

Health Studies Australian National Data Asset (HeSANDA) program

Building national infrastructure to support the
sharing and reuse of health research data

Background

The value in sharing health research study data

Health research studies generate a wealth of data, including information about the people taking part in the research, their health and their response to interventions being studied.

The data collected in one study can be extremely valuable to other studies. However, the challenges of patient privacy and the naturally siloed approaches of research groups and state jurisdictions have created barriers to efficient data sharing. Overcoming such barriers and tapping into health research data will maximise the return on investment of past research and allow future research to build upon it to improve health outcomes for Australians.

Similar capability has already been established in European health research infrastructure (ECRIN and EOSC Life), and data sharing platforms are emerging in the UK and USA. The Australian Research Data Commons (ARDC) is playing the critical role in ensuring Australia is not left behind by partnering with the health research community to synchronise efforts, align approaches and build national data capability.

Led by the ARDC, [Health Studies Australian National Data Asset \(HeSANDA\) program](#) aims to:

- bring together the health research community to establish national infrastructure to support the sharing and reuse of health research data.
- bring value to the research community by stimulating new ideas and enabling the data outputs of one study to become the inputs for another. The effect will stimulate new ideas and reduce resources through the reuse of existing data and identification of existing studies preventing duplication.
- increase research impact and integrity by supporting further research, meta-analysis, and clinical guideline development. This includes, but is not limited to, adopting a leading role in standardising both data governance frameworks (including participant consent) and the conventions and mechanisms that are adopted nationally for data sharing and secondary use.

ARDC conducted an 18-month consultation and codesign process (June 2020- December 2021) to establish consensus around the purpose, content, and requirements for the national health data asset to be created through the HeSANDA initiative. This was informed by the National Collaborative Research Infrastructure Strategy (NCRIS) facilitation process, with assistance from the Australian Institute of Health and Welfare (AIHW). Participants included clinical trialists, researchers, health consumers and research institutions, as well as infrastructure providers and policy makers involved in clinical trials research.

The outcome of this consultation identified three development priorities (Figure 1):

1. Coherent Data Practices: Research community and stakeholder-defined data sharing practices for minimum information requirements, metadata design, data access, and ethics and consent.

2. Coordinated Data Services: A distributed network of infrastructure nodes to supply clinical trials metadata and research outputs according to the Coherent Data Practices.

3. Federation Services: Interfaces, applications, and services to allow research and data discovery, data request and access, and additional functionality across the node network.

The initial phase of the program (December 2021 – June 2023) will focus on building robust and coordinated national infrastructure to support the sharing and reuse of clinical trial metadata (from investigator-led studies), with nine initial nodes. Future infrastructure expansion via additional nodes, will support high-value data from clinical and health service records, cohort studies, clinical quality registries etc. The HeSANDA program will consider how to incorporate these in the future, and how to extend the standards designed for sharing clinical trials data to these other types of research data.

