



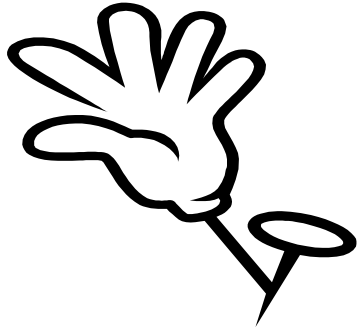
Meaningful engagement in research

SIREN Symposium 2018



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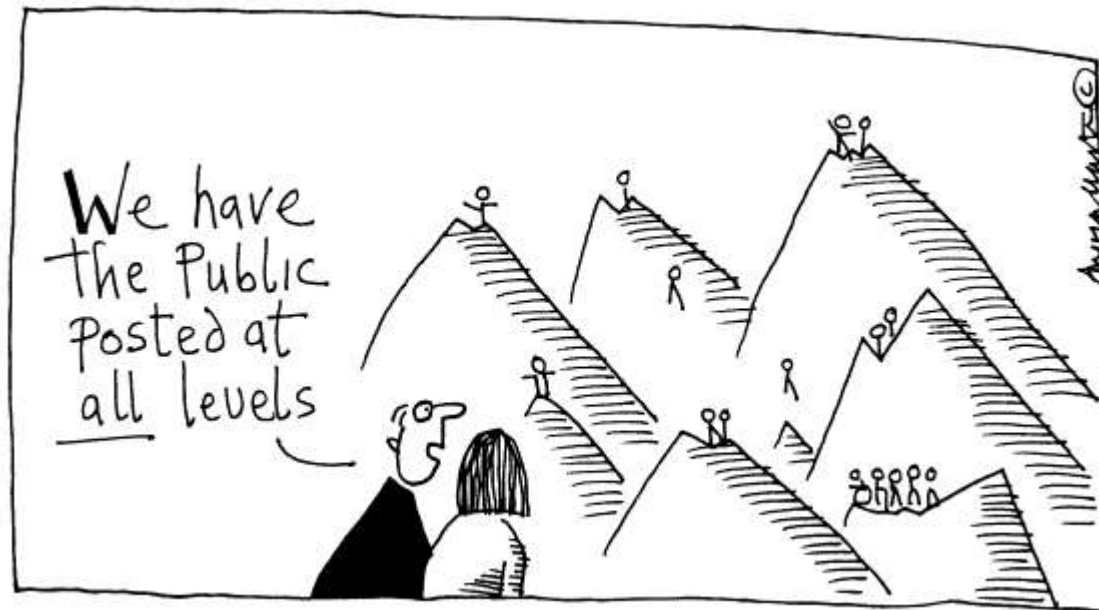


Hands-up research project

- **Have you ever been a participant in any 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 input into the research?**

What we will cover today

- What is consumer & community involvement in research
- Why it's important
- The principles, benefits and barriers
- Methods for involvement
- Good practice examples
- Support available



Definitions being used today

Consumer

refers to people who directly or indirectly make use of health service (i.e. patients, potential patients, carers)

Consumer representative

a member of a committee, steering group or similar who voices the consumer perspective

Community

a group of people sharing a common interest but not necessarily a common geographic location

Stakeholders

an individual or group from within or outside the organisation who has a key interest in the service or project

What is consumer and community involvement?

- Consumers, community members and researchers working in partnerships to make decisions about research priorities, policy and practice
- An active partnership that is sensitive to changing needs and priorities of the community
- It is about consumers and community being part of a process, rather than just observing or commenting on the process
- Conducting research that is with the community rather than to or for the community

What it's not about

- Researchers just raising awareness of their research
- The participants (subjects) taking part in research
- A recruiting tool
- An opportunity to 'tick the box'
- Fundraising or public relations



Why is it important?

