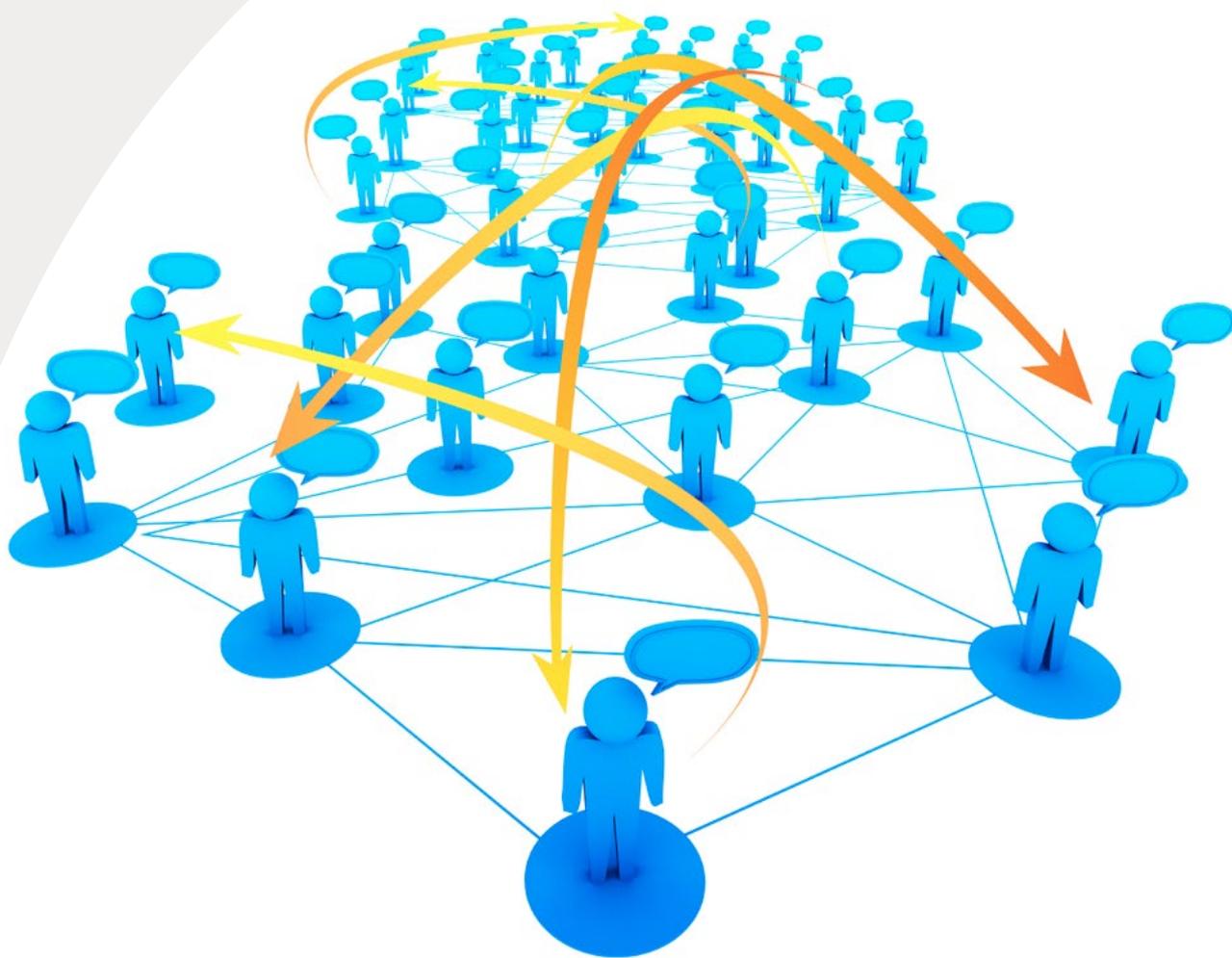


# FROM APPLICATIONS TO OUTCOMES

Consumer and community participation in health and medical research



A resource for researchers and consumers

*APRIL 2014*

## National Breast Cancer Foundation

jointly with

Anne McKenzie, The University of Western Australia  
and the Telethon Kids Institute



THE UNIVERSITY OF  
WESTERN AUSTRALIA



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# ABOUT THIS RESOURCE

The participation of consumers – generally defined as patients, survivors, their families and carers – has significant potential to positively impact on the way that health and medical research is prioritised, commissioned, undertaken, communicated and used. It is also critical in ensuring that investments in cancer research are relevant to, and reflective of, the needs of those affected by the disease, and their families.

There are many ways in which consumers can participate in the research process from the inception of ideas and development of relevant research questions, through the design and conduct of the research, to the dissemination of research outcomes to maximise impact. The benefits of consumer participation in research were highlighted in the recent, independent evaluation of National Breast Cancer Foundation (NBCF) research investment conducted by the Health Economics Research Group at Brunel University in the UK<sup>1</sup>. Various national organisations such as the NHMRC, Cancer Australia, and Cancer Voices have also produced guidelines and frameworks for consumer involvement (see subheading 'Useful Resources'). Furthermore, the Cancer Council NSW, together with Cancer Voices NSW, held a consumer research forum in 2009 with an aim of identifying cancer consumer research priorities across the cancer control spectrum i.e. from prevention through to survivorship and bereavement. The feedback from the forum provided valuable information for future planning and funding<sup>2</sup>.

