Consumer and Community Involvement in Research

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3 May 2019
Consumer and Community Involvement

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Consumer and Community Involvement in health research: Getting started!

Research Skills Seminar Series, CAHS Research Education Program

Anne McKenzie AM
3 May 2019

Introduction to consumer and community involvement in health research

- Foundations of involvement
- Barriers to involvement
- Implementing involvement - getting started
- Sources of help and advice

Foundations of involvement

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

Source: INVOLVE UK 2008

It’s all important
What is consumer and community involvement?

- Community members and researchers working in partnerships to make decisions about research priorities, policy and practice

- Partnerships that are sensitive to the needs of the community

- Community members are part of a process, rather than being invited to observe or comment on the research

- 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

What’s the difference

Participation
- Participating in a research project

Involvement
- Consumers and community members working in partnerships with researchers, clinicians, government agencies, policy makers and funding bodies to shape decisions about research

Engagement
- Researchers or research organisations telling people about the research
Why is consumer and community involvement important?

Some key reasons for involving consumers and community members

1. Funding bodies require some form of involvement
2. Consumer and community involvement helps to enhance or improve the quality of research
3. Accreditation requirements
4. Human Research Ethics Committee requirements
5. Involvement can help to empower people

1. Funding, government or policy requirements

NHMRC 2019 requirements for clinical trials or cohort studies:

- Does the research question(s) meet the needs of research end-users, such as consumers, community members, policy makers and clinical practitioners?
- Were relevant research end-users, such as consumers, community members, policy makers and clinical practitioners, engaged during the development of the research plan?

Requirements for Ideas Grants:

- Qualifying applications must address NHMRC’s Indigenous Research Excellence Criteria for community engagement.
- Proposals must demonstrate how the research is a priority for Aboriginal and Torres Strait Islander communities with relevant engagement in all stages of the research
2. Improving the quality of research

Consumers and community members can:
• Provide perspectives and advice based on ‘lived experiences’
• Make sure practical issues are considered
• Help to ‘unpack’ unexpected or unusual findings or results

Researcher’s comment after a community forum on leg ulcers:
“I knew what the common issues were because they were mostly obvious and also reported in the literature. However, the consumers highlighted one that I had not even thought about - Depression!”

3. Accreditation requirement

Australian Commission on Safety and Quality in Healthcare requirement: Standard 2

4. Human Research Ethics Committee requirements

5. Involvement can help to empower people

Consumers and community members will have:
• A better understanding of the importance of research and be able to promote its value to the wider community
• Increased support and advocacy for change and/or funding
• Greater interest in seeing research results translated into policy and practice

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

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 consumer and community involvement


Researcher’s perspectives on barriers

• Time and money
• Lack of training and confidence
• Lack of support from funding bodies to meet their requirements
• Lack of a coordinated approach and rewards
• Lack of evidence for benefits
• Concerns about ability and knowledge of consumers
• Loss of position and control
Implementing consumer and community involvement

Planning for involvement – it’s crucial!
Take the time to plan - consider the following:
• Why are you involving community members?
• What do you want to achieve?
• What level of involvement are you aiming for?
• What stage of the research will you involve the community?
• How will you find community members?
• What methods will you use?
• What resources will you need?

Stages and levels of involvement
Ideally consumer and community involvement should occur at all stages and in every level of the research process but its never too late to start

Tools to support planning

Source: INVOLVE UK 2008
Ladder of involvement

Levels of involvement
- high
- low

Community role
- lead
- informed

Important points to consider

- Be clear about the stage and level of involvement you are seeking
- Use a framework or tools to help everyone consider the appropriate stage and level of consumer and community involvement
- Support consumers and/or community members to make informed decisions about becoming involved

Involvement methods

Currently there are 500+ people involved in decision-making activities across the WA Health Translation Network. These include:

- Reviewing grant applications, commenting on documents and plain language summaries
- Attending community conversations, events and training
- Serving as community representatives, research buddies, members of reference groups, steering groups or advisory councils

The importance of plain language

Research “speak”
Commonly used research words & terms
(not always understood by consumers/community)

