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# Researchers + Consumers + Community = Partnerships

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Faculty of Medicine, Dentistry and Health Sciences Research Day

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# Stand-up research project

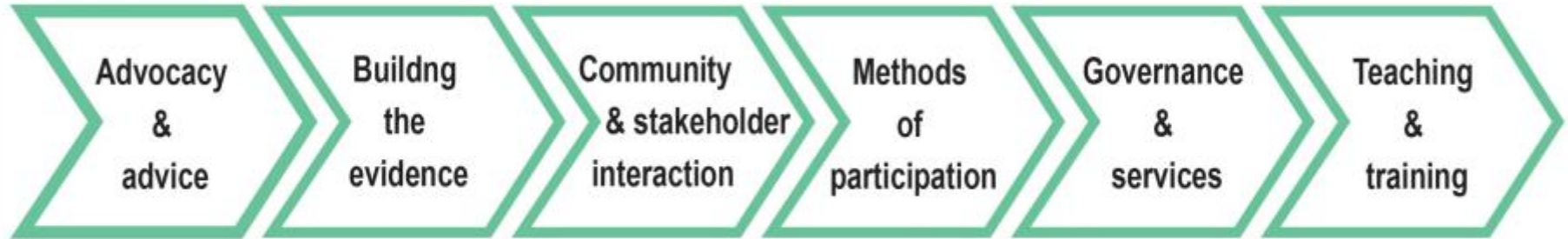
- Have you ever been a participant in a research project?
- Were you unhappy about any aspect of the research?  
consider: questions, methodology, times
- Did you have ideas to improve the research?
- Were you invited to give feedback about the research?

# The Consumer and Community Participation Program

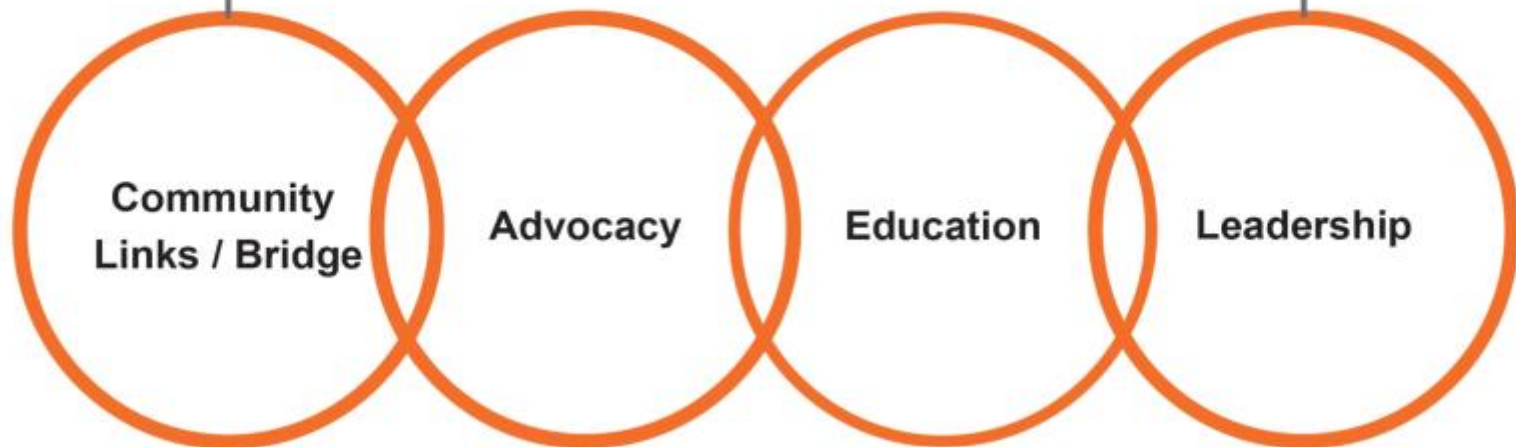
- One-of-a-kind joint program in Australia that develops and implements participation activities across both organisations
- Established in 1998 in response to community concerns about linked data research.
- Receives national and international recognition.
- Multi-faceted program of work that delivers a wide range of activities, resources and support.



## Consumer and Community Participation Program



### Key Deliverables



# About the Program

## *Ethos*

Underpinned by the philosophies of the National Health and Medical Research Council and Consumer Health Forum's *Statement on consumer and Community Participation*

## *Aims of the Program:*

Consumers, community members and researchers working in partnership to make decisions about research priorities, policy and practice

## *Key components:*

- Senior level support and champions
- Dedicated positions to develop, implement and support participation

# Program website

The website houses:

- Resources
- Methods we use
- Publications
- Events & training
- Hot topics
- Committee vacancies