Like many other research funders, NBCF recognises the importance of consumer involvement in the allocation of its grant funding, and has introduced a specific consumer assessment into the review process for all grant schemes. As a solely community-funded organisation, this also ensures that NBCF's investment in research remains relevant to, and reflective of the needs of its end users and beneficiaries.

This resource, for both researchers and consumers, aims to enhance effective community participation in research, by presenting information and practical suggestions on the 'how and why' of effective consumer engagement. It was developed in close consultation with Anne McKenzie, Consumer Advocate at The University of Western Australia (UWA) School of Population Health and the Telethon Kids Institute, and combines outputs from an NBCF-hosted workshop held in November, 2013 and attended by researchers and consumers, together with the Fact Sheet Series developed by McKenzie and Haines<sup>3</sup>.

## ***This resource highlights:***

- The role and value of consumers and community participation in the research process
- Commonly cited barriers to consumer involvement in research, and potential solutions
- Ways to increase consumer participation in the research process

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<sup>1</sup>Donovan C et al. Evaluation of the impact of National Breast Cancer Foundation-funded research. *Med J Aust* 2014; 200 (4): 214-218.

<sup>2</sup>Saunders C, Crossing S. Towards meeting the research needs of Australian cancer consumers. *BMC Res Notes*. 2012;5:667.

<sup>3</sup>McKenzie A, Haines H. Consumer and Community Participation Fact Sheet Series (2011)

# ABOUT THE NATIONAL BREAST CANCER FOUNDATION

NBCF is the leading community-funded organisation in Australia raising money for research into the prevention and cure of breast cancer.

We are privileged to work with the public who both give and raise funds and the research community to whom we grant funds to change the health future. Since NBCF was established in 1994, \$105 million has been awarded to fund over 370 Australian-based research projects across every state and territory to improve the health and wellbeing of those affected by breast cancer.

We are very proud that NBCF raises and grants funds exclusively for research, because we believe research is the most effective way to end breast cancer. We are also very proud of the fact that NBCF has a commitment to funding research right across the spectrum – from understanding the fundamental basis of the disease to psychosocial research aimed at improving the quality of life for all those living with, or at high risk of developing, a diagnosis of breast cancer and their families.

Our aspirational goal is to achieve zero deaths from breast cancer by 2030. With 42 Australians diagnosed each day and seven dying from the disease, there is still much to do.

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## ABOUT ANNE MCKENZIE

Anne McKenzie has worked as the Consumer Advocate at The University of Western Australia, School of Population Health and the Telethon Kids Institute since 2004.

Anne now leads and manages the joint Consumer and Community Participation Program at both organisations. Her role is to support and facilitate active consumer and community participation in the research and teaching programs at the School and the Institute. Providing training on the 'how and why' of implementing consumer and community participation in research has been a core function of the Participation Program.

Training workshops, specifically for researchers were originally developed in collaboration with UK Consumer Advocate Bec Hanley, in response to requests from researchers, students, and clinicians. Since 2007, 33 workshops have been held in WA, SA, Vic, NSW, ACT and QLD and attended by over 700 people.

Anne is also a senior consumer representative for Consumers Health Forum of Australia and former Chair of the Health Consumers Council of WA and serves on key national committees for the National Health and Medical Research Council, the Department of Health and Ageing and The National Prescribing Service.

# DEFINITIONS

A variety of terms may be used to refer to consumers, carers and/or community members in health policy, service delivery, research and organisational development. The definitions below are taken from the National Health and Medical Research Council and Consumers Health Forum of Australia's *Statement on Consumer and Community Participation 2002*, Cancer Australia and Cancer Voices Australia's *National Framework for Consumer Involvement in Cancer Control* and the *Consumer and Community Participation Program* at The University of Western Australia, School of Population Health and the Telethon Kids Institute.

## **Consumer**

A person affected by cancer as a patient, survivor, carer or family member; or a consumer organisation representing the views of consumers.

## **Consumer representative**

A member of a committee, steering group or similar, who voices the consumer perspective and takes part in the decision-making process on behalf of consumers. This person is usually nominated by an organisation of consumers and is accountable to them

## **Carers**

Families and or friends providing unpaid care.

## **Community**

A group of people sharing a common interest but not necessarily a common geographic location, it is important to recognise that different types of communities are likely to have different approaches to participation.

## **Stakeholders**

An individual or group from within or outside the organisation who has a key interest in the health service delivery, policy and research.

## **Engagement**

This term can be interchangeable with consumer and community participation or consumer and community involvement. It can be used to describe the active involvement of health consumers in their own health care and/or service design and delivery.

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## CONSUMER AND COMMUNITY PARTICIPATION FACT SHEET P01:<sup>4</sup>

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# WHY INVOLVE CONSUMERS AND COMMUNITY MEMBERS IN RESEARCH?

### ***What is consumer and community participation?***

- Consumers, community members and researchers working together to shape decisions about research priorities, practice and policies.
- It is an active partnership that is sensitive to changing needs and priorities.
- It is about being part of the process as well as observing or commenting.
- Conducting research that is with the community rather than to or for the community.

### ***And what it is not....***

- Being the participants (subjects) in research.
- A recruiting tool.
- An opportunity to 'tick the box'.
- Fundraising event or opportunity.

### ***Requirements for consumer and community participation***

- Funding requirement.
- Ethics requirement; research that involves Aboriginal and Torres Strait Islander communities in Australia must involve the community in all aspects of the research.
- National Health and Medical Research Council requirement.

