



Australian Government

National Health and Medical Research Council

A Model Framework for Consumer and Community Participation in Health and Medical Research

INVESTING IN AUSTRALIA'S HEALTH

DECEMBER 2004



Consumers' Health Forum
of Australia



Australian Government

National Health and Medical Research Council

A Model Framework for
Consumer and Community Participation
in Health and Medical Research

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PART ONE OVERVIEW

OVERVIEW

ABOUT THE MODEL FRAMEWORK

This *Model Framework for Consumer and Community Participation in Health and Medical Research* is based on the objectives of the *Statement on Consumer and Community Participation in Health and Medical Research*¹ (the *Statement on Participation*). The *Statement on Participation* was developed in 2000-2001 as a partnership between consumers and researchers.

The *Model Framework* is intended for use by research funding bodies, organisations or teams who wish to develop consumer and community participation in their work. It is accompanied by a *Resource Pack for Consumer and Community Participation in Health and Medical Research*, which may be useful for consumers.

The *Model Framework* needs to be adapted to local circumstances. If a research team or organisation has little experience of consumer participation then it can seem like a daunting task. It is probably best to begin with a series of small, achievable steps. This will help to build understanding of consumer participation and to develop thoughts on what it might look like in the context of a particular research team or organisation.

The key components of the *Model Framework* are:

1. That both senior leadership and operational capacity will underpin success in developing consumer and community participation in research. Whilst all researchers have a part to play in developing consumer participation, it is helpful to have a designated person who is responsible for ensuring progress at an organisational level and who can facilitate the attempts of researchers and consumers to work together.
2. That building consumer and community participation into the structures of research funding bodies, organisations and teams will strengthen and support its implementation.
3. That resources are needed to help consumer and community participation to work well. Such costs could be budgeted in and funded through grant proposals.
4. That developing and sustaining consumer and community participation requires changes to structures and attitudes, which take time and commitment.

¹ NHMRC and CHF, (2002) *Statement on Consumer and Community Participation in Health and Medical Research*, Commonwealth of Australia. Available at: <www.nhmrc.gov.au/publications/synopses/r22syn.htm> website viewed on 14th December 2004.

CONSUMER AND COMMUNITY PARTICIPATION IN HEALTH AND MEDICAL RESEARCH

This document is not primarily concerned with the role that consumers might play as people involved as participants in a research study.

It seeks to encourage a different kind of participation, where consumers and researchers work in partnership with one another to shape decisions about research priorities, policies and practices.

Consumer and community participation in health and medical research has mostly been in the areas of health services research, clinical research and multidisciplinary research. The potential contribution of consumer and community participation to scientific discovery has been less recognised, perhaps because this type of research is more often curiosity driven, that is based on the questions of researchers, rather than on immediate improvements in health outcomes. The degree of consumer and community participation may reflect the degree to which the research impacts upon consumers and community members. However, it should be remembered that many significant breakthroughs have been the result of basic science, such as the importance of clean water and a better understanding of how diseases spread. Similarly many of the concepts which currently challenge our society, such as the mapping of the human genome and its potential use, began in basic science. Consumers and community members therefore have a legitimate interest in this area and would welcome greater public accountability and discussion.

Beginning in the 2005 grant round, the National Health and Medical Research Council (NHMRC) will ask grant applicants how consumer and community participation will be involved in the proposed research, and will expect reports about this aspect of the research. This *Model Framework* aims to provide advice to researchers and research teams or organisations on how to develop consumer and community participation in their work.

Consumers are already participating in health and medical research at local, national and international levels. Indigenous health research has led the way in creating a climate of close co-operation between researchers and Indigenous communities². Some consumers and researchers have learnt how to work together well but there is still a significant way to go before consumer and community participation is an expected part of research policy and practice.

Consumers' Health Forum of Australia (CHF) December 2004

² NHMRC, (2003) *Values and Ethics: Guidelines for Ethical Conduct in Aboriginal and Torres Strait Islander Health Research*, Commonwealth of Australia, Canberra, viewed 13th December 2004 <<http://www.nhmrc.gov.au/publications/pdf/e52.pdf>>.

INTRODUCTION

THE STATEMENT ON CONSUMER AND COMMUNITY PARTICIPATION IN HEALTH AND MEDICAL RESEARCH

The *Statement on Consumer and Community Participation in Health and Medical Research*³ (the *Statement on Participation*) was developed in 2000-2001 as a partnership between consumers and researchers.

The work was funded by the National Health and Medical Research Council (NHMRC) and undertaken by the Consumers' Health Forum of Australia (CHF). The consumers and researchers involved shared their hopes and concerns about consumer and community participation in research and learned much about each other's viewpoints. Their shared vision was: *Consumers and researchers working in partnerships based on understanding, respect and shared commitment to research that will improve the health of human kind.*

The objectives of the *Statement on Participation* are that:

- Consumers and researchers will collaborate and draw on each other's knowledge to build on and strengthen the quality of health and medical research in Australia;
- This collaboration will be achieved through partnerships of consumers and researchers based on mutual trust and shared social responsibility, giving consideration to what each can reasonably expect from the other;
- The partnership of consumers and researchers will shape decisions about research priorities, specific research questions and design of research projects in a way that recognises and responds to the rights of all voices to be heard;
- The partnership of consumers and researchers will support the rights of research participants to their own results, be accountable to them for the results of the research and facilitate dissemination of balanced information about the research and its results to the community; and
- Consumers and researchers will advocate for the resources needed for effective consumer and community participation in health and medical research.

³ NHMRC and CHF, (2002) *Statement on Consumer and Community Participation in Health and Medical Research*, Commonwealth of Australia. Available at <www.nhmrc.gov.au/publications/synopses/r22syn.htm> website viewed on 14th December 2004.

THE CHF / NHMRC RESEARCH PROJECT 2004

In 2004, NHMRC funded CHF to conduct a pilot project to implement the *Statement on Participation* at two sites. The chosen sites were the Queensland Institute of Medical Research in Brisbane and the National Ageing Research Institute in Melbourne. These sites provided a contrast in terms of size, research interests and existing consumer links. Their experiences inform this *Model Framework*.

The National Ageing Research Institute (NARI) is a small organisation of about 15 staff and 30 students. It conducts research into the biological and clinical aspects of ageing and into health service delivery. NARI has a large Volunteer Network of older people who contribute to its work through administrative tasks or as research participants. For some years, it has had a consumer representative on the Board, nominated by Council on the Ageing, Australia.

During this project, NARI tried the following new activities:

- Hosted a Consumer Participation and Priority Setting Workshop, which sought to identify consumer priorities for research and to elicit consumers' ideas about how they could become more involved in NARI's work. There was a good rapport between researchers and consumers at this workshop, as many had met each other previously at Volunteer Network activities. Consumers' priorities for research were developed into a submission to an NHMRC consultation on *Ageing Well, Ageing Productively*;
- Improved its methods of providing information to participants about the progress of the research they are involved in, as a result of comments from the consumer workshop;
- Developed a Consumer and Community Participation Policy;
- Developed plans for a Consumer and Community Advisory Committee, which was first suggested by participants at the consumer workshop;
- Increased the awareness of researchers about how consumers can contribute to research;
- Wrote a research application for a small research project involving the CHF as a partner, which was successful in obtaining funding. The project will evaluate uptake and sustained engagement of recommendations on falls prevention strategies by older people attending specialist Falls Clinics; and
- Contributed an article for publication in *The Australian Health Consumer*, the CHF journal, describing a key area of NARI's research (falls prevention).

The Queensland Institute of Medical Research (QIMR) is one of the largest research institutes in the southern hemisphere with about 700 staff and students. Its diverse research interests encompass infectious diseases and immunology, cancer and cell biology, population studies and human genetics, therapeutic development and clinical research, and Indigenous health research. QIMR had adopted a consumer and

community participation policy in early 2003 after the publication of the *Statement on Participation*. It has a strong public relations department and conducts tours of its facilities for interested members of the public.

During this project, QIMR has:

- Established a Community Liaison Committee, which includes representatives from each Division of the Institute;
- Hosted a consumer workshop in which scientists gave lay presentations of their work and consumers provided advice on how to improve the recruitment of healthy participants as controls in a population based case-control study;
- Surveyed its scientists, asking them to consider who their research might be relevant to and prompting them to consider any links they could develop with such consumers; and
- Included a session on consumer and community participation at QIMR as part of its Scientific Conference. This brought together about 125 senior QIMR scientists who listened to five talks on consumer and community participation by consumers or researchers who had worked closely with consumers. This provided an opportunity for senior scientists at QIMR to develop their thinking on consumer participation.

HOW CONSUMERS ARE INVOLVED IN RESEARCH

Consumers and community members already participate in health and medical research in a variety of ways. As taxpayers or charitable donors they make a large investment in funding research. As health consumers they may be involved as participants in research projects. Ultimately, they may receive treatment or benefit from improved health awareness that was developed through health and medical research.

In some cases, health consumers have also initiated or run research projects, seeking to address their issues in their ways. Some consumer groups, such as the Juvenile Diabetes Research Foundation, have gone further, setting research priorities and allocating research funding to meet needs identified by children living with Type 1 diabetes and their families.

Such examples of consumer and community participation in research are encouraging but they stand out because they are unusual. In most cases, health and medical research proceeds with little or no consumer input. The *Statement on Participation* and this *Model Framework* can contribute to a change in this culture by outlining the principles and practice of consumer and community participation. Both have been developed by consumers and researchers working together.

WHY IS CONSUMER AND COMMUNITY PARTICIPATION IN RESEARCH IMPORTANT?

As the end users of health and medical research, consumers can provide valuable input to decisions about research policies and practices. If such research is to continue to provide high quality outcomes, it is important that consumer and community involvement in research and its ongoing development is facilitated. This includes participation by consumers as partners in the development of research goals, questions, strategies, methodologies and information dissemination. Research methods and results that are open to informed public scrutiny and debate also help to ensure the integrity of research and accountability to the community for the quality of the research. Consumer and community participation in research brings with it responsibilities for consumers, community members and researchers — the responsibility to be respectful of each other’s knowledge, to share information with each other about research issues, and to be open about potential interests in the outcomes of research (such as a consumer’s individual health or the researcher’s financial benefits from a funder). The shared responsibility of consumers, community members and researchers is to ensure that ethical requirements are met and that there is value to the research.

As one researcher has commented, “The better that common experience is understood, the greater the potential for research to find application.”

WHAT IS MEANT BY CONSUMERS AND COMMUNITY?

