NATIONAL BREAST CANCER FOUNDATION

CONSUMER AND RESEARCHER GUIDELINES

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1. Overview

Consumers and community members offer unique and valuable insights that strengthen the quality, relevance, and impact of health and medical research. Best practice across the Australian sector emphasises that research is most effective when designed *with* and *by* the people it aims to benefit.

The purpose of this resource is to clearly articulate National Breast Cancer Foundation's (NBCF) expectations for consumer involvement in research. It also describes how NBCF integrates consumers into its grant review processes to ensure that lived-experience perspectives inform assessments of the relevance, feasibility, appropriateness, and potential impact of proposed research.

2. National Breast Cancer Foundation

The National Breast Cancer Foundation (NBCF) is Australia's largest not-for-profit organisation funding world-class breast cancer research towards our vision of Zero Deaths from breast cancer.

Since our inception in 1994, NBCF has invested over $250 million dollars towards more than 650 world-class research projects across Australia. In this time, the death rate from breast cancer in Australia has reduced by over 40%.

We have seen remarkable progress, but the job is not done.

At NBCF, we're determined to create a better tomorrow. We know research matters, and it is central and critical to improving breast cancer outcomes. That's why we fund the very best breast cancer research in Australia by awarding grants via open national, competitive, and rigorous peer review processes.

3. Key Definitions

These definitions build on the National Health and Medical Research Council's (NHMRC) Statement on Consumer and Community Involvement in Health and Medical Research and other relevant sector-wide principles.

Consumer: A person affected by breast cancer as a patient, potential patient (people at risk of breast cancer), survivor, carer, partner, or family member.
A consumer is **not**:

- A researcher or academic with no lived experience of breast cancer
- A clinician or healthcare professional acting only in their professional capacity

Consumer Participation: taking part *as a subject* in research (e.g. completing surveys, donating biospecimens, joining clinical trials). Research is done *to* participants, and they do not influence study design.

Consumer Involvement: an active, respectful partnership between consumers and researchers where consumers help shape research priorities, design, implementation, analysis, or translation. Involvement is defined as research conducted *with* or *by* consumers, not *to*, *about* or *for* them.

Best practice levels of involvement include:

- **Consultation** – seeking consumer views on specific elements. For example, seeking feedback on sections of a grant proposal written for consumer peer reviewers.
- **Collaboration** – shared shaping of research priorities and design.
- **Co-production** – shared responsibility, accountability, and decision-making across the entire project.

Consumer Engagement: when information and knowledge about research is shared with the public (e.g., community forums, lab tours, outreach events, blogs, focus groups). Engagement encourages feedback, which can be very beneficial for researchers, but does not involve consumers in shared decision-making.

Research: an original investigation undertaken to gain knowledge, understanding and insight.

Research process: the planning, funding and conduct of an individual piece of research in addition to implementation of research findings and publication of research findings.

Researcher: a person who conducts or is responsible for the conduct of research.

4. Benefits of Consumer Involvement in Research

Consumers enhance research at every stage. Both consumers and researchers benefit from consumer involvement.

Involving consumers in a research project improves its quality, credibility, feasibility, ethical integrity, and real-world impact.

4.1 Enhancing Research Quality and Relevance

Consumer involvement ensures:

- Research questions reflect the actual needs and priorities of people affected by breast cancer.
- Lived-experience insights identify conceptual and practical problems that researchers may overlook.
- Study materials (e.g., plain-language summaries, consent forms) are clearer, more accessible, and more acceptable.
- Outcomes measured in research align with what is meaningful to patients and families.

4.2 Improving Feasibility and Study Conduct

Consumer input strengthens:

- Recruitment strategies by identifying barriers and motivators for participation.
- Study feasibility by ensuring protocols are realistic for participants.
- Ethical decision-making and acceptability of study approaches.

4.3 Supporting Communication, Dissemination, and Impact

Consumer involvement helps:

- Improve how research findings are communicated in clear, accessible ways.
- Strengthen dissemination through public events, open days, blogs, and social media.
- Increase real-world relevance and translation of findings into practice.

4.4 Strengthening Governance, Ethics, and Accountability

Consumer involvement:

- Increases transparency, accountability, and public trust.
- Enhances ethical review by ensuring participant needs and vulnerabilities are appropriately considered.
- Improves funding decisions by integrating lived-experience perspectives into assessing research proposals.

4.5 Benefits for Researchers

Researchers gain:

- Deepened understanding of lived experience and patient priorities.
- Stronger communication and co-design capabilities.
- Clearer, more compelling grant applications through consumer-responsive design.

