West Moreton Health

Guideline

Researcher Guide to Consumer Involvement in Research

1. Purpose

The purpose of this document is to describe the process by which researchers can involve consumers in their research projects.

2. Scope

This guideline applies to all WMH staff undertaking research at WMH.

3. Statement of Commitment

This guideline is consistent with:

- WMH Strategic Plan 2021-2025 (2022 Revision)
- WMH Research Strategy 2021-2025
- WMH Consumer and Community Involvement in Research Guideline
- WMH Engagement Strategy 2020-21 and related WMH Engagement Framework
- NHMRC Statement on consumer and community involvement in health and medical research
- NSQHS Standards 1: Clinical Governance and Standard 2: Partnering with Consumers.
- Health Consumers Queensland Strategic Direction 2022-2025

4. Guideline

4.1 Value of Consumer participation in research

The participation of WMH health service consumers in research undertaken by WMH staff adds value to the development of research protocols, the conduct of research and the dissemination of research findings to the WMH community. It is both the right and responsibility of consumers and community groups to participate in research at WMH.[1]

The National Health and Medical Research Council (NHMRC)[1] outlines the benefits of involving health service consumers in research programs:

- Benefits to the community:
    - Research being conducted that is relevant to community needs
    - Public awareness of, and support for science and research
    - More effective translation of research to deliver improved health outcomes

- Benefits to researchers and health services conducting research:
    - Increased community relevance of research, through improved research priorities and projects informed by consumer and community perspectives and lived experience
    - Public confidence in research through openness and transparency in the conduct of research, and accountability in the use of public money
    - Communities being better informed and having a greater understanding of research
    - Increased opportunities to continuously improve the quality of research.

The three phases of the research "process" where consumers can add the value are: planning phase, doing phase and sharing phase[2]:

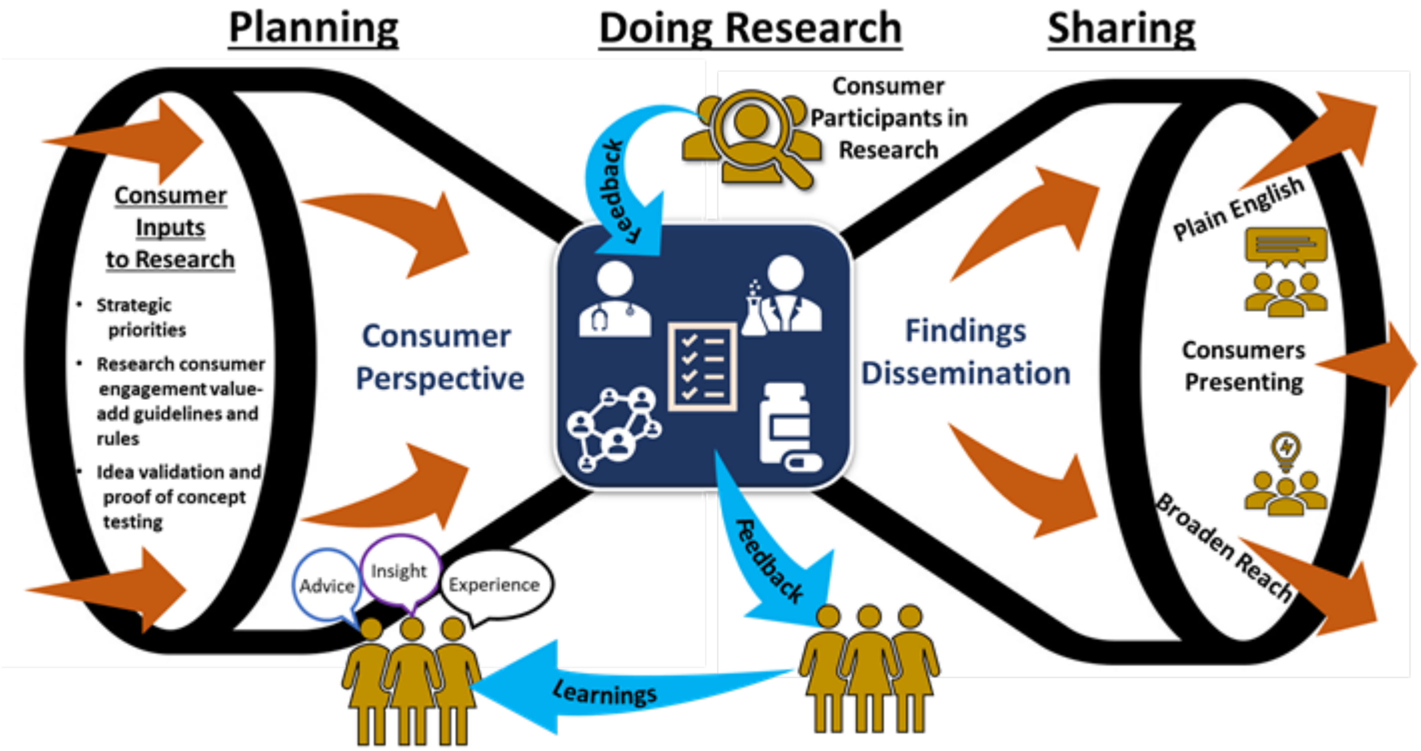

Diagram courtesy of Sunshine Coast HHS[2]

Planning Phase

- Consumers can add value to the planning stage of a research project when:
    - Identifying a research question
    - Developing a research protocol
    - Developing a bid for research grant funding
    - Providing a critical, consumer view to researchers to validate their research protocol, including:
        - The construct of the research methodology
        - Consumer perspective on the ethical basis of the research prior to submission to the Ethics Committee.
        - The expectations placed on participants in the research process
            - Undertaking a survey, additional clinic attendances, participation in face-to-face groups

- The design of survey questionnaires, including the readability and flow of the survey, use of plain language and the use of languages other than English

Doing Phase

- Consumers can provide feedback and/or insights to researchers about the experience of research participants as the research project is undertaken.
- Consumers can provide insights into participant recruitment, particularly if a project is encountering difficulty in recruiting participants.

