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

Indigenous Research Excellence Criteria Review and Public consultation on Section 4 of the National Statement joint submission

Submission to the National Health and Medical Research Council (NHMRC)

The Lowitja Institute, September 2023

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National Health and Medical Research Council
16 Marcus Clarke Street
Canberra
Australian Capital Territory 2601

Dear National Health and Medical Research Council,

Re: Indigenous Research Excellence Criteria (IREC) Review and Public consultation on Section 4 of the National Statement

The Lowitja Institute is Australia's national institute for Aboriginal and Torres Strait Islander health research, named in honour of our Patron, Dr Lowitja O'Donoghue AC CBE DSG. We welcome the opportunity to provide a submission to this review.

As an Aboriginal and Torres Strait Islander community-controlled health research institute, research ethics is an important focus for Lowitja Institute. Our organisational priorities include investment in Aboriginal and Torres Strait Islander community driven best practice health research and enhancing the capability of the Aboriginal and Torres Strait Islander health research workforce.

Lowitja Institute was established to centre our peoples within research, to ensure that research is no longer done on and about us; and instead advocate for and facilitate **research done by us and for us**. Our establishment was a response to the unethical and racist research practices imposed on our peoples since colonisation. As such, this review and public consultation are of key importance to the work that we do.

As outlined in the below submission, if done correctly, Lowitja Institute sees this as an opportunity for significant impact. By improving the IREC and the National Statement Section 4, the NHMRC can play a role in healing the harms of the past, building trust between our peoples and research institutions, ensuring that research relating to our peoples is driven by our community and is therefore relevant and impactful, and in supporting the development of the next generation of Aboriginal and Torres Strait Islander researchers.

We encourage the NHMRC to dig deep, look unflinchingly at the history of research in this country, be ambitious in the outcomes of the review, and strive to develop an improved IREC and National Statement that will lead to improved health outcomes for our peoples.

Please find our submission attached. We would welcome the opportunity to further discuss our recommendations therein.

Warm regards

Dr Janine Mohamed
CEO, Lowitja Institute

About the Lowitja Institute

The Lowitja Institute is a national Aboriginal and Torres Strait Islander Community Controlled Organisation working for the health and wellbeing of Aboriginal and Torres Strait Islander peoples through high impact quality research, knowledge translation, and by supporting Aboriginal and Torres Strait Islander health researchers.

Established in January 2010, we operate on the key principles of Aboriginal and Torres Strait Islander leadership, a broader understanding of health that incorporates wellbeing, and the need for the work to have a clear and positive impact.

The Lowitja Institute has a longstanding commitment to the National Agreement on Closing the Gap, as members of the Coalition of Peaks, National Health Leadership Forum, and the Close the Gap Steering Committee, including authoring the Close the Gap Report over the past 4 years.

Based on this experience we offer the following general comments and note some specific issues for consideration.

General preamble

Indigenous peoples were the first researchers on this continent and our methodologies are distinct from mainstream dominant cultural approaches. This is recognised in the NHMRC's Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (Ethical Guidelines). Before responding to the review discussion paper, it is important to understand the Indigenous Research Excellence Criteria (IREC) review and the NHMRC Statement 4 within the more recent history of colonisation.

From the early days of European settlement in Australia in 1788, our peoples were forced off Country onto missions, reserves, and into housing commissions with prohibitive rules that prevented many of us from connecting with family, community, and culture.[1] Our systems of governing, and the ways in which we learned, shared knowledge, and did research, were disrupted. Colonial policies

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[1] Anderson, I., Baum, F. & Bentley, M. (eds) 2004, *Beyond Bandaids: Exploring the Underlying Social Determinants of Aboriginal Health*. Papers from the Social Determinants of Aboriginal Health Workshop, Adelaide, July 2004, Cooperative Research Centre for Aboriginal Health, Darwin, p. 27

removed us from the connected and strong communities, cultures and Country that had previously sustained our good health and social and emotional wellbeing. Our health deteriorated under the imposed colonial conditions generating profound health impacts across multiple generations. Race was the basis of the inhumane treatment of Indigenous peoples and racism has taken many forms over the centuries. As Professor Warwick Anderson argues in 'The Cultivation of Whiteness: Science, Health and Racial Destiny in Australia' (2002) race shaped the nation's view of itself and the treatment of others.[2]

Science and medical research was a tool in developing ideas of racial superiority and inferiority, which included unethical research practices – Research has been a tool of colonial violence and data has been weaponised against our peoples. Non-Indigenous researchers would come into our communities to conduct research on us under the impression that they better understood what our communities' priorities ought to be; research was driven by Western research priorities.[3] To this day research questions have been framed by colonising perspectives and research is conducted using methodologies that lack cultural safety and are inappropriate for engagement with our peoples.

