IUIH institute for urban indigenous health

31st May 2024

To Whom It May Concern
National Health and Medical Research Council (NHMRC) &
Consumers Health Forum of Australia Ltd (CHF)

BY EMAIL ONLY: priorities@nhmrc.gov.au

To Whom It May Concern:

Thank you for inviting submissions on the **Review of the *Statement on Consumer and Community Involvement in Health and Medical Research 2016*.**

The Institute for Urban Indigenous Health (IUIH) is the regional Aboriginal and Torres Strait Islander Community Controlled Health Organisation (ATSICCHO) for South East Queensland (SEQ), and the "backbone" organisation in a network of SEQ ATSICCHOs. Through the IUIH Network, we provide to our growing region comprehensive primary health care, aged care, disability support and social support services, including housing support, legal services and family and youth wellbeing programs.

As an MRFF Eligible Organisation, and with a highly experienced Aboriginal and Torres Strait Islander health research team, IUIH is well placed to make recommendations and comment on the Review of the Statement on Consumer and Community Involvement in Health and Medical Research 2016.

I am pleased to enclose a copy of our submission for your consideration. If you require any further information, please contact policy@iuih.org.au.

Yours sincerely,

CARMEL NELSON

Executive Director – Clinical Leadership

Encl. *IUIH submission on the* ***Review of the Statement on Consumer and Community Involvement in Health and Medical Research 2016*.**

Institute for Urban Indigenous Health (IUIH)

Submission to the Review of the *Statement on Consumer and Community Involvement in Health and Medical Research 2016*

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About the IUIH Network

The Institute for Urban Indigenous Health Ltd (IUIH) is a not-for-profit Aboriginal and Torres Strait Islander Community Controlled Health Service that leads regional-level service planning, development, and delivery of health and social support services for Aboriginal and Torres Strait Islander people in the Southeast Queensland (SEQ) region.

IUIH was established in 2009 by its four founding Member Organisations:

- Aboriginal and Torres Strait Islander Community Health Service (ATSICHS) Brisbane Limited
- Kalwun Development Corporation Limited (Kalwun Health Service)
- Kambu Aboriginal and Torres Strait Islander Corporation for Health
- Yulu-Burri-Ba Aboriginal Corporation for Community Health

Since then, IUIH has established the Moreton Aboriginal and Torres Strait Islander Community Health Service. Together these entities comprise the IUIH Network.

The IUIH Network provides integrated health and social services to one of Australia's largest and fastest-growing Indigenous regions. SEQ is home to around 41% of Queensland's and nearly 12% of Australia's Indigenous population. Since 2011, the IUIH Network footprint population has dramatically increased from 59,483 people to an estimated population of 129,224 in 2023.[1] The IUIH Network organisations provide care to around 40,000 regular Indigenous clients in SEQ through 19 community-controlled clinics (see Figure 1).

The IUIH Network aims to achieve family wellness through a one-stop-shop model of integrated health and social support services for Aboriginal and Torres Strait Islander families, known as the IUIH System of Care (ISoC).

At IUIH, as well as providing 'backbone' functions for the Network, we deliver a range of health and social support services to the region, including, but not limited to, specialist medical and allied health services, aged care and disability supports, legal services, our Mob Link virtual care and care coordination service, and a Prison Transition Support Service for adults.

The IUIH Network organisations deliver a comprehensive range of services to their local communities including, but not limited to, primary care, Family Wellbeing Services, kindies, youth programs, and child protection services.

These services are all connected and supported through the ISoC.

Figure 1 The IUIH Network

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[1] IUIH estimated population projections based on 2021 Census data for the IUIH catchment.

Recommendation 1: The revised Consumer Statement should expressly identify and make central Aboriginal and Torres Strait Islander consumers, community members and stakeholders as Australia's First People. The revised Consumer Statement should emphasize our right to self-determination as it applies to community leadership and involvement in all health and medical research about us and from us.

Recommendation 2: Aboriginal and Torres Strait Islander consumer and community 'involvement' in health and medical research about us and from us is a substandard and deficient approach. Aboriginal and Torres Strait Islander people, including Aboriginal and Torres Strait Islander Community-Controlled Health Organisations (ATSICCHOs), must be part of all research facets (including research governance and funding decisions) to ensure Indigenous health and medical research is led by us and advances our rights to self-determination and Indigenous Data Sovereignty.

Recommendation 3: Our community are the experts on Aboriginal and Torres Strait Islander health and wellbeing, and how research should be optimally and respectfully conducted according to Aboriginal and Torres Strait Islander Ways of Knowing, Being and Doing. Aboriginal and Torres Strait Islander peoples' leadership is crucial in building broader Indigenous community trust in health and medical research endeavours to maximise transformative research outcomes and impact.

Recommendation 4: It is essential to ground the revised Consumer Statement in the Australian Government's commitments to achieving Aboriginal and Torres Strait Islander Health Equity and to the Australian Government's obligations under international right to health law as highlighted by the Government in its draft resolution on the Health of Indigenous Peoples unanimously adopted at the World Health Assembly in 2023.

