

Guidance for Consumers and the Community: Consumers as active partners in research

Purpose

- a) To guide consumers and the community to be active partners in the design, delivery, dissemination, 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 get involved with research?

There are many reasons to be involved with research, including:

- Giving researchers new ideas and setting priorities and areas of interest
- Help provide feedback on consumer materials to ensure they are readable and understandable to the everyday person
- Help suggest strategies and design the research so that it makes it easier to participate
- Helping be part of funding bids or to assist funders in assessing applications (e.g. Cabrini Foundation Grants)
- Helping with ideas around the best way to share the results
- Provide a consumer perspective as part of a committee (e.g. CRCCIC or Cabrini Research Governance Committee)
- Telling your story and sharing your experience for the purpose of education, awareness and training

- Providing feedback on your research experience so that improvements can be made
- Increasing the diversity of perspectives
- Ensuring clinical trials are conducted at an acceptable standard

Regulations

Any health service organisation who participates in clinical trials research must meet certain quality and safety standards as part of their hospital accreditation. This is known as the National Clinical Trials Governance Framework. When a hospital implements the Governance Framework there is a commitment to partnering with consumers so that you can be assured that:

- Clinical trial services are patient-centred and meet community needs
- Consumers are supported and encouraged to be partners in their own care
- Consumers are supported to be partners in the design and governance of clinical trial services
- Consumers can ask for more information about clinical trials in different formats
- The health service communicates with consumers in a way that is respectful and supports effective partnerships.

Toolkits for involvement in health and medical research

- a) The Australian Clinical Trials Alliance and CT:IQ have a Consumer Involvement Pack, [How to get involved in health and medical research](#) which covers Frequently Asked Questions such as:
- Have I got the right experience?
 - What will I be expected to do?
 - What training and support might I be offered?
 - What difference will I make and how might I benefit?

- b) [Partnering with Consumers: A guide for consumers'](#) by the Australian Commission on Safety and Quality in Healthcare.

Developed by consumers for consumers, the Guide explains how to build and strengthen consumer partnerships at all levels of the health system to support person-centred care and drive positive change.

Consumers should be supported to be active partners in the design, delivery and evaluation of health care by being:

- Supported to understand and exercise their healthcare rights
 - Provided with evidence-based information about treatment options for their medical conditions
 - Encouraged to share decision making about their health care to the extent that they choose
 - Involved in making decisions about how health services are designed and operate, how care is delivered, and in measuring and evaluating care and services.
- c) [Guidelines for Consumer Representatives](#) by the Consumers Health Forum of Australia. These guidelines include the role of a consumer representative, obligations and expectations, entitlements, preparation and briefings, making your point, participating in meetings, reflecting and evaluating, and dealing with difficulties. Includes useful scenarios and interactive stories of consumer participation.

How can I be involved with clinical trials?

As a consumer, you can take an active role in providing feedback, concerns and compliments about your experiences in clinical trial participation.

You can also be involved by:

- Advocating for, or representing other patients in focus groups and meetings to improve clinical trial participation
- Participating in the review of incidents or other serious adverse events relating to clinical trials
- Reviewing and commenting on reports on safety and quality in clinical trial operations
- Communicating with your health service about potential safety and quality risks in clinical trial services
- Sharing your experience through patient stories, information sessions, letters, pictures or presentations at meetings or training sessions for the workforce
- Participating in patient experience surveys
- Participating in the development and review of health information for consumers about clinical trials.
- Consumer representative stories – In your words ‘what does it mean to be a consumer representative’

What qualities make an effective consumer representative?

(Source: Consumers Health Forum of Australia, Guidelines for Consumer Representatives)

There are qualities which are important in ensuring that you are an effective consumer. It helps if you have ability to:

- try to base your argument on the broader consumer experience, not just your own personal story
- analyse an issue, and determine its effects on consumers
- consider more than your own opinion with a viewpoint that takes account of the diversity of experiences and needs of consumers
- present an argument rationally and convincingly
- understand the consequences of decisions, in the short and long term
- negotiate and always speak with respect and sincerity.

There is no correct way to become an effective representative, much of it is learned from experience and networking. Seek out relevant information and workshops and take every opportunity to speak with other consumers and organisation contacts to improve your skills.

Managing for success

(Source: Consumer Involvement in Health and Medical Research, WAHTN)

Be clear about your motivation for involvement and what you want from it.

Think about your reason for being involved. Examples of reasons include a desire to ‘give back’, being a voice for others, meeting people and sharing experiences, turning a negative experience into something positive, using your experience with a disease/health condition to inform and enhance research.

Questions to consider:

- Is the role clear? Ensure that your involvement arrangement is clarified through a suitable document e.g. Terms of Reference, Letter of Agreement
- Does the role align with your values and interest?
- Do you have time to fulfil the role well?
- Check any expense reimbursement or remuneration process

- Clarify requirements and expectations, including your own
- Communicate regularly with the researcher or the key organisation contact
- Attend all meetings where possible. Prepare for the meeting, including reading meeting papers. Participate and contributing at the meeting
- Participate in any formal evaluation of the involvement
- Take time to reflect on the involvement, consider learnings and suggest or make changes
- Celebrate shared success and ensure that your contribution has been appropriately acknowledged on all reports, documents and/or presentations
- Invest in yourself and take all formal and informal learning opportunities provided – learn as much as you can
- Keep good records of reviews and discussions to inform reporting, evaluation and improvement

Training and building skills

[What are Clinical Trials?](#)

What are clinical trials (other languages)

[Chinese simplified](#), [Chinese traditional](#), [Filipino](#), [Greek](#), [Hindi](#), [Italian](#), [Punjabi](#), [Spanish](#), [Vietnamese](#)

Cancer Council eLearning module on helping consumers work with researchers <https://www.cancer.org.au/online-resources/elearning/consumers-in-research-training>

This training program is a series of four short online modules, designed to inform and prepare consumers (cancer patients, survivors, carers, and family members of those with cancer) to be involved in health and medical research.

Resources

- [Information for consumers](#)
- [The NSQHS Standards consumer fact sheets](#)
- [Fact Sheet National Clinical Trials Governance Framework - Information for patients and consumers](#)
- [Australian Charter of Healthcare Rights](#)
- [Person-centred Care Network](#)

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](#)

References

[Guidelines for Consumer Representatives](#), Consumers Health Forum of Australia

[Consumer Involvement in Health and Medical Research](#), WAHTN

[Partnering with Consumers: A guide for consumers'](#), the Australian Commission on Safety and Quality in Healthcare

Acknowledgment

Cabrini Research Consumer & Community Involvement Committee.

CT:IQ and the Australian Clinical Trials Alliance (ACTA) for the toolkit and consumer involvement evaluation forms

Australian Clinical Trials Alliance for the clinical trials information, including other languages

Cancer Council for online consumer modules

Consumers Health Forum of Australia for the Guidelines for Consumer Representatives

Western Australian Health Translation Network (WAHTN) for [*Involving Consumers in Health and Medical Research: A practical handbook for organisations, researchers, consumers and funders*](#)

Further information

Contact the Cabrini Research Governance Office - email: researchgovernance@cabrini.com.au or visit:

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