CAHS Research Education Program
Research Skills Seminar

Consumer and Community Involvement in Research

30th July 2021

Presented by

Anne McKenzie AM
Manager, Community Engagement, Telethon Kids Institute

CAHS Research Education Program
Research Skills Seminar Series
☎ (08) 6456 0514  ✉ ResearchEducationProgram@health.wa.gov.au
Consumer and Community Involvement in Research

PRESENTATION SLIDES
Consumer and Community Involvement in Health Research

Getting Started!

30 July 2021
Presented by Anne McKenzie AM
Community Engagement Manager, Telethon Kids Institute

Research Education Program | Research Skills Seminar Series

Acknowledgement of country

I would like to acknowledge the traditional custodians of the land, the Noongar Whadjuk people, and pay my respects to their elders, past, present and future.
Introduction to consumer and community involvement in health research

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

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
Stakeholder Wheel

Complete stakeholder wheel

Policy makers
Health administrators
Non-government organisations
Clinicians
Funding bodies
Researchers
Consumers and community members
Commercial and industry

Incomplete stakeholder wheel

Policy makers
Health administrators
Non-government organisations
Clinicians
Funding bodies
Researchers
Consumers and community members
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Some labels…

Many different words are used to describe people who get involved…

Community members
Citizens
Patients
Advocates
Communication
Consumers
Lay members
Research partners

Remember - the person should always come before the label
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

Source: INVOLVE UK 2008
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

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

1. Funding, government or policy requirements

Funding bodies

NHMRC Framework & Statement
NHMRC 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

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 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 involvement

Source: INVOLVE UK 2008
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 it's never too late to start.

Source: INVOLVE UK 2008
Tools to support planning

- 1. Deciding what to research
- 2. Deciding how to do it
- 3. Doing it
- 4. Letting people know the results
- 5. Knowing what to research next

THE RESEARCH CYCLE

Levels of involvement

Consumer and Community Involvement
- Inform
- Consulted
- Advise
- Equal partners
- Lead the research
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 hundreds of people involved in decision-making activities in research across the state - these include consumers:

• Reviewing grant applications, commenting on documents and helping to write plain language summaries

• Attending community forums, events and training

• Serving as community members, research buddies, members of reference groups, steering groups or advisory councils
The importance of plain language

Are you using research “speak”?

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

WA Youth Health Policy

- 6 community conversations held across WA in 2017 (metro, rural and remote)
- Youth Advisory Group had input into questions
- 122 young people aged 14 – 20 attended
- Report informed development of the Policy
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 is evaluating 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
- Youth
- Parents/partners and carers

The advisory groups have provided input into the design of an electronic consent process and security of storing identifiable data.

A new initiative to acknowledge and thank people for the many ways they contribute to research at the Institute:

Diabetes ‘Come & Have a Cuppa’ event

Walyan Respiratory Centre’s consumer evening
Covid-19 Community Advisory Group

- Input into 25 projects
- Wide range of projects
- Priorities for future research
- 15 virtual meetings
- 100’s of emails and post meeting feedback
- 450+ cumulative hours

“It’s a real priority to ensure COVID-19 research is properly in synch with the needs of our community. The community cost of COVID-19 is so high, so it will be great to see consumers and researchers working together to ensure that research is going to be of maximum benefit to the community.”

Cath – Community Advisory Group member

“It was important to ensure the scientific approach was integrated with Consumer views. By participating in the group I came away confident that researchers were truly seeking to partner with consumers and their views were respected and appreciated, even when they differed from those held by the research team.”

Amber – Community Advisory Group member
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 and community members
- A named person with responsibility for involvement activities
- Administration support

Remember: HREC approval is not required for involvement activities

Resources

Support & advice available for CAHS researchers

engagement@telethonkids.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

Upcoming Research Skills Seminars

8 Aug  Knowledge Translation with A/Prof Fenella Gill
13 Aug  Media and Communications with Elizabeth Chester
27 Aug  Oral Pres. of Research Results with A/Prof Sue Skull

Register → https://researcheducationprogram.eventbrite.com.au

We love feedback
A survey is included in the back of your handout or complete online via: https://tinyurl.com/consumerandcommunity

Source: INVOLVE UK 2008
Consumer and Community Involvement in Research

RESOURCE NOTES
# Table of Contents

2. State resources  
   2.1. Telethon Kids Institute  
      2.1.1. Barriers Report  
      2.1.2. Purple Book  
      2.1.3. Fact Sheets  
      2.1.4. Green Book  
      2.1.5. Program Report  
   2.2. The Consumer and Community Involvement Program  
2.3. The Health Consumers' Council of WA (HCC)  

