

# Patients' willingness to share their genomic data

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## Background

The data generated through clinical genomic testing has high value in medical research. As genomics is increasingly incorporated into practice, consideration needs to be given to how to share the resulting data while ensuring patient trust is maintained. Patients should not decline a clinical test due to concern about sharing of their data for research purposes.

In Melbourne Genomics' Clinical Flagships, patients received genetic counselling – which included discussion of data storage and sharing – prior to consenting to the test. Patients could opt to share their potentially re-identifiable data for research that may benefit their future healthcare.

## Project description

The objectives of this project were to:

- Identify actual decisions patients make about sharing their clinically-generated genomic data for research
- Explore patients' perceptions of the adequacy of counselling regarding data storage
- Understand hypothetical patient preferences regarding the future storage, access for research and use of genomic data generated through clinical care

The choices patients made about data sharing were determined from the consent forms.

More than 1,400 patients and parents of paediatric patients who consented to genomic testing were invited to complete a survey after pre-test counselling, but prior to receiving their results.

## Activities, outcomes and lessons learnt

Findings from this project will be made available following publication of results.

## Impact

This study was the first internationally to demonstrate that patients having clinical genomic testing for a range of conditions agreed to share their genomic data for research.

These results informed the parameters of data governance for GenoVic, the Melbourne Genomics system for analysing, storing and sharing clinically-generated genomic data (see separate GenoVic summaries). The results also have wider implications, including for national data sharing systems.