

About us

20+ years of an organisational-wide consumer and community involvement strategy. Key ingredients to our success:

- Senior level champions
- Funding for dedicated roles, training and resources
- Strategic Goal of the organisation
- Strong networks

<https://www.telethonkids.org.au/our-research/help-shape-our-research/>





Community Engagement
Team



Responding to COVID19

March 2020 in response to:

- Queries from researchers about accessing community members
- Concerns about lack of involvement in research being developed

We invited 20 experienced community advocates from across Australia to form a national advisory group to provide input into COVID19 projects



Activities and achievements of the Advisory Group to date

- Provided input into 17 projects: local national and international
- Range of projects: clinical, laboratory, mental health, infectious diseases, health promotion
- Priorities for future research
- 8 virtual meetings +100's of emails
- 250+ cumulative hours of input



“It’s a real priority to ensure COVID-19 research is properly in synch with the needs of our community. The community cost of COVID-19 is so high, so it will be great to see consumers and researchers working together to ensure that research is going to be of maximum benefit to the community.”

Cath – Community Advisory Group member



“It was important to ensure the scientific approach was integrated with Consumer views. By participating in the group I came away confident that researchers were truly seeking to partner with consumers and their views were respected and appreciated, even when they differed from those held by the research team.”

Amber – Community Advisory Group member



“The COVID-19 Clinical Data Analytics Platform aims to improve the management of COVID-19 patients by learning from previously treated patients. The CAG provided important independent feedback on a number of issues. As clinicians and researchers, it has been invaluable to hear directly from consumers how they want their data to be used, and what safeguards they expect to be applied regarding security and privacy.”

Professor Tom Snelling - researcher



In conclusion, my reflections on what enabled us to facilitate a critical service of providing rapid community input into COVID19 research:

- Our team was responsive to the urgency of the situation
- We are supported and trusted by the Institute's Leadership Team and senior researchers both locally and nationally
- We leveraged our existing relationships with community members and their strong commitment to community engagement in research