



the
Lowitja
INSTITUTE

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

*Incorporating the Cooperative Research Centre
for Aboriginal and Torres Strait Islander Health*

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Submission for the Evaluation of Aboriginal and Torres Strait Islander Health Research

The Lowitja Institute is pleased to provide the following submission.

Yours sincerely,

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The Lowitja Institute

Submission to the

National Health and Medical Research Council's

Aboriginal and Torres Strait Islander Health Research Ethics Evaluation

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Background to Our Submission

About Us

The Lowitja Institute is Australia's only national health research organisation with a sole focus on the health and well-being of Aboriginal and Torres Strait Islander peoples.

We bring together Aboriginal organisations, academic institutions and government agencies to make possible collaborative, evidence-based research into Aboriginal and Torres Strait Islander health. Our approach to research is driven by Aboriginal and Torres Strait Islander people in collaboration with world-quality researchers, service delivery organisations, and policy-makers. We have a strong focus on the translation of knowledge into the kind of practice that makes a difference to Aboriginal and Torres Strait Islander people's lives.

Evolving out of the Cooperative Research Centre process since 1997, the Institute currently hosts the Cooperative Research Centre for Aboriginal and Torres Strait Islander Health (CRCATSIH).

In May 2013, the Institute was successful in securing Commonwealth Government funding of \$25 million to extend the term of the CRCATSIH until 2019.

The changing face of Aboriginal and Torres Strait Islander health research

Historically, many Aboriginal and Torres Strait Islander communities were deeply suspicious of research. This distrust grew out of conventional research processes which treated Aboriginal and Torres Strait Islander people as the passive subjects of research rather than active participants, and which all too often failed to translate research findings into meaningful changes in health policy or practice.

How research was conducted began to shift in the 1980s and 1990s. Aboriginal and Torres Strait Islander organisations began to play more significant roles in identifying priorities for research, participating actively in its conduct, and ensuring that its results were translated into policy and practice. In parallel, there were a growing number of Aboriginal and Torres Strait Islander researchers bringing their own perspectives and skills to the research task.

The 1991 publication of the NHMRC's *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*¹ was part of this re-examination of the nature and processes of Aboriginal and Torres Strait Islander health research. However, the Guidelines in the document were very brief – barely 2 ½ pages long – and concentrated on a list of issues which Ethics Committees should consider in assessing proposals for research involving Aboriginal and Torres Strait Islander people.

¹ National Health and Medical Research Council (NHMRC) 1991, *Guidelines on Ethical Matters in Aboriginal and Torres Strait Islander Health Research*. Available: https://www.nhmrc.gov.au/files/nhmrc/file/health_ethics/ahec/history/e11.pdf

The 1991 document was replaced by the current Guidelines² in 2003. Created through an extensive consultation process, these Guidelines are more substantial. They also embody an explicit change of focus: from a set of rules with which researchers are expected to comply, to the promotion of an 'awareness of difference' amongst researchers and an attitude of respect towards the Aboriginal and Torres Strait Islander communities with which they work. The Guidelines were supported by the publication in 2005 of a guide for Aboriginal and Torres Strait Islander peoples about health research ethics³.

Given the length of time since their publication, and the changing policy, service delivery and research environments over the last decade, the Lowitja Institute fully supports the NHMRC's decision to evaluate and review the Guidelines and supporting documents.

Nevertheless, we believe that as they currently stand, they represent a significant contribution to ensuring that research involving Aboriginal and Torres Strait Islander people is appropriate and effective. The values and ethics they contain and the approach to research that they support match closely with those developed by the Lowitja Institute and its precursor organisations from the 1990s onwards.

Many of the recommendations we make below reflect, therefore, the need to ensure their widest practical use in the current environment, rather than a need to substantially alter them.

The Guidelines in Context

This submission is structured around the key questions contained in the evaluation consultation paper. However, there are two broader issues that the Lowitja Institute believes the evaluation should also consider that address the context within which the Guidelines operate: the need for strategic research partnerships, and the need to build an evidence base around the Guidelines' effect on research practice and outcomes.

Supporting strategic research partnerships

Much has changed in the last twenty years in the way that Aboriginal and Torres Strait Islander health research is carried out. This has been accompanied by changes in attitude in the Aboriginal and Torres Strait Islander community towards research, from positions marked by distrust and avoidance towards ones of engagement.

