



Genetic Research in Aboriginal and Torres Strait Islander Communities: Continuing the Conversation

Discussion Paper

Emma Kowal and Ian Anderson



THE UNIVERSITY OF
MELBOURNE



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INSTITUTE

Australia's National Institute
for Aboriginal and Torres Strait
Islander Health Research

*Incorporating the Cooperative Research Centre
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Definition: Within this discussion paper the term ‘Indigenous’, when used in an Australian context, refers both to Aboriginal people and to Torres Strait Islanders.



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Abbreviations

AIATSIS	Australian Institute of Aboriginal and Torres Strait Islander Studies
BMI	Body Mass Index
DNA	deoxyribonucleic acid
GR	genetic research
GRF	genetic research findings
GWAS	Genome Wide Association Studies
HPV	Human Papillomavirus
MJDF	Machado Joseph Disease Foundation
NHMRC	National Health and Medical Research Council
RHD	Rheumatic Heart Disease
T2D	Type 2 Diabetes



Preface

2011 was a landmark year for genetics and Aboriginal and Torres Strait Islander Australians. While very little genetic research has occurred in Indigenous communities in the past, this issue received worldwide media attention in September 2011 when the first genome to be sequenced from an Aboriginal or Torres Strait Islander person was published in the international journal *Science*. The research was done on a hair sample collected by British ethnologist Alfred Haddon in 1923 and held for decades in a museum in Cambridge, UK. The researchers who sequenced the genome travelled from Denmark to Kalgoorlie to seek permission from the Goldfields Land and Sea Council to complete and publish the research. Along with the interesting scientific findings, the ethical issues raised by this were also the subject of discussion in the media. As my colleague Dr Emma Kowal was quoted as saying in the journal *Nature*, 'To be sequencing DNA from the hair of a deceased indigenous person is uncharted ethical territory.'¹

Last year also saw funding awarded to two genetic research projects directly related to Aboriginal and Torres Strait Islander health. Funded by the National Health and Medical Research Council (NHMRC), one project will examine genetic associations with renal disease in a remote Indigenous community, while the other will look at rheumatic heart disease in another community. All these developments are further evidence that issues relating to the use of genetics in our communities are not going away. Rather, as time goes on, more and more Aboriginal and Torres Strait Islander people and communities will be affected by genetic research and have to make informed decisions about their level of participation in such research. At the same time, the issues raised by genetics are highly sensitive. In other countries, for example, unauthorised use of DNA samples from Indigenous people and insensitive reporting of genetic research findings in the media have caused harm to Indigenous communities.²

This is why the ongoing work of the Lowitja Institute in this area is so important. The 2nd Lowitja Institute National Roundtable on Genetic Research in Aboriginal and Torres Strait Islander Communities was held on 27 July 2011 at the University of Melbourne. The Roundtable brought Aboriginal and Torres Strait Islander researchers, ethics committee members and community representatives together with non-Indigenous researchers, genetic literacy experts and bioethicists to talk through the wide-ranging issues that genetics raises for Aboriginal and Torres Strait Islander communities. This year, major stakeholder organisations the NHMRC and the Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) were also represented. More than 40 people attended the Roundtable, which I co-facilitated along with my colleague Associate Professor Ted Wilkes.

The day's discussion covered issues of community consent, storage of biological samples over the long term (including biobanks), cultural perspectives on blood samples and the possible health benefits that whole genome sequencing may eventually hold for Indigenous communities. The discussions were aided by the use of an 'Issues Map' that was the result of a collaboration between

1 E. Calloway 2011, 'Aboriginal Genome Analysis Comes to Grips with Ethics', *Nature*, vol. 477, pp. 522–3.

2 M. Mello & L. Wolf 2010, 'The Havasupai Indian Tribe Case – Lessons for research involving stored biologic samples', *New England Journal of Medicine*, vol. 363, pp. 204–7; R. Hook 2009, "Warrior Genes" and the Disease of Being Maori', *MAI Review*, pp. 1–11.

Dr Kate Silburn from La Trobe University, Dr Emma Kowal from the University of Melbourne and the Lowitja Institute's Ms Barbara Beacham.

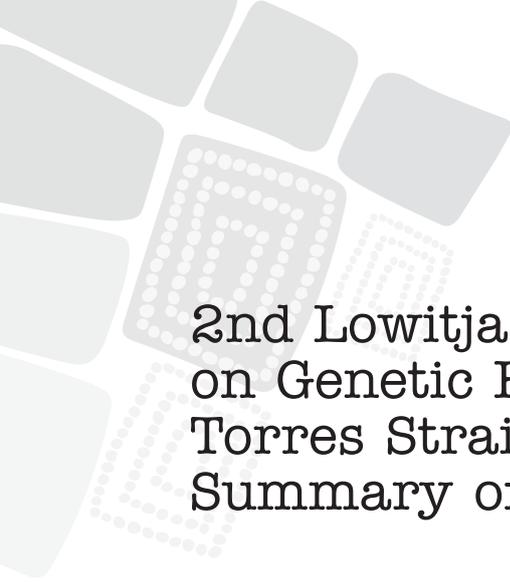
This discussion paper is the companion to *Genetic Research in Aboriginal and Torres Strait Islander Communities: Beginning the Conversation* by Emma Kowal, Lobna Rouhani and myself (available at www.lowitja.org.au/lowitja-institute-publishing). The first discussion paper presented a number of background papers as well as a summary of what was discussed at the 2010 Roundtable. I direct any readers interested in the academic literature on this issue to the first discussion paper that included comprehensive literature reviews of relevant areas.

The current discussion paper continues this valuable conversation with a summary of discussions at our most recent Roundtable. Participants at the Roundtable were offered the opportunity to amend or comment on this summary and approved the final version. We hope that it encourages many more conversations around the country about the potential of genetic research to contribute to Aboriginal and Torres Strait Islander health research efforts, and, more importantly, the mechanisms that need to be in place to ensure that Indigenous communities are empowered to make informed decisions about participating in genetic research.

Professor Ian P. S. Anderson

January 2012





2nd Lowitja Institute National Roundtable on Genetic Research in Aboriginal and Torres Strait Islander Communities: Summary of Discussion

Welcome, aims and overview

Facilitators: **Professor Ian Anderson**, Director of Research and Innovation at The Lowitja Institute and Director, Murrup Barak, Melbourne Institute for Indigenous Development, The University of Melbourne and **Associate Professor Ted Wilkes**, Aboriginal Research Programs, National Drug Research Institute, Faculty of Health Sciences, Curtin University

Professor Anderson welcomed attendees to the Roundtable and encouraged them to:

- continue the conversation around Indigenous genetic research that has been built over time,
- approach the day with a focus on finding tools and resources to further this area of research, and
- build and manage collaborative research relationships.

He encouraged participants to keep a number of ethical issues in mind, including the governance of research, the ownership of samples, the implications of new capabilities for genome sequencing and the representation of research findings in the media.

Co-facilitator A/Professor Wilkes also welcomed attendees and paid recognition to those involved in Indigenous genetic research.

It's an interesting field of research and an exciting field for Indigenous Australians to be involved in. Your work has convinced me to hang in there and look at what might happen.

He stated the importance of researchers and Aboriginal and Torres Strait Islander Australians finding an amicable way forward, and spoke about the balance between achieving solutions in the short term while ensuring research quality.

Launch of *Genetic Research in Aboriginal and Torres Strait Islander Communities: Beginning the Conversation – Discussion Paper*

A/Professor Wilkes introduced Dr Kerry Arabena, Chief Executive of the Lowitja Institute, to the Roundtable. Dr Arabena began by acknowledging the Traditional Owners of the land on which participants were meeting. She then launched the discussion paper based on the previous year's (2010) Roundtable. Dr Arabena stressed the importance of the Lowitja Institute in this discussion process and the 'willingness and the desire of the organisation to make safe spaces for difficult and challenging conversations to take place'. She then thanked attendees for their courage and their commitment to Indigenous genetic research, and emphasised the impact that research into this area will have on people's lives in the long term.

The issues are difficult and challenging, and we are the first people in this country to... have this conversation about these ethical issues... We need to be mindful of people in this room, and the people we are talking about. These discussions will eventually have a huge impact for people and their lives. This issue is controversial, to say the least, and some [Lowitja Institute] board members have had phone calls from people saying, 'Are you involved in genetics work?' But sometimes you have to be the 'first' to talk about issues.

Dr Arabena highlighted the challenge for the diverse range of people involved in the sector to collaborate effectively to tackle controversial issues in a way that does not hinder Aboriginal community control, and where a difference of views can be tolerated.

Professor Anderson followed up on Dr Arabena's comments:

We increasingly came to the view that we had to test the water in this area. We didn't want to wait 20 years and find a whole field of research had passed us by.

Presentations

Following the launch of the discussion paper, presentations were given by: Dr Emma Kowal, The University of Melbourne; Ms Libby Massey, Machado Joseph Disease Foundation; Ms Heather D'Antoine, Menzies School of Health Research; Professor Simon Foote, Menzies Research Institute Tasmania; Associate Professor John Condon, Menzies School of Health Research; and Professor Jenefer Blackwell, Telethon Institute of Child Health Research.

Speaker 1: Dr Emma Kowal

Dr Kowal brought attention to the concern that genetics has been excluded from Indigenous research in Australia, even though it is increasingly being used in mainstream health research. She highlighted the important role that genetics could potentially play. Genetic research can provide insight into why some people from the same family respond differently to treatments; why some people are resistant to disease and others susceptible to the same disease, even when they might live in identical environments; and can provide clues about how diseases develop. Genetics has the potential to add value to certain Indigenous health research projects in a strategic way, Dr Kowal said, but this potential is not being used.

Dr Kowal highlighted the dearth of Indigenous genetic research in Australia by looking at such research in the United States (US) and Canada. She brought attention to the existence of more than 1600 scientific papers on genetics and Native Americans, and less than 40 papers on Australian Aboriginal and Torres Strait Islander populations. This difference may be related to a lack of discussion of this issue in Australia, and a lack of ethical frameworks for conducting such research. By contrast, in Canada, high-level discussions of this issue over a number of years has led to the idea that biological samples donated by Indigenous people should be considered 'on loan' to researchers by individuals. Dr Kowal claimed that it is due to ethical, cultural and political reasons that genetics generally is not a major topic for discussion in Indigenous health in Australia. Genetics tends to be in the 'too hard' basket, she said, which becomes a self-fulfilling prophecy.

