

Cabrini Guideline for Partnering with Consumers in Research

Guidance for Researchers and Organisations: Consumers as active partners in research

PURPOSE

- a) To guide researchers and organisations on how to implement person-centred research, and to build consumer partnerships in the design, delivery and evaluation of research.

DEFINITIONS

Community – a group of people sharing a common interest (e.g. cultural, social, political, health, economic interests) but not necessarily a particular geographic association. Different types of communities are likely to have different perspectives and approaches to their involvement in research.

Consumer – patients and potential patients, carers, family members, support people and people who use health care services.

Consumer representative – someone who voices consumer perspectives and takes part in the decision-making process on behalf of consumers. This person may be nominated by, and may be accountable to, an organisation of consumers.

Consumer engagement reflects an approach involving the development of meaningful relationships with a shared focus. Consumer engagement is underpinned by trust and mutual respect, a commitment by all involved and active two-way dialogue. The term consumer engagement indicates that action is more than simply taking part.

Consumer and community involvement – the active partnership between consumers and/ or the community in research and healthcare improvement projects.

CRCCIC – Cabrini Research Consumer and Community Involvement Committee. A volunteer group of consumers with experience with research participation

CRGO- Cabrini Research Governance Office. Email researchgovernance@cabrini.com.au

Human Research: research conducted with or about people, or their data or tissue.

Person Centred Care: Care that respects and responds to the preferences, needs and values of patients and consumers.

Why involve consumers?

There are many reasons to engage with consumers as research partners:

- Fosters public confidence in research through collaboration, inclusivity, and priority setting, leading to more effective and meaningful outcomes for both researchers and the community.
- Person-centred care in research places the individual at the centre of the research process, with a focus on promoting dignity, autonomy, and improved outcomes.
- Consumers possess invaluable first-hand knowledge, perspectives and experience.
- Participation is an ethical and democratic right.
- Helps researchers set priorities and focus on outcomes important to consumers.
- Improves study quality and effectiveness via communication strategies including improved recruitment and retention strategies, health literacy considerations, and enhanced dissemination of results.
- Funding of research increasingly stipulate consumer co-design and engagement.

- Participation is a mechanism to ensure accountability.

The Regulatory Environment

The NHMRC's '[Statement on consumer and community involvement in health and medical research](#)' recognises that appropriate consumer involvement in research should be encouraged and facilitated by researchers and research organisations because it is likely to improve the design, recruitment, conduct, and translation of research.

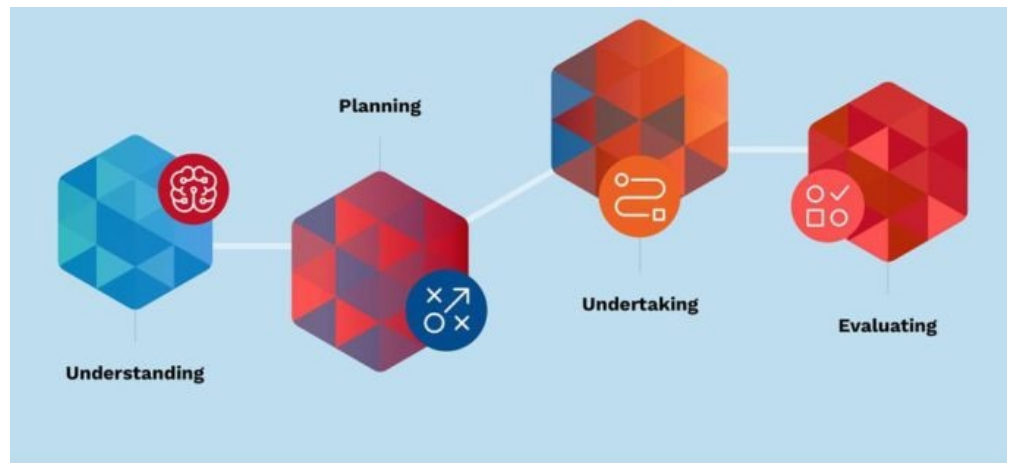
The *National Statement on Ethical Conduct in Human Research (2023)* states that researchers have significant responsibilities in ensuring ethical conduct of research and engaging appropriately with communities and/or consumers relevant to their research.

The Australian Commission on Safety and Quality in Healthcare's *National Clinical Trials Governance Framework* places significant responsibilities on health service organisations to take actions to meet Standard 2: Partnering with Consumers.

Tools for Researchers

There are many tools and guides available for researchers. Below are a selection of Toolkits/Handbooks and online modules:

- [Consumer Involvement & Engagement Toolkit](#), a collaborative project co-funded by CT:IQ and the Australian Clinical Trials Alliance - ACTA



Source: [Consumer Involvement & Engagement Toolkit](#),

- Handbook** by Western Australian Health Translation Network (WAHTN) [Involving Consumers in Health and Medical Research: A practical handbook for organisations, researchers, consumers and funders](#)
Quick Guide version: [Steps for Consumer and Community Involvement](#)
The Handbook contains clear steps for each stakeholder and the tools for Five Phases for successful embedding of Consumer Involvement: Commitment, Planning and Preparation, Managing for Success, Evaluating the Involvement, and Concluding the Involvement.
- Monash Partners *Consumer and Community Involvement* series of six [self-paced online modules](#), providing general and practical information and strategies to meaningfully conduct and embed consumer and community involvement in research and healthcare improvement projects
<https://monashpartners.org.au/education-training-and-events/ccli/>
- Health literacy editor for researchers. Online and free
<https://www.sydneyhealthliteracylab.org.au/health-literacy-editor>
- Protocol Development: The [TransCelerate Patient Protocol Engagement Toolkit](#) makes available tools and resources for researchers and organisations involving consumers in the development of a study protocol.

