Beyond Chapter 4.7

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Introduction

As a Human Research Ethics Committee (HREC) works through an application for ethics approval of a research proposal, the process assists and insists that each committee member consider their reaction to the application in a reasoned, reasonable and well-expressed way, so that colleagues can understand their response, and consider their own. The happenstance of committee members' experience, interest and approach helps to inform the committee's response. The process permits and encourages the members to bring the perception of their 'community' to the consideration. This is usually more than one 'community' – musicians, academics, parents, lawyers, ethnic and religious communities, teachers, counselors, patients, volunteers, carers, healthcare providers and many others.

The National Statement on Ethical Conduct in Human Research[1] guides committee members in their considerations. Developed by the National Health and Medical Research Council, the Australian Research Council, and the Australian Vice-Chancellors' Committee, the document insists that when considering research related to work with Aboriginal and Torres Strait Islander Australians, the process includes expert assessment for or by the members of the HREC. In Chapter 4.7 of the Statement, there is clear guidance about the points at which researchers working with Aboriginal and Torres Strait Islander Peoples must consider their approach, and in particular involvement of Aboriginal and Torres Strait Islander individuals, communities or groups as participants. This article examines Chapter 4.7, its history, and application to research with Aboriginal and Torres Strait Islander Australians, and then moves to consider whether this Chapter could inform a renewed approach to all research.

Diversity acknowledged

Talk of 'Indigenous Australians' or 'Aboriginal and Torres Strait Islander Australians' allows us to conflate a group of diverse people, and the National Statement acknowledges "The message for researchers is that there is great diversity across the many Aboriginal and Torres Strait Islander cultures and societies"[1]. Thus

- Two Indigenous[1] populations are recognised in Australia: Aboriginal Australians and Torres Strait Islanders. However, our problems with remembering diversity begin here. Very little information, for example health data, is published separately for Australian Aboriginal people and Torres Strait Islanders, and usually no attempt is made to provide separate summaries for these two sub-groups of the Indigenous population[2], though Torres Strait Islanders have a unique cultural and political history.
- 'Aboriginal Australians' fails to convey the cultural diversity and identity throughout Australia – Koori, Murri, Anangu, Arrente peoples, and many, many more.

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[1] The use of the word *Indigenous* mirrors many documents and organisational names, for example Australian Indigenous Doctors' Association. Current convention would now encourage the acknowledgment of diversity, by using the term Aboriginal and Torres Strait Islander Australians.

- The geographical diversity of Indigenous Australians is often confounded by the popular perception of the population being largely limited to rural, remote and very remote Australia, when in fact 75% live in cities and non-remote regional areas.[3]
- Whilst the country's oldest university proudly announced the appointment of an Aboriginal man to the position of Deputy Vice-Chancellor[4] in 2011, three-quarters of Year 3 and Year 7 Aboriginal and Torres Strait Islander students met the national minimum standards for reading and numeracy in 2009, compared with about 95% of non-Indigenous students.[3]

Despite this diversity – instructions for researchers refer to all members of this diverse group, acknowledging (at least) a shared country, and history of dispossession.

Exceptionalism

Chapter 4.7 of the National Statement on Ethical Conduct in Human Research[1] asserts an exceptionalist position on research with Aboriginal and Torres Strait Islander communities. It proposes that this research is different (an exception to the rule) and makes particular demands of those involved in it: both researchers and review committees.

This exceptionalism leads us to two questions. Why Aboriginal and Torres Strait Islanders, and why make special provisions?

The answers lie in the past, and in the strength of the Aboriginal and Torres Strait Islander response to that past.