Dr Kowal discussed the multiple concerns that Indigenous people have regarding genetic research. She drew upon the concerns raised during the Human Genome Diversity Project (also known as the

'Vampire' project) in the 1990s. These included concerns surrounding individual and group consent, secondary use of samples, and benefit sharing. Although these are 'generic' issues that apply to genetic research in other populations, Dr Kowal also noted that cultural issues have been raised by Indigenous scholars around the world, including the idea that DNA is collective cultural property (Mick Dodson) and is sacred (Frank Dukepoo).

She highlighted the contrast between the Indigenous perspective expressed by these scholars and a scientific approach to genetic research. From this Indigenous perspective, genetic information is an inalienable part of oneself that remains the property of the collective even after its removal from the body of the individual. This is in conflict with the scientific approach where genetic material donated for scientific research is considered the property of the scientist or institution that funded the research. Indigenous people can also object to genetic research that looks at past movements of human populations that may be in conflict with traditional views about the origin of Indigenous groups. The very idea of conducting genetic research on a specific population group can reinforce a biological view of race, she said.

Dr Kowal discussed an example to illustrate the possible misuse of genetic samples. In the case of the Havasupai nation, who live in the base of the Grand Canyon in the United States, DNA samples taken by a university for diabetes research were used for other research projects without the specific permission of the community or individuals involved in the original project. The community felt their history and sovereignty had been threatened and disrespected. The legal case lasted for seven years and resulted in a settlement by the university involved.

Looking at the risks associated with genetic research in Indigenous communities, Dr Kowal encouraged participants to consider whether the benefits of research can outweigh them and, if so, how they can be effectively managed. She noted an additional current issue of whole genome sequencing, as the cost of sequencing an entire genome is now similar to other methods of analysing genetic material. There is currently a 'race' of sorts to sequence the first genome from an Aboriginal Australian. It is possible that researchers who do this may use old samples held overseas, and may not have the same understanding of ethical processes as Australian-based researchers. It remains unclear, she said, what impacts will result if an 'Aboriginal genome' is published, especially by an international group with little understanding of Australian Aboriginal culture and history.

Speaker 2: Ms Libby Massey

Ms Massey gave an outline of the Machado Joseph Disease Foundation (MJDF), an organisation set up to support families in Arnhem Land affected by Machado Joseph Disease, a genetic disease that causes degeneration of the neurological system over time. Symptoms typically start around the ages of 30 and 50, but can begin earlier including in childhood. Within 10 to 15 years of onset, sufferers are completely reliant on carers for all activities of daily living. It is autosomal dominant, meaning that if a parent has the disease, children have a 50 per cent chance of also developing it. The disease has been in Arnhem Land for four generations and 500 people are either affected or at risk of the disease. MJDF is both a grassroots movement and a charity. It is the only organisation in Indigenous Australia concerned with a genetic condition and has conducted ground-breaking work on the communication of genetic concepts to Aboriginal people. It operates as a subsidiary of Anindilyakwa (Groote Eylandt) Land Council with a small number of staff. While the Foundation has

a strong partnership and sponsor focus it is run by an Indigenous board. Ms Massey highlighted the benefit of not having tied government funding, which allows for increased flexibility.

Ms Massey outlined the goals of MJDF, which aims to promote genetic education, research and advocacy. The research is guided by the concerns of the individuals affected as well as the needs of the community. Specifically, the MJDF aims to disseminate disease and care information to government agencies, while the MJDF therapy program improves the social and emotional support for MJD sufferers and their families. Ms Massey highlighted the role of families and the impact of the disease on those who support MJD sufferers.

Speaker 3: Ms Heather D'Antoine

Ms D'Antoine discussed the relationship between genetics and Rheumatic Heart Disease (RHD) and a project she is involved in that includes Jonathan Carapetis, Michael Inouye, Steven Tong, Andrew Steer, Dawn Bessarab, Ngiare Brown, Jenefer Blackwell and Paul de Bakker. She mentioned the alarming rates of RHD in Aboriginal populations, which are comparable to those in the mainstream population at the beginning of the twentieth century. Northern Territory rates of RHD are the highest recorded in the world. Ms D'Antoine brought attention to the questions that continue to surround RDH and the need to discover the origin of the disease. It is caused by Group A Streptococcus sore throats or skin sores, and that 5 per cent of those who are exposed to it get the disease. She explained that:

RHD is a disease of poverty and we need to address the social determinants, but as those determinants are not going away, we need to look at genetics. The genetic project is part of a wider program. Housing is one issue, and we are trying to eliminate scabies, and find ways to diagnose the disease early and find better treatments. Secondary prophylaxis (monthly injections of antibiotics) does work but compliance is very difficult. Is there a genetic association we need to explore? We need more information on the pathogenesis of the disease.

Ms D'Antoine outlined the project. Community consultation was tentatively begun in 2011 with a few communities. An earlier workshop showed that 500 people with RHD and 1000 people without the disease are required for the study. In order to find these numbers, she speculated on the need to go outside the NT, and seek participants from other States such as Queensland.

Ms D'Antoine also highlighted the need for the workshop to focus on one area and then go from there, and not jump from population to population. She pointed out that different communities will be at different stages of awareness, approachability and willingness to consent to such research. There is a need to be clear about solid governance, sample use (saliva samples, for example, will be analysed at the Walter and Eliza Hall Institute in Melbourne), and benefit sharing from the early stages of the project, she said. They are currently waiting to hear about increased funding for the project.

Speaker 4: Professor Simon Foote

Professor Foote spoke about a research project that focused on the genetics behind renal disease in Tiwi Islands' communities, a disease that was not apparent before the advent of colonisation and Western influences. He stated at the outset that the community had requested he refrain from showing the results of the project until they are approved by the Land Council.

Professor Foote then gave a brief outline of the project, led by Russell Thomson, which aims to discover whether or not there is a genetic basis to renal disease on the islands. He explained that even though in 1994 there were samples collected for genetic analysis from people with kidney disease, genetic research did not begin on the islands until about a decade following this because of concerns from the Menzies School of Health Research ethics committee in the wake of the Human Genome Diversity Project.³ Three hundred samples are available for genome-wide association studies, but since these were collected many of the donors have passed away due to renal disease.

Professor Foote explained how the disease had changed since the 1990s when renal disease was a problem for Tiwi Islanders aged between 20 and 30 years; now early signs of renal disease are seen in teenagers. They are not sure, however, if there is a genetic basis to it. As well as collecting more samples from community members, the researchers want to conduct full genome sequencing on the genomes of a dozen people (with sequencing done in the US). The Tiwi leaders suggested that they pay for this sequencing themselves so they own all the data. Professor Foote explained that there were some significant technological difficulties in the initial stages of the project, as samples had degraded and only small amounts of DNA remained. However, he said, these issues have been overcome. He attributed this in part to the large amount of community support.

Professor Foote then spoke about the results that had been obtained so far. Genome-wide association studies (GWAS) have found some peaks, including one over a detoxifying enzyme which, in Professor Foote's opinion, may indicate that an environmental influence was involved in renal disease, although it is unclear as to what kind exactly. They hope to look more at what is happening at the DNA level.

Speaker 5: Associate Professor John Condon

A/Professor Condon spoke about a research project investigating a cluster of cancer of the vulva cases in several remote Aboriginal communities. He explained that as the issue was 'women's business' he would not go into details of the disease, and that female researchers were undertaking all of the research work with the communities.

The project arose after gynaecologists working in communities in Arnhem Land observed an excess of this type of cancer in younger women. Stage 1 investigated whether this clinical observation was correct; it was confirmed that, for the period 1996–2005, the incidence of cancer of the vulva for women aged under 50 years in the affected Arnhem Land communities was approximately 70 times the national rate. Nothing similar has been reported anywhere else in the world.

Stage 2 investigated whether the Human Papillomavirus (HPV), which is known to be a cause of this cancer in younger (but not older) women, was to blame. A steering group of Indigenous women from the affected communities oversaw the ensuing research. Stage 2 has now been completed with cancer-causing strains of HPV found in most of the pathology specimens from affected women. However, HPV does not appear to cause the high cancer rates: no unusual (high-virulence) strain was found nor a high prevalence of infection with cancer-causing strains. There was also no excess of cervical cancer (which is also caused by HPV) in those communities,

³ This was an international effort to collect DNA samples from Indigenous people in order to understand human genetic diversity. It generated controversy when Indigenous people in many countries opposed it, calling it the 'vampire' project.

compared to the incidence in women in other Northern Territory Aboriginal and Torres Strait Islander communities. At the same time, a cancer control strategy was initiated with the Northern Territory Department of Health, focusing on early detection and treatment and involving community awareness and training of primary health care staff.

Stage 3 is now investigating whether there is a familial susceptibility to this disease (clinicians have noted that many of the affected women are related). Genetic epidemiology research is currently being conducted to determine whether there is a genetic susceptibility. Stage 3 also involves an anthropological study investigating the history of, and community knowledge and beliefs about, the disease, and whether it was caused by topical uses of a carcinogenic substance. There is no evidence to suggest specific carcinogens as causes of vulvar cancer, so finding a topical carcinogen as the cause of the cluster is a 'long shot'. If it is found that genetic susceptibility and a topical carcinogen are not the explanations, Condon was not optimistic the cause of the cluster would be found.

Speaker 6: Professor Jenefer Blackwell

Professor Blackwell spoke about a family study of Type 2 Diabetes (T2D) that involved research in a remote Aboriginal community in the mid-west region of Western Australia. Ethical approval was granted in 2009 by the Western Australian Aboriginal Health Ethics Committee and in December data collection was undertaken. DNA samples of people who had consented to participate in the research were collected along with family trees and health data.

Her presentation centred on a recent project to communicate and discuss the results of studies that had been conducted during the previous two years with the community. This involved, in part, a report of results to the Ngangganawili Aboriginal Health Service Board to gain permission to publish scientific and medical findings. Professor Blackwell explained what was said to the board: that the aims of the project were to compare patterns in DNA with patterns of T2D.

As part of the presentation to the board, Blackwell explained how the researchers mapped Body Mass Index (BMI) onto pedigrees to determine the 'heritability' or degree of inheritance of BMI. They found that the heritable proportion of BMI is 55 per cent, with the remaining percentage influenced by environmental factors.

Just to show the board was listening, one of them said – 'Hey! Is that the same as other populations?' 'It's exactly the same as other populations,' I told her. And you can overcome your genes with environmental and behavioral changes.