Leading such changes in the way research is conducted, our predecessor, the Cooperative Research Centre for Aboriginal Health (CRAH) established the Facilitated Development Approach⁴ to research. This approach ensures that research is directed towards priorities identified by Aboriginal and Torres Strait Islander people and partners, who in turn can make use of the research findings.

² National Health and Medical Research Council (NHMRC) 2003, *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Research*. Commonwealth of Australia. Available: <http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e52.pdf>

³ National Health and Medical Research Council (NHMRC) 2005, *Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander peoples about health research ethics*. Commonwealth of Australia. Available: <http://www.nhmrc.gov.au/files/nhmrc/publications/attachments/e65.pdf>

⁴ Cooperative Research Centre for Aboriginal Health (CRAH) 2006, CRAH Annual Report 2005-2006. Available: <http://www.lowitja.org.au/sites/default/files/docs/FDA-july-2007.pdf> For more information on this approach see: <http://www.lowitja.org.au/making-research-work>

Key features of this approach include research transfer and capacity development. The experience of the CRAH has shown that Aboriginal direction of and participation in each step of the research process is most likely to ensure research that is appropriate, relevant and useful.

For the Lowitja Institute, it is important to keep building genuine partnerships between Aboriginal and Torres Strait Islander communities and organisations and researchers. Significantly, such partnerships need to be founded on the priorities and needs that the Aboriginal and Torres Strait Islander organisations and communities themselves identify: the key questions remain – what are *they* trying to do and how can research help them achieve *their* goals? This requires collaborative strategic goal setting, rather than basing research priority setting solely on conventional competitive grants processes where researchers identify what *they* believe are the research needs, and then subsequently in effect ask the community for permission to carry out the research thus identified.

The need for strategic and genuinely collaborative setting of research priorities – at both national and local / regional levels – is at the heart of the Lowitja Institute's approach to research, and was recently given strong support by the McKeon Review⁵.

Guidelines on research values and ethics need to be consistent with, and support in practice, such strategic approaches to priority setting.

Recommendation 1. That the evaluation strongly support strategic and collaborative processes for setting research priorities in Aboriginal and Torres Strait Islander health. These processes should involve Aboriginal and Torres Strait Islander communities, service agencies and representative organisations, policy makers, and researchers, and be founded on the needs identified by Aboriginal and Torres Strait Islander communities. These processes need to be resourced, at the local / regional and national levels.

Evaluating the effect of the Guidelines

Most researchers agree that the current Guidelines have contributed to changes in Aboriginal and Torres Strait Islander health research practice. However, there is little literature exploring the actual conduct of Aboriginal and Torres Strait Islander health research⁶. There is no systematic evidence that answers questions about how the Guidelines are used, and how, or to what extent, research practice reflects the content of the Guidelines. Monitoring and evaluation processes (for example, reports to Ethics Committees on the conduct of approved research) tend to be based on self-reporting, and are not collectively subject to analysis. Developing an evidence-based literature is an important way to evaluate the effect of the Guidelines over time, and critical to their long-term success.

Recommendation 2. That the evaluation support the building of a critical literature around the issues the Guidelines seek to address, with aim of exploring how their use affects the conduct and outcomes of research in practice, with a particular focus on the experience of Aboriginal and Torres Strait Islander communities, research partners, participants and researchers.

⁵ Department of Health and Ageing 2013, *Strategic Review of Health and Medical Research in Australia – Better Health Through Research (the McKeon Review)*. Commonwealth of Australia. Available: <http://www.mckeonreview.org.au/>

⁶ One exception to this gap is Dunbar T, Arnott A, Scrimgeour M, Henry J & Murakami-Gold L 2004, *CRCATH 1997–2002: Working towards change in Indigenous health research*. CRAH, Darwin. Available: <http://www.lowitja.org.au/crcath-1997-2002-working-towards-change-indigenous-health-research>

Consultation Questions

Aboriginal and Torres Strait Islander awareness and use of the Guidelines

There are many Aboriginal and Torres Strait Islander 'communities' relevant to health research, including individual members of Aboriginal and Torres Strait Islander society, service and representative organisations (particularly Aboriginal community controlled health services and their peak bodies at the state and national levels), Aboriginal and Torres Strait Islander professional groups, and the 'community' of Aboriginal and Torres Strait Islander health researchers.

