

Aboriginal Health and Medical Research Council of NSW

HREC Statement Biological Samples V1.0 March 2021



**Aboriginal
Health & Medical
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of NSW**

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Background

The AH&MRC Human Research Ethics Committee (The HREC) reviews proposals to conduct Human Research in accordance with the National Statement on Ethical Conduct in Human Research (2007 updated 2018) and the Ethical Conduct in Research with Aboriginal and Torres Strait Islander Peoples and Communities: Guidelines for researchers and stakeholders (2018). These National Guidelines provide a framework for a thorough review of applications for HREC approval.

Biological Samples:

The HREC considers that for applications which plan to collect, analyse, or store biological samples, that researchers adequately consider and are conscious of the historical impacts and harmful effects that this research has had on Aboriginal people and communities.

Historically, research of this nature had been exploitative, caused harm and was of little to no benefit to Aboriginal people and communities. The HREC has previously had ethical and cultural concerns related to the following:

- Informed consent was not obtained.
- There were data sharing uncertainties.
- Aboriginal people were not given formal data ownership rights.
- There were unjustifiable storage timeframes, some requesting for indefinite periods.
- There was no consultation that occurred with Aboriginal people and communities.
- There was no transparency over what the samples would be used for.
- There were no benefits to community, as determined by the community.
- There was poor Aboriginal governance.
- The research team was not adequately skilled to undertake the research.
- Sequencing often occurs outside of Australia and is subsequently owned and maintained by international companies.
- No guidelines for the long-term storage and how and when permission would be sought to move bio samples.

Applicants who seek to undertake research of this nature must demonstrate strong Aboriginal governance and oversight of all components of the project; this includes developing formal agreements with each of the Aboriginal communities affected by the research, which additionally outlines:

- All planned data sharing arrangements between each party and/or third parties
- Where data is planned to be stored and who has access.
- That ownership of samples remains with Aboriginal people and communities
- That Aboriginal people may withdraw their consent at any time and in choosing to do so, their respective biological sample may need to be destroyed and removed from the research
- That there is an agreeable period for which the samples may be kept and that this is not longer than necessary.
- That there is an agreeable validity period for which a reconsenting process may be required, the reconsenting process may require contacting the next of kin if the participant has passed away and if unable to contact the next of kin, then the sample should be destroyed.
- Employment opportunities for Aboriginal people, with an emphasis on employing local Aboriginal people.

- The Aboriginal community is satisfied that the research team has skills to undertake this work.
- The destroying of bio samples is undertaken in a culturally appropriate way that has been approved by Aboriginal people.

For the HREC to determine whether an application of this nature can be approved, researchers must demonstrate a thorough understanding and commitment to addressing the abovementioned ethical issues.

If you are seeking further information regarding this statement, please contact the Ethics Secretariat at ethics@ahmrc.org.au