Research was and still is embedded in what we call the 'deficit discourse' where Aboriginal and Torres Strait Islander peoples are framed as a problem to solve. This dehumanising and racially biased approach to research does not acknowledge the systems and practices that have caused harm to our communities and led to health inequality.

We know that in its most sinister form, colonial scientists and ordinary doctors practiced inhuman medical experimentation and other harms on our peoples in the name of research. For this reason, our communities remain suspicious of research. For those of our people who wish to become researchers, the pathways are narrow and difficult to navigate.

The NHMRC has rightly recognised that they have a role to play in improving Indigenous health outcomes through ethical research practices and supporting capacity building. We also encourage the NHMRC to see part of this role as healing past harms and building trust for our peoples. The IREC are vital to this; criteria that reflect our ways of knowing, being and doing, and that ensure that our communities' priorities and leadership are driving the research, is key.

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[2] Anderson, W, 2002, *The Cultivation of Whiteness: Science, Health and Racial Destiny in Australia*, Melbourne University Press, Melbourne.

[3] Lowitja Institute, 2017, *Changing the Narrative in Aboriginal and Torres Strait Islander Health Research*, The Lowitja Institute, Melbourne, p.1.

We wish to highlight a section in *Road Map 3 – Report of Community Consultations:*

> "However, stakeholders also called for greater clarity around how [the IREC] are defined and applied by review committees throughout the grant application process. In particular, they highlighted the importance of defining 'Research Excellence' and the four criteria from an Aboriginal and Torres Strait Islander perspective. Stakeholders also felt that the definition of whether a project qualifies as Aboriginal and Torres Strait Islander health research is currently too ambiguous and could be tighter with stronger and more ambitious targets. Stakeholders at a number of the workshops suggested that NHMRC could consider adopting the principles that the Lowitja Institute identifies as underpinning their approach to research."[4]

We strongly endorse the above statement and mirror its sentiment in this submission. We agree that adopting Lowitja Institute's principles would be a solid foundation upon which to build the IREC, and we recommend this approach. These principles are:

- **Beneficence** – to act for the benefit of Aboriginal and Torres Strait Islander peoples in the conduct of our research.
- **Leadership** by Aboriginal and Torres Strait Islander peoples.
- **Engagement** of research end users (Aboriginal and Torres Strait Islander and communities, policymakers, other potential research users).
- **Development** of the Aboriginal and Torres Strait Islander research workforce.
- **Measurement** of impact in improving Aboriginal and Torres Strait Islander peoples' health.

We also recommend incorporating them into Chapter 4.7 of the *National Statement on Ethical Conduct in Human Research* (National Statement).

We are grateful for the advice of Distinguished Professor Aunty Aileen Moreton-Robinson in the preparation of this submission.

Further, Lowitja Institute is soon to publish a discussion paper by Associate Professor Michelle Kennedy and Dr Jamie Bryant, *Ethics in Aboriginal and Torres*

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[4] NHMRC 2018, Road Map 3 – Report of Community Consultations. Accessed on 19 September 2023 at https://www.nhmrc.gov.au/about-us/publications/road-map-3-report-community-consultations#toc__95

Strait Islander health research.[5] We encourage the NHMRC to read this paper when it is published and implement the recommendations made therein.

Discussion paper questions

In this submission we are responding to both above noted NHMRC consultation processes. We structure our response around the IREC review questions, including relevant content for the National Statement Section 4 consultation as appropriate.

Question 1: Are all of these four criteria still appropriate? If not, why not and what should be used instead?

The four criteria are not appropriate and should be revised. While we address the individual criteria below, it is important that the criteria be considered holistically as well as practically.

Benefit

1. BROADENING THE DEFINITION OF 'BENEFIT'

The benefit criterion is too narrow and vague. It requires broadening to include other types of research, focus areas, and clarity regarding timeframes for – and type of – research impact.

Benefit is described as "demonstrated by addressing an **important public health issue** for Aboriginal and Torres Strait Islander peoples."[6] This narrow definition of Indigenous health issues excludes some of the areas to which research funding is flowing. The 2022 NHMRC Aboriginal and Torres Strait Islander Report Card of Achievements shows that half of research funding goes to areas that are not public health:[7]

- Basic science – 2.9%
- Clinical and medical science – 25.9%

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[5] Lowitja Institute, forthcoming, *Ethics in Aboriginal and Torres Strait Islander health research*, Lowitja Institute, Melbourne.

