

Understanding parents' service experiences of genomic testing

Paediatric doctors can now order certain genomic tests. This change aims to help more families access accurate diagnoses more quickly. We're developing a tool to help healthcare providers capture families' experiences and make sure families receive the support they need.

How can you help?

We want to work out what is important to capture from parents' perspectives. **If your child has had outpatient genomic testing (exome or genome sequencing) for a condition (excluding cancer) in the last 5 years**, we'd love to hear from you.

What's involved?

- 1. Answering some questions** so we know who is taking part
- 2. Participating in a 1.5-hour online focus group** where you will
 - Watch a video about what matters to parents based on past research in genetic settings
 - Discuss if this is an accurate summary of parents' needs & what would make for good service delivery by paediatric doctors

1-1 interviews are available if you prefer
- 3. Sharing any further thoughts (<20 mins)** 1 week later

What happens to your data?

We'll record the focus group sessions and transcribe the audio. Video recordings will be deleted and transcriptions will be de-identified. All data will be stored securely, and only researchers involved in the study will have access to the files.

Understanding the benefits and risks

Benefits

- While this project is unlikely to benefit you personally, it will:
- Help doctors, hospitals and researchers understand parents' experiences of genomic testing
 - Help improve services to better meet families' needs in the future

Risks

- While we'll remind everyone to not share what's been discussed in focus groups, we can't guarantee everyone will comply.
- Discussions may trigger memories of poor care experiences. Please note you can take a break at any point. We can also connect you to organisations like Beyond Blue.

What else you need to know:

Participation is voluntary. It may not be possible to remove data already collected and de-identified for analysis, but all reasonable attempts will be made to remove information specific to you at your request to withdraw.

We'll send you a summary of the project's results.

We want this study to be accessible to people of all abilities. Please let us know about any support you may need to participate.



You'll receive a \$30 gift voucher after the focus group to thank you for your time!

Ethics ID# 25541

If you're interested or would like to know more, contact PhD student Erin Crellin crelline@student.unimelb.edu.au