### ***What are the benefits?***

- Research is more relevant to the community.
- Greater transparency, openness and accountability.
- Consumers and community members can help with recruitment of their peers by overcoming barriers to being part of the research.
- Consumers and community members can help to access other people including those who are marginalised.
- May help to avoid making practical mistakes that are obvious to consumers; e.g., are you holding a meeting for mothers at 8.00am just as they are preparing children for school?
- Consumers and community members can help to disseminate the results of research and lobby to ensure that changes are made and research is more widely applied.

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<sup>4</sup>McKenzie A. Haines. H, *Consumer and Community Participation Fact Sheet P01: Why Involve Consumers and Community Members in Research?* (2011). These factsheets are available for educational purposes. No alteration or adaptation of these materials may be made without obtaining permission of Anne McKenzie.

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## CONSUMER AND COMMUNITY PARTICIPATION FACT SHEET P02:<sup>5</sup>

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# PRINCIPLES OF PARTICIPATION

There are certain key principles which underpin all consumer and community participation activities. Regardless of the level of participation that is being used, these principles can help to guide and support all participation activities.

### **Over-arching principles**

**Start participation as early as you can.** The earlier you start the consumer and community participation process the better the consumers and community members will understand and feel part of the project. Don't be put off if you didn't start participation at the beginning – it's never too late.

**One size doesn't fit all.** It is important to work with consumers and community members to find the best level of participation for your project. Work together to decide what will be most appropriate and will suit the consumers or community members involved in your research team.

**Share information willingly.** Keep everyone informed and involved by sharing information willingly and in language that everyone understands.

**Consumer and community participation should add value to the research.** Work with consumers and community members to decide the best way to achieve this. Be clear about what you are hoping to achieve.

**Treat everyone with respect.** Consumers, community members, researchers and other stakeholders should all treat each other with courtesy and respect. It is important to respect all stakeholders' ideas and perspectives. Consumer and community participation is about giving a 'voice' to these differences.

Good practice standards should apply to all consumer and community participation activities; these will include discussions about expectations and role; outline of time commitment; discussion about expenses and honorarium.

Consider training needs for researchers as well as consumers and community members. Training can help develop the necessary skills and abilities required to implement and support consumer and community participation.

Cancer Australia states that organisations which are committed to involving consumers should demonstrate the following:

- a. Governance
- b. Cultural engagement
- c. Clear objectives
- d. Resources and support
- e. Education and training
- f. Facilitation
- g. Research, data and evaluation

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<sup>5</sup>McKenzie A. Haines. H *Consumer and Community Participation Fact Sheet P02: Principles of Participation (2011)*. These fact sheets are available for educational purposes. No alteration or adaptation of these materials may be made without obtaining permission of Anne McKenzie. Email Anne.McKenzie@uwa.edu.au

## CONSUMER AND COMMUNITY PARTICIPATION FACT SHEET T03:<sup>6</sup>

# LADDER OF PARTICIPATION

Being clear about the level of participation you are seeking is very important. It helps you understand what you are aiming for, and in turn enables consumers and community members to make an informed decision about whether or not they want to work with you.

Using a ladder, as shown below, can help to illustrate the levels of consumer and community participation. It can also be shown as a continuum where there are no clear steps but a gradual change from low to high level as modelled by INVOLVE [www.invo.org.uk](http://www.invo.org.uk). Using either model can be helpful in identifying and explaining the level of participation that is planned for a research project.



Taken from McKenzie & Hanley, (2007) *Consumer and Community Participation on Health and Medical Research: A practical guide for health and medical research organisations*.

<sup>6</sup>McKenzie A. Haines. H. *Consumer and Community Participation Fact Sheet T03: Ladder of Participation* (2011). These fact sheets are available for educational purposes. No alteration or adaptation of these materials may be made without obtaining permission of Anne McKenzie. Email [Anne.McKenzie@uwa.edu.au](mailto:Anne.McKenzie@uwa.edu.au)

# BARRIERS TO CONSUMER AND COMMUNITY PARTICIPATION

Following are some of the barriers to consumer and community participation identified by researchers and consumers who participated in the NBCF-organised Consumer Engagement Workshop held in November, 2013.

***“There is a lack of policy surrounding consumer participation...”***

Guidelines and recommendations on engaging consumers and community members have been developed by several national organisations including the National Health and Medical Research Council (NHMRC), and Cancer Australia / Cancer Voices Australia, and the Telethon Institute/University of Western Australia (see subheading ‘Useful Resources’).

Good practice standards should apply to all consumer and community participation activities. These will include discussions about expectations and role, outline of time commitment, discussion about expenses and honorarium. It is important for each research project to consider issues about ethics, confidentiality and bias.

The NHMRC has published a *Resource Pack for Consumer and Community Participation in Health and Medical Research* (see subheading ‘Useful Resources’) which include some checklists to help guide plans for, and assessment of, consumer participation.

***“I’m unsure where to access to consumers/ source the right consumers...”***

1. Consumer groups publish their members’ interest in research and research priority involvement on their websites. They also have electronic request forms which enable “match-making” between researchers and informed consumers. Most of their nominees have undertaken the Cancer Council NSW’s annual Consumer Involvement in Research Training courses, and understand their role and responsibilities.

2. The Consumer Health Forum of Australia (CHF) offers advice on locating consumer groups in Australia. CHF’s membership comprises around 100 health consumer organisations across the country reaching nearly 1,000,000 health consumers.

3. Cancer support groups including cancer consumers, and their families and carers.

4. NBCF’s Register4: <http://www.register4.org.au/>.

5. ‘The Participation Network’ brings together consumers and community members who share an interest in research, and researchers.