[6] National Health and Medical Research Council, *Indigenous Research Excellence Criteria (IREC) Review – Discussion Paper*. Accessed on 21 September 2023 at https://www.nhmrc.gov.au/about-us/publications/indigenous-research-excellence-criteria-irec-review-discussion-paper.

[7] National Health and Medical Research Council, 2022, *2022 NHMRC Aboriginal and Torres Strait Islander Report Card of Achievements*. Accessed on 14 September 2023 at https://www.nhmrc.gov.au/aboriginal-and-torres-strait-islander-report-card-achievements-2022.

- Health Services Research – 21.2%
- Public Health – 50%

The distribution of research funding requires benefit to be assessed against all four areas. There is a body of evidence recommending that funding be directed to improve the quality and use of clinical treatments for Aboriginal and Torres Strait Islander peoples. Lowitja Institute supports increasing funding to these additional areas of research, which are appropriate and needed.

An unintended consequence of limiting the benefit to public health research is that this risks reducing Aboriginal and Torres Strait Islander academics and the communities that they seek to work with to public health issues. This in effect would create a barrier to the career opportunities and development of our health and medical researchers, who wish to undertake clinical and medical research.

The second part of the descriptor for 'benefit' states, "This benefit can have a single focus or affect several areas, such as knowledge, finance and policy or quality of life. The benefit may be direct and immediate, or it can be indirect, gradual, and considered."[8]

Whilst this is not an exhaustive list of focus areas for benefit, the list can be read too narrowly and exclude other benefits for communities. For example, a research project may benefit the political determinants of wellbeing[9] as experienced by the participating community or communities. Research findings may be used to enable communities to advocate more effectively in political settings or for further research in line with their priorities and goals.

The connections made between the core value of equity in the Ethical Guidelines and the concept of benefit is a good base for reflection. As stated in the Ethical Guidelines, the distribution of benefit in research is a fundamental test of equity in a mutually beneficial relationship. Equity is reflected in ensuring "the fair and reasonable distribution of benefit for Aboriginal and Torres Strait Islander people and communities to achieve equity in economic, legal, social and health status[…] Some benefits may not relate to the research project in

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[8] National Health and Medical Research Council, *Indigenous Research Excellence Criteria (IREC) Review – Discussion Paper*. Accessed on 21 September 2023 at https://www.nhmrc.gov.au/about-us/publications/indigenous-research-excellence-criteria-irec-review-discussion-paper.

[9] Rigney, D, et al., 2022, *Indigenous Nation Building and the Political Determinants of Health and Wellbeing – Discussion Paper*, Lowitja Institute, Melbourne), pp. 5–6. Accessed 18 September 2023 at https://www.lowitja.org.au/content/Document/LI_IndNatBuild_DiscPaper_0822.pdf

question."[10] This is much broader than the benefit criterion and it would include political benefits as an unintended but beneficial consequence of research.

2. EMPOWERING COMMUNITIES TO DECIDE WHAT BENEFIT MEANS TO THEM

It is important that communities are actively involved in determining the potential benefits of a research project. It states in the Ethical Guidelines under the core value of reciprocity that,

> *[Reciprocity is reflected through] Ensuring Aboriginal and Torres Strait Islander people and communities have the right to define benefits according to their own values and priorities and may place greater or lesser value on the various returns than do researchers and others. Benefit in this context describes the establishment or enhancement of capacities, opportunities or outcomes that advance the interests of Aboriginal and Torres Strait Islander Peoples and communities.*[11]

This connects directly with the context provided in our general preamble to this submission. Our peoples and communities will often have vastly different priorities and values to researchers, especially when researchers do not come from the community or communities in question. Aboriginal and Torres Strait Islander peoples have the *right* to define benefits – when this occurs, it ensures more appropriate, targeted, and effective research. Aboriginal and Torres Strait Islander involvement will solve the problem of how to measure benefit, which is a pertinent ongoing challenge for researchers. It is therefore vital that this is reflected in the criteria.

Lowitja Institute advocates strongly for all research relating to Aboriginal and Torres Strait Islander people to include community engagement **and knowledge translation**. Knowledge translation is a reciprocal process that combines Indigenous people's experiential wisdom with academic research.[12]

> *Knowledge translation is the complex series of interactions between knowledge holders, knowledge producers and*

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[10] National Health and Medical Research Council, 2018. *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*, Commonwealth of Australia, Canberra, p. 6.

[11] National Health and Medical Research Council, 2018. *Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders*, Commonwealth of Australia, Canberra, p. 7.

[12] Williams, M. 2021, *Profiling Excellence: Indigenous Knowledge Translation*, Lowitja Institute, Melbourne, p. 8.