Sharing Phase

- Consumers assist the dissemination process to the community by:
    - Assisting researchers to provide the outcomes of research in "plain English".
    - Facilitating researchers to present their research outcomes to community groups
    - Broaden the awareness of research projects and outcomes undertaken at WMH, particularly where research has led to a specific health benefit to the community, or improvements to delivery of health services has improved access, quality, or health outcomes for the community.

The research phase and process of engaging with consumers should be outlined in the research protocol, under the study design heading.

4.2 Ways in which Researchers can engage with Consumers

WMH has developed a Consumers in Research Council to provide:

- Strategic advice to WMH about research strategies
- An avenue for researchers to engage with consumers as research projects are developed, implemented, and disseminated.

Consumers have been identified with lived experience and expertise in the following areas of research:

First Nations Health	Emergency and Critical Care	Health Prevention	Elder Care
Allied Health Services	Surgery	Rehabilitation	Health Service Improvement
Women's and Childrens Services	Medical Services	Mental Health	
Disability Services	Chronic Disease		

Consumers selected for membership of the Council have signed confidentiality agreements and are set up in the Queensland Health financial system as vendors, to enable payments.

WMH has developed an information sheet template and consent form have been developed as part of the consumer on-boarding process expected for each research project. These are available on the WMH Research SharePoint page.

It is best practice to engage early with consumers, preferably before the protocol is written so there is genuine co-design of the research process. Research Grants now usually provide funding to engage consumers in the research design process, so this can be accomplished prior to application for ethics approval.

Researchers can engage with consumers members by:

- Contacting the WMH Community Engagement Office:
    - wm_communityengagement@health.qld.gov.au
    - In the email, please outline:
        - The research topic
        - The area of expertise or lived experience sought by the consumer to bring to the project.
        - An outline of expected contribution and meetings
            - This could include review of grant application, project design, review of ethics application, review of data, review of write up, assistance in dissemination.
- Engaging directly with consumers, for example recruiting a patient who has expressed an interest in research during delivery of clinical care. In this circumstance, researchers should be aware of:
    - Providing patients/consumers the freedom to participate as a consumer on a research project and outlining that their participation will not have any effect on their clinical care or relationship with West Moreton Health.
    - Consumers should sight an information sheet about the project and sign a participation consent form. If reimbursement is being considered, documents to enable payment also need to be signed.
        - These forms are available on the WMH Research SharePoint page.
        - The WMH Community Engagement Office can assist with providing payment forms and managing these processes.

4.3 Consumer Reimbursement

There is an expectation, especially if the project is funded by a grant which supports consumer involvement, that consumers will be paid for their consultation:

- The current rate, set by WMH, based on a fee structure adopted by Health Consumers Queensland, is about $50.00 per hour

Consumers will need to be set up as a “vendor” in the Queensland Health financial system.

If the research is being conducted without grant funding, this should be outlined to consumers before they begin work on the project. Consumers may still be interested in participating in the project even if there is no payment; it is always best to check with the individual consumer.

4.4 Consumer Recognition in Publication

Consumers can be given recognition for their contribution to a research project in published journal articles:

- Recognition in the acknowledgements section of the article
- Recognition as a contributing author to the article
    - Researchers should be aware of the International Committee of Medical Journal Editors recommendations[3] around who should be included as an author in a journal article. Authors must have contributed substantially to the conception or design of the work, acquisition,

analysis or interpretation of data, drafting and review of the work, approval of the final version and willing to be accountable for all aspects of the work and Outline expectations of including consumers as an author in a published paper, or recognition within the paper.

5. Development, Revision and Approval History

ID & Version No.	Approval Date	Effective Date	Review Date	Document Custodian/Author	Approving Authority
WMHHS [number] v [number]	21 Nov 2024	21 Nov 2024	November 2028.	Director of Research and Innovation	Executive Director, Medical Services
WMHHS [number] v [number]					
	Summary of changes				
	☐ New (include information/background as to why the document was developed e.g. new treatment for an identified risk) ☐ Scheduled review, minor changes including: ☐ Scheduled review, nil changes.				

6. Key Words

- Research
- Consumer

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[1] National Health and Medical Research Council and Consumer health forum of Australia. Statement on consumer and Community Involvement in Health and Medical Research. 2016. Available at https://www.nhmrc.gov.au/node/21 accessed on 11 March 2023

[2] Sunshine Coast Health and Health Service. Guideline: Access and Utilisation of the Services of the Consumer Research Engagement Group. 2022 Unpublished

[3] International Committee of Medical Journal Editors, Recommendations for the Conduct, Reporting, Editing and Publication of Scholarly Work in Medical Journals, 2024 available at CP-ACPJ220177 1..20 (icmje.org) accessed on 4 November 2024.