Supporting families through genomic testing

We are interested in your experiences with genetics services in Australia

What supports did you need and how would you like to be supported?

Please take our survey to help us understand if the genomic testing process can be improved.

Parents or legal guardians of children who had genomic testing since January 2017 are invited to participate in a research study called "Supporting families through genomic testing". The study aims to understand how genetic services support families of children with rare conditions in Australia. The study involves completing a survey about your experiences with genetics services, including preparing for testing, receiving your child's genomics results, and any follow-up care provided by genetics services in Australia. The project will help identify what supports are needed and preferred by families. Survey results will be reported back to the study team in an anonymised way to help improve the genomic testing process and genetics services for families going through similar experiences. More information about the study is available at the start of the survey.

The survey will take approximately 20 minutes to complete and can be completed online at this link:
https://redcap.link/ixyo7koa

This project is being carried out by the Murdoch Children's Research Institute (MCRI). The Results of the research will be used by Ms Samantha Evans as a partial requirement of the Masters of Genomics and Health degree at the University of Melbourne.

For further information about this study, please contact the research team:
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To ask for a paper copy of the survey, please contact:
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