6. Tap into any existing links the research organisation has with consumer and community groups. For example, mailing lists for newsletters, organisations or individuals who have donated funds or volunteered to help the organisation on previous occasions.

7. Network with experienced researchers who have received input from experienced consumers who may in turn help identify other consumers and community members in the area.

***“I’m constrained by ethics around sharing data and samples...”***

This can be easily overcome by discussing the overall combined results and trends of the findings with consumers. Consumers who are engaged to provide their input on a research project do not need to know the personal details/data of the consentee.

***“I’m too busy applying for grants, and conducting lab work to find consumers... I never have time to get consumer input on my grant applications”***

Consumer engagement does require time to build relationships and communication channels between consumers/consumer organisations and researchers/research groups foster this. However, many research funders now require appropriate consumer engagement as part of their application process, as well as involving consumers in the grant allocation, so time invested in involving consumers in research is likely to increase the chances of attracting funding. NBCF’s Consumer Review Questions and the Consumer Assessment Report are enclosed in Appendix A.

Start consumer participation as early as possible. By initially providing consumers with a well-written lay summary of the research, followed by regular updates on research findings, the consumer will be well-informed and able to provide timely feedback on/contribute to future grant applications when the time comes. This approach will result in less pressure and angst which may be experienced by both researchers and consumers during the grant writing period.

***“Consumers don’t have time available to be involved...”***

Plan ahead and book time in advance with consumers to ensure they will be available. Consider holding meetings outside of work hours if the consumers involved in your research project are working.

It is important to work with consumers to find the best level of participation for each individual project. The ‘Green Book’ (also known as *Consumer and Community Participation in Health and Medical Research – A practical guide for health and medical research organisations*; see subheading ‘Useful Resources’) illustrates examples of good practice stories of consumer and community participation in individual research projects.

Let consumers know in advance what will be discussed at the meeting, and the duration of the meeting.

***“I don’t have the support of my Institute...my organisational culture is not supportive...”***

Success in developing consumer and community participation relies on designated senior leadership and operational capacity. Building and sustaining consumer and community participation requires changes to structures and attitudes, which take time, effort and commitment on the part of the researcher (and consumer).

The Green Book is a practical guide to establish participation at an organisational level. Ideas for consumer and community involvement in the research organisation can be found in NHMRC’s *A Model Framework for Consumer and Community Participation in Health and Medical Research* (see subheading ‘Useful Resources’).

Some institutes and research organisations have established their own ‘in-house’ Consumer Advisory Panels to assist their researchers to access consumer involvement.

***“There are not enough opportunities for Q&A with consumers...”***

Organise an annual or bi-annual community research conference /symposium in lay language for researchers and consumers with an emphasis on two-way communication. Regular research ‘update’ days or seminars where researchers invite consumers to hear about their research are also opportunities for researchers and consumers to freely engage in Q&A.

***“As a researcher, what is the benefit in engaging consumers in my research...I’m afraid consumers may change my research priorities...”***

There is an increasing call, both nationally and internationally, to involve the public in identifying health research priorities especially where funds for research are derived from public money/the community. Harnessing consumer experience and needs is invaluable for informing science-driven research, and would increase the likelihood of success in attracting research funding, and the research results are more likely to respond to a prevailing problem and to be utilised in the real world. For example, the independent evaluation of NBCF-funded research

undertaken by Brunel University in 2012, found that consumer participation in research projects significantly increased research impact<sup>1</sup>.

Effective consumer representatives are able to move away from a personal opinion to a viewpoint that takes account of the diversity of experiences and needs of consumers, and should be able to:

- i) Analyse an issue and judge its effects on consumers
- ii) Consider the consequences of decisions in the short and long term
- iii) Present an argument rationally and convincingly

***“As a consumer I don’t feel I can make valuable contributions to research projects...”***

Effective consumer involvement requires consumers to be well prepared for the roles through training and development programs for consumers. Various organisations such as Breast Cancer Network Australia (BCNA), Cancer Australia, and Cancer Council NSW offer consumer training and support. In addition, networking with other consumers (from consumer groups/organisations) can

provide support and consumer insight into experiences of contributing to, and participating in research. The Cancer Voices model supports this approach.

***“My research is focused on breast cancer patients with the poorest outcomes but they are difficult to get access to...”***

Experienced consumer representatives, whilst not necessarily having personal experience of poor prognosis nevertheless usually have broad networks and can utilise these networks and vast experience to provide valuable feedback.

***“We are a small research team and do not have staff dedicated to administrative support...”***

This could be addressed in a number of ways, including pooling resources to engage consumers with other research teams in your organisation, and implementing a rotating roster for the administrative support role in the research team.

***“I’m doing basic research and I can’t see how consumers can add value to my research...”***

Try to think about the end point of your research and its potential clinical impact – however far down the track that may be. Most trained consumers have a broad understanding of the principles of the research process, the relationship between basic and applied research and that research can sometimes take a long time to achieve benefits to health.

Consumer participation in basic research could also occur in the following ways<sup>7</sup>:

- At a policy level, consumers could be consulted about the ethics of a particular type of research or involved in considering who owns or has access to human tissue samples
- Researchers could offer tours of their laboratories to the public or to schools groups to help people gain a better understanding of basic research and its relationship to changing clinical practice; and
- Researchers could try to learn how to communicate the results of their work in ways that are meaningful to consumers.