4.6 Benefits for Consumers

Consumers benefit through:

- Empowerment and sense of agency in shaping research.
- Increased confidence, skills, and knowledge.
- Personal fulfilment and pride in contributing to improved outcomes.

5. Consumers

An effective consumer brings the knowledge gained from their personal experience with breast cancer and is also able to represent the views of others when engaging with research.

Effective consumers:

- Bring diverse lived experiences.
- Are motivated to contribute to improving outcomes for others.
- Understand the research or health context.
- Are supported through training and networks, including conference and forum attendance and co-authoring journal articles, and through connections with consumer organisations, networks and support groups.
- Can encourage and support other consumers to actively participate and develop in the role of consumer representatives
- Can represent broad consumer perspectives.

6. Principles for Consumer Involvement

Consumer involvement must be:

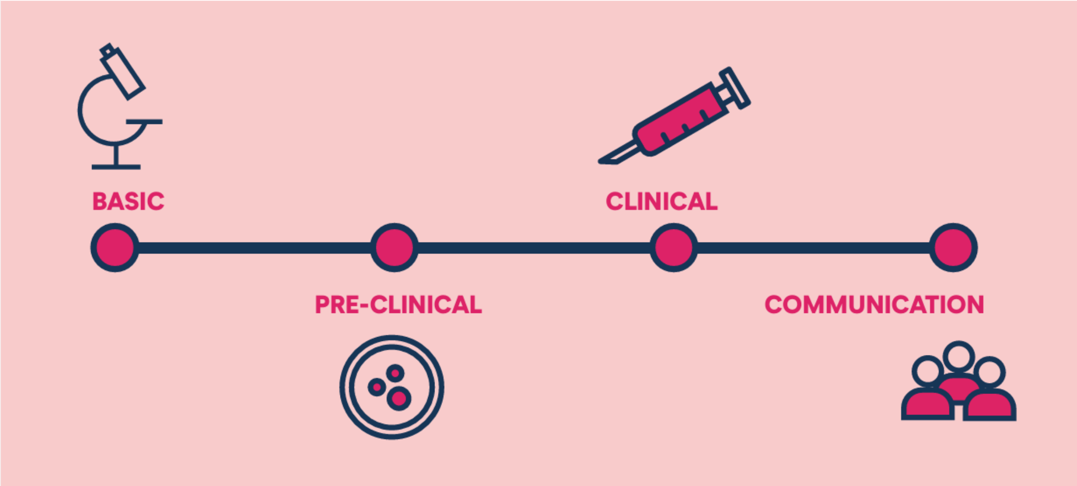
- **Early:** beginning at project conception.
- **Respectful:** fostering integrity, transparency, and trust.
- **Mutually beneficial:** recognising complementary expertise.

- **Inclusive and diverse:** involving priority populations.
- **Meaningful:** avoiding tokenism and enabling genuine influence.
- **Accessible:** using plain language and culturally sensitive communication.

7. The Research Pathway

Many research projects follow a pathway which includes four stages of research:

- **Basic research** – forming new ideas and conducting research that explores and reveals fundamental biological mechanisms.
- **Pre-clinical research** – testing which takes place in cells in a laboratory or in biological models.
- **Clinical research** – testing the research on patients in a controlled environment, such as a clinical trial to confirm safety and effectiveness
- **Translational research** – dissemination of the research findings to the broader community, such as communication and incorporating research findings into clinical practice.



It is worth noting that not all laboratory-based research is intended to proceed to clinical trials. Likewise, not all research pathways begin as basic or pre-clinical such as psycho-oncology research.

Consumers can be involved in all the different stages of the research pathway. The level of input and type of involvement can vary and will depend on the stage of the research.

Examples of consumer involvements in a basic and/or pre-clinical research projects may include:

- Discussing ethical considerations.
- Helping articulate the potential end benefits for people with breast cancer.
- Supporting communication of emerging findings.

8. The Research Cycle

The research cycle has five key stages:

Consumer contribution is valuable at each stage:

1. **Deciding what to research:**
   - Identify where consumer involvement is most relevant.
   - Engage consumers early in shaping research questions.
   - Discuss anticipated benefits and integrate their input.

