



Consumer participation in research

Never Stand Still

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Why?

Authentic, genuine, impact research

- Questions posed – relevant to community, policy appropriate
- Respectful recruitment, participation, care
- Interpretation of data
 - Why >1 needle/injection
- Careful expression in written reports
- Innovative dissemination
 - Research as fable
- Insights that would otherwise miss
 - Earn/urn

Ethics committees

- More and more looking for appropriate engagement with participants eg via representative groups

At all levels

On high level Scientific Advisory Committee

As investigators

- Researcher initiated
- Consumer initiated

As colleagues

- Facilitate planning (esp recruitment and participant care)
- Co-moderated focus groups
- Co-authors on peer review papers

As peer workers

Resources

Peer workers

- Have to be prepared for a high level of management for some
- Balancing “professional life” and “own life”
- Stuff happens at any hour

Colleagues and friends

Criticisms?

Mind the gap

Can researchers and consumers be too close?

– Or perceived to be?

Can both sides retain their independent voices and still collaborate closely?

Outcomes

Has been and continues to be a learning journey – trust is key
–Still make mistakes

Has profoundly shaped my language, orientation to research and to policy

Offer close relationship to community/consumers as selling point to students (and a fundamental aspect of their training)

I recognise that I have “more legitimate” voice and seek advice on how to use it

An absolute privilege to have developed mutual trust