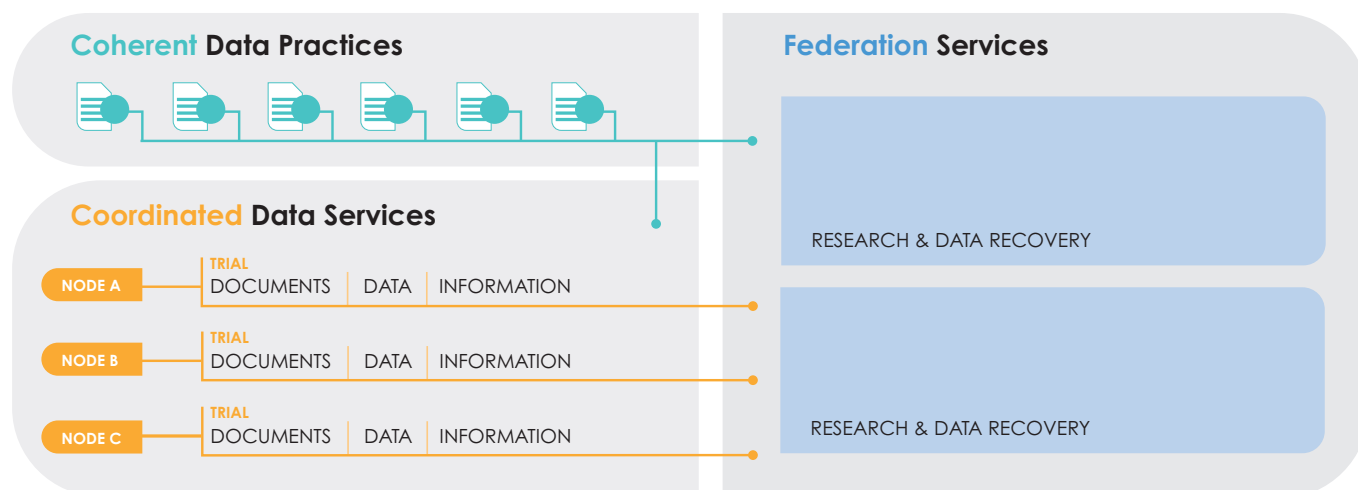


Figure 1. The three development priorities of the HeSANDA ecosystem

National Program Plan

Phase 1 Clinical Trial Data

ARDC is taking an incremental approach to the HeSANDA program over a 3-year period (2020-2023). The initial focus is on sharing and reusing data from publicly funded clinical trials research conducted in the academic sector.

The program consists of 3 workstreams as illustrated in Figure 2:

- **Data Development:** identifying the data needs, standards, and practices required by researchers involved in data sharing.
- **Infrastructure:** investing in a coherent nationally distributed infrastructure.
- **Culture & Policy:** enabling the culture and policies required to make the health data asset beneficial for the research and wider communities.

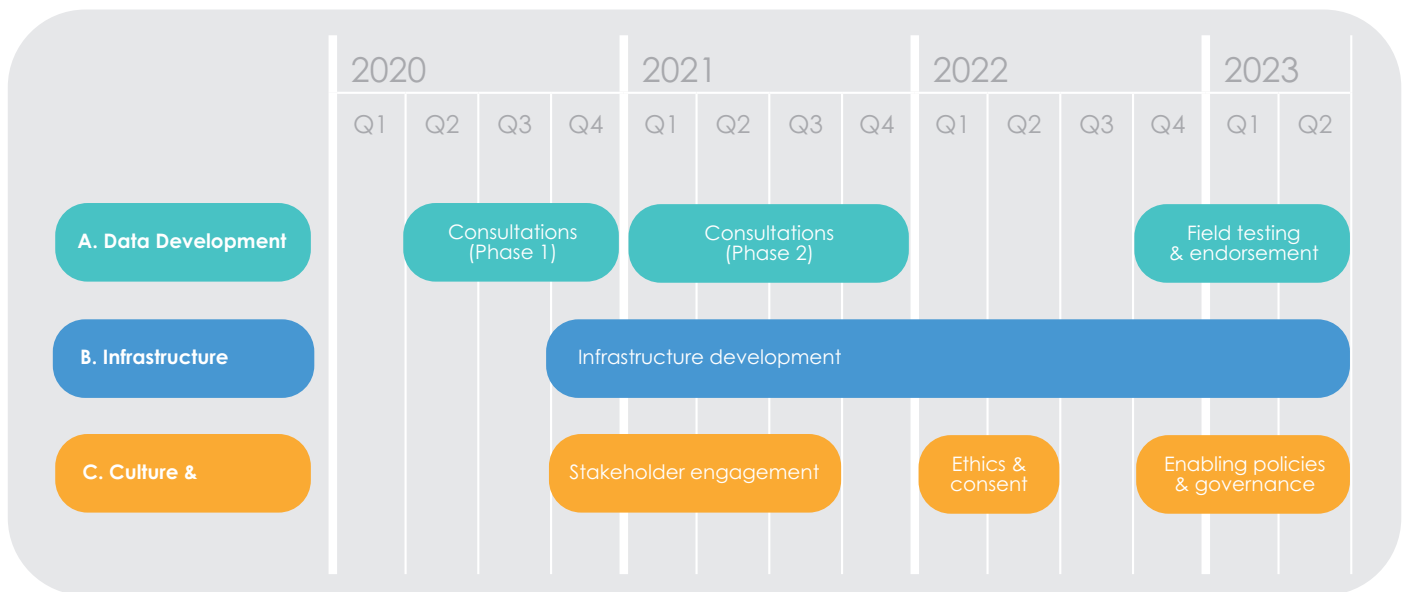


Figure 2: HeSANDA program timelines

Who is involved?

An initial nine nodes were appointed as part of the HeSANDA network to support the infrastructure development. The nine nodes cover 72 health research organisations in Australia, including 18 universities, 10 medical research institutes, 19 health service operators, 16 clinical trial networks and nine other organisations. Health Translation SA (HTSA) is South Australia's NHMRC Research Translation Centre and is one of the nine nodes. It is based at South Australian Health & Medical Research Institute.