> *knowledge users, with the goal of achieving research impact, which we define as positive and sustainable long-term benefit for Aboriginal and Torres Strait Islander peoples, beyond the realm of academia.*[13]

As noted in a Lowitja Institute anthology paper edited by Dr Megan Williams, *Profiling Excellence: Indigenous Knowledge Translation*, it is rare that both activities are funded by government bodies such as the NHMRC.[14]

3. DOES THE BURDEN OUTWEIGH THE BENEFIT?

Another key consideration is that where there is benefit, this can be outweighed by the potential harm or burden on the community and/or the researcher(s). This concept is articulated in the National Statement,[15] although 'risk' is defined in Section 2 as not including a 'burden'.

While the draft revised Section 4 includes the same definitions of the key terms, 'benefit', 'risk' and 'burden' and differentiates 'burden' from 'risk', section 4.7.8 states that "design of research should take account of risks, burdens and benefits of the research with reference to Chapter 2.1 of the National Statement." This is a positive step. While Section 2.1 does acknowledge burden as a factor to consider, it also explicitly notes that "neither burden nor inconvenience should be considered a type of harm or discomfort and therefore should not be viewed as a risk". The concern here is that the implication is that burdens will be downgraded in their significance as opposed to risks.

Omitting burdens as a key consideration is problematic because it can negate time and resourcing as significant barriers to appropriate, adequate, and well-targeted research – and therefore to the career development of Aboriginal and Torres Strait Islander researchers. Excluding burden from this ethical assessment about benefit ignores the wider socio-economic context resulting from colonisation.

Many of the ethical requirements for research are predicated on a model that requires significant time and resources to be invested in the process of the research grant application. However, this does not reflect the reality, which is that academics and Aboriginal and Torres Strait Islander communities are

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[13] Williams, M. 2021, *Profiling Excellence: Indigenous Knowledge Translation*, Lowitja Institute, Melbourne, p. 8.

[14] Williams, M. 2021, *Profiling Excellence: Indigenous Knowledge Translation*, Lowitja Institute, Melbourne, pp. 9-10.

[15] National Health and Medical Research Council, 2023, *National Statement on Ethical Conduct in Human Research 2023*, National Health and Medical Research Council, Canberra, pp. 12-15.

generally time-poor and under-resourced. Academics have full teaching loads, onerous marking requirements, committee work, journal reviewing responsibilities, and often supervise PhD candidates. The NHMRC research system generally requires researchers to have a funded fellowship, the success rate being 15.9% in 2022.[16] With this limited success rate, researchers are still required to have a top-up salary from their university. Funding is not sufficient to cover ethical research practice requirements, including relationship building, knowledge translation and impact, this is often unfunded.

Limited funding also means that most successful grant applicants cannot afford to employ the number of full-time equivalent research assistants that are needed for extensive consultations and community engagement. Further, an Aboriginal and Torres Strait Islander research assistant is employed, they may require training and additional support due to limited pathways for our early career researchers. There is no infrastructure to support hiring and developing Research Assistants, but employing undergraduate and Aboriginal Higher Degree Research students is an important part of capability building. There is no NHMRC impact metrics to support grant applications that takes this into account.

Consequently, funded researchers are often placed under considerable duress. Full time academics need to squeeze their research in around their other mandatory activities and have reduced capacity to commit a large amount of time to conduct the research to its highest level of quality and benefit to Aboriginal and Torres Strait Islander communities. This is even more acute for Aboriginal and Torres Strait Islander academics who have additional community and cultural responsibilities and community accountability in their research practice.

As noted, the issue of burden on researchers is also a key factor in applying for grants, given that application processes are often onerous and required within inadequate timeframes. Too frequently, academics do not have adequate time and resources to engage at length with communities on the question of benefit, or to decide on research questions through a collaborative process grounded in cultural protocols. This is a huge hindrance to Aboriginal and Torres Strait Islander research and researcher development and empowering communities to exercise self-determination.

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[16] National Health and Medical Research Council, 2022, Investigator Grants 2022 Outcomes Factsheet. Accessed on 21 September at https://www.nhmrc.gov.au/sites/default/files/documents/attachments/Investigator_Grants_2022_Outcomes_Factsheet_updated%20%281%29_0.pdf

Further, a researcher's track record for community research does not align with grant requirements; whether they have engaged ethically with communities is not a metric of success.