***“I have difficulty communicating my research in lay terms... I feel that the loss of scientific detail may lead to misunderstandings and assumptions on the part of the consumer...”***

Researchers could practice communicating their research in non-technical language with anyone who is not a scientist (family member, friends, neighbours etc), and ask for their feedback as well as ask questions to gauge their level of understanding. Try to break down a summary of your research into the following questions: what is the clinical problem I am trying to solve? What approaches am I taking to address it? If successful, how will my research make a difference to people living with this disease?

***“I don’t have research funding to pay consumers...”***

Include into grant applications a budget for expenses related to consumer engagement. Apply to other funding sources such as industry (for example, pharmaceutical companies), for extra funding to include consumer activities in research.

<sup>7</sup>National Health and Medical Research Council, 2005. *Resource Pack for Consumer and Community Participation in Health and Medical Research*. Commonwealth of Australia, Canberra, ACT.

## CONSUMER AND COMMUNITY PARTICIPATION FACT SHEET M01:<sup>8</sup>

# PLANNING PARTICIPATION

Taking the time to plan properly for consumer and community participation will ensure you get the best results throughout the research project. It is important to note that your plan does not have to be detailed as it is likely to change once you begin to engage with consumers and community members. Having a plan will provide you with a guide for starting the participation activities. Allow yourself time to consider the following questions:

### Why are you involving consumers and the community in your research?

- Decide what you want to achieve from the participation before you proceed with planning the participation activities. What role do you want consumers and community members to have in the project?

### What level of participation do you want to achieve?

- One size does not fit all.
- The level of participation may change at different times of the study. Using the ladder of participation (page 7) may help to decide which level is appropriate.

### What stage of the project do you want consumer and community participation to occur?

- You may choose to involve consumers and community members at any or all stages of the research project (Fact Sheet T02; page 13). It is important to remember that participation can be started at any stage of the research, but starting early will ensure the best results.

### Who are the consumers and community members that you could involve?

- Consumers, community members or carers that have experience of the condition or situation that you are researching.
- Community members who may benefit from or be influenced by the research, or who were uniquely placed to contribute to the research.
- A consumer and community representative is not a participant in a focus group, an in-depth interview or participant in a research study.

### How will you find them?

- Consumers and community members can be found through a variety of ways such as: consumer and community organisations, personal contacts and networks or discussions with colleagues and other researchers. It is always good to make personal contact as early as possible with people you want to join the research team.

### What methods will you use to enable consumer and community participation?

- Decide what method you want use to achieve the level of participation you are aiming for and will add most value to your project.
- Allow enough time for participation activities to be carried out.
- You might also consider using more than one method at different stages of the project.

### What resources will you need?

- Plain language summaries of research, plain language PowerPoint presentation, etc.
- Budget – honorariums for out-of-pocket expenses (parking, child-minding), refreshments.
- Time - plan, manage and coordinate processes involving communication, meeting procedures, provision of documentation.
- Administrative support - note taking, records of meetings, circulation of agendas etc.

<sup>8</sup>McKenzie A. Haines H. *Consumer and Community Participation Fact Sheet M01: Planning Participation (2011)*. These fact sheets are available for educational purposes. No alteration or adaptation of these materials may be made without obtaining permission of Anne McKenzie. Email Anne.McKenzie@uwa.edu.au

## CONSUMER AND COMMUNITY PARTICIPATION FACT SHEET T02:<sup>9</sup>

# THE RESEARCH CYCLE

The research cycle as described in the National Health and Medical Research Council's *A Model Framework for Consumer and Community Participation in Health and Medical Research (2005)* has five stages. Below are some methods that work well at each stage. Remember: the participation activities can commence at any stage of the cycle.

### 1 Deciding what to research

Deciding what to research can be influenced by a number of groups;

- Funding body interests
- Researchers, professionals, staff and students
- Consumers and community members through advisory councils and groups or consultation forums

### 2 Deciding how to do it

Traditionally this has been done by researchers but consumers and community members can be involved using the following methods

- Writing/commenting on documents, surveys, questionnaires
- Writing grant applications
- Reviewing grant applications
- Advisory councils and groups
- Research buddies

### 3 Doing it

Consumers and community members can be included in doing the research in a number of ways:

- Consumer and community researchers
- Advisory councils and groups
- Community consultations and forums

### 4 Letting people know the results

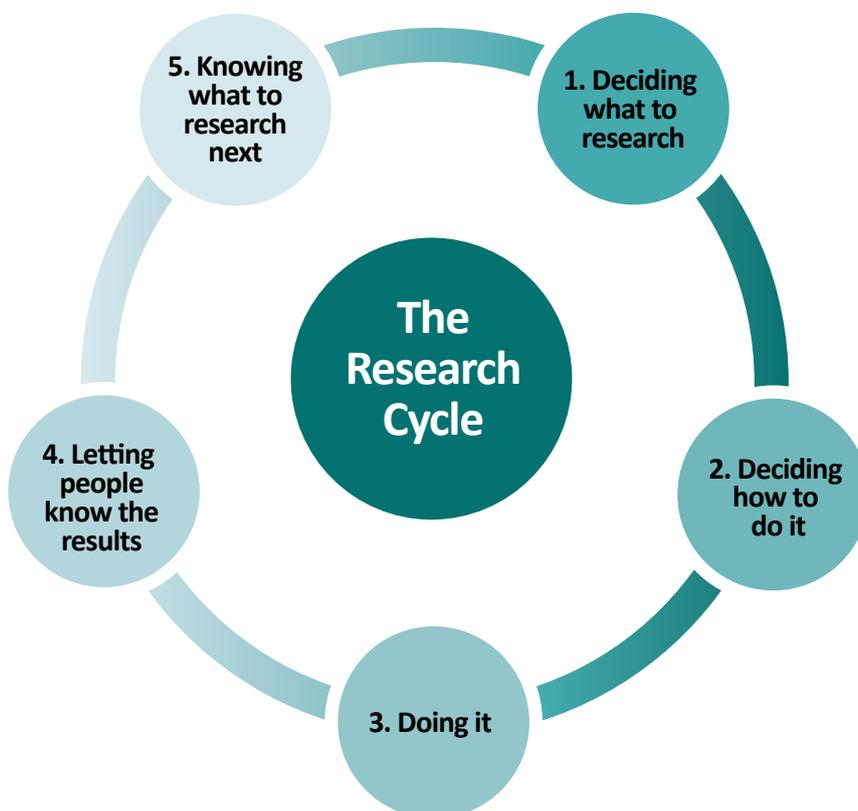
Researchers can share the results of research with consumers and community members through