Recommendation 5: That the revised Consumer Statement include and apply the principles of Indigenous Self-Determination, Indigenous Leadership, Impact and Value, Sustainability and Accountability, Spirit and Integrity, Reciprocity, Respect, Equality, Survival and Protection, and Responsibility in the context of Indigenous health and medical research**.**

Recommendation 6: That the revised Consumer Statement highlights the central leadership role that Aboriginal and Torres Strait Islander Community-Controlled Organisations (ATSICCHOs), and Aboriginal and Torres Strait Islander consumers and community members must play in all facets of Indigenous health and medical research.

Recommendation 7: That the revised Consumer Statement emphasises the research leadership, governance and ownership roles and responsibilities that our ATSICCHOs and community members must play in the transparent and accountable conduct of Indigenous health and medical research.

Recommendation 8: That the leadership (not 'involvement') of ATSICCHOs and our consumers and community members should be an expectation of health and medical research about us and from us. This includes Aboriginal and Torres Strait Islander health and medical quantitative research that uses large population datasets.

Recommendation 9: IUIH recommends that established research institutions, such as Australian universities, have a role and responsibility in decolonising research, ceding power, and proactively supporting the sustainable establishment of community-controlled research institutions and organisations as leaders of Aboriginal and Torres Strait Islander health and medical research in this country.

Recommendation 10: That the Department of Health creates new Personnel Support Packages on NHMRC and MRFF grant programs that appropriately and respectfully recognise and reward the rich expertise, knowledge, skills and networks that Aboriginal and Torres Strait Islander consumers, community members, and staff from ATSICCHOs bring to Indigenous health and medical research.

Recommendation 11: That the Department of Health amends its NHMRC and MRFF grant guidelines relating to Indigenous health and medical research to appropriately and respectfully remunerate Aboriginal and Torres Strait Islander consumers, community members, and staff from ATSICCHOs who generously agree to hold Associate Investigator roles on NHMRC and MRFF research projects.

Recommendation 12: That the Department of Health review the indirect research costs that the Department will currently not fund under the NHMRC and MRFF grant schemes pertaining to Indigenous health and medical research, with a view to fund Aboriginal and Torres Strait Islander consumers, community members and staff of ATSICCHOs to attend and participate in (for example) conferences and other research capability and capability strengthening activities in Australia and overseas.

Recommendation 13: That NHMRC and MRFF grant schemes fund Open Access publications on all Indigenous-led health and medical research projects.

Recommendation 14: In the context of Aboriginal and Torres Strait Islander health and medical research, IUIH recommends that funders such as the NHMRC and MRFF mandate the leadership of Aboriginal and Torres Strait Islander researchers, including ATSICCHOs and our community representatives, in funded research. This is consistent with the principles of Indigenous Self-Determination and our right to self-determination (including in research contexts), Indigenous Leadership, and Indigenous Data Sovereignty.

Background & context to IUIH's submission to the Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research

We thank the National Health and Medical Research Council (NHMRC) and the Consumers Health Forum of Australia Ltd (CHF) for the opportunity to respond to their joint Position Paper on the Review of the *Statement on Consumer and Community Involvement in Health and Medical Research 2016.* We understand that the intention of a revised Consumer Statement is "to provide an opportunity to streamline and refocus it as a high-level national statement", and that the revised Consumer Statement "is not intended to be tied to specific detail but rather offer guidance on actions and concepts that promote and strengthen consumer and community involvement".[2] We also note that for the purpose of the Position Paper -

The people who are referred to using the terms 'community', community member', 'consumer', 'stakeholder', 'patient' are as diverse as the Australian population in terms of gender, sexual orientation, age, socio economic status, physical abilities and religious beliefs.[3]

As one of Australia's largest Aboriginal and Torres Strait Islander Community Controlled Health Organisations (ATSICCHOs) that has a multidisciplinary, vibrant, and growing research team, the framing of the NHMRC and CHF Position Paper – and the Consumer Statement from 2016 – are of concern in terms of their lack of respectful Acknowledgement of Australia's First People who have resided on the Australian continent for over 2,000 generations: since Time Immemorial.

Indeed, the above statement quoted from the Position Paper makes no explicit mention of Aboriginal and/or Torres Strait Islander people, or of race or ethnic origin. Aboriginal and Torres Strait Islander people are not "specific issues that would be addressed in an implementation context", which might lead to the avoidance of express and substantive focus on First Nations peoples in Position Paper responses and in the revised Consumer Statement. Considering the unconscionable health and wellbeing gap in life expectancy experienced by Aboriginal and Torres Strait Islander people in comparison to their non-Indigenous counterpart, and that NHMRC funded research must and will continue to play an integral role in providing evidence to Close that Gap, it is incumbent that there is affirmative and special focus on Aboriginal and Torres Strait Islander peoples and communities within a revised Statement on Consumer and Community Involvement in Health and Medical Research. This is especially the case if, in conducting their review, the NHMRC and CHF meaningfully intend to ensure that the revised high-level document is "to maintain its relevancy and currency".[4]

Therefore, we make this submission with reference to the following documents:

- **AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research** and the **principles** contained therein –
    - **Indigenous Self-Determination**
    - **Indigenous Leadership**
    - **Impact and Value**
    - **Sustainability and Accountability in research.**
- **AIATSIS Keeping Research on Track: A guide for Aboriginal and Torres Strait Islander Peoples about**

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[2] NHMRC (2024) Review of the Statement on Consumer and Community Involvement in Health and Medical Research 2016 | Position Paper at page 2.
[3] Ibid at page 3.
[4] Ibid at page 2.

health research ethics.
- **NHMRC Ethical conduct in research with Aboriginal and Torres Strait Islander peoples and communities: Guidelines for researchers and stakeholders, 2018** and the **principles** contained therein -
    - **Spirit & Integrity**
    - **Reciprocity**
    - **Respect**
    - **Equality**
    - **Survival and protection**
    - **Responsibility**
- **NHMRC Keeping research on track II**
- **National Closing the Gap Agreement, 2020.**

We also ground our submission responses in the authoritative content of the *UN Declaration on the Rights of Indigenous People 2008 (UNDRIP)* and *Human Rights Act 2019 (Qld)*, given IUIH is situated in what is now known as the state of Queensland.