Professor Blackwell then outlined the results of the genome wide analysis, which involved 435 people. There were a number of peaks including two on chromosomes 1 and 21. On chromosome 1, Professor Blackwell explained, a gene that showed a strong association with T2D is also associated with hyperlipidemia and blood pressure in T2D in European populations. A gene that showed a strong association with T2D on chromosome 21 is a gene involved with regulating insulin. These results, according to Professor Blackwell, were not contentious. She emphasised that researchers should try to replicate the findings of the study in other Indigenous and international populations.

Professor Blackwell recounted how she asked the board to consider the following issues: whether they wanted the community to be named in publications or whether they would like to be referred to simply as 'a remote Aboriginal population'; whether they wanted the principal components analysis diagram (depicting the community graphically in terms of its genetic relationship to other

populations in the world) to be included in publications; how the community wished to manage the extensive family trees that had been collated by researchers; and whether the animation that was made as part of a community feedback project could become more widely available.

In response to the questions, Professor Blackwell said that the board resolved to have the results published, so that other groups may readily replicate the research. However, it decided it did not want the community named and did not want researchers to publish information relating to the principal components analysis diagram. The board also wanted the family tree information to be kept in the clinic and made available to community members, and that a 'visitors book' be kept to record who viewed the information. The board also agreed to the posting on Youtube of an animation made by the community about the research.

Professor Blackwell then explained that an animator had been brought in by the researchers to work in the community. The researchers worked in the school with the teachers and animator for two weeks during which time the children developed the storyline and made the animation with the animation facilitator – no other white person was involved. The children were enthusiastic and took on board all the information about genetics and diabetes and how food is digested. The whole community was involved, with the Elders as well as the children making lanterns for a lantern parade at the end of the project to celebrate the animation. Professor Blackwell said that the school put on the parade, during which the students held lanterns in a procession and the principal acknowledged their achievements. Professor Blackwell then showed the animation that was made by the community (which is available at www.youtube.com/watch?v=xrGRfrRGBLE).

She said they have many people to thank for the success of the research project – including Ted Wilkes, Gabrielle Wongawol and Joella Ashwin (who were also at the Roundtable) – and highlighted the importance of involving the community in order for projects such as these to be successful.

A/Professor Wilkes wrapped up the session with praise for Professor Blackwell's project:

This research is really about a relationship between scientists and traditional people. It hasn't been an easy road for Jennie, but she has shown us that it can be done.

Group Session – Mock Ethics Application

After morning tea, the five groups were asked to consider the brief mock genetic research project below.

Mock Genetic Research Project: Genetic associations with trachoma in the Windy Desert region

Professor Illumina, the eminent ophthalmologist, is proposing to investigate genetic associations with trachoma in Aboriginal communities in the Windy Desert region. Trachoma is caused by infection with the bacteria *Chlamydia trachomatis*. Infection can be treated with antibiotics, but can be complicated by follicular trachoma, scarring trachoma and trichiasis.

In Australia, trachoma is found almost exclusively within the Aboriginal and Torres Strait Islander population and remains endemic in large areas of WA, SA and the NT. Trachoma is the major cause of blindness among Indigenous people. Screening in the Top End of the NT in the 1990s showed high rates of trachoma in some communities – in the Katherine region there was a prevalence of 38 per cent for children up to 10 years of age. More recently, 26 per cent of 849 children aged 4–15 years living in East Arnhem Land in 2002 were found to have trachoma. Those children are at risk of blindness in later life from the complications of trachoma.

Trachoma control programs are based on the Surgery, Antibiotic, Facial cleanliness, Environment (SAFE) strategy, but these programs have had limited success in the Australian context.

In populations in Africa, risk of infection with trachoma, active trachoma and trachomatous scarring have all been associated with specific genotypes. It is likely that in Aboriginal populations there are different gene sequences that are associated with susceptibility or resistance to trachoma infection and complications. Finding these genotypes may help us find out why some families have higher rates of trachoma than others, and why some individuals in families are more susceptible or resistance to trachoma and its complications.

This study will conduct a comprehensive survey of trachoma and complications and collect DNA samples from consenting participants in the four remote communities associated with the Windy Desert Aboriginal Health Service. A genome-wide association scan (GWAS) will be conducted to detect genetic associations, and 2.5 million points on the genome will be examined using a single nucleotide polymorphism assay (a 'SNP' chip). If it is found that some areas of the genome are associated with susceptibility or resistance to trachoma infection or complications, these areas may be sequenced. All samples will be de-identified before they are analysed.

Samples will be taken from consenting adults and children from all families, and will be held in a secure location at the Major Hospital where Professor Illumina is based and kept for future studies into eye disease. Other researchers on the team are experienced geneticists and genetic epidemiologists.

Professor Illumina has had a long association with the Windy Desert region, including 10 years as the regional ophthalmologist. He has a letter of support for the proposed study from the Health Service board.

The concerns raised by the different groups are summarised below.

Consent

A primary concern was the issue of informed consent, with all groups highlighting the need for more details to be included in a complete ethics application, including the possibility of withdrawing from the project.

Another concern was the importance of returning to communities for consent for any new phases of the project. Some thought that participants should be contacted periodically to ask about new techniques that could be used for research on their samples or to check if they had changed their minds about participation. Others suggested a layered or stepped consent process at the outset where all participants indicate whether they want to be contacted about further uses of their sample, whether they want their sample destroyed, or whether researchers can use it for other purposes without additional consent. While this would be a long and complex initial consent process, and would require more funding, it would help to prevent a loss of trust in researchers and counter any sense of powerlessness that Aboriginal people may feel if international researchers can publish research overseas without local consent or knowledge.

The issue of whether a family can remove consent after a person dies was raised. The facilitators suggested that, due to the significance of death as ‘the birth of something else’ in many Aboriginal communities, it would be best to take the person out of the study if this would not impact on the study. One participant discussed their experience of making a video to help MJD sufferers understand the course of the disease. Participants in the video expressed that when they die, they give permission for their image to remain in the video, but their family members should also be asked for their approval.

A/Professor Wilkes responded:

That's because of Aboriginal culture. I still go out and hunt and I'm still communal. When someone passes away you don't call them by their name. Death means something different in Aboriginal culture. It is different in remote places to rural and urban locations. If you ask me if you can use my image [after death], sure you can.

Some participants suggested that, to communicate the purpose of the research more effectively and ensure ethical community consent, the plain language statement could come in the form of a large booklet with pictures illustrating what the research would mean for the community.

Another participant discussed their experience in developing a cord blood bank for Indigenous people, and how that involved a lot of negotiation with Aboriginal leaders and communities: an experience that genetic researchers could learn from. Yet another participant was involved in the repatriation of strontium brain samples taken from Aboriginal victims of the South Australian Maralinga nuclear tests conducted throughout the 1950s and '60s, and thought that this could also offer lessons for the conduct of genetic research.

Risks

Participants identified the possibility that discrimination may occur from research and the results that are found, such as discrimination in employment or for insurance purposes if people are found to be susceptible to trachoma.

Benefit sharing

The issue of how any potential profits from research could be shared with participants was raised. One participant asked:

If research were to result in profit, would that be unethical? Who is benefiting from it? Is it the pharmaceutical company?

Another participant thought that even though very few, if any, genetic research projects will lead to financial benefits (e.g. new drugs), benefit-sharing agreements should be included at the start of the research 'rather than waiting for things to hit the fan'. A/Professor Wilkes suggested that commercialisation be dealt with from the outset, rather than addressing it later on. However, he also argued that making money is a relatively minor issue if the development of a drug will benefit communities. Another participant argued that:

There is a perception that people make money from research. This is not true. Some researchers spend their own money, and if we are lucky enough to get funding we are accountable for that.

Another participant made a related point:

I would love a drug company to come along and make a drug targeted at a target that we have identified. Drug companies making money is a minor event compared to my community having that drug.

A/Professor Wilkes responded by saying that:

If people were making money out of my illness and my disadvantage, we [the community] would want to be a part of that, we would want to talk more about that.

Community involvement

It was suggested that mechanisms be established and stated in the application relating to community involvement. The effect of community control on research quality was identified as a key issue. One group raised the question of whether communities have the right to prevent inclusion of particular findings and even publication of the research. Another mentioned that if researchers are unable to identify from which communities the samples originated that this could negatively impact upon research quality. In such cases an agreement may be needed so that the community can be identified to bona fide researchers. One facilitator emphasised the importance of science and research quality:

If scientific rigour is not implemented then it is a waste of time.

Biospecimen handling

More information about how the samples would be dealt with was seen as essential to include in the application. Whether samples would be permanently de-identified was also an issue, for while it is important to protect the identity of participants, samples must be able to be re-identified if they are to be removed in the event that consent is withdrawn.

There was discussion about whether Aboriginal and Torres Strait Islander people in general prefer to have samples taken for medical research or even clinical care returned to them. One participant argued that samples should be returned for cultural reasons:

Samples should be repatriated. We need them back.

Another participant argued that this was unworkable in the clinical context:

What samples do you mean? Urine, saliva, hair, blood? If all of these had to be repatriated there would be 30–40 samples repatriated to each community every day. People are happy to hand over these samples for clinical purposes. What is the difference between these clinical samples and research samples?

Other participants responded that ‘people are entitled to make a decision about what they want done with their samples’. The first participant argued that a discussion about repatriation is appropriate ‘if the sample is still stored when a person dies’.

Publication of results and data

How researchers would present findings ethically and responsibly was discussed. Some were concerned that research findings from one place would be extrapolated to other communities. Others thought the consent process should identify whether participants or community representatives would be able to approve or withhold approval for the publication of the results.

Whether the data from GWAS or sequencing would be made publicly available was also discussed. While there is a move internationally towards making data available online to other researchers, this may not be supported by communities and researchers working in Indigenous populations.

Ethics of conducting genetic research

Concerns were raised about how communities can benefit from genetic research generally. One participant queried whether the study proposed in the mock application should proceed at all:

Trachoma is a disease of poverty. What does genetics add? It is the same for chronic disease. Is it the best use of money, is it cost effective? We know that if we fix up environmental conditions than these conditions will improve.

Another participant argued that the pursuit of knowledge was not a sufficient reason to conduct genetic research and asked whether genetics should be the ‘last resort’ if the use of other research methods had failed, particularly if the research is a public health issue that may be easily addressed with a change in lifestyle. Other participants argued that if genetics is an issue of priority for the community then the research should proceed. The first participant expressed concern that:

Researchers can influence people quite easily. The professor [in the mock application] can say, ‘if we study genes we can fix up eye conditions’. Do they have the best interests of the community at heart and how is it possible to determine this? The consent is gained by the researcher looking after their own interest. If you have got good relationships, they will support the research.

