

Evidence Summary

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Australian Genomics Coordination & Core Capabilities

Australian Genomics is operating nationally to support the delivery of national genomic research activities.

The **core research capabilities** of Australian Genomics include a national network of experienced research coordinators and genetic counsellors; mature governance structures and advisory boards; and research programs providing assessment and evaluation of genomic research outputs in policy, ethics, implementation and cost effectiveness.

This established research support capacity has taken more than three years and \$6.3M to develop, and an additional \$3.2M has been invested in the data management infrastructure for the secure storage and interrogation of the clinical and genomic information of the 25,000 people participating in our research programs.

These capabilities have supported the delivery of the \$25M NHMRC grant outcomes, and are leveraged by Genomics Health Futures Mission (GHFM)-funded Mackenzie's Mission (\$20M), the Cardiovascular Genetic Disorders project (\$6M), and the Leukodystrophy Project 'Massimo's Mission' (\$3M).

Australian Genomics was also approached by a number of applicants for the initial competitive round of GHFM funding for research, seeking to leverage our established coordination, governance and research capabilities.

We have partnered with three Cancer/Low-Survival Disease projects; four Paediatric Acute Care and five ELSI proposals, in addition to a \$10M Congenital Heart Disease Accelerated Research Grant submission.

Australian Genomics' core capabilities can be leveraged and expanded to deliver other genomic research programs:



- A national coordination network of research managers, genetic counsellors and project officers
- A research governance framework providing operational oversight, project progress and risk management, and strategic and community guidance
- Human research ethics and governance management
- Recruitment site management
- Media, communications and engagement support
- A suite of established participant materials and resources: consent, education and information
- The CTRL participant portal and dynamic consent platform
- Established gene lists, minimum clinical datasets, and data management tools
- A portfolio of patient survey and evaluation tools
- Expertise in health economics, implementation science, policy, ethics and law
- Overarching project guidance, evaluation and reporting / finance support.

Supporting new genomic research programs with established and experienced coordination and core capabilities **reduces project expenditure** through economies of scale and scope; **mitigates project risk** through governance; and **accelerates patient enrolment** by reducing establishment time.