3. National resources  
   3.1. Cancer Australia  
   3.2. Health Issues Centre  
   3.3. Consumers' Health Forum of Australia  
   3.4. The National Health and Medical Research Council  
   3.5. National Health and Medical Research Council.  
   3.6. NHMRC Consumer Involvement Guidelines  

4. International resources  
   4.1. Health and Care Research Wales  
   4.2. National Institute for Health Research  
   4.3. Canadian Institutes for Health Research  
   4.4. Patient-Centered Outcomes Research Institute  

5. Barriers  

6. Writing in plain language
2. State resources

2.1. Telethon Kids Institute


2.1.1. Barriers Report

2.1.2. Purple Book

2.1.3. Fact Sheets

2.1.4. Green Book

2.1.5. Program Report

2.2. The Consumer and Community Involvement Program
https://cciprogram.org/

2.3. The Health Consumers’ Council of WA (HCC)
http://www.hconc.org.au
3. National resources

3.1. Cancer Australia

3.2. Health Issues Centre
   www.healthissuescentre.org.au

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

3.4. The National Health and Medical Research Council

3.5. National Health and Medical Research Council.
   *Expectations and Value - Framework for Effective Consumer and Community Engagement in Research.pdf*
   (scroll to ‘Download’ section)

3.6. NHMRC Consumer Involvement Guidelines

4. International resources

4.1. Health and Care Research Wales
   http://www.healthandcareresearchwales.org/

4.2. National Institute for Health Research
   https://www.nihr.ac.uk/

4.3. Canadian Institutes for Health Research
   https://cihr-irsc.gc.ca/e/193.html

4.4. Patient-Centered Outcomes Research Institute
   https://www.pcori.org/
5. Barriers


6. 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.
  https://www.nihr.ac.uk/documents/plain-english-summaries/27363
Ensuring that research findings are translated into practice involves a systematic approach from the beginning when you are designing your research. Implementation science bridges the gap between developing and evaluating effective interventions and implementation and de-implementation in routine practice. This seminar covers key elements of implementation research; theoretical approaches, research designs, involvement of stakeholders, behaviour change interventions.

About the Presenter
Assoc Prof Fenella Gill

Fenella is Associate Professor - Acute Paediatric Nursing at the School of Nursing, Midwifery and Paramedicine, Curtin University and Perth Children’s Hospital (PCH), Child and Adolescent Health Service. She leads research focused on paediatric inpatient and family experiences, safety and outcomes.

Fenella’s PhD work resulted in national practice standards for critical care nurse education, incorporating the views of health consumers. Fenella holds an inaugural West Australian Health Translation Network (WAHTN) and Curtin University 2019 Early Career Fellowship in Research Translation and in 2016 Fenella was honoured as a life member of the Australian College of Critical Care Nurses (ACCCN).

Contact
Phone (08) 6456 0514
Email researcheducationprogram@health.wa.gov.au
Intranet cahs-healthpoint.hdwa.health.wa.gov.au
About the Presenter

Elizabeth Chester

Director of Communications & Development at Telethon Kids Institute, Liz leads a team who support researchers in translating their work for the broader audiences.

Liz has extensive experience as a journalist and producer in broadcast media.

Understanding how to work with the media is essential and a critical responsibility for all researchers, whether it’s the newspaper, TV, radio, or social media. This seminar will provide practical techniques on working with the media and ensuring your bottom line is delivered in an engaging, accurate, and responsible way.

Click here to register online or visit https://20210813.eventbrite.com.au

Discover

To watch past seminar recordings, download presentation material or subscribe to our event notification newsletter, visit: cahs.health.wa.gov.au/ResearchEducationProgram

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The Research Skills Seminar Series is part of the Research Education Program presented by the Child and Adolescent Health Service, Department of Research. Seminars are hosted by WA Department of Health.
Effective presentation of research results is a key component of research translation, a moral responsibility to undertake for your research participants, funders and institution, and an opportunity to get important feedback. This seminar includes a range of tips on choosing and organising materials, delivery styles and techniques, preparing for questions, gaining confidence, and how to run a session effectively.

About the Presenter

Associate Professor Sue Skull
Associate Professor Sue Skull is based at Perth Children’s Hospital, where she is Head of the Research Education Program. She holds positions as a Consultant Paediatrician at CAHS and Clinical Associate Professor for the Division of Paediatrics and Child Health at UWA. She remains actively involved in teaching research methods and enjoys helping others improve and enjoy their research experience.

