



Submission to the Public Consultation into the Revised Aboriginal and Torres Strait Islander Research Ethics Guidelines

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To the National Health and Medical Research Council,

Thank you for the opportunity to submit to the public consultation into the revised Aboriginal and Torres Strait Islander Research Guidelines (hereafter 'the Guidelines'). The Koorie Youth Council¹ (KYC) is a representative body for Aboriginal and Torres Strait Islander young people in Victoria. Our work is guided by an Executive of 15 Aboriginal² young people. KYC believes that involving young people in decision-making that affects their lives is a crucial part of improving systems and communities. Our practice involves empowering young people to be active participants that have a say in shaping research.

Our submission draws on our experience applying for ethics approval at a Human Research Ethics Committee (HREC) that we will not identify in this submission. This process posed considerable barriers that almost led us to discontinue the research. Gaining approval for the project took eight months, four rounds of significant amendments to the submission and excessive resources from our small team. During this time we were struck by the need for the HREC to better understand cultural respect, participatory research practice and representation. In our experience, the HREC acted as a barrier to research rather than an enabler of ethical practice.

We are pleased to be able to contribute to the conversation about best practice research with Aboriginal people. Throughout this letter, we reflect on our experience with research ethics and make recommendations that would have better enabled our positive inclusion and outcomes as an Aboriginal organisation. We acknowledge that our experience is not universal, and we do not claim to speak on behalf of other Aboriginal organisations and individuals. We share our experience to assist the National Health and Medical Research Council (NHMRC) to understand the barriers and enablers of inclusion in their systems.

While the Guidelines can be useful in building cultural understanding for non-Aboriginal researchers, they are only one tool within complex system that requires a significant shift in its cultural paradigms and practice. We propose that the Guidelines further emphasise our recommendations and that the NHMRC implement other tools, partnerships and practices that enable culturally aware, ethical research. Our submission considers four key areas of focus needed to assist this shift towards better practice: cultural understanding, collaborative ethical practice, empowering research participants and representation.

Cultural understanding and reflexivity

KYC recommends that research ethics bodies:

- **Recognise their cultural bias through engaging in cultural reflexivity**
- **Work in partnership with Aboriginal people and organisations to improve the cultural capacity of research ethics bodies**

Working respectfully with Aboriginal people should be an ethical priority for research bodies. Achieving this requires cultural reflexivity on behalf of research bodies such as HRECs. Cultural reflexivity involves reflecting on the cultural norms and values of an individual, institution or discipline to understand the implicit bias in epistemology and practice. It is particularly important for

¹ The Koorie Youth Council uses the term Koorie in our organisation's title as inclusive of all Aboriginal and Torres Strait Islander young people living in Victoria.

² We use Aboriginal as a term also inclusive of Torres Strait Islander people.

traditional research bodies to understand that their work is not culturally neutral, but rooted in Western knowledge and culture. This is an important starting point for cultural inclusivity and accessibility of research methods. Our experience with the HREC demonstrated their resistance to recognising this bias. As a result, we had to compromise the cultural integrity of our project in order to gain ethics clearance. There are many ways that Aboriginal culture and research ethics can integrate without diminishing their core values and cultural reflexivity is the first step to achieving this.

Cultural understanding cannot be effectively gained by reading a static document or attending cultural awareness training. True cultural competency recognises that working ethically and respectfully with Aboriginal people requires ongoing relationships that recognise the evolving nature of culture and research practice. A partnership that recognises the importance of continual learning would assist research ethics bodies to be culturally accessible for Aboriginal organisations. This kind of awareness would have improved our experience with the HREC as we would not have to explain the cultural imperatives of our work. Diverse organisations are often required to expend extra resources to 'educate' mainstream institutions and justify the culturally specific aspects of their work. This barrier discourages many organisations from participating in research ethics processes. Due to their static nature, guidelines are a limited tool for creating culturally aware institutions. Developing partnerships and relationships between research ethics groups and Aboriginal people better reflects the complex dynamism of cultural awareness and would lessen the 'us and them' relationship created by the cultural disjunct of the current system.

