

Building national research infrastructure to share health research data: Lessons from HeSANDA and

Health Data Australia

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### What is Health Data Australia?

Health Data Australia (HDA) is a national catalogue of Australian clinical trials data designed to facilitate access, sharing and reuse of health research data.

Health and medical researchers can use HDA to discover and request access to data for their own research, or to register descriptions of their data to enhance discoverability by others.

Health Data Australia was developed by the Australian Research Data Commons (ARDC) in partnership with the health research community across Australia via the **Health Studies Australian National Data Asset** (HeSANDA) program.

### **Lessons Learned**



#### Standards and Interoperability

- Metadata harmonisation and adherence to FAIR principles were crucial for national discoverability
- Without common standards, scaling across institutions would not have been possible



#### **Building trust via Co-Design**

- Transparency is crucial for building trust
- Sharing methods and data validates research findings and reusing data and increases confidence in research processes
- The Node Network facilitates cross fertilisation of ideas and practices enabling data sharing maturity development across the nodes and their partners
- Co-design demonstrates the importance of understanding the different settings at the nodes and that of the researchers



#### Importance of Ethics and Governance

- Ethics and governance are as important as technology
- Open communication about research data handling demonstrates a commitment to ethical conduct
- Commitment to ethical conduct through public transparency builds the confidence of researchers and the public increasing social licence for research data sharing and trust in research processes



#### **Balancing Autonomy with National** Coordination

- National coordination has facilitated common understanding of the fundamental building blocks for increasing the capacity and capability of research data sharing, and making the best use of research data generated across the nation
- The Node Network model recognises that the Nodes and their partners may be at different stages with research data sharing.
- The Node Network enables opportunities for joint working and learning, which translates to improved workflow and increased convergence of good working practices