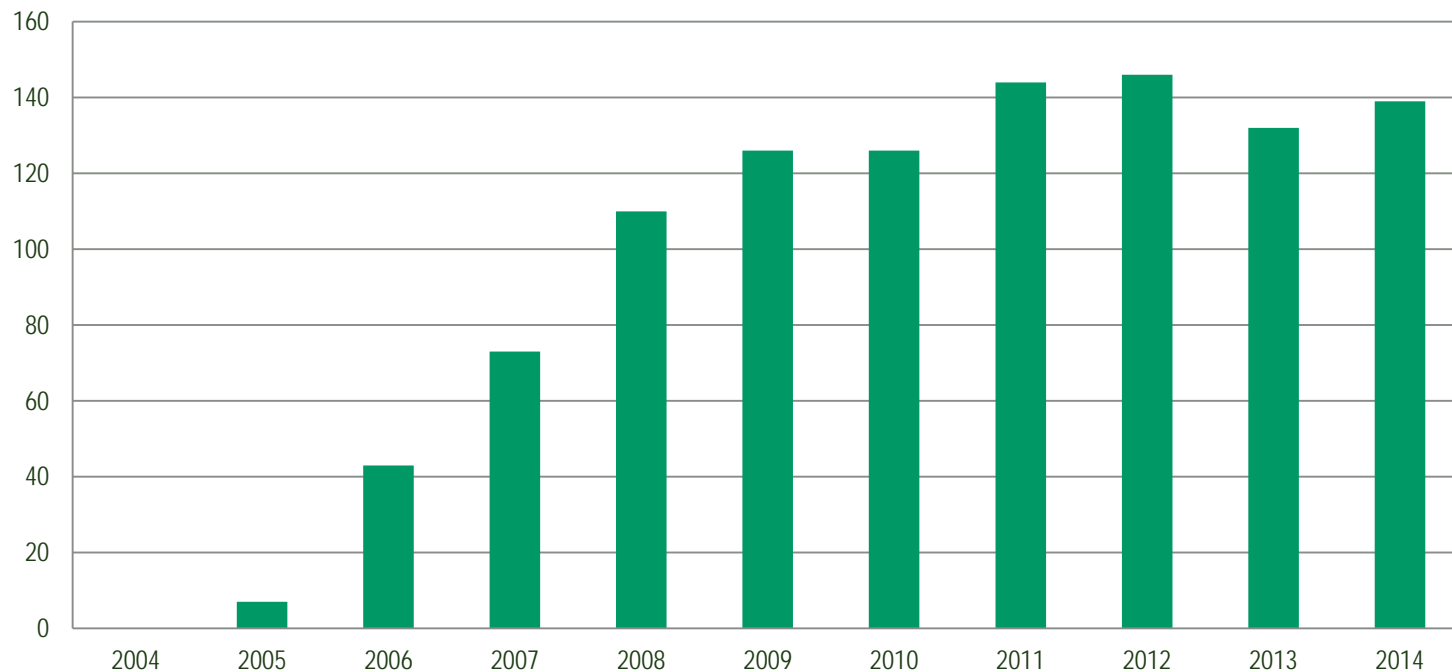


The screenshot shows the homepage of the 'Involving People in Research' website. At the top, there is a navigation bar with links for Home, Community, Methods, Network, Publications, Resources, Training and events, and Vacancies. Below the navigation bar is a row of ten small images depicting various people and activities. The main content area is divided into several sections: a 'MAIN MENU' on the left with links to Home, About Us, Our People, and Contact Us; a 'WELCOME' section with introductory text and a 'What is consumer and community participation?' section; a 'PROSPECTUS' section with a group photo; a 'CONSUMER AND COMMUNITY ADVISORY COUNCIL' section with a logo and 'Applications open' text; and a 'Researcher Training 2014' section with a poster. The website is branded with the logos of The University of Western Australia and Telethon Kids Institute.

[www.involvingpeopleinresearch.org.au](http://www.involvingpeopleinresearch.org.au)

# Committee involvement

## Consumer and community members involved in research committees 2004 - 2014



Current: 139 community members involved in 26 projects or programs

# Community interaction

## Community forums

58 events to discuss:

- Current projects / findings
- Gaps and priorities
- Hot topics / issues
- Showcase research





# Governance



## Consumer and Community Advisory Councils which provide:

- Community oversight
- Advice and advocacy on
  - Policy
  - Programs
  - Minimum standards
  - Grant applications
  - Strategic planning
- Participation Awards

# Training workshops

Training workshops on consumer and community participation in research developed and delivered across Australia - 800 participants have attended 44 workshops

- Researcher workshops: ‘how and why’ of implementing participation
- Consumer and community workshops on basic research information including data linkage
- Short courses on writing in plain language

In the pipeline for 2015: online training



# Good practice examples

## *Unexpected safety and quality issues highlighted by the Consumer Panel*



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### Branding & packaging confusion