- Requirement of funding bodies
- Enhance the quality of research
- Accreditation /ethics requirements
- Involvement can help to empower people



Underlying principles

- Start involvement as early as you can
- Involvement must add value
- Be inclusive and reach out to diverse groups
- Treat everyone with respect and integrity
- Work in partnership
- Keep everyone informed and involved
- Use language that everyone understands

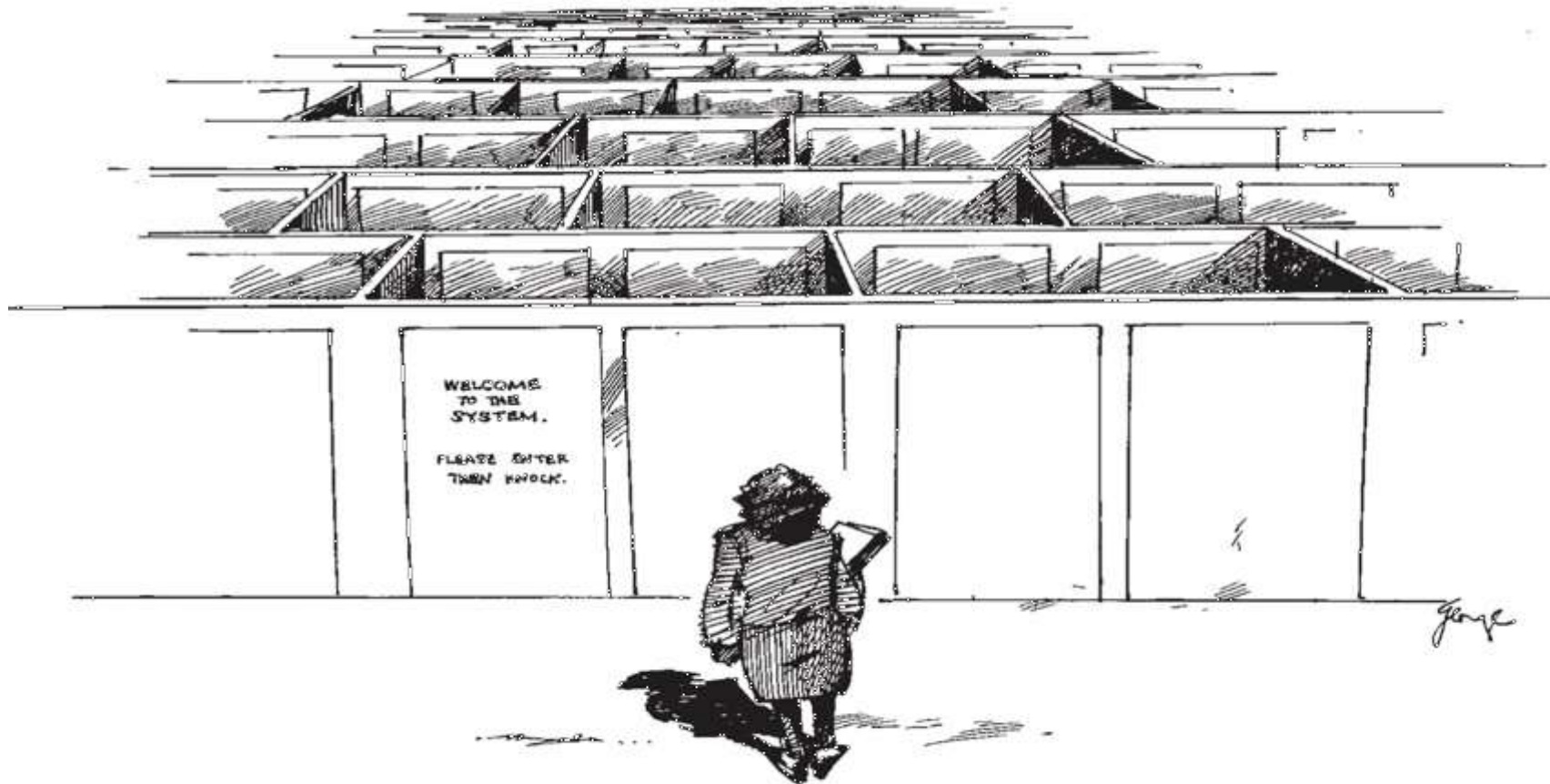


One size doesn't fit all

Benefits of involvement

- Improved openness and accountability for the use of public money
- Increased transparency for the the conduct of research
- The community is better informed about the value of research
- Consumer and community involvement enhances the relevance of research questions and topics
- Policy makers and government agencies are better informed of consumer issues and perspectives

