



Data Management

Protecting participants and the responsible handling of their information is extremely important in human research. Confidentiality and privacy processes must be implemented for all research projects conducted within the WA health system. Every state-wide health data collection containing health information from WA health system patients must have approval from the relevant Data Custodian. Data custodians will only approve access and disclosure of data when:

- consent has been provided by the participant for their data to be used for research purposes;
- the empowering legislation governing the relevant data collection(s) allows for participant information to be released for a specific research project in absence of participant consent; OR
- if the information being requested is non-personal health information and the disclosure of information in absence of consent is not prohibited by legislation.

In the site application consider the following:

- how data will be recorded from the source documents, for example, electronic CRF, paper CRF or entered directly into a database such as REDCap.
- if REDCap, who is hosting this instance of REDCap, is data leaving WA Health?
- will the data recorded be identifiable, re-identifiable or de-identified?
- if re-identifiable, where will the master contact list be kept and who will have access to it?
- where will the data be stored, and if any data will be leaving WA Health IT servers, where will it be held?

Note that if data is leaving WA Health Server, an agreement is needed with the recipient of data (refer to Agreement Table Guideline)

- how long will you be storing both hard copy and electronic copies of the data and how will this be destroyed?
- please view the WA Health Information Retention and Disposal Policy <https://www.health.wa.gov.au/~media/Corp/Policy-Frameworks/Information-Management/Information-Retention-and-Disposal-Policy/Information-Retention-and-Disposal-Policy.pdf>
- WA Health follows the WA University Sector Disposal Authority schedule for the retention of research records.
- research records must be destroyed as per the WA Health Information Retention and Disposal Policy after the minimum retention period and approval from sponsor.
- also note that the management of data must be consistent with what is in the PICF as the participant must be made aware of where and how their data will be used, stored and destroyed.