<table>
<thead>
<tr>
<th>Term</th>
<th>Definition</th>
</tr>
</thead>
<tbody>
<tr>
<td>Adiposity</td>
<td>Fatness</td>
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<tr>
<td>Adjustment for confounders</td>
<td>Adjusting for factors that may influence the results</td>
</tr>
<tr>
<td>Blinding: single, double, triple</td>
<td>Blinding to prevent bias</td>
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<tr>
<td>Bio markers</td>
<td>Biomarkers</td>
</tr>
<tr>
<td>Burden of disease</td>
<td>The impact of a disease on an individual's health</td>
</tr>
<tr>
<td>Case control</td>
<td>Study design in which the groups are not comparable</td>
</tr>
<tr>
<td>Causal pathways</td>
<td>The relationship between cause and effect</td>
</tr>
<tr>
<td>Chief Investigator</td>
<td>The person in charge of a study</td>
</tr>
<tr>
<td>Clinical trial Phase 1, 2, 3, 4</td>
<td>Stages of clinical trials</td>
</tr>
<tr>
<td>Cohort</td>
<td>A group of subjects with similar characteristics</td>
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<tr>
<td>Comorbidity</td>
<td>The presence of two or more diseases or conditions</td>
</tr>
<tr>
<td>Conceptual framework</td>
<td>The theoretical framework</td>
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<tr>
<td>Confounders</td>
<td>Variables that may affect the outcome of a study</td>
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<tr>
<td>Control Group</td>
<td>The group that receives a placebo</td>
</tr>
<tr>
<td>Co-stimulator</td>
<td>The drug being studied</td>
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<tr>
<td>Data analysis</td>
<td>The analysis of data</td>
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<tr>
<td>Data linkage/record linkage</td>
<td>Linking data records</td>
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<tr>
<td>Determinants</td>
<td>Variables that define the study</td>
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<tr>
<td>Double blinded</td>
<td>Blinding applied in both groups</td>
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<td></td>
<td>Epidemiology</td>
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<td>Fetomaternal</td>
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<td>Heterogentic disease</td>
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<td>Human capability</td>
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<td>Hypotheses</td>
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<td>Incidence vs. prevalence</td>
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<td>Immunotherapies</td>
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<td>Infant</td>
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<td>Logistical regression</td>
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<td>Longitudinal</td>
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<td>Meta analysis</td>
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<td>Morbidity</td>
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<td>Mortality</td>
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<td>Multi level modelling</td>
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<td>Odds ratio</td>
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<td>Pathogenesis</td>
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<td>Pharmacovigilance</td>
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<td>Participant observation</td>
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<td>Peer review / journal</td>
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<td>Predictors</td>
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<td>Prognosis</td>
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<td>Protein pathways</td>
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<td></td>
<td>Protein signalling</td>
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<td></td>
<td>Qualitative / quantitative</td>
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<td></td>
<td>Randomised control trial</td>
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<td></td>
<td>Risk factor</td>
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<td>Screening algorithm</td>
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<td>Surveillance</td>
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<td>Sequelae</td>
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<td>Subject</td>
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<td></td>
<td>Track record</td>
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<td>Thematic</td>
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<td>Trajectory</td>
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<td>Upregulation</td>
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<td>Variables</td>
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Consumer issues

Using language that is not easily understood can limit meaningful involvement

Consumers see it as:

- Power imbalance (real or perceived)
- Elitism
- Isolation in a strong organisational culture

Good practice examples of consumer and community involvement

The Raine Study: Pregnancy cohort

- ‘T Team’ established in 2006 following a forum held with parents and young people to discuss increasing involvement (and retention)
- Led to some involvement of the young people over the next decade
- New structure established in 2016 for involvement across the cohort

Raine Executive has appointed community members to all committees

The Participate Project

- A project with five studies, aiming to facilitate participation in community-based recreation activities for children with Acquired Brain Injury
- All studies guided by a steering group which included two parents, one teenager, clinicians and service providers

“I was surprised you were interested in what a mother has to say about this” (Parent (1) Steering group)

“A team...that could train and play together on the same day as the ‘AusKick’ program. And so that if they are there with their big brothers or their little brothers or whatever, they can take part” (Parent (2) Steering group)

Alcohol, Pregnancy & Fetal Alcohol Spectrum Disorders Research Program

Over a decade of community involvement in all studies:
- Alcohol in Pregnancy Projects
- Partnerships with Aboriginal communities
- Development of a diagnostic instrument
- Justice projects
- National Centre of Research Excellence

FASD Research Australia Centre of Research Excellence
- Priority setting Partnership project

A national community reference group established with membership from all states

Laboratory based research

Consumers and community members are working with researchers on a range of laboratory based projects such as:
- Cancer
- Asthma
- Autism
- Cystic Fibrosis

There has been an enormous growth in involvement activities in cancer research largely due to changes in requirements of funders

Consumers are helping with grant applications, plain language summaries, presentations and serving on committees

Beat CF Trial

The BEAT CF trial will evaluate a range of treatments and eliminating those found to be inferior paving the way for more effective available alternatives.