We assume that the evaluation's consultation process will elicit authoritative information on the awareness and use of the documents by all these groups. However, we provide the following points based on our experience.

First, it appears that Aboriginal and Torres Strait Islander health researchers are widely aware of the Guidelines, and actively use them throughout the research process (see section on *Researcher use of the Guidelines* below).

However, at the level of individual community members, it is our experience that very few Aboriginal and Torres Strait Islander people are explicitly aware of the documents. Community members are unlikely to have sighted, much less read, the documents unless researchers themselves have presented and/or explained them.

Knowledge of the documents amongst service organisations such as community controlled health services, their peak bodies and Aboriginal and Torres Strait Islander professional groups is, we believe, patchy. Most will be unaware of them, although some (especially if they are regular partners in research, or are formally involved in ethics approval processes), may know of and use them.

The lack of knowledge of these documents, however, does not imply that the Aboriginal and Torres Strait Islander groups involved do not have an understanding of and commitment to ethical behaviour in research. However, the limited awareness and use of them would suggest a need for a greater effort in making them accessible and having a strategic (rather than ad hoc, researcher-driven) process for distributing and promoting them and their use.

One barrier to the use of the documents is their complexity and length. The Guidelines themselves are aimed primarily at raising awareness amongst researchers; their audience and their purpose lead inevitably to some degree of complexity. *Keeping Research on Track* is aimed at the Aboriginal and Torres Strait Islander community and is more appropriately presented, but its length (over 50 pages) will presumably still be a barrier for some. Developing some more introductory resources (physical documents, or websites) may therefore be appropriate.

Supporting the broader awareness and use of the Guidelines in Aboriginal and Torres Strait Islander communities will require not just the production of more accessible resources, or better distribution, but also an ongoing program of engagement and discussion of them with Aboriginal and Torres Strait Islander stakeholders, including face-to-face through forums such as peak body meetings, conferences, and professional bodies. While the Guidelines should be at the centre of this process, this engagement should seek to increase Aboriginal and Torres Strait Islander understanding of research and research culture, and of the potential benefits and costs of engaging in research

Recommendation 3. That the evaluation support a strategic approach to promoting awareness and use of the values and ethics Guidelines, including through developing appropriate introductory resources, a strategic approach to distributing the Guidelines and supporting documents, and an active process of engagement with Aboriginal and Torres Strait Islander stakeholders including through meetings, forums, conferences and professional bodies. The engagement process should also seek to increase Aboriginal and Torres Strait Islander understanding of research and its processes.

Researcher use of the Guidelines

The Lowitja Institute believes that the content of the current Guidelines are of high value to the research community, in that they are:

- widely known and used amongst researchers with a strong interest in Aboriginal and Torres Strait Islander health, including Aboriginal and Torres Strait Islander researchers themselves;
- authoritative, providing a widely agreed standard for assessing the merits of particular research proposals or approaches;
- appropriate, as the non-prescriptive nature of the guidelines focuses on developing open-minded awareness and questioning of assumptions, rather than fostering a 'tick box' approach;
- a good framework for structuring the research process: they provide a basis for developing, conducting and continuously evaluating the research process; and
- a good reference point for researchers new to Aboriginal and Torres Strait Islander health, providing an introduction and an aid for reflection that encourages questions rather than giving answers.

Nevertheless, against these positives there are a number of issues which the evaluation of the Guidelines should consider.

Not all researchers use or understand the guidelines

There is a core of researchers and research agencies with long-standing experience in Aboriginal and Torres Strait Islander health who are aware of the Guidelines and attempt to embed them throughout research processes in which they are involved.

However, it appears there are others who are either unaware of the Guidelines, unfamiliar with them, or unsure about their use. Responses in ethics approvals or grant applications often show a lack of understanding of the values and ethics outlined in the Guidelines or how to apply them in practice. This lack of familiarity with the Guidelines and their use seems (not surprisingly) more prevalent amongst those less experienced in Aboriginal and Torres Strait Islander health research.

It also appears that the supporting document, *Keeping Research on Track*, is not widely known, even amongst researchers experienced in the field. While it is aimed at the Aboriginal and Torres Strait Islander community, it too is regarded as a highly useful resource by those researchers who know of its existence.