Colonial history

The colonial brutality experienced by Aboriginal and Torres Strait Islander people in this country is breathtaking. It was embedded in the psyche of those working on 'The Frontier', and many have documented it. By way of a single example, Henry Meyrick was a Gippsland squatter in Victoria, who wrote a letter home to his relatives in England in 1846:

> *The blacks are very quiet here now, poor wretches. No wild beast of the forest was ever hunted down with such unsparing perseverance as they are. Men, women and children are shot whenever they can be met with … For myself, if I caught a black actually killing my sheep, I would shoot him with as little remorse as I would a wild dog, … [the Aborigines] will very shortly be extinct.*[5]

Research and research ethics history

The history of ethically unjustified research practice in Aboriginal and Torres Strait Islander communities has also been documented and "the outcomes from this research have not always benefited Aboriginal and Torres Strait Islander peoples and communities."[6]

By 1980, Bear[7] was stating that "it is no longer necessary or productive to make surveys unless they are associated with a treatment programme. The magnitude of the problem is known." The need for capacity building was noted. The people he was meeting with firmly believed "that Aboriginal nursing aides must be recruited if possible from persons suggested by the Aboriginal community itself. They can be trained to maintain a more constant watch on the ever-present ear problem, …" Bear was reporting on a seminar held in Melbourne in October 1979. He closed with the prescient note:

> *The seminar closed in the same atmosphere of pessimism in which it had opened as we could not see a quick improvement in the socioeconomic state of the people and with the problem continuing to attract political fire.*

More than thirty years later the Australian Institute of Health and Welfare[3] noted that

> *Indigenous young people have one of the highest rates of hearing impairments (and loss) in Australia. Based on data from the 2004-5 [National Aboriginal and Torres Strait Islander Health Survey], …*

In a comprehensive work published in 2004, Thomas[8] meticulously examines Indigenous health research in Australia, across 100 years, from 1870 to 1969. He describes a typical example of the scientific expeditions reported in the Medical Journal of Australia: a 22-day expedition in August 1931, to Cockatoo Creek, saw Doctor JB Cleland publish a detailed report describing Aboriginal research participants, allocated a number, which was painted on their shoulder or buttock. A cardboard number was also hung around their neck or attached to some clothing. Then came the cattle race of researchers.

Thomas goes on to draw parallels with health screening for a research project he was involved with in 1990 when he was "part of a similar cattle race of several health professionals making a series of anthropometric and clinical measurements and then taking blood samples to make several biochemical and haematological measurements. … The data collection was probably excessive for the evaluation of such a small project, but was not atypical."[8]

The progression of research, particularly health research, and research ethics in work with Aboriginal Australians, parallels the progression of Australian history – from protection and biological assimilation, through cultural assimilation to political activism and self-determination.[9] In 1991, the National Health and Medical Research Council (NH&MRC) issued the Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research[10] following three major meetings and considerable consultation. Revising them 10 years later the Australian Health Ethics Committee took the advice proffered that "Aboriginal and Torres Strait Islander communities, researchers and health organisations still saw a clear need for a separate, complementary set of guidelines covering research in Aboriginal and Torres Strait Islander health." [11]

What does Chapter 4.7 say?

Chapter 4.7 (Aboriginal and Torres Strait Islander Peoples) sits within Section 4: Ethical Considerations Specific to Participants. Fundamental to this chapter is a "respect for, and valuing of cultural and language diversity." The Chapter does not consider that it should stand alone, because "Other documents … might provide useful guidance". In fact HRECs are "required to apply the Values and Ethics Guidelines[11] as the basis for assessing proposals for health research …", a document that outlines six core values as being important to Aboriginal and Torres Strait Islander Peoples: reciprocity, respect, equality, responsibility, survival and protection, spirit and integrity must inform research with Aboriginal and Torres Strait Islander Australians.

Chapter 4.7 provides specific guidelines. The process of HREC consideration must have included assessment by or advice from:

- "People who have networks with Aboriginal and Torres Strait Islander Peoples and/or knowledge of research with Aboriginal and Torres Strait Islander Peoples; and
- People familiar with the culture and practices of the Aboriginal and Torres Strait Islander people with whom participation in the research will be discussed."