There was discussion as to whether it was reasonable for communities to engage in research relationships with researchers that they trusted, or whether an ‘independent third party’ should be involved to ensure that the decision to participate in research was made without coercion. Others thought that Aboriginal involvement in the research team was an important factor in this issue.

One participant raised the question, ‘Does the 10 years that Professor Illumina [from the mock application] spent in the region count?’ A discussion ensued that centred on Fred Hollows, the eminent ophthalmologist who spent much of his career addressing eye disease in Indigenous

Australian communities and in developing countries. Some expressed that ‘Fred was impatient’. A/Professor Wilkes commented that:

Fred Hollows broke a lot of rules on the way. As a result of Fred we better get in there and tell whitefellas how to do it better.

Professor Anderson raised a related point that ‘it is tricky to get behind letters of support from communities to ethics committees to assess the relationship [between communities and researchers]. You need to have some skepticism.’ Another participant defended Fred Hollows and suggested that those who attacked him sometimes had other motives:

Fred made people in governments upset. People speak on behalf of communities [against Fred] when they are in positions of authority for other reasons that are not in the interests of those communities.

Other discussion focused on whether the process of naming a disease as ‘genetic’ can have an impact on communities. One facilitator commented:

Genetics isn’t necessarily the only answer. We need to make sure we don’t intrude where other solutions are happening already. Let’s be careful and seek out other alternatives where possible.

A discussion ensued about whether doing genetic research means that social and environmental causes are discounted. Some argued that it is wrong to think about it as genes vs environment, nature vs nurture: social and environmental factors effect gene expression, and genes effect how we experience our environment. Doing genetic research does not imply that social and environmental causes are not important. Looking at genes can tell us important things about the environment. A/Professor Wilkes responded that:

I could have a robust discussion with you – we need to understand the physical causes of disease but I don’t want to diminish the responsibility of governments to build better houses.

One participant expressed concern about conducting research in remote communities:

Genetic research in remote communities devalues people in urban environments. We need to look at people from remote communities who live in urban areas to understand the effect of genetics versus environment. I am from a community that gets trachoma – why don’t I get trachoma living in the city? Are there people from Arnhem Land who live in Darwin who we could look at?

Another participant responded that while this is a good point we need to continue research such as Professor Foote’s project in remote communities as ‘we don’t know the biology of diseases well enough’. Another commented that these issues were beyond the purview of an ethics committee:

We’re [pretending to be] an ethics committee, not a research grant committee. We do have to separate out the economics of what is important to study from ethics.

Professor Anderson commented that he didn’t think this issue was entirely outside the purview of an ethics committee. Another participant expressed this issue as ‘the burden of regulation versus the management of risk’.

The issue of ‘research burden’ on communities was also discussed. One participant argued that:

Communities get ‘research fatigue’. There should be rules that you can only do a study in a community twice in ten years.

Also highlighted during discussion was the need for researchers to consider historical factors and how history impacts on current research. For instance, the issue of trachoma that was used in the mock ethics application is a disease of poverty that is influenced by factors broader than health. One group mentioned the Shared Responsibility Agreement between communities and the government introduced by former Prime Minister John Howard ostensibly to address trachoma in 2005. The agreement was that if the community made sure that children's faces were washed daily the community would be given a petrol bowser.⁴ This agreement caused much concern among Aboriginal groups and there was wide media coverage. Having an awareness of previous policies such as this, and their impact on communities, is important for researchers they said.

Professor Anderson then brought the discussion to a close. He stressed that discussion regarding ethical consent does not have an endpoint and it requires ongoing dialogue. Certain issues warrant particular attention in the case of genetic research, he suggested, such as sample management and the longevity of samples obtained. A/Professor Wilkes highlighted that 'these discussions are embryonic, we are just in the first decade of this kind of research'.

Working with the Issues Map

In the afternoon, the five groups were asked to consider three domains relating to the Issues Map (see page 17): biological samples, research data and findings, and issues of representation. Groups were required to answer the following questions in relation to each of the topics:

1. What needs to change?
2. How critical is this change?
3. What needs to happen to achieve this change and who needs to be involved?

Participants were also required to answer specific questions to each of the topics.

Topic 1: Biological Samples

The key issues that need to be negotiated to facilitate the ethical management of biological samples were considered, as well as how they should be collected and managed for genetic research. Groups thought it necessary to identify who the community is in order to ensure good community representation. Some participants believed that a process of 'step-wise' consent should be developed and endorsed by the NHMRC so that individuals could decide how their sample is managed, including how long it is stored, what it can be used for and what should happen to it if the donor dies. Some thought that as the design of the consent form and the options offered may be different for each community that they would require regular monitoring and reviewing, which would involve a high level of trust with the community. Sending samples overseas for analysis was seen by some to be problematic.

Issues relating to possible future uses for previously collected samples were discussed. For example, if subsequent research on a sample reveals a genetic condition or association, re-identification of

⁴ For further discussion of this see E. Kowal 2006, 'Mutual Obligation and Indigenous Health: Thinking through incentives and obligations', *Medical Journal of Australia*, vol. 184(6), pp. 292–3.

the sample may need to take place so that the relevant person can receive genetic counselling. This issue should be dealt with in the original consent process.

Topic 2: Research Data and Findings

For the second topic participants were asked to consider the key issues to be negotiated to facilitate the ethical management of research data and findings.

Long-term community involvement was considered key. Some groups discussed the idea of community ownership of research findings and the need for researchers to seek permission to publish results. They stressed the importance of considering how to manage public access to the information, as this may prevent information being used for something for which permission was not given. Researchers need to consider these ethical issues as there is a scientific need to share data with other researchers to build up the sample size for a particular study. One participant suggested that potentially sensitive data, such as principal components analysis graphs, could be made available to journal editors if necessary but not published.

One group brought attention to the tension between international best practice in genetic research and the protection and autonomy of Indigenous communities. For instance, what happens when funding bodies such as the National Institutes of Health in the United States wants public access to data as a condition of funding? Some made reference to the Fort Lauderdale Agreement, a set of guidelines for fair use of data generated by 'community resource projects', where the aim is to generate genomic data for use by the general scientific community.⁵ Participants also thought it would be useful to look at other relevant protocols, such as those relating to Native American peoples or First Nations communities in Canada.

Some participants expressed concerns about the long-term storage of samples collected from Indigenous communities, particularly where scientists might retire and the samples remain in an institution. Participant suggestions for possible long-term storage and management options included the idea of a culturally managed collection (or biobank) or an independent third party to manage the samples and/or the data. One group stressed that guidelines for storage and management should be established at the outset. There was also discussion about whether data, samples and results could be thought of separately, or whether they should be considered interchangeable from the perspective of ethics and governance.

Topic 3: Ethical Reporting of Research Findings

Topic 3 asked participants how the reporting and publishing of genetic analyses that are potentially sensitive should be managed. For instance, issues including population structure, heterozygosity and 'admixture' may be sensitive for communities. Some participants argued that researchers cannot be responsible for how results are reported in the media. Another said that researchers need to minimise ambiguity in their reporting of results, and that vetting of publications by the community is important.

⁵ This report is available at: www.genome.gov/Pages/Research/WellcomeReport0303.pdf.

One group spoke about the necessity for consultation in the early stages, so that Aboriginal communities are aware of what publishing really means. Moreover, it was thought that the relevant Aboriginal leaders and representatives need to be informed all the way through the process and involved in decision making, which would require increased funding for travel and consultation. One participant reported that the NHMRC should provide funding not just for research grants, but for engagement and capacity development to support these kinds of activities.

Another group argued that researchers should be aiming to do the best research, not just average research, and should always go back to what ethics might mean to the community concerned to ensure the research is ethical. It is important to train researchers about the need to understand what issues are of concern to specific communities. Track records need to include recognition of the additional work required to engage in ethical research with Aboriginal communities.

General Discussion

In summing up, the facilitators emphasised the importance of the Roundtable in enabling discussion between people from very different perspectives and disciplines. Professor Anderson pointed out that the conversation is not one that has an endpoint, but is one that will involve ongoing dialogue:

A lot of issues have been raised here that need more unpacking. There are some issues particular to this ethical field, and others that overlap with other kinds of research. Of primary importance is the building and maintenance of relationships of trust in a rapidly developing field.

He posed a number of questions to prompt further discussion:

- » What is informed consent?
- » How do you get community consent?
- » What should be published?

He also identified a cluster of issues that warrant more attention, including sample management in the longer and shorter term, and issues relating to cultural governance and biobanks.

Professor Anderson also spoke about the relationship between international and local practice, given that there are samples from Indigenous Australians held in institutions overseas. While ethical practice can be developing well locally, there is a risk that they will be sideswiped by international developments, as occurred with the Human Genome Diversity Project in the past. There are also issues with media management. It is important in media releases to be clear and mindful of the ways findings can be misinterpreted.

A/Professor Wilkes spoke about how the discussions had improved his appreciation of the many issues surrounding genetic research. Referring to discussions earlier in the day, he expressed concern about the possibility of overseas researchers publishing an Aboriginal genome ‘without anyone in Australia taking on the “gatekeeping” role’.

*There needs to be a statement about this from the group – we have concerns about this. We have to talk to colleagues about how this will impact on Aboriginal people here.*⁶

A/Professor Wilkes spoke of the importance in remembering that Indigenous people are situated all around Australia in three distinct locations – urban, rural and remote – but predominantly in the urban setting. He also spoke about the need to find an equitable answer to Aboriginal disadvantage

Professor Anderson and A/Professor Wilkes brought the Roundtable to a close by thanking participants for their contribution and identifying the main points of discussion that had been made throughout the day. They noted that there was commonality between groups regarding informed consent, the process of shared understanding and issues of representation. They noted that although significant issues were raised and discussed during the Roundtable, many were yet to be raised. They emphasised that more debate and ongoing conversation is necessary to begin dialogue about the issues that were not addressed and to continue with those that had been.

⁶ This research was published in September 2011 in the journal *Science*. Researchers did, in fact, seek approval from the relevant Aboriginal organisation where the sample they used originated from, the Goldfields Land and Sea Council. See Rasmussen, et al. 2011, 'An Aboriginal Australian Genome Reveals Separate Human Dispersals into Asia', *Science*, vol. 334(6052), pp. 94–8.

Genetic Research with Indigenous Communities: An Issues Map

Kate Silburn, Barbara Beacham and Emma Kowal

Theme issue

All states of health and illness are a result of complex interactions between our environment and our genes.

