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# **NATIONAL BREAST CANCER FOUNDATION CONSUMERS AND RESEARCHERS WORKING TOGETHER IN BREAST CANCER RESEARCH**

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**Guidelines for Consumers and Researchers**

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## **1. About this Resource**

Consumers and the community offer unique and valuable insights as research is designed, conducted and translated. Consumer engagement with research helps to ensure high research quality and relevance.

The key objective of this resource is to communicate to both consumers and breast cancer researchers the National Breast Cancer Foundation's expectations of consumer engagement with research.

In addition, this resource outlines how NBCF involves consumers in its grant review process.

## **2. National Breast Cancer Foundation**

The National Breast Cancer Foundation (NBCF) is Australia's leading national body funding game-changing breast cancer research with money raised entirely by the Australian public.

Since 1994, NBCF has awarded over \$170 million to 534 breast cancer research projects across the country. NBCF is committed to funding research right across the spectrum - from understanding the genetic basis of the disease, to developing new diagnostic tools, preventative measures, targeted treatments and ways of improving the quality of life for all those living with the disease.

Our determined goal is to achieve zero deaths from breast cancer by 2030. With eight Australian women dying from the disease every day, there is still much to do.

## **3. Key Definitions**

The following definitions have been adopted by NBCF from those described in the Statement on Consumer and Community Involvement in Health and Medical Research, National Health and Medical Research Council (2016) and Consumers' Health Forum of Australia and Cancer Australia and Cancer Voices Australia,

2011, National Framework for Consumer Involvement in Cancer Control. Cancer Australia, Canberra, ACT.

**Consumer** - a person affected by breast cancer, a patient survivor, carer or family member

**A Consumer is NOT ...**

- a patient who is a participant in a research study, but is not providing direct feedback into the design or conduct of the research;
- a layperson/community representative who has no input into the conduct or communication of the research; or
- a researcher or individual with a specific research role in the project.

**Consumer Involvement** - an active partnership between consumers and an organisation involved in cancer research in the policy, research or service delivery process. This refers to doing projects 'with' or 'by' consumers, rather than 'to', 'about' or 'for' the consumer.

**Consumer Engagement** - refers to consumers being involved in planning and developing health policies, contributing to research and clinical trials and in the dissemination of research outcomes.

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

**Bidirectional relationship** - communication and information that is shared between consumer and researcher and vice versa.

**Research process** - the planning, securing funding and conduct of an investigation of interest which also includes the presentation, publication and implementation of research findings.

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

## 4. The Benefits of Consumer Involvement in Research

Consumers provide valuable input to the planning, development, conduct and review of research projects. Both consumers and researchers benefit from consumer involvement.

Involving consumers in research can ensure that:

- research is focused on the end user;
- researchers are more accountable and processes more transparent;
- conceptual and practical problems that researchers may not see are identified by consumers;
- outcome measures that are important for consumers and community members are clearly identified; and
- the results of research are disseminated as and where appropriate.

## 5. Consumers

A valuable 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.

The key characteristics of consumers who are most suitable for engaging with research are:

1. Consumer experience: experience of cancer either as a patient, carer, family member or survivor.
2. Consumer motivation: motivated to participate in a largely voluntary role to improve outcomes for others.
3. Consumer understanding of context: develop an understanding of the health context where they are involved, and the types of consumer involvement.

4. Learning and development: undertake learning and development opportunities, including conference and forum attendance and co-authoring journal articles, to build their expertise in consumer participation.
5. Consumer support and networks: seek support through connections with consumer organisations, networks and support groups.
6. Consumer mentoring: encourage and support other consumers to actively participate and develop in the role of consumer representative.
7. Consumer ability: be able to evaluate issues from a consumer perspective and make relevant recommendations. They are also able to “represent” a wide range of experiences, not just their own.

## 6. Principles for Consumer Involvement

Regardless of the level or method of participation of the consumer, the principles described below provide support and guidance to the consumer and the researcher:

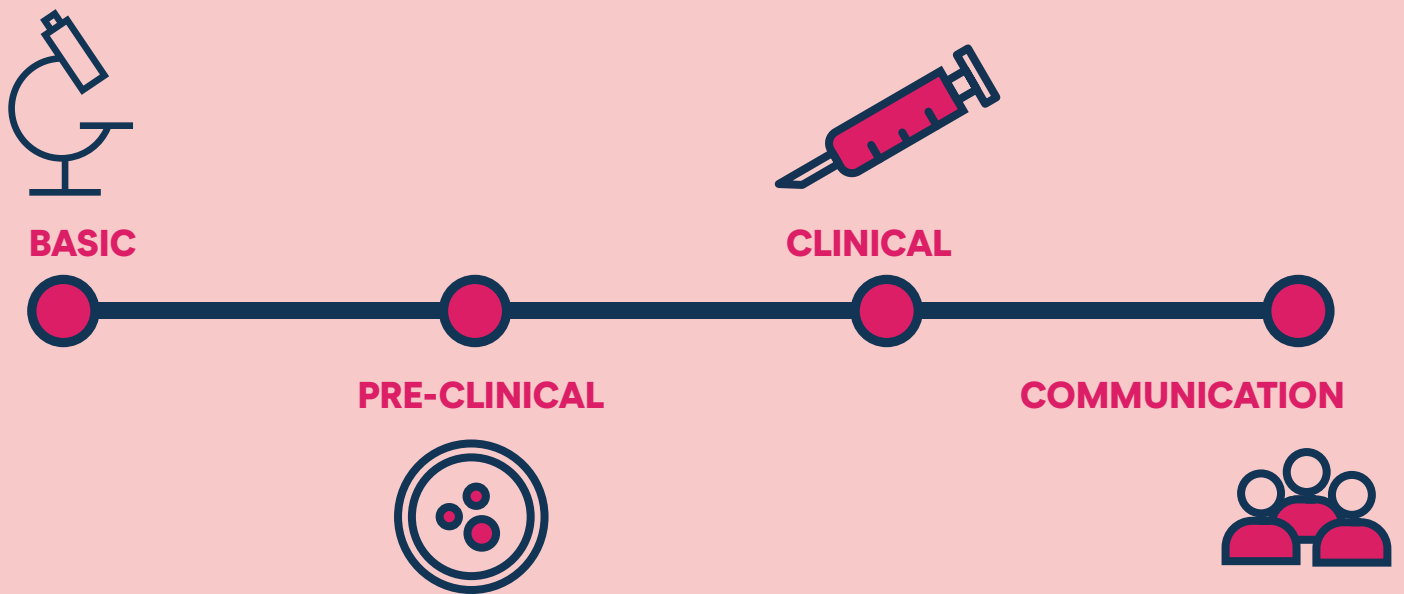
- Consumers are involved as early as possible in the research.
- Everyone is treated with respect and integrity.
- The relationship is a partnership and is inclusive.
- Everyone is kept informed and involved.
- The language used is easily understood by everyone.
- The participation adds value to the research, researchers and/or consumers.

## 7. The Research Pathway

The image below shows one pathway of research. The terms used to describe different stages of research include;

- Basic – taking an idea to experiments designed to be conducted in the lab;
- Pre-clinical testing - taking place in cells in a laboratory or in animals;
- Clinical trials – testing the research on patients in a controlled environment and finally
- Communication of the findings to the broader community.

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:

- consulting consumers about the ethics of particular type of research;
- helping researchers think about the end point of their research and the benefits to the end user;
- helping researchers communicate the results of their findings to the boarder community.

## 8. The Research Cycle

Research typically follows a cycle of five key stages (as shown in the following image) and consumer input is important at every stage.

Consumer involvement for a particular research activity will depend on the purpose of the involvement and the type and subject of the research.



Some ideas about how researchers and consumers might work together at each stage are outlined below.



## 1. Deciding what to research:

- At the beginning of a project, the researcher should consider where consumer and community involvement will be focused.
- The researcher should seek consumer representatives from recognised consumer organisations to contribute the broad consumer perspective to the research project.
- The researcher should discuss with their consumers the potential research questions and the anticipated benefits of the research and incorporate any suggestions/comments from consumers as appropriate.

## 2. Deciding how to do it:

- The level and type of consumer involvement appropriate for each project will vary depending on the nature of the project. Basic, pre-clinical and clinical research could involve different consumers with different degree of expertise.
- Consumers can contribute to the development of the methodology for a research project in a number of ways including:
  - writing / commenting on documents, surveys, questionnaires, consent forms and information sheets,
  - writing / reviewing the consumer-related sections of grant and ethics applications, and/or
  - writing / editing the lay summary of grant applications.
- Consumers can also be involved in discussions about recruitment of potential participants to research studies.
- They can provide their perspective on the translation of research into patient care.
- The researcher can identify and discuss with consumers their plans to disseminate research findings and results to other consumers and the wider community.
- The researcher can also consider inviting consumers, consumer organisation and community members to be investigators on grants and/or co-authors in publications where appropriate.

### **3. Doing it:**

- The researcher should ensure that the timelines, boundaries and confidentiality requirements are known by consumers.
- 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:**

- The researcher should work with consumers to develop plain language summaries and presentations of research findings to communicate with the public clearly and effectively.
- They can also invite consumers to co-present at academic conferences, presentations and media briefings.

### **5. Knowing what to research next:**

- The researcher can involve consumers in assessing and implementing the research findings and evaluating any outcomes from the implementation.
- They can also involve consumers in identifying and guiding the future direction of the research.

