

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

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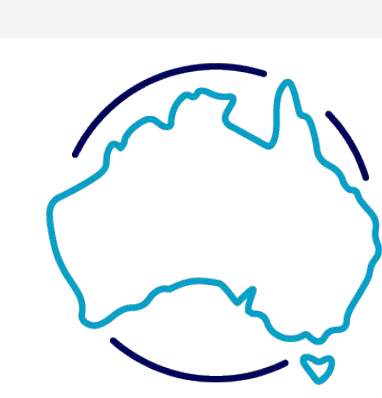
What is Health Data Australia?

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



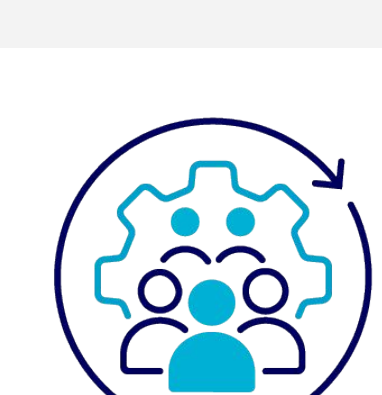
Standards and Interoperability

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



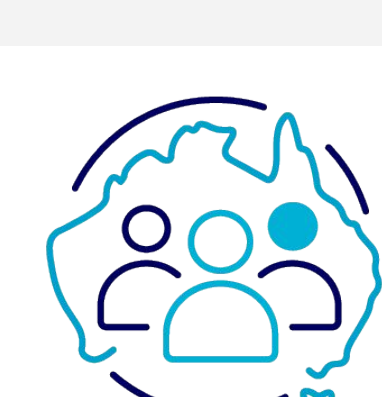
Building trust via Co-Design