Node Title	Lead Description
Health Studies Australian National Data Asset: Queensland Node Proposal	Brisbane Diamantina Health Partners (University of Queensland)
Northern Australian Node	Menzies School of Health Research
Sydney Health Partners led by NHMRC Clinical Trials Centre, at The University of Sydney	University of Sydney
WAHTN Clinical Trials and Data Management Centre	Curtin University
MACH Clinical Trials Consortium	University of Melbourne
Mental Health	Deakin University
Monash and Partners HeSANDA Node	Monash University
SA HeSANDA Node	Health Translation SA (HTSA) based at South Australian Health & Medical Research Institute (SAHMRI)
National Cancer Cooperative Trials Groups	Australasian Leukaemia and Lymphoma Group

Mobilising access to clinical trial data

The HeSANDA program will focus on secondary use of clinical trial data where consent has been given by trial participants and by the original investigators. It is not intended to be an open data asset. A researcher may browse through the HeSANDA catalogue and may see a trial that has collected data that will be valuable for their new research project (e.g., writing a clinical practice guideline or systematic review). However, they will not be able to access the data without first getting permission from the original researcher who conducted the trial. Permission may be needed from an institution and/or university and/or health service rather than an approval sought from the relevant human research ethics committee(s).

The HeSANDA system aims to curate, find and access clinical trial data. It is described below and illustrated in Figure 3:

- 1. Nodes** collate the non-sensitive clinical trial descriptive metadata which is shared through the registration of clinical trials (ANZCTR, DOI) with the Federation Service.
- 2. Federation Service** creates a catalogue of all trials which are publicly available.
- 3. Secondary Researchers** review the catalogue and submit a request for access to the research outputs.
- 4. The data request** is reviewed by the data custodian who decides what research outputs can be shared with the secondary researcher.