Process

KYC recommends that:

- **NHMRC build the capacity of research ethics bodies in non-traditional research such as participatory social research**
- **Implement an application system that engages with prospective researchers to understand their project and collaborate on ethical design**
- **Use the recommendations above (among others) to reduce the resources needed for organisations to take part in a research ethics process**

A functional research ethics body creates a community of ethical practice and enables researchers to gain capacity in ethical research design. A research ethics process should improve the proposed research and find ways to meet objectives ethically through clear guidelines and mutual understanding between researchers and committees. Our experience of the HREC was as a gatekeeper of research, rather than a resource for advice on ethical practice. As our project was not traditional research, the Committee did not have the necessary tools to advise us within our research paradigm. The Committee's requested amendments often contradicted our values and aims for the project or were impossible to implement. This demonstrated a lack of understanding of the project's outcomes despite our explanation. Ultimately, the Committee insisted we adopt a more traditional approach to be approved. Had the Committee meaningfully engaged with us and the project early on to work together for a solution, we would have saved resources. This process would also have helped KYC understand the Committee's way of thinking to work towards a timely design solution. Shifting Committee practice to improve its understanding of participation and prospective researchers is an important step towards cultural competency and functional partnerships with Aboriginal researchers.

Resourcing is another barrier to the inclusion of small organisations like KYC in research ethics processes. Like many Aboriginal organisations, KYC has a small staff and limited resources, so this process comes at a significant cost to our organisation (see Confidential Appendix I, Letter regarding barriers in research ethics process). The eight months of work for this ethics process left us without adequate funds to complete the project, and we have since had to apply for further funds. The cost of these processes leads some organisations to withdraw applications, while others choose to not apply. This inaccessibility means that important research is not done by the Aboriginal organisations best placed to undertake the work. In fact, this process blocks Aboriginal organisations from researching within their own communities. If Committees were to properly engage and work with organisations to understand projects, it would require far less resourcing, resulting in a more accessible and equitable system for Aboriginal organisations. Research ethics bodies require structures that facilitate continual learning for Committees and organisations through mutual understanding. This would assist Committees to understand diverse research methods, such as participatory engagement.

Empowering research participants

KYC recommends that:

- **That research ethics bodies value the role of active research participants, particularly in the Aboriginal context**
- **NHMRC build the capacity of research ethics bodies in co-designed research methods such as participatory social research**

Empowering research participants is at the core of KYC's work and this sets our work apart from traditional research practice. KYC's code of ethical conduct requires that young people must drive the work that we do. As a result, we engage young people in meaningful research that gives them a say in how they want to engage and what they want to share. This approach aims to value participants as people, rather than research 'subjects'. Our method is key to helping young people feel safe and respected in research settings as well as enabling them to share their unique and personal perspectives. As an Aboriginal organisation we also recognise that Aboriginal people are heavily researched. This research is often conducted in a way that does not involve them in decision-making. This disempowering process can evoke negative experiences and distrust of white institutions, ultimately discouraging participation in research. Our participatory approach aims to break away from the traditional research practice that views participants as passive respondents.

Unfortunately, the rigidity of the Committee's ethics process did not recognise the importance of our practices and was largely unresponsive to these ethical considerations. This forced us to give research participants less power in the project by working within a traditional, Western research model. We expect this will negatively affect participants' positive experiences of the project and the quality of our data. Our application clearly described our participatory model from the beginning of the research ethics process (see confidential Appendix II, Letter Regarding Participatory Research). Regardless, we consistently faced a lack of understanding from the Committee that would have been remedied by improved understanding of non-traditional research.

Representation

KYC recommends that:

- **Research ethics bodies include Aboriginal people as members and/or advisers**

Partnership with Aboriginal people is key to culturally competent, inclusive research practice. Aboriginal representation on research bodies and as advisers to committees is essential to improve the cultural awareness of these bodies. Representation helps alleviate an Aboriginal researcher's work of explaining cultural imperatives to a non-Aboriginal Committee. Representation also helps build the cultural knowledge of the Committee, resulting in culturally inclusive research practice.

The HREC we submitted to did not have any Aboriginal members. During our meeting with the Committee, it became clear that members did not understand the importance of representation. When the Chair asked about our experience with the ethics process, KYC suggested that the Committee include an Aboriginal and member. The Chair responded that representation was unnecessary as the Committee did not receive "many Aboriginal applications". This response shows a lack of reflection regarding the cultural accessibility of this resource-heavy process that deters many Aboriginal organisations from applying. It also fails to acknowledge that Australia needs better research in this area, done by the identified researchers who are best placed to understand and work with their communities. Lastly, this comment makes a false assumption that an identified member of a committee would only be knowledgeable about Aboriginal specific research.

The Guidelines are one step towards more inclusive, culturally respectful research ethics bodies, however guidelines alone will not achieve this goal. The changes in cultural understanding, process, research paradigms and representation that are required to achieve inclusivity in research ethics are complex amendments that are enabled by meaningful partnerships between Aboriginal people and research ethics bodies. Our recommendations present opportunities for research ethics bodies to challenge their current practice and move towards a more inclusive and accessible way of working. KYC is happy to provide further information about our recommendations and assist in creating pathways to better research.

Sincerely,

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