Recommendation 4. That the evaluation support a process for distributing and promoting the Guidelines and supporting documents across the broader research community, with a particular focus on gaining the understanding of and commitment to the Guidelines by senior leadership in research organisations.

NHMRC Project Grant Application alignment with the Guidelines

The six principles in the Guidelines (*Reciprocity, Respect, Equality, Responsibility, Survival and protection, and Spirit & integrity*) that underpin the values and ethics in Aboriginal and Torres Strait Islander health research are appropriate, authoritative and were developed in collaboration with Aboriginal and Torres Strait Islander people.

However, the NHMRC's Project Grant Application process uses a different set of principles against which proposals are to be assessed (*Community engagement, Benefit, Sustainability and transferability, Building capability, Priority, Significance*)⁷.

This lack of alignment may cause confusion amongst some researchers about what are the fundamental principles that should underlie their proposed research, as well as creating additional effort as researchers attempt to address, in effect, twelve criteria against which their proposal is to be assessed. In addition, by not including the Guidelines at an earlier stage, it encourages their use merely as an 'add on' required only to gain ethics approval, rather than as an important guide whose principles should be embedded throughout the research process.

Recommendation 5. That the evaluation support the alignment of the NHMRC's Project Grant Application process principles contained in the 'Criteria for Health and Medical Research of Indigenous Australians' with those in the Guidelines.

Human Research Ethics Committee use of the Guidelines

The role of ethics committees, and the ethics approval process, is to facilitate high quality, effective and ethical research. The Guidelines and supporting documents are important resources for this task as it relates to Aboriginal and Torres Strait Islander health research.

Skills and focus of HRECs

There appears to be some variation in how the Guidelines are used by Human Research Ethics Committees (HRECs) to undertake ethical review of Aboriginal and Torres Strait Islander health research.

Ethics committees (or sub-committees) formed specifically to deal with Aboriginal and Torres Strait Islander health research, in Western Australia, South Australia, the Northern Territory and New South Wales, apparently use the Guidelines extensively as a basis for their work.

'Mainstream' HRECs, however, may need additional support to effectively use the Guidelines – there may be some uncertainty about whether and how to apply them when considering Aboriginal and Torres Strait Islander health research, in particular whether the perspective and expertise of an Aboriginal and Torres Strait Islander person is needed to be able to effectively assess proposals against the Guidelines. This uncertainty is understandable, and points both to the need for additional training and support for these bodies, plus the need for HRECs with a specific focus on Aboriginal and Torres Strait Islander health to be set up in all jurisdictions, with links to a national body (or process) to consider multi-site, multi-jurisdictional research proposals.

It also appears that at least in some cases, new members of ethics committees are not necessarily oriented to the Guidelines and supporting documents. Given their importance, this would reinforce the need for a structured support and up-skilling program to be in place for all ethics committees.

⁷ National Health and Medical Research Council (NHMRC) nd. *Criteria for Health and Medical Research of Indigenous Australians*. Available: <http://www.nhmrc.gov.au/grants/apply-funding/project-grants>

Recommendation 6. That training and support processes are resourced for mainstream Human Research Ethics Committees, to make them aware of and assist them to understand and use the Guidelines.

Recommendation 7. That Human Research Ethics Committees with a specific focus on Aboriginal and Torres Strait Islander health be set up and resourced in those jurisdictions where they do not yet exist, with a national committee or process to consider multi-site, multi-jurisdictional research proposals.

Reporting and assessment processes

HRECs inevitably face a tension between their responsibility to ensure that research is carried out appropriately, and the level of effort required for researchers (and Committee members) in reporting and assessment processes.

The Lowitja Institute does not advocate for unnecessarily adding to the burden of assessing ethics approvals, or reporting back on them. We also note that solely adding more rules and regulations around research approval and reporting processes, without recognising and addressing the more fundamental power imbalances inherent in Aboriginal and Torres Strait Islander health research, may result in processes that are burdensome for all involved but which do not facilitate more genuinely collaborative approaches to research.

Nevertheless, there appears to be a gap as there is nothing currently in ethics approval processes that requires researchers to verify that communities or service organisations have or will be informed of the existence of the Guidelines or supporting documents, or that these have or will be provided and/or explained. Given the apparent widespread lack of awareness of the Guidelines in the Aboriginal and Torres Strait Islander community and even their representative service organisations, we believe this gap should be addressed.