- 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

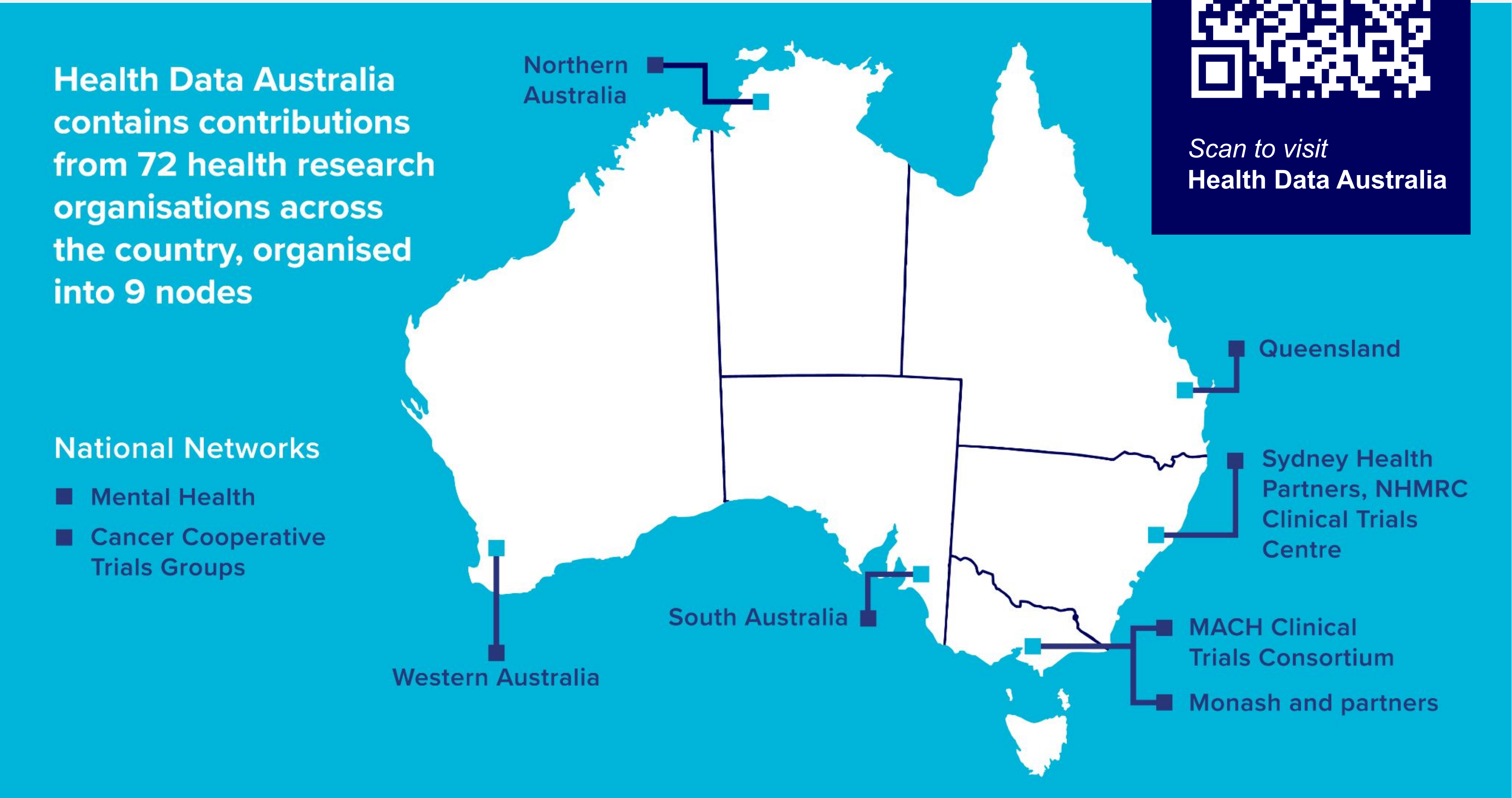


Figure 1. The HeSANDA program consists of 9 nodes across Australia, representing 72 health research organisations. To see if your institute is affiliated with HeSANDA, visit Health Data Australia (QR code above)

How It Works

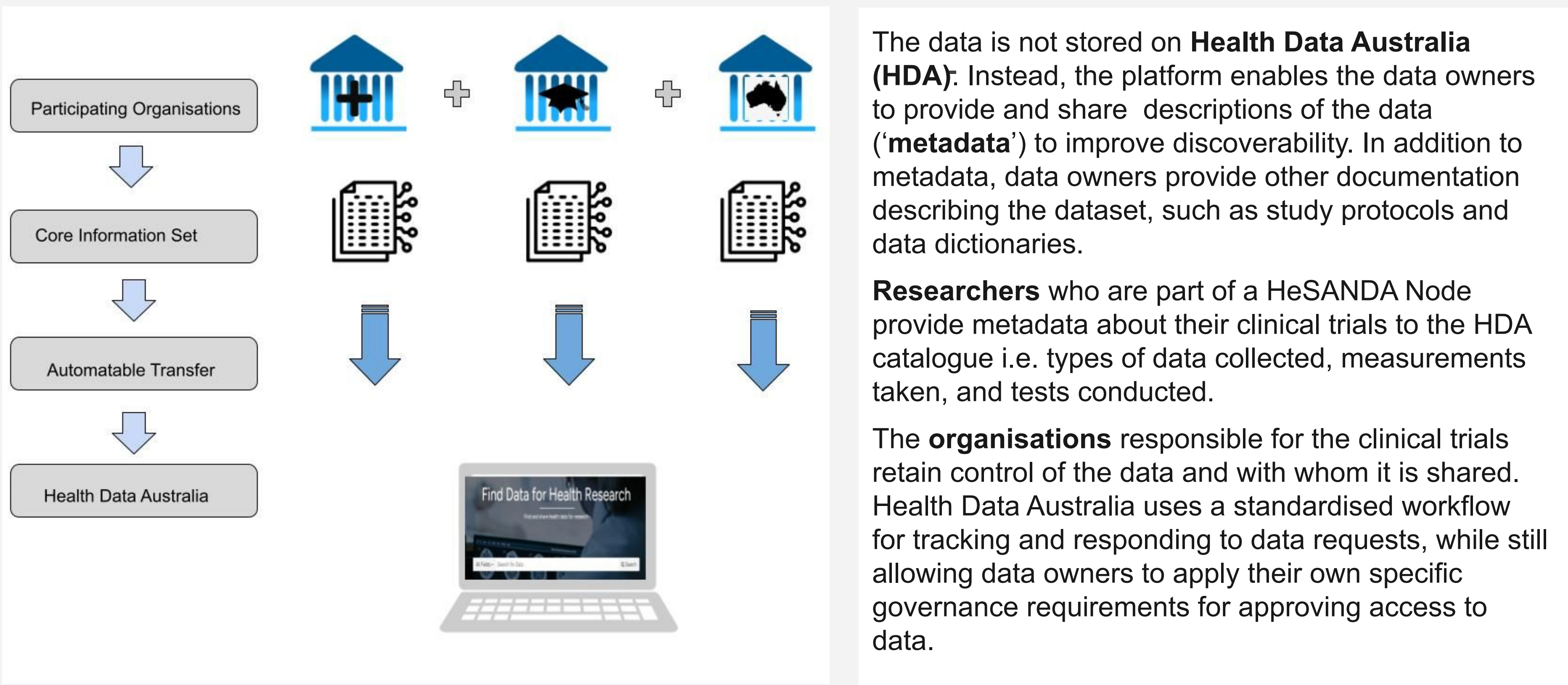


Figure 2. Information flow from Participating Organisations to Health Data Australia

