Health
Mid North Coast
Local Health District

Consumer and Community Engagement Framework for Research

2019 - 2023

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Introduction

Aligned to NSW Health's Core Values of Collaboration, Openness, Respect and Empowerment, Mid North Coast Local Health District (MNCLHD) is committed to continued development of our approach to consumer and community engagement to ensure the needs of the community are central to health service planning and health care decisions.

We recognise consumers, their families, carers and community members as partners in care and value their positive contributions to improve quality of care and the health and wellbeing of the local community.

MNCLHD Partnering with Consumers Program, developed in collaboration with North Coast Primary Health Network (NCPHN) and the joint Community Reference Groups (CRGs), guides our shared approach to effectively engage with consumers and the broader community in the delivery of MNCLHD Strategic Directions and in the planning, delivery and evaluation of health care and services across the Mid North Coast.

The MNCLHD Consumer Engagement Framework for Research sets out our approach as it relates to the engagement of consumers and our community in our research endeavours.

Purpose and Scope

Purpose

The purpose of this Framework is to:

- Demonstrate MNCLHD's commitment to meaningful and effective engagement with consumers and the community in its research endeavours.
- Clarify the expectations of consumer and community engagement in research across the LHD.
- Provide guidance and support to staff in planning and implementing engagement initiatives associated with research.
- Outline the MNCLHD approach and its core research engagement strategies.
- Describe the organisational infrastructure and governance mechanisms to support consumer and community engagement in research.

Audience and Scope

This Framework is written for clinician/researchers working within MNCLHD and is designed to provide guidance to engage consumers and community representatives in its research endeavours, defined as follows:

Consumer

Patients and potential patients, carers, organisations representing consumers' interests, members of the public who are targets of health promotion programs. This may include groups seeking research because they believe that they have been exposed to potentially harmful circumstances, products or services.

Consumer representative

A member of a committee, steering group or similar, who voices the consumer perspective and takes part in the decision-making process on behalf of consumers. This person is usually nominated by an organisation of consumers and is accountable to them.

Community

A group of people sharing a common interest (for example cultural, social, political, health, economic interests), but not necessarily a particular geographic association. Within this definition, it is important to recognise that different types of communities are likely to have varying approaches to engagement in research.

Engagement

Engagement is where consumers and researchers work in partnership with one another to shape decisions about research priorities, policies and practices. It is about being an active part of a process, rather than just observing or commenting on processes.

For the ease of readability, in this document the term 'consumer' is to considered to include both consumers and community.

Goals of consumer engagement in research

- Consumers representatives will be actively engaged in our research endeavours.
- Consumers and researchers will work together to shape decisions about research priorities, practices and policies.
- Our collaboration will be an active partnership that is sensitive and responsive to changing needs and priorities.
- Our approach will design and conduct research in collaboration with the community rather than 'to or for' the community.

Consumer engagement is not ….

- Being the participants (subjects) in research.
- A recruiting tool.
- An opportunity to 'tick the box'.
- Fundraising event or opportunity.

Consumer engagement is a prerequisite when….

- It is a requirement of the research grant from the funding body, for example National Health and Medical Research (NHMRC).
- Ethics requirement; research that involves Aboriginal and Torres Strait Islander communities in Australia **must** involve the community in **all** aspects of the research.

The benefits of engaging consumers in research

- Research reflects the consumer voice and is relevant to the community.
- Greater transparency, openness and accountability.
- Consumers can help with recruitment of their peers by overcoming barriers to being part of the research.
- Consumers can help to access other people including those who are marginalized.
- Consumers can help to disseminate the results of research and lobby to ensure that changes are made and research is more widely applied.

National Safety and Quality Standards

As a fundamental element of quality and safety, partnering with consumers is embedded within the MNCLHD Strategic Directions and Clinical Governance Framework.[1]

A community engagement structure consisting of the MNCLHD Community Engagement Sub Committee (CESC) of the Governing Board, Community Reference Groups (CRGs) and Community Connections forums, has been established.

Further, the Australian Commission on Safety and Quality in Health Care's National Safety and Quality Health Service 'Standard 2: Partnering with Consumers', requires the involvement of consumers in the organisational and strategic processes that guide the planning, design and evaluation of health services.[2]

Key Points for Consideration

It is important to consider strategies to effectively engage consumers. Factors to reflect upon include:

- The lack of clarity on the type and purpose of engagement.
- Insufficient resources available or allocated for engagement.
- Attitudes, understanding and competency among staff on engagement.
- Lack of integration involving engagement mechanisms within the formal service planning, delivery and evaluation processes.
- Adequacy of representation is likely to impact on effective engagement and the achievement of anticipated goals.
- Poor communication and non-collegial approaches between staff and consumers, including unequal power relationships.
- Consumers may have support requirements that, if not supported, may prevent engagement.

