




Australian Research Data Commons



MONASH
University

Workshop on Federated secure environment for health data

ARDC Discovery Project
21st October 2019



Identify { Challenges with collaborations over sensitive data A strategic approach for health data

What

Organise a workshop to identify how Universities, as trusted data custodians, can manage health data to make it FAIR in order to accelerate and advance health research and translation

Why

- Secure, connected and governed ecosystem for data management
- Trusted collaboration environment for data custodians
- Data linkage and data quality

Who

- Universities
- State governments
- Academic Health Science Centres
- World-leading experts
- Allied initiatives / organisations
- NCRIS capabilities



Key Issues for multi-institutional research collaborations

- Connected and secure health data ecosystem within institutions and interoperability across institutional systems
- Data governance frameworks
- Collaborations over sensitive data
 - Access controlled by custodians, while avoiding data silos
 - Secure and governed analysis environments
 - Sustainable and scalable data linkage capabilities
- Data quality
 - Common data models
 - Conversion of unstructured to structured data
 - Secure & reliable data feeds
- Big data with clinical genomics & imaging
- Jurisdictions and legal/regulatory obligations



Delivering secure infrastructure for sensitive data

- Trust is critical
 - The data is only as secure as the weakest link
 - In the absence of trust, custodians will lock up data - careers & reputation at stake
- Institutional collaboration over research infrastructure is a necessity
 - Jurisdictional restrictions for data movement
 - Scale of investment needed to do it well
 - Big data challenges are harder
 - Leverage existing know-how and expertise locally/globally
- Shared standards & protocols for better data quality
- Data governance to minimise risk

PREFERENCE FOR A FEW INTEROPERABLE SOLUTIONS
SUPPORTED BY A COMMUNITY OF PRACTICE

Acknowledgements



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