The UNDRIP highlights the rights of Indigenous peoples, many of which directly apply to how Aboriginal and Torres Strait Islander health and medical research is designed, engaged in, conducted, *and governed.* However, it is Indigenous peoples' right to self-determination that underlines all rights set out in the UNDRIP. Sighting the Australian Code for the Responsible Conduct of Research, AIATSIS makes clear:

The right of Aboriginal and Torres Strait Islander peoples to be engaged in research that affects or is of particular significance to them is now a fundamental principle that underpins all research in Australia.[5]

In light of both the *policy onus* and *legal imperative* to advance Indigenous self-determination, leadership and autonomy, health and medical research engagement is – and the specific engagement of Indigenous consumers and our Community in research - demonstrably different to consumer 'consultation' or 'partnership'. Scientific research and the extrapolation of findings and solutions must be Indigenous led, local and place based, and rigorously supported by the evidence that includes our diverse voices and lived experiences.

Our people's health and culture are intimately intertwined, and achievement of the cultural determinants of health the key to unlocking the good health and wellbeing of our people across the life course.[6] **Therefore, Aboriginal and Torres Strait Islander people as '*community', 'community member[s]', 'consumer[s]', 'stakeholder[s]', 'patient[s]'* <u>and community-controlled health organisations</u> must be engaged in leading health and medical research that is about us and from us and the health and wellbeing of our diverse Communities**. In the Queensland context, this is implicitly enshrined in law:

Section 28(1) (Cultural rights - Aboriginal peoples and Torres Strait Islander peoples) *Human Rights Act 2019 (Qld)* reinforces – *Aboriginal peoples and Torres Strait Islander peoples hold distinct cultural rights.*

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[5] AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research (page 12). See reference 33: Australian Code for the Responsible Conduct of Research, principle 6, p.2; see also responsibility 19, p.4.

[6] Lowitja Institute (2020) Culture is Key: Towards cultural determinants-driven health policy | Final Report. Available: https://www.lowitja.org.au/wp-content/uploads/2023/06/Lowitja_CultDetReport_210421_D14_WEB.pdf

Section 28(3) - *Aboriginal peoples and Torres Strait Islander peoples have the right not to be subjected to forced assimilation or destruction of their culture.*

We should not be forced by researchers or funders to assimilate to non-Indigenous, Western research ways of 'doing' 'science' that do not respect the synergistic relationship of our culture, health, and human rights. Western ways of doing research can fail to acknowledge that many Aboriginal and Torres Strait Islander health and medical research consumers and stakeholders have a long-standing mistrust of Western research institutes, research priorities and agendas, and impacts of non-Indigenous led research conducted or 'co-designed' 'for the benefit' of Community.[7] Compounding this, many of our Community mistrust the quality and culturally safe care they'll receive in and from health services; concerns that are often grounded in ongoing experiences of direct and indirect discrimination, institutional racism, and healthcare worker racism and bias.[8] Thus, Indigenous health and medical research is often rightly perceived as a highly political activity, and to whose benefit in light of Aboriginal and Torres Strait Islander health not demonstrably improving in recent decades.[9]

Therefore, our leadership and ownership of health and medical research about us and from us is critical for Aboriginal and Torres Strait Islander people to build trust in the research endeavour and all actors and institutes involved, and for our exercise of control of the data ecosystem, which affects Indigenous Data Governance and the genuine achievement of Indigenous Data Sovereignty throughout Australia.[10]

It is our Aboriginal and Torres Strait Islander consumers and Community who are 'the experts' on our individual and collective health and wellbeing, not 'the scientists'. This is inherent to Aboriginal Ways of Knowing, Being and Doing, and our collective human right to self-determination.

Our peoples' approach to all facets of research, and the principles that underpin research, are very different to those values and principles that underpin the academy. For Aboriginal and Torres Strait Islander peoples, research urgently needs to be decolonised.

We submit the revised Consumer Statement is an important pivot point to accelerate decolonisation.

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[7] R Bainbridge, K Tsey, J McCalman et al (2015) No one's discussing the elephant in the room: contemplating questions of research impact and benefit in Aboriginal and Torres Strait Islander Australian health research. *BMC Public Health* 15:696

[8] DA Askew, W Foley, C Kirk et al (2021) "I'm outta here!": a qualitative investigation into why Aboriginal and non-Aboriginal people self-discharge form Hospital. *BMC Health Services Research* 21:907; Bourke CJ, Marrie H, Marrie A (2019) Transforming institutional racism at an Australian hospital. *Australian Health Review* 43:611-618;
Marrie A (2017) Addressing Institutional Barriers to Health Equity for Aboriginal and Torres Strait Islander People in Queensland's Public Hospital and Health Services Report. Brisbane: Anti-Discrimination Commission Queensland, 2017.