How to Engage Consumers in Research

Use this guide and its resources, to assist in the planning of consumer engagement (each heading is hyperlinked).

1. Decide on the level of engagement

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2. Planning Engagement

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3. Identifying appropriate consumer and community members

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4. Meeting with Consumer and Community Members

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[1] MNCLHD Clinical Governance Framework June 2017
[2] ACSQHC National Safety and Quality Health Service Standards: Second Edition: November 2017

1. Planning Engagement

Taking the time to plan properly for consumer engagement, will ensure the best results throughout a research project. It is important to note that a plan does not have to be detailed, as it is likely to change once the research team has begun to engage with consumers. Having a plan will provide a guide for starting the engagement activities. Allow time to consider the following questions:

Why involve consumers in research?

- Decide what the team wants to achieve from the engagement before proceeding with planning the activities. What is required from consumers in the project?

What level of engagement does the research team want to achieve?

- One size does not fit all.
- The level of engagement may change at different times of the study. Using the ladder of engagement, may help to decide which level is appropriate.

What stage of the project should consumer engagement occur?

- The team may choose to involve consumers at any or all stages of the research project. It is important to remember that engagement can be started at any stage of the research, but starting early will ensure the best results.

Who are the consumers that could be involved?

- Consumers, community members or carers that have experience of the condition or situation that you are researching?
- Community members who may benefit from or be influenced by the research, or who were uniquely placed to contribute to the research?
- A consumer representative is not a participant in a focus group, an in-depth interview or participant in a research study, however they may be. This would need to be assessed on a project-by-project basis.

How will the research team find them?

- Contact the MNCLHD Partnering with Consumers Program for advice and guidance (MNCLHD-CommunityEngagement@health.nsw.gov.au)
- Consumers can be found through a variety of ways such as: consumer organisations, personal contacts and networks, or discussions with colleagues and other researchers. It is always beneficial to make personal contact as early as possible.

What methods may be used to enable consumer engagement?

- Decide what method to use to achieve the level of engagement you are aiming for and will add most value to the project.
- Allow enough time for engagement activities to be carried out.
- The team might also consider using more than one method at different stages of the project.

What resources will be needed?

- Training opportunities/support for all team members.
- Budget - reimbursement for travel, accommodation, parking.

- Time - plan, manage and coordinate processes involving communication, meeting procedures, provision of documentation.
- Administrative support - note taking and records of meetings, circulation of agendas and documents.
- Pull together a pack of information for consumers. This *could* include;
    o Information about the organisations involved in the research.
    o The National Health and Medical Research Council Statement on Consumer and Community Involvement in Health and Medical Research.
    o The MNCLHD program information/contact on consumer and community engagement.
    o Draft a plain language summary of the research project and any other relevant information.
    o Draft Terms of Reference for the group.
    o Selection criteria and application forms.
    o Fact sheet for consumers and community members
    o A glossary of research terms applicable to the project.
    o Project team and contact person

2. Level of Engagement

It is important to be clear about the level of engagement required. It helps the research team understand the aims and in turn, enables consumers to make an informed decision about whether or not they want to work on the project.

HIGH

Lead the Research

Consumers identify the research need and set the appropriate research agenda. They then undertake the research themselves, or commission researchers to do this on their behalf.
Methods often used:
Consumer or community researchers, community led steering groups

Equal Partners

Researchers work in partnership with consumers to plan, undertake and/or disseminate the results of research.
Methods often used:
Consumer or community researchers, membership of steering group

Advise

Researchers seek the advice of consumers e.g. about how to recruit participants or how to disseminate results.
Methods often used:
Asking consumers to comment on documents, community forums or conversations, reference groups, research buddies, meetings with community or consumer groups

Consulted

Offer information about a research study or plan to consumers and seek their views about it. They do not necessarily take these views on board, but they will usually offer feedback about what they have done in response to comments.
Methods often used:
Community conversations, focus groups, surveys, meetings with consumer or community groups.

