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

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The Health Studies Australian National Data Asset (HeSANDA), led by the Australian Research Data Commons (ARDC), is building national research infrastructure to enhance the discoverability, access, and reuse of data from health research studies across Australia. HeSANDA was established as a response to the critical need for more accessible and interoperable health research data.

The HeSANDA initiative has brought together diverse technical and institutional stakeholders across Australia to facilitate a cohesive and collaborative endeavour, formally known as the HeSANDA Node Network. This network comprises nine nodes across Australia, each representing a consortium of health research organisations. Collectively, these nodes encompass over 70 health research organisations, including universities, medical research institutes, health services, and clinical trial networks.

In 2023, the HeSANDA Node Network, alongside the ARDC, launched Health Data Australia (HDA). HDA is a national catalogue of Australian health data for researchers to discover and request access to data for their research (researchdata.edu.au/health/). The development of the platform was grounded in extensive consultations with the research community and key stakeholders. The framework for sharing clinical trial data was co-designed with ARDC and the HeSANDA Node Network.

HDA operates on a federated infrastructure model, where data remains under the control of the original data providers. The platform hosts metadata descriptions of datasets, allowing researchers to discover and request access to data without the data itself being stored centrally. This approach respects data custodianship and governance while promoting data discoverability and reuse.

In our poster, we outline the multi-layered infrastructure model that supports the control of the data with the data provider, while enabling national discoverability. We also highlight the collaborative work undertaken with the HeSANDA Node Network to develop standards procedures, best practices, and shared governance approaches. Our experiences addressing challenges we have encountered in harmonising metadata standards, policies and procedures, effective strategies for community co-design, and how we address consent and privacy concerns will also be shared.

The lessons learned during the development of HDA through the HeSANDA initiative provide insights for others seeking to build interoperable, researcher-focused data infrastructure.

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