The researcher is required to demonstrate their research methods are respectful, acknowledge cultural distinctiveness (4.7.1; 4.7.10), and that they have identified potential negative consequences and ways of minimising them (4.7.4). The development of the methods should be an opportunity for partnerships (4.7.5) that involve Aboriginal and Torres Strait Islander participants (4.7.6). There must be evidence of support from relevant Aboriginal and Torres Strait Islander communities (4.7.2), and the researcher must work in a way that acknowledges and values the knowledge and wisdom of Aboriginal and Torres Strait Islander Peoples (4.7.11) including work with the community or group to agree on how participants are recruited and informed, and how they consent (4.7.3). Progress of the research (4.7.3) and interpretation of the data (4.7.11) should involve the participants, and the final reporting should have been agreed to at the start of the project (4.7.3). The benefits of the research work should include capacity building and opportunity development for the Aboriginal and Torres Strait Islander Australians involved (4.7.7). Those benefits must be discussed and agreed to (4.7.8) and they must be distributed in a way that is considered fair (4.7.9). Researchers working at a national or multi-centre level are also required to ensure that their methods respect cultural and language protocols.

The nature of this response

The legacy of Australia's colonial history, the violence, the injustice and the blood spilled, supports the call for a restorative justice, and the history of unproductive and unethical health research similarly calls for a strong response.

However – most importantly – this response, to the injustices in Aboriginal and Torres Strait Islander history and to the history of research with them, sits uniquely. Chapter 4.7 is perhaps motivated by outrage at past wrongs, and a sense that Aboriginal and Torres Strait Islander peoples might be particularly vulnerable, and might need special kinds of advocacy. However, the framing of this response as a problem of vulnerability ignores an enormous part of Aboriginal and Torres Strait Islander history: the history of resilience, strength, determination, and leadership. Framing it as a response to outrage is appropriate, but outrage is not enough. The emotional reaction is an important indicator. But, this is more than outrage at past wrongs. As a response to vulnerability - this is more.

This is a rational, institutionalised, systematic demand for a different perception of what

a) Should inform the area of research;
b) Processes researchers should go through to engage with the community of participants; and
c) The relationships that should be integral to the research project, before, during and after the project's completion.

Justice is of all kinds, and includes restorative justice to address past wrongs and social and distributive justice to address current inequities. But the instructions contained in Chapter 4.7 are more than that. This is a demand for a higher-order response. This is a response, which goes to the heart of how decisions are made about research priorities, funding and approaches. It requires the development of a relationship between researcher and community, before the research begins, embedded in the research, and after the research is finished.

Extending this to others

Why extend?

It may be argued that all research participants have some degree of vulnerability. The participant-researcher relationship is at risk of being exploited, and this prompts the National Statement to require “that participants be accorded the respect and protection that is due to them”. If participants who have particular vulnerabilities are specified, why not apply this to all participants? A fundamental principle of the National Statement[1] is to “help to shape that relationship as one of trust, mutual responsibility and ethical equality” between researchers and participants, thus implicitly recognising of all participants, the potential for exploitation and failure to respect participants. Could the quality of the researcher-participant relationship be improved by extending the requirements outlined in Chapter 4.7 to all research?

There is already an extension of the ‘specialness’, as a response to vulnerability, to other populations. The National Statement[1] has chapters on women who are pregnant and the human fetus (Chapter 4.1), children and young people (4.2) and various other particular populations (4.3 to 4.8), implicitly recognising that there are groups within the community who need specific provisions, ensuring protection and advocacy on their behalf. Should we limit these specifics to Aboriginal and Torres Strait Islander Australians, and to those designated as vulnerable?

What could Chapter 4.7 provide?

If Chapter 4.7 is compared to what is otherwise required for the ethical conduct of human research, it can be seen that the emphasis is different. The emphasis is on partnerships and mutually agreed outcomes – for the researcher and the community. For example, in Chapter 4.7 the researcher is asked to negotiate with the community. This is different to asking the researcher to make sure that the participant knows about and agrees to the research. The researcher working with Aboriginal and Torres Strait Islander Australians must demonstrate evidence of respectful engagement **before** the research commences, in contrast to the development of most research proposals and projects that occur in isolation, often at a distance to the participants, and possibly unrelated to the needs as perceived by the participants.

Aboriginal and Torres Strait Islander Australians have wrought a unique approach to research, out of a history of exploitation, and outrage, and a disregard for their dignity and humanity. This is not to ignore or belittle what has informed the evolution of Chapter 4.7. Rather it is to recognise that current research practices might be reconsidered. Aboriginal and Torres Strait Islander Australians have led the way here.