Genetics is important in medical research and can lead to better understandings of disease, better treatments and new prevention strategies.

Genetics is rarely used in Indigenous health research projects in Australia.

Little is known about the contribution of genetics to health issues in Indigenous communities

Indigenous peoples may miss out on potential benefits from genetic research

Legend

GR = Genetic research

GRF = Genetic research findings

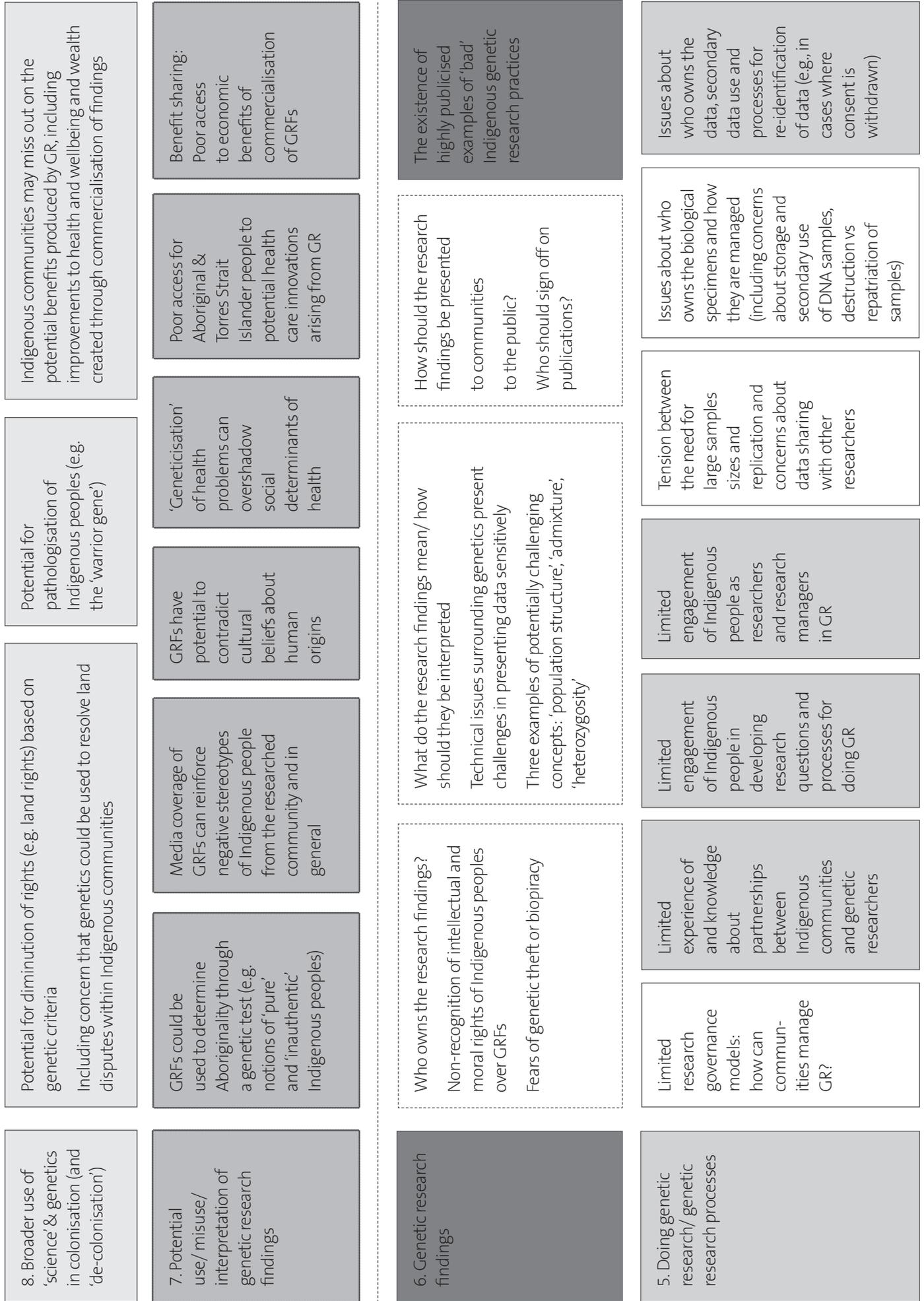
A note to readers – how to read the diagram on the following pages

In the diagram on the following page we have tried to set out what is known about the issues associated with doing genetic research with Aboriginal communities in Australia. We understand that the issues will all intersect with each other, but have tried to set them out in a way that helps us discuss them.

Please read from the bottom of the page upwards. The logic behind organising the diagram in the eight levels is as follows.

- (Level 1) Genetic research within Aboriginal communities sits within a context/environment in which there is a history of colonisation.
- (Level 2 & 3) Within this environment there are Aboriginal communities and scientific communities (in this case genetic researchers). There are a series of issues each will have in relation to thinking about/engaging in genetic research with Aboriginal communities.
- (Level 4) Ethical practice should underpin all research and research processes and provide guidelines for the interaction between Aboriginal people and communities and researchers.
- (Level 5) Then there are issues associated with doing the research.
- (Level 6) Then flowing from this, there are issues associated with the research findings themselves.
- (Level 7) Then flowing from this there are issues associated with the potential use or interpretation of genetic research findings.
- (Level 8) Flowing from level 7 are a set of issues about the broader use of GRFs and how they may contribute to ongoing colonisation and its effects (which can then feedback into Level 1).

We have also highlighted some ‘hotspots’ (in white boxes) which are important issues that will be further discussed in the afternoon session of the workshop.



4. Ethics underpinning research processes

Limited knowledge about ethical practice specific to Indigenous genetic research from community, individual participant, ethics committee and researcher perspectives

Issues include: increasing the capacity of ethics committees; the role of Aboriginal ethics committees; the role of ethics committees in monitoring and reviewing publications; the role of ethics committees in ensuring appropriate management of research processes and research samples; how to judge the real extent of community engagement in the research and researcher experience in working with Aboriginal communities; tensions between individual consent and community consent; culturally appropriate management of samples and data (e.g., after someone dies); how to assess potential benefits (and risks) of proposed studies (including whether there are existing solutions that should be applied instead of doing GR), whether immediate benefits should be provided as a condition of GR (e.g. health education, genetic literacy); whether findings with clinical relevance should be reported back to individual participants, how proactive ethics committees should be in assessing the total burden of research occurring in any one community; that different Aboriginal communities will have different issues to be considered, and issues associated with whole genome sequencing, genome scanning and incidental findings

3. Aboriginal and Torres Strait Islander communities

Aboriginal & Torres Strait Islanders & genetic researchers often have different world views/ knowledge systems/ cultural locations

Genetics is unfamiliar to non-Indigenous people

GRs may have limited understanding about working with Indigenous people

Limited public community discussion about genetic research

Incredible pace of change of genetic technologies

Power imbalance may exist between researchers and community members

Lack of culturally specific genetic literacy tools to communicate risks and benefits of research

Challenges for Indigenous leaders to make decisions about participation on behalf of their communities

Limited number of models of good practice to guide genetic researchers

2. Scientific (GR) communities

1. History of colonisation

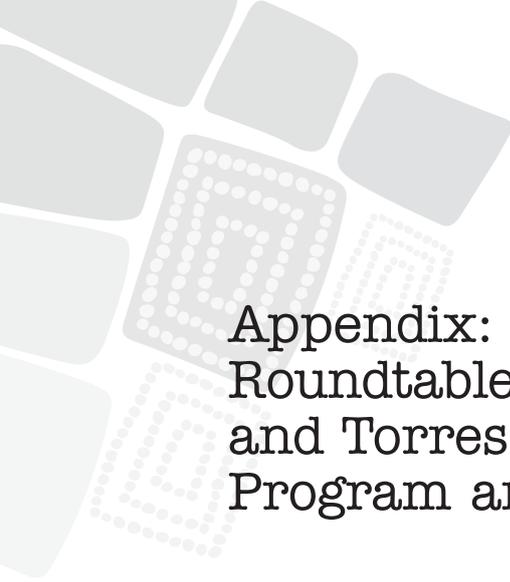
Dispossession and exploitation

Historically negative relationship between Indigenous peoples and research, particularly genetics

Ongoing inequities in health and its determinants

Race-based discrimination

Lack of trust between Indigenous & non-Indigenous peoples



Appendix: 2nd Lowitja Institute National Roundtable on Genetic Research in Aboriginal and Torres Strait Islander Communities Program and Participant Biographies

Roundtable Program

Wednesday 27 July 2011

Graduate House, The University of Melbourne

0830 – 0845 **Welcome to Roundtable** and launching of *Genetic Research in Aboriginal and Torres Strait Islander Communities: Beginning the Conversation – Discussion Paper* – Dr Kerry Arabena, Chief Executive, The Lowitja Institute (to read comments prepared by Ms Pat Anderson)

0845 – 0900 **Overview of day**, ground rules, housekeeping – Professor Ian Anderson and Associate Professor Ted Wilkes

0900 – 1030 **Session 1: Outlining the issues**

- Emma Kowal to present a summary of the issues surrounding genetic research and what it could potentially contribute to improving health in Aboriginal and Torres Strait Islander communities, including discussion of Issues Map and domains. 0900 – 0930

- Short updates from some participants on genetic research projects (5–10 minutes each), 0930 – 1000:

- » Ms Libby Massey (Machado Joseph Disease Foundation)
- » Associate Professor Ngiare Brown, Ms Heather D'Antoine (MSHR)
- » Professor Simon Foote (Menzies Research Centre Hobart)
- » Associate Professor John Condon (MSHR)

- Presentations by Professor Jenefer Blackwell (TICHR, 15 mins) and Ms Gabrielle Wongawol and Ms Joella Ashwin (NAHS, 15 mins). 1000 – 1030

0900 – 1030 Networking morning tea

1100 – 1230 **Session 2: Ethics and genetic research**

- Small group exercise: discuss the pre-circulated mock ethics application. What are the main ethical issues? What further information or changes would you request from the researchers? 1100 – 1130
- Group discussion: Feedback on small group exercise, including comments from members of ethics committees. 1130 – 1230

1230 – 1330 Networking lunch at pre-assigned tables

1330 – 1500 **Session 3: Working with the Issues Map**

- Six small groups to consider three domains related to Issues Map. 30 mins small group discussion for each domain.

1500 – 1515 Networking afternoon tea

1515 – 1600 **Session 4: Bringing it all together**

- Co-facilitators to summarise outcomes of Session 3 and lead discussion on lessons learned and next steps.