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Perth Children's Hospital
Level 5, 15 Hospital Ave Nedlands
Accessible via pink or yellow lifts
- OR -
Access online via Avaya Workplace
- OR -
Watch live from a hosted video-conferencing site at
  - Fiona Stanley Hospital
  - Lions Eye Institute
  - Royal Perth Hospital

Click here to register online or visit https://20210827.eventbrite.com.au

27th August 2021 | 12:30pm – 1:30pm | Perth Children’s Hospital
## 2021 Seminar Schedule

<table>
<thead>
<tr>
<th>Date</th>
<th>Topic</th>
<th>Presenter</th>
</tr>
</thead>
<tbody>
<tr>
<td>Feb 5</td>
<td>Research Fundamentals</td>
<td>A/Prof Sue Skull</td>
</tr>
<tr>
<td>Feb 19</td>
<td>Scientific Writing</td>
<td>A/Prof Sue Skull</td>
</tr>
<tr>
<td>Mar 12</td>
<td>Introduction to Good Clinical Practice</td>
<td>Natalie Barber</td>
</tr>
<tr>
<td>Mar 19</td>
<td>Research Governance</td>
<td>A/Prof Sunalene Devadason</td>
</tr>
<tr>
<td>Apr 30</td>
<td>Using Social Media in Research</td>
<td>Dr Kenneth Lee</td>
</tr>
<tr>
<td>May 7</td>
<td>Using REDCap for Data Capture and Management</td>
<td>Telethon Kids Biometrics Team</td>
</tr>
<tr>
<td>May 14</td>
<td>Survey Design and Techniques</td>
<td>A/Prof Sue Skull</td>
</tr>
<tr>
<td>May 28</td>
<td>Getting the most out of Research Supervision</td>
<td>Prof Jonathan Carapetis AM</td>
</tr>
<tr>
<td>Jun 18</td>
<td>Introductory Biostatistics</td>
<td>Dr Julie Marsh</td>
</tr>
<tr>
<td>Jun 25</td>
<td>Sample Size Calculations</td>
<td>Dr Julie Marsh</td>
</tr>
<tr>
<td>Jul 23</td>
<td>Data Collection and Management</td>
<td>A/Prof Sue Skull</td>
</tr>
<tr>
<td>Jul 30</td>
<td>Consumer and Community Involvement</td>
<td>Anne McKenzie AM</td>
</tr>
<tr>
<td>Aug 6</td>
<td>Knowledge Translation</td>
<td>Dr Fenella Gill</td>
</tr>
<tr>
<td>Aug 13</td>
<td>Media and Communications in Research</td>
<td>Elizabeth Chester</td>
</tr>
<tr>
<td>Aug 27</td>
<td>Oral Presentation of Research Results</td>
<td>A/Prof Sue Skull</td>
</tr>
<tr>
<td>Sep 10</td>
<td>Conducting Systematic Reviews</td>
<td>Prof Sonya Girdler</td>
</tr>
<tr>
<td>Sep 17</td>
<td>Involving the Aboriginal Community in Research</td>
<td>Glenn Pearson &amp; Sue Skull</td>
</tr>
<tr>
<td>Oct 22</td>
<td>Rapid Critical Appraisal of Scientific Literature</td>
<td>A/Prof Sue Skull</td>
</tr>
<tr>
<td>Oct 29</td>
<td>Statistical Tips for Interpreting Scientific Claims</td>
<td>Dr Julie Marsh</td>
</tr>
<tr>
<td>Nov 5</td>
<td>Grant Applications and Finding Funding</td>
<td>Tegan McNab &amp; Sue Skull</td>
</tr>
<tr>
<td>Nov 12</td>
<td>Research Impact</td>
<td>Tara McLaren</td>
</tr>
<tr>
<td>Nov 19</td>
<td>Ethics Processes for Clinical Research in WA</td>
<td>A/Prof Sue Skull</td>
</tr>
<tr>
<td>Nov 26</td>
<td>Qualitative Research Methods</td>
<td>Dr Shirley McGough</td>
</tr>
<tr>
<td>Dec 3</td>
<td>Innovation and Commercialisation</td>
<td>REP &amp; Telethon Kids Institute</td>
</tr>
</tbody>
</table>

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Consumer and Community Involvement

Thank you for your interest in this seminar

Your feedback will help guide future presentations and educational activities.

How did you attend the seminar?

- Live seminar at Perth Children's Hospital
- Hosted video-conference on-site (e.g. FSH, Lions Eye, RPH etc.)
- Online via Scopia
- Viewed online recording

Please rate your agreement with the following statements:

<table>
<thead>
<tr>
<th>Statement</th>
<th>N/A</th>
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What were the best aspects of the seminar?

What changes or improvements would you suggest?

How did you hear about the seminar?

(You can select multiple answer)

- Email invitation from Research Education Program
- CAHS Newsletters e.g. The Headlines, The View, CAHS Research Newsletter
- "Health Happenings" E-News
- Healthpoint Intranet Upcoming Events
- Collegiate lounge screen or other posted promotional material
- Telethon Kids Institute screen or other posted promotional material
- Telethon Kids Institute Newsletter
- Other

Thank you!