Challenges

Extending the principles of Chapter 4.7 to all research could extend some challenges to all researchers.

Who speaks for community?

An application for funding requires a thorough examination of why the work should receive funds. In this process the funder, whether private bodies, or government, has a very loud voice on the nature, duration and direction of the work. Writing a grant application is a huge task and takes many hours of (often unsuccessful) work[15], so the educated and the articulate must be the seekers of funding, the recipients of grants and those that determine research directions. Regardless of their need, poor and illiterate people may have no say.[2]

A definition of "community" is fraught. By maintaining their communities, their ties with land and family, the lines of responsibility are more recognisable for Aboriginal and Torres Strait Islander Australians, and that enables researchers to work out with whom to negotiate. "Community" may be clearer when work is with Aboriginal and Torres Strait Islander Australians, but this is still complex, as the boundaries and relationships are less clearly drawn than they might once have been[12].

"Community" is diverse. There are many communities. And there are communities with multiple organisations claiming to speak on their behalf, communities that are not formally recognised, communities that have dissent within them. But, as discussed earlier, we already conflate the diversity of Aboriginal and Torres Strait Islander communities.

How can HREC members represent "community" interests? Whilst it is challenging, there are already some requirements. The composition of an HREC must have representation (Chapter 5.1.29[1]) of groups on the review committee: people with expertise in a range of fields, lay people, current researchers, lawyers and clinicians "and includes members of the general community"[13]. Explaining your idea, your plan, your expertise, and your expected outcomes to non-experts may be difficult. However, if researchers had to ensure there was some return of benefit to the community, then they would have to demonstrate to that community, a need for, interest in or benefit from the knowledge sought in the research. Counting, enumerating, interviewing, examining, re-telling the stories of and surveying participants may not be enough. The way has been paved – as there is an expectation that

> *5.2.16: Information about research should be presented to participants in ways that help them to make good choices about their participation, and support them in that participation.*

What should be returned?

As the community contributes (finance, participation, ideas, commitment to implementation), what should it expect in return? We should be thoughtful and cautious here: return to community and coercion are either ends of a spectrum. Determining where the right balance lies is difficult. However, we may follow the lead of Aboriginal and Torres Strait Islander Australians. By spreading the return and by not individualising it, by embedding principles of capacity building, service delivery and something beyond simple enumeration into every research project, the effect of coercion is blunted. The idea of return to community allows generosity. It allows researchers to look beyond the immediate outcomes of their research, to consider a reduction of personal gain – and recognise the opportunity provided by their connection with the community they serve, to be generous. The return need not be financial. It may be that it will cost money, but this paper seeks to encourage a broader interpretation of return, a reconfiguration of the currency. The exchange may be unequal and not always exact. It may, for example, be the building of capacity, as Bear[7] suggested 35 years ago.

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[2] There are those that may claim to speak for them. However, it is exactly this claim on their behalf that prompted Aboriginal and Torres Strait Islanders to insist that they have an actual voice; to insist that they "had to create their own 'voices' to be heard."[16]

The bartering process, the negotiation and the consequent development of relationships and partnerships, needs to be shaped in order to take this out of a simple financial arrangement. Such negotiation – difficult, messy or straightforward – can be the basis of a partnership between researchers and the community they serve. The currency is negotiable; the process of negotiating (and therefore engaging) with participants is critical.

> *4.7.10: The research processes should foster respectful, ethical research* ***relationships*** *that affirm the right of people to have different values, norms and aspirations.*[1]*(My emphasis)*

Conclusion

Within the National Statement, HREC members are given (and instructed to use) their discretion, because

> *These ethical guidelines are not simply a set of rules. Their application should not be mechanical. It always requires, from each individual, deliberation on the values and principles, exercise of judgement, and an appreciation of context.*[1]

However, the ethics review process allows and guides articulation of disquiet or concern with a research proposal. Chapter 4.7 scaffolds the approach if the participants are Aboriginal and Torres Strait Islander Australians. It is possible that all research participants could benefit from a similar set of demands and protection to those of Chapter 4.7, to ensure they participate in and benefit from research, in a way that is meaningful for them.

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