Participant Biographies

Professor **Ian Anderson** is the foundation Chair of Indigenous Health at the University of Melbourne. He is currently the Director of Murrup Barak, the Melbourne Institute for Indigenous Development, and Director of Research and Innovation at the Lowitja Institute incorporating the Cooperative Research Centre for Aboriginal and Torres Strait Islander Health (CRCATSIH). Ian also chairs the National Indigenous Health Equality Council (NIHEC). With a professional background in medicine and social sciences, Ian has written widely on issues related to Aboriginal health, identity and culture. He has a broad interest in the sociology of health and illness, related policy analysis, and theory development in the social sciences. Ian has worked in Aboriginal (Koori) health for more than 20 years, during which time he has been an Aboriginal health worker, health educator, general practitioner, policy maker and academic.

Ms **Pat Anderson** is an Alyawarre woman of Stolen Generation heritage known nationally and internationally as a powerful advocate for disadvantaged people, with a particular focus on the health of Australia's First Peoples. She has extensive experience in all aspects of Aboriginal health, including community development, advocacy, policy formation and research ethics. Pat has spoken before the United Nations Working Group on Indigenous People, and was the Chair of the Cooperative Research Centre for Aboriginal Health (CRCAH) from 2003–09. She has also been the CEO of Danila Dilba Health Service in Darwin, Chair of the National Aboriginal Community Controlled Health Organisation, and at different times founding Chair and Executive Officer of the Aboriginal Medical Services Alliance Northern Territory (AMSANT). Pat was co-author of *Little Children Are Sacred*, a report on the abuse of Aboriginal children in the Northern Territory. In 2007 she was awarded the Public Health Association of Australia's Sidney Sax Public Health Medal.

Ms **Joella Ashwin**: I come from a small community by the name of Wiluna also known as Bondini to the Marjinjarra Tribe. Wiluna is in the centre of Western Australia on the edge of the Gibson Desert. I'm a Junior Aboriginal Health Worker (AHW) at the local Aboriginal Medical Service. I was educated mostly around the Small Communities but spent most of my schooling years in Karalundi. Before I became an AHW I worked at the local Centrelink agency and at my old school Karalundi as an Aboriginal Teachers Assistant. Then one day I decided to become an AHW to help my people live strong and healthy in both ways non-Indigenous and Indigenous. Thank you for having us here in Melbourne for the conference and have a nice night. And last but not least I just want to give a big thank you to Jenefer and the team for everything that they have done.

Associate Professor **Kristine Barlow-Stewart**, BSc (USyd), PhD (UNSW), Genetic Counsellor (FHGSA), is the Foundation Director of NSW Health's Centre for Genetics Education based at Royal North

Shore Hospital, Sydney (1989). Her career has focused on addressing the information and support needs of the community, education and training needs of professionals, and the impact of the rapidly developing field of genetics and genomics technologies. Kristine has contributed widely to the development of policies in this area and was the first in Australia to be certified as a genetic counsellor by the Human Genetics Society of Australasia in 1991. She is also a clinical Associate Professor with the University of Sydney's Medical School and is Director of the Master in Genetic Counselling program.

Ms **Barbara Beacham** has a Bachelor of Social Science (Human Services) and a Master of Community Development and Management. Prior to joining the CRC for Aboriginal Health as a Program Manager in January 2006, she worked as a Research Officer and more recently as a Research Associate in complex collaborative and multidisciplinary research environments. Barbara was closely involved in the CRCAH's facilitated approach to research project development, and particularly with the four major projects within the Comprehensive Primary Health Care, Health Systems and Workforce program. Her major areas of interest include consumer participation in health, health system and collaborative research, developing effective research partnerships between Indigenous and non-Indigenous stakeholders, and the transfer of research findings into practical change that makes a difference to people's lives and circumstances.

Associate Professor **Dawn Bessarab** is an Aboriginal social worker who is currently working at the Centre for Health Innovation and Research Institute at Curtin University, WA where she is engaged in research looking at interventions and collaborative approaches to addressing Aboriginal health. Dawn graduated with her PhD in 2007 and is extremely interested in the application of Indigenous research methodologies and the translation of research into policy and practice. She has extensive experience in Indigenous and community issues and is a chief investigator on several National Health and Medical Research Council (NHMRC) grants looking at the application of participant action research in engaging with and including Aboriginal communities in health research.

Professor **Jenefer Blackwell** heads the Genetics and Health Laboratory at the Telethon Institute for Child Health Research (TICHR) in Perth. She is a University of Western Australia (UWA) Winthrop Professor and, following her return to WA in 2007, retains an Affiliated Principal Investigator position at the Cambridge Institute for Medical Research, UK. She has current research collaborations in Brazil, India, Sudan, Thailand and USA. At TICHR her goal is to build capacity for the application of genetics as a research tool to underpin epidemiological studies. Ongoing studies include genome-wide association studies of metabolic disease and associated traits in a remote Western Australian Aboriginal community.

Associate Professor **Ngiare Brown** is one of the first Aboriginal medical graduates in Australia. Since graduating from the University of Newcastle in 1992, she has been a leading advocate for Indigenous health and social justice. During her career Ngiare has held a variety of positions and undertaken work in education, mentoring, clinical practice and advocacy. She played a key role in the establishment of the Australian Indigenous Doctors Association and has held a number of Ministerial appointments. Ngiare was Assistant Director at the Menzies School of Health Research in Darwin, where she developed a program around child health and human rights within the Child Health Division. She has a Master of Public Health and Tropical Medicine (James Cook University) and is a Fellow of the Royal Australian College of General Practitioners and well advanced in her research towards a PhD. (NB: A/Professor Brown was ultimately unable to attend the Roundtable.)

Mr **Alwin Chong** is a Wakamin man from North Queensland and is currently the Senior Research and Ethics Officer for the Aboriginal Health Council of South Australia (AHCSA). He also manages the Aboriginal Health Research Ethics Committee (AHREC), a sub-committee of the Council and the peak ethics body for Aboriginal health research in SA. Alwin is a member of the SA Statewide Cancer Clinical Network, the Statewide Cardiology Clinical Network and the Statewide Rehabilitation Clinical Network and the Rural and Remote Mental Health Service Advisory Committee. He was Project Leader for the 'Improving the Culture of Hospitals' project and assisting with the CRCAH's successful bid in 2009 for a five-year extension to its research program as the CRCATSIH. Alwin is particularly keen to contribute to building the capacity of Aboriginal and Torres Strait Islander health networks through his program leadership role in the CRCATSIH.

Associate Professor **John Condon** is an epidemiologist with extensive experience in primary health care service delivery and management in remote Aboriginal communities in the Northern Territory, and in the development of population health monitoring systems (particularly relating to Indigenous health) at the Territory and national levels. His main research interests are in cancer, health system performance, and the use of routine data collections and data linkage methods. He is currently leading a study investigating whether genetic predisposition is the reason for a cluster of vulvar cancer in young women in Aboriginal communities in Arnhem Land.

Ms **Heather D'Antoine** is Associate Director of Aboriginal Programmes at the Menzies School of Health Research, Darwin. She has extensive experience in many aspects of Aboriginal health research.

Professor **Simon Foote** is a geneticist who uses genetics as a tool to understand and perhaps develop treatments for complex human disease. He is involved in a project with the Tiwi people and Wendy Hoy to find genetic associations with the renal disease that affects many Aboriginal communities. Simon also works on developing new anti-malarial drugs, again using genetic analysis to identify candidate host target molecules, and has an interest in the genetics of multiple sclerosis and cancer. He is director of the Menzies Research Institute Tasmania, an institute of the University of Tasmania.

Associate Professor **Jane Freemantle** holds a Master of Public Health from the University of Adelaide and a PhD from the University of Western Australia. She is a paediatric epidemiologist working with total population linked data describing Indigenous infants, children and young people and communities, nationally and internationally. Jane is currently leading an international consortium that will focus on more accurate and complete reporting on Indigenous child health within an international context. She holds a position as Principal Research Fellow at Onemda VicHealth Koori Health Unit at the University of Melbourne and is an Australian Research Council (ARC) Australian Research Fellow. Jane is Chief Investigator on other NHMRC and ARC grants and holds honorary academic positions at UWA and Monash University. She is currently leading a ARC Discovery Grant funded project that will develop an accurate and complete total population mortality profile of Victoria's Aboriginal (and non-Aboriginal) children born between 1998–2008, using an innovative method and research process, funded by the ARC.

Mr **Lyndon Gallacher** completed his Bachelor of Science (Hons) in 2010 and is currently studying for his Master of Genetic Counselling at the University of Melbourne. As part of this course he will complete a minor thesis looking at the provision of genetics services to Indigenous Australians and interview health professionals who work in this context. Lyndon works at the Murdoch Childrens

Research Institute, continuing his Honours research into communication of genetic information in families, and for Genetic Health Services Victoria, as an intake worker for the paediatric genetics clinic at the Royal Children's Hospital (RCH).

Mr **Graham Gee** is a descendant of the Garawa nation and grew up in Darwin. He has a prior teaching background in education, and worked for some years in the area of Native Title and land justice. After completing his postgraduate diploma in psychology, Graham began working as a counsellor at the Victorian Aboriginal Health Service, while also undertaking a combined Masters/PhD in clinical psychology at Melbourne University. The focus of his PhD is on resilience and trauma recovery in urban Koori communities. Graham sits on the Board of Directors of the National Aboriginal and Torres Strait Islander Healing Foundation, and the Steering Committee of the Australian Indigenous Psychologists Association.

Mr **Tim Goodwin** is a member of the Yuin people of the south-east coast of New South Wales. Currently a Lawyer at Allens Arthur Robinson, he graduated from the Australian National University with a Bachelor of Arts and Bachelor of Laws with Honours in 2007. After graduation, Tim was an Associate at the Federal Court of Australia from 2008–2010. He is also a Board Member of the Australian Research Alliance for Children and Youth, a Trustee of the Reichstein Foundation and serves on the editorial boards of the *Australian Indigenous Law Review* and *Ngija: Talk the Law*. Tim was a member of the Steering Committee for the establishment of the National Congress of Australia's First Peoples from 2008–2010.

Ms **Kalinda Griffiths** is a Yawuru woman with more than 13 years experience in Aboriginal and Torres Strait Islander health research. She is currently undertaking a PhD through the University of Sydney looking at 'Disparities in Outcomes and Care for People with Cancer'. Chair of the Aboriginal Ethics Sub-Committee for the Northern Territory Department of Health and Families, Kalinda also coordinates and lectures in public health and epidemiology at Charles Darwin University.