Such compressed timeframes also undermine free, prior, and informed consent. *Keeping Research on track II: A companion document to Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders (Keeping Research on Track)* aims to connect the Ethical Guidelines with the National Statement. The document notes that for Aboriginal and Torres Strait Islander research, both individual **and community** consent may be required.[17] Without adequate time to have preliminary conversations with community about research, there cannot be genuine community-level consent, as "adequate understanding of the purpose, methods, demands, any risks, and potential benefits of the proposed research" is required.[18]

Considering the above, we recommend that the benefit criterion be revised to ensure that it aligns with the Ethical Guidelines and the reality of research funding distribution, and to enable communities to determine what benefit means to them.

Community engagement

'Community engagement' is defined in the IREC as: "The proposal demonstrates how the research and potential outcomes are a priority for Aboriginal and Torres Strait Islander communities with relevant community engagement by individuals, communities and/or organisations in conceptualisation, development and approval, data collection and management, analysis, report writing and dissemination of results."[19]

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[17] National Health and Medical Research Council, 2023. *Keeping Research on track II: A companion document to Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders,* National Health and Medical Research Council, Canberra, pp. 9-10.

[18] National Health and Medical Research Council, 2023. *Keeping Research on track II: A companion document to Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders,* National Health and Medical Research Council, Canberra, p. 10.

[19] National Health and Medical Research Council, *Indigenous Research Excellence Criteria (IREC) Review – Discussion Paper*. Accessed on 21 September 2023 at https://www.nhmrc.gov.au/about-us/publications/indigenous-research-excellence-criteria-irec-review-discussion-paper.

The accompanying documents – the Ethical Guidelines, Keeping research on track II, and the National Statement – only make fleeting and undefined references to "engagement". In the National Statement, there are ethical requirements of 'meaningful engagement',[20] 'respectful engagement', and 'active engagement' with our peoples[21]. None of these terms are defined in the document. In the proposed revised National Statement Section 4 more guidance is provided. Under 4.7.2. 'meaningful and respectful engagement' is said to include a research engagement, or a process in which there are meetings between potential participants and communities.

The revised Section 4 refers to the *AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research*. This document provides slightly more guidance, noting that "engagement is different from consultation and, importantly, includes building relationships of trust from which respect and the integrity of the research can flow"[22] The *AIATSIS A guide to applying: the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research (AIATIS Code of Ethics Guide)* includes some partnership options and conceptualises the difference between consultation and engagement along the spectrum of inform to collaborate.

The AIATSIS Code of Ethics Guide also includes some ways to ensure that participation is meaningful, including employing an Aboriginal and Torres Strait Islander project staff, forming an Aboriginal and Torres Strait Islander Advisory committee, or seeking involvement from Aboriginal and Torres Strait Islander Organisations. However, in practice this requires resources and funding, which are often not available to researchers. The AIATIS Code of Ethics includes ongoing Indigenous governance under Responsibilities at 4.3, which Lowitja Institute endorses as a vital component of ethical research practices.

In Keeping research on track II, engagement is not mentioned at all, except for a link to the National Museum of Australia's Indigenous cultural rights and engagement policy in the refences; the link to this policy as of 14 September 2023 is broken. The ethical guidelines refer to equitable and respectful engagement as part of reciprocity[23] and notes that engagement is as important as scientific rigour and is part of the core value of respect and is a key part of

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[20] National Health and Medical Research Council, 2023, *National Statement on Ethical Conduct in Human Research 2023*, National Health and Medical Research Council, Canberra, p. 24.

[21] National Health and Medical Research Council, 2023, *National Statement on Ethical Conduct in Human Research 2023*, National Health and Medical Research Council, Canberra, p. 81.

[22] Australian Institute of Aboriginal and Torres Strait Islander Studies, 2020. AITSIS Code of Ethics for Aboriginal and Torres Strait Islander Research, Canberra, p. 12

[23] National Health and Medical Research Council, 2023, *National Statement on Ethical Conduct in Human Research 2023*, National Health and Medical Research Council, Canberra, p. 7.

ensuring the necessary conditions for consent.[24] The document also refers to the National Museum's policy. Again, none of these terms are defined.

It is therefore unclear how the criterion of 'community engagement' is to be assessed when there is no guidance on what 'relevant community engagement' is. The vagueness around what is expected in engagement is reflected on the ground and is a significant issue for research.

The 'eight steps of the research journey' in Keeping research on track ii gives some indication of expectations around process.[25] In this table, the first step outlined is building relationships. However, even this stage in practice requires a huge amount of time and resourcing. While not directly related to the criteria, it is important to understand the on the ground experience of researchers and communities because a criterion that is impossible to satisfy is not a useful criterion.

One difficulty on the ground for researchers, which connects to the consent issue above, is that to properly inform people of research they need to have base knowledge. This is not something that communities will necessarily have, and engaging with communities and building trust takes time. Some communities or people who should be engaged with in designing the research project will not want researchers coming in. It is therefore important and necessary to be funding Aboriginal and Torres Strait Islander researchers to undertake research. However, there is a perception that our researchers have differing capabilities and need capability building but what constitutes capacity building is unclear.