The terms ‘consumers’ and ‘community’ can mean different things to different people. For example, a research team or organisation would be aware of health consumers but could also think of its sponsors or of the clinicians who use treatments developed as the consumers of its research. The following definitions were used for the purposes of the *Statement on Participation*:

- *Health consumer* — patients and potential patients, carers, organisations representing consumers’ interests, members of the public who are targets of health promotion programs and groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services;
- *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; and

- *Community* — a group of people sharing a common interest (e.g. cultural, social, political, health, economic interests) but not necessarily a particular geographic association. Within this definition, it is important to recognise that different types of communities are likely to have different approaches to participation in research.

A variety of other terms may be used to refer to consumer and community members. Examples include:

- Patient
- Layperson
- Volunteer
- Member of the public

The key attribute that these people share is that they are not researchers or health professionals. Their main experience of health research is as a health consumer or community member.

WHAT IS MEANT BY PARTICIPATION?

This document is not primarily concerned with the role that consumers might play as people involved as participants in a research study. It seeks to encourage a different kind of participation, where consumers and researchers work in partnership with one another to shape decisions about research priorities, policies and practices.

Consumer and community participation includes consumer and community involvement in policy formation and the role of consumers and community members as advocates on certain issues. The Australian Communications Authority⁴ noted the following differences between consumer and community participation and consumer and community consultation:

“Participation is about being part of the process...It is about more than observing and commenting on processes but actual involvement in forums, the authoring of solutions or the development of regulatory instruments...

Consultation is when consumers are asked for their views...Consultation is a level of participation at which people are offered some choices on what is to happen, but are not involved in developing additional options or actions.”

⁴ Australian Communications Authority, Consumer and Community Driven Communications: Strategies for Better Representation – Issues Paper, 2004. Available at <[www.aca.gov.au/consumer and community_ info/CDC_committee/index.htm](http://www.aca.gov.au/consumer_and_community_info/CDC_committee/index.htm)> Website viewed 14th December 2004.

INVOLVE⁵, a UK organisation which facilitates consumer participation in research, explains that:

“By ‘involvement’ we mean an active partnership between the public and researchers in the research process, rather than the use of people as the ‘subjects’ of research. Active involvement may take the form of consultation, collaboration or user control. Many people define public involvement in research as doing research ‘with’ or ‘by’ the public, rather than ‘to’, ‘about’ or ‘for’ the public. This would include, for example, public involvement in advising on a research project, assisting in the design of a project, or in carrying out the research.”

BENEFITS TO RESEARCH TEAMS OR ORGANISATIONS

Research teams or organisations that make use of this *Model Framework for Consumer and Community Participation in Health and Medical Research* could benefit in the following ways:

1. Improved engagement with the communities they serve leading to a better understanding of the organisation in the local community.
2. Contribution of valuable consumer perspectives on its research, facilitated by the use of a *Model Framework* developed by CHF, Australia’s national health consumer organisation.
3. Greater understanding of and experience in working with consumers as partners in the research process.
4. Greater relevance of their work to the lives of health consumers and community members.
5. Opportunity to lead the field nationally and internationally through the implementation and promotion of a *Model Framework* for involving consumers in research.

STRUCTURE OF THE MODEL FRAMEWORK

The Model Framework is split into three main parts:

- The first part provides an overview of the document for those who are looking for a place to start or for ideas on something to try. This includes a section on ‘Getting Started;’
- The second part focuses on research funding bodies, research organisations and research teams and makes suggestions for developing consumer and community participation within research; and
- The third part discusses consumer and community participation in each stage of the research cycle.

It would be most helpful to read the ‘Overview’ and ‘Getting started’ in depth, and then refer to the appropriate sections in parts two or three.

⁵ INVOLVE – <www.invo.org.uk> Website viewed on 14th December 2004.

POTENTIAL USERS OF THE **MODEL FRAMEWORK**

This *Model Framework* is based on the objectives of the *Statement on Consumer and Community Participation in Health and Medical Research*, (the *Statement on Participation*) available online at <www.nhmrc.gov.au/publications/synopses/r22syn.htm>

WHO IS THE MODEL FRAMEWORK INTENDED FOR?

The *Model Framework* is primarily intended for people working in a research team or organisation, to help them develop consumer and community participation in their work. It is accompanied by a *Resource Pack for Consumer and Community Participation in Health and Medical Research*, which is aimed primarily at consumers and community members.

Some potential users of the *Model Framework* are profiled below:

*You sit on the **decision-making body** of a research team or organisation, which has recently begun to consider consumer and community participation. How does the Model Framework help you?*

- The decision-making body of a research team or organisation can ensure that consumer and community participation is part of good governance. It can adopt a comprehensive organisational policy on consumer and community participation and can establish structures to support it, such as the establishment of a Consumer and Community Advisory Committee and, where possible, the appointment of a consumer member to the decision-making body itself.

*You work in a **research organisation** and have just been asked to facilitate the development of consumer and community participation. How does the Model Framework help you?*

- Congratulations on being selected for this important role. The *Model Framework* should give you some ideas of how you might develop consumer and community participation in the work of your organisation. It is good that your organisation has identified someone to facilitate consumer and community participation as experience shows that this is a key element in its development. Remember that it does not all rest on you. Your role is to encourage other staff to involve consumers and community members in their work and to take a lead in ensuring the organisation's policies and practices enable effective consumer and community participation.

*You are a **researcher** who is open to consumer and community participation but has no experience of it. You are under both financial and time pressure. You don't know any consumers interested in your work. How does the Model Framework help you to build consumer and community participation into your work?*

- Consider the kind of research that you do. Who are the people who could benefit from your work? Are they women, men, older people, children, adults,

or people with, or at risk of developing, a particular health condition or disability? Try to create a picture of the health consumers your work might be relevant to. Are there any relevant health consumer groups? Does your organisation have a Consumer and Community Advisory Committee or a similar group that could offer advice or assistance?

If you don't have much spare time or funding, then start small. How much time and effort would a presentation at a meeting of a consumer group really take? This is your work and people are giving up their own time to hear about it, think about it and make comments.

*You are a researcher who is about to begin a new **grant application**. The form includes a new question asking how you will involve consumers in your work. How does the Model Framework help you?*

- As of 2005, the NHMRC will ask grant applicants about consumer and community participation in their work and will expect reports to include information about this aspect of the research. The *Model Framework* should help you to plan this participation.

*You are involved in developing **clinical practice guidelines**, building on the relevant research you have done. How does the Model Framework help you?*

- Part 2 briefly discusses the involvement of consumers in developing clinical practice guidelines.

*You are a **clinical scientist** running trials which involve human participants. How does the Model Framework help you?*

Clinical research is probably the most familiar type of research to consumers.

- The *Model Framework* provides advice on involving consumers in planning and carrying out your research and disseminating your results to participants and the wider community.

*You are a **public health scientist** running studies which rely on existing population data or on surveys or clinical samples provided by a random sample of participants. How does the Model Framework help you?*

- This sort of work means you might be a little removed from your research participants. Though they are important contributors to your work, you might never meet them in person. You could still develop consumer and community participation in your work though. You could work with a relevant consumer group in deciding what to research and in designing appropriate questions to ask participants. This is about involving consumers in the early stages of your research – it is different to running a focus group as part of your research. A partnership with consumers and community members could help you to disseminate your results to consumers and the wider community through community radio or the newsletters of consumer groups. They could also help you to communicate your results to research participants.

*You are a **basic scientist** at a laboratory bench. How does the Model Framework apply to you?*

- Basic research may be the most challenging area for consumer and community participation. Such scientists may be primarily laboratory based and working at a level of technical detail which is not easy to translate into lay language. Whilst consumers may find it easier to contribute to clinical trials or population studies which address questions closer to their life experience, they do have a strong commitment to basic research, recognising that it is the foundation for other types of research.

Many researchers regret that the community does not know about the importance of their work. There is potential for partnerships of researchers and consumers to raise awareness of basic research and to learn more about consumer and community priorities. You have a responsibility to explain its significance to the community.

*You are a **health consumer** and you would like your local medical research team or organisation to do more about consumer and community participation. How does the Model Framework help you?*

- The Model Framework is aimed primarily at research funding bodies, organisations or teams and makes recommendations about the structures, policies and practices that enable effective consumer and community participation. The Model Framework might help you to make some recommendations to the organisation. You might find it useful to read the Resource Pack for Consumer and Community Participation in Health and Medical Research, which is primarily for consumers and community members interested in research. The Resource Pack is available from the Consumers' Health Forum of Australia on 02 6273 5444 or on the internet at: <http://www.chf.org.au> or <http://www.nhmrc.gov.au>

*You **work in a funding organisation** and you want to find ways of ensuring consumer and community participation is built into grant proposals. Does the Model Framework help you? Does it give you a better idea of suitable ways of involving consumers?*

- Yes. You have the opportunity to involve consumers more closely in your own structures by appointing consumer representatives to your key committees and grant assessment panels. You can also influence researchers to adopt consumer and community participation by asking for evidence of it. You may need to be prepared to release funds to help researchers develop this participation.

*You sit on a **Human Research Ethics Committee** and your colleague is on an **Animal Research Ethics Committee**. How does the Model Framework help you?*

- The *National Statement on Ethical Conduct in Research Involving Humans* (1999) is under review and the CHF has proposed that it should make reference to the *Statement on Participation* in its guidance to ethics committees on consumer and community participation. As funding bodies begin to ask grant applicants about consumer and community participation, this may become something that ethics committees have to consider.

The *Model Framework* provides some advice on how to develop consumer and community participation at an organisational level and in a particular research project. It is not exhaustive nor is it anticipated that all parts will be implemented at once or will be relevant to every circumstance. However, it should help ethics committees to determine what is or is not appropriate in consumer and community participation in research and to make suggestions to applicants, particularly those who are reluctant to involve consumers and community members.

Ethics committees may also benefit from links with their organisation's Consumer and Community Advisory Committee.

*You work in a **regulatory** role in the health system. How does the Model Framework help you?*

- There are several different processes which contribute to the regulation of health and medical research in Australia. Your role might be in the Therapeutic Goods Administration's (TGA) Clinical Trials Notification Scheme, ensuring that trials of drugs or medical devices conform to the *Note for Guidance on Good Clinical Practice*, (CPMP/ICH/135/95) and to the *National Statement on Ethical Conduct in Research Involving Humans*. Or you might work for the Health Care Complaints Commissioner in your State or Territory, dealing with complaints about trials or approving the wording for consent forms and information sheets for research participants. Alternatively, you might be employed by the Human Rights and Equal Opportunities Commission or the Patent Office, whose role in relation to genetic research was highlighted in the recent report by the Australian Law Reform Commission⁶. Public hospital boards also have a role to play in regulating research as much of it may be carried out in public hospitals.