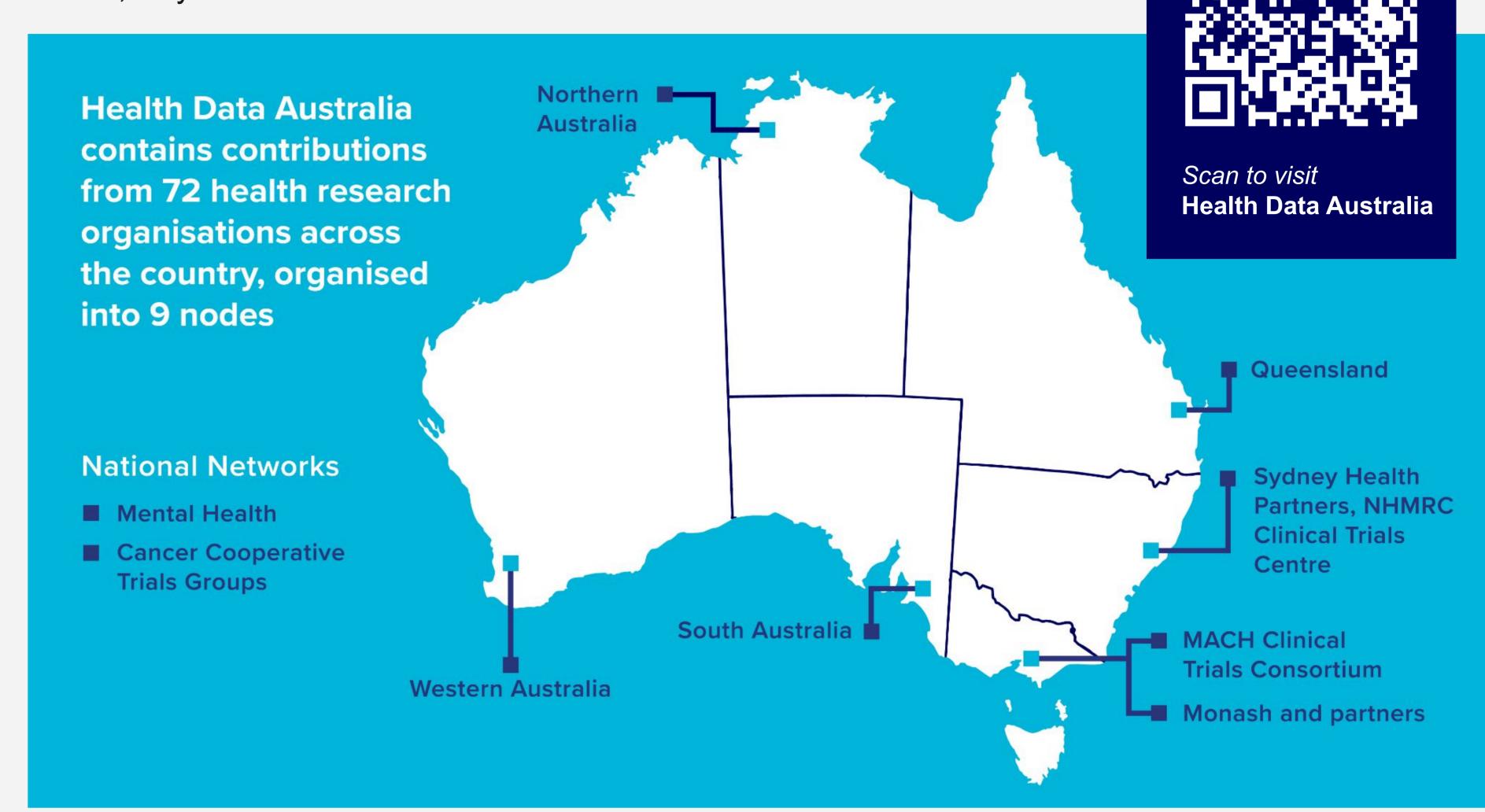


Figure 1. The HeSANDA program consists of 9 nodes across Australia, representing 72 health research organisations. To see if your institute is affiliated with HeSANDA, visit Health Data Australia (QR code above)

# **How It Works**

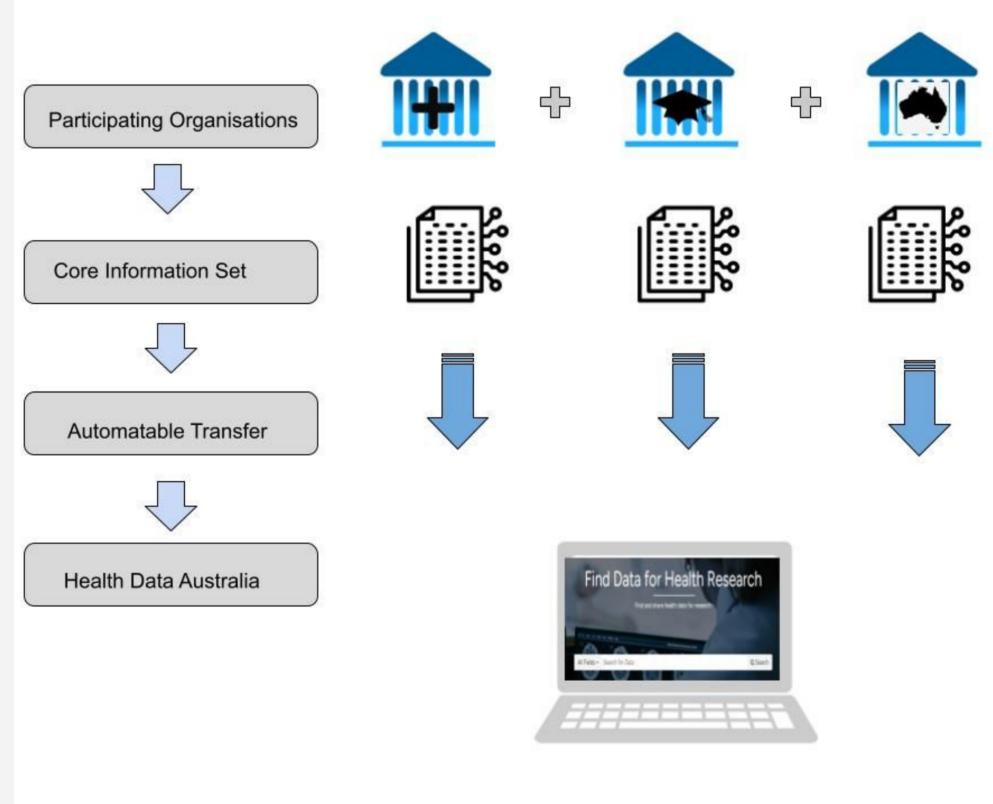


Figure 2. Information flow from Participating Organisations to Health Data Australia

The data is not stored on **Health Data Australia** (HDA). Instead, the platform enables the data owners to provide and share descriptions of the data ('metadata') to improve discoverability. In addition to metadata, data owners provide other documentation describing the dataset, such as study protocols and data dictionaries.

Researchers who are part of a HeSANDA Node provide metadata about their clinical trials to the HDA catalogue i.e. types of data collected, measurements taken, and tests conducted.

The **organisations** responsible for the clinical trials retain control of the data and with whom it is shared. Health Data Australia uses a standardised workflow for tracking and responding to data requests, while still allowing data owners to apply their own specific governance requirements for approving access to data.