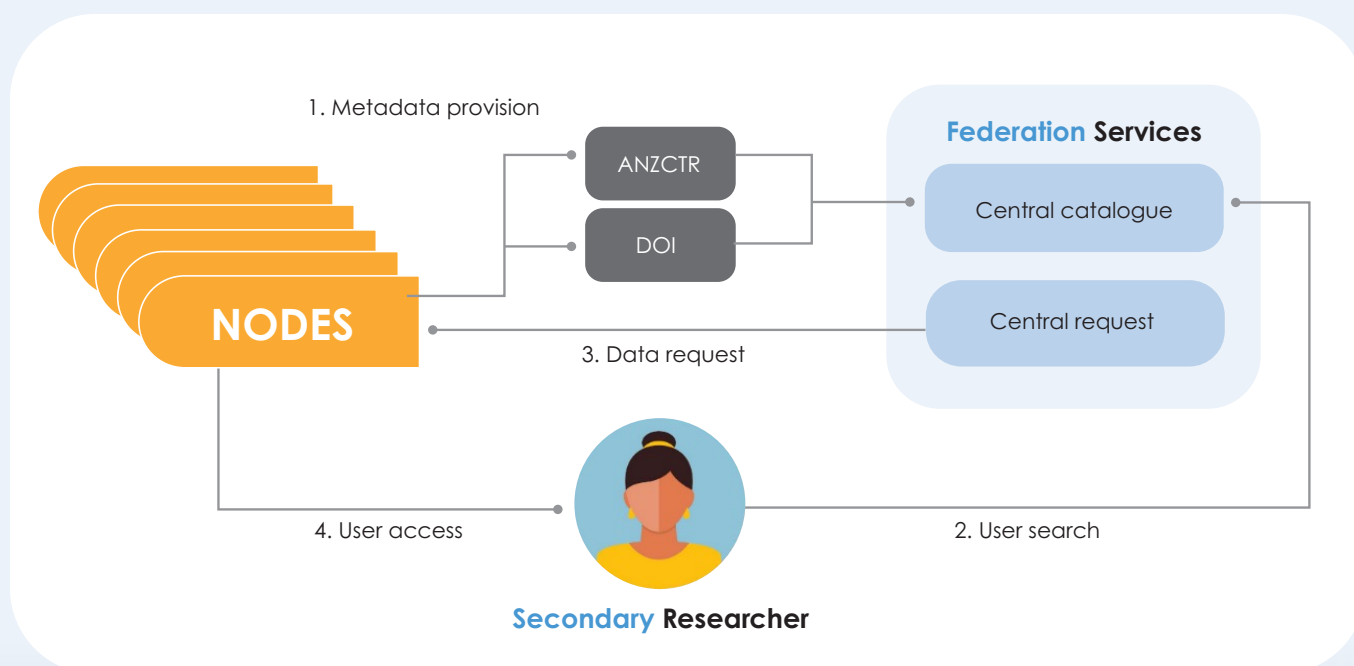
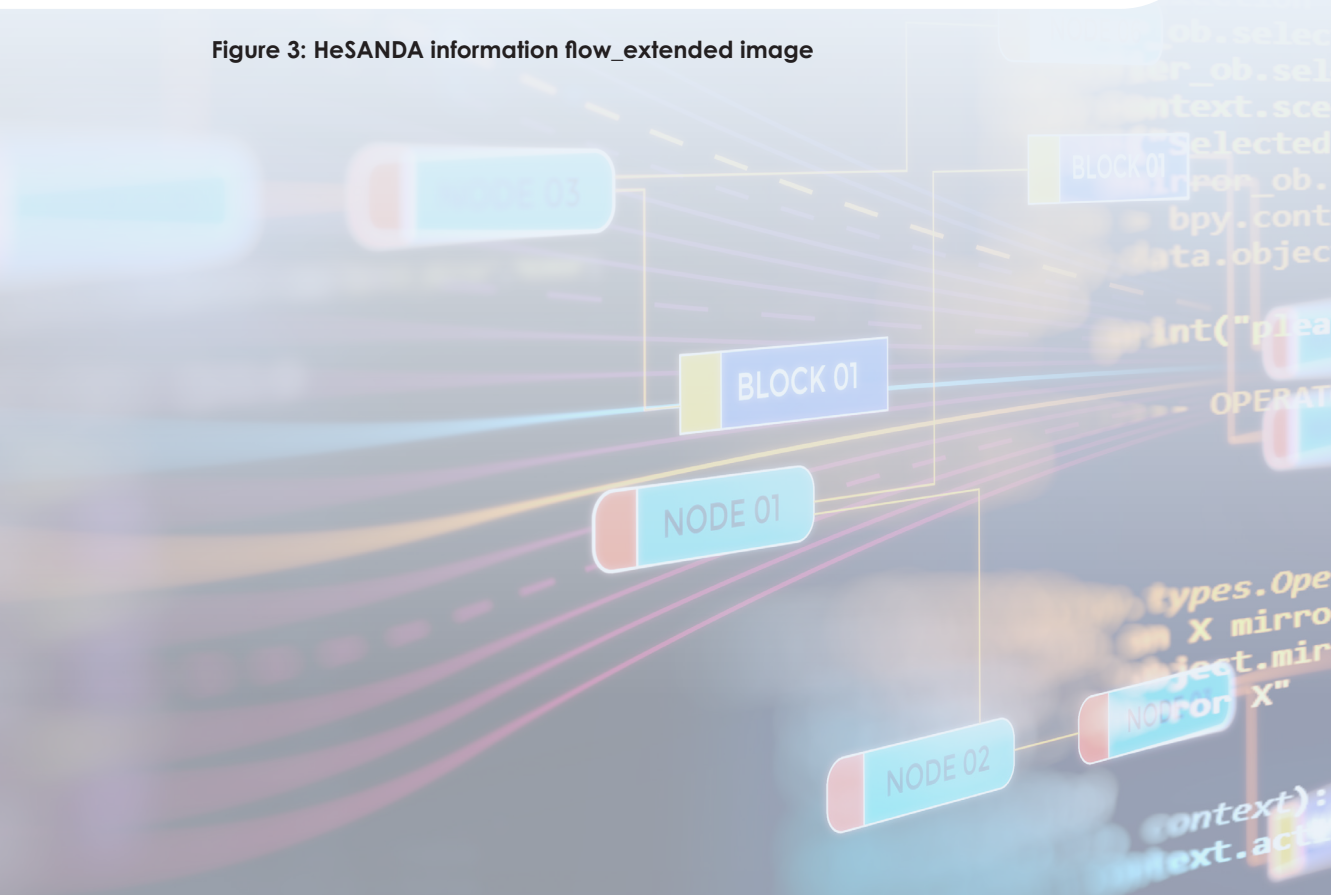


Figure 3: HeSANDA information flow_extended image



SA HeSANDA Node Plan

HTSA in collaboration with SA partners, is leading the SA HeSANDA Node. Three clinical trials have been selected to be used as demonstration projects.

Specifically, we are working together to:

- Determine the best approach for SA.
- Incorporate the nominated projects and testing elements within the HeSANDA initial program phase.
- Discover and develop business processes to ensure sustainability for future trials.
- Review, expand and create research policies applicable for data sharing.
- Define data requirements and activities for new trials.