### Unsafe labeling: non-specific dosing instructions



# Fetal Alcohol Syndrome Disorders Projects

## *Alcohol in Pregnancy: Health Promotion for Health Professionals 2006 – 2008:*

- 2 reference groups established to inform development of resources

## *Alcohol and Pregnancy: Health Promotion Messages that Work Project (2009-2010)*

- Reference group established

## *Provision of a Screening-Diagnostic Instrument for Fetal Alcohol Spectrum Disorders for Australia Project (2011-2012):*

- 2 community conversations and 3 community members on steering group

alcohol &  
pregnancy



# Outcomes from the 'community conversations'

- Understanding Disability
- Immunisation Consent
- Cerebral Palsy Register
- Medicine costs
- Developmental Pathways Project grant application
- Mental Health Community Forum on physical health issues



# Impact of the Participation Program so far .....

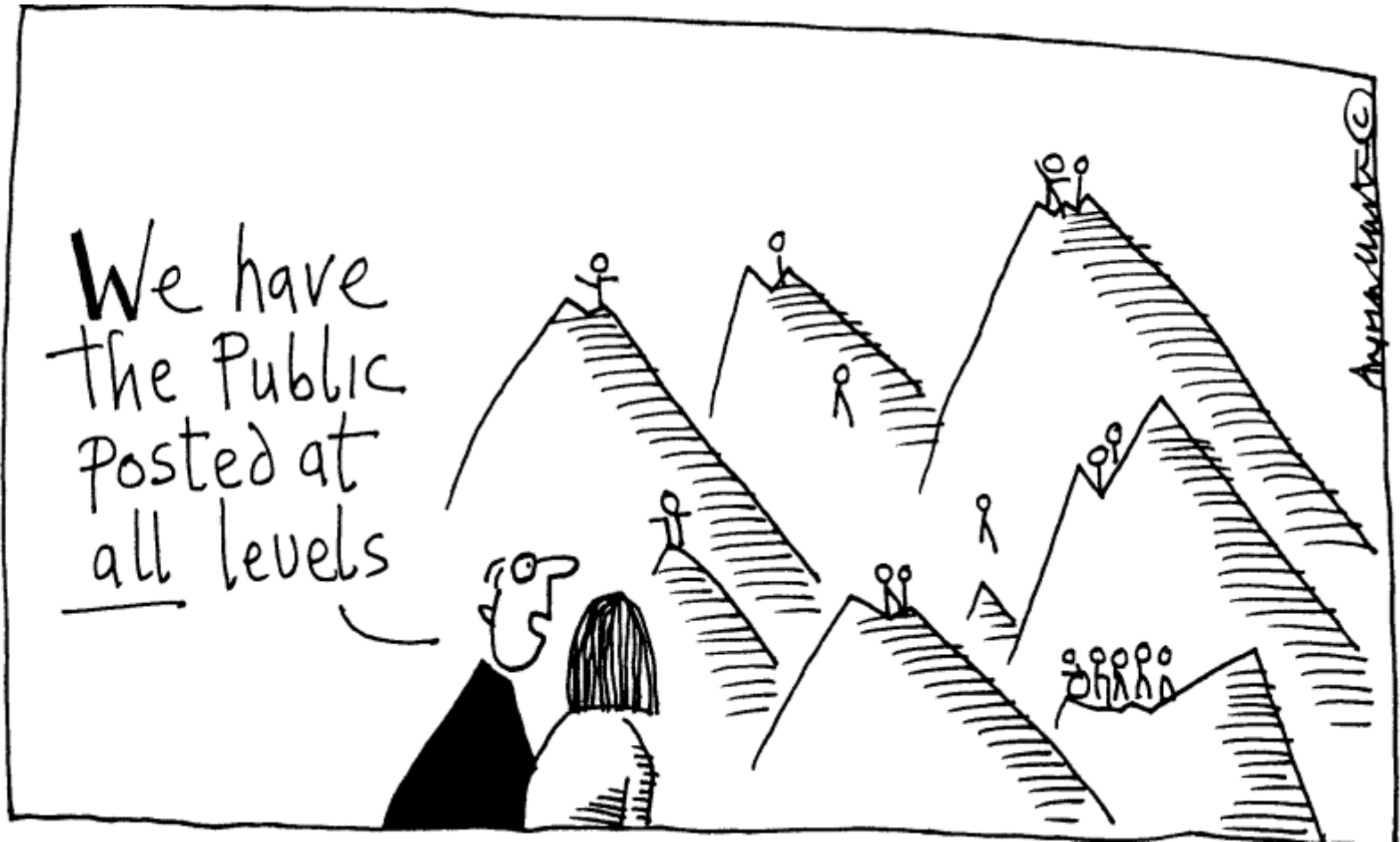
- Increased ‘buy in’ for consumer and community participation across the two organisations
- Engaged consumers who are advocating for change and greater translation of research findings
- Engaged researchers who are experiencing the value of active participation
- Greater awareness amongst policy makers of consumer issues
- Stronger local, national and international awareness and collaborations

# Any questions?



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# *Thank You*