[9] K Gatwiri, D Rotumah, E Rix (2021) BlackLivesMatter in Healthcare: Racism and Implications for Health Inequity among Aboriginal and Torres Strait Islander Peoples in Australia. *International Journal of Environmental Research and Public Health* 18(9):4399.

[10] Lowitja Institute (2024) Taking Control of Our Data: A Discussion Paper on Indigenous Data Governance for Aboriginal and Torres Strait Islander People and Communities. Melbourne. Available: https://www.lowitja.org.au/wp-content/uploads/2024/01/Taking-Control-of-Our-Data-Discussion-Paper.pdf.

IUIH response to Position Paper Questions | Review of the 2016 Statement on Consumer and Community Involvement in Health and Medical Research

Question 1: What parts of the Statement have or have not worked well.

1.1 The 2016 Statement is of concern in terms of its lack of respectful Acknowledgement of Australia's First People who have resided on the Australian continent for over 2,000 generations: since Time Immemorial.

1.2 Not only does it fail to specifically highlight the critical role Aboriginal and Torres Strait Islander people must play as consumers and community members in all components of Indigenous health and medical research, but the 2016 Consumer Statement fails to highlight our community's important research leadership and ownership role in all health and medical research about us and from us, and the important role Aboriginal and Torres Strait Islander consumers must play in advancing Indigenous Data Governance and Indigenous Data Sovereignty. Apart from Community's brief mention in the Foreword about different types of health and medical research,[11] and in Appendix 2: Levels of consumer and community involvement and Appendix 4: Useful resources, the 2016 Consumer Statement is an anaesthetized document that speaks about 'the public' and 'consumers' 'working in partnership' with researchers and research organizations. It is not a statement that adequately identifies, includes, or respectfully elevates our people.

1.3 Health is political.[12] The political determinants of health wholly shape Aboriginal and Torres Strait Islander health and wellbeing, and our individual and collective experiences of health equity and health justice.[13] The right to the highest attainable standard of physical and mental health, including our peoples' access to non-discriminatory healthcare services, is our human right – it is not a 'benefit'.[14] Similarly, we are not beneficiaries of research "and advances in health care", or *ought* to be involved in research activities about us and from us.

1.4 Thus, given Aboriginal and Torres Strait Islander people and communities lack visibility and centrality in the 2016 Consumer Statement, there is a failure to acknowledge deeply entrenched power dynamics in Australian health services and systems and research projects and research institutes that impact our people. Unfortunately, in its present form, this is not a Statement that includes or is about Us and Our Way of Knowing, Being, Doing and Leading health and medical research.

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[11] "'Health and medical research' encompasses diverse activities ranging from investigation of the fundamental processes that underpin life, to discovering new ways to treat disease, characterising and preventing illness, learning how to develop and innovate health care services and determining how to close the gap in health and life expectancy between Aboriginal and Torres Strait Islander peoples and non-Indigenous Australians" Statement on Consumer and Community Involvement in Health and Medical Research (September 2016) at p.1.

[12] Bambra C, Fox D, Scott-Samuel A (2005) Towards a politics of health. *Health Promotion International* 20(2):187-193.

[13] Global Governance Project (2024) Health: A Political Choice | Advancing Indigenous peoples' rights and well-being. I Kickbusch, J Kirton & C Chamberlain (editors), London (UK): GT Media Group Ltd; Creamer S, Toombs M, Tarrago A et al (2023) More than black printed words on white paper: intergenerational health justice for Aboriginal and Torres Strait Islander peoples. In B Bennett & I Freckelton (editors) Australian public health law: contemporary issues and challenges. Alexandria: Federation Press; Bond CJ, Singh D. More than refresh required for closing the gap of Indigenous health inequality. *Medical Journal of Australia* 2020;212(5):198-199.e1

[14] A/77/197: Report by the Special Rapporteur on the right of everyone to the enjoyment of the highest attainable standard of physical and mental health – Racism and the right to health (20 July 2022). Available: https://www.ohchr.org/en/documents/thematic-reports/a77197-report-special-rapporteur-right-everyone-enjoyment-highest

Recommendation 1: The revised Consumer Statement should expressly identify and make central Aboriginal and Torres Strait Islander consumers, community members and stakeholders as Australia's First People. The revised Consumer Statement should emphasize our right to self-determination as it applies to community leadership and involvement in all health and medical research about us and from us.

Question 2 and 3: Why is consumer and community involvement research valuable; why does consumer and community involvement in research matter to you.

2-3.1 IUIH views Aboriginal and Torres Strait Islander consumer and community involvement in health and medical research about us and from us to be integral and an inherent part of our Propa Ways. However, as part of our Propa Ways, 'involvement' (as worded in the 2016 Consumer Statement) is not enough: Aboriginal and Torres Strait Islander community voice and leadership in all facets of research is crucial and a key part of our right to self-determination.

2-3.2 As an Aboriginal and Torres Strait Islander Community-Controlled Health Organisation (ATSICHHO) with a dynamic and growing research team and research agenda, and with MRFF Eligible Organisation (EO) status, IUIH advocates the importance of ATSICCHO and community leadership of health and wellbeing research about us and from us as fundamental to achieving Indigenous Data Governance, Indigenous Data Sovereignty, and the Closing the Gap agenda.

