

## Guidance on Data Storage and Retention Questions in the HREA

### Data Management, Storage and Retention

There are a number of key software tools, documents, policies and legislation shaping this terrain:

- The Australian Code for the Responsible Conduct of Research – Section 2 – Research data should be made available for use by other researchers unless this is prevented by ethical, privacy or confidentiality matters (2.5.2)
- The Western Sydney Research Code of Practice - Data Management, Storage and Retention and Procedures Relating to Data Storage and Retention
- NSW Privacy and Personal Information Protection Act 1998
- NSW Health Records and Information Privacy Act 2002, NSW State Records Act 1998, and
- the University's Privacy Policy and Records Management Policy, including Western Sydney University Library ResearchDirect.

### Retention periods

In general, the minimum recommended period for retention of research data is five years from the date of publication. However, in any particular case, the period for which data should be retained should be determined by the specific type of research.

Research projects which have been funded may have data management requirements specified in the funding contract. Researchers who are undertaking medical research should note that medical research data may be required to be kept for a minimum of 15 years.

## FAQs re data management and the HREA – Data and Privacy

### HREA Q3.4

Indicate the degree of identifiability of information/data you will be using in this project.

- Individually Identifiable information
- Re-identifiable (coded) information
- Non-identifiable information

**Explanation:** This question refers to information collected, and not the analysis or dissemination of data. Consider the following when answering this question:

- If the information is being collected directly from a participant, then the information is “individually identifiable”.
- If the information is being accessed from coded data, then it is “re-identifiable”.
- If the information is being collected from anonymous online surveys, then the data is “non-identifiable”.

### HREA Q2.2.2.1

What is the scope of consent that you will be seeking?

**Explanation:** This refers to participant consent to future use of the data. The National Statement outlines the meanings of these terms (2.2.14).

- specific means limited to the project related to this NEAF;
- extended means use in projects closely aligned to this application;
- unspecified is for use in any future research.

The researcher should ensure that the option chosen is clear to participants and that the data retention timeframes reflect the choice made.

### **HREA 3.18**

Describe any ethical considerations relating to the planned or possible future use of information/data in this project.

- Consider whether non-identifiable data could be used in future research.
- Ethical considerations may include your potential obligations to act on the findings of your research in the future.
- Consider who will have ongoing custody of data or research outputs, including any intellectual property ownership.
- If data will be made available for any purpose, describe how the approach will protect participant privacy.
- Consider whether appropriate consent for the future use of data has been sought.

**Explanation:** Data collected by Western Sydney employees are normally owned by the University. Generally speaking, students own the data in their research projects. However, research projects with contractual arrangements may have data ownership and publication issues stated in the contract. Researchers should ensure that data ownership and publication is discussed and where necessary approved by all parties, and the outcomes of these discussions are reflected in the ethics application.

### **HREA 3.14**

Describe how the information/data will be stored, accessed, archived and/or destroyed?

The University's Research Code of Practice states that:

(79) The academic unit or division is responsible for ensuring the retention of research data and records of research data. It is inadvisable for individual researchers to hold the sole copy of the data.

The NEAF should specify details of where the data will be held. This may be followed up for audit purposes; and

(96) In the event that the Chief Investigator leaves the University, the academic unit or division should ensure that the outgoing Investigator transfers storage protocols to another member of the University staff. It is imperative that the University continues to maintain the data and observe storage requirements.

Western Sydney University provides data planning, storage and management tools for both working data and datasets from completed projects. See:

[http://westernsydney.edu.au/research/researchers/data\\_management](http://westernsydney.edu.au/research/researchers/data_management);

[http://library.westernsydney.edu.au/uws\\_library/researchers/data-management](http://library.westernsydney.edu.au/uws_library/researchers/data-management)

<http://researchdirect.westernsydney.edu.au/>

### **The Participant Information Sheet and Consent form**

Participants must be informed of what will happen to their data and how long it will be stored. The information provided in the Participant Information Sheet and Consent Form must be relevant to the methodology of the project, any intended re-use of data and reflect the statements made in the HREA.

### **General Query**

**Can paper files be scanned and then destroyed or do they need to be kept as the original data source?**

Yes - once documents are scanned and a quality check has been completed. To be complete the copy must be an accurate, legible reproduction of the original or source record in its entirety. This means that:

- the copy must be legible at the required level of detail
- all pages, annotations, attachments and enclosures are captured
- colour markings on maps and plans may be essential, but a coloured logo, letterhead or invoice may be less important.

If there are concerns regarding accurate, legible reproduction then the originals must be retained.

When an original or source record is destroyed, the copy becomes the official record of the business of the agency and must be retained and be accessible for the period specified in the disposal class under which the original or source record was covered.

Once checked that the documents have been scanned properly and all information has been captured, the document must be placed into TRIM in a relevant file. After that the original paperwork can be destroyed by placing it in a red locked security bin.

### Human Research Ethics Guidance Documents available from Research Services

- Guidance for Researchers New to Human Ethics Review
- Guidance Human Research Ethics Protocols for Coursework Masters
- Guidance on Choosing the most appropriate PIS and Consent
- Guidance on Completing the Project Description
- Guidance on Creating Research Project Flyers
- Guidance on Data Storage and Retention Questions
- Guidance on Ethics Review Exemption
- Guidance on Issues with Informed Consent in Research
- Guidance on Levels of Risk and the Ethical Review Process
- Guidance on Making an Amendment to an Approved Project
- Guidance on Organisations in Research
- Guidance on Questions Related to Cultural Sensitivities
- Guidance on Questions Related to Restrictions on Publication of Results
- Guidance on Receiving and Responding to Ethics Committee Assessor Comments
- Guidance on Research Projects Seeking to use Western Sydney Staff as Participants
- Guidance on Reimbursements
- Guidance on The use of 'Opt Out' or Passive Consent in Human Research
- Guidance on Writing Participant Information Sheets and Consent Forms
- Guidance on Research Involving Young People
- Guidance on Research Projects and DFAT Advice
- Guidance on Using Focus Groups in Research

Human Research Ethics Team Contact: [humanethics@westernsydney.edu.au](mailto:humanethics@westernsydney.edu.au)