2. **Deciding how to do it:**
   - Tailor involvement to project type.
   - Involve consumers in reviewing patient materials and ethics submissions, including:
     - writing / commenting on documents, surveys, questionnaires, consent forms and information sheets.
     - writing / reviewing the consumer-related sections of grant and ethics applications.
     - writing / editing the lay summary of grant applications.
   - Co-develop plain-language summaries and dissemination plans.
   - Invite consumers as co-investigators or co-authors where appropriate.

3. **Doing it:**
   - Clarify research plan and confidentiality requirements.
   - The researchers and consumers should be clear about each other's expectations.
   - Together they can establish the times and frequency that researchers and consumers will meet and communicate on a regular basis.
   - It is important that the relationship between research and consumer is bidirectional – the consumer is a partner who can make a valuable contribution.

4. **Letting people know the results:**
   - Communicate the key findings and research outcomes to consumers.

- Work with consumers to develop plain language summaries and presentations of research findings to communicate with diverse audiences clearly and effectively.
- Co-present findings at academic conferences, presentations or media opportunities.

5. **Knowing what to research next:**
   - Engage consumers in interpreting outcomes and identifying future priorities.
   - Involve consumers in evaluating the impact of research and guiding future directions.

9. Consumer involvement in the NBCF Review Process

NBCF involves both researchers and experienced consumers in its review of research grant applications.

9.1 Review Panel

Grant Applications submitted to NBCF are reviewed by an expert, peer review panel, comprised of scientists, clinician researchers, and consumers. Consumers are requested to score applications that they review, reflecting the significance of the consumer voice in the review and decision-making process.

Consumer review of applications aims to ensure that funded research will be relevant, feasible and impactful to those affected by breast cancer and the broader breast cancer community.

10. Guide for Researchers

For finding consumers, researchers should:

- Work with their research organisations to seek advice on how best to source and work with consumers.
- Engage consumers who may have completed relevant training (e.g. Cancer Council, Health Consumers NSW).
- Include **at least two consumers**, in line with NBCF Grant Guidelines.

For working with consumers, researchers must:

- Meet with their appointed consumer(s) at an appropriate frequency for the type of research project.
- Reimburse all out-of-pocket expenses incurred.
- Maintain clear, bidirectional communication.
- Document and demonstrate ongoing consumer involvement throughout the project.
- Provide support, training, and accessible materials to enable meaningful involvement.

11. Consumer Remuneration

NBCF recognises and values the important contribution of consumers in informing and strengthening our research programs and is committed to ensuring that consumers are appropriately remunerated for their time, expertise, and lived experience.

NBCF's remuneration framework is designed to align with recognised national and state guidance while ensuring consistency, transparency, and fairness across all activities. It acknowledges both preparation time and active participation and supports meaningful and equitable consumer involvement in research.

11.1 Remuneration Rate

Consumer participation is remunerated at an hourly rate aligned with established guidance from Health Consumers NSW and NSW Health:

- 2026/2027 rate: $62 per hour

This rate is consistent with sector benchmarks for consumer participation in health and research settings, including advisory committees, review panels, and governance activities.

11.2 Scope of Remuneration

NBCF provides remuneration for time spent contributing to agreed activities, which may include:

- Attendance at meetings (e.g. Research Advisory Committees, Peer Review Panels)
- Review of materials in preparation for meetings (where applicable)

In addition to hourly remuneration, NBCF reimburses reasonable, pre-approved out-of-pocket expenses associated with participation, including:

- Travel costs
- Other approved participation-related expenses

The examples below illustrate how remuneration may be calculated for common activities:

Activity	Component	Calculation	Amount (AUD)
Peer Review Committee Member	Review of 10 applications	10 x 0.5hrs x $62	$310
	Panel meeting attendance (2hrs)	2 x $62	$124
	Total (excluding expenses)		**$434**
Research Advisory Committee Meeting	Review of meeting papers	1hr x $62	$62
	Meeting attendance (2hrs)	2 x $62	$128
	Total (excluding expenses)		**$184**

12. Useful Resources

Statement on Consumer and Community involvement in Health and Medical Research, National Health and Medical Research Council (2016), Consumers Health Forum of Australia.	https://nhmrc.gov.au/sites/default/files/documents/reports/consumer-community-involvement.pdf
Cancer Council - Consumer Training Course	https://www.cancer.org.au/about-us/consumertraining.html
Cancer Voices Australia	https://www.cancervoicesaustralia.org/
Consumer & Community Involvement Program (CCIProgram)	https://cciprogram.org/resources/
Consumers' Health Forum of Australia	www.chf.org.au
Health Consumers NSW Training Courses	Joint training for researchers and consumers in research - Health Consumers NSW