Barriers to involvement



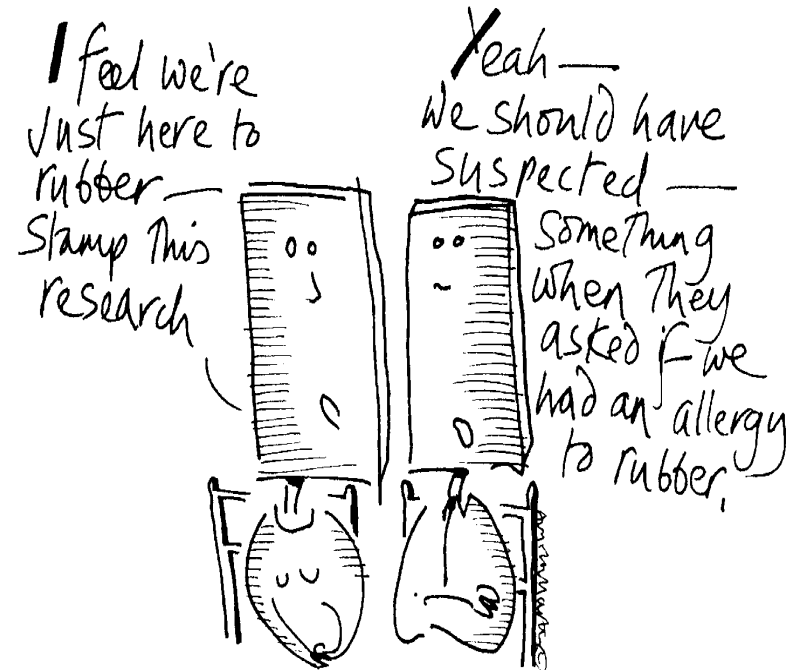
Methods for consumer and Community involvement

- Document reviewers
- Consumer or community representatives
- Consultations and forums
- Research buddies
- Reference groups
- Steering groups
- Consumer or community researchers
- Consumer & Community Advisory Councils
- Priority Setting Projects



Important points to consider

- Planning the involvement activities is crucial to achieving meaningful involvement
- Budget for involvement activities
- Be clear about the stage and level of involvement you are seeking – use a framework or tools
- Support consumers and/or community members to make informed decisions about becoming involved



Good practice examples

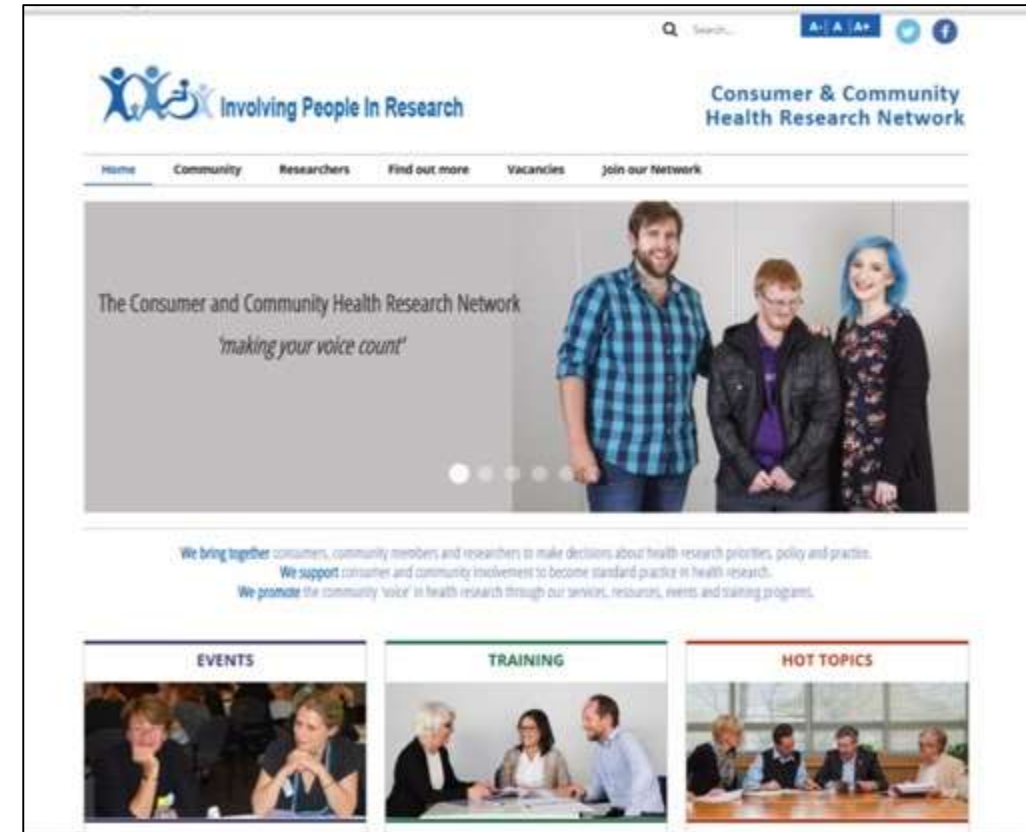
- Medical Cannabis Project at Curtin University
- Cancer Epidemiology Network at Curtin University
- Family and Domestic Violence Priority Setting partnership project at UWA
- FASD research at Telethon Kids Institute



