiences of the few genetic counsellors and clinical geneticists who currently provide health services to Indigenous Australians. We hope that these findings will generate further interest in this issue.

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Competing interests: No relevant disclosures.

doi: 10.5694/mja.12.11113

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Kowal