2-3.3 **Our peoples' and communities' leadership of health and medical research is crucial because we are 'the experts' on Aboriginal and Torres Strait Islander health and wellbeing.** Our leadership is highly valuable in building the trust of our community in health and medical research endeavours, and their purpose, outcomes, and impact among, for, and with our diverse peoples.

Recommendation 2: Aboriginal and Torres Strait Islander consumer and community 'involvement' in health and medical research about us and from us is a substandard and deficient approach. Aboriginal and Torres Strait Islander people, including Aboriginal and Torres Strait Islander Community-Controlled Health Organisations (ATSICCHOs), must be part of all research facets (including research governance and funding decisions) to ensure Indigenous health and medical research is led by us and advances our rights to self-determination and Indigenous Data Sovereignty.

Recommendation 3: Our community are the experts on Aboriginal and Torres Strait Islander health and wellbeing, and how research should be optimally and respectfully conducted according to Aboriginal and Torres Strait Islander Ways of Knowing, Being and Doing. Aboriginal and Torres Strait Islander peoples' leadership is crucial in building broader Indigenous community trust in health and medical research endeavours to maximise transformative research outcomes and impact.

Question 4: What overarching values are essential to include in the value statement of the revised Consumer Statement, and Why?

4.1 Consumers and community members are not created equal, nor are the health outcomes and disparities – the burden of disease and morbidity and mortality rates - experienced by different populations throughout Australia. Aboriginal and Torres Strait Islander people know this all too well. Therefore, the values that must underpin the revised Consumer Statement include a commitment to the achievement of Health Equity; specifically, the achievement of Aboriginal and Torres Strait Islander Health Equity through a human rights approach.[15]

4.2 IUIH advocates that the revised Consumer Statement's values are aligned to reflect Australia's commitments, responsibilities and obligations under international human rights law – specifically international right to health law[16], the *UN Declaration on the Rights of Indigenous People 2008,* and the World Health Assembly Resolution of May 2023 directing World Health Organization Member States like Australia to take concrete actions to improve health outcomes (that the research endeavour clearly contributes to), which are firmly grounded in the advancement of Indigenous people's human rights.[17]

Recommendation 4: It is essential to ground the revised Consumer Statement in the Australian Government's commitments to achieving Aboriginal and Torres Strait Islander Health Equity and to the Australian Government's obligations under international right to health law as highlighted by the Government in its draft resolution on the Health of Indigenous Peoples unanimously adopted at the World Health Assembly in 2023.

Question 5: The values that underpin the 2016 Statement are 'shared understanding, respect and commitment'. How might this be strengthened and improved in the revised Consumer Statement.

5.1 IUIH submits that the revised Consumer Statement will be tremendously strengthened and improved if it is not underpinned by values but by principles, as well as Australia's commitments under international human rights law as per our response to Question 4 above.

5.2 Principles are rules or laws that are permanent, unchanging, and universal in nature. In contrast, values are internal and subjective, and they may change over time. Values are ultimately malleable and subject to political whim in a settler/colonial country.

5.3 Therefore, IUIH strongly recommends that the principles contained in the AIATSIS Code of Ethics for Aboriginal and Torres Strait Islander Research and the 2018 NHMRC Ethical conduct in research with

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[15] *National Aboriginal and Torres Strait Islander Health Plan 2021-2031*. Available: https://www.health.gov.au/sites/default/files/documents/2022/06/national-aboriginal-and-torres-strait-islander-health-plan-2021-2031.pdf

[16] See Office of the High Commissioner for Human Rights. Committee on Economic, Social and Cultural Rights (CESCR) General Comment No. 14: The Right to the Highest Attainable Standard of Health (Art. 12). Adopted at the Twenty-second Session of the Committee on Economic, Social and Cultural Rights, on 11 August 2000 (Contained in Document E/C.12/2000/4). Available: https://www.refworld.org/legal/general/cescr/2000/en/36991

[17] In fact, Australia was one of the countries that proposed this resolution to the World Health Assembly, see: World Health Organization. The health of Indigenous Peoples. 76th World Health Assembly A76/A/CONF./1 Agenda item 16.3. A76/A/CONF./1 (23 May 2023). Available: https://apps.who.int/gb/ebwha/pdf_files/WHA76/A76_ACONF1-en.pdf.

Aboriginal and Torres Strait Islander peoples and communities: Guidelines for researchers and stakeholders are included and *explicated* in the revised Consumer Statement. These principles are:

- Indigenous Self-Determination
- Indigenous Leadership
- Impact and Value
- Sustainability and Accountability
- Spirit & Integrity
- Reciprocity
- Respect
- Equality
- Survival and Protection
- Responsibility

5.4 The objective of the National Closing the Gap Agreement 2020 (the Agreement) is “to overcome the entrenched inequality faced by too many Aboriginal and Torres Strait Islander people so that their life outcomes are equal to all Australians”.[18] Two outcomes of that Agreement seek to:

Priority Reform 2 | Building the community-controlled sector: There is a strong and sustainable Aboriginal and Torres Strait Islander community-controlled sector delivering high quality services to meet the needs of Aboriginal and Torres Strait Islander people across the country.

Priority Reform 4 | Aboriginal and Torres Strait Islander-led data: Aboriginal and Torres Strait Islander people have access to, and the capability to use, locally-relevant data and information to set and monitor the implementation of efforts to close the gap, their priorities and drive their own development.