- Community consultations
- Research buddies
- Utilising members of advisory councils and groups to spread the word
- Consumer and community networks
- Plain language summaries

### 5 Knowing what to research next

The results of the research can help to identify what should be researched next. Consumers and community members can help to do this through:

- Advisory councils & groups
- Consultation forums



<sup>9</sup>McKenzie A. Haines.H. *Consumer and Community Participation Fact Sheet T02: The Research Cycle (2011)*. These fact sheets are available for educational purposes. No alteration or adaptation of these materials may be made without obtaining permission of Anne McKenzie. Email Anne.McKenzie@uwa.edu.au

# METHODS FOR INVOLVING CONSUMERS AND THE COMMUNITY

There are many ways that consumers and community members can be meaningfully involved. All stakeholders should be involved in deciding which method is most appropriate. Below and on the following pages are some suggested methods that can be adapted to suit most types of projects.

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## CONSUMER AND COMMUNITY PARTICIPATION FACT SHEET M07:<sup>10</sup>

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### RESEARCH BUDDIES

#### What are they?

Research buddies are consumers and community members that provide links between the researcher, consumers and community members, organisations and/or research funder. They may be helpful when the researcher is using linked data or working in a laboratory and does not have any direct contact with consumers or community members.

#### How does it work?

- The researcher will either meet or send the research buddy a report once or twice a year on the research progress.
- Research buddies may also provide insight into unexpected or unexplained research findings.
- Research buddies will feedback the report to their consumer and community organisations.
- Research buddies can also help with the dissemination of the research findings.

#### Practical considerations

- Develop draft Terms of Reference and a plain language summary of the research for the research buddies. Be clear about the role and expectations of the buddies as contact may be limited.
- Consider the ability of the buddies: will the report be technical?
- Write reports in plain language – avoid using jargon and give explanations of any technical terms
- Draft parameters of the report: what will it include and when will be completed?
- It is essential that the buddies understand any issues so they can be accurately reported back to consumers and community members or organisations.
- Consider how the research buddies will be supported to engage with other consumers and community members. Discuss honorarium and payment of expenses.

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<sup>10</sup>McKenzie A. Haines H. *Consumer and Community Participation Fact Sheet M07: Research Buddies (2011)*. These fact sheets are available for educational purposes. No alteration or adaptation of these materials may be made without obtaining permission of Anne McKenzie. Email Anne.McKenzie@uwa.edu.au

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## CONSUMER AND COMMUNITY PARTICIPATION FACT SHEET M10:<sup>11</sup>

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# WRITING GRANT APPLICATIONS

### Why involve consumers and community members in writing grant applications?

- Funding bodies such as NBCF and the Cancer Council NSW require researchers to state in the grant application how they intend to involve consumers and community members in their project.
- NBCF, Cancer Councils, Cancer Australia and others engage consumers to be involved in the assessment of grants and allocation of funding (see Appendix A).
- Consumers and community members can make valuable contributions and add a different perspective to other stakeholders in the development of a grant application.
- It is integral to high level consumer and community participation.
- It demonstrates the openness and transparency of the project.
- It's a good way of ensuring participation from an early stage.

### How can consumers and community members be involved?

Consumers and community members can be involved in writing grant applications by:

- Being co-applicants on the grant application.
- Reading through and commenting on the application so that amendments can be made prior to final application.

- Helping to write the plain language summary.
- Planning the proposed consumer and community participation activities.

### Practical issues

- Identify consumers and community members to assist in writing the grant application.
- Draft an outline of the participation activities for discussion with the consumers and community members. They can then help with developing a plan for the participation activities.
- Discuss what support will be needed and/or offered.
- Meet or be in contact with the consumers and community members frequently throughout the grant writing process.
- Being clear about roles and expectations from the outset may avoid problems along the way.
- Payment of expenses and/or honorarium should be discussed.

### On the grant application remember to include:

- Details of the groups who worked on the grant application should be included, remember to check they are happy to be named.
- Details on meetings researchers had with consumer and community groups.
- The levels and methods of participation to be used in each stage of the research project.
- A budget for the consumer and community participation activities.

