

Aboriginal Health and Medical Research Council of NSW

HREC Statement Retention of Data V1.0 March 2021



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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.

Retention of Data:

The HREC recognises potential ethical issues related to institutions retaining data permanently or for extended periods of time than what is necessary for the purposes of the proposed research. The National Health and Medical Research Council outlines in the *Management of Data and Information in Research* that “ownership of data and information used in or generated by research involving Aboriginal and Torres Strait Islander peoples and communities, institutions or researchers may hold data or information; however, they should not make decisions about access to or reuse this data or information without proper consultation with its Indigenous owners, if any” (page 2. 2019).

Applicants must also acknowledge that Aboriginal and Torres Strait Islander peoples have a right to exercise ownership over Indigenous data, the communities affected by the research should have an on-going and meaningful role in the monitoring, storage, changes, archiving and destruction of data. This includes defining the terms on which a community may exercise a right to veto or edit the publication of sensitive information.

The HREC suggests that for data and information to be maintained by institutions appropriately, that a formal agreement must be developed with the Aboriginal people and communities affected which clearly articulates:

- Storage and archiving of data
- Access to data and security
- Publication procedures and protocol
- Changes in the proposed use of the data
- Community ownership of biological samples gathered
- Negotiation over the disposal or storage of unanalysed data
- Publication and appropriate acknowledgement of all parties involved
- The terms on which a community may exercise a right to veto or edit the publication of sensitive information.

Please see chapter 7.4 of the AH&MRC Ethical Guidelines: Key Principles (2020) for further information.

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