

Data and Services Discovery projects - Institutional Role in a Data Commons

Title

Federated secure environment for health data

Approach

The project aimed to organise a national workshop with participants from the University, government and health care sectors to develop a consensus on the core principles of a national secure research ecosystem and create a roadmap to achieve this goal.

The key questions that needed to be considered were:

- How can collections of sensitive data be made available through fully governed and secure environments?
- How can the university, government and health care service sectors collaborate effectively and securely to create collections that enable the secondary use of health data on a national scale?
- How can health researchers get access to a secure national ecosystem that ensures the management and provenance of sensitive health data and also enables sustainable and scalable collaborations over sensitive data within secure environments?

As proposed, a workshop was organised on 11th September at Monash University and included the following participants.

University sector:

- Curtin University
- Latrobe University
- Monash University
- University of New South Wales
- University of Sydney
- University of Melbourne
- University of Wollongong
- University of Queensland / QCIF

Precinct, state and data owners:

- Department of Health and Human Services Victoria
- eHealth New South Wales
- Queensland Health
- Biogrid Australia

- Digital Health CRC
- Monash Partners Academic Health Science Centre
- Melbourne Academic Centre for Health

World-leading expertise on collaborative research environments for sensitive data and distributed computing:

- Swansea University, UK
- Population Health Research Network (PHRN)
- Australian Research Data Commons (ARDC)

The outputs of the workshop include a collection of presentations that capture a snapshot of the current landscape, specifically the challenges faced by Universities in managing and supporting data collaborations over sensitive data, the solutions available to Universities to manage this data better, the external data environment and funding landscape that can help shape the future.

FAIR

[FAIR assessment spreadsheet](#)

Collaboration

The workshop objectives were

- Identify the challenges faced by Universities in managing and supporting data sharing collaborations over sensitive health data collections.
 - Role of the Universities as data custodians
 - Making health data FAIR
 - Working with Data Owners/Custodians and the roles and responsibilities
- What are the solutions available to Universities to manage data better
 - Options
 - Defining what is technically federated infrastructure for data access, queries/analysis, and/ or linkage?
 - Feasibility of developing a federated SeRP capability across institutions to build greater capacity for the research sector for data sharing and data linkage
 - Principles for interoperability across different technologies
- Funding landscape / external data environment
- Agreement for priorities for a larger ARDC/NCRIS proposal - “Getting people onboard”

This workshop provided a unique opportunity to bring together some of the key stakeholders to frame the major challenges and prioritise desired outcomes. The primary outcome from the workshop was to identify Universities interested in collaborating to develop a national capability incorporating a carefully selected suite of technical solutions that will provide secure environments for health data; and to strive for interoperability between these systems to enable collaborations over sensitive data sustainably and at scale.

Sustainability

The workshop and subsequent discussions led to the development of a response to the ARDC call for Platforms EOI titled “Secure Environments for Research in Australia”. This proposal was jointly developed by the University of New South Wales, Swansea University, University of Melbourne, University of Wollongong, Latrobe University, Curtin University, QCIF, PHRN and Monash University.

Learnings

The key message from the workshop was the Universities aim to provide secure environments to enable researchers to collaborate over sensitive data and to transition from a landscape where data is locked away in silos to one where sensitive data is FAIR within the bounds of governance, legal and regulatory obligations. There was also a united view that there needs to be a carefully selected suite of technical solutions that need to be identified, developed, supported and made interoperable to allow for a scalable and sustainable ecosystem. This would provide a strong foundation to underpin best practice data governance, data sharing and linkage; which are key elements of a national data commons.

The ARDC is best positioned to support these collaborations through funding and enabling the university, government and health services sectors to build connections at the infrastructure and data governance and data sharing layers to enable effective and efficient research collaborations.

Impact

The research areas that handle sensitive data will benefit the most from the outcomes of the project, particularly health research.

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