Professor **Douglas Hilton** is the sixth Director of the Walter and Eliza Hall Institute, Head of its division of Molecular Medicine and Head of the Department of Medical Biology in the Faculty of Medicine, Dentistry and Health Sciences at the University of Melbourne. His research aims to understand which of the 25,000 genes are important in the production and function of blood cells and how this information can be used to better prevent, diagnose and treat blood cell diseases such as leukaemia, arthritis and asthma. Douglas has been awarded many prizes for his research into how blood cells communicate, and has led major collaborations with industry to translate his discoveries from the bench to the bedside.

Mr **Adam Hochman**: I am a philosophy PhD candidate at the University of Sydney. In my thesis I defend a version of social constructionism about 'race' against recent attempts to revive 'race' as a legitimate scientific category.

Dr **Michael Inouye** is currently a NHMRC postdoctoral research fellow at the Walter and Eliza Hall Institute of Medical Research. He completed his PhD in human genomics at the Wellcome Trust Sanger Institute and Leiden University under the joint supervision of Professor Leena Peltonen and Professor Gert-Jan van Ommen. Michael's research interests are in genomics, systems biology, and statistics where his specific goals are to identify disease genes/variants, to understand disease pathogenesis through the dynamics of biological networks, and to develop methods for the genetic prediction of complex disease.

Dr **Sarra Jamieson** is a Research Fellow at the Telethon Institute for Child Health Research in Perth with an interest in understanding how genetic factors contribute to health and disease in populations. This includes several infectious diseases such as otitis media, or ear infections, which are very common in childhood and a particular problem for Australian Aboriginal children. To further understand why some children are prone to recurrent ear infections they are carrying out large-scale studies to look at the genetic and environmental factors that may contribute.

Dr **Misty Jenkins** has Guditjmarra heritage and is also a cell biologist. She completed a Bachelor of Science with 1st class Honours at the University of Melbourne, followed by a PhD with Nobel Laureate Professor Peter Doherty. The focus of her work is killer T cells and their mechanism of killing cancer cells and virus-infected cells. Misty has just returned to Australia after spending four years working at the Universities of Oxford and Cambridge in the UK, and is now based at the Peter MacCallum Cancer Institute in Melbourne.

Ms **Jocelyn Jones** has extensive knowledge and experience working in the health industry. She is currently Senior Research Officer at Perth's Telethon Institute for Child Health Research but recently held a management role at the Office of Aboriginal Health. Jocelyn has had an ongoing involvement with various professional committees including the WAAHIEC (Western Australian Aboriginal Health Information and Ethics Committee), the NHMRC Indigenous Health Research Panel and the National Aboriginal and Torres Strait Islander Health Workforce Working Group. She was formerly portfolio manager for Kimberley Aboriginal Health Planning Forum.

Mr **John Kelly**: I have worked in the health, aged care and non-profit governance space for the past 35 years – 16 of those years in clinical and management roles as a nurse and psychologist, and for the past 20 years as a lawyer in the same sectors. I am the legal member of the NSW Aboriginal Health and Medical Research Council Ethics Committee and hold academic appointments at University of Technology Sydney and the University of Sydney.

Dr **Emma Kowal** is a postdoctoral Research Fellow supported by a NHMRC Aboriginal and Torres Strait Islander Training Fellowship. She is a cultural anthropologist who has previously worked as a doctor and public health researcher in Indigenous health settings. Her work in Indigenous health research has included projects on mental health/social and emotional wellbeing, Indigenous community health initiatives and child health. Emma has written numerous book chapters and articles in medical and anthropological journals. Since 2007 she has been researching the sociopolitical implications of genetic research in Aboriginal and Torres Strait Islander communities.

Ms **Bianca Lena**, LLB GDLP is currently employed as a solicitor by the South Australian Native Title Services Ltd, the native title service provider for SA. She works with Aboriginal people in South Australia to achieve their aspirations in relation to Country, including the protection of Aboriginal sites, objects and remains. In Bianca's employment, issues related to genetic research and DNA analysis has arisen, and is giving rise to, implications for the communities with which she works. Bianca is also a member of the Aboriginal Health Ethics Research Committee (SA), which has endorsed her attendance at the Roundtable.

Ms **Jiin Lim** is a 2nd-year student in the Master of Genetic Counselling course at the University of Melbourne. She has completed a BSc with a double major in Biochemistry & Molecular Biology and Genetics at the University of Melbourne, and has genetic counselling experience in Malaysia and Singapore.

Mr **Ray Lovett** is a Wongaibon man from far west New South Wales whose career has spanned a number of settings, including Aboriginal health services both in the community and government sectors. He has also worked at the policy and clinical levels in nursing and public health. In the private sector he has assisted non-government and government organisations in business improvement, evaluation, survey design and health service planning. Ray is currently completing a PhD at the National Centre for Epidemiology and Population Health at the Australian National University. His research focuses on identifying risky alcohol consumption, and the contributing factors among the local Indigenous population.

Associate Professor **John C. MacMillan**, FRACP, FRCP (Edin.) graduated MBChB in Medicine in 1983, and MD in 1991 from the University of Aberdeen. His current position is as Senior Staff Specialist at Genetic Health Queensland, and he is an A/Professor in the Departments of Medicine, University of Queensland and the Genomics Division of Griffith University. John's clinical practice particularly involves diagnosis and assessment of neurogenetic disorders. He is a member of the Queensland Health Clinical Ethics Advisory Committee, and from 2007 to February 2011 provided genetic services to the Indigenous communities of East Arnhem. John continues to work with the Machado Joseph Disease (MJD) Foundation providing education and advisory services to Indigenous MJD families and communities.

Ms **Libby Massey** grew up at Angurugu on Groote Eylandt and her family have lived there for nearly 40 years. She has known the Groote MJD families since she was a child and having had the opportunity to study occupational therapy, public health and law 'down south' believes passionately in the need to provide equality in care options in remote communities. In collaboration with Anglicare NT, Libby project managed the development of the aged care facility at Angurugu and helped establish the programs that operate from it. She sees the MJD Foundation as the logical next step to secure a dignified future for the families with MJD on Groote and across the other remote communities where it occurs. Libby is responsible for the overall delivery of the MJD Foundation's services, as well as all research and education projects.

Professor **John Mathews** is an epidemiologist and public health researcher. He was the Foundation Director of the Menzies School of Health Research in Darwin (1984–1999), the CRC for Aboriginal and Tropical Health (1997–1999) and senior adviser to the Australian Government on public health (1999–2004). John is currently Executive Director of the Menzies Foundation and Honorary Professorial Fellow at the School of Population Health at the University of Melbourne. He is continuing his research interests in Aboriginal health and education, and in modelling the effects of ionising radiation and influenza in human populations.

Ms **Gloria O'Hare** is affiliated with the Machado Joseph Disease Foundation and Angurugu Health Clinic, Groote Eylandt.

Dr **Yin Paradies** is an Aboriginal–Anglo–Asian Darwinian who has lived in Melbourne since 2007. He is a Senior Research Fellow at the Centre for Health and Society, Onemda VicHealth Koori Health Unit and the McCaughey Centre: VicHealth Centre for the Promotion of Mental Health and Community Wellbeing. With qualifications in mathematics and computing (BSc), medical statistics (MMedStats), public health (MPH) and social epidemiology (PhD), Yin's research focuses on the health effects of racism as well as anti-racism theory, policy and practice. He also teaches multicultural competence to researchers and professionals in Indigenous affairs. Yin has received a range of awards including a Fulbright scholarship to study at the University of California, Berkeley,

the Australia Day Council's 2002 Young Achiever of the Year award, and Scholar of the Year in the 2007 National NAIDOC Awards.

Mr **Matt Sammels** is the Director of the Health & Research Ethics Section of the NHMRC. Joining the NHMRC in early 2006, he saw through the finalisation of the National Statement and has become the point person in the organisation for this document. Matt has worked on other NHMRC ethics issues including NEAF v2, organ donation and commercialisation of human tissue products. Prior to this, he spent six years working in the non-government / not-for-profit sector in the Mekong region, basing himself in Cambodia and working on community empowerment projects. Matt has a BA (Hons) in Anthropology and Archaeology from UWA.

Mr **Elizabeth Scaman** graduated in 2004 with a BA (Hons) in Sociology. Following this, she worked for UK child and youth organisations with a focus on children from disadvantaged backgrounds or with special needs. Elizabeth worked as a Children and Family Support Worker for a foster agency to facilitate children's interactions with birth and foster families. After moving to WA in 2008, she began working for the Telethon Institute for Child Health Research. Her role is to recruit families onto genetic-based health research studies in metropolitan and remote rural communities. Elizabeth works with families to explain the study and assist them through the recruitment process.

Professor **Rodney J. Scott** obtained his PhD from UWA in 1987. During his career he has been engaged in research directed at understanding the genetic basis of disease and how environmental exposures interact to result in disease. Rodney's achievements were recognised by the award of Privatdozent in Cancer Genetics, by the University of Basel (Switzerland) in 1997 and his Fellowship of the Royal College of Pathologists in 2005. Since 1997 he has been the Director of Genetics at the Hunter Area Pathology Service and Head of the Discipline of Medical Genetics at the University of Newcastle.

Dr **Kate Silburn** is Senior Research Fellow at the Australian Institute for Primary Care and Ageing at La Trobe University. She has worked in research, evaluation and policy development in a range of health-related fields including infectious diseases, women's health, women's safety, consumer health issues and primary health care. Kate has particular interests in health systems development, equity, and consumer and community participation. Recently she has worked on evaluating the CRCAH and on a project about corporate support systems for Aboriginal Community Controlled Health Services.

Mr **Fred Stacey** is currently Manager of Strategic Relationships at the Kulunga Research Network, Telethon Institute for Child Health Research. He has a BA in Social Science with a double major in Sociology and a major in Public Administration. Fred has a strong background in public policy and has held senior positions in government both in the NT and WA. In the NT he was a member (representing the Department of Health and Families) of the senior officers work group to the NT Research and Innovations Board, and was also involved in the work program at Charles Darwin University, the Menzies School of Health Research and the CRCAH. More recently, Fred has held positions providing policy advice to the Board of the Aboriginal Health Council of WA and change management consultancy at Danila Dilba Health Service (Darwin) and Derbarl Yerrigan Health Service, including the development of the GP Super Clinics in Palmerston (NT) and Midland. He is also currently involved with Associate Professor Ted Wilkes in revitalising the role and reach of the Nyungar Health Council both in Perth and in the south-west of WA (a proposed trial site for the

Aboriginal genetics research project). Fred brings to his position as the new manager at Kulunga 17 years of experience in Aboriginal health.