5.5 All Parties to that Agreement acknowledge -

“[T]hat Aboriginal and Torres Strait Islander community-controlled services are better for Aboriginal and Torres Strait Islander people, achieve better results, employ more Aboriginal and Torres Strait Islander people and are often preferred over mainstream services. Priority Reform Two received the strongest support in the 2019 engagements”.[19]

5.6 IUIH highlights Priority Reforms 2 and 4 in the National Closing the Gap Agreement because they apply to the practice of health and medical research throughout Australia and reinforce the important leadership role ATSICCHOs and our consumers and community members must have in the health and medical research endeavour. The revised Consumer Statement will be greatly strengthened and improved through overtly incorporating the principle of Indigenous Self-Determination (along with the other principles highlighted above in section 5.3, p.12) and highlighting the central leadership role ATSICCHOs and Aboriginal and Torres Strait Islander consumers and community members must play in Indigenous health and medical research.

Recommendation 5: That the revised Consumer Statement include and apply the principles of Indigenous Self-Determination, Indigenous Leadership, Impact and Value, Sustainability and

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[18] Para. 15, p.3.

[19] Para 43, p.3.

Accountability, Spirit and Integrity, Reciprocity, Respect, Equality, Survival and Protection, and Responsibility in the context of Indigenous health and medical research.

Recommendation 6: That the revised Consumer Statement highlights the central leadership role that Aboriginal and Torres Strait Islander Community-Controlled Organisations (ATSICCHOs), and Aboriginal and Torres Strait Islander consumers and community members must play in all facets of Indigenous health and medical research.

Question 6: Should values such as accountability, transparency, collaboration and partnership, equity, diversity and inclusiveness be included in the revised Consumer Statement?

IUIH refers to our response to Question 5. We submit that there should be a shift from value statements to principles in the revised Consumer Statement. We also submit that should the term equity be included, that reference is specifically made within that document to Aboriginal and Torres Strait Islander Health Equity.

Question 7: What do you regard as the most important principles that should be included in the revised Consumer Statement?

7.1 We refer to our response to Question 5 and emphasise the principles of Indigenous Self-Determination and our peoples' right to Self-Determination, Indigenous Leadership, Indigenous Data Governance, and Indigenous Data Sovereignty.[20]

Question 8: What roles and responsibilities for consumers and community members should be included in the revised Consumer Statement?

8.1 IUIH recommends that the revised Consumer Statement emphasises the research leadership and governance roles and responsibilities that our ATSICCHOs and community members must play in the transparent and accountable conduct of Indigenous health and medical research.

Recommendation 7: That the revised Consumer Statement emphasises the research leadership, governance and ownership roles and responsibilities that our ATSICCHOs and community members must play in the transparent and accountable conduct of Indigenous health and medical research.

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[20] Please see: Griffiths K, Diaz A, Whop LJ et al (2022) The Health and Wellbeing of Indigenous and Tribal Peoples around the Globe: Ensuring and Promoting Best Practice in Research. *International Journal of Environmental Research and Public Health* 19:261; Griffiths KE, Blain J, Vajdic CM et al (2021) Indigenous and Tribal Peoples Data Governance in Health Research: A Systematic Review. *International Journal of Environmental Research and Public Health* 18:10318; Harfield S, Pearson O, Morey K et al (2020) Assessing the quality of health research from an Indigenous perspective: the Aboriginal and Torres Strait Islander quality appraisal tool. *BMC Medical Research Methodology* 20:79; Huria T, Palmer SC, Pitama S et al (2019) Consolidated criteria for strengthening reporting of health research involving Indigenous peoples: the CONSIDER statement. *BMC Medical Research Methodology* 19:173.

Question 9: Should involvement of consumers and community members be an expectation of research? Yes, No, Not Sure. Provide reasons for your response.

9.1 As IUIH has submitted throughout this submission, the leadership (not 'involvement') of ATSICCHOs and our consumers and community members should be an expectation of research about us and from us. This includes quantitative health and medical research involving large datasets.

Recommendation 8: That the leadership (not 'involvement') of ATSICCHOs and our consumers and community members should be an expectation of health and medical research about us and from us. This includes Aboriginal and Torres Strait Islander health and medical quantitative research that uses large population datasets.

Question 10. Is there an ethical imperative to involve consumers and community representative s in research? Yes, No, Not Sure. Provide reasons for your response.

10.1 Yes, as IUIH has emphasized throughout this submission, there is an ethical and human rights law imperative to involve Community in all facets of research, as research leaders and collective owners of health and medical research data about us and from us.

Question 11. What roles and responsibilities for research institutions should be included in the revised Consumer Statement.

11.1 IUIH strongly recommends that established research institutions such as Australian universities, built on Western pedagogies and practices, have a role and responsibility in decolonising research, ceding power, and proactively supporting the sustainable establishment and advance of community-controlled research institutions and organisations as leaders of Aboriginal and Torres Strait Islander health and medical research in this country.

Recommendation 9: IUIH recommends that established research institutions, such as Australian universities, have a role and responsibility in decolonising research, ceding power, and proactively supporting the sustainable establishment of community-controlled research institutions and organisations as leaders of Aboriginal and Torres Strait Islander health and medical research in this country.

Question 12. What roles and responsibilities for research funders should be included in the revised Consumer Statement.