# **Data Sharing Workflow**

Health Data Australia (HDA) consists of two components: the clinical trial metadata catalogue and data access request system.

The catalogue entry is created by combining metadata already supplied as part of ANZCTR trial registration with a new Health Data Australia metadata record created via the HeSANDA node network.

The HDA metadata record includes a **Digital Object** Identifier (DOI) for the data, and additional information about the available data and any restrictions on its use.

Following the successful search of the HDA catalogue, researchers are able to complete a form via the data access request system, which will send the request to the Node, relevant researcher, research team or data custodian.

For more information, it is best to contact your local HeSANDA Node Network (scan QR code above) as this process does vary. The decision about whether to share data and the process of sharing the data rests with the original research team / data custodian.

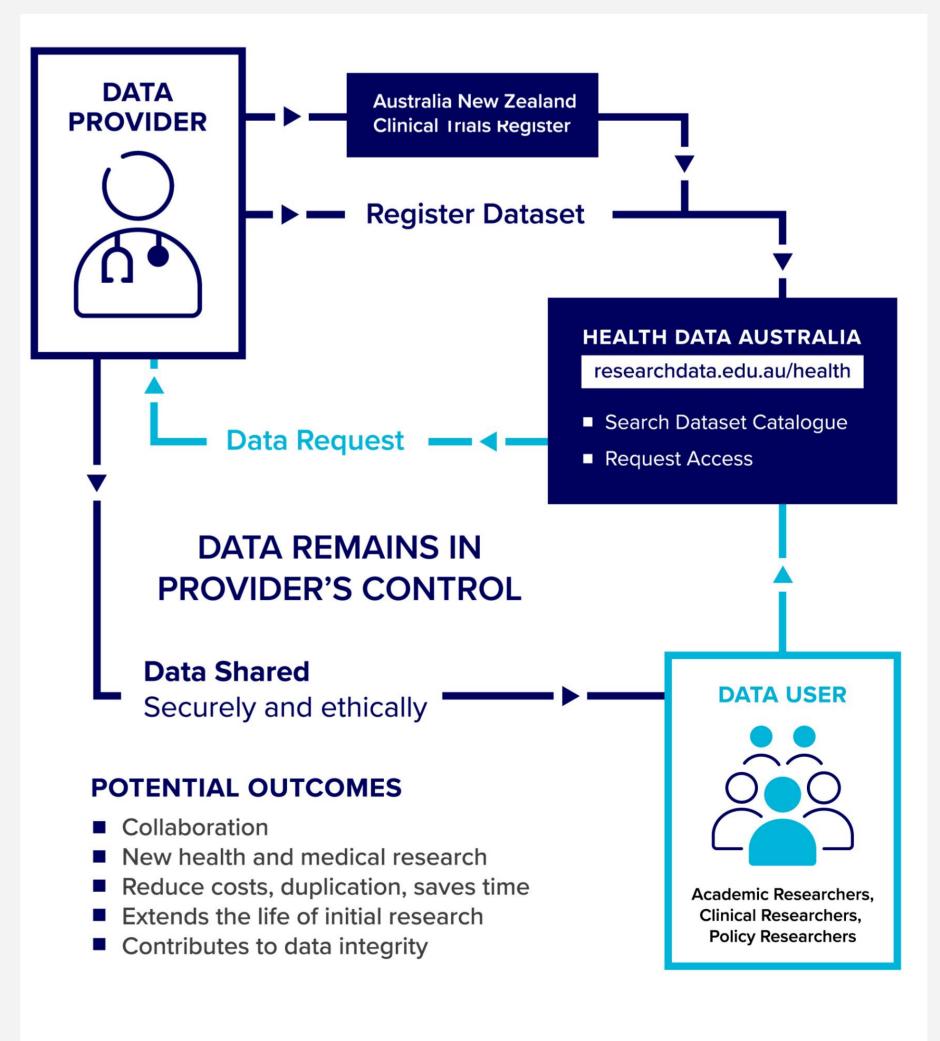


Figure 3. Data sharing workflow on Health Data Australia.

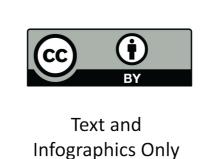
Contact us for for more information

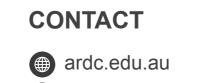
HeSANDA Team - hesanda@ardc.edu.au

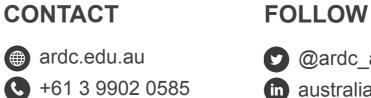
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