Data Sharing Workflow

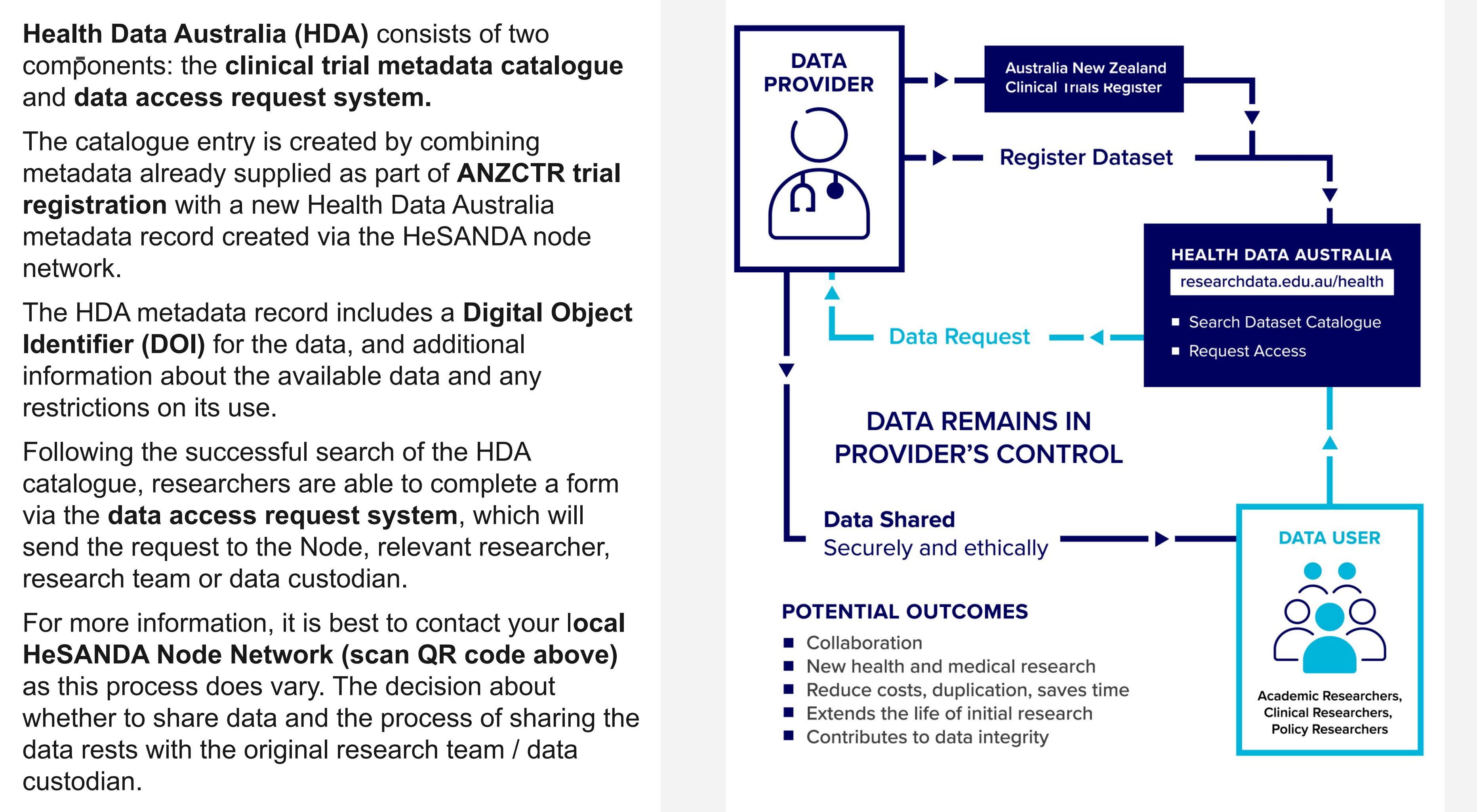


Figure 3. Data sharing workflow on Health Data Australia.