Mr **Jim Stankovich** is a statistician working on 'gene-mapping' projects to identify genes that influence susceptibility to complex diseases. He is particularly interested in gene-mapping methods that make use of distant genealogical links between individuals, research that was originally motivated by studies of large Tasmanian families. Jim collaborates on two Indigenous gene-mapping projects: a study of a vulvar cancer cluster in East Arnhem Land, and a study of renal disease in the Tiwi Islands.

Dr **Andrew Steer** is a paediatrician and paediatric infectious diseases physician at the Royal Children's Hospital, Melbourne. He is a Senior Research Fellow at the Centre for International Child Health, Director of Advanced Paediatric Training at the RCH and in 2011 was awarded a NHMRC/NHF post-doctoral fellowship. Between 2005–07, Andrew undertook a US National Institutes of Health-funded project investigating the epidemiology of group A streptococcal disease and rheumatic heart disease in Fiji, for which he was awarded a PhD from the University of Melbourne in 2009, and a 2010 Dean's Award for Excellence in a PhD Thesis. Andrew's interests centre on the control of group A streptococcal disease in developing countries, with specific interests in: public health efforts at controlling rheumatic heart disease, impetigo and scabies; understanding the pathogenesis of acute rheumatic fever; and developing a global group A streptococcal vaccine.

Dr **Sheila van Holst Pellekaan** trained in nursing and medical research, after which she studied Anthropology and Archaeology (USyd), focusing on Aboriginal studies. She initiated her own PhD research (1997, USyd) exploring maternal lineages by studying mtDNA variation in consenting participants from Aboriginal communities in western NSW. Sheila has had continuous extensive consultation and negotiation with Paakintji and Ngiyambaa Aboriginal communities since 1991. She was a Senior Lecturer in the Faculty of Nursing, University of Sydney (1985–2002), where her academic activities included extensive involvement in Indigenous health and education issues, and she continued her research on mitochondrial variation and health-related nuclear markers. Sheila is currently retired from teaching and is a Visiting Senior Research Fellow at the University of NSW. Her current work includes ethically approved DNA studies with medical, anthropological and Indigenous colleagues, and continued liaison with participants and communities regarding the reporting of results and future research.

Associate Professor **Roz Walker** is conducting research at the Centre for Research Excellence in Aboriginal Health and Wellbeing at the Telethon Institute for Child Health Research in Perth. She has extensive experience in qualitative research, evaluation and community development in Aboriginal community contexts with an interest in empowering, decolonising methodologies and research ethics and principles. Roz led the implementation of the Australian Early Development Index and the Indigenous Adaptation trial across the Pilbara in 2007 and 2008. She is doing research in maternal health and early child development with Martu communities in the Western Desert funded by BHP Billiton Iron Ore; research initiated by the WA Women's and Newborn Health Network to improve communication and decision-making among health professionals working with Aboriginal women around critical care; and has collaborated on the development, implementation and evaluation of a cultural competence toolkit, which was successfully trialled in 2010, to enhance organisational and professional practice and promote culturally secure care for Aboriginal families.

Mr **James Ward** is a descendant of the Nurrunga and Pitjantjarra clans of Central and South Australia. As Senior Lecturer and Head of the Aboriginal and Torres Strait Islander Health Program at the Kirby Institute, he leads a research program addressing sexually transmitted infections (STIs) and blood-borne viruses (BBVs) in Indigenous communities. The program has developed strong national research collaborations and, more recently, with international Indigenous research organisations. A number of large-scale epidemiological research studies are currently underway. Prior to taking up his current post James held senior public service and public health roles within both government and non-government organisations. In 2010 he was the lead author of the *Third National Aboriginal and Torres Strait Islander STI and BBV Strategy 2009–2013* and has been a member of Ministerial committees, and professional, technical and expert committees in the area of STIs and BBVs.

Professor **Bob Williamson**, AO, FRS, FAA, became Professor of Molecular Genetics at St Mary's Hospital Medical School, Imperial College London in 1976. In 1995 he moved to Melbourne as Director of the Murdoch Institute and Professor of Medical Genetics, retiring in 2004. Bob worked on genes for thalassaemia, craniofacial abnormalities, cystic fibrosis, myotonic dystrophy and Alzheimer's disease. He takes a major interest in national science policy and the ethical issues posed by 'the new genetics'. Bob is a Fellow of the Australian Academy of Science (where he is Secretary for Science Policy), a Fellow of the Royal Society, and an Officer of the Order of Australia.

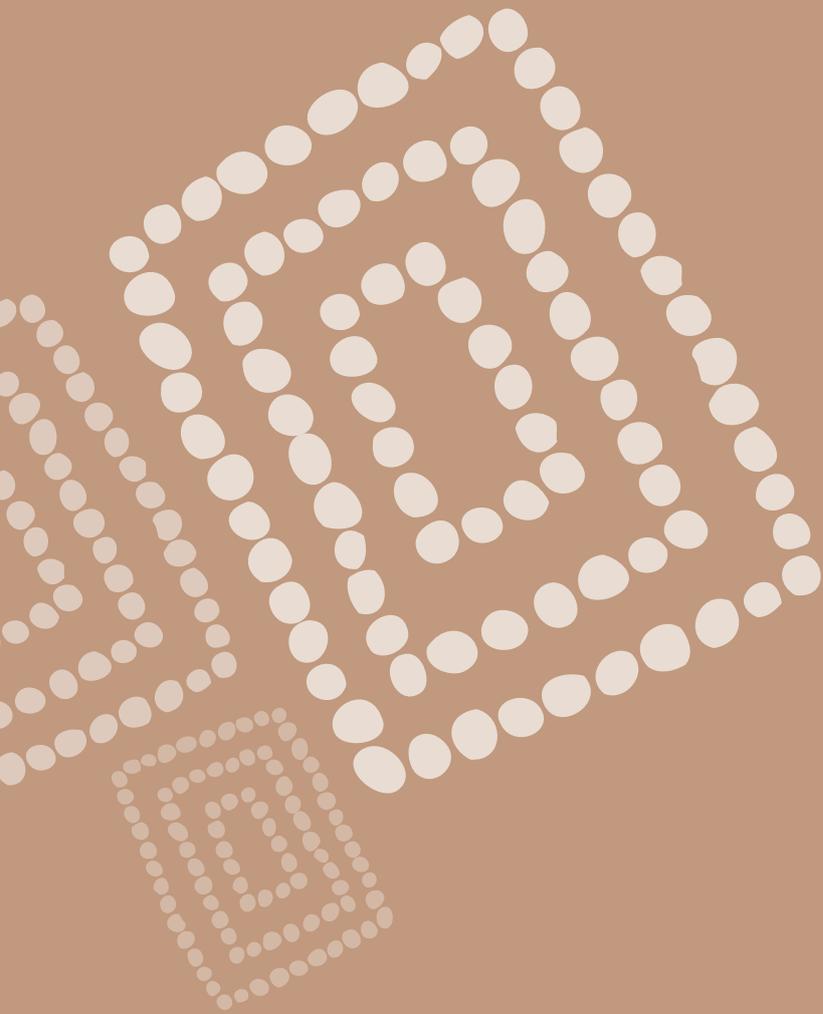
Professor **Ingrid Winship** has a wide range of clinical and research interests in inherited disorders, focusing on those with onset in adulthood, including familial cancer, and where foreknowledge of genotype may influence clinical or lifestyle measures to create positive patient outcomes. She has experience in gene discovery and in the translation of such discovery into clinical practice. Ingrid has also highlighted societal implications of her discipline with research into the ethical, legal, cultural and psychosocial domains of genetic technology, and was a member of the inaugural Independent Biotechnology Advisory Council for the Ministry of Research Science and Technology in New Zealand. Appointed as the Inaugural Chair of Adult Clinical Genetics at the University of Melbourne, and Executive Director Research for Melbourne Health in 2006, Ingrid is also Chair of the Victorian Cooperative Oncology Group Committee, and past Chair of its Cancer Genetics Advisory Committee. She chairs the Clinical Services Committee and the Cancer Special Interest Group of the Human Genetic Society of Australasia, and is a member of the Victorian Cancer Agency. Ingrid is on the Board of the Walter and Eliza Hall Institute, and the Scientific Advisory Council of the Bio21 Cluster, where she chairs the Hospital Research Directors Forum. A member of the National Advisory Group on Genetics Education for GPs and of the Genetic Services Advisory Committee to the Department of Human Services, Victoria, she has strong community links and is a member of the Genetic Support Network Victoria.

My name is Ms **Gabrielle Wongawol**. I'm 22 years of age and have no children of my own. I'm from Wiluna in the centre of Western Australia on the edge of the Gibson Desert. I have two brothers and one sister, and a little nephew. My education was in Karalundi Aboriginal Education Centre for three years, 55km out of Meekatharra, and my secondary schooling was in Carmel Adventist College in Perth for two years. After my schooling I did casual work at the Community Development Employment Projects for three years. I then commenced at Ngangganawili Aboriginal Health Service in December 2010, and at Marr Mooditj studying for a diploma in Aboriginal Health in February 2011. This is an 18-month course, which I am doing to show young people they can do

something for themselves in their life and education, and that learning is a very positive thing in my life. It allows me to help people in the community with health and wellbeing. Joella and I helped Jenefer Blackwell and the team with their studies, which was interesting, enjoyable and fun looking at the painting that the kids have done at the Wiluna School. Thank you for inviting me to this meeting.

Associate Professor **Edward (Ted) Wilkes** is A/Professor of Aboriginal Research Programs at the National Drug Research Institute (NDRI), Faculty of Health Sciences at Curtin University. Previously Ted worked as the CEO of the Derbarl Yerrigan Health Service and as an A/Professor at the Centre for Developmental Health at the TICH. He has dedicated his life to fighting for a better quality of life for Indigenous Australians and joined the Aboriginal team at NDRI to enhance the use of Aboriginal research and information. Ted has engaged with many forums and committees at the State, national and international level and is involved in several research initiatives dealing with alcohol and drugs in Indigenous Australia. A Prime Ministerial appointment to the Australian National Council on Drugs, he is also chairperson of the National Indigenous Drug and Alcohol Committee and Derbarl Yerrigan Health Service.





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