Whatever your role in the regulation of research, you should be aware of changing community attitudes as you may need to adapt your processes in the light of consumer and community participation in research. Do your own processes involve consumers and community members?

*You are a Clinical Research Manager for a **multinational pharmaceutical company**. How does the Model Framework help you?*

- Clinical trial protocols are developed and reports are prepared in your company's head office. You make sure trials are implemented in Australia according to the *Note for Guidance on Good Clinical Practice* and the *National Statement on Ethical Conduct in Research Involving Humans*. You could involve consumer organisations in planning for trial implementation. You could work with them to add specific Australian questions, especially to Phase IIIb and Phase IV trials. You could ensure that researchers report to participants on the progress of the study and the timetable for reporting the results. As a high priority, you could ensure that there is public reporting of all trial results (whether positive or negative). You need to be aware of the changing role of consumers and community members as active participants in the research process. Your company's activities may need to be modified in the light of this.

⁶ Genes and Inguenuity: Gene Patenting and Human Health, ALRC Report 99, Commonwealth of Australia 2004, available at www.alrc.gov.au/inquiries/title/alrc99/index.html

GETTING STARTED

If a research team or organisation has little experience of consumer participation then it can seem like a daunting task. It is probably best to begin with a series of small, achievable steps. This will help to build understanding of consumer participation and to develop thoughts on what it might look like in the context of your research team or organisation.

These ideas could be relevant at an organisation-wide level or within a particular research team or department. It is usually helpful for a designated person to take responsibility for each stage.

Try to find out more about consumer participation in research

It is always helpful to learn from the experiences of others who have tried something similar. Such experiences can inform local plans. The following might be useful sources of information on consumer participation in health and medical research, either in Australia or overseas:

- The *Statement on Consumer and Community Participation in Health and Medical Research*. The joint NHMRC / CHF *Statement on Participation* provides objectives and principles for consumers and researchers working in partnership. It is available from <www.nhmrc.gov.au/publications/synopses/r22syn.htm>;
- The Primary Health Care Research and Information Service (PHCRIS) has experience of involving consumers in general practice and primary health care research, evaluation and development. Further information is available at <www.phcris.org.au/resources/consumers/conresearch_frameset.html>;
- The Garvan Institute of Medical Research has a Public Awareness and Community Education (PACE) Program to promote understanding of both the genetic and environmental components of disease and to raise community awareness about the impact that genetic research will have on the future health of all Australians. Further information is available at <<http://www.garvan.org.au/content.aspx?mid=4&iid=253>>; and
- INVOLVE is a UK organisation established to promote public involvement in research, in order to improve the way that research is prioritised, commissioned, undertaken, communicated and used. INVOLVE believes that the active involvement of the public in the research process leads to research that is more relevant to people and is more likely to be used. INVOLVE has produced some useful resources for researchers and consumers who would like to begin working together. Further information is available at <www.invo.org.uk>.

Audit the level and types of existing consumer participation within the research team or organisation

It is helpful to begin with a clear picture of the starting point for the research team or organisation. Is there any previous experience of consumer participation? If so, how and where were consumers involved? What was learnt from the experience?

Such an audit can provide a baseline which can inform local plans for developing consumer participation. Progress can be evaluated against this baseline.

Consider the barriers and enabling factors for consumer participation in the research team or organisation

There will be some local factors that will help the development of consumer participation and others which will hinder it. It may be important to be aware of these barriers or enabling factors when preparing local plans for consumer participation so that they can be worked with or around.

Run a workshop on consumer participation for researchers

It is often useful for staff to discuss proposed initiatives because this enables them to play a significant role in shaping plans such as increased consumer participation. If there is a regular program of seminars or staff training, perhaps a session could be set aside to discuss consumer participation. If there is no regular program to slot into, then it may be necessary to plan a stand alone event.

If there is a senior person in the team or research organisation who is committed to consumer participation, it might be useful for them to play a role in the workshop. Demonstrated commitment at senior level can provide leadership and authority for developing consumer participation and may raise its profile in other people's minds.

Useful topics to cover in the workshop might include:

- The *Statement on Participation* as this sets the overall vision of consumers and researchers working in flexible partnerships throughout the research process;
- Definitions of what is meant by 'consumers' or by 'participation';
- The results of the local audit of consumer participation (if one has been done);
- Questions and discussion to encourage reflection on current practice and to generate ideas for new ways of involving consumers in research; and
- Identification of any training needs staff might have relating to consumer participation in their work.

The University of Western Australia's School of Population Health and the Telethon Institute for Child Health Research have been developing consumer participation during 2004. This began with a series of group discussions to help researchers begin thinking about consumer participation in their work. These questions could be adapted for use in other organisations.

Example questions to encourage reflection by researchers on developing consumer participation

What are some of the ways consumers and the community can become more involved or contribute to research projects here?

What can we do to make it easier for consumers and the community to be more involved in our research?

What can we do differently to attract or engage with consumers and the community?

Do we need to raise the level of trust and confidence in our research projects - if so what needs to be done?

When consumers and community members become more involved in research what supports will they need?

Could we:

- Form a steering committee/consumer advisory council?
- Run public forums/discussions on specific issues relating to consumer participation i.e. payments, consent and privacy?
- Build any consumer participation into existing research projects?

How will we know when we have started to make a difference?

Thanks to Anne McKenzie, Consumer Research Liaison Officer, The University of Western Australia

Identify consumer and community groups who might be interested in the work of the research team or organisation

Some research teams or organisations will already have links with health consumer and community groups; others will need to begin by building these networks. One way of identifying consumers is to consider who or what the research is relevant to:

- Does the research contribute to improved treatment and care for people with a particular health condition? If so, is there a consumer group organised around this condition? The national or state group may be able to provide contact details for local members;
- Does the research have a geographical focus, such as a local community or health service facility? If so, are there any local community groups for the area or for the health service? and

- Is the research intended to increase understanding of how the body or its cellular systems work? If so, there may not be any obvious consumer group to contact. However, it might be possible to think of longer term applications or relevance: for example, women with breast cancer would be interested in learning more about the lymphatic system as lymphoedema is a common problem after breast surgery. Improved understanding of the causes of autoimmunity would be of interest to many consumers affected by autoimmune disorders such as diabetes or multiple sclerosis.

Building links with members of the local hospital's Consumer and Community Advisory Committee may be worthwhile as such members are likely to be connected to local consumer networks and may be able to offer advice and assistance.

Further information on finding consumers and community members interested in the research is provided in the part for research teams or organisations.

Hold a workshop on consumer participation for consumers

It may be useful to bring together health consumers and community members to discuss consumer participation in the work of the research team or organisation and to hear their ideas about how they could be involved. This need not be an expensive exercise if the organisers have access to a meeting room and a small budget to cover refreshments and car parking or public transport costs.

An informal style is often best for consumer workshops as people tend to open up more if the environment is easy-going and welcoming. Visual aids are helpful but try to avoid complicated and flashy presentations, which can leave a consumer audience in stunned silence.

This could cover similar topics to the researcher workshop. In addition, it might be helpful to include:

- Questions and discussion to encourage reflection on ways of involving consumers in research. Are there any immediate activities that consumers and researchers could begin working on together? These could be small initially to build confidence and trust; and
- What happens next? Will participants receive a summary of the workshop discussions? When and how will the researchers consider their suggestions? When might they be able to begin closer involvement with the research team or organisation?

The workshop should be advertised several weeks in advance as participants may need to arrange time off work or make alternative childcare arrangements. There is likely to be a better response if a number of different advertising methods

are used, for example, flyers, announcements on community radio stations, direct invitations to relevant consumer groups or individuals (followed up with a phone call if at all possible).

Remember that university campuses, hospitals or research institutions can all be intimidating environments for people who are not used to them. It is very easy to get lost unless the directions are crystal clear. Try to choose a venue that is easily accessible to people in wheelchairs, people who can't walk too far or up many flights of stairs and to those who rely on public transport.

The invitation could include the following information:

- What the workshop is about (in plain English);
- Date, start time and finish time;
- Venue – if possible provide information about public transport, parking and wheelchair access. Specify the exact location people should come to or make clear that someone will meet them at the reception desk to take them to the right room;
- Whether or not parking or public transport costs will be reimbursed;
- A reply form with a closing date and, if possible, a reply paid envelope; and
- A telephone number to call for further details.

The Consumers' Health Forum has produced a *Guide for Community Organisations Running Health Workshops with Consumers* which is available at <www.chf.org.au/Ds/Downloads/S288_guide.pdf> or by calling 02 6273 5444.

Provide staff training

Researchers may identify training needs to help them work more closely with consumers. This could be addressed by building training into a regular seminar program. There could be some specific sessions for interested researchers. For example, researchers who want to improve their ability to communicate their work in non-technical language could attend a workshop co-hosted by the research team and a consumer group. Researchers could then work with consumers to practice communicating their work in easy to understand terms.

Other ideas could include:

- Inviting members of the Consumer and Community Advisory Committee (if established) or lay members of the Human Research Ethics Committee to talk to researchers about their experiences as partners or participants in research;
- Inviting local consumer and community organisations to talk to researchers about their work;

- Ensuring every member of staff receives a copy of the *Statement on Participation* and a briefing on consumer and community participation as part of their induction to the research team or organisation;
- Providing training on writing for and speaking to a lay audience to build the pool of researchers who are able to communicate their work to consumers and community members. Such training could be provided by a journalist or could be provided by a consumer and community organisation; and
- Providing opportunities for consumers, community members and researchers to work together.

Budget

It will be very difficult to progress consumer participation without a budget. This does not need to be large but there needs to be some way of funding workshops or staff training events. Consumer participation within actual research projects could be included as a budget line in the grant application.

The research team or organisation will need to consider how it plans to reimburse or remunerate consumers who become involved as partners in its work. It is usually seen as good practice to reimburse any workshop attendees for the cost of their attendance to one-off or occasional events (e.g. public transport or parking costs). Where consumers become more regularly involved, for example as members of a committee or steering group, it is seen as good practice to offer payment of a sitting fee⁷, in recognition of the fact that other members of the committee are paid to be there because the work forms part of their professional responsibilities, whereas the consumer may either be out of work or foregoing income to attend the meeting (e.g. by using holiday leave to free up time for the meeting).

