

HeSANDA: An Update from the WA Node

The Health Studies Australian National Data Asset (HeSANDA) program is led by the Australian Research Data Commons (ARDC) to build digital research infrastructure.

WHAT IS THE WA HeSANDA NODE?

We are one of 9 Nodes across Australia supported by the ARDC to create a national infrastructure to support sharing and reuse of sensitive health data.

The WA HeSANDA Node is a collaboration of the WA Health Translation Network (WAHTN) and its 23 Partner Organisations, which includes our universities, research institutions and public and private health service providers.

The Operations Team, responsible for daily activities, is led by Prof Chris Reid at Curtin University. The Steering Committee provides strategic oversight and includes a consumer representative, the Executive Director of the WAHTN, Curtin University's Dean of Research from the Faculty of Health Sciences, the Chair of the Operations Team and a representative from ARDC.

Our Advisory Committee consists of representatives from WAHTN Partner Organisations, and its members play a critical role in connecting us to the diverse and dynamic community of researchers in Western Australia who are engaged in a wide range of health and medical research.

METHOD

A co-design approach was used to develop coherence of data standards and practices, with a six-month Design Phase and 12-month Development Phase. WA HeSANDA Node members contributed to four working groups:

- Information Design – to determine the information requirements and specifications of data assets.
- Data Access - to develop a framework and workflows for requesting and providing access to data
- Technology - to develop standards, protocols, tools and a central catalogue
- Ethics & Consent - to develop resources for researchers on consent for data sharing

The system is based on the FAIR principles – Findability, Accessibility, Interoperability, and Reusability.

OVERVIEW OF WORKFLOW

1. Trials must be registered in ANZCTR. This is a standard requirement for clinical trials, and it ensures transparency and accountability.
2. The WA HeSANDA Node will collect and curate data assets. This is a crucial step in the workflow, as it involves harmonisation of records for the central catalogue.
3. The WA HeSANDA Node will generate a DataCite DOI and metadata record for each data asset. This step is important because it provides a unique identifier for each dataset and enables efficient search and retrieval.
4. The WA HeSANDA Node will store data assets or metadata records but not Individual Participant Data. This is a necessary precaution to protect the privacy and confidentiality of research participants.
5. ARDC will harvest metadata from ANZCTR and DataCite to build a central catalogue. This step ensures that the data assets are discoverable and accessible to researchers.
6. Requesting Researchers will search the central catalogue and submit an EOI for a data asset. This step facilitates efficient and targeted access to the data assets.
7. The WA HeSANDA Node will monitor the Data Access Request Management System (DARMS). This is an important step in ensuring that access requests are managed effectively.
8. The WA HeSANDA Node will respond to EOIs received, including facilitating (i) a response from Data Custodians for requests for IPD, and (ii) access to data in a secure electronic research platform. This step ensures that access to data assets is controlled and managed appropriately.

STATUS UPDATE

The proof of concept infrastructure development stage will be completed in June. The HeSANDA program will be extended to other health research, including cohort studies and quality clinical registries. The WA HeSANDA Node will contribute to a Community Connect Program to deliver eLearning materials to enable sustainable ongoing skills opportunities for researchers who want to use the infrastructure.

CONTACT

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