Recommendation 8. That the evaluation investigate an appropriate way of ensuring that HRECs include, as part of the assessment and reporting process on research proposals, verification that communities and/or community organisations will be or have been informed about the Guidelines and supporting documents.

Other relevant documentation

The Lowitja Institute recommends the following documents as being useful in the evaluation and review of the Guidelines.

- Aboriginal Health & Medical Research Council of New South Wales (AH&MRC) 2013, *Guidelines for Research into Aboriginal Health: Key Principles*. Available: http://www.ahmrc.org.au/index.php?option=com_docman&task=cat_view&gid=22&Itemid=45
- Aboriginal Medical Services Alliance Northern Territory (AMSANT) 2009, *Aboriginal Health Research Policy*. Available: <http://www.amsant.org.au/attachments/article/88/AMSANT%20Research%20Policy.pdf>
- Alison Laycock with Diane Walker, Nea Harrison & Jenny Brands 2009, *Supporting Indigenous Researchers: A Practical Guide for Supervisors*, CRCIAH, Darwin
- Alison Laycock with Diane Walker, Nea Harrison & Jenny Brands 2011, *Researching Indigenous Health: A Practical Guide for Researchers*, The Lowitja Institute, Melbourne
- Australian Health Ministers' Advisory Council (AHMAC) 2004, *Cultural Respect Framework For Aboriginal And Torres Strait Islander Health*. Available: <http://www.health.gov.au/internet/main/publishing.nsf/Content/health-oatsih-pubs-crf.htm>
- Australian Health Ministers' Advisory Council (AHMAC) 2006, *National Aboriginal and Torres Strait Islander Health Data Principles*. Available: <http://www.aihw.gov.au/naqatsihid/>

- Australian Institute of Aboriginal and Torres Strait Islander Studies (AIATSIS) 2012, Guidelines for Ethical Research in Australian Indigenous Studies. Available: <http://www.aiatsis.gov.au/research/docs/GERAIS.pdf>
- Department of Families, Housing, Community Services and Indigenous Affairs (FaHCSIA) 2012, *Engagement with Indigenous Australians information sheets*. Available: <http://www.fahcsia.gov.au/our-responsibilities/indigenous-australians/programs-services/recoognition-respect/engagement-with-indigenous-australians>
- Paul Stewart & Priscilla Pyett 2005, *Victorian Aboriginal Ethics Project Report: A Community Report from Onemda VicHealth Koori Health Unit*. Victorian Aboriginal Community Controlled Health Organisation and Onemda VicHealth Koori Health Unit. Available: <http://www.onemda.unimelb.edu.au/sites/default/files/docs/VicAboriginalEthicsProjectReport.pdf>

Issues for further exploration

There are a number of areas which the evaluation might consider for inclusion in any updated version of the Guidelines, reflecting the changing nature of the research and service delivery environment over the last decade.

Acknowledgement and co-authorship

Acknowledgement and co-authorship in publications for those individuals, organisations or communities who have contributed to research has increasingly become an issue in recent years. While researchers would wish to acknowledge assistance broadly, journal publication guidelines often do not offer sufficient space to be able to include this.

Research linking electronic data sources

Ethical challenges are emerging for researchers, service organisations and other agencies from the increasing ability to gather and link large amounts of data electronically, across multiple databases. This provides new opportunities for research that could potentially illuminate, for example, the effect of policy, resource investment or service delivery changes in a way that conventional research would struggle to do. Nevertheless, there are also risks for the Aboriginal and Torres Strait Islander community in this type of research, and in the collection of data that might underpin it.

Genetic research

Genetic research is an area of particular sensitivity for Aboriginal and Torres Strait Islander peoples, given (amongst other things) its potential links to issues of identity as well as to its supposed use in explicitly racist theory and practice in the past. Nevertheless, there may be benefits to the health of Aboriginal and Torres Strait Islander people including in the emerging field of gene therapy.

Recommendation 9. That the evaluation consider providing additional specific ethical guidance on emerging issues including:

- *appropriate acknowledgement in publications where there are multiple communities, organisations or individuals who have contributed to the research. This may include separate on-line processes for providing this information;*
- *the challenges for researchers, service organisation and other agencies posed by the increasing ability to gather and link large amounts of data electronically, across multiple databases; and*
- *genetic research including the possible emerging benefits of gene therapy.*