Informed

Researchers make information about the research available to consumers. They do not seek views on the research.
Methods often used:
Websites, talks or presentations.

LOW

3. How Consumers can be Involved in the Research Process

Setting Research Priorities
- Gap analysis
- Matching unmet needs with research
- Defining patient-relevant added value and outcomes

Research Design
- Procedures
- Quality of life and patient reported outcomes
- Ethical issues
- Mobility issues / logistics
- Adherence measures

Patient Information
- Content
- Visual design
- Readability
- Language
- Dissemination

Ethical Review

Progress Meetings
- Challenges and opportunities for recruitment

Post Research communication
- Contribution to publications
- Dissemination of research results to patient community

Research Priorities → Research Design and Planning → Research Conduct and Operations → Dissemination and Communication

Fundraising for Research

Practical Considerations
- Contractual issues
- Travel expenses
- Support for family members
- Mobility

Informed Consent
- Content
- Visual design
- Readability
- Language

4. Identifying Appropriate Consumers

Planning and careful consideration of consumer engagement will ensure that the correct resources and the right people are in place to have real impact on the project. Why is engagement of consumers important to the research project? Engagement of consumers should have a clear purpose that is agreed and clearly defined.

- The method of consumer engagement will influence the number of people who participate in the research project; ideally there will always be at least two consumers involved. One person can feel very much like they are outnumbered and can easily be disempowered by a large group of researchers and other professional people.
- Work with consumers to decide what is the right number of people for the project.

Deciding if consumers of steering groups can also be participants in the research, can be a dilemma. It is important for each research project to consider issues about ethics, confidentiality and bias.

Decide who should be involved

- Consumers and community members
- Members (including carers) of the consumer or community group that you are researching.
- Organisations which represent consumer or community groups.
- Members of relevant support groups.
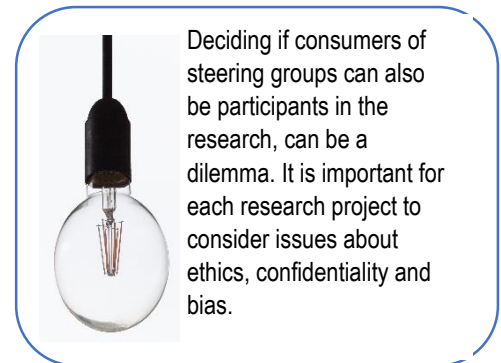
Think about the range of different skills, knowledge and experience that consumers can bring to a project. They may be:

- Living with the condition or health challenge being researched.
- Working for a consumer organisation that focuses on the condition or health challenge being researched.
- Caring for someone who lives with the condition or health challenge being researched.
- A member of a relevant support group.
- A member of a generic consumer organisation
- A member of a community or social group.

5. Meeting with Consumers

Organising the first meeting

- The time and place must be practical for consumers as well as other stakeholders e.g. early morning or early evening and places with little or no parking are often not suitable.
- Face-to-face meetings need to be in an accessible and comfortable room/venue.
- Consider using technology if face-to-face meetings are not possible i.e. teleconferences, Facebook, e-mail, video conferencing (resources may have to be provided to do this).
- All information must be accessible to consumers, print large documents and post them out in time for the meeting, consider using websites.
- Meet consumers and community members before they become formally involved.
- Make sure that information about the meeting (and future meetings), is received well in advance.
- Ask consumers what support they need.
- One of the important things to discuss when you meet is what support the consumer might need. This could include:
  - Training about research or about the particular research method that is being used.

- o How they would like to receive information - do they prefer email or paper? Do they need large print?
- o Is any jargon likely to be used? This is a research project so the answer is almost always yes. If so, explain the jargon in advance.

At the meeting

- Introduce all members. Ensure consumers are accompanied and provided with support before, during and after meetings.
- Work through documents/drafts making amendments as necessary.
- Avoid using acronyms and technical language. Use of these terms will inhibit and negatively impact consumer participation.
- Discuss confidentiality and if appropriate, sign agreements.
- Allow time for members to ask questions and ensure that all questions are clearly answered.
- Consider and discuss any training needs that consumers and community members may have. Provide opportunities to provide such training to support ongoing consumer involvement in the research project.
- Ensure all members show respect by not interrupting one another. Ensure everyone's voice is heard.
- Remember, not all consumers have printers or photocopiers in their homes. Make sure relevant information is sent on paper and by post if that's what they would prefer. Do not assume everyone has email.
- Have a separate note taker.
- Ensure there are adequate breaks and refreshments if it is a long meeting.
- If required, set a time for the next meeting.
- Issue/complete claim forms for payment or issue payment itself if able.
- Thank members for coming and advise when further contact will be made.
- If technical terms are constantly being used, you may wish to provide a glossary.