Feedback mechanisms

Once it is clearer how consumers might become involved as partners in the research, it could be useful to develop feedback mechanisms and a complaints policy. This means that people are aware of how they can provide feedback to the organisation on their experiences of consumer participation within it. A complaints policy serves a different purpose but highlights the organisation's willingness to take participation seriously. Human Research Ethics Committees have such policies and these would form a good starting point.

⁷ Commonwealth Consumer Affairs Advisory Council, (2002) *Principles for the Appointment of Consumer Representatives: A Process for Government and Industry*, Commonwealth of Australia, Canberra. Available at <<http://www.treasury.gov.au/documents/371/PDF/conrep.pdf>> Webpage viewed on 14th December 2004.

Increasing consumer and community participation at the University of Western Australia's School of Population Health and the Telethon Institute for Child Health Research

Anne McKenzie began work as a Consumer Research Liaison Officer for The University of Western Australia's School of Population Health and the Telethon Institute for Child Health Research in January 2004. Anne's three-year position was funded through a capacity building grant from the NHMRC. Anne's reflections on her first year are as follows:

I started by building a knowledge base, by spending time researching what is happening both nationally and internationally. This proved to be an effective starting point for establishing the role of Consumer Research Liaison Officer. This was a great opportunity to establish networks by contacting people who had published articles on consumer and community participation, as well as contacting those from my own existing networks within the Health Consumers' Council of WA and the Consumers' Health Forum of Australia. I have been constantly gratified by the goodwill and willingness of these people to share their information and experiences.

At the time I was uncertain if I was wasting time which could have been better utilised on other tasks, but looking back I realise that I have constantly used this early research: firstly as a valuable benchmark for monitoring the direction of my plans and performance, and secondly using the successes and trials of other organisations' experiences of consumer and community participation as an awareness raising mechanism. It has proven to be extremely beneficial to be able to speak knowledgeably about what is being done nationally and internationally during discussions and in presentations, both with researchers and consumers.

Building on the experiences of other research organisations and the work already in progress with the NHMRC/CHF project, a proposal was developed and endorsed to increase consumer and community participation in the School of Population Health and the Telethon Institute for Child Health Research. This plan aims to address the needs of consumers and the community and the needs of the researchers. It attempts to deal with the complexity of bringing about sustainable organisational change with a series of small incremental steps that lead to a goal of researchers and consumers valuing and expecting increased participation in all projects.

Whilst the progress has been slower than anticipated there have been some real successes during the year such as:

- increased awareness within both the consumer group and staff at both organisations of the role of the Consumer Research Liaison Officer and a subsequent increase in awareness of consumer participation;
- successful staff and consumer forums; and
- development and implementation of an audit tool.

There also remains the constant challenge of budget issues and seeking a catalyst that will move thinking amongst some researchers from continuing with the status quo to one of desire to take on board the need for increased participation.

Anne McKenzie, December 2004.

PART TWO CONSUMER PARTICIPATION IN THE STRUCTURES OF RESEARCH

RESEARCH FUNDING BODIES

Research funding bodies are uniquely placed to foster a climate of consumer and community participation in health and medical research because they set the conditions for the award of research funding. Funding organisations have two levels of consumer participation to consider:

- Developing consumer participation in their own organisation; and
- Fostering consumer participation in the research they fund, perhaps by including it as one of the assessment criteria (note that the degree of consumer participation in a proposed research project is likely to reflect the degree to which the proposed research impacts on consumers).

Some funding bodies are also involved in developing clinical practice guidelines, which are one way of improving health care in the light of research findings. The National Health and Medical Research Council (NHMRC) *Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines*⁹ is the most recent statement on the NHMRC's position about consumer involvement in guideline development.

It notes that, "The process of guideline development should be multidisciplinary and should include consumers. If guidelines are to be relevant, those who are expected to use them or to benefit from their use should play a part in their conception and development. Involving a range of generalist and specialist clinicians, allied health professionals, experts in methodology, and consumers will improve the quality and continuity of care and will make it more likely that the guidelines will be adopted."

⁸ Commonwealth Scientific and Industrial Research Organisation

⁹ NHMRC (1998) *Guide to the Development, Implementation and Evaluation of Clinical Practice Guidelines*, Commonwealth of Australia, Canberra. <<http://www.nhmrc.gov.au/publications/pdf/cp30.pdf>> page viewed 14th December 2004.

EXAMPLES OF CONSUMER PARTICIPATION IN FUNDING BODIES

National Health and Medical Research Council [www.nhmrc.gov.au]

NHMRC is Australia's largest public funder of health and medical research. In recent years, NHMRC has made a significant commitment to its own consumer and community participation work with the appointment of consumer representatives to Council and to each principal committee. Consumer representatives are involved in the development of clinical practice guidelines.

NHMRC has funded the development of the *Statement on Participation* and jointly endorsed it with CHF. In 2004, NHMRC funded the CHF / NHMRC Research Project which piloted the implementation of the *Statement on Participation*.

Juvenile Diabetes Research Foundation [www.jdrf.org]

Founded by parents of children with juvenile diabetes, JDRF has one mission: to find a cure for diabetes and its complications through the support of research. Embedded in JDRF's mission are its three cure goals:

- Restoring normal blood sugar levels;
- Preventing and reversing complications; and
- Preventing type 1 diabetes.

Contained within these broad goals are specific research pathways to a cure—treatments with the potential for having the greatest impact on all people with type 1 diabetes. The pathways are defined by specific scientific milestones to ensure progress toward a cure.

JDRF's funding and leadership are associated with many of the scientific breakthroughs in type 1 diabetes research, including islet cell transplantation and stem cell research. Research proposals undergo peer review by the Medical Science Review Committee (MSRC) relying on multiple criteria for the various types of grants available. After the scientists have conducted peer review, the proposals undergo lay review by carefully selected JDRF volunteers who make up the Lay Review Committee (LRC). The MSRC and the LRC work together to ensure that JDRF funds the best science to find a cure for type 1 diabetes.

A Consumer Involved in a Research Funding Body

Involvement in health and medical research demands patience, humour and tenacity. And that is just the consumer perspective.

My interest in research was developed in the late 1980's while working at the WA AIDS Council. Both social research and biomedical research appeared to be real events, happening in the real world rather than isolated in a laboratory or university. Research gave policy and practice evidence to base action on, and thus the opportunity to improve the quality of life and death for people.

As a "subject" in maternity research in the late 1970's people / researchers were kind if patronising, appeared secretive and we never really understood what the research was for, let alone were told the results. Twenty years later, as a member of a Review of Research Panel, great changes have taken place.

The major change is from "subject" to informed participant – well in some parts of Australia. And the willingness of the research community to consider consumer and community participation. I guess for many consumer and community groups it is the time that it takes to build trust, relationships and partnerships that is most discouraging. It feels like we have waited so long to participate, that it is surprising that the research community is not as enthusiastic as us, don't they see the obvious benefits? Well actually no...

Part of the joy and excitement of participating in research now is that many researchers have great ideas about the questions to ask, but are not sure how to ask them. Researchers occasionally also want to hear the kind of ideas consumers have about research, the priorities that consumers identify and realise the need for reporting back on what happened.

Well, perhaps that is rather idealistic but hopeful, for a future partnership that is pragmatic and effective. My ideal scenario would have NHMRC engaging with the community in a priority setting consultation every three years, in advice, research and ethics. This consultation would make a particular effort to give a voice to those who are often silenced by the dominant culture and would be inclusive and Australia wide. A report on the research, advice or ethics would be made easily available to the community and at least the top 5 priorities would be acted on. Those top 5 research, advice or ethics priorities would have to include consumers and community groups in the design, planning and evaluation of the project. As partners, with mutual respect and a willingness to work together.

Maintaining energy and enthusiasm for the consumer enterprise in research over the long haul will be the big test. It will take 5 – 7 years for consumers and community groups to contribute to research in a meaningful way, to add value not fear, to convince the research community that we are not policemen or auditors, but colleagues who wish to participate and contribute.

*Michele Kosky, consumer representative on NHMRC
Health Consumers' Council of Western Australia, December 2004*

IDEAS FOR DEVELOPING CONSUMER PARTICIPATION IN RESEARCH FUNDING ORGANISATIONS

- Develop transparent processes and communicate with consumers about the research the organisation funds
- Appoint consumer representatives to decision-making committees^{10, 11}
- Develop a strategy for consumer engagement, working with consumers already involved in the funding organisation
- Develop research priorities in consultation with consumers
- Ensure a majority of funding is directed into agreed priority areas
- Make public details about research funded by the organisation as well as the results of that research
- Ask grant applicants how they will involve consumers in their work and how they will provide information on the results of their research to participants and/or the wider community
- Agree to meet the reasonable costs of consumer participation in research as discussed above. In addition, consider whether a ‘sitting fee’ is appropriate for consumers who participate in advisory (or similar) committees – researchers may need to include a budget line for such activities in their grant proposals. The funding body may need to reassure researchers that this is expected and accepted
- Provide funding for the appointment of consumer participation facilitators in key organisations. This could be through a capacity building grant or similar. To be worthwhile, such positions would need to be of several years’ duration.

¹⁰ CHF has produced a checklist to help committees to enhance the contribution of consumer representatives. This is available at <www.chf.org.au/consumer_reps_program/checklist_for_committee_secretariats.asp>. Webpage viewed on 14th December 2004.

¹¹ Commonwealth Consumer Affairs Advisory Council, Principles for the Appointment of Consumer Representatives: A Process for Government and Industry, Commonwealth of Australia, Canberra 2002. Available at <<http://www.treasury.gov.au/documents/371/PDF/conrep.pdf>> Webpage viewed on 14th December 2004.

RESEARCH ORGANISATIONS

CURRENT PRACTICE

In Australia, health and medical research is carried out in universities, hospitals and medical research institutes as well as government agencies (such as CSIRO), health service groups, research consortia, pharmaceutical companies, biotechnology enterprises, and other health interest groups. An increasing number of community based health groups, such as Divisions of General Practice, are undertaking research relevant to their fields of interest.

Some organisations are largely funded through the public purse. Others rely primarily on private funding from wealthy individuals and businesses for their core budget, seeking public grants for specific research projects. Some research organisations have developed strong public relations strategies to help raise their profile and funds. Such public relations activities, which seek to promote the organisation to the community, must be distinguished from consumer and community participation which seeks the engagement of the community in the organisation's work.

