

A consumer perspective on involvement

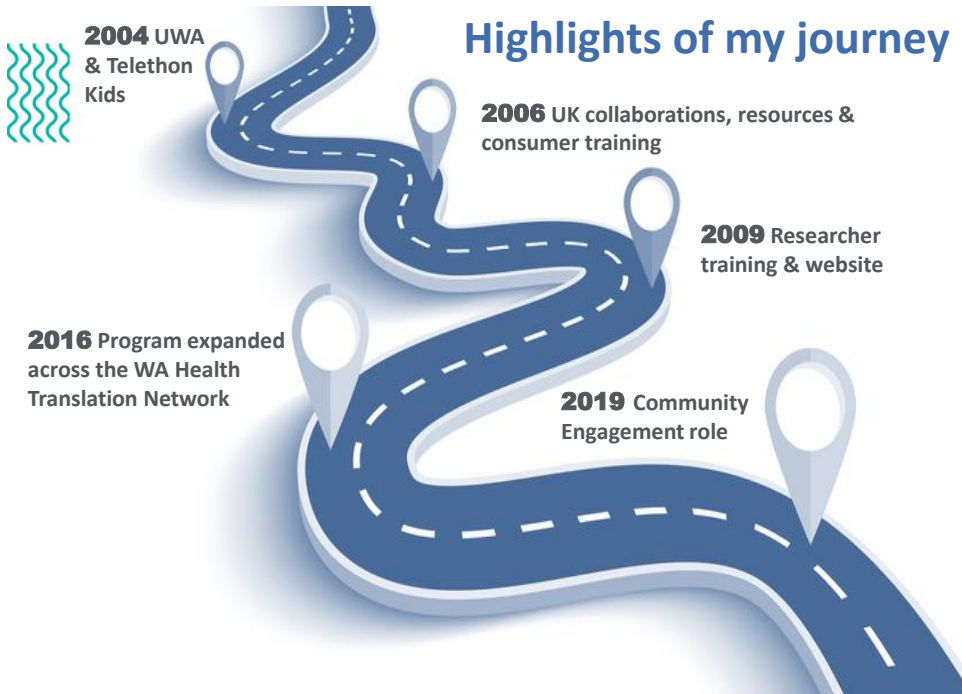
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ACTA International Clinical Trials
Conference 2109



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Highlights of my journey





What's worked for me



Key ingredients:

- Senior level champions
- Funding for dedicated roles, training and resources
- Strong networks – 100's of committed consumers and community members
- International collaborations and mentors
- Having a large soapbox and never moving off message:

"consumers add value to research"



What's worked at Telethon Kids Institute

15+ years of an organisation-wide consumer and community involvement strategy that includes:

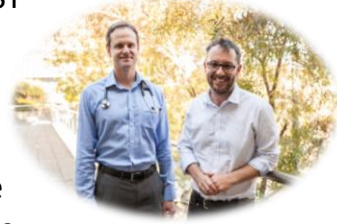
- Committed leadership
- Goal of the Strategic Plan/s
- Mandatory requirement for internal funding schemes
- Budget for involvement activities
- +10 Incentive scheme for external grants





Good practice examples

- Researchers consulted with the AREST CF Community Reference Group for advice on the BEAT CF proposal
- A consumer advocate as a CI
- A consumer advisor is employed one day a week to provide ongoing advice
- Three national Community Advisory Groups with 27 members having input into ethics application, electronic consent and secure data storage



Preterm Paediatric Inhaled Corticosteroid Intervention Trial

Part of long-term research program on lung health of very pre-term children and young adults

Consumer reference group provides input

- Development of grant application/s
- Study documents
- Strategies for recruitment
- Dissemination strategies
- Priorities for future research





Neuromuscular Disorders Study

- Pilot project where parental input changed sleep studies being held in hospital to the home
- Parents consulted on proposed study
“it will be hard yakka’ but we’ll get better treatment so please go ahead”
- Community Reference Group now advising on study documents, links to consumers, priorities, advocacy and dissemination of results



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9 remote Aboriginal communities
in the Kimberley region of WA
Extensive community consultations
Local Aboriginal-led recruitment

- Consent flipchart – visual consent tool
- >700 children enrolled



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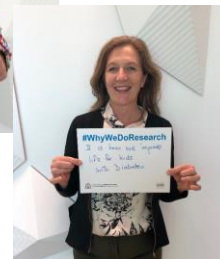
Local Aboriginal Research Assistants:

- Design/implement community driven skin health promotion activities
- School healthy skin checks & data collection
- Community engagement



The future

- Developing a wider engagement program that will include everyone who interacts with Telethon Kids
- Working with Perth Children’s Hospital on cross-campus activities such as:
 - International Clinical Trials Day initiatives
 - priority setting projects



#WhyWeDoResearch

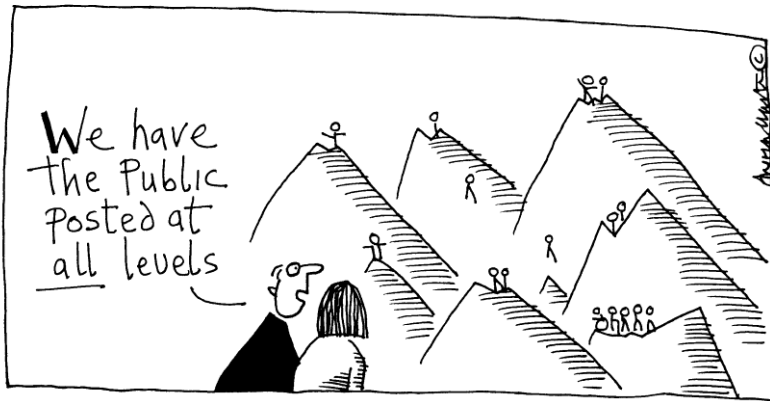


Government of Western Australia
Child and Adolescent Health Service





In 2016 ACTA asked about my hopes for consumer involvement in 5 years?

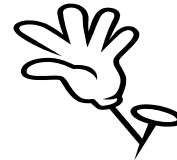


Source: INVOLVE UK 2008

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Hands up research



- Hands up if you conduct clinical trials
- Keep your hand up if you have consumer involvement in the decision-making of your trial
- Keep your hand up if you have consumers involved at all levels and stages of the trial:
 - Management, design phase, implementation, dissemination
- Keep your hand up if you have/or plan to evaluate the impact of consumer involvement activities

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Thank you

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