The Consumer and Community Health Research Network

We provide:

- Advocacy and support
- An evidence base
- Community links and networks
- Methods for involvement
- Resources
- Teaching and training

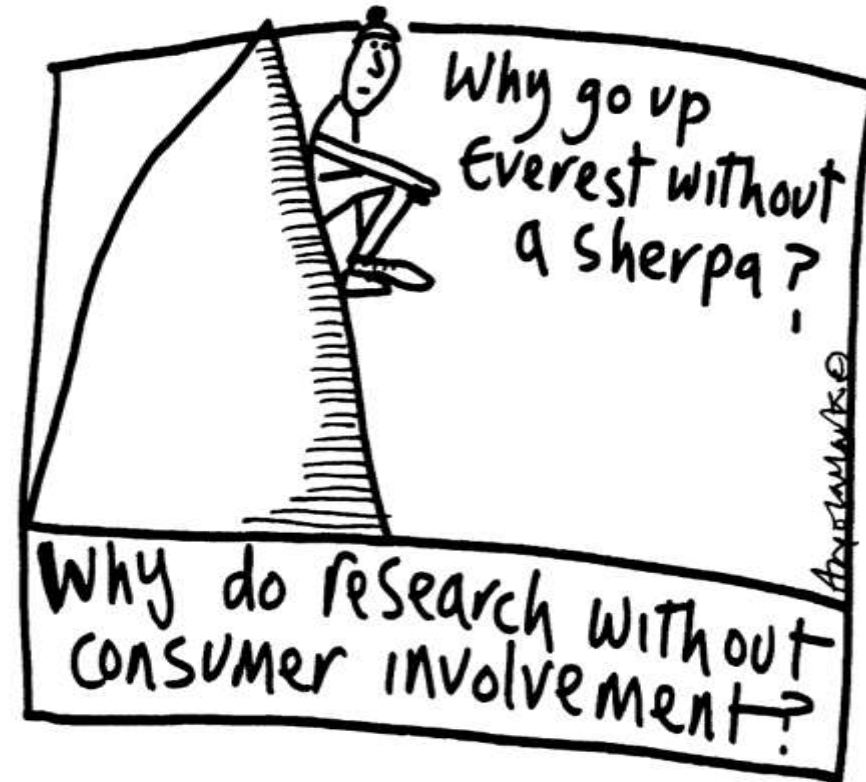


www.involvingpeopleinresearch.org.au

Some concluding thoughts.....

Having consumers and community members involved increases the likelihood of research being:

- Relevant
- Accountable
- Transparent
- Issue driven
- Supported by the community
- Translated into policy and practice



THANK YOU

Contact details:

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