Structured consumer and community participation in health and medical research is still quite rare in Australia. Several organisations have taken steps to develop consumer and community participation but most organisations do not involve consumers as yet. Some possible obstacles to consumer and community participation are:

- Researchers being unconvinced of the value of consumer and community participation or fearful that consumers will obstruct their work rather than working in partnership with them;
- Researchers lacking the time or funds to initiate consumer and community participation; and
- Researchers who are willing to involve consumers but are unsure of how to do so.

BUILDING CONSUMER AND COMMUNITY PARTICIPATION INTO THE RESEARCH ORGANISATION

Developing consumer and community participation will take time and effort on behalf of the research organisation and consumers. Progress is made more easily when there is a high level champion of consumer and community participation who can influence others in the team or organisation. However, such influential people will not usually have the time to do the groundwork necessary to bring about change. Other people are required with the capacity to reflect on current practice, reach out to the community, develop policies, organise training and bring together researchers

and consumers. In some organisations, these tasks may be split across existing staff. In other cases, it may be necessary to employ someone with the right mix of skills, contacts and experience to create partnerships between researchers and consumers. Such a person needs to have credibility with both consumers and researchers.

Progress may be slow initially as researchers' beliefs about consumer and community participation are uncovered. It is important to work with staff in the research team or organisation to ensure that their views are considered and, if possible, their concerns addressed. Working in partnership requires both parties to be willing to work together therefore imposing consumer and community participation on researchers is unlikely to be successful. The challenge is to nudge people out of their comfort zones of working without consumers but not to push them faster than they are capable of moving.

If there are areas where both consumers and researchers are willing to work together, then it could be helpful to focus attention there initially. As the relationships develop there may be a greater interest in developing consumer and community participation in other aspects of the organisation's work.

FINDING CONSUMERS

Does the organisation have any existing links with consumer and community groups? If so, what are they? Are there mailing lists for newsletters, groups who have requested a researcher to speak to them, organisations or individuals that have donated funds or volunteered to help the organisation on previous occasions? Such existing links can provide a basis for developing closer relationships with consumers and community members.

Another approach is to consider the work done by researchers in the organisation. Who is it relevant to? Who might the research benefit? From this information it should be possible to compile a list of consumer groups who might be interested in the work. It could be helpful to think of the following types of consumer or community groups:

- *Population groups* with an interest in health, such as women's groups, older people's groups, culturally and linguistically diverse groups;
- *Condition specific groups*, for example asthma, diabetes, chronic fatigue, cancer, mental health groups; and
- *Health interest groups*, such as carers' organisations.

To find local groups, it may be helpful to contact the national offices of relevant groups (such as Council on the Ageing or the Arthritis Foundation) to find out if they have a local branch. The local Council or library may have listings of community groups that meet locally. This can be a good way of finding smaller support groups.

Some States have a state level health consumer organisation, which can provide advice on locating consumers in the area. These are:

- South Australia** Health Consumers' Alliance
GPO Box 2248
ADELAIDE, SA 5001
Tel: 08 8232 0422
- Western Australia** Health Consumers' Council of WA
GPO Box C134
PERTH, WA 6001
Tel: 08 9221 3422
<<http://www.hcc-wa.global.net.au/index2.html>>
- Australian Capital Territory** Healthcare Consumers of the ACT
PO Box 171
MAWSON, ACT 2607
Tel: 02 6290 1660
<<http://www.actcommunity.org/hcca/hcca.htm>>

Another organisation, which might be useful in Victoria, is the Health Issues Centre, which can provide a consumer view on research issues.

Health Issues Centre
Level 5, Health Sciences 2
La Trobe University VIC 3086
Tel: 03 9479 5827
<<http://www.healthissuescentre.org.au/>>

The Consumers' Health Forum of Australia (CHF) can also offer advice on locating consumer groups in Australia. CHF's membership comprises around 100 health consumer organisations across the country reaching nearly one million health consumers. The member list on CHF's website provides links to websites of member organisations, some of whom may have people interested in the work of the research organisation or team.

Consumers' Health Forum of Australia
PO Box 3099
MANUKA ACT 2603
Tel: 02 6273 5444
www.chf.org.au

In the early stages, one or two interested and experienced consumers could be asked to help identify other consumers and community members in the area.

A Resource Pack for Consumer and Community Participation in Health and Medical Research accompanies this *Model Framework*. The *Resource Pack* is primarily intended for consumers though its contents may also be of interest to researchers. Copies of the *Resource Pack* can be obtained from CHF.

IDEAS FOR CONSUMER AND COMMUNITY INVOLVEMENT IN THE RESEARCH ORGANISATION

At an organisation level, the research organisation could create opportunities for consumer and community involvement in the following ways:

- By promoting consumer and community participation in the organisation through discussions at staff or team meetings and addressing difficulties or concerns;
- By developing a page on its website on how consumers and community members can contribute to the research team or organisation's work. This would include information on a Consumer and Community Advisory Committee if one were established. It could also include information about the work of the research team or organisation (in plain English) and about research itself such as ethics approval, funding sources, and articles on research methodology;
- By encouraging the reporting of all research results to other scientists and to consumers;
- By adopting a policy on consumer and community participation and ensuring it becomes part of good governance;
- By establishing a Consumer and Community Advisory Committee (CCAC) to ensure ongoing advice and development of consumer and community participation;
- By involving consumers and community members in strategic planning, organisational development and research priority setting¹²;
- By appointing consumer representatives, linked to the CCAC, to *key decision-making committees* within the organisation (if such exist);
- By involving consumers and community members in the development of any clinical practice guidelines it produces; and
- By providing resources to support consumer and community participation. These could include an agreed position on the process for reimbursing consumers who attend one-off workshops and for remunerating consumers who provide ongoing expertise to the organisation as part of a committee or steering group.

¹² See the section on 'Deciding what to research'.

RESEARCH TEAMS

Australian health and medical research includes basic, laboratory based research, clinical research, public health research, and health services research. Some projects do not involve human participants at all, though there may still be considerable consumer interest in the implications of the research.

In some projects, participants will undertake a one-off procedure such as the completion of a survey or the donation of a blood or tissue sample. These bring the accompanying ethical issues of confidentiality, use of biological material and the implications of the genetic information that can be obtained.

Other projects may require more active participation over a longer period of time, such as taking a particular course of treatment in a particular way, or making a significant lifestyle change. Some researchers therefore have far greater contact with participants in their research than other researchers do. Some researchers are far more comfortable with the idea of consumer and community participation in their work than others.

IDEAS FOR CONSUMER AND COMMUNITY INVOLVEMENT IN RESEARCH TEAMS

The involvement of consumers and community members in a particular research project is likely to vary, depending on the project itself. However some key points might be to:

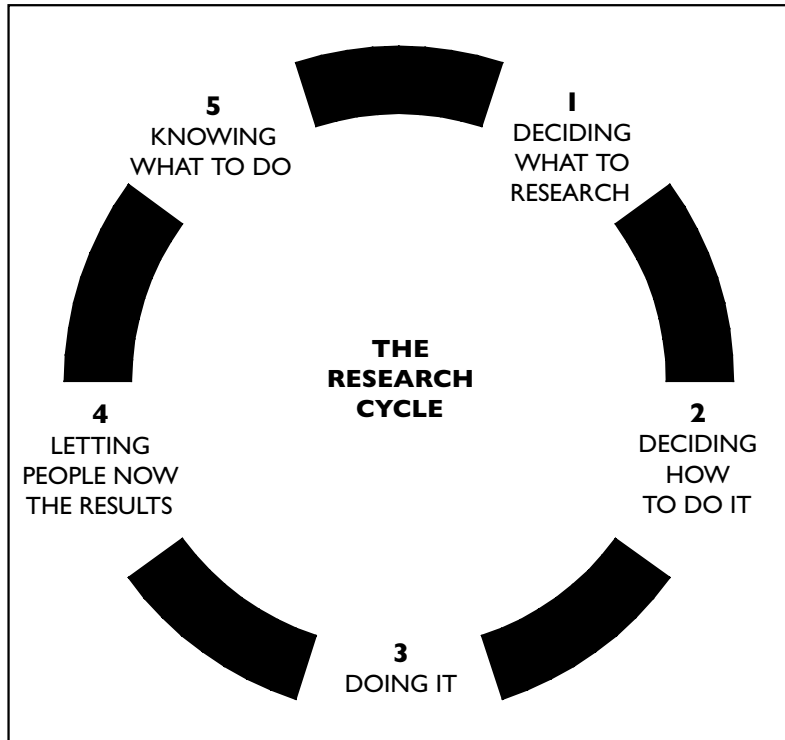
- Consider whether the proposed research fits with the priorities identified by consumers and community members and researchers in your organisation;
- Consider how consumer perspectives could inform the development of grant proposals. From 2005, the NHMRC will ask grant applicants about how they will involve consumers and communities in their work. The researcher could include a good lay summary of the proposed project as part of the application and ask consumers to comment on a draft version. This could then be used for a variety of purposes including
 - NHMRC requirements for a lay summary
 - Recruitment of any participants
 - Promotion of the work through consumer and community networks
 - Reporting of the research through consumer and community networks
 - Lay summary in the organisation's annual report;

- Consider including a consumer or community member on the research team. This would provide opportunity for the perspectives of any research participants to inform the progression of the study. Such a team member would share the characteristics of those in the trial (e.g. gender, age, personal experience of the condition being studied, and links with consumer and community networks) but would not be a participant in the study themselves. For example, a study into arthritis could involve a member of the Arthritis Foundation. The inclusion of a consumer and community member on the research team can help with strategies for recruitment of participants, inform other consumers and community members of the trial's progress and bring a consumer and community perspective to the progression of the research¹³; and
- Keep research participants and the wider community informed of the progress of the research. There are potentially three groups of consumers and community members to consider:
 - *People who participate in studies* do so because they want to contribute and they are interested. It takes time and energy to participate. Many research participants say they've been put off future participation because they were never told the results of previous research they took part in. This could be addressed by the provision of a newsletter to participants at the end of the trial or at key points throughout it. Researchers should work with some consumer and community representatives in developing this newsletter to ensure it is free from jargon and addresses participants' needs.
 - *Other people with the condition* may be interested in finding out about the research. For example, *Balance*, the quarterly journal of Diabetes UK, would publish 'behind the headlines' which presented the results of key research in consumer and community friendly language. These were balanced articles, produced by researchers and consumers, which provided information about key diabetes research in terms relevant to consumers. This was very important in getting beyond the 'cure for diabetes' headlines in the papers and helping people understand what the research was really finding and how long it was likely to take.
 - *The wider community* may also be interested. They could be reached through community radio, presentations to community groups and through the press. Research teams or organisations could also publish lay summaries on their own websites.
 - *The research team* could develop a list of consumer and community groups, policy-makers and other groups likely to be interested in its work and could circulate lay summaries of its research to them.