There is also no funding available for communities to conduct their own research, nor do they receive investments aligned with Universities such as the National Competitive Research Grants Program and Research Block Grant funding.[26] Further, when engagement happens, researchers need to make sure that they are engaging with all parts of the community so that they don't miss out on hearing from important knowledge-holders. This is acknowledged in the AIATSIS Code of Ethics Guide:

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[24] National Health and Medical Research Council, 2023, *National Statement on Ethical Conduct in Human Research 2023*, National Health and Medical Research Council, Canberra, p. 9.

[25] National Health and Medical Research Council, 2023. *Keeping Research on track II: A companion document to Ethical conduct in research with Aboriginal and Torres Strait Islander Peoples and communities: Guidelines for researchers and stakeholders,* National Health and Medical Research Council, Canberra, p. 18.

[26] Upholding our rights in research: calling for urgent investment in Aboriginal and Torres Strait Islander health research ethics | The Medical Journal of Australia (mja.com.au)

> *Aboriginal and Torres Strait Islander worldviews and Western worldviews differ on the origins of authority. While authority in Western systems is given through roles and bureaucracy, authority in Aboriginal and Torres Strait Islander communities is based on age, cultural knowledge, and relationships. In many Aboriginal and Torres Strait Islander cultures, Elders — as distinct from others who may hold specific offices or jobs — are the bosses. The process of decolonising research includes recognising and honouring the role and status of Elders in Aboriginal and Torres Strait Islander culture and putting them at the centre of the research process.*[27]

It is important to ensure that the diverse views within communities as to what the ethics of a research project are and what the potential benefit is are heard. This is noted in the AITSIS Code of Ethics Guide: "it will be important for you to recognise the diversity of Indigenous communities, to consult widely and where possible to have Indigenous leadership and/or researchers directly engaged on the project."[28] **We recommend exchanging the 'community engagement' criterion for a criterion that assesses 'Aboriginal and Torres Strait Islander leadership and governance'.**

4. CONTRADICTION BETWEEN COMMUNITIES' PRIORITIES AND THE NATIONAL RESEARCH PRIORITIES

Lowitja Institute **strongly recommends that the national research priorities in Aboriginal and Torres Strait Islander health be reviewed to give effect to the IREC**. Currently they are in opposition with the national priorities being set by government and the NHMRC. The IREC, the national statement of ethics and the AIATSIS ethical guidelines specify developing research in consultation and engagement with Aboriginal and Torres Strait Islander communities. However, research determined by communities are made to fit national priorities so that researchers can source funding for projects. These competing priorities are not risk adverse as they create tension and a burden for researchers and communities in managing expectations of the research process and outcomes.

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[27] Australian Institute of Aboriginal and Torres Strait Islander Studies, 2020, *A guide to applying: The AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research*, AITSIS, Canberra, pp. 5-6.
[28] Australian Institute of Aboriginal and Torres Strait Islander Studies, 2020, *A guide to applying: The AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research*, AITSIS, Canberra, p. 9.

This consultation process is a sound example of the issue of priority setting not being Aboriginal and Torres Strait Islander community led. Lowitja Institute was not actively involved in the process. This is despite our relevant expertise as a National Aboriginal and Torres Strait Islander community controlled health research institute. Lowitja Institute was recently engaged by MTPConnect to facilitate the needs assessment process to determine the Indigenous-specific priority areas for research into D&CVD in Round 3 of the Targeted Translation Research Accelerator Program.[29] Lowitja Institute developed a prioritisation framework that was based on a literature review and a roundtable with a broad range of relevant Aboriginal and Torres Strait Islander stakeholders, with positive results. [30] **We recommend that future NHMRC consultation processes engage more meaningfully and actively with Lowitja Institute.**

Further, these processes enable non-Indigenous experts to set the research priorities. Part of Lowitja Institute's core business is developing research priorities and an agenda determined by Aboriginal and Torres Strait Islander peoples.[31] We administer seeding and major grants to Aboriginal and Torres Strait Islander researchers based on this self-determined research agenda. We know that priorities determined by our people for our people lead to effective and empowering research outcomes. **We recommend that consultations regarding our peoples' research priorities should engage only Aboriginal and Torres Strait Islander peoples.**

Building capability

Regarding the building capability criterion, it is noted in the Ethical Guidelines that ethical research with Aboriginal and Torres Strait Islander peoples should "develop and/or strengthen research capabilities of Aboriginal and Torres Strait Islander people and their communities."[32] This is narrower than the criterion, which requires demonstration of how "communities and researchers will develop

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[29] Lowitja Institute, 2023, *Targeted Translation Research Accelerator Needs Assessment and Prioritisation Project*, Lowitja Institute, Melbourne.

