



WE WANT TO HEAR FROM YOU!

Help Shape Rare Disease Research in Australia

Rare Voices Australia (RVA), the national peak body for Australians living with a rare disease, and The Kids Research Institute Australia (formerly Telethon Kids Institute) are conducting a Rare Disease Research Priority Setting Partnership Project. This project aims to identify and prioritise the *Top 10 Most Important Unanswered Research Questions for the Future of Rare Disease Research in Australia*.



We are looking for:

1. People living with a rare disease (18+ years of age)
2. Parents or carers of people living with a rare disease
3. Health professionals working with people living with rare diseases



What do we need your help with?

We are looking for people to fill out an online survey that asks you about your most important research questions or concerns about rare disease. This survey takes about 5-10 minutes.

This study is approved by the UWA Human Research Ethics Committee (Ref: 2024/ET000158)

CONTACT US

To access the survey:

- Click [HERE](#)
- Scan the QR Code
- Or email RareDiseaseResearchPriorities@thekids.org.au

SCAN ME