¹³ For examples of consumer and community participation in research teams, see issues 13, 18 and 21 of *Beacon*, the newsletter of the Breast Cancer Network of Australia, at <www.bcna.org.au/beacon_index.htm>, which discusses the SNAC trial. Also visit <www.bcia.org.au/cap/default.asp> for information on the Australia New Zealand Breast Cancer Trials Group's Consumer and community Advisory Panel.

PART THREE CONSUMER PARTICIPATION IN THE STAGES OF THE RESEARCH CYCLE

Research usually follows a cycle as illustrated below. This section discusses how consumers could contribute to each stage of the research cycle.



DECIDING WHAT TO RESEARCH

CURRENT PRACTICE

In many research teams or organisations, decisions on research priorities are guided by the following considerations:

- Funding opportunities – staff submit applications for funding, often at short notice. Such applications must be tailored to the funding body’s interests;
- Staff and students’ research interests;
- The priorities of professionals and researchers; and
- Previous work – a strong track record in a particular field can help to gain funding for more work in that area.

HOW CONSUMERS COULD ADD VALUE TO THIS PROCESS

Consumers have helped to put unrecognised issues on the research agenda, such as Alzheimer's disease, sudden infant death syndrome and chronic fatigue syndrome.

Consumer groups may identify a research need then work with researchers to investigate the issue. For example, members of Stillbirth and Neonatal Death Support Queensland (SANDS) identified a growing need for support among women who had experienced miscarriage. Based on contact with some hundreds of clients, concerns had been raised about the apparently high level of variation in terms of the quality of care received by women following miscarriage. SANDS wanted to look at this more closely therefore worked with researchers at the University of Queensland to design a study in which GPs in two local Divisions of General Practice participated. Further information about this research is available at <www.sph.uq.edu.au/CPHC/research/Miscarriage.html>

During the 2004 Research Project, the Consumers' Health Forum (CHF) and the National Ageing Research Institute (NARI) hosted a workshop on Consumer Participation and Priority Setting. NARI invited people from its Volunteer Network and from a number of consumer and community groups with an interest in healthy ageing. The workshop elicited the priorities of older people for research into healthy ageing.

The group placed a strong emphasis on the preventive aspects of ageing and the need to prevent a frail and isolated old age by maintaining physical, mental and social activities throughout life. Comparatively few comments were made in relation to clinical research, although clearly this also needs to be a strong focus for optimal health outcomes for those older people who do develop chronic health problems. Participants thought that the negative stereotypes of ageing in our society need to be challenged.

IDEAS FOR ENSURING THAT DECISIONS ON WHAT TO RESEARCH REFLECT THE PRIORITIES OF RESEARCHERS AND CONSUMERS

Host an annual consumer priority setting workshop:

- Identify the best point in the year to seek consumer views on research priorities. For example, prior to the next National Health and Medical Research Council (NHMRC) grant round or as part of the organisation's strategic planning;
- Plan the workshop in conjunction with some consumer advocates, who can ensure that it meets consumers' needs; and
- Remember that consumer and community organisations have their own timetables and are often run on a voluntary basis. It is best to plan well in advance.

Ask consumer groups relevant to the research to consult with their members on research priorities:

- Ask research teams or departments to identify consumer groups relevant to their research (at local or national level);
- Contact these groups to ask for feedback from their members on research priorities (remember to allow at least six weeks for a consumer organisation to consult its members); and
- Work with the consumer organisation on the details of the consultation methods.

DECIDING HOW TO DO IT

CURRENT PRACTICE

Research usually follows structured and established methodologies to reduce the possibility of bias or error so that reliable conclusions may be drawn from its results. Researchers are highly trained in the techniques relevant to their field. Their technical expertise is applied to decisions on how to do the research.

Consumers may have more to contribute to research methodologies that will involve people as study participants. Where there are no study participants, as in laboratory based research or some types of public health research, consumers could provide a view (either at national or local level) on ethical issues such as data privacy or consent to use genetic material.

HOW CONSUMERS COULD ADD VALUE

The specialist skills of researchers are required to determine scientifically valid ways to do the research. The expertise of consumers can strengthen these approaches by:

- Making sure that the proposed methods are consumer friendly and that the research does not impose undue burdens on any participants. Consumers can warn of approaches which may be regarded as insensitive or inappropriate;
- Helping to write information sheets about the research to ensure the style and content is useful for potential participants. This is also a good opportunity to let participants know how and when the study's overall conclusions will be communicated to them;
- Suggesting alternative methods to increase participation
 - The Queensland Institute of Medical Research invited consumers to provide advice on increasing participation in a population based case-control study of cancer incidence. The consumers talked about their likely responses to receiving unsolicited mail and suggested possible approaches which might encourage community members to participate as controls in the study;
- Ensuring the question is asked in a way that might provide an answer relevant to consumers. For example, a research proposal to improve the mobility of people with knee problems could focus on a practical outcome important to consumers, such as regaining the ability to drive, as well as a clinical measurement such as the ability to walk a certain distance; and

- Consumers might be the best people to approach their peers as they are part of the community rather than outside it. This is particularly true where the topic is sensitive or the community may be wary of outsiders
 - Women from the Horn of Africa were concerned about gambling in their community in Melbourne. Researchers trained the women to conduct focus groups amongst their peers and to be peer educators¹⁴.

IDEAS TO ENSURE THAT RESEARCH METHODS ARE CONSUMER FRIENDLY AS WELL AS SCIENTIFICALLY VALID

- Assist researchers to understand consumer perspectives on issues such as access to and storage of genetic material, consent, privacy, or ‘hot topics’ in the relevant research field by inviting consumers to run sessions on these topics as part of a regular seminar program.
- Assist researchers to understand the experiences of research participants by inviting consumers to run sessions on the perspectives of trial participants as part of a regular seminar program
- Assist consumers to understand more about research methods so that they can offer realistic advice, for example by
 - Providing information on research methods, which may be suitable for consumers (non-technical)
 - Providing small bursaries to enable consumers working closely with the organisation to attend conferences and seminars about research.
 - Inviting researchers to address consumer meetings

Research Bites is a useful series of one page articles on research methods, available from <http://www.phcris.org.au/resources/phcred/redresources_frameset.html>

CHF has produced a *Resource Pack for Consumer and Community Participation in Research*, which is available by calling 02 6273 5444.

¹⁴ S Brown, K Johnson, J Wyn, (2001) ‘Minimising the health impacts of gambling for women – Horn of Africa community’ *Australian Journal of Primary Health*, Volume 7, Number 1, p124.

The SNAC Trial

Lymphoedema is swelling of the arm suffered by many women who have had surgery for breast cancer. This was highlighted as a major issue at the first national conference for women with breast cancer in Canberra during 1998.

The Sentinel Node biopsy versus Axillary Clearance (SNAC) trial began in 2001 and is comparing two different operations for detecting cancer cells in the lymph nodes of women with early breast cancer. Axillary clearance, the usual method, involves removing most of the lymph nodes under the armpit, which can result in lymphoedema. Sentinel node biopsy removes only the first few lymph nodes closest to the tumour.

The SNAC Trial Management Committee includes a consumer representative from the Breast Cancer Network of Australia. The Network believes the SNAC trial is important because it is the only one to emphasise the issues women consider important. These include women's ratings of arm swelling, symptoms, function and body image.

The Management Committee meets by monthly teleconference, providing an opportunity for consumers to contribute to the development of questionnaires and to ensure that the issues women consider important are those receiving attention from the researchers. It has also ensured the production of a quarterly newsletter to participants and to breast cancer consumer groups. For further information, see issues 13, 18 and 21 of Beacon, the newsletter of the Breast Cancer Network of Australia, at <www.bcna.org.au> or at the NHMRC Clinical Trials Centre's breast cancer trials page at <www.ctc.usyd.edu.au/trials/cancer/breast.htm>¹⁵.

¹⁵ Websites viewed 15th December 2004.

DOING IT

RESEARCH WITHOUT HUMAN PARTICIPANTS

Consumer and community participation in health and medical research is mostly in the areas of health services research, clinical research and multidisciplinary research. Many types of health and medical research do not involve human participants. Rather the studies are conducted on animals, cell lines, or on a molecular or sub-molecular level in the laboratory.

The potential contribution of consumer and community participation to scientific discovery has been less recognised, perhaps because this type of research is more often based on the questions of researchers than improving health outcomes.

It should be remembered that many significant breakthroughs have been the result of basic science, such as the importance of clean water and a better understanding of how diseases spread. Similarly many of the concepts which currently challenge our society, such as the mapping of the human genome and its potential use, have their roots in basic science. Consumers and community members therefore have a legitimate interest in this area and would welcome greater public accountability and discussion.

Ideas for involving consumers in the conduct of research without human participants

The degree of consumer and community participation may reflect the degree to which the research impacts upon consumers and community members. Where there are no study participants, as in laboratory based research or some types of public health research, consumers could provide a view (either at national or local level) on issues such as ethics, data privacy or consent to use genetic material.

At present, although consumers may not contribute directly to the conduct of research without human participants, researchers could:

- Create links with any consumer participation activities in their organisation, for example any engagement of consumers in priority setting or strategic planning. In addition researchers could benefit from
 - Engaging with consumer views on issues such as data privacy, use of animals for research purposes, implications of advances in genetics
 - Better understanding consumers' priorities for research;
- Raise public awareness of the work that they do, for example by providing guided tours of their laboratories and giving talks on the techniques used; and
- Improve their public accountability by providing lay summaries of their work and its implications.

RESEARCH WITH HUMAN PARTICIPANTS

Until relatively recently, the main role consumers played in health and medical research was as ‘subjects’ in research studies. This document is not primarily concerned with the role that consumers might play as people involved as participants in a research study. It seeks to encourage a different kind of participation, where consumers and researchers work in partnership with one another to shape decisions about research priorities, policies and practices.

Ethical requirements for research involving humans are underpinned by the NHMRC *National Statement on Ethical Conduct in Research Involving Humans*¹⁶, which takes into account the welfare and rights of participants in research, including those who may be affected by the research¹⁷ as well as those directly involved.