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<sup>11</sup>McKenzie A. Haines H. *Consumer and Community Participation Fact Sheet M10: Writing Grant Applications* (2011). These fact sheets are available for educational purposes. No alteration or adaptation of these materials may be made without obtaining permission of Anne McKenzie. Email Anne.McKenzie@uwa.edu.au

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## CONSUMER AND COMMUNITY PARTICIPATION FACT SHEET M08:<sup>12</sup>

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# WRITING OR COMMENTING ON DOCUMENTS

### What documents are we referring to?

Consumers and community members could help with writing or commenting on:

- Information sheets and consent forms.
- Pamphlets and brochures.
- Plain language summaries.
- Reports.
- Documents about the dissemination of research results.

### Why get consumers and community members to write or comment on research documents?

If consumers and community members cannot understand the information on these documents, then it is likely a potential participant of the project may not understand them either. The easier a consent form is to understand the easier it is for someone to decide if they, or their child, will take part in the research project.

### Who can write or comment on research documents?

- Members of the consumer and community group the research is focused on.
- Organisations which represent the consumer and community group.
- Carers or carers of children in the consumer and community group.

### Planning considerations

- What type of document is being reviewed?

- Are consumers and community members involved enough in the project to be able to write one of the documents which explain it?
- Will the consumers and community members require any training e.g. are the consent forms required to contain legal information?
- Provide clear instructions of what is expected of consumers and community members.
- Will consumers and community members be paid? Discuss this with them.
- Do consumers and community members know the privacy/confidentiality requirements?
- Consider meeting with the consumers and community members to discuss your requirements.

### Examples of questions that could be asked about the document

- What is the purpose of this document?
- Who is the audience of the project?
- Does it provide all the information required by participants about this research project?
- Is there anything that is not easy to understand such as jargon, acronyms, and technical words?
- Is the information in plain language?
- Does the format suit the audience e.g. do pamphlets for children contain illustrations?
- Are there alternate formats or languages available?
- Would this information encourage me to take part in the research, or put me off? Why?

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<sup>12</sup>McKenzie A. Haines H. *Consumer and Community Participation Fact Sheet M08: Writing or Commenting on Documents* (2011). These fact sheets are available for educational purposes. No alteration or adaptation of these materials may be made without obtaining permission of Anne McKenzie. Email Anne.McKenzie@uwa.edu.au

# SOURCES OF HELP AND ADVICE

<p><b>Involving People in Research</b>  <a href="http://www.involvingpeopleinresearch.org.au">www.involvingpeopleinresearch.org.au</a></p>	<p>Supporting consumer and community participation in research with resources and information</p>
<p><b>Cancer Australia</b>  <a href="http://canceraustralia.gov.au/clinical-best-practice/service-delivery/key-elements-cannet/active-consumer-engagement">http://canceraustralia.gov.au/clinical-best-practice/service-delivery/key-elements-cannet/active-consumer-engagement</a></p>	<p>The lead national cancer control agency. Co-funds breast cancer research with NBCF through the Priority driven Collaborative Cancer Research Scheme, involving consumer review.</p>
<p><b>Breast Cancer Network Australia</b>  <a href="http://www.bcna.org.au/">http://www.bcna.org.au/</a></p>	<p>The peak national organisation for Australians affected by breast cancer.</p>
<p><b>Cancer Action Victoria</b>  <a href="http://www.canceractionvic.org.au/">http://www.canceractionvic.org.au/</a></p>	<p>Independent voice for all Victorians affected by cancer. Good source of consumers for participation in research.</p>
<p><b>Cancer Voices NSW</b>  <a href="http://www.cancervoices.org.au/">http://www.cancervoices.org.au/</a></p>	<p>Independent voice for people affected by cancer. Good source of consumers trained in research.</p>
<p><b>Cancer Voices South Australia</b>  <a href="http://www.cancervoices.org.au/">http://www.cancervoices.org.au/</a></p>	<p>Independent voice for people affected by cancer. Good source of consumers trained in research.</p>
<p><b>Cancer Voices Australia</b>  <a href="http://www.cancervoicesaustralia.org">www.cancervoicesaustralia.org</a></p>	<p>As above, but for research at national level.</p>
<p><b>CanSpeak Queensland</b>  <a href="http://www.canspeakqld.org.au/">http://www.canspeakqld.org.au/</a></p>	<p>Independent consumer advocacy body representing the interests of all Queenslanders whose lives have been affected by cancer.</p>
<p><b>Consumers' Health Forum of Australia</b>  <a href="http://www.chf.org.au">www.chf.org.au</a></p>	<p>The national voice for health consumers, helping to shape Australia's health system by representing and involving consumers in health policy and program development</p>
<p><b>The National Health and Medical Research Council</b>  <a href="http://www.nhmrc.gov.au/">www.nhmrc.gov.au/</a></p>	<p>Australia's peak body for health and medical research</p>
<p><b>Health Care Consumers' Association of the ACT</b>  <a href="http://www.hcca.org.au/">http://www.hcca.org.au/</a></p>	<p>The principal health consumer advocacy organisation in the ACT</p>
<p><b>Health Consumers NSW</b>  <a href="http://www.hcnsw.org.au/">http://www.hcnsw.org.au/</a></p>	<p>Providing the voice of health consumers in shaping policy and service in NSW</p>
<p><b>Health Issues Centre</b>  <a href="http://www.healthissuescentre.org.au">www.healthissuescentre.org.au</a></p>	<p>Health Issues Centre is an independent, not-for-profit organisation that promotes equity and consumer perspectives in the Australian health system</p>
<p><b>Health Consumers Alliance Inc of South Australia</b>  <a href="http://www.hcasa.asn.au/">http://www.hcasa.asn.au/</a></p>	<p>South Australia's peak body for health consumers</p>

## OTHER USEFUL RESOURCES

McKenzie A., and Haines H., 2011. Consumer and community participation in Health and Medical Research Fact Sheet Series.