- e) Questions to ask consumers reviewing patient facing information: [Tip Sheet 6: How to get feedback from consumers on patient information publications](#), Australian Commission for Safety and Quality in Healthcare.
- f) [Project Manager Checklist for engaging with consumers](#). Provides a practical everyday checklist from supporting a new consumer through to periodically checking in for ongoing support.
- g) Guidance for engaging with Aboriginal and Torres Strait Islander people, including applying the principles of self-determination: [marra ngarrgoo, marra goorri The Victorian Aboriginal Health, Medical and Wellbeing Research Accord. Indigenous data and governance and sovereignty resources](#)

Planning & Involvement - how to set up for positive consumer engagement

- The values and attitudes of the researcher and organisation clearly demonstrates a commitment to partnership and co-design in research by embracing a philosophy of research and innovation in partnership *with* the community, rather than *for* the community.
- Provide an opportunity for consumers to meaningfully contribute
- Act upon consumer contributions and acknowledge and recognised their involvement
- Identify consumers who are best suited to a particular activity
- Clearly articulate the aims of the activity, and what is required of the consumer
- Prevent power relationships where the organisation or individual priorities dominate
- Wherever possible seek opinion at conceptual stage
- Provide clarity around terms and conditions of involvement
- Ensure appropriate organisational resourcing to support involvement

Avoiding Common pitfalls

Common pitfalls are described in [Involving Consumers in Health and Medical Research: A practical handbook for organisations, researchers, consumers and funders](#) and may include:

- Lack of adequate preparation or rushing processes, policies and people
- A culture that does not understand or support involvement
- Lack of an Involvement Agreement
- Poor communication, or a lack of ongoing communication
- Lots of discussion followed by little or no action, or words that don't match actions
- Ineffective, invisible or absent leadership
- Over-complicated processes
- Failure to include the right people in the involvement process
- Failure to adequately resource the involvement process
- Over-focus on processes and systems at the expense of people and culture
- Assuming that all stakeholders will see things the same way
- Failing to be flexible and responsive to changing circumstances

Practical Tips & Considerations

Many of the most successful research teams engage with consumers well before they even decide on their research questions. Researchers may contact CRGO who can facilitate access to consumers who have experience with research via the Cabrini Research Consumer and Community Involvement Committee (CRCCIC). Alternatively, researchers may engage patients and families via Cabrini's consumer body, Cabrini Community Voice, which is managed and maintained by the Patient Experience team. Refer to [Patient and Family Participation](#) for engagement via Cabrini Community Voice.

Tips:

- Consent forms and information sheets should be written in plain English pitched at school grade 8 readability level.

- Make patient-facing materials easier to understand or more engaging (e.g. writing or reviewing participant information sheets, questionnaires or lay summaries).
- Identify additional/alternative participant recruitment strategies.
- Ensure the study is designed to minimise disruption to participants; for example, by making the ‘participant journey’ as convenient as possible by scheduling visits at suitable time
- Cabrini clinical trial research consent forms are to include information about Australian Healthcare Rights, and Open disclosure. CRGO can provide the QR codes for links to this required information
- Understand how to access interpreters for research participants
- Seek regular feedback from consumers and build in evaluation into any plans
- Provide results of research back to participants and the wider community
- Remember to include consumer stories in training and education of the workforce
- Listen and act upon feedback from patients and carers about the information communicated to them during research or related to their ongoing care. Consumer feedback, including complaints can be used to improve the quality research services.
- Provide trial participant information packages or resources about treatment and consent processes that are available for consumers in different formats and languages, consistent with the patient profile
- [Consumer Engagement in Research -Top 10 tips for researchers written by the Victorian Comprehensive Cancer Centre \(VCCC\)](#)

Education and Training:

- Health Literacy training for researchers: <https://www.healthliteracytraining.com.au/health-literacy-essentials-course/>
- Consumer and Community Involvement in Health Research course by WAHTN [is an online](https://www.retprogram.org/training/consumer-and-community-involvement-in-health-research) interactive course explaining community participation, involvement and engagement <https://www.retprogram.org/training/consumer-and-community-involvement-in-health-research>

Resources

- Consumer Representative Role Description - [Example template](#)
- Undertaking [Consumer Focus Groups](#)
- [Person Centred Care hub](#)
- [Fact Sheet for clinicians- Informed consent in health care](#) from the Australian Commission for Safety & Quality in Healthcare
- <https://ahra.org.au/2023/11/29/national-collaboration-builds-capacity-and-advances-implementation-of-consumer-and-community-involvement/>
- Safer Care Victoria, [How to engage consumer representative](#)
- [Attributes of person-centred healthcare organisations](#). Australian Commission for Safety & Quality in Healthcare
- [Health Literacy - Taking action to improve safety and quality](#)

EVALUATION

Evaluation should be a continuous process with members of a research team or committee periodically reflecting on what is working well, what the challenges are, and what could be improved. The following templates from ACTA/CT:IQ may be downloaded and adapted.

- [Consumer Involvement Evaluation Form](#)
- [Consumer Involvement Evaluation Form: one-off event](#)

Key Legislation and Standards

NHMRC [Statement on consumer and community involvement in health and medical research](#)

[National Statement on Ethical Conduct in Human Research \(2023\)](#)

[National Clinical Trials Governance Framework and User Guide](#)

Acknowledgment

Cabrini Research Consumer & Community Involvement Committee

Further Information

Contact the Cabrini Research Governance Office

<https://www.cabrini.com.au/research/research-with-us/ethics-and-governance/>

email: researchgovernance@cabrini.com.au

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