Melbourne Genomics
Health Alliance

Global knowledge. Individual care.

Patient experience of genomics

Background

Melbourne Genomics placed patients' needs and trust in the system at the heart of its program.

Studies have explored the medical impact of genomic sequencing tests on the care of patients, but have not consistently investigated the perspectives of diverse patients having testing within clinical care provided by a range of medical specialists.

From 2016 to 2019, 11 different Clinical Flagships provided testing to patients in parallel with the usual care for their medical condition. Flagships spanned hereditary diseases, infectious diseases, haematological and cancer, and paediatric and adult care. Genetic disease Flagships focused on diagnostic utility and the clinical utility of diagnoses. Cancer Flagships explored the impact of testing on treatment decision-making.

Project description

Objective: to investigate the experience of patients having genomic testing and their perspectives on the value (or otherwise) of this testing.

Patients in nine Flagships[1] were asked to complete surveys. Each patient was asked to complete two surveys. Patients were asked to respond to questions relating to genetic counselling, understanding of test results, anticipated and actual value of the testing. Quality of life and psychosocial impact were assessed where possible.

The demographics of the respondents were analysed and compared both to the Victorian population and (where feasible) to patients from the Flagship who did not respond.

Activities, outcomes and lessons learnt

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

[1] One Clinical Flagship tested microbial samples. Patient experience in the Perinatal Autopsy Flagship was explored through interviews.