National Health and Medical Research Council, 2005. A Model Framework for Consumer and Community Participation in Health and Medical Research. Commonwealth of Australia, Canberra, ACT.

National Health and Medical Research Council, 2005. Resource Pack for Consumer and Community Participation in Health and Medical Research. Commonwealth of Australia, Canberra, ACT.

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

McKenzie A., and Hanley H., 2007. Consumer and Community Participation in Health and Medical Research, A practical guide for health and medical research organisations (Also known as 'The Green Book').



## APPENDIX A: NBCF CONSUMER REVIEW QUESTIONS AND CONSUMER ASSESSMENT MATRICES

### NBCF Consumer Review Questions 2014 Application Form

#### 17.5 Consumer Review: Outcomes and impact

*Please note that this item will be reviewed by NBCF Consumer Reviewers and scores will contribute to the final ranking of the application.*

17.5.1 Please describe the potential outcomes of your research proposal, with focus on relevance to the breast cancer patient, those at risk of the disease, and / or the breast cancer survivor community (Maximum ½ page).

17.5.2 How could / will your research outcomes be directly or indirectly translated to impact on breast cancer incidence, prevention, diagnosis, management, treatment or policy? Please identify the key steps required to realise these potential benefits in the long-term, including a projected timeline if appropriate (Maximum 1 page).

17.5.3 Will this research proposal directly address differences in breast cancer care, outcomes or responses to treatment in different population groups? If not, please highlight ways in which your potential research outcomes could benefit under-studied patient groups and/or those with a high disease burden (Maximum ½ page).

17.5.4 Please indicate whether consumers (breast cancer survivors / advocates) have been involved in the development or planning of this research proposal. If so, describe how consumers have been engaged and ways in which this will continue throughout the duration of the project. For pre-clinical research, please illustrate how consumers could / will be consulted or represented at a level that is appropriate for the proposed research (Maximum ½ page).

<b>Consumer Assessment Sheet</b>	
<b>Assessment Method</b>	
The assessment process will utilise a 1-7 scoring matrix with descriptors as outlined below:	
Descriptor	
<b>7</b>	<b>Outstanding.</b> Highest international quality, provides all the information required with no perceived possibility of improvement. Clearly explains how consumers have been and will be engaged in a two way exchange throughout the duration of the project, including the evaluation and dissemination of research outcomes. Clear pathway identified for the clinical benefit of the research.
<b>6</b>	<b>Highly competitive.</b> Gives all the information in a clear way with no gaps or omissions. Consumer involvement is very impressive and specific details on consumer engagement in almost all the steps of the project are provided. Pathway to improved health outcomes for patients is clearly articulated.
<b>5</b>	<b>Excellent.</b> All the information is provided in a clear and detailed manner. Consumer engagement is detailed across most stages of the project, and is mostly a two way exchange. The pathway to benefit has been clearly thought-through and described.
<b>4</b>	<b>Good.</b> Responses are sound, but there are some minor gaps and omissions and would have been improved by more details in some areas. Consumer engagement is described, but there are some gaps and slight confusion on their role and importance.
<b>3</b>	<b>Satisfactory.</b> Questions are answered but lacking in detail with confusion in areas. The pathway to benefit is not clearly articulated, although some attempt at addressing it has been made. Consumers will be engaged in parts of the project, but details are not provided and the engagement is mostly one way – researchers informing rather than engaging.
<b>2</b>	<b>Poor.</b> Significant inadequacies with the responses and much information is missing. Clear confusion in addressing many of the questions. Consumers have limited involvement in the project.
<b>1</b>	<b>Inadequate.</b> Responses do not address the questions and are poorly understood. No clear pathway to benefit is described. Consumers may be involved in the project but their involvement is minimal and there is significant confusion on the importance of their role.

<b>SELECTION CRITERIA</b>	<b>Score</b>
<b>1. Outcomes</b>	<b>1-7</b>
When assessing the application against this criteria, please consider the following: <ul style="list-style-type: none"> <li>Potential outcomes of the research proposal</li> <li>Relevance of those outcomes to the breast cancer patient, those at risk of the disease, and/or the breast cancer survivor community</li> </ul>	
<b>2. Impact</b>	<b>1-7</b>
When assessing the application against this criteria, please consider the following: <ul style="list-style-type: none"> <li>Ability to be directly or indirectly translated to clinical benefit</li> <li>Impact on all aspects of breast cancer, including causes, incidence, prevention, detection, diagnosis, management, treatment or policy</li> <li>Key steps required to realise these potential benefits in the long-term are clearly articulated</li> </ul>	
<b>3. Equity</b>	<b>1-7</b>
When assessing the application against this criteria, please consider the following: <ul style="list-style-type: none"> <li>Ability to directly address differences in breast cancer care, outcomes or responses to treatment in different population groups</li> <li>Potential for research outcomes to benefit under-studied patient groups and/or those with high disease burden</li> </ul>	
<b>4. Consumer engagement</b>	<b>1-7</b>
When assessing the application against this criteria, please consider the following: <ul style="list-style-type: none"> <li>Involvement of consumers (breast cancer survivors/advocates) in the development or planning of this research proposal</li> <li>Level of engagement of consumers throughout the duration of the project.</li> <li>For clinical research, engagement of consumers at a level appropriate for the proposed research</li> </ul>	
<b>TOTAL SCORE</b> <b>(out of 28)</b>	





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