Melbourne Genomics
Health Alliance

Global knowledge. Individual care.

Making clinical genomic data available for sharing

Background

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

Genomic data from Melbourne Genomics Clinical Flagships[1] was made available to be reanalysed for research purposes where the researcher had appropriate ethics approvals.

Melbourne Genomics undertook work (DASh system[2]) to ensure that Flagship data would be available to the members and their collaborators during the 2016 to 2019 program.

Project description and activities

The objective: to establish a process to transfer Clinical Flagship data from laboratories to a single data store to enable access among the Melbourne Genomics members and their collaborators.

Detailed transfer and storage processes for Flagship data were established and documented for each genomic testing laboratory. The Controlling Superbugs Flagship's pathogenomic data was not included, as the data model for access and storage is human-specific. Data from the Kidney Genetics Flagship was also excluded[3].

The Melbourne Genomics Health Alliance members involved were: Australian Genome Research Facility, Peter MacCallum Cancer Centre, Monash Health, Murdoch Children's Research Institute / Victorian Clinical Genetics Services, the Royal Melbourne Hospital and Austin Health.

Outcomes

All Flagship data has been transferred from laboratories to a single data store.

This initiative resulted in increased quality and safety for the data transfer process – enabling harmonised, structured and centralised storage of Flagship data. More reliable and efficient access to participant genomic data was established overall.

Laboratories gained expertise in large-scale genomic data transfer processes, and now have improved storage.

Impact

Knowledge gained through this project has subsequently informed data transfer processes implemented by the Australian Genomics Health Alliance.

[1] See project summary 'Evaluating clinical utility of genomics in care: Overview', as well as individual Clinical Flagship summaries for results.
[2] See project summary, 'Data access and sharing'.
[3] Data from the Kidney Genetics Flagship is managed by the KidGen national project: http://www.kidgen.org.au/

Lessons learnt

- Retrospective data retrieval and transfer processes from unstructured data stores involve significant complexity, rely on highly manual steps, present significant data governance and systems challenges, and are a barrier to timely, accurate storage and access for secondary use of genomic data.
- Patient and sample information discrepancies are common between the consent form (in RedCAP study database) and test request source (laboratory LIMS systems). This has required thorough, resource-intensive, manual database audits to identify and resolve discrepancies prior to data transfer.
- In the absence of a shared clinical system (GenoVic[4]), laboratories require tailored data transfer solutions to meet the needs of different internal systems, infrastructure, policies and procedures.
- Timelines for execution of data transfer need to be established from the outset, to ensure clear expectations and accountability that allow laboratories to plan data transfer activities. Higher accuracy of the data transfer process is achieved after all results have been returned to patients from a given Flagship cohort, due to laboratories' internal processes.

[4] See GenoVic project summaries.