[30] Lowitja Institute, 2023, *Targeted Translation Research Accelerator Needs Assessment and Prioritisation Project*, Lowitja Institute, Melbourne.

[31] Lowitja Institute, *Research Agenda 2019-2023*. Accessed on 21 September 2023 at https://www.lowitja.org.au/page/research/research-agenda-2019-2023.

[32] Australian Institute of Aboriginal and Torres Strait Islander Studies, 2020. AITSIS Code of Ethics for Aboriginal and Torres Strait Islander Research, Canberra, p. 1.

relevant capabilities through partnership and participation in the project"[33] (emphasis added).

The National Statement includes guideline 4.7.7 that the "benefits from research should include the enhancement or establishment of capabilities, opportunities or research outcomes that advance the interests of Aboriginal and Torres Strait Islander Peoples."[34] While recognising its importance, none of the related documents – Ethical Guidelines, Keeping research on track ii, nor the National Statement – further define what capability building should look like or how to assess this component.

Regarding the criterion itself, the question remains, what are relevant capabilities? Relevant to whom? How is this measured? And, as noted above, what is partnership and participation look like? Capability building requirements will vary depending on the cohort, so the question of relevance will be contingent on this and there is nuance. Academics require different capability building depending on what stage in their career they are at. The capability building required for that cohort also differs compared to community, and government-sponsored research. This is why proper engagement in the initial stages is so important.

Another important consideration is looking beyond which capabilities need development to consider how they are to be developed to ensure efficacy of proposed approach. For example, in Lowitja Institute's *Further Strengthening Research Capabilities: A review and analysis of the Aboriginal and Torres Strait Islander health researcher workforce*, it was found that cohort-driven research training models are effective and should be prioritised.[35] Peer to peer learning via peer networks was also found to be key. The paper includes an Integrated Research Capability Strengthening Framework.[36] We encourage the NHMRC to

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[33] National Health and Medical Research Council, *Indigenous Research Excellence Criteria (IREC) Review – Discussion Paper*. Accessed on 21 September 2023 at https://www.nhmrc.gov.au/about-us/publications/indigenous-research-excellence-criteria-irec-review-discussion-paper.

[34] National Health and Medical Research Council, 2023, *National Statement on Ethical Conduct in Human Research 2023*, National Health and Medical Research Council, Canberra, p. 81.

[35] Ewen, S., Ryan, T. & Platania-Phung, C. 2019, *Further Strengthening Research Capabilities: A review and analysis of the Aboriginal and Torres Strait Islander health researcher workforce*, The Lowitja Institute, Melbourne, p. 8.

[36] Ewen, S., Ryan, T. & Platania-Phung, C. 2019, *Further Strengthening Research Capabilities: A review and analysis of the Aboriginal and Torres Strait Islander health researcher workforce*, The Lowitja Institute, Melbourne, pp. 37-29.

refer to this framework, in particular the action-based principles[37] that were seen as key to its efficacy and incorporate these into the National Statement.

Further, there is no place to include what the potential capability development of the project is in the NHMRC ethics application form. This would be a useful addition and helpful in assessing applications.

We suggest broadening the criteria beyond capability to ‘capacity’. As outlined above, capacity is also a key factor that impacts on research and can be a barrier. Key factors that need to specifically align with the budget include:

- Time available
- Staffing and resources
- Equipment or database needs
- Analytical tools available

These also need to be sustainable and transferable to mitigate risk if people holding certain skills or resources move away.

Sustainability and transferability

This criterion relates to cost effectiveness and impact on policy and practice. It requires knowledge translation, as defined above. However, the sustainability and transferability criterion are vague. It is unclear how what is considered achievable and effective is to be determined. There is little guidance in the related documents. As noted in the descriptor, this criterion also ties into benefits. For example, a political benefit to a project can go towards ensuring sustainable health benefits in a community. Sustainability and transferability require further ongoing resourcing.

The AIATSIS Code of Ethics Guide recognises the National Agreement on Closing the Gap and the Uluru Statement from the Heart as national priority setting exercises, and the connection between ethical research and these priorities is worth noting.[38] **We recommend including within the criteria that the research project has to demonstrate potential to contribute to improving Aboriginal and Torres Strait Islander health outcomes relating to the socioeconomic targets**

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[37] Ewen, S., Ryan, T. & Platania-Phung, C. 2019, *Further Strengthening Research Capabilities: A review and analysis of the Aboriginal and Torres Strait Islander health researcher workforce*, The Lowitja Institute, Melbourne, pp. 39.

