A data governance framework for federated data: Challenges and benefits

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Federated Data Governance Framework

Health Data Overview

Health data is:

• Dispersed throughout numerous systems (electronic and analogue) throughout the health system
  – Clinics, Departments, Health Services, Jurisdictions

• Increasingly used to drive efficiency, improve patient outcomes and for translational research

• Managing access to/use of health data requires robust data governance frameworks
  – Custodianship, privacy, security, ethical, legislative
Federated Data Governance Framework Planning Considerations

• Objectives/Purpose
  – What are you trying to achieve?

• Context
  – Research vs. government reporting

• Capabilities/Limitations
  – Resources – IT Infrastructure, expertise

• Flexibility
  – Data cannot always be handled in a ‘preferred’ way
    – Iterative implementation

• Stakeholder Requirements
  – Custodians, Executive, IT department
  – Patients
Federated Data Governance Framework
BioGrid Australia

- Developed from grass-roots by researchers wanting clinical data across institutions and jurisdictions to be made available for collaborative research.

- Built on 3 pillars of Collaboration, Custodianship, Privacy
  
  - **Collaboration**: Data Contribution/Access, Intellectual Property, Individual Privacy, BioGrid Legal Agreement, HREC
  
  - **Custodianship**: Custodian retains full control over Data, Collaborative Intent, Technology solution to facilitate (BioGrid Legal Agreement and HREC Oversight)
  
  - **Privacy**: Individual Privacy, HREC Review and Approval, Appropriate Use of Data (Privacy Legislation, BioGrid Legal Agreement and HREC Oversight)
Federated Data Governance Framework
Managing Data Access

• Framework governs how data access is managed
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• BioGrid has developed a web-based application for managing data access application and approvals.
Federated Data Governance Framework: Collaboration Governance

- Overarching legal agreement
  - Provides framework for collaboration
  - Requires executive ownership

- Researchers agree to T&Cs (per project)
  - Aware of responsibilities
  - Requires researcher ownership
Federated Data Governance Framework: Custodianship

- Always retain full control over data access
- Maintaining engagement with custodian

- Enables access to health data for research that would otherwise be unavailable
- Requires custodians that are willing to collaborate and share data
Federated Data Governance Framework: Privacy and Ethics

- Overarching ethics approval for federated data linkage process (per institution):
  - Allows flexibility in processes
- Streamlined ethics approval required for each application
  - Approved projects bypass further ethics review (still require custodian approval).

- Requires resources to maintain approval and engagement (per institution)
Australian Sarcoma Study Group
Account for less than 3% cancer diagnoses
- 5 sites currently linked
- 2500 patients (100-1000 per/site)
National Pituitary Tumour Group
- 3 colleagues; 2 (separate) database; common research interests
  - Includes Sydney Pituitary Tumour Group, other clinicians
- BioGrid currently working with group to develop national database
Federated Data Governance Framework

Summary

• A good data governance framework for federated data:
  • Increases opportunities for collaboration (data custodians, executive)
  • Enhances real-time access to health data for research purposes
  • Facilitates research that improves patient outcomes
  • Is flexible enough to accommodate different requirements
  • Provides benefits that exceed the resources required to establish and maintain it
Thank You

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