Researchers + Consumers + Community = Partnerships

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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

Advocacy & advice → Building the evidence → Community & stakeholder interaction → Methods of participation → Governance & services → Teaching & training

Key Deliverables

Community Links / Bridge → Advocacy → Education → Leadership
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

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
  o Policy
  o Programs
  o Minimum standards
  o Grant applications
  o 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

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
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?

We have the public posted at all levels.

Thank You