Melbourne Genomics
Health Alliance

Global knowledge. Individual care.

Data access and sharing

Background

The delivery of high-quality genomic medicine depends on ethical, secure access to genomic information for clinicians and patients.

Melbourne Genomics Health Alliance has broken new ground in demonstrating that multiple organisations can adopt and share approaches at each point in the patient care pathway – including infrastructure, software, policies, procedures and agreements.

Melbourne Genomics developed and operated a prototype genomic information system, DASh, which supported access to data (with patient content) for analysis and research. This initiative complemented the work to establish a common system for the management of clinical genomic data – GenoVic[1] – and also fulfilled the data sharing needs of the Melbourne Genomics' Clinical Flagships[2].

Project description

The Melbourne Genomics Data Access and Sharing prototype system (DASh) was developed to share clinical- and research-generated Flagship data between member organisations and collaborators, for clinical, research and laboratory validation purposes ('secondary use').

Developed from 2016, DASh comprises a web portal and database for semi-automated handling of applications for data access, as well as Data Access Committee review processes and a data request interface.

Unlike existing systems, which were designed to manage researcher access to research-derived data cohorts, DASh is unique in handling requests for clinically generated genomic data.

Data access and sharing policies, procedures and agreements were developed and deployed. These align with the data governance environment within Melbourne Genomics[3] and with evolving regulations and standards in the field of healthcare genomics.

Outcomes

DASh supported secure and ethical access to patient-level, consented genomic data from clinical testing[4].

Development of the DASh system has facilitated additional diagnoses for patients, as well as advances in research for medical conditions investigated by Melbourne Genomics.

Further benefits include:

- Increased collaboration among the Melbourne Genomics members and with external collaborators through data sharing

- The development of the DASh system has informed planning for future implementation of data access and sharing systems within the GenoVic platform

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[1] See project summaries, 'GenoVic system: Selecting the best genomic tools' and 'GenoVic system: Build and implementation'.
[2] See project summaries, 'Evaluating clinical utility of genomics: Overview'.
[3] See project summary, 'Governance of genomic data'.
[4] See project summary, 'Making clinical genomic data available for sharing'.

- Melbourne Genomics members have gained expertise in data access and sharing systems, and now have an enhanced ability to contribute to national and international discussion and approaches to data sharing

Lessons learnt

- The project brought into sharp focus the challenges associated with data sharing, including ethics considerations, complexities in data transfer and the variation that exists in data structures, systems and processes across multiple laboratories. Iterative improvements were made as new challenges were encountered and solutions developed.

- A project of this magnitude requires a team appropriately resourced to scope and execute effectively within a committed timeframe.

- Researchers and clinicians want secure and ethical access to patient-level, consented genomic data. Projects such as DASh are needed and will improve clinical care for patients over the longer term.