The *National Statement* is applicable to all research involving humans, in that the key ethical principles can be used to guide the design and conduct of any research (medical, health, social science, humanities) which involves human participation. The *National Statement* is intended to be a document which provides a national standard for best practice. Any organisation that receives NHMRC funding for research is bound through a contractual agreement to adhere to the *National Statement* and to obtain ethical review for research involving humans. Other funding bodies, such as the Australian Research Council, may also place a similar requirement on the funding they provide. In addition, some agencies have decided to include reference or adherence to the *National Statement* (or other NHMRC guidelines) in their legislation. For example, the Therapeutic Goods Act refers to the *National Statement* to regulate the conduct of clinical trials. There is also some legislation at the State/Territory level that also references the *National Statement* for specific purposes.

Consumer participation and ethical review are separate but complementary components of any research involving humans. Involving consumers in the planning of research may identify some ethical issues earlier, giving chance to address them before submitting the proposal to a Human Research Ethics Committee (HREC). Consumers working with a research team may find it useful to make links with the HREC, particularly with its lay members.

¹⁶ NHMRC (1999) *National Statement on Ethical Conduct in Research Involving Humans*, Commonwealth of Australia (under revision)

¹⁷ People who may be affected by a research project include participants, their carers, and other people living with the condition being studied.

CURRENT PRACTICE

At present, the *National Statement* protects participants in research and addresses informed consent, complaints and monitoring the approved research. However, it is relatively rare for consumers to be partners in the conduct of research.

HOW CONSUMER AND COMMUNITY PARTICIPATION COULD ADD VALUE

Consumers could add value to the research team through involvement in the oversight of research as it progresses. Including a consumer on the research team would provide opportunity for the perspectives of the research participants to inform the progression of the study. Such a consumer member may share the characteristics of those in the trial (e.g. gender, age, personal experience of the condition being studied, and links with consumer networks) but may not be a participant in the trial themselves as this could constitute a conflict of interest. For example, a study into Crohn's disease could involve a member of the Australian Crohn's and Colitis Association. The inclusion of a consumer member of the research team can help to design effective recruitment strategies, inform other consumers of the trial's progress and bring a consumer perspective to the progression of the research.

The Queensland Institute of Medical Research (QIMR) included a session on consumer and community participation at its Scientific Conference in 2004. Consumers (and researchers) presented their experiences of consumer and community participation in research. This provided some ideas for scientists at the conference, who were asked to consider how they could improve consumer and community participation in their own work.

IDEAS TO ENSURE THAT CONSUMER PERSPECTIVES INFORM THE CONDUCT OF RESEARCH INVOLVING HUMANS

- Include a consumer as a member of the research team or its advisory structures (e.g. a steering committee or reference group).
- Try to estimate the level of commitment required before seeking consumer members. For example, how often will the team meet? Is this in person or by teleconference? How much work would the consumer need to do in between meetings?
- Is it possible to pay a sitting fee to the consumer member?

Try to introduce the consumer member to any other consumers involved in the work of the research organisation or team.

The consumer member could be asked to sign any confidentiality agreements necessary to access the data gathered in the study. Every effort should be made to ensure that he or she has equal rights to other members.

Researchers could find ways to gather unidentified feedback from participants in their research, if this is possible within ethical guidelines. Participants may have many practical suggestions about how future studies could be improved for consumers.

Australia New Zealand Breast Cancer Trials Group

The Australia New Zealand Breast Cancer Trials Group has established a Consumer Advisory Panel <www.bcia.org.au/cap/default.asp>

This group's role is:

- to improve recruitment to breast cancer clinical trials; to advocate for women who may be participating, or who are participating, in clinical trials;
- to raise community awareness of breast cancer clinical trials and research;
- to provide the ANZ BCTG with a consumer perspective on relevant issues about clinical trials including recruitment, patient information for informed consent, new trial protocols, and ethical issues; and
- to represent consumer views on behalf of the ANZ BCTG in government, community, consumer and research funding forums to promote the importance of clinical trials.

LETTING PEOPLE KNOW THE OVERALL RESULTS OF THE RESEARCH

CURRENT PRACTICE

Research has traditionally been published in peer-reviewed journals, written in scientific language. This important process allows other experts to verify or critique the results. However, other methods of dissemination may be required if consumers are to learn about the results of research relevant to them. The mass media has its usefulness but can also cause problems if research results are sensationalised¹⁸.

There is also a well-recognised systemic bias towards publishing positive results rather than negative ones. This is not to suggest bias on the part of individual researchers but rather to highlight that there are biases in the system that favour the publication of positive results. The Cochrane Collaboration notes that

“The results of many studies are never published, and most of these probably remain unknown. If studies showing an intervention to be effective are more likely to be published, then any summary of only the published reports may result in an overestimate of effectiveness due to a publication bias¹⁹.”

Both consumers and researchers could benefit from knowing what does *not* work, as well as what does. It is not in either’s interest to expend effort duplicating previous unpublished work.

If consumers have been appointed to the research team, then it would be hoped that they had the same access to data as other team members. This may need to be written into the study protocol and the consumer may be required to sign a confidentiality agreement.

Consumers participating in a research project would normally expect to receive the results of their individual tests, unless the study’s methodology prevented this. This section is primarily concerned with informing any participants and the wider community of the **overall conclusions** of the research. It is important that the results are disseminated in this way as they may assist with advocacy, community development, and implementing research findings.

¹⁸ The Media: Take Twice Daily with a Large Grain of Salt, (Melissa Sweet), The Australian Health Consumer, 2003/2004, Number 3. Available at http://www.chf.org.au/Docs/Downloads/The_Media.pdf

¹⁹ P Alderson, S Green, JPT Higgins, editors. Formulating the problem. Cochrane Reviewers’ Handbook 4.2.2 [updated December 2003]; Section 5. <<http://www.cochrane.dk/cochrane/handbook/hbook.htm>> website viewed on 14th December 2004.

FINDING MORE EFFECTIVE WAYS TO SHARE INFORMATION WITH CONSUMERS

Better results may be obtained if researchers work with consumer and community groups to explain their findings. There are potentially three groups of consumers to consider:

- *People who participate in studies* do so because they want to contribute and they are interested. It takes time and energy to participate. Many consumers say they have been put off future participation because they were never told the outcomes of previous research they took part in. Obviously, not all research involves people but where people do take part as study participants, it is courteous to keep them informed of the study's progress and its findings;

Where de-identified data has been used, researchers may not be in direct contact with study participants. However, it may be possible to provide information about the study's progress to participants through a third party, such as the people or organisations which helped to recruit participants in the first place. Another idea would be to provide information about how the results will be communicated to participants as part of the process of informed consent to participate in the study. People could then opt-in or out of receiving this information;

- *Other people with the condition* may be interested in finding out about the research. For example, *Balance*, the quarterly journal of Diabetes UK, publishes 'behind the headlines' which presents the results of key research in consumer friendly language. These are balanced articles, produced by researchers and consumers, which provide information about key diabetes research in terms relevant to consumers. This is very important in getting beyond the 'cure for diabetes' headlines in the papers and helping people understand what the research has really found and how long it might be before a new treatment was widely available; and
- *The wider community* may also be interested. They could be reached through community radio, presentations to community groups and through the press. Research teams or organisations could also publish lay summaries on their own websites.

Many research teams or organisations produce newsletters for their supporters. These could be expanded to provide more detailed information about the organisation's work and its significance. Consumer organisations relevant to the research could be added to the mailing list to ensure they receive information about the progress of the research.

IDEAS ON HOW RESEARCHERS AND CONSUMERS COULD WORK TOGETHER TO ENSURE CONSUMERS ARE MADE AWARE OF THE RESULTS OF RESEARCH

- Prepare a newsletter (or similar communication) to any participants at the end of the study. If the research has a long timescale, then a newsletter at each key milestone might be appropriate. Consumers could be asked to comment on a draft of the newsletter to make sure it is providing the sort of information they would like. The newsletter could provide information such as:
 - The stage the research has reached;
 - The next steps;
 - Information about the results of the research, or about how participants will be told of these at a later date;
 - The policy implications of the research; and
 - The value of the contribution made by participants.
- Inform other consumers of the results of the research:
 - Perhaps publish an article about the research in relevant consumer journals or newsletters; and
 - Alternatively, give a talk to the local consumer group relevant to the research (e.g. the local Multiple Sclerosis support group).
- Inform the local community of the results of the research, and of the research process and methods themselves:
 - Plan lay seminars into the regular seminar program; and
 - Invite local consumer and community groups to the event, giving at least 3 weeks' notice.
- Inform the wider community of the results of the research:
 - Try to think creatively about the group in question. For example, articles about sun protection or men's health issues in fishing or golfing magazines may reach people who do not normally consider health issues very often; and
 - Contribute to the development of clinical practice guidelines to assist in implementing research results.

DECIDING WHAT TO RESEARCH NEXT

CURRENT PRACTICE

As noted in the section on deciding what to research, funding opportunities and researcher interests are the usual drivers of decisions about what to research. A good track record in a particular field will also help researchers to gain funding for further work in that area. Many proposals for new research are built on the knowledge and experience gained in previous projects. In many ways, research follows a cycle and lessons from one piece of work inform plans for the next.

INCLUDING CONSUMERS

Many of the relevant points have already been covered in the section on deciding what to research. The additional step would be to learn from the experiences of participants in the current study as their insights could inform decisions on what to research next and how to research it in a consumer friendly manner.

IDEAS TO ENSURE THAT CONSUMER PERSPECTIVES INFORM DECISIONS ON WHAT TO RESEARCH NEXT

- Researchers could find ways to gather unidentified feedback from any participants in their research, if this is possible within ethical guidelines. Participants may have many practical suggestions about how future studies could be improved for consumers.
- Researchers could report their findings to the Consumer and Community Advisory Committee or other relevant consumer groups and seek the Committee's input on where the research might lead.
- Researchers could seek input from a wider group of consumers and community members:
 - Make use of activities listed under “Deciding what to research” and “Letting people know the results”; and
 - Use such opportunities to seek input from the community and consumers on what to research next.

CONCLUSION

This *Model Framework for Consumer and Community Participation in Health and Medical Research* aims to provide some suggestions for developing consumer and community participation in Australian research. It should be read in conjunction with the *Statement on Consumer and Community Participation in Health and Medical Research*. It is accompanied by a *Resource Pack for Consumer and Community Participation in Health and Medical Research*, which aims to assist consumers and researchers to understand one another's cultures and experiences. This also provides background information on research for consumers who are unfamiliar with it.