12.1 In 2021, the $10 million National Network of Aboriginal and Torres Strait Islander Health Researchers was established (now known as OCHRe). From 2022 onwards, the NHMRC has set a target of 3.4% of NHMRC grants awarded annually that are led by an Aboriginal and/or Torres Strait Islander researcher. IUIH welcomes the growth in dedicated NHMRC funding for Indigenous-led research.

12.2 Research funders, including the NHMRC, have an important role and responsibility in ensuring and promoting that appropriate funding is allocated and available for Aboriginal and Torres Strait Islander people to engage in Indigenous health and medical research as consumers and community members, including as (for example) Chief Investigators on research projects or as members on Indigenous-led research governance committees and working groups.

12.3 Consequently, the Department of Health has a responsibility to change the Personnel Support Packages (PSPs) available on NHMRC and MRFF grant applications (**Table 1**).[21] The level of PSP requested in an application purportedly must match the roles and responsibilities of the position on the proposed research project, and the percentage of the PSP requested must reflect the required time commitment. However, the tremendous professional experience outside of the academy, and/or rich lived experience, of an Aboriginal and Torres Strait Islander person (such as an Elder) who is without a post-graduate qualification including a PhD, is without a commensurate PSP level.

12.4 Further still, should an Aboriginal and Torres Strait Islander consumer or community member commit to being an Associate Investigator on a health and medical research grant, then they are unable to apply for a PSP package.[22] Lack of remuneration for the individual's Associate Investigator role - for their time, health systems and services knowledge, including cultural knowledge and cultural networks and brokerage skills - is unacceptable and improper.

12.5 IUIH further advocates that the Department of Health has a responsibility to change what Indigenous health and medical research projects cannot use as grant funds or Indirect Research Costs within NHMRC and MRFF grant applications.[23] It is of tremendous importance to build the capacity and capability (and

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[21] The PSP Package Table is copied from the Medical Research Future Fund – Indigenous Health Research Fund 2024 Indigenous Health Research Grant Opportunity Guidelines, pp.15-16.

[22] According to the Medical Research Future Fund – Indigenous Health Research Fund 2024 Indigenous Health Research Grant Opportunity Guidelines at p.16 – *"An Associate Investigator (AI) is an individual who provides intellectual input to the research and whose participation reasonably warrants recognition. AIs are ineligible to draw a salary from this grant opportunity. Up to 15 AIs may be named in an application".*

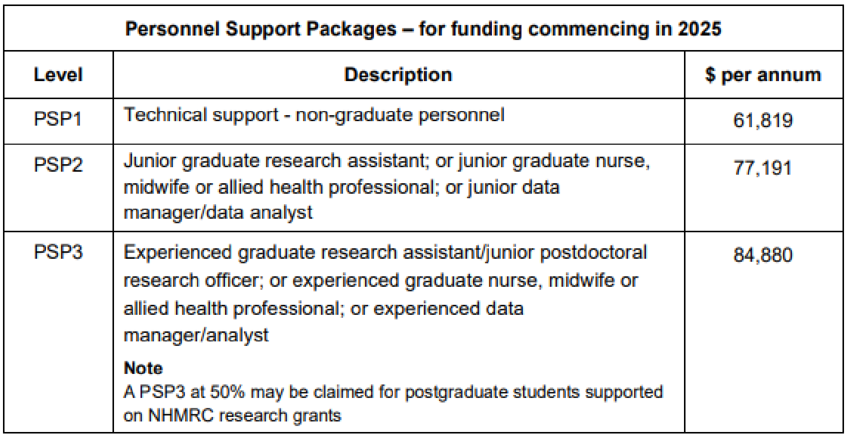
[23] According to the Medical Research Future Fund – Indigenous Health Research Fund 2024 Indigenous Health Research Grant Opportunity Guidelines at p.18 –
"4.7 What the grant money cannot be used for
Indirect costs of research
You cannot use grant funds to pay the indirect costs of research.
Indirect costs of research are organisation overhead costs that benefit and support research. They can include the operations and maintenance of buildings, provision of facilities and libraries, hazardous waste disposal, regulatory and research compliance and administration of research services. Although they are necessary for the conduct of research, and may be incurred in the course of research, they are costs that do not directly address the approved research objectives of a grant. Costs that cannot be paid with grant funds include, but are not limited to:

- airline club memberships
- computers, computer networks, peripherals and software for communicating, writing and undertaking simple analyses
- communications costs (mobiles, telephone calls)
- conference attendance and associated travel
- entertainment and hospitality costs
- ethics approval costs
- furniture
- health insurance, travel insurance, foreign currency, airport and related travel taxes, passports and visas
- organisational overheads and administrative costs
- non-project related staff training and development
- overseas travel (except as provided for in section 4.6)
- patent costs
- personal membership of professional organisations and groups

quantitative numbers) of Aboriginal and Torres Strait Islander consumers, community members and staff of ATSICCHOs involved in health and medical research. Therefore, our people who are engaged on NHMRC and MRFF research should be funded – for example - to attend and participate in conferences (in Australia and overseas).

