Meaningful engagement in research
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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

Source: INVOLVE UK 2008
Why is it important?

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

Source: INVOLVE UK 2008
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 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

Source: INVOLVE UK 2008
THANK YOU

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www.involvingpeopleinresearch.org.au