Three national community advisory groups established with members from the following groups:
- Adults – seven members
- Youth – four members
- Parents/partners and carers – sixteen members

The advisory groups are providing input into the design of an electronic consent process and security of storing identifiable data.
Final tips on getting started
Planning for involvement – it is important to ensure you have the following in place before you begin involvement activities:

- Senior level support and sign off
- Budget
- Time
- Training needs of researchers, consumers and community members
- A named person with responsibility for involvement activities
- Administration support

Support & advice available for WA researchers
The Consumer and Community Health Research Network
Website: www.involvingpeopleinresearch.org.au

The Western Australian Health Translation Network
- A collaboration of 22 research organisations coming together to ensure research findings are integrated into healthcare policy and practice
- The Consumer and Community Health Research Network is an ‘enabling platform’

Resources
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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2 CONSUMER AND COMMUNITY INVOLVEMENT - ADDITIONAL NOTES AND RESOURCES

2.1 WEB RESOURCES

2.1.1 State
The Consumer and Community Health Research Network
www.involvingpeopleinresearch.org.au

Program Publications – free to download from
http://www.involvingpeopleinresearch.org.au/researchers/our-resources

Barriers Report

Purple Book
ISBN 978-0-9872783-3-3

Fact Sheets

Green Book

Program Report

Consumer and Community Organisations
State
Health Consumers Council WA
http://www.hconc.org.au
2.1.2 National
Cancer Australia

Health Issues Centre
www.healthissuescentre.org.au

Consumers’ Health Forum of Australia
www.chf.org.au

The National Health and Medical Research Council

National Health and Medical Research Council. *A model framework for consumer and community participation in health and medical research*. Canberra: Australian Government; 2005

NHMRC Consumer Involvement Guidelines

2.1.3 International
INVOKE
www.invo.org.uk

Involving People
https://www.wales.nhs.uk/sites3/home.cfm?orgid=1023

National Institute for Health Research
http://www.nihr.ac.uk/get-involved/shape-research.htm

Canadian Institutes for Health Research
http://www.cihr-irsc.gc.ca/e/41696.html

Patient-Centered Outcomes Research Institute
http://www.pcori.org/get-involved

2.2 USEFUL READING
Foundations of consumer and community involvement
The following papers discuss:

- Model frameworks
- Exploring the principles of consumer involvement
- The Ladder of Participation

Saunders C, Crossing S, Girgis A, Butow P and Penman A. *Operationalising a model framework for consumer and community participation in health and medical research.* Australia and New Zealand Health Policy 2007

Telford R, Boote J, Cooper C. *What does it mean to involve consumers successfully in NHS research? A consensus study.* Health Expectations 2004

Arnstein S. *A Ladder of Citizen Participation.* Journal American Institute of Planners 1969

Titter J Q, McCallum A. *The snakes and ladders of user involvement: moving beyond Arnstein.* Health Policy 2005

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National Health and Medical Research Council, Consumer Health Forum of Australia. *Statement on consumer and community participation in health and medical research.* Canberra: Commonwealth of Australia 2002


National Health and Medical Research Publication. ‘*The Roadmap II - A Strategic Framework for Improving Aboriginal and Torres Strait Islander Health through Research’* 2010


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2.3 BARRIERS


2.4 WRITING IN PLAIN LANGUAGE
TwoCan Associates. *Getting it right for service users and carers, getting it right for researchers: How to decide whether to help researchers find people to take part in research*. UK 2008

How to write reports in plain English. New Mills: Plain English Campaign
www.plainenglish.co.uk

The National Institute for Health Research website dedicated to supporting each research study it funds has a clear and concise plain English summary.

http://www.invo.org.uk/makeitclear/

INVOLVE is a national advisory group funded by the National Institute for Health Research to support public involvement in NHS, public health and social care research