Future expansion beyond the nominated trials could include other study designs such as cohort studies and registry science. This is planned for post June 2023.

Stages

Node activities are divided into four stages as illustrated in Figure 4. The SA Node is currently in Stage 3, with collaboration underway with the nominated clinical trial data custodians; SAHMRI Women & Kids and Flinders University Health Data & Clinical Trials.

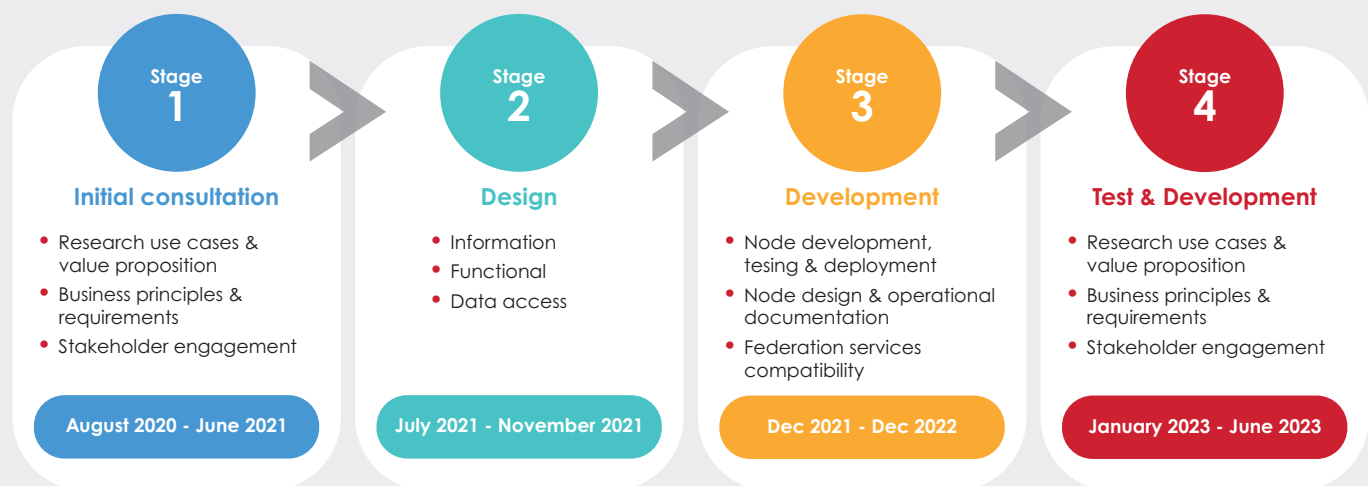


Figure 4: Node activities four stages

Governance

A Steering Committee (SC) has been established which includes nominees from HTSA Partners to ensure the alignment of strategic goals between and across partner organisations, and the delivery of the HeSANDA network requirements. The Steering Committee reports directly to the HTSA Board of Partners, which unites eleven academic, research and health care agencies in SA.

Expert Working Groups assist the SC, as needed, with members selected based on their expertise.

This structure supports systematic coverage of a significant number of research-intensive organisations across SA ensuring direct links from the node to operations, strategy and workflow

Steering Committee	SA HeSANDA Node Team
Professor Derek Chew, CEIH, Flinders University	Wendy Keech, HTSA CEO, SA HeSANDA Node Lead
Dr Karen Best, SAHMRI Women & Kids Theme	Andrew Brock, SAHMRI ICT
Dr Erin Morton, Flinders University	ARDC representative
Dr Liz Buckley, Flinders University	Tamara Hooper, Project Manager, HTSA
Professor John Beltrame, University of Adelaide	Nicole Sargent, Senior Project Officer, HTSA
A/Prof Stephanie Reuter Lange, University of SA	
Dr Elsa Dent, Torrens University	
Melanie Gentgall, SAHMRI	
Dr Gerry O'Callaghan, SA Health (CALHN)	
Ben Shores, SA Health	
Professor Chris Karapetis, Consumer_Secondary Researcher, SA Health (SAHLN)	
Saran Chamberlain, Consumer_Clinical Trial Participant	

Find out more

Wendy Keech

Node Lead

wendy.keech@healthtranslationsa.org.au

Tamara Hooper

Node Project Manager

tamara.hooper@healthtranslationsa.org.au

www.arcdc.edu.au/collaborations/strategic-activities/national-data-assets/health-studies-national-data-asset-program/
Published April 2022

SA HeSANDA Node Partners