## 9. Consumer involvement in the NBCF Review Process

NBCF involves both researchers and a group of highly trained and experienced consumers in its review of research grant applications.

### 9.1 Peer Review Committee

Research Grant Applications submitted to NBCF are reviewed by Peer Review Committees (PRC). The PRCs are a group of researchers with the required breadth of expertise who review and score the grant applications for scientific merits and quality.

### 9.2 Consumer Advisory Panel

In parallel with the PRC scientific review, the consumer review of applications is conducted by the NBCF Consumer Advisory Panel (CAP) .

The CAP assesses the consumer targeted questions in grant applications submitted to NBCF against the following criteria;

1. Relevance, Equity and Alignment
2. Consumer Engagement
3. Translation and Impact

The review of the consumer section of the grant application is designed to be assessed independently of the scientific sections of the application. Consumers are not expected to comment on, or score, the scientific or technical aspects of a grant application.

As with the PRCs, CAP members are required to inform NBCF of any conflicts of interest (COI) with any grant applications under review. NBCF's consumer review process aims to ensure that funded research is relevant to those impacted by breast cancer and the broader breast cancer community. NBCF also aims to improve consumer engagement for NBCF funded projects and ultimately derive greater benefit for those affected by breast cancer

During the CAP review, if the level or type of consumer engagement is deemed to be unsatisfactory, the CAP has the opportunity to make recommendations to researchers on how to improve consumer engagement for the project. If funded, the Principal Investigator for the application will have one year to address the recommendations of the CAP and provide the required information in their first annual progress report.

The CAP also provides expert advice to the NBCF Research Advisory Committee (RAC) and Peer Review Committees (PRCs) on consumer-related matters and issues that may affect grant applications to NBCF. In addition, there are 2 consumer members on the RAC.

## 10. Guide for Researchers

All grant applications submitted to NBCF will be assessed by the CAP on the type of consumer involvement and the level of engagement with the proposed research project.

When finding and working with consumers the following points are recommended:

### Finding Consumers

- researchers work with their institutes to seek advice on how best to source and work with consumers;
- local consumer representatives are appointed;
- consumers that have undertaken formal training, see Cancer Council link;
- employees of the research institute where the research will be conducted are not to be appointed consumer representatives;
- research projects directly engaging with participants should appoint more than one consumer.

### Working with consumers

- researchers meet with their appointed consumer(s) at regular intervals suitable to the type of research project;
- out of pocket expenses incurred by the consumer(s) in the course of engaging with research are covered by the research institution;
- the communication between researcher and consumer(s) is bidirectional;

- the responses on NBCF grant application forms relating to consumer engagement provide detailed information about the role of the consumer(s) appointed to the research project;
- ongoing consumer engagement is demonstrated in the research project.

## 11. 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.	<a href="https://nhmrc.gov.au/sites/default/files/documents/reports/consumer-community-involvement.pdf">https://nhmrc.gov.au/sites/default/files/documents/reports/consumer-community-involvement.pdf</a>
Consumers Health Forum of Australia and Cancer Australia and Cancer Voices Australia, 2011., National Framework for Consumer Involvement in Cancer Control. Cancer Australia, Canberra, ACT	<a href="https://canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf">https://canceraustralia.gov.au/sites/default/files/publications/national_consumer_framework_web_504af020f2184.pdf</a>
Cancer Council - Consumer Training Course	<a href="https://www.cancer.org.au/about-us/consumertraining.html">https://www.cancer.org.au/about-us/consumertraining.html</a>
Cancer Voices Australia	<a href="https://www.cancervoicesaustralia.org/">https://www.cancervoicesaustralia.org/</a>
Cancer Council Australia	<a href="https://www.cancer.org.au/">https://www.cancer.org.au/</a>
Cancer Australia	<a href="https://canceraustralia.gov.au/">https://canceraustralia.gov.au/</a>
McKenzie A., Hanley R. (2014) Planning for Consumer and Community Participation in Health and Medical Research: A practical guide for health and medical researchers.	<a href="https://www.involvingpeopleinresearch.org.au/images/docs/PURPLE_PLANNING_BOOK_271015.pdf">https://www.involvingpeopleinresearch.org.au/images/docs/PURPLE_PLANNING_BOOK_271015.pdf</a>
Breast Cancer Network Australia	<a href="https://www.bcna.org.au">https://www.bcna.org.au</a>
Consumers' Health Forum of Australia	<a href="http://www.chf.org.au">www.chf.org.au</a>

## 12. Acknowledgments

We would like to sincerely thank those who provided valuable feedback to this consumer resource including Jane Bennett, Cheryl Grant, Kathryn Leaney, Mara Lidums, Derek Maule, Vanessa Smith, and Lisa Vaccaro.



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