The *Model Framework* needs to be adapted to local circumstances. However its key components are:

1. That both senior leadership and operational capacity will underpin success in developing consumer and community participation in research. Whilst all researchers have a part to play in developing consumer participation, it is helpful to have a designated person who is responsible for ensuring progress at an organisational level and can facilitate the attempts of other researchers and consumers to work together.
2. That building consumer and community participation into the structures of research funding bodies, organisations and teams will strengthen and support its implementation.
3. That resources are needed to help consumer and community participation to work well. Such costs could be budgeted for and funded in grant proposals.
4. That developing and sustaining consumer and community participation requires changes to structures and attitudes, which takes time and commitment.

APPENDIX A SAMPLE CONSUMER AND COMMUNITY PARTICIPATION POLICY

SAMPLE CONSUMER AND COMMUNITY PARTICIPATION POLICY

Date endorsed: *year*

Review date: *year*

PREAMBLE

The *Statement on Consumer and Community Participation in Health and Medical Research* envisages consumer and community participation throughout the research cycle. Consumers, community members and researchers are encouraged to develop partnerships based on mutual respect for one another's different knowledge and experience.

The *research organisation* recognises the central role of health consumers and community members in its work and seeks to build partnerships in which researchers and consumers shape decisions about research priorities, questions and design. It is acknowledged that these partnerships will be flexible and will vary depending on the nature of the research in question.

WHAT IS MEANT BY CONSUMERS AND COMMUNITY MEMBERS AT THE RESEARCH TEAM OR ORGANISATION

The *Statement on Participation* defines consumers as: patients and potential patients, carers, organisations representing consumers' interests, members of the public who are targets of health promotion programs and groups asking for research because they believe that they have been exposed to potentially harmful circumstances, products or services.

Community is defined as: a group of people sharing a common interest – for example, cultural, social, political, health, economic interests – but not necessarily a particular geographical association.

There are likely to be many avenues for consumer and community participation in research. These range from broad advice to the organisation through to detailed input to a particular research project. Researchers are encouraged to seek appropriate avenues for consumer partnerships in their work, in accordance with the principles of the *Statement on Participation*.

Notes

Further headings for the policy could include:

- The purpose of the policy - the *Statement on Participation* may help;
- Scope - specific purposes for the *research organisation*;
- Benefits – for the *research organisation*;
- Governance;
 - Will the *research organisation* form a Consumer and Community Advisory Committee?
 - If so, how will it relate to other governance structures and feed into decision-making processes?
- Types of participation;
 - Where does the *research organisation* envisage it will begin?
- Responsibilities – who will take on particular tasks?
- Evaluation; and
- References to other organisational policies as appropriate.

APPENDIX B CONSUMER AND COMMUNITY ADVISORY COMMITTEE

SAMPLE TERMS OF REFERENCE

PURPOSE OF THE CONSUMER AND COMMUNITY ADVISORY COMMITTEE

The Consumer and Community Advisory Committee (CCAC) will advise the *key decision-making committee* on consumer and community issues in relation to *the research organisation's* priorities, practices and organisational development. It could:

- Act as a liaison between the community, consumer organisations and the *key decision-making committee*;
- Advocate to the *key decision-making committee* on behalf of consumers and the community;
- Identify and advise on issues requiring consumer and community participation, including input to the development of the research team or organisation's strategic plans and initiatives; and
- Provide advice on how to ensure consumer and community representatives on other committees and working parties established by the research team or organisation.

TERMS OF REFERENCE

The Terms of Reference for the Consumer and Community Advisory Committee could include:

- Providing information and advice from a consumer and community perspective to enhance the role and the work of *the research organisation*;
- Participating in the strategic planning of *the research organisation*;
- Advising on consumer research priorities or on how to seek this input;
- Advising on consumer and community participation in research projects;
- Suggesting to the *key decision-making committee* further opportunities for consumer and community involvement in programs and activities in order to implement the *Statement on Consumer and Community Participation in Health and Medical Research* at *the research team or organisation*;
- Monitoring the development of consumer and community participation at *the research team or organisation*;

- Assisting *the research team or organisation* in building partnerships with consumers and communities and consumer and community groups; and
- Undertaking other activities and projects as agreed with the *key decision-making committee* from time to time.

ACCOUNTABILITY

The Consumer and Community Advisory Committee could report to the *key decision-making committee*.

Information about the Consumer and Community Advisory Committee could be provided on *the research organisation's* website and in its publications. This information could include:

- Contact details for the Chair (via the research team or organisation office);
- Meeting dates;
- Membership; and
- Progress reports on consumer and community participation at *the research organisation*.

COSTS

The research organisation will seek to ensure it values the input of Consumer and Community Advisory Committee members and will find appropriate ways to demonstrate this, whether by payment of a sitting fee or by other means as agreed with members of the Consumer and Community Advisory Committee²⁰.

To assist Consumer and Community Advisory Committee members, *the research organisation* could:

- Develop clear written policy statements and easy to follow processes for swift reimbursement of public transport and parking costs for committee members;
- Decide whether or not to pay a sitting fee to committee members; and
- Provide Consumer and Community Advisory Committee members with written information on what they can claim and how²¹.

²⁰ A sitting fee may be required to enable the participation of people on low incomes or those who stand to lose income by attending meetings of the Consumer and Community Advisory Committee.

²¹ Many organisations overlook the need to inform consumers and community members about how to claim their expenses and this can become a cause of tension for consumers and community members.

MEMBERSHIP

The CCAC membership could include a mix of health consumer and community groups relevant to the work of the organisation.

There will be 5-8 members of the CCAC. Sixty percent of the members are required for a quorum. Members will normally be appointed for a two year term; though it is suggested half of the original appointments should be for one year only. This means that half of the members would change or be re-appointed each year ensuring a staged turnover of membership. Members may resign at any time by notifying the Chair in writing.

Membership is not open to service providers or industry bodies. Members are accountable to their consumer or community organisations for the input they give to the Consumer and Community Advisory Committee.

SELECTION PROCESS

Committee members will be appointed through a fair and transparent selection process. *Selection criteria could include:*

1. The nominee's interest in the work of *the research organisation*
2. Health consumer interests in the area of *the research organisation's* work
3. What experiences the nominee has had that will be helpful in a role as a consumer and community representative and / or are relevant to the work of the committee. This includes membership of groups / committees and any previous consumer and community representative experience
4. Consumer or community organisation(s) the nominee belong to or works with that could provide support to the individual nominee
5. Skills or perspectives other than consumer and community experience that the nominee will bring to the committee, and whether any conflict of interest exists (for example, a professional interest in the issue or a relevant work history). Note that formal qualifications are not required for consumer and community representation but that participation in training courses for consumer and community representation is helpful as are strong networks
6. Enthusiasm for the work of *the research organisation* and a willingness to take on the role of a Consumer and Community Advisory Committee member.

Consumers and community members should be key members of any selection committee as they are best placed to determine whether or not a nominee can be an effective member of the CCAC.

For additional information, please see the Treasury's *Principles for the Appointment of Consumer Representatives: A Process for Government and Industry* available at <<http://www.treasury.gov.au/documents/371/PDF/conrep.pdf>>.

APPENDIX C SAMPLE JOB DESCRIPTION FOR A CONSUMER AND COMMUNITY PARTICIPATION FACILITATOR

SAMPLE POSITION DESCRIPTION²²

PREAMBLE

Provide an explanation of the research organisation's reasons for developing consumer and community participation in its work.

SUMMARY OF RESPONSIBILITIES

The successful applicant will be expected to provide leadership in consumer and community participation through the development of *the research organisation's* consumer and community participation plan. This will include establishment and support of a Consumer and Community Advisory Committee (CCAC) reporting to the *key decision-making committee*, and advising management on strategies to embed consumer participation into the culture of *the research organisation*.

KEY RESPONSIBILITIES

The appointee will provide leadership and co-ordinate the implementation of *the research organisation's* community participation agenda. While the work program will be developed in consultation with key collaborating community partners and researchers, key elements of the Facilitator's work will be to:

1. Facilitate the development of consumer and community participation in the research team or organisation
2. Facilitate the involvement of consumers and community members
3. Provide support to researchers in working with consumers
4. Undertake activities to embed consumer and community participation in the mainstream work of *the research organisation*
5. Monitor and report on themes arising from consumer and community participation strategies across the organisation.

²² Note that it may be possible to fund such a position through a grant.

ESSENTIAL REQUIREMENTS

These could be determined by the organisation but could include:

- Experience in working with consumer and/or community groups²³.

[Consider carefully where to advertise this position. In addition to the usual newspapers or professional journals it may be necessary to advertise through community and non-government organisations' networks].

²³ It is recommended that a consumer or community member be invited to sit on any selection panel.

The National Health and Medical Research Council

The National Health and Medical Research Council (NHMRC) was established in 1936 and is now a statutory body within the portfolio of the Australian Government Minister for Health and Ageing, operating under the *National Health and Medical Research Council Act 1992* (NHMRC Act). The NHMRC advises the Australian community and the Australian Government, and State and Territory governments on standards of individual and public health, and supports research to improve those standards.

The NHMRC Act provides four statutory obligations:

- to raise the standard of individual and public health throughout Australia;
- to foster development of consistent health standards between the states and territories;
- to foster medical research and training and public health research and training throughout Australia; and
- to foster consideration of ethical issues relating to health.

The NHMRC also has statutory obligations under the *Prohibition of Human Cloning Act 2002* (PHC Act) and the *Research Involving Human Embryos Act 2002* (RIHE Act).

The activities of the NHMRC translate into four major outputs: health and medical research; health policy and advice; health ethics; and the regulation of research involving donated IVF embryos, including monitoring compliance with the ban on human cloning and certain other activities. A regular publishing program ensures that Council's recommendations are widely available to governments, the community, scientific, industrial and education groups. The Council publishes in the following areas:

- Aged Care
- Blood and Blood Products
- Cancer
- Cardiovascular Health
- Child Health
- Clinical Practice Guidelines – Standards for Developers – Topics
- Communicable Diseases, Vaccinations and Infection Control
- Diabetes
- Drug and Substance Abuse
- Environmental Health
- Ethics in Research–Animal
- Ethics in Research–Human
- Genetics and Gene Technology
- Health Procedures
- Health Promotion
- Human Cloning and Embryo Research
- Indigenous Health
- Injury including Sports Injury
- Men's Health
- Mental Health
- Musculoskeletal
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