Have members agree to simple ground rules at the start of each meeting.

After the meeting

- Summarise notes of the meeting including action points and post or e-mail them to the members in a timely way. Detail the next steps; date of the next meeting or when you will next be in contact.
- Update consumers on changes that have been made to the project as a result of their input. If any ideas were not followed through, explain why. It is important to inform everyone about out of session decisions that may be made.
- After meetings, get in touch with consumers. Thank them for coming. Discuss where their input added value to the meeting. Ask them for their feedback on the meeting, and what the team could do to make their involvement more effective. If there are minutes or actions statements from the meeting, make sure they are sent out as soon as possible after the meeting.

Throughout the research project

- Keep consumers updated throughout the project even if they were only involved in one part of the research project.
- Always share the results of the project with every applicant who wanted to be involved with the project, even if they were unsuccessful, this will strengthen consumer networks.
- Make sure consumers do not hear the results of the research through the media, before the team has let them know about the results. One effective way to involve consumers at the dissemination

stage is to ask them to assist in the development of the lay summary of the findings, and perhaps to give talks to relevant community groups about the research and what was found.

6. Plain Language Summaries

What are they?

A plain language summary is a brief outline of a research project or research proposal that has been written for members of the public, rather than researchers or professionals. They are helpful in making information about research more open, transparent and accessible.

Plain language summaries are not an attempt to 'dumb down' scientific information. It is important to be able to speak or write clearly about research in a way that potential funders, supporters, policy makers, consumers and the community can understand.

What should be covered in a plain language summary?

- Aims and purpose of the research.
- How the research will be conducted?
- What are the intended benefits of the research?

Researchers suggest plain language summaries are also useful for:

- Developing grant and ethics applications.
- Scholarship / bursary applications.
- Seeking consumer support and/or input.
- A recruitment tool.
- Media releases and informing the wider community.
- Presenting to a non-scientific audience.

Practical considerations

Write as if you were explaining your research to a friend or family member with no scientific knowledge or background.

- Talk directly to the reader.
- Use simple words, avoid jargon and don't use acronyms.
- Be positive and direct, making sentences short and using bullet points.
- Use active verbs rather than passive.
- Don't turn verbs into nouns.
- Test your writing with consumers and community members.

References

This document was developed from a number of online resources:

McKenzie A., Haines H. Consumer and Community Participation Fact Sheet Series, Second Edition (2014) The University of Western Australia School of Population Health and Telethon Kids Institute. (https://www.involvingpeopleinresearch.org.au/find-out-more/publications-about-consumer-and-community-involvement/)

McKenzie A., Hanley r. (2014) Planning for consumer and community Participation in Health and Medical research: A practical guide for health and medical researchers. (https://www.involvingpeopleinresearch.org.au/find-out-more/publications-about-consumer-and-community-involvement/)

McKenzie A., Bulsara C., Haines H., Hanley B., Alpers K. (2016) Barriers to community involvement in health and medical research - Researchers perspectives on consumer and community involvement in research: a qualitative study. The University of Western Australia School of Population Health, Telethon Kids Institute and The University of Notre Dame (https://www.involvingpeopleinresearch.org.au/find-out-more/publications-about-consumer-and-community-involvement/)

Statement on Consumer and Community involvement in Health and Medical Research, National Health and Medical Research Council (2016), Consumers Health Forum of Australia. (https://www.nhmrc.gov.au/about-us/publications/statement-consumer-and-community-involvement-health-and-medical-research#block-views-block-file-attachments-content-block-1)

MNCLHD Clinical Governance Framework June 2017

ACSQHC National Safety and Quality Health Service Standards: Second Edition: November 2017 (https://www.safetyandquality.gov.au/standards/nsqhs-standards)

Appendices

The following appendices to support this document may be found in a separate file in Word format for ease of editing as required:

1. Appendix 1: Fact Sheet for Consumers and Community Members
2. Appendix 2: Terms of Reference Template
3. Appendix 3: Advertisement-Expressions of Interest
4. Appendix 4: Role Statement and Selection Criteria
5. Appendix 5: Application Form for Consumer or Community Member