[38] Australian Institute of Aboriginal and Torres Strait Islander Studies, 2020, *A guide to applying: The AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research*, AITSIS, Canberra, p. 5.

under the National Agreement on Closing the Gap. We also advise that specific details regarding knowledge translation be required.

Question 2: Is the 20% threshold still appropriate and relevant?

The 20 per cent threshold is insufficient. This is because all research on Aboriginal and Torres Strait Islander lands will affect our peoples. **We recommend that all research be required to address the IREC.**

Question 3: How can we ensure a rigorous peer review process using the IREC? For example, should consideration of the four IREC criteria be aligned to scoring of application assessment criteria?

There have been calls for a National Aboriginal and Torres Strait Islander Health Research Ethics Committee since 1987, and Lowitja Institute has been calling for its establishment since 2012. Greater detail on the history and reasons for this will be outlined in the forthcoming discussion paper.[39] Lowitja Institute was recently successful in securing funding for this purpose. This can support the NHMRC in refining their practices through strong partnership.[40]

In sum, the current ethics approval process is ineffective, overly complex, and does not adequately consider nor centre Aboriginal and Torres Strait Islander peoples. It is a system that has been designed on the assumption that research is being conducted by non-Indigenous peoples on a foundation of Western paradigms. It does not adequately respond to the complexities and diversity of our communities. (Some of these matters have been discussed in more detail above.) This means that without Aboriginal and Torres Strait Islander peoples being responsible for and leading the ethics review process, it will continue to fall

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[39] Lowitja Institute, forthcoming, *Ethics in Aboriginal and Torres Strait Islander health research,* Lowitja Institute, Melbourne.

[40] Kennedy, M., & Mohamed, J, 2023, 'Upholding our rights in research: calling for urgent investment in Aboriginal and Torres Strait Islander health research ethics', *Medical Journal of Australia,* vol. 219, no. 1. Accessed on 21 September 2023 at https://www.mja.com.au/journal/2023/219/1/upholding-our-rights-research-calling-urgent-investment-aboriginal-and-torres.

short of our needs and be a barrier to our peoples' health research – and ultimately, therefore, a barrier to our health and wellbeing.

We note that the IREC is weighted in the assessment metrics and peer reviewed and scored using a panel, not just individuals. While for Aboriginal and Torres Strait Islander academics, there needs to be an exploration of conflicts of interest, this should not limit peer reviewing. We suggest blind reviewing could be applied to the IREC to solve this issue.

Further, the IREC should advise applicants that it is a stand-alone assessment. Some applicants will not realise that they need to include all details if they have included there elsewhere in the application. This means that vital information may be omitted.

Given the various commitments and ethical requirements of research in Aboriginal and Torres Strait Islander health we believe the IREC criteria should be an integral part of the assessment criteria for NHMRC grant funding. To not include the criteria as part of assessment is a negation of the ethical guidelines stipulated in numerous documents including those of the NHMRC.

Question 4: Is there anything else you'd like to tell us? For example, are there other models that you strongly favour?

Another important consideration is cultural and intellectual property. This isn't included or addressed in the IREC, nor by the National Statement, which leaves researchers to tackle complicated questions alone. This includes questions such as, what can a researcher do with research when it is completed? How will intellectual property disputes be resolved between community members? When the researcher is themselves an Aboriginal or Torres Strait Islander person and community member this adds a level of complexity. The supporting documents are written with an assumption that the researcher is non-Indigenous and there is no guidance on this.

The Ethical Guidelines do note the complexity inherent in considering property rights in research and encourages researchers, participants, and communities to seek further advice from "appropriate professionals in this field".[41] When time and resources are limited (as written above), how are research project stakeholders supposed to access such legal advice? While University supported

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[41] National Health and Medical Research Council, 2023, *National Statement on Ethical Conduct in Human Research 2023*, National Health and Medical Research Council, Canberra, p. 18.

researchers will be able to access advice through the University, this is especially difficult for participants and communities. This creates an unequal power dynamic.

We recommend that Indigenous intellectual property be addressed within the benefit criteria; this would also ensure that the risks to intellectual property and the burdens that consideration of intellectual property puts on community are considered and are compliant with the Nagoya Protocol on Access and Benefit Sharing.

We also recommend greater investment in Lowitja Institute. In 1987, Aboriginal and Torres Strait Islander peoples called for Aboriginal and Torres Strait Islander community control over research funding, but this has not eventuated**. We recommend that the NHMRC strengthen their partnership with Lowitja Institute**.