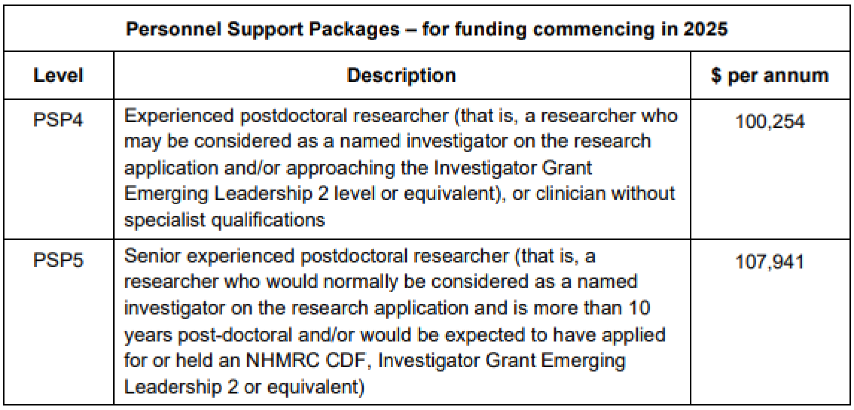
12.6 Aboriginal and Torres Strait Islander consumers, community members and staff of ATSICCHOs should also confidently engage in developing Indigenous-led health and medical research outputs that are Open Access – so all First Nations peoples and communities in Australia and globally can benefit. Open Access is also important for the promotion of Indigenous Data Sovereignty. For emerging Aboriginal and Torres Strait Islander researchers (including consumers and community members) to grow and thrive, and to increase their knowledge, skills and networks, such researchers must be able to attend academic, community-controlled, and/or industry conferences both in Australia and overseas. At present, the NHMRC and MRFF often will not fund Open Access fees or for researchers to attend conferences and other vital activities that speak to building and maintaining Indigenous research trust and relationality, skills, capacity, and capability that is consistent with achieving the IREC criteria. Therefore, IUIH strongly recommends that the NHMRC and MRFF grant schemes fund Open Access scientific publications and conference attendance on Indigenous-led health and medical research projects.

Table 1. Personnel Support Packages – for funding commencing in 2025.



Personnel Support Packages – for funding commencing in 2025		
Level	**Description**	**$ per annum**
PSP1	Technical support - non-graduate personnel	61,819
PSP2	Junior graduate research assistant; or junior graduate nurse, midwife or allied health professional; or junior data manager/data analyst	77,191
PSP3	Experienced graduate research assistant/junior postdoctoral research officer; or experienced graduate nurse, midwife or allied health professional; or experienced data manager/analyst **Note** A PSP3 at 50% may be claimed for postgraduate students supported on NHMRC research grants	84,880

- personal subscriptions (e.g. private journal subscriptions)
- physical space and all associated administrative, laboratory and office services
- purchase of reprints
- research infrastructure: facilities necessary for the research endeavour that a responsible



Personnel Support Packages – for funding commencing in 2025

Level	Description	$ per annum
PSP4	Experienced postdoctoral researcher (that is, a researcher who may be considered as a named investigator on the research application and/or approaching the Investigator Grant Emerging Leadership 2 level or equivalent), or clinician without specialist qualifications	100,254
PSP5	Senior experienced postdoctoral researcher (that is, a researcher who would normally be considered as a named investigator on the research application and is more than 10 years post-doctoral and/or would be expected to have applied for or held an NHMRC CDF, Investigator Grant Emerging Leadership 2 or equivalent)	107,941

Recommendation 10: That the Department of Health creates new Personnel Support Packages on NHMRC and MRFF grant programs that appropriately and respectfully recognise and reward the rich expertise, knowledge, skills and networks that Aboriginal and Torres Strait Islander consumers, community members, and staff from ATSICCHOs bring to Indigenous health and medical research.

Recommendation 11: That the Department of Health amends its NHMRC and MRFF grant guidelines relating to Indigenous health and medical research to appropriately and respectfully remunerate Aboriginal and Torres Strait Islander consumers, community members, and staff from ATSICCHOs who generously agree to hold Associate Investigator roles on NHMRC and MRFF research projects.

Recommendation 12: That the Department of Health review the Indirect Research Costs that the Department will currently not fund under the NHMRC and MRFF grant schemes pertaining to Indigenous health and medical research, with a view to fund Aboriginal and Torres Strait Islander consumers, community members and staff of ATSICCHOs to attend and participate in (for example) conferences and other research capability and capability strengthening activities in Australia and overseas.

Recommendation 13: That NHMRC and MRFF grant schemes fund Open Access scientific publications on all Indigenous-led health and medical research projects.

Question 13: Should funders of research mandate the involvement of consumer and community representatives in the research they fund. Yes, No, Not Sure. Provide reasons for your response.

13.1 In the context of Aboriginal and Torres Strait Islander health and medical research, IUIH recommends that funders such as the NHMRC don’t mandate the involvement *but the leadership of ATSICCHOs and community representatives* in the research they fund. This is consistent with the principles of Indigenous Self-Determination and our peoples’ legal right to self-determination (including in research contexts), Indigenous Leadership, and Indigenous Data Sovereignty.

Recommendation 14: In the context of Aboriginal and Torres Strait Islander health and medical research, IUIH recommends that funders such as the NHMRC and MRFF mandate the leadership of Aboriginal and Torres Strait Islander researchers, including ATSICCHOs and our community representatives, in funded research. This is consistent with the principles of Indigenous Self-Determination and our right to self-determination (including in research contexts), Indigenous Leadership, and Indigenous Data Sovereignty.